

ABORIGINAL WOMEN LIVING WITH HIV/AIDS: AN EMPOWERMENT PERSPECTIVE

by

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## Abstract

This qualitative research study focuses explicitly on understanding the experiences and perceptions of urban Aboriginal women living with HIV/AIDS. Stigmatizing attitudes and language have serious impacts upon the lives of HIV-positive Aboriginal women. The ways our society presently addresses the women needs to change. With the insights and assistance of four Aboriginal women living with HIV, this project adds to the presently sparse qualitative literature in this research area. Current research indicates that there are many factors associated with urban Aboriginal women being at higher risk for infection and lower physical and mental health, such as race, socio-economic conditions, isolation, oppression and violence, family history, substance abuse, discrimination, and often the responsibilities of childrearing. However, current research analysis and presentation is insufficient, and more in-depth questions arise.

Material was collected using semi-structured, open-ended questioning conversations with the participants. Two guiding research questions were asked: 1) What is it like for you, living with HIV right now? and 2) What would you want other people to learn from your experiences? The women's stories provide an avenue for participants to voice some of their triumphs and challenges about being an Aboriginal woman living with HIV/AIDS. For the community at large, this is also an opportunity to hear first hand, important information such as this. In this work, I have tried to adhere to the tenets of Indigenous methodologies by allowing the life-stories to resonate as holistic representations. Rather than deconstructing the women's stories through naturalistic analysis (which continues to categorize and to objectify participants), the stories are viewed through a Health Narrative Topography whereby thematic genres such as *Restitution*, *Chaos*, and *Quest* are illuminated, while also being critically aware of some of the limitations to this framework. Three overarching themes are revealed through the women's stories: 1) the empowerment and resiliency demonstrated by the participants; 2) the need for cultural competency in a society that continues to stigmatize Aboriginal and HIV-positive women; and, 3) the need for a more holistic approach within society when it comes to education, learning, and healing.

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# Introductory Poem

## Erasure

You begin to feel like nothing  
else matters when you are downtown  
Vancouver, Eastside, and are welcomed into a group  
of First Nations women, gathering as a starting point  
before making our way over to the celebrations for  
National Aboriginal Day.

Check-in goes informally around the circle  
as most know one another. When it's your turn  
you are glad to be here, to know the women,  
but you still throw in that you're Métis so you appear  
even less like the token white girl in the crowd.

One woman, who instead, should be revered  
as an Elder by now, is coughing with a cold and  
in between puffs on her inhaler casually says  
she's HIV, as if commenting on the weather.

Another woman beside you found out a week ago  
she has AIDS, her T-cell count is down to 200,  
but they knew two years ago, she says, and didn't tell her.  
*There's going to be a fucking lawsuit over this—  
I won't see it, but at least my kids will.*

Back in the car, somehow you know the truth and  
say to your friend, *There won't be a lawsuit, will there?  
Probably not.*

You begin to feel nothing else matters  
when you know the momentum of those thoughts  
is what keeps her alive.

Donna Michele Hill  
June 2006

# 1. 1st Stanza: Intending

You begin to feel like nothing  
else matters when you are downtown  
Vancouver, Eastside, and are welcomed into a group  
of First Nations women, gathering as a starting point  
before making our way over to the celebrations for  
National Aboriginal Day.

When we look at this 1<sup>st</sup> stanza of my poem, *Erasure*, I believe it offers a sense of where I was positioning myself at the time, feeling as if nothing else mattered except the women I was with, listening to their stories being shared. We were gathering together, heading out on a journey of celebration, not unlike this thesis and the years during which it was created. This first stanza/section of the thesis is about *intending*. I share with my readers, the purpose and intention of this study through an overview of HIV/AIDS, background information to the issue at hand, the problem and purpose statements, and my standpoint and impetus for this research.

\* \* \*

In much of the provincial, national, and international literature, women are identified as being at greater risk than men for HIV-infection (Canadian Aboriginal AIDS Network [CAAN]a, 2003; CAANb, 2004; Hill, 2003; Mill, 1997; Rohleder & Gibson, 2006; Smith, 2002; Steele, Brooke, Richmond-Reese, & Lomax, 2006; Watson & Bell, 2005). This is particularly true of Aboriginal women who face tremendous challenges for accessing health services (Browne & Fiske, 2001; CAANb, 2004; CAANd, 2003). These disadvantages stem from multiple overlapping cultural and socio-economic factors such as age, gender, race, poverty, housing, substance abuse, and violence (Browne & Fiske; CAANb; Ship & Norton, 1999; Ministerial Council on HIV/AIDS, 2000). Other specific risks for HIV-infection related to socio-economic conditions include low rates of condom use and high rates of sexual abuse or non-consensual sex (Ministerial Council on HIV/AIDS). Critically low levels of research still exist regarding how and why Aboriginal women are not receiving the adequate health care and social services necessary for the support they need (Waldram, Herring, & Young, 1995; Legare, Ross, & Bognar, 2003; Royal Commission on Aboriginal People [RCAP], 1996; Vernon, 2001). This study is in response to my perception of a gap

in HIV/AIDS literature about women and, more specifically, Aboriginal women living with HIV/AIDS. However, before focusing on Aboriginal women and the participants of this study, I first survey many of the predominant reasons women, in general, are often at a disproportionately high risk of being infected with HIV. I then introduce some of the additional constraints specific to Aboriginal women, which are invariably also interwoven with some of the broader barriers women face.

The purpose of this study is three-fold: It is to 1) highlight many of these multiple contextual barriers to HIV-prevention most specific to Aboriginal women; 2) hear from the participants their own life-stories in order to explore and to create a better understanding of the impact of HIV/AIDS on the lived experiences and perceptions of HIV-positive urban Aboriginal women; and, 3) add to the literature about the women and HIV/AIDS in order to encourage and to inform medical and social policy changes. As Anderson, Dyck, & Lynam (1997) argue, “[t]he material circumstances of women’s lives—the institutionalized practices and systematic barriers which have shaped their realities—need to be understood and acted upon” (p. 76). Taken together, these three aims will result in affecting in a positive way the quality of women’s experiences and perceptions about living with HIV/AIDS.

## **1.1 A Note on Terminology**

For the purposes of this study, I use the term Aboriginal or Indigenous to refer inclusively to Canadian Aboriginal, Inuit, and Métis peoples. This definition is in keeping with currently accepted discourse as outlined by the Canadian Constitution (Constitution Act, Section 35 (2), 1982) and the Royal Commission on Aboriginal Peoples (RCAP, 1996a). Some scholars refer to Aboriginal as meaning local, or Canadian, and Indigenous meaning Aboriginal peoples more globally (Cohen, personal communication, 2007). I use both terms interchangeably in this study.

I attempt to honour Aboriginal people by using culturally sensitive, respectful, and accessible language. My goal is to democratize the language used within this study, rather than to write strictly for the elite and the academy. To ensure this goal, I submitted for critical feedback a section of this thesis to a UBC class of Aboriginal writers and their professor, Richard Van Camp of the Dogrib (Tlicho) Nation, who is a poet, novelist, and short-story writer. He and the class confirmed that, to them, my hybrid of accessible and academic language is culturally sensitive and respectful to Indigenous peoples. Other

examples include 1) using the “4 R’s” of Aboriginal Research (*Respect, Relevance, Reciprocity, and Responsibility*), a framework coined by Kirkness and Barnhardt (1991) and now used by the B.C. Aboriginal Capacity and Research Development Environment (BC ACADRE), (this framework will be discussed in more detail within the section, *Ethics*, in the 3<sup>rd</sup> Stanza); 2) using the term *story(ies)* rather than *narrative(s)* to honour oral tradition; 3) using *discussion* or *conversation*, rather than *interview*; and, 4) using *material* rather than *data*.

Words reframed to be more culturally respectful lend to the authenticity of Aboriginal research. Edward Said (1978, cited in O’Riley, 2004) suggests colonialism “is not only a process of physical displacement, it is a mode of discourse” (p. 84). I define discourse as the communication of thought (discussion, dialogue) by written or conversational words.

Another dialogue I am concerned with is Frank’s (1995) “illness narrative topography,” through which I have analyzed the participants’ stories. After meeting with the participants and completing this study, I have concluded that their stories are not illness narratives, and the women do not consider their stories to be ones about “illness.” They are, instead, stories of health, resiliency, and well-being. We need to interrogate the ways we can affect positive healthcare and social changes in society, and one way is to approach this study from a culture of *health* rather than from *illness*. Cole (2003) asserts,

language is technology    it can join us    or separate us  
it can make us believe    in bipolarities    in opposites    it can make us afraid of  
contradiction    it can make us believe in reason rather than reasons  
it can become cliché    leading us away from spirit (p. 52).

Wherever possible, I use the discourse of “health” and “well-being.” I base my use of culturally appropriate language on Indigenous scholars such as Archibald (1997), Battiste & Henderson (2000), Brown (2004), Cole (2003), and Marsden (2005).

## 1.2 An Overview of HIV/AIDS

The Human Immuno-Deficiency Virus (HIV) is a tiny infectious particle that attaches itself to white blood cells called CD4 cells. These cells are a vital part of the body’s immune or defensive system needed for the body to stay healthy. The virus then makes more copies of itself until it takes over and

diminishes the number of white blood cells a person normally has to fight off infections (AIDS Vancouver [AV], 2008; Living Positive Resource Centre [LPRC], 2008). Acquired Immune Deficiency Syndrome (AIDS) occurs in the final stages of HIV-infection, usually after about 10 years or more. At this point, the body's defence or immune system is so burdened that serious infections and/or cancers arise. Although new treatments are significantly improving live expectancy, AIDS is still considered a fatal illness. A person is diagnosed with AIDS when they have tested positive for HIV and have one or more opportunistic infections. An opportunistic infection (OI) is an infection that takes advantage of a weak immune system. An OI may be a rare pneumonia, a rare cancer, or an illness like tuberculosis. There are 20-30 common OIs that people with HIV may contract and these are the illnesses that people with AIDS may die from (AV; LPRC). The virus is found in blood, semen, vaginal fluid, cerebral fluid, and breast milk. It is transmitted through unprotected sex, through sharing needles (intravenous drug use), and vertically through mother to child, either during late pregnancy, during birth, or when breastfeeding.

### **1.3 Background to the Problem**

The dominant Western ideology of today continues to disadvantage Aboriginal peoples. "The colonial legacy of subordination of Aboriginal people has resulted in multiple jeopardy for Aboriginal women..." (Browne & Fiske, 2001, p. 127). The universal category of "woman" fails to encompass the many intersecting realities Aboriginal women experience such as gender, ethnicity, age, parenting, violence, and oppression (McCall, 2006). To create the social awareness and health care policies necessary to better address the concerns of Aboriginal women, the women's voices need to be expressed and no longer silenced or further marginalized. Aboriginal women living with HIV/AIDS deserve to be, and must be, heard.

Within this exchange of knowledge, attention is necessary to the culturally sensitive language needed in talking to, and hearing from, Aboriginal people. Further, knowledge needs to flow from the source up (the women), rather than just from the top down (the "professionals" and/or the policy makers). For example, the RCAP (1996) documents the importance of recognizing the multiple barriers Aboriginal women perceive and experience as heard from the women themselves.

Aboriginal women lag behind men and well behind Canadian women as a whole on many social and economic [and health] indicators, but statistics do not reveal why. Women themselves provide a deeper understanding of the barriers that have been placed in their path, barriers that must be recognized, acknowledged and removed before real progress can be made. We believe that by going through the process of acknowledging the harm caused by these barriers, individuals, communities, nations and governments will be able to work together to eliminate them (p. 17).

I intend that three interrelated matters be illuminated: 1) ways to practice Indigenous knowledge and methodologies; 2) ways to focus on engaging Aboriginal community members to find and to express the problems they feel most impact them; and, 3) ways for the non-Aboriginal community to effectively hear and to act upon the insights of Aboriginal people. In order to share this authentic transfer of knowledge between Aboriginal people and researchers, Aboriginal methodologies need to be continuously applied in the area of Aboriginal community-based research (Anderson, 2004; Battiste & Henderson, 2000; Brown, 2004; Cole, 2003; Fourier & Crey, 1997, Kelm, 1998).

Community-based research<sup>1</sup> is an approach to research that shifts ways of knowing, and ownership of knowledge away from conventional university-led research. Traditionally, research has been organized by scholars, presumed to be the holders of knowledge, and focused on those presumed to *need* the research. In the case of Aboriginal peoples, they were the subjects, or the object of study, and predominantly, research was done *on* them, and not always primarily *for* them. However, increasing numbers of community members and researchers are coming to understand this paradigm shift: research needs to be not only about the people, but for the people and by the people.

Community-based research follows the ground-breaking work of Indigenous scholars such as Vine Deloria Jr. (1969) and more recently, Linda Tuiwai Smith with her cornerstone book, *Decolonizing Methodologies* (1999) (Evans, Hole, Berg, Hutchinson, Sookraj, & The Okanagan Urban Aboriginal Health Research Collective [OUAHRC], n.d.). Both paved the groundwork for what is known today as Indigenous methodologies, or Aboriginal research frameworks, which “have become a near necessity for the implementation of research in Indigenous communities” (Evans, et al.). Aboriginal and community-

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<sup>1</sup> Information from this section about community-based research appears in Hill, Donna. M. Community-Based Research: Shifting Western Gaze toward Aboriginality. *Questioning Research: A research guide for Aboriginal communities addressing homelessness*. Social Planning and Research Council of BC.

driven research provides alternatives to scientific, researcher-centred studies. They provide a platform for community members and marginalized voices to be heard. This kind of research situates the gaze of the research being done, not from the outside looking in, but from those conducting the necessary explorations about their own community. Those who identify the research problem should become actively engaged in the research solution. Knowledge translation, the sharing of knowledge learned, should be considered an integral part of the entire research process. Reciprocity involving community-based research creates a win-win situation significantly different from the current mainstream system which continues to marginalize Aboriginal women.

## **1.4 Problem Statement**

Historically, Aboriginal people have faced many challenges as a result of Western colonization over the last 500 years. Most recently, one of the most harmful chapters of this time frame has been the residual effects of residential schooling in British Columbia (Boyer, 2006; Chrisjohn, Young, & Maraun, 2006; Fournier & Crey, 1997; Frohlich, Ross, & Richmond, 2006; Wardman, Clement, & Quantz, 2005). Children's years away from families resulted in the loss of learned parenting skills and cultural knowledge (Campbell, 2002; Ship & Norton, 2001; Walker, Logan, Jordan, & Campbell, 2004; Wuest, Ford-Gilboe, Merritt-Gray, & Berman, 2003). These intergenerational challenges have left Aboriginal women to be more vulnerable to the higher risks of HIV-infection (CAANb, 2004; CAANd, 2003; Ship & Norton, 1999). Aboriginal women living with HIV/AIDS tend to delay accessing medical care until they experience acute symptoms and their disease is already advanced (Vernon, 2001; CAANb, CAANc, 2005; Ship & Norton). The reasons for delay in access are complex and are influenced by numerous factors. Aboriginal people, in general, tend to underutilize available health services (Waldram et al., 1995). In avoiding mainstream healthcare, Aboriginal women are not being tested for their HIV-status as early as necessary (CAANb, 2004; CAANc, 2005, Ship & Norton, 1999). This delay in diagnosis and treatment can result in an earlier death. According to a 2003 study by researchers at the B.C. Centre for Excellence in HIV/AIDS, one-third of British Columbia residents who died of HIV-related causes did not access life-saving treatment. Although HIV-medications (Highly Active Antiretroviral Therapy [HAART]) are provided free by the

provincial government, people who did not seek treatment were mostly Aboriginal, female, and poor and/or living in Vancouver's Downtown Eastside.

## **1.5 Purpose Statement**

Using an interpretive descriptive approach, this research project is intended to better understand some of the lived experiences and perceptions of urban Aboriginal women living with HIV/AIDS in Vancouver, British Columbia. More specifically, this study shares the stories of four Aboriginal women. Within the existing body of HIV/AIDS literature, women's voices and concerns are rarely given prominence. In this thesis, I intend to make central the participant women's otherwise silenced voices and marginalized lives.

## **1.6 Standpoint: Impetus for the Study**

Sinclair (2003) outlines the purpose of locating oneself as a researcher in Aboriginal research:

It means revealing our identities to others; who we are, where we come from, our experiences that have shaped those things, and our intentions for the work we do. Hence, 'location' in Indigenous research, as in life, is a critical starting point (p. 122).

Brown & Strega (2005) encourage researchers to position themselves at the beginning of their work. They advocate that location "is essential to Indigenous methodologies and Aboriginal research/world view/epistemologies" and suggest that as Aboriginal researchers, the reason we write about ourselves is because "the only thing we can write about with authority is ourselves" (p. 97). Creswell (2007) suggests that such positioning is more than autobiographical, but also focuses on "how individuals' culture, gender, history, and experiences shape all aspects of the qualitative project" from question choices, data collection, and interpretations (p. 47). "Taking a standpoint requires self consciousness about how the fate and choices in your life have positioned you in the world and with whom you have been positioned" (Frank, 2000, p. 356). Frank argues that having a standpoint from which to position one's self-reflections is not an option; it is a requirement. The fact that one has choices from which to derive a standpoint "supposes that there are other issues of significance beyond self-choice" (p. 356). I naturally concede

that my first cornerstone standpoint is from a woman's perspective, although, as will be noted in the 3<sup>rd</sup> Stanza of this thesis, I do not claim feminist theory<sup>2</sup> as a specific foundation for my methodology. Lather (1995) positions herself as a translator, a medium through which women living with HIV can be heard and understood, which I also see myself being, as I highlight the women's stories.

Positioning myself as a translator bearing witness, then, the women's words become the motor of inquiry. As such a researcher, one becomes a witness to questions we do not own and do not yet understand, but which summon and beseech us (p. 49).

Following the inherent female lens through which I view my research, my secondary standpoints are more expansive. I believe they involve three viewpoints: 1) aspects of personal identity, 2) the insider/outsider continuum of research, and, 3) determinants of personal drive and passions. Each of these is multifaceted and cross-contextual.

First, regarding my standpoint stemming from personal identity, I have much to reflect upon. Recently, I was asked by Dr. Francisco Ibáñez-Carrasco, a B.C. HIV/AIDS Community-Based Research Facilitator, what seems a simple question, yet, can also be quite complex: Why this topic? Why was I studying HIV when I had before me the unquestionably richness of the field of disabilities in general, and more specifically, my own disability, Cerebral Palsy? Although Dr. Ibáñez-Carrasco gave me the space to be heard and understood, I found myself almost at a loss for words. My answer to him, in short, was this: It must have to do with distance, that feeling of wanting to distance oneself from that which you know only too well. For example, I have never felt the need or the desire to place a call to the Cerebral Palsy Association of BC. On the other hand, I have had a passion to work with people living with HIV/AIDS since I was a young adult. My convictions have led me to an understanding of many underlying complexities for HIV-positive people and also to the sincere enjoyment of being a volunteer educator and board member in this field for the past 11 years. Nevertheless, I do not completely dismiss my own struggles with a disability. I believe that my many adversities have afforded me some additional insight

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<sup>2</sup> I have not chosen a lens of Critical Feminist Theory through which to view this study. However, I do acknowledge that Indigenous knowledges and methodologies used throughout this study are similar to feminist theories; they involve countering the dominant scientific representation, collaboration rather than exclusion, and acknowledging responsible and respectful ways of doing research. Therefore, along with many Indigenous scholars, I also reference throughout this thesis feminist scholars such as Donna Haraway, Sandra Harding, Patti Lather, and Laurel Richardson.

and sensitivity to respond to persons living with HIV/AIDS and to those most marginalized in our society in ways that others might not fully understand.

Second, as I reflect on the insider/outsider researcher discussion, I am cognizant of two dichotomies. First, while I am Métis, I do not have dark skin; I have not experienced the perpetual racism that many Aboriginal men and women have faced and continue to feel on a daily basis. Second, I am not HIV-positive; I have not experienced one of the loneliest and most marginalizing illnesses in our society. However, Ibáñez-Carrasco (1993) suggests “the infamous HIV+/HIV- dichotomy” (p. 21) is problematic. Rather than binary, he reminds us, HIV/AIDS is a continuum, where culturally speaking, everyone is at risk because we are all inherently sexual.

Anae (n.d.) also addresses the insider/outsider dilemma. She writes of the increasing scholarly concern about who is best suited to be a researcher within the area of health (and within her own Samoa/Pacific Islander community).

What we need in the Pacific are researchers who care about people. In all research investigations, mutual trust and understanding must be built carefully and sensitively. As with any human relationship, reciprocity, mutual participation, responsiveness, commitment and responsibility are essential. In turn this relationship will form the basis of our intellectual pursuit—the need to comprehend something in as many ways as possible to construct the composite that finally, more comprehensively allows us to understand an issue, phenomenon, or culture from perspectives of both the researcher and the researched (p. 276).

Anae offers further insights regarding appropriate researchers as well; she discusses ethnic identity in relation to personal identity.

Ethnic identity, in the context of opposition and conflict is therefore, personal with long-lasting attachments experienced in the economical, spiritual, historical symbols that one is espoused to during a lifetime, and must be differentiated from the status-sets which are transient and not emotionally-binding but a mere fact of circumstance (p. 275).

My ethnic identity is indeed personal with long lasting and emotionally-binding attachments to my journey thus far. I am a Métis woman on the life-long journey of reclaiming traditional knowledge, customs, and understanding. I have shared this journey with many others, not the least of which include the women

who participated in this study. While volunteering in the field of HIV/AIDS awareness and prevention, I learned about some of the critical barriers that many Aboriginal women face in relation to their health and well-being, and in particular, our fight against the spread of the HIV-virus. This path has led me to my current study.

The issue of women's voices and the silencing of them through hegemonic societal forces is perhaps the topic which most drives my passion and commitment to this study. Not unlike many Aboriginal and non-Aboriginal women, as well as many people living with HIV/AIDS, I have experienced both the implicit and explicit attempts to silence my voice, my thoughts, and my perceptions. I have experienced this throughout my childhood as someone living with a disability, in the workforce as a woman (and a person with a disability), and also within the professional community. Although I cannot speak for others, I may surmise that one difference between me and other women who have experienced similar circumstances may be that I have often refused to let myself be deterred. I have learned to reject intimidation from those who have sought to overtly discount my views, or through subconscious subtleties, to imply that I should abandon my values, opinions, and pursuits.

Regarding dominant voices and the sequestering of weaker ones, Armstrong describes the Okanagan Peoples' *En'owkinwixw* Discourse Model as a means to quite the opposite of silenced voices (personal communication, 2007). She advocates for listening to all people and for respecting diversity. The *En'owkinwixw* process activates creativity; it supports and encourages even the most quiet, unexpected persons from which answers, viewpoints, and solutions might arise. Armstrong contends that everybody can offer what uniqueness is inside of them. Other Indigenous scholars such as Brown (2004) and Gonzales remind us that Indigenous peoples' knowledge "is in our head, our heart, and our spirit" (personal communication, 2006). "As the Elders say, 'If you have important things to say, speak from your heart'" (Brown & Strega, 2005, p. 25).

Another rationale for the impetus of this research has been Fuller's book (2004), *Somebodies and Nobodies: Overcoming the Abuse of Rank*. Reading this book left me feeling relieved to find some of my experiences, and perhaps those of the women I choose to work alongside, explored within a meaningful context. Fuller takes the analysis of discrimination beyond classism, sexism, racism, (and able-ism), to reveal a form of injustice that everybody knows, but few see: discrimination based on rank, or "rankism"

(p. 2). He addresses the fact that low rank—signifying weakness, vulnerability, and the absence of power—marks people for abuse in much the same ways that race, class, and gender have long done. *Somebodies and Nobodies* unmask rankism as the “Mother of Isms” (p. 5), demonstrating its pervasiveness throughout our personal lives and social institutions. It illuminates the subtle, yet, dysfunctional workings of power in all of our interactions.

Fuller (2004) argues that to combat society’s racism, sexism, and other pervasive discriminatory attitudes, we need to look beyond these to the pinnacle of abuse (and the silencing of voices), to what he declares, is rankism. Fuller writes:

In the US, perhaps twenty percent of us have suffered directly from racism, and about fifty percent from sexism. But virtually all of us suffer from rank based abuse—which I shall be calling “rankism”—in one context or another, at one time or another. Sooner or later, everybody gets taken for a nobody. Sooner or later, most of us treat someone else as a nobody. It hurts to be “dissed,” no matter what your status. Yet, if it weren’t for the fact that most everyone has known the sting of rankism, would there ever have been empathy for victims of racism and sexism? (p. 2)

The author claims that regardless of the “surface distinctions such as ethnicity, religion, color, gender, persistent abuse and discrimination are predicated on power differences inherent in rank” (p. 3). Neither I, nor Fuller, contest the fact that rank differentiations are an essential classification within society, or that power imbalances and hierarchies do, and will, continue to exist. However, I also believe that despite the respect often afforded to those individuals who have earned their status and rank beyond others, this does not give unequivocal consent for the abuse of rankism towards another individual to occur, or for it to be dutifully accepted. As Vartan Gregorian so aptly states, “Dignity is not negotiable” (cited in Fuller, 2004, p. 7).

Fuller (2004) purports that rankism erodes the will to learn, the drive to attain, the desire (and the belief in the right) to speak out, and the motivation to maintain convictions. Part of my intention in writing this thesis is related to my ongoing reaction to those people who have tried to impose upon me the silences of nobodiness. They have not intimidated me; they have not deterred me. Conversely, they have implicitly strengthened my resilience to succeed in life and in the field of community-based research.

Most importantly, they have reinforced my ability to understand on a deeper level my connectedness with Aboriginal women living with HIV/AIDS.

## 1.7 Organization of the Thesis

Scholars such as Battiste and Henderson (2000), Brown and Strega (2005), Cole (2003), Graveline (2000), O'Riley (2004), and Swisher (1998) encourage Indigenous researchers to break through boundaries of Western academic writing. Cole (2003) and Graveline (2000) discuss the circle as methodology in the framework of Indigenous research. Cole argues that concepts of beginning/middle/end are Western ideals, and that not all theses must have a conclusion (personal communication, 2007). Incorporating some of these Indigenous notions, I have started my journey through this thesis with a poem and then finished it with more poems. The final section, *Thesis Poetry*, is reflective of my learning experiences throughout this process. I also reject the necessity to use "chapters" and instead, to remain consistent with my poetic framework: I present my thesis sections as "Stanzas" in relation to my introductory poem.

the idea of the chapter is anathema to who I am as an Indigenous person  
it implies western order as 'the' legitimate shaper of discourse  
the universe being ordered into rationally constructed geometries  
precluding enthalpy to be the prescribed means of navigating  
rather than entropy devaluing our own symbolic sense of ourselves  
perceptions of our perceptions making us take up the tools of the settlers (Cole, 2003, pp. 9-10).

In addition, each Stanza, or section, is titled with a single verb rather than a selection of nouns. Western research is about centering knowledge with a single or group nouns as evidence (Cole, personal communication, 2007). Conversely, many Aboriginal languages are about the process; they are verb-driven (Battiste and Henderson, 2000; Brown, 2004; Brown & Strega, 2005; Cole, 2003). They remain about the flux, the process, and the evolution of learning.

