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“Write My Story Before I Forget”: An Auto-Ethnography Of Aboriginal Alcohol Dementia

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Graduate Program in Anthropology
A thesis submitted in partial fulfillment of the requirements for the degree in Master of Arts
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“WRITE MY STORY BEFORE I FORGET”: AN AUTO-ETHNOGRAPHY OF
ABORIGINAL ALCOHOL DEMENTIA

(Thesis format: Monograph)

by

Danielle Alcock

Graduate Program in Anthropology

A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Arts

The School of Graduate and Postdoctoral Studies
The University of Western Ontario
London, Ontario, Canada

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Abstract

The diagnosis of Alcohol Dementia and its health implications comes with an uncertain future for the individual and their families. To add to the minimal existing literature on the subject, this auto-ethnography focuses on three generations of Indigenous oral storytelling to re-construct the past of an Anishanabe father to understand his addiction in connection to broader social constructs. Decolonizing methodologies are used in the form of first person experience and connecting research to activism. Alcohol Dementia is examined using Aboriginal social determinants of health to critically discuss the direct affects of intergenerational trauma, uprooting and displacement and flaws within the Canadian health care system. Neo-liberal governmentality within the perception of healthcare professionals towards Alcohol Dementia is analyzed including the lack of support and services for diagnosed individuals and their families, especially in First Nations communities.

Keywords

Auto-ethnography, decolonizing methodology, activism, Aboriginal social determinants of health, addictions, alcoholism, neo-liberal governmentality, oral storytelling, Anishanabe, intergenerational trauma, Alcohol Dementia, dementia, Alcohol Neuropathy, neuropathy

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Miigwech to you both.

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Chapter 1 : Methodology

1 Personal Introduction

Before embarking on discussing my Master's thesis, it is important to introduce who I am. I am Anishanabe and belong to the Chippewas of Rama. Our nation is situated ninety minutes north of Toronto located on the Eastern shores of Lake Couchiching and is a part of a tri-council with the Beausoleil First Nation and the Chippewas of Georgina Island (Chippewas of Rama, 25 Feb 2014). I have never lived in Rama and have only been visiting more frequently over the past two years with the development of my research focused on the life histories of my Grandma, Dad and myself. I grew up without my Anishanabe identity because my parents separated when I was young and my Mom remarried. My stepfather is from Trinidad and I grew up there as well as lived in New York City, Buffalo, Vancouver, all over Ontario and in Hong Kong as an English teacher. Although I have travelled and resided in various places, my research is important to me because it has been an opportunity to get to know myself through the stories of my Grandma and Dad.

1.1 Development of Research

When I decided to pursue a Master's degree, I wanted to examine First Nations women's perceptions of motherhood and their lived experiences of Intimate Partner Violence (IPV). First Nations women's perceptions of motherhood and their lived experiences of Intimate Partner Violence (IPV) is a subject that is lacking discussion in existing literature. Literature that has focused on mothering and IPV,

... do[es] not account for the complexity of women's experiences – including the difficulties and threats they face when they go through domestic violence and when they attempt to leave their partners – and are often perceived as unhelpful and punitive. In addition, these practices tend to shift the focus away from men's violence onto women's 'failures' as mothers' ” (Lapierre, 2010:343).

I wanted to take a positive approach to my research by focusing on the resourcefulness and successful tactics that First Nations mothers use to protect their children when they are in domestically violent relationships. I also wanted to explore whether there is a comparison between women's experiences and perceptions of motherhood when they are experiencing IPV versus the aftermath of leaving the relationship. My proposed methodology was Participative Action Research (PAR) using photovoice to create a collaborative framework with the research participants. As stated by Julie George in emphasizing such a methodology “whereas traditional approaches separate knowledge and action, PAR evokes a systematic process to increase understanding and achieve social change” (2012:67). Unfortunately, I was unable to conduct research on this subject because a support group for First Nations women who have experienced IPV was no longer being offered because grant funding was not available.

Thus, when determining an alternative approach to violence against women and children, I decided to continue research that began in a paper I wrote examining the rural-to-urban migration of Aboriginal women based on the life history narrative of my amazing Grandma. My grandma Annie Miller is a stubborn, strong woman who has faced racism, sexism, and structural violence throughout her life. Regardless of the adversities she faced, her children and being a good mother has always been her priority. I spent a lot of time with her as she told me stories about her life growing up in Rama, about attending residential school and moving to Toronto where she lived for several decades.

1.2 Research Question

Last year my thesis topic shifted once more from events within my own life. In August 2013, my Dad was hospitalized and diagnosed with Alcohol Dementia and Alcohol Neuropathy at the age of fifty-seven. My research focuses on the implications of this illness and how it affects three generations of my family. Most importantly, my research is shaped by the interconnected narratives of my Grandma, my Dad and I, which would not exist outside the framework of the colonization of First Nations peoples in Canada. What I mean by this is that colonization has shaped my Grandma's life. Although she maintained her language, she was forced to follow Christianity that was introduced two preceding generations. She struggled with addictions, persevered as a single parent and

coped with the structural violence she faced as an Aboriginal woman. My Dad grew up with the lack of opportunities inflicted upon my Grandma and him as a result of colonialism. Forced assimilation for my Grandma removed her connection to land along with family ties. Her Anishanabe culture was not passed unto her children. Thus, the language, culture and connection to land have not been passed on to her grandchildren, continuing the cycle of intergenerational trauma.

Focusing on three generations of my family and how colonization has been a part of our everyday lives is a way to show that the past and present are connected. There is a dominant discourse that colonization of First Nations peoples in Canada is solely in the past, a part of history that will not be repeated. But, there is extensive research documenting that the effects of colonization pass forward to the next generation. Policies imposed through the *Indian Act*,

...a series of pronouncements and regulations, rights and prohibitions, originally struck in 1876, which has wound its snaky way along to the present day. The Act itself does more than just define Legal Indians. It has been the main mechanism for controlling the lives and destinies of Legal Indians in Canada, and throughout the life of the act, amendments have been made to the original document to fine-tune this control (King, 2013:70).

Focusing on my Dad's diagnosis, I am able to examine the systemic flaws within the Canadian health care system that are discriminatory because he is First Nations and because his illness is a result of addiction. No services exist to deal with the complexity of Alcohol Dementia, which is a trifecta of dealing with behavioural monitoring, the stigma of addictions and the physical and mental disability of the illness. With the intersecting lack of culturally sensitive or relevant support or services, I decided to examine my family's life histories to understand my Dad's addiction and the effects of intergenerational trauma on his life and my own, as the daughter of an alcoholic.

Deciding to focus on my own family was a difficult decision since I knew that it would be emotionally daunting to be coping with and living the everyday trauma of my Dad's diagnosis as well as critically examining it anthropologically. My Dad's diagnosis shifted my research to focus on Alcohol Dementia and its implications. I will elaborate on the following reasons individually: 1) there is no existing research on the subject, 2) there are

social and health constructs of Alcohol Dementia, 3) there are silences associated with illness as a result of addictions, 4) my Dad asked me to, “write his story down before he forgets” (Miller-Alcock, 2013/2014) and told me that, “it’s important to let people know what can happen when you drink your whole life” (Miller, 2013/2014) and 5) starting with researching my Grandma’s life provides insight to the social and intergenerational trauma that is a part of my Dad’s diagnosis. Within my Grandma’s stories about her life, there has been structural violence because of gender and Indigeneity; there has been loss of children through the *Children’s Aid Society*; and addictions have been a form of coping and easing the gendered suffering of mothers (Bourgois and Schonberg, 2009:135). My Grandma’s experiences as an Indigenous woman and a mother affected my Dad and led to the trauma he faced and using alcohol as a way to cope.

After my Dad’s diagnosis, I began researching Alcohol Dementia in order to gain information on the illness. My search was futile since there has been minimal research on Alcohol Dementia, especially focused on First Nations peoples in Canada. In order to broaden my search, I began reading studies that focused on dementia for First Nations peoples in order to understand the long-term implications as well as the progression of the disease. That there is limited research of dementia among First Nations peoples in Canada is interesting considering that, “the number of First Nations people in Canada is on the rise and expected to increase 1.4 times between 2006 and 2031. Importantly, the number of First Nations people aged 60 and older is expected to increase in number by 3.4 times from 54,165 in 2006 to 184,334 in 2031” (Jacklin et al., 2013:39). Within research on the Aboriginal¹ population in Canada, there is little focus on their experiences of dementia, especially looking at social implications such as the roles of family, community and cultural and language specific services. Research that has focused

¹ “The term First Nation(s) is the widely used contemporary term for status and non-status Indians, and it is utilized formally to reference registered bands (e.g., Kettle and Stony Point First Nation). Aboriginal is the term used to describe all original inhabitants of Canada, including First Nations, Inuit, and Métis, regardless of history, language, and culture. Indigenous refers to Aboriginal people who are native to a specified country (e.g., First Nations people in Canada and Maori people in New Zealand). The term is used internationally to refer to Aboriginal peoples across the globe” (Indian and Northern Affairs Canada 2004 in George, 2012:1).

on dementia among Aboriginal populations exists (Pace 2013, Jacklin et al. 2013, Lanting et al. 2011, Finkelstein et al. 2011, Hendrix and Swift Cloud-Lebeau, 2006) but all have noted the lack of research focused on First Nations peoples compared to non-Indigenous populations. As stated by Yeo and Gallagher-Thompson, who wrote a book dedicated to dementia among minority groups within the United States, the field for examining dementia among First Nations populations is wide open because little is known about it (2006:87). For a focus on Alcohol Dementia, finding information that offered a social examination instead of a medical one was rare. I realized that I should discuss Alcohol Dementia to contribute to the limited resources available and to offer insight as a caregiver, daughter as well as an anthropologist by critically examining the larger social and health implications. In terms of addictions, there are many studies that offer statistics on the issue of alcohol and drug dependence for First Nations peoples in Canada. I want to make the connection that the meaning of illnesses as a result of addictions are constructed in social action and social relationships, not just phenomena to be studied in terms of the quantitative data. Through examining the impacts of colonization as it spans three generations of my family and discussing Alcohol Dementia using Aboriginal social determinants of health (Loppie and Wien 2012, Reading et al. 2013) I can humanize the statistics. My Dad has a complex history and is more than just a statistic of someone who has had a lifelong addiction.

Examining Alcohol Dementia is also a way to express the distinction of addiction among minority groups. For non-Indigenous individuals with alcohol addictions, “they get to make their mistakes as individuals, not as representatives of their entire race” (King, 2013:187). My Dad has experienced racism throughout his life because of his Indigeneity and is further marginalized and stigmatized because of his alcoholism. But my family’s life histories are not reflective of all First Nations peoples in Canada. My Grandma often says about her own life that, “a lot of people have different lives you know. Nobody’s got the same life. You can’t go by me. I’ve lived a very strange life. I’ve lived my own life. I didn’t go by anyone else’s rules” (Miller, 9 March 2013). My Grandma’s experiences of systemic racism are further complicated because of how her Indigeneity intersects with her gender. For my Dad and myself, the flaws within the health care system and the lack of services and treatment available point to broader issues of systemic racism. The non-

existence of services for Alcohol Dementia is just one example of human rights violations against First Nations peoples in Canada. Access to equal health care services, housing, education and employment opportunities are inadequate in comparison to those provided to non-Indigenous peoples. The vast difference between access to health care and health disparities for First Nations peoples in Canada are, "...symptoms of deeper pathologies of power and are linked intimately to the social conditions that so often determine who will suffer abuse and who will be shielded from harm" (Farmer, 2005:xiii). My Grandma and Dad's lives have been shaped by social conditions that cause social suffering and within my own life as I contend with becoming a caregiver for a parent at the age of twenty-five.

Another element that shaped my decision to focus on my family and my Dad's diagnosis was the conspiracy of silence connected to addictions, dementia and disabilities. The silence can be a contributing factor to the minimal research focused on dementia for First Nations communities, "...due to fear and stigmatization of dementia, denial, and a lack of information about the disease – until a crisis occur[s]" (Finkelstein et al., 2012:264). The fear stops First Nations individuals from seeking help within reserve communities and is further complicated by the lack of services available for dementia treatment. Listening to, and retelling parts of the narratives of my Grandma and Dad and including my story is a way to combat the silence and stigma attached to Alcohol Dementia. Through the stories we tell about our lives and experiences with the illness, it is "...a way in which we act in the face of forces that render us inactive and silent" (Jackson, 2013:23). The shame associated with my Dad's illness for him and myself makes us feel powerless and places the blame on my Dad. Blaming my Dad without the contextualization of his experiences and why he used alcohol to cope perpetuates neo-liberal governmentality, which will be critically discussed. I critique the Canadian health care system for dealing with Alcohol Dementia and more broadly, the inadequacies of health care for Aboriginal peoples in Canada. By giving voice to my family, we are able to remove the shame we feel because I recognize critical discussion is needed to understand Alcohol Dementia connected to intergenerational trauma, perpetual loss of family members, culture and identity. Shame is a powerful tool to place the blame for my Dad's illness on him and removes the

responsibility from the afflictions of colonization within his life, my Grandma's and mine. Feeling,

the sense of shame that condemns one to remain silent about experiences that cry out to be told is a function of the impossibility of converting what is felt to be private into a story that has public legitimacy or social currency. Shame, in other words, is an affective measure of the socially constructed and uncrossable line between private and public space (Jackson, 2013:69).

Writing my family's life histories includes topics that are usually not shared because it means discussing the great amount of suffering experienced and using addictions to cope. Crossing the line from the private sphere to public discourse, I am able to show the resiliency of my family regardless of the impacts of colonial policies and the systemic violence and racism that we have all faced as an Anishanabe family, and have become more apparent with my Dad's diagnosis.

My Grandma has faced many tribulations as an Aboriginal woman and as a mother, which will be discussed in further detail by focusing on Aboriginal social determinants of health. Learning about her life through her stories has been a way to gain insight to my Dad's life and my own in order, "to understand how disadvantage can be linked both within and across the generations" (Locke and Lloyd-Sherlock, 2011: 1143). All of our lives and stories intersect with one another. The experiences and effects of colonization have wide implications as intergenerational trauma is passed on across three generations. Through sharing my Dad's stories and how he views his illness, it is a way to "restore the human subject at the centre—the suffering, afflicted, fighting human subject—we must deepen a case history to a narrative or tale; only then do we have a 'who' as well as a 'what', a real person, a patient, in relation to disease—in relation to the physical" (Mattingly and Garro, 2000:8). His diagnosis has changed my Grandma's relationship and my own with my Dad. Most importantly, the diagnosis of Alcohol Dementia and Alcohol Neuropathy have altered my Dad's view of himself since being an alcoholic has been a central part of his daily life for more than forty years. He has been sober as required for his long-term health for more than ten months. This has altered his everyday routine, his overall health and how he now has to cope with losing his memory. But he is more than his illness and his stories are important in understanding his shift in viewing

himself as well as the shift in his perceptions of his history, life and future. Most importantly, discussing my Dad's Alcohol Dementia using a framework critically examining colonization across three generations in relation to Aboriginal social determinants of health, is a way to show that illness is more than a diagnosis and that their social, cultural and historical background are imperative to understanding their overall health.

The main reason why I decided to examine Alcohol Dementia and its implications was the opportunity to hear and understand my Dad's life history through the stories he tells. Although he struggles with remembering daily activities, my Dad often brings up that he wants to write his stories down and he: "...always wanted to write something, but I never did. Even my short stories, I liked them more than anybody else" (Miller-Alcock, 15 Oct 2013). Hearing my Dad's stories about growing up and recounting memories that he tries to forget is important to me for analytically understanding his struggle with losing his memory. Writing about my Dad's life is important to him in order to share his experiences, to teach other people about what can happen when you struggle with alcoholism. He tells me many times when we spend time together that he wants to have his life history written down before his long-term memory deteriorates. There are limitations with a Master's thesis to include my Dad's life history told in his own words, but the goal is to co-write his life history so that in the future I can help fulfill his request. Recording the oral storytelling of my Dad also allows me to get to know him since he was an absent parent my entire life.

1.3 Flexibility of Research

For this thesis, my methodology consisted of spending a lot of time with my Grandma and Dad separately and together on a few occasions². I initially focused on studying only

² All of the conversations with my Grandma and Dad were recorded using the application called *Garage Band*. Our time spent together can be better categorized as conversations or discussions rather than interviews since they were informal and relaxed. I visited my Grandma at the Long-Term Care Home in Rama and would visit my Dad in his home. After my Dad's hospitalization, I also recorded conversations we had at the hospital and while driving to visit family. Sometimes my Dad and I would visit my Grandma

my Grandma's life history and when I visited with my Dad, I would ask him questions to corroborate details and to gain an alternative perspective from him as one of her eldest sons. All of the conversations consisted of me asking a few questions about their lives. With my Grandma, our interaction consisted of me listening as she told her stories. I would transcribe the interviews afterwards and would return with more questions for clarification the next time I visited her. She often requested that I come with questions to prompt her about what elements of her life that I wanted to hear about. But as the project progressed, the most insightful aspects were the stories she shared that I did not ask her about. It was best to let her choose what stories she wanted to tell. It was more difficult recording stories from my Dad before he was hospitalized. I would visit him early in the morning in order to ensure clarity since before August 2013 he was still a heavy drinker. Talking with my Dad also consisted of allowing him to choose the subjects to discuss and I would engage in the stories if I wanted more information.

Listening to my Grandma's stories about her life "...depict resilience and resistance to colonization" (Archibald, 2008:42). Throughout her life, she persevered as a mother and although she faced traumatic experiences, she has viewed her life with pride and the strength she had to raise her children. When reflecting on her life, my Grandma has said, "my life isn't some great love story. But it's my story and I've lived a good life...a crazy life, but a good one" (Miller, 9 March 2013). My Grandma's resiliency is something that I am learning from as I hear more about her life history through her stories. I have tried to have the same attitude towards traumatic experiences within my life, to have a perspective focusing on the positive so that painful moments in time will pass. For my Dad, who has used alcohol as a way to cope and erase his negative memories, he faces judgment because he has not exhibited resiliency. The judgment towards those who are

and we would listen to her stories together. I would take minimal notes so that I could focus on listening to their stories and engaging in conversation. I would transcribe each of our conversations afterwards. Spending time with my Grandma spanned from March to October 2013 and with my Dad, from June to October 2013. I have included elements from discussions that I have with my Dad when I spend time with him that continued from October 2013 into the end time of writing in June 2014.

viewed as doing well and those that are not is an assault on human dignity. Judgment attached to my Dad's diagnosis of Alcohol Dementia removes the impact of his history; his struggles with identity, losing siblings and using alcohol as a way to deal with the trauma in his life which in turn is directly connected to the trauma that is inflicted upon First Nations peoples in Canada.

Within my Master's degree, there were several topic shifts as a result of not being able to research my original topic, which is common among socio-cultural anthropologists because ethnographic research changes depending on options for conducting interviews, finding participants and chances for participant observation. Switching topics, especially to such a personal focus, can be daunting and requires flexibility in topic and methodologies. Fieldwork and research focus require fluidity because, "the living social context of ethnographic research is *expected* to transform one's original framing or animating questions" (Cerwonka and Malkki, 2007:79). The experiences in my life connected to my research focusing on my family requires flexibility in terms of choosing a topic that did not have a definitive focus and developed as more time went on and more stories were told by my Grandma and Dad. With my Dad's diagnosis of Alcohol Dementia and the problems that arose as I tried to find services, I decided to shift from solely focusing on my Grandma and Dad's life histories, to use them to examine the social and cultural context for understanding my Dad's illness.

Through focusing on my Dad's Alcohol Dementia and the intergenerational trauma within my family, my research evolved from our everyday experiences. I had qualms about writing about my own life for fear that it would not be a topic that carried academic merit because it was personal. However, writing about my own narrative connected to my Dad and Grandma's life histories is a way to "...disrupt and disturb discourse by exposing the complexities and contradictions that exist under official history" (Denzin et al., 2008:13). Writing first hand experience is a way to counteract the Canadian discourse that colonialism is a part of the past and that oppression is not a contemporary issue. The loss of our Anishanabe culture and language has been detrimental to my identity and my Dad's. This can be traced back to colonial policies of parents not being allowed to speak

Anishanabe to their children on the reserve. My Grandma discussed the difficulties these posed for parents:

Danielle: “So did your Mom know how to speak Indian, but she wasn’t allowed?”

