

**“Diaspora *health* literacy: reclaiming and restoring
Nibwaakaawin (wisdom) and mending broken hearts”**

**“DIASPORA HEALTH LITERACY:
RECLAIMING AND RESTORING NIBWAAKAAWIN (WISDOM) AND MENDING
BROKEN HEARTS”**

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Abstract

Cardiovascular diseases are major causes of mortality and hospitalization for adult Indigenous peoples. Historical, socio-economic, environmental and cultural risk factors have been identified in the literature and new evidence is emerging regarding culturally relevant health promotion approaches for Indigenous peoples at risk of developing or currently experiencing cardiovascular disease. Self-management of care is considered a central component to effective cardiovascular disease management. This approach requires a working knowledge and understanding of cardiovascular disease medications, and an ability to effectively communicate with healthcare practitioners. Another important associated risk factor for Indigenous peoples with heart disease, is the gap between patient - practitioner understanding of heart disease. The biomedical perspective supported by Western scientific evidence, makes little room for Indigenous knowledge. Indigenous peoples may wish to include Indigenous knowledge and/or Traditional Medicine in their self-care approach. The findings of this research demonstrates that Indigenous peoples primarily have a biomedical understanding of their heart disease and most are unaware of how various socio-historical and socio-cultural factors such as the negative inter-generational impact of residential school and contemporary experiences of oppression and discrimination are linked to their heart disease. This situation can be attributed to an Indigenous knowledge diaspora experience that includes the severance of access to Indigenous knowledge and Indigenous languages during the residential school period and the dominance of biomedicine in health care delivery. The concept of 'diaspora *health* literacy' is critically discussed as a potential tool to address the Indigenous knowledge diaspora barrier. It is proposed that Indigenous peoples with heart disease can enhance their self-care when culturally relevant health literacy approaches are available to them. In turn, healthcare practitioners can broker an 'Indigenous therapeutic relational space' with their Indigenous patients by initiating a culturally relevant health literacy assessment and a harmonized implementation model.

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TABLE OF CONTENTS

CHAPTER 1: Introduction & Background	13
Purpose of research	13
Health Literacy for Indigenous peoples & socio-structural barriers	16
Key themes in the dissertation	20
A call for educational equity	23
Reclaiming and restoring Indigenous voices	26
Health literacy as a research focus	29
Chapters Outline	30
CHAPTER 2: DISSERTATION THEORETICAL FRAMEWORK	34
Reclaiming and Restoring Nibwaakaawin	35
Sharing health information with Indigenous peoples: harmonizing the approach	36
Challenges related to ontological intersection	38
Anishinaabemowin: importance of language	39
Research Goal and key assumptions	42
CHAPTER 3: ODAYIN (HEART) TEACHINGS: CARDIOVASCULAR DISEASE & HEALTH LITERACY	50
Cardiovascular disease and Indigenous populations	50
Health inequities and disparity	54
Causal Factors	55
Historical Factors	56
Socio-economic factors	57
Environmental and Structural Factors	58
Genetic Factors	59
Risk Factors	60
Lack of exercise and diet	61
Hypertension	62
High Cholesterol	62
Associated Risk Factors	63
Exposure to biological and socio-environmental determinants of health	63
Meaning of Cardiovascular Disease illness	64
Health Literacy for Indigenous Populations	65
The concept of health literacy	67
Cardiovascular disease and the need for health literacy	69
Health Literacy Assessment and Barriers	69
Socio-structural barriers	71

Barrier: lack of Indigenous context in health science curriculum	79
Barrier: restricted access to Indigenous knowledge and Traditional healing	81
Anishinaabemowin: The importance of Language	81
CHAPTER 4: METHODS AND FINDINGS	84
Methods: Research Segment One	84
Ethics and Community Partnership Building	84
Research Interviews	85
Patient Participant Characteristics/socio-demographics	86
Age-gender	86
Expression of Indigenous Identity	87
Staff Participant Interviews	90
Methods Research Segment Two	91
Research Interviews	92
Summary of Findings	94
Indigenous socio - cultural factors	96
Impact of Traditional knowledge on health beliefs and self-management of health	96
Themes Related to Patient Participant Self-Perception: Health & Well-Being	100
Perception of Health status	100
Patient Participants' perception of causes of cardiovascular disease	100
Cultural Beliefs and values from others about health and well-being	103
Themes Related to Healthcare Experience	106
Relationship with healthcare practitioners	108
Link between a positive relationship between healthcare practitioners and patient perception of improved health	112
Themes Related to Empowerment and self-care	113
Beliefs and Values Regarding Responsibility for Self-Care	113
Confidence in ability to improve their own health	115
Special needs related to Aboriginal Identity	117
Special needs and Fatalistic Attitudes	118
Special needs and structural barriers	120
Health Literacy Assessment	121
Patient Participant Management of Medications	123
Staff Participant Interviews	124
New Zealand Research Segment: Maori Staff	125
Chapter Summary	129

CHAPTER ~ 5 ~ MAKING THE CASE: INDIGENOUS KNOWLEDGE DIASPORA AND THE NEED TO RECLAIM AND RESTORE NIBWAAKAAWIN IN HEALTH LITERACY APPROACHES FOR INDIGENOUS PEOPLES	133
Accessing Nibwaakaawin to achieve Bimaadiziwin	134
The inter-relationship of all things	135
Use of Traditional Medicines	135
Relationship between health and spirit	136
Personal Responsibility for physical health and well-being	137
Ascribing Meaning to health and illness	138
Defining diaspora	142
Indigenous Knowledge Diaspora and cardiovascular disease	146
Cultural knowledge distortion and diaspora health literacy for Indigenous peoples with cardiovascular disease	151
Structural Violence and Indigenous knowledge diaspora	154
The role of Healthcare practitioners in an Indigenous Knowledge diaspora	159
Dominance of biomedicine as a structural barrier	161
Summary: What we know, what we don't know and what needs to be done	164
CHAPTER 6: ADDRESSING INDIGENOUS KNOWLEDGE DIASPORA: SEEKING NIBWAAKAAWIN: A HARMONIZED HEALTH LITERACY APPROACH FOR INDIGENOUS PEOPLES	168
Accepting the need for health literacy reform for Indigenous populations	169
Bimaadiziwin (good way - healthy life): Ojibwa teachings for a healthy, balanced life	170
Description of a harmonized Indigenous health literacy model: a Medicine Wheel Framework	171
Description of directional elements and protocols	173
Implementing the model	178
Eastern (waabinong) Direction: Assessment	178
Southern (zhaawanong) Direction: Patient Engagement	180
Western (epangishmok) direction: sharing knowledge	182
Northern (kiiwedinong) direction	184
CONCLUSION	186
WORKS CITED	192

APPENDICES

Appendix 1 - Background: International Indigenous Health Literacy Study	201
Appendix 2 - Patient Interview Guide	204
Appendix 3 - Staff Interview Guide	207
Appendix 4 - New Zealand Interview Guide	209

LIST OF ILLUSTRATIONS

Figure 1 - Aboriginal identity population, Canada, 2011

Figure 2 - Perceived causes of cardiovascular disease

Figure 3 - Factors Related to a Positive Healthcare Experience

Figure 4 - Factors Related to a Negative Healthcare Experience

Figure 5 - Contributing Factors to a Positive Relationship With Healthcare Practitioners

Figure 6 - Contributing Factors to a Poorer Quality Relationship With Healthcare Practitioner

Figure 7 - IALS Literacy Levels

Figure 8 - Harmonized Indigenous Health Literacy Model

Figure 9 - Assessment of patient needs

LIST OF ABBREVIATIONS AND SYMBOLS

(CVD) Cardiovascular disease

(DAHAC) De dwa da dehs nye>s -Aboriginal Health Access Centre

(IALSS) ‘International Adult Literacy and Skills Survey’

(IK) Indigenous knowledge

(MHC) Te Hononga o Tamaki me Hoturoa (Te Hononga) - Maori Health Centre

(NAHO) National Aboriginal Health Organization

(NCCA) National Collaborating Centre for Aboriginal Health

(PHAC) Public Health Agency of Canada

(RCAP) Royal Commission on Aboriginal Peoples

(TM) Traditional medicine

(WHO) World Health Organization

DECLARATION OF ACADEMIC ACHIEVEMENTS

This research was undertaken in two segments. The first segment was nested within the study; *'Strengthening health literacy among Indigenous people living with cardiovascular disease, their families, and healthcare providers'*; the Canadian arm of a larger international health literacy study. The Canadian team included Dr. Janet Smylie, Principal Investigator and Co-Investigators; Dr. Marcia Anderson, Ms. Constance McKnight, Nancy Cooper, Conrad Prince, Research Manager; Sanjeev Sridharan, Chester Langeville.

The second segment of my research was undertaken with the support of staff at the Te Hononga o Tamaki me Hoturoa (Te Hononga) - Maori Health Centre.

CHAPTER 1: Introduction and Background

Purpose of research

The following quote describes an Ojibwe Medicine Wheel teaching and demonstrates how Indigenous knowledge conveys essential teachings and guidelines to live a healthy, balanced life. As William Commanda, a respected Elder from the Algonquian Nation and keeper of the sacred wampum belts who has since passed on to the Spirit World, said in the opening of his June 10, 2010 message to the Algonquins of the Ottawa River Watershed:

“I have been blessed by the guidance and strength of the Sacred Wampum Belts of our Anishinabe ancestors to assert their presence over the past forty years, and many, Indigenous and non-Indigenous, have been awakened to our history, wisdom and relevance in these times of unprecedented global uncertainty and chaos. But, in our Traditional way of thinking, the individual is only a cornerstone of a community, and we must bring our individual strengths together to recreate the strong communities we developed in the past. I have often said that Indigenous Peoples are the only ones who have never gone elsewhere to make new homes, we are at home here; we maintain the sacred unbreakable connections with Mother Earth, and we have to assert this reality with even greater vigor and perseverance in these times of war and strife, climate change and environmental crisis. Without doubt, Mother Earth’s voice is loud now, and she is calling urgently to draw us back to her. We have a crucial role to play in restoring balance on Earth, and our Earth based and cyclical ways of thinking have a vitally important role to play in human evolution and growth. We can all see the huge deficit and spiritually bankrupt legacy looming in the global landscape.”

Indigenous peoples have understood their health and well-being within the context of their own Indigenous ways of knowing for millennia. This way of knowing is intricately linked to the way their lives are intertwined with the world around and beyond them and manifests in their beliefs, customs, traditions and languages. While there are diverse visions of health and wellness among Indigenous groups in Canada, an underpinning of the Indigenous perspective is their wholistic worldview (NAHO 2003). The construct of health is considered *in relation* to the

physical, emotional, mental and spiritual realms of the individual and the ties to family, community and nation.

Through hundreds of years of colonization and the assimilative practices of European settlers, their governments and their clergy, many Indigenous people have become disconnected from their Indigenous knowledge systems and languages, both of which hold the beliefs, values and a way of life that guided them to a balanced state of physical and inner well-being¹. This can be framed within the experience of ‘Indigenous knowledge diaspora’, a tragic situation that has restricted Indigenous peoples’ ability to access and integrate Indigenous knowledge into their daily lives.

Currently, mainstream health literacy approaches draw from a dominant positivist theory and focus on a (dominant) cognitive or deficit model. These approaches are not inclusive of Indigenous knowledge nor do they facilitate access to Indigenous knowledge. Therefore, they are not culturally congruent with a wholistic Indigenous worldview; more specifically, they are not congruent with Indigenous beliefs and values about physical and inner well-being. This mainstream approach can be considered a major contributing factor to the serious health challenges that Indigenous peoples in Canada are experiencing including cardiovascular disease, diabetes and other chronic illness.

The overall goal of my research was to further understand the cultural context of both the Indigenous patient experience of cardiovascular disease and the patient-practitioner relationship. My thesis: Indigenous peoples with cardiovascular disease require culturally relevant health literacy approaches that are informed by both biomedical and Indigenous knowledge.

¹ The term ‘physical and inner well-being is used to convey an Ojibwa teaching regarding the inter-relationship of all things; “of the need for harmony and balance as a integral part of the Ojibwa sense of wellness, of the recognition that we must attend not just to our physical selves, but also to the emotional and spiritual parts of our lives in order to be whole (Peacock and Wiser 2002:94).

This research consisted of two segments. The first segment was nested within the study²:

'Strengthening health literacy among Indigenous people living with cardiovascular disease, their families, and healthcare providers', the Canadian arm of a larger international health literacy study. Two specific areas of inquiry were included in research segment one: understanding the meaning of heart disease for Indigenous patient participants and understanding the nature of their healthcare experiences with healthcare practitioners. Did patient participants hold Indigenous cultural beliefs regarding their health and well being and more specifically, regarding their heart disease? How did they understand their illness? Did they receive culturally relevant messaging from family, Elders or healers regarding their health or illness? If so, how were their own understandings and cultural beliefs being accommodated by healthcare practitioners? Did they see themselves having special needs because of their identity as an Indigenous person?

The second segment of my research was an iterative extension of the first, following a preliminary analysis of segment one research findings. I wished to explore how Indigenous healthcare practitioners and Elders perceived their Maori patients' awareness and understanding of the cultural value of 'personal responsibility for health and well-being'. An international project meeting hosted by the New Zealand team provided this opportunity.

I advance the idea that Indigenous notions of empowerment, including the relationship to both individual and collective efficacy, within the construct of personal agency, are tied to cultural beliefs and values embedded within Indigenous knowledge systems and languages and that this is an important socio-cultural factor to be considered in the goal towards increasing health literacy among Indigenous populations. I also propose that the concepts of 'Indigenous

² The term 'nested' refers to my project being embedded within a larger international study. Therefore, my research questions were included in Phase 1 of the larger study and contributed to findings of the larger study as well.

knowledge diaspora’, and ‘structural violence’ are key socio-historical, socio-cultural and socio-structural causal factors linked to the notion of empowerment and personal agency for Indigenous peoples. Indigenous peoples have acquired a ‘diaspora consciousness’ regarding their cardiovascular disease, a consciousness that is rooted in biomedical theory and is devoid of Indigenous knowledge thus, contributes to a negative ‘Indigenous knowledge-diasporic experience’. The concept of ‘diaspora health literacy’ is critically discussed focusing on its potential utility as a tool to address the Indigenous knowledge diaspora barrier when trying to self- manage heart disease in a culturally relevant way.

It is also proposed that my research findings may positively inform the health literacy practice of both Indigenous and non-Indigenous healthcare practitioners working with Indigenous peoples who have heart disease or other chronic illness. Increasing the awareness and understanding of healthcare practitioners regarding the cultural context of health literacy has potential to yield more effective sharing of health information with this population group.

A culturally relevant, ‘harmonized health literacy model’ will result in the creation of an ‘Indigenous therapeutic relational space’, a space that equalizes power between healthcare practitioner and patient and can be inclusive of both biomedical and Indigenous knowledge. In the long-term, this may positively influence improved health outcomes as patients will be better informed and ultimately, empowered in the self-management of their heart disease. This is in keeping with an Indigenous self-determining approach to health and well-being.

Health Literacy for Indigenous peoples and socio-structural barriers

To understand the Indigenous cultural context of health literacy is to know that information about physical and inner well being has been passed on in the oral tradition by Indigenous people

over many generations. Many sought the spiritual guidance of Medicine men or women, Traditional healers, shamans and seers. Stories, metaphors, dreams and experiences hold messages about how to maintain a wholistic balanced lifestyle. The concept of personal volition with respect to one's health and well-being was promoted and adhered to and was also linked to messaging about health and well-being. Reciprocity in the healing relationship, where both the healer and the individual seeking healing have obligations related to the healing process, was valued. Medicine cannot be effective unless the receiver fulfills their obligations in an intentional way. For example, one might be asked to engage in a fast to prepare for participation in a spiritual ceremony, or they may be instructed to pick sweetgrass and cedar to prepare for a cleansing ritual.

A Canadian Expert panel on Health Literacy, commissioned by the Public Health Agency of Canada defined health literacy as; “the ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course” (2008:3). Health Canada's position is that literacy is one of the major influences on health status and further, that health is negatively impacted by low literacy levels (Korhonen 2006:1). Poorer health outcomes including reduced life expectancy and higher rates of infant mortality are often associated with Canadians who have lower levels of education (Public Health Agency of Canada 2008:49). Weiss summarizes the serious consequences related to inadequate health literacy that include less health knowledge, lower health status, higher utilization of health services and higher health care costs than those with higher literacy levels.

(Weiss 2005:pg). For example, patient safety³ becomes a concern when limited health literacy skills may lead to errors in the self-administration of medication (2005:24). Finally, health care reform options may include self-managed care approaches that are designed to assist eligible individuals (i.e. patients with chronic disease diagnoses) to function independently (Government of Nova Scotia 2008:n.p.).

Autonomous health care requires a level of literacy skill sets to manage this approach. However, health literacy approaches for Indigenous⁴ populations needs to move beyond improving of reading skills. Healthcare practitioners and policy makers also need to be aware and understand various socio-cultural factors related to the poor health status of their Indigenous patients. The emerging literature on this subject indicates that links are beginning to be made between the social determinants of health and other socio-psychological factors, such as the impact of residential schools on the overall health of Indigenous peoples⁵. However, an

³ The concept of patient safety is defined by the WHO as the reduction of unnecessary harm associated with health care to an acceptable minimum. An acceptable minimum as noted by the Canadian Patient Safety Institute refers to “the collective notions of current knowledge, resources available and the context in which it is delivered weighed against the risk of non-treatment of other treatment. <http://www.patientsafetyinstitute.ca/English/research/commissionedResearch/primaryCare/Documents/PrimaryCare2010.pdf>

Statistics Canada identifies First Nations (North American Indian), Métis or Inuk (Inuit) and/or being a Registered or Treaty Indian, (that is, registered under the *Indian Act* of Canada) and/or being a member of a First Nation or Indian band. Aboriginal peoples of Canada are defined in the *Constitution Act, 1982*, section 35 (2) as including the Indian, Inuit and Métis peoples of Canada. <http://www12.statcan.gc.ca/nhs-enm/2011/as-sa/99-011-x/99-011-x2011001-eng.cfm#b6x>

A working definition of the term ‘Indigenous’, proposed by Jose R. Martinez Cobo for the the United Nations: “Indigenous communities, peoples and nations are those which, having a historical continuity with pre-invasion and pre-colonial societies that developed on their territories, consider themselves distinct from other sectors of the societies now prevailing on those territories, or parts of them. They form at present non-dominant sectors of society and are determined to preserve, develop and transmit to future generations their ancestral territories, and their ethnic identity, as the basis of their continued existence as peoples, in accordance with their own cultural patterns, social instituti⁴ons and legal system. Retrieved from website: <http://indigenouspeoples.nl/indigenous-peoples/definition-indigenous>

⁵ Dion and Kipling discuss the negative impact of residential school on Indigenous individuals, families and communities. Their search of the literature cites a wide range of impact among individuals with commonalities such as post-traumatic stress disorder-like symptoms, nightmares, sleep problems, blackouts, apathy and depression; difficulty relating to others, low self-esteem, alienation from parents and communities, feeling ashamed of Aboriginal heritage and feeling consumed with anger and guilt. The authors cite the important issue of survivor - early death with high rates of suicide, deaths due to violence or alcohol related causes. Destructive patterns of behavior and high incidence of sexual problems are also reported (2003:v).

important area of consideration, in the health literacy discourse for this population group, is the relevance and importance of both Indigenous knowledge/Nibwaakaawin⁶ and language; specifically, how they are linked to the meaning of illness and Indigenous beliefs regarding physical and inner well-being. Without this understanding, the health literacy goal is focused only on the treatment from a biomedical perspective; for example, can the patient read their pill bottles? do they understand how to manage their blood sugar monitoring? Health messaging certainly needs to include the ins and outs of self-care management. However, for Indigenous peoples, there is also a need to know about their heart disease in a way that makes sense for them. The messaging needs to be harmonized by including both biological and Indigenous knowledge/Nibwaakaawin. Otherwise, health literacy approaches risk maintaining the status quo with a less than adequate uptake of health messaging and ongoing unequal power relations in the healthcare practitioner - patient relationship. This situation perpetuates an oppressive and disempowering dynamic thus, negatively affecting an individual's personal agency to effectively manage their heart disease and treatment. This situation can be situated within a frame of socio-structural violence for Indigenous populations.

As noted earlier, it is critical to ensure that health literacy approaches are sensitive and inclusive of Indigenous perspectives of how meaning is ascribed to illness. Further, it is equally vital that the approach is harmonized to provide both biomedical based information and acknowledge, respect and facilitate access to Indigenous knowledge. This approach has potential to more effectively increase the uptake of health information provided by healthcare

⁶ In Ojibwe culture, the term Nibwaakaawin translates as 'wisdom' and is the parallel term for Indigenous knowledge. 'Knowledge' is a Eurocentric term that implies the presence of a valid scientific theoretical base. Therefore, the term knowledge/Nibwaakaawin is used to maintain the focus on the Indigenous construct of wisdom.

practitioners, thereby addressing structural barriers and achieving a more equitable and culturally relevant health literacy approach.

Key themes in the dissertation

“If the Native peoples and their heritage are to be understood, it is their beliefs, understandings, insights, ideals, values, ethics and attitudes that must be studied and, not as at present, their kinship systems, structures of their organizations or forms of their religions.” (Johnston 2011:214)

There are two key structural elements in this dissertation that merit explanation. First, wherever possible, the ontological emphasis and the discussion is framed to situate Indigenous pedagogy at the centre. Ontology refers to a branch of metaphysics concerned with the nature and relations of being. This concept is discussed more fully in chapter two.

It is often a major challenge for Indigenous academics in their scholarly pursuits to break through the bastion of a Western Eurocentric knowledge hierarchy to articulate their ideas in a way that effectively channels the oral or written Indigenous knowledge/Nibwaakaawin they have been given or that others before them have written down. The task is more daunting and difficult because of the limited literature on the topic of Indigenous knowledge. In addition, the student finds her/himself in the precarious position of having to defend sources of information that would not meet the rigor of long-held Academy standards. Thus, in keeping with the scholarly aspiration of emphasizing Indigenous pedagogy, or Indigenizing the concept of health literacy, discussion in this thesis emphasizes Indigenous knowledge/Nibwaakaawin. Information is drawn from Ojibwe teachings about ‘Bimaadiziwin’ (good way-healthy life). I draw on sources from the historical ‘orature’ of Elders, prayers, stories that engender teachings of morality and values, personal dream teachings; and academic writing of Indigenous scholars to inform the discussion. Literature from the fields of anthropology, sociology and biomedicine are woven into

the discussion with the objective of promoting a harmonized health literacy approach for Indigenous populations. The discussion throughout will move freely between bio-medical and Indigenous knowledge based concepts. It is proposed that this approach is consistent with how healthcare practitioners need to engage with their Indigenous patients.

The second important dissertation organizational element is in keeping with a reclamative approach⁷ to post graduate education for Indigenous graduate students, namely, to situate the Indigenous scholar's voice within the academy in an equitable way. This reclamative approach provides an opportunity to articulate the research, analysis and experience of the Indigenous scholar from an Indigenous perspective. Critical discussion is infused with concepts that are drawn from Ojibwe Indigenous knowledge and at times from an Indigenous collective experience.

The need to emphasize Indigenous knowledge as critical for Indigenous scholarly pursuits within the Academy coincides with an increase in the numbers of Indigenous students entering MA and Ph.D. level programs and their attempt to mitigate the marginalizing experiences that they encounter. Scholarly immersion into a Western, hierarchical pedagogical knowledge system that at best yields a documented chronology of the colonizing perspective and at worst, can never fully support the application of Indigenous knowledge systems. This situation can be described as 'cognitive imprisonment'. Daes, a Greek scholar and past Chair of the United Nations Permanent Forum of Working Group on Indigenous Peoples in '*Reclaiming Indigenous Voice and Vision*', discusses the impact of 'oppression' experienced by Indigenous peoples in the wake of European settler arrival to North America. Daes proposes that the

⁷ The term 'reclamative' is used here as a term that promotes a self-determining approach to graduate education. However, the term can also be applied to the notion of 'reclaiming' Indigenous knowledge to guide us on a path of understanding how our own cultural beliefs and values regarding health have sustained us for generations.

experience of oppression is spiritual death. Further, Daes argues that victims of oppression not only lose interest in self-preservation but also find it difficult to maintain their relationship as parents, friends and neighbors. According to Daes cited in Battiste, victims internalize the oppression as “an accumulation of implicit, sub-conscious limitations on freedom” and the ‘external’ oppression becomes ‘self’oppression (2000:4). Battiste, an internationally respected Mi’kmaw scholar and activist, aptly notes that Indigenous voices in the Social Sciences have historically been silenced. In *Reclaiming Indigenous Voice and Vision*, Battiste describes how European colonization and its resulting systemic oppression created a ‘cognitive imperialism’ and contributed to establishing ‘cognitive prisons’ for Indigenous peoples. Battiste and other respected Indigenous scholars articulate how the first generation of Indigenous scholars paved the way towards addressing this issue. Scholars “sought ways of healing and re-building nations, peoples, communities and selves by restoring Indigenous ecologies, consciousnesses and languages and by creating bridges between Indigenous and European knowledges” (2000:xvii). Absolon, a Cree scholar in *Kaandossiwin: How We Come to Know*’ notes how the first generation of Indigenous scholars and activists in the academy applied socio-cultural models of social science research and used history as a methodological tool towards addressing historical, economic and political issues (2011:28). Martin et al. cite Brant - Castellano, a prominent Mohawk scholar, in their book, *Knowledge Translation: A Quest for Understanding* and critically discuss the current practice of Indigenous scholars who are required to *validate* Aboriginal worldviews and knowledge systems by comparing them against Western or dominant knowledge systems (Martin et al 2006:13). This deconstructive approach detracts from the flowing, interconnected, collective approach required to appreciate the concept of wholism that

underpins the Indigenous worldview. This culturally relevant approach is in keeping with those of other Indigenous scholars who are paving the way within the Academy towards situating Indigenous pedagogy at its centre.

Battiste notes that in the early years, the focus of Indigenous scholarship was on liberal solutions in an attempt to make modal adjustments to existing institutions. However, the agenda of Indigenous scholarship is described as aiming to transform Eurocentric theory so that it will “not only include and properly value Indigenous knowledge, thought, and heritage in all levels of education, curriculum and professional practice” but will be achieved through a “cooperative and dignified strategy that will animate Indigenous languages, cultures knowledge and vision in academic structures” (2000:xxi). Taiaiake Alfred, a Mohawk Scholar, echoes this position in *Wasáse: Indigenous pathways of action and freedom* and calls for Indigenous peoples to “redefine the terminology of our existence” (2005:25). Indigenous scholars are responding to this call for establishing an Indigenous lexicon. A scholarly literature that positions Indigenous knowledge in its rightful place at the centre is slowly emerging. (Battiste 2000; Johnston 2011; Absolon: 2011). A common thread found in Indigenous scholarly work is that a *reclamation* and *restorative process* is required to clearly state this objective. For example, Battiste advocates that Indigenous knowledge, including oral modes of transmission is “a vital, integral and significant process for Indigenous educators and scholars” (2000:xx).

A call for educational equity

Battiste et al. also assert that there is a need to establish an ‘educational equity’ towards remedying the failure of the current Eurocentric system; Indigenous education is described as “not one site of struggle but multiple struggles in multiple sites”. She argues that interventions

and transformative strategies must be as complex as the diverse struggles and that “they must be able to engage with and react to the multiple circumstances and shapes of oppression, exploitation, assimilation, colonization, racism, genderism, ageism and the many other strategies of marginalization (2000:xxi).”

This equity related recommendation is shared by Paulo Friere, a critical education theorist⁸. Friere advocates for a ‘libertarian’ education that is closely linked towards reconciliation. He asserts that education must begin with the teacher - student ‘contradiction’ by reconciling the poles of contradiction so that both are simultaneously teachers and students⁹ (2000:72).

Another challenge is the expectation within the Academy that scholarly discussion must ‘prove’ to Western scholars the authenticity of Indigenous knowledge as a sound, scientific knowledge base. Supporting an equitable approach demands both the acknowledgement and *acceptance* of Indigenous knowledge as an ethno-ontology in its own right and an awareness that integration of health literacy approaches that include or facilitate access to Indigenous knowledge, have potential towards significantly improving the health status of Indigenous peoples. This concept will be discussed further in Chapter five.

Friere is described as “the singularly important figure in the post-modern debate involving the constructs of teaching and learning....humanization of society is the ultimate goal of his liberatory pedagogy. (Reference: Freireian Pedagogy, Praxis and Possibilities: Projects for the New Millennium By Robert E. Bahruth, H. Mark Krank, Peter McLaren, Stanley F. Steiner - Garland Science, Feb 3, 2000 Retrieved on Aug 27, 2013 from website: http://books.google.ca/books?hl=en&lr=&id=EDeFUjVawScC&oi=fnd&pg=PP1&dq=Paulo+Freire+bio&ots=xANNm_3hfl&sig=ZSx0UQDh_XPS0dUti5e6d_wegvs#v=onepage&q=Paulo%20Freire%20bio&f=false)”

⁹ Friere states that this objective cannot be achieved through use of the ‘banking concept’ of education a concept that ‘minimizes or annuls’ the students’ creative power; changes the consciousness of the oppressed - not the situation which oppresses them. For further discussion on the banking concept of education see Friere in *The Pedagogy of the Oppressed* (2000).

It is also important for Indigenous scholars to go inward and challenge the imposition of the colonizer/oppressor's ontology on our ability to freely critically analyze, synthesize and organize from within our own ontological perspective. Freire describes the ambivalence of the oppressed to challenge the oppressor due to fearfulness and internalizing the consciousness of the oppressor. He calls this a "tragic dilemma" and poignantly identifies how the oppressed have been "castrated in their power to create and re-create and to transform the world" (1970:33). Friere's recommendation for freedom calls on the individual to become one's 'authentic self' and challenges the oppressed to reflect on their oppression which will lead them to "necessary engagement in the struggle for their liberation" (1970:33)¹⁰. Grande notes that academic theory is in itself viewed as Eurocentric and describes it as "inherently contradictory to the aims of Indigenous education." The requirement in the Academy to use only Eurocentric knowledge can be seen as creating oppressive academic boundaries for Indigenous scholars. As noted earlier, victims of oppression internalize the oppression as "an accumulation of implicit, sub-conscious limitations on freedom" and the 'external' oppression becomes 'self' - oppression. Grande advocates for educators to link their lived experience of theorizing to the processes of self-recovery and social transformation (2004:3).

Battiste acknowledges the process of how the use of Indigenous languages, metaphors, symbols, characters, stories, teachers and teachings can be used as a model for reconnecting with what was once hidden or suppressed; "to find ourselves whole, balanced, open and responsive, ready to assume the map that we have inherited and enfolded within each of us" (2000:xxix). For example; Absolon articulates 'Kaandossiwin' (how-we-come-to-know) as an Indigenous

¹⁰ Sandy Grande, a Native American educator in *Red Pedagogy* also proposes that Indigenous scholars must mitigate the space between adoption of Anglo-Western theories and the acceptance that "they need nothing outside themselves to understand their world or places within it".

approach to research. Cajete (2000), a respected Pueblo theorist, is cited by Battiste for his work in applying Pueblo metaphor as a way to reflect on how the tools of education can be used in the process of redefining and reinventing the contemporary philosophy of Indigenous education (2000:xxix). These examples provide the Indigenous scholar with ontological models with Indigenous cultural integrity. The following discussion describes the ‘going inward’ process required for the Indigenous scholar to situate their own voice in the mix.

Reclaiming and restoring Indigenous voices

“YES! You can harmonize Indigenous wisdom and biomedical understandings of health”

“These are the words that best capture the thought that entered my mind after an intense dream state and upon opening my eyes. I had clarity of vision and this thought seemed to be enveloped in a white light. A momentary flash of insight accompanied this thought....that I was on the right path with my work; that I was being guided by something greater than myself. That my ancestors approved and I could move forward in a good way.” This dream state followed an intense Yuwipi ceremony.¹¹ During the ceremony, I experienced a connection with the spirits that embodied both a tactile - physical and spiritual presence for me” (Downey, 2013).

Indigenous scholars face a long and at times, arduous journey in their attempt to weave the story of their Indigenous history, traditions and customs into the fabric of their writing. As previously discussed, contemporary Indigenous scholars provide culturally relevant models for reclaiming and reshaping our experience within the Academy and finding our Indigenous voice. To follow this path requires a ‘going inward’ process; drawing on our Indigenous languages, metaphors and teachings to articulate and apply our own Indigenous based ontologies to the academic experience.

¹¹ "Yuwipi is a Traditional ceremony of the Lakota people that is used for curing, prophesy, and to find lost items or people. Yuwipi means "they wrap him up" or "they bind up". The ceremony can be performed at any time, it is not an annual ceremony. It is usually performed to heal a sick or injured person but can also be used to find something that is missing or lost. This ceremony is practiced by many other tribes in the Americas but is not called Yuwipi, which is a Lakota word.

I am of Oji-Cree and Celtic heritage. My Irish father passed when I was a small child and extended family involvement on his side was minimal during my early developmental years. My Oji/Cree/Métis mother remarried another Irishman who was openly racist towards her when inebriated, which was often. There were no other Indian children in my school or neighborhood that I was aware of. I used to wonder why my skin was so dark. My grandmother's attendance at residential school in Brandon, Manitoba influenced my own mother's identity and experience in a way that led her to mask her indigeneity. Raising her own family was grounded in survival instinct: she needed to do whatever was required for her children. The only way to achieve a better life was to suppress her Indian-ness and fit in, as much as possible, with the oppressors. My mother would say: "There was no future for us back home, so I left for the bright lights of the big city". There was no place for fluent Indigenous language speakers in a mostly non-native urban landscape. Education in the dominant urban culture was promoted as the key to 'success'.

My mother's Indigenous identity crisis is consistent with key informant accounts in Lawrence; *"Real" Indians and Others: Mixed-Blood Urban Native Peoples and Indigenous Nationhood*. Lawrence, a Mi'kmaw Scholar in Indigenous Studies, explores the tensions and complexities of mixed -blood identity of those living in an urban environment who either possess or lack legal "Indian" status or band membership (2004:6). She critically discusses the pressure individuals experienced to abandon their identity when a family member was a survivor of the Canadian residential school system¹². She describes how these complex realities are often negotiated at the same time that mixed - blood individuals are also facing "histories of

¹² Residential schooling was in effect from the 1890s until the late 1960s and the goal of the system was to assimilate Native people into mainstream Canadian society by removing children from their families and communities, forcibly suppressing their language and negating the values of Native culture. (Grant in Lawrence 1996)

internalized racism and the fears that haunt many urban mixed-blood Native families that Nativeness, like any space of racialized ‘Otherness’, is a deeply dangerous place” (2004:10).

As a young adult, I began to seek opportunities to learn about my culture from the world around me. I purposefully chose employment that would immerse me in the world of Indigenous health. As I wound through this life journey, I met many mentors along the way. I engaged with Elders who supported my journey and answered my questions as best as they could. These experiences also ‘bridged’ me closer to my mother and provided a way for us to more easily connect with this aspect of herself as an Oji-Cree woman. She was amazed at what I was learning and was proud of my accomplishments in the ‘Indian’ world. I believe it gave her the freedom to shed internalized notions of racial oppression and talk about who she really was. My passion to understand my Indigenous heritage became a liberating factor for her. She began to share stories about herself, her language and her culture.

Over time, I discovered that I did indeed embody Indigenous values and knowledge. Whether intentional or unintentional, my mother instilled Ojibwe¹³ values, ethics and morals in her children. I know that as I pursued (and continue to pursue) a greater understanding of myself as an Oji-Cree woman, that her voice is strong in my heart. What I was hearing from other Elders, I already knew. Because my mother spoke the same words to me or advised me to act, speak or present myself in a certain way. Her stories of myth and symbolism in the natural world around us echoed in my consciousness as other Elders shared similar or exact teachings.

For those Indigenous peoples who have been raised on reserve and who may be fluent in their Indigenous language and customs, the process of ‘going inward’ may be less challenging

¹³ My mother’s father died when she was four. Her maternal grandfather was Cree and her mom was Saulteaux/Ojibwa. My mother’s language was rooted in Saulteaux/Ojibwe.

because they have the experiences of living on reserve, for example, and the language and knowledge to guide them. They also may have easy access to those who carry and teach others about Indigenous knowledge. They can draw on this knowledge to resist the Eurocentric dominance and reclaim their academic Indigeneity. For those whose experience was separation or severance from the cultural/community/family ties, the process may be more daunting. This situation is more the norm, unfortunately; however, it is important to acknowledge that it in no way discounts the individual scholar/researcher's personal expression of Indigeneity. This perspective is captured by M. Young who cites Restoule (2000), an Ojibwe historian, who advocates:

"In our lives, in our work, in our efforts to educate others, let us identify as Aboriginal people from our inside place, from ourselves, our communities, our traditions." (2005:37).

