

Depression Among Aboriginal People Living With HIV in Canada

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ABSTRACT

This paper explores the ways that Aboriginal people living with HIV and AIDS experience feelings of depression. Seventy-two individuals participated in an in-depth semi-structured interview. Many participants described their depression in terms of their relationships, including isolation or a disconnection from people, communities, and culture. Depression was closely linked to their individual experiences with racism, a history of fostering and adoption, childhood abuse, disconnection from family and community, and substance abuse.

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The paper ends with a discussion of how our findings compare to those from research on non-Aboriginal populations and with a consideration of their service-related implications.

Keywords : HIV/AIDS, depression, Aboriginal community

Depression is one of the most common mental health concerns in Canada. Evidence suggests that about 8% of the Canadian population meet the criteria for major depression at some point in their adult lives (Parikh & Lam, 2001). A recent study revealed that 16% of adults seen by a physician in Alberta were diagnosed with depression (Slomp, Bland, Patterson, & Whittaker, 2009). As well, between 3% and 6% of adults in Canada experience a milder and more chronic form of depression, dysthymia (Bland, 1997). These statistics do not include those who have not sought medical care, and who remain undiagnosed. While experienced by many people, depression can be complicated to understand and address, and as Kleinman (2004) notes, the term depression can refer to an emotion, a symptom, or a disorder. Fenton and Sadiq-Sangster (1996) suggest that depression, as it is understood in biomedicine and in Western cultures, is not a universally shared experience; emotions such as depression cannot be assumed to be the same in different cultures. How people experience depression, the emotions they express, and how others respond to them can vary considerably from culture to culture (Kleinman & Good, 1985).

Depression is more prevalent among persons infected with HIV than the general population (Bing et al., 2001; Valente, 2004). Studies indicate that anywhere from 10% to 50% of persons infected with HIV suffer from depression (Ciesla & Roberts, 2001; Penzak, Reddy, & Grimsley, 2000). This is perhaps not surprising, as infection with HIV can bring a variety of stressors that can affect the individual's mental health and well-being, such as the disclosure of infection to family and friends, changes in lifestyle, and changes in health status over the course of infection (Dickey, Dew, Becker, & Kingsley, 1999). Moreover, stigma continues to be a central feature of people's experience of HIV (Herek, 2002; Mill et al., 2009). Depression can also be related to medication side-effects, such as lipodystrophy (Collins et al., 2006; Power, Tate, McGill, & Taylor, 2003; Trépanier et al., 2005). Age, employment status, and the availability of social support affect rates of depression among people living with HIV (Catalan, Klimes, Day, & Garrod, 1992; Dickey et al., 1999; Judd & Mijch, 1996; Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003; Katz et al., 1996; Schrimshaw, 2003). A history of drug and alcohol use is associated with increased risk of depression (Komiti et al., 2003). Depression can be difficult to diagnose among people living with HIV, as many of its symptoms can also be symptoms of HIV infection or the result of medication side-effects (Canadian Psychiatric Association, 2003). Depression can influence the quality of life of people living with HIV (Worthington & Krentz, 2005). It has been shown to influence the course of HIV-related disease, either through impairing immune function or influencing behaviour (Komiti et al., 2003; Leserman, 2003), and it generally leads to poor rates of antiretroviral treatment adherence (Boarts, Sledjeski, Bogart, & Delahanty 2006; Mugavero et al., 2006; Yun, Maravi, Kobayashi, Barton, & Davidson, 2005). The links between depression and HIV are complex, and "despite the intuition that HIV disease might bring on depression, the evidence suggests that there is rarely a cause-and-effect relationship between the two" (Rabkin, 1995, p. 1).

