

Understanding the Intergenerational Effects of Colonization: Aboriginal Women with Neurological Conditions—Their Reality and Resilience

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Abstract

The “Understanding from Within” (UFW) project was part of the National Health Population Study of Neurological Conditions (NHPSNC), a 4-year study aimed at better understanding the scope of neurological conditions in Canada, and funded by the Public Health Agency of Canada. The goal of the UFW project was to develop a better understanding of how Aboriginal people conceptualize neurological conditions and the impacts on their families and communities, and the resources and supports needed to provide culturally safe and appropriate care. The research was qualitative and used an Indigenous Research Methodologies (IRM) approach to guide the design, collection of data, and analysis. Two methods were used to collect information: in-depth interviews and research circles (focus groups). A total of 80 people participated in the research, 69 women and 11 men. In-depth interviews were undertaken with key informants (22), with Aboriginal people living with a neurological condition (18), and with Aboriginal people caring for someone with a neurological condition (40). This paper examines the physical, mental, emotional, and spiritual impacts of neurological conditions on Aboriginal people, primarily women. It also examines other themes that emerged from the narratives, including recommendations to healthcare providers and cross-cutting themes that are relevant to culturally safe care and how it relates to neurological conditions.

Keywords

Dementia, caregiving, Indigenous health, cultural safety, neurological degeneration, colonialism, healthcare, women’s health

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Introduction

In 2010 the Native Women's Association of Canada obtained funding through the Public Health Agency of Canada to undertake a research project entitled "Understanding from Within: Developing community-driven and culturally relevant models for understanding and responding to neurological conditions among Aboriginal Peoples (UFW)." The project was one of 13 that were funded as part of the 4-year National Health Population Study of Neurological Conditions (NHPSNC), focused on filling gaps in knowledge about individuals with neurological conditions, their families, and caregivers. The UFW team received funding, over the course of 27 months, to study the impacts of neurological conditions on Aboriginal women, their families, and their communities. The research team looked at the impacts of neurological conditions, the risk factors associated with neurological conditions, and at health services utilized, including any gaps in services.

Fourteen conditions¹ were selected, according to NHPSNC specifications based on the lack of knowledge and potential population disease burden. However, the UFW research team and advisory committee, both comprising Aboriginal and non-Aboriginal individuals experienced in Aboriginal research, neurological research, and traditional methods of gaining and translating knowledge, recognized that there is a huge knowledge gap in regard to neurological conditions among Aboriginal people and did not limit the scope of the study to the prescribed 14 conditions. The UFW team expanded the scope to include any conditions that impact the brain, the spine, or the nervous system. Literature on the impacts of neurological conditions on Aboriginal people is lacking in spite of the fact that they have higher rates of chronic diseases (Loppie-Reading & Wien, 2009) and bear a disproportionate burden of mortality and morbidity (Tjepkema, Wilkins, Senécal, Guimon, & Penney, 2009). It is imperative that a full range of the social determinants of health be included when looking at the health and well-being of Aboriginal peoples.

Aboriginal Women Experiencing Neurological Conditions

Aboriginal women were the focus of our study because they have a longer lifespan than Aboriginal men (O'Donnell & Wallace, 2011) and also represent the majority of caregivers in Aboriginal communities, whether they are formal or informal, paid or unpaid (Hennessy & John, 1995; Hennessy & John, 1996; Korn et al., 2009). Specific data regarding Aboriginal neurological health is very limited. A detailed environmental scan and literature review revealed little in the way of data for the neurologic conditions defined for the project by the Public Health Agency of Canada.

Dr. Janet Smylie completed a scan of available literature and data and confirmed that only three Canadian datasets had disaggregated Aboriginal neurologic health data: the Canadian Community Health Survey (CCHS), First Nations Regional Longitudinal Health Survey (RHS), and the National Population Health Survey (NPHS) (First Nations Centre, 2005; First Nations

¹ Alzheimer's disease and related dementia; amyotrophic lateral sclerosis (Lou Gehrig's disease); brain tumours; cerebral palsy; dystonia; epilepsy; Huntington disease; hydrocephalus; multiple sclerosis; muscular dystrophy; neurotrauma (including brain and spinal cord injuries); Parkinson's disease; spina bifida; Tourette syndrome.

Information Governance Centre [FNIGC], 2012). Of these three, only the RHS has readily accessible Aboriginal data currently available. We were not able to identify Aboriginal data tabulations for the CCHS or the NPHS.

