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Strategies Employed by Community-Based Service Providers to Address HIV-Associated Neurocognitive Challenges: A Qualitative Study

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Abstract

Background: HIV-associated neurocognitive disorders and other causes of neurocognitive challenges experienced by people living with HIV (PLWH) persist as public health concerns in developed countries. Consequently, PLWH who experience neurocognitive challenges increasingly require social support and mental health services from community-based providers in the HIV sector. **Methods:** Thirty-three providers from 22 AIDS service organizations across Ontario, Canada, were interviewed to determine the strategies they used to support PLWH experiencing neurocognitive difficulties. Thematic analysis was conducted to determine key themes from the interview data. **Results:** Three types of strategies were identified: (a) intrapersonal, (b) interpersonal, and (c) organizational. Intrapersonal strategies involved learning and staying informed about causes of neurocognitive challenges. Interpersonal strategies included providing practical assistance, information, counseling, and/or referrals to PLWH. Organizational strategies included creating dedicated support groups for PLWH experiencing neurocognitive challenges, partnering with other organizations with services not available within their own organization, and advocating for greater access to services with expertise and experience working with PLWH. **Conclusion:** Through concerted efforts in the future, it is likely that empirically investigating, developing, and customizing these strategies specifically to address HIV-associated neurocognitive challenges will yield improved social support and mental health outcomes for PLWH.

Keywords

HIV-associated neurocognitive disorders, community-based research, service providers, strategies, social support, mental health

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Introduction

Despite advances in HIV treatment and substantial improvement of survival rates of people living with HIV (PLWH), HIV-associated neurocognitive disorders (HANDs) continue to represent a significant public health concern.¹⁻³ HIV-associated neurocognitive disorder leads to cognitive, behavioral, and motor dysfunctions and is described as a spectrum of HIV-related syndromes with varying degrees of cognitive impairment and associated functioning; currently divided into 3 subdisorders: asymptomatic neurocognitive impairment, mild neurocognitive disorder, and HIV-associated dementia.⁴⁻⁸

The introduction of combination antiretroviral therapy (cART) in 1996 had a dramatic effect on HIV treatment, but its impact on HAND remains uncertain.^{1,8-10} Although a considerable decrease in the incidence of HIV-Associated Dementia has been reported with the use of cART,^{1,2,4,5,8,11,12} the

prevalence rates of milder but functionally important forms of neurocognitive decline have increased over the last 2

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What Do We Already Know about This Topic?

We know that people living with HIV experiencing neurocognitive challenges increasingly need support of health care and social support service providers from the community and that community-based service providers are encountering significant barriers to addressing these HIV-associated neurocognitive challenges in their work.

How Does Your Research Contribute to the Field?

Our research has identified several different strategies that community-based service providers use to address the HIV-associated neurocognitive challenges that their clients experience—strategies that could potentially be explored and evaluated by future empirical studies for effectiveness and client preferences.

What Are Your Research's Implications toward Theory, Practice, or Policy?

Our research on the work and lived experiences and perspectives of community-based service providers in the HIV sector shows that there are distinctly identifiable strategies that service providers have been using to address HIV-associated neurocognitive challenges experienced by their clients; strategies that could potentially be tested and proven useful by further investigation, and later, incorporated in HIV sector service provision policy and practice.

decades.^{4,5,8,13} HIV-associated neurocognitive disorder most prominently affects the domains of executive functions, motor skills, speed information processing, attention, and language^{1,14,15} and ranges from mild cognitive changes to significant impairment affecting mental health, instrumental activities of daily living, and overall quality of life.^{2,16-18}

Even with the use of cART, it is estimated that up to 50% of PLWH are affected by some form of neurocognitive impairment.^{1,2,7,8,13} In addition to HAND, other conditions (eg, comorbidities, depression, substance misuse) may cause PLWH to experience neurocognitive challenges similar to those resulting from HAND.^{3,14,19} With longer life expectancies of PLWH approaching population norms and estimated prevalence rates of neurocognitive impairment remaining stable for 20 years,^{1,2,8,19} it is reasonable to anticipate that many PLWH will require evidence-informed services to help them address the day-to-day impact of neurocognitive challenges on their lives.

