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Supporting the Mothers
An Exploration of Maternal Health, Well-being and Support Service Needs for HIV-Positive Mothers

Like all those living with HIV, mothers must cope not only with their physical problems but also with the discrimination, stigma and isolation that society imposes on them. As mothers, their physical problems are further complicated by child care, and their emotional concerns focus not only on themselves, but also on their children. This paper examines the lives and realities of HIV-positive mothers who require continual support in coping with their illness while caring for children. Open-ended probe questions were used to draw out personal experiences regarding issues such as disclosure of HIV status and the challenges of childcare; to get an understanding of the support services that the mothers accessed in the community; and to gain a better sense of what they wanted from support services. Drawing from feminist scholarship of maternal identities, along with grounded theory and theories of stigma management, I discuss several themes relevant to the needs of HIV-positive mothers as they emerged from focus groups. The themes that will be explored are: factors affecting mothers' overall health; stigma and discrimination, cultural identity and barriers to health care and support; disclosure; parenting challenges; and, support program needs. For the HIV-positive mothers in this study, disclosure decisions were based on their identity as mothers rather than as individuals, as they were primarily concerned about how their children would be treated if their mother was known to be HIV positive. This paper examines the implications for programs which currently serve HIV-positive mothers and suggests several strategies that could be developed further for their support. Focus group participants 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. Findings of the study will assist HIV/AIDS service organizations in providing this population with appropriate and needed services. With the support of AIDS service organizations and other health care related agencies, strategies can be developed to improve

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HIV-positive mothers' lives in relation to poverty, isolation, sexual health, stigma, discrimination, disclosure, and in overcoming barriers to health care.

Like all those living with HIV, mothers must cope not only with their physical problems but also with the discrimination, stigma and isolation that society imposes on them. As mothers, their physical problems are further complicated by childcare, and their emotional concerns focus not only on themselves, but also on their children. While the literature on stigma and illness disclosure has largely focused on isolated individuals, these mothers see the decisions to disclose or conceal their illness centrally in terms of how they feel their children will cope with society's response. HIV support programs targeting mothers can be effective if they target both HIV-positive mothers and their children in terms of their physical and emotional needs.

Between 1985 and 1994, women in Canada accounted for 9 percent of the total reported HIV infections. In 2006, they accounted for 28 percent of positive HIV results, 71 percent of which were in women between the ages of 15 and 39 years (Public Health Agency of Canada, 2008). While the face of the epidemic has changed, research pertaining to women and HIV rarely ventures beyond the vertical transmission of HIV to children. Prevention programs and services are more concerned with women's function as child-bearer than with focusing on the physical and emotional health of the mothers themselves; emotional health that is tied to feelings about how their children will cope with the stigma of HIV (Connell, 2001; Loppie and Gahagan, 2001).

This paper examines the lives and realities of HIV-positive mothers who require continual support in coping with their illness while caring for children. The complex issues which factor into the pressing need for accessible support services for HIV infected mothers are addressed. The experiences of HIV-positive mothers often revolve around the connections between childcare responsibilities, poverty, illness, cultural identity, isolation, lack of power in relationships and the main focus of this paper, stigma (Hunter, 2007). Previous literature on stigma and disclosure has examined stigma largely in terms of isolated individuals. I will argue however, that HIV-positive mothers are more concerned about disclosure of their HIV status for their children than for themselves. This transforms their consideration of whether or not to disclose their status. The main thematic areas that will be explored in this paper are those that emerged during focus group discussions: factors affecting mothers' overall health; stigma and discrimination, cultural identity and barriers to health care and support; disclosure; parenting challenges; and support program needs. This study provides insights from HIV-positive mothers themselves about the support systems they perceive to be in place, the barriers which they face with respect to health care and support, and their perceptions of what further systems are needed in order to assist them with their overall health care. Findings of the study will assist HIV/AIDS service organizations in providing this population with appropriate and needed services. The conclusion will argue

that HIV/AIDS service organizations should focus on helping HIV-positive mothers with their medical problems and emotional issues in ways that allow the mothers the option of concealing that their physical and emotional health issues are linked to their HIV status.

