

**TWO-SPIRIT MEN IN WINNIPEG
AND THE EXPERIENCE OF HIV/AIDS**

by

Randall Jackson

**A thesis submitted to the Faculty of Graduate Studies
in partial fulfilment of the Requirements
for the Degree of**

Master of Arts

**Department of Sociology
University of Manitoba
Winnipeg, Manitoba**

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**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University
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Abstract

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by Randall Jackson

This exploratory study describes the everyday life concerns of seven HIV-positive two-spirit men living in Winnipeg, Manitoba. The focus of this study is on the intersection between presenting one self as gay and Aboriginal, and the reconstruction of identity following a positive diagnosis for HIV disease. Guided by standpoint epistemology, notions of "the other," phenomenology and use of the medicine wheel, qualitative methods were utilized to collect and analyse the data. Findings revealed a coalescing of themes around four discrete categories that express the essence of participants' experience of HIV infection and AIDS. This study highlights (1) how these men experienced life prior to diagnosis, (2) how they dealt with the initial knowledge of HIV infection, (3) what everyday life with HIV entails, and (4) how they cope with future representation of HIV as illness. In examining these themes, this study reveals how these men imbue their on-going struggles with HIV/AIDS with a sense of spirit, focus, and emotional strength using cultural resources.

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TABLE OF CONTENTS

Abstract	i
Acknowledgments	ii
Table of Contents	iii
List of Tables	v
List of Figures	vi
 Introduction	 1
The Research Question	3
Rationale	3
 Theoretical Perspectives	 8
Standpoint Epistemology and the Concept of "The Other"	9
The Phenomenological Perspective	16
The Medicine Wheel	19
 Review of the Literature	 26
HIV/AIDS History, Disease Spectrum and Epidemiology	26
Disease Spectrum: AIDS and HIV Infection	27
HIV Transmission	28
AIDS Disease Spectrum	29
A Brief History: AIDS in Canada	31
Conceptualizing HIV/AIDS as a Chronic Disease	36
The Sociology of Chronic Illness	39
Disrupted Biographies	41
Uncertainty	44
Stigma	49
Sexuality	54
Treatment Regimens	58
Gay Culture and the AIDS Epidemic	63
 The Study	 67
Research Methods	67
The Interview Guide	72
Analysis	74
Ethical Considerations in the Conduct and Analysis of the Interviews	77
Validity	79
 The Study Participants	 84
 Analysis of Thematic Content	 104
Life Prior to HIV Diagnosis	108

Discovery of HIV Positivity	121
Everyday Life with HIV Infection and AIDS	131
Facing the Future	137
Discussion	145
Implications for Policy and Practice	154
Recommendations for Future Research	155
Lessons Learned from the Conduct of this Study	156
Limitations	160
Appendix A: POSTER/NEWSPAPER ADVERTISEMENT	165
Appendix B: BUSINESS CARD ADVERTISEMENT	166
Appendix C: INFORMATION BROCHURE, CONSENT AND ETHICS FORM	167
Appendix D: THE INTERVIEW GUIDE	171
Bibliography	173

LIST OF TABLES

Table 1: The AIDS Spectrum in the Canadian Population	30
Table 2: Selected Participant Characteristics	85
Table 3: Themes about HIV Experience Prior to HIV Infection	109
Table 4: Themes about HIV Experience Upon Discovery of HIV-Positivity	121
Table 5: Themes about Everyday Life with HIV Infection and AIDS	132
Table 6: Themes about Facing the Future with HIV Infection	138

LIST OF FIGURES

Figure 1: HIV/AIDS Medicine Wheel	22
Figure 2: Two-Spirit Men and Identity Shifts: Identified Thematic Categories	107

Chapter One

Introduction

As rates of HIV infection within the Aboriginal community continue to climb, it will be necessary for AIDS service organizations, medical practitioners and mental health professionals to respond in a culturally appropriate manner. In order to be credible, accessible and relevant to Aboriginal people, services and programs for the care, treatment and support of those with HIV infection will need to address cultural and social realities (Casimir and Morrison, 1993). As Jean Lau Chin states, "[Standards] of culturally competent health care need to be developed, mandated, and monitored across [...] the [entire] health care system to be responsive to all segments of the population" (2000: 33). This seems particularly important given that Aboriginal persons living with HIV/AIDS tend to seek Western medical intervention at much later stages in the progression of the disease. At the *Seventh Annual Canadian Conference on HIV/AIDS Research*, Goldstone, Demerais, Hogg, Perry, Albert, Markoski and McLeod reported that, "First Nation persons were sicker earlier, [had] shorter survival rates, more admissions and hospital days, and fewer palliative care days than non-Aboriginal persons" (1998: 136). Anecdotal reports have found a number of Aboriginal people refusing treatment at a community health centre in Winnipeg, Manitoba (Smith, 1998). Research among other cultural groups lends support to this observation. As Saskoff, McFarland and Shin observed:

The use of antiretroviral therapy often differs in sub-populations of HIV-infection patients. Lower rates of zidovudine (AZT) and other NRTIs have been reported for non-white patients and for injection drug users (IDU), and longer delays in starting AZT after it is first

offered have been observed among nonwhite females and IDUs. When PIs [protease inhibitors] were first introduced in 1996 and 1997, lower rates were reported in IDUs, blacks and patients at public clinics. (2000: 178)

In another study, Black Africans living in London, England tended to be diagnosed later than Caucasians and appeared to have a lower uptake of antiretroviral treatments (Erwin and Peters, 1999: 1520). Adams (1997) has pointed out that in Aboriginal people, and presumably other cultural groups, this reluctance to engage with health care may be the result of social marginalization, and the pressing concern to deal with other issues, such as unemployment, poverty, housing, violence or addiction. In other words, HIV simply presents itself as another challenge for populations already at risk or living on the margins of society.

Another possible reason for poorer health outcomes may be that Aboriginal people refuse Western medical intervention for HIV infection, and at least for some, prefer more natural, holistic, traditional approaches to disease management. As Schilder, Strathee, Goldstone, Trussler, and O'Shaughnessy state, "Culturally competent health care must provide social safety to foster self-identity within care relationships, [...] to improve health outcomes and adherence to HIV therapy" (1998: 159).

With the exception of the studies noted above, to date there has been few studies that focus attention on the lived experience of HIV/AIDS for Aboriginal community members. Most studies focus on the epidemiology of HIV/AIDS, the natural history of the disease, and transmission risk factors. While attention to HIV/AIDS has increased in recent years in the area of uncertainty (Weitz 1990b; Steven and Doerr 1997; Davies 1997), stigma (Weitz 1990a; Carricaburu and Pierret 1995; Lawless, Kippax and

Crawford 1996), treatment (Sowell, Phillips and Grier 1998; Broun 1998) and the impact of HIV/AIDS on human sexuality (Sandstrom 1996; Tweeksbury 1995), none of these studies has focussed specific attention on what it means to be gay, Aboriginal and be HIV-positive or have AIDS. In order to begin the process of rectifying this gap in the sociological literature, this study explores the experience of HIV from a two-spirit male perspective.

The Research Question

The purpose of this qualitative study was to explore various aspects of gay Aboriginal (two-spirit) male experience of living with (and in spite of) HIV infection and AIDS. Specifically, I am concerned with highlighting the intersection between presenting one self as gay, Aboriginal and HIV-positive. I am also interested in the reconstruction of identity following a positive test result for HIV infection.

Rationale

There are at least three reasons for a qualitative exploration of the experience of HIV among two-spirit men in Winnipeg. The first reason is the absence of any other such analyses in the sociological literature. While the literature since the 1960s has documented the lived experience of other illnesses, sociologists have only recently become interested in studying these experiences in the context of HIV/AIDS (Weitz, 1990a: 24). Moreover, in my review of the literature I have encountered little about the experience of illness with respect to the Aboriginal population. As Rowell states, "Research on American Indian health in general and AIDS in particular is scarce" (1997: 87). Certainly, no sociological studies were located that deal specifically with the HIV-

positive two-spirit experience with illness. A qualitative study of this type will contribute significantly to our understanding of this experience and as well suggest possible future research directions.

Another reason stems from a desire to influence the development of culturally sensitive and appropriate responses within health care. As suggested above, the production of knowledge may stimulate such responses and will no doubt benefit HIV-positive gay Aboriginal males as they seek medical care and treatment for their infection. As Charmaz has noted in her research on chronic illnesses, such analyses "can provide physicians with alternative understandings of [patients'] beliefs and actions [not] readily available in clinical settings. Subsequently, physicians may use these understandings to improve communication and to act on problems which patients define" (1990: 1161). Thus, physicians and other care providers may be provided with the necessary understanding to adapt and respond to the needs presented by Aboriginal HIV-positive gay male clients. As Waldram, Herring and Young state, "a culturally sensitive environment must be created in order for the whole person - mind, body, and spirit - to be healed" (1995: 254). In short, knowledge of this group's experiences may stimulate the development of sensitive, relevant and culturally appropriate health care for HIV-positive two-spirit males. To ignore this fact may create inhospitable environments for Aboriginal people seeking competent health care. Cultural barriers within health care, at least in part, account for reduced demand and reduced use by Aboriginal people (Waldram, Herring, and Young, 1995). Indeed, this may tentatively explain results presented by Goldstone, et al. (1998) in which HIV-positive Aboriginal

people were found to be sicker and dying sooner than non-Aboriginal people.

My own experience provides yet a third reason for this study. I am not totally outside nor am I am far removed from the experience of HIV/AIDS. My first experience with AIDS occurred in 1986 when a close friend, Frank, disclosed his HIV status over dinner. I have since been a witness to HIV/AIDS as much more than a medical phenomenon with a devastating disease trajectory. I watched as my friend struggled and adapted to the often profound social and political ramifications of this disease. It was also during this time, some four years later, that I too was diagnosed with HIV infection. I had joined Frank in his struggle to find competent health care, in a social world and a political system that too often ignores the larger issues AIDS raises. In late 1993, as I was nearing the completion of my undergraduate degree in Sociology, Frank died of complications related to HIV infection. It was then that I resolved that something more needed to be done.

Beginning graduate studies at the University of Manitoba also marked my full-fledged involvement in the Canadian AIDS movement. For the next two years, I chaired the board of a community health clinic with a specialty in HIV care, treatment and support, and I attended numerous AIDS conferences across the country. I also, over this time, volunteered time and energy in several other organizations, including the Manitoba Aboriginal AIDS Task Force and AIDS Shelter Coalition of Manitoba.

Later, concerned with a number of HIV/AIDS issues that were not being addressed, I along with several other similarly minded individuals helped organize the Manitoba AIDS Cooperative (MAC), whose central mandate is political and system

advocacy. MAC addresses the issues of standards of care in HIV/AIDS care, treatment and support. Over time, I became increasingly aware that many HIV-positive individuals were often no longer able to work, living in poverty, and also had to contend with treatment access issues determined by a bureaucratic process in which they had no voice and little control.

This growing awareness led me to the national level in which I served as a board member with the Canadian Treatment Advocates Council, an organization dedicated to addressing various treatment advocacy issues such as reforms to the Health Protection Branch (Health Canada), opposing drug pricing structures, and direct-to-consumer marketing campaigns sponsored by large and powerful multinational pharmaceutical companies. As well, I participated on the HIV Advisory Committee of the Canadian Palliative Care Association, played a minor role in developing a program for a national conference hosted by the Canadian AIDS Society, and reviewed community-based research funding proposals for Health Canada.

My involvement in the Canadian AIDS movement has led me to an understanding that Aboriginal people may have a much different experience of HIV/AIDS and approach to treatment than non-Aboriginal people. In 1996, I attended the *Healing Our Nations: Fourth Canadian Conference on HIV/AIDS* in Halifax, Nova Scotia. Dr. Terry Tafoya, a two-spirit psychologist, whose AIDS and addiction work is well known in the United States, delivered the keynote address. A gifted storyteller, he related the tale of a young man's encounter with Darshea, a member of the Sasquatch family and reputed to live off human flesh, while being forced to camp deep in a

northwest coast forest. On that particular night, the moon was full. This full moon is of central importance to Tafoya's keynote. According to Tafoya, European culture teaches that the face of the full moon is that of a man, whereas the Chinese tradition holds it is a rabbit. Still others believe that it is a woman. For Aboriginal people living on the northwest coast, and other cultures of Native society, wise old elders teach that the face of the moon is really a frog (Tafoya, 1996: 3). "In other words, even though we have the same physical experience of reality our culture teaches us to understand that experience in a different way" (Tafoya, 1996: 4). For me, Tafoya's keynote provided grounding in a belief that as an Aboriginal person my experience and understanding of HIV/AIDS may be quite different than those of other individuals of different cultural groups. It would therefore be important to explore the experience of HIV/AIDS from the perspective of two-spirit men in their own right and to explicitly examine the 'situatedness' of their experience relative to HIV/AIDS as a chronic illness.

It was on this basis and against this backdrop that this research was originally conceived. In short, this research is much more to me than a theoretical abstraction and the application of expert methodology. My passion and desire are for the results of this study to influence the quality of health care that is provided to two-spirit people. Its findings may be important to the two-spirit men, women, children who in future may join the path of living with HIV/AIDS.

Chapter Two

Theoretical Perspectives

The literature to date reflects an impressive accumulation of knowledge on the subject of illness experience, particularly identity reconstruction (Bury, 1982; 1991; Charmaz 1983; 1992; Frank 1993; 1995). However, researchers have often overlooked two-spirit experiences, particularly those related to HIV/AIDS. In most cases, the sociological literature on HIV/AIDS describes ill individuals as culturally homogeneous, or refers to other marginalized groups such as individuals who inject illicit drugs, blacks and Latinos.

It cannot be assumed that research on gay men of European descent with HIV captures the diversity of experiences for those who have been diagnosed. Similarly, the studies that focus on other cultural groups such as blacks and Latinos may not apply to two-spirit men. While two-spirit men with HIV may share some experiences with other gay men, and with members of other minority groups, all of whom have been diagnosed with HIV infection or AIDS, it is nevertheless important to ascertain what their experiences are in their own right, and as they may be compared to others facing HIV/AIDS. In this chapter, I outline the various theoretical perspectives that are used to ground this study.

Several theoretical perspectives are useful in identifying and understanding aspects of the lived experience of HIV/AIDS from a two-spirit point of view. This analysis of two-spirit experience of HIV/AIDS draws upon feminist standpoint epistemology, utilizes the concept of 'otherness,' the phenomenological tradition, and the medicine wheel to

construct a plausible outline of experiences from the perspective of HIV-positive two-spirit men.

Standpoint Epistemology and the Concept of "The Other"

Is the lived experience of HIV-positive two-spirit men different from that of non-Aboriginal people living with HIV infection and AIDS? Are there any similarities in their experiences? These questions can be best addressed as a starting point that includes the experiences of HIV-positive two-spirit men. In this vein, it is therefore important to first highlight the particular merits of feminist standpoint epistemology coupled with a brief discussion of the notion of 'otherness.'

The underlying focus of feminist standpoint epistemology is the 'situatedness' of the subject or 'knower.' This framework purports that knowledge arises from the place that women occupy within society. As Smith states, "The fulcrum of a sociology for women is the standpoint of the subject" (1987: 105). It is essentially a framework that acknowledges and supports the development of knowledge that springs from the everyday lives of individual women within society, considering them experts on particular subject matter. Experience of the social world is shaped by social groups in which individuals hold membership. As such, feminist standpoint epistemology gives power and authority to the collectivity of experience of individual members of a given social order.

It is a sociology for women and of women, that for Smith, grew out of the ideas, writings, and thoughts of Karl Marx. Marx suggests that the role of the proletariat within civilized society was positioned around and reflects the experiences of an oppressed class. A history of civilized society, he felt, was primarily centred on a history of different types

of class exploitation and domination. Furthering his concept of class exploitation, he believed the proletariat, unlike the exploiting class of bourgeoisie, possessed a greater ability to capture and understand their experiences of oppression and of the oppressor clearly (Millen, 1997). In some senses, the history of class struggles continues although for Smith it has continued through the lens of gender in which women are an exploited and dominated class. In short, a feminist standpoint epistemology allows one to develop an understanding of systems of power and how they shape experience within the social order (Smith, 1987). It is a criticism of the status quo because the structure upon which it rests largely dominates and oppresses those who do not occupy positions of power.

Smith contends that a sociology for women must necessarily explore the material relations within which women are active participants. As Smith states:

[It is a] sociology [of] systematically developed knowledge of society and social relations. The knower who is construed in the sociological texts of a sociology for women is she whose grasp of the world from where she stands is enlarged thereby. For actual subjects situated in the actualities of their everyday worlds, a sociology for women offers an understanding of how those worlds are organized and determined by social relations immanent in and extending beyond them. (1987: 105-6)

In reorienting the scientific pursuit of knowledge production, standpoint epistemology stands in opposition to more dominant sources of knowledge and values - namely, positivistic, objective, and neutral stances of a researcher vis-à-vis research participant. In short, standpoint epistemology rejects the notion of objectivity and neutrality in the development of knowledge (Millen, 1997). It argues that individual members of the social order, when making statements or assertions about the world in which they are a part, are necessarily subjective, and that objective standards can often be

falsely applied in the measurement of particular standpoints. In short, the development of a position starts where the 'knower' is situated, thereby rejecting and avoiding the world as neutral and objective.

Thus, standpoint epistemology is a critique of the dominant structures that embody scientific pursuits. It is essentially an analysis of power that is central to the production of scientific knowledge. As Lorber states, "Simply put, standpoint feminism says that women's 'voices' are different from men's, and they must be heard if women are to challenge hegemonic values" (1997: 22). As such, standpoint epistemology stands on a principled rejection of notions located within the boundaries of conventional science. The dominant structures of scientific discourse conceptualize the research participant as an object of study where the social scientist has been, and in many ways, continues to be seen as primary 'knower.' Social scientists, in traditional social scientific discourse, hold ultimate knowledge about the social world, and therefore power within society and in the organization of the material relations of the social order. Smith continues, "A sociology for women preserves the presence of subjects as knowers and as actors. It does not transform subjects into the objects of study or make use of conceptual devices for eliminating the active presence of subjects" (1987: 105). In this sense it uses methods of scientific discovery that accomplish the preservation of women as 'knowers' within the scientific pursuit of knowledge.

Embodied within this criticism, standpoint epistemology embraces the notion of individualities and rejects the position that would lead to assimilation into a (European) male view of the world. Turner states, "feminist standpoint epistemology is based on the

idea that knowledge begins with women's lives and experience. Multiple feminist standpoints are possible, all of which are different but not necessarily disjointed. Feminist standpoint epistemology allows for a multiplicity of ideas of truths" (2000: 4-5).

Women's standpoint is situated in the everyday world as problematic, as Smith (1987) suggests, but situations differ, and consequently, so do perspectives. Scientific knowledge, and therefore, scientific truths must necessarily be viewed as partial (Harding, 1991). It is this diversity that is the greatest strength of feminist standpoint epistemology (Turner, 2000).

Overall, a similar logic applies when considering the experiences of two-spirit men whose otherness stems from their multiple locations, as Aboriginal persons in a predominantly white society, as gay in a heterosexist society, and in some cases, as poor people in a wealthy society. In our society, for example, many of our unquestioned assumptions about the nature of experience concerning HIV/AIDS as a chronic illness have been built upon unquestioned assumptions. They arose out of social scientific discourses pertaining to the experience of gay males of European descent or other marginalized groups, notably individuals who use injection drugs, blacks or Latinos. Most members of our society believe unquestionably these 'scientific facts' and rarely, if ever, question their objectivity (Lorber, 1997).

Just as women's experiences are grounded in the material reality of the social world in ways that men's are not, so too are the experience of Aboriginal individuals vis-à-vis white persons and other marginal groups. For much of Canada's history, Aboriginal people have been excluded from the production of socially acceptable scientific

knowledge, and from the social, economic, and political realms in ways that men located within the dominant circle are not. Knowledge produced within Aboriginal culture, for the most part, was largely ignored and had little validity in relation to the dominant structure within society. If two-spirit men living with HIV were allowed to produce knowledge, it would be more in tune with their everyday material world and with the (inter-)connectedness among people. As such, it would not simply be enough to include a two-spirit man (myself) at the head of a research project, to conduct research on other members of Aboriginal society (two-spirit men living with HIV infection). A standpoint epistemological framework offers a critique of mainstream concepts and definitions that have in the past been used to justify and establish lines of power and domination, and recognizes that scientific facts and knowledge reflect current values and past history.

What is most unique about this feminist perspective is that it does not reject accumulated knowledge concerning experiences about HIV/AIDS. It does, however, present the possibility that two-spirit experiences of HIV/AIDS may assume a rightful place and enhance existing knowledge about experiences of HIV/AIDS as a chronic illness that requires significant adaptations and adjustments.

As suggested earlier, the notion of 'otherness' is a central issue and important concept in the development of a sociology of the two-spirit experience of HIV/AIDS. Much conventional sociological thought has embraced the objectification of the subject into sociological texts. In short, a social science built on objectification of research respondents allows us to conceptualize some individuals as 'other.' In this sense, it would flow seamlessly to speak on behalf of this 'other' for there is "no need to hear

[their] voice[s] when I can talk about [them] better than [they] can talk about [themselves]" (hooks, 1999: 151-152). Social science, and indeed, sociology has been built upon the principles of neutrality and objectivity, to produce scholarly discourse that is at once understandable, presentable, and acceptable to much of our social scientific inquiries.

However, such speech can, and has been oppressive, racist, and used by the social sciences as a tool of domination (Fine, 1994). This point is highlighted here, using a metaphor developed by Smith (1987) to highlight the notion of 'otherness.' As a passenger on a train she may look upon, as the train glides by, a group of Aboriginal people watching. At first glance, they appear to be family. For Smith (1987), this metaphor described the process of 'othering' and provides a spring board for the need to account for a 'situated knowledge perspective' within research. As Smith acknowledges, "her ordinary descriptive procedures incorporate interpretations unchecked by the experience of those she describes. She has called them 'family,' but were they a family? Were they actually watching the train? But the issue is not only that of accuracy. It is also that she has laid down the agenda of description and its terms" apparently without allowing the voices of those she has observed to illuminate her understanding (1987: 112). For Smith it was necessary to move beyond mere description, of observing, of reporting these observations to a wider academic community. "The problem," according to Smith, "confronted her is how to do a sociology that is for women and takes women as its subjects and its knowers when the methods of thinking, which we have learned as sociologists as the methods of producing recognizable sociological texts, reconstruct us

as object” (1987: 109). For Smith, it is necessary for us to move beyond mere description to the “investigation of these relations and the exploration of the ways they are present in the everyday and must be a specialized enterprise, a work, the work of a social scientist” (1987: 110).

The concept of ‘otherness’ is a particularly important concept when considering this research project as it is not only about discovering the everyday world of two-spirit men living with HIV infection and AIDS; It is also geared towards inspiring social change, to stand in both social and political solidarity with those studied. The notion of two-spiritedness, and of their experience with AIDS demands, confronts and resists the “consolidated white wash” (Fine, 1994: 72) so often presented in the ‘scholarly discourse’ of the HIV/AIDS illness experience. As Fine states, “When we opt, instead, to engage in social struggles *with* those who have been exploited and subjected, we work the hyphen” between self and other (1994: 72, italics in original). Working the hyphen requires a researcher to examine his/her own relationship in a given research context, and to elaborate on the relationship to those researched. Such accountings present the possibility of allowing the voices of participants to be heard in “all its noisy dialect of the other” (Fine, 1994: 73). Notions against ‘othering’ direct the researcher to stop attempting to gain knowledge about the ‘other’ or even to give voice, and instead to listen and reveal (Fine, 1994). Moreover, the possibility of social research for social change is engaged; to interrupt the process of ‘othering’ and present the voices of HIV-positive two-spirit men that otherwise would have been ignored. This powerful notion of ‘other’ is firmly entrenched in social inquiries and has been centred on objectification of

the 'knower,' especially given its implied assumption that it equally represents the experiences of two-spirit men living with HIV/AIDS.

The Phenomenological Perspective

The problem, then, is how to use and understand the perspective of two-spirit men living with HIV infection and to develop knowledge where the subject of social investigation is both the object of study as well as the 'knower,' i.e., to start from the 'situatedness' that is peculiar to two-spirit men living with HIV/AIDS.

In this study of HIV-positive two-spirit male experience of HIV/AIDS, this has directed me towards a phenomenological approach. Phenomenological studies have the potential to provide rich and detailed descriptions of the lived experiences of individuals in a given social context (Creswell, 1998). Phenomenology is based on the assumption that social actors actively construct experience (Holstein and Gubrium, 1994). That is, "phenomenology discloses the manner in which individuals actively constitute the meaning of his experience" (Toombs, 1987: 220). Social science, according to Schutz, needs to focus on the variety of ways the life world is "produced and experienced by [its] members" (Holstein and Gubrium, 1994: 263). Such social science inquiries must examine the commonsensical world of social actors and the "practical reasoning members use to 'objectify' its social forms" (Holstein and Gubrium, 1994: 263). As Toombs states, "Phenomenological approaches [...] emphasize that illness is intelligible as a lived experience - an experience that can be rigorously examined and elucidated" (1987: 220). According to Holstein and Gubrium, the resulting "typifications make it possible to account for experience, rendering things and occurrences recognizable as *being of a*

particular type” (1994: 263, italics in original). Thus, the goal of phenomenological inquiries is to provide thematic descriptions of the lived experience of reality for a given set of members within a given social order (Thompson et al., 1998: 137).

This being the case, language is the necessary means by which members of the social order express these themes and attach meaning to experiences and events (Holstein and Gubrium, 1994: 263). In short, language is used to convey information and to describe the reality of lived experience. In this way, members of the same order are able to understand the actions and meanings of another (Holstein and Gubrium, 1994). Narratives convey to the listener the meaning of that experience (Kelly and Dickinson, 1997: 255). The task for phenomenological researchers is to draw out the patterns that emerge from first-person accounts of lived reality. As Thompson et al. state:

Phenomenology's world view is a contextual view in which experience is seen as a pattern that emerges from a context. The ontology (nature of being) is in-the-work: experience and work are viewed as co-constituting. The research focus is on experience as described from a first-person view. [...]The research goal is to give a thematic description of experience. (1989: 137, italics in original)

A phenomenological approach to the study of HIV/AIDS has the potential to highlight the lived experience of reality for HIV-positive two-spirit men. Coupled with a standpoint epistemological framework, and the notion of 'other,' it has the added potential of developing knowledge about two-spirit men living with HIV/AIDS from their position within the social order. Furthermore, phenomenology presents the possibility that everyday lived experiences of HIV/AIDS can be described. As Toombs (1987) suggests, the meaning attached to this experience can also be elucidated through sharing stories or narratives of that experience.

In short, while an individual may not consciously reflect on the manner in which reality is experienced, through a process Edmund Husserl called “‘reduction’ or ‘bracketing’ [...] the individual makes explicit the activity of experiencing itself. His concern is no longer with the object-as-such, but rather with object-as-it-is-perceived or as-it-is-experienced” (Toombs, 1987: 221). In this study, utilizing an interview method, two-spirit men are asked to share their experiences living with HIV infection, including their personal discoveries of HIV infection, their experiences accessing conventional medicine and traditional modalities, and the meanings they attach to such experiences. Using a phenomenological perspective, it will be possible to explore the shifts (physically, socially, psychologically) that individuals have experienced during the time that they have been living with HIV/AIDS. That is, the significance of this disease in their lives can be explored, as well as how they have accommodated to the condition since being diagnosed.

It is important to note that language is often used to convey information and attach meaning to experience. It is, therefore, entirely possible, if not probable, that members of similar social orders may ascribe divergent meanings to the same or similar experiences. Take the use of the word ‘faggot,’ as an example. For a gay man to use this word to describe his experience of his sexual orientation, the term is used as a cultural reference. It can be taken as entirely agreeable reference by other gay men, for it denotes a political stance that is meant to reclaim the word that is often thrown at them by others to hurt or harm. For another individual, for example, a heterosexual, to use this word to describe a gay man’s experiences, it has a meaning that denotes perversion or

sexual deviance. In short, the use of the word 'faggot' to describe a gay male experience of his sexuality is taken in a derogatory sense, a disgusting view of individuals who have sexual relations with members of his own sex.

It is this possibility, the importance of considering the contextualization of meaning, that makes phenomenology appealing. This example and others discussed in this research highlight the importance of standpoint epistemology, or 'situated knowledge,' and notions of 'otherness.' That is, when considering the situatedness of two-spirit men living with HIV, how does context and meaning differ from other cultural groups of individuals also living with HIV?

The Medicine Wheel

Sociological researchers have extensively studied the experience of illness. Still, some populations have been ignored in the extant research literature. In addition, meanings that fall within the metaphysical realm have been largely ignored. As Conrad states:

[The experience of illness includes] as central the meaning people attribute to their experience and how they make sense of what is happening to them and their bodies. The definitions people hold of health and illness, as well as the explanatory models they use, affect both their experience and what they do about it. As some recent investigators note, people's interpretations of illness embody their attempts to deal with the problems of meaning linked with illness, pain, suffering, and death. Thus, we can think of meaning here in two ways: the interpretive sociological sense of meaning people create and attribute in the course of their everyday lives and the more 'ultimate' meaning including the more 'metaphysical' understandings in terms of an individual's personal meaning of life, death and the unknown. (1990: 1261)

Sociological research that seeks to understand the Aboriginal experience of illness must bridge understanding in order to create or reflect a holistic perspective or experience

of illness. Explanations of two-spirit illness experience, including identity reconstruction, must include sociological inquiry into physical, mental, emotional and spiritual components of an illness experience. As Conrad asserts, it is time for sociologists to provide conceptual models of the "theological and philosophical meaning of maladies" (1990: 1261). This type of conceptual work can develop explanations of alternative meanings associated with a two-spirit experience with HIV/AIDS. Moreover, it presents the possibility of identifying concepts, categories, and explaining relationships between concepts that can provide an initial framework for guiding prediction (Charmaz, 1990).

