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HIV/AIDS Impact on Aboriginal Women's Lives: A Meta-Analysis Review

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ABSTRACT

Worldwide, the rate of women living with HIV/AIDS continues to be on the rise. While a burgeoning of research into the experience of these women has occurred in the last decade, a paucity of understanding exists on Aboriginal women living with HIV/AIDS. Meta-analysis findings from extant literature will be provided in this article. Overall, positive experiences and impacts for women living with HIV/AIDS include: (a) connection to spirituality, (b) increased positive relationships, and (c) self-change. Negative experiences and impacts involve: (a) stigma, (b) depression and suicide, and (c) affected identities of mothers. Studies focusing on Aboriginal women living with HIV/AIDS confirm these general experiences and highlight additional impacts. Positive aspects for Aboriginal women also include: (i) connection to spirituality and culture, (ii) increased identity as mother, and (iii) personal growth. Negative aspects include: (i) historical factors of colonization, (ii) addictions, and (iii) isolations and stigma. Recognition of these impacts of HIV/AIDS on Aboriginal women will help shape future HIV/AIDS interventions and prevention programs. Recommendations for future research and HIV/AIDS program development will be discussed.

Women are quickly becoming the leading group infected with HIV (UNAIDS, 2006). In Canada, HIV is infecting Aboriginal women at an alarming rate (Public Health Agency of Canada [PHAC], 2006). The Aboriginal population comprises only 3.8% of the total population of Canada as of the 2006 census (Statistics Canada, 2008). Yet, the number of Aboriginal people testing positive for HIV represents 22% of the total number of people testing positive (PHAC, 2006). This may not be a complete representation of the HIV statistics in the Aboriginal community because not all provinces collect information on race when testing HIV. Until 2005 only 29% of tests for HIV had information related to ethnicity (PHAC). Consequently, there remains a lack of clear statistics of Aboriginal women living with HIV. What is evident is that Aboriginal women comprise up to 47.3% of the Aboriginal HIV epidemic (PHAC). This mimics global populations of women from resource poor countries, such as Sub-Saharan Africa, Caribbean, and Ukraine. There is an apparent pattern of women who are socio-economically disadvantaged being infected with HIV at a higher percentage. A key difference in the rates of HIV for women in Sub-Saharan Africa and the rates of HIV in Aboriginal women is that the majority of women in Africa contract HIV through heterosexual intercourse (UNAIDS). Aboriginal women's risk category, on the other hand, is predominately IDU (Intravenous Drug Use) and heterosexual intercourse comes in as the second mode of HIV transmission (PHAC).

HIV is a virus that ultimately leads to AIDS, which is presently a terminal illness. Given the fatal nature of this disease, women invariably experience a cycle of grief and develop strategies for coping following a diagnosis. Prior to highly retroactive antiretroviral therapy (HAART), the research on HIV/AIDS was quite bleak, given short life expectancy. Since HAART, people living with HIV who have access to medications are living longer and productive lives. The impact of HIV has had many effects on the lives of women globally. In the last decade, there has been a burgeoning of HIV research focusing on women. While researchers have outlined some aspects of the trajectory in living with this illness for women in general, no synthesis of the research has been published. Likewise, the unique experience of living with HIV/AIDS as an Aboriginal woman has not been systematically detailed from existing research. It is imperative that health professionals, counsellors, public health educators, and policymakers understand the experience of women living with HIV/AIDS and the ways in which a diagnosis impacts women's lives.

The central purpose of this paper is to shed light on the experiences of Aboriginal women living with HIV/AIDS. Given the paucity of research on this population of Canadian women, we anchor the discussion more broadly in the experience for women in general and draw some references from research on women living with HIV/AIDS in resource poor countries. By reviewing, amalgamating, and summarizing the extant research we glean a meta-analysis understanding to further our own lives and work. Furthermore, we hope to contribute to shaping future interventions, prevention programming, and support services for these women.

METHODS

SEARCH STRATEGY

The strategy used for this meta-analysis review followed general steps put forth by Leedy and Ormrod (2005). First, a search of Academic Search Premier, PsycINFO, and Social Work Abstracts databases was conducted. Next, a search of the University of Calgary library catalogue followed by various search engines on the World Wide Web identified further relevant research. Several government and larger organizational websites were accessed. The key words used were HIV and women, HIV impact and women, HIV and Aboriginal women, HIV and coping, and HIV diagnosis. By using these terms an initial set of articles and research papers were identified. A further search was conducted using the ancestry approach. While searching for relevant Aboriginal research, an attempt was made to honor research conducted by Aboriginal people themselves; however, very limited studies of this nature have been published.

