"Turning Poison into Medicine": Creating Space for the Sacred and Decolonizing Health Care

by

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Submitted in partial fulfilment of the requirements
for the degree of Doctor of Philosophy

at

Dalhousie University
Halifax, Nova Scotia
October 2021

Dalhousie University is located in Mi'kma'ki, the ancestral and unceded territory of the Mi'kmaq. We are all treaty people

Acknowledgements and Dedication

I would like to thank my supervisor Dr. Oakley for her consistent and profound support throughout this entire process. She has been a mentor and a friend and has tirelessly spent many, many hours meeting with me and reading the various iterations of this manuscript, providing thoughtful feedback and gently pushing me to explore my ideas further and deepen my analysis. I have learned so much from our discussions and your insights and gentle guidance. It is your support and guidance that have helped ensure that I stay on course through these turbulent times. I would also like to thank my PhD committee members, Dr. Richardson and Dr. Waldron. First, Dr. Ingrid Waldron, who has been a vital and dedicated committee member since I began this degree in 2015. I am grateful for her commitment to see me through to the end of this program. I especially thank her for your valuable, detailed and thoughtful comments on my work throughout the degree and especially for your careful reading and advice on this manuscript over the summer of 2021. Abundant gratitude, to Dr. Richardson who helped connect me to the Indigenous Navigator Program, through Cancer Care Ontario, which set in motion my contact with the Traditional Healer which led to much of the content of this body of work. Your commitment as Indigenous clinician and your tireless and important efforts are deeply inspiring. I would also like to extend my gratitude to you, Dr. Jeffers, who sacrificed his time by stepping late in this process to ensure I was able to finish during these challenging times. I would also like to thank my external reviewer Dr. Anna Waldstein for her constructive report, and the questions and suggestions during my thesis defence.

I dedicate this thesis to my father who passed away unexpectedly in April 2021 just as I was finishing revisions of this manuscript. My father was an immense support and my biggest fan the last few years of his life. His encouragement for me to keep going and finish this degree will be forever part of his loving memory. I did it Pops! I will miss you always.

I also dedicate this thesis to my Indigenous ancestors, those who have passed into the spirit world. We share the blood and memory that is embedded throughout this thesis and without their strength and resilience I would not be here.

I would also like to dedicate this work to my partner Morgan. Without his kindness, love, support and the many cups of tea he brought me when I was freaking out (many, many times) I would have thrown in the towel long ago! We have been through so much these last few years, and we are still standing!

And to my beautiful, brave and talented daughter Kailan, I pass this story onto you so that you may understand some of where you came from, your roots. I hope you always feel grounded and loved.

Lastly, to my friend MA. You helped me change my life. I know we are sisters from another life! Your love and power are like nothing I have ever seen before. Miigwetch!

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Abstract

This thesis explores several intertwined stories. The main story is written from an auto-ethnographic perspective exploring my recent experience with cancer, seeing an Indigenous Traditional Healer, as well as an oncologist as part of my health care. I also narrate the collision of two approaches to healthcare: biomedicine which strips the mind from the body and prioritizes the physical, in contrast to approaches, such as Indigenous healing, which integrate these and consider the wider social, historical, biographical environment into consideration. These latter approaches which often get driven underground, marginalized or erased through biomedical dominance. I engage in storying[1] my own experience of finding and holding space for the sacred[2] amidst fear of a serious illness and its recurrence and how *Etuaptmumk*/Two-Eyed Seeing can be drawn upon to theorize the integration of Indigenous knowledges/medicines into health care in Canada more broadly. *Etuaptmumk* is a Mi'kmaq guiding principle that posits that we learn to see with one eye the best of Indigenous Knowledges and with the other the best of Western knowledges for the betterment of all. I argue here for the need to highlight the imbalance in power that might afford more weight to one eye than the other when *Etuaptmumk* is taken up in research due to biomedical dominance. I further suggest drawing on critical political economy when engaging with *Etuaptmumk* to be able to destabilise this potential imbalance in power, so that the application of the *Etuaptmumk* principle actually results in seeing with both eyes equally. As such, I posit that instead of integrating and trying to smooth out tensions between Indigenous and western Euro-centric knowledges, we must first highlight and explore these potentially generative spaces while also considering how industry and capitalism increasingly are shaping knowledges and approaches to health and health care, particularly in the realm of biomedicine.

[1] Throughout this dissertation I draw on Joanne Archibald's view of storying (Archibald, 2008)

[2] Sacred spaces here means places that are deeply spiritual and that have healing potential, spaces that have not been contaminated by the plunders of neoliberalism capitalism and marketization for example.

List of Abbreviations Used

BBC	British Broadcasting Corporation
CBC	Canadian Broadcasting Corporation
CCO	Cancer Care Ontario
CEO	Chief Executive Officer
COVID19	Corona Virus Disease 2019
CT	Computed Tomography
GAVI	Global Alliance for Vaccines and Immunization
IRS	Indian Residential Schools
IV	Intravenous Line
OHIP	Ontario Health Insurance Plan
RCMP	Royal Canadian Mounted Police
TRC	Truth and Reconciliation Commission
TV	Television
WHO	World Health Organization

Chapter 1 Introduction

Stories are medicine. (King, 2003, p. 92).

Decolonization is not an event but a continuous, life-long process of turning deadly poison into good medicine available to all, based on the teachings of the trickster poison itself (Ahenakew, 2019).

I am not ready to write. But I have to. I need to tell this story somehow. I need to create space by placing these words on a page as maybe they will resonate with others. I need to attempt to make sense of things, for myself at least. I must write for my 'self', my family, and community as a way to transcend my lived experience of cancer and honour the sacred, a crucial part of my healing. There are certain things I will not say here though…they are mine.

This doctoral study started off as a "neat and tidy" research idea. That is, before I had cancer, and before the world had COVID19. I was planning on exploring the integration of Indigenous medicines into biomedical health care settings using a specific health care institution that was just embarking on its journey towards answering the Truth and Reconciliation Commission Calls (TRC) to Action, to "improve" Indigenous[3] health. I was moreover, embarking on a personal journey as well to gain a better understanding of my family's Indigenous history at a time when my grandmother was not well and our family was trying to learn more about her family history before she passed away. Then cancer struck. Shortly after finishing my first comprehensive exam, I found out I had

[3] Throughout this document I use the term Indigenous to refer to First Nations, Inuit and Métis Peoples . The term Indigenous in Canada is more often used in the public domain than the constitutional term Indigenous Peoples and is being used to refer to First Nations (status and non- status Indians), Métis and Inuit Peoples living in Canada. The term "Indigenous", in the Canadian context anyway, has replaced the hard-fought constitutional term "Indigenous Peoples" in recent years. The term Indigenous recognizes the diversity among Canada's first peoples and serves as a statement against assimilation. Colonial and post-colonial practices and policies, such as demographically erasing people through the colonial period to the virulent Indian Act. The inclusion in the Canadian constitution of "Indigenous peoples" was a fight against assimilation and it is notable that the Canadian state has often eliminated the use of the "s" in their dealings with Indigenous peoples in Canada who, like the peoples of Australia, New Zealand and USA, come under the unique international law (for a more in-depth discussion of this (see Oakley, 2021).

colon cancer. I went to emergency because of severe pain in my side and blood in my stool. I had a colonoscopy on a Monday and surgery the next day. They removed a large tumor, some local lymph nodes, and a significant section of my colon. There were times during this whole period where we were not sure how bad the cancer was; times when I thought this is *it*, I am going to die. Luckily although the kind of cancer can have a severe prognosis if not caught 'in time', the cancer was contained within my colon. I took time to recover, and I am currently undergoing active cancer screening every six months for five years. The cancer surveillance is disruptive and for me it means having to revisit fear, fear of a bad result and being thrown into another cancer diagnosis; ultimately a fear of my life being cut short. Yet, I feel it is also important to state here, I am not only surviving cancer I am thriving through cancer.

This is part of my biomedical cancer story. There are other stories to tell. I am using storying n my approach to this dissertation to capture the unfolding nature of lifeworlds, in this instance my own, and to mitigate how linear words can come across once committed to these pages. Storying involves the telling of living stories, stories that are unfolding, never ending. I am storying this story (McCormack, 2004) also as an act of decolonization as it places my *self* and through association and inclusion in the work, my Indigneous ancestors, at the centre (Sium & Ritskse, 2013). It is an "act of self-narrative" (Carson, 2015, p. 3). Like surviving cancer, my family and many other Indigenous Peoples and families have also survived colonization and assimilation, but not without scars. Cancer demands attention and the gravity of such a diagnosis has required that I deconstruct, redefine, and rebuild my sense of self, identity, and community. It has created unexpected profound chaos and the need to draw consciously, actively, and devotedly on my instinct to live a healthy, long life. At this time of fearing for my own life, I was flooded with the need to preserve, for my daughter and my family, my experiences as a survivor of cancer, but also to honour my Indigenous ancestors who had to endure 500 years of colonization. For me this has included exploring and honouring my reawakening connection to my indigeneity[4], as it was suppressed and hidden growing up, in the context of Canada's colonial history, deepening identity politics, ongoing

[4] I use the term reawakening Indigeneity here as I was not raised traditionally or connected to one particular nation. Many pieces of our family history have been lost due to colonial processes as has been expressed by (Richardson, 2004)

assimilationist strategies and the continued impact of the Indian Act, which resulted in lost stories and broken histories in my family. It also has included finding and holding spaces where I feel a sense of belonging.

I begin the dissertation with this small piece of *my cancer story* because it has had a profound impact on my 'self' (Narayan, 2012), not as an object with an illness (see Jackson, 2013; Richards, 2008), but as a human being living with and through a cancer experience. This experience has had an impact on my entire life; my relationship with my 'self', my family, and this research. I tell these stories with the understanding that, as Absolon (2019) notes,

> *I send out these words, I can only do so from where I sit and from where I am located. Through my sharing of who I am, I establish the parameters of what I may know and not know. In doing so, readers can determine what fits for them and what doesn't. (p. 24).*

These stories are based on my experiences and may not be applicable to others in any way. Throughout this thesis I locate myself in an evolving way as my knowledge about my family history is evolving and with it my location.

This thesis tells many intertwined stories. The main story is written from a first voice perspective exploring my recent experience with cancer, seeing an Ojibwe and Cree Traditional Healer, as well as a western trained oncologist as part of my health care. It also includes aspects of my own path of learning about my family history, and especially honouring my ancestors (Richardson, 2004) to find 'a way home' (see Narayan, 2012). I engage in storying my own experience of finding and the need for holding space for the sacred[5] amidst fear of a serious illness and its recurrence and death. As Narayan (2012) notes of Ethnographers like Zora Neale Hurston, Peter Jackson and Amitav Ghosh, who narrate the self into their projects, "the pull of your past is especially strong if your project is taking you home" (p. 101). For Indigenous scholars (e.g., Archibald, 2008; Atalay, 2019; Dutta, 2018; Houston, 2007; Wastasecoot, 2015; Whitinui, 2013), this is particularly poignant. I engage in storying my experience while navigating biomedical

[5] Sacred spaces here means places that are deeply spiritual and powerful for me, spaces that have not been contaminated by the plunders of neoliberalism, capitalism and marketization for example.

care and trying to hold onto the sacred amidst the penetration of capitalism and neoliberal capitalist ideologies into more and more facets of our lives, something Brosio (1994) calls 'capitalist colonization' (see also Coburn, 2000, 2010; Coburn & Navarro, 2015; Hickel & Khan, 2012; Navarro, 2007). This also includes structural violence, a form of violence that results from social structures that perpetuate inequities which result in suffering that could otherwise be prevented (see Farmer, 2004), against Indigenous Peoples and ways of life. The structural violence of settler-colonialism continues to influence the lived experience of Indigenous populations (Maddison, 2013; Oelke et al., 2016). For example, fears of claiming an Indigenous identity in the context of identity politics that are becoming increasingly charged, guarded and contested. Claims to Indigenous identity are reportedly increasing, as are the surveillance and investigations into the authenticity of these claims. It has even recently been suggested that claiming a false Indigenous identity should be a criminal offence that could result in a $250,000 fine or jail time (Sterritt, 2021). Of course, "identity" is never straightforward, particularly in the context of colonization, where the Indian Act in Canada continues to determine who is 'legitimately' Indigenous and who isn't in the eyes of the state. Many Indigenous peoples had to hide their identity, were forced to abandon their identities and culture, and their families in order to survive. That so many people were enfranchised during colonization and ties to Indigeneity stripped away is a testimony to the power of the state, the forces of colonization, and the powerful push to turn land and resources into profit for few (Donald, 2012; Palmater, 2011).

The structural violence also includes the violence of degradation of the environment for profit at the expense of health (Chomsky, 1999), and most recently the multifaceted impacts of COVID19 which along with mortality, has contributed to strained social interactions in public (Calbi et al., 2021), increased isolation, mental health problems, and economic hardship (Kar et al., 2020), an "infodemic" through social media platforms (Cinelli et al, 2020) and fear (Walsh, 2020). Indeed, as Manderson, Burke and Wahlberg, (2021) note, we may not know the full extent of this impact for years to come.

This thesis goes beyond a linear approach to research, storying and writing. Linda Tuhiwai Smith (2012), in her exploration of the "western archive" of knowledge, points out that linear thinking is one of the pillars of this archive along with dichotomies rooted

in Judaeo Christian thinking such as good and bad, mind-body separation, start and finish, black and white and so on (see also Grøsneth & Josephides, 2017, p. 13). Instead, in this thesis, I wander into and explore various 'inner worlds' down to the microscopic level of cells, and outwards into the broader socio-political and economic context while considering colonization and its impact on my own family, and Indigenous Peoples in Canada general. With regards my positionality I write as someone with mixed ancestry (métis, Mi'kmaq from Gaspe, Quebec), who, along with others in my family, are trying to honour my family's experiences of survival in the context of assimilation, as someone surviving cancer, a Healer's apprentice, and emerging scholar. I also write as someone who is active in the urban Indigenous community in Toronto. Most of my teachings I write about in this thesis come from Ojibwe and Cree healers, teachings from my elder family members, some of whom passed away recently due to COVID19 or old age, and some who are still fighting strong to assert their *right to be* for the younger generations. In this regard, it is quite important to point out that my experience, while may have broad patterns of similarity to others is ultimately my story and I don't speak for anyone else's experiences, communities, or nations. I here strongly assert the diversity of Indigenous Peoples and Nations in Canada, all of whom have their own unique stories, experiences, histories, and medicines which have survived more than 500 years of colonialism and who still often have to vigorously resist marginalization by the settler using various means and tactics (Corntassel et al., 2009). In many cases, the fight is a fight for life itself as can be seen on a daily basis in emergency wards, in rural areas, in cold cities and through a protracted period of time, as has been evidenced throughout the history of Canada. While here I explore some medicines and forms of healing that can be helpful for cancer patients, I acknowledge that for some, even accessing public healthcare at all is a chronic issue (Allen & Smylie, 2015; Richardson & Crawford, 2020)

Adams and Jones (2008) along with Friedwald (1996) agree that autoethnography is a form of knowledge creation and a "… kind [of art] that takes you deeper inside yourself and ultimately out again" (p. 126). In relation to this Josephides and Grøsneth (2017) pose questions about research and the creation of knowledges that might help make "everyone more capable of dealing with their life concerns as well as what possibilities does the new knowledge add to everyone's life course and well-being?" (p.

9). To this end I offer this thesis as my personal "narrative of emancipation and enlightenment" (Graveline, 1998, p. 35). I hope it is a unifying narrative, one that does not contribute in any way to more divisiveness between peoples, land and communities. I also hope this thesis will stimulate further thought and discussions, and perhaps help others who might find themselves in a similar situation, facing a cancer diagnosis and its aftermath, as well as trying to piece together their fragmented family history; others trying to turn poison into medicine.

As introduced above I draw heavily on Indigenous First voice, a form of auto-ethnography (Graveline, 1998), using my 'living' experience with cancer as a major component of this doctoral work. I reflect on the process of navigating and utilizing Indigenous medicines alongside biomedical care using First Voice / Self-In-Relation (Graveline, 1998), as a case study to help *story* ways we might decolonize health care, public health and cancer care in particular.

I engage with and endeavour to honour and build off of the *Etuaptmumk*/Two-Eyed Seeing principle to help make sense of my experience of living *in* and *between* different worlds, as a person with mixed 'settler' and Indigenous ancestry raised in a cultural context where Indigenous attachments were hidden, suppressed, and devalued, as well as someone who is navigating both biomedical care and Indigenous healing for colon cancer. Bhabha (1994) calls this the third space, a space rich with potential imaginaries for creating and holding space for the sacred (see also Dutta, 2018). As such I focus largely on the spaces of epistemological and ontological tensions between "Indigenous" and "Western" knowledges throughout, while also realizing that these tensions sometimes also manifest in material ways, such as social inequities, and land abuses. I argue that instead of integrating and trying to smooth out these tensions, we must also highlight and explore these potentially generative spaces while considering the impact of industry and market capitalism on knowledges, particularly in the realm of science, medicine, and health care.

As a unifying principle/narrative *Etuaptmumk* is increasingly being used as a guiding framework for understanding and reducing tensions between Indigenous and Western knowledges/medicines in the context of health care. However, it is argued in the following pages that how this framework tends to be taken up (Roher, et al, 2021) may

unintentionally contribute to concealing or washing over how health, public health and healthcare in Canada are increasingly shaped by industry and profit in ways that cannot be rectified by mere perception (e.g., Navarro, 1976; Panitch & Leys, 2010). Fundamental changes need to take place to put resources where they are needed for preventative and curative service and praxis. It is not just epistemological or ontological tensions that need attention in this instance but very real material tensions, such as access to clean water, safe housing and healthy food, the basic building blocks of health for everyone. This also includes the violent ways that colonialism's many assimilationist strategies despite Indigenous Peoples incredible resilience have already obliterated, devalued, and absorbed Indigenous knowledges and ways of life. All of these factors impact our health, yet they are continually downplayed, instead Indigenous Peoples tend to be blamed at the individual level for their ill health, or 'poor life choices', or disease is reduced to mere cells gone haywire or exposure to germs. If we merely see the best of western knowledges with one eye and Indigenous knowledges with the other then we may lose the opportunity to challenge dominant forms of knowledge, like western science and biomedical knowledges. Additionally we may also miss opportunities to prevent Indigenous knowledge and approaches to health and healing from being subsumed into biomedical institutions and frameworks. At this stage in history given the dominance of Eurocentric knowledges and biomedicine, we need to honour other ways of knowing and the spaces in between, otherwise the rich diversity of Indigenous knowledges/medicines risk being absorbed, altered, and potentially lost (see Ahenakew, 2019). Reducing tensions risks leading to furthering homogenization and assimilation, likewise, the reduction of tensions is often a result of assimilation and homogenization, or what some scholars call spirit injury (Ahenakew, 2019; Jimmy et al., 2019). Instead of seeing in-between spaces as mere places of problematic tensions I argue that we need to consider how these spaces might be rich with potential for change and growth that are necessary if we are to even begin to decolonize health, public health and health care (see Ahenakew, 2019). Moreover, the dynamic spirit of *Etuaptmumk* must remain alive, and at the core of any space where it is taken up, something which requires an open mind, body and spirit, not as separate entities but an embodied whole. To truly engage with the spirit of *Etuaptmumk* we cannot merely strip pieces of Indigenous knowledges, which tend to be

land based, wholistic and relational, away from each other and put them together with other ways of knowing (Absolon, 2016; Ahenakew, 2019), nor can we just superimpose Indigenous knowledges and practices onto existing biomedical knowledges and health care settings, for example. We must deconstruct the dominance of western Eurocentric forms of knowledge over the others to truly make change. We must, as Cree scholar Cash Ahenakew (2019) says, sit with the tensions and not wash over differences and incommensurabilities if we want change that doesn't merely reproduce colonial relations (p. 19). This must be an authentic open and multi-directional and multi–dimensional endeavor, it can't be rushed because "there is a strong desire to move forward" (Ahenakew, 2019, p.19).

1.1 Sharing Stories

An important aspect of this doctoral work is carving out the space through writing to tell a 'living' story, a story in progress, that can be shared to hopefully help others who might find themselves' living a similar experience: trying to 'be' who you are in spite of the 'cancer' of assimilation, trying to occupy liminal spaces while coping with a frightening disease, endeavouring to create and hold sacred spaces that are increasingly difficult to find and maintain given the pervasive nature of colonial and neoliberal capitalist ideologies that permeate our thinking and tend to absorb other ways of knowing, living and doing (e.g. Fournier & Oakley, 2018; Hickel & Khan, 2012). I hope to contribute to theorizing this liminal space, a space Dutta (2018) calls "full of imaginaries," by considering an eclectic approach to theory that combines anti-colonial theory and critical political economy theorizing with *Etuaptmumk*, with the understanding that *Etuaptmumk* is by nature anti-colonial, to create a framework for building resistance to colonization and other ongoing assimilationist strategies in Canada. I would like to contribute more broadly to understandings of how living and moving between worlds, a place Hernandez-Wolfe (2013) calls 'the borderlands' is navigated on a personal level with implications for other contexts. The 'borderlands' is a place in between dual, and sometimes, conflicting identities and spaces, and even false binaries, for example: traditional medicine and biomedicine; my mixed ancestry and upbringing; 'western' and 'Indigenous knowledges'; and the dual and seemingly incommensurable explanations of an illness such as cancer,

from different epistemological perspectives, and experiencing and navigating care from an oncologist, family physician, and an Ojibwe and Cree Traditional Healer.

By exploring the dichotomies of western and Indigenous knowledges I paradoxically risk recreating, or reifying them, that is not my intention here. However, we must be careful not to only focus on them as bounded spaces to do this it is important to draw attention to rather than neglect the shared fragments of space between them. The tensions between these spaces that sometimes get bounded and guarded so tightly, remain important starting off points for discussion and analysis, particularly when we consider the various forms of assimilation and appropriation that have already occurred (see Ahenakew, 2019; Aikenhead & Ogawa, 2007).

1.2 Outline of Chapters

This thesis has seven chapters in total. Writing in bounded chapters risks fragmenting aspects of this work that is meant to be more circular and free flowing, like memory, and experience itself (Struthers, 2001). As such, I have endeavoured to link each chapter towards a wholistic body of work that comes from my body/mind/spirit (Absolon, 2016, p. 44), yet each chapter carves out its own space. The chapter format provides a sense of organization that makes it easier to read and make sense of. The following is the outline of the chapters.

In Chapter Two, I provide a detailed account of the methodologies employed during this doctoral study, which includes a mixed methods, interdisciplinary methodological framework informed by decolonizing methodologies, which includes a reflexive Indigenous First Voice/ Autoethnography[6] and a critical personal narrative approach. At the heart of my writing is a narrative approach (Absolon, 2016; Archibald, 2008; Atalay, 2019; Carson, 2015; Iseke, 2013; Mattingly & Garro, 2000; Mattingly & Lawlor, 2001; Narayan, 2012) to storying my experience with biomedicine and Indigenous healing. I draw on my cancer journal notes compiled over the last three years, some of which were written in retrospect as I reflected on my experiences, others were written in the moment, for example while waiting for a doctor's appointment for

[6] I utilize the terms Indigenous First Voice, and auto-ethnography interchangeably throughout this thesis, both of which refer to an auto-ethnographic approach to research that places myself at the centre of the storying and analysis while considering the broader socio-cultural, economic and political contexts of our life worlds.

important test results or waiting for testing. I sometimes carried a tape recorder with me and spoke about my experiences which I later transcribed into my cancer journal.

In Chapter Three, '*Erased Histories, Live in Blood and Bones'* I explore aspects of my family history alongside the history of colonization in Canada with its brutal assimilationist strategies, the continued impact of the Indian Act, the Doctrine of Discovery, and one of the initiatives meant to begin a process of healing, the TRC. I aim to connect some of the fragmented family stories and braid them together into the broader context of colonialism in Canada. I weave in and out between analysis of historical texts, governing documents and my family history.

In Chapter Four, titled '*Storying and Re-storying cancer: Turning Poison into Medicine',* I use a narrative first voice/autoethnographic approach to storying my experiences of biomedical care and Indigenous healing for cancer care. This includes, experiencing and navigating Indigenous healing ceremonies, and care from a Healer, as well as biomedical forms of care such as surgery, medication, and testing. I focus on the tensions I navigate as I move between varying forms of care as I endeavour to transform spaces of sickness, fear and vulnerability into my healing and health.

In Chapter Five, *'Embodying and Building Theory'* I explore the *Etuaptmumk* and propose an expansion of this framework towards a theoretical lens using anti-colonial and critical political economy perspectives, while considering the potentially generative spaces of tension between my experiences of navigating Indigenous forms of healing and ceremonies, and biomedical care from an embodied/sensory perspective. I argue that the ways in which *Etuaptmumk* tends to be employed in health research may lead to an oversimplification of knowledges, obscuring and washing over the nuances and complexities inherent in each. I also explore socio-economic and political factors that influence knowledge production and what knowledges are validated and circulated in public spheres, as well I also challenge the 'false binaries' such as 'Indigenous' and 'Western' which some scholars problematize (see Granholm, 2013; Appiah, 2016), while also engaging in a discussion on how these binaries can also be useful points of reference for protecting Indigenous knowledges and healing given the insidious nature of biomedical hegemony.

In Chapter Six, *Biomedical Hegemony and COVID19: Is there space for the Sacred in Public Health,* I use the current COVID19 crisis to explore how sacred spaces might be altered, and the ways Indigenous knowledges might be vulnerable (Heck et al, 2021). I argue for more expansive and inclusive public health perspectives and measures that employ the spirit of *Etuaptmumk* to help the decolonize public health, while also understanding the importance of public health rules during a pandemic that are meant to help keep people safe. This also includes a discussion related to ways non-dominant knowledges and perspectives may be obscured because they challenge the dominant western biomedical narratives. During these processes, non-biomedical knowledges may be relegated to the sidelines that could lead to deepening the crisis.

In Chapter Seven I conclude with a discussion that brings together, in broad strokes, the thesis towards a wholistic body of work that aims to contribute to the expansion rather than contraction of sacred spaces as they pertain to health and healing. It is my hope that this thesis might contribute to ways to resist the deepening impact of the market and industry on how health and health care is being shaped. This includes the need to shift away from the technologicalization of health and health care (Fisher, 2013; Vargas, 2019), the focus on high profit technologies, away from "…reductionist, profit-based pseudo-science …" (Grøsneth & Oakley, 2007, p. 4; Nanda, 2003) towards spaces of healing. Spaces that allow for the rich diverse approaches of Canada's Indigenous Peoples to be incorporated and valued, and that counteract the impact of colonialism, and capitalism on how knowledges are shaped and enacted in the realm of healthcare.

1.3 Storying and Vulnerability

I begin this thesis with the trepidation that goes along with sharing very personal stories. As Thomas King (2003) reminds us there is profound vulnerability that goes along with telling our own stories and as such, I enter this dissertation wanting the reader to note the following,

> *I tell stories not to play on your sympathy, but to suggest how stories can control our lives... Stories are wondrous things. And they are dangerous… For once the story is told, it cannot be called back (p. 10).*

It is my intention to contribute to the creation of healing spaces for myself and anyone else who might resonate with these words I have now committed to these pages. These stories are at times deeply personal, revealing parts of myself that are fragile. I also want to remind the reader that these stories, these words, are situated in a particular fixed space and time and these stories, and like all stories, are not yet done and they may not ring true to others at all, nor capture anything similar to their experiences. As such I present this as a living document, with its own limitations some of which may be what I consider its core strength; the focus on my own stories and experiences and not those of others. This doctoral work is a starting off point and in the future I aim to learn from others who might have related experiences.

Chapter 2 Storying Methodology

Research is ceremony, and the purpose of any ceremony is to build stronger relationships or bridge the distance between aspects of our cosmos and ourselves. The research that we do as Indigenous peoples is a ceremony that allows us a raised level of consciousness and insight into our world." (Wilson, 2008, p. 11)

In this doctoral work I use an interdisciplinary methodological framework informed by decolonizing methodologies, which includes a reflexive Indigenous first voice/ autoethnography[7] and narrative inquiry. This approach is termed by some a form of 'bricolage' or more aptly in this context, 'Indigenous métissage' (Donald, 2012). Indigenous métissage' is described by Chambers et al. (2008) as,

> *a counternarrative to the grand narrative of our times, a site for writing and surviving in the interval between different cultures and languages, particularly in colonial contexts; a way of merging and blurring genres, texts, and identities; an active literary stance, political strategy, and pedagogical praxis…We braid strands of place and space, memory, and history, ancestry and (mixed) race, language, and literacy, familiar and strange, with strands of tradition, ambiguity, becoming, (re)creation, and renewal into a métissage (p. 534).*

The spirit of métissage is embedded within this body of work and my efforts to braid together theory, such as anti-colonial and critical political economy theorizing, different methodologies, stories, and my own identity struggles as someone with mixed blood. "[M]étissage is about relationality and the desire to treat texts – and lives – as relational and braided rather than isolated and independent" (Chambers et al., 2008, p. 538). It is in the spirit relationality and unification that I write this thesis.

Indigenous autoethnography and narrative inquiry can serve as what Mutua and Swadener (2004) call, "a central genre of contemporary decolonizing writing…a creative analytical practice… used to criticize prevailing structures and relationships of power and

[7] I utilize the terms Indigenous First Voice, and auto-ethnography interchangeably throughout this thesis, both of which refer to an auto-ethnographic approach to research that places myself at the centre of the storying and analysis while considering the broader socio-cultural, economic and political contexts of our life worlds.

inequity in a relational context" (p. 16). To this end and in keeping with the interdisciplinary methodological framework I also draw on literature from critical medical anthropology (Baer et al., 2013), critical political economy (McKenna, 2010, 2012; Navarro, 1976; Singer & Baer, 1995), Indigenous and anti-colonial studies (e.g., Dei, 2011; Smith, 2012; Kincheloe, 2006; Wilson, 2008) as an avenue to critically unpack relationships of power within a relational context.

I situate this research, including the auto-ethnographic component, within an Indigenous research paradigm, (Wilson, 2008), defined here as part of a decolonizing approach to research that challenges dominant Eurocentric approaches to research and instead privileges Indigenous knowledges, voices, and experiences (Denzin et al., 2008; Smith, 2012; Wilson, 2008). The overarching questions that guide this research are: Using auto-ethnography, how are sacred spaces of resistance, hope, and healing created in health care, while dealing with a life-threatening illness? What is the nature of the tensions that arise in the navigation of Indigenous healing and biomedical forms of care? What are the implications of these tensions and the way they are managed? How might honouring these tensions help protect Indigenous knowledges? How can these tensions be theorized using sensory aspects of healing to build on existing theoretical understandings of healing? Within these spaces of healing, can theorizing become an embodied experience as well as an intellectual exercise?; and finally, how can this contribute to decolonizing health care?

As I query the need to accentuate/highlight the spaces and tensions *between* "Indigenous" and Eurocentric" ways of knowing, I explore the *Etuaptmumk* principle as a framework, while drawing on notions of embodiment and "embodied" space (see Low, 2003; McPhee, 2003; Waldstein, 2016). In this instance I refer to embodiment as engaging in acts that help bring back the inherent unity between mind/body/spirit as a form of (auto)ethnography that is experiential (Waldstein, 2016). Bringing awareness back into our bodies/spirit not just the mind is an "…affirmation of bodily wisdom and experience as a critical component of Indigenous methodologies" (Ritenburg et al., 2014, p. 77). I also take this further and argue that we must move beyond mere physically embodied space towards a wholistic space that includes other aspects, such as our spiritual and emotional beings, as well as historical realms (see Blackstock, 2011; Walters

et al., 2011). I argue here that honouring and even accentuating these tensions (Ahenakew, 2019) is becoming increasingly important particularly given the present context of the global health crisis we are in. Indigenous ceremonies such as the sweat lodge, and approaches to healing are in some instances being pushed to the sidelines within the dominant etiology of disease. For example, at one Indigenous women's centre where I am an Oshkaabewis, all services and ceremonies were cancelled for months during the lockdowns to help protect the women they provide services to. These services are critical to the health and wellbeing of the 'at risk' women they serve.

Ultimately, I am endeavoring to find ways to help decolonize thinking and practice in Canadian healthcare by defying neoliberal theory and the penetration of public health by corporate agendas and embracing time trusted approaches that fall outside of biomedicine. Much like the narrow, invasive, and depersonalized approach to "treating" cancer I experienced and explore in this thesis, the COVID19 crisis tends to reinforce the idea that there is only one acceptable "scientific" body of knowledge, that of western biomedicine and science, and all others may be suspect or potentially dangerous. Understandably funding is being prioritized toward the virus, and we are already seeing cancer surgeries deemed 'non-essential' in Canada being cancelled, cancer screening delayed and wait times for any medical care are increasing due to an already underfunded and overloaded health care system and health care providers which COVID19 has amplified (HealthCareCAN, Policy Brief, 2021). In this climate bringing in elements of health care that might bridge the mind-body dichotomy of biomedicine as Indigenous approaches could do are also being restricted. With the ending of the TRC undertaking, the rise of COVID19 and associated funding, it is difficult to say where the current interest in Indigenous approaches to health and healing will lead and what direction they will take in Canada.

2.1 Positionality and De-problematizing Subjectivities

Ellis et al. (2010) argue that "[a]utoethnography is one of the approaches that acknowledges and accommodates subjectivity, emotionality, and the researcher's influence on research, rather than hiding from these matters or assuming they don't exist" (p.2). It is a first voice approach that can be used to help us develop understandings of

cultural experiences (Ellis, 2004; Holman Jones, 2005), "while resist[ing] colonialist, sterile research impulses of authoritatively entering a culture, exploiting cultural members, and then recklessly leaving to write about the culture for monetary and/or professional gain while disregarding relational ties to cultural members (Ellis et al., 2010, p. 274; see also Conquergood, 1991; Ellis, 2007; Riedmann, 1993).

These strengths of auto-ethnography are viewed by some scholars as weaknesses as it has been also described as "self-indulgent", narcissistic (see Méndez, 2013), or merely as Geertz (1988) states "author saturated texts." These critiques of auto-ethnography noted here however are arguably framed within a Eurocentric notion of what counts as legitimate forms of knowledge (see Graveline, 1998; Smith, 2012; Wilson, 2008). As such using auto-ethnography can contribute to decolonizing academic spaces by pushing the boundaries as to what is considered legitimate approaches to knowledge creation. However, I have tried here to weave in and out of my stories, from the micro perspective of my own experiences and thoughts to the broader socio-economic and political contexts within which we live to avoid being reduced to mere "author saturated texts" with the acknowledgment that these experiences I write about here are my own and may not apply to others in any way

One of the reasons a researcher may have for using auto-ethnography is to "embrace vulnerability as a way to understand emotions and improve social life" (Adams et al., 2015, p. 38). Adams and colleagues (2015) argue that while some stories are linear, many are not, and, arguably even stories that follow a temporal timeline may need to meander through time in a more circular way to reflect ones' experience more closely (see also Graveline, 1998; Ellis, 2004; Hughes & Pennington, 2017). Adams and colleagues (2015) also suggest that the personal narrative of "auto-ethnography helps avoid the ways other types of texts have been used to "diminish, silence, and control marginalized others" (p. 43). For example, it is partially through texts written by 'others', that the stories/histories of Indigenous Peoples in Canada have been retold according to the influence of the state, used to support Canada's reputation as a diverse, benign, and peaceful country, a country "founded" by Europeans rather than land inhabited by hundreds of thousands of Indigenous Peoples living there since time immemorial, viciously forced to leave their land (see Regan, 2010). As such it is important for me to

focus on personal storying, to tell my own story one which includes the fragmented pieces that are known about my family history, and the voices of my ancestors in this research.

Holman Jones (2005) tells us we should use auto-ethnography as "a radical democratic politics – a politics committed to creating a space for dialogue and debate that instigates and shapes social change" (p. 763). She argues that auto-ethnography writes "a world in a state of flux" (p. 764). However, for meeting western academic institutional guidelines this research must still be written in text form and as such is fixed in a location and time, at least partially. Houston (2007) contends that auto-ethnography "is the new ground where storytelling and research are merging on the borderlands of academia" (p. 47). These are potentially emergent spaces where academia and Indigenous decolonizing methods can try to work in unison, spaces where academia and Indigeneity can meet. Auto-ethnography is meant to challenge the dominant structures that shape academic institutions and what is considered legitimate knowledge, as such it contests western cognitive imperialism and ongoing colonization (Battiste, 2011; Graveline, 1998; Smith, 2012).). As such it sits within an Indigenous research paradigm and is consistent with a decolonizing approach to research (Wilson, 2008; Smith, 2012). I draw on anti-colonial theory which "builds on insights and narratives of 'indigeneity' (Dei and Asgharzadeh (2001, pg. 297) and critical political economy. Both of these theories are "western" theories, however, both are in line with critical Indigenous theories as they seek to understand, and deconstruct structures and relations of power in settler colonialism. Smith (2012) a Maori scholar, reminds us that decolonization doesn't mean that we need to totally reject Eurocentric based knowledge and theories, but rather "it is about centering our concerns and world views and then coming to know and understand theory and research from our own perspectives and for our own purposes" (2012, p. 89), something Tuck and Yang (2012) might call decentering the settler perspective. However, we must also consider how colonization in this era is accomplished "not through guns and threats, but through people who change the hearts, minds and spirits of others by promoting their own cultural belief system" (Hernandez-Wolf, 2013, p. 20), or in many instances the invisible internalization of one dominant cultural belief system. As such we must be aware of the insidious nature of Eurocentric knowledges and colonization of the mind,

body and spirit as they are reaching and can seep into our consciousness unseen. Ways of understanding the world are impacted, without us being consciously aware, by dominant thought, narratives, and worldviews that have been internalized. Maldonado-Torres calls this "colonization of being" (in Hernandez-Wolf, 2013, p. 21) and telling our own stories is a powerful form of resistance.

Attending to oneself and one's positionality in auto-ethnography is crucial. Auto-ethnographers study culture like other ethnographers through field work with the self, in relation to the broader world around them. In this way we become co-story tellers through "collaborative witness[ing]" (Adams et al., 2015, p. 56). Adams et al. (2015) argue for relational research and ethics, an ethical approach that "values mutual respect, dignity and connectedness between researcher and researched…" (p. 60). In relational research and ethics, we need to highlight and remain aware of our connectedness rather than our objectivity, something which Gespe'geaw'gi Mi'gmawei Mawiomi (2016) also consider crucial for indigenizing research.

