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Barriers to addressing HIV-Associated neurocognitive disorder (HAND): Community-based service provider perspectives

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ABSTRACT

HIV-Associated Neurocognitive Disorder (HAND) is an emergent public health issue in developed countries. Consequently, people living with HIV who experience HAND will increasingly require support from community-based HIV service providers. The objective of our qualitative study was to identify barriers service providers face in addressing HAND among people living with HIV. Thirty-three providers from 22 AIDS service organizations across Ontario, Canada, were interviewed. Using thematic analysis, three types of barriers were identified: (a) personal/professional, (b) service access, and (c) systemic. This paper draws attention to HAND-related obstacles that service providers encounter in their work and presents options to overcome them.

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HIV-Associated Neurocognitive Disorder (HAND) is a major public health issue in developed countries where combination antiretroviral therapy (cART) is widely available (Nightingale et al., 2014). HAND is described as a spectrum of neurocognitive dysfunctions associated with HIV infection, which has been divided to three subdisorders: Asymptomatic Neurocognitive Impairment (without observable functional impairment), Mild Neurocognitive Disorder (with observable mild functional impairment), and HIV-Associated Dementia (with observable marked functional impairment) (Sanmarti et al., 2014).

The introduction of cART during the mid-1990s had a profound effect on the treatment of HIV, but its impact on reducing or preventing HAND remains unclear (Elbirt et al., 2015). Although a significant decrease in the

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incidence of HIV-Associated Dementia has been reported with the use of cART over the last decade (De Cock, Jaffe, & Curran, 2012), the prevalence rates of the less severe forms of neurocognitive impairment have notably increased (Mind Exchange Working Group, 2013).

HAND most prominently affects the neurocognitive domains of memory, learning, complex attention, information processing, and executive functioning (Moore et al., 2006), and ranges from mild cognitive impairment to more significant disruptions affecting instrumental activities of daily living (including work), mental health and wellbeing, and quality of life (Heaton et al., 2004; Rourke, Halman, & Bassel, 1999; Trepanier et al., 2005). Research studies have estimated that between 30% to 50% of people living with HIV (PLWH) are affected by some form of neurocognitive decline in their lifetime, even with the use of cART (Mind Exchange Working Group, 2013; Sanmarti et al., 2014). With a prolonged life expectancy of PLWH and estimated prevalence rates of neurocognitive decline remaining consistent in recent years (Watkins & Treisman, 2015), it is reasonable to anticipate that PLWH will need to avail themselves of services and supports that will help them address the impact and consequences of HAND on their day-to-day lives.

Although research has been conducted to identify factors related to the standardization of diagnostic screening tools, classification, and clinical treatment options for HAND (Elbirt et al., 2015; Sanmarti et al., 2014; Zipursky et al., 2013), as well as challenges related to the lived experience of PLWH and neurocognitive impairment that emphasize the need for appropriate and accessible rehabilitative services (Eaton, Craig, & Wallace, 2017; Gallagher et al., 2013; Hopcroft et al., 2013), to date, there has been no research carried out to identify the potential barriers service providers face with regard to addressing HAND in their work. The main objective of this study was to address this research gap.

Method

For this qualitative study, a Community-Based Research approach (Israel, Schulz, Parker, & Becker, 1998) that emphasizes the importance of collaborating with relevant community stakeholders and valuing their input at every stage of the research process was utilized. A collaborative relationship was forged with the research project's community partner organization, the Ontario HIV Treatment Network (OHTN). With the support of OHTN, a Community Advisory Committee (CAC), comprised of PLWH and providers from an AIDS service organization (ASO) and an agency that delivers support services to PLWH, was established to collaborate with the research team to help identify the study's objective, methods, and target population. The study's objective, procedures, and intended conduct were reviewed and approved by the Research Ethics Board (REB) of the Centre for Addiction and Mental Health in Toronto, Canada.