Although research has identified factors related to standardization of diagnostic tools, nosology, and treatment options for HAND,⁵⁻¹⁰ as well as challenges related to lived experience of PLWH with neurocognitive impairment,²⁰⁻²² to date, there has been scant research conducted to identify strategies service

providers utilize to address HAND and support PLWH who are experiencing neurocognitive challenges;²² strategies that once identified from service providers' lived and work experiences could potentially be examined and evaluated for their effectiveness in empirical studies. The main objective of this study was to take the first important step to fill this research gap—identify service provider strategies for addressing neurocognitive challenges experienced by PLWH.

Methods

Setting

The present investigation entailed a qualitative, community-based research study, which was conducted in partnership with the Ontario HIV Treatment Network (OHTN) from June 2016 to May 2017. With OHTN's support, a Community Advisory Board (CAB), composed of PLWH and providers from an AIDS service organization (ASO) and an agency that provides primary care services to PLWH, was created to collaborate with the research team and determine the study's aim, methods, and target population.

Participants

A purposive sampling approach was utilized to recruit participants²³. Individuals were eligible to participate if they were providers based at either a publicly funded ASO or a not-for-profit agency that provided services to PLWH in Southwestern and Central Ontario, Canada, and whose work involved face-to-face interaction with PLWH. This included providers with prolonged interaction with clients during most of their work (eg, support workers, caseworkers, counselors), as well as providers who interfaced with clients as part of their work (eg, directors, managers). Potential participants and organizations likely to employ eligible individuals were identified in collaboration with the CAB. Participants were recruited until data saturation for main themes was achieved (ie, no new information relevant to the themes emerged as additional interviews were conducted). All in all, 39 providers were recruited via e-mail to participate. Of the 36 who responded, 33 participated, and data saturation for main themes was achieved with the participation of the 33 providers. The 33 participants were from 22 ASOs/agencies, with some participants belonging to the same ASO/agency (Table 1).

Procedures

Participants took part in hour-long, one-on-one, digitally recorded interviews conducted by the first author at the interviewees' offices. Interviews followed a semistructured interview protocol, which was developed with the community partners and CAB. The protocol utilized open-ended questions to (a) explore participants' work experiences related to clients' neurocognitive issues, (b) determine participants' familiarity with HAND, (c) examine obstacles participants experienced as they addressed clients' neurocognitive issues, and (d) identify strategies they employed to support these clients. In the subsequent discussion

Table 1. Participant Characteristics.^a

Race/Ethnicity	n (%)
Aboriginal	1 (3)
African/Caribbean/black	4 (12)
Hispanic/Latino	2 (6)
South/Southeast Asian	6 (18)
White	20 (61)
Gender	
Female	17 (52)
Genderqueer	1 (3)
Male	15 (45)
Age range	
<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)
Years in HIV services	
1-2 years	6 (18)
3-5 years	16 (48)
>5 years	11 (34)
Services provided mostly to	
Aboriginal clients	1 (3)
Racial minority clients	14 (42)
White clients	18 (55)
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)
Location of agencies	
Downtown Toronto	21 (64)
Greater Toronto Area	6 (18)
Southwestern Ontario	6 (18)

^aN = 33.

of the study's findings and analysis, however, this article specifically focused on data related to strategies enacted by providers to address HIV-associated neurocognitive challenges experienced by their clients, as the other study findings have been analyzed and discussed in previous publications²⁴⁻²⁶ (eg, providers' work experiences; familiarity, education, and training related to HAND; barriers to addressing HAND).

Participants received a CAD \$25 gift card as compensation for their participation in the study. Interviews were transcribed verbatim by a research assistant and then crosschecked by the first author prior to analysis.