Colonization in Canada

Aboriginal women are the most marginalized population in Canada. They experience higher rates of poverty, ill health, and violence when compared to the general Canadian population (Bourassa, McKay-McNab, & Hampton, 2009). This disparity can be attributed to the colonial experience in Canada, which is unique to Aboriginal Peoples. The forced removal of children from families to be stripped of their identities in residential schools, outlawing of traditional ceremony and practices, and the stripping of power from people and communities caused intergenerational trauma for individuals, families, and communities, the effects of which are apparent in the health outcomes of Aboriginal people.

Aboriginal women have been targeted through colonial policy, which has served to marginalize them and make them a particularly vulnerable population. Prior to contact, Indigenous societies valued both men's and women's roles. Those roles changed when patriarchal systems were introduced accompanied by sexist legislation (Amnesty International, 2009). The Indian Act was used to “define who Indians were and were not; manage Indians and their lands; concentrate authority over Indian people (Indians were to be civilized and Christianized)” (Wotherspoon & Satzewich, 2000, p. 30). This legislation was sexist in that between 1876 and 1985 Status Indian women would lose status if they married Non-Status men. The same was not true for Status Indian men (Bourassa, 2010).

The removal of children through the residential school system and the “Sixties Scoop” also contributed to the marginalization of Aboriginal women (Amnesty International, 2009; Kubick, Bourassa, & Hampton, 2009). The mandate behind the residential schools was to “kill the Indian and save the child” (to paraphrase Richard Pratt, the army officer who developed the first American Indian boarding school). The Sixties Scoop further contributed to the cultural genocide of Aboriginal people, by removing Aboriginal children from their families and communities. According to the Royal Commission on Aboriginal Peoples report (1996), placements in non-Aboriginal homes typically ranged from 70 to 90 percent in most provinces. The only exception was Quebec, where Cree and Inuit child placements, reported separately, were almost entirely in Aboriginal homes that were usually in the children's home communities. Many parents did not know why their children were taken away from them. “The grief and anguish birth parents suffered often led to the abuse of alcohol as a way of trying to cope with the situation, which often led to the removal of additional children” (Royal Commission on Aboriginal Peoples, 1996). As Amnesty International (2009) notes, “...the mass removal of Indigenous children from their families and communities have all undermined the traditional cultural and subsistence activities of Indigenous societies in Canada” (p. 6).

Racism and sexism combine to create greater inequalities for Aboriginal women. In fact, Voyageur (2000) indicates that the situation of Aboriginal women can be referred to as “multiple jeopardy” because these women experience multiple economic, social, and political barriers within and outside Aboriginal communities as a direct result of colonization.

Brasfield (2001), Corrado and Cohen (2003), and Robertson (2006) refer to the intergenerational impacts and symptoms associated with the schools as residential school syndrome (RSS). They state that RSS is somewhat similar to posttraumatic stress disorder (PTSD) but differs in the cultural impacts. Brasfield (2001) states:

The residential school syndrome diagnosis is different from that of post-traumatic stress disorder in that there is a significant cultural impact and a persistent tendency to abuse alcohol or other drugs that is particularly associated with violent outbursts of anger. (Symptomology section, para. 6)

Brasfield (2001) further recognized that an individual could still suffer from RSS even if he or she did not suffer from a specific traumatizing incident:

- A. The person has attended an Indian residential school or is closely related to or involved with a person who has attended such a school.
- (1) The school attendance was experienced as intrusive, alien and frightening
 - (2) The person's response to the school attendance involved fear, helplessness, passivity, and expressed or unexpressed anger (Table 1)

Indian residential schools were a place of terror for many Indigenous people. The legacy surrounding the schools has had a great impact on former students, their families, and their communities. As one of our co-researchers (a key informant) stated:

We talked about the impacts of the residential school, the cross-generational impacts, and so much of the work on residential school is to compensate the people, to have them disclose and come to some terms of understanding about what happened to them. But there is . . . the destruction of families and the loss of . . . the majority of them fit in the loss of culture which you'll want to deal with, the breakdown of families and dealing with emotions, and dealing with mental.

The loss of culture and breakdown of families, along with the physical, mental, emotional, and spiritual abuse experienced as a result of the residential schools, continue to impact Aboriginal families and communities. This impact is seen in the disproportionately high levels of abuse that continue to plague our communities in terms of addictions, violence, and suicide. In order to stop this cycle of abuse and trauma, healing needs to occur on all levels including individual, family, community, and nation.