2.2 Auto-ethnography, Relationality and Centering of Self

I draw on my experiences navigating and utilizing Indigenous medicines for cancer as a path of healing and resisting assimilation related to my own family history and reawakening métis identity. Specifically, I am interested in how sacred spaces are carved out and held amidst the plunders of a neoliberal model of health care in which health and health care are increasingly becoming private, for profit and commoditized (Flood & Archibald, 2001; Raphael et al., 2020; Panitch & Leys, 2010). I also want to contribute to efforts to unpack the increasing dominance of biomedical theories of disease, as a means to begin to decolonize health care experiences particularly as they relate to cancer and healing from intergenerational trauma. I embrace an ontological position, which Graveline Fyre calls 'self-in-relation' (1998) as an integral component to this research. Self-in-Relation is defined by Graveline (1998) as, "an understanding of the interdependence between self and community that provides a place from which to view "life, the natural world, and one's place in it" (p. 57). In this instance self-in-relation is a form of wholistic embodied relationality that situates the self as one of the points of connection between *self* and all life forms and forces past and present, including people,

places, and things such as institutions, policies and worldviews, and our ancestors (Graveline, 1998). On these pages I share a living story; a story about my life experiences in relation to the past and present (Connelly and Clandendin, 1990; Mattingly and Garro, 2001), and the natural and spirit worlds (Graveline, 1998) and in the exploration of my broader research questions, a form of wholistic storying (Absolon, 2010). I endeavour to construct a relationship between lived experience and building theory, which I am referring to as embodied theorizing. In particular, I engage with narrative inquiry and auto-ethnography reflections of my own experiences with cancer as an (re)emergent métis woman[8], while considering the broader context of Canadian public health and cancer care, and Canada's history of colonization, as well as my own journey towards my (re)emergent identity and the struggles therein. As Métis scholar Catherine Russell (1999) reminds us, self-reflection is a potentially powerful "... vehicle and a strategy for challenging imposed forms of identity" (p. 276). I include my experiences with Indigenous healing and the natural evolution of becoming an *Oshkaabewis* (Healer apprentice) as my healing/teachings progressed; uncovering and learning to trust what the Healer calls 'my healing gifts', and becoming a Healer myself, an integral part of the path towards my emergent and evolving identity, which is a form of resistance and healing from both colonization and cancer. It is also fundamentally a way to honour my ancestors who did not have this opportunity. It is also a way to honour my blood memory.

2.3 Decolonize, Decolonizing…

I employ an Indigenous and decolonizing framework to this research as a whole. This perspective is informed by Indigenous scholars such as Cash Ahenakew, 2019; Smith (2012), Chilisa (2019), Kovach (2009), and Wilson (2008). A decolonizing approach entails privileging, throughout the research process, Indigenous worldviews and knowledges that come from an Indigenous paradigm, and not just an Indigenous perspective (Wilson, 2001 see also Absolon, 2010). An Indigenous paradigm derives from the "fundamental belief that knowledge is relational" (Wilson, 2001, p. 176; see also Blackstock, 2011; Josephides & Grøsneth, 2017).

[8] I use emergent métis woman here as my identity as a métis woman is re-forming through learning about my family's history, the severing of Indigenous ties that took place due to colonial processes that I am now trying to braid together (see Harris, 2013 for discussion on emergent identities)

Throughout this study I also draw on Buroway's (2009) extended case method, which encourages a reflexive model of research/science that emphasizes, rather than tries to underplay or obscure, the intersubjectivity between researcher and "subject". His extended case method purposefully blurs and even tries to erase the bounded spaces of 'researcher' and 'researched' and is in line with Indigenous methodologies and concepts and enactments of relationality (Absolon, 2010; Ahenakew, 2019; Chilisa, 2019; Kovach, 2009, 2010; Smith, 2012; Wilson, 2008). This method,

> *...applies reflexive science to ethnography order to extract the general from the unique, move from the "micro" to the "macro", to connect the present to the past in anticipation of the future, all by building on existing theory (Buroway, 2009 p. 21).*

I use the current COVID19 crisis and its potential impact on certain Indigenous ceremonies such as the sweat lodge and shake tent, as a case study to examine the ways sacred spaces might easily be absorbed and lost via powerful forces such as biomedicine or more accurately the biomedical-industrial complex (McKenna 2012; Navarro, 2007; Sundar Rajan, 2007).

Denzin, Lincoln, and Smith (2008) define Indigenous methodologies as "research by and for Indigenous Peoples, using techniques and methods drawn from traditions and knowledges of those peoples" (p. x). Indigenous methodologies highlight the role that past and present forms of colonization, imperialism and globalization play in the construction of knowledge, and help illuminate the ways that euro-centric paradigms tend to carry with them "imperial power" over vulnerable populations (Chilisa, 2019, p. 8). Shawn Wilson, a Cree scholar (2008), maintains that Indigenous research needs to be enacted as a form of ceremony in itself, a pathway of learning and healing in its own right, while other Indigenous scholars such as Linda Tuhiwai-Smith (2012), argue that we must deconstruct Western scholarship through carving out spaces for Indigenous peoples to tell their own story in their own way, purposefully and without apology. Indigenous methodologies, including Indigenous first voice/auto-ethnographies, help honour this goal as they bring to the fore a relational ontological stance to understanding the world; a stance that opens space for Indigenous perspectives and ways of understanding disease and wellness, a space where a person is considered an integral part of a wider social, and

natural world; a world where one is also connected to a powerful spirit realm. During this research I have tried to honour these views and have endeavoured to engage in research as a form of ceremony, alongside other ceremonies, such as using sweat lodges, drumming, and singing to help me through the difficult process of revisiting and writing the stories on the pages that follow. My daughter and my husband are also part of this research by association as they are part of and impacted by the stories on these pages. They have both played an important role in reviewing this thesis and providing feedback. This was a difficult and healing process for both of them as well; our poison, and our medicine.

Before moving towards the main auto-ethnographic component of this study related to my experience with cancer and navigating biomedicine and Indigenous healing, I start by storying aspects of my history alongside the history of colonization in Canada, the impact of the Doctrine of Discovery and the Indian Act, with its brutal assimilationist strategies and one of the initiatives meant to begin a process of healing in Canada, the TRC. The TRC is attempting to right past atrocities Indigenous Peoples suffered at the hand of the state during the colonial era and beyond. The Doctrine of Discovery and the Indian Act are powerful governing documents that have impacted Indigenous Peoples, including my own family for over 150 years. I start with this discussion as background to what I believe lead to cancer in my body, and ultimately as a way to frame my own experiences of cancer, and healing. These spaces are fraught with important tensions, for example, the spaces between biomedical care and Indigenous forms of healing, as someone with a few different Indigenous bloodlines, who grew up with only occasional glimpses of this side of my family's history, and someone who is navigating the terrain between an emergent métis identity (see Harris, 2013), and a lack of connection to a specific community. This also includes the gaps in some of the details about my grandparents' and great grandparents' particular histories, in hopes that some of these long-held family secrets can be uncovered or at least understood through these powerful governing forces. I also examine my own experiences of care as they relate to health and healthcare more generally as an entry point into the deeper work of carving out of spaces for the sacred amidst the dominance and pervasiveness of the western biomedical

etiologies of disease that tend to be considered as the only legitimate forms of knowledge, perhaps at this point in history more insidiously than ever.

2.4 Storying and Embodying Methodology

Throughout this dissertation I purposefully try to disrupt my thinking, my internalized colonial ways of thinking that may go unnoticed, by writing in a way that attempts to decolonize my approach to knowledge exploration and creation (Smith, 2012). As such I insert myself using self-in-relation' as an approach to auto-ethnography and writing throughout. As noted above, self-in-relation is embedded within a relational ontology, one that views the natural, physical, emotional and spirit worlds as not just interconnected but *inseparable* at a fundamental level (Graveline, 1998). As Caine et al. (2013) note, "[a] relational and transactional ontology precedes narrative inquiry research, because stories are about what happens to and between people" (p. 583), and I would add between people and "things", events, and the natural and spirit worlds. This accentuation of the inter-connectedness of all things reflects many Indigenous worldviews (Wilson, 2008).

I engage with several theoretical frameworks, such as anti-colonial theory, critical political economy, as well as the *Etuaptmumk* framework throughout this research, as perspectives that challenge and defy more conventional approaches to knowledge creation and are in line with Indigenous wholistic theory that is meant to contribute to decolonizing research (e.g. Absolson, 2019). I endeavour to contribute to building on the *Etuaptmumk* as a framework using anti-colonial theorizing and critical political economy perspectives as a pathway towards honouring and highlighting the various nuances and tensions between the spaces of "Indigenous" and "non-Indigenous" knowledges and perspectives, as well as the wholistic, land based and relational nature of Indigenous knowledges; to develop *Etuaptmumk* towards a more dynamic multi-eyed seeing framework, which more accurately captures the intended essence of the *Etuaptmum*k paradigm, according to Elder Albert Marshall (Bartlett, Marshall & Marshall, 2015; Roher et al, 2021; Marshal, 2019, public lecture).

2.5 Borderlands: Theorizing the Space Between Bounded Spaces

Hernandez-Wolfe (2013) posits that 'borderlands' or 'in between spaces' reflect broader socio-economic and political relations. She argues that although they operate outside of the physical borders of the body they manifest in, and through our bodies, through struggles with health for example. Cancer provides a salient example to explore 'borderlands' as it is a prominent and growing health problem affecting bodies, minds and spirits, and is increasingly affecting more and more Indigenous Peoples. Further, although cancer has become more of a chronic disease than a death sentence in North America, there is currently no cure, and the mere word 'cancer' has the power to shake up our sense of self and being in the world, as does colonialism, capitalism and neoliberalism (e.g., Alfred, 2009; Ho, 2011; see also Jain, 2013), as these forces impact our lives, causing trauma, as well as how we live and what we have access to in material and other ways.

2.6 Cancer, Colonization and Capital

Perhaps because of the latter two aspects, cancer is big business in North America. Cancer as an objective illness reflects not only how diseases can be profitable, through the many technologies and products produced and used in its management, but also how the body and potentially life-threatening diseases are vulnerable to being commoditized under the power of market capitalism (Collyer, 2015; Hammod-Mrig & Spencer, 2018; Ho, 2011). Cancer provides a critical example of how the market can exploit vulnerability and continually searches for new ways to commoditize suffering. We now have a *cancer-industrial complex* firmly in place, obscured by the ongoing hope for a 'cure' (Ho, 2011; Jain, 2013). Cancer is big business with a global market profit of over 123 billion dollars a year and an expected growth upwards of 100 percent over the next few years (Herper, 2015). Cancer drugs bring in the most revenue for pharmaceutical companies compared to all other drugs (Bulchholz, 2021). Yet rooting out the causes from big toxic industries, petrochemicals and increasing environmental destruction is often downplayed or completely ignored in biomedical contexts with the focus remaining on finding drug therapies to prolong life and the illusive 'cure'.

In many ways, cancer can be a trope for colonialism, assimilation, and capitalism, for these, like cancer can eat away at one's being, reshaping or even destroying one's sense of self, and ways of living in fundamental ways (see Ho, 2011). Scheper-Hughes

and Lock (1987) suggest that "cultural constructions of and about the body are useful in sustaining particular views of society and social relations" (p. 19). In this sense the body and its various diseases are potentially a terrain, where capitalist and neoliberal ideologies manifest and shape how we relate to, and feel about our bodies, and our health, and how our very *being* is vulnerable to being turned into something that can be exploited and commoditized; our primal fear for our very lives in this instance is in effect commoditized. This also includes how we navigate "care" and how the content of care, and all it entails, influences how we think and feel about our bodies and selves in relation to particular illnesses. While the hallmark of biomedicine is to strip away the mind from the body, the reality is that these aspects of the self are not divided as such, furthermore, this division represents another form of colonization (Hokowhitu, 2009). In the contemporary period, the body, and more broadly our health, continues to be a terrain that is increasingly appropriated as a ground for market exploitation and neo-colonialism (Leys, 2010). Both colonization and neoliberal capitalism, the dominant economic system globally, shape not only institutions, such as healthcare (Navarro, 1976, 2007), but also our day-to-day bodily, and illness experiences (Klawiter, 2007). For Indigenous Peoples this has been a toxic experience across generations (e.g., Kelm, 1999). In her paper exploring post-colonial technologies Vincanne Adams (2002) argues that market interests in some cases become underpinned by "scientific knowledge practices that, long after colonialism, continue to serve as instruments for producing globalized medical 'truth' (p. 661)

2.7 Limitations of this Self-in-Relation (Em)bodied Work

This thesis, like all written forms, is by nature static, situated and 'finished' in a way that real life never is, the influx of emotions, various teachings/learnings that I am experiencing at this time that are influencing who and where I am in relation to this research as time passes. This means that I am evolving and changing, as are my thoughts and ideas (Gespe'geaw'gi Mi'gmawei Mawiomi, 2016).

In their book examining the history of colonization amongst the Mi'kmaq people in eastern Canada, Gespe'geaw'gi Mi'gmawei Mawiomi, (2016) argue that when "[y]ou put it in writing you ruin it." (p. 50). In reference to decolonization they state, "[s]eeking

truth and coming to knowledge necessitates studying the cycles, relationships and connection between things" (p. 53). In a Mi'kmaq worldview, for example, everything exists in constant cycles of transformation – and once something is written down "it becomes fixed and fossilized from that moment. Thus, it becomes sort of inaccurate from then on because the written version cannot correspond to any further transformation" (p. 50). People can respond to what is written and then rewrite, but it is not a dynamic, 'living' exchange that takes place in the moment. Gespe'geaw'gi Mi'gmawei Mawiomi, (2016) suggest that we remember that the "world is in constant flux" as are our ideas and perceptions. However sometimes writing is the "only tool we can offer" (p. 50) and in certain instances it is the only acceptable 'product' to create. This is the case for this thesis, I must commit ideas in the form of words to a page, as it is a major requirement set by the university and my department for completing a doctoral degree.

One form of resistance against these limitations, suggested by Wane (2006) is decolonizing the self. Decolonizing the self includes engaging in rituals to reclaim the mind, body, and spirit and challenge the dominant worldview that we have all naturally internalized (see Young and Nadeau, 2005). However, if as Thésée (2006) asserts "[t]he superiority of western knowledge has been internalized both by the colonizer and the colonized" (p. 33), then it follows that how we disentangle ourselves from colonization and begin to actually decolonize our minds, our thinking is complicated and perhaps not even entirely possible. Pieterse and Parekh suggests that decolonizing our imagination may be a place to begin, allowing ourselves to create space for imaginaries of change (1995). Thésée (2006), argues that we fight against the pervasiveness of dominant western ways of thinking and creating knowledge, by continually questioning dominant knowledges. She suggests engaging critical theory, such as anti-colonial theory, to help uncover and challenge dominant ways of thinking and knowing to create change. In other words, we must develop a critical consciousness as part of this process, and to do this we must "scrutinize social realities…question expressions of liberal humanism which can anesthetize the minds… and revalorize subjective and affective realities" (Thésée, 2006, p. 38), to reclaim silenced voices and hidden/lost knowledges (Lawrence, 2004, p. 82). We must also, as Gespe'geaw'gi Mi'gmawei Mawiomi (2016) suggest, study the

interconnectedness of all things and work towards understanding their relationships in order to decolonize our perspectives.

Engaging with anti-colonial theory is useful in this context as it helps develop a counter-hegemonic consciousness and contributes to acts of resistance, and, consequently, the transformative human agency of Indigenous as well other non-dominant and racialized peoples and consciousnesses. Anti-colonial theorizing provides an oppositional politics in which spaces for reimagining, and re-centering counter-knowledges and non-dominant voices are created and held. Central to anti-colonial theorizing is a reassertion and centering of Indigenous and other traditional counter-knowledges, or ways of knowing, and the de-centering, subversion, and disruption of "normative" Eurocentric narratives embedded in virtually every social institution, including healthcare (Dutta, 2018). Post-colonial scholar Mohan Dutta (2018) calls auto-ethnography, "a radical form of making embodied knowledge claims that resist the normative use of knowledge as an inherently colonial tool" (p. 94). These small acts can contribute to powerful forms of change as they accumulate. Furthering this I also engage a critical political economy lens in this work. Critical political economy is a form of analysis that critiques the influence of capitalist ideologies and dominant political economic arrangements and challenges the seeming logic behind these dominant paradigms and ideologies deployed in their defense (Coburn & Navarro, 2015; Collyer, 2015; McKenna, 2010, 2012; Singer & Baer, 1995; Navarro, 1976, 2007).

2.8 My Self-in-Relation to this Research

Where I am presently and have been throughout this doctoral study and writing process, is not only healing from cancer but also questioning my identity, my métis identity. I feel uneasy 'claiming' an Indigenous identity as that part of my family and culture was stolen (Lawrence, 2004, p. 85) and it sometimes feels false to reclaim it now when it was hidden for so long. Further, I wasn't raised in a traditional Indigenous family. However, I feel I must also question this uneasiness and try to understand it within the context of Canada's colonial history and assimilationist strategies that impacted my family of origin. It is not my fault indigeneity was stripped away from my family for generations, no more than it was my fault that I got sick with cancer, yet assimilation and 'whiteness' remains in my

consciousness, and it is a daily struggle to feel I have the right to reclaim what has been lost, particularly in the context of presumed racial characteristics that permeate Victorian society and its aftermath (Conlin, 2018). Cancer, and the fear of recurrence is also a continual struggle, and something that remains in my consciousness on a daily basis as I continue to focus on living and thriving *through* cancer. In both cases there is never an end product, one is in continual negotiation that puts one face to face with the state and state policies, such as the Indian Act, on who is allowed to claim Indian status and who is not, the other is face to face with biomedicine, a space where the body is objectified and placed under surveillance by technology; a 'problematic' body that is not to be trusted on its own (Foucault, 1963). A space where patients are defined and even confined by their illness. In these spaces the body becomes a site of colonization through biomedical surveillance, and the hegemonic biomedical paradigm (Kelm, 1999). It can also be a space that places us directly in front of our mortality, with news about life and death delivered by someone we may have never met before, a space never easy to occupy.

In this body of work, I do not want to reify racial or pseudo-ethnic categories by using the terms 'whiteness', "settler" or 'indigenous' but I think it is sometimes necessary to use these terms to draw attention to the fact that they do exist within the particular politics of identity that are more and more fraught and palpable in Canada (Tuck & Yang, 2012). My own struggle with identity is partially the result of state enforced assimilation processes and relate to Samantha Vice's (2010) suggestion that,

> *despite our context no life and no self are only political; no one can think of herself as only a citizen and only and essentially constituted by factors external to her… [p]art of eradicating racism would be to eradicate the forced identification of oneself as a particular public and political product (p. 323).*

As such it is important that I do try to assert my indigeneity, despite colonization and other assimilationist strategies used in Canada, to honor myself and my ancestors who hid their identity to survive (Lawrence, 2004, p. 173), as it is my right to live despite cancer, to remain healthy, intact and whole; to thrive and continue to reclaim my body/mind/spirit and culture. For me this is an act of resistance against disease, colonization, and assimilation.

These factors and struggles influence my position in this research. As such, my 'positionality' will continue to be in flux throughout the process, as I change, reclaim, learn, develop, and grow. To start off, I was raised in Canada throughout the reign of the Indian Act and my families' Indigenous blood was often brought up when someone was drunk, usually my grandfather, or in the summer when our skin turned reddish brown from the sun and as a result sometimes, we were called 'half breeds' by kids at school. We heard occasionally how one of our great grandfathers "was Indian", but it was always talked about as if it was a secret. While we have since found more formal documentation of métis and Mi'kmaq ancestry on my mom's mother's side, and now have stories about my great grandfather, my mothers, father's father, carrying medicines, and engaging in healing ceremonies in hiding. There is still much that is unknown and may never be known as all those that held those stories have passed on. When growing up, my siblings and I also heard occasional whispers that our great grandmother was Mohawk, and during a recent visit with my 92- year-old maternal grandmother, she said in hushed tones when I asked her about her she responded by saying, "she was native you know". My great grandmother died when my grandfather was four years old and with her the particulars of her life story and her history and Indigenous identity. My great grandfather also passed away many years ago and with him the stories he held about his own identity, history, Indigenous medicines and healing he carried. One thing that stood out in my family members' conversations over my life was that our grandmothers and great grandmothers lived in dire poverty, and were the recipients of various forms of physical, mental, and institutional violence. One of my grandmothers, who recently passed away, was put into foster care when she was a child and was forced to work for her foster family. She suffered much trauma and abuse at the hands of her family and state institutions. These acts of brutality contributed to my grandmother and great grandmother hiding aspects of their past, their identity, because they were ashamed or in order to survive. My grandmother, was also forcefully placed in mental health institutions throughout her life and forcefully, given electric shock therapy, the trauma from which I believe she never recovered.

Psychologist Hernandez-Wolf (2013) pointedly reminds me that, "…we always speak from a particular location within power structures, as such nobody escapes the

class, sexual, gender, spiritual, linguistic, geographical and racial hierarchies of the 'modern/colonial capitalist/patriarchal' world system (p. 27). Indeed, I and my family did not escape the shadow of violence over us, and its legacy lingers in my consciousness and continues to manifest in my body (see Walters et al., 2011). I was told by the Healer and an Elder that my cancer is related to intergenerational trauma and abuses. As such part of my healing requires telling these stories so that my daughter may have a healthier life.

As Thésée (2006) reminds us, in order to decolonize our own minds (and by association our bodies and spirit), which is an ongoing process (see Freire, 1994; Waziyatawin & Yellow Bird, 2012), we must start by questioning dominant knowledges, as our intellects, our ideas even our emotions have been shaped by colonization, imperialism and globalization, as well as capitalism (see also Chilisa, 2019; Dei & Kempf, 2006) to varying degrees no matter who we are. This was not possible for my 92-year-old grandmother, who passed away last year, nor for my great grandmother, who lived in severe poverty and had to try and survive in a patriarchal society that sought to extinguish her history and identity. For these women, who lost their status if they married non-Indigenous men (see Cannon, 2007; Lawrence, 2004; Smith & LaDuke, 2005), the struggle for survival meant assimilating into the dominant culture and hiding aspects of themselves to survive. But perhaps, my generation, my daughter and generations after, at a time in the Canadian and international public domain where some past wrongs are at least being acknowledged. The need to reclaim knowledges before Elders pass away continues to be a pressing matter even after decades of this being acknowledged as essential (Battiste & Youngblood Henderson, 2000; Brosius, 1997; Rowe et al., 2020; Simpson, 2004).

What I have learned so far through the research experience has been influenced/shaped in ways I may not always be able to see clearly yet, so I need to continually scrutinize these power/social structures and reflect on how they might be impacting my thinking. I find this to be the case with my cancer experience as well, the sense of moving between different paradigms of treatment and concepts of 'health' is fraught with inherent tensions that force me into sometimes uncomfortable, lonely spaces, spaces that are not easy to disentangle and make sense of; it also includes the lingering and palpable fear of recurrence I face most every day. My 'gaze' into my experience of

cancer and its aftermath, is also influenced by a particular set of values, and ways of understanding the world from living in a western Euro-centric society, with all of the visible and invisible power structures firmly in place; in other words, my 'gaze', my thinking and perspectives (Foucault, 1963), have been colonized and I need to continually problematize my thinking and de-colonize my gaze (Chilisa, 2019; Wane, 2006). I must attempt a process of 'decolonizing' my own mind in order to see the influence it has on my outlook more clearly. This includes working towards seeing the interconnectedness of things and seeing my self- in-relation to everything around me (Graveline, 1998; Wane, 2006), as well as my relationship with myself, my ancestors, and Indigenous culture, as I move through a cancer diagnosis in the broader context. This is also a major part of my own ongoing healing.

Many scholars assert that decolonization must involve "detachment or delinking from Euro-centric ways of thinking" (Hernandez-Wolf, 2013, p. 30; see also Chilisa, 2019; Mertens et al., 2013; Naseba Marsh et al., 2015; Dei & Kempf, 2006; Smith, 2012; Wilson, 2008), or what Hernandez-Wolf (2013) calls "epistemic disobedience" (p. 30). In order to work towards decolonizing our minds and our thinking we must not only question our thinking, but the types of knowledge that are valued in our society (see Chilisa, 2019; Graveline, 1998; Loppie, 2007; Smith, 2012). Dei and Kempf (2006) suggest the use of anti-colonial theory as a useful tool in this endeavor. They call anti-colonialism a theory of a "politic of resistance" when speaking about colonialism and imperialism as it exists today, imploring that "what matters is not to know the world but to change it" (Dei & Kempf, 2006, p. 1). However, it has also been argued that,

> *one of the most important tasks of a critical anti-colonial theory… is to capture and critique the continuities and discontinuities of the colonial and neocolonial era in order to make sense of our currently…colonized life…and worlds (Rabaka, 2009 in Dei & Kempf, 2006, p. 2)*

In other words, 'knowing' the world can help us identify and deconstruct the "masters tools" thus contributing to social change in a meaningful way. We do not just need knowledge for knowledge's sake, but rather must use knowledge to begin to empower those most vulnerable and create change, however small. Chilisa (2019) supports the

promise of anti-colonial theory in the struggle to decolonize our thinking, our knowledges, and worldviews, and reminds us of the importance of critical theories to challenge eurocentrism and to help us uncover their power and control over knowledge,

> *[a]n anti-colonial critique framework, using critical theory, postcolonial discourses and critical race-based theories, is challenging every discipline to assess how knowledge production and theories of the past and present have been shaped by ideas and power relations of imperialism, colonialism, neocolonialism, globalization and racism (p. 6).*

Dei and Kempf (2006) also attest that the nonmaterial legacies of colonization, those that have infiltrated our thinking, are equally as important as the material manifestations of colonization when engaging with resistance and recovery (p. ix). The colonization of our minds is harder to identify and resist however, as discussed earlier, as it is insidious and perhaps invisible.

2.9 Decolonization, Continuities and Time

The imposition of the academy to fulfill particular degree requirements in a timely way, and my need to respect my own inner timeline and healing, is an example of 'academic colonization' (Chilisa, 2019; Graveline, 1998; Lavallee, 2009; Loppie, 2007; Wilson, 2008). Likewise, in his book 'Research is Ceremony' Shawn Wilson (2008) draws our attention to the challenges of trying to fit indigenous methodologies into western academic contexts and constraints, particularly as they relate to time. He argues that Indigenous research paradigms are needed to better understand and meet the needs of, as well as to create knowledges that are meaningful to Indigenous Peoples (see also Chilisa, 2019; Cochran et al., 2008; Graveline, 1998; Lavallee, 2009; Dei & Kempf, 2006). Supporting this, Auger (2016) highlights the importance of cultural continuity in decolonization, something that requires a shift away from both acculturation and enculturation theory towards cultural continuity, a manifestation or form of cultural connection. She calls cultural continuity,

> *a strengths-based alternative to Western notions of enculturation and acculturation theory, cultural continuity describes the integration of people within their culture and the methods through which traditional*

knowledge is maintained and transmitted (2016, p. 1).

Cultural continuity is associated with better health and is considered a social and structural determinant of health (see Auger, 2016; Metzl & Hansen, 2014; Loppie, 2007), or rather a social and structural *dynamic* of health. I suggest the term *dynamic* rather than *determinant* here as the term determinant negates the incredible resilience, strength, and agency that Indigenous Peoples embody and continue to try and realize today despite so much resistance. Using the term social *dynamics* of health is also in keeping with Auger's suggestion to shift away from a deficit model of Indigenous Peoples, and not simply reducing Indigenous Peoples to helpless, victims, which diminishes us to having no free will, or agency (see also Tuck & MacKenzie, 2012).

Métis scholar Monique Auger (2016) confirms the importance of shifting away from a deficit model, one that merely focuses on negative factors and their impact on health and instead she suggests we focus on a strengths-based approach. Cultural continuity and regaining culture are important components of resilience, and include, being proud of who you are, having a positive identity and self-esteem, and a sense of belonging to a community, all of which are associated with better health (Auger, 2016). Intergenerational knowledge transmission is a crucial element of renewing and preserving cultural continuity for Indigenous Peoples and is also positively associated with better health (Auger, 2016; see also Bartlett et al., 2015; Bartlett, 2005; Chilisa, 2019; Graveline, 1998; Smith, 2012). It is increasingly timely and crucial to consider this as many Elders and Traditional knowledge keepers are old and passing away, and with them important knowledges and ways of being that influence those around them.

As discussed earlier, cultural continuity is important for healing. However, what about those who are cut off from even knowing about their culture, the ones who lost touch with their Indigenous roots because of the noxious Indian Act, that forced loss of identity particularly for many Indigenous women who married non-Indigenous men (Gespe'geaw'gi Mi'gmawei Mawiomi, 2016), and continues to shape "who" is accepted as "Indigenous" today. Under this rubric, "whole families have been decimated for generations" (Graveline, 1998, p. 21).

2.10 Embodiment and Self as Methodology

Csordas (1990) argues for a paradigm of embodiment that transcends methodology. In this sense the "body then is not an object to be studied in relation to culture but is to be considered as the subject of culture, or in other words as the existential ground of culture" (p. 3). This includes our emotional bodies. While considering using my own body as inseparable from my 'self' as a subject in this proposed research, I will need to be aware of the tendency to objectify my body and my 'self' while using my living experience of cancer (see Jackson, 2013; Richards, 2008). To do this I think it is necessary to always remember that I, my 'self', my body, my spirit, my experience with cancer, are something that are not separate from the core of my being, nor are they something to be studied *on*, rather I must study *through* them (see Waldstein, 2016). As such, my body/self is an instrument of study, an instrument that explores *through* my experiences from inside out, as well as in relation to the broader social, political and economic structures around me (Ellis, 2004; Houston, 2007; Whitinui, 2013); the outside in.

Nancy Scheper-Hughes and Margaret Lock (1987) remind us of Marcel Mauss's description of the body as the "first and most natural tool of man" (p. 7) and also perhaps the most natural tool of research, learning, and knowledge as the "body is an intellectual domain we all share" (p. 7).

> *Sickness is not just an isolated event, nor an unfortunate brush with nature. It is a form of communication – the language of the organs – through which nature, society and culture speak simultaneously. The individual body should be seen as the most immediate, the proximate terrain where social truths and social contradictions are played out, as well as a locus of personal and social resistance, creativity and struggle (Scheper-Hughes & Lock, 1987, p.31).*

Yet what does this mean exactly? How does this explain cancer for example, especially given how as a result of market capitalism, and the ongoing exploitation of resources for profit at the expense of the earth there are mixed explanations for cancer, such as environmental toxins, chemicals in our food, and stress. There are also the dominant biomedical views of cancer as purely related to genetics and in more recently epigenetics. Was there a form of social resistance playing out in my colon, or were social truths, and

social contradictions playing out in my intestines with me unaware? What communication was taking place? What is my personal and social form of resistance, creativity, and struggle? Is cancer a metaphor for capitalism and its impact on the earth (Ho, 2011)? There are obviously social factors involved in any bodily manifestation, but it is also related to nature, the toxicity of the earth, the trees, our water; nature, ultimately the scourge of capitalism, and we are intimately connected to them even if they appear to exist outside of the boundaries of our skin. We are all porous.

2.11 Auto-ethnography and the Centered Self

Holman Jones (2005) tells us we should use auto-ethnography as "a radical democratic politics – a politics committed to creating a space for dialogue and debate that instigates and shapes social change" (p.763). She argues that auto-ethnography writes "a world in a state of flux" (p. 764). However, for meeting western academic institutional guidelines this research must still be written in text and as such is fixed in a location and time, at least partially. However, some scholars argue that auto-ethnography is "the new ground where storytelling and research are merging on the borderlands of academia" (Houston, 2007, p. 47). Yet, auto-ethnography is still marginalized in terms of its level of legitimacy in most western academic circles. Auto-ethnography is a method that challenges the dominant structures that shape academic institutions and what is considered legitimate knowledge, as such it contests western imperialism and ongoing colonization (Graveline, 1998; Smith, 2012), something which is always fraught.

2.12 Concluding Thoughts

This chapter has explored many the methodologies, guiding frameworks, theories, and ways of thinking about this research, or rather, what Wilson (2008) calls 'strategies of inquiry'. I have also raised many questions that linger in my mind, questions about decolonization and how to do research that profoundly engages with decolonizing ways of thinking and learning. Some of these will be the subject of future study.

While I have argued here for the importance of decolonizing our minds and imaginations in order to contribute to real change through research, it remains that we live in a world dominated by western Euro-centric thought and what counts as legitimate

knowledge, a world dominated by capitalist and neoliberalist ideologies. How does one resist that which has infiltrated our thinking: our very imaginations. Hickel and Khan (2012) convincingly argue that even our resistance against neoliberal capitalism has become marketized, stating that the "logic of capitalism and the logic of resistance against capitalism have converged" (p. 206). They suggest this is a clear example of the pervasiveness of "capitalism's hegemony, that it has colonized our capacity to imagine [or maintain] alternatives and has transformed our potential for meaningful political critique and activism into a profoundly depoliticized, consumerist passivity" (p. 221). As such decolonization itself, its many initiatives and endeavours, risk becoming domesticated, entwined with the market, and our critical consciousness risks gentrification, as our ability to create and engage with forms of resistance are in danger of keeping centre, not only 'settlers' perspectives, but the underlying ideologies that created and contributed to colonization in the first place (see Hickel & Khan, 2012; Dei & Kempf, 2006).

As Linda Tuhiwai-Smith (2012) reminds us decolonization is messy, and not only messy but by necessity disruptive. Diseases like cancer are also disruptive. Indigenous women who refuse to continue to be erased are also becoming disruptive as we take up space and honour our voices, community, and collectives. Change can be disruptive to those who have been accommodated within oppressive structures for generations. As we find a space for ourselves amidst these transforming relations and social spaces, we need to be vigilant about whose knowledge and practices are promoted as normative and avoid initiatives that merely pay lip service to indigeneity and decolonization.

In this thesis I try to honour these perspectives and work towards decolonizing my own mind, body and spirit as well as this doctoral thesis. Decolonizing is a lifelong process, not something that can be done through one major project, or over even a few years. It takes a lifetime and it is a continual battle to resist the pull towards colonial perspectives, governed and imprisoned by capitalist and neoliberal ideologies.

Chapter 3 Storying Histories: Erased Histories, Live in Blood and Bones

The body. Flawed, scarred, and embattled, it is also beautiful, capable, and trustworthy. It is the most basic location of our memories and our stories (Warrior, 2008 g. 350).

3.1 Introduction

One of the first things the Healer said to me about my cancer was that it was connected to spirit and intergenerational trauma, that it was an opportunity to "turn poison into medicine", not just for myself but for my ancestors, past, present and future. They said that all sickness begins in spirit that is why it is so important to take care of our spirit. As such pain and illness are not seen as a punishment, but rather an opportunity to heal what Duran and colleagues (1998) call our "soul wounds" (see also Ahenakew, 2019). Pain has many possible functions such as "a visitor, a teacher and offering or a test" (Ahenakew, 2019, p. 36). In this chapter, I explore aspects of my family history alongside the history of colonization in Canada with its brutal assimilationist strategies and one of the initiatives meant to begin a process of healing, the TRC. I also integrate aspects of the Doctrine of Discovery and the Indian Act, two powerful governing influences on the lives of Indigenous Peoples that continues today.

3.2 Looking for 'Truths' Mired in Myths

The TRC is attempting to right past atrocities Indigenous Peoples suffered at the hand of the state during the colonial era and beyond. One of the goals is to tell truths about Canada's history, a history that has been purposefully hidden and mired in the myth of Canada as a benign peacemaker. This historical backdrop is integral to storying my experience with cancer, which is the main focus of this dissertation, as it is part of the backdrop in which I live and write, part of my family history and the context within which my illness manifested. Illness, in the form of cancer took root in my body long before it was discovered. It took generations for it to grow and manifest, to make itself known. It took, accumulative and ongoing invisible traumas that were part of my life, part of my mother's life, and her mother before her and so on, our collective soul wounding (Ahenakew, 2019). In western biomedicine they might relate this to epigenetics, a study

into the impact of trauma over generations on our genes (Paradis, 2016), something which Transcultural Psychiatrist Kirmayer et al. (2014) might consider reductionist, as it takes trauma and its impact on lifeworlds to its cellular level, rather than a more wholistic perspective. Through this chapter, and this dissertation as a whole, I aim to engage with what Garcia Navarro (2019) calls building resilience by storying "one's traumatic past" and that of past generations, as a strategy to "initiate a transformative healing process" (p. 51; see also Sium & Ritskes, 2013), carving out spaces of hope and healing, sacred spaces.

A keystone of the myth of Canada as peacekeeper, involves the virgin soil hypothesis, which argues that Indigenous populations lacked immunity and could not fight off opportunistic infections. However, in his book 'Epidemics and Enslavement', Kelton (2007) contends that Indigenous Peoples resistance to disease was weakened because of malnutrition, major disruptions in lifestyle, the crushing stress of being displaced, and being unable to access traditional livelihoods. It was not the genetic inferiority of Social Darwinism, which neglects the purposeful and crafted nature of their demise, that was responsible (see Daschuk, 2013; Mann, 2009), nor was it because they were immunologically virginal (Kelton, 2007). Rather, the processes of colonialism themselves impacted Indigenous Peoples immunity to infections and co-infections. Stress, overcrowding, lack of nutritious food and rest, all established an ideal condition for opportunistic infections to thrive (Kelton, 2007). Indeed, taking this further, the attempted genocide of Indigenous Peoples centered on biology, in which a form of germ warfare, such as purposeful contamination, facilitated by colonization processes, was used to overpower and conquer Indigenous Peoples, so that resource rich land could be taken over by European settlers (see also Bodley, 2015; King, 2012; Mann, 2009; Said, 1994). The shift from hunting and gathering to horticulture, and more sedentary ways of life, due to land appropriation for resource exploitation, also contributed to an environment where disease could spread easily (Bodley, 2015; Dashcuk, 2013; Kelton, 2007). The spread of disease and the massive death toll on Indigenous Peoples, it is argued, was ultimately the result of commerce; the increasing reliance on trade of European goods for Indigenous Peoples 'subsistence meant increased contact with settlers and contaminated wares, and forcing Indigenous peoples into slavery, also lead to increased power imbalances between

the European settlers and Indigenous Peoples (e.g., Bodley, 2015; Daschuk, 2013; Mann, 2009). All these factors had a devastating impact on all aspects of Indigenous Peoples lives, culture and health (Oakley, 2021).

Mann (2009) also debunks the myth of Native American superstition and refusal to use European medicine as being to blame, another invented story that has been told and perpetuated (Kelm, 1999). Mann (2009) and Kelm (1999) both highlight how European medicine at the time was actually quite barbaric, with bleedings, blistering and elemental medicine often containing mercury, or other poisonous ingredients as the main treatments. They both argue that it was the Europeans who were superstitious, but instead the demise of the Indigenous Peoples was blamed on superstition, ignorance, barbaric practices, and lack of disease theory. Along with other scholars (see Daschuk, 2013; Keller, 2006; Kelm, 1999; Robbins & Dewar, 2011). Mann (2009) contends that it was a conscious political strategy, to perpetuate the myth that Indigenous Peoples were too ignorant to get vaccinated, for example, and that is why so many died of smallpox. As discussed earlier the purposeful spreading of disease was not only political, but also related to increasing the market economy and profit through land expropriation and control (Bodley, 2014; Jalata, 2013).

