Archives of Women and Mental Health

***“Under My Umbrella”*: The Housing Experiences of HIV Positive Parents who Live with and Care for their Children**

Saara Greene^{1,2}; Ruthann Tucker³; Sean B. Rourke^{3,8}; Dale Guenter¹; Jay Koornstra⁴; Michael Sobota⁵; LaVerne Monette⁶; Steve Byers⁷; Stephen Hwang^{8,9}; James Dunn^{8,9}; James Watson³; Pius White³

¹McMaster University; ²Fife House; ³Ontario HIV Treatment Unit; ⁴Bruce House, Ottawa; ⁵AIDS Thunder Bay; ⁶Ontario Aboriginal HIV/AIDS Strategy; ⁷AIDS Niagara; ⁸University of Toronto; ⁹St. Michael's Hospital Centre on Inner City Health

ABSTRACT

This is the first longitudinal community-based research (CBR) initiative in Canada to examine housing status and stability and its relationship to health related quality of life (HRQOL) for people living with of HIV/AIDS (PHAs). As part of our data collection strategy in-depth, semi-structured qualitative interviews were conducted with 50 PHAs across the province to provide a deeper understanding of the impact that housing instability has on their health. PHAs who live with and care for their children face dire housing, economic and social challenges that are associated with significant risks for poor health outcomes. Poor housing conditions, living in unsafe neighborhoods, lack of access to supports for themselves and their children, HIV related stigma and discrimination, racism, sexism, and poverty have been identified by these families as being among their most pressing concerns. These issues often result in increased stress and anxiety that negatively impact on the mental health of both HIV positive parents and their children.

Background

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 applying for funding through the Ontario HIV Treatment Network (OHTN) that would enable them to examine the housing needs and experience of PHAs in Ontario. Positive Spaces, Healthy Places 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.

Methodology

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. Face-to-face surveys with 605 people with HIV from across Ontario were collected at baseline and at one year follow-up underway to examine: (a) housing status of people with HIV in Ontario; (b) range of housing and supportive housing options available across Ontario, including those provided by community-based health and social service organizations and other housing agencies; (c) variations in housing experiences of people with HIV from specific communities, including aboriginal communities, ethnocultural communities, women, families with children, sexual minorities, youth and ex-prisoners; and (d) the kind of housing options desired or required by people with HIV that will ensure access to, and utilization of, health care, treatment and social services for optimal health. Of the 605 participants, 23% identified as women and 78% of these women lived with their children. Of the women who lived with their children, 86% identified as African or Caribbean. In addition to the survey, 50 of the participants engaged in in-depth qualitative interviews with peer research assistants of which, 13 were HIV positive individuals who lived with and cared for their children. The parents included one man and twelve women. Three of the women identified as aboriginal, 3 as Caucasian, 2 as African, and 2 as Caribbean. The interviews were taped and transcribed and then underwent thematic analysis and triangulation. This paper focuses on our qualitative analyses of the housing experiences of thirteen HIV positive parents living with and caring for their children in Ontario.

HIV/AIDS and Housing Instability

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, 2003). Studies have also shown that most individuals who are homeless have intermittent periods of stable housing (Phelan et al, 1999) and that there exists a range of homelessness and housing arrangements that impact on an individual's experience (Kushel, 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 living in and out of day and night drop-ins, to living in shelters and rooming houses, to having 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 a "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, 2004, Murphy, 2006). Moreover, studies have also shown the ongoing relationship between the quality and security of housing and mental, physical and social health, and that bad 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 cumulates into four main themes that highlight the importance of addressing the health of PHAs within a social determinant of health framework. These are: (1) economic vulnerabilities associated with maintenance of and access to stable housing; (2) access to and utilization of health care and rehabilitation support and services; (3) housing status related to access and adherence to HIV treatment regimens; and (4) housing status related to improvements in clinical indicators of health and health-related quality of life among PHAs (Dunn, 2000). This suggests that when attempting to address the housing experiences of people living with HIV/AIDS, their housing needs 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 'homeless career'¹.