Today, in spite of my urban roots and the separation from my family in Manitoba, I situate myself as a woman of both Indigenous and Celtic heritage and I honor both aspects of my identity.

Health literacy as a research focus

As a healthcare professional for over 35 years, I became aware of how the sole focus on biomedical knowledge affected my own clinical practice and served as a major barrier towards the provision of culturally relevant care for the Indigenous people I engaged with in my practice. For example, I instinctively would inquire about my patients' spiritual well-being, a health status indicator that is usually not assessed by non- Indigenous healthcare practitioners or done so in a limited way. I always believed this aspect of one's self was closely tied to their physical health

status and as such, I knew there was something missing in how I had been educated as a health professional.

I found myself seeking a deeper level of understanding of myself but I didn't know why this was. I began to think about returning to school and over the next ten years worked towards an undergraduate degree in nursing. This period of time was intense in terms of continuing the journey towards understanding my Indigenous heritage. I worked for Indigenous organizations or for agencies that served Indigenous populations; important conduits of information that informed both my understanding of myself as an Indigenous woman and the serious population health issues for Indigenous peoples.

Over time, I have recognized the importance of ensuring that the health information that Indigenous patients were receiving was culturally relevant thereby, optimizing the opportunity for them to make positive choices that could effectively improve their health.

Chapters Outline

This thesis is organized into 6 chapters. Chapter one identifies the purpose of the research and introduces the construct of health literacy for Indigenous peoples. Critical discussion on the topic of health literacy also provided and the central argument is introduced.

Chapter two provides a theoretical framework that underpins the dissertation discussion. The ontological emphasis is placed on Indigenous knowledge but is also pluralistic to include Western knowledge. The framework includes four key assumptions that will inform the findings discussion and the relevant informing literature. These are:

1. Indigenous knowledge provides culturally based information that can positively affect the physical and inner well-being of Indigenous populations.

2. Indigenous peoples ascribe meaning to their physical and inner well-being in a way that is closely linked to socio-cultural factors and Indigenous knowledge. However, Indigenous peoples' link to Indigenous knowledge has been severed and has resulted in Indigenous knowledge diaspora that has negatively affected Indigenous peoples' health and well-being over generations.

3. Current health literacy approaches for Indigenous populations are not culturally relevant and create a socio - structural barrier for Indigenous peoples in the self-management of cardiovascular disease and other chronic illness.

4. The utilization of a pluralistic knowledge framework that is inclusive of Indigenous knowledge/Nibwaakaawin will facilitate the development of a culturally relevant health literacy approach for Indigenous patients with cardiovascular disease and other chronic illness.

A more in-depth discussion of these four key assumptions is provided in related chapters.

Chapter three provides an review of the literature on cardiovascular disease among Indigenous populations with critical discussion regarding the need for an Indigenous culturally relevant health literacy approach for Indigenous peoples experiencing cardiovascular disease and other chronic illness. Indigenous knowledge/nibwaakawin, population health and social determinants of health perspectives frame the critical discussion.

The concept of health literacy will be critically examined and it will be argued that there is a need to harmonize health literacy approaches. The concept of health literacy within an Indigenous socio-cultural context and the agentic capability of Indigenous populations will be positioned as closely tied to socio-historical and socio-structural factors. Currently, the concepts of 'risk' and personal 'asset' are key concepts to the development of health literacy approaches.

The risk concept is rooted in recognizing that low levels of literacy can negatively impact clinical care. The personal 'asset' root is linked to educational research regarding adult learning and health promotion. Nutbeam notes that there is less science to support this conceptualization and the focus is on the development of skills and capacities to enable individuals to have greater control over their health and the factors that shape health (2008:2074). Critical discussion will focus on how current health literacy approaches create structural barriers for Indigenous populations and how this situation can be situated within a structural violence framework, thereby, obstructing the agentic capability of Indigenous patients and negatively affecting both their ability to utilize and apply health information and their overall health and well-being.

It is proposed that the inclusion of Indigenous knowledge in the development of health literacy approaches for Indigenous peoples is critical for achieving an optimal state of physical and inner wellbeing for the individual, the family, the community, the nation and future generations. Furthermore, an optimal health literacy approach for Indigenous populations ideally should be a harmonized one, one that is informed by *both* Indigenous and Eurocentric ontological knowledge systems.

Chapter four provides the methods and findings of my research. As noted previously, this research is nested within a larger international Indigenous health literacy study. The chapter is formatted to provide the reader with background on both the IHLS methodology, my research methodology and relevant findings. The research was undertaken in two segments. The first as noted earlier was nested within a larger study. The study design for the larger project was a multi-method approach. Baseline in-person key informant semi-structured, in-depth qualitative interviews were conducted and the research questions related to this dissertation were included in

this interview guide. (See Appendix 1 ‘Background: International Indigenous Health Literacy Study’ and Chapter 4 ‘Methods and Findings’ for further information on methodology.)

Chapter five critically discusses specific themes from the findings described in chapter four. The focus is tied to discussing how patients ascribe meaning to their heart illness. The concept of Indigenous knowledge diaspora is introduced and discussed. Critical discussion regarding a healthcare practitioner’s role and ability to mitigate the negative effects of Indigenous knowledge diaspora through the promotion of ‘diaspora health literacy’ to Indigenous peoples with cardiovascular disease is presented.

Chapter six proposes the development of a harmonized, Indigenous health literacy model; a model that is inclusive of or facilitates access to Indigenous knowledge. The conceptual model will be promoted as an iterative one that may inform the development of an ‘Indigenous therapeutic relational space’; an approach that can be used by healthcare practitioners to more effectively provided health information to Indigenous patients with heart disease.

CHAPTER ~ 2 ~ DISSERTATION THEORETICAL FRAMEWORK

“If the Native Peoples and their heritage are to be understood, it is their beliefs, insights, concepts, ideals, values, attitudes and codes that must be studied. And there is, I submit, no better way of gaining that understanding than by examining native ceremonies, rituals, songs, dances, prayers, and stories. For it is in the ceremony, ritual, song, dance and prayer that the sum total of what people believe about life, being, existence and relationships are symbolically expressed and articulated; as it is in story, fable, legend and myth that fundamental understandings, insights, and attitudes toward life and human conduct, character and quality in their diverse forms are embodied and passed on.” (Basil Johnston, 1976)

The structure of this dissertation theoretical framework is intended to further the objective of ‘indigenizing’ health literacy approaches for Indigenous peoples. It also provides an opportunity to articulate the research, analysis and understanding of this scholar from an Indigenous personal perspective. There are four key assumptions that underpin the dissertation:

1. Indigenous knowledge provides culturally based information that can positively impact the physical and inner well being of Indigenous populations.
2. Indigenous peoples ascribe meaning to their physical and inner well-being in a way that is closely linked to socio-cultural factors and Indigenous knowledge. However, Indigenous peoples’ link to Indigenous knowledge has been severed and has resulted in an Indigenous knowledge diaspora.
3. Current health literacy approaches for Indigenous populations are not culturally relevant and create a socio - structural barrier for Indigenous peoples in the self-management of cardiovascular disease and other chronic illness.
4. The utilization of a pluralistic knowledge framework that is inclusive of Indigenous knowledge/Nibwaakaawin will facilitate the development of a culturally relevant health literacy approach for Indigenous patients with cardiovascular disease.

The framework is organized to provide a brief overview of the key elements of the thesis and the relevant informing literature. A more in-depth discussion regarding the contributing elements is provided in related chapters.

Reclaiming and Restoring Nibwaakaawin

“We need this old knowledge in our teachings to get through this new age” (Elder William Commanda,¹⁴)

“To cherish knowledge is to know Wisdom. Wisdom is given by the Creator to be used for the good of the people. In the Anishinaabe language, this word expresses not only “wisdom,” but also means “prudence,” or “intelligence.” In some communities, Gikendaasowin is used; in addition to “wisdom,” this word can also mean “intelligence” or “knowledge.” (Ojibwe Elder)

As noted earlier, it is proposed that the inclusion of Indigenous knowledge/ Nibwaakaawin in the development of health literacy approaches for Indigenous peoples is critical for achieving an optimal state of physical and inner wellbeing for the individual, the family, the community, the nation and future generations. An optimal health literacy approach for Indigenous populations ideally should be a harmonized one, one that is informed by *both* Indigenous and Eurocentric ontological knowledge systems. However, the majority of healthcare practitioners providing healthcare services to Indigenous peoples are non-Indigenous and have been educated within a Western biomedical model. A reclamative and restorative process of acknowledging and integrating Indigenous knowledge within the Academy can address this gap. This will facilitate the development of a relational health knowledge dissemination mechanism. This concept is in keeping with an Indigenous worldview and one that will assist in the creation of an ‘Indigenous therapeutic relational space’ between non-Indigenous

¹⁴ William Commanda, an Algonquin elder and former chief of the Kitigan-zibi Anishinabeg First Nation, was the wampum belt keeper for the Seven Fires Prophecy.

healthcare practitioners and their Indigenous patients. This concept will be further described in Chapter six.

The discussion is organized to situate Indigenous knowledge/Nibwaakaawin at the centre. As such, while the ontological emphasis is placed on Indigenous knowledge/Nibwaakaawin, it is also pluralistic with the inclusion of Western knowledge. Ontology refers to a branch of metaphysics concerned with the nature and relations of being. This dissertation argues that it is critical to ensure that health literacy approaches for Indigenous peoples are relational in nature and are inclusive of Indigenous knowledge/Nibwaakaawin ontology to facilitate an effective uptake of health information by this population group.

Literature from the fields of anthropology, sociology and biomedicine are referenced in conjunction with Indigenous knowledge sources to illuminate the critical discussion as required. The Seven Grandfather Teachings from the Ojibwe Nation and the Midewiwin Seven Fires Prophecy are examples of Nibwaakaawin and oral history handed down over the generations that are applicable in a contemporary time to guide Anishinawbe to live their lives in a good way. These Indigenous knowledge sources are important for understanding Indigenous beliefs and values regarding physical health and well-being and, in turn, for developing culturally relevant and empowering health literacy approaches for Indigenous peoples.

Sharing health information with Indigenous peoples: harmonizing the approach

The health status of Indigenous peoples in Canada paints a picture of high levels of infectious and chronic disease, including HIV/AIDS, cardiovascular disease and diabetes. (Waldram Herring and Young 2006:73). There is also an awareness of the link between the health disparities of Aboriginal people in Canada and the health inequities which profile the underlying

causes of the disparities including social determinants such as poverty, poor housing, low income and others (Adelson 2005:45). As such, Indigenous scholars, researchers, and health care practitioners have identified an urgent imperative to ‘decolonize’ health related education, research, policy and services for Indigenous peoples and thereby, move toward achieving a balanced physical and inner well being. Linda Tuhiwai Smith, a Maori scholar in her book, *Decolonizing Methodologies: Research and Indigenous Peoples* offers a critical discussion regarding the need to address the ‘colonization of the mind’, a phenomenon she asserts has occurred through the use of knowledge gained through the colonization of Indigenous peoples by European settlers (1999:59).

In the spirit of adhering to the decolonizing agenda, an attempt is made here to harmonize the culturally relevant health literacy discussion by not only emphasizing the use of Indigenous knowledge, but also by identifying the supportive ontological intersection with literature from anthropological sources and other appropriate social science or biomedical knowledge bases. As such, theoretical constructs and assumptions are drawn from appropriate Western based knowledge sources. These include, academic literature synthesized from the fields and sub-fields of medical anthropology and critical medical anthropology, health science and education and the practice of healthcare practitioners and the literature regarding health policy and services from both government and civil society organizations. The harmonizing approach also supports Indigenous notions of reciprocity. There is an acknowledgement and respect for both schools of thought and an understanding that each perspective contributes to the whole. This approach promotes accountability and is in keeping with the value of reciprocity.

Challenges related to ontological intersection

Seven Fires Prophecy

“The accounts of our life that have been handed down to us by our Ojibway Elders tell us that many years ago, seven major nee-gawn-an-kayg (prophets) came to the Anishinabe. They left the people with seven predictions of what the future would bring. The seventh prophet who was young and had a strange light in his eyes said: In the time of the Seventh Fire a Osh-chi-bi-ma-id-zeeg (New People) will emerge. They will retrace their steps to find what was left by the trail. Their steps will take them to the Elders who they will ask to guide them on their journey.....if the New People will remain strong in their quest, the Waterdrum of the Midewiwin Lodge will again sound its voice. There will be a rebirth of the Anishinabe nation and a rekindling of old flames. The Sacred Fire will again be lit.....it is at this time that the light-skinned race will be given a choice between two roads. If they choose the right road, then the Seventh Fire will light the Eighth and Final Fire - an eternal Fire of peace, love, brotherhood and sisterhood. If the Light-skinned Race makes the wrong choice of roads, then the destruction which they brought with them in coming to this country will come back to them and cause much suffering and death to all the Earth's people.” (Benton-Benai,1988).

The Seven Fires Prophecy quoted above speaks to the notion of how two very different value systems, materialism and spirituality, clash and how Anishinaabeg were warned to heed this prophecy if they were to survive. The dire tone of this message captures the ontological importance of Indigenous knowledge and spirituality to the Anishinaabeg. The message of the prophets is used as a metaphor for the reality of Indigenous people's task to choose the path of integrating Indigenous knowledge and spirituality into our lives.

Identifying points of ontological intersection is not without its challenges. For example, while Indigenous pedagogy respects and acknowledges the plurality of knowledge systems; Western constructs are founded on the notion of knowledge hierarchies. Horizontal ordering of what used to be “diverse but equally valid systems into a vertical ordering of unequal systems”. Martin Hill (2006) situates Indigenous knowledge in a marginalized position considered to be ‘folklore’. Indigenous scholars argue for the validity of Indigenous knowledge and situate it at

the centre as oral tradition and oral history. According to Hanson the historical record and continuity of culture and identity among North American Indigenous societies has relied on oral transmission of stories, histories, lessons and other knowledge. Hanson draws on Hulan and Eigenbrod who convey that oral tradition is the means by which knowledge is “reproduced, preserved and conveyed from generation to generation” (2009:n.p.).

Another important issue regarding the issue of Indigenous knowledge, is the limited body of scholarly knowledge available to support the primary hypothesis as noted above. The knowledge base is limited in the following areas:

- health literacy approaches specific to Indigenous populations;
- notions of structural barriers and structural violence with respect to healthcare service delivery for Indigenous populations;
- Indigenous knowledge related specifically to health and well-being
- utilization of Indigenous knowledge in health services and health literacy approaches for Indigenous populations.

Anishinaabemowin: importance of language

Another important issue related to Indigenous knowledge sharing is that of knowing and using our Indigenous languages. Cajete elaborates on this topic in the following passage:

“Language is our symbolic code for representing the world that we perceive with our senses. Meaning is not connected solely to intellectual definition but to the life of the body and the spirit of the speaker. At the deeper psychological level, language is sensuous, evocative, filled with emotion, meaning and spirit. In its holistic and natural sense, language is animate and animating, it expresses our living spirit through sound and the emotion with which we speak. In the Native perspective language exemplifies our communion with nature.” (Cajete, 2007)

This quote captures the essence of the importance of language (Anishinabemowin: the language of the Ojibwe) for M. Young who describes feeling more spiritually connected with her heart and soul when she speaks her language. Young, along with several other authors contribute to the discourse on why language is critical to effectively understanding and sharing Indigenous knowledge. She shares the viewpoint of Kirkness (1998) and Sachedev (1998) who suggest that if we lose our languages, we lose the essence of who we are as a people. Young reports that she has explored the relationship between language and the cultural identity of Aboriginal people as a way of reclaiming her own voice and vision (2005:34). Tom Porter, Mohawk Elder and spiritual advisor, affirms Young's position who compares the experience of hearing and understanding the language as a "3-D technicolor" experience. One in which he saw vivid pictures of action, of colors, of even songs in the language (2008:91).

"The Autissokaunuk too sang to him, for it was they who had summoned him to the skies and by chanting to him, gave him their language. They then returned him to the earth. As the manitous, for that is what the Autissokaunuk are, summoned him to their presence, so the young man could, with the language conferred upon him, summon the manitous for their help and guidance on behalf of the people." (Johnston 2011:12).

In this quote, Johnston illuminates the important role that language plays in linking the physical and spiritual world for the Anishinaabeg. Johnston echoes Young (2005) and advocates for learning our language to ensure the survival of tribal language and "the whole body of tribal knowledge that is embodied in the oral literature". He cautions that tribal identity will be lost with the language (2011:29).

The next section introduces the main argument of the thesis and describe the goals of the research.

Thesis: Indigenous peoples with cardiovascular disease require culturally relevant health literacy approaches that are informed by both biomedical and Indigenous knowledge/Nibwaakaawin

The Canadian Expert Panel on Health Literacy (Expert Panel) concluded that overall, there is a lack of awareness and understanding of the concept of health literacy in Canada. The Panel also concluded that there is a lack of systematic information in Canada on levels of literacy and health literacy in certain populations including Aboriginal people. The Panel recommended that policies to raise average health literacy levels might lead to improvements in population health and a reduction in health costs (CPHA 2013:n.p.).

Another important consideration related to health literacy, is the presence of individual and system barriers. Examples of individual barriers include, declines associated with aging, low levels of formal education, lack of health knowledge and skills, having a mother tongue other than English or French, living with disabilities, social stigma and early childhood experiences (CPHA 2013:n.p.). The Expert Panel also identified several systems barriers to health literacy that included, school health and physical education programs implementation issues, limitation in resources for language programs (English/French) and inadequate workplace training and education.

Health literacy approaches undertaken by non-Indigenous healthcare practitioners working with First Nations, Inuit and Métis populations are grounded in dominant Western theory (i.e. biomedicine). I suggest that existing health literacy approaches that are *not* inclusive of Indigenous knowledge impede access to culturally-based health information. This creates a structural barrier and perpetuates an assimilative, oppressive force that impacts personal agency

among First Nations, Inuit and Métis people. It impedes their ability to live their life ‘*in a good way*’ and fosters an ever-widening health disparities gap among these population groups¹⁵.

Research Goal and key assumptions.

Cardiovascular disease (angina, myocardial infarct, stroke and transient (ischemic attack) are major causes of mortality and hospitalization for adult Indigenous peoples in Canada. There are also significant inequalities in cardiovascular disease related morbidity, mortality and the prevalence of cardiovascular disease risk factors between Indigenous and non-Indigenous populations.

The goal of this thesis was to explore and understand both the meaning of cardiovascular disease for Indigenous peoples who were participants in the study and their experiences with healthcare practitioners in the exchange of health information regarding their cardiovascular disease and treatment. More specifically, I wished to explore how Indigenous peoples’ interactions with healthcare practitioners may influence their sense of personal agency with respect to the self-management of their cardiovascular disease. I began this research with the hypothesis that Indigenous notions of empowerment is an important socio-cultural factor to be considered in the goal towards improving health literacy approaches for Indigenous populations and positively affecting health outcomes.

I expected that my research findings could potentially increase awareness among health care practitioners regarding how they can facilitate and support the agency of Indigenous patients

¹⁵ For example, the National Collaborating Centre for Aboriginal Health reports the average life expectancy at birth for Canadians was 82.1 years for women and 77.2 years for men. While for First Nations women, it was 76.6 years and 68.9 for First Nations men. (2007:10)

within the therapeutic relationship thus, increasing the overall effectiveness of the health literacy approach.

Four key assumptions frame the main argument presented in this thesis. A brief description of each assumption follows; along with the contributing literature.

Assumption #1:

Indigenous knowledge provides culturally based information that can positively impact the physical and inner well-being of Indigenous populations. Many Indigenous scholars have articulated the complex nature of Indigenous knowledge and its importance to physical and inner well being for Indigenous populations. (Cajete 2000; Dion Stout 2003; Smith 1999) Indigenous knowledge has been passed down for thousands of years and is central to the role of health research for Indigenous Peoples (NAHO 2003). If one is to appreciate and ‘come to know’ about Indigenous science, an understanding about Indigenous culture, worldview and paradigm is required (Cajete 1999). Sources of Indigenous knowledge include Traditional teachings, empirical observation and revelation (Brant-Castellano 2000:23). Discussion will also be drawn from Battiste 2000, 2002; Bruchac 2003; Benton-Benai 1988; Davis 2008; Henderson 2000; Johnston:1976, 2011; Martin Hill 2008; Porter 2008; Young 2005.

Western constructs of knowledge are founded on the notion of knowledge hierarchies while Indigenous knowledge is pluralistic and acknowledges ‘diverse ways of knowing’. Western cultural constructs of ‘valid’ empirical research have marginalized Indigenous ways of knowing (Martin Hill 2008). Indigenous scholars and health researchers are moving beyond the practice of validating Indigenous worldviews and knowledge systems by comparing them against western or dominant knowledge systems (Brant-Castellano 2000:23). Indigenous knowledge is a ‘stand-alone’ knowledge system that should be accepted and valued as being unique and

distinctly separate from Western Culture (Martin et al. 2006; Sillitoe 1998; Dudziak 2006; Lux 2001;

Assumption #2:

Indigenous peoples ascribe meaning to their physical and inner well-being in a way that is closely linked to socio-cultural factors and Indigenous knowledge. However, Indigenous peoples' link to Indigenous knowledge has been severed and has resulted in an Indigenous knowledge diaspora.

For millennia, Indigenous peoples have understood their own health within the context of their own Indigenous ways of knowing, a way of knowing that is intricately linked to the way their lives are intertwined with the world around and beyond them and manifests in their beliefs, customs, traditions and languages. While there are diverse visions of health and well-being among Indigenous groups in Canada, (NAHO 2003), an underpinning of the Indigenous perspective is their wholistic worldview¹⁶. The construct of health is considered *in relation* to the physical, emotional, mental and spiritual realms of the individual. There is a need to further understand how Indigenous peoples ascribe meaning to illness and how it is related to their worldview. Ojibwe teachings are described with an emphasis on the Ojibwe notion of 'Bimaadiziwin' or 'a healthy way of life'. Indigenous teachings used to interpret this thesis research, are drawn from the work of Lillian Pitawanakwat, Ojibwe Elder and Wisdom Keeper, Thomas Peacock, Indigenous scholar (2002) Basil Johnson, Anishinaabe Wisdom Keeper and scholar, (2002) and Edward Benton -Benai, Indigenous educator and spiritual teacher (1988).

The intention is to ground the discourse regarding how Indigenous peoples make meaning of the

¹⁶ The use of Ojibwe teachings regarding Indigenous health and well-being to inform the development of a culturally relevant health literacy approach for Indigenous populations may be considered a limitation of this thesis. There is great diversity in the ways of knowing regarding health and well-being among other First Nations, Métis and Inuit peoples. Thus, there could also be a wide variance in their approaches to health literacy.

concept of illness and of physical and inner well-being. Furthermore, I study how they make the important connection to Indigenous ways of knowing¹⁷. Medical anthropology perspectives on the meaning of illness are drawn from Nancarrow (1992); Kleinman (1995); Baer, Singer and Susser (2003); BJ Good (1993); Farmer and Good (1991).

Assumption #3

Current health literacy approaches for Indigenous populations are not culturally relevant and create a socio - structural barrier for Indigenous peoples in the self-management of cardiovascular disease and other chronic illness. The WHO describes the term 'health literacy' as referring to an individual's ability to read, comprehend and act on medical information and defines the concept as; "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" (World Health Organization 2008:n.p.). Currently, the dominant health literacy approach draws from a dominant positivist theory related to 'literacy'. Literacy interventions to date have focused on a dominant cognitive or deficit model. Discussion regarding health literacy in Canada are drawn from; Rootman and Gordon - El-Bihbety 2008; Baynham 1995; Schaefer 2008; Street 2005; Nutbeam 2006 and Weiss 2005.

Critical discussion related to the need to 'indigenize' health literacy approaches for Indigenous populations is drawn from; Smylie Williams and Cooper 2006; Korhonen 2006; Muspratt, Luke and Freebody 1997; Prinsloo and Breier 1996; Robinson-Pant 2004; Nutbeam 2006.

¹⁷ It is respectfully noted that writing about Indigenous knowledge or defining Indigenous knowledge within Eurocentric language and constructs has been described by contemporary Indigenous scholars as not being congruent with Indigenous ways of knowing and erodes the nature of it.

Biomedicine has assumed a dominant role in the delivery of health information in Canada. This creates a major structural access barrier for Indigenous peoples who wish to integrate Indigenous knowledge in the self-management of cardiovascular and other chronic illness. Indigenous patients use *both* Indigenous knowledge *and* biomedical health information in their efforts to self-manage their physical and inner well being. Kleinman (1980) Polit et. al (2001) and Winkleman (2009) who are critical medical anthropologists have articulated the dominance of biomedicine and the need to champion pluralistic approaches to health services.

It is proposed that culturally inappropriate health literacy approaches for Indigenous peoples creates a socio- structural barrier and impedes the uptake of health information which negatively impacts personal agency, perpetuates oppression and results in the continuing overall poor health outcomes for this population group.

Assumption #4

The utilization of a pluralistic knowledge framework that is inclusive of Indigenous knowledge/Nibwaakaawin will facilitate the development of a culturally relevant health literacy approach for Indigenous patients.

The acceptance of the importance of theoretical pluralism is identified as a key component towards ameliorating the structural barrier by emphasizing the use of Indigenous knowledge/Nibwaakaawin to inform academics, policy makers and educators regarding the health literacy needs of Indigenous populations. This is an emerging area of scholarship and discussion in this thesis will be drawn from contemporary Indigenous scholars including; Battiste 2004; Daes, (2000) Henderson, (2000) Little Bear, (2000) Alfred and Smith (1999). The discourse draws on Battiste's call to "liberate Indigenous thought, practices and discourses rather

than relying on existing Eurocentric or colonial theory” (2000). Native ceremonies, rituals, songs, dances, prayers and stories can inform the discussion related to Indigenous knowledge.

The following quote from Basil Johnston speaks to the significance of this approach:

“For it is in ceremony, ritual, song, dance and prayer that the sum total of what people believe about life, being existence and relationships are symbolically expressed and articulated; as it is in story, fable, legend and myth that fundamental understandings, insights, and attitudes toward life and human conduct, character and quality in their diverse ways are embodied and passed on.” (1988:7).

Oguamanem, a scholar who has written extensively on Indigenous knowledge and legal issues, reports that more than 80 percent of Indigenous peoples are said to rely on Traditional medicine practices for their health care (2006:5). A majority of a 2003 First Nations poll respondents reported using Traditional Healers and medicines and would be more likely to use Traditional care if it were locally available and covered by the health care system (NAHO 2003). Treatment of illness involves understanding multiple factors that disturb balance and are situated both within the individual and the world around them (NAHO 2003). Traditional healing methods include healing circles, sweat lodges, Traditional medicines, songs, dancing, feasts and other ceremonies. Other factors related to restoring balance and health include self-determining activity, community and economic development, family healing and personal change (NAHO 2003). As noted previously, Indigenous knowledge has long been marginalized by non-Indigenous social science scholars from within the academy, and by health/social policy-makers and health science educators. Various factors related to this situation include:

- Institutions of higher learning revere pedagogical knowledge that is grounded in Eurocentric scientific assumptions
- Indigenous knowledge was most often labelled as ‘folklore’ and rejected as a legitimate scientific pedagogy that could adequately inform the development of scholarly discourse

- There has also been a dominant biomedical focus within the sub-field of medical anthropology

As a result, the scholarly study of Indigenous knowledge by Indigenous academics is an emerging one. Contemporary Indigenous scholars are now challenging the Eurocentric dominance of knowledge within the academy and bridging the scholarly chasm between Eurocentric and Indigenous pedagogies. Now that they have accessed the Academy, scholarly based reclamation strategies have facilitated the emergence and integration of Indigenous knowledge/Nibwaakaawin through tribal teachings, stories and narratives and situated them in the discourse regarding Indigenous health and well-being.

Theoretical assumptions regarding pluralism are drawn from the sub-fields of medical and critical medical anthropology as captured in the discourse related to the notion of ethnomedicine; (Winkleman; 2009) and explanatory models of illness (Kleinman 1995).

Another important contributing factor, is the need to increase awareness and understanding among health care practitioners regarding the socio-historical and socio-cultural context of Indigenous health. It is proposed that this factor is linked to the lack of or minimal Indigenous-specific health science curriculum that is otherwise, rooted in the hierarchy of Eurocentric scientific knowledge within the Academy. This situation perpetuates the dominance of the biomedical approach to healthcare and results in a distorted perspective regarding the health literacy needs for Indigenous populations.

This chapter has provided an overview of the structure of the dissertation theoretical framework. It was intended to further the objective of ‘indigenizing’ health literacy approaches for Indigenous peoples. It was also intended to situate my own perspective and understanding as an Ojibwa-Cree woman in the research, analysis and interpretation of the findings. Four key

assumptions have been presented as underpinning the theoretical framework of this dissertation.

The importance of reclaiming and restoring Indigenous knowledge or Nibwaakaawin in the process to develop a relational health knowledge dissemination mechanism has been presented as a concept that is in keeping with an Indigenous worldview. It is proposed that this process will lead to the development of an 'Indigenous therapeutic relational space' and a harmonized health literacy approach for Indigenous peoples that will be discussed further in Chapter six.

CHAPTER ~ 3 ~ ODAYIN (HEART) TEACHINGS: CVD & HEALTH LITERACY

This chapter provides an overview on cardiovascular disease among Indigenous populations with critical discussion regarding the need for an Indigenous culturally relevant health literacy approach. The first section provides information on morbidity, mortality, causal factors, disparities and risk factors. The evolving concept of health literacy is critically discussed in the second section including various factors and barriers related to the development of a culturally relevant health literacy approach for Indigenous populations.

Cardiovascular disease and Indigenous populations

The National Collaborating Centre for Aboriginal health (NCCA)H) cites Medicine Net and reports that cardiovascular disease is inclusive of “a wide range of ailments that affect the heart or blood vessels, including arteriosclerosis, coronary artery disease heart valve disease, arrhythmia, heart failure, hypertension, orthostatic hypotension, shock, endocarditis, diseases of the aorta and its branches, disorders of the peripheral vascular system and congenital heart disease” (2012:18). According to Waldram et al., cardiovascular disease can be described as a “heterogenous group of diseases of the heart and blood vessels” (2006:93). The heart and blood vessels, whether the blood vessels are affecting the lungs, brain or other parts of the body are included in the description of cardiovascular disease by the Public Health Agency of Canada (PHAC 2010:n.p.).

Cardiovascular diseases are major causes of mortality and hospitalization for adult Indigenous peoples and there are significant inequalities in morbidity, mortality and prevalence of risk factors between Indigenous and non-Indigenous populations (Toronto Academic Health Sciences Council Human Subjects Research Application (TAHSC): ‘Strengthening health

literacy among Indigenous people living with cardiovascular disease, their families, and health care providers' 2011:4). The Indigenous population of Canada represents 4.3 percent (1,400,685) of the total Canadian population¹⁸ (35,141,542)¹⁹ (Statistics Canada 2006). Of this figure, 61 percent identified as First Nations, 32 percent as Métis and 4 percent as Inuit²⁰. (See Figure 1)

Aboriginal Identity	Number	Percent
Total Aboriginal identity	1,400,685	100
First Nations single identity	851,560	60.8
First Nations single identity (Registered or Treaty Indian)	637,660	45.5
First Nations single identity (not a Registered or Treaty Indian)	213,900	15.3
Métis single identity	451,795	32.3
Inuit single identity	59,445	4.2

Figure 1 Aboriginal identity population, Canada, 2011²¹

¹⁸ This reflects a increase from the 2006 Census which reported that Aboriginal people accounted for 3.8% of the population.(Stats Can - The Daily- **2011 National Household Survey: Aboriginal Peoples in Canada: First Nations People, Métis and Inuit** - <http://www.statcan.gc.ca/daily-quotidien/130508/dq130508a-eng.htm>)

¹⁹ Statistics Canada In the News:Latest Indicators - Population Estimate' <http://www.statcan.gc.ca/start-debut-eng.html>) Retrieved August 4th.

²⁰ First Nations totaled 851,560 representing 60.8% of the total Aboriginal population; 451,795 identified as Métis representing 32.3% of the total Aboriginal population and 59,445 identified as Inuit representing 4.2% of the total Aboriginal population.

²¹ Reference: StatsCan - 2011 National Household Survey: Aboriginal Peoples in Canada: First Nations People, Métis and Inuit -Aug 4th-<http://www.statcan.gc.ca/daily-quotidien/130508/dq130508a-eng.htm>)

Current health statistics²² reflect major health disparities for First Nations compared to the rest of Canada²³. For example, First Nations communities face high risk of suicide, substance abuse, community and family violence, high rates of infectious and chronic disease and high levels of injury (NCCAH 2007:10). First Nations have a much shorter life expectancy than their Canadian counterparts; 4.4 and 6.3 years shorter for men and women respectively and they are at an increased risk for causes of death that occur more frequently at younger ages, such as injuries and suicides. For Inuit, this pattern is similar. For Métis, life expectancy was 3.3 and 5.5 years shorter for men and women respectively²⁴ (Statistics Canada 2009:n.p.).

Cardiovascular disease has been identified as the leading cause of death in adult Canadian men and women (Public Health Agency of Canada 2010:n.p.). This is confirmed by the ‘Canadian Heart Health Strategy and Action Plan’ which reports that cardiovascular disease kills more Canadians each year than any other illness (2009:n.p.). This report also notes that 1 in 20 people in Canada report that they have a cardiovascular disease or illness. (2009:1).

In spite of the limited national-level data, cardiovascular disease is considered to be a major cause of mortality and hospitalization for adult Indigenous peoples. The RHS 2008/10 Adult Survey reports that heart disease is prevalent in 5.7 percent of the adults surveyed. High

²² Smylie et al. (2011) report an important consideration in the critical discussion related to the health of Indigenous populations in Canada is the issue of the lack of population-based health assessment data for urban Aboriginal health information. For example, in Ontario with over 60% of the Aboriginal population living in urban areas, public health data is almost non-existent despite its size (150,570 persons) (Reference: Our Health Counts - Smylie Firestone Cochran Prince Maracle Morley Mayo Spiller and McPherson 2011:16).

²³ As noted in chapter one, the average life expectancy at birth for Canadians was 82.1 years for women and 77.2 years for men. While for First Nations women it was 76.6 years and 68.9 for First Nations men.

²⁴ “For both Aboriginal groups, mortality rate ratios were highest at younger ages. Mortality rate differences among Métis men were particularly elevated for external causes and circulatory, respiratory and digestive system diseases; among Métis women, for circulatory system diseases, cancers, and digestive and respiratory system diseases. Generally, rate differences for Registered Indian men and women were further elevated.” <http://www.statcan.gc.ca/pub/82-003-x/2009004/article/11034-eng.htm>(Statistics Canada, 2009)

blood pressure is reported at 21.8 percent and is noted to be the most reported chronic condition among the adults surveyed. A higher percentage of First Nations men (6.7 percent) reported having heart disease than First Nations women (4.2 percent) (2012:116).

An important consideration regarding the prevalence of heart disease among Indigenous population groups is the co-morbidity of diabetes. Reading reports that diabetes “is one of the most reported on and documented chronic diseases in Aboriginal health because of its recent status as an epidemic among Aboriginal Canadians” (2009:79). The co-morbidity of diabetes and cardiovascular disease is important, in part, because of the relationship with cardiovascular disease as a major risk factor. Harris et al. in a 2002 study, measured cardiovascular disease risk factors and their relationship to glucose intolerance among Ojibwe-Cree individuals ages 18 and over in Sandy Lake, Ontario. They discovered that high rates of obesity were associated with increasing glucose intolerance for both males and females; rates of smoking exceeded 70-80 percent in females and males respectively; and with worsening glucose intolerance, TC, TG, LDL-C and HDL-C dramatically deteriorated in comparison to national published levels. The authors note that these changes in cardiovascular disease risk factors, as a consequence of diabetes, appear to be resulting in increase clinical outcomes. They note that admission to hospital for IHD increased from 34.8 to 109.1/10,000 in 15 years. The impact of diabetes on lipid risk factor is described as having devastating consequences on cardiovascular disease related outcomes (2002:165).

Health inequities and disparity

In the 1970s-80s, ischemic heart disease and stroke mortality for Indigenous females was reported to be higher than for all Canadians and for males, was higher than other Canadians excluding ischemic heart disease. By 1999-2000, the age –standardized mortality rate (ASMR) of all cardiovascular disease among First Nations was reported to be slightly higher than that of all Canadians. However, “ the ASMR for IHD was not significantly different between First Nations and Canada in 2003” (Waldram, Herring and Young 2006:93).

