BRITISH COLUMBIA
CENTRE *for* EXCELLENCE
in HIV/AIDS

July 2022

THRIVE RESEARCH REPORT: POLICY AND CARE RECOMMENDATIONS

Obstacles and Pathways on the Journey to Access Home and Community Care by Older Adults Living with HIV/AIDS in British Columbia, Canada

Prepared by: Anna Vorobyova, Rana Van Tuyl, Antonio Marante, Claudette Cardinal, Patience Magagula, Sharyle Lyndon, Surita Parashar

BC-CfE Thrive

Table Of Contents

Summary

Older adults living with HIV (OALHIV) (i.e., age ≥50) now constitute over 50% of all people accessing HIV treatment in BC [1]. As OALHIV age, the need for supportive care in non-acute settings, including home and community care (HCC), is increasing. The Thrive research project was co-created alongside OALHIV in BC to support people to *thrive* during all stages of life. Phase 1 of the project linked treatment and demographic records for OALHIV accessing care in BC. Phase 2 took a community-based research approach to understand obstacles and pathways experienced by OALHIV in accessing HCC. On the HCC journey travelled by OALHIV in BC, we identified four main junctures at which obstacles and pathways appear: 1) before referral, 2) during the referral process, 3) at the assessment, and 4) while receiving services. Obstacles are largely related to fluctuating HCC priorities and funding cuts tied to election cycles, requiring systemic and policy changes to enable positive outcomes and impacts in the provision of HCC services. These obstacles can be transformed into pathways through the following policy and care recommendations.

POLICY AND CARE RECOMMENDATIONS TO TRANSFORM HCC OBSTACLES INTO PATHWAYS

1

Before Referral

- Expand HCC services funding, increasing the types of services provided and the number of hours, to improve the quality of life for OALHIV and the general population.
- Develop and proactively promote resources/advocate about what HCC services are and how to access local HCC services.
- Embed cultural safety principles into pre-referral services and resources, such as creating safe spaces and translating resources into multiple languages with culturally relevant imagery, to improve equitable access for diverse communities.
- Build relationships with ASOs and other community organizations and peer navigators who can help share HCC resources and information with their clients and members to increase equitable HCC application.

2

Referral

- Develop and communicate a clear, transparent list of eligibility criteria for the HCC services.
- Create partnerships between physicians (who work outside of multidisciplinary clinics) and social workers or peer navigators who can provide support in referring patients for HCC services.
- Communicate with the individuals who are in the referral process on a consistent basis.
- Provide respite care, enabling both OALHIV and informal caregivers to be supported and recharge.
- Embed cultural safety into the referral process to reduce intersectional obstacles.

3

Assessment

- Change the definition of HCC services to provide more than “supplementary” support to those who do not have access to informal caregivers.
- Update the assessment questionnaire with input from clients, healthcare providers, and social workers.
- Provide clear communication of the assessment process, including a physical copy of the assessment with the rights and responsibilities of the client.
- Ensure collaboration between the assessor and the primary care provider or social worker who knows the client’s needs in-depth.
- Increase the length of time for conducting assessments, enabling a more thorough assessment.
- Establish an accessible appeal center, with transparent communication about the appeal process.
- Create an assessment training program through a cultural safety lens (e.g., terminology, language, diverse cultural considerations, etc.), co-designed/delivered by clients, assessors, primary care providers, and social workers.

4

Receiving

- Increase funding for HCC services to include a wider variety of services and additional hours based on global best practices.
- Establish formal accountability for quality assurance of HCC services.
- Establish a formal complaint process and inform clients where and how they can direct their concerns.
- Improve scheduling practices, with enough time for HCC workers to perform their duties and a reasonable continuity of HCC workers for the same client.
- Introduce annual cultural safety training for HCC workers, assessors, and case managers, co-designed/delivered by people with lived/living experience.
- Provide continuing education, in-service training, and professional development to HCC workers based on best practices.
- Institute a contract about the rights and responsibilities of HCC clients and workers at the beginning of services, through which both parties are informed and accountable to each other, including respective checklists for duties to be performed.
- Conduct regular follow-up calls by HCC case managers, including an annual review of HCC services received/needed to inform policy and services development by the BC Ministry of Health and regional health authorities.

Introduction

Older adults living with HIV (OALHIV) (i.e., persons living with HIV/AIDS [PLHIV] age ≥50) now constitute over 50% of all people accessing HIV treatment in BC [1]. While advances in combination antiretroviral therapy (cART) alongside BC's Treatment as Prevention® (TasP®) strategy mean that OALHIV have life expectancies approaching that of the general population [2], many health and social challenges persist [3-5]. OALHIV experience higher rates of comorbidities than HIV-negative individuals, and these conditions can be worsened by persistent inflammation and chronic immune suppression [6]. Socio-structural inequities associated with HIV also have cumulative effects on mental, emotional, and physical health [7-9]. The healthcare needs arising from these distinct challenges have implications for the provision of aging-related health services [3, 9, 10]. There is a growing need to appropriately support the unique psychological and psychosocial challenges associated with HIV and aging (e.g., long-term cART toxicity, dementia, menopause, mobility challenges) and to understand the impacts these demands have on available healthcare and ancillary services [11-20], in urban, rural, and remote areas of the province.

As PLHIV grow older, it is more likely they will need to access supportive care in non-acute settings, including home and community care (HCC) [21]. In BC, publicly funded HCC services include home support, community nursing, community rehabilitation, assisted living (AL), and long-term care (LTC). A 2016 study found that BC had the highest prevalence of HIV among home support clients—0.49%, over double the 0.21% prevalence of HIV in the general Canadian population—when compared with Manitoba, Ontario, Nova Scotia, and the Yukon [10]. These HCC services may not be designed to encompass the unique healthcare needs, family, and support structures of the populations most affected by HIV in BC (i.e., gay, bisexual, or other men who have sex with men; people who use substances; people of African-Caribbean descent; and Indigenous individuals).

Thrive was a 3-year Canadian Institutes of Health Research (CIHR)-funded, Community-based Research (CBR) study focused on OALHIV accessing HCC in BC, led by the BC Centre for Excellence in HIV/AIDS (BC-CfE).

Despite the role HCC may have in the healthcare experiences of OALHIV as they age and require higher levels of formal care [22], this field remains relatively unexplored, particularly in Canada and British Columbia's context of fluctuating HCC priorities and funding cuts tied to election cycles [23-27]. The Thrive research project was co-created alongside OALHIV in BC to support people to *thrive* during all stages of life.