Contemporary Aboriginal women experience "multiple jeopardy" in their everyday lived experiences. For example, according to the Canadian Research Institute for the Advancement of Women (CRIAOW, 2002), 43 percent of Aboriginal women live in poverty. CRIAOW (2002) also notes that Aboriginal women have lower incomes, less formal education, poorer housing, lower health status, and a greater chance of becoming lone parents than Aboriginal men or non-Aboriginal women in Canada. Status Indian women are five times as likely as non-Aboriginal women to be nonparticipants in the labour force. Aboriginal women are also more likely to experience emotional abuse than non-Aboriginal women are.

The complicated dynamics of racism and discrimination, as well as cultural values and beliefs, frequently make it difficult for Aboriginal women to disclose abuse to both formal services (i.e., police, shelters, and healthcare professionals) and informal supports (i.e., family and relatives). Some Aboriginal women are afraid of disclosing abuse to formal services for fear they will have their children removed, and some may not have support where they are living. If they moved from the reserve to the city, they may not have family support. If they live on a reserve, they may not have access to formal support systems, or fear others will find out about

their situation in a small community. Many Aboriginal women living in northern and remote communities are faced with the additional challenge of finding services specific to Aboriginal culture and with an awareness of the harmful effects of colonization (McGillivray & Comaskey, 1999; Thomlinson, Erickson, & Cook, 2000).

Many Aboriginal women who do find the courage to fight for services are often faced with other barriers and challenges, such as discrimination and racism within the healthcare system. Most of the Aboriginal women that we spoke with shared that they were more willing to continue fighting for services for their children than they were for themselves, especially when faced with rude or judgmental providers. For example, one co-researcher shared how she would push back and stand her ground in fighting for services for her daughter, even when faced with ignorance or discrimination:

When this first started happening I was very young, so I was in my late twenties, early thirties, and I was thinking like I'm young, First Nations, single parent, and they don't really know what Rett syndrome is because the pediatrician didn't really know a lot of the symptoms. I felt like I was being judged. It was frustrating and it was hurtful, but at the same time I felt more mad about it and when it comes down to it, it doesn't matter what they're trying to think, I'm going to get whatever done that my daughter needs. And I wasn't going to let anyone's ignorance stop me. And so I just started being really hard, like, it's almost like I would go into communicating-with-a-difficult-person mode and I'd get this really—I could feel the really hard exterior; it's like I had to really stand my ground and show that I wasn't going to back down or I wasn't going to go away or that I wasn't going to bend.

Standing one's ground in fighting for services takes a lot of strength and determination. Unfortunately, not everyone has that ability to advocate for themselves and would rather try to take care of any health issues on their own than face any kind of judgmental behaviour from healthcare staff or providers. For example, one of our co-researchers stopped going to her doctor because of the way the nurse spoke to her:

She kind of scared me—that's why I don't go and see my doctor anymore . . . I don't know; it's just the way her voice scared me inside, so I said, "That's it; I'm not going to see the doctor."

These types of stories are documented in Allen and Smylie's (2015) report and help explain why Aboriginal women experience a greater burden of ill health than other Canadian women. According to Mann (2005), in 1999–2000 life expectancy for First Nations women was 76.6 years and for Inuit women in Nunavut 70.2 years, compared with 81.8 years for Canadian women in general. Aboriginal women have higher incidences of diabetes, tobacco addiction, and HIV/AIDS. They are also more likely to be affected by drug and alcohol abuse than are other Canadian women. Aboriginal women also have a suicide rate up to eight times that of other Canadian women, depending upon age (Native Women's Association of Canada, 2004; Prentice, 2005).

According to the Regional Health Survey, Aboriginal "women are more likely than [Aboriginal] men to experience difficulties with: long waiting lists; the availability of a doctor or nurse in their area; seeking approval for NIHB covered services; arranging for and costs of

transportation; and the costs of childcare” (FNIGC, 2004, para.14). Not being able to access services in a timely manner, as well as not having access to culturally safe care, can put Aboriginal women at greater risk for acquiring a neurological condition. For example, prevalence rates for diabetes, obesity, depression, and substance abuse are higher for the Aboriginal population than the general population. If Aboriginal women do not feel safe or secure in accessing treatment for these conditions, they will end up waiting until the situation becomes more dire. Doing so can have serious implications for neurological health, especially in terms of cognitive function, dementia, or strokes (Pollitt, 1997; Smith et al., 2010). Allen and Smylie (2015) state: “Racism serves as a serious barrier to health care access that can lead to delayed treatment or a lack of treatment altogether, either of which can have devastating effects on Indigenous people, their families and communities” (p. 27).

