“I’m Positively Positive” – Exploring how Older Adults Living with HIV maintain resilience

Antonio Marante, Claudette Cardinal, Patience Magagula, Sharyle Lyndon, Anna Vorobyova, Surita Parashar*

The Thrive Project, BC Centre for Excellence in HIV/AIDS

Prepared for the 30th Annual Canadian Conference on HIV/AIDS (CAHR 2021)

We acknowledge with gratitude all the participants of the Thrive study – those who are living and those who have gone on to the spirit world – who have shared their stories with our team in hopes of supporting research projects that will make a difference in their communities.

~Thrive team.

*We have no conflicts to disclose.

Is a Community Based Research study conducted on the traditional, ancestral, and unceded homelands of the territories of the *xʷməθkʷəy̓əm (Musqueam), Sḵwx̱wú7mesh (Squamish) and Səl̓ílwətaʔ (Tsleil-Waututh) Nations.
Background

• Life span of older adults (>50 years) living with HIV (OALHIV) and virally suppressed approaches that of the general population;
• OALHIV have distinct physical and mental health needs as compared to their HIV-negative counterparts
• Stigma and discrimination prevents OALHIV from accessing non-HIV specific services
• Resilience improves HIV-related health outcomes for PLHIV (CD4 count, clinic attendance, viral load) (Akilah et al. 2018)
• More research is needed to identify the sources of adversity and resiliency among PLHIV

Methods

• Study objective: How does aging with HIV affect well-being of OALHIV?
• Strength-based participatory research design
• Peer Research Associates (PRAs) and study coordinator co-conducted 27 qualitative interviews with OALHIV
• Sample questions: “How does aging with HIV affect your mental and emotional health?”, “How would your life be different if you had all the services you need?”
• Resiliency identified as a theme of importance by PRAs who wanted this question to be answered: “What are the sources of resiliency for OALHIV?”

We define resilience as “positive psychological, behavioral, and/or social adaptation in the face of stressors and adversities (Fletcher & Sarkar, 2013)”
Resiliency – Extrinsic sources

- Someone to talk to;
- Trusting relationships with care teams;
- Community and personal networks supports;
- Peer support (both informal and formalized);
- Support of AIDS service organizations.

“Also, I am just meeting my birth family, it’s a great thing for Facebook because I wouldn’t have known my birth family. And being First Nation and being raised White, I had nobody around. So, now I’m meeting family. Actually, I just went out with my niece the other day and I had like 20 people of my birth family, and it’s like, wow.” (Participant A)

“I didn’t really have the energy and the wherewithal to really reach out to service workers or things like that, until it got unmanageable, like really unmanageable. Then, I talked to my doctor and through him I was able to reconnect with that agency and then carry on. And, they offered me the services.” (Participant F)

“My doctor ... I think it’s just that she’s worn out of her service. She’s ready to retire and she has done a good job downtown. I really appreciate what it was, that they brought a lot of people to life. They are here for that reason, the home care support.” (Participant H)

“I have many friends that are Christian to help me and a lot of people in recovery that are helping. And, of course, I have the centre. Yeah, I have a lot of people to come and help me out. If I need help, I’ve got people that want to help me.” (Participant A)
Resiliency – Intrinsic sources

- Setting boundaries in the care they want to receive;
- Knowing their aspirations and needs;
- Physical, mental and emotional self-awareness;
- Substance use recovery;
- Optimism and self-efficacy
- Acceptance of HIV diagnosis and rejecting the HIV stigma;
- Cultural and religious or spiritual practices.

“I don’t feel old. I feel better because it’s another year that I cheated death. It makes me realize that HIV is not a death sentence. Back when I got it in ’94, it was they gave me five years. Well, it’s 2020.” (Participant B)

“I don’t like to be greedy. I take only what I need, and I don’t take no more. I leave it for somebody that might need it.” (Participant G)

“...in all the equations that they’re working out, they’re missing that one element, the purpose to go on. And what does that look like? It could look like a million and one different things.” (Participant C)

“R: I’m going to be 60 here, I have been with AIDS for how many years now? Since I was 27 years old. Well, I guess it’s not really affecting me so much, you know?

M: Emotional health?

R: Emotionally, I have come this far, why quit now? (Participant D)

“I was trying not to leave my addiction. And yet at the same time, I wanted to leave it. And then my health got really bad. At that time, I didn’t want help I guess in a way. And yet at the same time, I did... but they made me so welcomed.” (Participant A)
Conclusion

OALHIV face multiple sources of adversity, including, but not limited to: stigma and discrimination, socio-economic marginalization, trauma and loss, episodic disability, side effects of the ARV medication;

- OALHIV draw on multiple sources to adapt positively to the barriers they face, that can be broadly characterized as intrinsic sources (positive attitude, self-awareness, having a sense of purpose, and taking ownership of one’s health and HIV treatment) and extrinsic sources (being engaged in the community, receiving and giving peer support, seeking help from healthcare professionals and community-based organizations).

- Intrinsic and extrinsic sources of resiliency can be mutually reinforcing.

- There is potential to enhance extrinsic sources of resiliency (improved peer supports and culturally safe HIV care), which can further strengthen the intrinsic sources of resiliency.

- Our findings echo Akilah et al. 2018 systematic review that PLHIV experience multiple and intersecting sources of adversity beyond living with HIV; that personal (intrinsic) and interpersonal (extrinsic) sources of resiliency are both essential to well-being among PLHIV, although literature heavily emphasizes the personal sources; and positive relationships with healthcare providers are an interpersonal source of resiliency for PLHIV.