In this 1<sup>st</sup> Stanza, *Intending*, I have reviewed the background for our community-based research study. I have stated the study's problem and purpose, and explained the standpoint/impetus for my chosen field of interest. In the 2<sup>nd</sup> Stanza, *Seeking*, I detail a review of relevant literature which gives

context to this current study. In the 3<sup>rd</sup> Stanza, *Shapeshifting*, I explain my Indigenous research paradigm, including my methodology, methods, sample and material collection, an overview of empowerment ideology, scientific criteria, and ethical considerations. I share research findings, the stories of the women participants, in the 4<sup>th</sup> Stanza, *Conversing*. In the 5<sup>th</sup> Stanza, *Understanding*, I develop a discussion about the women's lives and analyze them in relation to a health narrative topography (Frank, 1995, *The Wounded Storyteller: Body, Illness, and Ethics*), specifically, the three genres of *Restitution*, *Chaos*, and *Quest*. I also look at Frank's book through a critical lens and identify aspects where I believe it fails to encompass considerations related specifically to Aboriginal women's stories of health and well-being. The 6<sup>th</sup> Stanza, *Reflecting*, brings my thesis full circle; the process originates with poetry, and finishes with a poetic section about my journey. It is at the end of this section that I share more of my original poetry written throughout the two years during this research process. Some researchers "journal" as well as take field notes; my poetry *is* my journaling. It is my reflexive, narrative contribution to this study (Brown & Strega 2005; Cole 2002, 2003, 2004; Graveline 2000; Lather, 1993; Richardson, 1997). These poems have been inspired by some of the many books and articles I have read, and more importantly, by the women I have met over the course of my research. The poems are my personal perceptions and reflections during this time period in my life—shared in poetic form—rather than in academic writing. Smith's (1999) description of creativity resonates with me.

The project of creating is not just about the artistic endeavors of individuals but about the spirit of creating which indigenous communities have exercised over thousands of years. Imagination enables people to rise above their own circumstances, to dream new visions and to hold onto old ones. It fosters inventions and discoveries, facilitates simple improvement to people's lives and uplifts our spirits (p. 158).

Finally, included in this Stanza, I discuss what I believe to be the study's successes and limitations. I then make some recommendations in relation to health care providers, policy makers, and the non-Aboriginal community at large.

## 2. 2<sup>nd</sup> Stanza: Seeking

Check-in goes informally around the circle  
as most know one another. When it's your turn  
you are glad to be here, to know the women,  
but you still throw in that you're Métis so you appear  
even less like the token white girl in the crowd.

A check-in is customary in a talking circle, and one was necessary within the sharing circle of women gathered at this women's drop-in centre, just as it is within this thesis. We shared information to learn about one another, to become comfortable with our time of being together, to understand underlying issues that brought us together as a community. Similarly, this literature review seeks a greater understanding of background information in which the reader can contextualize the rest of the thesis' purpose and journey.

\* \* \*

### 2.1 Introduction

The purpose of this literature review<sup>3</sup> is to provide for both researcher and the reader a context for this study. It demonstrates the need for the study by first highlighting the relevant research, and then by revealing some of the gaps in the literature. "Critical analysis of existing knowledge provides a platform on which to build the design of the study and allows the findings to be constructed with attention to the linkages that can be drawn to the work of others in the field" (McCall, 2006, p. 16).

This study explores the experiences and perceptions of urban Aboriginal women in Vancouver, British Columbia, living with HIV/AIDS. It explores, through the personal stories of four women, how they live with the virus in a society which continues to discriminate against them based on their race, gender, and HIV-positive status. Although the study is primarily qualitative, I also report relevant statistics to illustrate certain information within the current literature. However, it should be noted that many working in the field of HIV research remain skeptical about the true accuracy of these data (Crozier, personal communication, AV, 2008). There are three main reasons that affect the utility of statistics in HIV

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<sup>3</sup> Information from this thesis chapter appears in Hill, Donna M. (under peer review). HIV/AIDS among Aboriginal Canadians: Disproportionate Rates as Compared to other Canadians. *Alternative: An International Journal of Indigenous Scholarship*.

research. First, many HIV-positive persons do not get tested (CAANb, 2004; CAANc, 2005; Crozier; Ship & Norton, 1999). This results in often inaccurate quantitative summaries about infection rates (and assumed but obviously unquantifiable under-reporting). Second, regarding statistics specific to Aboriginal persons, not all Canadian provinces break their infection rates into categories of ethnicity (such as Ontario and Quebec) (CAANc; Public Health Agency, 2007). For example, of the reports citing the positively tested Aboriginal persons from 1998 through the end of 2006, ethnicity was reported in only 29.2% of records and “is not available for all provinces” (Public Health Agency). And, third, many Aboriginal people in Canada do not always declare themselves so, especially in the context of official and quasi-official documents.

For the purpose of this study, I have surveyed nine main areas of literature: 1) Background to Canadian Aboriginal Peoples and HIV/AIDS; 2) Background to Canadian Aboriginal Women and HIV/AIDS; 3) Age; 4) Gender Relations, Violence, and Oppression; 5) Stigma and Discrimination; 6) Access to Health Care; 7) Vulnerabilities to Treatment; 8) Poverty and Homelessness; and, 9) Colonization. Statistical data is presented primarily in sections I and II, and in later sections as appropriate. The latter sections of the literature review, III through XI, deal more qualitatively with the high risks of infection and contextual barriers impacting many Aboriginal women. Further, in each of these latter sections, actual statistics become more problematic for the reasons described above.

My assessments in the literature review (and throughout the rest of the thesis) are intended to focus on Aboriginal women, and their higher risks of infection, and are not meant to be generalizable across all Aboriginal peoples. Stake (2004) cautions “generalization can be an unconscious process for both researcher and reader” (p. 44). I seek a position along a continuum of generalizability—while the researcher and reader cannot claim that all Aboriginal women living with HIV experience these same experiences and perceptions as this study’s participants, we can infer that their living situations may be common. I believe that doing so is beneficial, and that thinking about the words of the women in this study can lead to a better understanding of the social conditions in which many Aboriginal women live, and to a decrease in stigmatizing attitudes they constantly face. By showcasing the four participants’ stories, my purpose has been to illuminate just some of the complexities of daily living these women experience in relation to their health and well-being. Some of these barriers to healthy living found in the

current literature, such as socio-economic marginalization, isolation, homelessness, discrimination, and compromised health and well-being appear to be common threads among the women's stories. So it is that the literature review contextualizes the words of the women at the same time the women provide greater depth to our understanding and consequences of the conditions reported in the rest of the literature.

## **2.2 Background to Aboriginal Canadians and HIV/AIDS**

Among Aboriginal peoples throughout Canada, the HIV/AIDS epidemic continues to rise at a disproportionate rate compared to the rest of Canadians. The HIV and AIDS in Canada Surveillance Report (Health Canada, 2006) records that 2,558 people tested positive in 2005. Of these, (26.7%) were Aboriginal people, as compared to 2.1% South Asian, 4.1% Asian, 10.9% Black, 2.7% Latin American, 52% White, and 1.4% Other. Comparatively, HIV-positive Aboriginal people equalled nearly half of the white population testing positive, more than any other ethnic minority group. Aboriginal people are three times as likely to be HIV-infected than other Canadians, with exposure occurring predominantly as a result of intravenous drug use (IDU) (53%) (Public Health Agency, 2007).

Aboriginal persons continue to be over-represented in the HIV-epidemic in Canada. They make up 3.3% of the Canadian population, and yet an estimated 3,600 to 5,100 Aboriginal persons were living with HIV in Canada in 2005, representing about 7.5% of all prevalent HIV-infections. This is higher than the estimated 3,100 to 4,400 for 2002 but represents the same proportion (7.5%). Approximately 200 to 400 of the new HIV-infections in 2002 and 2005 respectively occurred in Aboriginal persons, which is about 10% of the total for 2002 and 9% for 2005. Therefore, the overall infection rate among Aboriginal persons is about 2.8 times higher than among non-Aboriginal persons. The distribution of exposure category among newly infected Aboriginal persons in 2005 was 53% IDU, 33% heterosexual, 10% men who have sex with men (MSM), and 3% MSM-IDU, which is unchanged from 2002 (Public Health Agency, 2007, p. 4-5).

Beyond giving basic epidemiological context, this study, however, does not further explore actual rates of incidence occurring locally, provincially, or nationally (or across ethnicity). Neither is my study a comparison study about the HIV-rates of infection between Aboriginal and non-Aboriginal Canadians

(statistical reporting of Canadian ethnic categories living with HIV are not available). Finally, in noting infection rates for men as well as for women, my study is not a comparison between Aboriginal men and women (provincially, in 2006, 10,484 vs. 1,755 respectively). For example, in 2005, more than half of the newly diagnosed people in Vancouver (119) were MSM, and nationally that rate was 45% (Vancouver Coastal Health). It is the rate of increase among a specific population that should, and does, concern experts. The reasons for higher risks for infection among Aboriginal women form the cornerstones of this study.

The rate for new infections for Aboriginal women has been steadily on the rise for the last two decades (CAANb, 2004). The primary focus of this study is about the Aboriginal women participants' experiences living with HIV/AIDS as represented in their personal life-stories. As this literature review reveals, there are a number of underlying social factors that contribute to Aboriginal peoples being at an increased *risk* for infection, (not actual *incidence* of infection), such as socio-economic marginalization, oppression, racism, discrimination, and access to healthcare. Within these multifaceted contexts, Aboriginal women find themselves even further disadvantaged.

Nationally, Aboriginal people accounted for 14.1% of new HIV/AIDS cases reported in the first half of 2002, up from 5.3% in 2001, and 10% in 1999 (Public Health Agency, 2007). According to the 2006 Census, Aboriginal people in Canada make up only 3.8% of the total population (up from 3.3 in 2001) (Health Canada, 2006). Provincially, "Aboriginal people are overrepresented in the HIV epidemic. Although Aboriginal people are less than 5% of BC's population, they make up around 14% of its HIV-positive population" (Vancouver Coastal Health, 2007). A review of the literature highlights critical local, provincial, and national information and the need for more knowledge about the historical, economical, and social contexts in which many Canadian Aboriginal people live. Another key area of literature which needs to be highlighted is work on the disparities in health between Aboriginal peoples and non-Aboriginal people in Canada.

Compared to the Canadian average, life expectancy at birth for Aboriginal people is 68.9 years for males and 76.6 years for females. This is 7.4 years less for men and 5.2 years less for women than non-Aboriginals (Health Canada, 2001). Other research confirms that Aboriginal people die sooner than non-Aboriginals and have a greater burden of physical and mental disease (RCAP, 1996; Dion Stout, Kipling

& Stout, 2001; Wardman et al., 2005). Heart disease is 1.5 times higher for Aboriginal peoples, while Type 2 diabetes remains 3 to 5 times higher (Health Canada, 2006). Prevalence rates for high blood pressure and arthritis are also higher (Tjepkema, 2002).

## **2.3 Background to Canadian Aboriginal Women and HIV/AIDS**

Among Aboriginal peoples, women made up 48.1% of all positive HIV-test results from 1998 through 2006 compared to non-Aboriginal people where women made up a much smaller percentage of positive test results (20.7%) (Public Health Agency, 2007). In 2005, Aboriginal women represented 27% of new infections nationally and 14% of new diagnoses in Vancouver (Vancouver Coastal Health, 2007).

Of the 1,404 positive HIV test reports with known exposure category (information on gender missing for four cases) reported among Aboriginal persons between 1998 and December 31, 2006, there were 732 male cases and 672 female cases... Of female reports, 64.4 % were attributed to IDU and 34.1% to heterosexual exposure, proportions similar to those for reported AIDS cases (Public Health Agency, 2007, p. 50).

Taken together, these statistics suggest, as CAANb (2004) reports, "Aboriginal women are greatly overrepresented in HIV/AIDS statistics, yet there is a startling lack of gender-specific, Aboriginal specific, HIV/AIDS resources, programs and services to support them." Critically low levels of research still exist regarding how and why women are not receiving the adequate health care and social services necessary for the support they need (Waldram et al., 1995; Legare, Ross, & Bognar, 2003; RCAP, 1996; Vernon, 2001). Some of the influencing barriers that most impact Aboriginal women in the prevention of this disease are: age; ethnicity; poverty; power imbalances and oppression; violence; lack of ability to negotiate safer sex practices; gender roles; sexual orientations; stigmatizing attitudes; and, historical and socio-cultural factors (Browne and Fiske, 2001; CAANb, 2004; Smith, 2002; Watson & Bell, 2005).

## 2.4 Age

Young women are increasingly at risk for HIV-infection because of many overlapping vulnerabilities (CAANe, 2004; Smith, 2002; Watson & Bell, 2005). Aboriginal youth are overrepresented in the Canadian HIV-positive population. CAANe (2004) reports that “30% of Aboriginal HIV infections are in youth between 20-29 years old (compared to only 20% in the non-Aboriginal population)” (p. 3). The Public Health Agency (2007) reports higher figures.

Aboriginal persons with a diagnosis of HIV tend to be younger than non-Aboriginal persons. Almost a third (32.4%) of the positive HIV test reports from Aboriginal persons from 1998 to the end of 2006 were younger than 30 years as compared with 21.0% of this age among infected non-Aboriginal persons (p. 47).

Many young women are at higher risk because of neglect and abuse they experienced as a child (CAANb, 2004; CAANe, 2004; Smith, 2002). Their lowered sense of self-worth and esteem diminish their capacity for selection of healthier relationships as young adults. Early neglect and abuse contribute to their insecurities about finding relationships that do not perpetuate the cycle of abuse (Kirkham & Lobb, 1998). Women with a history of childhood sexual abuse who are not able to break this cycle often find themselves unable to avoid engaging in risky behaviours such as sex trade work for survival that may lead to infection (CAANd, 2003; CAANe, 2004; Ship & Norton, 2001; Vernon, 2001; Varcoe & Dick, 2008). If young girls have escaped abusive homes to the streets, they often find themselves in relationships that are socio-economically dependent on men, older men in particular (Smith, 2002; Worth, 1996). Smith notes that inner-city women are especially vulnerable to the poverty-HIV cycle. Socio-economic factors force many women to live on the streets. While living on the streets, the likelihood of becoming addicted to drugs and of having to become sex workers for survival greatly increase their risks for contracting HIV (CAANd, 2003; CAANe, 2004; Smith, 2002; Varcoe & Dick, 2008). The two highest risks for viral transmission are unprotected sex and IDU, from sharing dirty (used) needles (Vancouver Coastal Health, 2007). “Among Aboriginal Canadians the portion of new HIV infections in 2005 attributed to IDU (53%) was much higher than all Canadians (14%)” (Public Health Agency, 2007).

Whether women are literally living on the streets or close to this based on their poverty levels, relationship principles also influence their health circumstances. Two prevailing myths are likely to

interfere with young women's access to safer relationships. First, the "White Knight" or romance narrative about being in a relationship with a man often clouds the women's judgments and prevents them from escaping these confounding experiences of vulnerability and exploitation (Watson & Bell, 2005). Worth (1996) suggests a woman's search for romantic love may "represent a search for love to replace the love and care they had not received as children" (p. 127). Second, is what Smith (2002) refers to as the "Virgin Myth" (p.64). This falsehood is the perception of older men that young women, preferably virgins, are less likely to have already been infected with the HIV-virus because of their age and lack of sexual experience. Some men intentionally seek out younger, more vulnerable women as a way of supposedly protecting themselves from the virus.

As well as studies representing high risk factors for younger women, some researchers now focus on infection rates among women over the age of fifty (Henderson, Berstein, St. George, Doyle, Paranjape, Anuradha, & Corbie-Smith, 2004; Smith, 2002; Spearman & Bolden, 2005; Watson & Bell, 2005). Older women and their relative inability to decide on safer sex practices, for example, using condoms, as well as the prevalence of violence against them, had not previously been widely studied (Smith, 2002; Watson & Bell, 2005). In spite of education and prevention strategies, the number of elderly people diagnosed with HIV/AIDS continues to rise (Roberts, personal communication, LPRC, 2007). Involved are a number of multi-layered factors such as longevity, changes in relationships, complex and chronic health problems, and late-stage diagnosis (Smith, 2002; Watson & Bell, 2005). Henderson et al. (2004) did not, however, identify much of a variety of cultural subgroups (other than widowed and African American women, which 35% and 73% of participants respectively self-identified), and did not include some of society's most marginalized<sup>4</sup> and vulnerable women: those from the Aboriginal community.

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<sup>4</sup> In this paper I use the term *marginalize*, not to imply some inherent characteristics associated with particular people or groups, but rather, to refer to people who have been most affected by historical, structural, and social inequities. Frequently, these are people who also experience related disadvantages stemming from mental health, substance use, or stigmatizing conditions such as HIV/AIDS, and issues arising from profound social inequities such as involvement with drugs, the sex trade, or the justice system.

## 2.5 Gender Relations, Violence, and Oppression

Within the Aboriginal community, the relative rates of new infection for women are much higher than those within the non-Aboriginal population. The Red Road HIV/AIDS Network (n.d.) confirms a high incidence among Aboriginal women, who “make up 40% of all new infections in the Aboriginal community as compared to only 17% of total non-Aboriginal cases” (p. 4). Aboriginal women are also faced with substantially higher rates of mortality, injury, suicide, obesity, and chronic disease (Dion Stout, Kipling, & Stout, 2001).

Rohleder & Gibson (2006) suggest women’s experiences of living with HIV are intensified because of gendered subordination in society. Gender role differences are reflected in Western society’s mores. For example, men with numerous sexual partners are considered virile and manly while women with many partners are considered “deviant, dirty or damaged” (p. 27). When a woman becomes HIV-positive, she becomes “the recipient of these social projections” (p. 28). For women in relationships, Sobo (1998) identifies two additional interconnecting factors related to unsafe sex practices and women: the monogamous and wisdom narrative. This narrative refers to women who consider themselves to be in a committed, monogamous relationship. They are less likely to advocate for using condoms. Their trust levels are elevated and they are less likely to suspect their partners may be having sex outside the relationship and becoming HIV-infected. Through feelings of trust and security, the women’s judgments about choosing good partners are also compromised (Watson & Bell, 2005).

Women’s subordination to men is a key factor to understanding their increased levels of risk for HIV. Often circumstances prevent a woman from being able to negotiate safer sex practices, which, in turn, can lead to compounding consequences of further abuse or abandonment, as this woman explains: “It was a violent sort of encounter...he was on top of me, pulling off the condom...finding out you are positive a month later...then being abandoned” (Ship & Norton, 1999, p. 29). Aboriginal women face increased risks of violence as compared to non-Aboriginal people (Dion Stout, 1996). According to the RCAP (1996b), as many as 8 out of 10 Aboriginal women have experienced violence, both within their own communities and in the greater society (Ship & Norton, 2001). Rates for intimate partner violence (IPV) or spousal abuse are significantly higher among Aboriginal women than Aboriginal men, or among non-Aboriginal people (Statistics Canada, 2006).

A growing body of literature documents the health effects of IPV (Campbell, 2002, Walker et al., 2004). Wuest et al. (2003) also report evidence that health problems suffered by women because of violence continue long after the violence stops. Aboriginal women's health and well-being is impacted by IPV which is embedded in socio-cultural, historical, political and economic contexts that often destroy the family unit leading to family denigration, homelessness, crime, incarceration, and murder (Campbell, 2002; Walker et al., 2004; Wuest et al.). Subsequently, there also exist many associated consequences. IPV is not simply an individual or couple's issue; rather, it often impacts the well-being of women, men, children, and communities at large. These socially interlocking processes need to be understood and to be addressed; they are further perpetuated by racism, sexism, levels of the education, employment abilities, justice inequalities, and the isolating practices that pervade our health and social policies, health services, and society at large (Campbell; Ship & Norton, 2001, Walker et al.; Wuest et al.).

Anderson et al. (1997) remind us that while the work process in the family is inherent, yet often invisible, it is still primarily relegated to women across race, gender, and class. In relation to women's role as mother, another transmission route for the virus is vertical—perinatal and through breast milk. In the absence of treatment, approximately 25% of babies born to HIV-positive mothers are infected with the virus (Mahy, personal communication, Oak Tree Clinic, 2006). If an HIV-positive woman's pregnancy is intervened with treatment, the risk of perinatal transference is lowered to 1% (Mahy; Mofenson, Lambert, Fowler, et al, 1999; Robinson, 1998). In socio-economic circumstances where poverty and oppression are prevalent, mothers often cannot meet the needs of nutritional supplements. While breastfeeding is commonly accepted as the best source of nutrition for infants, the greater risk for mothers who are HIV-positive is that they find themselves with no support or resources for alternative nursing practices (Hill, 2003; Mofenson, Lambert, Fowler, et al.; Robinson). "Life is a daily struggle as many positive women experience difficulty providing for basic needs—food, shelter, clothing and transportation—for their children and for themselves. Many women access food and clothing banks" (Ship & Norton, 2001, p. 27).

Additionally, Aboriginal women face distinct risks of violence in the home as compared to non-Aboriginal people (Dion Stout, Kipling, & Stout, 2001).

My mother and father drank. They were products of residential schools. I was the youngest...I was placed in a foster home. It's tough being an Aboriginal woman. I was part of an abusive relationship.

What I saw in him was what I got from my family. I was sexually abused (Native Social Work Journal Board, 2000, p. 79).

Aboriginal women often live through multiple forms of inequality in their relationships. Drinking and using drugs can become a way of escape from the legacy of colonization and residential schooling. Some women end up surviving on the streets by turning to sex trade work (CAANd, 2003; CAANe, 2004; Ship & Norton, 2001; Vernon, 2001; Varcoe & Dick, 2008). In turn, the familial cycle of dysfunction, including poor health, lower education, low coping skills and parenting skills, and poverty, is passed down from generation to generation (Campbell, 2002; Ship & Norton; Walker et al, 2004; Wuest et al., 2003). These intergenerational challenges have led Aboriginal women to be more vulnerable to the higher risks of HIV-infection (CAANb, 2004).

## 2.6 Stigma and Discrimination<sup>5</sup>

The discourse or language of stigma has debilitating effects on Aboriginal women stemming from societal fears and discriminating attitudes about HIV/AIDS. Stigma “refers to a condition of ‘difference’ and is used to label people who deviate from the socially constructed definition of normal that is at work in their community” (McCall, 2006, p. 25). Poindexter (2004) describes stigma as “labeling differences negatively or stereotyping based on cultural beliefs. ...HIV stigma, is a particular form of discrimination that causes social and emotional problems for persons with HIV and their associates” (p. 498). HIV/AIDS has come to be known as a socially constructed illness that affects the most marginalized of people. It is understood and experienced within social and cultural contexts. “HIV/AIDS has been conceptualized and perceived as a viral ‘attack,’ or ‘plague’ that often guarantees one’s membership in a particular ‘risk group’ worthy of society’s condemnation, criticism and judgment” (Ryan, 2000, p. 102). Society has learned to view the illness and HIV-positive people with stigmatizing attitudes, which, in turn, influence the ways people live with the illness (Clarke, Friedman, & Hoffman-Goetz, 2005). The ways in which Western society presently addresses stigma, specifically that which is directed towards Aboriginal women

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<sup>5</sup> Information from this section appears in Hill, Donna M. & Kurtz, D. L. (2008). The Effects of Stigma on Aboriginal Women living with HIV/AIDS. *Canadian Journal of HIV/AIDS Community-Based Research*. Supplement Edition, pp. 5-15.

living with HIV/AIDS compound the effects of the illness. Their experiences in life are laden with discrimination, social rejection, marginalization, and violence against them. Stigma impacts the vulnerabilities of women in numerous physical and emotional ways, and Ryan (2000) suggests we do more than simply 'pay attention' to such social determinants of health. "This is particularly crucial with regards to stigmatized and stereotyped women who, because they [may] use drugs or sell sex are often judged as 'immoral' or 'unworthy' of our attention, research, or funds" (p. 102).

The HIV-epidemic in the Aboriginal community is not decreasing. There are multiple notions about why this is happening, many of which are related to stigma. Fear of being judged by family, their community, and society often interferes with testing, and results in delayed diagnosis (McCall, 2006; Varcoe & Dick, 2008), and poor outcomes. Judgments by society can make an individual feel shame for becoming infected or for living a 'risky' lifestyle.

Often women must bear the burdens of blame and humiliation for their possibilities of transferring the virus (Smith, 2002). As a consequence of being perceived as dirty, tainted, and undesirable, women living with the virus often attempt to "pass as normal," rather than as HIV-positive (Rohleder & Gibson, 2006). Passing includes choices such as not being tested, not informing anyone of their status, or not seeking medical care. There is a strong fear of disclosure to anyone, in case of being shunned by people in society (Barosso & Powell-Cope, 2000). Women also fear stigmatization from healthcare professionals. This prevents HIV-positive women from getting early treatment which could prolong their life (McCall, 2006).

## **2.7 Access to Health Care**

Aboriginal people tend to underutilize available health services (Waldram et al., 1995). Aboriginal women who are living with HIV/AIDS tend to delay accessing medical care until they experience acute symptoms and their disease is already advanced (Vernon, 2001). The reasons for delay in access are complex and are influenced by numerous factors. Legare et al. (2003) identify a number of these in their report on the status of HIV-positive women in BC: later diagnosis; delay of treatment; exclusion from drug trials; higher rates of poverty; and conflicting demands on their time due to child care and family responsibilities. Further, a lack of research that pertains specifically to women has limited effective

interventions in this regard. The report, however, looks at women in general. Aboriginal women have specific challenges beyond those addressed.

Aboriginal women's access to health care and their responses to its availability need to be examined within the context of a colonial history (RCAP, 1996b). The effect of colonial and post-confederation legislation has been to marginalize Aboriginal women and to diminish their social and political roles in community life. The conditions of health care have been shaped for over a century by internal colonial practices, policies, and politics (Kelm, 1998; RCAP, 1996a; Waldram et al., 1995).

The legacy of colonial health care continues to be evident in various ways, particularly through explicit as well as implicit discriminatory practices and structural constraints that have marginalized many Aboriginal people from the dominant health care system. For example, studies demonstrate how Aboriginal women face serious access problems stemming from discrimination based on race, gender, and class (Benoit, Carroll, & Chaudry, 2003; Browne & Fiske, 2001; Dion Stout, Kipling, & Stout, 2001, Kurtz et al., 2008). These socio-political realities shape Aboriginal women's everyday social experiences and access to routine services necessary to them as HIV-positive women. A more critical lens is needed to reduce the implicitly accepted historical and socio-structural issues contributing to Aboriginal peoples' health, and to the explicit barriers to health care that many women face.

## 2.8 Vulnerabilities to Treatment

Treatment of HIV-positive people requires medicine to relieve symptoms, to prevent or treat opportunistic diseases<sup>6</sup>, and to lower the risks of viral transference (Health Canada, 2003). Testing and treatment are major factors in the health and well-being of people living with HIV/AIDS. "Discrimination inhibits people, especially women, from revealing their status and taking action to stop further transmission" (Smith, 2002, p. 66). Women experience shame, guilt, despair, and feelings of visible contamination once they become infected. These internalized thoughts, in turn, influences their self-

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<sup>6</sup> 'Opportunistic infections' or 'opportunistic conditions' are those otherwise probable benign infections, such as a cold, the flu, shingles, or respiratory infections like *Pneumocystis Carinii* Pneumonia (PCP), which cannot be normally fought by an HIV-positive person's weakened immune system (AIDS Vancouver 2008; Living Positive Resource Centre, 2008). Many AIDS-related opportunistic infections that affect only women include increased vaginal infections, cervical cancer, pelvic inflammatory disease (PID), and menstrual changes (Ryan, 2000).

interest and motivation for effective health care and treatment. Even before a formal diagnosis of the disease, many women face the stigma and shame of having to go to their doctor or a clinic to ask for an HIV-test. Not being tested only results in self-harm if they are positive for the virus. Time is wasted before treatment is begun, and possibilities remain that the virus will be unknowingly transmitted to another person. Often loneliness and isolation play a part in women's vulnerabilities to access treatment as well (Health Canada, 2003).

