



“I die silently inside”. Qualitative findings from a study of people living with HIV who migrate to and settle in Canada



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ARTICLE INFO

Keywords:

HIV/AIDS
Stigma
Immigrants
Sub-Saharan Africa
Caribbean
Canada
HIV care cascade

ABSTRACT

We report on qualitative findings from a mixed methods study, examining enacted and internalized stigma during mandatory HIV screening among immigration applicants living with HIV in Canada. Qualitative findings show alignment with characteristics of internalized HIV stigma. We conducted 34 semi-structured interviews, and analyzed the data through thematic analysis, using Intersectionality and the Internalized HIV Stigma Scale as our theoretical and analytical frameworks. Participants described experiences of enacted and internalized HIV stigma in ways that were consistent with the four main domains of stereotypes, disclosure concerns, social relationships, and self-acceptance, but also extended the description of HIV stigma beyond these domains. Experiences of internalized HIV stigma and enacted stigma during the Canadian Immigration Medical Examination could potentially influence individuals' long-term engagement in the HIV care cascade during the process of migration to, and settlement in, Canada. We present recommendations for the broader migrant health research agenda, health and social care providers, and public health policies.

1. Introduction

Human immunodeficiency virus (HIV) remains a global public health issue, with approximately 38 million people living with HIV in 2017 (UNAIDS Joint United Nations Programme on HIV and AIDS [UNAIDS], 2020). Although 25.4 million people are now on treatment, millions of people are still waiting for access to treatment, and people living with HIV (PLWH) continue to face HIV stigma in their everyday lives (UNAIDS Joint United Nations Programme on HIV and AIDS [UNAIDS], 2020). In Canada, there are approximately 63,110 people living with HIV, with a diagnosis rate of about 6.5 per 100,000 people (Haddad et al., 2019). Epidemiological evidence suggests that the HIV

infection rate among residents born in HIV-endemic countries is disproportionately higher than the rate of other Canadians (Haddad et al., 2019). The Government of Canada maintains a list of 71 HIV-endemic countries from which people migrate, including 68 in sub-Saharan Africa (SSA) and the Caribbean (Public Health Agency of Canada, 2012). Black people of African and Caribbean descent bear a disproportionate burden of HIV in Canada. The African, Caribbean, and Black (ACB) population represents 2.2% of the Canadian population yet represents nearly 20% of people living with HIV in Canada (Haddad et al., 2019).

In 2002, mandatory HIV antibody screening was integrated into the Canadian immigration medical exam (IME). Generally, all foreign nationals 15 years of age and older who are applying for immigration, and some applying for migration to Canada, must undergo an IME, including

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<https://doi.org/10.1016/j.jmh.2022.100088>

Received 2 October 2021; Received in revised form 24 February 2022; Accepted 25 February 2022

Available online 11 March 2022

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a mandatory HIV test (Government of Canada, 2019). As stipulated by the Immigrant and Refugee Protection Act, applicants are determined as either admissible or inadmissible to Canada based on various criteria, including findings from the IME (Minister of Justice, 2019). For some immigration applicants, the IME mandatory HIV antibody test confirms prior knowledge of an HIV diagnosis, but for other applicants, it is the initial diagnosis.

Immigration applicants living with HIV experience stigma within the Canadian IME, migration, and settlement process (dela Cruz et al., 2020). Stigma is defined as an undesirable attribute of an individual that affects the person's status in society (Goffman, 1963). HIV-related stigma is the single greatest obstacle to HIV testing and engagement in the HIV care cascade (UNAIDS Joint United Nations Programme on HIV/AIDS [UNAIDS], 2018). Stigma may be internalized by people living with HIV, in part due to stigmatizing practices by service providers in the health care system (Visser et al., 2008). There are several types of stigma as it relates to people living with HIV, and they are shaped by individual, social, and systems factors (Stangl et al., 2012). For example, *internalized stigma* is "the acceptance among people living with HIV of negative beliefs and feelings associated with HIV about themselves" [10, p.4]. Whereas *enacted stigma* is defined as "acts of discrimination, such as exclusion, or physical or emotional abuse towards an individual's real or perceived identity or membership to a stigmatized group" [(Canadian HIV/AIDS Legal Network, 2017), p. 1]. *Internalized HIV stigma* is associated with delays in seeking HIV testing, prevention practices, poor HIV medication access and adherence, poor engagement in the HIV care cascade and poor health and social outcomes (Blake Helms et al., 2017; Sayles et al., 2009; Turan et al., 2017; UNAIDS Joint United Nations Programme on HIV/AIDS [UNAIDS], 2014).

There is some evidence indicating that immigration applicants do not receive adequate post-test counselling during mandatory HIV screening. For example, dela Cruz and colleagues (dela Cruz, 2014) found that many immigration applicants did not recall receiving any pre-test counseling, and thus were not even aware that they had been tested when they received their HIV-positive diagnosis during the IME. In another study, immigration applicants reported insensitive, flippant and cursory post-test counseling, leaving people with a sense of shame, fear and apprehension about their health and immigration prospects (dela Cruz et al., 2020). Furthermore, participants rarely recalled receiving any advice, referrals or even reassurance from IME physicians about accessing treatment in Canada. Appropriate post-HIV testing counselling is critical in supporting the person living with HIV and overall public health management of HIV. Inadequate post-test counseling, including follow up care and specialist referrals can result in HIV treatment interruptions or delays during the immigration and settlement process (dela Cruz et al., 2020). Furthermore, insensitive delivery of a positive HIV test result can leave individuals with a sense of alienation from health care and support services. Such experiences contribute to consequences such as HIV-related stigma among immigrants living with HIV, which may influence the ongoing management of HIV at the individual and population health level (dela Cruz et al., 2020).