Aboriginal communities in Canada have been disproportionately affected by both HIV and depression. HIV infection is a serious and growing health problem among Canada's indigenous communities. Aboriginal people account for 3.8% of the Canadian population but represented about 4.1% of the total number of AIDS diagnoses from 1979 to 2008 (Public Health Agency of Canada, 2009). There are alarming trends in recent epidemiological data. For example, the percentage of HIV test reports for the years 1998–2008 from Aboriginal people ranges between 22% and 29%. In 2008, 13.9% of AIDS diagnoses and 29.4% of new HIV-positive test results were among Aboriginal people—although such statistics need to be interpreted with care, as information on ethnic status was missing in the majority of test results (Public Health Agency of Canada, 2009). Despite gaps in the data, it seems clear that Aboriginal people are significantly over-represented in the incidence of HIV infection. The Public Health Agency of Canada (2008) estimates that the HIV infection rate is 3.6 times higher among Aboriginal people than non-Aboriginal Canadians. This increase has been most pronounced in the inner cities where an increasing proportion of Aboriginal people, especially the young, now live. The Public Health Agency of Canada (2009) indicates that the profile of Aboriginal AIDS diagnoses from 1979 to 2008 differs from non-Aboriginal diagnoses in three important ways: gender, age, and exposure category. While less than 10% of non-Aboriginal people living with AIDS are female, 29% of Aboriginal people diagnosed with AIDS are women. Second, the epidemic in Aboriginal communities is skewed toward a younger population; 25% of Aboriginal people diagnosed with AIDS are under the age of 30 as compared to 16% for the non-Aboriginal Canadian population. Perhaps the most significant contrast is the difference in exposure. The Aboriginal population was much more likely to have contracted AIDS through injection drug use than were non-Aboriginal Canadians (52.7% vs. 22.2%; Public Health Agency of Canada, 2009).

No previous research directly examines depression among Aboriginal people living with HIV and AIDS; however, a variety of factors suggest that this group may be at increased risk of depression. In Canada, Aboriginal people appear to suffer from psychological distress, such as depression, at a greater frequency than non-Aboriginal people (see Kirmayer, Brass, & Tait, 2000). Writing in the American context, Manson, Shore, and Bloom (1985) observed that depression was “the most frequently diagnosed problem among American Indians presenting for treatment at mental health facilities” (p. 332). The data they cite suggest that the prevalence of depression within some communities may be 4 to 6 times higher than what is seen in the U.S. population generally. The Canadian Community Health Survey (Health Canada, 2002) demonstrated that Aboriginal people living off-reserve were 1.3–1.5 times more likely than the non-Aboriginal population to have experienced a major depressive episode in the previous 12 months. Rates of suicide among Aboriginal groups in Canada, as one measure of community levels of depression, are between 3 and 5 times higher than the rest of the Canadian population (Health Canada, 1998; Kirmayer, 1994; O’Neill, 1992). Drinking and drug use are strongly related to problems with depression, and substance use in Aboriginal communities can be seen as both a cause and a result of depression. Alcohol and drug use increases one’s vulnerability to depression and to higher rates of suicide (Hirschfeld, Hasin, Keller, Endicott, & Wunder, 1990; Jacobs & Gill, 2001). At the same time, substance use can provide a means of coping with negative feelings, such as depression (Gray & Nye, 2001; Mason, 1994). The subjective experience of distress can vary between Aboriginal and non-Aboriginal cultures, and between different Aboriginal cultures, which can have their own indigenous forms of distress that are similar but not identical to Western notions of depression (O’Neill, 1996). Despite such differences, depression, and related issues of high rates of substance use and suicide,

represent major concerns in many Aboriginal communities. However, as Cohen (2008) notes, “it is not easy to quantify the prevalence of depression among American Indians because it is likely that the great majority of sufferers are not counted” (p. 127).

This paper reports the findings from a national community-based project that examined self-reported depression among Aboriginal people living with HIV. The purpose of our study was to understand how participants described their depression and how they perceived its causes and its relation to HIV. The discussion focuses on how they made sense of their depression, particularly in relation to their Aboriginal background. We provide an analysis of the depression narratives of our participants in comparison to those described in other studies. Finally, we consider the implications of our findings for practice.

METHODS

Community-Based Design

This project was prompted by concerns expressed by Aboriginal people living with HIV (APHAs). The APHA Caucus of the Canadian Aboriginal AIDS Network (CAAN), a national coalition of individuals and organizations that provides leadership, support, and advocacy for Aboriginal people living with and affected by HIV and AIDS, asked the organization to address the mental health concerns of its members. Depression was identified in community consultations organized through CAAN as the most pressing mental health issue facing Aboriginal people living with HIV. As there was no previous research on the topic, CAAN decided to conduct a community-based research project to explore mental health issues of Aboriginal people living with HIV. In keeping with the principles of community-based research, investigators from CAAN were active members of the research team, and the project was guided by a National Research Advisory Committee that was composed of Elders, Aboriginal people living with HIV, and Aboriginal community members from across the country. Fifteen community organizations (Aboriginal AIDS service organizations, Friendship Centres, and Aboriginal health centres) assisted with recruitment in several locations across the country: Ottawa, Toronto, Vancouver, Edmonton, Winnipeg, and the Atlantic region. The research was guided by the principles of community ownership, control, access to and possession (OCAP) of research data and findings, which aim to ensure that Aboriginal cultural values and self-determination are respected and protected in the research process (Schnarch, 2004). The study design was reviewed by members of the APHA Caucus at CAAN, and following this, ethics approval was obtained by each of the university-based members of the research team.