DEFINITIONS

For the purpose of this paper, 'Aboriginal' is defined as "indigenous peoples in Canada, including Inuit, Métis, and First Nations who are Status or Non-Status, On or Off- reserves" (Canadian Aboriginal AIDS Network [CAAN], 2003, p. iii). We respect and celebrate that each group of Aboriginal people is as diverse as the regions they come from and that within the communities, there is further uniqueness and diversity. Nevertheless, for the purpose of this article, we use the term Aboriginal more generally to facilitate our discussion.

BACKGROUND

WOMEN AND HIV GLOBALLY

Globally, women have been greatly affected by HIV/AIDS. Almost half of those living with HIV/AIDS are women: 17.3 million women ages 15 and over according to UNAIDS (2006). Sub-Saharan Africa suffers the greatest devastation of the HIV/AIDS epidemic. That is, of those infected with HIV in Sub-Saharan Africa, 59% are women; 51% of those infected with HIV in the Caribbean are women; 46% in the Ukraine. In Canada, the rates of HIV infection among women increased from 12% in 1988-1995 to 25.4% in 2005 (PHAC, 2006). Although Canada's rates for women are not as high as other countries, there is an obvious increase in HIV incidence. This increase echoes the need for more research and programming for women in Canada.

The gender inequalities of resource poor nations have made the fight against HIV/AIDS particularly challenging (UNAIDS, 2006). Not uncommonly, survival for women of these resource poor countries includes prostitution for food, stable living conditions, and other basic necessities. Women in these countries are often subjected to violence in intimate relationships and have little control of their partner's use of condoms or whether they have been monogamous. Furthermore, in relation to HIV/AIDS, there is often fear of violence in being labeled HIV positive. Stigma of this diagnosis precludes women from getting tested, accessing treatment, care, and necessary support. Although Aboriginal women live in a resource rich country, their situation is akin to women in resource poor countries (Aboriginal Nurses Association of Canada, 1996).

WOMEN LIVING WITH HIV/AIDS

POSITIVE COPING

Several researchers have focused on the positive ways of coping with the diagnosis of HIV for women in general (DeMarco, Miller, Patsdaughter, Chilsholm, & Grindel, 1998; Doyal & Anderson, 2005; Dunbar, Mueller, Medina, & Wolf, 1998; Goggin et al., 2001; Jenkins & Guarnaccia, 2003; Moneyham et al., 1998; Siegel & Schrimshaw, 2000; Siegel, Scrimshaw, & Pretter, 2005; Turner-Cobb et al., 2002; Updegraff, Taylor, Kemeny, Wyatt, 2002). Eight of these studies focused specifically on minority women or economically disadvantaged women or had participant samples that were 70% or greater that met those two criteria (see DeMarco et al.; Doyal & Anderson; Dunbar et al.; Goggin et al.; Moneyham et al.; Siegel & Schrimshaw; Siegel et al.; Updegraff et al.). All eight studies used structured or semi-structured interviews to gather information that was then coded for themes. The participation ranged from 34 women to 184 women interviewed. From these eight research studies, several themes emerged relative to the positive impact that HIV/AIDS had in women's lives. The following section explores the predominant themes: connection to spirituality, increased positive relationships, and self-change.

CONNECTION TO SPIRITUALITY

Dunbar and colleagues (1998) and Siegel and Schrimshaw (2000) found positive growth in spirituality after HIV diagnosis. Women were able to redefine their lives, deal with death, and create meaning for their lives. Similar results were obtained by Goggin and associates (2001) who revealed an enhanced closeness to God.

Researchers also found that spirituality was an effective coping strategy in distressful times (Doyal & Anderson, 2005; Goggin et al.; Moneyham et al., 1998; Siegel & Schrimshaw). Women turned towards spirituality when coping with emotional distress and physical illness and this was evident despite the extent of religiosity in the communities that women resided.

INCREASED POSITIVE RELATIONSHIPS

It was evident from the research that women experienced positive changes in their relationships. Women identified that living with HIV gave them the strength to improve their relationships with their children, family members, and friends (Dunbar et al., 1998; Goggin et al., 2001; Siegel & Schrimshaw, 2000; Updegraff et al., 2002). Wong-Wylie, Doherty-Poirier, and Kieren (1999) confirmed this experience for both men and women living with HIV/AIDS. Goggin et al. also reported that women became closer to their families and relied on them for support. Sixteen percent of the women they interviewed became closer to their family, regained custody of their children, and established new romantic relationships. They were also able to create new support networks. Although there were positive changes in relationships, researchers have suggested that program development should not discount that a large percentage of women identified no known family or friend support. Dunbar and associates also noted that an HIV diagnosis empowered women to end various relationships that were not meeting their needs.

