‘Got a room for me?’ Housing Experiences of Older Adults Living with HIV/AIDS in Ottawa*

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RÉSUMÉ

Le VIH/SIDA et le vieillissement constitue un thème émergent important et pertinent pour la gérontologie. Les expériences des personnes âgées vivant avec le VIH relatives au logement sont encore très peu connues. Le présent article explore cette problématique en examinant les données issues d'entrevues portant sur les expériences relatives au logement de 11 adultes âgés (de 52 à 67 ans) vivant avec le VIH/SIDA à Ottawa (Ontario). Les histoires des participants ont révélé des préoccupations relatives aux trois thèmes principaux: l'acceptation dans les maisons de retraite ou dans les centres d'hébergements de soin de longue durée, le manque d'accès aux logements subventionnés et l'itinérance. Les participants rapportaient ressentir un manque de reconnaissance et de la confusion concernant leurs perspectives d'habitation. Ces résultats suggèrent qu'un changement se produit peutêtre dans les besoins de logement de personnes qui vieillissent avec le VIH. Cette population émergente apporte des défis aux idées dominantes sur le vieillissement. Nous concluons qu'une attention accrue est nécessaire au niveau de la recherche, des politiques et de la pratique pour aborder le problème du logement chez ce groupe d'âge de personnes vivant avec le VIH.

ABSTRACT

HIV/AIDS and aging is an important emerging topic with relevance to gerontology. Currently, little is known about the housing experiences of older adults within the context of HIV/AIDS. This article explores the issue and examines interview data concerning the housing experiences of 11 older adults (52 to 67 years old) living with HIV/AIDS in Ottawa, Ontario. Participants' stories revealed concerns relating to three major themes: acceptance into retirement homes and long-term care communities, barriers to accessing subsidized housing services, and homelessness. Participants reported feeling that they lacked recognition and experienced confusion about their future housing prospects. These data suggest that a shift may be occurring in the housing needs of people aging with HIV/AIDS. This emerging population presents challenges to mainstream ideas of aging. We conclude that increased attention is needed in research, policy, and practice to address housing issues among this age group of people living with HIV/AIDS.

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* The authors thank the research participants who gave of their time. Thank you to Khaled Salam, Susan McWilliam, and Dr. Isabelle Wallach for their contributions, feedback, and support in the development of this article.

This first author of this manuscript received a $1,000 community-based research honorarium jointly from the Ontario HIV Treatment Network and Ontario AIDS Network.

Manuscript received: / manuscrit reçu : 14/12/10

Manuscript accepted: / manuscrit accepté : 04/08/11

Mots clés : vieillissement, SIDA/VIH, logement, soins de longue durée, l'itinérance

Keywords: aging, HIV/AIDS, housing, long-term care, homelessness

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Canadian Journal on Aging / La Revue canadienne du vieillissement 31 (1) : 37–48 (2012)
doi:10.1017/S0714980811000584

Introduction

Little is known about the housing experiences of older adults living with the human immunodeficiency virus (HIV). Although existing research has focused on housing issues for older adults in general, we know of no study that has focused specifically on housing of Canadians aging with HIV, the virus that causes acquired immunodeficiency syndrome (AIDS). Because the importance of HIV/AIDS in conjunction with aging is quickly emerging as an important issue in gerontology, we have examined the housing experiences of 11 older people living with HIV/AIDS (PHAs) in Ottawa, Ontario, and report on those experiences here.

To help answer the question, "How far behind the curve are we?", asked by local AIDS service organizations (ASOs) that provide housing assistance in Ottawa, we outline prevalence and incidence data, research findings on aging and HIV, and relate these to the problem of appropriate housing. We then describe and discuss a pilot qualitative study of how housing fits into the landscape of aging with HIV. Our interview data reveal concerns about acceptance into retirement homes and long-term care (LTC) communities, about a lack of access to subsidized housing services, and about homelessness.

Background and Significance

HIV and Aging

Older adults living with HIV/AIDS are a growing segment of a diverse aging society. In the past two decades, our response to the North American HIV/AIDS epidemic has improved considerably. Although HIV/AIDS in Canada continues to challenge medical and social sciences, developments in long-term therapies such as antiretroviral (ARV) treatments and protease inhibitors (PIs) make it possible for many people to live considerably longer (Antiretroviral Therapy Cohort Collaboration, 2008; Scott & Constantine, 1999). Many PHAs now experience fewer episodes of illness related to primary and opportunistic infections, compromised brain function, and dementia – which means that older PHAs have increased energy to lead their social and sexual lives.

