

Motherhood and HIV

Stigma, Disclosure and Educational Opportunities

This paper will argue that stigma directed toward HIV positive women and mothers is the main reason some women are reluctant to discuss prenatal HIV testing with health care providers and fear disclosure or discussion about their positive status. While taking antiretroviral therapies during pregnancy and childbirth can greatly reduce the risk of HIV vertical transmission from mother to child, some women remain reluctant to discuss testing due to the prevailing social stigma surrounding the topic. Open-ended questions were used to draw out personal experiences regarding stigma from HIV positive mothers who participated in focus groups. Drawing from feminist scholarship of maternal identities, along with theories of stigma management, we discuss several themes relevant to HIV positive mothers as they emerged from focus groups. This paper will discuss legal (mandatory disclosure laws) and medical (prenatal testing) issues related to HIV, along with the concept of the 'good mother', the complexities of stigma and HIV disclosure, and educational strategies to reduce HIV related stigma. In order to successfully reduce HIV related stigma, it is necessary to strongly promote the issues relevant to pregnant women and mothers in educational HIV/AIDS programs and services as well as in HIV/AIDS awareness campaigns produced in Canada. There is an urgent need for prevention responses to address the unique aspects of HIV for women and mothers in Canada.

It is estimated that 71,300 Canadians are currently living with HIV and an estimated 25 percent of these individuals are unaware of their infection. Among HIV positive adults in Canada, 23 percent are women, 75 percent of whom are in their childbearing years. The rates of HIV infection in Canadian women and mothers are continually rising, with a 12.6 percent increase in infection rates in women from 2008 to 2011 (Public Health Agency of Canada Summary,

2012). Without medical diagnosis, HIV positive women are not accessing counselling, treatment, support, and needed services to help manage illness, resulting in significant implications for the lives of these women and mothers. This paper will argue that stigma directed toward HIV positive women and mothers is the main reason why some women are reluctant to discuss prenatal HIV testing with health care providers and fear disclosure or discussion about their positive status. While taking antiretroviral therapies during pregnancy and childbirth can greatly reduce the risk of HIV vertical transmission from mother to child, some women remain reluctant to discuss testing due to the prevailing social stigma surrounding the topic. This paper will discuss legal (mandatory disclosure laws) and medical (prenatal testing) issues related to HIV, along with the concept of the 'good mother', the complexities of stigma and HIV disclosure, and educational strategies to reduce HIV related stigma. In order to successfully reduce HIV related stigma, it is necessary to strongly promote the issues relevant to pregnant women and mothers in educational HIV/AIDS programs and services as well as in HIV/AIDS awareness campaigns produced in Canada.

Theoretical Focus

Drawing from feminist scholarship of maternal identities, the concept of the 'good mother' and theories of stigma, we discuss several issues relevant to HIV positive mothers as they emerged from focus groups. This paper identifies and conceptualizes issues that are of concern to HIV positive mothers with regard to stigma and disclosure, presented from their point of view and stressing their own experiences. The intersection of gender, class, culture, ethnicity and power are considered, while focusing on some of the complex challenges facing HIV positive mothers with regard to prenatal testing, disclosure, and everyday care.

Feminist mothering theories stress that the empowerment of mothers is of primary importance (Green; O'Reilly 2007, 2004; Ruddick). In the words of Andrea O'Reilly, feminist mothering theory recognizes that a mother must "live her life and practice mothering from a position of agency, authority, authenticity and autonomy" (2007: 802). Mothers living with difficult and complex health, financial, and stressful family dynamics are limited in achieving agency, and have little of these necessary attributes.

HIV positive mothers, such as those in our study, are concerned about HIV testing and prenatal HIV testing due to stigma. Bruce Link and Jo Phelan (367) posit that stigma involves a process of labelling with a negative stereotype, with a distinction made between 'us' and 'them'. The stigmatizers, using their power to discriminate against those who are labelled, create a process that generates unequal and disadvantageous outcomes for the labelled. Stigma management

and issues of disclosure are central to the lives of HIV positive mothers. Disclosure decisions are based on their identity as mothers and their decisions around disclosure are made on behalf of themselves and their children.