More recently, the prevalence of cardiovascular disease among Indigenous populations must be considered within the construct of health disparity and further, be linked to health inequity. Adelson, a medical anthropologist, in her article, *The Embodiment of Inequity: Health Disparities in Aboriginal Canada*, makes a link between health disparity and health inequities. Health inequities point to the underlying cause of disparity many of which Adelson proposes sit largely outside the domain of health (2005:S45). The National Collaborating Centre for Aboriginal Health (NCCA) also cites a disproportionate burden of ill - health that can largely be attributed to adverse socio-economic conditions and historical circumstances (2008:10). According to Crengle, Smylie and Anderson, there are significant inequalities in cardiovascular disease related morbidity, mortality and the prevalence of cardiovascular disease risk actors between Indigenous and non-Indigenous populations (2009:n.p.). Reading reports that the morbidity and mortality rate are double that of the general population ²⁵. The First Nations

²⁵ However, an important issue in the discourse related to the prevalence of cardiovascular disease among Indigenous populations in Canada is the need for data. Urban, Inuit and Métis populations are important populations to target for future research in order to better understand the burden of cardiovascular disease among Indigenous populations (2009:89-90). Reading cites Yusuf, Reddy, Ounpuu and Anand (2001) who also note that there are important regional and intertribal differences in CVD risk factors and disease rates which is also an issue that needs to be considered.

Regional Health Survey 2002-03 (FNRHS) reports that 7.6 per cent of respondents reported having heart disease versus 5.6²⁶ per cent of the general Canadian population (2007:n.p.). Bjerregaard et al. cite Waldram et al. who report that Inuit have a lower incidence of IHD (2006:94). For stroke, Bjerregaard et al. in Waldram et al. reports that the ASMR is reported as 1.7 times higher for men and 1.4 times higher for First Nations women (2006:94). According to Bjerregaard et al. mortality from stroke among Inuit is similar or higher than among other Western populations (2003:356). While the incidence of myocardial infarction mortality is increasing among Inuit in Nunavut, it is declining in the rest of Canada (2006:95). The 'Canadian Heart Health Strategy and Action Plan' reports that cardiovascular disease is a 'crisis' for Aboriginal peoples who are 1.5 - 2 times more likely to develop cardiovascular disease (2009:1).

Causal Factors

Researchers, policy makers and health professionals have made some headway in recent years towards identifying historical, socio-economic, environmental and cultural factors related to cardiovascular disease among Indigenous populations. In addition, modifiable risk factors for cardiovascular disease have been assessed among some Indigenous groups and new evidence is emerging regarding culturally specific health promotion approaches for Indigenous peoples at risk of developing or currently experiencing cardiovascular disease (Welty 2002:97). A number of factors have been found to be associated with the rising levels of cardiovascular disease among Indigenous peoples in Canada including historical, socio-economic, environmental and genetic factors. The following provides an overview of these factors.

²⁶ The RHS 2008/10 Adult survey indicates there is little change in this statistic with a prevalence of 5.7 percent.

Historical factors

Historically, the process of European colonization influenced a Traditional way of life for Indigenous peoples that included an active physical lifestyle and a diet that met their nutritional needs. Indigenous peoples lost “Traditional lands and practices such as trapping, hunting and fishing” (Reading 2009:72). This led to a more sedentary lifestyle and subsequent health problems such as inactivity and obesity. In more recent historical times, Shephard and Rode note that during the early 1960’s, circulatory disorders were low on the list of causes of death (40/100,000) in the North West Territories (1996:40). Northern populations generally were at a low risk of atherosclerotic heart disease (1996:40). Food sources were very high in protein and polyunsaturated fats and very low in carbohydrates; possibly a main contributing factor to low blood lipid profiles (1996:41).

In addition, health policy for First Nations, Inuit and Métis peoples, has been tied to colonization by the Federal Government whose aim was to assimilate Aboriginal people into mainstream society. Adelson (2005) notes that the health disparities that currently exist among Indigenous peoples are entrenched in the history of relations between Aboriginal people and the nation-state. Frideres, (Indigenous sociologist) and Gadacz (anthropologist) (2008) discuss the context of colonization in the provision of low-quality social services for colonized Aboriginal individuals in areas of health and education. They cite a 2001 Indian and Northern Affairs Canada survey that confirmed a desperate need for adequate health and social services and acknowledge the lower life expectancy in comparison to the non-Aboriginal population. They note that while some modest housing improvements occurred; social problems, new diseases and other social ills have increased. In short, inadequate, culturally inappropriate and government-

imposed approaches to health care are not achieving the intended improvement of health outcomes for Indigenous peoples (2008:5). Health service issues for Indigenous peoples such as jurisdictional wrangling can be linked to factors that include a relationship with government that is shaped by colliding worldviews and resistance to self-determination, culturally inappropriate health policy, the complexity of jurisdictional accountability, and inadequate financial resources. These issues serve as structural barriers to the effective implementation of culturally appropriate health services for Indigenous peoples. Reading cites the First Nations Centre at the National Aboriginal Health Organization (2005) and Kirmayer, Brass and Tait (2000) who note that the efforts of the Canadian government to oppress “Indigenous cultures, traditions and community structures of Aboriginal peoples has caused collective trauma and grief that is thought to have cumulated as health problems in many Aboriginal communities (2009:9).

Socio-economic factors

Diabetes, IHD and other chronic diseases were once associated with wealth and affluence. According to Kirmayer, et al., (2000) in Reading and Waldram et al. (2006:93) they are more likely to affect those experiencing lower socio-economic conditions (2009:10). The lived realities of Indigenous peoples demonstrate a complexity of socio-economic issues that can be linked to poor health. Overall income demonstrates one aspect of this reality. Reading cites Sin, Wells, Svenson and Man who report that for Aboriginal people, 73.4 per cent were earning less than \$20,000 per year and the average income was \$15,699 versus \$25,414 for the rest of Canada in 2002 (2009:12).

Emerging evidence links chronic disease with socio-economic status among Aboriginal people. A picture of the far-reaching impact of poverty on health is emerging in the literature.

Reading draws from Indian and Northern Affairs Canada (2004), O'Neill (2007) and Blackstock (2005) in a summary of the prevalence of poverty among Aboriginal populations in Canada that highlights the gap in the quality of life and well-being between Aboriginal Canadians and the rest of Canada (2009:11). Marmot and Wilkinson (1999) in Reading, report that there is an “abundance of data showing a link between poverty and ill-health” (2009:13). For example, psychosocial stress is linked with ill health for those living in poverty and is described as “loss of control over one’s destiny”. Reading discusses this theory and cites the work of Marmot and Smye (2004; 2005) and McEwan and Swan (1998; 2006) who argue that lack of control over life circumstances creates stress load which then contributes to diseases such as diabetes and cardiovascular disease, alcoholism, suicide and cancer (2009:13). Reading reports on the work of Health Canada (2006a) Warry (1998) and Wilton (2004) regarding the link between socioeconomic disparity and the loss of control of destiny as a major risk factor for mental health problems (2009:14). Reading also calls for further research on the nature of the complex relationship between poverty and chronic disease among Aboriginal populations (2009:15).

Environmental and Structural Factors

According to Waldram et al., diseases originate from structural and functional derangements; biological in nature in the human body at the molecular, cellular, tissue, organ and organism levels. Human biology as a health determinant has traditionally encompassed studies into the genetic contributions to specific diseases and physiological adaptations to the environment. In the Canadian context, these are primarily cold related (2006:113). For example, pollution from large-scale industrial projects powered by coal affects the environment and contaminates Inuit Traditional foods with man-made chemicals (Bjerregaard et al. 2004:393).

Inuit infants are also exposed prenatally to heavy metals such as mercury and lead. Children may experience adverse effects of exposure to organo-chlorines and mercury and be neuro-psychologically affected in their development. According to Bjerregarrd et al. Environmental health problems related to housing, water supply and sanitation are also still evident (2004:394).

Reading cites Carson, Dunbar, Chenhall and Bailie (2007) regarding the negative impact on health that housing disadvantages can have. Homelessness is one example of a housing issue of concern among Aboriginal groups. Reading also cites Helin (2002) in a review of the general literature that shows that Aboriginal people are at an increased risk of becoming homeless. Wentz is also quoted (2000) as reporting that 24 percent of Toronto's homeless population are people of Aboriginal ancestry (2009:17). Homelessness remains a serious psychosocial stressor and risk factor linked to heart disease.

Genetic Factors

Genetic susceptibility can also be a causal factor with many diseases as Waldram et al report (2006:114). According to Hegele, Connelly, et al. (1997) and Hegel, Sun et al. (1999) and Hegele, Young and Connelly (1997) in Waldram et al., numerous research studies, since the 1990s have been conducted regarding the genetics of diabetes, cardiovascular disease, and lipid abnormalities in Aboriginal populations, especially the Oji-Cree of Sandy Lake, Ontario and the Inuit in the Kivalliq region of Nunavut (2006:114). Diabetes and heart disease are “complex, multi-factoral and polygenic” and are not the result of a single gene but are controlled by the action of many different genes that interact among themselves and with other environmental factors to produce the clinical features of the disease (2006:114). The next section will discuss

the modifiable risk factors related to cardiovascular disease and will present the argument related to 'associated risk' for Indigenous populations.

Risk Factors

The Public Health Agency of Canada reports that the most common type of cardiovascular disease is ischemic heart disease and that it affects men and women equally. They also report that aside from age and heredity, the majority of cases of cardiovascular disease are related to modifiable risk factors including, smoking, lack of exercise, unhealthy eating, high cholesterol, high blood pressure, sodium, stress and diabetes (PHAC 2010:n.p.). Kuh and Ben-Shlomo cited in Reading, note that policy makers and health professionals have targeted these modifiable risk factors as a model for prevention and intervention of chronic disease (2009:5). According to Welty et al., both mortality rates and incidence rates are rising among American Indian populations and several studies have reported a rapid and alarming increase in cardiovascular disease risk factors among American Indian communities (2002:97). More recently, Chateau-Degat et al. (2010) and Kuhnlein et al. (2004) report in the RHS 2008/10 Adult Survey that evidence suggests the rates of type 2 diabetes and related cardiovascular disease risk factors among Inuit are increasing (2012:128). The following provides an overview of several risk factors related to Indigenous populations.

Smoking is a serious problem among Indigenous populations. Almost half of all First Nations participating in the 2002/03 FNRHS, reported that they are daily smokers (46 percent) and an additional 12.8 percent self-identified as occasional smokers. In comparison, the *Canadian Tobacco Use Monitoring Survey* in Reading, reported that 21 percent of the general Canadian population smoked in 2003 (2009:69). Of particular concern, is that younger First

Nations adults (18-29 years) have the highest proportion at 53.9 percent of daily smokers (2007:17). In a 2002 Northwest Territories study Waldram et al. reported that 36 percent of Aboriginal children between the ages of 10 and 17 were identified as current smokers (2006:116).

Retnakaran et al. found that in Aboriginal communities where cigarette smoking was reported as 'remarkably high' that "an independent dose-response relation was found between current smoking exposure and blood pressure and homocysteine levels. The authors conclude that "the association of cigarette smoking with an enhanced cardiovascular risk profile at an early age may be a factor contributing to the high prevalence of CVD in this Aboriginal population." (2005:885).

Diet and lack of exercise

People who do not exercise regularly are at a greater risk of having heart disease. (Health Canada 2010 n.p.). Inactivity has become a key contributing factor to obesity in both Aboriginal and non-Aboriginal populations. Reading cites the First Nations Centre at NAHO (2005) regarding an American Indian and Alaskan Native (AI/AN) study, which reported that 37.2 percent of AI/AN reported no physical activity during their leisure time. Reading also reports that the reasons for reduced physical activity are linked with the loss of First Nations Traditional lands and an active lifestyle (2009:72). According to Waldram et al., the Aboriginal People's Survey (APS 1993) reported that 54 percent of Aboriginal adults nationally participate in leisure-time physical activity (2006:119). Bjerregaard et al. reports: "The lifestyle of the Inuit is rapidly changing towards an increased cardiovascular risk factor profile". "Physical activity declines, obesity is widespread, the reliance on imported food increase and the smoking rates are

alarmingly high”. The authors advocate for studying Inuit Elders for potential determinants of Inuit cardiovascular disease and mortality pattern by studying the life of the Elders in a historical perspective and following their disease and mortality pattern over the coming years.” The authors caution however, that time is running out and that in a few years, we may not be able to find out why the Inuit were protected against ischemic heart disease – if ever they were (2003:356).

Hypertension

Hypertension or high blood pressure is an issue of serious concern for Indigenous populations and thus, is a major risk factor. The First Nations and Inuit Regional Health Survey (FNRHS) (2004) is cited in Waldram et al. as reporting 18 percent of respondents or 1 in 5 people reported being diagnosed with high blood pressure (2006:95). The FNRHS (2004) also reported that, 20.4 percent reported high blood pressure compared to 14.4 percent of their Canadian counterparts (2007:12). Inuit blood pressure rank is reported as intermediate on a global scale but low in comparison with most European populations (Bjerregaard et al. 2004:392). The RHS 2008/10 Adult Survey reports that a higher proportion of First Nations adults reporting a diagnosis of high blood pressure has increased (21.8 percent vs. 13.4 percent) since the 2002/3 RHS report. Hypertension is the most commonly reported health condition (2012:116).

High Cholesterol

According to Waldram et al., there is limited data on the lipid levels of Aboriginal people. However, a Nutrition Canada Survey in 1975, reported on lipid levels within 29 First Nations across the country and 4 Inuit communities in Northwest Territories. Their findings indicated that First Nations men aged 55 and older were considered high risk and all other categories were a

lower risk than their Canadian counterparts (2006:96). Anand et al. cited in Waldram et al. reported a mixed pattern in a Six Nations study with “no significant difference in mean total and LDL-cholesterol while the mean triglycerides was higher and HDL-cholesterol “found to be no different from the rest of Manitoba although the level of triglycerides was lower than that of HDL cholesterol was higher than in Manitoba except for women aged 25-44” (2006:96). An American study by Welty et al., a 4-year follow up to the ‘Strong Heart Study’ which studied a cohort of American Indian adults ages 45-74 years; found that the surviving women who participated in the follow up study, had lower baseline total cholesterol levels than those who did not survive (2002:100).

Associated Risk Factors

Exposure to biological and socio-environmental determinants of health

There is an emerging literature (Kuh et al. 2003; Reading (2009); Moore and Davis 2005) that makes a case for linking the long – term effects of physical and social exposures during early developmental periods in one’s life to one’s developmental health and later disease risk. Reading proposes that a ‘life- course’ model provides a way to “conceptualize how underlying biological and socio-environmental determinants of health, experienced at different life stages can differentially influence the development of chronic diseases (2009:6). Lynch and Smith (2005) in Reading note that this approach shows how risks that occur through one’s life can be identified and then corrected or modified over the long period of time it takes for the chronic disease to develop (2009:6). Danton – Hill et al. argue that one can see health differences among populations and social classes that illuminate disadvantage and wide variance in economic and social life circumstances. These authors also assert that strategies that address risk factors must

continually account for underlying social determinants that “foster disease risks within all age groups and across generations” (2009:6). Reading notes that the method provides researchers with tools to integrate scientific, cultural and sociological knowledge in a meaningful way and states that this “fusion is necessary to satisfy both the scientific and cultural requirements of Aboriginal health research”. The approach also complements Indigenous conceptions of health and well-being because as Lynch and Smith (2005) note; “life course research understands health in a wholistic way” (2009:7). The concept of holism is a central tenet to Indigenous worldview and values.

Meaning of Cardiovascular Disease illness

Another important consideration is the variation in how cardiovascular disease is perceived by healthcare practitioners and their Indigenous patients. Healthcare practitioners are educated in the biomedical perspective. Biomedical understandings of cardiovascular disease are informed by a broad range of technological and biomedical assessment and supported by Western scientific evidence. The Indigenous perspective, on the other hand, may be grounded in oral history. The following quote provides an example of this view.

“The west also represents the heart, the evaluator of what’s going on in my life. As adults, we need to be in touch with this evaluator, because it helps us to see the cycle of life, to appreciate and enjoy the fruits of life, and to accept aging and change, making peace with our lives and deaths. We are given the responsibility to nurture our hearts, so that we may be in balance, and see the Medicine Wheel for what it is. And so to help us we have been gifted the medicine of sage. When we smudge ourselves, burn the sage and bring the smoke over our bodies, we are given the gift of clearing our minds and hearts, so that we may prepare well for the rest of our journey.” (Ojibwe Elder, Lillian Pitawanakwat)

This gap in perception becomes in turn, an ‘associated risk factor’ for cardiovascular disease. There is a need for health care professionals to further understand how Indigenous peoples ascribe meaning to illness and how it is related to their worldview towards ensuring health literacy approaches are culturally relevant and free from structural barriers. For example,

Garro's study regarding perception of hypertension among Ojibwa people in Manitoba, provided support for a shared cultural model for knowledge about high blood pressure. An exploration of a prototypical model indicated that it could be both general and flexible enough to accommodate diversity (1988:98).

Health Literacy for Indigenous Populations

As noted previously by the Canadian Expert Panel on Health Literacy, there is a need to increase the knowledge base regarding literacy and health literacy for Aboriginal people. An important element to this endeavor, is to raise awareness and respect for the diversity and complexity of Indigenous knowledge and how it contributes to one's beliefs and values.

Indigenous creation stories provide an example of how story can contain important information that can be linked to beliefs regarding health. The following is an account of the Ojibwe creation story²⁷.

"When Ah-ki" (the Earth) was young, it was said that the Earth had a family. Nee-ba-gee'-sis (the Moon) is called Grandmother, and Gee'-sis (the Sun) is called Grandfather. The Creator of this family is called Gi'-tchie Man-i-to' (Great Mystery or Creator).

The Earth is said to be a woman. In this way it is understood that woman preceded man on the Earth. She is called Mother Earth because from her comes all living things. Water is her life blood. It flows through her, nourishes her, and purifies her.

On the surface of the Earth, all is given Four Sacred Directions - North, South, East, and West. Each of these directions contributes a vital part to the wholeness of the Earth. Each has physical powers as well as spiritual powers, as do all things.

When she was young, the Earth was filled with beauty. The Creator sent his singers in the form of birds to the Earth to carry the seeds of life to all of the Four Directions. In this way, life was spread across the Earth. On the Earth the Creator placed the swimming creatures of the water. He gave life to all the plant and insect world. He placed the crawling things and the four-leggeds on the land. All of these parts of life lived in harmony with each other.

²⁷ According to Benton-Banai, for Indigenous people, creation stories are viewed as a knowledge base that can be seen as the equivalent to a scientific theory.

Gitchie Manito then took four parts of Mother Earth and blew into them using a Sacred Shell. From the union of the Four Sacred Elements and his breath, man was created. It is said the Gitchie Manito then lowered man to the Earth. Thus, man was the last form of life to be placed on the Earth. From this Original Man came the A-nish-i-na'-be people. (From whence -lowered-the male of the species). The man was created in the image of Gitchie Manitu. He was natural man. He was part of Mother Earth. He lived in brotherhood with all that was around him.

All tribes came from this Original Man. The Ojibway are a tribe because of the way they speak. We believe that we are nee-kon'-nis-ug' (brothers) with all tribes; we are separated only by our tongue or language." (Benton-Banai 1988:2-4)

Indigenous knowledge transmission often occurs in the telling of stories. Many well known Indigenous authors; (Johnston 2011; Peacock and Wisuri 2002; Benton-Banai 1988) have affirmed the importance of story-telling in the Ojibwe culture to teach, amuse, to open minds, to cheer and uplift the hearts and spirits of their listeners. Listeners learn about their history, traditions, customs, beliefs, rituals, codes, the manitous, the other world, the afterlife, the before-life, language, medicine, zoology, botany, geography, songs and dreams (Johnston 2011:155). Johnston also describes how important storytelling was to teach the youth what they needed to know in life and how doing so provided the old with the opportunity to pass on what they know. By listening, youth grew in mind, heart, soul and spirit. He makes the important point that as individuals grow, so does the nation's knowledge base and its sense of worth and purpose (2011:155). Copway (1987: 72-73) in Peacock and Wisuri notes that stories remain as the way that knowledge and wisdom is passed down in Ojibwe communities. Clifford (1986) in Peacock and Wisuri makes the important point that stories grow and change to fit the times; it is also believed that this is the nature of stories (2002:28).

It is said that our stories are no different from the words of our languages. They both have many meanings and applications and Johnston argues that they also bear our “tribal perceptions, values and outlooks” (2011:79).

The creation story as noted above, is very pertinent to the notion of physical and inner well being of Indigenous peoples. While various Oji/Saulteaux groups may have some variance to the details of the Creation Story, there is a central theme of belief in the presence of spirit; a Great Mystery. The emphasis on the spiritual is in keeping with Indigenous values of wholism and balance; both considered to be closely connected to the notion of bimaadiziwin. As such, Indigenous knowledge/Nibwaakaawin has potential to convey and affirm cultural values regarding health that can potentially inspire a wholistic, balanced approach to one’s way of living. Health literacy approaches for Indigenous patients with cardiovascular disease that promote and facilitate access to knowledge/Nibwaakaawin, may support the adoption of these and other cultural values that can positively influence self-care management strategies.

The concept of health literacy

As noted previously, health literacy is identified as a key driver of knowledge, self-management of care and health outcomes. Nutbeam, an international public health expert and researcher,²⁸ discusses the development of health literacy as a concept and notes that there are two different roots to its development; clinical care and public health. Both ‘risk’ and ‘personal asset’ concepts reflect health literacy. The risk concept recognizes the impact that low levels of literacy can have on clinical care. The ‘risk’ root is supported by ‘strong’ science to support screening for poor literacy skills in clinical care. This approach is leading to clinical practice and

²⁸ Dr. Don Nutbeam is a world-renowned expert on public health, and over his thirty-year research career has made a substantial international impact on the theory, science and practice of health promotion. His research interests include public health intervention, health literacy and adolescent health behaviour.

organization. The ‘personal asset’ has roots in educational research into literacy with concepts of adult learning and health promotion. Nutbeam notes that there is less science to support this conceptualization and the focus is on the development of skills and capacities to enable individuals to have greater control over their health and the factors that shape health. Nutbeam’s position is that both conceptualizations are important and are illuminating health communication practice and factors impacting its effectiveness. Recommendations include improved interaction between researchers working within the two health literacy perspectives and further research on the measurement of health literacy (Nutbeam 2008:2072).

Health Canada’s position is that literacy is one of the major influences of health status and further, that health is negatively impacted by low literacy levels (Korhonen 2006:1). Poorer health outcomes including reduced life expectancy and higher rates of infant mortality are often associated with Canadians who have lower levels of education. (Rootman and Gordon- El Bihbety 2008:49). Weiss summarizes the serious consequences related to inadequate health literacy that include, less health knowledge, lower health status, higher utilization of health services and higher health care costs than those with higher literacy levels (2008:12).

An Expert Panel on Health Literacy, established by the Canadian Public Health Association (CPHA) in 2006, defined health literacy as; “the ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course” (Rootman and Gordon-El-Bihbety 2008:3). There is also an increasing awareness that health literacy is linked with social determinants of health such as literacy, education, income and culture (Mitic and Rootman 2012:3). The Panel concluded that overall, there is a lack of awareness and understanding of the concept of health literacy in

Canada. Further, there is a lack of systematic information in Canada on levels of literacy and health literacy in certain populations including Aboriginal people. They recommended that policies to raise average health literacy levels might lead to improvements in population health and a reduction in health costs (Rootman and Gordon-El-Bihbety 2008:3).

Cardiovascular disease and the need for health literacy

An international Indigenous health literacy study²⁹ reports that patients and families are considered the primary ‘manager’ of their chronic illness. Self-management of care is considered a central component to effective cardiovascular disease management. This approach requires a working knowledge and understanding of their cardiovascular disease medications, and an ability to effectively communicate with healthcare practitioners. The limited knowledge available indicates that intermittent use of medications and non-adherence with prescription instructions is common. Following an acute myocardial infarction, for example, approximately 24 percent of patients discharged from hospital did not have their prescriptions filled within 7 days of discharge; 34 percent stopped at least one medication and 12 percent stopped all three medications within 3 months of discharge (Downey, Nepinak, Cooper, Prince and Smylie 2013:26-30). It is noted that longer term adherence is even lower. The next section will discuss select socio-cultural and socio-historical factors related to health literacy for Indigenous populations.

Health Literacy Assessment and Barriers

As noted previously, serious health challenges for Indigenous peoples in Canada including cardiovascular disease, diabetes and other chronic illness, indicate that this population

²⁹ Strengthening Health Literacy Among Indigenous People Living with Cardiovascular Disease, Their Families and Health Care Providers - Phase 1 Report

is an important target group for ensuring high levels of health literacy that will then support self-management approaches to health care. However, various issues and barriers exist that impede progress in the development of a culturally relevant health literacy approach for Indigenous populations.

The aforementioned Expert Panel concluded that despite recent progress defining and measuring health literacy, there has been no consensus on these issues; a situation that has negative implications for all Canadians (Rootman and Gordon-El-Bihbety 2008:3). The Panel's position was that data from Canada's 'International Adult Literacy and Skills Survey' (IALSS) provided the best information regarding the extent and distribution of health literacy within Canada. The IALSS was an initiative that seven countries conducted in 2003. It is a psychometric test to measure prose and document literacy as well as numeracy and problem-solving skills³⁰. The survey's main purpose was to determine how well adults used printed information to function in society. Another objective was to collect data that would inform the understanding of the incidence and volume of participation in adult education and training, and to investigate relationships between initial and adult education; literacy, numeracy and problem-solving proficiency and wider economic and social outcomes. It is noted that the sample survey did not represent First Nations on reserve, although urban Aboriginal populations in Manitoba and Saskatchewan and three northern territories were included (Statistics Canada 2007:n.p.).

Another important consideration regarding health literacy as noted by the Panel, is the presence of individual and system barriers. Individual barriers include; declines associated with aging; low levels of formal education; lack of health knowledge and skills; having a mother

³⁰ In Canada, the survey population was expanded to provide information on respondents over the age of 65.

tongue other than English or French; living with disabilities; social stigma and early childhood experiences (Rootman and Gordon - El-Bihbety, 2008:4). The Panel also identified several systems barriers to health literacy that included school health and physical education programs implementation issues; limitation in resources for language programs (English/French); inadequate workplace training and education; confusing or conflicting health information from the media and the internet; complex health systems; demanding self-care regimes for chronic diseases; and lack of awareness and knowledge about health literacy among health and literacy professionals (Rootman and Gordon-El-Bihbety 2008:4).

Socio-structural barriers

This section critically discusses key systemic and socio- structural factors related to health literacy that serve as barriers to the development of a culturally relevant, harmonized health literacy approach for Indigenous peoples. The focus here is two-fold, the dominance of biomedicine and resistance to accepting Indigenous knowledge as a valid scientific body of knowledge and restricted access to Indigenous knowledge and Traditional healing services for Indigenous peoples.

Barrier: dominance of biomedicine and resistance to accepting Indigenous knowledge as a valid scientific body of knowledge

While there may be a growing appreciation of an Indigenous epistemology among mainstream healthcare practitioners, there is still a long way to go towards acceptance and horizontally situating Indigenous knowledge in its rightful place alongside Western knowledge systems. Various factors related to the dominance of biomedicine, create a structural barrier for

Indigenous patients who may want to also access and utilize Indigenous knowledge and Traditional healing.

Biomedicine is a term used to refer to a health care model that is referred to as ‘allopathic’ (against symptoms). It is also used to refer to other terms such as ‘medicine’, allopathic medicine and scientific medicine, among others³¹ (Winkleman 2009:193). The field of ‘biomedicine’ is often considered the dominant approach for health problems (Winkleman, 2009:6). Kleinman notes that medicine is “so widespread around the globe that it is surely a universal in human organizations” (1995: 21). It is also distinguished from most other healing systems cross culturally and he establishes the global perspective of the ‘primacy of its “epistemological and ontological commitments”’; basically, on a global level, biomedicine is considered the “gold-standard” in terms of health care. According to Eisenberg (1977) and Hahn (1995) in Winkleman, biomedical practitioners view illness primarily as ‘disease’ which is considered to be “biologic abnormalities in the body’s structures, chemistry, or functions”³² (2009:38). Winkelman, an American anthropologist, proposes that biomedicine is grounded in four basic assumptions; diseases are basically, biological and are indicated in the departure from normal measures of biological functioning; generic conception of diseases is reflected in a universally valid system of classification; each disease derives from a specific physical cause of etiology and medical practice is culture-free and scientifically neutral and objective. Winkleman, provides an example of a biomedical assumption from the mental health field that is deeply

³¹ Practitioners of biomedicine are physicians and others who work under direction of a physician including nurses, respiratory therapists, laboratory technicians and pharmacists There are also other practitioners who treat a specific part of the body such as dentists, optometrists and physical therapists.

³² Winkelman notes that while some specialties within biomedicine, such as psychiatry, do use psychological, behavioral, and social models of illness, biology is still the dominant model embodied in various canons of reference such as the ‘Diagnostic and Statistical Manual of Mental Disorders (DSM). This is the official diagnostic manual of psychiatry and psychology.

engrained by most health professionals; that is, that mental health problems are primarily related to biological abnormalities, particularly neurotransmitter levels and need to be modified with medication³³ (2009:38). The concept of culture is proposed by Winkelman as fundamental to understanding health and medicine because personal health behaviors and professional practices of medicine are described as being deeply influenced by culture (2009:3).

An important consideration in understanding biomedicine as a dominant model is the fact that health policy and the development of health services is informed by evidence; namely, health related research. According to Polit and colleagues, the ‘scientific’ or biomedical approach to conducting research “has its underpinnings in the philosophical paradigm known as a *positive paradigm*.” and thus, can be referred to as ‘positivist’ (2001:12). This approach calls for orderly and disciplined procedures to test the researcher’s ideas. The process is a systematic one with a set plan and the researcher uses mechanisms to control the study meaning that there is also an imposition of conditions on the research situation to minimize bias and increase validity and precision (2001:14). Positivists believe in an *objective* reality separate from their personal beliefs and bias (2001:12). The goal is to acquire *empirical evidence* that is rooted in this objective reality. Typically, a *quantitative* approach to the research methodology is most often associated with the positivist approach.

The measures used within a biomedical framework as proposed by Winkleman include: mortality, morbidity, life expectancy, reserve health or the capacity to resist disease and stressors, social support, overall birthrate and the population growth rate (2009:15).

³³ Winkelman critically argues that an examination of specific disease and their outcomes illustrates limitation of these assumptions and illuminates the role that culture plays (2009:38). He provides a critical review of the four areas noted above and challenges how the concept of culture intersects within each.

The concept of resistance can be linked to the hierarchical positioning of biomedicine and its hegemonic influence on society. For example, physicians are considered one of the most powerful and influential groups with authority and control of resources in settings such as hospitals, public health agencies and national politics³⁴ (Winkleman 2009:194). The power of biomedicine and its status as the ‘exclusive, legitimate medicine’ is considered to have occurred fairly recently and is the result of political actions taken by professional medical organizations in the late nineteenth and early twentieth centuries that led to the exclusion of other forms of medical practice (2009:193). Non - medical practitioners such as chiropractors, homeopaths, naturopaths, herbalists and midwives were often marginalized in their practice by the efforts of physicians to maintain control over health care services³⁵ (2009:193).

According to Singer and Baer, the biomedical interpretive focus can be seen as hegemonic in nature. Hegemony is achieved and maintained through the spread of ‘self-interested values, attitudes, ideas and norms from the dominant group to the rest of society’. It reinforces the ‘ultimate social legitimacy of the existing structure of society’. These authors also note that biomedicine as a core institution of capitalist society, is a system that reinforces dominance at the micro-social level and therefore, plays a vital hegemonic function (Singer Baer and Susser 2003:62). This concept has important implications when considering the notion of ‘indigenizing’ health literacy approaches for Indigenous populations; more specifically, accepting the validity of Indigenous knowledge/Nibwaakaawin as a scientific body of knowledge and using it in an applied way for Indigenous peoples.

³⁴ Although more recently, Winkleman notes that their power has been decreasing in the face of public reaction to the rising cost of healthcare (194)

³⁵ Winkleman notes that osteopath physicians managed to maintain an autonomy.

Winkleman proposes that culture³⁶ is a principal determinant of health conditions, that expose or protect us from disease through structuring our interactions with the physical and social environment. (i.e diet, clothing, hygienic practices, work activities etc.). Cultural knowledge is seen as essential for addressing public health mandates to assess community health needs, develop appropriate health policies and programs and ensure adequate and culturally competent health services (2009:3). It is important that health policy makers, educators and health professionals who utilize health knowledge in their practice with Indigenous peoples, do so with an understanding of the Indigenous cultural context. This would include moving beyond an awareness that Indigenous people with cardiovascular disease and other chronic illness have a culturally unique worldview, to an acceptance and respect that they are stewards of important knowledge and furthermore, they may wish to utilize *both* western and Indigenous knowledge systems in their approach to health. To do so, would contribute to the development of a respectful and culturally safe interface between healthcare practitioners and their Indigenous patients. As a result, health literacy approaches would also be adjusted to reflect this harmonization of worldviews. To achieve this objective, mainstream health policy makers, educators and health care professionals must acknowledge and accept that knowledge flows both ways and there are knowledge systems beyond a Western scientific orientation. A relationship of equality requires an acceptance that Indigenous knowledge is of equal value.

Indigenous peoples have long held their own knowledge generation and knowledge sharing systems. Indigenous knowledge/Nibwaakaawin is central to culturally relevant Indigenous health literacy approaches. While it is acknowledged that literature on the topic of

³⁶ Winkleman's definition of culture: "Culture involves the learned patterns of shared group behavior. These learned shared behaviors are the framework for understanding and explaining all human behavior. This includes health behaviors, particularly intergroup differences in health behaviors and beliefs." (3)

Indigenous knowledge does exist, it is only just emerging and thus, is limited in scope and depth³⁷ (Battiste 2002:2). However, contemporary Indigenous scholars have articulated the complex nature and importance of Indigenous knowledge towards the development of culturally safe services for Indigenous populations (Dion Stout 2003; Smith 1999; Cajete 2000 and NAHO 2003).

Indigenous knowledge can be considered a knowledge 'paradigm' in its own right. Bohm and Peat's description (1987) of a paradigm is quoted by Little Bear in Cajete, as including "tacit infrastructures, which are mostly unconscious pervading the work and thought of a community". Little Bear describes a Native American paradigm as being comprised of ideas of constant motion and flux; existence consisting of energy waves, interrelationships, all things being animate, space/place, renewal and all things being imbued with spirit" (2000:x). Each of these descriptions captures the emphasis on wholism; of something that is the sum of its parts with a commonality of thought and fluidity of concepts. Sefa Dei et al. describe their conceptualization of Indigenous knowledge as; "a body of knowledge associated with the long-term occupancy of a certain place." (2000:3).

Indigenous knowledge is an integral component of Indigenous peoples' being and identity (Oguamanam 2006:4). According to Sefa Dei et al., Indigenous knowledge refers to Traditional norms and values, mental constructs that guide, organize and regulate people's way of living and help them make sense of their world. The authors describe Indigenous knowledge in this way:

³⁷ Lux in 'Medicine that Walks' also notes that, apart from oral histories, historical documents [regarding Indigenous peoples' health] were limited in their accounts and recorded observations often focused on negative aspects such as practices that resulted in fatalities. Rarely were effective responses to disease and illness cited (14)2001:14)

“... It is the sum of the experience and knowledge of a given social group and forms the basis of decision making in the face of challenges both familiar and unfamiliar.” (2000:6).

The concepts of ecology and spirituality are noted to be the foundation of Indigenous or non-western epistemic world views (Oguamanam 2006:4). Traditional teachings relayed by Elders, empirical observation and revelation are also considered Indigenous knowledge; all handed down over the generations and remaining relatively intact (Brant-Castellano 2000:23). Battiste notes that Indigenous knowledge comprises a set of technologies that have been developed and sustained by Indigenous civilizations (2002:2)

Indigenous knowledge is closely tied to the concept of Traditional healing (TH). Traditional healing systems are noted to be knowledge-based practices that are used by Indigenous peoples to maintain harmony with their communities and with the surrounding universe (WHO 1999:46). Traditional healing practices are designed “to promote mental, physical and spiritual well-being based on beliefs that go back in time, before scientific biomedicine”. They are described as responding to “the internal logic of each of the Indigenous peoples and are a product of their unique vision of the universe or cosmo vision” (RCAP 1994:n.p.). Traditional healing activities include use of medicinal plants, communication with spiritual beings, dreams and the use of the healing power of water and minerals. These practices also have a strong spiritual element which requires special powers and strength. They are conducted by healers who are selected members from the community (WHO 1999:46). They are known to possess a broad knowledge base garnered from thousand of years of learning experience that has been passed between generations. Traditional healers are considered to hold special strength and wisdom and they have a responsibility to maintain and transmit the teachings of their ancestors (1999:46).