Families with Children affected by HIV

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 from 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 can have only one homeless incident while others experience multiple episodes. 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 more generally, but they also face some unique challenges due to the impact that HIV has on the entire family system. Most of what we currently know about the impact of HIV positive parents and their children as been conducted in the U.S. These families are characterized by chronic poverty, homelessness, multiple losses, substance use, and are often from marginalized communities in terms of ethnicity; Racialized families,

¹ The 'homeless career' of a homeless person is frequently made up of several exits and returns to homelessness interspersed with periods of housing (Anucha, 2006, Wong and Piliavin, 1997).

especially those of low socio-economic status have been particularly affected by HIV and is it mainly women who tend to be the caregivers in families affected by HIV (Pequegnat and Bray, 1997). More recently, studies have shown that families who are affected by HIV continue to cope with discrimination, stigma, poverty, secrets about HIV status and planning for the possibility of parental sickness or death, as well as the everyday issues of life and parenting (Draiman, 2000). Moreover, DeMatteo et al (2002) found that HIV positive parents have unique experiences, concerns and challenges which impact their physical and mental health and quality of life in particular for women who take on the majority, if not all of the care giving responsibilities. These challenges include: financial pressures and concerns; uncertainty about the future; disclosure; psychosocial issues; lack of access to practical supports; and housing. DeMatteo also found that housing presented as a major concern for over 50% of the families interviewed. These issues are often exacerbated for HIV positive women who are living in overcrowded housing or who remain in violent relationships for the purpose of having a place to live (Kappel Ramji, 2002).

These issues when compounded by a HIV positive parent's housing status can lead to short and long term consequences. These include unwanted family separation and/or the involvement of Child and Family Services, 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, 2002). Hence, while interventions that support families 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.

Findings

“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 mothers. These included: sporadic adherence to medication; living in inappropriate and unsafe housing conditions and neighborhoods; involvement with Child and Family Services (CAS); stigma and discrimination; poverty; and concerns about the future. The overarching theme that transcends these issues were the recurring statements reflected in their narratives about how these issues and concerns affected the mothers' mental health.

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”..

There are number of financial and personal costs that impact on an HIV positive woman’s ability to adhere to medication. For many this includes having to make the decision to pay for medication or to pay the rent, the hydro bill and even food. While this is an important issue for HIV positive parents in general, it has unique consequences for HIV positive women even before their child is born.

When asked to share her history of her housing situations from the time of she was diagnosed with HIV Rose, an HIV positive aboriginal woman, shared her long term experience of moving in and out of the apartment she shared with an emotionally abusive partner while she was pregnant with her eldest child. Throughout this period in her life it became clear that Rose’s housing trajectory was influenced by a number of factors. These factors included her having to make a choice between being housed and thus staying in an abusive relationship or to leave the situation, which would render her homeless. Consequently, Rose lived in a constant state of housing instability throughout her pregnancy which, in turn affected her ability to adhere to her antiretrovirals. 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...”

Rose highlights a number of important issues that are significant for HIV positive women who are also pregnant. Echoing Leaver et al (2007), Rose’s personal experience reflects what has already been documented in earlier research that demonstrates how homelessness and/or housing instability can be a significant determinant in a person’s ability to adhere to complex HIV drug regimens, regular treatment and monitoring. Rose also demonstrates how vital it is for HIV positive women to adhere to antiretroviral therapy throughout their pregnancy. This is because non-adherence to antiretroviral therapy can, as in Rose’s case, 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, 2007). Reaffirming a recent study on HIV risk factors for women experiencing sexual violence and dislocation (McKeown et al, 2002), Rose’s experience also highlights how the fear and/or consequences of homelessness maintain HIV positive women in abuse living situations and housing arrangements and/or put them at risk of contracting HIV.

Navigating the Neighborhood

Stigma in the Community

“Like, you’re kind of shunned. People actually cross the street and a walk on the other side of the street”.

In many cases, HIV positive parents found themselves in situations where they had to leave their homes, neighborhoods and communities as a result of HIV related stigma and discrimination. This was most poignantly narrated by Chris, a parent of 2 small children when asked to share the details surrounding their long standing small town community to the rural setting where they currently reside:

“It got down right dangerous. The church had a big meeting [and] some of the things that came back was about whether or not we were going to continue being allowed to go to the church, you know what they need to do to stay away from us, how to separate the children and like the schools called us up, the daycare called us up because the kids were very young so the daycare called us up wanting to know all about their health issues...we were shunned”.

While Chris was fortunate in finding alternative housing quite soon after this incident, the result was living in an area where there are little if any access to HIV related services and supports. As Chris stated, this decision was made for the sake of “privacy...so we can protect our anonymity as far as relationships to the HIV...We’ve been down that road, it didn’t work out well”.

