

“Under My Umbrella”: The housing experiences of HIV positive parents who live with and care for their children in Ontario

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Abstract Positive Spaces, Healthy Places (PSHP) is the first longitudinal community-based research (CBR) initiative in Canada to examine housing stability and its relationship to health related quality of life (HRQOL) for people living with of HIV/AIDS (PHAs). As part of our mixed method data collection strategy in-depth, semi-structured interviews were conducted with 50 PHAs across Ontario to provide a deeper understanding of the impact that housing instability has on their mental and physical health. Emerging from the qualitative interviews were the unique issues and concerns that were reported by parents who live with and care for their children. These parents face dire housing, economic and social challenges that are associated with significant risks for poor health outcomes. Poor housing conditions, unsafe neighborhoods, barriers to supports for themselves and their children, HIV related stigma, discrimination, racism, and poverty have been identified by these families as being among their most pressing concerns. This results in increased stress and anxiety that has a negative impact on the mental health of HIV positive parents. In order to more effectively support HIV positive parents and their children, health and social service practices and policies must respond to the unique challenges that face these families.

Keywords HIV · Families · Mothers · Housing instability · Mental health

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Introduction

Positive Spaces, Healthy Places (PSHP) is a community based research study that emerged out of community concerns about the lack of appropriate and affordable housing for people living with HIV in Ontario. In response to this concern, community leaders from a range of AIDS service organizations in Ontario led a process of developing a research proposal and receiving funding from the Ontario HIV Treatment Network, which enabled them to examine the housing needs and experience of people living with HIV/AIDS (PHAs) in Ontario. PSHP is the amalgamation of this earlier study with a more in-depth longitudinal mixed-method study funded by the Canadian Institute for Health Research (CIHR) that is aimed at exploring the range of housing situations, including homelessness, of people living with HIV/AIDS in Ontario and the impact that their housing has on their health. PSHP is the first longitudinal community-based research initiative in Canada to examine housing status and stability and its relationship to health outcomes and health-related quality of life in the context of HIV and AIDS.

HIV/AIDS and housing instability

Social determinants, HIV, health and housing

As clearly stated in the Ontario and pan-Canadian HIV/AIDS Strategy (CSHA), community-based AIDS organizations have reported a significant increase in the proportion of clients experiencing housing problems and, in many cases, have suggested that housing is the most urgent unmet need for people living with HIV (OACHA 2002). Studies have also shown that most individuals who are homeless have

intermittent periods of stable housing (Phelan and Link 1999) and that there exists a range of homelessness and housing arrangements that individual's experience (Kushel et al. 2006; Murphy 2006). Furthermore, Tremblay and Ward (1998) describe homelessness as a continuum of the actual current housing situation that goes from sleeping rough, to day and night drop-ins, to shelters, to rooming house, to unstable housing, to stable housing. This suggests that it may be more appropriate to use the term 'housing instability' when discussing the housing experiences of people living with HIV. Moreover, because 'homelessness' can be viewed as occurring episodically, it must also be understood as "fluid and dynamic" process that is "characterized by multiple transitions, role exits and role entries" (Peressini and McDonald 2000:526). Consequently, housing status must be recognized as existing along a continuum of housing/homeless situations in order to reflect the reality that for many PHAs, their 'housing' is state that is in, or is at risk of, constant transition.

Clearly the primary and essential function of housing is to provide a safe and sheltered space and therefore appropriate housing is absolutely fundamental to the health and well being of individuals (Dunn et al. 2004; Murphy 2006). Studies have shown the ongoing relationship between the quality and security of housing and mental, physical and social health, and that poor quality of housing has a significant negative impact in terms of a range of health outcomes (Hwang 2001; Frankish et al. 2005; Murphy 2006). A review of the literature on housing and health in the context of Persons Living with HIV/AIDS highlight the importance of working within a social determinants of health framework that understands how housing is associated to access to and utilization of health care, adherence to HIV associated treatment regimens; and improvements in clinical indicators of health and health-related quality of life among PHAs (Dunn 2000). Echoing Aidala (2005), this suggests that housing must necessarily be understood as being part of a larger system of services that are required by HIV positive individuals throughout their housing and/or housing trajectory.