Highly Active Antiretroviral Therapy (HAART) has altered the path of HIV/AIDS from a fairly rapidly fatal disease to a chronic, long-term illness (McCall, 2006). However, HIV-positive women need motivation to stay connected with medical and social services, to stay on the drugs, and to reduce high-risk behaviours (Holstad, McDonnell, Dilorio, & Magowe, 2006). Side effects and conflicting responsibilities can present difficulties for women attempting to adhere to a drug regimen. Most women will place the socio-economic needs of their children before their own needs for medicine and good nutrition. The effects of poverty are compounded by childcare responsibilities, and indeed, for Aboriginal women, many of the other vulnerabilities I have discussed in terms of becoming infected with the virus complicate treatment.

## 2.9 Poverty and Homelessness

Aboriginal people are particularly vulnerable to poverty in many larger Canadian cities. According to the Urban Poverty in Canada report published by the Canada Council on Social Development (CCSD) (2000), "the poverty rate for Aboriginal people in cities was 42.8% – more than double the rate for non-Aboriginal people (19%)" (p. 18). Of the 17 cities listed in the study, Vancouver reported the highest Aboriginal poverty rate at 59.5% (CCSD). Several factors may contribute to high poverty rates such as barriers to education and employment opportunities, which in turn, also affect housing conditions for many people (CCSD).

The Greater Vancouver Regional District (GVRD) Homeless count (Goldberg, Graves, Eberle, et. al., 2005) used two categories of homelessness: *street homeless*, those who live outdoors, on streets, in parkades, parks and beaches; and *sheltered homeless*, those who have temporary shelter in emergency

or transition shelters or in a friend's home (no security, not paying rent). Reasons given for homelessness were multifaceted, with most declaring deficiency of earnings (44%); living with health conditions (such as asthma or diabetes) or addictions (25%); and, the high costs of housing (22%) (p.15). Street homeless point to lack of money as the major cause of their homelessness, while the sheltered homeless indicate health and addictions more often were their problems. Of all the people counted, 35% were homeless for 1 year or more, with some stating they have been without a home for more than 10 years, and 24% were newly homeless, being without a permanent home for less than 30 days (p. 15).

Those surveyed were asked directly if they considered themselves Aboriginal; 30% of the respondents self-identified as Aboriginal, indicating this group is over-represented in the homeless category, as Aboriginals make up only 2% of the GVRD population (p. 27). Street homeless among those surveyed revealed that 70% were Aboriginal (p. 27), suggesting Aboriginal homeless people avoid shelters; they are inadequately served by shelters; or, they were under-reported by shelter staff. Women made up 26% of the total counted homeless, while Aboriginal women accounted for 36 % of the homeless population (p. 11). "There were proportionately more women among the total Aboriginal homeless population (35%) than among the total non-Aboriginal homeless (27%)" (p. 27).

## 2.10 Colonization<sup>7</sup>

The Royal Commission on Aboriginal People (1996) was established to better meet the growing needs of Aboriginal peoples in Canada. The RCAP Report Card (Assembly of First Nations, 2006) has recently issued the federal government an inclusive failing grade for their failures to provide the necessary changes in the economic, social, cultural, and health status of Canadian Aboriginal peoples. The Report Card condemns the Canadian government's lack of progress, stating:

The reality for First Nations communities today is *ongoing poverty* [formatting in original], and an increasing gap in living conditions with other Canadians, which were reported during the RCAP

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<sup>7</sup> Information from this section may appear in the literature review of PhD student, D. Kurtz. In 2007, I worked as her research assistant while also writing my own review; I researched material relevant to both our studies.

hearings. Any major improvements in individual communities or regions have been led *by* those communities *for* those communities [not by the Canadian government] (p. 2).

The Assembly of First Nations remains acutely aware of the ongoing conditions of poverty in which many Aboriginal Canadians live, and of the inequities in adequate health care they continue to face today. In an attempt to improve the health of Aboriginal peoples, various health initiatives have been implemented (Romanow, 2002; National Aboriginal Health Organization [NAHO], 2002). However, according to the Report Card, not many of these critical initiatives are succeeding, as the current conditions of Aboriginal peoples would suggest. Healthcare professionals, policy-makers, Aboriginal communities, and the general population should be aware of these cultural contexts in order to end racial discrimination, and to better assist Aboriginal communities in the fight against the spread of HIV/AIDS.

One of the predominant contributing factors for higher HIV-infection rates in Aboriginal peoples is the lasting effects of colonization and the residential school system in Canada. The Canadian Institute for Health Information (CIHI) (2004) confirms Aboriginal people identify the legacy of residential schools as a determinant of health that has significantly contributed to their poorer health status. As seen on the streets of many urban cities across Canada, the historical impacts of colonization have led to much poverty, lack of education, emotional trauma, and other social problems for many Aboriginal peoples (Boyer, 2006; Chrisjohn et al., 2006; Fournier & Crey, 1997; Wesley-Esquimaux & Smolewski, 2004). Boyer confirms: "Colonization, racism, the *Indian Act*, residential schools, laws, policies, and regulations that have subjugated Aboriginal women to a lifetime of violence, poverty, and degradation have created the crisis in Aboriginal women's health today" (p. 19).

Residential schools were begun by churches in the 1840s. They were later institutionalized by the Indian Act of 1876, which sanctioned Canadian government personnel (the Ministry of Indian Affairs) to remove Status Indian (not Aboriginal) children from their homes to be placed in residential schools (Heritage Community Foundation, 2002). Children were prevented from learning basic parenting skills, cultural traditions, and their Native way of life. Many others were subject to physical and mental abuses which strongly affected their self-worth as they grew up and attempted to parent their own children (Chrisjohn et al., 2006; Fournier & Crey, 1997).

The residential school system virtually wiped out seven generations of parenting skills. Sure, the schools were of a patriarchal nature, but this is not the same as basic parenting skills. And when this void is present, the need is to fill it...with drugs, alcohol, obesity, abuse, whatever works to fill this void of not knowing how to effectively parent our children (Mairs, personal communication, LPRC, 2003).

Many researchers confirm the immediate and lasting effects of this period in Canadian Aboriginal peoples' lives (Boyer, 2006; Chrisjohn et al., 2006; Fournier & Crey, 1997; Frohlich et al., 2006; Wardman et al., 2005). The impact of residential schooling has influenced the multitude of social determinants facing Aboriginal peoples. These, in turn, have shown health-related links to higher rates of HIV-infection among this population. Repercussions from the residential school system are still evident today. They impact many Aboriginal families in many ways (Boyer; Browne and Fiske, 2001; CIHI, 2004). The effects of the residential schools can lead to feelings of low self-esteem, resulting in depression, abusive relationships, economic difficulties, substance abuse, and ultimately suicide (Boyer; Chrisjohn et al., 2006; Fournier & Crey, 1997). All of these in turn become contributing factors for the prevalence of high risk behaviours among Aboriginal peoples.

To date, limited qualitative literature exists about the experiences and perceptions of Aboriginal women who are living with HIV/AIDS. Little has been published which looks at the daily experiences of HIV-positive Aboriginal women and the many barriers they face in the context of living with their illness. This literature review has focused on a number of key barriers to healthy living that the women face, and has contextualized them in relation to the higher risks for infection that remain a constant challenge to many Aboriginal women. It has highlighted a number of gaps in the literature where statistical reporting fails to take into account the lived experiences of the women. It has also helped to reveal the need for this study, which builds on previous qualitative works by Ship and Norton (1999, 2001) and McCall (2006) that focused primarily on Aboriginal women living with HIV/AIDS.

### 3. 3<sup>rd</sup> Stanza: Shapeshifting

One woman, who instead, should be revered  
as an Elder by now, is coughing with a cold and  
in between puffs on her inhaler casually says  
she's HIV, as if commenting on the weather.

Sometimes events or ideas and their meanings appear simple: an Elder in our midst, a casual comment about one's HIV-status, a label such as Aboriginal research. Other times, the layered meanings of such occurrences and ideologies in which they are embedded need to be explored further. Why does this woman deserve the kind of respect given any Elder? What meaning lies within her experiences of being HIV-positive? And, how should an Indigenous researcher approach sacred gifts of knowledge? Through "shapeshifting"<sup>8</sup> of conventional forms of methodology into an Aboriginal framework (Cole, 2002; O'Riley, 2004), I explore ways to learn, to present, and to disseminate Aboriginal knowledge in ways respectful of traditional Indigenous knowledge.

\* \* \*

#### 3.1 Research Paradigm

This research is focused explicitly on understanding the experiences and perceptions of Aboriginal women living with HIV/AIDS. Stigmatizing attitudes and language towards Aboriginal women have serious impacts upon the women's lives (Barrios & Egan, 2002; Browne & Fiske, 2001; Hill & Kurtz, 2008; Kurtz et al., 2008). This is most poignantly the case in the lives of Aboriginal women living with a stigmatized medical diagnosis such as HIV/AIDS. Two guiding research questions were asked during conversations with participants in this study: 1) What is it like for you, living with HIV right now? and 2) What would you want other people to learn from your experiences? With the insights and assistance gained from the participants' shared stories, this project adds to the qualitative literature in this research area. Harding (1987) and Lather (1992a) distinguish between the terms *methodology* and *method*.

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<sup>8</sup> Shapeshifting is a term used by Cole (2002) and O'Riley (2004) to describe a shift in the emphasis of research away from Western imperialist standards towards Aboriginal methodologies whereby decision-making processes and positions shape who, how, where, and why Aboriginal research is to be performed. This topic is further explored in its own upcoming section.

Similarly, I refer to methodology as “the theory of knowledge and the interpretive framework[s] that guides a particular research project,” and to method as “techniques for gathering empirical evidence” (Lather, p. 87).

## 3.2 Theoretical Perspectives

using aboriginal knowledges protocols and practices rather than western ones  
is seen by the colonizer as being problematic  
our methodologies and protocols are not deemed to be *scientific*  
or rigorous or valid they're seen as being primitive second class at best  
our methodologies don't fit the white rules the house rules dealer's choice  
and of course, our protocols are simply pre-Columbian  
how our elders say (though not in so many words) has it come to be  
that scientific rigor (mortis) has infected this land of our ancestors  
how have the mis taken assumptions of science come to be privileged  
over other ways is the scientific method itself not fundamentally flawed  
an intellectual virus which has become the agent of transmission for western hubris  
so is perpetrated *ad ministratum* (Cole, 2004, p. 16).

Cole (2004) discusses the problems of using Aboriginal methodologies within academia. On the same topic of Indigenous education, Elder Rose Point suggests that “intelligence is not an excuse for common sense” (personal communication, 2008). Verna Kirkness talks about “standing on the shoulders of those who have come before us” (personal communication, 2008). The theoretical perspective in which I ground my research is Indigenous knowledge, informed by scholars such as Archibald (1997), Battiste & Henderson (2000), Brown (2004), Brown & Strega (2005), Cole (2003), Graveline (2000), O'Riley (2004), Marsden (2005, 2006), and Urion (1999). While I do not present any new theoretical perspectives, I build on the integrity of Indigenous knowledge, and strive for my own Indigenous research to find its own ways of *being* in the academy within the transformation of Indigenous learning. There are multiple ways in which Indigenous knowledge can be (re)presented, such as through family, community, work, and the university. Vine Deloria (1995) comments on the nature of Aboriginal knowledge.

The problem with Indian traditions is that hardly any open minded scientist has heard them, and an even lesser number know how to listen to Indian Elders, catch the nuances of meaning, and be prepared to elicit the proper information from the story (p. 232).

To “catch the nuances of meaning” in this study, I have received constant guidance from a Community Mentor, one whom I consider to be an Elder in her own rite, her own degree of Aboriginal life-experience. Self-identifying as an Aboriginal woman, she has experienced family-member effects of HIV/AIDS, poverty, and homelessness, and has extensive work experience with non-charitable foundations such as Food Banks, Homeless Shelters, and Aboriginal and AIDS Service Organizations [ASOs]. Priscilla has provided ongoing feedback throughout this study in relation to the invitational prompt questions and thematic analysis of the participants’ stories. Smith (1999) states, “the word itself, ‘research,’ is probably one of the dirtiest words mentioned in the indigenous world’s vocabulary” (p. 1). “Research is one of the ways in which the underlying code of imperialism and colonialism is both regulated and realized” (p. 7). My goal, through an Aboriginal perspective, or methodology, is to remove the negative stain of research and its regulated code of Western standards from this study. Instead, I hope to change “the angles of western gaze” (O’Riley, 2004, p. 90) for the benefit of the participants, our community, healthcare providers, and interested/willing scholars. About theoretical frameworks and the paradigm shifts still to be made within academic thought processes, Cole (2002) states,

a framework is not just an architect/ural or /tectonic manifestation of a blueprinting

For us it is the enactment of a respectful relationship

with the rest of creation which shares the earth with us

a framework is never a noun never simply a metaphor

it cannot be captured thus as a part of speech a figuration

it is more than any words which attempt to denote it

a framework is a journey/ing with (Cole, p. 453).

O’Riley (2004) advocates for such a paradigm shift also.

From arrogant and self-referential reflections to more modest and shared research practices [that] might invite and embrace diversity of knowledge communities, and stimulate disruption and

shapeshifting of research on Aboriginal and other “othered” communities towards a more equitable, habitable, and sustainable world for all people all living things with the environment (p. 90).

I intend my research to be just this, a sound example of an Aboriginal research paradigm that goes beyond the rhetorical efforts to push boundaries of the Western Institution(ally) accepted theories. I expect my theoretical framework of Indigeneity to do as O’Riley suggests, to prompt a shift in the angle of “Western gaze,” (a notion that will be further discussed in its own upcoming section).

### **3.2.1 Indigenous Education and Knowledge**

Marsden (2006) affirms Indigenous education to be holistic; it includes the procedures necessary to sustain equilibrium among people and their society, environment, and other beings. Urion (1999) believes traditional knowledge is often presented as a metaphor—effective because an information rich idea allows for various insights for various situations. This practice requires the learner to be an active participant in the reading of the metaphor in order to benefit from the traditional knowledge.

“Traditional-based Indigenous world views...are those dynamic systems of beliefs and values that have arisen from long-term, intimate relationships between and specific lands, waters, and beings” (Marsden, 2006, p. 137). This worldview reflects the ethics of holism, involving interdependencies of the mind, body, spirit, and environment, fostering a considerate and honourable connection of the individual with others and the world at large. Indigenous health educators are Elders, senior relatives, and less often, those who possess specialized knowledge. Anyone granting traditional knowledge to aid the mind or body, or reinforcing cultural behaviour (to be a good person) is at that time a health educator. The specialist, a healer, is one who has dedicated much time gathering traditional knowledge prior to sharing or practicing this knowledge (Marsden). About Indigenous education, Verna Kirkness recently implored our current “third wave” of Aboriginal scholars, “The Elders have opened the doors. You can do better; you can do more” (personal communication, 2008).

I do not advocate that one system of knowledge is better than another, nor should one be privileged over another. Instead, I suggest that researchers find connections and solutions to community problems through collaboration and respect for the two different worldviews, Western and Indigenous. Having said

that, researchers should also not have to justify the use of Aboriginal methodologies; they already exist and for good reason, as many Indigenous scholars cited throughout this study demonstrate.

### **3.2.2 Shapeshifting Research**

O'Riley (2004) asserts shapeshifting research on Indigenous peoples requires immense concessions on the part of Western epistemological methodology. Presently, there is a grave imbalance weighted in favour of Western academic knowledge systems, which have an imperialist legacy in the belief that theirs is the only right way to perform valid research, and that knowledge for its own sake is appropriate. She likens current research methods to colonial acts; research is performed on, while rarely benefiting, Aboriginal peoples. In order for Canada's Indigenous people to become self-determining where research is concerned, they must be in decision-making positions shaping who, how, where, and why Aboriginal research is to be performed.

While Western discourses are thought to be the apex of knowledge, these have caused worldwide destruction: poverty, pollution, climate change, and atmospheric damage (O'Riley, 2004). Indigenous knowledge is now considered necessary to save the world. She sees the collection of traditional ecological knowledge (TEK) to be a neo-colonial act; Indigenous people are required to donate this newly worthy information. But Indigenous people must maintain control, for one part of TEK (i.e. ecological) cannot be removed from its holistic relationship to "humans, animals, plants, natural forces, spirits and land forms of a particular locality" (Battiste & Henderson cited in O'Riley, 2004, p. 86). Deconstructing Indigenous knowledge to fit Western paradigms violates its interconnectedness and weakens its viability (O'Riley).

### **3.2.3 Health Narrative Topography**

The methodology I have chosen for analyzing the women's life-stories about living with HIV has been adapted from Arthur Frank's book, *The Wounded Storyteller: Body, Illness, and Ethics* (1995). Frank's illness narrative topography is constructed of three main genres: *Restitution*, *Chaos*, and *Quest*, the

thematic frameworks within which he views the stories of most people facing an illness<sup>9</sup>. Seriously ill people need to think differently; before they became ill they had a sense of direction, where their life may be going and how they may get there. With the onset of illness, and the loss of their “destination and map” (Frank, 1995, p. 1), they may learn through telling the story of their illness. This is done through hearing themselves speak it or through others’ responses to it. The act of sharing helps them to create a new map. Frank indicates there are two sides to these illness stories: the personal and the social. The personal element of telling illness stories aids the changed body to become recognizable to the teller. The stories become social when they are told to someone. The structure of illness is formulated by stories told by friends and family, advertisements for aliment remedies, and which symptoms are and are not related to the doctor. People have been socialized as to what information is and is not acceptable to reveal.

Illness can be viewed through an historical as well as a present-day lens (Frank, 1995). In pre-modern times, Frank contends ill people did not know what afflicted them, or that illnesses could be deadly. The most they could do was describe their symptoms and be cared for by family or those skilled in ethnomedicine. Modern times brought the introduction of skilled professionals using medical jargon in an authoritarian voice, with the patient surrendering the narrative voice. In post-modern times, the ill person is taking back his or her voice. They are using illness stories to construct a life after illness, to create new pathways while existing within their healed, healing, or wounded bodies.

Frank (1995) also describes this historical shift in illness and medicine as a movement towards “The Remission Society” (p. 8). The modernist methods of an institutionalized medical system allow for ill people to escape death, but define people as being either sick or well. Subsequently, a person surviving a serious disease or living with a chronic illness, does not go back to being well; rather they see themselves as in remission. Their condition remains socially hidden, until it must be revealed. For example, a man in an airport is required to disclose he has a pacemaker. His condition becomes an

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<sup>9</sup> As I stated in 1<sup>st</sup> Stanza of this thesis, I do not believe the discourse of “illness” is necessarily the most appropriate term for the women in this study. Rarely, if at all, do they refer to themselves as “ill”, or to their stories as narratives about “illness.” Instead, the women’s speak of physical, mental, emotional, and spiritual health and well-being. In the 5<sup>th</sup> Stanza, I have chosen to use the terms of “health” and “well-being” instead of “illness”. However, for the purposes of giving an overview of Frank’s theoretical perspective, and a synopsis of each specific genre, I continue to use the “illness” discourse for now.

immediate concern, in order to pass through the metal detector; his remission status temporarily fades. Modernist medicine is likened by Frank to colonialism. During treatment the doctor claims control over the patient's body. Those with long term or chronic illness can become frustrated or angry under medical care, feeling they have lost their status as *people*. Instead, they become *patients*. In the early stages of modernity, a new social type of sick person emerged, as not everyone died from their disease. However, in order for medical success, the individual's suffering had to be reduced to a general medical view. This form of colonization was deemed acceptable if it provided a cure. Post-modern and post-colonial ill individuals want their own suffering recognized, along with their place within the medical narrative.

Frank (1995) uses a political colonialism model to express the concerns of those in remission that have experienced medical colonialism. He relates a story of a man's reconstructive surgery. His case was written in a medical journal, but his name was never mentioned, though his picture was included. As an individual he was ignored; he was no more than an ill body. This article belongs to the doctor, not to him. "This is exactly the colonization that Spivak speaks of: the master text of the medical journal article needs the suffering person, but the individuality of the suffering cannot be acknowledged" (p. 12). Post colonialism results when illness stories do not include medicine or doctors, rather they are told to others who are in remission, and are "taking responsibility of what their illness means in their life" (p. 13).

According to Frank (1995), within this medicalized colonialism, modernist medicine sees illness responsibilities given over from the patient to the physician, who is dedicated to professional codes over an individual's concerns. However, personal responsibility is paramount in the post-modern era. Storytelling, like that shared by the women in this study, facilitates this; it assists the understanding of the transition of the ill person's identity. It also guides the listener's own self-formation, which in turn, validates the value of the story and its teller.

### **3.3 Methods**

Researchers have reported many cultural factors associated with Aboriginal women being at higher risk for infection and lower physical and mental health (Browne and Fiske, 2001; CAANb, 2004; Dion Stout, Kipling & Stout, 2001; Health Canada, 2006; Legare, Ross, & Bognar, 2003; RCAP, 1996; Smith, 2002; Waldram et al., 1995; Wardman et al., 2005; Watson & Bell, 2005; Vernon, 2001). However, more

in-depth questions arise, such as: What are some of the experiences of Aboriginal women relating to health concerns, education and prevention, cultural influences and traditional values? How are the women living with their experiences of fear, isolation, and oppression? And, what factors empower the women to live well with their illness?

The primary method of gathering material for this study is narrative inquiry through conversations between researcher and participants.

Conversation is a basic mode of human interaction. Human beings talk with each other—they interact, pose questions, and answer questions. Through conversations, we get to know other people, get to learn about their experiences, feelings, and hopes and the world they live in (Kvale, 1996, p. 5).

Using a broadly participatory approach we (the participants and I) have developed life-stories and have identified possible health-related improvement measures. The stories provide an avenue for participants to voice their triumphs and challenges about being an Aboriginal woman living with HIV/AIDS, and, for the greater community to hear first hand, important information such as this. They may also be distilled into future research reports that can be used to frame subsequent interactions between community leaders, service providers, and policy makers in community forums. The analysis may also frame future quantitative work and be a legacy that can be used by the community for other related purpose.

### **3.3.1 Narrative Inquiry**

I use narrative inquiry (NI) as an in-depth, descriptive, interpretive strategy for representation of the women's lived experiences and perceptions. "Qualitative research is a form of inquiry in which researchers make an interpretation of what they see, hear, and understand" (Creswell, 2007, p. 39). NI is a way to present and to extract understanding about the ways in which people make sense of their world. The method has more to do with how participants (and researchers) interpret things (Reissman, 1993). Narrative is a way by which we speak or write about and make sense of our world and interpret our experiences and perceptions about the life stories we live. Personal narrative gives order and a sense of

cohesiveness to one's life (Mathieson & Barrie, 1998). Because NI "gives prominence to human agency and imagination" (Reissman, 1993, P. 5), it is well suited to Aboriginal methodological studies about participant subjectivities and identities. Reissman also notes that it is because of this participant subjectivity, rooted in time, place, and experience, that we value narratives. Indigeneity is about time, space, place, and the fluid process of life. Brown suggests, "Look out the window; Indigeneity is all around us" (personal communication, 2007).

Narratives provide not only subjectivity about a phenomenon being studied, but also a methodological approach that recognizes there is not one singular, empirically found truth (Clandinin & Connelly, 2004; Reissman, 1993; Richardson, 1997). This fluid, multiple notion of knowledge is consistent with Indigenous knowledge.

I believe the NI method best complements the Aboriginal methodological framework in which this study about personal experience is situated. Scholars such as Dion Stout, Kipling, & Dion (2001), Battiste & Henderson (2000), Evans et al. (n.d.), Kirkness and Barnhardt (1991), Kurtz et al. (2008), and Ship and Norton (1999, 2001) inform my decision by the ways in which their chosen theoretical frameworks illuminate Indigenous knowledge as a priority to researching concerns and issues relevant to Aboriginal communities. In particular, the NI framework of Clandinin and Connelly (2000) guides my primary research method.

Clandinin and Connelly (2000) use the concept of *experience* developed by Dewey (1916, 1922, 1929, 1934, 1938, cited in Clandinin & Connelly, 2000). They refer to experience as "both personal and social. Both the personal and social are always present" (p. 2). This experiential relationship is considered when Clandinin and Connelly, who are educational researchers, examine an individual student's learning. They recognize learning takes place within a social context consisting of other students, a teacher, and that it takes place within a school, the larger community. Dewey (cited in Clandinin & Connelly, 2000) indicates continuity is a principle element of experience. Past experiences cultivate present experiences, which guide future experiences. Clandinin and Connelly say this is a key concept in their education research, whether it is concerning "a child's learning, a school, or a particular policy, there is always a history, it is always changing, and it is always going somewhere" (p. 2). Experience fluctuates between the personal and the social.

NI is both the occurrence being studied and the technique of study. According to Clandinin and Connelly (2000), narrative inquiry is both the “embodied individual and social stories” (p. 4), and the structure used to research, collect information, and compile storied depictions of individuals’ lives. The authors find their type of inquiry has found a broader use among researchers in various disciplines of the social sciences over the past 20 years of their career. For example, Geertz (in Clandinin & Connelly) reflects on his life as an anthropologist and his work over a 40 year career. He sees change, large and small, affecting every aspect of his work. Change is found in the town he studied, and in the world encompassing it. Change is also within the anthropologist and his disciplines, morals, values, and methods. He believes careful observation and gathering information for later study reveals the connectedness of all things, “to produce a sense of how things go, have been going and are likely to go” (cited in Clandinin & Connelly, p. 6). Along this same vein, Bateson, an anthropologist whose field of study is learning, sees adaptation and improvisation to life’s uncertainties as a means of allowing “the past to be connected and have continuity with the future” (cited in Clandinin & Connelly, p. 7).

Clandinin and Connelly (2000) are pragmatic about NI’s implications for everyday living and learning. This notion is especially relevant to my research with Aboriginal women; I believe they are the experts of their experiences, and that we, as a greater community, have much to learn from them. Clandinin and Connelly speak of Cole, a teaching practitioner of psychiatry, who was encouraged by his residency supervisor to use narrative inquiry to listen to his patients. While the patient becomes teacher, the doctor becomes student, learning from the stories of a “lived life rather than the confirmation such a chronicle provides for some theory” (p. 12). A patient should be carefully listened to, for diagnosis purposes because “what we say tells us what is happening to us—what we are thinking, and what may be wrong with us...their story, yours and mine—it is what we all carry with us on this trip we take, and we owe it to each other to respect our stories and learn for them” (Williams cited in Clandinin & Connelly, p. 13-14). My motivation and purpose for this study remains the belief that Aboriginal women living with HIV have a particular story to tell, one that should be heard and understood by many. Once we can accomplish this, bringing forward such richly lived stories to become a part of mainstream knowledge and awareness, then, and only then, can the women’s experienced marginalization and stigmatization begin to unfold and to dissipate.