Participants

Participants were recruited using a purposive sampling approach (Palys, 2008) in accordance with recommendations from community partners and CAC members. Individuals were eligible to participate if they were providers based at either a publicly-funded ASO or a not-for-profit agency that delivered support services to PLWH in Central and Southwestern Ontario whose work involved face-to-face interaction with PLWH. This included both providers with prolonged face-to-face interaction with clients during most of their work (e.g., frontline workers such as caseworkers, counselors, and support workers), and providers who interfaced with clients as part of their work (e.g., program managers and directors). In order to reflect the range of knowledge amongst providers in the community, level of awareness of and amount of knowledge about HAND was not a consideration in eligibility or sampling.

Thirty-nine providers were invited to participate in the study through email using an REB pre-approved recruitment message. Out of the 36 providers who responded to the emails, 33 agreed to participate. The 33 participants were from 22 different ASOs/agencies, with certain participants belonging to the same ASO/agency in some cases. The participants represented a diverse group of providers based on work locations, job titles, and other socio-demographics (Table 1).

Procedures

Participants took part in 1–1.5 hour long, digitally recorded, one-on-one interviews, which were conducted by the first author at the participants' offices. Interviews followed a semistructured interview guide, which was developed in collaboration with community partners and CAC members. The guide utilized primarily open-ended questions to (a) explore participants' work experiences related to clients' neurocognitive problems, (b) assess participants' familiarity with HAND, (c) probe the obstacles participants faced while they attempted to address clients' neurocognitive impairments, (d) identify strategies they took to support these clients, and (e) determine what they needed to better support their clients in the future.

Participants were sampled until data saturation for key themes was achieved (i.e., no new information relevant to the key themes emerged as additional interviews were conducted). Each participant provided informed consent prior to the interviews and received a \$25 gift card as compensation for their participation. Interviews were transcribed verbatim by a research assistant, then crosschecked and verified by the first author prior to analysis.

Analysis

Due to its inherent flexibility, thematic analysis (Braun & Clarke, 2006) was chosen as the method to analyze the interview data. It was deemed the best

Table 1. Participant characteristics ($N = 33$).

Age range	<i>N</i> (%)
<25 years old	1 (3)
25–34 years old	11 (34)
35–44 years old	10 (30)
45–54 years old	7 (21)
55–64 years old	4 (12)
Gender	
Female	17 (52)
Genderqueer	1 (3)
Male	15 (45)
Race/ethnicity	
Aboriginal	1 (3)
African/Caribbean/Black	4 (12)
Hispanic/Latino	2 (6)
South/Southeast Asian	6 (18)
White	20 (61)
Years in HIV services	
1–2 years	6 (18)
3–5 years	16 (48)
>5 years	11 (34)
Location of agencies	
Downtown Toronto	21 (64)
Greater Toronto area	6 (18)
Southwestern Ontario	6 (18)
Job title of participant	
Caseworker	4 (12)
Counselor	9 (27)
Outreach worker	2 (6)
Support worker	6 (18)
Executive/services director	4 (12)
Program manager/supervisor	8 (25)
Services provided mostly to	
Aboriginal clients	1 (3)
Racialized clients	14 (42)
White clients	18 (55)

approach to fulfill the study objective because its theoretical and epistemological freedom allowed for a flexible examination of multiple perspectives from various interview sources.

Because community partners and CAC members personally knew many of the providers from the various ASOs/agencies in Ontario from previous work interactions, the raw data were not made accessible to them but only to members of the research team. This decision was made to allay prospective participants' apprehensions on the possibility of being identified in the interview transcripts and to further ensure confidentiality in the research process.