In this study, exploration of spiritual experiences and meaning attached to illness from an Aboriginal perspective is essential. To the traditional mind-body dualism we add the spiritual component and lay it bare, exposing and revealing a critical aspect of the HIV-positive two-spirit male experience of HIV/AIDS. For example, holistic approaches inherent in the medicine wheel used in many Aboriginal cultures may provide an initial outline of concepts and categories, and explain possible relationships, thus allowing for potential prediction of the nature of the HIV/AIDS experience with respect to HIV-positive two-spirit men.

Introducing a feminist epistemology married with a phenomenological perspective to the study of two-spirit experience of HIV/AIDS would require a willingness to abandon beliefs about the nature of how the world can be (objectively) known and experienced. However, an important issue arises when we consider whether it is possible to couple a positivistic view of the world, inherent in the medicine wheel, with more interpretive formulations of knowledge produced and located at the centre of a feminist

standpoint epistemology and a phenomenological framework.

The point here is to examine the interpretive understanding through which empirical and subjective realities converge, or rather collide, and are created. As Ezzy states:

To 'seriously question' the 'ontological status' of the empirical world [...] is not to deny it, but to problematize it. These are very different things. Some analysts seem to think that the problematizing of empirical reality means denying its existence. However, the point is to examine the interpretative process through which empirical and subjective realities are created. (1998: 170)

To question the very nature of being through interpretive understanding is not denying the existence of a positivist view of empirical reality, it is to merely think about and to question what is seen and experienced by members of a particular social and cultural order, and consequently to arrive at some notion of understanding about that experience. It is therefore entirely possible, as I understand it, to describe the empirical world through interpretive processes; indeed it is necessary to developing and acknowledging the world arrived at through subjective standpoints. Ezzy follows Ricoeur:

I [too] argue that the dichotomy between objective uninterpreted experience is a false one. [...] To dichotomize experience and interpretation demonstrates a misunderstanding of the hermeneutic point about the nature of reality and can be seen as the result of a lingering positivism that attempts to deny the linguistically mediated nature of the events of lived experience. (1998: 172)

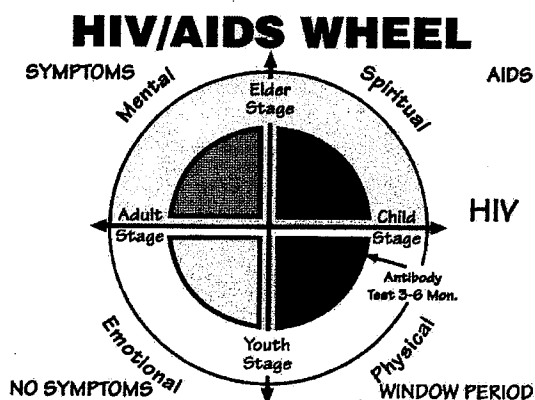
Action, much like lived experience, is "symbolically mediated, symbols acting as a quasi-text that allow conduct to be interpreted" (Ezzy, 1998: 172).

Founded on Native cultural traditions, the HIV/AIDS Medicine Wheel is a symbol and conceptual tool that has the potential to provide more detailed and complete descriptions of HIV-positive two-spirit experiences. It focuses on the metaphysical as

well metaphorical, rather than relying solely on spoken words, a situation that Smith (1987) says social scientists must attempt to rise above.

The wheel represents Mother Earth, the universe, all life, their cycles, and the seasons. Figure 1 depicts a conceptual tool, first developed by an HIV-positive

Figure 1:
HIV/AIDS Medicine Wheel



(Manitoba Health, 1998)

Aboriginal man in British Columbia (representing Healing Our Spirit, a community-based Aboriginal AIDS service organization), it is now often used in Aboriginal communities in Manitoba to explain HIV/AIDS and the stages of illness, or the disease trajectory. The HIV/AIDS medicine wheel is a typological representation, adapted from the concept of the medicine wheel, which deals with the effects of HIV/AIDS within Aboriginal communities. It explains HIV/AIDS within a holistic perspective that accounts for the physical, emotional, mental, and spiritual aspects of living with and experiencing HIV/AIDS. It begins in the east with initial HIV infection (the east direction or child stage) and continues through the asymptomatic (south direction or youth stage),

symptomatic (west direction or adult stage) to full-blown AIDS (north direction or elder stage).

Starting in the east, this position highlights stages of mental, emotional, and spiritual development needed to adapt to and live in balance with HIV/AIDS. In the east, the 'window period' begins shortly after a person is infected with HIV. It is the child stage of development and the physical component of HIV, and is represented by the colour red and the invasion of HIV into the blood system (sero-conversion). It acknowledges the need to connect with a strong, accepting community, before acquiring skills and tools for dealing with HIV infection (south position).

In the south position, the person is asymptomatic. This period lasts approximately 10 or more years, and approximates the youth stage of development. Represented by the colour black, it speaks of the stigma and shame, fear and anger that are common reactions to an HIV diagnosis. It is the emotional phase relating to how individuals experience HIV on an emotional level, as they work through issues of disclosure, confidentiality, and counselling. The south position also represents a stage of learning and exploration in which individuals adjust to and learn to live with HIV.

The teaching of the west is adult-centred, and focuses on the need to develop a sense of independence prior to movement to the north, or elder stage. Represented by the colour white, it acknowledges aspects of hope, knowledge and acceptance of HIV infection. It is the mental phase of development in which such important decisions about treatment and disclosure are considered.

In the elder stage, an individual is prepared to share his/her gifts or talents with a

wider audience. Woven into this movement is one's spiritual life. As Kutcher, Olfert, and Schellenberg state, "Sharing by teaching and doing is necessary for our spiritual growth and to grow out of self-centredness. Everyone needs the opportunity to 'give away,' to give back to the circle, to share their story" (1998: 21). Represented by the colour yellow, it is also a time when a person has developed AIDS, is confronted with notions of his/her own mortality, and a time when healing and resolving old issues is paramount. It is the stage of finding closure, healing, and self-acceptance. In short, the HIV/AIDS medicine wheel not only provides HIV-positive two-spirit individuals with a 'road map' for living a full and meaningful life, it can also provide physicians and other care providers with alternative approaches to delivering treatment, care, and support to HIV-positive two-spirit people.

Central to presenting the medicine wheel as a framework to guide analysis is the over-arching question of whether it has utility. Can it be used to accurately filter an interpretive understanding of an Aboriginal worldview and to describe the experiences of two-spirit men living with HIV/AIDS? The important point here is to acknowledge the medicine wheel as a conceptual tool that would allow understanding of transitions as an individual moves through the illness trajectory. As well, it allows for comprehension of the multidimensional features of experience, that is, focussing our attention as Conrad (1990) notes, on spiritual, emotional and social aspects of illness experience.

The guiding principle that is gleaned from the various perspectives highlighted in this chapter and that are used to ground this study, include the notion that like women, gay men and Aboriginal men who are gay and living with HIV infection are marginalized.

Standpoint epistemology, the notion of otherness, and a phenomenological perspective allows one to understand the 'situatedness' of the male two-spirit experience of HIV and AIDS. The medicine wheel, rather than being deterministic in nature, provides a culturally-relevant framework to understand how two-spirit men might experience HIV.

Chapter Three

Review of the Literature: HIV/AIDS History, Disease Spectrum and Epidemiology

Knowledge of epidemic trends, distribution and epidemiology, including an understanding of the history of the AIDS epidemic, are important factors in understanding the two-spirit experience of HIV/AIDS and in planning/developing programs and services to address the needs of this particular population.

Just a little less than twenty years ago, few Canadians had heard of the Human Immunodeficiency Virus (HIV) or Acquired Immune Deficiency Syndrome (AIDS). The first case of AIDS in Canada occurred in 1979, but it was not officially recognized as such until 1983. Since that time, reported cases of HIV and AIDS have increased exponentially. In April, 2000, Health Canada reported, “[s]ince the beginning of the epidemic a total of 45,534 positive HIV tests and 16,913 AIDS cases have been reported [...] from all provinces and territories of Canada” (Laboratory Centre for Disease Control [LCDC], April 2001: 1). Whereas initially the majority of persons contracting HIV/AIDS were gay men, increasingly the newly infected are women, heterosexuals and injection drug users (LCDC, April 2001: 1).

Today, HIV is infecting and affecting all segments of Canadian society, including Aboriginal communities. Studies show that individuals in Canada’s First Nation communities are increasingly at risk for HIV infection and the development of AIDS. In April 2000, Health Canada reported that the “Aboriginal community [is] at increased risk for HIV infection” (LCDC, May 1998b: 1). In April 2000, Health Canada reported 371 cases of AIDS within the Aboriginal population. “Although Aboriginal persons

represented 2.4% of AIDS cases with known ethnicity (n=15, 273), the annual proportion of AIDS cases attributed to Aboriginal persons has increased over time, from 1% before 1990 to 15% in 1999" (LCDC, April 2000: 35).

AIDS data provide a view of HIV infection that occurred approximately 10 years earlier. However, HIV data provide a picture of more recent infections. In this respect, Health Canada notes, "the possibility that rates are in fact higher among Aboriginal people" (LCDC, April 2000: 37). Overall, the number of AIDS cases and reported HIV infection within the Aboriginal population are likely underestimated due to delays in reporting, incomplete ethnic data or variations in reporting of ethnic identity between provinces (LCDC, April 2000; Waldram, Herring and Young, 1995). Although the absolute number of cases is small, high rates of sexually transmitted diseases and the disadvantaged socioeconomic position of Aboriginal people within Canadian society place them at a greater risk for exposure to HIV infection and the development of AIDS. As Hodel notes, "AIDS disproportionately affects the poor, predominantly persons of colour, and women and young gay men constitute the fastest growing demographic groups" (1997: 551).

Disease Spectrum: AIDS and HIV Infection

Acquired immune deficiency syndrome (AIDS) is a recently recognized disease entity first reported in the male homosexual community in the early 1980s in the United States. In Canada, the first reported cases of AIDS were first recognized in 1983 (Health Canada, 1997; Rayside and Lindquist, 1992). AIDS is a medical condition caused by the human immunodeficiency virus (HIV). HIV attacks CD4 lymphocyte receptors in the

immune system of the body and produces a progressive deterioration in immune system function. This deterioration leads to increased liability for exposure to opportunistic infections (viruses, bacteria, fungi, and protozoa) and nervous system deterioration (mental deterioration, seizures, and sensory or motor changes). In short, individuals diagnosed with HIV infection increasingly develop a heightened susceptibility to opportunistic infections (Nichols, 1986).

HIV Transmission

The modes of HIV transmission are well documented. HIV is primarily transmitted from person to person through three possible routes. Exposure may occur through unprotected sexual contact including, but not limited to, sexual intercourse (anal and vaginal) or sharing of sexual devices. It is important to note the emphasis on high-risk behaviours which contribute to increased susceptibility to HIV infection. This is in contrast to membership in social groups, traditionally recognized as 'high-risk groups,' which is now recognized as contributing to increased susceptibility to HIV infection (Canadian AIDS Society, 1994). The HIV virus may also be contracted via exposure to infected blood or blood products (i.e., through injection drug use or as a recipient of infected blood or blood products). Finally, HIV transmission can occur through vertical transmission between a HIV-positive mother and her fetus during pregnancy or during labor and delivery (College of Family Physicians of Canada, 1996). More recently, HIV transmission has also been found to occur during breast-feeding (Canadian AIDS Society, 1994). Various studies have reported that normal daily casual contact with infected individuals does not contribute to the spread of HIV (King, 1993; Nichols, 1986; Bateson

and Goldsby, 1988; Canadian AIDS Society, 1994).

AIDS Disease Spectrum

HIV infection and the progression to a medically defined AIDS diagnosis are characterized by three separate stages. Each stage involves its own distinct clinical manifestations. Developed from a review of the literature, Table 1 identifies each stage and its associated medical conditions in the progression of HIV infection.

The first stage is often referred to as the asymptomatic phase of HIV infection. Following sero-conversion (exposure to HIV), many individuals appear outwardly healthy. This period can last approximately seven to 10 years, but varies greatly from individual to individual. The only noticeable clinical condition will be a gradual decline in CD4 cells.

The second stage of HIV infection produces the early clinical manifestations of the disease. Symptoms will range from unexplained weight loss to drenching night sweats, fevers, chronic fatigue and other related complications associated with AIDS-defining medical conditions. This phase of infection is often referred to as the symptomatic phase of HIV infection. Individuals diagnosed as HIV symptomatic do not meet the formal criteria labeling an individual as living with AIDS.

The final stage of infection is often characterized by more direct and observable clinical conditions. In defining AIDS, medical researchers have used the presence of opportunistic infections and other associated clinical markers as primary indicators of the development of AIDS. As previously stated, AIDS refers to a group of conditions occurring as a result of the collapse of the immune system. Many individuals

Table 1: The AIDS Disease Spectrum in the Canadian Population, June 30, 1994.*

Disease Progression Group		Definition	Reported Cases (%)	Known Deaths (%)
HIV	Asymptomatic	The asymptomatic phase shows no direct clinical manifestations of HIV infection. Infected individuals may remain symptom-free for a period of seven to ten years.	N/A	N/A
	Symptomatic	Early clinical manifestations of HIV infection range from unexplained weight loss, night sweats, fevers to chronic fatigue, etc.	N/A	N/A
AIDS	Pneumocystic Carinii Pneumonia (PCP)	A parasitic protozoan that produces difficulty in breathing, dry coughs, and high fevers, causes PCP. Many individuals experience complications related to the sulfa drugs used to treat this illness.	53	72
	Kaposi's Sarcoma (KS)	KS is a cancer characterized by blue-violet skin lesions. It is commonly treated with alpha interferon, radiation or chemotherapy.	21	71
	Candidiasis	Candidiasis is a yeast-like infection and often the first sign of a weakened immune system. It is characterized by whitish sores in the mouth but also commonly infects the esophagus or brain. Treatment often consists of anti-fungal therapy.	19	67
	HIV Wasting Syndrome	HIV Wasting Syndrome refers to severe rapid weight loss not attributable to diet or exercise.	11	81
	HIV Encephalopathy	HIV-related diseases of the brain include tumors and AIDS dementia.	6	85
	Non-Hodgkin's Lymphoma	A disorder of the lymph nodes, symptoms can include weight loss, fever and fatigue. It is often treated with chemotherapy or radiation therapy.	5	82
	Other Opportunistic Infections	Other HIV-related conditions include parasitic infection (toxoplasmosis or cytomegalovirus), fungi infections or other forms of cancer.	42	80
	Pulmonary Tuberculosis	A disease that infects the lungs (one or both) and produces weight loss, weakening, cough, sputum and loss of appetite.	<1.0	21

* Based upon information on HIV/AIDS symptomatology described in Nichols (1986) and Bartlett (1996). This table is derived from 9083 cases reported by the Laboratory Centre for Disease Control (1994). The percentages do not total 100 as most reported cases and deaths involve multiple disease manifestations.

will be rendered susceptible to a host of, and at times, multiple opportunistic infections. The most common opportunistic infection that affects Canadians diagnosed with AIDS is pneumocystic carinii pneumonia (PCP). PCP is one the leading causes of death in individuals diagnosed with AIDS (LCDC, 1994).

A Brief History: AIDS in Canada

Although the wide-spread dissemination of HIV appears to have begun in the 1970s, it was not visibly recognized until the early 1980s when a very small number of men in the United States (Los Angeles, San Francisco and New York) developed several unusual diseases related to immunodeficiency. Observers quickly noted the common thread shared among these first reported cases. Each of the men had histories of sexual relationships with other men, and they were members of the gay community.

In Canada, with a relatively short lag time, this situation replayed with the same alarming similarity in three of the largest cities in Canada - Toronto, Vancouver, and Montreal. "A year later, when twenty-five AIDS cases had been reported in Canada, the gay community became more attentive to the threat and by 1983, concern about the spread of the epidemic was great enough that the AIDS Committee of Toronto (ACT) was established" (Rayside and Lindquist, 1992: 59). Also, at this time Ontario's Conservative government made AIDS a reportable disease. By 1985, a total of 351 cases were reported in Canada and Rock Hudson's death heightened public interest in HIV/AIDS. Gilmore stated, "June Osborn [a respected American epidemiologist and researcher in HIV/AIDS and public health policy] likened the world with AIDS to the day after Hiroshima, and for many people, the bomb detonated in the spring of 1985: Rock

Hudson had AIDS" (1992: 22)!

Intensified interest in the issue of AIDS did not escape the Canadian two-spirit community. HIV/AIDS issues were also becoming a priority for Aboriginal gay and lesbians. In 1989, following the federal announcement of a funding commitment to AIDS, several Aboriginal two-spirit organizations were also founded. These included the Gay and Lesbians of the First Nations (2-spirits of the First Nation), based in Toronto, the Manitoba Aboriginal AIDS Task Force in Winnipeg, and in Vancouver, Healing Our Spirit AIDS Prevention Society (Roscoe, 1998). These organizations, with federal and provincial funding, were able to maintain offices, hold talking and healing circles, publish newsletters, and offer HIV/AIDS-related support services.

However, Aboriginal AIDS-related organizations across Canada encountered a number of obstacles to providing care, treatment, support and prevention services. For example, LCDC did not initially collect or require AIDS cases to be reported by ethnicity. Primarily through the efforts of community activists and professionals throughout the country, health authorities have been convinced to monitor, study and serve the Native population. The Canadian Aboriginal AIDS Network (CAAN) and its member organizations, which was founded in Winnipeg early in 1994 and later established a national office in Ottawa, played a significant role in the success of the progress made towards inclusion of Aboriginal cases in epidemiological data. Aboriginal members, through a dedicated working group with LCDC, continue to work closely in monitoring the epidemic in Canada's Aboriginal population.

Native individuals with HIV also face a variety of other special problems. On

many reservations, the combination of homophobia with "AIDSphobia" has, in some cases, created an environment of extraordinary hostility. Although Health Canada's First Nations and Inuit Health Branch (FNIHB) has primary responsibility to provide health-related services within reserve communities, the devolution of health services to individual bands has prompted Aboriginal activists to be concerned that health services will be denied to First Nation members with HIV/AIDS. Confidentiality at both FNIHB and band-administered health care facilities has been a problem as well. All too often, personal information can quickly become common knowledge (Roscoe, 1998).

Urban Aboriginals living with HIV face other difficulties. Studies as early as 1999 have demonstrated Aboriginal people living with HIV encounter racism, discrimination and/or cultural insensitivity. Matiation states:

Discrimination against Aboriginal people living with or affected by HIV/AIDS comes from a variety of sources. It is often associated with misunderstandings or lack of knowledge about AIDS. Such discrimination is often further reinforced by other social problems and forms of discrimination. Finally, it finds its roots in a history of oppression, cultural disintegration, and racism. (1999: 3)

Indeed, much of the work that has occurred within the Aboriginal AIDS movement in Canada has been frustrated by such obstacles. In other words, because Aboriginal people are at times removed from decision making bodies, discrimination and racism remain unchecked and often the result is "characterized as, [... for example,] an ability to turn a blind eye to a 10-year old Aboriginal sex worker [or] by a reluctance to overcome jurisdictional barriers to the delivery of services (Matiation, 1999: 9).

However, several tribal and reserve organizations have undertaken culturally-specific AIDS/HIV initiatives. The Swampy Cree Tribal Council in Manitoba, for

example, a member organization of the Manitoba Regional AIDS Working Group, has produced AIDS information brochures in English, Cree, Dene, and Ojibway. In addition, a number of reserve communities, utilizing the speaker's bureau at the (Village Clinic) Nine Circle's Community Health Centre, contract HIV/AIDS educators to provide information about HIV transmission, disease progression, and experience with HIV to members of their communities.

"Other problems associated with the epidemic are not unique to gay native people. As HIV/AIDS programs and organizations become increasingly professionalized to obtain funding, there is a tendency to 'de-gay' the disease" (Roscoe, 1998: 107). Much like non-Aboriginals living with HIV, two-spirit men and women must continually advocate to ensure they are represented and served by organizations that provide services. This pressure has produced "fundamental shifts in the relationship between doctor and patient, between researcher and subject" (Hodel, 1997: 553). Commonly, doctor and patient are now viewed as collaborators in the maintenance of personal health and well-being.

The disease itself is often characterized by a constant source of setbacks. As two-spirit men and women living with HIV succumb to illness, a vital link with corporate history is lost, not to mention skill and commitment. That is, a two-spirit men and women living with HIV are lost to the illness, so to is the knowledge they have carried about AIDS service organizations they were connected to and assisted in managing. "La Verne Monette, Provincial Coordinator of the Ontario Aboriginal HIV/AIDS Strategy, concludes that HIV/AIDS presents a considerable risk to the aspirations of

Aboriginal people to form self-governing, independent First Nations" (Matiation, 1999: 12). A similar situation has also occurred within the Aboriginal AIDS movement in Canada. As individuals succumb to their infections, they must be replaced. Other problems include issues of morale. Efforts must constantly be directed to renewing the established consensus (Roscoe, 1998). That is, Aboriginal people within the AIDS movement are often faced with updating and renewing previous decisions prior to moving forward to address the problem of the AIDS crisis in Aboriginal communities.

In 2001, where is Canada 20 years later when it comes to the question of addressing the HIV/AIDS epidemic? Primary responsibility for health care falls to provincial and territorial governments, where the "substantial portion of the responsibility for public health is devolved to municipal governments or regional health agencies" (Rayside and Lindquist, 1992: 50). However, in 1998 Canada implemented the first national HIV/AIDS strategy, now called the Canadian Strategy on HIV/AIDS (CSHA). In short, the CSHA provides direction and funding to a network of community-based AIDS service organizations. So, by the year 2001 virtually every province and territory has established HIV/AIDS service organizations, not to mention a national Aboriginal AIDS lobby group, where the primary mandate includes dealing with the biological, social, political and economic realities of HIV/AIDS.

Canada's yearly report on HIV/AIDS lists several key policy directions (Health Canada, 2000). The CSHS is committed to preventing the spread of HIV infection in Canada, to finding a cure, to developing effective vaccines, drugs and therapies to ensure effective care, treatment and support for Canadians living with HIV/AIDS, to minimize

the impact of HIV/AIDS on individuals and communities, and to counter social and economic factors that increase individual and collective risk of HIV infection. To this end, the Canadian government commits \$42.2 million annually to CSHA, of which \$2.6 million are directed to Aboriginal health and community development initiatives. In addition, "provincial and territorial governments provide support [...] through [...] the delivery of HIV/AIDS-related health care services, research and prevention activities" (Health Canada, 2000). In Manitoba, the provincial government, as of January 2001, spends approximately \$1 million on community-based care, support and prevention initiatives, not including costs associated with treatment or hospital stays.

As a result of government leadership, community-based initiatives are now recipients of large numbers of government grants or contracts specifically for health care services at a local level. A number of activists remain committed to ensuring increased federal/provincial/territorial cooperation. Under one such funding arrangement, the Nine Circles Community Health Centre in Winnipeg has developed a service delivery model that integrates a client perspective with traditional healing, referral services, emergency food and shelter services, primary health care case management, prevention services, and social and psychological support programs. Increasingly, a number of these services are being provided by individuals of Aboriginal descent or culturally sensitive program personnel. Roscoe states, "when comprehensive case management services are delivered by native providers, client retention rates are as high as 90 percent" (1998: 105).

Conceptualizing HIV/AIDS as a Chronic Disease

Since the early 1980s, HIV/AIDS has been conceptualized as a devastating, fatal

and incurable illness. Indeed, many HIV-positive individuals experience the initial diagnosis as a 'death sentence' (Stevens and Doerr, 1977; Pakenham, Dadds and Terry, 1996). Statistics seem to bear this point out. Since the beginning of the epidemic, 73% of all AIDS cases in Canada have ended in death. However, with the advent of newer treatments for HIV infection, survival rates have improved significantly (Sowell, Phillips, and Grier, 1998). In Canada in 1999, the LCDC reported a decrease in the number of AIDS-related deaths. As LCDC reports, "The number of reported AIDS deaths peaked at 1,422 in 1995. Since 1995, the number of reported AIDS deaths each year has significantly declined, with a 92.5% drop in reported AIDS deaths in 1999 as compared to 1995" (April 2000: 3). Medical researchers have credited highly active antiretroviral therapy (HAART) with this outcome. HAART normally consists of triple drug combination therapy. It includes two nucleoside analogues and a protease inhibitor. Advances in therapy are believed to be one reason for the dramatic decreases in the number of AIDS-related deaths (Bartlett, 1998; LCDC, May 1998; Saskoff, McFarland and Shin, 2000). However, the cost for this therapy is approximately \$1,000 per month per patient, with the cost borne by Medicare or FNIHB. Has HIV/AIDS been transformed into a chronic and manageable illness with the introduction of new treatments?

In the sociological literature, chronic illness is defined as a long-term, often permanent, disruptive event in a person's life (Bury, 1991). One of its most salient features is its insidious nature, often 'creeping' up on an individual's life (Bury, 1982). The disease spectrum of HIV infection certainly seems to fit this conceptualization of

chronic illness. This is especially true given that many people receiving HAART have experienced increases in CD4 cell counts and a reduction in HIV viral load that has contributed to “improved immune status, energy, well being, and functional ability” (Sowell, Phillips, and Grier, 1998: 34). Very little is known about protease inhibitors, their effect on the body, including how long this form of treatment will remain effective. These drugs, however, present the possibility that HIV may be controlled to the point that HIV/AIDS becomes a manageable, chronic, long-term condition (Roth and Nelson, 1997).

When conceptualized as a chronic illness, AIDS may influence how individuals define the self and their relationships with others, and it may require a myriad of other significant adaptations to deal effectively with the effects of chronicity. Such changes will span the entire disease trajectory. As Roth and Nelson state, “Construction of a new identity as a person with AIDS is not complete at diagnosis; rather it is an ongoing process engaged in by the person [...] within a macro-social context” (1997: 162).

Conceptualized as status passages, Lewis found in her interviews with 25 HIV-positive gay men that they identified three status passages that roughly correspond with the AIDS disease spectrum (1999). As she states, “Experiences reported by respondents suggest that PHAs [people living with HIV/AIDS] may tend to focus more on the movement from HIV negative to positive and positive to PWA [people with AIDS] as turning points in their HIV career, each with its own corresponding benchmarks [...]” (1999: 111).

Lewis found that with each turning point, new challenges emerged for the men in her study. Challenges appear in shifts prior to diagnosis, following diagnosis and on learning

to accommodate HIV, to HIV-positive and gradual disease progression, and in recognizing that health has deteriorated to the point of acute illness with accompanying reductions in quality of life (Lewis, 1999). The entire process of movement from one status passage to another “parallels those of adapting to other stigmatized statuses, especially chronic and terminal illness” (Lewis, 1999: 111). With the introduction of improved therapy options, an entirely new set of issues is experienced, including concerns about how long the medication will work, fear of relapse, and explaining to potential employers absences from the workforce, etc. In short, Lewis recognizes the importance of conceptualizing HIV/AIDS as a chronic and manageable illness, one that involves various multiple status passages (Lewis, 1999: 113), although she does make a distinction between being ill and dying.

The Sociology of Chronic Illness

What is the experience of living with a chronic medical condition? What are the “steps people take to manage, mitigate, or adapt to it, and [what is] the meaning attached to these actions” (Bury, 1991: 451-2)? In general, the traditional medical model has often dominated explanations. This perspective seeks to reduce people to their body parts and focuses solely on the disease that afflicts them. Thus, individuals are often conceptualized as diseased rather than as persons living with disease.

The study of illness, by contrast, attempts to understand and conceptualize the experience of illness from the ill person’s point of view. Thus, the illness perspective is an insider’s perspective that focuses on subjective experiences of living with disease (Conrad, 1990). As Morse and Johnson state:

The illness perspective provides a more comprehensive view, incorporating individuals and families as they make sense of, respond to, cope with, and adapt to symptoms and disabilities. [...] The illness perspective overcomes the limitations inherent in the medical model and ensures that patients are treated as persons and not as objects. The illness perspective integrates the mind-body dichotomy within the social context, acknowledging that people are more than physiological entities. (1991:2)

In this manner, sociologists analyze meaning, the social organization of the ill person's world, and the strategies used to adapt to illness from an ill person's perspective (Conrad, 1990). These types of analyses entail moving away from analytic emphases that highlight service providers' treatment of, and interactions with ill people to how individuals with illnesses manage their conditions in everyday life at home, work and in various other social settings.

