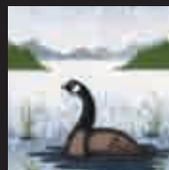
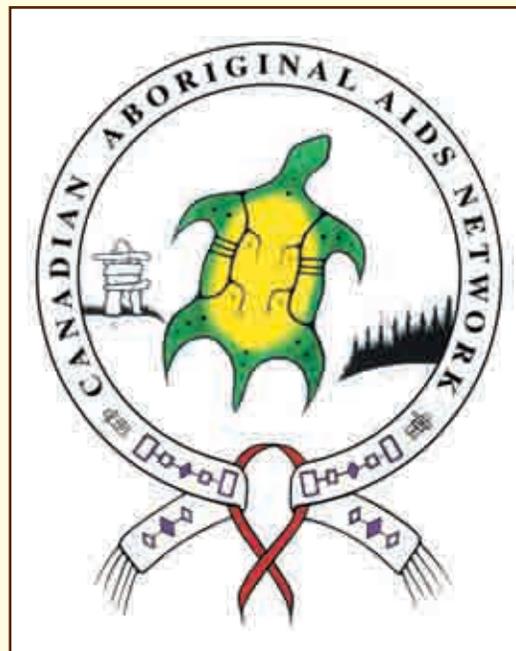
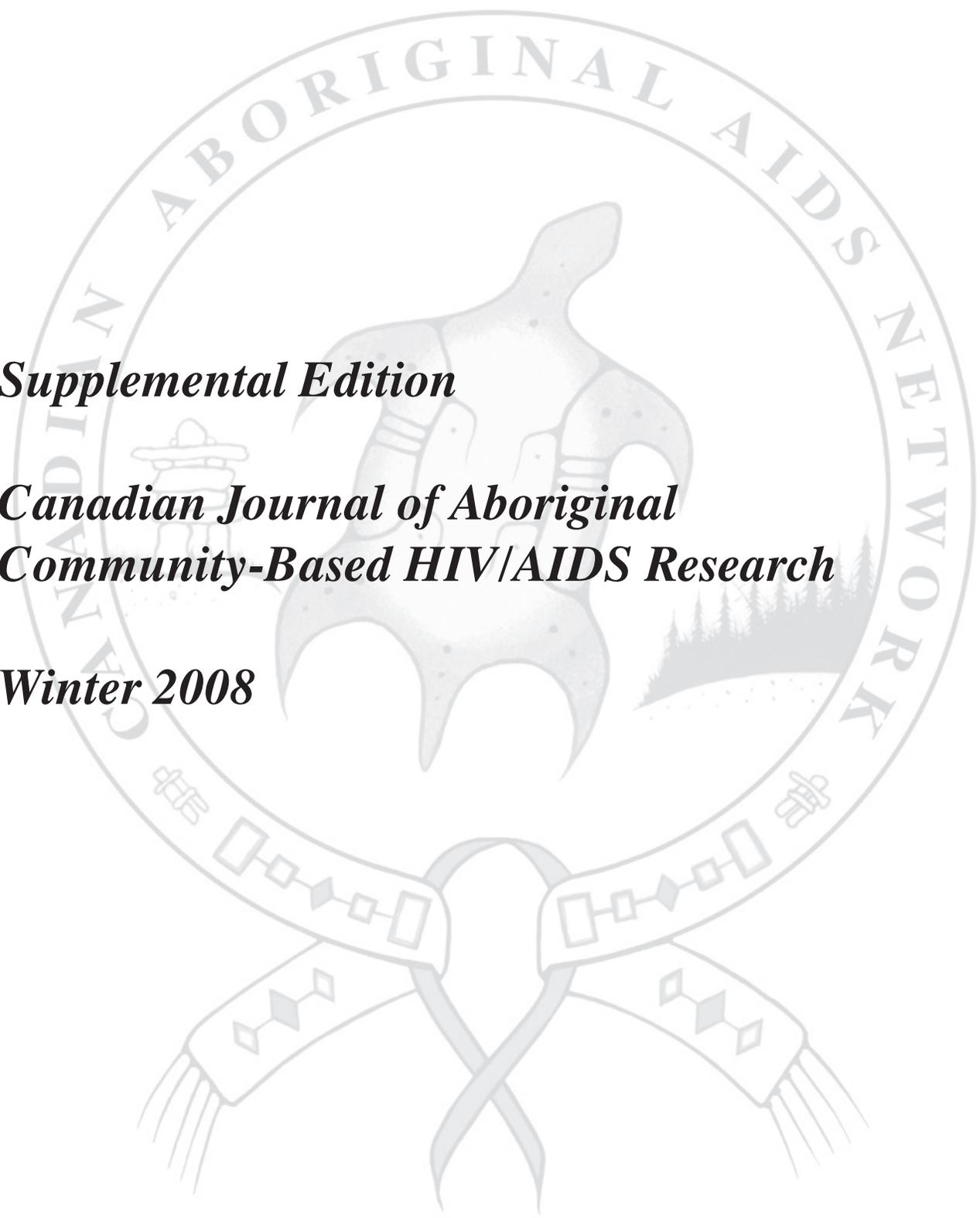


CANADIAN JOURNAL OF ABORIGINAL COMMUNITY-BASED HIV/AIDS RESEARCH

SUPPLEMENTAL EDITION • WINTER 2008





Supplemental Edition

*Canadian Journal of Aboriginal
Community-Based HIV/AIDS Research*

Winter 2008

THE CANADIAN ABORIGINAL AIDS NETWORK (CAAN)

Overview

The Canadian Aboriginal AIDS Network is a national, not-for-profit organization:

- Established in 1997
- Represents over 340 member organizations and individuals
- Governed by a National thirteen member Board of Directors
- A four member Executive Board of Directors
- Provides a National forum for members to express needs and concerns
- Ensures access to HIV/AIDS-related services through advocacy
- Provides relevant, accurate and up-to-date HIV/AIDS information

Mission Statement

As a key national voice of a collection of individuals, organizations and provincial/territorial associations, CAAN provides leadership, support and advocacy for Aboriginal people living with and affected by HIV/AIDS. CAAN faces the challenges created by HIV/AIDS in a spirit of wholeness and healing that promotes empowerment, inclusion, and honours the cultural traditions, uniqueness and diversity of all First Nations, Inuit and Métis people regardless of where they reside.

Acknowledgements

Production of this document has been made possible through a financial contribution from the Canadian Institutes of Health Research (CIHR). The views expressed herein do not necessarily represent the views of CIHR.

ISBN No. 1-894624-62-9

Canadian Aboriginal AIDS Network
602-251 Bank Street
Ottawa, Ontario, K2P 1X3
Telephone: 1-613-567-1817
Toll-Free: 1-888-285-2226
Internet: www.caan.ca
Email: info@caan.ca

Winter 2008

Canadian Journal of Aboriginal Community-Based Research (CJACBR)
Published by the Canadian Aboriginal AIDS Network (CAAN)

Editorial Policies: Purpose and Audience

The CJACBR is an annual on-line and paper journal published by CAAN as a service to its members and anyone with an interest in Aboriginal Community-Based Research.

The CJACBR is a peer-reviewed journal which welcomes contributions for any author. Priority however, may be given to an author of Aboriginal ancestry/background, should manuscripts of comparable quality be available. First consideration will be given to innovative articles covering areas identified as HIV/AIDS research-intensive which demonstrates the use of Aboriginal Community-Based Research (ACBR) methods or philosophy.

Articles published in CJACBR are directed toward several audiences. The primary audience is Aboriginal HIV/AIDS service organizations and Aboriginal people living with HIV/AIDS (APHAs). The CJACBR secondary audiences include community leaders, policy and decision-makers, and anyone with an interest in HIV/AIDS, particularly within Aboriginal populations and communities.

Acknowledgements

CAAN would like to acknowledge the members of the Editorial Peer Review Board. Each member contributed to the development of review policies in addition to contributing to the peer review process.

Editorial Peer Review Board members were:

Harry Adams
Valerie Galley
Charlotte Loppie
Namaste Marsden
LaVerne Monnette
Gabe Saulnier
Lucy Barney

CAAN Editors:
Randy Jackson, MA, and Renee Masching, MSW

Journal Layout:
Allegra Print & Imaging, 1069 Bank Street, Ottawa

Table of Contents

Introduction	1
Section 1 – Aboriginal community-based HIV/AIDS research and development	3
The Effects of Stigma on Aboriginal Women Living with HIV/AIDS	5
<i>Donna M. Hill and Donna L.M. Kurtz</i>	
Section 2 – Dissemination of Results / Findings	15
“I can’t deal with this alone”: Support for Aboriginal men and women living with HIV	17
<i>Judy Mill, Louanne Keenan, Denise Lambert, Kecia Larkin, and Ken Ward</i>	
Call for Papers	31

Introduction

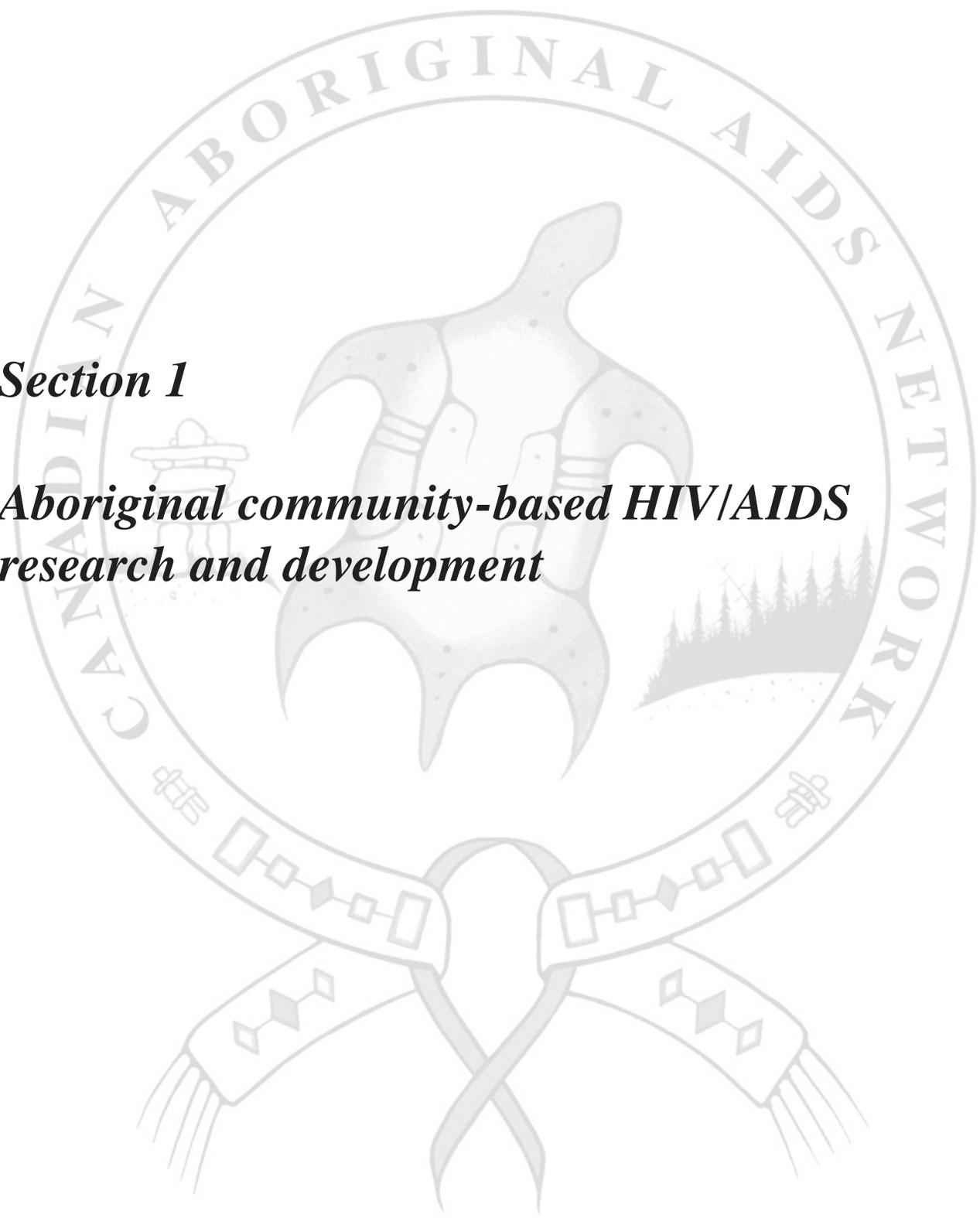
The inaugural edition of the Canadian Journal of Aboriginal Community-based HIV/AIDS Research (CJACBR) was published in the Summer of 2006. This was an exciting time when the International AIDS Conference was held in Toronto. The CJACBR was launched during the International Indigenous Peoples Satellite, an event preceding the conference itself. Response to this new forum for sharing research results and reflecting on Aboriginal community-based research has been overwhelmingly positive. It is with great pleasure that we move forward again with the production of a supplement to the first edition.

