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RESEARCH ARTICLE

Mental health related experiences among African Caribbean, and Black immigrant and refugee families living with HIV/ AIDS in Greater Toronto Area, Canada

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Abstract: *Introduction:* In 2021, there were nearly 38 million people living with HIV worldwide and approximately 61,110 in Canada. Africans, Caribbean people, and the Black community make up less than 3.5% of the Canadian population, but account for 22% of people living with HIV in Canada. Our study explores the mental health related experiences of African, Caribbean, Black immigrant families living with HIV in Canada's Greater Toronto Area. *Methods*: A qualitative descriptive study was carried out between September, 2022 and December, 2023. Purposive sampling was used to select 20 participants, and semi-structured interviews were conducted. Content and thematic analyses of data were performed. *Results:* Participants ranged in age from 32 to 73 years, 60% were female, the majority had only completed college (65%), and most of them were not working. Three themes were identified: 1) HIV related struggles (neurocognitive impairment, HIV-related stigma and shame, racism and discrimination, and the impact of HIV-related stigma on mental health); 2) Systemic barriers (racism, stereotyping, systemic discrimination, employment and housing issues); and 3) social network building (isolation and solitude, disclosure dilemma). *Discussion:* Intersecting and complex factors associated with immigration and resettlement of African immigrants living with HIV affect their mental health and that of their families. Isolation and social exclusion are major stressors for these families, and their mental health is compromised by everyday encounters with systemic barriers. *Conclusion:* African immigrants and refugees living with HIV/AIDS experience mental health challenges related to co-morbidities caused by the HIV Virus. Integration of mental health services into HIV services would strengthen HIV prevention and care outcomes and improve access to mental health care.

Keywords: Immigrants and refugees, HIV/AIDS, mental health, families, Canada.

Résumé: *Introduction*: En 2021, près de 38 millions de personnes vivaient avec le VIH dans le monde et environ 61 110 au Canada. Les Africains, les Caribéens et la communauté noire représentent moins de 3,5 % de la population canadienne, mais 22 % des personnes vivant avec le VIH au Canada. Notre étude explore les expériences liées à la santé mentale des familles immigrées africaines, caribéennes et noires vivant avec le VIH dans la région du Grand Toronto au Canada. *Méthodes***:** Une étude qualitative descriptive a été menée entre septembre 2022 et décembre 2023. Un échantillonnage raisonné a été utilisé pour sélectionner 20 participants et des entretiens semi-structurés ont été menés. Des analyses de contenu et des analyses thématiques des données ont été effectuées. *Résultats:* Les participants étaient âgés de 32 à 73 ans, 60 % étaient des femmes, la majorité d'entre elles avaient seulement terminé le collège (65 %) et la plupart d'entre elles ne travaillaient pas. Trois thèmes ont été identifiés: 1) les difficultés liées au VIH (déficience neurocognitive, stigmatisation et honte liées au VIH, racisme et discrimination, et impact de la stigmatisation liée au VIH sur la santé mentale); 2) les obstacles systémiques (racisme, stéréotypes, discrimination systémique, problèmes d'emploi et de logement); et 3) la constitution d'un réseau social (isolement et solitude, dilemme de la divulgation). *Discussion***:** L'intersection et la complexité des facteurs associés à l'immigration et à la réinstallation des immigrants africains vivant avec le VIH affectent leur santé mentale et celle de leurs familles. L'isolement et l'exclusion sociale sont des facteurs de stress majeurs pour ces familles, et leur santé mentale est compromise par les rencontres quotidiennes avec les barrières systémiques. *Conclusion***:** Les immigrants et les réfugiés africains vivant avec le VIH/sida sont confrontés à des problèmes de santé mentale liés aux comorbidités causées par le virus VIH. L'intégration des services de santé mentale dans les services de lutte contre le VIH renforcerait la prévention du VIH et les résultats des soins, et améliorerait l'accès aux soins de santé mentale.

Mots-clés*:* Immigrants et réfugiés, VIH/sida, santé mentale, familles, Canada.

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Introduction

Advances in Human Immunodeficiency Virus (HIV) treatment have led to increased longevity and an overall health improvement among people living with HIV and Acquired Immunodeficiency Syndrome (AIDS) (Canada's Course for HIV and Hepatitis C Information (CATIE), 2024). Nevertheless, many People living with HIV/AIDS (PHA) continue to experience mental health challenges, and physical disabilities associated with long-term adverse effects of HIV treatment. HIV related neuro-cognitive impairment, economic marginalization, psychosocial distress related to HIV stigma, and stress related to fluctuating health condition have significant impact on their overall health and well-being and contribute to physical as well as mental disabilities (Akhtar et al., 2017; Wong et al., 2013).

HIV disability, as defined by the Social Security Administration (SSA), refers to the condition in which HIV infection and related symptoms prevent an individual from engaging in substantial gainful activity for an extended period of time, typically 12 months or more (Nall, 2022). Disability may be broadly defined as cognitive, physical, mental, and emotional symptoms and impairments, challenges to social inclusion, difficulties with day-to-day activities, and uncertainty or worrying about future health that may be episodic in nature (O'Brien et al., 2008; O'Brien et al., 2009).