Theoretical focus

Drawing from feminist scholarship of maternal identities, along with grounded theory and theories of stigma management, I discuss several themes relevant to the needs of HIV-positive mothers as they emerged from focus groups. Grounded theory seeks to understand and explain how individuals define their reality and how they behave in relation to their own beliefs and realities (Ingram and Hutchinson, 2000). This paper identifies and conceptualizes issues that are of concern to HIV-positive mothers, presented from their point of view, stressing their own experiences and their definitions of the situation. Participants shared their perspectives about their efforts to balance childcare and health issues, financial worries, and for some, their struggles with parenting alone. The intersection of gender, class, culture, ethnicity and power were considered, while focusing on some of the complex challenges facing HIV-positive mothers in their day-to-day lives.

Feminist mothering theories stress that the empowerment of mothers is of primary importance (Green, 2006; O'Reilly, 2007, 2004; Ruddick, 1989) and, 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). Agency refers to "being in control of one's life and having the ability to make choices and changes within one's life" (Middleton, 2006: 74). However, as Amy Middleton argues, mothers living with difficult and complex financial, health, and family dynamics are limited in achieving agency, and have little "authority, authenticity and autonomy" (O'Reilly, 2007: 802). Agency is not easy to achieve for HIV-positive mothers, as they are often dependent on other family members or agencies for assistance with their children and in managing some of their practical needs. However, as Fiona Green (2004: 35) reminds us, there is "room for women to practice agency, resistance, invention and renewal," even within patriarchal institutions. AIDS service organizations and other health care agencies, addressing the needs of women and mothers, must continue to strive for practical and efficient ways to support mothers which "confers and confirms power to and for mothers" (O'Reilly, 2004: 15) in their efforts to achieve agency and autonomy in a society where gender based inequities affect women's health.

Stigma management and issues of disclosure are central to the lives of HIV-positive mothers. Bruce G. Link and Jo C. Phelan (2001: 367) posit that stigma involves a process of labelling with a negative stereotype, people making a distinction between 'us' and 'them', the stigmatizers using their power to discriminate against those who are labelled, and a process that generates unequal and disadvantageous outcomes for the labelled. While Link and

Phelan's (2001) approach to stigma is more sophisticated than others, as it stresses that the stigmatizers must have power to generate unequal outcomes, like other studies (Corrigan and Penn, 1999; Goffman, 1963; Fife and Wright 2000), their analysis also treats coping with stigma as an individual experience. This individualistic focus has permeated the health care literature on illness, disclosure and stigma (Åsbring and Närvänen, 2002; Butt, Paterson and McGuiness, 2008; Corrigan and Matthews, 2003; Waltz, 1990). While these studies identify the impact of stigma on others as one factor influencing the decision to disclose HIV status, the impact on others is not identified as the fundamental lens through which the disclosure decision is approached. For the HIV-positive mothers in my study, stigma disclosure decisions are based on their identity as mothers rather than as individuals, and, as such, they see this decision as one they make on behalf of themselves and their children. Consequently, as stigma and disclosure are usually tackled as an individual decision, I decided to listen to the voices of HIV-positive mothers as they coped with this difficult issue for 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. Participants learned of the study through an information notice that was posted in the offices and on the websites of these agencies. Two African Canadian, one Aboriginal, and three Caucasian mothers, between the ages of 21 and 40, participated in the focus groups. Two of the women were living with their male partners, two were in relationships, but not living with their male partners and two were single. They had one, two, or three children each. The participating mothers were fully informed about the design and intent of the research, were assured of the confidential nature of the study, and that any care or services they received from the agencies would not be adversely affected by their decision of whether or not to participate.

Open-ended probe questions were used to draw out personal experiences regarding issues such as disclosure of HIV status and the challenges of childcare; to get an understanding of the support services that the mothers accessed in the community; and to gain a better sense of what they wanted from support services. The discussions were audio taped and transcribed.

