

Metis Autoethnography:  
Women's and Two-Spirit Beadwork about Chronic Illness and Disability  
By  
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## Abstract

Metis people live with disability and chronic illness which is largely under reported and undocumented in Canada. In an age of Truth and Reconciliation, this thesis demonstrates the lived experience of the same Metis and appeals to all Canadians to understand Metis life as unique and deserving of culturally relevant support and health services in order to allow for Metis self- actualization. By sharing beadwork sewn by the author and their late mother, this thesis demonstrates wealth of knowledge available within the Metis embodied experience with chronic illness and disability.

Feminist disability theory and Manitoba Metis Federation's (MMF) Wellness Models are an excellent way to explore the theoretical undertones of the family's beadwork completed while living with disability and chronic illness. Through storytelling and beading this thesis utilizes MMF's Wellness Models to highlight the importance of dialogue with disabled Metis people. Non-Indigenous people can use this knowledge sharing to understand how Canada should meet Truth and Reconciliation Calls to Action for Indigenous health.

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This thesis is dedicated to many departed Metis: Sharon, Alice, Chuck and Lawrie.

And, to my Mom's Dad who survived life in a prisoner of war camp  
in Hong Kong during World War Two,  
a Tuberculosis Sanatorium at Ninette, Manitoba,  
who died of cancer many decades later.

We Remember Them.

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## List of Abbreviations: Acronyms and Shortened Words

BC – British Columbia

BIPOC – Black and Indigenous, People of Colour

CRAB's – injectable MS medications first created and made available around the world:  
Copaxone, Rebif, Avonex and Betsaseron.

INAC - Indian and Northern Affairs Canada

FNIHB - First Nations Inuit Health Branch

Folx – a gender inclusive term used to refer to a group of gender diverse people which includes people who do not identify their gender in a binary manner.

LGBTQ2S+ - Lesbian, Gay, Bisexual, Transgender, Queer, Two Spirit and all other gender and sexual identities.

Gramma - Grandmother

lowercase m metis - Indigenous peoples who do not qualify for band membership and are called metis by people who are not citizens of the Metis Nation

capital M Metis – Citizens of the Metis Nation which draws its roots to the Red River Settlement

MLPF - Metis Life Promotion Framework

MRI - Magnetic Resonance Imaging

MMF - Manitoba Metis Federation

MS - Multiple Sclerosis

UNDRIP - United Nations Declaration on Rights of Indigenous Peoples

## Prologue

### She Was a Childhood Rape Survivor

He knew that.  
She had many illnesses.  
He knew that.  
She was diagnosed with endometrial cancer.

The confirming tests were invasive,  
the constant bleeding her shame.  
Blood poured from her broken womb when she knelt to do the things she loved on the land.

She stayed on bed rest.  
He resented her for not fulfilling the duties of a wife,  
like the dishes. Or was that it?

She died alone in a hospital.  
No family by her side.  
An infection ravaging her body after singing gospel hymns.

She passed into the spirit world the night of a full moon.  
I looked up at the sky and cried, fuck!

The phone call came;  
she had a heart attack and was on life support.  
The northern lights danced in the sky.  
And I knew it was my Mom,  
leaving us alone in her treasured house.

The funeral was a church service.  
I preached a good sermon about her godliness.  
Then He preached, and He preached, and He preached.  
And He shook my hand.

My Dad hurt.  
He blamed himself. He blamed me. He was fine.  
We tried to maintain our family unity. We could not.

He bragged.  
Of how great the sex was when they were first married.  
Of how much passion they shared.  
But I am her child, and she is gone.



## Introduction

This thesis will demonstrate the best way to address the distinct needs of disabled and chronically ill Metis who are more likely than Manitobans to have chronic disease as adults and are the least healthy of all Manitoba Metis in the Thompson region where the author resides. Our poor health status has resulted in disabling and life-ending chronic illnesses.

Those who are familiar with the University of Manitoba may also be familiar with the National Centre for Truth and Reconciliation (NCTR) which is housed at the University. The NCTR is relevant to this thesis in that as a Metis person living with chronic illness, the 20th and 44th Calls to Action of the Truth and Reconciliation Report state:

#20

In order to address the jurisdictional disputes concerning Aboriginal people who do not reside on reserves, we call upon the federal government to recognize, respect, and address the distinct health needs of the Métis, Inuit, and off-reserve Aboriginal peoples.

#44

We call upon the Government of Canada to develop a national action plan, strategies and other concrete measures to achieve the goals of the United Nations Declaration on the Rights of Indigenous Peoples. (*Truth and Reconciliation Commission of Canada: Calls to Action*).

The disparity between Indigenous and non-Indigenous peoples is vast in Canada. Chronically ill and disabled Indigenous peoples do not have access to the quality of life enjoyed by the non-Indigenous people in Canada (Adelson)(Martens et al.). In the spirit of Truth and Reconciliation, this reality must change, and it must be the disabled and chronically ill First

Nation, Metis and Inuit peoples who direct the changes. The United Nations Declaration on the Rights of Indigenous Peoples goes as far as to say in Article 21 that:

1. Indigenous peoples have the right, without discrimination, to the improvement of their economic and social conditions, including, inter alia, in the areas of education, employment, vocational training and retraining, housing, sanitation, health and social security.

2. States shall take effective measures and, where appropriate, special measures to ensure continuing improvement of their economic and social conditions. Particular attention shall be paid to the rights and special needs of indigenous elders, women, youth, children and persons with disabilities. (“United Nations Declaration on the Rights of Indigenous Peoples”).

Now is the time to act in the spirit of reconciliation for Metis disability and chronic illness needs. There is no time to waste; we are dying of our chronic illnesses and have shorter life expectancies than non-Indigenous Canadians (Martens et al.)(Statistics Canada)(Adelson). Let us find common ground and strive to improve life with chronic illness for all Indigenous peoples in Canada. Metis peoples disabled by their chronic illnesses deserve the same health care access as all other Canadians.

#### Self-location

My name is Valdine Alycia Flaming. My family is from Winnipegosis and Crane River, and I am related to the Sanderson family in Wabowden. I am a fat, white skinned, two-spirit Metis person living on Treaty Five. The name Valdine was chosen to honour my mom’s best friend with the same name, and Alycia was given to me to honour Mom’s mother whose name was Alice. My last name is Flaming spelt with an A because my Dad’s Dad changed it back to the original spelling rather than with an E which was used to better assimilate in Manitoba as

Prussian immigrants. I was the first person on both sides of my family to attain a university degree and am the first person to attend graduate school.

My spirit name is Brown Buffalo Woman. There are many teachings involved in understanding my spirit name which gives me strength and a connection to my Indigenous self, and I have not learned them all yet since I do not live on my traditional territory. The first time this name came to me, an Elder gave it to me in a carved stone and I immediately rejected it in myself because I was immersed in my eating disorder and could not bear to identify as a brown large animal. The last time that this name came to me that I was finally open enough to hear it because I had grown and learned to love and accepted myself. In a grief support group, an Anishinaabe medicine woman told a story that resounded with me: when a storm is approaching on the prairies, cows see the storm approaching and run in the opposite direction to avoid it. But brown buffalo turn towards the storm and walk directly through it. It is because of this approach to storms that brown buffalo women are resilient and determined, like all women from our territory. We are the survivors of the cultural genocide experiment that is Canada, residential schools, the 60's scoop, roadside allowance and generational trauma that has forced generations of children to grow up without knowing their own history, language, culture and ourselves.

Brown Buffalo Woman as a name suits me because I am a child of sexual abuse who was raised in a cult-like missionary Christian family. I was taught to believe I was only worthy of my parents' love as a member of the cult-church, volunteering my time as a child to 'save all native people from their sinful nature' in order to share the hope of white Jesus; so that Jesus could heal them of their sins or chronic diseases. Suffice to say that emotional neglect, abuse, and co-dependency were my childhood realities as my late Mom struggled to survive her marriage with my Dad who was a non-Indigenous man who was born in rural Saskatchewan and believed his

children could not possibly be Indigenous. I internalized this belief for much of my life, and am doing supported self-work to address the harm of being raised in an environment where questioning authority was not tolerated at the threat of abandonment by my family in the rapture.

As a minor, I spent much time working for free at the cult-church building. When I was young, I helped my parents clean the facilities, and as I entered the pre-teenage years I was asked I joined the stereo team where I operated a sound system for Sunday services which were nearly three hours in length. I have many memories of packing up heavy sound equipment as a teen, and helping to haul it to the downtown of our town where sound equipment loudly blasted evangelizing across the area to encourage the homeless Indigenous population to seek forgiveness from their sin. When I was old enough to work, I gave ten percent of my income to the cult-church so that I would go to the same heaven as my parents. I did not stop working for free in the cult-church while I worked part-time at Walmart and attended high school. I succeeded at school while sewing my pants with discount fabric I bought from Walmart. I survived a crushing amount of control from my parents, and felt much remorse for my younger brother, who has his own stories of surviving our parent's abuse after I moved away for university.

As an adult, I become a citizen of the Manitoba Metis Federation (MMF) after Mom secured her Metis citizenship in an effort to secure educational funding for me. MMF is the government of the Manitoba Metis, which are historically connected to the Red River Settlement, the birthplace of the Metis. While I was born on Treaty One, where the Red River Settlement once was; I grew up and live on the Treaty Five territory of Nishishwayashik Cree Nation, in the Thompson region of the Manitoba Metis Federation. I am a fat person living with Multiple Sclerosis; my pronouns are they and them because I identify as two-spirit. I

acknowledge that my gender is a construct that I have acted out my entire life as a way to escape bullying for appearing androgynous. I was spit on, punched, and hit by my peers as a child during the years I appeared most androgynous and quickly learned that dressing in pastel colors and keeping my hair long allowed me to pass as a fat woman rather than the physical violence of appearing androgynous. As I have learned to accept my disabled and Indigenous selves and be proud of them, I have remembered my androgynous self and reclaimed them.

It has been 15 years since my MS diagnosis and more than 20 since my late Mom was diagnosed with her first autoimmune chronic illness: diabetes. The storms that this brown buffalo woman has moved through include being raised without any knowledge of Metis culture on a land far from my homeland, only to learn as an adult that I am both Red River Metis and Anishinaabe which means that I am both eligible for Indian Status under C3 of the Indian Act amendments, because my Gramma lost her Indian Status due to sexist discrimination of the Indian Act, and I am Metis and have ancestral ties to an original holder of land script at Red River Settlement. Having the ability to regain Indian status as well as be connected to a family holder of script at the Red River Settlement forces me to choose a single identity in the eyes of the Canadian Government. I cannot hold be both a member of MMF and apply to regain my Indian Status, I am only permitted to hold one identity. Because MMF was the first to actively claim me, I claim Metis in reciprocity. Being acknowledged by my Metis community has changed my life and I am determined to contribute back in a meaningful way.

According to my parent's religious cult, I am the chronically ill Indigenous person I was taught as a child to save from hell. I am also the first in my family to acquire a university degree, and the first to gain entrance to graduate school. As my non-indigenous Dad said when I told him as a teen that I would be going to a university of my choice, I was alone in this decision. I

was not supposed to be educated; instead, I was supposed to act like the billions of other girls around the globe who attend only to domestic life by finding a husband and raising a family. As a fat, chronically ill person I am regularly told by those around me that I am not good enough, smart enough, or deserving enough for my house, job or quality of life. I am tired of proving those people wrong. Feeling proud of myself as a chronically ill, fat Metis beader has given me the safety to identity as Two-Spirit, and know that I am more than whatever gender I perform to avoid physical assault from strangers.

This thesis will share lived experiences with chronic illness and disability as Metis people balancing geographic isolation and repression of identity and culture with disabling chronic illnesses, our experiences and value are not often seen or validated by mainstream society. Using an autoethnographic methodology I will share stories of our illnesses with beadwork which provide a traditional therapeutic tool to cope with our marginalization. Our Métis beadwork helps us to understand our lives, by providing a meditative and culturally meaningful form of self-expression which helps us accept the intersectional oppression navigated by chronically ill and disabled northern Metis people like my mother and myself. I will use several frameworks that I used to help me navigate the layers of oppression and integrate my identities, while I share our art and stories in a culturally safe way (Kovach)(L.Smith)(Wepa). The lenses used will include critical discourse from the field of Disability Studies, including feminist theories of disabled people. This thesis will conclude with a beadwork application of the Metis Life Promotion Framework, which was developed by Metis for Metis and is “simply a way of thinking about the complexities of life, and health and wellbeing.” (Martens et al., *Profile* 33)

Mom lived outside a small village named Winnipegosis for her child and elder years. I have lived in Thompson for all of my life with the exception of the brief periods that I left to

attend university. I mention our geographic locations because where we live as Metis is important to our identity as displaced people who were previously settled in the land that is now Winnipeg. Returning to her childhood land gave her strength, because she loved tending a garden there and while she was alive, I visited her every month near Winnipegosis. After I was diagnosed with MS, my mother and I became friends because chronic illness became our shared experience. As a child I was taught by my Dad that my Mom was constantly out to get him, so I learned to be his emotional caregiver and hate and not trust my Mom. Thankfully, with disability in common as adults, I was able to encourage her to switch to insulin as I overcame my own fear of needles. We became fast friends as Mom helped me cope with the grief of learning to live with MS and simultaneously moving into my childhood home while she lived nearby, also on Treaty Five.

When my parents relocated to a reserve on Treaty Five, Mom learned to bead for the first time in her life in an effort to fill her days while Dad worked for First Nations Inuit Health Branch (FNIHB) and for the first time, Mom's indigeneity was a positive aspect of her life and she blended seamlessly into living on reserve, sharing her knowledge of medicinal plants, sewing and even being tested for Tuberculosis like her new friends. No sooner did she learn how to bead than she was making gifts for her family and teaching us as well.

I am talking about my mother first because my life is about much more than myself. I am connected to the experiences and wisdom of those that came before me, and I am protected by their spirits. I carry the wisdom and stories of the people that came before me. I am an Indigenous feminist who uses ceremony to connect to my ancestors and the earth. I do not practice the religion I was raised in, but I understand why many do. It shares similarities to traditional Indigenous ceremonies held on this land. For example, mandatory ribbon skirts at

ceremony as well as gifts to initiate ceremonial protocols and community acceptance seem similar to rituals at my parent's cult-church where we were expected to give more than we took in all aspects of the community and maintain modesty.

As a disabled Metis whose 60-year-old Mother passed away while recovering from her hysterectomy, I have been doing self-reflection on grief, disability and my Metis identities. Since my mother transitioned to the spirit world, I have focused my graduate program on better understanding my disabled life by finding a place for myself within disability theory and disability justice as well as Metis and queer communities in northern Manitoba. Reaching out to Metis community and learning more about myself as Metis through beading helped me cope and find grounding when I lived in Winnipeg for graduate school, disconnected from my family. Creating my Metis identity after Mom died helped me feel connected to her and helped me feel like I needed to continue to grow and learn; essentially giving a reason to push through the depression associated with navigating unexpected death. I have been gathering with other Metis beaders on the Metis homeland. It seems fitting that I bring all my identities together to complete an autoethnography, and contribute to the system of knowledge that has shaped me as a grieving disabled and chronically ill person who is grounded in Metis ways of knowing. These are all identities I have previously rejected, much like my body was rejecting itself on a cellular level with MS. Completing this thesis has forced me to reconcile who I am in order to best advocate for myself and people like me, in my day job as a student disability advocate.

Like Carolyn Ellis, who created the methodology utilised in this thesis, I find myself living in a reflective state. I am always looking to better understand myself and my bias in order to contribute to a more just society, despite my appearance as a white-passing able-bodied cisgender woman (Adams et al. 3)(Ellis). I hold the class privilege of having a mortgage and a



job along with access to libraries and the internet to expand my mind on the subjects of anti-racism at no personal cost to myself, unlike other Black, Indigenous, and People of Colour who survive racism in their very existence in a colonized society. From my iPhone, I can learn about current Indigenous issues, LGBTQ2S+ advocacy and disability justice everyday courtesy of free social media advocacy that is available any time I find myself immobile and in need of community connections as a result of my disability, and I am working to decolonize my own mind from the knowledge systems ingrained in me by imperialism (Sins Invalid) (Maracle)(Mayer)(L.Smith)(Taylor).

Linda Smith is a Maori academic who has written a landmark book called *Decolonizing Methodologies: Research and Indigenous Peoples* which outlines how academic colonizes knowledge into disciplines to reflect imperialist values, that is values which aim to extend power through diplomacy or overt or covert force. As an Indigenous person, I must resist having my thought process colonized in order to support a socially just society, where people like my late Mom do not die while recovering from hysterectomies. I must actively use and reflect on Metis ways of knowing in order for my culture and people to resist imperialist colonization of our minds and bodies (L.Smith). Sonya Renee Taylor is a queer, fat, and black advocate who founded [TheBodyIsNotAnApology.com](http://TheBodyIsNotAnApology.com) which “fosters global, radical, unapologetic self-love, which translates to radical human love and action in service toward a more just, equitable, and compassionate world.” (Taylor About TBINAA). Sonya’s work is accessible as close-captioned videos for free on Instagram.

I write to heal myself in addition to providing a way forward for others like myself. Writing this autoethnography is therapeutic for me; however, it is also a result of years of self-interrogation, writing and beading (Ellis). Rather than exploit my own healing for the sake of

research, I use beading in order to maintain my own wellbeing amongst the trauma of sharing unspoken stories as I grew up in a family where bad things were not discussed and the only way to be a Christian child who was not sinful enough to be left behind in the rapture was to not acknowledge that bad things happened to our family. Most of the truth shared in this thesis are the unspoken things sewn into our beadwork projects; these are the family stories that are not supposed to exist. I am breaking my family pact of never acknowledging negative emotions by bringing my truth into a public domain in an effort to heal my own heart.

This journey has been a long time coming, and I cannot share my beadwork and stories without sharing the beadwork and stories of my first teacher, my Mom. Please grab a cup of tea and join me. These stories will take a while to tell, and good beadwork does not occur instantly. It takes patience and dedication, and is best done in community. In Metis culture, our style of beadwork was used to distinguish ourselves from others and has become a way for me to belong to community without my Mom. The people I bead with have become my family, as beading in community allows for knowledge and resilience sharing (Belcourt, *Beadwork*)(Barkwell et al). In beading with others, I am able to feel less alone and by sharing beadwork with you, the reader, you are being included in the circle of knowledge created by my family beadwork. You are no longer an observer taking in art and stories, you are part of my healing by bearing witness to what was previously taboo and unspoken. Like my Mom, beading is medicine to me, and giving my art away to others creates connection and healing medicine for everyone connected to our beadwork. The focus and breath work I do as I sew supports my wellness, and gifting this art to my family and friends helps us all feel holistically connected in good relationships. Giving gifts is a way to show love and caring for each other, and many Aunties have taught me this by example (Maddes)(Absolon)(Flaming).