Grandma: “Yeah, she spoke it. They spoke it in the house. But as a kid, going to school, I don’t know why they told us we couldn’t speak our language. But I guess they thought it would interfere with our learning. But I think speaking it would have helped more to speak two languages. Parents couldn’t really talk to them. All the parents were always talking Indian and to translate was hard for them” (Miller, 28 June 2013).

My Dad never grew up learning Anishanabe and a large component retelling stories about his life pertain to his identity. He was constantly forced to prove his Indigeneity except when he lived in British Columbia with his partner Veronica³:

Dad: “I was Native out there. If you stay with somebody who’s Native and they say you’re Native, then you’re Native. But if you go around, saying it yourself, they say, ‘oh yeah? Prove it’. Like you say with Veronica, she knows a million people. So she’s says you’re Native, you’re Native. It gets around quick. Plus, she doesn’t like going around with white people” (Miller-Alcock, 2 Aug 2013).

1.4 Institutional Ethnography

Discussing being prohibited from speaking her language in school because of assimilation policies and my Dad omitting his Indigenous identity so he would not be forced to prove it by showing his *Indian Status Card* are parts of their stories that point to larger social issues for First Nations peoples in Canada. By focusing on the stories told by my Dad and Grandma, I am able to use their narratives, “...as a vehicle for the problematic issue of representing experiences and events as seen from the perspective of particular actors and as elements of a cultural account that can tell us something about a social world, however local that world” (Garro and Mattingly, 2000:24). My

³ Pseudonym

methodological approach using my family's narratives, including my own, to connect our everyday experiences to the social interactions and institutions that create social inequality, are framed after Dorothy Smith's institutional ethnography (2005:xx1). Institutional ethnography is a sociology,

...to reorganize the social relations of knowledge of the social so that people can take that knowledge up as an extension of our ordinary knowledge of the local actualities of our lives. It is a method of inquiry into the social that proposes to enlarge the scope of what becomes visible from that site, mapping the relations that connect one local site to others (Smith, 2005:29).

From the stories told to me, I critically examine aspects of my Grandma and Dad's lives to understand the impact of colonization. I am affected by colonization as the caregiver for my Dad as I try to navigate the complex health care system for First Nations peoples. This requires contacting several institutions across multiple jurisdictions to determine who provides services, which are minimal or non-existent for Alcohol Dementia. From the time perspective of three generations, I can map the connections of our lives and how trauma is prevalent in all of our stories.

Using elements of institutional ethnography as a methodology, I am starting at the localities of our lives. I developed the research as the problems and issues presented themselves and determined the direction of my inquiries (Smith, 2005:32). Institutional ethnography used as a part of methodology requires fluidity and basing research on the issues presented within the lives of the people who are being interviewed. For my research, the topic shifted with more conversations and with the issues that became a part of my life and my Dad's as we dealt with his diagnosis of Alcohol Dementia. Not having a fixed methodology is decolonizing research in that there is not an adherence to strict research methods or methodologies and it is not contingent on a single set of guidelines (Denzin et al., 2008:33). My methodology focusing on my own life experiences is a way to reclaim a feeling of having control during a period within the lives of my Dad and myself where we both feel lost and hopeless. Telling our stories is a way "...of transforming our sense of who we are, recovering a sense of ourselves as actors and agents in the face of experiences that make us feel insignificant, unrecognized or powerless" (Jackson, 2013:17). Telling our stories is a verification that we matter, that

our experiences are connected to broader issues for treatment and access to health services for First Nations peoples that are inadequate or non-existent.

Writing from a first person narrative creates an internal ethical struggle of balancing between being a caregiver, a daughter and a granddaughter as well as being analytical. Since I am writing some of the stories from the lives of my Grandma, Dad and myself, I have to be cognizant of what elements to include. With the consent of my Grandma and Dad, they are both comfortable with me including excerpts from the stories they have shared. They both know that I am focusing on the connections between our lives and critically discussing Alcohol Dementia using Aboriginal social determinants of health. It is my responsibility to balance what elements to include while remaining analytical about the issues present within our lives as an Anishanabe family. Trying to balance my family obligations as well as examining Alcohol Dementia from an anthropological perspective, I am borrowing from Lila Abu-Lughod's concept of the 'halfie' dilemma. I am forced to confront squarely the politics and ethics of their representations (Abu-Lughod, 1991:142). As an Anishanabe woman who has grown up separate from my Dad and Grandma, I have to be accountable to tell their stories in their own words. Listening to their stories about their lives, events they experienced and people that they choose to discuss has allowed me to

...understand others' positions in life or description of themselves and their relations to others, to let their voices be heard, to let them speak for and about themselves first. If we want to know the unique experience and perspective of an individual, there is no better way to get this than in the person's own voice (Atkinson, 1998: 5).

I am a 'halfie' as an academic through discussing our life histories connected to being Indigenous, how gender affected their options and opportunities and most importantly, the effects of intergenerational trauma and addiction within my family. Through our stories, I am able to connect how policies affect each of our lives especially for my Grandma who endured policies that determined where she could live, the extent of her education and legal control within her life. By tracing policies and health care flaws for my Dad and myself, our stories are mediums for connection to significant social facts (Garro & Mattingly, 2006:4) that exist within our histories, memories and stories.

1.5 Insider/Outsider Positionality

Incorporating my personal narrative into my thesis is also a way to combat the ‘insider/outsider’ issue of my positionality. I am an insider because of my Anishanabe background and I am connected to my Grandma and Dad through relations. But my academic background makes me an ‘outsider’ in that I have different life experiences, connected to colonization since our historical and social positions are divergent. Debating how to tackle the ‘insider/outsider’ dilemma I felt during research, I recognize these binaries do not acknowledge the complexity of my identity as a daughter, granddaughter, caregiver, Anishanabe woman and anthropologist. As discussed by Narayan, “a person may have many strands of identification available, strands that may be tugged into the open or stuffed out of sight” (1993:673). There are countless facets to my identity and I contemplated their role within my research in regards to sharing the stories of my family members. Their identities are also complex and this multiplicity of identity is apparent within the stories they shared with me. They would share parts of their identities and hide others depending on our interactions, the amount of time we spent together and what they wanted to exclude. The issues of researching your own community, let alone your own family, requires being humble as discussed by Linda Tuhiwai Smith in *Decolonizing Methodologies*. Smith offers advice for other researchers in a similar position in that being humble must be a part of the process during interactions with community members and research participants (2012:139). Being humble is the recognition that those who are sharing their experiences with you are the experts on their own lives. This ensures that research is focused on humility and recognition of your role as a community member and that the researcher lacks the same amount and kind of knowledge and experiences as the participants (Kaomea, 2004:38). I can never fully understand the complexity of the lives of my Dad and Grandma. Therefore, humility within research methodologies ensures that I am respectful sharing their stories in their own words and by being a good listener.

Writing about my own life has been emotionally and psychologically tolling since my research is not distinct from my everyday life. I am immersed with my research since analyzing my Dad’s diagnosis of Alcohol Dementia is perpetual. My attempts to compartmentalize my emotions from the research project have been futile and instead use

a methodology of good-enough ethnography in that the anthropologist is flawed with their bias and cultural self (Scheper-Hughes, 1992:38). I think this is applicable to my research because I am telling the story of my Dad and Grandma from my perspective. Gender is thus significant within my research because my experiences as a female anthropologist are not separated from my lived reality since I cannot filter my emotions and experiences as the caregiver and daughter to my Dad. Not excluding my own stories of coping and social suffering is a way to work from an Indigenous methodology since I do not need to compartmentalize. Including my experiences within my thesis is a way for others to learn from me although no one can fully understand my positionality as an Anishanabe woman who has become a caregiver while critically analyzing the micro and macro social factors of the lives of my Grandma, Dad and myself.

Sharing some of the stories of my family is important because I am able to speak and to give voice to my Dad and Grandma who are marginalized because of their Indigeneity. Telling the life histories of my family as well as my own is a way to understand the historical legacy of discrimination and the contemporary manifestation of that discrimination (Parker 1998 in Denzin et al., 2008:93). Starting from the particularities is a way to connect to micro issues within specific lives in that, "...the effects of extra local and long-term processes are only manifested locally and specifically, produced in the actions of individuals living their particular lives, inscribed in their bodies and words" (Abu-Lughod, 1991:150). Inscription on the body is a common theme within the stories that my Dad tells. Destroying your body using alcohol and drugs was a way to cope as discussed in one story in particular about his elder brother Shannon. Shannon passed away before the age of twenty-five from being addicted to sniffing nail polish remover and my Dad shared stories about sniffing nail polish remover as a teenager:

Dad: "He was swinging from the chandeliers and shit like that. Shannon. They said that stuff eats your whole body up from the inside out. Mind you, I did it for about two years. Maybe that's what's wrong with me? From fourteen to sixteen in the summers. It was too cold to do it in the winters. Cheap high. Actually it was very cheap. We used to steal it from *Woolworths*. All you need is toilet paper, but *Kleenex* was better because it didn't

fall apart. My brother's hands were all calloused from holding that gasoline in his hands, raw".

Danielle: "Did he do gasoline too?"

Dad: "No, it was like gasoline. It's a solvent. It's like me when I'm drinking. I get drunk off the fumes" (Miller-Alcock, 15 Oct 2013).

Destroying their bodies using drugs and alcohol from the perspective of my Dad is way for him to comprehend his present illness and to search for answers through the effects on his body. Many of our conversations focus on his body and how he perceives what is happening to him. Most of his stories focus on trying to understand his present state through discussing his past.

Through stories that my Dad chooses to share with me about his life and as he tries to understand his Alcohol Dementia and Alcohol Neuropathy, storytelling is a way to discuss the effects the diagnosis has had on his life and perceptions of the past and future. Stories about illness told by the affected person are a way for them to discuss the change in their identity, relationships and time as well (Raoul et al., 2007:5). For my Dad, he has difficulty remembering elements of his past, such as my elder brother as an infant, and is aware of the changes in the dynamics of his relationship with his long-term partner, Cecilia:

Dad: "Funny, I don't remember him being small".

Danielle: "When he was a baby?"

Dad: "I was either kicked out or don't remember. I know I get on Cecilia's nerves. It's hard when you have someone move in with you. You have to look after them; have to cook, clean and take care of you. I can't believe they want to take my kneecaps out unless they heal".

Danielle: "They won't heal and that's why you have to use your chair".

Dad: “When someone starts talking *Frankenstein*, I stop listening. It’s just an impulse. ‘What are you going to do to me?’ Get out of here! A hundred years ago, they didn’t do that. But then again, a hundred years ago, people didn’t make it past fifty. I’ll make it to retirement” (Miller-Alcock, 15 Oct 2013).

For my Dad, his medical understanding of his illness is that he needs surgery to fix the problem in his knees. His conception of his illness is that poison in his bloodstream from drinking has caused his memory loss and inability to walk. He believes that his condition will improve with time and that he will make it past the age of the legal age of retirement in Canada which is sixty-five. He does not realize that his physical and mental conditions will most likely deteriorate and many of our conversations discuss his perception of his illness and sifting through his past and sharing his memories as he tries to contextualize his illness in the present.

Most of my Dad’s stories and our conversations shift from different times in his life. He tries to remember parts of his past and continues to forcibly not remember negative memories. With my Dad’s diagnosis, he knows that he has memory loss and recognizes the shift in his relationships as well as his perception of self since he often says that he does not feel like he has a brain anymore (Miller-Alcock, 15 Oct 2013). Our discussion every time we see one another focuses on how my Dad’s life has shifted since his diagnosis. Telling me stories from his past connected to his present state, it is apparent that “goals, plans and expectations about life were...radically revised in the face of an illness with no foreseeable end” (Garro and Mattingly, 2000:28). For my Dad, his life has been drastically altered since he is healthier than he has been in decades. He has to deal with severe memory loss and the inability to use alcohol as a way to ensure that he forgets elements of his past. My Dad’s previous goals were to drink to forget the past and to survive each day. He did not care about his well-being. Now that he is unable to drink, his focus is on thinking about his memories and how his days consist of trying to force himself to remember daily activities. Since his life before his hospitalization and diagnosis was focused on forgetting the past, now my Dad remembers negative experiences and the attached emotions. He tries not to think about them and tries to not let painful memories creep into the present. Mark Dolson’s research focused on street

involved youth in London who experienced personal trauma while trying to navigate the *Ontario Works* program. Dolson's discussed the hauntings of past memories of his informants and that,

...the pain and suffering of loss felt by my informants was a truly polyvalent experience: it had multiple dimensions, multiple effects and affects, yet the one commonality of experience was that it led to a looming, spectral sense and feeling that the past was something to escape, to flee, to run as fast as one could—regardless of its fog-like creep and parry at every confrontation or line of flight away from it. It would not be too far off to say that, for most of my informants, the past was violent, poison-like and destructive in its persistence (Dolson, 2012:328).

With the inability to forget the past using alcohol, my Dad now remembers memories he has tried to forget. Remembering the past in his present is difficult for him and this comes up within the stories he tells. He also states that, "I try not to remember...the bad things from the past" (Miller-Alcock, 2013, 2014). For someone who has fought to forget the past, with a diagnosis of Alcohol Dementia, my Dad is trying to remember the present, but is frustrated and angry that he is unable to.

1.6 Co-creating Stories

My Dad's struggle to remember daily activities means that writing down events and memories has become a method of recollection. Through recording his oral story telling, as well as my Grandma's, we are co-creating stories through our time spent together and the conversations we have. As the listener, I am a part of the storytelling experience since my Grandma and Dad chose to share certain stories with me based on our relationships. Within the stories about their lives that were shared with me, my Grandma and my Dad predominantly focused on place and family relations. Reflecting on the past in connection to place and relations are part of the experience of co-creating stories because I am a part of the stories they tell. I am eager to hear stories about their lives and about family members. As the listener while transcribing and hearing stories repeatedly, I recognize the co-construction of my Grandma and Dad's stories because I choose what elements I should include. Through them being the storytellers and I being the audience, I recognize that "telling a story, enacting one, or listening to one is a constructive process, grounded in a specific cultural setting, interaction and history" (Garro and Mattingly, 2000:22).

Using storytelling as a methodology to critically examine Alcohol Dementia also allows me to see how colonization has been a part of all our lives and shaped our geographic localities, positionalities as well as interactions. With a focus on three generations, I also see how our lives are intertwined and how the impact of one life will affect the next generation. By focusing on my own family, our stories show how, “a family can be compared to a spider web-you can't touch one strand without the whole web reverberating” (Medalie, 1994: 163).

Most importantly, through listening to stories from their lives, I gain insight to their experiences as an Indigenous woman and man, as well as how their lives differed based on historical context. Including my own experience and elements of my story of coping with my Dad's diagnosis and how it has altered my life, I am able to give voice to my Dad, my Grandma and myself. Our lives are important for critically examining colonization as well as the flaws within the Canadian health care system for dealing with Alcohol Dementia. By focusing on the everyday experiences, I can, “tell the stories from the side of policy that is never asked to speak out, to interrupt the hegemony of elite voices dictating what is good for this segment of the population” (Culhane, 2009:173). As an Anishanabe family, our lives are impacted by the *Indian Act*, which still determines access to health care, education and job opportunities that are a part of forced migration. Forced migration because of a lack of opportunities within reserve communities pushes Indigenous individuals to move to urban centres in order to thrive or simply survive as in the case within my family moving to Toronto. Our lived experiences are not considered when the Canadian government creates policies. We do not have a direct role to play in the decision making process and our life histories are not considered when policies that affect First Nations peoples in Canada are put into place. Through sharing our stories, I am confronting colonizers and making them accountable for colonization (Denzin et al., 2008:12). Our stories have power to exemplify the impacts and that our voices matter because our family has been affected for generations. Through our storied lives, I am writing using examples to show structural violence instead of focusing on defining it (Farmer, 2005: xiii). Using a methodology focused on examples, instead of definitions, is more pragmatic and is more relevant to the experiences of the lives of my Grandma, Dad

and I because it is more powerful to focus on the effects of structural violence than to discuss it theoretically.

1.7 Oral Story Telling

Since I focus on our experiences of structural violence through stories about our lives, what is lost when stories are written is the oral tradition of Indigenous methodology. Writing stories instead of retelling them orally represents ethnocentrism in that oral storytelling is viewed as "...something that exists only in the imagination of the story teller, cultural ephemera that is always at the whim of memory" (King, 2003:98). Since stories are written, the individuality of the storyteller and the interaction with the audience is lost. When I was recording the stories of my Grandma and Dad, their emotion, syntax and unique styles of storytelling are missing and not transmittable through written words. When my Grandma discusses difficult periods in her life, the emotions are lost as are the moments of silence as she collects her thoughts and pauses when deciding where to continue the story. With my Dad, his sense of humour is embedded within every story he tells, even if it is painful and a reminder of trauma. Orally telling their stories is important and valuable because within their stories, "...there is a delightful inventiveness of tone, a strength of purpose that avoids the hazards of the lament and allows the characters the pleasure of laughing at themselves and their perils" (King, 2003:117). Humour has been a foundational element of the time I have spent with my Grandma and Dad. They are witty and able to see the humour in their memories of family members they have lost. When my Grandma told stories about the two times she has been pronounced dead while hospitalized to my Dad and myself, she told it with humour and suspense:

Grandma: "It was Norm's⁴ voice I heard the last time I almost died. If I had opened one of those doors, I would have been dead. I was walking along a corridor and saw these three doors and I turned around to see who was talking".

⁴ Norman is my Grandma's nephew who is also a Minister

Danielle: “He was visiting with you when that happened?”

Dad: “Yeah, at the hospital”.

Grandma: “He just started talking to me and all of a sudden I was looking right at him. We were laughing and joking while everyone else was crying. I don’t remember anything before that. I remember it wasn’t scary. When Don⁵ was born, I went down that tunnel. I walked to the end, and it was beautiful. All I remember saying is, ‘is that all it is?’ All my sisters were all in a row waving at me when I was going by. They’re all gone now. Looking back, I think it meant that they were all going to go before me. I can still see them standing there all smiling and waving at me. I woke up and I figured I might stay. They came in and say, ‘oh, you’re awake! How do you feel?’ I said, ‘I feel like there’s a person standing on my chest’ (Miller, 18 June, 2013).

With my Dad, he makes stories funny with his hand gestures, impeccable timing of punch lines and sarcasm that add to recreating the images and personalities of the people and places that he describes.

Another key element of oral storytelling that is a part of Indigenous methodology that I am working from is a focus on repetition. Most of the stories that I have heard from my Grandma and Dad focus on recurring themes, adding more details to stories I have heard before and recounting memories that seem to always be at the forefront because they are hard to forget or are enjoyable to re-tell. I am incorporating a, “...narrative style that privileges repetition” (King, 2003:117) which contributed to a richer story. Corroborating details from stories told by my Grandma by questioning my Dad, I was able to hear alternative perspectives of the same stories depending on how they were remembered. I would also corroborate details through researching supporting documents, primarily birth and marriage certificates. Long-term engaged discussions with my Grandma and Dad who have unique, but overlapping experiences provided in-depth and contextualized raw data in ways that are not often employed in academic research methodologies. Repetition

⁵ Don is my Grandma’s first born son

is a part of Indigenous story telling and is a method for focusing on the elements of the story that need to be remembered by the audience. Including a narrative focused on repetition is an intentional tool to ensure that the reader understands what are the important aspects of my research that I want to be remembered. It also exemplifies that within First Nations discourse, the sharing of knowledge is spiral, not linear and, “it illustrates how the process is characterized by partial understanding as well as floods of insight...” (Cerwonka and Malkki, 2007:17).