People living with HIV, including immigration applicants, may also experience health and social consequences such as: severe depression, social isolation, disengagement with the HIV care cascade, suicide ideation, and post-traumatic stress disorder (PTSD) (dela Cruz et al., 2020; dela Cruz et al., 2016; Sherr et al., 2010; Sweeney and Vanable, 2016; Turan et al., 2016a). PTSD is a lasting mental health condition after exposure to a traumatic event, and studies show that receiving an HIV diagnosis can be traumatic for individuals (Kelly et al., 1998; Olley et al., 2005), and can influence HIV medication adherence and health outcomes (Sherr et al., 2010). In the immigrant population, particularly newcomer refugees living with HIV, factors related to people's migration and settlement experiences include gender, race, culture, legal status, past traumatic experiences, and social marginalization. The intersections of receiving an HIV diagnosis, displacement, being socially marginalized, being a racialized group (United Nations,

n.d.), and institutional-state factors such as mandatory HIV screening (Gkiouleka et al., 2018), can potentially influence the health and social outcomes in this population.

Interruptions in the HIV care cascade have profound consequences at both the individual and population health level (UNAIDS Joint United Nations Programme on HIV/AIDS [UNAIDS], 2014). The HIV care cascade is a continuum of psychosocial and medical care between the time of HIV diagnosis to viral suppression (Kay et al., 2016). First encounters of stigma during the Canadian IME have been linked to immigration applicants not accessing or delaying engagement in the HIV care cascade (dela Cruz et al., 2020). HIV-related stigma remains pervasive in this population (dela Cruz et al., 2020; dela Cruz, 2014; dela Cruz et al., 2016). With limited research examining the experiences of stigma within the Canadian IME and engagement in the HIV care cascade during migration and settlement, research is warranted to further understand how this stigma is entrenched through the IME process, and as well as the impact of stigma on the level of engagement in the HIV care cascade during migration and settlement.

2. Methods

The findings of this paper focus on the qualitative findings from a larger mixed-methods study. The research question was: How do African and Caribbean immigrants living with HIV in Canada internalize and experience HIV-related stigma, during their experiences of the IME process, migration, and settlement? Applying a theoretical lens of intersectionality (Cho et al., 2013), we explored the experiences of internalized HIV stigma with factors such as the social environment, social status, and systemic environments such as immigration policies and procedures, as well as other factors located in participants' socio-political environment. Ethics approval was obtained from two Canadian University health research ethics boards. Informed consent was established with each participant prior to data collection. An honorarium in the form of a gift card valued at \$20CDN was provided to each participant upon completion of the interview.

2.1. Inclusion criteria, recruitment, participants, and sample

Inclusion criteria were adults who were 18 years or older and who have migrated to Canada from an African or Caribbean country, have a confirmed HIV-positive diagnosis, have received an HIV test as part of the IME (this applies to immigrants who arrived in Canada after 2002), were able and willing to provide informed consent, and were able to understand and speak English, and/or communicate with a translator. Through purposive sampling, participants were recruited. Through established partnerships in various communities across Canada, the research team recruited from AIDS Service Organizations, infectious disease clinics, and other non-profit organizations that provide programs and services for newcomers to Canada. The main mixed-methods study had a sample of 123 participants who were surveyed using the Internalized HIV Stigma Scale (IHSS) (Sayles et al., 2008). Of the 123 participants who completed quantitative data collection, 34 agreed to meet with a researcher for a follow up interview. Most of the study participants either had protected status under the UNHCR Refugee Convention or were awaiting application for refugee status in their new host country of Canada.

2.2. Data collection and analysis

Qualitative data were collected, using a semi-structured interview guide to explore the experience of HIV-related stigma during the processes of the IME, migration, and settlement. Individual interviews were conducted in-person or by telephone. Interviews lasted 45–60 min. We utilized NVivo software to manage qualitative data, initial stages of data analysis, and to facilitate our team approach to qualitative data analysis. We followed thematic analysis techniques outlined by Braun and

Table 1
Demographics of interview participants ($n = 34$).

Characteristic (n/%)
Gender
Male 15 (44%)
Female 19 (56%)
First time learning of HIV positive diagnosis during Canadian IME
Yes 19 (56%)
No 13 (38%)
No answer or unknown 2 (6%)
Country of Origin prior to migration to Canada
SSA 32 (94%)
Caribbean 2 (6%)
Legal Status on migration to Canada
Government-Assisted Refugee 19 (56%)
Privately sponsored refugee 2 (6%)
Claimed asylum for refugee status in Canada 10 (29%)
Family sponsor 3 (9%)
Other (other visa, then applied for asylum) 3 (9%)

Clarke (Braun and Clarke, 2012). In our first line of analysis, we familiarized ourselves with transcribed interview data, noting ideas found in the data. This was followed by initial coding of data or identifying features of the data systematically and across the entire data set. Third, the research team compiled codes into themes that resonated with IHSS features of internalized HIV stigma, namely, stereotypes, disclosure concerns, social relationship factors, and self-acceptance (Sayles et al., 2008). In this iterative process of qualitative data analysis, research team members worked together to define and refine themes, systematically identifying key stories around our research question and the experience of internalized HIV stigma during the processes of the IME, migration, and settlement. Research team members with expertise in qualitative methodologies led the analysis and reporting of qualitative data findings, adhering to principles of qualitative research rigor (Booth et al., 2014; Mackieson et al., 2019). For example, researchers practiced reflexivity during all phases of the qualitative study, attending consciously to the researcher's ongoing reflection of their engagement with participants during data collection, as well as data analysis. Reflexivity also minimizes researcher bias during data analysis, synthesis, and reporting of findings (Booth et al., 2014; Mackieson et al., 2019). Finally, we achieved saturation when our analysis reached conceptual depth and understanding of internalized HIV stigma based on the complexity and richness of our qualitative data (Braun and Clarke, 2021; Nelson, 2016).

