"I CHOSE TO FIGHT": THE LIVES AND EXPERIENCES OF

ABORIGINAL WOMEN WHO ARE LIVING WITH HIV/AIDS

by

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ABSTRACT

The increasingly high rates of mortality and morbidity amongst HIV+ Aboriginal women indicate that there is a need to address deficiencies in the delivery of supportive services and health care. The purpose of this study was to develop a greater understanding of the barriers, challenges and successes that Aboriginal women face in the context of living with HIV/AIDS. It is anticipated that the findings from the study will be used to inform decision making around the development and delivery of appropriate, responsive and accessible policies and programs that will assist Aboriginal women who are living with HIV/AIDS achieve a state of health and well-being that is equitable and that they perceive as optimal.

This study utilized a qualitative interpretive descriptive methodology to gather data from eight Aboriginal women living with HIV/AIDS. Data were collected utilizing one on one, semi-structured interviews. Two of the women were contacted by telephone for follow-up interviews to review the preliminary findings. An expert informant, who self-identified as Aboriginal and who has expertise in the field of HIV/AIDS, provided ongoing advice and feedback throughout the study in relation to study design, analysis and interpretation of the data as well as write up of the findings.

The data analysis proceeded simultaneously with the interviews utilizing a process of constant comparative analysis. Thematic analysis was completed as I moved between the transcripts to identify commonalities and variations within the emerging themes. The ultimate result was a description of five themes that described the range of experiences that the women discussed. The five themes that were identified included: fear of rejection; looking for friendship; the struggle to stay well; finding strength in

adversity; and HIV is just one problem among many. Three overarching issues were apparent, including the intersecting social, economic and political forces that constrained the women's lives, and the resultant experience of social suffering. Also of note was the significant degree of resilient behaviour that the women brought to bear on their life circumstances.

TABLE OF CONTENTS

List of Tables

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This has been more challenging than I ever anticipated and I could not have done it without the ongoing support of a number of people. My husband Stuart has been a godsend, patiently listening to my angst and being an uncomplaining sounding board for my continued frustrations. My advisor Annette Browne did her level best to keep me on track, despite all my attempts at procrastination. The other members of my committee, Sheryl Reimer Kirkham and Patricia Spittal, were, as I expected, an amazing fund of information and knowledge that was inordinately helpful as I struggled to identify and understand the themes and concepts that the data was pointing me to. Melanie Rivers was an invaluable source of wise advice and helped me maintain my perspective about the issues that the women were raising. And finally, this could not have happened without the generosity of the eight women who agreed to participate and who shared their thoughts, feelings and stories with me. Their courage and tenacity in the face of almost insurmountable odds will stay with me forever and will serve as an inspiration whenever I think that life has handed me more than I can cope with.

CHAPTER ONE

There have been countless studies over the past two decades that have examined

the experiences and characteristics of people living with HIV/AIDS. The lives and

experiences of men who have sex with men, injection drug users, women and certain

selected cultural groups have been exhaustively documented. Despite the sustained

attention of researchers to this issue however, one group seems to have escaped notice to

a large extent. Aboriginal women in Canada comprise a notable proportion of positive

HIV test reports (Health Canada, 2003). They represent close to half of all positive test

reports among Aboriginal persons, compared to a rate for non-Aboriginal females of

approximately 20% (BC Aboriginal HIV/AIDS Task Force, 1997). They die of AIDS

sooner than the general population and have a lower utilization of antiretroviral treatment

(ART) programs (Wood et al., 2003). Despite these overwhelming statistics, with the

exception of a handful of programs, Aboriginal women remain virtually invisible in

HIV/AIDS research, policy and services (Ship & Norton, 2000) and despite efforts to

articulate the health and social concerns of Canada's marginalized populations, the voices

of Aboriginal women have not been given sufficient attention (Benoit, Carroll &

Chadhry, 2003).

A Note about Terminology

"Aboriginal" is defined for the purpose of this study as status and non-status First

Nations, Métis and Inuit peoples, although it is anticipated that the participants will be

primarily, if not exclusively First Nations as this is the population that is most readily

accessible in the study location. This terminology is in keeping with currently accepted

practice, as outlined by the Report of the Royal Commission on Aboriginal Peoples

(RCAP, 1996a). Terms such as Indian will continue to be used where such terms are used in quotations from other sources.

Background to Problem

The conception of "woman" as a category of analysis in HIV/AIDS research does not adequately address the significant social and economic inequalities that many Aboriginal women face. Universal categories such as "women" fail to account for the diversity of the female gender and also fail to acknowledge the very real bias towards the perspectives of dominant groups (McCormick, Reimer Kirkham & Hayes, 1998). In order to create policies and interventions that give voice to Aboriginal women's concerns and that assist Aboriginal women living with HIV/AIDS in a real and constructive fashion, it is imperative to arrive at an in depth understanding of the experiences of Aboriginal women who are living with HIV/AIDS and the challenges they face in accessing health care services.

Nursing is mandated both socially and morally to illuminate the experiences of those people who are marginalized both within society and within healthcare (Reimer Kirkham & Anderson, 2002). Researchers have recognized that transformative knowledge that helps us to recognize the institutionalized practises that influence health is essential if we are to reach a clear understanding of the challenges that marginalized groups face in the context of health (Anderson & Reimer Kirkham, 1998; Anderson, 2002; Brown & Fiske, 2001; Williams, 1990). Transformative knowledge is knowledge that treats as legitimate the voices of those who have been muted in the production research and illuminates unequal power relations. It also challenges the racialized and

culturalist theories that have led to a health care system that institutionalizes racist and cultural stereotypes such as "dependent" and victimized "Indians" (Anderson, 2002; Waldram, Herring & Kue Young, 1995).

This study proposes to generate knowledge that is based on the experiences of Aboriginal women who are living with HIV/AIDS in order to reach a broader appreciation of the intersecting factors that impinge on the health and well-being of this population and come to a clearer understanding of the measures needed to ensure that Aboriginal women are able to access appropriate treatment. It is anticipated that this knowledge may be used to inform the perspectives and practises of front-line providers who provide HIV/AIDS related treatment and care as well as add to the growing body of literature that can be used to support changes in current policy and programs which effect the lives of Aboriginal women.

Problem Statement

Aboriginal women have historically faced many challenges – the lasting effects of residential schooling and colonization, including multigenerational abuse, substance misuse and cultural disruption; economic, social and physical power imbalances; and subordination in education, employment, social and legal status (Dion Stout, Kipling and Stout, 2001; Ship & Norton, 1999). Although an increasing number of Aboriginal women have managed to thrive despite these challenges, many Aboriginal women have had and continue to have difficulty in many aspects of their lives as a result of the adversities they have faced. These complex factors are often inter-related and lead to vulnerability for HIV infection and increased mortality and morbidity for Aboriginal women who are

living with HIV/AIDS (ANAC, 1996). Specifically, women in general and Aboriginal women in particular who are living with HIV/AIDS are diagnosed later in the course of their infection, less likely to access treatment, and tend to have poorer treatment outcomes (BC Aboriginal HIV/AIDS Task Force, 1997; Legare, Ross & Bognar, 2003; Vernon, 2000; Woods et al., 2003).

Despite the development of numerous innovative prevention and treatment programs that have been designed for hard to reach populations there are still high rates of infection, poor uptake of treatment programs, and disproportionately high rates of morbidity and mortality amongst Aboriginal women who are at risk for and living with HIV/AIDS. Dedicated and targeted prevention programs have slowed the rate of new infections in both the injection drug user and men who have sex with men populations (Health Canada, 2003) and the advent of triple therapy[1] in 1996 has dramatically reduced both the number of new AIDS cases, despite the increasing number of persons living with HIV infection, and the death rate from AIDS (Health Canada, 2003). Aboriginal women have not benefited in the same way from these trends however, which calls into question the effectiveness of existing programs in addressing the needs of this population. Developing knowledge about women's experiences of living and coping with HIV/AIDS – from the perspective of Aboriginal women themselves – will ultimately inform the development of responsive, accessible services.

1. Triple therapy is a term used to describe antiretroviral therapy (ART) which is the drug combination which is given to persons living with HIV to control viral replication and delay progression to AIDS related illnesses.

This thesis will address the central problem of how to establish appropriate, responsive and accessible policies and programs that will assist Aboriginal women who are living with HIV/AIDS to achieve a state of health and well-being that they perceive as optimal. It will provide an opportunity for the voices of Aboriginal women who are living with HIV/AIDS to be heard and it will also provide a forum for expressing how multilayered socio-political forces contextualize health and illness (Anderson, 2000).

Purpose of the Study

This study used an interpretive descriptive approach to identify the contextual and constructed nature of health-illness experiences of Aboriginal women who are living with HIV/AIDS. The design of the study will allow for the generation of new knowledge, insights and understanding about the barriers, challenges and successes that Aboriginal women face in the context of living with HIV/AIDS. It is anticipated that the findings will inform future research in this area and provide insight – from the perspective of Aboriginal women - into how to design and deliver HIV/AIDS related services to best meet the needs of Aboriginal women who are living with HIV/AIDS in a compassionate, effective, and accessible manner.

The three research objectives that were used to frame the study and guide the development of the interview guide were to:

1. Explore and understand some Aboriginal women's experiences of living with HIV/AIDS within the context of their everyday lives.

2. Gain an understanding of how Aboriginal women who are living with HIV/AIDS experience formal support systems, including AIDS service organizations and health care services.

3. Make recommendations for program design and policy development that will specifically address the needs of Aboriginal women who are living with or at risk for HIV/AIDS.

Organization of the Thesis

In this chapter, the background for the proposed research has been reviewed, the problem has been stated and the purpose of the study has been discussed. In chapter two, research based literature which locates the problem within existing knowledge will be reviewed and related literature will be identified. Chapter three will address the research design, including theoretical perspectives, methodology, ethical considerations, and scientific quality. Chapter four will contain a review of the findings as revealed by the participants. Chapter five will discuss the findings and relate them to existing literature. The final chapter will explore the implications of the research findings for health program planners, care providers, researchers, and the Aboriginal population at large. Recommendations for future research and policy and program development will be outlined.

CHAPTER TWO

Review of the Literature

A review of the literature is useful to establish context and to get a sense of previous published work (Burns & Grove, 1997). Thorne, Reimer Kirkham and MacDonald-Emes (1997) suggest that interpretive description should be located within existing knowledge. Critical analysis of existing knowledge provides a platform on which to build the design of the study and allows the findings to be constructed with attention to the linkages that can be drawn to the work of others in the field.

A disproportionate number of Aboriginal women live lives that are characterized by poverty, powerlessness, and disconnectedness. They bear a burden of ill health, premature death, and marginalization to a degree that is unimaginable to most Canadians (Dion-Stout et al., 2001). The review of the literature will examine the historical context, health status, and socioeconomic status of Aboriginal women. The intersection of these factors in the context of Aboriginal women's lives, the relationship of these factors to vulnerability and stigma in the context of HIV/AIDS, and related literature in regards to Aboriginal women and HIV/AIDS will be discussed.

The Historical Context of Aboriginal Women's Lives

It has been over five hundred years since Europeans first made contact with the Aboriginal peoples of North America. The results of this contact are well known to even the most casual of observers. Aboriginal peoples have faced the wholesale co-option of their land, the introduction of previously unknown diseases, the virtual destruction of their culture and way of life, and relegation to a position of relative powerlessness. The passage of centuries has done little to mitigate the effects. Government policies and

public perception is still based to some extent on the false assumption that Aboriginal ways of life are at a primitive level of development and that the only viable alternative for Aboriginal success in the modern world is the adoption of the culture of European colonists (RCAP, 1996a). As Loomba (1998) points out, people who live in once colonized and once colonizing countries are still subject to the oppression that was a result of colonialism. Canadian culture "...remains resolutely colonial in shape, content, meaning and practice." (Furniss, 1999, p.12).

Colonization has resulted in a legacy of subordination for Aboriginal peoples, who face a multilayered reality of discrimination and disadvantage on both an individual and institutional level (Browne & Smye, 2002). The provision of health care services to Aboriginal peoples has been profoundly shaped and influenced by the process of colonization, and has contributed to the culture of disempowerment and dependency that Aboriginal peoples experience in relation to the health care system (Kelm, 1998; O'Neil, 1986; RCAP, 1996a; Waldram et al., 1995). Lack of control and influence over the design and delivery of health care services has undoubtedly influenced both the health status of Aboriginal peoples and their utilization of health services.

It is generally accepted that colonization fundamentally altered the health status of Aboriginal peoples (Furniss, 1998) and arguably not for the better although Waldram et al. (1995) take issue with the widely held view that the pre-colonial Aboriginal population had a robust state of health. Aboriginal women have experienced some particular and devastating challenges as a result of colonization. As Diamond (1999) observes, governments organize conquests but it is religion that justifies them; the first social policies in Canada were established by missionaries (Armitage, 1995). It is widely

accepted that many traditional Aboriginal societies were matriarchal, with women playing a central role in their communities (LaRocque, 1994). The arrival of the colonists and the missionaries, with their patriarchal worldview, changed everything. The missionaries attempted to transform Aboriginal societies by imposing patriarchal family structures and by undermining the traditional independence and autonomy that Aboriginal women had possessed (Stevenson, 1999).

The original colonizers have been abetted in their efforts by successive governments. The BNA Act of 1867 and the Indian Act of 1876 formalized the continued subjugation of Aboriginal women (Stevenson, 1999). The Indian Act contained gender discriminatory clauses that deprived Aboriginal women of the social rights and legal status afforded to their male counterparts (Fiske, 1993). Bill C 31, which was an attempt to redress the imbalance, did not eliminate gender discrimination. "Reinstatement of Indian status remains dependent on male lineage..." (Fiske, 1993, p. 22) which flies in the face of the system of matrilineal lineage that formed the basis of traditional Aboriginal societies. From forced education at residential schools to imposed male-dominated political structures to the ongoing removal of their children by child welfare authorities, many Aboriginal women continue to be systematically undermined by the Canadian state (RCAP1996b; Turpel, 1993).

The impact of colonization has been to fundamentally alter the positioning and image of Aboriginal women, both within their communities and the community at large. The Victorian morality that was at play during the colonization of Canada was the standard against which Aboriginal women were judged and they were found wanting in almost every respect (Stevenson, 1999). This judgement continues to frame society's

characterization of Aboriginal women, who are persistently and somewhat contradictorily characterized as either "dirty squaws" who are not worthy of time and attention or as helpless victims who require ongoing and patronizing "help" in order to survive in today's world. Whichever view is taken, the ultimate outcome has been that Aboriginal women have had little input or control over the political and institutional forces that play a significant role in the promotion of health and well-being.

The effect of colonial and post-confederation legislation has been to marginalize Aboriginal women and diminish their social and political roles in community life (RCAP, 1996b). Aboriginal women have historically been given little or no opportunity to influence the political landscape and scant attention has been paid to their needs and concerns by the Canadian state, Canadian society in general, and the Aboriginal male leadership (Dion Stout & Kipling, 1998). The historical experience of being colonized has had a negative effect on the psyche of many Aboriginal women, leading a number of them to exhibit a lack of self-confidence, a fear of action, and a tendency to believe that the ravages and pain of colonization and its consequences are somehow deserved (Daes, 2000).

Health Status: A Social Determinant Perspective

Mortality and Morbidity

Aboriginal peoples have been portrayed by the dominant players in the health care system as pathetic, pathological, and powerless in relation to their health and well being (Kelm, 1998). Although this portrayal is disturbingly discriminatory and judgemental, the statistics do bear out the impression that Aboriginal peoples, and Aboriginal women in particular, bear a disproportionate burden of ill health. Dion-Stout et al. (1998) observed

in their report that Aboriginal women, "…are characterized by a health profile that one would normally associate with the developing world." (2001, p.16). Life expectancy for Aboriginal women is about 7 years less than that of non-Aboriginal women in Canada (Dion Stout et al., 1998). Aboriginal women have a significantly higher prevalence of chronic diseases (Health Canada, 1999) and Aboriginal women also suffer from higher rates of cervical cancer, sexually transmitted infections and cirrhosis of the liver (Dion Stout, 1996).

HIV/AIDS Statistics

The effects of HIV/AIDS in the Aboriginal population have been of increasing concern since the early nineties. In 1994, Frideres (in Dion Stout, 1996) observed that AIDS was expected to be the "…leading cause of death for Indians as we move into the next millennium." (p. 4). The Aboriginal Nurses Association of Canada (ANAC, 1996) has noted that Aboriginal women are particularly susceptible due to their high rates of sexually transmitted infections and inequitable gender relations. These predictions have been borne out by the data. In 2000, Health Canada reported that Aboriginal women represented a significantly higher proportion of HIV/AIDS diagnoses than non-Aboriginal women (18% vs. 6%). The VIDUS study in Vancouver, which is an open prospective cohort study of injection drug users, has recorded its highest HIV seroconversion rate amongst its Aboriginal female participants. Aboriginal female participants in the VIDUS study had a seroconversion rate of 47% versus a rate of 20% amongst non-Aboriginal female participants (Craib et al., 2003). In British Columbia (BC), Aboriginal women represented 29% of new diagnoses among women between

1995 and 2000, despite representing less than 5% of the BC population (Legare et al., 2003).

In addition to a higher rate of infection, Aboriginal women fare poorly when it comes to disease progression. HIV is a life threatening but manageable infection. Current treatment regimes can delay the progression of HIV to AIDS almost indefinitely. The advent of triple therapy has had a pronounced and positive effect on the AIDS case rate in the general population but there is evidence that Aboriginal women have had an increase in AIDS deaths whilst at the same time as there has been a dramatic decline in the general population (Vernon, 2001). Aboriginal women have an AIDS case rate that is twice that of the general population (ANAC, 1996).

Use of Health Care Services

Aboriginal people in general tend to underutilize available health services (Waldram et al., 1995). Vernon (2001) also notes that Aboriginal women who are living with HIV/AIDS tend to delay accessing medical care until they experience acute symptoms and their disease is already advanced. The reasons for delay in access are complex and attributable to numerous factors. Legare et al. (2003) identify a number in their report on the status of HIV positive women in BC: later diagnosis; delay of treatment; exclusion from drug trials; lack of research that pertains specifically to women; higher rates of poverty; and conflicting demands on their time due to child care and family responsibilities. This report however, looked at women in general. Aboriginal women may have specific challenges and characteristics that are not addressed in this survey. Mill's study (2000), which examined the perspectives of Aboriginal women in relation to an explanatory model of HIV illness uncovered that for a number of the

participants, the disease must be felt before treatment is sought. This is disquieting because HIV infection has little to no symptoms for approximately eight to ten years from the time of seroconversion. The onset of severe symptoms is associated with advanced disease and immunosuppression.

The structure of health care delivery for Aboriginal peoples cannot be discounted as a factor in the poor outcomes for Aboriginal women who are living with HIV/AIDS. The negative experiences that some Aboriginal women have had with the mainstream health care system (ANAC, 1996; Dion Stout et al., 2001) have justifiably led Aboriginal women to avoid health care encounters. The structure of the health care system has been resolutely colonial (Kelm, 1998) with its construction of Aboriginal peoples as "...culturally crippled..." (Waldram et al., 1995) and an approach to service delivery that Aboriginal women perceive as discriminatory and judgemental (Browne, Fiske & Thomas, 2000). In recent times, there has been an attempt to redress the imbalance with programs that are targeted towards Aboriginal health, the devolution of power from the federal government to local Aboriginal communities, and an increasing effort to target vulnerable populations, including Aboriginal women. However, the statistics bear out the reality, which is that the health care system is not currently designed to best meet the needs of Aboriginal peoples in general and Aboriginal women who are living with HIV/AIDS in particular.