Clandinin and Connelly (2000) suggest narrative elements of any story include emplotment, character, scene, place, time, and point of view. In an endeavour to relate narrative ideas, they illustrate narrative thinking by employing a metaphor. A lathe, which is a woodworking tool, when found in various places, such as schools located in a wealthy suburb, an inner city neighbourhood, (or Aboriginal communities), will have vastly differing uses and will make various items in the hands of different people. The lathe has a social context which varies in time and place and this will produce an array of possible outcomes. These are fundamental characteristics of NI. Narrative thinking requires context. Lived experiences, thus becoming narrated stories, are reflected in grand narratives that, “think in a language of objectives, think in terms of observable behavior, think numerically, think causally, think generally with a god’s-eye view, think about the here and now” (p. 25). I remain hopeful that the women’s stories in this study can be read within the context of a metaphor like the lathing tool. Each woman is unique, and their lived experiences, although touched by the same tool (an HIV-diagnosis), have differing individual contexts, social contexts, and vary in their stories of time and place.

### **3.3.2 Merging Indigenous Knowledge and Shapeshifting Research with Narrative Inquiry**

Brown & Strega (2005) consider the process of storytelling as important as the story itself. “We resist colonial models of writing by talking about ourselves first and then relating pieces of our stories and ideas to the research topic” (p. 98). Tobias (2001) suggests “[t]he social scientific model of inquiry has been parachuted in on top of the traditional indigenous way of passing knowledge from one person to another” (p. 42).

According to Brown and Strega (2005), Indigenous epistemology “includes a way of knowing that is fluid and experiential, derived from teachings transmitted from generation to generation by storytelling; each story is alive with the nuances and wisdom of the storyteller” (p. 27). The notion of story in the Aboriginal tradition of sharing knowledge is not to create them, but to convey them (Marsden, 2005). The women in this study have an important story to convey about their experiences living with HIV/AIDS. Indigenous scholars such as Blue Cloud (1996), Cole (2002, 2003, 2004), Graveline (2000) and Ortiz (1996) use storytelling as a form of academic writing. I use storytelling in the last Stanza of this thesis.

And while I acknowledge that different storytellers and stories may have different meanings when shared with different people, and for different reasons, I believe my role as researcher in this storytelling process has not impeded the ultimate and still multiple messages of the women.

Silence is not always absence some/times it is the un/heard the un/hearable  
what cannot be seen or other/wise experienced (Cole, 2003, p. 59).

Much of the silence that impedes Aboriginal women from speaking out is not of their choice (Kurtz et al., 2008), nor is it about an absence of perceptions, experiences, and stories to share, as this study demonstrates.

Some Indigenous people assert that all knowledge derives from the source of “global flux” and that “indigenous knowledge is the way of living within contexts of flux, paradox, and tension, respecting the pull of dualism, and reconciling opposing forces” (Battiste & Henderson, 2000, p. 42). The RCAP (1996b) views Indigenous knowledge “as a cumulative body of knowledge and beliefs, handed down through generations of cultural transmission, about the relationship of living beings (including humans) with one another and with their environment” (p. 454). Within Indigenous knowledge, no separation of the arts, sciences, religion, or philosophies exist (Brown & Strega, 2000). For these reasons, Aboriginal methodology and a method of storytelling are best suited to this study.

### **3.4 Participants**

The intent of this study is to learn from a specific marginalized group of women about their similarities (and possible differences) about living with HIV. Therefore, purposeful sampling criteria for this study involved homogeneity. Participants are members of Vancouver’s urban Aboriginal community, above the age of 19, and one year or greater post-HIV diagnosis. Age (being under the legal age of majority in BC) and a new diagnosis (needing a period of emotional and social adjustment) were reasons for exclusion; however, neither of these situations presented themselves. Creswell (1998) advises that four case studies are sufficient for valid qualitative research. He states, “What motivates the researcher to consider a large number of cases is the idea of *generalizability* [italics in original]” (p. 63). Stake (2004) describes qualitative research involving case studies such as these as an

*instrumental case study* if a particular case is examined to provide insight into an issue or to redraw a generalization. The case is of secondary interest, it plays a supporting role, and it facilitates our understanding of something else... A researcher may jointly study a number of instrumental cases in order to investigate a phenomenon, population, or general condition (p. 437).

Due to the vulnerable population within which this study is situated and the difficulties in finding willing participants, an average of three to five participants were sought; four women participated. Cooper (2004), in fact, sets an example of the validity of an in-depth study created with a single participant, her sister, Alex, who lives with HIV/AIDS.

The women chose to have their conversations with me in pairs. Each of the two conversations were recorded and then transcribed. Because the women basically took turns during our conversation, I was later able to break their contributions into individual stories, which are shared in the 4<sup>th</sup> Stanza. For their voluntary participation in the study, I honoured each of the women with a small gift, a journal, and two pens. They also received in their thank-you cards, an honorarium of \$20.

As per the UBC Behavioural Research Ethics Board protocols, recruitment for the study was done at arms-length, through AIDS Service Organizations [ASOs] and posters. Out of nine ASOs I contacted, both personally and via email, four did not respond, one allowed me to hang a poster (which generated no response), and three responded but had no possible participants to contact. The Positive Women's Network (PWN) asked for a written proposal from me to present to their board of directors, which they passed, and then their support worker contacted me with possible participant names to contact. Of the seven names given to me who had originally expressed to the support worker an interest in this study, when contacted, six said "no thank-you," and one I met in person at a PWN hot luncheon day along with a friend of hers.

Settings for this study were varied and required extreme flexibility. For the first conversation, I picked up the two women from a Skytrain station in Vancouver and served them lunch in my home. Afterwards, we sat down in the living room to have our recorded conversation and then I drove them back downtown to where they wished to be dropped off. For the second conversation with a participant contacted through snowball sampling, I was given permission to enter a Vancouver women's shelter facility to visit in her dorm room. When I arrived, it was established that her roommate, too, met the

criteria for the study; she spontaneously volunteered to join in. Half way through our conversation, the first participant announced she had to leave to give a eulogy at a friend's funeral. The second woman and I completed our discussion that day. After the weekend, I reconnected with the first participant; however, shelter rules dictated that I not be allowed back into the secured building a second time. So I picked her up in my car and we parked on a neighbourhood side street. We walked to a nearby Starbucks for two coffees to go, and once back in the car, we completed our recorded conversation.

During the time I sought agency and participant support, I had preliminary consultation with a group of peer researchers of one Vancouver Downtown Eastside group, the Maka project. The Maka project is a Canadian Institute for Health Research (CIHR) funded project that addresses health-related challenges and the impact of current harm reduction and HIV-prevention strategies among women in survival sex work. Participants suggested two themes that helped guide my theme of research: 1) empowerment of the women: the lack of culturally sensitive health care and culturally sensitive information available to Aboriginal women; and, 2) the potential benefits of the women conceptualizing their living with HIV, health, and well-being in the framework of the traditional medicine wheel.<sup>10</sup>

### **3.5 Collection Methods and Procedures**

Smith (1999) suggests a useful set of questions for undertaking Indigenous research, which I bore in mind when approaching the women and this study regarding my two main research questions: 1) What is it like for you, living with HIV right now? and, 2) What would you want other people to learn from your experiences? (The entire Conversation Guide appears in Appendix D.) Each of the two conversations with the two pairs of women had a different “feel” to them, based on the settings in which they took place. For the first one, in my home, Ginew, Storm, and I had a chance to visit over lunch and get to know one another before beginning our recorded session. Therefore, this conversation begins more directly, with “What is it like for you, living with HIV right now?” The second conversation, with Roxanne and Blue

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<sup>10</sup> Aboriginal community perceptions of well-being are realized in several different ways, one of which is reported in the Medicine Wheel. This is a circle indicating a relationship with and between individuals and the four elements as earth, wind, water, fire; the four seasons; the four races; and the four elements of the individual, the physical, emotional, social, and intellectual (Adelson, 2000; Brendtro, Brokenle, & Van Brockern, 2005; Bopp, Bopp, Brown & Lane, 1984).

Stone, began after I first met them and settled into their shelter dorm room. Hence, the invitational question here was more inviting: “Can you tell me a little about yourself?” Below are Smith’s nine suggested questions which I kept in mind throughout the process.

Who defined the research problem?

For whom is this study worthy and relevant? Who says so?

What knowledge will the community gain from this study?

What knowledge will the researcher gain from this study?

What are some likely positive outcomes to this study?

What are some possible negative outcomes?

How can the negative outcomes be eliminated?

To whom is the researcher accountable?

What processes are in place to support the research, the researched and the researcher? (p. 173)

Answers to these questions are either implicitly or explicitly revealed throughout the thesis, which will be shared with the participants, and numerous community Native Health and ASOs throughout Vancouver. I do this with Cole’s words in mind: “Sustainability [and reciprocity] means leaving the researched community in a better place than you found it” (personal communication, 2007).

Conversations with the women participants were open-ended and semi-structured. While I assisted the conversation with occasional invitational probes (previously piloted with my Community Mentor), I did not enter our dialogues with any preconceived notions about specific content the women might share. I base this loosely structured material collection method on Cole’s (2003) work with Indigenous “coparticipants” (p. 63).

the ‘data’ from my coparticipants is derived from conversations

not from question/answer format I avoided asking questions as much as I could

knowing questions shape the answers they seem to solicit

interrogation in my nation is seen as invasive

I want to be uncoersive in my work as unmeddlesome in my research as I can be

Though perhaps coercion is better accepted than avoided or disguised (Cole, p. 63).

Cole goes on to note the certainty of the power differential between ourselves and those we speak with “on a shared journey of learning together” (p. 63). However, by following an Indigenous framework of respect and reverence, I remain convinced the level of this power imbalance could be diminished to the extent to which the women felt comfortable with me and with sharing an authentic story about themselves. One participant poignantly told me I was the first person to ever ask about her story, and thus, was the first person with whom she had shared it.

To protect anonymity, each of the women was offered their own choice of a pseudonym. Conversations with the women to elicit their experiences were recorded with their permission and then turned into “clean” transcriptions. Cleaned transcripts are those edited for the natural flow of narration without such interfering utterances as “ums” and “ahs.” Raw transcripts, i.e. directly transcribed and unedited transcripts, can be viewed by participants as insulting or demeaning because of the way most people’s oral language varies from standard written language. As this study does not rely on micro-linguistic analysis, this “cleaning” has no substantive effect on the study, while at the same time demonstrates a respectful stance toward the participants (Evans, personal communication, 2007).

Participant verification was accomplished with three of the four women in order to ensure the accuracy of their contributions to the final transcription of their story and to its trustworthiness. I was not able to find the fourth woman in Vancouver, nor did PWN or any of the other three participants know of her whereabouts after she left the shelter in which we had met.

After reading their transcripts, the women’s comments included the following:

*Ginew: It was better than I thought. I thought it would be more intense reading what I had told you.*

*Storm: Great, Everything’s fine. I can’t believe how long mine is compared to Ginew’s...How much I told you! (Laughs). This is great. It’s like a check list; I’ve done everything I told you I was going to, got my housing subsidy, and now all I have to do still is go to rehab.*

*Blue Stone: Fine. Everything looks good. Can you just change “my \_\_\_\_\_” to “a friend” in case they ever read this and get mad or something (Laughs)?*

Each of the women responded with interest about having a draft of their stories. I offered them a fresh copy of their own stories, or if they wanted to wait, a copy of the entire thesis as soon as it was finished. All participants decided to wait for the final publication. Participants are not identifiable in the

stories they shared. Transcripts of the conversations are not linked with names or identifiable personal location markers. Because the agency through which I met two of the four women is a reputable one and is highly praised by the women who frequent it, I have identified it by name.

Ginew, Storm, Roxanne, and Blue Stone's transcribed stories make up the body of the 4<sup>th</sup> Stanza of this thesis, *Conversing*, which refers to the conversations the participants and I had with one another. Cole challenges researchers to find that place of "witness" between researcher and participants (personal communication, 2007). Frank (1995) also challenges researchers not to think "about" narrative stories, but "with" them. He suggests considering them not as "data", but as gathered "material" (p. 23). In my material collection and dissemination, I seek to avoid notions of doing a study *on* a particular Indigenous community. Instead, as represented through this thesis, I strive for a sense of inclusion. This research is intended to be about the process and the accomplishment of findings *with* the women participants.

### 3.6 Material Analysis

According to Stake (1995), "There is no particular moment when data analysis begins. It begins before there is a commitment to do the study" (p. 49). He refers to analysis as "a matter of giving meaning to first impressions as well as to final compilations" (p. 71). I acknowledge my cumulative project about the women is a (re)presentation of their stories, just as their stories shared with me are a (re)presentation of their past and present perceptions and experiences living with HIV/AIDS. Smith (1999) has this to say about Indigenous representation:

Representation about indigenous people by indigenous people is about countering the dominant society's image of indigenous peoples, their lifestyles and belief systems. It is also about proposing solutions to the real life dilemmas that indigenous communities confront and trying to capture the complexities of being indigenous (p. 151).

At best, all qualitative analysis is interpretive. Stake (1995) argues the following.

A considerable portion of all data is impressionistic, picked up informally as the researcher first becomes acquainted with the case. Many of these earlier impressions will be refined or replaced, but the pool of data includes the earliest of impressions (p. 49).

I used a very hands-on approach to the interpretation and dissemination of findings. Transcripts were printed out and read through several times; they were noted and marked throughout for genre themes. After this initial stage, I gave copies to my Community Mentor, Priscilla, and to a second friend and Aboriginal community member, Bernadette, (a UBC graduate in Anthropology) for them to read. I also ensured that each had a copy of Frank's (1995) book to read. We later met for a day in my home to discuss the three main genres and themes (or differences) that resonate from the stories. We also discussed our own varying ways of reading *with* the participants to better understand their stories. Bernadette and I had read silently our copies several times and had made notes throughout them. Priscilla, on the other hand, had sat down with her sister and read each of the transcripts aloud for contextual affirmation and discussion. She wrote down her sister's comments and later gave them to me to lend towards the validity, authenticity, and trustworthiness of the study.

I felt Donna was at the right level with assessing the approach of how her questions were answered and acted accordingly. When Donna spoke of HIV+, it appeared that the women's experiences were validated by her respectful approach and (non-emotional <*not sure of the right words*> reaction). Her concentration on the women's feelings was very sensitive to them. I felt the question and answer approach was the most appropriate way and that Donna's approach was respectful to the women's views (without judgment). She was respectful and comforting and comes across as soft, gentle and compassionate (personal communication, 2008).

Smith (1999) notes the strength of Indigenous researchers to “rise above present day situations which are generally depressing, dream a new dream and set a new vision” (p. 152). This encouragement reflects the goals of my research, to (re)present with the women, their stories of empowerment from which Aboriginal communities, academe, and our greater society must learn. “Creating is about channelling collective creativity in order to produce solutions to indigenous problems” (p. 158).

### **3.7 An Empowerment Perspective**

The underlying focus of this study involves empowerment—empowerment experienced by the women as they share their stories, and especially empowerment facilitated when their voices and experiences are heard by others. According to Giddens (1993), “[p]ower refers to the transformative

capacity of human action” (p. 117). The paradox of power is that you have to own it to be able to give it away. I accept a certain amount of power in my position as researcher and in my goals to give the women the chance for their stories to be heard by the broader Aboriginal and healthcare communities. But I cannot accept responsibility for the power, strength, and resiliency the women already possess and express in their daily lives as they struggle with their health and with society’s stigmatizing reactions towards them. Nor in the empowerment they will share with others as their voices are heard. Empowerment, in this context, involves taking control of one’s life-situation and liberating one’s self by being willing to share what she has learned from her experiences living with HIV, and about living well with them. When I began researching the possibility of a place for myself in the academic field of HIV and what I might be able to contribute, I contacted Kevin Barlow, Executive Director of the Canadian Aboriginal AIDS Network. He expressed his concerns to me: “We know what is wrong and why. What we need to know is what is working right” (personal communication, 2006). This was, and still is, the springboard statement from which this research—an empowerment perspective—has emerged. To me, empowerment is about the powerless gaining the experience and the confidence needed to influence the decisions that affect their own daily lives. It is also about how they can look beyond their own struggles to share with others in the hopes of making a difference in the larger scope of matters. “In a place where there is no innocent discourse of liberation, my hope has been to use both our internal contradictions and our differences across one another to refigure community...” (Lather 1992, p. 132).

### **3.8 Verification and Validation of Study**

When we have overcome the myths of value neutrality and objectivity; when we insist on historical contextualization and cultural acknowledgement, and when we have complete access to technical knowledge and ownership of our research; we will improve the quality and value of research concerning Aboriginal people. Only then will we fully realize the rights of Aboriginal people and construct our own reality (Gilchrist, 1997, p. 80).

Brown (2004) notes the position of an Indigenous researcher doing work within an Aboriginal community is “a relatively new and rare phenomenon that often raises issues of objectivity, validity, and reliability because of the insider closeness of the researcher to the community” (p. 47). However, this

should not negate the integrity of any study based on sound validity standards. In research, the measurement of quality occurs within the context of validity or trustworthiness (McCall, 2006). While it is clear that qualitative research must attain standard benchmarks of validity, it is less clear what this criterion is (Whittemore, Chase, & Mandle, 2001). The debate continues about what constitutes sound validity. Qualitative research uses an interpretive perspective while quantitative uses a positivistic measurement. Returning to the primary method reflected in this study, NI, and its validity, Kvale (1996) also has this to say about conversations.

The use of the interview as a research method is not mysterious: An interview is a conversation that has structure and a purpose. It goes beyond the spontaneous exchange of views as in everyday conversation, and becomes a careful questioning and listening approach to the purpose of obtaining thoroughly tested knowledge (p. 6).

In and of themselves, I believe the women's stories are, in fact, personally "tested knowledge."

The challenge remains for the researcher to balance the level of creativity necessary for an artful and sensitive approach to meaning with the quality of the science (McCall, 2006; Sandelowski, 1993). Ultimately the evaluation of a research project is a matter of judgment on the part of the researcher (Sandelowski). The researcher must ultimately make a decision about the criteria to be used for the verification and validation of the qualitative study. I have chosen criteria of authenticity and trustworthiness as central to the validity of this research.

The first measure, authenticity, includes the integrity of methodological design and methods and the setting of parameters in which the study takes shape. Authenticity is derived from the women's stories and must be trusted as a reliable (re)presentation of their lived experiences as they sought to share them. This research follows an Indigenous perspective such as that offered by Haig-Brown & Archibald (1996).

In our journeys as educators we seek respectful ways of bringing First Nations contexts and ethnographic research together: perhaps to create an appropriate meeting place. We seek ways for our research motives and methods to honor, or at least be compatible with, First Nation ways (p.1). Authenticity includes, along with the authentic ownership of the participants' information, the respectful ways in which this study is accomplished in the context of its chosen methodology. It also must include care for the researcher's authentic interpretations of meaning from the stories. For this very reason, I

included the responsibility of participant checking / transcript verification as a way of hearing from the women that I have authentically (re)presented their stories in the transcripts. Authenticity has also been validated by Priscilla, my Community Mentor, and her sister. Such efforts to validate the authenticity of this study are concerned with respect. Brown (2004) suggests the “framework of respect, relevance, reciprocity, relationship, reverence, and responsibility is a value-based framework that can provide an academic foundation to inform research” (p. 47).

Truthfulness is the second measurement of quality for this study. However, a discussion of its multifaceted nature is necessary. Riessman (1993) suggests,

meaning is ambiguous because it arises out of a process of interaction between people: self, teller, listener and recorder, analyst, and reader. Although the goal is to tell the whole truth, our narratives about others’ narratives are our worldly creations (p. 15).

Haraway (1988) discusses situational reality as the terms “situated knowledge” and the “god trick” of reality, “seeing everything from nowhere” (p. 581). She argues that one of the reasons the objectivity debate matters, metaphorically and otherwise, is that omnipotence is not our goal as researchers. As a qualitative researcher, I am not seeking to know *all* phenomenon and the meanings behind them.

Instead, this study seeks to (re)present merely a snapshot vantage of the women’s shared stories at the time of our discussions about that which they feel most reflects their lived experiences with HIV/AIDS.

However, I do contend we need reliable accounts of our studies that are concerned about such criteria as authenticity and truthfulness. I believe stories are situated realities for the participants (re)presenting them in their storytelling, presented for the researcher to listen, to learn, and to interpret them as closely to the participants’ original meaning as possible. As Richardson (1997) suggests, truths can be multiple and multidimensional—like a view through a crystal. Metaphorically, the truth for any one individual depends on the angle the person looks into the prism and the angle of the light reflecting through the prism.

Unlike the standard paradigm of Western science, Aboriginal epistemologies—ways of knowledge and of knowing oneself—are situated, partial, and interpretive truths. Brown & Strega (2005) suggest multiple paradigms (a balance between Western and traditional frameworks) are an “evolutionary

necessity and part of a commitment to social justice” (p. 10). I believe the debate about narratives and their validity does not negate the integrity of a research project, but rather, enhances it.

### 3.9 Ethical Considerations

This study is situated within the BC ACADRE’s “4 R’s” of Aboriginal Research, used by the Institute for Aboriginal Health at UBC. The “4 R’s” is a framework outlined by Kirkness and Barnhardt (1991) and includes: *Respect, Relevance, Reciprocity, and Responsibility*.

*Respect* is afforded to the community in two ways: 1) by following an Aboriginal methodology for this study, and, 2) by acknowledging researching health issues of fundamental importance for Aboriginal women. Currently, many Aboriginal women avoid accessing mainstream healthcare because of past experiences of racism and oppression, and also because of the colonial legacies of residential schooling, thus placing their health and well-being and that of their families at risk (Kurtz et al., 2008; CIHI, 2004; RCAP, 1996). *Respect* is also encompassed in culturally sensitive ways that contribute to each of the “4 R’s”.

Addressing *Relevance*, the research will add to the critically low amount of literature about HIV/AIDS among BC’s Aboriginal women. Motivation for this study is twofold. First, the research seeks to empower Aboriginal women by addressing (or inquiring about) such issues as the factors that lend to women’s increased capacity to lead their own way. The aim of empowerment is to reduce vulnerability. Second, the project aspires to bring awareness to others in order to illuminate the situation and to disrupt the harmful effects of stigmatizing discourse directed towards the women. *Reciprocity* within Aboriginal research should be about giving back more than was taken (or learned) from the community. Reciprocity occurs when Indigenous researchers turn inward towards the university institution and teach about it (us) and about Indigenous methodologies (Kirkness, personal communication, 2008). I will be giving participants and interested community institutions and agencies a final copy of this thesis. Reciprocity will also continuously take place through remaining in contact with local, provincial, and national leaders in the field of HIV/AIDS, and by continuing to facilitate participant-focused communication in culturally sensitive ways about HIV/AIDS awareness and prevention within Aboriginal communities.

Finally, I believe as researcher, I have a *Responsibility*. First, it is to the participants of this study and to our/their community to conduct this study through culturally appropriate Indigenous ways of knowing. A second responsibility involves furthering the women's empowerment about their health and well-being. Finally, responsibility is about furthering our academic knowledge about Aboriginal education. The ultimate aim and responsibility of this research is to present, through Aboriginal methodology, collaborative findings as published reports about the women's experiences and perceptions of living with HIV/AIDS. Hence, the marginalized voices of Aboriginal women may be heard, valued, respected, and acted upon.

Addressing ethics as an overarching consideration, there was no reason to anticipate any particular risk to participants as there is no reason to expect a level of risk exceeding that faced by the women in their everyday lives. It was possible that the sharing of stories may have an emotional impact on participants. However, it is important to distinguish between the harm done by people's negative experiences as they live with HIV/AIDS and harm done by talking about those experiences. In other words, the harm is not done in speaking; it is in the events spoken about (Evans, personal communication, 2007). Nonetheless, the stories could have evoked strong emotion and a researcher should be prepared. Before beginning my community involvement in the field of HIV/AIDS, I worked as both a Crisis Line Counsellor and as a Community Lay Counsellor. For our researcher-participant conversations, I was cognizant of community resources such as Friendship Centres for support and Vancouver Coastal Health's Aboriginal Wellness Centre for counselling services available should strong emotions have arisen for my participants.

## 4. 4<sup>th</sup> Stanza: Conversing

Another woman beside you found out a week ago  
she has AIDS, her T-cell count is down to 200,  
but they knew two years ago, she says, and didn't tell her.  
*There's going to be a fucking lawsuit over this—  
I won't see it, but at least my kids will.*

This poem stanza is about listening, listening to the words being said, and to the underlying messages beneath this woman's introduction about herself. It didn't matter that I instantly knew the system had failed her. That I was aware, like she, that even anonymous HIV-tests have attached to them some sort of tracking system that enables healthcare providers to notify clients of their positive-status outcome. Nor, that this woman was a resident of the Downtown Eastside (where she was first tested), and could have been sought out with relative ease. Instead, I respectfully engaged in a conversation with her that did not engage my knowledge, perceptions, or judgments of her life-situation. In the same way, I listened to the participants about their stories living with HIV, and now convey our four conversations in this 4<sup>th</sup> Stanza.

\* \* \*

## 4.1 Ginew's Story

Ginew: Study Participant; Storm: Study Participant

Both Storm and Ginew were present during our conversation together; as discussed above, I have severed the stories here.

*What it is like living with HIV for you right now?*

Ginew: Right now it's terrible—being homeless. I've been homeless for the last two weeks. I've stayed in a hotel for maybe a week, then I ran out of money and basically I'm homeless; gone to the shelter yesterday, and I stayed there one night. And it's terrible to have no home to go to.

*Do you feel that's because of your being HIV- positive?*

Ginew: No, because of my addiction. With my addiction I spent my rent money and that's why it's my addiction. That's why I did it to myself, you know. Sorry that I did, but there's nothing I can do about that now. Hope for the best.

*So that is something that you are working on?*

Ginew: Yeah, hope for the best. I'm waiting for the fifteenth of the month.

*What were things like before you were positive, as opposed to now?*

Ginew: I was always positive, that was a long time ago. That's like 20 years ago. Yes, I'd just turned 19 and pretty sure I got it then. I really can't remember. I was going to school; everything was good until I became pregnant with my second child. I was in a relationship and he was abusive. He was an IV drug user. Okay, I had no idea he was positive or anything like that. It was like in the 1980s. It was 1979, probably. Yeah... [REDACTED] was 4... sorry, 20 years ago. I was six months pregnant.

*How old were you?*

Ginew: 27. Yeah, I just found out I was six months pregnant. The doctor told me I was unhealthy in his office.

*Was there any support offered to you?*

Ginew: No, there was nothing back then. I think PWN [Positive Women's Network] was running then, and I was kind of scared to go ask for any help. I just wanted to forget that I had it.

*You mentioned there was no counselling back then. Have things changed?*

Ginew: Oh, a lot, a lot more support. All kinds of support.

*Can you share about some of your challenges and some of your successes?*

Ginew: I think my successes are not having any AIDS related illnesses so far. I just had the pneumonia but it didn't tear me to pieces. I haven't been hospitalized yet for any HIV-related illnesses. Challenges— not seeing my daughter. She's been with her father right now for like, a year and a half, and I get to see her once, maybe twice a month. So that's kind of hard on me and especially hard on her, not knowing where I am and if I'm ok.

