







Home Care Our Way

Findings from a Community-Based Study on Access to Home and Community Care Service amongst Older Adults Living with HIV in British Columbia

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

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Is a Community Based Research study conducted on the traditional, ancestral, and unceded homelands of the territories of the x^wməθkwəÿəm (Musqueam), Skwxwú7mesh (Squamish) and Səʾlílwəta? (Tsleil-Waututh) Nations





Background & Methods

- ~ Home and Community Care (HCC) services in British Columbia: home support, community rehabilitation, assisted living and long-term care
- ~ HCC services are for people who have acute, chronic, palliative or rehabilitative health-care needs and are designed to supplement, not replace, the care a person is able to provide for themselves with the assistance of family, friends and community
- ~ HCC services steps: referral, assessment by health authority and care plan set-up

- ~ 27 qualitative interviews (7 in-person conducted prepandemic and 20 phone interviews during pandemic) with older adults (50 years and older) living with HIV/AIDS (OALHIV) co-led by Peer Research Associates (PRAs) and study coordinator; 5 virtual interviews with HIV service providers.
- ~ Coding and analysis (NVivo); participatory approach (virtual team meetings): codebook development, coding, categorizing and theme description
- ~ Analytical frameworks: Patient-oriented care, social determinants of health, and two-eyed





HCC services journey for OALHIV: Barriers Pathways

Lack of information; rural or remote location; fear of being mistreated in an AL facility as an OALHIV because of the stigma associated with ethnicity, substance use

Lack of information; stigma associated with substance use, not having a home, ethnicity; cumbersome HCC referral system Extra support from care teams and informal networks; certain demographics (gender, Indigeneity) to meet quota for HCC services; peer-to-peer support

Extra support from care teams and informal networks for OALHIV; extra support from social workers to doctors referring their patients to HCC; individual resiliency

Before HCC referral

HCC workers overscheduled; insufficient HCC services package; HIV, race-based, and substance use stigma

Receiving appropriate HCC services

HCC Referral

Cumbersome application process, stigma associated with not having a home, substance use, gender, ethnicity; HCC system relying on informal caregivers; assessment questionnaire appears superficial and inflexible; lack of collaboration between HCC assessors and primary caregivers

Assessment for HCC services

Before HCC referral

Extra support from care teams and informal networks; individual resiliency and advocacy, targeted services for people with urgent health needs; assessments following hospitalization

Extra support from care teams and informal networks; increased HCC services package; improved training for HCC workers; cultural safety in HCC services for sexually and ethnically diverse OALHIV; individual resiliency and advocacy; quality assurance; peer-to-peer support

Receiving appropriate HCC services

Assessment for HCC services

HCC Referral



IN THRIVE PARTICIPANTS' WORDS:

"M: Do you have concerns about maybe in the future having to move to a certain assisted living facility, considering this issue?

R: A bit, yes. I have heard some people have had to kind of go back in the closet, because they were moving into an assisted living place. It's unfortunate that even today this is still happening, but that's just the way things are, I guess. Nobody learns. I don't know how things could be changed. Unless the government is willing to build a senior's home for gay people, which is not going to happen. But, the staff at the care facility needs better training, I guess. They need to have knowledge."

Participant K.

"I put the referral through social worker and they refused it because they said oh no, we did see him, we did an assessment and we believe that he can live independently. My answer to the person from Vancouver Coastal that came on I said, well how long did you stay with that client and he said, well 15, 20 minutes. I said I know him for years and I don't know how you that see him for 15, 20 minutes can tell me that he's functional when I've been seeing his deterioration and I know. As his family doctor I see how limited he's (inaudible) deteriorations. That's the kind of thing. They base the assessment in probably a questionnaire and they tick mark based okay, well he passed all these little tick marks and we assume that he's fine." Participant Provider A.

"My outreach worker from the XXX Clinic (name of the worker), she helped me get in there. And my doctor from the XXX Clinic as well.

M: If you didn't have their support, do you think you would be able to get those services on your own?

R: Probably not without a referral, but I would probably be dead if I didn't get that service."

Participant C.

"Home care is not home care, and I think they should change the name from home care. My theory is if you cannot bathe yourself, obviously you can't make your bed up, obviously you can't cook for yourself, obviously you can't clean your house. And when home care tells you that the only thing they do is give you a sponge bath and one bath a week, that's substandard for a first world country."

Participant B.







Conclusions

Individual level barriers: episodic disability, fear of stigma and discrimination in HCC services associated with HIV, substance use, ancestry, not having a home

Individual level pathways: extra support from care teams in HCC application and assessment; individual advocacy and resiliency, informal caregivers

System level barriers: lack of information, cumbersome application process, rigid assessment criteria, stigma and discrimination, social isolation, reduced HCC services package

Insufficient system-level pathways in accessing HCC services; OALHIV are left to depend on their informal systems of support

System level pathways: referral and assessment following hospitalization

Way forward: simplified application process, formalized peer support and HCC worker continuous education about HIV/AIDS and cultural safety, expanded HCC services package to include light cleaning and meal preparation