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## About the Pacific AIDS Network (PAN)

PAN is a pro-active member-based coalition that provides a network to promote and enhance the efforts of its over 40 member organizations to respond to HIV, hepatitis C and related issues in BC. PAN facilitates communication and the sharing of best practices, and provides professional and workforce development and leadership training to its members and people with lived experience from across BC. PAN acts as a voice for the community-based response to the HIV/AIDS and hepatitis C epidemics. It provides face-to-face opportunities for networking and mutual support, education and skills development, evaluation support and capacity building. PAN promotes and carries out community-based research (CBR) and undertakes collective action to influence public perceptions and policies affecting persons living with HIV/AIDS, hepatitis C, and those most at risk.

## Background

*Positive Living, Positive Homes* (PLPH) is a longitudinal, qualitative, community-based research (CBR) study examining the relationship between housing and health for adults living with HIV in three BC communities (Prince George, Kamloops, and Greater Vancouver). The objective of this analysis was to explore the factors that interacted with HIV disclosure (sharing your HIV status with others voluntarily or involuntarily) in housing and service access situations, as well as people living with HIV's (PLHIV's) experiences, both positive and negative, following disclosure.

## Methods

Between June 2015 and October 2017, in-depth, semi-structured interviews were conducted with 99 adults living with HIV. In order to trace participants' experiences with health and housing over time, follow-up interviews were conducted one year later. These interviews explored PLHIV's experiences accessing housing and other services since being diagnosed with HIV, and how these experiences have influenced their health and well-being. Interview transcripts were team analyzed, and included "data parties" in each participating community. This analysis on the relationships between stigma, housing/service access and disclosure was performed collaboratively by the authors.

## Results

For PLPH participants, disclosure experiences were complex—with both positive and negative experiences related to disclosure reported by participants across various housing and service access contexts. The complexity of experiences and decisions about HIV disclosure were compounded by many intersecting factors that influenced them, including: geography, aging with HIV, religion and spirituality, cultural background, and intersecting stigma.

## Intersecting Factors

- ★ **Cultural background:** Several participants shared that their cultural background, or being part of a smaller cultural minority community, affected their fear of explicit disclosure (due to their perception of a higher level of HIV stigma within their communities) and implicit disclosure when accessing HIV-specific housing and services.
- ★ **Intersecting stigma:** Many participants shared that their fear of HIV stigma following disclosure was compounded because of other intersecting stigma that they experienced related to other parts of their lives or identities, including: using substances; race/ethnicity; and identifying as a gender and/or sexual minority.
- ★ **Geography:** Many participants spoke about how their geographic location (within the province, or within particular neighborhoods) affected disclosure risks and chances of unwanted implicit disclosure. Many participants pointed out that stigma and implicit disclosure were of more concern in smaller communities compared to a larger centre like Vancouver.
- ★ **Religion and spirituality:** Overlapping with cultural background, some participants shared that their fear of disclosure was affected/enhanced by certain religious beliefs (held by themselves or others).
- ★ **Aging with HIV:** A common story shared by participants was an increased comfort with disclosure that came with increased age and more time living with HIV. However, there were counterexamples. Some participants spoke about learning to limit disclosure over time as a self-protective mechanism and others mentioned a particular fear of encountering stigma in seniors housing.

## Conclusions

People living with HIV navigate complex contexts and may face positive and negative outcomes when their HIV status is shared or disclosed. It is important that people living with HIV have self-determination regarding if and when they disclose their status, and that they have choice about whether or not their HIV status will play a part in their housing. It is also important that people living with HIV understand their rights around disclosure when accessing housing.

## Positive Experiences

shared by participants about disclosure when accessing housing and services

Greater level of access to HIV-specific and other needs-based housing and services

"That was really exciting having people -- to feel like they were on my side, and to help connect me with some services that I was having difficulty reaching out to, like finding treatment or, or worrying about my, my HIV health."

"Because I live in a suite for an HIV positive person. So I couldn't live there were not HIV positive."

Receiving higher quality/ less discriminatory services when accessing HIV specific housing and services

"That's where they got the [clinic with HIV specialty] and the doctors who know what they're doing and you don't get treated like garbage. You really don't."

Greater level of understanding and support from others, particularly during periods of poor health

"It's just if I need help getting around, or somebody to carry my bags, they're very helpful that way."

Empowerment and increased opportunity for community connection (e.g., built in community in HIV-specific housing and services, volunteering/work opportunities within the HIV community)

"And if we keep it all in secret to ourselves, then how can we learn and grow and evolve through these things if we -- everyone keeps a secret about everything? That's why I've not been shy about sharing with people now."

"But I just want -- because it's not -- it's lonely living there by myself. There's nobody I know in the building. So I'm really hoping to try and see if I can get into IHIV-specific housing!"

Disclosure as a technique for deciding who to live with

"With me I tell them. I don't hold nothing back. If you're going to say ... *inaudible* ... then fine. Then I don't want to live there, right."

## Negative Experiences

shared by participants about disclosure when accessing housing and services

Losing or being denied market housing, employment and potential roommates after disclosure (which present further barriers to affordable housing)

"The landlord called me and said no, sorry, that apartment has been taken, and don't bother going to the other building because we don't have anything for you."

"I think that corporations, organizations, mainstream organizations, business, restaurants all different types of businesses. I don't think they're open to hiring someone who is living with HIV once they've disclosed."

Unwanted implicit disclosure when seen accessing HIV specific housing and services

"It's this internal wrestling match for them because they have a place where they feel welcomed and a community -- a built in community. It could be quite insular. But when they're out on the street and they're walking towards their IHIV-specific housing building they get this rise of anxiety or shame that somebody, who they don't want to know -- they're disclosing their status every time they go into their home. And so that can be dangerous on many levels."

"... but my concern is having whole buildings that are just known as the HIV building. That creates a petri dish of where stigma can really grow quickly."

Poor/discriminatory treatment in housing and services

"but I've got treated like a piece of shit in there. I hate that shit, you know, like don't stereotype me man, you know there are some really good doctors in there ... I'm a person anyways, no matter what. Then there's one's that are just like ... eww ... she's HIV positive, so she doesn't exist in society."

Feeling defined or constrained by HIV

"I'm not ready. I don't want the virus to have that much control over my life, to limit me in such a way that I can't go and do whatever I feel like in terms of work, in terms of dealing with people and interacting with people. I don't want those constraints."

Decreased sense of control and personal privacy

"I think that's more my concern. Because you're telling people, then pretty much you're giving them free reign to do whatever they want with that information that you've given them. That's more my concern. I'm not really concerned anymore what they're going to think. It's really more of what they're going to say to other people in terms of privacy."

Unwanted disclosure by third parties without consent (e.g. social worker, housing staff, insurance company)

"The social worker here told [a third party], which she had no right to do.. I don't understand why they had to put my kids through that."

## Intersecting Factors