The social determinants of health framework also acknowledges that whilst PHAs are at risk of homelessness, there are both similarities and differences regarding how and why this risk is experienced. Recent studies have shown that PHAs most at risk of homelessness are women (Gielen et al. 2000), Aboriginal populations (Duran et al. 2000) and new Canadians (Li et al. 2001). Housing is also a critical determinant of mental health that plays an important role in prevention, resilience and recovery from mental illness and addictions (Nelson et al. 2007; Bryant 2004). This is an important factor given that a significant number of homeless people are HIV positive or at risk of becoming HIV positive also live with a mental illness and/or

substance use issue that prevents them from accessing and/or maintaining housing (OACHA 2002). This suggests that many PHAs who live in unstable housing situations also experience intersecting oppressions including stigma due to HIV status, mental health status, and race, amongst other social determinants of health such as gender, sexual orientation and poverty.

Women, HIV and housing

Recent studies have shown that women are particularly at risk for poor health outcomes as a result of being at the center of two converging epidemiological trends: HIV transmission and homelessness (Kilbourne et al. 2002). Canadian HIV prevalence estimates indicate that the number of women in Canada living with HIV continues to grow. By the end of 2002, an estimated 7,700 women were living with HIV, accounting for about 14% of the national total, an increase of 13% from the 6,800 estimated at the end of 1999 (Geduld et al. 2003). Statistics indicate that about 3,895 of these women live in Ontario of which, 344 were diagnosed in 2006 alone (Remis et al. 2008).

Studies in both Canada and the U.S. show that homeless women are particularly vulnerable to HIV/AIDS (Culhane et al. 2001; Weinreb et al. 1999) and that HIV has been found to be among the leading causes of death of homeless women between the ages of 18–44 (Cheung and Hwang 2004). This highlights the importance of understanding the role that housing plays in the increase in HIV/AIDS among women, particularly as it relates to the risk factors associated with contracting HIV such as drug use, sex trade work, mental health, domestic violence and sexual abuse (Wenzel et al. 2007; Song 2003; Kilbourne et al. 2002). Poor women who are prone to living in unstable housing situations are at a disproportionate risk of HIV/AIDS regardless of their lifestyles (Zierler and Krieger 2000). This is because housing instability, homelessness and transience compromise access to adequate health care (Parish et al. 2003), and create barriers to accessing appropriate and effective social supports (Fisher et al. 1995). Homeless mothers, in particular, have been found to subordinate their own health care needs for the needs of their children (Song 2003), which leads to competing subsistence needs and caregiver roles that have been found to adversely influence health care access for women living with HIV/AIDS (Shelton 1993). As such, HIV infected parents, in particular mothers, may have unique housing needs that are related to both their physical and mental health suggesting that there is a need to develop a deeper understanding of how HIV and housing instability are implicated within their overall parenting experience.

HIV positive parents and housing instability

Little is known about the impact of homelessness and housing instability on Canadian families. The information that is available is mainly through government reports or research that is based on very small population samples that often fail to reflect the “spectrum of homeless families” in Canada (Waegemakers Schiff 2007). Families who experience homelessness live on the streets, in cars or abandoned buildings, in temporary or emergency shelter, in shelters for those fleeing domestic violence, in temporary or transitional housing, with family or friends or in motel rooms rented on a monthly basis. Just as in the general population of people experiencing homelessness, families may have only one homeless incident while other families may experience multiple episodes of homelessness. Many families also experience housing instability or the threat of homelessness due to the imminent risk of losing their housing (Waegemakers Schiff 2007).