For people living with HIV, disability status recognises the impact of the virus and related complications on their ability to work and support themselves financially. It recognises the challenges posed by HIV-related symptoms, treatments and associated health problems that may limit their ability to maintain employment over an extended period (Nall, 2022). The SSA's recognition of HIV as a potentially disabling condition underscores the importance of access to disability benefits and support services for people who are unable to work because of their health condition. These benefits aim to provide financial assistance and access to health care to help manage the impact of HIV on daily life and overall well-being (Nall, 2022).

Uncertainty related to work, income and access to health care is a significant source of stress for newcomers with HIV/AIDS, and significantly impacts on their health and wellness. Research on migration, mental health and HIV shows that immigrant and refugee families experience high levels of settlement stress (Luenen et al., 2018). Their health outcomes are influenced by interrelated factors including pre-migration experiences, education, citizenship and social status, settlement experiences, access to adequate income, health and social care, employment, housing, social support, and community connections (Kastrup, 2016; Wagner et al., 2018). Studies reveal that unemployment, underemployment, and poverty among immigrants and refugees are associated with discrimination and social exclusion (Logie et al., 2016; Samhkaniyan et al., 2015). Their migration is seldom a planned choice, and they cannot return to their home countries for fear of persecution; at the same time, they face significant uncertainty about their Canadian residence/citizenship. Overall, they tend to have poorer health status compared to the documented migrants such as the economic or skilled categories (Freedman, 2016; Turan et al., 2016).

Insight gained from research suggests that the mental health of African, Caribbean, Black (ACB) immigrant and refugee families living with HIV is influenced by a myriad of intersecting factors linked with their multiple identities holding an HIV diagnosis, being a racial minority, belonging to the ACB community, and being an immigrant or refugee (Haddad et al., 2019). In addition to managing their migration and settlement stressors, they also must deal with HIV related stigma and discrimination, HIV associated co-morbidity, effects of the HIV virus on their bodies, side effects of HIV medications, and natural consequences of aging within their cultural communities and the Canadian society at large (Cruz & Ramos, 2015; Haddad et al., 2019). While research has begun to address mental health issues among PHA, research on the mental health of racial minority immigrants and refugees, including ACB immigrant and refugee families living with HIV/AIDS, is scant. Given the research gap, our study explores the disability experiences among ACB immigrant families living with HIV in the Greater Toronto Area (GTA) in Canada.

Methods

Study Design

A qualitative descriptive approach was used to allow participants to tell their stories in great depth, building up a detailed picture of complex issues that are, to date, under explored. Rationale for the use of qualitative descriptive design is to provide an accurate, clear, and comprehensive description of experiences and perceptions (Sandelowski, 2010).

Our qualitative descriptive research study was carried out in Greater Toronto Area (GTA) between September 2022 and December 2023. The Greater Toronto Area encompasses the city of Toronto and the surrounding municipalities of Durham, Halton, Peel, and York. We employed purposeful sampling to recruit participants that met the inclusion criteria which included: persons over 21 years of age from GTA's ACB communities living with HIV and having experienced an episode of illness attributed to their HIV status.

Human Participants Review Sub-Committee at York University reviewed and approved this project on April 26, 2023 with the #: e2023-141. Each participant was requested to give informed consent to participate in the study and participation was voluntary. Participants were recruited thought an e-distribution of study flyers through Africans in Partnership Against AIDS (APAA) organization in GTA. For consistency and to add rigor to the study, all interviews were conducted by the same interviewer (JK), the principal investigator of the study and first author.

Recruitment and Data Collection

Participant recruitment was carried out in partnership with APAA leaders and community supporters who shared our recruitment flyers within their networks. Research participants contacted the researcher to further explain the project, and to obtain signed consent forms. At the beginning of each interview, the interviewer obtained consent from each research participant.

All interviews were conducted in English using an open-ended interview guide. In total, 34 participants were contacted the researchers to show their interest. After they answered the screening questions, 20 met the inclusion criteria and were interviewed using semi-structured interviews. Interviews inquired about the health-related challenges of living with HIV, as well as the difficulties faced in their day-to-day lives. Interviews also aimed to understand how these challenges affected the quality of life of people living with HIV/AIDS. Interviews were on average an hour in length and conducted through Zoom or telephone. The interviews were audio-recorded and transcribed verbatim. Demographic information was also collected.

Data Management and Analysis

We used a thematic analysis approach to understand the disability experience of the immigrant and refugee families living with HIV. Initially, three research team members (1st, 2nd, and 4th author) independently coded the first three transcripts and then met to discuss the emerging themes. Based on these discussions, a codebook was refined and developed, which was then applied to the remaining transcripts by the first author independently, who met periodically with research team members for feedback and input. A reflexive memos and field notes were incorporated throughout the process to enrich the analytic interpretations. Emergent and final categories and themes were developed through consensus of all members of the research team. The research team met periodically during the analysis process, documenting key methodological decisions along the way. Atlas-ti software was used to facilitate the analysis and organize the data.

Results

With regards to HIV testing and diagnoses, the data in Table 1 shows that there was a spike (2000-2010) in HIV diagnoses among the participants. This could be due to awareness campaigns, testing initiatives, or changes in healthcare practices.

