Elders Living with Dementia:
Nuu-Chah-Nulth First Nations Family Perspectives on Elder Healthcare

by

Cheryl Lavern Aro
B.S.W. , University of Victoria, 2004

M.S.W. , University of Victoria, 2009

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Requirements for the Degree of

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Supervisory Committee

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Abstract

In Canada, the literature regarding First Nations people's experiences with dementia is sparse, as is the literature relating to the health and wellness of Indigenous dementia caregivers. Colonization has imposed physical, psychological and structural disadvantages on Indigenous communities that impact the family's ability to provide informal dementia care. The First Nations senior population is growing rapidly and there is a pressing need to gather knowledge about the unique needs of First Nations informal dementia caregivers. This doctoral research seeks to contribute to the growing body of literature on this vitally important topic. This thesis reports the findings from my PhD research study, which was conducted in collaboration with the Nuu-Chah-Nulth Tribal Council, and with generous support from the Nuu-Chah-Nulth community.

Using an Indigenous storytelling research method, the study explored the following questions: What are the experiences of Nuu-Chah-Nulth First Nations dementia caregivers? What support services do caregivers access and what services do they perceive are lacking? Nine Nuu-Chah-Nulth caregivers shared their experiences providing support and care to a family member with memory loss, and their perspectives on memory care resources. Dialogical interviews were conducted in various locations within the Nuu-Chah-Nulth territories to gather the caregiver's knowledge. The author's story as an informal dementia caregiver is also interwoven throughout the dissertation.

The Nuu-Chah-Nulth caregivers narratives revealed diverse and complex experiences with the following central themes and sub-themes: trauma over the life-cycle (residential school, family violence, grief and loss); pressures of caregiving (managing the symptoms of dementia, health and family dynamics); and finally, participants' perceptions of community resources. The

findings from this research reveal that Nuu-Chah-Nulth dementia caregivers and the family members they supported were still healing from the various traumas that were inflicted on their mind, body and spirit through residential school experiences. Most of the caregivers reported that they prefer to care for their family member at home but community supports are limited.

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Page xi: Her Hands. Photograph taken by Andrea Monteiro in June 2016 during my mother's final year of life.

Acknowledgments

There are many beautiful people who supported me through the years. I would like to begin by acknowledging that I have worked and studied as a visitor on the traditional territories of the Lekwungen speaking peoples for the past 20 years. I have been welcomed and supported by the WS̱ANEC and Esquimalt Peoples and I want to acknowledge that my life has been enriched through this experience. I live and study on the traditional territories of the Komox First Nations People. I would like to acknowledge that I am an uninvited visitor on these beautiful lands. I extend my gratitude to the First People of these territories their generosity in allowing me to thrive here as an uninvited visitor on these unceded lands.

I could not have completed this study without the amazing support that I received from the Nuu-Chah-Nulth community. I am particularly grateful to the Nuu-Chah-Nulth participants who are named in this thesis Jill, Sherry, Ellen, Connie Sam, Harold, Katie, Lorne and Alexie. Participating in this research took courage and time out of their busy schedules. It is not easy to share trauma and grief but they did so with dignity. Each story shared was a precious gift. I would like to acknowledge and thank Elder Barney Williams for sharing his teachings and welcoming me into his home. I extend my sincere thanks to the staff and Executive Director of the Port Alberni Friendship Centre, Cindy Stevens, for her support and kindness. I would like to acknowledge and thank the Manager of Nursing at the Nuu-Chah-Nulth Tribal Council, Jeanette Watts, and the Home and Community Care team for their amazing support and guidance.

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I thank my ancestors who were always with me guiding me during the gathering and writing of stories.

Dedication

This dissertation is dedicated to my mother, the late Kathleen (Gladys) Danes. Mom's guidance and support, from here and the spirit world was a blessing throughout my educational journey. Mom's gentle nature emerged in the final years of her life as her memory and abilities gradually drifted away. She filled my life with love and light and beauty. I feel her presence with me and will always cherish the memories that I shared with her while she was here on earth. I love you Mom and miss you every day.

Her Hands

At the end she said nothing with her voice and everything with her gentle caring hands.

Definitions and Abbreviations

Elder: The term Elder is used throughout this article to describe Indigenous people 55 years of age and older. Dumont–Smith (2002) notes that within the mainstream 65 is the age to determine senior status, but due to a lower life expectancy 55 is the age that Health Canada uses to determine old age in Aboriginal communities. The word Elder capitalized is usually used to represent the specific sub-set of seniors who are recognized to have a special role in their communities because of their cultural and spiritual knowledge. I have deliberately capitalized the word Elder throughout this dissertation because I believe it is respectful.

Indigenous: The word Indigenous is an umbrella term that includes First Nations, Métis and Inuit people. The terms First Nations and Indigenous are used interchangeably in this document. The only time the term Aboriginal is used is in direct quotes as that language is commonly used in government documents and other scholarly studies. I have also noted the specific band and Nation in this document wherever possible.

The following abbreviations are used frequently throughout this thesis.

ADRD - Alzheimer's Disease and Related Dementias

PWD – Person with Dementia

NTC – Nuu-Chah-Nulth Tribal Council

CIHR – Canadian Institutes of Health Research

Chapter 1: Introduction

Positioning the Researcher

I would like to begin by acknowledging that I am a visitor on the traditional territories of the Lekwungen and WSANEC speaking people. I study, work and play on these traditional territories as an uninvited guest. I am so grateful for the support that I have received throughout my educational journey from the local First Nations communities, Chiefs and Elders in the area now known as Victoria British Columbia (BC). I also live on the traditional territories of the Komox people. I acknowledge the caretakers and ancestors of this land for allowing my presence here. It is important that I situate myself in this research and introduce myself, as this is a protocol within my community. I am a member of the Gitxsan Nation from the Gutginuxw House and the Fireweed Clan. My band, the Gitanmaax band, is located in Old Hazelton in BC. My patrilineal ancestry is German, English and French. Although I feel a strong connection with my First Nations culture and ancestral roots, I have never lived in Hazelton BC where my mother Kathleen Gladys Danes, Grandmother Matilda Danes, and great-grandmother Susan Danes were born, and many of my family still reside.

My identity, personal and professional experiences have motivated me to design this study. I am an educator, social worker, and Elder caregiver. The topic of dementia is one that is close to my heart. As the child of a person with Alzheimer's disease, I know how devastating this disease can be on individuals and families. My mother was diagnosed with Alzheimer's disease at the young age of 67. I assumed a supportive caregiver role in her life at the time of her diagnosis until she died in 2017. When my mother began exhibiting the signs that are typical of Alzheimer's disease, such as wandering behaviours and short-term memory loss, I supported her

to seek community services. At that time, I learned that there are few culturally relevant Alzheimer's disease and related dementia[1] (ADRD) care resources for First Nations families on Vancouver Island. This was a difficult time for both my mother and I, the emotional upheaval that we have experienced could have been lessened with more information and support. My relationship with my mom moved me to wonder how other First Nations families coped with memory loss in old age, and what supports were needed to contribute to Elder and family well-being. Through my volunteer work with the Alzheimer Society of BC and paid employment I have learned that there are still few culturally safe community supports for First Nations families on Vancouver Island.

Over the years, I reflected on the possible role that trauma and structural oppression may have played in my mother's early Alzheimer's disease diagnosis. As a child, she witnessed the violent murder of her mother. Shortly after this horrific event, my mother was removed from her aunties' care and forced to attend residential school a thousand miles from her home in Port Alberni BC. At a time when she should have received extensive counseling and supports, she was removed from her community and placed in an institution. Poverty and dislocation from her community, as well as a lack of social supports, led to chronic mental health issues throughout my mother's life, and her life story is not unique. Forced attendance in residential schools, social isolation, dislocation from the land and trauma has affected the mental health of many First Nations people in Canada (Kirmayer et al., 2009).

I chose to conduct this research within the Nuu-Chah-Nulth territories which span a large geographical area covering most of the west coast of Vancouver Island (Appendix I). Although I

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[1] Dementia is an umbrella term that refers to a class of disorders characterized by the gradual deterioration of thinking ability and memory as the brain becomes impaired. Alzheimer's disease is the most common form of dementia (Alzheimer's Society of Canada, 2010).

am not Nuu-Chah-Nulth, I have a strong heart connection with the land, the people and the cultures of the Indigenous people who reside on Vancouver Island. My mother and many of my extended family members attended residential school in Port Alberni, which is located within the Nuu-Chah-Nulth territories on the west coast of Vancouver Island. Mom lived in Alberni residential school for a large percentage of her childhood and, because she was an orphan, did not return home during holidays as the other children did. As a child my mother shared many stories of her time in residential school which left an imprint on me.

The choice to collaborate with the Nuu-Chah-Nulth people with this research is a highly personal and emotional one. I chose to pursue this study with the intension of documenting my mother's life and experience with dementia, and my experience as her primary family caregiver. My story as a Gitx̱san First Nations dementia caregiver is not separate from this study, it is woven throughout the thesis. I entered the research with the intention of documenting Nuu-Chah-Nulth Elder caregivers' unique perspectives on dementia and dementia, which I have done. It is my hope that Nuu-Chah-Nulth First Nations health care professionals and families will continue to share and document their stories and knowledge on this important and sensitive topic.

My Story as a Dementia Caregiver

My story as a caregiver begins on Christmas Eve 2002. I recall picking my mother up from her apartment in the busy downtown core of Courtenay BC as I had done for many years, to bring her home for the holidays. We lived in the same community and mom always liked to visit our quiet acreage, especially at Christmas. I never wanted her to be alone during the holidays like she had been as a young child. Mom lived at the Alberni residential school year-round during most of her childhood, so she never experienced a family Christmas when she was young. Residential schools were used as orphanages for parentless First Nations children. Mom's

memories of the Christmas season were especially unhappy ones, so when she became a mother, she sought to make Christmas a spectacular event for her own children. I remember our home being decorated to the hilt with piles of gifts under the tree and homemade goodies in canisters on the table. This Christmas I noticed that mom had a bag of gifts that were unwrapped, and that she didn't seem to know who the gifts were for, which was peculiar indeed. Usually, she would go out of her way to ornately wrap even the smallest most inexpensive gift. At the time I was an undergraduate student at the School of Social Work at the University of Victoria. I traveled to Victoria from my home in Courtenay weekly, and was preoccupied with my studies. For a year or so I hadn't visited my mother as frequently as I had in previous years. So, what had I been missing…? When I look back now, I realize that there were little clues that she was forgetting things, but I just overlooked them. Now I couldn't help noticing that something was wrong, and I sensed that my mother needed my help. I began to pay greater attention to her social activities and ask questions about her healthcare, and finances.

After completing my Bachelor of Social Work degree, I postponed my acceptance into graduate school and took a social work job in downtown Courtenay so I could visit mom frequently. One thing I learned was how resourceful people with memory loss can be when it comes to hiding their forgetfulness and developing new ways to cope with it! At first mom denied that she needed support with everyday tasks such as paying bills, cooking and setting up social activities. Once I began spending more time with mom it became obvious to me that she needed support, but it took me a year to convince her to let me help. No one is eager to accept help when they think that it might mean giving up control of their life, even when they trust the person who is extending the olive branch. Being diagnosed with Alzheimer's disease is scary for a regular person, but my mother had been an in-home care-aid before retiring, and had provided

care to many people with Alzheimer's disease. She was acutely aware of the symptoms of dementia and what to expect as the disease progressed. For months I gently offered to help and was met with avoidance, anger and resistance. When I think about this period my heart goes out to other family caregivers who are in a similar situation today. It was a difficult stressful time for mom and I; at times our relationship was very strained. Finally, during an emotional visit mom admitted that she needed support and agreed to let me help.

The next year was a blur of appointments with social service professionals, doctors and lawyers to get a diagnosis, set up support services and put an enduring power of attorney in place. My assistance with financial matters came in the nick of time. Mom's bills had not been paid for 8 months and many of her services were on the brink of being discontinued. When I tried to make an appointment for mom with the person she identified as her family doctor, I found out he died five years previous! I wondered how long she had struggled with declining health in silence. After several months I finally had supportive community services in place to support mom to live at home and she seemed so much happier. Yet, as previously mentioned, I worried about the lack of cultural supports for First Nations Elders with dementia in urban communities. I sought social /cultural activities for my mother within the local First Nations community, and at the time there were few. I was sensitive to mom's need to connect with her culture so I took her to First Nations events in the community whenever I could. But what happens to Indigenous Elders who have no family support? Mom lived in her home for another three years with assistance from community services and family, but we knew the day would come that living at home would no longer be viable.

That day came in December 2005 when the landlord of my mother's building phoned me to let me know that she was evicting my mother for wandering into another tenant's apartment. I

advocated with the landlord on my mother's behalf so that mom could stay in her home until we could figure out a housing solution. I knew it would be illegal for the landlord to insist she leave without a plan of care. I wanted to care for mom, but my partner Genevieve and I lived in a small trailer and we both worked and had numerous obligations. At a certain point it became clear that we would have to move mom to a care facility, and this was a decision that I felt miserable about. I talked to community services and had her bumped up to the top of the list for a room at Cumberland Lodge where she had been attending an adult day program for a couple years. Mom was familiar with the staff and she was fond of the Cumberland Lodge community.

It felt like we had no choice as we were unable to care for mom 24 hours a day, but it felt like I was abandoning her. I was especially distressed about moving her into an institution as an Elder when she had spent her whole childhood in an institution ~residential school. I helped her move in to the facility and had to leave her to drive to Victoria to my new job. I cried for the whole week feeling a sense of enormous guilt and sadness. When I returned to the Cumberland Lodge the following weekend to visit mom, I was surprised to see that she was dancing around the hallways, hugging other residents and laughing! I realized she had always been a "social butterfly" but Alzheimer's disease had limited her ability to engage with others in a social way. Now she was sharing all her meals with other seniors, talking to people who did not judge her for her memory loss, and she was completely happy and safe.

As a First Nations caregiver I struggled to reach out for help for my mother from mainstream healthcare system but, in the end, I was happy that I did. Mom lived for another 11 years because of the good care she received from the caring staff at the Cumberland Lodge in Cumberland BC. My mom adjusted well to life at the care facility where many others may not have. As an urban Indigenous woman, the shift from her apartment to a residential care facility

may not have been as difficult as it would have been for a First Nations person living on-reserve entrenched in culture.

Significance of the Research

The prevalence of ADRD across the globe has grown in the past few decades, and the public's awareness of this disorder has also risen (World Health Organization (WHO), 2012). The number of seniors in Canada, 65 and older, increased in the 2011 census by 14. -1 % to nearly 5 million (Statistics Canada, 2015). According to the most recent statistics there are more than 452,000 senior citizens living with dementia in Canada (Government of Canada, 2022). Aging is the leading risk factor for ADRD, and people are living longer in industrialized nations (WHO, 2012). The World Health Organization, (2012) maintains that developing a strategy to care for people with ADRD is a "public health priority" for health planners worldwide, and they estimate that the number of persons living with some form of dementia will double globally by 2030, and triple by 2050. Correspondingly, Statistics Canada (Caron et al., 2011) estimates that the number of First Nations people, 60 years of age and older, will grow 3. 4 times by 2031, which has implications for this population and for healthcare providers.

The *National Household Survey* (NHS) report indicated that there were 1,400,685 Aboriginal people in Canada in 2011, making up 4.-3% of the Canadian population (Statistics Canada, 2011). Furthermore, the Canadian Indigenous population increased 20. 1 percent between 2006 and 2011, in comparison to a 5.-2 percent increase in the mainstream population during the same period. The 2016 Canadian Census reported a similar trend upward within the Indigenous population. Between 2006 and 2016 the Indigenous population in Canada increased to 1,673,785 people which is 4.9 percent of the total population. During this period Indigenous population growth increased more than 4 times faster than the non-Indigenous population

(Statistics Canada, 2017). One of the reasons noted for this rapid population growth within Indigenous populations is that Indigenous people are living longer (Statistics Canada, 2017). Yet, at present there have been few studies done to develop knowledge that could be used to inform health care planning, policies and services for First Nations senior populations (Jacklin et al., 2013; Pace, 2013). Two recent studies conducted in Canada, suggest that various inequities put Indigenous populations at greater risk of developing ADRD than the general population (Jacklin et al., 2013; Jacklin et al., 2015). Lower education levels and socioeconomic status, hypertension, cardiovascular disease, higher rates of diabetes, a larger population of Elders, and poorer overall health places First Nations people in a high-risk category for dementia (Jacklin et al., 2015). First Nations Elders represent the most rapidly growing demographic group in Canada, and as the life expectancy of First Nations adults continues to increase, the need for research with this population becomes imperative (Lanting et al., 2011).

In 2015, the BC Seniors Advocate reported that there were over 30 thousand seniors in BC that year receiving informal care services from a friend or family member. Further, approximately one-third of the caregivers who are providing informal care to family members in British Columbia are distressed due to lack of support services (Office of the Seniors Advocate BC [OSABC], 2015). The BC Senior's Advocate, Isobel McKenzie continues to identify issues with a lack of services for caregivers in her most recent report in September 2019, particularly in more isolated communities in BC (OSABC 2019). The senior population has risen rapidly while services such as adult day programs, respite, and home support have not kept pace (OSABC, 2015, 2017, 2019). The BC Senior Advocate's reports do not specifically look at dementia care in First Nations communities in British Columbia and I did not locate statistical data that specify the number of First Nations individuals who are providing informal care to a loved one in BC.

However, Indigenous cultural beliefs and traditions compel family members to care for aging Elders. It is probable that many family members in the Nuu-Chah-Nulth territories currently provide informal supports to family members with memory loss.

Indigenous families believe that Elders have important cultural teachings to share with the whole community; hence, they should be supported to stay at home for as long as possible (Green, 2007; Jacklin et al., 2015). Yet as Haisla Elder Mary Green (2007) notes colonial policies and practices have altered BC First Nations family's ability to care for their Elders as they once did (Green, 2007). Many of the Nuu-Chah-Nulth communities on the west coast of Vancouver Island are isolated. Very little is known about Nuu-Chah-Nulth dementia caregivers' needs or perspectives on memory loss and, ADRD. Indeed, there is a gap in the literature concerning dementia care within First Nations communities in all coastal communities in British Columbia. This gap signifies a need for more research in the future.

A Statement of the Problem

First Nations Elders are living longer and within the next couple of decades the First Nations Elder population will increase significantly (Assembly of First Nations [AFN], 2007b). In fact, over the next two decades the number of First Nations Elders over 65 is expected to triple in Canada (O'Donnell & Wendt, 2017). Yet, at present First Nations communities offer fewer services to seniors and their families than any other communities in Canada (AFN, 2007b). It is likely that many First Nations Elders living on Vancouver Island and the caregivers who support them have experienced trauma and oppression through mandatory attendance in residential schools and/or Indian hospitals. The Regional Health Survey results showed that across Canada 47% of First Nations seniors aged 50-59 years and 43. 3% percent of First Nation seniors aged 60+ attended residential schools and frequently experienced negative impacts such as isolation

from family and community, verbal or emotional abuse, and loss of cultural identity (AFN, 2007b). The intergenerational effects of residential schools and Indian hospitals have certainly impacted all First Nations people in Canada, and Vancouver Island. The NTC (1996) estimates that approximately 5000 Nuu-Chah-Nulth children were removed from their homes and forced to attend residential institutions. Many Elders and caregivers across Canada were institutionalized at the beginning of their lives in residential schools or Indian hospitals. It is important that dementia care supports be provided to First Nations communities to ensure that Elders are not removed from their homes and institutionalized in provincially run long term care homes at the end of their lives. The literature suggests that at present Elders and their families are often forced to seek help from mainstream health services outside of their home community. The lack of dementia care resources in First Nations communities may result in significant stress, trauma and grief for First Nations Elders and their caregivers (AFN, 2007; Cammer, 2006; Green, 2007). But without research to back up this view, changes to existing policies that influence care practices and support services may not occur quickly.

First Nations communities in British Columbia have endured a history of racist laws, policies and practices which have contributed to the burden of ill health, violence, disability and premature death (Adelson, 2005; Kelm, 1998). Caregivers face several barriers such as chronic health issues, a lack of community resources, and economic barriers. In the past First Nations families and communities in British Columbia cared for vulnerable people, but changes to the traditional family structure, colonial policies and practices, large geographical distance between families may have impacted the family's ability to provide care (Green, 2007). First Nations families on Vancouver Island are often depicted as living in large extended families, but that may no longer be the case. Further, the literature suggests that First Nations women often shoulder the

care of Elders themselves and that places a great strain on women and their families (Gahagan et al., 2007; Haug & Prokop, 2004). However, the extent of the strain and stress that First Nations women on Vancouver Island face is largely unknown. Again, research is necessary to fully understand the dynamics of the care practices that are currently taking place and the needs that exist.

There is consensus within the sparse literature available on the topic of Indigenous populations and dementia care, for the need for research to inform resources related to aging and dementia in Indigenous populations (AFN, 2007; Green, 2007; Pace, 2013; Smith et al., 2011). Many Elders were dislocated from their traditional territories through child welfare processes and residential schools (AFN, 2007). These Elders may be isolated and lonely with no way to return home once they have been diagnosed with Alzheimer's disease or a related dementia (ADRD). The Assembly of First Nations (2007a) project that as the average life span increases in First Nations populations as many as 34% of the off-reserve community may migrate home near the end of their lives. In the interests of social justice, it is vital that research be developed around dementia care to support applications for funding to ensure that First Nations Elders and their caregivers receive the resources and support at the end of their lives. This study is important because it sheds light the impact that colonization has had on both Nuu-Chah-Nulth Elder's with dementia and their caregivers and the unique challenges that they are faced with.

Elder Care Services - NTC

Several services are offered to Elders and their families through the Home and Community Care Nursing team at the Nuu-Chah-Nulth Tribal Council (NTC). Home and Community Care nursing services are offered in all regions of the Nuu-Chah-Nulth territories

(see Appendix 1). The following excerpt from the Nuu-Chah-Nulth Tribal Council website describes verbatim the philosophy of care that underlies the services provided to Nuu-Chah-Nulth families including Elders with dementia and their family caregivers.

Nursing the Nuu-chah-nulth Way Means That:

- We welcome you and ensure your comfort
- We listen to you
- We work in a Quu?as way
- We respect you
- We connect with you to know who you are, where you come from and who your family is; who holds traditional roles in your family and how can we connect with the resources that are most precious to you
- We recognize and acknowledge who you are and what your strengths are
- We care about what has happened for you and your family and the reasons you are seeking services
- We invite you to share in and guide the health care decisions that affect you
- We support you to be a full partner in your care by documenting the story of your health and guiding decisions that affect your health
- We encourage you to use your strengths, traditional knowledge and connections with your family and elders,
- We support you to further explore your family's spiritual ways, traditional medicines, protocols and preparations
- We share our documentation with you so that you know what is on your chart, what your plan of care is all about and what your role is in supporting your care plan
- We support you to use the gifts and strengths that Naas[2] gave you when you were born
- We care that you can trust us

[2] The creator.

3. NTC (2020). Nuu-Chah-Nulth Nursing Services: Hupiimin wiiksahiiy'ap helping us to be well. Available: https://nuuchahnulth. org/services/nuu-chah-nulth-nursing-services

- We care that you feel cared for
- We believe that you are the expert of your own life and health

To us, you are not simply a diagnosis or a patient - You are a precious life. [3]

The philosophy behind Elder care at NTC Home and Community Care flows from holistic cultural belief that, "each life is a precious journey" (NTC, 2020). Nursing care for all community members seeks to nurture mental, physical, spiritual and emotional health with the premise that everyone in the community is valuable and respected, everything in the universe is interconnected. At the core of this philosophy is the idea that life is a cycle from birth to death. As noted on the NTC (2020) website, "Each life completes its cycle. Together we ask for protection, strength and guidance from Naas. Together we show compassion, respect and dignity from conception to death". Additional community services such as care-aids and respite care are offered through the West Coast Native Health Care Society and Island Health in Port Alberni British Columbia. Yet, these services may not be reflective of the local culture and philosophy of care. The NTC nursing program notes, "When we work with you – as Nuu-chah-nulth-aht – we do our work differently than the way you may have experienced with other health care professionals. We take great pride in practicing nursing the Nuu-chah-nulth way" (Nuu-Chah-Nulth Tribal Council, 2020).

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3. NTC (2020). Nuu-Chah-Nulth Nursing Services: Hupiimin wiiksahiiy'ap helping us to be well. Available: https://nuuchahnulth. org/services/nuu-chah-nulth-nursing-services

Purpose of the Research and Questions

The purpose of this research was to document Nuu-Chah-Nulth family caregivers' experiences and present them back to the Nuu-Chah-Nulth community. Recent North American studies with Indigenous communities and my personal experiences led me to wonder how Nuu-Chah-Nulth First Nations families view ADRD, and where they perceive gaps in existing ADRD care services. Discussions with the nursing team at the NTC show that there are many services currently offered by the NTC. Still, there is room to develop more knowledge about the caregiver's experiences and perspectives on memory loss. First Nations people have unique health needs, which require responsive programs, policies and care that are designed specifically for First Nations people (Jacklin et al., 2013). Collaborative discussions with Nuu-Chah-Nulth First Nations caregivers is essential to help to inform future policies, programs and healthcare practices. The following questions guided my inquiry.

1. What are the experiences of Nuu-Chah-Nulth First Nations dementia caregivers?

2. What support services do caregivers access and what services do they perceive are lacking?

I believe that it is vital that Nuu-Chah-Nulth caregivers voices be centered in this research. Their perspectives on dementia are highlighted in Chapter five of this thesis. In the next section of this chapter, I provide a brief overview of the dissertation contents.

A Forward Glance

In this introductory chapter I presented my personal experiences with dementia care to provide the reader with a greater understanding of my motivation for choosing to do this research. I outlined the significance of the research and communicated the purpose and questions that drove the study as well as a brief outline of the services for Elders offered through the Nuu-

Chah-Nulth Tribal Council Home and Community Care nursing team. In this section I provide a brief outline of the upcoming chapters.

Chapter two of this dissertation is an overview of the literature that looks at Indigenous dementia care and caregiver experiences in Canada. I provide a summary of the literature that outlines mainstream and First Nations models of care. I discuss emergent themes within current literature on family caregiving. Scholars have begun to research Indigenous dementia and dementia care across Canada, but there is still scant information about the number of Indigenous informal dementia caregivers in British Columbia and the burden of care experienced by those families.

In chapter three I review literature written by Indigenous scholars and allies that examines the root causes of health disparities in Indigenous communities. I provide a historical overview of Indigenous health to put the study into context and introduce the determinants of Indigenous health as a theoretical framework for analysis. Studies show that First Nations people are at a greater risk of developing chronic disorders which most likely puts them at a greater risk of developing dementia.

In chapter four I discuss the theoretical knowledge that informs my analysis of the participant interviews and outline the methods that I undertook to gather the participants knowledge. My identity and worldview as a Gitx̱san scholar informed the methods that I chose in this study. Critical theories align with my values as a social worker and underlie my motivations to examine Nuu-Chah-Nulth caregivers experiences.

In chapter five I present the participants' stories. To the best of my ability, I describe the context of their experience to enable the reader to envision their realities. Nine Nuu-Chah-Nuth family caregivers shared their experiences and insights into dementia care. Each of their stories

was unique and rich with insight into caregiving on the Westcoast of Vancouver Island. I present the caregivers' individual experiences using a storytelling method. I recounted the participants' stories using the interview notes and journal entries that were made immediately following each interview visit.

In chapter six I present the themes that emerged from the interview transcripts from my perspective. The Nuu-Chah-Nulth caregivers had provided informal support and care to a broad range of family members; a grandmother, father, mother, brother, wife and husband. While their experiences were distinctive, they shared a common story of trauma over their life cycle brought about through colonial oppression. The care providers struggled with the burden of caregiving while managing the disfunction that emerged from racist colonial policies. Yet, love, strength and resistance and a deep and enduring connection to culture also emerged in the stories.

In chapter seven I offer my analysis of the stories and weave my experience into the dialogue as a means of transparency. My interpretation the participants stories was influenced by my personal experiences as a dementia caregiver. My and my mother's experiences were similar to those of many of the informal family caregiver's and/ or Elders with dementia who participated in this study. Colonial traumas, violence, loss of culture and connection with our way of life has harmed Indigenous families and communities and added unique challenges to the participants experience providing dementia care. The final chapter concludes with an analysis and summary of recommendations for policy makers to promote healing and reconciliation.

Chapter Two: Dementia & Indigenous Caregiving

Introduction

While there are few published descriptions of traditional caregiving practices within First Nations communities in British Columbia (BC), it is widely believed that Indigenous people in North America historically relied on their families and communities when they were ill or in need of support (Green, 2007; Jervis & Manson, 2002; John & Hennessey, 1996). At present, there is limited literature that describes the provision of dementia care in First Nations communities and even less documentation of caregiving practices on Vancouver Island specifically thus I expanded my literature review to include North American literature that informs this study. I begin by discussing the current approaches to dementia care in Canada, Indigenous dementia care and caregiving practices. This chapter begins with a brief overview of various diagnostic and care approaches to dementia care. The biomedical and bio-psychosocial approaches to care are discussed as well as First Nations approaches to healthcare. The cultural philosophies that underpin First Nations approaches to health, ageing, memory loss and well-being are discussed to situate the distinctiveness of First Nations perspectives on health. The next section examines recent studies on Indigenous dementia care and the available literature that describes First Nations caring practices. Much of the literature on dementia and caregiving explores the challenges of care in contemporary communities (Haug & Prokop, 2004; Pace, 2013). Families face several barriers when they take on the responsibility of providing care to ageing family members who are experiencing memory loss (Finklestein et al, 2012; Habjan et al., 2012). I conclude with the literature that describes who the caregivers are and how they cope with the demands of caring.

Approaches to Dementia Care

The Biomedical Perspective

The biomedical view of dementia largely underpins current health and community care services for people with dementia (Sabat, 2001). Thus, it is useful to begin this chapter with a brief description of the knowledge that informs current dementia care policies and practices. There are several forms of dementia that are considered irreversible including Alzheimer's disease, vascular dementia (VaD), Creutzfeldt-Jakob disease, dementia with Lewy bodies (DLB), and frontotemporal dementia (FTD). Alzheimer's disease is the most common form of dementia; 60 - 80 percent of persons diagnosed with dementia are diagnosed with Alzheimer's disease (Alzheimer's Association, 2021). Alois Alzheimer first located and described the neurological disease near the turn of the 20th century, in 1907. In 1960s and 70s the disorder was reassessed, and the more common neurological condition known as senile dementia was included within the Alzheimer's diagnosis (Herskovits, 1995). At that time there was a dramatic increase in the number of individuals diagnosed with the Alzheimer's disease. In addition, pharmaceutical drug companies began looking for cures more aggressively, services and resources grew, and new diagnostic criteria was developed to better distinguish the symptoms of dementia and Alzheimer's disease (Herskovitz, 1995). For example, the World Health Organization's definition of dementia states that:

> Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, and comprehension, calculation, learning capacity, language and judgment. Consciousness is not clouded. Impairments of cognitive function are

> commonly accompanied and occasionally preceded by deterioration in emotional control, social behavior, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions which are primarily or secondarily affecting the brain (WHO, 2012:7).

Symptoms of cognitive impairment vary from person to person; however, a diagnosis of dementia is warranted when a person displays noticeable evidence of short- and long-term memory impairment accompanied by at least one of the following: issues with aphasia (language), apraxia (motor skills) or agnosia (perception) (Sabat, 2001).

There are several stages of cognitive decline involved in the progression of the disease. The Alzheimer Society Canada (2019) notes that "the Global Deterioration Scale, also called the Reisberg Scale"[4], is still used by many practitioners to measure the progression of Alzheimer's disease. This scale divides Alzheimer's disease into seven stages of ability".

Global Deterioration Scale

Global Deterioration Scale[5]

Stage # 1: No Cognitive Decline	• Experiences no problems in daily living.
Stage 2: Very mild cognitive decline	• Forgets names and locations of objects. • May have trouble finding words.

[4] Reisberg, B., Ferris, S. H., de Leon, M. J., and Crook, T. (1982). Modified from Global Deterioration Scale. American Journal of Psychiatry, 139:1136–1139.

[5] The stages of deterioration outlining the progression of Alzheimer's disease was copied from the Alzheimer Society Canada website. https://alzheimer. ca/en/Home/About-dementia/Alzheimer-s-disease/Stages-of-Alzheimer-s-disease/Global-Deterioration-Scale It was modified into table form.

Stage 3: Mild cognitive decline	• Has difficulty travelling to new locations. • Has difficulty handling problems at work.
Stage 4: Moderate cognitive decline	• Has difficulty with complex tasks (finances, shopping, planning dinner for guests).
Stage 5: Moderately severe cognitive decline	• Needs help to choose clothing. • Needs prompting to bathe.
Stage 6: Severe cognitive decline	• Loss of awareness of recent events and experiences. • Requires assistance bathing; may have a fear of bathing. • Has decreased ability to use the toilet or is incontinent.
Stage 7: Very severe cognitive decline	• Vocabulary becomes limited, eventually declining to single words. • Loses ability to walk and sit. • Requires help with eating.