Included in the spectrum of homeless families are families with children who are affected by HIV. These families share many of the same experiences as homeless families in addition to additional unique challenges related to the impact that HIV has on the entire family system. Most of what we currently know about the experiences of HIV positive parents and their children has been conducted in the U.S. These families are characterized by chronic poverty, homelessness, multiple losses, substance use, and racialization. Racialized women living on a low income have been particularly affected by HIV and it is mainly these women who tend to be the sole or primary caregivers in families affected by HIV (Pequegnat and Bray 1997). More recently, studies have shown that HIV positive parents continue to cope with discrimination, stigma, poverty, secrets about HIV status and planning for the possibility of sickness or death, as well as the everyday issues of life and parenting (Antle et al. 2001; Salter Goldie et al. 2000). These unique experiences, concerns and challenges negatively impact their physical and mental health and quality of life (DeMatteo et al. 2002; Salter Goldie et al. 2000). These issues are often exacerbated for HIV positive mothers who are living in overcrowded housing or who remain in violent relationships for the purpose of having a place to live (Kappel Ramji Consulting Group 2002). Other concerns include unwanted family separation and/or the involvement of social service agencies that have a mandate for the welfare of children, and the longer term intergenerational impact of both HIV/AIDS and housing instability, particularly in cases when children take on roles beyond those of their peers in terms of caregiving and providing emotional support (Kappel Ramji Consulting Group 2002). Hence, it has been argued that while interventions that support parents around challenges such as disclosure to children,

planning for illness, helping children adjust to new caregivers and goals in the event of parental death are important, unless basic survival and security needs (food, shelter, employment, health care) are met first, these interventions are unlikely to succeed (Rotheram-Borus et al. 2005). What follows is a discussion of the themes that emerged from in-depth interviews with HIV positive parents about their housing experiences in addition to the implications their experiences have on the future development of housing policies and practices.

Methodology

As part of our community based research model, 7 people living with HIV were trained as research assistants. The research assistants were responsible for collecting both quantitative and qualitative data. The study engaged in a mixed method design that included 605 administered quantitative surveys with a regional epidemiological representative sample of people living with HIV/AIDS from across Ontario and 50 in-depth interviews with a representative sub-set of the participants. Ontario was initially stratified into four regions, Greater Toronto Area, Eastern Ontario, Central & South West Ontario and Northern Ontario. The sample was further stratified by Ontario based HIV epidemiological data (Remis 2006) with minor adjustments that resulted in an over sample of women (23%) and the aboriginal community (10%) in order to respond to ongoing increased diagnoses for both populations in Ontario.

This paper focuses on the qualitative analyses of the housing experiences of thirteen HIV positive parents living with and caring for their children in Ontario. Thirteen of the fifty qualitative interview participants identified as parents who were currently living with one or more children under the age of 18. This population included one man and twelve women. Two of the mothers identified as Aboriginal, four as Caucasian, four as African, and two as Caribbean. Five of the participants identified as immigrants to Canada. Five lived in the Greater Toronto Area, three lived in the South West, two lived in Northern Ontario, and one in Eastern Ontario. The interviews were semi-structured and focused primarily on the participants’ health and housing experiences since diagnosis. The questions were open ended and were organized around receiving concrete information about the participant’s housing trajectory since diagnosis and the details about their physical and mental health at various times throughout their housing experiences. The semi-structured nature of the interviews were aimed at developing an in-depth understanding of the relationship between HIV, housing and health while also providing flexibility for the participants to share the unique narratives about their

individual housing experiences. The participants were not asked directly to share positive or negative experiences but rather, were probed for clarity and details about their overall reflections regarding their housing and their health. The interviews were approximately 1–1.5 hours in length. The interviews took place at a locally based HIV/AIDS organization. Interviews were taped and transcribed and underwent thematic analysis and triangulation. All names and places have been changed to protect the identity of the participants. Participants from African countries are identified as coming from Africa rather than the name of the participant's country of origin in order to ensure the participants' anonymity. This study received ethics approval by McMaster and York Universities.

Results

“Housing is the biggest concern because you don't want to be on the streets especially with your family... housing is always the biggest concern”.

Emerging from the analysis of the in-depth interviews with the participants are a number of housing related issues and concerns that highlighted the challenging and complex experiences of HIV positive parents. These included: sporadic adherence to medication; living in inappropriate and unsafe neighborhoods and housing situations; involvement with social service agencies with a mandate for the welfare of children; stigma and discrimination; poverty; and concerns about the future. The overarching themes that transcended these issues were recurring narratives about how these issues and concerns affected the participants' mental health and the particularized the thoughts and actions that HIV positive parents experience as a consequence of the intersecting issues of HIV, housing status, parenthood.

