# To the Beat of Our Own Drum:

## African, Caribbean and Black Canadian Elders on Aging with HIV

**November 2019**

realize
FOSTERING POSITIVE CHANGE FOR PEOPLE LIVING WITH HIV AND OTHER EPISODIC DISABILITIES

# Land Acknowledgement

***Realize*** acknowledges this land on which we work. Turtle Island, is the territory of diverse First Nations, Inuit and Métis Peoples.

We are grateful to have the opportunity to live and work on this land.

Acknowledging the Cultural Mosaic of Canada, we acknowledge the many other peoples who have contributed to this place we now call home. We want to acknowledge the many traditions and cultural backgrounds that are represented. You, your families, and your ancestors, all have roles to play in making this space an inclusive and welcoming one and for that, all of us at ***Realize*** say, Thank You!

# Background and Introduction

People aging with HIV experience unique issues and concerns compared to people aging without HIV, for example, an increased burden of aging-related health conditions, requiring them to develop long-term self-care practices. [3] [4] [5]

For African, Caribbean and Black (ACB) community members aging with HIV (AAWH) stigma and discrimination related to many dimensions of a person's identity including age, HIV status and race, among other factors such as immigration status and gender, further impact healthy aging.

***Realize***, as the secretariat for the National Coordinating Committee on HIV and Aging, has been the leader in Canada in conducting community based research, leading discussions and holding conversations over the years about what it means to age with HIV and to be an older person living with HIV. We were cognizant, however, that all narratives about aging with HIV and being an older person living with HIV are not homogenous and as such, partnered with a number of ACB stakeholders to inquire about – for the first time by any national HIV organization in Canada – what it means to age well with HIV in the ACB community.

**Fast facts about HIV in Canada:**

- There are approximately 63,110 people living with HIV [1]
- There were over 2000 new HIV diagnoses in 2017
  - ▶ 22.9% were among people 50 years or older [2] which makes sense since, by 2030, 23% of people in Canada will be seniors [3]
  - ▶ 25.3% were among people from African, Caribbean, and Black (ACB) communities even though ACB communities represent only 5% of Canada's population [2]

It is our hope that this resource serves as only the beginning of this conversation and in fact, will be used by academic and community-based researchers, public policy decision makers, community based HIV organizations, aging services organizations, and most importantly older adults with HIV, to come together to share information and experiences of the many narratives around aging with HIV, as well as to identify strategies to collectively enhance future practice, programming and policy which impact ACB community members aging with HIV in Canada.

# What is Aging well with HIV in the ACB community?

Narratives around aging vary across ACB communities due to the immense cultural diversity that exists; but overall there is a true desire to age. ACB community members generally perceive aging as a blessing and respect the aging process. Like most aging people, they want to age amongst their loved ones and community. AAWH view 'aging well' as more than living up to a biomedical standard of health. To age well with HIV means to take into consideration the diverse array of challenges a person may experience.

***"Being emotionally, physically, mentally, and spiritually fit, while having access to ALL necessary medical, financial, and housing services as you age." (Francophone Community Member)***

# What we did

### Literature Review

We searched for published literature on HIV and aging among ACB people using the search terms: HIV, Age, Aging, African, African American, Black, Caribbean, Canada, and United States. We found a total of 1182 articles and reviewed the abstracts of the 35 we felt were the most relevant. Articles that focused on the needs and experiences of AAWH in Canada were limited. A total of 13 studies conducted in the United States were chosen for full review. The following themes were identified:

(1) stigma and discrimination
(2) comorbidities,
(3) mental health and resilience,
(4) barriers to necessary services,
(5) social support and religion,
(6) relationships and sexuality, and
(7) self-care and wellness.

### Focus Groups and Interviews

***Realize*** conducted focus groups and interviews with 9 AAWH and 4 service providers who work with older adults from ACB communities to further explore the themes emerging from the literature review. Most older adults with HIV who participated identified as women, age 50-59, and heterosexual.

**What are the needs of ACB community members aging with HIV in Canada?**

**What does aging well with HIV mean for ACB community members in Canada?**

# Project findings

## Common Concerns about Growing Older with HIV

Some concerns about HIV and aging expressed by AAWH are also commonly expressed by older adults living with HIV from other racial and ethno-cultural backgrounds. These include worries about developing age-related health conditions; changes in sexual health; uncertainty about the future, especially with respect to financial security; and end-of-life planning.