A Brief History:

HOME & COMMUNITY CARE IN BC

1978
Program established under the Ministry of Health

1983
Completion of the initial **growth phase**, in which home care nursing and homemaker services (now referred to as home support) were scaled up

1991
The Seaton Commission (Royal Commission on Health Care and Costs) called for **deinstitutionalization,** with care provided closer to home

1993
Funding and capacity for residential care **diverted** towards homemaking and home care nursing sectors

1995
Impact of **federal funding cuts** reached home and community care. Services became more medically focused and were restricted to individuals with higher care needs

2001
BC Liberals won the provincial election. Their platform included a promise to build **5000** new long-term and intermediate care beds by 2006, as a result of increasing pressure on these services

2002
BC Liberals implement the **Continuing Care Renewal Plan.** Planned to expand assisted living and home care services in order to prevent unnecessary institutionalization

2006
BC Liberals did not meet their goal of 5000 intermediate and long term care beds

2008
The **BC Ombudsperson** launches an investigation of HCC services. **176 recommendations** are put forward

2010
Report by the **Canadian Centre for Policy Alternatives** finds that access to home support services have decreased by **30%** since 2001

2014
Ministry of Health creates the **Office of the Seniors Advocate**

2016
Report by the **Canadian Centre for Policy Alternatives** finds that access to assisted living and residential services have decreased by **20%** since 2001

2017
BC Liberals announced an additional **$500 million** over four years to increase staffing levels in residential care facilities

Both the BC Liberals and BC NDPs make statements about their potential contributions to HCC as part of their campaign platforms during the **provincial election**

2020-2022
The COVID-19 pandemic highlighted already-existing critical issues and care needs in HCC across Canada.

[23-28]

Methods

Thrive's purpose was to evaluate the impact of shifting priorities and funding for HCC on the health outcomes and healthcare experiences for OALHIV, that is PLHIV ≥50 years of age. The research design was informed by OALHIV, *The BC Home and Community Care System and Older Adults Living with HIV* environmental scan, and a *Provincial Overview of Community-based Organizational Supports for Older Adults Living with HIV.* The study's mixed methods design included:

Phase 1 – A quantitative arm that leveraged administrative data to monitor trends in health and healthcare utilization among a cohort of OALHIV compared to the general population in BC; and

Phase 2 – A qualitative arm exploring obstacles[1] and pathways experienced by OALHIV accessing HCC services in BC.

DATA AND PROCEDURE

Phase 1: Administrative Data

The public HCC system offers formal support that OALHIV may turn to as they age, yet little is known about HCC access amongst PLHIV in BC. Using data from the STOP HIV/AIDS® cohort, which includes linked treatment and demographic records for PLHIV accessing care in BC, we compared OALHIV (defined as those age ≥50) who did and did not access HCC services. We estimated adjusted odds ratios (aORs) for factors associated with HCC service utilization using logistic regression. This study included 5,603 OALHIV age ≥50, 837 (14.94%) of whom accessed HCC services between 2005 and 2015.

Phase 2: Qualitative Data

The research team co-developed a coding framework based on priori categories to inform the interview guide, focusing on the social, structural, and spatial dimensions of aging with HIV and accessing HCC. The Peer Research Associates (PRAs)—OALHIV trained in qualitative research methods—and the study coordinator co-conducted 27 semi-structured interviews with OALHIV (n = 27) in the Vancouver Coastal Health (VCH) and Fraser Health (FH) regions. Of the OALHIV interviewed, 15 had used HCC services and 12 had not, including three people who had applied for and were denied services. Interviews were conducted over the phone July to December 2020, with the exception of seven in-person interviews conducted in February 2020 prior to the onset of the COVID-19 pandemic. Interviews with service providers (n = 10) were conducted from January to June 2021, including perspectives from social workers, HIV specialists, and peer navigators. The team piloted the codebook by coding an interview transcript together (in NVivo) to facilitate immersion into participant stories and determine a coding approach, including emergent categories that arose from the data. The 37 semi-structured interviews (27 OALHIV and 10 service providers; N = 37) were then analyzed thematically in two streams: pathways and obstacles in accessing HCC services experienced by OALHIV.

---

[1] Following the guidance of the team's Indigenous PRA, we use the terms "obstacles" and "pathways" instead of "barriers" and "facilitators" to decolonize research language.

Participants

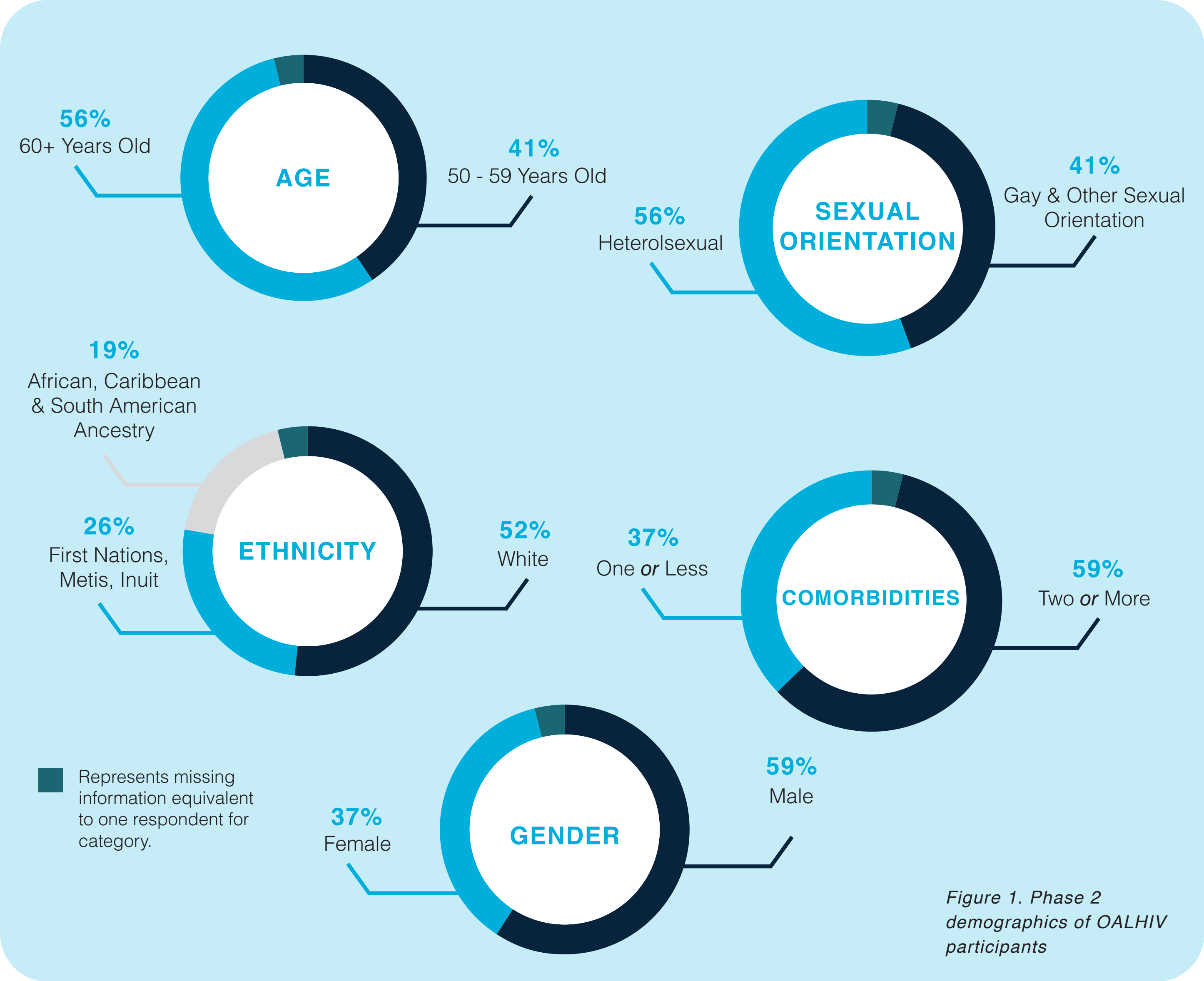
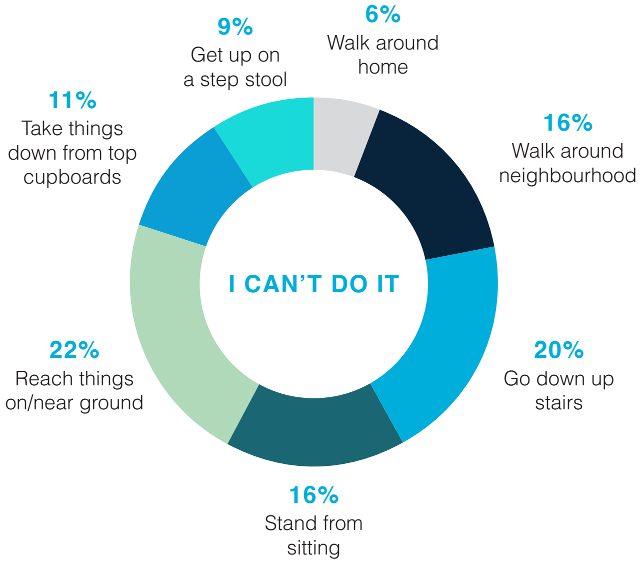
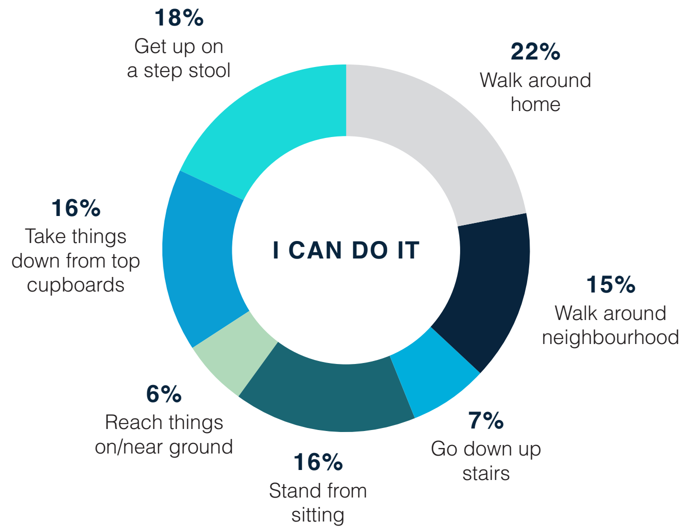


