



# DEPRESSION AMONG ABORIGINAL PEOPLE LIVING WITH HIV/AIDS

## RESEARCH REPORT

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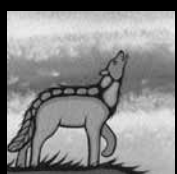
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# Executive Summary

Mental health issues, and particularly depression, have emerged as important concerns for persons living with HIV and AIDS. In response to this concern among its members, the Canadian Aboriginal AIDS Network (CAAN) partnered with researchers at McMaster University and the Universities of Toronto and Alberta between 2005 and 2008 to develop and implement a community-based research (CBR) project. The project aimed to explore the ways that Aboriginal People Living with HIV and AIDS (APHAs) experienced depression, the impact of depression on how they managed their HIV infection and the strategies that they found helpful in dealing with their feelings of depression.

In keeping with the principles of CBR, the research questions were identified by the community and community investigators were active members of the team. In addition the project was guided by the principles of community ownership, control, access and possession (OCAP) and a National Advisory Committee at CAAN comprised of Elders, APHAs and Aboriginal community members from across Canada.

Fifteen service organizations assisted with the recruitment of participants in several locations across Canada: Ottawa, Toronto, Vancouver, Edmonton, Winnipeg, and the Atlantic region. Seventy-two APHAs who identified as First Nations (76%), Métis (15%), Inuit (3%) or other (7%) participated in an in-depth, semi-structured interview lasting from 60 to 90 minutes. In addition, 24 service providers including nurses, physicians, social workers, community HIV workers, community mental health workers, counselors, Elders and traditional counselors participated in an in-depth interview in one of five cities (Toronto, Ottawa, North Bay, Sudbury and Thunder Bay) in Ontario. The service providers were asked to describe their experiences providing services to APHAs with depression, including the challenges that they faced.

Among study participants, depression presented with a range of feelings, including some that might not be typically associated with depression. Many participants spoke primarily of their depression in social terms, including isolation, dissatisfaction with others or disconnection from people, communities, and culture, rather than in terms of psychological feelings of sadness or hopelessness. Although many participants did not use the terms depression or sadness, they had clearly experienced periods of great personal distress. About half of the sample had thought about killing themselves or had actually tried to commit suicide. For some participants suicidal thoughts started prior to their HIV diagnosis, while others stated that they had become suicidal following their diagnosis.

The relationship between HIV and depression was diverse, complex, and inter-connected, although almost all participants believed that HIV and depression went “hand-in-hand”. HIV was only one of the many factors in how participants understood their depression. For many participants, depression was linked to broader community issues such as poverty, unstable housing, fostering/adoption, cultural disruption and substance abuse. The initial depression associated with an HIV diagnosis was made worse by stigma and an accompanying fear of disclosure. Loneliness or lack of significant partnerships contributed to depression in some participants. Participants described ways in which they believed their Aboriginal background played a role in their experience of depression. A number of participants suggested that their experiences of racism during childhood negatively influenced how they saw themselves and contributed to their depression. Similarly, many participants believed that the disconnection that they felt from their Aboriginal culture contributed to experiences of depression. Childhood abuse was a factor in the depression stories of about one-quarter of the sample, while almost all participants reported excessive drug or alcohol use in the past or present. There was no ‘typical’ pattern of substance use in the context of HIV and depression, however, for most participants a diagnosis of HIV would exacerbate substance use for a period of time.



In an effort to manage HIV and depression, participants reported drawing on a range of overlapping strategies. Formal approaches to managing their illness were grounded in a Western view of health and illness and included involvement in community services, counseling, and medication. Informal approaches, on the other hand, included traditional Aboriginal healing, social support from friends and family and the use of humour. Some participants continued to use drugs and alcohol to manage their depression. Many participants reported that coping with depression had become easier over time, however a few had found that living with HIV had become more difficult due to the unrelenting demands of managing their illness. Although most participants had developed a range of unobtrusive strategies for managing their HIV illness, physical or medical reminders of the disease, such as taking medications or attending doctors' appointments, were often accompanied by increased feelings of depression.

Virtually all service providers viewed depression from a Western perspective and believed that it was a very common experience among APHAs. Similar to the views of APHAs, service providers felt that for some APHAs depression pre-dated the HIV diagnosis, while for others depression was a consequence of HIV. Depression was seen as very complicated for APHAs both in terms of causation and symptoms, and service providers had observed that drug and alcohol use was both a contributing factor to depression and a strategy to manage it. When describing the experience of depression among APHAs, psychological, social and cultural losses were common themes. All of the service providers were open to dealing with depression in APHAs with a combination of Western and traditional Aboriginal healing approaches.

The report concludes with the following recommendations: an awareness campaign to help APHAs recognize depression; programs to target stigma on and off reserves; training for service providers in the areas of HIV, mental health, substance use, traditional health approaches, and the broad psychological, social, and cultural issues surrounding HIV; services that provide complementary and integrated models of care; increased access to drug and alcohol programs and to Aboriginal HIV/AIDS services; and continued support and expansion of traditional cultural programs.



# Sommaire

Des problèmes de santé mentale, notamment la dépression, se sont distingués en tant que préoccupations importantes pour les personnes vivant avec le VIH ou le SIDA. En réponse à cette préoccupation parmi ses membres, le Réseau canadien autochtone du SIDA (RCAS) a travaillé en partenariat avec des chercheurs de l'Université McMaster, l'Université de Toronto et l'Université de l'Alberta entre 2005 et 2008, aux fins d'élaboration et de mise en œuvre d'un projet de recherche communautaire (PRC). L'objectif du projet visait à explorer les formes de dépression vécues par les personnes autochtones vivant avec le VIH et le SIDA (PAVS), l'impact de la dépression sur la façon dont ils prennent en charge leur infection au VIH, ainsi que les stratégies qu'ils considèrent efficaces en ce qui concerne le traitement de leur état dépressif.

En conformité avec les principes de recherche communautaire, les questions de recherche ont été formulées par la collectivité et les enquêteurs communautaires étaient membres actifs de l'équipe. Le projet a été réalisé en fonction des principes de propriété, de contrôle, d'accès et de possession (PCAP) par la collectivité et sous la conduite du comité consultatif national du RCAS comportant des Aînés, des PAVS et des membres de la collectivité autochtone de partout au Canada.

Quinze organismes de services ont collaboré au recrutement de participants provenant de plusieurs endroits partout au Canada: Ottawa, Toronto, Vancouver, Edmonton, Winnipeg et la région de l'Atlantique. Soixante-douze PAVS, qui s'identifiaient comme Premières nations (76 %), Métis (15 %), Inuits (3 %) ou autres (7 %), ont participé à des entrevues en profondeur et semi-dirigées qui duraient entre 60 et 90 minutes. De plus, 24 fournisseurs de services, y compris des infirmières, des médecins, des travailleurs sociaux, des travailleurs communautaires du domaine du VIH, des agents de santé communautaire, des conseillers, des Aînés et des conseillers traditionnels ont participé à une entrevue en profondeur dans l'une de cinq villes (Toronto, Ottawa, North Bay, Sudbury et Thunder Bay) en Ontario. On a demandé aux fournisseurs de service de décrire leurs expériences en matière de prestation de services aux PAVS qui souffrent de dépression, y compris les difficultés auxquelles ils ont fait face.

Parmi les participants à l'étude, la dépression se manifestait par l'intermédiaire d'une gamme de sentiments, dont certains qui ne sont pas généralement associés à la dépression. La plupart des participants parlaient de leur dépression surtout en termes sociaux, notamment d'isolement, de mécontentement à l'égard des autres ou de détachement face aux gens, à la collectivité et à la culture, plutôt qu'en fonction d'états psychologiques de tristesse ou de désespoir. Quoique plusieurs participants n'aient pas employé les termes dépression ou tristesse, ils ont indéniablement vécu des périodes de grande détresse. Environ la moitié des personnes sondées avaient contemplé de s'enlever la vie ou avaient effectivement fait une tentative de suicide. Chez certains des participants, les pensées suicidaires s'étaient manifestées avant de recevoir un diagnostic de VIH, tandis que d'autres ont affirmé qu'ils étaient devenus suicidaires après avoir reçu leur diagnostic.

Les liens entre le VIH et la dépression étaient variés, complexes et interdépendants, même si la plupart des participants estimaient que le VIH et la dépression allaient de pair. Aux yeux des participants, le VIH ne représentait qu'un des multiples facteurs qui sous-tendent leur dépression. Pour la plupart des participants, la dépression était liée à d'autres problèmes dans la collectivité, comme la pauvreté, la précarité du logement, le placement en foyer d'accueil et l'adoption, la dislocation culturelle et la consommation abusive d'alcool ou d'autres drogues. La dépression initiale associée au diagnostic du VIH était aggravée par la stigmatisation et la crainte que leur maladie soit divulguée. La solitude ou l'absence de relations significatives ont contribué à l'état dépressif de certains participants. Les participants ont décrit des façons dont ils estiment que leurs origines autochtones ont joué un rôle dans leur





expérience de la dépression. Un certain nombre de participants ont indiqué que les expériences de racisme qu'ils ont vécues durant leur enfance ont nuit à leur perception d'eux-mêmes et ont contribué à leur dépression. Dans un même ordre d'idées, plusieurs participants estimaient que leur sentiment de détachement à l'égard de leur culture autochtone a contribué à leurs expériences de dépression. Les abus subis durant l'enfance ont été mentionnés comme un facteur de dépression dans les témoignages d'environ le quart des personnes sondées, alors que presque tous les participants ont indiqué qu'ils consommaient des drogues et de l'alcool de façon excessive et ce, dans le passé et actuellement. Il n'y avait aucune tendance profonde type quant à la consommation de substances dans le contexte de VIH et de dépression, par contre, pour la plupart des participants, un diagnostic de VIH aurait exacerbé leur consommation de substance pendant une période.