Analysis

Thematic analysis²⁷ was chosen as the method to analyze interview data due to its inherent flexibility. It was considered the best approach to achieve the study aim because its epistemological and theoretical freedom allowed for a comprehensive examination of many perspectives from diverse interview sources. The first author and research assistant/transcriber conducted the initial phase of the analysis. Prior to coding, the first

Table 2. Strategies Utilized by Providers to Address Neurocognitive Challenges Experienced by PLWH.^a

Intrapersonal Strategies	n (%)
Learning about HAND through:	25 (76%)
Conferences	16 (48%)
Colleagues	8 (24%)
Community members	6 (18%)
Previous studies	5 (15%)
Staying informed about HAND through:	19 (58%)
Conferences	12 (36%)
Online information	8 (24%)
Community reports/organization documents	6 (18%)
Peer-reviewed journals	6 (18%)
Interpersonal strategies	
Providing practical assistance in the form of:	20 (61%)
Information on diet, exercise, and medications	18 (55%)
Practical advice (eg, recommending consults, memory aids)	15 (45%)
Peer/professional counseling	12 (36%)
Providing referrals to other services	16 (48%)
Organizational strategies	
Creating dedicated support groups	12 (36%)
Partnering with other organizations with different resources	9 (27%)
Advocating for greater access to services	6 (18%)

Abbreviations: HAND, HIV-associated neurocognitive disorder; PLWH, people living with HIV.

^aN = 33.

author reviewed all the transcripts to gain thorough knowledge of the data and then chose 8 transcripts that would be representative of the entire data set in terms of participant characteristics, perspectives, and contexts for the transcriber to review. As separate coders, the first author and transcriber identified initial codes and then searched for themes from the representative transcripts. Next, the coders met and compared their codes and themes. Then, they defined, revised, and finalized the codes and themes, which they then used for their analysis of the remaining 25 interview transcripts. After completing the initial phase of the analysis of all 33 interview transcripts, the coders created and presented a deidentified preliminary report of their analysis to the rest of the research team, community partners, and CAB, to obtain their feedback on the themes, quotes, and overall quality of the report. Based on the feedback that the rest of the research team, community partners, and CAB provided, revisions in the themes, codes, and quotes were made, and a final report was completed to reflect the input of the collaborative group into the end phase of the analysis of all 33 study interviews. Pseudonyms were used for each participant to maintain anonymity.

Ethical Approval and Informed Consent

The research ethics board of the Centre for Addiction and Mental Health, Toronto, Ontario, Canada approved this study

(research protocol # 048/2016). All participants provided written informed consent prior to enrolment in the study.

Results

Three types of strategies that providers utilized to address their clients' neurocognitive challenges were identified (Table 2). These types included (a) intrapersonal—strategies that involved providers working toward self-improvement, (b) interpersonal—strategies that involved direct interaction with clients experiencing neurocognitive challenges, and (c) organizational—strategies that necessitated the involvement of the providers' service organizations. Each of these types of strategies is described in the next 3 sections.

Intrapersonal Strategies

The intrapersonal strategies identified in the analysis include providers: (a) learning and then (b) staying informed about HAND, its differential diagnoses, and how to support clients experiencing neurocognitive challenges.

Initially Learning about HAND. Although some providers first heard about HAND from a study, colleague, or community member, most became aware of and initially learned about HAND from conference presentations. For example, Felix, an outreach worker working for 2 years at his ASO in the Greater Toronto Area (GTA) reported, "It was at a conference three years ago where I heard about HAND. There wasn't much in the way of online resources on HAND for providers at that time." Similarly, Gina, a GTA ASO caseworker for nearly 2 years stated, "I was at a conference where I learned about HAND, what its symptoms are, and how to support clients experiencing cognitive challenges. I think increasing my own knowledge was the first step for me towards being able to help them."

Staying Informed about HAND. Learning about HAND and other causes of neurocognitive impairment in PLWH was only the initial step toward providing support to clients experiencing neurocognitive difficulties. Participants added that staying knowledgeable about HAND and other causes of neurocognitive challenges was important to remaining prepared to address them in their work. Participants made efforts to stay informed through various ways. Livia, who had been a support worker at her Downtown Toronto ASO for 5 years, encapsulated the different ways participants stayed informed:

I access all avenues. Anytime I need to find out about something, I'll go read about it . . . online, in documents from community organizations, and in journals. I also directly ask people who I believe know more about HAND . . . mentors, coworkers, and community organizations known to have information. I also attend conferences and like to learn from new resources.

When asked about what they believe are the best ways to receive and retain information about HAND and other causes

of neurocognitive challenges, many participants replied that accessible documents and speaking engagements worked for them best. Shaan, a support worker from a Southwestern Ontario ASO for over a year, expressed what many participants agreed on regarding retaining information, "Structured education geared not only towards staff but clients would be really helpful. If reports, pamphlets, and information sessions were provided in accessible language, it saves providers the trouble of finding ways to translate or simplify them for clients."