Chronic illness also involves experiences that are multi-layered and change over time. As Bury states:

Chronic illness is, by definition, a long-term, and perhaps [a] permanent event in a person's life. [...] In chronic illness these features are often only partially characteristic of experience, overlaid as they are with poor or limited recovery prospects. (1991: 452)

Illness evolves through stages. It "passes through and [. . . interacts] with the individual's age and position in the life course" (Bury, 1991: 452). Thus, chronic illness carries with it an "'unfolding' or 'emergent' character" (Bury, 1991: 452). Research on the experience of chronic illness has thus far been fruitful. Sociological researchers have delved into such diverse areas as "uncertainty, careers, stigma, biographical work and reconstitution of the self, managing regimens, the role of information, awareness and sharing, and family relationships" (Conrad, 1990: 1260). In this respect, my reading of the literature leads me to conceptualize the experience of HIV/AIDS as a disruption to

self, what Bury labels as “disrupted biographies” (1991:453). Indeed, those living with HIV must reconstruct their lives and their identities, and learn to adapt to a variety of situations, including dealing with the diagnosis itself, and dealing with family and friends, treatment regimens, uncertainty and stigma.

Disrupted Biographies

The onset or initial diagnosis of HIV represents an “assault not only on the person’s physical self, but also on the person’s sense of identity” (Bury, 1991: 453). This assault has a number of consequences for the individual.

First, illness interferes with the day-to-day tasks of living including work, school, doing dishes and cleaning house, walking the dog, or juggling complicated drug therapies. Efforts are made to mediate the disruptions that symptoms have on daily life in a number of concrete ways. Individuals may seek information from their peers by attending self-help groups and searching the Internet, always with an eye for best practice models that assist in the adaptation to daily life with illness. The critical juncture for many individuals is during the early period following diagnosis “as trade-off[s] between the effects of symptoms, and efforts to minimize them are undertaken” (Bury, 1991: 453).

Second, the individual must assess the meaning associated with chronic illness, and the significance it has for him or her. As Bury states, “different conditions carry with them different connotations and imagery. These differences may have a profound influence on how individuals regard themselves, and how they think others see them” (1991: 453). Furthermore, the symbolic connotations people assign not only vary by chronic condition but between different cultures as well, and these in turn affect

adaptation to illness (Bury, 1991). For example, the experience of illness for individuals diagnosed with multiple sclerosis and those diagnosed with HIV may differ. As well, if there are differences in the cultural meanings attached to situations, these may influence the illness experience and an individual's definition of self. While the physical reality of illness may be remarkably similar, culture may teach us to understand and adapt to illness quite differently (Tafoya, 1996). In short, "biographical approaches to chronic illness stress the dual effects of 'disruption' in the practical organization of everyday life and in self-understanding and identity" (Charmberlayne and King, 1997: 605).

Meanings associated with illness may also be combined to form stereotypes of illness, and meaning may change along the disease/illness trajectory (Bury, 1991). Meaning can be both negative and positive. By meaning, I am referring to how individuals explain illness to themselves and others, as well as how illness itself is experienced. For example, disclosure is a negative issue most individuals diagnosed with HIV must grapple with (when, how much and who to tell?). Some HIV diagnosed individuals may experience the illness positively as an epiphany; others may experience the diagnosis entirely in negative terms. Also, "changes in symptoms over time may affect social responses, and these in turn will influence experience" (Bury, 1991: 454). Such changes in symptoms may have implications for self- and social-identity as well. For individuals living with HIV, they begin the process when symptoms are invisible and progress to opportunistic infections which, at times, can be enormously disfiguring, as with the case of Kaposi's Sarcoma. As symptoms change with AIDS, so do social responses. For example, it is difficult to not disclose one's HIV status if one is covered

with the lesions that are characteristic of Kaposi's Sarcoma.

Significance and consequence, and the resulting meanings attached to illness, create a situation Bury labels "meanings at risk" (1991: 454). As Bury states:

In responding to chronic illness, individuals constantly test the meanings attached to their altered situation against the reality of everyday experience. It is a situation of risk because individuals cannot be sure that their own developing perceptions and 'definition of the situation' will be shared by others, whether in the formal setting or in interactions with professional caregivers. (1991: 454)

In short, ill individuals may at times respond inappropriately to their situation producing, for example, dependence on others. They may also request sympathy that may lead to rejection by others. As individuals adapt to their illnesses, they learn what works and what does not. However, uncertainty and unpredictability will always remain a core experience throughout the illness life cycle (Bury, 1991). As Weitz states, "uncertainty centers not so much on what they should do as on what will happen to them despite their actions, when it happens, and why" (1990b: 111).

In the context of HIV/AIDS, the introduction of new therapies for the treatment of HIV has created a 'new' situation in which 'meanings at risk' are amplified. In other words, as health improves because of HIV therapy, the prospect of returning to the work force carries a renewed level of uncertainty. As Sowell, Phillips and Grier state:

One person facing reconstruction of his life exemplified this dilemma by stating, 'I started taking protease inhibitors about 6 months ago. My viral load is so low now that it is almost undetectable. I wasn't ready for this. I was prepared [reluctantly] to die ... so now what do I do? Get a job, go back to work, have a life, and then do I have to go through getting ready to die again if this doesn't last.' (1998: 34)

Clearly, an individual with a positive response to drug therapy must identify appropriate responses to his or her situation. For many individuals it involves yet another disruption:

living prepared to live as opposed living prepared to die. In this respect, the issue of uncertainty throughout the life cycle of an illness, and to the experience of a 'disrupted biography' is an important concept to understand.

Uncertainty

Sociological research in the area of chronic illness has shown that the issue of uncertainty is a major concern. This holds true for those living with HIV infection as well. In a 1990 study, Weitz interviewed 25 individuals living with either HIV symptoms or AIDS. She concluded that uncertainty affects people living the HIV in four distinctive ways (1990b).

First, many individuals seek only confirmation of their HIV-status. They already have an awareness that past behaviours have placed them at risk for infection and have greatly increased their chances of producing a seropositive test result. Likewise, they may already be experiencing symptoms they know to be related to HIV infection. This knowledge often drains emotional and physical resources long before they become ill (Weitz, 1990b: 119). Steven and Doerr draw a similar conclusion in a 1997 study of women's narratives about being informed of positive HIV antibody test results. They state, "Thirty-seven per cent (14) experienced HIV discovery as a confirmation. [...] Being informed of their HIV sero-positivity corroborated something they [had] somehow already suspected" (1997: 530).

Second, people living with HIV are more likely to experience guilt associated with past high-risk behaviour. Once diagnosed with HIV infection, new questions are raised for the HIV-positive individual. Why has this dreadful situation occurred? The search

for meaning is often difficult, one that is “set in the context of [the] popular belief that AIDS was divine punishment” (Weitz, 1990b: 116). Consequently, many feel as if they deserve their illness. The public and media reinforce this guilt by placing the blame squarely on the backs of individuals diagnosed with HIV infection (Weitz, 1990b). Lawless, Kippax and Crawford refer to this as the “discursive construction of HIV and AIDS” which “elicit[s] punitive judgements of personal responsibility and blame” for those living with this disease (1996: 1371).

Third, individuals living with HIV are more likely to have difficulty in obtaining accurate diagnoses of medical conditions they face while living with HIV infection (Weitz, 1990b: 119). HIV and AIDS often produce multiple infections. Physicians have great difficulty diagnosing HIV/AIDS “because physicians often deliberately (although at times unconsciously) avoid questions or actions that would lead to [a] diagnosis” (Weitz, 1990b: 119). Doctors, for example, often neglect to consider HIV infection as a possible diagnosis or as part of regular monitoring. Indeed, Manitoba Health recommends “physicians offer testing to pregnant women and that pregnant women should take the initiative and seek HIV testing” (Blanchard, 1995: 1). Results of an HIV seroprevalence study show an increase in the number of women at risk for HIV infection. As Weitz states, “Several respondents complained that physicians neither tested them for, nor diagnosed them with AIDS, even though the clients had multiple, classic symptoms” (1990: 115).

Lastly, and most importantly, because AIDS is still a relatively new medical phenomenon, medical specialists often lack answers with respect to treatment and

prognosis. My own situation is testimony to the uncertainty that can often be experienced. I have been told by a care provider three times that I have about one, and at the most two years, to live. The first time was approximately nine years ago when I first tested positive. The last time this occurred was while writing the final draft for this thesis. Compounding this, individuals living with HIV, like physicians, are aware that medical advancements in the treatment of AIDS are rapidly developing and constantly changing, and individuals with AIDS are therefore unable to trust the answers they do receive (Weitz, 1990b). With the rapid production of new research and, consequently, the changes to treatment management strategies that are required, a physician must be able to remain current with treatment protocols for the effective care and treatment of persons with HIV infection.

Despite the uncertainty either produced by HIV infection or an AIDS diagnosis, many individuals are able to develop creative ways of living with and managing uncertainty in their lives. Weitz's study highlights "the role control plays in making uncertainty tolerable" (1990b: 120). Helping individuals achieve a sense of control reduce the stress and depression that so often accompany a life of uncertainty. In this respect, Davies highlights the role temporal orientation plays in helping individuals regain a sense of control of their lives (1997). Two of three temporal orientations are considered helpful.

The first, which Davies labels "living with a philosophy of the present," refers to how individuals abandon future orientations and focus on obtaining a sense of peace that comes with living in the moment (1997). In this context, an appreciation of death as

inevitable affords the opportunity for spiritual growth and personal development for some HIV-positive individuals. It allows, for example, the development of “new values and meaning in the context of learning to live with HIV” (Davies, 1997: 566). Living in the present, without worries about the past and the future, has helped some individuals living with HIV illness to experience a feeling of liberation. As Davies states:

This sense of freedom derives from the fact that the HIV positive individual is, to a certain extent, freed from the responsibility of having to construct a meaningful long term plan for his/her life and, subsequently, is enabled to enjoy the present for what it is [. . .], rather than deliberating upon its implications or possibilities for the future. (1997: 567)

The other possibility for positive adaptation to a life of uncertainty involves individuals with a temporal orientation towards the future. As Davies states, “they [are] determined not to let their HIV positive diagnosis ‘ruin’ the plans that they had, in the past, held for the future” (1997: 567). Unlike the living in the present orientation, individuals with a future orientation “refuse to relinquish their routine future orientation, thus refusing to entertain the possibility of the imminence of their death” (1997: 567). Life continues as before the diagnosis.

Adopting either a present or future temporal orientation means learning to live with the uncertainty HIV/AIDS has brought to bear on one’s life. The quality of uncertainty shifts to that of “tragic optimism” (Davies, 1997: 569). Although these individuals acknowledge the existence of HIV in their lives, they retain a sense of remaining open to the possibilities life can offer (Davies, 1997). Individuals adopting either of these two temporal orientations are able to construct positive meanings in a life within the context and consequences of HIV/AIDS.

A third, less attractive temporal orientation Davies labels as “living in the empty present” (1997: 568). Roughly a quarter of the sample in Davies’ study were unable to compensate for the loss of self by adopting either one of the two temporal orientations discussed earlier. As one individual in this study described the experience, “I don’t worry about the time of day anymore, it has not become more precious to me [. . .]. I am just quite happy to get by each day” (Davies, 1997: 568). This individual’s comment highlights the hallmark of ‘life in an empty present.’ As Davies observes, “numerous [individuals] state that they do not like to think about, plan or commit themselves to future possibilities because they are afraid that they will ‘disappoint’ themselves if things ‘fall through’ by them ‘falling ill’ (1997: 568). Likewise, holding on to the past is another damaging aspect of ‘life in the empty present.’ A preoccupation with the past hampers future planning and may lead to a loss of the sense of meaning in life (Davies, 1997). Individuals ‘living in the empty present’ remain closed to the possibilities life has to offer. From a clinical perspective, it may be that these individuals are experiencing depression related to HIV-positivity.

Important areas not addressed in Davies’ article are the shifts individuals undertake in adopting a positive response to an HIV diagnosis. For example, is the shift to a ‘philosophy of living in the present’ from a future orientation not in and of itself disruptive? How is this shift in temporal orientation facilitated? Is the shift to a ‘philosophy of living in the present’ less of an issue if an individual already had a present-temporal orientation prior to diagnosis? Lastly, what about shifts from a present orientation to an empty present orientation? Is a shift required at all, particularly if an

individual already adopted, prior to diagnosis, a philosophy of living in the present?

Clearly, what is shown in Davies' research is that individuals living in an 'empty present' lack an ability to locate meaning and value in their lives following an HIV diagnosis (Davies, 1997). How can shifts to more positive adaptations be facilitated? These points are important factors considered in interviews with the two-spirit men with HIV/AIDS in this study.

Stigma

Another area explored in relation to the experience of chronic illness is stigma. Much of our current understanding of the effects of stigma and HIV infection have been guided by what is now considered a sociological classic, Goffman's Stigma (1963).

Goffman updated the Greek use of the term and identified three types of stigma:

First there are abominations of the body - the various physical deformities. Next there are blemishes of individual character ..., these being inferred from a known record of, for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, suicidal attempts, and radical political behavior. Finally, there are the tribal stigmas that can be transmitted through lineages. (1963: 4)

In this respect, two-spirit men living with HIV infection or diagnosed with AIDS potentially face a situation of, what I would term, *triangulated stigmatization*. All three types of stigma converge and can potentially affect the lives of two-spirit men living with HIV or AIDS.

Virtually every HIV-positive two-spirit man meets the first definition of stigma provided by Goffman, 'abominations of the body' though their experience of HIV infection as a progressive chronic illness. Weitz states, "as disease progresses, PWA [persons with AIDS] may become emaciated, exhausted, and, in some cases, covered by

disfiguring rashes or cancer lesions” (1990: 23). Over time, individuals are often unable to care for themselves, unable to walk, talk, or see.

Two-spirit men living with HIV/AIDS are homosexual or may also have the additional burdens of addiction or a alcoholism, what Goffman described as ‘blemishes of character.’ As Weitz states, “PWA who have contracted AIDS ... frequently find that other people stigmatize them and consider their illness a deserved and divine punishment” (1990: 24). In a recent Canadian HIV/AIDS Legal Network and Canadian Aboriginal AIDS Network document, Matiation noted, “two-spirit people are often seen as unhealthy, sinful, and/or unbalanced. The atmosphere in many communities is homophobic” (1999: 10). During the recruitment phase for this study, I received information about an Aboriginal man being forced off his reserve due to his positive diagnosis of HIV infection. Roscoe states, “On many reservations, irrational fears of AIDS combined with homophobia create an environment of extraordinary hostility” (1998: 105). Indeed, it is widely believed that confidentiality at health care facilities on reserves is a grave problem in which personal information can quickly become public knowledge, particularly when sparked by the fear of AIDS or of homophobia.

The third type of stigma, ‘the tribal stigma of race, nation, and religion’ compounds or heightens the experience of stigma for HIV-positive two-spirit men. As McRae states, “Goffman uses the word tribal, the term in today’s society is much more indicative of caste and racism [...] and when [two-spirit men] test HIV-positive, they are confronted with [...a combination of] three stigmas, which pushes them further toward outcast status” (1991: 144-145). Two-spirit men have already been “stigmatized

characterologically and by race and ethnicity" (McRae, 1991: 145). Late in 1999, an Aboriginal man living with AIDS attempted to obtain care in a large Winnipeg hospital. While waiting for treatment he became agitated and was consequently escorted out of the building by hospital security, who alleged he was drunk (he was not). In the following hours, this man again attempted to obtain care in another hospital where he later died (Matiation, 1999). HIV-related stigma heightens Aboriginal experiences of discrimination in health care producing a situation of "systemic discrimination, [...] particularly for inner-city and street-involved [Aboriginal] people" (Matiation, 1999: 11). In Winnipeg, for example, only a small handful of dedicated physicians and nurses provide primary care service to the HIV-positive population. Experience suggests that replacing these highly trained health care providers is often exceedingly difficult, if at all possible. "Through trial and error, most PWAs eventually [can locate] primary practitioners who, they believe, provide good and nonjudgmental care" (Weitz, 1990a: 30). This 'discursive construction of HIV/AIDS' has contributed to a situation of enhanced stigma for those living with this illness.

How then do individuals adjust, adapt, or change this situation? According to research in this area, individuals living with HIV deal with stigma using a variety of successful tactics. According to Weitz,

[Individuals diagnosed with HIV] avoid stigma by concealing their illness, learning when and to whom they should reveal their illness, changing social networks, educating others about AIDS, developing nonstigmatizing theories of illness causation, and using bravado to convince others that they are still functioning social beings. (1990a: 25)

Carricaburu and Pierret (1995), in a qualitative research project involving 44

HIV-positive men, explored the issue of 'biographical disruption' and necessarily touched on strategies for dealing with the stigma of HIV and AIDS. For these men, like those in Weitz's study (1990a), managing whether or not to tell, who and when to tell was a central feature of dealing with the stigmatizing effects of living with HIV infection.

Most individuals choose to tell only a few close family and friends. However, PHAs also run the risk that families or friends, previously unaware of their sexual orientation, may reject them. As Weitz states, virtually every respondent reported that at least one family member had ceased contact with him after learning of his illness" (1990a: 27). Even when families or friends had known about their sexual orientation, for a number of men, learning also of their HIV-infection "made [...] homosexuality more real and salient" (Weitz, 1990a: 27). In response, families who previously "tolerated their [family member's] homosexuality despite deep reservation about its morality find that they can no longer do so [... and] even when families do not overtly reject ill relatives, their behavior may still create a sense of stigma" (Weitz, 1990a: 28). Moreover, families may also reinforce the experience of stigma through adoption of extreme and medically unwarranted anti-contagion measures.

A similar situation occurs with respect to once trusted friends. Weitz states, "Typically, PWAs reported that some friends 'are very supportive, come around, enjoy coming over here [...] but most of them have backed off'" (1990a: 29). In some cases, shortly following diagnosis, PWAs were often forced into a situation of locating new housing arrangements because of roommates who asked that they leave or themselves left.

Fear of rejection or dismissal from work motivates many individuals to live with this secret. "All interviewees, strongly experienced a 'felt stigma' because their bodies were both infected and, we might say, 'infectious' (Carricaburu and Pierret, 1995: 72). The situation is exacerbated by diagnoses of AIDS. Outward, physical symptoms often create situations in which the stigma of AIDS is more visible, as in the case of HIV wasting and Kaposi Sarcoma.

Bury (1991) points out that adaptations may have either negative or positive associations. Unfortunately, for some, positioning themselves to avoid stigma may lead them to withdraw from or to avoid HIV treatment altogether. In their study of HIV-positive women, Lawless, Kippax, and Crawford state:

Interview data indicate that any instance of discriminatory practice is reported to other HIV-positive women, and thus it has an impact on more than the particular woman who is involved in the incident. Women who withdraw from or avoid health services miss out on the level of care to which they and their dependents are entitled. When women feel they are being judged or doubted they are likely to protect themselves by avoiding medical and other support services, which they may actually need. As indicated in the women's accounts in the interviews, such avoidance occurs over a long period and frequently when the need is greatest. (1996: 1374)

As reported earlier, Aboriginal people diagnosed with HIV/AIDS are often sicker earlier, spend more time in hospitals, have fewer palliative care days, and death occurs sooner. Does HIV-stigma and resulting discriminatory practices influence experiences of HIV/AIDS, or lead to earlier death? Clearly, research that focuses on Aboriginal people's methods of disclosure and adaptation to HIV infection and stigma may provide clues.

Sexuality

The expression of one's sexuality and the experience of intimacy is another area in which HIV impacts, causing a 'disrupted biographical' experience. Analyses of "sexual self-images, negotiations, and outlooks of gay men with HIV disease" have shown how "sexuality and identity intersect within serious chronic illness" (Sandstrom, 1996: 258). HIV disease often has a profound impact on sexual expressions of self. Sandstrom (1996), in interviews with 25 gay men diagnosed with HIV/AIDS, highlights four areas in which HIV affects their sexual selves.

When HIV causes disruptions to sexual self-images, individuals often feel as if they are both infected and infectious, and indeed, they are. That is, they experience feelings of "contamination" (Sandstrom, 1996: 244). Avoidance of sexual encounters is a characteristic expression of feelings of 'contamination.' This is particularly true if one's partner is seronegative. However, feelings of contamination and anxiety decline once HIV-negative sexual partners reassure their HIV-positive counterparts of their continued desirability and convey little fear of infection. However, exacerbated feelings of contamination can be experienced should HIV-negative partners express fear of infection for themselves (Sandstrom, 1996). Moreover, through a process of social interaction with others (doctors, media, partners, friends, family, etc.), the contamination message can be reinforced (Sandstrom, 1996). Sandstrom states, "this sense of sexual pollution [...] did not hinge on these reactions. Instead, feelings of sexual contamination or stigma derive from a diagnosed individual's realistic appraisal of himself as someone who could potentially transmit HIV through sex" (1996: 245).

Individuals living with HIV also face challenges in negotiating sexual relationships. According to Sandstrom (1996), the adoption of innovative methods for negotiating sexual involvement is a necessary criterion for restoring a valued sense of a sexual self. This negotiating differs whether one is negotiating with either an existing partner or a new partner. Men seeking to establish new sexual relationships face the biggest challenge. Disclosure of one's HIV status is a difficult decision. One must balance disclosure against fears of rejection and facing the prospect of possible stigmatization. Two strategies are often employed. Either one conceals one's HIV status and engages in only safer sex practices, or one reveals his HIV status and asserts that potential partners have the right to be aware of the risks involved (Sandstrom, 1996).

Negotiating a new sexual identity following an HIV diagnosis in an ongoing sexual relationship removes the challenges of disclosure. Current sexual partners are often the first to hear of a seropositive test result, particularly if their partners are also seropositive (Sandstrom, 1996). However, what becomes critical for many couples is either avoiding infecting an HIV-negative partner or avoiding the prospect of re-infection should both individuals be HIV-positive. Negotiating sex thus means learning to negotiate changes in sexual practices. Most HIV-positive couples in this situation express resentment at forced changes to their current sexual practices. For them, the experience of a positive HIV diagnosis negates the possibility of full enjoyment and appreciation of the kinds of sexual activities once enjoyed, and demands changes to one's sexual self identity (Sandstrom, 1996). For couples where only one person is seropositive, integrating HIV into their lives comes much more easily. Sandstrom found

that complaints about changed sexual practices were fewer. "Instead, they stressed their commitment to safer sex and their desires to minimize the risk of transmitting HIV to their lovers" (Sandstrom, 1996: 250). Couples in this situation expressed anxiety over whether their changed sexual practices will be successful. As Sandstrom states, "They [typically] expressed anxieties about the prospect of infecting their lovers, even if they practiced only safer sex" (1996: 250).

For couples where one is seronegative, there may also be struggles because the HIV-positive person becomes less interested in having sex (typically because of disease progression or the consequences of HIV treatment). Adopted strategies include either encouraging the seronegative partner to take up masturbation or seek sex outside the relationship which reduces sexual pressure for both (Sandstrom, 1996: 251). As HIV illness advances, HIV-positive men often experience declines in sexual attractiveness, desire, and ability. This is true regardless of whether or not an individual has a lover. For example, physical symptoms of HIV infection (e.g., candidiasis and KS, etc.) or extreme physical weakness, often make "impossible [the maintenance of] the bodily appearance necessary to sustain conceptions of themselves as sexually desirable persons" (Sandstrom, 1996: 251). Consequently, body image also suffers. Sustaining a favourable and desirable physical and sexual self is very nearly impossible.

For HIV-positive men, as illness unfolds, sex often acquires a different sense of importance and meaning. In short, intimacy becomes a more strongly motivating factor in the expression of one's sexuality. As Sandstrom states, "Those with lovers typically become more committed to maintaining romantic and monogamous relationships with

them. On the other hand, those without lovers often affirmed the romantic ideal of becoming involved in a loving and committed sexual relationship" (1996: 256). Although sex and sexuality are still viewed in positive terms, more emphasis is placed on developing or sustaining relationships.

Tewksbury (1995) looks at the sexual adaptations made by gay men diagnosed with HIV. In a series of in-depth, semi-structured interviews with 45 HIV-positive men, Tewksbury documents the ways in which "sexual behaviours and perspectives have changed" (1995: 227) following a positive result for HIV infection. While some men abandon sexual activity, the vast majority of HIV-positive men continue to be sexually active, particularly if they are otherwise healthy (Tewksbury, 1995). Like the men in Sandstrom's study, the men in Tewksbury's study were also negotiating changes in the expression of their sexuality. They express less satisfaction with their changed sexual selves (Tewksbury, 1995). Tewksbury offers one possible reason for the dissatisfaction with changed sexual practices. When HIV illness begins to affect a gay man, it leads to questions of the role masculine gender identity has in his life. Often this core element of identity must be reconstructed (1995). In addition to changes in their sexual self, HIV-positive men must also deal with a sense of loss of control. As Tewksbury states:

Traditional constructions of masculinity have included an ability to control one's self and surrounding and demonstrable achievements of success. HIV+ gay men have lost significant measures of control. Success in physical attractiveness and sexual conquests have been forfeited or significantly reduced. Hence, two central measures of masculinity slipped out of HIV+ gay men's reach. Maintaining a strong sense of masculinity then, became increasingly difficult. (1995: 228-229)

The reconstruction of masculinity becomes a focus for many HIV-positive men.

As Tewksbury states, a sense of masculinity must be "refocused; sexuality no longer provide[s] a foundation on which to build a gender identity" (1995: 230). Sexuality is reworked into different forms of expression and often does not include participation in sex acts. At least some of the men in Tewksbury's study were able to reconstruct masculinity by exploring new areas of sexuality and personal growth. Men in relationships, for example, were able to replace sex acts with "heightened levels of emotional intimacy" (Tewksbury, 1995: 236). Furthermore, men who had given up sex were more positive than those who had simply changed sexual activities and/or reduced their number of partners. Tewksbury states, "This suggests, then, that progression of disease is accompanied by acceptance of disease (and its inevitable consequences)" (1995: 237).

Treatment Regimens

The impact of treatment regimens, in general, has radically altered the life-course of many individuals dealing with chronic illness. For example, in-vitro fertilization to deal with infertility has become common place, so too has dialysis for disease of the kidney.

Gerhardt states:

Modern medicine has been so successful regarding the treatment of chronic illness that prevalence rates have risen considerably in most Western countries, due to two related but separate accomplishments of clinical practice: one is that secondary infections have virtually become extinct [...]; the other is that dramatic intervention has drastically improved the life expectancy of diabetics, cancer patients, post-myocardial infarction patients, epileptics, sufferers from multiple sclerosis, and many others. (1990: 1149)

To this lengthy list, we can add HIV/AIDS. Rapid advances in medical science and practice have affected the course of HIV infection and greatly improved life expectancy.

The LCDC has reported an overall trend of declining numbers of AIDS cases (May 1998a:1). As already noted, the decrease in the number of new AIDS cases has been attributed to improvements in antiretroviral treatment and drug prophylaxis to guard against opportunistic infections associated with HIV infection (LCDC, May 1998a; Sowell, Phillips, and Grier, 1998). Other possible reasons include more sophisticated diagnostic tests, and improved understanding by HIV-positive individuals of how best to incorporate illness into their lives.

However, the declining number of AIDS cases and deaths is not without its own problems. Gerhardt states:

In the emerging era of treatable long-term sickness with relatively minor effects on physical capacity and life-style, it becomes vital for physicians who treat the chronically ill to know what the effects of technology and drugs are, not only in clinical terms, but also on their patient's lives. (1990: 1149)

What are the impacts of medical intervention on people prescribed such measures?

With respect to the treatment of HIV infection, sociological research has only recently begun to examine the impact that complicated regimens have for individuals living with HIV.

In an exploratory qualitative study, Sowell, Phillips, and Grier (1998) described the psychosocial and care delivery issues faced by 11 HIV positive men following the introduction of protease inhibitors. Because protease inhibitors are relatively new, and what is known about them is limited, including how long these medications will continue to work, many HIV-positive individuals are reluctant to accept that a solution has been found to HIV/AIDS. Thus, related experiences are ones of 'guarded optimism' and 'buying time'. As Sowell, Phillips, and Grier state, "The men's fear and feeling of

uncertainty about how long the positive effect of protease inhibitors would last were not unfounded, as all of them had experienced drug failure or HIV breakthrough in the past” (1998: 36). Indeed, it is widely believed within the Canadian AIDS community that newer treatments are not benefitting everyone. Many HIV-positive individuals are unable to tolerate the side effects or quickly develop resistance rendering these drugs ineffective. Uncertainties in terms of treatment for HIV continue for many HIV-positive individuals.

Recent improvements in HIV therapy have also produced changed perspectives on roles and relationships for a number of people. As Sowell, Phillips, and Grier state, “The participants described not only changes in their perspective of intimate relationships but also having become isolated from friends and the community as they became more ill, and they are now looking at ways to be more connected” (1998: 37). Many individuals look for innovative methods to re-connect that do not involve going to bars or ‘partying,’ as is often the case prior to serious illness with HIV. Often, one’s social circle evolves to include others who are HIV-positive or HIV-knowledgeable people who possess the ability to support the ‘new’ HIV-positive self.

While a number of individuals express interest in resuming former lives (including work roles), uncertainty exists as to whether their health will support this return. For the most part, individuals maintain the status quo because they remain uncertain about how long HIV medication will remain effective (Sowell, Phillips, and Grier, 1998). A related issue involves the medication regimen itself. “Some regimens require taking medication as prescribed and balancing medications that need to be taken 1h or 2h after meals”

(Sowell, Phillips, and Grier, 1998: 37). Indeed, some treatment regimens require upwards of 60 pills per day. This alone requires considerable adjustment in life patterns and routines.