It is acknowledged that there is also critical debate on how the notion of ‘Traditional’ healing is defined; specifically, Traditional healing cannot be separated from the contemporary context (Waldram Herring and Young 2006:237). Waldram et al. propose that, ‘Traditional’ healing approaches in contemporary times are ever - evolving systems of knowledge and practices that synthesize borrowed and newly developed ideas whatever the source, with existing ideas³⁸ (2007:237). However, Battiste affirms the nature of Indigenous knowledge transmission as being oral and symbolic. She notes that Indigenous knowledge is typically embedded in the cumulative experiences and teachings of Indigenous people and has its own internal consistency and ways of knowing and that there are limits to how far it can be comprehended from a Eurocentric point of view (2002:2)³⁹. In addition, the nature of Indigenous knowledge accommodates a fluidity and complexity described by Youngblood - Henderson (2000:260). Therefore, the melding of a Traditional practitioner’s body of shared inter-generational, Traditional knowledge with his/her experiential knowledge in the ‘here and now’ would be the norm. It would not be considered as ‘watered down’ or lessen the complexity nor the historical authenticity of the body of knowledge that they have come to know.

The need for reform in the provision of healthcare services for Indigenous peoples has been acknowledged by healthcare practitioner networks. For example, the potential positive effect of Indigenous Traditional healing ways has been acknowledged the Canadian Medical Association who testified to the Royal Commission on Aboriginal Peoples that values and

³⁸ Based on this factor, the authors reject the term ‘Traditional’ and adopt the term ‘Aboriginal Healing’ as an alternative. However, the term ‘Aboriginal’ is oft considered a Government - imposed term and is not well received by Indigenous groups.

³⁹ The context of Battiste’s statement is captured in her work related to the undertaking of a literature review regarding Indigenous knowledge for the work of a National Working Group on Education for Indian and Northern Affairs Canada in 2002.

practices adapted from Aboriginal healing traditions offer both immediate and long-term positive effects to health status. Several areas of health care were identified as areas where Traditional healing may add value. These include health promotion, support for increased personal responsibility for health and care system reorientation (to increase comfort level for Aboriginal people) (1994:n.p.). As noted previously, while there have been some successes towards advancing awareness and support of Indigenous knowledge/Traditional healing, there is still work to be done.

Barrier: lack of Indigenous context in health science curriculum

The second structural barrier can be framed as a resistance of biomedicine to accept Indigenous knowledge as a valid scientific knowledge system. Namely, that there is a lack of substantive health science curriculum that is inclusive of Indigenous knowledge and Traditional healing systems, Indigenous socio-historical and socio-structural realities and the population-specific social determinants of health that negatively impact their overall health and well-being. It is noted that the positivist or scientific approach is at the core of medicine's knowledge-generating and training system (Kleinman 1995:21). Medicine insists on materialism as the grounds of knowledge and further, expresses discomfort with dialectical modes of thought. It requires a single causal chain to specify pathogenesis as the rational for therapeutic efficacy in a language that Kleinman notes has structural flaws and mechanisms (1995:29). Biomedicine contrasts itself with ethnomedical systems in that it criticizes ethnomedicine for being 'religious', 'superstitious', 'quackery' or fraud (Winkelman 2009:6). However, according to Polit and colleagues, because there are always multiple interpretations of reality, this would then imply that there is no one process to determine the ultimate truth of falsity of the constructions

being considered (2001). For example, researchers who aspire to the foundation of a *naturalist paradigm* which is also sometimes referred to as a *phenomenologic paradigm*, believe that reality is not a fixed reality but rather, one that is constructed by the individual participating in the research and that it occurs within a context. This position is known as one of *relativism*.

Anthropologists have long concerned themselves with the study of non-Western practices towards treating health related illness from a cultural perspective. These are described as ‘ethnomedical systems’ (Erickson Murphy 2008:192). For example, the study of shamanism could be considered an ethnomedical practice. Ethnomedicine is described in ‘A History of Anthropological Theory’ as the anthropological study of non-western medical systems (Erickson Murphy 2008:192). Earlier generations of socio-cultural anthropologists viewed ideas about health, illness, misfortune, and supernatural power as part of an integrated social and cultural structure. More recently, the influence of postmodernity, feminist anthropology and political economy have resulted in the emphasis on the ‘ideological or conflicted nature of indigenous practice’. Erikson and Murphy, in their discussion of ethnomedical systems acknowledge that various activities related to spirituality could be considered an ethnomedical practice. These authors argue that ‘folk medical practices’ are now viewed as “one site of contest between conflicting local and trans-local ideologies that variously square off against one another or mingle to create new forms of practice, belief and power relations” (2008:192).

Winkleman notes that ethnomedical systems occur within all cultures and describes them as “institutionalized practices for addressing health maladies” (2009:192). According to Coreil and Mull ethnomedical studies focus on illness terminology, theories of causation, folk illness categories, diagnostic criteria for evaluating symptoms and what is termed the ‘language of

distress' that is used to describe the illness experience in addition to concepts of disease, the predominant focus of biomedicine (1990:11).

Barrier: restricted access to Indigenous knowledge and Traditional healing

Indigenous peoples have identified that access to Indigenous knowledge and Traditional healing is an important part of a culturally relevant approach to healthcare. An Aboriginal Peoples Survey indicates that 10.1 per cent of respondents living on reserve, 4.6 percent of the urban sample and 3 percent of the Métis sample had consulted a Traditional healer in the previous year (Royal Commission on Aboriginal Peoples 1994:n.p.) A national level survey of First Nations and Inuit found that eighty-five per cent of those surveyed indicated that a return to Traditional ways is a good way to promote wellness (1999:193). A 2003 First Nations poll, indicated that the majority of respondents, reported using Traditional healers and medicines and would be more likely to use Traditional care if it were locally available and was covered by the health care system⁴⁰ (First Nations Centre at NAHO 2003:18). A second factor related to access, includes how Indigenous knowledge is shared among Indigenous populations. Indigenous knowledge has been passed between generations for thousands of years (NAHO 2003:3). Various ways are employed to pass on knowledge. These include Traditional teachings, ceremonies, healing practices and everyday living (NAHO 2003:25). Indigenous knowledge sharing also

⁴⁰ It should be noted that since 1984, in Ontario, the Aboriginal Healing and Wellness Strategy a joint program between the Ontario government and First Nations and Aboriginal organizations boast many successes both on and off reserve by providing combined Traditional and mainstream programs and services to help improve Aboriginal health and reduce family violence. Services include community wellness programs, Aboriginal community wellness programs, Aboriginal Healthy Babies, Healthy Children Program, counselling to address mental and emotional issues, crisis intervention services, healing lodges, health care, health promotion and education, shelters and safe houses for women escaping domestic violence and their children, pre and post-natal care and substance-abuse treatment centres. Since the program's inception, there is improved access to health care, enhanced services to address family violence, and increased capacity of First Nations, Métis and Inuit communities within a wholistic and culture-based framework. (Refn - <http://www.mcass.gov.on.ca/en/mcass/programs/community/programsforaboriginalpeople.aspx>)

employs the use of allegory and Elders' teachings (Szasz 2008:8). Martin et al. note that narrative in the form of oral tradition is essential in maintaining Aboriginal society and culture (2006:16). Battiste affirms the orality and symbolic features of Indigenous knowledge and describes the inter-generational sharing as occurring through modeling, practice, and animation rather than through the written word (2002:2). Many anthropologists considered native oral histories as 'peripheral' and further, they have clung to beliefs that Eurocentric English held an inherent moral superiority (Szasz 1994:8).

Anishinaabemowin: The importance of Language

As noted previously, another important factor integral to the sharing of Indigenous knowledge is fluency in an Indigenous language. Reyhner (1996) in Peacock and Wisuri ⁴¹ notes that language contains the subtleties, nuances and deeper meanings of culture and without it, a culture will die⁴². Without knowledge of the language, participants to Indigenous spiritual ceremonies that include stories, prayers or songs will not know the meaning of them (2002:31). Healing ceremonies are primarily conducted in an Indigenous language. This is a significant detrimental factor and presents as a major barrier towards understanding values and customs related to the promotion of physical and inner well being and the sharing of Traditional healing knowledge. Also, importantly, there are fewer and fewer fluent Indigenous language speakers. This means that for those wanting to learn their language and understand various cultural values related to physical and inner well-being; there is limited access. Peacock and Wisuri describe this

⁴¹ Thomas Peacock is an Ojibwe scholar and member of the Fond du Lac Band of Lake Superior Chippewa. Wisuri is credited as the photographer in 'Ojibwe Waasa Inaabidaa: We Look in All Directions'

⁴² Peacock and Wisuri discuss the debate on the schools of thought related to the links between language and culture. Another school of thought presented is that culture exists regardless of language; that cultural mannerisms, cultural events and means of survival are ways of transmitting cultural knowledge and history through English rather than Ojibwe language.

situation as a ‘cultural vacuum’ that was left when healing skills were not passed down through the generations.⁴³ They also make the important point that for Ojibwe people, Traditional health practices, especially those combined with prayer and ceremony, were also closeted in mystery for generations because they were banned for many years by European colonizers (2002:102-103).

In summary, existing health literacy approaches that are *not* inclusive of Indigenous knowledge/Nibwaakaawin perpetuate an assimilative, oppressive force that impacts personal agency among First Nations, Inuit and Métis people, impedes their ability to live their life ‘*in a good way*’ and fosters an ever-widening health disparities gap among these population groups. This situation can be framed as a structurally violent experience for Indigenous peoples, a concept that will be critically examined in Chapter four.

It is proposed that pluralistic knowledge frameworks namely; the inclusion of Indigenous knowledge is critical to the development of optimal culturally relevant health literacy approaches for Indigenous populations. Further that ideally, the approach should be a harmonized one that is informed by *both* Indigenous and Eurocentric ontological knowledge systems. This structural reform will require acceptance of Indigenous knowledge as a valid body of scientific knowledge, collaboration and support from biomedical healthcare practitioners and health science educators and health policymakers.

⁴³ Peacock and Wisuri discuss the impact of European settler colonization and assimilation efforts that included forbidding the Ojibwe language to be spoken in residential schools. This is described as a major external force that led to the decline of the Ojibwe language.

CHAPTER ~ 4~ METHODS AND FINDINGS

This chapter provides an overview of the research methodology and findings of my dissertation project on health literacy programs for Indigenous peoples. The overall goal of my research was to further understand the cultural context of both the Indigenous patient experience of cardiovascular disease and the patient-practitioner relationship. This research was undertaken in two segments. The first segment was nested within the study; *'Strengthening health literacy among Indigenous people living with cardiovascular disease, their families, and healthcare providers'*; the Canadian arm of a larger international health literacy study. (See Appendix ~1~ Background: International Indigenous Health Literacy Study). The second segment of my research was an iterative extension of the first.

Methods: Research Segment One

Ethics and Community Partnership Building

"To improve the wellness of Aboriginal individuals and the community by providing services that respect people as individuals with a distinctive cultural identity and distinctive values and beliefs." (De dwa da dehs nye>s - Aboriginal Health Access Centre, Board of Directors Manual)

Ethics approval for my research was obtained through the McMaster University Research Ethics Board. In addition, my research methodology was guided by the larger international study protocols approvals obtained for each country through the Health and Disability Multi-region Ethics Committee, in New Zealand; the University of Melbourne Research Ethics Committee in Australia and the St. Michael's Hospital Research Ethics Board in Canada.

A research agreement⁴⁴ was negotiated between St. Michael's Hospital and the Aboriginal Health Centre Board of Directors. The purpose of the agreement was to ensure that the project was respectful to cultures, languages, knowledges, values, and rights to self-determination of the Aboriginal Health Centre. It also provided a framework for the use of data collected during the research project. It was intended to support the principles of an Aboriginal collective and self-determined data management and governance process (Phase 1 Report 2013:9). From a local, community perspective, the agreement supports the information needs of the DAHAC and represents the aspirations of the Principal Investigator and the research team to conduct the research in a collaborative and iterative process that demonstrated a partnership approach that moves beyond an agreement. The research team inclusive of DAHAC administration and staff members engaged and collaborated on activities such as preparation of the actual grant, in multiple planning and implementation meetings. This methodological approach is in keeping with 'OCAP' research principles; namely, ownership, control, access and possession⁴⁵.

Research Interviews

Research interviews for the first segment of my research took place at both the Hamilton and Brantford Ontario sites of the De dwa da dehs nye>s -Aboriginal Health Access Centre (DAHAC). Both sites of the De dwa da dehs nye>s - Aboriginal Health Centre (DAHAC) assist First Nation, Inuit and Métis people in accessing culturally relevant health care programs and services. The focus is on a holistic, preventive and primary health care that includes physicians,

⁴⁴ Research, Data, Statistics and Publication Agreement' Between De dwa ad dehs nye>s-Aboriginal Health Access Centre and the Centre for Research on Inner City health (CRICH)/St Michael's Hospital (SMH)

⁴⁵ These principles first emerged from the National Steering Committee of the First Nations and Inuit Regional Longitudinal Health Survey and they are applied to all research, data or information initiatives that involve First Nations. The implementation of research that ascribes to OCAP enables a self-determining process over all research concerning First Nations and provides a way to improve research relevance for First Nations (First Nations Centre at the National Aboriginal Health Organization 2007: 1-2).

nurse partitioners, Traditional healing and other primary health services, mental health support and community health supports - advocacy and outreach, health promotion and education services (De dwa da dehs nye>s-Aboriginal Health Centre, Board of Directors Orientation Manual 2013:3). The DAHAC serves all Indigenous peoples, regardless of status and offers assistance to outside service organizations to provide care in a culturally appropriate way to nearly 6000 Indigenous peoples across the two sites (2011:21).

Patient Participant Characteristics/socio-demographics

Patient participants who have cardiovascular disease or diabetes⁴⁶ and take medications to manage their chronic illness were recruited by the Aboriginal Health Centre staff across both sites and contacted by myself for scheduling of interviews according to the ethics - approved protocols. A formal demographic profile was not completed with the patient participants as participants were referred to the study by the DAHAC staff thus, I did not have access to their files. The interview guide was also fairly lengthy and it was deemed important to avoid interview fatigue. However, several patients informally offered additional information. The following captures information regarding the socio-cultural demographic profile relevant to the area of inquiry.

Age-gender

At the Hamilton site, a total of 17 client participants were interviewed. Of the 17 interviewed, 9 were male and 8 were female. The age of the patient participants ranged from 49 to 71 years. At the Brantford site, a total of 8 client participants were interviewed. Of the 8 interviewed, 3 were male and 5 were female. The age of patient participants ranged from 45 to

⁴⁶ Patients required to be on two meds for high blood pressure or high cholesterol or diabetes diagnosis

73 years old. Thus, the majority of the participants were in their sixties and the next largest category group were in their forties.

Within the Hamilton patient participant group, 7 of 10 participants had a familial history of cardiovascular disease. In Brantford, 4 of 4 patients asked had a familial history of cardiovascular disease⁴⁷. All patients from both sites reside in the DAHAC catchment area which the cities of Hamilton and Brantford Ontario.

Expression of Indigenous Identity

The De dwa da dehs nye>s-Aboriginal Health Centre notes that many First Nations living in Hamilton (and presumably Brantford) have geographic and family ties to Six Nations and fifty-one percent report as Registered Indians.⁴⁸ (DAHAC, 2007:21). More specifically, across both sites, 38 percent of patient participants self-identified as First Nations - single. Of these, 6 identified as Mohawk and 3 as Oneida. Twenty - nine percent identified as First Nations with 7 participants identifying as First Nations - combined, meaning parents were descended from different First Nations or from one First Nations parent and one non-First Nations. Three participants claimed Métis heritage. Of these, 1 participant identified as Métis/ Ojibwe; 1 as Métis/First Nations and 1 as Métis/Irish. One participant identified as First Nations -Mohawk/ Anglo; 1 as Ojibwa/Irish and 1 as Delaware/Irish. One participant refused to identify their specific Indigenous affiliation and 1 identified as Native and non-Native. One participant identified as 'Mohawk' but did not participate in cultural activities or have any desire to.

⁴⁷ The total number of patients interviewed was 6 but two patients were not asked about their familial history as these two interviews were conducted by another team member.

⁴⁸ The DAHAC is situated in Hamilton, Ontario with a satellite site in Brantford Ontario as noted previously. There are two First Nations reserves nearby; Six Nations of the Grand River and the Mississaugas of New Credit. The total Aboriginal population as shown by the 2006 Census indicates that the total Aboriginal population in Hamilton is 13, 735 by ancestry and comprises 2.8% of the overall population of the city (497,395).

Participants also identified a range of descriptors that they associated with their Indigenous identity. These included being raised or living on reserve at one time in their life; being a fluent or partial Indigenous language speaker or having family members who were language speakers; attending or practicing Indigenous spiritual ceremony (i.e. Longhouse); exploring or using Indigenous medicines; participating in urban Indigenous cultural events (i.e. teaching circles, spiritual ceremony and other activities).

Semi-structured, in-person, in-depth, qualitative individual interviews were held with patient participants across both sites who met the recruitment criteria as noted earlier. Patients were instructed to invite family members to participate. It was expected that family involvement would benefit them by generating an increased awareness regarding their family member's cardiovascular disease/diabetes, risk factors, and chronic disease self-management and that this would contribute to improved health outcomes and reduced inequalities in cardiovascular disease/diabetes risk. A total of 4 family members participated; 2 from each site. Oral and written consent was obtained according to ethics protocol and DAHAC policy and interviews were recorded and transcribed. Participants were interviewed across both sites until saturation was achieved.

Two specific areas of inquiry were included in research segment one: understanding the meaning of heart disease for Indigenous patient participants and understanding the nature of their

healthcare experiences with healthcare practitioners. The specific research objectives of the first segment of inquiry included the following⁴⁹:

1. To explore and increase awareness of the cultural and family context; Patients were asked to share their cultural or family background. (Responses were monitored in consideration of the following: Did they self-identify as First Nations, Inuit or Métis? Were they raised on a reserve, in an urban environment or both? Do they speak an Indigenous language? Were there other descriptors they might have that they link to their cultural identity?)
2. To explore and understand the patient's experiences with various healthcare services; (Have they been in a doctor's care a lot in their life? How did they perceive their healthcare experience; positive? negative?)
3. To explore and determine what the patient's cardiovascular diagnosis means to them; (How did they perceive their heart health? What do they think caused their heart problems? Were they able to make a link to social determinants of health, common cardiovascular disease risk factors, associated risk factors such as socio-historical events?)
4. To determine if Indigenous Traditional teachings about health and well-being have contributed to the patient's belief about their own health/cardiovascular disease; Do they have their own beliefs about health and well-being that they have learned from family, friends or others in their community?)

⁴⁹ The goal of Phase One of the Canadian study was to develop a cardiovascular - health literacy intervention and assessment tool and collect the baseline information required for case studies at the two intervention sites. The case studies were planned as supplementary to the main intervention in that they would contextualize the pre-post intervention data collected in Phase Two by providing site specific information. It was expected that the interviews would collect information about social and health services; health literacy; their experience of education/information about medications (what they have been told, who by, how effective was it); what they want to know about medications; how they want to receive this information (orally, written, other visual or auditory methods); knowledge, attitudes and beliefs about cardiovascular disease medications and health). An analysis of the health literacy demands of documents that are used in the health service such as patient information sheets, pamphlets etc was also completed. Similarly, an environmental scan that assessed health literacy demands in the health service environment was undertaken by the team literacy expert.

5. To explore the patient's sense of personal agency with respect to their own health and heart illness?; (What are some of the ways that they take responsibility for their own health? How confident are they in their ability to improve their health?)

6. To explore the healthcare practitioner-patient relationship; (How would they describe the relationship with their healthcare practitioner? Do they think there is a link between this relationship and an improvement of their overall heart health? Do they think their healthcare practitioner is able to help improve their health? If so, in what ways?)

7. To explore the cultural context of the healthcare practitioner-patient relationship; (Do they feel they have special healthcare needs because of their identity as an Aboriginal person? Do they believe their healthcare practitioner understands or takes these needs into account?)

Staff Participant Interviews

Health care practitioners from medicine, nursing, and health promotion recruited from both sites were interviewed.⁵⁰ A total of 6 interviews were conducted with staff across both sites from various disciplines including health promotion, medicine and nursing⁵¹. Semi-structured, in-depth individual key informant interviews were recorded and transcribed according to ethic protocols.

The aim of the staff interview element of the Canadian study was to collect information about (a) contextual factors and mechanisms in the health service environment that impact on patient participants' access to cardiovascular - health literacy and knowledge and (b) staff's

⁵⁰ Specific disciplinary background of staff participants was not identified to protect confidentiality as it was a small sample. The reason for not identifying discipline - specific responses is to protect confidentiality as this was a very small key informant sample.

⁵¹ The staff respondent group is a small sample. As such, the disciplinary - specific identification of staff participants is not included in order to protect their confidentiality.

understanding of health literacy and its effect on their management of cardiovascular disease among this population group.

Methods Research Segment Two

The second segment of my research was planned following a preliminary analysis of segment one research findings. I found that patient participants involved in the first segment of research, demonstrated a limited awareness or understanding of Indigenous-specific cultural beliefs or values regarding health and well-being. This finding and the fact that the healthcare practitioners involved in the Canadian study were non-Indigenous were precipitating factors which led to the second segment of research. I wanted to explore how Indigenous healthcare practitioners and Elders situated at the Te Hononga o Tamaki me Hoturoa (Te Hononga) - Maori Health Centre (MHC) (one of the community partners of the New Zealand study team); perceived their Maori patients' awareness and understanding of the cultural value of 'personal responsibility for health and well-being'. An international project meeting hosted by the New Zealand team provided this opportunity.

Ethics approval was obtained for this segment of my research through the Health and Disability Multi-region Ethics Committee, in New Zealand⁵². Study participants were recruited through a member of the international New Zealand team who contacted the manager of the MHC. The manager then identified potential participants who were then contacted by myself. Recruitment and engagement activities were undertaken according to ethics approved protocols.

⁵² An amendment process with both the McMaster Research Ethics Board and the St. Michael's Hospital Research Ethics Board was also completed.

Individual staff participant interviews were held using an in-depth semi-structured interview process and manually recorded according to ethics approved protocol.⁵³

As a Maori - led organization, the MHC is described as a ‘kaupapa Māori Whānau Ora non-government organization, delivering services to predominantly ‘high need’ populations in the Auckland and Counties - Manukau District Health Board areas⁵⁴. The organization has an enrolled population of approximately 80,000 people. The services provided include; child health, lifestyle coaching, lifestyle coaching-cardiac, cardiac rehabilitation, long-term conditions, workforce development and family violence (Te Hononga o Tamaki me Hoturoa (Te Hononga year:n.d.).

Research Interviews

Semi-structured individual interviews were held with two community - based liaison workers, two healthcare providers and two Traditional healers. A Maori literacy expert, another member of the New Zealand study team was also interviewed. It was expected that their perceptions might identify causal factors or other socio-cultural factors that would assist me in the analysis of the first segment findings. Research interviews took place at the MHC and the literacy expert’s interview at an off-site location.

The specific objectives for the second research segment were as follows:

⁵³ All but two interviews were recorded. Detailed notes were taken during the two interviews that were not recorded.

⁵⁴ The MHC has established 12 key principles that guide them in their work that include: Kaupapa Māori owned, Māori led, Māori governed; Hauora Mā, Hauora Whānau, Hauora Tangata; Responsibility to Whānau Ora, Tanager Ora, Māori Ora; Responsive to Māori and other high needs populations; Responsive to its health and service providers; Financially sustainable and not for profit; Financially viable-able to build and invest for the future; innovative; credible and reputable; Action-oriented- nimble and quick to deliver; Provides evidence-based, clinically-led health services focused on ensuring quality outcomes; stay focused on the people we serve.

1. To further explore the cultural context of how Indigenous peoples understand their cardiovascular disease or other chronic illness: (diabetes, hypertension, hyperlipidemia). (How do their Maori patients ascribe meaning to their cardiovascular disease illness? Is there a link to their cultural teachings or beliefs? How important is the value of ‘personal responsibility’ for health and well-being for Indigenous peoples with respect to managing their health care?)
2. To explore the participant’s perspective on the relationship between European colonization and the notion of personal responsibility for health and well-being: (Do they believe that European colonization and assimilation efforts have negatively impacted Indigenous peoples’ ability to manage their own health? Are there other factors that negatively impact an Indigenous person’s ability to manage their own health? (social determinants, Indigenous vs non-Indigenous healthcare practitioners, access to health information in one’s own language) How would they describe the power dynamic between Indigenous patients and their healthcare practitioners? (equal - somewhat equal - somewhat not equal - not equal)
3. To explore potential participant ideas/suggestions towards facilitating improved personal agency for Indigenous patients: (How important is a self-determining approach to one’s own health care? (very important - important - somewhat important - somewhat not important -not important) How can healthcare practitioners best support Indigenous peoples’ self-determining approach to health? (improve access to culturally relevant health information?; develop Indigenous-specific health literacy approaches? increase number of Indigenous healthcare providers? improve access to Indigenous healers and helpers?)
4. To explore how Elders- Traditional Healers perceive the patient’s personal responsibility for health and well-being: (In addition to the above objectives/questions, Elders and Healers were

also asked to describe how they view the individual's role in the helper/client relationship? When they provide instructions about medications do they refer to Traditional teachings about personal responsibility for health and well-being?

It was expected that my research findings could contribute to an increased understanding of the Indigenous cultural context of cardiovascular disease-related health literacy. More specifically, how may an understanding of Indigenous concepts of health and well being influence an individual's ability to manage the self-care aspect of their heart disease? This information could potentially inform the Canadian team's health literacy intervention development in the second phase of the larger study.

Summary of Findings

In keeping with the aforementioned focus on Indigenous knowledge pedagogy throughout this thesis, it is an Indigenous knowledge theoretical lens that is used in the analysis of findings. As described in Chapter two, in the 'Framework of Assumptions', Assumption #1- 'Indigenous knowledge provides culturally based information that can positively impact the physical and inner well-being of Indigenous populations'; is the culturally relevant assumption that guides the interpretation of participant responses.

In an emerging decolonizing research agenda, Indigenous scholars have articulated the complex nature of Indigenous knowledge within the realm of its importance to both the methodology of research and the interpretation of data in a culturally relevant way for Indigenous populations (Martin Hill 2008; Dion Stout 2003; Smith 1999; Cajete 2000).

Indigenous knowledge systems have a pluralistic nature with diverse ways of knowing. Both the gathering and sharing of knowledge with and by Indigenous peoples in a way that is

congruent with their own cosmologies and lived experience, is deemed to be a critical element of the research process. Indigenous knowledge has been passed down for thousands of years and is central to the role of health research for Indigenous Peoples (NAHO 2003). Many Indigenous scholars have articulated the complex nature of Indigenous knowledge and its importance to physical and inner well being for Indigenous populations (Cajete 2000; Dion Stout 2003; Smith 1999).

As an Ojibwe Indigenous scholar engaged with others in the pursuit to advance the acknowledgement and utilization of Indigenous knowledge theory in research processes for and with Indigenous peoples, I utilize the values and concepts of Indigenous knowledge/ Nibwaakaawin and Bimaadiziwin in the analysis of the findings. I draw from the work of Peacock and Wisuri who describe Bimaadiziwin as grounded in a belief system that frames the interrelationships of all things; it is a wholistic perspective that is central to an Indigenous worldview. The need for harmony and balance is an integral part of the Ojibwe sense of wellness in that one must attend to the physical, emotional, and spiritual parts of life to be whole (2002:94). The notion of inter-relatedness is a common belief among many Indigenous peoples. This extends to all things on the earth.

While the larger study design is not underpinned in anthropological theory, my questions and analysis of the findings also utilize a relativistic - medical anthropology lens. As noted earlier, researchers who aspire to the foundation of a *naturalist paradigm* which is also sometimes referred to as a *phenomenologic paradigm*, believe that reality is not a fixed reality but rather, one that is constructed by the individual participating in the research and that it occurs within a context. This position is known as one of *relativism*. Medical anthropologists have made

a significant contribution from a social science perspective towards understanding the cultural interface between health professionals and individuals seeking their care. They have long been advocates for the amelioration of systemic barriers and the integration of culturally relevant healthcare approaches. I draw from this sub-field in the analysis to argue the inequity that is pervasive in the health status of Indigenous peoples with heart disease and other chronic illness, to make the link between structural violence as a socio-structural factor that inhibits access to Indigenous knowledge for Indigenous peoples and to frame the discussion regarding the meaning of illness and personal agency.

Indigenous socio - cultural factors

In this section of the findings, an overview of Indigenous cultural factors related to patient participants' cultural identity or Indigeneity is provided. Participants were asked to share information regarding their cultural or family background. The objective was to increase awareness regarding the cultural and familial context. It was expected that the self-identification of their Indigenous identity would be relevant to how they explained the meaning of their cardiovascular disease. Would individuals who self-identified as First Nations, Inuit or Métis hold and draw on Indigenous knowledge regarding physical and inner well-being to manage their heart disease?

Impact of Traditional knowledge on health beliefs and self-management of health

Indigenous knowledge includes information which can positively impact health and well-being. The occurrence of health information sharing between participants and their family and community networks was explored to determine if Indigenous healing/knowledge has

influenced or guided them in the management of their cardiovascular disease or other chronic illness. Participants were asked if they have their own beliefs about health and well being that they have learned from family, friends or others in the community. Responses indicate that patient participants for the most part have not engaged in Indigenous spiritual practices or received health messaging from Indigenous - specific sources; (i.e. Elders counsel, utilizing Indigenous medicines, attending spiritual ceremony). While others reported that they or other family members attended Haudenosaunee Longhouse or used a blend of Traditional and mainstream religious approaches. Only one participant reported being raised in the Longhouse tradition and attending ceremonies. A significant finding however, was that several participants reported that they were interested in learning more about their Indigenous heritage and/or utilizing Indigenous knowledge or healing approaches to address their health issues.

“So spiritual health is just as important, that whole balance thing and also that Traditional knowledge or Traditional medicine is just as effective.”

“Yeah, I think I would really like to do something like that, you know, because I get peace again within when I do talk about it. [Indigenous teachings/knowledge] It's like I get this special comfort in every morsel of my being and I can just go on and on about it and I feel so good about it.”

Some participants recalled receiving health related information from their parents that was consistent with an Indigenous wholistic value system. One participant commented on the contemporary relevance of Traditional teachings:

“Well I guess just realizing that some of the teachings people think that was a hundred years ago, it doesn't apply today. But I guess as an adult now and having a lot more time to think about it is the evolution of the culture and that what my grandmother told me of long ago applies just as connectedly today I guess I'd say.”

Another participant commented on the importance of continuing to share information in a culturally relevant way:

“As Native people when we sit in a room here, when we gather here in our circles we always start off with prayer first and we end with prayer. In mainstream society I don't think they do that, I know some do but not a lot. I tell our people, if you put the Creator first above everything else then he'll... He knows what's going on and he'll help you. Why do we go through all the things we go through in life? Because it's a training experience, it's how He builds character within us. And people don't know this sort of stuff, they've never been told it. I believe that we're in the seventh generation of our people and all these teachings and knowledge is coming back to our people, and it's the responsibility of the older ones, people my age, the Elders, to pass that knowledge on.”

It was also noted that there are various socio-structural/socio-historical factors related to patient participants' lack of awareness regarding Indigenous knowledge and Traditional healing approaches. For example, being fluent in an Indigenous language; when one does not have an understanding of their language, there is often a sense of shame or stigma and a longing to know one's language. Most participants identified that they did not speak their Indigenous language but relayed the importance of it or the respect they had for family members (i.e. parents or grandparents) who were fluent in their language. The following quote illustrates the lack of connection to one's culture that may be experienced in the absence of language fluency:

“Well, I hear people talking out there on the reservation, I go out and visit. They're talking to their grandchildren, they're talking to their kids in the language. And then I see foreign people down here, whatever it might be, talking to their family in their language, and I'm kind of ashamed that I can't get up there and do that one hundred percent. I can teach the little ones 'come here, 'go to sleep', 'you want to drink', you know, 'go outside', 'rabbit', 'squirrel', stuff like that, 'fish'. And little words like that, some counting, but I wished I could really, really, really...[speak the language]”.

Some expressed a sense of regret that they did not have the opportunity to learn their language. Others were accepting that their parents chose not to teach them. A relevant structural issue for Indigenous peoples living in urban environments is that there is limited access to language

instruction; while there are existing on-reserve options to language instruction, access can therefore, be a challenge when financial means for transportation is not available.

An important socio- structural factor is that many participants who were raised or currently living in an urban environment, experience an access barrier to Elders or others who can provide Indigenous knowledge. Social determinants including economic poverty and lack of transportation contribute to this access situation. Another important structural factor related to access to Indigenous knowledge, is that many non-Native healthcare practitioners are not aware of or potentially do not support the blending of Indigenous knowledge or healing methods with biomedical approaches. This is illustrated in the following patient participant quote.

“ I don't know. I think maybe they were just catching up as well. I mean, doctors are only - you know they can only prescribe western medicine, but they can't... they can't do nothing with Traditional medicine I guess. So we have to sort of forego that ourselves I guess.”

In spite of the various challenges related to having an awareness of or utilizing a self-care approach that includes Indigenous knowledge, there were also several participants who were able to identify potential benefits of doing so. For example, two responses indicated that participants felt a sense of belonging, and support.

“There is an expectation that you do your homework and that you act or do for yourself on the information that you receive and that if you need help you can return to the Traditional medicine man for more help or to answer questions. Spiritual faith can have a direct impact on health.”

“Well, I think... Thinking back I think going to the longhouse, it was like the people didn't judge you. You were... I wouldn't say openly welcomed but it wasn't like you were, you know, shoved aside or anything. It was like, you know, “Come on in.” And, you know, you took part in everything and, you know, nobody, you know, said any... There was real no judgement on you being there, you know, “Why are you here?” and, you know...”

THEMES RELATED TO PATIENT PARTICIPANT SELF - PERCEPTION: HEALTH AND WELL-BEING

As noted previously, my research interest was to further illuminate various socio-cultural factors that could contribute to the development of an ‘Indigenized’ (culturally relevant) health literacy approach. The findings in this next section provide a picture of how patient participants perceived their cardiovascular disease and/or diabetes. Specifically, regarding their health status and the causes of their cardiovascular disease. Did they have an understanding of their health status with respect to their cardiovascular disease or diabetes? Were they aware of the risk factors related to their chronic illness? Self-management of care is critical to the effective management of cardiovascular disease and other chronic illness. Patients and their families are considered to be the primary ‘managers’ of their care. Patients’ beliefs and values about health and well being were also explored to determine if there was a link to how they self-managed their care.

Perception of Health status

While some patient participants were not sure of their health status, most perceived their health in a positive light. Participants’ descriptions ranged from ‘stable’; ‘not bad’; ‘okay’; ‘in control’; ‘fair to well’; ‘pretty good’; ‘good’; and ‘perfect’. Most participants were also able to state their CVD/chronic illness diagnosis.

Patient Participants’ perception of causes of cardiovascular disease

Patient participants attributed their cardiovascular disease to a range of factors that can be grouped into three areas: socio-cultural, socio-economic and risk behavior. They also made connections between family and a history of cardiovascular disease. One or both parents of the

patient participants were reported as having a chronic illness (Downey Nepinak, Cooper, Prince and Smylie 2013).

Perceived Causes of CVD	Contributing Factors
Socio - economic	poverty, employment, worrying about the future,
Socio - cultural	stress: life, relationships, family pressures, diet, weight, family history, genetics, menopause
Risk related	chronic disease, smoking, weight, alcohol & illicit drug use-misuse,

Figure 2 Perceived causes of cardiovascular disease

Fully understanding the purpose of one’s cardiovascular medications and how they work, requires a basic understanding of the diagnosis and etiology of the cardiovascular illness. A few participants reported their diagnosis and discussed causal factors with very little prompting. Most were able to describe one or more causal factors for their heart disease or other chronic illness. Others had only a vague understanding of their diagnosis and causal factors as noted in the following quote.