There is also, however, evidence to suggest "accelerated" disease progression for older adults living with HIV (Adler et al., 1997). Justice (2010) has outlined the new paradigm in clinical presentations of HIV among older adults. Staff at Bruce House, an Ottawa-based housing organization for PHAs founded in 1988, report having witnessed emerging issues of aging among AVR-adherent clients for some time. It remains unclear as to what health and social services are required by older adults living with HIV/AIDS, and whether service providers are prepared to address the distinct housing issues of these older Canadians. In particular, we question what the retirement home and LTC situation will look like for this age group of PHAs, and to what extent subsidized housing services may be required for this group.

To date, most research on HIV and aging has defined "older adults" to mean 50 years of age and over, rather than the more widely used cut-off of age 65 and over. This change may be due to a combination of two factors: (a) standard HIV/AIDS-related age groupings observed by national health agencies such as the United States Center for Disease Control (CDC) and the Public Health Agency of Canada (PHAC), and (b) a reconsideration of what is considered older within the context of "premature" aging that has been suggested as accompanying HIV-disease progression (Deeks & Phillips, 2009). Although older adults with HIV make up a small proportion of older adults in Canada, aging with HIV is an issue that affects thousands across the country and is of growing concern to stakeholder communities. This demographic includes two subgroups: PHAs who are aging beyond their sixth decade, and people who become newly infected after their sixth decade. Adults over the age of 50 make up about 10 per cent of the more than 65,000 people reported to be living with HIV in Canada (Public Health Agency of Canada, 2010a). This is comparable to the number in the United States, where a steep increase in prevalence is projected. By 2014, it is estimated that 50 per cent of people living with HIV in the United States will be over age 50 (Effros et al., 2008).

Similarly, older adults make up a large percentage of people whose disease has progressed to AIDS. A person is considered to have progressed from HIV infection to AIDS when their viral load and CD4 cell counts reach levels that allow co-infections to occur (Wooten-Bielski, 1999). Although general numbers of AIDS cases in Canada have decreased over time (due to the effectiveness of ARV treatments), the proportion of AIDS cases among people aged 50 years and older has actually increased, from 16 per cent in 1999 to 22 per cent in 2008 (PHAC, 2010a), suggesting that in addition to living with HIV, a large proportion of older Canadians experience disease progression to AIDS.

The incidence of new HIV infections among older adults is also on the rise. In Canada, annual positive test results among adults 50 years of age and over has risen from 11 per cent in 1999 to 16 per cent in 2008 (PHAC, 2010a). Despite popular assumptions that deny or ignore sexual activity and shared injection drug use among older adults, the transmission routes of HIV among older adults are similar to those of younger adults. Myriad risk factors are associated with older adulthood such as (a) reduced immunity from new viral infections; (b) oral, vaginal, and anal mucosal membrane thinning; (c) multiple and compounded loss including partner loss and widowhood; (d) new late-life relationships; (e) self-esteem, image, and identity issues; and (f) sexual risk-taking behaviours (Eldred & West, 2005).

Although researchers have been aware of HIV and aging since the early days of the AIDS epidemic, the limited amount of research about older adults in the past 25 years has led authors to refer to older adults living with HIV as "overlooked" (Riley, Ory, & Zablotsky, 1989), "invisible" (Genke, 2000), or "unseen" (Emlet & Poindexter, 2004). Those of us experienced in AIDS care view this lack of information as somewhat similar to the information gap that existed about women and HIV in the late 1980s and early 1990s. Several steps have been taken to close this gap, however. For one thing, studies have been conducted with older women and men living with HIV/AIDS in British Columbia, Ontario, and Quebec (Fritsch, 2005; Furlotte, 2009; Robinson, Petty, Patton, & Kang, 2008; Wallach, 2009). Moreover, a focus on the social issues of aging with HIV has been established, particularly within the field of social work (Emlet, 2004; Maclean & Clapp, 2001; Poindexter, 2004). Yet considering the paucity of research in this area, the question of whether older PHAs in Canada experience barriers to safe, adequate, and sustainable housing remains unanswered.

Housing

Stable housing is an important social determinant of health (Shapcott, 2004). Older adults often experience transitions in housing which include a number of options such as owned houses or rental units, subsidized housing, retirement homes, and LTC facilities. In this article, we focus specifically on subsidized housing, retirement homes, and LTC facilities, since these were topics raised by the participants in our study. Housing status is a key determinant of health outcomes for people living with HIV (Leaver, Bargh, Dunn, & Hwang, 2007). "Positive Spaces, Healthy Places", a community-based longitudinal study of housing, reports that in Ontario, about one-half of PHAs have problems with housing (Tucker & Koornstra, 2008). Preliminary findings suggest that compared to younger adults living with HIV, PHAs aged 50 and over are more stably housed, have higher levels of onsite support, have moved less in the previous year, and experience a higher sense of belonging in their communities (Hambly, 2010).