3. Results

We present key demographic information of the sample for the qualitative component of our study ($n = 34$) in Table 1.

We found that many experiences of the study population reflected the four domains of internalized stigma measured by the IHSS. However, we also found that people's experiences of HIV stigma extended beyond the IHSS domains. The findings presented here are organized using the IHSS four domains as a thematic framework (stereotypes, disclosure concerns, social relationship, and self-acceptance), with additional subthemes that reflect the intersectional and layered aspects of social exclusion generated not only by HIV stigma, but also stemming from the challenges of settling in a new host country during migration and settlement.

3.1. Stereotypes

Participants experienced feelings of being judged differently by others due to their positive HIV status. For example, participants described how they felt their HIV-positive status and stereotypes towards PLWH

influenced their self-worth and lost opportunities in their new host country.

3.1.1. A diminished sense of self-worth

Several participants interrogated their own moral values and integrity after receiving an HIV positive diagnosis, expressing feelings of both shame and disbelief about being HIV positive. Participants recounted their experiences of the stereotypes associated with HIV, describing how they felt others perceived them:

They think you are a prostitute. (Participant 10)

People think ... when you are like that [having HIV] it's because you are a bad person, or you are promiscuous, or you've got so many boyfriends... Just the shame ... and the stigma. I mean I was scared of all those things. (Participant 21)

Furthermore, several participants also described how PLWH are unfairly treated in society, based on societal perceptions towards PLWH, and how criminality or blame are used to intimidate and threaten their social worth:

They [still] challenged me, they treated me like, you know, not dirt [but] they told me about the criminal thing [Canadian laws] ... I said I know about it...as if you are coming here to spread [HIV and] other illness... as if [we are] some kind of criminal when we have [HIV]. (Participant 26)

In my community, it is a disgusting disease, that's why I hate [being] HIV positive, you feel like it's a punishment for people who are careless, like me... (Participant 34)

As a result, some participants struggled to form positive self-images and life goals in the face of a perceived tarnished image.

3.1.2. A fear of lost opportunities

Participants described how their HIV-positive status shaped notions of loss, particularly, loss of socioeconomic status and opportunities in life in their new host country. The act of receiving a positive HIV diagnosis was shrouded with loss of life, and fear of death. Participants described a loss of hope, anticipating lost opportunities such as migration to a new host country, or not being able to achieve personal goals in life to improve one's socioeconomic status in their new host country. Further, participants spoke of the overpowering fear and threat of losing the opportunity to migrate to Canada after receiving a positive HIV test:

... [I asked] the medical technologist to do the test again. It came back positive again. But, once they told me I was inadmissible [in Canada] ... my husband [appealed through] a lawyer. (Participant 8)

Another participant felt her positive HIV test result meant the termination of the academic goals she set as a newcomer in Canada:

I decided to quit [school]. I was thinking, why? How can I go to Canada and I'm HIV positive? (Participant 6)

The same participant described that at the immigration interview she was informed that she could pursue studies in Canada, renewing her hopes to pursue further education, but she then faced another threat from her HIV positive status, after learning of the criminalization of HIV in Canada:

In Canada ... they accept HIV positive [people] but you must ... protect others ... if you don't do that, it will be a crime ... to contaminate [an]other person. (Participant 6)

For participants, stereotypes towards PLWH also meant feeling like nobody, or being invisible, resulting in lost opportunities to build social networks. Several participants were very fearful and reluctant to disclose their HIV status to their friends and family members, both in their home countries and in Canada.

The loss of the potential for rich relational opportunities was particularly devastating for participants who identified with cultural values of being a woman. Several women commented on how a woman's status in society is measured by one's ability to marry and become a mother. One participant described the impact of her HIV positive status on her identity as a woman, and her fears of dying in isolation:

I was so discouraged ... it was painful to me because ... I'm very young and... I was saying nobody's going to marry me with this kind of disease....and once I get sick, I'm gonna die without telling people what happened to me. [...] I just keep quiet and then die silently inside. (Participant 10)

Despite the availability and advancements in HIV treatment in their new host country, participants demonstrated a pervasive fear of not only an array of social exclusions, but also death due to their HIV diagnosis. Such fears were often rooted in participants' perceptions and/or experiences of societal stereotypes towards PLWH.

3.2. Disclosure

Participants described disclosure concerns during the immigration process, particularly during the IME. They worried about how non-voluntary disclosure of their HIV-positive status would impact their immigration application and ability to migrate to their new host country.