Process: Methodology, Methods, and Analysis

This research was qualitative and used an Indigenous Research Methodologies (IRM) approach to guide the design, collection of data, and analysis of the research. The four Rs of research involving Aboriginal Peoples—respect, reciprocity, relevance, and responsibility, described by Kirkness and Barnhardt (1991)—provided a simple framework for understanding and engaging in research in a culturally appropriate and safe manner. These principles were actively considered when purposefully engaging the expertise of the advisory committee to add community voice to the project (the committee provided guidance throughout the project). These principles were also considered when creating safe environments for Aboriginal people to share their stories and experiences. The choice to use a narrative approach to analyze data collected for this project emphasized the need to allow the participants to tell their story. This approach also privileged that “story” as a culturally informed interpretation process. The research was then capable of yielding findings that provided an accurate interpretation of the information that was gathered and that reinforced the views of Aboriginal women living with a neurological disorder.

Narrative analysis emphasizes a story-based approach to understanding a given phenomenon by taking, as its object, the “story” (Liamputtong & Ezzy, 2005). This is consistent with and respectful of the oral tradition of storytelling as a method of transferring knowledge among Aboriginal people (Kovach, 2009). The advisory committee supported the idea of drawing out and analyzing the participants’ knowledge in the form of stories. Taking the advice of the committee was one way to ensure respectful research was undertaken and that the project remained relevant to the Aboriginal communities under study.

Through following Indigenous research methods that support and uphold a narrative approach, we were able to hear about the impacts of living with a neurological condition or caring for a loved one with a neurological condition, as well as participants’ experiences in navigating their way through the healthcare system. For some, getting a diagnosis and eventual treatment plan took a lot of strength and determination in terms of getting second opinions, asking for referrals, and fighting for services. This information is not always captured in health system reports or case studies.

Methods

Data were collected from two distinct groups: key informants (KI—knowledge holders, health administrators, or health practitioners) and Aboriginal people experiencing a neurological condition or Aboriginal people caring for someone with a condition (ID – individual interviews). The process used two different methods of collection: in-depth interviews and research circles.

In-depth interviews allowed us to gain insight into a person's lived experience and to hear their story by allowing a less structured process in guiding the questioning of participants (Kovach, 2009). Research circles were also undertaken with those experiencing a neurological condition and their caregivers but not with key informants. Research circles are based on the sharing circle used within Aboriginal cultures for sharing and gathering knowledge, which was adapted for research purposes (Kovach, 2009). It works like a focus group. Instead of trying to get people in the group to build dialogue through discussion, it is more aimed at letting a person tell their story and then passing the floor to the next participant (Kovach, 2009). The UFW research team worked with a community contact person to ensure the research circles were culturally appropriate for the region and traditional protocols were followed. Where appropriate, Elders were presented with tobacco, cloth, and an honorarium to open and close the circle with a prayer. These offerings are a part of the protocols followed within many Aboriginal communities.

Analysis: Collective Coding, Reducing, and Contextualizing

The qualitative data collected for this project was collectively coded by research team members into logical chunks or pieces of a story. These pieces were organized into nodes (subthemes) using the qualitative analysis program NVivo. The nodes, which are collections of coded data organized for similar content, were summarized. Continual reconsidering and re-coding of the data resulted in at least 60 nodes for each of the KI data and the ID data groups. The KI data were then further reduced by the research team into eight overarching theme areas by combining similar or related nodes into major theme areas. The ID data were put through a second phase of collective analysis utilizing the entire research team and some members of the advisory committee. This paper is based on one of the major themes that developed during this process and was one of the major discussion points during the reflection aspect: *Colonial and Systemic Factors*.

Discussion: What Their Stories Told Us

This research revealed incredible stories of strength from our participants. It also exposed barriers and truths that healthcare providers, policymakers, and educators need to hear and understand. We are honoured to share their stories and experiences so that we might learn how to improve health outcomes and experiences for Aboriginal women with neurological conditions.

Cycle of Trauma

Prior to asking the women how neurological conditions impacted their lives, we asked them to tell us a little about themselves. This open-ended question allowed the women to share as much or as little as they wanted about their lives, their families and communities, their neurological conditions, and how long it took for them to get a diagnosis. The caregivers of those with a neurological condition would often share a bit about their lives and their relationships with those suffering from a condition. Many of the women spoke about their experiences and separated their life story in terms of before the symptoms started and after the diagnosis.