Because I was taught that community caring, generosity and reciprocal relationships are the most important part of being Metis, from being in the kitchen with my Mom and Aunties; I designed a community research project to tell the oral history of chronically ill Metis like my late Mom. I built beadwork into my project recruitment and planned to offer beading activities while interviewing, like Cathy Mattes did at *Sparking Miyeu Pimatishiwani*, an Indigenous art presentation in the format of a kitchen table talk. As northern Metis, I knew that my new knowledge about beading was needed in the north, as a resource to be shared to give others the sense of belonging I found within beadwork and the community that taught it to me (Maddes)(Flaming).

Unfortunately, the oral history community research was not welcomed at my campus because I signed an agreement with MMF, which granted ownership of all data to MMF, who retained final approval of the research data's interpretation and portrayal. As a citizen, neither of these concepts threatened me, because I trust my community leaders at MMF. Poor health indicators in my region of Manitoba plague northern Metis. Many of our relatives have taken Indian treaty status under bill C-31 which allowed non-status Indians to regain status if their matriarchs lost their Indian status due to sexist discrimination formerly part of the Indian Act. Autoethnography was my backup plan in case my oral history community research project did not pass ethics. After MMF withdrew their data sovereignty rights, I pulled my ethics application from the ethics board to avoid participating in colonizing Metis research, and moved to my backup methodology. Beading became the way I coped with the hardship of writing about the trauma of existing in a world without the northern Metis community I planned to grow. I am not a highly skilled beader, and many of my beginner projects have beginner mistakes. As I pursue beading as a healing modality, it becomes increasingly difficult to refrain from comparing my

novice beadwork with beaders who have much more skill than I. I was taught from a young age that everything I do must be perfect to be worthwhile, but beading, autoethnography and feminist disability theory demonstrates the fallacy of that belief. My body and my art need not be perfect to be of benefit to myself and others.

#### Methodology: Autoethnography

Autoethnography is not simply autobiography which seeks to tell an individual life story. Nor is it simply ethnography, which has tended to study a culture from an outsider's perspective. Rather autoethnography is a mix of both with one difference: critical examination of one's self through their own lived experiences (Berger and Lorenz) (Anderson)(Pace).

Autoethnography is a qualitative methodology which allows us to understand ourselves in a better way by telling our own stories in a meaningful way, in order to contribute to our collective wellbeing. It is quite different from a quantitative methodology of using a large amount of generalized data to assert knowledge (Adams et al.)(Foster et al. 46). As a child of Indigenous intergenerational trauma (O'Neill et al.), a personally focused qualitative methodology such as autoethnography has been something I kept my distance from. I share Leon Anderson's assertion that the methodology can be simply "an exercise in narcissism" in order to "create emotional resonance with the reader"(Anderson 337). As the only person I know of at the intersection of all of my identities, I am compelled to share what I know, in the hope that others like me will be able to complete the research I originally intended for this thesis: recording Metis women's oral history of chronic illness.

Autoethnography is an in-road for people like me to prove that we exist. Rather than analytic autoethnography, as I had first intended to utilize when I approached the methodology (Anderson)(Ellis), art based autoethnography allows me to tell my story in my own

words, with my own craft-- which is Metis two-needle beading. Just as Metis people use our sashes to tell our stories and each color in a sash holds meaning to the wearer, this autoethnography will be part performative (Berger and Lorenz) and part evocative (Adams et al.). This is because the beading allows me to remember a time in my life that I would rather forget, as I have internalized my family's expectation to keep all unpleasant emotions completely secret. Presenting beadwork in an artistically appealing supports the exploration and understanding of my painful memories. In remembering the stories as a chronically ill and disabled Metis person exploring their identity, I hope that I now possess the tools to deal with my painful experiences.

Carolyn Ellis's autoethnography framework, which is accessible to anyone with lived experience, willing to write about it, rather than Anderson's conception of autoethnography which is only accessible to established academics who can prove their lived experience with their own published work, is best suited for my part explain performative, part evocative thesis exploration. Not only do these forms of autoethnography provide me with a way to emancipate myself from those that would not allow my original Metis oral history project to proceed, it allows me to define what counts as knowledge in a society which devalues both Indigenous and disabled life experience (Adams et al.)(Anderson)(McCallum and Perry). Both disabled and Indigenous peoples have been historically excluded from our own care and research, and autoethnography empowers me to centre both of these identities to explore the knowledge which is created as a result. Like Linda Smith asserts Indigenous peoples must use their ways of knowing to guide their own research (L.Smith)-- I will use my late mother's and I's beadwork to remember our stories with life and chronic illness and ways of understanding our experiences. I will examine the intersections of our identities, while balancing my academic pursuit with my

own creativity and emotional reaction to my experiences. In this way, I hope to show others how they can potentially use my experiences as a road map to make chronically ill and disabled Metis lives better. Adams et al outline this improvement as the foundation of good autoethnography. (Adams et al. 1-2)(Ellis)(P.Smith)(Foster et al.). Richards asserts that autoethnography as “one way of resisting objectivation by others is by writing about oneself.” (Richards 1719) and that is exactly what I intend to do.

“Autoethnography is not simply a way of knowing about the world but a way of being” (Holman Jones et al. 10). While researchers in the academy worked in the last few decades to detach themselves from the outcomes of their research, and to demonstrate scientific fact apart from personal bias, autoethnography delves into the lived experience of the researcher, who is part of an underrepresented people group. (Richards)(Adams et al)(Ellis)(Mayer)(Thistle).

Autoethnography as self-inquiry within the social sciences remains difficult to define as a methodology. As Smith says: “It keeps wanting to change itself. This is much like the identity that autoethnography seeks to uncover—always changing never single, its position hiding from both self and other. You look at it, and it is gone, or changed, or moved, or it was never there...all by or through or with the acting of looking.” (P. Smith 17) Nevertheless, the method was created as a resistance - to colonialization, differences of identities and cultures and lack of representation of marginalized groups not represented by traditional research (Adams et al. 22)(Ellis 276) and undergoes regular adaptation (Pace 195).

Rather than focusing on the lack of insider knowledge produced by traditional research, quality autoethnography aims to counter the lack, producing a personal way of knowing that can be connected to a larger community, evocating stories while using creativity and intellect. Of course, it must do no harm to those implicated in the personal storytelling (Adams et al.).

Autoethnography is also fluid and dynamic, like the identities of those who pursue it (Mayer)(Thistle)(L.Smith).

In order to conduct this autoethnography in a culturally safe way for myself and to ensure no further harm comes to me, beading will be the method in which my stories are shared. By ensuring I take an anti-bias approach which requires I be informed about the layers of oppression resulting in the personal experiences woven into beadwork, I will be able to maintain my own mental health and self-compassion. Without the cultural safety of beading, which allows me to remember the historical trauma which results in negative experiences and examine the bias survived by disabled, fat, Metis people (Wepa) I do not believe I would have been able to openly share the harm that I have endured as a Metis.

Beading is the way I come to know things; slowly, and comprehensively. As a child who was taught not to trust my own understanding of life, it takes me concerted effort in meditative breathing and regularly meetings with a counsellor to recognize emotions as they arise and practice self-compassion for all of my experiences and dreams. I live with vivid memory flashbacks much like the kind that are experienced by trauma survivors with Post Traumatic Stress Disorder. I believe that I am living with complex post-traumatic stress disorder as a result of surviving decades of emotional neglect. As a small marker of the neglect I endured as a child, I have always had no sense of smell and did not realize I was different in this way until I was in my thirties.

While I cannot know exactly how long my late Mom took to complete all of her featured projects, each piece of my work featured here took me more than six months to complete. Thus, this thesis is a culmination of nearly four years of beading and counselling. In her death, I pursued intensive therapy to mitigate the physical manifestations of stress on my MS. After

many years of counselling and reflection, I found that writing autoethnography is the best form of empowering research for those with multiple marginalized identities who do not see their experiences reflected in academic thought. I have blazed a trail for other chronically ill, fat, Two-Spirit Metis like myself, and plan to share my knowledge with my northern community in relations reciprocity (Absalon).

### Metis Epistemology

In his book *Threads of the Sash*, Fred Shore outlines the history of the Metis people, recounting the Metis resistance to displacement by the federal government and our dispossession from the Red River Settlement. Shore's book uses color codes, much like the colors found in the Metis sash, where the colours used in the sash can be used to tell the family history of its wearer. The sash also helps us remember our stories and helps us create unity among ourselves and others. Metis are a matriarchal people, in that women make family decisions and also pass down healing traditions. Traditionally the women did brightly worn handiwork like sash making and beadwork. These cultural expressions continue to heal and unite us to this day (Shore)(Mayer)(Barkwell et al.) (Belcourt, *Beading*)(Racette).

Christi Belcourt is a famous Metis who turned her Metis citizenship back into the Metis Nation of Ontario (MNO) in protest against the MNO's actions. As a member of the MNO, Belcourt disagreed with their decision to support energy and mining exploration and contracts and had her name and her daughter's name removed from the Metis Nation of Ontario's registry (CBC News). Christi is a renowned beader, and Indigenous activist who shares her beadwork and painting in an effort to support Indigenous self-determination and sovereignty. In her book, she outlines the healing effects of beadwork as a means of coping with grief. When a person passed into the spirit world, family would gather and hand incomplete beadwork projects to the



bereaved survivor “we did our bead project to honour someone who helped us survive and cope...It had a therapeutic quality.” (Belcourt, *Beading* 15).

Like Belcourt, art is the way I understand and interact with the world as a creative Metis. Not only does my beadwork represent me within my Metis community, but it also helps me understand my place in the world as I contribute to a cultural tradition which is often overlooked. Much like autoethnography encourages the exploration of the evolving self, “[Metis] beading and all its accompanying knowledge [is] a fluid, living entity which grows and expands”(Bourgeois 9).

Beading helps me understand my relationships with others, making it a natural fit for sharing the stories and subsequent theoretical frameworks needed for a complete autoethnography. Since “Beading occupies a central and revered place in Métis culture” (Bourgeois 2), practicing this cultural knowledge grounds me in my Metis identity and gives me a feeling of connection to my ancestors. With the Metis epistemology of beadwork, I am able to talk about difficult things. With beading, I hope to make “concrete the abstract theoretical findings of research.” (Kovach 60). In linking my beading stories to theory, I respond to the health and identity needs of my northern Metis community (Kovach). Rather than tell mythical stories of Metis epistemology which I did not learn as a Christian child, beading will tell the personal stories of my late Mom and myself to foster collective strength and unity. Like the infinity symbol used on the Metis Nation flag, stories remind us who we are and where we belong (Kovach)(Barkwell et al.).

Stories are our Metis way of sharing information and reaffirming what we know with our community. Creation teachings form the first type of stories shared within Indigenous communities, and personal narratives about events and experiences form the second type of

stories that form oral tradition (Kovach). “Stories are vessels for passing along teachings, medicines, and practices that can assist members of the collective.” (Kovach 138).

An Indigenous community’s collective memory is maintained with storytelling. But as Kovach notes, it can be a struggle to maintain oral tradition as valid academic qualitative research. In order to utilize story as method, one must examine the epistemological understandings at play, and realize that Indigenous storytelling traditions are intended to be reflexive rather than literal and empirical (Cruikshank). “Knowledge embedded in oral traditions remains...more like experiential than experimental science.” (Cruikshank 391).

The community knowledge shared in storytelling and oral history demonstrates to community members that all actions are interconnected and have an impact. “Oral traditions are more transparently reflexive than science which often seems more likely to bury its assumptions and be less self-consciously aware of the institutional history of its practices.” (Cruikshank 391). The underlying assumption that everyone has the capacity and insight to understand the story, to help them understand how the world is understood within Indigenous communities (Kovach). The relational grounding of storytelling in our community’s mandates that when storytelling is used in research, the research be relationship driven. Within the context of relationships our stories give us a sense of purpose and direction, or a means of resistance (Brown and Strega). In telling our stories, we counter what has been previously counted as knowledge; by passing our values through stories, we place the highest value on our own experiences, centering ourselves (Thomas).

Telling our stories is important. In them, we are not people disabled by chronic illness or our location in a vast region, or as disabled northerners struggling to access services that allow for a better quality of life, but as Metis whose ancestors were part of the Red River Resistance,

we are able to assert ourselves like Louis Riel encouraged to do before he was hung; we have courage even when life is dire (Gibbons). To accurately reflect the relational nature of Northern Metis life, the researcher must be a reflexive narrator aware of cultural meaning and the decolonizing nature of the research; stories are truly “who we are” (Kovach 157). By sharing my beadwork stories with you, the reader, you are invited to understand the world in a Metis way - an interconnected way that knows that we are all dependent on each other. We are in a relationship with everything, all of the time. (Kovach)(Martens et al.)(Bartlett). In her book *Kaandossiwin: How We Come to Know*, Kathy Absalon, an Anishinabe academic explains the interconnections of community ways of knowing within Indigenous peoples with the framework of a flower and all its pieces; petal, centre, stem, and leaves; “Each element of the pedal flower is connected and interrelated to the whole of the flower and ought not to be interpreted in the absence of its wholistic context...indigenous worldviews are wholistic, relational and interdependent.”(48). Like the beadwork presented in this thesis, which was sewn in different times of life; each pieces holds stories that connect to other times and places.

The phrase ‘Nothing About Us Without Us’, is not just applicable to the disability rights movement ; Indigenous peoples are often left out of Indigenous research with our own ways of knowing the world abandoned in favour of Western frameworks (Brown and Strega)(L.Smith). Linda Smith outlines an Indigenous research agenda as being one of self-determination; “indigenous communities as part of the self-determination agenda engage quite deliberately in naming the world according to an indigenous world view. What researchers may call methodology, for example, Maori researchers in New Zealand call Kaupapa Maori research or Maori-centered research”(127).

Much like disability communities have fought for recognition within research as experts of their own experiences, so are Indigenous peoples asserting their knowledges as the best fit for research within their communities. Emancipating oneself self through transformative research often requires “violating research and academic norms” (Brown and Strega 2) to centre oneself in the creation of knowledge. To create research from the margins of society, as a disabled and chronically ill Metis I must refrain from objectifying myself and transform what I know about academia and take up space that is unique and undefined in an effort to speak to the intersectional oppression I survive (Brown and Strega). My survival is like my beadwork “There is no right or wrong way. No one way of beadwork is better than another way. Each person brings something important to each piece that they do.” (Belcourt, *Beading* 11).

Autoethnography within Metis epistemology is possible, and beading is the visual method that I will use to incorporate the way I experience the world, informed by disability studies and Metis knowledge recorded by MMF. Like beadwork is unique, so is my reflexive examination of Metis chronic illness and disability experiences lived by my mother and me. The frameworks within disability studies and the MLPF allow me to define the spaces held by our beadwork stories and share them with you, the reader.

The roles of Indigenous researchers are many-fold: creating knowledge that demonstrates social injustice, recovering lost knowledge, and creating space for those previously silenced to challenge our intersectional oppressions. Decolonizing of our realities must take place; to do so, we must question the construction of history. Reframing our past is an important part of decolonization and as Smith concludes “the need to tell our stories remains the powerful imperative of a powerful form of resistance.” (L.Smith 47). As a disabled and chronically ill Metis, I must question what is centered in my life and reframe my own narrative to center

myself. Like medical institutions define who is disabled and chronically ill, so are governments responsible for defining who is Indigenous and what medical services are assigned to us. By sharing our beadwork stories, I am helping build the resistance against those that would say we do not exist or matter as disabled and chronically ill Metis.

In Canada, many do not comprehend who the Metis are, let alone care about our health and disability status. As Metis who was indoctrinated as a child to be a Christian settler, decolonizing involves me examining the euro-centric influences that shaped me and choosing to live in a different way as an adult. I am within a system of government and systems that are not my own, and I must work daily to affirm my Metis understanding of the world. Beading helps me affirm the way I understand the world as Metis and is an integral part of who I am, as I cope with disability, illness, and grief. Locating myself within the colonial construct is part of my work to decolonize and work to mitigate the oppression I perpetuate with my class and skin colour (Brown and Strega).

Absalon and Willet reinforce Smith's statement on decolonization; resistance of colonial models can only be furthered by locating and centering ourselves before trust can be established that the storytellers remember themselves for our research purposes. Weaving our stories through narratives that include teachings, myths, and personal histories resists colonial presuppositions about written knowledge. Story telling encourages the reader to engage in an inherently Indigenous knowledge sharing method (Absalon and Willet). Decolonization does not necessarily entail a complete and utter rejection of all Western knowledge; like autoethnography it centres a narrative which might otherwise not be known. Metis decolonization involves centering our concerns as Metis with disabling chronic illnesses, and "coming to know and understand theory and research from our own perspective for our own purposes" (L.Smith 52).

Metis epistemology forms the way I understand and write this autoethnography: I am always growing and learning as Metis and this autoethnography provides a snapshot of how I see myself at this point in space and time: I have changed as I wrote it and look forward to learning even more about myself in the future.

### Metis History

The Government of Canada recognizes three groups of Indigenous peoples: First Nations, Metis and Inuit. First Nations and Inuit peoples comprise both the largest population and the smallest population of Indigenous peoples, and both are eligible for Non-Insured Health Benefits as part of Indian and Northern Affairs Canada's (FNIHB). Metis people are distinct in our history and culture, but the government of Canada does not provide us any health care through FNIHB. Metis health indicators are largely underreported and underrepresented by Federal government agencies, since a treaty obligation to provide for our health care is not established (Statistics Canada)(Thistle).

Metis are not just simply half European and half First Nations: Metis culture is unique and was born out of the Rupert's Land fur trade in the 1700's. Before Canada assimilated the West, the Metis worked as hunters, traders, travellers and an impressive military force. We provided for ourselves by hunting Buffalo and trading with the Hudson Bay and North West Companies. We have a history of being strategic and collaborative in both the way we governed ourselves and the way we travelled in groups with Red River Carts (Shore).