3.2.1. Concerns about non-voluntary disclosure during the IME

Given the stigma attached to HIV, many participants felt they could not trust the IME physician or clinical staff to keep their HIV diagnosis confidential. Several participants described the ways in which they felt their privacy was not protected during the IME process:

I think people just know that when people are sitting there [clinic where IME is conducted], this case, they know that, I think, she has been called, they already know that maybe she's HIV positive. [...] So I think everybody waiting in the room just knew that maybe I'm HIV positive. I feel so bad, I feel so ashamed. (Participant 3)

Several participants worried that they would be seen by others. One participant knew the health worker taking the blood sample for the IME and was worried about disclosure:

What I was more afraid of, the person that did the tests, the person that took the sample from me because she knew me. We went to school together. I was really scared because that information get[s] out, I don't know how to trust people then... (Participant 16)

Another participant expressed worries that multiple workers in the clinic (receptionist, nurse, physician) would have access to their test results:

Yes, I was told [about my HIV positive test results] in private. He [IME panel physician overseas] had secretaries and nurses maybe who worked with him and I'm sure definitely no matter how confidential he wants to keep that information, there's no way just him would know about it. (Participant 19)

One participant noted that immigration officers encouraged disclosure to their sponsor.

The Canadian government, they have the responsibility of protecting Canadian citizens. So they say that I have to tell my host [about my HIV] ... and it was up to him [sponsor] to decide if he wanted me to come anyway or that he didn't want to. So I had to call my host and let them know. (Participant 37)

This particular situation demonstrates the undue and sometimes inappropriate influence that staff within the immigration process have on immigration applicants. This is especially problematic when considering the vulnerability of individuals experiencing the uncertainty and stresses of both an HIV diagnosis and the immigration process.

3.2.2. Concerns that one's HIV status will be revealed because of HIV treatment

One participant worried that the side effects from antiretroviral therapy (ART) would reveal their HIV status and therefore did not want to take medications:

I wasn't on meds 'cause when [my friend] told me about meds was like "when you take meds the first maybe one month you're gonna lose weight, you're gonna get rashes, this is what I went through, I don't know if it will happen to you but it's likely to happen." ... So I refused to take the medication. (Participant 4)

One of the participants suspected that their HIV status had been disclosed through the process of getting HIV medications, and that this information in turn would be shared within the social circles of their employment and housing community:

Somehow people around got to know where I was living...So it could be traced to the medical side of it, like the hospital... So I believe that it's from the place that I received my medication, whatever my medical situation was kind of leaked from there. (Participant 17)

3.3. Social relations

Participants experienced internalized HIV stigma in interactions with health providers during the IME, and social relations with family, friends and broader society.

3.3.1. Social relations and IME physicians

Several participants felt the impact of HIV stigma in their social relationships with care providers. One participant described negative experiences, that they not receive adequate support and counselling from the IME physician:

I was mistreated...they need a counsellor, they need nurses, they need a doctor who understands people... [The IME and HIV testing was] really messy. Really messy. Even in clinics in Uganda, in small clinics when you go to test they counsel you before testing, they counsel you after testing with the IOM, which is a very big international body. But [with the IME] they don't have... Like if you are crying, no one cared, no one bothered. (Participant 4)

Often participants felt powerless during the IME exam, stunned by the results, and overcome with shock:

Being on the medical list [for immigration] you're happy. [...] I went in there, I did my medical and they told us to come back after 3 days. We went and they called us one by one. Then my time came, I went in there, I found this doctor, and the medical office is brutal [...] They strip you naked. They check you everywhere. They really, really embarrass you, and this is a lady checking men. ... I went in there, this lady [IME panel physician at IOM] was like you know what, did you know you have HIV?... I was like what do you mean? [...] Since I came here I never tested. (Participant 4)

In some cases, participants experienced the relational distance between the IME physician and themselves, and this was underscored by indifference, silences or a lack of offering follow-up treatment, after receiving a positive HIV diagnosis:

So I just came to reality that OK, he [IME physician] was just doing his job and he has done his job, and I needed to move on and leave him, and find someone else to help me out, so I stopped calling him or trying to get more information from him. (Participant 19)

It was evident that the experience of stigma and a lack of care had significant impacts. One of the participants described:

Like if you are crying, "what is happening?" no one cared, no one bothered. (Participant 4)

The emotional impact was still palpable in many of the interviews, with one participant calling the interaction with the IME physician "emotional torture" (Participant 1). Some participants strongly suggested to increase the educational efforts for IME panel physicians, particularly in the areas of delivering positive HIV diagnoses in caring and compassionate ways.

Very few participants described positive interactions or a sense of care that was extended to them. Even some of the positive encounters were marked by a sense of inattentiveness of individual needs or the impact of the diagnosis. Some participants experienced positive encounters with some of the health care staff at clinics, while feeling stigmatized by others:

Those people [IME panel physicians and staff], they are educated, they know about HIV. So the people at the clinic were very good...There's one doctor though... I felt so small and I could feel the HIV stigma with him and it made me so sad. (Participant 21)

There were times when translators were used to communicate test results and it was not always clear if the stigma also extended by and through the people who acted as translators. The feeling and sense of judgement was often present in the social interactions of personnel who were part of the IME process, raising questions about the psychological safety of their care. Given the IME panel physicians' association with Canada, participants had particular expectations, such as:

He [IME panel physician overseas] didn't explain [to] me, nothing, he don't tell me nothing to help me or something like that, he just delivered me the results and that's it and I was like wow, what I'm going to do now? I was expecting, he's working for immigration, he's going to be more, like someone that can provide you more information or more support ... (Participant 25)

3.3.2. Impacts on personal relationships

Participants also recounted the impacts of HIV stigma on their personal relationships. Participants described, for example, that they felt abandoned by family members and treated as less than human due to their HIV positive status. This radical change that follows a positive HIV diagnosis often leads to a sense of loneliness and a lack of connections to others. Many of the participants had to renegotiate social relationships, while others chose to be more isolated. Participants with young children often focused on the relationships they held with their children.