The development of my research was not chronological, but unfolded as events occurred within my own life. Including repetition within my research is an attempt to make the reader aware of the parts of the stories that I want them to think about. Repetition is not just about reading and understanding, but evoking emotion. Some of the stories that were shared with me are traumatic and should be remembered by the reader in hopes of provoking thought on the impacts of colonialism. Another usage of repetition focuses on the lack of services available for Alcohol Dementia because hearing that nothing exists has been a part of our lives almost every day. Hearing the same response from health care practitioners has created anxiety and hopelessness for our family as we struggle to cope with my Dad’s dementia while having no support. Lastly, repeatedly focusing on my Dad's use of alcohol to forget is important to understand how his past, present and future are connected to one another.

An important part of my research is that lives are linked and that time is continuous. Telling stories of their lives to me is a way, “...to relate—through and in narrative, whether this narrative is oral or pictorial—the occurrences of the past (fantastical, imagined, exaggerated or real). Through this relation the past is brought to life in the vivid (and creative) present of listeners” (Dolson, 2012:297). As the listener, my role is important because it is therapeutic to have your story heard and as a way to remember, regain accounts of what happened and to no longer experience in solitude. For my Grandma especially, we often spoke about her son Murray who was a part of the ‘Sixties

Scoop'⁶ and whom she has not seen in more than fifty years. She had never told stories about Murray, and I was honoured to listen. Many of her stories about him focused on what a wonderful boy he was and remembering the day he was taken away from her after a court proceeding.

With sharing these traumatic memories with me, it is a way for my Grandma,

...to unburden [herself] of private grief in a context of concerted activity; they bind people together in terms of meanings that are collectively hammered out. It is this sharing in the reliving of a tragedy, this sense of communing in a common loss, that gives stories their power, not to forgive or redeem the past but to unite the living in the simple affirmation that they exist, that they have survived (Jackson, 2013:112).

For my Grandma to recount the painful memories of losing her son is a way to affirm her resiliency through sharing her stories with me. My Grandma focused all of her stories on her family and especially her children and striving to be a good mother to them. For my Grandma, she says that now she has the time to reflect on her life. She has faced hardship because of her Indigeneity intersecting with her gender. Sharing these stories with me is a way to lessen the pain and bond us since she is comfortable sharing these traumatic moments in her life with me because of our relationship as Grandma and granddaughter.

For my Dad, telling his stories is therapeutic because it is a way for him to understand his illness in the present connected to his past of using alcohol to cope. Now that he is unable to forget the past with intention, we spend a lot of time together reminiscing and discussing his diagnosis. My role is different as the listener to my Dad's stories in comparison to my Grandma's because I affirm his

⁶“The term Sixties Scoop was coined by Patrick Johnston, author of the 1983 report *Native Children and the Child Welfare System*. It refers to the mass removal of Aboriginal children from their families into the child welfare system, in most cases without the consent of their families or band. The Sixties Scoop refers to a particular phase of a larger history, and not to an explicit government policy. Although the practice of removing Aboriginal children from their families and into state care existed before the 1960s (with the residential school system, for example), the drastic overrepresentation of Aboriginal children in the child welfare system accelerated in the 1960s, when Aboriginal children were seized and taken from their homes and placed, in most cases, into middle-class Euro-Canadian families. This overrepresentation continues today” (Hanson, 15 Dec 2013, “The Sixties Scoop & Aboriginal Child Welfare”)

diagnosis as he tries to understand how it happened as connected to his past of struggling with alcoholism. It is difficult for him to understand that he has dementia and neuropathy and constantly asks me what is wrong and if he will get better. Through sharing in his process of telling stories and connecting them to his present, "...it allows one the freedom to articulate the tragedy of [one's] situation in [one's] *own words*" (Grossman in Jackson, 2013:17). Although his short-term memory has been affected, it is important for my Dad to retell his stories to me and that I affirm what is happening to him presently. As not only the audience, but also the caregiver, I provide the confirmation of the past and my Dad's current health status, which provides relief for him since he becomes anxious trying to understand why he cannot remember and what the precise diagnosis is.

1.8 Therapy of Sharing Stories

Through the process of spending time with my Grandma and Dad, it is therapeutic for me to share stories about our lives and how they intersect. Through writing down their stories and critically analyzing Alcohol Dementia and its implications connected to colonization within our family, it is a way for me as the re-teller of their stories and telling my own as a way to heal. As discussed by Gloria Alvernaz-Mulcahy, "the resolution of personal negative feelings is fundamental to establishing one's cultural identity" (1999:64). I am able to deal with my negative emotions of the trauma I carry connected to the silence of not speaking about my Dad's alcoholism and diagnosis because it carries judgment. Through writing down the issues connected to the health care system not offering services for my Dad, as a First Nations man, I recognize that our trauma is not an isolated incident and is connected to the daily effects of colonialism. It is not a way to remove my Dad's agency since he is honest about his usage of alcohol to cope and forget. But it is important to recognize that, "...the stories exchanged (whether medical or personal, in the form of aesthetic or didactic accounts) are governed by cultural metanarratives that carry according to time, place, and socio-political context" (Raoul et al., 2007:5). Each of our lives and the stories that we tell are connected to larger social processes because of "...the shifting dynamic between the individual

and society, subjectivity and sociality: between fears, hopes, desires, and pain, and the greater social, moral, political and economic structures that subtend and play a part in determining their meaning and orientation/re-orientation to the world” (Dolson, 2012:6). Our stories convey only a small portion of the complexity of the interplay between the micro and macro.

The therapeutic qualities of telling our stories also connect to the importance of temporality and that stories reflect the spiral, rather than linear concepts of time since, “in storytelling, past occurrences are drawn into present experience. The lived present, however, is not set off from the past of the story. Rather, past and present are continuous” (Ingold, 2011: 161). Through examining three generations of my family, it has become apparent that the past and present are in constant exchange with one another, within the stories that I have heard and the stories from my own experience that I share. Through hearing stories from my Grandma and my Dad as they reflect on the past, I recognize the importance of discussing how time is used to absolve responsibility of the impacts of colonization that are still happening today. Colonization is viewed as a part of the past through the public discourse perpetuated within the Canadian education system, media and in connection to structural violence. Colonization of First Nations peoples in Canada is often apologized for and carries the connotation of forgetting. But, “...apologies seem to have little to do with responsibility, and it appears that one can say ‘I’m sorry’, and ‘I’m not responsible’ in the same breath” (King, 2013:124-125). This dissolution of responsibility and non-acknowledgement of colonialism reinforces structural violence for First Nations peoples and is present with the lives of my own family. The fallible discourse that colonialism is a part of the past exemplifies that there exists an “...understanding time that passes as if it were really abolishing the past behind it” (Latour, 1994, 68). The passage of time is circular as it is within our narratives. There is no distinction between the past and present. They are in constant interaction with one another. Thus I examine the connection of the past to the present and demonstrate that colonialism is still affecting First Nations peoples in Canada and globally.

1.9 Colonialism Continues

Another element connecting to the theme of time within my methodology is the importance of focusing on the particularities of the three generations of my family. Our lives and experiences are not representative of all First Nations peoples in Canada, but including our stories is a way to examine the commonalities of colonialism in that it affects the lives of *all* First Nations peoples. Lives are impacted through intergenerational trauma and paternalistic policies that shape the everyday choices, feelings about identity and options. Our experiences are unique and particular to our social, political and temporal localities, but through focusing on my family, I define a way to subvert them being perceived as timeless. Through examining the stories from the lives of my family and “by focusing closely on particular individuals and their changing relationships, one would necessarily subvert the most problematic connotations of culture; homogeneity, coherence and timelessness” (Abu-Lughod, 1991:154). What I want to achieve through sharing our stories is to demonstrate that colonialism has not ended and has been passed onto the next generation. Most importantly, our experiences are not embedded in the past, but are continuous in that the remembrances are a way to show how the past, present and future are in constant flux with one another. As the listener to the stories of my Grandma and Dad, through hearing their recollections, our relationships develop and deepen. Hearing my Dad’s stories has been important to altering our future in that I have gained better understanding of his decisions to erase the past and this has made me a more empathetic caregiver and daughter. Our relationship has positively developed because of my focus on the particularities of his life and his memories.

1.10 Pragmatic Research

As the audience for my Grandma and Dad’s stories and interweaving my own experiences, I have been fortunate to get to know my past and where I come from. But most importantly, “rendering judgment based on careful observation can be a powerful experience” (Farmer, 2005:143). From these experiences in my life, I

have also recognized the importance of research being pragmatic and connected to everyday lived experiences in order to enact change. I want to use my research to aid others who become caregivers for loved ones diagnosed with Alcohol Dementia to provide hope, understanding and support. Through sharing our stories and experiences (Jackson, 2013: 15), I hope that others can relate to the struggles, resiliency and strength that are present within our narratives. As a part of my methodology, I used liberation theology focused on “observe, judge, act” (Farmer, 2005:140). As discussed by Farmer,

liberation theology uses the primary tools of social analysis to reveal the mechanism by which social structures cause social misery. Such analysis, unlike many fraudulent dispassionate academic treatises, it meant to challenge the observer to judge. It requires a very different approach than that most often used... (2005:143).

My concerns for a methodology focusing on story telling and my personal life has led to the internal debate of, what do I want to achieve through telling our stories? Will it have an impact? I have recognized that I should use our stories to examine the faults within the Canadian health care system in providing services for First Nations peoples. Addiction further complicates access to services since the history of colonization, stigmatization and Aboriginal social determinants of health are not factors in providing care for my Dad. My observations through critical analysis of the stories of our lives have forced me from judgement towards action.

Paul Farmer, Nancy Scheper-Hughes, Philippe Bourgois and Dorothy Smith all conduct their research for social activism and I want to do the same. Focusing on the particularities of our lives is a way to “... shift the focus from ‘blame the victim’ to recognition of oppressive systemic structures” (Kirmayer et al., 2009:458). I discuss extensively the neo-liberal governmentality of health services towards my Dad with judgment that his Alcohol Dementia is his fault because of his ‘choice’ to be an alcoholic. Therefore, services do not exist for someone who has willfully destroyed their bodies and has to suffer the consequences. Observing this treatment has motivated me to contribute in some way in the form of activism,

linking suffering to power through a theory that analyzes the multiple levels of...abuse coincides with redefining violence as something more than a directly assaultive physical and visible phenomenon with bounded limits. Violence operated along a continuum that spans structural, symbolic, everyday and intimate dimensions (Bourgois and Schonberg, 2009:16).

The complexities of structural violence affecting the lives of my Grandma, Dad and I has forced me to find healing through activism because “stories are usually not just about things (experiences), they also do something, they get things done—they are social action” (Dolson, 2012:296).

I have tried to formulate a way to find power as a caregiver for my Dad, a role that is confusing, frustrating and entails an immense amount of hopelessness since no services or support exist to deal with the complexities of Alcohol Dementia. Every day since my Dad’s diagnosis has been a struggle for our family, for him and the women who have taken on the full time roles of caregivers. Our struggle is discussed by Linda T. Smith as, “...simply what it feels like when people are trying to survive in the margins, to seek freedom and better conditions, to seek social justice” (2012:199). My role as the listener and re-teller of stories is that I am seeking better health and treatment for my Dad and justice for the effects of colonization that is so entangled in our lives stemming back generations. Within bureaucratic health policies, there needs to be an alternative to the judgment, stigma and mistreatment towards my Dad because of the intersections of his health, Indigeneity, history, struggles with addictions and not upholding neo-liberal governmentality by controlling himself to ensure good health. In order to work from a decolonizing methodology that is pragmatic, it is important to just imagine possibilities because, “imagining a different world, or reimagining the world, is a way into theorizing the reasons why the world we experience is unjust, and posing alternatives to such a world from within our own world views” (Smith, 2012:204). The mistreatment and lack of health options for my Dad and myself have helped me to consider alternative possibilities using my experience to share with other Indigenous women who might be in the same position and do not have support.

1.11 Creating Support for Female Caregivers

Since women predominantly become full time caregivers when a family member becomes ill, they take on the additional responsibility, stress and worry. For my Dad, the women, including myself, who are his caregivers are integral to his overall well-being and health since we provide the daily supports. Without women as supports for my Dad, I cannot fathom what his life would look like. Thus, I recognize the need for support for Indigenous women who are providing care for loved ones diagnosed with Alcohol Dementia. After my thesis is complete, I want to create a blog for a space dedicated to discussing Alcohol dementia from an Aboriginal perspective. The decision to create a blog is a way to provide a resource for other people who are trying to find accessible information. When my Dad was diagnosed, I immediately tried to search information. There were minimal resources available, which only contributed to furthering the feelings of hopelessness. On my blog, I want to include all the resources I have compiled that not only focus on the medical terminology and explanations of Alcohol Dementia and its health implications. I also want to include resources to connect to the historical legacy of colonization and the existing flaws in the Canadian health care system that we encountered. Another aspect of creating an online resource providing the information I have collected on Alcohol Dementia is the inclusion of an online forum for support to caregivers. I want to offer a safe space for discussion and exchange of ideas and sharing of stories. Through having an online forum, it is also a way for people to share without the stigma of in-person interaction. Initially, I wanted to form a support group for First Nations Alcohol Dementia caregivers, but realized that the stigma attached to the illness in connection to the legacy of colonization would restrict people from wanting to attend an in-person group. Forming an online resource and forum is a way to begin the process of sharing information and making connections before a support group can be formed.

Creating an online space to discuss Alcohol Dementia is my way to feel empowered as a caregiver and to use my research as a form of activism. Since there are no existing support services for caregivers of loved ones diagnosed with

Alcohol Dementia, I am using different social services in order to deal with the complexity of the illness. I access counseling services to deal with my own emotional trauma and to find coping mechanisms. Support services exist for caregivers of loved ones diagnosed with dementia and support groups for someone whose alcoholism affects their life. It is exhausting trying to attend all these different support services and only adds more stress as I try to cope on a daily basis. Thus, a blog is a small start to try to offer support to other women who do not have time to access different services to deal with their roles as caregivers. I decided that I could contribute in a small way through the nexus of research and activism (Smith, 2012:226) instead of waiting for services to develop. My personal experiences contribute to activism because I understand first-hand the trauma, resiliency and hope for the creation of treatment and services for Alcohol Dementia. Just attempting to offer resources and support to other caregivers is a way to feel like there exists a potential for change. Our negative treatment and experiences with health care practitioners are indicative of larger issues within the treatment and relationship between the health care system and Indigenous peoples in Canada connected to generations of colonization. Although I am only one person who is trying to imagine a different world, the quote, “never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it’s the only thing that ever has” (Mead in Grinker, 2007:301) has restored my confidence when I struggle with whether my decision to create a blog can enact change. Through a blog, even if it does not change the existing social order, I recognize the importance of the role of informal caregivers when there is uncertainty about their loved ones’ mental and physical health and without existing support services. Providing a space for women to share and connect can be a small step in an unknown direction. This may show my idealism, but I would rather be an idealist who is hopeful and tries to do something instead of waiting for change to occur on behalf of others.

Chapter 2 : Aboriginal Social Determinants of Health

2 Approaching Health Wholistically

My Dad has used alcohol as a way to erase his past and as a form of coping. These intersecting factors can be traced back several generations to understand the long-term effects of colonialism that it is within my own family and still affects the daily lives of First Nations peoples in Canada. Most importantly, I do not want to discuss Alcohol Dementia as just an illness. There are larger factors that have affected his life as a First Nations man and have shaped his opportunities, everyday choices and that health is not just determined through medical terms. Health must "...include circumstances and environments as well as structures, systems and institutions that influence the development and maintenance of health along a continuum from excellent to poor" (Loppie Reading and Wien, 2009:1). As described by Julie George, who applied Aboriginal social determinants of health as a framework to examine Intimate Partner Violence (IPV), there are three categories of social determinants. The three categories are, "distal (e.g., historic, political, social and economic contexts), intermediate (e.g., community infrastructure, resources, systems and capacities), and proximal (e.g., health behaviours, physical and social environment)" (Loppie Reading and Wien, 2009 in George, 2012:10). Each of these categories is present within the stories of my Dad, Grandma and myself. I will be connecting them to some of the themes that were discussed above to examine how our experiences are not reflective of all First Nations peoples, but that there are commonalities because of colonization such as intergenerational trauma. The distal determinants of intergenerational trauma are colonization, racism and forced assimilation. Distal determinants are a result of the intermediate determinants of the colonial education requirements of the *Indian Act* and the lack of legal rights for parents and children whose families were destroyed when children were forcibly removed. Proximal or the everyday experiences of intergenerational trauma was living with the effects of my Grandma attending a day

school and residential school. For my Grandma, attending day school on reserve in Rama until the eighth grade, being sent to a residential school for a year and the residual effects exemplifies "...the legacy of residential schools [which] has had a devastating impact on over 90,000 survivors—not including their children and grandchildren" (Alvernaz-Mulcahy, 2012:183). The social determinants of health categories are important to critically examine Aboriginal health, but I will not be dividing my research into distal, intermediate and proximal determinants, since they are intersectional and present in the different elements of my family's narrative that I chose to examine.

There are limitations of critically discussing Alcohol Dementia using the interconnected narratives of my family across three generations, but using the framework of Aboriginal social determinants of health with an institutional ethnographic methodology "...may start in an individual's experience, but as it moves to explore the social relations in which that experience is embedded, it necessarily brings under scrutiny relations that aren't peculiar to that individual. Rather, these relations are part of a complex of relations that reach beyond and coordinate what she or he is doing..." (Smith, 2010:41). I am starting with the lives of my Grandma and Dad through their own words and what elements of their story are connected to colonization and its effects. Colonization is a part of my life as the daughter who has become the caregiver for my Dad who needs to be placed in a Long-Term Care (LTC) Home and requires twenty-four hour supervision. Writing an auto-ethnography and critically analyzing Alcohol Dementia is "...also about coming home and seeing your own world...in a new light. It's about finding that, in the end, the people who can teach you the most might very well be in your own backyard" (Grinker, 2007:34-35). Using the narratives of my family is also a way to examine how symbolic order is maintained across generations. This relates to intergenerational trauma in that social, economic and health issues span across generations because of the social inscriptions on the body of addictions to cope with structural forms of violence (Bourdieu, 2000:244).

Aboriginal social determinants of health, "depicts life stages, socio-political contexts and social determinants as nested spheres of origin, influence and impact; each affecting the other in temporally and contextually dynamic and integrated ways" (Loppie Reading and

Wien, 2009:25). Using the lens of Aboriginal social determinants of health allows the examination of Alcohol Dementia, not solely as an illness, but as health constituting the mental, physical, emotional and spiritual state of the individual (Loppie Reading and Wien, 2009:25). Using Aboriginal social determinants of health framework to examine my family's narratives is a way to understand the importance of health and its connection to broader social frameworks. The framework also allows me to discuss addictions that causes Alcohol Dementia and its health implications not solely as a personal choice, but as connected to colonial health policies and programs that do not allow self-determination for First Nations communities. There is an absence of access to health services and programs because of a lack of control over funding on reserves and in urban centres (George, 2012:149). There are no existent services on and off reserve for Alcohol Dementia, which is an example of how, "...the 'soft knife' of routine processes of ordinary oppression [and] social suffering ruins the collective and the intersubjective connections of experience" (Kleinman et al., 1997:x). It is the everyday processes that I will be discussing in order to make it relevant and relatable that the effects of colonization are not abstract and historical, but are a part of everyday lived experiences, choices and options for health and well-being.

I have spent many hours with my Grandma and Dad learning about them through their stories. In order to try to understand Alcohol Dementia, my Dad's life needs to be examined to connect micro and macro social processes using the lens of Aboriginal social determinants of health. Throughout spending time together, I will discuss some of the themes that were brought up. These themes connect to the importance of Aboriginal social determinants that can shape an individual's quality of life, their personal choices and methods of coping with the effects of colonialism. To contextualize my Dad and Grandma's lives, I have included excerpts from the stories they have shared with me. I will provide a medical discussion of Alcohol Dementia followed by the themes that I will focus on, which are access to educational opportunities, intergenerational trauma, uprooting and displacement, fractured family, loss of identity and addiction as a coping mechanism.