The Intersection of Socioeconomic Factors and HIV/AIDS

Intersectionality refers to the experience of differing constellations of inequities that marginalized populations experience as a result of their social positioning within hierarchies of power relations (Collins, 2000). When gender intersects with other issues

such as poverty, racism, abuse, lower levels of education, and socio-historical positioning, Aboriginal women are at increased risk of being socio-economically disadvantaged (Browne, Smye & Varcoe, 2005a).

Socioeconomic Status

It is now generally accepted that socioeconomic status (SES) has a profound influence on health status. In a review by Williams and Collins (1995), many sources were cited that support the concept that there is an inverse and robust association between SES and health status. Higher levels of education and income have both been associated with lower levels of morbidity and mortality (Williams, 1990). Additionally, persons with a lower SES not only receive more exposure to psychosocial risk factors such as health practises, perceptions of control, social ties, and stress as well as deficits in medical care but also may be more vulnerable to them (Coburn, 2000; Williams).

HIV/AIDS has only served to amplify the effects of social and economic inequalities on health status. HIV infection has cut a swath through the world's most vulnerable populations. Social inequalities lie at the heart of risk for HIV infection and women who are living with HIV/AIDS have borne the brunt of persistent forms of social and economic inequality (Zierler & Krieger, 1997). SES has had an inverse effect on the rate of HIV infection (Hankins et al., 1998; Hargreaves, 2002), uptake of treatment and utilization of health services (Gebo, Keraly & Moore, 2003; Goldman & Smith, 2002; Schecter et al., 1994; Tramarin, Campostrini, Tolley & De Lalla, 1997), and long-term survival with HIV (Hogg et al., 1994; Wood et al., 2002).

Many Aboriginal women have had and continue to have profound struggles to achieve a standard of living that is enjoyed by the general population. They lag behind

Canadian women as a whole on many social and economic indicators (RCAP, 1996b). In comparison to non-Aboriginal women they have lower incomes, lower educational status, are more likely to be unemployed or underemployed, and more likely to head single parent households (Dion Stout et al., 2001; Indian and Northern Affairs, 2001; RCAP, 1996b). They continue to face "…a multiple jeopardy on the basis of a number of objective indicators of social and economic well-being."(Gerber, 1990, p. 6). The links between the socioeconomic status of Aboriginal women and their challenges of living well with HIV/AIDS are inescapable and must be taken into consideration when considering the perspectives and experiences of Aboriginal women who are living with HIV/AIDS.

Injection Drug Use

It is well documented that Aboriginal people in general and Aboriginal women in particular struggle with addiction. This has been directly related to the trauma that Aboriginal people have experienced as a result of colonizing practices such as residential school, enforced assimilation, removal of children, and disruption of culture (Adelson, 2005). Although not all Aboriginal people have issues with addiction, Aboriginal women have a disproportionately high rate of injection drug use. Aboriginal women have a rate of injection drug use of 23.1% compared to a rate of 8.2% of non-Aboriginal females in relation to AIDS (Health Canada, 2003) and injection drug use is a particularly important risk factor for HIV among Aboriginal females (Health Canada), accounting for well over half of all infections (Dion Stout et al., 2001) although it is difficult to clearly separate the risk of heterosexual transmission from the risk of injection drug use. Spittal et al. (2003) revealed that active injection drug use increases womens' vulnerability to heterosexual

infection due to an increased predilection for high-risk sexual behaviours amongst injection drug users. Injection drug use also has a negative influence on the health seeking behaviours of women living with HIV (McCoy, Metsch, Chitwood & Miles, 2001; Solomon, Frank, Vlahov & Astemborski, 1991).

Violence

Aboriginal women have a particular and unique risk of violence in the home (Dion Stout, 1996). As many as 8 out of 10 Aboriginal women have experienced violence (RCAP, 1996b), both within their own communities and the community at large (Ship & Norton, 2001; Schwarz, 2004). Violence has a multitude of impacts – fear of violence leaves Aboriginal women reluctant to demand condom use from their partners (Ship & Norton) and it also is associated with behaviours that leave women at risk for HIV infection (Vernon, 2000). Kirkham and Lobb's (1998) survey of 110 HIV positive women revealed an association between childhood sexual abuse and/or adult sexual abuse and HIV infection. Jauvin, Clement and Damant (as cited in Dion Stout et al., 2001) emphasized that experience of violence has a number of health related consequences, including mental health problems, substance use, and suicidal thoughts. They also argue that violence should be seen as an obstacle to good health, in that it interacts with other health determinants in complex and multifaceted ways.

Stigma

Concept of Stigma

Stigma is a concept as old as humanity. The term refers to a condition of "difference" and is used to label people who deviate from the socially constructed definition of normal that is at work in their community. In his seminal work, Goffman

(1963) defines stigma as an attribute or characteristic that is considered deeply discrediting by the society or culture to which the individual possessing the attribute belongs. Stigma not only refers to the trait itself but to the outcome of being known to possess the trait. Stigma is a discrepancy between the expected and the actual that "spoils" the social identity. Goffman identified three types of stigma: abominations of the body, blemishes of individual character and tribal stigma. Abominations of the body include the various physical deformities that constitute a visible stigmatizing mark. Individual character blemishes include any personal characteristics that are perceived as deviant by the dominant society or culture. Examples that are common in western culture include addiction, mental illness, homosexuality, and unemployment. Tribal stigmas are the stigmas of race, nation, and religion that are transmitted through lineages and equally contaminate all members of a family or group. There is an obvious intersection between Goffman's theory and the stigma that Aboriginal peoples have historically experienced as members of an identifiable group.

HIV infection continues to elicit a level of negative judgement and blame to an extent not seen in any other disease condition (Lawless, Kippax & Crawford, 1996). The high level of stigma related to HIV/AIDS is a feature of the disease and has significant consequences socially, psychologically, and physically for people at risk for or infected with the virus.

It is apparent from the above description that Aboriginal women who are living with HIV/AIDS are stigmatized in multiple ways. Dominant society characterizes them as "...all purpose deviants..." (Sandelwoski, Lambe & Barosso, 2004). They are stigmatized as a result of their race and cultural identity, their positive diagnosis and the

poor health and physical changes that are a result of disease progression, their gender, their risk to their sex partners and unborn children, and their subordinate and subjugated position within society. In addition, Aboriginal women who are poor, are street involved, and/or have substance misuse issues bear an additional burden. Their experience of stigma is reinforced by other forms of discrimination and finds its roots in their history of oppression, racism, and colonization (Canadian HIV/AIDS Legal Network, 1999).

The Influence of Stigma on Living with HIV/AIDS

Stigma has a profound impact on the health of individuals who are living with HIV/AIDS. Stigma or fear of stigma prevents people from being tested for their HIV status (Barth, Cook, Downs, Switzer & Fischkoff, 2002). Many people living with HIV/AIDS (PHAs) also fear disclosure of their status, which leads many HIV+ people to suppress the fact that they are infected. Research by Green (1995) revealed that fear of stigma was often more real than the presence of enacted stigma, but was no less disruptive in terms of its impact on the social, psychological, and physical well-being of the PHA. Stigma acts to alienate women from seeking care (Trzynka & Erlen, 2004). In the later stages of the disease, fear of stigmatization by health care workers leads many PHAs to delay accessing services until they are too sick to avoid it (Herek, Capitanio & Keith, 2002; Lawless et al., 1996; Taylor, 2001). Social isolation is a reality for many PHAs. Those whose status is not known may choose to limit social contacts in an effort to reduce the chances of exposure as a PHA. For people who are known to be positive, avoidance by people in the general population is a common occurrence (Barosso & Powell-Cope, 2000; Crandall & Coleman, 1992).

The limited research that has focussed on Aboriginal women living with HIV/AIDS certainly bears out these findings. Aboriginal women cite being fearful of being ostracized by their home communities (RCAP, 1996b; Ship & Norton, 2001) and because of this elect to spend their last days far from the support of their families and friends (Schneider, Marsden, Copley, Skaling & Nowgesic, 2000). They tell stories of being treated in a judgemental and discriminatory manner by physicians and other health care providers (Ship & Norton, 2000). They are fearful of getting tested and disclosing their status to their partners and others (Ship & Norton 2000) because they anticipate that they will be rejected or subjected to violence (Nerron & Roffey, 2000). They also express reluctance about accessing needed services because they are afraid of being observed by someone they know (Ship & Norton 2000).

Vulnerability

Concept of Vulnerability

To be vulnerable is, simply put, to be at risk for harm (Spiers, 2000). Traditionally, the definition of vulnerability has reflected epidemiological principles and has been commonly used to describe populations at risk (Spiers, 2000). In general, individuals are labelled as vulnerable if they are known to possess traits that put them at greater risk of poor health such as SES, minority status, or another stigmatizing trait (Spiers, 2000). This has proved to be problematic for two reasons. Firstly, it puts the burden of vulnerability on the group or individual who possesses the trait and secondly, it ignores the broader societal and political forces that construct and determine these traits. A number of commentators (De Guzman, 2001; Delor & Hubert, 2000; Spiers, 2000) have recommended broadening this definition to focus not just on the risk factors that

contribute to susceptibility for disease and poor health but also on an appreciation of the unique lived experience of vulnerability as experienced by an individual. By broadening the definition in this way, the concept of vulnerability is more clearly linked to the forces that contextualize and influence a person's experiences. When this lens is used to describe an individual or group's vulnerability, the focus shifts to the "...consequences of... reduced access to and ability to utilize information and services, powerlessness in sexual and economic relationships, stigma and discrimination, and poverty." (De Guzman, 2001, p. 665).

The Consequences of Vulnerability

Aboriginal women, who have had to cope with a history of subordination and subjugation, and disproportionate rates of poverty, poor health, unemployment, low education, and violence, are unavoidably positioned to experience the effects of vulnerability. There is a definitive link between vulnerability and susceptibility to HIV infection (De Guzman, 2001; Spittal & Schecter, 2001; Zierler, 1997). The stress and anxiety that can result from the experience of being vulnerable can weaken an already damaged immune system (Rogers, 1997). A sense of vulnerability can engender feelings of hopelessness and helplessness, and a sense of powerlessness. Such feelings can lead to self-destructive behaviours such as substance misuse, or a decreased ability to protect oneself from harm (Rogers, 1997). Vulnerability increases the likelihood of negative consequences from substance use (Ministry of Health Services, 2004). There is also evidence that vulnerability affects a person's ability to access and utilize health care services (De Guzman, 2001; Rogers, 1997), which has implications for ongoing treatment and support for Aboriginal women who are living with HIV/AIDS.

Existing Research

The situation has improved marginally since the Aboriginal Nurses Association of Canada (ANAC) noted the complete lack of written HIV/AIDS material specific to Aboriginal women (ANAC, 1996). ANAC led the way with the publication of a study in 1996 that assessed the knowledge, attitudes, and risk behaviours of Aboriginal women in relation to HIV/AIDS. This mixed methods study utilized a variety of methodologies to provide detailed demographic information related to socioeconomic factors and risk behaviours as well as to uncover knowledge and attitudes about HIV/AIDS. This study focussed primarily on prevention and transmission issues as opposed to the issues of women who are living with HIV/AIDS. Among its recommendations it clearly states the importance of ensuring that control and responsibility for HIV/AIDS prevention, treatment, and care should rest with the Aboriginal community.

Ship and Norton (1999, 2000, 2001) have published a variety of reports based on their research with Aboriginal women who are living with HIV/AIDS and caregivers of Aboriginal people who are living with HIV/AIDS. As with this proposed study, they focussed on the experiences and perspectives of their participants. However, they approached this work with a social worker's perspective as opposed to this study, which has the primary objective of developing transformative knowledge that will help the nursing profession appreciate their role in fostering social justice, incorporating the perspectives and experiences of vulnerable peoples into the fabric of nursing science and practise, and advancing policy issues (Reimer Kirkham & Anderson, 2002).

Ship and Norton (1999, 2000, 2001) conducted qualitative research based on semi-structured focus groups and interviews with First Nations and Inuit women who are

living with, or providing care to people who are living with HIV/AIDS. They have produced the richest data to date in terms of gaining an understanding of the experiences and perspectives of Aboriginal women. They have proposed a number of key findings, including the concept that HIV is a legacy of cultural disruption and residential schooling, that HIV affects women differently from men, that First Nations women experience gender discrimination, that there are multiple barriers to services, that reproductive issues and sexuality are fraught with difficulty, and that First Nations women who are living with HIV/AIDS are socially and emotionally isolated. Ship and Norton (1999, 2000, 2001) note the limitations of their research due to small sample sizes, inadequate pre-testing of interview questions and time constraints. Despite these limitations, Ship and Norton's research is useful in that it clearly situates the experiences of Aboriginal women living with HIV/AIDS within the context of broader historical, political and societal forces, and the need for policy makers and care providers to consider these forces when designing and delivering programs.

Mill (1997) published a qualitative study in which she interviewed eight Aboriginal women in order to understand the cultural factors that relate to HIV infection in Aboriginal women. Her findings revealed that Aboriginal women engage in HIV risk behaviours in order to survive in the face of significant challenges as a result of physical sexual and emotional abuse, turbulent childhoods and addicted parents. This study is useful in helping to create a framework for understanding the context of Aboriginal women's lives.

The final piece of original research which was located was a qualitative study by Mill (2000) which utilized information from open-ended interviews to conduct a

comparative analysis between an explanatory model of HIV illness as described by the participants and the conventional biomedical paradigm of HIV disease. Mill extracted several themes from her findings that are potentially useful for health service design and delivery. A drawback of this study however is that it does not appear that the participants themselves provided input about health services, rather that conclusions were deduced from the women's responses about their beliefs about HIV and illness.

It would be remiss not to mention Dion Stout and her colleagues (1996, 1998, 2001), who have published extensive work about the health of Aboriginal women in Canada. However, although they often mention HIV/AIDS in the context of their work, it has not to this point been the primary focus of their research.

To date, the limited literature that has been published about Aboriginal women who are living with HIV/AIDS has focussed exclusively on their experiences and perspectives about their condition. There has been little published which looks at the experiences of HIV+ Aboriginal women with health care and support services or that identifies the particular issues that Aboriginal women who are living with HIV/AIDS commonly face. Furthermore, the literature produced to date has primarily come from a social science perspective. It is important to bring a nursing perspective to this field of study. As the predominant players in the health care field, nurses are more likely to come into contact with Aboriginal women who are living with HIV/AIDS than any other health care provider.

This thesis will build on previous work by expanding on the findings of Ship and Norton's (1999, 2000, 2001) research into examining the experiences and perspectives of Aboriginal women who are living with HIV/AIDS. Additionally, a more focussed look at

the perspectives of Aboriginal women living with HIV/AIDS in relation to their experiences in accessing and utilizing health care and other related services will hopefully broaden our understanding of what needs to occur to ensure that Aboriginal women get the services that they need to live well with HIV infection. Finally, this thesis will bring a nursing perspective to this field of study. Because of their holistic perspective and client centred approach, nurses are uniquely positioned to produce transformative knowledge that can illuminate the broader issues that affect an individual or population's state of health and well-being.

CHAPTER THREE

Research Design

In this chapter, the research design will be outlined. The theoretical

underpinnings, methodology, study design, research setting, sampling strategies, data

collection methods and procedures, data analysis, ethical considerations, and scientific

quality will be discussed. It is increasingly recognized that Aboriginal peoples have been

excluded from the research process. Steps must be taken to ensure that the research

methods are respectful of Aboriginal women's multiple burdens, allow for Aboriginal

women to attain a degree of participation and control over the research process, and that

opportunities are sought to share the findings with the participants and Aboriginal

organizations with the goal of promoting dialogue and planning future directions (Dion

Stout et al., 2001). The Canadian Aboriginal AIDS Network report (CAAN, 2004), which

outlines the principles of Aboriginal research – ownership, control, access and

possession, will be used to guide the research process. The research design has been

developed to reflect these considerations.

Theoretical Underpinnings

Allen (1999) points out that cultures and cultural differences are constructed and

unless this construction is adequately articulated, social inquiry will inevitably create an

"other", an "outsider", a "not us". In order to minimize the potential for colonialist

appropriation, a post-colonial feminist perspective will inform the research approach of

this study. Brown and Smye (2002) contend that post-colonial perspectives are especially

relevant to research within Aboriginal communities because of the identified and

established impact of colonialism on the health and social status of Aboriginal peoples.

Research has the potential to further colonize Aboriginal peoples (Gregory, 2005). A post-colonial perspective can redress structural inequities and health disparities by redirecting attention to how socially constructed views of "race", ethnicity, and culture continue to create patterns of inclusion and exclusion (Browne et al., 2005a).

Simplistic categories such as race, gender, or sex do not capture the multiple subject positions of women (McCormick et al., 1998). A post-colonial feminist perspective allows for the identification of the multilayered socio-political contexts of health and illness, and for the inclusion of subaltern voices (Anderson, 2000). It allows for the construction of knowledge from the perspective of marginalized women whose voices have been subsumed in the traditional process of knowledge production (Anderson, 2002).

A postcolonial feminist perspective provides direction for research with Aboriginal communities in four interrelated ways. These strategies include:

"...(a) issues of partnership and "voice" in the research process, (b) a commitment to engaging in praxis oriented inquiry, (c) understanding how continuities from the past shape the present context of health and health care, and (d) the colonizing potential of research." (Browne et al., 2005a).

There are a number of criteria that characterize a post-colonial feminist methodology. Firstly, it is important to do "the looking" through a conceptual lens that accounts for the histories of colonization and frames this history within the intersecting forces of gender, "race", class, and socioeconomic status, secondly, the data is interpreted within this contextual framework, and lastly, theory is constructed from context embedded data (Anderson, 2002).

Methodology

Theory and research in the social sciences are increasingly emphasizing everyday life experience, the significance of multiple constructions of reality, and the complexity and ambiguity that are inherent both in everyday life and the research process (Lowenberg, 1993). Interpretive description is a qualitative method that acknowledges the constructed and contextual nature of human experience whilst at the same time it allows for shared realities (Thorne, Reimer Kirkham & O'Flynn-Magee, 2004). This approach is grounded in and appropriate for the generation of nursing practise knowledge (Thorne et al., 1997), and its emphasis on examining the constructed and contextual nature of everyday life makes it a good fit with the post-colonial feminist perspective that frames this project.

Three philosophical criteria underpin the design of interpretive description:

1) Reality is multiply constructed, complex, contextual and subjective and can only be studied holistically.

2) The inquirer and the object of inquiry interact to influence one another and meaning must be constructed through negotiation with research participants as opposed to the researcher imposing meaning on the findings.

3) Due to the probable emergence of multiple realities from the findings, theory must emerge or be grounded in the data (Thorne et al., 2004).

Study Design

This study focuses on examining the experiences and perceptions of HIV positive Aboriginal women. Human experiences are complex and are rooted in a contextualized and constructed reality. A methodology that is capable of eliciting a rich description is

most suited to a study such as this. Qualitative analysis focuses on uncovering knowledge about how and what individuals think and feel about the situations that they find themselves in (Thorne, 2000). It is oriented towards the understanding of cases as opposed to variables, and towards the discerning of the particulars presented by each piece of data (Sandelowski, 1995). Qualitative research attempts to illuminate the universally true by revealing the particular.

Interpretive description is a qualitative research method that can be used to enhance our understanding of how people experience health and illness (Thorne et al., 1997). It is generally utilized for conducting a smaller scale investigation of a clinical phenomenon of interest (Thorne et al., 2004). Sandelowski (1995) contends that qualitative research is focussed on developing deep understanding about information rich cases. The product of interpretive description "...is a coherent conceptual description that taps thematic patterns and commonalities believed to characterize the phenomenon being studied..." (Thorne et al., 2004) as well as to account for individual variations. A qualitative, interpretive descriptive design is well suited to the research objectives of this proposal.