Data Collection

People were invited to participate in this study if they self-identified as Aboriginal (First Nations, status or non-status; Inuit; or Métis), were HIV positive, and had experienced what they defined as depression or profound sadness. We decided not to limit our sample to those diagnosed with clinical depression, even though this would have allowed us to more easily compare our findings to the previous literature. Limiting our study to clinical depression might hide cultural differences in how emotions, such as depression, are experienced and understood, and we were also concerned that many Aboriginal people do not seek or have access to formal Western psychological or psychiatric diagnosis and treatment. Our purposive sample included individuals

of various backgrounds, ensuring that our participants differed along the lines of Aboriginal group, gender, sexual orientation, age, length of time living with HIV, and self-perceived health status. We conducted in-depth semi-structured interviews that lasted from 60 to 90 minutes and focused on participants' experiences of HIV and depression, how they understood the causes of their depression, how they responded to it, and the ways in which depression influenced how they managed their health and their HIV. All interviews were conducted by a non-Aboriginal team member who had 5 years of research experience with this community. The vast majority of interviews were conducted in a private office provided by the community organizations that assisted us in recruitment; however, a few participants chose to be interviewed in a neutral location such as a coffee shop or hotel room.

Data Analysis

With the permission of participants, interviews were audio recorded, transcribed, and later thematically coded and analyzed using Atlas.ti. A coding scheme was developed by three members of the research team. Family background, cultural issues, depression and HIV infection, formal and informal supports, identity, substance use, and recommendations for services emerged as thematic areas. Each of these broad themes included a number of subthemes. For example, the theme "family background" contained subthemes relating to such issues as a history of depression in the family, a history of substance use in the family, and a history of foster care or adoption. Similarly, the theme "cultural issues" included subthemes related to participants' connections to Elders, traditional ceremonies, and their experiences of racism. As suggested in the methodological literature (Patton, 2002), we started with a set of initial themes and subthemes based on our research questions and starting assumptions, and then this coding scheme evolved as more data were collected and analyzed. Research team members analyzed several early interviews to ensure consistency in how we were reading the transcripts, and then the research coordinator and a research assistant analyzed the remainder of the data. To help ensure the trustworthiness of our analysis and the relevance of our study to community needs, we presented our research plans at a national conference on HIV in Aboriginal communities and consulted with our National Research Advisory Committee early in the project. As the study progressed, we discussed our preliminary findings at annual meetings of the Canadian Aboriginal AIDS Network, and consulted again with the National Research Advisory Committee. We also presented findings from the study at a national conference on community-based research in Aboriginal communities. In these ways, we sought input from community members, some of whom were participants in the study, on our research design, our research questions, and our analysis. This process helped to validate the results of our study.

Sample

In total, we interviewed 72 Aboriginal people living with HIV or AIDS from across Canada. Fifty-five participants (76%) self-identified as First Nations, 11 (15%) identified as Métis, 2 (3%) identified as Inuit, and 4 (6%) identified as "other" or did not identify their background, perhaps indicating that they did not see themselves in one of the categories offered. Forty-five (63%) participants were male, 23 (31%) were female, and 4 (5.5%) were transgender. Twenty-four participants (33%) self-identified as gay/lesbian/Two-Spirited, 42 (58%) identified as heterosexual, and 6 (8%) as bisexual. The age of participants ranged from 26 to 54 years, with an average age of 40. The length of time that participants had been living with HIV or

AIDS at the time of the interview varied between less than 1 year to 22 years, with an average of 9 years since diagnosis. Forty-two participants (58%) reported that they had mild symptoms related to their HIV. Twenty-seven participants (38%) reported no symptoms, and 3 (4%) reported serious symptoms at the time of their interview. Twenty-eight participants (39%) reported that they were not on HIV medications at the time of their interview.

FINDINGS

In this section, we present the major findings from our study with regard to how participants described their experiences of living with feelings of depression, how they understood the sources of their feelings, and how they saw the links between their individual experiences and broader social and cultural factors in Aboriginal communities.