Pour combattre le VIH et la dépression, les participants ont dit avoir recours à une gamme de stratégies qui se chevauchent. Les démarches structurées, adoptées aux fins de prise en charge de leur maladie, étaient fondées sur une conception occidentale de la santé et de la maladie et incluaient l'engagement dans les services à la collectivité, la thérapie et la médication. Les démarches non structurées en revanche incluaient la guérison traditionnelle autochtone, l'accompagnement offert par la famille et les amis et la mise à profit des forces culturelles, comme l'humour. Un certain nombre de participants ont continué à consommer de l'alcool et des drogues afin de rendre leur dépression tolérable. Plusieurs participants ont affirmé que l'adaptation à la dépression s'effectuait plus facilement avec le temps, mais certains ont indiqué qu'il était devenu plus difficile de vivre avec le VIH en raison des demandes implacables associées à la prise en charge de leur maladie. Même si la plupart des participants avaient élaboré une gamme de stratégies discrètes pour prendre en charge leur maladie du VIH, les rappels de la maladie sur le plan physique et médical, comme prendre des médicaments ou se présenter à des rendez-vous de médecin engendraient souvent un état dépressif aggravé.

À peu près tous les fournisseurs de services percevaient la dépression d'un point de vue occidental et estimaient qu'il s'agissait d'une expérience très courante chez les PAVS. Les fournisseurs de services partageaient le point de vue des PAVS, selon lequel certaines PAVS souffraient de dépression avant d'avoir reçu un diagnostic de VIH tandis que pour d'autres PAVS, la dépression était une conséquence du VIH. Les causes à l'origine ainsi que les symptômes de la dépression étaient perçus comme très compliqués pour les PAVS et les fournisseurs de services ont constaté que la consommation de drogue et d'alcool était un facteur contributif à la dépression autant qu'une stratégie pour oublier la dépression. Le sentiment de perte sur les plans psychologique, social et culturel constituait le dénominateur commun aux PAVS qui décrivaient leur expérience de la dépression. Tous les fournisseurs de services étaient ouverts à l'idée de traiter la dépression chez les PAVS par l'emploi de pratiques de guérison occidentales combinées à des pratiques de guérison traditionnelles autochtones.

Le rapport énonce les recommandations suivantes: une campagne de sensibilisation permettant aux PAVS de reconnaître les symptômes de la dépression; des programmes visant à éliminer la stigmatisation sur les réserves et à l'extérieur des réserves; de la formation à l'intention des fournisseurs de services dans les domaines du VIH, de la santé mentale, de l'alcoolisme et de la toxicomanie, des pratiques traditionnelles en santé et des grandes questions se rapportant aux aspects psychologiques, sociaux et culturels du VIH; des services offerts selon les modèles de soins coordonnés et complémentaires; l'amélioration de l'accès à des programmes destinés aux alcooliques et aux toxicomanes et l'accès à des services liés au VIH/SIDA pour les Autochtones; et finalement, le soutien continu et l'élaboration de programmes culturels traditionnels.



# Introduction

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This report on the experiences of depression among Aboriginal people living with HIV/AIDS (APHAs) is in response to a call from the APHA Caucus of the Canadian Aboriginal AIDS Network (CAAN) to pay more attention to issues of mental health and mental health services. CAAN approached partners from McMaster University, the University of Toronto and the University of Alberta to collaborate on this national community-based research project about the experience of depression for APHAs. The team conducted five preliminary interviews with APHAs in Toronto and a group consultation with APHAs and service providers was held in Vancouver to help focus our question and to ensure the relevance of the project to community concerns. This preliminary work helped identify depression as an area of particular importance.

The project focuses on understanding the various ways that APHAs define and experience depression, the impact of depression on how they manage their HIV infection, and what they find helpful in dealing with their depression. A clinical diagnosis of depression was not necessary to participate in this study. Rather, we asked people to self-identify as having experienced depression.

The project also explores the perspectives of Aboriginal and non-Aboriginal service providers who provide services to APHAs experiencing depression. Their perspectives were used to assist in understanding the challenges related to the provision of services and support to APHAs, and the development of recommendations for service delivery for APHAs.

In the following pages we provide a brief summary of the published research related to depression among APHAs. This provides a background for our study and helps to contextualize our findings. We also provide a brief description of our research methods, and a discussion of some of the ethical issues we addressed in the course of the project. Our findings are divided into three main sections: Experiencing Depression, Responding to Depression and Service Provider Perspectives on Depression. Finally, we offer summary thoughts on our findings followed by recommendations for service providers, for further research and for next steps.



# Background

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Mental health issues, particularly depression, have emerged as important concerns for persons living with HIV/AIDS<sup>1</sup>. Since the mid-1990s, more effective treatments for HIV infection have meant that many people are living longer and healthier lives with HIV. This means that health-related quality of life has become an increasingly important issue<sup>2</sup>.

## Depression among Aboriginal People

Little is known about the prevalence of mental illnesses in Canadian Aboriginal communities. Psychiatric studies are problematic in Aboriginal communities where Western notions of mental health and illness may not be culturally appropriate<sup>3</sup>. For example, cultural differences can lead to errors in diagnosis and treatment<sup>4</sup>. In addition, much of the mental health research among Canadian Aboriginal populations has focused on elevated levels of suicide. As a result, our understanding of the extent of depression, which is a key contributing factor to suicide, is limited.

Despite limitations in empirical evidence, there is a general consensus that rates of depression in Aboriginal groups are higher than in the rest of Canada. The Canadian Community Health Survey<sup>5</sup> reported that the Aboriginal population was 1.3 - 1.5 times more likely than the non-Aboriginal population to experience a major depressive episode in the twelve months prior to the survey. Among Aboriginal groups, rates of suicide, as one measure of community levels of depression, are between three and five times higher than the rest of Canada<sup>6</sup>. Particularly profound stress stems from acculturation, cultural discontinuity, economic and political marginalization, and colonial oppression. For some, depression can be related to the legacy of the residential school experience<sup>7</sup>.

Substance use has also had a devastating impact on many Aboriginal communities<sup>8</sup>. Drinking and drug use are strongly related to problems with depression, and substance use can be seen as both a cause and a result of depression. A personal history of alcohol and drug use increases a person's vulnerability to depression<sup>9</sup>. At the same time, drugs and alcohol are often used as a means of coping with feelings of depression<sup>10</sup>.

## HIV/AIDS and Depression

We found no literature on depression among APHAs, but research on non-Aboriginal people living with HIV suggests that depression is more common among persons living with HIV than the general population. While 10% - 20% of the general population experiences major depression at some point in their life, studies of persons living with HIV suggest that 10% - 50% suffer from depression<sup>11</sup>. In general, studies indicate that HIV-positive individuals are twice as likely as the general population to have a major depressive disorder<sup>12</sup>.

Depression affects the quality of life of people living with HIV in many ways<sup>13</sup>. Depression can be related to symptoms of HIV infection, certain HIV medications, or the appearance of medication side effects, such as lipodystrophy<sup>14</sup>. Depression has also been shown to influence the course of HIV-related disease by impairing immune function or influencing behavior<sup>15</sup>. For example, depression among PHAs generally leads to less-than-optimal adherence to antiretroviral treatment<sup>16</sup>. HIV infection can also lead



to poverty<sup>17</sup>, which in turn can impact depression. As well, poverty can influence disease progression, as individuals are less able to afford health care, medications, adequate nutrition, or appropriate housing<sup>18</sup>.

Stigma continues to be a central feature of people's experience with HIV<sup>19</sup> and on-going CAAN research shows that HIV/AIDS continues to be highly stigmatized in Canadian Aboriginal communities<sup>20</sup>. This can have a profound effect on APHAs' mental health and well-being. For example, having to tell family and friends about one's HIV infection, being discriminated against because of one's HIV infection, or belonging to a stigmatized group, can all impact the emotional well-being of people living with HIV<sup>21</sup>.



# Method

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We used a community-based research (CBR) design in this project. In keeping with the principles of CBR, the research problem and questions were identified by the community, and community investigators were active members of the research team. In addition, the project was guided by a National Research Advisory Committee (NRAC) at CAAN comprised of Elders, APHAs, and Aboriginal community members from across the country.

There were two components to our study. In the first component, we interviewed APHAs about their experiences with depression. In the second, we interviewed service providers about supporting APHAs who experience depression.

## APHA Interviews

APHAs were eligible to participate in this study if 1) they self-identified as Aboriginal (First Nations – status or non-status, Inuit, or Métis)<sup>22</sup>; 2) they were HIV positive;<sup>23</sup> and 3) they experienced what they considered to be depression or profound sadness. We talked to APHAs of various backgrounds, ensuring that participants differed along the lines of Aboriginal group, gender, sexual orientation, age, length of time living with HIV/AIDS, and self-perceived health status.

Fifteen service 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.

We conducted in-depth semi-structured interviews due to their similarity with traditional Aboriginal storytelling as a way of sharing information. Interviews usually lasted 60 to 90 minutes and focused on APHAs' experiences of HIV and depression, what they do about their depression, and the ways in which depression may influence how they manage their health and their HIV. To ensure a balance of flexibility and consistency in the interviews, we used the same guiding questions for all participants; however, we emphasized particular questions according to the experiences of the interview participant. All interviews with APHAs were conducted by the research coordinator (TP), a non-Aboriginal woman with 5 years of research experience with this community. All participants completed a short demographic survey to allow for comparison of experiences across groups.

With the permission of participants, interviews were audio recorded, transcribed and later coded and analyzed using Atlas.ti®. A coding scheme was developed by three members of the research team who read and discussed several interviews and agreed on emerging themes. A descriptive label or a code was assigned to each theme and all interviews were then coded and analyzed accordingly. Research codes evolved as more data were collected and analyzed.

## Service Provider Interviews

We also conducted a series of in-depth interviews with workers who provide services to APHAs. A female Aboriginal research assistant (BF) conducted 24 in-depth interviews with practitioners from various backgrounds, including social workers, physicians, nurses, community HIV workers, community mental health workers, counselors, Elders and traditional counselors.



We asked service providers to describe their experiences in providing services to APHAs with depression, including challenges they faced in providing these services. In addition, we explored the prevalence of depression in their practice with APHAs, gaps in services, and the strategies and resources used to support APHAs who experience depression.

