March 2016

WOMEN HIV & AGING
A FIFE HOUSE LED STUDY

"I am a human being, but I don't have human rights"

About

Women aging with HIV are subject to unique health experiences and health care needs. The issues of women aging with HIV continue to be marginalized and subordinated within HIV research, policy, service provision, and program development. There is an immediate need to address this issue; in 2008, 15.8 % of positive HIV test reports were older Canadian women (PHAC, 2010-HIV/AIDS EPI updates). While this study has paid particular attention to the emerging housing challenges for women aging with HIV, a number of other challenges have also been highlighted.

Study Objective

- To identify the individual and structural barriers to social support and health care services that women aging with HIV/AIDS experience.
- To understand the housing experiences of women aging with HIV.
- To explore the issue of stigma as experienced by women aging with HIV/AIDS.
- To document the variation in experiences of aging aboriginal, visible minority and other women living with HIV.

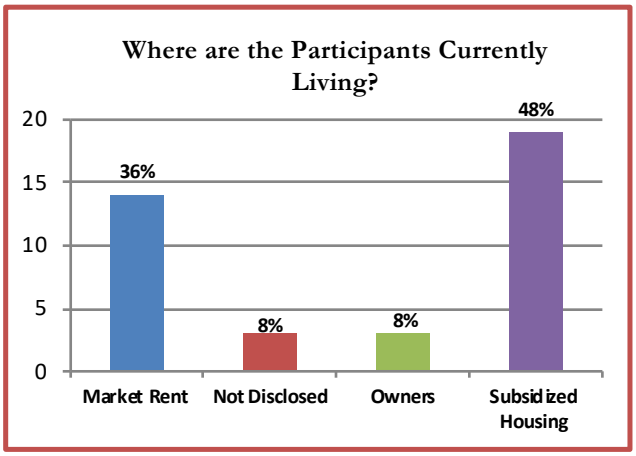
In-depth interviews (39) were conducted over the span of 12 months with:

- Individuals who identified as women
- 40+ years of age
- Living with HIV
- Living in Toronto or the GTA

"I put my application into housing connections 10 years ago…and up until now they still do not have a place for me to live. And the place (where) I live now, every winter time I could not afford the hydro bill…sometimes (I) only have electrical baseboard heater …one time it was very cold and …it cost me $900 …so I was totally broke for that year. For the following year, I did not turn it on much…and then ended up with pneumonia. So now I end up with pneumonia every winter time…".
(Participant, 59 years)

Ethno-racial Identity and Age of Participants

	Age of Participants					
Ethno-racial identity	40-45	46-50	51-55	56-60	61+	Total
African/African- Caribbean	7	6	4	3	0	20
East Asian	0	0	0	2	0	2
South Asian	2	0	2	0	1	5
Hispanic/ Latin American	0	1	0	0	0	1
Aboriginal	1	1	3	0	0	5
Euro-Canadian or Caucasian	1	2	1	1	1	6
Total	11	10	10	6	2	39



Experiences of Physical Violence and/or Sexual Assault/Abuse

Thirteen (33%) of the women related experiences of some form of violence: physical and/or sexual. Of the thirteen, seven (54%) related experiences of sexual assault or abuse.

"…emotional issues stem from a violent relationship that I had before I came here, and it's left me with scars…you can do all the therapy in the world, but once you're scarred it's difficult to recover. You're scarred mentally and physically."
(Participant, 54 years)

Findings

Older Women (50+) Aging with HIV

1. Older women aging with HIV struggle with current housing situations and fear their future housing will not be affordable, safe, or meet their health needs.

- Participants experienced anxiety over where they will live as seniors.
- Long waitlists for subsidized housing made older women vulnerable to precarious arrangements (e.g. basements, absence of lease agreements, areas with limited service access) rendering them even more vulnerable to health instability.
- Older women experienced anxiety over safety and inadequate sanitary conditions within buildings/units.
- Racialized older women experience additional challenges due to limited access to culturally responsive housing and services (multi-generational families, intersectional stigmas etc.).
- Need for basic amenities (e.g. laundry) within the units vital for seniors due to foreseeable decline in mobility in the future.