The only way to conclusively diagnose Alzheimer's disease is through a post-mortem examination of the brain tissue. Thus, diagnosis of the disorder is never definite, it is probable (Sabat, 2001). A clinical post-mortem examination of the brain would reveal "senile plaques composed of beta- amyloid tissue, an abnormal protein, and neurofibrillary tangles (strands of axonal material that replace normal neural neurons) in the cerebral cortex" (Sabat, 2001:5). This degeneration within the brain interferes with the neuron's ability to send and receive information. Other clinical markers of Alzheimer's disease include a reduction of chemical transmitters such as dopamine, serotonin and acetylcholine (Sabat, 2001). Sabat (2001) notes that the cortex shrinks during the progression of the disease, yet some areas of the cortex remain unscathed. This is significant because there may be some areas of the brain that are still intact that clinicians

are unaware of since people with Alzheimer's disease and related dementias (ADRD) have difficulty speaking.

The primary intervention for individuals in advancing stages of dementia is residential home care and psychosocial interventions (WHO, 2012). In earlier phases of the disease people with dementia often receive informal care from family members to continue to live at home. In the past, clinical practice guidelines often advocated for the use of acetylcholinesterase inhibitors (AChIs) (Mehta et al., 2005), yet there is growing evidence that these drugs are ineffective past twelve to fourteen months (Knowles, 2006). In addition, clinical practices in care homes approve the use of various pharmaceutical drugs to control challenging behaviours (Kitwood, 2012). Some authors assert that medicalized care interventions are focused on the diseased body with less concern for the social, psychological and cultural aspects that influence the person with ADRD's subjective experience (Downs, 2000; Iffle & Manthorpe, 2004). Over the past few years there has been a shift towards the bio-psychosocial approach in high income countries such as Canada, and a shift away from task driven medical approaches to care (WHO, 2012).

The Bio-psychosocial Perspective

Much has been written within the past couple decades to evaluate previous clinical practices and to develop a more fulsome understanding of the subjective experiences of people diagnosed with dementia and their social, and psychological needs (Cotrell & Shultz, 1993; Kitwood & Bredin, 1992; Kitwood, 2012; Kontos, 2005; O'Connor, et. al, 2007; Sabat, 2001). The bio-psychosocial model places an emphasis on nurturing the person with ADRD's intact abilities and personhood (Sabat, 2011). Personhood as described by Kitwood (2012:8) is "the standing or status that is bestowed on one human being by others in the context of relationship

and social being. It implies recognition, respect and trust". Sabat (2011) argues that the quality of life for individuals with ADRD depends on the caregiver's ability to recognize the individual's undamaged abilities while minimizing "excess disabilities". A term coined by Kitwood (2000); excess disabilities are disabilities that are assigned due to the perception that the person with Alzheimer's disease has experienced a loss of many of their capabilities. Kitwood (2012:4) uses the term "malignant social psychology" to describe the depersonalizing treatment that is often provided to people who have been diagnosed with dementia. Further, Kitwood (2012) argues that certain aspects of malignant social psychology such as isolation, banishment, stigmatization and infantizing can further damage the cognitive health of the person with dementia.

A diagnosis of ADRD can be damaging to the social and psychological well-being of individual due in part to the way that the disorder is socially and culturally constructed in western societies. Dementia of any kind is often presented as terrible disease, one that results in progressive loss and death (Herskovitz, 1995; Kitwood & Bredin, 1992). A diagnosis of dementia may inspire fear and depression due to a universal acceptance of the disease construct (Henderson & Henderson, 2002). Yet, people with ADRD can enjoy an enhanced sense of well-being if care practices are altered to minimize excess disabilities (Kitwood, 2012). Kitwood & Bredin (1997: 282) present several indicators of well-being, the most significant are "personal worth & self-esteem; a sense of agency; social confidence and hope". Care that nurtures these elements of selfhood are more likely to support the individual with ADRD's well-being. Sabat (2011) advances the notion that caregivers who are knowledgeable about ADRD and aware of a person with dementia's intact abilities are more empathetic and patient in their approach to care. There is also evidence to show that a person who has been diagnosed with ADRD may benefit from a delayed progression of the disorder if the care they receive supports their personhood

(O'Connor et al., 2007). Kitwood & Bredin (1997) further suggest that when conditions of a person with ADRD life improve (particularly social conditions) they may develop a "remission" of the symptoms associated with ADRD.

The shift to a "person centred approach" to care in senior residential care homes has been beneficial to the quality of life of people with dementia (WHO, 2012). Many elements of person-centred care may be beneficial in First Nations Elder care as well, but little has been written on the topic. Henderson and Henderson (2002) note that the way that an individual makes sense of dementia is influenced by biomedical input, shared cultural understandings and their own unique circumstances. It is reasonable to expect that First Nations people in BC have been influenced by biomedical interpretations of dementia as a disease (Hulko et al., 2010). Still, First Nations people have unique cultural understandings of health and aging that influence the services they provide for Elders and their families, which I discuss in the following section.

First Nation Perceptions of Health Aging & Memory Loss

It is important to note that Indigenous cultures and belief systems vary across North America (AFN, 2007; Waldram et al., 2006); subsequently each tribal group may have a different understanding of health, ageing and memory loss. In fact, First Nations healing practices like the cultures themselves were very complex at the time of first contact with European settlers (Waldram et al., 2006). Culture influences the way that groups make sense of health and illness (Jervis et al., 2006; Waldram et al., 2006) and First Nations people in British Columbia had "(and in some cases still have)" very distinct bodily practices and "systems of medicine" that flow from their worldview (Kelm, 1998: 83). Mary Ellen Kelm (1998) states that, First Nations people historically believed that diseases were a product of both natural and

supernatural causes. Hence, treatments included spiritual practices and ceremonies, in addition to herbal remedies.

Not surprisingly European settlers viewed Indigenous healing practices with skepticism, as there was no Eurocentric scientific basis for the healing practices (Waldram et al., 2006). The healing practices of Medicine people came under fierce attack and were banned and illegal to practice in the first half of the 20th century. First Nations health practices and ceremonies went underground with other cultural practices such as the potlatch and the sun dance (Waldram et al., 2006). Mary Ellen Kelm (1998) notes that over the 20th century many BC First Nations deployed healthcare practices from both traditional healers as well as medical doctors so that a state of medical pluralism existed. Indigenous healing practices have re-emerged since the mid 1980's in the form of community healing (Kelm, 1998; Waldram et al., 2006). In a health study conducted in British Columbia, 66 % of the 91 First Nations respondents who were interviewed said that there were traditional healers practicing in their communities. Traditional healers were defined as "people who are knowledge keepers, people who are gifted and people who are spiritual" (First Nations Health Society, 2010: 6).

First Nations communities view health and wellness through a holistic lens (FN Health Society, 2010) which bears some similarity to the bio-psychosocial method (Pace, 2013). In contrast to the biomedical approach, a holistic model of health is concerned with the whole person not simply the part of the person that is diseased or injured (Adelson, 2005). Holistic approaches to health take into account the mental, emotional spiritual and physical elements of the individual (AFN, 2007). The well-being of First Nations people is connected to the culture and staying close to the land, their families and communities (Adelson, 2005). Indigenous ways of knowing emphasize communal values and the interconnectedness of all things. Social support

networks remain strong in most communities in BC today, even in the wake of historic traumatic events such as residential schools (First Nations Health Council, 2010).

First Nations people believe that Elders perform an important role in their communities and that respected position may not be greatly altered when signs of memory loss emerge (Hulko et al., 2010). On Vancouver Island Elders in early stages of memory loss are often included in community events[6] as they are highly valued members of the community. Elders contribute to the health and wellness of the community through sharing and transfer of knowledge and culture, (AFN, 2007: National Aboriginal Health Organization [NAHO], 2010) including knowledge of traditional healing practices and medicines (Kelm, 1998; Parrack & Joseph, 2007). First Nations people are taught from a young age to care for vulnerable people in their communities including Elders, and caring for Elders is viewed as a privilege rather than a burden (First Nations Health Society, 2010; Green, 2007; Habjan et al., 2012).

Over the years a few studies conducted with First Nations groups and individuals suggested that First Nations people view memory loss as a natural part of aging and they may not see memory loss as a negative characteristic (Hendrix & Swift Cloud, 2006; Hendrie et al.,1993; Hulko et al., 2010). In more than one study Elders and community members reported that the regression from adult to baby is part of the "cycle of life" (Hulko et al., 2010; Griffith-Pierce et al., 2008). As Hulko et al., (2010) note, the cycle of life to return to a baby does not mean the same thing in First Nations communities as it does in contemporary dementia literature. In First Nations culture babies are very highly revered and the "cycle of life" symbolizes a return to the spirit realm. In another study with American Indian Elders the symptoms of dementia were

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[6] Personal Communications, Tina Biello, Alzheimer Society of BC First Link Coordinator, November 2013.

interpreted as “supernormal abilities” to connect with the spirit world (Henderson & Henderson; 2002). Elders who experience the hallucinatory symptoms of dementia may be admired for their connection with ancestors in the spirit world (Henderson & Henderson; 2002; Hulko et. al, 2010).

Downs (2000) notes that, “Not all cultures view dementia as a disease. In fact, the disease model of dementia is a relatively recent one within the Western culture and is not universally held” (370). Traditionally First Nations people viewed the symptoms of memory loss as a natural part of life. Some authors assert that knowledge of dementia and Alzheimer’s disease is low in Indigenous communities (Hendrix & Swift Cloud-Lebeau, 2006; Pace, 2013). In some Indigenous communities, the term dementia may not be known or used, or the term may be associated with mental illness and may carry a stigma (Hendrix & Swift Cloud-Lebeau, 2006). Yet, as awareness of ADRD has grown, Elders and their families are beginning to see dementia as a terrible disease that has come to First Nations communities with the “white people” (Hulko et Al., 2010; Lanting et al., 2011; Pace, 2013).

Historically there was little literature that described First Nations perspectives of what it means to experience a sense of well-being in old age. A 1997 report by the National Indian and Inuit Community Health Representatives Organization provides a good description of First Nations cultural perspective on aging well in their report *Ageing and cultural diversity: A cross cultural approach*. Essentially the report suggests that Elders perception of aging well involves,

> …physical, mental, emotional and spiritual well-being; empowerment (ability to make decisions about one’s life); awareness of and access to information about existing programs and services; easy access to medical, social and other support services; aging in place with respect and dignity, for as long as possible (independent and interdependent living); a

> supportive social environment; continued community involvement and participation; financial security; adequate and affordable housing; and accessible and affordable transportation (16).

Indigenous Elders view successful aging through a holistic lens striving to maintain health so that they can give back to their families and communities (Baskin & Davey, 2015; Tonkin et al., 2018). Indigenous Elders value being active in their communities and passing their knowledges to the younger generation (Tonkin, et al. 2018). In the next section, I discuss recent studies with informal Indigenous caregivers and Elders with dementia in Canada. First Nations people are living longer, risk factors for dementia are more widespread, and colonization has created distinct health vulnerabilities in First Nations populations (Jacklin et al., 2013).

Recent Studies on Dementia within Canadian Indigenous Populations

Kristen Jacklin and her colleagues (2015) studied the experiences of First Nations informal caregivers in seven culturally diverse communities in Ontario, Canada. This study sought to explore Indigenous models of care to gain perspectives on how to best support informal family caregivers. The themes that emerged centered around "how participants came to the caregiving role; the challenges, struggles, and decisions along the way; and reflections on the rewards and benefits of caring for a loved one with dementia" (Jacklin et al., 2015:106). Findings from the study showed that the Indigenous caregivers face significant challenges in part due to settler- colonial relations and policies, which govern community support services. The caregivers in this study reported that they did not view caregiving as a burden, which is consistent with other recent Canadian studies with First Nations dementia caregivers (Finkelstein et al., 2012; Jacklin et al., 2015; Parrack & Joseph, 2007). Moreover, caregiving was looked upon as an honor

and a cultural obligation rather than a burden. The authors noted that more research needs to be done to fully understand First Nations cultural models of care (Jacklin et al., 2015).

There have been few studies done with First Nations Elders and dementia caregivers in British Columbia. One study that is significant to this research was conducted in 2010 by Wendy Hulko and her colleagues with Secwepemc Elders in the interior of British Columbia (Hulko et al., 2010). The findings of this study indicated that ideas with regard to memory loss and memory care within the Indigenous community have shifted over the past century. Dementia was described as a terrible disease rather than a normal part of aging. Elder participants identified changes in traditional diet, loss of culture, residential schools and trauma as possible influences that may be responsible for increase in the prevalence of ADRD. Strategies for supporting Elders with memory loss revolved around bringing back a traditional lifestyle and supporting one another (Hulko et al., 2010).

In 2009, British Columbia Provincial Health officer Dr. Perry Kendall reported that dementia rates were slightly lower in British Columbia for First Nations populations between 2002 and 2007 (British Columbia Government, 2009). The rate of dementia between males and females was not appreciably different for either First Nations or non-First Nations populations. Yet, the findings from another more recent study in Alberta showed a significant rise in the prevalence of ADRD within the First Nations population in that province. Jacklin et al., 2013: e42 reported that, dementia rates grew in Alberta status First Nations populations, from “3. 9 per 1000 to 7. 5 per 1000” between 1998 -2009. The prevalence of dementia rose 34 percent more rapidly for First Nations people than their non-First Nations counterparts during this study. Notably, the findings in this study also indicated that dementia disproportionately affects younger age groups and males in First Nations communities in contrast to non-First

Nations populations. Both of these studies differ from national studies that indicate that women have a higher risk of developing ADRD (Azad et al., 2007).

Culture plays and important role in shaping caregiving practices. In her doctoral dissertation, Pace (2013:171) notes "culture shapes the type and amount of care that is given, who provides care, the coping strategies that caregivers employ, the use of formal supports and social services". Caregiving been shown to manifest itself differently across different cultures therefore it is important to consider caregiving practices within the cultural contexts with which they occur (Pace, 2020). Indeed, there are few published articles that describe dementia caregiving within an Indigenous context, as the notion that memory loss in old age is a disease is a relatively new concept in First Nations communities. There are few published works that explore informal dementia care within First Nations groups on Vancouver Island. Yet, there are several articles and books that describe caregiving in Indigenous communities in more general terms. In the next section I deliberate the literature that describes First Nations caring frameworks, the challenges that First Nations people face and the coping methods that they employ.

First Nations Models of Care

There are similarities in the way that Indigenous peoples across North America view healing, helping and caregiving. Research suggests that extended families traditionally provided primary care for ailing Elders and other vulnerable people within their kinship group. Moreover, the entire community played a part in the providing care (Buchignani & Armstrong-Esther, 1999; Lanting et al., 2011). Members of the First Nations communities worked together to ensure that individuals who were exhibiting symptoms of cognitive decline were safe and cared for (Lanting et al., 2011). In Pacific Northwest Coast communities, the most basic social and economic unit is

the house, which is a group consisting of several extended family members (Muckle, 2012). On Vancouver Island Elders would have lived within a large extended family unit only a couple of centuries ago. Large extended families lived together in a longhouse in the winter and lived closely in the spring and summer. Elders were part of every activity that the family was involved in including gathering food and childcare. In this context caregiving was a way of life (Muckle, 2012). Elder Mary Green (2007) notes that First Nations families and communities in BC assumed a collective approach to caring for the ill and vulnerable people within the community, but that trend has changed over the last 100 years because of the loss of culture that occurred due to residential schools.

Caregiving: Contemporary Trends

A significant theme that emerges in the literature is the impact that colonization has had on culture and family caregiving traditions (Green, 2007; Lanting et al., 2011; Sutherland, 2007). There is a trend towards informal caregiving in First Nations communities but changing community dynamics make it more difficult for family to provide care (AFN, 2007; Jacklin & Walker, 2020). First Nations communities are facing a declining number of caregivers due to migration of young people from reserve communities to the cities for employment. Elders who may have been part of a large extended family in the past are now more likely to live alone (Buchignani & Armstrong-Esther, 1999). According to Habjan and colleagues (2012), Indigenous caregivers often provide support to elderly family members from a distance which puts an additional strain on the caregiver and the Elder.

Jervis and Manson (2002) suggest that the prevalence of informal care in Indigenous communities is likely due to cultural traditions and a lack of available resources. Even when formalized dementia care supports are available First Nations families may be reluctant to access

mainstream health care services due to oppressive past experiences with public health care professionals (Cammer, 2002; Hendrix, & Swift Cloud, 2006; Loppie & Wein, 2009). Racism in the healthcare system on Vancouver Island specifically has been well documented (Barrera, 2020; Turpel-Lafond, 2020). A recent independent review in British Columbia found that anti-Indigenous racism in the healthcare system is prevalent. Eighty four percent of the Indigenous people who responded to the independent review reported that they experienced some form of discrimination while accessing health care services (Turpel-Lafond, 2020). Families who have experienced racism at the hands of the healthcare system are more reluctant to reach out for help again. Indeed, Elders and family members who have attended residential school and/or an Indian Hospital may fear the health care system (Adelson, 2005; Cammer, 2006). Lack of formalized care supports and information on the disorder may add to the stress that families experience while providing care. The Assembly of First Nations (2007a) strongly recommends that care supports such as respite care, adult day care, nursing hours, information on medical conditions and training on how to provide good care be extended to Indigenous informal caregivers. The AFN (2007a) also stresses the importance of including cultural contents when designing programs and information for Indigenous caregivers to ensure that the supports will be utilized. Nuu-Chah-Nulth healthcare practitioners acknowledge a need for culturally safe trauma-informed approaches to eldercare

Some authors note that Indigenous informal caregivers may struggle with the economic realities of negotiating care for Elders with memory loss (Cammer, 2006; Jervis et al., 2004; Parrack & Joseph, 2007). Families living on the margins do not always have the basic resources to help or care for their elderly family members, and that may lead to stress and guilt (Brown & Gibbons, 2008). Caregivers may struggle because of the poverty and lack of long-term care,

respite care and other support systems on reserves (Crosato et al., 2007; Finkelstein et al., 2012; Jervis & Manson, 2002). First Nations Elders are twice as likely to live with extended family members as their counter parts in the non-Indigenous community. Private care or extra health care supports for Elders is often out of reach for First Nations families who are experiencing financial hardships. Of particular concern is when families are not functioning well and Elders living with extended family may not receive the care they need (Jervis & Manson, 2002). Issues such as poverty, mental health substance abuse and housing shortages increase the risk of Elder-abuse (Dumont-Smith, 2002). Caregivers who have few supports and little information on the disease are more likely to neglect the care recipient's basic needs (Jervis & Manson, 2002).

Caregiver Health

Many past studies have focused on the burden of care and the impact that caregiving may have on the informal caregiver's health (Bedard et al., 2004; Bradley, 2003; Goins et al., 2011). Caregivers face multiple stresses including a lack of leisure, stress and worry about the progression of the disorder, lack of finances, lack of resources, mental health challenges and strains with personal relationships (Gahagan et al., 2007; Hennesey & John, 1996). First Nations Elders have more complex care needs because they live within lower socioeconomic conditions and often have comorbid health issues (Reading, 1999). Indigenous communities are often located in rural and remote areas which impedes their ability to receive formal supports (AFN, 2007; Cammer, 2006). Many First Nations communities on Vancouver Island are geographically located in remote areas only accessible by boat or a small plane, so issues of isolation are a concern. Some authors posit that the impacts of caregiving may be more profound on individuals living in rural locations. In more than one study caregivers living in isolated communities reported that they experienced more difficulty with problem behaviors by care recipients and

they managed with fewer formal supports (Bedard et al., 2004; Crosato et al., 2007). Formal support systems are most often non-existent in rural and remote First Nations communities which may increase the burden of care as well as impacts to the care giver health if social networks are limited.

Another area of concern for First Nations caregivers that emerged from the literature is the high risk of chronic health issues that exist in the First Nations community (Parrack & Joseph, 2007). Often the family members who are available to provide care are struggling with a chronic disease themselves (Bradley, 2003). John et al., (1996) found that dementia care causes more strain on the caregiver than caring for a family member with a physical disability. Providing dementia care is perhaps the most difficult kind of caregiving, because the care recipient may become irrational or violent (Bradley, 2003). Caregivers who are struggling with poor health experience more stress and strain than those who are in good health and may not have the strength or ability to manage the difficult behaviors that are often characteristic in the later stages of dementia (Bradley, 2003). Colonial structural inequity had contributed to health disparities in First Nations communities. Elder caregivers, and particularly spouses who are Elders themselves, may suffer from chronic health issues that impede their ability to provide care (Habjan et al., 2012).

Gendering of Care

Many Indigenous women across Canada live in extreme poverty due to the socio-economic implications of colonization and patriarchy (NWAC, 2017). Yet, the burden of caring for Elders most often falls on First Nations women (Gahagan et al., 2004; Habjan et al., 2012; Ward- Griffith, 2007), many of whom are working and raising children (Parrack & Joseph, 2007). Several studies report that the typical caregiver is a female family member between the

ages of 50 and 80 (Ber-Weger et al., 2001; Bradley, 2003; Quinn et al., 2012). Socially constructed norms influence the perception that caretaking is solely a women's responsibility, but that role may add undue stress and strain on Indigenous women (Gahagen et al., 2007). Haug and Prokop, (2004) note that the development of home care services has increased in Saskatchewan over the past few years and there is a growing need for care services for Indigenous people. Indigenous women are the primary support givers for Indigenous Elders in that province. Yet, Indigenous women are largely absent in the planning and implementation of programs aimed at seniors and Elders. The authors argue that Indigenous women must be included in "research, policies, training and services", to inform the creation of culturally safe home care services for Indigenous Elders, as to often support services for Indigenous Elders is conceptualized through a Western model of care (Haug & Prokop, 2004:3). Indigenous women's experience and knowledge is disregarded.

Some authors contend that women and people from marginalized groups experience the highest level of caregiver burden (Kim et al., 2012). Indigenous women report that they are less burdened when caring for Indigenous Elders when their families and communities are supportive. In one study Indigenous women caregivers living within the Indigenous community identified their community as a major source of emotional support and respite care (Gahagen, et al., 2007). In another study Indigenous caregivers reported that they drew strength and support from healers, family and friends and that social support decreased their perception of being socially and geographically isolated (Crosato et al., 2007). This research found that social support was a social determinant of health for caregivers in rural and isolated communities. When communities and families view caring for Elders as a healthy part of their cultural traditions, they are more supportive to the caregivers within the community.

The Rewards of Caregiving

Indigenous people report that they would prefer to provide informal care to keep their Elder family member at home for as long as possible (Pace, 2020). The impact of colonization has hindered the communities' ability to provide caregiving, yet Elders are still very highly regarded within First Nations communities in BC (Green, 2007). Not all caregivers report that caregiving is a burden. In fact, most First Nations communities still look at the act of caring for a family Elder as a privilege, an act of love (Gahagan, et al., 2004). Hennessey and John (2006) found that Indigenous caregivers are most likely to emphasize the positive aspects of caregiving along with the struggles of providing care. In addition, the perception of care through a positive light has been shown to improve caregiver's self- esteem and well –being (Berg-Weger et al., 2001). Indigenous families report that the rewards of caregiving include development of better relationships with the care recipient and seeing an improvement in the care recipient's health (Hennessey & John, 1996; Jervis et al., 2010). Indigenous caregivers in more than one study have stated that they would welcome more training, support groups and resources outlining the expectations of care (Buchignani & Armstrong-Esther, 1999; Hennessey & John, 1996). Caregivers would be better equipped to support their Elder family members to remain in their homes longer with access to culturally sensitive information on the disorder (Pace, 2013).

Summary

In this chapter I provided a general overview of the literature that discusses Indigenous caregiving and differing approaches to health and dementia care. Indigenous communities view Elder health and wellbeing through a holistic lens which includes elements of spirituality and culture. Dementia care in Canada is built on the medical model which treats the symptoms of the

disease and addresses health deficits but may not be culturally safe for Indigenous people. Dementia has emerged as a concern within Indigenous communities in Canada in the past couple decades. Cultural beliefs and traditions shape the way that First Nations people view ageing, memory loss, and caregiving in First Nations communities. In the absence of First Nations community-based dementia care services, First Nations families and communities are forced to reach out to mainstream resources and services that are culturally incompatible with their worldview. The consequences of being forced to access mainstream dementia care systems may be significant for First Nations people.

Chapter 3: Theorizing Elder Healthcare using Indigenous Knowledge

Introduction

Over the past few decades, the topic of (ADRD) has emerged as a health issue facing Indigenous people in North American and abroad (Flicker, Lautenschlager et al., 2008; Jacklin et al., 2015; Lindeman et al., 2012; Radford et al., 2015; Warren et al., 2015). The health of Indigenous Elders and their caregivers in contemporary communities is very closely entrenched with the historic relations that Indigenous people have endured with the state (Adelson, 2005). Elders with memory loss and their caregivers are more likely to have a chronic medical condition, live in substandard housing, and live in social isolation (Loppie & Wein, 2009). The common root of all these issues is poverty, which is a result of colonial imperialism and structural inequality (AFN, 2007). Therefore, it is crucial to examine the social determinants of First Nations health to put the contemporary practices of dementia care into perspective. In this chapter I provide a brief overview of the history of Indigenous healthcare in Canada, and the risk factors that may contribute to the increasing prevalence of dementia in First Nations communities. I contend that the determinants of Indigenous health provide a valuable framework for analysis of the caregiver's stories in this research. Indigenous theorists examine the ways that social, political, historical and economic determinants intersect to create health disparities in First Nations communities in Canada (Reading, 2015). As a social worker and educator, I conceptualize Elder health care through a social justice lens which aligns well with the determinants of Indigenous health framework.

Indigenous Health

Colonial oppression has had a profound influence on the health of Canadian First Nations families and communities in British Columbia. Moreover, the link between colonization and the health and wellness of Indigenous people in Canada has been well documented (AFN, 2007; BC Health Officer, 2009; NAHO, 2010). According to the literature, First Nations people on Vancouver Island thrived in relatively good health prior to contact with European settlers (BC Health Officer, 2009; Kelm, 1998). Several authors assert that the health disparities that Indigenous people suffer from in the present day can be directly linked to the effects of colonization (Adelson, 2005; Kelm, 1998; Reading, 2009; WHO, 2012). Health disparities are indictors that show an unequal burden of disease on a population, while health inequalities are the underlying causes of the disparities (Adelson, 2005). The health disparities that First Nations communities on Vancouver Island face in the present day are related to racist legislation that has led to decades of social, economic, political and cultural inequality (Adelson, 2005). Policies of assimilation resulted in forced internment of thousands of children in residential schools and Indian hospitals, which was an assault to the health and overall well-being of all First Nations people on Vancouver Island.

There is evidence to show that First Nations people have occupied the land now known as British Columbia for 12,000 years. First Nations people have unique creation stories and oral histories which document their existence on their lands. Before that time ice covered most of the land base. Prior to the arrival of European settlers, the First Nations population in BC is estimated to have been 200,000 to 300,000 people (Muckle, 2007). As well, First Nations populations were reasonably disease free during the pre-contact era. This was due to their access to a healthy varied diet, a physically active lifestyle, and knowledge of herbal/plant medicine and

holistic health practices (Kelm, 1998). The health issues that contribute to dementia risk such as diabetes, heart disease, and obesity were virtually non-existent in pre-contact times (BC Provincial Health Officer, 2009). First Nations healers used a variety of herbs, plants and techniques to heal the community. Over five hundred of the ingredients used pharmaceutical medicines today were used by First Nations people in the pre-contact era (BC Provincial Health Officer, 2009). Many Vancouver Island First Nation people still rely on traditional medicines and ceremonies as a means of maintaining good health (Kelm, 1998).

The arrival of Europeans in British Columbia in the 1800s severely altered First Nations people's way of life and by 1929 the First Nations population dipped to an all-time low of 23,000 people (BC Provincial Health Officer, 2009). First Nations people were particularly vulnerable to diseases that they had never been in contact with as they had no immunity to new illnesses. Viral diseases such as smallpox, tuberculosis, influenza, scarlet fever and measles spread uncontrollably in Native communities, where vaccines had not been distributed (BC Provincial Health Officer, 2009; Kelm, 1998; Muckle, 2007). Infectious diseases played a part in the health and population decline of First Nations in BC, but the enduring causes of First Nations health disparities are the socio-economic, political and cultural inequities that persist to this day. Many of the people providing informal care to Elders with memory loss have been impacted intergenerationally by the implementation of residential schools and Indian Hospitals.

Residential Schools & Indian Hospitals

Residential schools operated for approximately 100 years in the Nuu-Chah-Nulth territories, ending in 1983 (Nuu-Cha-Nulth Health Council, 1996). A large percentage of the ageing First Nations population in BC and their family caregivers attended residential school in

the past century. Yet, the effect that these institutions have had on the provision of Elder care practices on Vancouver Island remains largely unknown. Residential Schools were introduced by the Canadian government and churches in the 1890s with the goal of assimilating Indigenous people and eradicating the First People's culture, values and beliefs. The utimate goal of annihilating Indigenous people was to gain access to their land and resource (Alfred, 2005). Mandatory attendance in residential schools has had a profound effect on BC First Nations people's health and wellbeing. Nearly all survivors of residential schools report some sort of mental, physical, spiritual or emotional harm to their health (Reading, 2009). For instance, one qualitative study exploring the experiences of close to a hundred survivors on the Westcoast of Vancouver Island found that 91% reported loss of language and culture, 92-% had witnessed abuse of other children in the schools, 90% reported having been abused themselves in one or more ways (e. g. , physically, sexually and/ or emotionally), 84% reported problems with family, parenting, relationships and communication, 76% stated that they experienced feelings of inferiority and a loss of their self-respect, and 93% of the residential school survivors reported feelings of severe loneliness and abandonment (Nuu-Cha-Nulth Health Council, 1996). These reports are consistent with the stories shared by Coast Salish Elders in a recently published anthology of stories entitled "*Speaking our Truth: Cowichan Stories of Residential Schools*" (Cowichan Tribes, 2009). In the preface of this document Cindy Daniels (2009) notes,

> To explain that such a high percentage of our band's population had attended residential school it stands to reason that 100 % of our membership is affected by "intergenerational" effects that have been passed down from one generation to another. Each of us has either attended residential school or is related to a family member who attended (4).

Many Vancouver Island First Nations Elders and their family caregivers attended a residential school as a child. If caregivers did not attend a residential school, they were indirectly impacted by the intergenerational effects. While there is sparse literature on the impact that residential schools have had on the cognitive health of Indigenous survivors. Some researchers have noted that the link between dementia and residential school attendance is an important area for future research as recent studies link post- traumatic stress as a risk factor for dementia (Hulko et al., 2010; Jacklin et al., 2013).

Another colonial institution that has impacted Coast Salish people's perception of public health care was the establishment of Indian Hospitals in BC. The early part of the 19th century heralded a rise in knowledge that was produced through the disciplines of medicine and science. The general belief at the time was that science could cure any ill. During the same period there were attempts to undermine and ban First Nations traditional health practices (Kelm, 1998; UVic, 2011). First Nations healers sought help from the newcomers to help them heal their community members who were dying from European illnesses, which only served to further legitimize European medical practices. Health officials and governments authorities held racially prejudiced belief that First Nations populations were weak and that their predisposition to illness may be a threat to Europeans (Adelson; 2005; Kelm, 1998; Lux, 2010). A decision was made to segregate First Nations populations in "Indian hospitals" as a means of controlling the spread of disease, and this strategy also furthered the goals of assimilation. Thousands of children were physically removed from their homes to sanatoriums far away from their reserve communities (Adelson, 2005; Drees, 2010; Lux; 2010). Many of the children died without ever seeing their families again (Kelm, 1998).

In British Columbia the first Indian hospital, Cooqualeetza Indian Hospital, was created near Sardis BC in early 1930. It was the primary sanatorium in BC until the 1940s when sanatoriums were created in Nanaimo and Prince Rupert (UVic, 2011). The Nanaimo Indian Hospital was one of the largest Indian hospitals in western Canada with a 210-bed capacity and it was in the heart of Coast Salish territories (Drees, 2010). Like residential schools, children who survived the Nanaimo Indian School reported multiple abuses that resulted in lifelong scars on the child victims. Small children were forcibly removed from their families and required to live in the sanatorium for two to fifteen years (UVic, 2011). Coast Salish Elders who attended the Nanaimo Indian Hospital reported experimental treatments including electroshock treatments as well as a multitude of experimental drug therapies (UVic, 2011). Other hospital survivors reported the use of full body casts, beatings, isolation and severe loneliness (Lux, 2010). Adelson (2005:S57) states that, "To this day, for many Aboriginal people, there is a lingering fear of institutions that can be traced back to the intensive treatment of those with tuberculosis". Without a doubt, the public health care services that are available today on reserve are a vast improvement on the care that was administered to First Nations people in the Indian hospital era. Still, the services are terribly inadequate in contrast to public health services (Adelson, 2005). The historical literature provides context for a study with Vancouver Island First Nations families.