Methodology and Focus Groups

HIV positive mothers were recruited from three different AIDS service organizations in three communities in South-Western Ontario for participation in two separate focus groups during the Fall of 2012. Participants were informed of this qualitative study through an information notice that was posted in the offices of these agencies. Six African Canadian, one Latin American, and three Caucasian mothers, between the ages of 21 and 50, participated in the focus groups. Participating women were fully informed about the design and intent of the research, were assured of their confidentiality as participants, and further assured that any care or services they received from the agencies would not be adversely affected by their decision of whether or not to participate. The discussions were audio recorded and transcribed.

The purpose of the focus groups was to gather information from mothers themselves about issues concerning stigma and disclosure and their perspectives on educational health promotional strategies. The thematic areas that will be explored in this paper are those that emerged during focus group discussions. Through open-ended probe questions participants shared their perspectives about the following: identity and perceptions of being an HIV positive mother; mother to child HIV transmission; prenatal testing; the effects of stigma and disclosure while seeking treatment; disclosure of HIV status to partners; children and health care providers; support services that would be helpful during pregnancy and after childbirth; and, their thoughts on educational health promotion strategies that could better inform HIV positive pregnant women and mothers. Before discussing the perspectives of the focus group participants, background information on mandatory disclosure laws and prenatal testing, which are relevant to women's experience of stigma and disclosure, will be addressed.

Background: Legal and Medical Issues

Mandatory Disclosure Laws

The stigma experienced by HIV positive mothers is heightened by the presence of mandatory disclosure laws. Knowingly exposing a sexual partner to HIV constitutes aggravated assault under the *Criminal Code of Canada*. Canadian courts have ruled that disclosure is mandatory in cases where a significant risk of infection, defined by either a moderate to high viral load *and/or* not using a condom, are present under the *Criminal Code of Canada*. This statute

also applies to HIV positive women who are exposing their infant(s) to risk through breast-feeding.

If a woman discloses an HIV positive status to a potential partner, the resulting stigma may negatively influence both her and the partner's decision to pursue a sexual relationship. In 2012, the law was clarified by the Supreme Court of Canada, which determined that only HIV infected individuals who were placing their partner at a realistic risk were liable for criminal prosecution. HIV positive people who use a condom *and* have a low or undetectable viral load are not legally bound to disclose their status. A law requiring an HIV positive individual placing a sexual partner at risk for transmission to disclose only if this possibility is significant, requires a certain threshold of risk. Alternatively, any risk of transmission, no matter how small, is still a real risk. As this ruling forces HIV positive individuals to disclose their status in cases where the risk of transmission is approaching zero, this ruling serves to merely influence societal standards of acceptable behaviour regarding disclosure, rather than serving as a mechanism of safety (O'Byrne). Although ignorance is not a defence for women who have placed themselves at risk for HIV it is a common misconception that those who do not know their status are not responsible for disclosure. This misconception may discourage women from prenatal HIV testing.

Prenatal Testing: Opt-in and Opt-out Screening Strategies

While the number of infants born to HIV positive mothers is rising, new medical treatment options have led to a decrease in the rates of mother to child transmission. Today, vertical transmission can be reduced to less than 1 percent through the use of non-invasive medical intervention, including antiretroviral therapy, and by formula feeding rather than breastfeeding (Women's College Research Institute). In the absence of any medical intervention, the risk of HIV transmission from an infected mother to a child during pregnancy is between 15-45 percent (WHO). Reducing barriers such as stigma, which can deter mothers from obtaining medical intervention, is key in reducing the overall rate of new HIV infections.