The first author and research assistant/transcriber conducted the initial phase of the analysis. Prior to coding, the first author read and reread all the transcripts to gain intimate knowledge of the data, and then chose eight transcripts that would represent the data set in terms of participant characteristics, perspectives, and contexts (e.g., race/ethnicity, gender, years in HIV services, frontline/management position) for the transcriber to read and

re-read. As separate coders, the first author and transcriber identified initial codes, and then searched and reviewed for themes from the eight representative transcripts. Next, the coders met and compared their initial codes and themes. Then, they defined, named, and finalized the codes, subthemes, and themes, which the first author used for the analysis of the remainder of the transcripts. The coders produced a deidentified report containing the themes, subthemes, and supporting quotes for the rest of the research team, community partners, and CAC members to review. At subsequent stages, the rest of the research team, community partners, and CAC members reviewed the deidentified report and provided feedback on the themes, subthemes, extracts, and overall quality of the report. This process was conducted using different techniques to establish transferability (i.e., thick description), credibility (i.e., source triangulation), confirmability (i.e., reflexivity, analyst triangulation), dependability (i.e., external audit), as well as uphold the trustworthiness and rigor of the study's findings and analysis (Lincoln & Guba, 1985).

While several themes were identified from the data during the analytic process, this paper focuses specifically on themes that related to barriers to addressing HAND based on the perspectives of the participants. Pseudonyms were used for each participant to maintain anonymity.

Results

Three types of barriers that providers encountered while addressing their clients' neurocognitive impairments were identified. These included: (a) personal/professional, (b) service access, and (c) systemic. The way the barriers were identified and categorized to three types in this study turned out to be similar to how barriers to accessing HIV services not related to HAND have been categorized (e.g., individual, structural, institutional) in previous literature (Smith, Simmons, & Mayer, 2005). In the sections that follow, each of these types of barriers is described in turn.

Personal/professional barriers

Two personal/professional barriers were identified in the analysis. Participants candidly talked about both their lack of awareness of and limited knowledge about HAND and how these factors presented barriers to addressing HAND in their work. Although many providers were already aware of HAND as a condition that could cause neurocognitive changes prior to their study participation, there were several respondents who had never heard of HAND before agreeing to join the study. For example, Feven, a support worker who had been working for two years at her ASO in the Greater Toronto Area (GTA) confided, "To be quite honest, before I agreed to be interviewed, I'd never heard of HAND before. I knew HIV could affect

memory and focus, but I've never heard of a label for it till now." Similarly, June, a Southwestern Ontario ASO program manager for over five years stated, "This was a new term to me, HAND. We've supported people with AIDS-related dementia. But I've not heard of HAND before."

Among the participants who were already aware of HAND, most reported that they became aware through conferences and information sessions they attended, or community reports and fact sheets they read. However, when asked about how much knowledge they had about HAND, the majority of participants felt they did not have enough, especially for their role in their agency. Ali, who had worked as a program manager at an ASO in Southwestern Ontario for three years, shared:

We actually had a "lunch and learn" for our staff about HAND, and everyone was going "I've seen this since I've started here." When we started getting to the symptomatology of it, it sounded very familiar. Later, we found out there was a lot about HAND we did not know about ... that it's divided to three subtypes and it's not just dementia ... what to watch out for in our clients, and how we could possibly help with their challenges.

Barry, a respondent in a GTA ASO management position for more than five years, talked about the responsibility of providers to stay informed:

As ASO providers, we need to be more knowledgeable about HAND so we can share information and make sure it gets to the right people. I think a lot of times its ignorance we're hiding behind! If we don't know enough, we don't have to address it.

Several participants were worried about not knowing how to distinguish neurocognitive impairments due to HIV infection from other causes of changes in memory, attention, or information processing (e.g., Alzheimer's disease). Rekha, a Downtown Toronto ASO frontline worker of nearly three years, earnestly asked a series of questions: "So I'd love to know, is there something that differentiates cognitive impairments in HAND versus those from other clinical conditions? Does progression look different with HAND? Will all clients with HAND progress to dementia?"