CAAN continues to advocate for an increase in the scientific examination of the HIV epidemic as it impacts the Aboriginal community. We are invested in developing the CJACBR as a well respected academic journal with absolute relevance to the grass roots communities that we serve from sea to sea to sea. We continue to engage in community-based research as an organization and support capacity building at the community level. The CJACBR provides an excellent resource to share insights learned through CAAN's work and to highlight the hard work that is ongoing across Canada and around the world in response to HIV/AIDS and Indigenous Peoples.

Once again, the Editorial Peer Review Board offered carefully considered feedback for each article submitted for publication. The outcome is a supplement to the inaugural edition of the journal which shares articles that meet the high standards we have set for both academic and community integrity. These articles address the needs of APHAs and the reality of the impact of stigma. Both of these issues are core concerns for the CAAN membership as demonstrated through resolutions from our Annual General Assemblies.

The CJACBR is still a new medium for sharing insights regarding research processes within the Aboriginal HIV/AIDS movement and we look forward to nurturing the growth of the journal. The ongoing publication of this journal continues to fill a significant void in the literature base regarding Aboriginal Peoples and HIV/AIDS. We will continue to use this as a resource to create opportunities to highlight excellence in Aboriginal community-based HIV/AIDS research.

Kevin Barlow
Chief Executive Officer



Section 1

***Aboriginal community-based HIV/AIDS
research and development***

The Effects of Stigma on Aboriginal Women Living with HIV/AIDS

Donna M. Hill¹ and Donna L.M. Kurtz²

ACKNOWLEDGEMENT

The authors wish to thank Dr. Cynthia Mathieson, professor of Psychology, University of British Columbia Okanagan, for her time and scholarly contributions to the initial draft of this paper.

ABSTRACT

Stigma has a serious impact upon the lives of HIV-positive Aboriginal women. The ways in which Western society presently addresses stigma, specifically that which is directed towards Aboriginal women living with HIV/AIDS are unacceptable. Their experiences in life are laden with discrimination, social rejection, marginalization, and violence against them—this needs to be changed. In this paper, we offer a critical view of three kinds of discourse around stigma, social, statistical reporting, and medicalization, that influence the ingrained societal ideologies around stigma. We will use the literature to critically analyze the dominant discourse around stigma and to briefly unfold common strategies for anti-stigma discourse. Through exposing these discourses, we hope to uncover the negative impact that stigma has on the lives of Aboriginal women with the intent to shift the perceptions of the public, thus assisting the women in the reconstruction of a healthier social and personal identity of self. The social contexts surrounding the discourse of stigma can, and must, transform for the benefit of women living with HIV/AIDS and their healthy identities.

INTRODUCTION

HIV has come to be known as a socially constructed illness that affects the most marginalized of people. HIV/AIDS is understood and experienced within social and cultural contexts. Society has learned to view the illness and HIV-positive people with stigmatizing attitudes, which, in turn, influence the ways people live with the illness (Clarke, Friedman & Hoffman-Goetz, 2005).

For Aboriginal³ peoples throughout Canada, the AIDS epidemic continues to rise at a disproportionate rate as compared to the rest of Canadians (Health Canada, 2003). Aboriginals accounted for 14.1 of AIDS cases reported in the first half of 2002, up from 5.3 percent in 2001, and 10 percent in 1999 (Public Health Agency, 2007). Aboriginal people are three times as likely to be HIV-infected than other Canadians with exposure occurring predominantly as a result of intravenous drug use (53 percent) (Public Health Agency, 2007). As many as 25 percent of all AIDS cases in Canada are Aboriginal, and of those, nearly half are Aboriginal women (Barrett and Bissel, 1999, Hill, 2003, Canadian Aboriginal AIDS Network [CAAN], 2003, Majumdar, Chambers, & Roberts, 2004). More and more Canadian women are being diagnosed with HIV-infection and Aboriginal women are most at risk (PHAC, 2005). Health Canada (2003) reports Aboriginal women represent a significantly higher proportion of HIV/AIDS diagnoses than non-Aboriginal women (45.3 percent vs. 19.9 percent).

The HIV epidemic in the Aboriginal community is not decreasing. There are multiple notions of why this is happening. Bucharski, Reutter, and Ogilvie (2006) found that fear of being judged by family, their community, and society often interferes with seeking testing resulting in delayed diagnosis. Judgments by society can make

¹ Métis Nation, MA Graduate Student (2006) BC ACADRE Grant Recipient), University of British Columbia Okanagan, dmhill@shaw.ca

² Métis Nation, Associate Professor School of Nursing, University of British Columbia Okanagan, donna.kurtz@ubs.ca

³ The term 'Aboriginal' is used to refer to First Nations, Métis, and Inuit Peoples in Canada, whereas the term 'Indigenous' refers to Aboriginal Peoples globally. These terms are used interchangeably depending on the language used by the author cited. (Kurtz, Nyberg, Van Den Tillaart, Mills, & Okanagan Urban Aboriginal Health Research Collective [in press]).

an individual feel shame for becoming infected or for living a 'risky' lifestyle. Self-shame is one stigmatizing attitude among others such as fear and denial. Poindexter (2004) describes stigma as: "labeling differences negatively or stereotyping based on cultural beliefs. ...HIV stigma, is a particular form of discrimination that causes social and emotional problems for persons with HIV and their associates" (p. 498). The ways in which Western society presently addresses stigma, specifically in relation to Aboriginal women living with HIV/AIDS, are unacceptable and need to change.

Before changes in the societal view can be made, we need to understand how stigma impacts the lives of Aboriginal women living with HIV/AIDS through a critical lens of the underlying societal ideologies of three kinds of stigma discourse. We define discourse as the communication of thought (discussion, dialogue) by written or conversational words. The three edged sword of stigma includes: 1) social stigma, 2) statistical or qualitative reporting of HIV/AIDS, and 3) the medicalization of stigma. In reality, these three kinds of stigma are often inextricably woven together and influence each other. Therefore, they cannot bethere may be some difficulty individually discussed discussing them without losing the depth of the significance of the individual and the interwoven impact on individuals.

To illustrate how social/public discrimination is intertwined with statistical reporting and the medicalization of HIV, we present a case study of one family's experience with a daughter's illness leading to HIV-diagnosis. The events immobilize the parents, and their young daughter, resulting in a two-year struggle preceding the HIV-diagnosis. They face a multitude of issues related to stigma that are common for many people going through the question of infection and diagnosis of HIV. We contend that social discrimination, statistical reporting, and the medicalization of stigma are devastating and debilitating for those living with HIV/AIDS.

SOCIAL DISCRIMINATION

Poindexter's study (2004) of caregivers provides the case study of two parents, Peg and Mike, and their belief that their daughter Kate (pseudonyms) is free from contracting HIV because she did not fit the stereotype of a person at high risk for contacting HIV. This assumption delayed HIV-testing and her "gender, race, education, appearance, and socio-economic status contributed to her not receiving an accurate [HIV] diagnosis despite repeated medical examinations" (p.496).

Had Kate been Aboriginal, the events leading to her diagnosis may have been more severe. Bucharski et al. (2004) found that some Aboriginal women fear being tested because a positive diagnosis could lead to rejection by family and society, depression, suicide, and being stigmatized by their own communities. The women's past negative experiences with mainstream service agencies cause hesitancy in accessing healthcare services, which delay early diagnosis and treatment.

Western medicine relies on medical/professional/researcher scientific evidence for diagnosis of illness. "Physicians, charged with being efficient and accurate as they strive to diagnose quickly and treat appropriately, at times use epidemiological and prevalence data or consult profiles and protocols to determine who is most likely to have a particular ailment" (Poindexter, 2004, p. 496). These statistics can negatively impact women living with HIV/AIDS through the medicalization of stigma and social discrimination.

In Poindexter's study (2004), Peg and Mike are working class, Irish-American, ex-Catholics, with four grown children, the youngest of whom is their daughter Kate. What becomes evident in the story they share about their daughter Kate's illness is the fact that, they, along with the medical system, seemed to inadvertently add to the stereotypical images of their daughter. Kate, in everyone's eyes, did not fit the profile of someone needing to be tested for HIV. Peg's comments are stigmatically related to the picture of her daughter and "it" as not fitting the "lifestyle" of anyone with HIV/AIDS. "'It' seems to mean the possibility of HIV infection, and 'lifestyle' seems to refer to the antecedents: not too much drugging and not too much sex" (Poindexter, 2004, pp. 502-503). Peg often refers to "we," meaning her and her husband (and possibly Kate) as not understanding how the possibility of HIV-infection could have become a part of their lives.

Kate's mother, Peg, was aware that her daughter was having unprotected sex, but did not broach discussion of sexually transmitted infections (STIs) with her. Nor did she consider that any STIs could harm Kate, or ultimately, be the cause of her deteriorating health. Peg considered Kate's ability to stay working as traits of strength and courage, and as a rationale that she could not have such a serious infection as HIV.

The diagnosis of HIV for an Aboriginal woman has an additional impact on her life because of colonization and the history of government involvement in the apprehension of Aboriginal children (residential schools, foster care) (CAAN, 2004, Mill, 2000).

Many HIV infected women are primarily responsible for their own self-care, and the care of their children, partners and other family members who may also have HIV or AIDS. The day to day stress of living with HIV, being forced to survive on an inadequate income in poor living conditions with little or no community supports often force women to place their health and needs at the bottom of their priority list. This is consistent with the tendency among women in general, and Aboriginal women in particular, to put the needs of others ahead of themselves. (CAAN, 2004, p. 8)

By delaying or avoiding their possible HIV-diagnosis in order to remain primary caregivers for their children, Aboriginal women often decide the not knowing (about their status) is the better alternative for themselves and their families. Lather and Smithies (1997) formed a support group for minority women living with HIV and recorded some of their experiences. Rita (who moved from a different state where she was "out" as a positive woman) had this to say about keeping her family safe from stigma:

Being out brings you more peace of mind, but it's still hard. I worry about the stigma on my son, especially. I was like a freak when I was out as HIV+. That's part of the reason I moved. I choose very carefully who I tell. You might be able to handle it, but what about your family? You can't really think about you wanting to tell the world. You have to stop and think how this will affect your family. (p.9)

For many Aboriginal women, facing an HIV-diagnosis means additional burdens that the greater community is often not aware of. As Rita explains, many have to consider the well-being of their families. This, in turn, jeopardizes the women's willingness to be tested in the first place, and then their ability to receive necessary healthcare and treatment options available to them. Not only are the experiences of living with HIV multicontextual, but so are the very decisions to be tested, and to acknowledge an HIV- positive status.