We used a similar method to manage and analyze these data as in the APHA component of the project: interviews were audio recorded, transcribed verbatim, and coded; a coding scheme was developed from our initial questions; and codes evolved as more interviews were analyzed.

## Ethical Considerations

Our research was guided by the principles of community ownership, control, access and possession (OCAP)<sup>24</sup>. OCAP principles ensure that Aboriginal cultural values and self-determination are respected and protected in the research process. To ensure that Aboriginal culture and Aboriginal content were respected, the OCAP principles were addressed in the following ways:

- 1) Our research team included 4 Aboriginal members (1 co-principal investigator, 1 co-investigator and 2 research assistants),
- 2) The project was guided by a National Research Advisory Committee comprised of Aboriginal people living with HIV/AIDS, Elders, and representatives from First Nations, Métis and Inuit communities, and
- 3) All members of the research team agreed to uphold the principles of OCAP and to share in decision-making by signing a document called Principles of Research Collaboration<sup>25</sup>.

The study design was reviewed for ethics by members of the APHA Caucus at CAAN. Their comments and suggestions were incorporated into the research design. Following this, approval was obtained from the Research Ethics Boards of McMaster University, the University of Toronto and the University of Alberta.

Given our focus on depression, we expected that the interviews might raise difficult issues for participants. On the advice of the APHA caucus, we took a number of steps to ensure the emotional safety of participants. Prior to the interviews, we collaborated with local service organizations to ensure that Traditional and Western-style counseling were available on-site should participants wish to speak with someone immediately following their interview. We also prepared referral lists for those who wished to speak with someone off-site. In addition, the interviewer and participant discussed this issue before the interview and agreed that the interview could be stopped at any time and that participants could control the direction and depth of the interview. Following the interview, the interviewer checked in with the participant to assess their emotional state. Arrangements for counseling were made when requested. A number of participants made their own post-interview self-care arrangements.

Issues of privacy and confidentiality were addressed in the following ways: participants were invited to use a false name of their choice for the study's consent form. Demographic data (which did not have the participant's name) were kept in a separate file from consent forms and all identifying information was removed from transcripts before they were shared with the research team.



## Participant Characteristics

In total, we interviewed 72 APHAs from across the country. Fifty-five (76%) self-identified as First Nations, eleven (15%) identified as Métis, two (3%) identified as Inuit, and five (7%) identified as Other, perhaps indicating that they did not see themselves in the limited number of categories that they were offered.

Forty five (63%) of our participants were male, twenty-three (31%) were female, and four were transgender. Twenty-four participants (33%) self-identified as gay/lesbian/Two-Spirited and six (8%) identified 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 three (4%) reported serious symptoms at the time of the interview. Twenty-eight participants (39%) reported that they were not on HIV medications at the time of the interview.

We interviewed 24 service providers in Ontario. Eight of these providers worked in Toronto, five worked in Ottawa, five in North Bay or Sudbury, and six in Thunder Bay. Half of our service provider sample identified as Aboriginal and half as non-Aboriginal. Fifteen providers worked in agencies that had an HIV/AIDS mandate, and the remaining nine providers worked in agencies that did not have an HIV mandate. Ten worked in agencies that had a mandate to provide mental health services, and 11 agencies had a mandate to provide health services.





# Experiencing Depression

We set out to understand how our participants' background influenced how they experienced, understood and dealt with their depression. In our interviews, we asked participants to describe what their depression felt like. Participants used a wide range of images to describe the emotions they felt. To give a sense of the kinds of imagery used by participants, we provide a number of quotes from interviews:

*I was sad. I was scared. 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.*

*You know how there are bottom feeders in the ocean and, that water's so heavy. They survive down there. And it's just like I'm being pushed and take on a whole bunch of negative stuff... It's just the heaviness that's there.*

Participants provided two kinds of stories about their depression: we heard of their struggles with their inner emotions, and we heard about their social struggles and sense of disconnection from others.

Relatively few of our participants actually used the word sadness to describe their experiences, despite the fact that we often used the word in our questions. They might talk about feeling empty, lonely, tired, guilty, scared, disappointed, inferior, messed-up, lost, agitated, or angry – but not necessarily sad. The lack of feelings of sadness sometimes made it difficult for them to understand what was wrong. 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 emotions appeared in many stories of depression that we heard, participants often talked more about their feelings of anger than feelings of 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' stories often focused on dissatisfactory social relations more than their inner feelings. They told us how their parents or siblings mistreated them when they were younger, or how they have been betrayed by trusted others, or how they felt harassed and discriminated against when they attended school. Even when their stories were not about betrayal or mistreatment, many participants often spoke of their depression in social terms of isolation or disconnection from others, rather than psychological feelings of sadness or hopelessness:





*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 often overlapped: sometimes their stories of inner emotions predominated, but it seemed just as often, the gist of their story was about social disconnection and alienation.

## Talk of Suicide

Although many of our participants did not speak explicitly about sadness, many had clearly experienced periods of great distress. Suicide was an element of the depression stories of half of our participants: thirty-five of our 72 participants described how they have experienced moments when they have thought about killing themselves or when they have actually tried to commit suicide. These participants considered a range of methods: for some, it was an overdose of their street or prescription drugs, like anti-depressants. 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,” where 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 the following:

*It's something that I wished for...for years, something that would just end it. Because I'm not going to kill myself, so why not come to the point where something else will kill me.*

This participant described his thinking during a time when he was very sick and feeling hopeless. His difficult story, punctuated by laughter, was similar to many of our participants:

*When I was feeling really, really sick, I sort of resigned that this could possibly be the end ... and that if I should go, I should go. It would be almost a blessing if I did because I wouldn't have to deal with this, with HIV, and being lonely and feeling like crap. I wouldn't have to pay rent [laughter]. I don't have to worry about socializing [laughter]. So in many ways, I looked at it as a sort of passive suicide.*

As discussed below, most participants who contemplated or attempted suicide did so before their HIV diagnosis, although several described how they became suicidal after learning of their HIV infection. After finding out that she had HIV, one woman jumped from a bridge, breaking her pelvis and several other bones. Another participant described how he reacted to his HIV diagnosis:

*In the beginning when I first found out I was HIV, I was in a stage of suicide, depression and suicide because I only had six months left to live. Well, the first thing I did was I bought a 60-ouncer of rye. If I'm going to die, I'm going to die partying.*



Others directly attributed their suicidal thoughts to their HIV medication. They stated that their thoughts were caused by particular medications, like Sustiva.

For a few, suicide represented a way to take care of their family:

*I said fuck it, I'll just make it easier on myself and everybody else, I'll try to put myself away.*

Others, however, talked about how their responsibilities to others, particularly their children, stopped them from acting on their suicidal impulses:

*I wanted to commit suicide. A lot of times I wanted to commit suicide. The only thing that keeps me going is my two daughters. If I didn't have no children, I would commit suicide.*

## Understanding Depression & Aboriginal Experience

Participants identified the ways that they believed their Aboriginal background played a role in shaping their experience of depression. Several noted that depression was a fairly common experience among Aboriginal people. In the words of one man, "I think Aboriginal people live with depression all their life. It's part of their mentality." Some attributed this to community issues, such as historical trauma and the legacy of residential schools. Participants often spoke of common Aboriginal experiences of poverty, lack of housing, unemployment or racism as underlying their own depression.

Most of our participants lived in urban settings at the time of their interviews, and several talked about how living on reserve was a problem for them. This seemed to be a particular concern for those who somehow felt different from others on the reserve, such as those who were questioning their sexual identity or who knew themselves to be gay, lesbian, bisexual, or transgendered. 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." However, moving away from their community to live in a city could also lead to depression:

*If you were brought up on a reserve for 20 - 25 years and you move to the city, naturally you're going to be depressed because it's going to be a whole new world for them, they are not used to this, they are not used to a lot of people, they're not used to wait[ing] for buses or the bull shit that happens in the city.*

For many, the inability to afford adequate housing in cities, or the lack of support and services made life difficult. Such concerns made the availability of culturally appropriate services all the more important.

**Racism:** A number of respondents described experiences of racism in their childhood that negatively influenced how they saw themselves. These experiences, they felt, led them to feel shame about their identity, and were a source of their 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 ways I was brought up, was how bad we were – how good-for-nothing we are.*



Another participant described his experience of racism in school in the following way:

*I was called a fucking wagon burner, a fucking Indian, growing up in an all white school. I was the only Native person in it.*

Several participants reported experiencing racism at home, particularly those raised in non-Aboriginal foster or adoptive homes. This was even sometimes true for individuals who were raised by Aboriginal family members. They 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 his home community because they were concerned about the level of drinking and violence there. When he wanted to visit his uncle 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." A few participants mentioned that their parents did not want to talk about their Aboriginal heritage and that discussion of Aboriginal culture was discouraged at home. One Métis participant noted,

*I saw some pictures of my grandmother. She had darker skin and she had a very Ojibwa look to her almost and we talked about it very briefly, but it was something that was not really talked about in the family at all. It was very suppressed.*

**Community and cultural disconnection:** Most of our participants spoke about how important their Aboriginal culture was to them, but many reported that they did not actually know much about their cultural background or traditions. Moreover, many of those who considered themselves somewhat knowledgeable about their community and culture had only recently started learning their traditions. Many of our participants described themselves as disconnected from their culture:

*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 happened for a variety of reasons. Many were not raised in Aboriginal communities or had little contact with other Aboriginal people. Significantly, almost one third of the sample (23 of 72 participants) were raised in foster care or in adoptive families, and of these, almost all were raised by non-Aboriginal families. Participants described being removed from their homes and placed in non-Aboriginal environments, and feeling disconnected from their culture, as a result. As one participant reported:

*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 the children from their parents, and putting them in foster homes and that, because of their alcohol abuse.*



These participants described feeling 'outside the circle' and 'never really belonging'. A number of participants who were raised by their biological families never actually lived on reserve or reported that their family moved off reserve when they were young.

Participants could become disconnected from their culture as they got older. Those who described themselves as gay or Two-Spirited often talked about the homophobia they experienced, and how it led them to feel alienated from their community. These participants typically moved to the city at an early age, and some described how they felt closer to non-Aboriginal gay people than to people who shared their cultural background.