In Canada, prenatal testing falls under two models known as the opt-in and opt-out strategies. The model used is set by each provincial health ministry throughout the country. An opt-in HIV screening process involves a health-care provider specifically asking a pregnant woman whether she would like to be tested for HIV. In this model a woman must consent to receive the HIV testing (Canadian AIDS Society). This strategy also provides an opportunity for women to engage in pre and post-test counselling. The opt-in model can give the pregnant woman a sense of control about her decision of whether or not to take the test. However because of stigma, some women choose to not take the test as they are concerned they may be perceived as the stereotype of

those who are at risk, as HIV continues to be associated with sex workers and injection drug users. Additionally, some women do not choose to opt-in as they assume that their behaviour, or their partner's, has not placed them at risk for HIV infection. Further, some women do not take the test because they simply don't want to know if they are HIV positive. The potential consequences of a positive test are of great concern to many women. The fear of losing one's health, one's partner, one's children and possible employment are overwhelming. Moreover, the recent criminalization of HIV non-disclosure poses a barrier to testing as women who know their status may be at risk for criminal charges. Recent data reveals that only 50 percent of mothers choose to opt-in to this screening process (Public Health Agency of Canada, 2010). While Ontario currently uses the opt-in model of testing, in most provinces a pregnant woman receives prenatal testing through the opt-out model.

In provinces that utilize the opt-out model of prenatal screening, HIV testing is included as one of several routine prenatal tests. In the opt-out strategy a woman has the right to refuse the test, but she must specifically state that she does not want it (Canadian AIDS Society). Due to an often present power imbalance between a healthcare provider and patient, a woman may not always feel comfortable declining an HIV test, regardless of her right to do so. Additionally, women who are tested under the opt-out model do not always understand that they have the option to refuse the testing, and in some instances have been tested without knowing. In these cases, some women who did not voice concerns about testing have been shocked to learn the results of their positive HIV status and may be emotionally unprepared to deal with the consequences of such a result. In some cases, this can lead to increased depression and suicide in HIV positive women (Hammond et al. 15). For HIV positive mothers, being in control of one's life and achieving agency, "the ability to make choices and changes within one's life" (Middleton 74), is not easy. While the opt-out model is helpful in identifying a greater number of HIV infections, it does not provide a woman the same sense of agency and control over her diagnosis, when compared to the opt-in testing model. Despite the testing model used, a pregnant woman or mother who is HIV positive may have difficulty identifying as a 'good mother'.

HIV Status and the 'Good Mother'

Mothers who are HIV positive identify as mothers first and foremost yet their HIV positive status carries great weight in terms of their identity. In contemporary Canadian society motherhood is socially constructed to encompass assumptions about 'good' traits. The 'good mother' is associated with femininity, which is constructed as the pure and gentle biological nature of a woman

(Kramer; Martucci; O'Reilly 2007). Three skills are thought to embody the essence of mothering: protection, nurturance and training for social acceptability (Ruddick, 1989). This concept has been expanded by Stutterheim, who argues, “good mothers’ are those who are selfless, nurturing and feminine role models” (2011). Because HIV positivity is strongly associated with assumptions of promiscuity and injection drug use, any association with these actions can limit one’s ability to be seen as a positive, feminine, role model within society. Therefore, perception and related associations of HIV can hinder the ability of an HIV positive mother to be accepted as “good,” in a culture that dictates that stereotypes about HIV are not associated with the “good mother.” The women in this study spoke of the stigma associated with HIV and pregnancy, and feelings of being judged. As one mother comments:

Some people actually think it is irresponsible for me to have a baby when I am HIV positive. People say, “Why would she do that?” “Why would she want a baby?” “Why would she want another one?” “That is so selfish.” People are knocking me down and cutting me up because I was pregnant and HIV positive. They think I am putting death to a child. But that child is going to be healthy and he was born without HIV.