Despite evidence of housing stability among this group, there is evidence that older adults may be poorly linked to sources of community support. Of concern, a large-scale study in New York found that many older PHAs live alone, experience loneliness, and are at risk of isolation (Karpiak, Shippy, & Cantor, 2006). Nichols (2002) reported that older PHAs in West Central Florida accessed housing through ASOs, but none of the study participants reported living in retirement homes or LTC facilities (including nursing homes, hospitals, and palliative care settings). It remains unclear what problems, if any, that older adults living with HIV experience.

Transitions into long-term care often involve tension and instability for individuals and families, as well as the psychosocial concern about the LTC experience, or the "nursing home specter" (Friedan, 1993). These transitions may be complicated by intersections of poverty, gender, race, and sexual orientation. Previous research, for instance, has described the risks of new HIV infections in low-income seniors' housing complexes (Schensul, Levy, & Disch, 2003). Several authors have examined the LTC experiences of older PHAs in the United States (Fox-Hill, Gibson, & Eagle 2004; Wyatt, 1996) and of gay and lesbian seniors in Canada (Brotman, Ryan, & Cormier, 2003; Richards, 2009), but the question remains whether access to these environments is further complicated by HIV/AIDS.

Older adults make up a small proportion of the homeless in Canada. For the purposes of this article, the definition of homelessness we used is "living on the street, in temporary shelters, couch-surfing, or living in a location not meant for human habitation … repeatedly evicted or at a constant risk of homelessness" (Canadian Mortgage and Housing Corporation, 2007, p. 2). Stergiopoulos and Herrmann (2003) found that, since 1997, of the total number of shelter users in Toronto, 2 per cent were over age 65, and 12.3 per cent of adult hostel users were over age 50. Stuart and Arboleda-Florez (2000) estimated that among 250 emergency shelter users in Calgary, 6 per cent were aged 55 years and over. This group is not homogeneous, however; MacDonald, Dergal, and Cleghorn (2007) found differences between newly and chronically homeless older adults, highlighting variability among those homeless within this age group.

Homelessness, irrespective of the person's age, is connected to the risk of HIV transmission, disease progression, and ARV medication adherence (Canadian AIDS Society, 2009); moreover, housing has been posited to be an effective HIV-prevention intervention (Aidala & Quattrochi, 2007). Those individuals who have social support that includes stable housing may fare better in mitigating the risks of becoming infected with HIV (Shubert & Bernstine, 2007). Increasing evidence shows that HIV outcomes improve as people are stably housed. For example, a recent randomized control trial on the effectiveness of a rental assistance program on homeless or unstably housed PHAs in New York City ($n = 630$) revealed improvements at 18 months on housing status, health, and mental health outcomes (Wolitski et al., 2010). Similarly, a housing intervention program was found to have improved the health of HIV-positive homeless people in a randomized control trial ($n = 105$) in Chicago (Buchanan, Kee, Sadowski, & Garcia, 2009).

In summary, previous work has been conducted either on HIV and housing, or aging and housing, but, as of yet, we are not aware of any attempt to integrate these issues in a Canadian context. There is a critical gap in knowledge of the experiences of older adults living with HIV/AIDS. What do older PHAs have to say about their housing? What barriers exist for this group to safe, secure housing? Does social location linked to HIV status, age, gender, race, sexual orientation, ability, and poverty render PHAs invisible in popular discourse about retirement homes and long-term care? Homeless older men and women have been referred to as “aged care’s forgotten people” (Lipman, 2009), and there are also many unanswered questions about homelessness among older PHAs.

Methods

Based on expressed need by communities and service providers for more knowledge about these issues, we have thus developed a pilot study about housing issues among older adults living with HIV. This article is a component of a larger pilot project carried out by Furlotte (2009) which broadly addressed health and social service experiences of older adults living with HIV/AIDS in Ottawa, Ontario. Our study, which was reviewed and approved by the Carleton University Research Ethics Committee, reflects the ontological assumption that social problems have structural roots (Moreau, 1979). Notably, we worked within an axiological value system of social justice-oriented approaches to social work (Lundy, 2004; Moreau, 1979; Mullaly, 2007).

We recruited participants for the study in 2007 through posters placed strategically at a local ASO and by referral to the project by the ASO programming coordinator and case manager. This type of sampling has been previously used in studies with older PHAs (Emlet & Poindexter, 2004; Heckman, Kochman, & Sikkema, 2002). The target age group we selected was 50 years and over to be consistent with current Canadian research (Public Health Agency of Canada, 2010b).