*When I accepted my being gay and left home and became involved in the gay community. That was my family. That was the type of thing that I wish I had if I went to the reserve. It was the same type of openness, that "you're welcome here".*

Participants often spoke with considerable regret about not having learned their culture earlier, or having rejected it when they were younger. Because of the disconnection they felt from Aboriginal culture, many talked about needing to learn their traditions. One man reported:

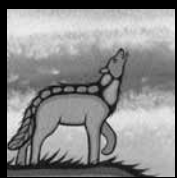
*I guess it was about 1990 when I first started learning about these things, this traditional stuff, like the sweat lodge, all these traditional ceremonies. I was once negative towards these, because I didn't understand them because I was, you know, brought up in a Christian home with a fundamentalist background. I was taught that these things were not good. But an Elder once told me, "you're an Aboriginal, you should be practicing these things and getting into your culture." So ever since then, I've been involved in culture, and my life has changed quite a bit.*

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 sought out Elders to teach them, and several described learning about their traditions after they entered drug and alcohol treatment or after they became involved in an Aboriginal AIDS service organization.

**Childhood abuse:** Abuse was a 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 – about 12% of our sample – 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. I never had the support as a child.*

One man believed that the sexual abuse he experienced during his pre-adolescent years was linked to his depression. In the following passage he describes how his abuse led him to feel depressed:

*Depression was like ... abandoned ... I felt abandoned. I felt worthless. I felt like I couldn't relate to other children, so I felt like I was outside. Outside of our community and outside of ... where other normal kids are.*

**Substance use:** Most of our participants reported experiences with excessive drug or alcohol use, either in the past or the present. These stories were entirely unsolicited – we did not ask questions about substance use unless participants raised the issue. Drinking and drug use were cited as main factors in the vast majority of participants' stories of depression.

Many participants reported growing up in homes where excessive alcohol use, and to a lesser extent drugs, was a fairly 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 a more tangible fear of violent or abusive behaviours that accompanied their parents' bouts of drinking. For example, one participant noted that:

*A lot of times, we were, 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.*

Participants also spoke about the role of substances in their lives in relation to their HIV. Almost always, a diagnosis of HIV would exacerbate substance use for a period of time and cause a re-lapse among participants who had been "clean" or "dry" for various lengths of time. For example, one woman reported that:

*In the year and half [after I found out I was HIV-positive] I did a lot of drugs, I did a lot of drinking. I thought it would kill the pain. Not that it did, it just caused more trouble.*

This was by far the most common experience, but it wasn't always the case. A few participants reported that they stopped drinking and using drugs after their diagnosis. One participant described his feelings after receiving his HIV diagnosis:

*It was the scariest, the most loneliest time of my life ... And I can remember leaving [the doctor's] office and standing at the [public transit] station, standing there. The hardest and scariest, loneliest time of my whole life was standing right there. All I remember is standing there arguing out loud should I live or should I die? Well for a while I stood there arguing out loud about the pros and cons of each. I decided I wanted to live. I never, even to this day, I haven't stuck a needle in my arm and I haven't had a drink since.*

The contrast between these two participants reminds us that there is no 'typical' experience of substance use in the context of HIV and depression.





Despite all of the problems it created, substance use had positive connotations as a kind of social lubricant for some participants. Participants 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.' Substance use can be seen by participants in a positive light, but there is a flip side. Substance use could be viewed as a problem when it got out of control or when it became the only means of dealing with strong emotions. 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.*

The role of substances in participants' lives was varied and complex. For many participants, alcohol and drugs served many purposes and was related in a variety of ways to depression. Participants 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 – in fact a few participants reported crashing so hard that they wound up in hospital-based treatment centres. For others, substances were used as a response to depression – to either mask emotions or help deal with them, and this was a largely conscious effort on the part of participants in this study.

## Understanding Depression & HIV

For participants in this study, the relationships between HIV and depression are diverse, complex and inter-connected. Some participants reported their first experiences of depression long before receiving an HIV diagnosis. A number of participants who reported prior experiences of depression noted that their depression contributed to engaging in behaviours that increased their risk of acquiring HIV. For example, one participant reported that repeated physical and sexual abuse in childhood led to depression, which led to frequent drug use combined with unprotected sex with multiple partners:

*I think what it is, is that I really didn't feel so good about myself and I just didn't care ... Because looking back, you say, ok, crystal meth and the raw sex and the HIV, it was like a slow kind of suicide for me. I just wanted to get it over with. This is one way of doing it ... and it's all because of depression.*

**Diagnosis & Depression:** Participants sometimes reported that living with HIV was just one of many issues that contributed to their on-going depression. Issues such as poverty, housing, addictions or other health challenges were paramount in the lives of some participants so that HIV was a lesser, although constant, contributor to their depression. Despite the variation in reported experiences, almost all participants in this study noted that HIV and depression "go hand-in-hand"; that "probably every single person that's diagnosed [with HIV] has fought with depression at one point or another".

Some reported that their first experience of depression coincided with testing positive for HIV or disclosing their HIV status to family or friends. These participants reported a direct and on-going link between their depression and living with HIV. Testing positive for HIV made their pre-existing depression worse and increased their struggle to bring it under control.



*I was diagnosed as suffering from depression...but since I've had this news [HIV diagnosis], it's been more...I don't know, hard to cope with. I'm feeling down in the dumps a lot. It seems to be more increased.*

With few exceptions, receiving a diagnosis of HIV was a challenging and life-altering moment, regardless of prior experiences of depression. Some recalled “shut[ting] down” and getting “tunnel vision” when they were given their test results. For some, “the whole world just stopped for a second” and others “just lost it... Yeah, I just flipped right out... totaled the whole waiting room.” For these participants, the depression that accompanied and followed diagnosis was driven in part by a belief that testing positive for HIV meant having “a death sentence hanging over my head”; “I thought, oh shit! I’m going to die in a couple of years!”

**Stigma & Depression:** For most participants, the initial depression associated with diagnosis was worsened by stigma and an accompanying fear of disclosure. Some participants were concerned about HIV-related stigma while others were anxious about being labeled a sex worker, an injection drug user or gay. This led participants to isolate themselves from friends and family and to try to deal alone with the diagnosis, the depression and its consequences.

*It's really hard because I want to tell people. But I'm just really afraid of how they're going to react or what they're going to say. And I've already lost a lot of people through my drug use. I'm just afraid of losing more people in my life.*

For many participants, the fear of being rejected by family and community was realized. While some had supportive family, friends and communities, more frequently, participants told stories of being cut-off from those they loved. Despair, depression and thoughts of suicide were common outcomes. One participant described how his family’s rejection had affected him:

*I told my family about [my HIV] and ever since I told them they haven't written or phoned me ... I just feel so rejected by my real family. And I don't like it. I sit at home sometimes and just cry. I miss them and everything but they don't write to me or anything.*

The fear of rejection was so strong that many participants reported rarely returning to their home communities. Participants spoke of disclosing to a sibling or siblings first, as a kind of dry run, to see how the rest of the family might take it. In some cases, participants were rejected by these siblings or discouraged from disclosing to other family members, such as parents or grandparents, and encouraged to stay away from the community.

Feeling shame at being diagnosed with HIV was frequently reported and some participants felt compelled to protect their families from community gossip and from “the burden of having a person in the family with AIDS.” In some cases, participants took it on themselves to break contact with family and community despite the family’s wishes to have them home.

**Relationships and Support:** While a number of participants in this study reported supportive long-term partnerships that were essential to managing both their HIV and their depression, the majority reported loneliness or lack of significant partnerships as a contributing factor to their depression. One participant rationalized why not having a partner is probably a good idea, despite the loneliness:

*Lonely. Very lonely. When I found out I had HIV, I didn't have no sex, in like, 6 years. I chose not to have it. That's how I got into trouble in the first place so I decided, well, okay then, I won't have to worry about spreading it to anybody.*



The fear associated with disclosing their HIV status to potential partners was enough to dissuade some participants from seeking the partnerships they desired. For example, one participant noted that “I’d just rather break off with [women] than let them know I have HIV.” Other participants in this study stopped themselves from pursuing long-term relationships, believing that they were “damaged goods,” “a walking disease,” or “not worthy of a relationship.” However, this is not to say that participants with long-term partners, or open to establishing a relationship, were necessarily insulated from depression. For these participants, depression in the context of a relationship was largely associated with premature end-of-life issues. In the words of one participant, “the relationship is not a problem; it’s the fact that I ain’t going to be there after. That’s the depression part for me”.

**Daily Life with HIV:** Many participants had developed unobtrusive strategies for managing their HIV and getting on with their lives as if they did not have it. However, physical or medical reminders of their HIV, such as taking medications, doctor appointments or regular blood testing were frequently accompanied by periods of depression. Several participants associated their depression with physical limitations that they felt were HIV-related. A number of participants could no longer do the work that they loved and had not been able to find a suitable replacement. They felt they were now deprived of satisfaction they had once derived from their work. Other changes in physical or medical condition, such as increases in viral load or decreases in CD4 counts, the appearance of HIV-related symptoms, or side-effects of HIV medications often caused great anxiety. Side-effects that were obvious to others were reported as particularly troublesome.

*I have this bad body image of myself. I won't even wear shorts because my legs are so skinny. I stopped doing that two years ago ... I think a lot of depression starts when your body changes.*

Most participants who were using substances at the time of their interview reported that they used drugs and alcohol to mask the physical and emotional pain associated with HIV. The excessive use of alcohol or drugs negatively affected most participants’ willingness and ability to care for their HIV. Participants reported that they were likely to miss doctor appointments or doses of their HIV medications when they were drinking or using drugs. They were less likely to eat nutritious meals, to exercise, or attend to daily hygiene. This explained in part, why participants who were active users at the time of the interview felt that dealing with their addictions was their number one health concern, followed by HIV, somewhere down the list.

**Changing Health Status:** For some participants, any change in health status, such as a common cold or an unexplained pain was imagined to be an indication of an escalation of HIV and therefore contributed to depression. Related to this, was the distress caused by a lack of information about their prognosis. A number of participants reported not knowing what to expect as their illness progressed. Participants reported, “you get a cold, a virus of any kind, a flu or pneumonia, you’re screwed ... [Not] knowing what disease you’re going to get next, or virus ... It’s stressful for me.”