Descriptions of Depression

We set out to understand the subjective experience of depression from the perspective of participants. To elicit these descriptions, we asked them to tell us their story of depression. Participants used a wide range of images to describe their experiences:

When I really think about it, I don't think I was really feeling. I think I just went onto autopilot of survival.

I was just dead. I was so dead inside at that time. It wasn't sad, it was dead. I was completely dead inside.

I've collected a lot of shit from my past, and I just drag it with me everywhere, and it weighs me down when I'm walking.

Feeling like I'm worthless, that I really can't do things right. In the last couple of weeks, that's how I have been feeling, and I have been feeling it right to the bone.

Unexpectedly, few participants actually used words like "sadness" to describe their experiences, despite the fact that the interviewer often did in her questions. They talked about feeling empty, lonely, distant, tired, guilty, scared, disappointed, messed-up, or lost—but not sad. One respondent described her feelings in her teenage years in the following terms:

I didn't even know what depression was. All I knew was I didn't necessarily feel sad. I just didn't feel anything. You know? Just like dead, no emotions.

To the extent that they talked of their inner emotions, many participants talked more about feelings of anger than sadness:

The only thing I could think about was how angry I was at my family, how angry I was at the world, how angry I was at everybody.

Participants' descriptions often focused on dissatisfactory social relations more than their inner feelings or emotions. When asked to describe their feelings of depression, they told us how their parents or siblings mistreated them when they were younger, how they had been betrayed by trusted others, or how they were discriminated against or harassed by others. Even when their stories were not about betrayal or mistreatment, many participants spoke primarily of their depression in *social* terms of isolation or disconnection from others, rather than *psychological* feelings or mood:

I just feel isolated and not included in everything. Even though people still say that it's okay and stuff like that, but you still have that barrier. And I don't really connect sometimes. I'm sort of off, not really involved in the circle.

These narratives of depression often overlapped: sometimes descriptions of inner emotions predominated, but just as often, participants told us stories of disappointing and hurtful relationships with others. A frequently occurring theme in our interviews was about social disconnection, loneliness, and isolation. Hearing similar descriptions in his study of depression among non-Aboriginal Americans, Karp (1996) concluded, "Depression is a disease of isolation" (p. 13).

Participants clearly experienced periods of great distress, even if they did not necessarily describe their distress in terms of sadness or hopelessness. Half of our sample talked about suicide: 35 of our 72 participants described thoughts of killing themselves or actual attempts to commit suicide. For some, it was an overdose of street or prescription drugs, like antidepressants. Others jumped, or imagined jumping, from a building or a bridge, or jumping into traffic. Several of these participants noted that they did not consider themselves actually suicidal, but were bothered by recurring thoughts of dying or of harming themselves: "I wouldn't try to commit suicide, but the thoughts were there and that scared me. That scared me because I knew that's not what I wanted, but I couldn't help but feel it." Others talked about what one participant referred to as "passive suicide." Rather than actively taking their lives, they waited for their HIV infection or their drinking or drug use to finally kill them. One man said, "It's something that I wished for, for years—something that would just end it. I'm not going to kill myself, so why not come to the point where something else will kill me?"

Roots of Depression

We were interested in exploring how Aboriginal people living with HIV understood the sources of their depression. We asked participants to discuss any connection they saw between their depression and their HIV status or their Aboriginal background. We began this study expecting that HIV would be understood by participants as a key cause of their depression. As discussed above, the literature identifies a number of ways in which a diagnosis of HIV infection, HIV-related stigma, medications, or the everyday realities of living with a chronic health condition could all contribute to depression among people living with HIV. Some participants did speak of such factors as important sources of their distress. A few participants believed that their HIV diagnosis was a death sentence, and several dated the beginning of their depression to the time when they received their HIV diagnosis. Many participants talked in particular about the rejection they felt from others as a result of their HIV status. One woman described her experience with HIV-related stigma and discrimination:

I've had people spit on me. I've had people push me away. I've had people run away and yell, "She's got AIDS, that's an AIDS victim. She's got HIV, man! Stay away from her." Wow, I've even had a lady assault me.