In some cases, HIV related stigma resulted in family separation. As Claire explained when she was explaining why she chose not to live with her daughter:

“I didn’t want to stick around long enough to figure out if everybody knew and for the sake of my own child who is kicking ass there, you know I don’t want to step on that. And they don’t have the proper medical resources there. They don’t have any support groups there. I didn’t have any friends there. It sucked like it really sucked”.

Hence, there are many consequences that families have to face as a result of HIV related stigma and discrimination that are related to their housing. These include the loss of one’s community, neighborhood, and, as a result of fear of further discrimination and in the desire for “privacy”, this can also result in creating barriers to accessing the very kinds of support that HIV positive parents and their children may need the most. Finally, in some cases HIV related stigma and discrimination can also lead to family separation as a way to meet the health and social needs of both parent and child.

Barriers to Resources

“Ever since I’ve had my kid I’ve never lived more than five minutes away from work, and my daughter’s school has always been within a five minute walking radius as well. It’s something that’s just really important to me”

Important resources such as education and employment were often the main criteria of the parents when looking for a suitable neighborhood for themselves and their children. However, the lack of these resources, put parents in the position of having to turn down housing which, in turn put them at risk of losing housing support. As Elizabeth shared:

“There was no school...there was no where for me to work if I was trying to locate a job...so I said no to that one and then they said to me this is your last chance, if you don’t take the next place we show you, we’re not helping you, too bad and you’re going to have to find somewhere else to live and we’re done...”

Moreover, not only was Elizabeth unable to find appropriate housing under supportive conditions, but as a result of this, she was also prevented from come to terms with her HIV diagnosis:

“I didn’t even get a chance to deal with the fact that I was positive, so after all of that mess I kind of sat down and realized what had hit me and how everything was. I was on anti-depressants and I had just started medication too, so this was all when I just moved to the new place...”

It was not until one year after she was diagnosed that Elizabeth eventually found stable housing for herself and her two children. Consequently, it was not until she “settled in” to her new place that she felt able to start coming to terms with being HIV positive. This suggests a link between the stress and anxiety of housing instability and the impact this has on accessing HIV related emotional support. This is particularly important for PHAs who are also living with depression and who must also find the necessary resources to care for their children.

Poor Housing Conditions

“I lived in a smaller town that was not ready to deal with such a disease I guess and the landlord did not understand why after six months of living with mold and whatever that it was more important to get that fixed”.

Due to the lack of affordable housing in all parts of Ontario, many of the participants shared stories about the poor housing conditions that were relegated to living in. As one participants shared:

“After I was diagnosed I decided I was going to move out and get my own place. So I went and I got a space, it was very, very bad. It was covered I would say, with cock roaches, mice, so much in the apartment that you could smell the mice. And on top of all that the heat was not working...I spent six or seven years in that condition...lying in bed at night and they were on my pillow and I was sleeping and you can smell them. You

open your eyes and they were on your pillow. It was that bad. And the kids would get up screaming in the night that cock roaches were running over them you know”.

Hence, as reflected in the above narratives, people living with HIV are often relegated to living in poor housing conditions that put the health of themselves and their children at risk for ill health. As with the general population of people living in poor housing conditions, this is a critical issue because of the negative impact this has on mental, physical and social health (Hwang, 2001). This is a particularly significant concern for people living with HIV because of the impact that these housing conditions will have on their physical health. However, as the quotes above suggest, landlords are either unaware or are insensitive to the negative health outcomes that moldy or vermin infested living conditions will have on the health of their tenants.

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 associated with 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, require times when more practical support is needed to help them to care for their children. These issues are exacerbated by the other challenges that face HIV positive mothers such as uncertainty about the future, HIV related psychosocial issues and barriers to access to 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. 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 (CAS) 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 family and children 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 in turns instills fear and anxiety about the potential of CAS involvement of 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 experiences highlight the interconnection between HIV status, poverty and housing and the impact this has on the way CAS workers enter into the lives of these families. The consequences of this may be an increase in stress, anxiety and depression among HIV positive parents regarding the fear of losing their children. This also raises the need for HIV education amongst CAS workers in addition to the developing of effective working relationships between AIDs service organizations and Children's 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 has 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” (Waegemakers-Schiff, 2007) 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. 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 and 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 the 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.

Conclusions