“Not... Well not really. I mean I kind of do a little bit but even if somebody said what would be the signs that you're having a heart attack or a stroke, I don't know that I would know and then the little bit that I do know I think would almost make me... It almost at some point makes me a little bit paranoid. Because every now and then I'll get a ache in this arm and that's the first thing I think. You know, is that what that is? And I just kind of like work it off and it never lasts long but, you know what? That's the first thing that pops in my mind is this the start of something? But I couldn't tell you what the signs of a, you know, heart attack or a stroke... I mean I hear about dizziness and, you know, slurring and stuff like that. I've never been in the

presence of somebody who was going through that so that I could actually see what it might look like.”

Widely promoted, more common risk factors such as smoking, over-weight and high-risk lifestyles related to alcohol and illicit drug use were cited by several participants. Lesser known socio- economic and socio-cultural factors as noted in Figure 2 were identified by only a few participants.

“I was told that stress creates blockages, you know, that builds up plaque in your vessels and I believe that's what happened to me.”

Awareness of genetic pre-disposition to cardiovascular disease; in the Hamilton patient participant group, 7 of 10 participants reported a familial history of cardiovascular disease. In Brantford, 4 of 4 patients reported a familial history⁵⁵.

In 2003, the Heart and Stroke Foundation of Canada reported that nearly two-thirds of Canadians have misconceptions regarding heart disease and stroke. A 2010 study involving a cohort of cardiac patients, demonstrated relatively adequate knowledge of the warning symptoms of heart attack. However, they were not as aware of the most important risk factors associated with heart disease. Knowledge of stroke symptoms was also poor. The researchers also found that variable such as socioeconomic status, a personal history of heart attack and stroke were positively correlated with good knowledge. They concluded that “future patient education efforts should address the awareness of the important cardiovascular risk factors and knowledge of cardiovascular warning symptoms (especially for stroke), as well as inform patients of appropriate actions during a cardiovascular emergency.” In addition, the researchers recommended an emphasis on primary and secondary prevention, and further, that interventions

⁵⁵ The total number of patients interviewed was 6 but two patients were not asked about their familial history as the interview was conducted by another interviewer.

should be directed toward low-income cardiac patients (Gill and Chow 2010:pg). This profile would be a match with many Indigenous peoples for whom it is generally known, experience socio-economic hardship among the presence of other known risk factors.

Cultural Beliefs and values from others about health and well-being

Indigenous knowledge related to health and well-being or healing is often exchanged through oral-based teachings between family members or an Elder, healer or shaman. One patient participant described the teachings shared by her grandmother regarding the use of Traditional medicine. Her healing related experiences with her grandmother influenced the development of positive feelings towards the use and effectiveness of Traditional medicine.

“Absolutely. Knowing Traditional medicines that I participated [in the harvesting of]with my grandmother, harvesting some Traditional medicines, observing the various teachings around the proper way to harvest, the thankfulness that we still have medicines available to help with conditions. And I remember being young, I had asthma very bad as a child; severe asthma and using that my grandmother would make for me and feeling even today as an adult, when I smell that on the stove getting ready and when I taste it, it just feels so calming and makes me feel good. That it is my connection to the earth and the Creator and I know how to say the words to help it be strong, harvest now myself for my children.”

Another participant describes the close urban connections that develop between individuals and how supportive networks can be a source of health information.

“Well I think being part of this, in the community, has helped. I have other people that I've been close with over the years that work at different places like Native Women and we've kind of all gone through the same thing, you know, whether it's, you know, learning that we're diabetic and, you know, having our family now and having our grandchildren. I've learned from them, you know, different things and keep in contact and are aware of things going on in the community and, you know, why we need it, is, I think, most of what I learned over the last few years.”

However, most participants relayed feelings of disconnection from their Indigeneity including beliefs, values and messages regarding health and well being and language. One

participant reported that his father went to residential school and described Indigenous beliefs about health and well-being that were different from his own.

“A little different from my belief, which I don’t know because I wasn’t raised with it. See mostly what I know now is, even about Longhouse is when I go there for something, you know, mainly it’s for funerals. It’s always the connection there where... But she doesn’t come outright and tell me, I have to ask because she don’t know whether I want to or not, you know, how I’m... That’s just the way we did it.”

Several participants discussed the language fluency factor as described earlier and how this played an important role in not feeling connected to their culture. A few patient participants spoke about their aspirations and experiences reconnecting to their Indigenous family and social networks. The following quote describes a participant’s journey to learn more about her heritage and language.

“I’m learning more and more about it. That is a very major goal for myself because when I was little my mother was a very private person and we were very close in family but, as far as our cultural background, I’m still learning and want to learn more. I also want to learn the language but it’s a very difficult language to learn. I do have a cousin that I’m in contact with constantly who lives on the reserve and works for the [name] tribe and she’s been telling me more and more and she’s actually sending us some books. She... When I was in the hospital for six months in 2009/ 2010 she sent me a whole - two big boxes of information. It was really interesting; I’ve got lots of books. My grandpa was very well known. He worked in the camps. He was also in the war. Our family is very well known in the tribe.”

Unfortunately, some participants reported negative experiences regarding their efforts to reconnect with their culture. One woman described a painful rejection from new-found family members who were mistrustful of her efforts to connect.

“And my family is not raised in, you know, in any culture at all, but I mean I started to want to be, and I went back to the family and asked what we were and who we were and whatever. And we didn’t get much answers because they’re scared to talk to people. They thought I was from the government (laughs), so they wouldn’t talk to me. I tried to explain over the phone that I’m

family, but they said no, we don't want to talk to you, talk to so and so, and they just pass me around and I never really got anything out of it as to what was going on really."

Some participants described challenges related to accessing Indigenous health related information in the urban environment.

"Yeah. I mean we just try to follow the cycle, I guess as best we can. But sometimes if you're in an urban setting or city, city, it's kind of hard to study it, I guess. Nobody else speaks your language there or to follow different things, you know. But I get back when I can. You know, I go back when I can and I get involved with the – in the community when I go back, everything. But other than that, I just try to... I guess as best as I can, you know, because it's fast paced out here. It's for a reason that I'm out here, you know, just closer access to my kids or whatever. Maybe a five- or six-year plan is - is, you know, to get - you know, get back to the reserve, I guess, but..."

A few participants described themselves as believing in both a mainstream and Indigenous knowledge/Traditional healing approach.

"Not really because I was like church too. I did go to the longhouse but I just went to kind of see what was going on in there and see what it was all about and stuff like that. I did go to a couple of strawberry festivals things they have and stuff like this, but no I didn't go steady because I couldn't really understand what was going on in there like when they were talking. I suppose I could have educated myself more with the language, I wish I did."

In summary, most participants were not able to define beliefs or values about health that they learned from others in their family or the community.

THEMES RELATED TO HEALTHCARE EXPERIENCE

This section of my research findings provides insight into how patient participants perceived their healthcare experience and their relationship with their health care practitioner. Generally, patient participants reported both negative and positive health care experiences and attributed this to a range of factors. Several patient participants reported a positive healthcare experience. Reports of a positive healthcare experience were correlated to various aspects of the healthcare practitioner relationship. Establishing trust was the most important element of a positive relationship with their practitioner.

“It’s a game but it’s a way to interact, like you wait and you see the information and you’re kind of, you’re building the relationship with the person, right?”

“You treat me the way you would want to be treated. Because if you treat me wrong, I’m going to treat you really bad. But usually any medical staff I had has been pretty good at stuff, for a couple of doctors and one nurse.”

Patients expressed a need for continuity when being attended by a physician. They also were appreciative of those who take the time to explain things and assist them in learning more about their chronic illness.

Factors Related to a Positive Healthcare Experience	
Relationship with healthcare practitioners	<ul style="list-style-type: none"> - good relationship; - continuity in relationship with MD; - helpful with medications; - took time to explain things; - learned more about chronic illness

Figure 3 Factors Related to a Positive Healthcare Experience

Participants also reported a range of factors regarding their negative healthcare experiences. These were organized into three groups; healthcare practitioner - related, systems -

related and relationship with healthcare practitioner. As tabled in Figure 5, patient participants described a range of factors related to their healthcare practitioners⁵⁶. One participant reported that her heart attack had been misdiagnosed. Another participant relayed his negative experience with his medication.

“So he just let it go, and then lately before he left about six months I guess before he left, I said, can I stop taking these, I said, I don’t think they’re doing me much good, naproxen. Well he said, if they’re not doing nothing, you don’t need to take them. Then he explained, he said, they brought your blood pressure up anyway. And I’m thinking, why did you give me something when I’ve got high blood pressure? Why did you give me this if it’s going to push my blood pressure up? But I didn’t ask him, no I didn’t want to....”

Several participants commented on the lack of continuity of care and inconsistency between the disciplinary approaches. Patients often may not be aware of the administrative or systems related reasons for situations or issues that negatively impact their care. For example, with the scheduling of rotating part-time staff, patients may not always see the healthcare practitioner they saw previously, even if they made this request. This contributes to a perception that the care they are receiving is piecemeal and inconsistent. An interesting point in this discussion, is that most participants were aware of the clinic personnel - related transition that was underway during the time that the study was taking place. While they acknowledged this factor, their complaint still appeared to focus on the healthcare practitioner.

⁵⁶ Although there could be some overlap between the categories, they are grouped for discussion purposes.

Factors Related to a Negative Healthcare Experience	
Health care practitioner related	<ul style="list-style-type: none"> - mis-diagnosis of heart attack - lack of continuity of care - interruption in medical service - inconsistent follow through by nursing staff - lack of physician consistency
Systems related	<ul style="list-style-type: none"> - problem-oriented approach to health versus health promotion and prevention - access barriers to Indigenous Traditional healing/medicine - delays in receiving approvals for medications
Relationship with healthcare practitioner	<ul style="list-style-type: none"> - perception of racism and receiving 'second-best treatment' - Indigenous cultural needs is not always considered - belief that healthcare practitioner attitudes towards Indigenous peoples needs to be changed

Figure 4 Factors Related to a Negative Healthcare Experience

The next section further discusses the patient - practitioner relationship.

Relationship with healthcare practitioners

The sharing of health information between a healthcare practitioner and a patient can be enhanced when a positive, trusting relationship has been established. The uptake of health information is also an important element in a self-care approach to chronic illness. For example, patients often have many fears or concerns about their medications. Failure to understand their concerns and assist them in understanding their medication use better may result in non-compliance. The following illustrates one patient’s fears about the long-term effects of taking their heart medication.

“There probably is but I look at those things there and I think, gosh what are they feeding me, all this stuff, do they really know what this stuff does to people? Long-term effect on human beings? You’re giving me this medication but are you poisoning me and, you know. Because sometimes these medications, people have been taking them and they find out later on what it’s done to their body, it’s a poison because it’s chemicals.”

Both negative and positive factors that influence the quality of the relationship with their healthcare practitioners were reported by patient participants. While there were fewer positive comments regarding the relationship with healthcare practitioners, a few patient participants were able to identify specific positive factors. (Figure - 4) A direct communication style was acknowledged as a factor related to the classification of a ‘good’ relationship with their healthcare practitioner. Explanation of various medications or health related activities, use of teaching materials and a thorough approach were also valued by those who chose to describe their healthcare professional relationship as ‘very good’. The following quotes also provide examples of how important a positive, trusting relationship is for patients.

Well even [name]. I would come and see [name] and, you know, I would know I could get in, wouldn't have to wait a whole long time for him, get him, see him, talk him. He was like... I could talk to him. He was the best thing going and we could joke around and stuff like that but I could tell him like it is without pulling any punches and tell him the way I wanted to tell him. And he would, you know, usually talk back to me the same way that I... So I could understand. So now he’s gone so I don't know how things are going to happen...”

“Yes, very much so. I totally believe that because if they can be open and honest, I can be more open and honest and it seems like an open book policy.”

Contributing Factors to a Positive Relationship With Healthcare Practitioners	
Relationship described as 'good'	- direct communication style;
Relationship described as 'very good'	- always explains things - uses teaching materials (book or picture) - very thorough;

Figure 5 Contributing Factors to a Positive Relationship With Healthcare Practitioners

Factors contributing to a poorer relationship with healthcare practitioners can be grouped into clinical practice and systems related categories. One participant commented on the practitioner’s ability to convey sincerity and reported that this was a personality trait that some practitioners were lacking in.

“It depends, probably what you’re saying there is how you would react to this person on that one side, and I’m going to say, all right now how does she project? Because you can tell the sincerity of the person by listening to them, how they sound. I think it’s a person individual.... you either have it or you don’t.”

Patients need to be able to relate to their physician in order to establish a trusting relationship. The following quote describes the disconnect the patient felt from the first appointment with a physician.

“Well, I guess it would all be on that person’s personality because, like I said, I had other doctors. I had an appointment with the one doctor one time, I only went to them the once, but I walked in, for some reason I think I had my son with me. And he wouldn’t have been a little kid but, you know, I think I had my son with me but I went from a waiting room into his office and his office. Now I don’t even remember if he... He might have been a specialist but it was like immaculate. Desk, just so. You walked in there and you felt like you didn’t want to touch nothing. You know, and that desk was between you and him. I never went back to him. I only saw him the once. I couldn’t even really tell you what his name is right now but so there was no relationship with that doctor.”

Several patient participants described a perception of inequality in their relationship with their healthcare practitioner. This is an important finding for consideration by healthcare practitioners in that a key factor in achieving a positive healthcare experience for patients correlates with their relationship with their healthcare practitioner. The following quotes illustrate this perception theme.

“Not with the doctors because I’ll put them here and I’m here. I’m not the same level, put it that way.”

“You know, he doesn’t talk to me. He was ordering me what to do. You don’t... You give me the decision; it’s my decision if I want the medical help. But if you’re going to tell me that I have to do it. No, I don’t go that way. And I didn’t get to talk to my husband, my kids or nothing. You don’t tell me that I have to do this, no way and I told him straight out. I said, “No, I want to go home right now.” I said, “I’ll walk. I’ll take my buddy with me and I’ll go home.” I was so pissed off with them and so he goes, “Okay. You got to go home.” I said, “Yeah, I’m going home.” He just stared at me.”

One patient participant noted some variance in the negative power differential between doctors and nurses. However, the description of nurses’ ability to treat patients equally was described as “comme ci, comme ça” at best.

Language issues are also connected to how a patient may feel an inequality in the relationship. The following quote describes one patient’s negative experience related to a language barrier with their healthcare practitioner.

“I think they can be intimidating with that because, you know I mean I’m fortunate that I have quite a good command of the English language but not everybody does. And if, you know, like with his family if English is not your first language I think that that would be very, very hard. Because I mean most of them, I mean [name], like his mother, she only knew basic English, didn’t she? Very basic English. So to go to a doctor who was not Aboriginal and who didn’t speak the language, and then have him use all these words that she wouldn’t have a clue what he was saying to her, not a clue. So I think they can be pretty intimidating sometimes.”

Another language related factor that one patient described, was the need for healthcare practitioners to be direct in their communications. The following quote captures this issue.

“I think it made me feel a whole lot better when I left here because he wasn’t beating around the bush about nothing. Okay, this is going to be like this, and this is going to be like that, and this is going to be like that if you don’t do this right. It’s not them kind of words but I understood what he was saying.”

Contributing Factors to a Poorer Quality Relationship With Healthcare Practitioner	
Healthcare practitioner practice related	<ul style="list-style-type: none"> - lack of follow through with requests for signing forms or to monitor regular bloodwork; - lack of interest - perception of power imbalance in the patient: healthcare practitioner relationship - not a lot of time to talk with healthcare practitioner
Systems related	<ul style="list-style-type: none"> - lack of continuity of care - frustration with transition of medical coverage - access to timely care is a problem

Figure 6 Contributing Factors to a Poorer Quality Relationship With Healthcare Practitioner

Link between a positive relationship between healthcare practitioners and patient perception of improved health

The majority of patient participants reported that a positive relationship with their healthcare practitioners has a positive influence on their health. Only one patient disagreed and reported that it is the treatment provided for the ailment that is important. It is also important for healthcare practitioners to foster trust in their relationship with their patients.

“I think so. I think that really helped and he would, you know, he would kind of like tell me like it is too because we were that way back and forth with other. And so, you know, he would kind of let me know some things without, you know, being overpowering about it. So yeah, I think got he me to understand a bit better and I do think our relationship made a big difference in how things went.”

THEMES RELATED TO EMPOWERMENT AND SELF-CARE

As noted in the section introduction, it was expected that improved self-management and engagement with health professionals would improve the delivery of primary health care and therefore, improve the Indigenous burden of disease and existing inequalities in health outcomes. There was also an interest in understanding if beliefs and values regarding personal responsibility for health were passed on to patients from family members or others in the community.

Beliefs and Values Regarding Responsibility for Self-Care

The findings demonstrate that patient participants are making efforts to adapt and learn about their cardiovascular/chronic disease. They undertake various activities to manage their own care. For example, they try to be proactive and learn more about their chronic illness as the following quote demonstrates.

“So I'm very self motivated to learn, learn, learn, learn. And so when I first realized there's something going on, my first option is, “What other kind of books can I read? What's on the internet?” And when that's not getting me where I go then I'm like, “I guess I'll go to the doctor. I got to get back into therapy,” you know, and so I realized now that part of being a strong woman, for me, meant I can learn this myself.”

Patients are also taking active responsibility for their own care as demonstrated by the following quotes.

“Something that I make a routine of, once I'm in a routine I can try and keep that going. So when I do my blood in the morning is before I go to work and after I've had my... No, it's before I have my coffee. I put my coffee on and then I go and do my blood. So that's a weekday thing when I go to work. Weekends are different and sometimes I forget that routine. So I might not always do my blood on Saturday and Sunday but back to the routine on Monday to Friday then I do it.”

“Well I try and watch what I eat because I know that's important. But I still try and be truthful to the doctor about how I eat. Like I live by myself. I only work part time so I have limited income. Cooking for one person is not fun and I don't do it a lot because I'm only one. So I admit, you know, I'll go home and have a hot bowl of cereal for supper. My breakfast consists of a cup of coffee and toasted cheese sandwich. It's been the same thing every morning for 10, 20 years, I don't know and it's not going to change.”

Themes related to beliefs and values regarding health, included evidence that patients draw on Indigenous Traditional teachings and support when self-managing their healthcare.

Their personal beliefs and values appear to empower them to draw on Indigenous Traditional knowledge where they experience problems.

“As far as drawing [water], we would cheat and use the wagon once in a while and we got caught. And he says, “No, you're supposed to carry them. Carry the buckets of water. You don't put it in the wagon and pull it down the road; you don't pull it to the house.” You know, or we'd draw wood from the bush, we would put it in small pieces, you know, small ones to carry. And we weren't getting any muscle so he was getting us to carry longer and heavier pieces to get us more muscle and stronger legs and back I guess you might say. That way was good. I thought that was very good.”

Participants also reported that they pass on personal responsibility values to their children. They seek support from others when they need it and families are an important motivation to stay healthy. They also report trying to accept and maintain a positive attitude regarding their illness.

“Just like to walk to get your exercise. Not to stay dormant, you know, and if you're not feeling well, don't lay there, get up and push yourself to get yourself better and don't baby yourself. Be strong is what my mum used to say. You know, that's why I think today I push myself to do what I have to do, you know. Like I don't have very good function in my legs but I push myself to walk. You know, and I push myself to do housework which I know I can't do too much but I push it to do it, you know. Don't I?”

“You know what you're doing wrong or right, you know this yourself, it's just up to you. Again, you're the person that has to live with yourself.”

Confidence in ability to improve their own health

“Well, because as long as I keep taking my medications, going to my doctor’s appointment, doing things that I, you know, avoiding things that I know that are going to cause me problems, you know, I’m in charge of my own destiny.” “Just because somebody’s done something to me doesn’t mean that I have to be a victim. I can, you know, I can make my choices. So either dwell on it or just get over it.” [Patient Participant]

Most participants were either somewhat confident or confident that they had the ability to improve their own health. One participant reported that their experience with successful change with one health-related behavior is motivational for additional behavior change needed to improve health. Another participant ties her experience as closely connected to how she feels about personal responsibility to health - one has to take care of themselves because “nobody else is going to do it”.

Patient participant autonomy varied; some followed doctors orders without question, while others listened to advice given by their healthcare practitioner and then decided what was a good fit for them.

Themes of influence emerged linked to confidence levels include parental influence, example of others, religious beliefs, fear of the unknown and positive thinking. For example, one participant remembers their parents advisement.

“Well later on I remember my dad and my mum saying, don’t let nothing stop you, if you want to do it, you go and do it. You think you can do it, go try it.”

One participant relayed the story of his neighbour who experienced a major stroke accompanied by complications that resulted in major changes in his lifestyle.

“Well my neighbour about five years ago he had a problem with his sugar, cholesterol whatever it was, he’s about 67 years old. Five years ago the doctor told him to quit smoking, just last spring... Mid-summer this year, he lived across the street from me, he went down with a stroke

and now he can't hardly walk. His left arm is no good and he has to have a wheelchair; he can walk but not good. Now I looked at him, I don't want that, that's why I get my education, my papers, whatever I can get to read up on to avoid this and avoid that. Like the two demons I got to fight with, it's kind of hard to get away from but I have to, that's cigarettes and alcohol."

Other influences include religious beliefs and and fear of the unknown.

"Oh constantly, everybody's always saying, [name]; you're strong, you can do it. God never gives you more than you can handle. That is a famous saying in my family. My brother's constantly saying that to me. God never gives you more than you can handle. Never puts more on your plate that you can't handle. You can do it. Yeah."

"I just feel that there's a lot of people that have Diabetes that isn't controlled properly. They don't follow through on their daily medications and stuff like that, they don't follow through on mammograms, they don't... I don't know why, whether it's fear or, you know, I don't know what it is really, why they don't. I mean I follow through on a lot of things. I don't, I'm not like the Aboriginal woman in my age group. They don't seem to take things seriously or something, I think it's...Fear of finding out something that might be wrong, fear of the actual test, what it's going to do to them. Believe me, the mammograms kill you, I can see their point there."

A few patient participants acknowledged the benefit of positive thinking regarding life choices and healthy lifestyle.

"Well because as long as I keep taking my medications, going to my doctor's appointment, doing things that I, you know, avoiding things that I know that are going to cause me problems, you know, I'm in charge of my own destiny."

"You can have control if you want it."

Some patient participants admit that they use both a western, biomedical and Indigenous

Traditional approaches to health as described in the following quote.

"Well, I'm from Oneida. It's 25 miles southwest of London. And you know, there's eight of us in our family. We're from the Bear Clan and we've grown up in Longhouse tradition all our lives. So we kind of go back and forth between, you know, Traditional medicine I guess, and modern day stuff, I guess."

Special needs related to Aboriginal Identity

Most patient participants when asked if they believed they had special needs because of their Indigenous identity, referred to their bio-medically defined chronic illness and in most cases, the diagnosis of diabetes. Seven participants reported that they did not see themselves as having special needs because of their Indigenous identity.

“I know the diabetes has a great impact on native people like if you have diabetes and you're native, that's more serious than if you have diabetes and you're Caucasian or whatever it is. I understand that. But I just feel like I'm one of the other people like one of the... I'm just a person. I don't decipher because I'm native that... I don't decipher the difference. Other than I know that the native people have a higher risk of diabetes.”

One patient reported that information they received needed to be more Aboriginal - specific. Stress related to poverty and unemployment, suicide and alcoholism was reported as being associated with Indigenous identity.

“I'm sure they're aware of our problem. I know it's hard when you live on a reservation for some people because there's no work. You've got no work you've got no money, you've got no money you've got no entertainment or whatever; you just sit.”

Some participants identified special needs related to a mainstream diet and illnesses that they are not familiar with and thus, are unable to use Traditional approaches to healing. For example, diabetes is a more contemporary ailment for Indigenous peoples related to adaptation to a more sedentary lifestyle and other socio-cultural factors.

“Native people have so many illnesses now that our ancestors never, ever heard of. That's why they need so special needs now because they don't know how to fight these new diseases, eh? That, at one time, no matter what was wrong you could go to the bush and get the medicine to cure it. Can't do that now.”

Some participants expressed their concern about how they were treated in the health system. There is a perception of discrimination towards Aboriginal people.

“And it wasn't until his life was at risk before we really got the service that he should have gotten right from the beginning. So I have lots of stories like that, you know, unfortunately and, again, didn't think nothing of it because lots of aboriginal people have the very same experience.”

A few participants expressed concerns related to health care practitioners; namely that they often are not educated regarding Aboriginal - specific issues and also, that there are not enough healthcare practitioners who are Aboriginal.

“I'm not sure they're quite that much aware. I'm not sure if they're that educated on that part. I'm not confident about that, at least at this moment. I think there's a lot to be learned especially since I don't think any of them are aboriginal heritage. I think it's more important that they do learn more about that. It's hard to treat somebody when you don't know anything about them.”

On occasion, participants are not able to relate to the information that they are provided regarding management of their chronic disease as the following quote illustrates.

“I need to know... I need to understand why and what that relationship is in order for me to even go to that next step of not eating white bread and trying to do other breads. So it's those kind of things but I will admit and I've gone to those classes and I understand about cooking, you know, foods and having... But, you know, not to discredit those people but, you know, even in a couple of those classes that we had, they would say certain things and we're all Native, the people participating. And we all kind of looked at each other and started laughing. Unless that person teaching us is Native and know where we come from, some of that stuff they're trying to convey to us just...”

Special needs and Fatalistic Attitudes

A theme of fatalism also emerged in the responses to the question of whether they had special needs because they were Aboriginal heritage. There were expressions of resignation that their Indigenous heritage and familial history predisposed them to diabetes and there was almost

a fatalistic attitude for some that there was nothing they could do to prevent the contraction of the illness.

“Yes, because I think diabetes is.... a lot of Aboriginal people have it. I knew I was going to get it before I even had it. My mom had it and my grandfather had it so I just knew it was coming”

“Yeah just being diabetic, like I know there’s a lot of diabetics out there but it does seem to be more common with Native people.”

While some participants expressed a measure of resignation regarding genetic predisposition to diabetes and other chronic illness, they also believed that they needed to prepare and not just accept that there was nothing they could do.

“I don't think I have special but I think, because I'm Native, I'm... I don't want to say destined but I'm destined to have certain things happen. Like I was destined to have diabetes. I knew that before I even had gestational diabetes because it runs rampant in my family. Right from my grandmother... I have a cousin who died; she was actually blind from diabetes. I have a number of them that have juvenile diabetes. So it's everywhere in my family. So I knew that was going to happen and my mother was diabetic and she never got diabetic until much later in life. I mean much, much later. She was over 50, maybe even over 60 before she got diabetic. But it happened.”

At times, patients perceive that healthcare practitioners also expect Aboriginal people to develop chronic illness. For example, in the following quote, the participant acknowledges that the doctor automatically started screening for heart disease.

“Because when I started going back to him the first things he started checking was the sugar and the high blood pressure and stuff like that right away..... Because I never asked him to, so he just did it right away”

An attitude of resignation and fatalism is also linked with the participants’ awareness of ageing as noted in the following quote.

“ I do have them, I'm getting that stage. Here I go again, repeat, is I'm in that stage, like there's a lot going on with me that I don't understand, I've never experienced it, you know. I'm starting over again it seems. Not starting over but it's this, how can I put it, it's just happening.”

“I don't know. There's quite a few diabetic people. I know my father was one for years. It's mostly diabetics and old age you just can't stop.”

Special needs and structural barriers

The issue of discrimination and racism also emerged within the context of identifying special needs related to culture. For example, in the following quotes the participants expressed a sense of discrimination with a clinic-related transition and the negative emotional impact they experienced.

“Satisfied yes, happy it all depends. Like this place, when we had [Name 1] everything was... We walked in, said how are you, explained what our problem was, he looked at us like we were people. Nowadays with the new staff in here, right, the new doctors, and I guess there's new rules about they want to look at I guess your medication, what kind of medication you're taking. And then they ask you if you were on drugs, they ask you if you were abused, something like that, it's along that line. Well the way they presented it to I, it was like they asked us if... The way they pointed it out to me it was like every Native was a drug addict or an alcoholic, or abused our system, or that we sold our medication; that's what they said, it's almost like that. And irritating, oh it was real bad, I didn't want... I got to the point where... That poor lady downstairs, I just, you know you get frustrated and you raise your voice a little. And yes, I felt sorry for her but do not box me up with everybody else. I am Native, I'm proud to be Native. If in the past they've had people do certain things, do not put that on me, I mean that's...”

“We're looked at... A few others too because I know a few other people that come here. We're looked at like... Because of the rule changes, this is what they've told us. Because of the rule changes they have to ask us more questions right to the point, and a lot of... You ask a lot of Native people certain questions and look at them, they're thinking you know what, there's something wrong because you're boxing us together with some people who made mistakes in the past or have done things wrong; we're not all that. So that's the only discrepancy I have with this.”

“Exactly, because the truth is when I went and seen Nutritionists, every Nutritionist I had a conversation with and the way they explained it... Not once did they ever say anything about low income, not once. They all figured that everybody could afford it.”

Health Literacy Assessment

As noted previously, a Canadian Expert Panel on Health Literacy concluded that despite recent progress defining and measuring health literacy, there has been no consensus on these issues; a situation that has negative implications for all Canadians (Rootman and Gordon-El-Bihbety 2008:3). The patient participant health literacy assessment criteria and levels were based on the 2006 IALS in addition to the two decades of adult native literacy experience of the health literacy consultant. The 5 levels of the IALS were used as a guideline for the additional assessment criteria which included childhood educational and family experiences, pharmaceutical use/abuse, incarceration, adoption, residential school experiences, educational attainment, ease of use of internet, job history and learning disabilities (Downey, Nepinak, Cooper, Prince and Smylie 2013:pg). The health literacy assessment for the IHLS also explored issues such as patient participant understanding of written materials, ease of understanding of healthcare provider instructions, where patient participants access health information, and experiences of self-advocacy in health care situations. The description of the 5 literacy levels regarding reading and deciphering skills are included in Figure - 7 - IALS Literacy Levels

Literacy Level	
Level 1	People at this level have difficulty reading and have few basic skills or strategies for working with text. They often can't figure out how much medicine to take from the information on the package.
Level 2	People at this level can read, but do not read well. They need material that is simple and clearly laid out.
Level 3	People at this level can read well but may have problems with more complex tasks. This level is considered by many countries to be the minimum skill level for successful participation in society. (*Please note that the Canadian IALS team purchased extra survey findings from urban centres that had higher representation of Aboriginal participants. From this information it was found that many Aboriginal Canadians have an even lower literacy level than the minimum skill level for successful participation in society.)
Level 4-5	People at this level have strong literacy skills and many strategies for dealing with complex materials. These individuals can handle new reading challenges and meet most reading demands.

Figure 7 IALS Literacy Levels (Strengthening Health Literacy Among Indigenous People Living with Cardiovascular Disease, Their Families and Health Care Providers: Phase 1 Report, 2013)

The findings indicated that many of the patient participants struggle to understand information from their healthcare practitioners. They reported that they rely heavily on their pharmacist to explain the information provided by their healthcare practitioners. Their ability to pronounce the name of their medications and to explain why they were prescribed informed the literacy assessment.

The majority of patient participants scored in the level 2-3 range which means that they would have difficulty with comprehension and advocacy when it comes to health information and instructions (Downey, Nepinak, Cooper, Prince and Smylie 2013:26-30).

According to the Expert Panel on Health Literacy, many people in Canada are lacking health literacy skills. There is also a significant variance of levels of health literacy from jurisdiction to jurisdiction in Canada and among sub - groups of the population⁵⁷.

Patient Participant Management of Medications

Across both sites, 12 of 25 or 50 percent of the patient participants knew the names and purpose of their cardiovascular disease diabetes medications. However, they generally rely on pharmacy support to learn about their medications rather than their healthcare practitioner. They also learn more about their medications from friends and family members. Approximately 50 percent do not understand why their medications have been prescribed. They also have difficulty remembering reading their prescription bottles labels and understanding pharmacological/generic drug names; remembering to take their medications, (although some use artifacts such as dosettes and blister packs). A few patient participants report using Traditional medicines along with their mainstream medications.

Some patient participants will ask their healthcare practitioners questions regarding their medications but others do hold back or rely on peers. Others rely solely on their pharmacist for information. Although many rely on the written information they receive from the pharmacist, is not always easily read. They also discuss the information received with the pharmacist. Finally, they also utilize information from other sources such as workshops or information placed on bulletin boards (Downey, Nepinak, Cooper, Prince and Smylie 2013:21).

⁵⁷ The Expert Panel acknowledges that there is a lack of systematic information in Canada on levels of literacy and health literacy in certain populations including Indigenous people.

Staff Participant Interviews

A total of six staff members from various disciplines across both DAHAC sites including a physician, 3 nurse practitioners and allied professionals were interviewed. Staff participants from various disciplines have a basic understanding of how health literacy is defined. They report that there are structural barriers regarding their ability to assess their patient's health literacy that includes lack of adequate resources to ensure adequate staff coverage. They may have limited time to actively engage in formal assessment of health literacy but they informally follow up with patients who they perceive as potentially not understanding the health information they have been given.

They report that patients have literacy issues with both understanding basic information related to their chronic disease and their medication. They identified patient health literacy issues and also acknowledged barriers to health literacy that are related to social determinants of health. (i.e. poverty)

Staff at times experience frustration when faced with the health literacy related needs of the Aboriginal population. They also advocate that engagement with patients requires the development of a trusting relationship. Staff were also aware of stigma issues for client participants (For example: low literacy carries a measure of stigma; staff were sensitive to the potential of embarrassing patient participants.) In addition, some staff observed fatalistic attitudes surrounding chronic disease.

The following section provides a summary of the New Zealand based research.

NEW ZEALAND RESEARCH SEGMENT: MAORI STAFF

A total of seven interviews were held; four were Maori staff members, 1 was a Maori literacy expert and two were Maori Elders. Participant interviews were held using an in-depth semi-structure interview⁵⁸ process. The transcripts and notes were reviewed and manually thematically coded by the student researcher.

Maori staff also perceived their patients as understanding their cardiovascular disease only from a western bio-medical perspective as illustrated in the following quote.

“None saw it through anything other than a western paradigm” “Even though they were steeped in Maori Tunga (Maori culture) they still saw their heart disease through a western paradigm lens. This may be because we were talking to them about medication which after all is another western paradigm”

Staff participants described patient’s viewing cardiovascular disease as a ‘new disease’, a serious illness with patients knowing that they are sick and that there is a problem. Some will accept their illness even when they don’t understand how they acquired it. Socio-economic situations influence how they see their cardiovascular disease; those experiencing poverty may feel helpless because they are marginalized. These findings are similar to the findings in the Canadian segment of my research.

⁵⁸ See attached interview guide.

Maori staff participants also conveyed that the concept of personal responsibility for health is very complex and there are many factors to consider. For example, there is a tendency for some patients to prioritize their children's well being ahead of their own. There may be a lack of knowledge or skills even when there is motivation to self-manage care. The value of collective responsibility is also very important to Maori. There is a link to Whanau (family) and the notion of family responsibility. Individual approaches to programmes are not always a good fit and need to be inclusive of family members. There are concerns that the younger generation do not have the same cultural values. Reciprocity is also a cultural value linked to the concept of personal responsibility. Each individual brings something to the healing relationship and must do their part in the healing process.

Maori healthcare practitioners identified specific structural barriers to self-management of health care for Maori patients. For example, health service fees, challenges getting time away from work to attend appointments, transportation, cost of petrol and for some, not seeing healthcare as a priority. Patients do develop strategies to manage their medications. Often there is a lack of family support; in that, they may be disconnected from their family. There is an understanding of risk factors but also a sense that they can't control it. There is a fatalistic attitude that cardiovascular disease is inevitable for Maori. They also may link their cardiovascular disease to hereditary factors versus lifestyle.

Maori healthcare practitioners identified gaps in the transmission of culturally relevant health information and advocated the importance of health literacy approaches that engage the patient and build trust. Health messaging also needs to include a social determinants of health and socio-historical context.

Generally, there was a much broader understanding of socio-cultural-historical factors regarding the overall health status of Maori. Maori healthcare practitioners reported several examples of the negative impact of colonization and assimilation efforts on Maori's ability to manage health. For example, loss of language, culture, Traditional lifestyle and land; barriers to culturally relevant healthcare and services as European perspective is individualistic. They noted that not everyone is aware of these impacts. Many Pacific Islanders tend to blame themselves. Also that socioeconomic realities negatively impact their attempts to live in a healthy way.

Several participants noted that while some healthcare practitioners are well intentioned, Maori relationships with their healthcare practitioners are generally not equal. The unequal power dynamic is complex and challenging to address. Patients feel marginalized and many are not aware that they can refuse treatment; others like being directed. Many experience systemic discrimination; they describe systemic issues and a need to change the model of care because the power differential still exists. Advocating support and a cultural brokering approach are seen as positive aspects of the healthcare practitioners' role by patients.