Finally, Sowell, Phillips and Grier refer to the 'need for advocacy and support.' This revolves around three separate issues. The first, access to medications, is probably the most important. As previously noted, in Canada, HIV therapy can cost upwards of \$10,000 to \$12,000 per year. Consequently, maintaining access is vital given the high cost of effective treatment (Sowell, Phillips, and Grier, 1998). For Canadians, guarantees of access to these medications occur through either third party payment plans or inclusion of drug therapies on provincial and federal formularies. Related to this issue is access to competent care. As Sowell, Phillip, and Grier report, "finding a physician or other health care providers they trusted [has] been difficult. [Men . . .] often reported having more knowledge about protease inhibitor therapy than did many health care providers" (1998: 38). However, as stated earlier, it is difficult even for the most well intentioned physicians to keep up-to-date with the developments in AIDS treatment. For many HIV-positive individuals, a working partnership with one's physician proves most beneficial in terms of decision making around new treatment. As Sowell, Phillips, and Grier state, "[most] viewed those health providers who were willing to work with the patient in staying abreast of the latest treatment developments and making decisions about drug regimens as most effective" (1998: 38). That is, both physician and patient take responsibility in assessing treatment options, and in decision making around best practice approaches to effective disease management.

A related theme not identified in the Sowell, Phillips, and Grier article is the need for continued research and development into new HIV treatment areas. As HIV evolves and adapts to the effects of treatments, it is necessary to introduce new HIV medications to continue to slow the progression of HIV. Continued development of new HIV treatment compounds is required for ongoing benefits (reduced AIDS morbidity and mortality) that have been recently associated with HAART therapy. For persons living with HIV, the "most pressing need is for therapies that will control the conditions associated with HIV infection and prevent the onset of full-blown AIDS. [... To this end, there exists a need] for more effective treatments" (Bee, 1991: 161).

Lastly, the men in Sowell, Phillips, and Grier's study articulated the need for focused support services. Changes in an individual's needs and concerns often accompany changes in treatment regimens. As Sowell, Phillips, and Grier state, "What is needed are groups that allow men to get information they need about treatment, rules that affect their work and disability benefits, and potential sources of education or training" (1998: 38-9). Moreover, in many situations the needs of a newly diagnosed population differ substantially from those who have lived with the virus for a number of years. In a related article, this distinction has been highlighted. Based on his professional experience of facilitating two support groups for those infected (one for men, and the other for women) Broun writes:

In my groups now, there already exists a schism, between those newly infected and immediately started on combination therapies and those who have been on numerous drugs for years and are less optimistic about the future. [...] Those who have been infected longer are much more skeptical. One of my patients, a woman, has been through so many wonder drugs that she does not comply with her medications because she does not want to get her hopes up and then have them

smashed again. (1998: 485)

At the International AIDS Conference, held in Durban, South Africa, Johnson and Ramer presented research that outlined specific quality of life issues that have occurred in the post-HAART era in a multicultural AIDS population (2000). A sample of 420 HIV-positive individuals was recruited in a multicultural clinic setting. They reported that although CD4 levels increased and viral load measures declined, the result was improved quality of life which allowed participants to resume some of their former activities. Yet they also found that depression and fatigue, particularly pain, seem to continue as an important component in diminishing quality of life for persons living with HIV (Johnson and Ramer, 2000).

What, if anything, have we learned about the experiences of HIV-positive two-spirit men dealing with and adapting to life with HIV therapy? Anecdotal reports confirm that Aboriginal people are not properly benefitting from the many positive aspects associated with antiretroviral treatment. Are they refusing treatment or not actively seeking it out? Are cultural barriers in the delivery of services responsible for Aboriginal people refusing treatment? If little is learned from the literature about two-spirit male experiences with HIV treatment, it would therefore be important to explore these concerns as a component of this study.

Gay Culture and the AIDS Epidemic

In the early years, before the AIDS epidemic, gay culture celebrated a newly found openness connected to sexuality. Gay sex was defined as a source of pleasure and was separated from notions of love and commitment, what Sandstrom refers to as, "the

libertarian sexual ideology" (1996: 253). The traditional view of sex as connected to a monogamous commitment to one lifetime sexual partner was rejected. As a master narrative of gay culture in the past, this view was widely accepted (Rotello, 1997; Gagnon and Nardi, 1993). Rotello states "Having gay sex was seen by many as an act of defiance. Gays were considered, and often consider themselves, sexual renegades" (1997: 53). Gay culture has often felt the need, both individually and collectively, to challenge social norms to define meaning in individuals' lives (Schwartzberg, 1996). In this respect, sexual activity often served as a means for developing lasting friendships and connections to the gay community, and as a way for gay men to obtain a sense of belonging. Furthermore, gay men in larger urban centres were the most likely to be exposed to this libertarian sexual outlook (Sandstrom, 1996).

Sex was often viewed as an adventure, that is until HIV disease became known and prompted major changes in sexual opportunities, a revision in the libertarian sexual outlook, and sexual practices within the gay community (Sandstrom, 1996). As routes of HIV transmission become known, the 'party-like' atmosphere of this era ended. The first halting attempts to reconfigure the libertarian sexual ideology began almost as soon as HIV appeared to be affecting the gay community (Rotello, 1997: 91). Indeed, many gay men expressed anxiety about sexual practices and consequently adopted conservative measures in sexual practice. As Sandstrom states, "Sex became associated with disease and death and thus sexual activity became more threatening and restrained" (1996: 254). Also, upon receiving a HIV diagnosis, many gay men find great difficulty in engaging in sex or even in establishing or sustaining sexual relationships, particularly as the disease

advances.

In making sense of the AIDS epidemic and the changes in gay culture, many individuals in the community adopted a stigmatizing stance toward the libertarian sexual ideology that characterized life before. As Sandstrom states, "As the HIV epidemic progressed, a number of gay spokespersons proposed that HIV/AIDS revealed the failure of the gay subculture and its libertarian sexual ethos" (1996: 255). HIV was viewed by these spokespersons as having serendipitous consequences with respect to remaking gay culture through more stable sex relations modeled on patterns of heterosexual marriage and commitment (Sandstrom, 1996). Men diagnosed with HIV often adopt this message following a HIV diagnosis. As reported previously, HIV-positive men in relationships often affirm the romantic ideal of love while those unpartnered often aspire to more loving, committed relationships with significant others. This is especially true as the disease progresses.

Today, for the most part, AIDS has become an accepted reality within the gay community. Woven into the fabric of gay culture is the reality of HIV/AIDS. When one goes to a gay bar, bath house, or a gay community-sponsored event, the words AIDS or HIV are commonplace. Recently, for example, the gay calendar in Winnipeg included a weekend long fundraiser for AIDS-infected and affected children, gay bingo in which one must construct a red ribbon of bingo numbers called, and a HIV/AIDS community forum. As Schwartzberg states, "Over the years we have moved from disbelief - 'this cannot be' - to incorporating the fact of AIDS into our expectations about life. How extraordinary the ability, given time, to acclimate to something even so incomprehensible as [an]

epidemic" (1996: 241).

This review of the literature has demonstrated the notion of biographic disruption in the context of HIV-positivity in which this illness has been conceptualized as a chronic disease. Often, individuals who are diagnosed with HIV infection engage in a number of struggles. These have been described by attempts to respond and locate meaning in an uncertain situation, and in dealing with issues of stigma, treatment and sexuality. However, as suggested earlier, it is difficult to draw conclusions based on the literature and to extrapolate to Aboriginal two-spirit male population. Without taking away from accumulated knowledge, as suggested by standpoint epistemology and the concept of "the other," the issue confronted here is to begin the process of capturing the diversity of experiences for individuals diagnosed with HIV infection. Although the literature can inform, in short, this study explores these and other issues that two-spirit men encounter as they struggle with HIV infection. Now, we turn our attention to a discussion of the research design and the thematic content of interviews with two-spirit men living with HIV infection.

Chapter Four

The Study

An interactive model, as outlined in Maxwell (1996) guided the development of this research project. Briefly, utilizing an interactive model involves detailed consideration of five separate, but interconnected, components to highlight a study's strengths, weaknesses, and implications. Directly bearing on this section is the importance of making explicit how the study was actually conducted, approaches and techniques used, the relationship to those participating, the site selection and sampling decisions, data collection methods and techniques used in the analysis of data (Maxwell, 1996). It is also important to be mindful of the overall study design in relationship to other aspects of the research design, specifically, the purpose for undertaking the study, research questions, ethical considerations, and issues of validity. Overall, each aspect must inform, interact, and integrate with every other component of the research design (Maxwell, 1996). This chapter deals with the study design and includes a discussion of the research methods used, the interview guide and analysis, issues of validity, and ethical considerations.

Research Methods

This study is based on interviews with seven HIV-positive two-spirit men aged 18 years or older. Those who were recruited were asked to participate in a semi-structured, open-ended interview about their lived experiences as HIV-positive two-spirit men. Interviews occurred between April 5 and November 26, 1999. A further follow-up interview occurred in May 2002. Each interview took place at a location the participant

chose, including space offered through local AIDS service organizations. Only one individual indicated a preference for another location for his interview. He would have preferred that the interview take place outdoors, in a park-like setting. However, given outside noises might interfere with the quality of the audio-recording, I suggested a local AIDS service organization which was agreed upon.

A number of different recruitment strategies were used to obtain a sample of participants. Participants were recruited through advertisements (see Appendix A) placed in a local community paper and at various access points for health care and other services, through referral from medical and other health professionals, through personal contacts, and through use of snowball techniques. Participants were asked whether they knew anyone who would also be interested in participating in this study. Participants were provided with a business size card that provided details of the study (see Appendix B). All advertisements sought HIV-positive two-spirit men willing to be interviewed about their experiences living with HIV/AIDS. Interested individuals were asked to contact the investigator by telephone at which time the purpose of the research was more fully explained, and interviews were scheduled.

At the scheduled interview, all individuals were provided with an information brochure that outlined the study's purpose and objectives, the voluntary nature of participation and a promise of confidentiality. Furthermore, participants were informed that the study's principal aim was to fulfil partial requirements for the degree, Master of Arts in Sociology. Individual participants signed a consent form that included a statement outlining that they had been informed about the study's purpose and objectives, and they

had consented to participate. Included in Appendix C is a copy of information brochure, consent form and ethics approval.

All participants received monetary compensation (\$20 each) for their involvement in the study. This monetary gift respected the notion of gift-giving in many traditional Aboriginal cultures, and also recognized the severe economic impact AIDS may have had on their lives.

The goal of each interview was to obtain a first-person account from two-spirit men about their experience living with HIV/AIDS. In this respect, the interview, as a research method, was best suited for the task of obtaining vivid descriptions of life with HIV/AIDS (Thompson, Locander, Pollio, 1989). Interviews that generate narratives of illness provide a powerful voice for experience. As Hydén states, "The narrative's importance lies in its being one of the main forms through which we perceive, experience, judge our actions and the course and value of our lives" (1997: 49). A number of researchers have also found value and applicability in the interview method in their own research of the HIV/AIDS experience (Roth and Nelson, 1997; Stevens and Doerr, 1997; Viney and Bousefield, 1991). The selection of the interview method was also guided by the cultural importance given to oral story-telling in many Aboriginal cultures. Such an approach, respectful of cultural modes of communication and expression, facilitated rapport and established a safe and culturally appropriate setting in which the participants shared their own stories of life with HIV/AIDS.

All interviews were audiotaped and later transcribed, utilizing a transcription service. A verbal agreement between the transcriptionist and myself ensured

confidentiality. Validity concerns were addressed through a review (myself) of each completed transcribed interview to ensure the transcriptions faithfully represented the dialogue.

In most cases, participants expressed nervousness about the recording, both verbal and nonverbal, particularly at the beginning of the interviews. However, once the conversation started, nervousness faded and was replaced by conversational exchanges that were often punctuated by laughter and tears. Several participants experienced the sharing of their stories as a cathartic releasing of emotion and left the interviews saying that the experience served as a catalyst for future action and the setting of direction.

Throughout this project I maintained field notes that recounted observations, conversations and impressions before and following the interviews, including verbal and nonverbal communication during the interviews. For example, some participants asked about community resources that may be available. Using a collection of pamphlets and brochures obtained from various service providers, I directed the participants to various sources that might aid them in resolving difficulties, accessing information, and services. One individual indicated hardship accessing treatment. For another, it was a desire to obtain a membership in a health/exercise facility. Each participant was provided with the best information I had on hand about services, or he was referred to an appropriate service agency.

Several issues arose for me as interviewer and researcher. First and foremost were the difficulties I encountered in battling my own demons and baggage. I often doubted my abilities to capture detail in the interviews. As well I continued to doubt my

ability to faithfully analyse the data I had collected. For example, early in the interview process, I questioned whether I had solicited adequate detail about lived experience or 'stories.' During the analytic phase of this research, I worried whether I had fully understood that which was so freely shared. Continually removing these emotional barriers proved a successful tactic. I was somehow able to persevere by bouncing my doubts off colleagues, friends, and family, particularly those who had also been through the process of thesis preparation.

Another issue I continually dealt with was my own, at times, failing health, coupled with the rather hectic obligations I undertook in the AIDS community. I was often overwhelmed by fatigue following the interviews. At times, this prevented me from completing my field notes until such time as my energy rebounded. No doubt, recounted impressions lost the edge that was subject to my own ability to recall conversations and impressions. Around the end of the data gathering stage of the research, I was forced to change my treatment regimen. This experience not only heightened fatigue but also left me feeling emotionally drained and depressed with yet a new realm of side effects (short- and long-term) from medications. I learned to not only break my goal down into manageable steps, but to remove physical, mental and emotional obstacles, to never stay far removed from my desire to complete this thesis.

I also discovered the process of research differed substantively from that which is presented in the published scholarly literature. Studies are typically presented in clear, crisp tones of absolute self-assuredness in which one idea generates the next. What I did find was that this particular research topic was in practice rather messy. So it may be

with all research regardless of the research topic. The process of developing an understanding of social phenomena is a sometimes chaotic but hopefully fruitful endeavour. When one applies analytic strategies, and is guided by a theoretical framework, the process of research can be a highly challenging and creative activity.

Lastly, it was often difficult to hear the struggles involved in learning to live with HIV infection and AIDS. It was equally liberating to note descriptions of achievements, of mastery that comes with the passage of time. What appears often at times contradictory was only made clear after I had examined my own struggles and achievements of living with HIV. I had not only learned about the process of research but was able to account for myself the experience of HIV as a two-spirit man. Gatter writes, "On the basis of the style of analysis [presented] here, we are forced into examining our own and other identities, and indeed the process of research identity, reflectively" (1995: 1531). This mirrors my own experience in this study.

The Interview Guide

The primary objective of each interview was to encourage conversation, avoiding as much as possible an interview structure that resembled a question and answer period (Thompson, Locander, Pollio, 1989). As Riessman states, "It is preferable to ask questions that open up topics and allow respondents to construct answers, in collaboration with listeners; in ways they find meaningful" (1993: 54). Within this broad inquiry, each participant was asked to describe events in their lives relating to life with HIV infection, particularly issues of uncertainty, stigma, sexuality and HIV treatment. In this respect, Conrad offered a series of question topics that helped highlight the

experience of illness during interviews. He states:

Relevant questions include how people first notice 'something is wrong' and what it means to them, what kinds of theories and explanations they develop to make sense of these unusual events, what they do about their problem, how they come to seek medical care and with what concerns and expectations, what impact diagnosis has on them, and how they cope with a medical label and managing regimens. It must examine the relationship with family members, friends and work associates. It needs to consider how people contend with formal and informal disenfranchisement based on a diagnosis, how people adapt to physical discomfort, what it is like to make routine visits for medical care, how medical personnel and others appear to patients, and what strategies people use simply to 'get by' in their lives. (1990: 1260)

The interview guide (see Appendix D) broadly focussed on these areas as they relate to the men's experience of HIV/AIDS. It should also be noted that probes were used in an attempt to draw out more detailed responses, particularly in areas related to the intersection of culture and sexuality, uncertainty, stigma, and disrupted biographies. For example, related to the issue of testing HIV-positive, at times I requested clarification or simply asked, "can you tell me more?" Suggested here, probes were used primarily to explore, seek explanation, clarification, and description. Subsequent questions were asked only when I felt I had achieved sufficient detail with respect to the nature of the experience.

Also, in an effort to establish rapport, interviews often opened with dialogue and prompting suggested by interview participants. Likewise, at times I would also nod my head in agreement, 'yes,' to indicate I had heard and validated their experience of living with HIV. Such tactics proved, I believe, beneficial in that they set a tone for the interview that was non-judgmental, and made participants feel comfortable when sharing their stories about life with HIV infection. In this context, the interview schedule was

primarily used to guide conversation towards issues related to the purpose and objectives of the study.

The beginning of the interview gathered basic demographic data and identified the interview referral source. Once rapport was established, more reflective questions were asked. Such questions highlighted the emotional world of the participant and the meaning each participant attached to experience. Lastly, "ending questions [were] designed to complete the interview on a positive note" (Charmaz, 1990: 1167).

The original interview schedule was modified to account for issues arising in previous interviews. Early on, for example, following the first couple of interviews I decided to add a question concerning relationships with other family and community members, whether they had been able to disclose, what prompted disclosure, and what may have prevented it. As one participant discussed the difficulties he had visiting home, adhering to a complicated treatment regime, it became explicitly apparent he had been unable to share his experience of HIV with members of his family or his community. This prompted me to inquire of other participants whether they had also confronted similar difficulties and how they managed these situations and dealt with them. Overall, through trial and error, I learned to trust my ability to elicit detailed responses, to dialogue with participants, and to draw out meaning attached to individual experience. A copy of the revised interview guides is also found in Appendix D.

Analysis

The narrative approach as elaborated by Hydén (1997), Riessman (1990; 1993), Roth and Nelson (1997), Stevens and Doerr (1997), Williams (1984), and Vinney and

Bousefield (1991) guided my approach to the interview data. That is, I conceptualized HIV/AIDS as a disruption to one's personal biography. The personal narrative approach was appropriate for exploring the two-spirit experiences and subsequent reconstruction of identity to an HIV-positive self. That is, individuals diagnosed with HIV often choose the story form to highlight aspects of their experience to their physicians, other care providers, and significant others (Hydén, 1997; Frank, 1995; Riessman 1990; 1993; Roth and Nelson, 1997; Viney and Bousefield, 1991). As Frank states:

Serious illness is a loss of the 'destination and map' that had previously guided the ill person's life: ill people have to learn to 'to think differently.' They learn by hearing themselves tell their stories, absorbing others' reactions, and experiencing their stories being shared. [In essence,] the body sets in motion the need for new stories when its disease disrupts the old stories. (1995: 1-2)

By closely examining the raw data of the interviews, their content and context, one can interpret the challenges faced by HIV-positive people in presenting a re-constructed self (Roth and Nelson, 1997).

The beginning phase of data analysis involved the construction of a simple matrix in which interview questions were listed and participant statements in response to interview questions were listed alongside. This initial attempt at data reduction provided the basis of a rudimentary coding scheme. The matrix which was developed, including analytic memos generated, was cross-referenced both with the interview data, and to a lesser degree, with the existing literature. Later, key statements were grouped according to common themes and placed on index cards and used in the analysis of the data. The main goal to this form of categorizing strategy was "not to produce counts of things, but [rather] to 'fracture' the data and rearrange it into categories that facilitate[d] comparison

of data within and between [...] categories and that aid[ed] in the development of theoretical concepts” (Maxwell, 1996: 78-9).

In order to develop an understanding and to clarify the issues related to the lived experience of HIV/AIDS from the perspective of two-spirit men, I utilized a tool known as concept mapping, first developed by Joseph Novak and presented by Maxwell (1996). In short, the concept mapping procedure I utilized consists of identifying concepts and exploring the relationship between them. Key statements transcribed to index cards were moved around to explore “possible arrangements and connections” (Maxwell, 1996: 37). In this way, analysis utilizes a conceptualizing strategy as described by Maxwell, in which “attempts to understand the data [...] are placed] in context” in an effort to explore and “identify the relationships among the different elements of the text” (1996: 79). The final product is presented in the chapter on the analysis of the thematic content. In short, it represents an abstract framework that demonstrates the relationship among the themes that were generated and thus provides a conceptual tool for how the two-spirit men in this study experience HIV/AIDS.

Additionally, the method of analysis outlined above was complemented through additional application of a method of constant comparison as outlined by Glaser and Strauss (1967) and Glaser (1992). That is, the themes and concepts generated were later subjected to a method of constant comparison in which integration with the existing literature was of primary importance (Glaser, 1992). As Glaser states, “Especially during sorting and then writing, the researcher-analyst by constant comparison reconciles differences, shows similarities in concepts and patterns, and imbues his work with the

data and concepts in the literature” (1992: 33). The purpose here was to suggest a provisional theory that is “integrated, consistent, plausible, [and] close to the data” (Glaser and Strauss, 1967: 103). As Glaser and Strauss state, “the constant comparative method is concerned with generating and plausibly suggesting (but not provisionally testing) many categories, properties, and hypotheses about general problems” (1967: 104). That is to say, aspects of grounded theory are used in terms of identifying similarities and differences.

Throughout analysis of the interview data, the general problem was to understand identity re-construction that occurs at the intersection of culture and homosexuality following a positive result for HIV infection for a sample of two-spirit Aboriginal males living in Winnipeg. The interview data were analysed utilizing a simple matrix that was developed into a concept map. Finally, loosely guided by aspects of grounded theory, themes and concepts were subjected to a comparison with existing literature on the subject of HIV/AIDS experience.

Ethical Considerations in the Conduct and Analysis of the Interviews

In this study it is important to recognize the researcher’s position of power vis-à-vis the study participants. This is largely the result of the status and education accorded to those who carry out research. I had hoped this power imbalance would be reduced, if not eliminated, by allowing study participants an opportunity for free and open discussion about their experiences with HIV/AIDS. In essence, the researcher and participant must establish a position of equality between themselves. As Thompson et al. state “The interviewer does not want to be seen as more powerful or knowledgeable because the

respondent must be the expert on his or her own experience" (1989: 138). Brant argues that any attempt to show that a researcher knows more about a particular subject than a participant will be "seen as an attempt to establish dominance" (1990: 535), a situation not likely to produce a successful research outcome.

Participation in this study was voluntary and informed. All participants were asked to complete a consent form indicating that they were informed of the purpose of this study. At no time were confidential medical records consulted. Rather, each individual participant provided whatever information he felt necessary and was comfortable providing.

In addressing the issue of confidentiality, several measures were taken. The Canadian Oxford Dictionary (1998) defines confidentiality as the safeguarding of secrets. Confidentiality can be expressed in both the written or spoken forms. Anonymity, on the other hand, designates a state that is "unknown, featureless, [or] impersonal." Clearly, given the nature of the research design, it was impossible to guarantee participants complete anonymity. In short, they would be known, not only to me, but also to individual service providers and members of their social networks who may have referred them for recruitment into this study. However, it was possible to provide written and verbal assurances as to the confidential nature of their participation. Participants were informed that once the data had been collected and transcribed all identifying information would be removed. At no time do names appear in this thesis. Rather, each participant chose a pseudonym that is used throughout the study. Furthermore, all information was stored on computer in encrypted and password-protected files. Upon completion of this

study, audio-recordings, transcripts, and related computer documents were destroyed.

With respect to the issue of transcription, as outlined above, a verbal commitment with the transcription service provided guarantees of confidentiality. As noted earlier, a copy of the ethics approval has been included in Appendix C.

Validity

In tackling the issue of validity, whether the results are irrefutable, it is important to note, as Maxwell states, “[that in doing qualitative research] the validity of [...] results is not guaranteed by following some prescribed procedure” (1996: 86). Instead, validity “depends on the relationship of your conclusions to the real world. [...] Validity is a goal rather than a product” (Maxwell, 1996: 86). In assessing the validity of the findings presented here, several items are noteworthy. The first issue with respect to validity arises when considering the recruitment of study participants. One participant, at his request, was interviewed on two separate occasions. Another, at my request, participated and agreed to a follow-up interview. These second interviews raise important points with respect to the issue of validity.

While I had hoped to include between 12 and 15 participants, several issues arose which may account for reduced enrollment into this study. The first issue arose over confusion surrounding the term two-spirit. At least one individual I spoke with did not consider himself two-spirit. Once I explained that I used the concept two-spirit to describe gay Aboriginal men who were living with HIV, he agreed to participate. It is entirely possible that other individuals did not contact me directly because they assumed they did not fit the inclusion criteria. I therefore refined the recruitment strategy making

more explicit the term two-spirit. Another issue arose following a presentation of this research project to a service provider who felt I was limiting myself by specifying recruitment within Winnipeg. Many individuals accessing HIV-related services come from outside the Winnipeg area, and live in rural areas (in some cases, within their home communities). Lastly, there was a problem when scheduled participants did not keep appointments for whatever reason. When a participant originally called to schedule an interview, often they were unable to provide a telephone number in the event I needed to reconnect with them, or wrong numbers were provided either by my own error or that of the participant. In short, at times it was difficult to contact and reschedule missed appointments.

As suggested earlier, because of reduced enrollment and in an attempt to achieve saturation of the data, one individual (Darren) was approached at a later date to participate in a follow-up interview. Primarily, the reason for approaching Darren was one born out of accessibility. Once the study data collection was finished and I was in the process of drafting the findings, conveniently, we found that we had both moved to the same city. This individual was by far more accessible to me than the other men in the study, many of which are lost to followup.

In a similar vein, a threat to validity also occurred when another participant (Curtis) approached me for a second interview. It was my feeling that this individual needed the honorarium that was offered to participants (during the second interview, he indicated his continuing use of cocaine). Individuals living with HIV may experience, "a number of negative sequelae including social exclusion, anxiety, alienation, loss of self-

esteem, discrimination, and social [and economic] disenfranchisement” as a result of their illness (Siegel, Lune, and Meyer, 1998: 4). Attempts to mitigate such circumstances may propel individuals towards situations in which they may feel compelled to, for example, participate in research, particularly where honoraria are provided in exchange for their participation.

This case raises some questions about how to address ethical considerations in the conduct of research and about the validity of the accounts provided. I say accounts because Curtis provided different information on the two occasions when he was interviewed. He also asked that these accounts be reported as if they reflected the experiences of two different individuals. This request placed me in an ethical quandary; that is, how could and should I reconcile the obligation to, on the one hand, respect the research contract between me and the participant and, on the other hand, the obligation to report truthfully and not fabricate the data on which this thesis is based? In the end, I felt that truth was the higher value to uphold. Consequently, I present “Curtis” as one individual (rather than two), and I have been cautious and selective in terms of integrating his experience of HIV/AIDS with those of the other participants.

After this experience, I concluded that it would be useful during future screening procedures to include a question about the nature of their decision to take part in research projects. Assessing responses may highlight the need to guard against, or be mindful of, potential validity threats.

An unrelated validity issue occurs when considering whether individuals participating in HIV-focussed research are in fact HIV-positive? In the early

development of this research project a decision was made to obtain self-reported disclosure of HIV status, to not verify HIV-positivity through independent sources, such as medical records. Some participants may not truthfully represent their health status, so a strategy was utilized to guard against this. I focussed primarily on the role service providers would play in recruiting and referring potential participants. A series of presentations was made to service providers, outlining the purpose, objectives, and nature of the study, requesting assistance recruiting HIV-positive two-spirit men into the study. A similar strategy was adopted with those who participated. Following each interview, participants were provided with business cards to provide to members of their social network, individuals who were also living with HIV infection. However, posters and ads placed in local community newspapers and at various service organizations created the potential and increased the likelihood that individuals might be recruited because they presented themselves as HIV-positive when they were in fact not, a situation not entirely unheard of. Primarily, this results because additional benefits (increased services and attention) are available to individuals living with HIV. For example, an HIV-positive individual enrolled in a social assistance program would not be required to submit to regular job search requirements, but could remain within the program indefinitely. Considering this point, it was necessary to balance the need for recruiting individuals willing and able to participate with threats to validity.

Overall, given the difficulty assessing and then gaining valid and useful data that will inform an understanding of the lived experience of HIV/AIDS, it remains essential to recognize that in some ways insights are potentially biased. However, equally important

to note is the assertion that insights may represent a closer approximation to reality than originally known prior to any research taking place. It therefore has the potential to be more valid and representative of those participating than what someone, located outside the boundaries of the HIV/AIDS experience or of this community of two-spirit men, might initially understand about this specific social phenomenon.

To summarize, then, issues for future research include how to minimize threats to valid conclusions through refinement and evaluation of data collection techniques and recruitment strategies. It is important to understand the causes of threats to validity, and to make these explicit so that those who may eventually read the final research will be able to judge for themselves whether validity issues have been dealt with adequately.

Chapter Five

The Study Participants

This chapter provides an overview of the men participating in this study. By way of introduction to the men in the study, the term two-spirit requires more detailed definition. Two-spirit refers to Aboriginal gay men and lesbians. It is an attempt by these groups to define themselves in a contemporary context while reclaiming some of their traditional past and place in history. Before European contact, two-spirit men and woman held a place of honour in Aboriginal society. Two-spirit people occupied special roles, such as "counselling, healing, being pipe carriers, visionaries (seers), and conducting oneself in accordance [... with] respect for all life" (Deschamps, 1998: 10). The concept of two-spiritedness is rooted in spiritualism. Two-spirit people bridge the difference between man and women; their spirit is comprised of both. As Williams states, "Since they mix characteristics of both men and women, they possess the vision of both. They have double vision, with the ability to see more clearly than a single gender perspective can provide" (1992: 41-42). The contemporary term two-spirit is a commonly held perspective within the gay urban Aboriginal population (Pilling, 1997), and is used within the context of this study as "it is more culturally relevant to Aboriginal lesbians and gay men" (Deschamps, 1998: 10). Thus, this study refers to HIV-positive gay Aboriginal males as two-spirit.

