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

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ABSTRACT

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

INTRODUCTION

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

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BACKGROUND

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

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

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

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

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

DESIGN AND METHODS

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

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

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

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

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

FINDINGS

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

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

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

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

Personal Support

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Organizational Support

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Aboriginal spirituality and heritage

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

DISCUSSION

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

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

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

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

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

CONCLUSION

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

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