Adherence to medication

“I don't care and I can't afford to...it's just easier to say piss on the health and worry about everything else”.

The intersection between housing instability and HIV has unique consequences for HIV positive women during pregnancy. When asked to share her housing history from the time she was diagnosed with HIV Rose, a pregnant HIV positive aboriginal woman shared her housing trajectory during the time she was living with an emotionally abusive partner. As Rose explained:

“I was put on antiretrovirals (during pregnancy), or I was still on anti-virals but they had to change my

antiretrovirals at one point because I failed, I missed too many pills or something and my anti-virals stopped working for me so they had to change them...I don't know, I guess if you miss too many, because I take off for days and I don't take my pills with me and I tend to miss a few...”

Throughout this period in her life it became clear that Rose's housing trajectory was influenced by a number of factors including the 'choice' between staying in an abusive relationship in order to maintain her housing or to “take off for days” and live on the street. This echoes previous research that argues that the threat of homelessness can maintain HIV positive women in unsafe and unhealthy living situations and/or housing arrangements (McKeown et al. 2002). Rose's narrative also highlights the impact that housing instability had on her inability to consistently adhere to her HIV medication. This is particularly important for people living with HIV because compliance to HIV medication is of key importance in fending off drug resistance. Rose's personal experience reflects what has already been documented in earlier research, that being, how homelessness and/or housing instability can be a significant determinant in a person's ability to adhere to complex HIV drug regimens and regular treatment and monitoring (Leaver et al. 2007). Rose also demonstrates how vital it is for HIV positive women to adhere to antiretroviral therapy throughout their pregnancy. As in Rose's case, this is because non-adherence to antiretroviral therapy that can result in developing a resistance to drug therapy in addition to putting the baby at risk for perinatal transmission of HIV (McGowan and Shah 2000; Enriquez et al. 2007). This suggests that HIV adherence interventions must address the intersecting issues of housing instability, gender and other social determinants of health in order to increase the effectiveness of adherence amongst HIV positive women who are living in unstable housing situations.

Finally, another significant issue emerging from Rose's narrative is the impact that non-adherence had on her view of herself. This can be heard most clearly in Rose's assertion that she “failed” to take her medication implying that she believed it was her fault that she missed too many pills. This is a particularly important and concerning issue because in many cases, non-adherence is a result of multiple stressful life events and not a person's inability to take responsibility for their health (Leserman et al. 2008). This emphasizes the importance of addressing the issues that result in living a chaotic and stressful lifestyle, the impact this has on adherence and how both these concerns impact the mental health and well-being of HIV positive women during pregnancy and beyond.

Safety, stability and stigma

“When you have kids it’s hard... You have to live in a place where you feel secure and comfortable”.

Housing safety, stability and HIV related stigma and discrimination emerged as complex and interconnected issues for HIV positive mothers. A strong example of this is demonstrated through Sheila’s story of moving numerous times over the course of twelve months in the hopes of finding safe and secure housing:

“My last year was the worst because my child knew a couple guys that lived there [in the apartment building] and um they dealt drugs...and it was scary because I didn’t want my child involved in that. But when I moved out of there and into a town house and they found out I had HIV, oh that was hell. Every day I had writing on my walls...I had letters saying if I didn’t move out I was dead. And then me and my child had to move to a women’s shelter...then living on the street and at another homeless shelter”.

Sheila’s concern about the availability of drugs by other residents in the building is one that is echoed by the majority of the parents who participated in the interviews. This is because the housing that they can afford is generally situated in areas of high crime and drug use. Although this is a concern that all parents have, these fears are exacerbated by the impact of HIV related stigma and the very real discrimination that puts one’s housing stability and safety at risk. Moreover, the number of times Sheila and her child had to move and the reasons for these moves resulted in Sheila stating that moving so much “really brings me down” and resulted in her feeling “very depressed” and “really worried”. This is not surprising given that housing instability has been shown to result in lower levels of mental health quality of life amongst people living with HIV and that the mental health of HIV positive individuals decreases with the number of times they move within a twelve month period (Greene et al. 2007). Hence, HIV positive parents are constantly weighing their housing choices, particularly as it relates to the mental health and well being of themselves and their children, their housing and neighborhood safety and the potential for encountering HIV related stigma and discrimination.