Being diagnosed with a neurological condition is a traumatic experience for the individual and for family members. Evans-Campbell (2008) describes a traumatic event as being “outside the normal range of an individual's experience and constituted for that individual, an exceptional mental and physical stressor” (p. 318). This sentiment is echoed by one of our co-researchers:

She [the counsellor] asked me what I thought what a trauma was, and I thought if someone had an accident and they have a blunt-force trauma for one, watching CSI and stuff like that and they get hurt. And she was like: “Well, that’s partly right, but it’s something that [is] more than one person can handle. And, like one time I understood what she was talking about and I could feel that happening, and I could recognize when it was happening and I realized that I was going through these cycles. I felt like I was getting depressed and feeling anxiety, and I wanted it to stop; what could I do to make it stop? But then it was just kind of understanding that it’s like an overflow of trauma, like more than I could handle, and I just had to go through the cycle and stop resisting it.

For this caregiver, along with many of the other women we talked with, these traumatic stressors are complex in that they are often ongoing and are not just a one-time occurrence. Trauma at the individual level is often characterized as being simple, as in a one-time occurrence not involving physical or sexual abuse, or complex, as in occurring repeatedly or cumulatively, and may involve physical or sexual abuse (Evans-Campbell, 2008; Haskell, 2009).

For many Aboriginal women we spoke with, the traumatic event of coming to a diagnosis was often compounded by past traumas experienced at the family, community, and multigenerational level. Many of the women we spoke with talked about the legacy of colonization in terms of the abuses and traumas that impacted their lives, their families, and their communities. The legacy of colonization can be looked at in terms of the historical trauma, a “collective complex trauma inflicted on a group of people who share a specific identity or affiliation. . . It is the legacy of numerous traumatic events a community experiences over generations” (Evans-Campbell, 2008, p. 320).

For Aboriginal Peoples the legacy of colonialism is still felt far and wide. Wesley-Esquimaux and Smolewski (2004) state, “Aboriginal people never had enough time, between various sequences of new world epidemics, genocide, trauma, and forced assimilation to develop tools for passing through the periodic social and cultural disintegration of their nations” (p. 77). Intergenerational and multigenerational trauma happens when the effects of trauma are not resolved in one generation. “When trauma is ignored and there is no support for dealing with it, the trauma will be passed from one generation to the next” (Aboriginal Healing Foundation, 1999, p. A5).

Many of the women we spoke with talked about the intergenerational impacts of the residential schools. In the words of one co-researcher:

Anyways, after the funeral my mom didn’t return back to work ever. After that she kind of went crazy, she didn’t have much support and she didn’t like talking about our problems and I was always severely beaten and told not to talk about this and that. It wasn’t until I was older I realized my mother was a product of residential school abuse.

The residential school experience left a lasting scar on Aboriginal people, impacting multiple generations. For this co-researcher the trauma her mother experienced at the residential school carried over to impact upwards of four generations. Many of the women talked about how they dealt with some of their traumatic experiences. Some used drugs and alcohol as a way to mask the pain of experiencing various levels of trauma throughout their lives. One co-researcher recognized she was using alcohol as a way to mask her pain:

Well, you know how, when I went to that treatment centre, you know they looked at things from that First Nations perspective and that was so healing for me, and again alcoholism it is another disease you know and I believe that, I believe that it's a disease of the mind and our emotions and our mind and our spirit is so confused and suffering . . .

This co-researcher was able to recognize that she was using alcohol to mask the pain from the various levels of trauma that she experienced throughout her life. Unfortunately, not everyone has this level of awareness.

Many of the women were further traumatized by their interactions with the healthcare system. The following section looks at some of the stories that resulted from dealing with the healthcare system and its practitioners.

Racism, Stereotyping, and Discrimination

Our participants' revelations strongly reinforce the assertion that colonization has shaped their experiences. Racism and sexism combine to produce poorer health outcomes and experiences for them in the healthcare system.

Racism itself is increasingly being examined as an underlying root cause of ill health among Indigenous populations around the world (Larson, 2007). Many co-researchers described their experiences in the healthcare system and were explicit about systemic racism. One co-researcher shares her experience:

But they're deeming them disabled. They say well, you Indians should—you guys should be out there working. You're able to work. I will not do this for you. That's the comeback they get. Then they come and they're discouraged and they want to be suicidal.

Another co-researcher shared a similar story describing her experience with racism and discrimination:

You're repeatedly going to the doctors and you've got these symptoms and nobody is really . . . you know, especially in our communities there is a lot of . . . in the hospital system there is a lot of racism and discrimination and stuff and people prejudice and say, "Well, you know . . ."; they chalk it up to other things as opposed to what . . . you know, instead of looking a little bit deeper and really exploring what the issues could be.