Selfless mothers can be defined as those who consistently put their children’s well-being ahead of their own by, for example, taking appropriate antiretroviral therapies and formula feeding their infant to reduce the risk of mother to child transmission as well as by being compliant with medical regimens while caring for children. Selfless mothers could also be seen as those who protect their children from disclosure of their family’s HIV status to the community and public institutions. Participants in the focus groups were concerned about the stigma that their child would endure if the school system were to learn of the mother’s status. Many women in this study chose not to disclose their status to their children and others to prevent their child from facing the effects of stigma, such as other parents not allowing their children to play together. In addition, some HIV positive mothers felt that disclosing their status to their child would create too much of an emotional burden. However, failing to disclose often means difficulty in accessing proper medical care, social services and support. A woman who chooses to keep her HIV status to herself may experience many emotional, financial and health concerns which prevent her from fully caring for her children or experiencing her own quality of life.

Further, a ‘good mother’ is one assumed to be nurturing. A mother who is reliant on medical treatment and unable to fully care for herself may not be seen as someone who is able to fully nurture a child. A major theme emerging from the focus group discussions was the continuous struggle the mothers

experienced in balancing their own health concerns with their family's needs. The mothers explained that they were often expected to be the primary caregiver, even if they were ill. As one participant lamented:

I'm a caregiver and even when I am sick I still take care of the others. I always am the last one to get my plate because I serve everyone else first. I put everybody in my family before myself.

In contemporary Canadian society, there is evidence that the concept of motherhood is no longer encompassed by a dichotomy of “good mother” and “bad mother.” A third category—the “good enough mother” has emerged. A “good enough mother” is defined as one who is able to fulfill her infants needs at birth, but gradually increases her detachment from her child as she starts to see herself as doing a poor job (Winnicott 33). The “good enough mother” can “provide the necessities in order for a child to have a sufficient ... but not thriving life” (Shira 67). This status is attributed to a mother who embodies the traits needed to be a “good mother” but has been enduring a form of trauma, such as HIV, that hinders her ability to fully give herself in support of her child's development. The concept of a ‘good enough mother’ provides a concrete barrier to achieving the master status of ‘good mother,’ increasing the difficulty for an HIV positive mother to obtain this status in the eyes of society. Even if an HIV positive mother is able to provide a nurturing environment, despite HIV infection, stigma may still lead to the title of “good enough mother” as being her master status.

The Effects of Stigma and Disclosure for Mothers Seeking HIV Treatment

Social stigma exists for mothers whose life experiences differ from those of the culturally accepted norms of motherhood. Although HIV testing rates among pregnant women have increased over time, some women are reluctant to undergo prenatal testing due to the stigma surrounding HIV. Further, the impact of HIV-related stigma has been shown to deter HIV positive women from obtaining full care for themselves. For example, individuals with high rates of concern about HIV stigma are 3.3 times more likely to be non-adherent to their medication regimen than those with low rates of concern, as compliance with HIV medical treatments may be considered acknowledgment of being HIV positive (Reece et al.). A lack of adherence to medical treatment can not only exacerbate the symptoms and ailments faced by a person infected with HIV, but a lack of early treatment can lead to more serious health concerns. Failure to seek early medical treatment results in a poorer prognosis for the individual

and inhibits her abilities to fully care for her children.

Moreover, the threat of social stigma often prevents people living with HIV from revealing their status to others. As one participant in the focus groups commented about disclosure:

People still think that you have committed a big sin to get HIV so it is not easy to disclose to people. Instead of getting help you become isolated. People are so full of fear and stigma that I don't feel comfortable telling people. Instead of disclosing, you prefer to keep quiet and be friendly.