The Red River Settlement in what is now Winnipeg is our homeland, and we continue to advocate for recognition in the political landscape of Canada. The Metis' original settlement was rejected by Canada despite Louis Riel, the father of Manitoba, forming the first provincial government; Manitoba was resettled by Canadians and settlers from Ontario and Riel was hung

in 1885. Thus, the federal government disavowed Metis authority to govern ourselves, and appropriated the first Manitoba government. With the hanging of Louis Riel, the Metis' place in history was solidified as an inconvenience to the western expansion of Canada. Metis had to be displaced from Red River before treaties could be secured with First Nations in the West.

Remaining Metis were offered scrip in lieu of the occupation of our homeland; the scrip was quickly appropriated with discriminatory government policies. Metis remain displaced from Red River and the land that was promised to us by the Canadian government; we fled for our lives after Riel was hung, and we live dispersed across Western Canada to this day

(Osborne)(Stevenson)(Thistle). Being displaced and finding new locations to settle has made Metis are a highly transient people, because we are used to relocating and living in poverty much like the Romani population in eastern Europe.

In 2016, Indigenous or Aboriginal peoples account for just under 5 percent of the total population. Metis account for 35% of Indigenous peoples in Canada; out of 34,000,000 Canadians, Metis are almost 600,000 strong and nearly 1.5% of the total population. In Manitoba's population of nearly 1,240,000, Metis represent about 90,000, or about 7% (Statistics Canada).

As a minority population in the province that we helped create, Metis live a complex legacy of colonization, displacement, marginalization, and poverty, without a recognized land base. Metis have been assumed to be assimilated into Canadian society, because we are assumed to occupy the spaces between established First Nations communities and the cities that Canadians live in (Shore)(Barkwell et al.)(Stienstra).

In Northern Manitoba, Metis communities of mixed non-treaty status Indigenous people are found outside many First Nations, where the residents fail to qualify for membership with the

local First Nation, and are ineligible for treaty status under the Indian Act. Other Metis communities tied to the Red River Settlement are found along the rail line that cuts across the northern tundra and connects goods to the Port of Churchill. Red River Metis people live in Thicket Portage, Pikwitonni, and the town of Churchill all along the rail line, but have limited rights as Metis living on treaty land. As northern Metis connected to the Red River Settlement, we have no rights to harvest or hunt on the land that we live on, outside of regular provincial authority and we are regularly consulted by the federal government about our land use, as the surrounding First Nations look to increase their own land capacities. The geographic region within Manitoba that we live on creates a second-class Indigenous group, as our harvesting and hunting rights remain unrecognized. As a displaced Indigenous group, Metis have settled all over Western Canada without losing their Indigenous rights to hunt and harvest, but northern Manitoba remains an exception to the same rights. We are not allowed to exercise the Metis right to harvest or hunt in northern Manitoba. This federal government failure to recognize Metis rights recently resulted in the murder of two Metis hunters in northern Alberta (Cecco).

Because the settler state does not take a leadership role in explaining the rights of Indigenous peoples across Canada, we are subjected to violence in every province by non-Indigenous residents who do not understand Indigenous rights. Indigenous peoples are left to die while non-Indigenous people see the exercising of inherent Indigenous rights as exploitation. The violence of non-Indigenous people who do not understand Indigenous rights, which the government has agreed to, is demonstrated across Canada as bureaucratic systems like hospitals, schools and courts of law perpetuate discrimination against Indigenous peoples. This systemic discrimination results in further marginalization and death. Much like the United States of America was built on the premise of Black chattel slavery. Canada relies on Indigenous lands



and extinction of Indigenous nations to continue to exist. This is white supremacy which is thoroughly racist. (Brown and Strega)(Thistle)(Weaver)(Blackpast)(McRae).

While Metis thrive in a racist and white supremacist country, we must reclaim our language and culture. Known as the “flower beadwork people” (Belcourt, *Beadwork*), Metis people are known as creators of beautiful art in both bead and woven form. In the 1800’s, Metis could be recognized across the Prairies by the way they dressed – with bold colors and bright beadwork. Metis incorporated many cultures into one and made it all distinctly their own (Barkwell et al.)(Racette). Metis people value and respect all different ways of life and belief systems, and there are no outsiders in Metis community because we know how painful it can be to be an outsider (Campbell).

#### Disability Theory

Not all disciplines in academia are shaped by modernity equally, while imperialism dictates that Eurocentric thought and the disciplining of knowledge are the formal structures found in academia, anti-oppressive work in fields like Disability Studies centres the lived experience of people which are rejected from Eurocentric ideals by the very nature of their existence (L.Smith) (Davis). Historically, academic disciplines were dominated by the most privileged people: white, heterosexual, cisgender, able bodied, thin and those with the wealth to spend on pursuing knowledge (L.Smith)(Bishop)(Maracle)(Oliver). For example, human biology as a field was founded with the bodies of minority populations which were used as research subjects, and not as authors of biology textbooks. Like the disabled and chronically ill people who were murdered by the Nazi’s of World War Two and Henrietta Lacks, whose cells have been used since her death in 1951 for medical research to this day (Gill and Erelles) and the Indigenous people in Manitoba who were sent to Tuberculosis sanatoriums in the 1900’s for

isolation treatment; only to be experimented upon by doctors who performed exploitative, inhumane and non-consensual procedures. Indigenous peoples in Manitoba Tuberculosis sanatoriums like my maternal grandfather had their lungs purposefully collapsed or singularly removed in an effort to find a cure for the disease suffered by many Canadians (Lux).

It is in the face of this violence, that I utilize Disability Studies frameworks for discourse to support the understanding of Metis people living with chronic illness. The three frameworks utilized in this thesis are: the social model of disability, Susan Wendell's feminist disability reflections found in *The Rejected Body*, and Rosemare Garland-Thomson's article titled; *Misfits A Feminist Materialist Disability Concept*. The social model of disability, originally created by disabled men in Europe in the 1970s, asserts that disabled people are disabled by their environments not by their bodies, and that disabled people are not inherently flawed, rather society is: the flaw is found in the way society is structured around able bodies only. The social model asserts that medical understandings of disability are flawed and false, but does not make efforts to include those who are disabled by chronic illness (Oliver)(Wendell). Unfortunately, as a chronically ill disabled person, the social model does not fully account for my experience of disability which is largely a result of my bodily impairments. So much so, that when I first applied to graduate studies I remained unsure if disability studies as a field would require that I not utilize medical advances which allow me access to CRAB medication.

A feminist disability understanding allows for a less constrictive binary view of disability and disabling barriers than the social model of disability. In feminist disability theories, disability exists in intersectional realities that require discourse to best understand how disabled people engage with society. Within a feminist disability model, Metis identity, disabled identity, gender identity, and human suffering like grief, can all coexist rather than the simplified binary

understanding put forward by the social model of disability (Davis) (Garland Thomson)(Wendell).

*The Rejected Body* is written by a chronically ill Canadian author who identifies as disabled and wrote a book examining the layers of oppressive norms utilized by society to limit the definition of disability and thereby resources available to bodies which do not conform to the same prescriptive norms. To reckon with these layers of norms; “Social analysis helps a lot...most non-disabled people cannot wrap their minds around the possibility that somebody can be disabled or ill and also work productively, have intimate relationships, or be happy.” (Wendell 4). *The Rejected Body* presents many opportunities to socially analyze one’s lived experience with disabling chronic illness by questioning who is disabled and questioning biomedical knowledge of disability in a way that demonstrates the fluidity of a chronically ill person identifying as disabled (8). From examining stigma, social and cultural factors which result in disability, objectification of bodies in the media, the cognitive authority of biomedicine, and locating value within embodied experiences of disabled people and their carers; Susan Wendell offers perspective and guidance to conceptualizing disability and chronic illness past the social model of disability and concludes her written offering with strategies for survival in said bodies. *The Rejected Body* is the first practical guide to navigating life I read as a graduate student, and am compelled to include her work as I share the stories of my family beadwork.

Rosemarie Garland-Thomson’s work on misfitting is best described by Garland Thomson herself; “A fit occurs when a harmonious, proper interaction occurs between a particularly shaped and functioning body and an environment that sustains that body. A misfit occurs when the environment does not sustain the shape and function of the body that enters it” (594). By

naming the nature of misfitting in environments, disabled people are empowered to centre their own experiences rather than contend with medical victimhood which “emanates from prejudicial attitudes that are given form in the world through architectural barriers, exclusionary institutions and the unequal distribution and access to resources”(591). By exploring our embodiments and their fluid meanings within the concept of a misfitting society, disabled people like myself can ascribe the value that is due to be assigned by an ableist world. I will explore the misfitting evoked upon my mom and myself as we attempt to fit into a able-bodied Canadian society which does not value our existence. Our beadwork is record of our resistance but also our dependence, vulnerability, and interconnection with one another, which Garland-Thomson notes as a highlight of disabled misfitting in a non-disabled society (591).

#### Beadwork Stories

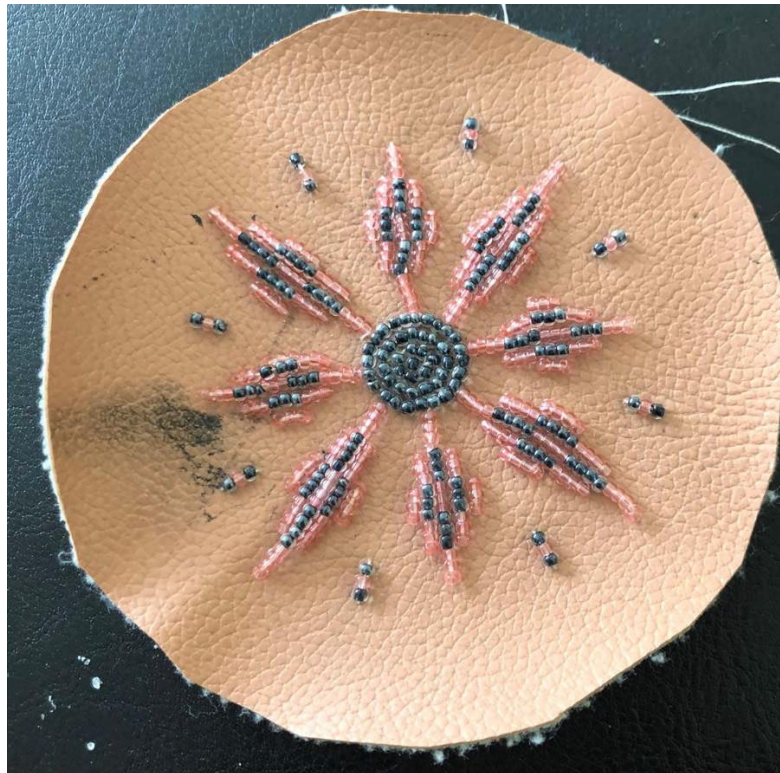


Figure 1. Multiple Sclerosis & A Weight Loss Cure: My Christmas Star beaded by Valdine.

Figure 1 is a one needle style star that I learned how to make while spending Christmas on a reserve with my family, is 10.5 cm in circumference. As part of the activities and experiences my Mom had while she lived on a reserve to support my Dad's work, she taught me how to be bead and sew a small project. At the time, I found beading far too tedious and I gave up before my first project was complete. Fortunately for me, Mom was proficient in beading and insured I left that holiday with a small pair of ornamental beaded moccasins, which I carry to this day.

The stitches in my Christmas star are crooked. I used only two colors and I rushed but this project still took me multiple days and much physical pain to complete. There is a black ink stain on a section of the bead work now; it comes from the time it has spent displayed at my desk at work. I skipped the step of securing most of the pattern because I got bored. But that is not the story this piece tells; this piece shows how I understand and interact with the world. I began my life thinking that all Indigenous cultures were inherently wrong. Now I have grown to love and accept myself as a chronically ill and disabled Metis. Beading has given me a way to belong and contribute to Metis culture.

In 2003 when Mom told me that she had successfully become a member of the Metis Nation and that I qualified as a result of her genealogy which showed our link to Red River settlement: I became eligible for Metis university funding. I remember dancing in our backyard at my sheer luck, now that I could declare Metis identity in my future scholarship and job applications. As a child, I always knew my Mom's family was partly Indigenous. But it was a matter of family shame, and I did not know that I was Indigenous as well as I was raised to be only strictly non-denominational Christian.

By receiving membership in MMF, I began to feel like a fraud and Metis imposter because I had no knowledge of my culture and believed that being Indigenous was sinful, which thereby

decreased my likelihood of getting into heaven or being taken by Jesus to ascend in the rapture with my parents. This was incredibly stressful once the Metis local government in Thompson delivered a letter to me informing me of my full sponsorship supporting my final year at university.

After a month in my life as a sponsored student, I began to lose vision in my left eye. At the time, I thought nothing of it, because as a child I saw an ophthalmologist in Winnipeg every six months. I assumed that my eye issues in Vancouver were simply related to my lack of seeing an eye doctor as an adult. I remember one morning sitting in my apartment and realizing that the items displayed in front of me were floating in midair, and that when I focused on a single item, it started to appear to bend and melt. I promptly went to the campus doctor, who assumed I was a stressed-out woman manifesting ‘symptoms’ he told me to come back after seven days has passed.

I felt a lot of pressure as the university’s registration office had yet to receive tuition payment from MMF, and regularly threatened me via email with my loss of enrolment; I did not understand how to help the situation. The mounting pressure of not being able to complete my degree caused a great deal of panic. I did not have the financial resources to pay for school on my own and the dream of being the first on both sides of my family to complete university felt like it was slipping away.

Eventually enough time passed and I was referred to an ophthalmologist locally, who conducted extensive eye testing on me alone one evening which I found quite frightening, and I was called back a week later for the results. I remember politely declining the call back appointment when the receptionist on the phone asserted that this was not an appointment I should postpone. I took a friend with me and we sat and listened patiently as the doctor informed

me that I did not have a brain tumor; rather I had MS, which I thought was hilarious due to my lack of symptoms that the doctor listed for MS. I was referred to complete a CT scan with contrast dye and that is when more disturbing MS symptoms started to appear.

Suddenly the next day I had intense vertigo and trouble walking as a result. I lost the fine motor ability to write my own name - which would not have been a big deal had I not been a member of the orchestra. The loss of the ability to walk on my own combined with the loss of fine motor skills in my dominant hand resulted in my inability to play bass trombone in the orchestra at a public concert a week later. Bass trombone was an instrument I had played for more than a decade.

I remember trying to play a line from a mambo from West Side Story which is a fast-paced piece, moments before a performance for the orchestra director, but I discovered that I could not move my hand quickly enough to articulate the notes. It was the first time in my life I had to fake-play an instrument, which was deeply distressing. It was devastating, and I felt like a fraud to have to pretend to perform. Unfortunately, that was not the end of the devastating new MS symptoms: because of my trouble walking, I fell at the venue where we performed and developed a noticeable bump on my forehead. The older members of the orchestra informed me that it looked like I had had a stroke because they noted a difference on one side of my face. The shame I felt from having an older adult observe MS symptoms in me before I knew them myself was especially pervasive as I was the only fat woman in the orchestra.

After my results appointment with the ophthalmologist, I was referred to a neurologist, who ordered an MRI to confirm the ophthalmologist's suspicion. I had begun to manage my vertigo with anti-motion sickness medication which allowed me to walk, but also forced me to sleep a lot more than usual. I shared an apartment with two women who were also completing

their degrees. One of them took the liberty to wake me up one day and inform me that it was not good for me to be sleeping this much. I told the other woman that I lived with that I was experiencing the symptoms of multiple sclerosis (MS) but that I did not want to talk about it. She proceeded to remind me of the symptoms of MS casually throughout the semester. Our friendships did not last very long, because I felt dehumanized by each of them.

By December, only two months after my first MS symptoms, my neurologist informed me that I had a classic case of MS but that he could not do anything about it until I had another flare-up. I pursued extensions on my fall final essays thanks to a medical emergency notification that my school's campus doctor sent to all of my instructors, and then I then took my term papers home to northern Manitoba to complete my fall term. I remember thinking that despite MS, there was no way in hell I was giving up my MMF sponsorship in order to move home to my isolated northern community without a degree or appropriate healthcare. I chose to stay in school several provinces away from home despite how scary it was to manage new specialist appointments without my family.

When the new academic term began in January 2006, my MS symptoms had gone into remission, and my denial was full-blown. I was able to achieve several months of academic success without further symptoms. But as I neared my final exams, the familiar loss of fine motor control returned. It was at this point that I approached the accessibility office on my campus to ask for accommodation for my disability, because MS was clearly affecting my ability to complete my degree. No sooner did I disclose my diagnosis to the staff person that they informed me I did not qualify for accommodation as I did not possess a learning disability and I left confused and ashamed.



It was at this point that desperation struck. I took matters into my hands, and approached each of my instructors individually. The chair of my department allowed me to write his exam on his laptop at the front of the class while another instructor allowed me to take a D on the exam so that I could focus on resting the day of the exam, in order to successfully walk on the stage at my convocation the following day which my family had travelled to attend.

My balance was so poor the day of convocation in April that I staggered into the church where the event took place with my family. I was terrified that I would be removed from the church for appearing to be intoxicated. I wore my Métis sash over top of my convocation gown and suggested that school employees were racist for demanding that I remove it before I receive my degree. I proudly and cautiously walked across the stage while wearing the sash, representing the Metis community who helped me complete my degree! It was the first time in my life that I was able to visibly be a proud Metis in front of my family. My Dad had told me that I was not really Metis because I was not raised in the culture and my skin was fair like his, so I continued to feel shame for accepting MMF sponsorship. Accepting my degree as a visibly proud Metis reaffirmed the sense of fraud I felt, as not really Metis. I felt like I had stolen money from the MMF by allowing me to be an education sponsored student when I was not raised in my culture and did not have brown skin.

The two different colors in the beaded star represent my able-bodied life and my disabled life. The colours also represent Metis identity and my settler Christian identity. The centre of the star is black, much like the feeling of loss I had when I was diagnosed with MS, as well as my feelings of fraud when granted MMF student sponsorship, given that I was raised as a Christian to believe that all Indigenous culture was demonic. This star reminds me of the north star and hope that endures in my life when uncertainty is present. The north star is always present in the

sky and acts as a wayfinding point when one is under the night sky. In a region which is dark for the majority of the eight-month long winter season, the north star is a reminder of how to find one's way.

Much like the circle on which the star is beaded, my journey has high points and low points. Even the imperfections have artistic meaning; the black ink stain represents the pain and difficulty I endured to incorporate all of my identities into one. Despite growing up as a fat girl who tried to mold herself into a thinner, 'healthier', more Christian body; I continue to live with MS which was not cured by starving myself or obsessively exercising and I have learned to trust my body's regular need for food and rest. I am both disabled and able to pass as able-bodied, and just because I was raised as a non-Indigenous person does not make me less Metis.