We conducted semi-structured interviews in Ottawa, a mid-sized urban capital of around 900,000 people and from which 13 per cent of HIV diagnoses in Ontario are found (Remis, Swantee, & Liu, 2009). Ottawa is a diverse community with populations living at increased risk for HIV – including gay men, women, people from countries where HIV is endemic, and injection drug users. Poverty is on the increase here, along with a steady annual increase in the use of shelter beds (Alliance to End Homelessness, 2011). Health and social services available in Ottawa include Bruce House, a subsidized housing service for people living with HIV/AIDS.

To participate in our study, participants had to be age 50 or over and living with HIV – there were no other inclusion or exclusion criteria. HIV status was determined through self-report. The 11 individuals we recruited into the study were asked to read and fill out an informed consent form, followed by a demographics and descriptive information questionnaire containing questions regarding age, sex, marital status, education, language, employment, income, overall health, and HIV disease progression (e.g., asymptomatic, symptomatic, AIDS, comorbidities), medications used, and age first diagnosed with HIV. Following this process, participants completed a 26-item inventory which the authors developed to assess participants’ use of existing health and social care services in the community. Participants were offered an honorarium of CAN$20 to participate.

We collected qualitative data through one-time interviews, recorded as MP3s, in which participants were asked to talk openly about their experiences. The exploratory conversation was guided by a previously established interview guide listing potential topics, one of which was housing. Within subgroups (women, gay men, homelessness), many of the same themes emerged until data saturation was research (Tutty, Rothery, & Grinnell, 1996). Member checking was done in vivo by our paraphrasing and asking participants to clarify comments in an open-ended manner. We also gave participants the option to review their interview data at a later date, and one participant asked to do this. Quantitative data from the demographics questionnaire were tallied and summarized. For this article, we summarize some quantitative aspects of the data but focus on the rich qualitative data that gives voice to participants’ experiences.

Our plan of thematic analysis used coding methods of participant interview data that we adapted from Tutty et al. (1996). This qualitative research guide outlined five systematic steps for analyzing qualitative interviews: (a) preparing interviews in transcript form, (b) establishing a plan for data analysis, (c) first-level coding, (d) second-level coding, and (e) interpreting data and theory building. Interview transcripts were anonymized and transcribed verbatim. For each interview, separate password-protected electronic text documents were produced. We conducted a priori, or theoretically driven, coding. First-level coding involved our previewing the data, developing a set of topics, assigning each topic a different color code, identifying meaning units (i.e., sections of interviews containing words, sentences, and statements deemed relevant to particular themes), refining categories, and, finally, deciding to stop (Tutty et al., 1996). The process of second-level coding included "getting a gestalt", or global sense of the themes across interviews, re-reading, fleshing out the themes (similarities and differences between participants), and tying emergent themes to existing literature. The first author then compiled coded data into text documents organized by theme (Tutty et al., 1996).

To assist in meaning-making, we developed a conceptual classification system, in the form of a matrix chart outlining overlap between topics and themes, to explain how topics overlapped and related to each other (Tutty et al., 1996). Data were also represented in an electronic spreadsheet containing horizontal headings of potential themes, supporting quotes, relevance to service experience, theoretical relevance, and implications for practice and policy. Themes, which we labeled either strong or weak, were considered strong if mentioned independently three or more times by participants (Tutty et al., 1996). We analysed weak themes to see if they fit into broader strong themes, and then parsed, combined, and revised themes as necessary to facilitate understanding.

Two of the coauthors subsequently reviewed, discussed, and reached consensus on theme decisions. Community members of the research team who were also experienced service providers contributed their comments on the themes and implications for policy, practice, and the future direction of research. We made several efforts to ensure the findings' trustworthiness, credibility, and transferability. For instance, we strengthened the study by the use of peer debriefing (Erlandson, Harris, Skipper, & Allen, 1993) concerning the methodology, project progress, and interpretation of themes. Further credibility was achieved by our reflecting on journal entries and memos made during and after each interview (Tutty et al., 1996). In sum, we report our findings through a thematic analysis of mostly qualitative interview data that engages in a rich, practical process of interpretive theme identification, systematic coding, and meaning development on the topic of housing and older PHAs in Ottawa.