While the majority of participants reported that depression became easier to live with over time, a few participants reported that living with HIV became harder. For some, the emotional strain of living day-in and day-out with HIV was “getting to us. We [used to] look for a cure, [but] I don’t think about it anymore. It’s just a matter of living with it ourselves”. For others, the knowledge that their illness was likely to progress over time contributed to their depression. For still others, increased depression was associated with the unrelenting routine of managing HIV with medication. After living more than a decade with HIV, one participant reported being so tired of the routine that he took a medically unsupported drug holiday.





*I went on the [drug] holiday, just because I needed a break and I just wanted to feel normal again. I wanted to be able to sleep in, I wanted to be able to eat when I wanted to eat and eat the things I wanted to eat when I wanted to eat them, and I guess I was kind of hoping that some of the facial changes might reverse themselves if I just took a little break or something like that.*

Unfortunately, the drug holiday had the opposite of the desired effect: as his viral load increased, so did his anxiety and depression.

Underlying each of the contributing factors to depression listed above seemed to be an end-of-life anxiety. Participants in this study knew many other Aboriginal and non-Aboriginal people living with HIV/AIDS, many of whom had died. Hearing of yet another passing from HIV/AIDS was a commonly reported reason for depression.

*Another thing I don't like is when people die on me. I'm serious. This friend of mine here, he came over to my house one day, and the next day, he's dead! I mean, for heaven's sakes! Creator, what's going on here? And I start getting really mad at God? "Why are you doing this? Why are you allowing this, all these good people," you know? And it's so sad.*

## Multiple Causes for Depression

Participants in this study rarely reported one cause to their depression. Rather, they generally spoke of multiple causes and a compounding effect that made already challenging lives even more of a struggle.

*When I'm in a state of depression it's not over just one thing, it's over everything. Everything that's possibly wrong with the world.*

In addition, some participants had multiple health issues that contributed to their depression. In fact, for some participants HIV was a secondary concern, particularly if they had few, if any, HIV-related symptoms. When asked what health issue they were most concerned with, several participants spoke of the need to deal with their Hepatitis C infection, other mental health issues, such as obsessive-compulsive disorder, or their addiction to drugs or alcohol, before dealing with their HIV. One man talked about how HIV is not the most pressing health issue in his life right now:

*I don't really think about the HIV too much. I'm more concerned with the drug use, which I guess is related to HIV, because that's how I got HIV right? But, it doesn't bother me right now, the HIV, but that doesn't mean that I'm happy with it, you know, the way things are right now. Because, basically my HIV status right now is kind of stable, but I worry about other things like my Hep C, and you know, the drug issues, like I'm not happy to be a drug addict, but it's not easy to walk away from, right? My HIV is stable right now, so, it's not something I'm thinking about.*

This participant explained how the health issues he confronted were interconnected.

*They are connected, the HIV and the whole health, but yeah ... if I didn't have Hep C, or if I didn't have HIV, I wouldn't be a dope fiend. I wouldn't be [living in this neighbourhood], but*



*they're all connected together. And I know a lot of the reason that why I'm sleeping at home all the time it's because of these things... And not necessarily... maybe I'm not thinking about them but they are affecting me in the back of my mind.*

A diminished quality of life for APHAs resulting from poverty or unstable housing was frequently cited as a cause for depression. The vast majority of APHAs in this study reported social assistance or provincial disability as their primary source of income and thus money was often in short supply. This "ordinary, everyday stress" made it difficult for some participants to fulfill their roles as caretakers of other family members and compounded the depression participants already live with.

*I can't do nothing for my kids because I don't have any money. That's another thing. I don't have any money to do things for family. Makes me feel less as a mother. You know, kids need stuff and my girls are having a hard time [...] and I just feel really bad. I can't do nothing.*

In addition, many participants described inappropriate housing conditions that contributed to their depression and interfered with their ability to manage their HIV.

*And not eating right, not getting the proper exercise, not having the right food because you buy food and people break in and they steal it ... I need food to take certain medications and I can't because I don't have the food. And then trying to take it on an empty stomach, I end up hacking it, it's like cayenne coming out of your nose and it burns, your throat burns and it hurts so you can't take your meds. It's really frustrating sometimes. You can't take your pills, that's the other part of it. So now I'm trying to find a place, another place, to get out of this place that I'm at.*



# Responding to Depression

In an effort to manage HIV and depression, participants reported drawing on a range of overlapping strategies. Many described using community services, such as peer support groups or volunteering at their local agency, while others sought professional counseling and used medications to deal with their depression. Although these approaches were generally viewed as helpful, participants also reported that formal services favoured “Western” approaches to care. Some reported stigma, racism, uncaring staff or services that were neglectful of Aboriginal identity. Possibly to counter this or simply to strengthen already effective formal responses, participants reported blending approaches with more informal strategies that included relying on family and friends, participation in traditional ceremonies or sharing experiences with other Aboriginal people living with HIV. The use of humour was viewed as a uniquely Aboriginal approach to take the edge off depressing circumstances.

## Formal Responses

**Community Services:** For many participants, involvement or use of community services, such as peer support or volunteer work, became one of several combined approaches to reduce loneliness, to connect with others, or to obtain HIV specific information. For some APHAs it was often enough to know a community service existed in case it was needed. For others, the safety of community supports served to strengthen connection to peers living with HIV, and for many, served to increase self-esteem and a sense of personal accomplishment and lessened experiences of depression.

*Just knowing that I have resources, knowing that there's medication to prolong my life and everything and that, you know? ... [When I was] first diagnosed, I thought I was the only one, the only woman in the world type-of-thing, or the only woman in the city ... I'd say it changed, it's not like ... I don't feel as lonely, as alone or empty anymore. I know that when that depressed feeling comes on, I know that I can go somewhere ... I can do something about it to make myself feel happier.*

For some participants, involvement in community services was based on cultural values and perspectives. With knowledge of culture and with personal experience of HIV and depression came a sense of social responsibility. One participant expressed his view of this responsibility, including sharing and supporting others who may also be struggling:

*That's a part of it because I know my background. I know some of my culture. I feel more comfortable and I also see the need. Like [another member] for instance, he just found out he was HIV and I think the Aboriginal community needs everybody to stand up and think of each other.*

For many, community services are also used as a way to be active and keep minds focused on something other than HIV or depression. For some, volunteering was viewed as an opportunity to deal with one's own problems and gaining a new perspective by focusing on others. As one participant described:

*I do speaking; I do professional speaking about HIV. [We] drive all over the place. I've worked the food bank, I've worked the drop-in centre, I'm the vice-president of [an ASO,] and I just keep really busy, to keep my mind off things. Whenever I find myself sitting at home, or being*



*alone which is pretty common with me, I start falling into the really extremely depressed state, and then I have to get busy and that's about the only [way] I deal with it right now.*

*Coming back to [name of agency] and connecting with the people, and the other clients and stuff here helped a lot, too. It really did. Made a big difference, because sometimes you feel so focused on your own self that you forget there's other people around you that have problems too?*

Several participants recognized the value of positive role modeling. Some participants thought that peers were in the better position to be helpful because they were able to share their own first-hand experience managing depression. Several participants believed that peer groups provided the opportunity for APHAs to offer something of value, while simultaneously receiving benefits for themselves. This strategy, as described by the two participants below, served to reduce feelings of aloneness, connected them with others, and reminded them that they were not alone - others shared their difficulties and had strategies to deal with them:

*Well, what I'd like to see is ... a group of people, peer support that have lived it, who are living it and [...] have improved in their life, you know, and have shown that there is life after HIV.*

*One-on-one with [...] an APHA worker [..who is] open about their disability, and being able to go there and talk with them – I think that's what helps a lot - [... talking] to somebody who knows what's going on. That's what I would love to see is more APHA counselor's.*

Despite the buffering effect of these new social roles, participants acknowledged they do not become immune to depression. Several participants shared stories of continuing loss, including death of family members, their own failing health or managing difficulties associated when friends become ill. All of these situations potentially lead to periodic feelings of loneliness. As one individual shared:

*I've been here for a year now and picked myself up and it really helped me because it actually started to help me realize that even [though I lost] family [and] prior to that I lost a lot of friends [...] – I lived with that, I dealt with it, I learned from it. So there was a great big support at [name of agency] through that period. I'm not alone as much. [...] It helped me so much to detach off the grieving of my family and on to "you can live with this."*

Accessing community services can be difficult for some participants. They reported concerns related to confidentiality, language, and availability of services. Some of the obstacles to involvement in or use of community services are highlighted in the following quotes:

*They say there's supposed to be confidentiality, right? Well, when you know everybody and you know everybody likes to talk a little bit – that is going [to breach] confidentiality, right?*

*Me, I like to talk to someone when I can, who understands my language and culture but there doesn't seem to be someone that I'm comfortable with.*

**Western Services(counseling):** In addition to using community services, many participants also reported the use of western psychotherapeutic services. For these participants, the value of using a psychiatrist, psychologist or counselor was clear. Many acknowledged that counseling may have saved them or pushed them in a direction that was particularly useful in dealing with the roots of their depression.



*So yeah, I was seeing [a psychiatrist ...] and she's the one who told me or helped me realize that I needed to identify myself with other Indian people [and] learn to become more Traditional.*

For several participants, it did not matter whether or not counselors were Aboriginal. For them, the most relevant aspect of counseling services was access and knowing that services existed in the event they were needed. It was also equally important to participants that these services were delivered in a non-judgmental fashion. As one participant described:

*To me it doesn't matter [if they are Aboriginal or not]. Yeah, it really doesn't matter as long as they're able to be open and understanding enough and not judgmental about who you are or whatever ... Yeah, to me it isn't like it wouldn't matter, but you know, a lot of other people might.*

The value placed by participants on the need for non-judgmental approaches suggests that the use of Western approaches is not without difficulty. Some participants reported not feeling understood by Western counselors, and several noted that their counselors offered an account of HIV and depression that was at odds with Aboriginal experience. One participant expressed his discomfort with this differing world view:

*I haven't met one [non-Aboriginal counselor] that I feel comfortable enough to speak with. [They would have] to be on the same kind of level as I am, not as I am but that person has to at least be able to see beyond their world and into my world and every professional counselor that I've been to tries to make me see things through their eyes. I found that Aboriginal counselors are the best counselors ... because we're able to look through the same eyes.*

Another participant described the strategy he used to reduce the sense of discomfort he experienced when using Western approaches. For him, the experience of HIV and depression were divided from his view of Aboriginal spirituality, each requiring their own specialized practitioner and approach to healing.