Determinants of Indigenous Health as a Framework for Analysis

The social determinants of health framework have emerged over the last decade as a method for analyzing health disparities within marginalized communities. While Indigenous scholars note that the concept of social determinants of health is a useful framework to analyze health inequity, it "may not be nuanced enough to fully conceptualize the disparities and

inequities lived by Indigenous peoples" (deLeeuw et al., 2015: xvi). One needs to look at Indigenous health through a broader lens to understand the ways that structural inequity - social, historical, political, and economic determinants – intersect to create health disparities in Indigenous people's health in Canada (Reading, 2015). Colonialism is the largest and most fundamental determinant of Indigenous health and well-being in countries where European settlers continue to govern (Greenwood et al., 2018). Colonization has had dire effect on the wellbeing of First Nations communities in Canada and contributed to myriad health vulnerabilities that did not exist before contact (Boyer, 2014; Loppie & Wein, 2009). Many authors argue that structural inequity, trauma, and racism have contributed to poorer health outcomes for First Nations people in British Columbia and across Canada (Adelson, 2005; Allan & Smylie, 2015; AFN, 2007; Loppie & Wein, 2009), and within British Columbia (BC Health Officer, 2009).

The most known risk factor for ADRD is age, which rises with increasing age (Evans et al., 1989). Other known risks factors include: chronic disease, obesity and smoking (Patterson et al., 2007), as well as social determinants such as low educational attainment (Kukull et al., 2002) and socioeconomic status (Jacklin et. al, 2013; Warren et al., 2015). Some of the literature suggests that the emergence of ADRD in First Nations populations may be influenced by the fact that Indigenous people are living longer (Henderson & Henderson, 2002), and not aging well due to a higher incidence of disease and comorbid health conditions (AFN, 2007a; Warren et al., 2015). Some of the most notable ADRD risks for First Nations people are a higher prevalence diabetes, hypertension and cardiovascular disease (Goins & Pilkerton, 2010). First Nations Elders are three-to-five times more likely to be diagnosed with diabetes, are twice as likely to report a chronic disorder, and are two-to-three times more likely than their non-Indigenous

counterparts to report comorbid health conditions (AFN, 2007; Statistics Canada, 2011). First Nations people are three times more likely to be diagnosed with heart disease and 2. 5 more likely to develop hypertension (Reading, 2009). All these health conditions are known to contribute to the risk of developing ADRD (Patterson et al., 2007). All these health vulnerabilities can be linked to racist colonial policies and practices.

Stress related to these structural disadvantages may also play a role in brain health. Although the exact cause of ADRD is still not known, increasing stresses to the mind, body, and spirit over the life course may increase the risk of ADRD (Mah et al., 2016; Wang et al., 2012). Recent studies have indicated that there is a link between post-traumatic stress disorder and the development of ADRD in later life (Desmarais et al. 2020; Qureshi et al., 2010; Yaffe et al. 2010). These findings have grave implications for First Nations populations in the future (Jacklin et al., 2013), as research has confirmed that loss of culture, dispossession of land as well as residential school attendance is linked to intergeneration or historical trauma (Duran & Duran, 1995; Kirmayer et al., 2009; Loppie & Wein, 2009). In fact, Kirmayer et al., (2009: 453) contend that, "The suffering of current generations of Indigenous people can be understood regarding the transgenerational transmission of collective and historical trauma".

Historical trauma is passed on from one generation to the next in much the same way that all other characteristics of culture are passed on (Duran & Duran, 1995). Historical trauma is linked to anxiety, depression and post-traumatic stress disorder. Residential schools had a particularly negative impact on the health and well –being of First Nations people in Canada (Loppie, & Wein, 2009; TRC, 2015). The Truth and Reconciliation commission recommended that the Canadian government recognize the health inequities that have resulted from residential schools and other discriminatory social policies. In the final report, the commission called for

governments to work with Indigenous peoples to identify and close the gaps in health outcomes (TRC, 2015). Many residential schools operating in Canada were located in British Columbia and the Prairie provinces. In British Columbia, there were 18 residential schools in operation during the most aggressive period of the assimilation era, from 1930 to the 1970s. These institutions were rife with disease and children were often severely abused and malnourished (UBC, 2021). Many of the children who entered the schools did not return home. From 1883 to 1983 approximately 5000 Nuu-Chah-Nulth children were torn from their home and placed in a residential school in BC (NTC, 1996). Many of the students who attended residential schools during the height of the operation are Elders today if they are not deceased.

At present little is known about the impact that residential school trauma has had on ADRD risk among First Nations; yet, as previously mentioned Elders in a recent study in British Columbia believe that residential school and trauma does contribute to ill health in old age (Hulko et al., 2010). There is an absence of research that examines First Nations experiences with illness, neurological conditions or dementia care services (Jacklin, Walker & Shawande, 2013). As noted in the literature presented in chapter two there are a number of variables that may contribute to the growing prevalence of dementia in First Nations communities in Canada including a growing elderly population, a high rate of comorbid health conditions and risk factors that emerge from colonization, and inadequate healthcare (Jacklin et al., 2015).

Decoloniziation Theory

I completed Bachelor and Master's degrees from the school of social work at the University of Victoria. Many of the classes attended throughout my educational journey were rooted in critical theories such as decolonizing (Tuck & Wang, 2012), anti-oppressive practice

(Thomas & Green, 2015), and anti-racist theory (Reading, 2013). These theoretical frameworks inform and influence how I make sense of the world and thus my interpretation of the stories I was gifted with in this research project. I examined the stories through a decolonial lens and noted the themes that emerged as a direct result of structural inequity, and racist colonial policies, and practices. It is important to note that knowledge production is never a value-free process. The choices that we make in designing the research and analyzing research narratives are informed by our experiences, values, and beliefs (Potts & Brown, 2015; Smith, 2021). My goals in this study were to contribute to community healing and create an opportunity for Indigenous knowledge production. Social justice is at the heart of my intentions in research and practice as an Indigenous social worker with personal experience as a dementia caregiver.

Summary

Nuu-Chah-Nulth communities on Vancouver Island thrived prior to contact with settlers. A diet rich in whale meat, seafood, berries and venison supported good health and longevity (Atleo, 2004; BC Health Officer, 2009; Cote, 2010). European people brought with them a hegemonic assumption that First Nations people and their structures were inferior to their own. They introduced racist assimilation policies that featured the reserve, residential school and Indian hospital systems, which seriously undermined the health of all First Nations people in British Columbia. Colonialism is the main determinant of Indigenous health and well-being in Canada (Greenwood et al., 2018). Nuu-Chah-Nulth Elders and their caregivers have been socially, economically and structurally disadvantaged by colonization; therefore, they experience memory loss and dementia care uniquely. In this study I examine dementia care using a determinant of Indigenous health as a framework to make meaning of the themes that emerged

from the participants' stories. As a social worker I am also influenced by critical theories which align well with the methodology and methods introduced in the coming chapter.

Chapter 4: Gitxsan Research Framework: Methodology

Introduction

This research is a qualitative study using an Indigenous storytelling methodology that draws on a Gitxsan epistemology. I used dialogic interviews, which I also refer to as conversations, as a means of documenting the nine participants' experiences of dementia care in the Nuu-Chah-Nulth territories. As a Gitxsan graduate student, I am naturally drawn to the use of a storytelling methodology. Orally based knowledge systems are predominant in First Nations communities in British Columbia. Gitxsan educator, Xsiwis Dr. Jane Smith (2004) notes that storytelling methods, which emerged from oral history philosophies, have always played a fundamental role in Gitxsan research and educational processes. My goal in this work was to reclaim and hold up the oral traditions of my own people and the Nuu-Chah-Nulth people who partnered with me in this study. In this chapter I discuss the use of storytelling as a methodology, the unique way that I approached this research as a Gitxsan student and the methods that I used to gather and document the Nuu-Chah-Nulth family caregiver's narratives.

Storytelling as a Methodology

Throughout history, First Nations peoples in British Columbia have depended on the oral transmission of stories, histories, and lessons to maintain historical records and sustain their cultures and identities (Archibald, 2008; Atleo, 2004; Smith, 2004; Thomas, 2015). Lyackson scholar Qwul'sih'yah'maht, Dr. Robina Thomas (2015) asserts that storytelling has played an essential role in the survival of First Nations people in the area now known as Vancouver Island. Indigenous worldviews and philosophies informed all the elements of the research paradigm and

the research methods utilized in the study. As Thompson (2008:29) notes, methodology and epistemology are intertwined or connected like "threads in a blanket" in Indigenous research. Indigenous epistemologies (what counts as knowledge) are derived from teachings, or knowledges that have been passed down through the generations through stories (Hart, 2010). In Indigenous research the methodologies emerge from Indigenous epistemologies, and ontologies, that are based on relationships with the environment, our ancestors, the universe and every living thing. As Margaret Kovach (2010, p. 57) notes, "Indigenous epistemologies live within a relational web, and all aspects of them must be understood from that vantage point".

One of the key differences between Indigenous and Western research is the fundamental belief that knowledge is shared and with all of creation, rather than created by an individual researcher (Wilson, 2008). Indigenous researchers also draw on information from metaphysical elements such as visions and dreams, ceremonies, prayer; an approach that diverges significantly from Western approaches to research (Wilson, 2008). Indigenous epistemologies are woven tightly with identity, past experiences, culture, language and place. Geographical places link the present to the past and Indigenous people's personal self with their extended family group (Kovach, 2021). In my introduction I said that I am Gitxsan from Gutginuxw House and the Fireweed Clan, which tells others who are familiar with my traditional territories exactly where my family is from. Songs, stories and names are connected to the land and the people who have occupied the land for a millennium. When First Nations people share their land connection, they are providing others with information or knowledge about their relationships with the social and cultural environment. Brasso (1996) asserts that places possess the ability to trigger self-reflection, inspire thoughts about who one currently is, memories of who one was in the past, and musings on who one might become in the future. This research was done over the course of

several years. Following meetings with Elders, research participants and community partners I often went for quiet walks on the beach or in the forest on the Nuu-Chah-Nulth territories. I sought a private place to pray to my ancestors for guidance and thanked the ancestors of the land for allowing my presence on the land. During these peaceful walks I reviewed the meeting, presentation or interview and I made journal entries of the thoughts that came to me.

Decolonizing Approach

Story sharing is a decolonizing method that recognizes the relevance of First Nations knowledge. The decision to reclaim research methods that emerge from traditional Gitx̱san oral traditions is emancipatory and a political choice. First Nations culture and methods of creating knowledge in British Columbia have been marginalized since Western settlers colonized our territories (Thomas, 2000). Indigenous knowledge and research methods have historically been characterized as subjective and biased in academic circles, in contrast to the presumed rationality and objectivity of positivist, post-positivist Western research (Smith, 2021). The teachings that I received through public education omitted Indigenous knowledge. Sto: lo scholar Q'um Q'um Xiiem, Dr. Joanne Archibald (2008:13) notes: "Losing the eyes, or the understanding of a worldview embedded in Aboriginal oral traditions, particularly the stories, is strongly linked to the legacy of forced assimilation during the missionary and residential-school eras and even through the public-school systems."

Indigenous research methodologies have gradually gained acceptance within academia in the last couple of decades (Kovach, 2008; Wilson, 2008). This shift towards acceptance has largely been due to the hard work and courage of Indigenous researchers and non-Indigenous allies who paved the way for others wishing to utilize a storytelling methodology. Therefore, it is

important for me as a Gitxsan student to reclaim research approaches that honor my ancestral teachings and continue to pave the way for future Indigenous students in academia.

Dialogic Interviews

In her seminal book *Life Lived like a Story*, Dr. Julie Cruickshank (1998) argued that recording and documenting life histories is a valid and useful approach for research with Indigenous communities. Cruickshank (1998) recorded the life histories, or stories, of three First Nations Elders from the Yukon. Interviews with the Elders were conducted over 10 years in a collaborative project that included the Elders in every aspect of the research including authorship of the final book publication. Similarly, Qwul'sih'yah'maht, Dr. Robina Thomas (2000) recorded the life histories or stories of residential school survivors in her MSW thesis *Storytelling in the Spirit of Wise Woman: Experiences of Kuper Island Residential School*. Both Cruickshank (1998) and Thomas (2000) utilized several dialogic interviews with each individual research participant in their research. Thomas (2000:24) describes dialogic interviews as “more storytelling and interactive” than traditional interviews that feature a questions and answers format. The interview is only a part of the process, the relationship that develops between the participants and the researcher is also key in storytelling. Storying is an “organic” process that can include information about a number of topics over a person’s lifetime (Kovach, 2021; Thomas, 2000). The interview used in storytelling is unstructured, utilizing open ended questions that leave room for the participant to selectively disclose elements of their experience with a topic that they are comfortable sharing. Participants have the flexibility to share their experiences, and perspectives about a topic, in a free-flowing manner (Kovach, 2021). The unstructured interview method is congruent with the relational epistemologies (Kovach, 2010) and it is a good choice for this proposed research.

Reclaiming the Bundle – Who am I in the research?

I first wrote this short reflective story in 2015 when I was studying the methodology literature. Researchers utilizing Indigenous methodologies don't seek to have an objective unbiased view on the research topic. On the contrary, Indigenous scholars often choose to research topics that are close to our hearts, topics that matter to us, topics that we have strong opinions about (Hart, 2008). I am an insider in this research and I am tasked with analysing and providing my interpretation of the research stories. I know that another researcher would have a differing interpretation. I choose to include pieces of writing throughout this dissertation to show where my experiences intersect with the participants and make my biases more transparent.

When I entered into my doctoral research, I realized that my understanding of what I bring to the research is vital. While reviewing the methodology literature in the early part of my degree, I kept having this feeling that I was missing something. What is an Indigenous epistemology and how does my identity Gitx̱san woman influence the way I make sense of the world and research? Just as I was pondering this, my uncle the late Elder Bobby Woods (Tantonka Husti) sent me an email attachment of my great grandmother, the late Susan Danes. In it he wrote,

> Cheryl, I have enclosed a picture of your great grandmother, in her regalia. She was a medicine woman, and her bundle was passed to your grandmother when she died. As you can see our family has strong traditional roots.

I wondered for days what my great grandmother's bundle would have contained. One evening I decided to Google Gitx̱san medicine bundle on the internet, and I immediately found an excerpt from Gitx̱san writer Xsiwis Dr. Jane Smith (2015). Xsiwis is a member of my family tree, so her perspective on storytelling is particularly relevant to my research.

Xsiwis writes,

> Everyone comes into this world with a bundle of talents. You have to take your bundle whether it be a dream bundle, a medicine bundle, or a sharing bundle, whatever you choose. Then you have to carry your bundle to another place in your future where you will create a gift and share it with others (Smith, 2015).

At this moment, I realized that my great grandmother's medicine bundle was her sacred toolkit. Her medicines were used to heal, and the bundle could be used as a metaphorical expression to conceptualize my research framework. Just as my great grandmother sought to use her knowledge to contribute to the health of her community, the research that I am proposing is motivated by the desire to contribute to Indigenous community health and wellness. I have a bundle of talents and knowledge, a research bundle that is informed by my identity as a Gitx̱san woman, a mother, daughter, sister, and grandmother. The skills and knowledge that I have acquired over my life, my cultural teachings and the teachings I have received from mentors, Gitx̱san scholars, Indigenous teachers and Elders are all critical to how I make sense of the world and research. My bundle is the theoretical knowledge that informs all the choices I make in this research and the way I make sense of the stories that were gifted to me. I resolved to call my uncle the following day to ask him more about my great grandmother.

The next day I consulted my family tree to locate my great grandmother. I learned that our family tree was constructed as evidence in the court case of Delgamuukw vs. the Queen when I reconnected with my band in 1987. The Delgamuukw court case has important implications for the history of Canada and for First Nations rights in general. In this case, the court awarded greater weight to oral history than to written evidence; the court also acknowledged that title to the land had never been relinquished (Mills, 2008). Oral histories have

played a significant role in knowledge transference in my family through the sharing of stories.

Language is at the heart of culture and oral histories, but this part of my heritage was lost when my mother was removed from her home and placed in residential school in Port Alberni at age 7. The violence that mother experienced in early childhood coupled with oppressive colonial polices led to my family's dislocation from our culture and traditions. Much of life has been a journey of learning about who I am as a Gitx̱san woman and what I believe to be true. I draw on the teachings and written work of other Gitx̱san scholars, Elders and family members from here and the spirit world to make sense of the world and research. At the very heart of my beliefs are the "Gitx̱san principals of Guxs Luu Yaldinsxw and Gwalx Yeedinsxw, to give back and pass on the knowledge that has been taught to you" (Cheynne (Morgan) Gwa'amuuk, 2017: 20). From this place of understanding I have a deep moral responsibility to look for ways to give back to the communities and participants who shared their stories with me. Throughout the project I asked myself, "how can I give back to the community with this research, what do I need to do this research in a good way? Intuitively I knew that I would need to walk gently as a visitor in the traditional territories of the Nuu-Chah-Nulth people. I understood that I would need to seek advice from Nuu-Chah-Nulth leadership.

Ethical Framework - Community Consultation & Protocols

Indigenous scholars note the importance of consultation, transparency and careful preparations when entering research within an Indigenous community (Kovach, 2021; Wilson, 2008). Relationship building and consultation for this study was done over several years. I began by reviewing websites and literature as well as talking to Elders and other health care professionals to learn as much as I could about the history and culture of the Nuu-Chah-Nulth people. Through volunteer work and community engagement I began to establish relationships

with several Elder health care providers within the Nuu-Chah-Nulth First Nations territory. I attended events designated for Elders in Ucluelet and Port Alberni BC and presented information on the topic of aging and dementia. I was fortunate to have a contact within the Alzheimer Society of BC who invited me to accompany her to Elder events within the Nuu-Chah-Nulth communities. Through these early contacts and conversations, I learned that there was a need for research on dementia care and that leaders in Nuu-Chah-Nulth community health care were interested in the study.

I realized early that I needed to seek guidance from a Nuu-Chah-Nulth community member about how to enter the research, so I made an appointment to talk to a Nuu-Chah-Nulth academic advisor at the University of Victoria. The advisor made several contact suggestions for Elders and organizations within the central region of the Nuu-Chah-Nulth territories. She provided me with valuable insights and information about how to enter research within the Nuu-Chah-Nulth territories in a respectful way. My meeting with the advisor helped me to realize that research protocols may differ from community to community because some of the Nations have accepted treaty agreements and some have not (NTC, 2008). I learned that I should consult with community agencies within the Nuu-Chah-Nulth territories as well as the Nuu-Chah-Nulth band Council to ensure that **all** the community would be consulted about the research and this was an important teaching. Thus, I reached out to Executive Directors from Kackaamin Family Development Center and the Port Alberni Friendship Centre before moving forward, to explain the research. Both prominent community leaders were enthusiastic and supportive of the research and agreed to support me to distribute the call for participants.

The Nuu-Chah-Nulth student support advisor also recommended that I contact a Nuu-Chah-Nulth Elder to receive guidance before embarking on the research. Before leaving I

humbly offered the advisor a gift and card to acknowledge and thank her for her incredible gifts. I gifted all the people I met with handmade gifts during the consultation phase of this research and in some cases tucked an honorarium into the card to show respect for the community member's time. Indigenous researchers often seek support and guidance from an Elder when they are entering research.

From an Indigenous worldview, research done "in a good way" is a sacred endeavor that illuminates the connections between the spiritual and physical world. Elders have a special role to play in this work. (Fickner et al, 2015:1149). I consulted my Gitxsan Elder, my uncle Bobby Woods, many times during the early days of my research and his guidance was a blessing. Sadly, he journeyed to the spirit world on December 28th, 2017. Even if my uncle would have been living, I would have still sought guidance from a local Elder as this is a cultural protocol that I have learned from my academic mentors. A Nuu-Chah-Nulth Elder has vital knowledge about the land, culture and community. "Elders are keepers of Indigenous knowledge, dynamic ethical consultants, community protectors, and credible sources of information who are able to counsel and support, mediate conflict, provide local context and history, and conduct ceremonial roles (Flicker et al, 2015:1149)." With help from a staff member from the Office of Indigenous Academic and Community Engagement department at the University of Victoria, I contacted Nuu-Chah-Nulth Elder Barney Williams. I was privileged to be invited to Barney's home in Errington BC. His generous support and the wisdom he shared with me helped me begin the research in a good way. I gifted Barney and thanked him for his generosity. After leaving his home I walked on the land, prayed and found a quiet place in nature to take notes in my journal to record the teachings that I had received.

Through my online research I discovered that the Nuu-Chah-Nulth community had damaging and exploitive experiences with researchers associated with the academic institutions in the past[7]. As a result, the Nuu-Chah-Nulth Tribal Council (NTC) (2008) published the "*Protocols and Principles for Conducting Research in a Nuu-Chah-Nulth Context*" which I read thoroughly at the onset of this research. Section 3. 1 to 3. 4 of the NTC (2008) research guidelines state that the researcher should seek consultation with community contacts, Hawiih (Hereditary Chief) elected council and community resources. Section 2 of the "*Protocols and Principles for Conducting Research in a Nuu-Chah-Nulth Context*" states, "Ideally, the researcher will partner with communities and involve them in the development of the research project" (2008:4). This research approach is also consistent with the requirements set out in the ethical guidelines outlined in *Chapter 9* of the *Tri-Council Policy Statement on Ethical Conduct for Research Involving the First Nations, Inuit and Métis Peoples of Canada* (TCPS2, 2014) and the National Aboriginal Health Organization principles of ownership, control, access and possession (NAHO, 2003; Schnarch, 2004).

The next step in the consultation process was to contact the Nuu-Chah-Nulth Tribal Council (NTC) to present my research ideas[8]. My primary supervisor was critical in helping me develop a connection with the manager of nursing at the NTC, Jeannette Watts. I telephoned Jeannette and made an appointment to meet with her in her office in Port Alberni BC. I emailed Jeannette an Information for Participants document (Appendix V) and in turn she provided me

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[7] See http://www. hashilthsa. com/archive/news/2013-07-22/genetic-researcher-uses-nuu-chah-nulth-blood-unapproved-studies-genetic-anth

[8] NTC Home and Community Care Webpage: http://www. nuuchahnulth. org/tribal-council/nursing. html

with information about how to create the ethics application to the NTC. Jeannette was enthusiastic and supportive about the research right from our first conversations. She took the time to meet with me on many occasions in her office and she introduced me to members of the home and community care team. Jeannette offered me many opportunities to connect with the local community and the support was invaluable. I was invited and attended an all-day research retreat in Ahousaht BC that was organized by the NTC Nursing team for academic researchers and that was an invaluable experience. The research retreat helped me to gain a better awareness about the expectations that the Nuu-Chah-Nulth community have of academic researchers.

I submitted a letter of request and a draft of the Collaborative Research Agreement (Appendix III) to Jeannette Watts to be submitted to a NTC Executive Committee meeting . I offered to meet with the committee to answer questions about the project, but I found that it was not necessary. The research application was approved on August 2nd 2018 and an ethics application to the University of Victoria was submitted and approved within a month thereafter. During the course of the research, I experienced three significant family losses which impacted the timeline for completion outlined in the Collaborative Research Agreement. At each stage new timelines were discussed and agreed upon.

Research Methods

Recruitment

Following the ethics approvals, a one-page call for participants (See Appendix IV) was distributed amongst community contacts at the NTC, Port Alberni Friendship Centre and Kackaamin Family Development Centre. The call for participants poster and community information letter (Appendix V) were forwarded directly via email to the Executive Director of

Kackaamin Family Development Centre, Lisa Robinson and she shared the research poster with her contacts. I was honored to be invited to attend an Elder luncheon at the Port Alberni Friendship Center (PAFC) in Port Alberni BC where I made a short presentation to the Elders informing them about the research. The call for participants poster was distributed amongst the attendees at the end of the presentation and pinned to the PAFC information bulletin board. I presented information about the research to the Home and Community Care nursing team during their annual three-day professional development meeting in Qualicum BC. Presenting to the nursing team allowed me to develop a relationship with the nurses and answer questions about the research face to face. I passed out my one-page call for participants poster to the nursing team and community members at the PAFC following the presentations and asked them to distribute to anyone who might fit the research criteria which is clearly outlined in the call for participants poster (Appendix IV). In this initial stage of the research, I consciously attended several community events so that the community to develop a relationship with the community.

Even now as I reflect back on the recruitment phase of this research, I remember some of the challenges that I confronted as an outsider to the community. I could not have completed this research without the kindness and support from my community partner Jeannette Watts. Within a couple months of the distribution of the call for participants, nine people fitting the research eligibility criteria responded via email and telephone. I shared information about the purpose of the study with potential participants via telephone and forwarded a handout I created with information about the research via email to those with email accounts (Appendix V). Two of the individuals who responded decided not to participate after reconsidering the emotions that would emerge from sharing their experience as a dementia caregiver. Many of the people who participated in this study worked and it was challenging to find time in their busy schedules to

meet. One participant was keen to participate but her busy schedule made it difficult to find time for a face-to-face meeting. After 6 months of trying to schedule the interview, I applied to the University of Victoria Research Ethics committee for a modification to my research methods to include the option of a telephone interview. Consequently, eight of the dementia caregivers participated in face-to-face interviews and one participated in two - 1-hour phone calls. After a year I had completed seven interviews and was keen to include more caregivers in the study. I met with my community partner Jeannette Watts to discuss options. She connected me with Ha-Shilth-sa newspaper editor Eric Plummer and he agreed to interview me and write a piece about the research for the Nuu-Chah-Nulth paper which helped to introduce the research to a larger audience[9]. This was a final call for participants. Immediately following publication of the article on May 9th 2019 three more potential participants came forward and two fit the research criteria. In the Research Agreement I stated that I hoped to speak to 12-20 caregivers. In the end it was difficult to recruit that number but my community partners were supportive and approved a smaller number of participants.

Informed Consent & Confidentiality

I reviewed the information enclosed in the informed consent form (Appendix VI) with each participant prior to each face-to-face interview. One of the participant interviews occurred over the telephone and in that case, the consent form was emailed ahead of the scheduled meeting and reviewed over the telephone. After signing the form, the participant scanned and forwarded the informed consent to me ahead of our first interview call. I informed the

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[9] Plummer, E. (2019). Childhood trauma and memory loss: A researcher explores the effects of residential school on elders with dementia. https://issuu. com/hashilthsa/docs/may_9__2019

participants that participation was voluntary, and that they would have the right to discontinue their participation at any time. The risks involved in participating in the study were discussed and various community resources shared. Participants were informed that they would have an opportunity to review and edit their interviews. I also requested permission to audio-record the personal interviews and asked if they had any questions about the research before the interviews commenced. At the end of each interview, I gifted the participants a healthy gift from my garden and provided them with a fifty-dollar honoraria. It was important to acknowledge the participants for their stories and time.

It was important to protect the anonymity of the caregivers in this study. Some of the caregivers were receiving community supports and may have been reluctant to participate if their identities were exposed in this thesis and subsequent community presentations. In the interest of providing a safe space for the participants to share their experiences openly, I assigned pseudonyms to each of the participant interview. During the interviews I coded the interviews KD # 1 – 9, KD was my mothers' initials. Once I began to analyse the stories the numbered pseudonyms seemed impersonal, so I assigned names to each participant. I randomly chose to name the participants Jill, Sherry, Sam, Ellen, Connie, Harold, Katie, Lorne and Alexie. Participants were told that their transcribed interviews would be kept in locked desk and destroyed after the dissertation was completed. I transcribed the taped stories verbatim immediately following each interview.

Analysis

I utilized a narrative, thematic analysis approach described by Indigenous scholar Bagele Chilisa (2012) to analyse the participant narratives. Chilisa's method uses thematic coding and interpretive analysis to condense the interview narratives into smaller stories. Xsiwis, Dr. Jane

Smith (2004) reasons that the Gitxsan have used interpretive methods to make meaning from stories since time immemorial. Gitxsan analytical methods also include cultural and spiritual practices such as prayer, smudging and journaling dreams that pertain to the research. The use of thematic coding was practical because it allowed me to organize and manage the large volumes of narrative data that were created from interviews.

"Talking, hearing and feeling" the stories during the interviews with the caregivers helped me to visualize the participants stories (Archibald, 2008:93). Journaling immediately following each interview helped me to establish some early thematic notions that I later verified or disqualified as I reviewed the transcripts of all the participants stories together. Thus, I began the analysis stage of the work by reviewing all my journal entries collectively. I followed by reading and re-reading the transcribed interviews multiple times to locate and organize the dominant patterns, themes and reoccurring words within the participants discussion narratives (Chilisa, 2012). I began assigning descriptive codes to segments of the participants stories making notes in the margins of each of the transcribed interviews. While reading the transcripts I noted responses to the questions as well as themes that were similar across the caregiver's stories. Chilisa (2013: 214) states that open coding refers to the process of "breaking down the transcribed narratives into themes, patterns and concepts to create a meaningful story from the volumes of data. During this process I identified twenty-two themes which I later conflated into three main themes and nine sub-themes as presented in chapter 6 of this document. Indigenous methods are inherently relational and the analysis is personal.

Personal Methods

As noted, I kept a research journal to record the thoughts, insights and feelings that came to me immediately after the personal interviews and throughout the data collection. The

transcribed written record of our meeting lacked the nuanced information that emerges when two people sit together to share their knowledge through stories (Archibald, 2008). I often left an interview with strong feelings that I recorded. Many of my family members passed over to the spirit world during the data collection and writing of this dissertation. As a result, the study took years longer to complete than I first anticipated. Journaling helped me to remember my thoughts and feelings during and after the interviews, it helped me to conceptualize the places where my own story intersects with the Nuu-Chah-Nulth caregivers. It was an essential tool to remember the teachings that Elders and community members shared with me during the consultation stage of the work. As an informal family caregiver, my stories, feelings, thoughts, and memories are part of the research. I recorded my thoughts in a journal immediately following interviews with the family caregivers. I journaled memories that I had of my mom and our relationship during her last years while I was her primary family support. Emerging from my epistemological position, I believe that my ancestors come to me in dreams, in visions during ceremony and through intuition. I kept my journal at my bedside with a pen and many times woke up with thoughts and ideas of how I should approach my research or thoughts about what the participant stories were telling me.

Summary

In this chapter I described the methodology, methods and what I bring to the research. As an active participant in this research, I told the story of how I metaphorically conceptualize the beliefs and knowledge's that I bring to this research as a bundle of gifts. My mother's connection to her language, culture, and ceremonial practices were almost lost in residential school, but she did not lose the memories that she held from the early years that she spent with her family and community. Over the years, she shared stories with me about her home, her traditional territories

and community that helped shape my view of the world and reality. Mom's stories were meant to convey life skills teachings and to acquaint me with knowledge about my culture and history. Storytelling can be used to teach life lessons, teach morals and values, or provide a historical account (Thomas, 2000). In Gitxsan beliefs, our ancestors and Elders play a prominent role in knowledge transference. Oral histories and stories have played a significant role among my people for millennia, and my family fought to have the legitimacy of our adawaks (stories) recognized (Mills 2008; Smith, 2004). My life experiences and the teachings that I have received from my family, Elders and mentors in the communities I belong to inspire the methodology and methods that I used in this thesis research. I believe that re-establishing First Nations methods of knowledge creation in the field of healthcare is important as First Nations people in British Columbia continue to heal and become self-determining and that motivates me to create a research study that is grounded in Indigenous ways of knowing.

Chapter 5: The Family Caregiver ~ Stories

> Stories are who we are. They are both method and meaning. Stories spring forth from a holistic epistemology and are the relational glue in a socially interdependent knowledge system. In listening to the research stories of others, it is evident that research stories reveal the deep purpose of our inquiries (Kovach, 2021:108).

Introduction

In this chapter, I recount the stories that were generously shared with me by Nuu-Chah-Nulth Elder caregivers. The perspectives presented are my interpretation of the interviews, and I humbly acknowledge that another researcher might interpret the interview narratives differently. The stories that I witnessed in this research are deeply personal and, in some cases, difficult to hear because they include experiences of abuse, pain and grief. I want to acknowledge that these stories might be triggering for some readers. The stories represent a glimpse into the participants' lives in their role of informal dementia caregiver. As an Indigenous scholar I am cautious not to present what Adichie [10](2009) refers to as the single story. That is, a biased negative snapshot or story of the Indigenous caregiver's life, one that pathologizes the family or individual without disrupting the root causes of their circumstances. Western research so often portrays Indigenous people and families in a dysfunctional light (Smith, 2021). I want to be clear that the root cause of health disparities in Nuu-Chah-Nulth communities, and all First Nations communities in Canada, is oppressive violent colonial rule (Adelson, 2005). The single story may exacerbate or create stereotypes, and they present assumptions about individuals and nations that are racist and incomplete (Adichie, 2009). The Nuu-Chah-Nulth people's story did not start when Captain

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[10] Adichie C. (2009). The danger of a single story. (Video File). Ted Talk. Retrieved from: https://www. ted. com/talks/chimamanda_adichie_the_danger_of_a_single_story

James Cook landed on the pacific west coast in 1778[11]. Prior to colonization the Nuu-Chah-Nulth were a thriving Nation and they still are. Some of the personal stories in this chapter include experiences of past traumas that occurred to both the PWD and their caregivers, and their stories are linked to structural oppression.