Research Setting

This study seeks to broaden understanding about the health and illness experiences of Aboriginal women who are living with HIV/AIDS. It is important to talk to women who have had experiences with the health care system. For this reason, participants were sought at an acute care hospital and at a drop in clinic that specializes in services for PLWHAs. The drop in clinic is in a very poor neighbourhood in a large urban centre in a western Canadian province. Approximately 4,000 Aboriginal people

live in this neighbourhood (M. Tyndall, personal communication, Sept. 11, 2006). These settings were convenient for me and participants who fit the inclusion criteria were relatively easy to access.

Sampling Strategy

Qualitative data collection and analysis is demanding and the sample size must be selected with a view towards neither being so large as to inhibit deep, case-oriented analysis nor so small that a richly textured understanding cannot be achieved (Sandelowski, 1995). Interpretive description, with its emphasis on eliciting the constructed and contextual nature of human experience whilst allowing for shared realities, generally builds upon relatively small samples (Thorne et al., 2004). In general, it is recommended that qualitative studies that are directed towards discerning the essence of experiences should include approximately six participants (Sandelowski, 1995). With this in mind, purposeful sampling methods were utilized to recruit eight participants. Table 1 outlines some key demographic characteristics of the participants. Names have been changed to maintain anonymity.

Table 1.

Name	Age	Level of education	Taking ART	Income	Housing
Roberta	43	Grade 8	No	Income assistance	On reserve
Fiona	47	Grade 9	No	Income assistance	None
Cathy	45	Grade 9	Yes	Income assistance	Subsidy
Elizabeth	31	Grade 10	No	Income assistance	None
Justine	45	Grade 12	No	Income assistance	Subsidy
Coralee	47	Some post-secondary	Yes	Employed	Independent
Natalie	38	Grade 12	Yes	Income assistance	Independent
Mary	38	Grade 10	Yes	Income assistance	Subsidy

Brief information sessions were presented to the nurses on the acute care unit and with the staff of the clinic to inform them of the study, and flyers were distributed that described the study (Appendix A). The clinical nurse leaders and primary nurses on the acute care unit and the nurse at clinic were asked to identify and approach potential participants to inform them of the study and provide them with an explanatory letter (Appendix B). They obtained permission from the prospective participant for me to make contact. Three of the participants were recruited on the acute care unit and three of the participants were recruited from the clinic. The last two participants independently contacted me after getting information about the study from a friend who had already participated.

Participants self identified as Aboriginal and HIV positive. Other requirements were that they identify as female, be able to speak English, and be over the age of

eighteen. Additionally, they had to be cognitively capable of understanding the terms of the study and the consent process. The input of the nursing staff on the nursing unit was sought by myself to ensure that the potential participants' illness did not preclude their ability to take part in the study, and to ensure that their participation would not interfere in any way with their ongoing care and treatment. For potential participants at the clinic I relied on the judgement of the clinic nurse to determine those people who were suitable to participate.

Data Collection Methods and Procedures

Qualitative researchers generally hold to the principle that people who have lived with certain experiences are usually the best source of knowledge about those experiences (Thorne et al., 1997). Data for this study was collected via the use of in-depth, semi-structured interviews, which were audio taped and transcribed verbatim. A private room on or near the acute care nursing unit and one of the offices at the clinic were utilized for the five of the interviews. One interview was conducted at the participant's workplace. The last two interviews took place in the participant's homes. Interview questions were broad-based "trigger questions" that were intended to stimulate conversation (Appendix C). The participants' responses were used to generate more in-depth exploration of a particular area. The goal was to encourage participants to talk freely about themselves. A second interview was conducted over the phone with two participants (Coralee and Mary). The purpose of the second interview was to focus on sharing the preliminary analysis of the findings with the participants. It was assumed it would add depth to the analysis by enabling the participants to contribute to the construction and validation of meaning and the extension and clarification of existing

interpretations ((Irwin, Thorne & Varcoe, 2002). Involving participants in this way is an

important feature of interpretive description (Thorne et al., 2004). Giving voice to

participants in the development of the findings is also an essential element in postcolonial

feminist scholarship, which demands that researchers mediate "…between people's

understandings and the need for ideological critique and transformative social action

without becoming impositional." (Reimer Kirkham & Anderson, 2002). Unfortunately,

due to the chaotic lives of many of the participants, and the deaths of three of them during

the course of the research it was very difficult to conduct follow up interviews. The lack

of opportunity to conduct second, follow-up interviews is a limitation of the study.

Detailed and accurate field notes are essential for the success of a qualitative

study (Morse & Field, 1995). Field notes were recorded immediately after the interviews.

The notes served four purposes. Observational notes provided an objective description of

the event and the conversation. Methodological notes were utilized to reflect on the

interview process and provide instructions and reminders about the conduct of

subsequent interviews. Theoretical notes provided a beginning interpretation of the

meanings of the interaction. Reflexive notes contained comments about my own feelings

during the interview process (Polit & Hungler, 1995). Reflexive notes were an important

venue for recording early hunches and possible biases that I became aware of during the

course of the study. It is important to keep track of these impressions because it is

essential to account for them as analysis proceeds (Morse & Field, 1995).

Data Analysis

The purpose of data analysis is to extract meaning from the data set and rebuild

and present the processed data set in a thematic or conceptually relevant whole (Knafl &

Webster, 1988). Data analysis in interpretive description involves moving beyond the theoretical framework towards an abstracted interpretation that will illuminate the phenomenon that is being investigated in a novel and meaningful fashion (Thorne et al., 2004). In qualitative work such as this, the stages of analysis are non-linear, with data collection and analysis occurring concurrently. Data analysis in the interpretive descriptive tradition requires an immersion in the narrative accounts to develop themes within each account and through constant comparison, a description of the patterns between and among the narratives (Irwin et al., 2002). The two main tasks in data analysis utilizing interpretive description are the identification of themes within coding categories and identification of themes across coding categories (Gillespie, 2002).

As the data was gathered, the interview transcripts were read repeatedly to identify recurring, converging, and contradictory patterns of interaction, key concepts, emerging themes, symbolic examples from the data, and possible connections to the underlying theory. As the data was reviewed, emerging concepts and themes were developed, and used to categorize and code the data. As each transcript was coded, I compared them to identify similarities and differences. Discrepancies are useful for identifying areas for further exploration and possibly for the development of new coding categories (Anderson et al., 2003). As coding progressed, categories were expanded or collapsed to reflect the developing picture. This flexible and evolving process is a hallmark of qualitative analysis (Sandelowski, 1995). Emerging themes and categories were reviewed and compared and taken to a higher level of conceptualization with the aim of developing broader theoretical constructs. At this point, the data, concepts and themes that had arisen from the analysis were reviewed with two participants in a second

interview. The insights and feedback from these participants were incorporated as analysis continued. The input of participants in the construction of meaning is an essential component of the interpretive descriptive approach (Thorne et al., 2004).

Although current knowledge forms the basis for a preliminary analytic framework, it is important to develop distance from it as the analysis progresses and alternate concepts and themes arise (Thorne et al., 2004). The field notes were particularly useful in helping me to maintain distance. Writing and reviewing the notes as data collection and analysis proceeded assisted me in identifying my own feelings, values, and perceptions in relation to the findings, and reoriented the analysis to focus on constructing the knowledge from the perspective of the participants. This was very important because I have a long history of working in an inner city emergency department and have met many women who live lives of marginalization. It would have been easy for me to make assumptions about the challenges that the participants faced.

An expert informant was utilized to provide feedback and perspective as the analysis progressed. The expert informant was an Aboriginal woman who works in the field of Aboriginal HIV/AIDS and hepatitis C prevention. In addition to the expert informant, feedback was sought from a discussion group at an Aboriginal HIV/AIDS conference [2] that takes place in western Canada where the findings were reviewed. The discussion group comprised 12 people of both Aboriginal and non-Aboriginal descent. All were working as health care providers or support workers in the field of HIV/AIDS. The group were very receptive to the findings and indicated that the findings resonated

2. This conference is organized by a provincial organization that provides support services to Aboriginal persons who are living with HIV/AIDS. The name of the organization has been withheld to preserve anonymity.

with what they knew to be true and had personally witnessed or experienced. In addition, they provided some helpful advice on recommendations and dissemination of the findings.

Ethical Considerations

The use of face-to-face interviews makes anonymity impossible to ensure for the participants. For this reason, I made every effort to ensure that identities remained confidential and that the use of context-embedded descriptions in the report of findings did not allow for identification of informants. Specific strategies to protect the participants' identities included the use of a unique code number for each person on all data sheets, avoidance of identifying participants on transcripts and analytic memos, and the use of fictitious names in the final report. The audiotapes, codebook and all transcribed interview data were maintained in a locked file cabinet. In accordance with university policy, they will be retained for at least five years after the conclusion of the study. If the data is disposed of after this time, all paperwork will be shredded and audiotapes erased.

Potential participants were identified by the acute care nursing staff and the clinic nurse and were approached by them to seek permission for me to discuss the study with them. I approached potential participants to describe the study and the consent process only when prior permission had been obtained.

I obtained written consent from all the participants prior to the interviews (Appendix D). The consent form was reviewed by the participant, and myself and understanding of the study, its implications, and possible effect on the participant was verified prior to the participant providing signed consent. Consent should be viewed as an

ongoing and transactional process (Wax, 1982) and with this in mind, consent was verified verbally and on an ongoing basis with participants as the interviews progressed.

Ensuring Scientific Quality

The production of quality research can only occur within the context of validity or trustworthiness (Field & Morse, 1995; Vezeau, 1994; Whittemore, Chase & Mandle, 2001). Whilst it is commonly accepted that qualitative research must achieve the benchmark of validity, what is less clear is the validity criteria that are utilized to attain this benchmark (Whittemore et al., 2001). Qualitative research utilizes an interpretive perspective as opposed to a positivistic approach and this has led to continued discussion and dispute about what constitutes sound validity criteria. The challenge is to balance the creativity that is necessary to an artful and sensitive approach to meaning with the quality of the science (Sandelowski, 1993). It is also important to remember that the field is not neutral. It is a negotiated site of historically located yet shifting researcher and researched subjectivities (Reimer Kirkham et al., 2002). Although ultimately the evaluation of a research project is a matter of judgement on the part of the researcher (Sandelowski, 1993), evaluating scientific quality in qualitative research necessitates making a decision on the utilization of a set of established criteria.

For this study, a contemporary synthesis proposed by Whittemore et al. (2001) was utilized. They propose that validity is illustrated through the explication and differentiation of primary criteria, secondary criteria, and techniques. Primary criteria are necessary to all qualitative inquiry and include credibility, authenticity, criticality and integrity. Secondary criteria are more flexible and differ depending on the particular investigation but for a study such as this, which portrays an emic perspective within a

historical, social and political culture they recommend that the secondary criteria of sensitivity, explicitness and vividness should take precedence. Techniques refer to the methods that are employed to demonstrate or assure specific validity criteria. Underpinning all of this is the concept of reflexivity, which is considered integral to qualitative studies (Dyck, Lynam & Anderson, 1995).

Credibility

Credibility is attained through a conscious effort to establish confidence in an accurate interpretation of the meaning of the data (Carboni, 1995). This study utilized a number of methods to enhance credibility. Concurrent, comparative analysis allowed for ongoing checking of the representativeness of the data, coding categories, and emerging consistencies and discrepancies. Validation through the use of a second interview enhanced and expanded the construction of meaning. Utilizing an expert informant was helpful in aiding me to attain some distance from the data, as it is inevitable that the closeness of the researcher-participant relationship and immersion in the data impacted on my ability to separate my own experiences from that of the participants. The expert informant also played the role of "thoughtful clinician" (Thorne et al., 2004). Her knowledge of the lives of Aboriginal women who are living with HIV/AIDS enabled her to provide relevant feedback on the plausibility of the findings. The discussion group at the Healing our Spirit conference also provided valuable feedback on the findings and potential utilization of the data.

Authenticity

When a study presents the descriptions and interpretations of a human experience in such a way that they are recognized by people having that experience as their own it is

considered authentic (Sandelowski, 1986). It is essential to remain true to the phenomenon under study (Whittemore et al., 2001). In studies that utilize an interpretive perspective, there is an inevitable and in fact, necessary interaction between the researcher and the researched. Involvement of the inquirer can influence the ability to speak authentically for the experience of others and conscious attention is required to appreciate the influence of the researcher. A number of strategies were employed to address this criterion. I kept field notes throughout the collection and analysis phases and this allowed me to reflect upon and respond to issues that arose as the study unfolded as well as to achieve a clearer appreciation of how the my positioning impacted on and influenced the process and the findings. The use of a second interview and an expert informant was key in checking and validating the findings and ensuring that the voices of the participants were heard and adequately portrayed without distortion or bias.

A potential limitation to authenticity was the use of a hospital and clinic setting to recruit and interview participants. This had the potential to limit the sample to a certain group of women who have similar challenges that have led to treatment for an acute illness. Additionally, the hospital and clinic environment, which were busy and demanding, may have limited the participants' ability to speak freely and without constraint, even with the use of a private and quiet interview area. The last three participants addressed this concern to some extent. All three of them were interviewed outside of the context of a health care facility, one at her place of work and two in their own homes.

Criticality

Evidence of critical appraisal is necessary for a sound research design (Whittemore et al., 2001). In the process of data collection and analysis, the researcher needs to be critical in the search for alternative hypotheses, negative instances and the explicit accounting of biases (Sandelowski, 1986; Thorne et al., 1997; Thorne et al., 2004). The practise of concurrent, comparative analysis was useful in identifying similarities and discrepancies that were arising in the findings. In addition, reflexive field notes were written and reviewed on an ongoing basis to quickly identify the underlying biases that I brought to the study. Observational and methodological field notes were useful for establishing a definitive trail that explicates the process of collection and analysis. A responsible and substantiated scientific process is integral to the demonstration of criticality (Whittemore et al., 2001).

Integrity

Qualitative research is subjective and the unique interpretation that the researcher brings to the data is an essential ingredient in the process, but integrity must be evident to assure that the interpretation is valid and grounded in the data (Whittemore et al., 2001). It is important for the researcher to be self-critical and to seek integrity at each phase of inquiry in order to ensure that uncritical verifications and dogma are averted (Johnson, 1999). As with criticality, integrity is represented through recursive and repetitive checks of interpretations (Whittemore et al., 2001). In this study, this was addressed through the use of concurrent comparative analysis, a second interview, an expert informant, field notes and reflexive notes.

Reflexivity

Reflexivity is a tool for analyzing how subjective and intersubjective elements influence the researcher (Finlay, 2002). It involves a process whereby the researcher engages in an explicit and self-aware analysis of their role in the study. This personal analysis needs to be purposeful and primarily focused on the participants and the data as opposed to being a navel gazing exercise (Finlay, 2002). The ultimate goal is to capture the connections and influences that the researcher and the participants have on each other and an awareness of how meaning is constructed within this context. Research is an essentializing process (McCormick et al., 1998). It is important for the researcher to give voice to the participants in a way that addresses the social, political and economic context in which they live without setting them apart as "the other". In this study, reflexivity was enhanced by a process of data collection and analysis that was framed within the theoretical perspective that underpins the study, a consideration of the existing knowledge that was revealed in the literature, and the use of field notes and a key informant to aid me in locating myself in relation to the participants.

I am acutely aware of my positioning as a privileged, middle class, white health care professional and the influence that my perspective has on the findings. Bringing a postcolonial feminist perspective to the work is a strategy for addressing this challenge. It allowed me to begin from the standpoint of the participants and locates the findings within their material and local world. It allows the participant to speak rather than to be spoken for (Reimer Kirkham & Anderson, 2002).

It is important to ensure that the "voice" of the participants is central in the research process (Reimer Kirkham & Anderson, 2002). I addressed this by trying to give

the participants space to freely express themselves within the limitations of a semi-structured interview. Although a price was paid to some extent in that the interviews did not consistently address the same issues, which made analysis more challenging, the women were able to speak to the issues that were most important to them. In addition, follow up phone conversations were held with two of the participants to verify that the findings that I was uncovering resonated with them. The expert informer was also very helpful in providing feedback as the data collection progressed.

A commitment to praxis-oriented inquiry necessitated me becoming aware of how my interpretive perspectives were informed and shaped by the wider social discourse. As a member of the dominant culture, it is difficult to completely disassociate oneself from the mainstream thinking about Aboriginal women as dependent, marginalized and entitled. Utilizing a post-colonial feminist perspective enabled me to frame my approach in a way that took into account the multilayered social and political contexts that influence these women's lives.

A postcolonial feminist perspective must also take into account how past and present social, economic, and political forces shape the lives of Aboriginal women (Browne & Smye, 2002). The data collection process was directed at assessing how these forces had affected the lives of the participants. In addition, I utilized literature that addressed the historical context, heath status, socioeconomic factors, stigma, and vulnerability to frame the interview process and data analysis.

Although most research which is conducted with indigenous peoples is well-intended, there has been an inevitable outcome of distancing and "otherness" which is inherent in a process whereby a White researcher attempts to gain understanding of

another culture (Browne et al., 2005a; de Ishtar, 2004). This can have the effect of further colonizing already colonized peoples. de Ishtar talks about the importance of building a bridge towards collaboration. I approached this project with an awareness of the importance of avoiding essentializing the lives and experiences of the participants. Strategies that were utilized to minimize the colonizing effect of the research and build bridges included involving some of the participants in the analysis process, utilizing an expert informant who was Aboriginal herself, asking for input from an Aboriginal HIV/AIDS conference discussion group (which included leaders and clinicians with expertise in Aboriginal health and HIV/AIDS) about how to present the findings and what to do with the findings, and developing recommendations that require the active involvement of Aboriginal peoples in both planning and implementation.

CHAPTER FOUR

Findings

It is important to take the time to listen to people's life stories if you truly want to understand their experiences, the reality of their lives and how they see themselves in relation to the world at large. The purpose of this research project was to pay heed to the stories of Aboriginal women who are living with HIV/AIDS in an effort to understand the social context of their unique lives and their experiences and perceptions in relation to their HIV + status and how the health care system helps or hinders their ability to live with this illness.

The eight women who were interviewed were unique in their abilities to tell their story. Some were exceptionally articulate in relating how their HIV+ status has shaped their lives and experiences and were open and willing to share their stories. Others were more reticent, exhibiting reluctance in talking about how HIV/AIDS has affected their lives. They all expressed considerable emotion about how HIV/AIDS has affected their lives – fear, anger, self-blame, laughter, hope and hopelessness, and sadness were common to them all.

A close and repeated analysis of the data revealed five broad themes common to all eight women. The first of these, "fear of rejection", was unsurprising given the consistent and overwhelming findings in the literature about the experience of stigma for PHAs. The second theme, "looking for friendship", is also not an unexpected finding. The literature clearly reveals that isolation is common for PHAs and Aboriginal women, who are often vulnerable due to their SES, the effects of colonization, their gender, and their ethnicity, are at greater risk of isolation. The third theme, "strength in the face of

adversity", was a finding that reflected the women's strength and resiliency in the face of tremendous hardship. There has been a consistent and objectifying discourse that defines Aboriginal women as victims without agency (LaRocque, 1993). This finding turns that discourse on its head and points the way to future policy and program planning which looks to women's strengths instead of their weaknesses. The fourth theme is "the struggle to stay well". A number of the participants had AIDS related infections and experienced difficulty in accessing health care services as and when they needed them. The final theme is that "HIV/AIDS is just one problem among many". This reflects the reality of the women's lives and the challenge of living within a social, economic and political context that has a significant influence on their ability to stay well. Taken together, these five themes indicate the complexities of living with HIV/AIDS, which is marked by the intersecting forces of discrimination, poverty, violence, substance use, gender inequity and isolation but is also characterized by an attitude of resilience.