*[...] AIDS service organizations deal with APHAs all the time and they need to figure out a way, or find the best way to have ... not an Elder, an Elder can't do the work. I'm sorry. An Elder is for spiritual. We need to have someone who is [also a] professional who can bring that professional information to the table and work with the clients directly. Because that's all we're asking for.*

Several participants mentioned that it would be helpful if counselors were also living with HIV. Despite recognition of continuing concerns related to confidentiality, counselors who also lived with HIV potentially offered a safe place based on shared experience. As one individual revealed:

*It would be nice if [...] it's somebody that, yeah, that is already kind of [known] so that people are comfortable with opening up or talking about some certain things about it, you know? Like I know there's always going to have to be that confidentiality and stuff like that, but ... it's just a thing I mentioned (... chuckle), somebody that seems genuinely focused on another person's feelings and what they're going through [...] being positive. Yeah, some people think they know but ... or try to be; try to be helpful like that but they aren't or they can't be.*



**Western Approaches (medication):** There was a range of attitudes towards taking medication to treat both depression and HIV disease. For many participants, the use of anti-depressants was connected to improved mental health. One participant, while acknowledging how anti-depressants helped, also noted it took several attempts before finding the correct medication.

*I was scared of something but I didn't know what, and I still don't know what it was, but ... they just kept trying me on all these different anti-depressants until one of them worked.*

The need to take other medication in addition to their HIV medication could represent a significant barrier to some participants' willingness to begin antidepressants. Several respondents noted their preference for counselors or peers over the use of anti-depressants.

*I see a lot of people ... they're depressed and [...] they take other medications on top of their HIV meds. And you don't know whether or not they're coming or going and I don't want that. So I try to deal with it in a different way like, keep myself busy or be around other people.*

For others, depression was viewed as episodic, and did not require the ongoing use of anti-depressants. As one participant described:

*My doctor just says that I should get anti-depressants. I say no [chuckle]. I don't want that because to me it's like most of my depression I'd say [is] episodes [that] I deal with just by talking to someone. Yeah, I thought I don't want to be full of anti-depressants.*

HIV medication was seen by some as more beneficial than anti-depressants. As one participant shared:

*I thought I was going to die and [anti-depressants] just made me really sick. I don't like to rely on medication too much like for depression or losing weight. But I don't mind taking the HIV medication because it's helped me.*

For this individual, using HIV medication potentially offered a sense of continued health or hope that a longer life would follow. Despite this, many participants expressed their nervousness with the use of HIV medication. They shared their fears of side effects or of dying earlier despite HIV medication.

## Informal Responses

**Traditional Approaches:** Traditional healers are often held in high regard by Aboriginal people. To counter the less-than-optimal Western care approaches described above, many participants opted for approaches more consistent with their cultural belief system. While tension might have dominated encounters with the Western medical system, a sense of re-connection emerged when participants attempted to incorporate uniquely Aboriginal approaches. As one respondent shared:

*It was the Healing Circle where ... like going to an AA meeting, the format and the preamble and how it works, and all this stuff, was English. It's an English way of treatment. However, when I got to the lodge and I sat down and it was a Healing Circle and how they conducted them ... there was no write up, there's no big speech, there's no preamble, no "this is how it*





*works and this is what we do.” There was sit down and this are the medicines and we have sage and cedar and sweet grass and tobacco and this is what they mean and this is why we put them in the direction that they are and it was actually hands-on learning. I didn’t know it at the time but I felt more at ease, relaxed [...], it was focused more on the Aboriginal. Us!*

However, accessing Traditional support could be difficult. For some, the services were far away and participants lacked transportation. For others the lack of acceptance of HIV-positive individuals or gay/Two-Spirited people by Traditional healers was problematic:

*I think they just like call in somebody if you wanted to talk to an Elder or something. And they do have their sweats once in a while. Yeah, but like I said, it’s getting there for me that’s a problem.*

*[I said to the counselor at the organization,] “Do you think it would be alright if I came out and told everybody else that I was gay, HIV?” He said the [Elders] were not quite ready for that. So I couldn’t tell anybody. [...] So I know that there’s still that stigma when it comes to being gay, HIV, especially in the Aboriginal community.*

**Friends and Family:** Many participants reported the use of informal social support provided by friends, partners/lovers, and family. Some preferred informal social support to professional counseling services.

*I would talk to my family and my friends and be more open. I wouldn’t go to counselors or peer counselors. I just rely on my own wits and my family and my friends.*

Although many participants relied on family and friends for support, not every participant was equally convinced that family members understood the full meaning and impact of HIV. Although family and friends were important, some participants felt they were not able to provide the kind of social support that was needed. Some participants shared that they were not yet able to disclose their HIV status to family:

*When I tested positive, I told my family. I don’t think they really understood the impact of it. They just knew AIDS was really deadly, serious disease and people were dying on it and all this stuff. So I know they had that sort of slim education part on it but they had no idea what AIDS is, how do you get AIDS, how do you treat AIDS, how do you live with AIDS.*

*Well no, because my family doesn’t understand it as much as we do here, I just feel more comfortable here [at the ASO] because this is a place about HIV and AIDS and so on, so this is the place I would talk to about it.*

**Humour:** Participants described the use of humour to lighten particularly difficult situations or experiences. Some participants viewed the use of humour as a uniquely Aboriginal response to HIV and depression. To highlight the importance of humour to participants we provide a number of quotes from interviews:

*You know, you think that you’re depressed because you’re sick and you can’t move and you’re in a compromising position and then all of a sudden ... it’s just humour. I don’t know. I have a natural ability to make myself laugh at the worst times possible.*



*I like their humour and their wit, [shared laughter] and their kindness and their blessings. There are so many different nations in this office and we all get along. We all have our little talks on the side and you know, share messages. It's like one big happy family to me. I enjoy being here.*

**Substance Use and its treatment:** While participants employed a range of both formal and informal strategies to deal with their feelings of sadness and the emotional pain associated with depression. As noted in the previous section of this report, some used drugs or alcohol as a way of managing their depression. As one participant described:

*I was basically on my own and I felt that booze and drugs were working a lot better for my depression than some friggin' little pill that they give you at a hospital (laughs).*

Other participants reported use of 12-step programs, attending treatment centres or using harm reduction approaches by changing the types or frequency of substances used. Below, two participants comment on how participation in these types of treatment settings could alleviate depression and improve a sense of self-worth.

*[...] sometimes I go to a meeting, an AA meeting and it takes my mind off a lot of things too ... I'll go talk to a friend, if I feel depressed or something. I'll go talk to a friend and we'll go out and do something, right? And then, the next thing you know, all those hours are gone, right? That helps too.*

*Yeah but at least I'm not going to die as a frigging overdosed drug addict. At least I'll die [...] in recovery. And I think, to me, that's more, that's what more important to me. I think to my own self-being, I think that's more important to me ... I think I'll actually live better ... I know I feel better about who am I now, than I ever have in 20 years. In the last six months, I have totally changed who I am. I am really, really grown up.*

This report has thus far focused on the experiences of Aboriginal people living with HIV/AIDS. In the following section, we draw on interviews with service providers to gain an appreciation of how they understand depression among APHAs and their successes and challenges in providing service.





# Service Provider Perspectives on Depression Among Aboriginal People Living with HIV/AIDS

This component of the study explored how service providers viewed depression in APHAs. We asked service providers similar questions to those asked of APHAs. For example, we asked them about how they understood depression and its root causes among Aboriginal people, how they saw the relationship between HIV and depression, what services were available and useful for responding to depression, and how Western and Traditional approaches differed from one another.

## Understanding Depression

Virtually all of the service providers viewed depression as a very common experience in Aboriginal people living with HIV/AIDS. As one provider noted, “pretty much anybody who comes through our door with HIV has dealt with a depression issue”.

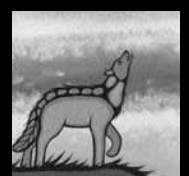
In general both Aboriginal and non-Aboriginal service providers viewed depression in a Western paradigm. It was seen as an emotional state with feelings of sadness, loneliness, hopelessness, often accompanied by physical signs of loss of appetite, sleep and energy. An Aboriginal HIV worker noted:

*Depression is, for me, it's kind of an ongoing experience where somebody feels down, doesn't have energy, may be having difficulty getting up, getting motivated, getting dressed or showered, sometimes expressing a desire to end their life ... Some people with depression, it's situational, there's a whole lot of stuff going on but anybody would be depressed by that - would feel down about that. And, some of it is probably chemical imbalance and that's when we need a doctor to help us lift that.*

Service providers observed that depression in most clients pre-dated the diagnosis of HIV, whereas in others, depression was seen as a consequence of an HIV diagnosis. Most saw depression as predating HIV, and that it was often was a contributing factor to infection. Some saw that a diagnosis of HIV helped improve people's depression through a new sense of perspective and resilience, whereas others saw the depression worsening after diagnosis.

*I think personally, what I have seen is that depression happens before, and that's why they become HIV infected. It's because the low self-esteem and that they're willing to put themselves out there, to be accepted, and that's how sometimes, they contract HIV. So the depression, for me, for the ones that I know, is happening before. It just intensifies after. Because there's the stigma and discrimination about HIV, it's overwhelming for them.*

Depression was seen as very complicated for APHAs, both in terms of causation and symptoms. Many service providers cited the role of drug and alcohol use as either contributing to depression or being used as a method of self-medicating the experience of depression. Additionally, the use of medications to treat Hepatitis C infection was cited as a contribution to depression, as were anti-retroviral side-effects, the experience of abuse, social determinants of health like poverty, residential schools and cultural dislocation and the experience of inter-generational trauma. In general, the experience of depression was seen as multi-faceted and complex.