Some co-researchers provided recommendations to healthcare providers. They spoke about the need to reduce discrimination and stereotypes and to treat each person with dignity and respect. Practicing culturally safe care means providing a healthcare environment that is free from systemic racism and stereotyping. It is about respectful communication, self-reflection, and understanding the colonial underpinnings of the institutions within which we work (Aboriginal Nurses Association of Canada, 2009; Health Council of Canada, 2012). This co-researcher shared her feelings:

Get rid of the stereotypes and treat people with dignity and respect. The healthcare practitioners need to listen and hear what people are saying to them. They need to be respectful of other ways of being and doing things.

Also they need to stop giving Indians crappy providers, just because they [the doctors] are there. For example, a lot of doctors get signing bonuses to work in the north.

Similar to the in-depth interviews with co-researchers, the interviews with key informants, who included healthcare practitioners also revealed systemic inequities linked to colonization, such as systemic racism, discrimination, and stereotyping within the healthcare system. Many spoke to the need for the implementation of culturally safe care. One key informant shared:

Let's get to the issue at hand, which is: What can we do together or what can your agency do to help us out? So, if you were visiting with a neurological ward, I'm sure that the staff there would say to you: "Well, why don't Aboriginal people do this and that and this?" And then, they'll say: "Ok, now what can we say or do to actually help the people here who are actually Aboriginal and have neurological disorders." And that would be a new question . . . they'll say: "I never thought about that!" That's neglect and I mean neglect, it's actually part of [a] history of neglect where institutions and policies are set up without consideration of us. So they have to be reminded, but that's actually part of our colonial experience. And it must not continue, and if they continue to do that then we will stop and come back when they are ready to talk, or we will work against their current lack of policy, which is a form of violence and racist. It's a colonial, racist, thing for them to not consider us, because we are an important part of the population.

Others spoke about stereotyping directly affecting their healthcare. Some described their experiences in obtaining accurate diagnoses when seeing physicians and specialists. They often referred to their condition as an "invisible disability" and described the impacts it had on them. First, they had difficulty obtaining the diagnosis and were often labelled as hypochondriacs or depressed. Second, they continued to be labelled even after a diagnosis, because the disability is not overtly visible. One co-researcher shared her experience:

This can be termed an invisible disability in terms that I can do things until I can't. Other people can't understand it and it's hard to get a diagnosis. It's really hard to get people to understand why I can't do certain things, or why I can do those things sometimes and then not again.

There's a lot of labelling associated with having an invisible disability. A lot of people don't take you seriously and think that it's "all in your head" or that you are overexaggerating or depressed.

Stigma

Stigma is a related subtheme that emerged throughout the research. The co-researchers expressed that stigma was an important issue that many of them experienced on a daily basis. While racism, stereotyping, and discrimination are often systemic, stigma is more of a sociocultural construct. One caregiver shared:

There needs to be more awareness and education about conditions like his because of all the stigmas that are attached to it—the dementia, the HIV, and the hepatitis C. I feel like we're being treated differently and he is too, but we need to be telling people and family and educating them so that there aren't any of these stigmas and fears.

Many of the co-researchers indicated that they experienced being stigmatized in healthcare settings and in everyday life situations, whether it was going to the grocery store or taking their

child for a walk. The need for greater awareness, education, and respect emerged, as this co-researcher shared:

More awareness and I feel that there's a stigma towards epilepsy. Some people see it as a disease of alcoholism. My husband once said to me that I got seizures because I'm an alcoholic; he was being mean. It's just downright cruel to say. I told my doctor about this and she said that she would confirm this, that my condition has nothing to do with alcoholism, if I ever needed it.

Resiliency

Aboriginal Peoples have endured over 500 years of colonial policies and practices aimed at destroying their cultural practices. While the assaults on culture may not be as overt as they were even 60 years ago, they are still seen in terms of the inequities of government funding of Aboriginal-specific initiatives relating to education, healthcare, and housing (Best Start Resource Centre, 2012). The stories in the previous sections touch on the historical and contemporary forms of colonialism Aboriginal people face. There were also amazing stories of strength and resiliency interspersed throughout these narratives. While the UFW project did not seek out narratives of resiliency, they did emerge as one of the subthemes during the analysis. This is not really surprising given the fact that Aboriginal people have continued to survive and thrive in spite of the colonial assaults on their minds, bodies, and spirits across multiple generations.

Many Aboriginal people use their life stories and stories of their ancestors as a source of strength. Denham (2008), drawing from Neimeyer and Stewart (1996), states, "Trauma narratives transmit strength, optimism and coping strategies that family members internalize and use to 'employ' their own narratives, or organize life events and experiences into a coherent and ever-evolving story" (p. 360). These narratives can be seen as a source of strength in terms of recognizing what one is capable of doing during times of hardship. This strategy was used by one of our co-researchers in overcoming her fears of presenting:

When I started going to university, I hated doing presentations, I hated them and I sat down and said you've been through the residential schools—if you can go through that you can go through anything. That's how I overcame my fear of presenting.