*"The HIV doesn't scare me no more, it's the other comorbidities that scare the dickens right out of me."*
*(Community Member 1, Man)*

*"To me that's the biggest impact, I think for me I don't have any sexual drive at all. Like it's just gone. I don't feel like I want it, I have no desire… It doesn't impact me so much. It does impact my husband because I'm not in the mood."*
*(Community Member 3, Woman)*

*"I left my job because again, and I think this is important, we were told we had 3 years to live. In fact, the doctors were sure of it, tops 3 years. So, you know you had that in the back of your head, that 'I am not going to live' which really isn't conducive to making plans or anything of that nature, any forward thinking." (Community Member 2, Man)*

*"Financially, of course I'm worried because there is a lot of stuff that is limited, that because of your HIV status, you can't have." (Community Member 3, Woman)*

For further information on many of the common concerns of people aging with HIV, you can refer to:

- The Graying of AIDS (http://www.grayingofaids.org/)
- HIV & Aging in San Francisco: Findings from the Research on Older Adults with HIV 2.0 (http://gmhc.org/files/ROAH_2.0_San%20Francisco_ACRIA_HIV_Aging_White_Paper_FINAL.PDF)

## Specific Concerns about Growing Older with HIV as an African, Caribbean or Black Person

In addition to sharing some of the same concerns about aging with HIV as their non-ACB peers, AAWH may experience unique issues related to the intersection of HIV, aging, cultural norms, and racial identity. Intersecting forms of stigma, access to mental health care and lack of culturally competent services are three such issues.

### STIGMA

Experiences of stigma and discrimination may have complex effects for AAWH whether it is experienced at the interpersonal, institutional, or societal level.

Within families and social networks, disclosure of an older person's HIV status can lead to:

- isolation and rejection from family, friends and one's cultural and religious community resulting from ignorance and a lack of knowledge of HIV
- stigmatizing comments and behaviour, including refusing to touch, use shared dishes, or interact with AAWH [6] [7]
- further disclosure among other friends, family, and community members without consent [7] [8]

*"I was ostracized from my community when they found out. So, I couldn't go to anything that had to do with my community at all. I couldn't go to weddings, I couldn't go to funerals, I couldn't go to parties, I couldn't go to any events. I wasn't invited, I wasn't welcome, I wasn't allowed to… When you come to Canada as an immigrant, all you have is your community. We need our community and after I was diagnosed my community was taken away from me." (Community Member 3, Woman)*

Rejection and isolation by those in their innermost circles can have a traumatizing effect on AAWH and may lead to inter-generational trauma and community isolation since rejected AAWH may choose to separate their children and families to avoid further stigmatization.

Within institutions like the healthcare system and the workplace, the intersection of HIV status with other identities, including race and age, has the potential to compound stigma and discrimination. In healthcare, ignorance about HIV can make it difficult for people to access care, even if it is available in their backyard. Focus group participants spoke of challenges finding practitioners who are knowledgeable of the needs of people aging with HIV, and/or willing to consider that some health concerns may not be directly HIV-related. Not only does stigma act as a barrier to care, resources, and services, but it necessitates having to repeatedly disclose one's HIV status to new service providers causing trauma. Anti-blackness is also a concern since the narratives surrounding Black people living with HIV have negatively impacted the ways ACB community members navigate and interact with society. Stigma may be even worse for ACB persons living with HIV who are new migrants, speak little English, or encounter stereotypes related to HIV and their country of origin.

*"Accessibility isn't just about transportation. If you have a bad experience you're not going to want to go back." (Community Member 3, Woman)*

**Aging as a Black Woman Living with HIV**

Black women are likely to face specific gendered and racialized forms of HIV-stigma based on assumptions of sex-work and sexual promiscuity. [7] [9] Due to the association of "immoral" behaviour with HIV, HIV-positive Black women's ability to fulfill gendered roles like caregiving and child rearing can brought into question. [9]

Furthermore, the intersection of negative attitudes toward Black women and HIV can also increase Black women's vulnerability to gendered and domestic violence due to internalized stigma, and feelings of worthlessness. [9]

**Aging with HIV as a Man who has Sex with Men**

Older Black gay, bisexual, or other men who have sex with men (gbMSM) living with HIV may experience homophobia, racism, HIV stigma and/or ageism when trying to connect with peers that share one of their identities.

For example, BlackMSM may experience racism from the gbMSM community and within spaces designed for LGBTQ community members. Homophobia can lead to Black gbMSM being rejected from their cultural and religious communities. Black gbMSM living with HIV may be marginalized within both LGBTQ and ACB communities due to HIV stigma. An increased risk of violence, including structural violence from institutions that are meant to serve them such as police and healthcare services, is a resulting reality for this population [8] [11] [12].