*Are you going to contact her?*

Ginew: Well, her dad doesn't like me talking to her. I don't know, he doesn't like me talking on the phone to her, so it's a struggle. She's going through counseling, all kinds of counseling with psychologists to see if she has FAS [Fetal Alcohol Syndrome] so that is kind of weighing heavily on me right now. They didn't get the results back yet so it's definitely a challenge, and not seeing her is really hard. It's stressful for me, it's taking a toll. I've been drinking almost every day, and drugging when I have the money.

*What does a good day look like for you?*

Ginew: Just having a bed to sleep in right now is a good day for me.

*So opposite of that, what does a bad day look like for you?*

Ginew: Being sick. [Ginew was dealing with a cold and respiratory infection when we met.] I've actually thought of suicide a couple times.

*But the truth is you haven't done it so that's another success. What has kept you from those negative thoughts?*

Ginew: It's my daughter. She's little, she's young. She'll be 8 in 10 days. And my youngest son, his father passed away in '96 so he doesn't have a father. All my kids have different fathers and I haven't lived with them—they were taken from me when they were two. They were in foster homes, and for the past 8 years living with their grandparents up in Manitoba. I have three children.

*Do you see them?*

Ginew: I saw them in June. I went to his graduation, [her youngest son] for all of them. That was a positive thing for me. His graduation was awesome. My oldest son, he lives on the island. I just found out that I was a grandmother about 4 months ago. He didn't know either.

*Congratulations!*

Ginew: Thank you. She's like a year and a half old now. I have pictures of her at home, in storage. ██████████ is my savior, she's my rock.

*In your daily living, what is helpful for you and what gets in the way?*

Ginew: Helpful things, how about all the support from the outreach workers and having them drive me around and support, that's all I can say. Having someone to talk with them, you know.

*And what about things that might get in your way?*

Ginew: Same as her, addictions [referring to Storm]. As soon as I head downtown I get this feeling in my stomach and I gotta go get it, I gotta go get it. It's just so over-powering.

*Are there different stages you went through after your diagnosis?*

Ginew: Depression, depression, and then trying to mask it with alcohol and drugs. I'm still there, at the second stage; I'm waiting to go to the first stage and accept it and deal with it. Hopefully, better myself, where I can start taking my meds on a regular basis and be healthy.

*How do you take care of yourself? What does that look like for you?*

Ginew: To eat healthy, keep myself clean, take my medication. But I haven't been doing that.

*What prevents you from doing that?*

Ginew: Right now, the homelessness and not having anything you know, or any permanent place to call home. When that gets settled, hopefully I'll get back to taking my medications regularly, get rid of this cough and cold. My doctor says get lots of rest, you know, and you can't do that on the street. And eat properly, yeah.

*What about your relationship with your body? Has that changed for you since getting HIV?*

Ginew: Yes, it has changed quite a bit. In probably about 3 years, I've lost about 10 lbs. My normal weight used to be 135, now it's at 122. So, yes, just the weight problem. I have a hard time gaining weight. I've eaten like a horse sometimes and can't gain weight. It's hard.

*How about being in tune with your body? Do you agree with Storm?*

Ginew: Yes, especially thrush. That's what I have right now, canker sores, like when I eat spicy stuff.

*How long did it take you to be able to tell your story? When you were first infected, when did you become comfortable sharing with other people?*

Ginew: Probably in the last six, seven years. I was afraid to tell any, you know, even [redacted] [her partner]. It's hard.

*Even before you became comfortable, were there earlier ways, earlier stories you told, and who would you tell them to?*

Ginew: Just immediate family. Although I had a hard time even telling them.

*What was that like to tell your family?*

Ginew: Oh, they were very emotional. I mean, like, I don't know, they didn't believe it, you know, that I got it. But one of my sisters found out first, it came out accidentally by me, and she just started crying, saying, "oh my God, you're gonna die, you're gonna die." That was about, maybe like a year after. Yeah, I kept it from them for a year.

*So when you started talking about your story, who would understand it? And who wouldn't get it?*

Ginew: Probably the ones without the disease wouldn't get it. I mean the ones who don't have the disease. It would be hard for them to understand what we're going through. Actually, I don't even know. My friends probably heard it through other family members. I didn't, I don't even know if I told them. No, I don't think I did. The two oldest boys, but my daughter doesn't know yet, about this illness, she's 7. My dad had a rough time with it.

*Who else that wasn't family? Is it people who are not positive that have the most trouble?*

Ginew: Yes. It's not a death sentence when you find out. My doctor said, "I hope to see you when you're 68 years old," so that kind of gave me some hope with the medications and that. LTS, [Long Term Survivors], people like that are inspiration for me.

*Sharing about your illness, what is it that's the most important to you for people to know?*

Ginew: That they can have children with HIV. It's not a good thing, it just isn't a good thing. It's awful, awful, it's awful, HIV and addiction.

*What does that light at the end of the tunnel mean to you? [Responding to Storm's mention of her light at the end of the tunnel.]*

Ginew: Same thing [Housing and family]. Getting the apartment and getting more access to see my daughter. It's not custody, but getting to know my kids.

*I'm hearing from you a lot about family, and that you're less concerned about your own health and your own living, and more concerned about those outside of you.*

Ginew: Yeah, for me it is. I care more about my kids than, well, I did care about myself, but, you know. It's more about my children, and I would not commit suicide, because that would be too selfish.

*Was there a time when you were suicidal?*

Ginew: Oh, I went on a crack binge for 5 days. I never slept, well maybe minimal sleep, couple hours here, and drinking, and then all the money was gone, and I was coming down, and depressed, and didn't phone my partner for 5 days, and knew I was going to be in trouble. Not a good feeling... the having to put up with your partner when you got home and facing the consequences.

*So the suicidal times were related to the drug use?*

Ginew: Yes, and writing the same old story over and over again. You just knew what was coming. Yeah, feeling like hell and wanting to vomit.

*If you are you comfortable, is there anything else you wanted to say?*

Storm and Ginew [in agreement]: No, I think we covered it.

*Once I have a written document and your stories are shared, strictly confidentially, and I bring to light important things you've said, how would you to see that document used?*

Ginew: Educate children, young kids, about HIV and drugs.

*So you'd like your story to be shared with children?*

Ginew: Yes.

*How do you think we should go about that?*

Ginew: Well, even getting it into the school, because that is where it starts.

## 4.2 Storm's Story

Storm: Study Participant; Ginew: Study Participant

Both Storm and Ginew were present during our conversation together; as discussed above, I have severed the stories here.

*What it is like living with HIV for you right now?*

[Ginew has spoken first with quite a bit of information, and now Storm is beginning to share some of her thoughts – See Ginew's Story.]

*How about you, Storm, would you like to share something now?*

Storm: No, [Laughing], no. I'm kind of in the same boat as Ginew. [Ginew is currently homeless and living at a shelter because she spent her rent money on drugs. Storm is homeless also, but staying at a friend's house.] I've been spending my rent money also. I chose to get out from where I'm at because the partner that I'm with now, I figure is abusive, mentally. Not physically, mentally, and I can't live like that because I've been HIV now, how old is [her daughter]? She's six... 14 years, no 13 years I've been HIV.

*How did you find out?*

Storm: I just went for a random test. I was in my addiction but not realizing I was going to become a full fledged addict. I am now a full fledged addict I want to add. But the first time I ever shot up, [is when I became infected.] I knew I did not get it through sex because I was monogamous with my partner for years before that. So I got it through a needle. The guy I had shared it with had HIV and it was just that first time that I did it, now 14 years ago. He left town, he knew what he had done. I've never seen him since.

*What's that like for you, knowing the exact moment when you became infected? That must be difficult.*

Storm: There was a free clinic back then, it was called ... Anyway, downtown on Burrard, the free clinic, I worked there and just got a test at random, not thinking. But it would be in the back of my head that I shared this needle, and I didn't know, so I thought well, I'll go get it checked. I remember there was no counselling, no pre or post counselling. The doctor brought me in and said, "You want to sit down, you are HIV-positive." I remember walking out of there, not feeling my legs but I could see my feet moving. I couldn't feel the bottom part of my body, I was so numb.

*You mentioned there was no counselling back then. Have things changed?*

Storm: It's more talked about now. It's more open now to the public. When I was that young, it was just beginning to come out.

*Can you share about some of your challenges and some of your successes?*

Storm: The biggest challenge is my addiction – my addiction to cocaine. I no longer shoot, however, I do smoke rock, literally on a daily basis. I always find somehow, someway to get it. For ten dollars a day I'll do it. I mean, this is how bad it's gotten, that nothing else matters and I'm realizing that I've... my relationship has fucked up over it. With my ex-partner, I won't mention his name, but I didn't realize how good I had it and I lost him. He's been clean for 2 years. He did get Hep C, however, but he did not get the HIV-virus. But, yes, that is the biggest challenge, my addiction. Another big challenge is the illnesses that go along with it [HIV].

*You mentioned [during lunch] the PCP pneumonia you had...*

Storm: Yeah, I was always scared of PCP pneumonia because I heard that when you got PCP it meant death. And then I got PCP pneumonia. I had lost so much weight, and so, my body... I was scared to look at myself. I thought that from that, it would teach me not to use again, but look at me, using again. And my partner now, who I'm leaving, always says, "There is no such thing as an addiction, you're just a weak person." To me that's abuse. That's really abuse to me because I'm not a weak person. I've gone through a lot in my life such as losing my son to cancer when he was 12, and I gave up my daughter for adoption. I'm a strong person, mentally I'm strong.

*That sounds like your success.*

Storm: Yes. That's the way I look at them. For me it's the successes first. I'm strong. That's a good point, you know. I just think that no one of the opposite sex is going to take control of me or take over my life any longer. My children are grown up and they know about my illness as well as my addiction because I came clean with them.

*What was that like for you to come clean with your kids?*

Storm: I cried, it was really quiet; as a matter of fact that was just a week ago. I came clean with them. We were at the Four Seasons and we went outside for a cigarette and I said, "I gotta tell you kids something. Mom doesn't have a place to stay right now; I'm staying at [REDACTED]'s. Mom's not a well person, mentally or physically." They said, "What do you mean?" I said, "Just sit down, I want to tell you, I've got HIV." They knew, their dad told them, but they just wanted to hear it [from me]. I said, "I'm also an addict." They were actually quite shocked at that, saying "What? Mom?" And I said, "Yeah," and told them the truth. And I also said, "But I'm going to get our lives together, all three of us, if it's the last thing I do in my fight, in my heart of hearts. I'm going to get us housing, and I'm going to get us counseling and we are all going to be together again and I'll be strong." So this is where I got the housing subsidy. [Storm's application was recently accepted and now she is looking for housing.] I got to get a place... and go to rehab.

*It sounds like you're on the right track. And that your strength will get you where you need to go.*

Storm: Yes, I know.

*What does a good day look like for you?*

Storm: A good day for me is having a bed to sleep in and being able to get up and have a shower. To start a day like this morning, I got up, I was able to have a shower and clean clothes to change into. That's a good day.

*Right now you're at [REDACTED]'s and have housing, right? So what does a bad day look like for you?*

Storm: A bad day for me is that I haven't slept due to cocaine and I can't face the problems of the future because I'd been up all night using cocaine. That's a bad day. And my money is low, three hundred dollars short. That's a bad day. You're coming down off the cocaine and you just want to... I've actually thought of suicide a couple times.

*But the truth is you haven't done it ...*

Storm: It's because I lost my son to cancer and I just think my children need me now. They haven't had their mother all their lives. I'd be such a loser. It would be for everybody, later on in the future to say, "See, I knew she was a failure. I always knew she was kind of..." I'm not going to give in to please them—mostly because my children need me.

*In your daily living, what is helpful for you and what gets in the way?*

Storm: There has got to be light at the end of this dark tunnel that I'm in. There's got to be light, and I have to survive every day for my children. Even though I don't talk to them on a daily basis, they don't need to know that mom is out there with a crack pipe in her mouth trying to get money for more crack. This has got to be my second chance.

*You mentioned [during lunch] rehab in January?*

Storm: Yeah, I'm probably going to Round Lake. It's an Aboriginal treatment... [centre]. So I'm probably gonna go there and come back. I want to get all my supports set up as far as that goes, because I know I have to work the program and not just slide off the scale and fall through the cracks again.

*What do you think is helpful for you to reach that goal?*

Storm: I've got to start setting up everything now because if I got the housing now, I got to work on January. When I leave in January, I'll make sure my rent is paid, make sure my furniture is delivered. I'm setting up all my supports now.

*And what gets in the way of your daily living?*

Storm: My addiction. Addiction is a big thing. Maybe people think that, because I work at looking healthy, that I am healthy. Maybe on the outside, yes, but mentally I'm not, I feel like I'm just a walking skeleton with no feelings inside. Honest to God, that's how I feel sometimes. I don't have feelings and I use the drugs to mask my pain so I don't have to...

*Where does some of that pain come from?*

Storm: It stems from my childhood, but a lot of it stems from abandonment in my life. My children have abandonment in their lives. I haven't abandoned them but because I was diagnosed I gave them to their father because I thought I was going to die right away or something. So they have abandonment issues like I do. I gave up my daughter for adoption as well, she's 7. She's not positive, she's not Hep C.

*Do you see her?*

Storm: Yes, I do. I gave her up to my sister, in Calgary, so I see her all the time. Well, when I go down there... Unfortunately, she's looking more and more like her dad. (Laughs)

It is...It really is hard. I was talking to [REDACTED] today about that and [REDACTED], her son, is in addiction right now, in one of the centers downtown. But she's been such a good friend of mine and she said, "I don't expect you to pay me back. If there is any way I can help you I will." She's been really great. You know, if it wasn't for her, I don't know. I've often, honest to God, thought of standing on the corner and even selling myself for rock. That's pretty ridiculous when you think like that but I've honest to God thought that.

*But there's something...*

Storm: I think it's my pride that gets me... that my dad never taught me that, and how could I do that... I sit there talking to myself... why would you lower yourself like that, how could you do that? I'm not going to lie; I have done that a couple of times. But I'm thinking, oh, if I start this, the money is going to be so easy, so easy. It's going to come in and I'll be full-fledged like one of them out there.

*It sounds like that is not a place you want to go. Definitely, your strength is showing again.*

Storm: Yes.

*Are there different stages you went through after your diagnosis?*

Storm: I think I've gone through those stages. The first one is depression and the second one is just like she [Ginew] said, maximum pain, with alcohol and drugs. But I've come to terms that I'm always going to be positive. It's me, I have to learn, I have to be comfortable with myself. I have to learn to try to love myself and I've accepted it. I've accepted it because I'm HIV-positive and whether I get hit by a bus or I die today, you know, it doesn't make me any less of a person than the next person. So that is the way I look at it. I've done [contributed to] books with biographies on myself about how I've contracted it. I put my face out there to the public to say, "Yeah, this is me. And I am positive, and I am Native." I have a system to teach the younger generation that you don't do... drugs are not something to be taken. I've done a couple biographies. One is coming out again with [an AIDS Service Organization].

*It seems important to you to share your story and for others to learn from it.*

Storm: People have come up to me and asked me, because I work in [an AIDS Service Organization], "Are you HIV?" And I say, "Well that's kind of... I don't see that as a requirement [to working there and helping others]. But if I weren't HIV and I did this, to me, I wouldn't die." I've got to be positive too in what I'm going through. Now, *doing*, to me that's the first step. I'm going out there and helping people, you know, this is what I'm doing. This is what I am, this is what I'm about.

*What's that like for you sharing with people? What do you gain, and what do you think they gain?*

Storm: For me it's healing. It's a lot of healing. I've come to accept it. This is me and I don't know about the other people, but I always get told that I'm doing a great job. You know, many people would be afraid, but in my biography I said, "I don't know what everyday holds, but I should thank our higher power every day for allowing me to wake up today." And sometimes, yeah, I forget to pray at night for allowing me to live that day. I don't know what purpose I'm here for, but I'm going to keep going.

*Do you think your purpose lies in what you're doing?*

Storm: I think so, I think so.

*How do you take care of yourself, what does that look like for you?*

Storm: Right now, even though I'm homeless, [REDACTED] is there and makes me take my pills every morning. Not that she makes me, but she's really a good reminder, and I attend to my medication regularly. But the last two months I'm undetectable. As far as my viral load goes, I'm undetectable. But my CD4 is 210. They [doctors] say maybe they should boost them. But I refuse to take antibiotics because I was on antibiotics and had PCP and they did a number on my body. That's why I lost all that weight. I will not take antibiotics unless I really have to. They're really not good for you. I did research on them. But taking care of myself, yeah, eating healthy, taking your meds, and having a good night's sleep.

*What about your relationship with your body? You mentioned all your weight loss. Has that changed for you since getting HIV, your relationship with your body?*

Storm: I find that, yes, I'm more in tune with it. I don't know, just different things, like the different meds you go on do different things to your body. You're really more in tune with vaginal stuff, say. We, HIV people, are more prone to yeast infections and stuff like that. So, yes, you are more in tune with your body, pay more attention to your body. A cold, skin lesions, anything like that, we have to go to a doctor.

*Do you look at that attunement as a good thing? Or as a bothersome thing?*

Storm: If you pay attention to it and go to a doctor, yes, then it's a good thing. But if you don't pay attention to it and just leave it then it's a bothersome thing. When you're trying to use, it becomes cumbersome, like, oh God, because addiction is a big part of my life. Like even oral stuff such as thrush. I really pay attention to my body. We kind of have to.

*How long did it take you to be able to tell your story?*

Storm: Well, actually, the last 4 years I've really come out. People will ask me, "Are you positive?" And I tried to tell one person because I believe in building my friendship on friendship. I've had a person get close to me and I tell them that I'm positive and then the friendship's gone. And I'm really quite hurt by that. So, now, when somebody gets close to me, or starts getting close, you know what, I'll push them away before they get too close. There's only a circle of friends that I have and they are positive friends. And she's one of them, [referring to Ginew] and we all know who's who. Yeah, about 4 years ago, I started. And so when people ask me, yeah, I am positive, I am HIV positive. How long have you been? 13 years. People get blown away.

*Even before you became comfortable, were there earlier ways, earlier stories you told, and who would you tell them to?*

Storm: Earlier, that's when PWN opened. No, I just told basically PWN. But other than that, my family members now know. My brothers and sisters, well, they knew. But it's a stigma of course, like my family, they may know it. There's 21 children in my family. (21?) Storm: Yes. I'm not one to say that, but hey.

*What's that like for you to be one of 21 children in this family?*

Storm: I hate it. I hate it. The older ones were going away when we were growing up. My dad had 5—my mom raised his 5. And my mom and dad had 16 together. So my dad had 21. And then, never mind that, and then she foster-cared on top of that. I think ohhhhhhhh, raising grand children, and oh, I mean like, how do you do it?

*Wow, well, thank you for sharing your family story. So when you started talking about your HIV story, who would understand it? And who would not?*

Storm: People that don't have addiction or HIV are the ones I find very judgmental. I'm not saying it's a good thing or anything, but addiction is a big thing in our lives. Being addicted and living HIV-positive is hard to live with, and hard to understand too.

*What was the most difficult thing about sharing your story when you started talking?*

Storm: My kids, the fact that I had to give up my kids. I went to rehab twice, I tried it twice and I gave up my kids because of my illness. Where I was, in Aurora, people didn't know I was positive, then I came out and said, "Yes, I'm positive, I want to let you all know I'm positive." I came out with my story and they were flabbergasted that I'd given up my kids because of my addiction, and because I'm HIV-positive.

*What is Aurora?*

Storm: Aurora is a treatment center for women and children.

*Is there anything else you would like to share?*

Storm: I think I'd like to share that it's not a curable disease but it's a manageable disease. It's a manageable sentence, not a death sentence. And there's LTS, we call them LTS, Long Time Survivors who have had it for how long now? 20 years, and I've had it for 13. So, people like that are... She's had it for 20 years, [referring to Ginew] and she hasn't had... She's an inspiration to me.

*Sharing about your illness, what is it that's the most important to you for people to know?*

Storm and Ginew: [In agreement] That they can have children with HIV.

*If you wanted to share your experiences with others, what would you want them to learn from all you've gone through?*

Storm: To stay away from drugs because addiction and HIV don't mix. HIV you can manage, but addiction... Because we both have addictions [referring to Ginew]. But there is light at the end of the tunnel.

*What does that light look like for you at the end of the tunnel?*

Storm: I think my kids and I will live in an apartment together. We're going to get back on track, get them back in school, get them back into Cadets, and just being together with my kids again.

*I'm hearing from you a lot about family, and that you're less concerned about your own health and your own living, and more concerned about those outside of you.*

Storm: I agree with Ginew. Suicide is a selfish act. I have the same feeling.

*What stage were you at, or, what was going on in your life when you were suicidal?*

Storm: Being on crack binges and then coming down from them and having to return home after five days to your partner. I hate that. You know when you walk in that door, that cold treatment, go to your room, change your old, get some clean clothes, have a shower so the smoke smell is off you, and eat. As soon as you eat, you want to sleep, but then that's when, blah, blah, blah. You probably want to sleep after you eat because you haven't slept in 5 days, I know the feeling. You feel like hell, smell like smoke. Speaking of smoke, I need to have one.

*If you are you comfortable, is there anything else you wanted to say?*

Storm and Ginew in agreement: No, I think we covered it.

*Once I have a written document and your stories are shared, strictly confidentially, and I bring to light important things you've said, how would you to see that document used?*

Storm: You can use it to teach, beginning with young children.

### 4.3 Roxanne's Story

Roxanne: Study Participant; Blue Stone: Study Participant

Both Roxanne and Blue Stone were present during our conversation together; as discussed above, I have severed the stories here.

*Can you tell me a little about yourself, Roxanne?*

Roxanne: I'm thirty-seven, no, actually thirty-nine. I was born and raised in Ontario a very small town, very tight family-orientated, not very open or educated. They are very old school, very old fashioned when I was growing up. There is no such thing, as children's aid and stuff like that. My parents were not educated; I was taken out of school quite a bit to stay in little tourist camps with my family, my mother and father. I was the only child. My father was married twice so I do have 13 half brothers and sisters from his first marriage. They were Catholic so it was kind of hard.

And I went into the relationship at the age of sixteen and I stayed in that relationship up until probably a year ago. I was a pretty heavy drinker. I think that's how I caught [HIV], how [the drinking] was affecting me because I started doing drugs. We started doing using cocaine. We started smoking at first, then using needles. I left him about a year ago and wanted to make this new life for myself here in this city, this beautiful city—except it is so expensive.

*What is something that you would like to share about being positive? What comes to mind for you first?*

Roxanne: Yes, for sure. [Roxanne is agreeing with Blue Stone when Blue Stone speaks of fear and shame—that people were not going to want to be around her. Blue Stone speaks more to this question than Roxanne.]

*Can you tell me something about your challenges and successes living with HIV?*

Roxanne: I guess challenges were leaving my relationship because of the fact that I was co-dependent. We started to do drugs together and I became addicted because of my unhappiness in the relationship and got careless shoving needles [and became infected with HIV]. I was totally use to the money that we had because he was a dealer so we had a lot of money. So I didn't have to worry about the money, and I didn't have to worry about being alone. I always dreaded being alone, I was always afraid; I thought I would be all by myself, and actually, it's not so bad. So, that's one of my successes, breaking out of that relationship.

*So this was both a challenge and a success?*

Roxanne: Yeah, exactly.

*You're both roommates here [in a women's shelter]. Can you tell me a little about what brought you here for the moment?*

Roxanne: I can't go to a different shelter previous to this one...my time lapsed over there. And they didn't have a shared room; you just get your own room... [I'm here now] because my apartment isn't going to be ready until the end of this month or next month. I got a co-op that I was accepted to. So, I move in the end of this month or next month. I go and see the new apartment next week.

*Living with HIV, what is helpful for you and what gets in the way?*

Roxanne: As far as that, there's PWN and then AIDS Vancouver. The resources. Then there's Healing Our Spirit, which is a really a nice place to go... for counselling, and I don't think you have to be HIV to go there even. I think if you even have a partner or friends that are...to go there to help understand the illness. So, that's really helpful. It's really nice there; they get free lunches and a lot of bannock and soup.

*What is helpful for you in your daily life living with HIV?*

Roxanne: I think for myself it is just having a better understanding of my situation and coming to terms with it is making life easier.

*And what are some things that might get in your way?*

Roxanne: Finances, like everybody. Now the things that get in my way are just probably actually myself. I don't get up and do things or go and do stuff, it's just... I guess lack of funds. Even though I work part-time and then I'm on disability, it's a struggle. You know, [doing] what other people do... Go out to the movies, go and eat, and those things cost you money. Yes, it costs, and PWN gives out free movie tickets. My husband used to take me to restaurants. And that's good, they [PWN] have spa days; unfortunately I was sick and couldn't make it. You can have your hair done, coloured, everything, and your toes, your fingernails, whatever, a facial... they have nice things like that, which I like, and they have retreats that you can go on.

*Are there any stages that you went through after being diagnosed with HIV?*

Roxanne: Depression, yeah, I felt depressed; I thought that my life would be over.

*What brought you out of that depression?*

Roxanne: Understanding that it isn't actually the end of the world. Understanding, just coming to terms with my condition. Realizing as long as I take care of myself ... I may live as long as anyone else, if not even longer. It is all a matter of taking care of my own health.

*How do you take care of yourself?*

Roxanne: I try to get proper rest, try to eat properly, and walk instead of ride. That's basically it, eat right, and get rest. I don't take vitamins really, that's about it.

*Tell me about your relationship with your body and having HIV. Has anything changed for you?*

Roxanne: Um, no.

*Nothing has changed for you?*

Roxanne: No.

*How long did it take you to start telling your story like this and sharing with people?*

Roxanne: Probably about two years.

*What brought you to that place?*

Roxanne: Once again, it's just coming to accept myself. And I would also have to say supports too. Having people like Blue Stone, I'm glad I met her. I'm sure we'll become really good friends after we've both gone our separate ways...having supports like that, people that just understand.

*Who would you have told your story to at an earlier time?*

Roxanne: My best friend.

*And who are some people you wouldn't tell?*

Roxanne: Co-workers that I have. Some of the people that I wasn't associating with at that time... I realize now that are not friends anymore. I am in a totally different space than I was back then.

*Did you notice a change in your story when you were telling it before?*

Roxanne: Well, yeah, absolutely, if I would have compared to when I first told people. It's all about me—about my understanding.

*It sounds like you've taken a lot of ownership.*

Roxanne: For sure. That's it, yes. Taking ownership is exactly it, I think.

*What was the most difficult thing about beginning to tell your story?*

Roxanne: Rejection, definitely rejection.

*Was that fear of rejection or actual experiences of rejection?*

Roxanne: It was fear of rejection, for sure.

*Who did you fear?*

Roxanne: People who weren't really important, actually. It was a fear that I had that really didn't... doesn't make a difference now. My life that I had associated with at that time and what my life is like now are two different things, it's like black and white. Yeah!

*Can you describe that for me, the black and white?*

Roxanne: Well, I was pretty wild, careless, and so were the people that I associated with. Now I'm more settled, I think, and more grounded. And the people that I want to have in my life are going to be caring and understand and not so judgmental and quick to judge.