The so-called civilizing Indigenous Peoples missions were mainly assimilationist missions, a means to gain access to land and rich resources Indigenous peoples occupied, as they got in the way of exploiting land for profit (Comack, 2018; Coulthard, 2014; Jalata, 2013; Willow, 2016). Said (1993) agrees, arguing that the growing needs of the industrial nations for resources was and remains "a primary cause of the transformation of tribal cultures, the appropriation of resource rich land to be exploited for profit'" (pg. 15; see also Lenin, 1999). Assimilation was done in the interest of the state and the ruling class, whose main goal was to spread, and firmly establish market capitalism in this point and time in history (see also Césaire, 1972). Industrialization, commercialization and exploiting land and resources for profit comes into conflict with many Indigenous relational worldviews in which all things in nature are interconnected and should be taken care of as such (Bodley, 2015; Hart, 2010; King, 2012).

3.3 The Disappearing of Indigenous Lives and Truths

Many Indigenous Peoples have been made to disappear at the hands of the state or have been silenced. Some scholars argue this silence extends to the TRC report and the related Calls to Action, particularly as they pertain to health and health care, as many voices are absent in the TRC process (Chrisjohn & Wasacase, 2009; James, 2012). Many Indigenous Peoples and voices were forced into silence and were buried during the colonial era. My great grandfather and great grandmother for example, were forced to hide parts of their identities to survive. For example, my great grandfather hid the healing ceremonies and medicines he carried and had to conduct healing ceremonies in secret with his family and others in his back shed. My aunt recently recounted how he had spent time in the Black Hills with a medicine man when he was young, who he received many teachings from. He once took my cousin out during the night and picked some medicines under a full moon for a sickness she had. He then did a healing ceremony with her where he chanted and applied the medicine to her skin. She said he sang in an "native language" she didn't recognize, but she didn't ask any questions at the time, she recounted with a lot of regret. My mother added to this that my great grandfather could heal with his hands. All of his healing work was done quietly and in secret.

My family didn't ever speak much about my great grandmother (my grandfather's mom), other than she died very young, when my grandfather was 4 years old. When I was young I only heard in whispers that she was "native" like it was something to be ashamed of, whispers my grandmother (my mom's mom) repeated to me as she lay in bed during what ended up being the last few months of her life. Even so many years later she still didn't feel comfortable speaking those words out loud (see Appadurai, 1988).

Below is a picture of my great grandfather. I am still trying to find pictures of his wife, my great grandmother who we believe was Mohawk based on information from some other family sources. I hear he was a quiet and soft-spoken man, a gentle soul with many stories I will never hear.

Figure 1 Great Grandfather

Not everyone gets to or even wants to tell their story (Smith, 2012, p. 59), yet the missing voices are gaps in the bricolage of history, our personal histories and those of the land now known as Canada. We need to fill in these spaces to move forward towards healing our soul wound (Ahenakew, 2019). At least I feel I need to. My story of cancer and healing is entwined with the history of my family, our stories, our history, a history of trauma, poverty, institutionalization, and incarceration; intergenerational trauma that was buried deep in in my body without me knowing. As Ziarkowska (2014) says our "bodies become texts onto which different histories are inscribed" (p. 4). In this sense my body, which is part of my whole being, not just an object of illness, was cut open, the scars are both visible and non-visible, all of them just as real, they are written on/in my skin, my tissues, my blood. This cutting open was physical, mental, emotional and spiritual. I feel privileged to be able to take up space on these pages to write my story, as a foundation toward to intergenerational healing.

3.4 Truths then Maybe Reconciliation?

Recently there has been increasing recognition about the brutality inflicted upon Indigenous Peoples. The TRC (TRC, 2015) has been promoted as a significant part of in this recognition process. Created as a component of the Residential Schools Settlement Agreement, one of their mandates is to 'tell the truth' about Canada's history, and the brutalities that occurred in relation to the Residential Schools. The TRC is a five-year mandate supported by the federal government, which began in 2008. The Commission set out to record, through public education and documentation, the experiences of residential school survivors, their families and the broader communities affected. Those affected were invited to share their stories through one-on-one interviews, written documentation and publicly held forums. The TRC's goal is to "guide and inspire Indigenous Peoples and Canadians in a process of reconciliation and renewed relationships that are based on mutual understanding and respect" (TRC, 2015), yet continues to adhere to the Indian Act as the governing rubric for managing Indigenous Peoples of Canada. Further, the TRC makes it very clear that this process is not a 'criminal tribunal' although the historical record clearly reveals that criminal acts were perpetrated on Indigenous Peoples in a multiplicity of ways during the colonial era in Canada, particularly through the residential school system. The TRC, is a component of the Indian Residential Schools Settlement Agreement, created with the support of the Assembly of First Nations and Inuit organizations in which, former residential school students took the federal government and the churches to court (TRC, 2015). These cases led to the Indian Residential Schools Settlement Agreement, the largest class-action settlement in Canadian history. The agreement sought to begin repairing the harm caused by residential schools (TRC, 2015). The TRC's mandate was to inform all Canadians about what happened in Indian Residential Schools (IRS) in Canada between 1883 and 1996, and to address the ongoing impact of colonization on Indigenous Peoples today (TRC, 2015).

The TRC committee's attempts to address past atrocities faced by Indigenous Peoples in Canada obscures and neglects many Indigenous lives, experiences, and voices. In some instances, it is those most affected by social and economic disparities, those most economically and politically marginalized, even within their own communities that are the most invisible (see Chrisjohn & Wasacase, 2009). Further, many of the initiatives that

have been put in motion merely pay lip service to creating any real change or healing (Ahenakew, 2019; Chrisjohn & Wasacase, 2009; Jimmy et al., 2019). For example, massive amounts of funding are being invested into health care initiatives, yet little is being done to return land and water that was stolen from Indigenous Peoples, land free of carcinogens, and provide access to safe housing, clean water and healthy food, the basic building blocks of health.

Concerns have also been raised by Indigenous Peoples, communities, as well as scholars, that the TRC is largely a tool of the state to manage the 'Indian problem' in modern times, although in a less violent and overt way than during the colonial era (Corntassel & Holder, 2008; Corntassel et al., 2009). Further, Corntassel et al. (2009) argue that the approach taken by the TRC is informed by a western model of justice that attributes reconciliation to financial compensation instead of true reconciliation and healing. Others argue that the TRC may lead to further assimilation (Barker, 2005; Chrisjohn & Wasacase, 2009; Corntassel et al., 2009; Corntassel & Holder, 2008). For 'truth' and meaningful reconciliation to manifest in Canada, the TRC report and its many calls to action need to go beyond lip service, and what Regan (2010) calls ethically suspect acts of reconciliation. A number of scholars agree that in order for true reconciliation to occur we would need to dismantle the ideological, socio-economic structures that contribute to maintaining the status quo, and that lead to colonization in the first place (Bodley, 2015; Césaire, 1972; Corntassel et al., 2009; Farmer, 2004; Freire, 1970), including not allowing profit and corporations to take priority over people and the planet.

Similarly, Roland Chrisjohn and Tanya Wasacase (2009) contend that the TRC is mostly a persuasive rhetoric and should not be taken at 'face value' at all. While others have called the TRC a form of "colonial shapeshifting" (Alfred & Corntassel, 2005, p. 601), a form of colonialism that is more ideological than in the past. Chrisjohn and Wasacase argue that the TRC implies that somehow Indigenous Peoples and settlers used to live in a state of harmony on the land that is now called Canada. Another concern raised is that the TRC in Canada, as in South Africa, individualizes victims of violent assimilation tactics and attempted genocide (Mamdani, 2002). Instead of the TRC

focusing on Indigenous communities and the state, it focuses on *individual* Indigenous Peoples and the state.

Storying our lives and traumas is a crucial aspect of healing (Archibald, 2008), however in this instance a number of scholars are critical about the emphasis being only on individuals telling their stories in public state-controlled forums, rather than the state, and others involved being held accountable in a concrete way for the atrocities, including genocide, and creating structural and ideological change (Chrisjohn & Wasacase, 2009; Czyzewski, 2011). Corntassel et al. (2009) also make the point that,

> *State-centred processes of reconciliation attempt to repair the damages caused by residential schools but do little to reunify and regenerate families and communities dispersed and dislocated by the trauma of these schools. (p. 140)*

Some Indigenous Peoples who have come forth have been reimbursed financially for the past atrocities, but the effects of residential schools, as well as the imperialist and racist ideologies behind them, are much more complicated and far reaching than financial compensation could ever make up for, particularly for elderly and middle-aged people whose lives were ruined and have little time left to rebuild. Recently, in 2021, the truth about the atrocities committed in residential schools is being uncovered as the remains and unmarked graves of children that died at the hands of the state are being uncovered. Further, racism against Indigenous Peoples continues to exist. As noted above, Corntassel et al. (2009) also state that the TRC is informed and modelled after a "Western model of justice where individuals may seek compensation (usually financial) for their losses" (p.146), but as stated above this does little to repair ongoing damages caused to families and communities, and when one considers that the state continues to have the power to define who is a 'registered Indian', it means that a large percentage of the Indigenous population are completely left out of these liberal reconciliation processes. Furthermore, another problematic issue is that the government is still allowing industry to exploit and destroy Indigenous land in Canada while paying lip service to truth and reconciliation (see Datta & Hurlbert, 2019; James, 2012; Jimmy et al., 2019).

3.5 Lost Voices Live in Blood

While speaking about his own 'pain as teacher 'journey, Ahenakew (2019) draws our attention to the importance of "reconciliation with the land and the sun, … of attachments, of entitlements, of human-centred authority" (p. 30). The TRC uses a restrictive and colonial paradigm for healing, and lacks a critical ontological perspective, that of relationality that Ahenakew (2019) highlights. Reconciliation requires also healing from "human-centred authority" as noted above and the exploitation and devastation of capitalism (Ahenakew, 2019). This restrictive model ends up circumscribing lasting healing and change, as it misses a key point, that healing needs to happen to not only our spirit, body, mind but also the land, and the water. We are interconnected. We need reconciliation with the land by stopping its destruction, full stop.

As stated above that there are many Indigenous Peoples who do not have registered Indian or Treaty status and this needs to be taken into account when considering the impact of the TRC, as this impacts their rights in relation to the state. Without addressing the ongoing impact of the Indian Act for example, many Calls to Action may be implemented in ways that do not meaningfully address the abuses Indigenous Peoples in Canada have endured and continue to face. A large percentage of Indigenous Peoples are not able to trace family ties in a way that the government deems legitimate or because records have been purposefully erased (Lawrence, 2004; Oakley, 2019, 2021). These factors complicate identities. They complicate Indigenous identities as many connections were severed via colonial processes, many Indigenous Peoples were enfranchised, they were forced to give up their Indian status to survive or automatically lost it if they left the reserve or if an Indigenous women married a non-Indigenous man. More recently, perhaps partly in relation to the TRC, Indigenous identity and identifying as Indigenous is increasingly fraught; exploited, and guarded, particularly as it become increasingly entwined with access to new resources, for example, funding and jobs. Some people are being accused of falsely claiming Indigenous identities, in some instances to gain access to resources. However, Métis scholars Malette and Marcotte (2017) argue that the reconnection of Indigenous roots particularly for the many Quebec Métis, for example, whose ties to Indigeneity were purposefully disappeared due to colonial processes that stripped them of their culture in the first place is critical to resisting

assimilation. Many Métis, like myself and my family, wish to reconnect these ties to their blood lines that were forcibly severed and now contested to help find a sense of belonging, to honour our ancestors (St. Denis & Walsh, 2016). Others are being denied their Indigenous identities as they don't meet state requirements for status, which can tend to be based on blood quantum (Palmater, 2011). And yet others remain uncomfortably in-between, not sure if they can claim Indigenous identity given history and current politics. This in-between space I shift in and out of often. I am not sure who I am with regards to my Indigenous roots. Connections were forcibly severed; stories and details have been lost forever as those who carried them have passed on. There are no easy answers to questions about my own identity. For now, I continue to focus on honouring my ancestors, some of whom didn't have the privilege to be themselves and openly identify as Indigenous, their survival depended on its denial. I continue to dedicate my heart and spirit to learning ceremonies, spiritual practices and teachings; being an Oshkaabewis (ceremonial/healer's apprentice) for a Healer I love and respect and learning as much as is possible about my family. I also want to honour the profound sense of connection I feel to the cultural teachings and the ceremonies. I am reconnecting myself with that which was lost. This is integral to my healing journey.

3.6 Bodies Telling Stories…

Ziarkowska (2014) reminds us that histories may be erased by the state, rewritten by family, but they live on in our bodies, our blood, our spirit. The following quote articulates this point,

> *Native history is inextricably connected with ancestral geography, replicated, like DNA, in contemporary Native bodies… history [is]expressed in terms of geographical locations as well as bodily experiences and sensations that are remembered, passed on and inherited in the same way genetic material is transmitted from one agent to another. Hence, history, memory and indigenous bodies become integral and integrated components of contemporary Native American identity (Smith 2012, p. 1).*

In this way broken, scarred bodies communicate "the truth about the state of the world"; our bodies become as broken as the earth, and through extraction and abuses, the land, the

earth becomes as broken as our bodies and so on (Ziarkowska, 2014, p. 2). We are intricately connected, inseparable. Cree scholar Cash Ahenakew (2019) states,

> *we need to re-centre the earth in our individual and collective existence in order to re-activate our sense of entangled relationality that will show us that we are interwoven in (rather than with) each other through the metabolism of the land. This re-centring of the land is a precondition for us to start the journey towards scarring the collective soul wound, a wound caused by the imposition of a sense of separation between "man and nature" and between each other. Centring the land is not about centring the concept of the land, but about centring the land as a metabolism. It is not about seeing the land as an extension of ourselves, but the other way around; seeing ourselves as an extension of the land that, through different waves of colonialism, has been objectified, occupied, and violated. This involves un-numbing ourselves to the pain of the land (p. 15).*

My cancer experience was also for me a form of connecting to the "pain of the land", the continued abuses it endures in the name of profit for few. Re-centering the land, for me also includes reconnecting the fragmented parts of self, and my family history towards becoming whole again, hopefully one day. When I was young, I *felt* part of the natural world, I felt connected in my bones, it was natural. That feeling was harder to hang onto as I got older, and it even disappeared for a long while, I fought against it, but now I am fighting for it.

3.7 Indian Act Impacts

I think it's important here to provide a bit more context information about the noxious Indian Act as it has had and continues to have tremendous impact on Indigenous identities and lives in Canada and is based on European notions of racial and cultural superiority (Palmater, 2011). The Indian Act is a Canadian federal governing document, with legal implications, that allows the government to control many aspects of Indigenous Peoples lives including who is considered Indigenous in the eyes of the state and it is implicated in present Indigenous identity politics (Lawrence, 2004; Palmater, 2011). As Burton (2012) explains,

> *The Act has accomplished the creation of a racist and patriarchal system of status provisions, which have furthered the goal of assimilation of Indian people into Canadian society and caused major damage to their families and communities (p. 1).*

It was and remains part of the assimilationist strategy in Canada (Palmater, 2011), along with forcing people to take up agriculture instead of gathering, hunting and fishing, (Grygier, 1994), slavery (Neeganagwedgin, 2012), banning of essential economic and spiritual practices, (Kelm, 1999), conversion to forms of Christianity (Rahman et al., 2017), starvation (Daschuk, 2013), forced sterilization (Stote, 2015), shaming and devaluing language/culture and erasing women's and off reserve people 'right to claim Indigenous status' (Cannon, 2007).

The Indian Act is a state structure of violence against Indigenous Peoples (Kennedy, 2010; Kurtz et al., 2013) used to contribute to their erasure. In his examination of structural violence in Haiti Anthropologist Paul Farmer (2004) states that "[e]rasing history is perhaps the most common explanatory sleight-of-hand relied upon by the architects of structural violence" (pg. 308). Histories are erasable in some contexts, but their impact lingers beneath the surface, they penetrate human tissues, our blood and bones, imprinting themselves in our DNA, where they get passed down through generations (Ziarkowska, 2014). And as Ahenakew (2019) reminds us they are part of the land; "[m]y body is the land, the other-than-humans are the land, the plants are the land, the earth is the land, the wider cosmos is also the land" (p. 21).

The erasure and denial of our interconnectivity is impacting the health of all life forms and it is getting harder and harder to deny this, given climate change, and the continued dumping of toxic waste particularly in areas close to First Nations reserves and other racialized peoples (Waldron, 2018). This impact on life and all life worlds may go by go unnoticed for some populations, but they manifest in poor health, and death, particularly among the most vulnerable (Farmer, 2004). Yet there is little acknowledgment in dominant policies and practices that these factors are making people sick.

It is easy to alter stories, even whole histories; they can be rewritten to put a particular image forward. The story, that many Canadians were taught in state educational

institutions up until recently, is that Canada was built by creating 'civilization' out of 'wildness', part of a so-called noble humanitarian act, done for the good of Indigenous Peoples, who were considered nothing more than "savages" (Paul, 2006), and that it was a Christian, moral obligation to modernize and tame Indigenous Peoples (Paul 2006; Robbins, 2013). In this story, the violence of theft of land, obliteration of subsistence and trade economies, the imposition of foreign western principles, language and worldviews (Corntassel et al., 2009; Mackey, 1997, 2002) onto people is erased almost entirely, or it is justified through lies. This myth lingers, in our spirit, our minds, our bodies, our blood (see also Corntassel et al., 2009; Paul, 2006). Canada has simultaneously created and endorsed its own national identity, branded itself as global 'peacekeeper' (Regan, 2010), obscuring its brutal history of colonization and genocide, yet it is stored in the earth, our bodies, our cells. During the colonial era Indigenous Peoples were enslaved, purposefully exposed to diseases, murdered, banned from traditional practices, and forcefully assimilated into Euro-Canadian society (Mann, 2009; Daschuk, 2013; Regan, 2010). These tactics were used in the name of ensuring the survival of the British colonies and the appropriation of land for resource extraction (Robbins, 2013; Bodley, 2014).

Cash Ahenakew (2019) and Elwood Jimmy et al., (2019) remind us that when we hurt others, when we hurt the land, we hurt our own bodies/minds/spirits. We are all part of the same 'body'. The atrocities inflicted during colonization have etched their mark on everything, they have penetrated beneath our skin, and into our cells in ways that may escape our conscious knowing. They colour the present no matter who or what we are. We are also hurt by the lies the state continues to tell us about colonial processes and the devastation they caused even as truths begin to become part of our collective consciousness there is still so much ignorance and resistance to even believing these past atrocities occurred.

3.8 Re-storying Family History

My grandmother, on my mom's side, never openly acknowledged or spoke about her family history. We know that her family has Mi'kmaq and métis blood lines and her great grandmother was Mi'kmaw. I only recently learned that my grandmother was taken from her family when she was young, her and her sister were sent to live in foster care. Her

family was so poor she and her siblings used to have to steal to eat. Violence was a regular occurrence in her life. She ended up working at the age of 8 for a foster family she lived with, she did the cooking and cleaning and taking care of children. My grandmother was also not allowed to attend school past grade three because she had epilepsy and used to have seizures. At that time, it was believed that people who had epileptic seizures were possessed by the devil. My Grandmother was actually kicked out of school because they thought she was a witch and possessed by the devil. My grandmother never did talk about this herself, but we heard the stories, and they seeped through her skin, her eyes, her health. My grandmother was diagnosed in her late 20's as schizophrenic and forcibly institutionalized and treated with electroshock therapy on and off for many years during her adult life. I witnessed her so called "episodes", her lapses into violence, violence she herself endured for much of her life. I also witnessed her being forcibly taken to the hospital. I remember her being taken one night, strapped down, and put in an ambulance while she screamed for them to let her go. When they took her away, she was gone for weeks and sometimes months at a time. She was terrified of doctors and never willingly saw one in her life. Not once was it ever considered by doctors that her family history of trauma, within the context of colonization, was at the heart and soul of it all. She was never asked to tell her story, nor was she really shown any compassion or understanding of her history and its impact. She was seen as out of control, defective and possibly dangerous. My grandmother had a strong spirit, she had what I have often thought of as a kind of 'wild 'woman living inside her, that would come screaming out when she couldn't hold her in anymore, she was powerful that way. If she was born at a different time her life would have been much different. However, she kept the gift of a huge loving heart despite everything until she died last year. When I was young, I once had a dream about her wearing different clothes, drumming with other women, singing, shining and happy. Witnessing her anguish and being forcibly taken away for many years as I was growing up made me internalize a fear of being institutionalized myself, of being forced into a type of care that is terrifying and doesn't make sense to me. Many times, during my life I truly felt terror that I would be subjected to what she had to endure.

Figure 2 My grandmother when she was in her sixties

Figure 3 My Grandmother a few weeks before she passed away

3.9 Earth, Land, Bodies and History

The missions to "civilize" Indigenous Peoples were mainly assimilationist missions driven by the state, a means to gain access to land and rich resources Indigenous peoples occupied, as they got in the way of exploiting land for profit (Hart, 2010; Jalata, 2013; Willow, 2016). Assimilation was done in the interest of the state and the ruling class, whose main goal was to spread, and firmly establish market capitalism (see also Césaire, 1972). Capitalist forms of domestication were forced upon Indigenous Peoples.

Like the exploitation and extraction of resources from the earth, our bodies often end up wearing the brunt of the cold brutalities of capitalism, profiteering at the expense of people, of land, of spirit, our cells. These repetitive abuses manifest not only through physical sickness, but also through mental, emotional and spiritual sickness. History may "belong to a far past" but the past is not easily forgotten (Garcia Navarro, 2019). Hogan (2001) argues that the "status of the body is a map in a long journey" (p. 56), a historical journey that is part of our inner lifeworlds (see also Jackson, 2013). She elaborates further,

> *. . . history, like geography, lives in the body and it is marrow-deep. . .*
> *It is recorded there, laid down along the tracks and pathways and synapses. . .*
> *Those of us who walked out of genocide by some cast of fortune still*
> *struggle with the brokenness of our bodies and hearts. Terror, even now,*
> *for many of us, is remembered inside us, history present in our cells that*
> *came from our ancestor's cells, from bodies hated, removed, and killed.*
> *(Hogan, 2001, p. 59).*

The geography of my body, its ugliness, its beauty, is found in the most unusual places; its scars sometimes make me cry with tenderness, and love and other times with shame and self -loathing. Trauma was remembered inside my grandmother, and they tried to remove the stories, the abuses imprinted in her body, her cells, her spirit through electro-shock therapy, they literally zapped her brain, she was seen as fragile, and broken (van Daalen-Smith, 2011). When we were young, we tiptoed around her when she would fall into these dark spaces. We could all tell by the look in her eyes that she had broken off,

entered into another world where she became a different person; when she got that look, we all knew to be careful.

I have felt deep sadness and fear live in my body for as long as I can remember, you could see it in my body language I was told, the look in my eyes, tension in my muscles, my shoulders curving inward to protect my heart. This sadness and fear were both familiar, that which could be named and at other times vague and shapeless, beneath the surface. This sadness and fear that lived on inside me at a cellular level came from my family's collective soul wound, which became buried deep within me, in my bones. I believe my cancer also came from this place.

3.10 Doctrine of Discovery

A keystone of the myth of Canada as' discovered land' involves the Doctrine of Discovery. This Doctrine is a series of formal statements from the Pope in the 1400's. This doctrine basically gave permission for Christian explorers to claim land for their monarchs regardless of the original peoples who had been occupying the land since time immemorial. The underlying ideology of this document is that Christian Europeans were considered superior in relation to Indigenous Peoples. This ideology and practice continue today in the land now called Canada (Assembly of First Nations, 2018). The Doctrine of Discovery was articulated as an international law that gave license to explorers to claim vacant land (terra nullius) in the name of their sovereign. Vacant land was defined as land that was not populated by Christians and/or not being used for agriculture. In other words, any land that was not inhabited by Christians or being used for agriculture was considered unowned and uninhabited, and thus up for grabs (Reld, 2010). This law still has impact today in legal realms related to land claims and Indigenous and Treaty rights.

This doctrine has had and continues to have devastating consequences for Indigenous peoples. Yet many Canadians are still not even familiar with it or its continued impact. The Doctrine of Discovery laid the very foundation of genocide, gave permission, in effect from a Christian notion of God to enslave and kill peoples and take over land.

3.11 Erasing History and Myth Making

Said (1993) affirms that the main battle in imperialism is a battle over land, who owns the land, who has the right to settle on the land, and exploit the land for resources and profit (see also Bodley, 2014). The narrative taught in schools and subsequently passed down from generation to generation to Canadians that Indigenous Peoples were *less than,* gets entwined with the cultural and societal narrative that has become a deeply engrained 'truth', told, and retold in many forums. Said contends that these battles are "reflected, contested and even for a time decided through narrative" (pg. xiii) in the stories we are told in various formats within a society. For example, Indigenous Peoples are portrayed in history books, novels and films as vicious savages or silly children (King, 2012; Said, 1993). Said also argues that "the power to narrate, or block other narratives from forming and emerging, is very important to culture and imperialism, and constitutes one of the main connections between them" (p xiii; see also Lenin, 1999). The narrative taught in schools and subsequently passed down from generation to generation to Canadians that Indigenous Peoples were *less than,* gets entwined with the cultural and societal narrative that has become a deeply engrained 'truth', told, and retold in many forums, for example. This myth making and theft of land is imprinted in our bodies, the sense of inferiority unconsciously internalized. What we weren't taught in school as these false stories were told is that we are all connected to the land and what is done to the earth is mirrored in our spirits, minds, and bodies, so what is really gained by exploiting resources, our ultimate mother, the earth? It isn't a matter of how the so-called new world was won but what we have all lost through the process.

I remember being taught in school that Indigenous People were savages that had to be tamed with violent force because they were so dangerous, that the colonizers were more human, more civilized. In this story, the violence of theft of land, obliteration of subsistence and trade economies, the imposition of foreign western principles, language, and worldviews (Corntassel et al., 2009; Mackey, 1997) onto people is erased almost entirely. Even as voluminous evidence about violence being the main approach taken by colonial rule and the Canadian state (see also Corntassel et al., 2009; Daschuck, 2013; Kelton, 2007; Mackey, 2002; Paul, 2006), Canada has pushed its own national identity as global 'peacekeeper' (Regan, 2010), obscuring Canada's history of colonization and

genocide. Canada's mythological kindness to Indigenous Peoples is part of the fabric of Canada and has largely been perpetuated without question up until recently (Mackey, 2002; see also Bodley, 2015; Regan, 2010). During the colonial era Indigenous Peoples were enslaved, purposefully exposed to diseases, murdered, banned from traditional practices, and forcefully assimilated into Euro-Canadian society (Mann, 2009; Daschuk, 2013; Regan, 2010). These tactics were used to ensure the survival of the British colonies and the appropriation of land (Robbins, 2013; Bodley, 2015). I believed some of these false stories up until I became an adult and began to question what I was taught in history class and wanted to learn more. Here is a quote from Joseph Conrad's book the Heart of Darkness that Said (1993) uses to illustrate Western imperialism and racism further:

> *We Westerners will decide who is a good native or a bad…*
> *We created them, we taught them to speak and think, and when*
> *they rebel they simply confirm our views of them as silly children,*
> *duped by some of their Western masters (in Said, 1993, p. xviii).*

This quote illustrates how resistance against imperialism can serve to deepen and 'confirm' the view that Indigenous Peoples had to be saved for their own good, that they were incapable of taking care of themselves, and how Western imperialism as a result is seen as above reproach.

Growing up I heard story fragments growing up about my grandfather, my great grandparents, and their Indigenous blood, on both my mom's parent's side of the family, the same blood running through my veins and how this 'blood 'made them do crazy things, violent things. My grandfather was so soft and so hard all at the same time. He scared me sometimes. He never spoke to me about his family history, but I knew he held a lot of secrets, you could see it in his eyes when he thought no one was looking. My Grandfather was also a joker, he loved to tell stories and despite everything he had a warmth and twinkle in his eyes, except when he was angry. I was a quiet watcher growing up, that is partly how I survived. I figured out how to blend into the background so as not to draw attention to myself. I disappeared myself. This meant that I saw or heard stuff that I shouldn't have, but it also meant I didn't't become a target, instead I was watchful, on the lookout for dangers, so I was spared some traumas that way. I didn't sleep much when

I was growing up, mostly I remember being awake, always ready, watching, and waiting for more bad things to happen.

3.12 Truth and Unlearning Lies

Unlearning the imagined history of Canada will not be easy, it may not even be possible for decades, centuries, if ever. The stories are imprinted into the very fabric of the society and have made their imprint on the earth, our spirits, our bodies, through contaminated water, the bottling and selling of water by multi-nationals, replacing trees and forests with housing developments, more industries. Unlearning altered family histories is also difficult. They are hard to disentangle, to heal from. I became part of the family history, the one I witnessed and the one I was told, a story which had major pieces missing, truths left out. When we are young these altered histories are all we might know on the surface. In my experience growing up there was so much going on beneath the surface that I could feel but couldn't identify. But history runs deep, into our blood, our cells. Part of my healing has meant working towards decolonizing my mind, body and spirit, which means trying to uncover truths, including family truths that were left out. The sense of shame and worthlessness I internalized runs deep, it contaminates my spirit, impacts my cells. It is hard, ongoing work to try to change this.

3.13 Capitalism has No Place in Reconciliation

It is important to note that many of the TRC public events, the public living story telling of residential school survivors are sponsored by banks and industries involved in or that invest in oil sands, pipelines and mining companies that have a major impact on Indigenous communities and treaty lands today. For example, the Royal Bank of Canada, a major investor in fossil fuels, and Cameco, the world's largest publicly traded uranium company[9] (TRC, n.d.) are two of the major sponsors of the TRC public events. This means that as Canada is saying it is working towards reconciliation with one hand, with the other they are engaging in similar processes of land appropriation for resource extraction that continues to impact Indigenous Peoples and the further destruction of the earth. The governing institutions of the nation continue to facilitate the extraction of raw

[9] See https://nctr.ca/nctr-and-rbc-collaborate-again-to-deliver-nations-first-ever-truth-and-reconciliation-week/

resources, while also being the judge and jury of the past market-based activities of capital accumulation, surplus extraction, land usurpation, and so on. This is, moreover, done with a sense of entitlement for settler society to retain the power to define the parameters of Indigeneity through the Indian Act. Above all, those invested in the State continue to insist that their objectives are benevolent. Yet these activities really only benefit company shareholders and their state apologists. Again, we see that denial of history, creation of national myths and capital penetration are still very intimately intertwined.

Given that the foundational status quo is being retained, how can the TRC result in any positive changes for Indigenous Peoples? Ahenakew (2019) reminds us,

> *…in Canada, we believe that more money, more credentials, and more positions of power for Indigenous people in Western institutions and corporations will create a more just society We forget that what is called inclusion in an inherently harmful system requires the expansion of violence towards the land, other species, and people somewhere else (p. 33).*

There is the risk that resistance to and healing from colonization through measures such as 'inclusivity 'in spaces controlled through capitalism and neoliberal ideologies, that Ahenakew (2019) points to above, can lead to peoples being absorbed into the dominant body politic, to be altered by the very system they are trying to resist and change (see Hickel & Khan, 2012). There is a tension that must be negotiated, between surviving in this capitalist world and our resistance to it if we are to heal our soul wound. We need to be able to enter these spaces but create change, and not merely be absorbed into them, and only being changed towards them. We must be watchful not to be absorbed into the individualistic, increasingly business driven, divisive world that is so prevalent in academia (Hil, 2016; Lynch & Ivancheva, 2016). We need to be aware of how easily we can slip into this paradigm, to be cognizant of how these settings celebrate these forms of lateral and structural violence for some. We need to foster collectivity in these spaces, change them from the inside if possible. We must continually resist being seduced into seeing "the worth of our life defined as market exchange value," and resist becoming "human capital" (Ahenakew, 2019, p. 56).

3.14 Colonization and Medicine

Western biomedicine played a key role in colonization in Canada and was instrumental in the expansion of the Euro-Canadian frontier (Kelm, 1999; Robbins & Dewar, 2011). Kelm (1999) argues this happened in two ways. Firstly, imperial biomedicine was constructed as superior, while Indigenous medicine was reduced to superstitious quackery and witchcraft. According to Kelm (1999), one of the missions of western biomedicine was to destroy the trust and prestige Indigenous Healers had within Indigenous communities. This was done by promoting the alleged superiority of western biomedicine and using it as an assimilationist tool that coerced Indigenous Peoples to reject their own cultural healing practices, and the Healers themselves (Kelm, 1999; Martin-Hill, 2003). Western biomedical practitioners helped spread the gospel of "the true nature of disease and death" (Kelm, 1999, p. 105), which promised not only relief from disease, but also Christian spiritual salvation to a Christian notion of God.

Prior to their introduction to western biomedicine, we have been told, Indigenous Peoples lacked the ability to heal themselves (Kelton, 2007, 2015). However, before contact, Indigenous Peoples lead relatively healthy lives relying solely on their own medicines (Martin-Hill, 2003; Robbins & Dewar, 2011). During colonization Indigenous Peoples found ways to retain Indigenous medicines, despite many of their practices being made illegal (Martin-Hill, 2003). Kelm (1999) calls this an act of subversive resistance to the colonizing efforts of Indigenous Affairs, and an example of Indigenous peoples enacting agency in their choices for health care despite the dire situations and oppressions they had to endure (see also Robbins & Dewar, 2011). During this time many Indigenous Healers were charged with witchcraft, fraud, and some ceremonies were raided by police, such as the smokehouse, and spirit dances, and made to stop (Martin-Hill, 2003; Kelm, 1999). The Healer I see said my grandmother, who got kicked out of school for being a witch was a 'seer' but instead of it being seen as a gift she was pathologized and so it manifested as sickness. While focusing on African Canadian women, Waldron (2002) argues that psychiatry relies on western scientific conceptualizations of mental illness and wellbeing that are ultimately racist and violent. This is also applicable within the Indigenous context in Canada and was certainly the case with my grandmother, as had

she been born at a different time in history, she perhaps would have been recognized for her gifts rather than punished for them.

3.15 Healing Thoughts

Colonization continues to work in sometimes invisible and insidious ways not just on bodies, but whole beings, minds, spirits, emotions, and ways of life. Colonization has left many legacies and was perpetrated through fear, violent assimilation strategies, and genocide. Other ways colonization profoundly affected Indigenous Peoples is through loss of land, the degradation of land, and disrupted ways of living with the land, which have ultimately led to poverty, malnutrition, unsafe housing and increased susceptibility to illness (Daschuk, 2013). Illnesses that manifest in the body must be viewed not only as a metaphor for the earth's destruction and pollution, the two are inseparable. If there is sickness in one it exists in the other.

The following excerpt is from my cancer journal written after I had surgery to remove a large tumour from my colon as well as a large portion of my colon, and many lymph nodes.

> *My body feels like a small piece of earth that's been excavated; cut open, dried out, left with a gaping hole, pieces of my insides extracted. I am so sore I can't even move without pain, trying to stand up, to walk to move, causes excruciating pain, even as my body tries to re-inflate through my breathing… I feel like everything has contracted into a very dense little knot and I am having to fight so hard to stretch it open, to become whole again. It isn't just stretching the fibres of scar tissue, it is stretching all that had coiled inward from the trauma, from the surgical incision, the trauma of diagnosis, from the fear and the coldness these hospital spaces carry with them, and family history... It has taken me a couple of years to not feel quite as broken open, not as damaged, it is taking time to heal (Fournier, Cancer Journal, February 2018).*

Reading this excerpt now reminds me of how I am an integral part of the earth, it speaks of an embodied sense of fragility we all share that came right to the surface. The surgery and in those moments when I was recovering from surgery, something bigger was also cut open. These moments beckon my attention and demand I do the hard work of healing

so I can continue to live in a good way. Part of this involves navigating and negotiating on a daily basis who I am, where I come from, and what that means in terms the complexities of identity. It also means beginning to build resistance to the internalized feeling of being or having a 'broken' body, being blamed for my human fragility. I am now working towards decolonizing my body, or my view of my body, from seeing it as weak, sick, imperfect, and ugly, to honouring its strength, like the strength of my ancestors and all of the brutalities they endured and kept hidden. I can begin to see my body as part of a larger whole with all of its imperfections is still whole, and my spirit is beginning to shine through again.

Dehumanizing strategies used during colonialism, such as forced assimilationist tactics, and other violent actions affect not only the vulnerable, but also the perpetrators. Freire (1994) believed that we are all affected by injustice, exploitation, and oppression – it is just more apparent for those who are oppressed. Oppressors may benefit in the short term but are not ultimately liberated through their dehumanization of others. Furthermore, both the oppressed and the oppressors are connected not just by the atrocities that force the oppressed into submission, but also by our fundamental human and earth connection (Freire, 1970; 1994), our basic humanness. Freire also reminds us that despite everything we need hope, not fatalism, to fuel change. Fatalism robs passion and the strength to resist and make change. I liken this to cancer, cancer can rob your strength, and for me sometimes, still three years later, my strength gets eaten up by fear, by the palpable proximity of death that I felt, and sometimes still feel, but this fear can also be transformed into resistance and change. I heard one Elder speak about cancer once at a public talk, and they said that the Mohawk term for cancer translates into something like *that which eats meat*. Cancer absorbs and assimilates healthy cells into ones that begin to attack your own body. Like colonizers stealing land and causing harm, cancer cells can begin to take over healthy cells if we don't find a way to heal, and resist. From a western biomedical approach, this involves cutting them out, and blasting them with chemotherapy. Other forms of medicine promote healing to *decolonize* at the cellular level, so instead they will begin to work together again for the health of all cells, for the body, mind and spirit, the collective.

For my mom her sickness manifested in the form of so-called nervous breakdowns. She would stop eating and sleeping and would 'see' things. The biomedical doctors called it being out of touch with reality. My Healer said she too was a 'seer .' When she was in one of her "breakdown" states she could intuit things happening before they did, she picked up on things no one else noticed. She was institutionalized numerous times when I was young and so we lived with my grandparents in the country after my parents split up, when I was eight years old. Me and my aunts, who were all close in age, and my brothers stayed outside all day in the woods close by, riding horses, playing in the water, out in the snow. That is how we stayed away from the chaos inside, we created our own world out there where we felt part of the land, the big outdoors. This is how I managed to cope with my mom being sick and being sent to the psychiatric hospital for weeks at a time, where she would be given drugs to make her sleep, so she could get back to her life. My mom is the oldest female in her family, she also looked after her siblings since she was little, and witnessed and experienced much trauma growing up, some of which she is only beginning to remember, in her 70's (see Isobel et al., 2021). She too rewrote her own history until it snuck up on her and demanded her attention, and healing.

Frantz Fanon (1963) long established that "decolonization can only be understood as a historical process that ultimately culminates in changing the social order" (p. 130; see also Dei & Asgharzadeh, 2001). Colonization is also a cellular process, like with cancer and metastasis, cells joining forces to *eat meat*, proliferating out of control. Colonization at the cellular level leads to death through metastasis, as cancer cells in effect turn against the body and take over and destroy healthy cells. The colonization of Peoples, of land has also led to death and destruction. But we can and must fight back.

