

**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
of Manitoba in partial fulfillment of the requirements of the degree
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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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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; Tweksbury 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*