Goffman (1963) discusses the notion of passing: persons not appearing to be ill or different from persons considered normal and healthy. He illuminates that the control of identity information has a bearing on relationships. We interpret this ability for passing, and the sense of blindness and lack of family discourses, as stigmatizing discourse, including both what is said, and that which is actually not said, or intentionally avoided. To avoid social stigma, Peg sought to respect Kate's determination to pass as healthy as an act of seeking normalcy in each of their lives and of avoiding those possibilities for her illness that would be more discriminatory, such as an HIV-diagnosis. The notion of normalcy is especially problematic as we perceive our identities. Dominant belief or discourse purports that if someone is normal, then they are (or must be) healthy, and visa versa (Goffman, 1963). This belief—the dismissal of symptoms and ignoring possible illness—seem to be one of the causes that resulted in the delay of Kate's diagnosis, thus causing more serious illness, progression of the disease, and risk of spreading the infection.

The invisible and deeply internalized feelings of stigma have been categorized as "courtesy" stigma, in relation to accepting guilt and shame on behalf of family and friends (Byrne, 2000, Goffman, 1963). Sandelowskie, Lambe, & Barroso (2004) report their integrated findings from studying stigma in 93 reports of qualitative studies conducted between 1991 and 2002 with a total of 1,780 women, mostly from minority groups: "A factor likely accounting for the frequent blurring of perceived and actual stigma was the women's internalization of negative cultural views of HIV-infection that contributed to their feeling dirty, deadly, and deficient" (p. 124). In response to the health implications of historical labels for Aboriginal women such as "drunken squaw, dirty

Indian, easy and lazy” (Anderson, 2000, p. 99), Kurtz, Nyberg, Van Den Tillaart, Mills, & Okanagan Urban Aboriginal Health Research Collective (in press) comment: “This negative portrayal of Aboriginal women, along with racism and discrimination, contributes to their silencing, thus pushing them into an oppressed position in society and leading to their poor health today.” While Sandelowskie et al. (2004) highlight the negative impacts of social discrimination on the women’s identities, the distinction between “perceived and actual stigma” (p. 124) has not been established. However, the realities of stigma continue to exist for Aboriginal women regardless of them being defined as perceived or actual.

Within current societal views, social processes and social relations are entrenched in dominant discourses of white middleclass norms. Subsequently, they are also embedded in the perceptions of normalcy that contributed as a negative discourse to Kate’s stigma. As Mill (2000) suggests, stigma may be related to the continued epidemic of HIV-infection for Aboriginal people by delayed testing. The minority women in Sandelowskie et al.’s study (2004) reveal family members refusing to accept the HIV-diagnosis of a loved one, discrimination from friends, family, and professionals, and receiving severely prejudice remarks about HIV-positive people. The authors conclude that “[b]oth perceived and [actual] stigmas were pervasive in the lives of the HIV-positive women. HIV-related stigma was intensified in women because they were women” (p. 122). This “pervasive” (p. 122) social stigma that Sandelowskie et al. (2004) refer to does not specifically address the effects of stigmatic discrimination for Aboriginal women. However, they do successfully report the pervasiveness and felt stigma for women in general, as opposed to generalizing stigma for both genders. Such significant effects of stigmatizing discourse directed towards HIV-positive women include: living in fear and the hurtful effects of stigmatization; social rejection; discrimination; violence in relation the children, partners, friends, relatives, and acquaintances; and, feeling and reporting the effects of stigmatization even when none was directed towards them (Hill, 2003, Mill, 1997, Sandelowskie et al., 2004). Aboriginal women diagnosed with HIV, who are faced with specific health disparities compared to other Canadian women, such as shortened life span, higher incidence of chronic illness (diabetes, arthritis, heart disease), also bear the burden of ill-health, premature death, and marginalization that is unimaginable by most other Canadians (Dion-Stout, Kipling, & Stout, 2001).

The effects of an HIV-diagnosis with the burden of societal discrimination of stigma are demonstrated by Kate’s father. His narrative about Kate’s HIV-diagnosis is imbedded with stigmatizing responses based on dominant discourses. He divides his life in two parts: fun and normalcy before the knowing, and then afterwards, the traumatic process of dealing with Kate’s new diagnosis. When asked how Kate’s illness has affected him, Mike answers “with a confession about how he was ‘wrong’ about HIV before he knew his daughter has it” (Poindexter, 2004, p. 504).

STATISTICAL REPORTING

Just as social discrimination impacts the lives of those diagnosed by HIV/AIDS, the way in which research studies are reported can lead to naming, blaming, and marking populations. Studies often report quantitatively, rather than qualitatively, about the disparities in the health of Canadians that exists among Aboriginal women (CAAN, 2004, Health Canada, 2003). It is about both kinds of perpetuating stigmatizing discourses, that of lived experience as well as that of statistical marginalization, that prompts our discussion. Statistical analysis, for public health and epidemiology reporting, is often vital to the progression of effective research and policy change.

For marginalized people such as Aboriginal women, these numbers can lead to the women’s objectification and to further mobilization of social stigma, blame, and isolation (Byrne, 2000). The anticipation of questions about their assumed and statistically reported risk behaviors is a barrier for Aboriginal women accessing services. Some women are not familiar with the statistics about their “Aboriginal and gender risk” of HIV-infection and wonder about the necessity of the questioning during testing, thus resulting in the hesitancy to disclose the truth or to go for testing (Bucharski et al., 2006).

One term for this kind of pathologizing philosophy, where statistics categorize and further spotlight those already marginalized, is individualism. Individualism involves a form of finger pointing or blaming the individual for his or her social and personal problems, rather than taking a critical look at the social or societal context. This view point changes the source of the problem from society as a whole to the person, rather than being concerned with the social problems of the greater society in which we live. When left unchallenged, the ideology of individualism assumes behaviors that are inaccurate; promotes the rise of isolation and marginalization of individuals; convinces society to avoid social justice causes for the benefit of such individuals; and “in short, maintains and elaborates the oppression of all peoples by distracting our attention away from the ‘man behind the curtain’.” (Chrisjohn, Young & Maraun, 2006, p. 285).

Clarke’s (2005) study is an example of blaming the individual for their HIV-status: “Those with the disease were characterized [in the media] as outsiders, considered to be at fault and themselves blamed for their diagnosis of HIV/AIDS [homosexual activities or illegal drug use]” (p. 2170). In such instances, where statistical reporting further marginalize, categorize, and finger-point towards Aboriginal women, they are further isolated from their communities and burdened with feelings of guilt, shame, and blame (Byrne, 2000).

In Kate’s situation, she may have been shielded from the social stigma of HIV initially as she did not fit the ‘profile’ based upon statistical reporting for HIV-infection. However, her HIV- illness signs and symptoms were ignored, delayed, and her parents and physician were blinded by her white middle-class position in society and by the statistical reporting, resulting in more serious health problems due to a late diagnosis. This in itself further marginalized her and contributed to her poor health by not receiving a timely diagnosis and treatment and by the perpetuation of stigma, statistically and socially.

In comparison to Kate’s delay in diagnosis and HIV-related stigma, some Aboriginal women who are pregnant are often told they have to get tested for HIV, or are automatically given a requisition for the blood test (or other tests) without explanation by the health care professional, or are threatened with having their children taken away by the government if a woman refuses to be tested (Bucharski et al 2006).

Ryan (1976) describes individualism in another way, as socially imposed alienation. This kind of stigma should be critically reviewed in relation to the way in which statistical data is reported, particularly with respect to Aboriginal women:

The new ideology attributes defect and inadequacy to the malignant nature of poverty, injustice, slum life and racial difficulties. The stigma that marks the victim and accounts for his victimization is an acquired stigma, a stigma of social, rather than genetic, origin. But the stigma, the defect, the fatal difference—though derived in the past from environmental forces—is still located within the victim, inside his skin. (p. 7)

Our argument is in agreement with Ryan, that stigma—in this case, statistical highlighting—significantly categorizes those living with HIV/AIDS. In Western society, where Aboriginal women already face social discrimination based of their ethnicity, the practice of further marginalizing them based on the kind of social illness they may have contracted needs to be seriously addressed.

In Poindexter’s study (2004), Mike speaks about Kate’s HIV-diagnosis as an ‘acquired’ stigma, thus framing the stigma socially. He blames Kate’s boyfriend who may have given her the virus, rather than considering that Kate may have been infected elsewhere:

106: If it isn’t going to bother you,
107: You have nothing to gain by learning about it,
108: Why bother?
109: If it isn’t interesting.
110: I mean, just look at *her*.

111: And think, I think that guy that brought it in, into Kate's *life*.
112: Is a guy that came into our *house*.
113: Had dinner at our *table*.
114: Dated Kate. (p. 504)

There does seem to be a shift (beginning to accept the diagnosis) in Mike's perceptions and stigmatic discourse, however, as he slowly comes to terms with both the virus and its impact on his family member's lives. He goes on to say:

115: It was just one of those *things*, you know, and it's *sad*.
116: Yeah, I look at that today, I thought it was *dirty*.
117: I thought, well, you weren't supposed to *get* it.
118: Well, she *did* get it.
119: And uh, then you find out *anybody* can get it
120: Doesn't matter where, what, *where* you are. (504)

Mike admits his previously held stereotypes about HIV and people living with the disease in the ways he uses the word "dirty," makes reference to "that guy" who sat at the family dinner table, and when he implies his daughter was not "that kind of girl." However, his narrative also voices a paradigm shift, as he moves through a place of confusion during the two years of not knowing about Kate's true illness, to a current place of more understanding and acceptance.

MEDICALIZED STIGMA

To synthesize Poindexter's position on HIV stigma within this family, "the parents were also experiencing stereotyping, profiling, and blindness. The parents shed their ignorance suddenly, just as the physicians did" (2004, p. 508). Some of the patterns explored throughout their narratives include their confusion of not knowing, their shock and trauma of finding out, and their profiling (just as the medical system did). Kate and her parents, along with their doctors, exemplified a parallel process of social discrimination, statistical assumptions, and stigmatizing medicalization. Even if Peg and Mike were correct to assert the medical profession's blindness to Kate's diagnosis based on typical gender, class, and lifestyle profiling, the doctors were not alone. They were assisted by Kate's parents' inability to also see and accept. Kate simply did not *appear* to be sick with the HIV virus. Subsequently, this double-edged sword of "othering," of incorrectly profiling, and thus, of further jeopardizing Kate's life with a delayed diagnosis, is an example of the absence of overt discrimination. But it is, in fact, still a negative part of the discourse of stigma that many Aboriginal women, especially those living with HIV/AIDS, endure.

Lather and Smithies (1997) share Diane's personal testimony: "Also it is hard when you are a woman, because with the diagnosis you are either promiscuous, or labelled as not normal." When asked what she meant by label, Diane's answer is, "Well, I mean, like people stereotype people who are infected with the virus. I mean, we are very stereotyped. We are gay. We are uneducated. We are, you know, sleeping around" (p. 4). Kurtz et al. (in press) confirm the difficulties many Aboriginal women and their families struggle with:

As the healthcare decision-spokesperson for the family, they attempt to negotiate healthcare services in environments where their 'Nativity' labels them as 'Other' and keeps them outside the dominant culture in which health care is delivered (Barrios & Egan, 2002). Many such issues result in Aboriginal women choosing to avoid or seek access to mainstream health care.