Maori healthcare practitioners identified the importance of a self-determining approach. They believe that there is a right to know; to receive information in a cultural way, to build knowledge. Stories about health are handed down from previous generations. However, there is also a cultural value of respect involved as it is considered disrespectful to question the healthcare practitioners. There is a feeling that it is important to have good information from reliable people that the community respects and consults. One participant indicated that a tool for the people is needed. (Wananga)

Maori healthcare practitioners are aware of what is needed for a more self-determining approach to health services. They advocate for increasing the number of healthcare practitioners; development of Indigenous - specific health literacy approaches; acknowledging reciprocity in the relationship; maintaining anonymity and confidentiality; maintain a wholistic, approach; and assist patient to address their health issues in a pragmatic approach.

The importance of access to Traditional Medicine was acknowledged and it was affirmed that some people use both Traditional Medicine and Western medicine. Access to cultural teachings and beliefs make a positive difference. Traditional healing won't work unless individuals do their part. They must first agree to help themselves. They can't be just a listener. Language was acknowledged as important because 'protocols' disappear when it is lost. The role of Traditional Healers varies. However, there were also concerns expressed regarding the use of Traditional Medicine. Young people may be stigmatised for utilizing Traditional Medicine. Some healthcare practitioners are also concerned about the risk of losing their healthcare practitioner licence as Traditional Medicine is not included standards of practice.

In summary, there were many similarities in the findings of the Canadian segment of my research and the New Zealand based findings. For example, Maori patients mainly perceive their cardiovascular disease within a biomedical frame of understanding. They see cardiovascular disease as a 'new disease'; one that is linked to socio-economic factors and they are able to identify risk factors that pre-dispose them to chronic illness.

There are also similarities in how Maori perceive their personal responsibility for health compared to Indigenous patients in Canada. They view this responsibility as very complex with many factors to consider. There is also a 'collective' element in this self-care value that adds a cultural dimension to the approach required. There is also a similar understanding of socio-cultural cardiovascular risk factors but also a sense that they can't control it. There is a fatalistic attitude that cardiovascular disease is inevitable for Maori. They also may link their cardiovascular disease to hereditary factors versus lifestyle.

From a staff perspective, there was a much stronger awareness by Maori staff participants than Canadian non-Indigenous staff participants of the culturally relevant needs of Maori clients and a clear understanding of the link to socio-historical factors such as colonial oppression and assimilationist events that can be linked to negative health outcomes for Maori in contemporary times. This awareness of the needs of Maori is an important factor linked to the relationship between Maori patients and their healthcare practitioners and has implications to how they support self management of their cardiovascular disease and other chronic illness. For example, staff participants identified gaps in the transmission of culturally relevant health information and reported that there is a need for healthcare practitioners to be aware of the power differential in the relationship, to actively engage the patient toward building trust and to support a self-determining approach to their self-management of care.

Chapter Summary

My research illuminates several key considerations regarding the cultural context of health literacy for Indigenous patients with heart disease. As noted in the introduction to this chapter, there were two segments of my research. The objectives in the first segment of the research included attempting to understand how patient participants perceive their cardiovascular

disease and if Indigenous peoples hold beliefs regarding their heart disease or diabetes that stem from their Indigenous heritage or culture. The second objective was to learn more about their experiences with healthcare practitioners specifically, how interactions with healthcare practitioners may have influenced personal agency regarding their use of Indigenous values and beliefs related to health and well-being.

It appears generally from the findings, that Indigenous peoples have an understanding of their heart disease that is grounded in biomedical, scientific theory. There is a general awareness of common risk factors related to their cardiovascular disease diagnosis. They have learned that risk factors related to life style such as diet, exercise and stress are attributed to heart disease. Many are aware that social determinants such as poverty/low income are also related. A few are aware that socio-historical factors such as the generational impact of residential school and contemporary experiences of oppression and discrimination are also linked.

It is not a revelation that most Indigenous peoples ascribe meaning to their heart disease or chronic illness from a biomedical perspective in light of the dominant presence of biomedical evidence-based primary healthcare services that are available to them in both urban and on-reserve settings. Yet, some patients are aware of or utilize Indigenous Traditional healing services for their heart disease or diabetes. While access barriers are predominant for most living in an urban setting, some Traditional healing services are available through local Indigenous organizations.

Most patients are also not hearing messaging regarding culturally-based values and beliefs related to health and well-being. While there are a few examples of Indigenous values or beliefs that have been conveyed via family members, most people interviewed did not receiving

messages from their family or community networks. This is an important finding as it indicates Indigenous peoples are experiencing an ongoing, pervasive detachment or isolation from culturally - relevant information regarding their health and well- being. For a millennia, Indigenous peoples have understood their own health within the context of their own cultural belief systems, customs and Indigenous ways of knowing. A way of knowing that is intricately linked to the way their lives are intertwined with the world around and beyond them. This issue will be explored in the next chapter with the objective of understanding causal factors related to what can be labeled as a 'diaspora of Indigenous knowledge'.

Relevant to the second objective, which was to learn more about patient experiences with healthcare practitioners, specifically, how interactions with healthcare practitioners may have influenced personal agency regarding their use of Indigenous values and beliefs related to health and well being. Healthcare practitioners including physicians, nurses and other allied professionals play a key role in the uptake of health information and as such the relationship they establish with Indigenous patients and the awareness and understanding they have of Indigenous cultural contexts regarding health are critical success indicators from a health literacy perspective. Issues linked to a lack of awareness regarding Indigenous health related issues; patient perceptions of inequality in their relationships with healthcare practitioners and a lack of understanding regarding the socio-historical issues related to contemporary problems are important findings for consideration by educators and healthcare practitioners. The research proposes that Indigenous patients do have special needs regarding their heart disease and other chronic illness. Of particular concern is the evidence that suggests Indigenous patients express a fatalistic view or resignation regarding their heart disease and diabetes. This may be a significant

finding when considering patient's ability and confidence to manage their self-care. Health literacy approaches need to correct or challenge fatalism attitudes.

The evidence suggests that Indigenous healthcare practitioners enhance the relationship with their Indigenous patients, although the Maori context indicates that there are many similarities in the issues that Maori face towards accessing and integrating Traditional healing services into their self-care management approaches.

A key factor in achieving a positive healthcare experience for patients correlates with their relationship with their healthcare practitioner. Further exploration of how both patients and healthcare practitioners can achieve a more equitable and engaged relationship is undertaken in Chapter 5.

CHAPTER ~ 5 ~ MAKING THE CASE: INDIGENOUS KNOWLEDGE DIASPORA AND THE NEED TO RECLAIM AND RESTORE NIBWAAKAAWIN IN HEALTH LITERACY APPROACHES FOR INDIGENOUS PEOPLES

The purpose of my research was to understand how Indigenous patient participants ascribe meaning to their cardiovascular disease. A second objective was to learn more about their experiences with healthcare practitioners. More specifically, how interactions with healthcare practitioners may have influenced personal agency regarding their use of Indigenous values and beliefs related to health and well-being. One key finding from my research is that while some of the participants may draw from Indigenous cultural values, beliefs or teachings, most ascribe meaning to their heart disease from a biomedical perspective that is relayed to them by the healthcare practitioners they seek health services from.

It is proposed that this situation can be attributed to an Indigenous knowledge diaspora experience that is linked to socio-historical and socio-cultural factors; including the severance of access to Indigenous knowledge and Indigenous languages during the residential school period and the dominance of biomedicine in health care service delivery. These factors serve as socio-structural barriers preventing the effective uptake of health information for Indigenous peoples.

In the first section of this chapter, Indigenous knowledge and language are situated as culturally relevant health information sources that can inform an Indigenous person's perspective on physical and inner well being. The intention in this section is to provide an Indigenous - specific example of how values and beliefs related to the notion of physical and inner well-being are informed by Indigenous knowledge and Traditional healing practices. A description from Ojibwe/Saulteaux teachings provides the reader with a glimpse into the Indigenous knowledge

system related to the Ojibwe teachings of 'Bimaadiziwn'. Medical anthropological perspectives regarding why it is important to understand how people make meaning of their illness experience are integrated into the discussion. The second section explores the concept of diaspora as related to Indigenous knowledge and how it can be applied to Indigenous peoples' understanding of their cardiovascular disease. Namely, that Indigenous peoples have acquired a 'diaspora consciousness' regarding their cardiovascular disease; a consciousness that is rooted in biomedical theory and is devoid of Indigenous knowledge thus, contributing to a negative Indigenous knowledge diasporic experience. The concept of 'diaspora *health* literacy' is critically discussed focusing on its potential utility as a tool to address the Indigenous knowledge diaspora barrier when trying to self- manage their heart disease in a culturally relevant way.

Accessing Nibwaakaawin to achieve Bimaadiziwin

"We listened to three women yesterday. What they had to say tells me that spiritual rebirth is happening; spiritual rebirth is absolutely essential. The imperative for us now, as Native people, is to heal our communities, and heal our nations, because we are the final teachers in this sacred land. We have to teach how to live in harmony with each other and with the whole creation. People will have to put down their greed and arrogance before they can hear what we are saying. I am not sure how many will do that. So we are in the process of healing ourselves, healing our communities, and healing our nations." (Closing words of Anishinawbe Elder Art Solomon at a conference at University of Sudbury in 1992)

For millennia, Indigenous peoples have understood their own health within the context of their own cultural belief systems, customs and Indigenous ways of knowing. A way of knowing that is intricately linked to the way their lives are intertwined with the world around and beyond them. Solomon's quote speaks to the importance of Indigenous peoples drawing from the spiritual knowledge that has been passed on for many generations as an essential resource of

information to heal ourselves and our communities. The following attempts to capture key elements of Ojibwe Indigenous knowledge/Nibwaakaawin related to physical and inner well being.

The inter-relationship of all things

Many Ojibwe health practices have been closeted for generations due to government - imposed bans in their attempt to suppress Indigenous spiritual practices. However, inter-generational knowledge related to health and healing and Ojibwe healing practices has emerged in the writing of Ojibwe scholars, to promote 'bimaadiziwin' [a healthy way of life].

Bimaadiziwin is grounded in a belief system that frames the interrelationships of all things; a wholistic perspective that is central to an Indigenous worldview. The need for harmony and balance is an integral part of the Ojibwe sense of wellness in that one must attend to the physical, emotional, and spiritual parts of life to be whole (Peacock and Wisuri 2002:94). The notion of inter-relationship is a common belief among many Indigenous peoples. This extends to all things on the earth. Ojibwe people believe that the Earth is the mother of all life. Johnston (1976) notes that Mother Earth is the giver of healing plants and animals that are used for sustenance. Many Ojibwe acknowledge the beauty of Mother Earth as beneficial to our emotional and spiritual well-being and are mindful in our prayers and ceremony of the inter-relationship with her on a daily basis (Peacock and Wisuri 2002:96).

Use of Traditional Medicines

Ojibwe people used an array of herbal medicines to treat various sicknesses. For example, We-kay (bitterroot) was used for sore throats. Treatments were available for skin eruptions, symptoms of tuberculosis, fevers, heart trouble (mixing a root found in swamps -

mackwo'kawac) and catnip (namewac') that revived fainting persons or quickened heart beats (Peacock and Wisuri 2002:101). Hilger (1992) noted that squirrel tail was used to coagulate the blood; swamp tea was brewed for colds. Knowledge of Traditional herbs and medicines was obtained by both the Waynabozho (also called Nanabush, who is the benevolent culture hero of the Anishinaabe tribes) and by observing animals which were considered the elder brothers (Peacock and Wisuri 2002:pg) Johnston conveys the story of how a frog escaped a predatory snake by hiding in poison ivy and once the snake abandoned its quarry, then rolled itself in jewel weed, a plant that counteracts the effects of poison ivy. From this, the Ojibwe learned the cure for poison ivy exposure. Johnston notes that the sick were treated not only with herbs and medicines for their physical well being but in the name and through the name of 'Nawneedis' who was known by the Ojibwe as the patron of well-being. In this way, the inner well being of the person was fostered and sought (1976:169).

Relationship between health and spirit

There is a fundamental belief in the close relationship between everyday existence and things of the spirit. Spirits are noted to be all around and in one's hour of need, one is encouraged to call upon the Creator and also the spirits of one's ancestors who have passed before us to give one support, to be with one and guide one in making important decisions (Peacock and Wisuri 2002:99). If an affliction was considered to be of a spiritual nature, a medicine person could be consulted. The medicine man would conduct spiritual ceremonies that have been handed down through generations. Examples include 'bone' healing, tipi-shaking, drumming and are considered to be channels for healing spirits. Medicine men and women also believed that knowledge of medicine and healing alone could not guarantee a long life; one must also live a

‘good’ life. Illness was also considered a misfortune that represented punishment. Long life was considered the product of ‘good, upright living’. These values were demonstrated in the life-long practices of medicine men and women who were members of the ‘Midewewin’; a society of healers whose members are chosen by elder Midewewin members. They then dedicate their lives to understanding the healing ways of plants and how to develop their character and inner spiritual self in the practice of healing (Johnston 1976:83).

Personal Responsibility for physical health and well-being

“Each of us carries a fire within....whether it’s through the knowledge we have, or through our experiences and associations, we are responsible for maintaining that fire.At the end of the day maybe we should ask ourselves: “how is our fire burning?” Maybe that would make us think of what we’ve gone through that day — if we’d been offensive to anyone, or if they have offended us. Maybe we should reflect on that because it has a lot to do with nurturing the fire within. And maybe if we did that....to let go of any distractions of the day by making peace within ourselves....maybe then we could learn to nurture and maintain our own fire within.” (Ojibwe Elder)

This quote demonstrates another important aspect of ‘bimaadiziwin’; to foster and enlarge one’s inner being and embrace the duty to know and understand what this inner being is about. Johnston describes the process of understanding oneself and self-directing the growth of inner spirit. Every man and woman is given different powers and gifts of insight that only he or she is capable of understanding. There is a value of personal responsibility for one’s well being; each man or a woman is accountable for his/her self-development. The following quote capture’s one patient participant’s perspective on this value.

“Just like to walk to get your exercise. Not to stay dormant, you know, and if you're not feeling well, don't lay there, get up and push yourself to get yourself better and don't baby yourself. Be strong is what my mum used to say. You know, that's why I think today I push myself to do what I have to do, you know. Like I don't have very good function in my legs but I push myself to walk. You know, and I push myself to do housework which I know I can't do too much but I push it to do it, you know. Don't I?”

One is expected to live a good life and to do so, ensures one's entrance to the 'Land of Souls' among the soul-spirits beings in a peaceful state (1976:138). There is an expectation that men and women also have to develop courage, fortitude, endurance, patience, perseverance, cheerfulness, generosity and resourcefulness to face the hardships of life. They are also expected to know and live within the laws that govern both the physical world and natural, primal laws that regulate 'the cosmos, the coming and going of the seasons, the wax and wane of light and darkness, the division of rock, fire, water, and wind' (Johnston 1976:138). There is also a collective responsibility to consider the well-being of the people of one's community. Leaders are expected to base their decisions in council on the principle that the well - being of the people "takes precedence over form, custom and even tradition" . They also petitioned Kitche Manitou for wisdom and guidance (1976:139). Women roles were entwined with looking after the well-being of others (1976:114).

Ascribing Meaning to health and illness

There are many interpretations of health as people develop their own concept of well being from their internal logic and intimate theory of knowledge (WHO 1999:n.p.). From a Western perspective, the focus is on treating the body, mind and society in isolation from each other (WHO 1999; Winkleman 2009:135). The WHO proposes that there are however, common and unifying elements regarding how health is interpreted across Indigenous cultures. Indigenous healing systems are grounded in the concept of holism and well-being is viewed as the harmony that exists between individuals and communities and the universe that surrounds them. Nature, human beings and the collective history of their ancestors are intertwined with each other.

This value of wholism was captured by a patient participant in the following quote:

“So spiritual health is just as important, that whole balance thing and also that Traditional knowledge or Traditional medicine is just as effective.” (refn)

Illness is a phenomenon of the soul as well as the body. Another important factor is that it is believed that all elements of the universe possess spiritual qualities and therefore, every natural element can cause either illness or cure. (For example, bad air can bring illness and a plant can restore health.) Earth is considered the mother and therefore, the well being of the land is related to the well-being of the people. Social norms and compliance with moral obligations are related to health and if there is a transgression, illness may occur. Retribution may be required to restore harmony and promote healing (WHO 1999).

The concepts of ‘mino’ or health inform Ojibwe understandings of physical and inner well being. For example, sickness can never be separated from life; it is a state of being and existence, as abiding as well being. The well being of the body is directly related to the well-being of a person’s inner self. Sickness is construed as the physical form of inner turmoil therefore, healing requires inquiry into the nature and character of dreams. It is expected that men and women ‘grow in spirit’ to teach others. The well being and the continuity of a community require that the spirit be enlarged and passed on through the generations. Full life would be achieved not by the knowledge of curing sickness but rather by living a good life (Johnston 1976:pg). Ojibwe teachings related to physical and inner well being are woven from stories passed on through generations. The people were to live in a way that would yield a strong physical body based on the understanding that in order for people to be completely healthy, they

also had to develop themselves spiritually and find a balance between the physical and spiritual worlds. This value is demonstrated in the following quote from a patient participant.

“As far as drawing [water], we would cheat and use the wagon once in a while and we got caught. And he says, “No, you’re supposed to carry them. Carry the buckets of water. You don’t put it in the wagon and pull it down the road; you don’t pull it to the house.” You know, or we’d draw wood from the bush, we would put it in small pieces, you know, small ones to carry. And we weren’t getting any muscle so he was getting us to carry longer and heavier pieces to get us more muscle and stronger legs and back I guess you might say. That way was good. I thought that was very good.”

Spiritual customs such as the Vision Quest, a ceremony to assist one with seeking out the knowledge of the Spirit World through fasting, dreaming and meditation, assisted them in achieving this balance (Author1988:66).

From a sociological perspective, sickness is viewed as the social actions that a person takes as a result of illness or disease, such as taking medication, visiting the doctor resting or being absent from work. It is proposed that patients feel illness and act out sickness (Nancarrow 1992:132-133). The following quotes demonstrate that patient participants engage in numerous social actions related to managing their cardiovascular disease and diabetes.

“Something that I make a routine of, once I’m in a routine I can try and keep that going. So when I do my blood in the morning is before I go to work and after I’ve had my... No, it’s before I have my coffee. I put my coffee on and then I go and do my blood. So that’s a weekday thing when I go to work. Weekends are different and sometimes I forget that routine. So I might not always do my blood on Saturday and Sunday but back to the routine on Monday to Friday then I do it.”

“Well I try and watch what I eat because I know that’s important. But I still try and be truthful to the doctor about how I eat. Like I live by myself. I only work part time so I have limited income. Cooking for one person is not fun and I don’t do it a lot because I’m only one. So I admit, you know, I’ll go home and have a hot bowl of cereal for supper. My breakfast consists of a cup of coffee and toasted cheese sandwich. It’s been the same thing every morning for 10, 20 years, I don’t know and it’s not going to change.”

Cornwall (1983) in Nancarrow Clarke notes that medical anthropologists and sociologists who have examined beliefs about illness in modern Western communities, discovered that there is variance related to the cultural background. The authors report that non-medical people hold ‘immensely strong beliefs’ about illness, causes and treatments. They also point out the differences and contradictions between medical and lay ideas (year:136). Nancarrow Clarke argues that individual views are affected by society and “by a particular place at a unique point in time in that society.” Further, that meanings are a social construct with social, political, economic and *historical* contexts and reflect a person’s position in that social structure along with their personal relationships and experience (1992:147).

An important socio-historical factor that contributes to Indigenous peoples’ meaning of illness and their ability to draw from their culturally based teachings regarding health is the colonizing and assimilating practices of European settlers and missionaries. For example, the imposition of the reservation system whereby, Indigenous peoples’ nomadic way of life was interrupted. The literature is abound with stories regarding residential schooling and the devastating impact on the mental health and well-being of Indigenous children and subsequent second and third generations. Language loss is also an important factor. Children attending residential school were not allowed to speak their Indigenous language. This resulted in a severing of health related indigenous knowledge sharing between family and community members. The following quote from a patient participant illustrates the situation of many Indigenous peoples who are unable to speak their language. The patient was asked about his understanding of why he didn’t know his language.

“ Yeah because my mother and father didn’t stay 100% with the longhouse, they chose to go to the church, and I just kind of followed them along. I could have later on if I wanted to but when you’re a young man, you know, that’s not the first thing on your mind is... Well not all people anyway, some people yes, they have to go there but that’s what they want. But with me I was torn between two of them, the longhouse and the church.”

The cultural oppression and resulting loss of health-related Indigenous knowledge can be situated within a diaspora frame. The following section will critically explore the concept of diaspora and how it can be linked to the notion of health literacy for Indigenous peoples with cardiovascular disease.

Defining diaspora

Butler acknowledges the agreement of most diaspora theorists that there are three basic features of diaspora; dispersal to two destinations, relationship to homeland and awareness of identity (2001:192). Similarly, Brubaker affirms that the three core elements constitute diaspora are; dispersion in space, orientation to a ‘homeland’ and boundary-maintenance⁵⁹ (2005:n.p.). According to Brubaker, there has been a proliferation of the use of the term since it emerged in the scholarly literature in the late 1980’s (2005:n.p.). Initially, scholars discussed diaspora as being rooted in a conceptual homeland that was primarily linked to Jewish diaspora and eventually Armenian and Greek diasporas. African diaspora was introduced by engaging the Jewish experience. Brubaker describes an extension of the term to what he describes as an ‘attenuated’ reference; with some emigrant groups’ continued involvement in homeland politics and labour migrants who maintain emotional and social ties with a homeland. In some cases he argues that the reference to the conceptual homeland has been lost altogether; such as transethnic and transborder linguistic categories - Francophone and Anglophone communities that have been

⁵⁹ Brubaker acknowledges that there is evidence of tension in the emerging literature regarding the way that these core elements are understood.

conceptualized as diasporas. There are also ‘putative’ diasporas; the ‘white’ diaspora, the deaf diaspora, the queer diaspora and others⁶⁰ (2005:n.p.).

Brubaker also reports that the concept is suggestive of a staged process that includes; initial displacement and defamiliarisation; reception and accommodation in new diaspora locations amid an uncertain welcome and possible fragmentation of homeland cultural orthodoxies in different diaspora location. Burke also draws from Thomas (Thomas1982; Thomas 1992; Thomas 1994;) which include ‘possible acceleration of the objectification of homeland culture and ‘complexifying of worldviews’ as the engagement with the encapsulating society is intensified’ (2005:n.p.). King, a black American scholar and activist, notes that the concept of diaspora has been adapted to describe the experience of ‘cultural knowledge distortion’. The experience of school desegregation for black students in the United States illuminates the concept of cultural knowledge distortion. King, draws from the discourse related to a controversial 1954 judicial decision; *Brown v. Board of Education* that ruled in favor of school desegregation in the United States to illuminate her position on the notion of ‘knowledge distortion. King argues that the decision did not take into account the ways “that ideologically distorted knowledge sustains societal injustice, particularly academic and school knowledge about black history and culture”⁶¹ (2006:337). King utilized a morally engaged pedagogical approach and identifies the ‘diaspora literacy’ (culturally informed knowledge) and ‘heritage knowledge’ (group memory) as conceptual tools to define the logic of this pedagogical praxis

⁶⁰ Brubaker laments that dispersion has involved the application of the term to an ‘ever-broadening’ set of cases; ‘essentially to any and every nameable population category that is to some extent dispersed in space. He cites (Sartori, (1970) who argues that this watering down use of the term stretches the category ‘to the point of uselessness (2005: n.p.). Indeed, there has also been a proliferation of terms related to diaspora. Brubaker provides a comprehensive listing of these terms⁶.

⁶¹ King makes the poignant point that even if there was equal access to education for black students, the curriculum was faulty in that it reflected the ideology of “white supremacy racism”

(2006:337). King also make the important argument that African people's humanity has been denied and that a key outcome is that the next generation is alienated from their identity and heritage and unprepared to participate in the struggle for justice⁶² (2006:162). The notion of 'complexifying worldviews', as Burke proposes, resonates in the discourse related to the clash of Indigenous and Eurocentric worldviews. For example, Ermine et al. captures the essence of this clash in the Indigenous research arena as "the schism of understanding that contributes to the tension - riddled enterprise of cross cultural research involving Indigenous people" (2004:19). The notion of 'language shift' that occurred as a result of colonial assimilation efforts can also be linked to how Indigenous peoples' understanding of physical and inner well being and how they assign meaning to their experiences of heart disease has become a complex one.

Various scholars (Charlisheela 2007; Pasura 2010;) argue the case for application of the term diaspora to various processes and experiences that do not strictly adhere to the Traditional definition. For example, Charlisheela argues that diaspora can be applied to groups *within* nations; that they may enter a diasporic experience without traveling. She argues that exploring the notion of diaspora in this way, allows for the critical reexamination of binaries of national-cosmopolitan and assimilation-resistance which is necessary for projects of cross-disciplinary conversation (2007:n.p.). Charusheela makes the case that diaspora is useful for various reasons such as subject-formation, or narrating a subject into being, for profiling various power dynamics (social and structural) and for locating cultural experience within these power scenarios and for identifying who is inside/outside or who belongs/doesn't belong. She also argues that the

⁶² King also argues that there is a dehumanization, alienation and the assigning of an 'alter-ego' role as the "penultimate other to whiteness" as slaves, second-class citizens. She notes that dominant society assumes that to be white is to be more intelligent, more civilized and thus more human within the proposed cultural framework; a mode of black thought exists that is alternative to these 'rationalizations' of Western thought and as Wynter in King notes; the white 'monopoly' on humanity.

“recompositions and fusions of identities’ can also be found as groups move across the nation state and “transverse varied internal boundaries of regional and lingual identity” (2007:295).

The notion of recombination and fusion of identity is captured in the identity stories of several of the patient participants. Participants identified a range of descriptors that tied them to their Indigenous culture; including being raised or living on reserve at one time in their life; being a fluent or partial Indigenous language speaker or having family members who were language speakers; attending or practicing Indigenous spiritual ceremony (i.e. Longhouse); exploring or using Indigenous medicines and participating in urban Indigenous cultural events (i.e. powwows) or other activities.

Clifford (1997) in Shackleton, is noted for attributing Native “tribal predicaments” such as land claims, common claims of historical decimation and marginality to diaspora (2001:69). Shackleton also acknowledges the work of other diaspora theoreticians such as Brah (1996), who situates Native Americans and Native Australians as oppressed peoples embodied in the concept of diaspora; and McLeod (1998) who describes two types of diaspora among Indigenous groups: ‘spatial diaspora’ (removal from their land) and ‘ideological diaspora’ (alienation from collective memories as found in tribal stories). The concept of ideological diaspora resonates with the notion of Indigenous knowledge diaspora; Indigenous knowledge sharing fosters a understanding of who we are as Indigenous peoples and the importance of a balanced, wholistic worldview and lifestyle. As Indigenous peoples, we value, protect and share our Indigenous knowledge, cultivating an ideological boundary that promises to extend to future generations. The threat to this objective is the negative impact of Indigenous knowledge diaspora.

Clifford argues that Indigenous attachments to place are complexly mediated and notes that continuous residence in cities for many Indigenous peoples can be related to Indigenous diasporas (2013:70). Calloway, (1990) in Clifford, in his ethnohistorical analysis of the Abenaki in the United States, used the term diaspora to describe the dispersal of local Indian groups in the face of settler encroachments during the nineteenth century (2013:72).

Shackleton also makes the important point, that based on its literary production, diaspora theory is not developed enough to fully explore the diversity of the Native experience⁶³(2001:69). However, the findings of this study indicate that there may be a practical utility in the application of the concepts of diaspora and diaspora literacy to the experience of Indigenous peoples diagnosed with cardiovascular disease and other chronic illness.

Indigenous Knowledge Diaspora and cardiovascular disease

Seventh Fire Prophecy

“The Seventh Prophet that came to the people long ago was said to be different from the other prophets. This prophet was described as “young and had a strange light in his eyes” and said: In the time of the Seventh Fire, New People will emerge. They will retrace their steps to find what was left by the trail. Their steps will take them to the Elders who they will ask to guide them on their journey. But many of the Elders will have fallen asleep. They will awaken to this new time with nothing to offer. Some of the Elders will be silent because no one will ask anything of them. The New People will have to be careful in how they approach the Elders. The task of the New People will not be easy. If the New People will remain strong in their quest, the Water Drum of the Midewiwin Lodge will again sound its voice. There will be a rebirth of the Anishinabe Nation and a rekindling of old flames. The Sacred Fire will again be lit. (Benton-Benai, 1988)

This seventh fire prophecy is an example of Indigenous knowledge that is passed on through the generations. The metaphor of our ‘Elders falling asleep’ is a poignant one. The passing on of Indigenous knowledge has been interrupted because many Elders are not able to do

63 Shackleton does acknowledge that diaspora theory deals with issues (identity, home, exile, heritage, location, and so on) that are important both to Native and to Postcolonial Studies.

so. European settler government and religious assimilationist practices such as residential school severed many Indigenous peoples from this exchange by banning them from speaking their language and engaging in spiritual ceremony. This situation has contributed to the aforementioned, complexifying of worldviews. The example of how Indigenous peoples with cardiovascular disease perceive their illness will be critically explored with a focus on how Indigenous peoples' Traditional health related beliefs and values have been grossly influenced and in most cases, been replaced by dominant Western biomedical theory.

This situation is framed as a negative diasporic experience for Indigenous peoples; one in which Western biomedical health services are most often the only option and where there is minimal access to Indigenous knowledge exchange. Further, this thesis proposes that the construct of diaspora and diaspora literacy can be considered as important socio-cultural factors in the discourse regarding health literacy for Indigenous peoples with cardiovascular disease.

Three key factors are proposed in framing the construct of an Indigenous diaspora. They are categorized as socio-historical, socio - structural/geographical and ideological. The first factor is a socio-historical one; that is the forced removal of children to residential schools where the assimilative agenda was to sever the link to Indigenous values, beliefs, customs and language and assimilate them into the dominant mainstream society. The devastating negative impact of this situation, was the interruption of the Traditional oral practice of sharing health related information. Indigenous scholars (Battiste, 2008; McGregor, 2004; Semali, Kincheloe, 1999) in Vent, note that Indigenous knowledge is understood to be tied to the "local natural, social and cultural conditions and requirements and to be derived from the local people's experiences, reasoning, beliefs and memory" (2013:245). Those who attended residential schools were

forcibly separated from family and Elders and therefore, were cut off from hearing the stories and knowledge of their ancestors (Dion Stout and Kipling 2003; Miller 2000; Frideres and Gadszac 2008). The following quote from a patient participant, illustrates the negative diasporic impact of language loss which prevented this individual's ability to understand the Longhouse ceremony and teachings because they are conducted in an Indigenous language of the Six Nations.

“ Not really because I was like church too. I did go to the longhouse but I just went to kind of see what was going on in there and see what it was all about and stuff like that. I did go to a couple of strawberry festivals things they have and stuff like this, but no I didn't go steady because I couldn't really understand what was going on in there like when they were talking. I suppose I could have educated myself more with the language, I wish I did.”

The second factor to be considered in the development of an Indigenous knowledge diaspora, is a two-part interconnected, structural-geographical factor. The first part is the Canadian government's forced relocation of First Nations to lands designated as Indian reserves, banishment of Inuit to unfamiliar northern lands and displacement of Métis people to Métis settlements. Often these relocation processes were a long distance away from their heritage homeland and affected their ability to engage in a Traditional and physically active lifestyle on the land that included trapping, hunting, fishing. In addition, access to ecologically-based Indigenous knowledge which contributes to the body of knowledge regarding Traditional healing and medicine has been restricted as part of this process. The second structural - geographical factor, is the migration from Indian reserves and northern remote areas to urban centres. This situation often results in restricted access to family and community networks that provide information regarding heart disease and other chronic illness. Such is the case for most of the patient participants in my study. For example, 10 of 17 participants were raised or reside in an

urban environment. Limited access to transportation and a limited or absence of connection to family or community are also fairly common occurrences. The following quote illustrates the level of disconnection one patient participant has experienced.

“Ojibwa yeah, because I can't really, I don't really know for sure what we were. But I know that I'm a Métis, I'm not full Indian. There was Indian on my father's side and my mother's side but neither one of them followed the culture.”

An example of how the notion of diaspora can be applied to Indigenous migration from homelands within the nation state, is also drawn from Burke's anthropological perspective regarding the circumstances of an Aborigine group of central Australia known as the Warlpiri. Burke's research examines the cultural implications of what is described as the more - or - less, permanent migration of 25 percent of the Warlpiri away from their home settlements. The concept of diaspora, is used to acknowledge the continuing importance of the Traditional homeland to the Warlpiri to those who settle at a distance. Burke draws on Clifford (1994:309-310) who suggested that the concept of diaspora could be applied to contemporary tribal peoples within nation states. Clifford suggests that this is because Indigenous identity is frequently attached to a lost or alienated homeland described as 'aboriginal' and therefore, outside the nation state (2013:n.p.). Burke draws on scholarly discourse regarding diasporic experience that is in alignment with Charlisheela's discussion as noted earlier, and proposes that the Warlpiri project scales down the idea of global diasporas to the confines of the nation state.

Finally, the third key factor is an ideological one. Namely, the dominance of a Eurocentric, Western biomedical worldview and its negative impact on Indigenous values, beliefs and practices related to physical and inner well being. The dominant worldview construct is captured by Battiste in Martin Hill: the notion of knowledge hierarchies that perpetuate what is

described as “diverse but equally valid systems into a vertical ordering of unequal systems” (2003:8). This situation marginalizes Indigenous knowledge and contributes to the diaspora phenomenon. Charusheela’s argument (2007:295) that groups can experience a recomposition or fusion of identity as they move across the nation state and transverse internal boundaries of identity has utility with the notion that Indigenous peoples have adopted mainstream beliefs about heart disease that are rooted in Western biomedical knowledge as their own. Their experience of various assimilative practices such as suppression and banning of ceremony and language, and severance from family and community networks that passed on health related Indigenous knowledge has resulted in a detachment from their own Indigenous belief system which was based on health and wellness. In addition, their encounters with healthcare practitioners educated in biomedical theory both on and off reserve, has reinforced the biomedical perspective.

The urban drift for many Indigenous peoples seeking employment or access to improved social and health services has contributed to this cultural adaptation of mainstream lifestyle and adoption of non-Indigenous values and beliefs regarding health and healthcare services. There is some complexity to understanding this situation. For example, an urban Aboriginal task force identified the prevalent notion that Aboriginal culture is static and cannot change. In their study, they found that tensions have evolved in urban centers around varying perceptions of ‘Aboriginal authenticity’ and can result in pressure for those living in the city who may be economically successful and experiencing a general sense of wellness can serve as a threat to preconceived ideas of Aboriginal identity. Interestingly, the task force report indicated that the majority of

respondents (76 percent) stressed the importance of Traditional Aboriginal culture; and 80 percent participated in Traditional cultural activities (2007:72-73).

The adoption of non- Indigenous or mainstream biomedical values was a dominant theme in my research with patient participants who could make very little connection to having special needs because they were of Aboriginal heritage. The following quote demonstrates this phenomenon.

“I know the diabetes has a great impact on native people like if you have diabetes and you're native, that's more serious than if you have diabetes and you're Caucasian or whatever it is. I understand that. But I just feel like I'm one of the other people like one of the... I'm just a person. I don't decipher because I'm native that... I don't decipher the difference. Other than I know that the native people have a higher risk of diabetes.”

Cultural knowledge distortion and diaspora *health* literacy for Indigenous peoples with cardiovascular disease

King's aforementioned argument regarding the construct of '*cultural knowledge distortion*' and the need for a diaspora literacy, can be applied to Indigenous peoples' heart illness experience in Canada. Their access to Indigenous knowledge was severed or restricted by European settler government's colonizing and assimilative practices whereby, Traditional teachings regarding health - related values, beliefs and practices would not be passed on to the next generation. Indigenous knowledge that informs culturally relevant health promoting beliefs and practices has generally been replaced by Western biomedical knowledge. This situation can be situated as a cultural knowledge distortion for Indigenous peoples, whereby, their understanding of heart disease excludes Indigenous knowledge that may guide them in their self-care management approach. The findings from this study support this position. Participants were asked if they have their own beliefs about health and well being that they have learned from family, friends or others in the community. Most participants report that they have not engaged in

Indigenous spiritual practices or received health messaging from Indigenous - specific sources.

(I.e. Elders counsel, utilizing Indigenous medicines, attending spiritual ceremony). The following quote from a patient participant illustrates this perspective.