However, most participants reported experiencing depression prior to their HIV diagnosis. When asked how they understood the relationship between their depression and their HIV infection, many did not cite HIV as a cause, although some said that their pre-existing feelings of depression became more pronounced as a result of living with HIV. A number of participants denied that HIV played a major role, if any, in their depression. In the following quote, a participant traces the roots of his depression to his home environment as a child, and to alcoholism, not to HIV:

I can't place the depression with HIV because it was not an issue at first. The depression was always there, but the HIV wasn't. The alcoholism was there, but the depression wasn't. So, if I can place anything with the depression it has to be the booze, it can't be the HIV. . . . There's the depression, there's the booze, then there's HIV. . . . The cause of my depression when I was 16 years was the abuse and fighting and drinking and everything at home. The lack of love, the lack of understanding, you name it, I wasn't getting it. So, I'm sure my depression then, that's what it had to do with. Today, even being HIV, if there's a connection between depression and HIV it has to do with the loss of the friends that I had.

Participants were often more likely to state that their social background played the central role in causing their experience of depression. Participants spoke of their experience of poverty, a lack of housing, or unemployment as underlying their depression. One man cited the isolation of life on reserves to be an underlying factor in Aboriginal depression: "It's too isolated. I'm always afraid on my reserve. I get stuck. There's nothing there but forests and lakes and islands." Living on-reserve was a particular concern for those who somehow felt different from other members of the community. In particular, those who described themselves as Two-Spirited, gay, lesbian, bisexual, or transgendered talked about the homophobia they experienced in their home communities, a not uncommon experience among Two-Spirited people (Tafoya & Wirth, 1996). One man said of his home reserve, "There's a lot of prejudice about me being gay back home and that caused a lot of depression in my life. A lot."

Racism was cited by several participants as a causal factor in their experience of depression. These experiences, they felt, led them to feel shame about their Aboriginal identity, which in turn led to depression. One man talked about how he was treated by other students in school: "I was really embarrassed to be an Indian, I was belittled so much." Another man who grew up off-reserve had this to say:

When I was growing up, I was hated. I was embarrassed and I hated my culture and my people because all I heard about was the winos, stinking bums, Listerine-drinking Indians, right? It was a shitty way to grow up. I grew up in a white man's world. And so that's the way I was brought up, was how bad we were—how good-for-nothing we are.

Several participants, particularly those raised in non-Aboriginal foster or adoptive homes, reported experiencing racism at home. This was sometimes even true for individuals who were raised by Aboriginal family members, who reported that their families had uneasy relations with people and traditions in their home community. For example, one man who was raised off-reserve by an Aboriginal grandmother reported:

I always knew that Natives were part of my life. However, to know a Native and to be a Native are totally different, right? Like, I was being raised white. It was like there was no culture or heritage. It was just, "we are who we are" and that's it.

This man's family did not let him visit their home community because they were concerned about the level of drinking and violence there. When he wanted to visit relatives who lived on the reserve, his grandmother would tell him, "I'm not going to send you up with a bunch of wild Indians. Are you crazy?" Other participants talked about how their parents actively discouraged them from socializing with other Native children: "I wasn't raised [Aboriginal] and I wasn't allowed to hang around with—believe it or not, me being Native—with Native people."

Childhood abuse was cited as a causal factor in the depression stories of 17 of our participants, representing about one quarter of our sample. For some it was verbal abuse, for others it was physical abuse by

family members. Nine of these participants reported a history of sexual abuse. These participants believed that their history of abuse was part of the reason for their ongoing depression: “When I think of depression, it wasn’t so much related to HIV in the beginning as it is now, but it was mostly due to coming from a family of alcoholics, verbal abuse, emotional abuse, stuff like this.”

Loss was a common theme in participants’ accounts of depression. They often spoke at length about the many losses they had experienced in their lives, and how this sense of loss was connected to their feelings of depression. Some participants saw the deaths of family members and friends as an important cause of their depression:

I spent 40 years burying people and I’m getting tired of it. And there’s always triggers—Christmas, holidays, vacations, summer time, barbeques, cottages, trips, any little thing that I happen to experience or hear or sit around and listen to other people sharing will always trigger a sadness of “why them, not me? Why don’t I have a family today? Why did my family have to die?” But I’ve also said that my entire life. “Why did my father have to die? Why did my father’s side all have to die?” ... You know, there’s just too much missing.