Findings

Demographics

The study sample consisted of 11 older adults in Ottawa living with HIV/AIDS. Table 1 presents demographic information about these participants including information about their housing status and health. The sample consisted of two females and nine males, with an age range of 52 years to 67 years ($M = 60$). Three of the participants were over age 65 and six were over age 60. Eight of the participants had known they were HIV positive for 10 years or more; three had known of their HIV status between 5 and 10 years. Most (7) participants learned of their HIV status after age 45. Therefore, the sample consisted of participants who, on average, learned of their status in middle adulthood and had lived with this knowledge for 10 years or more.

Participants reported various housing statuses. Three participants reported that they lived in rental units, four owned or mortgaged their own homes, two lived

Table 1: Participant demographic information

Age	Gender*	Housing**	Annual income (CAN)	Income source***	Health status	Reported comorbidities (*n* = 6)
Mean = 60	Female: 2	Rental unit: 3	Less than $10,000: 1	ODSP: 5	HIV- positive and asymptomatic: 6	Hepatitis, thrush, lipodystrophy, Kaposi's sarcoma, yeast, bladder, heart, and e coli infections.
Range = 52–67	Male: 9	Own or mortgage home: 4	$10–25,000: 5	CPP/QPP: 6	HIV positive and symptomatic: 2	
		Living with family: 2	$25–40,000: 2	Private insurance: 3	AIDS: 1	
		Homeless: 2	$40–60,000: 3		Didn't know progression of their disease/Didn't disclose: 2	
		Long-term care: 0				
		Lives alone: 8				

*** No one identified as transgendered or intersex.**

**** Rental unit includes boarding houses, apartments, and could be subsidized or not. "Homeless" means either living on the street, temporarily staying with family or friends ("couch-surfing"), or living in a shelter.**

***** Participants reported accessing one or more of: ODSP = Ontario Disability Support Program, CPP = Canada Pension Plan, QPP = Quebec Pension Plan**

with family members, and two reported being homeless. Eight of the 11 participants reported living alone. The participants were mostly white, of European ancestry, English-speaking, well-educated adults of varying relationship status, incomes, and sexual orientation. Participants reported being gay, bisexual, straight, and two-spirited – that is, a person who has both a masculine and a feminine spirit, according to indigenous aboriginal beliefs. More than one-half of the participants identified as either gay men, bisexual, men who have sex with men, or two-spirited. These participants came from various educational and occupational backgrounds. All but one participant self-identified as being retired. Of the 10 participants that self-identified as retired, the mean number of years since retirement was 11.40.

Given the small sample ($n = 11$), it was not possible to identify any trends in the demographic data. However, by examining housing status of the participants by their income and income source, we found that participants who relied solely on the Ontario Disability Support Program (ODSP) reported the lowest income and the least reliable housing (or lacked housing altogether). Particularly concerning was that the two participants with the lowest annual incomes reported they "did not know" the progression of their HIV disease. The only participant diagnosed with an AIDS-defining illness reported the highest income (CAN$40,000 to $60,000). Only two participants (18%) reported accessing housing services or home care, whereas seven (64%) reported using food banks and eight (73%) reported having community meals (on a drop-in basis). This suggests that food security was an issue for most of the participants.

Common Themes

Several common themes emerged, suggesting participants' concern about access to and acceptance into retirement homes and long-term care. Other themes revealed participants' concern about access to subsidized housing in the city. Several participants indicated they are or were previously homeless, and described living in unhealthy shelter environments. These data are summarized in Table 2.

HIV and Aging in Retirement Homes and LTC Facilities

Access to retirement homes and to LTC facilities was a major concern for many of the participants we interviewed. Many expressed serious worry about having adequate availability of resources and confusion about housing opportunities in environments for older PHAs.

> *Right now, when we talk about housing services and all that, we haven't caught up with the long-term survivors [of HIV/AIDS]… there's still an awful, awful lot of [work] to do… where do we go when we retire?* (Male, 58)

> *I do sometimes think that someday I will be in a residential area for older people and I do wonder, will they let people in who are HIV positive? Will I be able to go to a residential area?* (Female, 61)

> *What happens when you become [a] senior and need the extra care, you know? Is there going to be a place that's going to have a nurse available?* (Male, 66)

> *I think about services that I may require later on – you know: geriatric care, long-term nursing placements, those kinds of issues – and worry … if there's going to be a place with appropriate care.* (Male, 52)

One male participant, 66, asked "Is there ever going to be something available, say an extension of Bruce House – a pipe dream! – or another building just for seniors that have HIV?"

Such comments raise the question of whether retirement homes and LTC facilities are prepared to provide appropriate care for an influx of older PHAs, and whether a community-based alternative exists.