SELF-CHANGE

One of the most noted positive changes for women living with HIV/AIDS was change in their selves. The voices of women from various studies revealed that despite the initial hopelessness upon diagnosis, HIV prompted them to make personal changes in their lives (DeMarco et al., 1998; Doyal & Anderson, 2005; Dunbar et al., 1998; Siegel & Schrimshaw, 2000; Updegraff et al., 2002). Many women developed a more positive sense of self and felt that the diagnosis made them stronger and more caring. Furthermore, Goggin and colleagues (2001) and DeMarco and colleagues found that women living with HIV/AIDS not only developed a positive sense of self but also felt empowered to advocate for themselves. They reported that many women found strength in the face of adversity to rise above the situation, improve their sense of self, and lobby for their needs.

Another notable change in self was dealing with drug addictions-- not necessarily abstaining from drugs completely, but reducing the amount of harm they did to themselves (Goggin et al., 2001; Siegel & Schrimshaw, 2000). Goggin and associates found that 25% of the women they interviewed entered recovery for substance abuse. These women specifically conveyed that the diagnosis of HIV forced them to reevaluate their lives and cease the drug abuse. Consistent with these reports, Siegel and Schrimshaw found that women who had substance abuse histories reported the most profound changes and growth. These results may be encouraging for the link with Aboriginal women who are becoming infected with HIV predominately by IDU. With increased research on the factors involved in these women's reduction or cessation of drug use there could be positive implications in working with Aboriginal women living with HIV and dealing with substance abuse.

NEGATIVE IMPACT

Just as there are positive impacts and ways women have coped with the diagnosis of HIV/AIDS, there are also negative aspects. This section focuses on the negative impacts women have experienced with their HIV diagnosis. More general research on minority and economically disadvantaged women are included given the similarities to Aboriginal women's oppressive circumstance. Three predominant negative themes gleaned across the research on negative impacts of HIV/AIDS on women's lives included: stigma, depression and suicide, and the identity of motherhood.

STIGMA

Along with the epidemic of HIV/AIDS comes the epidemic of stigma and discrimination. Since the first days of HIV, the general population has put the blame of the spread of HIV on those that are infected. First, it was a “gay disease”, then a “prostitute’s disease”, and a “druggies disease”. These are all marginalized people from society that often bear the burden of others’ discriminatory behaviours. The result of a fear or stigma is lack of disclosure among those who are infected. They then may live in isolation and limit efforts to seek out support.

Several studies reported on stigma as a source of negative impact for women (Abel, 2007; Doyal & Anderson, 2005; Goggin et al., 2001; Walker, 2002; Wilson, 2007). Walker investigated a small group of rural women with HIV. As mentioned, the fear of stigma left many of the women in isolation and kept them from accessing services. Smaller communities leave women with HIV exposed to rejection in many areas of life: dentist, restaurants, and schools. The fear of stigma can also create a barrier to treatment for women. Women are less likely to go for counselling or medical attention if they believe their HIV status will be discovered. In rural communities there is a perception of a lack of confidentiality; therefore, women living with HIV/AIDS are reluctant to seek services. Goggin and associates also discovered that stigma impacted these women’s ability to disclose their HIV status to their families. The link between rural women to Aboriginal women is important, especially for those Aboriginal women living in First Nation and Inuit communities that are small and often isolating. That is, information about rural women living with HIV informs researchers and program planners about obstacles many Aboriginal women living with HIV may encounter if living or returning to First Nations and Inuit communities, which are often similar to a rural setting.

DEPRESSION AND SUICIDE

An HIV/AIDS diagnosis is devastating to most people even to the point of wanting to end their lives (Cooperman & Simoni, 2005). There are obvious reasons why many may feel this way: along with the stigma, HIV is a virus that will ultimately lead to AIDS, which is fatal. Even in the era of HAART, many people still feel a sense of hopelessness and despair with their diagnosis (Wong-Wylie & Jevne, 1997). Depression in women who are diagnosed with HIV/AIDS is not uncommon. Catz and colleagues (2002) found that 56% of the women they interviewed reported significant depressive symptoms. Nevertheless, the women in this study were all economically disadvantaged. The question arises as to whether these women are depressed because of the HIV diagnosis or because of living in poverty. However, other studies corroborate the increased rate of depression and suicidal attempts. Stevens and Hildebrandt (2006) examined depression in women with HIV and found that 20% were suicidal in the first year of diagnosis. Furthermore, 33% of women were depressed even 10 years after initial diagnosis. Cooperman and Simoni (2005) further underscored the significance of depression and suicide in the lives of women living with HIV/AIDS. Their study involved 207 HIV positive women: 78% of women reported suicidal thoughts since their diagnosis.