The most important thing in my life, it's this tiny girl right here (*pointing to daughter*). Just to make sure she's happy and healthy. And also besides that, myself. 'Cause if I'm not healthy, there's no way I'm going to be able to look after her. [...] it's difficult, especially for people like us who've migrated, you have no close family here. (Participant 28)

The challenges of settling in a new home can be overwhelming, with the added burden of worrying about one's own health and ability to care for loved ones.

We also found that for some participants, HIV-related stigma was experienced differently in Canada than in their country of origin. This participant described the difference between overt and indirect or subtle forms of HIV stigma and social exclusion:

So life hasn't been that easy for people with HIV. Even in Canada ... people judge us: You've been promiscuous, been sleeping around, you deserve it, you're cursed ... Our brothers and sisters from Africa, and our hosts, people we find here, yes. There is stigma in Africa, in very primitive way. There is stigma in Canada in a very smart way. You will never tell, yes. It's visible [in African countries], someone will tell you boom, I don't trust you ... Point blank, yes. And he will go and tell a neighbor who will go and tell his wife and he tells ... stay away from me, yes. In Canada, it's not like that. But it's there. They just keep a distance. (Participant 4)

One participant described their experience of social exclusion and disadvantage, as a migrant living with HIV:

I don't have friends because everyone is afraid to be friends with me, that I'm gonna give them HIV too. [...] Here [in Canada] is like I'm in the jail, I don't like it here at all. (Participant 12)

3.4. Self-Acceptance

We examined the domain of self-acceptance and found that participants experienced internalized stigma at the individual level, as influenced by social and cultural factors.

3.4.1. 'I tried to keep a low profile'—Avoiding others

Participants described how the anticipation of discrimination from others led them to withdraw from relationships:

I know there are some who know but I try to keep it away from them because you cannot trust anyone about your HIV status. (Participant 5)

Another participant described the fear they had, that others in their workplace would learn about their HIV status. One participant described how difficult it was to learn of their HIV-positive status and decided

to conceal their HIV from others, and another participant poignantly described their fear of the consequences of others learning of their HIV-positive status:

It was all scary. It's scary and then people if they find out [I have HIV] and then they'll reject you. (Participant 29)

Settling as a newcomer and feeling compelled to keep a major health issue a secret created conditions for social isolation and exclusion. Many participants described experiences of keeping their HIV positive status a secret from those in their social networks.

3.4.2. Carrying the secret of HIV

For those who felt the importance of keeping their HIV status secret, they did so to protect themselves from discrimination, as well to avoid hurting their immediate family members. One participant described the great effort he made to hide his HIV-positive status from his sponsor family as well as his partner. He used his chronic disease, type II diabetes, as his 'cover story', to explain why he had many appointments with an HIV-specialist during his early settlement days in Canada:

And I didn't want to let anybody know about it...[one] time my, my [sponsor] asking me. 'What are these letters from [these Health Services] ... what's wrong?' ... Oh they are about my diabetes I said to him, like I was cheating, ... It's a cover. (Participant 34)

In addition, this participant took much effort to hide his HIV-positive status from his partner during medical appointments; he used his ability to speak and read English to communicate his health status with health providers while keeping information from his partner, who did not speak, understand, nor read English. Avoiding disclosure to his partner meant that this participant not only had to live in secrecy, hiding his treatment, but that he also experienced isolation from his immediate family and lacked social supports from family.

3.4.3. Gaining support through honesty with others

There were, however, some exceptions to this, in which several participants described self-acceptance of their HIV-positive status through social interactions with others. There were exceptional cases in which participants felt they had to accept their HIV-positive status as part of their life. In addition, some participants felt they could openly discuss their HIV within their social networks (family, friends), or publicly such as with health providers or immigration officials. One participant described how they became more comfortable over time in disclosing their HIV with others:

I had already disclosed my status to some [people at immigration], I was very open because they had all my information.... So I was growing stronger every time I could disclose this information to other people. (Participant 5)

Another participant discussed how she disclosed her status to her children. She described how her children responded in a way that helped her 'normalize' HIV, and felt this helped her accept her HIV-positive status:

Oh, back home I told them [my children] I was HIV positive and actually they encouraged me... they were, like, 'Oh mom, don't worry. You shouldn't worry about that, you know? It's not [like]...you are not the first one. You should just take your medication, eat the proper foods and to go on with life.' (Participant 32)

One participant described how they vehemently denied having HIV after being diagnosed during the IME process. Because of their disbelief in having HIV, this person went for multiple HIV-tests at different clinics to confirm their diagnosis. However, over time and with support from others, the participant was able to accept their HIV-positive status:

I went through a very difficult situation... I couldn't believe it or accept that I'm HIV because it was so strange. It's something which is very shocking, it really shocked me. But I had to accept after some time. The good thing, all these doctors where I went to do my blood test, they were keeping very close to me, they were trying to check on me to see how I'm trying to go through the situation. And after some time, they were giving me very good counseling, visiting me, inviting for me for

more appointments, to talk to me every day, to make me feel strong because they knew how I was feeling and what I was going through during that time. (Participant 5)

It was encouraging to learn that some participants were able to manage their HIV stigma through the acceptance and support of others, in both personal relationships and with healthcare providers.