The majority of participants said they were in fair or poor health, which fits with the chronic nature of HIV, and that people with HIV also have other health problems. Almost all the participants had additional health problems in addition to HIV, which highlights the challenges of people with HIV in managing their health. This was

Table 1: Characteristics of Participants in the Study including Health

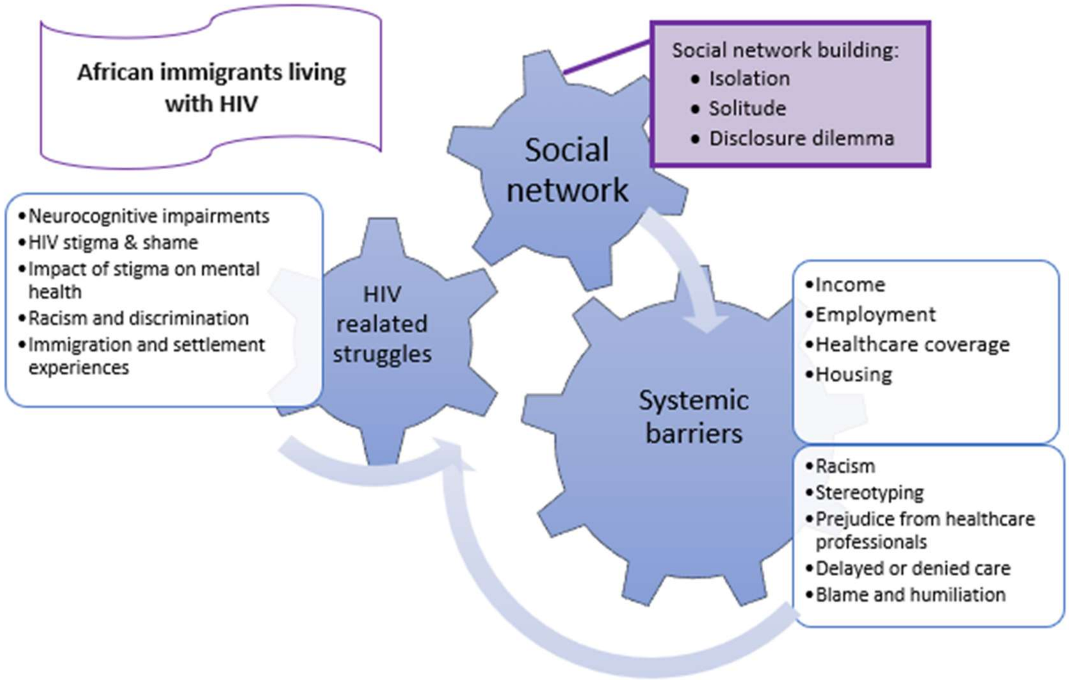
Characterstic	Number N= 20	Range (mean)	Category %
Age		32-73 (49)	
Gender			
Female			60
Male			40
Others			0
Education level			
High school			25
College			45
Undergad degree			15
Masters			15
Marital status			
Single			65
Married			10
Seperated			15
Widowed			10
Children			
No child			5
One child			20
Two to Three children			55
Four to Five children			15
Household income			
Less than 20K	17		85
35K to less than 50K	3		15
Employment status			
Not working			65
Part time			25
Full time			10
Living situation			
Rent	12		60
Government subsidized	8		40
Tested postive for HIV			
Before 2000			10
Between 2000 - 2010			70
After 2010			20
Health problems			
Heart disaese	16		75
Diabetes	3		15
Obesity	1		5
Other illness	1		5
Overall health			
Poor	6		30
Fair	11		55
Good	3		15
Time spent without OHIP coverage			
Less than 3 months	3		15
3-6 months	11		55
More than 6 months	6		30

compounded by delays in obtaining an Ontario Government issued health card (OHIP), thus delaying access to essential healthcare. The findings spotlight the problems of people with HIV with varying complex healthcare needs, including managing other health problems, getting timely access to healthcare and understanding the healthcare system.

The mental health determinants that affect overall health outcomes, well-being, and treatment adherence of ACB immigrants and refugees living with HIV are numerous and complex. These determinants are influenced by a range of economic, cultural, social, and psychological factors.

Three themes were identified from the data, which provide insight into the mental health experiences of ACB immigrant and refugee families living with HIV in GTA. The three themes are: 1) HIV related struggles 2) systemic barriers, and 3) social network building. They have a great impact on the mental health of ACB immigrants and refugees PHA. (See Figure 1).

Figure 1. Study Themes: Mental health determinants of ACB Immigrants/ Refugees Living with HIV in GTA



Themes 1: HIV related struggles

The research participants mentioned that they are confronted with considerable challenges pertaining to their HIV illness and status. The difficulties outlined included neuro-cognitive impairment, HIV-related stigma and shame, impact of HIV-related stigma on mental health, and racism and discrimination. These challenges are profound and interrelated.

Neuro-Cognitive Impairment due to HIV.

Neuro-cognitive impairment can affect various aspects of daily life, making tasks that were once routine more difficult to manage. The social barriers, feelings of isolation, and discrimination that result from HIV stigma further exacerbate these challenges. Feeling unwelcome is likely to stem from societal prejudices and the stigma associated with HIV, which can make individuals feel excluded or marginalised. Furthermore, the cumulative effect of these struggles can severely impact mental health, contributing to stress, anxiety, depression, and other mental health issues.

Research participants provided rich descriptions of experiences of neuro-cognitive impairments related to HIV such as difficulty in staying focused on mental tasks, loss of memory, and feeling depressed. These mental health problems affected their ability to go to school and/or excel in employment training.