Rates of stigma toward HIV positive individuals are increasing in contemporary Canadian society. In a 2011 Canadian study, 16 percent of survey respondents said that they “feel afraid” of people living with HIV/AIDS (Public Health 2011). This is up by three percent, when compared to 2006 data. Stigma is present both in places of employment, where 18 percent of individuals would be uncomfortable working in an office with someone who is HIV positive, and in close relationships where 54 percent of individuals would be uncomfortable if a close friend or family member were to date someone with HIV (Interagency Coalition). Further, 72 percent of Canadians believe that HIV positive individuals would be unwilling to disclose their status because of stigma (Ekos). The fear of many positive mothers, that their child will be stigmatized if they were to reveal their status, is well supported; 35 percent of respondents claimed that they would be uncomfortable if their child went to school with a child who was HIV positive (Interagency Coalition). This is especially true in some cultural and ethnic groups, where stigma toward HIV may be heightened. As one African Canadian mother voiced:

My child, in elementary school, knows she has to keep her HIV and my HIV a secret because another kid could tell their parent who will not want their child to play with my child. I have had that experience with my daughter being positive—another parent said—oh, that little girl is positive, don't play with her.

Another African Canadian mother shared, “I did not want to tell my children because I just wanted to protect them. In our community, when you have HIV, it is seen as forbidden.”

Aboriginal people and individuals from countries where HIV is endemic continue to be over-represented in Canada's HIV epidemic highlighting the need for specific measures to address the unique aspects of particular communities. Aboriginal people currently make up nine percent of all prevalent HIV infections, while constituting only four percent of the general population (Public Health

Agency of Canada, 2012). HIV is seen as a disease predominantly affecting cultures which are already marginalized within society, such as African-Canadian or Aboriginal ethnic groups. Individuals in these communities face dual stigma because of their minority status and their culture's perceived association with HIV. The highly stigmatized nature of HIV has serious implications for mothers belonging to these cultural groups. African-Canadian mothers in this study spoke of how they were reluctant to access healthcare services because they feared that any publicity around rates of infection in the Black community would generate racism and discrimination in housing and employment. Fear of stigmatization and concern for the well-being of the community as a whole, is often a personal reason why some women in the study avoided treatment in health care agencies.

Patterns surrounding the race and age of individuals who choose to opt-in to prenatal screening show that Aboriginal women aged 20-24 were the group least likely to opt-in and Aboriginal women have a higher than average risk of becoming infected with HIV (Public Health Agency of Canada 2010). The choice to forgo prenatal HIV screening is often based on the stigma attached to this virus in the Aboriginal community. Many Aboriginal women incorrectly believe that HIV is fatalistic, predetermined, and infects only individuals who "deserve it" as a payment for past mistakes (Gahagan and Ricci). The fear of being exiled from communities is higher on Aboriginal reserves (Gahagan and Ricci). This correlates with the rural location of almost all reserves, which poses an enhanced opportunity for stigma to be prevalent.

In rural areas, healthcare is often provided through the use of community midwives, who are also members of the community. In smaller communities, where healthcare professionals have direct relations with most other community members, mothers may fear accidental disclosure or differential treatment because of their HIV status. While there are strict privacy laws surrounding the sharing of a patient's medical information, mothers may view their HIV status, or the fact that they are getting tested, as conversation-worthy. This also applies to a woman's interaction with her pharmacist. Women in the study spoke of concerns about picking up their medication or prescribed infant formula because they may be identified as HIV positive. They worried that this information would be shared and spread within the community.

Even if a medical professional does not disclose the woman's HIV status to others, they may begin to behave differently around her. Whether perceived or real, this stigma can result in a lesser quality of future medical care or dissuade a mother from seeking prenatal HIV testing. One participant in the focus group noted that upon disclosure, her doctor would not treat her and the nurse that did care for her in the hospital *"looked like she was wearing a space suit."* Another woman in the focus group admitted *"I was afraid to tell the doctor I*

was HIV positive and get prenatal testing.” The stigma attributed to HIV positive women, can lead to increased risks of vertical transmission, as a mother who does not disclose her status will not receive appropriate medical treatment. Furthermore, with the pervasive nature of ‘breast is best’ campaigns, where breastfeeding is painted as the norm, some HIV positive mothers feel that they may be seen as a ‘bad mother’, or thought to be infected, when feeding their infant with formula. Educational strategies to reduce HIV-related stigma can make a great difference in societal perceptions about women and mothers with HIV and further can positively reflect the lived realities of women with HIV.