Stigma and discrimination, fuelled by a healthcare system that perpetuates racist attitudes such as these, have serious social and physical implications for Aboriginal women who must face these ongoing barriers that impact their health and well-being.

With social discourses about stigma inclusive of discrimination, quantitative statistical highlighting, and medicalization, HIV-positive Aboriginal women's marginalization and despair will only continue. The stigmatizing lens through which the women are viewed, directed by such statistics, only intensifies with the interlocking oppressions of classism, race, gender, and sexual orientation. Butler (1998) contends it is impossible to isolate gender when deconstructing oppressions just as Razack (1998) notes the equal impossibilities of unlocking race, place, and space from gender politics. These interlocking oppressions need to be slightly deconstructed.

Stigma related to position in society, sexual orientation, and the workforce surfaces from the medicalization of HIV/AIDS. If we consider class, those HIV-positive women best able to manage the worst effects of their stigmatization are white and middle-class (Poindexter, 2004, Sandelowskie et al., 2004). Earlier findings by Collins (1993) also defend this premise: "White feminists routinely point with confidence to their oppression as women but resist seeing how their white skin privileges them" (p. 25). Gender orientation and race are further areas of discrimination. These include relational intersections of oppression, heterosexism, and limited vision (Razack, 1998, 2002, Zinn & Dill, 1996). For example, some time ago, an Aboriginal woman disclosed to me (author, Donna Hill) that she was recently diagnosed with HIV (personal communication, 2006). Even though testing can be, or for many clients, is meant to be, anonymous, there still exists an information tracking system. In the unfortunate result of a positive viral test, identifiable markers such as initials and birthdates are used so the client can be traced and given the appropriate health information and counseling. This woman continued to share with me that, although she was informed of her positive status only a week prior, "they've [the medical staff at the clinic] known I was positive for two years." Considering the invisibility imposed upon her, we might ask, were health protocol and procedures not followed because this client is a woman? Is it because she is Aboriginal? Or, did her invisibility occur because she perhaps transgresses the social norms by being a sex worker or a drug addict? The complexities from which these questions stem embody the medicalization of stigmatizing discourse.

Poindexter (2004) addresses the intersections of medicalization, social expectations and discriminations, and the realities of being faced with an HIV-diagnosis. Ultimately, the parents in the explored case study do not blame the doctors, nurses, or the medical system for their lack of early diagnosis of their daughter's illness. Nevertheless, this does not negate an emphatic example of the medicalization of stigma attached to the discourse of HIV/AIDS for women. It is an example that creates stigmatizing responses towards women. In this situation, the doctors may not have had all the "right answers" but in their search for a correct diagnosis, their hegemonic power prevailed over everyone, including themselves, in the consideration of HIV as a source of illness. We argue that the family's societal status, ethnicity, and employment advantages privileged them over other minority women such as the Aboriginal woman mentioned above. This Aboriginal woman is someone who experienced, either implicitly or explicitly, multifaceted layers of oppression, limited vision, and marginalization from various mainstream healthcare professionals. We believe her situation is an example of the medicalization of stigma.

Medicalization is the dominant medical power over a subjugated group (Byrne, 2000, Poindexter, 2004). It is the dominant belief in our society that doctors have the right to tell their patients what to do, and that doctors have all the answers. Medicalization is an assumption that Western medical hegemony is the best health care for everyone concerned. The medicalization of stigma is the more insidious process that reproduces the *status quo* of women and HIV. This is evident in both academic and popular literature that theorizes women's vulnerability toward HIV/AIDS. For example, as J. Weeks contends;

AIDS has become the symbolic bearer of a host of meanings about our contemporary culture: about its social composition, its racial boundaries, its attitudes and social marginality; and above all, its moral configurations and its sexual mores. A number of different histories intersect in and are condensed by AIDS discourse. (Cited in Shefer, 2004, p. 3)

Relating to Weeks' concerns about the varying intersections of AIDS and histories, we acknowledge the historical and postcolonial contexts of these challenges, such as racial boundaries; colonialization and the lasting effects

of residential schooling; multigenerational abuse; drug and alcohol addictions; economic, social and physical power imbalances; and, subordination in education, employment and social and legal status (Campbell, 2002, Chrisjohn et al, 2006, Ship & Norton, 2001, Wuest, 2003). Although such encompassing issues cannot be covered within the scope of this paper, we concede they are crucial to understanding Aboriginal people and the historical and the societal contexts in which they live that affects who they are as people today.

ANTI-STIGMA STRATEGIES

So far, we have briefly surveyed three cornerstone examples of discourse around HIV-related stigma: social discrimination, statistical reporting (stigma resulting from quantitative statistics) and medicalization. We have also touched upon socially interlocking oppressions for HIV-positive women, particularly, Aboriginal women, such as categorization, isolation, poverty, race, gender, and sexual orientation. We will now look at a few interdependent anti-stigma strategies.

Briefly, a blueprint for anti-stigma strategies includes self-advocacy, specific target groups based on prior discriminatory attitudes, lack of public backlash, flexible education packages, intervention over time, and continuing contact to maintain momentum (Byrne, 2000, Smith, 2002). We, along with Byrne and Smith, advocate for a shift away from stigmatizing discourse, if not a complete disbanding of such discourse. However, researchers such as Guttman and Salmon (2004) place more focus on the strategies themselves, and remind us of the ethical considerations in public health communication interventions. Since the focus of anti-stigma strategies is already about ethical considerations for improving the lives of marginalized people, we agree, only to a point, with Guttman and Salmon. If ethical deconstructions of stigma interventions were to land too far to the conservative right along the continuum of helping those most negatively affected by stigma, then we would argue for more caution about their concerns. Instead, what is needed is a greater sense of concern about more marginal assumptions, rather than the *status quo*. There needs to begin a greater valuing of inclusion and diversity, rather than remaining persuasively situated within the hegemonic discourses of “othering” and marginalizing people in our society.

CONCLUSION

Our intent in this paper has been to critically challenge the three dominant discourses around stigma and their effects on Aboriginal women living with HIV using current literature and one woman’s personal experience. Both suggest it is time to disband all forms of stigmatizing discourse, particularly that which surrounds HIV-positive women. We encourage working together to put an end to the women’s experiences of discrimination, social rejection, and marginalization. Society needs to assist the women in the reconstruction of healthier social and personal identities for themselves. After all, “[h]uman development is an ongoing effort to affect a balance between these needs and these fears [about stigma]” (Josselson, 1989, p. 104). We concur with Josselson that the ability to affect change influences the identity of human development. This identity is one that is shifting, altering, and fluidly affecting, and being affected by, our society. Within this cultural embeddedness, we believe that our social constructs of identity do, and are able to, change over time. The social contexts surrounding the discourse of stigma can, and must, transform for the benefit of women living with HIV/AIDS and their healthy identities. As Clarke et al (2005) concedes, “Stigmatization is still a significant component of the experience of Aboriginal people with HIV/AIDS, it needs to be addressed” (p. 2178). This needs to be addressed with Aboriginal women living with HIV/AIDS, leading the way with the support of their families, communities, and society.

REFERENCES

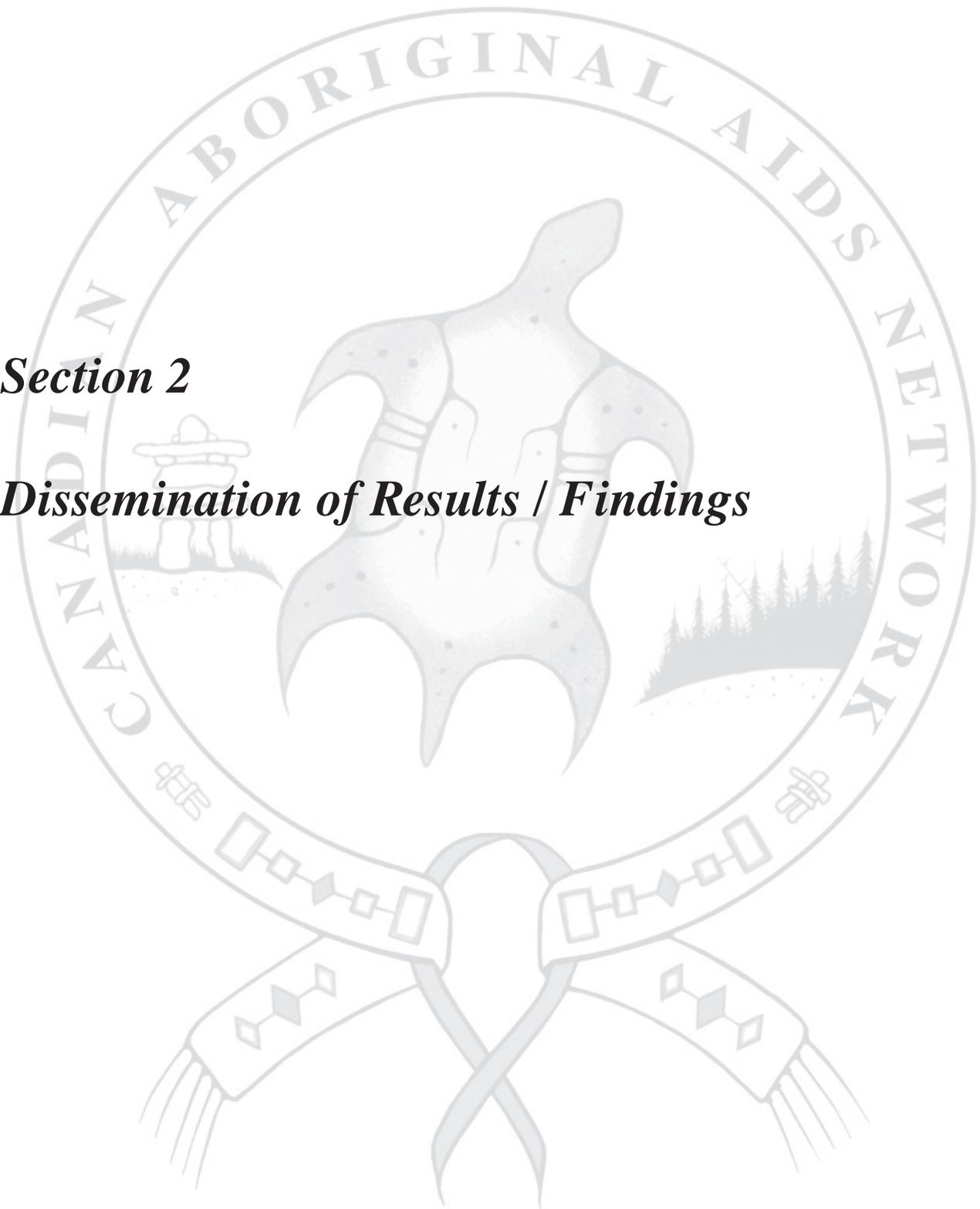
Anderson, J. M. (2000). Gender, ‘race’, poverty, health and discourses of health reform in the context of globalization: A postcolonial feminist perspective in policy research. *Nursing inquiry*, 7(4), 220-229.