2.1 Alcohol Dementia and Alcohol Neuropathy

In order to examine Alcohol Dementia for my Dad, a brief medical overview is needed. Alcohol Dementia is an affect of, "...long term heavy drinking that directly damages brain cells or causes health problems that produce brain damage" (Powers, 2005:1). Treatment requires sobriety, vitamin replacement, correction of medical problems and management of behavioral problems. Unlike Alzheimer's disease where patients' mental state deteriorates, with Alcohol Dementia, intellectual improvement is possible but not certain. Diagnosis is difficult since most doctors and family members do not recognize the symptoms early enough. Another contributing factor is that "patients cannot be diagnosed with dementia while they are in withdrawal or experiencing serious medical complications resulting from the substance abuse..." (Powers, 2005:1). It is not until a crisis arises when the family member or loved one is hospitalized, usually for health related complications that a diagnosis is possible. With my Dad, he was hospitalized for a terrible fall and the inability to walk even short distances. Once he was admitted and detoxed, then the doctors were able to assess him physically and cognitively to provide his diagnosis of Alcohol Dementia and Alcohol Neuropathy.

In conjunction with the dementia caused by neurological damage as a result of long-term alcoholism, physical disabilities are common because of nutritional deficiencies "...such as folate and vitamin B12 deficiency" (Laufer et al., 2004 in Martin and Knoefel, 2011). Alcohol Dementia thus has a twofold effect in that damage is done to the brain tissue and the lack of proper nutritional health causes physical disabilities. For my Dad, who has struggled with addiction for more than forty years, neurological damage has affected him physically because "heavy alcohol abuse damages the nerves in arms and legs as well as the cerebellum that controls coordination. Individuals diagnosed with Alcohol Dementia frequently have problems with sensation in their extremities and may demonstrate unsteadiness on their feet" (Powers, 2005:2). My Dad uses a wheelchair and a walker since he is unable to walk long distances without falling down. Since he has been sober for more than ten months, there have been physical improvements. He is able to walk short distances with the aid of his walker. An occupational therapist is working with him and has told me that strength in his arms and legs is improving.

The most unique aspect of this illness is the uncertainty that exists with a diagnosis. The only existing research (Harper 1983, Rourke and Grant 1999, Moriyama et al. 2006, Oslin et al. 1998, Oslin and Cary 2003) is studies by neurologists who examine post-mortem brain tissue of alcoholics or psychologists who approach the illness as a clinical study. My experience with doctors, nurses and specialists is that no one can offer insight as to whether my Dad's mental and physical capacity will improve or deteriorate. The overseeing physician when Dad was hospitalized was unable to give any indication about his long-term prognosis. The doctor explained that there has been extensive damage to the nerves and nervous system and that there is no guarantee that his mental and physical functioning will return with long-term sobriety (Dr. Smith*⁷, Sept. 30, 2013). Since there is no existing research on Alcohol Dementia and the long-term health effects, we are told to wait and see what happens. This level of uncertainty for the diagnosed individual and their family members creates additional stress and anxiety since there are no long-term studies on individuals diagnosed with Alcohol Dementia and the reversibility of the effects if they are able to maintain sobriety. Rourke and Grant discuss the lack of existing literature in that most studies that have been conducted were less than two years, thus there is no documentation of neurological and physical recovery if alcohol is abstained for several years (1999:243). As previously stated, most studies on Alcohol Dementia and its health implications work from a clinical framework and do not examine the illness holistically or discuss the social factors connected with addiction.

In order to examine Alcohol Dementia, a definition of the illness is needed for contextualization, but I need to reiterate that it cannot be discussed strictly in medical terms. It is a complex illness, and within my Dad's case and among other First Nations peoples of Canada, addictions are a coping mechanism for dealing with the daily effects of the legacy of colonization. Medical practitioners constantly state that my Dad needs to stop drinking and then there might be a chance for his cognitive and physical functioning to improve or recover; but it is his decision ultimately if he has the will to improve. This connects to doctors and social workers continuously stating that my Dad needs to quit

⁷ Pseudonym

drinking without offering any support or understanding of the social and historical contextualization for his choices or lack thereof.

2.2 Access to Educational Opportunities

Through hearing my Grandma and Dad's stories and examining them using Aboriginal social determinants of health analysis connected to my stories, I recognize that education contributes to overall well-being. The lack of educational opportunities within my Grandma and Dad's lives are implicit within larger issues connected to colonization. One of the only studies that focused on Alcohol Dementia for Aboriginal men, in Australia, found that there was a direct correlation between "demographic factors, older age, male gender, and no formal education...associated with a diagnosis of dementia" (Jacklin et al., 2013:42). Education has been a prominent part of my life as an Anishanabe woman that it has given me the opportunity to have access to a higher income, better job opportunities and therefore overall better health. Education has also been my personal way to stop the cycle of violence, addiction and loss that has been a part of multiple generations of my family. As the first person in my immediate family to attend post-secondary education and attain a graduate degree, I recognize the importance of education as a critical preventive action (Durst and Bluechart, 2001:40).

Education was an important element of shaping my Grandma's childhood and adolescence. I want to discuss the historical contextualization and implications of the residential school system for Indigenous culture and forced migration as well as how the curriculum shaped the employment potential of Aboriginal students. Within the narrative of my Grandma, there are also gendered elements of the curriculum that had an intersecting role with the employment opportunities that she would be able to obtain after completing her education. My Dad also discussed educational opportunities, in that he was aware that attending a post-secondary institution was not an option for him because of poverty, thus access to furthering his education.

2.3 Residential School

The implications of Aboriginal children being sent to residential schools has long lasting impacts on those who were forced to leave their families, language and culture. The majority of residential schools were institutions that were rampant with maltreatment and neglect. Not only the individuals who attended the school were affected, but also their families, communities and future generations because residential schools removed children from their parents' care and encouraged them to abandon and denigrate their Aboriginal language, culture, and religious practices (Barnes et al., 2006:20). The forced migration of Aboriginal children to residential schools had devastating effects on the personal, kinship and community level. Since the majority of Aboriginal parents did not voluntarily send their children to residential schools, the Canadian government amended the *Indian Act* to force all parents to send their children to attend residential schools or day schools. If parents did not comply, they were incarcerated or forced to pay a penalty that was often beyond their economic means (Blackstock and Trocmé, 2005:14). Therefore, it was difficult for Aboriginal communities to avoid the colonial impact of generations of children losing their language, kinship ties and culture.

With the amendment of the *Indian Act* in the early 1900's to make school compulsory for all children from the age of five to fifteen (Barnes et al., 2006:20), my Grandma was forced to return to school by the Rama Indian Agent for not complying with the required education parameters. At the age of fourteen, my Grandma and her older sister Mary moved to Toronto. My Grandma worked as a mother's helper for a family, but explained she had to return to school:

"...in September, the Indian Agent from Rama came and got us and told me I had to stay in school for another year. He didn't say, 'do you want to go?' He just said, 'we're going'. He put us on the train and we went to, a...London to go to a town called Muncey" (Miller, 9 March 2013).

In 1938, my Grandma and her sister Mary were sent to *Mount Elgin Residential School* located in Muncey which was run by the United Church of Canada. This in itself is an

example of structural violence because they were not given a choice to attend the residential school where they remained for a year. Forcibly moving to a residential school was not a decision to be objected to on behalf of Aboriginal families or children because the Indian agent had the power to send children away for not adhering to the education policies of the *Indian Act*.

When my Grandma attended *Mount Elgin Residential School*, the curriculum was focused on teaching the Aboriginal students gendered vocational training. My Grandma discussed the training that was provided while attending residential school: “they had a big farm and the boys worked the farm, the machinery and things like that. The girls did the housework, learnt how to do cooking and sewing” (Miller, 18 June 2013). Like most residential schools, “industrial training was often more about the upkeep of the institute than about learning” (United Church of Canada, “Residential School Archive Project”, 16 Jan 2014). My Grandma talked about learning to weave and teaching the other children. They would make clothes and blankets from whatever material was available in order to supply for the students.

The residential school curriculum had social implications because academic instruction ended at grade eight and vocational training consisted of low skilled tasks (Barnes et al., 2006:21). When asked about attending high school, my Grandma reiterated this colonial policy. She stated:

“You only had to go to school until grade eight. There were no schools after that here in Rama and nobody had a car. You had to take a bus back and forth. I went on the train, but it left early in the morning and late at night. Then I went to a cooking school after that the next year because I couldn’t go and teach in Northern Manitoba. I was only sixteen then and my Grandma said, ‘she’s not going that far away’ ” (Miller, 18 June 2013).

The gendered low skilled vocation training limited the education and employment opportunities for the majority of Aboriginal youth who attended residential schools who migrated to cities instead of remaining on reserves in order to obtain jobs. After attending *Mount Elgin Residential School*, my Grandma decided to not return to Rama because there was no advancement of education that was geographically viable since she was

unable to travel to Orillia. If she attended high school in Orillia, it would have been a predominantly white school and would have cultural implications in itself. She decided to attend a vocational school in Cambridge where she learnt to be a cook instead (Miller, 7 May 2013). Not having the option to further her education was common among the majority of youth, considering that almost eighty percent of the Aboriginal identity population who are now sixty-five and older had not completed high school (Mendelson, 2004:16). Not having the option of furthering education beyond the most rudimentary levels was a key tactic of the education policy of the *Indian Act*. The broader implications for First Nations peoples having, "...less than high school education has been shown to significantly reduce the prospects of employment, income and other outcomes later in life, including health outcomes" (Loppie Reading and Wien, 2009:13). Since attending high school was not an option for my Grandma, she decided to migrate to a city in order to gain training as a cook, which shaped her job prospects, income level and social exclusion since education provides access to better health, job security and increases the chances for the next generation to attain higher education.

My recognition of the benefits of completing high school and obtaining a post secondary education led to asking my Dad about what career he wanted to pursue. As a child, my Dad said that he wanted to become a police officer. I quickly realized after transcribing our interviews that education beyond high school was not seen as a viable option in my Dad's perspective:

Danielle: "Did you ever want to go to college or university?"

Dad: "I wanted to go to college; I said that right up until grade twelve until they kicked me out".

Danielle: "Why did you get kicked out?"

Dad: "Wasn't going enough. They said, 'you pass all the tests, but you don't come to class'. A lot of people went to tech school back then. Only the ones who wanted to go to university went to grade thirteen. I didn't go that far. I should have. I should have gone to college. University was out of the question. I even knew that when I was a kid".

Danielle: “Why?”

Dad: “Money. Only rich kids went to university. You see it on TV” (Miller-Alcock, 12 Oct 2013).

My Dad was aware as a child that attending university was not an option for him since his family did not have the money to afford it. My Dad grew up in Toronto being aware of his social positioning as well as trying to cope with domestic violence, alcoholism and the loss of siblings while attending high school. My father was kicked out of school because of poor attendance, which exemplify that, “certain Native dropouts lacked parental support because of the many social problems that affected their families” (Mackay and Myles, 1999:166). Without support and trying to deal with a multitude of issues within the family, my father started working as a teen. My Grandma and Dad’s experiences exemplifies the fact that the lack of education for First Nations peoples in Canada is directly linked to, “the difficulty in maintaining a sense of well-being...and undermined in the daily lives of this group of people. The low educational levels, poverty, and frustrations batter the self-esteem, leading to a downward cycle of despair and depression” (Durst and Bluehardt, 2001:68). My Dad was the second generation where the lack of education opportunities determined career prospects and therefore his overall health. Using alcohol has been a method to escape the negative memories of abuse, loss and an internal lack of confidence.

Although my Grandma, Dad’s and my own life histories span over a ninety-year period, issues connected to education, poverty and job opportunities are still a present issue for First Nations peoples. There is a great disparity for post-secondary education in that only, “eight percent of Aboriginal people had completed a university degree in 2006, compared to 23 percent of all Canadians” (Statistics Canada, 2008 in George, 2012:46). The low rate of post secondary education connected to job opportunities and income is present today in that, “...while the average income for all Canadians has increased in the past decade, and income disparity has narrowed, it will take an estimated 63 years for the income gap between Aboriginal people and the rest of non-Aboriginal Canadians to be erased” (Wilson and Macdonald, 2010 in George, Julie, 2012:46). Education as an

important Aboriginal social determinant of health shows that First Nations peoples are still facing effects of colonialism. These stem in part from the generational impacts of residential school. Colonial policies and practices in education that are still in existence today limit opportunities for Aboriginal peoples and perpetuate the cycle of poverty.

2.4 Intergenerational Trauma

My Grandma who turned ninety this year is a strong, resilient woman whose life has been shaped by sexism, racism and structural violence, which have had long lasting effects on her children and grandchildren through intergenerational trauma. Intergenerational trauma results from historical trauma, which is the:

...cumulative emotional and psychological wounding, over the lifespan and across generations, emanating from massive group trauma experiences. The historical trauma response (HTR) is the constellation of features in reaction to this trauma. The HTR may include substance abuse, as a vehicle for attempting to numb the pain associated with trauma. The HTR often includes other types of self-destructive behavior, suicidal thoughts and gestures, depression, anxiety, low self-esteem, anger, and difficulty recognizing and expressing emotions. Associated with HTR is historical unresolved grief that accompanies the trauma; this grief may be considered impaired, delayed, fixated, and/or disenfranchised (Brave Heart, 2003:7).

Intergenerational trauma is a strong social determinant of health because it is the intersection of distal, intermediate and proximal factors. The severing of culture, language and ties to the land are passed on to the next generation and that loss is irreplaceable.



Figure 1: Annie Miller (second from the left)

The photo I included is of my Grandma when she was showcased at the *Canadian National Exhibition* in 1939 when she attended *Mount Elgin Residential School* where gendered skills and proof of assimilation into the Canadian culture were put on display. She was chosen to be a part of the exhibit because she was an excellent weaver whereas the boys showed their farming abilities. Showcasing Aboriginal children who attended residential school was a form of oppression because, “brute torture on the body of the colonized was not the same as the public exhibition of a colonized body, but these two moments of colonial power shared in more than they differed” (Dirks, 1992:5). It is impossible to discuss intergenerational trauma without connecting it to the colonial policies of residential school and their effects. Research by Maria Yellow Horse Brave Heart has found that, “the trauma symptoms of the parents, rather than the trauma exposure per se, are the critical risk factors for offspring manifesting their own trauma responses” (Brave Heart, 2003:10). My Dad and his siblings suffered the consequences of

my Grandma attending day school and residential school and the structural violence she experienced because of her gender and Indigeneity. My Dad and his siblings grew up surrounded by substance abuse, abject poverty and violence. Throughout several of our discussions about his childhood, my Dad would recall growing up with a stepfather who was abusive and recounted a story of witnessing Intimate Partner Violence:

Dad: “Frank⁸ broke mom’s arm and he didn’t go to jail”.

Danielle: “No?”

Dad: “No”.

Danielle: “Did she go to the hospital?”

Dad: “Yeah, he broke her arm. He twisted it too far”.

Danielle: “Did they stay together after that?”

Dad: “Yes, this happened when I was about four years old. You just remember pieces, but I remember the broken arm”.

Danielle: “So he would hit her?”

Dad: “Restrain her. She was quite a fighter. There was always alcohol involved too I guess. After bingo, it’s two hours after at the pub” (Miller-Alcock, 15 Oct 2013).

For my Dad, he recounted stories of violence and fear in their household as a result of alcohol abuse. Alcohol was a method of coping for my Grandma until she turned forty and decided to quit and she has remained abstinent ever since. Alcohol abuse as a coping mechanism and Intimate Partner Violence (IPV) for First Nations families, especially for Aboriginal women, needs to be contextualized in that,

⁸ Pseudonym

the difficulty lies in fully capturing the legacy impact of colonization, residential schools, and numerous other policies and practices on traditional gender roles and family structure across generations. Each of these adds a layer to the likelihood, severity, and persistence of Intimate Partner Violence. This includes: lack of parenting skills; the normalization of violence; and lack of self-esteem stemming from historical trauma and loss (George, 2012:24).

When I asked my Dad what my Grandma was like when he was younger, he responded, “I don’t know. Mom did the housework and made sure we ate I guess and went out on her nights, bingo and whatnot. She had Frank there, so he was taking up most of her company and my Dad at times” (Miller-Alcock, 2 Aug 2013). My Grandma worked two jobs, six days a week in order to provide for her children since she was predominantly a single mother financially and emotionally. My Grandma juggled the “high costs of housing and other living expenses, combined with inadequate or inaccessible community services, especially for women with young children, compounded by the dilemmas of unemployment and low-wage work” (Williams, 1997: 84). Although my Grandma faced many adversities in her life that connect to broader social issues for Aboriginal women because of macro-contextual factors as well as her personal experience, she always strived to be a good mother. When I asked, “what difficulties did you face in Toronto as an Aboriginal single mother?” My Grandma responded that it was difficult, but “you had your babies, you keep them and you look after them” (Miller, 28 Apr 2013). Throughout the discussion of my Grandma’s life that she chose to share with me, the most important part of her stories was telling me about being a good mother and her family. Although my Grandma was unable to reside on the reserve until the passing of *Bill C-31*⁹ in 1985, she returned to Orillia in order to be close to her family who remained or returned to Rama (Miller, 10 May 2013). Throughout her life she was forced to migrate because of the

⁹ “Bill C-31, or a Bill to Amend the Indian Act, passed into law in April 1985 to bring the Indian Act into line with gender equality under the Canadian Charter of Rights and Freedoms. It proposed modifications to various sections of the Indian Act, including significant changes to Indian status and band membership, with three major goals: to address gender discrimination of the Indian Act, to restore Indian status to those who had been forcibly enfranchised due to previous discriminatory provisions, and to allow bands to control their own band membership as a step towards self-government” (Hanson, 23 June, 2014, “The Indian Act”)

education policies of the *Indian Act* and in order to find employment in urban centres, severing her connection to her family and community.

2.5 Uprooting and Displacement

Uprooting and displacement not only affects the connection to family and community, but also stems from disconnection to the land that has been perpetuated through the creation of reserves. For my nation, the Chippewas of Rama, displacement occurred because of forced removal from the land by the Canadian government. Removal occurred several times and began,

...around 1830, [when] our community was moved to the Coldwater Narrows area by the Crown, part of an ‘experiment’ which shaped ‘Indian Reserves’. We continued on as industrious people, building a road for commerce which is known today as Highway 12, establishing farms, mills, and markets for selling produce, fish and game to settlers and travellers. Forced to move again after our land was taken in what is now being termed an ‘illegal surrender’, we purchased land in Rama Township in 1836 and made a new beginning for our people. The land was difficult to farm and, with the loss of our inherent right to fish and hunt with the disputed Williams Treaty in 1923, we pursued other entrepreneurial opportunities in the tourism market (Rama First Nation, 25 Feb 2014).

The loss of land has larger implications such as access to hunting and fishing for sustenance, ties to traditional knowledge and the sustainability of the community. My nation successfully disputed the illegal surrender of the land. The land could not be returned because it has been settled, but a monetary settlement was given instead. The initial land owned by the Chippewas of Rama who were a part of the Chippewa Tri-Council was 10,000 acres (Carson, 11, May 2011) and now is 2,500 acres (Rama First Nation, 25 Feb 2014). The loss of land through the creation of reserves caused First Nations peoples, especially women, to migrate to urban centres since there were no education or employment opportunities available.

After vocational training to be a cook, my Grandma stated that she decided to migrate to Toronto instead of returning to the reserve, “because I couldn’t get a job on the reserve” (Miller, 7 May 2013). Existing literature examining the migration flows of Aboriginal members moving to cities in Canada over the last century often discusses that, “the push

of life on the Aboriginal Reserve community was accompanied by the pull of the city; the potential for educational, economic, political and social benefits prompted movement to the city” (Williams, 1997:79). Opportunities for the majority of Aboriginal youth returning from residential school was minimal and thus many decided to migrate for the economic benefits that were non-existent on reserves. As a result of the limited academic training and emphasis on vocational training offered to Aboriginal children, in conjunction with the economic and social realities of reserves, when Aboriginal individuals migrated to cities for employment, “the wages were low and employment conditions were poor; job insecurity and temporary work are two such conditions that accompany the low incomes earned. In terms of average incomes, Aboriginal peoples rank near the bottom relative to the incomes of other ethnic and racial groups” (Williams, 1997:81). My Grandma worked most of her life as a domestic worker or cook. These professions paid low wages and the work was labour intensive, but for my Grandma she said:

I never let money rule me. If I haven't got it, I haven't got it...because the next day something always comes up...if you're not greedy. If you're greedy, you want more; and it will make you a miserable person. I've seen people like that. So that's why I never let it rule me. As long as I had a roof over my head and food on the table and clothes on my back, I'm happy (Miller, 9 March 2013).