*If you could share something with others, what would you want others to learn from your experiences?*

Roxanne: Well, I would have to say, to take better care of yourself, to love yourself more. It's hard to say, but just, know that you do matter. I would hate for the next young woman to be where I was... where I took for granted... [for another women not] to take your body and yourself for granted as well. The young girl that's confused and scared, yes... the young woman, the young girl that is reaching womanhood. There's that time when we're all confused and scared, right? Yes, so, women out of school, women in school...

*I can tell by your expressions there's a lot of concern for the person you use to be, a lot of worry that other people don't go through what you have.*

Roxanne: Exactly, I'm glad that you recognized what I mean. That's what I would definitely say—care for herself.

*How do you see us reaching them?*

Roxanne: I think we've got to go right there; I think we have to go right into there, into the schools. And they are doing it somewhere, in some places. I know a friend of mine back home goes to the schools in Ontario and she speaks about her condition.

*What do you think of that?*

Roxanne: I think it's a great idea. I haven't heard how she presents, I can only imagine. I also haven't heard from any of the students. But I think it's definitely something that's a good thing. To have somebody that's been there, or is there, has more truth to it than someone who's reading it somewhere, if you know what I am trying to say.

*Absolutely. So what might have made a difference in your life?*

Roxanne: Exactly that, probably. Having somebody like her tell her story, and I would have been sitting there probably thinking that could have been me. Do you know what I'm saying?

*Yes, about having that role model. Who might have been your role model in your life?*

Roxanne: I didn't have any. I definitely did not have any. I looked to the older kids for acceptance, for protection because my parents weren't there.

*Where were your parents?*

Roxanne: Drinking. They had alcohol issues.

*Did your siblings protect you?*

Roxanne: No, not at all. I don't hold them responsible anymore. I've come to terms with that. I still am, actually. [Laughing]

*What's that like for you?*

Roxanne: It's difficult sometimes because I want answers; I want to understand more about what they were thinking and conceiving. Some have passed away now.

*Is there anything else you want to share?*

Roxanne: No.

## 4.4 Blue Stone Woman's Story

Blue Stone: Study Participant; Roxanne: Study Participant

Both Blue Stone and Roxanne were present during our conversation together; as discussed above, I have severed the stories here.

*Can you tell me about yourself, Blue Stone?*

Blue Stone: Well, I am originally from Manitoba and what I remember, my nationality, it has such a long name I can't remember what we use. I am forty-six and I think I was only home for maybe up until the age of two and a half, three years, and then I was adopted, oh, fostered out of my home, taken away to a family... And then somehow I went over to the United States and then I was adopted and grew up. Like Roxanne says, things like that steered me towards drinking when I got older. I'm not blaming exactly everybody for that; it was all our own choice, but that's the only way I knew how to handle the things I went through.

*What brought you back to Canada?*

Blue Stone: I came from [the US] around Christmas time from the Arctic, a couple of weeks afterward and wanted to meet the family. I fell in love with them, they were just real happy to have me back and wanted me to stay. But it was too much like a cultural shock; I mean the one's running water but no toiletry, you know flushing toilets, [Laughing]. I wasn't judging, well maybe a bit, but it was a cultural shock so I went back, then came back Christmas time, it was eighty-five.

*Living with HIV, what is one of the first things that comes to mind?*

Blue Stone: Well, you know, at first I didn't like it. I was terribly in denial, really angry right away and right away [not] knowing what it would pick up because I injected it [was infected through intravenous drug use]. I started snorting and then we... I don't know... I was into mine, well, the ones I was kind of hanging around with were doing it. As far as HIV, [sighs], it was horrifying. I... I hate it. It stems from my upbringing and choosing the wrong crowds.

[Roxanne: Yeah, you do, you medicate yourself to the part where you don't feel anything.]

Blue Stone: Yes. Also secrecy and shame, I think. I felt a lot of shame and fear that people were not going to want to be around me. I still feel that way sometimes in certain circumstances because a lot of people are not educated like they should be, and they don't really think. [They think] that they can catch it from having a sip out of my coffee... Or pop, or silly stuff like that. With some people you have to be careful because they just don't know, and even though I haven't let it be known to everyone...

*How long have you been positive?*

Blue Stone: A couple of years. I can't completely remember. It just goes so quick, so fast. I try to keep myself from death, actually.

*Do you pick and choose who you tell about your status?*

Blue Stone: Yes, if I feel that someone is educated enough to understand it and mature enough to, and I am close enough in the relationship with that person then I'll share my status with them. And if not, then I don't just tell them.

*Can you tell me something about your challenges and successes living with HIV?*

Blue Stone: Sometimes it's a challenge to get up in the morning. After sleeping all day and I know I have appointments. Or with this last week, I was at work most of the week. It's not like I don't have fun at work. I work all over the city. I am an interior-exterior painter. I've done that for twenty years on and off and I also do some renovations... That was a challenge to get through, because I always wanted to do that. I always wanted to complete it [apprenticing as a painter]. I am still working on it because I have to find the person, in order for me to go up to my apprentice; I need to find someone that's a journeyman who has their ticket. I will finish it, I know I will [Laughing].

*So it sounds like some days getting up in the morning is your first challenge?*

Blue Stone: It is, because, to be honest, I relapsed and have been drinking and drugging again. Not lots of drugging, just mostly drinking. And, you know, it's depressing right now. It's that waking up, and, oh God, what am I going to do now. [Laughing], I do that. And then it gives me myself. I think love. A little fall, right? [Laughing]. For the longest time I had a big book sitting out here. It makes sense coming back out. Anyway, I know someday I will bring it back again. It's a big book to study with.

*Alcoholics Anonymous?*

Blue Stone: Yeah.

*Okay, so you're probably going to get out again?*

Blue Stone: Oh, yes, when I'm ready; when someone socks me on the head.

*You're roommates here, can you tell me a little about that? What brought you here for the moment?*

Blue Stone: Well, okay. I was staying in a nice place in the West End for almost nearly ten years. The landlord; however, sold the condo suite and didn't even give us enough time to find something. Then the second place a friend got me kicked out, which I should have not let them in there, and then it led to, yeah, then quite the same as... then here... Roxanne is a fabulous roommate. [Laughing]. I was always scared of what was coming, then my roommate came... I've just been searching [for housing], not full time like I should be but it's getting close to, well, December 1<sup>st</sup>, right? So I don't have to be out of here by then, but I want to be moved in somewhere. My old home, I don't even want to share with my ex. No, no, I have plans, [Laughing] so, I just want to find my own place. And I will.

*Living with HIV, what is helpful for you and what gets in the way?*

Blue Stone: The resources. [They are helpful]. I think for myself is just having a better understanding of my situation and just coming to terms with it, is making life easier.

*What does that mean for you, coming to terms?*

Blue Stone: I was in denial, like what Roxanne had said earlier. I was in denial for a really long time... And just feeling sorry for myself and being destructive. I still am to an extent, but nowhere near what I was when I first found out [about being HIV-positive].

*What does destructive look like for you?*

Blue Stone: It looks very chaotic, and very ugly, dark and... Now I, I still feel like there's plenty to live for; I don't think it's all over now anymore.

*What are some things that hold you back from living in that good stage that you just talked about?*

Blue Stone: It would definitely be finances. Everybody struggles. Rent, you know, bills everything.

*You have a cold right now, but even when you're not feeling sick, how do you take care of yourself?*

Blue Stone: Well, just rest. It's hard sometimes to do that right. I have to look for a place... I just try to take good care by eating and by taking my medication and vitamins. So all that's covered. [Highly Active Anti-retroviral Therapy (HAART) medication is covered by the government]. Unfortunately now, because of my cold or my sinus and bronchial, it's not directly covered, only a certain percentage. I have to have it paid for from something or somewhere.

*And that's a struggle right now.*

Blue Stone: It has been because I want to get better and I'm sick. [Laughing]

*How long did it take you to be able to talk about your story?*

Blue Stone: A while because I was in denial at first and anger set in and then I carried on my addiction because of it. It was so hard, my God, it was so devastating. What we do as addicts of alcohol, or narcotics, we just run back. For myself, I'm speaking, I run back to my drugs and my alcohol... I feel for me, it's for me, when we know in our heads we should just turn around and try to do something else with it, get help resources. You go through those stages. I did anyways. Then acceptance comes and then doing something about it, getting better by finding out about a specialist doctor, doing as much as you can to keep healthy and alive. And that's what I've been doing these last few years.

*What do you think was the turning point for you; what helped you reach this stage of acceptance?*

Blue Stone: I think that it was a lot of people calling me with concern because I went into a big hibernation. I wouldn't go anywhere, I just stayed in and that was it. Just people coming around and being concerned [and saying] "Hey, what's going on?" and then just showing me I can't lie to friends and family. I care, I just... you know... help me get out of my mode, mood. And... get me up and going. And saying, "We care about you and if we care then you gotta start caring about yourself too right?" My twenty-one year-old son was always calling me, "Mom eat, Mom take your meds, Mom..." constantly saying, "We're part of your family." I think my addiction was quite heavy for a few years. You don't remember things too much when you're like... time, right?

*Do you remember in the earlier days, were there different ways you told your story?*

Blue Stone: No, just to my family and friends, I never went anywhere else other than this project... [Blue Stone is sharing that our conversation together is the first time she has shared her story with anyone other than family and friends]. I've gone to counseling and stuff to help cope with it.

*How has the counselling helped?*

Blue Stone: It helped to talk about it, and to find more resources for help, places to relax, or just new friends, yeah, a lot of new friends. You know, people who were with it, [also HIV-positive]. PWN used to have sponsor nights; us women would get together and talk and get more information. I would go on retreats and get information on the disease.

*So you would talk to your family and close friends. Who wouldn't understand?*

Blue Stone: Just people like, I guess when I was in my addiction there would be people downtown who don't ... People in general, like that are still in usage, in near denial, they would judge. Judgmental people, I would avoid telling, of course, people at work or anything like that because I just thought, well, there's not enough knowledge out there. It's your fear, just getting to know that's it about people needing more education.

*What led you to slowly start sharing your story?*

Blue Stone: Oh, with other people, just getting to know who was safe enough to talk to. For years I didn't tell my closest family. My sister and nieces knew, but the other ones back home I didn't tell because they're from the reserve right, and they don't know much about it, so I didn't disclose to them until this last year, actually.

*What was that like for you to tell them?*

Blue Stone: It was more support from them and worry... not worry, concern. And they wanted to [know]. My mom knew, I told her before she passed on and she got me to come home. She said, "Stay here, I want you to eat and get better." But otherwise, as far as people at work, or, I just didn't tell anyone because you just don't go blurting out, "I have HIV, la la la, poor me, whatever." You don't. I don't talk to people about it other than small groups.

*What would you want others to learn from you, from your story?*

Blue Stone: I don't know, it's kind of hard because when you first start it's kind of a shock, so I would suggest to people to try to get resources right away, and not go into denial like I did for such a long time. Jeopardizing our health, right? So just getting help right away from doctors, or calling, I think that they have a hotline for children. I'm not sure, but...

*Is there anything else you would like to share with me about these past few years and your experiences with HIV?*

Blue Stone: I like don't have too much... I mean, I've just actually... I was in denial, and then not accepting it for a long, long time. I would suggest to people not to do that, [Laughing]. Try to get help right away; it works easier that way. It's...it is a struggle to stay clean and sober because I want to, I know my addictive mind wants to go back and say, "Give up give up," and go have some fun, but it's not really fun.

*Once my project and your story are printed, what would you like to see done with it?*

[Blue Stone did not have any response to this question].

## 5. 5<sup>th</sup> Stanza: Understanding

Back in the car, somehow you know the truth and  
say to your friend, *There won't be a lawsuit, will there?*  
*Probably not.*

In this Stanza, a kind of truth is sought. The woman has shared with our group that she has recently found out she has been HIV-positive for the past two years, and that health care workers knew this and did not notify her of her status. Although she does not give details, we in the room have understood her inference that this lack of notification may have something to do with her race, (perhaps also gender), poverty, and living conditions in the Downtown Eastside. Understandably, some of her first reactions are still of hurt, anger, and blame. Yet, she is also aware of the present-day level of her health, and that even if she could make “the system” accountable for her “falling through the cracks,” such a lawsuit may come after her death. While listening supportively, I also began to register a form of truth for myself, which I later checked with my friend. Our healthcare system does not work this way; it will not be held accountable in the ways this woman predicts. And Aboriginal women, like her, will continue to face discrimination and be virtually invisible until societal attitudes and healthcare policies begin to focus on the well-being of Aboriginal women living with HIV. Another kind of truth is sought throughout this 5<sup>th</sup> Stanza, that of understanding the participant’s stories in relation to Frank’s three thematic narrative genres: *Restitution*, *Chaos*, and *Quest*.

\* \* \*

### 5.1 Dissemination of Findings

“Stories are maps of the geography of a human life, showing us where to find the important things” (Muller, 1996, p. 34). Each of the women who contributed to this research has a different story to share about important indicators in their past, their present-day living situations, and about hopes for their future. As each woman struggles to position herself in the midst of her HIV-positive status and challenges with her health and well-being, each story, too, reflects elements of Frank’s (1995) three genres. In the following three sub-sections, I illuminate some of my contextual understandings about the women’s experiences. I do so by reflecting upon several examples from collected material organized in terms of

the story plots of restitution, chaos, and quest. It should be noted, however, that Frank's frameworks are not mutually exclusive of one another; each of the women's stories involve elements of all three. This is another reason Frank's work fits an Aboriginal research project such as this one; it demonstrates how we, as people, move through our lives with constant fluidity.

### **5.1.1 The Restitution Narrative**

Frank (1995) asserts the restitution narrative is the narrative type he most frequently hears from the newly ill, and less so from the chronically ill. This narrative focuses on the return to the social norm of the healthy state. Its storyline is "[y]esterday I was healthy, today I am sick, tomorrow I'll be healthy again" (p. 79). These stories are about tests and what treatments may follow, medical practitioners, and their alternatives to healing, but all end in the patients' ultimate return to health. Restitution stories can be prospective, retrospective, and institutional.

Most prospective and restorative stories end with the firm declaration, "I'm fine" (Frank, 1995, p. 78). By ignoring the stories of distress, people display an affinity to restitution stories by their willingness to suppress other types of illness narratives. Institutional restorative stories are those conveyed in the media. They are a model of how illness is understood. For example, Frank examines a hospital's brochure for its cancer treatment center. The narrative emphasizes a rapid restitution of health, of how people soon returned to the routine of their previous lives, or how their lives have improved. According to Frank, here, "Institutional medicine is asserting its preferred narrative" (p. 79).

In the institutional restorative narrative, the patient is exempt from all obligations save getting well under the authority of a doctor; thus assuring medical leave produces the desired result of health. This narrative aids social control, as the sick are urged back to health and not made at least partly responsible for that end. A return to health is the medical and social expectation. Medical intervention can seem endless, with tests leading to more tests, until health is restored or the patient dies; "medicine's hope of restitution crowds out any other stories" (Frank, 1995, p. 83). The narrative has the patient handing over the responsibility of getting well to the medical institution by taking the medicine or treatment prescribed by the doctor. This narrative is limited when health can no longer return. When the condition becomes

chronic or the person is dying, new stories must be constructed, and show elements of the *chaos* and *quest* narratives.

Because HIV is a chronic illness, participant's stories do not reveal much of the restorative genre, other than a sense of relinquishing control over to their doctors. In Ginew's story, we can sense an illness almost being imposed upon her, and her unquestioning acceptance of this authority, when she tells of finding out her positive status. "I was six months pregnant. The doctor told me I was unhealthy in his office." Storm shows aspects of a restorative plot in the beginning of finding out about her chronic illness as well. "Anyway, downtown on Burrard, the free clinic, I worked there and just got a test at random, not thinking. But it would be in the back of my head that I shared this needle, and I didn't know, so I thought well, I'll go get it checked."

Roxanne's story reveals a similar subplot in the restorative genre, one of relinquishing control, and of medical and social expectations. Of the four women's stories, Roxanne's seems to share the greatest difficulties in transitioning from the chaos narrative, in which an "ill" person lives in denial of their illness and in the immediate chaos of the moment, to the quest narrative, in which the person has come to accept their chronic health condition and live as best they can with it. (These latter two narratives will be discussed in greater detail in their respective sections below.) Near the end of Roxanne's story, where she talks about educating young women, one can also sense her instincts to remain in a familiar stance of restitution. In other words, to continue doing what others expect of her. When asked who she might like me to share her story with for others to learn from, she responded, "The young girl that's confused and scared, yes... the young woman, the young girl that is reaching womanhood. There's that time when we're all confused and scared, right? Yes, so, women out of school, women in school..." In her examples of restitution, she seeks to fill the role that might be expected of her, as a woman living with this illness, who perhaps now "should" be educating others.

*How do you see us reaching them?*

I think we've got to go right there; I think we have to go right into there, into the schools. And they are doing it somewhere, in some places. I know a friend of mine back home goes to the schools in Ontario and she speaks about her condition.

*What do you think of that?*

I think it's a great idea. I haven't heard how she presents, I can only imagine. I also haven't heard from any of the students. But I think it's definitely something that's a good thing. To have somebody that's been there, or is there, has more truth to it than someone who's reading it somewhere, if you know what I am trying to say.

### 5.1.2 The Chaos Narrative

Counter to restoration narratives, which end in the return to health, the chaos narrative contains no such hope; life never returns to what once was. This narrative reflects the teller's life experience if the *when* and the *why* things occur is absent. There is a foreign quality to chaos narrative; the events do not unfold in chronological order, often making the listener uncomfortable.

The lack of any coherent sequence is an initial reason why chaos stories are hard to hear; the teller is not understood as telling a 'proper' story. But more significantly, the teller of the chaos story is not heard to be living a 'proper' life, since in life as in story, one event is expected to lead to another (Frank, 1995, p. 97).

Ginew tells a classic chaos narrative when asked how things were different for her before becoming HIV-positive. She struggles to focus on any sequence of events such as her age when first diagnosed and other historical dates.

I was always positive, that was a long time ago. That's like 20 years ago. Yes, I'd just turned 19 and pretty sure I got it then. I really can't remember. I was going to school; everything was good until I became pregnant with my second child. I was in a relationship and he was abusive. He was an IV drug user. Okay, I had no idea he was positive or anything like that. It was like in the 1980s. It was 1979, probably. Yeah... [REDACTED] was 4... sorry, 20 years ago. I was six months pregnant.

More frightening to hear is the failure of modern medicine's ability to restore health, exposing the vulnerability of the teller and listener. Blue Stone expresses the depth of her vulnerability in her blunt answer to the question, *How long have you been positive?* "A couple of years. I can't completely remember. It just goes so quick, so fast. I try to keep myself from death, actually." Her words exemplify a key reason chaos stories are difficult to hear. It is because they are threatening. "Words suggest [the chaos story's] rawness" (Frank, 1995, p. 98); however, such stories cannot be truly told in words. As the

teller truly becomes “the wounded storyteller”... “[t]he story traces the edges of a wound that can only be told around” ( p. 98).

Narrative requires a reflection of events; this necessitates a sense of distance in order to collect one’s thoughts. This cannot occur when an ill person is living in a condition of chaos, where life is lived moment by moment in a body with ever changing urgent needs. “Lived chaos makes reflection, and consequently storytelling, impossible” (Frank, 1995, p. 98). The telling of a story depends on a kind of distance from the body—from the uncontrollable chaos in which a person lives. Storytelling requires a plot where past events affect present ones leading to possibilities of future events. Chaos contains none of these connections; it is “an anti-narrative of time without sequence, telling without meditation, and speaking about oneself without fully being able to reflect on oneself” (p. 98). Chaos narratives really are not told, rather they are lived. Within these narratives, a predominant feature is that of run-on thoughts and sequencing. Both tellers and listeners perceive events take place “on and on and on,” in a kind of “and then... and then... and then...” format. Blue Stone demonstrates her lived narrative of chaos and of reflective disconnection from her story. It avoids any location, identity, or familial details.

*Can you tell me about yourself, Blue Stone?*

Well, I am originally from Manitoba and what I remember, my nationality, it has such a long name I can’t remember what we use. I am forty-six and I think I was only home for maybe up until the age of two and a half three years and then I was adopted, oh, fostered out of my home, taken away to a family... And then somehow I went over to the United States and then I was adopted and grew up [before moving back to Canada].

This kind of chaos is also reflected in Ginew and Blue Stone’s stories about when they first became infected. As previously noted, Ginew has difficulty with chronological recollections, while Blue Stone reflects a sense of living urgency in a story that demonstrates a run-on thought pattern.

Well, you know, at first I didn’t like it. I was terribly in denial, really angry right away and right away [not] knowing what it would pick up because I injected it [was infected through intravenous drug use]. I started snorting and then we... I don’t know... I was into mine, well, the ones I was kind of hanging around with were doing it. As far as HIV, [sighs], it was horrifying. I... I hate it. It steams from my upbringing and choosing the wrong crowds.

Storm reveals her own sense of chaos when events merge together in her story about what a bad day looks like for her.

A bad day for me is that I haven't slept due to cocaine and I can't face the problems of the future because I'd been up all night using cocaine. That's a bad day. And my money is low, three hundred dollars short. That's a bad day. You're coming down off the cocaine and you just want to... I've actually thought of suicide a couple times.

The difficulty in hearing stories such as these lies in their overwhelming state of immediacy. No timeline is present, no relatable past, or hopeful future. Problems are followed by seemingly endless problems, as indicated in their "and then...and then" stream of narrative. Roxanne's plot about some of her challenges in life is also revealed in this chaotic fashion, lending to the immediacy of her living conditions.

*And what are some things that might get in your way?*

Finances, like everybody. Now the things that get in my way are just probably actually myself. I don't get up and do things or go and do stuff, it's just... I guess lack of funds. Even though I work part-time and then I'm on disability, it's a struggle. You know, [doing] what other people do... Go out to the movies, go and eat, and those things cost you money. Yes, it costs, and PWN gives out free movie tickets. My husband used to take me to restaurants. And that's good, they [PWN] have spa days; unfortunately I was sick and couldn't make it. You can have your hair done, coloured, everything, and your toes, your fingernails, whatever, a facial... they have nice things like that, which I like, and they have retreats that you can go on.

Roxanne labels the challenges she works through, as "what other people do," while combining them with a multitude of other "nice" thoughts that bring her peace of mind. However, the overall structure of storytelling remains one of chaos.

Restoration stories reflect the control modern medicine has over disease. But when medicine fails, the ill person feels a loss of control, and her life becomes chaos. The ill person living in chaos begins to dissociate herself from her body, which starts to be referred to as "it". It hurts rather than I hurt. Or in Roxanne's case, when asked what changes she has noticed in her body, there seems to be no awareness of the body at all.

*Tell me about your relationship with your body and having HIV. Has anything changed for you?*

Um, no.

*Nothing has changed for you?*

No.

Conversely, both Storm and Ginew relate more closely with their bodies. Storm summarizes and Ginew then agrees with her.

I find that, yes. I'm more in tune with it. I don't know, just different things, like the different meds you go on do different things to your body. You're really more in tune with vaginal stuff, say. We, HIV people, are more prone to yeast infections and stuff like that. So, yes, you are more in tune with your body, pay more attention to your body. A cold, skin lesions, anything like that, we have to go to a doctor.

*How about being in tune with your body [Ginew]? Do you agree with Storm?*

Yes, especially thrush. That's what I have right now, canker sores, like when I eat spicy stuff.

The chaotic body has experienced failure in trying to gain control and predictability in life, so it gives itself over to a life lived in contingency; events may or may not happen. The body ends up flowing through life with no agency. Personal relationships suffer; chaos stories force people away, stalling the desired recognition of the teller's physical pain. This causes the ill person to reach out the only way she can, by relating chaos narratives, resulting in a distance rendering support difficult. This distance grows through the listener's fear of their health, control, and discipline being stripped away, leaving a chaotic body. However, "[f]or a person to gain such a reflective grasp of her own life, distance is a prerequisite" (Frank, 1995, p. 98). The person living a chaos narrative has no distance from her life, and, therefore, experiences much difficulty in gaining a reflexive grasp upon it.

In order to provide empathic care, medical professionals must allow for the expression of chaos and concede it is an acceptable social condition. To write off chaos narrative as depression is to force the familiar, favoured restoration narrative, where progress is the natural state of being. To recognize chaos is to admit life is sometimes horrible (Frank, 1995). Those living in chaos are seen as outside society, no group more so than the homeless. Their health issues stem not always from disease, a medically controllable circumstance, but from "living a life of overwhelming trouble and suffering" (p. 113). Their

condition is not improved via medical intervention. What is required is an immense social shift allowing for the inclusion of chaos as a part of, not apart from, society.

Aboriginal women, similar to the participants in this study, need a safe place and space to share their stories, and for listeners to care about the realities of their chaotic lives. This is where they are in the moment, and if their stories do involve some details beyond what may be considered mainstream norms, they still deserve to be heard and understood. Storm talks about the pain of not seeing one of her daughters very often, which then leads into another closely woven narrative about how ultimately difficult life can be for her.

I gave her up to my sister, in Calgary, so I see her all the time. Well, when I go down there... It is...It really is hard.... I've often honest to God, thought of standing on the corner and even selling myself for rock. That's pretty ridiculous when you think like that but I've honest to God thought that.

*But there's something...*

I think it's my pride that gets me... that my dad never taught me that, and how could I do that... I sit there talking to myself... why would you lower yourself like that, how could you do that? I'm not going to lie; I have done that a couple of times. But I'm thinking, oh if I start this, the money is going to be so easy, so easy. It's going to come in and I'll be full fledged like one of them out there.

Life for Storm is not often the “neat and tidy” reality others would impose upon her. Nonetheless, it is her story, aspects of which are, indeed, strands of a chaos plot. She deserves a voice in what matters most to her, to be listened to and understood, in order for society to then take the next step. Although quite a chasm, that next step involves helping to make those positive changes in the healthcare, social services, and supports sectors; changes that would benefit HIV-positive Aboriginal women, their well-being and living conditions, rather than further marginalize them.

When asked what prevents her from taking care of herself, Ginew summarizes some of the important differences that improved living conditions would make in her life.

Right now, the homelessness and not having anything you know, or any permanent place to call home. When that gets settled, hopefully I'll get back to taking my medications regularly; get rid of this cough and cold. My doctor says get lots of rest, you know, and you can't do that on the street. And eat properly, yeah.

The challenge of listening to chaos plots is not to steer the teller away from her story, but to assist her with the embodiment of it. Listeners have trouble not only hearing what is being shared, but also with what might become a possibility in their own lives. “If chaos stories are told on the edge of a wound, they are also told on the edges of speech. Ultimately, chaos is told in the silences that speech cannot penetrate or illuminate” (Frank, 1995, p. 101). However, as much as this may be a challenge for listeners, for society to hear about the lives of the women, it must be done. They are the people, in fact, living the far greater challenges of staying healthy and coping with the many discriminatory barriers imposed upon them, and it behooves society to make the necessary attitudinal and policy changes for the benefit of all (to be explored further in the 6<sup>th</sup> Stanza).