- Barrett, M., & Bissell, M. (1999). Seiccan newsletter. *The Canadian Journal of Human Sexuality*, 8(2), 151-154.
- Bower, J. Gurevich, M., & Mathieson, C. (2002). (Con)tested identities: Bisexual women reorient sexuality. *Journal of Bisexuality*, 2(2/3), 23-52.
- Bucharski, D., Reutter, L.I., & Ogilvie, L.D. (2006). "You need to know where we're coming from": Canadian Aboriginal women's perspectives on culturally appropriate HIV counseling and testing. *Health Care for Women International*, 27, 723-747.
- Butler, J. (1998). *Gender trouble*. New York: Routledge.
- Byrne, P. (2000). Stigma of mental illness and ways of diminishing it. *Advances in Psychiatric Treatment*, 6, 65-72.
- Canadian Aboriginal AIDS Network (CAAN). Aboriginal AIDS Awareness Day Fact Sheets. Retrieved June 28, 2006, from <http://www.caan.ca> 2003
- CAAN. (2004). HIV/AIDS and Aboriginal women, children and families: A position statement. Retrieved August 7, 2006 at http://www.caan.ca/english/grfx/resources/publications/Women_and_HIV.pdf
- Campbell, J.C., Zhu, F.C., & Xu, X. (2001). Intimate partner violence against Chinese women: The past, present, and future. *Trauma, Violence & Abuse*, 2(4), 296-316.
- Chrisjohn, R., Young, S., & Maraun, M. (2006). *The circle game: shadows and substance in the Indian residential school experience in Canada*. Penticton, BC: Theytus Books.
- Clarke, J.N., Friedman, D.B., & Hoffman-Goetz, L. (2005). Canadian Aboriginal people's experience with HIV/AIDS as portrayed in selected English language Aboriginal media (1996-2000). *Social Science & Medicine*, 60, 2169-2180.
- Collins, P. H. (1993). "Towards a new vision: Race, class, and gender as categories of analysis and connection. *Race, Sex and class*, 1(1), 25-41.
- Deschamps, G. (1998). *We are a part of tradition: a guide on two spirited people for First Nations communities*. Toronto: (Press not given).
- Dion-Stout, M., Kipling, G.D., & Stout, R. (2001). *Aboriginal women's health research synthesis project: Final report* [Electronic version]. Vancouver: BC Center for Excellence in Women's Health. Retrieved November 25, 2006, at <http://www.bcewh.bc.ca/pages/pubspdflist.htm>.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York: Touchstone Books.
- Guttman, N. & Salmon, C.T. (2004). Guilt, fear, stigma, and knowledge gaps: Ethical issues in public health communication interventions. *Bioethics*, 19(6), 531-552.
- Health Canada. (2003). *HIV/AIDS Among Aboriginal Persons in Canada: A Continuing Concern* [Electronic version]. Ottawa: Health Canada. Retrieved November 25, 2006 at, http://www.phac-aspc.gc.ca/publicat/epiu-aepl/hiv-vih/aborig_e.html
- Hill, D. M. (2003). HIV/AIDS among Canada's First Nations peoples: a look at disproportionate risk factors as compared to the rest of Canada. *Canadian Journal of Native Studies*, 2, 349-60.

- Josselson, R. (1988). "The embedded self: I and thou revisited." In D.K. Lapslez & F.C. Power, F.C. (Eds.), *Self, ego, and identity: Integrative approaches* (91-108). New York: Springer-Verlage.
- Kurtz, D.L., Nyberg, J., Van Den Tillaart, S., Mills, B., & Okanagan Urban Aboriginal Health Research Collective (in press). Silencing of voice: an act of structural violence. urban Aboriginal women speak out about health care. *Journal of Aboriginal Health*.
- Lather, P. & Smithies, C. (1997). *Troubling the angels: Women living with HIV/AIDS*. Boulder, Co: Westview Press.
- Majumdar, B. B., Chambers, T.L., & Roberts, J. (2004). Community based, culturally sensitive HIV/AIDS education for aboriginal adolescents: Implications for Nursing Practice. *Journal of Transcultural Nursing*, 15(1), 69-73.
- Mill, J.E. (2000). Describing an explanatory model of HIV illness among Aboriginal women. *Holistic Nursing*, 15(1), 42-56.
- Mill, J.E. (1997). High risk behaviors become survival techniques for Aboriginal women. *Western Journal of Nursing Research*, 19, 466-489.
- Poindexter, C. C. (2004). Medical profiling: Narratives of privilege, prejudice, and HIV stigma. *Qualitative Health Research*, 14(6), 496-512.
- Public Health Agency of Canada (PHAC). (2005). *HIV/AIDS among Aboriginal peoples in Canada: A continuing concern. HIV/AIDS EPI updates*. Surveillance and Risk Assessment Division, Centre for Infectious Disease Prevention and Control, Public Health Agency of Canada, Ottawa, ON.
- Razack, S. (1998). *Looking white people in the eye: Gender, race, and culture in classrooms and courtrooms*. Toronto: University of Toronto Press.
- Razack, S. (2002). *Race, space, and law: unmapping a white settler society*. Toronto: Between the Lines.
- Reinharz, S. (1992). *Feminist Methods in Social Research*. New York: Oxford University Press.
- Ryan, W. (1976). *Blaming the victim*. New York: Random House.
- Sandelowskie, M., Lambe, C., & Barroso, J. (2004). Stigma in HIV-positive women. *Journal of Nursing Scholarship*, 36(2), 122-128.
- Ship, J., & Norton, L. (2001). HIV/AIDS and Aboriginal women in Canada. *Canadian Women Studies*, 21(2), 25-31.
- Smith, L. T. (1999). *Decolonizing methodologies: research and Indigenous peoples*. NY: Zed Books.
- Smith, M. (2002). Stigma. *Advances in Psychiatric Treatment*, 8, 317-325.
- Wuest, J. Ford-Gilboe, M., Merritt-Gray, M., & Berman, H. (2003). Intrusion: the central problem for family health promotion among children and single mothers after leaving an abusive partner. *Qualitative Health Research*, 13(5), 597-623.
- Zinn, M. B. & Dill, B. T. (1996). Theorizing difference from multiracial feminism. *Feminist Studies*, 22(2), 321-331.

Section 2

Dissemination of Results / Findings



***“I can’t deal with this alone”:* Support for Aboriginal men and women living with HIV**

Judy Mill⁴, Louanne Keenan⁵, Denise Lambert⁶, Kecia Larkin⁷, and Ken Ward⁸.

ACKNOWLEDGEMENTS

We would like to acknowledge our study participants for being willing to share very personal aspects of their lives and our advisory committee members for providing ongoing guidance and wisdom during the project. We also wish to acknowledge the many community organizations that assisted with the recruitment of study participants. Finally, the research team would like to acknowledge the funding received from Health Canada through the Aboriginal Community-Based Research Program of the Canadian Strategy on HIV/AIDS.

ABSTRACT

Diagnosis with HIV or AIDS has the potential to elicit profound suffering and lead to psychological and psychiatric problems. HIV and AIDS are serious concerns in the Canadian Aboriginal population, and mental health issues including depression and suicide are more prevalent in Aboriginal persons living with HIV (APHAs). A participatory action research design was used to examine the experience of APHAs in Alberta, Canada following diagnosis with HIV. A qualitative methodology using in-depth interviews to collect the data was used for the study. Thirty-one individuals participated in the study: 16 were males and 15 were female. Participants were 38 years on average and had known their diagnosis from 1 month to 19 years. Support emerged as a key theme and a critical need for participants. Some participants preferred individual, personal support while others were comfortable accessing organizations for support. Many of the participants found support in their Aboriginal spirituality and heritage. Participants emphasized the importance of a strong support system following diagnosis, however often took several years to accept their HIV diagnosis and access the support available. Support services must be ongoing to ensure that APHAs who are in different stages of readiness to acknowledge and deal with their diagnosis can access services when needed. In addition, services for APHAs must be designed to ensure that they include formal and informal services, Aboriginal-specific services, and are provided in differing formats.

INTRODUCTION

Diagnosis with HIV or AIDS may elicit profound suffering and is associated with psychological and psychiatric problems including substance and alcohol abuse, depression, anxiety, and severe mental illness (Chander, Himelhoch & Moore, 2006). Approximately 10 to 20% of adults experience a major depression during their lifetime, however 10 to 50% of individuals living with HIV suffer from depression (Penzak, Reddy & Grimsley, 2000). Depression may affect the progression of HIV disease and has been associated with poorer rates of adherence to antiretroviral treatment (Chander, Himelhoch & Moore). Social contact and support are critical to guide Aboriginal persons living with HIV (APHAs) through the process of dealing with their illness.

⁴ Associate Professor, Associate Dean, Global Health Director, PAHO/WHO Collaborating Centre for Nursing and Mental Health, Faculty of Nursing, University of Alberta, email: judy.mill@ualberta.ca. Principal Investigator on the research project “Challenging Lifestyles: Aboriginal Men and Women Living with HIV”.

⁵ Research Director of the Division of Continuous Professional Learning in the Faculty of Medicine and Dentistry, University of Alberta, email: louanne.keenan@ualberta.ca. Project Director for “Challenging Lifestyles: Aboriginal Men and Women Living with HIV”.

⁶ Executive Director, Kimamow Atoskanow Foundation, Onoway, Alberta, email: info@treeofcreation.ca. Co-Investigator on “Challenging Lifestyles: Aboriginal Men and Women Living with HIV”.

⁷ Member of Kimamow Atoskanow Foundation, email: info@treeofcreation.ca. Co-Investigator on “Challenging Lifestyles: Aboriginal Men and Women Living with HIV”.

⁸ Member of Kimamow Atoskanow Foundation, email: info@treeofcreation.ca. Co-Investigator on “Challenging Lifestyles: Aboriginal Men and Women Living with HIV”.

BACKGROUND

HIV and AIDS are serious concerns in the Canadian Aboriginal population. In 2006, Aboriginal persons accounted for 24.4% of the reported AIDS cases for which ethnicity was known (Public Health Agency of Canada [PHAC], 2007) however, only 3% of the Canadian population reported an Aboriginal ancestry in the 2001 census (Statistics Canada, 2006). Quality of life and well-being may be impacted in persons living with HIV (Williams et. al., 2005; Worthington & Krentz, 2005), however no published research was identified that explores the mental health issues of APHAs.

Mental health issues including depression and suicide are more prevalent in the Canadian Aboriginal population (Government of Canada, 2006). Cultural discontinuity and oppression in Canadian Aboriginal communities have been linked to higher rates of depression, violence and self-destructive behaviours such as suicide, alcoholism, and violence (Kirmayer, Brass, & Tait, 2000) resulting from diverse societal processes including epidemics of infectious diseases, colonization, and the separation of families through residential schools (Adelson, 2005; Barlow, 2003; Kirmayer, Brass & Tait). Among male survivors of residential schools, 100% had experienced sexual abuse, 90% physical abuse, and the majority suffered from mental health problems [post-traumatic stress disorder, substance abuse disorder, and major depression] (Aboriginal Healing Foundation, 2003). The loss of culture and marginalization of survivors of residential schools has also been associated with increased vulnerability to HIV infection (Barlow).

Support is a key aspect of comprehensive care and treatment for PHAs and lack of support has been associated with mental health problems including distress and depression. Family or social support has been positively associated with use of and adherence to anti-retroviral therapy (Ammassari et al., 2002; Edwards, 2006); however, this relationship is contingent on disclosure of HIV status to family, friends or acquaintances (Waddell & Messeri, 2006). American studies demonstrated that perceived social support among HIV-positive drug users (Mizuno and colleagues 2003) and satisfaction with social support among HIV positive youth (Murphy et. al, 2000) were associated with lower levels of depression. Similarly Gielen and colleagues (2001) found that HIV positive women with larger social support networks reported better overall quality of life and mental health. A study with HIV-positive women (Hudson, Lee, Miramontes, & Portillo, 2001) reported an inverse relationship between social support and distress.