The mothers in this study also highlighted the importance of living in a neighborhood that allowed them easy access to both their place of employment and their child’s school. While this is not a unique desire for parents more generally, this holds different meaning when both the parent and the child is HIV positive. As Claire shared:

“I need to be there. Like I just—it makes me very uneasy, uh, that I wouldn’t be able to get to her in a

very short period of time. So if she gets hurt at school, where they don’t know her status, I don’t want them being the ones taking her to the hospital. I don’t want that. So it’s very important for me to be very close by. Um, so that’s always been set up that way. So we did end up moving to the bachelor apartment which was, again, ridiculously close to school and work”.

Hence, for HIV positive parents who also have an HIV positive child, finding housing in a location that is within the vicinity of their place of employment and their child’s school is of the utmost importance. The reasons for this are associated with ensuring that they can be with their child in situations where their health is at risk in addition to their need to ensure that their child’s HIV status is not discovered by the school. Again, parents are in the position of making housing choices that they would not have necessarily made if their child was HIV negative in order to protect their safety, stability and knowledge of their HIV status due to fears about their child’s experience of HIV related stigma and discrimination. For Clair, this meant choosing to live in a bachelor apartment where she and her child shared a bed and where her child is unable to invite her friends over to play. As will be discussed further on in this paper, this raises other fears and anxieties for HIV positive parents including concerns about what the school’s administration or child welfare professionals will think about her housing situation.

Finally, there were a number of narratives that demonstrated the ways that the additional issue of racism exacerbated a parents housing experience as it related to safety, stability and stigma. For example, Elizabeth, a black woman from East Africa, shared a difficult time in her housing trajectory. Elizabeth shared her experience of having difficulty in finding appropriate housing following a recent HIV diagnosis whilst at the same time living with depression. However, Elizabeth’s narrative also highlights that she believed that racism was the dominant issue that was affecting her ability to access secure housing. As Elizabeth stated, “*once you’re black they want to put you in the “ghetto neighbourhoods”*”, which resulted in a challenge to her housing worker that she was “*very sorry that this is how you treat people of colour*”. Elizabeth also asserted that this housing experience prevented her from “deal[ing] with the fact that I was positive”, highlighting the way that HIV, poverty and housing intersect and the impact this has on the mental health of individuals who have a history of experiencing racism and who are also living with HIV. This narrative also illustrates the equally pressing issue of prolonging one’s need to come to terms with an HIV diagnosis in situations where there is the more immediate priority of having a roof over their children’s head. This

illustrates the unique needs of HIV positive parents as they navigate their housing and health trajectory.

The intersecting issues of HIV, racism, poverty and housing instability can also be understood through Wanda's experience from the perspective of an HIV positive African immigrant woman in her search for appropriate housing for her and her daughter. When she was asked about her experience of receiving culturally appropriate housing support she answered:

“When I go to the [African/Caribbean] community in which they don't talk about AIDS...you don't really feel comfortable just talking about being HIV positive 'cause of discrimination and stigma. Of course some people, at the first sign any woman mentions that you're HIV positive it's ... everyone disappears in your life, you know?”

Wanda's statement suggests that HIV related stigma and discrimination also exists within the African and Caribbean communities as a result of internalized oppression. This corresponds with research that argues that the racialization of HIV through the media and institutions has a detrimental impact on the African and Caribbean community with regard to openly discussing HIV as well as in creating of barriers to seeking and accessing HIV related services within one's community (Lawson et al. 2006). Consequently, this can result in isolation from one's cultural, racial and linguistic community. However, Wanda also expressed difficulties with the idea of living in an HIV associated housing situation. As Wanda articulates, “Everyone says, in HIV people's building so those labels...sometimes I don't feel comfortable to invite people...it's hard you know?” Hence, living in an HIV designated housing situation made it difficult for her to keep her HIV status a private matter from both her child and her community. The combination of these factors not only resulted in concerns related to accessing safe and appropriate housing for herself and her daughter, but in ongoing feelings of depression because she felt that she “had to” to live in the HIV designated building due to its affordability. Hence, attempts to meet both the need for affordable housing in addition to maintaining confidentiality about her HIV status was not possible. As argued by Lawson et al (2006), this results in feelings of isolation and living in fear of unwanted disclosure.