Factors affecting mothers' overall health

Focus group participants spoke of several factors such as poverty, isolation and sexual health concerns, which affected their overall health and often impeded access to health care. The physical and emotional issues raised reflect the themes found in P. Solomon and S. Wilkens' (2008) study of HIV-infected mothers' degree of participation in society.

Physical and Emotional Issues: The physical difficulties of being HIV positive along with the responsibility of looking after their home and children

were the base line realities for these women. Difficulties with eating, sleeping, and the numerous side effects of medication prevented these mothers from participating fully in society. As one mother voiced:

> *Because of my neuropathy, it is so hard to move my legs and that makes it hard to get around. I had periods where I got so skinny and just could not eat at all. I felt so sick. I also had repeated cases of shingles and was constantly on pain medication. Now I am afraid to go outside because I am worried about feeling sick or worried about being sick. If there are flu bugs out there, I don't want to catch them. Sometimes I just feel too ill to go out and do stuff. In the morning I have a really hard time getting up and in the afternoon I have to take pills to get some sleep because I have insomnia. I am so tired after doing errands, phone ringing, try to have a nap, feel like crap, give me a break, I feel like crap, and on and on. That is how every day goes.*

Some participants have been coping with HIV alongside substance abuse, creating more obstacles to accessing appropriate medical care and support services. Due to various addiction issues, these women have dropped out of health care, although they desperately need support with their addictions, housing, finances, nutrition and transportation. As one mother stated:

> *There are lots of emotional challenges when living with HIV and addiction. My partner and I both have addiction issues so we may separate for a while. He is always worried about me dying so we talk a lot. I haven't been using services much but I have to start again. I have to do what is good for me.*

While some mothers engaged in high-risk activities prior to their pregnancies and prior to becoming mothers, this study found that maternal identity and feelings of maternal protectiveness motivated HIV-positive mothers towards healthier lifestyles and in becoming more receptive to various community supports. As one participant stated:

> *Learning about my HIV helped me to become a better mother because I looked at my priorities differently and I tried to live healthier for the sake of my children. You know, I didn't think I would be able to have children and now that I do I try to stay alive longer.*

Being HIV positive generated many emotional and psychosocial concerns specific to their illness, including a loss of joy in life, a loss of trust, less intimacy in their relationships, worries about unsafe sex and possible re-infection with new strains of HIV, and worries about their health deteriorating further. All of these were compounded by their concern about their children's

future and feelings of guilt when they were not able to provide support for their children's personal, social, and educational development. Still, despite the many challenges and stresses, the experience of mothering provided the participants with a more emotionally fulfilling life. Some expressed how their children helped to give them a sense of purpose and connection with the community.

While most of the mothers in the focus groups did not work outside of the home, those who did, saw work as a valuable part of their lives, not only for the income but because of the feelings of self worth that came with their job. As one mother stated:

> *The good feeling I get from working and being involved helps me. Along with my paid job, I do volunteer work at the drop-in centre talking to young people. This makes me feel better. I am actually doing something helpful.*

Another mother shared:

> *I find that if I stay busy and keep active then I have things to look forward to. I can say, when I do die, that people won't forget about me. I don't live in vain. I really don't want to be the woe is me and, oh I am so sad, I need help. I want to help others.*

Living in Poverty and Isolation: All of the women in the focus groups had limited financial resources and this affected all aspects of their lives. One mother commented that she was not able to afford a diet of the healthy food necessary for her to stay well. She stated, "*There used to be fresh fruit and veggies provided for us, here at the agency and now it is not around. I am not getting enough greens.*" In addition, although the women in the focus groups realized that becoming involved in various activities would contribute to their overall health, poverty made this difficult. Some mothers felt very isolated because they could not always afford the cost of transportation and lacked a car. As one mom stated: "*When you're stuck at home, alone, taking care of yourself and your kids and you have no help to get anywhere – to the grocery store or wherever, you get lonely.*" Several mothers attributed their isolation to simply being too sick to leave their homes, and being too ill to work outside of the house. The unpredictability of their illness and the side effects of medication made several mothers reluctant to work.

