

“You got five strikes there already”: Characterizing the lived experiences of older people living with HIV in Ontario, Canada through community-based research

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Background

PANACHE (Preferences and Needs for Aging Care Among HIV-Positive Elderly People) is a community-based, participatory research program aimed at describing the self-reported healthcare and social support needs and preferences of older people living with HIV in Canada. The objective of this pilot project was to characterize the lived experiences of a diverse sample of older people living with HIV from Ontario communities.

Recruitment and Sampling

Community-based HIV organizations engaged as project partners facilitated recruitment using passive methods. Purposive sampling ensured the inclusion of communities disproportionately affected by HIV in Ontario.

Data Collection and Analysis

Descriptive analysis summarized demographic data collected from a written survey.

Qualitative data was collected during 2-hour focus groups co-facilitated by pairs of trained older people living with HIV. A semi-structured interview guide was used, facilitating discussion on seven themes: social supports and stigma; sexual health; physical health; mental health; housing; food security; and finances. The focus group discussions were recorded and transcribed verbatim.

The DEPICT model for participatory qualitative health promotion research analysis informed codebook development, coding, thematic analysis, and collaborative interpretation.

PANACHE ONTARIO AT A GLANCE

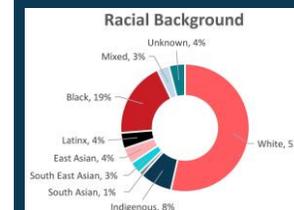
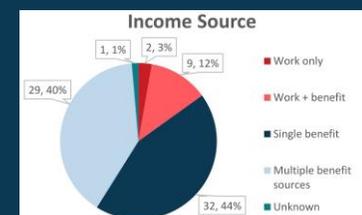
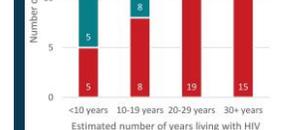
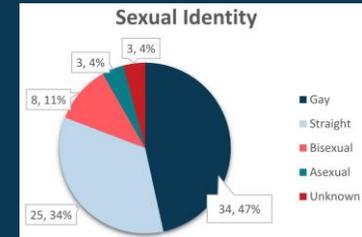
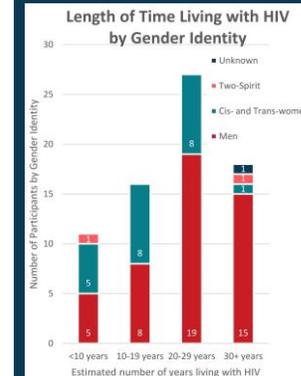
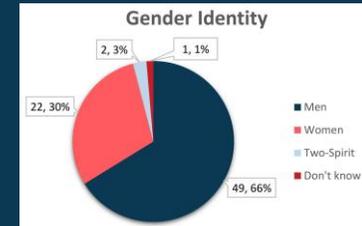
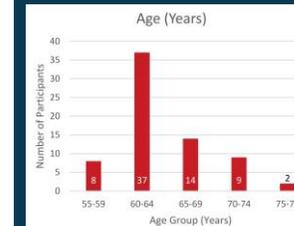
Community-based participatory research project
9 focus groups • 7 municipalities • 73 older people living with HIV
Mean age of participants = 64 years
Median time living with HIV = 23 years (range 2-37 years)

For more information, email: kmurzin@realizecanada.org

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To all the PANACHE Ontario Research Team Members, Peer Researchers and Research Participants: we offer our sincerest thanks for your time and willingness to share your experiences and expertise.

Participant Characteristics



* The total number of responses graphed is not always equal to the total number of study participants. In some cases, participants did not respond or provided >1 response.

Results

Numerous questions about future health and care, and several factors that detract from present-day well-being, including resource insufficiency, gaps in support, and intersecting forms of stigma, emerged through this research.

Resource Insufficiency

Most participants relied on income support programs and/or pension(s). Many struggled to afford adequate food, shelter and health-related resources, especially those living long-term with HIV.

Creative strategies for making ends meet were shared.

“I try to eat out at free meals, community meals...”

“I see people on ODSP that line up every month at that payday loan up the road just like myself.”

“I don't have a payment for Internet every month. So I have to use the public library...”

“I had to leave, I was so sick I was incontinent at my desk in 1990. My pension from 14 years of working on The Hill, is \$800 bloody measly dollars a month.”

“I'm sitting here starving, not being able to eat, with a landlord keeps threatening to evict me every other day, I'm not in a place where I'm healthy, I can't be healthy in this environment.”

“And heaven help you if you catch a cold, or anything, 'cause you don't have resources for that. You don't. You have to hope that there's something that's covered so the doctor can give you prescription that the government hasn't changed that one now...”

“But I think what scares me the most is if something happens to my partner, I know I'm going to be out on the street because I have not worked enough in my lifetime to get anything on old-age pension and CPP. I will be living below poverty line...”

“...unless there was a geared to income place where you had a shared room with 13 other people. I'll be in a lot of trouble. And that's unfortunate.”

Gaps in Support

HIV/AIDS-related loss, disclosure-related estrangement, and/or internalized cultural norms about intimacy were frequently mentioned as experiences having lasting negative impacts on participants' social networks.

While many said they rebuilt or maintained a reliable support network with their local community-based HIV organization playing a central role, some participants described being alone or lonely. About two thirds lived alone and many reported difficulties carrying out day-to-day tasks necessary for independent living.

“...you start to get a little fearful 'cause you're living alone like what the hell's going to happen, you know there's no money to get anybody to come in and do anything...”

“I have been HIV for a very extended period of time, and have lost a lot of my connections, people have died. Period, that is our reality. As an individual, you don't have that sort of formative relationship with new people. So the dynamics in terms of looking for support from them is a bit different, it almost is nonexistent. So you have to rely more on whether they are good agencies that you're connected with, whatever family members are remaining...”

HIV Stigma, Ageism and Ableism

Participants frequently mentioned experiences of HIV stigma, homophobia, and racism from family members, employers, service providers, and strangers across the life course.

“You know, and so that is one of my greatest concerns, getting to that age where you're so defenceless, like, you have no form of defence, and the people who are supposed to take care will make sure that you're safe, are not concerned.”

Older people living with HIV described feeling increasingly vulnerable to violence and neglect with age, and invisible to political decision-makers. Many older people living with HIV voiced rejecting HIV stigmatization, but several narratives suggested internalized ageism and ableism continued to affect them.

“Just even to dress yourself, like, it's impossible, I have to lay on my back, roll around my bed like a beached whale trying to put my socks on. And that's... like, that's embarrassing, like, to me it really is embarrassing.”

Conclusions

Older people living with HIV in Ontario have developed diverse personal strategies for aging that lessen, but do not eliminate, the negative impact of interpersonal losses and systemic inequities experienced while aging with HIV. This data will inform both the development of a national survey, and the creation of practice and policy recommendations to improve the quality of life of older people living with HIV in Canada.