> For PHA, maybe I am speaking about myself. I think my mind is not working like before, not shaping like before in learning new tasks and memorizing things. In terms of going back to school, I think it is a big challenge for PHA, their mental and physical are very weak and get tired so easy (P5).

Moreover, their struggles in coming to terms with their HIV status frequently resulted in a sense of mental health barriers that further hindered them from pursuing their life's goals:

> Perhaps it is even mentally. Because I am HIV positive, I feel like I am not normal. I can't think and function normally, I can't do this, I can't do that. The mental part of me tells my body how to respond and do things. Sometimes I wake up in the morning and I say, "I am sick," and the body will feel sick. A lot of PHA have stopped going to school; we think HIV is eating our brain, and it could be true, or it could be something psychological (P2).

In order to address these challenges, it is necessary to adopt a comprehensive approach that includes medical support, social services, mental health care, and community outreach in order to combat stigma and promote inclusion and understanding. It is important to recognise the resilience of individuals facing these struggles and to advocate for policies and practices that support their well-being and dignity.

HIV Stigma and Shame.

All participants described HIV as a sickness of shame, and led to self-stigma and loss of self-esteem. Participants believed that HIV related societal stigma was associated with societal perceptions of promiscuous sexual behavior and practicing low moral standards.

> Yeah, you are perceived as like you have been not a good person for you to contract HIV. You are made to feel like it is your fault all the time and, unless you talk to someone and you hear their testimony, you don't know how they got it and it is a shame because we then paint it with just one brush, you have all been not looking after yourself or you have been sleeping around or yeah. So, it is sad.

The feeling of shame because of their HIV status was also echoed by P11, who stated:

> In our communities, when somebody has got it, it is disgrace, it is shame, you know you have to be left to die and thinks like that. So, when I was diagnosed with this sickness, I was in denial for many years, and skipped taking medications and took multiples tests to different places just because I can't admit this virus lives in my body. Even now I am still doubting, uhm, pause. Then after my self-esteem gradually became lower with self-stigma and self-shame. I am thinking okay, it is a sickness of shame, and now I am going to die, nobody will want me, nobody will want to talk to me.

Impact of Stigma on Mental Health.

Several participants in this study identified HIV related stigma and discrimination as the key stressors in the lives of Africans immigrants and refugees living with HIV, as one participant explained:

> People do not have knowledge about HIV transmission, despite education level. You go anywhere, and do you disclose that you have HIV? People would stare at you like you are different. You feel down, they think that you are mentally disturbed; they say you are not mentally competent enough to fit into anywhere; not in the workplace, or your own community, or society (P10).

Unlike other immigrants and refugees who openly look to their communities for support, many PHA participants in this study were reluctant to connect with their own communities, as one participant explained (P.12), "*if they find out your HIV positive status, they will think that you are a bad person, and nobody wants to connect with you. If they reject you, you are left with nobody*". The fear of being stigmatized and discriminated against by their own immigrant communities deepened the social isolation experienced by PHA. Many learned to live with their hidden PHA identity, which often led to a sense of incoherence:

> One of the big issues is suspicion and mistrust. I see that in my peers. Should we tell people? Shouldn't we tell people? As newcomers, we live in very small communities, so we are always paranoid and afraid that someone will know our status and it is very stressful (P7).

Although many PHA desired to embrace their own social identity and to receive support from their families, friends, and communities, they were caught in the dilemma of disclosure and nondisclosure which further compromised their mental health. Participants reported experiencing the mental health impacts of stereotyping and stigma associated with racialized immigrants and refugees living with HIV. One participant shared, "*people have stereotypes about immigrants and refugees as outsiders exploitative. They think that we are ignorant, uneducated, and only want to take advantage of the system" (P.3)*. Participants felt a sense of powerlessness, agony, and frustration that often made them feel depressed. Most ACB immigrant and refugee living with HIV attempted to resist these stereotypes by seeking to establish careers and financial independence, but lack of access to equitable income and employment opportunities impeded their resistance:

> Being an immigrant and/or refugee, you don't want to be on social assistance, but you don't find the job because your home qualification is not being recognized. Once you are living with HIV, you are qualified to the government disability benefits. That makes you feel you are disabled and that impacts on your mental health (P6).

Racism and Discrimination.

Most participants reported experiencing racism and discrimination as refugees/migrants living in Canada. Participant 7 specifically, spoke about their situation as a refugee: *"Up to now, I am still struggling with that issue (being unwelcome because she is a refugee), but I hope it is going to be okay".* Furthermore, P2 said:

> It is hard and hard sometimes. Sometimes there are situations that always remind you that you are a refugee … Once they know that you are a refugee that sort of look down upon you and the make you feel rubbish and nothing.

It was noted by participants that racial and HIV-related discrimination persists within the health system. This discrimination can take a number of forms, including an inadequate level of support for marginalised communities, differential treatment based on race or HIV status, disparities in access to healthcare services and discrimination from healthcare providers. One participant said:

> They refused, yes. So, you can see that in [name of city], discrimination is really deep, and even the racism – that racism. Because they don't – they imagine having these black people educating us, teaching us to do our job. But it's not teaching, you know, it's just reminding you of your sickness, with a lot of judgements behind HIV status, because we know that you are professionals, you are told (P10).