3.4.4. 'Just keep myself busy'—Occupying oneself to avoid thinking about HIV

Participants described various ways in which they negotiated self-acceptance of their HIV status and how they coped with the effects of internalized stigma and enacted stigma. Some described accepting their HIV as a deliberate choice, while for others, it took time to accept their HIV:

You may be surprised, I didn't feel anything ... I started thinking ... and then after some time, just I accepted it. In my insides feeling, I just accepted it [HIV]. (Participant 15)

While another participant described a 'switch' that they could turn on and off to distract them from thinking about their HIV:

It's like I've got a switch now. (Participant 21)

Other participants discussed how they needed to occupy themselves in order to avoid focusing on their HIV. One participant explained that they try to keep themselves busy and only think about HIV when they see their physician (Participant 1). Another described how she focused on living a full life in her new host country, carrying on with her social relationships and advancing herself economically, just as she would have prior to being diagnosed with HIV:

I realize I have food and I want to do good in school, so I'm just concentrating on that 'cause that's important and I want a good job to make money. [...] I even communicate with my friends [back home] the same way and my best friend... I don't really have to think about it like to say OK I have this [HIV] and I should be sad, no I don't. I don't need to just sit down and bring down myself more. (Participant 2)

One participant described the need to focus on other things in life as a newcomer and to not let HIV 'break' them:

No, I do not have anything on my mind now about living [with HIV], 'cause I realize there are options and right now, on my mind is that I'm living with it and that's the only thing... I think about it and I try to think about something else 'cause it would really break me down and [I will] cry and I remember I can't bring back the past but I have to just deal with it ... I'm still normal like everyone else, it's just that what's in my blood has been contaminated, and hopefully they have a cure about that [some day]. (Participant 2)

In this population, participants described that support from others is essential for social and emotional wellness, both in the context of migration and settlement, and in coping with an HIV diagnosis.

4. Discussion

The findings of this study support the need to revisit the IME screening process in the context of racialized ACB immigrants and refugees who are seeking entry into Canada, to ensure this population is appropriately supported, given the intersectionality of race, legal status, state institutions and laws, and marginalization of PLWH. Given that "an initial HIV diagnosis is likely to be correlated with the onset of HIV stigma" internalized stigma influences how PLWH cope with the diagnosis, disclose, and access HIV care, treatment, and support services [28, p. 761]. This study adds to the evidence showing the disempowering and disruptive impact of an HIV positive status (Kingori et al., 2012; Cao et al., 2010; Eke, 2003) among ACB individuals who receive a life-changing medical diagnosis during the IME process. Irrespective of immigration status, an HIV positive diagnosis or status presents self-acceptance challenges that must be understood within a cultural and intergenerational context. The negative experiences recounted by the study participants call into question the intended spirit of refugee protection.

The ensuing mental health challenges and power inequalities within this population, in the context of mandatory HIV screening must be urgently attended to (United Nations High Commission for Refugees [UNHCR], 2014). The 1951 Refugee Convention and the follow-up protocol of 1967 brought commitment from global states to protect/meet needs for the wellbeing and protection of refugees (United Nations High Commission for Refugees [UNHCR], 2011). The Refugee Convention outlines host countries' obligation to ensure refugees have access to the same rights as their nationals (United Nations High Commission for Refugees [UNHCR], 2011). Basic rights of the refugee in a host country include the rights to be protected from refoulement, to work, to housing, to education, and the right to public relief and assistance (United Nations High Commission for Refugees [UNHCR], 2011). Thus, IME processes must re-structure the HIV screening/care access, and reduce alienation of ACB populations (Duracinsky et al., 2020).

As member state of the Refugee Convention, Canada has a long history of commitment to protect refugees and to resettle refugees in Canada (Government of Canada, 2020). The Canadian Refugee program has two main components: The Refugee and Humanitarian Resettlement Program, for people who need protection from outside Canada and those in the In-Canada Asylum Program for people making refugee protection claims from within Canada. This is important in the context of our study, as most participants had protected status under the UNHCR Refugee Convention or were awaiting application for refugee status. Despite Canada's commitment to the Refugee Convention, we found that many individuals experienced extraordinary challenges as migrants living with HIV in Canada. Individuals described ways that their access and rights to basic social programs and services were obstructed. In many instances, we found that being HIV positive had significant consequences on a person's ability to access health and social care, housing, meaningful employment, and in some cases, movement between countries. The experience of internalized stigma, and enacted stigma during the Canadian IME resulted in profound fear, emotional distress, disengagement in the HIV care cascade, and struggles with establishing/nurturing social relationship and social structures within society. These findings support revisiting IME processes to ensure an integrated empathetic non-alienating HIV testing for PLWH [(United Nations High Commission for Refugees [UNHCR], 2014; Rotheram-Borus et al., 2009)].