As mentioned earlier the caregivers' identities were protected by pseudonyms. Nine Nuu-Chah-Nulth people responded to my call for participants and agreed to share their experiences with me. Three of the nine caregivers shared stories of caring for a loved one who had already journeyed to the spirit world. Three of the caregivers were providing support to a family member with dementia in the home at the time of the interview. One of the caregivers was providing support to her mother who lives in her own home. The final two caregivers cared for family members with dementia until their condition worsened and the PWD was moved to a residential care facility outside of their community. At the onset of each interview visit I introduced myself and shared my dementia care experience. As is so critical in First Nations protocol, my introduction included my Nation and the last names of several of my extended family members.

Jill's Story

I met with Jill at her home in the central region of the Nuu-Chah-Nulth territories. Her kids run in and out of the kitchen until finally she firmly tells them to go upstairs and play! I have met Jill before our visit, so I already know that she is a working professional with a large extended family, children and a demanding full-time job. I began by introducing myself and sharing my story as a dementia caregiver. Jill mentions that her grandmother (Gran) had

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[11] Canada's First People: First Portraits of North West Coast People. Retrieved from: http://firstpeoplesofcanada. com/fp_furtrade/fp_contact_nootka. html

dementia for the last few years of her life and Jill provided myriad supports to help her grandmother live independently at home. Later, when Gran's condition worsened Jill frequently visited her in the hospital before she passed away. When I sat down with Jill, I immediately noticed the family pictures she had displayed all over her kitchen. In fact, one of the first things she did was to proudly show me a black and white picture of her Gran to ensure that I would have a visual picture in my mind when she described her grandmother's life and her experience as a caregiver. I mentioned that I had created poster sized black and white pictures of my mom when she was in her early 20s and hung them in her room at Cumberland Lodge to ensure that the staff knew that she was a person not just a patient.

Jill's eyes saddened when she described some of the hardships and losses that her grandmother had endured as a young woman and all through her life. In Jill's own words her Gran "had a very hard life". She attended residential school and lost one of her younger brothers to a cougar attack, so she experienced significant trauma and grief at an early age. Jill noted that her grandmother never talked about her experiences in residential school. Gran married and divorced twice and had 5 children, two of whom died before the age of 30. Gran's second husband was diagnosed with mental health issues and he was abusive, so they split up. Her mother also died young, so Gran had to raise her children without support from her mother or husband. Still, Jill mentioned that Gran was very close to her children and she was "family oriented". Jill noted that her grandmother's life was always chaotic and stressful. Jill said,

> So, she was very, very stuck in her groove for most of my adult life…. she didn't have her parents, she didn't have a good spouse support, her children were also going through grief and had their own issues and their own family issues and it was just compounding traumas everywhere you go.

Jill disclosed that her grandmother coped with stress, grief and trauma by drinking, smoking and using marijuana throughout most of her adult life. Later Gran suffered from anxiety and restlessness and stomach problems. Jill said, “I don’t know you could see a lot of anxiety especially as she got older. She was really restless, and she would kind of shake. She’d be zipping around, and her stories were so fast”. For a period, she isolated herself and shut out her family. She wasn’t eating much or taking good care of her health and eventually Gran had the first of a couple strokes. Jill noted that she really began noticing her grandmother’s forgetfulness after her first stroke. Gran still managed to live alone for a time with help from family, but her abilities were declining. Jill was aware that her gran was vulnerable, so she was concerned about her well-being. She noted that she had to take a lot of time off work to take her grandmother shopping, help her with her medical appointments and listen to her concerns.

> Like I said her repetitions and her stories that took about a two-hour visit to be respectful and listen to her and let her vent and take some of that stress of her, because she was in a bad way. Every time I went to see her, she was upset… And with her amount of stress that she shares all the time, like you take it home because that’s your gramma and you know that’s your blood and if family is not stepping up who live there what can I do but I live two hours away.

Jill’s grandmother lived on her own, but she was in an out of the hospital until she finally had to be institutionalized for her own safety when her condition became more advanced. She lived in a semi- independent home but kept escaping and finally she moved into the geriatric ward at Tofino hospital. Jill noted,

> She had a stroke so she was even using a walker. There was just so many variables that could have placed her in a really bad spot and it wasn’t safe for her anymore and family couldn’t manage anymore.

Jill mentioned that she visited her grandmother regularly in the hospital and was with her when she died. Jill was close to her grandmother so she provided as much support as she could with some help from other family members. She had a lot of admiration for her grandmothers' spirit and wished she could do more. Our conversation turned towards dementia care supports and Jill felt that much could be done to improve supports for PWD and their family caregivers.

Sherry's Story

Sherry provides support with the tasks of daily living to a husband who has memory loss. I agreed to meet with Sherry outside of her home in a quiet environment so she could talk freely without her husband present. Again, I began by introducing myself and sharing my story as a dementia caregiver. My mother's story inspired Sherry to reflect on her residential school experiences. Sherry said,

> I was born in Port Alberni. I was brought up for a couple of years down in Kildoan. Then of course the white man came along and took us off to residential school… They beat us, they raped us, they starved us, they did whatever they wanted to do. There was nothing we could do about it.

Sherry said that her children ask her about her experience at residential school, but she doesn't tell them anything. My thoughts wander back to my childhood and I remember that my mother wouldn't talk about residential school either, no matter how hard I tried to pry a story or two out of her. Sherry notes, "I don't want to put them through it. I don't want to tell my children." And I begin to understand that our Elders protected us by omitting horrific stories of the abuse they endured in residential school.

One of the first things that I noticed at the onset of our visit was that Sherry seemed very unhappy with her life. On many occasions during our conversation, she said that she felt trapped. There is a deep sadness in her eyes, and she indicates that she is desperate for her current situation to change. Sherry is an Elder and she has complex challenges with her health. I immediately noticed a stent and enlarged veins in her arm. When I asked her about it, she said that she is in kidney failure and had to have dialysis weekly. Sherry mentioned that she looks forward to going to the "kidney place" because it gets her out of the house and away from her husband. She also goes to bingo every week and those outings are the only thing that she looks forward to.

Sherry was a stay-at-home mother earlier in life and her pension is small. She feels trapped by her economic situation and she seemed resentful about caring for her husband. Sherry stated that her husband has complete control of the bank accounts and he is verbally abusive if she spends his money. She said, "If I even so much as take 100 dollars out of the account, wow, get the hell out of the house!" Sherry is very unhappy, and she is not coping well with her husband's memory loss. She stated,

> He remembers everything from age one to age ten… And he'll tell you all day long about it. I get so fed up I tell him to shut up, you've already told me 50 thousand times. I don't want to hear about it anymore!

From her description of her husband's abilities I conclude that Sherry's husband has mild cognitive decline. He is unable to drive but he can still cook and he is able to take care of his own personal hygiene and finances. He is only able to walk on a familiar route for fear of getting

lost. According to Sherry, "That's the only place that for the last three years he's been able to go on his own". It is clear that Sherry and her husband are both unhappy. She declared,

> He's grumpy any time. When he gets up in the morning by the time, he puts his foot out of bed he's already at it. He's the nastiest son of a bitch on this earth. He really is! There is absolutely nothing nice he can say to me.

Sherry mentioned that sometimes she is a little forgetful too. She attributes her memory loss to the stress that she is under living with a person with dementia. She noted "it feels like I am getting the disease from the stress of living with him".

Sherry has three children and she and her partner access some services from the Nuu-Chah-Nulth community. Through our conversation I learned that Sherry does not receive a lot of support with her partners care from family or community resources. Feeling a little concerned with her level of support I asked if she has anyone to talk to when she is really frustrated with her husband. She does access services from her own First Nations band office and she noted that she can "go down there" anytime she needs to talk. Our conversation moved towards the high cost of living and at that point I got the sense that Sherry worries about what will happen to her when her husband's condition worsens. She mentioned that her brother and son have offered to house her if need be. She is certain that her band office would also support her.

Ellen's Story

I met Ellen at her home on a beautiful summer day. She was friendly and welcoming, and she seemed comfortable about inviting a stranger into her living room. Ellen and I had shared emails prior to the interview so I knew that Ellen provided dementia care and support to her mother before her recent passing. I started the conversation by introducing myself and sharing

my caregiving story to break the ice. We talked about our early years living in small fishing communities on the coast of Vancouver Island and realized that we had some similar experiences. Ellen described her early childhood as carefree and happy. She mentioned that she never really knew her parents when she was a young child. Her parents struggled with alcoholism and family violence was a common occurrence in her family home, so she often lived with aunties or her grandparents during her early years. Ellen's face lit up as she described early childhood memories spending time with 10 cousins and siblings on her grandfather's fish boat. Ellen came from a very large extended family; her mother had sixteen children, but she disclosed that she only knew nine of her siblings. She noted,

> When my sister got married, I think I was about eleven and I finally realized, well I didn't know she was my sister, but I was in the wedding party. She got married and I stayed with her for three, three and a half years and I started calling her mom. Like then after a while, like I never knew I had parents because I was always pushed around like a ball.

Ellen shared a few stories of her early childhood and her stories illustrated a traditional Nuu-Chah-Nulth way of caring for children when parents were unable. We reminisced about our childhoods and discussed the traditional cultural values embedded in First Nations child and Elder care. Even though Ellen did not share a close relationship with her mother during her childhood she developed a close bond with her mother later in adulthood and she had empathy for her when she developed memory loss. The values that she learned from her grandparents to care for family through her childhood were deeply ingrained in her.

Ellen seemed eager to share her dementia care experiences with me. As we sat and sipped our tea, Ellen recounted that she and her sister and other extended family members supported their mother during the early stages of memory loss. Mom started to show signs of dementia after

her husband died but the family didn't realize why she was so forgetful. Ellen had moved to a larger urban community to work and escape memories of an abusive intimate partner relationship. Her sister moved into their mother's home when she was in the early stages of memory loss to support her with the tasks of everyday life. Ellen was in close contact with her sister and she supported her sister to make decisions and help with her mother's care. Ellen said,

> She (sister) was living with my mom at the time and she would phone and she would say mom's doing this, mom's doing this again. It was things that were out of the ordinary. She'd walk around with no clothes on you know. You'd try to dress her and she'd get mad and she'd get violent and start hitting with her cane.

Ellen shared stories about managing the challenging behaviors associated with dementia, many of which seemed comical after the fact but at the time had been distressing. Ellen shared that she was concerned about her mother's financial vulnerability during the time she lived in her home in Ahousaht. She confided that she thought that family members were borrowing money from their mother knowing she would forget that they owed her. Ellen said,

> You know my brother was just using her for the money and knowing that she would forget…He used her to pay for his insurance, car insurance plus she would give him money too because that was her baby. Anything he wanted he got it from her because she wouldn't remember. So, when they dropped her off in Port Alberni at the bingo, they didn't even go pick her up.

Mom's memory was deteriorating, and Ellen was worried that she needed more care, so she moved her from her small remote community into her own home in Nanaimo British Columbia. Her mother could not cope with the tasks of daily living without assistance. At that time Ellen was working fulltime, so she accessed community supports such as care-aids and an

adult day program during the day. Her partner also supported her to provide informal dementia care at home. It was a challenge to care for her mother and work, but Ellen didn't look at it as a burden. Her mother had moderate to severe cognitive decline when she moved into Ellen's home, but she still remembered some stories from her youth that she shared with Ellen during this special time. Ellen cared for her mom for a couple of years until her mom's health worsened and she was forced to move her into a care facility. She chose to place her mother in a care facility near her own home so she could visit her mother daily.

Interwoven throughout the interview were stories of family violence and various forms of trauma that Ellen and her mother had endured during their lives in a small isolated reserve community. Both mother and daughter had suffered frequent beatings from their husbands during their marriages, in early adulthood. Speaking about her mother Ellen said,

> I've known and heard stories that she (mother) was a really chronic alcoholic cause my father used to beat her, not just a slap. It was a big one, he'd kick her, break her arm, or leg you know.

Similarly, Ellen's first husband beat her on a regular basis. Ellen said that she, "I had nine children, but four of them lived. So much beating, so much beating. . ." Her mother had sixteen children and both women grieved for children who died prematurely. Ellen mentioned that her mother lost five sons and she said, "I could never imagine…I lost a son when he was eighteen, they said he died of alcohol poisoning …but I kept working so I didn't really grieve." Ellen stated, "so my life was similar to my mom's". Yet Ellen now lives with a peaceful man and has been clean and sober for years. As I prepared to walk out the door, she commented that telling her story was a good healing.

Connie's Story

Connie has a demanding full-time job and she is a leader in her community. I met Connie at a local restaurant and immediately felt relaxed in her company. The restaurant was noisy, but we had a table in a private corner. Connie has a friendly gregarious personality but when she started to talk about her mother her demeanour became more subdued. Connie lives in the same community as her mother and she provides informal supports to her on a regular basis. Her mom doesn't drive so she needs help getting groceries, going to medical appointments and attending social cultural events. Connie said that her mother can live alone in her own home with support from her two daughters who live nearby, but recently her mother's needs had escalated. Her husband recently passed away and that is when Connie became even more concerned about her mother's cognitive abilities. Connie said her stepfather sheltered her mother and "covered up for her" memory loss. Connie's mother has mild cognitive decline, but she is in denial about her memory loss, which is frustrating for Connie. She said;

> That's the same thing with my partner's dad too. He was in the same place. I don't need help. I don't need anybody. Because people don't want to lose their independence, right? I don't blame them for not wanting to lose it, but at the same time they're highly dependent.

Connie revealed that her mother forgets names and events that have happened and frequently loses her purses and other valuable items. Her mom accuses others of stealing the items she has misplaced and is beginning to exhibit inappropriate rude behaviour in public. Connie finds it difficult to communicate with her mother about her future care. She knows that her mother is lonely and grieving the recent loss of her partner. I could see the empathy and love in her eyes as she described her mother's situation. Still, Connie is buckling under the weight of her mother's demands, and the stress of worrying about her.

Connie's concern led her to organize in-home care for her mother. A care-aid was hired to check in on her mother twice a day to help her take her medications. But as Connie noted, her mother "put the kybosh" on that support arrangement. She let the care-aid know that his services were no longer needed. That disappointed Connie but she said that care-aids in the Nuu-Chah-Nulth territory don't get paid to spend enough time with the Elders. They are only paid to drop into the home for 15 minutes twice a day. Connie felt that her mother could easily live in her home for many more years with more home support. She declared,

> For me, it feels like there needs to be at home support. And I mean real at home support, not just stop in for five minutes and check in. That's what they do, the majority of them. They stop in, grab the binder, check off that she's taken her meds, put the binder back and say see ya later and that's not support.

Connie noted that Elders are lonely, and it would be nice if the care-aids were paid to "actually engage" with them, have a cup of coffee and visit with them. Traditionally First Nations people would spend time with the old ones. She noted it is also hard on the care-aids because they struggle to make a living, they are underpaid and don't get enough time to spend with the Elders.

As we continue to talk the biggest source of Connie's stress begins to emerge. Connie has a brother and sister who live a distance away from her mother. Both siblings are in favour of moving her mother to an assisted living facility while Connie is opposed to this idea. She is worried that her mother is being bullied to move from her home and that she would not be happy if she is forced to move to assisted living.

I think with my brother's plan, and my sister and him, they're going to get power of attorney. He doesn't want me on it because my mom has asked to have me on it. I don't know if

that's going to happen, but this is about my brother and I think he's a bit intimidating to her too because she did say that to me a couple times. My mom does say things. She said he was being very mean to her and he was saying mean, mean things to her. So, I think he's sort of a bit aggressive verbally.

She feels her brother has a financial agenda and is not thinking about his mother's happiness. Furthermore, she is worried that her brother is going to get power of attorney in place and, in her words, "have her committed".

Connie said that her mom is 77 but she has been showing signs of memory loss for about 20 years. She attributed her mother's early memory loss to medications she has taken for many years. She said, … "I wonder about all these medications my mom has been on for the last 25 or 30 years". When I asked what kind of medications her mom is taking, she said;

> Anti-depressants, anxiety medication. You know and then all of the medication to get rid of the things that happen as a result of the medication. So, she is on probably 20 different meds at some point in time.

Our conversation moved to the etiology of her mom's mental health struggles. I learned that Connie's mother did not attend residential school and she doesn't like to talk about negative experiences she had when she was a child. Speaking of her mother's early life Connie said, "I know that she had lots of trauma she just doesn't talk about it. "

Sam's Story

I drove to Sam and his wife Clair's home on a bright sunny day. Sam met me at the door and invited me to sit at the kitchen table with him and Clair. A healthy young woman working in a large garden outside was visible through the kitchen window. I asked about her and Sam

replied that she was his granddaughter and that his daughter was outside somewhere too! Sam is an Elder and he is caring for his wife Clair at home. Through our conversation I learned that the couple had been married for sixty-two years. I sat next to Clair on a kitchen bench and could not help but notice was how happy and well cared for she was. Although clearly non-verbal she communicated contentment through her infectious smile. She looked lovingly at Sam during the whole visit. Even though I was a stranger the love that this couple shared was obvious to me immediately.

We began our conversation about gathering traditional foods, gardening, fishing and hunting. Sam is a natural storyteller and he enjoyed having an audience. It didn't take long for him to warm up to me and share his biggest concerns as a dementia caregiver. Both he and Clair have critical health issues. Sam has kidney disease and needs to go to the hospital three times a week to undergo dialysis. Clair has diabetes and advanced dementia and requires full time care. Sam achieves this with help from his daughters, one of whom is a nurse, support from home and community care and extended family. He also hires someone to help in the yard. Yet, he does not have consistent support to leave his wife at home, so he is forced to take her to the hospital with him while he attends dialysis which has become a stressful situation for him.

> I go to dialysis. I'll be starting tomorrow. I'll be looking at the time. It's 5 after 1, 10 after it's time to head for the car and head for 6th avenue for dialysis. I'm looking at now, getting down to business right here, what if she gets sick? I can't take her if she's really sick. Where do I turn with her, she's got dementia?

Sam is especially anxious because his wife is incontinent, and he is worried that she will have an accident while they are at the hospital. He noted that the nurses don't get paid to attend to his wife during his procedure. He said, "What would happen if I take her to dialysis because she

comes with me and they have a chair provided and if she ever makes a mess there? You can't ask the nurse to help. " Dialysis session is 4 hours long, so Sam tries to make sure Clair goes to the washroom before the session begins. On top of the strain of sitting still for 4 hours three times a week he has the pressure of worrying that Clair will require care when he is incapacitated. This concern is paramount and came up repeatedly through out our visit.

I noticed that every where that Sam went Clair followed closely behind. During the interview visit she did not let him out of her sight. I commented on this and Sam explained that he recently had a medical emergency during his dialysis treatment. He was rushed to the hospital in Nanaimo and his family presumed he would die. He said,

> So, my daughter got a room in a motel not too far away. They couldn't keep her in there, she was uncontrollable I guess screaming and crying because I was leaving. So, they had to bring her to the hospital, and I explained, and they said oh don't worry we'll get a chair for her. She sat right beside me that and that's the way it's been ever since.

Clair feels safe with Sam and she loves him. He is her rock.

Sam is an Elder himself and the pressure of caring for himself and his wife's health is wearing. He lamented,

> I had to give her diabetes pills. We have a fight sometimes, and sometimes she cooperates…Sometimes she won't cooperate, and I have to get L (daughter) to hold her arms back and get that down with water and lie down and get her needle for diabetes. So, I hold one arm and I've got to threaten her all dramatizing.

It is a lot of work for Sam to keep his wife safe and the pressure of caring for her is hard on his health. He is worried that she will leave the home and get lost or put herself in harm's way. He noted, "I want to get a deadbolt on the top of that door because sometimes she would open the

door and look for me you know. She's dangerous to herself. " Sam told me stories about times when Clair wandered out of the house looking for him and it took awhile to find her. Another time she locked herself in the family car during a heat wave and Sam had difficulty coaxing her to open the door so he could get her out. She was worried he was planning to leave the home without her.

As our conversation progressed Sam noted that Clair has had dementia for approximately nine years and her symptoms have progressed rapidly within the past couple years. She was in her late sixties when she first started showing signs of memory loss. He attributes at least part of her memory to the physical trauma she experienced in residential school as a child. He said;

> She spent over 6 years in the residential school here. I guess the principal at that time Mr. C at that time had a thing going for himself in the basement. He used to line up about six girls and strip them down to the waist, you know and by force, and cooperate or he'd grab them by the hair and slam their head into the concrete.

Sam felt that the emotional and physical trauma of being victimized by a sexual predator may have contributed to her early diagnosis of memory loss. He also spent a large portion of his childhood in residential school and he believes that the beatings he endured during his time in residential school contributed to his kidney disease. Sam said, "I'm still paying for that residential school and so is she". Sam concluded that his struggles could be alleviated with a little bit of support so he could hire someone to help stay with Clair during his dialysis sessions.

Harold's Story

One of the participants shared information about the research with Harold and he contacted me to find out more about the research. Harold cared for his father in his own home with help from his partner after dad began showing signs of memory loss. Harold's father has

journeyed to the spirit world but his memories of him are still vivid. Harold began by sharing stories about his childhood growing up on the Nuu-Chah-Nulth territory. His mother died when he was just six years old, so he spent a lot of time with extended family when his father was away fishing. Harold noted,

> We were shipped between our families, my father's side and my mother's side. We spent time with my grandparents on my mother's side for the summer. Sometimes we'd get shipped to our older sisters and we'd spend time on our home territory because he was always fishing but he always would try to provide for us. He'd see us, visit us and spend time with us.

Harold's face softened as he recounted the special memories he had of his father from childhood. His father taught him many things and Harold spent time fishing with his dad during his teenage years. He paused and said, "he was a quiet man…he never got mad at us he would always just let us do it and make a mistake and then go and show us". There was love in his voice as Harold's recounted memories of his father from his early childhood. He said that he had a close relationship with his father throughout his life. He was remorseful about losing touch with his father as a young adult. Harold said,

> When I left home I just moved into a logging camp. I never saw him again for a few years. I was always logging, always away from home… It was me, it was basically my choice. I stayed in a logging camp and stayed away from family. They never knew where I was. I was always gone. I lost an aunt, a sister and I had no clue. When I came home I found out about it. It's always been a part of me that I'm sorry I missed family time.

Harold was proud that he stepped up to support his father in the last years of his life. He said; "He told me that I don't want to go into a home when I'm old. I said okay dad you won't. That was something that I'm really glad about." His dad was 95 when he passed away and he lived

with Harold and his wife for the last few years of his life. Harold worked fulltime but he had help from community services and his partner.

Harold first became aware that his dad had memory loss when his father did not come home from his daily 2-hour outing. His dad went out every day and took the bus downtown to walk around the pier in Nanaimo BC. Harold looked everywhere for him and he was frantic. He drove around trying to find him, visiting all his fathers' usual haunts.

> It was raining and blowing and in wanders my father, big smile on his face. I said where were you, we were looking for you. Oh I got lost. That's when we realized that something was wrong. He didn't know where to get off the bus. He said I don't know where I got off but I got lost.

Dad's memory health steadily deteriorated after that incident. He had his own room and would sometimes be awake in the middle of the night. Chuckling under his breath Harold remembered that his father would go to the kitchen with his walker for a snack and fill his pockets up with dry cereal. Harold said he and his wife would wake up in the morning to a little trail of cereal from the kitchen to his father's room. As his condition continued to deteriorate dad became incontinent and the family had to take care of his toileting needs. His food had to be pureed so he wouldn't choke but he ate only small meals. Caring for his father at home became a fulltime job, one that is usually done in an institutional care home setting. Harold noted that he was lucky because his dad was small and he could pick him up to move him from his chair to the bed when need be. A couple times dad had to go to the hospital and Harold stayed with him after work and slept on the floor by his father's bed. In the final year of life Harold's father fell in his room and broke his collar bone. The doctor put a splint which dad ripped off as soon as he was in his room. Still, Harold did not renege on his promise not to send him to a nursing home.

Reflecting Harold said, “I never really let my father go yet even though he’s been gone for a while now…I still haven’t let him go…. The hardest is when Father’s Day rolls around. ” He concluded that it was stressful caring for his father at home but, “you don’t really start to appreciate it though till after it’s all done”. Reflecting on his experience as a caregiver Harold noted that’s “one thing that has really come out for me lately is how much I appreciate the help I got from my own family when I was taking care of him”. Harold was especially grateful for the support he received to care for his father from his partner and friends. Harold noted that his father could talk but only in a very low voice and he had a limited vocabulary. Still, his memories of his father and the last things he said to him are precious to him now. I walked away with feeling admiration for Harold and his family. Caring for his father had been a labour of love.

Katie’s Story

Katie and I struggled for months to connect. She works fulltime, manages a home and spends as much time as possible with her children and grandchildren. Katie noted in an email we shared when she first contacted me that she provides informal dementia support to her husband at home. She was keen to share her story as a caregiver, but she had difficulty finding time to meet. I asked if it would easier for her to fit in telephone calls to share her story and she responded enthusiastically, “yes, that would work!” I modified my ethics application to include telephone interviews to accommodate Katie’s busy schedule. Her partner has mild cognitive decline, so he is still able to contribute at home. Like Sherry, Katie’s day to day stresses seem to result from her husband’s irritability. In our conversation she mentioned, “He gets put off because he can’t remember. And I will say, I told you this morning and I am trying to train myself to say it more gently than irritatingly…”

Katie implied that her husband is happier with structure, but she does not access community care services yet. Instead, she relies on friends and family for support. She noted;

> He is good when he is kept busy. It is when he stresses out that I have seen him start losing it again. Me and my girl N (daughter), we watch him and that is why we watch him. Because we know the consistency of, I don't know if this sounds silly…normal for him. What normal looks like and when he is starting to escalate.

At the moment Katie is managing without respite or community support but she believes that family caregivers should receive help in the home to help care for their loved ones with dementia. She said that more services are needed to support dementia caregivers in her community to provide care in the home. She said, "We don't have the strength to be constantly helping them in and out of the tub, changing them." We want to care for our Elders and in the old days we did but "we have to work now to make it". Katie suggested that the community does still collectively look out for Elders that they know struggle with memory loss. The traditional value of caring for the old ones is still very much alive in Nuu-Chah-Nulth community. Katie said she feels supported by the nurses in the organization she works for. She has accessed information about how to care for a person with memory loss from colleagues and she is coping well now.

Katie acknowledged that her husband's memory loss became more prominent after he had a stroke. His health has had a negative affect on her health and well being as illuminated by the following statement.

> He had a stroke last year and he keeps telling people that he did not have a stroke, but no one lives with him to see what I deal with (laugh)…And after his stroke, before his stroke I had him to a level of (sigh) calmness (sigh) but he wasn't blowing up at the snap of a finger. But

> now he is back to that again so I have been trying to take care of my health cause I can't blow up at him. He won't remember! He won't remember anything that happened two hours ago.

Katie mentioned that her husband uses marijuana to self regulate when he is feeling irritable and this helps him to remain balanced and calm. She also suggested that unresolved grief and trauma play a part in her husband's irritable moods.

> He is very private and as terrible as it sounds he smokes a lot of pot because it calms him. He is the type that doesn't, how do I put this? I have dealt with everything I think I need to but I know there is stuff that he hasn't dealt with, and he doesn't want to.

Katie did not want to go into detail about the trauma and grief that her husband experienced. She did talk briefly about her own personal experiences of childhood sexual abuse. Katie said, "and then we were all abused as young kids, all of us have different strengths, all of us have very different strengths. There are 5 of us left out of the 17." During my conversation we discussed the sexual abuse that is still rampant in BC First Nations communities. She shared that in her family sexual abuse is still common but she feels that the abuse is often ignored by the community. Katie also asserted that many of the illnesses our families face are linked to unresolved trauma and grief. After I hung up I reflected on Katie's words and I was grateful for her honesty.

Lorne & Alexie's Stories

Lorne contacted me directly after a story about this research in the Nuu-Chah-Nulth online newspaper, Ha-shilth-Sa[12]. He was enthusiastic about sharing his story with me and I was grateful to connect someone from a northern Nuu-Chah-Nulth territories. All the previous participants live in the central and south regions of the Nuu-Chah-Nulth territories. I called the NTC Home and Community Care nurse in the northern region to let her know that I was coming to her community and she provided me with Alexie's contact information. She had previously shared information about the research with Alexie. I was excited about the prospect of visiting the remote community and grateful for the opportunity to witness the unique stories of caregivers living in the northern region. As I drove down the bumpy active logging road trying to avoid logging trucks and black bears, I tried to envision what the community would look like as it had been years since my last visit. At the time I had no idea that Alexie and Lorne were close relatives, and that they would both be waiting to meet with me at the band office. Yet, once I arrived, I found out that Lorne is Alexie's uncle and they hoped to meet with me together to share their family story, so I went with the flow. As our conversation progressed, I began to realize that many of the people in this isolated First Nations community are related to one another, and all the members of the community know one another.

Lorne and Alexie have a large extended family and a high number of the family members have suffered with memory loss. Lorne said he was the youngest in the family and he had 6 brothers and 2 sisters. "There are only three of us left", he lamented. He has two brothers who are living with dementia now, and both of his sisters had dementia before they died, so half

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[12] E. Plummer. (2019). Trauma, residential schooling and memory loss. https://hashilthsa. com/news/2019-05-13/trauma-residential-schooling-and-memory-loss

of his siblings have developed dementia. Lorne's youngest sister was Alexie's mother. He said, "My younger sister she died from the disease but there were extenuating circumstances. She got cancer… The cancer weakened her body so much that it speeded up the memory loss. " Lorne noted that he extended support and care to his brothers at different times over the recent years and Alexie is currently supporting a brother with dementia. Both family members had similar but unique caregiving experiences and had lived in small northern communities within the Nuu-Chah-Nulth territories for most of their lives.

Lorne

Lorne's brothers were both in care in hospital at the time of the interview visit. He said; "My two surviving brothers are in the early stages, actually have probably progressed beyond that. Lee is in the hospital in Victoria at Royal Jubilee. Tom in St Paul's hospital in Vancouver." He is not able to visit them as frequently as he would like because the hospitals are in the city miles away from his home on reserve on northern Vancouver Island. Lorne went on to reveal that the brother Tom is sixty-six and Lee is seventy years of age and they have both shown signs of memory loss for many years. Lee was living in a care home in Campbell River, but he had an "incident" at the facility where he lived and had to be moved to Victoria. Lorne stated, "Anyway, they have him there and he is locked up because if the door is open, he will run. He will take off, and he does not know why he is locked there. He thinks he is okay… ".

Lorne noted that his brother Tom has been homeless for "30 - 40 years". And, knowing his brother is homeless and vulnerable has been heart-breaking for Lorne. Lorne said that the St Paul's hospital recently called him to let him know Tom was there. It was a relief to know he was safe. He said,

> He was living on the streets in Vancouver and he broke his collarbone. But in order for them to release him out of the hospital they said he needs to have a place to stay. I didn't want to tell them that he lives under a bridge. He is homeless and that is where he prefers to be.

When Lorne became aware that his brother had memory loss, he tried to help Tom by inviting him to stay at his home. Lorne proceeded to tell me a story about traveling to Vancouver to find Tom to bring him back to their home community. He said Tom stayed for a couple weeks then one evening he walked away from his home in the middle of the night and hitchhiked back to Vancouver. Tom just disappears when he leaves, without telling anyone which is especially troubling for Lorne. He said he has had to "put the word out" to family and friends over social media to find out if anyone had seen Tom. Lorne said he worried for months, "then 3 months later he called, and I asked him "where are you?" and he said I am in Vancouver." Lorne noted, "I really need to keep track of him because of his condition!" He acknowledged that the streets are a dangerous place for a person with dementia. Lorne knows his brother needs support, but he can't intercede unless Tom is willing to accept help, which has left him feeling frustrated and helpless. He has tried to extend support to his brother Tom on more than one occasion.

Lorne believes that the high rate of dementia in his family might be linked to the physical and emotional trauma they experienced in residential school. He and all his siblings attended residential school, but his parents didn't attend and they did not have dementia. He noted,

> …there was so much stress in those institutions. It was like we were in jail. We were told what to do, when to do it and if we did not do what we were told there was a price to pay, and it was a heavy price. There was a lot of beatings that went on and things like that.

Lorne acknowledged that he was told that two of his brothers were treated very badly at residential school, in his words "like the worst extent of any treatment", but he doesn't

remember seeing them even though he attended the Christie residential school in Tofino at the same time as they did. Lorne has little memory of the five years he attended residential school. He said,

> I remember being home with them during the summer, because we would all be there at Queens Cove. Queens Cove was like a refuge and it's like the light goes on that when we would go off to residential school the light would go off again. It is weird how that happened.

Lorne noted that those were "dark times" for his family. He knows that he and all his siblings experienced trauma, but he has blocked out the memory of that time. Then, he said his sisters got dementia at an early age. Lorne stated,

> I don't know if they were ever diagnosed with dementia. I don't ever remember them going to the doctor to be diagnosed. It was like the family took care of them. We didn't know what it was, I did not know what it was.

The family provided care to their extended family out of necessity but they were not aware at the time that they had a medical disorder.