Several participants also revealed that they would occasionally confuse HIV-related neurocognitive impairments with mental health issues due to other conditions (e.g., depression) or circumstances (e.g., problematic substance use). Participants knew that PLWH are more susceptible to experiencing mental health concerns, but they were not always sure whether their clients' problems were mental health issues not directly related to HIV or HIV-related neurocognitive changes. Natalia, a Downtown Toronto ASO social worker of more than three years, reported:

I know of three clients who are experiencing mental health changes but haven't been diagnosed with HAND. One has been HIV-positive for over 20 years and

he's been telling me that he's been experiencing anxiety and difficulty with memory retention. He also suffers from depression and has problematic substance use so it's a challenge for me to figure out what he's going through.

Because many of the participants felt they did not know enough about HAND, they were not always confident to address their clients' neurocognitive impairments in more specific ways other than providing them practical supports such as reminders for appointments, accompaniment to doctor's offices, and tips on how to remember when to take medications. They believed their lack of awareness of and limited knowledge about HAND prevented them from providing better support to clients. Mary Anne, a counselor in Toronto HIV services for over five years, shared:

I think my biggest challenge when it came to helping folks with neurocognitive problems was not knowing enough about HAND. After attending a workshop recently, I learned more about what HAND is, what its signs and symptoms are, and how to support someone. I think increasing my own knowledge about it was the first step for me towards supporting my clients with neurocognitive challenges more effectively.

Service access barriers

The second type of barriers participants encountered was related to their clients' access to healthcare and support services. According to the respondents, many of their clients had limited access to primary care, mental health, and other services, and had difficulty finding providers possessing adequate expertise and experience working with PLWH. The participants also described the impact of stigma towards PLWH among agencies outside of dedicated HIV services as a barrier to connecting their clients with neurocognitive challenges to services they needed to access.

Lack of local primary care, mental health, and other services

Participants reported that they routinely encountered difficulty finding a doctor or social worker to refer clients to in their local area. Peter, a frontline worker at an ASO in Southwestern Ontario for two years, expressed what other participants who worked far from Downtown Toronto experienced day-to-day trying to get healthcare and other services for their clients with neurocognitive challenges:

The folks that we see who want to access these services on an ongoing basis have a lot more complex health needs than people who have just been newly diagnosed. We've had problems identifying healthcare providers for them to refer to in our region. We've started to build relationships with our community health centre, which is the only one in our region. Unfortunately, they can only take on so many of our clients. The majority of healthcare providers who could take them are still in Toronto.

However, this barrier was encountered not only by providers from ASOs at a significant distance from Downtown Toronto, but also by providers from agencies at the immediate outskirts of Toronto that had limited access to services. Isabelle, a frontline worker who had been working for two years at a GTA ASO, explained:

We don't have an affiliated healthcare group here. A few other agencies further away from Toronto are affiliated with positive care clinics. So they have some sort of doctor or nursing staff. There can be a little bit more collaboration between them. Here, we don't have that. We have kind of this burden. We're close enough to Toronto that our clients are expected to go to Toronto for other services. But then, we don't have as much of a connection with the doctors and providers there because they're not really close enough.

Among the 12 ASOs outside of Downtown Toronto that had providers who participated in our study, there were only two that did not significantly encounter this local services access barrier. One ASO was part of an integrated care clinic and the other was strongly affiliated with a positive care clinic in the community run by healthcare providers with strong connections to their ASO.

Limited access to services with adequate expertise and experience working with PLWH

Some participants shared that even though hypothetically there was access to primary care, mental health, or support service providers in their area, the available providers for referral were not equipped to provide services to PLWH; lacking expertise and experience to do so. Ryan, a participant in a management position for five years at an ASO outside of Downtown Toronto, expressed, "It has been a challenge getting family docs in the region who can provide HIV care as part of their practice or physicians willing to take on somebody living with HIV." Olga, a participant who had been in a management position for almost three years at another ASO outside of Toronto, echoed similar frustration:

We did a survey of physicians and providers in the area who we could refer to, and none of them said they had stigmatizing attitudes. What they did identify as obstacles to taking on people with HIV was related to what they felt were their deficits in knowledge around HIV. Another problem was related to mental health. Many assumed there would be mental health issues that came along with living with HIV, which they didn't feel like they had the expertise to deal with. A third reason was just that their knowledge of community resources for PLWH was low.