This chapter will open with a demographic description of the participants. Knowledge of their lives provides important context for the interview findings. All of the women identified as either First Nations or Metis. The description will be followed by a detailed discussion of the five major themes and their associated concepts. The descriptions have been rendered anonymous with regards to name, place of origin, nation affiliation, illnesses and present residence in order to protect the participants.

A Brief Description of the Participant's Life Circumstances

Roberta

Roberta is a 43-year-old First Nations woman who lives on a rural reserve. She did not claim affiliation with any particular nation, just naming the reserve that she lived

on with her male partner. She had three children but she had lost contact with them as they were all placed in foster care at birth. Roberta lived in a poor neighbourhood of a large western Canadian city as a teenager and into her early thirties. She stated that these were her lost years when she was actively addicted to heroin and cocaine and turned to sex trade work to support her habit. She tested positive for HIV at the age of 34 after a series of illnesses. Following her diagnosis she moved back to the reserve where she lived with her partner. Her family was for the most part unaware of her diagnosis. She was admitted to the hospital for an AIDS related illness. She claimed to have a supportive GP but she was not on ART despite her compromised immune system. Roberta died of an AIDS related illness three months after I interviewed her.

Fiona

Fiona is a 47-year-old woman who identified as First Nations. She was originally from a rural reserve in a western Canadian province. She lived in a large western Canadian city for over 20 years and was an active substance user for most of this time. She lived on her own in subsidized housing and maintained infrequent contact with her two teenaged children. Fiona was actively addicted to crack cocaine and injection cocaine and heroin and had recently been in recovery but relapsed shortly after release. Fiona discovered she was HIV positive in 1997 after enrolling in a study about injection drug users. She was on ART but had a detectable viral load [3]. Her chaotic lifestyle made adherence to her medications impossible. She was admitted to hospital with

3. In order for ART to be successful in controlling HIV progression, the viral load must be suppressed to an undetectable level.

a serious respiratory infection and died in the ICU of respiratory failure, four months after the interview, having never been discharged from the hospital.

Cathy

Cathy is a 45-year-old First Nations woman who grew up on a reserve in a rural area of a western Canadian province. She moved to another western province when she was a teenager, first in a northern town and more recently in a large city in the south. She related a history of having abusive and addicted parents and left home at the age of 15 to escape the abuse. Consequently, she entered into a relationship with an older man in a northern city who also turned out to be abusive. She left him nine years ago along with her four-year-old child. Her child is now 13 and is in foster care because she feels unable to care for him due to her ongoing addiction issues and her recurrent AIDS related illnesses. She continues to battle profound fatigue and recurrent vaginal yeast infections. She has been on ART but has difficulty taking her pills and maintaining a suppressed viral load due to the challenges of her life. She is on income assistance and lives in a large western Canadian city.

Elizabeth

Elizabeth is a 31-year-old First Nations woman from a reserve in the northern region of a western Canadian province. She has lived in a variety of communities and had an unsettled and transient childhood. She has very limited contact with her family. She has two young children, both of whom are in the care of a relative. She has an on again, off again relationship with her HIV+ partner and relates a history of physical and emotional abuse. She is actively addicted to crack cocaine and engages in sex trade work to support her habit. She discovered her HIV status from prenatal testing four years ago

and thinks that her seroconversion was related to unsafe sexual behaviour while she was intoxicated on crack cocaine. Due to her erratic lifestyle, she is not on ART despite having had a CD4 nadir of 100, which is below the threshold for starting treatment. She is having problems with recurrent vaginal yeast infections and fatigue but has not yet experienced a significant opportunistic infection. She is presently estranged from her partner and has no stable housing.

Justine

Justine is a 45-year-old woman who identifies as Metis. She grew up in a western Canadian city in an abusive household. She graduated from high school, got married and had two children, who are now 23 and 22 years old. She remained in occasional contact with her children although she lost custody of them due to her addiction. She divorced her husband 18 years ago when she started having problems with addiction and at the time of the interview was not in a relationship. She was diagnosed with HIV 10 years ago but was reluctant to disclose the possible mode of her infection. She had been admitted to hospital several times for opportunistic infections and was recently admitted to acute care with non-Hodgkins lymphoma, which is an infection that is indicative of a severely compromised immune system. She was briefly on ART when she was first diagnosed but discontinued treatment because she did not like the way it made her feel and she found it difficult to be adherent while still using drugs. She lived on her own in subsidized housing and relied on disability for her income. Three weeks after the interview Justine died from advanced lymphoma.

Coralee

Coralee is a 47-year-old First Nations woman from a reserve in the northern region of a western Canadian province. She spoke of a happy childhood with a stable upbringing. Both her mother and father were employed and were able to provide a secure and loving home for their six children. She is in fairly close contact with her parents and three of her siblings. She had a child at the age of 18 whom she gave up for adoption. She was married at 19 and had another child who is now an adult. She is in close contact with the child she raised but only very rarely communicates with the child who was adopted. Her husband left her 12 years ago and it was two years later that she contracted HIV whilst engaging in unprotected sex with an abusive partner. Coralee was unique in that she was the only participant who had any kind of post-secondary education and was employed. She has been married twice and stated that her second marriage was abusive. She has a full time job and lives independently with her partner of two years.

Natalie

Natalie is a 38-year-old First Nations woman originally from a rural reserve in a western Canadian province. She is the 2nd youngest of a very large family. She is in infrequent contact with a number of her siblings, all of who live in another province. She was removed from the family home at the age of 11 when her elder sister became concerned about the ability of her parents to care for her due to their age and alcohol addiction. She spent five years in foster care, which she described as "nice". It was a stable and structured environment that she feelt gave her some life skills that she draws on to this day. At the age of 16 she returned to the reserve. She was able to complete high school but soon began having problems with alcohol and drug use. Natalie had five

children. One died at a young age. Her eldest child is in the care of her ex-husband, two children are in the care of her ex-partner and her sister adopted her youngest. Natalie made the decision to relinquish responsibility for her children because she feels that her continued drug addiction leaves her unable to adequately care for them. Natalie lives on her own in an apartment in a western Canadian city. Despite her crack addiction she is able to pay her rent and bills with assistance from her ex-partner, and with the judicious use of food banks she maintains a good level of nutrition. She sees her two of her children on a regular basis and has a good relationship with her ex-partner. She is on ART for her HIV infection but has a detectable viral load. Her continued crack use makes it difficult for her to maintain the adherence necessary to reduce her viral load to an undetectable level.

Mary

Mary is a 38-year-old woman from a rural reserve in a western Canadian province. She identifies as First Nations. She comes from a large family. Her parents are both dead. Mary describes her childhood as very poor. Her father was a hunter and they lived a subsistence lifestyle in a rudimentary log cabin. At the age of 13 Mary moved to an urban setting in southern BC to live with an elder sister and attend school. She left school after grade 10 and has been on her own ever since. Her family all live in another province. She found out she was HIV+ 18 years ago during prenatal testing. She attributes her infection to unprotected sex with an injection drug-using partner. She has never used injection drugs. Mary has two children – a teenager who lives in another province with relatives and a young child who lives with her and her partner. Mary lives in a subsidized apartment. She is on ART and has an undetectable viral load.

Themes

The review of the literature revealed that many Aboriginal women live lives that are contextualized by a history of colonization and its attendant issues of racism, powerlessness, gender inequity and loss of cultural identity. The themes that arose from my interviews with the participants reflected these realities. Many of the women also lived lives that are challenged by extreme poverty, abuse, substance use and vulnerability. The women for the most part live in a reality that is circumscribed by intersecting social and economic forces. They struggle to stay well in spite of the many challenges they face.

Fear of Rejection

The women in this study consistently related experiences of being stigmatized and expressed a level of fear of rejection that I have not witnessed in any other HIV + individuals in my care over the past twenty-three years. My interview field notes reveal that when the women talked about these experiences they were angry, sad and often expressed a sense of fatality, as if they deserved it. Follow up phone contact with Coralee and Mary and the Aboriginal conference discussion group validated the experiences expressed in this theme. Both Coralee and Mary confirmed that fear of rejection had a significant influence on the way they lived their lives, including who they disclosed to, who they associated with and where they lived. In her first interview, Coralee talked about how she chose to live in a large western Canadian city, far from her family, because it was "safe." Her safety perception was to a great extent a reflection of her sense of risk around the possibility for experiencing rejection. The women manifested

fear of rejection in a number of ways, including feelings of being judged, guilt and

shame, keeping a secret, and stigmatizing experiences.

Feelings of being judged.

People who possess a characteristic that they or society at large perceive as being

abnormal or abhorrent are sensitive to the experience of judgement by others. Fiona

talked about how she was afraid to disclose to health care workers because of fears of

how they would treat her if they knew. "I think that's what I'm afraid of like to find out."

Elizabeth related her experience of being in hospital after a miscarriage. "...I told them I

was HIV positive, pregnant, they just, they were so cold." Justine talked about how

"...we're mainly labelled as the drug addicts and the prostitutes and the unworthy, right?"

Coralee, who had no history of substance use or sex trade work, mentioned the difficulty

of countering the assumptions of people she came into contact with about her lifestyle.

"They think if you are HIV+ you must be a drug user or a prostitute." A number of the

participants indicated that they avoided health care encounters in an effort to reduce their

negative experiences. They were aware that they would need to disclose their HIV status

in a health care setting and they were fearful that if they did so that they would encounter

judgemental and discriminatory behaviour. As Cathy stated, "Why should I put myself in

that position? I know what they're going to say and what they're going to do. That's why

I only go to [specialty clinic] or [drop-in clinic]. I don't go to the hospital until I'm

practically dead." All of the women related instances of overt judgement and criticism

but their avoidance of situations where their HIV status would need to be discussed

indicated that fear of judgement seemed to be as profound as the actual experiences of

being judged. This was also reflected in the findings from Green's (1995) research, which

revealed that fear of stigma was often more real than the presence of enacted stigma, but no less disruptive to the social, psychological and physical well-being of the PHA.

Guilt and shame.

For the participants, the sense of guilt and shame was profound. Roberta found it so difficult to express her feelings about her HIV diagnosis that she could not stop crying. She was completely unable to talk about the experience, merely stating it was "...too difficult..." to recall and made her "...feel bad." I was concerned that she would be unable to continue with the interview due to her distress but upon being asked she stated that she would continue although she indicated that she was uncomfortable talking about her HIV status specifically. When I asked her why it made her so upset to talk about it she stated it was because it made her feel "...so ashamed." Elizabeth talked about how the worst thing about her diagnosis was "Knowing that I ruined other people's lives, that's really huge." Living with the guilt was "...one of the huge reasons why I keep going back to my [abusive] ex." Coralee expressed self-blame in regards to her diagnosis. Despite the fact she was sexually assaulted, "...mostly I felt like I was to blame...I knew all about HIV. I should have known better." Mary talked about how when she received her diagnosis she didn't want to get any follow-up. "I didn't want any kind of help, you know, I was too ashamed..." The interview field notes revealed that the women consistently expressed a sense of fatality and deservedness about contracting HIV infection. They perceived their infection and illness as being somehow inevitable. Despite her emotional response when she spoke about her HIV status and the obvious effect it has had on her emotionally, Roberta talked about how she felt "nothing" on receiving her diagnosis. She wasn't surprised – she indicated that it was just another

challenge in an already challenging life and she felt it was her punishment for her lifestyle.

HIV is a physical disease that is embedded in a moral context (Hodgson, 1997). Like all PHAs, the women have learned that society at large views HIV+ individuals as being deficient. A number of the women made self-blaming statements that indicated that they held themselves accountable for their condition. For instance, Cathy talked about how it's "...all my own fault. It's what I get for doing crack." For Aboriginal women, there is an additional layer of judgement. LaRocque (1996) talks about how the internalization of the dominant society's view of Aboriginal peoples can lead to shame and rejection of oneself. "Internalization occurs when a colonized group begins to judge itself by the standards of the colonizing society." (1993, p. 77) For the women, HIV infection is just another manifestation of their inadequacy as persons. This is compounded by the connotation of guilt and sin that is a familiar discourse for HIV infected women (Sandelowski et al, 2004).

Keeping a secret.

Disclosure of HIV status is difficult. Although Cathy claimed that she didn't care if people knew about her HIV status all of the participants, including Cathy, were very selective about whom they told and under what circumstances. Fiona, who was seriously ill with a life-threatening infection, had told no-one outside of the health care setting. "And right to this day nobody, none of my family knows. Not even my mother." She has kept it a secret because she is fearful of the reaction she will get and potential rejection by her family. "...it's been my secret for so long, it just is a part of me." She is also reluctant to disclose to health care providers because of the potential for involuntary disclosure.

She is very concerned that they will disclose her status to co-workers and patients without her consent. "I don't know because like when they ask me if I have, I just say look in my file, you know, because sometimes they ask me in front of a whole bunch of people." Her fears are well founded. There is ample evidence in the literature about the negative responses that health care workers exhibit towards PHAs (Lawless et al., 1996; Malcolm et al., 1998) and the potential for the PHAs status to be disclosed in an indiscriminate manner (HIV/AIDS Legal Network, 1999).

Roberta has told no one with the exception of her GP and her partner because she is so fearful of the response. Reserve communities are for the most part small communities. PHAs fear that their HIV status will not remain confidential and that they will be humiliated as a result by community gossip (LaRocque, 1993). Coralee's experience exemplifies this. She was initially open about her diagnosis but negative experiences have changed her strategy. She told me that her parents were ostracized in her reserve community "...and they requested I stop talking." Justine also talked about the difficulty of disclosing HIV status in reserve communities. "...it's very difficult to go in to see [a health care provider] when you're on a small reserve...because gossip runs very high..." With the exception of Roberta all of the women spoke about the difficulty of returning to their reserve communities. In most cases the primary health care worker is a band member and there was little confidence that their confidentiality around their HIV status will be maintained.

As discussed in chapter two, stigma is a social construct. In our search for self-identity, we use the concept of "other" to define ourselves (McLachlin, 2003). An inevitable outcome of this is that we look to create a category of "normal" which depends

on some kind of consensus about what it means not to be normal (Paterson, 2005).
Persons who possess an invisible discrediting trait such as HIV infection typically spend
a great deal of time struggling with decisions about who to tell, how to tell and when to
tell in a effort to avoid judgement.

Managing disclosure is a classic strategy in relation to HIV status. Sandelowski
et al. (2004) have noted in their research that women manage this issue by controlling
whom they disclose to and by selective concealment of their infection. The eight
participants represented a continuum of disclosure from Cathy, who claimed to be very
open about her HIV infection, despite the negative responses she has experienced, to
Fiona and Roberta, who are very secretive about their status. Persons who possess a
discredited trait will attempt to pass as normal, and when the secret can no longer be kept,
will seek out "the own" and "the wise" (Goffman, 1963) – those people who share the
trait and sympathetic others such as health care workers, to support them. All of the
participants spoke about selectively sharing their secret with their HIV+ friends and
selected family members. Elizabeth talked about the problems that resulted from
disclosing her status. "I keep it a secret but my mother doesn't...I have strangers coming
up [and asking] is it true...[did you] give AIDS to [your] kids." For the most part they
only told health care workers when they had to. Most had learned the hard way that open
disclosure was a risky endeavour.

Stigmatizing experiences.

Enacted stigma becomes an issue when the community at large knows the
discredited trait. The stories about enacted stigma that the participants experienced were
many and varied. Cathy, who was the most upfront about her status, stating "...I don't

really give a shit how people are going to react to me..." was very articulate about her experiences:

> Oh yeah, I have family members that won't even let me play with their kids. Yeah, I have people who, um, don't even want to touch me, I have, I have doctors who won't even let me in their office because they figure I'm going to infect everything, infect their whole staff members.

Elizabeth talked about what happened to her after her daughter was born and a nurse disclosed her status in front of some other patients and their visitors.

> And the nurses and everything, they didn't even care, they just blurted everything out right in front of everybody else...and right away they threw it an AIDS case, look at what you did to your kid, you know, how can you live with yourself, what kind of fucking woman are you to have kids in the first place, you know, you shouldn't even have sex.

Although the nurse probably did not intend to be judgemental, the involuntary disclosure of Elizabeth's status in front of patients and visitors left Elizabeth feeling negatively judged.

Justine spoke at length about the stigma that is present in reserve communities. "You know, they're still lying on bands about people dying with this disease, you know, they're still saying well if we bury them on our lands they'll be contaminated." Research by Health Canada (2003) reveals that there is a persistent lack of knowledge in the general community, especially amongst persons with lower incomes and less education, about how HIV is transmitted that adds to the stigmatization of PHAs. A significant proportion of the population still believes that HIV can be transmitted through casual

contact and the association of HIV with sex and injection drug use only adds to the negative connotations that living with HIV raises. This is augmented by the denial, rejection and fear of HIV/AIDS that is found in many reserve communities (Health Canada, 1996; Ship & Norton, 2003).

Natalie talked about the negative experiences she has had with her family. "Very judgemental, very judgemental....I mean I can't even drink out of the same cup" and her brother "...thinks I am going to hell." Mary talked at length about her negative experiences with health care workers. "I've had some experiences with health care in the hospitals...when I had my daughter, god. They had big signs saying I was positive and, you know, the whole nine yards, the gown and the mask." This enacted stigma is complicated by the fact that all of the women bear a burden of multiple stigmas that makes their experience extremely difficult. As HIV+ women they are often assumed to be promiscuous and infectious to men and babies (Lawless et al., 1996). Six of the women struggle with substance use, which is a source of stigmatization by society at large. Lastly, all of them are Aboriginal, which marks them as "Other" in the eyes of general society. Cathy expressed it in blunt and uncompromising terms.

Um, I get calls, um, people call me a squaw who has AIDS and, you know, you probably deserve it because squaws all fucking deserved dying, you know, since we can't kill you all off, you might as well die off by AIDS...

Fiona talked about how her Aboriginal identity made her a target for discrimination. "Being First Nations, well...it just makes it worse. People treat you badly." The breadth and depth of discrimination that is contained in these statements reflects the significant judgement that all of the women experienced.

The experience of stigma was a real and ongoing issue for all of the participants. There was compelling evidence that all of the women altered their interactions, changed their social circle, and engaged in covering behaviour in an effort to protect themselves from the profound and negative consequences of being rejected. There was also some evidence that they internalized the stigma. Elizabeth was certain that she had infected her partner although there was no evidence that this was true. Lawless et al (1996) noted this as a common thread in their research about the positioning of HIV+ women. Women tend to appropriate stigma messages because they are not provided with alternative messages that are supportive and non-judgemental and indeed that was true of the women in the current study. With the exception of Coralee, Mary and Natalie, no other participants were able to articulate examples of supportive friends or family members. For the most part, they relied on HIV+ individuals, specialty HIV health care workers and AIDS service organizations (ASOs) for non-judgemental support.

Fear of rejection is almost universal amongst PHAs (Paxton, 2002) but the fear of rejection that the women experienced was complicated by a number of intersecting factors including assumptions around "bad" behaviour such as illicit drug use or sex trade work, the idea that they are polluted in some way, and the risk they pose to others. In addition, the racism that is inherent in the lives of many Aboriginal women compounds the stigma to a significant degree. The fear of rejection is unsurprising when the context of their lives is considered. Most of them have experienced poverty, abuse, and issues around substance use and these factors intersect with their social positioning as Aboriginal women and concomitant racist stereotypes. They have all had first hand experience with rejection on many levels. Their personal and social vulnerability puts

them at great risk for rejection (HIV/AIDS Legal Network, 1999) so their fear is well founded.