Darren, a care coordinator in a Downtown Toronto ASO for 2 years, emphasized why staying knowledgeable about HAND and other causes of HIV-associated neurocognitive challenges is necessary for supporting PLWH:

As service providers, we need to have current knowledge about HAND and other reasons why clients experience cognitive issues. Not only do we need to be aware of them . . . we also need to stay informed because it's part of our job to make sure accurate information gets to the right people.

Interpersonal Strategies

The interpersonal strategies include (a) providing practical assistance, information, and peer/professional counseling, as well as (b) providing service referrals to PLWH.

Providing Practical Assistance, Information, and Counseling to PLWH Experiencing Neurocognitive Challenges. Providing practical assistance was the most common interpersonal strategy participants used. Kathleen, a program manager for a Downtown Toronto ASO for 3 years explained, "We would support clients with neurocognitive challenges by making sure we call to remind them about their appointments. If they have a series of appointments in a day, we accompany them to their appointments, which they really appreciate." Rachel, an ASO caseworker for 5 years from Downtown Toronto, elaborated on other practical ways they helped:

I think there are some very practical ways to support clients with neurocognitive issues. Helping people learn how to work with pill-boxes, day planners, calendars on their computer or phone, and sticky notes on cupboards and fridges. There are all kinds of things that can help people on a daily basis. But also, providing them supports to help overcome anxiety related to their neurocognitive issues.

These supports came in the form of information about HAND and other causes of cognitive impairment, how to navigate problems related to them, and how to improve cognition (eg, maintaining nutritious diets, staying physically active, exercising brain functions, adhering to prescribed medications); practical advice (eg, encouraging them to see primary care physicians); flexible appointment schedules (eg, after office hours, longer sessions); and peer/professional counseling, if available within their organization.

Providing Service Referrals to PLWH Experiencing Neurocognitive Challenges. Nearly half of the participants provided referrals

to agencies that can provide social support and mental health services related to neurocognitive challenges. Allison, an ASO support worker in Downtown Toronto for 5 years, shared, “We’ve provided referrals to different hospitals [names three] with counselling related to neurocognitive challenges. Some clients though prefer the nonclinical, peer counselling we provide because they feel more comfortable with us.”

Organizational Strategies

The organizational strategies identified were (a) creating dedicated support groups within their own organization for PLWH experiencing neurocognitive challenges, (b) partnering with other organizations with social support and/or mental health services not available within their own organization, and (c) advocating for greater access to local primary care, social support, and mental health services, as well as services with expertise and experience working with PLWH on behalf of clients.

Creating Dedicated Support Groups. Because support groups worked well for client populations dealing with other issues, participants formed dedicated support groups for clients with neurocognitive challenges within their ASOs/agencies. Alex, a social worker for 3 years at a nonprofit organization with mental health services for PLWH with self-reported neurocognitive problems in Downtown Toronto, explained the benefits he has seen in clients who have participated in dedicated support groups:

The group is designed to be psycho-educational. There is content about HAND that we cover within the weeks. I think there are lots of shared experiences within the group. It really is a way for clients to connect, talk about their experiences, and provide support to one another. Also, to leave with that emotional impact that “I’m not alone in this. There are others in this room like me with the same problems. Here’s the space to talk freely about my challenges.” It’s quite cathartic for them!

Rebecca, a Downtown Toronto ASO social worker for 5 years, echoed similar remarks regarding the merits of creating support groups:

To know from each other that it’s not necessarily progressing to dementia! Having these dedicated support groups for people is key. It’s the people that come to these groups that are giving each other emotional support . . . fantastic ideas on how to deal with all kinds of HAND issues on a daily basis.