Opportunities for Change: Educational Strategies to Reduce HIV-Related Stigma

The obvious long-term effects of stigma clearly identify the need for policy changes in the strategies used to create HIV educational awareness campaigns. Overall, the most effective strategy to prevent mother to child HIV transmissions is a combination of individual educational initiatives and those provided by educational health campaigns.

Education: Individual Initiatives

Education from an individual includes the provision of HIV education in the public school system, and the promotion of discussions in family and community settings around the complex realities of living with HIV. Education provided by an individual on a localized level or interpersonal level can help to destigmatize HIV and AIDS within a community. Since schools are the only formal educational institution to have meaningful contact with nearly every young person they are in a unique position to provide youth with the knowledge and skills they need to both make and act upon decisions that promote sexual health throughout their lives, and an appropriate place to educate and raise awareness about the effects of stigma around HIV. Mothers in the focus groups stressed that the public school system was the ideal place for HIV education. One mother commented:

Education needs to start at the elementary level so younger kids can take that knowledge to their parents too and not wait until high school. Kids need to get knowledge from their schools. They need to learn from the teachers. At home sometimes when we start talking about something, they don't listen—they don't take it seriously. But at school they take it seriously.

Another participant commented on the positive experiences she has encountered while public speaking at schools:

I have done public speaking about living with HIV and I know the young women were really listening to me and I thought, “boy this is really having an impact.” All the public speaking that I have done about my life and HIV has helped me more than anything. When you share that with other people, you see in their eyes that it is having an effect. My whole life is out there and they know everything about me, but in doing that I’m helping others. We have to get the message out there and only we can do that because we are living it.

In addition to promoting clear information surrounding HIV, mothers in this study pointed out that individual initiatives can foster conversations about HIV in smaller group settings. Accurate information and perspectives around HIV that stem from an individual whom one knows and trusts may have a greater influence on the internalization and understanding of this information. Mother to child HIV transmission has rarely been a focus of HIV educational awareness campaigns and by promoting an ongoing conversation within personal or familial relationships, the misconceptions surrounding mother to child HIV transmissions can begin to be challenged, resulting in a breakdown of the associated stigma. Interpersonal communication can also assist in keeping a topic such as mother to child HIV transmission part of an ongoing conversation in families or communities once a media campaign begins to lose influence. The more an individual learns about the realities of HIV and AIDS, the more likely they are to be accepting and supportive of infected individuals. The interpersonal discussions surrounding this topic may be vital in comprehensively educating young women on HIV and motherhood. It has been shown that sustained promotion of information among individuals and groups requires an interpersonal communication component for behavioural change (Hanan). Women in this study expressed that discussing HIV in families would help to both reduce stigma and risk of HIV. As one participant commented:

People think of AIDS as a scary thing but the more they get educated the more they will understand. More dialogue would help reduce discrimination. Interpersonal discussions will help. I don’t like the way that AIDS is treated as the elephant in the room—people don’t talk about it.

The reduction of stigma that can result from discussion was confirmed by another participant:

I started to teach my kids about HIV so that they will know it is treatable and then when I am ready to tell them that I have HIV, they will see that you can live a long time with HIV and you can deal with the disease. I want

them to know more about HIV before they hear the news. I think if people got more education about HIV, then they would be more likely to disclose.