Figure 1. Phase 2 demographics of OALHIV participants

Mobility





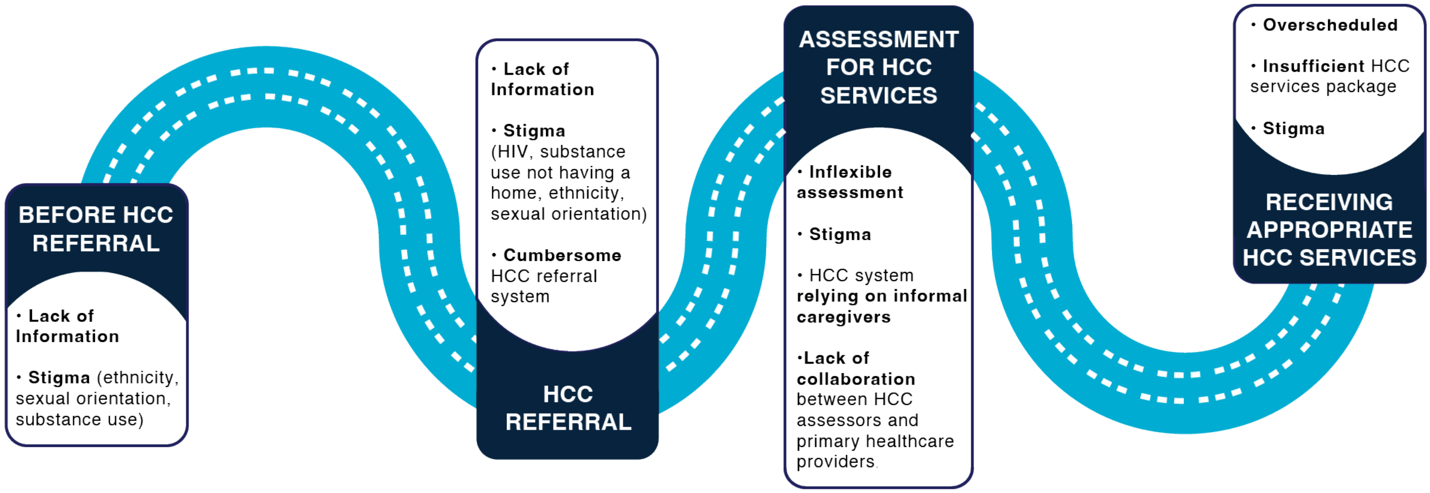
Phase 1: Findings and Direction For Further Research

Over half of OALHIV engaged in care in BC are age ≥50 [1]. This study included 5,603 OALHIV age ≥50 (N = 5,603), 837 (14.94%) of whom accessed any HCC service between 2005 and 2015. Services most commonly used were community nursing (8.98%, n = 503) and rehabilitation (7.73%, n = 433). Those who received HCC were more likely to be female (adjusted Odds Ratio [aOR] = 1.56, 95% Confidence Interval [CI] = 1.24, 1.98), have a history of substance use (aOR = 1.88, 95% CI = 1.57, 2.25), have a higher Charlson comorbidity score (aOR = 1.11, 95% CI:1.07, 1.15), and have visited a general practitioner in the past year (aOR = 2.17, 95% CI = 1.77, 2.67) [1]. Approximately 15% of OALHIV in BC have accessed HCC. The extent of potential unmet need for these services required further research to understand lived and living experiences of OALHIV in this context.

Phase 2: Findings and Recommendations for HCC Services

On the HCC journey travelled by OALHIV in BC, we identified four main junctures at which obstacles and pathways appear: 1) before referral, 2) during the referral process, 3) during the assessment, and 4) while receiving services. Some obstacles and pathways are unique to each step, while others cut across multiple points of accessing HCC services.

There are many system-level obstacles on the HCC services journey (see Figure 2), from before referral through to receiving HCC services, all of which are underpinned by uncertainty. Addressing these obstacles requires improving the quality and expanding the availability of HCC services in BC and beyond. Changes that address obstacles at the systemic and policy levels are critical for enabling positive outcomes and impacts in the provision of HCC services. The recommendations included in this report highlight how obstacles can be converted to pathways through HCC system change and policy development.



BEFORE HCC REFERRAL

- **Lack of Information**
- **Stigma** (ethnicity, sexual orientation, substance use)

HCC REFERRAL

- **Lack of Information**
- **Stigma** (HIV, substance use not having a home, ethnicity, sexual orientation)
- **Cumbersome** HCC referral system

ASSESSMENT FOR HCC SERVICES

- **Inflexible assessment**
- **Stigma**
- HCC system **relying on informal caregivers**
- **Lack of collaboration** between HCC assessors and primary healthcare providers.