*The whole addiction issue and the whole concurrent disorder...depression and addiction and which came first? Was the depression there and drugs are there and people are self medicating to try to deal with their depression or is the depression drug-induced by long term use? The problems of our clients is so multi-faceted and so complex, that you don't really know.*

For most service providers this complexity was seen most especially in the causation of depression. The multiple determinants of depression were seen as difficult to tease apart. An Aboriginal mental health worker noted:

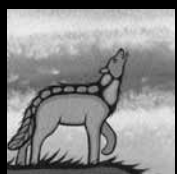
*Well, it could be the whole experience of our colonization that manifests itself differently for everyone right? So it could be that they've been in foster care. It could be that they've been abused whether emotionally, physically, sexually, you know mentally. It could be mental health. It could be that a couple family members that they have, a couple of relatives have committed suicide. It could be the poverty that they've experienced growing up or that they're living with... It's just all those things that can happen and have happened to aboriginal people that can make them go, "Oh man, life just sucks!"*

Despite tending to view depression in a Western context, many service providers talked about ways in which depression manifested itself differently in Aboriginal people. Some mentioned the role of storytelling and narratives in describing personal experiences, and also the importance of language especially among different Aboriginal groups.

*And I think sometimes that there are some similarities in terms of you know, hopelessness, and that kind of thing, but I think sometimes people will also speak in metaphor. And speak in stories. And again, unless you're tuned to that, sometimes that's not always well understood you know? Having said that... anybody could express their depression in a myriad of ways, but we have to be attuned to the fact that it might be described in a way that we don't typically hear, and so we have to be able to ask the person the meaning of that.*

In considering the different things that contributed to the experience of depression in APHAs, a dominant theme for the service providers was the experience of loss. Participants sometimes spoke of physical loss, such as the loss of energy or physical functioning. They also spoke of the psychological losses they experienced, such as the loss of self-esteem or coping skills. Many also spoke of social losses, such as the loss of social support from friends and family, and friends who die. Finally, participants often spoke of cultural losses, such as the loss of traditions or language. An example of psychological loss is given by this quote from an Elder and Traditional counselor:

*Well because we lose so much. There are so many deaths. I mean HIV is just the tip of the iceberg. ...we also have car accidents and alcohol and drug related deaths and murders, and you know suicides and just violence, constantly against our people that and people die when you have high blood pressure and diabetes and cancer and stuff that we've never had before. And people are just dying. And it's constant. The bigger family you have the more you're engaged with your extended family, the more grief you go through. And it's multigenerational. You know you barely get out of one grief mode, into another, into another, into another and you're still dealing with all the other stuff that happens. So it feels like we're constantly in a grieving mode.*



An Aboriginal mental health worker talked about social and cultural loss:

*It's about everything that should be important... or culturally, historically was important was taken away and told was wrong and negative, or bad. So I think that if you go to that level, I don't think everybody that I deal with realizes that, which is why I think it's important to educate around historical trauma. And then you'll also be talking multi-generational issues. People that were moved into residential schools didn't learn how to parent, they become parents, they're not very effective parents. So those kids grow up to be parents without the skills they need to be parents, and like things don't get any better... You don't really give back everything that was taken away or destroyed.*

## Responding to Depression

Whereas most service providers viewed depression using a Western paradigm, all were open to dealing with depression in their Aboriginal clients with a mix of Western and Traditional Aboriginal healing modalities. Mention was made of ceremonies, Traditional medicines, smudging, talking circles and sweat lodges as well as having people see Elders. One Elder described her approach:

*If they show an interest in it, then I will certainly do everything I can possibly can to make those kinds of services available to them. Either through the counseling I do with them or connecting with community members that can do that for them. If they want to do smudging as a way of grounding in there, before or after their sessions with me, they can do that. If they want to talk about different aspects of culture at anytime, I'm happy to discuss it with them, or answer questions about things like Birthing Ceremonies, and Naming Ceremonies, and Colours - and what those mean. How to approach an Elder appropriately, things like that - talk to them about Sweat Lodge teachings, Full Moon Ceremonies... So, I do a lot of translation, especially if they're interested in culture and tradition, of modern Western way of looking at mental health, substance use treatment, and outreach treatment counseling. I sort of translate it into how we view the world.*

Most tended to see Traditional healing methods as complementary to Western treatment for HIV and depression, as in this quote:

*I think knowing a Western approach and knowing an Aboriginal approach and different kinds of cultural teachings would be the best because we don't live outside of the western world. We live in it. And some people would only respond to it because they've been hurt by a lot of Aboriginal people along the way. So we need to know about both. Everything has to be hand and hand now, the way that we live now you know. If we're in an office and we're in the city, they're taking Western medicine, so yeah I think we would need to know about it.*

Some participants raised concerns about some aboriginal services and Elders: some services are abstinence-based, some can be homophobic, and some Elders encourage people to go off their HIV medications. One Aboriginal service provider described it this way:

*In my field you have to be very careful who you refer to. You can't refer to any old Elder because you don't know what they're going to do, right? I've seen some people get off all their medications, because this Elder told them to, and then something bad happens.*



In discussing how the services could be improved for APHAs, most recommendations related to connecting the isolated silos that exist in both service delivery and in the training of providers. People called for more links and partnerships between agencies in different sectors, and training in different approaches; more mental health training for those doing HIV work; more HIV/AIDS training for those doing mental health work; a better linking between hepatitis C, HIV/AIDS, and services for drug users; cultural sensitivity and better understanding of the Aboriginal experience for those working in non-Aboriginal agencies; and harm reduction, anti-homophobia and HIV/AIDS education for Elders and those using Traditional approaches to treatment. In the following passage, an Aboriginal service provider emphasized the importance of community partnerships:

*And that's where our partnerships with community agencies are so important because it's sometimes is a case of educating staff and that's what we are really trying to focus on, educating staff around harm reduction because a lot of people in the community feel that Traditional teachings and harm reduction are completely in opposition of one another. They don't even want look at that as an option. We have a number of Elders in the community that are working with us that in fact have really been able to sort of embrace harm reduction with traditional teachings and look at it from a whole different perspective.*

This education and training goes beyond formal health and social services, they have to address community concerns and link to community development. One service provider talked about the need to address the larger issues surrounding HIV and depression:

*Aboriginal people living with HIV and AIDS, and depression, and mental health - is such a huge topic area, and there's a lot of ways to address that. Research is one, but I think another is community development. So, probably developing resources and material for our communities to help them understand mental health, depression and HIV and AIDS go hand in hand, and how complex I said it was. And one of the things that we need to make them recognize is that in doing this work we need to look at the individual, the person living with HIV and AIDS. But also the family unit and the support that is required to provide that to that individual. The whole community needs to be supportive of the family, and then the individual and this needs to happen right across the country.*



# Discussion

Our study began in response to concerns raised by the APHA Caucus of the Canadian Aboriginal AIDS Network. Caucus members identified mental health issues as a growing concern, and asked that CAAN begin to address them. CAAN formed a research team that included academic and community partners to begin to explore mental health issues affecting Aboriginal people living with HIV/AIDS. We soon discovered that there was little or no published literature in the area, and our preliminary interviews suggested that depression was the predominant concern needing attention. As a result, we developed a community-based study that focused on how APHAs experienced depression, how they understood the links between their depression and their HIV infection, and how they tried to manage their depression.

Our study provided rich information about the various ways that depression is experienced, the many social and biographical factors that are seen by APHAs to contribute to its development, the complex relationship they see between depression and HIV and between depression and substance use, and the many ways that APHAs tried – with varying degrees of success – to manage their depression. To augment our findings, our study considered the views and experiences of service providers who offer a range of health, mental health, and HIV services to APHAs. Their views, which were largely consistent with what we heard in our APHA interviews, helped us identify strategies and challenges to the provision of services to Aboriginal people living with both HIV and depression.

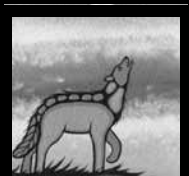
In this final section of the report, we provide some summary thoughts on our findings and some of their implications. We also offer a series of recommendations for service providers, policy makers, and APHAs.

## ***Depression among APHAs does not always look or feel like Western-defined depression***

Depression often presents in ways that many people would not normally expect. Rather than feelings of sadness or hopelessness, depression often appears more as anger, a dissatisfaction with others, or a disconnection with people, communities and culture. As a result, depression is often hard for APHAs to recognize and label as such, which makes it hard for them to respond appropriately to it. As well, it can be unnoticed by friends and family, and service providers.

## ***Depression among APHAs is often related to factors other than HIV***

People often assume that HIV leads to feelings of depression. While this is no doubt often true, HIV was only one of many factors influencing how participants understood their depression, and it may not be the primary factor in their minds. In the current study, HIV usually followed experiences of depression, not the other way around. Our participants most often understood their initial depression to be the result of an unstable or unhappy background, a history of foster or adoption as children, or their own or their family members' struggles with substance use.





## ***Community concerns are often seen as central to depression***

Our findings also suggest that service providers need to attend to a broad array of possible factors in understanding the roots to depression among APHAs. Many participants linked their depression to broader community issues, such as poverty, unstable housing, fostering/adoption, cultural disruption, and substance use. Service providers cannot simply focus on HIV when providing services to APHAs; they must also attend to broader community issues that affect individuals living with HIV and depression.

## ***Depression is related to substance use in complex ways***

Our findings demonstrate that depression can be linked in complex ways to substance use. A number of participants cited drinking and drug use of 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. Dealing with depression may help reduce the risk of substance use problems, and reduce the chance of other high risk behaviours for HIV.

## ***HIV can help people find ways of dealing with depression***

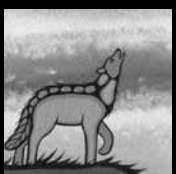
HIV sometimes helped provide a way for participants to get support in dealing with depression or substance use issues. Several noted that they first found help in addressing their depression in an AIDS service organization. The implication of our findings are that workers need to be aware of depression and the various ways that it can be manifest in practice, and HIV services need to be ready to provide support and referrals, when appropriate.