Similarity, being raised in a cult-church which incorporated more Indigenous spirituality practices than many other churches, while at the same time condemning Indigenous culture, spirituality, fatness or 'gluttony', disability and chronic illness as 'demonic and evidence of sin', does not make me less of a disabled fat feminist today. I have lived experience on the intersectionality of disability, Metis, and feminist identities and fatness both on the side of oppressor and oppressed. I spent the first 21 years of my life centering a patriarchal, able bodied religion which told me that my worth could only be found in the ability to be attractively thin and agreeable enough to marry and 'bear children' to a man. Like Sabrina Strings notes in *Fearing the Black Body*, Indigenous bodies are only valuable if it conformed to the idea of a godly Christian woman which leaves no room for sinful fatness (Strings). At more than three hundred pounds and a couple inches short of standing six feet tall, I was not seen as virtuous as I was not 'in control' of my weight, like a good Christian.

The leather on which the pattern is sewn was some of the first leather my late Mom used for her first beadwork projects. She shared a piece of her original leather with me for the star. Now that she's gone, I know that by sharing that hide, she shared her strength, compassion, and love with me. By sharing her knowledge, she gave me the teachings and coping skills to live without her.

While that was my first Christmas living with MS, it was also the Christmas that she taught me to bead. In addition to a new MS diagnosis, I was also disabled by the way I thought about Indigenous cultures and being fat; I did not identify any part of me as Metis despite being an MMF sponsored education student and I was on a personal vendetta not to gain any weight during the holiday, as I had been obsessively exercising and starving myself for several months. The side effects of beginning to inject interferon while distressing, motivated me to control my eating and exercising as much as possible in order to eradicate my MS. I truly believed that my MS diagnosis was a result of my sinful fatness and that eliminating my fat would heal my MS.

I returned to beading nearly fifteen years after I being first taught; when I was looking for a way to remember my mother's memory and begin to honour my grief. Beading became my self-care activity while completing graduate school, and the way I affirmed my Metis identity without my matriarchal connection and familial relationships. I slowly learned, after years of beading on my own that by beading, I was sewing myself together, healing my heart and sharing my truth.

A legacy of self-colonization of mind, spirit and body was imposed on all of my family. Now beading gives me the strength to integrate all of my identities: Metis, disabled, and Two Spirit. It has taken me a long time to accept that I am not inherently demonic for being these things, as taught by my parent's cult-church.

The undergraduate university I attended created a disabling environment by assuming that all students were able bodied, average weight, non-Indigenous people much like normative conceptions of bodies found in the medical model of disability (Thomas) and Christianity (Strings). By not being having a body that conformed to wealth and size ideals; my inability to pass as a healthy Christian became more dramatic, and rather than be accommodated formally by the school I was forced to appeal to the compassion of each individual instructor. Relying on individual levels of compassion in order to be accommodated within each instructor's comfort level allowed me to complete my degree, although pleading my new disability to numerous instructors took a toll on my mental health, and the self-disdain of my fat disabled body stayed with me for more than a decade as I navigated a society not built for chronically ill young adults. The social model of disability as applied to this story highlights an inaccessible society functioning in a dysfunctional manner: ignoring disability and disregarding those that do not conform to normative ways of having a body (Davis)(Oliver). The university I attended creating additional barriers to completion of my degree, and being told I wasn't disabled at an institution contributed to my denial about having MS. The relapsing nature of the disease contributed to my misunderstanding that I could cure myself of the sin of being fat, Metis and sick. If the university had subscribed to the social model of disability, my bodily differences would have been accepted and alternative methods of assessment, supportive technology and tools would have been available to the entire community much like the best practice known as Universal Design for Learning, which focuses on the intrinsic ability and natural bodily diversity found in the general population, thereby allowing all bodies to demonstrate learning in the manner which best fits their ability (Katz).

Susan Wendell surmises the situation I survived in undergraduate studies well; “identifying individuals as disabled are social practices that involve the unequal exercise of power and have major economic, social and psychological consequences in some people’s lives.”(23). Wendell’s conception of chronic illness as disability helps me understand the power dynamics I struggled to navigate and conform to as a young adult, and allow myself more compassion for the following years that I felt like a disability imposter despite being sick from interferon.

“It is in the interest of many providers to define disability narrowly, so that fewer people are seen to be entitled to the benefits they are supposed to provide.” (Wendell 24). While the bureaucracy of the university was not supportive of me as a person with MS because it would cost money; my Metis government continued my sponsorship funding through the entirety of my diagnosis. As the first sponsored Metis to attend the school, I was mentally and emotionally disabled by the university’s threats to de-register me while they waited to receive payment from MMF. The gaslighting effect of being deemed ‘not disabled’ took years for me to unlearn as I learned that I could be disabled and still appear to be able bodied (Wendell).

Rosemarie Garland-Thomson’s work on misfitting provides the most holistic understanding of the Christmas Star beadwork story: living with MS as a young adult results in numerous and repetitive misfits between myself and a society not designed to allow for the existence of young adults with episodic disabilities. As a newly chronically ill person, I was particularly vulnerable to see my body as inferior and immobilized. Fortunately, due to the relationships I held with the majority of my instructors I was able to maintain enough agency to complete the degree; within my misfitting they saw my vulnerability and inter-dependence on them to support my completion by allowing me to complete assignments and exams in different ways and times than they ascribed in course syllabi (Garland-Thomson 591). The impairment

granted to me by having MS was mitigate by having instructors who refused to devalue me like the accessibility office before them for not having a “generic disabled body” (592).



Figure 2. Diabetes and Being Out of the Closet as Metis by Sharon.

Each leather miniature moccasin is 7.5 cm long x 3 cm wide and the connecting leather is 33.5cm long x 1cm wide. After Mom taught me to bead a star, she tried to teach me to make a pair of decorative baby moccasins. I remember giving up shortly after I realized that Mom was hand sewing the moccasins, meaning she did not use any of the sewing machines I had used growing up to make clothing with. Gaining her MMF citizenship gave her the freedom to acknowledge her Indigenous identity for the first time in her life and living on a reserve with my Dad gave my Mom permission for the first time to engage in an Indigenous cultural practice. Once traditional handiwork became part of Mom's belonging on a reserve along with my Dad's incorporating into a community for work, it become acceptable. That was quite a change. As a child raised in Thompson, I vividly recall weaving my own dreamcatcher in grade eight and bringing it home to show off, only to have it destroyed in front of me by my parents because they believed that all Indigenous culture was demonic.

Mom was raised on a small piece of land outside of the village of Winnipegosis. Her Mother lost her Treaty 2 First Nation status when she fled her first marriage on the reserve to

escape domestic violence. After moving from Crane River to Meadow Portage, my Gramma remarried her first cousin who was adopted. As an adoptee, my grandfather's skin was quite fair, and his Ukrainian last name allowed both him and my non-treaty status grandmother to assimilate into Ukrainian culture. She did not raise her children to identify as First Nation or Metis, but she did provide care to her First Nations father, who became blind as a result of drinking moonshine. My Mom used to smile fondly remembering stories of her grandfather, who lived with them on the acreage outside of Winnipegosis. Her family had to run a string from their home to the outhouse so that he could go to the bathroom without help. This man gave all the nine grandchildren nicknames, which is how my Mom became to be known as robin, or pipichiew to her family.

Mom developed pre-diabetes with each of her two pregnancies, which is why my Dad had a vasectomy without her knowledge. Shortly after my younger brother was born, Dad as a newly Registered Nurse made the unilateral decision that his wife's health would not remain intact should she bear the additional children she desired, and he had the procedure completed. Despite his effort to 'save' her from a life with chronic illness, Mom developed type two diabetes nearly ten years later. As a family, we all embarked on a sugar free lifestyle with the higher protein and fat foods saved for Mom as part of her diabetic diet. Mom got first choice of all the meat served at meals, and had access to larger meat portions and real cheese than the rest of us. Cheese whiz and ketchup were staples of my childhood nutrition; and the foundation of many meals. As a teenager I regularly stole and ate the high protein foods reserved for my Mom when I was hungry.

Mom completed all the work on these miniature moccasins that she gave to me as a first beading project. Just like she did work of securing our MMF citizenship; paying to have our

genealogy professionally completed, which provided evidence of land script from the Red River Settlement. After a lifetime of hiding the truth of who she was in order to survive: from having cousins stolen in the 60's Scoop, to having a sibling forced to attend residential day school-- Mom was encouraged by Dad to obtain Metis citizenship. Then, she started telling other Indigenous peoples in her Thompson cult-church that she was also Ojibway. I believe that starting beadwork on reserve helped her come out of the closet as Metis and Ojibway and that being accepted by both the Metis and First Nation communities gave her the confidence to begin speaking her truth. She began to remember who she was, and not just who she practiced being in church throughout her lifetime.

Just as knowing about Metis culture and history makes me feel connected to Metis culture and resiliency, I am inspired to question what I know about myself in a deeper way. Once I realized that my Indigenous culture was not actually demonic or sinful--I was able to look closer at my childhood experiences and accept myself at a level I had not known. I was bullied a lot as a child but especially when I looked androgynous due to a short haircut and my fat body. Unable to find feminine clothing that fit me, I resorted to wearing men's jeans and sewing my own clothing until I could save enough money to shop for myself in Winnipeg at a plus size women's store. It cost a lot of money to present myself in feminine clothing and I quickly learned that the shortest route to not being punched in the face was to maintain my hair at as long a length as possible and make consistent effort to appear feminine to minimize physical assault and bullying. Since I began this thesis, I have remembered my truth of acting out feminine body characteristics in order to be physically safe from assault. I am inherently gender fluid and identify as Two Spirited now that I am safe to do so. Those who assaulted me as a child are still



alive, but they do not shape my physical appearance any longer and am slowly addressing the ways in which I perform feminine body characteristics to feel safe in my body.

Because of Mom's willingness to complete my bead project for me and honour the space I was in at that time, I feel confident that I can now complete this phase of my life with her in the spirit world, supporting me. I will claim my heritage and be proud of who I am, even if most of her family will not do the same. I am healing the inter-generational trauma (O'Neill et al.) of shame by loving and accepting myself exactly as I am in this moment, without trying to force myself to fit into able-bodied, gender ideals that I do not embody. I am Metis, chronically ill and disabled, fat and Two Spirited and I do not need to change any of these things; I am worthy of life just because I exist ("United Nations Declaration on the Rights of Indigenous Peoples")(Lang et al.)(Detrick)(Boivin).

The black-and-white beads used on this project represent two different cultures within my Mom's family: Indigenous and Ukrainian; the hide rope that connects the two moccasins represents Christianity. My Mom's family colonized themselves and built a church on their little piece of land outside Winnipegosis in an attempt to save themselves and others from the perceived sinfulness of being Indigenous. The two bead colours also represent her two children, my brother and I.

I was raised as 'the golden child' who followed all rules out of the terror of being abandoned in the rapture and was praised as conscientious on numerous school report cards. My brother was the black sheep who was known as the troublemaker by teachers and my parents, who once fell into a local river with strong undercurrents because 'he was bored'. My brother was born with birth defects of his legs that 'required' being broken and 'corrected' repeatedly. His mobility and quality of life remains permanently affected, and I was born with vision loss

that required childhood surgery which was never completed. Despite our disabilities as children, our mother loved and cared for us to the best of her ability, while Dad worked shiftwork throughout the north. I did not realize we were poor for the beginning of my childhood due Mom's dedication to creating anything we needed and ensuring we saw the land and plants around us as playgrounds and toys. I still collect rocks like she did and remember how to create a duck out of a piece of reed and a twig.

After I was diagnosed with MS in 2005, my neurologist in BC advised me to pursue MS medications as soon as possible given the severity and rate of relapses during my first year of MS. I moved back to northern Manitoba immediately after graduation, and began the process of seeking health care referral to Winnipeg in an effort to access disease modifying injections as soon as possible. I qualified for MB pharmacare immediately as a low income resident, and hoped that securing a neurologist who understood my BC medical chart would allow me to slow the progression of the disease with 'brand new' MS medication. In fact, I was considered lucky to be diagnosed with MS only a year after medications became available for the first time in the existence of the disease, also known as CRAB medications. Unfortunately, these CRAB medications have proven to be poorly tolerated by most and subsequently successful in a small margin of people. I am one of those people, my liver enzymes, thyroid function and critical blood levels have remained relatively stable since beginning my CRAB medication and unlike most of my peers with MS, I have never changed my disease modifying medication.

During the Christmas that Mom taught me to bead I did not have time or patience to do beadwork and mistakenly thought it would be as straight-forward as cross stitch or knitting. By that point in time, Mom who was well versed in living with chronic illness and subsequent medication while it was a scary time for me because I was newly trying to find my grounding

with work and a CRAB medication. I later learned that Mom also spent most of her 20's in a state of self-starvation because she was trying to control her weight.

The Christmas Mom made these moccasins was the first Christmas I actively starved myself. While my Mom was joining her community on reserve through beading and sewing, I was trying to achieve a version of myself without disease and fat which I thought caused MS. I used the side effects of the CRAB medication and MS symptoms to motivate myself to continue to starve. In that way, the two color beads of this project represent my internal war against my own body, mentally and physically which Mom also endured in her 20s as an able bodied closeted Indigenous person. I had no willingness to embrace the Metis identity Mom was creating for herself until after her death many years later.

The social model of disability can be applied to the story of the miniature moccasins by noting the changes undertaken by various members of her family—particularly on the collective change we undertook as an immediate family to alter our diets to eliminate food that would raise Mom's blood sugar (Davis). It could be argued that even Dad was attempting to eliminate disabling barriers for her (Oliver) by seeking a vasectomy, so that she would not experience gestational diabetes regardless of the misogyny involved.

Susan Wendell's work highlights the "myth of control" (Wendell 137) invoked by our family in regards to Mom's diabetes noting that "the desire to control the body contribute significantly to determining medicines priorities; medical practice is strongly oriented toward life-saving interventions and relatively unequipped to help patients live with conditions that cannot be cured." (137). As a family, we believed in the ability to manage diabetes with food alone, and later as a young adult I believed I could manage MS by performing health activities in an effort to cure myself when neither Mom or myself could be cured by any of our modified

behaviors as we tried to conform to the standard of health expected by society. “To the non-disabled...people with dangerous or incurable illnesses symbolize, among many other things, imperfection, failure to control the body, and everyone’s vulnerability to weakness, pain and death.”(60). By performing diet changes as a family for Mom, we demonstrated how self-controlled and good our family was to healthcare professionals like Dad, and to the cult-church we attended several times a week hoping to prove that despite diabetes, our unilateral effort to control our fat bodies could avoid “the most powerful symbol of disability” (61) the failure to control one’s body.

Rosemarie Garland-Thomson’s application of misfitting to this beadwork story would note the vulnerability navigated by Mom throughout her pregnancies with gestational diabetes, and later in life when her family shifted their behaviour to allow for a positive experience of interdependence in a way that prioritized the quality of food she ate for the first time in her life. As a family we engaged in “subjectivity through an exchange of mutual recognition” (Garland-Thomson 596) so that the domestic world she was relegated to would allow her to experience food as a way to manage diabetes only. We desperately wanted her to feel comfortable with her diagnosis (597). But the fluidity of Mom’s life with diabetes changed each time her family environment shifted each time she moved to support Dad’s work, just like her children’s experiences of misfitting changed as we aged.

While my brother had his feet broken so many times that they appeared to be normal, he lived with one leg that would freeze when playing in northern elements due to reduced blood flow and I continued to change the shape of my body to fit into the world. Neither of us should have been subjected to because neither of us had to change or be changed to deserve a right to existence (597). Mom’s perpetual shifting through environments meant that she never fully

misfit in a space as a diabetic, and was not given the chance to form bonds with others like her, until she was living in a remote community and being tested for tuberculosis. For Mom in this particular remote community; her health, fatness and Metis misfitting bonded her with other Indigenous misfits who shared similar bodies and impairments. She found a collective outside of our family unit and found strength and fearlessness in that community fitting (601).



Figure 3 Sarcoidosis and Using Culture to Pass as an Ally by Sharon

Each mini gauntlet is 7.5 cm long and 4 cm wide at the thumb. The connecting leather is 23 cm long and 1 cm wide. As a healthcare professional, Dad worked numerous jobs in northern MB. His northern work placement included a staggering workload and a more than eighty-hour work week where all staff were regularly called into the nursing station for emergencies or ‘all hands-on deck’. Unfortunately Dad was banned from the last community where he worked, and it was then that my parents decided to relocate to my Mom's abandoned family land hundreds of kilometers south near Winnipegosis; where Dad secured a job at the village hospital.

Mom made this pair of mini gauntlets for Dad to wear at work. The hospital received many ambulances from nearby communities, and Dad hung the mini gauntlets around his stethoscope to show his Indigenous patients that he was trustworthy despite being hard of hearing, fat and a white man. He was regularly found speaking louder than necessary because of his deafness, and this affected his career specifically his ability to hear with tools like stethoscopes.

Dad did not want to believe that his children or his wife were Indigenous, and Mom always tried to look both whiter and less fat than she was. She coloured her hair blonde and wore a lot of makeup, always presenting herself in a well-kept way. She performed well as a housewife; made all the meals, baked all the bread, made all the jam and pickles, and grew multiple gardens to ease the poverty our family experienced. I knew how little we had because Dad was regularly worried about money and both my brother and I dreamed of securing enough money to rid our Dad of his worries. As a young child, I began to hate my Mom for how much suffering she caused Dad. Because I saw her in the villainous way based on the suffering of my Dad, and I do not have positive childhood memories of my Mom. All memories are framed with the lens of her being a villain to Dad. As a child I felt emotionally responsible for him since he regularly confided in me about his work and financial stresses. Our family lived paycheque to paycheque and efforted as best we could so as not to further harm Dad with our existence.

Dad is the white beads on the gauntlets, and Mom is the red beads. The bead pattern is my brother and I; having children kept my parents together. I remember spending an evening in the basement with Dad when Mom came downstairs upset, and threatened to divorce him. I remember being terrified and begging my parents to stay together. In hindsight I wish she had left him: after she died, he continued to tell me about how she victimized and persecuted his white self. This was the first time I saw him as 'just another white man' that believed women

were out to get him. I understood this more fully as his white bead stories after Mom died slowly changed, and began to feature me as a new red bead villain.