Among the many losses participants cited was the loss of community ties and the loss of culture. Most participants spoke about how important their Aboriginal culture was to them, but noted that they did not actually know much about their cultural background or traditions: “I don’t know much about my culture, like the Indian medicines and sweet grass and dancing, the Native stuff. I’m not much aware of it.” This disconnection happened for a variety of reasons. Many were not raised in Aboriginal communities or they had little contact with other Aboriginal people during their formative years. Significantly, almost one third of the sample (23 participants) were raised in foster care or adoptive families, and almost all of these families were non-Aboriginal. A number of participants who were raised by their biological families never lived on reserve or their family moved off reserve when they were young. As a result, they learned little about the traditions of their community. Participants often spoke with considerable regret about not having learned their culture earlier, or having rejected it when they were younger. Of those who considered themselves somewhat knowledgeable about their community and culture, most had only recently started learning their traditions.

Drinking and drug use were cited as a main causal factor in the vast majority of participants’ stories of depression. Most participants reported excessive drug or alcohol use, either in the past or in the present. These stories were entirely unsolicited: We did not ask questions about substance use unless participants raised the issue. Many participants reported growing up in homes where excessive alcohol use, and to a lesser extent drug use, was a regular occurrence. This was often accompanied by parental neglect or, in some cases, violent or abusive episodes that were either directly experienced or witnessed by participants. For some, being neglected as a child while their parents and grandparents drank was an experience that left long-lasting emotional scars and feelings of rejection that were difficult to heal. Other participants spoke of growing up fearful of violence or abusive behaviours that could accompany their parents’ bouts of drinking. For example, one participant noted that “a lot of times, we . . . my sisters and I, were scared of [our mother] because she was drunk and when she was drunk she would act all violent and try to hit us—well, not try, but did.”

Most participants also discussed their own history of substance use and its relation to their depression. They spoke of their substance use as both a cause and effect of depression. For some, depression was brought on by periods of excessive substance use; a few participants reported crashing so hard that they wound up

in hospital-based treatment centres. Others reported using substances as a response to depression, to either mask emotions or help deal with them. One participant reported that he spent the better part of his life using substances to suppress experiences and emotions that he did not want to think about.

That was my whole life for 30 years. Being raped, I suppressed. Being abandoned, I suppressed. And every little thing that happened in between, I suppressed, because I didn't know how to deal with any of this stuff. The only way I knew how was bury it.

Depression was related to substance use in our participants' stories in complex ways. Despite the problems it could cause, substance use had positive connotations as a kind of social lubricant for some participants. They reported that drinking or using drugs made socializing easier by allowing them to overcome anxieties or insecurities, at least temporarily. At times, it was a bit of a "pick me up" when they were down or having a bad day. It helped some participants show strong emotions. For others, it was a way to "blow off steam." While some saw their drinking and drug use as a way of dealing with their feelings of depression, most participants believed that they needed to deal with their substance use before being able to address their depression or issues relating to their HIV.

Linking Individual and Collective Experiences

We were interested in hearing whether our participants made links between their own individual experiences and the broader challenges facing many Aboriginal communities in Canada, and whether their identity as Aboriginal helped them talk about depression as a shared experience. We wondered, for example, whether participants would understand their depression as rooted in the oppression of Aboriginal people in Canada, and whether they would attribute their own family's problems to the broader social issues—colonization, racism, discrimination, and so forth—that characterize so many Aboriginal communities. In other words, we wanted to know the extent to which participants explicitly linked their *individual experiences* of depression to *community experiences* of oppression and marginalization.

Some participants spoke eloquently about the links they saw between their personal experiences of depression and broader community concerns. One man noted that depression was a common experience among Aboriginal people. He said, "I think Aboriginal people live with depression all their life. It's part of their mentality." A few participants attributed the relatively common experience of depression to the legacy of Indian residential schools, where over the course of about 100 years, thousands of Aboriginal students were removed from their homes and placed in church-run schools that aimed to eradicate their language, traditions, and communities (Royal Commission on Aboriginal Peoples, 1996). One man described himself as "a by-product" of the residential school system: He believed his parents' experience in residential schools had shaped his experience of anger and depression. Talking about his parents, he noted:

I don't know what their thing was, but I know they went to residential school. And I know a lot of residential schools were not happy places, nice places. And I knew from the way that they [my parents] treated me and my sister, that they weren't the happiest people either, you know?

Another recalled his 8-year experience in residential schools:

I don't know how prisons are, but I went home once a year and that was for Christmas and that was it. It was real strict you know. I don't want to talk about that. When I was there I got molested, even by a priest. It was bad. . . . It's sick what people can do and get away with.