Discrimination and racism within the healthcare system can have severe consequences, such as individuals dropping out of treatment programmes or avoiding accessing necessary medications. When individuals experience discrimination in healthcare settings, they may feel marginalised, misunderstood, or mistreated, which can erode trust and lead to reluctance in seeking medical care. This is particularly relevant in the context of HIV/AIDS treatment, where consistent access to medication is essential for effective management of the condition. Discrimination can impede individuals from following treatment plans, resulting in suboptimal health outcomes and potentially increased transmission risks within communities. As one participant stated:

> And at the end of the day with discriminating hospitals, and some of them, they end up shying away from services, and these are the people who end up not accessing their medication (P13).

The discrimination faced by immigrants and refugees from their home countries resulted in significant challenges in accessing health services and disclosing their HIV status. These sentiments were expressed by one participant:

> …. When they get here, when they come to this country, they come with scars – scars of stigma. And they've been discriminated where they were, they've had some harsh comments, and they don't want that to continue. So, when they come here, they hide; they don't want to access services, and also, they don't want to open up to anyone, so they tend to stay in their homes. That is one, fear of stigma too. Stigma, fear, discrimination, hide come with scars (P6).

P15 mentioned that mental health support, counselling and mental healthcare play a crucial role in improving an individual's mental health and long-term engagement in HIV care:

> Integration of mental health care into HIV testing and treatment settings would not only strengthen HIV prevention and care outcomes, but it would additionally improve global access to mental health care.

Immigration and Settlement Experiences.

It is recognised that the processes of settlement and immigration can give rise to a number of stressors for individuals and families, which may impact their well-being and ability to adjust. Participants mentioned feeling unwelcome as a significant emotional and mental health stressor that immigrants often experience during their settlement and immigration processes. Like other newcomers, many PHA participants spoke of the stressors associated with their settlement and immigration processes in Canada:

> I lost my memory; I can't remember many things. I can't even remember my children's birthday sometimes because I am thinking about too many things. I think about (pause) the immigration status comes first, what if my refugee application fails? Then I am thinking: if I lie in a hospital bed, do I have anyone to visit me? And I don't have money, how would I have a funeral service? What am I going to do? You just think about dying (P12).

Some of the study participants did not plan to migrate to Canada; they had to flee from war, conflict, and violence in their origin country. Their mental health was extensively compromised by their lack of choice in leaving their family, children, and social network behind, and the uncertainty of being a refugee clamant. Their minds were pre-occupied with interlocking fear of homelessness, deportation and dying alone.

> For many immigrants or refugees, their survival depends on the Canadian support systems when they come to the country. If you don't have any family member in Canada, then you feel isolated with a lot of hopeless, sleepless, loneliness, and aggressivity. And then having HIV, they may not be feeling very safe to talk about it. Even if there is community and settlement support of newcomers, you don't know how they will respond to HIV. I think the issues of fear, isolation, and loss are huge (P17).

Theme 2: Systemic Barriers

By addressing systemic barriers and promoting equity in healthcare delivery, health systems can ensure that all individuals have equal access to high-quality care and achieve optimal health outcomes. Systemic barriers in healthcare create a systematic disadvantage for certain groups or individuals. These barriers can lead to inequalities in access to healthcare services and contribute to disparities in health outcomes. The most frequently cited forms of discrimination within the healthcare system, as reported by participants, included delayed or denied care, blame and humiliation, and excessive precautions.

Care Received by Health Professionals: "I Am the one Carrying the Body".

Participants mentioned that, despite their conditions, the type of care they received was typically focused on reducing the physical symptoms of HIV, rather than taking a holistic care approach that could address both their physical and mental health needs. This was well exemplified by P.18 who, when talking about mental health problems, said: "*Antiretroviral treatment, I get it from the general practitioners, mental health help, nothing really*." Most participants indicated that their family doctors, who they saw regularly for routine check-ups, were supportive and empathetic towards them. For instance, P.19 said that she built a relationship with her family doctor overtime and could talk freely about her health concerns: "*We have a very good communication with my family doctor, I feel more happy, whenever I go and sit with her, just to talk to her, explain to her how I feel."* However, participants felt that they were not treated with the same respect by other health professionals involved in their care and they felt disempowered by some of the dentists, occasional doctors, and nurse practitioners on duty. This is well exemplified by P12, who stated:

> There are times when you book an appointment and you see just any other doctor, they don't want to listen. There are times when I say, you are not listening to me, you are telling me, but I am the one carrying the body that you are working on, and you have to listen to what I am saying that I am feeling. Yes, I know it is part and parcel of the condition but at the same time, I am not well, you have to listen

> that I am saying I am not well. But sometimes they will say, oh there is nothing else we can do.

Participants indicated delayed care because of their HIV status even in situations requiring urgent treatment and care. One woman said:

> I was nine months pregnant and felt my baby was about to come. I went to the maternity unit with my husband, and I was sent back home even though I was in much pain, and it was my first pregnancy. Without examining me the nurse at the maternity unit asked my husband to take me back home and come back after three or five days. The time we reached home, my water broke immediately, and I started pushing very hard. My husband was under pressure and had no time to call for the ambulance. He drove me back to the hospital and I was rushed to the delivery room. I had my baby about ten minutes after I arrived. I still have pains in my lower back, and I believe they originated from the unattended labor (P16).