Looking for Friendship

All of the women talked about being lonely. They had lost contact with their families, they were unable to maintain ongoing supportive relationships, and most of them were living far from their home communities. HIV/AIDS can be a profoundly isolating condition. Being diagnosed with an HIV infection influences a PHA's social interactions, SES and sense of place in the world at large. As the women described, lack of social support and isolation were dynamics that contributed to their sense of being unloved and lonely.

Lack of social support.

It is well documented in the literature that human connectedness or social support is a buffer for dealing with the challenges of living with HIV/AIDS, particularly the stigma (Barroso & Powell-Cope, 2000; Inkovics et al., 2001; Metcalfe et al., 1998). For the participants, lack of social support was a significant and ongoing barrier. Social support comes in many forms, including health care services, community services and informal relationships with family and friends. In all respects, the women were challenged in their efforts to create a supportive network.

Roberta was unable to name any source of support except "…[my] family doctor. He knows everything about me." As a person living on reserve, with a very real fear of having her infection known to the community at large, Roberta saw the physician as the only person that she could entrust with the secret of her diagnosis. Fiona, who has not told her family or friends about her diagnosis, is reluctant to use AIDS related community

services for fear of people finding out about her status. She relies for support on a casual group of women who don't know her status that she meets at a downtown women's centre. A number of the women talked about the challenges of accessing traditional AIDS related community services due to the predominance of men. Coralee stated, "...I didn't know that the [AIDS support organization] was a gay community [laughter] when I first went there because I was, you know, it was kind of a rude awakening..." Justine talked about how, "There are a few places around here like I said most of them are for gay men" and "...the services are getting better but they're still not there for, um, heterosexual women, they're not." With the exception of a provincial ASO situated in a large urban centre that is specifically for HIV+ women, there are no services that are geared solely to HIV+ women. When I interviewed the women at the drop-in clinic, the disproportionately large number of men in comparison to the few women that were using the service struck me. A number of the participants indicated to me that they avoided the clinic precisely because they felt threatened by the presence of the men.

A few of the women also talked about the differences between living in a large city and in other jurisdictions in terms of the support available. Natalie had lived in a suburban farming community. "I lived there for five years, it's like the bible belt." She was fearful of letting her status be known because of the potential for negative reactions from the community at large and found the local health care providers to be uninformed about HIV/AIDS and judgemental about PHAs. Justine echoed these concerns. "You know what, in [western Canadian city] we have great health care for those who are HIV + but you start going into the suburbs and further out, the health care is the shits, bottom line..." This seemed to be a common concern. All of the women indicated that they lived

in the city because they felt that they were more likely to be able to access appropriate services, both in terms of health care and support.

The lack of social support that these women experienced is of concern because the literature is quite clear about the value of social support for PHAs. Social support has been strongly linked to better health outcomes, improved psychological well-being and adherence to ART (Brashers, 2004; Hough, 2005; Katz, 2005). It was evident from speaking to the women that the fear of rejection that they have experienced has played a role in their inability to find social support, but other factors such as poverty, abuse and substance use have also had an effect. This is borne out in the literature. It is clear that women who face social inequalities have difficulty garnering appropriate social support due to the chaos of their lives, their low self-worth and lack of resources (Inkovics et al., 2001; Ship & Norton, 2001; Zierler & Krieger, 1997). For Roberta, who lived on reserve, there was "...nothing. I just depend on me." But even for the women who lived in the city, social support was sometimes difficult to access. Natalie talked about the challenges of finding transportation "I don't have a car and sometimes I'm just too tired to cope with the bus." Elizabeth, who spent her days turning tricks to earn money for drugs, stated, "I just don't have time for that. I need my drugs more." All of the women with the exception of Roberta were aware of the support services that were available, but their use of them depended on a number of factors, including access to transportation, dealing with abusive and controlling partners, and the ability to control the chaos that was created by their drug use.

Isolation.

As with the lack of social support, there was a clear link between the fear of

judgement and the isolation that most of the women experienced. They were very careful

about who they disclosed to and were consequently very selective about who they looked

to for informal support. All of the women had limited contact with their extended

families. Most of the women lived by themselves. Only Coralee, Roberta and Mary had a

regular partner. Justine talked about the difficulty of maintaining a relationship: "…one

of the partners I had, he sometimes got tired of me coming home and being in bed all the

time." She also talked about the difficulty of establishing a relationship with a man. "…if

you say you have HIV, you just see the fear in their eyes…and I haven't felt like a full

woman to be able to make love to a man…without having to stop, put on a condom…"

She also talked about how the isolation had affected some Aboriginal women in terms of

the risks they took in finding partners. "They're [Aboriginal women] looking for love in

all the wrong places." A negative consequence of the isolation was that it impaired their

ability to extend their social networks. For Natalie the worse thing about living with HIV

was "…the loneliness, it's the loneliness…" The women's sense of isolation is consistent

with findings from the research about living with HIV/AIDS, which reveals that the

isolation can be overwhelming (Barroso & Powell-Cope, 2000).

Isolation is not just physical it's existential. All of the women expressed feelings

of loneliness. The sense of otherness that they had as a result of their HIV infection

inhibited their ability to connect with other people. For example, in their discussion of

women, HIV and stigma, Carr and Gramling (2005) talk about how for women in

particular, HIV infection completely redefines their identity. In an effort to keep their

diagnosis a secret, all of the women in the study cut themselves off from their traditional support systems. Although this may have saved them from rejection, the price, as Carr and Gramling's study revealed, is isolation.

Finding Strength in Adversity

Humans have an astounding capacity to survive in the face of adversity. We all have inner resources that we draw on to cope with the challenges that we face. The personal attributes that the women brought to their lives and the challenges they faced played a significant role in ensuring that they had the strength to go on. The participants, with their humour, outspokenness, faith and flexibility, demonstrated that they have significant inner resources that they draw on to cope with the demands of living with HIV/AIDS within the context of socioeconomic challenges.

Despite the many challenges of their lives, almost all of the women described a sense of facing the future with determination. Each of the women talked about the strategies they invoked to deal with their HIV infection and its consequences in their lives. For example, Justine talked about how "...I chose to fight it..." She was very clear that she would make the decisions about what treatment she would use for her HIV infection, not the medical community. "I tried them [ART] but they were hard on me, it was a reminder every day when I opened my meds cap that I had this disease and I swore I was going to live as normally as possible." The other women all indicated that they had particular strategies that they used to find strength. There were a number of approaches that the women used, including focusing on their children, drawing on inner resources, activism and the use of selected community resources and social supports.

Focus on children.

A striking feature of the women's narratives was how important their children were to their survival. When I asked the women what kept them going in the face of the enormous challenges that HIV/AIDS created for them, the answer was universal – "my children." Although only Coralee and Mary had maintained custody of their children all of the women talked about their children and it was apparent that their children were the most important reason for living. Elizabeth put it the most succinctly – "Even though I don't see my kids, they're the ones that keep me alive." Fiona talked about how she felt when she received her diagnosis. "I wanted to kill myself…but then I just started really thinking about my children and that's what really kept me going." Natalie stated "…you have to keep going…don't give up because I have my boys, even though I don't have them with me, they're with me." For Mary, having her child living with her gives a focus to her life and a reason to keep taking her ART "…I have a child to look after…I have to focus on her…" All of the women spoke lovingly of their children and it was evident to me that they had a true sense of longing to be with them.

The striking way in which the women talked about the significance of the children in their lives reflected the work of Sandelowski and Barroso (2003) who found that motherhood was central to the lives of HIV+ women. In the current study, even for the women who did not have custody of their children, preservation of their identity as mothers was important, which is in keeping with Sandlowski and Barroso's research. Additionally, for these women, their children's health, well-being and security are of far greater importance than their own needs. A number of them spoke about how they wanted their children to be safe and well. Elizabeth commented, "It's hard, but I know

they are safe with my mother. I just hang on to that." This is in keeping with Ship &

Norton's (2001) research of HIV + Aboriginal women. Children are a source of hope and

a primary motivation to find the strength to live with HIV/AIDS (Ship & Norton,2001).

Similarly, in their study on motherhood in the context of violence, Irwin, Thorne and

Varcoe (2002) noted that motherhood helped women preserve their sense of self and lent

them a sense of empowerment and self-worth. In view of the limited access most of the

women had to their children, it is significant that they saw their children as their single

greatest source of strength in the face of adversity. The women did not stop being

mothers just because their children were not physically with them.

Inner resources.

Several of the women alluded to personal resources that they drew on to cope

with the challenges of living with HIV/AIDS. Cathy and Fiona both talked about how

their First Nations identity was a source of strength. Fiona said, "We [First Nations

people] have to be strong, eh. We've put up with so much shit." She looked proud as she

spoke, evidently aware that although her strength was borne out of negative experience it

was still something to value. Her previous experiences with adversity have made her

more able to cope. Natalie referred to how she draws on her inner strength. "Yeah, I, um,

I tell myself that, like Natalie you're a strong person, it's that inner strength that's going

to keep you going…" She has a desire to make the best of things that give her the

strength to deal with the challenges of her HIV infection.

Like many other Aboriginal women in Canada, Coralee, Justine and Natalie lived

in non-native households when they were growing up. For them, the ability to identify

with both worlds has given them a set of skills that are useful for navigating in the world

at large. Natalie talked about how having the "...two different cultures..." made it easier to survive. Justine spoke of how important her mixed heritage was to her. "I just made sure I took care of me, my medicine world, my spiritual, my mental, my emotional...It's important...both sides of my heritage..." She also spoke about the importance of having faith.

> Yeah, I believe in faith, not necessarily religion but believing that there's something out there that keeps me going and there's reasons and we need to learn from the reasons and why sometimes we fail and why sometimes we're successful and actually there's really no such thing as a failure more so it's a success because with each thing we do, while we may categorize it as wrong, if we learn from it it's alright.

None of the women describe being religious in the traditional sense, but five of them alluded to the importance of taking care, as Natalie put it "...of my spiritual side." As with most people, the women needed to reconcile their spiritual, physical, and emotional needs. As Fiona put it, she needed to "...eat well and take care of myself...I try to be with people that make me feel good...I listen to my spirit." Wilson (2005) noted that for Aboriginal people (as with most persons), health is defined as a balance between physical and emotional well-being and spirituality and, in fact she notes that this wellness model is an important component of Aboriginal cultural identity. Most of the programs that the women described that they used in relationship to their HIV/AIDS did not appear to address all of these components, focussing almost specifically on the physical aspects of living with HIV/AIDS. Relying on their inner resources, including strategies to

incorporate their spiritual values, was a strategy most of the women turned to to address the shortfalls of existing healthcare and support programs.

   Activism.

   Not all of the women were involved in activism due to their reluctance to disclose their status, but those who did seemed to find it helpful in developing a sense of identity, building community and resisting despair. Cathy talked about how being open about her diagnosis gave her a sense of worth. "...its actually helped me...I'm an educator, I do a lot of workshops out in the community." It makes her feel "...worthwhile, worthy, worthy, yeah." Justine proudly told me about a video that she appeared in where she talked about her diagnosis and her challenges. "I did education for the general public. I talked about my story and I talked about my life. I found it as being very healing." Coralee has been active in HIV work since her diagnosis. Initially she was very open about it. "I talked at the international AIDS conference out here..." Negative repercussions for her family in their reserve community have made her more circumspect about her activism but she is still active in the HIV/AIDS movement, commenting that the HIV/AIDS community is "...where I find my strength." Community activism is an important strategy for helping individuals develop a positive sense of them-selves as well as affect change in communities and there is a relationship between activism and resilience (Ramirez-Valles, 2002). As Cathy, Coralee and Justine talked about their activism efforts, it became evident that this was a strategy that they relied upon to create a sense of belonging and control for themselves. Activism is a form of empowerment that allows people to exert some control over their destiny (Cadell, Karabanow & Sanchez, 2001). Out of all the women interviewed, Coralee, Justine and Cathy exhibited the most

comfort in talking about their HIV status. It is difficult to say whether the comfort led to the forthrightness or if the act of publicly talking about their condition led to their higher degree of comfort but there was an evident connection between their activism and their sense of personal strength in the face of adversity.

The importance of women centred HIV/AIDS support services.

With the exception of Roberta, who lives in a rural community with little in the way of community resources for PHAs, all of the women used community support services to a greater or lesser degree. Many of the women spoke highly of an ASO that is located in a large urban centre that specifically addresses the needs of women who are living with HIV/AIDS. This program is specifically designed for women who are living with HIV/AIDS, and has staff and volunteers who are well versed in the challenges and issues that result from living with HIV/AIDS. A number of the staff and volunteers are HIV+ themselves. Natalie talked about how it was "…like one big family…the staff are really supportive…" Mary uses a number of their services. "…once in awhile…just for the clothing…and they have lunches there…and Thursdays they have sandwiches and a support group for women which is pretty good…" Coralee spoke about how it was nice to have a service specifically for women. "…when I went to [the ASO] I didn't realize that there were other positive [women]…" This is a common issue for HIV positive women. Because women are so reluctant to disclose their diagnosis they often do not appreciate that they are not alone in their struggle with HIV infection (Carr & Gramling, 2005). There were a number of other ASOs that the participants used to a greater or lesser degree and the common thread that kept them going back was the sense of being accepted for who they were and a sense of belonging.

All of the women with the exception of Roberta looked primarily to their HIV+ friends for social support. Even Coralee and Mary, who had live-in partners, seemed to find more comfort and support in their positive friends. Coralee's partner was not especially supportive about her ongoing treatment. "...I always try, kind of, kind of urge him a lot of times to, you know, at least come with me..." but he refuses to, "...fear mostly..." Her HIV + friends on the other hand, she describes as her "family". Natalie also talked about how her HIV+ friends were "...like one big family..." Mary spoke about how her HIV+ women friends were the "...only friends I have...[and]...we try to support each other." Roberta, who lived in an isolated rural community, chose not to associate with other HIV+ people for fear of having her condition disclosed and did not appear to have developed a social support network to any degree. She talked about how she relied on "...just...myself." She seemed particularly lonely and vulnerable. When Coralee and Mary were contacted for follow-up they both strongly agreed that HIV+ friends were an important factor in coping with their HIV infection and life's challenges in general. Coralee stated, "If it wasn't for my [HIV+] friends I don't know where I would be. I know I'm not alone."

It is not surprising that the women looked to HIV+ friends and ASOs for support. The literature is quite clear that in general, PHAs find the support of positive people and community organizations to be more helpful and less risky than seeking the support of family members (Cadell et al., 2001; Paxton, 2002). In Dyer et al.'s (2004) research, Aboriginal persons who were living with HIV were found to benefit more from social support than from a sense of individual mastery. For the women in the study, the benefits

of the support that they received from their positive friends and local ASOs outweighed the risk of their status being inadvertently disclosed.

The Struggle to Stay Well

With the exception of Coralee, Natalie, and Mary, all of the women had experienced AIDS related illnesses, ranging from recurrent vaginal yeast infections to serious illness such as meningitis and lymphoma. For the most part, they expressed resignation in the face of their struggle. It was almost as if they felt they deserved to fall ill. This is unsurprising considering the context of their lives. This sense of deservedness has been fostered by a lifetime of coping with colonial attitudes and policies, poverty and, for most of the participants, abuse. Lack of HIV knowledge and underuse of health care services were two factors that contributed to their struggle to stay well.

Lack of HIV knowledge.

Knowledge is an important aspect for avoiding and managing a chronic, life threatening condition such as HIV infection (Nokes & Nwakeze, 2005). There is emerging literature about the role of the expert patient in managing a chronic illness such as HIV/AIDS (Fox, 2005). A number of the women expressed surprise and shock about their diagnosis despite the conditions that put them at risk and several of them are battling symptoms and AIDS related problems as a result of poor medical follow-up and inadequate use of health care resources.

Fiona, who has used a variety of illicit substances for many years, had no idea she was infected until she participated in a study of injection drug users. "And so I went and did this survey and that's when I found out...I was really surprised...I never thought I'd, I never thought I'd get it." Cathy talked about how she got the test fully expecting it to

come back negative because "...I didn't think it was ever going to happen to me." Elizabeth discovered her status as a result of prenatal testing. She had "No clue...I know, I know, I mean I figured, you know, it doesn't happen to me, it doesn't happen at all." Coralee was the only participant who was unsurprised by her diagnosis. She had become educated about HIV while she was a university student and she was aware of the risk. In fact, she delayed starting a relationship with a man after she broke up with her husband because it "...was my worst fear..."

The finding that in general the women were surprised by their diagnosis is borne out by the literature, which indicates that people tend to think of HIV as something that happens to "other" people despite the fact that the population at large has a fairly high level of understanding of HIV transmission (Health Canada, 2003). In general, people ascribe risk for HIV infection as something that happens to persons that they identify as different from themselves and in this respect, the participants were no different than the population at large.

Five of the women have impaired immune systems and struggled with AIDS related illnesses despite the availability of health care services and ART. For all of them, a lack of understanding about HIV progression and the efficacy of treatment seemed to be a contributing factor. Cathy gets "...sick quite often" and has suffered significant AIDS related illnesses. Elizabeth complained about how "...I have so much yeast infection" yet despite a low CD4 count has not sought medical attention. Justine is not on ART despite a perilously low CD4 because "...I don't believe that they work." She talked about how ART is "...not a hundred percent. And there's lots of side effects to them." Roberta, who was seriously ill and wasted, equated all of her symptoms to "...change of weather...Its

hot and cold." It seemed that a number of the women did not appreciate the link between their low CD4 counts and their ongoing struggles with early onset AIDS related illnesses such as vaginal yeast infections. In their research, Ebrahim, Anderson, Weidle and Purcell (2004) found that HIV+ persons of colour and those from a lower socioeconomic bracket had lower knowledge levels about the efficacy of treatment and were less likely to start and/or stay on ART. This finding is also in keeping with Mill's (2000) research with Aboriginal women with HIV/AIDS in northern Alberta. In her research she found that the women she studied tended to delay treatment until they felt "sick". However, treatment is initiated based on CD4 count, a marker of immunologic function, not on the onset of symptoms, which are in general a later sign. Five of the eight women in this study were either not on ART or were not taking it on a regular basis. Because their viral loads are not being controlled, they will inevitably progress to full blown AIDS.

Lack of knowledge is not the only barrier to the women in terms of accessing and staying on treatment. Vernon (2000) noted that the experience of some Aboriginal people with the mainstream healthcare system has been difficult. They often have little reason to have trust in the system or in the providers. A number of the women related negative experiences with the health care system that undoubtedly impinged on their willingness to access care and treatment.

Underutilization of health care services.

All of the women were willing to share their stories about their experiences with the health care system. With the exception of Roberta, who lives in a rural setting several hundred kilometres from the city and relies solely on her GP, all of the women used a specialty HIV medical clinic for their care. This clinic is virtually unique in western

Canada for the services that it provides. It is an interdisciplinary model and has a philosophy of women centred care that is well received by its clients. It works in partnership with the ASO mentioned previously to provide women with services that attempt to address all of their needs. The women were universally enthusiastic about the clinic. Mary reflected the views of each woman when she said, "...I like going there because, yeah, they, they treat me with respect...the nurse is fine, the doctors are good too..." The issue did not seem to be the lack of quality HIV health care services for the women in the city but accessibility. Because the specialty clinic is situated in a central location in a large urban centre, some of the women were challenged in terms of attending on a regular basis. Elizabeth, who battles with an active addiction and an abusive partner, acknowledged that "...leaning on the crack pipe..." made it difficult for her to get to the clinic when she needed to. Natalie talked about how difficult it was to get to the clinic when she was living in a suburb 50 km outside of the city. When she was in the third trimester of her pregnancy and had to go once a week, her partner "...just stayed home, he took off some time..." to drive her to her appointments. Justine commented on the lack of HIV services. "[The clinic]...is wonderful for Aboriginal women but you start going into our suburbs and you'll see more of a judgement and the prejudice coming in and you go onto reserves, well..." This resonates with Ship and Norton's (2001) research, which revealed that the lack of accessible services and knowledgeable staff, and racially discriminatory practices were noted to be a common barrier for HIV+ Aboriginal women.