“A little different from my belief, which I don’t know because I wasn’t raised with it. See mostly what I know now is, even about Longhouse is when I go there for something, you know, mainly it’s for funerals. It’s always the connection there where... But she doesn’t come outright and tell me, I have to ask because she don’t know whether I want to or not, you know, how I’m... That’s just the way we did it.”

It is argued that a ‘diaspora *health* literacy’ is required to ameliorate this situation.

Clark (1984) in Welentz, a black American scholar and diaspora theoretician, is recognized in the literature as coining the term ‘diaspora literacy’, and she defines the construct as; “the ability to read and comprehend the discourses of Africa, Afro-America and the Caribbean from an informed, indigenous perspective”. Diaspora literacy has been identified as a tool of critical inquiry for black women writers of Africa and the diaspora, to reclaim and re-articulate a “usable past; a past that can function in the future”. They “give voice” to undocumented women story tellers who draw from a woman - identified tradition based in the orature of their African and African-American/Caribbean foremothers (1992:401). King draws on Busia (1989) and explains diaspora literacy as ‘understanding our story’; within the context of Black cultural dispossession.

This discourse can be applied to the Indigenous knowledge diaspora as described above: patients with heart disease have little or no awareness of Indigenous knowledge that could further inform a culturally relevant understanding of their heart disease. Indigenous diaspora *health* literacy can assist Indigenous peoples to manage their heart disease in a more culturally relevant way and can be used as a conceptual tool in a reclamative and restorative process to

address the cultural knowledge distortion related to Indigenous knowledge diaspora. An increased awareness and understanding of Indigenous knowledge and Traditional healing will result in an enhanced and empowered, self-care management approach to their heart disease.

Mainstream biomedical healthcare services are for most Indigenous peoples, the primary source of healthcare for their cardiovascular disease. Healthcare practitioners have been educated in health science programs also grounded in biomedical theory. They are also likely to be non-Native. In addition, as noted previously, Indigenous people have limited and restricted access to Indigenous knowledge, thus resulting in limited recourse to foster Indigenous diaspora health literacy.

It is argued that this Indigenous knowledge diaspora presents as a socio-structural barrier that impedes access to culturally relevant heart health information thereby, perpetuating the cultural knowledge distortion and cultural oppression initiated by a European settler assimilative agenda. It can be argued that the Indigenous knowledge diaspora experience is also consistent with the negative diasporic impact that King reports may include the experience of culture shock, isolation, racism, language shift and language barriers and inability to navigate a foreign, mainstream educational system. (or in this case; healthcare system) (2006:337). The emergence of literature regarding historical trauma is an important body of work that has relevance to the impact of Indigenous knowledge diaspora. Yellow Horse Brave Heart (1999), a Lakota historical trauma theorist in Esquimaux and Smolewski, draws from a Lakota collective of social workers, addiction counsellors educators, community leaders and Traditional healers, who adopted a definition of historical trauma as “cumulative emotional and psychological wounding spanning generations, which emanates from massive group trauma” (2004:54). Symptoms of historical

trauma include elevated suicide rates, depression, self-destructive behaviour, substance abuse, identification with the pain ancestors endured, fixation to trauma, somatic symptoms that do not have a medical reason, anxiety, guilt and chronic grief (2004:54).

Indigenous knowledge diaspora experience can be situated within the frame of structural violence, a phenomenon that contributes to the erosion of personal agency of Indigenous peoples striving for effective self - management of their cardiovascular disease. The end result unfortunately is the fostering of continued health disparity.

Structural Violence and Indigenous knowledge diaspora

The notion of structural violence emerged from Johan Galtung's work in the field of peace studies more than forty years ago. Galtung's (1969) definition of structural violence acknowledges that violence occurs when there is no identifiable actor responsible for the violence as it is for personal violence. Vorobej's review of Galtung's work captures this difference with the example of inequity that some individuals experience, in an ethnic group for example, when there is a much lower life expectancy than another and there is no clearly identifiable agent responsible for such an avoidable discrepancy (2008:87).

Paul Farmer, an internationally recognized American medical anthropologist, expands our understanding of how the presence of structural barriers with respect to health, can be described as 'structural violence'. The notion of structural violence as conceptualized by Farmer, is framed within the concept of 'restrained agency'. Namely, that personal suffering is 'structured by "historically given and often economically driven" processes and forces that limit one's ability to make personal choices. Farmer identifies racism, sexism, political violence and grinding poverty

as examples of such forces and draws from his extensive work with the impoverished in Haiti (2005:49). He makes a connection between human ‘suffering’ and structural violence.

Farmer also describes how the presence of structural violence obscures the visibility of suffering and articulates three primary reasons for this. He reports that an ‘exoticization’ of suffering distances the suffering of those that is remote from one’s own whether because of geography or culture and makes it less affecting. Furthermore, when there is enormous suffering, it makes it difficult to render the suffering. The level of suffering cannot be conveyed in pure facts and figures which usually allows for the objectification of suffering. Finally, there is still minimal understanding of the dynamics and distribution of suffering. Farmer proposes that to really understand, one has to explain the suffering and further that one must go beyond case study approaches and ‘embed individual biography in the larger matrix of culture, history and political economy’ (2005:41). Farmer et al. also argue that although physicians appreciate that large scale social forces often determine who becomes ill and who is able to access care, this awareness seldom results in formal frameworks that link social analysis to everyday care (2006:1686). The following quote provides an example of one patient’s negative experience and perception of the healthcare system that can be situated within a structural violence frame. When asked if he felt he had special needs as an Aboriginal person he replied:

“Yes, because we don’t assert ourselves enough to say to a doctor, this isn’t right with me, we more or less kind of whine about I’m not feeling good, I hurt here and I hurt there. Rather than say, I want you to do a test on this.I don’t know why, I’ve been thinking about that and... I guess I’m thinking they should be reading between the lines, like... And some of the blood work that’s been asked for costs money to do so as an Aboriginal person, a poor Aboriginal person it’s hard to get them do, like \$50 for a test.”

When asked if he thought Aboriginal people understand the healthcare coverage that the government provides he responded:

“Not really, I don’t think they do. I look up on the website of what’s covered and what’s not covered, what they’re going to... What they’re cutting out and what they’re not. But most people are not into politics and they, you know, and they’re still back at okay give me this script and Indian Affairs will pay for it. They don’t realize Indian Affairs keeps cutting back, cutting back all the time. We have to use no name drugs all the time; they won’t cover the good stuff.”

Kleinman weighs in on the discourse of suffering with a critique on biomedical interpretations of illness; namely, the exclusion of the experience of suffering in the assessment of disease (1995:100). He cautions that both biomedicine and anthropology are at risk of leaving the experience of suffering out of the equation and labeling disease or creating illusions of finality, continuity and coherent meaning, when in fact, that may not be the case. He cautions against “doing violence” by making personal experience too abstract. He asserts that there are ‘routinized’ forms of suffering related to shared aspects of the human condition. For example, chronic illness or death, experiences of deprivation exploitation, degradation and oppression. It is normally the poor, vulnerable and defeated in societies that are exposed to these categories of experience while others are protected from exposure (1995)

A poignant example from the findings of this study perhaps illustrates Kleinman’s position. The findings showed that several patient participants commented on the inevitability of the morbidity and in some cases the mortality of diabetes and heart disease among Indigenous populations. The following quotes demonstrate the idea of how patient participants experience a measure of suffering related to their sense of fatalism regarding their diabetes and heart disease.

“Yes, because I think diabetes is.... a lot of Aboriginal people have it. I knew I was going to get it before I even had it. My mom had it and my grandfather had it so I just knew it was coming”

“Yeah just being diabetic, like I know there’s a lot of diabetics out there but it does seem to be more common with Native people.”

“I don't think I have special but I think, because I'm Native, I'm... I don't want to say destined but I'm destined to have certain things happen. Like I was destined to have diabetes. I knew that before I even had gestational diabetes because it runs rampant in my family. Right from my grandmother... I have a cousin who died; she was actually blind from diabetes. I have a number of them that have juvenile diabetes. So it's everywhere in my family. So I knew that was going to happen and my mother was diabetic and she never got diabetic until much later in life. I mean much, much later. She was over 50, maybe even over 60 before she got diabetic. But it happened.”

There were also for some, a resignation that healthcare practitioners expect Indigenous peoples to develop chronic illness. For example, in the following quote, the participant acknowledges that the doctor automatically started screening for heart disease.

“Because when I started going back to him the first things he started checking was the sugar and the high blood pressure and stuff like that right away..... Because I never asked him to, so he just did it right away”

The notion that various socio-structural elements in our society negatively impact health status is also captured within the construct of syndemic suffering. The field of syndemics has emerged 20 years ago and is described as a biocultural and political economy concept. Syndemics raises awareness to adverse and unjust social conditions that play a role in what Singer et. al. describe as the “deleterious clustering and interaction of diseases”. It has also promoted as a useful conceptual framework for the study of global health inequity and become a widely used multidisciplinary disease model (Singer, Bulled and Ostrich 2012:n.p.). Mendenhall argues that biocultural and critical medical anthropology have established the important link between disease and suffering and the social condition. Biocultural theorists utilize a political-economy and sociocultural frame to explore changes that impact human biology. While macro-social factors such as social inequality are the focus for critical medical anthropologists.

Mendenhall draws from the field of critical medical anthropology regarding the notions of structural, symbolic and everyday violence to frame her analysis of social and political-economic inequities and individual traumas that contribute to the poor mental and physical health of Mexican immigrant women (2012:14). I propose that the notion of syndemic suffering can be linked to the negative diasporic experience endured by Indigenous peoples with heart disease and other chronic illness and the measure of structural violence it imposes. Namely, that existing health literacy approaches are not inclusive of, nor do they facilitate access to Indigenous knowledge. This results in both the sharing of only the dominant biomedical health information and the perpetuation of cultural oppression which in turn, negatively impacts individual personal agency regarding self-management of cardiovascular disease. An important finding from my research is the awareness that some participants have regarding the potential to connect to their Indigenous heritage and learn more about health related Indigenous knowledge.

“I don't know what it is about a powwow, I went there the first time and it's something like that, the sound of that drum was like in my blood, just right through me.”

“I'm learning more and more about it. That is a very major goal for myself because when I was little my mother was a very private person and we were very close in family but, as far as our cultural background, I'm still learning and want to learn more. I also want to learn the language but it's a very difficult language to learn. I do have a cousin that I'm in contact with constantly who lives on the reserve”.

The challenges people experience in the journey to reconnect with their culture and learn more about health related Indigenous knowledge continues to compromise their overall health. This results in a health inequity for Indigenous peoples who have heart disease. As noted earlier, Adelson makes this link between health disparity and health inequities (2005:S45). She provides an overview of how the present-day health status of Indigenous peoples in Canada are directly linked to decades of inequity and a resulting disproportionate burden of illness. Peacock and

Wisuri affirm the health inequity that many Ojibwe people experience and cite various systemic issues as causal factors including, oppression, overt and covert racism and internalized oppression which they argue is closely linked to negative health outcomes (2002:106-107). The next section explores the role of healthcare practitioners in the Indigenous knowledge diasporic experience.

The role of Healthcare practitioners in an Indigenous Knowledge diaspora.

Today, in Canada, healthcare practitioners from various disciplines practicing in primary healthcare settings are generally utilizing a biomedical approach that is in keeping with their professional standards and practice guidelines. Professional standards and guidelines are informed by policies, research and education curricula that are grounded in a scientific knowledge base. A current trend that calls for the provision of ‘evidence-based health care’ requires healthcare practitioners to ground their practice in research-based findings “rather than tradition, intuition or personal experience” (Polit, Tatano Beck and Hungler 2001:11). As noted earlier, it is critical to ensure that health literacy approaches for Indigenous peoples also accommodate for the inclusion of Indigenous knowledge to ensure that they can access culturally relevant health information regarding their heart illness. This approach has potential to support Indigenous patients’ self-care management of their heart disease.

Kleinman, in his seminal work, *Writing at the Margin: Discourse Between Anthropology and Medicine*’ provides an overview of Good’s analysis of medicine, science and rationality and how medicine constructs its objects. Good, also a medical anthropologist, notes that medical students are taught in a distinctive manner and approach to the reality of diagnosis and the nature of treatment that seems “natural” and “outside of culture”. Medical students learn a “hierarchical

order of biological reality” and eventually a biological reductionism becomes their central vision. He describes this reductionism as “an active process of ontological genesis (objectification) of medical objects out of human problems” (1995:243-244). Further, seeing, writing and ‘talking’ medically’ authorizes the student to participate in a ‘language game’ that in turn, creates a way of life or an ‘ontology’ of being medical. This ontology, Good asserts, has “tremendous consequences in the real world”. He demonstrates that the students are socialized into a hierarchy “whose control is exerted through the transformation of the arbitrary into the logical, the symbolic into the real, and that also teaches them to mis-recognize what is ‘cultural’ for what is ‘natural’ (1995:245).

In the nursing profession, Winkleman reports that anthropological and cultural perspectives have contributed to the shift in nursing practice from a biomedical paradigm to a psychosocial framework. The nursing focus is now on humans’ responses to health problems, rather than disease and pathophysiology (2009:198). Nursing concerns are reported as focused on peoples’ view of their condition and their social/personal needs. They mediate between patient perceptions and the biomedical orientation towards a patient’s total well-being. Nursing also has a long history of focusing on cultural issues and incorporating cultural models into education and care. There is an emerging trend in Canadian nursing policy towards the provision of culturally safe care and the development of cultural competencies for nurses working with Indigenous populations. These concepts are further discussed in the next section.

Winkelman notes that differences between healthcare practitioners and their clients interfere with their clinical work; including, consultation with patients, treatment and program development and disease prevention. Further, that this is true not only in the area of health

beliefs and behaviors; “but also in styles of communication, social expectations, worldviews and other aspects of culture” (2009:84). The biomedical health focus is on biological diseases that often clash with patient’s conceptions of health to the point where effective care is impeded (2009:15). Winkelman notes the variance of perspectives even between doctors and patients from the same culture and attributes this phenomenon to the education that socializes physicians into a worldview that what patients don’t generally share. Physicians are trained with an emphasis on detection, diagnosis and treatment of disease rather than health and well being (2009:15). The relationship between a healthcare practitioner and a patient is a critical component to the effective uptake of health information. The following discussion explores this notion.

Dominance of biomedicine as a structural barrier

As noted previously, a biomedical health care model can be described by many other terms including ‘scientific’ medicine⁶⁴ (Winkleman 2009:193). The field of ‘biomedicine’ in previous discussion is noted to be widespread globally and is situated as a potential universal health care approach. (Kleinman 1995:21).

While biomedicine’s important contribution to health care services for Indigenous peoples is acknowledged; there is also a need to both understand how the dominant approach creates a major structural barrier and to undertake a pluralistic approach. For example, the use of culturally inappropriate health literacy approaches for Indigenous peoples presents as a major structural barrier to the uptake of health information which negatively impacts personal agency (Tang and Anderson 1999; Alfred 1999; Bandura 2000; Farmer 2008) and perpetuates overall

⁶⁴ Practitioners of biomedicine are physicians and others who work under direction of a physician including nurses, respiratory therapists, laboratory technicians and pharmacists There are also other practitioners who treat a specific part of the body such as dentists, optometrists and physical therapists.

poor health outcomes for this population group. Moreover, it results in structural violence. The following quote from my research findings demonstrates the patient participant's negative experience with health information that was not culturally relevant.

"I need to know... I need to understand why and what that relationship is in order for me to even go to that next step of not eating white bread and trying to do other breads. So it's those kind of things but I will admit and I've gone to those classes and I understand about cooking, you know, foods and having... But, you know, not to discredit those people but, you know, even in a couple of those classes that we had, they would say certain things and we're all Native, the people participating. And we all kind of looked at each other and started laughing. Unless that person teaching us is Native and know where we come from, some of that stuff they're trying to convey to us just..."

Efforts to address the culturally-specific health issues of Indigenous peoples has resulted in a trend towards the development of cultural competencies among healthcare practitioners.

Winkleman notes that cultural competence includes both individual and organizational capacities, behaviours, attitudes and policies that address cultural difference in an effective way, through the use of cultural knowledge and intercultural skills. According to Winkleman, cultural competence levels range from destructiveness (ethnocentrism) , incapacity and blindness through various skill levels proposed as; cultural awareness, sensitivity, responsiveness, competence, and proficiency (2009:10). Various health professional organizations have achieved a substantive uptake of the Indigenous cultural competency - related discourse and integrated this concept into the development of policy and practice guidelines of their respective organizations. However, according to Spector, the process of becoming culturally competent is not generally provided for. (2009:xv).

The cultural safety discourse can also be linked to the efforts of Maori nurse theorists who argued that healthcare practitioners providing care for Indigenous patients need to consider

the construct of cultural safety as an important element of their clinical practice. Historical colonizing processes and the resulting negative impact on the health of Maori people in Zotearoa New Zealand, was a critical impetus for this body of work. Health professional educators integrated the construct into the curriculum and identified expected outcomes of a culturally safe graduate health professional (Wepa 2005:25). Wepa, describes the evolution of the cultural safety definition which culminated in a Nursing Council of New Zealand adopting the following definition:

“The effective nursing of a person/family from another culture by a nurse who has undertaken a process of reflection on own cultural identity and recognizes the impact of the nurse’s culture on own nursing practice. Unsafe cultural practice is any action which diminishes, demeans or disempowers the cultural identity and well-being of an individual. (Nursing Council of New Zealand, 1992)

Over the past 15 years, several Indigenous healthcare professional organisations in Canada such as the Aboriginal Nurses Association of Canada and the Indigenous Physicians Association, have adopted the concept of cultural safety. However, Canadian health literacy theorists, while acknowledging the dearth of Indigenous cultural information regarding health literacy, remain outside of the margin of culturally competency and cultural safety policy and practice development.

Efforts to ameliorate systemic structural barriers must be undertaken by and for Indigenous peoples to improve access for those who wish to access various elements of Indigenous knowledge or Traditional healing. Anthropologists, specifically those from the sub-field of medical and critical medical anthropology have long been advocates for the amelioration of systemic barriers and the integration of culturally relevant healthcare approaches. The historical and contemporary relationship between anthropology and biomedicine attests to this.

For example, as noted in reference to her work with socially disadvantage women, Mendenhall argues that the three forms of violence discussed in the anthropology literature; (structural, symbolic and everyday violence) are important for understanding health disparities in high income countries⁶⁵. She draws from the works of Galtung (1969) Farmer (1997, 2004) and Farmer et al. (2006); Bourgois (2001, 2009) and describes structural violence as stemming from the intellectual roots of Marxism and liberation theology and refers to the political-economic and social inequalities that can be both cause and consequence of poor mental and physical health. Further, that structural violence can be understood as a form of subjugation that is institutionalized and associated with health and social problems (2012:15).

Summary: What we know, what we don't know and what needs to be done

“Our peoples’ hearts are broken. We have endured so much pain and hurt and oppression. The chronic disease.....heart attacks and other illness is a part of this. They are connected. We also have lost our way with our spiritual understanding of how to heal ourselves. We are stressed with the sickness because our hearts are broken...it is so easy to heal our broken hearts.....to forgive and to love and to let go. We need to return to our spiritual ways and meditate and open ourselves to our spirit side.” (Ojibwa Seer)

I use the frame of ‘what we know’, ‘what we don’t know’ and ‘what needs to be done’ to summarize this chapter. To begin, for millennia, Indigenous peoples have understood their own health within the context of their own belief systems, customs and practices. The wholistic, element of their worldview means that their perspective on health and wellness is woven through their lives and the world around and beyond them.

⁶⁵ Mendenhall uses these three modes of violence to frame Mexican immigrant womens’ experience and how it shapes their lives. She also notes that interactions between the three frequently compound the effects of any one of the forms of violence (2912:14).

What we know from the literature and the findings of my research, is that in spite of the availability of Indigenous knowledge from Traditional healers and Elders, Indigenous peoples primarily have a biomedical understanding of their heart disease that is relayed to them by the Western, biomedical trained healthcare practitioners they engage with in the healthcare system. Further, most are unaware of the how various socio-historical and socio-cultural factors such as the negative inter-generational impact of residential school and contemporary experiences of oppression and discrimination are linked to their heart disease. This situation can be attributed to an Indigenous knowledge diaspora experience that includes the severance of access to Indigenous knowledge and Indigenous languages during the residential school period and the dominance of biomedicine in health care service delivery.

The quote above poignantly captures perhaps the grimmest outcome of Indigenous knowledge diaspora; namely, that many Indigenous peoples literally have a ‘broken heart’. The insidious poison of inter-generational historical trauma⁶⁶ still courses through our veins, weakening our spirits and our minds, negatively affecting our ability to trust and enjoy enduring relationships with ourselves, our families and the world around us and ultimately causing our bodies to break down. It has been an imposed experience of wandering in a spiritual wasteland, bereft of the knowledge and language of their ancestors to guide them as they struggle to cope with the physical, emotional and mental stressors this life journey creates.

66 Historical trauma is a concept that is predominant in Native American scholarly writing regarding the devastating impact of colonizing practices of European settlers on Native Americans. Pierce et al. defined historical trauma as having at least one parent who attended a residential school and/or ever having been taken from biological parents into care. They acknowledge they are limited in that they do not directly assess the extent of the historical trauma experienced by the youth in their study. However, these measures do provide information on the effect of specific events (e.g., having a parent who experienced residential school) associated with colonization in Canada.

Yet, for many, there exists a cultural ‘blood memory’⁶⁷; a precursor perhaps to achieving a diaspora literacy that has potential to nurture resiliency. Making connections between the colonizing legacy of ongoing oppression and discrimination, socio-economic and health inequity and their heart disease strengthens the mind. Making the connections to the knowledge of their ancestors strengthens the spirit. This in turn nurtures hope and purpose; fostering an agency to break through the cultural vacuum they have endured and embrace the health related Indigenous beliefs and values that sustained us for millennia. This is the process that will mend the metaphorical broken hearts and spirits of Indigenous peoples. This creates potential to enhance the uptake of biomedical health information thereby, fostering improved self-care management of their cardiovascular disease.

If we accept that Indigenous knowledge diaspora creates a socio-structural barrier and results in less effective self-care of their heart illness, ultimately contributing to the ongoing disparity in cardiovascular related morbidity and mortality among Indigenous populations; then we have to acknowledge that this is a situation of health inequity for Indigenous peoples and can be situated as structural violence.

The issue of what we don’t know needs to be considered with the understanding that currently, there is a dearth of both academic and grey literature, regarding culturally relevant health literacy approaches for Indigenous peoples. Scholars, policy makers, educators and healthcare professionals would benefit from a more informed approach to health literacy practices for Indigenous populations. Patients with heart disease would likely have improved health outcomes.

⁶⁷ Lawrence discusses the notion of ‘blood memory’ relative to how identity is also lived as a deeply embodied reality and blood memory is a term that people involved in an urban case study used to speak of this experience.

We also need to know more about the link between Indigenous knowledge diaspora and the agentic capability of Indigenous peoples in self-care approaches for heart disease. My research was embedded in the first phase of the larger study and patient and staff participant samples were small. Further exploration of the link between understanding Indigenous knowledge and cultural beliefs, values and practices regarding physical and inner well-being and managing one's heart disease could contribute to a more robust evidence base.

Nevertheless, there is an urgent need to move forward and work with what we know. For example, health science educators within various disciplines need to further develop curricula devoted to culturally relevant approaches for Indigenous patients with heart disease. Evidence-based models need to cultivate a measure of pluralism and accept Indigenous knowledge as a valid scientific pedagogical body of knowledge. Indigenous scholars are leading the way with this objective; Ojibwe healing practices has emerged in the writing of Ojibwe scholars, to promote 'bimaadiziwin' [a healthy way of life].

We need to also promote a diaspora *health* literacy, raise awareness and address the systemic structural barriers linked to the negative Indigenous knowledge diaspora experience among Indigenous peoples, policy makers and healthcare practitioners. We need to collaborate with Indigenous and non-Indigenous literacy/health literacy experts to further define and articulate the parameters of the Indigenous diaspora literacy concept and to develop a culturally relevant health literacy model for Indigenous peoples with cardiovascular disease.

CHAPTER ~ 6~ ADDRESSING INDIGENOUS KNOWLEDGE DIASPORA- SEEKING NIBWAAKAWIN: A HARMONIZED HEALTH LITERACY APPROACH FOR INDIGENOUS PEOPLES

“The Fourth fire prophecy was delivered by a pair of prophets. The first prophets said, you will know the future of our people by the face the light skinned race wears. If they come wearing the face of brotherhood then there will come a time of wonderful change for generations to come. They will bring new knowledge and articles that can be joined with the knowledge of this country. In this way, two nations will join to make a mighty nation. This new nation will be joined by two more so that four will for the mightiest nation of all. You will know the face of the brotherhood if the light skinned race comes carrying no weapons, if they come bearing only their knowledge and a hand shake.” (Ojibwe Elder)

The critical discussion of the previous chapter unpacked the concept of Indigenous knowledge diaspora and established the link between its serious negative impact on Indigenous peoples’ agency with respect to the self-management of their heart disease. Yet, the spirit of the above quote infuses an optimism for the development of a culturally relevant health literacy approach for Indigenous peoples with heart disease that can be inclusive of Indigenous knowledge about physical and inner well being. Various players from both Indigenous and non-Indigenous cultures can participate in a collaborative process; Indigenous peoples living with heart disease, Traditional knowledge keepers and healers, researchers and scholars and non-indigenous healthcare practitioners and health policy makers.

In this chapter, the case is made for the development of a harmonized Indigenous health literacy approach and a culturally relevant model is proposed that can be utilized in the care of Indigenous peoples with cardiovascular disease and potentially other chronic illness.

Accepting the need for health literacy reform for Indigenous populations

While there may be a growing appreciation of an Indigenous epistemology among mainstream healthcare practitioners; there is still a long way to go towards accepting and utilizing Indigenous knowledge in the care of Indigenous peoples with heart disease and other chronic illness. The need for reform in the provision of healthcare services and health literacy for Indigenous peoples has been acknowledged by healthcare practitioner networks. For example, the potential positive effect of Indigenous Traditional healing ways has been acknowledged by the Canadian Medical Association who testified to the Royal Commission on Aboriginal Peoples (RCAP) that values and practices adapted from Aboriginal healing traditions offer both immediate and long-term positive effects to health status. Several areas of health care were identified as areas where Traditional healing may add value. These include health promotion, support for increased personal responsibility for health and care system reorientation (to increase comfort level for Aboriginal people) (1994:n.p.). These ideas have potential utility in addressing the need for culturally relevant health literacy approaches for Indigenous peoples with heart disease. Patient efforts to self-manage their care including their medications will be enhanced by their uptake of health information that they can understand and relate to.

As noted in the report, ‘An Inter-sectoral Approach for Improving Health Literacy for Canadians’; an Expert Panel called for major reform in health literacy approaches including; “the development of policies, programs and research to improve low literacy levels as one important step towards reducing health disparities in Canada.” The Panel describes a framework for action that includes the value of equity and the inherent right of all Canadians to “accurate, understandable and culturally appropriate health information” (Mitac and Rootman 2012:2).

In keeping with this recommendation; it is proposed that Indigenous peoples with heart disease can enhance their self-care when culturally relevant health literacy approaches are available to them. In turn, healthcare practitioners can broker an ‘Indigenous therapeutic relational space’ with their Indigenous patients by initiating a culturally relevant health literacy assessment and a harmonized implementation model. This approach has potential to establish a positive and supportive therapeutic relationship with their patients who have heart disease. It also has potential to be applied to self-care management approaches with other chronic illness. The discussion that follows attempts to unpack this process and describes a practical application for healthcare practitioners and Indigenous patients. The Ojibwe Bimaadiziwin values of relationality and personal responsibility for health are discussed including how they can be applied to a harmonized Indigenous health literacy approach.

Bimaadiziwin (good way - healthy life): Ojibwa teachings for a healthy, balanced life

The Ojibwa concept of ‘Bimaadiziwin’ is grounded in a belief system that frames the interrelationships of all things; a wholistic perspective that is central to an Indigenous worldview. The need for harmony and balance is an integral part of the Ojibwe sense of wellness in that one must attend to the physical, emotional, and spiritual parts of life to be whole (Peacock and Wisuri 2002:94). The notion of inter-relationality is a common belief among Indigenous peoples. There is a close inter-relationship to all things on the earth.

Another important aspect of ‘Bimaadiziwin’ is to foster and enlarge one’s inner being and embrace the duty to know and understand what this inner being is about. Johnston describes the process of understanding oneself and self-directing the growth of inner spirit. Every man and woman is given different powers and gifts of insight that only he or she is capable of

understanding. There is a value of personal responsibility for one's well-being and each man or woman is accountable for his/her self-development.

Description of a harmonized Indigenous health literacy model: a Medicine Wheel Framework

“Ojibwa Medicine Wheel Teachings are vast and include layers of information intended to guide Ojibwe people on their life journeys. Central to the conceptual frame is the four cardinal points or the four sacred directions represented by the colours yellow, red, black and white. These colours are significant for the four races in the world. Blue represents Father sky in the upper realm, Green for Mother Earth below and purple represents the self, that spirit that journeys in this physical world at the centre of the wheel. The Seven Stages of Life are also found on this Medicine Wheel. They begin in the east and move across the Wheel to the West. The Seven Stages of Life are: The Good Life, The Fast Life, The Wandering Life, the stages of Truth, Planning, and Doing, and The Elder Life. The Seven Grandfather Teachings, Honesty, Humility, Courage, Wisdom, Respect, Generosity and Love begin in the Northern direction and move down to the centre of the Wheel. There are seven teachings within each direction on the Ojibwe wheel, and all these have sub-teachings to them, such as where all the medicines like sweetgrass came from, and what they mean.” (William Commanda, Elder from the Algonquian Nation and keeper of the sacred wampum belts, June, 2010)

The notion of a harmonized Indigenous health literacy model draws from an Indigenous worldview about health and well-being. Ojibwe teachings regarding Bimaadiziwin (good way-healthy life) can inform the development of this proposed model that promotes access to and inclusion of Indigenous knowledge for Indigenous patients living with heart disease.

The Medicine Wheel provides a cultural symbolic frame to organize Indigenous knowledge teachings about our life journey. The Medicine Wheel teachings are also vast and considered to be sacred. While the details may vary between Indigenous nations, the basic teachings are the same and they have been shared and followed for generations. It is suggested that the Medicine Wheel symbol can also be used to frame a culturally relevant harmonized health literacy model that can guide healthcare practitioners engaged with Indigenous peoples who have cardiovascular disease.

The Ojibwe Medicine Wheel teachings described here are adapted from the teachings of Lillian Pitawanakwat, a respected Ojibwe Elder who has gone on to the spirit world. Following the teachings is a way to honor our ancestors because it is they who sat in circles and prayed that their children and grandchildren would follow their path. It is taught that when we honor our ancestors, we honor ourselves.

There are four directions on the Medicine Wheel and each direction has seven teachings; with each of those seven having seven sub-teachings. The four directions remind us of many things including the need for balance in the world and the balance that we have to strive for everyday within ourselves. Within ourselves, it is said that we carry a fire and that we are responsible for maintaining that fire through the knowledge we have, or through our experiences and associations. These cultural values can be applied to the health literacy model. A balanced approach is needed to ensure that patient health literacy needs are met. The preferred outcome of a health literacy approach is the effective uptake of health information that fosters an understanding of health related issues and management of same. Thus, knowledge is accrued to assist an individual in 'maintaining the fire' within her/himself.

A more detailed description of the Medicine Wheel teaching is provided. Four elements of a proposed harmonized Indigenous health literacy model are integrated into the four directions of the model. The objective is to present the key elements in a balanced, wholistic and relational way. Each direction of the Medicine Wheel framework relates to the other and situates the relevant protocols for the directional element. Each element stands alone, yet is linked to the other elements to inform the development of an Indigenous therapeutic relational space.

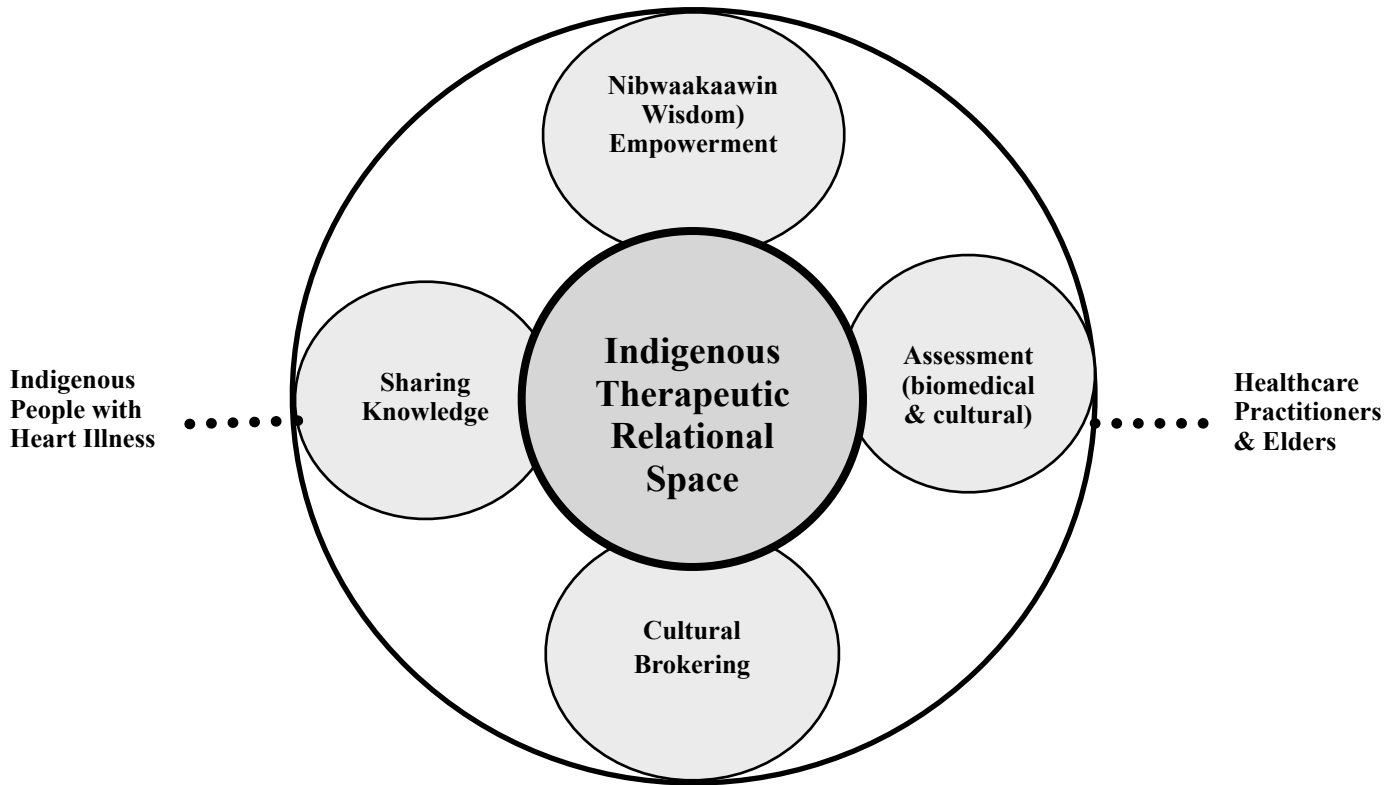


Figure 8 Harmonized Indigenous Health Literacy Model

The centre represents a relational space between the healthcare practitioners, Traditional practitioners and Indigenous peoples with heart illness. This is shown as a dotted line that moves across the Medicine Wheel at its centre and links the two individuals engaged in the therapeutic process promoting a relationality. This demonstrates equal responsibility in the therapeutic relationship. It also equalizes the power imbalance that occurs when the healthcare practitioner is seen as the expert. The Indigenous value of reciprocity is acknowledged in the relationship; there is an accountability and respect for each party involved and for each knowledge base employed in the delivery of health messaging. The outcome of the process is the development of an Indigenous therapeutic relational space. A more detailed presentation of how to apply the model as a health literacy approach for Indigenous patients with heart disease follows.

Description of directional elements and protocols.

In the **Eastern (waabinong)** direction, we acknowledge where we come from, it represents the season of spring and the spring of life. We begin our journey as humans coming

from the spirit world to the physical world. Mother is here, the one that brings life. We are born when as a spirit, we ask the Creator to go on this physical journey. The Creator grants us with four gifts: picking our mother and father who will help us come to a balance within ourselves, the gift of picking and choosing how we are born and how we will die.