Furthermore, some participants felt that other health professionals (not from the HIV clinic) involved in their care fear contracting HIV from them. The fear of being contaminated is visible through the healthcare providers' reactions at the time of disclosure of HIV status. P10 stated: "*When I mentioned that I am living with HIV sometimes their face drops. They are like careful in this and that way, so when I go. Yes, I am HIV positive, but it is undetectable if you treat me."* Another participant, P6, talked about her struggle when disclosing her HIV status to a dentist she was referred to. She had indicated her HIV positive status in the pre-assessment form and this generated fear of contracting the virus in the dentist. After a very long wait the dental receptionist handed back her form. P6 believed this was due to the dentist not knowing how to handle her situation: "*But as soon as I signed that on the form, my time I waited was up to almost five hours. He (the dentist) could not touch me*." P6 then explained: "*it took time, and I was the last one (in the waiting room)*." P6 indicated that she reported this case to her designated support worker at the HIV organization, who wrote a letter to the dental clinic to inquire what had happened. The dental clinic wrote back and said, *"we are very sorry, some people don't know how to take this, but we need to train them."* This experience discouraged P6 from returning to that dental clinic: "*So, I never went back."*

Employment and Housing Issues.

Systemic barriers leading to underemployment and unemployment among ACB immigrants and refugees are well documented in the literature (Abdelkerim & Grace, 2012; Nwalutu & Nwalutu, 2021). Many ACB immigrants and refugees living with HIV desire full participation in Canadian society through work and civic engagements, but they are frequently caught between a rock and a hard place because of the eligibility criteria (e.g., a Canadian work experience is required for attaining a job). This poses a barrier to employment, and successful integration of immigrants and refugees into Canadian system and society. Some ACB immigrants and refugees living with HIV, who were recipients of disability benefits, felt trapped because taking on a low paying job without extended health benefits could lead to their loss of access to expensive anti-HIV medications covered by the government disability benefit program.

Immigrants and refugees in Ontario also experience a waiting period of more than 3 months before they can access health care coverage.

The intersecting effects of mental health, being a newcomer diagnosed with HIV, and lack of citizenship status impact the health and wellbeing of immigrants and refugees living with HIV. For instance, the lack of affordable, accessible, and safe housing was a key stressor. Some participants reported that their families kicked them out of the house when their HIV status was revealed, and they were left homeless and financially broke. Many tried to access social housing, but were faced with a long waiting period, and had to use the shelter system:

> Housing is a big issue and a source of stress. When you can't find housing, what to do? It is very hard to go to the shelter; there are too many noises, fights, and drugs. It is a stressful place. You can't rest properly, and your sleep is disturbed, but what can you do? (P15).

Furthermore, PHA living in low-income social housing experienced day to day challenges. Many PHA experienced mental health problems in the context of the hardships they had gone through and the frustration they felt. For instance, P3 said: "*I got housing, and I have to go to third floor high and there is no elevator. Because of my diabetes, I was amputated in my left leg, and I can't walk properly. I walk with a cane and every day presents* *hardship*." As documented in other studies, the lack of safe and stable housing contributes to increased stress and mental health problems. Living in substandard housing also makes it difficult for immigrants and refugees PHA to manage their HIV treatment and care (Logie et al., 2016; Saadat et al., 2015).

Theme 3: Building Social Networks: "I Have Nobody to Go to!"

The participants identified multiple risk factors that significantly impaired their ability to integrate and rebuild social networks. These included the practical challenges of being an immigrant or refugee with a chronic health condition and being exposed to HIV related stigma, racism, and discrimination. HIV organizations, Black Coalition for AIDS Prevention (Black CAP), Africans in Partnership Against AIDS (APAA), and People with AIDS Foundation (PWA) in Toronto were very supportive, and helped to address the loneliness of PHA. Participants explained that the APAA staff were very helpful, supportive, and understanding of their problems, knew how to deal with practical issues, and made them feel valued. One participant said:

> They make me feel like it is nothing, you know life continue and I can continue to be productive and contribute to the personal and family development. If I don't have an appointment, then I stay home. I don't go anywhere; I just stay indoors (P12).

Participants also discussed the detrimental effects of isolation and solitude on their mental health. In this regard, P15 stated:

> So, I am always in the house … Like some people organize to go out for drinks. I don't go out for drinks due to my condition, I can't walk very far, so I get left behind because I can't do much. I have nobody to go to visit, I stay home doing nothing. That is it…, I don't have friends and I don't trust anybody, I am afraid for involuntary disclosure. Sometimes I can stay in the house for more than one week and I haven't seen anybody. Everybody is busy … I don't live with anybody and because of this situation (being HIV positive).

The lack of social relations had an impact on PHA's mental health and caused fear to meeting people due to their mental health conditions, as P11 indicated:

> … I have so much fear, anxiety, and frustration of meeting other people and because of what happened before. … the only thing I don't want is to be by myself, … when I am alone, I start thinking about a lot of things and become unable to cope with daily problems, trouble to relate with people and build trust, with a depressed mood.

For most participants, living with HIV affected many aspects of their lives, in particular social aspects that are often taken for granted by non PHA people:

> Sometimes this life is very hard to live with. If someone who is not living with HIV comes to you and he says, "I want to be your boyfriend", what are you going to do? Are you going to tell him that you have HIV? And if you do, what will happen to the relationship? (P16).