AFFECTED IDENTITIES OF MOTHERS

Women may evolve through various roles and identities over the course of their lives: daughter, sister, friend, lover, worker, and mother. The research indicates that a diagnosis of HIV for women threatens their identities, particularly that of ‘mother’. In exchange, many women feel that they become a face of HIV/AIDS: promiscuous, vile, dirty, and shamed. These labels may be internalized and invariably affect women’s ability to cope with their diagnosis.

Women living with HIV/AIDS are “[s]ocially marginalized women in particular, [who] frequently report both the stress of motherhood but also its importance as a ‘normalising’ activity” (Doyal & Anderson, 2005, p. 1732). Although being a mother gave women something positive to focus on, not all mothers felt this way. Cooperman and Simoni (2005) found that women with children were more likely to have suicidal ideation and attempts. Mothers receiving an HIV diagnosis explicitly voiced their experiences of fear in having their children

discriminated against (Cooperman & Simoni; Doyal & Anderson; Wilson, 2007). In particular, Wilson revealed that mothers were very concerned about the stigma and discrimination their children would likely encounter due to their association with HIV. Mothers also experienced anxiety in being deemed a bad mother as a result of their HIV status. The illness threatens the motherhood identity at once in that they will either be judged as a bad mother for contracting the virus and/or they will get sick and someone else will assume the role of mother in their children's lives. Motherhood, although a reason for some women to strive to continue life normally, is a demanding role that can compound the stress of living with HIV/AIDS.

ABORIGINAL WOMEN AND HIV/AIDS

Turning to the research conducted specifically with Aboriginal women living with HIV/AIDS, our analysis revealed only seven articles related to the topic (see Aboriginal Nurses Association of Canada, 1996; CAAN, 2005; McKay-McNabb, 2006; Mill, 2000; Romanow, 2003; Ship & Norton, 2000, 2001). Of those seven, only four articles fit the parameters of this analysis. The three excluded were for the following reasons: Aboriginal Nurses Association of Canada did not research HIV positive women; Ship and Norton (2001) was not a research paper but a discussion of previous research; CAAN focused on recommendations for overcoming barriers in programming for Aboriginal women living with HIV/AIDS.

The four studies remaining that centered on the lived experiences of Aboriginal women with HIV/AIDS included: McKay-McNabb, 2006; Mill, 2000; Romanow, 2003; and Ship and Norton, 2000. Each of these studies involved a small group of women and one study also included women that were Hepatitis C positive only or co-infected with HIV and Hepatitis C. Participants were recruited utilizing a convenience sample from local health clinics or AIDS service organizations. These qualitative studies employed face to face interviews with Aboriginal women. Overall, these studies confirmed the aforementioned themes derived in the experience of women living with HIV/AIDS and highlight additional impacts. Without these four studies, the in-depth and unique experiences and challenges for Aboriginal women would be lost. Positive aspects and impacts for Aboriginal women with HIV included: connection to spirituality and culture, increased identity as mother, and personal growth. Negative aspects included: historical factors of colonization, addictions, and isolations and stigma. The following is a discussion of the themes that were consistent in the research.

POSITIVE IMPACT

CONNECTION TO SPIRITUALITY AND CULTURE

Mill (2000) revealed that many women found a cultural connection after HIV diagnosis. The diagnosis led them to want to connect with their traditions and traditional healing practices. Even when it came time for treatment, some women chose a combination of traditional healing ways and modern medicine. The reconnection to a higher power and traditional way of life was how Aboriginal women were trying to cope positively with their illness.

INCREASED IDENTITY AS MOTHER

Another positive impact that helped these women cope with their HIV illness and their addictions was their children. Although the burden of stigma and related discrimination hindered their own perceptions of themselves as mothers, these women took the love for their children as a way to turn their lives around (Mill, 2000; Ship & Norton, 2000). Mill highlighted that Aboriginal women felt motivated to regain custody of their children and to raise their children differently than they were raised.

PERSONAL GROWTH

Mill (2000) conveyed other positive consequences that HIV/AIDS had on Aboriginal women's lives. Most of

the women “experienced personal growth, felt more honest with themselves, developed greater self-respect, and viewed their lives from a more positive perspective” (p. 49). In turn, this prompted women to have better respect for others and to become more involved in their community. Despite experiencing past traumas and the initial crisis that the HIV diagnosis triggered, the majority of the women were able to forge ahead and cope positively and productively with HIV/AIDS in their lives. Likewise, McKay-McNabb (2006) underscored that “[s]ome of the Aboriginal women have embraced their new identities as Aboriginal women living with HIV/AIDS” (p. 13). These women found pride in who they are and how they overcame obstacles in their life. This newfound appreciation facilitated a holistic healing journey including mind, body, and spirit, which reflects the medicine wheel and the emphasis in the Aboriginal culture on illness as holistic.