Despite knowledge of the importance of support in mediating depression, it is not always available or accessible by persons living with HIV. A Canadian study found that HIV sero-positive youth experienced isolation, loneliness and hopelessness following diagnosis; however, had difficulty accessing appropriate support services (Flicker et al., 2005). Stigma and discrimination, and the need for secrecy that accompanies it, may decrease the likelihood that persons living with HIV are able to develop and utilize social support (Schrimshaw & Siegel, 2003). Persons with more advanced HIV disease (e.g. more symptomatic) may be less likely to report a supportive relationship (Fleishman et. al., 2000).

The literature highlights the cultural factors that lead to increased risk of HIV disease in Aboriginal people, the value of supportive environments, and the barriers to this support in Aboriginal communities. The purpose of the current study was: 1) to examine the experiences of APHAs in the period following diagnosis; and 2) to identify culturally and situationally relevant HIV prevention interventions for APHAs. Although not a specific research question, support emerged as a key theme and a critical need for participants. Therefore, an operational definition of support was not developed. The research was carried out between September 2002 and November 2004 in Alberta, Canada. In the current paper we address the experiences of APHAs in relation to support following diagnosis. A description of participants' experience receiving and adapting to the diagnosis of HIV is described elsewhere (Mill, Lambert, Larkin, Ward, Harrowing, in press, 2007).

DESIGN AND METHODS

A participatory action research (PAR) design guided the study and provided congruence with the principles of ownership, control, access and possession (Patterson, Jackson, & Edwards, 2006) that are foundational to research with the Aboriginal community. Fundamental principles of PAR include a collaborative relationship with the partners in the research (Reason, 1994), a valuing of the experience and popular knowledge of people (Fals-Borda, 1991), and recognition that knowledge is shared with the community or group rather than being owned and disseminated by academia (Mill, Allen, & Morrow, 2001). In the current study findings were shared through community presentations in several Aboriginal communities in Alberta.

A qualitative methodology, using in-depth interviews to collect the data, was used for the study. Members of Kimamow Atoskanow Foundation, a community-based AIDS service organization in Alberta, worked with faculty at the University of Alberta to conduct the study. A Community Advisory Committee (CAC), including one elder and two APHAs, provided guidance throughout the project. The CAC members were selected by the community research partners based on their knowledge of HIV in Aboriginal communities. Community approval for the study was provided by the CAC while ethical approval was obtained from the Health Research Ethics Board at the University of Alberta, Canada.

The target population was drawn from Aboriginal men and women in Alberta, Canada. The term Aboriginal as used in this study included individuals who identified themselves as Métis, First Nation or Inuit regardless of treaty status (Ermine, Sinclair, & Jeffrey, 2004). The inclusion criteria for the participants included being: over the age of 14 years; not currently an in-patient; English speaking; and HIV sero-positive. Eleven community organizations providing care to persons living with HIV assisted with the recruitment of participants. The research assistant and project coordinator (Aboriginal and non-Aboriginal respectively) worked with staff at each site to ensure that they understood the 'culture' of the organization and the specific issues that their clients faced. Convenience and snowball sampling (Morse & Richards, 2002) were used to recruit participants to the study. Contact persons in each organization approached individuals who met the inclusion criteria and asked them if they were interested in participating in the study. After the individual indicated their interest in speaking with research staff, arrangements were made for them to be interviewed at a location convenient to the individual.

The project coordinator and research assistant conducted all of the interviews to ensure consistency in the interviewing process. The interviews were completed over a 6-month period, with each interview lasting one to three hours. Guiding questions were prepared by the research team and vetted by the Community Advisory Committee to ensure that they were culturally appropriate. The interviews were tape-recorded following informed consent.

The process of analyzing the data occurred in stages, following procedures outlined by Miles and Huberman (1994). Verbatim transcriptions were made of the audiotaped interviews. The principal investigator and project coordinator conducted the first level analysis, compared and assigned descriptive codes (labels) and organized the codes into themes. The qualitative software program QSR*^{N6} was used to assist with labeling, revising and retrieving codes during analysis. Five members of the research team discussed the coding framework and themes until there was consensus.

FINDINGS

Thirty-one individuals participated in the study: 16 were males and 15 were female. The participants ranged from 27 to 57 years with an average age of 38.8 years. Participants had known their diagnosis from 1 month to 19 years, with an average of 6.5 years. Fifty-five percent of subjects were Cree, 19% were Métis, 16% were Blackfoot, 3% were Inuit and 3% were Mohawk. Intravenous drug use was the most common method of acquiring HIV among the participants. In the following sections, illustrative verbatim quotes (using pseudonyms) are provided to highlight the theme of support.

Almost all of the participants emphasized the importance of a strong support system to assist HIV infected individuals to adapt to their diagnosis. Mark emphasized the need for support regardless of age and recalled hoping that: "...somebody [would] help me because I can't deal with this alone". Participants indicated that it took from days to several years to begin to accept their diagnosis, however they were often surprised by the amount of support that was available once they knew where to find it and were able to ask for it. For example, Edward found it helpful for others to identify their willingness to provide support:

I needed somebody to bring it out, because it's been inside me for a long time, and I haven't been able to tell anybody. Nobody's even asked me these questions. I feel comfortable to tell, to say, to express what I went through, what I experienced, how I feel.

Some participants preferred individual, personal support while others were comfortable accessing organizations for support.

Personal Support

Personal support was received by participants from family members, partners and co-workers; the findings presented here will focus on support from families and partners. Most of the participants had at least one family member who provided support to them following their diagnosis. A few participants, however, were reluctant to speak with their family about their diagnosis, preferring to protect them from the pain and suffering that might follow disclosure. Parents played an important, primarily supportive role in the lives of participants following diagnosis. Support was usually positive however some participants had experienced non-supportive interactions during the period following diagnosis.

Kathleen's parents had provided ongoing support for her including during the times when she was in jail:

They come see me, they don't judge me, they don't tell me -- you know. They NEVER have judged me, really; they just keep telling me they love me. Now, THOSE are real Christians right there, I think. You know what I mean? They don't sit there and henpeck you and stuff.

Betty invited her daughter, son, brothers and sisters to a conference on HIV and AIDS. She believed that the support of family helped her to go forward as an advocate for others who were living with HIV. Olive received mixed messages from her mother: some of the time she experienced silence and chastisement while at other times her mother was supportive. Olive commented, "She's really a nice woman. [She's] really supportive."

A few of the participants did not feel that their families had provided the support that they would have liked at the time of, and following, their diagnosis. Amy recognized that her family felt like they were "in a maze" and she did not blame them for not calling her. She remained hopeful that "they'll come around". Anna recognized and appreciated the support she observed in other families and longed for the same understanding. Although Anna's mother cared for her children, Anna would have liked more support for herself:

I don't even have one family member that I can -- if I'm sick in the hospital or if somebody's -- my Mom's there to take care of my kids, but I don't have anybody that will come and sit with me, or have anybody that will, [pause] how can I say? ... for me, my family is not there for me.

Anna said that her family did not understand that HIV is an "emotional disease" and she therefore could not share her emotions with them.

Many participants described their relationship with their partner after they had been diagnosed. Most partners continued to support the participant following his or her diagnosis and became the primary mode of support, however a few partners were unsupportive following the diagnosis. Mark and his wife, both HIV positive, were committed to not blaming the other. Instead they took a different approach:

Okay, this is what we have, and see what we can find out about it, and take it from there.... I've never had anything negative to say about my support team because they also provide their support to my wife and they've always been there. They've always had our best interests at heart.

Henry believed that like any couple he and his wife shared their ups and downs and on three occasions his wife had threatened to kick him out but their relationship had endured:

No matter we're broke, we have nothing; we're still happy we got together, we have each other. What more do you need when you [have] got somebody that'll support you, that'll hold your hand through the deepest waters of life? When I'm feeling down and out, she'll give me my space. She'll talk to me, but she'll also give me my space...

Providing support to a partner was often very challenging, particularly if the couple was discordant. Bill's partner was HIV negative however he had continued to support Bill:

Well, considering he's negative and I'm positive, we're living a very difficult life. But he just sticks in there, and really is not – is interested in going through this with me, which has been a great help. He's more significant in my life than anybody else, including my parents -- one of them is now gone; but he's the most significant person.

Catherine was grateful that her spouse remained with her even though he knew she was sick:

I used to think then, 'God, what if he leaves me?' Cause I would never go with anybody else...So thank God he stayed with me, or I probably would have been alone the rest of the time.

Christopher did not leave his wife, despite knowing that she had purposively infected him:

I didn't know until a year later, after I found out I was positive, that she already knew that she was positive 2 years ahead of time, and she gave it to me on purpose. But she knew that she would get sicker faster, and she needed somebody to look after her children. I could have left her and washed my hand with her, but I stayed with her till the end.

The support and encouragement provided by partners gave the participants a sense of purpose and the courage to continue living in the face of their illness.

Organizational Support

Most of the participants had received support from AIDS Service Organizations (ASOs), inner city organizations, conferences and forums related to HIV and AIDS, and Health Care Providers HCPs. ASOs participated in the recruitment of participants and therefore it is not surprising that they were often mentioned as a source of support. Christopher went to an inner city organization whose mission it was to increase access to anti-retroviral drugs: "You get up and you come here, and you can talk to people, you can have something to eat. They give you \$5 a day, and you take your meds, and they give you support." Some of the women who used ASOs stated that they had very good 'vibes' in the ASOs and that the staff who worked there were "awesome" and "caring". Olive received bus fare and a salary when she cooked in the kitchen and made lunches for other people who visited the inner city centre she attended. Amy felt angry and confused following diagnosis but found the support from the women in an inner city organization made her feel less isolated. Several participants suggested that persons living with HIV should be matched with someone who was living a similar lifestyle so that their personal questions could be answered.

Some participants isolated themselves from others when they were first diagnosed and reflected that HIV was a 'lonely disease'. Despite the tendency to become isolated, there appeared to be a point when individuals

recognized that they had to face their disease. At that point it was helpful for the person living with HIV to have someone else that could reframe the information, accompany them to the doctors and HCPs, remind them to take medicines, prepare meals with them and remind them of their place within a caring community. Some participants also found benefit in offering support to others. Bill's solution to his isolation was to increase his own involvement in support networks for others who were recently diagnosed and were having difficulty coping. Similarly, Patrick decided to get involved with helping others:

Because if you just shut down, if you stop. It'll catch up to you. If you don't care, you'll die. I care, I care for everybody, and so what I do, I'm doing not only for me. I'm doing it for other people.

Not everyone was comfortable receiving services in a group setting and preferred to speak privately to someone in an ASO. For example, Catherine had spoken with a few people at an ASO, but had never been to a group meeting there:

It's been a long haul. The first year I didn't...and I still haven't been to any meetings at [ASO] or any of the Aboriginal meetings. I've seen a lot of the commercials on TV for Aboriginal people and for those dealing with AIDS. But I am just [pause] just scared I guess...I've talked to a couple of people but mostly just who I've seen over there at [ASO] and sit down and talk to them for a few minutes. But I don't have a counselor and I've never been to a group.

Catherine said that she was not a "big people person" [didn't like groups]. She did not want to admit that she was sick and didn't want to sit around with others who stated what anti-retroviral drugs they were taking because she did not want to take any pills.