While the challenges of HIV disclosure to potential intimate and sexual partners is comparable for both men and women PHA, the women in this research suggested that they experienced more pressure due to gendered and heteronormative expectations for women to be wives and mothers:

> You know HIV affect both men and women in different ways. Our greatest fear as women is getting sick and not having nobody around to take care of our children. We worry sick that people and/or government will take away our children (P10).

Discussion

This study reports on mental health related experiences among African, Caribbean, and Black immigrant/refugee families living with HIV in Greater Toronto Area in Canada. The study results indicate the intersecting effects of the complex factors associated with immigration and settlement, and living with HIV on the mental health of immigrant and refugee people living with HIV and AIDS. Similar to findings of other studies, our study shows that isolation and social exclusion are key stressors for immigrant and refugee people living with HIV/AIDS (Freedman et al., 2016; Turan et al., 2016).

The mental health of ACB immigrants and refugees living with HIV in this study was compromised by their everyday encounters with racist stereotypes, systemic discrimination (e.g., underemployment or unemployment, and educational qualifications and trainings not recognized in Canada), and a lack of clarity regarding the future prospects of these individuals, particularly in relation to the immigration process and poverty (Wong et al., 2013). Due to HIV illness, attempts to integrate into Canadian society by acquiring skills, training, and attending school programs were impacted by their inability to concentrate on tasks and lower energy levels making it difficult for them to achieve their learning goals (Remien et al., 2019). Our study shows that these challenges deepen their sense of loss, further contribute to their depression, and affect their mental health.

Many immigrants and refugee people living with HIV and AIDS in this study experienced diminished social support when they left behind their families and social networks to come to Canada. Social isolation was particularly high for those who were refugee claimants or without any immigration status because their migration was unplanned. Like other refugees, many of them had experienced pre-migration traumas, and had to leave their spouses, children, friends, and families for an undetermined period (Wagner et al., 2018). Being alone and faced with many uncertainties about their future, many of them experienced intense depression and anxiety associated with multiple fears including safety of their loved ones back home, potential deportation, living in poverty, becoming ill, and dying alone. Many immigrant and refugee people living with HIV and AIDS lacked stable housing and economic resources, which further compromised their mental health (Logie at al., 2016).

Several participants identified connection to HIV/AIDS community service organizations and peer support groups as key resources for their emotional and mental health. People living with HIV and AIDS participants who had received community support seemed to have an increased capacity to become PHA advocates and demonstrated a commitment towards providing peer support to other immigrant and refugee PHA in their communities. Furthermore, the results of this study suggest that immigrant and refugee PHA are at increased risk of non-adherence of HIV treatment associated with their experience of displacement, pre-migration trauma, and social and economic marginalization in Canada. Evidence shows that HIV treatment adherence is negatively associated with lack of access to income, food insecurity, unstable housing, lack of health and social care, and lack of social support (Waldron et al., 2021; Wong et al., 2013). In addition, immigrant, and refugee PHA experiencing post-traumatic stress disorder, anxiety, depression, loneliness, and other mental health problems are less able to manage their overall health or adhere to their HIV treatment regimens (Vitale & Ryde, 2018). On the other hand, improved access to social support, affordable and safe housing, and adequate income are found to be positively associated to HIV treatment adherence, improved mental health, and overall quality of life among immigrants and refugees PHA (Orza et al., 2015).

Concerning barriers to accessing healthcare, participants felt disappointed by the relationships they had with some of their healthcare providers, particularly with those who were not directly involved in their HIV care. For instance, when they tried to access emergency and dental services, they experienced stigma and discrimination. Good communication and discussion between patients and healthcare providers can improve quality services. Individual empowerment to make decisions about their own care is considered one of the key factors in supporting the recovery of individuals experiencing mental distress (Kamanzi & Richter, 2022; Samhkaniyan et al., 2015). This is also in line with the World Health Organization (WHO) Global Health Strategy which recommends enabling people living with HIV to be important partners in their treatment (WHO, 2016). However, the findings from our study indicate that the participants felt empowered and did have a voice in the care provided by their general practitioners; this supports the need to provide adequate support from general practitioners in their role of managing patients with chronic diseases (Remien et al., 2015; Sweeney & Vanable, 2016). This is also in line with the current WHO Global Health Sector Strategy on HIV which stresses the need for PHA to have a continuum of care across health services starting with primary care (WHO, 2016).

Despite the need for mental health interventions, participants received only treatment for their HIV related health problems. This represents a public health concern as there is evidence that poor mental health can lead to rapid disease progression and worsening of physical health issues (Chibanda et al., 2016; Yehia et al., 2015). In addition, it is becoming increasingly clear that physical health cannot be detached from mental health and well-being (Remien et al, 2019). It is important, therefore, that immigrant and refugee PHA have appropriate access to comprehensive HIV care, treatment, and support (Remien et al, 2019; WHO, 2016). The crossing of many adversities that participants experienced might have worsened their mental health, already impacted by their pre-migration and settlement challenges as well as the trauma of having contracted HIV and the effects of the HIV virus. It is, therefore, important to provide effective care for immigrants and refugees PHA with a holistic approach that addresses their physical and mental health needs and fosters their social recovery and community integration (Remien et al, 2019).