Regardless of the economic realities my Grandma faced as an Aboriginal woman, her focus was always her family and keeping her children together, rather than on money.

Among Aboriginal communities in Canada, historically and contemporarily, women are more likely to live in urban centres than on the reserve. According to research conducted by Peters, there is a migration trend that,

First Nations men are more likely than First Nations women to live on reserves. The reasons for these differences are not well understood and they may have to do with differences in employment opportunities for men and women, responsibilities for children's education and other services, access to social assistance and other factors (2006: 318).

This was an element of my Grandma's life because she did not return to live on the Rama reserve again until she was eighty-six years old, a decision she made because of the opportunities that urban centres offered in terms of jobs.

The migration flows of Aboriginal individuals to urban centres from reserves were not only gendered, but created political and cultural boundaries through government policies. The increase of Aboriginal migration to cities throughout the twentieth century:

challenged governments to revisit the scale at which services for First Nations were provided. In the early 1950s, the federal government developed its position that federal constitutional responsibility for registered First Nations people applied only on reserves and that First Nations people living off the reserve become the responsibility of the provinces for the purpose of most social services (Peters, 2006:316).

The federal government perspective was that the responsibility of social services for Aboriginal peoples who migrated to urban areas was nullified because Aboriginal peoples were giving up their political rights associated with the reserve. Intersecting with the political context of the federal government absolving their responsibility to treaty and Aboriginal rights was the view that individuals who left the reserve also wanted to assimilate with mainstream Canadians.

Migrating to the city from the reserve is a decision confounded by a multitude of social, political and economic factors that impinge on individual decisions. For Aboriginal peoples who decided to move to urban areas, there is a lack of social services to meet their needs and, "their histories as Aboriginal people create political and cultural geographies that do not always match those of the groups and organizations that organize service provision in urban centres" (Peters, 2006: 316). When my Grandma moved to Toronto, she volunteered at the first social service agency that evolved in response to the needs of urban Aboriginals called *The Native Canadian Centre of Toronto*. Based on the Canada census of 1951 showing that approximately seven percent of the Aboriginal population were living in cities (Peters and Starchenko, 2005:319), the lack of social services shows the boundaries created by the government that reserves were defined as segmented physical places and that First Nation peoples were out of place in cities (Peters, 2006:316). The absolvment of federal responsibility and the perspective that

Aboriginal peoples who move to the city should be treated like mainstream citizens, shows that the government strictly viewed the spatial boundaries of reserves as the only designated places where Aboriginal culture and their minimal rights existed.

My Dad moved to Rama reserve a few years ago, but he has never had a connection with the land and the community. Since he was unable to gain his Indian status until my Grandma's was reinstated, his ties with the land were severed. Even when asked about living on the reserve growing up, he said, "No, maybe babysitting here a few times when Mom had babies; but that's about all" (Miller-Alcock, 2 Aug 2013). Even my Grandma has only returned to live on the reserve when she was placed in the *etsidjig Endaawaad* (Where our Elders/Seniors Reside) Home and Extended Care Facility when she was unable to live on her own. She lived most of her life in Toronto and in Orillia for the last forty years. We discussed that she only lived in Rama until she migrated to Toronto for work:

Grandma: "I didn't really live on the reserve. I lived here until I was fourteen and I've just come back two years ago. A little old lady coming back and doesn't know anybody".

Danielle: "What about your sisters? Did they come back to the reserve?"

Grandma: "My sisters? Just Margaret and Jackie lived on the reserve. Mary lived in Orillia, Gladys lived in Orillia and Belva and I lived in Toronto".

Danielle: "So you were all spread out?"

Grandma: "All spread out. But we always got together for different things".

Danielle: "Like birthdays and Christmas..."

Grandma: "And weddings. We always got together".

Danielle: "What about your Mom and your Grandma? Did they stay here?"

Grandma: "My Grandma didn't go to too many things and Mom was always at the church. I don't remember my Grandma going anywhere. I seldom saw them after I

moved to Toronto. I didn't come home very often. I would only come home if somebody got married or something like that, I would come back here" (Miller, 17 June 2013).

The displacement of migrating to the city for work and not returning to the reserve to raise her children because of loss of residence rights meant the loss of land tied to culture, language and history. This connects with the idea that identity is nested in layers connected to place (Alvernaz-Mulcahy, 2012:192). My father moving to the Rama reserve a few years ago and my Grandma's recent return meant that their absence also caused a disconnect with the community. Both of them have stated that they feel like outsiders. It is more difficult for my Grandma because most people from her generation as well as her family members have passed on. For my Dad, he has struggled with his identity and has not engaged with the community including cultural events.

Having a sense of belonging and identity are key factors of determining health

...because indigenous people are inextricably related to land: it sustains our spirits and bodies; it determines how our societies develop and operate based on available environmental and natural resources; and our socialization and governance flows from this intimate relationship (Report of the Royal Commission on Aboriginal Peoples, 1996 in Denov and Campbell, 2002:24).

Connection to the land means confidence in your self worth and identity. Alcohol and substance abuse are coping mechanisms for many First Nations peoples who have been forcibly displaced from their traditional territories. But studies on resiliency are finding that a reconnection to culture, land and language can be successful methods of healing for, "individuals... to engage in their Aboriginal culture and this is seen as therapeutic as they are taking part in a 'restoration of the self' in living the life destined for them as an Indigenous person" (Pickel, 2012:14). For myself, I have been working with local First Nations organizations in the London area to cope with my own trauma. Through traditional healing, I hope to find healthy ways of dealing with the legacy of trauma within my own life in order to be a better caregiver for my father. Although I do not have the connection to the land which in turn means my cultural, spiritual connection, a key part of my Indigenous identity, I am trying to find peace through Indigenous methods of

healing that I am fortunate to be offered in the urban centre of London that caters to the diverse and complex Aboriginal community.

2.6 Fractured Family

Education, intergenerational trauma, connection to the land and our Anishanabe culture and identity are examples of Aboriginal social determinants of health that have affected the lives of our family. In order to understand my Dad's usage of alcohol to forget, understanding the effects of our family being torn apart has helped me to empathize with my Dad and understand my Grandma's strength surviving the perpetual destruction to her family connected to colonial policies such as the *Gradual Enfranchisement Act* that was passed in 1896 and in affect until 1985. My Grandma was subject to the *Gradual Enfranchisement Act* that, "stipulated that any Indian woman who married a white man would lose her Indian status and any right to band membership" (Lawrence, 2003:7). As stated by my Grandma, "I lost my status when I married my husband" (Miller, 18 June 2013). This example of gendered discrimination meant that my Grandma and other First Nations women with status who married a non-Native lost their band membership and their right to residency on the reserve. Not only did this have legal ramifications, but also, "taking into account that for every woman who lost status and had to leave her community, all of her descendants also lost status and for the most part were permanently alienated from Native culture" (Lawrence, 2003:9). First Nations women who had to leave the reserve as a result of marrying a non-Native can be connected to the gendered forced migration of Aboriginal women to cities and contributed to creating spatial and identity boundaries between First Nations members on the reserve and their families who still had membership and residency rights and those who did not because they married a man without Indian status. Thus, because my Grandma lost her band and residency rights and could not return to the reserve, she moved to a house in Orillia, located ten minutes away, where she lived for thirty-seven years (Miller, 9 March 2013) in order to remain close to her family who also lived in Orillia and Rama. This meant that my Dad and I did not have Indian status until the late 1980's and 2010 respectively.

2.7 The ‘Sixties Scoop’

Gender discrimination within the *Indian Act* not only created political, social and spatial boundaries between First Nations members on reserve and those who migrated to cities because they lost their rights, but discrimination existed within police, judicial services and welfare services. Losing her status as a First Nations woman meant that my Grandma no longer had constitutional rights on the reserve or in the city while still facing discrimination because of her race and gender. Throughout my Grandma’s life story, I learned about an uncle named Murray whom I was never aware of. My Grandma told the story about uncle Murray being kidnapped by a babysitter and then placed in the *Children’s Aid Society* where he was adopted. I have included an extensive excerpt from my Grandma telling the story of losing Murray because it is important that it is told in her words. Hearing this story several times throughout my Grandma’s narrative allowed me to empathize the grief she must have experienced and the impact it had on her life, my Dad’s and my own since we all had to live with the residual effects of the family being destroyed:

Grandma: “He must have been a real nice little boy because the babysitter I had, I would go get him when he was sleeping at night. She said she would look after him and said, ‘you go have a good time with your sister’. I didn’t know she liked him that much. I didn’t even recognize him when I saw him”.

Danielle: “When you saw him when he was older?”

Grandma: “Yes, I saw him when he was nine years old at the courthouse. That must be my little boy. I was going to get up and go open the door”.

Danielle: “You could see him, but you didn’t get to talk to him?”

Grandma: “No, they wouldn’t let me talk to him. I said to that girl after we left the courthouse, I said to her, ‘what happened? I was coming to get my son’. She said, ‘so and so who works at the office wanted to adopt him’. I said, ‘how could she adopt him when he belongs to me?’ She said, ‘the court just took him away from you’ ”.

Danielle: “So it didn’t matter that you wanted him back”.

Grandma: “Nope. They knew this lady, but they didn’t know me. It was just the one question. You know when they give you five questions you had to answer, ‘yes, no, no, yes, no’. I had the answers memorized in my brain that’s the order they go in. You know what he did to me? He switched two questions. One was, ‘do you know who the father is?’ That one I was supposed to say ‘yes’. But he asked me the ‘no’ question. I hesitated, ‘that’s a no question’, I said to him. I answered ‘no’ when I should have said ‘yes’. That confused me so badly. They cut it off right then and there. That’s what they had planned on doing to me. They knew I was nervous. They drummed those ‘yes, no’ questions into my brain so that’s the way I was supposed to answer it. As soon as I answered ‘no’, that I didn’t know who Murray’s Dad was, oh my God, right then and there it ended. They walked me out and I said, ‘how could they do that? How could they do that to me?’ I was crying my head off up and down the streets”.

Danielle: “Did they not give you a lawyer when you went in?”

Grandma: “Nope. It was me who called the *Children’s Aid* to help me find him in the first place and they were the ones who took him away from me. I phoned them several times. Her husband used to call and tell me where she was, and I would call and tell them where she was so they could go pick him up. How she ever knew that her husband phoned me or knew where she was. She moved so she couldn’t get caught. If she didn’t die in her sleep. Murray had broken his arm and I didn’t know that they had found him two months before that. They had him for two months before they told me I had to go to court. I didn’t know all this still until a while later because I didn’t bug them about him. I didn’t keep phoning them to ask them about him. I said, ‘he is still my son and I still want to know why’. She said, ‘you have other children’. Other children? He’s still mine”.

Danielle: “What was their reason?”

Grandma: “Because this lady wanted him. She wanted to adopt him from the *Children’s Aid*. So we were going to try to look for him. But I thought, maybe we should let him be. Maybe he’s happier”.

Danielle: “Would you ever want to find him now?”

Grandma: “I don’t know. I don’t think so. I don’t want to have my heart broken. He might have had a different life, a better life. I can’t say. I can’t see how people lived. At least I made the other kids as happy as I could. I gave them everything I could. They were all right” (Miller, 17 June 2013).

As a non-status Aboriginal woman, my Grandma’s loss of her son to a welfare agency is an example of the ‘Sixties Scoop’ when thousands of Aboriginal children were removed from their families and placed in non-Aboriginal homes (Blackstone and Trocmé, 2005:16). As previously discussed, Aboriginal women who resided in Canadian cities for a multitude of reasons including gender discrimination because of the *Gradual Enfranchisement Act* or the social and economic restrictions available on reserve, did not have access to agencies that served the Aboriginal community. My Grandma relied on the *Children’s Aid Society* to help search for her kidnapped son. But losing Murray and never seeing him again connects to the inadequacies of social service agencies that did not understand the, “experiences of living in poverty or the needs, perspectives, cultures and traditions of First Nations clients” (Alston-O’Connor, 2010:54). Social agencies that removed thousands of children during the ‘Sixties Scoop’ had long lasting, multi-generational implications for Aboriginal communities and individuals. My Dad and his siblings grew up without a brother who was taken away and was the first of three brothers who were kidnapped. The two eldest sons were kidnapped by their father only a few years after Murray was taken away. Since my Grandma had lost all trust for social agencies, she did not contact the police for assistance. It was not until fifty years later that she was reunited with her two sons when they decided to search for her.

The trust for urban social agencies that my Grandma lost because of gender and racial discrimination she experienced through losing her children connects to the legacy of barriers and mistrust between most Aboriginal communities and social service agencies on reserves and in cities. The legacy of distrust between Aboriginal individuals and communities with social agencies has had long lasting effects on the development or implementation of community based initiatives since trust is integral to success (Alston-

O'Connor, 2010:58). Although the 'Sixties Scoop' occurred several decades ago, mistrust of social agencies on the reserve and in cities is still a prominent issue because the federal government still does not fund services for Aboriginal children and families off reserve. Therefore, Aboriginal peoples who do not reside on the reserve are referred to provincial child welfare agencies, which may or may not offer culturally based services (Blackstone and Trocmè, 2005:16). The existing high rate of child apprehension from First Nations families and communities continues to impede trust with social service agencies. Social services agencies within urban cities need to be culturally relevant and need to be founded on trust in order for Aboriginal women to use their services. The legacy of the 'Sixties Scoop' has resulted in multi-generational grief due to loss of culture, identity and family for the children who were taken away, and the parents such as my Grandma who do not know what happened to their children. The loss of children within my family life illustrates how ongoing colonial violence creates multiple ruptures in every aspect of the life of the colonized, including the most intimate; the family.

2.8 Loss of Identity

Loss of culture and language because of cultural genocide are important elements connected to Aboriginal social determinants of health and overall well-being. Growing up on the reserve in the early twentieth century, my Grandma attended a day school that was a part of the Indian Residential school system. She was fortunate that the Rama reserve had a day school that was located next to her Grandma's house and she was able to return to her family every day once lessons ended. With the adoption of the *Indian Act* in 1876, "government policy mandated that Aboriginal children be taught English or French language, Euro-Canadian ways, and Christian religious practices; these policies were implemented in ways intended to eradicate aboriginal language, culture, and religious practices" (Barnes et al., 2006:20). My Grandma was able to maintain her Anishanabe culture and family ties because she was able to spatially remain in her community as opposed to many children who were sent away to attend distant residential schools.

Although the Canadian government instituted the residential school system and forced thousands of children to be far from their families and community, my Grandma's

experience was unique because she was able to maintain her Anishanabe language. When my Grandma began school she met her life long friend named Iva when she was five and Iva was four years old. When they met, Grandma "...couldn't speak Indian and Iva couldn't speak English" (Miller, 9 March 2013). Within a year, Grandma, "was speaking 'real good Indian' and Iva was speaking 'real good English'. I couldn't tell ya' how we taught one another, but we did" (Miller, 9 March 2013). My Grandma and her best friend taught one another although they were forbidden from speaking their language in the classroom. Since they both attended school on the Rama reserve, they were able to keep their language. Even though children in the colonial school system, "...were forbidden to use their aboriginal language even among themselves or when communicating with schoolteachers or staff" (Barnes et al., 2006:23), the spatial context of my Grandma remaining in her community allowed her to learn Anishanabe. Removing the ability of Aboriginal children to speak their language was a key part of the school system, but my Grandma was able to subvert this system because she only attended day school.

Anishanabe spiritual beliefs and cultural transmission being forcibly removed through Canadian government policies in conjunction with missionaries can be traced back several generations before my Grandma. We talked about her upbringing as a Christian and the women in her family's active engagement with the Anglican Church located on the reserve:

Grandma: "They used to do the Indian ceremonies. They used to dress up in the different Native things. My aunt Dora didn't like it".

Dad: "So you weren't allowed to go?"

Grandma: "I guess not. She said, 'that's not our way...wrong costume' " (Miller, 18 July 2013).

My great, great Grandma and her generation were raised Christian and this illustrates the loss of transmission of identity through the "process of colonization and varying degrees of assimilation into the dominant cultural value system have resulted in altered states of an Indian sense of self" (Weaver and Brave Heart, 1999:22). My Grandma grew up

Anglican and had no connection to her First Nations cultural beliefs, thus it was not passed on to her children and grandchildren. For myself and other First Nations peoples, there is an immeasurable grief attached to not having the language and culture passed on because of colonial policies of cultural genocide.

The Anishanabe language, culture and history was not taught to my Dad and his siblings by my Grandma, and they grew up away from their extended family and community because of forced migration for my Grandma. My Grandma is still a fluent speaker, but she never taught her children. My Dad recounted that his perspective was that, “it was like a secret language for her. She could get on the phone and nobody would know what she was saying. Her best friend Iva could speak it well” (Miller-Alcock, 2 Aug 2013).

Growing up without the Anishanabe language has broader implications for my Dad and affected his struggle with his identity. He stated in many interviews he is “...only half Indian” (Miller-Alcock, 30 Sept 2013). Throughout his life, he would not tell people about his Indigeneity because he would be criticized and required to prove it:

Danielle: “Did you tell people growing up that you were Native?”

Dad: “Nope. Why would I?”

Danielle: “You wouldn’t tell people?”

Dad: “No. We lived with the Italians. Also the fact that they wouldn’t believe me. I had blonde hair when I was little. When you live with the same people, we lived in the same area for thirteen years. By the time we moved, nobody had asked. They could tell by Mom. I wouldn’t tell people I was Native unless I was with Mom. Otherwise they would say, ‘are you nuts?’. ‘You just want to get on *Cher*’s band wagon’ is what they would say. ‘You want to be a Cherokee’ ”.

Danielle: “Nope, wrong one”.

Dad: “Out West, I don’t know how many times I had to show my card because I hung around with them. They would say, ‘how come you’re bringing a white guy?’ I would have to show my card to shut them up. That would shut them up and then they would say,

‘he probably stole it’. Then after a while, you just grow on them. Drink the same stuff they drink, and you’re friends for life. But at first, you’re an outsider” (Miller-Alcock, 2 Aug 2013).

I know that growing up without his culture and language impacted his pride in who he is. Hiding his identity also contributed to his coping mechanism of alcohol abuse because he would be responsible for proving his Indigeneity instead of being believed when he told people.

The loss of Indigenous identity is connected to language. If my Dad grew up learning Anishanabe from my Grandma, I think this would have positively contributed to his confidence in his Indigenous identity. Language revitalization has become a prominent issue for First Nations communities because, “our stories go missing along with the lost language and so do the cultural ceremonies and understandings” (Alvernaz-Mulcahy, 2012:185). For my generation and for me personally, there is a struggle of identity since I did not grow up with any knowledge of Anishanabe cultural ceremonies, language or teachings. I am trying to break the cycle of assimilation through my personal journey of learning about my Indigenous identity. One method of remedy is to learn as much of the language as I can from my Grandma. Since she is one of the last remaining individuals from her generation in Rama, she does not have anyone to practice with on a daily basis and is attending classes held at the Long-Term Care Home. Even if I do not learn how to fluently speak Anishanabe from her, recording her words and learning their meanings will help me to understand my own identity.

2.9 Addictions as a Coping Mechanism

In my family, in order to deal with trauma and loss, addictions have been a coping mechanism to erase the past and to try to forget. For my Dad, alcohol has been a way to deal with loss throughout his life. He has lost his wife and children because of his addictions and two older brothers, who both passed before the age of thirty to addictions. Here my Dad is talking about his brother Shannon:

Danielle: “What was it like after Shannon passed?”

Dad: “I don’t know. Shannon was always weird and a little bit older”.