Child support is housing support

Parenting alone

“I'm the only person who is going to look after those kids”. And you know I basically just sat there and just talked to myself and telling myself I gotta do this”.

Not unlike other single mothers, the burden of doing everything on one's own becomes increasingly exhausting and can lead to feelings of stress, anxiety and depression. Some of the mothers were able to cope with these kinds of feelings more successfully than others as a result of having the external support of parenting groups and friends. However, while this kind of support offered them a place to share their challenges of mothering alone, it did little to offer the kind of practical support that these mothers needed when they were unwell.

Some participants however, received the support of their own parents during times when they were ill. For example, one mother shared a story about “*driving around with a bag attached around my ears because I was throwing up all the time*” while she was raising two small children on her own. Fortunately, she was able to rely on the support of her own parents who would often babysit or cook meals for the children in addition to taking the children under their care during the times she was in the hospital. Hence, HIV positive mothers who are attempting to cope with the episodic nature of the illness may require practical support that will help them to care for their children. These issues are exacerbated by the other challenges facing HIV positive mothers such as uncertainty about the future, HIV related psychosocial issues and barriers to accessing HIV related practical supports. This highlights the connection between mothering with HIV, housing and the need for supportive housing programs such as respite services.

Child and Family Services

“I says what's the best way to find housing if I'm going home now and they told me well talk to somebody over there and we made arrangements. I thought it was just going to be for housing purposes but next thing you know I had Children's Aid getting involved with me when I got back here and I'm like what for?”

While many of the mothers struggled to find and/or access appropriate housing and allied supports for themselves and their children, it appears that other kinds of ‘support’ came looking for them. In Canada, Children's AID or what is more commonly known as Child and Family Services are social service agencies that have a mandate for the welfare of children. One of the main issues that emerged over and over again in the women's interviews was their forced relationship with Child and Family Services in connection to their positioning as HIV positive single mothers. As highlighted above, this relationship developed as a result of the mother's need for housing support. For others, it developed in response to concerns

about the mother’s ability to care for her children as a result of her HIV status. As one woman shared:

“I was very depressed, I was upset. Because like children and family services said ok you’re sick and if you don’t have family how are you going to take care of your daughter? And how are you going to take care of your son? And that really bothered me because when I was diagnosed they didn’t care and then when I got sick all of a sudden my daughter was taken away from me and then my son and that really hurt me”.

These kinds of stories also appear to make their way into the larger HIV positive mothering community, which instills fear and anxiety about the potential of Child and Family Service involvement with HIV positive mothers and their children:

“I’ve heard from other parents’ horror stories about how social workers are called in for absolutely no reason. But they assume that you have a social problem in your family. [If there’s HIV] Yeah, like you just seem to be flagged in a way. And actually it all ties into the housing thing as well because my nightmare is that somehow, some social worker will come into our life and realize we’re living in a junior one-bedroom and that my kid would be taken away”.

These fears can be exacerbated for HIV positive women who are newcomers to Canada. For example, Sharon, an immigrant woman from Africa with one child, shared her frustration of interacting with her child’s school and Child and Family Services in the midst of attempting to balance a range of housing and employment difficulties. As a result of her ongoing experiences with these systems Sharon feels that:

“the system is very discriminating and especially to us immigrants... what I found quite challenging with the system, [is] the fact that I’m an immigrant, and a single mother and a woman with HIV and a black woman was all working against me”.

The consequences of the lack of cultural, racial and linguistic understanding of the complexity of Sharon’s housing needs as an HIV positive mother and newcomer to Canada resulted in an ongoing negative relationship with child and family services. These experiences highlight the interconnection between HIV status, poverty and housing and the impact this has on the way child and family service workers enter into the lives of these families. These issues are exacerbated for HIV positive mothers who are immigrants to Canada, particularly in situations where they are not accessing culturally sensitive services and programs. The consequences of this may be an increase in stress,

anxiety and depression among HIV positive parents regarding the loss of or fear of losing their children. This raises the need for HIV education amongst child and family service workers and teachers in addition to the developing of effective working relationships between AIDS service organizations, the education system, and Child and Families services.