Education: Health Campaigns

While HIV educational awareness campaigns have historically been aimed at educating Canadians about strategies to reduce the risk of contracting HIV through safer sexual practices and safer drug use, there has been far less focus on vertical transmission from mother to child. The inclusion of mothers in governmental and non-governmental poster campaigns has been notably limited in all previous Canadian HIV/AIDS awareness campaigns (1986–2013). The few HIV/AIDS poster campaigns that have featured mothers depict these women as young, racialized and without the support of a spouse or family. Educational poster campaigns have failed to address issues surrounding vertical transmission, subsequently failing to reduce stigma or promote educational tools to assist mothers in learning about risk prevention and/or living with HIV. In addition to the focus on racialized individuals and men who have sex with men, previous HIV education and awareness campaigns have primarily utilized fear as a method of gaining attention (Hunter 2005, 2007). The notion that HIV is something to fear further marginalizes and stigmatizes HIV positive individuals.

The only Ontario Ministry of Health educational poster which focuses on mother to child transmission states “HIV is testing for you and your baby,” and asks “Have you been tested?” Prevention programs and services tend to be more concerned with women’s reproductive function and health than focusing on women’s sexuality and communication around safer sexuality. Although pregnant women may be represented in awareness posters due to concerns about infections to their babies, there is a lack of representation of services that would improve the health outcomes and overall physical and social support for mothers. Although the majority of women living with HIV are in their childbearing years, there is a dearth of HIV awareness posters which target mothers themselves. However, one poster produced jointly by Health Canada and the Canadian Public Health Association did address some concerns of mothers, “How Could Someone Like Me be HIV Positive?,” which depicts a quizzical young woman looking up toward the viewer. We are not aware from the image that the woman is an HIV positive mother, but the text states she “gets angry when she hears people say that HIV/AIDS isn’t a big deal anymore.” Although the poster makes clear that HIV affects women with children, there is no information presented that is relevant to the particular concerns of mothers; there is no information provided on testing, viral transmission, antiretroviral therapies, communication strategies with partners, children or families, and no information provided on support resources for mothers and their children.

Education about HIV plays a pivotal role in reducing stigma. The very limited campaigns addressing mother to child HIV transmission means that there is a wide opportunity to promote information aimed at educating and empowering women, rather than reinforcing stigma. Presenting new information and new advances surrounding mother to child transmission, framed in a positive light, can motivate individuals to become better informed around the many complex issues facing women and mothers.

The social construction, or framing, of an educational health campaign also requires accessibility to individuals of various cultures, education levels and value sets. Messages and information material should be developed in languages specific to the target community. Aboriginal Canadians, for example, currently hold one of the highest risks for mother to child HIV infections. Providing information in English to Aboriginal Canadians who predominately use a native language may impede their ability to fully comprehend or internalize the information provided. Additionally, the use of simple language without medical terminology would improve the likelihood of the proper message being effectively delivered. This can help to eliminate the alienation of the message to those who may be intimidated by, or not understand more complicated medical terminology, in addition to their cultural inclusivity (Hanan; Jones and Sargeant).

HIV continues to threaten young mothers of colour, particularly Black, Caribbean, and Aboriginal women, at astonishing rates. There is a need for greater healthcare services targeting women from diverse communities who face multiple forms of oppression and discrimination. It is crucial that responses to HIV and motherhood begin with an understanding of the unique social, cultural and economic issues facing women. The mothers in the study agreed that tailoring programs to meet the needs of ethnic populations can increase the numbers of those accessing treatment and care services and help to enable women to make empowered choices and decisions about their health.

Health promotional campaigns can play an effective role in reinforcing interpersonal communication on the topic of mother to child HIV transmission through the use of positive emotional appeals. As opposed to fear campaigns which have been used extensively in previous HIV educational material, campaigns which use “an attractive spokesperson, visual images, beautiful art, popular songs, memorable words and slogans” may better engage the target audience (Hanan). Within HIV educational health campaigns, celebrities can play an important role in creating a positive emotional appeal, removing social stigmas related to HIV. The use of celebrity influence has yet to occur in Canadian HIV/AIDS poster campaigns, and their role as public figures could be used to help raise awareness of mother to child transmission and further promote prenatal testing. The success of celebrity influence has been seen in other sensitive areas of public health such as recent health campaigns