Alexie

Alexie remained quiet while her uncle talked but I sensed she wanted to share so I turned to ask her about her experiences as an informal family caregiver. Alexie noted that she is from a family of eleven children and that 2 of her sisters and 1 of her brothers are currently showing signs of memory loss. She stated that she is especially worried about her brother Vern because his memory loss has escalated quickly in the past few years. Alexie noted that she recently talked to the community health nurse about how to support him and she is actively planning to help him get a dementia assessment so that he will be eligible to access more community supports. Vern is in his fifties and he does not acknowledge that he is struggling with memory loss, which makes it

more difficult to provide support. He has forgotten that he was fired from his job and he is eager to stay busy. Alexie said, “He lost his job a couple years ago now and he still thinks he works for the tribes, so he comes in for garbage bags and goes and gathers garbage on the reserve to do what he can.”

Everyone in the small community knows that Vern has dementia, so they support him and watch out for him. Alexie said that he has begun to wander off and she worries about his safety. He was living with her while she was in Gold River taking courses at North Island College and he wandered off with a stranger who offered him a ride. She said, “He usually never wandered off, but he did one time and he ended up in Campbell River and I was living in Gold River.” He ended up sleeping on the streets in Campbell River for a couple weeks.

Vern was living with Alexie for months, but he was not living with her at the time of the interview. Alexie said she had some previous training as a caregiver, but Vern’s behaviours were becoming too difficult to manage. For example, at times he would be up at all hours of the night looking for lost money and belongings. Occasionally he accused her of taking things that he had misplaced. She is a single mother with 9 children and was struggling to pay for his food and extras. Alexie described locking up snacks in her room so she would have food to put in her children’s school lunches. In addition, Alexie was hurt when Vern’s grown children accused her of taking his money. A disagreement between family members erupted about how to care for Vern mixed with suspicion about how his finances were being managed. Alexie said;

> I talked to him about it and told him, you are going to your sons. He said but I am not a city person and I said your son is complaining about me on Facebook and it is not nice. What he is saying about me and my family.

It was clear to me from the stories shared that Alexie's brother Vern is vulnerable and he needs more consistent support. Yet, he doesn't want to move from his small community.

Both Alexie and Lorne noted that their family and community would benefit from additional dementia support and resources within the community. Alexie shared that a few years prior to our interview the NTC supported fifteen Nuu-Chah-Nulth people to take a community support worker training program through North Island College. Four of the members of the support worker cohort were residents of her small community but they did not work as support workers for long because the work was part-time and it did not pay well. Alexie mentioned that it is hard to keep people in support worker roles in her small village when their roles are undervalued. Lorne said, "I would like to see our people trained so that we don't need outside services coming in. So, we could learn how to take care of our own people those who are diagnosed." Alexie noted, "it would be a good idea to have services here in the community because a lot of the Elders don't like to leave" their homes. As our visit ended, we all agreed that caring for our Elders should be a health priority for our communities and for those in public health.

Summary

The Nuu-Chah-Nulth family caregivers shared rich information about their experiences caring for a family member with dementia. I concluded each visit by gifting the caregivers with homemade canning, a card I made and a small honoraia. After each interview visit, I took time to journal and reflected on the stories and walk on the land. I prayed for the families and after some of the interviews I cried. I was moved by the strength and resilience of each of the caregivers even through adverse conditions. I could not help but to reflect on the similarities between the participants stories and my own experience as a dementia caregiver. In many cases the caregivers

experienced similar stresses and hardships so I could relate to their suffering. The stress and frustration of caring for a loved one with dementia was evidenced in each of the interivewee's stories. In the next chapter I explore the meaning that I drew from the caregivers stories.

Chapter 6: Unpacking the Bundle

Introduction

Following an Indigenous methodological approach, I presented an account of the caregivers' stories in the previous chapter. In this chapter I present my analysis of the stories I was gifted. As I reflected on the participants' stories it became clear that the nine participants' lives and experiences were diverse and complex however their stories did share some commonalities. The health of all the families was impacted in one way or the other by historical racist colonial policies and practices. For example, most of the Elders with memory loss and their caregivers attended residential school and experienced various types of traumas, grief and loss throughout their lives. Many of the caregivers talked about the stress of caring for a person with memory loss and most felt that their stress levels would improve with greater access to dementia care services. Dementia care is challenging for all caregivers, but the challenges for Indigenous dementia caregivers are exacerbated because of the historical, structural and political oppression they have endured as a result of colonization. Culture played an important role in the caregivers' experiences and perceptions of what is important in Elder dementia care. Love and cultural obligation motivated many of the dementia caregivers to provide care even when it was difficult to do so. Some of the participants shared their vision of what dementia care could look like and commented about the services they currently receive and how they could be improved. In this chapter, I will explore the themes that emerged from the caregivers' stories: **Trauma over the Life Cycle ~** (Residential School, Family Violence, & Grief and Loss); **The Pressures of Caregiving ~** (Managing the symptoms of Dementia, Health, and Family Dynamics); and, **Participant Perceptions of Dementia Care** ~ (Love, Community Care Resources & Culture).

Trauma over the Life Cycle

Most of the caregivers recounted that they, or the person with dementia they supported, experienced trauma in early childhood and over their life span. The Centre for Mental Health (2019), defines trauma in the following way[13];

> Trauma is the lasting emotional response that often results from living through a distressing event. Experiencing a traumatic event can harm a person's sense of safety, sense of self, and ability to regulate emotions and navigate relationships. Long after the traumatic event occurs, people with trauma can often feel shame, helplessness, powerlessness and intense fear.

Trauma in early childhood and all through the life cycle was a significant theme across the participants' stories. The violence and trauma that was shared during the interview visits were assaults to the physical, sexual, emotional and spiritual wellbeing of the participants and their family members. In the next section I will highlight the areas where trauma emerged in their stories though residential school experiences, stories of grief, loss and family violence.

Residential School

Most of the caregivers who participated in this study, and many the family members with memory loss (PWD), attended residential school. I did not ask a specific question about residential school attendance. At the start of each interview, I shared my story as a dementia caregiver with each of the participants and I noted that my mother attended Alberni residential school as a way to share my interest in the topic of study and develop a relationship of trust. My story seemed to open the topic with some of the participants. A couple of the interviewees talked

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[13] Retrieved from CAMH website https://www. camh. ca/en/health-info/mental-illness-and-addiction-index/trauma

about their family members' experiences with residential school in depth, while others chose to just touch on the topic during interview. Seven out of nine caregivers confirmed that they attended residential school, while the final two chose not to discuss the topic. Seven of nine caregivers also mentioned that their family member attended residential school, some only touched on the topic.

The participant caregivers tended to share their own traumatic experiences with residential school in greater detail as these were vivid memories. Some of the caregivers shared that they knew that their family member (PWD) attended residential school but they noted that the PWD did not talk about the abuses they endured during in their early childhood. For example, Jill noted, "my grandparents didn't really talk about their residential school experiences. She did go to Alberni Indian residential school though". Harold and Ellen acknowledged that their parents did attend residential school, but they could not recall hearing them talk about their experiences. I believe that some of the participants did not know very much about their family members' early childhood experiences. Elders may not share their experiences with their young family members if they are horrific. When the topic of residential school came up in my conversation with Sherry for instance, she noted that she is still haunted by her memories from residential school. Sherry said,

> Residential school was the most unpleasant thing that has ever happened to me. They beat us, they raped us, they starved us they did whatever they wanted to do. There was nothing we could do about it. It plays on your mind all the time. It's just something you can't get over. My children keep asking me about it and I won't tell them. I don't want to put them through it. I don't want to tell my children.

Elders do not want to share experiences with their children or grandchildren that will hurt or traumatize them. Harold noted that his dad did go to residential school but he did not really talk about it. Connie said that her mother did not attend residential school although she did experience trauma as a child. Connie noted, “she lived outside the reserve in Ahousaht. I know that she had lots of traumas growing up she just doesn’t talk about it.” Katie did not specifically say that she or her husband attended residential school, but she noted that they had both experienced trauma that they needed to heal from. Katie said, “I have dealt with everything I think I need to, but I know there is stuff that he hasn’t dealt with and he doesn’t want to”. Katie agreed that most Nuu-Chah-Nulth Elders attended residential school and did not elaborate further to respect her husband’s privacy. Alexie mentioned that both she and her brother Vern (PWD) attended residential school but stopped short of describing their experiences in detail. Again, I didn’t specifically ask questions about whether the participants attended residential school. Sharing traumatic experiences is sensitive, so I was careful not to probe for more information. Still, the topic of residential school came up many times during the interviews.

Two of the caregivers shared that they believed the abuse their family members received in residential school contributed to poor health in later life and dementia. Speaking about his wife Clair’s experiences Sam said,

> She spent over six years in the residential school here. I guess the principal at that time Mr. C at that time, had a thing going for himself in the basement. He used to line up about six girls and strip them down to the waist, you know and by force, and cooperate or he’d grab them by the hair and slam their head into the concrete. You know, he was pounding on them. When they give you orders you do it, you know. He used to get from behind and grab onto their breasts and feel them. She wouldn’t cooperate.

Sam was certain that the physical abuse his wife Clair experienced in residential school contributed to her early dementia diagnosis. At the end of our conversation Sam and I reflected on the possible links between residential school abuses and poorer health in later years. Sam said, “yeah the dementia goes back to the residential school.”

Lorne shared that his brothers experienced extreme forms of trauma in residential school. He too felt there was a link between their early childhood trauma and early dementia diagnosis. He mentioned he attended the same residential school as his brothers and sisters but he couldn’t remember seeing them. He noted that the stress from the institution impacted his memory of attending the school. Lorne said,

> So, when I was in residential school I was in with my brothers and two of my sisters. But the thing is, I only remember seeing one of my brothers and that is because he was going to run away and I asked him if I could go with him, and he said no, your too small. And I was in for 5 years in that residential school and I don’t remember seeing my brothers… I was told that two of my brothers got treated really badly. Like the worst extent of any treatment. Other people remember that eh, and like I say I don’t even remember seeing them. I don’t remember interacting with them at all.

Lorne noted that he didn’t remember a large part of his childhood. Speaking of residential school Lorne said “everything just went dark.” He could not remember his experiences in residential school. When I asked if he thought he might have blocked out memories Lorne responded,

> I guess, yeah, but I remember being home with them (family) during the summer. Because we would all be there at Queens Cove. Queens Cove was like a refuge and it’s like the light goes on that when we would go off to residential school the light would go off again. It is weird how that happened…There was so much stress in those institutions. It was like we were

> in jail. We were told what to do, when to do it and if we did not do what we were told there was a price to pay and it was a heavy price. There was a lot of beatings that went on and things like that.

Lorne felt that the stress from residential school played a part in his siblings early dementia diagnosis and he stated that he wondered how their lives may have been different if they had not been forced to attend these abusive institutions.

The caregivers in this study also shared their personal experiences at residential school which impacted them their whole lives. For example, Sam recounted physical, and emotional abuses at the hands of those tasked to care for him. Even though he is nearly eighty now, he recalled a time when he was nearly killed as a young child at the residential school school with vivid clarity.

> Then the last year they tried to shove me out the window from the top floor, but they couldn't get my hands off that windowsill, my left hand. I was screaming at the top of my lungs out the window face down… You know so they pulled me in and that was the end of that episode. The next day somebody on the other side in the front of the residential school went out the window. He died, but it was on the lower floor.

Sam noted that he was lucky to survive his stay in residential school. He stated that his kidney disease was also linked to being kicked in the kidneys by the priests at the residential school he attended.

> That's where my trouble started. So when I went upstairs next day there was a supervisor coming so I moved to the left, he moved to the left, I moved to the right, he moved to the right. Then he grabbed me by the hair and swung me down to the floor and I got booted across the room. I got booted every day for two years.

Sam went on to share that he was mistreated and starved as a child in residential school.

> I was starved you know. Every day we had mush. I never saw toast. I never saw eggs, bacon or anything. Just that little tiny bowl of mush… No lunch I don't know what we had for supper. I don't remember ever seeing any meat. They killed one horse, no they didn't kill it. It was missing. I guess they found it a week later and they butchered it and they fed it to us. Horse meat.

Sam said he was severely beaten daily and he believed that his "kidney trouble was from residential school". He asserted that lack of proper nutrition, daily physical beatings and emotional abuse impacted his health, which ultimately made it more difficult to provide care for Clair.

Family Violence

Although the topic of the interview was memory loss and caregiving a few of the caregivers shared stories of being physically and sexually assaulted by a familiy member during our conversation. These stories were heartbreaking and difficult to process because they were stories about violence against women and children. For example, during our visit Katie reported having been sexually abused by her brother in early childhood. While she talked about her experience I could feel the anger still resonating in her words. I was a little shocked when Katie recounted the following story.

> So it was even priceless because when he (abuser / brother) was dying, it was really crazy because when he was dying I went to Victoria to pay my respects, but I was paying my respects to my nieces and nephews. I was not there for my brother or sister in law, I was there

> for my nephews and nieces. You know, um, my sister in law came up to me and said "are you going to go in" and I said, do you want me to unplug him?

While sharing about her life as a dementia caregiver living in a rural Nuu-Chah-Nulth community, Katie's story overlapped with the sexual and emotional abuse she endured as a child in her home. And even though the abuse happened long ago, the hurt was still present in her voice.

Ellen also shared a horrific story about the sexual, physical and spiritual abuse at the hands of her intimate partner.

> Like for my children's father it wasn't just a slap, it was always a punch or really literally beaten. One time, that was my reason for drinking. I finally admitted it because I got dragged from the float for a long distance. I had nine children but four of them lived. So much beating, so much beating. You know I had to sneak to the doctor. So finally he passed out and we had just gotten our house and I crawled and it wasn't too far to the clinic. Right away the doctor called the police and they put me on a stretcher and they brought me down the dock and I went to the hospital. They x-rayed me and my black eyes. They said do you want to press charges and I didn't know what that meant.

Ellen shared this story to explain her reason for leaving the small isolated village where she grew up. She moved to a larger city to heal and recover from addictions. Ellen noted that the intimate partner violence she experienced as a young woman was tragically like her mother's life. As a child she did not have a close relationship with her mother because she often lived with extended family to avoid the stress of her home. She said, "her father yelled all the time" and she described violent interactions between her parents. Ellen said,

> I've known and heard stories that she was a really chronic alcoholic cause my father used to beat her, not just a slap. It was a big one, he'd kick her, break her arm, or leg you know. She was always laid up. Then when my brothers were born, five of them, that's when I realized they were my parents. She would always have a black eye and it was just ongoing when they were drinking and I couldn't stand it so I ran away. I didn't run very far just in the village and I shacked up at a very young age. I ended up going through the same thing, I got beat up too.

Ellen knew that others in her small community were aware of the family violence that she and her mother endured in the small community they lived in. She said, "I know a lot of people always talked about my dad, and how abusive he was". Her mother developed dementia in her late 60s and she wondered if the beatings and hard life she suffered contributed to her mom's memory loss.

Grief and Loss

Grief and loss were themes that emerged from some of the caregivers' stories. Both the caregivers' who participated in this study and the persons with memory loss whom they supported suffered losses and experienced grief. For example, Jill noted that her grandmother "had a hard life" and had experienced considerable grief and loss. She said that losses began in childhood and continued over her grandmother's life. Jill said that when her Gran was just a child, she "lost one of her little brothers to a cougar. He was taken by a cougar when he was five, he was taken by a cougar!" Jill is a young woman with several children and I could see the horror in her eyes when she recounted that particular detail of her grandmother's social history. Jill had a lot of empathy for her grandmother and she clearly loved her. She felt compassion for the deaths and trauma that her grandmother experienced and the lack of support she had as a young mother.

> She lost her mom too at a younger age. Probably when my dad was young. She lost a daughter in 1989. She was 29 years old. She lost her younger son, one night they were partying, like both of them were partying and he passed away. So, she was very, very stuck in her groove for most of my adult life. With that there was, she didn't have her parents, she didn't have a good spouse support, her children were also going through grief and had their own issues and their own family issues and it was just compounding traumas everywhere you go.

Jill noted that she was about 5 years old when her uncle died, and her mother and grandmother grieved the loss together. She said, "that they would be crying a lot and they'd be drunk and they were both not coping well".

In addition to the grief Jill's Gran also experienced a loss of love. Jill mentioned that her Gran grieved the loss of her husband when they split up and never really healed from the split up.

> You know she would have been 29 when she lost the love of her life. The first love she ever had with two young girls…. She said she really loved him, but he really loved women. So, they split up. Then she had a second husband and they had 3 more kids. So, she had 5 kids. That second husband is my mom's uncle. Anyway, I called him grandpa and that's who I grew up with. It wasn't until later, they split up too. She was really close with all her kids. They were really family oriented and close with their dad.

Jill felt that the grief and loss her grandmother experienced culminated in poor health and memory loss later in her life. "But as time went on, she was still holding onto that grief. You could see a lot of anxiety especially as she got older. She was really restless, and she would kind of shake".

Grief and loss were mentioned in several of the caregivers' stories. For instance, Harold shared that his mother died when he was six years old and he remembered that his father suffered

from the loss but did not show it in an outwardly demonstrative way. Harold said, “he was one of those men who was quiet you know”. Harold observed that his dad was the kind of man who didn’t share his feelings openly and he did not talk about the loss even years later when Harold was an adult. When I asked how he felt about losing his mom at an early age, Harold said, “I never really got to know my mom because she died when I was so young”. Harold was still grieving his father though. Near the end of our visit he said, “I haven’t really grieved for my father… the hardest is when Father’s Day rolls around”. At the end of the interview visit Harold thanked me for giving him the opportunity to talk about his dad and share his feelings.

The topic of grief and loss emerged in my interview visit with Ellen. Ellen’s mother lost her husband just shortly before her memory loss became acutely noticeable to her children. Speaking about her father’s death Ellen said, “He died, and it was really hard on my mom. Like I didn’t know whether it was great loss for her you know but she was so depressed”. Even though he had been abusive Ellen’s mother grieved her husband when he passed to the spirit world. Ellen mentioned that her mother had 5 sons who died prematurely but did not choose to elaborate further. She mentioned that her mother became a “bingo-aholic” after her 5 sons died. I empathetically responded, “that is a lot of loss”. Ellen agreed and began to reflect on the losses she experienced and again, how her own experiences mirrored her mothers.

A look of melancholy emerged on Ellen’s face as she began to reflect on her own losses. She said “I could never imagine how hard it was for my mom, I lost two sons. One committed suicide when he was 19, the other died of heart failure. They said he died of alcohol poisoning when he was 18, … but I kept working so I didn’t really grieve”. She revealed, “At a healing retreat I was at I actually cried for my youngest son that I put up for adoption. I never realized I’d never grieved for him. So, I was grieving for him, my father-in-law, my mother and my father.”

Ellen went on to say, “sometimes I feel myself, you know missing them but I tell my partner and he always just reassures me. ” At this point in her life, Ellen has a healthy relationship with a supportive partner and she is stable and happy in her life. She has done extensive healing work to recover from an abusive childhood and marriage.

Harold and Alexie talked about losing many of their family members to dementia and other diseases such as cancer. During our interview luncheon Connie mentioned that her stepfather passed away recently and her mothers memory loss had hastened since his passing. Sam also talked about losing 2 children, one at eleven months and at birth. He said,

> I lost a child; he died in my arms…he went to Vancouver for eleven months after he was born. and I started to cry when I was going to dialysis thinking about my arm. How many needles did he get a day? They said he was given 500 pints in 11 months. That’s how many times a day they must have given him blood.

Sam’s eyes saddened and he said, “how many times did he cry and we weren’t there?” The grief of losing this child still hurt so many years latter.

Then Sam’s wife was pregnant again and when she was in labour and almost ready to deliver the baby and Sam was asked to leave her bedside. Sam said,

> Then the doctor came in and said you better leave she’s going to have her baby now. You can wait in the backroom. I went down to the backroom and wahhh you know. My ears were sharp, even though it was way down the hall … I could hear it, I swear. Then he came and said I’m sorry the baby didn’t make it.

The doctor told Sam that his wife had been given a sedative and that they would take care of everything. Sam said he was told, “we’ve got a furnace, we’ll take care of everything. There will be no cost whatsoever. ” Sam did not trust the doctor and the medical system. He said, “So I

started thinking about that about a year ago, did they take that child and sell it and lie to us? Can’t do nothing. can’t prove it.” He still thinks about the child he may have lost. This mistrust of the healthcare system still lingers in the hearts and minds of Elders

The Pressures of Caregiving

Managing the Symptoms of Dementia

All the participants in this study were supporting loved ones who were in different stages of dementia and some reflected on caring for a family member who had recently passed away. Some of the caregivers lived with their loved one and others supported their family member to live with dementia in their own home until their symptoms became unmanageable, and they had to be institutionalized in a care facility. Those who had to move their family member to a dementia care facility lamented that they wished they could have done more to keep their family member at home or in their home community. The burden of caring for a loved one with dementia was apparent in all the stories that the informal caregivers shared with me. Naturally those who lived with a person with moderate to severe dementia were especially weighed down by the responsibility of care. As I listened intently to the caregivers’ stories, I could feel the stress that they experienced and I remembered how difficult it was to support my mother before she was moved to a care facility.

Sherri and Katie were caring for their husbands in the home at the time of the interview. The stories they shared suggested that their husbands had mild to moderate cognitive decline. They could still talk and accomplish the tasks of daily living at home with help from their caregivers. Connie’s mother was also able to live at home alone with assistance from her daughters and in-home care-aids. The struggles that they shared were managing unpredictable

moods and angry outbursts, forgetfulness and repetition, inability to remember appointments, inappropriate behaviour in public and help with transportation.

Sherry said her husband is frustrated and angry about his memory loss and she believes he takes it out on her. She mentioned that she struggles with his forgetfulness and foul moods many times during our conversation. She said that she is not coping well with the realities of living with someone with memory loss. She said,

> And he'll tell you all day long about it. I get so fed up I tell him to shut up, you've already told me 50 thousand times. I don't want to hear about it anymore. It's very aggravating. Oh, just to get him out of the house so that he stops picking on me!

Katie is also caring for her husband at home. Her partner's dementia is less advanced, so he helps with some of the housework and cooking. Katie works full time and manages most of the home responsibilities. Like Sherry, her day-to-day stresses result from her husband's irritability. Katie said, "he get's put off because he can't remember. And I will say, I told you this morning and I am trying to train myself to say it more gently than irritatingly". Katie noted that her partner was happier with structure.

> He is good when he is kept busy. It is when he stresses out that I have seen him start losing it again. Me and my girl N (daughter), we watch him and that is why we watch him. Because we know the consistency of, I don't know if this sounds silly…normal. He is very private and as terrible as it sounds he smokes a lot of pot because it calms him. He is the type that doesn't, how do I put this? I have dealt with everything I think I need to but I know there is stuff that he hasn't dealt with and he doesn't want to. And more power to him. And after his stroke, before his stroke I had him to a level of (sigh) calmness (sigh) but he wasn't blowing up at the snap of a finger. But now he is back to that again so I have been trying to take care of my

> health cause I can't blow up at him He won't remember! He won't remember anything that happened two hours ago.

Harold, Ellen and Sam provided dementia care in their own home, to family members who are in the later stages of dementia. Harold's father has since journeyed to the spirit world, but he and his wife took care of him in his final years. Stressors emerged as the clinical symptoms of dementia worsened - wandering, sleeplessness, and incontinence. Harold shared,

> We'd have to ask every day; do you want to go out? He had a routine. He'd go to the bar for 2 hours. That was his limit. He'd sit in there for 2 hours. I'd say okay, dad, I'd drop you off and say I'll be back in 2 hours.

Then he started to wander off and forget how to get home.

> It was raining and blowing and in wanders my father, big smile on his face. I said where were you, we were looking for you? Oh, I got lost. That's when we realized that something was wrong. He didn't know where to get off the bus. He said I don't know where I got off, I got lost.

He went on to say,

> He would stay up till 2 or 3 o'clock in the morning. If he couldn't sleep, he'd get up and have a coffee and sit there. My father was quite unstable, but he didn't like help. He didn't like the walker. But then with the walker we'd try and help, and he'd shake us off. One night we heard a loud sound up in his room. The Mrs. went to check on him and he was on the floor, he fell and broke his collar bone. We brought him to the doctor, and they checked him out and said to put a sling on it to keep it still, but he took it off right away.

Some of the family caregivers in this study struggled to ensure the safety of their family member at the end stages of their lives. Protecting them from wandering from home or falling and injuring themselves was a source of considerable stress.

Ellen shared many stories about the strain that she and her family endured providing support and personal care for her mother. She said, "we'd leave her for five or ten minutes and we would go in the room and it was a disaster, she would pull everything down. Even in the cupboards in the kitchen everything would come out." Ellen's mother had lost all inhibitions and she would take all her clothes off which was challenging for the family. Ellen said, "She'd walk around with no clothes on you know. You'd try to dress her, and she'd get mad and she'd get violent and start hitting with her cane. " Ellen's mother required round the clock care at the end of her life and it was difficult for Ellen to manage.

Sam's wife Clair also requires full-time care, help with toileting, dressing and every aspect of living. His biggest stress seems to emerge from the fear that Clair will have a toileting accident during the time he is doing dialysis.

> What would happen if I take her to dialysis because she comes with me and they have a chair provided and if she ever makes a mess there? You can't ask the nurse to help. They've got, you know, 4 patients all sitting together.

Sam must sit still for 4 hours during his dialysis treatments which take place 3 times weekly. It is essential that Clair accompany Sam to the hospital because she cannot be left alone. Occasionally a family member is available to care for Clair, but most of the time Sam does not have help with care during his medical procedure. Harold, Ellen and Sam all accessed home and community care and family support to help manage the care of their family member with dementia.

Some of the caregivers provided support to a family member (PWD) who lived on their own until they were moved to a care home or hospital. These caregivers were concerned about their loved one's safety because they realized how vulnerable they were. Both Lorne and Jill recalled feeling somewhat relieved when their family member was hospitalized and safe in the care of the healthcare system. Lorne said his brother Tom was placed in hospital in Vancouver BC when he broke his collar bone. When the doctor realized that Tom had dementia and nowhere to live, they kept him in the hospital. St. Paul's hospital called to inform him that his brother had been admitted. Lorne said that prior to the call he had been frantic trying to find his brother. He said, "I really need to keep track of him because of his condition". Tom had quietly left Lorne's home in the middle of the night without leaving a note. He had to "put the word out" to family members and friends to find him. Lorne lost track of his brother for 3 months and he was fearing the worst. Lorne would rather support his brother to live in his home community, but Tom requires hospital care for his own safety.

Jill's Gran was also placed in a care home and a hospital when it became unsafe for her to live alone in the community. Jill was afraid for her grandmother's safety when she was still living in her apartment alone and started wandering. Jill said she noticed that her grandmother wasn't eating properly and she started wandering by herself at all times of the day or night. Jill said she was overextended with various responsibilities but she loved her grandmother, so she found time to support her. Jill said,

> She lost her teeth in the toilet or something…So I was finding myself going to help her a lot more. She was giving her alcoholic friend her money. She was very easily influenced. So, I was bringing her to do her shopping because she called me. She was calling me a lot more and it was a lot of work. To get her dentures was a lot of work. I took a lot of time

> off work and everything. Like I said, her repetitions and her stories that took about a two-hour visit to be respectful and listen to her and let her vent and take some of that stress because she was in a bad way. Every time I went to see her, she was upset.

Both Lorne and Jill lived in different communities from their family member (PWD) at times which created additional strain. They would have to travel from one community to another to ensure that their family member was safe and well cared for.

Health

Both caregivers and the family members they support reported health challenges that contributed to the burden of care.

As Sam notes,

> Both of us take medication. We took some this morning. L gave it to us. She (Clair) was bad about a week ago, even at night. It had me scared. Then I had to give her diabetes pills. We have a fight sometimes, and sometimes she cooperates. A lot of times she likes to stick one in the back and hide it and bring it out later. I told her how important it is and about five minutes later she's forgotten all about it. She'll take it and show it to me, you've got to swallow that. Sometimes she won't cooperate, and I have to get L to hold her arms back and get that down with water and lie down and get her needle for diabetes. So, I hold one arm and I've got to threaten her all dramatizing.

Connie felt that her mother's early childhood experiences of abuse led to chronic mental health issues. She believed that that the cocktail of medications that her mother was taking was hurting her health and contributing to memory loss. Connie said that her mother has taken pharmaceutical drugs such as "anti-depressants and anti-anxiety medications for over 25 years". She said, "I honestly think that if she hadn't been on all these medications, she would have dealt

with some of the issues. I do feel like a lot of it has been suppressed". She said her mother is often on 'several different medications at the same time". Connie noted that she has also struggles with depression, but she manages without medication because she has witnessed the toll that pharmaceutical medications have taken on both her sister's and mother's health. Connie stated that she noticed her mother's memory loss years earlier and she attributed it to the medications.

Sherri also had complex health issues. During our visit I noticed that Sherri seemed thirsty, so I offered her a bottled water which she gratefully accepted. She said that she brought water, but she would drink my offering as well. "I've got Sjogren's syndrome" she said, "and I am also in kidney failure". She continued, "I must drink water all day long or my eyes get blurry and my mouth gets dry from the Sjogren's". Sherri said that also goes to the "kidney place" weekly to be monitored. She pointed to an enlarged ropey vein and said that she is all ready to do dialysis, "they did that 10 years ago and I haven't had to use it, that is why my vein is so big." I compassionately noted that the stent in her arm looked painful and, in my mind, I thought no wonder she seems so unhappy. Sherri mentioned that she was going to be 77 years old soon, "to old to care for someone else".

Family Dynamics

Most of the caregivers in this study shared that they came from big families – 3 to 17 children. For example, Katie noted that, "There are 5 of us left out of the 17" in my family of origin. Some of the caregivers mentioned that they had difficult relationships with one or more of their family members, which at times made added to the stress of caregiving. Some caregivers recalled that their families collaborated in caregiving which enabled them to keep their loved one out of formalized care. People with memory loss are highly vulnerable, so it did not surprise me

when distrust concerning the management of finances came up in more than one of the interview visits.

For example, Connie shared that she has had a difficult relationship with her brother. During our conversation I asked if she was worried that her brother would put her mother in a care home and Connie responded, “I’m worried about that. I’m worried that he’s just going to put her in a home. I’m worried that he’s going to get power of attorney over her and have her committed!” Communication is strained between the siblings and that situation adds to the burden of care. Connie noted, “I do find it quite hard lately and I think part of that is because of my step dad passing away. My brother kind of distancing himself and basically just not responding to me at all now. ” As our conversation continued I realized that Connie feared that her brother was positioning himself to take control over their mother’s assets so he could put her in a care home and sell her luxury home. I felt empathy for Connie at that moment remembering how challenging it all is.

Alexie provided care for her brother in her home, but her brothers’ son was highly suspicious of her. He believed that Alexie was financially abusing his father and skimming off his welfare cheque. She said,

> I got a private message on Facebook from my nephew’s girlfriend saying that he, that my brother’s son, wanted money so they could go get groceries. I just said, I don’t have any of his money, I never have his money. I said he did lose money; I don’t know where he lost it.

Alexie lamented that her brother needed food, clothing and shelter so she took him in and helped him. Her brother was homeless when he moved in with her. There was frustration and anger in Alexie’s voice as she shared this story and the underlying distrust and implication that she might be stealing from her brother.

Suspicion of financial abuse also came up in Ellen's story as she also mentioned that she thought her youngest brother took advantage of their mother's memory loss. She said,

> We found out my brother W had brought her to Port Alberni. Had used her to pay for his car insurance, plus she would give him money too because he was her baby. Anything he wanted he got it from her because she wouldn't remember.

Ellen also worried that her mother was losing her money at bingo and to family members. When she realized her mother was no longer capable of managing her money, she moved her into her home so she could help her.

Discussions about family members took some unexpected turns. In one instance the caregiver suggested that past abuses perpetrated by a family member prepared her to be a better caregiver. Katie believed that she had more patience as a caregiver because of the abuse she endured as a child at the hands of her brother.

> … I have been abused so I got like so much… you should see the patience I have. You know I don't know if it sounds weird because I was abused but it makes it easier to talk about difficult things the older you get and not carrying anybody else's stuff.

Katie felt quite supported by her daughter and colleagues in the organization she worked for but she still held deep wounds about the abuses she endured as a child at the hands of her own family members.

When the topic of children came up in my conversation with Sherry, she said she had a daughter and two sons. I mentioned that I was my mother's only daughter and that I did a lot to help my mother. I asked if her daughter visits and helps with her husband. Sherry replied,

> Well…she'll talk to my husband but she hasn't talked to me for the last 3 years because she overheard me discussing his Alzheimer's down at the clinic. She overheard part of the conversation and on the way home she went through the roof of her car I don't know how many times screaming at me and telling me I have no business talking to anyone about her dad.

Sherry looked sad and defeated. She said, "she doesn't believe I should get help". Sherry remarked that her daughter is in denial about the severity of her father's memory loss.

Harold had 7 brothers and sisters, but he had little help with his father's care.

> It's can be a bit of a stressful time cause you love your parent. The thing is…the family never came to help us or ask how my partners mom was doing or my dad was doing. My brother's, they just asked over the phone how is dad?

Harold sighed and said that he knew that his family were not healthy enough to help care for his father.