The co-researcher used her residential school experience to push her forward in accomplishing her goals and conquering her fears. We need to keep in mind, though, that not everyone has the ability to use experiences as a way of moving forward and overcoming challenges. Another one of our co-researchers states:

You know, some of us are stronger than others, some of us could've been sexually abused and hurt in a thousand ways and they seem to be able to function and learn and to grow. Others don't have that, you know, so why condemn them because they don't have that? Thank the Creator that some of us have strength to help the ones that don't.

The ability to function, learn, and grow in the aftermath of personal trauma and intergenerational trauma takes a tremendous amount of strength and perseverance. Having a strong connection to family, community, or other trusted people helps some in talking about certain traumatic experiences and aids in their healing process. Other individuals may find great solace in taking part in cultural practices and teachings (Lalonde, 2006).

The women who shared their stories with us talked about the coping mechanisms they used in various situations. They also spoke of the protective factors they drew from in order to deal with living with a neurological condition or caring for someone with a neurological condition. One co-researcher drew heavily on her family and her upbringing:

I don't know, like I said, you have to believe and I think in my darkest hours that's where you got to dig down and you really got to remember like where you came from, who your parents were, your family, friends.

Another co-researcher drew strength from following her traditional ways, while incorporating the songs from the church:

I guess my adversity that I've had to deal with—the Anishinabe ways helped me the most, they've been the strongest and then my mother playing the organ in church—I'd really like to go there and sing the songs—that helps me a lot as well.

After speaking about the impacts of a neurological condition on their life, family, or community, many of the participants would talk about how they dealt with certain situations and what coping mechanisms they used to get through their day. One co-researcher, who cares for her mother and her sister, spoke specifically about drawing strength from her family and their upbringing. She spoke of how her family used humour to deal with painful or frustrating situations:

I get angry and resentful sometimes about what I've got to do and why I have to do it. I get mad, but I'm better at sorting it out because, like she said, we have a pretty humorous family.

We are always making silly jokes, always, constantly; constantly, and it keeps the mood up all the time. You can't get too far into depression because that is just how they've always been, and my grandparents were like that. I know that you don't dwell on those negative emotions; they're always looking for the bright side and I think that's because of the adversity we've always faced as a people; it's that humour that's really important. And you know, I never would have appreciated that unless we hadn't been going through all this.

This ability to use humour in an otherwise stressful situation demonstrates the strength and resiliency of the family unit over time. Other caregivers spoke about personal strength and the need to be strong for their family members who were living with a condition. One co-researcher, who is a caregiver of a young child with a severe neurological condition, states:

The only person that I'm bending to, I thought in my mind was S—, and also in my mind I thought no matter how wrong this person's being or the situation is. The worst thing already happened to me and that's when S— was diagnosed. I felt like you can't take anything away from me, you can't hurt me, so in a way almost gave me strength.

In addition to putting up a strong front for her family, the co-researcher also talked about focusing on the good because the ability to focus on the good in one's life plays a tremendous role in keeping a positive attitude:

So I feel like I'm at a point now where I can see and experience so much and that I have to just take myself out of there and just try to turn a blind cheek, but that's nearly impossible for me to turn a blind cheek. So I just try to focus on the positive and the good. So that's when I switched things and completely focused things on my son and S—

Resiliency on the individual level was also seen throughout the narratives shared. One of our co-researchers, who lives with ataxia, told the research team what she did to keep her body, mind, and spirit active in response to the physical toll her condition was taking on her ability to be independent:

My sons are very helpful, they seem to really want to help, but I want to do it myself. My husband changed our shower to add a rail and a seat for me to sit on. I exercise every day—I was at risk for osteoporosis and now I have it, so I exercise daily. I walk on the treadmill every other day for 30 minutes, and every other day I do weights. I meditate for half an hour every day. I devour books, I still feel like I'm going to university—always studying and doing researching. I love jigsaw puzzles, the really challenging ones. They absorb my attention, I don't want to just sit there and wallow in self-pity.

This narrative is important in that the co-researcher recognizes that she has a choice in how she lives her life in spite of her condition and the impacts it has on her mobility and her ability to be independent. In choosing to focus on what she can do, the co-researcher is taking steps to protect her health and well-being.

Conclusion: Moving Forward

While colonization has shaped the experiences of many Aboriginal women with neurological conditions, it does not define them. Aboriginal women are strong and resilient, and they have much to offer society. The women we spoke with shared stories of strength and hope and had a vision for the future through incredible words of wisdom and advice for change.