NEGATIVE IMPACT

HISTORICAL FACTORS OF COLONIZATION

A central theme in three of the studies was the impact of colonization, residential schools, and the subsequent abuse Aboriginal women encountered. The women themselves reported that either they or their parents were in residential schools (Romanow, 2003; Ship & Norton, 2000). Furthermore, Ship and Norton found that eight out of the eleven women interviewed had been sexually abused as children. Romanow reported that 95% of the women interviewed experienced some form of abuse: physical, emotional, or sexual. Many linked their experiences with residential schools or non-Aboriginal foster homes. They also spoke of abuse in their homes from their own family members. As a result of this abuse, women often escaped to the streets and engaged in high risk behaviours that included prostitution, IDU, and often crime. For example, in Romanow’s study 73% of the women reported prostitution as their form of occupation. The past abuse these women experienced has been linked to the legacy of abuse from residential schools and cultural stressors on Aboriginal peoples’ lives.

In turn, this link to the past and factors of colonization has been shown to lead Aboriginal women to engage in high risk behaviours that ultimately exposed them to HIV. Many women commented on the need to heal from past abuse and that the inability to heal was thwarting their ability to cope with HIV. In order for them to become substance free or reduce their harm of certain substances, those wounds of the past needed healing. Aboriginal women in these studies voiced their need to find the strength to start on their healing journey.

ADDICTIONS

There were many similarities in the four studies in terms of alcohol and drug use by Aboriginal women living with HIV/AIDS. All the women in both Romanow (2003) and Ship and Norton’s (2000) research had used or were still using alcohol. Nine of the eleven women interviewed by Ship and Norton used injection drugs as did the majority of women in Romanow’s and McKay-McNabb’s (2006) studies. The overwhelming use of drugs for these women prior to knowing they were HIV infected led them to continue or increase their drug use to cope with their diagnosis. One woman’s response to drug use was as follows: “Usually when I get sick, I cope with it by doing heroin, morphine. It helps me cope with the pain” (McKay-McNabb, p. 12). Aboriginal women were identified in the research as using drugs to cope with the diagnosis, sickness, and pain of HIV.

ISOLATION AND STIGMA

Ship and Norton (2000) conveyed that many of the Aboriginal women living with HIV/AIDS believed that isolation thwarted their ability to heal from the past and from the impact of HIV. Women described the experience of isolation from a lack of community and family closeness. Further impeding their access to support, the isolation also impinged on effectively coping with HIV/AIDS (McKay-McNabb, 2006; Romanow, 2003; Ship & Norton). These women reported feeling isolated because the services they sought were not gender friendly or Aboriginal friendly. If the organization was culturally sensitive, Romanow found that many women still felt judged by the staff because they were deemed as bad mothers who used drugs and had HIV. Moreover, many

Aboriginal women were fearful of returning to their home communities because of the HIV stigma.

HIV brings stigma regardless of one's age, gender, sexual orientation, and cultural background. The fear of stigma-related discrimination can often paralyze people living with HIV/AIDS. One of the respondents in Ship and Norton's (2000) study explained the stigma-related impact of HIV/AIDS as follows:

It's the stigma that goes with it. It's not the death part. It's how you got it. You must be homosexual. You must have used IV drugs. You must have done something wrong. That's the fear for me, the rejection because of stigma. (p. 82)

The related stigma and secrecy of their infection is paramount to many women, especially Aboriginal women with children. Mothers also want to protect their children from being stigmatized. Once again because of the stigma related fear, women are less likely to seek support and services to help them cope more effectively with their illness and the related emotional issues, as well as coping with their lifestyles.

LIMITATIONS OF RESEARCH

The area of HIV/AIDS is a sensitive topic and many people, men and women, are (not surprisingly) not outspoken about their condition. The fear of stigma and discrimination highlighted throughout the research forces many people to live in shame and to be less forthcoming in participating in research. For this reason, the information gleaned from the research may not be representative of women living with HIV. That is, most of the samples of Aboriginal participants were recruited utilizing convenience sampling and often yielded a small number of participants. Those women too afraid to participate in research that highlights the experience of living with HIV/AIDS may have different experiences not captured by the research. Convenience sampling impedes accurate representation; nevertheless, the research captured the voices and lived experiences of those who participated, which is fundamental and lends invaluable insight.