Mom was a good Christian wife and followed Dad's unspoken patriarchal beliefs about her. She never talked openly about the Indigenous history her family had disowned. Still, she remained very connected to the land and her extensive family on Treaty Two. There were many trips south with Mom, my brother and I to visit her family and camp on Lake Manitoba together. This is where I learned to appreciate fire-cooked bannock and tea. Camping at St. Ambroise became our quality time on the land and both my brother, and I have many fond memories of the campground there before it was devastated by flood waters.

I think the flood waters on Lake Manitoba at St. Ambroise are like white supremacy in Canada – obliterating Indigenous knowledge we held on the land, and decimating the earth to leave no trace of the stories and ways of life held before it.

I share my story in the hope that you the reader will see the need to be acquainted with Indigenous ways of knowing truth. Both fat and disabled people are dehumanized by a medical system that centres western knowledge, just as Indigenous peoples are colonized and survive genocide by governments who erase our inherent rights. Surviving widespread genocide as Indigenous peoples which culminates in systemic discrimination throughout institutions that fat and disabled people also face.

In *Fearing the Black Body*, Sabrina Strings outlines the racial origins of fatphobia; anti-fat bias is linked to racial, gender and moral discrimination. Fat-phobia is applied to all bodies perceived as embodying “savage blackness” (Strings 21). Anti-fat bias is upheld by Christian ideologies around the world which simultaneously uphold whiteness as godliness and polices the bodies of Christian women. Not only is fatness seen as correlated to savage blackness, but it is

also framed as sinful within Christianity (20). As aptly put by Kimberly Dark, a woman of colour at the 2020 Fat Studies virtual conference “We all understand, without saying why, that no one is supposed to want a fat body like mine.” (Dark). Indeed, being fat, BIPOC, and a woman or two-spirit represent intersections of oppression that Indigenous peoples, disabled people and gender fluid folx hold in varying ways.

In Disability Studies, the social and medical models of disability illustrate opposing frameworks of conceptualizing disability. The social model locates disability within a disabling society which creates barriers with the medical model locating disability within an inferior victim. The belief that disabled people are inferior victims forms the discriminatory belief system known as ableism, which values normative bodies functioning in a normative manner. Much like the Body Mass Index functions to moralize bodies in relation to their level of fatness (Davis)(Rothblum and Solovay).

As mentioned earlier, Maori academic, Linda Smith wrote *Decolonizing Methodologies* to outline the manner in which Indigenous academics can share their knowledge in an imperialist and colonizing Academy. In order to best do this while best honouring our ancestral way of knowing within a knowledge system which values strict fields of study and academic disciplines, Indigenous peoples must remember that we were in existence before the academic knowledge system and continue to speak truth about the ways we live. *Decolonizing Methodologies* gives Indigenous peoples a road map to transcend the fields created by academia and liberates us to speak and share our ways of knowing. “This collective memory of imperialism has been perpetuated in the ways in which knowledge about indigenous peoples was collected, classified and then represented in various ways back to the West, and then, through the eyes of the West, back to those who have been colonized.” (L. Smith 15). Much like fat people navigate thin



society, and disabled people are dehumanized by medicalized ways of categorizing bodies, so are Indigenous peoples charting paths to their knowledge systems within institutions which previously aimed to eliminate us and our ways of knowing ("Truth and Reconciliation Commission of Canada : Calls to Action"). The phrase, 'Nothing About Us Without Us' applies to fat, disabled and Indigenous peoples alike because the intersections of oppression which we survive are connected (Bishop) (Boylorn and Orbe). As Audrey Lorde, a black, disabled, gay Cancer survivor and feminist so succulently surmised at Harvard University at a celebration event for Malcom X: "there is no such thing as a single-issue struggle because we do not live single issue lives" (Blackpast) To isolate an issue and create a discipline of knowledge around it only is the epitome of imperialism and colonizing white supremacy.

The red beads on these gauntlets are equal to the white beads despite being surrounded by white beads, just like white supremacy and colonization dictate the oppression of Indigenous peoples in Canada. Dad defined Mom's life as his subordinate, and even got a vasectomy to prevent her from having multiple children like she wanted.

I struggle to articulate how he treated Mom because she never acknowledged any mistreatment when I was a child; I only heard from Dad about how awful Mom was to him, and I grew to increasingly hate her. Thankfully, when I was diagnosed with MS, Mom was there for me in a way that helped me continue living. I am grateful for the gift of a friendship with my Mom that MS gave me. I am ready to step into my Metis identity and accept my red bead identity as a chronically ill, Metis misfit looking for collective belonging and strength (Garland-Thomson 601).

After she moved back to the mouldy trailer located on her family land near Winnipegosis, Mom developed a second autoimmune disease: sarcoidosis. It attacked many of her organs, but

especially her lungs and kidneys, and she developed large brown circles all over her skin.. Suddenly, Mom became critically sick, and her ability to function deteriorated. As a family we started talking about a kidney transplant, and making changes in our lives to allow for a successful in-family transplant. My brother went as far as to pursue blood pressure medication in his mid 20's to ensure that he would remain an eligible kidney donor, should Mom need one. We made as many trailer modifications as possible, and took her companion dog north with us after an intensive care unit hospital visit in Dauphin. We tried desperately to modify her environment from hundreds of kilometers away, but the majority of changes were left up to Dad, who pursued things that would help Mom maintain her remaining kidney function while taking new medication that eased the effects of sarcoidosis, but amplified the severity of diabetes.

She could no longer look down or do chores for any length of time. This change in ability affected her ability to manage the home in the way Dad expected, and he told me so.

During her time in intensive care in Dauphin due to kidney and lung failure as a result of her sarcoidosis, she nearly died. Her ability to bead never fully returned after sarcoidosis became part of her life, but everything changed again after Christmas in 2015 when she started bleeding, despite being fully menopausal. When she mentioned in to me a few weeks later, she dismissed it as simply something needing to be cauterized, like the regular colonoscopy activity our family was accustomed to undergoing. Unfortunately, it was not that simple, and the decades of sexual abuse that she endured affected her ability to pursue gynecological health care for the bleeding. Mom could count on one hand the number of vaginal exams that she agreed to within her lifetime. I think she would have preferred to die than be subject to them.

The social model of disability offers a way of thinking about barriers of the vastness of Manitoba that Dad travelled across to find meaningful work with his bodily differences. As a fat

person who was hard of hearing, fitting into remote communities did not occur quickly for him and finding work became a burden forced on him because he was so different and unable to conform to biomedical expectations of larger facilities. His fatness and disability affected his perception as a discrete professional. While he was disabled by the medical system that he worked in, he continually worked to acquire increasingly more advanced tools to mitigate his hearing loss. Unfortunately, the biomedical system he was most noticeably disabled within was also the only way he knew to support himself. He was victimized for most of his life while working within and not conforming to biomedical knowledge (Thomas), and I can understand why he felt obligated to share this burden with me as a child. I am incredibly privileged to access the education which allows me to name the barriers he faced.

Once my parents moved south, Mom left several of her supportive collectives and was forced to manage her conditions individually. The isolation estranged her from meaning-making within her fat, Metis and chronically ill life. Feminist disability theory becomes critically important to understanding Mom's lived experience near Winnipegosis, because her existence became both about rejecting her old physical appearance, and surviving with comprehensive disability (Wendell), which amplified her vulnerable embodiment to "literal marginalization" (Garland-Thomson 601). She was completely dependent on her spouse to meet her health care needs and provide resources (Garland-Thomson 591). The myth of control and subsequent expectations of performance (Wendell) fully dissipated for her during this time as sarcoidosis affected most of her previous abilities, and the only treatment amplified her diabetes to the point that it was nearly impossible to manage a safe blood sugar level despite her best effort. No attempt at perfect health behaviour impacted her diseases anymore, and I remember talking to Dad about her worsening mental health as her old methods to objectivity herself and conform to

beauty standards with makeup and clothing no longer succeeded in executing the same familiar control of her body (Wendell 88). Instead, she spent much of her time in her 'farm clothes' making the most of her gardening and landscaping skills; she started growing the most amazing food and flowers on her homeland.

When Mom developed sarcoidosis after moving to Winnipegosis, environmental changes were no longer within our family reach, because we could not support her in practical ways like adjusting the way we lived as a unit. My parent's decision to relocate to Treaty Two territory in an abandoned family trailer where Mom was raised only isolated her from supportive relationships, and immediate family in northern Manitoba, and forced her to rely solely on Dad and a trailer filled with black mold. The local doctor tried to determine the cause for her sudden vertigo, until she was hospitalized in Dauphin with much more severe symptoms which threatened her life.



Figure 4. Endometrial Cancer: Life with Multiple Marginalized Identities is Short sewing by Sharon and drawing by Valdine

Each full-size gauntlet was approximately 25 cm long x 12 cm wide measured at the thumb. There was two in the pair and they were the last project Mom made in her life was for her mother. She used the mini gauntlets she made for Dad as the pattern to sew a women's pair of gauntlets with the single heart stitched on each with the word 'Mom' beaded in white into the heart. Her work on this project was slow because she lived with vertigo which worsened when she looked down at her sewing. She could not work as a part time educational assistant, and managing fatigue became a daily struggle that she tried to hide from my brother and me when we visited. She was diagnosed with endometrial cancer a few days before her 60<sup>th</sup> birthday in May 2016.

The gauntlets were Mom's expression of love, despite the emotional neglect she received from her own mother during a lifetime of sexual assault, and despite having to rebuild her Metis Ojibway identity without guidance. The fact that the gauntlets were fully completed yet Mom

had not gifted them to her Mom, tells me that more work was outstanding on the sewing project, and within her family. So much internalized racism held against their own First Nation, and the stories of victimhood passed down through generations, prevented my Mom's family from being able to look at themselves the way my Mom had - with compassion and love. She loved them all despite their intertwined shared history of childhood sexual assault; all of her siblings and their children were childhood sexual assault survivors. I remember her crying a few months before she died when a family member who took advantage of her body as a child was also taking advantage of her emotionally as a disabled adult. It hurts my heart to know I could not protect her from that family member while she was alive, or prevent them from attending her memorial service. They expressed so much guilt about not getting to her Winnipeg hospital before Dad removed her from life support, which I never understood as the child who lived 700 kilometers north of the city, and also was not present at that moment. They were not the only people who tried to make me responsible for their feelings when Mom left this world.

I remember receiving Mom's cancer diagnosis phone call while I was at work in Thompson days before her birthday the last year she was alive. She was very upset that a gynecologist from Winnipeg, who she saw in Dauphin, blamed her for her own delayed cancer results. Because Mom lived outside of Winnipegosis, a fishing village without cellular reception; it took her six weeks after the doctor called to check her cell phone voicemail. It was a hard summer for Mom, who passed daily numerous blood clots before going on bed rest, while waiting for her hysterectomy appointment in Winnipeg that August. It was difficult to read her text messages when she would get a new clot and be disappointed in her personal failure of managing the bleeding. I spent much time crying for her while she was alive while still trying to be strong. I

remember feeling so guilty for sobbing into her arms before she went into the hospital operation room preparation area, where family could not go with her.

The two weeks she spent in the hospital trying to recover from her hysterectomy are mostly a blur of her not eating, various family members showing up unannounced and taking the only chairs available in Mom's hospital room. My silent hope was that the white privilege demonstrated by her children and husband would allow her enough quality health care to survive. Unfortunately, she had a heart attack on August 16, 2016 and was taken off life support a few hours later, in the middle of the night. I remember seeing really bright northern lights the following night and crying because I knew it was her spirit celebrating its transition from physical form (Manitoba First Nations Education Resource Council).

After Mom passed, Dad mailed me the pair of gauntlets Mom made for Gramma, seen in Figure 5. Because of the Cree teachings I have learned from the elders on Treaty Five, about living in a good way with my connection to the land and others; I hold much respect for others' projects, and know they become sacred as each detail is sewn. Once the gauntlets arrived at my home, I was compelled to complete the cycle of energy Mom created as she sewed. Just like the earth is a balance of ecosystems and Metis knowledge is holistic, projects like sewing create energy that must be completed in a way that best honours the creator's wishes. Because Mom wanted to give the gauntlets to her Mom, the gauntlets' journey had to be completed by being laid at her mother's grave on Treaty Two territory outside Portage La Prairie. By doing this, I was able to return energy to the matriarch that carried me in her womb and the matriarch that carried us both. The cycle of energy was completed by laying the gauntlets to rest there (Absolon)(Belcourt, *Beading*).

Gramma passed away in her sleep six weeks after Mom died. She never received the handmade gift her daughter sewed for her. I left Mom's gift at Gramma's grave and drummed a thank you song to her for carrying both me and my mother as embryos. As I walked to my Mom's marker, which was placed between each of her parents, I felt so calm and at peace. In many ways, by completing the gauntlets' energetic circle, I was able to complete my own circle. In her life, Mom demonstrated how to perform in life as a trauma survivor who never had access to therapy and professional healing modalities, and I unknowingly walked in her footsteps of self-abandonment.

For her and her family, disconnecting from feelings was a survival pattern I copied throughout my life to the detriment of my mental health. After years of grief therapy, support groups and beading circles—sought out only because of her sudden death--I finally saw the shame about my identity for what it was; lies to hide who I am. My disability and Metis identity make me unique, because I see and experience the world in so many different ways. I am the unique Indigenous star my Mom taught me to bead many years ago when I was learning to live with MS.

Because of my own multiple marginalized identities, I am propelled to examine the ways I perpetuate harm on Indigenous folx like my mom. White supremacy is a system closely tied to Christianity that I have first-hand experience surviving, and I was both embarrassed and devastated that I was unable to leverage my whiteness to keep mom alive. In hindsight, all of her white privileged family was also very fat. Like Sabrina Strings states, we were “a corollary of illness” (355). Even with the whiteness we possessed. While our white privilege afforded us the power of purity when interacting with health care professionals, it did not erase the stigma of our fatness (Strings)(Rothblum and Solovay).



In the days of her life in hospital, I did not think about how the stigma of having her fat family at her bed also hindered her chances of appropriate and responsive health care (Thomas)(Rothblum and Solovay). Not only did our bodies imply to the medical personnel that we as a family had chosen to die fat deaths, but her disability status and darker coloured skin demonstrated to the same that she should be discharged as quickly as possible to avoid incurring additional costs of Indigenous healthcare, and if not – she was to be utilized as a teaching aid to show medical students ‘what kidney failure looked like’ because her legs were dark brown. The white privilege we held collectively was negated by our fatness, and as a fat Indigenous woman living in a time of Missing and Murdered Indigenous Women and part of a fat family; she was seen as seeking inevitable death (Gibson)(Taylor)(Rothblum and Solovay)(McCallum and Perry).

In hindsight, our meager attempts at creating an accessible trailer home environment for Mom’s health did nothing to improve the collective strength of others with chronic illness. By managing her chronic illnesses alone, she was isolated further from similar others (Garland-Thomson). When I learned that Mom had been avoiding the switch to insulin for her diabetes. I attempted to show her how easy it was for me to inject my medication in the hope that it would normalize injections for her, but at the last minute I developed a cold sweat in my palms and needed Dad to help me administer my syringe with a family audience. I failed to align myself with “the disciplines of normality” (Wendell 68) that directed Mom’s lifetime effort to appear non-Indigenous, feminine, docile, and less fat than she was. She made the switch to insulin shortly after my lacklustre demonstration, but I think she did it out of compassion for me and the new chronic illness friendship we had formed. In these moments, we became each other’s supportive cheerleader, and I travelled hundreds of kilometers every long weekend to spend time

with my new best friend. We found strength in our chronic illness coping similarities, and compared levels of pain on things like speed of injections. Rosemarie Garland-Thomson would note that we created our own meaning through our friendship based on living with illness and coping in a way that gave us each appreciation for the little things in our lives. This meaning making gave us both a common world we had not known (600).

Managing MS and CRAB medication side effects became something I had to do in Thompson while my brother learned to live from another round of ‘failed’ of bone surgery to become nondisabled. We did not have understand the causes of my brother or I’s suffering as adults, and assumed we had brought it on ourselves as my brother worked long hours on his feet as a teen. Our early adult imperfections and failure to perform life as able bodied adults (Wendell 60) illustrates the difference between the family’s belief that we could to manage Mom’s chronic illnesses with health behaviors, but somehow not my brother’s foot and leg bone pain or my neurological autoimmune disease. I fought this assumption of imperfection by being as compliant with CRAB medications as possible, despite being afraid of needles. I complied with injections to regain control of my abilities; not realizing that the myth of control would not protect me from fatness or MS (Wendell) and my brother did as much to prove that he could continue to work despite struggling to walk after each shift.

When endometrial cancer struck, additional environmental changes were undertaken, and I became deeply concerned that she would not pursue the necessary healthcare due to the teachings from the cult-church which discounted medical knowledge in favour of miraculous healing. Mom went on high doses of iron to combat the profuse bleeding she endured while her prayers for healing slowed. She limited her gardening activities, ultimately staying on bed rest in an effort to limit the blood clots that were becoming all too regular occurrences. The medically

normalized way of thinking about fat, disability, and chronic illness – locating the disability and illness in the action or inaction of a single person - was present at Mom's first CancerCare appointment. While my Dad and I recognised the existing chronic illnesses Mom had to manage would necessitate a nuanced approach to her care, her new oncologist only cared about evaluating Mom for her hysterectomy, not the illnesses that were complicating Mom's care. The shame I felt for having the same body as Mom is tied to the isolation of disability within individuals rather than society, and the fear I had regarding encountering fat phobic doctors in the future (Wendell)(Garland-Thomson)(Rothblum and Solovay).

Susan Wendell notes that “Stigma, stereotypes and cultural meanings are also the primary component[s].. [of] not having an acceptable body.” (44). There was nothing in the CancerCare offices environment that indicated either Indigenous, fat patients or groups were welcome from the typical arm chair seating to the reduced number of chairs in the consultation room. A cancer diagnosis was clearly not a community experience, rather an individual failing. I left Mom's appointment with a sense of dread that I too would be in this situation because I shared so many similarities to her. Mom's oncologist was clearly associating her body size with endometrial cancer when she described the additional risks associated with surgery for someone with Mom's body size - as if Mom even deserved to have cancer for simply having a body which did not warrant holistic care. Indigenous, disabled and fat people all live with stressful amounts of stigma regarding their health and as a result are forced to survive poor quality healthcare (Rothblum and Solovay 31)(Wendell)(Adelson). Rothblum and Solovay's *Fat Studies Reader* goes as far as to suggest that Mom's race, socioeconomic status and body size all contributed to her death, as a person at the intersection of many oppressed people groups (24). Both Fat and Disability Studies refute the medicalization of bodies which results in a dehumanizing reduction

of people to their health condition or body mass index, Fat Studies and Native Studies additionally note that disregarding human size diversity and centering the experiences of those with a Eurocentric, and small body size - much like the winners of a human eugenic lottery-- ultimately resulting in poor medical care, and death for any that would dare to be disabled, Indigenous, and fat (Davis)(Wendell)(Rothblum and Solovay)(McCallum and Perry). McCallum and Perry refer to this combination of dehumanization and disregard as “structures of indifference”(12) wherein disabled and chronically ill Indigenous people are essentially ”waiting to die” (125) because of their systemic poverty and oppression (Thistle).