Malcolm, a respondent who had been in a management position in a GTA ASO for more than five years, was quite clear about what he believed was a service access barrier:

We need to provide a broader base of services to our clients through our community partners. The problem is, those partners don't have the experience working

with PLWH. So there's a massive disconnect! We need to invest time, energy, and resources into training providers outside of HIV services on how to equitably deal with PLWH.

Janice, a participant in a management position for nearly five years in a Southwestern Ontario ASO, concurred:

Family doctors who are working in solo practices independent of each other in our region aren't necessarily seeing themselves as being tied into opportunities for continuing education that often happen for Toronto doctors who really want to find out what is happening with the HIV sector. We need to get more HIV training for physicians in our area. More importantly, we need physicians here to want that training.

Sinthu, who had been a caseworker at a GTA ASO for almost two years, noted that it wasn't just doctors who had little expertise and experience working with PLWH:

It's important that providers outside of HIV services to have knowledge on HIV and experience dealing with issues related to it. Providers in shelters, for example, need to be trained on HIV, mental health, etc., so that they could better serve our clients. Our clients have other needs tied to their neurocognitive impairment. Providers in these services should learn how to appropriately work with them.

With limited referral options regarding providers who possess adequate expertise and experience working with PLWH, participants claimed that helping clients with neurocognitive impairment seemed like an uphill battle.

Stigma toward PLWH in agencies outside of dedicated HIV services

Participants described stigma toward PLWH in agencies outside of HIV services that prevented them from connecting clients with necessary resources outside of their ASOs. For example, Indira, who had been a caseworker for over a year at an ASO just outside of Downtown Toronto, revealed, "There are a lot of agencies with very conservative healthcare and service providers here. We've had a lot of clients go to them. Oh what a surprise! The doctor or counselor doesn't feel comfortable working with someone with HIV!"

Janice echoed similar experiences:

There have been instances when we tried to get individuals placed in long-term care facilities and were told they would not accept our referrals, either being openly phobic around HIV, or in a roundabout way saying the individuals we are referring are too young when there is no age criteria for taking in clients with neurocognitive impairment in long-term care facilities. The people who come to us are isolated, shut out by other organizations, and shunned by family and friends. They've experienced a lot of stigma when they've tried to access other services. They have had their HIV status disclosed inappropriately and told they cannot have their needs met there.

It was not only participants who worked outside of Downtown Toronto who shared stories about clients experiencing stigma towards PLWH in agencies outside of HIV services. Scarlett, a frontline worker in an ASO in Downtown Toronto for two years, expressed:

There's a lot of stigma around HIV that most of the folks I'm seeing are experiencing in services outside of ASOs. I'd love to say to them, "There will be a world when folks living with HIV aren't going to experience those concerns," but I think we're going to continue to need supports around this.

Ira, who had been a social worker for five years in a Downtown Toronto agency that provides services to PLWH, similarly talked about the experiences of his clients with providers in other agencies without dedicated HIV services, "The reality is, once our group session is done, the stigma towards them still exists beyond the doors of where we hold group. It has become increasingly difficult to convince clients to avail of some outside services."

Systemic barriers

The third type of barrier is related to a systemic issue. Participants pointed out that a major systemic barrier that has adversely affected support for PLWH and neurocognitive impairment is the lack of capacity in the Ontario HIV sector. Participants perceived that this lack of capacity stems from increasing budget cuts and the lack of funding for ASOs, which have led to higher turnover and burnout rates among providers. Janice described the effect of lack of funding on the services her organization is able to provide:

We are at the point where the same pocket of operational funding we've had for the last six years is not cutting it anymore. We will have to move our operation because while inflation occurs, our funders don't recognize it. Our federal funder has cut our funding and the pool that we get our money from hasn't been increased in over ten years. Our ability to provide support to clients with neurocognitive problems is becoming incredibly constrained and we are concerned about sustainability.