In smaller communities support groups included all HIV positive individuals in the community: gay men, straight men and women, fathers and mothers, Aboriginal and non-Aboriginals. Larger communities were able to offer support groups for HIV positive individuals with similar backgrounds and concerns. When Michelle moved to a larger community she was able to share her story with other women and discovered how to deal with the unique issue of having a baby that is HIV positive. Jessica had great praise for the network of positive women that she had developed, while Helen was grateful for a women's program that provided housecleaning, babysitting and visiting. Both women found comfort from the support they received as mothers who were dealing with issues concerning their children. The social worker at a women's shelter was the only person that took the time to convince Kathleen that she was a beautiful person and helped her overcome her addiction to drugs and alcohol.

Symposiums, forums, conferences and workshops that focused on the HIV and AIDS were also extremely beneficial to many of the participants. Andrew's experience at his first symposium on HIV and AIDS triggered his ongoing involvement with ASOs:

I found out a lot of information that I didn't know... things to do when you're positive, and how to live properly, how to eat properly, and a lot of things I never found out until I attended the conference. From then, I became involved with ASOs.

Two male participants attended forums that provided support through the sharing of stories. Greg described in detail a forum he attended for 'two-spirited' individuals and very eloquently described the issues faced by two-spirited individuals and the benefits of support:

So that they can begin looking at how can they support Aboriginal two-spirit people through the maze of sexual identity and HIV/AIDS disease transmission issues, healthy lifestyle issues. Getting them to the circle, getting them to a healthy supportive circle so that they don't have to struggle out there by themselves in the dark bushes or in the dark bath houses or in the dark clubs. And they don't have to struggle with addiction issues by themselves, that they have a support network...that they're recognized

as part of the circle, and they're not excluded. 'Cause in my own life, I've been part of the circle.

Participants sought treatment for their illness through HCPs including doctors, nurses, psychologists, social workers and counselors. Most of the experiences described by participants with HCPs were supportive. Accessibility and continuity were both factors that enhanced the relationship with HCPs. As Mark recalled:

You have a team that's created initially once you're diagnosed. You have a doctor, you have a social worker, you have a nurse. My experience with my support team is if I have a question or a concern or [long pause] if I'm getting sick or whatever, I can page them...So that type of support I mean...But no, I've never had anything negative to say about my support team because they also provide their support to my wife and they've always been there.

Ingrid felt that the nurses had never treated her like a number, but took the time to ask questions: "Hey, how's it going? What's up lately? Tell me what's going on." She appreciated their gift of being "truly there for the client". Kathleen and Amy had both found that their psychologist was the first HCP to raise their spirits by telling them that people live 10 - 16 years with HIV and are fine. This motivated the women to be healthy and clean from street drugs. Oliver didn't usually like authority figures, however had found the staff at an inner city ASO to be very supportive.

Despite these positive encounters, a few of the participants described experiences that were non-supportive. In addition, some of the participants who lived outside major urban areas found it very difficult to access specialized HIV services in smaller centres. Mark had both positive and negative encounters when he had shared his diagnosis with HCPs in different facilities. His experience seemed related to how familiar the HCP was in caring for persons living with HIV. He recalled accessing a hospital for the treatment of thrush:

...you get the 20 questions: "How did you become infected? How long have you been infected? Who's your doctor?" It's, like, a new -- like a nurse just coming on the job, all thrilled to find out all the wonderful things about their new career, and you're a guinea pig. They have no compassion whatsoever, they have no [pause] no concern. You don't like talking about it; you don't need that reminder; you don't have to explain yourself, and I hate doing that. Some hospitals -- it got to the point later on that there was somebody that was on call that deals with HIV clients, and then HE come in and talked to me. And then you're comfortable talking with him, because he knows part of the talk to make you feel comfortable, and it wasn't such a big thing.

Support from community health nurses varied. Jake appreciated talking with community health nurses about strategies to cope with his diagnosis. Furthermore a nurse referred him for counseling services where he was able to talk about his thoughts of suicide. Elizabeth did not feel that the community health nurses appreciated her limitations with her small children, and ignored their suggestion to "keep up your strength and eat; if you don't, you'll get sicker." The nurse in Henry's community did not visit him and "...never came to give support."

Aboriginal spirituality and heritage

Many participants spoke about the support that they received from Aboriginal ceremonies, Aboriginal spirituality, and their Aboriginal heritage. Aboriginal ceremonies and traditions included healing circles and spiritual guidance from elders. Jessica had discovered her Aboriginal spirituality following her diagnosis:

I believe a lot in prayers. Being aboriginal is on my side. I didn't know about elders, I didn't know about all the spirituality and this and that. I didn't know what it meant to be native. But if you're diagnosed, you really [pause] just pray; go see an elder, and let them know what you're going through, and let them guide you and teach YOU the way of life, especially nowadays, because we're young people, and we don't know. And I'm beginning to learn, and I'm going to pass it on to my children.

David found support in healing circles and smudges at a local HIV organization. He believed that "...we all have to look after each other and share each other, and support each other. We don't talk about it on the street, which is a healthy thing." David explained that it would not be safe to mention his status publicly, so the supportive environment where he could get nutritious soup and his favorite native food, bannock, was comforting and made him feel better.

Kathleen was introduced to native spirituality to help her "get off dope and stuff." While she thought that native spirituality was beautiful, she said I "...feel undeserving of being able to be in any kind of spirituality ...because I've been using and stuff. I feel like I can't even touch it right now, because it'll be tainted." Norman found that his Christian family and the churches on the reserve did not accept him because he was gay and because of his HIV status. Conversely, he believed that the Creator did not judge him, unlike other religions: "I'm not judged; I'm accepted by Him." Catherine and Christopher did not reconnect with their Aboriginal heritage until they were in jail or undergoing rehabilitation. Christopher commented that "they're [Aboriginal people are] more humble and they're more kind". Similarly, Catherine found Aboriginal people "...a lot easier to get along with and easier to talk to." Frank wanted to speak in his own Cree language:

I was just tripping over my English. When I spoke Cree, it was much better. But there's nobody speaks Cree. [laughs] Seems like nobody speaks Cree any more.

Aboriginal traditional healers and support persons were used by some of the study participants. Ingrid's traditional healer helped her to deal with her anger. She said that the traditional healer knew where to go and who to phone: "For other people, they may not know that. So in hospitals and treatment centres, [it would] just be nice if a lot of people could be prepared so that they could help – you know, know the services that are available for Aboriginal people." Ingrid recommended the development of a separate place for Aboriginal people, with experienced staff who knew where clients were in their journey with HIV and AIDS and who could discuss drug abuse, sexual abuse and physical abuse. Helen suggested that hospitals set up a 'buddy system' for individuals who gave permission to be contacted by an Aboriginal advisor. Helen believed that persons living with HIV would appreciate being called, even though they would not make the initial contact themselves.

About two-thirds of the participants mentioned support that they had received from other Aboriginal persons who were living with HIV. For the most part, the participants found it very helpful to talk with other men and women who were HIV positive. Mark found the support group that he had attended at a hospital to be very beneficial, but he found it very distressing early in the series of meetings when a group member had died:

You had an avenue to voice your concerns and talk and share with somebody that's infected with HIV, versus having somebody talk to you about your disease that doesn't live and breathe it. So they can kind of relate to some of the things that you've probably experienced; they've been down the road before.... But going to that group initially, there was a girl that was there. She was in the hospital because she was sick and she died shortly after – I would say within three weeks after us attending...so your hope part of it just kind of goes poof – gone. You wonder why she died and what did she die of.

Henry believed that meeting others who were HIV positive was instrumental in learning to accept his diagnosis:

What I think has made me accept having HIV? My attitude...meeting other people that are HIV positive. There's really no choice in it. In order to stay alive, you've got to accept the problem, you've got to accept whatever lies ahead of you.

Jake preferred to live in Vancouver because the drop-in centre he used was open 7 days a week and he could play cards and talk with people who were also living with HIV. He felt that in a smaller community staff working at ASOs were not HIV positive and could not relate to his issues. Norman also found that in Vancouver "there's a lot more Aboriginal HIV and AIDS Service Organizations." Through group therapy Norman discovered his 'voice' and began to provide support to others living with HIV.

Some of the participants found it helpful to meet other APHAs in a group setting, while others were not comfortable in group situations. Helen found that when she went to a meeting she always met someone else with more problems than she had, so she felt “better off”. While she felt better off than others, she also found that groups could be depressing: “Lots of people go there to do “poor me.” That’s hard to hear, week after week.” Anna felt uncomfortable when she first arrived at a support meeting for APHAs and their families, however she did appreciate the opportunity to talk to someone who was going through what she was:

I started talking with this lady, and she kind of figured that I was there on my own. She said, “Is it YOU that’s positive?” and I said, “Yeah.” And she said, “Do you want somebody to talk to?” So that was the very first time that I got to talk to somebody that was positive, that went through the same thing that I went through, having to live with it.

Frank had mixed feelings about receiving support from other APHAs. Although he thought it would be good to talk with someone who was HIV positive because he would feel on “the same level playing field”, he was not comfortable sharing his feelings in a group setting:

Even with 10 of them like that, even then, I don’t - I don’t really like talking about it, especially among others. And I know they have the same thing I do, but maybe these guys have been doing this kind of circle thing years before I come along. Maybe farther down the road, I’ll be able to associate with them, whatever they’re talking about and all that.

Similarly, Catherine appeared to have mixed feelings about the support that other APHAs could provide to her. She stated that she did not want to participate in a group with other APHAs because it would force her to face her own illness. But, like Frank, she later stated: “I could probably meet someone who’s been where I am now, and a little bit further along on their journey, and can help me come to terms with what I’m going through right now. That would be a good thing I guess.” Despite this, Catherine still preferred to receive support privately.

DISCUSSION

Social support plays an important role in helping individuals to accept their diagnosis and learn to live with HIV. Individuals living with HIV and AIDS may become isolated due to the stigma associated with the illness (Flicker et al., 2005; Majumdar, 2004) and therefore support is critical following diagnosis. In the current study, participants found that supportive individuals listened and understood them, encouraged spiritual avenues for coping, and provided information and advice about their medical concerns.

Support for APHAs must be provided using different approaches, including individual and group strategies, and through different organizations, including Aboriginal ASOs and health care agencies. The unconditional support participants received from at least one family member has been reported previously (McKay-McNabb, 2006). The benefits of support services provided by ASOs have also been documented in recent Canadian studies (Crook, Browne, Roberts, & Gafni, 2005; Williams et al., 2005). These authors noted that community based services enhanced health-related quality of life and reduced isolation for individuals living with HIV. The finding that not all support from family and friends was positive has been reported elsewhere. Schrimshaw and Siegel (2003) found that some individuals living with HIV received stigmatizing reactions from family and friends following disclosure of HIV status.

The need for culturally sensitive, competent care, treatment and support services for Aboriginal individuals living with HIV and communities providing services for APHAs has been advocated (Jackson & Reimer, 2005) and is supported by the current findings. Participants took part in a wide range of Aboriginal traditional ceremonies to regain and maintain their health following diagnosis. The men and women in the study sought spiritual guidance from elders, and many spoke of the nonjudgmental, supportive environment that they encountered when accessing services that were Aboriginal specific. They also spoke of the benefit of talking to other Aboriginal persons who were living with HIV. Approximately 60% of Aboriginal participants in a recent

Canadian study (Jackson & Reimer) reported that they needed or used one or more traditional Aboriginal health and wellness services (eg healing circles, elders, traditional medicines, ceremonies, camps/retreats) to manage their HIV illness.