The other issue that is presented by the lack of readily accessible HIV services is that with the exception of Roberta, almost all of the women had made a conscious

decision to live in the city, far from their extended families and their children because it was the only place that offered an acceptable level of treatment and care for HIV/AIDS. Coralee talked about how women have "...to leave their community to come and see their doctors, the doctors, the HIV specialists and that." Natalie moved to her home community after her diagnosis but ended up back in the city. "I was really, really sick when I got back...[women are] not as supported...as here..." The reality in Canada is that there is a dearth of specialized HIV/AIDS services for all PHAs in rural areas. This can be particularly problematic for Aboriginal people. Although there is a sizable population of Aboriginal people living in urban centres across Canada, many originate from isolated reserve communities and continue to live in rural or isolated regions.

The participant's experiences with their initial diagnoses were much more negative. Almost all of the women recounted a difficult experience receiving the news from an unsupportive care provider. Natalie's experience was typical. "...I got tested and then they told me...they just came in and I went into their office, yes, you're HIV and that was it...I didn't get any counselling...." Post-test counselling, including referral to appropriate services, is the standard of care in Canada (Canadian Medical Association, 1995), and yet for these women, that was the exception rather than the rule. The stigma that is associated with an HIV diagnosis means that health care providers do not always provide appropriate care. Research by Barroso and Powell-Cope (2000) and Worthington and Myers (2003) revealed that just the act of providing a positive test result could be the cue for stigmatizing behaviour on the part of a health care professional. The experience of getting an HIV test is potentially stigmatizing for HIV+ individuals, as the women's experiences illustrated.

A number of the women recounted difficult stories of being stigmatized in health care settings that were removed from the specialty services of the city. Elizabeth talked about a hospitalization in a small city in a western Canadian province. "...it was last September...I miscarried a baby and I went to the hospital and I got such horrible treatment like as soon as I told them I was HIV positive..." The outcome of their negative experiences is that the women all indicated that they were very selective about when and where they sought health care services and often delayed accessing services in an effort to avoid stigmatizing and judgemental behaviour. For the most part, if they couldn't get to the specialty clinic, they didn't go anywhere at all unless they were in desperate straits. The unfortunate outcome was that they often ended up in busy emergency departments, where the level of staff knowledge and willingness to treat them was unpredictable. This is in keeping with the literature, which consistently notes that health care workers who do not have ongoing contact with HIV+ patients often have quite negative attitudes towards them (Knussen & Niven, 1996; Hodgson, 1997; Wyatt, Myers & Loeb, 2004). This has clear implications for the design and delivery of health care services.

HIV is Just One Problem Among Many

All of the participants lived lives that were influenced by an intersecting network of the social, economic and political forces that provided a context to their existence. The participants needed to balance their needs for housing, food, getting access to their children, avoiding abuse and coping with their substance use with their need for HIV treatment and care. The forces that the women faced to a varying degree included

profound poverty, drug addiction, abuse and a colonial legacy that impacts on their ability to manage their HIV infection and stay well.

The effect of poverty and unstable housing.

With the exception of Coralee, all of the women were living on social assistance. A number of them had substandard housing, which has been clearly linked to risk for HIV infection and poor health (Zierler & Krieger, 1997; Spittal & Schecter, 2001). Cathy talked about the insecurity of her subsidized apartment. "...even today I still have people fucking ripping me off, I have people come in my house fucking stealing off me, I have fucking people stealing my food, you know..." Because of this insecurity Cathy felt that her apartment was not safe. She spent her days at various drop-in services around the city that provided her with a modicum of security. She found this constant upheaval difficult because of the profound fatigue that she is experiencing as a result of her HIV infection. Fiona has lost her subsidized apartment since being in hospital and has no idea where she will go if she is discharged "I'll go stay with my daughter till I find a place..." Elizabeth has once again left her partner and is currently on the street, spending nights with various friends. Justine has finally just moved into subsidized housing after two years on the street. She talked about how "I've had everything and I've had nothing...I've lived down here in the [city]...and owned a house and I've lived on the street only." One of the challenges of doing follow-up interviews with the women was their inability to provide me with a phone number or address for follow-up. Concern with accessing safe, secure housing was an evident priority for all of the participants and frequently superseded considerations about their ongoing health issues.

A number of studies have also established a definitive link between failure to access HIV treatment and care, and poverty (Anastos & Marte, 1989; Vernon, 2000; Walmsley, 1998; Wood et al., 2003). For women who are poor, treatment for their HIV takes a back seat to all the other challenges they face in terms of meeting their basic needs. A number of the women, despite low CD4 counts, are either not accessing treatment or indicated that they were having difficulty with adhering to treatment due to their preoccupations with maintaining housing, finding transportation and buying food.

Elizabeth talked about the difficulty of taking her meds when she didn't have anywhere to live. As is typical with a number of antiretrovirals, hers needed to be taken with food. "The dietician wants me to eat [laughter] and right now that's virtually impossible." HIV is a metabolically demanding infection and PHAs require a high protein, high calorie diet in order to support their immune system function. In addition, several of the ART medications require a meal in order to be adequately absorbed and some also need refrigeration.

Coralee, Natalie and Mary were exceptions in terms of their living situation. They all had supportive family members who were helping them with their living expenses and were able to maintain a decent level of nutrition. All three of them lived in secure, safe housing of a reasonable standard. They were also the only women who were able to stay on their ART and for Coralee and Mary at least, achieve an undetectable viral load, which is an essential goal if progression to AIDS related illness is to be avoided. Social support, secure housing and a stable income are significant contributors to supporting the health of PLWHAs (Wood et al., 2002). Coralee, Natalie and Mary's experiences demonstrate the profound influence that stable housing, supportive relationships and a

reliable, although modest income can have on their capacity to stay healthy in the face of the other hardships that they are dealing with.

Struggles with substance use.

With the exception of Coralee, Roberta, and Mary, all of the women were struggling with addiction to crack cocaine and heroin. Elizabeth talked about her continuing battle with cocaine addiction. "…I hate leaning on the crack pipe…I don't even enjoy it anymore…but that's all I think about." Between her drug addiction and her continued abusive relationship with her partner, Elizabeth finds it difficult to access ongoing health care. "I try to get to [specialty HIV clinic] but it's hard." Fiona talked about how her addiction overwhelmed her ability to deal with her HIV infection, stating, "When I'm using…I don't really think about it [her HIV infection]." Justine, seriously ill in hospital with a life-threatening illness, was primarily concerned with earning money to buy drugs. When provided with her honorarium she stated "Good, now I can go and score some crack." For the women who were currently using substances, it seemed to be the priority issue. They were very open about their drug use and were clear that their participation in the study was because it gave them a way to earn a small amount of money to purchase drugs. It is difficult to manage addiction, especially in the context of the poverty, violence and lack of social support that the participants were experiencing.

Research by Shannon et al. (2005) revealed that women with a history of injection drug use had a low uptake of ART. Continued substance use also influences the ongoing health status of HIV+ women due to poor use of services. In addition, a study by Varela et al. (1997) noted that the malnutrition that is associated with problematic substance use contributes to depleted immune function and progression of HIV infection to AIDS

related illness. In general, despite an awareness of the importance of ongoing medical care, with the exception of Mary and Coralee, none of the women were in regular contact with their primary care providers. This is in keeping with research by Stajduhar et al. (2004) who found that despite having a good understanding of the importance of medical care, many active injection drug users did not take advantage of services because their need for drugs can take priority over all other issues. This is unsurprising in light of the stories a number of the women told. They were subjected to profound stigma and poor treatment by health care professionals as a result of their substance use and as a consequence they lacked trust that they would be treated well when they presented for services.

The relationship between violence and HIV/AIDS.

Abuse was not a universal experience amongst the participants but several of the women alluded to abusive situations in both the past and the present. Cathy experienced abuse at both the hands of her parents, "…they both abused me very badly" and her ex-partner, "…I was in a very abusive relationship…he started to abuse my son too at the same time…" Elizabeth talked about her partner, with whom she has an on again, off again relationship. "…the father of my kids is extremely violent over the years…and then I got back together with him, right away started using and back to the old, same bullshit…" She was also subjected to emotional abuse due to the fact that her partner is convinced that she infected him despite his own high-risk injection drug use behaviour. "…the main reason I keep going back to my X is all the guilt…with all this guilt and everything I was working the streets…like I was doing it out of love for him…" Justine suffered at the hands of her mother. "…my mum was a part of my abuse for most of my

life..." Coralee had an abusive partner after her marriage ended. "Well I've gone through two marriages, the last one was extremely violent..." Violence is a sad reality for many Aboriginal women, as revealed by the literature. (Dion Stout et al., 2001; RCAP, 1996b; Schwarz, 2004; Ship & Norton, 2001). It is also clear from the literature that women living with HIV who are subjected to or have a history of being abused are less likely to access treatment and more likely to develop AIDS related illnesses (Mannheimer & Beirn, 2005; Wyatt, 2005).

The experience of violence is not unique to the participants. As noted in the review of the literature, violence is perpetrated against Aboriginal women in a disproportionate manner (Walters & Simoni, 1999). What makes the experience unique is the profound effect that the experience of violence has on their ability to manage their lives. In particular their need to balance their need for personal safety with their need to access health care and support services for their HIV/AIDS related issues. Walters and Simoni (1999) noted that trauma was a better predictor of risk for HIV infection than social cognitive variables and they contend that the violence that is perpetrated against Aboriginal women is a direct outcome of the colonizing events that Aboriginal peoples have been subjected to.

The burden of history.

The thread that binds all the other issues together, weaving a complex pattern of marginalization, challenge and discrimination, is the historical and present day colonialism that shape the women's lives. None of the women directly spoke about how colonialism had influenced their lives, but from Roberta's sense of deservedness over the

difficulties she has faced to the overtly stigmatizing encounters that Cathy has experienced, the influence of colonialism was omnipresent in the women's stories.

As Mill (1997) noted in her study, the very issues that have arisen as a result of colonization put Aboriginal women at risk for HIV infection as they struggle to survive in the face of overwhelming barriers. This was borne out by the women who participated in the study. Roberta, Justine, Cathy, Natalie, Elizabeth and Fiona had all engaged in substance use and sex trade work and they indicated that for them, these activities were a matter of survival. As Cathy put it, "…the drugs are the only thing that keep me going." Duran and Duran (1995) propose that the unresolved grief and trauma reactions that are the result of loss and destruction of lands, community, and loved ones as well as social and spiritual dislocation lead to dysfunctional family coping patterns and ultimately to HIV risk behaviours such as substance use.

The women also demonstrated a significant degree of mental distress and trauma about the issues they have faced in their lives. Roberta talked about how living on the streets was the most difficult situation she had ever confronted. "It was so hard. I never felt safe and I got hurt [assaulted] so often." Cathy recalled growing up in an abusive household. "I will never forget it. My Mum and Dad were so mean when they were drunk. No kid should have to go through that." Both Elizabeth and Fiona talked about the difficulty of losing their children to the child welfare system. Fiona stated, "It was the hardest thing I have ever been through." Although colonization does not contribute directly to these traumatic incidents, it is recognized that colonial practises and attitudes have sown the seeds for the present day reality of abuse, dislocation, substance use, and poverty that all of the participants struggle with to a greater or lesser degree (Griffiths,

Werbury & Weafer, 1987). Walters and Simoni (2002) propose that for Aboriginal women, the trauma that is the result of such colonial practices as residential schooling, seizure of children and gender biased policies has resulted in a state of cumulative trauma or post traumatic stress disorder which leads to high rates of substance use, depression and vulnerability to abuse. The cumulative effect of the injustices that many Aboriginal people experience has been described as a "soul wound" which influences health and mental health outcomes (Walters and Simoni, 2002).

Summary of Findings

I was touched and honoured by the willingness that the women demonstrated in sharing their thoughts, feelings and lives with me. What I found striking was their strength and determination to survive in the face of what seemed like insurmountable barriers. All of the participants showed an intelligent and creative ability to adapt to constantly shifting challenges. In particular, I will remember Justine, Roberta, and Fiona, who despite their serious illnesses, did not let the prospect of death get in the way of their determination to keep on living. As Fiona said, "I don't think about it....[I] stay strong...stay strong."

In view of the context of the women's lives, the findings of this study are in no way surprising. As noted by Adelson (2005), there is a direct association between the health challenges the women face and social, economic, cultural, and political inequities. Systemic discrimination has led to a significant fear of rejection for the participants. This fear is revealed by their efforts to reduce opportunities for stigmatizing encounters by keeping their HIV+ status secret whenever possible, avoiding interactions with people

that they think or know to be judgemental, including health care providers, and their sense of guilt and shame about their positive status.

The profound loneliness that the women experience is the inevitable result of living far from family and traditional support systems. Adelson (2005) notes that policy makers have largely ignored the plight of urban Aboriginal women and many face formidable barriers in accessing timely and appropriate care and yet for the participants, there is little sense of a choice. Staying on reserve means substandard HIV care and loss of privacy around their diagnosis.

Their poor health status and struggle with symptoms is a direct result of the poverty, abuse, substance use and substandard housing that is the reality for almost all of the women. With the exception of Coralee and Mary, all of the women were struggling to maintain housing, survive on a limited income and deal with the issues of substance use. Notably, Coralee and Mary are the only women who had managed to adhere to ART, achieve an undetectable viral load and avoid the AIDS related illnesses which are an outcome of progressive HIV infection.

The reduced sense of priority that the women give to their HIV status is also a direct result of their struggles with issues of survival – finding and keeping housing, maintaining contact with their children, avoiding and coping with abusive situations, and coping with addiction. The women were all very clear about where their HIV infection fit in the context of their lives. They were aware of it, they knew it was important to deal with it, but for the most part, other issues took priority.

The degree to which the women were able to cope with seemingly insurmountable odds was striking. All of the women had strategies that they used to manage in the face of

adversity. In particular, their focus on the well-being of their children and their efforts to maintain a connection with them even if they were in care was remarkable. Maintaining contact with their children was a priority for all of the women. To a greater or lesser degree, with the exception of Roberta, all of the women had developed social contacts within the HIV community in an effort to reduce their sense of isolation and resist the stigma that is so prevalent. For some of the women, activism within the HIV/AIDS community had become a way of asserting their identity and combating the sense of stigma that is so integral to HIV infection.

In general, it can be seen that for the participants, HIV infection is another layer in a multi-layered context of challenges and barriers. It is evident that the historical and present day forces of colonialism and the consequences of poverty, marginalization, abuse, substance use and stigma have left the women vulnerable to HIV infection and the associated health challenges. The findings reveal three overarching themes – the intersecting forces of colonialism, poverty, marginalization, and racism that shape the participant's lives and their ability to deal with their HIV infection and AIDS related illnesses, the lived reality of social suffering that the women described, and the extent to which resiliency was enacted in the context of the women's lives in ways that helped to ensure their survival. These themes will be discussed in the next chapter.

CHAPTER FIVE

Discussion of Findings

This study used a descriptive interpretive approach to examine the lives and

experiences of Aboriginal women who are living with HIV/AIDS. There were three

research objectives: explore and understand some Aboriginal women's experiences of

living with HIV/AIDS within the context of their everyday lives; gain an understanding

of how Aboriginal women who are living with HIV/AIDS experience formal support

systems, including AIDS service organizations and health care services; and make

recommendations for program design and policy development that will specifically

address the needs of Aboriginal women who are living with or at risk for HIV/AIDS.

It was readily apparent from the interviews conducted for this study that the lives

and experiences of Aboriginal women who are living with HIV/AIDS are affected by a

number of intersecting forces. As Adelson (2005) points out, it is the forces of history,

the colonial practices and politics of the past and present, and the current economic

marginalization and ongoing racism by dominant society that makes it difficult for many

Aboriginal people to achieve a state of health and well being that is comparable to that of

the dominant Canadian population. Although a superficial assessment would accord

blame to the disproportionate rates of discrimination, poverty, violence and abuse that the

women endure, the whole is greater than the sum of the parts. The concept of

intersectionality is useful for understanding the issues that underlay the difficulties that

the women are living with. The collective experience of violation that Aboriginal peoples

in general and Aboriginal women in particular have experienced as a result of

colonization has resulted in an individual and community reality of social suffering.

Despite this, there is clear evidence that the participants in this study drew on resilient behaviours to withstand the forces that are arrayed against them.

The Effect of Intersectionality

It was clear from the findings that to a greater or lesser degree all of the women faced a powerful constellation of inequities that were inextricably linked to their social positioning in relation to the dominant society. The intersecting issues that they were dealing with, including relatively low levels of education, extreme poverty, gender inequity, racism, violence, and substance use, left them at increased risk for poor health. Their experiences of poverty, racism, and subjugation as a result of colonial practices and policy are such tightly bundled constructs that it is difficult to understand one without reference to the others (Collins, 1998).

There is a clear relationship between these intersecting historical and social forces and health. There is a core truth about the social determinants of health and that is that the forces that systematically influence health are "…humanly factored, socially influenced and unequal." (Lang, 2001, p. 162). There is a current discourse to account for differences among people as being a result of individual factors, "culture", chance or genetics but "Class, colonialism, [and] social tension not only never went; they merely changed their clothes." (Lang, p. 162). The social conditions that intersected to make life so difficult for the women in this study were, to a large extent, a result of our colonial heritage.

The Intersecting Force of Colonization

As was noted in the chapter three, a post-colonial feminist perspective was used in this study to understand the links between racism, poverty, gender inequity and marginalization that are legacies of colonial oppression. As LaRocque (1996) comments:

Colonization has taken its toll on all Native peoples, but perhaps it has taken its greatest toll on women. Racism and sexism found in the colonial process have served to dramatically undermine the place and value of women in Aboriginal cultures, leaving us vulnerable both within and outside of our communities…the tentacles of colonization are not only extant today, but may also be multiplying and encircling Native peoples in ever-tighter grips of landlessness and marginalization, hence, of anger, anomie and violence, in which women are the most obvious victims (p. 11-12).

Aboriginal people in general, and many Aboriginal women in particular, face individual and institutional discrimination in the form of racial, gender and class inequity. In relation to health, this discrimination manifests itself in overall poor health, vulnerability to infection and disease, and limited access to health care services. Colonization is a determining factor in the participants' risk for HIV infection and their resultant struggles as they live with HIV/AIDS.

Colonization and HIV/AIDS.

Colonization has resulted in stigmatization, marginalization, loss of cultural identity and poor health for Aboriginal peoples in Canada (Moffitt, 2004). HIV/AIDS has an unerring instinct for persons who are vulnerable, regardless of whether the vulnerability is a result of discrimination, gender, poverty, lack of access to education or

a history of abuse. The findings revealed that the women were vulnerable on a number of levels. Only four of the women had completed high school. All but one of the women was living on social assistance. Almost all of them volunteered experiences of abuse, either at the hands of their family or their partners. Four of the women had unsafe and unstable housing. Five of them engaged in problematic substance use.