Danielle: “So he wasn’t home much?”

Dad: “Reform school when I was really young and the streets when I was older. He wasn’t allowed a lot of places because he was always sniffing and his eyes were crazy. Even if you talked to him, he probably didn’t know what you were saying. It was probably just an echo, echo. He knows what he wants to do. He used to fall down a lot. He always had hurt legs but he would always walk around. He never went to the hospital or anything until he had to. Then he would be in there to observe him. Why was he so crazy like this? His hands were scaled from sniffing. Imagine what his lungs were like. I would say his dying early was a good thing. Yet it still feels like he’s still around. He was a funny guy. He had a personality which you never would have thought of. He was a real nut bar and that stuff is addictive. It took up almost all his waking time”. (Miller-Alcock, 12 Oct 2013).

Shannon struggled with addiction and was court ordered to attend reform school on several occasions for petty theft such as stealing nail polish remover from local stores. My Grandma regretted sending Shannon to the reform school because that was where he was introduced to sniffing solvents:

Grandma: “He was stealing and of course I said, ‘put him in training school’. I don’t know how come they singled him out. To show other kids what will happen to you if you do something wrong? That was the most horrible thing to happen to him when he went to that place in Bowmanville. We went go see him a couple times. They would say, ‘they’re not related to him’. Then those boys went and bought nail polish remover and had a party by themselves. Then they...I can’t remember. He was so good at home. That’s what I can’t get over. He was so good with the kids. He would play with them and feed them if they were hungry, change their clothes. He was so good with them, the younger ones. As soon as he got outside, he was a different kid altogether. I always think about that; what could I have done? What I didn’t do.” (Miller, 2 Aug 2013).

The court system did not believe Shannon was Anishanabe when he requested cultural services as a youth and my Grandma's role was to prove his Indigenous identity. As demonstrated through my Grandma's discussion, the assumption that Shannon was not related to my Grandma and his siblings connects to the broader discourse of who fits the ideals of what First Nations peoples look like. Shannon struggled with intergenerational trauma, disbelief in his Indigenous identity and was sent to reform school that was a part of "Ontario's training school program -- a long-defunct, 60-year project to house and rehabilitate 'unmanageable' and 'incorrigible children' " (CTV News, 13 Apr 2003). The reform school Shannon was sent to in Bowmanville was called *Pine Ridge Training School* and was a provincially run institution that has been sued for physical, emotional and sexual mistreatment on behalf of youth who were sent there (McCarten, 14 Apr 2003). While at the school, Shannon and other boys became addicted to sniffing solvents. I can only imagine this as a form of escape from being institutionalized, from the abuse they probably faced, along with being far away from their families. My Grandma did her best as a single mother who was dealing with her own traumas. My father used alcohol to cope daily, which

...increases when children are subjected to: non-nurturing and ineffective parental disciplinary practices, absence of family rituals, alcohol-related violence, parental psychiatric problems such as depression, sibling alcohol use, and stressful life events such as verbal, physical, and sexual child abuse perpetrated by a family member (Brave Heart, 2003:9).

For my Grandma, she had lost three sons who were kidnapped and two sons who passed away because of their addictions. My Grandma is a resilient woman whose focus was being a good mother and providing for her children although she had to deal with immeasurable loss.

My Dad still struggles with the loss of his older brother Alan who was hit by a car on the *Don Valley Parkway* in Toronto when he was trying to cross the highway while intoxicated. My Dad and Alan had the same father though they did not know who their biological father was until they were teenagers. I asked my Dad if anyone in the family spoke about Alan's death or dealt with their grief. He responded:

“No. It was something you just keep to yourself. It’s a feeling, not something you really talk about. Everybody feels differently. I was supposed to feel differently because he was my only brother. But I just felt weird because he was just like a brother. Not special or anything. Even back then, I don’t think I felt for Dad or anything because he wasn’t really in our lives. I was too young to realize that he probably felt worse than I do because he lost his son” (Miller-Alcock, 12 Oct 2013).

My Dad’s stories about his relationship with his brothers and their lives ending so young, has helped me to better understand his addiction. With the continuous loss of siblings, no one in the family spoke about their deaths or dealt with their grief, thus they were carrying a burden of sadness that I could not fathom. For my Dad, he is forthcoming that alcohol has been a method of erasure. When I asked how old Alan was when he died, my Dad said, “see, I don’t remember bad things. Maybe twenty-seven at the most. Yeah, just starting to party good. He was becoming a landscaper. Always wanted to be a cook” (Miller-Alcock, 2 Aug 2013). My Dad has used alcohol to escape his reality and to not deal, “...with loss through death of family members, incarceration of family members, forced separation from their children, parents, and siblings (Durst and Bluehardt, 2001:68). Using alcohol as a way to forget the past and to numb grief and loss has continued the cycle to my Dad losing his wife and children because of his inability to be an active parent and husband. Unfortunately, the trauma is passed on to my generation and the vicious cycle of poverty, addictions and not coping with trauma is continued.

Chapter 3 : Recommendations for Health Care Practitioners and Services for Dealing with Alcohol Dementia and Alcohol Neuropathy

3 Colonialism in the Canadian Health Care System

After many months of doctors' appointments, hours of phone calls with social workers, government agencies, Rama Band Council and with the CCAC, the logic of neo-liberal governmentality is apparent within the discourse and interaction with health care providers in that my Dad did not make healthy decisions, therefore it is his fault and he must suffer the consequences. Health care practitioners need to be educated about the historical legacy and effects of colonialism and in order to deal with addiction. My Dad's life history has exemplified how Aboriginal social determinants of health are important to understanding that addiction is complex and that its connection to colonialism manifests itself within health, when someone is facing intergenerational trauma, coping with perpetual loss and the lack of education and employment opportunities. For my Dad, he is now dealing with Alcohol Dementia from the long-term effects of using alcohol as a coping mechanism to forget and erase his past.

I have discussed how colonialism has affected my Grandma's life, which in turn has shaped my Dad's by using Aboriginal social determinants of health as a framework of analysis. Colonialism affects my daily life since I am the caregiver who has to deal with the residual effects of intergenerational trauma, addictions and ongoing colonial health policies. I have to coordinate the different services and determine which are provided by the Rama Band Council or through the Community Care Access Centre (CCAC)¹⁰. Between on- reserve and off-reserve health practitioners and agencies, there is a lack of

¹⁰ The CCAC consists of nurses, social workers, doctors and health care professionals who determine the right care for individual patients through regular at home visits. When someone is no longer able to remain at home and live independently, the CCAC help make the transition for alternative living arrangements (Southwestern CCAC, 15 July 2014, "About CCAC")

continuity. This connects to jurisdictional issues in that, “provincial and federal authorities and Band members need to organize themselves to ensure that services are made accessible” (Durst and Bluehardt, 2001:208). I have been ping-ponged trying to gain information and realized that no services exist especially for informal caregivers like myself. Support services are provided through organizations such as the *Alzheimer’s Society*, but do not offer culturally specific support groups. There is a need for Alcohol Dementia caregiver support groups to provide a safe space to talk about the stigma, the different services needed since each case is unique and maneuvering through the health care system, which is legally and socially difficult since services for this condition, especially for First Nations peoples are non-existent.

3.1 Neo-liberal Governmentality

As the primary caregiver who has become responsible for coordinating all the social and health services since my Dad was diagnosed, health care practitioners have a perspective that self-imposed behavioural constraints are needed instead of providing social services. This is reflective in other research by anthropologists focused on addictions (Bourgois and Schonberg 2009, Bourgois 2000, Moore 2004). Neo-liberalism embodies an ethic of blaming individuals, in contrast to the traditional welfare state mentality.

In classical liberalism, a ‘welfarist’ rationality emphasized State responsibility for the care of citizens, in neo-liberalism, there has evolved a rationality in which citizens are increasingly responsible for the ‘care of the self’. There has been a move to noncollective and low-cost solutions to spiralling welfare budgets, a de-institutionalization of health care, and promotion of more active forms of citizenship (Nettleton and Bunton, 1995) (Moore, 2004, 1548).

My Dad has been repeatedly told that he is responsible for his health and it is his fault that he has Alcohol Dementia and Alcohol Neuropathy exemplifying how the notion of ‘risk’ and its avoidance has become a key technology of social control (Moore, 2004, 1548). There is no discussion or understanding of the effects of colonialism for my Dad, which extends to several generations before him including the social, economic and political context of being an Aboriginal man and dealing with a life long struggle against alcoholism. Doctors, social workers and nurses exhibited the neo-liberal governmentality

through their conversations with my Dad, other family members and myself. When my Dad was admitted to the hospital in August 2013, the doctor stated to my Dad that:

“... you are the only one who can change and you have to be the one who wants to change. We could want you to change and your family can want it for you, but you have to want to change yourself. Unless you want to end up back here with worsening nerve functioning, worsening cognitive function, avoidance of alcohol entirely is the only way to stay on track” (Doctor Smith, 30 Sept, 2013)¹¹.

This statement on behalf of the overseeing doctor describes my Dad as not being successful at avoiding risks for his health and implies that he chose to be an alcoholic. It is frustrating as the caregiver to repeatedly hear health practitioners' blatant disregard for the context of my Dad's Alcohol Dementia and the simplicity of their explanations for recovery. If treatment were as simple as stopping being an alcoholic, my Dad would not be dealing with Alcohol Dementia and Alcohol Neuropathy. Long-term addictions and the health complications as a result are not simple, and with the life history narratives of my family, I hope to show that Alcohol Dementia is complex and to humanize the illness through telling my Dad's stories through his own words and my own narrative.

Our experience dealing with health practitioners has been that they treat Dad as an illness and not a person who has a history that has shaped his present and future as well as the impact on family members. Shifting the blame onto individual First Nations peoples in Canada who are struggling with addictions removes the responsibility from the legacy of colonialism, and ignores the social basis of addictions as a way to cope with trauma, structural violence and racism. The Obstacles Report conducted by the Assembly of First Nations found “...alcohol abuse as the primary cause of physical and mental disabilities. They further identified the causes of many diseases and illnesses to be social, economic, occupational, environmental, nutritional, and spiritual in nature” (Canada, 1981: 132 in Durst and Bluehardt, 2001:40). Neo-liberal governmentality implicit within the Canadian health care system for dealing with Alcohol Dementia connects to the

¹¹ Pseudonym

treatment of addictions, in that a Western objectivist approach is used instead of viewing all elements of the individual's life.

Most importantly, this discourse denigrates my Dad's and our family's suffering for coping with the diagnosis of Alcohol Dementia since health care practitioners view his illness as self-inflicted. Through chastising my Dad for his addiction, instead of trying to understand why he is an alcoholic and how his life history is connected to my Grandma's generation and my own, it's a form of erasing the legitimacy of our suffering and trauma. Health care practitioners who are offering their medical expertise to individuals and families dealing with an illness because of addictions do not see that, "...the erasure has a far more pernicious origin: hiding this suffering, or denying its real origins, serves the interests of the powerful" (Farmer, 2005:17). By not acknowledging structural violence and addictions as a form of coping for First Nations peoples, especially men like my Dad, neo-liberal governmentality within the Canadian health care system sees good health as a binary choice, and imply that it is the individual's responsibility to attain good health. This ideology does not acknowledge external, structural factors such as access to health, poverty and intergenerational trauma, which is exemplified within my family's life histories (Petersen and Wilkinson, 2008:9).

When I visited my Dad after he was admitted to the emergency for a fall and prior to his diagnosis, we discussed the recommendations of the doctors:

Danielle: "So did the doctor recommend that you're not allowed to drink anymore?"

Dad: "They always say that".

Danielle: "Then why don't you listen to them?"

Dad: "No, it never helped last time. Might help this time, pretty painful".

Danielle: "Does the doctor say they can do anything? I'm guessing you just don't want to do it".

Dad: "Nobody's really got into it. Nobody has given me a remedy except not to drink" (Miller-Alcock, 25 Aug 2013).

The simplicity of telling my Dad to stop drinking is an easy equation that sobriety will lead to better health, but lacks the understanding or empathy for my Dad's desire to erase his past and forget his negative memories. Thus, the Canadian health care system absolves itself from its role of inflicting colonial policies that continue to affect generation after generation.

My Dad's honesty about using alcohol as a way to cope on a daily basis exemplifies bio-politics within the health care system for dealing with Alcohol Dementia and other addiction-related long-term illnesses, that his body is not physically and morally worthy. Bio-politics is defined by Michele Foucault as developing in the seventeenth century and is

centred on the body as a machine: its disciplining, the optimization of its capabilities, the extortion of its forces, the parallel increase of its usefulness and its docility, its integration into systems of efficient and economic controls, all this was ensured by the procedures of power that characterized the disciplines: an *anatomo-politics of the human body* (1978:139).

The functioning of the health care system is shifting the responsibility to the individual to regulate their bodies. Repeatedly within countless appointments with doctors, specialists and social workers, the word 'risk' was often used to describe what damage would be done if my Dad continues to drink; the focus was using fear tactics. Using the language of risk entails a negative view of behaviour and passes moral judgment of what bodies are worthy of saving and offering services. This connects to the social interaction of doctors and social workers for the treatment of Alcohol Dementia and using the word 'risk' repetitively to try to place the control on Dad that he is a risk to himself through his behaviour and drinking (Petersen and Wilkinson, 2008:4). When the social worker was discussing controlling Dad's access to alcohol, fear was placed upon his partner who took on the role of caregiver until he was placed in a Long-Term Care Home. The social worker, Sarah¹² stated: "There won't be anybody bringing it [alcohol] in, so it's a controlled environment. Hopefully, he's abstinent for a while. You might see small

¹² Pseudonym

improvements. But if you start drinking, the progression of the illness will be very severe” (Short, 30 Sept 2013). Regulating my Dad’s body as an alcoholic is described as a simple cause and effect relationship, which makes it frustrating that the only recommendations are abstinence or there will be dire consequences. This method within the health care system made my Dad’s life inferior through inscribing his body with meaning that he has the power to alter his health. This inscription upon his body connects to the worth of his body.

The simplistic medical prescription for my Dad to stop drinking inscribes his body as a damaged ‘machine’ that is not possible to fix unless abstinence is maintained, a choice only my Dad can make. With the lack of available services to deal with Alcohol Dementia, I recognize the connection between what health services are offered for individuals who have destroyed their bodies within the neo-liberal governmentality constructs. Bio-power has become a way to segregate and hierarchize bodies that are worthy and those that are not. Alcohol Dementia is treated as a body not worth as much because it is not healthy, therefore there are no support services. There are services in place for addictions and recovery, but these are based on the individual making the choice to take control of their health. My Dad drinking and being aware of the effects of what he has done on his body is a way to cope with being a sick body and to erase the trauma and structural violence he has faced because of his Indigeneity and struggles with his identity (Foucault, 1978:141). As the caregiver, I have realized that few supports are in place for people with addictions who have health complications as a result of their substance abuse. This intersects with racial and social hierarchies that shape how people are supported through their addictions. The health care system in Canada, being founded on neo-liberal governmentality, does not allow a space for helping bodies that have been destroyed. It is focused on bodies that can be fixed. There is no space to look at illness such as Alcohol Dementia wholistically to understand the historical, social, political and economic context of addictions for First Nations peoples in Canada and that destruction to the body is a form of erasure.

My Dad often discusses the damage that has resulted from his alcoholism. No one in my family, including my Dad, is naive about the connection between his alcoholism and his

Dementia and Neuropathy. But my Grandma and Dad do not examine his illness in terms of structural violence because it is a part of their everyday lived experience. Through my critical approach to my Dad's Alcohol Dementia, I have recognized that the logic of neo-liberal governmentality inherent within the health care system does not allow the understanding of the destruction of the self and the resulting health effects since every individual is supposed to make the right choice to have optimal health. But this idea of health perpetuates "the moral responsibility... put on the individual instead of providing services. There is also the discussion of the self perception of being willfully self-destructive instead of being a failure who lacks self control" (Bourgois and Schonberg, 2009:109). When my Dad was hospitalized and diagnosed, his long-term partner Cecilia and my Grandma discussed willful destruction of his body using alcohol:

Grandma: "You got to learn to take care of yourself. Not destroy yourself".

Cecilia: "That darn 'nikwa'(alcohol), the 'nikwa' ".

Grandma: "That's the destroyer"

Cecilia: "All that poison"

Grandma: "Now that you've gotten rid of it, don't go back to it Devon. It hurts me a lot to see you like that. It makes me want to cry. Leave that alone".

Dad: "What's that? The booze?"

Grandma: "It makes me so sad".

Dad: "I never drank that much".

Grandma: "To see you like this is good".

Cecilia: "No the booze is no good. You can't drink everyday for forty years and not have something happen to you. He's got a little bit of brain...his brain is shrunk" (St.

Germaine and Miller, 30 Sept 2013).

There is a perpetual cycle that First Nations peoples suffering with addiction are unable to meet the neo-liberal governmentality ideals in regards to health. Neo-liberal governmentality within the Canadian health care system does not examine the effects of colonialism that shape generations and individual lives as discussed previously using the lens of Aboriginal social determinants of health. My Dad has used alcohol abuse as a way to cope with not meeting social expectations of him such as making healthy choices as many of these choices were denied for him, because of the colonial control of so many aspects of our family's existence.

Inflicting harm upon his body is a form of control over his choices, which are limited. Struggling with his identity and having to prove his Indigeneity along with being an alcoholic is the intersectionality of double marginalization. Being Indigenous and using alcohol to cope with his struggles with identity while not meeting the social expectations of neo-liberal governmentality, promotes a cycle of failure. My Dad has used alcohol to forget while simultaneously intentionally destroying his body. In research focused on Intravenous Drug Users (IDUs) in Australia, Moore connected neo-liberal policies and self-inflicted harm in that when participants were, "...describing the drug related deaths of friends, many were unable to rule out suicide, reporting that the deceased 'didn't have much to live for'. These points raise the possibility that avoiding death, the primary logic driving overdose prevention, is viewed with considerable ambivalence by some street based IDUs" (2004:1554). My Dad has the same ambivalent view towards the damage that he has done to his body. When discussing being placed in the hospital to seek medical help, my Dad responded with, "I'm not going there. I'll start walking up a mountain, when I get to the top, I'll take the short way down" (Miller-Alcock, 25 Aug 2013). My Dad does not view his body as worthy and has made suicidal comments without concern. His whole life has been shaped by believing that he is not worthy, not meeting the social expectations of contributing to society and not being a body worth saving because of his alcoholism. When my Dad was first admitted to the hospital, he told my brother, "I don't have a will to live anymore and I don't care" (Miller-Alcock, 31 Aug 2013). Suicidal comments and ambivalent views towards their bodies as substance abusers shows that addiction is a coping mechanism for colonialism that shapes individual lives through policies that determine education, employment opportunities,

inflicts intergenerational trauma and are discriminatory and paternalistic because they do not allow self-determination within communities.

3.2 Listening to the Patient

The neo-liberal governmentality and Western approach to health for Alcohol Dementia means that health care practitioners do not listen to my Dad's perspective of his illness. Instead of helping him understand his illness, they use medical terminology and do not actively engage in conversation with him. This is an example of the clinical gaze for disease discussed by Foucault, where the focus by the medical experts is on the disease, thus dichotomizing the person from the disease while not examining the person's perspective and experiences (1973: 9). For my Dad, he is somewhat aware that he has dementia and neuropathy that is a result of his alcoholism. For him, he understands his memory loss and inability to walk as poison in his body. When discussing his perpetual feeling of forgetting, he said, "maybe I'm supposed to stay sober and it will heal me rather than make me feel dopey all the time. I just hope the poison isn't going into my bloodstream. Every time I fall I think that the poison is gushing out. It has to go somewhere. My whole body is probably working overtime trying to get rid of poison" (Miller-Alcock, 15 Oct 2013). His experience of losing his balance and falling connects to his belief that there is poison in his body affecting him. Instead of doctors using my Dad's understanding of poison in his body, they dismiss this notion and explain his condition in medical terms. Although my Dad will not fully remember discussions with doctors about his current health status, he should be listened to using his conceptions of his condition to help him understand every time he speaks with a health practitioner. The health care providers we have encountered are,

...guilty of promoting the view of the 'professional expert'. The nature of the expert role such as therapist, counselor or others assumes superiority over the client. Both the professional and the client frequently share this attitude and from it the professional derives power. With specialized knowledge and skills, which the 'expert' professional possesses, the client is maintained in a subordinate and often times powerless position (Durst and Bluehardt, 2001:22).