Stigma and discrimination, cultural identity and barriers to care and support

Stigma and Discrimination: Stigma and discrimination prevent many HIV-positive mothers from accessing health services and support programs as they often feel that they are being judged by health care providers. Mothers in my study also worried about people in the community finding out about their

status when they entered AIDS service organizations for support. They greatly feared losing respect and support from their own family members, which may be one of the more emotionally dire consequences of the disease (Bok, 2002). As one mother explained:

> *I made the mistake of telling my sister about my HIV and now she is using it against me—if she wants something she will say that she will tell people about my status, unless I give her what she wants. Also, if my daughter knew, she would use it against me. She would tell lots of people. She would say that I can't see her baby and she would say if you don't give me what I want, I will tell everyone."*

All participants expressed fear that stigma that would attach to their child if the school system was to learn of their HIV status. Mothers were very concerned about their children losing their school friends. As one mother stated, *"It's hard to keep it in, but if people at school know they won't want their kids to play with my daughter."* A mother of a high school aged child expressed similar concerns; *"I don't want high school kids to know about me. I used to do talks at high schools to warn kids about HIV, but now I can't because my son is high school age and he would find out."* These mothers chose to maintain their HIV status as a secret, despite secrecy coming at a substantial personal cost, as a major aspect of their being is not included in their public identity (Corrigan and Matthews, 2003; Cain, 1991). They wanted to connect with support networks and with others in similar circumstances but refrained largely for their children, not themselves. Keeping their diagnosis secret hinders their ability to discover effective coping mechanisms and leaves them isolated and open to depression.

Cultural Identity and Barriers to Health Care and Support: The over representation in the Canadian population of Aboriginals and immigrants from countries where HIV is prevalent can be attributed to socio-cultural and institutional factors that intersect with gender, race, class and political and economic conditions (Bell, Mthembu, O'Sullivan and Moody, 2007; Hackl, Somlai, Kelly and Kalichman, 1997; Tharao and Massaquoi, 2001). African-Canadian mothers in my 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. As one mother expressed:

> *I am afraid to enter AIDS organizations because I am afraid of being seen by someone from my community and being gossiped about. We are in a smaller town here and although a support group would be great, women from my culture do not want to be identified. In a bigger center I can see how getting together is appealing—people feel safer and they are not as easily identified. Men from my culture don't want their women to associate with other women who are HIV positive because word will get out.*

The concern about stigma goes beyond self and children to the community to which they feel a part. In addition, the impact of a positive HIV-test result on immigration status was a concern for immigrant and refugee women. One participant was concerned that her HIV-positive status might place her at risk of deportation and jeopardize her being able to sponsor other family members to Canada, a finding which echoes the work of Esther Tharao and Notisha Massaquoi (2001).

Disclosure

Many mothers struggled with decisions about disclosing their infection to their children and other family members both because of the implication of being HIV positive and because of the stigma attached to this condition (Hough et al., 2003; Murphy, Roberts and Hoffman, 2003; O'Sullivan et al., 2005; Schrimshaw and Siegel, 2002). Some mothers disclosed their status to their children because they wanted to be the person to tell them about their illness, to educate them about HIV, and to prepare them for what the future may bring (Schrimshaw and Siegel, 2002). Most mothers in the focus groups however resisted disclosing their status to their children, as they wanted to keep their children's lives carefree for as long as possible. Participants expressed concerns about their children's ability to understand what HIV entailed, that it would create too much of an emotional burden, and they worried about their children fearing the loss of their mother. In this regard, this research supports the findings of Beverly J. Antle, Lilian M. Wells, Robyn Salter Goldie, Dale DeMatteo, and Susan M. King (2001); Debra A. Murphy, *Kathleen Johnston* Roberts and Dannie Hoffman (2003); and Eric W. Schrimshaw and Karolyn Siegel (2002). The participants were also concerned that if they were to tell their children of their status, they would be compelled to answer questions about the lifestyle they had lived in the past and potentially lose their children's respect. Some study participants felt shame or anger about the way they became infected. Thus they were unwilling to share details about their infection with their children.