Participants perceived HIV as an exceptional disease in society. That is, participants felt society condemns PLWH and blames PLWH for getting what 'they deserve' (Sayles et al., 2008). In addition to non-edifying negative HIV stereotypes and stigma experiences, participants received negative disempowering comments from family members and healthcare providers. In the context of ACB communities, self-acceptance must be seen in the context of family and community cultural isolation, and intergenerational trauma of living with HIV (Eke, 2003). According to Earnshaw and colleagues (Earnshaw et al., 2012), devaluing stereotypes negatively impacts health-seeking behaviors. We also found profound emotional distress and negative psychosocial experiences among participants. For example, a collective experience of internalized stigma and moral distress may suggest perpetual loss of hope among PLWH in this population. The loss of hope was associated with threats to immigration to Canada, and not being able to achieve personal goals in order to improve one's socioeconomic status in their new host country. Further, participants described fear of lowered socioeconomic status as a migrant living with HIV in their new host country. Parker and Aggleton (Parker and Aggleton, 2003) discuss the loss of social status associated with HIV stigma more broadly. Though some participants described HIV as being no longer a "death sentence", others described death in symbolic ways, with HIV-related fear leading to role and identity loss (Dilmitis et al., 2012) and a poor quality of life.

Participants' fear of being known to have HIV during the Canadian IME or during settlement in Canada was evident. This fear and breach of privacy are connected to deep concern of being identified as having HIV as a result of unwanted disclosures resulting from physical changes (i.e., lipohypertrophy or lipoatrophy) due to ART treatment

(Glendinning et al., 2019), is a deterrent to seeking HIV treatment, care, and support (Sherr et al., 2010; Sayles et al., 2008; Kingori et al., 2012). Fear of non-voluntary disclosure became problematic when some participants opted to not access health and social care in their new host country.

Self-acceptance relates to how people experience shame in telling others about their HIV positive status (Sayles et al., 2008). People with low self-acceptance may feel it is important to keep HIV a secret from friends, family and co-workers and feel less comfortable in telling others about their HIV-positive status. Self-acceptance, as a domain of internalized HIV stigma is conceptualized as an individual-level concept (Sayles et al., 2008), and at intergenerational level (Eke, 2003) among ACB communities. That is, “internalized stigma occurs [when] an individual internalizes cultural norms and narratives that identify them as a member of a deviant group, and assumes a [tainted] identity” [26, p. 749]. Internalized stigma is significantly influenced by the familial, cultural, and societal factors that shape the public’s view towards perceived a deviant group in society. Our findings demonstrate the influence of social and public views on internalized stigma (Pryor and Reeder, 2011). Public stigma refers to narratives, and social and psychological reactions to someone perceived by members of the public to be deviant, whereas self-stigma occurs when people with stigmatized conditions such as HIV are aware of public stigma and internalize such stigma (Pryor and Reeder, 2011). Our findings demonstrate that self-stigma can result in negative emotional and psychosocial consequences (Meyer, 2003; Stutterheim et al., 2012), that influences the cognitive, affective, and behavioral aspects of individuals (Bos et al., 2013).

Additionally, we found an inconsistent picture of how HIV counselling was implemented during the HIV screening process. It was evident within the Canadian IME, that pre- and post-HIV test counselling guidelines were experienced inconsistently, and many participants felt unprepared to receive a positive HIV diagnosis. Integrating effective counseling into the IME process will ensure the dignity of individuals who undergo an HIV test (Rotheram-Borus et al., 2009; Byrskog et al., 2014). Furthermore, several participants reported significant emotional distress during HIV testing, resulting in suicide ideation (dela Cruz, 2014; Rukundo et al., 2016). Psychosocial and emotional challenges among those with complex and disempowering life situations have lasting effects (Onyut et al., 2009). These experiences demonstrate the harm that can be inflicted by insensitive and incomplete pre- and post-test counseling by IME physicians, again counteracting the obligation to protect the wellbeing of refugees.

Stigma shapes social relations and is closely connected to power dynamics within and between social groups. This holds true for HIV and the stigma associated with it. Our findings show that social relations were affected during the IME process. HIV stigma most often impacts the social relationships of people living with HIV in undesirable ways, as the negative social response to HIV remains pervasive. It is important within the context of this work to conceptualize stigma as a social process, which is visible within the relationships between PLWH and their care providers, including IME physicians, their personal relationships, as well as the relationships and social structures within the broader community. Parker and Aggleton (Parker and Aggleton, 2003) pointed out the need to move beyond the limitations of current thinking ...to reframe our understanding of stigmatization and discrimination ... as social processes that can only be understood in relation to broader notions of power and domination. (p. 16).

Reflecting on Parker and Aggleton’s work, now nearly 20 years ago, our findings reiterate the link between stigma and power. These interactions had long-lasting impacts on the relationships people formed with healthcare providers and carried over to (mis)trust of the healthcare system in Canada. In many cases, the stigma PLWH experience during this time can be “linked to social reproduction of difference” [37, p. 13], a difference that was emphasised by IME physicians, rather than mitigated. Community relations shape people’s lives and the experience of community stigma has detrimental consequences for people living with

HIV (Turan et al., 2016b). The Royal Tropical Institute (Royal Tropical Institute, 2004) showed that stigma often existed when two out of three circumstances intersect: low value, exclusion, and disadvantage. This study corroborates other studies (e.g., (Caiola et al., 2014)) that underscores the intersection of power inequalities, with HIV-stigma, (immigration) policies, as well as access to quality HIV services. It becomes visible that stigma is also linked to a community and political aspect. This is significant in the context of immigration and ACB communities in Canada, as stigma can both strengthen and reproduce existing inequalities.