Table 2 highlights some important participant characteristics. It provides a summary of participants' ages, tribal affiliations, length of time since diagnosis, current health status, and approach used in the management of HIV infection.

Table 2: Selected Participant Characteristics.

	Total (n=7)
Age (mean=32, range 23 to 44)	
20-24	1
25-29	2
30-34	2
35-39	1
40 or older	1
Tribal Affiliation	
Cree	2
Ojibway/Ojibway-Sauteaux	3
Métis	2
Length of Years Since Diagnosis (mean=6, range 2 to 10)*	
0-4	2
5-9	4
10 or more years	1
Current Health Status	
HIV asymptomatic	2
HIV symptomatic	2
AIDS	3
Use of Conventional Treatment for HIV Infection (HAART)	
Yes	3
No	4
Use of Traditional Approaches in the Management of HIV Infection	
Yes	6
No	1

*The length of time participants were diagnosed with HIV represents an estimate based on one participant's inability to recall the year of his diagnosis. It is important to note, however, Taylor was able to say he had tested HIV-positive in the late 1980s which meant he had been living with HIV infection for approximately 10 or more years.

Table 2 shows the average age of the participants was 32 (with a range of 23 to

44 years), the average length of time since they were diagnosed was 6 years (with a range of 2 to 10 years). The men participating in this study were either of the Cree, Ojibway/Ojibway-Sauteaux or Métis nations. A majority of respondents were either living with symptomatic HIV infection (n=2) or AIDS (n=3). It is interesting to note the level to which these men depended on traditional approaches (86%) to the management of HIV infection coupled with use of HAART based therapies (43%).

In what follows, I have included brief profiles for each participant in order to familiarize the reader with the men involved in this study. The names of the men are pseudonyms and are meant to ensure that their identities are protected. Personal details, such as geographic location of their home communities and other identifying information have been masked as well. Indeed, given the small HIV-positive Aboriginal community of which these men are a part, a great deal of identifying information had to be stripped away in the description of the men and in the discussion of their experiences. It is entirely possible that many individuals outside this research process will recognize the participants but every effort has been made to ensure that their identities are not revealed.

Curtis

Curtis is a 28 year old man of Ojibway descent currently residing in Winnipeg. He is originally from an area in northwestern Ontario, where he lived only for a short period of time in a reserve community. When he first moved to Winnipeg at the age of 16, he found himself homeless, frequently in and out of shelters, and migrating across the prairies to other cities as well. His family of origin continues to live in an Ontario city close to their reserve community. Curtis's world revolves around Winnipeg's HIV

community. Members of this community represent his primary social network and he resists disclosing to individuals outside of this community.

At the time of the interview he had been living with HIV infection for eight years.¹

Discovering he was HIV-positive was something that was not a huge shock. It was something he had already suspected, although he admits he went back for a second opinion. Testing positive produced a feeling that he was somehow tainted. He learned about his HIV status approximately two years prior to his partner's death from AIDS-related complications. Dealing with his partner's illnesses took the edge off learning he was HIV-positive. At the time, he was more concerned with his partner's health status than his own. However, he questions whether he has actually dealt with the consequences of his own HIV status. In short, he reveals, dealing with his partner's illness and eventual death was by far more traumatic and miserable than learning he, too, was HIV-positive.

Disclosure is a thorny issue for Curtis. He resists the notion that he must disclose his HIV status to anyone. However, he readily admits he will tell his sexual partners, who are individuals at risk of infection. Although he feels uncomfortable, he manages this by informing his partners only after they have left the bar where he contends there is less chance of public rejection.

¹It is important to note Curtis participated in two separate interviews. During the second interview, he disclosed he had been living with HIV for 10 years. Although there were some inconsistencies in the information presented in the two interviews, most information was the same, such as the location of his home community and the make-up of his social network. Also, the second interview includes additional information not discussed at the first interview, such as cocaine use and his family's involvement in the AIDS movement.

His family discovered he was two-spirit and HIV-positive at roughly the same time. His family's disbelief, initially, was confirmed when several years later they again asked whether or not he was HIV-positive. He admits that today he is embarrassed by his family's involvement in the AIDS movement, now that they have dealt with his diagnosis. He feels that any sense of privacy about his medical condition is now completely out of his control. This is a continuing struggle for Curtis because although he resents their involvement, he also admits it makes him feel good to have family members who are incredibly supportive. When it comes to the Aboriginal community, he fears disclosure will lead to being viewed as some sort of 'beacon of light.' Although he admits he would like some day to move home because he feels more connected to the land, he resists exploring this further. For him, he would be denying his gay identity within the confines of a smaller urban setting.

Curtis's health remains relatively stable and he has experienced no major problems related to his HIV-positivity. He continues to see his doctor on a regular basis for basic medical care, including physical examinations and blood work. However, he does not take any HIV medications. He prefers marijuana and at times uses cocaine when it is available. He appreciates his doctor's bedside manner. The doctor allows him to make decisions about his health based on medical information s/he provides him. This allows Curtis a certain amount of control over his care. He sees this as his right as a patient. He retains ultimate control over what he puts into his body, what goes into his head, and what he takes into his heart. He reasons that the decision to forgo HIV medication rests upon personal observation. He has seen how friends become very ill from side effects.

He feels that this treatment somehow makes you much more ill than the actual virus does. At some point, however, he admits HIV therapies may be an option.

Curtis does not describe himself as traditional, in the Native sense. Although he was raised in an environment that did not support his Aboriginal identity, he acquired an appreciation of ceremony and often attends a sweat lodge. He emphasizes that these experiences are particularly grounding. Curtis mainly uses the sweat lodge to detoxify his body, mind, and spirit, and he feels it is important to learn about his culture and some of the traditions. In short, participating in cultural ceremonies promotes a greater sense of Aboriginal identity for him. He maintains that being more conversant with ceremonies and traditions has helped him deal with being HIV-positive. However, he also feels, displaying an ongoing struggle, he would be 'fraudulent' practicing traditions, because he is 'so white.' However, overall being HIV-positive is an excessive burden, particularly when he is 'outed' by members of the gay community. At times he wishes his life was like it was before, prior to testing HIV-positive. He describes the gay scene as particularly 'cut-throat' where secrets, confidentiality, and control over disclosure are often beyond his control. This, he feels, is particularly the case if one is gay, HIV-positive, and Aboriginal. He believes there is more stigma attached to being HIV-positive and Aboriginal. Indeed, he believes if he were 'white' there would be more acceptance within the larger gay community of which he is a part.

Since testing positive he often feels his life is not any different than it was before, although he admits to being more future-oriented. If Curtis decides on a course of action, he is more cognizant of the impact this may have on his future. For today, he focuses on

taking care of himself, partying less often, having better sleeping habits, being more focused on obtaining goals he has set for himself, such as finishing his education.

Education represents a means to end, that is, being able to support himself.

Curtis displaying a sense of bravado, admits his mind is very strong. He states that the AIDS-related deaths of friends do not affect him. He rationalizes that what happens to one person may not necessarily happen to him. He takes comfort in the uncertainty HIV presents in his everyday life. That is, not learning about disease progression or of treatment regimens is a method used in the management of uncertainty. However, prior to the interview, he buried a close friend who also died from AIDS-related complications. This was an extremely difficult time for Curtis and, in some ways, he feels it changed how he thinks about HIV/AIDS. It seems at this point, he is more capable of witnessing the death of another and connecting it to his own illness. However, he continues to believe he is 'in this for the long haul' because he enjoys life and desires living. Overall, although he wishes he had never contracted HIV, he is thankful to be alive. In questioning the future, he is also beginning to realize 'how fragile the human condition' can be.

Walter

Walter is a 27-year-old man of the Cree Nation. At the time of the interview, he had been diagnosed with HIV infection for two years. Walter is originally from northern Manitoba and moved to Winnipeg to attend school and to explore his gay identity. He remains in the city so that he can access HIV care, support, and treatment.

Walter discovered he was HIV-positive following the end of a relationship with

another man, who he later learned had also been HIV-positive. He was unaware of this information while in the relationship. Walter's reaction to testing HIV-positive was pragmatic. He sought out information from a variety of sources. He was determined to learn all he could about HIV infection, how to live with the infection, and how to deal with significant others in his life.

Walter keeps regular appointments with his doctor and finds the anonymity of the waiting room a major factor in this decision. He obtains his care in a large hospital setting and is grateful that other individuals sharing the waiting room do not know why he has an appointment. In his words, 'it's not identifiable [as] a HIV-positive waiting room [and] mostly the other patients are senior citizens.' Confidentiality is an extremely important characteristic of Walter's life with HIV infection.

Walter began taking HIV medication shortly following his diagnosis of HIV infection. He places enormous faith and trust in HIV medication that has been developed by science and rigorously tested through clinical trials. The first combination of treatment he tried did not work as expected and he is now on his second course of anti-retroviral medication. He feels that HAART, particularly relying on protease inhibitors, is somehow toxic. From following results of his blood work, he knows this second round of medication is working, his viral load has decreased and his t-cell count has increased. However, he must now contend with what he describes as unexplained weight loss. Although he avoids worrying about his health, this is often quite difficult. He relies on the support of a few close Aboriginal friends to whom he has disclosed his HIV-positivity, although he sometimes feels they don't understand what he is going through.

Walter would like his life to be more centred on tradition and ceremony. He also enjoys being able to converse in his mother tongue with his friends and family members. At one point, while living in Winnipeg, he was invited to a sweat lodge with a friend. For him, this experience represented an attempt to remain in touch with his cultural upbringing. However, he finds access to traditional care a problem, partly because of the lack of opportunity in the urban setting, but also because he fears being asked where he is from and having to disclose his HIV status. Despite Aboriginal protocols preventing others from sharing the content of ceremony, he is worried that somehow it will get back to his home community and that his family will learn he is HIV-positive. Even when accessing HIV treatment, he first required assurances that non-insured health benefits of FNIHB would not report to his community the types of medication his doctor prescribed.

In dealing with the uncertainty of HIV he prefers his anonymity above all else. In this respect, Walter tends to isolate himself from the outside world, preferring contact only with individuals in whom he has been able to trust and confide. Walter has yet to inform his family he is HIV-positive. He fears what will happen should others in his community discover his secret. He has heard stories about others and some of the situations that arose through disclosure. He protects his family from this information for fear it may hurt them. When visiting his family, he has to hide to ensure he adheres to his medication regimen.

Taylor

Taylor is a 38 year old man of Ojibway-Sauteaux descent. Although he was unable to remember the exact year when he tested positive for HIV, he recalls this

occurred in the late 1980s. Taylor lives with his partner of four years, who is also HIV-positive. Taylor moved to Winnipeg for the opportunities that the gay scene presented. Taylor is actively involved in recovery from alcohol addiction. He attempts to learn as much as possible about living his life in physical, emotional, and spiritual balance. Currently, although he has a partner, Taylor admits that the sexual relationship he had with him at one point is now on hold. His partner is very ill and this is Taylor's way of respecting his situation. Shortly after the interview his lover died of HIV-related complications.

Finding out about his HIV status was a difficult experience for Taylor. He received no counseling about what to expect, or how to deal with and live with HIV infection. He felt, at the time, that his HIV infection might disappear on its own. He also thought the doctor had made a mistake. This prompted him to seek confirmation of his HIV-positive status from a number of different sources. Taylor describes his everyday life as a series of ups and downs. One day he is feeling sluggish, has a fever, is fatigued; and the next, he feels fine. At times, when frustrated with his doctor, he talks with his elder, who he finds more accepting of his two-spiritedness and his HIV-positive status.

Taylor visits his home reserve community on a regular basis and talks about moving back at some point when he becomes ill - 'after the storm dies down, once people learn to accept [he is] HIV-positive and gay.' However, certain members of his family still do not know he is HIV-positive. Although he was able to share this information with certain family members, he hasn't yet informed his mother, who contends with her own illnesses. He is afraid such information may escalate her condition, although he believes

she may suspect something, particularly given that other members of his family may have already shared his HIV-positivity with her. He is often asked, when visiting his mother, how he's feeling, evidence he believes demonstrates she is aware. As a result, he has concluded, when you share information in confidence it isn't always kept in confidence. Thus, he abstains from sharing much of his life in Winnipeg with members of his home community. Although he would like to be able to share his HIV status more openly, he is afraid of dealing with the stigma attached to individuals who are positive. Particularly when he attends traditional ceremonies and must undress or provide handshakes to others, he worries, 'they would make discriminating remarks.'

Taylor prefers to receive his medical care from an individual who is knowledgeable about gay issues. For him, this provides more safety and comfort in presenting issues related to his gay lifestyle. Taylor sees his doctor on a regular basis. At the time of the interview, he had already been on three different combinations of HIV medication, using them for short periods of time before frustration with the ever-present side effects forced him off his regimen schedule. He is more committed to this third round, however, after being hospitalized with PCP. He decided while in the hospital that he still had unfinished business and 'decided to pull through and live.' He now takes between 18 and 21 pills each day, depending on side effects. At times, however, participation in cultural ceremonies interferes with his ability to maintain his treatment regimen. It is difficult for him to leave ceremonies before they are finished to take his medication. He believes, however, this will change as more and more elders become aware of HIV, and of the need for persons living with HIV to take breaks. Accessing

care from an elder who is knowledgeable about HIV infection makes the experience more comfortable. Some elders are aware of medication schedules, that at times the ceremonies must stop in order for one to take medication, that one may need to break the heat from the sweat, or that sharing circles can fatigue you. Healers provide Taylor with a sense of hope, learning about new approaches to dealing with his infection, or using herbs and other different traditional medicines.

Although he doesn't believe he is traditional in the Aboriginal sense of word, he readily admits his stance is more contemporary in nature. He finds it difficult to live a traditional day-to-day existence. He admits that to be traditional would mean being friendly to all Aboriginal people he encounters, something that he struggles with because he feels uneasy that he may be perceived as 'being too gay.' Spirituality plays an enormous part of Taylor's life. It provides a sense of purpose, of contributing back to the community, and lending a helping hand to various friends and family. It provides a sense of grounding in knowing he treats others as he would expect them to treat him.

Darren

Darren is a 32 year-old man and a member of the Métis Nation.² Darren has been aware of his HIV infection for eight years now. He receives his medical care at a large teaching hospital and is currently on anti-retroviral medication. He decided to use the hospital because he feels they have 'a better handle on' or are more knowledgeable about HIV medication and managing his condition. However, he admits it sometimes makes

² It is important to note, Darren agreed to participate in a follow-up interview at my request. An attempt was made here to gather further data related to disrupted biography. A revised interview schedule, as stated earlier, has been included as Appendix D.

him feel as if he is a 'guinea pig,' being moved around from one medical specialty to another. For him trust is a very important factor. He is willing to be juggled around because he feels his providers have a solid knowledge about HIV infection. Having more information about what is happening with his body reduces his level of uncertainty.

Finding out he was HIV was a 'blow' to his self-identity. At the time, he experienced feelings of being 'dirty and polluted.' Testing HIV-positive marked the beginning of alcohol and drug abuse. Living in another province at the time, he later returned to Winnipeg, hoping his adoptive family would provide him with emotional support. Currently, Darren struggles with unexplained weight loss, the result of his HIV infection.

Darren believes that in some ways acquiring HIV infection has prolonged his life. He is not only learning about living with the disease, he is learning more about himself as a person. Early in life, Darren was adopted by a non-Aboriginal family and was raised in northern Manitoba. Adoption, he believes, set him on an early course towards alcohol and later drug addiction. Prior to learning he was adopted he felt secure and loved. However, when told he was adopted, he lost any sense of grounding and this caused him to disconnect with the world around him. Living as an Aboriginal man within a non-Aboriginal family made him feel as though he was caught in the middle of a predominantly white world and Aboriginal culture, and that his whole life up to that point had been a lie. His adoptive family found it difficult to believe he was HIV-positive. They questioned whether it was just another lie to gain financial support to continue his addictive lifestyle.

Recently, Darren was able to re-connect with his biological family. He was able to disclose both his two-spiritedness and his HIV-positive status. He feels he has found more support with his family of origin. For a period of time, he was able to live with his biological mother. Darren no longer has any contact with his adoptive family.

Darren continues to struggle with his identity as a gay man. He rejects the label two-spirit. He thought the term was akin to being female. It was almost as if he had to reject the male aspects of his person. Today, he has a greater understanding of HIV/AIDS which has brought him back to his two-spiritedness. For him, this represents the 'caring and sharing - of giving back to community, but also receiving.' He believes testing HIV-positive most likely saved his life. He has since given up most of the alcohol and drug addictions of his past, and he has been able to focus more on future goals.

Rick

Rick is a 44 year-old man of Métis descent, originally from north-central Manitoba. He moved to Winnipeg for employment and plans a future back in his home community. Rick has been living with HIV infection for eight years.

Rick learned he was HIV-positive when his partner disclosed his own status. Rick wasn't angry with his partner. Instead, he actually experienced a sense that they were now closer together, sharing and dealing with difficult news that together they managed to overcome. When Rick did have the HIV test completed, it wasn't a surprise to learn he was also HIV-positive. The social worker who provided this information displayed more emotion than he did - 'it showed [him] she really cared.' The only difficulties he has with being HIV-positive are the negative societal messages he receives, particularly

from individuals not respecting the choices he has made for himself.

Rick was able to share his HIV-status with all members of his family. He felt the disease 'was too underground,' that not enough individuals were able to share this information. He decided early on what was needed were more individuals willing to risk and benefit from the opportunities of disclosure. In his eyes, HIV would finally be normalized and accepted by the larger community, particularly if this type of information was more available - if AIDS had a face. Although he found disclosing difficult, he also felt as if it was by far more traumatic for his family. Only one family member alienated him as result of the disclosure, whereas the others rallied to support him. Rick was able to find the courage and energy to share his HIV-positive status with most members of his home community. Although members of his community don't directly address the topic of HIV with him, when he does see them on occasion, he is amazed they always ask how he doing and comment on how healthy and young he looks.

Generally, Rick's health is stable, and he has experienced no real major complications. He is in regular contact with his physician, about once every two months, for regular physical examinations and blood work to monitor the progress of the HIV. However, he had to stop taking his medication because he was unable to afford the cost of the provincial insurance deductible. He seems unconcerned, and readily admits he now feels much better, more healthy, since stopping his anti-retroviral medication. Being on medication 'was a sickening routine.' It interfered with his planned days because side effects often made him feel sicker than when he was not on HARRT. At one point, he felt the HIV regimen was doing him more harm than good.

Although Rick does not consider himself traditional, he has on occasion benefitted from using ceremony. This is one reason, he feels, he must return home. Being in his home community offers more opportunity to access ceremony when he feels the need. He admits, however, it would also take him away from the contacts he requires, including his physician and the gay community.

Rick feels that HIV/AIDS is the best thing to have happened to the gay community. HIV/AIDS has provided the gay community with much deserved recognition. Indeed, he states, 'It made me come out to my family, to my community.' He, too, feels this illness was by far too covered up.

Paul

Paul is a 23-year-old man of the Cree Nation. He had been living with HIV infection for four years at the time of the interview. Paul found himself in Winnipeg after he tested positive, primarily because he was unable to access treatment and knowledgeable service providers in his home community. Even so, he finds it limiting to have only one or two Aboriginal specific services from which to choose. If this situation does not change, he will eventually move to another province. Often when accessing non-Aboriginal specific services, he feels as though he is confronted with discriminatory practices. Also, he is frustrated about the absence of individuals living with HIV holding positions within AIDS service organizations. He feels he would be better understood if another two-spirit man living with HIV was his care provider because such a person would better understand what he is dealing with on a personal level.

Learning of his HIV status was difficult and trying. Although he suspected he

was potentially HIV-positive, it was nevertheless a frightening experience. His doctor provided little information about HIV, its prognosis, or how to effectively manage HIV infection. At roughly the same point in time, he also discovered he had hepatitis C and his service provider confronted him about the amount of alcohol he consumes. At times, he feels his doctor discourages him from using traditional medicines. He is cautious about the medical community. He believes they are making far too much money from HIV/AIDS to be bothered developing a cure.

Although his family members know of his HIV-positive status, he feels they too don't really understand what it means. For this he blames himself. He is unwilling and uncomfortable about sharing details of his medical condition. His family only became aware of his condition because he was constantly in and out of the hospital and they were worried. He finds his family supportive, particularly when he is in the hospital. Recently, a few days prior to the interview, he disclosed his HIV-positive status to members of his home community. He did so because at some point in the future he would like to be able live at home in his community, near his family, without being frightened about how the community would respond.

Paul continues to refuse treatment for his HIV infection. He firmly believes that the medication is responsible for destroying his immune system. He would much prefer to utilize an Aboriginal approach and its medicine to help him deal with HIV. For him, returning home represents more freedom in terms of accessing traditional care. However, he admits he must give up alcohol prior to using ceremony and tradition. He feels if he were to continue to use alcohol, the Aboriginal approach wouldn't work and may in fact

contribute to a decline in his health. Just the same, he does attend sharing circles with other individuals living with HIV. He was very outspoken when he declared what is really needed in Winnipeg is a place for Aboriginal males living with HIV to meet and share experiences.

Currently, Paul does not have any sexual relationships. He is afraid he may somehow accidentally infect his partners. He has a boyfriend living in another area of the province who pressures him for sex, but he is far too uncomfortable in putting his friend at risk. He is afraid a condom may break.

Since learning about his HIV status he feels more connected to the spiritual aspects of his personality. He has learned through participation in ceremonies to respect his health (eating healthier meals, for example) and this has increased his level of self-esteem. He firmly believes education and prevention initiatives are key, but often forgotten, that may end this epidemic.

Robert

Robert is a 30 year old man of Ojibway-Sauteaux descent originally from central Manitoba. Robert tested HIV-positive five years ago. At the time of his diagnosis, Robert was living with a man in another province. Although his partner was also HIV-positive, he was unaware of this for the first year of their relationship. Learning of his own HIV status was a devastating blow. At the time, he was attending university but was unable to maintain academic standards and did not complete the majority of his course work. Complicating his poor academic standing, Robert also became heavily addicted to alcohol. In some sense, he experienced a tremendous amount of guilt, shame, and

loneliness, and alcohol served to numb and calm the turmoil of his inner emotional world.

Although he suspected he was HIV-positive, finding out from a doctor was particularly difficult. The prospect of facing death was made painfully real. When he informed his family that he was two-spirit, his family did not connect with him for two years. When he informed them he was also HIV-positive, they did not speak with him for approximately four years. It has only been recently that he has been able to resume some communication with his siblings. His parents, for the most part, continue to be unsupportive.

When he tested positive, he relocated to another city and managed to continue and complete his university requirements. Although he would like to visit home, he plans to stay in Winnipeg, primarily due to what he feels is a high level of tension as a result of his disclosures to his family. As well, his band council has agreed to pay his living expenses if he remains in Winnipeg. The band readily admits they don't have the facilities or the experience to accommodate his medical condition.

Since his diagnosis, Robert has had pneumonia, night sweats, and shingles on a couple of occasions. It is during times of illness that he attempts to re-connect with his family of origin. Also, facing illness meant he needed to re-focus his life away from using alcohol. He was also able to locate information about living with HIV from a national organization that provided a framework for exercise, proper sleeping habits, and better nutrition.

Although Robert uses a medical doctor for monitoring his physical well-being, he prefers to use a medicine man. He stopped taking anti-retroviral medications when they

caused 'too many side effects,' and he now prefers to use the herbal medicine provided to him by an elder. Surprisingly, for him, his decision to access traditional care was supported by his mother. It was also a decision that received the support of his entire family. They have cultivated and hold a strong belief in the efficacy of the traditional approach to the management of HIV infection. Maintaining a traditional lifestyle means being able to use the medicine, to speak his mother tongue, and cultivating a belief in his dreams and the spirit world. With respect to living with HIV-infection, a belief in dreams and the spirit world have helped Robert to attain a level of mental and emotional preparation for what may take place in the future. Furthermore, he views this elder as much more than a provider of medicine. He also uses him as a 'counselor and psychiatrist.' He is able to share problems, as a whole, with his healer. He does not feel he can share his problems with his medical doctor.

The two-spirit men presented here demonstrate a range of experiences in terms of age, length of time since diagnosed, current health status, encounters with disclosure, use of and meaning attached to use of various treatment modalities, and the ability to effectively come to terms with their HIV-positivity. Now, we turn our attention to a discussion of the thematic content of the interviews to illustrate the impact biographic disruptions have had on the men's adjustment and adaptation to HIV infection.

Chapter Six

Analysis of Thematic Content: Opening Remarks

This chapter outlines the most encouraging ideas produced by this research in relation to the notion of a disrupted biography for Aboriginal men experiencing HIV/AIDS. What is also evident are some distinctive characteristics that arose from the interviews with two-spirit men that relate to some of the other concepts discussed earlier in this thesis.

I would like to preface the presentation of the results with the following orientation statement. As this health crisis moves into its third decade, I have personally witnessed countless variations of responses. I have observed, heard about, and experienced the complete continuum, from those grounded in utter denial through responses that reflect a total immersion into the world of HIV/AIDS. I have seen how lives continue to hang in the balance through the use of drugs and alcohol to those for whom a sense of total freedom has developed once they have received a positive test result for HIV infection. Roscoe, in "The Circle of Loving Compassion," (1995: 208) best summed it by writing, "I've learned to accept each person's response as valid for him. Who is to say what is the proper way to react to meaningless, random death and how to be human in an inhuman situation, to witness inconceivable suffering and the loss of friend after friend?" This is a sentiment that I have tried to embrace throughout the course of this study.

I believe, like many others I have met while living and working within the boundaries of the HIV community, the value of practising the principle of non-

interference. That is, to allow individuals to live their own lives as they see fit, unencumbered by those attempting to change them, and by extension, to change the world. Such a position potentially represents the most humane response one can choose in this inhumane situation. It provides individuals the opportunity and freedom to act, to control, to respond, and to craft their own destiny in a life that has otherwise been overtaken and controlled to a large extent by HIV infection and AIDS. In other words, it was important to recognize, acknowledge and respect that individuals have the agency to move through a multitude of responses.

It is also my hope that I have adequately begun the process of capturing and conveying to the reader the flavour of the discussions I had with HIV-positive two-spirit men living in Winnipeg. However, I have no one to blame if I should have missed or have been blinded to other rich and equally important detail due to my own conceptual baggage. This, I discovered through the process of researching two-spirit experiences of HIV/AIDS, was much more a part of me than I have originally been aware of prior to completing this study. Such is the challenge of mastery, particularly given the enormous amount of shared experience I had with those who chose to participate. Often the men challenged the very notions I held of what it meant to be two-spirit and to struggle with HIV-infection. As Gatter (1995) notes, once we begin to examine the identities of others we are also forced into exploring our own, and to reflect on our own experiences vis-à-vis research participants. It may be, and is probable, that as I continue to reflect on my own experience researching biographical disruption and my own personal experience of HIV/AIDS, the future will highlight and uncover gaps in my analysis and

my understanding of HIV/AIDS from a two-spirit perspective will continue to grow.

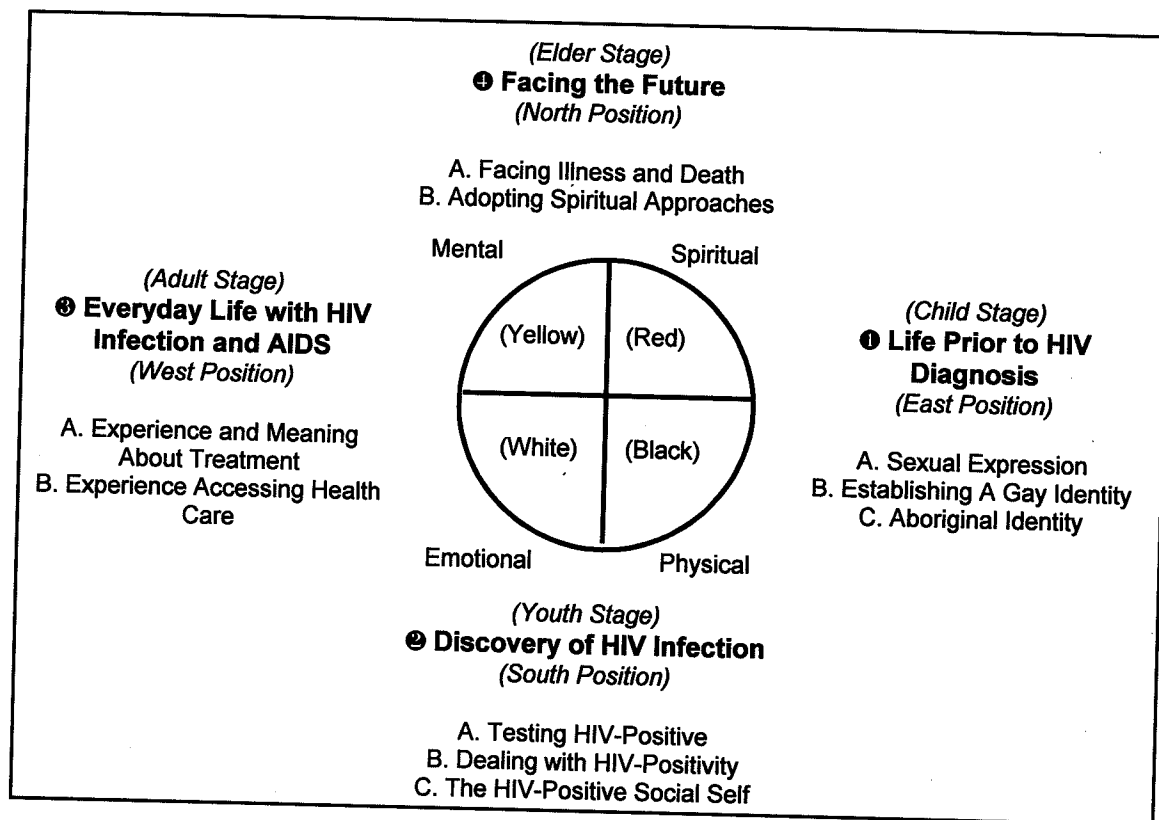
The Results

I have chosen to use the medicine wheel, as a conceptual tool, to highlight how two-spirit men might experience HIV/AIDS. Rather than present this tool as deterministic in nature, my use of the medicine wheel to describe the experiences of seven two-spirit men living with HIV represents an initial attempt to understand their world from within the boundaries of their perspective. In short, it should not be viewed as a model that dictates that *all* two-spirit men will experience HIV in similar ways. Rather, it potentially provides a tool to guide future attempts to increase our collective knowledge and understanding of biographic disruption vis-à-vis two-spirit men living with HIV infection.