Allan, a frontline worker for two years at another ASO in Southwestern Ontario, explained further how this overall lack of capacity is particularly a problem in relation to serving clients with neurocognitive problems:

Our federal funder massively shifted funding opportunities. Everyone submitted grant proposals and they took a long time to get back to us. They told a large number of agencies they weren't going to receive funding, so those were staff positions that just got cut! The staff members who lost jobs are the same people who know the agency's clients well, and who may have been able to say, "I'm seeing this come up for these clients that are indicative of HAND." If a new staff member comes in, they won't be able to recognize [cognitive] changes in clients that developed over time.

Allison, a program manager for nearly five years in a GTA ASO, similarly described the connection between budget cuts, overwhelming caseloads, and inadequate care for people who may be living with HAND, “Our case ratio is one support staff for over two hundred clients. Because there isn’t time to evaluate clients, it’s harder for staff to discern things that may be due to HAND.” Malcolm made similar remarks:

We’re funded for one caseworker, and we raise funds for a second. My caseworkers’ loads are ridiculous! ... We have one of them taking extra time to handle HAND-related issues. I’m pleased they’re putting in that effort, but what this means is there is less time for other clients. Also, there’s burnout and fatigue from working with people who continually regress. If your caseworker is repeatedly calling a client to remind them about an appointment they’ve missed for three or four times, how long does it take before that caseworker becomes impatient?

Besides the effects of untenable caseloads, participants also highlighted the impact of budget cuts on inadequate training related to HAND. As Iftikhar, a frontline worker for almost two years at an ASO in the GTA, commented, “With more money, some sort of introductory training [on HAND] can be provided to increase capacity. This has been done before for other issues and it involved many partner agencies.” Allison shared similar ideas:

We have not prepared for the kind of constellation of neurocognitive changes that are happening to our clients as they live longer with the virus. Previously, the funding that has been set up only provides for pay scales that attract people who deeply care about these issues. With more funding, we could compensate staff better and train them.

Janice also discussed how more funds for ASOs would increase capacity for Ontario HIV services:

I think that we need a lot of increased capacity within organizations! There needs to be a larger pot of operational funds to support the complexity of needs of PLWH. I think that our integration with clinical and other services is really important ... it has worked for certain ASOs because the flow of care is better with the integration of holistic services.

Discussion

This is the first qualitative study to explore the perspectives of community-based providers on addressing HAND in their work. Participants described encountering three types of barriers: (a) personal/professional, (b) service access, and (c) systemic.

Although previous studies have shown that lack of awareness of and limited knowledge about HIV/AIDS among people from the community have been significant barriers to accessing appropriate HIV services (Johnson et al., 2015; Heckman et al., 1998), there is currently no academic literature that

has specifically reported that lack of awareness of and limited knowledge about HAND among providers in HIV services as barriers to delivering needed care to clients with neurocognitive impairment. Participants of this study found that their lack of awareness of and limited knowledge about HAND served as personal/professional barriers that prevented them from better supporting clients with neurocognitive problems. During the analysis of the data, there were no significant differences noted in the level of awareness of and knowledge about HAND between the set of participants who provided services to predominantly white clients versus the set of participants who provided services to predominantly Aboriginal and racialized clients. Neither set of participants was more aware or knew more about HAND than the other. Several participants had never heard of HAND prior to their participation, and many of them readily admitted to not knowing enough about HAND to confidently help clients. The implication of these findings is that even providers in HIV services themselves continue to need greater access to more specific information about HIV-related conditions and issues such as HAND to be able to effectively support their clients. Since not many of the agencies in this study required formalized continuing education from their employees, providers were left to be mindful to keep themselves updated of knowledge that would help them support clients with neurocognitive issues.