## ACCESSING MENTAL HEALTH CARE

Mental health services are both needed, and desired, by AAWH who may experience a unique combination of mental health concerns, including:

- Symptoms of depression and anxiety [10] [11], and/or
- Trauma resulting from:
  - Isolation and rejection from family and social networks [6] [7]
  - HIV-associated stigma and discrimination, or
  - Events that occurred in their countries of origin.

When accessing mental health services AAWH may prefer one-on-one counselling and support groups over medications prescribed by psychiatrists due to the stigma of being labeled with a mental illness in many cultures. [8] [12] [13] In most settings, however, access to talk therapy is limited resulting in either long wait times for mental health care or unaffordable out-of-pocket costs.

## LACK OF ACCESS TO CULTURALLY COMPETENT CARE

Proximity, scheduling issues, and financial insecurity can all act as barriers to accessing culturally competent care for AAWH. ACB- or HIV-specific programming may be limited outside of major cities or in rural settings. Even if such programming is within driving distance, it may not always be easy for working AAWH to schedule appointments, especially those who have a "weeks on-weeks off" schedule. Transportation and childcare costs may be prohibitive, especially for women who may not want their children to know about their HIV status [8].

## CONCERNS ABOUT AGING-RELATED CARE AND SUPPORT

While it is traditional practice for older ACB people to spend their final years in their homes surrounded by family, AAWH may not have the same opportunity due to stigma or a need for more complex care. Anxiety about experiencing discriminatory behaviour from long-term care staff further amplifies concerns about future care.

Focus group participants also expressed anxiety about cuts to funding for community-based HIV organizations and a lack of support among younger generations for these vital supports.

*"We don't want our organizations to be cut because they don't understand. When they say the Black African population, that means we are here without our families, and the only thing that keeps us alive with HIV are our organizations. Because those are the ones we turn to when we are sick, they're the ones we talk to when we have problems, they are the ones we talk to when we feel alone."*
*(Francophone Community Member)* *

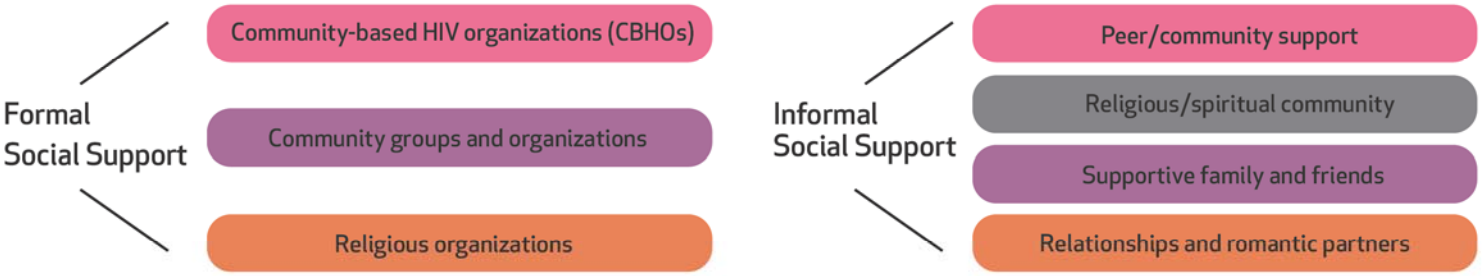
* Quotes translated from French may not be verbatim due to differences in dialects

# Social Support and Wellness

Social support and wellness have the potential to positively impact the quality of life of AAWH. Holistic views of health and a well-rounded approach to health maintenance may help AAWH move from "aging with HIV" towards "aging well with HIV".

## SOCIAL SUPPORT

As previously discussed, families and social networks can be a source of stigma and trauma for AAWH, however, if they are supportive, their presence is an invaluable resource. [8] [12] [13] Social support networks can be formal or informal and it is important that community members decide which work best for them.




Opportunities to socialize, whether with HIV-positive peers or others, are especially important to AAWH who have limited incomes or are isolated because of geography or discrimination. In some cases, interacting with friends who are not living with HIV allows AAWH to focus on interests beyond HIV.

## WELLNESS STRATEGIES

AAWH report using many different strategies, practices, and resources to maintain their wellness, including religion, self-care, putting themselves first, finding purpose, and utilizing health services:

***Religion and God:*** Religion and God play a central role in the lives of many AAWH, providing a source of strength and peace. Some AAWH say that, at their lowest points, their beliefs kept them alive.