Older PHAs may present unique care considerations for retirement homes and LTC facilities to address needs regarding treatment (e.g., medications, services), intimate relationships and sexual identity, and the mitigation of social stigma. Several participants expressed the view that people living with HIV require specialized health care services.

> *Why can't [PHAs] just go into a hospital or a recovery home or something? [Service providers] don't understand that this is specialized field, and they need the extra care, and they need people [who are] knowledgeable.* (Male, 66)

A female participant, 61, expressed her concern over the availability of alternative therapies for pain management in retirement homes and LTC facilities:

> *A lot of [PHAs] use pot because of the pain. Folks who don't have HIV [are] saying, "I don't ever want to go to a residential area, because I want to keep smoking my pot, and they might not let me, so I'm not going there." So we're a different generation. Residential homes for older people are going to have to make some adjustments as we start coming in … I'm thinking boy, when we start hitting the residential areas, [we're] going to say "Hi, I'm a woman first of all, second I smoke pot, and thirdly I'm HIV positive. Got a room for me?" You know, it might be a real problem.*

The scenario depicted by this study participant suggests that service providers in retirement homes and LTC facilities would do well to consider how they can better accommodate older adults living with complicated illnesses such as HIV/AIDS. In the case of pain management, for instance, housing providers might arrange access to areas that accommodate the safe, legal use of alternative therapies such as marijuana.

Table 2: Housing themes identified by participants

Theme	Participant-identified issues
Acceptance into retirement homes and long-term care communities	Availability, unique care considerations, sexuality, and HIV-related stigma
Access to subsidized housing	Failure to prioritize people living with HIV/AIDS on emergency housing registry wait-lists; income cut-offs
Homelessness	Unhealthy spaces in shelters

Several study participants voiced concerns about heterosexism, homophobia, and being out as openly gay in retirement home and LTC communities. A male participant wondered if LTC facilities would "be sensitive to my issues as a person aging with HIV, a person who is gay." Another male participant asked, "What about [those of] us who have money to go into a retirement home … [say] you have the hots for the old boy, 72, with his walker, you know … So, what about *us*?" This comment makes visible the issue of sexual orientation and intimate same-sex relationships in retirement homes and LTC facilities. This participant predicts: "[I will] go to the grave happy and that pecker of mine is going to get a lot of mileage", reflecting the active sex lives of HIV-positive older adults that are sometimes overlooked, based on the assumption of asexuality coupled with aging. In addition, some participants discussed HIV-related stigma (Herek, 1999). One participant expressed concern about accessing HIV-specific subsidized housing services and running the risk of being "outed" as HIV positive: "I don't want to live in a building where people say 'Now that's an HIV building.' You know … everyone has their own story".

In sum, these comments about the acceptance of older PHAs into retirement home and LTC communities reflect the study participants' very real concerns about a perceived lack of current and future housing prospects. These findings support the idea that members of PHA communities may fear the potential for HIV-related stigma and discrimination (Herek, 1999).

Subsidized Housing

One study participant described the importance of housing for older people living with HIV/AIDS in Ottawa: "Housing is the biggest issue here in the city – affordable, clean housing". Several participants reported that they used subsidized housing either currently or had used such housing at some earlier time in their lives. These participants described the benefits of rent-controlled environments, including improved life stability. In Ottawa, people living with HIV have access to specific housing assistance through agencies such as Bruce House and the AIDS Committee of Ottawa, as well as through public housing services. Ottawa's municipal social housing registry assigns housing based on availability of spaces and client need. Several participants reported inadequate availability of subsidized housing services despite need. For instance, in discussing the future, a male participant, 58, pessimistically predicted, "[We are] going to be with a bunch of street people". Another male participant, 61, who was homeless, reported that in the five years prior to his interview he had experienced barriers to accessing subsidized public housing:

> *I put myself on the list, but I never got to see someone about it … who knows? You think that they would take into consideration that I have HIV, and I am much older. You would think that they would help you get a place a long time ago, you know, instead of playing head games. They don't give you no reason why, they don't even try to contact you, you know.*

This comment identifies a need for improved coordination of wait lists for subsidized housing in Ottawa, an increased sensitivity to possibilities of advanced HIV disease progression with age, and a need to scale up outreach services to prioritize older PHAs who may require emergency placement.

A two-spirited aboriginal man, 61, identified another barrier to accessing subsidized housing support in the city:

> *A lot of it depends on your source of income, like I had put myself on a list for subsidized housing and I think because of my age I got interviewed quite quickly – I think within about a year I had my interview – and then I found out that I wasn't eligible for subsidized housing anyways because of my income level, but if it hadn't been for that I would have had some very economical housing.*

Local income cut-offs for rent geared to income-based housing requirements may exclude people from accessing these services despite their need. Outreach workers may not take into account how much of a person's income is used for coping with HIV (such as complementary therapies not funded by provincial health plans), when calculating program eligibility. By focusing solely on income as a marker of eligibility, the system fails to address access to affordable housing.