The evidence shows that social recovery promotes cohesion, personal and social identity as well as resilience in immigrant and refugee families (Marino, 2015; Saadat et al., Zeng et al., 2018). This is in line with the findings of the current study, which indicates that participants expressed the need for support to enhance their ability to cope with their HIV conditions as well as their social recovery and their ability to build cohesiveness and share their experience with other individuals in their situation. These factors are considered essential in supporting quality of life and the overall social recovery after HIV diagnosis (Remien et al, 2019; Samhkaniyan et al., 2015).

The results of this study have significant implications for HIV prevention, treatment, and care, especially in newcomer communities. At the end of 2020, it was estimated that approximately 6,590 people were living with HIV but did not know their HIV status, representing 10% of the estimated number of PHA (Public Health Agency of Canada, 2023). This study confirms the findings of other studies which show that HIV stigma and discrimination preserve silence about HIV/AIDS and discourage people from seeking HIV testing, treatment, and care. In 2018 racial minority immigrants and refugees made up almost 25% of all new HIV infections in Canda (Canada's Course for HIV and Hepatitis C Information [CATIE], 2024; Public Health Agency of Canada, 2023), thus, HIV stigma reduction efforts are critical to preventing HIV and promoting care particularly among newcomers.

Moreover, our study results suggest that immigrant and refugee PHA are at increased risk of HIV treatment non-adherence associated with their experiences of pre-migration trauma, displacement, and social and economic marginalization in Canada. Evidence indicates that HIV treatment adherence is negatively associated with lack of access to income, stable housing, food security, health and social care, and social support (Kamanzi & Richter, 2022; 2023). In addition, PHA experiencing post-traumatic stress disorder, depression, and other mental health problems are less able to adhere to their HIV treatment regimens or manage their overall health (Kamanzi & Richter, 2019; Kamanzi et al., 2022; Luenen et al., 2018). On the other hand, improved access to individual and structural determinants of health, including social support, affordable safe housing, access to affordable health and social services, and adequate income are found to be positively associated with HIV treatment adherence (Kamanzi et al., 2022). We argue that meaningful engagement of immigrant and refugee PHA and their families in program development, stakeholder collaboration, community-based organizations, such as Africans in Partnership Against AIDS and coordinated efforts among service providers across and within health, social, and private care sectors are critical to improving the mental health and overall quality of life among immigrant and refugee PHA and their families.

Limitation

This study included a small number of participants who were recruited through an HIV/AIDS organization in Toronto. The families who were interested in the study contacted the researchers and, following this contact, an interview was scheduled. As well, our study took place in one place (GTA) and one organization (APAA), and findings are limited to its context of immigrant and refugee PHA and their families. We believe that immigrant and refugee PHA who were not connected to the HIV/AIDS organizations might experience even more mental health challenges, exclusion, and marginalization. Another important limitation is that the analysis did not consider gender differences; this should be considered in future studies.

Another limitation is that all interviews were conducted in English, and participants had at least a minimum level of English-speaking ability. Therefore, experiences of immigrant and refugee families PHA who had very limited or no English language skills, were not captured by this study.

Finally, we recognize that immigrants are a heterogeneous group with different socioeconomic backgrounds, pre- and post-migration experiences, skills, and resources that shape their interests and needs. Our study findings are therefore limited to immigrant and refugee PHA and their families who are using APAA organization. Our findings may have limited applicability to other immigrant and refugee PHA groups who come from financially privileged backgrounds and are able to afford with ease multiple private services and respite supports.

Conclusion

Many African, Caribbean, and Black immigrant and refugee people living with HIV/AIDS continue to experience mental health challenges associated with co-morbidities, and the effects of the HIV virus. The mental health among people living with HIV/AIDS is a complex issue that is strengthened by the intersection of multidimensional health, psychological, social and systemic factors. Having contracted the virus, the side effects of HIV medications, natural consequences of aging, as well as poor living conditions contribute to the people living with HIV/AIDS' mental health.

This is an extremely vulnerable population, as they may be exposed to intersecting racial discrimination and prejudice as migrant and refugee PHA, HIV related stigma, low social economic status, as well as social exclusion. The mental health challenges they experience may discourage immigrant and refugee PHA from seeking adequate HIV treatment. In line with the current WHO global health strategy on HIV, the findings of the current study suggest that the emphasis on the treatment and care of the immigrant and refugee PHA should shift from the management of the physical symptoms of HIV to comprehensive and multidisciplinary care that addresses the multiple risk factors associated with their conditions (WHO, 2016). As well, immigrant and refugee PHA should have a voice in decisions about their care and they should be involved in the interventions that promote their mental health, integration, and their overall social recovery.

We recommend that Canadian HIV policymakers, practitioners, and stakeholders adopt a holistic approach to address the intersecting structural determinants discussed in this paper to improve the health and quality of life of immigrant and refugee PHA. Integration of mental health services into HIV services would not only strengthen HIV prevention and care outcomes, but it would additionally improve global access to mental health care.

Agree to Condition: All authors of the manuscript have read and agreed to its content and are accountable for all aspects of the accuracy and integrity of the manuscript. The submitted article is our original work that is not being considered or reviewed by any other publication and has not been published elsewhere in the same or a similar form.

Authors' contribution: JK, NK, AK, and FO were involved in the conceptualization of the study. JK is the principal investigator of the study and led the development and the preparation of the manuscript. All authors reviewed and provided input on drafts and approved the final version for submission.

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