As I have discussed above, colonization has led to death, physical and spiritual damage, intense intergenerational suffering and oppression, a collective soul wound. Mucina (2011) and others (see Corntassel et al., 2009; Dei, 2011) argue that to resist colonization, and ongoing coloniality, we need to engage with, and tell stories that contribute to spiritual healing using Indigenous methods and storytelling. "Colonialism has fragmented every society…" (Mucina, 2011, p. 163), which includes those colonized and the colonizers (see Freire, 1994). It includes individuals, families, communities, the land, everything, our human and non-human relations. I would also add that colonialism

has not just fragmented society but every aspect of society, as well as connections to land, people from land. Colonial processes undermined the significance and validity of oral forms of knowledge sharing, such as storytelling (Césaire, 1972; Hall et al., 2000; Mucina, 2011; Smith, 2012). Knowledge created through storying, restorying, and subjective experience is now critical for our healing. To bring to the fore the many diverse voices and experiences that have been made invisible (Brown & Strega, 2005; Dei, 2011). I am attempting to heal here through my own storying, with the hopes that it might resonate with others. I liken this to a form of what Haley Toll (2019) calls "mending", described here as

> *... the imperfect, ongoing process of repairing and caring for what we value. It seeks to bring separate parts closer together, while leaving each part intact. The imperfect nature of mending often leaves visible traces that add to its beauty as much as it shows the scars of its failings. It is a generative, creative, and collaborative gesture that supposes a willingness to honour rather than to consume and erase. (Chainey, 2019 in Toll, 2019, p 3).*

Storying helps me weave fragments of experience together towards a whole, and some of the layers and pieces that emerge as I write are surprising, not quite in my consciousness until I am in the moment of writing them down. This is an act of trying to make whole, a form of resistance against the silences my ancestors had to endure.

3.16 Storying the Fragmented Soul Wound Towards Wholeness

Colonialism and assimilation processes have fractured, and in some instances completely severed Indigenous identities, sense of community, connection to land, family and clan ties. Storying is a powerful way to help reconnect lost knowledges, connections and rebuild communities (Archibald, 2008; Corntassel et al., 2009; Mucina, 2011, Brown & Strega, 2005; Smith, 2012). Storying is an antidote to assimilation. For example, as discussed earlier, because of the many assimilationist and fracturing processes related to colonialism my own family's Indigenous roots were severed, and we have recovered them slowly and in painful fragments. Our family was fragmented and uprooted, forced to leave our land and extended community, and many of the stories, and specificities

connecting my family to our Indigenous roots have been lost. In my body cancerous cells invaded my tissues, secretly, quietly at first, their invasion invisible, it was only after enough damage was done, did the urgency to share my story becomes a pressing matter. Stories and histories have been buried, knowledges lost and it is becoming more urgent to connect and speak with Knowledge Keepers and Elders before they pass away.

I never met my great Grandfather, the healer, as he passed away before I was born, but I wish he was here; I have so many questions to ask him. My Healer has spoken often to me about the need for this connection to be nurtured and developed as part of my healing process.

There are so many important pieces of history that are missing, purposefully erased, or contorted, and in the Canadian context it is often up to Indigenous families, communities and peoples to fill in these gaps mostly on our own. It is both arduous and exciting. I am trying through this work to fill in these gaps in knowledge and memory as part of healing and honouring my family. I am trying to turn historical poison into family medicine. I end this chapter with a picture of my grandfather, me and my late brother Rob. He was a strong man, he could lift things no one else could, he also carried much that was hidden beneath his surface.

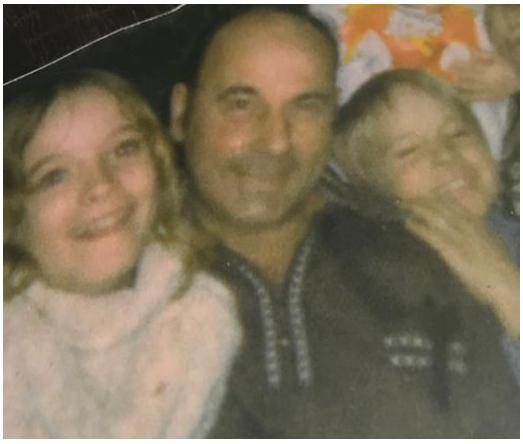


Figure 4 My Grandfather, me and my brother

Chapter 4 Storying and re-storying cancer: "Turning Poison into Medicine"

Dear cancer, I fucking hate you – you make me feel like I am a bad person that I did something wrong to deserve you sneaking up on me like you did and shattering my trust in myself, my body, and the whole universe. I hate you so much. All the people you sneak up on and take away, many good people kind people. I think you are mean and careless – you should be more discerning. You take so much – without asking (Fournier, Cancer Journal, January 2018).

4.1 Surviving Cancer: Surviving Assimilation

In this next section I explore my experiences of engaging with both biomedicine and Indigenous healing/ceremonies for cancer using case studies from my cancer journal notes as well as documents from biomedical care and my visit with a Healer at an Indigenous health centre. I endeavour here to highlight and begin to theorize the spaces of tension between biomedicine and Indigenous forms of healing as a form of resistance and what Graveline (1998) calls "part of the countercurrent of resistance to dominant hegemonic forces in the world" (p. 35), in this instance the hegemonic force of biomedicine. Ultimately, I aim to help transform spaces of sickness and vulnerability into healing, something the Healer calls 'turning poison into medicine', with hopes that it may also help others who find themselves in a similar situation. Transforming spaces of sickness while creating and holding space for the sacred is becoming more challenging given the current context of COVID19 lockdown restrictions and disruptions of care both in the biomedical context and with the Healer. For example, there are delays in my follow-up oncology visits and screening, and changes in the nature of my follow up appointments as they are moved from in person to over the phone. In my experience COVID19 restrictions are also profoundly impacting the Indigenous healing and ceremonies at the centre I have been working as an Oshkaabewis for the last three years, as all in person ceremonies have been cancelled, or moved to virtual forums. For me these virtual ceremonies and sessions have had an impact on the sense of community and connection that has been a rich part of my life. The circle of Indigenous women and ceremonies I was part of has been disrupted. As a result, my sense of feeling connected to a collective has been fractured over the last twelve months of lockdown.

What follows is part of the biomedical story of how I came to a cancer diagnosis. I use this story as a case study to examine the biomedical care I received, as well as my experiences with Indigenous medicines to begin to contribute to an embodied theorizing. This chapter was a difficult one to write and review. Having to go back and relive the biomedical part of the story was painful, a reminder of what I went through. I also had my daughter review this chapter for me and it was a hard thing for her to relive as well. For us both we had to put it down for days, and in my case sometimes weeks at a time before I could go back to it.

4.2 Biomedical Story

I started having abdominal pain and intestinal symptoms in November 2017, they came and went for a few weeks but then got more severe. In December I ended up going to the emergency room as the pain kept getting worse. I was too scared to go to the doctor any sooner; I worried about the worst and even at the best of times, visits to doctors fill me with fear and dread. This is in part related to trauma I experienced in the hands of a doctor when I was young, as well as witnessing both my mom and grandmother being forcibly placed into medical care and institutionalized for so called mental health issues for which I came to recognize later were a response to severe trauma they endured during their lives.

As soon as you enter the emergency department at the hospital you are told to take a number from a machine, just like at a busy local bakery in Toronto. When your number comes up they 'triage you'. This is done through a brief conversation with a nurse behind a plexiglass barrier. They ask a few basic questions about my symptoms and then send me to another waiting room where people are seen in order of the rated severity of their condition. After about an hour or so I am seen by the doctor there. He asks me a few questions about my symptoms, then says he is going to order some blood work and an ultrasound. I am escorted to another waiting room to wait to be called for testing. A few hours later they do blood work and an ultrasound. In between tests and results I wait in a small waiting room which is filled the entire time I am there. There is so much bustle in the emergency area, loud announcements, doctors and nurses rushing around, looking harried and tired; I find it is easy to lose myself in observing the activities all around me,

which provides some relief from my inner world of fear and anxiety. There is a TV blaring in the background, running through the same bad news stories over and over. The atmosphere does not feel conducive to health. The news drones on, stories of violence, oil spills, rising housing prices and homelessness. The lighting is so stark and unforgiving, everyone looks tired, anxious and scared, nervously waiting for their names to be called, like I am.

The atmosphere of the emergency waiting room is a critical space for analyzing the overall biomedical approach to health care and how it tends to separate mind, body and spirit, as well as the individual from the social and economic context. Many hospitals now have a separate space you can request to go to for quiet spiritual contemplation, but it is not visible and if you leave the waiting area to go anywhere else you may miss your name being called and then be forced to wait longer for testing and results. At the hospital I was at you also must arrange using that space ahead of time with the staff. The waiting room is also an example of the sensory factors that are present in the hospital that may not be conducive to a sense of health and wellbeing. There are pictures of people promoting the flu vaccine, asking, "who are you doing it for", and some generic pictures on the wall that I find unpleasant to look at. I do not experience any sense of warmth, nurturing or care, nothing that feels even the slightest bit comforting or healing. The atmosphere in the emergency waiting room is frightening, and as I sit there, I hear people crying, one woman is screaming, and another is loudly singing Christmas songs. I also hear coughing, deep coughing that sounds like the person might die right there on the spot. As I sit in the emergency room it is easy for me to imagine the worst. However, the noises all around me like the TV blaring, the beeping of vital function monitoring machines, and loudspeaker announcements paging doctors, distract me from my anxieties.

In this space only my physical symptoms that are asked about are seen as important and are attended to. I guess. I could say I felt *physically* safe in the waiting room, in that should anything physical go wrong and I need urgent care there are doctors all around me and surely, I would be attended to quickly. However, I also feel so powerless, like a child who has no control over what is taking place. In every sense I feel alone, alienated, and scared, yet in the waiting area I am surrounded by people probably who are feeling somewhat similar. My mental, emotional, and spiritual wellbeing is not

considered at all in this environment. I feel at the mercy of the various hospital protocols and schedules. The emergency room is overrun, and the staff and doctors look busy, distracted, pale and downright unhealthy to me. They don't have time to talk about anything other than my physical symptoms, they must get the information, make quick decisions and then move on to the next patient. Not during any of the interactions or consultations I have had with health care professionals while in emergency have, I been asked anything about my social circumstances, or any social dynamics of health such as whether I am safely housed, do I have enough to eat on a regular basis, what kind of work I do, if I am married or have children. I am not asked any questions about how I might be feeling, or what I think might be going on with my body. Yet it is my body, one I have known well for over 50 years. I am only asked questions about my signs and symptoms, the quality of pain, the duration, whether I have any fever, vomiting, all individual objective measures of my health status.

During the ultrasound when the sonographer presses over my ascending colon area it is so painful, I can hardly bare it. I flinch and break out into a sweat. The sonographer doesn't acknowledge the flinching, or my sweating, she just continues with the ultrasound. She is focused on doing a thorough scan. She applies more of the cool ultrasound jelly and continues to go back and forth over my abdomen as I continue to flinch. Then she stops suddenly and says, "we are done, I hope you feel better". She tells me to get dressed and leaves. She too has many other patients waiting, scans to complete. About 5 hours later I am seen by the attending doctor, to get the results, he says that all my blood work looks good and that the only thing they found on the ultrasound was inflammation around my ascending colon which he said is suspicious of colitis. He tells me to go home and follow up with my family doctor. That concludes this visit at emergency.

Two days later I see blood in my stool, and I am terrified. I go to my family doctor, they fit me in right away when I mention the blood, my symptoms have moved up the chain of importance. He says I need to get a colonoscopy to see what is going on. Then he says if I want to bypass the wait times for colonoscopy, as it could take weeks, I should go back to emergency. This is a work around for navigating health care system wait times for testing, that have increased since government funding cutbacks to health

care in Ontario[10] and elsewhere in Canada. More and more services are no longer covered by Ontario Health Insurance Plan (OHIP), and they have cut jobs. One can pay to get testing, like a colonoscopy, quickly in a private clinic but the cost is prohibitive for many.

I see another doctor this time in emergency. He asks similar questions about my symptoms as the last visit, but he seems more concerned than the last doctor did. Having blood in the stool raises the concern, as my family doctor said, having blood in your stool raises the anti. He palpates my right belly abdomen and I just had tears start coming down my face because it is so tender. He doesn't seem to notice my tears, but he quickly stops palpating and says he is going to send me for a Computed Tomography (CT) scan.

The CT scan is a more elaborate form of diagnostic imaging that requires exposure to radiation in order to get a visual that shows your bones, organs, and soft tissues more clearly than standard x-rays and can even show blood vessels and tumours. The scan shows severe inflammation around my ascending colon and cecum as well as the lymph nodes. The doctor giving me the results says this doesn't rule out colon cancer, but it is likely colitis. Then I am told I will be seeing an internal medicine doctor. The wait to see the internal medicine doctor takes about five hours. He is very nice and he assures me that my CT scan, blood work and symptoms do not indicate colon cancer, says it is more suggestive of Crohn's disease or ulcerative colitis. He even says that he is 98% sure it is Crohn's disease. The internal medicine doctor admits me and puts me on prednisone IV drip. Prednisone is a very strong and potentially toxic steroid medication for inflammation. I am admitted to hospital so I can get a colonoscopy sooner, otherwise I am told it could take weeks to get one done as an outpatient. He assures me I will get a colonoscopy the next day. Another work around to get quicker testing. I get admitted but end up having to sleep in the emergency department which is loud and chaotic as there are no beds available, another after effect of health care cutbacks.

I find being in the middle of the emergency department and the bustle distracting and it gets me out of my anxiety about my own health. I feel like I am outside of my body though, and everything seems surreal. I feel detached from my body, like I am watching this whole experience from outside myself. I am given a narrow bed to sleep on and a

[10] See Ontario Health Coalition Report, Mounting Health Care Cuts: https://www.ontariohealthcoalition.ca/index.php/update-mounting-health-care-cuts/

prednisone drip right in the emergency ward. I doze off for a few minutes here and there. At about 6:00 am in the morning a nurse comes in and stops the prednisone drip, I ask her why they are stopping it, and she says she was told to and doesn't know why, and that I will have to ask the doctor when he comes to see me. This is interesting to me, the nurse is given orders, tasks but not the rationale, or is she just not allowed or too rushed to tell me? I feel like I have no idea what is going on now, I thought there was a solid plan in place, and this drastically raises my fear and anxiety level. I feel totally at the mercy of decisions being made without my awareness or involvement even though it is my *body,* my being, that is being cared for in this space, I feel so powerless. I doze off a bit and am woken up around 7:00 am by the gastroenterologist.

The doctors and nurses attend to certain aspects of my body, my physiology, in particular my gastro-intestinal tract. It has been argued that it is this focus on the body, on our physiology, that contributes to a sense of disembodiment in the biomedical encounter (Lebacqz, 1995; see also Lock & Nguyen, 2018). "Physicians understand the workings of the human body by reducing them to basic biochemical principles with which they interpret somatic dysfunction" (Pliskin, 1983, p. 187). This "reduction of embodiment to biochemical principles" says Lebacqz, (1995, p. 156) takes us out of our social context. In this context we are not a self-in-relation to a larger whole, but rather merely a sort of body in isolation. Others argue that lying in the hospital bed "allows biomedicine full control and access to the body and renders the sick person as patient. Lying in bed becomes a position of passiveness, submission and vulnerability" (O'Brien, 2016, p. 9). Certainly, lying in a hospital bed is disorienting in my experience, as I am wheeled around to various tests that have been ordered without my knowing. The hospital feels like a maze.

The stomach doctor contradicts everything the internal medicine doctor said. I ask him why the prednisone was stopped, and he tells me he ordered it to be stopped because it is a "serious" medicine and that they need to find out what is wrong first. His manner is curt and cold, it feels like part of a business transaction, and we are talking about my car that is in need of repair. He also tells me that they cannot do the colonoscopy that day as my colon is not "prepped", he says that I have to clean out my colon first. He says you have a choice you can go home and make an appointment for colonoscopy, which would take at least a few weeks, or stay at the hospital until Monday and have one done then. I

opt to stay in the hospital so I can get the test done sooner. I feel it would be unbearable to wait to get the colonoscopy and results so I can know what is wrong with me and I am really getting more and more worried. Once again, I am offered another work around to the realities of health care cutbacks and wait times. I feel like I am privileged to even be offered this choice, yet it also makes me more nervous as I wonder if they didn't think it was anything serious why would they even offer me this choice.

The various information and contradictory information I get from these different biomedical encounters are intriguing particularly when we consider that one thing biomedicine prides itself on is it is based on an "objective" science, with extensive training that is standardized, and rigorous (Lock & Nyugen, 2018). However, these two doctors, albeit coming from 2 sub-specialties of medicine both had very different perspectives and treatment ideas based on my symptoms and test results: the same symptoms, the same test results. It seems even in this standardized biomedical model there is much left to chance, to opinion. If I had seen another internal medicine doctor initially would he have had the same take on my symptoms? Would I have been admitted to get the colonoscopy sooner? Would another stomach specialist have stopped the prednisone drip?

I am finally brought upstairs to a bed in a ward where I am visited regularly by nurses. They come and take my blood at least once a day and check my vital signs 2 or 3 times a day. The on-call doctor for the floor I am on is an internist who is about 35 or so, balding, and extremely pale looking. He assures me that my symptoms are not colon cancer symptoms so that I should just take a deep breath, he is sure I have Chrohn's disease, 99% sure. I am given numerous times these percentage odds of it being this or that at this stage of my care. On one of his visits he brings a student with him. She asks all of the questions I have been asked over and over again and palpates by belly. She is young and seems anxious to impress the attending physician who is asking her questions, in between her asking me questions. The attending doctor is definitely testing her knowledge and observing her. She presses hard on my abdomen right where it is so tender and it makes me feel ill. I flinch but she seems totally unaware that I am flinching. I don't feel like she is paying attention to me at all, she is more concerned with how well she is doing in the Doctors eyes, her superior, than focusing on how I might be feeling. She

provides answers to the doctor about me while I am right there, lying in the bed. I am a learning moment; I feel like a disembodied subject that she is trying to learn from 'objectively'. As I lie in bed waiting, getting probed, jabbed with needles, regular life feels suspended and removed. I feel like I am in a state of inertia, and I feel quite powerless, out of my body, detached from reality. I feel like I have unconsciously given my power over to the doctors, the nurses, the various hospital processes, and protocols of care; I just go along with everything they tell me, like a child. In some ways it feels good to feel so suspended in time and space letting others take charge but in other ways it makes me feel weaker, sicker and more vulnerable.

The colon cleanse I have to do in preparation for the colonoscopy is intense, almost violent. After drinking a heavy-duty laxative solution to clean my colon, I have to run to the bathroom every 10 minutes and have bad intestinal cramps. The floor nurse comes in every few hours to see how much I have drunk and reminds me that my colon needs to be clean to see when they do the procedure otherwise it won't work. I am being monitored.

I take many walks down the hall during my stay, out of boredom but also because it is now common procedure to give people an injection of a blood thinner each night to prevent blood clots forming due to lying in bed for long periods of time. While I understand that some people are just too sick to move it seems like the needle is filling the gap that the lack of nursing staff has left due to cutbacks, replacing having someone help patients move and walk around with a drug. I do not want any more needles or medicines, but I have to be very assertive each night so as not to get this shot as they push it quite strongly. I even have to sign something that says I refuse the shot, for liability issues.

The night before the colonoscopy I don't sleep very well. I am not sure you ever can in a hospital, they wake me up to check my vital signs at weird hours. Besides the hospital is never quiet and the room is lit up with light from the hall, as well as the body monitoring machines, and electronic intravenous line (IV) that I am attached to. I hear people moaning and crying, wandering the halls. I feel very nervous, anxious. I miss being in my own bed, my routine, my daughter, my husband. I miss my regular day to day life, and I just want to go home and be okay.

At about 8:00 am I am wheeled down in a bed to the colonoscopy testing department. I am wheeled down corridors, into elevators, around corners. It feels like such a long journey, and I am lightheaded from anxiety, not eating and from being wheeled while lying down. I can't see where I am going, it's quite disorienting. In the hospital bed we become "passive bodies" (O'Brien, 2016). As Jewson (1976) suggests "[w]ithin the bed the patient is designated a passive and uncritical role in the consultative relationship, his [or her] main function being to endure and wait'" (p. 235). Indeed, much of my time in the hospital has been spent waiting, enduring the waiting to get test results. Time feels suspended yet the waiting is fraught with fear of what they might find. All the technologies, even though I experience the various testing while there, they leave *me out* in a way. For example, I am not part of the process of diagnosis, once what is being sampled has been extracted, the viewing of *my* body images in the CT scan is done without me, in fact, I am not even permitted to be involved. I am not allowed to sit with the radiologist as they view my CT scan, I have to wait for the report to be sent the doctor in charge of my case to get the results. Nor am I privy to looking at my blood samples under the microscope, yet it is my blood, an integral part of me, I am left out of these processes once the blood is extracted, or once the scan has extracted the image of my insides. What do they do with all those blood samples and images once they are done with them, I wonder? For me this invokes further, the sense of powerlessness I feel, the sense of a disembodied self at the mercy of others called 'experts'. Lock and Nyugen (2010) argue that "health-related matters are routinely 'objectified' as technical problems, to be solved through the application of technology" (pg. 18). In this instance my body becomes separated from my *self*, like a machine or, an object that must be deconstructed, examined, and hopefully fixed (McKenna, 2012).

As I am transported in my bed, 'a passive body' (O'Brien, 2016) awaiting further testing, I get some relief from simple human connection. For instance, the person wheeling my bed to my next medical test is lighthearted, and jokes with me. It helps me relax. Even this little bit of human connection makes me feel less anxious and it helps transform the sense of disembodiment I feel in this biomedical space, and for a few moments thanks to this attendant who is wheeling me around in my bed I feel more than just a 'sick, passive body'.

My heart is pounding with anxiety fast as I wait for my colonoscopy, I have no idea what it will feel like and am terrified of what they might find. The colonoscopy room is cold and filled with these strange looking long tubes and a big screen. It looks very stark and intimidating. I am given a drug that makes me feel kind of strange, dopey but more just like I am not longer in my body, like I am in a strange dream, the nurse says, "its fentanyl, the good kind". Then the doctor comes over and asks me how I am feeling. I say the pain is better, and he says probably it was just an infection that has cleared up, but that they need do this test to make sure. A few minutes later I am looking at this screen that is right in front of me and I can see the inside of my colon. It looks kind of white and strange, almost other worldly, like an amoeba. Then a few seconds later I see an area that looks very different, it looks dark and cavernous with protrusions. Then from my drug induced haze I hear him say 'oh that is cancer, you have a large tumour here, we were not expecting this'. Then he goes on talking providing different statistics, it is almost like he is in shock and is just talking as he doesn't know what else to say. He goes on, with some prognoses, 'if it is contained and not spread to the lymph nodes then we remove it and it is a 100% cure'. Then he says this has been there a while and in another few months it would have become a bowel obstruction requiring emergency surgery. He says it may have already metastasized because it has been there so long. I am hearing all of this, but it just feels surreal, I am not quite in my right mind or my body. I feel totally separate from this body of mine. I am also in shock. He continues to look around and finishes. Then he says, 'we were not expecting this'. I feel like I am in a dream.

In this instance I am privy in real time to the medical test being done, and hearing the results, but from a drug induced haze. I feel outside of my body, in a dream state watching a screen, kind of floating above my *self* and watching. I am hazily present for the internal machinations of this doctor as he looks inside my colon and describes the cancer and the possible prognosis. He too talks about my body, my life as if from a textbook, as if I am not even in the room, as he rhymes off statistics, possible scenarios, and prognoses. He is not talking *with* me or even *to* me. I am not part of the conversation at all, he seems to be having it with himself.

I am then wheeled back to the waiting room and in a few minutes the nurse comes over and says, "I am so sorry". Then a few minutes later the doctor comes out and tells

me again “you have colon cancer, a tumour in your colon that looks like it has been there a while. This time I am more alert. He says, “we will have to check for metastasis, and have to do a scan of your lungs”. I am immediately thrown into feeling like oh my god this could be it for me, I could be dying, as in terminal cancer. I am so scared I feel numb, but part of me is outside of myself saying, so this is how it happens. I have heard the worst news I could have thought of – yet I also feel very pragmatic. The doctor seems oblivious to the impact of this diagnosis, for both me and my husband, who is standing beside my bed. I feel in shock but also my spirit kicks in and I also feel determined to deal with this. I feel like I can do this, I am going to survive this. To be honest I am too scared to think of any other possibility. I am thinking mostly of my daughter Kailan, I do not want to leave her without a mom.

I am wheeled back to the room and the pale doctor from the floor who had assured me I didn’t have colon cancer but Crohn’s, also comes and says, ‘ I am so sorry’ and then hands me a few sheets of paper, literature about colon cancer, the stages and prognosis. It feels like way too much information and kind of bad timing. It is also so impersonal, but I read it and just feel like I have to be hopeful. Again, I am too scared to not be hopeful, too scared to think negatively.

A whole stream of protocols and testing are set in motion by my diagnosis, without my knowing, nurses visit and take more blood, doctors visit, and talk about more scans. I am barely listening anymore, I feel like a numb puppet, just following orders from my bed with my daughter and husband beside me also in shock.

There is nothing healing about the hospital environment to me, the colours, the sounds. The bed has bars, so I don’t fall out, it makes me feel trapped. The mattress is thin and covered in plastic, so it makes that crinkling noise when I move and it feels cold. The sheets are scratchy, the blanket thin and palely coloured. There isn’t anything that feels comfortable. I feel infantilized, like I am a child being cared for by grownups. The walls are painted a cold green blue colour, and the air smells like sickness, and disinfectant. There are posters all over the walls advertising the flu shot, and signs for different hospital wards.

I have one reassuring exchange with a surgeon who comes to see me a few hours after the colonoscopy. He shows me his human side and tells me his mom had colon

cancer last year and she is fine now. He says hopefully you will be too. His words do reassure me but more it is that he openly recognized the impact this diagnosis might have on me. I feel hopeful. However, he tells me I am going to have to wait a few weeks or more for the surgery. He said they needed to do more tests to figure out what stage it is at.

About an hour later the surgeon comes back and says they have an opening for surgery tomorrow and if I want the spot, I can have it. I say yes! Then I am left alone, for a while in the hospital room, nobody comes to talk to me or help me manage how I am feeling. I am left alone with that. They just attend to my physical body except for one or two health care providers who see my fear and let me see their human side. For example, later a young nurse comes to take my blood and she is teary eyed and tells me she is so sorry about my diagnosis. She touches my arm. It is the first time other than for taking blood or doing one test or another that someone just touches me for reassurance. It feels nice. She then tells me she also has just been diagnosed with breast cancer but that she hasn't done anything about it yet because she is too scared. She tells me about her young children and her husband, how she thinks about how she may die and leave her children without a mom, we both tear up. She says she thinks about this stuff every time she looks at her kids. Sharing her story helps me feel so much less alone. She takes my blood and is so warm I just want her to stay with me. However, I wonder if this nurse's supervisor knew that she shared this part of herself with me, would they say she behaved unprofessionally? She helped me so much in that moment, I want to commend her for sharing and taking that risk. I feel like we connected and shared a moment in that cold stark hospital room that helped me feel so much less alone. It felt sacred to me. I feel like I need to surround myself with people who have gone through cancer. I later reflect on her sharing this story with me and how much that little human connection within these sterile hospital walls has helped me feel better, more hopeful. The moments of human connection with her and the surgeon earlier, help transform my experience of fear and aloneness, into connection. We both felt empathy for each other's situation, and this was healing for me. After I leave the hospital a week later, I actually go back and leave her a card thanking her so much.

A while later the first young surgeon comes back with another young female surgeon, she is now taking the lead. She is much less warm, she has papers for me to sign

about the risks of surgery, she tells me about all the risks, all the scary things that could happen during and after the surgery, it is too much information. She says 'the cancer' is probably stage 2 or 3. I start to cry at one point and so does my daughter who is sitting on my bed beside me. The doctor isn't unkind just very clinical. She doesn't acknowledge or interact with my daughter. She seems set on just giving me all biological the facts and getting my 'informed consent' but she is really scaring me and my daughter. She continues on about how they are not sure if my lymph nodes are affected or not at this point, but the doctor says it looks like they might be as they appeared so big on the CT scan. They tell me I may wake up from surgery with a colostomy bag if they can't rejoin the colon.

I ask for something to help me sleep that night. I am terrified, not sure what they will find when they "open" me up. I wonder, what if I don't make it through the surgery? I am anxious to just do it. They have to ask the on-floor doctor about giving me some anxiety medicine. Two hours later the nurse comes with a tablet. I actually do sleep that night, my daughter in the bed with me and my husband in the lounge chair beside me. They are allowed to stay with me tonight.

The next day after surgery I wake up in a room, foggy, kind of in a weird dream state. The lights are so bright, and I feel like I can't wake up. I hear the nurses from a distance telling me to take some deep breaths. Later, my husband is allowed in to see me. He and my daughter waited in a special room for family of those undergoing surgery. They are told the doctor will come out after the surgery is done to tell them how it went. I have other family members waiting in the larger waiting area, my father, brother, and my nephew.

The following is a first voice excerpt from my cancer journal which highlights my experience of going for surgery:

> *In the hospital everything is bright and cold, the lighting is stark. On the way to the surgery room I am alone, my family is left to wait in a separate room. Once I get to the operating room everything feels so cold, all shiny metal and more ultra-bright lights, the sounds in the room are echoey, and shrill, exaggerated by the starkness of the room and the sterility of everything in there. Then I am transferred to a cold metal bed, and there are so many machines, monitoring*

> *machines that keep beeping. I am then pricked in the arm to get an IV and a mask is put over my mouth, I can no longer speak, or move…they tell me to start counting to 10 and the next thing I know I wake up groggy and confused in another room, a 'recovery' room by myself with more machines beeping and nurses checking in on patients (Fournier, Cancer Journals, January 2018).*

My experience of being brought to the operating room and waking up alone as outlined above may be categorized as a 'mundane' experience in biomedicine. For the surgeons and hospital staff, the operating room is kind of like their office, a space where they do their everyday work. As a patient, I was in shock from a cancer diagnosis, fearful of not surviving the surgery and terrified of what else they might find when they cut into my abdomen. It has all been traumatic. The lights, the sounds, and the cold metal slab of a bed that I feel on my body as I lay down on the operating room bed make the fear more pronounced. They have nothing to do with healing, or feeling comforted, safe, I feel very alone and on the edge of a precipice that I just have to dive into. This experience causes me to feel powerless, I have to give my control over to the surgeon, to the drugs that put me to sleep. I put my trust in the surgeon, someone, I just met, who is after all a human being. These processes and procedures are standardized, marked by specific protocols and procedures (Lock & Nguyen, 2018), a routinized process which includes check lists that must be adhered to. As Lock and Nyugen point out, "operating theatres are in effect laboratories where disease is isolated from the body of the patient and its broader social circumstances" (pg. 60). My physical body is the focus, there is no space created for other aspects of myself, my life circumstances, all of which we know have fundamental impact on health (Lock & Nyugen, 2018; Bryant et al., 2019). Lock and Nyugen (2018) make this point,

> *Compared with other medical traditions biomedical explanations are, comparatively speaking, reductionistic, and focused primarily on the detection of named entities such as viruses, genes, biomarkers, or other signs internal to the body thought to be directly implicated in malfunction or incipient malfunction, even when the habits, lifestyle, and at times the environment in which the patient is living may be taken into consideration (p. 76)*

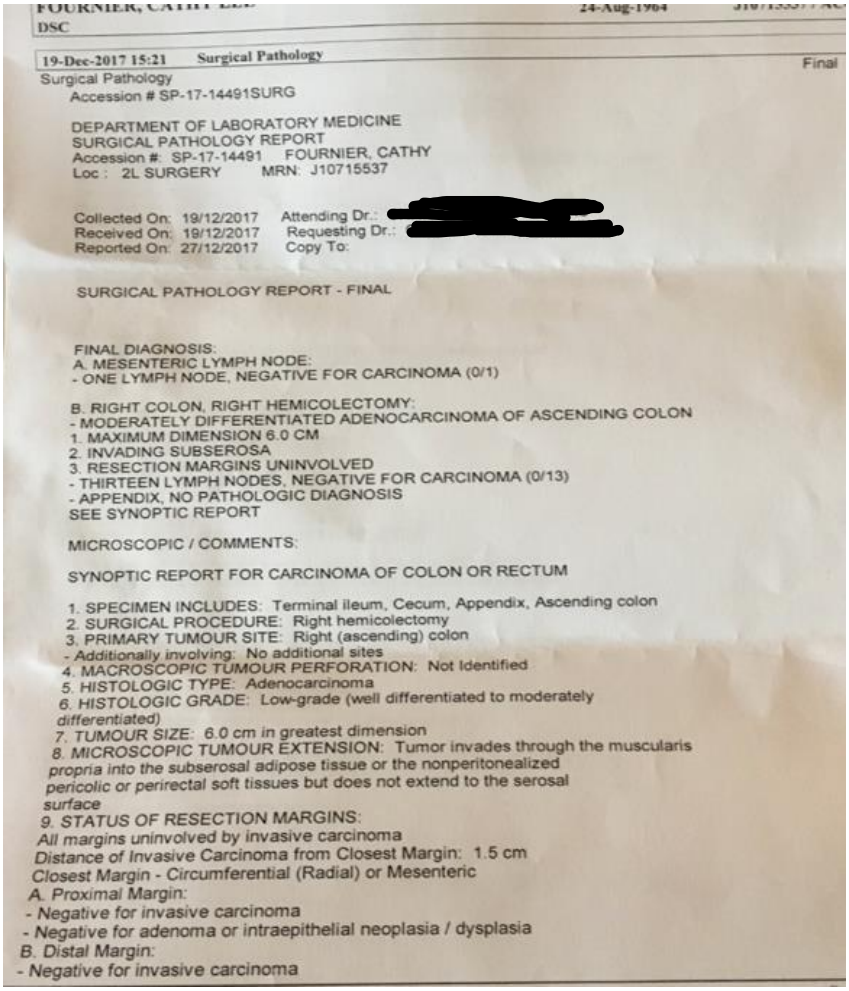
One of the most memorable and helpful moments of connection with a health care provider during my hospital stay occurs the day before I am discharged. The lead surgeon who removed the tumour, who I met 2 minutes before the surgery and don't see again until this day, comes into my room and stands by my bed and introduces himself. He actually then sits on the edge of my bed and says, 'this must be a whirlwind for you, it all happened so quickly". He then says he is "cautiously optimistic about a full cure". His words, his manner, his sensitivity to my experience feel so helpful. I start to cry a bit. I thank him. This surgeon's empathy is empowering to me. I feel seen, acknowledged that what has just occurred has indeed been a whirlwind, a traumatic whirlwind that isn't over yet.

After four days in hospital recovering from the surgery, where my bodily needs are tended to, I am sent home. I don't have the results from the biopsy yet that will confirm what stage the cancer is. I am told it will take two weeks to get those results. I am sent home with wound care instructions for my incisions and what to watch out for with regards to infection, as there is a high risk of infection with colon surgeries given their nature. During these 2 weeks of waiting the surgeon's words about being cautiously optimistic about a full cure ring in my head when I am overtaken with fear and anxiety.

Two weeks later I get the results, waiting for my appointment to get results I nearly pass out with anxiety, but I can't sit still so I get up and walk around back and forth. There are no real considerations for this; for the doctor providing results, this is just part of a day's work, giving people news about their very lives, their prognosis. For the doctor it is mundane. Finally, my name is called and before I even sit down, I ask if my lymph nodes were okay, he checks my chart and the surgeon says my lymph nodes are clear, and he makes an appointment for me to follow up with the oncologist. He is not sure if I should get chemotherapy or not. He is concerned because the tumour was so large, it is a grey area in terms of the follow up treatment protocol. Here is another example of how the body and care is divided up, he is the surgeon who removed the tumour but I have to see someone else to find out whether I need chemotherapy and to follow up with for my post cancer care. After I get the good news, I tell the doctor that I was so nervous coming here today, he responds by saying 'oh don't worry taking the

surgery staples out won't hurt.' I say, no, no, I meant waiting to find out if the cancer had spread. He seems surprised but then nods. I am surprised that he is surprised.

He prints out and gives me the pathology report from the tumour biopsy. The pathology report outlines all of the various microscopic aspects of the cancer they removed. In biomedical cancer care the diseased parts are cut out and then sent to lab to be looked at in closer and closer detail, more and more removed from my body as a whole, from my being as a whole. One is then placed into the 'system' and the management of the particular cancer is set in motion based on the cellular level characteristics of the cancer.



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19-Dec-2017 15:21 Surgical Pathology Final

Surgical Pathology
Accession # SP-17-14491SURG

DEPARTMENT OF LABORATORY MEDICINE
SURGICAL PATHOLOGY REPORT
Accession #: SP-17-14491 FOURNIER, CATHY
Loc : 2L SURGERY MRN: J10715537

Collected On: 19/12/2017 Attending Dr.: [redacted]
Received On: 19/12/2017 Requesting Dr.:
Reported On: 27/12/2017 Copy To:

SURGICAL PATHOLOGY REPORT - FINAL

FINAL DIAGNOSIS:
A. MESENTERIC LYMPH NODE:
- ONE LYMPH NODE, NEGATIVE FOR CARCINOMA (0/1)

B. RIGHT COLON, RIGHT HEMICOLECTOMY:
- MODERATELY DIFFERENTIATED ADENOCARCINOMA OF ASCENDING COLON
1. MAXIMUM DIMENSION 6.0 CM
2. INVADING SUBSEROSA
3. RESECTION MARGINS UNINVOLVED
- THIRTEEN LYMPH NODES, NEGATIVE FOR CARCINOMA (0/13)
- APPENDIX, NO PATHOLOGIC DIAGNOSIS
SEE SYNOPTIC REPORT

MICROSCOPIC / COMMENTS:

SYNOPTIC REPORT FOR CARCINOMA OF COLON OR RECTUM

1. SPECIMEN INCLUDES: Terminal ileum, Cecum, Appendix, Ascending colon
2. SURGICAL PROCEDURE: Right hemicolectomy
3. PRIMARY TUMOUR SITE: Right (ascending) colon
- Additionally involving: No additional sites
4. MACROSCOPIC TUMOUR PERFORATION: Not Identified
5. HISTOLOGIC TYPE: Adenocarcinoma
6. HISTOLOGIC GRADE: Low-grade (well differentiated to moderately differentiated)
7. TUMOUR SIZE: 6.0 cm in greatest dimension
8. MICROSCOPIC TUMOUR EXTENSION: Tumor invades through the muscularis propria into the subserosal adipose tissue or the nonperitonealized pericolic or perirectal soft tissues but does not extend to the serosal surface
9. STATUS OF RESECTION MARGINS:
All margins uninvolved by invasive carcinoma
Distance of Invasive Carcinoma from Closest Margin: 1.5 cm
Closest Margin - Circumferential (Radial) or Mesenteric
A. Proximal Margin:
- Negative for invasive carcinoma
- Negative for adenoma or intraepithelial neoplasia / dysplasia
B. Distal Margin:
- Negative for invasive carcinoma

Figure 5 A section of the tumour biopsy report

This report outlines the microscopic qualities of the tumour, and the other tissues they

removed. It reports on the tumour size, the type of cancer and tissue margins. This report objectifies my body, the tumour, and reduces the cancer to its microscopic level characteristics.