Although disclosure of HIV status is stigmatizing and has negative consequences for the family, withholding this information often leads to troubles, such as confusion and possible anxiety among children who may be aware of a problem, yet unable to identify it (Murphy et al., 2002; Murphy, Roberts and Hoffman, 2002). Among the benefits of disclosure, a certain amount of relief can be brought to children if they see their mothers in relatively good health. For those mothers in the focus groups who had disclosed to their children, careful thought went into the timing and the circumstances of their disclosure. Mothers stated that discussing the issue was easier when they were feeling healthy and optimistic and when they felt that they could answer questions without shame and embarrassment. The aforementioned strategies, utilized by my respondents, reflected those found in the literature (Murphy, Roberts and Hoffman, 2003; Brackis-Cott, Block and Mellins, 2003).

Parenting challenges

Caring for Children: A major theme emerging from the focus group discussions was the continuous struggle the mothers had in balancing their own health concerns with their families' needs. The mothers told of how family members expected them to be the primary caregiver, even if they were ill. Although some described their lifestyles as changing for the better (eating well, getting more rest and seeking assistance with any addiction issues), their attention was mainly focused on trying to maintain a happy home for their children. This was a great challenge, as the illness has affected their ability to parent. As one participant lamented, *"I am so tired all the time. I can't get out of bed in the morning and my daughter is so upset with me because I am not like other parents. I haven't told her what I have, just that I'm sick and she gets so mad at me."* Further, parenting issues that may have been a struggle under normal circumstances can turn into deeper problems when a mother is also dealing with illness. The mothers expressed great relief that their children were not infected, yet were saddened that their children were constantly affected by HIV, despite efforts to make their lives as normal as possible. Many mothers reported difficulties in preparing the father of their children (or their male partner), for their future responsibilities. They expressed concern about their partner's ability to care for the children and look after the household when they became too ill to cope. As one mother voiced:

> *I have tried to talk to her Dad about this. I say 'you need to learn how to look after her if something happens to me.' He doesn't really care. I cannot count on him. I am hoping as she gets older he will change.*

Role Reversal: The converse of "caring for children" is when teenage children take on responsibilities of caring for the family. An emotional concern of one of the mothers was her adolescent child's over involvement in her physical care and emotional support, often without any social service or practical assistance in place. Studies have shown that children who care for the physical and emotional needs of their mothers can become very isolated from peers, school and social activities (Hackl et al., 1997). Further, some studies have indicated that children of HIV-positive mothers have higher rates of destructive coping and acting out behaviours, poor psychosocial adjustment and academic problems due to stresses at home compared to those children with non HIV-infected mothers (Brackis-Cott, Block and Mellins, 2003; Kotchick and Forehand, 1999).

Support program needs

As this study has illustrated, mothers living with HIV require support services uniquely designed to assist them in their role as caregiver. The demands of parenting, in the context of their uncertain health and the fear of stigma must be understood if health care workers are to provide adequate support to infected mothers. Programs need to be comprehensive, easily accessed and

support the whole family. Several program and support needs emerged from the research findings: client-centred approach, caring for the whole family, and practical initiatives.

Client-Centred Approach: HIV-positive mothers must be assured a comfortable and safe environment where they can discuss personal issues and receive the services they require. Although focus group participants were appreciative of many of the support services provided by AIDS service organizations, the mothers felt that existing support programs were not fully adequate. They perceived AIDS support services as mostly catering to men and they wanted support specifically targeting HIV-positive mothers. As one mother stated, "*You can't eat, breathe and sleep aids on your own you know. Sometimes it is nice to have just a friendly support group to talk about things that affect us as mothers.*"