RECEIVING APPROPRIATE HCC SERVICES

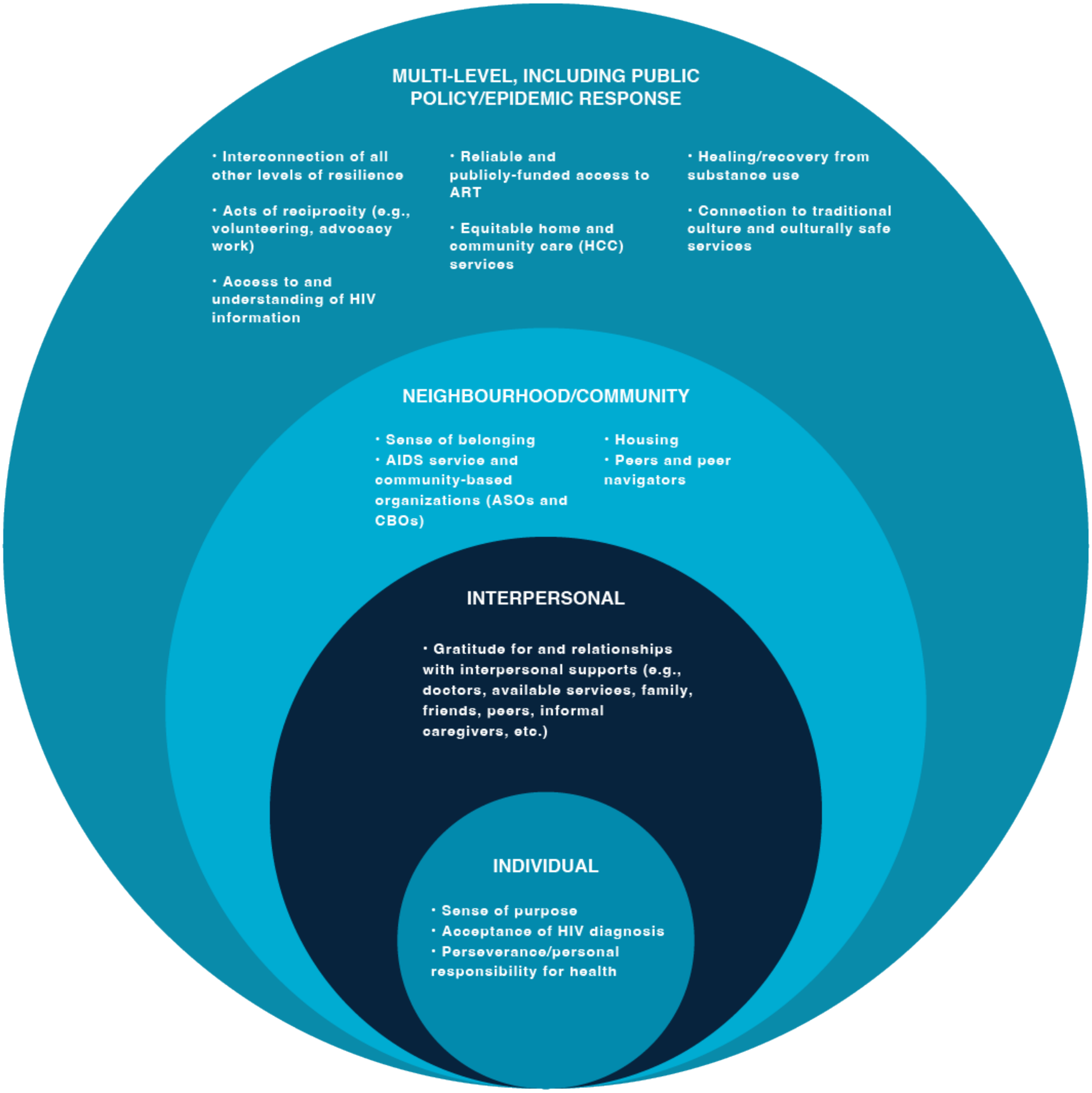
- **Overscheduled**
- **Insufficient** HCC services package
- **Stigma**

Figure 2. Obstacles on the HCC Services Journey

RESILIENCY WHILE WAITING FOR HCC CHANGE IN BC

In recent years, resiliency has become a widely-promoted attribute in public and private sectors and amongst the general public. OALHIV, their support networks, and allied healthcare and HCC practitioners are increasingly required to rely on their personal/relational resiliency while navigating limited HCC services and bureaucratic referral/assessment processes. While we greatly admire this personal/relational resiliency as shown in Figure 3, it is also important to call attention to discourses that have placed the responsibility of resiliency on the individual. Without resilient healthcare systems that are equitable and adequately funded, designed, and staffed to support diverse populations and withstand crises (e.g., pandemics, epidemics, outbreaks, and extreme weather events), the system's current approach unjustly places responsibility for resilience on individuals, and thus, becomes unsustainable.

Figure 3. Interconnected Sources of Resilience Amongst OALHIV



BEFORE REFERRAL

The most commonly identified obstacles for accessing HCC services are the referral and assessment processes. Participants described accessing HCC services as “not easily accessible,” “with so many different hoops and red tape,” “bureaucratic,” and/or “hard to navigate.” However, before a person can begin the referral and assessment process, they first need to know where to find this information (see Figure 4). This information is often not easily accessible, such as where to find it, who to contact, or what the eligibility criteria is. As a result, people often contact the wrong agencies (e.g., Ministry of Social Development and Poverty Reduction). Additional reasons that may preclude OALHIV from being referred to HCC services include: 1) fear of stigma and discrimination from HCC workers and in AL and LTC facilities, and 2) residing in rural and remote locations. OALHIV who knew about HCC services before their referral reported that they were either well-informed through their volunteer work or by being an active participant at an AIDS service organization (ASO).

CULTURAL SAFETY TIP

Embed cultural safety principles into pre-referral services and resources to improve equitable access for diverse communities.

Recommendations to improve accessibility of HCC services before referral

- Expand HCC services funding, increasing the types of services provided and the number of hours, to improve the quality of life for OALHIV and the general population.
- Develop and proactively promote resources/advocate about what HCC services are and how to access local HCC services.
- Embed cultural safety principles into pre-referral services and resources, such as creating safe spaces and translating resources into multiple languages with culturally relevant imagery, to improve equitable access for diverse communities.
- Build relationships with ASOs and other community organizations and peer navigators who can help share HCC resources and information with their clients and members to increase equitable HCC application.

Figure 4. Steps to Access HCC Services

REFERRAL

There is a stark contrast between referral from community versus following an acute incident and/or hospitalization. Referral from community is commonly supported by several professionals (e.g., physician, social worker, peer navigator) or via a community health clinic or specialized HIV/AIDS clinic where multidisciplinary teams help with referrals and assessment. Most participants had extra help in seeking and securing HCC services and believe their efforts would not have been successful without the help of a social worker, outreach worker, peer navigator, or their doctor.