featuring Olympian Clara Hughes, who suffers from depression, colon cancer survivor Sharon Osbourne, and testicular cancer survivor Lance Armstrong. Tremendous gains have been made in awareness and social acceptance of these illnesses with celebrity figures discussing their personal experiences. Similarly, pregnant celebrities could openly speak about undergoing prenatal HIV testing in order to normalize this behaviour and create a positive emotional appeal surrounding it. Modifying and expanding educational HIV campaigns, along with the continual re-evaluation of these strategies, can help to reduce stigma, and the subsequent rates of new mother to child HIV infections.

Recently, the Women and HIV research program at Women's College Hospital in Toronto produced several informative pamphlets which have been distributed to AIDS Committees and public health agencies across the country. The series of four pamphlets includes information on pregnancy planning, HIV positive women and their partners, women who are diagnosed with HIV during pregnancy, HIV positive new mothers, and pregnancy planning information for HIV positive men and their partners. These artistic, brightly coloured, welcoming and accessible pamphlets offer accurate and up-to-date information. They are a step in the right direction for further addressing the questions and needs of women and mothers around HIV prenatal testing and in providing other crucial information in a non-stigmatizing way.

Conclusions

The promotion of community resources that offer support to mothers with HIV, or that can provide information to mothers about various aspects of testing, is essential and demonstrates to women that they are not alone in any fears or questions they may have. Empowerment and agency for mothers can be better achieved through health campaigns that promote community-based programs, and improvements in services and health delivery systems. In addition to the reduction of stigma, it is necessary to promote both national and local services that can assist HIV positive women in their efforts to reduce the risk of mother to child transmission. All information provided to mothers through HIV-related health education campaigns should emphasize the privacy and non-invasive nature of procedures that reduce the risk of mother to child transmission (Jones and Sargeant).

This paper has addressed legal (mandatory disclosure laws) and medical issues (prenatal testing) related to HIV, along with the concept of the 'good mother', the complexities of stigma and HIV disclosure, and educational strategies to reduce HIV-related stigma. We have argued that stigma directed toward HIV positive women and mothers is the main reason some women are reluctant to discuss prenatal HIV testing with health care providers and why some are

fearful of discussing their positive status. This research has offered perspectives from women and mothers living with HIV about their experiences with stigma, disclosure, and prenatal testing. The focus group participants spoke of how they were coping with an immense range of practical problems in their lives; some that were compounded by emotional problems, many of which were linked to the issue of whether to hide their HIV positive status or cope with the stigma of disclosure. While the mothers were primarily concerned about how their children would be treated if their mother was known to be HIV positive, focus group participants also expressed that more opportunities are needed to share their experiences, to connect with other HIV positive mothers who share similar circumstances, and to learn from one another about useful resources within their community. Limitations of the study include a relatively small sample size (ten participants), the women were of similar ages and were living in similar geographic locations. A more comprehensive study would expand on the sample size and geographical areas.

There is an urgent need for prevention responses to address the unique aspects of HIV for women and mothers in Canada. With the support of AIDS service organizations and other health care related agencies, strategies can be developed to improve HIV positive mothers' lives in relation to disclosure, stigma, isolation, discrimination, and in overcoming barriers to health care. HIV prevention for women, mothers and babies requires enhancing public education about mothering and HIV, eliminating barriers to testing and support, and developing culturally-specific prevention programming. As well, HIV prevention services need to provide safe spaces for women where there is an understanding of the impact of the social determinants of health, such as culture, gender and poverty, on women's HIV-related prevention realities (Gagahan and Ricci). HIV and AIDS service initiatives must continue to target women who are most vulnerable to HIV infection and offer workshops around motherhood, pregnancy and prenatal testing. In consideration of the underlying inequalities for women, efforts must be made to empower women and mothers in decisions around their health care.

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