This removes my Dad's identity and his illness connected to larger social structures and further marginalizes him since his story and experiences are subordinate to the expertise of medical practitioners.

Listening to my Dad's understanding of his illness is an important part of creating trust for us with doctors, nurses and social workers. It is difficult to trust health care practitioners because of the stigma and lack of understanding of the historical impact of colonialism in our lives. Listening to my Dad is also important for removing the subordination of the patient through hearing how he feels about his Alcohol Dementia and Alcohol Neuropathy. Most importantly, interacting with him without the medical jargon and speaking to him instead of his family members present at appointments is key to treating him as a person and understanding that he is not defined by his illness as an Indigenous person with a history of oppression, racism and addiction. The majority of health practitioners

... "tend to view conditions as isolated problems and see the individual as being deficient or unable to fit into predetermined categories (RCAP, 1996, Vol. IV: 554). This lack of a holistic approach and appreciation of the special cultural perspectives creates a serious barrier for Aboriginal persons" (BC Society, 1993: 28; Canada, 1987: 5; NAND, 1994: 2-3 in Durst and Bluehardt, 2001:54).

A barrier because of a lack of trust has been created through the way that doctors and health care service providers do not communicate with my Dad combined with their clinical gaze. If doctors, nurses and social workers are not willing to see my Dad wholistically, then they are unable to grasp the understanding that his alcoholism, which caused his dementia and neuropathy, is not simply cause and effect. It is a complex illness shaped by specific Aboriginal social determinants of health and the use of alcohol as a coping mechanism and a form of erasure.

3.3 Educating the Educated

Throughout the inception of my Dad's admission to the hospital to the current situation of navigating the bureaucratic process of paper work to apply for financial and social supports, a key failing within the Canadian health care system for dealing with Alcohol

Dementia and substance abuse for First Nations peoples is educating health care practitioners about the impact of colonialism. With doctors and nurses just focusing on the illness and the medical requirements of maintaining sobriety to avoid the risk of further damage to his body, they are not aware of the impact of Aboriginal social determinants of health within my Dad's life. When explaining his diagnosis and his long-term health expectations, there is judgment attached to the doctor-patient interaction. When accompanying my Dad to an appointment with a neurological specialist, the doctor's body language consisted of no eye contact, not explaining his procedures and test requirements in laymen's terms, repeatedly using risk words and reiterated several times that this is what happens when you drink your entire life. Negative treatment on behalf of doctors because of their moralistic belief that my Dad's Alcohol Dementia and Alcohol Neuropathy stem from choices he made to be an alcoholic once again works from a neo-liberal governmentality framework based on 'rationale choice'. But the concept of choice "...suggests full knowledge of options and unlimited alternatives and denies the constraints posed by time, unequal access to resources and differences in individual's backgrounds, propensities and abilities" (Petersen and Wilkinson, 2008:9). Not having choice has been a part of my Grandma's life and my Dad's life, which has affected his overall health and well-being. Choice is an option for those who do not face systemic racism because of their Indigeneity. Using addictions is a way to deal with the stark lack of options faced by colonized peoples.

My recommendation to combat the lack of understanding of health care practitioners providing services to individuals and family members faced with a diagnosis of Alcohol Dementia is to provide education about Aboriginal social determinants of health and the colonial history of the Nation they are serving. The doctors we dealt with did not have any empathy for our family, which occurs because, "physicians enter cross-cultural situations with little or no preparation and bringing their own values which often differ from the values prevalent in the communities they serve" (Kelly and Brown, 2005:1646). Within my experience with doctors, they do not understand that my Dad's addiction is connected to a historical legacy of suffering, loss and the intentional erasure of identity and memories. If Aboriginal social determinants of health are a part of the curriculum for physicians, illnesses and diseases experienced by First Nations peoples in Canada

including Alcohol Dementia can, "...move away from genetic or biomedical inquiries and instead examine why some people and communities are more prone to health deficits, or suffer more severely from their outcomes, as a function of their social contexts" (de Leeuw et al., 2009:285). My Dad's Alcohol Dementia needs to be contextualized to understand his addiction and his current health state. The Western epistemology of examining health only in biological terms does not grasp the wholism of the lives of First Nations patients. If doctors were educated about the massive discrepancies of health for First Nations communities compared to their Canadian counterparts, they would have an understanding that illness is connected to macro social structures that shape everyday experiences.

It may seem insurmountable to combat the health disparities for First Nations peoples in Canada, but educating health care practitioners can be a start. Providing cultural training and historical education as a part of the medical school curriculum can allow health care practitioners to have better communication and bedside manner when offering medical services to First Nations peoples, especially for those experiencing health effects connected to addictions. The effects of colonialism within my Dad's life could be better understood if they were willing to discuss the "multigenerational trauma experienced by a client's family and nation. The assessment should explore the meaning of boarding schools, massacres, loss of land, and similar phenomena in relation to contemporary social and health problems" (Weaver and Brave Heart, 1999:29). An important critique emerging from within my interactions with doctors as the daughter and caregiver is about their body language. Many doctors had unwelcoming body language and did not make eye contact. They also did not take the time to listen to my Dad's understanding of his condition or to explain the medical terms in a way that was easy for my Dad to process. If doctors are going to be providing services in a community that has an Aboriginal population, they should be introduced to their practice with an education about the people that they will be offering services to. I know educating doctors is a short-term solution because of larger flaws within the health care system for providing services for First Nations individuals and communities.

3.4 Lack of Trust

Not trusting the health care practitioners was an issue that was apparent within our interactions. I developed a lack of trust in doctors, social workers and nurses because of the moral judgment that was attached to the care that was provided for my Dad. I am not stating that all the health care workers that provided care to my Dad were judgmental, but most were forthright through inserting their moral assessment of the situation. This created a lack of trust for me as the caregiver and the person responsible for coordinating the different services. I could not trust that they were offering the best services if they were judging our lives without knowing the social context of the struggles our family has faced as Indigenous peoples in Canada. This mistrust for the Canadian health care system and the individuals who work within it results from a legacy of colonialism and the bitterness of Aboriginal patients towards the Canadian government and people who are not a part of the community who are considered outsiders (Thibodeau and Peigan, 2007: 51). First Nations peoples have been test subjects for health studies such as the recent publications about children who attended residential school who were used to test the effectiveness of vitamin supplements (CBC, 30 July 2013). There is mistrust for government-run initiatives and health programs because of the ongoing negative treatment of First Nations peoples. These health programs also work from a Western framework, do not incorporate Indigenous approaches to health that are a part of the community being served, or recognize the diversity within urban centres. Within my family, distrust for government institutions stems back generations and is prominent within my Grandma's life and continues into my own.

When the decision was made not to have several Personal Support Workers (PSW's) in the home my Dad shared with his partner, it was met with opposition and a lack of understanding on behalf of the health care practitioners. Instead of trying to contextualize the reasoning for this decision, the assigned social workers stated, "there will be somebody coming in one hour at night and that's it at your decision making. We could have had more, but you decided you wanted less people in the home. I thought we should have gone with more services than that in the afternoon and the evening" (Short, 30 Sept 2013). Our family at this point had experienced racism and judgment on behalf of the

health care workers we dealt with and the decision was made to have less assistance in the home and that the responsibility for care would be taken on by Cecilia. This decision was made because of the judgment we felt would be perpetuated with having additional caregivers in the home. The decision was made to only have care for an hour in the morning and evening from a PSW that was provided by the *Rama Health Care Centre*. Through having a member of the community come into the home to provide assistance for my Dad's daily activities, it made it more comfortable for him and Cecilia since it was individuals that they were familiar with or knew well.

3.5 Self- Determination of Health Care Services in First Nations Communities

This lack of trust has larger implications of the discrepancies of health care for First Nations communities connected to a lack of self-determination. Research focused on dementia treatment and care services for First Nations communities found that there is,

a lack of basic dementia care resources... apparent in the reserve community: physician services, respite care, crisis support, emergency services, long-term care, visiting nursing services, and medical transportation were all limited or absent. In both the city and reserve locations, participants noted that First Nations community health services lacked personnel, resulting in extremely heavy workloads and participants having little time for anything other than crisis management (Finkelstein et al., 2012:260).

There is already a lack of resources and services to deal with dementia, and nothing exists for Alcohol Dementia, which is complicated further because of dealing with the addictions aspect of the illness and the double marginalization because of Indigeneity and disabilities. When trying to access health services on the reserve, they were able to provide wheelchair rentals and PSW's, but we were unable to place my Dad in the Long-Term Care Home on the reserve where my Grandma resides. They were unable to admit him to the Long-Term Care Home because they do not have adequate services to deal with his mobility issues and controlling his behaviour to insure that he has no access to alcohol. This is an example of a lack of self- determination on reserves, including my community because,

the right of Bands and Tribal Councils supercedes the rights of the person with disabilities. In other words, if the Band Council elects to deny a service or a program, there is little the consumer can do about it. Hence, the potential for further marginalization exists even within the umbrella of 'self-government' (Durst and Bluehardt, 2001:28).

Since it was decided on behalf of the Rama Health Care Centre administrators that they would not accept my Dad to the Long-Term Care Home, our only avenue for recourse was to apply to Band Council in hopes of reversing the decision. This is further complicated since no funding can be provided by Band Council to accommodate the costs of the Long-Term Care Home in Rama. Therefore, our family was responsible for the living costs, which were more than one thousand dollars per month. Myself as a graduate student, Cecilia and my brother not having the income to pay for my Dad to live in the Long-Term Care Home in Rama, meant that we had to look outside of the community.

This reinforced the lack of self determination on reserves; since there are not adequate services for my Dad to remain in Rama, we had to make the decision to work with the provincially funded organization of the *Simcoe-Muskoka Community Care Access Centre* to apply for Long-Term Care Homes off the reserve. Using the framework of Aboriginal social determinants of health has allowed my analysis, using my family's narratives, to understand the importance of health and its connection to broader social frameworks. The framework also allows me to discuss addictions that cause Alcohol Dementia and its health implications not solely as a personal choice, but connected to colonial health policies and programs that do not allow self-determination for First Nations communities. An example of colonial policies affecting access to health was in regards to putting in a wheelchair ramp at home for my Dad as a safety precaution if there was an emergency. Cecilia applied for financial assistance from Rama Band Council but was denied because she is the homeowner, not my Dad, therefore they could not legally provide funding because of home owner regulations within the *Indian Act*. This is an example of the everyday impact of colonization that there are restrictions on reserves depending on ownership of the home and how funds are allocated. Since no one in the family could afford to pay for a ramp, we could not put one in. This is a risk to my Dad's personal safety since he would be unable to get out of the home quickly on his own if there was an

emergency.

3.6 Continuity of Care

While my Dad was hospitalized and diagnosed, we were told that he would be eligible for the *Wait at Home* program where care would be provided eight hours per day for a total of fifty-six hours per week. The only reason we chose to discharge my Dad to return home was because we were told he was eligible for this program. We found out that this was not possible because PSW's would have to be provided by Rama and there were not enough PSW's available to provide necessary full-time care. The Rama Health Care Centre was able to provide care two hours per day. This is an example of the discrepancies between the reserves and the funding provided by the Canadian government. The responsibility is placed on the First Nation community to provide services, but they do not have enough funding to provide care especially for Alcohol Dementia, which is complicated by the intersectionality of mental, physical and addiction of the illness. There was perpetual confusion in regards to what services were provided by the Rama Health Care Centre or by the CCAC.

There was no communication between the different health care providers and as the informal caregiver, I had to liaise the different appointments and services, which were time consuming and aggravating since receiving answers were impossible. Coordinating on reserve and off reserve, "administration of health care in a First Nations context is complex, as users and providers must navigate 'mainstream' provincially operated primary-care, physician, specialist, and hospital services as well as federally funded Aboriginal health programs, including access to non-insured health benefits" (Finkelstein et al., 2012:258). Navigating the different health care services, the CCAC does not communicate with the Health Care Centre on reserve, so finding what services may or may not exist is time consuming and often results in an inadequate patchwork is stressful for caregivers like myself, simultaneously dealing with the illness while trying to search for services. To combat the increased stress placed on the caregiver to coordinate services, the assigned CCAC case worker should contact health services on reserve in order to organize what options are offered on reserve and which are not for assistant

devices and additional care with PSW's. Although no services exist to specifically deal with Alcohol Dementia, coordinating between health care providers should occur to support communication and collaboration, in order to provide continuity of care.

3.7 Illness in the Wrong Life Cycle

With no financial assistance available through the Rama Band Council, we attempted to find funding available through the Government of Canada, and were faced with no options, since Alcohol Dementia occurs in the wrong life cycle. As dementia is not usually a health concern until people are over the age of sixty-five, there is no financial assistance. Since my Dad has lived in poverty his entire life and is unable to work, there are no monetary supports. The issue of poverty connected to health is a prominent Aboriginal social determinant of health considering that, "ninety per cent (90%) of all First Nations people with disabilities living on reserve have income levels below the poverty line" (Durst and Bluehardt, 2001:18). In order to apply for financial support, I was directed by the social worker to call Social Services to look into *Ontario Works (OW)*¹³ for funding. I was told that my Dad would not be eligible since he resides with his partner and they look into her finances. He was also not eligible for the *Ontario Disability Support Program (ODSP)*¹⁴ because you have to be eligible for *Ontario Works (OW)* first before you can apply. Looking into other funding options, I found out that my Dad is also not eligible for *Old Age* pension because he is under sixty-five years of age and since he hasn't worked, there would not be *Ontario Pension Plan (OPP)* funding. Nothing exists to provide financial support until my Dad is moved to a Long-Term Care Home. Financial support was needed to deal with my Dad's diagnosis in that he requires walking supports like a wheelchair and walker as well as making the home environment safer and to provide independence. The financial burden was overwhelming because the responsibility was placed on his caregivers who do not have disposable income. Since

¹³ Ontario Works provides temporary financial need by providing money and help finding employment (Ministry of Community and Social Services, "About Ontario Works", 3 Feb 2014)

¹⁴ "The Ontario Disability Support Program helps people with disabilities who are in financial need pay for living expenses, like food and housing" (Ibid, "Ontario Disability Support Program", 3 Feb 2014)

Alcohol Dementia occurs before he is legally a senior and my Dad did not fit the neo-liberal governmentality of being a contributing body, there are no financial services available.

With a diagnosis of Alcohol Dementia, it is further complicated because it is often accompanied by physical disabilities. There is no funding to offer support services to help our family deal with the combination of mental and physical disability. Even though alcohol is the cause of many illnesses and disabilities experienced by First Nations peoples, there is no funding to support those who are suffering from the double disability. This is an example of complex marginalization. The funding eligibility for disabilities provided by the Government of Canada has requirements that cannot be met by my Dad. He does not receive funding since he has not worked in several years because of his addictions and inability to walk long distances. Access to health care services is a treaty right and “First Nations are unique in their relationship with the Canadian government with respect to provisions made under the Indian Act of 1876, which included health care. The contemporary outcome of the colonial process can be seen in political, social and economic domains” (Loppie Reading and Wien, 2009:2). First Nations peoples in Canada rely on the government to provide the funding and resources for healthcare, but services are generally inadequate, and do not exist for Alcohol Dementia. First Nations peoples face discrimination, racism, less access to social, education and employment opportunities. The intersecting complexities of Alcohol Dementia have allowed me to recognize that illnesses from addiction are not a priority in the Canadian health care system. Therefore no care is provided.

3.8 Non-Existent Services

In trying to find services that could provide assistance for the complexity of Alcohol Dementia for my Dad, I realized that nothing exists. Since there is no research on Alcohol Dementia, specifically focused on First Nations communities, no one can provide insight to the longevity or quality of life to expect for my Dad. Dementia is studied extensively, but a focus on First Nations communities is limited although, “Aboriginal seniors (55 and older) constitute the most rapidly growing demographic

group in Canada” (Lanting et al, 2011:104). There are no support services for my Dad to deal with the addiction aspect of his dementia. The most important aspect of Alcohol Dementia is behavioural modification; my Dad cannot have access to alcohol in order to maintain his sobriety for better health. When trying to find out if there were support or counseling services to help my Dad to understand and cope with his addictions, we were told that he no longer has the mental capacity to have insight and understanding through counseling or services provided by organizations such as *Alcoholics Anonymous*. This places all the responsibility on the caregivers to control his access to alcohol; therefore I contacted local alcohol delivery services and strict rules were put in place at home that no alcohol was permitted. Since screening for Alcohol Dementia is difficult because sobriety is required for several weeks in order to diagnose (Australian Alzheimer’s Society, 2012) it was impossible to intervene earlier without my Dad’s consent. Alcohol Dementia and its health effects is an illness that requires services to deal with the aftermath once a diagnosis is provided, which can usually only occur after an emergency admittance to a hospital. Nothing exists to deal with this complex illness, so we decided to admit my Dad to a Long-Term Care Home. This way he could have full time supervision, as he no longer has short-term memory and needs assistance with daily activities.

For Alcohol Dementia, there are no existing services because it does not fit the requirements of public outreach health programs. This connects to research conducted by Bourgois and Schongberg (2009) and Moore (2004) who examined the ‘logic of governmentality’ inherent within public health outreach programs for Intravenous Drug Users (IDU’s). Services that they provide to drug users shame them more than they aid since, “medical social services predicated on ‘empowering individuals’ to make ‘informed choices’ misrecognize the power relations that...shape subjectivities” (Bourgois and Schonberg, 2009:107). Since my Dad is an alcoholic, he does not fit the moralistic regulations of public outreach services that are offered for substance abuse such as rehabilitation clinics and counseling. Services are based on treating individuals who fit the ideals of neo-liberal governmentality, capable of making the right decisions for health if they just had the resources and knowledge. This rationale is predicated on standards that do not align with the realities of the individual’s lives, including my Dad’s. Since he has never made the ‘right’ health choices, the judgment extends to the lack of

options available, as services are only for those who are making the choice to no longer be substance abusers. This removes the complexity of my Dad's life and his choices for using alcohol. Services are created under the premise that individuals have a choice and it is their prerogative to choose better health. Since my Dad has failed at maintaining his health, no services exist. This presents a larger issue in that services are not offered if you have an addiction and do not start where the individual is in their life. Instead, it is founded on fitting the moulds of being in recovery before services are provided, an unrealistic option for most people struggling with addictions.

3.9 Bureaucratic Processes and Systemic Flaws

The bureaucratic process of applying for Long-Term Care Homes presented the flaws that exist with the process of application and acceptance. Since our family could not financially afford to keep my Dad within his community in Rama, we applied for Long-Term Care Homes located in the Orillia area in order to keep him close to family. The wait list for Orillia was up to three years, which is common because “thousands of people are on waiting lists for long-term care homes. As a result, people requiring long-term care (LTC) are confronted with a variety of ‘policies’ and ‘programs’ developed to ‘deal’ with these issues despite the legislation governing placement” (Meadus, 2013:1). One of the policies of applying for Long Term Care Homes is having a substitute decision maker for my Dad. The substitute decision maker is required in Ontario through the *Health Care Consent Act* when someone is deemed mentally incapable (Southwest Community Care Access Centre, 2013). My Dad was still making his own decisions, but I became the substitute decision maker, which is based on a kin-ranking process. Therefore, I had to obtain the consent of my Dad and the removal of decision-making power from Cecilia and my sibling to be the sole decision maker.