Another limitation to the existing research is the methodology. All of the studies on Aboriginal women were qualitative in nature, which can be criticized for being too open to interpretation. For example, researchers focusing on positive coping asked questions about the positive ways that HIV impacted their lives. Likewise, researchers who looked predominately at distress asked questions that focused on negative impacts. The results could be criticized as being suggested by the questions asked. While we acknowledge this limitation of the research, it is important to note the advantages of qualitative studies in generating rich, in-depth, and thick descriptions of lived experiences. Given the focus of the research on the experience of living with HIV, qualitative research was a most fitting research paradigm (Leedy & Ormrod, 2005)

Additional limits to the research include an assumption and reliance on the participants to disclose all involvement in high risk behaviours or attempts of suicide and other topics. In fact, shame and/or social desirability may compel women with HIV/AIDS to not completely disclose. It is important to bear in mind that participants may not have been totally forthright with involvement in certain activities. Finally, the dearth of research on women, and in particular Aboriginal women living with HIV/AIDS, thwarts our ability to fully understand the multifarious experience. These initial studies can provide a glimpse of the broader picture for Aboriginal women.

CALL FOR FUTURE RESEARCH

There is an urgent need for research on the experiences of Aboriginal women living with HIV/AIDS, given the high rate of infection in this population. A wide-range of research foci is needed to inform appropriate HIV/AIDS Aboriginal intervention and prevention programs and service delivery. Specific research directions emerging from our review include recognition that women in different regions of the world have different access to support and treatment. In Canada, treaty First Nations and Inuit people have access to free medications. As

such, Aboriginal people that do not qualify for free medication may encounter more stressors in their lives. Not one research study addressed the subject of access to medication and its impact on Aboriginal women coping with HIV/AIDS. It is an important area of focus for future research. While not discounting the critical importance of HIV/AIDS research on Aboriginal women as a whole, it is important to note that Inuit, Métis, and First Nations women who are Status or Non-Status, and living on or off reserves have many varied experiences. Consistent with the perspective that group differences exist with Aboriginal people, it is imperative for future researchers to capture the nuances of these groups distinctly. Furthermore, giving voice to Métis women, for example, would be empowering and legitimizing; and facilitate specific areas needed for advocacy and potential enhanced HIV/AIDS program planning.

There are ethical considerations in researching this population of women, which is considered greater than minimal risk by the Tri-Council Policy Statement (TCPS) (Canadian Institutes of Health Research, 1998). The TCPS was developed by the Interagency Advisory Panel on Research Ethics in Canada for ethical conduct and contains Section 6 for research involving Aboriginal peoples and articulates good practices, ethical principles, standards, and procedures. For example, it is suggested that ethics review of research should be proportionate to the risks of potential harm. That is, if there is any potential for participants' identity to be revealed due to involvement in the research, the research protocol should not be approved by the ethics board and a representative from the Aboriginal community should be involved in the review.

Informed consent as well as the utmost protection of anonymity and confidentiality of women participating in research would need to be thoroughly considered prior to inviting participants to the study. Patterson, Jackson, and Edwards (2008) have noted that work with the Aboriginal communities and researchers need to engage in a "reflexive process of negotiation, and build community capacity for research" (p.49). Therefore active engagement with Inuit, First Nations, and Métis women living with HIV in the research process would be key; especially in developing research questions and cultural perspectives.

PROGRAM RECOMMENDATIONS

This meta-analysis review of the extant literature and research sheds light towards needed program development strategies that would benefit the lives of Aboriginal women. Based on the scant research available, it is evident that historical impacts of colonization and residential school need to be addressed when working with Aboriginal women diagnosed with HIV. Culturally responsive and holistically delivered programming within a non-judgmental environment is essential. Inclusive of this would be addressing addictions, especially providing this non-judgmental support at the onset of diagnosis so future women diagnosed with HIV receive support in a much more timely way.

Researchers have indicated the strength in the identity of motherhood for creating a positive outcome for Aboriginal women. As such, programs incorporating an emphasis on the resiliency and empowering nature of the motherhood identity may prove beneficial. Likewise, programming that is responsive to the cultural, traditional, and artistic healing of mind, body, and spirit provided in nurturing and supportive environment accessible to all women, regardless of drug use would be beneficial. Finally, it is of critical importance to have continued education, awareness, and advocacy about HIV/AIDS in efforts to remove the barrier of HIV stigma in our society. In turn, these efforts would enhance Aboriginal women's lives so that treatment, support, and care are accessed when living or returning to their HIV discrimination-free communities.

SUMMARY AND DISCUSSION

Many themes emerged from this meta-analysis review of women living with HIV/AIDS. Overall, researchers identified fear of stigma, depression and suicide, and isolation-- which were themes apparent in the studies. Similarly, there was convergence on the experience of positive coping such as turning to spirituality and culture and finding something positive that came out of the HIV diagnosis. These positive impacts and aspects are

necessary for front line healthcare professionals and mental health counsellors to be aware of as they may aid in providing hope to other women. Addressing the negative impacts is also crucial in facilitating women to live better with HIV/AIDS.