*"My faith in God. I'm a Christian, I believe in God and I think my faith is one of my strongest things, that is 100% my go to… Somebody needs to do a study on how religion impacts health, especially Black people."*
*(Community Member 3, Woman)*

***Self-Care Techniques:*** Maintaining a focus on the present, meditating, and other forms of mindfulness are used by AAWH for grounding. Finding ways to eat healthily while still including foods they enjoy, while on a budget, is another example of how AAWH practice self-care in a balanced way.

***Putting Yourself First:*** AAWH describe that making their own well-being, including their physical appearance, a primary concern is important to their overall wellness. This is especially true for older women who may have cared for others for most of their lives. [11] [13]

***Finding a Purpose:*** Finding fulfillment or purpose in one's activities and/or feeling needed, whether by family, members of a social network, or others positively influences AAWH's quality of life and creates a positive outlook for the future.

*"I think working helps a lot, because I get up to go to work every morning. I have a purpose"*
*(Community Member 3, Woman)*

***Building a Supportive Medical Team:*** AAWHs say that having a competent, supportive, and knowledgeable medical team substantially increases their ability to manage comorbidities and take part in preventative care and thus increases their quality of life.

# Recommendations

**1. For Healthcare and Social Service Providers:**

- *Acknowledge and address the lack of knowledge around HIV and aging through continuing education.*
- *Embed ongoing anti-oppression and anti-racism training for students, physicians, nurses, other health professionals and administrative staff.*
- *Foster and maintain relationships with HIV organizations and community organizations serving ethno-cultural communities within your region of practice.*
- *Allow patients to decide how, when and to whom to disclose their HIV status.*
- *Actively engage and listen to patient concerns. Ask about their health beyond the biomedical.*

**2. For Community Organizations Serving People Living with HIV and/or ACB Older Adults:**

- *Connect with community and religious leaders to address HIV stigma, homophobia, and other forms of stigma within ACB communities.*
- *Address stigmatizing practices within the organization through policy change and anti-oppression training.*
- *Build relationships with other organizations and services to streamline referral processes for AAWH.*
- *Advocate for increased access to culturally competent health and mental health services for ACB communities and against policies and practices that support structural violence.*

**3. For Older ACB Persons Living with HIV:**

- *Join or inquire about local organizations and community groups with programming for older people living with HIV and/or people living with HIV from ACB communities.*
- *Build your own social network, and engage in activities that promote wellness and mindfulness.*
- *Consider making plans for the future using resources available through community-based HIV organizations and other community services.*
- *Inquire about and access mental health services when support is needed.*

*"If people with the illness are not involved from the policy, to the implementation, to the delegation, all of that, then it's rather pointless." (Community Member, Male)*

# Next steps

Based on this foundational project, ***Realize*** will continue to work in collaboration with ACB stakeholders and organizations to further our collective knowledge of the experience of aging with HIV among ACB community members.
Our next steps will include:

- Championing further research on the assets, needs and experiences of older ACB people living with HIV in the Canadian context, including exploration of the similarities and differences across diverse ACB communities;

- Undertaking awareness-raising, policy change and education initiatives that improve the quality of life of older ACB persons living with HIV; and

- Looking for new ways to engage older adults from ACB and other ethno-cultural minority communities in collaborative work on HIV and older adults in Canada.

## Community Resource List

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|---|---|---|
| **National**<br>• Canadian HIV/AIDS Black, African and Caribbean Network<br>• Canadian HIV/AIDS Legal Network<br>• CATIE | **British Columbia**<br>• Afro-Canadian Positive Network of BC | **Prairies**<br>• HIV Community Link<br>• HIV Edmonton |
| **Ontario**<br>• The African and Caribbean Council on HIV/AIDS in Ontario (ACCHO)<br>> Provides a list of service providers in Ontario that provide programs for PLWHIV in the ACB community | **Quebec**<br>• MIELS-Québec | **Atlantic**<br>• AIDS Coalition of Nova Scotia |

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## FOSTERING POSITIVE CHANGE FOR PEOPLE LIVING WITH HIV AND OTHER EPISODIC DISABILITIES

***Realize*** is the leading national, charitable, organization working to improve the health and well-being of people living with HIV and other episodic disabilities, across the lifespan, through integrated research, education, policy and practice.

Formed in 1998, ***Realize*** (formerly the Canadian Working Group on HIV and Rehabilitation) promotes innovation and excellence in rehabilitation in the context of HIV and other chronic and potentially episodic conditions. In order to promote a comprehensive approach, ***Realize*** is multi-sectoral and multi-disciplinary in its membership and activities.

***Realize*** members come from across Canada, as well as internationally, and include people living with HIV and other chronic conditions, members of community-based HIV and disability organizations, national associations of health professionals, government agencies, private businesses, universities and the employment sector.

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