> *"If I didn't have a team behind me to help me navigate, I probably would have a harder time doing it…The process is a little bit long. The wait is long. Anything that needs to be done has to go through so many different processing hoops and red tape that sometimes it feels almost like you're better off not even starting." Participant C*

In contrast, acute incidents and hospitalizations prompt HCC referral and assessment at discharge. Paperwork is completed by professionals in the hospital, supporting the client with the HCC referral. Although this usually happens, some participants did not receive HCC services because services were denied (assessed as ineligible), the client was not assessed for HCC services following an acute incident and hospitalization, or family members intervened despite the client's wishes to receive HCC services at home.

> *"I was unable to stay in my SRO [single room occupancy] housing in the downtown east side because of conditions. I couldn't stay in my room any longer. It was unfit to stay there. So, I went to a shelter in the downtown eastside, an emergency shelter, and I got a bed there. And through those services at the shelter, they extended my housing. I got my housing extended to a group home setting. And I was moved into a group home setting and then at that time, that was when I had an emergency situation and needed to be transferred to another group home setting where I could get almost like 24-hour care." Participant J*

Common obstacles experienced through both referral routes

- Unclear communication pertaining to eligibility criteria prevents some people from receiving an assessment because they are not aware of what key words need to be included in the initial referral conversation (e.g., what they are and are not able to do).
- Physicians are not compensated for their time referring patients and preparing documents.
- Wait times during the referral process are often long.
- Advocacy fatigue may be experienced by individuals, family, friends, and other informal caregivers.
- HIV/AIDS diagnosis, poverty, homelessness, and substance use converge and exacerbate one another, increasing the complexity of patients' experiences.

Recommendations to improve the referral process for HCC services

- Develop and communicate a clear, transparent list of eligibility criteria for the HCC services.
- Create partnerships between physicians (who work outside of multidisciplinary clinics) and social workers or peer navigators who can provide support in referring patients for HCC services.
- Communicate with the individuals who are in the referral process on a consistent basis.
- Provide respite care, enabling both OALHIV and informal caregivers to be supported and recharge.
- Embed cultural safety into the referral process to reduce intersectional obstacles.

ASSESSMENT

The point of assessment, guided by the contact person conducting the assessment, is a crucial step in receiving HCC services and determining what kinds of services will be granted. Several participants were denied HCC services or had their services discontinued following funding cuts. This finding parallels the conclusion of the 2020/2021 Annual Report by the Office of the Seniors Advocate, which states that “access to home health and home support services including limited hours of care and inconsistent scheduling of service” is one of the systemic gaps in senior services [28].

CULTURAL SAFETY TIP

Create an assessment training program through a cultural safety lens, co-designed/delivered by clients, assessors, primary care providers, and social workers.

Taking the Time versus Too Much Time

“Taking the time” while conducting the assessment was cited as one of the prerequisites for a proper assessment. Open and extensive communication with the client about their needs is also important to reach a satisfactory result. Some participants shared positive interactions with their assessor, emphasizing the importance of thoroughness and attentiveness to the individual’s needs and surroundings. As one participant put it, “[the assessor] did a pretty good job seeing what was needed in my home to keep my independence.” Other participants described unsatisfactory assessments, characterized by “a tick mark questionnaire,” “not very appropriate,” “very heavy top down,” “bureaucratic,” and “not fair.” As a family physician shared, he needed to advocate for a patient with deteriorating health, who was declined HCC services by an assessor after a 15–20-minute assessment. When quality of life and well-being are at stake, “taking the time” to conduct the assessment is integral to a comprehensive assessment.

The HCC Services Policy Manual suggests “collaboration between the assessor and primary physician” [29], which is a vague formulation of a valuable principle. Service providers (e.g., physicians, peer navigators, social workers) reported a lack of collaboration between themselves and individuals assessing their patients/clients for HCC services. Updating the policy manual to mandate that a care provider or social worker is present at the point of assessment may improve assessment outcomes for the patient/client.

PATHWAY STORY:

“My assessment was done basically through an interview. The lady came to my home, and she looked at the place and asked me questions about what I needed. Things like, do I need any meal preparation, do I need cleaning services, do I need help making lunch, those types of things. So, we just went through and decided what it was that I needed at this time, which was basically some support services around cleaning. That’s basically what my services are right now.”

Participant F

OBSTACLE STORY:

“I did request assistance after I had surgery due to complications from Hepatitis C. That operation put me in a weakened state, and I was unable to even get into a bath without being extremely careful. My doctor had suggested that I get some support, but when I approached the Ministry, I was declined due to the fact that I was not immobilized.”

Participant Z

At the opposite end of the spectrum of taking time was taking too much time and involving too many different entities in the assessment process. This was especially pronounced when services were sought for a chronic condition or if additional services were needed outside the scope of the HCC services (e.g., housing or transfer to an AL or LTC facility). Even with a streamlined process that occurs after an acute incident, it can still take up to six months for an individual to receive a permanent placement at a LTC facility. Before transfer to a permanent facility takes place, a person needs to have a safe transitional location. In the case of prolonged assessments, wait times could result in services being offered too late, when no longer needed.

> *"I broke my arm, and they were supposed to come and give me a hand. But by the time they were showing up, my cast was off. It took a very long time. It took over six weeks for them to get back to me." Participant Q*

Intersectional Obstacles

Episodic disability, where an individual experiences periods of ill health interspersed with times of being well, is a common condition among PLHIV [30]. Some participants shared how they presented better or worse during the time of assessment and how that affected the outcome. In some cases, participants were fortunate because assessors were understanding and flexible. On the other hand, some participants did not receive services because they were more mobile at the time.

By definition, HCC services are designed to "complement and supplement, not replace, your efforts to care for yourself with the assistance of your family, friends and community" [31]. This presents an obstacle for some OALHIV because they do not always have care support from family, friends, and community. For example, friends may have passed away, family might live in another country, peers may need to redirect attention to their own care needs, and some families withhold support based on stigma. As such, some OALHIV turn to informal caregivers to supplement services that are not provided through HCC yet are essential to survival (e.g., grocery shopping). OALHIV may be denied HCC services because they receive some support from informal caregivers. Some participants also shared stories that signalled commodification of relationships with their informal caregivers (e.g., when grocery shopping would be done only in exchange for money, food, or shelter). Such commodification can make any older adult vulnerable to abuse, and older OALHIV, who are often marginalized by socio-structural inequity and experience higher rates of poverty and isolation, are perhaps more at risk of being subject to such abuse. To prevent elder abuse, it would be beneficial for HCC services to be differentiated based on the availability of informal caregivers and their willingness to provide ongoing care.

Further, homelessness and precarious housing were commonly identified as obstacles in the assessment process. Safety of the HCC workers and absence of hazardous conditions is very important and can be written into the contract and working conditions. At the same time, we observed inconsistencies in what conditions were considered safe or unsafe for HCC workers dependent on their personal disposition. As such, it is unclear what policies exist, and therefore, how they are carried out formally in such situations. Policies about non-discrimination should be widely known and observed.