One of the major distinctions in the research between the more general population of women living with HIV and Aboriginal women was the emphasis on the past. In the Aboriginal-specific research, there was emphasis on how colonization, residential schooling, and past abuse have impacted their experience of living with HIV. Other studies on women and HIV/AIDS rarely acknowledged past issues as a contributing factor, or did so briefly in terms of impact of their current ability to cope. This is a key difference that also warrants attention for further research in the area.

Another difference between the two bodies of research was identity. Studies involving general groups of women living with HIV/AIDS predominantly focused on motherhood as exacerbating the inability to cope with the diagnosis. On the other hand, the limited research on Aboriginal women with HIV/AIDS underscored motherhood as a positive identity that motivated women to change their lives. More research is needed in the area to draw any further conclusions.

Finally, the major difference in the two bodies of research included in this analysis was in the area of addictions. The research revealed that drug abuse is a common method of coping for the participants who were Aboriginal women with HIV/AIDS. The same could not be reported from the research involving other groups of women. Drug abuse, as a way of contracting HIV and dealing with HIV, needs to be further explored in research involving Aboriginal women. A focus on addictions is also imperative in HIV intervention, prevention, and programming for Aboriginal women in light of this finding.

CONCLUSION

The rates of HIV in the Aboriginal community are increasing, especially for women. There is an urgent need for more programming and support for these women. Aboriginal women living with HIV/AIDS face many obstacles and require specialized programming to help them cope and live healthier with HIV/AIDS. The scant research on this topic points to other disparities such as culturally relevant programming with input from women who would be utilizing their services (CAAN, 2005). Through more financial support, research and theory-driven program development, and a relevant evaluation framework, programs can be made available that will address pertinent issues and foster healthier lives for the Canadian Aboriginal female population living with HIV/AIDS. It is hoped that reviews such as ours can be used by community-based organizations, AIDS service organizations, and Tribal Council health services to apply for community based research grants to help address these gaps in knowledge and programming.

REFERENCES

- Abel, E. (2007). Women with HIV and stigma [Electronic version]. *Family Community Health*, 30(1), s104-s114.
- Aboriginal Nurses Association of Canada. (1996, Revised March). *HIV/AIDS and its impact on Aboriginal Women in Canada*. Ottawa, Canada: Health Canada.
- Canadian Aboriginal AIDS Network. (2003). *Strengthening ties - Strengthening communities*. Retrieved September 27, 2007, from Canadian Aboriginal AIDS Network Web site: http://www.caan.ca/english/grfx/resources/publications/strengthening_ties.pdf
- Canadian Aboriginal AIDS Network. (2005). *Aboriginal Women living with HIV/AIDS: care, treatment and support issues*. Retrieved September 23, 2007, from Canadian Aboriginal AIDS Network Web site: http://www.caan.ca/pdf/Aboriginal_Women_Living_with_HIVAIDS_en.pdf
- Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada, *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. 1998 (with 2000, 2002 and 2005 amendments). Retrieved September 2, 2008 from Government of Canada website: <http://www.pre.ethics.gc.ca/english/policystatement/policystatement.cfm>
- Catz, S. L., Gore-Felton, C., & McClure, J. B. (2002). Psychological distress among minority and low-income women living with HIV [Electronic version]. *Behavioral Medicine*, 28, 53-60.
- Cooperman, N. A., & Simoni, J. M. (2005). Suicidal ideation and attempted suicide among women living with HIV/AIDS [Electronic version]. *Journal of Behavioral Medicine*, 28(2), 149-156.
- DeMarco, R. F., Miller, K. H., Patsdaughter, C. A., Chisholm, M., & Grindel, C. G. (1998). From silencing the self to action: experiences of women living with HIV/AIDS [Electronic version]. *Health Care for Women International*, 19, 539-552.
- Doyal, L., & Anderson, J. (2005). 'My fear is to fall in love again...' How HIV-positive African women survive in London [Electronic version]. *Social Science & Medicine*, 60, 1729-1738.
- Dunbar, H. T., Mueller, C. W., Medina, C., & Wolf, T. (1998). Psychological and spiritual growth in women living with HIV [Electronic version]. *Social Work*, 43(2), 144-154.
- Goggin, K., Catley, D., Brisco, S. T., Engelson, E. S., Rabkin, J. G., & Kotler, D. P. (2001). A female perspective on living with HIV disease [Electronic version]. *Health & Social Work*, 26(2), 80-89.
- Jenkins, S. R., & Guarnaccia, C. A. (2003). Concerns and coping with HIV: comparisons across groups [Electronic version]. *Aids Care*, 15(3), 409-421.
- Leedy, P. D., & Ormrod, J. E. (2005). *Practical research: Planning and design (8th ed.)*. New Jersey, United States: Pearson Merrill Prentice Hall. (Original work published 1989)
- McKay-McNabb, K. (2006). Life experiences of Aboriginal women living with HIV/AIDS. *Canadian Journal of Aboriginal Community-Based HIV/AIDS Research*, 1, (5-16). Retrieved March 20, 2008 from Canadian Aboriginal AIDS Network Web site: <http://www.caan.ca/pdf/CJACBR.pdf>