4.3 Storying Biomedical Post Cancer Care

As I write this thesis, I am entering year three of a five year standardized "active surveillance" protocol and so far my testing has all been good, no recurrence or metastasis. However, each time I must go back to the hospital for testing and results I feel re-traumatized, the whole experience comes flooding back, and I am terrified each time that they will find something, as I know now that this is possible.

This next excerpt from my cancer journal highlights some of the sensory experience of going for a CT scan.

4.4 Surveillance

I go into a small room and take off my clothes and put on the gown. I enter the room and am told to lie down. I lay down on a cold metal slab of a bed, the room is so bright and stark, and I feel really scared. What if the cancer has come back…I start to feel the drugs entering my body I feel them burning in my veins…then burning all through my body, it feels like I have no control and my body is burning up from the inside out. I feel so alone, I am alone. I close my eyes and try to breathe through it. Then the attendant comes back in the room, takes out the needle and escorts me out of the room (Fournier, Cancer Journals, June 2018).

This first voice quote illustrates the sense of isolation I feel as I navigate biomedical care. This is a mundane experience in biomedicine and cancer surveillance, where disease is made to cohere through a range of alienating sensory practices, narratives, documents, and files which helps normalize or standardize the experience at a broader level (see Lock & Nyugen, 2018; Mol, 2003). Yet on the personal level the experience of going to the hospital to get the CT scan on a regular basis is fraught with a sense of terror, and powerlessness. In part this is because even though it is my body being put to these tests, my life that is impacted, I am not privy to the results until a week later when I see the oncologist, something I have to arrange according to her availability. I am left waiting for

results that could profoundly change my life. I am completely left out of the process after the CT image is taken, only my oncologist can tell me the results. I am once again a passive body, under scrutiny, a body that can't be trusted and must remain under surveillance because of the existence of cancer cells, and the particular characteristics of these cells.

Further, in not one of these biomedical encounters is there any mention that the root of many cancers lies in the toxic activities of corporate industrial practices (see Kress & Stine, 2017; Singer & Baer, 1995; Tsing, 2015), and a flagrant disregard of subaltern communities who bear a heavy cost from these activities, sometimes referred to as forms of environmental racism (Waldron, 2018). Shouldn't doctors, especially oncologists be fighting for environmental justice (Witeska-Młynarczyk, 2015). Shouldn't that be part of their training and responsibility (see Downey et al., 2019; Franklin & Munyikwa, 2021; Hanna-Attisha, 2018; McKenna, 2021; Metzl & Hansen, 2014). I have never been asked where I live, what environmental factors or chemicals I might be exposed to, nor am I asked anything about my diet. Shouldn't that be part of my care.

In response to this phenomenon, medical anthropologist Brian McKenna (2012), states that "biomedicine focuses on diseased bodies, not the body politic" (p. 96; see also Holmes, 2013), yet as McKenna reminds us, the role of the social sciences is to be troublesome, to disconcert the habitual arrangements by which we manage to live along and to demonstrate the possibility of change in more adequate directions...Like that of a skilled surgeon… (Lynd, 1939, p. 181, in McKenna, 2021).

However, biomedicine is concerned with particular technologies of tending to diseased bodies, not the outside environment from which we are an integral part. Levin (1985) suggests that the body and the body politic have become one existential unit. Indeed, having cancer forces one to pay attention to the body in ways one may not have before and commands our "bewildered attention" (see Little et al., 1998) and here, I purposefully place my 'self' and its link to a wider environment and collective at the fore (Grønseth, 2001; Holmes, 2013). This cancer did not come out of nowhere, and for me it is not merely a physical issue. It commands not only my bewildered attention but managing my body/mind/spirit as one unit that has been thrust into chaos. Borrowing from an argument made by Grønseth and Oakley (2007) on ethnographic humanism in

health care in relation to migrants, I would like to extrapolate the following sentiment in relation to biomedical care by saying we need to place humanism in biomedicine first to mitigate the impact of a "the reductionist, profit-based pseudo-science that permeates biomedical systems" (see also Nanda, 2001, 2003). Empathy, compassion, and humanism need to occupy a more fundamental and central place in health care.

4.5 "The New Normal"

My last two CT scans have taken place since the COVID19 lockdowns began in March 2020, both times they were delayed and both times I get my results over the phone about a week later from the oncologist. Here is a first voice excerpt from my most recent biomedical cancer experience, my CT scan under new hospital procedures.

> *I had to go to the hospital today for my 6 month follow up CT scan. Things are very different this time around. As we approach the hospital there are strips of caution tape blocking the usual entrance I go in through. There are signs that say 'STOP' and 'Masks mandatory' and some directions of where to enter. There is only one hospital entrance open besides the emergency department. Usually, my husband comes with me for support, I get anxiety attacks whenever I have to go back to that hospital especially for testing as it is a stark reminder that the cancer could return. However today there are security guards by entrance and signs that say that only patients are allowed in unless they get special permission. I enter by myself. There are a few different check points. Once I get through the line up to get into the hospital, I am told to stand on a sticker on the floor that says 'wait here, then as people are checked through I am told to move to different spots, that are each the mandated 2 metres away. I feel like I am in the army, move here, stand here, wait here. As I stand on one of the designated spots, I lose track of my body in space for a moment and have unknowingly shifted from the centre of the dot and the security guard comes over and asks me to move back a few inches. A few minutes later I am told to walk up to a desk where a staff member sits behind a plexiglass barrier, wearing a mask. We are both wearing masks so only our eyes and the top of our head is visible. It is hard to hear her behind all of these barriers. She asks me a few COVID19 screening questions, the standard do I have*

any of the following symptoms, fever, cough…have you travelled outside of Canada in the last month. I answer no to all of them and so she waves me in. Inside the hospital there are floor stickers and signs everywhere telling people to stay 2 metres apart. There is hand sanitizer everywhere. Otherwise, the hospital seems mostly as normal, but strangely quiet. I check in and then wait in the waiting area which has every second chair taped off and a sign that says, 'we are promoting social distancing – do not sit in this spot'. I am there alone waiting for the test and really wishing Morgan was there with me… (Fournier Cancer Journals, June, 2020).

These changes may on the outside seem insignificant, but for me, given my already anxious state they feel enormous. My anxiety levels for these two scans has multiplied, partly because I am there alone, but also because the public health protocols sets a tone for the whole experience that feels so stark and cold, very militaristic. I guess because I am already feeling so much anxiety, my heart always pounds as soon as I get close to the hospital, these changes just add to that anxiety. I usually have my rituals, my routines as I sit in the waiting room for example, in the company of a supportive partner but that has been stripped away as well. What is worse is the fact that since last March all of my appointments with the oncologist to get results are over the phone. I find this unbearable, the waiting for the phone to ring at home is much worse for me than sitting in the waiting room, even though that too caused me so much anxiety, at least there I am in the company of other people who are there for similar reasons, they have the same look in their eyes, one I recognize. We don't speak but we know. The home appointment is so unstructured, I am given a two-hour time window that the oncologist will call. Waiting for that call makes me want to jump out of my skin. The human contact aspect of my care has now been reduced to this.

One of the things I have found comforting about my biomedical experiences is the structuredness of it, the set appointment times, the pre-established protocols of treatment and surveillance. These too are some of the weaknesses and things that make it less human, more technology focused but sometimes I feel there is a strange security in that. Since COVID19 however, this sense of comfort in the routine, the security in the set protocols is gone for me. Furthermore, for me the COVID19 protocols have taken some

of the humanity out of these biomedical encounters. This too is a loss I must work my way through.

In this next section I explore my experiences with Indigenous healing, medicines and ceremonies using first voice excerpts and storying.

4.6 Indigenous Approaches to Cancer Care

4.6.1 Cancer Care Ontario

In an effort to "decolonize" cancer care for Indigenous Peoples, Cancer Care Ontario (CCO), a provincial organization in Canada, implemented an *Indigenous Navigator* program in 2013 to help Indigenous Peoples navigate the heavily colonized and increasingly corporatized Canadian health care system (Coburn, 2010; Coburn & Navarro, 2015). CCO formally recognizes the brutal treatment of Indigenous Peoples in residential schools and Indian hospitals, the criminalization of healing ceremonies (Kelm, 1999), and ongoing experiences of racism and discrimination in the Canadian health care system (Boyer, 2017; Tang & Browne, 2008; Wylie & McConkey, 2019). This program also helps Indigenous Peoples with cancer access cultural and spiritual care and guidance alongside biomedical care. The goals of the CCO Indigenous Navigator program are to improve cancer care for Indigenous Peoples in Ontario, as well as provide "cultural competency/cultural safety" training for biomedical providers. This program is open to anyone who self identifies as Indigenous and has had a cancer diagnosis. Through this program I have been able to gain access to an elder, and an Indigenous Healer/counsellor. This is important in this instance as accessing indigenous medicines can be more complicated for Métis peoples as they often live in the 'borderlands' between indigenous and settler identities (Edge & McCallum, 2006). My relationships with the Healer and elder have reawakened parts of myself, my spirit, indigenous blood and identity and this is a crucial part of my healing (see Wane, 2006). This need for connection to others and to reclaim a belonging to culture and way of life during the healing process is a major component of my healing and wellbeing. (see Auger, 2016; Bartlett et al., 2015; Bartlett, 2005; Chilisa, 2019; Graveline, 1998; Smith, 2012).

4.7 Storying Indigenous Healing

This next section describes some of my experiences with Indigenous healing and ceremonies and explores notes taken from my cancer journal as case studies.

This first excerpt was written after my first visit with the Healer I was introduced to through CCO's Indigenous navigator a few months after my surgery. My first appointment with the Healer was arranged for me by the Indigenous navigator. I was feeling very vulnerable and fragile from the experiences I had just had with the cancer diagnosis as well as recovering from the major surgery I had. The local health centre is an "integrated" medical clinic that had both biomedical practitioners as well as Indigenous Healers, traditional counselling, programming, and ceremonies. When you walk in there is a waiting area with a few chairs, a front desk off to the side and many posters and images that reflect the urban Indigenous population in the region.

> *I leave my first appointment with a Healer, feeling like I have had a profound experience, like I transcended time and space while in the room with him. I am usually very sensitive to lighting and the lighting in the room was florescent and greyish, but as the session goes on it feels like a totally different space, it becomes warm and welcoming, the physical aspects of the room matter less and less. I feel a sense of safety, relaxation and belonging with the Healer. I feel like I am being included into a world that I have craved for a long time, it feels good. One of the first things they say to me is welcome to the circle. My sense of belonging arises partly because of the Healers words, their acceptance of me and my blue eyes, but it feels deeper than that. The Healer called it my blood memory. Indigenous blood runs through my body despite what I look like. He told me some people judge identity based on how you are supposed to look but he said it isn't about that, it's about your heart, your spirit (Fournier, Cancer Journals, February 2018).*

My session with the Healer contrasts sharply with my experiences at the hospital. However, both forms of care are and were crucial to my cancer care. The session with the Healer is guided by sacred spirit animals, sacred medicines that are burned, drank, inhaled, and is steeped in history and sacred knowledges passed down since time immemorial. There is a ceremonial pipe that was gifted to the Healer from his teacher, he is guided by this pipe, it helps connect to the spirit world, the sacred teachings it holds. Before seeing the Healer, I had attended teachings about the four sacred medicines, had

visited with Elders who shared teachings with me, but this was more intense, perhaps because after having cancer my life feels more precarious, more precious and I am hungry for a deeper meaning to all that I have been through. I also feel it is necessary for me to connect in a deeper way to my family's Indigenous roots and history. The Healer says all illness starts in the spirit and I want to heal mine. They also said sometimes poison is medicine.

On my next visit I see a different Healer, as the one I usually see is sick. He asks me how I am and I tell him about having cancer in December and that I am having a hard time. He talks a bit about intergenerational stuff, intergenerational trauma, how sometimes things get passed down through the generations so they can get cleared out, for healing. He said sometimes cancer is like that, sometimes it skips a generation. Neither my parents nor my grandparents have had cancer. We talk for a bit and then he says my journey now is to clear stuff out for future generations, for my daughter. He then bends over and takes a rattle out of his bag. He looks at me and then starts shaking the rattle and looking down with his eyes closed. As he shakes the rattle, he sings in Anishnaabemowin. As his voice and the rattle get louder and more intense I too close my eyes and try to focus inside. I feel sad but calm as he continues to sing. The sound of the words are beautiful, I can feel them in my body. He sings for quite a while maybe a few minutes or so. It seems like a form of prayer and meditation to me and as he continues to sing, I feel energy moving stuff around in my body, I can feel my scar, I can feel where they removed part of my colon. It feels like a deep ache, and a sense of grief.

After a few minutes he stops singing and he says he has started the prayer and that I need to finish it. He gives me some instructions for continuing the prayer at home and how to put out an offering to my ancestors and the spirit world. He tells me to put out a feast plate as a way of clearing out stuff from the past, present and future so that I can continue to heal. Then he says, 'it will be okay, you will see'. After he says this I start to cry.

> *I saw the Healer for the 5th time on Monday. I had gotten the results from my first post cancer CT scan on Friday and all was clear. I told him this and also told him that I had felt so elated on the weekend because of it but that the last few days I had felt a kind of free-floating fear, anxiety. He assures me this was normal that I*

have to balance out from the intensity of feelings of fear before the scan and waiting for the results which makes sense to me. Then he shares some stories about his life, his sadness and also about an accident he had when he was 16 where he was thrown from a car and had an out of body of experience. As we are there sharing stories, I feel like everything else disappears for the time being and all that exists is that moment, these stories and feeling connected to something larger than this earthly place. He talks about the spirit, the spirit world, and how experiences with death and life-threatening sickness can change us, that it helps our spirit develop. He tells me he wants to make me a pipe, he says I have earned it but that it is also a responsibility. He wants to make 2 pipes, one for me and one for the spirit world to put outside to remind me to trust, to help me feel safe again and to remind me about the Creator. I always feel so much better after seeing him, lighter, less scared, less sad. He is kind and gentle and tells me stories that help me feel less alone. Having cancer feels like a lonely place sometimes, like no one understands what I am feeling unless they too have had cancer or other life-threatening experiences. We talk about fear and sadness and how I need to hollow out those feelings, get them out of my body and that I need to start to pay more attention to my body, to how it feels. He also talks about how the "white coats" (the western doctors) think about cancer, and how a cure is coming but that they are just sorting out how to make profit from it.

Our session ends like it usually does as he pulls out his drum and then lights his pipe. Smoke billows around the pipe, around him and fills the room. I like the sound of the drum, the smell of the smoke and try and meditate on it by closing my eyes. I can feel the drum sound and beat in my body. He puffs on the pipe and the drumming lasts for about a minute or so then he tells me what medicine to take and how much, it changes a bit every time. The medicine I am given this time is a hollowing out medicine that will help clear/heal my mind and the body (Fournier, Cancer Journals, n.d).

My experience at the health clinic where the Healer works is so different than the hospital or any other medical clinic, I have ever been in. This Healer works out of a small medical clinic in an urban setting. It is a busy clinic but people in the waiting area and those that

work there talk to each other a lot. It feels busy but friendly. My visits to the Healer help me feel more connected in a deep inner sense to my roots, to my ancestors, to something larger than the material world. At the same time, I am continuing to learn more about my own family history. Some old stories from my mom, and my aunt, things I didn't know before about my grandfather and great grandfather. These visits and my relationship with the Healer also help me think and see my life, my health and healing and the cancer differently. It feels less and less like a form of punishment for something I have done wrong and more like a gift in many ways. I feel more connected to my spirituality, more connected to nature and beyond. I find deep solace in the rituals, the smudging, and the ceremonies.

Cree scholar Willie Ermine (2007) says in the Cree language health can be translated into the English language as "good positive movement", "dancing particles". He states that health is equal to all of our particles moving well. With regards to cancer the Healer says I need to negotiate with cancer to have a long life, not to battle with it but to negotiate.

Figure 6 An image I painted after a few visits with the Healer

This drawing represents my cancer and healing, something I painted about a year ago. I

did it as a reflexive exercise. In this image I see the cancer (in pink), an animal spirit (bear) and the smoke from burning sacred medicines clearing away or transforming cancer into health.

4.8 The Shaking Tent

One particularly powerful ceremony I have attended is the 'jeesekun', the Ojibwe word for shake tent, a ceremony which involves connecting to the spirit realm for healing. The shake tent is usually held in the pitch dark by a Healer(s), with the help of an 'Oshkaabewis' (ceremonial attendant). Shake tents are usually held on the land but within the urban setting they are sometimes held indoors in a darkened room. Shake tents are re-emerging as an important method for healing from trauma as a result of colonization within many Indigenous communities (see Struthers & Eschiti, 2005).

The first shake tent I attend is in December 2018. The Healer has a big bag of sacred items such as drums, rattles, pipes, tobacco and animal pelts. The tent is held inside in this instance however, there are 2 firekeepers out back that tend to the sacred fire while the shake tent is going on. People take turns going up to the tent, making an offering of tobacco and then asking a question or for some guidance and support. I go up because of my impending cancer screening, CT scan and colonoscopy within a week of each other. It has been a year since my surgery. I am really anxious and scared about having to go back and get the testing, scared the cancer will be back, that it will have planted itself elsewhere without me knowing. When it is my turn, I feel very emotional and my voice waivers when I speak. I speak in Anishnaabemowin, a language I have been learning this past year. The room is so dark and when I close my eyes there is no difference between what is behind my closed eyes and the room. I see sparks of light coming from the drumming, and I also see a big turtle watching over the shake tent in my mind's eye. The ceremony goes on for 6 hours, with everyone taking a turn to go up and ask for guidance and healing.

During the shake tent I am given a spirit name. I leave this ceremony feeling connected to a larger community, a sense of belonging and peacefulness. I feel less afraid and less focused on what might be wrong in my body and more in touch with my spirit and a collective of other women going through hardship.

The third shake tent I attend is as a helper and a participant, I am now an Oshkaabewis, a ceremonial helper and apprentice. I was asked to be a helper by one the Healers that I have developed a relationship with over the last two years. This shake tent is the most profound for me. I am a helper, in charge of preparing the medicines, and also a participant. I am having a hard time as I had some post-menopausal bleeding and now on top of everything, I was getting a biopsy to rule out endometrial cancer. I just felt I couldn't cope with one more thing, one more invasive test and waiting for the results.

While setting up for the shake tent one of the helpers tonight has a whole suitcase of stuff, rattles, stones, and a bear pelt. At one point I leave the room to get the medicines upstairs and when I come back downstairs the bear pelt is laying across the wooden platform. As I walk into the room and see it I am hit with profound emotions, out of nowhere I feel an intense sadness and a deep connection to this pelt. I ask if I can touch it and the Healer says yes. I kneel and touch it and I just start to cry. I just am overcome. It is like a whole other world resides in the fur, yet I feel like it is also part of me, so many strange feelings. The Healer says just go with it and leaves me in the room alone, telling me to lie down on it and give myself over to it. I lay down and feel like I am enveloped in the bear, enfolded in her thick, course fur. I feel a sense of safety I haven't ever felt before. I just start crying and sob for a long time, I just let the tears come. I lay there for about 20 minutes (I think) and my body melts into the bear skin and I feel so relaxed and at ease. I feel cared for in a way I never have felt before. I get up slowly and I feel grounded, relaxed and calm.

Since this experience I have had many dreams about bears, brown bears and polar bears. Later that week, after the shake tent when I had my uterine biopsy, I even felt the presence of a spirit bear in the doctor's office. It helped reassure me that everything would be ok. I also recently had a particularly powerful dream with a polar bear. In the dream I walk into a room with my daughter and when we open the door to the room there is a polar bear that is threatening to be violent, wanting to attack us, but I talk with the bear, and it calms down. Then the bear acts like it loves me and I am taking care of it, then the bear starts to relax and lays down and we are free to move around the room without fear.

When I talk to the Healer about the presence of the bear in the doctor's office they aren't surprised, they just say 'ya, of course'. When I tell her about the dream, she says it was a message, that my gifts are coming out, my healing gifts. I also see it as a sign that I am clearing out intergenerational trauma and that will help protect my daughter.

> *The sound of the drum, the smoke, the smell of burning sage. I feel it beyond the bone, I feel it in my blood, like my blood, is remembering something. I always cry when I hear that drumming not out of sadness, but a feeling of profound relief… (Fournier, Cancer Journals, n.d).*

This First Voice excerpt illustrates the importance of finding an embodied sense of sacred connection to my ancestors, a sense of belonging and community. In particular I am drawn to drumming, sacred plant medicines, and healing ceremonies such as the sweat lodge and shake tent. All of these ceremonies help me feel part of a larger collective, both human, and spiritually, which is important for my health. This sense of community, and connection to ceremonies is part of what sacred space means to me (Cooper et al., 2019). Sacred spaces can be internal as well as external places/spaces, and the sacred activities such as drumming and ceremony have become part of me, they are both external and embodied sacred spaces. Cooper and colleagues (2019) state that "our [r]elationships to sacred spaces sustain spiritual connections integral to our concepts of holistic health/well-being and are vital for cultural integrity" (p. 2). They are an integral part of my life now.

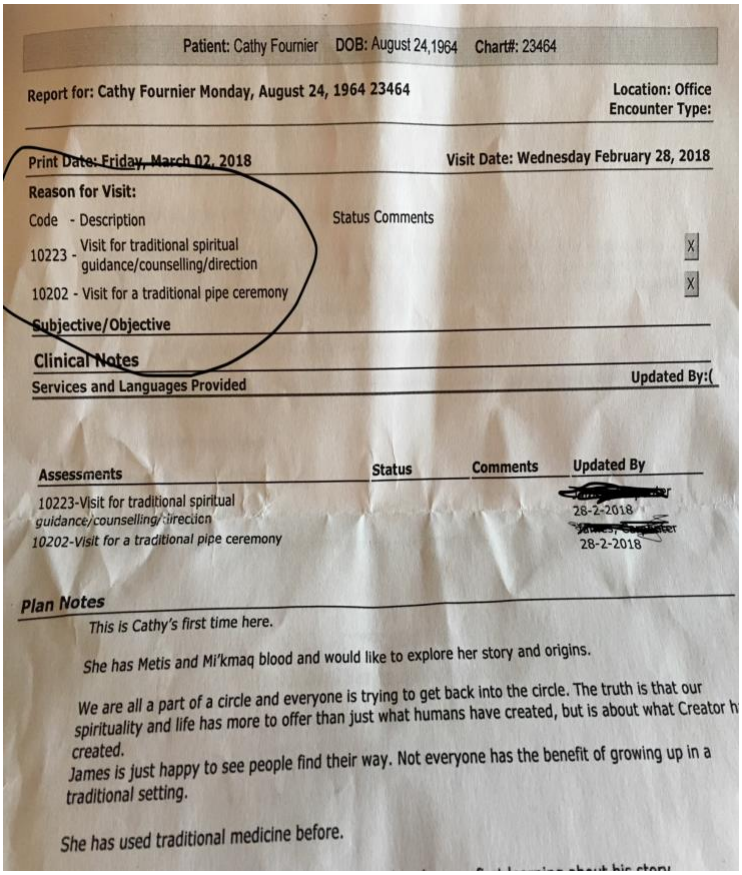
4.9 Worlds Clashing and Crashing

This next section examines my experiences both with biomedicine and Indigenous healing. Once again, I use First Voice excerpts from my cancer journal as a case study to explore their differences, contradictions and spaces of struggle as I try to make sense of my experience with cancer, biomedical care and indigenous healing as a whole being. I argue that we need to honour and allow the spaces of tensions between "Indigenous" and western knowledges in relation to cancer care in order to resist assimilation and homogenization of the diversity of Indigenous knowledges and practices in Canada.

It is difficult to compare biomedical care and Indigenous healing as they are from very different worlds. One is grounded in local knowledges and connections to the land,

and spirit, while biomedicine is increasingly permeated by what Grønseth and Oakley (2007) call "…reductionist, profit-based pseudo-science …" (p. 4; see also Nanda, 2003) that is more and more technology based (Lock and Nguyen, 2018). As noted by Qidwai (2017), "[w]ith technological advances in medical sciences, the emphasis has moved from listening to patients and doing a thorough physical examination to ordering a battery of investigations" (p. 185). In my experience this increasing aspect of biomedicine is mitigated by glimmers of the human, the occasional humanness of doctors, nurses, and attendants (Qidwai, 2017). Conversely, my experience with the Healer is steeped in the human, the spirit realm, which carries with it a sense of being connected to a broader realm.

As mentioned earlier, the Healer I see works in an integrated medical clinic, they offer biomedical care as well as access to Indigenous Healers, and traditional ceremonies, such as sweat lodges on site. After each appointment with the Healer which I described in detail earlier in this chapter, I get a printout of appointment notes taken by an assistant who is in the room during my appointment. They sit off to the side and type on a computer, I barely notice them once the session begins. The document they print out is a medical document with the date, my name and birthdate at the top. It also has a selection of numerical codes for the session. The pipe ceremony for example has a specific code, "10202" as does the "spiritual guidance/counselling/direction" session, code is "10223". It is fascinating to me that these codes are there, and that the session is described in such a way. Who created the codes and why? When I look at the paper with the codes and the summary of what the Healer and I have exchanged during the session it feels so distant and removed from my actual experience. Each time I see the Healer I feel transformed, it is always a profound experience. I cry, I tremble, and feel like I enter into another world or dimension while in their office, this medical clinic was transformed in my experience while I was in his office space. However, these notes take away from that, my experience is reduced to codes that seem so arbitrary and unnecessary.



Patient: Cathy Fournier DOB: August 24,1964 Chart#: 23464

Report for: Cathy Fournier Monday, August 24, 1964 23464

Location: Office
Encounter Type:

Print Date: Friday, March 02, 2018

Visit Date: Wednesday February 28, 2018

Reason for Visit:

Code - Description	Status Comments	
10223 - Visit for traditional spiritual guidance/counselling/direction		X
10202 - Visit for a traditional pipe ceremony		X

Subjective/Objective

Clinical Notes

Services and Languages Provided

Updated By:(

Assessments	Status	Comments	Updated By
10223-Visit for traditional spiritual guidance/counselling/direction			[redacted] 28-2-2018
10202-Visit for a traditional pipe ceremony			[redacted] 28-2-2018

Plan Notes

This is Cathy's first time here.

She has Metis and Mi'kmaq blood and would like to explore her story and origins.

We are all a part of a circle and everyone is trying to get back into the circle. The truth is that our spirituality and life has more to offer than just what humans have created, but is about what Creator h created.
James is just happy to see people find their way. Not everyone has the benefit of growing up in a traditional setting.

She has used traditional medicine before.

Figure 7 An example of the Indigenous Counselling Clinic Notes

Looking at this document I feel like what took place with the Healer in that room has been reduced to specific numerical codes. The notes describe a reductionist linear encounter, that has little to do with what I felt took place. How do I make sense of the experience while integrating my experience with the actual artifact created through the notes? It is a struggle for me to not let the notes in any way take away from what I experience during the session, what I learned, what we shared. It would be easy for me to think it was all just my imagination. I have to consciously fight against the tendency to reduce the entire encounter as a figment of my anxious imagination, and self, looking for meaning and support.

This experience is an example of the tensions between biomedical care and settings, and indigenous healing that I am arguing need to be highlighted rather than smoothed over. Reducing tensions can lead to monoculture, towards one dominant way of viewing the world, in this instance a biomedically informed one (Fournier & Oakley,

2018). Tensions are important (Ahenakew, 2019). These codes and the notes I later find out are necessary for filing, and are possibly tied to funding requirements, but they are the result of the push towards biomedical ways of enacting health care. In this instance a requirement for ongoing government funding.

This illustrates how carving out and holding space for the sacredness of my encounter with the Healer is crucial otherwise it risks being absorbed or pulled into the dominant paradigm of care, a type of care that tends to strip away the body from the mind/spirit/emotions (Grøsneth, 2001; Horden & Hsu, 2013; Hokowhitu, 2009; Ludtke, 2008; Lock & Nguyen, 2018; Mol, 2003, Scheper-Hughes & Lock, 1987; Young & Nadeau, 2005). Yet, these aspects of the self are not divided as such and this imposed division represents a form of colonization and ultimately impacts how we conceptualize particular symptoms, and illnesses, including the tendency to reduce illness to just the cellular level (Hokowhitu, 2009; Jain, 2013; Lock & Nguyen, 2018; Young & Nadeau, 2005). For me, this form of care renders me a helpless victim of genetics and family health histories, something which has contributed further to a profound sense of bewilderment and lack of control over my lifeworlds, something I am trying to transcend by connecting to a larger collective, a spiritual realm and doing the healing work.

In another example of trying to bring "two worlds" together, was when I tried to bring an important part of my emergent métis identity, sense of spirit and connection to community into the biomedical spaces I also encounter. The following is a story from my cancer journal, a story about my own struggle of trying to navigate tensions. The anxiety that goes along with waiting for results of scans has a sort of 'pet' name among cancer survivors, it is known as 'scanxiety'. This refers to the common anxiety amongst cancer survivors who have regular surveillance to see if the cancer returns. As such, it is a sort of regular and common feeling for cancer 'survivors', yet it is not spoken of in the waiting rooms I attend, spaces where we are all there for similar reasons. One of the ways I have been taught to cope with these leftover feelings of fear and anxiety is to put my hand drum close to my chest/heart and drum lightly. I made my own drum at an Oshkaabewis retreat and use it regularly at home and at drumming circles. At home I find the drumming very soothing, it helps me calm down when I am feeling anxious, for example, on the days preceding getting scan results. To help me cope with this anxiety, the Healer

suggested that I bring my smudge, and my drum, or even my rattle into the waiting room while waiting to see the oncologist for test results. They suggested that I just quietly and gently drum or shake the rattle to help change my energy and help myself stay calm and connected to spirit. So, on the next occasion I pack my rattle and drum and some sage into my bag to bring to my appointment. However, as soon as I sit down in the waiting room, I just can't do it. I couldn't even take the drum or the small rattle out of my bag. I didn't feel safe. I felt too self-conscious, like I might be ridiculed or cause a fuss or worse questioned, like someone saying, you can't do that here. I didn't want to make a fuss as I already was feeling so sensitive and vulnerable. I also worried about making others uncomfortable.

So, what are some of the tensions between these experiences with biomedicine and Indigenous healing? There are clear differences between biomedicine and Indigenous ways of understanding health (Manitowabi, & Shawande, 2013; Maar & Shawande, 2010; Martin-Hill, 2003). One is largely mechanistic, tending to reduce illness, for example cancer, to the cellular level, to cells gone haywire, or it is attributed to mere genetic factors. It strips us away from our social and physical environment, from spirit. Whereas an indigenous view as shown above, connection to spirit, nature, the land, community are at the centre (Cooper et al, 2019; Manitowabi, & Shawande, 2013). One of the first things that the Healer said to me was that we are all trying to enter this circle and that I have now entered into the circle; the circle of life, my ancestors, a community, and a sense of belonging. Cooper and colleagues, (2019) describe the difference between biomedicine and indigenous conceptualizations of health well,

> *Western conceptualizations of health focus on physical elements related to the biomedical being, while Indigenous epistemologies focus holistically on the physical, mental, emotional, and spiritual being… [Indigenous]ways of life and health incorporate philosophies of people in/striving towards harmony and spiritual relationships with the land, community, ancestors, and the spirit world. (p. 8).*

Traditional Indigenous views of health have tended to be very wholistic, not just looking at pathogens or physical causes of illness/disease but considering structural social, political, cultural, and environmental factors as well as spiritual, mental and emotional.

This perspective is crucial moving forward as health policies and practices are rapidly changing particularly in the current COVID19 context.

Another case study example I would like to explore that illustrates the tensions between biomedicine and indigenous healing is an encounter with my family doctor. I went for a checkup, and he asked my about my mood since "the cancer". I told him my mood was up and down (a common experience among cancer patients I am told). He then asked if I was crying a lot and handed me a paper with a depression scale questionnaire, with questions such as, in the past two weeks how often have you been bothered by the following: *little or no interest in doing things; little interest or pleasure in doing things and feeling tired or having little energy*. The possible responses range from *not at all; several days; more than half the days and nearly every day*. This depression scale was created by a large pharmaceutical company and is a standard evaluation form given to patients to assess their degree of depression and to determine prescription of psycho-trophic medications.

This depression questionnaire, an idiosyncratic cultural artefact endorsed by the pharmaceutical company who developed it, both objectifies and individualizes the illness experience in a peculiar manner and reifies any emotional experience into a tightly controlled and reductionist classification system to be measured. For me this scale didn't fit – the questions were too generic and vague. The "solution" if one scores high on this scale was very specific but not surprising: pharmaceuticals, in this instance anti-depressants. Additionally, my family doctor suggested I take a vacation, to go somewhere and relax in order to recover psychologically from having cancer, something which I guess he assumed I could afford. This type of biomedical encounter leaves it up to me to take a vacation, and/or rely on pharmaceuticals for support.

On the other hand, when I talked about my low mood and sadness with the Healer, they spoke about the need to cry to let the sadness out, and that not only the tears, but the cancer itself was medicine; a way of healing from intergenerational trauma, and the impact colonization and assimilation had on my family. They said I am turning poison into medicine. I wasn't asked about the frequency of my crying, instead I was encouraged to express my emotions and to engage with ceremony and community to help heal.

During this time, I received a spirit name, clan and clan colours, to help provide

me with a sense of belonging, and wider collective, a spiritual home. I also received a pipe: a sacred spiritual tool that is considered an honour to receive and is to be used to help me connect to the spirit realm for my own healing. I was told that going through cancer and other deep personal struggles I have experienced in my life to help heal myself and my family have earned me this honour.

As discussed earlier, it is this connection to community and ceremony that grew out of my cancer experience that has had a major impact on my healing. It took a cancer diagnosis to help connect me to community and ceremony. For many Indigenous Peoples, particularly those who did not grow up on reserve, or grew up in urban settings, or whose families hid their identities, it can be very difficult to find a sense of belonging to community. It took cancer to help me connect to community.

An Indigenous healing approach, as told here, enhances the interconnection with other people, the earth, animals, plants, and the spirit realm into a 'healing journey'. In this instance illness, poison, is being transformed into 'medicine', and cancer is a catalyst for intergenerational healing, resisting assimilation and strengthening Indigenous roots and traditions as well as developing a sense of community (Wane et al., 2011). Carving out spaces like this and navigating the health care system in a way that is meaningful, transformative, and also effective is challenging, yet crucial, particularly when one is dealing with a serious diagnosis such as cancer, (McCabe, 2008; Struthers & Eschiti, 2005), but my living a good life depends on it.

I think it is important to say that I had very good care within the biomedical spaces I encountered. I haven't experienced discrimination in terms of my skin colour or identity in my care as I have a choice as to how I identify, but I have experienced discrimination about my choices for care by friends, family, and colleagues. I have been asked incredulously by many when I tell them about my healing work and the importance of the ceremonies in my cancer healing, "do you believe in all that stuff"? Being asked this question seems benign enough on the outside perhaps but it makes me feel like maybe I am crazy, or stupid, or flaky, or all of the above, and I usually feel very befuddled and a sense of shame when asked this question. When I sense friends rolling their eyes, I am sure they are probably thinking, Cathy has lost it.

I am also not comfortable talking to my family doctor about my use of Indigenous

healing. Another example of the dissonance I have experienced is when told family doctor I had métis and Mi'kmaq ancestry on my mom's side and that I was seeing Healer, they said "that's nice". It was an offhanded remark and it felt like they just thought this was superfluous to my care. To me it is not only integral to my care but also integral to who I am. I do not feel comfortable telling the oncologist any of this either, there is no space to even do so. The check ins are quick and matter of fact, entirely focused on blood work results, or scan results and any physical symptoms. I am still vulnerable and comments such as "do you believe in all that stuff" or off-hand comments like "that's nice" feel harmful to me. This questioning of my choices is a form of epistemic racism, as in these contexts only certain knowledges and forms of care are seen as valid while others are still being seen as superstitious quackery.

My work around for this is I compartmentalize my care, aspects of my *self* and my identity. I don't share anything about the Indigenous healing ceremonies I engage with on a regular basis with the oncologist or my family doctor, nor do I share it with many of my friends and even some family members. But it is integral to who I am, my cancer care and staying well and living a good life.

The next chapter examines some of these stories with a more detailed analysis as I work to develop the Two-Eyed Seeing principle using anti-colonial and critical political economy perspectives on knowledge and the impact and constraints of colonization, as well as neoliberal and capitalist ideologies on knowledge "production".

Chapter 5 Embodying and Building Theory

5.1 Introduction

In this chapter I explore *Etuaptmumk* /Two-Eyed Seeing and suggest a broadened *Etuaptmumk* theoretical framework informed by anti-colonial theory and critical political economy as an avenue to protect sacred Indigenous knowledges. *Etuaptmumk* is a Mi'kmaq guiding principle brought forth my Mi'kmaw Elder Albert Marshall (2010) positing that we learn to see from both Indigenous and western euro-centric perspectives. *Etuaptmumk* has tremendous value and potential, however, the ways it tends to be interpreted and taken up may inadvertently wash over the nuance and complexity between "Indigenous" and "western," that could instead be highlighted and explored. Furthermore, the way it tends to be operationalized may oversimplify colonialism, 'indigenous- settler' relations and the impact of capitalism on knowledges, knowledge production and its translation. Although *Etuaptmumk* is by nature an anti-colonial framework, we need to recognize the imbalance in power that might afford more weight to one eye than the other when it is taken up in research while considering the impact of capitalist and neoliberal forces on western knowledges through the lens of critical political economy. I also think it is also crucial that we don't inadvertently reinforce a notion that all we need to do to create change is change the way we 'see' things rather than challenge and transform the status quo.

Anti-colonial theory begins from the stance of marginalized peoples, worldviews, and knowledges, and attempts to make visible perspectives that have become obscured by dominant worldviews (Hollenberg & Muzzin, 2010; King, 2003; Rao, 2010; Qadeer, 2011). While critical political economy is a form of analysis that critiques the influence of capitalist ideologies and dominant political economic arrangements and challenges the seeming logic behind the dominant paradigms and ideologies deployed in their defense (McKenna, 2010, 2012; Singer & Baer, 1995; Navarro, 1976). As such using these other theoretical frameworks to inform how the *Etuaptmumk* principle is taken up may help preserve Indigenous knowledges.