Additional evidence for this was provided by the mothers' reaction to my focus groups. They asserted that they benefited from participation in these groups, where discussion was centered exclusively on their needs and where there was a non-judgmental environment to share information about health care, to express anger, and to discuss childcare, relationships, and sexuality. The participants appreciated that their experience and knowledge was being valued by others with similar circumstances. They hoped for support groups with other HIV-positive mothers where they could together deal with feelings of depression, isolation, and anxiety around the unpredictability of their illness. As one mother commented, "*women really like the emotional support from other women that they don't get from men.*"

African-Canadian mothers expressed a further need for culturally sensitive support for Black mothers who face multiple oppressive forces of racial and sexual discrimination. 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 (Gardezi et al., 2008).

Caring for the Whole Family: Focus group participants revealed that they would like to see more support directed to families affected by HIV and more occasions for mothers and their children to spend time together in family-centered programs. Participants told of a special sponsored week-long summer camp that had been offered in the past for HIV-positive mothers and their children. This camp, with outdoor water activities, beautiful grounds, social time and HIV related counselling was extremely beneficial to participants. As one mother recalled:

> *I went to this camp for several years and then it was stopped. It was great for HIV moms getting together—a nice open area, first-aid, activities, babysitters, so the moms could relax. There were counsellors at the camp and there would be a group session with moms and kids so we could disclose if we wanted.*

The group lamented that this camp was no longer offered, at least in their community. Some mothers felt that their children needed to speak with a professional because they were keeping their feelings to themselves. Family focused therapies, held in a safe environment where it is acceptable to express emotions, would be of great benefit for families.

These mothers' concerns with services for the family as a whole echo the academic literature which stresses the need for agencies to provide a range of inclusive social services, which must be proactive and practical, by, for example, providing home care when the mother is too ill to cope (Antle et al., 2001; Bell et al., 2007; Carrière, 2008). Health care professionals, and particularly support workers, need to be sensitive to the complex dynamics in families living with HIV. Services are also very much needed to assist families where older children are major caregivers to a parent who is infected (Van Loon, 2000).

Practical Initiatives: Along with barriers resulting from stigmatization, racism, and poverty, HIV-positive mothers also faced barriers within health and social services because of a lack of funding for practical resources. Mothers in the focus groups expressed their desire for workshops to support them with their emotional health, where topics such as developing healthy coping strategies, stress management, relaxation, meditation, and spiritual development could be addressed. Further, participants spoke of the need for assistance with transportation costs, with legal and practical resources and in finding low cost housing.

Discussions in focus groups assisted the participants in building a sense of community as they shared and learned from one another about particular resources that have been helpful to them such as food banks and community kitchens, and also provided practical advice about the locations of specific medical pharmacies where their prescriptions could be filled without judgment from pharmacists. They wanted to connect with other HIV-positive mothers who were struggling to meet particular nutritional needs. They felt their family's nutritional needs could be better met with the setup of community kitchens where HIV positive women could join in for education on healthy foods, and more importantly, for communal preparation of nutritious cooking in an informal setting. The participants relayed that because they were responsible for cooking meals that the family would enjoy, they often ignored their own dietary needs:

> *The members of my family do not like many of the foods that I need to eat for my health and diet. One challenge that I really have is getting the proper nutrition. My husband hates vegetables and is a picky eater. My daughter is a picky eater but she will eat vegetables if I cook them a certain way. I end up having to make everybody their own separate meal so many times just to get my own nutritional value. Maybe something like a community kitchen or something like that where people could bring in ingredients and share in it and we could make some meals and divide them up for*

people to take home and then eat that with your family. I don't get enough vegetables otherwise.

While a communal kitchen may be structurally impractical, their concern illustrates their focus on the immediate needs of their family. Their suggestion of fresh produce at a drop-in centre may be more practical in helping these mothers maintain a better diet.

Participants spoke of the difficulty they have experienced in being on the receiving end of high staff turnover. As one participant complained:

They just don't know what it is like. If there is an issue it would be great to talk to someone but you can't really talk to anyone in the agency because the staff are always turning over. People that are supposed to be here for us end up getting changed every year. So you begin a relationship with someone here and then they are gone.