Metis style beading represents the social model of disability, because it requires me as the beader to think about beading in a different way. Rather than secure the beads by doubling back through small glass beads with a single needle like Mom tried to teach me with the Christmas Star, instead beads are secured individually in the way that best suits their placement. A skillful two-needle beader can secure their beads without the additional threads being visible. Since this was my first time learning this style, the securing threads are highly visible. As I learn to think about disability and chronic illness critically, and examine the disabling environment around me rather than locate my ‘problem’ in myself or my Mom, critical thinking becomes second nature. But, I have decades of experience in seeing myself in a colonized way and this affects the way I interact with the world.

The social model of disability informs the stories associated with this beadwork piece by illuminating the barriers to health care and pharmacare. Mom was not the only Metis person who experienced poor health leading to disability as a result of geographic isolation (Martens et al., *Profile* 65). The social model of disability is a refreshing antidote to a lifetime of enduring medicalization of our Metis bodies which never have been seen as normal. Unfortunately, it does

not offer the large-scale systemic change needed to change Metis lived experience with poverty and colonization. Mom still died and I now live alone in a remote community without the needed wellness facilities to maintain my mobility. The geographic location that allowed me to access MS medication and go into remission is now the same location that limits my mobility, simply because the municipal government permanently closed the only swimming pool for hundreds of kilometers. I have given myself hypothermia trying to ease my MS symptoms in the cold northern lakes in northern summer months.

Learning how to one needle bead with Mom was a failure of my youth. She taught me one needle style in 2006 and I hated the idea of hand sewing without the efficiency of a sewing machine, especially through animal hide that broke needles and drew my own blood on many occasion. I returned to beading after her death in a desperate attempt to feel connected to her and Metis culture. Her sudden death in hospital left a rawness in me that beading slowly mended. I joined a beading circle at MMF home office once I moved to Winnipeg and met many proficient Metis bead makers who taught me two-needle style beading on felt which I found much easier on my hands and connected me to knowledge holders within the Metis community, which eased the emptiness I felt. Lawrence Barkwell taught me how to sew this flower and I tried desperately to show him that I knew how to bead without his guidance. My first evening at beading circle on Henry Street, I worked as quickly as I could on my first two-needle style flower to try to show my proficiency. In hindsight, my discomfort with my own existence, and my inability to tolerate

difficult emotions shows in the tangle within my first flower. Beading medicine reminded me that not all things are within my control.



Figure 5. MS, Sciatica and Grief Are Difficult All at Once by Valdine.

The blue felt square is 9 cm by 9 cm. After my Mom passed away, I felt raw with grief and immediately switched into my own matriarch mode and began caretaking everyone else in the family but myself, in attempt to fill her shoes and maintain my immediate family's unity. I relocated to Winnipegosis because I feared for my Dad's life without Mom. After her memorial service, I drove my brother home to Thompson and drove back to Winnipegosis the day later. I travelled more than a thousand kilometers in that time and my health slowly deteriorated as a result of the self-neglect I went through for the sake of family unity. The amount of emotional pain I held in my body felt impossible to face, so I caretook for others despite knowing that untended stress manifests MS symptoms in my body.

Earlier that year, when Mom was alive, I flew to Winnipeg in June to attend her first CancerCare appointment, because I knew the type of Christianity she believed in also ascribed to healing in the name of Jesus, like many American televangelists preach. One televangelist duo which was a household name as I grew up was Kenneth and Gloria Copeland. A few years prior to Mom's cancer diagnosis, Gloria Copeland preached on choosing not to pursue traditional cancer treatments and instead on the power of belief in miraculous healing through God. The Copelands are wealthy televangelists who hold nothing in common with my disabled Indigenous family besides their religious beliefs. And, I was so grateful that Mom was willing to undergo a hysterectomy. In hindsight, it had been years since she attended the cult-church in Thompson, and that absence helped her choose healthcare.

At her appointment, I listened to an oncologist and a resident tell Mom about the characteristics of her body that made her hysterectomy a riskier surgery – essentially her body weight. They were not interested in her medical history or life experience with diabetes. I remember feeling a sense of dread in the CancerCare patient room, as I realized that my body was essentially a duplicate of the body being villainized by the oncologist: I shared all my clothing with my mom, because we were the same clothing size and regularly traded our favourite outfits. While I was relieved that Mom was willing to have surgery, I was also ashamed that I had the same medically inferior body as she. My lifetime of internalizing the message that fat was unhealthy prevented me from challenging Mom's oncologist on their stance regarding fat and chronically ill disabled bodies and our right to appropriate and compassionate care (Taylor). While I had become a recent believer in fat liberation, disability justice, and Indigenous self-determination I did not feel it was my place to speak up in a room with my parents who did not embrace any of these identities.

The body shame I felt got much worse after Mom's death because I stopped valuing my own fat disabled embodiment. The career I had worked to build and all the money I saved so she could access health care felt pointless and I stopped listening to pain, hunger, and sleep cues because I felt so heartbroken. I ended up with a new diagnosis after I moved to Winnipeg: sciatica. I believed this diagnosis was a result of my abandonment from my daily self-care routines of yoga and walking because I was no longer invested in performing any of the behaviors that granted me mobility (Wendell). The sciatica was so severe that I needed a cane to hold myself up during the spasms that felt like my spine was going to tear itself out of my back. This pain is especially evident in the stem of the blue felt flower. Flower stems are ideally flowing and smooth, but as a beginner two needle beader who learned this style of beadwork a month after Mom passed, I felt the need to control my beads much tighter than necessary. In my anxious and tense beading, I pulled the stem out of its original design and it appears now to be a broken flower stem. As a fat, disabled person newly diagnosed with sciatica and coping with mind numbing grief, I struggled to feel that anything in my life remained in my realm of control. This tight-to-the-point-of-breaking flower stem is a good way to understand the year of my life after Mom passed: clenched to the point of breaking as I desperately tried to present my life in a controlled and perfectionist way (Wendell).

Shortly after I moved to Winnipeg to begin my master's program, I saw a Metis beading circle advertised at the annual MMF governance meeting and I made up my mind that I would attend so I could learn more about a style of beading I had never done before; I desperately wanted to feel connected to Mom who was an active beader. I struggled to walk into the governance meeting because of sciatica, but I did have an opportunity to walk through the most vivid display of Metis culture I had seen in my life which inspired me to attend the beading



circle from that day forward. I inherently knew that if I was able to begin beading again, I would rejoin the energy Mom held while she beaded on reserve and in Winnipegosis. Metis women understand their lives as interconnected and intertwined much like our flower beadwork with connected and curving stems and leaves; so, we intrinsically possess the knowledge to live our lives with chronic illness. I am connected to both Mom and Metis culture through my beadwork, whether it be one needle on leather like Mom or two needle on felt like I learned in Winnipeg (Belcourt, *Lessons from the Earth*)(Racette).

Metis style beading was taught to me in Winnipeg by Lawrence Barkwell, and it remains an accessible beadwork option, since felt fabric is much easier for me to work with than the leather Mom used. The needles are also larger and easier to thread with Metis style. This style of beading is one that I find enjoyable because it is within my ability to sew on felt unlike the leather Mom taught me with, and I have dedicated myself to its regular practice, in order to feel connected to my Mom's spirit and to myself. Having my own flower beadwork helps me feel that I truly belong as a member of the flower beadwork people as outlined by numerous Metis; Sherry Racette, Lawrence Barkwell and Christ Belcourt all contribute to my understanding of myself through their art, writing and shared community knowledge (Racette)(Belcourt, *Beading*)(Barkwell et al.). My struggle is not unique to me, despite the settler Christian life I was indoctrinated to early in my life. Flower beadwork is the artistic representation of the theory and literature I discovered in graduate school, and the communities which embraced me. Through these communities I found collective strength, and new ways to cope (Garland-Thomsom).

As a Metis Two Spirit person living with disability and chronic illnesses, I find healing and peace in Metis beadwork. Beading has taught me many things but especially that perfection is in the eyes of the beholder, much like chronic illness and disability. As noted by Christi Belcourt,

“[Metis] are as resilient as a weed and as beautiful as a wildflower. We have much to celebrate and be proud of.” (Belcourt, *Lessons from the Earth*). Before graduate school and my own beading practice, I spent all of my adult life learning to manage my disability and medication side effects in a way that I could feel safe (Wendell). Finding myself outside of the colonial systems I survive has been a result of both Metis beadwork and graduate school that has helped me deconstruct the systemic influences I confirmed to by performing femininity and productivity (Racette)(Wendell). Beading and sewing is traditional practice when a community seeks to help a griever heal; unfinished projects are gifted to the griever, to help them move forward in a good way (Belcourt). I have spent years in survival mode, and I look forward to existing in my disabled body without fearing for my basic needs thanks to the privilege afforded me as an disabled Indigenous academic who is mistaken for an able bodied, non-Indigenous academic.



Figure 6. Depression as Disease Symptom, Medication Side Effect or Result of Workplace Discrimination by Valdine

The laptop sleeve is 30 cm wide x 21 cm high and shows that the barriers I faced after my MS diagnosis in 2005 did not end after completing university; difficulties continued as I tried to build a professional career. I survived workplaces dominated by ableism, misogyny, ageism, fatphobia, and anti-Indigenous racism which I attempted to thrive in. In her book, *Becoming an Ally*, Anne Bishop notes how people “reproduce the social, economic, and political systems that formed us by playing out our internalised oppression against ourselves and others” (47). In my desperation to provide for myself, I subconsciously supported many layers of oppression against myself and others with less privilege than me, making me complicit in oppression against

disabled people. I perpetuated the idea that bodies that are sick or disabled are rare, broken and inferior, which is ableism (Davis 4123) Misogyny is “mistreatment of women by individual men.” (Bishop 146). In my context, ageism is the pressure to pass as an able bodied young person due to not being seen as old enough to be acceptably disabled (Davis 5188). While “the belief that fatness directly indicates ones morality and class” (Rothblum and Solovay 13) is how I experienced the oppression known as fatphobia. Anti-indigenous racism “in this white supremacist construct called Canada, which only exists through the ongoing genocide and subjugation of Indigenous peoples and the theft and destruction of their traditional Indigenous territories.” (Cole 26). In my desperation to be employed, I made it my life’s purpose to identify as thin, able bodied, white and as energetic as any happy young adult in their early twenties. I wholly pursued my new public relations career and abandoned my passion for Indigenous self-determination in favour of my own survival.

My first full-time job was in marketing, and as a promoter I was required to work irregular hours with the assumed ability of an able-bodied person’s health and energy levels. I really enjoyed working in my chosen career but I struggled to maintain the pace of the workday, and I was not granted my request for health benefits to help with the costs of my MS medication which was allowing me to work without relapses. My supervisor at the time took offence at my insistence that my employer help me afford my medication, and declared to me that with my attitude, I would never amount to anything. They did not believe that I was disabled or that I brought value to the workplace because they were misogynistic, and I had no rights in the workplace as a young adult. I was additionally disabled by working for my first employer by the barriers to health benefits and workplace rights, and as desperately as I tried to perform as a good worker; my chronic illness required more health and pacing resources than the employer was

willing to provide. The social model of disability would highlight that the environment of that workplace reflected the physical and attitudinal barriers in both the building and the people running the organization (Davis) which created disability. The attitudinal barriers held collectively did not prioritize employee wellbeing or health, which I needed as a chronically ill employee. In order to get to work, I had to climb two flights of stairs.

From there I moved to another job where I worked long hours with no overtime, but I considered it worth it because I had extensive health coverage and unlimited sick days. I did not have trouble affording my MS medication. I did have one disease flare-up while working there and while I saw a doctor for an accommodation notice, my supervisor promptly informed me that he would be cutting my hours. I left that position shortly after, knowing that I needed to find a unionized workplace if I wanted a chance at being seen as a person in a workplace rather than a disobedient slave. At the first two workplaces, I struggled to live up to the expectations placed on me as an average weight able bodied twenty-two-year-old and my mental health suffered. I felt like I had so many secret identities that my fatigue and depression became much worse.

MS had made my twenties feel like it was life and death because MS flare-ups were so pronounced and dramatic when I was first diagnosed, and CRAB medication side effects took much longer for me to adjust to than reported by both the drug company and my MS clinic medical professionals. I could not be sure when I would lose any of my abilities again, and the injections I was taking only seemed to make me feel worse. After a particularly bad winter, I was evaluated by a local psychiatrist who informed me that I should have been evaluated for depression before beginning my CRAB medication. The uncertainty around my ability to control my body and my mood made me feel more afraid about my future because I did not know of

people like me who were active members of society. I was not able to let go of the idea that I was required to live an idyllic life fully within my own control (Wendell 110).

I was so worried about having MS flares as severe as when I was in university that I obsessively saved money in anticipation of the day that I would have additional disabling relapses. My internalized belief that I was not really disabled, and shame about my fatness both required that I fix my body as much as possible in order to deserve to earn a living. I truly did not believe I deserve to exist in a fat woman's body, and I starved myself for many more years. Capitalism, ableism and misogyny told me that I could earn a right to exist if I looked attractive enough, and when I interviewed for a job at the unionized workplace in the hope to gain some protection for my episodic disability. As a non-unionized employee I saw protection within a system that valued "the essential characteristic of being human." (Garland-Thomson 603). As an outsider to a strong labour union in my hometown, I saw great value in being part of a unionized workplace which valued a wide variety of human experiences as simple differing ways that a worker can produce work. It's in this way that the union I then joined contributes to a more just world, by "integrating disabled people into our societies."(603).

Working at a large, unionized workplace allowed me to connect to Indigenous culture in a safe way for the first time in my life as an openly disabled worker. As a member of the a union, I have been protected from overt discrimination by being part of a collective agreement which entrenches the way my employer must respond to disrespectful behavior from both coworkers and managers, and I have access to health benefits, sick days and accommodation. In this way the pressure I was placing on myself has been released since I have worked with this employer for long enough to have accumulated sick days which allowed me to take care of Mom while she was alive. In this way, the pattern which the beadwork of is sewn onto is illustrated by my

participation in a unionized workplace—I know the rights I have and rely on the collective strength of my coworkers to ensure that none of us will face treatment like I did at my first two employers, or when I was a contract employee within the same unionized workplace. As a disabled person, it is reassuring to know that my employer cannot withhold my employee rights like health benefits, or right to accommodation..

Before I became a union steward in my role, I was expected to conform to a team environment that partied with alcohol regularly at after-hours events. I endured unwanted sexual contact at holiday parties without knowing that I could speak up, and as the work slowly died down, abusive behavior in the workplace escalated. The fear of having benefits and accommodations withheld in addition to being exposed to sexual harassment further immobilized me, and I was informed that I would be working in an administrative assistant role for the rest of my life. By that point, I had already applied to graduate school, and knew that my intrinsic value was far greater than what any co-worker saw.

### Disability Studies and Hope

As previously mentioned, the social model of disability utilized by the global north is the foundation of disability studies. It asserts that individual impairments are not disabling but rather disabling barriers faced in society create disability; if all the buildings with steps had access ramps and everyone knew American Sign Language, the construct of disability would cease to exist (Oliver). Similarly, if colonial influences were undone; the impairing effects of imperialism, and resulting lack might cease to exist (Kumar et al.). Both situations are simplified examples we can strive for but in the meantime, work can be done by examining the embodied experiences of those with disabling chronic illnesses today and engaging in dialogue. Susan Wendell is a Canadian woman disabled by her chronic illness has written a book titled *The*

*Rejected Body* to encourage dialogue and reflection for inclusion of all chronically ill and disabled peoples. For the purpose of this thesis, Susan Wendell is like the matriarch of this auto-ethnography: her work has encouraged me to continue asking questions of myself and to remain open to the concept that there is knowledge in my own experiences; “people with disabilities have knowledge and ways of knowing that are not available to the non-disabled” (75). Like Linda Smith has noted, there is also a wealth of knowledge in Indigenous peoples, which have not been recognized historically by academia (Smith). This poses the opportunity to explore ways of knowing of chronically ill and disabled Indigenous peoples because “Appropriation of the land of indigenous peoples was and still is a particularly important part of the disabling process.” (Meekosha 672).

In disability studies, decolonizing work done by members of the global south illuminates the inequity of centering experiences of the global north (Meekosha). Globally, Indigenous experiences of disability have been disregarded, as the field of disability studies centers the embodied experiences of those who subscribe to the social model of disability. This ignores the colonizing effect of impairment as a cause of disability among women, Indigenous peoples, and anyone living with a disability that is not visible (Meekosha). “The sweeping power of the colonialists ... destruction of prior culture and the disabling of indigenous peoples... Disabling the indigenous population was then, as now, specially related to colonial power.” (672). In Canada, the resulting high rates of chronic illness found in Indigenous communities results in higher impairment and chronic illness effects than non-Indigenous peoples (Adelson)(Martins et al.)(Chartrand). Colonial power has dehumanized Indigenous peoples and isolated us so that our access to culturally competent health care is minimal.(Carter et al.)(Bartlett et al.).



As Indigenous communities seek equity in colonial systems like health care, the disabling effect of chronic illness impairments is disregarded in favour of health promotion. Meanwhile the cause of a chronic illness impairment is assumed to be in an individual's own lack of behavior, rather than a symptom of colonization and subsequent health related inequities (Meekosha)(Adelson). For example, Indigenous peoples across the globe experience alarming levels of violence in society resulting in poverty and poor access to health supporting resources like housing, education and health care. In Australia, Indigenous peoples were not included in population counts until the mid 70s meanwhile cattle were regularly counted, (Meekosha) and in Canada, Indigenous peoples could not vote until 1951, and were only permitted to join the army if they also renounced their Indian status ("Mapping the Legal Consciousness of First Nations Voters: Understanding Voting Rights Mobilization"). In order to best serve the chronic illness needs of Indigenous peoples, historical and ongoing violence must be addressed and reconciled in a way that honours the lived experience of the same (Meekosha)(Adelson)(McCallum and Perry)(Wendell)(Garson-Thomson).