During the analysis phase, I began to notice, whether or not the participants described themselves as traditional that they imposed order on their every day lived experience of HIV/AIDS in remarkably similar ways. Figure 2 is meant to complement the medicine wheel (Figure 1) discussed in Chapter 2. As stated earlier, the medicine wheel represents Mother Earth, the universe, all life, their cycles and the seasons. In this study, the medicine wheel depicts the shifts in identity and the experience of biographic disruption, that can occur at critical junctures along the HIV trajectory. In short, it represents the intersection between presenting the self as gay, Aboriginal, and HIV-positive. At the very least, it has the potential to demonstrate how the reconstruction of identity might occur following a positive diagnosis for HIV infection. The medicine wheel, in this context, represents the circle of life as individuals move from the child

through to elder stages of HIV infection. It can be used to graphically highlight pre-infection (the child stage), through the youth stage as individuals discover HIV infection, through the adult stage and everyday life with HIV infection, to the elder stage at which they must begin to grapple with the future.

Figure 2:
Two-Spirit Men and Identity Shifts: Identified Thematic Categories



Each stage represents critical junctures at which identity shifts might occur during an HIV career. Within each juncture, several themes are present. One of the goals here is to explore the experience of biographical disruption, as two-spirit participants move through the HIV trajectory and to explore the process by which some of them attempted to locate some resolution.

This "method also provides a way of transcending experience - to move experience from a description of what is happening to an understanding of the process by which it happens" (Cederfjäll and Wredling, 1999: 68). Rather, the stages described above are not mutually exclusive. That is, certain stages may be occupied simultaneously. For example, an individual may continue to experience struggles with multiple identities that entail adaptive demands involving substance use, such as drugs or alcohol while at the same engaging in cultural practices that promote a sense of well-being and acceptance of life's course. In this sense, everyday life with HIV infection may involve struggles that promote internal contradiction, denial and self-abuse.

Life Prior to HIV Diagnosis

We begin in the east position, the child stage, prior to discovery of HIV infection. In the child stage, there is a notable presence of conservative sexual values and this may be punctuated by struggles surrounding gay identity and meaning. In this sense, the colour red not only represents blood and HIV infection, but also highlights the struggles an individual must engage in to reconcile aspects of sexuality and culture. Thus, within the first quadrant of the medicine wheel, the east position, there are several thematic categories present.

Table 3 highlights several themes about life prior to diagnosis. The main thematic categories can also be divided into sub-categories representing contradictory aspects of the HIV experience. It is important to note that the men who participated in this study did not all experience or report the sub-themes as presented. This reflects, at least in part, the diversity of experience within this sample of male two-spirit men in

Winnipeg.

Table 3:
Themes About HIV Experience Prior to HIV Infection

Thematic Categories	Sub-Themes
Sexual Expression	Carefree Sexual Abandonment Cultivating Intimacy The Struggle for Intimacy
Establishing a Gay Identity	Connecting with a Community to Promote Self-Acceptance Difficulties Establishing a Gay Identity
Aboriginal Identity	Difficulties with Reconciliation Process of Reconciliation

The men who chose to participate in this study are from a variety of backgrounds. Equally important they represent a range of ages, had lived with HIV infection varying lengths of time or had different experiences in terms of whether they ascribed to traditional approaches. These differences potentially mean participants in this study either did not experience them, glossed over disruptions or chose not to report them. For example, some participants in this study did not experience Aboriginal identity as a disruption that required reconciliation. For these participant, possibly the result of grounding in Aboriginal culture at an early age, the process of reconciliation was simply not necessary. A brief discussion of these themes and sub-themes is presented below.

Sexual Expression

The first thematic category is a central aspect of life prior to diagnosis and is often represented by the presence of the libertarian sexual ideology, which challenges social protocols and norms, and is characterized by a desire to engage in heightened levels of intimacy. In short, virtually every respondent described himself as, in part, a

sexual being.

Carefree Sexual Abandonment. For the most part, the notion of conservative sexual expression became a common theme in the larger gay community following the introduction of HIV as a potential health hazard. As noted in the literature review, gay community leaders often promoted a position opposite the master narrative that dominated pre-AIDS discourses. Rather, discussion in the post-AIDS era focussed on decreasing the number of sexual partners, encouraging the practice of safer sexual relations, and the development of an intimate relationship with a primary partner. This is in contrast to the experiences of some of the men in this study who described situations of sexual experience focussing on individual pleasure or of an unending party-like and carefree atmosphere.

Before [HIV] I used to be so carefree, [a] happy-go-lucky sort of person. It [was] like living on the edge basically. I would party days on end or I'd be able to do this or maybe I would just do ... like childish behaviour, like teenage stuff, like you [could] never get the child out the adult sort of thing. - Robert

[I had] lots of good sex. - Curtis

[I had a] carefree attitude. [...] I loved the fact that men loved me because I got lots of love. - Darren

Some even indicated that they had moved away from home communities to explore a developing awareness that they preferred sex with other men. For these individuals, the life within small reserve or rural communities often did not provide needed outlets to explore an emerging gay identity.

I just needed something bigger, and I was coming to terms with my sexual life, and I definitely wanted to explore that avenue and there wasn't a heck of a lot [where I come from] - that kind

of stuff. - Curtis

[I came to Winnipeg] because of the gay lifestyle. Yeah, it's more private, in some parts, it's more open. - Taylor

The anonymity and increased opportunities that these men encountered in larger urban centres provided the necessary safety and openness to begin the process of exploring, adopting and 'trying on' gay identities. As we have seen above, it also provided the opportunity to explore a gay identity in a carefree and party-like manner that necessarily involved plenty of sex.

Cultivating Intimacy. However, despite the party-like atmosphere, for other participants being aware of HIV/AIDS meant they also focussed more on developing long-lasting friendships and partnerships with other men, as advocated by community leaders in the post-AIDS era. In some respects, they attempted to adopt this more conservative sexual position. However, the desire for intimacy circumvented the messages and they therefore reported unprotected sexual encounters with primary partners as a component of these relationships.

We were together for two months, [. . . and] we had unprotected sex every day, [. . . but] before we went out I had asked him if he did have it. He said, no, no. - Walter

Rick shared a similar story. Today he is positive because he chose not to engage in protected sexual relations with his partner. In some respects, it represents, as Sandstrom acknowledges, "the failure of the gay subculture and its libertarian sexual ethos" (1996: 255). That is, despite the messages these men received prior to infection, they continue to engage in unsafe sexual practices and as a result contracted HIV.

My partner told me. R- Told you that you were positive? Yes.

R- How did he know? Because he was HIV-positive, and it was very hard for him to tell me to get tested just in case. But actually, I wasn't mad at him or anything. I think it brought us closer together, you know, for that end of the deal. - Rick

The Struggle for Intimacy. During a second interview with Darren, he acknowledged his continuing struggles with issues of intimacy vis-à-vis the continued party-like atmosphere that pre-dated his own infection with HIV.

When someone tells you that you're HIV-positive, you don't realize the ramifications until much, much later. It takes away your ability to freely love, and by that I mean, to go out and have sex with someone, to go absolutely nuts, you know what I mean. You're worried about that person being infected, or that you can potentially kill him. I mean, it's an act of love - but when you have that thought in the back of your head, that you could potentially kill him, there goes your freedom. - Darren

In some respects, this passage demonstrates the dissonance that is bound up in notions of sex and intimacy, between the past self and the self as now. In other words, Darren has found himself occupying a similar position on the medicine wheel that pre-dates his own HIV infection. In other words, he has returned to deal with the issues of sex and intimacy following HIV infection. He speaks about the biographical disruption that relates to master narratives that dominated contemporary gay male discourses during both the pre- and post-AIDS eras. Darren's struggle surrounds attempting to reconcile the carefree attitude of the past with notions of love and intimacy in the present. For him, the past represents going absolutely nuts and of the love that men gave him. At the same time, Darren acknowledges present circumstances, that despite attempts to cultivate intimacy, HIV has somehow curtailed his freedom. In some respects, Darren has fallen prey to feelings that the experience of intimacy through

sexual expression has somehow ended and is now beyond him. However, HIV does not resign individuals to construct their houses "amidst the reality of a rapacious, sexually transmitted virus," (Rofes, 1998: 13) but can present the possibility that HIV infection has been transformed into a potentially chronic and manageable illness in which sexual expression can play a part. In other words, it is still possible to 'go absolutely nuts' and to fulfil sexual needs and intimacy, provided one engages in safer sex practices. Darren was not the only participant who demonstrated this struggle. Walter also reports his struggle with sex and intimacy in a post-AIDS era.

We weren't dating. It's just like he was interested in me and then the second [time we met] I let him know [that I was positive], and that's when he just kind of looked disappointed, but after that we just became friends. But I didn't ... if I didn't have what I had, that kind of thing, maybe I could have found the right person, but I can't because of what I have. Nobody really wants anybody like that. Well it can happen, but I just have to face facts that it might not. - Walter

Sexual relationships, love and intimacy are important aspects of two-spirit identity, whether these occur in the pre- or post-AIDS era. These men have demonstrated that carefree, going absolutely nuts, sex remains a desire that must be, they feel, moderated by the messages they received through the post-AIDS era. However, despite the fact that these men could realistically appraise themselves as individuals who can potentially transmit HIV, the possibility remains that negotiating a sexual relationship is still possible. However, as our review of the literature demonstrated this too can provide new challenges, particularly as individuals confront issues of disclosure, engaging in only safer sexual practices, or when health declines.

Establishing a Gay Identity

Building on the theme of sexual expression, in the pre-AIDS era, is the desire to explore and experiment with sexual identity, the second thematic category. This focuses on internal struggles and conflicts about what it means to be gay and to have sex with members of one's own sex. In the context of sexual identity, it can often be difficult for individuals to resolve the socially acceptable with more private and personal expressions of self.

Connecting with a Community to Promote Self-Acceptance. Some participants described the experience of resolving sexual orientation issues as particularly enlightening. That is, they presented themselves as not having too much difficulty with self-acceptance. This seems particularly the case when an individual is able to connect with other members of the gay community, whatever the quality, and to form friendships as well as sexual relationships. In many ways, connecting with a community of peers assists individuals to understand that they are not alone, that others share similar desires, and that this may potentially mean they are exposed to positive ideas about gay identity. Speaking in the context of discovery of the sexual self as gay, Curtis related the importance that meeting others with whom he could share, and the importance it had in orienting him to a gay community. Relationships that develop and the interactions that occur are viewed as particularly positive.

I didn't have anybody my own age and when I came to Winnipeg, I actually [...] came out when I was 14. I was staying with [family] here and one day I snuck out and whatever and came downtown and just met all these people that were my age, so I mean I established some sort of friendship

with them quite quickly, so that kind of kept me wanting to come because there's more up here. It was good to have that kind of life, interaction, because I didn't have it back home. - Curtis

In a second interview with Darren, he too related the importance of locating others within the community. However, he focuses on the acquisition of new ideas about what it means to establish a gay identity, to be labelled two-spirit.

Well, I remember when I came out of the closet, I went to the gay bars. I remember [this transgender girl from the bar] because she [was] really beautiful. I knew her when she was gorgeous and she still is. I remember her from high school. I remember her as strong. No one fucked with her at all. No one came around her, no one called her fag, she was like a spirit in our school. I think she saw that in me too, that I was two-spirit. - Darren

For Darren, his transgendered friend, originally from high school, modelled important aspects of self-acceptance. If one could manage, as his transgendered friend demonstrated, to adopt a positive image of self this could potentially generate the respect of others. Today, as Darren moves through the process of self-acceptance, not only in terms of his gay identity but his HIV-status as well, he attempts to model the lessons shared by his transgendered friend. Within his work environment and community, because of the position he holds, individuals are aware of both his HIV-status and his gay identity.

People call [. . . me] warrior princess (laughing). You know lots of people call me that, [people at work] call me that, you know, that's my nickname [. . .]. So, the short is, I'm accepted within my community. I don't want to go into the white world. I like the Aboriginal world. I feel safe. I'm empowered.- Darren

Difficulties Establishing a Gay Identity. Two participants talked about life prior

to infection, making reference to conflicting experiences surrounding expressions of a gay identity. For these participants, it was difficult to come to terms with a gay identity, particularly because of the public pressures to conform to heterosexual norms.

Darren, in the first interview, describes his experience this way:

I was always unsure of where I was placing myself, I thought maybe I should be a girl, you know what I mean, or should I go and get a sex change and become a girl? You know there's an option there. - Darren

For Darren, a gay lifestyle entailed adopting a stereotypical role of himself as a gay man, and this may be the result of his connecting with a transgendered friend both in high school and later, when he came out at the gay bars.

I remember acting out and doing drag in the early part of life being gay. - Darren

Taylor describes the difficulties he encountered in presenting himself as a two-spirit individual to his community, and of the pressure he encountered to conform to more socially accepted presentations of self.

I went to a church wedding [. . .]. The minister said at the time, this [is] good what we see today, what we're witnessing today, two people join[ing] together and getting married. [...]After he noticed me in the audience, then he said, I mean a man and a woman. See. I only went there because of the guy that was getting married, [he] was my ex-lover - I was with him for four years. So he was getting married to a woman and you know how it is, the Christianity and sometimes they want people to marry a girl and have kids. - Taylor

Both experiences describe either public pressures or confusion about whether to adopt stereotypical expressions surrounding sexual identity. The social world imposes a socially acceptable self-identity. As Schwartzberg states, "gay people are often forced

into a stance of private shame and public pretense. [...]Even as our culture inches toward acceptance of homosexuality, the social fabric remains oppressively homophobic"

(1996: 35). Whether individuals express difficulties accepting gay identities or they simply look for a safe and more open environment, each process involves challenges at different levels. Darren, for example, continues to struggle with his identity outside his Aboriginal community.

Aboriginal Identity

Aboriginal men who must deal with the thorny issue of sexual orientation are often no stranger to conflicting identities. They have a shared history involving other significant struggles where identity is placed under scrutiny. While some were able to resolve Aboriginal identity issues, a number of participants indicated they were not conversant or knowledgeable about traditional Aboriginal teachings.

Difficulties with Reconciliation. Some participants were able to discuss their struggles with the issue of self-acceptance and Aboriginal identity. Much like Anderson states, "My first, most basic realization was that *all* Native ancestry [has] 'Native experiences,' because, unfortunately, part of our [collective] experience as Native people includes being relocated, dispossessed of our ways of life, adopted into white families, and so on" (2000: 27). This is an important point when we consider the distance gay Aboriginal men are located from the centre of the material relations within society, of being dispossessed where issues of tradition and culture are concerned.

[Prior to HIV,] I was a very egotistical person, I did not want to

be Aboriginal and I cried, and I refrained [from] being with [other] Aboriginal people. [... But,] I'm more Aboriginal now than I was [when] growing up. [...] I've learned to accept my culture the way it is, and realize there is a good part of it and there is a bad part of it, and you take what you need from it and leave the rest. - Robert

I used to believe that Aboriginal people were lazy, they were all bums, that they were all drunks and [that] they stayed at home on welfare, and that is what I was led to believe. I really was denied the ability, the knowledge that, um, that could have guided me, if I was able to grasp onto ideas of traditional thoughts and belief, because [today] I really value those things. So, being Aboriginal [back then] was not something to be revered, um, I didn't realize in the context of now, what Aboriginal people are today, that they are struggling, that indirectly I was struggling, and I didn't know then that I was struggling. - Darren

I was never raised or brought up around tradition. I think, . . . I respect tradition, I respect people who have knowledge in their tradition. I'm not saying there is no place for tradition in my life, but I feel even if I were to get into the swing of things, I would feel so fraudulent at first because I'm so white, you know. - Curtis

For many Aboriginal people, "part of being Native is feeling like we aren't" (Anderson, 2000:27). For some of the participants in this study, they have had to work, and continue to work, at reconciling and making sense of their Aboriginal identity. However, it is not important whether one feels he is assimilated or whether one is conversant in tradition or ceremony. The lives of two-spirit people intersect at the point where policies of assimilation and cultural genocide entered our lives. In this sense, each of the men who participated in this study had Native experience they could draw upon. However, at least for the men who reported above, they have had to counter negative stereotypes of Aboriginal people as bums, drunks or lazy. At least for one, this meant they did not wish to cultivate relationships with other Aboriginal people.

Process of Reconciliation. However, to continue to hold the view Aboriginal people are not aware of tradition or ceremony, that they have been assimilated, means in some way we are perpetuating the assimilation practices of the past aimed at making Aboriginal people disappear into mainstream society. As Anderson states, "Once we are only half, or once we have become urbanized or non-language speakers, many non-Native people feel inclined to tell us that we no longer exist. We are no longer Native" (2000: 26). However, despite the stereotypical messages these men received, they continued to work at establishing a positive view of themselves as Aboriginal persons. In some ways, it was also "one way of telling the assimilation-makers that it didn't work. We may be struggling, but we are still here" (Anderson, 2000: 31).

It's just like getting back to your roots, especially as a kid never doing that, and then as an adult I can. I mean, in school you're with white teachers, so there you kind of forget your culture because they are more interested in you finishing school, learning the English language. Then once you've graduated, that's when you kind of feel more your own self again. [When I do use ceremonies,] it keeps me in touch with my culture. - Walter

I go to the Two-Spirit International Gathering, where you learn how to make the sweat lodge, you actually make the sweat lodge, the talking circles, where you are able to speak from your heart, you can cry, you can do whatever you want. Before, I could never release, and you know, that's where - I look for a place where I'm safe, where I can release, where I can learn, because I needed to be reprogrammed. So basically, I was debriefing and then reintroduced back into life because basically I was dead, from the whole adoptive family thing, I was already dead. - Darren

I grew up on a reserve in a small Aboriginal community on the southern shores of Lake Huron. I, too, for the most part, experienced a deafening absence of tradition and ceremony in my life. I remember the first time, not long after I had left home, when

I was provided with an opportunity to participate in a traditional smudge ceremony. I was standing with a rather large group of other Aboriginal people, on the banks of the Ottawa River on Victoria Island with the Parliament Buildings towering over us. We had come together to demonstrate our support for the Mohawk First Nation during the 1990 Oka Crisis. Needless to say, tension and emotion were running high. The day before, the Canadian government had announced the military would move into Oka in an effort to bring resolution, peace and calm. The entire experience reached deep within me, leaving tears running down my face, producing an incredible sense of peace and well-being. It was almost like I too had returned home after a lengthy absence.

Indeed, in some respects, this experience provided a catalyst for a changed life, one based more on a desire to gain knowledge and understanding of the meanings involved in adopting an Aboriginal identity. Today, as I travel across Canada attending various AIDS-related meetings and symposiums, this experience is never far removed from my consciousness. Through that experience I learned that there was value to be found within the boundaries of my culture, that I too could learn something about how to live my life.

Life prior to HIV infection involves a number of significant struggles, of discovering and establishing identity, whether as an Aboriginal or a gay man. Individual participants have demonstrated continuing struggles with both gay and Aboriginal identity, sexual experience and finally the process of reconciling private desires with the social demands focussed on conformity. In many respects, these struggles continue today as individuals attempt to establish safe environments to express and find meaning

in their identities.

Discovery of HIV Positivity

Moving to the south position, discovering one is HIV-positive, entails any combination of personal struggles. As noted earlier, two-spirit people are not strangers to questions of identity and meaning, particularly given their shared history of struggles surrounding Aboriginal and gay identities. Represented by the colour black, this position on the wheel demonstrates the shame, stigma, fear and anger that may accompany early knowledge of personal HIV-positivity. It approximates the youth stage of development and speaks mainly of how individuals experience HIV on an emotional level.

Thus, within the second quadrant of the wheel, several thematic categories are present. Table 4 highlights themes and their sub-categories that presented themselves for the men who chose to participate in this study as they learned of their HIV infection.

Table 4:
Themes About HIV Experience Upon Discovery of HIV-Positivity.

Themes	Sub-themes
Testing HIV-Positive	Disbelief Confirmation Dirty, Polluted and Tainted A Sense of Impending Illness and Death Multiple Diagnoses
Dealing with HIV-Positivity	Substance Use (<i>Drugs and Alcohol</i>)
Disclosure	Double Coming Out The Need to Protect Others/Self

For many of the two-spirit men participating in this study, learning of HIV-positivity prompted feelings of disbelief, a sense that they were dirty, polluted or tainted, thoughts

of impending death, or they simply experienced diagnosis as confirmation. As these men attempted to deal with HIV diagnosis, they often reported substance use and multiple diagnoses. Eventually, however, they had to tackle the issue of whom and when to tell.

Testing HIV-Positive

Virtually every participant told a story of what discovery of personal HIV-positivity entails, and what happened when he was informed of HIV test results. They were asked, How long have you been living with HIV? How did you come to find out that you had HIV? What was finding out like for you? The men who participated were aware of their HIV infection for between two and 10 years. Participants almost always described the experience of discovery of HIV infection in negative terms. In some respects, it marked the beginning calendar when lives undertook dramatic, tremendous change and upheaval. As Alonzo and Reynolds state, "a stress response characterized by disbelief, numbness and denial, followed by anger, acute turmoil, disruptive anxiety and depressive symptoms is typically seen after the diagnosis" (1995: 308).

Disbelief. For some of the participants in this sample there was an element of disbelief in learning about being HIV-positive. Several indicated their distrust of the test result and they sought confirmation through additional tests, often seeking out different medical service providers to administer the diagnostic test to confirm HIV infection.

I was prepared for it but I had two tests done, and that's the way it is. I went back for a second opinion, it came back positive also. I don't think I've ever really dealt with it fully at that

point because I was more concerned about my lover being in the hospital. - Curtis

It was hard because there was no counselling available from the doctor. When you are getting the news, you don't know what to say, what to do, or where to go. I guess I felt sorry for myself, and I felt that it (the HIV virus) might go away. I was thinking the blood was probably switched or maybe it's a mistake. So I had to go to get tested at different places. - Taylor

In some respects, the above passages demonstrate the importance of pre- and post-test counselling in which the range of issues is laid out. This could include, for example, what individuals can expect once the test has been performed, an outline of possible actions as a follow-up to a positive diagnosis, such as obtaining a medical assessment, and that they will most likely experience a range of emotions, including disbelief, denial and anger. They could also receive counselling about safer sex practices. It should not be assumed that individuals always have correct information about what is, or how to negotiate, safer sex.

Confirmation. The flip side of disbelief, particularly given an awareness of past behaviours that originally place them at risk of infection, meant they were seeking out a HIV-positive diagnosis as a confirmation. That is, at some personal level they were aware and suspected they had been exposed to HIV. This possibility led some participants to suspect their chances of producing a positive diagnosis would be greater.

It was something I kind of suspected. My lover [became] really, really ill and just came down with a whole bunch of stuff (illnesses), so I was pretty stressed out about that. I was in tears and of course when his family found out that [he] was positive they suggested that I should take the test also. I had the test done [. . .] and sure enough it came back positive. But to be honest, I wasn't shocked, I kind of suspected it. - Curtis

I had a boyfriend for two months and it ended very abruptly - almost like anger between us. I went home for Christmas after we broke up and when I returned, that's when I started going out and started to hear that he [had] full-blown AIDS. [...] I had it in the back of [my] mind just to go for a test to ease my mind, but after having all these people tell me this - that's when I kind of believed it. I guess [it felt] a bit comforting . . . I just felt comfortable that I finally knew about me - a confirmation sort of. - Walter

I knew already that I was positive because of some things that had happened to me but I was afraid to go to the doctor [. . .]. [My partner] was HIV positive first, and I didn't find out till about a year after we had been together. -Robert

Well, it wasn't a surprise, you know . . . my partner telling me that he was HIV-positive. When I went to get my test done, like I knew I was HIV-positive. I just put two and two together that there was a greater chance that I would [also] be HIV-positive. So when the news came, I just didn't . . . I wasn't surprised as much. - Rick

In many respects, the above passages also demonstrate the important part others can play to assist someone to acknowledge, to confirm for themselves that they have been at risk for HIV infection. In other words, these individual participants often did not arrive at the conclusion they were HIV-positive alone, but were encouraged by the actions or words of another.

In another vein, it is interesting to note that for at least one individual, he experienced his HIV-positive diagnosis with both disbelief and then as confirmation. In some respects, the disbelief may be associated with the lack of counselling he did receive or it may simply be that because others encouraged him to recognize that he was at risk he was also able to acknowledge his diagnosis as a confirmation. More importantly, however, it also highlights the various kinds of struggles an individual must engage in when dealing with a diagnosis. In short, a positive diagnosis potentially

represents a shortened life than had originally been anticipated.

Dirty, Polluted and Tainted. Learning that you have been infected by HIV often expresses itself as a cascade of emotional reactions, as already noted. For some of the men in this study, they reported feelings of contagion, that they were now dirty, polluted and tainted.

I felt dirty, you know, completed polluted. When I think about it now, I was just fucking scared. I just freaked out. [...] You can't see that I'm HIV-positive, but inside I'm completely destroyed. - Darren

I felt dirty at first because I was more, - I wasn't knowledge[able] about HIV. - Taylor.

Well, there might be a psychological-like residue, that kind of - well, I'm HIV-positive, I mean, I think there's [the] tendency [that it made] me feel dirty, at times, not filthy, but just kind of like tainted. - Curtis

A Sense of Impending Illness and Death. For others, there was a sudden sense of impending illness or death. Individuals were confronted with their mortality, and the uncertainty surrounding the illness. This was heightened by a lack of HIV information given to some participants by their service providers.

It was frightening because you don't know at the time exactly what your body is going through and that, because the doctors here don't explain everything. [...] It feels like you're going to die right way, and I guess I'm scared of death basically. - Paul

I thought I was going to die. I said, oh when am I going to die, holy smokes, I'm not even 30 and it's like . . . oh my God, all that was going through my mind, like my life flashed before my eyes and I was just like, holy smokes. There was like, there was a lot of stuff to deal with. Like, I can't really . . . like I noticed that the first thing I thought about was, I guess I'm going to die. Because you never really think about it until it actually ... if you get a disease of some kind, and there is medicine out there, but when you're told you're HIV-positive,

like there is no cure for that, and it's like ... do you know what I mean? - Robert

For others it may be a sense of impending illness to come. The issue of morbidity and the uncertainty surrounding illness may also colour the experience of HIV.

I've turned into a hypochondriac, I'm not kidding. After that, every little thing, I'm looking at the skin, I'm looking after a little spot, oh my God, I've got KS, you know what I mean. I start coughing, oh my God, I've got PCP, - any little thing, and I'm more aware of that, since I had that, every cold, I'm counting the days that I've had it for - do you know what I mean? That's how I am, that's what's left of me - [the] legacy. It's scary. - Darren

Multiple Diagnoses. Testing positive for HIV-infection also meant, for some, dealing with the issue of other medical conditions as well, including addiction and hepatitis C infection.

[My] whole life [became] completely consumed by working and drinking [alcohol] all the time and I started - I was introduced to marijuana and that was start of my drug addiction. - Darren

I got diagnosed with 'Hep-C' and they say it's gone, but my doctor said, no, no, don't listen to that because it never goes away. - Paul

The issue of co-morbidity in the context of HIV/AIDS is particularly important to acknowledge. As noted in the literature review section, HIV infection is at times diagnosed in tandem with other infections. The issue of co-morbidity increases complexity and produces situations in which physicians often encounter extreme difficulties diagnosing. Often it becomes difficult to untangle one symptom or infection from another. When treatment is offered, complexity is further increased as physicians

contend with not only difficult-to-diagnose symptoms but drug side effects as well. In short, co-morbidities, their symptoms and various treatments, can create an extremely confusing picture to unravel and deal with successfully.

Dealing with HIV-Positivity

Dealing with the knowledge of HIV-positivity spurred a variety of reactions for the men who participated in this study, ranging from substance use, disclosure, and the need to protect significant others or self.