## ***Stories of depression are not neat-and-tidy***

In writing a report such as this, it is necessary to impose a certain order to the stories that we heard, and to filter some of the chaotic and disorganizing details of APHA stories of depression. The organized and sometimes linear presentation of the findings, and our efforts to filter out details means that the resulting presentation might suggest that our participants' experiences are tidy, contained, or somehow under control. While this may be the case for some, it seems that for most participants, the experiences of depression are not neat and tidy. Participants often spoke of their ongoing and long-term struggles. At times, depression faded into the background, only to re-emerge once again.

## ***Traditional approaches to healing were often helpful to APHAs***

Traditional approaches were helpful to many, but not all, participants. They did not provide a simple "fix" for the complex personal and social problems experienced by our participants, but traditional approaches often helped people find important social and cultural connections that they felt were lacking. APHAs and service providers often spoke of the need to blend Western and Traditional approaches to provide culturally appropriate and comprehensive support to APHAs.



### ***There is a need for expanded and coordinated services***

The participants in both the APHA and the service provider components of our study stress that there is a need for more services that deal with both HIV and mental health issues. There is also a need for better coordination and training between these services. Participants felt that there were often separate silos of care for HIV and mental health, both in the health care system and at the community level. There is also need for more traditional Aboriginal healing and for better integration of Traditional approaches into Western HIV and mental health care.



# Recommendations

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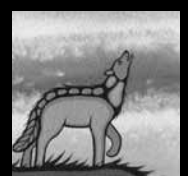
- We recommend that professional development opportunities be provided to HIV and substance use service providers so that they can better recognize depression among their clients.
- We recommend that an awareness campaign be launched, perhaps by an organization like CAAN, to help APHAs better recognize depression and understand where they might go for support and assistance. Our participants noted that APHAs often do not recognize their own depression, which can lead to delays in their seeking support and treatment.
- We recommend that Aboriginal communities continue to combat the ongoing stigma on and off reserves surrounding mental health issues, HIV infection, gay sexuality and substance use. Participants often linked their experiences with stigma and discrimination to their feelings of depression.
- We recommend that training be provided to service providers concerning HIV, mental health, substance use issues and Traditional approaches to care. A broader awareness of issues will help workers break down the silos of care that often exist between the different fields of service.
- We recommend that, to the extent possible, services should aim to provide complementary and integrated models of care, so that APHAs dealing with HIV, mental health concerns, and substance use issues, do not have to find and coordinate support from several different agencies.
- We recommend that HIV service providers be better trained to address the broader psychological, social and cultural issues that often surround HIV infection among APHAs.
- We recommend that HIV service providers be provided with training to better understand the many broad community issues related to Aboriginal people's vulnerability to HIV infection, substance use problems, and mental health concerns. Support services to APHAs need to attend to the many community issues identified in this report, such as inadequate housing, social isolation, stigma and discrimination, and the like.
- We recommend that Aboriginal specific AIDS service organizations and drug and alcohol treatment programs be expanded, as most of our participant found a level of comfort in these settings, even if they used services from other agencies.
- We recommend the continued support and expansion of Traditional cultural programs. These services were identified as essential to many of our participants in overcoming the challenges that they faced.





# References

- <sup>1</sup> Penzak, S. R., Y. S. Reddy, and S. R. Grimsley (2000). Depression in patients with HIV infection. *American Journal of Health System Pharmacology* 57: 376-86; Canadian Psychiatric Association (2003). *HIV and Psychiatry: A Training and Resource Manual*. Ottawa.
- <sup>2</sup> Elliott, A. J., J. Russo and P. Roy-Byrne (2002) The effect of changes in depression on health related quality of life (HRQoL) in HIV infection. *General Hospital Psychiatry* 24: 43-7.
- <sup>3</sup> Manson, S. M. (1994). Culture and depression: Discovering variations in the experience of illness. In W. J. Lonner & R. S. Malpass (Eds.), *Psychology and culture* (pp. 285-290). Needham, MA: Allyn and Bacon.
- <sup>4</sup> Brant C. (1990). Native ethics and rules of behaviour. *Canadian Journal of Psychiatry* 35: 534-9.
- <sup>5</sup> Health Canada (2002). *A report on mental illnesses in Canada*. Ottawa.
- <sup>6</sup> Health Canada (1994). *Suicide in Canada: update of the report of the task force on suicide in Canada*; Kirmayer, L. J. (1994). *Suicide among Canadian Aboriginal peoples*. *Transcultural Psychiatric Research Review* 31: 3-58; O'Neill, T. (1993). "Feeling Worthless: An ethnographic investigation of depression and problem drinking at the Flathead Reservation." *Culture, Medicine & Psychiatry*, 16: 447-69.
- <sup>7</sup> Corrado, R. & I. Cohen (2003) "Mental Health Profiles for a Sample of British Columbia's Aboriginal Survivors of the Canadian Residential School System." Ottawa: Aboriginal Healing Foundation.
- <sup>8</sup> Brave Heart Jordan, M. & L. DeBruyn (1999). "The American Indian Holocaust: Health Historical Unresolved Grief." *American Indian and Alaska Native Mental Health Research* 8, 2, 60-82.
- <sup>9</sup> Hirschfeld, M. D. Hasin, M. Keller, J. Endicott, & J. Wunder (1990). "Depression and Alcoholism: Co-morbidity in a longitudinal study. Pp. 293-303 in D. Maser & R. Cloninger (eds). *Co-morbidity of Mood and Anxiety Disorders*. Washington: American Psychiatric Association.
- <sup>10</sup> Gray, Norma & P. Nye (2001). "American Indian and Alaska Native Substance Abuse: Co-Morbidity and Cultural Issues. *American Indian and Alaska Native Mental Health Research* 10 (2), 67-84; Manson, S. M. (1994). *Culture and depression: Discovering variations in the experience of illness*. In W. J. Lonner & R. S. Malpass (Eds.), *Psychology and culture* (pp. 285-290). Needham, MA: Allyn and Bacon.
- <sup>11</sup> Penzak, S. R., Y. S. Reddy, and S. R. Grimsley (2000). Depression in patients with HIV infection. *American Journal of Health System Pharmacology* 57: 376-86.
- <sup>12</sup> Ciesla, J. A. and J. E. Roberts (2001). Meta-analysis of the relationship between HIV infection and risk for depressive disorders. *American Journal of Psychiatry* 158: 725-30.
- <sup>13</sup> Worthington, C. & H. Krentz (2004). "Employment status, level of income and quality of life in people living with HIV. Paper presented at the Canadian Association for HIV Research, Montreal.
- <sup>14</sup> Collins, E., C. Wagner & S. Walmsley (2000). "Psychosocial Impact of the Lipodystrophy Syndrome in HIV Infection." *AIDS Reader*, 10 (9), 546-50; Power, R. J. Tate. S. McGill & C. Taylor (2003). "A qualitative study of the psychosocial implications of lipodystrophy syndrome on HIV positive individuals. *Sexually Transmitted Infections* 79: 137-41.
- <sup>15</sup> Komiti, A., F. Judd, P. Grech, A. Mijch, J. Hoy, B. Williams, A. Street, and J. H. Lloyd (2003). Depression



in people living with HIV/AIDS attending primary care and outpatient clinics. *Australian and New Zealand Journal of Psychiatry* 37: 70-7.

- 16 DiMatteo, M. R., H. S. Lepper and T. W. Croghan (2000). Depression is a risk factor for noncompliance with medical treatment: meta-analysis of the effects of anxiety and depression on patient adherence. *Archives of Internal Medicine* 160: 2101-7.
- 17 Farmer, P. (1999). *Infections and Inequalities: The Modern Plagues*. Berkeley: University of California Press.
- 18 Bowie, R., M. Tobias & t. Williams (1996). "The private costs of HIV/AIDS." *New Zealand Medical Journal* 109, 51-54.
- 19 Herek, G.M., Capitano, J.P. & Widaman, K.F. (2002). HIV-Related stigma and knowledge in the United States: Prevalence and trends, 1991-1999. *American Journal of Public Health*, 92(3), 371-377; Mill, J.E. (2003). Shrouded in Secrecy: Breaking the News of HIV Infection to Ghanaian Women. *Journal of Transcultural Nursing*, 14(1), 6-16; Cain, R., Gillett, J. Guenter, D., Pawluch, D. & Travers, R. (2003). "Disclosing HIV to Others: Stigma and Everyday Interactional Work." Paper presented at the Canadian Association for HIV Research, Halifax.
- 20 Mill, J. et al. (2007). *Stigma Project: The Influence of stigma on access to health services by persons with HIV illness*. Ottawa: Canadian Aboriginal AIDS Network.
- 21 Dickey, W. C., M. A. Dew, J. T. Decker and L. Kingsley. (1999). Combined effects of HIV-infection status and psychosocial vulnerability on mental health in homosexual men. *Social Psychiatry* 34: 4-11.
- 22 In practice, this meant that at least one parent had to have been Aboriginal. Several participants of this study had learned of their Aboriginal heritage as adults. The vast majority of these had been adopted out or fostered into non-Aboriginal homes where their heritage was not spoken of openly.
- 23 In all cases, participants self-identified as HIV positive. We did not ask for a doctor's diagnosis or confirmation from a second party. However, in almost all cases, participants were recruited through Aboriginal/AIDS service organizations or other agencies where the participant was known to the staff of the organization. In the case of one participant, it became clear during the interview that the participant was not HIV positive; this interview was not transcribed and was not included in our database.
- 24 See, for example, the CAAN factsheet, "OCAP: Ownership, Control, Access & Possession," which can be found at [http://www.linkup-connexion.ca/catalog/prodImages/042805095650\\_314.pdf](http://www.linkup-connexion.ca/catalog/prodImages/042805095650_314.pdf)
- 25 A sample statement of research principles can be found at: [http://www.caan.ca/pdf/Principles\\_of\\_Research\\_Collaboration.doc](http://www.caan.ca/pdf/Principles_of_Research_Collaboration.doc)