Family was instrumental in supporting some of the caregivers to continue to informal care for their loved one (PWD) in the home. Sam had two daughters who live close to his home and he noted how grateful he was for their help. During our conversation I noticed a young woman outside in the garden and Sam said that was his granddaughter. Through shared dialogue I learned that one of Sam's daughters is a nurse and she helped him develop a better understanding of his wife's limiations. When his wife first became incontinent Sam struggled to keep her clean. He said " It's a total mess and then my daughter if she's here will shower her…

Yeah my older daughter cause she's a nurse. She says don't get mad at her, she don't know, you know".

Participants' Perceptions of Resources

Love

Love and a deep cultural obligation to care for family members was at the core of the participants stories. When I talked to Sam about his wife's decline, I said, "it must be a heavy load for you emotionally because you love her so much". He said, "Ahh yes, we all love her, and she could be sitting right there and going to the bathroom without even knowing it!" Sam was deeply worried that he would not be able to care for Clair as the disease advanced. She started showing symptoms of dementia in her late 60s and the whole family rallied around him to help him care for her. They loved her too much to put her in the care of strangers even though she required around the clock care.

Lorne also mentioned that caring for his family members with dementia caused stress for the whole family but they loved their family member, so they supported them. He said;

> And those were really stressful times for all of us. And two of my sisters wound up with it… I don't know if they were ever diagnosed with dementia. I don't ever remember them going to the doctor to be diagnosed. It was like the family took care of them. We didn't know what it was, I did not know what it was.

There was a high rate of dementia over at least two generations in this family. In a family of 7 children, 4 of Lorne's siblings developed dementia at an early age. They did not know "what it was" 20 years earlier but they were aware of the disease in the present. Lorne's oldest sister was Alexie's mother. Alexie looked forlorn when she mentioned that her mother had died when she

was young. Alexie also had 3 siblings with memory loss. This family lived in the north so there were no options to place them in a care home in their isolated community. Providing informal dementia care for this family was an act of love. In fact, most of the caregivers expressed directly or implied, that caring was an act of love.

Community Care Resources

The stress that burdened several of the participants could have been alleviated with more home care and dementia resources. Families cannot afford to hire extra help but they desperately need more support to care for their families at home. As previously mentioned, Sam is an Elder himself and constantly must worry about his wife's care which is a source of stress for him. He said "I want to get a deadbolt on the top of that door because sometimes she would open the door and look for me you know. She's dangerous to herself". Sam acknowledges that things would be easier if he had more paid help in the home. He noted "money that would solve the problem I face you know". It was clear that even though Sam was barely managing, putting Clair in a residential care home was not something he entertained. Caring for her at home meant that they could remain together as they had for 50 years.

Many of the participants expressed sincere gratitude for the professional services that they receive from the Home and Community Care nurses at the Nuu-Chah-Nulth Tribal Council. Yet many also commented that community care supports such as care-aides and homemakers are limited, especially in the more remote locations within the Nuu-Chah-Nulth territories. Both Jill and Connie were quite vocal about local supports for Elders who are experiencing memory loss and their families. Jill noted,

> So there wasn't enough care-aides and the care-aides often in many of the communities that I've worked they're First Nations and there's also problems with addictions and that comes with issues at work. You know, accountability issues, you know. So either there's not enough work. The work wasn't enough, not enough staff, not enough effort because you know it's just so much things .

Jill was especially concerned that the care-aids in her community are underpaid and that the important work that they do in the community is underrecognized.

> Then also the funding that is there for care-aides is underfunded by First Nations Health Authority which used to be Health Canada. There hasn't been a raise in the eleven years that I've been working with them. They haven't had a raise. Tax free or not that's still not fair. The band offices don't get support for supplying benefits so often those care-aides are hired casual. No benefits, they're casual so they're undervalued because of the lack of funding.

Homemakers play a part in supporting Elders to stay in their homes. Jill noted that help with the regular tasks of living falls on informal family support, but it would be helpful if the local bands had funds to support more homemakers.

> And then the homemaking part is huge to keep someone safe at home. You know they may have a fall if they're trying to mop the floor and clean the tub and it's because the Bands don't have funds for homemakers. If there is a homemaker hired they don't have enough hours to ensure that it is clean enough for the Elders.

Jill argued that it would be much safer for Elders to receive more help from homemakers. She believed that Elders would be happier if they were supported to stay in their homes as long as possible but if they do have to enter a facility it is critical to treat Elders with dignity and respect.

Connie mentioned that her life as a caregiver would be less stressful if the careaids who work with her mother were given more hours. She was surprised to learn that the care-aids are only paid to stop in and help dispense medications. Connie said,

> I find it interesting because I talked to one of the care-aides that I know who visited my mom and I was surprised to hear that they're only really contracted for 15 minutes. They're only scheduled for so much time because you know you think you're paying for an hour of support… I was appalled by that. Even twice as much is still only half an hour. That's barely time to engage with a person!

Connie pointed out that "Elders are lonely" and they would appreciate care that includes more personal engagement. She further stressed that it is important to hire care-aids that are qualified to work with Elders. Speaking of the care-aid who was working with her mother she noted, "He loves his job. He said something to me though, he said that he thinks the job is not made for younger people. That they don't have enough life experience to have the conversations with people that are elderly".

Many of the caregivers understandably struggled when they were faced with putting their loved one in a care home facility. Jill knew that her Gran needed more care but she struggled with the idea when the family moved her grandmother into a dementia care facility. Jill said,

> So she really struggled with it. She always wanted to go home and she talked about wanting to move back home. Her forgetfulness was real bad at that point. Oh yeah auntie S said I can move home and she can take care of me, which wasn't true. So a lot of things she was saying were not actual fact but she would talk like it was. So it was really confusing because I was in Port Alberni and the family was here, so I'd have to clarify what's really going on. Is she moving home, no we can't, we don't have care-aides.

Speaking of caring for his dad in his home Harold said, "But when my dad was at the end of his life, like, I wish that he could control everything and have everything set up here for nurses to come see him". Harold cared for his father for as long as possible but at the end of his father's life, he was forced to place him in the geriatric ward at the hospital just before he journeyed to the spirit world when his condition worsened and he could no longer care for him.

Connie felt that her mother would be unhappy in a residential care home. Connie mentioned that her father-in-law was moved into assisted living and her mother was clear that she did not want to move into a facility. Connie said,

> …we were talking about assisted living, B's (her partners dad) is now living in assisted living and it was a challenge to get him there. When we first talked to him about it he was like no, over my dead body. He says, shoot me first before I go into a place like that. He actually lives over here and my son actually moved in with him for a little while just to care for him cause he had had a stroke and that so he had 24 hour care for a little while. Then it just got better but he went for a visit and so he ended up in this assisted living. He actually likes it now but he told my mom about him having his food prepared for him every day and she said that's never going to happen to me. They're never going to make my meals for me.

All of the participants noted that more dementia care services within the community would benefit Nuu-Chah-Nulth families. Only one of the participants was averse to the idea of support services in the home. When I asked Sherri what services she might benefit from she said, "Oh I just want people to stay out of my house". She angrily went on to say that she didn't trust anyone to come to her home.

Culture

Several of the participants stressed that Nuu-Chah-Nulth Elders have cultural care needs when they live in care home facilities that might be overlooked by mainstream care providers. They suggested that dementia care services should be created by Nuu-Chah-Nulth people, for Nuu-Chah-Nulth people to ensure the cultural safety and dignity of the people with dementia and their family caregivers.

Lorne acknowledged the importance of food and language when he said,“the fish is very important. It would be nice if they (PWD) are in a community where there may be people that understand the language”. In fact, many people with dementia revert to their first language in advanced stages of dementia so it would be helpful for PWD to receive localized care. Ellen also noted that her mother asked her to bring traditional foods into the care home facility “like sea urchins” and mussels. These were foods that she had eaten all her life. Ellen leaned toward me and said that even though the residential care home she moved her to provided really “good food”, her mother still craved traditional foods. Ellen noted, “When she first went in, she used to ask for, like she wanted sea urchins or stew.” Her mother asked for barnacles and mussels until her condition worsened and she became disinterested in food.

Some of the participants acknowledged that beliefs, values and practices around Elder care have changed over the last few decades in First Nations communities. Jill said that her family appreciated that she had multiple roles that made it difficult for her to support her grandmother in the traditional way. Even her Gran understood that Jill had a job and children, so she was not always free to drop everything to support her.

> My Gran would, you know if I wasn’t available for a call I would say, I’m sorry Gran I’m working. And if I shut her down for something that she asked me to do like because I was at

> work or at a meeting and I couldn't make it. The next time I went to see her she would make sure to mention it. She'd say, oh you had to work. So just recognizing that values are changing too on her end, and my end. You know, I wasn't available for her. Not that she's shaming me but she's acknowledging it and to me that brought it to light that yeah, I do value family.

Jill shared that both her and her Gran were cognizant of the shifts to traditional ways of caring Elders had changed in her community.

Jill also remarked that repetition is a method of sharing teachings and not all repetitious dialogue is non-intentional. I was intrigued and asked her to go on. Jill said,

> You know there's a change in how we, you know a lot of our grandparents were taught by their parents and grandparents through storytelling and repetition and that's what they tell me. I can see when they're repeating things, or when they're gently teaching things.

Cultural knowledge and methods of sharing teachings may be different in every Nation. Jill and I agreed that helpers and caregivers who are familiar with the local knowledge are the best people to provide care, because they undertand the culture and they care deeply about the Elders. Jill said,

> It is hard work especially when you incorporate those values, if you're First Nations, you're going to care for your clients, you're going to take on extra because you care, because the family is not stepping up, you're going to give more.

Cultural accountabiliy motivates caregivers to provide the best care that they are able. Nuu-Chah-Nulth Elders are deeply respected even if they are not part of the caregivers direct family.

Beliefs about death and dying are unique in every First Nations community. Ellen's mother had moderate memory loss and she could still speak at the end of her life. Ellen vividly recalled the events of her mother's passing near the end of our visit. She said,

> I remember too just the day before my mom was dying cause she was bedridden now. I would hold her hand and she would start singing her song. I'd look at her and say mom why are you singing this song, you sing it every time. She said that's my song and I'm going to dance when I go home she said to me. Oh I said, just when they said they were going to give her so many hours. She said can you hear that, can you hear that. I said no I can't. I was looking right at her. She said you can't hear that. I said no, what is it then. She said can you hear the thunderbird. I said mom really! She said yes it's coming closer. It's getting louder, they're singing my song now, can you not hear it. She was singing louder. She was squeezing my hand. I'm just too tired now she said, I'm tired.

Ellen recalled that her mother passed away and suddenly the room filled up with people. There was little room for all the extended family. Ellen deeply believed that the thunderbird came for her mother and she said her sister saw the thunderbird. I also shared my memories of my mother's final days with Ellen and it was a special moment in our interview visit. The spiritual element inherent in Nuu-Chah-Nulth cultural beliefs emerged in Ellen's story and her beliefs comforted her. Cultural values and beliefs emerged in every interivew visit I attended.

Summary

The participants stories yielded rich insight into the lived experiences of Nuu-Chah-Nulth Elders with memory loss and their informal family caregivers. In this study, most of the informal caregivers, and the family member they supported, attended residential school. Most shared

stories about losing a loved one, grieving, and struggling to provide care because of health care concerns and/or family discord. Over the past 150 years racist colonial policies and practices have intentionally attempted to rupture Nuu-Chah-Nulth traditional governance structures, cultural practices and way of life. The caregiver's stories showed that this attack on has impaired Nuu-Chah-Nulth family's ability to care for their aging family members. In the following chapter I discuss how I make meaning from the gifts that I received during this research in the form of stories. In the next chapter I discuss the important teachings I take from the stories that were shared with me.

Chapter 7: Closing the Circle

> There were always old people in the community who forgot things and they were still valued members of the community. There are words in my language for the old ones who are forgetting, Ha ha pata iik – which means you forget things" (Elder Rose H., Ucluelet Band, Personal Communications, May 2013).

Introduction

My thoughts wander back to the beginning of this research project, to where it all began almost a decade ago in 2013 in Ucluelet BC. I entered the Nuu-Chah-Nulth communities as a volunteer presenter with the Alzheimer Society of BC, beginning my first workshop in Ucluelet British Columbia. As an outsider, I was excited about the opportunity to develop a relationship with the Nuu-Chah-Nulth people and the land, and eager to share my experiences as a caregiver of an Elder with dementia. I arrived a couple days early and rented a cabin in Ucluelet near the beach. I spent the weekend walking the beaches, smelling the salt air, and imagining what it would have been like to walk on this land two hundred years ago before extensive settler encroachment. Even now the rugged Westcoast of Vancouver Island is one of the most beautiful places on earth. The ocean holds a bounty of riches that sustained the Nuu-Chah-Nulth people for thousands of years (Atleo, 2010). During my first weekend visit to Ucluelet I read everything I could about the rich history of the Nuu-Chah-Nulth "saltwater people"[14] to prepare for the research. I learned that like other coastal Indigenous peoples, the Nuu-Chah-Nulth have always enjoyed a strong relationship with the ocean. Gathering food from the ocean and land resulted in a healthy diet and active lifestyle, which in turn contributed to good health and longevity.

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[14] In his Master's thesis, Clifford Atleo (2010) notes that the term "saltwater people" is commonly used in the Nuu-Chah-Nulth territories to emphasis the people's deep connection to the sea.

During that first dementia workshop in Ucluelet the oldest Elder in the room, Rose H. said there were people in her community living with memory loss, but not nearly as many as there are today. She shared that it was not uncommon for the Elders to live to a very old age and often the Elders began to lose their memories as old, old people. Nuu- Chah-Nulth families cared for their vulnerable old ones and everyone in the village looked out for Elders who were exhibiting signs of memory loss. Similarly, one of the participants noted, "it seems like years ago there were no people with memory loss, I never ever heard of dementia. Like, our older generation never seemed to have memory loss" (Harold, 2019). So, what happened in the last 150 years that has upset the balance and created health disparities and an increase in dementia in Nuu-Chah-Nulth communities?

In this chapter, I seek to unpack that question using the participants' stories to guide my analysis, and theory grounded in decolonial knowledge and scholarship. Connecting back to the questions that I had coming into this research; the findings indicate to me that Nuu-Chah-Nulth Elders and their caregivers experience greater hardships than seniors in the mainstream due to the colonial oppression that they have endured throughout their lives. This, in my opinion, serves as justification for funding to address the lack in dementia support services which the Nuu-Chah-Nulth dementia caregivers deemed lacking.

Social Determinants of Indigenous Peoples Health

As a Gitx̱san scholar with dementia caregiver experience, I expected that the Nuu-Chah-Nulth caregivers that I spoke to would share stories of pressures that are typical when caring for a person with dementia. From my own experience, I know that some of the common symptoms such as difficulty communicating, agitation, incontinence, confusion, and disorientation can lead to frustration, and stress for informal dementia caregivers. And many of the caregivers did share

stories about their struggles managing the behaviours that emerge with dementia. What I did not expect were the deeply emotional stories of grief and loss, stories about the trauma and abuse, that the caregivers themselves had experienced throughout their lives. Thinking back to the interviews, I realized that the caregivers who participated in this study were also healing from the deeply debilitating impacts of colonization, which adds significantly to the burden of caregiving. Colonization and all its associated practices are important determinants of First Nations peoples' health (de Leeuw et al., 2018). Stories of failing health, family violence, grief and loss in the present day are directly linked to the historic trauma, systemic racism and structural inequity that the Nuu-Chah-Nulth Elders and caregivers have endured over their life time.

Informal dementia care is a stressful role (Racine et al., 2021) that is further exacerbated by the suffering that colonization has brought to the Nuu-Chah-Nulth people. In 2017 the Office of the Senior Advocate in British Columbia (OSABC) published a report entitled *Caregivers in Distress a Growing Problem*. The report showed that 31% of informal caregivers in British Columbia are distressed due to a lack of supports and services. The trend was up 7% from a report done in 2015. No recent reports have been published on the topic of caregiver distress likely due to the emergence of the Novel Coronavirus COVID-19 pandemic, which now dominates the OSABC research efforts. The report did not look at First Nations caregivers specifically and there is a need to further document the stories that speak to the specific burden of care that First Nations people carry in BC or on Vancouver Island.

The stress of caregiving was explicit in all the stories shared in this study. For example, both Sam and Sharon suffered from advanced kidney disease and it was heart breaking to hear about the hardships and stress that they went through to provide informal dementia care while monitoring and caring for their own health. Sam said "if someone were to just stay with her

(Clair) for the three days I have to do dialysis I wouldn't feel so stressed out". Both participants linked their failing health to multiple abuses they sustained in residential school. The stress of providing informal dementia care can have widespread deleterious effects on the caregiver's health (Alzheimer's Society, 2014). For example, caregivers can forget to focus on their own health and wellness when they are overwhelmed and exhausted from caring for a loved one (CTV, 2021). But little is known about the intersecting effects of stress on dementia caregivers who have attended residential school and experienced colonial trauma.

Childhood Trauma & Dementia

According to recent studies, experiencing trauma in early childhood can place an individual at higher risk of developing dementia later in life (Demarais et al. 2020; Ouanes & Popp, 2019; Tani et al., 2020). In my research I found that there was a gap in the literature with regard to Indigenous brain health and residential school trauma. Recent research however, does show that residential school attendees and their families struggle with a broad range of chronic health conditions (Wilk et al., 2017). The Canadian government imposed residential schools on the Nuu-Chah-Nulth people for nearly 100 years (NTC, 1996). The lasting effects of the abuses that occurred within those malicious institutions still resonates with the Elders who were forced to attend as children. If this research is representative of the Nuu-Chah-Nulth population many of the Nuu-Chah-Nulth Elders living with dementia in the present day, and their caregivers, are survivors of the residential school system.

The outlawing of traditional ceremonies and banning of the whale hunt limited the autonomy of the Nuu-Chah-Nulth people, and had an impact on their mental, spiritual and physical health (Atleo, 2004; Cote, 2010). The historical trauma that Nuu-Chah-Nulth people have experienced has resulted in higher rates of suicide, incarceration, and struggles with mental

health and substance use (NTC, 1996) that also emerged in the participant stories. Epidemiologists have shown that there is a link between structural inequality and poor health, and racial discrimination at any economic level can be detrimental to an individual's health (Krieger, 2001). First Nations communities on the Westcoast of Vancouver Island and all across Canada have undergone considerable trauma through the public health and residential school systems. Ensuring that families are supported to provide adequate care may minimize the potential trauma that Elders, and their family caregivers may endure when Elders experience memory loss.

Racism in the healthcare system is also a source of ongoing trauma for Elders and their caregivers. Anti-Indigenous racism on Vancouver Island has been well documented in recent years (Kines, 2021; Turpell-Lafond, 2020). Nuu-Chah-Nuth people may not reach out for help when they have had negative racist experiences. Recent reports in British Columbia reveal that anti-Indigenous racism is widespread on Vancouver Island (Turpel-Lafond, 2020). Some of the caregivers' narratives described a reluctance to seek help from healthcare services even when their loved one was in the advanced stages of dementia. For example, Harold shared that he promised his father that he would not place him in an Island Health facility even though his health had deteriorated and he required around the clock care. Harold's father had complex care needs at the end of his life that were not easily managed without support. During the COVID-19 pandemic members of the Cowichan Tribes on Vancouver Island were scapegoated and refused some essential services due to race. First Nations people on Vancouver Island know that racism in the healthcare system is deeply engrained. As an Elder caregiver, I experienced racism personally on multiple occasions while assisting my mother to access health and dementia care

services on Vancouver Island. Experiences of racism and marginalization add to the compounding effects of trauma over the life cycle.

Trauma and the Caregiver: My Story

Reflecting on the narratives that were shared by the Nuu-Chah-Nulth caregivers in this study I realized that my experience parallels those of many of the other caregivers. Historical trauma impacts both the First Nations person with dementia and their informal family caregivers in significant ways. As mentioned in the introductory chapter, my mother's name was Kathleen (Kathy) Gladys Danes. Sadly, she passed on to the spirit world in 2018 during the writing of this dissertation. Mom's mother was Matilda Danes, and my great grandmother was Susan Danes. I am from a long line of strong Gitx̲san women who loved their children, families and communities. I always knew that my mother loved me. When I reflect on our time together, I think that she was the best mother in the world. If you have ever spent time with a First Nations woman you will know that most love their children with a love that is almost indescribable. Indigenous mothers look at their children as gifts from the creator. I was the only daughter and eldest child of three which contributed to my special status. I had one other older brother, but he died when he was a baby, so when I came along a few years later mom had a lot of love to give. My mother was fiercely protective of me when I was a child; she wouldn't have let anyone hurt me. She would never have hurt me herself, intentionally. But she did…. unintentionally. She shared the trauma she experienced as a child with me, when I was a child and again, later as her caregiver.

My mother was an amazing storyteller and even though it was fifty years ago I still remember how animated she would get when she told my brother and I a story of her childhood.

Her eyes would get big and her sun face would kind of glow, as she recounted her life as a young child in Hazelton British Columbia. She shared her memories of gathering and processing foods from the land and river with fondness. As a young child I begged her to tell me stories of her life on Anlow, the lax yip[15] that my grandmother and great grandmother Matilda held title to. One day when I was five, she told me the tragic story of what happened to her when she was five years old. She shared a graphic account of watching her mother and uncle be shot to death by a man with a hunting rifle in their home. He proceeded to look for all the children who had run and hid. I still remember my reaction even though it was over 50 years ago; I just cried and said, “do mommies die”? Mom comforted me and laughed, she held me close and said don’t worry honey I won’t die until you are old. This was the first of many stories that my mother shared with me, stories of grief, loss, family violence and trauma. Mom did not talk about her mother’s brutal murder again until she was an Elder and had been diagnosed with Alzheimer’s disease.

Later as my mother’s informal dementia caregiver and primary support, I would pick mom up from the care home facility and bring her home on weekends. At a certain point, when mom could still talk, she repeated the story of my grandmother’s brutal murder every week for months as if she were telling them for the first time. Finally, in a state of desperation I said, “mom, please don’t tell me that story again, it makes me so sad” and she never did. After that she seemed to forget the story entirely. People with dementia remember the most traumatic moments of their lives and they get stuck on stories that had an impact on their lives. They have the burden

[15] Land in the Gitsenimx language.

of reliving the trauma repeatedly, while their caregivers have the burden of listening to those stories continually until the memory finally fades from their loved one's mind.

Healing: Telling our Stories

The research interviews were gathering places where the caregivers and I met to share our experiences caring for a loved one with dementia. Sharing our stories is a method of healing in both Gitxsan and Nuu-Chah-Nulth communities. The relational aspect of the research design created space for healing from the trauma and institutional racism. As Simpson (2015) notes our stories, songs, ceremonies and connections to the land contribute to our healing. At the conclusion of the interview some of the caregivers noted that it felt good to talk about their experience. It is not easy to share experiences of suffering but each of the participants did so with dignity and grace. And this is a place where my story intersected with the participants stories. Because as First Nations dementia caregivers we have all experienced trauma and we are all healing from it when we came together to share our stories.

Nuu-Chah-Nulth authors and scholars confirm that their communities enjoyed good health prior to settler colonialism (Cote, 2010; Atleo, 2010). The critical health conditions that put Elders at risk of dementia, such as heart disease and type 2 diabetes were almost non-exsitent a hundred and fifty years ago while the Nuu-Chah-Nulth diet was still rich in traditional foods such as whale blubber and salmon (Cote, 2010). It is important to acknowledge the link between colonialization and the extraordinary struggles that informal caregivers face. Revitalization of Nuu-Chah-Nulth cultural, spiritual social and economic wellness relies on their ability to attain sovereignty over their lands and oceans.

Health and wellness in an Indigenous context are interconnected with the land and waters and every living thing (Richmond, 2018; Simpson, 2014). In nearly every exchange with the participants, the significance of the land and ocean came up as a way of life, a central part of the holistic health and wellbeing of the person with memory loss, and their caregiver. For example, Katie noted that her husband is happiest when he is on the ocean with his friends. Lorne noted that his brother "would go into the bush because he knew it was time to do the cedar." Almost all the participants mentioned fishing or connecting with the land and oceans within their Nuu-Chah-Nulth communities as a natural part of life. Half of the participants reflected on their childhoods where boating or fishing featured prominently in their memories of the person they care or cared for.

Nuu-Chah-Nulth people with memory loss, their caregivers and communities are gravely impacted by colonialism but their stories do not stop there. Settler colonialism disrupted Nuu-Chah-Nulth people's way of life but there was evidence of healing and resistance in the participants stories, that should not be overshadowed by the stories of suffering. Nuu-Chah Nulth scholar Wickaninnish (Cliff Atleo Sr.) refers to this time in history as hoquotish, a time when the Nuu-Chah-Nulth canoe has tipped over they are disoriented and have lost their way (Hunt, 2021). Johnny Mack (2011, p.295) states that "Hoquotist is the Nuu-Chah-Nulth metaphor used to describe a disoriented person or people" due to the effects of colonization. Decolonizing Elder care practices using this metaphor involves reorientating, righting the canoe and caring for all of our relations who are floundering in the water without leaving anyone behind. The Nuu-Chah-Nulth people have resisted colonial assaults on their way of life and they have maintained their culture and continue to heal. The NTC home and community care nursing program offers holistic

trauma-informed culturally sensitive caring services to Elders and their caregivers but their services may be limited due to funding.

In some cases, the participants reported that caring for an Elder parent was a means of healing past hurts and developing a relationship with their parent before they passed into the spirit world. Sharing our stories allowed us to reflect on the role that caregiving played in our personal healing. For example, speaking of her childhood Ellen said, “I didn’t want to know my mom at that time”. But while Ellen cared for her mother, she recorded her stories on tape and began to know her better. During our interview visit I shared how much I learned from my mother through the caregiving relationship. Ellen said, “That was how I was too with my mom, I was learning. And asking her questions about her young life. She would talk about it. I recorded her but I don’t know what has happened to the tapes. She would have funny stories.” Ellen smiled and laughed as she recalled her mother’s stories. Ellen held her mother’s hand and she journeyed to the spirit world feeling a sense of peace because she cared for her during the final years. Harold expressed a similar sentiment during our visit. He talked about some of the regrets he had in his life especially not seeing his father and his children for many years while he was away working in a logging camp. Caring for his father was a means of making amends for not being there for his father years before. He was proud that he had stepped up to care for his father. The memories he held from that time were important to him. As I was leaving Harold remarked how important it had been for his healing to share his experiences as a caregiver. Sharing our stories was an important part of our collective healing.

Reconcilliation: Finding a way Forward

Through the writing of the manuscript there has been many important events that have shone a light on the colonial violence that has impacted Indigenous people’s health. In June 2015

the Truth and Reconciliation Commission of Canada published 5 documents including 94 Calls to Action. The report of the TRC documented thousands of stories of the abuse that occurred in residential schools. In June 2018 the Prime Minister of Canada issued an apology to the Indigenous people of Canada for the unspeakable harms that were done to First Nations, Inuit and Metis children and families during the residential school era (TRC, 2015). In May 2021, the unmarked graves of 215 children who died in Kamloops residential school on Tk'emlúps te Secwépemc territories were located using ground penetrating radar (Sawyer, 2021). In April 2022 Pope Francis apologized to an Indigenous delegation in Rome for the role that the Catholic church played in the running of residential schools and the deplorable abuses that were inflicted on Indigenous children by some members of the Catholic church (Stefanovich, 2022). Many of the people in Turtle Island have begun to wake up to the atrocities that have been committed and covered up by the church and state. Indigenous people across Canada have grieved for the lost children, but the recent findings have not come as a surprise to Indigenous people who have always known that many children did not return from the residential institutions. The participant known as Sam in this research shared a story about a near death experience in residential school. Sam said,

> Then the last year they tried to shove me out the window from the top floor but they couldn’t get my hands off that windowsill… The next day somebody on the other side in the front of the residential school went out the window. He died but it was on the lower floor.

Along with other Chiefs on Vancouver Island the leadership within the Nuu-Chah-Nulth territories is looking at ways to locate any unmarked graves that might exist on the site of the Alberni residential school site (Judd, 2022).

Reconciliation must include meaningful actions rather than just a simple apology. The health of Indigenous Elders and their caregivers in Nuu-Chah-Nulth communities is very closely entrenched with the historic relations that Indigenous people have endured with the state (Belcourt, 2017; Cote, 2010). Meaningful actions must correct the wrongs of the past by supporting opportunities for community revitalization and healing in the present day. The health and wellness of the caregivers and Elders who participated in this study was clearly impacted by racist colonial policies and practices. As the incidence of dementia grows in Indigenous communities the need for culturally safe resources and supports will also continue to grow (Lewis, et al., 2021). Some of the participants believed that reconciliation should involve supporting families to manage the health inequities that have emerged as a result of the deplorable oppression they experienced as children in residential schools. For example, Lorne and Alexie argued that the health of several generations of their family were negatively impacted as a result of residential school. Truth and reconciliation should include financial support to create support services for the growing number of First Nations people with dementia in First Nations communities. Lorne said,

> I think if this government is remotely serious about helping our people, they could say yes, I would gladly help you out. What is it you need? That would be part of reconcilliation. It is like pulling teeth to get funding for the least little thing for our people. So in reality they would help us to be able to help ourselves. That is the way we can look at it and have them recognize that.

Alexie and Lorne’s family members have died or are presently living in an Island Health hospital settings miles away from their community due to a shortage of dementia care supports in their rural and remote area. The participants in this study were vocal about their need for additional

resources. Their voices echo in my thoughts as I consider the recommendations that emerge from this study.

Recommendations

1. *Governments must provide Indigenous communities with more funding for home care services to help informal caregivers to support their loved ones with dementia to live in their homes for as long as possible.*

The First Nations Health Authority (FNHA) receives funding from provincial, federal and other sources to fund First Nations communities to design culturally safe, trauma-informed health care programs and services in the province of British Columbia (First Nations Health Authority, 2022). The FNHA's mandate is to work with other health authorities to address the gaps in services for Indigenous people in BC. In the Nuu-Chah-Nulth territories healthcare services are managed through the NTC and Island Health. Several of the caregivers in this study mentioned that there are gaps in home care support services for people with dementia and their informal family caregivers which is contracted through Island Health. More precisely four of nine of the dementia caregivers stated that more in home care services would reduce their stress level. Most of the dementia caregivers expressed a sincere desire to support their loved one to continue to live at home, but they struggled to do so. There are many positive benefits to the provision of informal care in the home but caregivers also face intense emotional, financial and physical strain (Alzheimers Society, 2010) which came out in my analysis of the interivews.

The Nuu-Chah-Nulth Home and Community nursing team provide culturally safe trauma-informed care and those services are highly valued, but there are too few in home supports, day programs and respite care. These community Elder support services are typically contracted through Island Health on Vancouvers Island (Watts, 2022, Personal

communications). Jill mentioned that her Gran had to be moved from her home when the family could not manage her care. She said “You know like there was no care-aides regularly to keep her at home. So that’s the reason that she had to go move out.” Connie noted that the care-aid who assist her mother to take her medication only stay with her mother for fifteen minutes before leaving to assist another Elder. She said, “I was surprised to hear that they are only really contracted for 15 minutes… I was appalled by that. Even twice as much is still only half an hour. That’s barely time to engage with a person!” Connie’s mother had recently become widowed. Connie visited her as much as her demanding work schedule would allow but mom was lonely and grieving, and would have benefited from a more holistic approach to community care.

The bio-medical approach to Eldercare that is regularly practiced in mainstream community health does not meet the needs of aging Indigenous Elders. Holistic healthcare practices consider the well-being of the whole person, mental, physical, emotional and spiritual. As noted earlier in this thesis, cultural safety is built into the services that are offered by the NTC Home and Community Care Nursing team. The informal family caregivers were grateful for the nursing care they received but many expressed a need for more community support from care-aids or homemakers to manage day to day healthcare needs. Section 23 of the *Truth and Reconciliation Commission Calls to Action* (2015) calls on all levels of government to “increase the number of Aboriginal professionals working in the healthcare field”. The caregivers acknowledged that Nuu-Chah-Nulth care-aids who presently work in their communities provide the best culturally safe care. Several of the participants mentioned that the work that care-aids do is not highly valued, their wages are low and they don’t get enough hours to commit to the work. They recommended that people working with Elders should be paid fairly and that more money should be allocated to train Nuu-Chah-Nulth in home care attendees.

2. *Equitable government funding must be allocated to support the Nuu-Chah-Nulth community to plan and build culturally safe services and Eldercare facilities*

The caregivers acknowledged that they want to support their family member with dementia to stay in their home but sometimes it is not possible. There are a number of housing and care options funded by the British Columbia to support families when their family members enter the final stages of cognitive decline. Elders typically begin by entering into an assisted care unit when they are still able to manage the tasks of daily living with help. When the symptoms of dementia progress, Elders are moved to a long-term care facility or extended care unit in a hospital. Nuu-Chah-Nulth Elders and their caregivers have historically avoided mainstream services until they were in crisis. As mentioned earlier racism is embedded in the healthcare system on Vancouver Island (Turpell-Lafond, 2020). The informal caregivers who participated in this were very wary of mainstream health services. Very recently the First Nations Health Authority began working with Island Health to help guide them to provide culturally safe trauma-informed care to Elders entering into the West Coast General Hospital in Port Alberni BC for emergency care (Johnson & Hassan, 2021). This partnership is a step in the right direction and Nuu-Chah-Nuth families were encouraged by this work but it was noted that the Elders still experience racism when they seek medical care.