In this eastern direction, the health literacy process begins. The healthcare practitioner undertakes an assessment of the patient's needs regarding her/his heart disease. There are two streams of assessment. The first pertains to the patient's biomedical needs; such as, the cardiovascular disease diagnosis and history, use of medications and understanding of their purpose, self-care management strategies and proficiency and the patient's baseline level of health literacy according to mainstream health literacy measurement scales such as the IALS.

The second area of assessment is the patient's cultural needs. The focus here is determining the patient's health needs as a person with Indigenous identity. For example, do they see themselves as having special needs related to their Indigenous identity? If not, do they wish to learn more about their cultural heritage and Indigenous beliefs and values regarding health and their heart disease? At the same time, in keeping with the value of relationality and reciprocity, the patient engages the healthcare practitioner in a process that fosters an equality in the relationship and is viewed as a positive relationship that meets their needs related to both their heart disease and their Indigenous identity. They may wish to ask the practitioner about her/his experience working with Indigenous patients. They may also want to know about the practitioner's own cultural heritage.

In the **Southern (zhaawanong)** direction, everything is new and growing fast. Summer is here and everything is thriving. It is a time of continued furtherance for all of creation. The

southern direction reminds us to look after our spirits. When you are in balance within yourself, spirit will warn you of danger; when you listen to that spirit, to that intuition, it never deceives you. It's always right, because that's your guide. When that is disrupted, kids grow up without any direction, without any spirit nurturance and this results in a vulnerability to all kinds of dangers and distractions. Their youth, their wandering stage, becomes very distant. When Elders invite them to be a part of their journey and to hear what life has, what has meaning and purpose, their lives begin to change. They begin to take accountability and form a life style.

In this southern direction, the healthcare practitioner takes on a cultural broker role. They integrate the findings of their own assessment with the patient's own intentions about the harmonizing of both biomedical health information and Indigenous knowledge in the self-care management of their heart disease. They support patients in their brokering role and facilitate their awareness and understanding of Indigenous knowledge diaspora and the negative impact this phenomenon has on their heart health. They also support and assist the patient in managing the negative emotional fall out from this experience by referring them to Elders or Traditional healers who are able to support and inform this process.

In the **Western (epangishmok)** direction, it is the time of harvest and much of creation is finished with the physical world and preparing to cross back to the spirit world. We die many deaths as there is constant change within us. We dance around that western doorway many times in a day to honour the death spirit. The west also represents the heart, the evaluator of what's going on in our life. As adults, we need to be in touch with this evaluator, because it helps us to see the cycle of life, to appreciate and enjoy the fruits of life, and to accept aging and change, making peace with our lives and deaths. Finding peace doesn't necessarily come from the head –

it comes from the heart. We are given the responsibility to nurture our hearts, so that we may be in balance, and see the Medicine Wheel for what it is. Death can be a place of freedom: freedom to go on, freedom to be. It's very important to remember that, because only then can we go on to enjoy the northern direction after we have given careful consideration to these teachings in the west.

In this western direction, the healthcare practitioner in partnership with the patient, begins the process of building both the biomedical and Indigenous knowledge bases. Health information regarding their cardiovascular disease and the self-care management process is shared with the patient. Patients are supported as they engage and learn more about their heart illness and what responsibilities they have. Patients may also engage with Elders and Traditional healers who provide them with health related knowledge or Traditional medicines as part of their Indigenous healing approach. The development of diaspora *health* literacy has potential here; understanding how Indigenous knowledge connects them to their Indigenous identity and language, offers patients culturally relevant health information that can assist them to manage the negative diaspora experience and foster an Indigenous approach to managing their heart disease.

Finally, in the **Northern (kiiwediong)** direction, it is the rest period, or remembering period where we slow down and remember what happened in our lives. Rest is also used to be mindful of the physical body, to remember to care for and nurture our physical bodies: rest when we are tired, eat when we are hungry and be mindful of the food that is good for our bodies. It is here in the northern direction that we honor our Elders as this is where they reside; along with pipe carriers and lodge keepers, because their ceremonies provide us with teachings of the whole

Medicine Wheel, in all the directions. They also help us make peace through embracing all those aspects of ourselves - the child, the youth, and the adult - so that we may be able to feel and experience the fullness of self. It is a place of Nibwaakaawin.

In this northern direction, patients have achieved a level of empowerment and positive sense of self that assists them in their self-care management of their heart disease. They are able to utilize other tools to manage their medication use for example. Or they are able to evaluate blood test results in the monitoring of their treatment approaches. They are also cognizant of Indigenous knowledge that they have absorbed into a harmonized belief system regarding their health. They have established trusting relationships with both their healthcare practitioner (s) and their Elder (s) or healer (s) and view these relationships as positive and supportive. They also importantly, have adopted the role of self-care manager of their heart disease and are realizing positive health outcomes. They have attained Nibwaakaawin about their heart health and have achieved a strong balanced approach to their self-care.

The above application of contemporary health literacy concepts to the Medicine Wheel framework is not intended to be an exhaustive one. The fields of healthcare policy and service delivery are rife with theory and clinical practice guidelines are now reflective of cultural competence theory. However, the Canadian Expert Panel on Health Literacy identified a knowledge gap regarding health literacy for Aboriginal people. The objective of this thesis was to address this gap by promoting the need to develop and utilize culturally congruent health literacy approaches for Indigenous peoples. The following provides more detailed information on how to implement the model.

Implementing the model

“These teachings that are being shared are sacred teachings. From tribe to tribe, the details may differ but the basic teachings are the same. They have been followed and shared for many, many years. So we honour the ancestors, the ones that have walked before us, because they’re the ones that sat in circles many times before, and prayed that their children and their grandchildren would follow in their path. When we honour the ancestors, we honour ourselves.” (Ojibwe Elder, Lillian Pitawanakwat⁶⁸)

The Medicine Wheel- harmonized Indigenous health literacy model provides a way for healthcare practitioners to engage with Indigenous patients with heart disease and assist them in having their health literacy needs met. It is noted that the framework is a generic one with utility for adaption by all healthcare practitioners according to their disciplinary requirements. It is also noted that there is a need to research the implementation of the model to test its effectiveness.

The implementation process includes four streams of actions or protocols; assessment, engagement with the patient in a cultural brokering role; sharing of health information and supporting the empowerment of Indigenous patients with heart disease.

Eastern (waabinong) Direction: Assessment

The eastern direction protocol includes the assessment of both biomedical and culturally-based patient needs. A self-care management approach for cardiovascular disease illness requires understanding of basic health information such as diagnosis, risk factors and purpose of medications. Addressing the impact of Indigenous knowledge diaspora requires an understanding of personal experience regarding the development (or non-development) of their Indigenous identity. The findings of my research showed that while a few patients were able to state their

⁶⁸ Thunderbird Eagle Woman, Lillian Pitawanakwat was a respected Ojibwa-Potawatomi Elder whose life work was devoted to renewing Ojibwe traditions as a community worker and Elder.

diagnosis and identify causal risk factors, others had only a vague understanding as noted in the following quote.

“Not... Well not really. I mean I kind of do a little bit but even if somebody said what would be the signs that you're having a heart attack or a stroke, I don't know that I would know and then the little bit that I do know I think would almost make me... It almost at some point makes me a little bit paranoid. Because every now and then I'll get a ache in this arm and that's the first thing I think. You know, is that what that is? And I just kind of like work it off and it never lasts long but, you know what? That's the first thing that pops in my mind is this the start of something? But I couldn't tell you what the signs of a, you know, heart attack or a stroke... I mean I hear about dizziness and, you know, slurring and stuff like that. I've never been in the presence of somebody who was going through that so that I could actually see what it might look like.”

Most patient participants relayed feelings of disconnection from their Indigeneity including beliefs, values and messages regarding health and well being and language. Several participants reported lack of language fluency as a contributing factor to feeling disconnected from their culture. Several patient participants spoke about their aspirations and experiences reconnecting to their Indigenous family and social networks as captured in the following quote.

“I'm learning more and more about it. That is a very major goal for myself because when I was little my mother was a very private person and we were very close in family but, as far as our cultural background, I'm still learning and want to learn more. I also want to learn the language but it's a very difficult language to learn.....”

Eastern Direction: assessment of patient needs	
Biomedical treatment needs	- Cardiovascular disease diagnosis & history - Medication protocol - Health status
Health literacy needs	- Measurement of health literacy level (IALS) - Patient understanding of heart disease, risk factors and self-care management approach
Special needs as person with Indigenous identity	- Individual's Indigenous identity (self - identified) - Indigenous language fluency level - Affiliation with Indigenous community or urban residence or both - Preference for Indigenous - cultural information regarding their heart disease and self-care

Figure 9 Assessment of patient needs

The previous table organizes the three targeted areas of assessment.

Southern (zhaawanong) Direction: Patient Engagement

The southern direction protocol focuses on engagement of the patient with the healthcare practitioner assuming a cultural broker role. The concept of cultural brokering appears in the social science literature within discussions related to mediating the cultural divide (Szasz:2004, Hedican:2008; Kedia:2006). The role of a cultural broker can be considered perhaps a role that was borne out of necessity namely; the need for those of different cultures to communicate with the 'other'. Cultural pluralism is a contemporary societal norm and the role of a cultural knowledge broker is paramount to the successful uptake of health information by Indigenous patients. The issue of merging oppositional worldviews and embracing knowledge that is grounded in biomedical theory, clearly indicates a role of cultural interpretation and mediation. A culturally relevant knowledge brokering role of the healthcare practitioner that is inclusive of an awareness and understanding of Indigenous beliefs and values and how knowledge is shared, may facilitate a narrowing of the cultural divide. This approach has been captured in the Maori - led development of culturally safe approaches to healthcare for Indigenous populations; a service delivery approach that has had much uptake in Canada. Key principles in the cultural safety model include: awareness and understanding of cultural protocols of the user group and adoption of a self-determining brokering relationship that aspires to be culturally competent and safe (Downey 2009:19).

It is also important that healthcare practitioners assess their own level of knowledge and ability to competently assess the culturally - specific needs of their Indigenous patients. Self-assessment could include questions such as: What do I know/don't know about Indigenous

peoples and cardiovascular disease? How do socio-structural and historical factors impact patient experience of heart illness? How can Indigenous beliefs and values contribute to improved self-care of their heart illness?

Another important aspect of the brokering role is captured in the findings from this study; namely, that it is important for practitioners to cultivate an equality in the relationship with their Indigenous patients. Healthcare practitioners are considered to be advocates in the health literacy practitioner- patient relationship. There has been an assumption that the healthcare practitioner is the 'expert' and the patient they are caring *for* needs their expertise and experience to navigate the increasingly complex health care system at a time when they are most vulnerable. This perspective can also be applied more specifically to the advocacy element required to engage in health literacy interventions with Indigenous patients. Healthcare practitioners need to acknowledge an advocacy role that recognizes the power dynamics in these relationships (from a colonization perspective, the oppressor- oppressed) and how they may influence the patient's ability to both understand and *act* on the information they receive. Patients will negatively respond to a perception of unequal power in their exchanges with practitioners. The following quotes emphasize this point.

"Not with the doctors because I'll put them here and I'm here. I'm not the same level, put it that way."

"You know, he doesn't talk to me. He was ordering me what to do. You don't... You give me the decision; it's my decision if I want the medical help. But if you're going to tell me that I have to do it. No, I don't go that way. And I didn't get to talk to my husband, my kids or nothing. You don't tell me that I have to do this, no way and I told him straight out. I said, "No, I want to go home right now." I said, "I'll walk. I'll take my buddy with me and I'll go home." I was so pissed off with them and so he goes, "Okay. You got to go home." I said, "Yeah, I'm going home." He just stared at me."

In their cultural brokering role, practitioners integrate the findings of their own assessment with the patient's expressed needs regarding their heart disease and self-care. They establish a positive and trusting relationship with patients and support those who aspire to make links between Indigenous knowledge diaspora and their own heart health experience. Findings from my research indicate that patients believe that a positive relationship with their healthcare practitioner contributes to improved health. There was general consensus of this view among the patients interviewed.

“I think so. I think that really helped and he would, you know, he would kind of like tell me like it is too because we were that way back and forth with other. And so, you know, he would kind of let me know some things without, you know, being overpowering about it. So yeah, I think got he me to understand a bit better and I do think our relationship made a big difference in how things went.”

Patient participants also indicated that establishing trust was the most important element of a positive relationship with their practitioner as captured in the following quote:

“It's a game but it's a way to interact, like you wait and you see the information and you're kind of, you're building the relationship with the person, right?”

Practitioners also support and assist the patient in managing the negative emotional fall out from the Indigenous knowledge diaspora experience by referring them to Elders or Traditional healers who are able to support and inform this process. As such, practitioners need to establish a referral network to local Elders and healers. Practitioners also need to advocate on behalf of and with Indigenous patients to address the structural barriers they experience in their pursuit of Indigenous knowledge.

Western (epangishmok) direction: sharing knowledge

The western (epangishmok) direction protocol supports the sharing of biomedical and Indigenous knowledge between healthcare practitioners and patients, between Elders and Healers

and patients and between healthcare practitioners and Elders/Healers. Biomedical health information about their heart disease and its management is shared by the healthcare practitioner to the patient. Sharing of health information is consistent with the patient's needs and their ability to effectively undertake self-care management activities towards improving or maintaining a stabilized heart health status. Various health promotion/health literacy aids such as pictures, digital media and intervention tools may be used to facilitate an enhanced uptake of information. Staff participants reported a positive response to this approach as did patient participants.

Awareness and understanding of Indigenous learning styles is also conducive to effective knowledge sharing. A learner centred approach promoted by the Ningwakwe Clearing House is used in the native literacy field and recognizes that literacy goals can be met by using and enhancing the skills of the learner. Each learner is recognized as unique and has individual needs and ways of learning, her/his own bias, attitudes, values and personalities (1997:iii). This approach can be applied as a Medicine Wheel health literacy model protocol. The following quote illustrated one patient's view on the importance of sharing health information in a culturally relevant way.

“As Native people when we sit in a room here, when we gather here in our circles we always start off with prayer first and we end with prayer. In mainstream society I don't think they do that, I know some do but not a lot. I tell our people, if you put the Creator first above everything else then he'll... He knows what's going on and he'll help you. Why do we go through all the things we go through in life? Because it's a training experience, it's how He builds character within us. And people don't know this sort of stuff, they've never been told it. I believe that we're in the seventh generation of our people and all these teachings and knowledge is coming back to our people, and it's the responsibility of the older ones, people my age, the Elders, to pass that knowledge on.”

Patients who engage with Elders or Traditional healers/helpers will receive Indigenous knowledge that they may wish to integrate to their self - care approach. The development of

diaspora literacy has potential here whereby, patients may learn more about the connection between the negative impact of Indigenous knowledge diaspora and their heart health.

Patients also have obligations regarding the sharing of information about their self-care approach. They need to be aware of important information and how to acquire or strengthen self-care management skills. To promote a balanced, informed approach to the management of their heart disease, healthcare practitioners and Elders ideally, should be aware of all self-care strategies and medications or Traditional medicine that has been prescribed. The patient is also responsible to keep practitioners from both streams of care informed to ensure a safe, harmonized approach.

Northern (kiiwedinong) direction

It is in the northern (**kiiwedinong**) direction that the protocol is focused on patient empowerment achieved through the development of diaspora health literacy, positive relationships with their healthcare practitioner and enhanced self-care management skills. They have learned and successfully utilized tools to assist them. They are aware of their heart disease and risk factors.

“To cherish knowledge is to know Wisdom. Wisdom is given by the Creator to be used for the good of the people. In the Anishinaabe language, this word expresses not only “wisdom,” but also means “prudence,” or “intelligence.” In some communities, Gikendaasowin is used; in addition to “wisdom,” this word can also mean “intelligence” or “knowledge.” (Ojibwe Elder)

In this northern direction, patients have achieved a level of empowerment and positive sense of self that mobilizes them to take charge of the self-care management of their heart disease. They are able to utilize other tools to manage their medication use for example; or, they are able to evaluate blood test results in the monitoring of their treatment approaches. They are also

cognizant of Indigenous knowledge that they have absorbed into a harmonized value and belief system regarding their health. They have established trusting relationships with both their healthcare practitioner (s) their Elder (s) or healer (s) and view them in a positive light. They have achieved a fuller understanding of Indigenous knowledge and language through re-established or newly established connections to Elders, Healers/Helpers, community members or family and gained a measure of Nibwaakaawin

The value of reciprocity is linked to this direction in that both parties have gained important information about Indigenous knowledge and heart disease. Their relationship has become more equitable and the knowledge exchange is enhanced because of this change. Each party has a responsibility to improve the knowledge exchange.

In summary, this chapter has attempted to provide a practical, implementation process for the development of an Indigenous therapeutic relational space that will yield improved health literacy outcomes for Indigenous patients with heart disease. Healthcare practitioners can assume the role of cultural broker to address the structural violence and mitigate the Indigenous knowledge diaspora experience for their Indigenous clients. It is proposed that a harmonized Indigenous health literacy model can be used as a clinical practice tool by healthcare practitioners towards this objective. It is an iterative model, one that accommodates both evolving patient needs and the requirements of healthcare practitioners' clinical practice guidelines. As noted earlier, this Medicine Wheel- harmonized Indigenous health literacy approach provides a way for healthcare practitioners to engage with Indigenous patients with heart disease and assist them in addressing their health literacy needs. The model is a generic one and can be adapted to meet the multi-disciplinary requirements of healthcare practitioners

working with Indigenous patients and the needs of the diverse groups of Indigenous peoples in Canada living with heart disease or other chronic illness. An evaluative research component is required to determine the effectiveness of the model.

CONCLUSION

“To cherish knowledge is to know Wisdom. Wisdom is given by the Creator to be used for the good of the people. In the Anishinaabe language, this word expresses not only “wisdom,” but also means “prudence,” or “intelligence.” In some communities, Gikendaasowin is used; in addition to “wisdom,” this word can also mean “intelligence” or “knowledge.” (Ojibwe Elder)

Indigenous peoples have understood their health and well-being within the context of their own Indigenous ways of knowing for millenia. This statement brings this thesis discussion full circle and emphasizes the point that Indigenous knowledge/Nibwaakaawin must be considered in the development of health literacy approaches for Indigenous people with heart disease and other chronic illness. The aim of this research was to gain an increased understanding of the Indigenous cultural context of health literacy and self-management of care for Indigenous peoples who have heart disease.

Cardiovascular diseases are major causes of mortality and hospitalization for adult Indigenous peoples and there are significant inequalities in CVD morbidity, mortality and prevalence of CVD risk factors between Indigenous and non-Indigenous populations. It is reported that the morbidity and mortality rate are double that of the general population.

Researchers, policy makers and health professionals have made some headway in recent years towards identifying historical, socio-economic, environmental and cultural factors related to cardiovascular disease among Indigenous populations. Also, new evidence is emerging regarding culturally relevant health promotion approaches for Indigenous peoples at risk of developing or currently experiencing cardiovascular disease. However, it is argued that an

associated risk factor is the gap between patient - practitioner understanding of heart disease. Biomedical understandings of cardiovascular disease are informed by a broad range of technological and biomedical assessment and supported by Western scientific evidence. The Indigenous perspective on the other hand, is grounded in Indigenous knowledge. There is a need for health care professionals to further understand how Indigenous peoples ascribe meaning to illness and how it is related to their worldview towards ensuring health literacy approaches are culturally relevant and free from structural barriers.

Health literacy is identified as a key driver of knowledge, self-management of care and health outcomes. Self-management of care is considered a central component to effective cardiovascular disease management. This approach requires a working knowledge and understanding of cardiovascular disease medications, and an ability to effectively communicate with healthcare practitioners. It is recommended that policies to raise average health literacy levels might lead to improvements in population health and a reduction in health costs. There is a lack of systematic information in Canada on levels of literacy and health literacy in certain populations including Aboriginal people. As such, there is a need to increase the knowledge base regarding literacy and health literacy for Aboriginal people. An important element to this endeavor, is to raise awareness and respect for the diversity and complexity of Indigenous knowledge and how it contributes to one's beliefs and values regarding health.

There are key systemic and socio- structural factors related to health literacy that serve as barriers to the development of a culturally relevant, 'indigenized' health literacy approach for Indigenous peoples; for example, the dominance of biomedicine and resistance to accepting

Indigenous knowledge as a valid scientific body of knowledge and restricted access to Indigenous knowledge and Traditional healing services for Indigenous peoples.

Indigenous peoples have long held their own knowledge generation and knowledge sharing systems. Healthcare practitioners and policymakers need to both acknowledge that Indigenous peoples with cardiovascular disease and other chronic illness have a culturally unique worldview; that they are stewards of important knowledge that yields valuable ecological information and accept that patients may wish to utilize both western and Indigenous approaches to health. To do so, would contribute to the development of a respectful and culturally safe interface between healthcare practitioners and their Indigenous patients. As a result, health literacy approaches would also be adjusted to reflect this harmonization of worldviews.

Existing health literacy approaches that are *not* inclusive of Indigenous ‘ways of knowing’ can be linked to structural violence. Structural reform requires the inclusion of Indigenous knowledge; ideally, a harmonized approach that is informed by *both* Indigenous and Eurocentric ontological knowledge systems. This approach will require acceptance of Indigenous knowledge as a valid body of scientific knowledge, collaboration and support from bio-medical healthcare practitioners and health professional education and health policy reform.

The findings of my research demonstrate that Indigenous peoples primarily have a biomedical understanding of their heart disease that is relayed to them by the Western, biomedical trained healthcare practitioners they engage with in the healthcare system. Further, most are unaware of the how various socio-historical and socio-cultural factors such as the negative inter-generational impact of residential school and contemporary experiences of oppression and discrimination are linked to their heart disease. This situation can be attributed to

an Indigenous knowledge diaspora experience that includes the severance of access to Indigenous knowledge and Indigenous languages during the residential school period and the dominance of biomedicine in health care service delivery. The experience of Indigenous knowledge diaspora has negatively impacted Indigenous peoples' ability to access and integrate Indigenous knowledge regarding physical and inner well-being into self-management of their heart disease. This is an important socio-cultural factor that has potential to inform development of culturally relevant health literacy approaches for Indigenous peoples.

Indigenous peoples with heart disease can be described as having a 'broken heart'; a situation that is tied to processes such as inter-generational historical trauma linked to residential school and cultural oppression. We continue to experience a weakening our spirits and our minds, and have difficulty trusting and enjoying enduring relationships with ourselves, our families and the world around us. This ultimately causing our bodies to break down.

While very few participants reported engaging in Traditional practices or holding Indigenous cultural beliefs and values with respect to health, most expressed a desire to learn more about Indigenous knowledge and Traditional healing. It is proposed that a 'diaspora *health* literacy' has potential to nurture resiliency and improved health through a return to or adoption of health related beliefs and values embedded within Indigenous knowledge systems. Making connections about colonizing practices, and socio-economic and health inequity and their heart disease strengthens the mind. Making the connections to the knowledge of their ancestors strengthens the spirit. This in turn nurtures hope and purpose; fostering an agency to find out more about and perhaps embrace health related Indigenous beliefs and values. This creates potential to enhance the uptake of health information thereby, fostering improved self-care

management of their cardiovascular disease. Culturally relevant health literacy approaches can enhance and empower the agency of Indigenous peoples in the management of their heart illness.

In Absolon (1996) Vine Deloria explains that oral traditions are the “non-western tribal equivalent of science; where Indigenous experiences and knowledge are passed from generation to generation and where that knowledge explains the nature of the physical, emotional, mental and spiritual worlds of the people” (2011:24). I have oft asked myself the question; “If one has their language and Traditional teachings regarding Indigenous beliefs and values regarding health, can this be considered a form of literacy/health literacy?” I always added “if not, why not”? My answer to myself, in a small intuitive voice was always “yes it is”. Yet, there was never a forum for entertaining debate on this question. Attempts to do so always segued to discussions regarding literacy within the frame of education and ability to read and write. Even the discussions I had with Indigenous literacy experts resulted in a blank stare and an admission that they have not heard discussion of this idea. I finally posed the question to an American Anthropologist who was also of Indigenous heritage. At first, the same response was given when I asked her the question. She didn’t really have an answer for the question and initially, challenged the validity of the question. However, she came back a few days later and we talked at greater length. We delved into the intricate meaning of Indigenous words and marveled at the complex, sophisticated meaning of the most simple words (in English translation). The light came on for her and she acknowledged the important relationship between Indigenous knowledge/wisdom, Indigenous language and health literacy. It was a fascinating conversation for me because I was finally able to ask my question and collaborate in the answer with another individual engaged in Indigenous education and learning.

There is a parallel here for Indigenous peoples with heart disease who are diligently trying to follow doctor's orders and obediently taking their heart medication, yet, never really fully understanding it all. They may or may not have their language, they may have grown up in a city with no links to family. Yet, those same individuals when presented with an opportunity to talk about their experience as an Indigenous person, may embrace a chance to learn more about Indigenous beliefs and values regarding health or learn their language so they can pass it on to their children.

Healthcare practitioners have an opportunity to improve health literacy for Indigenous peoples. The role of the healthcare practitioner encompasses the effective delivery of health messaging to their Indigenous patients. Often, in working to achieve this goal, they are faced with diverse worldviews regarding health and well being that often diverge from both their own personal view and the biomedical perspective they have been educated in. The challenge remains as to how to bridge the divide. A Medicine Wheel- harmonized Indigenous health literacy model provides an engagement framework that can establish an Indigenous therapeutic relational space thus providing a way for both healthcare practitioners and Indigenous patients with heart disease to address their health literacy needs in a culturally relevant way. The model facilitates empowerment of patients with heart disease and fosters a reclaiming and restoring of Nibwaakaawin thus, enhancing their ability to achieve improved heart health and well-being and hopefully mending their broken hearts.

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Appendix - 1

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Appendix ~ 1 ~ Background: International Indigenous Health Literacy Study

My research was embedded in the Canadian arm of an international health literacy study undertaken by Indigenous health researchers from Australia, Canada and New Zealand. The goal of the international study was to develop a health literacy program for Indigenous patients and their families who have cardiovascular disease (CVD) or are at risk of developing CVD. The study would examine the effect of a customized, structured CVD medication programme delivered by health professionals. The primary outcomes were the patient's knowledge about CVD medications and the secondary outcomes examine changes in health literacy skills and practices.

Cardiovascular diseases are major cause of mortality and hospitalization for adult Indigenous peoples and there are significant inequalities in CVD morbidity, mortality and prevalence of CVD risk factors between Indigenous and non-Indigenous populations (Toronto Academic Health Sciences Council Human Subjects Research Application (TAHSC): 'Strengthening health literacy among Indigenous people living with cardiovascular disease, their families, and health care providers' 2011:4). As a chronic illness, CVD requires self-management of care whereby, the patient and their families are considered to be the primary managers. Knowledge about CVD risk factors and CVD medications is essential to effective self-management (TAHSC 2011:4). According to Crengle et al. the published literature focuses on CVD risk factors and understanding of CVD risk assessment versus knowledge and understanding of medications and their use. Intermittent use of medications or non-adherence is common and is linked with worse outcomes that include poorer control of risk factors, an increase in hospitalization, and an increase in morbidity and mortality (2014:n.p.). Crengle et al.

also report that Maori in New Zealand have higher health literacy needs than non - Maori. Furthermore, while there is insufficient population-based data in Australia and Canada, it is expected that the situation for Indigenous peoples in both of these countries is similar to New Zealand in light of the known inequities in health and education (2014:n.p.).

The Canadian arm of the project, entitled; ‘Strengthening Health Literacy Among Indigenous People Living with Cardiovascular Disease, Their Families and Health Care Providers’ was led by Dr. Janet Smylie, Principal Investigator⁶⁹. The study design was a multi-method approach. Baseline interviews were conducted in Phase one with patient participants at both the Hamilton and Brantford sites of the De dwa da dehs nye - Aboriginal Health Centre. It was expected that the baseline interviews would contribute to the development of case studies at both sites. They would also assist in understanding the health literacy intervention to be developed in Phase two and its effects in the organizational, systemic and policy environment in the context in which it operates (TAHSC 2011:5) Interviews with health professionals were also undertaken to explore their awareness and understanding of health literacy and how they addressed health literacy in their practice. As noted by Crengle et al. It was expected that the health professional data would allow for an assessment of whether changes in health professional’s awareness, knowledge and practices and changes in the health literacy environment would contribute to the results of the health literacy intervention trial (2014:n.p.). Phase two utilized a pre-post design with multiple measurement points used to assess the effect of the health literacy intervention. A six month retrospective and prospective analysis of

⁶⁹ The Canadian team also included Co-Investigators; Dr. Marcia Anderson, Cardiologist, Ms. Constance McKnight, Executive Director, De dwa da dehs nyes – Aboriginal Health Centre (DAHAC); Nancy Cooper, Indigenous Literacy Expert; Conrad Prince, Research Manager; Sanjeev Sridharan, Evaluation Design Consultant, Chester Langeville Interim Executive Director, DAHAC

routinely collected data to assess the complexity and stability of medicine regimes, prescription frequency and associated clinical indicators is planned to contribute to this assessment.

Appendix 2 - Patient Interview Guide

Patient/Family Member Participants

Objective: To explore and increase awareness of cultural and family context

1. Can you share your cultural or family background with us?

Objective: To explore and understand the patient's experiences with various healthcare services

2. a) Can you talk a little bit about your health care experience?
b) Have you needed to be in a doctor's care a lot in your life?
c) How would you describe this experience? (prompt if needed: good or bad)

Objective: To explore and determine what the patient's cardiovascular (CVD) diagnosis means to them.

3. a) How is your heart health?
b) What do you think caused your heart problems? (ie. Poor diet, lack of exercise, family history, smoking, stress, relationship problems, money problems)

Objective: To determine if Aboriginal Traditional teachings about health and well-being have contributed to the patient's beliefs about their own health/CVD

4. Do you have your own beliefs about health and well being that you have learned from family, friends or others in your community?

Objective: To explore the patient's sense of personal agency with respect to their own health/CVD.

5. a) What are some of the ways in which you care for your health?
b) How confident are you in your own ability to improve your health?
very confident – confident – somewhat confident – somewhat not confident - not confident

Objective: To explore the healthcare provider-patient relationship

6. a) What is the relationship between you and your care provider like?
b) Do you think that there is a link between this relationship and an improvement of your overall heart health?
c) Do you think that your healthcare provider is able to help improve your health? If so, in what ways?

Objective: To explore the cultural context of the healthcare provider – patient relationship

- 7. a) Do you feel that you have special healthcare needs because you are an Aboriginal person? If yes, can you tell me a little bit about these needs?
- b) Do you believe that your healthcare provider understands or takes these needs into account while caring for you?

Objective: to explore the patient’s perception regarding the information they have been given and about other resources available. To assess health literacy regarding current medication use and information about medications

8. Communication with health professionals
a) Did your doctor or nurse etc give you easy to understand instructions about how to take your medication? What did they do to make it easy to understand?
b) Did your doctor or nurse etc explain the possible side effects of your medication in a way that was easy to understand? Why did they explain – did you ask them or did they just do it? What did they do to make it easy to understand?
c) Did your doctor, nurse etc give you written information or write down information about how to take your medication? What was the information? Why did they write it down? Did you ask them to or did they just do it? Was the written information you were given easy to understand
d) How often did your doctor, nurse etc suggest ways to help you remember to take your medication? What did they suggest? Were those suggestions easy to understand? Why?
e) How often were the results of any tests about your medication easy to understand? What made them easy to understand?
f) How often did your doctor or nurse etc use medical words you did not understand when talking to you about your medication? Did you ever ask them to explain those words? If yes what made you feel it was ok to ask those questions?
g) How often did your doctor or nurse talk too fast when talking with you about your medication? Did you ever ask them to slow down or repeat what they said? If yes what made you feel it was ok to ask those questions?
h) How often did your doctor, nurse etc use pictures or drawings to explain your medication to you? What were the pictures/drawings? Why did they show you pictures? Did you ask them to or did they just do it? Were the pictures or drawings you were given easy to understand?
i) How often did your doctor or nurse answer all your questions about your medications to your satisfaction? What were your questions? Why did you ask them in the first place? Did you make a list of questions before you went to see the doctor or nurse etc or just asked them when you were there?
j) How often did your doctor or nurse etc give you all the information you wanted about your medication? Did you ever ask for more information? Did you ask anyone else later?

k) How often did your doctor or nurse encourage you to talk about your concerns about your medication? Was it because they thought you looked like you didn't understand or you told them you didn't understand? How did they do that? How often did they do that?

l) How often did your doctor or nurse ask you to describe how you were going to take your medication?

m) Sometimes your doctor or nurse etc. might give you instructions that are hard to follow. What do you do when that happens?

n) How often did your doctor or nurse ask you whether you would have any problems doing what you need to do to take your medication? For example do they ask you what you will do if you go on a trip or to a funeral or if you forgot?

o) What does your doctor or nurse do if you are prescribed any new medication or change any medication? How do they explain it?

Objective: to explore how the patient or family member would like to be given information and to identify examples of resources that they believe would be helpful.

a) What pamphlets, handouts, written or handwritten material has anyone ever given you about your medication? Do you read any of them? If so which ones and why read them and not others? If you don't read them why not?

b) Do you find it hard to read information about your medication such as labels or instructions? If you do what do you find hard and why?

Appendix 3 - Staff Interview Guide

Objective: to explore staff awareness and understanding of health literacy and health literacy practice

1. Can you talk a little bit about what your understanding of health literacy is?
2. What kinds of health literacy issues have you encountered in your work?
3. Do you think that the health service is accessible for people with health literacy needs?
4. What strategies do you use to address and lessen the impact of health literacy in your practice?
5. Are you aware of any other strategies to address and lessen the impact of health literacy barriers on patient/family member health, management of conditions and patient outcomes?
6. The environment that a patient is exposed to is also an important consideration with respect to health literacy.(i.e. office information, posters, pharmacy signage)
Thinking beyond your own personal communication style in your practice, what are some of the other environmental barriers/challenges that a patient might experience?.
Do you have any ideas about how these barriers and challenges could be addressed in your practice?
7. What are some of the challenges and opportunities in changing health literacy in the service environment?

Objective: to explore staff awareness and understanding of cultural safety with respect to health service delivery

1. Can you describe your awareness and understanding regarding the concepts of cultural competency and cultural safety theories in health care service delivery for Aboriginal people?
2. Have you heard of the terms cultural competency and cultural safety before?
3. If so, how would you describe these concepts?
4. How do you think these concepts apply to your work in a practical way?

Objective: to measure staff self- assessment of cultural competency with respect to working with Aboriginal populations

1. Do you think that your clinical practice is inclusive of cultural safety principles with respect to Aboriginal clients? How is this demonstrated, can you give some examples?

APPENDIX ~ 4 NEW ZEALAND INTERVIEW GUIDE

Addendum #1: Graduate Student Research Segment #2 - Interview questions

Objective 1: to further explore the cultural context of how Indigenous peoples understand their cardiovascular disease or other chronic illness. (diabetes, hypertension, hyperlipidemia)

1. Please describe how Indigenous peoples in your experience, ascribe meaning to their cardiovascular illness? Is there a link to their cultural teachings or beliefs?
2. How important is the value of ‘personal responsibility’ for health and well-being for Indigenous peoples with respect to managing their own health care?

Objective 2: to explore the participant’s perspective on the relationship between European colonization and the notion of personal responsibility for health and well-being.

3. Do you believe that European colonization and assimilation efforts have negatively impacted Indigenous peoples’ ability to manage their own health? If yes, please describe.
4. Are there other factors that negatively impact an Indigenous person’s ability to manage their own health? (i.e. social determinants; indigenous vs non-indigenous health care workers; access to health information in one’s own language etc.) Please describe.
5. How would you describe the power dynamic between Indigenous clients and their health care providers? Please comment on your answer.

Equal – somewhat equal – somewhat not equal – not equal

Objective 3: to explore potential participant ideas/suggestions towards facilitating improved personal agency for Indigenous clients.

6. How important is a self-determining approach to one’s own health care? Please comment on your answer.

Very important – important - somewhat important – somewhat not important – not important

7. How can healthcare providers best support Indigenous people’s self-determining approach to health? Please list the level of importance and/or describe other ways that healthcare providers can support

Very important – important - somewhat important – somewhat not important – not important

- a) Improve access to culturally relevant health information (i.e. printed, web-based)
- b) Develop Indigenous- specific health literacy approaches
- c) Increase number of Indigenous healthcare providers
- d) Improve access to Indigenous healers and helpers

Traditional Healers/Helpers - additional questions:

Objective: to explore how THs perceive the client's personal responsibility for health and well-being.

1. Please describe how you see the individual's role in the helper/client relationship?
2. When you provide instructions to your clients about their medications, do you refer to Traditional teachings about personal responsibility for health and well-being? If so, please describe.