2. Older women aging with HIV experience multiple levels of stigma and discrimination.

- Stigma and discrimination due to ethnicity, gender, age, and HIV experienced by women.
- Physician initiated conversation about sexual activity diminished based on advancing age (sexually reproductive age).
- Selective disclosure was predominant among older women especially from ethno-racial groups, due to fear of stigma and discrimination.

Stigma and discrimination create structural barriers for women aging with HIV– from acquiring housing, to receiving medical care, and building meaningful relationships.

"They made me feel like I had some kind of a plague. There were signs outside my hospital room that said 'hazard'". (Participant, 50 years)

3. Forming new intimate relationships a challenge for older women aging with HIV.

- Fear of disclosing their HIV status and infecting non-PHAs prevented older women from entering into/searching for new intimate relationships.
- Cultural influences and social expectations related to age restrict new intimate relationships.
- Experiences of violence in the past continued to impact current interactions, desire or ability to build trusting intimate relationships for older women living with HIV.
- Aging (and long term effects of ART) contributes to negative body image, influencing self-esteem and confidence.
- The need for emotional intimacy and a caring/understanding partner supersedes sexual intimacy.

"They don't want, you know , want [you]to have a boyfriend, even your children. They will say 'ha, you're older now, you're not supposed to have a boyfriend.' You see, they don't want to see you with men because they think you're older so you're not supposed to do that".
(Participant, 59 years)

4. Financial hardships faced by older women aging with HIV undermine their ability to support themselves and their families.

- Age was a deterrent in obtaining employment, causing financial instability.
- Inadequate social assistance, along with limited affordable housing options, hindered the ability to support families and negatively impacted the quality of life of older women living with HIV.
- Age related discrimination prevented older women's (re)entry into work, challenging their financial stability and subsequent access to adequate housing.
- Limited opportunities to upgrade education created barriers to financial independence for older women living with HIV.

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Acknowledgments

We thank all the participants whose cooperation made this study possible.
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Recommendations

1. Housing Service Providers

- Advocate for greater recognition at federal, provincial and municipal levels for affordable housing as well as health and income assistance issues of older women living with HIV.
- Explore creative solutions to house multi-generational households. Further advocate governments to incentivise construction of such units.
- Explore creative solutions to accommodate accessibility issues of women aging with HIV within their homes.
- Collaborate with specialized service providers (e.g. geriatric services, mental health) and engage older women in development of their care plan, unique to their needs.
- Collaborate with AIDS Service Organizations (ASOs) and Long Term Care facilities to build an agency culture that is well informed about the issues of older women living with HIV.
- Develop a culturally sensitive process for coordinated access to housing and health care system.

"What happens if my kids aren't going to take care of me? Am I put into a senior's home, then what happens? We should have something for [older] people living with HIV as well." **(Participant, 54 years)**

2. Healthcare Service Providers

- Primary care providers should develop best practice models to discuss sexual health practices, effects of HIV medications on physical appearance and accelerated aging with older women living with HIV.
- Develop collaborative support models, engaging trained allied health care providers (e.g. social workers, nurses, nurse practitioners) to support older women living with HIV.
- Health care and service providers should align their support models to an 'aging at home' strategy.
- Local Health Integration Networks (LHIN's), Community Care Access Centre's (CCAC)and community support organizations must recognize the needs of aging HIV female population and develop collaborative interventions to address their challenges.

3. Other Service Providers

- Develop collaborative support models, through partnerships, to address issues of trauma amongst older women living with HIV.
- Explore creative strategies for peer directed social engagement activities for older women living with HIV to address issues of isolation.
- ASOs should collaborate with support service agencies for older women recovering from sexual violence, rape and intimate partner abuse.
- ASOs must collaborate to develop mobile outreach to address the issues of older HIV+ women.
- Create collaborations with employment training services, to facilitate access to resources and skill building opportunities for older women living with HIV.

" This group is only for women with HIV and you talk about it…without being judged, I feel great. because they are all from different walks of life, sitting at the table…we talk about many things..and it is nice, I like going". **(Participant, 60 years)**

4. Research

- Conduct further research on the housing and support needs of older women living with HIV providing care (e.g. caring for children, grandchildren, elderly parents).
- Conduct strengths based review of existing housing models to identify best practice components to support older women living with HIV.
- Develop a strengths based KTE proposal to identify solution-focused strategies for older HIV+ women, through inclusion of their voices.

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