Picking battles

“It’s not a matter of am I comfortable; it’s, this is how I have to live for the moment and this is stuff I have to deal with on a daily basis... So if it’s not the hydro and it’s not the housing where you’re living in, it’s going to be a medication and if it’s not the medication it’s going to be about the food and if it’s not about the food it’s always about something. So it’s just, it’s up to the person to decide that you know, if this is a battle I want to fight, if this is a battle I’m going to put on the back burner... it’s something different everyday so you have to learn to choose and pick your battle”.

All the parents that were interviewed in this study talked about the various “trade-offs” they had to make concerning how and when they spent their money. This often meant choosing between paying the rent, hydro bill, buying food or buying HIV related medications. Furthermore, not only did this have an impact on their overall health as it related at times to not being able to meet their own or their children’s basic needs, but it also had an impact on their mental health. This was most poignantly expressed by one mother when answering the question of how she felt her housing situation had affected her health:

“Sometimes I just wonder if it’s easier not to bother. Just let life and nature take its course because you don’t have to worry about it when you’re dead. Forgive me for sounding callous but honestly do you have to worry about paying [the rent] when you’re dead? No. So sometimes it’s just easier to think like that than it is to like oh I wonder if I can get the hydro money in this week”.

Hence, although many families affected by HIV are housed, many of these families experience “near homelessness” as a result of the many social and economic challenges that they face on a daily basis and subsequently, the choices they need to make about where their limited income will go (Waegemakers-Schiff 2007). The culmination of these concerns can result in feelings of deep depression and a sense of hopelessness about the future.

The future

Every parent who participated in this study had concerns about their children's future. As discussed earlier these concerns are often connected to the parents' living arrangements, housing situations and conditions and the implications they believe this will have on the future of the children's safety, health and happiness. Perhaps the most devastating concern however, was related to their child (ren)'s future in the event that the parent became gravely ill or died. As Susan relates:

“Being a mother, being a positive mother, a single mother, you think about your child, because that's what you live for. But people, they don't really understand; it doesn't mean that because you're HIV positive you don't have plans, don't have pride. HIV's just a disease. It doesn't mean it stops me from thinking; doesn't mean it stops me from going to school; doesn't mean it stops me from working. Just when I wake up every day I'm just like every other mother. And when my child looks at me, I'm the best thing she has in the whole world. But in case something happens, we are living in this house, she's just under my umbrella; She's under me; my umbrella. But if something happens to me, then she doesn't have her home. That's my main concern... What happens to our kids?”

There are a number of key issues that are reflected in Susan's narrative. First, she believes that most people don't really understand the everyday realities of HIV positive mothers. These realities include making plans for themselves and for their children in both the present and future as it relates to employment, education and care giving. Second, Susan also expresses the way that HIV positive mothers are stigmatized as a result of their HIV status through a process of assuming that they “don't think” or that they are not like “every other mother”. Hence, partially as a result of this stigma in addition to the themes addressed throughout this paper, HIV positive mothers view housing as a main concern for their children. This concern is underpinned by their understanding that, in many cases, their children's access to housing is very much about their own ability to secure long-term, affordable housing and more importantly, an appropriate housing situation that will be maintained regardless of the health of the parent.

Discussion

The findings from this study highlight the complex and unique needs of HIV positive parents who live with and care for their children and the central role that housing