Recommendations to improve the assessment process

- Change the definition of HCC services to provide more than “supplementary” support to those who do not have access to informal caregivers.
- Update the assessment questionnaire with input from clients, healthcare providers, and social workers.
- Provide clear communication of the assessment process, including a physical copy of the assessment with the rights and responsibilities of the client.
- Ensure collaboration between the assessor and the primary care provider or social worker who knows the client’s needs in-depth.
- Increase the length of time for conducting assessments, enabling a more thorough assessment.
- Establish an accessible appeal center, with transparent communication about the appeal process.
- Create an assessment training program through a cultural safety lens (e.g., terminology, language, diverse cultural considerations, etc.), co-designed/delivered by clients, assessors, primary care providers, and social workers.

RECEIVING HCC SERVICES

Types of Services

HCC services commonly provided include bathing and grooming. OALHIV, particularly those without informal caregivers, commonly also require meal preparation, cleaning, laundry, and support to conduct errands (e.g., grocery shopping, medication pick-up/delivery), which are unmet needs by current HCC services. These services are necessary to enable independence and aging with dignity for those who desire to live at home (versus LTC). When these needs are not provided by HCC services, it requires people to pay out-of-pocket. Some OALHIV cannot afford out-of-pocket payments due to Canada’s disability benefit and Canada Pension Plan amounts, which are set below the poverty line.

> *“But I also have to seek help elsewhere to do all the other stuff that they do not do. So, I have to rely on the kindness of people so that I don’t live like a pig or below substandard living in a first world country. When the poverty line in Canada is $25,000, and that is by the government standard, that’s poverty, and the government turns around and give you less than half of that to live off for the month, how can you pay someone to do all the stuff home care will not do?” Participant C*

Quality of Services

From being denied basic services (e.g., requesting a bath more than once a week) to last-minute rescheduling, various OALHIV have noted a decline in the quality of services. When participants received excellent care, they credited HCC workers who love their job and provide care through a relational manner. This underpins the importance of HCC workplace cultures that attract, recognize, and retain exceptional staff.

> *“The lady that cleaned my room, she would be doing the dishes and then we’d be just talking. We need more people like that, that understand that person’s story.” Participant O*
>
> *“The building where I live is actually really, really great. They have support systems going there. They have people that will go to the Food Bank for you, because I can’t use my walker to get food. So, they actually have people there. They have people coming in and cleaning the*

> *place all the time. The building is so amazing. I can't believe I actually got into this place. And the people that work here and volunteers help out have got great hearts." Participant A*

Scheduling and Allotment of Service Hours

Scheduling conflicts in HCC workers' shifts were commonly observed by OALHIV clients. Examples included last-minute service cancellations, incomplete services due to juggling several clients and transportation time, and rotating HCC workers. As such, scheduling conflicts present unstable environments to both HCC workers and their clients.

> *"It was usually a different person. I had a different person come three or four times a week." Participant G*
>
> *"Every time we'd get a new worker, even though they had the list in front of them of what needed to be done, they didn't know where everything was. I had to explain where the mop is, where the vacuum is. It took more time explaining it to them, where everything was and what needed to be done, than what it took time to actually do it. It helped to just have the same person all the time, that knew where we kept everything and what needed to be done. How bad the place would be on a Thursday if we were both sick and all that sort of thing. It became easier with just one person, instead of always having a different person every week. Then, I had a cat, so it was hard at times, because some of them are allergic to cats, which for some reason the office would forget to tell them that we had a cat. So, they would be here for like 20 minutes and then they'd have to leave. There wasn't a lot of communication between the office and the homecare provider that they were sending." Participant K*

Communication and Follow-ups

Previously, clients received regular communication and follow-up calls from a HCC services case manager. A "twice-removed" phenomenon appears to have contributed to a lack of communication and follow-up calls. This generates uncertainty in how to issue a complaint.

> *"I think it would be better if there was just one person, a primary person involved so that the patient knows there's always one primary person that they can go to instead of all these titles, these societies, and these title heads. And then there's a house manager and then there's the part-time staff, and then there's the this and that and the other thing. You know what I mean? It can get really confusing." Participant J*

Client-centered, Culturally Safe Care

HCC services, and healthcare more broadly, requires an intersectional understanding of cultural safety to support client-centered care among OALHIV. This includes diverse sociodemographic characteristics, such as ethnicity and Indigeneity, all gender identities and sexual orientations, religious practices, socioeconomic factors (e.g., housed versus unhoused or underhoused, education, occupation), and comorbidities (e.g., episodic disability and medication side effects, substance use, etc.). Cultural safety, as continuous training and reflexive practice (versus one-time, check-the-box training), should be prioritized in HCC services.

CULTURAL SAFETY TIP

Introduce annual cultural safety training for HCC workers, assessors, and case managers, co-designed/delivered by people with lived/living.

INTERSECTIONAL STORIES OF OALHIV

Housing

“Do the service provider know what my status is? Because I’ve had an incident where somebody comes in. Now, I live in a building that’s stigmatised. And when somebody come to the door, open the door, look at me, and refuse to come in, or they come in with three gloves like back in the ‘80s, I am not comfortable. I already lived through that era. When they come in and it’s like, okay, you don’t want to put your bags down, you bring paper and plastic and you spread it out. And it’s like, do I really want you to touch me? When you stand in the bathroom and hand me a rag and go, basically indicating that I should do it myself, why are you getting paid to be here? If I could do it myself, I would not need you.” Participant C

Indigeneity and Gender

“Well, I thought they were downgrading me because I was sick and couldn’t do much for myself and they just let me be in pain. And the nurses would say, oh well, you’ve got another hour for your next medications, pain meds, so I didn’t think that was very good. They are supposed to be there to help you and your pain and they’re just laughing at you, that’s what I didn’t like about that…That’s stigma there, and being a woman, a native woman. I don’t know how to put it. If I had my way, I would have place for Aboriginal women only where they can go get healed, a healing lodge or whatever. Women specifically.” Participant D

Sexual Orientation

“They need to understand that it’s not just straight people that get old, gay people get old too. They’re allowed to have visitors; they’re allowed to have friends over. Unfortunately, when you do move into a situation like that, you have to be careful what you say, you have to look around, because two gay men or two gay women start talking to each other, they say things that might offend straight people… It’s hard for people that live in care facilities to be free, to be who they really are, because they’re always on the look-out.” Participant K

Mental Health and Substance Use

“I would say that I got some really good help, I really did. I was cared for very efficiently. There were times as the months went on that maybe I wasn’t followed as well as I could have been emotionally, because of the situation because I was still using drugs at that time too, and a lot of them. So, back then, I think there needed to be more of an intervention done or could have been, I don’t know if I would have accepted it, but I’m just saying if it did happen, if it was offered to me, more in all areas of my life looked at, not just the heath. Not just the physical health but the mental health and the emotional health as well. I know that’s a lot to ask for but I’m just saying, if that would have been possible, I think it would have maybe moved things along differently.” Participant J

Recommendations to improve the delivery of the HCC services

- Increase funding for HCC services to include a wider variety of services and additional hours based on global best practices (e.g., Denmark provides up to 10 hours of services/day per client and automatically offers a home visit/assessment by a nurse when people turn 80 [32]).
- Establish formal accountability for quality assurance of HCC services.
- Establish a formal complaint process and inform clients where and how they can direct their concerns.
- Improve scheduling practices, with enough time for HCC workers to perform their duties and a reasonable continuity of HCC workers for the same client.
- Introduce annual cultural safety training for HCC workers, assessors, and case managers, co-designed/delivered by people with lived/living experience.
- Provide continuing education, in-service training, and professional development to HCC workers based on best practices.
- Institute a contract about the rights and responsibilities of HCC clients and workers at the beginning of services, through which both parties are informed and accountable to each other, including respective checklists for duties to be performed.
- Conduct regular follow-up calls by HCC case managers, including an annual review of HCC services received/needed to inform policy and services development by the BC Ministry of Health and regional health authorities.