Participants revealed three service access barriers that made it difficult for them to address HAND. The first was the lack of local primary care, mental health, and other services available to PLWH in the GTA and Southwestern Ontario. Without these basic services to refer clients to in their regions and provide additional support, participants recognized the limits of what they could do to help PLWH and neurocognitive impairments. The second service access barrier was the limited access to providers with adequate expertise and experience working with PLWH. Even in areas that hypothetically had primary care and support services available to PLWH, there were not enough providers who had adequate knowledge about HIV/HAND and experience working with PLWH. The third service access barrier that prevented providers from connecting their clients to appropriate care is stigma toward PLWH in agencies outside of dedicated HIV services. Stigma toward PLWH in agencies outside of HIV services was a barrier found not only in the GTA and Southwestern Ontario, but also in Downtown Toronto where the majority of HIV services and their established external partners are clustered.

These three service access barriers have historically been persistent findings in different studies identifying barriers to availing and delivering necessary life care in HIV services (Deblonde et al., 2010; Heckman et al., 1998; Johnson et al., 2015; Smith et al., 2005). The need to travel long distances to medical and service facilities, the shortage of medical and mental health professionals adequately trained to deal with HIV concerns, and stigma toward PLWH in

agencies outside of dedicated HIV services have been pervasive access barriers to different services (e.g., HIV testing, prescriptions to medications) both in urban and rural settings (Deblonde et al., 2010; Heckman et al., 1998), and the findings of this study are consistent with those from previous academic literature that underscore the significant challenges that these service access barriers present to those who work to support PLWH. HIV/AIDS stigma in the community, in particular, has been found to be the most prevalent access barrier to many kinds of HIV-related care across many countries (Johnson et al., 2015), and research has shown that stigma, particularly in the healthcare setting, contributes to keeping people, including healthcare workers and service providers, from accessing HIV prevention, care, and treatment services, and adopting key preventive behaviours (Nyblade, Stangl, Weiss, & Ashburn, 2009).

Finally, participants revealed a significant systemic barrier during the interviews: the lack of capacity in the HIV sector. Participants described how difficult it was for them to support PLWH and neurocognitive impairments because of budget cuts and lack of federal funding, which led to decreased personpower, higher provider turnover and burnout rates, and inadequate resources for appropriate training on HAND. Not surprisingly, this lack of capacity in the HIV sector resulting from scarcity of financial resources has already been previously documented as a systemic barrier to adequately delivering different kinds of non-HAND-related HIV services not only in Ontario, but the rest of Canada (Easton, 2016), as well as in the United States (Smith et al., 2005), and Europe (Deblonde et al., 2010). In order for providers to deliver competent services to clients with neurocognitive problems, the capacity of the Ontario HIV sector will need to catch up with the reality that PLWH are living longer with chronic conditions such as HAND. This implies that an increase in the capacity of the HIV sector will need to compensate not only for the increase in the sheer volume of clients accumulating in the system but also the increase in the complexity of neurocognitive and mental health issues that clients will bring with them.

This study adds important knowledge to current academic literature by drawing attention to barriers to HAND-related service delivery for community-based providers but it is necessary to acknowledge its limitations. In particular, it is notable that none of the study's participants worked primarily with HIV-positive youth or transgender individuals; the perspectives that providers shared in this study were limited to insights from work experiences that involved HIV-positive cisgender adults. This is a significant limitation of the study since HIV-positive youth and transgender individuals are likely also at salient risk for developing neurocognitive impairment, and providers may experience unique barriers to delivering HAND-related services associated with their age and gender.

In conclusion, the findings of this study suggest that there is much room for raising greater awareness of and increasing relevant knowledge about HAND among providers in HIV services. However, in order to fully address the concerns raised by the study participants, this increase in awareness and knowledge must be accompanied by policies and programs to facilitate greater access to providers with adequate expertise and experience working with PLWH/HAND, address stigma toward PLWH in agencies outside of dedicated HIV services, and increase capacity in the HIV sector. Collectively, these efforts will enable community-based service providers to more effectively meet the needs of their clients with HAND.

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