HIV infection is primarily acquired through unprotected sexual activity and the sharing of injection drug using equipment. For the participants, life experiences have left them especially vulnerable to HIV infection. In her research, Mill (1997) revealed how HIV risk behaviours are related to survival strategies for Aboriginal women. Mill identified a number of factors, including turbulent childhoods, physical, sexual and emotional abuse and parental substance use that lead to survival behaviour such as running away from home, unprotected sex and substance use. The findings of this study echoed her research. A number of the participants had left home at an early age or had been in foster care. Most of the participants had engaged in risky substance use and high-risk sexual behaviours. The link with colonization is clear. It is colonizing practices such as the forced and at times indiscriminate and unnecessary removal of children, residential schooling, relegation to reserves and gender discrimination that has led to the disrupted childhoods and abuse that the participants have been subjected to (Kaha:wi & Gill, 2002). In an effort to cope with the resulting trauma, the participants have turned to behaviours that put them at risk for HIV infection.

Although it must be acknowledged that children are often taken into care because they are in unsafe situations and their removal is justified, the sometimes-indiscriminate removal of Aboriginal children to residential schools and foster care has resulted in

shattered families and a resultant loss of connection between grandparents, parents and children. This has fostered a sense of disconnection for Aboriginal peoples that have imperilled their sense of self, their cultural identity and their ability to develop positive relationships with their families. As Daes (2000) points out, one of the most destructive effects of colonization is the experience of intellectual and spiritual loneliness. Most of the participants had little to no ongoing contact with their families and limited social circles, placing them at even higher risk considering that there is a clear and negative link between isolation and the ability to live well with HIV/AIDS (Carr & Gramling, 2004; Crook et al., 2005).

The discriminatory practices that many Aboriginal people are subjected to have resulted in a high degree of stigmatization. Aboriginal women in particular have been targeted by colonial practices and policies, which sought to disrupt the traditional status of women in their communities (Moffitt, 2004; RCAP, 1996b). In addition, Aboriginal women have been subjected to a significant degree of stereotyping that undermines their value and image (Acoose, 1995). The consequence of this ongoing discrimination is that many Aboriginal women have lost their sense of self worth, been subjected to abuse both within their own communities and the community at large, and live lives that are characterized by poverty, poor health, and isolation. All of the women in this study spoke about the negative effects of stigma on their lives and all of them were attempting to alter their activities and their relationships in an attempt to minimize the discrimination that they experienced. Their experiences with stigma have constrained their social lives, disrupted their relationships with their families and friends, and made them reluctant to seek health care and ultimately influenced their ability to live well. When they do seek

health care the encounters can be difficult and demeaning. Most significantly, all of the women expressed a sense of marginalization and powerlessness in the face of the frequent discriminatory encounters that they experienced.

Poverty is prevalent in Aboriginal communities and particularly for Aboriginal women (ANAC, 1996; Dion Stout et al., 2001). Colonizing practices have limited the ability of Aboriginal peoples to achieve a viable level of socioeconomic well-being that is closer to that experienced within the dominant Canadian population. Relegation of Aboriginal peoples to reserve communities, often far from employment and post-secondary education opportunities have left Aboriginal people with little in the way of resources to improve their status (Kelm, 1998). The discriminatory practices that Aboriginal people face; both within work and school settings, have added another layer of limitation. In general, Aboriginal people, particularly Aboriginal women, have a lower income, even when they are employed. They are typically relegated to occupations in which part-time hours and low pay is common (Dion Stout et al., 2001). There is a clear and inextricable link between poverty and HIV/AIDS. Poverty puts people at risk for infection and limits their opportunities to maintain their health and reduce progression of their HIV infection (Hogg et al., 1994; Zierler & Krieger, 1997). All of the women in this study with the exception of Coralee were living in constrained circumstances, and they all spoke of the challenges of surviving on a limited income.

Colonization and health care services.

A number of sources have reviewed the role of colonization on the ability of Aboriginal peoples to stay well and access needed health care services (Adelson, 2005; Browne & Fiske, 2001; Hackett, 2005; Turpel, 1991). Health care services in Canada

have a history of being colonial in structure and delivery, although it should be noted that there have been efforts made in recent years to address this issue. Preferred patients tend to be those who are white, middle class and not presenting for issues arising from substance use (Jiwani, 2001). For Aboriginal people, accessing health care often means encountering isolation, alienation, and marginalization (Browne, 2005; Hart-Wasekeesikaw, 2003; Moffitt, 2004; O'Neil, 1989; Dion Stout & Kipling, 1998).

The effects of colonization in relation to the participants' ability to access health care services were manifested in various ways. Firstly, the availability of quality HIV/AIDS services was severely constrained by geography. With the exception of Roberta, all of the participants had elected to live in a large urban centre where services were more numerous. Roberta's health status was poor, which reflected to some degree her inability to access services in a rural reserve setting and in fact, she died of an AIDS related illness shortly after the interview. However, despite the greater availability of services in the city, there is nothing available that specifically addresses the needs of Aboriginal women. Adelson (2005) noted that this is a consistent failure of the health care system. Coralee and Elizabeth both commented that despite their support for the specialty HIV clinic they found the structure of the clinic difficult. It is very busy and the non-Aboriginal clinic staff did not have time to address the broader issues that the women are confronting. By necessity, the clinic focuses primarily on the physical aspects of HIV infection. There is little time to address the complex intersecting issues that affect the women, including their isolation, their lack of economic resources, their experiences with violence, and the ongoing experience of discrimination and racism that they endure.

Discriminatory attitudes of health care staff are an inescapable aspect of the colonial structure of health care services in Canada. A number of authors have noted the discriminatory judgements that are levelled against Aboriginal women (Browne & Fiske, 2001; Dion Stout et al., 2001; Shestowsky, 1995; Ship & Norton, 2001). This discrimination arises directly from colonial policy and practice, which has consistently set Aboriginal peoples apart as "Other" (Browne, 2005) and with the execution of policies such as the Indian Act has ensured that Aboriginal women continue to face systemic and entrenched discriminatory attitudes. All of the women in the study related episodes of discriminatory practice from health care providers and the fear of judgement made them selective about where and when to seek out services, regardless of their immediate health care needs. This is of concern, because HIV/AIDS does not have to be a death sentence. With appropriate and consistent primary care follow-up it can be transformed into a chronic, manageable disease. It is vitally important for PHAs that they access the treatment, care, and support services they need on an ongoing basis in order to maintain their health and well-being.

The Experience of Social Suffering

The social suffering that Aboriginal peoples experience is "...the kind of long-term, institutionalized and ultimately invisible suffering that has been referred to as the "soft-knife" of long term oppression. " (Adelson, 2001, p. 77). It is the intersecting issues that were discussed above that create the conditions for the experience of social suffering that the women in the study endured. Social suffering has been defined as the collective and individual experiences of human suffering that are associated with life conditions which are shaped by powerful social forces (Benatar, 1997). For the women in this study,

the unrelenting forces of poverty, marginalization, racism and violence that they confronted have sown the seeds for their experience. On a collective level, their social suffering was compounded by the trauma associated with the unresolved grief and mourning that is related to the loss and destruction of ancestral lands, community and loved ones, as well as social and spiritual dislocation. This trauma has been conceptualized as a "soul wound" (Walters & Simoni, 1999) that must be considered when addressing the health and illness issues that were experienced by the women in this study.

Social suffering is constructed through economic, military and cultural forces that have become accepted as inevitable aspects of modern life (Benatar, 1997). It is this acceptance that has relegated social suffering to an invisible and unacknowledged position in relation to human experience. In health care disciplines, social suffering has been effectively silenced by looking at individual experiences in the context of risk as opposed to acknowledging the very real and significant context of suffering that individuals and populations live with. Using the language of science and technical expertise, which tends to focus on what can be located, identified and acted upon, mutes the voice of suffering people (Adelson, 2001; Frank, 2001; Wilkinson, 2006). In failing to acknowledge social suffering, we consistently fail to attend to the consequences of suffering (Wilkinson, 2004). Social suffering leads to a sense of disconnection and distancing. As Frank pointed out in his essay outlining his experience with serious illness, "...I was becoming other to the person I had been and to those who knew that person."

The invisibility of social suffering leads in turn to a construction of a marked invisibility of Aboriginal women in public culture (Culhane, 2003). Suffering makes us

uncomfortable. It is easier to ignore it than acknowledge it because by acknowledging it we must also acknowledge the powerful social and cultural inequities that shape it (Culhane). For Aboriginal women in general, the shared cultural and community trauma is the result of two centuries of internal colonization, neglectful and discriminatory government practices, suppression or outright banning of traditional cultural practices, dislocation, and separation of children from families by enforced removal to residential schools and foster care (Adelson, 2001). For the women in the study, this trauma was exemplified by lack of access to their children, overt discrimination by both the public at large and health care providers, and a sense expressed by all of them that the difficult situation that they found themselves in was, if not deserved, at the very least not unexpected.

The Embodiment of Resilience

There is a danger in focussing exclusively on the historical and present day realities of colonization and social suffering experienced by Aboriginal peoples. By doing so, we run the risk of continuing to construct Aboriginal people as victims without agency and thereby shackling them to a history that was never theirs to decide (Adelson, 2001). As Das and Kleinman (2001) note, the altered everyday is marked not only by a new knowledge and memory of loss but also by a practical wisdom of how to negotiate the loss. Ultimately, relief from suffering can only come from the agency of Aboriginal peoples. As Adelson (2001) notes, responses to social suffering in the context of Aboriginal Canada must be processes that originate within and evolve from community and individual efforts at social reconstruction. Despite their experience of suffering, the

women possessed a remarkable degree of resilience, which must be recognized and supported if their suffering is to be alleviated.

Strategies for Survival

In chapter four it was noted that the women possessed a number of characteristics and engaged in numerous activities that enabled them to survive in the face of significant challenges. These characteristics and the behaviour they engaged in can be described as resilience. Resilience is the ability to adapt to, cope with and even be strengthened by adverse situations (Cadell et al., 2001). A resilient individual has the inner strength to adapt to and cope with problems that are seemingly insurmountable (Edward & Warelow, 2005). There are a number of characteristics that contribute to resilient behaviour, including personality, problem solving ability, social supports and existing resources (Cadell et al., 2001; Deeny & McFetridge, 2005; Edward & Warelow, 2005). The factors that predispose an individual to resilience are not just individual, but also arise from families and communities. What is also apparent however is that it is experience with adverse situations that provides the genesis for the development of resilience. The participants in the study have had lifelong experience with adversity and they responded to it in diverse and creative ways, including focussing on their children, participating in activism and developing relationships with other HIV+ women. The individuality of the participants in the face of common problems was clearly demonstrated. The women were very different in terms of their coping abilities and personal attributes. This serves as an important reminder of the need to avoid essentializing the experiences of vulnerable people.

Limitations of the Study

There are a number of issues that limit the study. As with all qualitative research, this study offers an interpretation from a small group of participants. The findings cannot be generalized in a statistical sense, but there is a strong degree of analytical generalizability. "Generalizability in qualitative research refers to the extent to which theory developed within one study may be exported to provide explanatory theory for the experiences of other individuals who are in comparable situations." (Horsburgh, 2003). My inexperience as a researcher is another significant limitation. This inexperience affected the quality of the interviews and the data collected as well as the process of analysis. I had never conducted a qualitative interview before and I found it challenging initially to conduct the interviews in a manner that allowed the women to be comfortable disclosing their thoughts and feelings. In addition, it was difficult to analyse the data without bringing my own biases and expectations into the process. I have worked in a clinical setting that serves marginalized Aboriginal peoples for over twenty years and have internalized a number of opinions and perspectives regarding this population. I managed this issue by keeping field notes as I proceeded through the data collection process. The field notes were useful as I conducted my data analysis to help me identify my biases, preformed opinions, and also my hunches regarding the themes that were emerging from the data. The expert informant provided invaluable feedback from the perspective of an Aboriginal woman. She was particularly helpful in assisting me to identify potentially objectifying language in my write-up of the data.

Summary

In order to move forward and provide an environment for economically disadvantaged Aboriginal women who are living with HIV/AIDS that allows them to live in a state of maximal health and well-being, attention must be paid to the intersecting factors that constrain their lives, the reality of social suffering that the women endure, and the importance of facilitating resilience. Program and policy planning must take these concepts into account if HIV+ Aboriginal women, particularly those who are indigent, impoverished and engaged in problematic substance use, are ever going to be able to achieve a state of health and well-being that can be achieved for a PHA. The concluding chapter will discuss how the study has contributed to an understanding and clarification of the research problem and the implication of the findings in the development of clinical practice, administration and education as well as health and social policy, and opportunities for Aboriginal leadership.

CHAPTER SIX

Summary and Recommendations

For the master's tools will never dismantle the master's house. They may allow us to temporarily beat him at his own game, but they will never allow us to bring about genuine change. (Lorde, 1984, p. 110)

Summary of the Study

The purpose of this study was to identify the contextual and constructed nature of health-illness experiences of Aboriginal women who are living with HIV/AIDS. It is anticipated that the findings from the study will be used to gain an understanding of some Aboriginal women's experiences of living with HIV/AIDS within the context of their daily lives, gain an understanding of how Aboriginal women who are living with HIV/AIDS experience formal support systems, including AIDS service organizations and health care services, and make recommendations for program design and policy development that will specifically address the needs of Aboriginal women who are living with or at risk for HIV/AIDS. The comparatively high rates of mortality and morbidity amongst HIV+ Aboriginal women indicate that there is a need to address deficiencies in the delivery of supportive services and health care.

In keeping with the methodological strategy, existing literature was reviewed to gain an understanding of the context of Aboriginal women's lives. It is clear from the literature that many Aboriginal women are challenged by high rates of poverty, significant violence enacted against them, substance use, discrimination and relatively high rates of HIV infection. Most, if not all, Aboriginal women continue to be affected by

the forces of colonialism, which although changed in the present day context, continue to exert a real and irresistible pressure that constrains their ability to deal with socioeconomic challenges. Despite the comparatively high rate of HIV/AIDS in Aboriginal women, there is a dearth of literature that examines how HIV infection influences their lives and well-being, particularly literature that takes a nursing perspective.

The study used a qualitative interpretive descriptive methodology to gather data from eight Aboriginal women living with HIV/AIDS. With the exception of Coralee, all of the women were coping to a greater or lesser extent with poverty, unstable housing and problematic substance use. Data was collected from one on one, semi-structured interviews. The interviews were audiotaped and subsequently transcribed verbatim. Informed consent was obtained and anonymity was ensured through the use of fictitious names and changes in demographic details. Two of the women were contacted by telephone for follow-up interviews to review the preliminary findings. The findings were also presented and reviewed by a discussion group at an Aboriginal HIV/AIDS conference. An expert informant gave ongoing advice and feedback throughout the study in relation to study design, findings and analysis, and the write up of the data.

The data analysis proceeded simultaneously with the interviews using a process of constant comparative analysis. Thematic analysis occurred as I moved between the transcripts to identify commonalities and variations within the emerging themes. The ultimate result was a description of five themes that were shared across the participants.

The five themes that were identified were: fear of rejection; looking for friendship; the struggle to stay well; finding strength in adversity; and HIV is just one

problem among many. A number of issues were linked to these findings, including the intersecting conditions of poverty, isolation, abuse, substance use, and discrimination and stigmatization.

It became evident from the stories that the women told and the lives that they were living that they experienced significant challenges as they endeavoured to survive in the face of the overwhelming obstacles that are outlined above. For three of the women, the obstacles that they were facing made it impossible for them to access the necessary treatment and care that they required to cope with their HIV infection, and the inevitable outcome was that they succumbed to an AIDS related illness. Of particular note was the obvious influence that intersectionality had on all of the participant's abilities to stay well, the significant degree of social suffering that all of the women endured, and the resilient behaviours they engaged in an attempt to minimize the consequences of the social, political and economic forces that were arrayed against them.

Conclusions

Based on the findings from the study, some broad conclusions can be drawn about the lives and experiences of the participants. Although the conclusions cannot be applied to all Aboriginal women who are living with HIV/AIDS, they may be applicable to Aboriginal women who are living in circumstances that are similar to those of the women in the study, that is, women who are living lives that are constrained by poverty, discrimination, substance use, and violence.

1. The participants of this study who were living with HIV/AIDS predominantly live lives that are characterized by poverty, overt discrimination, substance use, violence and isolation. This had a direct effect on their ability to manage and live

with their HIV infection. Three of the eight women died prematurely of AIDS related illnesses and the remaining women struggle to maintain their health and control their HIV progression.

2. Health care services contribute to the marginalization of Aboriginal women who are living with HIV/AIDS by perpetuating or reproducing stigmatization and "Othering" in ways that caused the women in the study to avoid seeking care.

3. Aboriginal women who are living with HIV/AIDS are likely to experience challenges accessing needed programs due to their inability, and in some cases reluctance, to access them. As the findings from this study showed, fear of discrimination means that the women were sometimes reluctant to access health care services when they needed them. The competing demands of poverty constrained their ability to access programs. The women had difficulty maintaining secure and safe housing, affording food, and accessing transportation to relevant services and programs. Lack of money meant that a number of the women turned to survival sex work, which put them at great risk. Geography impeded their ability to access programs, particularly for women in rural and suburban areas where there were very few HIV/AIDS services available. For some of the women, active substance use constrained their ability to access services and programs when they needed them.

4. There appeared to be a link between ongoing contact with children and ability to stay well and sustain hope for the women in the study. Although removal of children is at times inevitable and necessary, ongoing contact seemed to have a buffering effect on the challenges the women faced. Even if they did not see their

children, just thinking about them inspired the women to seek help and stay as healthy as they could, given the circumstances of their lives.

Implications for Health Care Providers and Policy/Program Developers

HIV/AIDS is a social problem that requires a social solution. Solutions will only come when there is a significant shift in the societal relations that position some Aboriginal women as economically deprived, subject to discrimination, and powerless. The findings of this study present implications for education, administration, clinical practice, research, public policy, and leadership in Aboriginal communities. The recommendations are formulated to address the conclusions reached above and are presented to inform the development of appropriate policies and programs that will support the health and well being of Aboriginal women who are living with HIV/AIDS.

Education

The conclusions of the study suggest a number of educational opportunities that should be undertaken. Health care workers need to have a much better baseline understanding of the issues related to HIV/AIDS. There are numerous studies that indicate that health care providers who are better educated about HIV/AIDS and the needs of PHAs have a better attitude towards them although this does not always translate into an increased willingness to care for PHAs (Brown, Macintrye & Trujillo, 2003; Hodgson, 1997; Robinson, 1998). The simple provision of information does not seem to be enough. Information needs to be accompanied by skills building strategies, such as contact with a PHA in an educational setting and activities that allow health care providers to examine how their values and attitudes may be a barrier to forming positive relationships with PHAs (Knussen & Niven, 1999; Robinson, 1998). Educational

interventions are also more effective if they directly address the fears and concerns of health care workers (Knussen & Niven 1999). There is some evidence that a perceived risk of contagion may contribute towards the negative and stigmatizing behaviour of some health care providers (Knussen & Niven 1999). Educational initiatives need to focus on ensuring that health care providers get clear and accurate information on the actual risk of HIV transmission in the health care setting, which is relatively low (McCall, 2005). Fear of contagion is an integral force in the development of stigmatizing behaviour (Goffman, 1963). The discriminatory attitudes that were displayed by a number of the health care providers that the women came into contact with may be modified if they are less anxious about the potential for acquiring HIV infection from their patients.