- Mill, J. E. (2000). Describing an explanatory model of HIV illness among Aboriginal women [Electronic version]. *Holistic Nursing Practice*, 15(1), 42-56.
- Moneyham, L., Hennessy, M., Sowell, R., Demi, A., Seals, B., & Mizuno, Y. (1998). The effectiveness of coping strategies used by HIV-seropositive women [Electronic version]. *Research in Nursing & Health*, 21, 351-362.
- Patterson, M., Jackson, R., & Edwards, N. (2006). Ethics in Aboriginal research: Comments on paradigms, processes and two worlds. *Canadian Journal of Aboriginal Community-Based HIV/AIDS Research*, 1, (47-62). Retrieved August 20, 2008 from Canadian Aboriginal AIDS Network Web site: <http://www.caan.ca/pdf/CJACBR.pdf>
- Public Health Agency of Canada. (2006). *HIV/AIDS Epi updates, August 2006*. Author. Retrieved September 25, 2007, from http://www.phac-aspc.gc.ca/publicat/epiu-aepi/epi-06/pdf/epi06_e.pdf
- Romanow, C. (2003). *HIV/AIDS and Aboriginal Women in Saskatchewan: Colonization, marginalization and recovery*. Unpublished master's thesis, University of Saskatchewan, Saskatoon.
- Ship, S. J., & Norton, L. (2000). "It's hard to be a woman!": First Nations women living with HIV/AIDS. *Native Social Work Journal*, 3(1), 73-89.
- Ship, S. J., & Norton, L. (2001). HIV/AIDS and Aboriginal women in Canada [Electronic version]. *Canadian Women Studies*, 21(2), 25-31.
- Siegel, K., & Schrimshaw, E. W. (2000). Perceiving benefits in adversity: stress-related growth in women living with HIV/AIDS [Electronic version]. *Social Science & Medicine*, 51, 1543-1554.
- Siegel, K., Schrimshaw, E. W., & Pretter, S. (2005). Stress-related growth among women living with HIV/AIDS: Examination of an exploratory model [Electronic version]. *Journal of Behavioral Medicine*, 28(5), 403-414.
- Statistics Canada. (2008). *Aboriginal Peoples in Canada in 2006: Inuit, Métis, and First Nations, 2006 census* (Catalogue no. 97-558-XIE). Ottawa, Canada: Author. Retrieved April 17, 2008, from <http://www12.statcan.ca/english/census06/analysis/aboriginal/pdf/97-558-XIE2006001.pdf>
- Stevens, P. E., & Hildebrandt, E. (2006). Life changing words: women's responses to being diagnosed with HIV infection [Electronic version]. *Advances in Nursing Science*, 29(3), 207-221.
- Turner-Cobb, J. M., Gore-Felton, C., Marouf, F., Koopman, C., Kim, P., Isrealiski, D., & Spiegel, D. (2002). Coping, social support, and attachment style as psychosocial correlates of adjustment in men and women with HIV/AIDS [Electronic version]. *Journal of Behavioral Medicine*, 25(4), 337-353.
- UNAIDS. (2006). *Overview of the global AIDS epidemic 2006*. Retrieved October 1, 2007, from http://www.unaids.org/en/HIV_data/2006GlobalReport/default.asp
- Updegraff, J. A., Taylor, S. E., Kemeny, M. E., & Wyatt, G. E. (2002). Positive and negative effects of HIV infection in women with low socioeconomic resources [Electronic version]. *Personality and Social Psychology Bulletin*, 28, 382-394.
- Walker, J. (2002). Rural women with HIV and AIDS: perceptions of service accessibility, psychosocial, and mental health counseling needs [Electronic version]. *Journal of Mental Health Counseling*, 24(4), 299-316.

- Wilson, S. (2007). 'When you have children, you're obliged to live': motherhood, chronic illness and biographical disruption [Electronic version]. *Sociology of Health and Illness*, 29(4), 610-626.
- Wong-Wylie, G., Doherty-Poirier, M., & Kieren, D. (1999). Family structure and functions identified by persons living with HIV/AIDS. *Canadian Journal of Home Economics*, 49, 91-96.
- Wong-Wylie, G., & Jevne, R. (1997). Exploring hope: Interactions between physicians and HIV seropositive individuals. *Qualitative Health Research*, 14, 31-49.