5.2 Honouring *Etuaptmumk*

In the words of Mi'kmaw Elder Albert Marshall *Etuaptmumk* is described as learning to see "from one eye with the strengths of Indigenous knowledges and ways of knowing, and from the other eye with the strengths of Western knowledges and ways of knowing, and to use both these eyes together, for the benefit of all" (Bartlett et al., 2012, p. 335; Marshall, 2010). *Etuaptmumk* is linked to the broader movement of "decolonizing" health care through integrating Indigenous medicines / knowledges and forms of governance, to help foster safer and more inclusive health care access for Indigenous people in Canada (Brunger & Wall, 2016; Chrisjohn & Wasacase, 2009; Hovey et al., 2017; Martin-Hill, 2003; Robbins & Dewar, 2011; Wright et al., 2019; Roher et al, 2021).

While *Etuaptmumk* is not "inherently a research methodology but rather a guiding principle that encourages self- reflection and emphasizes the transformational capacity of knowledge" (Forbes et al., 2020, pg. 2; see also Wright et al., 2019; Roher et al, 2021), it is being widely taken up by researchers, and organizations (Roher et al, 2021). For example, at the national level an *Etuaptmumk* framework is advocated by the Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council, and the Social Sciences and Humanities Research Council (Bartlett et al., 2012; Forbes et al., 2020; Wright et al., 2019). I suggest here that the merging of Indigenous knowledges within capitalist societies into settings that are dominated by a biomedical paradigm poses a risk of loss of sacred knowledges. Bringing Indigenous knowledges into these spaces together with dominant knowledges may constrain and contort them towards dominant Eurocentric ways of understanding the world. It may also contribute to furthering the belief that Indigenous knowledges are bounded, faith rather than 'evidence' based, and stuck in the past as they may be evaluated against Eurocentric perspectives that are considered the gold standard of what is legitimate knowledge (Fournier & Oakley, 2018; Hollenberg & Muzzin, 2010; Singer & Fisher, 2007). I argue for drawing on anti-colonial theory to guard against this tendency to view Indigenous knowledges through a Eurocentric lens. Even though *Etuaptmumk* is by nature an anti-colonial framework, we need to recognize the imbalance in power that might afford more weight to one eye than the other. I argue for drawing on critical political economy to be able to analyze this

potential imbalance in power, so that the application of the *Etuaptmumk* principle actually results in seeing with both eyes equally.

5.3 Integrating Indigenous Medicines and *Etuaptmumk* in Health Care

Knowledge about health and health care approaches is increasingly controlled and validated through dominant western discourses (Foucault, 1963; Fournier & Oakley, 2018) where it tends to be assimilated into a dominant health care paradigm (Hollenberg & Muzzin, 2010; Singer & Fisher, 2007; Fournier & Oakley, 2018). Within the context of neoliberal, late-stage capitalism sacred knowledges and artifacts tend to be altered, standardized, and commoditized (see Fournier & Oakley, 2019; Lokensgard, 2010; Shiva, 2000; Stewart-Harawira, 2013). Further, the very strengths of Indigenous knowledges, such as infusing spirit into medicine, a relational worldview, sacred plant medicines for healing, as well as teachings that have been passed down since time immemorial may get absorbed or altered if they are not honoured in meaningful ways. Is biomedicine for example, ready to take Indigenous medicines seriously, and incorporate Indigenous knowledges in a fundamental way? Based on my experience with individual biomedical health care providers and colleagues I would say it is not. For example, my own experience of being brushed off by my family doctor when I told him I was seeing an Elder for healing, and his offhand response "that's nice" or when I was asked incredulously by a colleague who is a well-known health care researcher, "do you believe in all that stuff"? shows that epistemic racism and a hierarchy of knowledge with regards to health is alive and well. Additionally, in order to honour and meaningfully incorporate Indigenous medicines not only requires reconciling with the colonial past to which biomedicine was complicit (Kelm, 1999), but also a radical paradigm shift, a major ontological shift and systemic change in the future. In the words of King (2002),

> *[d]espite its general disregard for indigenous health and largely futile efforts in combating infectious disease, Western medicine and public health were [and I would add continue to be] integral parts of the ideology of empire (p. 765).*

These ideologies are still dominant today. Western biomedicine was used as part of a "civilizing mission" during the colonial era on Indigenous Peoples (King, 2002, p. 765;

see also Kelm, 1999). I draw on King (2002) here once again as he states that, the so called, "… medical modernization of native populations, via export of western medical theories and practices, was part of the 'ideology of colonial healing', that justified colonialism as an ultimately humanitarian endeavour" (p. 765). Thus, biomedicine as a tool of colonization, which included the banning of Indigenous ceremonies and medicines in favour of biomedical approaches, was powerful in its ability to shape shift into a humanitarian act, rather than what it helped accomplish, genocide (Kelm, 1999).

Other scholars raise the important point that the integration of Indigenous medicines into formal biomedical institutions in the current context will lead to the contortion and appropriation of Indigenous knowledges and medicines by "the very society that oppressed First Nations Peoples for centuries" (see Cardinal, 2008 p. 20; see also Robbins & Dewar, 2011; Kincheloe, 2006; Dei et al., 2000). King's (2002) argument that the 'language of integration' contributes to rhetoric of inclusivity and medical pluralism that is largely unrealized is also relevant here. As such, how *Etuaptmumk* is operationalized and used in the integration of Indigenous medicines and knowledges into health care is critical for the survival of Indigenous knowledges and keeping spirit central and part of everything.

5.4 *Etuaptmumk* and Health Care: Addressing Health Disparities through "Integration"?

The increasing government funding for integrating Indigenous medicines into health care as part of the response to the TRC calls to action has been criticized as just another way to offload deeper structural problems that contribute to ongoing health disparities, poverty and inequities between Indigenous and non-indigenous peoples in Canada (see Bryant, et al., 2019; Corntassel et al., 2009; Raphael et al., 2020; Loppie-Reading & Wein, 2009). Some scholars even argue that assimilation and the perpetuation of colonial relationships is at the root of recent apologies and TRC calls to action (e.g., Chrisjohn & Wasacase, 2009; Corntassel et al., 2009).

One example of a basic necessity and fundamental building block of health that continues to be under prioritized is many First Nations communities in Canada do not having access to clean water, in large part due to being forced onto reserves close to

where toxic waste is being dumped into local water supplies (Waldron, 2018). Currently, some First Nations communities are being given priority access to vaccines for COVID19 in the name of 'equity', Indigenous rights and preserving Indigenous identity (Grabish, 2020), yet many of these same communities don't have safe water, safe housing or food security. Millions of dollars are being poured into vaccine development, distribution and surveillance, while the material, political, historical and social factors negatively influencing the health of Indigenous peoples continue to be ignored (see Bryant et al., 2019; Greenwood et al., 2015; McCallum & Perry, 2018; Raphael et al., 2020; Loppie-Reading & Wein, 2009).

Health disparities and the impact of the social and structural dynamics of health on Indigenous populations in Canada can be traced back to the history of colonization, and residential schools (Goodman et al., 2017; Czyzewski, 2011; Lavallee, 2009; Loppie-Reading & Wein, 2009), but it is important to remember it isn't only the legacy of colonization that is the issue here but ongoing marginalization, oppression, and structural violence due to many forms of racism that continue to exist today. Many studies show that poverty has a significant impact on health, costing the health care system vast amounts of money, and that health care spending on pharmaceuticals for example, could be decreased drastically by focusing instead on addressing social inequalities and poverty on a structural and practical level (e.g., Bryant et al., 2019; Castro & Singer, 2004; Kurtz et al., 2013; Leys, 2010; Raphael et al., 2020; Navarro, 1976, 2007). In this regard we have the scientific 'evidence base 'that social and structural factors have a major impact on health and disease outcomes, yet this knowledge is not integrated into policy change, initiatives or health care practice (Bryant et al., 2019). Instead, biomedicine and health care continue to become increasingly pharmaceuticalized, technologized, and shaped by these profit-based industries (Navarro, 2007; Sunder Rajan, 2007; Scheper-Hughes, 1993).

5.5 Continued Racism and Discrimination in Health Care

Many Indigenous Peoples in Canada face overt and covert forms of racism and discrimination within the health care system (Adelson, 2005; Allen & Smylie, 2015; Goodman et al., 2017; McCallum & Perry, 2018; Richardson & Crawford, 2020). In fact,

there are many documented cases of negligence and abuse that have led to unnecessary death, due to treatment delays, because the health care provider assumed the patient was drunk or just wanting pain medication (Burns-Pieper, 2020). This both contributes to further oppression and trauma and deters many Indigenous peoples from seeking out formal medical care in the first instance. Racism and discrimination are major ongoing social and structural dynamics of health that profoundly impact Indigenous and other racialized Peoples (Metzl & Hansen, 2014) and these issues need to be addressed.

There is a growing awareness that the poor health of Indigenous peoples is not going to be successfully addressed by western biomedicine alone (Maar & Shawande, 2010). Western biomedicine tends towards a reductionist and mechanical view of disease, and the body, and is not fundamentally oriented towards a wholistic paradigm of health, a framework in which many Indigenous understandings of health and illness are rooted (Manitowabe & Shawande, 2013; Martin-Hill, 2003). This creates discord between ways of conceptualizing and managing disease and is also part of a deeper pattern of epistemic and racism embedded within biomedicine (Mathews, 2019).

Many Indigenous Peoples are affected by social exclusion in the realm of health care, due to cultural discord between biomedical and Indigenous understandings of a particular illness or condition as well as cultural safety (Goodman et al., 2017). The differences between biomedicine and Indigenous healing may also be felt and experienced more profoundly by those for whom ceremony is integral to their way of life (Fournier & Oakley, 2019). As a result of colonization and efforts to suppress Indigenous culture, tradition and spirituality many healing practices, that had kept Indigenous peoples healthy since time immemorial, have been lost, but for those that did lose connection many are reviving some of these lost ceremonies and connecting with them again.

Recently, largely in response to the TRC, multiple calls have proliferated to explore how Indigenous healing differs from biomedicine, and the need to examine how best to incorporate Indigenous medicines and knowledges into biomedical contexts (e.g., Allen et al., 2020; Benoit et al., 2003, Hollenberg & Muzzin, 2010, Manitowabe & Shawande, 2013; Martin, 2012; Robinson et al., 2017; Sylliboy & Hovey, 2020; Waldron, 2010), and even whether we should at all (Watts, 2016). Many of these studies engage

with *Etuaptmumk* as a framework (see Forbes et al., 2020; Iwama et al., 2009; Wright et al., 2019).

5.6 Indigenous – Western Binaries: Loosening and Tightening Boundaries

In this next section I examine how the ways in which *Etuaptmumk* tends to be taken up may end up reinforcing what some scholars call a false binary between 'Indigenous 'and 'Western' (Dei, 2002; McEwan, 2009), which may inadvertently lead to fossilizing or oversimplifying the very nature of Indigenous knowledges. We must remember that [t]raditional knowledge is living knowledge" (Stewart-Harawira, 2013, p. 75; see also Urion, 1999). How *Etuaptmumk* tends to be taken up may also obscure the deepening impact of capitalist and neoliberal ideologies on the production and contortion of knowledges, particularly in the realm of health care (King, 2002; Navarro, 2007; Castro & Singer, 2004; Stewart-Harawira, 2013).

In general, Indigenous knowledges tend to be based on relationships with surrounding environments (Basso, 1979; Dei, 2002) and as Dei argues they are the "…direct experience of nature and its relationship with the social world. It is knowledge that is crucial for the survival of society" (2002, pg. 5) and our mother, the earth (see also Deloria, 1999). As such, given the very nature of our relationship with the social and natural worlds, knowledges are dynamic, influenced by various forces, and by their very nature fluid, continually evolving and adaptable (Deloria, 1999). As such we need to highlight and draw attention to the ways that Indigenous knowledges are different and because they are intricately entwined with the natural and spirit world they also need to be protected, in particular from the forces of neoliberal and capitalist ideologies and influences, our survival may even depend on it (Wildcat, 2009). For example, if the "best" of 'Indigenous' and 'Western 'knowledges are brought together, the tensions between them merely smoothed out, Indigenous knowledges may be further absorbed into dominant ways of thinking that are increasingly and insidiously shaped by neoliberal and capitalist ideologies (Hickel & Khan, 2012). Within neoliberal and capitalist frameworks, individualistic behavioural models of health reign, and expanding the global market at the expense of the broader community (including all life forms) is considered the most important goal (Coburn et al., 1983; Coburn & Navarro, 2015; Navarro, 1976, 2007;

Singer & Baer, 1995). Arguably, collectivity, relationality and spirit, all of which tend to be integral qualities of Indigenous worldviews, in such a context would not be considered strengths as these perspectives threaten the very foundation of neoliberal individualist perspectives, including the focus on the extraction of natural resources for profit. The nature of biomedicine has become embedded within the profit driven "medical-industrial complex" (Singer & Baer, 1995, pg. 66; see also McKenna, 2012) and is thus continually searching for expanding markets and increased profit (Sunder Rajan, 2007), just as the mining industry looks for more places to extract minerals from the earth. Biomedicine has also become interconnected with multi-national corporations, such as the pharmaceutical industry (Sunder Rajan, 2007), and insurance companies, both of which have tremendous political and economic influence (Singer & Baer, 1995) and an increasing interest in Indigenous knowledges (Gautam et al., 2003). The pharmaceutical industry's interest in plant derived and herbal medicines, for example, has grown exponentially over the last few years (World Bank, 2004; Gautam et al, 2003). Furthermore, it needs to be highlighted that biomedicine is not politically, culturally, or economically neutral. Biomedicine is the product of Eurocentric perspectives and ontologies and structural forces, both internal and external to biomedicine, and as such they are hard to 'tease 'out (McKenna, 2012, 2021; Navarro, 1976). As Navarro (1976) suggests, external social, economic and political forces have increasing influence on biomedicine, and biomedicine is part of a "larger social formation – society" (p. viii), largely governed by class relations and "contemporary capitalism" (p. viii). All these factors are suggestive of the level of contortion Indigenous knowledges, and medicines may undergo as they are integrated into health care. As such we need to ask who and what forces would influence what is considered a strength of biomedicine, and what would the biomedical-industrial-complex be willing to forsake to create space for Indigenous knowledges and views? As well, who would decide what the strengths of Indigenous knowledges and medicines are in this context, and how they are utilized?

Neoliberal and capitalistic ways of thinking are seeping into and shaping more and more aspects of our lives in insidious ways (Fisher, 2009, 2013; Hickel & Khan, 2012; Stewart-Harawira, 2013). Further as Hickel and Khan (2012) assert capitalist and neoliberal ideologies have even absorbed into our resistance to them, shaping the

resistance to them. Indigenous knowledges as a form of resistance against colonialism, capitalism and hegemonic worldviews are vulnerable to this as well (Fournier & Oakley, 2018, 2019). Knowledges are fluid, their boundaries permeable, and non-dominant worldviews, and ways of living out our lives are vulnerable to these forces. As such we need to scrutinize and unpack who is making the decisions about what is the 'best' of Indigenous knowledges, and why, if the strengths of each are merged. It would also require an awareness of the ways that capitalist and neoliberal ideologies are predatorial, absorbing what seeks to resist them (Hickel & Khan, 2012).

In the next section I focus on the differences between 'Indigenous 'and 'Western ' knowledges as a starting point (see Appiah, 2016) for exposing how Eurocentric forms of knowledge are valued and legitimated over Indigenous knowledges. In other words, rather than merely integrating these forms of knowledge into health care, we need to first honour the spaces of tension between knowledges and perspectives to generate new ways of doing health care. Further below, I explore these ideas through my own experiences of using Indigenous forms of healing and ceremonies as well as biomedical forms of care from an embodied/sensory perspective as a case study.

5.7 False Binaries, Nuance and Liminal Spaces

As a means to protect Indigenous knowledges, in this section I propose a *Etuaptmumk* framework that highlights it anti-colonial nature, so that it is purposefully informed by anti-colonial theory and critical political economy, an *Etuaptmumk* that is a type of 3rd space (Bhabha, 1994). Bhabha (1994) describes the third space as a space whose,

> *... unity is not found in the sum of its parts, but emerges from the process of opening a third space within which other elements encounter and transform each other. Thus, identity is not the combination, accumulation, fusion or synthesis, but an energy field of different forces" (p. 258).*

This third space allows movement beyond and between polarized notions, "the binary[ied] constructions" (Richardson, 2004, p. 57) of knowledges. This space also can contribute to resistance to assimilation and homogenizing forces (Bhabha, 1994), something we need to continue to resist, as well as heal from; part of this involves

decolonizing our minds and we have all been colonized to some degree towards a worldview influenced by the insidious forces of capitalism and neoliberalism.

5.8 *Etuaptmumk* and Holding Ethical Spaces

Willie Ermine, a Cree scholar (2007) suggests an ethical space, and the need to "… set boundaries that reinforce ethical conduct for the two worldviews to come together in a harmonious way that benefits all" (taken from Forbes et al., 2020, p. 3). The ethical space is similar to *Etuaptmumk* and as Ermine (2007) states it is also "…the thought about diverse societies and the space in between them that contributes to the development of a framework for dialogue between human communities" (p. 193). These liminal spaces are not only potentially generative but can be used to accentuate rather than smooth over tensions between them. Firstly, I would argue that these spaces between worldviews need to be in dialogue through characterizing where they converge and diverge. Conflicting worldviews need to be delineated before they can come together particularly in the realm of health care, a space where there is not only racial discrimination but epistemological racism, which impacts what knowledges are adopted and how Indigenous healing practices are enacted and regulated in biomedical spaces. King's (2002) critique may ring true in this context as well; "the goal is no longer to bring modern Western medicine to [so-called] primitive cultures, but rather to furnish them with Western medical technologies in an effort to foster the integration of underdeveloped nations into the world capitalist economy" (p. 780). As we know biomedicine or biomedical imperialism was a powerful tool of assimilation during the colonial era in Canada (Kelm, 1999) and elsewhere, something which continues today albeit in different and sometimes more hidden forms (King, 2002). Highlighting spaces of tension and resistance to dominant ways of viewing health and health care can be clarified through delineating, and honouring Indigenous knowledges, the impact of colonialism on knowledges and medicines, all of which may help prevent their contortion, assimilation, and erasure into western medicine. This also requires a need to "decolonize" health policy (Castro & Singer, 2004; Fournier & Oakley, 2018; Leys, 2010)

The cooption and exploitation of Indigenous knowledges, such as plant medicines by pharmaceutical companies, for example, has already taken place and the loss of rich

land/place based knowledges that began during the colonial era, knowledges that have been passed down through generations since time immemorial, are in danger of being further exploited and absorbed as a result of the neoliberalism and the focus on the development and infiltration of market relationships (Basso, 1996; Shiva, 2000; Stewart-Harawira, 2013). This could take the form of turning local land-based knowledges into commercialized medical, ecological, and agricultural knowledges and marketable products (see Gautam et al., 2003; Shiva, 2000). In the realm of academic research, Stewart-Harawira (2013) argues that the focus is on "promoting markets and private-public or Indigenous-industry partnerships" (p.40), as well as the knowledge economy. The market is a powerful knowledge shaper (Adams, 2002; Stewart-Harawira, 2013), a shape shifter. One recent example of appropriation of cultural practices for profit with regards to Indigenous medicines and ceremonies is you can now purchase a smudge kit from big box stores like Walmart or Sephora. The words of Nakata (2002), a Torres Strait Islander scholar trying to address concerns about the appropriation and commodification of Indigenous knowledges for profitable products are important here,

> *[w]hilst Indigenous peoples might welcome the elevation of status that comes with increased recognition of their Knowledge systems after centuries of dismissal and disintegration, nothing comes without a cost. Like colonization, the Indigenous Knowledge enterprise seems to have everything and nothing to do with us (p. 282).*

As research continues to expand in relation to Indigenous knowledges these knowledges are stored in information databases located in academic institutions (Nakata, 2002, p. 282), and regardless of whether Indigenous communities also own them or not, they are vulnerable once institutionalized.

Sociologists Singer and Fisher (2007) also raise concerns about the cooptation of traditional medicine knowledges by biomedicine calling it a "tactical strategy to preserve biomedical dominance through control of the knowledge base of 'other 'medicines" (p. 18), then calling these practices "traditional, complementary and alternative medicine" (see Fournier & Oakley, 2018), complementary and alternative to biomedicine, which further establishes its dominance (Fournier & Oakley, 2018). Singer and Fisher (2007) go on to say that the integration of traditional medicine into biomedicine is a "double edge

sword" which may contribute simultaneously to increased legitimization of Indigenous knowledges and the potential to undermine these practices if biomedicine remains the central tenet from which all else is measured and legitimated (see also Adams, 2002; Hollenberg & Muzzin, 2010). True pluralism would require a genuine uniting of the strengths of Western and Indigenous knowledges, and would also need biomedical dominance to be deconstructed, and rebuilt in a way that honoured and equally integrated Indigenous knowledges and medicines without profit being the bottom line, which seems unlikely at this point in history (Giroux & Searles-Giroux, 2008).

5.9 Unity and *Etuaptmumk*: Is there Space in Biomedical Health Care?

As a unifying principle/narrative *Etuaptmumk* is an important guiding principle and framework for understanding and potentially navigating tensions between Indigenous and Western knowledges/medicines in the context of health care. However, focus needs to remain on how it is taken up, as noted above, as it may inadvertently end up concealing the ways health and healthcare in Canada are increasingly shaped by industry and profit (Navarro, 1976; Panitch & Leys, 2010). Fundamental changes need to take place to put resources where they are needed for preventative and curative service, based on actual lived experience.

Further, it isn't just epistemological or ontological tensions that require attention but also very real material tensions that impact many Indigenous communities as a result of colonialism and the brutal assimilationist tactics used by the state that forced Indigenous Peoples to adapt to euro-western ways of life. Euro-western ways of life are more and more impacted by market capitalism and neoliberal ideologies that can't be changed by merely changing our perspectives. Not to mention the underlying reasons for colonization in the first place, access to land and resources; to extract and profit from the earth (see Shiva, 2000). This includes current and ongoing battles over access to land and water, despite Treaties made in good faith. Many of these Treaties are not being honoured by the state or are being manipulated and overthrown once again for access to resource rich land (i.e., pipelines). These are all examples of the violent ways that colonialism's many assimilationist strategies have obliterated, devalued, absorbed indigenous lives, ways of knowing and being already. Is there really a will to change this now?

5.10 Western? Indigenous?

Leroy Little Bear (2000), a Cree scholar who advocates for the collaboration of Indigenous and western science states that, "the problem with colonization is that it tries to maintain a singular social order by means of force and law, suppressing the diversity of human worldviews" (p. 77). Differing worldviews are suppressed for a variety of reasons, such as ingrained economic and structural factors. Neoliberal capitalism for example doesn't fit in with relational worldviews, and it has already infiltrated modern western science and biomedicine (Baronov, 2008; Baer et al., 2013; Grøsneth & Oakley, 2007; McKenna, 2012, 2021; Navarro, 2020). Biomedicine aligns well with capitalist ideology, with its focus on microscopic pathogens as the cause of disease, as it exonerates socio-economic disparities as a health determinant (Baronov, 2008; Baer, Singer & Susser, 2013; McKenna, 2012). David Baronov (2008) even bluntly states, the "scientific content of biomedicine is linked to the interests of industrial capitalism" (p. 246). Biomedicine and capitalism are already intricately and deeply enmeshed, and hard to disentangle (McKenna, 2012; Navarro, 1976, 2007).

To illustrate, many metaphors in biomedicine are reflective of industrialism and economic organization (Martin, 2001). This is evocative of the myriad ways in which biomedicine fits in with capitalist and neoliberal ideologies; for example, the body is seen as a machine that when sick needs fixing (Martin, 2001), or medicating, in order for 'it 'to 'get back to work'. Further, biomedicine tends towards focusing on separate body parts, and technological interventions. Alternatively, Indigenous medicines and healing practices tend to be based on a wholistic view of health, which considers the physical, social, and spiritual realms of health and healing. In many Indigenous worldviews, life and nature are understood as being interrelated and this interrelationship cannot be disentangled (Little Bear, 2000). How Indigenous medicines are integrated within biomedical settings will then require careful negotiation of these fundamental differences to ensure the integrity of Indigenous wholistic and relational paradigms.

However, Leroy Little Bear (2000) insists that focusing on the differences between Indigenous and Western knowledge given embedded knowledge hierarchies in the realm of science creates further "oppression and discrimination" for the non-dominant form of knowledge (pg. 77), and that this has been a form of social control used against

Indigenous communities. Instead of challenging the underlying political and economic forces that reinforce colonialism, how *Etuaptmumk* tends to be operationalized, may inadvertently contribute to maintaining the status quo and ignoring the impact of the Indian Act on assimilation in Canada today. As such learning to see the strengths of both may not benefit all, but rather a wealthy and dominant few.

Conversely some scholars argue that *Etuaptmumk* allows space for seeing with one eye our colonized thinking and with the other the possibilities of setting our thinking free, of seeing beyond colonized thinking (Bartlett, 2005; Bartlett, Marshal & Marshall, 2015), to not just integrate different worldviews, but to help decolonize our thinking and our 'gaze'. Using *Etuaptmumk* as a framework for our own internal processes of thinking about the world and why we tend to perceive the world and feel the way we do might prove valuable for untangling western euro-centric thinking, and the power capitalist and neoliberal ideologies have on our minds (Dei & Kempf, 2006). Canada's history of colonization and assimilation impact us today and if we don't fight back with more than our perception we will just continue to allow for the state and the powers that be to steal land for profit for the few and continue to allow corporations to majorly impact health care (Navarro, 2020). Change requires more than a mind shift. We need to use our minds to imagine and enact transformation, for example, lobbying to remove the Indian Act, which McGuire and Palys (2020) call the "colonial straight jacket", and reclaiming land; taking it out of the hands of the state, corporations and ultimately away from the grip of industrial capitalism.

5.11 Joining Hands: *Etuaptmumk*, Anti-Colonialism, and Critical Political Economy

Anti-colonial theory challenges euro-centric discourses (Chilisa, 2019; Dei & Kempf, 2006) and highlighting anti-colonial theory and the inherent anti-colonial nature of *Etuaptmumk* provides a lens that takes into consideration the complexities noted above for examining and understanding the world. Tuck and MacKenzie (2015) state that anti-colonial theory refutes "the centrality of colonialism as primary in the configuration of indigeneity" (p. 130). This is crucial to keep in mind as "colonialism seeks to impose the will of one people on another, and to use the resources of the imposed people for the benefit of the imposer (Dei & Kempf, 2006, p. ix). Decentralizing settlers/colonizers (see

also Tuck & Yang, 2012), and placing our 'gaze 'on those elements of culture and identity that are not completely overtaken is key. Colonized peoples, such as Indigenous Peoples in Canada, are not merely defined by colonialism, we have more resilience than the colonizers could have ever imagined. Indigenous Peoples have found ways to appreciate, maintain and reclaim some aspects of cultural identity through beliefs and ceremonies that could not be stripped away completely, despite all efforts to annihilate them in the past. Yet understanding a collective colonial past "is significant in pursuing political resistance" (Dei & Kempf, 2006, p. 1; see also Tuck & Yang, 2012).

It is difficult to refute or resist that which has become internalized and rendered almost invisible. Hernandez-Wolf (2013) argues that it has become difficult to challenge euro-centric worldviews and ways of thinking, and to decolonize our minds even with theories such as anti-colonial theory, as anti-colonial thinking has been influenced by "the same theories it criticizes" (p. 30). As she asserts, "we are all victims of modernity" (2013, p. 29), we have all been colonized to one degree or another, and from various positions, of power and privilege (Dei & Kempf, 2006). We are all also impacted by capitalism and the exploitation and destruction of the very environment we live in; our air, land and water bear the burden of the market capitalist relentless pursuit of profit in the name of modernity and increasing economic gain for fewer and fewer people (Giroux & Searles-Giroux, 2008). Neoliberal and capitalist ideologies have also infiltrated more and more aspects of our lives, our thinking, and worldviews (Giroux, 2005, 2010). Yet ultimately, we all share and need the air, water, and land to survive.

5.12 *Etuaptmumk* in the Realm of Health and Health Care

Taking the example of COVID19, in this instance, forms of Indigenous medicines are being relegated to the sidelines as not only unable to help with COVID19, but many healing ceremonies have been cancelled as they are seen as mere potential vectors of infectious disease spread. In this brief example, which I will address in more detail in the next chapter there is no space to even begin to explore the strengths of Indigenous medicines and healing. The knowledges and perspectives about COVID19 that are permitted in the public and social media platforms are under heavy surveillance. In the context of COVID 19 there is less and less space for discussion and anything that

challenges the dominant biomedical narrative as the only legitimate account of the virus, namely the germ theory of disease, is dismissed (Bavli et al., 2020; Manderson & Levine, 2020). There is less and less space to address the weaknesses of biomedicine in this instance, such as how it divorces germs from the broader social and political context (see Kelton, 2007, 2015), contexts that we know profoundly impact our health perhaps even more than a virus ever could on its own (Bryant et al., 2019; Greenwood et al., 2015). Furthermore, not only has the biomedical narrative dominated how we understand COVID19, but it has also been prioritized over other illnesses. For instance, cancer has taken a back seat, with surgeries cancelled, cancer surveillance and screening delayed (Lai et al., 2020) and in-person appointments deemed unessential now done on the phone or via a virtual video platform. In my case, all my follow up appointments, which occur every 3 months are over the phone, there is no in person contact with the oncologist, no clinical palpation assessment that used to be done and my six-month CT scans have been delayed twice. The personal contact with the oncologist, something that I found comforting and reassuring in the past, is now just a quick phone call, where she asks a few questions, and that's it.

Western medicine is a heavily protected industry, and in the case of both cancer and the germ theory, refuses to meaningfully consider the ways that colonialism and colonial processes continue to be a major social/structural determinant of health (see Bryant et al., 2019; Manitowabi & Maar, 2018; Metzl & Hansen, 2014). In biomedicine the tendency is to reduce disease down to the molecular level rather than having a focus on both the macro and micro levels. Indigenous knowledges in general tend towards a wholistic macro level. COVID19 is reduced to a virus gone rogue, mutating out of control. In the case of cancer, it is reduced to cells gone haywire and proliferating out of control. There are fewer and fewer permissible public and social media spaces where the strengths of Indigenous medicine/knowledges could even be explored these days. As well, as discussed above, COVID19 restrictions have many other costs on health and mortality rates from cancer that have only just begun to surface (see Hogan & Glanz, 2020; Lai et al., 2020; Moraliyage et al., 2020).

5.13 Creating Space for the Sacred

With or without COVID19, in cancer care within the hospital setting, Indigenous knowledges are habitually relegated to the sidelines if they are recognized at all. Many Ontario hospitals now have smudging protocols in place, but other forms of ceremony or Indigenous knowledges are not integrated in any meaningful way at this point (Watts, 2016). Further, my own experience of not feeling safe enough to ask to smudge or take out my drum or rattle in the oncology waiting room illustrates how difficult it might be for Indigenous Peoples to ask for access to smudging or to take up space with ceremony. In these contexts, Indigenous knowledges, ceremonies, and medicines are largely invisible, disregarded, and even further they may be regarded as dangerous. If someone decides for example to forego chemotherapy, and instead uses Indigenous medicine approaches they may be considered mentally unfit, immoral or at the least, irresponsible. In one example in the media, the family of a girl who refused chemotherapy and instead used Indigenous healing was investigated by child welfare services (Walker, 2015). On the *Canadian Cancer Society* website, they call Indigenous healing a form of 'complementary therapy'. They clearly state their position on Indigenous healing and cancer,

> *There is no evidence at this time that Indigenous traditional healing can treat cancer itself. Some research suggests that Indigenous traditional healing gives strong psychological, emotional and spiritual support to people living with cancer. People who are part of traditional healing rituals and ceremonies may feel a powerful connection with their community and the earth. Stress, anxiety and depression can be eased with the feelings of support and acceptance… There is very little research on the effectiveness of Aboriginal traditional healing methods (Canadian Cancer Society, n.d).*

This quote illustrates the dismissiveness and paternalistic view of biomedicine in relation to cancer care. There is no overt recognition in biomedicine that acknowledges the causes of cancer that lie in environmental degradation from toxic dumping and resource extraction, and the pouring of carcinogens into our earth and water (Lutdke, 2008), particularly in areas where Indigenous Peoples and other racialized groups live (Waldron,

2018). Given these factors, would there be space for honouring Indigenous knowledges within the *Etuaptmumk* framework when it came down to making changes?

Drawing on my own experience, one of the first things my Healer said to me in relation to cancer is that biomedicine strips the spirit from everything. It focuses instead on our physiological bodies as separate units and instead of infusing or taking care of spirit, it erases it. They said that cancer itself was a spirit, and that I needed to negotiate with it, to learn to live together, not wage a war against it. This is one of the key perspectives that I try to live by, particularly when I feel scared or when I must wait for test results. This way of understanding cancer for example, is what I believe is one of the strengths of Indigenous healing and a major difference in how cancer is understood between biomedicine and many Indigenous ways of understanding cancer. As noted in earlier sections of this dissertation, this perspective, one that I firmly believe in is not something I would share with any of the physicians I see. I compartmentalize my care and my inner perspectives to avoid ridicule, or discussions about whether I really believe in "all that stuff."

Based on my experience with cancer while also considering that the cause of many cancers is related to toxic chemicals in our environment and food chain, one of the strengths of biomedicine is its effectiveness in treating acute conditions. I also find the post cancer surveillance reassuring to me however this is partly because I struggle to trust my body once again due to the trauma of my biomedical cancer diagnosis and my particular experience. My body within a biomedical paradigm is now considered a problematic body, one that can't be trusted, one that must remain under technological surveillance. This is not to say that technologies and procedures that can identify a disease such as cancer before it spreads throughout the body are not important. However, one could argue that some aspects of modern medicine are a response to changes in our relationship to nature. New issues and needs are caused by things like environmental toxins leading to cancer, or so-called novel viruses that have become more virulent because of the impact of industry on nature and biomes. The medical-industrial-complex can be seen as a machine that feeds itself in effect ,as it creates a need for new technologies to manage diseases created by the environmental destruction waged on the earth for profit, which in turn creates more markets and need for such technologies. Many

types of diseases and cancers are created by environmental contaminants, such as the pouring of toxic waste into our water, earth, and air and then more resources are poured into developing highly profitable pharmaceuticals and technologies to treat such diseases. It is a vicious cycle, that needs to be redirected. Using my case study of having cancer, including leading up to the diagnosis, I felt the strengths of biomedicine are in large part its ability to see images beneath the surface of what is happening in our bodies, identify disease and then cut it out, dissect it and place it under a microscope to diagnose it and not the consideration of a social, environmental and political factors that have major and often direct impact on our health.

I argue based on my lived experience that there are many strengths of Indigenous healing and ceremonies. I experienced seeing the Healer, the ceremonies, and the medicines as much more than just a modality or something that I *take* or am just involved with. The medicines and the ceremonies are part of wholistic embodied experiences that can't and shouldn't be teased apart because that is one of their fundamental strengths. Indigenous healing, medicines, and knowledges are part of integrated, complex and nuanced networks and relationships, and a sense of belonging to community. The sensual and spiritual experiences of the ceremonies were all healing, for example, the texture of the bear pelt described in the last chapter, the impact the spirit of the bear had on me, the sense of feeling connected to a larger collective beyond this physical realm, the taste and smell of sacred medicines, the heat of the sweat, the prayers and drumming, and all of it as part of a whole is healing. It is not possible to break it down into smaller pieces. Actually, breaking them down or reducing them into compartments would be a form of contortion and assimilation into a biomedical paradigm. The forms of Indigenous healing I have experienced are intricately and fundamentally connected, and the actual ceremonies and relationships with the Healer are all integral to the experience, all interconnected; that is what makes them so powerful in my experience.

In biomedicine, a cancer diagnosis is placed into the biomedical assembly line of treatment protocols, its management set in motion based on the cancer's cellular level characteristics. Instead of being seen as a whole person, the patient is viewed/treated more like a mechanical body, broken down into diseased parts such as healthy and unhealthy cells, diseased and healthy organs, that are alienated from one's whole "self"

(Broom & Tovey, 2007; Grøsneth, 2014). Further, not only is our body, mind, and spirit not considered part of a unified whole but during the clinical encounter; we tend to also be stripped from our physical and social environment as well (Grøsneth, 2014; Ho, 2011).

5.14 Holding Space for *Etuaptmumk*

Etuaptmumk has tremendous value and potential, however the way it tends to be operationalized oversimplifies colonialism, 'Indigenous-settler 'relations and the impact of capitalism on knowledge, knowledge production and its translation. To be more specific *Etuaptmumk* is complicated by colonialism, western hegemony, and the influence of neoliberal capitalism on mainstream science, referred to by some scholars, as science under capitalism, and even pseudo-science (Jessop, 2018; McKenna, 2010, 2012, 2021; Medevdev, 1999; Nanda, 2001, 2003; Panitch & Leys, 2010; Navarro, 1976, 2007).

It can also be argued that how this framework tends to be taken up reinforces a notion that all we need to do to create change is to change the way we 'see 'things rather than demand that we challenge and transform the status quo (Aikenhead & Ogawa, 2007). Furthermore, Aikenhead and Ogawa (2007) contend that the categories of western and Indigenous knowledges are a false binary/dichotomy, deeply embedded in colonial discourses. They propose instead categories such as "indigenous ways of living with nature", "Eurocentric sciences" and "neo-indigenous ways of living with nature", arguing that these categories more accurately capture the complexities between knowledges than the binary of Indigenous knowledge and western science.

Additionally, as Simpson (2004, in Watts, 2016) points out, Indigenous knowledges are "increasingly becoming a provocative point of accessibility for settler governments and corporations to more expediently gain access to Indigenous lands and resources" (Watts, 2016, p. 161). As such, the taking up of *Etuaptmumk* by health care, government, and private research funding initiatives often, perhaps inadvertently, end up furthering assimilation and the homogenization of knowledges, towards a monolithic worldview under the guise of creating a more inclusive 'multi-world view'. It also negates the impact of colonization, western imperialism, and market capitalism on how knowledges are shaped. A such, how can there be a form of Indigenous knowledge that maintains its value in the face of such forces in such a context. Furthermore, given the

evolving and fluid nature of knowledges themselves and the powerful forces at play in knowledge production an important question needs to be continually asked; how can we protect sacred Indigenous knowledges, particularly if they are integrated into a system and form of medicine that is shaped more and more by industry and something which some scholars even call a form of "pseudo-science" (Grøsneth & Oakley, 2007; Nanda, 2001; McKenna, 2021; Navarro, 2020). I want to reiterate here the importance of querying who decides what is the 'best 'of Indigenous and western forms of knowledge and why? Taking this one step further, we also need to ask, is western knowledge in medicine flexible enough, is there space, and the will to allow other forms of knowledges to shape it in ways that might lead for example to emphasizing technology less in some instances and the human and spiritual side of healing and health more?