These stories suggest a precarious reality for those aging with HIV/AIDS who are concerned about access to subsidized housing. Although subsidized housing that also offers supportive services made a positive difference for several participants, not everyone who needs supportive housing can access it. Intersections of age and HIV status, gender, race, sexuality, and poverty may present barriers to subsidized housing access.

Homelessness

Some study participants reported having experience with homelessness. Two people reported being homeless at the time of interview, two others reported having experienced homelessness previously, and two more indicated that they felt they were at risk of homelessness. One homeless male participant, 54, spoke about the impact of inadequate housing on health and well-being, noting how he felt dehumanized by the fact of being homeless (Freire, 2007): “How many of us are living in rooms and shelters? I mean, give us some dignity for our last years. Give us some dignity, give us something to feel good about, help us to live longer”.

For some homeless participants, having to reside in local shelters was described as particularly difficult considering their physical health problems. One homeless male participant, 61, stated “I’d feel a lot better if I did have housing; [I’m] tired of running around the streets looking for a place to stay. It’s been [a] strain on my head, you know. I worry a lot when I don’t have a place of my own.” This participant’s precarious housing situation produced anxiety or worry. The participant expressed frustration with gaining access to a subsidized-housing wait list. Thus, systemic barriers may prevent this participant from accessing sufficient resources to keep him safely off the street.

Participants who reported having experienced homelessness – either previously or at the time of interview – referred to the conditions within Ottawa’s public shelters that have the potential for worsening health. Both participants who reported that they were homeless at the time of interview reported poor health outcomes related to living in these environments. One male participant suggested that his immune system might be particularly susceptible to diseases when living in the public shelters:

> *I will tell you right now, the longer I live in the shelters, I’m [exposed] to more things. I wake up everyday, and pretty much everyday I got a sniffle, you know. I mean, I’m not saying I’m germless, I can deal with mine, but I can’t deal with other people’s. I constantly get colds, constantly.*

This participant’s description of a germ-ridden shelter suggests that it presents a risk for people whose immune system is compromised due to HIV, and raises health and safety considerations specific to street-dwelling older adults living with HIV in Ottawa. This male participant, who reported living with HIV and hepatitis C co-infection, also described how his environment impedes his recovery from addiction to injection drugs:

> *I can never get clean, I cannot afford to live in a clean environment. I am living on the street and living in a shelter and it’s all around us. It’s very, very hard for me to stay away from the drugs [while] living in a shelter, and I would like to get better. You know, you sit in a barber chair long enough, you get a haircut. Living there is virtually impossible.*

Together, these participants’ stories of unhealthy living conditions provide further evidence of housing as an important determinant of health (Bryant, 2004).

Discussion

The need to acknowledge housing issues faced by older adults living with HIV/AIDS was evidenced by concerns our study participants raised over being accepted into retirement homes and LTC facilities, having access to subsidized housing, and enduring homelessness. Participants’ confusion over the availability of competent care, and their concerns about discrimination in aging environments, suggest that a strategy to address these issues is either lacking or poorly marketed in our society. These data further suggest that a lack of recognition (Young, 1990) and social exclusion (Galabuzi, 2004) are reflected in social housing practices and policies. These data support Emlet’s (2006) finding of the particularly problematic intersection of HIV-related stigma and ageism at play in the lives of older PHAs.

We have drawn upon work on intersectionallity (Hill Collins, 1998) and multiple forms of jeopardy (King, 1988) to better understand participants’ concerns as they relate to age, HIV status, race, gender, and sexual orientation. Participants articulated their housing experiences as intimately linked to intersections of these factors. During interviews, participants referred to social structures that are institutional (e.g., social welfare programs, the local social housing registry, and shelters) and ideological (e.g., ageism, HIV-related stigma, and heterosexism). The structures that participants cited fall within the theories of structural social work (Moreau, 1979; Mullaly, 2007). These structures may construct, shape, and reinforce inequitable social housing outcomes. There is a need to further examine how these structures impact the experience of aging with HIV/AIDS, and what structural change is required to achieve social justice vis-à-vis improved living conditions for PHAs.