plays in their lives. HIV positive parents experience a number of interconnected barriers to living in appropriate and stable housing for both themselves and their children. This includes concerns related to the safety of the neighborhood and/or the building in which they live; the stability of their housing situation as it relates to their physical and emotional safety; the potential for experiencing HIV related stigma and discrimination, and the impact on their mental health. Earlier studies have shown that parents who experience homelessness and housing instability have poor mental health outcomes (Tischler et al. 2007) and this has been supported by the experiences of the participants of this research. Perhaps the most salient issue that emerged from this study, are the multiple day-to-day and future concerns that HIV positive parents live with. This has been documented in earlier research arguing that HIV related losses and the grief associated with it, is often accompanied by stigma and discrimination that may increase the accompanying fear and anxiety of HIV positive mothers (Ingram and Hutchison 1999). For the parents in this study, stigma was experienced on a number of levels and was related to their social positioning as HIV positive parents who lived in poverty and subsequently, in unsafe and unstable housing situations. The losses associated with this stigma and discrimination was most often reflected in relation to their children. This was due to both the reality and/or the perceived potential of losing their children to the child welfare system as a direct result of their housing situation. In turn, the interconnection between grief, loss and depression emerged and was often associated with anxiety about the future. This was mainly discussed in terms of the loss of a parents' own life to HIV/AIDS and the potential loss of housing for their children.

Anxiety, stress and depression were also associated with housing conditions, housing costs, and neighborhood safety. At times, this was exacerbated by the process of attempting to navigate a housing system that did little, if anything to address the housing needs of HIV positive parents and their children. Most parents had to make accommodations that resulted in choosing between an appropriate number of bedrooms for themselves and their children and/or living in unsafe neighborhoods or in shelters. For parents who had not disclosed their HIV status to their children, living in a building, neighborhood, or community that enabled them to protect themselves and their children from the consequences of HIV related stigma and discrimination was particularly important. These issues are compounded by the additional experience of racism as highlighted by participants from the African and Caribbean community, particularly for those who are newcomers to Canada. This is not surprising in light of earlier research that has highlighted the ways government funding has excluded the health and social care needs of immigrant

families in Canada and the constraints this puts on women family caregivers (Stewart et al. 2006). Moreover, HIV positive parents from African and Caribbean communities also face the consequences of discrimination within their own communities in part because of the stigma associated with HIV and the role that this plays in marginalizing African and Caribbean newcomers to Canada more generally (Lawson et al. 2006). This suggests that HIV positive parents from African and Caribbean communities will continue to experience the intersecting oppression of stigma due to HIV status, racism, sexism and poverty amongst other social determinants of health such as gender, sexual orientation and income that negatively impact on their mental health and housing experiences.

The findings from this segment of the Positive Spaces Healthy Places community based research study raises a number of implications for the development of housing policy and practices in Ontario. As reflected in the 2007 report by the Toronto HIV/AIDS Community Planning Initiative (AIDS Bureau 2007), a crucial issue facing people living with HIV/AIDS is the lack of an effective referral relationships between the various sectors that support people living with HIV in all their diversity and at all stages along the housing continuum. One way of tackling this issue will be to develop coordinated program planning and increased communication within and between service sectors in order to influence system change. This could be achieved by developing avenues for increased cross-sectoral work with housing, immigration, mental health, child and family services and education that would include mobilizing multiple sectors and organizations to work together in order to address family need at both the societal and structural level (Stewart et al. 2006). On a micro level of practice, family support interventions would also have a key role to play in supporting families who are at risk of homelessness and housing instability (Tischler et al. 2004). Finally, there is also a call for cross sectoral anti-racist and anti-oppressive education and training on the multiple layers of oppression that are experienced by HIV positive parents and their children including the impact that HIV related stigma and discrimination, racism, sexism, violence and poverty have on the mental health of parents and their children. Hence, what is needed are housing strategies at both the practice and policy level that will lead to more appropriate and effective family based practices on the ground in addition to the creation of health, housing, social service and immigration policies that reflect the multiple needs of HIV positive parents who are living with and caring for their children.

The strength in the present study is the analysis of the parents’ narratives that assists in developing an understanding of the complex, multiple and interlocking issues that are connected to the housing experiences and concerns of HIV

positive parents. The limitations are in relation to the fact that the findings were a part of a larger mixed method study that was not primarily focused on the particular housing issues of HIV positive parents and their children. As such, the sample size is small and the in-depth interview questions were not specifically geared to exploring the complexity of the parents’ experiences. However, the analysis of the findings presented here reflect the range of issues faced by HIV positive parents and supports the need for more specific research that is aimed at understanding and representing their unique housing and housing related challenges.

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