The findings revealed that the participants did not, for the most part, have a good understanding of issues related to HIV/AIDS, including the factors that made them vulnerable to infection, the progression of the infection, and the potential success of ART in keeping them well. It is important for PHAs to be knowledgeable about HIV/AIDS and the self-management strategies that they can use in the context of their lives to stay as well as possible (Nokes & Nwakeze, 2005). A new program in British Columbia may serve as a model. Around the Kitchen Table is an HIV prevention and information program which is being piloted by the Chee Mamuk Aboriginal HIV/AIDS Prevention Program at the BC Centre for Disease Control (see www.bccdc.ca) The program facilitators have identified Aboriginal women leaders in reserve communities and in a downtown urban setting, and have provided them with the skills they need to teach the women in their community about issues related to HIV/AIDS. The program is

collaborative in nature and relies on a variety of strategies to attract participants, including traditional crafts, cooking and social time. This is in keeping with the values of many Aboriginal women, who tend to view health holistically, and see social and cultural conditions as integral to the health of individuals and communities (Deiter, 2002; Dion Stout, 2005). This program is targeted at both HIV positive and HIV negative community members and the goal is to increase awareness of issues related to HIV/AIDS as well as to address the continuing stigmatization against PHAs that is present in many Aboriginal communities. The program is in its infancy, but has been enthusiastically embraced by women in several reserve and community settings. The program could serve as a model for informal programming in a variety of settings.

Administration

It is clear from the experiences that the women related that their health care encounters, particularly in the acute care hospital setting, were fraught with discriminatory and judgemental behaviour on the part of health care staff. Health care administrators have a crucial role to play in ensuring that Aboriginal women who are living with HIV/AIDS, in particular those who are dealing with complex social and economic challenges, encounter a positive and healing environment when they present for treatment and care needs. They need to ensure that all health care personnel that the women are likely to come into contact with, including cleaners, lab technicians and kitchen workers, receive appropriate HIV/AIDS education. It appears from the research that health care workers who have less opportunity to develop personal relationships with PHAs are more likely to exhibit stigmatizing attitudes (Knussen & Niven, 1999). Administrators also need to create an environment that supports the efforts of health care

providers to fulfil their professional obligations to their patients. Burnout has been identified as a barrier to the appropriate care of patients with HIV/AIDS (Robinson, 1998).

Administrators also have a responsibility to ensure that they facilitate a safe environment for their patients by ensuring that all staff members have an understanding of the lives of diverse ethno-cultural groups including Aboriginal peoples. There needs to be a clear position that discriminatory practices are not acceptable and staff need to receive training to increase their understanding of how their social and economic positioning affect their ability to "see" and understand the realities of their patients lives.

Clinical Practice

There were two issues in particular that arose from the findings that need to be considered in the context of clinical practice. The first issue was the discriminatory and judgemental practices of many health care providers that the women encountered, and the second issue was the significant degree of resilience that the women demonstrated. The concept of cultural safety is a strategy that can be integrated into clinical practice in an effort to reduce discriminatory behaviour. Health care providers should be alert to how the resilient behaviours that are exhibited by their patients can be facilitated and supported.

Cultural safety.

Holistic models of care, which address the psychosocial, spiritual and physical aspects of living with HIV infection, are needed to successfully promote the health and well being of PHAs (Barroso & Powell Cope, 2000). If cultural and social interpretations around the meanings of health and illness are not integrated, treatment modalities may

very well be rendered irrelevant (Reimer Kirkham & Anderson, 2002). For Aboriginal communities, holistic care means culturally appropriate care that considers the entire picture of the person, not just physical and mental issues (Foster, 2006). The concept of cultural safety is useful when considering how to integrate culturally appropriate care into clinical practice. In order to achieve the recommendations that are outlined in the other sections of this chapter, the concept of cultural safety is useful in focussing health care providers, administrators, educators and policy maker's attention on the historical context of the embodied inequities that shape the lives of many Aboriginal women, particularly those who are living with HIV/AIDS. Cultural safety suggests that not only should practitioners respect an individual's cultural origins, beliefs and practices but also acknowledge the power relations that underpin constructions of culture (Reimer Kirkham et al., 2002). It points to a need to question and interrogate how the culture of health care is marginalizing patients. Inherent in the concept of cultural safety is the requirement for practitioners to acknowledge that they are bearers of culture and they need to examine their own behaviours, attitudes and cultural realities and the impact these factors have on others as well as to ensure that practice initiatives are only undertaken with the consent and input of the care recipient (Reimer Kirkham et al., 2002).

Cultural safety can be used as a tool for shifting health care providers' attitudes about Aboriginal peoples by helping them gain an understanding about the history of discriminatory practice against Aboriginal peoples in Canada and by helping them gain an awareness of how "Othering" attitudes continue to shape our relationships with Aboriginal peoples. It is common for non-Aboriginal Canadians to frame poverty, substance use and dependency as aspects of Aboriginal culture (Browne, Smye &

Varcoe, 2005b). The concept of cultural safety can be utilized for incorporating critical perspectives into nursing practice and education (Browne et al., 2005b), which allows health care providers to focus attention on power imbalances and individual and institutional discrimination. It serves to remind us that we must consider how policies, research and practices can recreate the traumas that have been visited upon Aboriginal peoples (Smye & Browne, 2002). It can also counter the tendencies of health care to create "cultural risk", which are the situations that arise when people from one particular culture believe that they are being "...demeaned, diminished or disempowered by the actions and delivery systems of people from another culture." (Ramsden & Spoonley, 1993, p. 164).

It was clear from the women's stories that they were subjected to a significant degree of cultural risk. They related many stories of discrimination and judgement and were reluctant to access health care services because they felt the services did not meet their needs. A cultural safety perspective would be helpful in ensuring that the context of the women's lives was acknowledged and that interventions addressed the complex issues that the women were dealing with.

Facilitating resilience.

It is important for care providers to assess their clients for resilient attributes and to plan interventions in collaboration with the client that facilitate their ability to utilize their resilient attributes. Although an individual's personality can confer an innate ability to react to adversity in a resilient fashion, resilience is a complex interplay of a number of learned responses. Resilient behaviour can be fostered. Being resilient means being hopeful. de Sales (2005) proposes that hope has four components: feeling "at one with",

having choices, connecting and being connected and having a driving force. In addition to personal attributes resilience is reliant on the existence of an appropriate community response. Resilient community responses include a clear mission, shared decision making, trust building, the encouragement of openness and the enhanced competence of the individual and the collective (Cadell et al., 2001).

Individual health care providers and those charged with developing programs can use knowledge of resilient characteristics to support their clients, both on a micro and macro level. On a micro level, health care providers can use their knowledge of resilience to assess and identify resilient attributes in their clients and assist them to transform adverse events into positive and self-enhancing ones (Edward & Warelow, 2005). On a macro level, program and policy design can take the resilient attributes of the client community into account to build capacity at both an individual and community level. Most importantly, the client and community who are the focus of program and policy design must be given the opportunity to take ownership of the strategy, and be given the economic resources and political autonomy necessary to achieve success.

In view of the significant problems that the women in this study have faced in their encounters with health care providers, which have been shaped by the racism, discrimination and structural inequities that marginalize and disadvantage Aboriginal women in general (Browne & Fiske, 2001) it may be difficult in the short-term for this strategy to bear fruit. The women are justifiably mistrustful of health care professionals and are likely to view with suspicion any attempts to "help" them develop resilient strategies. For this reason, it is vitally important that Aboriginal stake holders are included in any programs related to this issue, whether it is education sessions for health

care professionals around the strategies for building resilience or the design and delivery of programs and services for Aboriginal women that foster resilient behaviours.

Research

Research almost always provokes more questions than it answers and this study is no exception. The conclusions point the way to a number of research directions. It would be useful to conduct a larger scale ethnographic study that more clearly explicates the experiences of Aboriginal women who are living with HIV/AIDS with the health care system and other support services. The present study gave a beginning impression of the difficulties that some Aboriginal women living with HIV/AIDS face in their attempts to access health care and support services but it was a small group of women who shared many characteristics. It would be interesting to see if Aboriginal women who come from a more diverse background share the experiences that they had. Additionally, it would be valuable to gain a greater understanding of how health care service delivery differs in rural and urban settings.

An attitudinal survey of Aboriginal people in general in regards to HIV/AIDS would also be useful. There is a scarcity of information about the attitudes and values that Aboriginal peoples hold towards persons who are living with HIV/AIDS. In view of the fears many of the participants expressed about returning to their home communities because of stigmatizing behaviour it would be useful to get a clearer sense of this so that educational programs can be tailored to address the problem.

The women demonstrated varying degrees of ability to manage their HIV infection. It would be useful to conduct a study that looked more closely at the context of women's lives and the factors that influence the capacity of Aboriginal women to live as

well as possible with HIV infection. A mixed-methods study would probably be most appropriate, with some quantifying data on what personal characteristics and life circumstances are most supportive of living well with HIV/AIDS as well as women's stories about their experiences and strategies.

Any research that is conducted must be in accordance with the principles of Aboriginal research as outlined by CAAN (2004) – ownership, control, access and possession. Research is "...one of the dirtiest words in the indigenous world's vocabulary." (Ten Fingers, 2005). Aboriginal peoples have been the subject of numerous studies and often perceive that despite their participation they have had little control over the research process nor do they often witness positive change resulting from study findings. It is important that any research that utilizes Aboriginal people as participants involves them in a meaningful way in every respect.

Public Policy and Program Development

Decision making around policy and program planning has seen a shift away from opinion-based decision making to evidence-based decision making (Gray, 1997). It is important for policy planners to take heed of ongoing research efforts in relation to HIV/AIDS as they continue to develop and modify relevant public policy and programs. Health policy and program development needs to be rooted in Aboriginal culture (Ten Fingers, 2005) and needs to be situated in an indigenous framework as opposed to a colonial framework.

Another policy direction that must be undertaken is to make a concerted effort to train adequate numbers of Aboriginal peoples in health care and related professions. It is clear that until there is a critical mass of Aboriginal people in relevant positions in health

care disciplines and related professions it will be difficult for individual Aboriginal communities to truly take ownership of their health care and support services.

The women in the study all talked about how their children contributed to their desire to continue living despite their HIV infection and it appeared that there was a link between better health outcomes and maintaining a relationship with their children. For the women in the study their children were a source of hope and inspiration. The current policy around removing children from their families needs to be reviewed and consideration should be given to ensuring that Aboriginal women who are living with HIV/AIDS or who are at risk for HIV infection are provided with the resources and supports that they need to maintain custody of their children whenever possible and where this is not possible the ability of women to see their children should be supported.

The lack of accessible, women-centred, culturally appropriate health and support services needs to be addressed. The women in the study, as well as the discussion group at the Aboriginal HIV/AIDS conference all indicated that there is a need for a safe and welcoming space where Aboriginal women can go to have their health care and support needs addressed. This reflects the research of Benoit et al. (2003). They interviewed a number of Aboriginal women on the Downtown Eastside of Vancouver, who expressed a desire for a "Healing Place", which would be based on a model of care where their health concerns were addressed in a holistic manner, where they are treated with respect, and where they are given an opportunity to shape and influence decision making about the services that are provided. Another research project by Kellington et al. (2000) that documented the voices of HIV+ women also recommends that there be a network of women-specific "safe spaces" – open to both HIV+ and HIV – women in a variety of

communities around BC. A number of the women in the study talked about how much they valued the few existing services that addressed their needs in a holistic manner. Unfortunately the services that do exist are all situated in a large, western Canadian city. Aboriginal women with HIV/AIDS live in rural and urban communities all over Canada. Services need to be decentralized and available in a variety of settings and communities.

Implications for Leadership in Aboriginal Communities

Aboriginal leaders have a critical role to play in ensuring that HIV/AIDS stays on the political agenda. Most importantly, Aboriginal leaders need to be seen to be taking an interest in the issue of HIV/AIDS. "When community members see their Leader (sic) taking an interest and talking about the importance of HIV/AIDS awareness, it means a lot" (CAAN, 2006). Leaders need to work collaboratively at the community level, through regional bodies and on the national scene (CAAN, 2003). Aboriginal leaders need to be engaged so that community based staff get the direction and support they need to develop programs and services. There are a number of areas where Aboriginal leaders can direct their time and energy in order to ensure that HIV/AIDS gets the attention and resources that it demands. Leaders need to secure and support the human and financial resources that are necessary to build community capacity. They need to ensure that Aboriginal communities get the training and education that they need to prevent transmission of HIV and to support those who are living with HIV/AIDS. In addition, they need to ensure that HIV/AIDS work is incorporated into relevant services and agencies in a sustainable way, using partnerships and collaboration as appropriate. Lastly, Aboriginal leaders have an obligation to ensure that Aboriginal persons who are living with HIV/AIDS are protected from discrimination within their home communities. Fear

is a powerful obstacle to ensuring human rights are respected and the best way to remove the fear is through education and awareness, and by taking a leadership role that recognizes the reality of HIV/AIDS in Aboriginal communities, and that clearly sets out the obligations of Aboriginal communities towards persons who are living with HIV/AIDS (CAAN).

Concluding Remarks

Although the findings of this study are pertinent to anyone who delivers care and support to Aboriginal women who are living with HIV/AIDS, nurses have a pivotal role to play due to their history of providing direct care to clients in a number of health care settings. With their history of acting as advocates, culture brokers, and promoters of holistic care models, nurses, in collaboration with other health care providers and policy makers, are positioned to lead the way by working in collaboration with Aboriginal women who are living with HIV/AIDS to conduct pertinent research and to develop policies and programs that address the realities of their lives.

In her paper, Culhane (2003) comments on how Aboriginal women, particularly those who are marginalized due to substance misuse, poverty, abuse and HIV infection, are characterized as invisible. The findings from this study can be used to highlight and make visible the issues that some Aboriginal women confront in the context of their daily lives. Increasing the visibility of these issues is the first step towards ensuring that programs and policies are designed in a manner that best meets the needs of Aboriginal women who are living with HIV/AIDS. The women who participated in this study had a vision that we must share – a vision of living an engaged and productive life, of being loving and involved mothers and family members, and of participating fully and happily

in society without the chains of drug addiction and poverty. They cling to this vision despite their HIV infection and the challenges of economic, political and social structures that undermine their very existence. Despite the adversity they faced and the constant challenges they encountered, the women possessed an outstanding level of hope and optimism that their lives would improve. This was true even of the three women who died. Despite their obvious serious illnesses, none of them expressed a sense of despair. They all talked about the future and their expectation that their health, and their lives, would improve.

It is important for us to remember to hear the voices of others, to allow them to speak to us and tell us something, and to acknowledge their visibility and presence (Hart-Waseekeesikaw, 2003). It is imperative that the findings of this study are circulated and discussed, and that future research is directed towards understanding the lives and experiences of Aboriginal women who are living with HIV/AIDS, and also to the development of programs and policies that can bring about a positive change in their health and well being.

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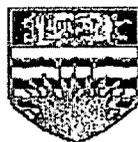
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APPENDIX B

Study: Aboriginal Women Living with HIV/AIDS: Their Experiences and Perceptions

Letter of Initial Contact for Potential Participants

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

The nurse researcher who is conducting the study is Jane McCall. She is a student in the masters of nursing program at the University of British Columbia and this study is part of her graduation requirements.

As an Aboriginal women who is living with HIV/AIDS, you are a potential participant for this study. If you are willing to give up 30 minutes to 1 hour of your time to participate in a confidential interview with Ms. McCall please let your nurse know and s/he will notify Ms. McCall who will contact you with the details of the research and clarify what is expected of you.

Please be assured that whatever your decision is, it will not impact on your treatment and care. You have the right to refuse to participate.

Thank you for giving this your consideration.

Jan. 17, 2005
Page 1 of 1

APPENDIX C

Interview Guide

Trigger Questions and Probes

1. Tell me about what it is like for you to live with HIV/AIDS
   Probes: How did you feel when you found out that you were positive?
   Has your HIV status affected your relationships with your partner, family, friends?
   What is the worst thing about living with HIV/AIDS?
   Has anything changed for the better since you were diagnosed?
   How do you tell people about your HIV status? Is it scary to tell people?
2. Tell me about your experiences getting health care since you were diagnosed with
   HIV?
   Probes: How do health care providers respond when you tell them that you are positive?
   Can you tell me about any health care services that are helping you stay healthy?
   Are you able to get the services that you need when you need them?
   Tell me about a particularly good experience with the health care system.
   Tell me about a particularly bad experience with the health care system.
3. What would you say needs to be improved about the health care you receive?
   Probes: What do you think you need to stay healthy despite your HIV infection?
   Is there anything you think you are entitled to that you aren't able to access?
4. Where do you look for support?
   Probes: do you get help from your family or friends? What does that help look like?
   Are there any support services in the community you like to use?
   How do you access them?
   Is it difficult to access them?
   Is there anything you would like to get that you aren't getting?
5. How do you find out information about HIV?
   Probes: What do you know about antiretroviral treatment? Are you on it? Have you ever been on it? What has your doctor told you about it?
   Can you tell me how it works?
   What kinds of health problems are you having? Are you able to get them treated successfully?
6. You seem to have some problems with your health. Do you think that is to be expected when you have HIV?
   Probes: What kinds of symptoms do you have on an ongoing basis?
   What do you do to manage them?
   What do you feel like when you feel healthy? What does healthy mean to you?

7. Is there anything you would like to comment on or ask of me?

8. I would like to provide the people who participate in this study a summary of what was learned. Would you like to receive this kind of report?
Yes_____ No_____

Confidential socio-demographic data to be collected (will be kept in a locked cabinet in a locked office):
Place of birth:
Date of birth:
Marital status:
Number of children and ages:
Present living conditions:
Presenting issue(s):
Aboriginal status and nation:
Contact information (for possible second interviews and for mailing of final report if requested):
Location of interview:
Length of interview:

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APPENDIX D

Informed Consent

Study Title: *Aboriginal Women Living with HIV/AIDS: Their Experiences and*

Perceptions

Principal Investigator: Dr. Annette Browne RN, PhD, Assistant Professor, UBC School of Nursing   Ph: 604-822-7558

Co-investigator: Jane McCall RN, BScN, MSN(C) is a student in the Master's of Science in Nursing program at the University of British Columbia. Jane McCall will be conducting this study as part of her requirements for graduation and it will be published as a thesis, which is a public document.

Purpose: You are being invited to participate because you are an Aboriginal women who is living with HIV/AIDS. The purpose of the study is to gain an understanding of the experiences, challenges and barriers that Aboriginal women who are living with HIV/AIDS face in their everyday lives and in their use of health care services.

Study Procedures: If you agree to participate you will be asked to participate in a private, confidential, face to face interview with Jane McCall. You may also be asked to participate in a follow up interview in a location of your choice to review the findings and provide your perspective and opinion on the findings of the research. It is anticipated that each interview will take approximately 30 minutes to 1 hour. The interviews will be tape recorded. However, you may ask for the tape recorder to be turned off at any point in the conversation or have the tape erased. None of the information that you share in the interview will be shared with the staff of the hospital who are providing care to you and your care and treatment in the hospital will not be affected by your participation in this study.

Risks and Benefits: It is not anticipated that there will be any risk attached to your participation although it is possible that disclosing personal information may be

the study nurse or participating institutions from their legal and professional responsibilities.

If you decide to be in the study and then change your mind, you are free to drop out of the study at any time.

Your signature below indicates that you have received a copy of this consent form for your own records, that you understand what is involved in participating, that the study has been explained and that all your questions have been answered.

Your signature indicates that you freely consent to participate in this study.

_____   _____

Participant signature   Printed name   Date

_____   _____

Researcher signature   Printed name   Date

Release of findings:

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

information.

Address:

Phone number:

Signature:

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APPENDIX E

Are you an Aboriginal woman who is living with HIV/AIDS?

This study might be for you.

Jane McCall is a nurse who is conducting a research project for her master's thesis requirements. She is interested in collecting the stories of Aboriginal women who are living with HIV/AIDS.

If you would be willing to give 30 to 60 minutes of your time talking to Jane about your life, please let Doreen Littlejohn know how Jane can get in touch with you.

The interviews will take place in a private place of your choosing and will be tape recorded. Any information that can identify you will be kept strictly confidential.

In recognition of your time and commitment, there will be an honorarium of $20.00.