This is not to say that they did not and do not experience barriers on a daily basis. Their stories reveal severe hardship, and many of the issues they face are intricately linked to the colonial experience. Issues regarding racism, stereotyping, and discrimination are institutional and intimately linked to Canada's history of colonization. Experiences regarding abuse and trauma are intergenerational in nature and also linked to colonization. A 2012 Health Council of Canada study documented widespread racism and stereotyping within the healthcare system and noted that many Aboriginal people do not seek treatment as a direct result:

It is well documented that many underlying factors negatively affect the health of Aboriginal people in Canada, including poverty and the intergenerational effects of colonization and residential schools. But one barrier to good health lies squarely in the lap of the health care system itself. Many Aboriginal people don't trust—and therefore don't use—mainstream health care services because they don't feel safe from stereotyping and racism, and because the Western approach to health care can feel alienating and intimidating. (p. 4)

These issues arose time and again throughout the experiences shared not only by Aboriginal women who had neurological conditions or were caregivers, but also by key informants, many of whom work within the healthcare system. The recommendations made by both those experiencing the healthcare system and those providing care in the healthcare system were around providing culturally safe care. Key informants spoke about institutional racism and stereotyping within the healthcare system and in medical school and to the need for more Indigenous-specific curricula and training given the growing health disparities between Aboriginal and non-Aboriginal people in Canada. Specific recommendations concerned more education and awareness training within medical schools and healthcare that focuses on cultural safety, where institutional racism and systemic barriers are addressed. This is where the personal biases and attitudes of healthcare providers are challenged as the providers undertake a process of self-reflection and examine the political and social structure within which they work (Aboriginal Nurses Association of Canada, 2009).

The Canadian Nurses Association (Aboriginal Nurses Association of Canada, 2009) acknowledges that colonization has contributed to the ill health of Aboriginal people and that intergenerational and historic trauma transmission and the direct and contemporary effects of colonization are experienced by Aboriginal people. They acknowledge that part of enacting culturally safe care is for healthcare providers to understand the intergenerational cycle of abuse and the effects on Aboriginal people and families and realize that Aboriginal people have strength that they have drawn on to survive these traumas.

In 2013 the Royal College of Physicians and Surgeons of Canada released a document aimed at advancing the new strategic plan of the college to improve the health status of Indigenous people (Royal College of Physicians and Surgeons of Canada, 2013a). The College also created the Indigenous Health Advisory Committee, comprising Indigenous health physicians, researchers, educators, and allies, to guide the College as it develops education policies and curricula and implements its strategic plan with the goal of improving Indigenous health and improving patient care. According to the Royal College of Physicians and Surgeons of Canada (2013b):

Physicians who apply critical thinking and self-reflection, within a context of social justice, are better equipped to practise cultural safety and deconstruct misinformation about indigenous health; they are more inclined to understand upstream factors (e.g., government policies, racism, historical legacies) and their connection to the downstream effects influencing the health and healing of populations at risk. (p. 2)

The College has made cultural safety education and training a strategic priority by framing it into its CanMEDS Intrinsic Roles (Royal College of Physicians and Surgeons of Canada, 2015). Since cultural safety exposes systemic health inequities, including racism and oppression, this connection of values and principles to CanMEDS facilitates transference into professional practice and should result in better patient care.

Our co-researchers said that culturally safe care must be practiced; racism, discrimination, and stereotyping must cease; respectful communication and dialogue between patients and healthcare providers must occur; stigmatizing patients must stop; and healthcare providers must learn more about the Aboriginal people they are caring for.

These recommendations were echoed in the 2012 Health Council of Canada report, which noted that, for some Aboriginal people, the Western healthcare system can “feel alienating

and providers can seem judgmental and arrogant” (p. 10). The authors stated that Aboriginal people “may have a heightened sensitivity to practices that are a routine part of hospital life” (p. 10). The report also highlighted that Aboriginal people have experienced trauma, including abuse in residential schools, and that healthcare providers must be aware of this in order to provide appropriate care. The recommendations made in the report point to the need for greater education and awareness for healthcare providers and suggest that healthcare providers must take this education and awareness a step further. They should be “encouraged to think about their own cultural beliefs and biases, their power and privilege” (p. 12) and how these influence their interactions with Aboriginal people.

The report recommended that cultural safety be prioritized by health regions across the country. It is something that must happen. It is about institutional reform and commitment to creating safe environments for Aboriginal people that will require, the Health Council says, “a culture shift” (Health Council of Canada, 2012, p. 15).

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