### **5.1.3 The Quest Narrative**

Those who have accepted their illness and believe they can use it to benefit themselves and others are able to tell quest stories, like the women in this study. The ill person’s voice is heard in the quest narrative; it is their own story being told. It is unlike the restorative narrative, whose active voice is that of the medical establishment, or the chaos story, where the person is suffering greatly and unable to articulate her pain. While many quest narratives are published, some are expressed orally, as brief as a statement. This framework for answering questions is seen throughout the participants’ stories; each woman invariably fell into the question and answer format within our conversations—something I, as researcher, readily accepted as the more comfortable way in which they felt their stories could best be told in context. Quest plots can also be expressed by action, which involves advocacy for the ill. With illness now having a sense of purpose, it becomes a journey. Although some of women’s stories linger more in the chaos plot than others, they all make aspects of their transformative journey clear, through their ultimate acceptance of their current state of well-being, and of moving forward.

Roxanne has this to say about her transition through denial and depression towards acceptance.

*What brought you out of that depression?*

Understanding that it isn’t actually the end of the world. Understanding, just coming to terms with my condition. Realizing as long as I take care of myself ... I may live as long as anyone else, if not even longer. It is all a matter of taking care of my own health.

Ginew expresses a kind of acceptance about her living conditions when asked about the light at the end of her tunnel. “Getting the apartment and getting more access to see my daughter. It’s not custody, but getting to know my kids.” She exhibits acceptance that she may never regain full custody of her children. Yet, she hopes for (and will accept, at least) greater access to visiting with them. Storm is able to more strongly articulate her journey of acceptance when asked about the different stages she went through after learning of her positive diagnosis.

I think I've gone through those stages. The first one is depression and the second one is just like she [Ginew] said, maximum pain, with alcohol and drugs. But I've come to terms that I'm always going to be positive. It's me, I have to learn, I have to be comfortable with myself. I have to learn to try to love myself and I've accepted it. I've accepted it because I'm HIV positive and whether I get hit by a bus or I die today, you know, it doesn't make me any less of a person than the next person. So that is the way I look at it. I've done [contributed to] books with biographies on myself about how I've contracted it. I put my face out there to the public to say, “Yeah, this is me. And I am positive, and I am Native.” I have a system to teach the younger generation that you don't do... Drugs are not something to be taken. I've done a couple biographies. One is coming out again with [an ASO].

Another aspect of the quest narrative is personal change. The change brings insight that enables a new comprehension of recollections, creating augmented meaning. The storyteller is no longer ill but “bears the mark of the brotherhood of pain” (Schwietzer, cited in Frank, 1995, p. 118). We see this mark of “sisterhood” in Storm’s earlier comment about her body, which is inclusive of “we—HIV-positive people.” In the quest narrative, people begin to search for alternative ways of being ill. Where the exercising of responsibility requires a voice, this voice has, indeed, returned to them. They gain a sense of purpose and meaning about their journey, through a “form of reflexive monitoring” (p. 118), which can also be seen as a greater sense of acceptance and awareness. The journey becomes a quest; the teller has a story to tell. Quest stories meet suffering head on. Storm talks about a sense of empowerment she has discovered in relation to her own contributions towards affecting social change.

*What's that like for you sharing with people? What do you gain, and what do you think they gain?*

For me it's healing. It's a lot of healing. I've come to accept it. This is me and I don't know about the other people, but I always get told that I'm doing a great job. You know, many people would be afraid, but in my biography I said, "I don't know what everyday holds, but I should thank our higher power every day for allowing me to wake up today." And sometimes, yeah, I forget to pray at night for allowing me to live that day. I don't know what purpose I'm here for, but I'm going to keep going.

In another example of personal change, Roxanne gives credence to her sense of new existence in her story about how far she has come in terms of acceptance and understanding.

I was pretty wild, careless, and so were the people that I associated with. Now I'm more settled, I think, and more grounded. And the people that I want to have in my life are going to be caring and understand and not so judgmental and quick to judge...If I would have compared to when I first told people. It's all about me—about my understanding.

Quest narratives require the ethics of recollection, solidarity, and inspiration. The ethics of recollection and solidarity are conveyed in taking responsibility for past actions, which may be seen disapprovingly, but cannot be disowned. Storm does not disown her plot about being an addict, when asked what a bad day looks like for her.

A bad day for me is that I haven't slept due to cocaine and I can't face the problems of the future because I'd been up all night using cocaine. That's a bad day. And my money is low, three hundred dollars short. That's a bad day. You're coming down off the cocaine and you just want to... I've actually thought of suicide a couple times.

Instead, she appears to take ownership of her past and wants to make changes necessary for a healthier future.

*You mentioned rehab in January?*

Yeah, I'm probably going to Round Lake. It's an Aboriginal treatment... [centre]. So I'm probably gonna go there and come back. I want to get all my supports set up as far as that goes, because I know I have to work the program and not just slide off the scale and fall through the cracks again.

The ethic of solidarity and commitment is displayed in the storyteller speaking with, though not for, those similarly afflicted.

The third ethic is inspiration. The storyteller is an exemplar to follow when situations appear impossible to overcome. Storm assumes this inspirational role as she discusses her own spirituality. "I don't know what everyday holds, but I should thank our higher power every day for allowing me to wake up today...I don't know what purpose I'm here for, but I'm going to keep going." She concludes our conversation together with more words of inspiration.

I think I'd like to share that it's not a curable disease but it's a manageable disease. It's a manageable sentence, not a death sentence. And there's LTS, we call them LTS, Long Time Survivors who have had it for how long now? 20 years, and I've had it for 13. So, people like that are... She's had it for 20 years, [referring to Ginew] and she hasn't had... She's an inspiration to me.

## 5.2 A Critical Look at Frank's Illness Narrative Topography

My methodological goal was to find a means to exploring the women's stories as holistically as possible. I chose to resist the urge to break them into several pieces for naturalistic observation that would perhaps have found several thematic strands throughout each of them. Instead, I sought in Frank (1995), a methodology that would view the stories more respectfully, seeking to honour them more as whole entities or (re)presentations the women graciously shared with me. However, I believe I would be remiss in my overall approach to this particular framework<sup>11</sup> if I did not also include my awareness about some of the limitations to Frank's approach. *The Wounded Storyteller: Body, illness, and Ethics*, is written through the lens of a White, middle-class, academic. This cannot be overlooked, and thus it may be problematic that I have chosen his theory to understand the stories of four Aboriginal women despite having learned much from it. I find three main limitations with Frank's theory: 1) discourse, which I have already previously mentioned, and will only briefly reiterate here; 2) the superficiality of the chaos narrative; and, 3) the lack of a holistic approach to wellness.

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<sup>11</sup> I acknowledge that I have chosen a pre-existing framework from which to view my participant's stories. My reason for doing so are that I believe Frank's (1995) illness narrative topography to be similar to Indigenous knowledges and methodologies; it demonstrates an awareness of fluidity, power shifting, personal journey, and historical, present day and future movements. Nonetheless, I acknowledge that in choosing a pre-existing framework for analysis, there may be some influence to the ways in which I have interpreted my participants' stories.

First, the predominant theme of “illness” discourse throughout Frank’s (1995) book remains unsettling for me. In the women’s stories, I do not hear them continuously identify themselves as an “ill” person or as having an “illness.” They often speak of their successes and challenges about “living with HIV,” about “being HIV-positive,” and feeling safe in their community of “positive” friends. They also talk about living well with what life has presented them. Rarely have I heard any of my “positive” acquaintances describe the virus in terms of an “illness, or themselves as being “ill.” They too, talk of healthy living and well-being. In fact, the discourse used by one friend, is about an agreement that the virus and he cohabit in the same body for as long as necessary. It has been a kind of, “if you don’t bother me, I won’t bother you” relationship. This negotiation has lasted well over twenty-five years.

The second limitation I find in Frank’s (1995) work is that he demonstrates little awareness about the extents of poverty, homelessness, dual-diagnosis (HIV and addictions, for example), and any of the personal or social structures of chaos in which the participants live. Such structures and barriers to health are noted in other studies (Browne and Fiske, 2001; Lather, 1995; Ryan, 2000; Ship & Norton, 1999, 2001; Waldram et al., 1995; Varcoe & Dick, 2008; Vernon, 2001). Primarily, Frank’s ideas of chaos do not delve deep enough to express the ultimate experiences of the women with whom I conversed. His treatment of the chaos narrative is superficial, whereby people with illness appear focused on the chaos of their health alone. While, being concerned about their own health, the participants also have so much more to be concerned with. Aboriginal and HIV-positive women face discriminatory attitudes through stigmatization (Hill & Kurtz, 2008), if not outright violence perpetrated against them (Varcoe & Dick, 2008). Their stories encapsulate something much more vital and poignant than simply being run-on thought processes that lack sequential arrangement, or have only an “incessant present with no memorable past and no future worth anticipating” (Frank, 1995, p. 99). Storm confirms this when asked,

*What gets in the way of your daily living?*

My addiction. Addiction is a big thing. Maybe people think that, because I work at looking healthy, that I am healthy. Maybe on the outside, yes, but mentally I’m not, I feel like I’m just a walking skeleton with no feelings inside. Honest to God, that’s how I feel sometimes. I don’t have feelings and I use the drugs to mask my pain so I don’t have to...

Ginew also gets to the heart of the matter by sharing what a good day looks like for her. “Just having

a bed to sleep in right now is a good day for me.” She is forthright about how she became homeless, thus sharing aspects of chaos (her living reality) that I feel Frank’s plot does not begin to encompass, let alone give any credence to.

*What it is like living with HIV for you right now?*

Right now it’s terrible being homeless. I’ve been homeless for the last two weeks. I’ve stayed in a hotel for maybe a week, then I ran out of money and basically I’m homeless; gone to the shelter yesterday, and I stayed there one night. And it’s terrible to have no home to go to.

*Do you feel that’s because of your being HIV- positive?*

No, because of my addiction. With my addiction I spent my rent money and that’s why it’s my addiction. That’s why I did it to myself, you know. Sorry that I did, but there’s nothing I can do about that now. Hope for the best.

Storm says it best when she states,

People that don’t have addiction or HIV are the ones I find very judgmental. I’m not saying it’s a good thing or anything, but addiction is a big thing in our lives. Being addicted and living HIV-positive is hard to live with, and hard to understand too.

The last area that I find missing from Frank’s (1995) chaos framework, in particular to participants of this study, is an awareness of Aboriginal spirituality. While I do not assert that he needs a deep understanding of Native spirituality, I do note the absence of a more holistic lens through which Frank views ill people and their stories. Storm shares her spiritual practice of praying about each new day and about her purpose in life. Blue Stone shares that her approach to healing is through an Alcoholics Anonymous 12-Step program.

To be honest, I relapsed and have been drinking and drugging again. Not lots of drugging, just mostly drinking. And, you know, it’s depressing right now. It’s that waking up, and, oh God, what am I going to do now. [Laughing], I do that. And then it gives me myself. I think love. A little fall, right?

[Laughing]. For the longest time I had a big book sitting out here. It makes sense coming back out.

Anyway, I know someday I will bring it back again. It’s a big book to study with.

Aboriginal ways of knowing and learning are based on spiritual approaches to knowledge (Brown, 2004). Although not adopted by all Aboriginal communities, the Medicine Wheel is often considered a strong

example of living life holistically, by including the four realms of well-being: the physical, the mental, the emotional, and the spiritual (Adelson, 2000; Brendtro, Brokenle, & Van Brockern, 2005; Bopp, Bopp, Brown & Lane, 1984). Storm affirmed this for me on the day I picked her and Ginew up for our conversation together in my home. Not knowing their personal customs or values, I thought the most respectful approach would be to at least offer some form of tradition. I asked the women if they would like to smudge<sup>12</sup> together before we began our recorded discussion. Storm politely declined, saying that “her mind and body are not in sync today.”

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<sup>12</sup> Elders suggest being cleansed of any bad feelings, negative thoughts, bad spirits or negative energy—cleansed both physically and spiritually. This is commonly called "smudging," to burn certain herbs, take the smoke in one's hands and rub or brush it over the body. In Western North America the three plants most frequently used in smudging are sage, cedar, and sweetgrass (Borden and Coyote, 2008).

## 6. 6<sup>th</sup> Stanza: Reflecting

You begin to feel nothing else matters  
when you know the momentum of those thoughts  
is what keeps her alive.

In this 6<sup>th</sup> stanza, my poem and this thesis, like many Indigenous worldviews, have come full circle. I had left the morning gathering with these women with quite similar feelings as when I arrived. They mattered, their stories mattered, and their perceptions and experiences were important; they needed to be listened to, and more importantly, understood. During those moments in my friend's car, I came to realize that the reality that guided this woman's embodiment of her HIV-status was first and foremost hers. It was her own view of reality that empowered her to carry out her daily living as best she could. What I sense from this last stanza is a merging of illness narratives, or stories, the stories of the women in this poem, in this research project, and my own story. In this final thesis section, I reflect upon *our stories*, perhaps those which have most personally affected me, as they have intersected over the course of this past two years.

\* \* \*

### 6.1 My Story / Our Stories

Clandinin & Connelly (2004) assert that within the process of narrative inquiry, researchers and participants intersect and affect contextual learning along a continuum of the past, the present, and the future. Represented within this thesis are the health narratives of its four participants. Reflecting upon the women's stories, I realized that that I had not yet considered my own health narrative. In my own sharing, another circular connection is made from the end of the thesis back to its beginning, reminding readers of my impetuses for doing this project: to overcome the silencing of Aboriginal women's voices in a way that also reflects my understanding and sensitivities towards the participants because of my own lived experiences. Smith (1999) notes the cyclical nature of Indigenous methodology to which I seek to be accountable; knowledge begins at the personal and the community level, extends through the researcher, and is returned to the community.

Acknowledging this qualitative study is interpretive, I accept Creswell's (2007) commentary that "[t]he researchers' interpretations cannot be separated from their own background, history, context, and prior understanding" (p. 39). Creswell goes on to suggest that as the writing is "clear" and "engaging", "the story and findings become believable and realistic, accurately reflecting all the complexities that exist in real life. The best qualitative studies engage the reader" (p.46). I now reveal aspects of my own story that unfolded while completing this research project.

During my first year as a graduate student, I carried a course load of six one-week modules in the summer of 2006, three courses in the Fall, and one course in the spring of 2007 while single-parenting my three teenage sons. On my birthday in January 2007, my dad had lung surgery and spent a month in hospital recuperating. My mom lived in a motel beside the hospital during this time, and I visited them several times a week. Five weeks after they returned home together, my mom passed away suddenly. I arranged and hosted two Life-Celebrations for her, one for the community in which they had lived for the past 15 years, and the second, here in Richmond, BC, where our family and close friends were raised and lived most of our lives.

In April 2007, I relocated from the Okanagan where I had been living the last 13 years, back to the coast, Richmond, to be with my partner of two years and to continue my research in the Lower Mainland. Although my sons were all self-sufficient in their chosen careers, and two of them were renting my home, it was a difficult transition for me to leave them. Although my humorous mantra had become, "My kids aren't leaving home... so I will," I soon discovered just how much I would miss them. I returned in June for my youngest son's 18<sup>th</sup> birthday and his high school graduation. Over the next several months, I cared for my dad as best I could between Richmond and his remote Cariboo community, a five hour's drive away. In September of 2007, we moved him here to the coast, and while he is both ailing but still fairly independent, I am his primary caregiver. Over the Fall, I cared for my dad, continued my studies, met with my participants, began networking to build a professional career here in Vancouver, and also applied to a PhD program at UBC. However, at the same time, I had begun experiencing increasing emotional mood swings that were becoming more and more difficult to cope with. Finally, in early December, I experienced a crisis.

Since I was diagnosed with depression 10 years ago, I have experienced a few less severe bouts of it, and occasionally needed medication to help me through them. But this was no minor bout of depression, and I knew it. I needed help from my doctor. I remember pleading to him through tears, "Please just tell me I'm not imagining this, that it's not my fault." I could also visualize myself grabbing him by the collar, exclaiming, *Just give me drugs! I can't handle this (my life) anymore!* I then spent two weeks in bed, in and out of sleep, in an emotional, blanketed state of emptiness, struggling through suicidal thoughts. I was also physically ill with side-effects from the new anti-depressant working its way into my body. The next few weeks I spent either on the couch or in bed solidly napping most afternoons. Eventually, as Christmas approached, I began my slow recovery, venturing out of our home on occasion, albeit timidly and with much anxiety.

I concentrated on avoiding any rash decision-making during this time. However, the questions did persist: Would I have to drop my studies? Would I become well enough again to complete this project? My greatest fear, apart from not returning to my cheerful and energetic self, was the possibility of having to abandon my participants and their stories. Nevertheless, slowly, I was able to regain focus on what this study, *our* study, was truly about: "An Empowerment Perspective." What is it that most empowers the women to carry on? For them, it is less about what is wrong in their lives, and more about what is working for them. It is about acceptance of their condition and reaching their quest narrative. It is about having a bed to sleep in each night, eating as healthily as they can manage, taking their medications, seeing their children, and offering goodness to others. Gradually, I began to believe again, that their voices needed to be heard, and I was meant to assist them through the completion of this project. Their lives and stories had become part of my own quest narrative.

By mid January, 2008, my medicines and vitamins were working effectively, I was eating and sleeping healthily again, and my depression had subsided. I had learned to better prioritize my life by resigning from volunteer positions, avoiding unnecessary meetings, trusting my dad to take better care of himself as I visited him less, at least for the time being, and focusing once again on my studies. As I struggle with questions about this reflexive portion of my thesis being unnecessarily personal, I also believe that scholars like Clandinin & Connelly (2004), Cole (2003), Cooper (2004), McCall (2006), Richardson (1997), Ryan (2000), and Smith (1999) would agree that the personal is the political, and

oftentimes, it too, must be explored. As this next section shows, perspectives of the personal and the political merge in others, just as they do in my story above.

## 6.2 A Conversation with my Community Mentor

Shortly before my breakdown, in November 2007, I finished the conversation with my last two participants. But rather than experiencing relief, I began driving home from Vancouver to Richmond with a nagging feeling. What was I really accomplishing? Was it anything positive in the lives of these women? Or was I, instead, a disturbance, an intrusion into their already chaotic lives? I recalled a particular section of Lather's (1995) reflexive field notes:

I think of myself frozen like a deer in D's glare in the hospital room where Chris and I had gone to arrange the interview that this very ill woman wanted to contribute in spite of not being able to attend her support group with whom we had just met. The weight of the indignity of being studied, the violence of objectification required by turning another's life into information for academic trade: This almost paralyzed me as I entered the room (p. 51).

For the first time, I had begun to doubt myself as a researcher and the main purpose of this project, so I turned to my Community Mentor for guidance.

On my way home, I phoned my Mentor, Priscilla, and asked if she was free to meet me for a debriefing session. I had no transcripts with me, only my conversations with four special women mulling over in my head. Priscilla had the time and we did meet. Right from the start of this study, I have attempted to maintain my own sense of scale—I have not foreseen myself, a novice researcher, enabling effective policy changes or decision-making at higher health/service levels. However, I do still see my role as being an avenue for the women's stories to be heard, and to affect in a positive way, *some* people's awareness and negative perceptions of stigma and discrimination, about HIV-positive Aboriginal women.

I asked permission to record Priscilla's and my spontaneous conversation, and what follows below, is our transcribed discussion. From the specific to the general, from the micro to the macro, the personal is still the political.

\* \* \*

*I'm questioning myself with the purpose of this study. I'm wondering if, instead of doing something positive in the women's lives like I had first hoped, I've imposing myself into their hectic lives.*

Priscilla: Well, I think Donna, that if you feel you are imposing on the women, in the long run, you are really doing well. Because these women's voices would never be heard in any other way than from you; they might be ignored.

*Even if sometimes our conversations together seemed less conversational than I had first imagined, and instead, more like a direct question and answer period, perhaps coming across as abrupt format, and then they had to leave?*

Priscilla: I think what the women have to say is very important and sometimes that's the way it has to be, that you can't have a kind of ongoing conversation. Even the fact that the women wanted to do their interviews together [in pairs], maybe it was in support of each other. Maybe they couldn't do it on their own.

*So there is still value in what I'm trying to do even though I am getting these feelings about encroaching upon their lives?*

Priscilla: For me personally, nobody talked to my sister who lived on the streets. Nobody heard her voice before she passed away on the streets. And I think it's really very important that you are hearing these women's voices and actually putting them down on paper.

*I've asked the women where they would like this report to go, where they would like to see their stories shared. How about if you offered your thoughts on this as well?*

Priscilla: Sincerely, I'd like to see this published, I'd like to see it go into studies, where people, like the Native Studies at UBC... I'd like to see it written in public.

*What venues in public?*

Priscilla: For all venues, because, especially, there's a lot of non Natives out there who have no concept or no understanding of how we are and what we survive. So I think that's the most important target, the non Native population. Even sections of it submitted to Canadian magazines, like Maclean's, for example.

*Actually, all four of the women talked about targeting young kids in school. They were all very altruistic like that, not wanting other people to go through what they have gone through.*

Priscilla: I think that is very, very important, I think that's a wonderful idea.

*I talked earlier about my frame of reference about some of my male friends, some of whom are HIV-positive. But they are not on the streets, they are not living in shelters, and they are not homeless. Yet the women I have met by accident and by blessing, this is where they are coming from. Can you share with me about this feeling of, "Boy, was I off the mark"? Are there reasons I wasn't prepared for these differences?*

Priscilla: Well, I think these women were in a place where they were ready to talk to you. They've accepted the fact that they are HIV-positive. Personally, I think it takes a very strong person to stand up and speak about their illness, and for me, I think you did the right thing. The way you went about finding these ladies and going to where they felt comfortable was the right thing. I know that derailed your question a little bit...

The men are not usually homeless because the women are vulnerable and there is very much violence against them and often they are in extremely unequal relationships, and often with non Native men. And when they are abandoned, there are no supports there for them. If they came off the reserve, they might

not be accepted back on the reserves by their families. And perhaps very, very strongly with the addictions that have taken over their lives and perhaps to support those addictions, they have gotten into prostitution and then they have slid down so far.

*Or spending their rent money on their addictions as I've learned.*

Priscilla: Yes, many, many times over.

*We talked about the system before, how government rent money should go straight to landlords instead of to the tenants living in difficulty. But many landlords avoid going into that kind of system.*

Priscilla: Yes, because of their own taxation issues, they're afraid to be or don't want to be accountable to the government for claiming the money or for admitting rental suites. That's occurred with a lot of families who I've supported in the past. Where these women living in poverty, the temptation is so great to spend that rent money on a bit more food or other things and then once things start sliding they get more and more desperate and become homeless.

*Some views I came across were homelessness, addictions, and family, getting their family back together. Is that a pipe dream for some of them?*

Priscilla: Based on what I've seen in the last twenty-five years, it mostly is. It is a pipe dream for most.

*So that wasn't a harsh statement for me to have asked? It just kind of popped out.*

Priscilla: No. Yes, I believe that even under the best circumstances, there is a lot of healing the women have to go through to become stable. And especially if they are struggling with their addictions, where is the money going to come from when they are busy sending the money to the drug dealer, to be able to perhaps keep their sense of sanity into that world, to, not deal with those harsh realities?

*Another theme came up, community agency support. The women listed four or five support agencies and they had nothing bad at all to say about them. So does this mean we are meeting their needs, or only superficially?*

Priscilla: I think it's great that the agencies are there, but as long as they are there, nothing is ever going to help the homelessness. Nothing is ever going to help the drug addictions without follow-through to the next step. Because why would you go get a place when you can go to that agency and get clean clothes and new socks and go to the other place and get your three meals a day? You can stay homeless and on your drugs for as long as you want. But the kinds of things the Women's Networks are doing (like free movie tickets and spa and hair care days) are a little different. They're dealing with some of the women that are still ok, that aren't completely homeless. They are dealing with the ones struggling with extreme poverty. They're just trying to make their lives a little better. The agencies I'm talking about are the breadlines, and the places like in the Downtown Eastside, like the Union Gospel Mission and the Salvation Army. I think they do wonderful things, don't get me wrong there, they do very good things for people on the streets. But as long as they are there, and there is no complete follow-through for the drug-addicted and the homeless, it will never completely go away.

*So what is it like for you to be my confidant, and to give me support like this?*

Priscilla: Well, personally, and emotionally, I find it very, very supportive and a sense of healing for myself because of the issues of survival of many, many abuses as a child and ... having to... go to six of my siblings' funerals. And having a person who can understand that, and perhaps even write about it, so that the world knows. I find that very, very supportive, that there is an ear listening, and a compassionate heart.

*Those were just some questions I thought of spontaneously as I was driving here after phoning you today, after my last interview. But can you think of anything else you would like to add?*

Priscilla: Well, I think the other thing affecting especially First Nations, Métis, and Inuit women in this country is the extreme levels of poverty. The helpless make the wrong decisions when that money comes, it's like we love our children dearly, the children are our gifts to us, but when the poverty comes upon us we make decisions that are not good for our children and we end up losing them. And if anybody has ever lost a child to Social Services they would know how evil it is and that's how you would stay in the addictions. You have to deal with the pain somehow. And I just get really upset at the levels of government that don't support First Nation women, that the Federal Department of Indian Affairs needs to deal with Aboriginal women in this country in poverty in a more equal way than they do.

*Is there anything about my research going strictly with thinking of Aboriginal women living with HIV that you would hope that I would learn? What do you hope I gain from this?*

Priscilla: Well, I already feel that you have compassion towards people in general, for peoples'... their circumstances. What I hope that you would learn is that there needs to be more education and training, for the young people, like these women have expressed, that there needs to be more education at earlier levels of life. And that your work, by sharing your work in writing, that would be a help.

*Can you think of anything else about the general information I've shared with you? Did anything surprise you?*

Priscilla: No. Not one bit. The fact that you had a very difficult time trying to find these women to interview is not a surprise to me at all. And as a person who has worked towards trying to help change things for First Nation people in this country, I know that your work is really, really important. I hope to be one of the public reading one of those published articles. I do, I sincerely do.

\* \* \*

Priscilla and I had covered much during our conversation: my growing doubts about the benefits of this research project; reflections about gender differences for HIV-positive people (also class and ethnicity differences); goals and hopes of the women participants; other possible realities they might face; structural barriers within our society regarding Aboriginal women; policy, governance, and plausible changes in order to help the women. Our conversation was what I needed to carry on with empowering myself to share the stories of these four women living with HIV/AIDS. It motivated me to continue exploring the empowering perspectives in their lives that most propelled them along their journeys.

### **6.3 In Review (Successes of the Study)**

In the 1<sup>st</sup> Stanza, I outlined the focus of this study with an overview of HIV/AIDS, the difficulties for Aboriginal HIV-positive women more specifically, and the various impetuses that has led me to choosing this particular community-based research. In the 2<sup>nd</sup> Stanza, I briefly outlined the historical and structural contexts which I have learned most affect the women's lives and health. The 3<sup>rd</sup> Stanza describes

Aboriginal methodologies and theoretical perspectives on which this study is based. The 4<sup>th</sup> Stanza introduced the four women who agreed to participate in the project and to share their personal and empowering stories about living with an HIV-diagnosis. It is they who are the experts in this research, and in what should be deemed most important within, and for, their lives. In the 5<sup>th</sup> Stanza, I discussed the women's stories in terms of Frank's (1995) illness narrative topography that most explain contextually, themes or genres contained within the stories. Coming to know and to understand aspects of the women's daily living is perhaps the cornerstone of this study. Lastly, this 6<sup>th</sup> Stanza illuminates my own journey through this process, and how my life has intersected with, and been inspired by, the women and their journeys.