Tsawaayuus Rainbow Gardens is a First Nation assisted living facility located on the Nuu-Chah-Nuth territories in the southern region. It is a smaller residence that houses 30 First Nations Elders in Port Alberni area (Tsawaayuus, 2021). This facility provides a needed service but it may not be big enough to accommodate the growing Nuu-Chah-Nulth Elder population. An increase in affordable subsidized assisted living facilities within First Nations communities would lessen the pressure on families, yet at that present there are too few Indigenous assisted

living facilities in British Columbia. Article 21.2 of The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP, 2008:9) affirmed that "particular attention shall be paid to the rights and special needs of Indigenous elders". Elders play an important role in the cultural transference of cultural knowledge, and they play a vital role in the healing and revitalization of Nuu-Chah-Nulth communities. It is critical to support Elders to stay in their communities.

When families and friends are unable to provide informal care, culturally safe formalized care services within the community may be the next best option. Yet, at present there are few culturally safe long-term residential care homes for First Nations and Indigenous people across North America (AFN, 2007; Brown & Gibbons, 2008; Parrack & Joseph, 2007). The only First Nations long term care home in British Columbia was the Pine Acres Home in Westbank BC. After operating for 38 years this 63-bed long term care facility closed its doors in January 2022 due to a shortage of staff who were fully vaccinated for COVID -1 9. Elders who lived in Pine Acres had to be moved to other facilities in the province (Szeto, 2021).

When long term care homes and dementia resources are not available within First Nations communities, Elders are often forced to leave their homes to enter provincial facilities outside of their communities (AFN, 2007; Cammer, 2006; Green; 2007). These care facilities can be hundreds of miles away from the Elders home community and family (Cammer, 2006). This displacement can be traumatic for Elders and caregivers, and the stress may have a detrimental effect on their health (AFN, 2007). In fact, there are many drawbacks for Elders and their families when care is provided in mainstream facilities outside of the community including isolation from family and friends, loss of the opportunity to participate in and contribute to cultural life (AFN, 2007). In addition, when Elders are uprooted from their community and

placed into an extended hospital care facility they often die sooner (AFN, 2007) and often they die alone (Green, 2007).

Indigenous Elders have a strong desire to grow old and die on their traditional territory, so that their spirit can remain on the land (Ranzijn, 2010). Nuu Chah Nulth people with dementia are resistant to moving away from their territories or to move into a medical facility where traditional foods and practices are absent, and it is too far away for family to visit. Speaking about her Gran Jill noted, “anybody that I’ve talked to they just want to be where their family can come see them. Even if they are in a hospital at least people can still come and see them. They want to still be treated like a human.” The land that First Nations people occupy is connected to their health, identity and culture. Wilson (2003, p. 83) that the land does not just represent a physical space but rather, represents the interconnected, physical, symbolic, spiritual and social aspects of First Nations cultures. The land is important part of Nuu-Chah-Nulth people’s health as it provides nourishment and medicines. Many of the traditional medicines and foods can only be found in the geographical area of the Nation (Wilson, 2003). The caregivers in this study realize the significance of the land and chose to provide informal supports to their family members to keep them at home and in the community for as long as possible. In British Columbia First Nations cultural traditions place an emphasis on honoring the loved one as they complete their life’s journey to and enter the spirit world (Green, 2007). Care homes that are close to the community allow the family to be close to their loved one at the end of their life.

The cultural protocols involved in caring for a person through illness and at the end of life are absent in medicalized approaches to caring that is dominant in provincial care facilities (Russell, 2018). Duran & Duran (1995) assert that western approaches to healthcare do not allow for other worldviews or knowledge in the therapeutic relationship with people who suffer

illnesses. Holistic culturally safe approaches to care are vital to ensure a positive quality of life for Elders with memory loss and their caregivers. Ideally, a truly Indigenous home care program is founded on Indigenous worldviews, knowledge, beliefs and understandings of health and illness, and utilizes Indigenous healing practices. Indigenous holistic approaches to care acknowledge the mental, physical, emotional and spiritual needs of the Elder and the caregiver (AFN, 2007).

In British Columbia cultural practices are an important part of the health and wellness of Indigenous communities. In her seminal book, *Colonizing Bodies*, Mary-Ellen Kelm (1998) stated that First Nations people in British Columbia accepted support for the treatment of diseases that originated with the settlers, but they never abandoned their own medicines, wellness ceremonies and practices. Spiritual practices such as praying, smudging and sweat lodges are still commonly used by First Nations people across Canada as a (Iwasaki, Bartlett & O'Neil, 2005). Ceremonies are an important part of dementia care supports, and care home environments must incorporate Indigenous philosophies of care as well as culturally safe practices truly be effective.

3. *There is an urgent need for more research to understand the unique needs of Indigenous dementia caregivers in British Columbia and Vancouver Island specifically.*

At present there has been little research to confirm the number of Indigenous informal dementia caregivers in British Columbia and their level of distress. Walker and Jacklin (2019) note that data on Indigenous peoples with dementia in Canada is relatively scarce. It is clear that Indigenous people in Canada are at higher risk of developing dementia and that the numbers of Elders with dementia is growing. As noted in a recent report by the Office of the Seniors Advocate in BC, there is much that needs to be done to address the gaps in the healthcare system

for seniors in British Columbia (OSABC, 2019). Without sufficient data it is difficult to know how many Indigenous dementia caregivers there are and what is needed to address their unique care needs.

Bringing the Bundle Together

It has taken me some time for me to complete this research. I had to develop relations with the land and people before I could be welcomed to come ashore by the Nuu-Chah-Nulth community and that takes time. Like so many of the Nuu-Chah-Nulth caregivers I spoke to I experienced myriad losses and grief during the writing of this dissertation. I know first hand how hard it is to go forward when your heart is broken. As a Gitx̱san woman I am accountable to my family and community to walk in a good way in my research, teaching and daily life. I turn to local Elders and my Indigenous colleagues when I seek guidance. I turn to my Gitx̱san family when I am in need of teachings, and I turn to my ancestors and prayer when my spirit is in need of replenishing. Our ancestral practices guide us in the work that we do and although I did not grow up in my community, I feel a deep connection with my ancestors and they have walked with me during the writing of this manuscript. Our Indigenous cultural practices, ceremonies, songs, dances and knowledges guide our caring practices and our research. Ancestral knowledge systems or epistemologies, underpin all of the work we do as caring professionals. It follows that we will have to draw on those knowledge systems, return to our ancestral knowledge when conceptualizing Elder healthcare and support systems for dementia caregivers in the future. At present the NTC Home and Community Care do just that, but they are limited in the services they can provide.

As a Gitx̱san scholar using an Indigenous methodology, I am accountable to the Nuu-Chah-Nuth community to share the findings of the research in a report. Dissemination of the

research findings will be accomplished through the completion of this dissertation and through a virtual community-based presentation. At the time of my Ph.D. defense, I had already collaborated with my community partner Jeannette Watts to host a virtual public presentation for nurses, homecare workers, caregivers and the general public. I will create a short summary of the research to publish in the Ha-Shilth-Sa online newspaper with an invitation to attend the public presentation. This research will contribute to planning for future planning for eldercare services in the Nuu-Chah-Nulth community.

My Gitxsan community is distant from the Nuu-Chah-Nulth communities so there was much that I did not know about the Nuu-Chah-Nulth people, their land, language and culture when I entered into this study. I cautiously began by using the words memory loss in place of the word dementia believing that dementia would be offensive and less well understood. I soon found out that the Nuu-Chah-Nulth Elders were very aware of dementia and they embraced a study that aimed to understand the reasons for an increase in dementia in their membership. Culture and language are closely linked to Indigenous knowledge (Thompson, 2008) so I could not have engaged in the creation of knowledge without the support of the community. The knowledge created by the participants in this study emerged from Nuu-Chah-Nulth worldview and it belongs to the people and the community. Dementia is a difficult topic to discus, but it is even more difficult to share stories about caring for a loved one with dementia with a stranger. I am deeply indebted to all the Nuu-Chah-Nulth people who opened their hearts to me.

Elder Rose H. said that there were people within the Nuu-Chah-Nulth communities who had dementia were not as noticable because they were few, but they are not few anymore. In addition, caregivers of family members with dementia continue to suffer the ongoing impacts of colonization, which adds to the burden of care. When my mother started to show symptoms of

memory loss, I did research to learn everything I could about dementia and how to support her. At that time there was little information regarding Indigenous people and dementia in Canada. I found that few studies on informal dementia care had been done by Indigenous scholars using Indigenous knowledge to guide them. Even now, few studies have been done by First Nations scholars who have personal experience caring for a loved one with dementia. My sincerest hope is that Indigenous scholars will embrace future research on this important topic. My story started fifteen years ago and fortunately interest in understanding Indigenous peoples experience with dementia and informal dementia care is on the rise in Canada. I chose to undertake this study in the hopes that other Indigenous caregivers would read the study, see themselves in the participants' stories and feel support in knowing they were not alone. I also chose to undertake this study to honor my mother, to document our story, to grieve, to heal and to move forward. As I come to the end of this journey, I realize that the biggest gift I received from participants was the healing that occurred for me when the participants and I collectively shared our stories from the heart and for that I say Haa'mii'yaa – thank you.

References

Alfred, T. (2005). Wasase: Indigenous pathways of action and freedom. Broadview Press.

Adelson, N. (2005). The embodiment of inequity: health disparities in Aboriginal Canada. *Canadian Journal of Public Health*, 96(S2), S45-S61. https://doi.org/10.1007/bf03403702

Allan, B. & Smylie, J. (2015). *First Peoples, second class treatment: The role of racism in the health and well-being of Indigenous peoples in Canada*. Toronto, ON: Wellesley Institute/Well Living House. Available from: https://www.wellesleyinstitute.com/wp-content/uploads/2015/02/Full- Report-FPSCT-Updated.pdf

Alzheimer Society of Canada. (2010). *Rising tide: The impact of dementia on Canadian society*. https://www.cancea.ca/sites/economic-analysis.ca/files/reports/Rising%20Tide%20-%20Dec%208%20(rev).pdf

Alzheimer's Association. (2021). Alzheimer's disease facts and figures. *Alzheimer's Dementia* 17(3), 327-406. https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf

Archibald, J. (2009). *Indigenous storywork: Educating the heart, mind, body and spirit*. UBC Press.

Assembly of First Nations. (2007a). *Sustaining the caregiving cycle: First Nations people and aging. A report from the AFN to the special committee on aging*. https://www.slideserve.com/hinto/sustaining-the-caregiving-cycle-first-nations-people-and-aging

Assembly of First Nations. (2007b). *First Nations Regional Longitudinal Health Survey 2002/03: Results for adults, youth and children living in First Nations communities.* Ottawa, ON: Assembly of First Nations. https://fnigc.ca/wpcontent/uploads/2020/09/0bc75bb9e0f03ebc28116a605432f73b_rhs2002-03-the_peoples_report_afn.pdf

Atleo, E. R. Umeek. (2004). *Tsawalk: A Nuu-Chah-Nulth worldview*. UBC Press.

Atleo, C. (2010). *Nuu-Chah-Nulth development and the changing nature of our relationships within the Ha'hoolthlii of our Ha'wiih*. Master's Thesis. University of Victoria. D Space. https://dspace.library.uvic.ca/bitstream/handle/1828/2981/CAtleoFinalThesis24August2010.pdf

Azad, N. A., Bugami, M.A. & Loy-English, I. (2007). Gender differences in dementia risk factors. *Gender Medicine*, 4, 120-129. https://doi.org/10.1016/s1550-8579(07)80026-x

Barrera, J. (2020, June 23). *Vancouver Island hospital named in allegations of racist "game" that sparked investigation*. CBC News. https://www.cbc.ca/news/indigenous/bc-hospital-staff-indigenous-health-game-1.5623759

Baskin, C., & Davey, C. J. (2015). Grannies, elders, and friends: Aging Aboriginal women in Toronto. *Journal of Gerontological Social Work*, 58(1), 46-65. https://doi.org/10.1080/01634372.2014.912997

Bedard, M. , Koivuranla, A. & Stuckey, A. (2004). Health impact on caregivers of providing informal care to a cognitively impaired older adult: rural versus urban settings. *Canadian Journal of Rural Medicine*, 9, 15-23.

Belcourt, C. (2017). *The revolution has begun*. Keynote address at the Maamwizing conference with Laurentian University at Science North, November. [Video]. YouTube. https://www.youtube.com/watch?v=XqBXDPzyLm0

Berg-Weger, M. , Rubio, D. , & Tebb, S. (2001). Strengths-based practice with family caregivers of the chronically ill: Qualitative insights. *Families in Society, 82* (3), 263-272. https://doi.org/10.1606%2F1044-3894.191

Boyer, Y. (2014). *Moving Aboriginal health forward: Discarding Canada's legal barriers*. Purich Publishing Limited.

Brasso, K. (1996). *Wisdom sits in places: Landscape and language among the western Apache*. University of New Mexico Press.

Bradley, P. (2003). Family caregiver assessment – Essential for effective home health care. *Journal of Gerontological Nursing, 29,* 29-36.

British Columbia Government. Provincial Health Officer. (2009). *Pathways to health and healing – 2nd Report on the health and well-being of Aboriginal people in British Columbia.* Provincial health officers annual report 2007. Victoria, BC: Ministry of Healthy Living and Sport. http://www. health. gov. bc. ca/pho/pdf/abohlth11- var7. pdf

Brown, C. M. & Gibbons, C. (2008). Taking care of our elders: An initial study of an assisted-living facility for American Indians. *Journal of Applied Gerontology*, 27(4), 523-531.

Buchignani, N., & Armstrong-Esther, C. (1999). Informal Care and Older Native Canadians. *Ageing and Society, 19*(1), 3-32. https://doi.org/10.1017/S0144686X99007254

Cammer, A, L. (2006). *Negotiating culturally incongruent healthcare systems: The process of accessing dementia care in Northern Saskatchewan*. Unpublished Master's Thesis, University of Saskatchewan.

Caron Malenfant É, Morency J-D. (2011). *Population Projections by Aboriginal Iden-tity in Canada, 2006 to 2031*. Ottawa, ON: Statistics Canada, Cat No. 91-552-XWE 2011. http://www. statcan. gc. ca/pub/91-552-x/91-552-x2011001-eng. htm

Cattarinich, X., Gibson, N., & Cave, A. (2001). Assessing mental capacity in Canadian Aboriginal seniors. *Social Science & Medicine*, 53,1469–1479. https://doi.org/10.1016/S0277-9536(00)00434-2

Chapelski, E. E. , Sobeck, J., & Fisher, C. (2003). Long-term care preferences and attitudes among Great Lakes American Indians. *Care Management Journal, 4*(2), 94-100.

Chilisa, B. (2012). *Indigenous Research Methodologies*. Sage Publishing.

Cote, C. (2010). *Spirit of our whaling ancestors: Revitalizing Makah and Nuu-chah-nulth traditions.* University of Washington Press.

Cotrell, V., & Schulz, R. (1993). The perspective of the patient with Alzheimer's disease: A neglected dimension of dementia research. *The Gerontologist*, 33, 205–211. https://doi.org/10.1093/geront/33.2.205

Cowichan Tribes. (2009). *Speaking our truth: Cowichan stories of residential school*. Ts'ewulhtun Health Centre Publisher.

Crosato, K. , Ward-Griffith, C. , & Leipert, B. (2007). Aboriginal women caregivers of the elderly in geographically isolated communities. *Rural and Remote Health*, 7, 796. http://www. rrh. org. au

Cruickshank, J. (1998). *Life lived like a story*. UBC Press.

CTV. (2021, December 4th). *Caregiver burnout: Alexi Next interview*. [Video]. YouTube. https://www.youtube.com/watch?v=qPUQ_9DGPOE

de Leeuw, S., Lindsay, N. M., & M. Greenwood. (2018). Introduction to the second edition: Rethinking (once again) determinants of Indigenous peoples' health. In Greenwood, M., deLeeuw, S., & Lindsay, N. M. (Eds.), *Determinants of Indigenous peoples' health: Beyond the social.* (2nd Ed.). Canadian Scholars.

Desmarais, P., Weidman, D., Wassef, A. Thibodeau, M. et al. (2020). The interplay between post-traumatic stress disorder and dementia: A systemic review. *The American Journal of Geriatric Psychiatry*, 28 (1), 48-60. https://doi.org/10.1016/j.jagp.2019.08.006

Drees, L. (2010). The Nanaimo and Charles Camsell Indian hospitals: First Nations narratives of healthcare 1945 – 1965. *Historie Sociale/ Social History*, 43 (3). University of Toronto Press. https://dx.doi.org/10.1353/his.2010.0002

Downs, M. (2000). Dementia in a socio-cultural context: an idea whose time has come. *Ageing and Society*, 20, 369–375. https://doi.org/10.1017/S0144686X99007758

Dumont-Smith, C. (2002). *Aboriginal elder abuse in Canada* http://www. ahf. ca/downloads/ahfresearchelderabuse_eng. pdf

Duran, E. & Duran, B. (1995). *Native American postcolonial psychology*. Chapter 6 - Intervention with families. State University of New York Press.

Evans D., Funkenstein H., Albert M., et al. (1989). Prevalence of Alzheimer's disease in a community population of older persons: Higher than previously reported. *Journal of American Medicine Association,* 262 (18), 2551-2556. doi:10.1001/jama.1990.03450230028021

Fickner, S. , O'Campo, P. , Monchalin, R. , Thistle, J. , Worthington, C. , Masching, R. , Guta, A. , Pooyak, S. , Whitebird, W. , & Thomas, C. (2015). Research done in "a good way": The importance of Indigenous elder involvement in HIV community-based research. *American Journal of Public Health*, June, Vol 105, (6), 1149-1154. https://dx.doi.org/10.2105/AJPH.2014.302522

First Nations Health Authority. (2022). *About: Mandate*. https://www.fnha.ca/about/fnha-overview/mandate

First Nations Health Society. (2010). *First Nations traditional models of wellness: Environmental scan in British Columbia.* https://www.fnha.ca/WellnessSite/Documents/Traditional_Models_of_Wellness_Report_2010.pdf

Finkelstein, S. , Forbes, D. , & Richmond, C. (2012). Formal dementia care among First Nations in southwestern Ontario. *Canadian Journal of Aging*, 31 (3), 257-270. https://doi.org/10.1017/S0714980812000207

Gahagan, J. , Loppie, C. , Rehman, L. , Maclellum, M. & Side, K. (2004). Caregiver resilience and the quest for balance: A report on finding from focus groups. Healthy Balance Research Program. https://dalspace. library. dal. ca/xmlui/handle/10222/22209

Gahagan, J. , Loppie, C. , Rehman, L. , Maclellum, M. & Side, K. (2007). Far as I get is the Clothesline: The impact of leisure and unpaid caregiving experiences in Nova Scotia Canada. *Health Care for Women International*, 28(1), 47-68. https://doi.org/10.1080/07399330601003408

Goins, R. T. & Pilkerton, C. (2010). Comorbidity among older American Indians: The Native elder care study. *Journal of Cross Cultural Gerontology*, 25(4), 343-354. https://doi.org/10.1007/s10823-010-9119-5

Goins, R., Spencer S., McGuire, L., Goldberg J., Wen Y., & Henderson J. (2011). Adult caregiving among American Indians: the role of cultural factors. *Gerontologist*, 51(3), 310-320. https://dx.doi.org/10.1093/geront/gnq101

Government of Canada. (2022). *Call for spring 2022 letter of intent: Dementia community investment.* https://www.canada.ca/en/public-health/services/funding-opportunities/grant-contribution-funding-opportunities/dementia-community-investment-spring-2022.html

Green, M. (2007). *Case study: First Nations Elder care home*. Social Work 598 Research Project. [Unpublished Paper]. Victoria, BC: University of Victoria.

Greenwood, M., de Leeuw, S., Lindsay, N. M. (2018). Determinants of Indigenous people's health: Beyond the social. (2nd Ed.). Canadian Scholars.

Grossman, A. B., Levin, B. E., Katzen, H. L., & Lechner, S. (2004). PTSD symptoms and onset of neurologic disease in elderly trauma survivors. *Journal of Clinical and Experimental Neuropsychology,* 26(5), 698-705. https://doi.org/10.1080/13803390409609793

Gwa'amuuk, C. M. (2017). Sharing sim algyax: Creating a user-friendly website for sharing language resources. Master of Education, Indigenous Language Revitalization. (Unpublished Paper). Victoria BC: University of Victoria. http://hdl.handle.net/1828/9848

Habjan, S, Prince, H. , & Kelly, M. (2012) Caregiving for Elders in First Nations communities: Social systems perspective on barriers and challenges. *Canadian Journal of Aging*, 31(2), 209-222. http://dx.doi.org/10.1017/S071498081200013X

Haug, E & Prokop, S. (2004). Aboriginal women and homecare. Saskatchewan Notes, Vol. 3(1). http://www. policyalternatives. ca/sites/default/files/uploads/publications/Saskatchewan_Pubs/sasknotes3_1. pdf

Henderson, J. N. , & Henderson, L. C. (2002). Cultural construction of disease: A "supernormal" construct of dementia in and American Indian tribe. *Journal of Cross Cultural Gerontology*, 17, 197-212. https://psycnet.apa.org/doi/10.1023/A:1021268922685

Hendrie, H. , Hall, K. , Pillay, N. , Rodgers, D. , Prince, C. , Norton, J. et al. (1993). Alzheimer's disease is rare in Cree. *International Psychogeriactics,* 5, 5-11. https://doi.org/10.1017/S1041610293001358

Hendrix, L. A. & Swift Cloud–Lebeau, F. H. (2006). Working with American Indian families: Collaboration with families for the care of older American Indians with memory loss. In G. Yeo & D. Gallagher – Thompson (Eds.), Ethnicity and dementias (2nd Ed.)147-162. Routledge.

Hennessey, C. & John, R. (2006). American Indian family caregiver's perception of burden and needed support services. *Journal of Applied Gerontology*, 15(3), 275-293. https://doi.org/10.1177%2F073346489601500301

Herskovitz (1995). Struggling over subjectivity: Debates about the “self” and Alzheimer’s disease. *Medical Anthropology Quarterly*, 9(2),146–164. https://doi.org/10.1525/maq.1995.9.2.02a00030

Hulko, W. , Camille, E. , Antifeau. E. , Arnouse, M. , Bachynski, N. , & Taylor, D. (2010). Views of First Nation elders on memory loss and memory care in later life. *Journal of Cross-Cultural Gerontology,* 25(4), 317-342. https://doi.org/10.1007/s10823-010-9123-9

Hunt, S. (2021). Scholarship as ancestral practice: Sage Workshop. February 3, 2021 Centre for Indigenous Research & Community Led Engagement. Victoria BC: University of Victoria.

Iliffe, S., & Manthorpe, J. (2004). The debate on ethnicity and dementia: From category fallacy to person-centred care? *Aging & Mental Health*, 8(4), 283−293. https://doi.org/10.1080/13607860410001709656

Iwasaki, Y., Bartlett, J., & O’Neil, J. (2005). Coping with stress among Aboriginal women and men with diabetes in Winnipeg, Canada. *Social Science & Medicine*, 60(5), 977-988. https://doi.org/10.1016/j.socscimed.2004.06.032

Jacklin, K. & J. Walker. (2020). Cultural understandings of dementia in Indigenous peoples: A qualitative evidence synthesis. *Canadian Journal of Aging*, 39(2), 220-234. https://doi.org/10.1017/S071498081900028X

Jacklin, K. , J. Walker and M. Shawande. (2013). The emergence of Alzheimer’s disease and dementia as a health concern among First Nations populations in Canada. *The Canadian Journal of Public Health*, 104(1), e39-e44. https://doi.org/10.1007/bf03405652

Jacklin, K., Pace, J. & Warry, W. (2015). Informal dementia caregiving among Indigenous communities in Ontario Canada. *Care Management Journals*,16(2), 106-120. http://dx.doi.org/10.1891/1521-0987.16.2.106

Jervis, L. L. , Boland, M. E. , & Fickenscher, A. (2010). American Indian family caregivers' experiences with helping elders. *Journal of Cross-Cultural Gerontology,* 25, 355-369. https://doi.org/10.1007/s10823-010-9131-9

Jervis, L.L., Cullum, C.M., & Manson, S.M. (2006). American Indians, cognitive assessment, and dementia. In G. Yeo &D. Gallagher-Thompson (Eds.), *Ethnicity and the Dementias,* (2nd Ed.) Routledge. https://doi.org/10.4324/9780203957271

Jervis, L & Manson, S. (2002). American Indians /Alaska natives and dementia. *Alzheimer Disease and Associated Disorders*, 16(S2), S89-S95. http://dx.doi.org/10.1097/00002093-200200002-00011

Jervis L. , Jackson M., & Manson S. (2004). Need for, availability of, and barriers to the provision of long-term care services for older American Indians. *Journal of Cross-Cultural Gerontology,* 17(4), 295-311. https://doi.org/10.1023/A:1023027102700

John, R. , Hennessey, C. H. , & Roy, L. C. (Eds.). (1996). *Caring for cognitively impaired American Indian elders: Difficult situations, few options*. Taylor & Francis.

Johnson, J., & Hasan, L. (2021) Paddling together for culturally safe emergency care for elders. *International Journal of Indigenous Health*, Volume 16, Issue, pp, 146 – 164. https://doi.org/10.32799/IJIH.V16I1.33051

Judd, A. (2022, February 9). Vancouver Island First Nation to begin work to locate unmarked graves at residential school site. Global News. https://globalnews.ca/news/8607894/port-alberni-vancouver-island-first-nation-unmarked-graves/

Kelm, M. (Ed.). (1998). *Colonizing bodies: Aboriginal health and healing in British Columbia 1900-50* (p. 125). UBC Press.

Kines, L. (2021, January, 23). Cowichan Tribes still facing racism in wake of COVID-19 outbreak. Times Colonist. https://www.timescolonist.com/local-news/cowichan-tribes-still-facing-racism-in-wake-of-covid-19-outbreak-4687018

Kim, H., Chang, M. , Rose, & Kim, S. (2012). Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing*, 68 (4),846–855. https://doi.org/10.1111/j.1365-2648.2011.05787.x

Kirmayer, L., Brass, G., & Guthrie Valaskakis, G. (2009). Conclusion: Healing /invention/ tradition. In L. Kirmayer & G. Guthrie Valaskakis (Eds.). *Healing traditions: Mental health of Aboriginal peoples in Canada*. UBC Press.

Kitwood, T. (2012). *Dementia reconsidered: The person comes first*. Open University Press.

Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: Personhood and well-being. *Ageing & Society*, 12(3), 269–287. https://doi.org/10.1017/s0144686x0000502x

Knowles, J. (2006). Donepezil in Alzheimer's disease: An evidence-based review of its impact on clinical and economic outcomes. *Core evidence*, 1(3), 195-219.

Krieger, N. (2001). Historical roots of social epidemiology: Socioeconomic gradients in health and contextual analysis. *International Journal of Epidemiology*, 30(1), 899-900. https://doi.org/10.1093/ije/30.4.899

Kontos, P. (2005). Embodied selfhood in Alzheimer's disease: Rethinking person-centred care. *Dementia*, 4(4), 553–570. https://doi.org/10.1177%2F1471301205058311

Kovach, M. (2021). *Indigenous methodologies: Characteristics, conversations and contexts*. (2nd Ed.). University of Toronto Press.

Kovach, M. (2010). Conversational method in Indigenous research. *First Peoples Child and Family Review*, 5(1), 40-48. https://doi.org/10.7202/1069060ar

Kukull, W., Higdon, R. Bowen, J., McCormich, W., Teri, L., Schellenberg, G., van Belle, G., Jolley, L., Larson E. B. (2002). Dementia and Alzheimer disease incidence: a prospective cohort study. *Arch Neurol*, 59, 1737–1746. https://doi.org/10.1001/archneur.59.11.1737

Lanting, S. , Crossley, M. , Morgan, D. , & Cammer, A. (2011) Aboriginal experiences of aging and dementia in a context of sociocultural change: Qualitative analysis of key informant group interviews with Aboriginal seniors. *Journal of Cross-Cultural Gerontology*, 26, 103-117. https://doi.org/10.1007/s10823-010-9136-4

Lewis. J., Manson S., Jernigan V., Noonan C. (2021). "Making sense of a disease that makes no sense": Understanding Alzheimer's disease and related disorders among caregivers and providers within Alaska Native communities. *Gerontologist*. 61(3), 363-373. https://doi.org/10.1093/geront/gnaa102

Lindeman, M., Taylor, K., Stothers, K. & Piper, K. (2012). We don't have anyone with dementia here: A case for better intersectional collaboration for remote Indigenous clients with dementia. *The Australian Journal of Rural Health*, 20, 190-194. https://doi.org/10.1111/j.1440-1584.2012.01284.x

Loppie Reading, C. & Wien, F. (2009). Health inequalities and social determinants of Aboriginal people's health. *National Collaborating Centre for Aboriginal Health*. http://www. nccahccnsa. ca/docs/social%20determinates/NCCAH-Loppie-Wien_Report. pdf

Lux, M. (2010). Care for the racially careless: Indian hospitals in the Canadian west, 1920 – 1950s. *The Canadian Historical Review,* 9(3), 407-434. https://doi.org/10.3138/chr.91.3.407

Mack, J. (2011). Hoquotist: Reorienting through storied practice. In Lessard, H., Johnson, R., & Webber. J. *Narratives of Contact and arrival in constituting political community: Storied Communities.* (pp. 301-327). UBC Press.

Mackenzie, J., Bartlett, R. & Downs, M. (2005). Moving towards culturally competent dementia care: have we been barking up the wrong tree? *Reviews in Clinical Gerontology*, 15, 39-46. https://doi.org/10.1017/S0959259805001644

Mah, L., Szabuniewicz, C., and J. Fiocco (2016). Can anxiety damage the brain? *Current Opinion in Psychiatry*, 29(1), 56-63. https://doi.org/10.1097/yco.0000000000000223

Mehta, K. M., Yin, M., Resendez, C., & Yaffe, K. (2005). Ethnic differences in acetylcholinesterase inhibitor use for Alzheimer disease. *Neurology*, 65(1), 159–162. https://doi.org/10.1212/01.wnl.0000167545.38161.48

Methot, S. (2019). *Legacy: trauma, story, and Indigenous healing*. ECW Press.

Mills, D. (2008). *For future generations: Reconciling Gitxsan and Canadian laws*. Purich Publishing Ltd.

Mitchell, T., Arseneau, C. & Thomas, D. (2019). Colonial trauma: Complex, continuous, collective, cumulative and compounding effects on the health of Indigenous peoples in Canada and beyond. *International Journal of Indigenous Health*, 14 (2), 74-94. https://dx.doi.org/10.32799/ijih.v14i2.32251

Morgan, D. G. , Semchuk, K. M. , Stewart, N. J., & D'Arcy, C. (2002). Rural families caring for a relative with dementia: Barriers to use of formal services. *Social Science and Medicine,* 55(7), 1129 – 1142. https://doi.org/10.1016/S0277-9536%2801%2900255-6

Muckle, R. J. (2007). *The First Nations of British Columbia* (2nd Ed.). UBC Press.

National Aboriginal Health Organization. (2010). *Perspectives of frontline staff on health issues and community service needs for First Nations Seniors*. http://www. naho. ca/documents/fnc/english/2011_frontline_staff_perspectives. pdf

Native Women's Association of Canada. 2017. *Poverty reduction strategy: The Native Women's Association of Canada engagement results.* http://www. nwac. ca/wp-content/uploads/2018/08/Poverty-Reduction-Strategy-Revised-Aug23. pdf

Nuu-Chah-Nulth Tribal Council. (2020). *Nuu-Chah-Nulth Nursing Services: Hupiimin wiiksahiiy'ap helping us to be well.* https://nuuchahnulth. org/services/nuu-chah-nulth-nursing-services

Nuu-Chah-Nulth Tribal Council. (1996). *Indian residential schools: The Nuu-chah-nulth experience*. Report of the Nuu-chah-nulth Tribal Council Indian residential school study.