They wanted, in consequence, to be connected with more than one support worker so they would not have to continually retell their stories in their efforts to garner emotional support.

Conclusions

This research has offered perspectives on the experiences of mothers living with HIV. Support services help HIV-positive mothers cope with or avert the negative judgements and stigma to which they are subject, as well as to assist mothers in communicating their needs and concerns to health care professionals. The focus groups show HIV-positive mothers coping with an immense range of practical problems in their lives; problems compounded for my study's participants by poverty, and in some cases, by being a single mother and/or being from a minority group. Mothers in the focus groups consistently faced problems posed by their illness in the context of their family responsibilities. Their practical problems 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. This disclosure decision, while partially a personal issue, was centrally an issue for them as mothers, as they were primarily concerned about how their children would be treated if their mother was known to be HIV positive.

Their concern not to be identified as HIV positive poses a problem for HIV/AIDS service organizations. These organizations need to provide services in a variety of ways which do not mark the mothers as HIV positive. First, respecting many mothers' decisions not to disclose their HIV positive status suggests service agencies should be as discrete as possible about the HIV positive status of the client and help the mother as best they can as a mother, without focusing on her HIV status. For instance AIDS service organizations should be located in centres with many other support services so that women can attend without

feeling 'outed' and therefore stigmatized. Second, AIDS service organizations should focus on coordinating help with other agencies behind the scenes. HIV and AIDS service organizations can play an important role in coordinating efforts with other community agencies to assist HIV mothers and their families. Third, service agencies need to attend to discussions of disclosure. The decision to reveal their HIV positive status ultimately rests with the mothers. Support agencies however, can usefully provide counselling for mothers about whether and how they reveal their illness to others in order to receive the support they need. Finally, in respecting many mothers' decisions not to disclose their HIV positive status, agencies should stress practical help to disadvantaged mothers with health problems without identifying what generates the health problems. An example of possible help is provided by the Teresa Group family support program, located in Toronto and funded through the Ministry of Health and Long Term Care, which provides free baby formula for a year to new mothers who are HIV positive living anywhere in Ontario. Those who benefit from this program are seen by others as mothers who have difficulty breastfeeding or as mothers who have reasons for not breastfeeding and are therefore not "outed" as mothers with HIV. Several agencies in the communities studied do offer services that are of benefit to the public, including HIV-positive mothers and their young children, such as food banks, women's shelters, community health services, and family and children's services. Ontario Early Years Centres offer support programs to parents in all aspects of early child development. They offer parent-child drop-in, resources, and support, which can be of great value to parents with young children. "Best Start," an initiative that has grown out of the Ontario Early Years Centres, assists families with child care services as well as programs for healthy development during a child's first years. "Healthy Babies, Healthy Children," a provincially funded, free program for pregnant women and families with young children supports the healthy growth and development of children. It offers an infant hearing program, speech and language therapy, prenatal phone calls, prenatal home visits, post partum contact, home visits, and family visitor support, whereby a community member assists families with problem solving and provides information on parenting issues, child development and community resources. For mothers who financially qualify, the YMCA provides childcare and some free time for mothers for a couple of hours a week. These few hours a week of support for mother and child help greatly with both mother care and childcare. If the mother has even a little free time to attend to her own self care and/or time to interact with others, there is a great psychological and social benefit. Being able to attend a support group or social network helps to create and maintain friendships, offers peer support and AIDs in breaking the isolation often felt by HIV-positive mothers. Further, any involvement with support or social groups has been found to decrease feelings of isolation and physical problems associated with depression among mothers with HIV (Brackis-Cott, Block and Mellins, 2003; Solomon and Wilkins 2008). As O'Reilly makes clear, parents need to be helped first

because "only then are they able to provide real and continued assistance to the child" (2006: 328).

Focus group participants 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. 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 poverty, isolation, sexual health, stigma, discrimination, disclosure, and in overcoming barriers to health care.

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