Rather than hope for the complete undoing of colonial influences and disabling barriers to rid society of impairment and disability, I utilize a Metis understanding of chronic illness to decolonize myself and examine the lived experiences of impairment on the lives of those with chronic illness without from the concept of medical tragedy, which is so often enforced on Metis people by medical professionals. Medical sociology reinforces the settler construction of biomedicine or health (Thomas), dictating to us that chronic illness and subsequent impairments are due to our own lack of action and knowledge, when imperialism and colonization are the true roots of our disease, displacement and poverty (Meekosha)(Adelson)(McCallum and Perry). Our lived experiences and knowledge (Garson-Thomson) are not made central to our care, so our

holistic wellness is not part of the care we receive in Canadian medical systems.(Meekosha)(Lambert)(Maracle). For example, Brian Sinclair was an Indigenous wheelchair using man who died after waiting for health care in a Winnipeg hospital waiting room for more than a day. Because of the assumptions made by the medical service providers, Brian sat for 34 hours waiting for health care until a member of the public observed that he had died while waiting in his wheelchair (McCallum and Perry). An inquiry was held into Brian's death and it was found that "Sinclair was not really in need or deserving of care,that his presence in a hospital was at its core illegitimate." (232). Much like my Mom's death ten days after her hysterectomy at a Winnipeg hospital, Indigenous peoples with disabilities are dismissed by medical professionals as not worth caregiving and medical support to live because Canadian society has decided that we do not have a right exist. "If patients are racialized as Indigenous by appearance, assumptions will not only be made about the state of their health, but also about whether or not they belong in a hospital or even deserve care at all." (238). Disabled non-Indigenous people experiencing an 'othering' that is not unlike racialized minorities, and Indigenous peoples. Both groups survive systemic discrimination that culminates in death, neglect, and erasure (Wendell)(McCallum and Perry).

Chronically ill and disabled people, whether their disability be physical or the result of a chronic illness, are resilient. They discover different spaces and timing requirements of their chronic illnesses and disabilities, and undertake routine tasks throughout their lives in ways that are not recognized in society. "The differences here are often regarded as insufficiently approximating what a supposedly 'normal' person can achieve, irrespective of the fact that tasks do get completed, sometimes better than they would by a non-disabled person, but often at great cost to the ongoing physical and mental health of the people concerned." (Hansen and Philo

499). As a Metis person, I know that this experience of time as fluid is parallel to the lived experience of Indigenous peoples, who do not experience the world in a singular chronological manner (Little et al.). Finding a collective of other Metis who are chronically ill has been a key component to my own flourishing; community provides strength (Garland-Thomson).

Examining the emotional and life paths of people with disabilities must be undertaken in order to understand time and space as it relates to the everyday lives of disabled and chronically ill people in a way that is respectful of the knowledge disabled people have regarding their navigation through space (Worth)(Garsan-Thomson). The best frameworks to examine Metis chronic illness and disability experiences are found within *Metis Life Promotion Framework* (Martens et al., *Profile*). However, many other frameworks allowed me to think critically about our lives as chronically ill and disabled people; the social model of disability, Susan Wendell's work on feminist disability reflections and Rosemarie Garland-Thomson's exploration of misfitting as a concept invoked to discuss the influence factors that can encourage dialogue to centre disabled people and their life paths. I utilized these disability studies tool to examine several beadworks stories in order to best recreate my knowledge discovery for the reader: as a grand beadwork project. While all beaded items are not the same colour, they are connected in the way that they are beaded by either me or Mom. All our sewing tells a part of who we are, and how we cope with the uncertainty of life as Indigenous chronically ill folk. For instance, I learned of the social model of disability years before I began studies at University of Manitoba, but I did not understand how my life could fit within the field until after Mom died.

While I did not know about disability theory when I was first faced with an MS diagnosis, the social model is the first disability model I ever learned about. I learned of this framework at a union activist summer camp in 2015, where I found a group of unionized chronically ill and

disabled women who found hope in understanding ourselves in a different way. With the help of a deaf union facilitator, we realized that we were not the problem, rather a disabling society that did not value us was the problem (Oliver). It was refreshing to learn about a different way to see with myself with MS, but I was wary of the practical applications of the social model, since medication allowed me to regain a much more abled existence than when I was first diagnosed with MS. My life experience told me that medication was something I would need for the rest of my life as a chronically ill disabled person who moved home to Manitoba specifically to access medication as quickly as possible. Manitoba pharmacare provides the most accessible environment for me to live well with chronic illness. I honestly thought that the more I learned about the model in school, the closer I would become to quitting the MS medication completely, in order to embrace my disability. While the union workshop on the model was excellent exposure, it did not provide the depth of experience needed to apply the model to my life, and to conceptualize the influences shaping my relationship with MS, an eating disorder, and mental health.

Rosemarie Garland Thomson's work on fitting and 'misfitting' is an intersectional way by which I can understand life with chronic illness for northern Metis people who find themselves unable to fit into colonized and European standards of health, simply because we are a displaced and transient people. While I did not fit at my undergraduate university because I was not disabled enough for formal accommodation, or wealthy enough to afford school without funding support, my late Mom did not fit into her Metis identity until she saw a need for me to gain funding dollars for school. Mom's life experience with diabetes, sarcoidosis and cancer repeatedly had her chronic illnesses blamed on her own self neglect. While medical professionals were eager to locate her illnesses in her own failure, the intersectional realities and geographic

distance to services were not their concern. The medical system did not see her as a person worthy of holistic healthcare which created a misfit with her cancer care team. In order to access CancerCare services, she had to erase her lifetime of experience as a fat person with diabetes who survived numerous sexual assaults. She had very few experiences with gynecological exams throughout her life because they were so traumatic for her, but she was subjected to an exam shortly after she met her oncologist and the medical students training with them. In this instance, Mom's misfitting with healthcare ultimately resulted in her death because her healthcare team in Winnipeg did not value her caregiver's expertise about her illnesses (Wendell)(Garland Thomson). Medical professionals in contact with her were trained to hold prejudicial attitudes about her body, its inherent value, and right to resources (591).

My own value for myself was much lower than the value I placed on my family unit. As Susan Wendell notes in *The Rejected Body*, I relegated myself to the 'weaker' private sphere. I supported my immediate family in maintaining their strong public lives, while voluntarily eliminating my own. I have struggled to fully return to the public world since Mom died in 2016. However, my disability has progressed; I now live with chronic pain, and struggle to maintain full time employment (Wendell 40). The myth of control over my body became a painful lesson that I learned many times over the years after Mom died, as the number and location of lesions in my central nervous system increased and my self-care stretching and eating stopped (Wendell). For the first time in my life, coping with body pain became the driving force to my existence, and I suffered immensely as I tried to ignore the pain (Wendell 173).

As a grieving graduate student with sciatica that prevented me from walking to or sitting in classes, I failed to integrate into a community of my peers. Instead, I had to leave classes regularly to attend a grief support group offered to students like myself. My first research paper

was a resounding failure, and I was fortunate to pass the class despite my D term paper. I found myself leaving the same class often to cry in the nearest bathroom, as my peers discussed the oppressive history of Canada which caused and continues to cause poor health indicators in First Nations, Metis and Inuit peoples. These discussions took place a block away from the hospital where Mom died. As a disabled Metis, I was a misfit for community health sciences classes. My grief and chronic pain loads took immense energy to contain as I watched my Canadian classmates talk in an unaffected way about the history and lived realities of people like my family.

Before graduate school, as a misfitting young adult who was vulnerable in a society that assumed I was not on immune modifying medication and disease that amplified the effects of the any virus, passing as an able-bodied person, and trying to build a career kept me focused on fitting in to a society for able-bodied folk. I tried desperately to hide my misfitting vulnerability and dependence on my brother who helped me administer the most painful injections, and I was afraid that MS already put me at a disadvantage compared to my able-bodied peers who were building their own families. I misfit as a woman who had no romantic or social experience as I built a career, and I tried to catch up to my peers who were not raised in controlling cult-like environments by having an active dating and party life. I was determined to experience as much life as possible before my thirties, when I believe MS would cause my long term institutionalization. There was no way for me to have known that other women with MS lived full and healthy lives on CRAB medications, and that the biomedical narrative of MS dedicated an end of life scenario was false. Susan Wendell identifies this gap as “knowledge lost...cultural silence about pain, limitation, suffering, and dying also increases our fear of them, and thus contributes to the need to believe that we can control our bodies.” (109).

Garland Thomson highlights how disability and feminist studies can benefit from each other. She also points out the need for additional discourse in order to allow for full participation from disabled people in society (Davis 334)(Garland Thomson 591). Rather than point to the complacency of feminism for its failure to provide discourse within racial spaces, (Hamad) I look for a collaborative alternative in the Metis specific discourse offered by the *Metis Life Promotion Framework (MLPF)* developed by Dr. Judith Bartlett. Dr. Bartlett is a Metis physician and academic from Flin Flon, Manitoba who founded the Manitoba Metis Federation's Health and Wellness Department. She was recognized in 2003 with a National Aboriginal Achievement Award for her work in Metis, Maori and First Nations health research and holistic health frameworks. The *MLPF* focuses on the lived experience of Metis people with chronic illnesses and gives us a way to think about our lives holistically through the categories placed on Figures 6 and 7.

Rather than assuming that our displacement, geographic isolation and lack of a land base does not affect our disability status, the *MLPF* identifies the varying ways in which Metis lives are affected, giving voice to many Metis who may not have thought about their chronic illnesses and disabilities in a holistic manner, which includes myself. Beading with Metis community after Mom's death gave me the confidence to know that I belong within Metis community, enough so that I feel confident that I can utilize a tool designed for Metis; despite having a non-Indigenous parent who insists that I am not Indigenous.

The *MLPF* is a framework created to encourage Metis dialogue of specific factors that influence wellness; it is a tool that helps me understand my chronic illnesses as a part of my Metis identity, and is the only framework I have found that provides a pathway for chronically ill and disabled Metis to engage in critical thought about our embodied experiences in a way that is

easy to understand. Every single Metis person will engage with MLPF differently based on their own experiences, which fosters community definition of lived experiences. For the purpose of this autoethnography, I am using the *MLPF* to understand my own experiences only.

A key component of disability studies remains that the content and theory must be accessible to the people for whom the content is created. In this, the *MLPF* is the most accessible theory for this thesis. I have beaded representations of MLPF models to help me understand my family's lived experience, which represent the best fit of all the concepts discussed in this thesis (Martens et al., *Profile*)(Davis)(Garland-Thomson)(Wendell). In order for me to engage with content, beading allows me to combine all of my identities and aspects of myself: one bead at a time, I gain understanding of myself through the *MLPF*. It is a resource that all Metis can use as a tool to gain critical understanding of themselves.

#### Metis Life Promotion Framework

In 2012, the Manitoba Metis Federation's Health and Wellness department, in partnership with the Manitoba Centre for Health Policy, developed a population-based study known as the *Metis Health Atlas*. It is a comprehensive document which gives a snapshot of health status of Metis across the province of Manitoba, including the poor health of northern Metis. Reading the study for the first time was like reading my family history; the illnesses reported as significant are all issues in my Metis family – diseases such as heart disease, cancer and diabetes (Martens et al. *Profile*).

Chapter Two of the *Metis Atlas* details the *MLPF* and the knowledge required to apply the framework to Metis. This includes several days of workshops, as well as defining Metis lived experience in ways that a Metis community can analyse in order to discover the version of the framework that best represents them. There are 16 categories identified in the *MLPF*; these cover



spiritual, emotional, physical and emotional parts of a Metis person across the life stages of child, youth, adult, and elder, at the level of individuals, families, communities, nations. These categories are placed within four contexts--cultural, social, economic and political--realities, all of which culminate to demonstrate Metis wellbeing in a demonstrable way that all Metis can use to know themselves better. In the *Metis Atlas*, all categories are placed on an image of the Metis flag to invoke Metis dialogue around them as “Determinants of Life” (Martens et al. *Profile 33*) and I have placed the categories over my own Metis beaded medallion shown in Figure 6.

Beading the medallion took several months because I ran out of beads as I neared completion, and had to order additional beads from Winnipeg. The additional time spent waiting for beads allowed me to think about the experiences and land that shaped my Metis family, and allowed me the space to practice self-compassion for my child self who was bullied by both my Indigenous family and my non-Indigenous classmates at school. I very much lived in a loop of poverty and bullying during my child years that shaped me into a youth that worked multiple jobs, and then an adult who no longer lived in poverty, but continued bullying myself with negative self-talk and self-harm. I continue to cycle through a loop of feeling like I am five years old, being physically assaulted, endlessly mocked and feeling terror in my disabled adult body where I have been conditioned to remain silent around authority figures. Beading in community helps me learn to value myself as much as I value everyone else. Beading this medallion helped me see the cycles I was recreating for myself, now that I am not being assaulted, and helps me gain understanding to why Mom was the way she was. I think she was a lot like me, surviving a lot of bad things the only way that she knew how. I am fortunate to have access to education and community members who shared the *Metis Atlas* with me; when I pair beading with MLPF concepts, I am able recall memories I had forgotten, and see my deceased Metis matriarchs as

interconnected parts of me. It is a challenge to explain to non-Indigenous people how I understand interconnected. My family is beadwork, my relatives are the landscapes I connected with my Mom on. My brain cannot comprehend not seeing the trees, lakes and the earth around me as my friends. In this way, Metis experience life in a manner like all Indigenous peoples: a holistic, intertwined, and sacred way. The seven teachings are a way that I explain the way I understand life to non-Indigenous people, like my friends at my undergraduate university. The biblical concept of the fruits of the spirit to demonstrate that “sharing, caring, kindness, honesty, respect, trust and humility” are the values of those that understand the world in a fluid and interconnected way with the seven teachings: love, truth, honesty, respect, courage, humility and courage (Martens et al., *Profile 33*) (Absalon 63).

While she was alive, neither Mom nor I knew about the *MLPF*. But, beading with it in mind now gives me a Metis way of understanding the comfort found within chronically ill and disabled Metis existence, just as my mother enjoyed many things in her life and did not let her disability and chronic illness prevent her from finding personal fulfillment.

As my two needle beadwork skills advanced, so did my understanding of our wellness within the *MLPF Determinants of Life*. Fuchsia, navy and silver were chosen to represent both myself and Mom.

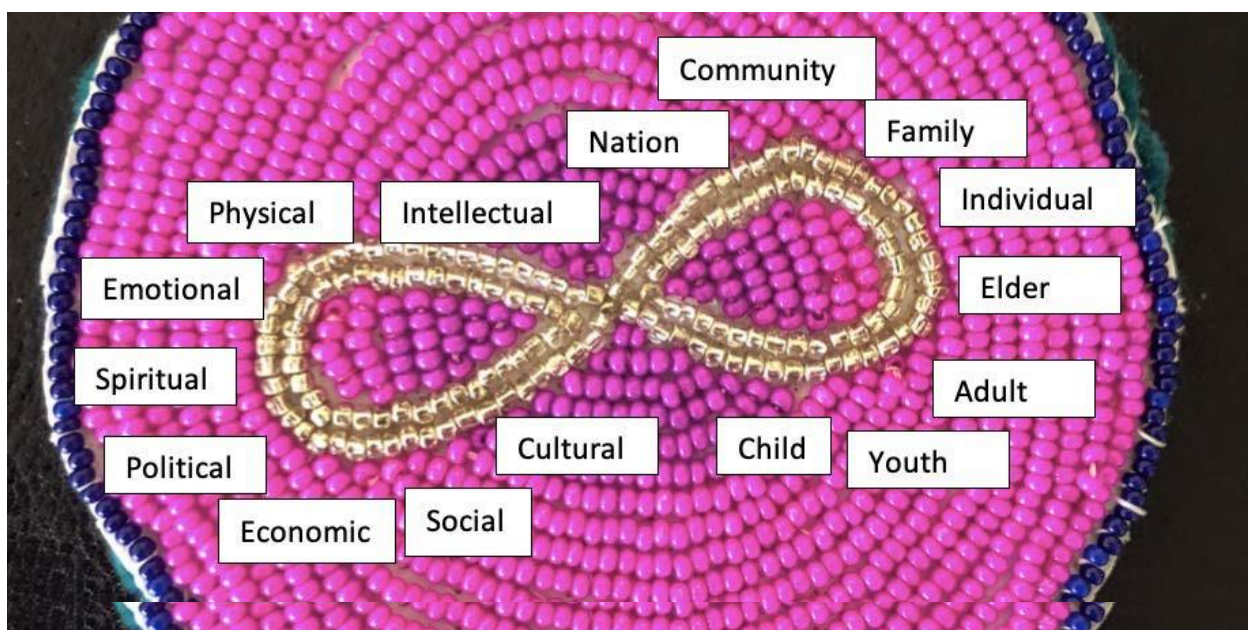


Figure 6's circumference is 9.5 cm and the components of the *MLPF Determinants of Life* have been placed on top to demonstrate how this sewing this piece helped me incorporate my understanding of Mom. As demonstrated by her previously featured beadwork, Mom was able to invoke her Metis identity as an individual and family member by teaching me and a community of others on the reserve. Her spiritual nature as a Christian helped her understand her emotional, physical and intellectual place in the world, and her short time as a senior amplified the need for Metis-specific services in Winnipegosis. This is where she ultimately fell through the cracks of a health system not designed for Metis women like her who live their golden years as much on the land as possible, out of cell reception and down a rural farm road.

Though my mother was unaware of the *MLPF Determinants of Life*, her bodily changes did require her to adapt further in her relationships, supports, environment, and self-governance. By the last year of her life, she was able to speak easily with me about her negative childhood sexual experiences. Hearing my Mom's understanding of her childhood experiences helped me see her in a new way, as a little girl who struggled to understand and love herself, rather than only as the senior living with profuse uterine bleeding.

By hearing the dehumanizing way Dad talked about Mom after her final hospitalization, I understood how she could have been stuck in a childhood or youth phase of life, because that was how her spouse spoke to and treated her. There were other times when Mom would get hurt that Dad would share graphic photos or information about her injury with my brother and me. I suppose being a registered nurse in a caregiving role with his spouse forced him to relate to her in a role that made him unhappy. It frustrates me is that she had no choice but to survive life with a reluctant caregiver because of her geographic isolation.