I now discuss some of the many successes encountered during this project.

I believe that to discuss the successes of this study is to uphold a large part of its purpose—to explore “an empowerment perspective.” I think one of the first successes has been my perseverance to complete this study, despite the numerous barriers I faced with community ASOs and their understandably protective stance towards the well-being of their clients. Apparently uncaring and/or unethical researchers have come and gone in the past, I have been told, without any regard for respect and reciprocity towards the community members they have researched. Near the end of our conversations, I asked the women where and with whom they envisioned their stories being shared. I believe this reflects that the focus of the study remains for and about the women and their community. Another success has been the sharing of the wisdom and insights of my Community Mentor, Priscilla, and Community member, Bernadette, and the ways in which we came together to debrief and to discuss the best ways to illuminate the women's stories in terms of narrative plots. Overall, this project has met my two original goals. First, it honours the participants and their strengths and challenges as HIV-positive Aboriginal women. Second, in a creatively hybridic kind of thesis, it includes the necessary academic language mixed with approachable, reader-friendly language to more effectively share the women's stories on a more personal level.

## 6.4 In Retrospect (Limitations of the Study)

There are some areas of this study that I had hoped would not have been as much of a challenge as they were. With my limited experience as a community-based researcher, my initial inability to “get my foot in the door” with community agencies was problematic. This took much time and patience on my part. These agencies are undoubtedly and legitimately gatekeepers for their clients. Unfortunately, due to past negative experiences, many agency staff members and executive boards are weary of present-day researchers and their intentions. This is reflected in the fact that out of nine organizations I contacted, one agency, PWN, offered me assistance and contact names to begin working from.

I also realize that with a more experienced researcher, the women's stories may have had the potential for more in-depth analysis. However, I am pleased to have completed the analysis phase with my original intent, to keep the stories respectfully whole by finding a method that would lend itself to observing them as such, which Frank's (1995) three genres do. As I have learned more about community-based research, I can see how a focus group made up of more HIV-positive Aboriginal women would have added further insight into this study. Limitations of planning, experience, and resources prevented greater participation. After reviewing the participants' transcripts, I am able to see points where I missed an opportunity to explore the moment further. Yet, with other topics, such as drug addiction, I consciously chose not to explore them in detail because addictions were beyond the intended scope of the study—awareness about living with HIV/AIDS is. Rather than viewing the women's health in terms of disease alone, I have emphasized the many barriers and constraints they face, as well as the many empowering choices they make on a daily basis. Finally, a larger research project could have included ethnographic research about living in Vancouver's Downtown Eastside community and the interconnections of drug addiction, poverty, oppression, and the cultural legacy of abuse and mistreatment that many Aboriginal women face.

## 6.5 Final Considerations

I do not really wish to conclude and sum up, rounding off the argument so as to dump it in a nutshell for the reader. A lot more could be said about any of the topics I have touched upon....I have meant

to ask the questions, to break the frame....The point is not a set of answers, but making possible, a different practice (Kappeler, 1986, p. 212).

I find the most difficult task of this project is now to “sum up” what has already been described in detail: conducting my research by following an Aboriginal methodology based on Indigenous ways of learning; listening to and hearing the experiences and perceptions of four HIV-positive Aboriginal women; and, finding a meaningful approach to interpreting their stories as honoured, whole (re)presentations. However, I see three overarching themes I can usefully address in this concluding section: 1) the empowerment and resilience demonstrated by the participants; 2) the need for cultural competency in a society that continues to stigmatize Aboriginal and HIV-positive women; and, 3) the need for a more holistic approach within society when it comes to education, learning, and healing.

First, McCall (2006) describes resilience as “the ability to adapt to, cope with and even be strengthened by adverse situations,” noting that a resilient person “has the inner strength to adapt to and cope with problems that are seemingly insurmountable” (p. 104). The lives of the women in this study often involve what may seem to many as insurmountably embedded in the crisis and chaos of poverty, homelessness, addictions, loss of children, and being infected with the HIV-virus. Yet, as this snapshot of their journeys shows, they have each bridged the chasm between living a story of chaos and horrid social conditions, to create meaning and purpose in their lives. The empowerment and resilience that each woman demonstrates illuminates their experience with adversity and personal coping abilities. The women’s journeys through chaos to quest narratives remain an empowering example to many.

Cultural competency involves outreach education programs about protection from the HIV-virus and community social services that most benefit Aboriginal people and the greater educational institutions responsible for most research. Cultural competence refers to an ability to interact effectively with people of different cultures, and includes four key components: 1) awareness of one's own cultural worldview; 2) attitude towards cultural differences; 3) knowledge of different cultural practices and worldviews; and, 4) cross-cultural skills (Mercedes & Vaughn, 2007). Developing cultural competence results in an ability to understand, to communicate with, and to interact effectively with people across cultures. Healthcare workers must develop a better understanding of a person’s cultural origins, beliefs, and traditions. People might better learn about healthy ways of living that are respectfully taught through cross-cultural methods.

The healthcare system needs to investigate how its policies, procedures, and professionals continue to marginalize clients, and to enact change to reduce this marginalization and stigmatization of Aboriginal people. As the literature review in this study reveals, the current situation in terms of race, class, gender, economical, and social contexts for Aboriginal people, women in particular, is not improving. Nor are the rates Aboriginal women are becoming HIV-infected decreasing. Elder Rose Point talks about common sense within the academy (personal communication, 2008). I believe this includes our greater community as well. Current education, healthcare, and social services being offered Aboriginal women are insufficient. As participants of the study detail, while coping with being infected, they also struggle with poverty, homelessness, losing their children, and addictions. As the literature reveals more generally, some of this stems from the legacy of colonization, racism, and stigmatization. The women's situations are multifaceted and contextually interwoven. Problems must be addressed from within this mindset. For example, when considering the implications of a dual-challenge, being infected and addicted to drugs, "HIV/AIDS and Addictions programs must have the capacity to identify and address the root cause of high-risk behaviour" (CAANf, 2004, p. 9).

Indigenous education also falls under the umbrella of cultural competency. Alfred (2004) comments on the shift from education within dominant culture to Indigenous ways of knowing.

As Indigenous scholars and teachers, we have a crucial role to serve. We have a serious responsibility to do what we can to resist the escapist temptations of the standard academic life and the material rewards of assimilation. Instead, we must stand and contend with the sick vision of the future that is guiding our leaders today and embedded within our modern institutions. We must do what we can to change the places we live and work from sites of imperialism into spaces of resistance, or regeneration, and of human freedom (cited in Mihhesuah & Wilson, 2004, p. 99).

Alfred reiterates the imperialist nature of research that surrounds Indigenous people, a structural boundary from which I have sought to break. He also illuminates what must be done to make positive changes. First and foremost should be the inclusion of Aboriginal methodologies when working with Aboriginal people. Ideally, the research concern about an Aboriginal community should be addressed by community members. Secondary to this, other academic researchers should have a greater understanding of Indigenous education, Indigenous worldviews, and Aboriginal methodologies and

ethics. All should be used as the foundation to any Indigenous research and/or healthcare service provider. For example, CAANf (2004) states,

In BC not many Aboriginal people are doing HIV work...The dominant culture must step way and let Aboriginal people do the work... We can't have one token Aboriginal person in a large health organization when Aboriginal people are the majority of the clients. We talk about equity and equality—if we make up the majority of healthcare problems—we should be the majority of workers. Instead we get services from the dominant culture. How we're treated—that's why we don't use the services—why HIV people don't get help (p. 8).

By including more Aboriginal people and Indigenous knowledge in the healthcare profession, I believe a more holistic approach to healing and well-being would naturally take shape.

Lastly, a holistic approach to healthcare that takes into account the physical, mental, emotional, and spiritual well-being of a person is good practice in both the prevention of illnesses for, and the care and treatment of, Aboriginal people and Aboriginal people living with HIV (Barroso & Powell Cope, 2000; CAANf, 2004). In their education, care, and treatment of Aboriginal people, medical and social support professionals need to be aware of the root causes for many Aboriginal living conditions, including the residual impacts of colonization and the residential school system. Only then can Aboriginal people begin to heal themselves surrounded by the dominant culture in which they live.

I conclude this thesis by returning its focus to the women, without whose support, this research would not have taken place. Ginew, Storm, Roxanne, and Blue Stone Woman are all someone's daughter. Some are mothers and grandmothers. All live with incredible strength and resilience. Each woman hopes for the day when she can be accepted for who she is, and not judged, mistreated, or forgotten because of her race, gender, socio-economic conditions, or health status. Each woman has a story to tell, one that, if listened to, can guide our society towards the social improvements needed to make their lives less traumatic and desiring of an escape. Each woman looks forward to the day she can be drug-free and can empower other women to understand how to best to protect themselves from the HIV-virus. It is imperative that we hear their voices and make the necessary adjustments to research, healthcare and support services, and policy to ensure this does not remain only a dream.

Ironically, perhaps, it is those who have suffered in their journey of healing and courage, that I have perceived most clearly the miraculous breathtaking resilience of the human spirit (Muller, 1996, p. 25).

## 6.5.1 Thesis Poems

### Hope

The flight is flawless. Leaving downtown  
Vancouver waterfront, we face an enchanting rainbow  
over the north shore, over the *Squamish* Nation reserve.  
The rainbow seemed to move with the floatplane until well  
after take off: twenty-minutes over the Straight and  
the islands, harbour to harbour, into Nanaimo.

We rent a car, drive the hour to Duncan to meet  
with the women of the Cowichan Tribes, the *Snunymuxw* Nation.  
It was on this ribbon of highway that she feels safe to begin  
Sharing—with slow and silent tears—her early years  
in Nanaimo, before the Ministry snatched them away.

*Dad swore, after my older siblings were sent to Cooper Island  
Residential School, my little sister and I would not have to go.  
The social workers couldn't do a thing about it; they were  
not allowed on reserve land. So they waited—and walking  
home from school one day, a block away, they grabbed us.*

The three and six-year old girls were placed in foster  
care, as were most Native children in the 1950s  
through today—their parents deemed unfit to raise them,  
a decision, then, based solely on race.

*I came home from school one day and  
could not find my sister. I searched the house but  
all I could find were boys laughing in the hallway.  
I pushed my way through the door, where more boys  
were taking turns raping her.*

Their next foster home was a Salvation Army Captain's.  
*He beat and abused us too, for being Native and ungodly.  
But as an adult, I faced him in court where he was finally held  
accountable. He was sick, and died in prison.  
My sisters were unable to face their healing,  
the way I continue to do, some have died of cancer,  
One brother died of AIDS, another committed suicide.*

When we reach our destination to begin our HIV/AIDS  
Workshop, and shared about our beautiful weather for the flight,  
an Elder tells us in *Hui'q' umin'um* language—*Rainbows means Hope.*

## Red Glow

His blue eyes ring out as inviting as  
country church bells on a Sunday morning,  
as they do every time he has something to say  
about which you are implicitly challenged not to  
challenge him. *And another bunch is those Indians!*  
*I've seen them since the 1940's and*  
*they still don't work*, he says emphatically.  
*They're all lazy, every last one of them.*  
I interject with about as much enthusiasm as butter  
riding the slice of a hot knife, knowing full well there  
would be no settlements gained from my advocating defiance,  
no foraging of knowledge vigorously imparted, nor  
graciously accepted. *Some do work, and I*  
*work side by side with them in Aboriginal communities,*  
I hear myself reverberate somewhat louder than a  
whisper along the taunt string-line of a child's two tin cans.  
My mother soon joins forces with  
I'm not sure which camp as if she were trying to feed  
the wolf that lives in each of us. *Ok, ok, calm down now.*  
*She's agreeing with you, can't you see that?*  
It is then that I return to my senses, enough to quietly  
remember the wisdom of my Elders is not something to be scolded,  
tossed aside like a used Earl Grey tea bag. Lived wisdom,  
entrenched racism, or self-perceived wisdom, he is finally right—  
*I'm seventy-seven years old and you aren't going to change my mind.*  
He closes the subject as air-tight as when he first opened it,  
reminding me of the time I'd taught my father-in-law years ago  
to close the lid on a Tupperware bowl: *Bring up the*  
*lip of the lid like this, and burp it, to let all the air out. Now*  
*it's sealed.* My dad crosses his legs triumphantly and  
lights another cigarette. I watch the brief red glow  
turn to white ash, disperse into nothingness  
as First Nation campfires did long ago by the  
self-perceived wisdom of white settlers.

## **In Our Grannies' Kitchens**

In our Grannies' kitchens, where the scent of wood  
smoke and sumptuous meals simmered over a thousand fires,  
lingered over the bare-wood walls and dusty  
compacted floors—  
this is where we learned the laws to love our children,  
our brothers and our sisters.

Today, as I seek meaning of my half-breed heritage,  
my source of knowing and protection from Grandmother Moon,  
through all time and all matters,  
I think of our petite Grams, the way she called out  
in her apartment hallway, slumped over to stillness in her scooter-  
chair from an aneurism. Yet my vision pulls me further,  
further back into the depths of those traditional fires, to know  
great-grandmother Leona, born and married in Québec City.

It could not have been many Grannies before her,  
of the nomad Algonquians,  
of those sweet smells and gentle words, stories offered  
as parables from which we sentiently learned,  
the woman to honor him, my French fur trapper, paternal  
caretaker in kind, respectful of our Grannies future legacies.

## All My Relations

It was in the old house they owned, on Watke Road;  
I remember the night my mom brought out  
my grandmother's jewellery box and allowed me  
to take whatever pieces I wanted, anything that held  
meaning for me. I was drawn to her pearl bracelets,  
the emerald and diamond, garnet and gold  
screw-on earrings, a few rhinestone and silver  
necklaces, some sparkle for elegance.

Mom and I talked about her own rings, the ones she wore,  
hers, grandma's, and great-grandma Leona's. Some day  
they would be mine. We knew this—then, before, and since—  
there was never any doubt. But the scripts we write for ourselves,  
for the sake of security and peace of mind; this one I wrote embodied  
my mom, one day, like this particular night, choosing the right  
moment she would pass on to me her cherished rings.

Four years later now, when we rush into her hospital room—  
we arrive too late, mom needed to rest—although she  
knew the boys and I were on our way, she needed to rest.

Numb with grief, my dad holds up for me a clear plastic bag,  
four rings earlier removed from her hands. Suddenly  
placed in my hands—is the Algonquin legacy of three  
generations—clinging together, *All my Relations*,  
waiting to be reclaimed once more.

Now they are mine to cherish. Back at the house,  
I spend quiet moments looking through both jewellery boxes,  
grandma's, and this time my mom's, thoughtful of heirlooms  
for her grandchildren. Among my grandmother's trinkets,  
I find a brown-beaded necklace holding a white abalone dove.  
Beating, soaring wings of incandescence. This time, four years later,  
I notice it. I reach behind my neck to put it on, spreading the  
love and care of my ancestors across my breast, nearest to my heart.

## Deception

From afar she looks clean and  
well-kept.  
As you approach her  
the signs are there—

the distance in her eyes,  
the hurt,  
the longing,  
the wear and tear  
on her body  
from the streets.

Perhaps she's 18  
and has been homeless since 16  
when she was kicked out  
of a foster home, still  
too young for income assistance.  
Perhaps she's in her 40's, seasoned to the realities  
of homelessness, the multitude  
of homes and struggles for income.

For some, survival means two things—  
prostitution for income,  
and the drugs to forget.

## Exact Moments

She's been clean now, for,  
do we want to know?

Tainted,  
the last several years.

She remembers the precise day and situation  
a fossil forever etched on her mind,

like we remember where we were  
When Kennedy was shot,  
Martin Luther King died,  
the day the *Challenger*  
exploded coming home

She remembers the very moment  
to sick for a fix,  
she shared the needle.

She can still vividly see  
those drops of blood, pooling in the barrel  
before sinking it.

Can infinitely describe the exact moment  
she became HIV-positive

and changed her life  
forever.

## Tall, Slender, and Well-Dressed

A burnt orange top,  
trendy straight-leg  
jeans, a black leather jacket,  
hair brushed just so,  
a little mascara,  
and a single glide of pearlized  
lip-gloss.

With a boisterous laugh,  
she jokes about *living under the Granville St. bridge*  
*while my friend occupies the nearby grain elevator.*

Positive and out, she hides nothing—  
*I'm an addict too.*

A part time outreach worker—  
the knower, lending guidance and understanding  
to the knowing.

Homeless and couch surfing,  
excited that a housing subsidy has come through  
so she can move in,

only to go away for treatment,

*To get my life  
and  
my children*

*back together.*

## **Identities**

I consider, *Who am I?*  
Fluidly,  
throughout my many life-roles.

Mother, Lover,  
as I cook and clean,  
drive back and forth  
across town to attend meetings,  
Dr. appointments, the Naturopath,  
tending to my dad,  
shopping.

Researcher, Writer,  
Woman of confidence,  
in constant struggle with self esteem.

I am fluid, no one of these roles,  
a hybrid of many.

\*

I consider, *Who are you?*  
Fluidly,

throughout your many life-roles.  
Mother, Lover,  
as addictions takes over,  
and you search for shelters  
instead of being able to pay the rent.

As you take the bus, skytrain,  
drive, or walk,  
go online at Carnegie Centre, visit a clinic,  
support group, or eulogize a friend at his funeral.

As an HIV-positive woman, an Aboriginal woman  
of strength and resiliency,  
of struggle, acceptance, and  
hope.

You and I,  
*Who are we?*

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## **Appendix A: Advertisement Poster**

Are You an Aboriginal Woman Living with HIV/AIDS?

**Will you consider sharing your experiences with me?**

I am a Métis graduate student wishing to have conversations with Aboriginal Women living with HIV/AIDS who want to share their stories so we can help fight against stigma and discrimination.

**The purpose of this collaborative study is:**

- To hear from Aboriginal women their own life-stories in order to explore a better understanding of the impact of living with HIV/AIDS
- To highlight many of the barriers to HIV/AIDS prevention for Aboriginal women
- To add to the low levels of information about Aboriginal women and HIV/AIDS in order to influence changes in social attitudes, healthcare providers, and medical policymakers

**How our findings (your stories) will be shared?:**

- In written form with your community, local agencies (service and healthcare providers), the university, research journals, and other groups of people you might suggest. (Your names will be kept confidential in all reports.)

If you are interested in hearing more about this study's goal to help eliminate stigma, or in talking with me, please leave your name with this agency you are visiting and I will contact you as soon as I am able. Or you may contact me at 604-910-8966 and leave a message. I will return your call.

Sincerely,  
Donna Hill  
Métis Nation, UBC Graduate Student

## **Appendix B: Letter of Initial Contact**

### **Study: Aboriginal Women Living with HIV/AIDS: An Empowerment Perspective**

#### **Letter of Initial Contact for Potential Participants**

A study is being conducted by a Métis Graduate Student that has the goal of coming to a greater understanding of what life is like for Aboriginal women who are living with HIV/AIDS. It is hoped that the information collected will be useful in improving the treatment and care of Aboriginal women who are living with HIV/AIDS, that it will discourage social discrimination and stigma related to living with HIV/AIDS, and that it will encourage future researchers to pay attention to this important area of study.

The Graduate Student who is conducting the study is Donna Hill. She is a student in the Interdisciplinary Graduate Studies department at the University of British Columbia, Okanagan, and this study is part of her Master's of Arts graduation requirements.

As an Aboriginal woman who is living with HIV/AIDS, and if you are of legal age of consent in BC (19 or older), you are a potential participant for this study. If you are willing to give up two to six hours of your time over the span of between one and three meetings with the researcher to participate in a confidential conversation with Ms. Hill, please let your service care agency contact person know. He or she will then notify Ms. Hill, who will contact you with the details of the research and clarify what is expected of you.

Please be assured that whatever your decision is, it will not impact any services, treatment, and/or care you may or may not be receiving from your service organization. Your participation in this study is purely voluntary, and should you participate, you are free to withdraw later if you want.

Should you wish to participate in this study, the information you provide will be kept confidential. Information that discloses your identity will not be released without your consent unless required by law or regulation. Your confidentiality will be protected in several ways (as mentioned in more detail on the Consent Form).

Thank you for giving this your consideration.  
Respectfully,

Donna Hill  
[dmhill@shaw.ca](mailto:dmhill@shaw.ca)  
Cell: 604-910-8966 (I will return your message)

## Appendix C: Consent Form

### Study: Aboriginal Women Living with HIV/AIDS: An Empowerment Perspective

#### Letter of Informed Consent

*Study Title:* **Aboriginal Women Living with HIV/AIDS: An Empowerment Perspective**

**Principal Investigator:** Dr. Michael J. Evans PhD, Canadian Research Chair, Community, Cultural, and Global Studies, Associate Professor, UBC-Okanagan.

Ph: 250-807-9401.

**Co-investigator:** Donna M. Hill, Hon. BA., is a Métis student in the Interdisciplinary Graduate Studies, Master's Program at the University of British Columbia-Okanagan. Donna Hill will be conducting this study as part of her requirements for graduation and it will be published as a thesis, which is a public document.

**Purpose:** If you are of legal age of consent in BC (19 or older), you are being invited to participate because you are an Aboriginal woman who is living with HIV/AIDS. The purpose of the study is to explore and to create a better understanding of the impacts of HIV/AIDS on the lived experiences and perceptions of HIV-positive Aboriginal women and their identities. It is also to inform and to affect in a positive way program and policy design and implementation to more specifically address the needs of Aboriginal women living with HIV/AIDS.

**Study Procedures:** If you agree to participate you will be asked to participate in a private, confidential, face to face interview at a location of your choice with Donna Hill. You may also be asked to participate in a follow-up interview to review the findings and to provide your perspective and opinion on the findings of the research. It is anticipated that each interview will take approximately one to one and a half hours. The interviews will be tape recorded. However, you may ask for the tape recorder to be turned off at any point in the conversation or have the tape erased.

**Risks and Benefits:** It is not anticipated that there will be any risk attached to your participation, although it is possible that disclosing personal information may be emotionally difficult. If this is the case, the researcher will ensure that you are aware of appropriate support services to assist you. Possible benefits include an opportunity to talk about issues that matter to you and the potential for the information to be utilized to improve health care services for Aboriginal women who are living with HIV/AIDS and to ultimately help reduce society's stigmatizing attitudes directed towards Aboriginal women living with HIV/AIDS.

**Confidentiality:** The information you provide will be kept confidential. Information that discloses your identity will not be released without your consent unless required by law or regulation. Your confidentiality will be protected in several ways:

1. All tapes, transcripts and notes will be labelled with a number code. This number code will be used for any reports or articles that are written about the study. Your name will not be used.
2. Information that could identify you or anyone else will be deleted from all interview tapes, notes and documents.
3. None of the people who are providing your treatment and care will see, read, or hear any of the information that you provide in a way that compromises your confidentiality.
4. The only people who will see the direct research information are the members of Donna Hill's thesis committee (Mike Evans, Jo-ann Archibald, and Rachele Hole), a typist, and Donna Hill. These people will be required to keep all information in strict confidence.
5. All information will be locked securely in an office located on UBCO Campus, Arts 382.

**Remuneration/compensation:** In recognition of your contribution to this research study, and in keeping with cultural and traditional gifting, a gift will be given to you in lieu of a monetary honorarium. Your level of participation will not affect payment of this honorarium/gift. You will still maintain the right to refuse to answer any questions that you are not comfortable responding to, end the interview, drop out of the study, or refuse a request for a second interview.

**Decision to Participate:** Please be assured that whatever your decision is regarding participation in this study, it will not impact any services, treatment, and/or care you may or may not be receiving from your service organization. Your participation in this study is purely voluntary, and should you participate, you are free to withdraw later if you want.

**Contact for information about the study:** If you have any questions or desire further information about this study, or would like a copy of the final results, you may contact Donna Hill at 250-306-4040.

**Contact for concerns about the rights of research participants:** If you have any concerns about your treatment or rights as a research participant, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598, or the Chair of the UBC-Providence Health Care Research Ethics Board at 604-682-2344 ext. 62325.

**Voluntary participation:** Your participation is entirely voluntary, so it is up to you to decide whether or not to take part in this study. Before you decide, it is important for you to understand what the research involves. This consent form will tell you about the study, why the research is being done, what will happen to you during the study, and the possible benefits, risks and discomforts.

If you wish to participate, you will be asked to sign this form. If you do decide to take part in this study, you are still free to withdraw at any time and without giving any reasons for your decision. By signing this form you in no way give up any of your rights and you do not release the study student or participating institutions from their legal and professional responsibilities.

If you do not wish to participate, you do not have to provide any reason for your decision not to participate, nor will you lose the benefit of any medical care to which you are entitled or are presently receiving.

Your signature below indicates that you have received a copy of this consent form for your own records, that the study has been explained to you and that all your questions have been answered, and that you understand what is involved in participating. If you are wishing to consent to participation in this study with verbal rather than written consent, the researcher will note this fact in the appropriate space provided below. You and the researcher will receive a copy of this "Informed Consent Form." Your signature or your verbal consent as noted below indicates that you freely consent to participate in this study.

\_\_\_\_\_  
Participant signature                      Printed name                      Date

\_\_\_\_\_  
Participant phone number

\_\_\_\_\_  
Notice of verbal consent given by participant, acknowledged in writing by researcher

\_\_\_\_\_  
Researcher signature                      Printed name                      Date

**Release of findings:**

If you would like a copy of the findings of this research please fill out the following: information.

**Address:** \_\_\_\_\_

**Phone number:** \_\_\_\_\_

**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

## Appendix D: Conversation Guide

Thank you so much for sharing what you are about to with me today. I know your stories are personal and intimate and I appreciate all you are willing for me to hear.

I am asking some questions to help our conversation along and to learn a little of what you experience so others can learn from it. If any of these are too personal or hurt your feelings, please accept my apologies, and simply tell me and we will pass on them.

Would you feel comfortable telling me what it is like for you living with HIV?

I'd appreciate hearing about some of your successes and challenges.

What is helpful for you?                      What gets in the way?

What does a good or a bad day look like for you?

Are there stages you went through as you lived with HIV?

How do you take care of yourself?

What about your relationship with your body? How has that changed?

How long did it take you to be able tell your story like you did today?

Were there earlier ways you told it? Who would you tell?

Who would understand you? Who wouldn't?

What led you to make some changes to your story?

What was the most difficult about first telling your story?

Who else would you tell it to because they would understand?

What would you want others to learn from your experiences living with HIV?

## Appendix E: UBC Research Ethics Board's Certificate of Approval

### H07-00856) HIV/AIDS Among Aboriginal Women

<b>Principal Investigator (PI):</b>	<a href="#">Michael J. Evans</a>	<b>Approval Department:</b>	UBCO Admin Unit 1 Arts & Sci
<b>Primary Contact:</b>	<a href="#">Cynthia M. Mathieson</a>	<b>Department Approver:</b>	<a href="#">Naomi M. McPherson</a>
<b>Type of Study:</b>	Behavioural	<b>Review Board:</b>	Behavioural Research Ethics Board
<b>Minimal Risk:</b>	no	<b>Co-Investigators with Signing Authority:</b>	There are no items to display
<b>Initial Approved Date:</b>	August 15, 2007	<b>Date Expires:</b>	June 28, 2008
<b>Current Approval Certificate:</b>	<a href="#">[View]</a>	<b>Version:</b>	1.0
<b>Type of Funding:</b>	Other (Enter details below), No Funding		