Reflecting on the history of residential schools, one man asked, “How can a society get away with doing something like genocide?” He described the clear connections he saw between the history of residential schools and the intergenerational struggles in Aboriginal families and communities regarding HIV:

We lost a lot of our culture, we lost a lot of our language, we lost a lot of our traditions, and we lost a lot of family values. So we’re starting, really, from the beginning. There’s families that really don’t know how to communicate with each other. There’s families who don’t know how to love each other. There’s families who are just totally lost. And how, if a family can’t communicate, how are we going to communicate about safer sex? How are they going to communicate about risk factors associated with HIV? How are they going to communicate that they shouldn’t be using drugs and alcohol to mask the abuse that’s happening in the family? When you think about all of the risk factors, the door is wide open and all of those risks are coming in, flying in.

While some participants offered thoughtful analyses of the social roots of depression among Aboriginal people living with HIV, most talked about their own personal experiences without directly linking them to broader community concerns. Even those who spoke about having experienced racism, poverty, sexual abuse, fostering or adoption, or drug and alcohol use, did so without explicitly relating their personal experiences to community marginalization and oppression. Instead, most participants spoke of their depression in fairly individualized terms. For example, participants who spoke about their own history in foster or adoptive homes and how this affected their depression typically did not connect their personal story to the history of child welfare “sweeps” in Aboriginal communities. One man described being removed from home and placed in a non-Aboriginal environment, and feeling disconnected from his culture as a result.

I wasn’t really brought up with my traditions ... because my mother was an alcoholic, and in those days, in the 1970s, that’s when they were taking away children from their parents, and putting them in foster homes and that, because of their alcohol abuse.

While recognizing the practice of “taking away children from their parents,” he attributed his foster placement to parental alcohol abuse, not racist child-welfare policies and practices.

Even though participants generally talked in individualized terms when discussing the roots of their depression, most participants recognized a potentially important healing role of Aboriginal cultures and traditions. Reconnecting to their community and culture represented an important way for them to address their depression. This finding is similar to that of a study of the portrayal of HIV/AIDS in Aboriginal media in Canada (Clarke, Friedman, & Hoffman-Goetz, 2005), where Aboriginal culture and spirituality were often portrayed as central to how people coped with HIV. One man talked about a newly discovered need to learn more about his culture, a need that was all the more pressing because of his feelings of depression:

I’ve never ever recognized my heritage or anything Native or Aboriginal about me. I don’t know my language, I don’t know where I’m from, I don’t know where my parents are from. I’m about as far away from my parents as I can get, from where my Aboriginal ancestry lies. But in the last couple of months, I am learning about Native medicine, ceremonies, sweat lodge, going to sweats, and I’m just thinking maybe I could learn something ... So, up until a couple of months ago I didn’t know squat about any kind of Aboriginal anything. But my knowledge is growing, and it’s kind of odd, because I’ve been feeling an urgent sense that I need to know more and I need to know quickly. I’m really hoping that I’ll learn something or come across something that might help me change my mind to get this depression under control.

Participants like this man sought Elders to teach them, and several described learning about their traditions after they had become involved in an Aboriginal AIDS service organization where they were encouraged to explore traditional approaches to healing, or after they had entered drug and alcohol treatment.

DISCUSSION AND IMPLICATIONS

Our study sheds light on the various ways that Aboriginal people living with HIV or AIDS experience depression, the factors that in their view contribute to its development, and the connections they make between their personal experiences of depression and broader social forces in Aboriginal communities in Canada. Participants' descriptions revealed that their depression often did not feel like psychologically oriented understandings of depression. Rather than focusing primarily on their inner selves, on feelings of sadness or hopelessness and on diminished interest in activities, many of our participants described their depression in relational or social terms. Depression was experienced more as anger at others, dissatisfaction with those around them, or a disconnection with people, communities, and culture. As a result, depression was often difficult for participants to recognize and label as such, which made it hard for them to respond to it. Similarly, the ways in which participants described their feelings might make it difficult for service providers to recognize and respond to their experiences as depression.