Our findings contribute to a broader agenda focusing on the health of migrants living with HIV and public health policy. Until 2018, immigration applicants living with HIV were generally deemed inadmissible to Canada, due to the high cost of HIV treatment and potentially “excessive demand” on publicly funded health or social services (Canadian HIV/AIDS Legal Network, 2018). Despite changes to threshold levels that constitute excessive demand, existing medical inadmissibility rules fundamentally discriminate immigration applicants who live with disability and/or complex medical conditions (Canadian HIV/AIDS Legal Network, 2018). Furthermore, mandatory HIV screening creates unjust and unwarranted inequities given that HIV is a chronic and manageable disease in Canada (Bisaillon, 2010; Bisaillon, 2013). Our study findings note the importance to carefully examine the ethical use of medical information during the immigration process (Bisaillon and Ells, 2014), appropriate informed consent during HIV screening, and the psychosocial consequences of mandatory HIV screening. Continuing medical education for practitioners who administer the IME is paramount. In particular, the development of policies and practices that aim to address inequities in accessing meaningful HIV care are paramount and are necessary contributions to upholding human rights.

Our findings also bear significance in the current COVID-19 global pandemic. The current public health crisis has created extraordinary challenges for racialized populations, including immigrants living with HIV in Canada (Logie and Turan, 2020). It is not the COVID-19 virus itself that has posed such challenges, but rather broader social policies and public health measures that have negatively impacted the lives of racialized populations. Public health measures such as physical distancing, remaining home when ill, working virtually have become topics of privilege, and are not accessible to people in many marginalized communities (Yancy, 2020), including racialized immigrants. Furthermore, evidence demonstrates that racialized individuals, experience disparities in the social determinants of health. For example, there are inequities in housing, income, employment, and education among racialized populations in Canada (Nestel, 2012; Public Health Agency of Canada, 2020). Systemic racism rooted in public policies, practices, and institutions (Thompson et al., 2021) contributes to such inequities. Thus, the layered effect of living with HIV, legal and/or immigration status, disparities in the social determinants of health among racialized immigrants living with HIV provides impetus for society to re-think public policies that promote discrimination, stigma, racism, and injustices towards racialized immigrants.

This qualitative study presents compelling accounts of ACB immigrants who feel excluded, isolated, and distanced by others because of their HIV positive status. This study fills a current gap in the research literature and makes visible the impact of social exclusion created by HIV stigma among ACB immigrants living with HIV in Canada while undergoing the IME or accessing related HIV support services. The findings reveal that social exclusion intersects with stereotyping, the quality existing personal relationships, and self-acceptance of living with HIV (Royal Tropical Institute, 2004). Despite unveiling the layered impacts of HIV stigma, a limitation of our current study is that we are unable to determine the extent of the magnitude of social exclusion challenges for ACB immigrants living with HIV in Canada. Involving French speaking ACB immigrants living with HIV in Canada, as well as those who speak languages other than English or French, could add additional insights on HIV stigma.

5. Conclusion

The experience of receiving an HIV diagnosis during mandatory HIV testing in the Canadian IME process provides a clear example of intersectionality, layered stigma and multiple forms of social exclusion and isolation. Participants, all of whom have countries of origin in Africa and the Caribbean, recounted their experiences of receiving an HIV diagnosis through the IME in ways that show enacted and internalized HIV stigma. Receiving an HIV diagnosis was compounded, in many cases, by insensitive interactions with IME physicians and clinic workers, by concerns about their families (including those family members that would be left behind in their home country), fears that their immigration status would be jeopardized, and fears about their future professional, educational and relationship prospects in Canada. Their accounts, however, also includes many expressions of resilience, resourcefulness and optimism. These counterbalances to feelings of internalized stigma and experiences of enacted HIV stigma are not captured in the IHSS measurement. In examining the effects of HIV stigma among newcomers living with HIV, it is important to include the risk/protective factors that impact and contribute to newcomers' positive health and social outcomes.

The four domains of HIV stigma measured in the IHSS – stereotypes, disclosure concerns, social relationship, and self-acceptance – proved to be salient in this study. HIV stigma were exacerbated by the challenging experience of being diagnosed during the process of immigration. While this study is not intended to evaluate the validity of the IHSS, we do note that it captures many but not all of the manifestations of internalized HIV stigma experienced. While we were able to quantitatively measure the magnitude of experiences of HIV stigma among our larger sample using the IHSS tool, the value of qualitative inquiry is the ability to delve more deeply into unexpected or additional forms of stigma, particularly those that were connected to an immigration experience.

Funding

This study was funded through the Faculty of Nursing Endowment Fund, University of Calgary.

Declaration of Competing Interests

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

The authors would like to acknowledge the participants across Canada who contributed to generating knowledge in understanding the experiences of internalized HIV stigma during Canadian immigration processes. We honor the many stories shared by many courageous people in Canada. Also, the authors would like to acknowledge the research team who undertook this study: The Newcomer, HIV, Immigration, Treatment Engagement, and Stigma (*NewHITES*) Canada Community Based Research Team: Aniela dela Cruz, Sithokozile Maposa, San Patten, Inusa Abdulmalik, Tsion Demeke Abate, Sipiwe Mapfumo, Patience Magagula, Robert Bardston (deceased), Muru Khamisi, Andrea Carter, Peggy Spies, Jean Harrowing, and Vera Caine. The *NewHITES* Canada Team would like to sincerely thank the many community-based organizations across Canada who supported this work by bridging the team to people in the community who gave their time and stories to this work.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at [doi:10.1016/j.jmh.2022.100088](https://doi.org/10.1016/j.jmh.2022.100088).

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