Receiving and accepting a diagnosis of HIV may be challenging for a variety of reasons. Following diagnosis, some individuals isolate themselves while others keep their diagnosis secret to avoid stigma and discrimination. Persons living with HIV however, often reach a turning point when they realize that they must come to terms with their diagnosis and learn to accept their illness (Mill, 2000). At this point in time, it is helpful for individuals living with HIV to have a supportive individual available to help them assimilate the information about their illness, listen to their concerns, accompany them to appointments with health professionals, assist with meals and housekeeping, and remind them that they are part of a larger caring community. Another critical component of HIV care and treatment is health care professionals and ASO staff who are supportive and knowledgeable about the potential mental health concerns of persons living with HIV. HCPs working with APHAs must receive training to ensure that their care is culturally competent (Majumdar, Browne, Roberts & Carpio, 2004) and that they can recognize and address depression in their clients (Williams et. al., 2005).

CONCLUSION

A strong support system is an essential component of a comprehensive system of care for persons who are diagnosed with HIV. The availability of support has been associated with better adherence to anti-retrovirals and with improved mental health, including lower levels of depression. Despite knowledge of the importance of support, it is not always available or accessible to APHAs. Participants emphasized the importance of a strong support system following diagnosis, however often took several years to accept their HIV diagnosis and access the support available. Support services must be ongoing to ensure that APHAs who are in different stages of readiness to acknowledge and deal with their diagnosis can access services when needed. Once APHAs had reached a readiness for support, they differed in the type of support that they felt comfortable with. Support services for Aboriginal persons living with HIV and AIDS must be designed to ensure that they are available at any time following diagnosis, include formal, informal and Aboriginal-specific services and are provided in differing formats.

REFERENCES

- Aboriginal Healing Foundation. (2003). *Mental health profiles for a sample of British Columbia's Aboriginal survivors of the Canadian residential school system*. Ottawa: author. Retrieved December 10, 2006 from <http://www.ahf.ca/publications/research-series>.
- Adelson, N. (2005). The embodiment of inequity: Health disparities in Aboriginal Canada. *Canadian Journal of Public Health, 96*, S45-61.
- Ammassari, A., Trotta, M. P., Murri, R., Castelli, F., Narciso, P., Noto, P., et al. (2002). Correlates and predictors of adherence to highly active antiretroviral therapy: Overview of published literature. *JAIDS Journal of Acquired Immune Deficiency Syndromes, 31*(Supplement 3), S123-S127.
- Barlow, J. K. (2003). Examining HIV/AIDS among the Aboriginal population on Canada: In the post-residential school era Ottawa: Aboriginal Healing Foundation; 2003 retrieved December 10 2006 from: <http://www.ahf.ca/publications/research-series>.
- Chander, G., Himelhoch, S., & Moore, R.D. (2006). Substance abuse and psychiatric disorders in HIV-positive patients: Epidemiology and impact on antiretroviral therapy. *Drugs 66*(6):769-789.

- Crook, J., Browne, G., Roberts, J., Gafni, A. (2005). Impact of support services provided by a community-based AIDS service organization on persons living with HIV/AIDS. *Journal of the Association of Nurses in AIDS Care*, 16(4), 39-49.
- Edwards, L.V. (2006). Perceived social support and HIV/AIDS medication adherence among African American women. *Qualitative Health Research*, 16(5), 679-691.
- Ermine, W., Sinclair, R., & Jeffrey, B. (2004). *The ethics of research involving indigenous peoples. Report of the Indigenous Peoples' Health Research Centre to Interagency Advisory Panel on Research Ethics*. Saskatoon, SK: Indigenous Peoples' Health Research Centre.
- Fals-Borda, O. (1991). Some basic ingredients. In O. Fals-Borda, & M. A. Rahman (Eds.), *Action and knowledge: Breaking the monopoly with participatory action-research* (pp. 3-12). New York: Apex.
- Fleishman, J.A., Sherbourne, C.D., Crystal, S., Collins, R.L., Marshall, G.N., Kelly, M, Bozzette, S.A., Shapiro, M.F., & Hays, R.D. (2000). Coping, conflictual social interactions, social support, and mood among HIV-infected persons. *American Journal of Community Psychology*, 28, 4, 421-453.
- Flicker, S., Skinner, H., Read, S., Veinot, T., McClelland, A., Saulnier, P., et al. (2005). Falling through the cracks of the big cities: Who is meeting the needs of HIV-positive youth? *Canadian Journal of Public Health*, 96(4), 308-312.
- Gielen, A. C., McDonnell, K. A., Wu, A. W., O'Campo, P., & Faden, R. (2001). Quality of life among women living with HIV: The importance of violence, social support, and self care behaviors. *Social science & medicine*, 52(2), 315-322.
- Government of Canada. (2006). The mental health and well-being of Aboriginal peoples in Canada. *In The Human Face of Mental Health and Mental Illness in Canada 2006* (pp 159-179). Ottawa: Minister of Public Works and Government Services Canada.
- Hudson, A. L., Lee, K. A., Miramontes, H., & Portillo, C. J. (2001). Social interactions, perceived support, and level of distress in HIV-positive women. *Journal of the Association of Nurses in AIDS Care*, 12(4), 68-76.
- Jackson, R., & Reimer, G. (2005). *Canadian Aboriginal People living with HIV/AIDS: Care, Treatment, and Support Issues*. Ottawa: Canadian Aboriginal AIDS Network.
- Kirmayer, L. J., Brass, G. M., & Tait, C. L. (2000). The mental health of Aboriginal peoples: Transformations of identity and community. *Canadian Journal of Psychiatry*, 45(7), 607-616.
- Majumdar, B.B. (2004). An exploration of socioeconomic, spiritual, and family support among HIV-positive women in India. *Journal of the Association of Nurses in AIDS Care*, 15(3), 37-46.
- Majumdar, B.B., Browne, G., Roberts, J., Carpio, B. (2004). Effects of cultural sensitivity training on health care provider attitudes and patient outcomes. *Journal of Nursing Scholarship*, 36(2), 161-166.

- McKay-McNabb, K. (2006). Life experiences of Aboriginal women living with HIV/AIDS. *Canadian Journal of Aboriginal Community Based HIV/AIDS Research, 1*, 5-16.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook*. Thousand Oaks, CA: Sage.
- Mill, J.E. (2000). Describing an explanatory model of HIV illness among Aboriginal women. *Holistic Nursing Practice, 15*(1), 42-56.
- Mill, J. E., Allen, M. N., & Morrow, R. A. (2001). Critical theory: Critical methodology to disciplinary foundations in nursing. *Canadian Journal of Nursing Research, 33*(2), 109-127.
- Mill, J.E., Lambert, D., Larkin, K., Ward, K., & Harrowing, J. (in press, 2007). Challenging Lifestyles: Aboriginal men and women living with HIV. *Pimatisiwin: A Journal of Indigenous and Aboriginal Community Health*.
- Mizuno, Y., Purcell, D. W., Dawson-Rose, C., & Parsons, J. T. & the Sudis Team (2003). Correlates of depressive symptoms among HIV-positive injection drug users: The role of social support. *AIDS Care, 15*(5), 689-698.
- Morse, J.M. & Richards, L. (2002). *Readme first for a user's guide to qualitative methods*. Thousand Oaks, CA: Sage.
- Murphy, D.A., Moscicki, A.B., Vermund, S.H., Muenz, L.R., & The Adolescent Medicine HIV/AIDS Research Network. (2000). Psychological distress among HIV+ adolescents in the REACH study: Effects of life stress, social support and caring. *Journal of Adolescent Health, 27*, 391-398.
- Patterson, M., Jackson, R., & Edwards, N. (2006). Ethics in Aboriginal research: Comments on paradigms, process and two worlds. *Canadian Journal of Aboriginal Community-Based HIV/AIDS Research, 1*(Summer), 47-57.
- Penzak, S. R., Reddy, Y. S., & Grimsley, S. R. (2000). HIV update. Depression in patients with HIV infection. *American Journal of Health-System Pharmacy, 57*(4), 376-389.
- Public Health Agency of Canada. (2007). HIV/AIDS Epi Updates, (Nov 2007). Ottawa: Surveillance and Risk Assessment Division, Centre for Infectious Disease Prevention and Control.
- Reason, P. (1994). Three approaches to participative inquiry. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Handbook of qualitative inquiry* (pp. 324-339). Thousand Oaks, CA: Sage.
- Schrimshaw, E.W. & Siegel, K. (2003). Perceived barriers to social support form family and friends among older adults with HIV/AIDS. *Journal of Health Psychology, 8*(6), 738-752.
- Statistics Canada. (2006). 2001 census of population- aboriginal identity population, percentage distribution, for Canada, provinces and territories- 20% sample data. Retrieved October 31, 2006, from <http://www12.statcan.ca/english/census01/products/highlight/Aboriginal/>

- Waddell, E. N. & Messeri, P.A. (2006). Social support, disclosure, and use of antiretroviral therapy. *AIDS and Behavior*, 10(3), 263-272.
- Williams, P., Narciso, L., Browne, G., Roberts, J., Weir, R. & Gafni, A. (2005). The prevalence, correlates, and costs of depression in people living with HIV/AIDS in Ontario: Implications for service and directions. *AIDS Education and Prevention*, 17(2), 119-130.
- Worthington, C., & Krentz, H. (2005). Socio-economic factors and health-related quality of life in adults living with HIV. *International Journal of STD & AIDS*, 16, 608-614.

Canadian Journal of Aboriginal Community-Based HIV/AIDS Research (CJACBR)

CALL FOR PAPERS

The Canadian Aboriginal AIDS Network (CAAN) is calling for papers to be considered for the third issue of the *Canadian Journal of Aboriginal Community-Based HIV/AIDS Research* (CJACBR). The CJACBR is a peer-reviewed journal, published by CAAN, which welcomes contributions from any author. Innovative HIV/AIDS research articles which demonstrate the use of Aboriginal Community-Based Research (ACBR) methods or philosophy are strongly encouraged. Submissions should be prepared in a language and manner appropriate for a diverse audience.

Articles will be accepted related to the following themes:

- **Aboriginal community-based HIV/AIDS research and development:** Either quantitative or qualitative research, community-based in design and process.
- **Dissemination of Results Findings:** These articles focus on results or recent findings related to Aboriginal Community Based HIV/AIDS Research.
- **Commentary:** Opinion pieces which speak to trends in Aboriginal community-based research, Knowledge Translation or other issues of importance to Aboriginal stakeholders.
- **Emerging Issues in Aboriginal Community-based HIV/AIDS Research (ACBR):** These articles focus on ground-breaking issues, findings and/or reports grounded in ACBR.
- **Ownership, Control, Access, and Possession:** Focus on the application of the Ownership, Control, Access and Possession principals.
- **International work that includes an Aboriginal Canadian component:** Articles written for an International audience about Indigenous peoples, HIV/AIDS and/or related issues. Articles must include a Canadian component.
- **Stories:** Personal accounts of experiences related to HIV/AIDS or accounts of successful and innovative approaches that address HIV/AIDS in Aboriginal communities.
- **Student work:** Students can submit articles (term papers, thesis, etc) that focus on HIV/AIDS in Aboriginal communities.

Submission Deadline: Monday, **April 28, 2008** by 4:30pm EDT. Please submit manuscripts via e-mail to Randy Jackson (randyj@caan.ca). All submissions are blinded for peer-review. Priority will be given to an author of Aboriginal ancestry/background, should manuscripts of comparable quality be available.

Inquiries: Information and policies for the Canadian Journal of Aboriginal Community-Based HIV/AIDS Research (CJACBR) are available at www.caan.ca. Inquiries related to the suitability of manuscripts, article submission, writing style, Peer review guidelines, updates or back issues, may be directed to Renée Masching (reneem@caan.ca).