Willie Ermine argues that there is huge potential for spaces of engagement between Indigenous and western knowledges (Ermine, 2007) and using *Etuaptmumk* as a way forward. However, this will be hard to realize at this point in time given Canada's brutal colonial history, the extent to which is still being uncovered, and continued health disparities, the continued control over Indigenous lives and land via the Indian Act, the dishonouring of Treaties and resistance against self-governance, as well as the influence of market capitalism on biomedicine. Eurocentric knowledges and perspectives on disease and treatment, as well as the influence of profit-based industries, such as pharmaceutical companies on health care, is also too dominant for there to be an equitable meeting place in the middle for the benefit of all (Hensley, 2019; Hensley & Gerner, 2019; Kitsis, 2011). As such, we need to maintain tensions to create change otherwise Indigenous knowledges and ceremonies risk being watered down, and absorbed, or being merely tokenistically integrated into healthcare. As stated earlier in this chapter we don't just need to see things differently we need to *make* things different, and the sustainable incorporation of "Indigenous health care" services require committed resources backed by policies over the long term.

The binary between Indigenous and western knowledge also negates the array of nuance among "Indigenous" Peoples (Shiva, 2000). Nor does it account for the way western biomedicine and health care reform in Canada is being shaped by neoliberal ideologies, such as the increasing privatization of health care services, and the increasing

influence of the market on health care (Coburn, 2010; Flood & Archibald, 2001; Leys 2010; Navarro & Shi, 2001; Raphael, et al, 2019). Additionally, within each term, "Indigenous" and "western," there is nuance and complexity that must be explored, a need to understand and illuminate the external forces shaping each. There are many ways to see the world and they can never be boiled down to one or two "siloed approaches" (Fournier & Oakley 2019; Waldron, 2010). There are also many ways to be Indigenous, many ways of looking, being and living one's indigeneity that must be honoured so as not to lead to homogenized, pan-indigenous perspectives and forms of knowledge.

Nonetheless, *Etuaptmumk* has the potential to highlight a way of seeing health and health care that includes, for example respecting on equal footing, and incorporating elements of Indigenous ceremony, such as sweats, smudges, drumming, Indigenous knowledges and so on, into biomedical public health care settings such as hospitals and clinics. This would include a recognition that health and illness involve wider social, emotional, biographical, and spiritual spheres, not just a fixation on the physical body. It also requires that different ways of conceptualizing health and disease be accepted into the fold.

Etuaptmumk as a "way" of understanding biomedicine's mind-body dichotomy is generative particularly if we draw attention to rather than obscure some of the tensions between differing perspectives. Orienting to these tensions in this way may serve as a means of protecting Indigenous knowledges and healing ceremonies that are at risk of being assimilated or contorted to fit within the boundaries of biomedical spaces. Cash Ahenakew (2019) summarizes this well,

> *The distinction I propose here between Indigenous and biomedical models of health is pedagogical and strategic. It highlights differences that are often glossed over when there is a strong desire to "move forward," that is, when people engage with Indigenous knowledge systems with the intent to focus on similarities rather than on differences. In a colonial context where the desire for so-called progress has resulted in Indigenous dispossession, destitution, and genocide, it is important to find the time and the stamina to sit with incommensurabilities, dissonances, and tensions before we create a generative space of encounter that does not easily reproduce colonial*

desires, entitlements, and relations (p. 19).

It is becoming increasingly crucial that we work to create and hold space for the sacred in health care in meaningful and profound ways by not washing over tensions between biomedicine and Indigenous knowledges and medicines, but instead accentuating the spaces between, the tensions that can help ensure Indigenous knowledges and medicines are not assimilated into a dominant system of care. Indigenous Peoples should not be subjected to the violence of being treated like strangers on their own land as they navigate the health care system. We need to complicate and honour the nuances within and the generative spaces between knowledges and account for the impact of capitalism and neo-colonialism on knowledge in this information age / knowledge economy. To realize the strengths of Indigenous knowledges and medicines in healthcare requires a sustainable incorporation of "Indigenous healthcare" services and committed resources backed by policies over the long term.

Chapter 6 Is there space for the Sacred in Biomedical Public Health?

In general, [bio]medicine doesn't act on people coercively but through the subtle transformation of everyday knowledge and practice concerning the body... This is how hegemony operates and this is why one encounters such resistance in attempting to challenge notions and relationships… (Scheper-Hughes, 1993, pg. 199).

I am writing this dissertation in the midst of the COVID19 crisis, where the dominance of biomedicine to health and illness is underscored each day in the news. Much like the dominant, reductionist, invasive and essentialized biomedical approach to "treating" cancer, discussed in earlier chapters, the current global health crisis is once again affirming the idea that there is only one legitimate body of knowledge while all others may be suspect (Menderson & Levine, 2020). Over the last year I have witnessed and experienced the transformation of some of the spaces of hope and healing that emerged out of the TRC calls to action in 2015, when I started this doctoral project. The calls to Action focused both on increasing the reach of public healthcare, but also to improving the social and economic determinants of health and incorporating other elements, a few of which have been discussed in other chapters. Furthermore, it is not only spaces for Indigenous sacred medicines and healing that have been created since 2015, that are in my own limited experience transforming, or perhaps put on hold in urban areas especially, but biomedical spaces and access are also being altered or diminishing. Cancer screenings and surveillance are being delayed significantly, surgeries cancelled, hospital and clinic spaces are heavily guarded and shrinking, or have gone virtual (Lai et al, 2020). For example, March since 2020, my oncology appointments have been all done over the phone, cancer screening and my regular surveillance protocols and procedures have been delayed multiple times and the status of my cancer is unclear at this point. At the same time, I am unable to access some of the vital services through my Healer that I explored above, and although I have been fortunate to be able to experience some ceremonies online, these experiences are not the same. Ceremonies, such as the sweat lodge and shake tent that contributed so profoundly to my sense of community belonging (Schiff & Moore, 2006), things that were helping me feel safe, healthy and cancer free are being

cancelled, and there is with no clear sense of any end to this in sight. People are, understandably, doing their best to make the best of a difficult situation (Heck et al., 2021; Richardson & Crawford, 2020). Hence, an important component of this chapter is remembering and honouring past harms that were done via western biomedicine during the colonial era at the hands of the state (Kelm, 1999) and to continue to hold the TRC calls to Action to heart which stated clearly:

Call to Action 22
We call upon those who can effect change within the Canadian health-care system to recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders where requested by Aboriginal patients; (TRC, 2015);

And

Call to Action 48: ii.
Respecting Indigenous peoples' right to self-determination in spiritual matters, including the right to practise, develop, and teach their own spiritual and religious traditions, customs, and ceremonies, consistent with Article 12:1 of the United Nations Declaration on the Rights of Indigenous Peoples. (TRC, 2015).

It is important to remember too that these calls to value Indigenous approaches to building and maintaining health, have deep roots in North America (Battiste & Youngblood Henderson, 2000; Hershman & Campion, 1985; Martin-Hill, 2003; Royal Commission on Aboriginal People, 1996; Tillson, 2002). But it was a very long battle in Canada to culminate with the TRC Calls to Action. Ensuring the old stereotypes don't again take hold to stigmatize or devalue time-trusted, multifaceted and varied, approaches to healing seems a timely and valid concern (Marker, 2004; Robbins & Dewar, 2011; Martin Hill, 2003). It is also important to remember that during the colonial era, Western Imperial medicine was constructed as superior, while Indigenous medicines were degraded as to superstitious quackery and witchcraft (Kelm, 1999; King, 2002).

According to Kelm one of the missions of western medicine was to destroy the trust and prestige 'medicine men' and so-called witch doctors had within Indigenous communities (see also Bodley, 2015; Martin-Hill, 2003). This was done through promoting the alleged superiority of Euro-Canadian medicine, using it as an assimilationist tool that coerced Indigenous Peoples to reject their own cultural healing practices, and the healers themselves (Kelm, 1999; Martin-Hill, 2003). Western medical practitioners helped spread the gospel of "the true nature of disease and death" (Kelm, 1999, p. 105), promising not only relief from disease, but also spiritual salvation. Vincanne Adams (2002) also highlights the ways that western science tends to discredit and even view spiritual practices as criminal among other Indigenous peoples of the world and that this "criminality is invoked by establishing that something uses 'magical' as opposed to 'scientific' reasoning" (p.680; c.f. Archibald, 2006).

The forceful westernization of health practices and banning of Indigenous healing ceremonies during the colonial era, it is claimed, was implemented as part of a 'humanitarian 'mission to bring Indigenous Peoples towards 'progress' for which they should be 'grateful '(Martin-Hill, 2003; Bodley, 2015). Prior to their introduction to western medicine, we have been told, Indigenous Peoples lacked the ability to heal themselves (Bodley, 2015; Kelm, 1999). However, before contact Indigenous Peoples lead relatively healthy lives relying solely on their own medicines (Martin-Hill, 2003; Robbins & Dewar, 2011).

Some forms of Indigenous medicine did survive colonialism, and they survived because they were an integral part of life, health and healing and so they never disappeared completely, they just went underground (e.g., Robbins & Dewar, 2011; Martin-Hill, 2003). For example, as discussed in earlier chapters, in my own family my great Grandfather did healing ceremonies in secret and by doing this he helped keep his family alive. The literature strongly affirms that Indigenous Peoples found a way, despite everything, to engage with Indigenous medicines and integrate them into their lives, despite many of these practices being made illegal (Martin-Hill, 2003). In Canada, the integrity of existing Indigenous healing systems was interrupted when the government outlawed First Nations traditional medical practices and ceremonies. This interruption was mirrored in policies like the amendment to the Indian Act 2 in 1884,

which banned ceremonies, such as the Sundance and the Potlatch (Robbins & Dewar 2011; see also Richardson & Crawford 2020). Kelm (1998) calls engaging in ceremony despite their being made illegal an act of subversive resistance to the colonizing efforts of Indigenous Affairs, and an example of Indigenous Peoples enacting agency in their choices for health care despite the dire situation and oppression (see also Robbins & Dewar, 2011). Kelm (1999) tells us that Indigenous peoples used both western and 'traditional' medicines in ways that were not obvious and had to be carefully negotiated, however it remains that many ceremonies and knowledges have been lost. Kelm (1999) also talks about how settlers used Indigenous medicines for themselves as needed, for example, they used Indigenous midwives and plant-based medicine for tuberculosis when that was all that was available, or when western medicine failed. Additionally, western medicine, through contact, absorbed Indigenous knowledges and practices into its repertoire of care, and many plant-based knowledges became the basis for so-called western scientific medicine discoveries (Hallet al., 2000; Shiva, 2000; Smith, 2012; Martin Hill, 2003), without any recognition or compensation. During this time many Indigenous healers were charged with witchcraft, fraud, and some ceremonies and sacred spaces were raided by police, spaces such as the smokehouse, and ceremonies such as spirit dances, were invaded and stopped (Martin-Hill, 2002; Kelm, 1999). Indigenous Peoples did not blindly and completely adopt western medicine, as there were many instances where it simply didn't work as well as their own. Some even refused western medical care particularly when it included hospital care, as during that time, like now, Indigenous Peoples were not treated well in the hospital, they experienced discrimination, racism, and neglect (Allan & Smylie, 2015; Kelm, 1999; Richardson & Crawford, 2020).

6.1 Then and Now: COVID and the Invocation of Colonial Era

While acknowledging the seriousness of the COVID19 crisis and the urgency of containing the spread of the virus in the present, it is important to also state that colonialism is implicated in diseases such as COVID19, for example, through the extraction of resources that interrupt biodiversity and contribute to climate change (Pongsiri, 2009; Wilkinson et al., 2018; WHO, 2021), and the unequal distribution of wealth and the impact of social and structural factors on people's health (Raphael, et al,

2019; Metzl & Hansen, 2014; Metzl et al., 2020; Smith-Morris, 2020).The social and structural dynamics of health also effect disease ecologies that influence who gets sick with COVID19 and whether they might survive it or die as a result of exposure. Further not only is this current pandemic a concern but there are serious concerns that they might become more frequent and more deadly unless we start to address climate change and decreasing biodiversity (WHO, 2021; UNESCO, 2020).

The specific experience of colonialization under the Indian Act was accompanied by the penetration of Christian missions and biomedicine into Indigenous communities which was instrumental in the expansion of the Euro-Canadian frontier (Kelm, 1999; Laugrand et al., 2014; Robbins & Dewar, 2011). As discussed earlier this happened partially through the construction of imperial biomedicine as superior, while Indigenous ceremonies / medicines were reduced to mere superstitious quackery and/or witchcraft (Kelm, 1999). Likewise in the dominant public COVID19 narrative explored here the voices of Indigenous Peoples and Healers who are exploring the potential of Indigenous medicines to prevent and treat COVID19 are also largely absent in the dominant narrative, as well as those who do not necessarily completely or only adhere to the biomedical germ theory of disease. Furthermore, in some mainstream media platforms such as the CBC (eg. Sterritt, 2020), ceremonies are being portrayed as potentially dangerous disease vectors. In effect this view may contribute to reducing sacred ceremonies such as the sweat lodge or shake tent to mere acts of potential infectious disease spread.

My purpose here is not to discount the germ theory of disease since Science and Technology Studies (e.g. Kabat, 2017; Latour & Woolgar, 1979; Lynch, 2007), History of Medicine studies (e.g. Arnold, 1993, Bashford, 2004; Wailoo, 2001) works) and Medical Anthropology (Adams, 2002; King, 2002; Mol, 2002; Scheper Hughes, 1993) in literature too extensive to fully cite here, have shown the ways that knowledge systems and paradigms of medical knowledge are closely linked to the ideologies of the day in the manner to which scientific knowledge is produced. Here, while pointing to the above well-established literatures, I suggest that in order to address health issues we need to also consider social and economic conditions and their impact on health, and the ways we tackle disease. One among many possible ways is to bring the spirit of *Etuaptmumk*, into

our understandings of some of the ways COVID19 is unfolding. There is a need for a wholistic focus, one that includes not only the important public health measures put in place, such as physical distancing and wearing masks, but also a focus on other forms of prevention or ways to mitigate the severity of COVID19 such as making sure our immune systems are strong, and ensuring everyone has the basic building blocks of health such as access to "…housing, water, food and income security…" (Richardson & Crawford 2020; p. E1098; see also Møller, 2007; Polsky & Gilmour, 2020; Raphael, 2020; Raphael, Bryant & Rioux, 2018). Likewise, it is important to support the array of initiatives in communities to support Elders, knowledges and ways to support communities as they navigate accessing the pandemic to find new ways to be culturally engaged (Richardson & Crawford, 2020; Heck et al., 2021).

It is well established in the literature that 'germs' do not function alone in determining disease spread and severity (Bryant et al., 2019; Butler-Jones & Wong, 2016; Iago, 1954; Kelton, 2007, 2015; Raphael et al, 2019; Richardson, 2020; Stewart, 1968; Seyle, 1956; Greenwood et al., 2015). As such, we need to be careful not to reduce the potential impact of COVID19 on Indigenous Peoples, or anyone else for that matter, to biological determinism as Tuhiwai Smith warned long back (1999; Mann, 2009). There are other factors at play, such as the legacies and traumas of colonialism, which is considered a social determinant of health in itself (see Czyzewski, 2011; Heaton, 2013; Kelton 2006; Richardson & Crawford, 2020), access to safe housing, fear, food security, stress, trauma, as well as critical structural factors such as systemic, epistemic and environmental racism, all of which impact our health (see Kulmann & Richmond, 2011; Greenwood et al., 2015; Metzl et al., 2020; Richmond et al., 2007; Richardson, 2020; Seyle, 1956; Waldron, 2018). Butler-Jones and Wong (2016) remind us that a key factor in infectious diseases that is often overlooked is the interplay between microbes and social determinants or dynamics of health (see also Freeman, 1960; Manderson, 1998; Stewart, 1968). These factors may make some Indigenous Peoples more vulnerable to COVID19 complications and a more severe illness as still many Indigenous Peoples are more impacted by the social and structural dynamics of health.

My experience with COVID19 is also deeply personal as over the last few months, I lost my father to COVID19 complications, and my husband and I recently

recovered from COVID19 ourselves. My grieving is made complicated by the fact that I had to say goodbye to my dad, who died in hospital, through Facetime as I was not allowed to visit. As a result, I missed the sacred time as he transitioned to the spirit world. My father died alone in the hospital without any family or friends around him and this is hard to reconcile with.

It is important to state here that with regards to my father's passing, his overall health and spirits were beginning to decline long before he was diagnosed with COVID19. He lost his livelihood and major source of joy in his life when the lockdowns began, as he used to sing in old age homes six days a week, even at the age of 81. He sang and played guitar and had sing-a-longs with the residents, most of whom had dementia and it was a source of joy for him and the seniors. All his gigs were cancelled over a year ago and subsequently he spent a lot of time alone in his apartment, feeling isolated, watching television. My husband and I noticed a major decline in his overall health and spirits over this last year. My father adhered to all of the public health measures that were meant to protect him but he still got sick. My father spent the last few days of his life in the hospital where he was treated with a number of medications to try to save him, but he died quickly within 10 days as the virus ravaged his body. Isolation was the theme of his last year of life, and his death, and has been a theme for many.

Slogans like "we are all in this together," "The new normal," "Do you part, stay apart" "Social Distancing," "Stay Home" and "No Mask No Service" are permeating the spaces of our daily lives and are discursive ways to motivate people to keep people safe. Also, since these are more homogenous or settler-based mainstream forms of discourse, important efforts are being made towards "indigenizing" COVID19 messaging, and treatment such as translating COVID19 information into Indigenous languages, working towards self-determination and engaging with Indigenous principles, as well as providing trauma informed COVID19 information such as initiatives through different initiatives championed by Indigenous physicians across Canada[11], however, the underlying principle guiding all of these efforts and approaches is that of the germ theory of disease.

[11] See Maad'ookiing Mshkiki — Sharing Medicine program at Women's College Hospital, https://www.womenscollegehospital.ca/research,-education-and-innovation/maadookiing-mshkiki—sharing-medicine

Butler-Jones and Wong, (2016) argue the following,

> *[the germ theory of disease …has led to some important breakthroughs in vaccines and antimicrobials—but also bred complacency. Now, in light of emerging and re-emerging infections and antimicrobial resistance, we know that a unidisciplinary approach to infectious disease control is no longer sufficient and that it is through working with others that we can identify practical ways to address all the factors at play in the emergence and persistence of infectious diseases (p. S1).*

The germ theory of disease, while of course a critical perspective that has revolutionized health and health care on many levels, overrides other conceptions of health and oversimplifies how infectious disease impacts humans and why (Butler-Jones & Wong, 2016; Das, 1990; Kelton, 2007, 2015; Metzl et al., 2020; Patel et al, 2020; Richmond et al., 2007; Richardson, 2020; Smith-Morris, 2020), rather than also giving some weight to disease ecologies (Kelton, 2008). An exclusively biomedical approach to infectious disease, one which focuses only on biomedical prevention measures, testing and treatment approaches has limitations noted by a number of critically engaged and community involved scholars/practitioners (e.g. Anderson et al, 2021; Freeman, 1960; Grygier 1997; Holmes 2013; Horrill et al, 2018; Iago, 1954; Metzl et al.; 2020; Richardson, 2020; Smith-Morris, 2020). As these scholars point out, how infectious diseases play out is entwined with social, political and economic issues and as such it calls for a multi-dimensional approach, one that requires systemic and structural change (see Anderson et al, 2021; Farmer, 1996, 1999, 2000; Lopping-Reading & Wein, 2009; Richmond et al., 2007). Sociologist Miwani (2020) reiterates this point,

> *Aboriginal ill-health was created not just by faceless pathogens but by the colonial policies and practices of the Canadian government." These include the appropriation of land and resources, the denial of sovereignty, the violence of the Indian Act, the coercion of the criminal justice system, and the ongoing racism in health care (p. 1).*

6.2 Biomedical Hegemony, Colonization and the Role of Narrative

The current crisis and the dominant public narrative of risk, prevention, and protocols, as represented in the media, and public health sites is dominated by biomedical, and behavioural models of health that focus on lifestyle changes to curb the spread (Menderson, 1998), and is evocative of the colonial era. Historian Paul Kelton (2007), argues that colonial accounts of the massive death toll from smallpox and other infectious disease impacts on Indigenous Peoples,

> *…created a powerful narrative that gave germs agency in the destruction of Native peoples, blamed the victims for their incompetent response to those germs, and thereby exonerated colonizers from responsibility (p. 10).*

He goes on to say that "colonization and disruption of communities and ways of life altered disease ecologies" (Kelton, 2007, p. 221) and the impact of this was downplayed. In the present context traditional ways of life, healing ceremonies, relationships, and the connection to community that have been altered due to the ongoing impact of colonization have already been altered in a similar fashion.

In order to explore the concerns raised above I use the current COVID19 crisis in relation to representations derived in the mainstream media, national and regional public health websites and the World Health Organization (WHO). I also draw on my own living experience of being cut off from ceremonies that have been crucial in my recovery from cancer. As such I want to state that my experiences may not be applicable to other Indigenous Peoples as we are diverse not just in our identities, ties to the land but also in our ways of life. I use an anti-colonial and critical political economy framework combined with the spirit of *Etuaptmumk* for examining how the implementation of lockdown measures and the policing of COVID19 information might invoke colonization, and the deepening naturalization of Eurocentric biomedical ways of understanding disease in the realm of public health (Lenzer & Brownlee, 2020). It has been suggested by some that how the COVID19 crisis has been handled inadvertently reproduces colonial relations (see Karan & Khan, 2020; Richardson, 2020). Physician and Anthropologist Eugene Richardson (2020) calls public health as a profession and an "academic enterprise" an "apparatus of coloniality" (2020, p. 1). Further, not only might some public health measures reproduce colonial relations and structures of power through their

unequal impact on those already vulnerable to the social and structural impacts of health through loss of work, but also not all people can socially distance if someone in their family gets sick as they just don't have the luxury of space, that others might, if they live in small quarters (Patel et al, 2020). Furthermore, not all people have the luxury of taking time off of work, even if sick, as they may then risk losing their jobs (Patel et al, 2020). In another sense how COVID19 is currently playing out in the media and public health agencies also contributes to silencing the voices of Indigenous Peoples, including Healers who may have differing theories of disease, those that may not adhere to the germ theory of disease or who prefer a more blended approach that does not devalue other knowledges.

6.3 Altering the Sacred

There are no easy answers to this pandemic but its impact on ways of life and the necessary changes it has caused need to be highlighted. For example, spaces for sacred knowledges, medicines and ceremonies that were opening up in various health care settings are in many instances now been moved to the sidelines due to COVID19 restrictions that are meant to help keep us safe. For example, while there are a number of important online support programs for Indigenous Peoples, as well as organizations such as the *Centre for Wise Practices* at a major urban hospital, and the *CCO Indigenous Navigator Program* through Cancer Care Ontario, that are advocating for culturally sensitive and trauma informed COVID19 care for Indigenous Peoples, hospitals that were honouring Indigenous Peoples 'rights to engage in healing ceremonies with family, may now be more difficult to access, due to no visitors policy currently enforced in hospitals. These COVID19 related policies may restrict access to ceremonies that involve more than one or two people, and they may deter people from engaging with them in the first place while in hospitals as they require special permission, which in my experience can be hard to ask for. Further, whether or not certain ceremonies are allowed to occur is largely left to whether current public health measures allow it and the discretion of biomedical health providers (see the Toronto Regional Cancer Program, Indigenous program).

Many Indigenous organizations that provide vital support services to the urban Indigenous community have had to shut down, cancel services or switch to online forums,

which has limitations, not everyone who needs these services has access to reliable wifi, or the needed bandwidth, or they may not have the needed technology. For example, all of the events and programs at the centre where I am an *Oshkaabewis* have gone online for a time, and while continuing these programs virtually is important to provide continuity of support for at risk community members, some of the people they provide crucial support for may not have access to the technologies needed to participate, as access to high-speed internet for remote rural areas and urban Indigenous peoples living in poverty is an ongoing issue.

In the realm of current mainstream public health approaches and lockdown restriction measures, Indigenous knowledges, and perspectives on health as well as the power of Indigenous ceremonies/medicines I would argue, are being undervalued. This could arguably be seen as a form of epistemic racism, something that is connected to the "cultural erosion of Indigenous Peoples as westernized views and knowledge concerning health and well-being are further prioritized, thus dominating and invalidating traditional Indigenous healing practices and customs" (Bourassa et al., 2020, p. 1). While all of these public health measures are important during a pandemic some of their impacts, outside of keeping the public safe at a population level, may contribute to pushing Indigenous perspectives and healing ceremonies for health and healing underground once again (Bourassa et al., 2020). They also might even contribute to the disappearance of sacred knowledges and spaces in health care that are already tenuous, as virtually all non-biomedical perspectives on COVID19, those that challenge the dominant narrative, or differ from the WHO, are under surveillance, particularly in social media platforms and are in some instances being removed (i.e., You Tube, Facebook and Twitter). Lenzer and Brownlee (2020) argue that as a result of policing of knowledge during the COVID19 crisis we may be missing important nuances in ways of understanding health and restricting rather than broadening our approach to health care, by considering other evidence based critical factors that impact our health such as social, and structural dynamics. The typhus scare during WWI and WWII is an interesting precedent (Weindling, 2000) in the health-based criminalization of marginalized peoples and regulation of knowledge that could be kept in mind (Bavli, et al., 2020; Joffe, 2021).

During the colonial era, genocide, via numerous avenues, including altered ecologies due to enforcing altered ways of life, banning of certain ceremonies, and germ warfare, played a key role in decimating Indigenous communities (Kelton, 2007, 2015; Mann, 2009). As such the current COVID19 crisis may invoke intergenerational trauma and blood memory related to colonialism and genocide in Canada for many Indigenous Peoples, and the fear of more Indigenous lives lost, in particular Elders and the sacred knowledges they carry. These factors must be kept in mind as public health measures continue to play out, they need to be considered in COVID19 health care initiatives (Heck et al., 2021).

6.4 Altering and Disappearing the Sacred?

The depiction of traditional Indigenous ceremonies, such as the sweat lodge, in the media and reducing it to being just a possible vector of disease without also considering their potential benefit bring to light how quickly sacred spaces can be altered, framed in derogatory ways, or even erased (King, 2003). For example, in one Canadian Broadcasting Corporation (CBC) report a local public health authority was quoted as cautioning against the sweat lodge by saying that "being in a hot room — surrounded by sweaty people — is the perfect way to spread a virus" (Sterritt, 2020). Not only does this statement show a lack of understanding of what a sweat lodge is, it uses disrespectful language that reduces the sweat lodge ceremony which is sacred to many Indigenous Peoples to "being in a hot room with sweaty people," it negates the healing spiritual element of the sweat lodge, which is an important aspect of health and healing for many Indigenous Peoples. A sweat lodge is not a local bath house, or gym sauna, it is grounded in many Indigenous Peoples spiritual practices and has been in existence since time immemorial. This statement also congers up fear and panic about the sweat lodge being a sure way to spread COVID19, implying that to engage in such a ceremony would be irresponsible and potentially dangerous.

In my own lived experience of carving out and holding sacred spaces while healing from cancer, discussed in detail in previous chapters, I feel like these same spaces of healing and connection I was a part of have now been drastically diminished. I am not denying the importance of the public health measures that have been put in place, my

intention here is to highlight the ways they have impact on multiple levels. Indeed, some ceremonies, as mentioned above have gone virtual due to lockdown measures, which has in some communities has been essential way of maintaining the ceremony. But in my experience, some people are not comfortable having sacred ceremonies held online. I myself have experienced a sense of profound loss every day in multiple ways, particularly through the loss of a sense of connection to a spiritual realm through a collective of women I have built relationships with over the last few years and who have become part of my family, several of whom don't have regular internet access, nor want to take their ceremonies online. In terms of my healing, it, has left me feeling less protected and more vulnerable to cancer returning.

Below is a First Voice excerpt from my cancer journals about an online ceremony I attended a few months ago,

> *I attended a virtual ceremony tonight, on zoom. I saw some of the women I have built relationships with over the last 3 years in the little picture boxes on my screen. We are all stacked in rows on the screen. The Healer who is leading the ceremony is in the middle of the screen and when they speak their image becomes larger. I almost cry seeing everyone as it has been about 9 months now since the lockdown but also seeing them online makes me miss the connection I felt even more in a way. The Healer does the teachings, but while she is speaking the screen freezes, the images she shows are blurry and although it is better than nothing, I feel so disconnected… I want to smell the same sage the Healer is burning. I want to feel our collective energy in the same room, it is powerful. I find it hard to really pay attention, it is too much like watching TV even though the Healer is sharing sacred teachings which I crave. These ceremonies were so important to me the last 3 years, but this one feels like a mirage, not quite real. We try and all drum together and sing but the timing is off, there is a delay so it sounds very unharmonious to me. I am left feeling alone, just one person singing, and drumming to a screen (Fournier, Cancer Journals, June 2020).*

The impact of the pandemic on certain ceremonies highlights how community, belonging, and spirit are all considered extraneous to our health and take a back seat to biomedical perspectives *a priori*. While efforts to maintain ceremonies online are vitally important,

and necessary in some contexts to protect those most vulnerable, I think this also is suggestive of how much our health care system tends to undervalue Indigenous forms of healing and in this sense is not honouring the TRC Calls to Action noted above. Further, online experiences of ceremonies while perhaps better than not having them at all is quite different based on my experience. From a sensory perspective alone ceremonies that are being held online alter the experience, you can't smell the sage, or offer your tobacco in the same way as you can in person for example which may seem like small things in the context of a pandemic but they do have impact.

6.5 Ceremonies are Essential.

Whether in person or online, ceremonies are essential to health for many Indigenous peoples (e.g. Ahenakew, 2019). An Indigenous law student in Saskatchewan, Andre Bear, is fighting to make ceremonies an essential service (see Eneas, 2020). He makes the important yet often forgotten point that for some Indigenous Peoples, telling them they can't do ceremony is like saying to other populations you can't go to the hospital (Eneas, 2020). He also points out some of the similarities between the colonial era banning of ceremonies and the current situation. Some Indigenous Peoples and communities are continuing to engage in ceremonies despite the COVID19 restrictions, however they worry their ceremony will be invaded and forced to stop and that they will get fined, all of which could be traumatic and more so given the history as noted above (Eneas, 2020; see Wolf, 2020). For example, in Saskatchewan the Royal Canadian Mounted Police (RCMP), carrying firearms invaded a local Sundance ceremony being held outdoors and told attendees to shut it down. This example of a police invasion into a sacred ceremony reproduces colonial relations, where during the colonial era authorities in the form of Indian Agents could shut down ceremonies, in this instance another type of state agent, the RCMP was able to shut it down. Andre Bear also reminds us that it is "a lack of understanding due to violent settler colonialism, due to the Indian residential school system, that [is why] we aren't able to comprehend traditional medical practices as essential anymore" (Andre Bear in Eneas, 2020, n.p.). For many Indigenous Peoples, or mixed ancestry people, myself included, ceremony *is* a critical part of health care. As Cash Ahenakew (2011, 2019) points out, the view of Indigenous healing as extraneous, or

not ‘real medicine’ is in contrast to the many peoples, including me, that have witnessed, felt, and embodied the healing power of ceremony (see also Heck et al, 2021).

Ahenakew is underscoring here, that our connection to community and human contact, is also an important health factor, and may even mitigate the risk of germ exposure according to some scholars (see Bryant et al., 2020; Butler-Jones & Wong, 2016; Richardson, 2020; Richmond et al., 2007; Singer, 2016; Stewart, 1968). One thing we know for certain is that social and structural factors have had powerful impact during the COVID19 crisis in who gets sick and who dies. Those that fare the worst tend to be those who are racialized, live in poverty, have insecure housing, insecure food and co-morbidities (Anderson et al, 2021; Bryant et al., 2020; Mykhalovskiy et al., 2020).

6.6 Indigenous Medicines and COVID19 Outside Canada

One notable exception to a strictly biomedical approach to COVID19 is in the Amazon where a group of Indigenous Peoples called the Kokama are favoring ayahuasca over western medical care for COVID19 with positive results so far (Ribeiro, 2020). In this article the author talks about how Indigenous Peoples in this community are seeking out care from shamans and using traditional medicines such as ayahuasca to treat and prevent COVID19 with success. Their confidence in western medicine fell quickly in relation to COVID19 as many people were dying in the hospitals. Ribiero (2020) states that the Indigenous Peoples in this community in the Amazon “have instead turned to traditional medicine and indigenous knowledge to treat the disease, replacing doctors with shamans and Western medicine with ayahuasca, ginger, garlic and lemon. White man’s medicine killed our people” they say (n.p.). This is illustrative of the legacy of colonization and the lingering distrust many Indigenous Peoples around the globe feel about western medicine in general. This mistrust needs to be addressed through open dialogue and respect for other ways of seeing and approaching any illness including COVID19.

However, in another example, the WHO is cautioning against the use of traditional medicines in Africa, saying that they first must be tested using western research methods such as clinical trials. An infectious disease expert in the United States is quoted as saying, “I’ve had to butt heads with traditional medicine men who think they can come out of the blue and claim that they have found a cure for COVID-19…We’re

not going to tolerate that at all" (WHO, 2020, n.p). This is a clear example of the dominance of biomedical perspectives, and an example of reproducing colonial relations and oppressions through western biomedical imperialism (Baronov, 2005) I spoke about earlier in this chapter. This implicit sense of superiority of this particular western trained doctor "not tolerating" any other form of medicine than western biomedicine is also illustrative of how the way the pandemic narratives may lead to furthering the devaluing of Indigenous knowledges and worldviews as they pertain to health if applied without care. Indigenous Peoples have had their own etiologies of disease and used their own medicines for many diseases since time immemorial, yet are now, in many instances, once again being subjected to restrictive western colonial models of approaching health as well as needing western approaches to research for validation of traditional medicines (Adelson, 1998; Waldram, 2000).

It is important to consider folk taxonomies, such as the vast array of diverse Indigenous knowledge perspectives and practices of everyday caregiving, that exist to account for, treat and cope with COVID19. The mainstream response to this pandemic has involved a one-way incursion of biomedical beliefs in a globally homogenized manner, yet there is no current cure for COVID19. Western biomedicine could not, for example, save my father's life. There is a noted absence of information about any folk taxonomies, or the potential of non-biomedical forms of medicine to prevent and even treat COVID19, with some growing exceptions in (see Devpura et al, 2021; Khadka & Khanm 2021; Singh et al, 2021. The WHO has publicly cautioned against the use of traditional herbal medicines for the treatment of COVID19, yet Kelm (1999) describes examples from the colonial era where Indigenous medicines were used to treat disease that colonial doctors could not. Here is one example she notes based on her historical research,

> *In the 1920s and 1930s there was little that white doctors could do for advanced cases of tuberculosis, but the family members of those afflicted would not be defeated by a negative prognosis. A Fort Rupert family returned home from Victoria, having been told that one of their children had only six months to live. Three times every day, the boy's grandmother gave him a dose of oolichan grease and a drink made of alder bark, and within six months he had*

> *improved so much that they decided to take him back to Victoria to see what the doctor had to say. Much to the doctor's amazement, the boy showed no sign of the disease (p. 162).*

And another,

> *The community health representative notes that there is a return to indigenous medicine for illnesses like the common cold that white medicine can do little about. Local Healers use juniper mixed with Labrador tea to take colds away before you know it. 'Heiltsuk people used devil's club, swamp gooseberry, and water hemlock for relief during the Spanish flu epidemic. Gitksan people also used devil's club during the same epidemic. Carrier elder Margaret Gagnon notes that herbal remedies were effective without having the deleterious side-effects associated with non-Native medicine (p. 163).*

These examples, not only illustrate the resilience of Indigenous Peoples during the colonial period where so much was brutally taken, but the extensive diverse knowledges related to medicines in the treatment of infectious diseases. Indigenous medicines do live on, yet much was lost. There are lessons here for the current COVID19 context, not just in terms of honouring and safeguarding sacred knowledges, ceremonies and medicines but also the potential of Indigenous medicines to help treat or prevent COVID19 that may be overlooked.

6.7 Western Biomedical Hegemony as Colonialism

This current COVID19 situation, it could be argued, invokes aspects of the virgin soil hypothesis, Kelton (2007), 2015) analysed in his study of frontier colonialism. While analyzing the colonial frontier era in the US Southeast, Kelton (2015) argues:

> *the "virgin soil" …thesis was not crafted as an apology for the colonizers, and it still has some utility in explaining how history has unfolded. It has, however, unfortunately hidden colonialism's violence under a cloak of biological determinism (p. 33).*

As many scholars confirm, our health is not solely determined by biology, or mere exposure to germs. The impact of social and structural dynamics of health are often washed over (Anderson et al, 2021; Bryant et al., 2019; Kulmann & Richmond, 2011;

Lock & Nguyen, 2018; Patel et al, 2020; Raphael, 2020). Yet, as Kelton (2007) points out,

> *Once infected, the chances of individuals dying from diseases depend considerably on environmental circumstances. Here one needs to look at nongenetic factors that shape the level of health and well-being of host populations. The connection between malnutrition and infection is widely known, as hungry and famine-stricken people are more susceptible to contracting diseases and dying from them. Nutritional and calorie deficiencies retard the immune response and accelerate mortality among infected groups. Similarly, diseases are known to work synergistically with each other; people suffering from one disease have a reduced ability to fight off infection from another germ. A high pathogen load—numerous pre-existing infections compromises the immune systems of victims of new diseases, causing death rates to surpass what would be expected among an otherwise healthy population. Whether host populations maintain access to an appropriate amount of nutritious food and whether they live in a relatively disease-free or disease-filled environment are key questions in understanding their vulnerability (p. 2).*

Further, the rise in infectious diseases and their devastation is influenced by colonial processes, such as the exploitation of the earth's resources, for profit, declines in biodiversity and rising levels of pollution (Jones et al., 2008; Keesing et al., 2010; Villeneuve & Goldberg, 2020). As such, focusing not only on the germ theory of disease, but also addressing climate change, and the destruction of natural world, as well as ensuring people have the basic building blocks of health such as safe and affordable housing, clean water and food, are important public health considerations that should also be considered in mitigating the impact of viruses on those most vulnerable. Singer (2016) states that,

> *[o]ne of the products of the emergence of biopower-driven government or institutional approaches to dealing with people and their problems is that people are thought of and are taught to think of themselves narrowly in terms of their biology and to overlook the broader set of political and economic conditions that*

both diminish the quality of life and the capacity for health (p. 253).