Substance Use. A couple of individuals acknowledged they panicked with fright, a not entirely unreasonable response, with the self-knowledge of HIV-positivity. Panic, fear, or whether as a coping mechanism, prompted a couple of men to report they resorted to alcohol to numb the feelings of shame and guilt that they were somehow dirty, polluted and tainted.

I basically drank a lot, I couldn't . . . just to get rid of the guilt, the feeling, the shame, the loneliness and whatever. I went on a drinking binge after I found out. - Robert

I went into a complete drinking binge for about three years. I drank every day, nonstop, for three years. I didn't do chemicals or anything anymore, I just basically drank, drank, drank. - Darren

In some respects, drinking was a continuation of previous behaviour, prior to HIV infection, that served here as a method to survive initial discovery of HIV-positivity.

Alcohol represented a numbing force to deal with shame, guilt, loneliness or feelings of being polluted, tainted or dirty.

It is equally important, however, to acknowledge that alcohol and substance abuse may also have been a contributing factor in HIV transmission (Canadian

Aboriginal AIDS Network, 2002). In many respects, the relationship between the Aboriginal population, HIV infection and alcohol or drugs can no longer be ignored. In one such other study, Miller, Spittal, LaLiberte, Li, Tyndall, O'Shaughnessy, and Schechter (2002) examined sexual and drug vulnerabilities in the context of HIV transmission. Their data demonstrated that for younger injectors (ages 13 to 24 years) of substances (n=232), individuals tended to be younger, female, and engaged in dual sexual and drug-related HIV risk categories. Miller et al., conclude that "targeted interventions are required, [particularly where] >50% of the HIV-positive youth were Aboriginal" (2002: 340). However, it is also important to note that alcohol and injection drug use in Aboriginal communities may be related to other social and economic factors. In other words, addressing social and economic circumstances under which Aboriginal communities currently live may reduce not only substance use but HIV infection as well.

Disclosure

Individuals who test positive for HIV must at some point deal with the issue of whom, when and what to tell. In some sense, disclosure speaks to the issue of how individuals can begin the process of dealing with the shame and guilt so often associated with HIV infection. For some participants, they report a double coming out and of disclosing both their two-spiritedness and HIV-positivity. Other participants, attempted to maintain HIV as a secret, often stemming from the belief that they were protecting others from terrible news and possible horrific consequences.

Double Coming-Out. For several participants, learning about personal HIV-positivity prompted a double coming out. HIV placed these individuals into situations

where it was not only time to disclose their health status, but also to share their gay identities and lifestyles with friends and family.

Yeah, I gave [my family] a double dose of reality. I told [them] at the same time I was positive and gay. - Curtis

For me personally, it made me come out to my family, to my friends, some of them, and to this day I'm very open with my sexuality and this disease. You know, when I meet people I tell them those two things, because I've got nothing to be ashamed of and it's educational for that person, anything to do with those two topics. - Rick

Oh, the first day I met [my biological family] I said to them I was gay and that I'm HIV-positive. And they're like - you know, like - yeah so, enough said, you're my son. That's when I knew that nothing was going to take us apart. It was said right to their faces, right there, you know, the first thing. By the way, I 'm gay, I just let them know. - Darren

In some respects, sharing both aspects of identity with friends or family provides some comfort, that they aren't facing catastrophic illness alone, but are rather sharing personal information and a journey with individuals of meaning. Double disclosure can also represent a personal affirmation. It demonstrates to others that being either positive or gay is nothing to be ashamed of, that to double disclose two separate identities can potentially provide an opportunity to educate.

The Need to Protect Others/Self. For other participants, the sense that only negative consequences would result from disclosure of HIV-status prompted them to remain silent about their illness. Keeping a secret may be about protecting others, close friends and family from potentially devastating information, or it may also be more related to the need to protect oneself from possible negative consequences that may be visited upon the self by others.

I'm protecting my mother because she's ill herself. She's diabetic and she's blind. I'm scared that she might have a heart attack or a stroke. - Taylor

To me, it's . . . I'm the youngest kid in the family and it would probably be way harder for them to accept that their younger son is dying of HIV. - Paul

My family doesn't know about this. I'm worried about something getting back to my hometown. I'm very cautious. [...]I've heard things about what happens to families when their children have HIV or AIDS. They are chased out of town. They think it's the black plague or something. I wouldn't feel right if that happened to my family. - Walter

Yet, what the same participants later shared during their interviews may also indicate that they are not only potentially protecting friends and family, but also themselves. For these men, HIV brought about the end to aspirations they had previously held for their former social and sexual selves.

If I didn't have what I have, maybe I could have found the right person, but I can't because of what I have, nobody really wants anybody like that. It could happen, but I have to face the facts that it might not. - Walter

I'm being myself. I'm just afraid of infecting other people, but I know there [are] other males or whatever that are [people living with HIV/AIDS] and I just feel uncomfortable that way. I'm afraid I would infect them or something. I won't go there. - Paul

Other participants also described the end to their former social and sexual selves that provide some confirmation that the fears some individuals hold either for family or themselves is not entirely unfounded. Two participants refer to the stigma of living with HIV, that for them it has come to represent a life of solitude and loneliness.

I'm single. I'm single for a reason. Not because I want to be, but because people know I'm positive and there is a stigma attached to this. I never really knew how stigmatizing this

illness really is. People are still in the closet when it comes to this disease. So, I lead a very silent, lonely life [. . .]. - Darren

It's limiting me in my actions of meeting people or having sexual experiences and that kind of stuff because that's still part of my makeup, right, I need that kind of stuff, so there's this stigma attached to me being who I am and I really don't appreciate it, and to me it's very limiting. So I find other ways to express to myself, you know. I got a cat, so I think that kind of helps. - Curtis

For these participants, HIV has had direct consequences that are related to disclosure. Frequently, as individuals disclose HIV status and this information becomes public knowledge individuals are stigmatized by others (Weitz, 1990b). As a result, as has been seen above, individual participants have learned to conceal their illness, rather than risk further stigmatization from community or rejection by family or friends.

In some ways, we have seen how participants in this study have experienced a range of emotion and reactions. Often, in attempting to deal with HIV-positivity, participants may engage in substance use or they attempt to conceal infection from others, because of the stigma, under the guise of protecting others/self.

Everyday Life with HIV Infection and AIDS

The adult position on the wheel, located in the west, teaches a sense of independence prior to movement to the north, the elder stage. Represented by the colour white, its position reflects acceptance of HIV infection. It is the mental phase of development in which decisions about treatment are considered.

Table 5 highlights the thematic categories that were expressed by the two-spirit men participating in this study. Individuals described their everyday lives dealing with HIV infection. The experience surrounding the decisions made concerning HIV

treatment is essentially about the issue of acceptance. Typically, as well, as participants become more experienced in accessing health care, they learn that barriers to services often exist.

Table Five:
Themes About Everyday Life with HIV Infection and AIDS

Thematic Categories	Sub-Themes
Treatment: Experience and Meaning	HIV Drug Therapy: Personal Meaning HIV Drug Therapy: Experience Reconsidering Options
Experience Accessing Health Care	Difficulties in Combining Approaches

Treatment: Experience and Meaning

The impact of treatment regimens has altered the life-course of many individuals living with HIV infection. The advent of drug therapy and highly active anti-retroviral therapy (HAART), although not without its own difficulties associated with side effects and toxicities, has greatly improved life expectancy. As already noted, this drug therapy has radically reduced the number of new cases of AIDS in Canada and we have witnessed a decline in the number of AIDS-related deaths (LCDC, May 1998a).

HIV Drug Therapy: Personal Meaning. The hope that a biomedical approach could potentially lengthen one's life prompted some of the men in this study to engage in struggles that focussed attention on drug therapy. The site for these difficulties, whether individuals used HIV drug therapy or had gone off treatment, often centred on the meaning individuals ascribed to such approaches.

I believe it eats your body faster. I don't touch it. I've seen too many people go fast and they were on the medication. - Paul

There is stuff like "AZT," that kind of stuff, it kind of scares me [...]. I mean, I hear so many horror stories about the sick . . . the heart attacks and I don't know if I really want to deal with that. I always kind of observe people who started off with their medications and they're just getting alerted to them and that's because I think those drugs are toxic. - Curtis

The protease inhibitor, once you swallow them they taste very toxic. So they kind of had that taste like when you don't want to take them. - Walter

It was just a sickening way of having to exist during the medication [. . .]. So I'm glad that I'm not taking them anymore and I feel a lot better without them. In fact, at a point there, they were, I think, feeling like they were doing me more harm than good. - Rick

Despite the promise that HIV drug therapy could potentially increase length of life, some of the participants continue to hold the view that they could die sooner, that they were toxic or that treatment could cause more harm. As noted earlier, some individuals remain reluctant to accept HIV drug therapy as a solution to HIV/AIDS (Sowell, Phillips, and Grier, 1998).

HIV Drug Therapy: Experience. However, some individuals who participated in this study did manage to adopt HIV drug therapy as a viable choice, despite experience with drug side effects. As evident from these reports, treatment uptake did not come without its own problems.

I get frustrated with these side effects, I get headaches, I get diarrhoea, I get an upset stomach and mood swings. I also get itchy rashes and it's so uncomfortable. I have not much side effects right now. - Taylor

I just don't like the way that I feel when I take them (HIV drug therapies). They make me very - I can tell that I'm very acidy, my skin feels different. [...]My life is being dictated by a chemical and that's something I've been working against all my life. Today, I'm not taking my medication today, not today. I

need a day off. - Darren

Unfortunately, drug side effects are a reality for individuals who choose HIV drug therapy as an option. Often, as reported above both in our review of the literature and in the content of the interviews, individuals are unable to cope with or tolerate drug side effect and therefore resort to dealing with illness without conventional treatment.

Reconsidering Options. It is important to explore why some participants have opted for HIV treatment in the management of HIV infection. For some it was the acknowledgement that using available drugs did not change their identities. As Aboriginal individuals, in acknowledging the physical aspect of self coupled with the mental, emotional, and spiritual, provided licence to reconsider anti-retroviral medication, particularly when on the heels of serious illness.

I understand that drugs do not change [me], okay, that's the misinterpretation that I [had] previously. I think a lot of Aboriginal people are not using these medications are sadly not seeing that. It doesn't alter who you are, it's just helping out the . . . biological component of your body. I see Western medicines [...] are available and saving my life. [I can continue] to use the traditional way of life to help me spiritually, not physically. I use Western medicine to help me physically. - Darren

I'm HIV-positive and I'm accepting it. I want to do something about it. I didn't say that at the beginning, it's just the last few months I started to think this way. When I was in the hospital, when I had PCP pneumonia, when I had that I said - oh good Lord, this is almost the end. And that's when I [began] taking all the meds because I had been refusing all the meds that was given to me. I want to get better [. . .]. - Taylor

For these individuals, sudden illness or the recognition that HIV drugs did not change identity provided the impetus to re-focus on physical and biological processes and to accept HIV drug therapy as a viable option in the management of HIV infection.

Earlier, I posed the question, what is learned from two-spirit men in the context of HIV treatment? It was noted that Aboriginal people may not be benefiting from the positive effects of treatment because they may not be actively seeking it out or they may have encountered cultural barriers in the delivery of services. From the above presentation of the data, we have noted that 4 of 7 participants hold somewhat negative but potentially realistic views of HIV treatment. They noted the belief that conventional therapy would hasten death, that they would suffer the toxic side effects of drugs, or that drugs could potentially do more harm than good. These views may have guided decisions about treatment uptake. In other words, beliefs about HIV treatment may influence decisions about whether they would engage in this approach in the management of HIV infection. Also, in an earlier chapter, we noted that only 3 of the 7 men use conventional therapy to deal with HIV positivity. For at least two cases, reconsidering this option has only come after difficult bouts with illness or on the heels of a personal acknowledgement that accessing treatment did not change who they were as an Aboriginal person. In many ways, for this individual, it has meant balancing a cultural perspective with more immediate concerns such as episodes of declining health and drug side effects. However, it would be important to note, 7 participants do not permit a generalization to a wider population. Therefore, it would be important to explore the issue of treatment for two-spirit men living with HIV in a more general way with a wider population of affected individuals.

Experience Accessing Health Care

Two-spirit men, when dealing with the prospect of HIV drug therapy, are faced

not only with that decision, but also with how to effectively combine this approach with more traditional methods of disease management. In the context of health care, it is particularly important that medical service providers recognize that individuals are faced with not one, but often two or more strategies to combine that may promote health and well-being.

Difficulties in Combined Approaches. For at least two of the men participating in this study, the difficulties in combining and adapting to the treatment of HIV infection are particularly evident. While one participant indicated forgetting about treatment until cultural activities concluded, another decided against adopting a combined approach, largely because of the lack of available evidence to suggest that a combined approach was suitable.

I forget to take my medication sometime, you know like culture stuff sometime. You're in the middle of a sharing circle and you're not going to run out the door. - Taylor

I'm not sure if, what will happen if I stop those (HIV drug therapies) and also I might try something else that's herbal or whatever, like it might slow it (the HIV virus) down but not as good. - Walter

However, elders who respect the reality of HIV for two-spirit men can be particularly important and powerful. As Taylor continued to share throughout his interview, the role elders play assisting two-spirit individuals to participate in cultural activities by acknowledging the demands of HIV infection should not be underestimated.

Well, like the elder was informed and educated, and was told that there were going to be people that are coming down that are HIV-positive, but not everyone was HIV-positive. And he

mentioned and spoke about the disease, which was very helpful. And he mentioned that it would be a lot easier, he was going to go easy on us, like especially [in] the sweat. Like the sweat, you're in there for half an hour [at a] time, and then with PHAs (people living with HIV or AIDS), they're there but they can get out if they want to, and come back and join in after, again, because the elders [are] educated, they say - well they need their medication, they need water, they need to use the washroom, or they get nausea, so they understand that they need to take that time out but [that you] also want this, want to be there. - Taylor

When elders provide a supportive environment, at least for Taylor, this is viewed as particularly helpful. Essentially, this would involve informing and educating elders about the reality of HIV infection. From Taylor's perspective, when elders become informed it becomes possible for cultural activities to adapt to fit specific needs.

However, for Walter, one issue remains. That is, virtually no clinical studies demonstrate the impact traditional medicines have in managing HIV infection. More specifically, what is the impact of traditional remedies combined with more conventional methods to maintain health and well-being? Given the lack of available research, it is difficult to conclude whether or not one approach, or combining treatment modalities, are more beneficial. However, until such knowledge becomes available it may be up to service providers, elders included, to recognize this reality and the struggle two-spirit men must engage in managing the effects of HIV disease.

Facing the Future

The north direction, or elder position on the wheel, represents healing, acceptance and closure. Represented by the colour yellow, the sun and provider of life, it also speaks to the issues involved in facing potential immune system failure and

eventual death. It is the spiritual aspect of life, when individuals recognize and attempt to incorporate ceremony into their lives. In so doing, they reach an uneasy acceptance of HIV which may provide a sense of closure. Table 6 represents the thematic categories of HIV experience expressed by the two-spirit men participating in this study as they look towards the future.

Table 6:
Themes About Facing the Future with HIV Infection

Thematic Categories	Sub-themes
Facing Illness and Death	Representations of HIV as Illness
Adopting Spiritual Approaches	Focussing on Ceremony Cultural Protocol and Structure Benefits of Ceremony and Tradition

Facing life with HIV for these 7 men has been expressed as a scary prospect. However, this view, can be tempered with a focus on cultural protocol and structure thereby individuals can derive some comfort. In other words, for several men in this study, cultural activities are often used to imbue on-going struggles with HIV/AIDS with a sense of spirit, focus and emotional strength.

Facing Illness and Death

Although HIV/AIDS has throughout this study been conceptualized as a potentially chronic and manageable illness, it is equally important to note that memories of AIDS as a death sentence are not all that far removed from the two-spirit public consciousness. Despite recent advances, HIV infection continues to remain a catastrophic illness that is as yet incurable and can potentially lead to AIDS- defining illnesses that cause death.

Representations of HIV as Illness. For the men participating in this study, facing the future with HIV infection means, that as their illness progresses, they may potentially lose independence, become disfigured, and die. This often creates a sense of despair and helplessness that colours experience.

We are at the point now, where we take medication and that bothered me at one time. I need chemicals to keep me alive. It goes up against everything I believe in, because [they are] chemicals and I don't want to do chemicals. [...] So you almost feel a sense of helplessness, because if you don't have those medications or if someone takes those medications away from you, you [may go] directly to the drug companies with a gun in your hand and tell them to give me the medication *OR* I'll blow my brains out because I don't want to go through with what I've seen. I've seen people get sick. I'm afraid of that, you know, [laughing] because I like to look good all the time, but you understand what I'm saying. - Darren

[I had] weight loss last year, unexplained weight loss. *R-How does that make you feel? To experience . . .* That's when I just kind of start trying not to think about it too much, but then I kind of worry, because then I think what happens, it could get worse or whatever. - Walter

[Illnesses] get me scared, really get me scared, so I really go on . . . like after [the pneumonia], that last time that happened to me, [. . .] I quit drinking for six months. I quit smoking. I basically walked a mile and a half every day, and [was] constantly exercising, just totally cleaned my body, it made me go on a . . . well, this is happening sooner than you think, so you better start living . . . doing other things as opposed to ... yeah, so this triggered this healthy response. - Robert

Previous sociological research has clearly demonstrated that the issue of uncertainty is, and continues to be, a serious concern. For several of the men in this study, thoughts of impending illnesses or death are difficult. Such thoughts do not end once they are distanced from discovery of HIV, but continue as they learn how to deal with HIV. As noted previously, many individuals living with HIV, whether two-spirit

or not, struggle with the issue of uncertainty (Sowell, Phillips and Grier, 1998).

However, the methods they use to confront struggles can be remarkably different.

Adopting Spiritual Approaches

Focussing on Ceremony. The difficulties associated with dealing with issues of illness or mortality, led many participants in this study to explore aspects of tradition and ceremony. It is what Davies (1997) already acknowledged: individuals come to adopt 'living with a philosophy of the present.' Individuals abandon their future orientation and focus on developing peace that comes with living in the moment. Such a stance affords individuals the opportunity to grow spiritually or to focus on personal development. It allows the development of "new values and meaning in the context of learning to live with HIV" (Davies, 1997: 566).

My spirit isn't depressed, just my body. *R-How is your spirit different?* Well, my body is being raped and pillaged. That's how I look at it, that life is slowly being sucked out of me. But I understand the whole circle of life. *R-What is the circle of life?* Um, it's baby, adolescence, adult, elder. *R-As it applies to you?* I understand this concept, . . . that it's easier to grasp and hold unto than just simply being dead, the circle of life. I'm not going to be here forever. I have a totally different understanding when it comes to things I need to do, I think that's what focusses me, what keeps me focussed. [...] We two-spirit are extremely powerful, our spirits, so to me when I look at life and death, I look at in those concepts, I'm looking out for the youth at the adult part of my life, but HIV is raping and pillaging me right now, and making that go much quicker. I may not make it to elder, but I try to live the life of elder. I was told by an elder, after my second sweat, that I have an extremely old spirit. That was the message for me, that I had better play the part. I'm not going to be here for a long time, so whatever time I do have I have to make the best of it. - Darren

I think [ceremony helps] because every morning, or every night before I go to bed, I have this stuff, and it totally lifts you up. You know, it doesn't bring you down at all, and not to be racist

or anything, but the white people [don't] believe in that, and they always ask, 'why are you so cheery and that?' You know, use the medicines! - Paul

[HIV] kind of forced me to look for a certain kind of spirituality that I'm still looking for. Probably for something creative in myself. I'm not looking to be saved but something that's going to guide me through, help me make the better decisions in my life, you know, sort of ... [...]. Emotionally, it kind of forced me to feel a little bit more responsible. - Curtis

I've grown a lot stronger for it, and yeah, that's all - I believe, that I've grown a lot stronger emotionally, and also spiritually. I think I've grown more spiritually aware of everything. - Rick

HIV affords some of the men participating in this study the opportunity to explore and develop new concepts, such as the circle of life, to shoulder added responsibility, and to adopt and incorporate spiritual and ceremonial practices into their lives. In many ways, it can provide a framework from which to base decisions, to serve as a guide, and to derive some emotional strength.

Cultural Protocol and Structure. Living life with a philosophy that encourages spiritual development can assist these men to reconcile a life with illness, to focus on something other than thoughts of imminent death. However, it can also provide structure and protocols to follow that had previously been absent or moved into the background. In some respects, ceremony can propel individuals to adopt health promotion strategies when dealing with thoughts of death or to obtain the sense that they are somehow detoxifying their bodies.

So, now I'm sort of like in a grey area because I'm not doing chemicals, I'm not sticking anything in my arms. I am drinking and I do smoke, occasionally [. . .]. So, [originally] it started off with small addictions, then it worked its way up into the big addictions. You know what I mean? If it wasn't for the [traditional] teachings I received, I probably would not be here.

[...]I know that I can't go to ceremony, to a sweat lodge, unless I'm 48 hours clean. I don't go there all sketching out and full of alcohol. I respect those parameters. You know, when I understand those parameters, it's easier for me to not go out and do it all the time. I look after myself today and I wouldn't have all that I have today, if I was still partying and feeling sorry for myself. - Darren

It definitely flushed out my system and helped me detoxify and I think about being Native, I think it's important that I do something about some of my culture and maybe some of the traditions, just for a greater sense of identity, being about to identify with being Native and what it means. - Curtis

R- Would you describe yourself as a traditional person? I wish I could, but I guess I fell off that. I fell off that way, as being traditional, but I believe if you're drinking you shouldn't really touch the medicine, because it will make you sicker. - Paul

Even as individuals admit they obtain benefits from ceremony, that it can cultivate a greater sense of responsibility for personal health, they also readily acknowledge that participation in ceremony is often accompanied by rules of conduct. That is, they respect that ceremony may often be accompanied by cultural protocols that have the potential to add structure to their lives. In other words, it structures life by providing a framework that prevent, for example, using alcohol and drugs prior to or while participating in ceremonial activities. Participation in cultural activity carries social protocol that dictate acceptable behaviour, such as abstinence. Ceremony has the potential to move an individual away from the unhealthy towards behaviour that promotes health, a form of harm reduction.

Benefits of Ceremony and Tradition. An important issue that was raised in the review of the literature was how shifts in temporal orientations are facilitated. For many of the two-spirit men participating in this study, shifts occurred as a result of returning

to ceremony and traditional methods of illness management. As Kim Anderson explains, "Identity recovery for our people inevitably involves the reclaiming of tradition, the picking up of those things that were left scattered along the path of colonization" (2000: 157). A basic idea in reconnecting with one's cultural heritage is coming to an understanding that all beings are sacred. When an individual begins to understand this, he also begins the process of building on that sacredness (Anderson, 2000). This in turn has assisted the men participating in this study to develop emotionally, to become stronger, to acknowledge that they may be in this for the long haul or respect their health in more concrete ways. In short, a sense of self-worth begins to develop.

I've grown a lot stronger for it, and yeah, that's all - I believe, that I've grown a lot stronger emotionally, and also spiritually. I think I've grown more spiritually aware of everything. - Rick

I think I'm here for the long haul. I have to. You know, I just want to live. I like life, I really enjoy life, even though it [can] be really crappy at times, but overall the experience is good. - Curtis

I feel more spiritual. I feel better about myself. And in that way, I respect my health more. I eat more. [I'm] probably active a little bit more, too in the community than I ever was. - Paul

What I've learned about myself is that I think I'm more aware of my innermost self, [the] spiritual aspect of my life. I'm more aware of it, but that's not all. I think I've learned [about] people more, like I'm accepted and to be able to communicate with people and be able to work with people and not be too uncomfortable, that's what I've noticed about myself. And wanting to have a helping hand, it's almost like - it's almost like I have something to do. I'm worth it and I can do stuff, you know. - Taylor

The individuals quoted above, because of ceremony and tradition were able to

feel stronger, to focus more on enjoying life, feel more spiritual and less uncomfortable, and more accepted within their chosen communities. In some way, as do their non-Aboriginal counterparts, the participants here reported innovative ways to manage the struggles they encounter. In many ways, self-identity dictates culturally appropriate strategies for life lived with HIV infection.

In some sense, the obstacles and tensions surrounding life with HIV infection are particularly evident. Participants tend to bounce between acceptance and dealing with HIV infection with more self-destructive behaviour. Often this behaviour can potentially be moderated by participation in cultural activities that promote rules of conduct and protocol. It is equally important to note, when dealing with issues of HIV therapy, that a biomedical approach may not be the only answer available to individuals. That is, there appears to also be some benefit to allowing two-spirit men the opportunity to focus on cultural identity, whether in deciding among various treatment options or in promoting a greater sense self through spiritual development. In this vein, it seem particularly important to begin advocating for research that demonstrates the impact of traditional approaches when combined with more conventional biomedical approaches.

Chapter Seven

Discussion

This study has attempted to highlight some of the complex intersections of being a two-spirit (gay and Aboriginal) man living with HIV infection. In other words, the purpose of this study was to explore the crossroads between presenting one self as gay, Aboriginal and HIV-positive and to focus some attention on the process of identity reconstruction following a positive diagnosis for HIV. This chapter attempts to link some of the findings of this research with the broader issues that were presented in the earlier discussion concerned with theoretical perspectives and in the sociological literature. In doing so, it would be equally important to highlight what new research may be appropriate as well as discuss some of the limitations of this study.

However, factors related to identity reconstruction are never simple or easy to distill over a few short paragraphs. Located within the boundaries of these men's stories we have learned a bit about the struggles, meaning and the strategies they have utilized in attempting to confront HIV-positivity. Although there may be similarities in meaning and struggles that relate to issues already presented in the sociological literature, two-spirit strategies to maintain a meaningful life and in adapting to issues of uncertainty, stigma, disease management and sexuality differed in one significant respect. That is, they increasingly found value and utility in Aboriginal culture, ceremony and tradition.

As the review of the literature has demonstrated, the issue of uncertainty is a major concern for HIV-positive individuals (Weitz, 1990b, Steven and Doerr, 1997). In this respect, some HIV-positive individuals approach HIV-positivity with knowledge

that past behaviour may have exposed them to the virus. That is, HIV discovery can be approached as a confirmation. The findings that were presented above have noted a similar experience for these two-spirit men. For at least four men in this study, HIV was 'something they had already suspected.' That is, an awareness of HIV risk developed on the heels of past behaviours that originally placed them at risk for HIV infection. It is equally important to note that in virtually every case presented these behaviours occurred while they participated in sexual relations with significant others.

This point has important implications for education and prevention initiatives. That is, this behaviour highlights the importance of focussing attention on men in relationships. These men seem to suggest that intimacy through sexual contact is an important component of significant relationships, one that may involve unsafe sexual practices. In short, it may be important that education and prevention initiatives target information at the sexual activity of couples. The potential result may be a reduction in HIV-infection for the two-spirit population. However, education and prevention programs may be complicated programs to implement effectively. Certainly, further research that deals with the issue of sexuality in the context of relationships for two-spirit men is warranted. Without developed knowledge that highlights the complexity of intimacy within two-spirit relationships, education and prevention efforts may fail. Specifically, what is the role of intimacy that propels individuals to engage in unsafe sexual practices in the context of a caring relationship between two-spirit men?

Another component of uncertainty results in individuals feeling as if HIV is some kind of 'divine punishment' (Weitz, 1990b). A majority of the men participating

in this study indicated that HIV somehow made them feel 'dirty, polluted or tainted.' As Lawless, Kippax and Crawford (1996) point out, the 'discursive construction of HIV' that is often reinforced by public and media images of individuals living with HIV/AIDS promotes a sense of 'personal responsibility and blame.' Again, this study has only briefly touched on the 'discursive construction of HIV.' Little is known beyond that it may be a factor for two-spirit men. How does a sense of personal responsibility and blame influence responses to HIV infection for two-spirit men? Lawless, Kippax and Crawford (1996) have already suggested personal blame may influence individuals away from obtaining care for HIV infection? Can the same be true for two-spirit men? Again, further research may highlight the effects these representations have for two-spirit men as they attempt to negotiate and obtain care for HIV infection.

A further feature of uncertainty arose as the men in this study attempted to deal or were confronted with multiple diagnoses. The issue of co-morbidity in the context of living with HIV produces a difficult situation in which individuals and physicians attempt to sort through and provide treatment for several medical problems simultaneously. At least five of the men indicated problems with substance abuse and one individual related the story of co-infection with hepatitis C. The medical treatment of HIV infection relative to other diseases, particularly in the context of providing drug therapies, produces a complex and complicated picture to unravel. It may be important, therefore, to address the issue of co-infection in the two-spirit population, particularly focussing on the issue of addiction. However, as pointed out earlier, often addiction is

the result of social, economic and political conditions that may need to be addressed first. Addressing these determinants of health, may prevent not only addiction but HIV infection as well.

Another area often explored in relation to chronic illness, particularly in the context of HIV/AIDS, is the experience of stigma (Weitz 1990; Matiation 1999; McRae 1991; Carricaburu and Pierret 1995). The experience of stigma is often layered, or as I already pointed out, *triangulated*, between 'abominations of the body, blemishes of character and the tribal stigma of race, nation or religion.' The men who participated in this study live with HIV, find they have adopted public and media images of HIV as a divine punishment, and that as Aboriginal people they have already been stigmatized by race and ethnicity. At least three of the men I interviewed related stories of a desire to shed their Aboriginal identity. The data seems to suggest, particularly in the context of the dialogues, these views pre-date HIV infection. They believed Aboriginal people were 'lazy or bums' and indicated that as a result, they would feel 'fraudulent' if as an Aboriginal person they participated in ceremony and culture. Are these the views of individuals dealing with the effects of assimilation? At least two individuals acknowledged the experience of adoption or lacked an introduction to ceremony tradition. In short, what are the effects of assimilation in the context of HIV transmission for two-spirit men? Again, further research is necessary to adequately understand this point. Could it be, that promoting self-identity within care relationships, as suggested by Schilder et al. (1998), not only mediates the acquisition of HIV infection and/or healthy behaviour but also positively influences the care relationship?