Mom balanced herself as best as she could, without being overly political or involved in the Metis nation. She never got to fulfil her Metis right to harvest the way she wanted to. Her connection to nature was strong and she was well versed in gardens and plant growing. She was dedicated to life in her home community of Winnipegosis, and always longed to be in southern Manitoba while my brother and I were children. There were many weekend trips south to see her family, without my Dad's involvement. It was like Mom's family tried to steal us away whenever they could. I did not understand why she felt so connected to them. I think her childhood self was still looking for love and comfort, and I do not think she received that care living in northern Manitoba with her children. She felt lonely as a southern Indigenous woman living in the north and hid away a large part of her Indigenous identity in order to conform to the ideal of a perfect fundamentalist Christian mother and housewife (Martens et al., *Profile 33*).

As an adult, the child part of Mom was often neglected. She did express her desire to be cared for during the last few years of her life like she cared for everyone else throughout her life. But neither the child, youth, adult, or elder parts of herself ever found full expression to my knowledge. She hid from us how sick she really was with sarcoidosis. She tried to control her chronic illnesses the same way she controlled her Metis identity, with denial.

By abandoning her Metis identity for the young adult part of her life; Mom abandoned the political, economic, cultural and social elements of her Metis identity. She only started speaking openly about Metis culture in food harvesting once I was an adult. I had been hoping to hear more of those stories, but she kept her life pretty tightly guarded. I think she was protecting herself from her own hurt. That hurt did not fit into fundamentalist Christianity.

Spiritually, Mom talked openly about the freedom she found in her life as a Christian. She truly believed that she would not be able to manage her life without her spirituality, although she

never made mention of her emotional, physical or intellectual wellbeing. I grew up believing that she was fairly stupid and therefore by inheritance, so was I. With their zealous dedication to their spiritual lives, since the only thing that really mattered was the afterlife, Mom and her family neglected their emotional, physical and intellectual lives. I believe the atrophy of these areas came at a dire cost for Mom, who used her spirituality as a sort of fatalism that drove her away from accepting her marginal status of being disabled and Metis for most of her life (Martins et al.).

The *MLPF* includes a wellness model for examining life with chronic illness and provides an opportunity to understand my wellness in a holistic way, with prompting questions which I wish Mom had had a chance to ponder. As a person living with MS for all of my adult life, new symptoms presented in my body during the years after Mom passed – the most dramatic being the resulting grief and development of sciatica, which made me unable to walk without nerve pain spasms that threatened my balance. I found much difficulty moving through grief as I feared for my mental health. As a person living with depression, the wellness questions make a perfect tool for observing my own embodied life. Because I did not learn about the *MLPF* and

subsequent wellness models until after Mom died, I will apply this discourse to myself only.

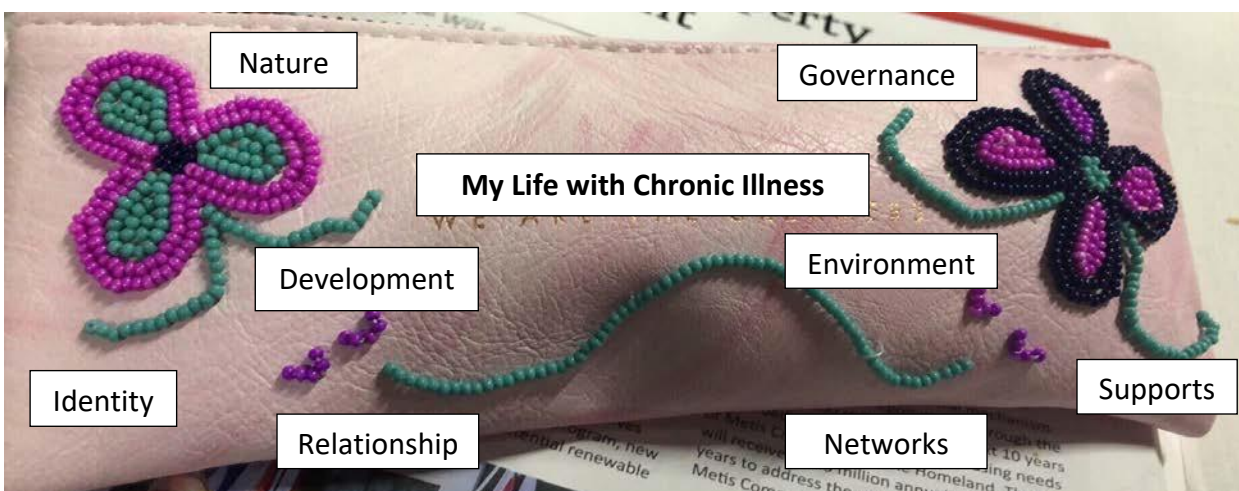


Figure 7. My Beadwork Interpretation of the MLPF Wellness Model for Examining Metis Lived Experiences with Chronic Illness

Figure 7's pencil bag is 18 cm long and 8 cm high. I placed wellness with chronic illness categories as defined by the *MLPF*, on my beadwork is my beading interpretation of a Red River Cart wheel model developed by the *MMF* for Metis to talk about their lived experiences with chronic illness through a *Metis Life Promotion Framework* lens. While the *Determinants of Life* were developed to address larger scale community concerns in knowledge translation workshops, the wellness model is a tool for me as a chronically ill Metis to critically think about my life in a wellness focused way. All wellness commentary and questions are from experts referred to in the *Metis Atlas*, while my experiences are sewn into the beaded model. A list of all wellness questions can be found in in the *Metis Atlas* (Martens et al., *Profile 22*). For the purposes of this thesis, I have answered the wellness questions in the order that I understand them within Figure 7's beadwork.

My sense of self-identity was shaped by my perception of normative society misunderstanding my chronically ill life, which was in conflict with how I wanted others to see me (Martens et al., *Profile 22*). When I was first diagnosed with MS, I thought my life was over

and I spent many years trying to cope with my new disease and develop a career. I spent most of my twenties figuring out how to balance my life in a way that I could proudly talk about my life with MS.

When Mom died, I also thought my life was over and I imagined that I did not want to live. I dedicated myself to taking care of my family and neglected myself, which is when I developed sciatica. Sciatica affects my ability to be there for my family because I cannot travel across the province to be with them. It also affects my identity as a student because I cannot sit through classes without taking many breaks. Sciatica makes me visibly disabled because I cannot walk without my cane. Grief makes me disconnected from not only my family but my peers in Winnipeg at the MS Society and in graduate school, because others are uncomfortable being around a person who cries as easily and as often as I do. I do not try to hide my tears because I feel like I am living without my own heart and unsure how long I will survive being unable to travel, sit or walk for any length of time. Travelling across Manitoba for work, and to see loved ones is an important part of my life.

Depression affects the way I interact with the world in my workplace. As a person who has become increasingly disabled as I enter my mid-thirties, I have struggled to advocate for myself in my unionized workplace. After having my job relocated due to my reporting the threats and actions of my supervisor, I have struggled to fit in with my coworkers who have not experienced the same severity and duration of harassment while at work.

My ability to maintain and hold relationships was influenced by chronic illnesses as it impacted my sense of self-respect, and subsequently the way I cared for my family and friends (Martens et al., *Profile 22*). When I was first diagnosed with MS, my family helped me to administer my injections, because I was afraid of needles and the sharp pain associated with

injection of a recently developed medication that was not created with ease of injection in mind. The first few years I was on my MS medication, certain spots of my body when injected would feel like a knife was being stabbed into me and twisted. It was hard to manage my fear of needles and maintain healthy relationships with my family who were helping me administer this medication. I did not feel like I was capable of caring for anyone but myself. Depression did influence me to adopt a dog in 2012, to have something else besides myself to love and care for.

When I lived with immediate grief and sciatica in late 2016, I felt disconnected from myself. I do not think that strangers that met me during that time saw the version of myself that I knew - an independent woman who can travel across the province to follow her dreams. Even now, I feel like people feel sorry for me and only see the parts of me that they can make fun of, like the way I walk when I am having a bad chronic pain day, or when my muscles are so tight that they dislocate my joints.

Life with MS has stunted my sense of life development. Being raised in a cult-like religion put me behind in terms of typical life experiences, but figuring out how to live with chronic illness negatively affected every part of my development as an adult, when I was figuring out how to leave the religion I was raised in. As a youth with MS, I did not know how to relate to the world as a disabled person and I stayed in denial for a really long time. After five years of starving myself and learning that Mom did something similar at my age to control her body, I was able to relate to myself as an adult by having compassion for her. My heart was so broken by the realization that my Mom did not believe she needed to eat that I could not keep denying myself food to control MS. I knew I needed to eat.



Despite grief, the child part of myself wrote my Mom's obituary and gave the eulogy at her memorial service in an effort to protect my Dad from harm, like I did as a child when he felt victimized by Mom. When I returned from Aotearoa in 2017 with sciatica, my adult self had hope for a future, and self confidence in my ability to handle new situations despite unpredictable illnesses. Having traveled overseas with sciatica, and warmly loved and accepted by my new Maori family allowed me to do the same for myself. When I returned to Canada, it became obvious that much of my Canadian family was not providing me the same love and acceptance. Depression has prevented me from expressing the adult part of myself in the last year because I have felt so victimized at work and in school by situations that felt out of my control.

Living with chronic illness dramatically changed my sense of who I really was. My nature went from adventure seeking, and family avoidance before MS to being scared of being alone and vulnerable (Martens et al., *Profile 22*). For as long as I have had MS, I have lived with my younger brother. Because he helped me when I was so low, I have done as much as I can to share my life success with him. I bought my parents' house in Thompson when I was 24 and have lived with him since before then. He is the best roommate I have ever had, because he is the most compassionate person I know. Living with him during my life with MS has been a blessing – yet also a curse, because now I do not have a lot of confidence in my ability to live without him. I blame MS and my upbringing for that.

Living with grief after Mom died made me unable to care for others. I sobbed a lot, ate very little and ran to my partner's apartment every weekend that I could while living in Winnipeg. I was constantly avoiding the despair I felt. I was afraid of sinking into depression and avoided feeling my feelings for as long as possible.

Living with sciatica makes me unable to care for others as well. I was unable to take flowers to my grandmother at Thanksgiving, because I had to take different and shorter driving route to Winnipegosis to ensure my sciatica pain or MS did not flare up. Gramma passed away in her sleep a few weeks later. I was also unable to maintain a friendship with my roommate in Winnipeg because I did not have the capacity to care about anyone but myself and my dog. It was a hard time in my life. The sciatica hindered my physical functioning, and emotionally, I was overwhelmed with grief. I was always scared of my grief causing me to sink into unbearable depression, like when I did when I was first diagnosed with MS. I think I gave my grief more power by being afraid of it.

My chronic illness also affected my network ability, or the ability to reach out and connect with others (Marten et al 22). Because, I did not know how to live with MS and I mostly starved myself to cope, I did not have friends for many years. All of my energy went to coping with MS, controlling medication, and holding down a job so I could pay my mortgage that gave my brother and me a place to live. Once I stopped starving myself, I was able to make friends and go out socially. The new challenge became dealing with a partying culture of binge drinking. Since I was unable to keep up to due to chronic illness, it became impossible to fit into in my community because I could not party like the other people my age.

The pain of sciatica limited my relationships and networking at school in Winnipeg. While professors were happy to introduce me to their peers, I had a lot of trouble navigating stairs in old buildings. Because I had to budget my energy to walk to my car, I missed out on meeting new people. Grief and the resulting depression made me unable to connect with anyone outside of my grief support group, where I was typically the ugly crier. I feel like I spent many years

sobbing before I was able to talk about losing my Mom, who I thought was the last connection to my Metis culture. I became pretty isolated when I could not avoid sciatica flares.

Living with chronic illness shaped my environment in a negative manner for many years due to the isolation I felt. My spheres of influence seemed to shrink while I focused on survival (Martens et al., *Profile 22*). MS affected my influence by forcing me to focus on surviving the next injection, mortgage payment or drug deductible. I did not believe I had any influence culturally, socially, economically or politically during that time (Martens et al., *Profile 22*). But I must have, because I was holding down a job in public relations and voting in every election. By the time I found a unionized job I was organizing events for the MS society so that I could find a community of others like myself, despite the depression I was facing due to the discrimination I endured in my first two jobs.

Sciatica limited my life a lot because of pain; I was not able to sit and study, like a typical student. I had to lie in bed to write or read in order to succeed. The political influence I had built before grief and sciatica was hard to maintain, because I could not participate at MS society events like I wanted to. I remember going to a federal government accessibility consultation and having to stand against a wall while the private invitation-only consultation took place because sitting was excruciating. Chronic pain negatively affected my ability to make small talk and talk in the light, perpetually optimistic tone that the MS Society staff expected from people living with MS. I truly believe that I was dropped as an MS Society contact after 2016 as I struggled with grief and sciatica.

I am lucky that I have been able to turn to the Metis government, which accommodates all of my needs without questions. I am pleased that I have also started to advocate for examination

of disability access at my workplace. Having this new influence has helped me see value in my graduate studies and my own journey with chronic illness.

Being diagnosed with chronic illness changed my ability to choose my future, and feel like I governed my future life (Martens et al., *Profile 22*). When I was diagnosed with MS and began medication, I did not feel like I had a choice in my future. I had to move back into my parents' house and let them take care of me while I recovered from a flare up and got used to medication. That was when my Dad started talking about 'end stage' MS, and told Mom that they may have to institutionalize me. It was a very hopeless time for me because I did not feel like I had a say in my life or what I did. I slowly was able to work more as I became used to my medication. That helped me buy a car and buy a house; these were different stressors that I was grateful to experience.

Sciatica and grief caused me to abandon any cultural, social, economic or political influence, because when I was not in classes, I was at my rental accommodation with my dog, coping with pain and trying to do homework. I slowly learned I had some influence as I was able to secure funding and a scholarship to pursue my studies. I built a new version of myself in graduate school, where what I had to say mattered and where my experiences were valid. It was a beautiful sensation for me to have multiple people have faith in me. It has been a challenge to return to my hometown workplace and lose all of that support and community. It has been harder to see that I can choose my future now because I am isolated from my new community and Mom has passed.

My sense of being supported by myself and others, and community involvement was negatively affected by MS for many years, until I learned through grief that I needed to purposely join collectives for my own well-being (Martens et al., *Profile 22*). I did not feel much

hope about my future when I was diagnosed with MS and again when Mom died. I felt numb because my family was all over the province and my Mom was dead. I felt so isolated both with MS and grief. As a grieving graduate student attending classes a block away from the hospital where Mom died, to talk about Indigenous health services helped me look at my history and Canada's hateful colonization practices that demonstrate why she is gone. Still, I struggled to accept the fact that I was alive and needed self-care to maintain the ability I previously held.

Depression, sciatica and MS continue to affect my ability to be involved in my community, because I cannot sit in a conventional chair for very long, and I cannot tolerate a lot of noise, light or stimulation. It is easiest for me to rest at home in a reclined position that takes the pressure off my hips and back while preparing for my next injection of MS medication. I feel like I am always preparing for my next injection, and that really limits my involvement at work and in the community.

As demonstrated by the discussion regarding the *MLPF's Determinants of Life* for my late Mom and my *Wellness Model* shown in Figure 7; beading allowed us both to embrace our Metis identities and our lives with chronic illnesses. This cultural practice helped each of us create space for ourselves in different but similar ways; we both learned how to use beading as a tool to express ourselves. I have been fortunate enough to engage critically with MMF models while she never knew of these tools. But she knew how to bead and that is strength and pride in itself.

## Conclusion

This thesis has briefly outlined the Red River Metis' displaced history and the northern Metis epistemology of myself as a chronically ill and disabled, fat, Two-Spirit beader. Autoethnography as a decolonizing methodology allowed me to centre the beadwork stories of myself and my late Mom. Our embodied experiences have included a vast array of disabling

chronic illnesses, resulting in barriers to our quality of life and access to healthcare. These illnesses have been devastating in various degrees – particularly the fact that Mom died in August 2016 at the age of sixty. Focusing on the beadwork stories and art created by myself and Mom have given me a culturally safe way to share these personal stories that I wish did not exist. By inviting you, the reader, to hear our stories, I hope to help further the justice sought out by all Metis, including fat and queer Metis. I will develop this thesis as a resource for other northern Metis to utilize the *MLPF* framework to better understand their lived experiences.

The social model of disability is a good tool for understanding disabled people within a disabling society, not due to the individual failings of disabled people. However, the social model cannot account for the nuance of living as a fat, chronically ill, queer Metis people. Feminist disability theories acknowledge the need for additional discourse to best identify the multiple identities held by chronically ill and disabled people with intersectional oppressions. The best way to understand Metis' experiences of disability and chronic illness is by engaging the same and providing accessible tools like the *Metis Life Promotion Framework* to help us understand ourselves and articulate our needs. The way we see the world with our chronic illnesses and disabilities is unique as we struggle to access physiologically and culturally safe environments within a country that has murdered many of us (McCallum)(Lux)(Thistle). Canada's government services must demonstrate an understanding that we live our lives in an interconnected and holistic way in our community. This holistic interconnection must shape the services provided to us in the future.

In order for Canada to abide by the United Nations Declaration on the Rights (UNDRIP) of Indigenous Peoples, and the Truth and Reconciliation Calls to Action twenty and forty-four, the Government of Canada must fund and plan for culturally responsive health care as defined by the

Metis Nation. Addressing Metis health disparities includes taking the lead in resolving jurisdictional disputes, and providing Metis-lead services by Health Canada. By addressing Metis health needs as identified by the Metis Nation, Canada can begin to demonstrate its commitment to UNDRIP. Canada must develop actionable plans to deliver culturally appropriate wellness and health services which support Metis life and well-being rather than providing support to First Nations and Inuit only. Canada's gross and genocidal neglect of Metis wellness in northern Manitoba results in the highest mortality among all Metis, and it must be reconciled in order for people like myself to live the same life expectancy of all Canadians.

### Epilogue



Figure 8. A Beaded Heart with a Nine Centimeter Diameter by Valdine

### My Miyeu Pimatishiwān – Good Life

I am not your labels.  
I am not your suffering.  
I am not your confidante.

I am not inferior to you.  
I am not responsible for your life.  
I am not an extension of you.

I am not a sinful Metis.  
 My fat disabled embodiment is important.  
 I am Two-Spirit. I am a Sacred Healer.

I define me.  
 I found myself with beading medicine.  
 I am proud of me.

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