Conclusion

On the HCC journey travelled by OALHIV in BC, obstacles and pathways appear: 1) before referral, 2) during the referral process, 3) at the assessment, and 4) while receiving services. To transform HCC obstacles into pathways in BC, systemic and policy changes are required in the provision of HCC services. When OALHIV are supported by pathways along their journey to access HCC in BC, they can *thrive* and age with dignity.

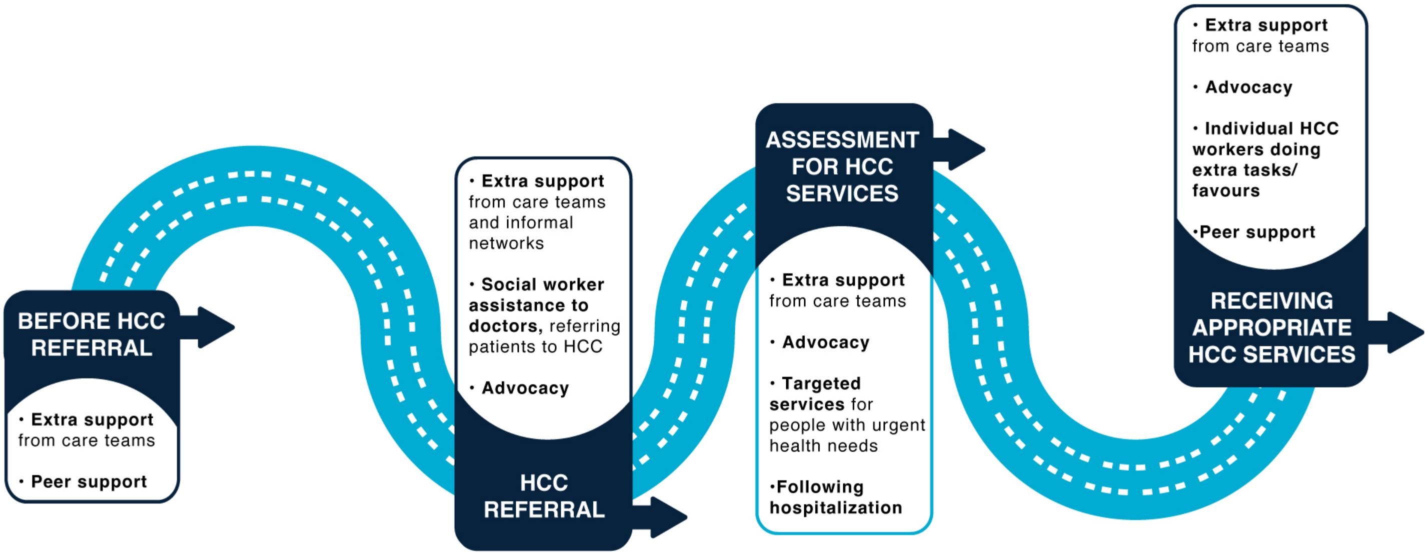


Figure 5. Pathways on the HCC Services Journey

When OALHIV are supported by pathways along their journey to access HCC in BC, they can *thrive* and age with dignity.

References
Acronyms
Appendices

Obstacles and Pathways on the Journey to Access Home and Community Care by Older Adults Living with HIV/AIDS in British Columbia, Canada

References

1. Koehn, K., Burgess, H., Lyndon, S., Lu, M., Ye, M., Hogg, R. S., Parashar, S., Barrios, R., & Salters, K. A. (2020). Characteristics of older adults living with HIV accessing home and community care services in British Columbia, Canada. *AIDS Care, 33*(1), 121–130. https://doi.org/10.1080/09540121.2020.1770673
2. Samji, H., Cescon, A., Hogg, R. S., Modur, S. P., Althoff, K. N., Buchacz, K., … Gange, S. J. (2013). Closing the Gap: Increases in Life Expectancy among Treated HIV-Positive Individuals in the United States and Canada. *PLoS ONE, 8*(12), e81355. https://doi.org/10.1371/journal.pone.0081355
3. Edelman, E. J., Gordon, K. S., Glover, J., McNicholl, I. R., Fiellin, D. A., & Justice, A. C. (2013). The next therapeutic challenge in HIV: polypharmacy. *Drugs and Aging, 30*(8), 613–628. https://doi.org/10.1007/s40266-013-0093-9
4. Ghidei, L., Simone, M. J., Salow, M. J., Zimmerman, K. M., Paquin, A. M., Skarf, L. M., Kostas, T. R., & Rudolph, J. L. (2013). Aging, antiretrovirals, and adherence: a meta analysis of adherence among older HIV-infected individuals. *Drugs and Aging, 30*(10), 809–819. https://doi.org/10.1007/s40266-013-0107-7
5. High, K. P., Brennan-Ing, M., Clifford, D. B., Cohen, M. H., Currier, J., Deeks, S. G., … OAR Working Group on HIV and Aging. (2012). HIV and aging: state of knowledge and areas of critical need for research. A report to the NIH Office of AIDS Research by the HIV and Aging Working Group. *Journal of Acquired Immune Deficiency Syndromes, 60*(Suppl 1), S1-18. https://doi.org/10.1097/QAI.0b013e31825a3668
6. Onen, N. F., Overton, E. T., Seyfried, W., Stumm, E. R., Snell, M., Mondy, K., & Tebas, P. (2010). Aging and HIV Infection: A Comparison Between Older HIV-Infected Persons and the General Population. *HIV Clinical Trials, 11*(2), 100–109. https://doi.org/10.1310/hct1102-100
7. Shippy, R. A., & Karpiak, S. E. (2005). The aging HIV/AIDS population: Fragile social networks. *Aging & Mental Health, 9*(3), 246–254. https://doi.org/10.1080/13607860412331336850
8. Shippy, R. A., Cantor, M. H., & Brennan, M. (2004). Social Networks of Aging Gay Men. *The Journal of Men's Studies, 13*(1), 107–120. https://doi.org/10.3149/jms.1301.107
9. Siou, K., Mahan, M., Cartagena, R., & Chan Carusone, S. (2017). A growing need – HIV education in long-term care. *Geriatric Nursing, 38*(3), 199–206. https://doi.org/10.1016/j.gerinurse.2016.10.014
10. Foebel, A. D., Hirdes, J. P., Lemick, R., & Tai, J. W.-Y. (2015). Comparing the characteristics of people living with and without HIV in long-term care and home care in Ontario, Canada. *AIDS Care*, 27(10), 1343–1353. https://doi.org/10.1080/09540121.2015.1058893
11. Linsk, N. L. (2000). HIV among older adults: age-specific issues in prevention and treatment. *AIDS Read, 10*(7), 430–440.
12. Genke, J. (2000). HIV/AIDS and older adults: the invisible ten percent. *Care Management Journals, 2*(3), 196–205.
13. Emlet, C. A. (2004). HIV/AIDS and Aging: A Diverse Population of Vulnerable Older Adults. *Journal of Human Behavior in the Social Environment, 9*(4), 45–63. https://doi.org/10.1300/J137v09n04_03
14. Cantor, M. H. (1979). Neighbors and Friends: An Overlooked Resource in the Informal Support System. *Research on Aging, 1*(4), 434–463. https://doi.org/10.1177/016402757914002
15. Baltes, P., & Baltes, M. (1990). Psychological Perspectives on Successful Aging: The Model of Selective Optimization with Compensation. In: P. Baltes, & M. Baltes (Eds.), *Successful Aging: Perspectives from the Behavioral Sciences (pp. 1–34)*. Cambridge University Press.