When trying to access counseling to deal with my Dad's diagnosis, I was fortunate to find services by an Aboriginal health organization offered in London. Through counseling, I am able to receive guidance and a safe space to talk to a counselor who has professional experience dealing with Alcohol Dementia. In order to try to stop the trauma from affecting me negatively, I am accessing services that work from a wholistic, Indigenous approach to dealing with my emotions and coping as a primary caregiver. The benefits of

receiving counseling from an Indigenous approach is that Alcohol Dementia like addiction and mental health is,

understood in a complex, nuanced, and big picture way: not as an occurrence that ‘just happened’ or as a tragedy contained within a specific space or time....[T]he broader social structures within which all co-exist, must be understood as historically informed, as socially produced, and as linked to broad conditions of health and wellness, including mental health and addictions realities, in Indigenous communities, particularly First Nations, in Canada. Indeed, as Indigenous peoples around the world have always argued, the treatment and rearing of children, and the way all aspects of childhood are understood and constructed, impact generations to come (de Leeuw et al., 2009:283)

My father not being an active part of my life because he used alcohol to cope with his own trauma has constructed my life history and now affects me while trying to process my role as a caregiver for a parent at an age where this responsibility is rare. I am trying to understand my Dad’s life-long addiction and have gained a more empathetic perspective after hearing my Grandma and Dad’s life histories. But the complexity of not only dementia, but my Dad’s and my own Indigeneity, and his alcoholism brings stigma and shame and I do not have anyone to share my emotions and turmoil about these life altering changes.

Throughout my experiences, I have recognized that caregivers for family members with long-term illnesses are gendered. Consistently within research that has focused on those who become the permanent caregivers for family members diagnosed with long-term illness, women take on the responsibility (Aldous, 1990:44). This is present with my Dad’s diagnosis that Cecilia brought him home to provide care and I am the caregiver once he is relocated to London. The gendered role of caregivers has been examined and,

there is a substantive body of literature that raises concerns over the exploitation of women[s] – unpaid labor. Aboriginal persons often prefer to utilize friends and the extended family for both personal (e.g. hygiene) and non-personal (e.g. transportation) services rather than turning to the Third Sector or the Private Sector ‘industries’ (Durst and Bluehardt, 2001:31).

My Dad has refused care from third party individuals including Personal Support Workers and relied on his long-term partner to aid with personal care and I provided non-

personal care by taking him to his appointments and being present at meetings with his CCAC caseworker. The issue of unpaid labour connects to broader issues in that the lack of funding to aid families and individuals diagnosed with Alcohol Dementia means that the family is responsible for care. Providing care for my Dad is time-consuming, financially straining and takes a toll mentally and physically. Since our family is already marginalized, have low incomes connected to the legacy of colonialism and lack of self-determination on reserves for health care services, the women in my Dad's life have taken on the responsibility of his full time care.

This level of responsibility and emotional stress creates a high risk of the female caregivers becoming a 'hidden patient'. As the primary caregiver for my Dad with no emotional or practical supports for Alcohol Dementia, I have developed covert and overt forms of illness (Medalie, 1994:164). The stress associated with trying to organize different services, planning for my Dad's short term and long-term health and dealing with my own turmoil with the diagnosis, my health has been affected. Accessing cultural services through counseling has aided with the turmoil and I am using traditional healing in order to deal with my emotions towards my Dad for being an absent parent and for becoming his caregiver. Traditional healing will also be a way to approach my health wholistically and to have a safe space to discuss the effects of Alcohol Dementia within my life history.

3.10 Family Support

With my Dad's diagnosis last year, it clearly outlined the struggles with addiction that exist within our family. Family support is lacking because the illness is a result of alcoholism; family members who struggle with their own addictions no longer know how to relate to my Dad, since the basis of their social interaction was drinking together. With the strict requirement that no access to alcohol is permitted within the home, family members have not come to visit or offer support because they have to be sober. Alcohol and drug abuse are coping mechanisms across several generations of my family and for other First Nations families, as a form of dealing with cultural and identity loss and the transmission of historical trauma.

Another element of the effects on the family is that a diagnosis of Alcohol Dementia comes with emotional turmoil of loss and anger. Some of my Dad's siblings are angry with him for the extensive damage he has done to himself as a result of his alcoholism. Perpetual loss is a part of the everyday experiences of First Nations families. Within my family, support has been lacking because his siblings cannot cope with another loss because of addictions. Research by Lanting et al. examined aging and dementia for Aboriginal elders who discussed the lack of family support because "changes in family dynamics and loss of filial responsibility, related to the 'big change in culture', have disrupted this practice" (2011:114). Family and community do not work together to support and provide care for someone who is ill or aging because of the multiple effects of colonialism. Thus, the cycle of trauma is continued and addiction is used a way to cope especially since it is difficult for my family to witness my Dad's health decline.

The lack of family support conflated by the lack of existing services to provide support for the individual diagnosed and family members contributes to the conspiracy of silence and stigma attached to addictions. As discussed in research focused on doctors who offered medical services to First Nations communities, "topics difficult to discuss and sometimes steeped in stereotyping were abuse, addiction, anger, sexuality, abortion, and end-of-life directives: Alcohol abuse was a difficult area because it's part of the stereotypic view that we have of Native patients, and they know it" (Kelly and Brown, 2002:1649). The stigma attached to illness because of addictions within First Nations communities means that it is not openly discussed. As the primary caregiver, it is difficult to talk about my Dad's illness because of the moral judgment and fear of perpetuating a stereotype. But I have realized the importance of my research because addictions and the long-term illnesses that can result are not examined from the everyday lived experiences of those who are affected. Discussing my Dad's Alcohol Dementia is also important because there are no existing resources for caregivers like myself that include an analysis of the implications of colonization connected to health across several generations.

Although it is emotionally and socially difficult to examine my Dad's illness as my research focus, I know that it is better to discuss it than to continue the silence of

suffering, especially since “medical technology is effective in curing many acute biological pathologies, but it is not designed to address the social structural problems that wreak havoc on the bodies of poor people” (Bourgois and Schonberg, 2009:304). The stigma attached to not only my Dad being a First Nations man diagnosed with a chronic illness because of addictions, but there is also stigma attached to his disability and dementia. The complexity of multiple stigmas is the recognition that “stigma is a branding, a way that society marks us for transgressing the bounds of what is considered normal” (Grinker, 2007:69). The stigma of this illness because my Dad does not fit the social expectations of society to take good care of himself, to work to contribute to society and to be a good parent and spouse, has allowed me to critically understand my Dad’s use of alcohol as a form of erasure and to manage his suffering on a daily basis. When stigma exists in connection to social and medical expectations, it highlights the flaws within the health care system, recognizing that, “...the health disparities realized by Indigenous peoples in almost all sectors of life as compared with their non-Indigenous counterparts, stem from or are related to colonial disruptions and ongoing erosion of human rights” (de Leeuw et al., 2009:285). Stigma is connected to colonialism in that the silence connected to addictions for First Nations peoples including my own family is that the shame and self-deprecation we feel is our fault for not meeting the moral regulations for health. The shaming treatment from health care providers is an example of this erosion of the human right to dignity. Alcohol Dementia is an example of the everyday lived experiences of First Nations families and individuals who are faced with the complexities of illness because of addiction. Addictions have been a part of several generations of my family and the stigma attached to it leads to no one discussing its impact on them, how it is used to cope for each generation and how it is nested in the colonized experiences.

Chapter 4 : Conclusion

4 Bearing Witness

Writing about the life histories of three generations of my family and discussing the difficulties and lack of services that are available for Alcohol Dementia is difficult, but important because I am bearing witness and writing for those whose lives are never examined. Since there is no existing literature focused on Alcohol Dementia, I can share my experiences for others, especially other First Nations families and female caregivers who may be experiencing the same frustrations with navigating the Canadian health care system. It is important to tell my story, thus the life histories of my Dad and Grandma because our lives show the continuity of colonialism and how it passes onto the next generation.

I am optimistic that through my research coming from a place of hope, trying to present Alcohol Dementia holistically and connected to the historical trauma of colonialism, I can discuss the critiques and recommendations for the health care systems on and off reserve to examine bigger picture implications. These bigger picture connections of illness for First Nations peoples in Canada are exemplified through Aboriginal social determinants of health such as self-determination, access to care and marginalization that is an effect of the intersectionality of my Dad's Indigeneity, disability and his lifelong struggle with addictions. Through offering a critique and using my research pragmatically, I want to enact change, even if it is small, through providing resources to others experiencing the same situation and eventually creating a support group for other First Nations caregivers looking after loved ones diagnosed with Alcohol Dementia or other long-term illnesses caused by addictions. The importance of this small act is to provide a safe place to discuss the impact of colonialism, the stigma and everyday struggles of being a caregiver because support and understanding are important to ensure that the caregivers do not become 'hidden patients'.

4.1 Urban Migration to Access Health Care Services

Since funding for services make it impossible for my Dad to remain in Rama, I have made the decision to relocate him to London so I can be closer as the primary care giver. My Dad wanted to remain close to Rama, so we explored the maximum amount of choices located in Orillia to respect his wishes. Although the waiting list for Orillia Long-Term Care Homes was up to three years, we were willing to wait for a placement to keep my Dad close to Rama, his long-term partner and family. The decision to relocate my Dad occurred after he left his home unattended on his partner's motorized scooter and could not be found. Leaving the home unattended can be dangerous for an individual with dementia since they may not be able to return home safely on their own. With this incident, my Dad was relabeled a high-risk case and we were able to have a re-assessment of his mental cognition and overall health status. The label 'high risk' is a part of the assessment process with CCAC that is problematic in that risk situations such as a harmful fall or wandering has to occur before it can be assigned. With a high risk labeling, it makes the case a priority and a placement is made as soon as a bed becomes available in a Long-Term Care Home. My Dad was not considered a high risk case prior to leaving the home unattended although he only had additional care two hours per day, falling was dangerous since he did not have proper equipment in the home for moving around freely and was predominantly unsupervised. After the re-assessment by a CCAC risk case manager, my Dad was deemed cognitively unfit to make decisions, and I became his legal power of attorney to make his financial and health decisions. With his consent, we began the process of relocating him to London since there is a shorter wait list and greater social supports for First Nations peoples in an urban setting.

This is a decision often made by First Nations peoples to leave their communities and families in order to access resources when diagnosed with long-term illnesses or disabilities. The impact of urban migration further alienates them from their community, their connection to the land, their language and culture. This reflects my Grandma's experience of relocation to access employment opportunities. Most importantly, it shows that treaty rights for health are not being upheld because of policies that do not allow self-determination exemplified through, "the lack of coordination among government

departments with different responsibilities for different groups results in no one department having a specific focus. The result is fragmentation, inconsistency in service, and ‘buck passing’ – ‘sorry, that is not my department’ attitude” (Canada, 1993:13,15 in Durst and Bluehardt, 2001:56). When trying to coordinate the mainstream services offered through the CCAC and on-reserve through the Rama Health Care Centre, there was constant confusion for who offered services for Personal Support Workers and assisted walking devices as well as where to apply for additional services. This lack of inconsistency represents a bigger issue of the lack of self-determination on reserves. Health care funding is not enough to provide adequate services to deal with addiction and disability related illnesses and individual families are forced to rely on mainstream services that lack the social and cultural understanding of care and continuity of care is impossible to achieve.

Relocating my Dad to a Long-Term Care Home in London is a relief for my family and I because we know that his physical, social and mental well-being are taken care of. He now has full time nurses and doctors, a building that is accessible and social activities to keep him engaged in the community. Since London has several agencies that offer services specifically for First Nations peoples, my Dad and I are both taking part in traditional healing in order to approach our health holistically. The agency we are receiving traditional healing with does not restrict my Dad from access to services because of short term memory deficiency since the approach is not focused on the medical determinations of aging and health (Pace, 2013:4). They are focused on healing him spiritually and culturally. My Dad and I have unique experiences of being Anishanabe (Hendrix and Swift Cloud-Lebeau, 2006:155) and can receive healing to deal with each of our own traumas. Engaging in traditional healing as well will aid with my overwhelming role as the sole primary caregiver for my Dad since I am the only family member residing in London.

Since there are no support services for caregivers of loved ones diagnosed with Alcohol Dementia, it is frustrating to apply for financial aid. My Dad was ineligible for government assistance since he resided with his long-term partner in Rama. Now that he is relocated and no longer in a common-law relationship, he is eligible for the *Ontario*

Disability Support Program (ODSP). Unfortunately, *ODSP* is founded on neo-liberal governmentality and mistrusting of those who apply, thus the burden of proof is placed on the individual to provide documentation of their disability and lack of financial resources. Even after forced migration to a city, my Dad faces further marginalization that we have to prove his inability to work and subject him to more testing and doctors appointments in order to have the paper trail required to receive funding assistance. A critique of the process of applying for *ODSP* is that funding will not be released until approval is granted which can take upwards of six months, as it requires an invasive and extensive assessment. This process is not practical for family members who have to relocate their family members who cannot live independently. Families like my own do not have the income to afford relocating their loved ones and have to wait months for funding assistance. This puts financial stress on the family. We had to relocate my Dad because our family does not have the finances to provide private in home care or placement in the Long-Term Care Home available in Rama. Therefore, relocation was the only viable option in order to provide my Dad with the full time care he required. A recommendation I have for *ODSP* is that an application should be started earlier based on the income of the individual moving into a home if their family or partners do not have the ability to financially offer support. This way, the application can be put on hold until the loved one is relocated and the family will not have the additional stress of finances.

4.2 Repetition of Colonial Experiences

Although my research focused on Alcohol Dementia using the lens of Aboriginal social determinants of health, there are similarities of experiences that I have documented within my own family that connect to Aboriginal peoples experiences with health care in Canada more generally. Phase two research conducted by the *First Nations Regional Health Survey* as "...the only First Nations-governed, national health survey in Canada" (FNRHS, 2013) found that "similar to the trends seen in RHS Phase 1, the proportion of those who perceived their level of health care access to be 'less' compared to the general Canadian population tends to increase as self-rated health decreases" (FNIGC, 2013). My recommendations to inform improvements in health care services and treatment for Alcohol Dementia are applicable to general improvements in health services provided to

Indigenous peoples in Canada. Within my research and connected to Aboriginal peoples and healthcare more broadly, the repetition of experiences of colonialism are reflected in urban migration. Within my family, all three generations have migrated to urban areas in order to access health services, support services, employment and so on. Trying to discern what services were provided on and off the reserve for my Dad and myself and the inter-jurisdictional wrangling between federal and provincial health care services are common for most First Nations peoples and poses a significant barrier to continuity of care. My experiences of trying to access services for Alcohol Dementia demonstrate the lack of adequate funding for on reserve services that are further constricted by policies of the *Indian Act* that is broadly relevant to the experiences of First Nations communities and the individuals and families whose healthcare needs are not being met.

My research connected to activism with the creation of an online resource for other caregivers, is also a form of knowledge brokerage. Using the evidence from my research to inform others is an important aspect of knowledge translation since I use my family's experiences across three generations of Indigenous men and women. Our experiences represent certain universal experiences of Indigenous peoples in Canada and I want to contribute to critiquing policies and practices that need to be improved through understanding the Indigenous contexts of health.

4.3 Positive Social Connections

My experiences coordinating the on reserve and off reserve services was tolerable because of the positive relationships that developed with certain health practitioners. The CCAC caseworker assigned to my Dad had a background in addictions and tried to find appropriate services to deal with the physical and behavioural issues. Although no services existed, she ensured that there were Personal Support Workers in place and kept in contact with me on a daily basis. Although she was unable to find services for Alcohol Dementia, communicating with me often and providing information about potential avenues for finding care eased the anxiety and stress of the situation because there was support. Frequent conversations to keep me updated on the services that were being provided for my Dad created trust between the caseworker and myself, because she

understood the complexity of the situation. Developing a relationship of trust was rare throughout our experiences dealing with health practitioners and social workers. The judgment and neo-liberal governmentality that we faced made my Dad and I mistrusting of the service providers we encountered. We did not have faith in them to provide the best care since they did not make my Dad and I feel like priorities and I had to make many attempts to get in contact. I can understand why caregivers do not feel supported, but it is related to a context of underfunding where both social workers and caseworkers, off reserve and especially on reserve being, "...overworked due to a lack of funding, services, and personnel" (Finkelstein et al., 2012:268). The lack of funding for caseworkers and health practitioners on reserve result in heavy case loads and the inability to offer exceptional services, continuity and communication.

4.4 "Write My Story Before I Forget"

Telling some of the stories that my Grandma and Dad have shared with me along with my own has forced the realization that our lived experiences show that colonization has never ended. Within our stories are examples of structural violence for each of us. Across three generations, "these large patterns, have just been repeating themselves. We haven't gotten any smarter, we haven't learned anything. What happened in the 1800's and the 1950's we're repeating today, this very day with the Harper government and the any pieces of legislation that they've brought out. So we haven't learned anything" (King, 2013:268). What I want the reader to take away from my thesis is that our stories tell the experiences of the connection between the macro and micro, how our lives, memories, interactions and remembrances are all part of the permeating impacts of colonialism. Kirmayer et al. discusses retelling traumatic stories and that they not only show inequities, but structural forms of violence and oppression (2009:458). My Grandma has been affected the most throughout her life and has showed strength, courage and determination as an Anishanabe woman and mother. It is through the resiliency in her stories that she has helped me to continue with my research focused on my Dad and that telling our stories is important and needs to be shared, to remove the shame and silence of our suffering.

4.5 Public Grieving

Telling the stories of my Grandma, my Dad and I are important to share because they are the stories that never make it into the history books, the public discourse or are considered when policies are being created that will affect us. The shame associated with my Dad's illness because of his lifelong addictions has been a part of my thesis that I have battled with, whether or not I should discuss it and share aspects of our private lives. After critically analyzing the perpetuation of silence connected to being Indigenous and intersecting with addictions, I now see the importance of shattering this silence by telling our stories. Stories about trauma and discussing difficult moments in the life of our family that should be kept private and out of public discourse, is a form of oppression in that

... certain images do not appear in the media, certain names of the dead are not utterable, certain losses are not avowed as losses, and violence is de-realized and diffused. Such prohibitions not only shore up nationalism based on military aims and practices, but they also suppress any internal dissent that would expose the concrete, human effects of violence (Butler, 2004:37-38).

I feel like we are not allowed to mourn for the loss of my Dad as his health and memory deteriorate because of health practitioners' view of his health effects as his fault. Throughout all of our interactions with health care practitioners, service providers and social workers, there has been no discussion about the grief associated with Dementia. Through frankly discussing the lack of services and support, and through the creation of a blog, I can create a resource and a space for it to be a part of public discourse. Publicly and critically discussing my experiences as an Anishanabe woman who has become a caregiver is way to stop the perpetuation of not discussing the effects of colonialism.

4.6 Our Stories

It has been important for my Dad to tell me his stories because, "the truth about stories is that that's all we are" (King, 2003:36). I am fortunate to be trusted to hear the stories from my Dad's life and fulfilling his wish to have his story written down. My Dad sharing stories with me is also a way to reflect on his life through orally remembering and

retelling. It is a way for him to process and try to sift through monumental moments and the memories that are surfacing that he has fought so hard to forget throughout his life.

By analyzing our stories, the

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

My Grandma, Dad and I have all healed through the process of sharing our stories and that we are all survivors. Connecting my research to activism is a way I am imagining an alternative world for the services, support and removal of stigmatization and silence for families when someone is suffering from an illness because of their addictions.

In closing, I want to end on a good note. I have been fortunate to get to know my past and where I come from through hearing my Grandma and Dad's stories. Through the spiraled development of research because of events in my life, I am able to share my experiences as a caregiver while providing a critical examination of the flaws within the Canadian health care system for dealing with Alcohol Dementia. This process personally and academically has been trying, but has helped me to learn about my Anishanabe identity and have pride in who I am. My roles as a caregiver, daughter and researcher have altered me inherently to persevere to contribute to change through activism. The difficult experiences I face have altered my perspective and motivations to realize that change can start at the individual level. I would not have been able to discover these aspects of myself without the trauma I have experienced and that "...something about who we are is revealed, something that delineates the ties we have to others, that shows [us] that these times constitute what we are, ties or bonds that compose us" (Butler, 2004:22). My bonds with my Grandma and Dad and their experiences of structural violence motivate me to contribute to the lack of research focused on Alcohol Dementia and to share my resources and experiences to provide hope and support for other First Nations women who become the caregivers for their loved ones.

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