In the context of biographic disruption, managing the effects of stigma often relates to making decisions about whether and who to tell about their HIV-status (Weitz, 1990a). For at least three participants, this prompted a 'double disclosure.' That is, they often provided family or friends with a 'double dose of reality' informing significant others that they were both gay and HIV-positive. However, for an equal number of participants, HIV propelled them to remain quiet about their HIV-status out of a sense that they were protecting others from potentially devastating information. In some respects, however, the need these individuals felt to protect others could also equally relate to the protection of self. For some two-spirit men, an HIV diagnosis may be experienced as 'limiting,' particularly in the context of developing sexual relationships with significant others.

In this vein, disclosure of HIV status is a further feature related to biographic disruption. For at least two of the men participating in this study, remaining single or having sexual experiences following HIV diagnosis meant they potentially faced a life of solitude and loneliness. As Weitz (1990) has pointed out, frequently as individuals disclose their HIV status they experience or are stigmatized by others. As a result, as seen above, individuals may have learned the art of secrecy in the context of HIV, particularly when dealing with friends and families, and as we have also seen, sexual partners. That is, for at least four of the men participating in this study, their own infection was attributed to the non-disclosure of HIV from previous sexual partners. Are these experiences the result of the 'discursive construction of HIV?' If they are, what is the impact, as suggested above, for two-spirit men attempting to negotiate safer

sex? That is, under what possible conditions can a two-spirit individual safely disclose HIV-positivity? Is this at all possible? Clearly, research in this area may provide information that can inform not only education and prevention programs, but support groups for those dealing with HIV infection.

In the context of these multiple struggles and decisions to disclose or not, how then do these men, as Bury (1991) points out, 'manage, mitigate, or adapt to' HIV infection? Certainly, individuals engage in guarded attempts to disclose or engage in substance use to numb feelings of guilt and shame, and deal with the perceived loneliness of life with HIV infection. However, in many cases the participants in this study have begun the process of dealing with HIV infection by emphasizing participation in tradition and cultural ceremonies. For at least four of the men participating in this study, focussing on ceremony has enabled them to deal with aspects of their life that they must deal with. It 'lifts them up.' They were able to promote creativity and were guided and felt stronger because of their ties to their cultural heritage. In this respect the men in this study, although they share tremendous similarities with respect to other research participants presented in the sociological literature, they have tended to gravitate towards cultural beliefs, practices and tradition as they move along the HIV illness trajectory.

In some respects, this emphasis has also provided structure and helped to shape behaviour and responses to HIV infection. As three men pointed out, they were no longer, at least while participating in ceremonies, 'sticking anything in their arms' or 'they didn't drink' and use the medicines of their culture. In some respects, these

reprieves into culture allow their bodies to 'detoxify' and be 'flushed out.' In other words, despite the perceived lack of cultural affinity, as two individuals pointed out, they have found renewed value in the face of HIV/AIDS through various cultural pursuits. Again, if this remains true beyond the seven men who participated in this study, how then do we influence HIV-positive two-spirit men to engage in cultural activities that may promote a greater sense of self? Certainly, the process by which two-spirit men come to the acknowledgement that their culture has utility and value would be an important point to explore in other research.

In exploring the dynamics that are imposed by a life with HIV, for two-spirit men, this study has highlighted the particular merits of standpoint epistemology and the concept of other (coupled with a phenomenological perspective and the use of the medicine wheel). In short, the combination of these theoretical perspectives has begun to answer the question of whether the lived experience of HIV-positive two-spirit men is any different from their non-Aboriginal counterparts.

With respect to standpoint epistemology and the concept of other, by taking the 'situatedness' of the 'knower,' this study has begun the process of acknowledging the development of knowledge about a particular subject (the experience of HIV) within a particular population (two-spirit men) that arises in everyday life. In short, this study has acknowledged that standpoint epistemology has merit and can therefore build our understanding of how two-spirit men experience the social reality of HIV/AIDS. In doing so, this perspective acknowledges the effects of assimilation, but also how culture and tradition can continue to shape the experience of two-spirit men confronting

HIV/AIDS. To paraphrase Smith (1987), in situating this study in the actualities of the two-spirit male everyday world, this study was able to begin the process of understanding and developing knowledge of how their worlds were organized within the material relations of society. A standpoint framework allowed the differences in these two-spirit male voices to be heard above the hegemonic values that dominate conventional social science research. In doing so, this study has not rejected, or challenged accumulated knowledge concerning lived experience and HIV/AIDS, but has rather enhanced the position of two-spirit experiences vis-à-vis knowledge that has been developed on the basis of their non-Aboriginal counterparts.

Through the review of the literature, for example, it is evident that life with HIV can be a never-ending struggle that individuals must confront in order to preserve a valued sense of self. However, for the men participating in this study, the process of responding to HIV has meant more often than not a (re)focus on the process of reclaiming and locating value in their cultural heritage. In some respects it has structured their responses to HIV in healthy ways. For many of the men in this study, cultural protocols have assisted in shaping responses, for example, towards limiting substance use. In some respects, we have heard the story of both despair and hope as two-spirit men confront HIV.

Likewise, the medicine wheel has provided an opportunity for sociological research to explore the experience of HIV more holistically from the perspective of two-spirit men. As Lambert states, "The use of the 'Medicine Wheel' in teaching is becoming an exciting area to share in. [. . .] These [approaches] are complementing

traditional teaching methods" (1993: S47). In short, the use of the medicine wheel has provided explanations of alternative meanings and way of dealing with HIV. It has provided the possibility that concepts, categories, themes and relationships could be shared in an initial way. That is, in developing programs that incorporate cultural competence, two-spirit men may be guided towards and re-educated in traditional methods of disease management in a way that respects cultural and social reality to promote health and well-being. In doing so, we can begin the process of incorporating both the metaphysical and metaphorical aspects of reality in HIV programming, particularly in the case of two-spirit men living with HIV disease.

Although it would not be appropriate to generalize the findings of this research to all two-spirit men, this research has also begun to answer a central question: Whether the medicine wheel has utility and can adequately filter an interpretative understanding of an Aboriginal world view and therefore faithfully describe a HIV-positive two-spirit experience of HIV/AIDS (at the very least, describe the world views held by the seven men who participated in this study). In some respects my application of the medicine wheel has highlighted struggles of the transition as individuals move through the illness trajectory, from moving to disbelief and the sense that one is dirty, polluted and tainted, to consideration of HIV therapy, and finally, to the focus on ceremony and its potential benefits. In many respects it has highlighted and focussed my attention on emotional, social, mental and spiritual aspects of HIV disease management for two-spirit men. For some, it may provide a culturally relevant framework that begins the process of developing knowledge related to how two-spirit men might experience HIV.

Implications for Policy and Practice

From the findings presented above, I would suggest some possible policy and practice interventions to improve the lives of HIV-positive two-spirit men in Winnipeg, as well as potentially other HIV-positive Aboriginals in other parts of the country.

The findings have suggested that although two-spirit men confront and face similar obstacles as do their non-Aboriginal counterparts, they seem to benefit from the process of incorporating culture and ceremonies into their lives. Culture and ceremony can have a mediating effect that can potentially focus and provide emotional strength and structure. However, further research is warranted. To make this point more definitely, it would be necessary to develop an understanding about two-spirit individuals who did not or will not, incorporate ceremony into their lives. What are the conditions that are necessary for individuals to adopt ceremony into their lives? Are these conditions necessary from the perspective two-spirit men and Aboriginal culture?

If we were to acknowledge that this has potential, it would be important that service providers and program planners attempt to understand and provide, whether or not individuals express cultural affinity or not, opportunities to participate in cultural activities. In some cases, not all two-spirit men start the process of dealing with HIV-status with a self-identity rooted in culture. However, individuals who provide service and support should *encourage* two-spirit men to combine allopathic with more traditional methods of illness and disease management. In doing so, service providers may provide meaningful structure and support to two-spirit men that takes as its starting position the social and cultural world of their clients. As suggested in the content of the

interviews, culturally appropriate support may provide two-spirit men with a reason to remain in care. This can potentially reduce morbidity and mortality.

Recommendations for Future Research

The findings of this study have broadened my understanding of the dilemmas encountered by HIV-positive two-spirit men living in Winnipeg. I am often asked to participate in service delivery planning and I believe such an understanding may facilitate the effective implementation of health care programming. It may also shape the way in which health professionals respond thus providing potentially more satisfaction to HIV-positive two-spirit men as they participate in these care relationships. However, as noted above, more studies are required regarding the lived experiences of HIV-positive two-spirit men.

An area that was not addressed in this study concerns combining allopathic with traditional approaches to disease management. How do two-spirit individuals successfully combine divergent approaches to the management of HIV disease? This seems particularly important given the importance of incorporating cultural practices with issues presented by several men in this study. That is, they often viewed HIV drug therapy based on the conventional medical model as 'scary,' that they were 'toxic' or felt anti-retroviral medication was doing 'more harm than good.' Efforts directed towards a combination of disease management approaches may mean two-spirit individuals will no longer face the prospect of increased hospitalization and of dying sooner than their non-Aboriginal counterparts (Goldstone et al. 1998). As Schilder et al.

state, "Culturally competent health care must provide social safety to foster self-identity within care relationships, [...] to improve health outcomes and adherence to HIV therapy" (1998: 159).

Lessons Learned from the Conduct of this Study

Several important lessons are to be taken away from the way in which this study has been grounded, from theory to design, and data conclusions. It is important that I ask the question, "If I were going to do this study over again, is there anything I would do differently and why?" By posing this question, several important features of the design and application became readily apparent.

The first and most obvious answer to this question centres on the issue of recruitment. It became apparent as the study progressed that it was becoming increasingly difficult to enroll the expected number participants (between 12 and 15). As already pointed out, this was primarily the result of my recruitment strategy that focussed on including HIV-positive two-spirit men living in Winnipeg. The issue was raised by a participant that the term two-spirit, even though I was referring to gay Aboriginal males, may not apply to him. He, and I presume others who didn't contact me about participation in the study, felt this label didn't apply adequately to how an individual may define the self. Recall, for him the label two-spirit should not be used to describe gay and Aboriginal. In other words, the self-identity of an individual (how individuals label themselves) was not adequately addressed as a component of the initial recruitment strategy. That is, rather than clearly specify my goal was to recruit gay Aboriginal males living with HIV, I chose to focus on a contemporary label the political

leaderships for this group had adopted.

Also, a component of my recruitment strategy was the focus on gay Aboriginal males living in Winnipeg. I did so, despite a warning received from a service provider that I would be limiting myself to individuals residing in Winnipeg when a number of her clients lived on reserve and came to the city to receive care. The potential is raised, that if I had chosen to open the inclusion criteria to individuals living outside the city of Winnipeg, I may have obtained the target enrollment of between 12 and 15 individuals. Clearly, it would be necessary in future studies to focus some attention on the demographics of the population under study, particularly where individuals live and receive care. I am left wondering whether the results I've presented would be any different if I had decided to open the study to potential participants living on-reserve.

Another difficult issue I encountered centred around the interviews. As I began the task of collecting data through interviews, I experienced this process as more of an art that develops over time. That is, listening is a skill that means knowing when to keep quiet or when to ask a probe to elicit further detail and provide a richness to the data. In some respects, I have learned that the art of conducting an interview requires skill that is built only after it is practised and lessons are incorporated into the strategy. In short, as a result of my own lack of skill in conducting an interview, I was required to approach an individual who had already participated in the study to ask him further questions. I now recognize the skills required to conduct an interview in a research setting. I do, however, find some limited comfort in the words of Chesney (2001), that individuals who participate in research do have the ability to resist the attempts of any

researcher, no matter how skilled, to pry into their lives with questions. Providing an answer to a well crafted and well-delivered question will always remain the research participant's prerogative. The skills needed and that are built over time only come as we "reflect on how we could have done it better. Reading the interview transcripts and field notes [raises] many questions that [will] require further fieldwork to answer" (Chesney, 2001: 134). In some way, this is the nature of research.

Another difficulty I encountered related to my decision to provide research participants with a monetary incentive to share their stories as a component of this research. Originally, this compensation was to recognize the poverty that some participants may be experiencing, and was a small token of appreciation that would not only serve to recognize this but also their expertise relative to the experience of HIV/AIDS from a two-spirit perspective. Other research in the area of monetary incentives has outlined the issues a researcher must overcome in providing compensation for study participation. Dickert, Ezekiel and Grady state:

The prominent ethical concern is that money may unduly induce subjects to participate in research by compromising the voluntary nature of their decisions or their willingness to explore the risks and benefits of the study. Others worry that payment may target economically vulnerable persons or compromise scientific integrity by altering the making of the subject population. No empirical data exist on the validity of these concerns. (2002: 369)

I was approached by one participant to conduct a second interview for payment. This case raised some ethical considerations in the conduct and validity of the accounts provided. Although I chose to proceed with the interview, it became necessary to report this truthfully, rather than fabricate any data upon which this thesis is based. In short,

great care was maintained to integrate the perspectives of both interviews as one individual, as was the case. Clearly, what is needed is policy development prior to research that addresses the payment of research participants (Dickert, Ezekiel and Grady, 2002). Although I continue to recognize the importance of payment to research participants, respondents should be aware that payment will only be rendered once, regardless how many interviews they choose to participate in. In other words, subsequent interviews should not require a further payment for time and expertise, particularly if the original amount of compensation is deemed as appropriate. Participants must also be made fully aware at the outset of the practice surrounding the amount of payment should they decide to contact the researcher for another opportunity to share further information in a follow-up interview.

A final lesson learned relates to the emotional distress I felt as result of what at times appeared as an enormous amount of similarity I shared with those who participated in my study. The larger question was, as Lofland and Lofland (1995) have pointed, how to maintain my research role within the research setting? In many ways this focus towards maintaining a research role has only come as a result of honest reflection and openness. Although I do believe that I have grown personally from my experience in the field it has been an extremely difficult process. I pointed out in the preface to the presentation of the data that time, I am sure, will reveal gaps and blind spots in my interpretations in the data. My strategy in dealing with this emotional malaise was to rely primarily on the process of quiet reflection and of allowing awareness to develop over time. As I became more comfortable with the data, with

problems and difficulties encountered by two-spirit men living with HIV, I was to acknowledge that I also struggled with developing a valued sense of self in the face of my own experience of HIV.

With respect to whether I would in future do things differently my answer would be a resounding yes. A strategy that I would use centres *more effort* at sharing my thoughts and reflections with peers, my supervisor and other two-spirit men. Having done *almost* the opposite, I have become a firm believer in the importance of sharing transcripts of interviews and drafts of the analysis with participants and members of the thesis supervisory team. I adopted this strategy much too late in the research process, since most of the individuals who participated in this research were lost to me. I was, however, able to share drafts of the analysis with one participant.

Limitations

Limitations accompany virtually every research project and this study is no exception. Therefore, it would not be appropriate to conclude without some discussion of the major methodological and substantive limitations of this study.

This exploratory study represents an attempt to gain a better understanding of the experiences of HIV/AIDS for two-spirit males living in Winnipeg. However, it is important to note that Aboriginal people are not a homogenous group. Canada has an estimated fifty native languages as well as many cultural traditions, practices and beliefs (McMillan, 1988). A sample size of seven men is much too small to provide a basis for extrapolation to the wider population of HIV-infected two-spirit men. I did not aim for representativeness within the sampling strategy. Further inquiries are clearly required to

know whether the responses described are representative of the entire community of two-spirit men or even if the findings can apply across gender lines. That is, are the findings representative of two-spirit females? Overall, it is important to acknowledge that this study was conducted in Winnipeg, with seven two-spirit men, and under particular circumstances. These factors taken together limit the generalizability of the findings. However, this study can potentially offer a limited perspective and insight into an under-researched field of inquiry.

Another issue arose from the self-selected basis upon which participation in this study was grounded. Although the data that were collected may be rich, detailed, and fruitful in terms of describing experiences with HIV/AIDS, the possibility exists that the respondents who chose to participate differed on some characteristics from those who chose not to respond and participate in this study. That is, virtually nothing is learned in this study of two-spirit men who chose not to respond and participate in an interview.

Yet another issue arose, "because all data was self-reported, [and] their validity is subject to a social desirability bias" (Simoni and Cooperman, 2000: 296). Did participants provide incorrect information or chose to not reveal because questions or probes explored areas they perceived they may have been judged? In other words, were certain features of HIV experience hidden from view because of perceived social desirability? For example, virtually no participant explicitly offered information with respect to injection drug use, despite this form of behaviour being a dominant method of contracting HIV within the Aboriginal community. In April 2002, Health Canada noted that injection use among reported cases of AIDS continues to be a major risk factor. As

the Centre for the Infectious Disease Prevention and Control (CIDPC) noted;

There have been 334 Aboriginal males with a reported AIDS diagnosis up to December 31, 2001. Of those with known exposure, 47.7% were men who have sex with men (MSM), 26.9% were injection drug users (IDU), 12.2% were MSM/IDU. (CIDPC, April, 2002: 35)

The Winnipeg Injection Drug Epidemiology (WIDE) Study (1999) bears this point out.

This study had two separate recruitment phases. The first involved a screening questionnaire (n=3,338) to identify individuals with a history of ever injecting drugs. This was done prior to an in-depth interview (n=608) with self-identified users of injection drugs (IDU). In short, this study sought to describe the IDU population in Winnipeg, drug(s) of choice, sexual risk behaviour, use of community health and preventive services and to estimate the prevalence of HIV infection among the IDU community. Of those completing the screening questionnaire and reporting a history of injection drug use (n=1068), 685 (64.2%) self-reported their ethnicity as Aboriginal (1999: 10). Similar numbers of ever IDU during in the follow-up interview also reported their ethnicity as Aboriginal (n=401 or 65.8%). Furthermore, of those interviewed and ever IDU, 22.6% reported men who have sex with men as a sexual risk characteristic (1999: 21).

Of the seven men I interviewed for this study, five indicated previous or continuing problems with addictions, ranging from alcohol to marijuana and cocaine. One individual, likely as a result of injection drug use (although this was not confirmed) indicated he was co-infected with hepatitis C infection. It seems possible that if injection drug use had been explored more closely during the interviews through direct

questioning, the data may have more adequately highlighted this as a phenomenon for this population. However, it may also be that a larger sample would have more adequately highlighted the injection drug use relative to the experience of HIV positivity.

Finally, as indicated earlier, I shared with the men who chose to participate in this study a tremendous amount of my own experience. That is, my daily involvement and the experience of HIV/AIDS also resulted in another limitation. As Riessman states, "The construction of any work always bears the mark of the person who created it" (1993: v). I shared with the men who participated in this study the experience of HIV/AIDS: how it has affected my life, my sense of self, my world view, and my relationships with family, friends, care providers and significant others. Primarily, I was stimulated to carry out this study to acknowledge and understand the two-spirit experience of HIV/AIDS. However, I also approached this study with a personal stake in its outcome. Knowledge of the experiences of two-spirit men may potentially contribute to improvements in health care for me as well as for others who share, or will in the future, a similar life passage. Therefore, I understood prior to this study that there would be numerous demands for personal reflection and emotional malaise, in order to produce a study that took up the challenge of allowing "research [to be] a chorus of voices" (Riessman, 1993: 16, paraphrasing Gorelick, 1991). I was not disappointed. I hope, however, that I was able to shed light on my own conceptual baggage and that this work is of some value to those who read it, they you have heard much more than my own voice, but have also heard the voices of the seven who participated.

In closing, despite the above listed limitations, it is hoped that this exploration of HIV-positive two-spirit male identity reconstruction will begin to fill the gaps in the sociological literature as well as contribute to the development of culturally sensitive and meaningful HIV/AIDS programs and services for this population. It too may further stimulate other researchers to explore through a sociological lens this crucial aspect of life for HIV-positive two-spirit men.

Appendix A

POSTER/NEWSPAPER ADVERTISEMENT

Research Project

Two-Spirit Men in Winnipeg and the Experience of HIV/AIDS

Two-spirit men living with HIV/AIDS are being invited to participate in a research project. The experience of HIV-positive two-spirit is a topic that is not yet fully understood. I would like to learn more about how being gay and Aboriginal have affected your experience living with HIV/AIDS. Interviews will explore issues of uncertainty, stigma, sexuality and treatment of HIV/AIDS. All information will be kept strictly confidential. Interviews will be scheduled at your convenience and in a location that is safe and comfortable for you.

For more information about this study or if you or someone you know would be interested in participating, please call me at XXX-XXXX. A small honorarium will be provided for your participation.

-Randy Jackson, Master of Arts student (Sociology), University of Manitoba.

Appendix B

BUSINESS CARD ADVERTISEMENT

Two-Spirit Men in Winnipeg and the Experience of HIV/AIDS

Gay Aboriginal men who live in Winnipeg are invited to share their stories about life with HIV. Interview questions will focus on issues of sexuality, stigma, uncertainty and treatment. Confidentiality is respected. A small honorarium will be provided.

Telephone Randy at XXX-XXXX to schedule an interview.

Appendix C

INFORMATION BROCHURE, CONSENT AND ETHICS FORM

Two-Spirit Men in Winnipeg and the Experience of HIV/AIDS

This study focuses on the experiences of gay Aboriginal men living with HIV/AIDS. Specifically, this study is concerned with issues related to one's sexual orientation, culture and testing HIV-positive as well as exploring how this illness has changed how you see yourself. The interview will explore the impact HIV/AIDS has had on your life in the areas of uncertainty, stigma, sexuality and treatment.

I am interested in this area of research because as a gay Aboriginal man living with HIV/AIDS myself, I am concerned with the lack of knowledge around the provision of culturally appropriate health care. It is my hope that by sharing your experiences of living with HIV/AIDS you will contribute to an increased understanding of the issues faced by HIV-positive Aboriginal men. Moreover, this study will contribute to partial fulfillment of the requirements for the degree, Master of Arts.

You have been selected to be interviewed for this study because you are an Aboriginal man living with HIV/AIDS. If you agree to participate, and with your permission, your interview will be audio taped for later transcription, so that I can analyze the data more completely. All information gathered in the course of the interview will be kept completely confidential, and at no time will your identity be divulged. As well, every effort will be made to protect anonymity. All audio tapes and transcripts will be destroyed at the completion of the study. None of the information you share with me will be disclosed to anyone, except in a form consistent with sharing findings of academic research. You are free to refuse to answer any of the questions you are asked during the course of the interview. You are also free to withdraw from the study at any time, without prejudice. You will be provided with a \$20.00 honorarium for your role as a study participant. Participants must also be aware that should child abuse be discovered, it must be reported to the legal authorities.

The Department of Sociology Research Ethics Review Committee has approved this study. Any questions regarding the project may be directed to either the investigator (Randy Jackson: XXX-XXXX) or the research supervisor (Karen Grant: 474-9912), or the chair of the Department of Sociology (474-9260) for referral to the Research Ethics Review Committee.

Two-Spirit Men in Winnipeg and the Experience of HIV/AIDS

Consent Form

I, _____, agree to participate in the study named above.

I have read the attached information sheet on this study. I understand that if I agree to participate in the study, my interview will be audio taped. Any information gathered in the course of this research may be published in academic journals and books, and may be presented at scholarly and other public conferences. I understand that all transcripts and audio recordings will be destroyed at the completion of the study. I understand I am free to refuse to answer any questions I consider too personal or objectionable. I understand that my participation in this study is entirely voluntary. I also understand that I may withdraw my participation at any time, without prejudice.

At the conclusion of the interview, I understand I will receive a \$20.00 honorarium, and, if I desire, at the conclusion of the study I will be provided with a summary of the research findings.

I wish to receive a summary of any research findings.

☐ Yes

☐ No

The Department of Sociology Research Ethics Review Committee has approved this study. Any questions regarding the project may be directed to either the investigator (Randy Jackson: XXX-XXXX) or the research supervisor (Karen Grant: 474-9912), or to the Chair of the Department of Sociology (474-9260) for referral to the Research Ethics Review Committee.

(Date)

(Signature in Ink)

(Date)

(Randy Jackson, Researcher as Witness, XXX-XXXX)

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Fax (204) 261-1216

PROPOSAL REVIEW REPORT

PLEASE PRINT

Principle Investigator(s):

Randall Jackson

Project Title:

Two-Spirited Men in Winnipeg and The Experience of HIV/AIDS.

This Proposal, as currently described, has been:

- ☒ Approved.
- ☐ Approved with modifications (minor changes; no re-submission required).
- ☐ Approved in principle (research tools have yet to be developed).
- ☐ Tabled (major modifications or information required).
- ☐ Found ethically unacceptable.

Comments:

 Chair, Research Ethics Review Committee

Feb. 24/99
Date

PROJECT TITLE AND LIST OF INVESTIGATORS

Project Title:

Two-Spirited Men in Winnipeg and the Experience of HIV/AIDS.

Principal Investigator(s):

<u>Name</u>	<u>Address</u>	<u>Telephone</u>
Randall Jackson		(204)

Status (circle): Faculty Post-
 Doctoral Graduate Undergraduate
 Student Student

Student Researchers:

Course Number: _____

Signature of Instructor

Thesis/Dissertation

Signature of Advisor

FOR RERC USE ONLY

Date Received: Feb 14/99 Reviewers: _____

The Project
Is approved ☒
Is approved with modifications ☐
Is approved in principle ☐
Requires major modifications ☐
Is unacceptable ☐

Feb 22/99
(Date)

(Reviewer's Signature)

Reviewers: if changes are required, please provide details on separate pages.

Proposal Review Report sent on Feb 24/99 Initials _____

Page 10, Information Sheet. Should be "Master of Arts"
not "Masters of Art"

Appendix D

THE INTERVIEW GUIDE

Interview Location

Interview Date

Interview Start Time

Introduction to Study (purpose, objectives, consent form, etc.)



Read onto tape

Demographic Information

Let's start with how you learned about this study? Did anyone refer you?

What year were you born?

To what tribal nation do you belong?

Is Winnipeg your primary residence (where you live most of the time)?



Probes, family members; Is the family aware of your HIV-positivity?; What would happen if your family was aware? Tell me about a time you visited with your family?

Living with HIV/AIDS

How long have you been living/aware of your HIV status? What were you feeling? What is it like today?

Can you tell about your current health status?

Are you seeking medical treatment for HIV infection? (Where? Experiences?)

Would you describe yourself as traditional?

Do you use a traditional healer; what traditional healing practices have you used?

Do you find this helpful? Why?

Tell me about everyday life with HIV infection?



Symptoms, illnesses, medication, treatment decisions



Probe for issues related to Aboriginality, sexuality, uncertainty, stigma, disrupted biography, time orientation; In what ways has HIV changed your sexuality; What was it like before you tested positive? What prompted you test for the HIV virus? Do you feel you have come to accept you are HIV-positive? What made acceptance possible?

Ending Questions

What have you learned about yourself since testing positive for HIV?

What advice would you give to someone in a similar situation?

We are almost done, would you like to add anything else?



Probe for issues related to Aboriginality, sexuality, uncertainty, stigma, disrupted biography, time orientation

Record Interview End Time



Read onto tape.

REVISED INTERVIEW GUIDE FOR SECOND INTERVIEW WITH SAME PARTICIPANT

Opening Comments

Interview Location

Interview Date

Interview Start Time

Review of study's purpose, objectives, consent forms, etc.



Read onto tape.

Life Prior to HIV Infection

Let's talk a bit about your life prior to HIV infection?



Probe for issues related to gay and aboriginal identities, how this has affected world view and relationships with self and others? Were there any struggles? How did these struggles manifest themselves, such as alcoholism or drug addiction? Have you been able to affirm your gay identity (are you comfortable with being gay)? What about Aboriginal identity? How did you accomplish this? As you continue to grow and understand gay or Aboriginal identity, does this cause further disruptions? Probe for specific experiences. Can you provide an example?

Living with HIV/AIDS

Upon first learning you were HIV positive, how did you initially attempt to handle or deal with this information?



Probe: How did you make sense of being gay, HIV-positive and Aboriginal? Does turning towards aspects of Aboriginal identity assist you in dealing with the affects of life with HIV? Again, probe for specific examples. Probe for issues related to disclosure, stigma, uncertainty. How has it been to share with others your HIV status?

Future Orientation

What does the future hold?



Probe for issues related to treatment uptake, views about treatment, spirituality, participation in ceremony, illness, etc. How do you think illness will affect your life, the plans you may have made for yourself? Do you or do you plan to use HIV medication? What does this mean to you, to now live a life using medication? How do you deal with the uncertainty of living with HIV?

Ending Questions

It has been awhile since we last spoke, have you had the opportunity to reflect on your participation in this study? What have you learned about living with HIV that you would like to share with others in your situation? We are now almost finished, would you like to add anything else?



Probe for issues related to Aboriginality, sexuality, uncertainty, stigma, disrupted biography, etc. Has the process of learning been difficult? Has it been worthwhile? How has HIV changed your view of whom you are?

Record Interview End Time



Read onto tape.

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