The stories of these participants reinforce the need to increase the visibility – in policy, research, and practices – of older adults living with HIV/AIDS. Canada may need to follow an example from the United States by scaling up policy and assistance programs on the basis of evidence that reliable housing equates to HIV prevention and care (Shubert & Bernstine, 2007). This especially needs to be the case in integrating people living with HIV – no matter what age, gender, race, socioeconomic status, or sexual orientation – into mainstream policy discourse on LTC and social housing in Canada.

It remains unclear just how far behind the curve housing agencies are in addressing HIV and aging. Local housing ASOs in Ottawa first offered help with transition housing in the 1980s and early 1990s; then they shifted to offering help with compassionate hospice care and, in the early 1990s, with permanent housing. It is possible that this small sample in our study reflects a shift in health prognoses over the past two decades for Ottawa's PHA communities. This shift may require transition from traditional AIDS care to mainstream retirement homes and LTC communities. Canada's allied health care professionals will play a major role in the development of best practices in partnership with aging PHAs. In their work formulating strategies to help clients secure stable housing, social workers' role also encompasses services such as intake, case management, advocacy, discharge planning, counseling, support, and community referral. Accordingly, compassionate understanding and knowledge of aging with HIV will be essential prerequisites if social workers are to respond effectively to the needs within these communities.

Our study had several limitations. Chiefly, the findings about housing and individuals with HIV/AIDS discussed in this article emerged as a secondary theme out of a larger research project that did not focus on housing. On the basis of these findings, we are developing a more focused interview protocol that addresses issues of housing specifically (including detailed housing history and expanded topical probes). A second study limitation is its small sample size which impacts the transferability of our findings. Persons who regularly access community-based ASOs were over-represented, and therefore this research likely does not address housing experiences of people not linked to such services. What's more, the oldest PHAs may not use the services of local ASOs, and as they may be the most isolated individuals in a community, their housing experiences might paint a far different picture. Recruitment of such individuals into future research study, therefore, is a future goal.

A third limitation was that, because we recruited participants who were community dwelling, the present study did not specifically address issues of older PHAs residing in retirement homes and LTC facilities. AIDS hospice care is a critically important service in Ontario, although it was not mentioned by the participants. Research needs to be conducted in all of these environments to improve our understanding of HIV and aging. Further study is needed, also, to determine the uptake and effectiveness of HIV prevention strategies such as housing, education, and condom distribution for older adults in community retirement homes and LTC facilities.

The prevalence of homelessness among the study participants was of concern and merits further study. We do not know to what extent older PHAs experience homelessness in Canada; homelessness in general impacts ARV medication adherence (Canadian AIDS Society, 2009). Recent evidence suggests older adults are more likely to adhere to their HIV therapies (Justice, 2010; Sherr et al., 2009), although it is unknown how homelessness impacts access and adherence to HIV medication among older adults. It is unclear how realities of aging with HIV and homelessness are linked, or how they might interrelate. Considering the risk of social isolation among older PHAs (Karpiak et al., 2006), the role of family and social support must be further explored. Future research should also acknowledge gender and culture.

By studying individuals with an age range of 52 years to 67 years, we were unable to generalize findings to the standard "older adult" category of age 65 and over. The use of the 50-years-and-older age range as indicative of older adulthood is not typical of research on aging, which traditionally posits older adulthood occurring later in life. However, using 50 years of age and older seems to be an emerging trend in research with this particular population (PHAC, 2010b). People living with HIV/AIDS make up a small proportion of older adults in general – it is likely that people living with chronic illnesses other than HIV are also marginalized in similar, albeit less stigmatized ways. HIV is a disease that carriers with it connotations of socially stigmatized behaviours – including sex and shared injection drug use. Gerontologists may lack complete knowledge of these issues as they pertain to older adults, which could present challenges for situating HIV/AIDS within mainstream research on aging.

This pilot study reveals how some older adults living with HIV feel they lack recognition and are excluded from a community's mainstream discourse on housing. Because the sample was so small, it is unknown whether these participants' stories are congruent with other older PHAs in Ontario or across Canada without additional research. Examples from this pilot study provide a rationale for more age-specific exploration of larger data sets. We recommend the establishment of community advisory boards consisting of older PHAs, loved ones, and service providers to prioritize research questions pertaining to issues of housing so as to reflect the principle of greater involvement of people living with and affected by HIV/AIDS (UNAIDS, 1999). Advanced age and HIV seems to be a largely western phenomenon and is not yet the case for people living in HIV-endemic countries. Research is needed to explore the politics of this difference. Access to AIDS care should be improved globally.

This research was exploratory in the sense that a small collection of community-dwelling participants' stories were analysed for anecdotal evidence of housing experiences. We believe this pilot study identifies the need to further examine how aging and HIV/AIDS intersect with housing, a key determinant of health.

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