Richardson (2020) confirms that we must interrogate power and its impact on how COVID19 has been handled. He also goes on to say that current public health approaches function to maintain health inequities on a global level through,

> *bourgeois empiricist models of disease causation which serve protected affluence by uncritically reifying inequitable social relations in the modern matrix of colonial power making them appear commonsensical or elevating them to unchangeable facts (Richardson, 2020, p. 1)*

This includes interrogating power relations that contribute to the skewed distribution of wealth on a global and local level, the exploitation of the environment, and the loss of biodiversity, which leave us more vulnerable to virulent microbes (Tollefson, 2020). Billions of dollars are being put into biotechnologies, such as diagnostic testing, and vaccines, yet many First Nations still don't have access to clean water, something which is necessary for basic hygiene measures and COVID19 prevention, not to mention survival[12] (Anderson et al, 2021). During the pandemic we are creating more single use plastics and disposable masks which is causing increasing pollution levels at an alarming rate (Adyel, 2020; Silva et al., 2021). Instead of putting all available resources into biomedical solutions to a complex problem we need to also consider putting some of these resources into making sure everyone has access to clean water, creating more equity in society, addressing the social and structural dynamics of health, and dealing with reversing environmental degradation. Somehow these basic building of blocks are being sidelined.

During the colonial era Indigenous medicines and healing were portrayed as barbaric, and Indigenous Peoples were portrayed as lacking the "proper skills" to treat infectious diseases, or not civilized enough to know better (Kelton, 2007, 2015). Healing ceremonies were described as dangerous. Yet, Kelton (2007) argues it was the forced adaptation to Euro-western ways of life, such as living in more centralized and contained spaces, commercial agriculture and malnutrition that contributed to the spread of smallpox and its death toll on Indigenous Peoples. Some of these ideologies are invoked

[12] see Neskantaga First Nation Still Doesn't Have Clean Water. Clean Water is an Essential Part of COVID Relief https://www.mcgilldaily.com/2021/01/neskantaga-first-nation-still-doesnt-have-clean-water/

today within the COVID19 context. There is only one truth, one treatment and prevention that is considered legitimate. The lockdowns, while an important broad population health measure, may similarly be contributing to forcing a way of life on certain populations, in this instance for some Indigenous populations across Canada. This includes things like being cut off from community gatherings, remaining at home, fearful of going outside, or only venturing out to buy essentials such as food. All of these factors may contribute more profoundly to increasing social dislocation, loss of a sense of community, and exacerbating social exclusion from the wider society amongst many Indigenous Peoples for whom this is integral to their way of life, and who are already at risk of exclusion, alienation and fragmented connections to community due to colonial processes (Heck et al, 2021).

6.12 Stripping away the Sacred: Biomedical Hegemony and the Deepening Technologicalization of Public Health

As suggested here the nature and content of the important public health measures bring to light ongoing aspects of colonization, such as the naturalization of contemporary biomedicine, as a singular and solely legitimate form of knowledge and perspective on infectious disease. This perspective tends to negate the impact of social and structural factors on health (Kulmann & Richmond, 2011; Butler-Jones & Wong, 2016) and the fact that biomedicine itself is multiple and nuanced (Mol, 2002). Since colonial times so called “traditional” medicines, particularly spiritual practices are presumed irrational and superstitious (Adams, 2002; Arnold, 1988; Hollenberg & Muzzin, 2010; Kelm, 1999), and as Adams (2002) argues in some instances even criminalized while biomedicine tends to be essentialized as western, rational, scientific and universalistic. These associations can be deployed as powerful tools of ongoing colonization and assimilation in Canada (Hollenberg & Muzzin, 2010; Kelm, 1999).

The use of mainstream media by those in positions of power in shaping public knowledge, perspectives, and behaviours is well established (Herman & Chomsky, 2002). The allocation of technologies and vast amounts of money for health surveillance and regulation to achieve biopower and govern people, was pointed out long ago by Foucault (1963). In the current context there seems a double jeopardy at play with undoubtedly

important efforts to manage the virus, but some of these resources may be better spent helping to ensure Indigenous Peoples have clean water and safe housing for example. The WHO has coined the term "infodemic for the so-called 'mis' or 'false' information that is present in the public sphere. The WHO has even publicly stated that:

> *[d]ue to the high demand for timely and trustworthy information about 2019-nCoV, WHO technical risk communication and social media teams have been working closely to track and respond to myths and rumours. Through its headquarters in Geneva, its six regional offices and its partners, the Organization is working 24 hours a day to identify the most prevalent rumours that can potentially harm the public's health, such as false prevention measures or cures. These myths are then refuted with evidence-based information. WHO is making public health information and advice on the 2019-nCoV, including myth busters, available on its social media channels (including Weibo, Twitter, Facebook, Instagram, LinkedIn, Pinterest) and website (WHO, 2020).*

Clearly, considerable resources are being put into regulating knowledge circulation that *may* be harmful to public health. But there is a noticeable lack of critical reflection over these measures, a missing dialogue about the impact and meaning of some of these measures. There is also a lack of information about who is deciding what is legitimate information during this crisis particularly as the WHO has given evolving and contradictory information itself (Nagler et al., 2020) as knowledge about this particular virus is changing rapidly day to day. For example, the WHO initially said wearing of masks was not only not useful but potentially harmful, yet are now recommending that everyone wear a mask, and in some regions, mask wearing in indoor and some outdoor public spaces has not only been made mandatory but citizens can be fined by police for not wearing one. In another example, in Canada information about the safety of the COVID19 vaccines, particularly the Astra Zeneca vaccine, the vaccine timelines between the first and second dose, and whether the vaccines are safe for children and pregnant women changes sometimes week to week[13] which has contributed to public mistrust (Latkin et al., 2021) that create new challenges to overcome or for example, how to get

[13] See Constantly changing guidelines are undermining public trust in all vaccineshttps://www.thestar.com/opinion/editorials/2021/03/29/constantly-changing-guidelines-are-undermining-public-trust-in-all-vaccines.html?rf

people who lack trust to enhance their trust.

These restrictive measures towards monitoring and controlling information about COVID19 provides a salient example of what anthropologists Shore and Wright (1997) call "normative claims used to present a particular way of defining a problem and its solution, as if these were the only ones possible, while enforcing closure or silence on other ways of thinking or talking" (p. 3). What is concerning in this instance is the demarcated scope of what are considered legitimate forms of knowledge and information that are allowed to circulate, and how the WHO, biomedical industry and other governing bodies have the power to shape these decisions.[14]

It is important here to consider the influence of capital, namely Big Pharma on public health policy and practice (e.g. Blunt, 2020; Brezis, 2008; Gøtzsche, 2013; Ventegodt, 2015). A cursory look into the WHO website and their funders reveals a large component of their funding comes from powerful industries and foundations connected to Big Pharma. For example, the Bill and Melinda Gates Foundation, which also has ties to the pharmaceutical industry, as well as GAVI Alliance (Global Alliance for Vaccines and Immunisation), are both major contributors to the WHO including their pandemic influenza preparedness response. See chart below as to the breakdown of funding the WHO receives.

[14] see Times article, We Don't Blindly Accept Data.' Top WHO Official Defends the Group's Response to COVID19 https://time.com/5824322/who-coronavirus-response-maria-van-kerkhove/
See also Globe and Mail article, at https://www.theglobeandmail.com/canada/article-canada-shifts-tone-talks-about-critical-need-for-who-review-of/

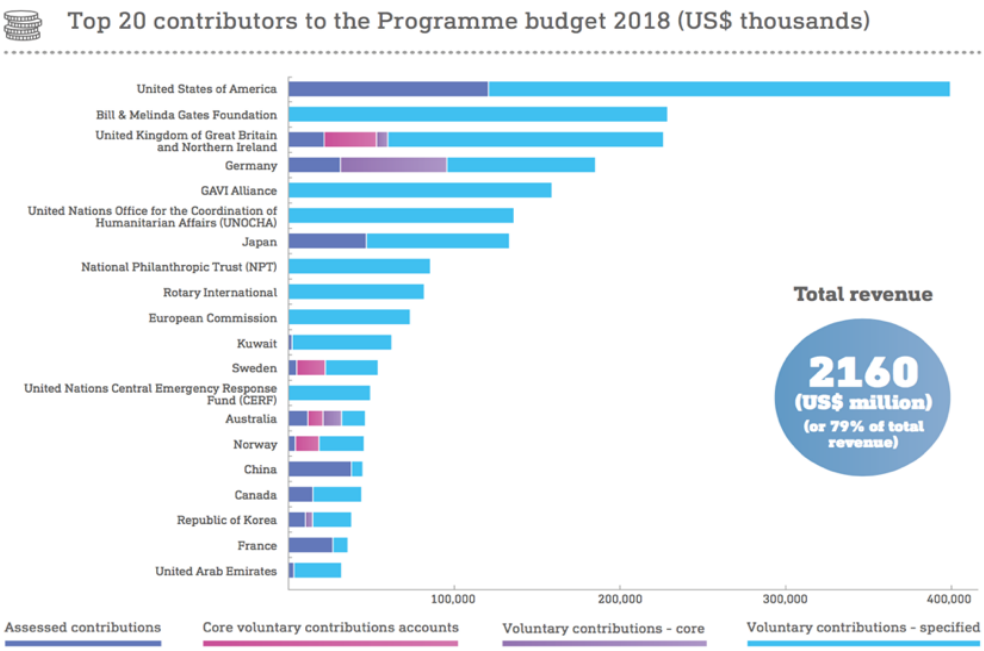


Figure 8 WHO Funding Chart taken from World Economic Forum[15]

Ventegodt (2015) explores how the increase in funding of the WHO from industry has impacted their policies and public health information. They call this the "biggest threat to the world's public health of our time" (p. 1). Ventegodt (2015) explains:

> *Ten years ago the WHO changed its financial policy and allowed private money into its system, instead of only funding from the member states. WHO has since been extremely successful in raising funds and is now receiving more than half of its yearly budget from private sources. Bill Gates has for example given more than one billion dollars to the WHO. The new system of private funding of WHO has brought WHO much closer to the pharmaceutical industry (p. 1).*

This change in funding policy towards allowing more private funding is a source of concern for some scholars (e.g. Blunt, 2020; Gøtzsche, 2013; Ventegodt, 2015). The salient question here is who decides what information can potentially harm the public's health, who is watching the watchdog and what will it mean in the long term for Indigenous

[15] Image taken from: https://www.weforum.org/agenda/2020/04/who-funds-world-health-organization-un-coronavirus-pandemic-covid-trump/

knowledges in Canada? What are the implications for the TRC calls to action 22 and 48 noted at the beginning of this chapter.

6.10 Capital and Coercion?

Bill Gates has been a major voice in the COVID19 crisis, yet he has no medical or public health training. Blunt (2020) says we should be skeptical about his and other billionaire so-called humanitarian motivations for funding COVID19 related initiatives and that we need to ask ourselves, "why so many lives depended upon the munificence of billionaires rather than transparent, accountable and adequately funded public agencies" (pg. 4). The Bill and Melinda Gates Foundation donates 12.8% of the total budget to the WHO, representing the second highest donation next to the United States (*see Figure 8*). The fifth largest funding body is GAVI alliance, a vaccine alliance that is also heavily funded by the Bill and Melinda Gates Foundation.

There is plenty of research on the impact of Big Pharma wining and dining and gift giving on physicians 'prescribing behaviours (see Katz et al., 2003; Every-Palmer & Howick, 2014; Lexchin, 2012), as well as medical education in general (Persaud, 2014), yet the impact of Big Pharma related funding to the WHO is not openly addressed (see Gøtzsche, 2013; Ventegodt, 2015). While these studies focus on individual prescribing behavior, or clinical trial results, it follows that entire organizations such as the WHO, could also be influenced by such funding (Ventegodt, 2015). Is it not naïve to think that large scale industry funding to the WHO and other organizations would not have impact on knowledges, policies and governance (Ventegodt, 2015)? These funding sources are arguably a conflict of interest, as they are known in other contexts to impact research (see Gopakumar, 2015; Resnik & Elliot, 2013), yet they continue seemingly unchecked. It is hard to imagine how the 'legitimate 'information that is allowed to flow from the WHO would not be influenced by these industry players as they stand to benefit from increasing the capacity and reach of western biomedical perspectives (Fournier & Oakley, 2018; Ventegodt, 2015). Arguably COVID19 as it is playing out is accentuating the influence and pervasiveness of the primary selective health care model in shaping health care systems and the technologicalization of health care in Canada in general (Magnussen et al., 2004; Fischer, 2013).

6.11 The Death of Medical Pluralism: A Contemporary Invocation of Colonization?

One of the reasons why the arguments I have made above are important is that the some of the recent public health measures, while important and have the intent to keep people safe, invoke troubling parallels between the early colonial era banning of Indigenous medicines and the devaluing of Indigenous knowledges related to health and approaches to healing that the TRC Articles 22 and 48 were addressing. The dominant voices tend to be from those from the colonial institutions and structures such as public health, the WHO, and WHO funders. There are a growing number of discussions on the potential increased and risk and impact of COVID19 on Indigenous communities in Canada (Levesque & Theriault, 2020), issues related to lack of clean water and how to prevent COVID19 through hand washing (Yellowhead Institute, 2020), and the dangers of having to live in close quarters (Patel et al, 2020; Wong, 2021) which are critical in this context. Other papers highlight how Indigenous communities in Canada have managed to do well in relation to COVID19 and have reportedly low incidence of the virus in their communities due to self-determination and implementing their own strict COVID19 lockdown policies in their own communities (Richardson & Crawford, 2020). These perspectives are crucial, particularly given Canada's history of brutal assimilationist strategies and genocide. Yet, there is still a notable absence of Indigenous perspectives and knowledges related to health, healing and COVID19. Also notably quiet is the potential for Indigenous medicines and ceremonies to contribute fundamentally to health in general. There is little to no discussion in the mainstream media of other ways to prevent the spread of COVID19, such as those based in Indigenous worldviews, or using Indigenous medicines. The focus is almost exclusively on biomedically informed risk reduction behaviors.

Betty Bastian (2004) argues that decolonization 'refers to deconstructing colonial interpretations and analysis of problems that are imposed upon tribal peoples through the process of colonialism' (p. 151). This includes making central Indigenous Peoples' "belief systems and values" (p. 151), even during a health crisis. "The 'colonial consciousness' has been internalized through the indoctrination of Euro-Canadian belief systems and ideologies, through schooling, and literature and other 'knowledge generating systems" (Bastian, 2004, p. 152). This means that in order to decolonize public

health, initiatives would need to integrate the diversity of Indigenous Peoples' belief systems and approaches on health and healing, some of which may be quite different than the dominant biomedical model.

As discussed earlier, in relation to the effects of colonization on health and health systems, Kelm (1998) argues that medicine became a domain where Indigenous Peoples were able to enact resistance to colonization, for example when they refused western medical treatment or practiced Indigenous healing practices in addition to western medical care when faced with the limits of biomedicine. During the colonial era Indigenous healers were sometimes considered by settlers as satanic, whereas use of western medicine was associated with Christianity (Kelm, 1999). Some Indigenous healers were even prosecuted for practicing witchcraft if they used Indigenous methods (Kelm, 1999; Marker, 2004; Martin-Hill, 2003). In the current COVID19 context non-biomedical knowledges, such the use of traditional medicines or the approaches of healers to the coronavirus are also being demonized, and even erased, as they are portrayed as dangerous without even considering their potential (Fofana, 2020; Mian & Khan, 2020). As such this context of the policing of knowledges related to COVID19 that fall outside of the mainstream narrative is potentially circumventing acts of colonial medicine resistance and furthermore may even risk pushing Indigenous knowledges and healing approaches underground again.

6.12 Decolonizing Public Health Care

Current public health care measures are Euro and bio-medicine centric (Keller, 2006; King, 2002; Wynter, 2003). Decolonizing public health care and public health measures requires accounting for the fact that disease, does not exist separately from socio-economic, political, emotional and biographical intergenerational contexts (see Horden and Hsu 2013; Kelton, 2007; Richardson, 2020; Singer, 2016). Fostering and maintaining sense of community and sense of belonging, is vital to our health (Berkman, 1995; House et al., 1988; Ross 2002), as well as biomedical informed public health measures in promoting and maintain health at a population health level. Decolonizing public health measures ultimately requires honouring the rich diversity of Indigenous ontologies, epistemologies, and values, such as seeing health more relationally and wholistically,

including not only spirit, mind, and body, but also the natural and spirit worlds (Affun-Adegbulu & Adegbulu, 2020). This requires "acknowledging that there are many ways of being and doing, unlearning the universality of being and actively engaging with pluriversalities of being" (Affun-Adegbulu & Adegbulu, 2020, p. 1). The TRC Calls to Action affirmed the salience of ceremonies as rights. Unfortunately, in the current context, the vast array of nuanced Indigenous epistemologies and ontologies with regards to health and healing are often tending to be overlooked or erased or judged and devalued by the mainstream media and some public health measures. We also need connection and contact for our health and our very survival, for the health of our spirit, and our whole being, as such I am suggesting that there be a more balanced approach to public health measures that accounts for all of these factors. There are many ways of knowing and doing and we need to create space for non-biomedical and non-eurocentric epistemologies and ontologies to be part of the overall approach to public health considerations and approaches. This requires a paradigm shift that the TRC asked all Canadians to pursue. It means more than just integrating Indigenous knowledges and worldviews into existing frameworks but an ontological shift into how we view health and how health care and crucial public health measures in some instances are enacted. We need to highlight and honour the spaces of tension between biomedicine and Indigenous forms of healing as a form of resistance to ongoing colonial practices and what Graveline (1998) calls "part of the countercurrent of resistance to dominant hegemonic forces in the world" (p. 35).

6.13 Concluding Thoughts

As this chapter illustrates, a more pluralistic or multi-dimensional approach is needed. Sacred spaces and knowledges are, at least in some spaces, media outlets and perhaps most significantly in, urban areas where people are already fragmented from one another, being in some instances altered or made silent in the dominant narrative in favour of a singular biomedical etiology. There is a notable lack of voices from Indigenous worldviews and knowledges that do not adhere to the dominant theory of disease in the realm of public health in Canada. As the COVID19 lockdown restrictions continue into their 2nd year, traditional healing ceremonies and medicines, may be vulnerable for some.

Non-biomedical approaches and cosmologies are in some instances being challenged and even worse are being seen as irresponsible and dangerous without due cause. Importantly as discussed in this chapter we must also bring to the fore the social, political, structural, and economic dynamics that impact our health in profound ways, including how infectious diseases such as COVID19 play out and impact us on a population health, community, family and individual level.

The fact that profitable biomedicine is fraught with limitations comes more starkly into view as this crisis continues into its second year. And as suggested by the Dean of Harvard medical school and college,

> *[w]hen major decisions must be made amid high scientific uncertainty, as is the case with COVID19, we can't afford to silence or demonize professional colleagues with heterodox views. Even worse, we can't allow questions of science, medicine, and public health to become captives of tribalized politics. Today, more than ever, we need vigorous academic debate" (Prasad & Flier, 2020, n.d; see also Lenzer & Brownlee, 2020).*

Once again, we are seeing Indigenous knowledges and ceremonies in some instances being subordinated and, and/or, regulated by the state, and shake tents, sweats, and so on, once again being called into question by a seemingly benevolent[16] government, science and technology that claim to have all the answers. Ceremonies are being cancelled and, in some instances banned for their seeming "risk" and people are being asked to comply with a universal norm of conduct around bodies and homogenized ideas of germs and contagion. The building up of immunity through access to culturally sound practices, plentiful food, decent shelter, and the means to access these, as well as access to education and curative systems when people fall ill (Kelton, 2007, 2015), are getting pushed aside for profitable vaccines and other biomedical technologies.

On the other side of the coin, understandably Indigenous communities fear the demise of Elders and in turn are in some instances by necessity becoming extra

[16] see Lane (1999) for a cogent comparison of the assimilation and governance of the Deaf by an army of non-Deaf healthcare workers, educators, physicians, social workers and so on, to indigenous peoples 1999; Sparrow 2010)

compliant, and extra vigilant within the dominant paradigm of disease causation. With all the work of the past TRC, and the 20 years since the United Nations decade of Indigenous peoples and al the successes made, it appears that the virus may override any interest in installing concepts of the sacred into healthcare. The germ theory wins again, overriding other etiologies of health and illness (Arnold, 1988; Inhorn & Brown, 1990; Leslie &Young, 1992; Dussert, 2010; Lyons, 2010).

As stated above it is not my intention here to downplay the seriousness of COVID19, the importance of public health measure to protect populations, or refute the devastating impact COVID19 is having on diverse Indigenous communities, particularly those that are most vulnerable due to the lack of access to economic and social determinants of health. My goal here is to raise concerns about the increasingly guarded and dominant perspective related to a singular etiological ontology, the impact of the market and capital on western science and biomedicine (Abbasi, 2020; Adams, 2002, 2020; Navarro, 2020; Panitch & Leys, 2010; Grønseth & Oakley, 2007), and to call for a re-opening of spaces by engaging an *Etuaptmumk* lens that considers the impact of colonialism and the market on knowledges and how this public health crisis is being shaped. Further exploration of the pandemic and public health approaches using an expanded *Etuaptmumk* lens could lead to new perspectives and innovations.

Chapter 7 Storying the Epilogue

7.1 Storying Endings, Storying Beginnings

This doctoral study started off as a tidy project that was to explore the creation of culturally safe spaces for Indigenous Peoples at a local hospital. Then life happened, perhaps my ancestors, spirit, had other plans for me. The study transformed into an exploration of my own experiences with the sacred, sacred ceremonies and medicines, healing, as well as biomedical care for cancer. Given the current COVID19 crisis I felt compelled to also include a related discussion into deepening hegemony of biomedicine and reproducing colonial relations in the various neo-colonial public health processes and protocols that are presently governing our lives. The COVID19 crisis has had an impact on my cancer care experiences and screening as well; both biomedical and Indigenous healing spaces have been altered, screenings delayed, oncology appointments and Indigenous ceremonies have gone virtual, not to mention the loss of my father and not being able to see him as he transitioned to the spirit world. I state again also, these experiences are my own and may or may not resonate with anyone else.

What is striking to me is how cancer is not considered a public health crisis that should result in the locking down of industries responsible for poisoning the planet. Based on the Canadian Cancer Society (n.d.) website on average, 228 Canadians died from cancer every day in 2020. It is also estimated that in 2020:

- 115,800 Canadian men diagnosed with cancer and 44,100 men will die from cancer.
- 110,000 Canadian women diagnosed with cancer and 39,300 women will die from cancer.
- On average, 617 Canadians diagnosed with cancer every day.

These are staggering and frightening statistics, yet the focus remains on finding biomedical technologies to “cure” cancer while the many known causes in our environment remain uninvestigated.

My cancer was a long time coming. It began in my family blood line through the impact and lingering toxicity of colonization, poverty, trauma and abuses as well as the increasing toxicity of our natural environment as we continue to extract resources for

profit and leave in its place toxic wastes. As Henri Giroux and Susan Searls-Giroux (2008) remind us,

> *Neoliberalism has become one of the most pervasive and dangerous ideologies of the 21st century. Its pervasiveness is evident not only by its unparalleled influence on the global economy but also by its power to redefine the very nature of politics and sociality. Free market fundamentalism rather than democratic idealism is now the driving force of economics and politics in most of the world. Its logic, moreover, has insinuated itself into every social relationship, such that the specificity of relations between parents and children, doctors and patients, teachers and students has been reduced to that of supplier and customer…Under neoliberalism, everything either is for sale or is plundered for profit (pg. 181).*

It is my intention that this thesis in its entirety embodies the spirit of *Etuaptmumk,* while considering the impact of colonialism, as well as ongoing capitalist and neoliberal ideologies on knowledges and our body/mind/spirit. This includes what knowledges are given space to circulate in the mainstream, as per the example provided in my discussion on COVID19 and biomedical hegemony. This also includes my experiences navigating cancer care, including biomedicine and Indigenous healing, the spaces of tension between them that I tried to delineate, to generate further thought. Knowledges *are* fluid and dynamic and this gives me hope that things could change.

I find these deeply disturbing and sad times, not just the last year of the COVID19 crisis but more generally. Sometimes as I read the news and sit back and watch all the world unfolding before my eyes I feel despair and a sense of powerlessness to fight back. I feel that capitalism and neoliberalism are contributing to our demise in ways that are becoming deafening, and the powers that be do not want things to change, in fact it seems like things are more divided, polarized and complicated than what I can ever remember in my lifetime. The 'machine' keeps grinding along, as our earth continues to be compromised, the quality of our air deteriorates, and the water is polluted and becoming scarce. Instead of focusing on cancer prevention by stopping the contamination of our food and water supply with carcinogens, the focus is on prevention through cancer screening and the creation of more technologies, while industries are allowed to continue

on as if everything is okay and make money off of others 'demise, including mother earth. Likewise, instead of also focusing on strengthening our immune systems with regards to COVID19 we are bombarded with fearful messages, being forced to alter our lives and livelihoods in drastic ways, and once again the overpowering focus is on putting billions of dollars into COVID19 technologies, testing, and vaccines for example. Moreover, Indigenous knowledges and other subjugated knowledges and perspectives on cancer and COVID19 are largely absent in mainstream discourses. In the case of COVID19 they are even being blatantly censored. With regards to Indigenous medicines and approaches to cancer care, there are too many people who still ask, "do you believe in all that stuff". There are still too many people for example, who have said to me when I talk about conversations with my Healer about Indigenous medicines for COVID19 "well you know those don't work right"? These are the medicines my husband I used for our COVID19 sickness.

7.2 Decolonize the Colonizers

Decolonization, truth telling and reconciliation require engagement from both settlers and Indigenous Peoples. We need to shift the focus that has been placed entirely on Indigenous Peoples, and also work towards decolonizing settlers (Regan, 2010). If settlers' consciousness is raised enough so that they free themselves from racist and oppressive ideologies that lead to colonialism in the first place, then perhaps change will come from its source instead of just from those most affected. Freire (1994) also claims that we all need hope not fatalism to fuel change. Fatalism robs passion and the strength to resist and make change.

Frantz Fanon (1963, p. 130) long established that "decolonization can only be understood as a historical process that ultimately culminates in changing the social order" (see also Dei & Asgharzadeh, 2001). This social order must be challenged, and Dei and Asgharzadeh (2001) and others (e.g., Bastian, 2004; Brown & Strega, 2005) suggest that one way to do this is to engage with anti-colonial and other critical social theories, and methodologies when examining these historical processes, in order to contribute to social and political change. For example, although speaking specifically about the academy, Dei

and Asgharzadeh (2001) argue that challenging what is considered legitimate knowledge is crucial;

> *we must challenge dominant and hegemonic Western canons in order to decolonize, otherwise the status quo remains and any initiatives implemented without this involvement risk becoming merely lip service and becoming co-opted by existing hegemonic structures and practices (p. 299).*

They go on to say that '[t]he anti-colonial discursive engages a critique of the wholesale denigration, disparagement, and discard of tradition and culture in the name of modernity and global space' (Dei & Asgharzadeh, 2001, p. 301).

Colonization has led to death, physical and spiritual damage, intense intergenerational suffering and oppression. Devi Mucina (2011) and others (see Corntassel et al., 2009; Dei, 2011) argue that to resist colonization, and the effects of continued colonization, we need to engage with, and tell stories that contribute to spiritual healing using Indigenous methods and storytelling. "Colonialism has fragmented every society…" (Mucina, 2011, p. 163), which includes those colonized and the colonizers (see Freire, 1994). I would also add that colonialism has not just fragmented society but land, the natural world and every aspect of society, and people, as it is rooted in deep-seated Euro-Canadian centrism, and racism, which fundamentally influences who is a valued citizen and who is not; ultimately whose lives matter more. Colonial processes undermined the significance and validity of oral forms of knowledge sharing, such as storytelling, and what is often referred to as knowledge production in academia, and instead modern western methods of scholarship are privileged partly because of their claims to objectivity (Césaire, 1972; Hall et al., 2000; Mucina, 2011; Smith, 2012). Knowledge created through storytelling, and subjective experience is criticized for what Indigenous ways of knowing view as its strength, subjectivity. However, more recently modern western methods and the assumed universal validity of western methods of knowledge production and perspectives are being challenged and criticized for their own inherent biases (Brown & Strega, 2005; Dei, 2011; Hall, et al., 2000; Smith, 2012). Colonialism and assimilation processes have fractured, and in some instances completely severed Indigenous identities, their sense of community, connection to land, family and

clan ties. Storytelling is a powerful way to help reconnect lost knowledges, connections and rebuild communities (Corntassel et al., 2009; Mucina, 2011, Brown & Strega, 2005; Smith, 2012). For example, because of the many assimilationist and fracturing processes related to colonialism my own family's Métis and Mi'kmaq roots have been severed, and only recently have we begun to uncover them through family stories that were kept secret. Our family was fragmented and uprooted, forced to leave our land and extended community, many of the stories connecting my family to our Indigenous roots have been lost.

7.3 Circling Back to the Circle

I feel like I have come full circle with this exploration. I started at a moment in Canadian history when the public and government were set toward a path forward to reconciliation. The proliferation of innovative projects to incorporate Indigenous Knowledges through the TRC mandates 22 and 48 into public healthcare was blossoming and it felt hopeful. Now we find a situation where some practices are again driven underground, like my own grandfather experienced, and people are silenced by the dominant values that are taken as faith. People finding new ways to experience ceremony also. Like cancer that is extinguished yet always lurking, so too dominant knowledges challenge diverse etiologies of health and illness. As Audra Lorde tells us, "I do not forget cancer for very long, ever. That keeps me armed and, on my toes, but also with a slight background noise of fear… (Lorde, 1980, p. 8). The salience of this quote from Lorde encapsulates how I feel in relation to not only cancer but to the particular histories, of my family explored in this thesis, that I believe lead to my illness, the traumas, the violence at the hands of the state. This includes Canada's history of brutal colonization and assimilationist strategies that are responsible for so many lives, so much loss and degradation, all of which whether we experience them firsthand or not are written in our cells, our blood, our bodies/minds/spirits. This also includes the continued destruction of the earth; air, land and water that we are an extension of (Ahenakew, 2019), in the name of profit for the few. Cancer and other illnesses, such as infectious diseases for example, are ultimately and intricately connected to the health of the planet; the air we breathe, the water we drink and the land where our food is grown, that are becoming more and more depleted

and polluted. As human beings, we need to take care of the mother of all mothers, Mother Earth.

7.4 Storying Writing and Decolonizing

During this dissertation writing process when I got stuck or unsure as well as at the start of each new chapter I would sit and drum for a while using the drum I made at a women's land-based retreat I attended almost 2 years ago. I sing some of the songs I have learned and try to connect to my heart.

Personal decolonization includes engaging in rituals to reclaim the mind, body, and spirit and challenge the dominant worldview that we have all internalized. Drumming and singing help connect me to a deeper place of knowing. I wanted this thesis to come from a place of spirit and to reflect my ongoing work of trying to decolonize my mind/body/spirit. Further, I wanted to heed Lynn Lavallee's words that remind us, "[w]hen locating ourselves within the research, it is also important to recognize that personal growth is an important end product" (2009, p. 26). Research should not leave us unchanged, and it isn't just our understanding of a particular topic that should change, but our 'selves'.

I feel like I have honored this in the best way I know how, at this time. In the last three years my life has changed dramatically in many ways. My relationship with myself, my family and the world around me has altered, and this has meant I have had to deal with loss but also a new strength of spirit that I work to build every day. Some days I feel I am able to embody a place where my interconnection with others, the earth, animals and plants is felt rather than just theorized, others, I feel like I am sinking, my spirit dulled again by a shapeless pull.

During the last three years I have received two different spirit names from my Healer. My spirit name changed because I grew. My spirit name has transformed into *Standing Eagle Woman*. This name rings true for me now, especially on days when I feel I can stand up strong and my spirit shines outward, something I try to embody everyday. I received this name at the last sweat I attended about a year ago. The first time I saw the Healer they told me my spirit was dull, that it was sick and that is why I got sick. I have

done a lot of healing work over the last few years, and I continue to working on letting my spirit shine through.

7.5 Fuck Cancer!

Below is a picture my husband took, an image on a car window. If you look closely, you can see the reflection of my husband in the image which I think is quite poignant. He too has been affected, like my daughter, by my having cancer, it has also caused them both a lot of fear, anxiety and grief.

Figure 9 Fuck cancer

Cancer has not left me unchanged. For that I am thankful too. As I reread these stories, all the words on these pages, I notice that there is little personal anger expressed here over getting cancer in the first place, over my family history in general. That doesn't mean it isn't there, underneath some of the grief and fear is anger. Anger because of things my family has had to endure, the lost connections and stories. Anger over the abuses my mom and Grandmother had to endure while they tried to live their lives the best they

could, and at the medical treatments they had to withstand in the name of healing their very human fragility.

It is so easy to get stuck on just the word ‘cancer’, it still feels just unreal that I even had it, and that it could come back. One thing that sticks with me is something another Healer, one who is now my teacher, told me. She said I was a Healer and that sometimes Healers take on other’s energies and don’t take good care of themselves – they take better care of others. I honestly feel I have been taking care of people in my family, my mom, my brothers when my mom got sick, since I was a child. As an adult, I reflect on this cost and realize that I gave part of myself away, but this has also given me gifts. I know I have a big heart just like my grandmother, something no one can take away. I also feel some parallels with my Great Grandfather now as I learn the teachings, the healing ceremonies, as I begin to learn to become a healer myself. Cancer is my medicine.

Another thing I have learned from one of the Healers I have been seeing over the last three years, is that Indigenous identity is not about blood quantum, it is about spirit, and what is in your heart. They said it is about entering the circle. I have (re)entered the circle. As I mentioned briefly in an earlier chapter, I received a sacred pipe about a year ago. The Healer said he got the message from the ancestors that my struggles, my family’s struggles, the fact that I am still alive, have earned me the pipe. They said first I should use it for myself and my family and then eventually, as I learn more, I need to use it to help community, to do healing work myself. I am not sure yet how academia and healing work will fit together but I am going to find a way.

Still three years later, each time I have to go back to the hospital for various testing, or to get results from the various testing I am filled once again with the terror of hearing those words ‘cancer’. I just can’t shake it. But I have found ways to cope, and they include the sacred teachings I have learned. It includes carving out and holding space for the sacred every day.

These words of Audre Lorde ring true to me as well,

> *Sometimes fear stalks me like another malignancy, sapping energy and power and attention from my work. A cold becomes sinister; a cough, lung cancer; a bruise, leukemia. Those fears are most powerful when they are not given voice, and close upon their heels comes the fury that*

I cannot shake them. I am learning to live beyond fear by living through it, and in the process learning to turn fury at my own limitations into some more creative energy. I realize that if I wait until I am no longer afraid to act, write, speak, be…, I'll be sending messages… cryptic complaints from the other side. When I dare to be powerful, to use my strength in the service of my vision, then it becomes less important whether or not I am unafraid (Lorde, 1980, p. 9).

7.6 Creating and Holding Space for the Sacred

The Indian act and Doctrine of Discovery are reductionist, patriarchal and disempowering governing documents and ideologies. They contribute to reducing Indigenous Peoples ' identities to blood quantum, give permission to control land and on how land gets used regardless of how it impacts Indigenous Peoples, resulting in its degradation. Both documents contribute to divisiveness between peoples and in that way, they are ideologically similar to biomedicine's reductionist approach to medicine and health in general. Principles that divide mind, body, spirit and the natural world. These noxious governing documents continue to manifest in our lives, reducing us to fragmented parts, in some instances fragmented diseased parts. Our strength is in our wholeness as human beings, as collectives, communities and beyond; it extends and is connected to the land, the water and the sky worlds.

I believe that creating and holding space for the sacred in health care and public health in general is becoming more urgent. This includes the need to shift away from the technologicalization of health and health care, the focus on high profit technologies (see Fischer, 2013), away from "…reductionist, profit-based pseudo-science …" (Grøsneth & Oakley, 2007, p. 4; Nanda, 2003) towards spaces of healing. Spaces that allow for the rich diverse approaches of Canada's Indigenous Peoples to be incorporated and valued, and that counteract the impact of colonialism, and capitalism on how knowledges are shaped and enacted in the realm of healthcare. We need to conceptualize and enact health care based on a more wholistic framework that considers Indigenous knowledges and ways of understanding the world as well as the social and structural dynamics of health, as well as

towards ensuring all have the basic building blocks of health. We need to infuse spirit into medicine and healing.

In the meantime, as neoliberal and capitalist ideologies and practices permeate more aspects of our lives and more deeply, our health and our very beingness, we need to be aware and reflect on their impacts. Otherwise, they will seep into our spirit unnoticed, and become part of our worldviews if we are not careful. "Under neoliberalism, the state now makes a grim alignment with corporate capital and transnational corporations" (Giroux & Searles-Giroux, 2008, p. 181) and this too is becoming part of health care and public health practices.

This following story illustrates to me how neoliberal ideologies permeate our daily lives. The other day I was walking on the sidewalk near a wooded park in Toronto and all of a sudden a man's hand extends out almost hitting me in the face as he passed by saying "stay 2 meters away you are not wearing a mask". This experience was shocking to me, it felt very aggressive. I was too stunned to say anything, and I also felt powerless to even fight back as I didn't want to escalate the situation. To me this experience exemplifies how the focus is being placed on individuals and our behavior modification through current public health protocols, rather than on the bigger picture, the macro factors impacting our health. So instead of working towards changing the world, protecting the environment, and working to ensure equity for all, we are policing each other's behaviors, attacking each other instead of fighting more for justice for all.

7.7 Storying Hope

There is hope, however timid, on the street corners, a hope in each and every one of us…. Hope is an ontological need (Freire, 1994, p. 8)

I have presented many problems here that don't have easy answers. I set out to write some recommendations, but I must admit I am struggling. I think the recommendations would require further investigation and is perhaps another study unto itself. In the words of political theorist Frederic Jameson, sometimes it does seem easier to imagine the end of the world than the end of neoliberal capitalism (Giroux & Searles-Giroux, 2008). Yet we must have hope. We need to begin by rehumanizing the world through decentering

ethics and values from the ethics of the marketplace (Denzin et al., 2008). This includes honouring the power of Indigenous knowledges in all domains of life. This means that in the realm of health care Indigenous knowledges and perspectives take up space, and that these spaces, these knowledges are neither governed, nor contorted or erased by dominant institutions such as biomedicine, the state, particularly given their "grim alliance with corporate capital and transnational corporations" (Giroux & Searles Giroux, 2008 p. 181).

I hope I have contributed to what Rabaka (2009) calls one of the most important tasks of a critical anti-colonial perspective…which "is to capture and critique the continuities and discontinuities of the colonial and neocolonial era in order to make sense of our currently…colonized life…and worlds" (Rabaka, 2009 in Dei & Kempf, 2006, pg. 2), to contribute towards change.

7.8 My Grandmother, My Mother, My Daughter, My Self

My daughter played a big role in this body of work, not only is she part of my family and an integral part of my story, she also helped me review and edit these chapters. Having her read this body of work allowed her to also participate in this thesis. My daughter, as she reads these words I have now committed to the page, is also learning more about her own history, as there are stories here she hasn't heard before. She is part of the circle. In the words of Mucina (2011), "we are a continuation of our ancestors 'legacy or, put another way, we are a reflection of their existence. Our well-being is their well-being" (p. 226). As such, I will continue to nurture my own spirit and try to humbly contribute to my past, present and future ancestors 'well-being, while I struggle through this life trying to uncover the fragments of history my ancestors endured and hid so that I could be here now.

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