Nuu-Chah-Nulth Tribal Council. (2008). *Protocols & principles for conducting research in a Nuu-Chah-Nulth context. Nuu-Chah-Nulth Tribal Council research ethics committee*. http://www. cahr. uvic. ca/nearbc/documents/2009/NTC-Protocols-and-Principles. pdf

O'Connor, D., Phinney, A., Smith, A., Small, J., Purves, B., Perry J. A, Drance, E., Donnelly, M., Chaudhury, H., & Beattie, B. L. (2007). Personhood in dementia care: Developing a research agenda for broadening the vision. *Dementia: The International Journal of Social Research and Practice*, 6(1),121-142. https://doi.org/10.1177%2F1471301207075648

O'Donnell, V., Wendt, M. (2017). Aboriginal seniors in population centers in Canada. Statistics Canada. Cat No. 89-653-X. Online: https://www150.statcan.gc.ca/n1/en/pub/89-653-x/89-653-x2017013eng.pdf?st=zNArq9Ln

Office of the Seniors Advocate British Columbia. (2015, September). *Caregivers in distress.* Report 5. https://www.seniorsadvocatebc.ca/wpcontent/uploads/sites/4/2015/09/CaregiversReport.pdf

Office of the Seniors Advocate British Columbia. (2017, August). *Caregivers in distress: A growing problem*. https://surveybcseniors.org/assets/media/caregivers_in_Distress_-_a_growing_problem_-_final.pdf

Office of the Seniors Advocate British Columbia. (2019, September). *Home support review*. https://www.seniorsadvocatebc.ca/app/uploads/sites/4/2019/06/Report-Home-Support-Review_web.pdf

Ouanes, & Popp (2019). High cortisol and the risk of dementia and Alzheimer's disease: A review of the literature. *Frontiers in Aging Neuroscience*, 11(43). https://dx.doi.org/10.3389%2Ffnagi.2019.00043

Pace, J. E. (2013). *Meaning and memory: Understanding aging and dementia in First Nations communities on Manitoulin Island, Ontario*. MacMaster University. https://macsphere.mcmaster.ca/bitstream/11375/13464/1/fulltext.pdf

Pace, J. E. (2020). "Place-ing" dementia prevention and care in NunatuKavut, Labrador. Canadian *Journal of Aging*, 39(2), 247-262. https://doi.org/10.1017/S0714980819000576

Patterson C, Feightner J, Garcia A, MacNight C. (2007). General risk factors for dementia: A systematic evidence review. *Alzheimer's & Dementia*, 3, 341-47. https://doi.org/10.1016/j.jalz.2007.07.00

Parrack, S. & Joseph, G. (2007). The informal caregivers of Aboriginal seniors: Perspectives and issues. *First Peoples Child and Family Review*, 3(4), 106-113. https://doi.org/10.7202/1069380ar

Potts, K. & Brown, L. (2015). Becoming an anti-oppressive researcher. In L. Brown, & S. Strega, (2nd Ed.). *Research as resistance: Critical, Indigenous and anti-oppressive approaches*. Canadian Scholars Press.

Quinn, C. , Clare, L. , & Woods, RT. (2012). The impact of motivations and meanings on the wellbeing of caregivers of people with dementia: a systematic review. *International Psychogeriatric*, 22(1), 43–55. https://doi.org/10.1017/s1041610212000889

Qureshi SU, Kimbrell T, Pyne JM, Magruder KM, Hudson TJ, Petersen NJ, et al. (2010). Greater prevalence and incidence of dementia in older veterans with posttraumatic stress disorder. *Journal of American Geriatric Society*, 58(9), 1627-33. https://dx.doi.org/10.1007%2Fs11920-017-0835-1

Racine L, Ford H, Johnson L, Fowler-Kerry S. (2021). An integrative review of Indigenous informal caregiving in the context of dementia care. *Journal of Advanced Nursing*, 2. https://doi.org/10.1111/jan.15102

Radford, K., Mack, H., Draper, B., Chalkley, S., Daylight, G., Cumming, R., Bennet, H., Delbaere, K., & Broe. G. (2015). Prevalence of dementia in urban and regional Aboriginal Australians. *Alzheimer's & Dementia*, 11(3), 271-279. https://doi.org/10.1016/j.jagp.2017.05.008

Ranzijn, R. (2010). Active ageing: Another way to oppress marginalized and disadvantaged elders? Aboriginal elders as a case study. *Journal of Health Psychology,* 15(5), 716-723. https://doi.org/10.1177/1359105310368181

Reading, J. (1999). An examination of residential schools and elder health. Chapter 2. First Nations and Inuit regional health survey national steering committee. National Report. https://www.researchgate.net/publication/266883338_An_Examination_of_Residential_Schools_and_Elder_Health/stats

Reading, C. (2013). *Understanding racism*. Prince George, BC: National CollaboratingCentre for Aboriginal Health. Available from: http://www.nccah-ccnsa.ca/Publications/Lists/Publications/Attachments/103/understanding_racism_EN_web.pdf

Rosenberg, R., Richter, R., Risser, R. Taubman, K., Prado-Farmer, I., Ebalo, E., Posey, J., Kingfisher, D., Dean, D., Weiner, M., Svetlik, D., Adams, P., Cullum, M.C., Schaefer, F.D., & Shellenberg, G. (1996). Genetic factors for development of Alzheimer's disease in the Cherokee Indian. *Archives of Neurology*, 53(10), 997-1000. https://doi.org/10.1001/ARCHNEUR.1996.00550100071017

Sabat, S. (2001). The *experience of Alzheimer's disease: Life through a tangled veil*. Oxford: Blackwell.

Sabat, S. R. (2011). A bio-psycho-social model enhances young adults' understanding of and beliefs about people with Alzheimer's disease: A case study. *Dementia,* 11, 95-112. https://doi.org/10.1177%2F1471301211416612

Sawyer, E. (2021, August 17) Six more First Nations in B.C Launch investigations into residential school sites. CBC. Available from: https://www.cbc.ca/news/canada/british-columbia/residential-schools-sites-investigations-1.6140931

Schnarch, B. (2004). Ownership, control, access, and possession (OCAP) or self-determination applied to research: A critical analysis of contemporary First Nations research and some options for First Nations communities. *Journal of Aboriginal Health*, *1*(1), 80-95. http://www. naho. ca/documents/fnc/english/FNC_OCAPCriticalAnalysis. pdf

Smith, A., Kobayashi, K., Chappell, N., & Hoxsey, D. (2011). The controversial promises of cholinesterase inhibitors for Alzheimer's disease and related dementias: A qualitative study of caregivers' experiences. *Journal of Aging Studies*, 25(4), 397- 406. https://doi.org/10.1016/J.JAGING.2011.03.002

Smith, A. & Kobayashi, K. M. (2002). Making sense of dementia in an intergenerational context: The case of a Japanese Canadian nisei (second generation) – headed family. *Dementia: The International Journal of Social Research and Practice*, 1(2), 213-225. https://doi.org/10.1177%2F1471301207075648

Smith, M. J. (2004). *Placing Gitx̱san stories in text: Returning the feathers. Guuxs mak'amik'aax.* Doctoral dissertation, University of British Columbia. UBC Research Repository. https://open.library.ubc.ca/soa/cIRcle/collections/ubctheses/831/items/1.0054675

Smith, M. J. (2015, May June). Everyone has a bundle. *Teacher newsmagazine*. BC Teachers' Federation. http://bctf. ca/publications/NewsmagArticle. aspx?id=25438

Smith, L. T. (2021). *Decolonizing methodologies: Research and Indigenous people*. (3rd Ed.). Zed Books.

Statistics Canada. (2011). Aboriginal *Peoples in Canada: First Nations People, Metis, and Inuit, National Household Survey, 2011,* Catalogue no. 99-011-X2011001. https://www12.statcan.gc.ca/nhs-enm/2011/as-sa/99-011-x/99-011-x2011001-eng.pdf

Statistics Canada. (2015). *The Canadian population: Age & Sex*. http://www12. statcan. gc. ca/census-recensement/2011/as-sa/98-311-x/98-311-x2011001-eng. cfm

Statistics Canada. (2017). *Aboriginal peoples in Canada: Key results from the 2016 Census*. https://www150.statcan.gc.ca/n1/en/daily-quotidien/171025/dq171025a-eng.pdf?st=i0q0CvWZ

Stefanovich, O. (2022, April 1). Pope Francis apologizes to Indigenous delegates for deplorable abuses in residential schools. CBC News. https://www.cbc.ca/news/politics/pope-francis-responds-indigenous-delegations-final-meeting-1.6404344

Syphers, D.G., Schumaker, C.J., & Hudak, R.P. (2019). Experiences of Formal Caregivers Providing Dementia Care to American Indians. *Journal of Social Change*, 11(1), 38-48. https://doi.org/10.5590/JOSC.2019.11.1.04

Szeto, W. (2021 October 21). First Nation in B.C closing it only long-term care facility due to shortage of vaccinated staff. CBC News. https://www.cbc.ca/news/canada/british-columbia/westbank-first-nation-pine-acres-home-closure-covid-1.6220386

Tani Y, Fujiwara T, Kondo K. (2020). Association between adverse childhood experiences and dementia in older Japanese adults. *JAMA Network Open,* 3(2):e1920740. https://doi.org/10.1001/jamanetworkopen.2019.20740

TCPS 2. Tri-Council Policy Statement. (2014). Research involving the First Nations, Inuit and Metis peoples of Canada. http://www. pre. ethics. gc. ca/eng/policy-politique/initiatives/tcps2-eptc2/Default/

Thomas, R. (2000). *Storytelling in the spirit of wise woman: Experiences of Kuper Island residential school*. M.S.W. Thesis. Victoria BC: University of Victoria. National Library of Canada. Bibliothèque nationale du Canada. https://central.bac-lac.gc.ca/.item?id=MQ52810&op=pdf&app=Library

Thomas, R. (2015). Honoring the oral traditions of my ancestors through storytelling. In Brown, L & Strega, S. (2nd Ed.). *Research as resistance: Critical, Indigenous and anti-oppressive approaches.* Toronto: Canadian Scholars Press.

Thomas, R. & Green, J. (2015). Indigenous children in the centre: Indigenous perspectives on anti-oppressive child welfare practice: In Sohki Aski Esquao (J. Carriere) & Susan Strega (Eds). *Walking this path together: Anti-racist and anti-oppressive child welfare practice*. Winnipeg:Fernwood Publishing. pp.25-42

Thompson, J. (2008). Hede kehe' hotzi' kahidi': My journey to a Tahltan research paradigm. *Canadian Journal of Education*, 31(1), 24- 40.

Tonkin, R., Freeman, S., Martin, J., Ward, V., & Skinner, K. (2018). First Nations elders' perspectives of engagement in community programs in Nak'azdli Whut'en, in British Columbia, Canada. *Canadian Journal of Public Health*, 109(5), 717-725. https://doi.org/10.17269/s41997-018-0125-7

Truth and Reconciliation Commission of Canada. (2015). Introduction. In *Honoring the truth, reconciling for the future: Summary of the final report of the Truth and Reconciliation Commission of Canada.* http://www.trc.ca/assets/pdf/Executive_Summary_English_Web.pdf

Tsawaayuus (2014). *Westcoast Native Healthcare Society*. http://rainbowgardens. bc. ca/

Tuck, E. & Yang, W. (2012). Decolonization is not a metaphor. *Decolonization: Indigeneity, Education & Society*, 1(1), 1-40.

https://clas.osu.edu/sites/clas.osu.edu/files/Tuck%20and%20Yang%202012%20Decolonization%20is%20not%20a%20metaphor.pdf

Turpel-Lafond, M.E. (2020). *In Plain Sight: Addressing Indigenous -specific racism and discrimination in B.C. Health Care.* https://engage.gov.bc.ca/app/uploads/sites/613/2020/11/In-Plain-Sight-Full-Report.pdf

UVIC. (2011). *Cultural Safety Module 1. Peoples' experiences of colonization*. University of Victoria. Victoria BC. http://web2. uvcs. uvic. ca/courses/csafety/mod1/notes4. htm

UBC. University of British Columbia. (2021). *Indian residential schools*. https://irshdc. ubc. ca/learn/indian-residential-schools/

United Nations Declaration on the Rights of Indigenous Peoples, March, 2008. https://www.achp.gov/sites/default/files/201807/UNDeclarationontheRightsofIndigenousPeoples.pdf

Waldram, J. B., Herring, D. A., & Young, T. K. (2006). *Aboriginal Health in Canada: Historical, cultural, and epidemiological perspectives.* (2nd Ed.). University of Toronto Press.

Warren, L., Shi, Q., Young, K., Borenstein, A & Martiniuk, A. (2015). Prevalence and incidence among Indigenous populations: A systemic review. *International Psychogeriatric Association*, 27, 12, 1959-1970. https://doi.org/10.1017/s1041610215000861

Wang, Wahlberg, Karp, Winblad, and Fratiglioni. (2012). Psychosocial stress at work is associated with increased dementia risk in late life. Alzheimer's & Dementia, 8 (2), 114-120. https://doi.org/10.1016/j.jalz.2011.03.001

Wilson, K. (2003). Therapeutic landscapes and First Nations peoples: an exploration of culture, health and place. *Health & Place,* 9(2), 83-93. https://doi.org/10.1016/s1353-8292(02)00016-3

Wilson, S. (2008). *Research is Ceremony: Indigenous research methods*. Fernwood Publishing.

Wilke, P., Maltby, A., & Cooke, M. (2017). Residential schools and the effects on Indigenous health and well-being in Canada – a scoping review. *Public Health Reviews*, 30(8). https://doi.org/10.1186/s40985-017-0055-6

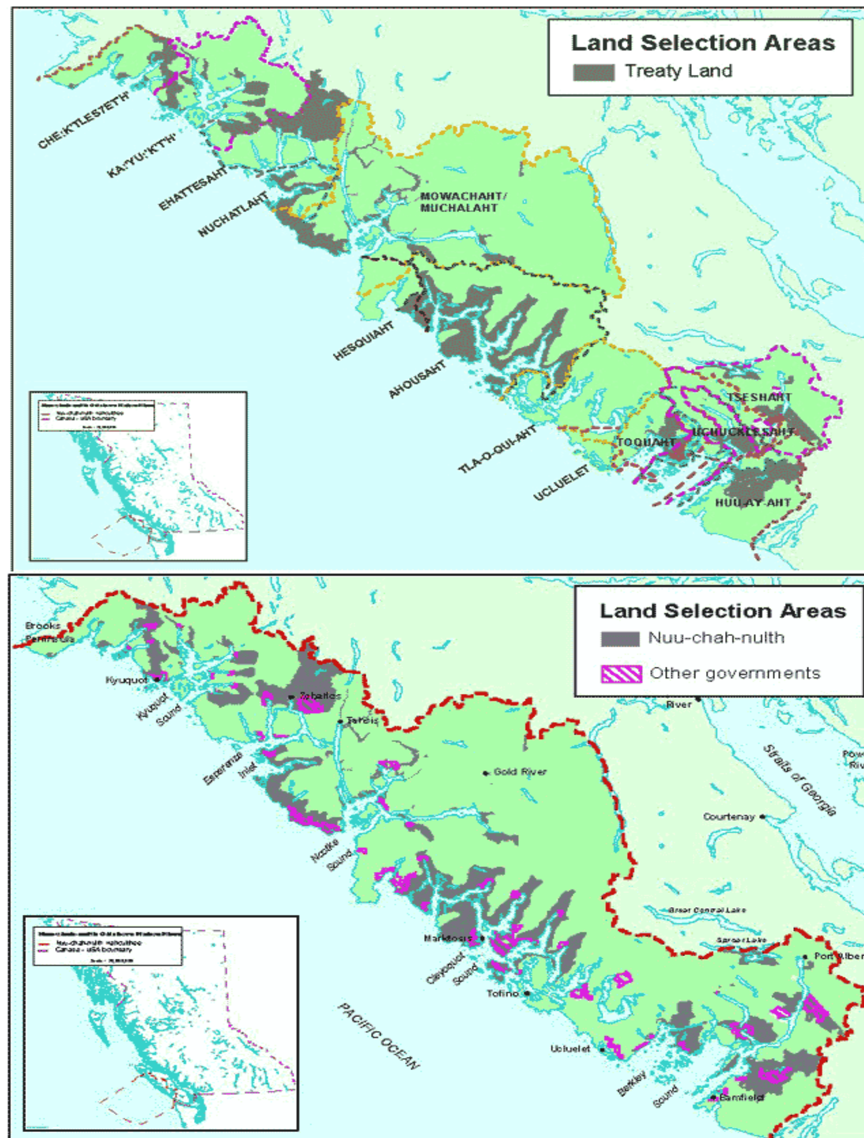
Wiwichar, W. (2000). *Genetic researcher uses Nuu-Chah-Nulth blood for unapproved studies in genetic anthropology.* NTC Publication *Ha-Shilth-Sa,* September. NTC Website. http://www. hashilthsa. com/archive/news/2013-07-22/genetic-researcher-uses-nuu-chah-nulth-blood-unapproved-studies-genetic-anth

World Health Organization. (WHO). (2012). Dementia is a public health priority. https://www.who.int/publications/i/item/dementia-a-public-health-priority

Yaffe, K., Vittinghoff, E., Lindquist, K., Barnes, D., Covinsky, K., Neylan, T., Kluse, M., Marmar, C. (2010). Posttraumatic stress disorder and risk of dementia among US Veterans, *Archives of General Psychiatry*, *67*(6), 608-613. https://doi.org/10.1001/archgenpsychiatry.2010.61

Yaffe, K., Blackwell, T., Kanaya, A., Davidowitz, N., Barrett-Connor, E. & Krueger, K. (2004). Diabetes, impaired fasting glucose, and development of cognitive impairment in older women. *Neurology*, 63(4), 658–663. https://doi.org/10.1212/01.WNL.0000134666.64593.BA

Appendix I – Nuu-Chah-Nulth Territories



Nuu-Chah-Nulth 14 First Nations Groups
Northern: Ehattesaht, Kyuquot/Cheklesaht, Mowachat/Muchalaht, and Nuchatlaht Central: Ahousaht, Hesquiaht, Tla-o-qui-aht, Ucluelet and Toquaht Southern: Ditidaht, Huu-ay-aht, Hupacasath, Tse-shaht, and Uchucklesaht[16]

[16] Image available online: https://www.pinterest.ca/pin/402438916680603998/

Appendix II - NTC Ethics Approval Letter

Cheryl Aro MSW, RSW
Courtenay BC

August 2, 2017

Re: Ethics Approval for Research Entitled: First Nations Elders Living with Memory Loss: Family Perspectives on Elder Health-Care

Dear Cheryl,

I am writing to confirm that we have reviewed your application to conduct a qualitative research study within the Nuu-Chah-Nulth Territories. Your application has been approved. It is our understanding that you intend to interview Nuu-Chah-Nulth people who voluntarily agree to participate. The goal of the research is to document Nuu-Chah-Nulth family dementia caregiver's perspectives on memory loss / dementia. This project will also examine the services that Nuu-Chah-Nulth family caregivers' access when they are seeking support services.

This research will be done in collaboration with the Manager of Nursing Services and the Home and Community Care Clinical Leader. The data from this research will likely be useful in future for government funding applications and program planning.

We look forward to receiving updates on your research and a copy of your dissertation when you have completed the work.

Sincerely,

Jeannette Watts, RN, BSCN, MPH

Manager of Nursing Program
Nuu-chah-nulth Tribal Council

Appendix III – Collaborative Research Agreement

First Nations Elders Living with Memory Loss: Family Nuu-Chah-Nulth Perspectives on Elder Health Care

THIS COLLABORATIVE RESEARCH AGREEMENT is made this ___2___day of _August_, 2017

BETWEEN:

Name(s): Cheryl Aro (Hereinafter referred to as Researcher)

Supporting Agency: University of Victoria

Address: PO Box 1700 STN CSC

Victoria BC, V8W2Y2

Telephone: Office: 250. 721-8040

Email: aroc@uvic. ca

AND:

Nuu-chah-nulth Tribal Council (Hereinafter referred to as NTC)

Contact person(s) Jeannette Watts, Manager of Nursing Program

Address: Nuu-chah-nulth Tribal Council

PO Box 1383 Mission Road

Port Alberni, B. C. V9Y 7M2

Telephone: 250-724-5757

Email: Jeannette. Watts@nuuchahnulth. org

The principal researcher, as named, and the Nuu-chah-nulth Tribal council agree to conduct the named collaborative research project in accordance with the guidelines and conditions described in this document.

1. The project:

There is increasing evidence in recent studies in Canada that suggests that First Nations people may be at a higher risk of developing dementia. [17] This qualitative research project seeks to explore Nuu-Chah-Nulth family dementia caregiver's perspectives on memory loss / dementia. This project will also examine the services that Nuu-Chah-Nulth family caregivers' access when they are seeking support services.

2. Possible Benefits:

a. Support the community planning for services to Nuu-chah-nulth Elders with dementia and their caregivers.

b. Contribute to conversations about the risk factors associated with Alzheimer's disease and related dementias, and prevention strategies for remaining healthy in old age.

c. Produce experience-based data on Elder care needs which can be used for advocacy or funding applications in the future.

d. Provide evidence that may be used in a future review of Elder care services.

3. Approval to proceed:

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[17] **Jacklin, K. M.** , **J. D. Walker**, and M. Shawande (2013). "The emergence of dementia as a health concern among First Nations populations in Alberta, Canada. " *Canadian Journal of Public Health* 104(1): e39-e44

The project has been reviewed and approved by the NTC Executive Committee.

4. Research Ethics

The Researcher will follow:

Protocols & Principles for Conducting Research in a Nuu-chah-nulth Context (attached)

and

The Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (2010), specifically Chapter 9: Research Involving Aboriginal Peoples.

In addition, an ethics application will be submitted and approved by the Ethics Board at the University of Victoria before the research commences.

Researcher will consult with the appropriate representative(s) for the NTC Nursing Services and/or participating communities during the research and data analysis, to ensure her writing accurately reflects the participants' experiences.

The Data from this research will be used to inform the principal researchers Ph. D. dissertation and a scholarly peer reviewed article. Data from this research project will not be used for other purposes without the written consent of the NTC.

5. Project outline, method and timeline: 15 Months Commencing Ethics Approval

Time	Research Phase	Activities

1-3 month	**Recruitment**	- Create poster to be distributed by NTC Nursing Team to Elders and their caregivers. - Consult and share information about the study with potential research participants who come forward. - Presentation will be made to Elders and caregivers at an Elders dinner at the Port Alberni Friendship Centre. Information poster will be disseminated to community members at that dinner meeting.
3 -5months	**Data Collection**	**Interviews**: - 12 -20 interviews with informal (unpaid) care givers will be conducted at locations of their choosing. - Participants will be presented with a healthy gift, a homemade card, and $50 honoraria to thank them for sharing their valuable insights. - Interviews will be transcribed and emailed or mailed to the research participants to check for accuracy. - Participants will be provided with the opportunity to edit interviews or request a second interview. **Personal Methods**: - Researcher will journal her observations and insights during the data collection phase.

3 months	**Data Analysis**	- Transcripts will be reviewed for emerging themes - Researcher will consult / check in with Elders and community collaborators. - NTC Nursing Program will be invited to review the transcripts and participate in the analysis.
6 months	**Report Writing**	Write Ph. D. Dissertation.
		Present findings of the research in one or more public presentations within the Nuu-Chah-Nulth community.
		Prepare a summary report of the findings of the research for NTC

Interview: Interviews typically last 1 -2 hour, though it would be possible to limit the length of time of interviews as well as the number to be conducted. Interviews will be conducted on a voluntary basis and interviewees would be welcome to withdraw from the research at any time.

Researcher has committed to following informed consent and strict confidentiality throughout her research.

Privacy and Security of Information

Researcher will support principles of Ownership, Control and Possession (OCAP) of First Nations Information and will sign a document to confirm adherence to NTC Privacy and Security Policy.

Researcher will ensure that NTC has an opportunity to review the research dissertation and summary report for accuracy, and to correct any errors, omissions or misstatements before it is finalized.

NTC shall receive a copy of the final report, including summary of data and findings.

6. **Not an Employee of NTC**

   Researcher confirms that she is not an employee, contractor, member or agent of Nuu-chah-nulth Tribal Council, and shall be responsible for any and all costs necessary to the project, including insurance;

7. **Indemnity:**

   Researcher shall indemnify the NTC and its directors, members, employees, and assigns from and against all actions, costs, damages, expenses, fees (including reasonable legal fees and disbursements and amounts paid in settlements), liabilities and losses that arising out of the Researcher's performance of the project.

   Researcher specifically recognizes that there are some risks associated with travel to and from Nuu-chah-nulth communities and agrees to be responsible for own safety and insurance against such risks.

8. **Dispute Resolution**

   In the event that a dispute arises out of or relates to this research project, both parties agree first to try in good faith to settle the dispute by mediation administered by an agreed upon neutral party before resorting to arbitration, litigation or some other dispute

resolution procedure. A mediator will assist the parties in finding a resolution that is mutually acceptable.

9. Term

This agreement shall have an effective date of September 1st, 2017 and shall terminate on December 1st, 2018, unless extended by mutual agreement in writing.

This agreement may be terminated by written notification to either party.

AGREED BY RESEARCHER	**AGREED FOR NUU-CHAH-NULTH TRIBAL COUNCIL**
Cheryl Aro	Jeannette Watts
Date: August 2nd, 2017	Date: August 2, 2017

Appendix IV – Call for Participants

Social Dimensions of Health
PO Box 3050 STN CSC
Cornett B138
Victoria, BC V8W 3P5
250-472-5185
E-mail idpassis@uvic.ca

VOLUNTEERS NEEDED FOR RESEARCH

Are you: A Nuu-Chah-Nulth Person?

Providing weekly supports to a family member or friend who struggles with memory loss with everyday activities of life – such as cooking, shopping, paying bills?

I am a Gitxsan doctoral student looking for volunteers to complete an interview. As a participant in this research, you will be asked to share your experiences as a family caregiver. The interview will take approximately 1-2 hours. In appreciation of your time, you will receive a small gift and honoraria.

If you are interested, please contact Cheryl Aro for more information

Email: aroc@uvic. ca Phone: 250 721-8040

Haa'mii'yaa Thank you!

This study has been reviewed by, and has received ethics clearance through the NTC and University of Victoria Research Ethics Committees.

This research was funded by the Canadian Institute for Health Research

Appendix V – Research Information Letter for Participants

Cheryl Aro Ph. D. Candidate

University of Victoria

Social Dimensions of Health

Telephone: 250. 721-8040

Email: aroc@uvic.ca

Purpose:

I am a Gitxsan First Nations graduate student at the University of Victoria and I have created this research project to fulfill the final part of my Ph. D. degree program in the Social Dimensions of Health. The purpose of this study is to share and document information about the resources that are available for Nuu-Chah-Nulth First Nations families who are caring for Elder family members that have exhibited signs of memory loss or have been diagnosed with Alzheimer's disease, or a related dementia. I am interested in learning more about your community's perspectives on memory loss, Nuu-Chah-Nulth caregiver's experiences with caring for a loved one with Alzheimer's disease and related dementias (ADRD), and what resources are available within the community for Elders and their family caregivers. Healthcare professionals will share my invitation to participate in this research, but they will not conduct the interviews. The services and relationships that you presently enjoy with the nurses and healthcare workers distributing this invitation to participate in this research will not be affected if you choose to participate. The findings from this study will be presented to the participating communities. I will

also report back to participating communities during the research process when the community asks me to. I am hopeful that this study will uncover information that will benefit First Nations health care professionals, Elders and family caregivers.

Study Methods:

I will conduct personal interviews with caregivers of Elders with memory loss and document the conversations. The criteria for participating in the research is that the caregiver is of Nuu-Chah-Nulth ancestry, are actively involved in providing supports to an Elder with memory loss or have taken on the role within the past two years. Nuu-Chah-Nulth family caregivers who choose to participate in this study will be invited to share information about their experiences in an informal two-way conversation. The interview will be audiotaped and transcribed, but I will only use a tape recorder if you agree to its usage. I will take notes during our meeting so that I can clearly recall your story and document it with accuracy. Once your story has been transcribed, I will forward a written copy of the interview to you for approval via email or regular mail. At this time, you will have an opportunity to edit any of the text that does not reflect your beliefs or intended contribution to the research. If I don't hear from you within two weeks, I will assume that you approve of the interview as written. Your total time commitment to this research will likely be no more than 5 hours including the interview, and the time it takes to review the interview transcripts and provide feedback. I intend to create a report of the findings and present the findings to the Nuu-Chah-Nulth community once the dissertation has been completed. Your name will never be used in any other public document.

Confidentiality:

All documents, tapes and transcripts will be kept strictly confidential. Information about this project will not be made public in any way that identifies the individual participants. The

Manager of Nursing Services is overseeing the project and will read my notes to ensure that I am on track, but she will not know your identity. I intend to identify interview tapes and transcripts or notes with numbers rather than names and secure a master list of names / codes in a locked desk in my home office. The results of this study will be reported in a research dissertation and an oral report during my thesis presentation. As well, parts of this research will be used in a journal article in the future. All University of Victoria dissertations are stored on UVic Space which is an online resource that is available to the public on the internet. The findings of this study will also be shared in public presentations within the Nuu-Chah-Nulth community. It is the University of Victoria's policy that the transcripts, field notes and tapes gathered during the research process be securely stored and destroyed when they are no longer needed. I plan to store them in a locked file cabinet in my home office during the research and writing process. The interview transcripts, field notes and tapes will be destroyed when the research publications have been completed.

There are limits to confidentiality that I must share with you. In the unlikely event that you disclose a story about Elder abuse or neglect I will be legally bound to report that to someone in a position of authority. Abuse can take many forms, such as physical, sexual, emotional, financial, or spiritual. Neglect happens when an Elder's health, safety, or well-being at risk due to a lack of care. If during our conversation you indicate that you have abused or neglected an Elder, or that you might hurt yourself or others, I have a professional duty to share this information with someone in a position of legal authority.

Participation:

Involvement in this study is completely voluntary. It may be discontinued at any time for any reason without explanation, and the information that you shared in the interview will not be used. No negative repercussions shall result if participation is discontinued and you will be allowed

to keep any gifts and honoraria that you have been given. Your stories will not be used in any document if you choose to discontinue your participation in the study. I can be contacted anytime at 250. 721-8040 or aroc@uvic. ca if you have any questions.

Haa mii yaa - Thank you,

Cheryl Aro

Appendix VI - Participant Consent Form

Social Dimensions of Health
PO Box 3050 STN CSC
Cornett B138
Victoria, BC V8W 3P5
250-472-5185
E-mail idpassis@uvic.ca

Research Title: First Nations Elders living with memory loss: Nuu-Chah-Nulth Family perspectives on Elder health care on Vancouver Island.

Conducted By: Cheryl Aro Ph. D. Candidate	**Supervisors:** Dr. Leslie Brown	Dr. Charlotte Loppie
Social Dimensions of Health	School of Social Work	Public Health & Social Policy
University of Victoria	University of Victoria	University of Victoria
Tel: 250. 721-8040	Tel: 250. 721- 8474	Tel: 250. 472- 5451
Email: aroc@uvic. ca	Email: lbrown@uvic. ca	Email: loppie@uvic. ca

The University of Victoria's Human Research Ethics Office can be contacted by telephone at 250. 472-4545 or through email at ethics@uvic. ca

Participant Consent

Your signature on this consent form indicates that;

- You have been informed about the purpose of this research study.
- You have had an opportunity to ask questions about the purpose of the research.
- The researcher has explained how your story or ideas will be used.
- The researcher has explained how your confidentiality will be protected.

- The researcher has explained the limits to confidentiality.
- The researcher has explained how your personal information will be handled.
- The researcher has explained that your participation in this study is completely voluntary and that you can leave the study at any time.
- You agree to have your interview or discussion narratives audio recorded.

Risks

Participating in this study may potentially bring up feelings or sadness or stress. The Port Alberni Friendship Centre and NTC offer a number of free supports which are easy to access. If you feel troubled after the interview contact NTC Health Outreach Services 250. 731-7331 or Family & Health Services at the Port Alberni Friendship Centre 250. 723-8281.

Consent

Your signature below indicates that you consent to participate in this study. Your signature also indicates that you understand that this research for a graduate degree and as such will be used in a dissertation, which is a public document.

____

Participant Signature Date

____

Printed Name of the participant signing above

____

Signature of the Researcher

Appendix VII- Interview Guide

Following the cultural protocol of my people, I began each interview with a brief introduction of myself, my family lineage and my personal connection to the research topic. I used the information in the information letter as a guide to review the purpose of the study, the study procedures, confidentiality and participation. I reviewed the consent form each participant and asked if they had any questions. When all questions have been addressed, I asked the participant to sign the consent form. With the participants consent I will turn on the audio recorder. I noted the interview code at the beginning of each interview. EG. This is interview KD1, KD2 etc. …

Participant Introduction

This is a dialogical interview so it will be conversational. I will share my dementia care experiences when it is relevant to do so. The questions are presented to show that I have a plan, however each interview will vary in this participant/s led the process .

1. I have shared some information about myself. Please tell me about yourself, your family and your community.

Perspectives about ADRD / Elder Care

When there is a gap in the conversation and I sense that the participant has no more to add, I will ask;

2. Tell me about some of the experiences of people who have memory loss in your family and community.
3. Tell me about your experiences as a caregiver of a person with memory loss.

Elder care services

Again, questions will follow if the speaker has exhausted the topic above;

4. Can you tell me about the services in your community that are available for Elders who are experiencing memory loss and their caregivers?

5. Is there anything else that you would like to share with me before I leave?

I will use encouraging comments to demonstrate that I was actively listening to the participants' story. For example, "that is interesting please tell me more" or, "I would like to know more about that". If I feel uncertain about a statement, I paraphrased the speakers' main point and ask; "Have I got that right"?

Participants will be thanked and gifted at the end of the storytelling session. I will ask the participant if they would prefer a hardcopy of the interview to be mailed, email or both. I will ask for their email and or mailing address and record that information before leaving