Participants' perceptions of the causes of their feelings show the complex relationship between depression and HIV. It is easy to assume that HIV leads to feelings of depression. This is no doubt often true, but HIV was but one of many factors in how participants understood the causes of their depression, and it was often not the primary factor in their minds. In our study, HIV usually followed depression, not the other way around. This raises questions about how depression might lead to an increased vulnerability to HIV. The legacy of colonization has been linked to increased substance use (Adelson, 2005). Injection drug use is the major mode of HIV transmission among Aboriginal people in Canada (Public Health Agency of Canada, 2010), and increased alcohol use can lead to an increased incidence of depression and of risk-taking behaviours that increase one's vulnerability to HIV (Thompson et al., 2009). Quite apart from their own substance use, participants cited drinking and drug use by their parents or other family members, and the problems it generated, such as violence, neglect, or the need for foster care, as a cause of their early depression. There is some research to suggest that a history of sexual abuse may increase the likelihood of a mental health diagnosis, suicide ideation and attempts, and HIV infection (Pearce et al., 2008).

Our paper contributes to the growing literature that examines depression from the perspective of those who are depressed (e.g., Black, White, & Hannum, 2007; Mallinson & Popay, 2007; Rodrigues, Patel, Jaswal, & de Souza, 2003; Stoppard, 2000). A key question for the research team was the extent to which participants related their personal experiences with depression to broader social and community concerns. In some ways, the stories of depression we heard did not differ very much from those discussed in the sociological literature on depression. For example, Karp (1996) reported that depression was often experienced as anger and a sense of profound disconnection to others. However, the narratives of our participants differed from those described in this literature in the degree to which their personal experiences with issues such as racism, family disruption, or drug and alcohol use were cited as important contributing factors. Some of our participants made explicit links between their personal experiences and the oppression of Aboriginal people in Canada, although most did not, a finding that is consistent with Kirmayer et al.'s (2000) observation that "many forms of violence against Aboriginal people are structural or implicit, and so may remain hidden in individual accounts" (p. 613). Nevertheless, the depression narratives we heard among our Aboriginal participants were different in important ways from what has been reported in other cultural groups.

Our findings have a number of implications for community mental health practice. Workers need to be aware of depression and the various ways that it can be manifested. Service providers cannot simply focus on HIV when providing services to Aboriginal people, but must also attend to the long-standing social and psychological issues confronting these clients, such as substance use and history of abuse (Pearce et al., 2008). Beyond an individual focus, services must also address community issues that affect individuals living with HIV and depression. By helping Aboriginal people recognize links between their individual experiences of depression and broader community concerns, practitioners may help reduce feelings of self-blame, stigma, and isolation. The recognition of these links may serve as a way to reconnect to community and culture. Our findings, like those of Clarke et al.'s (2005) study of the portrayal of HIV in Aboriginal media, point to the importance of understanding cultural differences in how health and mental health concerns are understood. The findings suggest that workers need to be aware of the potentially important role that cultural traditions can play in helping Aboriginal people deal with depression and the challenges of living with HIV (McCall, Browne, & Reimer-Kirkham, 2009), and with drinking and substance use. Our findings show, perhaps counter-intuitively, that having HIV often led participants to find ways of dealing with depression: A number of participants spoke of how HIV/AIDS service providers encouraged them to explore traditional Aboriginal approaches to healing. Such approaches helped them reconnect with culture and community, and to deal with the isolation and estrangement that they often felt. Learning about their own cultural traditions and ceremonies, seeking guidance from Elders, and rediscovering community roots were often cited by participants as key components of their healing. These measures did not provide a simple "fix" for the complex personal and social problems experienced by our participants, but traditional approaches often helped them find social and cultural connections that they felt were lacking. Traditional Aboriginal approaches were helpful to many, but not all, participants. Our findings suggest the need to blend Western and traditional approaches to provide culturally appropriate and comprehensive support to Aboriginal people living with HIV and AIDS.

RÉSUMÉ

Dans cet article, nous explorons les façons dont les Autochtones vivant avec le VIH ou le sida et qui souffrent de dépression perçoivent et ressentent la maladie. Pour ce faire, nous avons réalisé des entrevues semi-dirigées avec 72 personnes. Plusieurs participants ont décrit leur dépression en termes de relations sociales, expliquant qu'ils vivent de l'isolement et une coupure par rapport à leurs proches, à la communauté et à leur culture. Plusieurs éléments sont souvent intimement liés à la maladie : le fait d'avoir subi du racisme, un historique de placement en famille d'accueil ou d'adoption, le fait d'avoir été victime de violence pendant l'enfance, la séparation d'avec la famille et la communauté et l'abus d'alcool ou de drogue. Nous comparons ensuite nos résultats et ceux de recherches réalisées sur des populations non autochtones, et nous analysons les implications du phénomène en termes de types de services offerts à ces communautés.

Mots clés : VIH/sida, dépression, communautés autochtones

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