16. Poindexter, C., & Shippy, R. A. (2008). Networks of older New Yorkers with HIV: fragility, resilience, and transformation. *AIDS Patient Care and STDs, 22*(9), 723–733. https://doi.org/10.1089/apc.2007.0260
17. Karpiak, S. E., Shippy, R. A., Cantor, M. H. (2006). Research on Older Adults with HIV. *AIDS Community Research Initiative of America: New York*.
18. Blieszner, R. (1989). Developmental Processes of Friendship. In: R. Adams & R. Blieszner (Eds.), *Older Adult Friendship: Structure and Process (pp. 108–126*). Sage.
19. Kalichman, S. C., Heckman, T., Kochman, A., Sikkema, K., & Bergholte, J. (2000). Depression and thoughts of suicide among middle-aged and older persons living with HIV-AIDS. *Psychiatric Services, 51*(7), 903–907. https://doi.org/10.1176/appi.ps.51.7.903
20. Szirony T. A. (1999). Infection with HIV in the elderly population. *Journal of Gerontological Nursing, 25*(10), 25–31. https://doi.org/10.3928/0098-9134-19991001-10
21. Heckman, T. G., Somlai, A. M., Peters, J., Walker, J., Otto-Salaj, L., Galdabini, C. A., & Kelly, J. A. (1998). Barriers to care among persons living with HIV/AIDS in urban and rural areas. *AIDS Care, 10*(3), 365–375. https://doi.org/10.1080/713612410
22. Wallach, I., & Brotman, S. (2013). Ageing with HIV/AIDS: a scoping study among people aged 50 and over living in Quebec. *Ageing and Society, 33*(7), 1212–1242. https://doi.org/DOI: 10.1017/S0144686X12000529
23. Cohen, M., McLaren, A., Sharman, Z., Murray, S., Hughes, M., & Ostry, A. (2006). *From Support to Isolation: The High Cost of BC's Declining Home Support Services.* Canadian Centre for Policy Alternatives - BC Office. http://www.policyalternatives.ca/sites/default/files/uploads/publications/BC_Office_Pu bs/bc_2006/support_to_isolation_summary.pdf
24. Longhurst, A. (2017). *Privatization & Declining Access to BC Seniors' Care: An Urgent Call for Policy Change*. Canadian Centre for Policy Alternatives - BC Office. https://www.policyalternatives.ca/sitesf default/files/uploads/publications/BC Office/2017/03/access_to_seniors_care_report_l70327 FINAL.pdf
25. Hollander, M., Tessaro, A., & Health Canada. (2001). *Evaluation of the Maintenance and Preventive Function of Home Care*. Hollander Analytical Services.
26. Vogel, B. Y. D. , & Murray, S. (2000). Unfulfilled Promises: How Health Care Reforms of the 1990s Are Failing Community and Continuing Care in B.C.
27. BC Ombudsperson. (2012). *The Best of Care: Getting It Right for Seniors in British Columbia (Part 1). Vol. 2.* British Columbia Office of the Ombudsperson. http://www.ombudsman.bc.ca/images/resources/reports/Public_Reports/Public_Report_No_46.pdf
28. Office of the Seniors Advocate. (2021). *2020/2021 Annual Report*. https://www.seniorsadvocatebc.ca/app/uploads/sites/4/2021/08/Annual_Report_2020_21-FINAL.pdf
29. BC Government. (2019). *Home and Community Care Policy Manual*. https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/accountability/policy-and-standards/home-and-community-care-policy-manual
30. Realize Canada. (n.d.). https://www.realizecanada.org/en/our-work/episodic-disabilities/
31. BC Government. (n.d.). *Home and Community Care.* https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/home-community-care
32. Johnson, E., Foxcroft, T., & Pedersen, K. (2022, April 27). Stuck in bed 23 hours a day: What's wrong with home care in Canada and why lessons could be learned in Denmark. *CBC News.* https://www.cbc.ca/news/marketplace/home-care-canada-denmark-1.6430273

Acronyms

AIDS	Acquired immunodeficiency syndrome
AL	Assisted living
ART	Antiretroviral therapy
ASO	AIDS service organization
BC	British Columbia
BC-CfE	BC Centre for Excellence in HIV/AIDS
cART	Combination antiretroviral therapy
COVID-19	Coronavirus disease of 2019 and subsequent variants
FH	Fraser Health
HIV	Human immunodeficiency virus
HCC	Home and community care
LTC	Long-term care
OALHIV	Older adults living with HIV/AIDS
PLHIV	Persons living with HIV/AIDS
PRAs	Peer research associates
SRO	Single room occupancy
TasP®	Treatment as Prevention®, pioneered by BC-CfE
VCH	Vancouver Coastal Health

Appendices

APPENDIX 1: HCC RESOURCES

Accessing HCC Supports

What is Home and Community Care?

- Arabic
- Simplified Chinese
- English
- Punjabi
- Swahili

Home Care Our Way (BC-CfE webinar)

The BC Home and Community Care System and Older Adults Living with HIV
(BC-CfE environmental scan)

Provincial Overview of Community-based Organizational Supports for Older Adults Living with HIV

ADVOCACY SUPPORTS FOR OALHIV

Province-wide and National organizations

- Pacific AIDS Network
- Afro-Canadian Positive Network of BC
- Disability Alliance BC
- Office of the Seniors Advocate (BC's independent office acting in the interest of seniors and their caregivers)
- Office of the Ombudsperson (BC's independent office for fairness)
- Realize Canada
- Communities, Alliances and Networks

AIDS service and other community-based organizations in your region may provide HCC advocacy through navigation programs, peer supports, and other services.

Province of BC's HCC Legislation, Policy, and Standards

- Community Care and Assisted Living Act
- Home and Community Care Policy Manual
- Model Standards for Continuing Care and Extended Care Services
- Guidelines for Collaborative Service Delivery
- BC Residents' Bill of Rights

Thrive community-based research team

Horizons Community-Engaged Research Conference panel in Vancouver, May 2022

BRITISH COLUMBIA
CENTRE *for* EXCELLENCE
in HIV/AIDS