Partnering with Other Organizations with Social Support and/or Mental Health Services Not Available within Their Own Organization. Many participants revealed how they were able to support clients with neurocognitive issues by developing and sustaining partnerships between their ASO and other organizations. Because of these partnerships, participants were able to conveniently arrange counseling for clients at

partner organizations that offered mental health services, many of which helped address neurocognitive challenges. This convenience eliminated the participants’ need to provide their clients referrals to nonpartner organizations that offered mental health services, as well as the risk that their referrals may be refused by nonpartner organizations. Emily, a case-worker at a Southwestern Ontario ASO for 2 years, described how their ASO was able to provide counseling to clients with neurocognitive problems:

There are 3 of us that do counseling here [related to cognitive challenges], and we try to take most of the load. There are 2 mental health nurses and 1 social worker who come in part-time from the community health center that we have a partnership with. You see, our clients see the health team at the community health center for their cognitive difficulties, so they already have connections with the nurses and social worker there that come here.

Other participants were able to help clients access services from partner organizations committed to providing appropriate information, food security, stable housing, employment assistance, travel bursaries, and other resources that were not available at their own ASOs. These were social support services that their clients needed but found difficult to access due to obstacles brought about by neurocognitive challenges. Partner organizations included hospitals, community health centers, local public health agencies, regional branches of a mental health association, larger ASOs with more funding, other nonprofit HIV sector agencies, agencies with services specific for sexual/gender/racial minorities and newcomers, and community colleges. Ravi, who had been in a management position at an ASO in the GTA for nearly 3 years, shared how their ASO had been developing a community partnership:

We’ve been developing a relationship with [a regional branch of a mental health association] that would see them increasing their understanding of HIV and some of the needs of PLWH. There is openness on their part, but I would say that’s sort of a work in progress. Their services are designed to provide broader services. Our relationship now is a unique organization-to-organization negotiation specific to our region. We recently entered into a partnership with them on services around LGBT issues. There’s more openness there, and we’ve discussed adding services specific to PLWH, including those with neurocognitive issues, in the near future.

Advocating for greater access to local primary care, social support, and mental health services, as well as services with expertise and experience working with PLWH. Knowing that many clients experienced difficulties obtaining primary care and referrals for neuropsychological testing and counseling from family physicians due to logistical access barriers, some participants noted that they actively advocated for additional services in the community through their organizations on behalf of clients with neurocognitive challenges. Tim, who had been working in a management position in HIV services in the GTA for over 5 years, explained how they have expressed to

policymakers and funders the need for greater access to local primary care, social support, and mental health services outside of Downtown Toronto:

Over time, we have repeatedly reminded people from government agencies, the Ministry [of Health], and provincial and federal funders the need to provide more local primary care and mental health services in areas outside of Downtown Toronto. How can they expect our clients to utilize referrals to agencies that are not so accessible because of distance and clients' difficulties to get around due to neurocognitive challenges?

Other participants had related concerns, particularly about their clients' limited access to services with expertise and experience working with PLWH. According to Lauren, a manager at an ASO in Southwestern Ontario for 4 years, "It's important providers outside of HIV services to gain knowledge on HIV and experience dealing with issues of PLWH so they could better serve our clients who have needs tied to neurocognitive impairment that they are more equipped to address."

Discussion

This is the first qualitative, community-based research study to explore the perspectives of service providers on addressing HIV-associated neurocognitive challenges. The strategies for addressing HIV-associated neurocognitive challenges that participants described were categorized into 3 types: (a) intrapersonal, (b) interpersonal, and (c) organizational. Although identified from the data, it was recognized in the analysis that this thematic categorization of strategies is consistent with McLeroy and colleagues' *socio-ecological model*, which in academic literature has been proposed to help establish health promotion interventions,²⁸ and subsequently, adopted to address HIV-related issues such as stigma.²⁹ The *socio-ecological model* focuses attention on both individual and social environment factors as targets of health promotion interventions. It addresses the importance of interventions directed at changing intrapersonal, interpersonal, organizational, and community factors, which support and maintain unhealthy behaviors.²⁸

According to participants, the intrapersonal strategies they utilized were key to initiating support for PLWH experiencing neurocognitive challenges in the sense that before they could do anything else to address HAND and other causes of neurocognitive impairment, they first needed to learn and stay informed about them. Many participants claimed that although they became aware of HAND through conferences, it was only in recent years when resources became available to providers so they could stay informed about HIV-associated neurocognitive challenges.³⁰⁻³² The implication of this is that in order to facilitate the use of these intrapersonal strategies, not only do up-to-date resources need to be made accessible to providers but campaigns to help them appreciate the benefits of maintaining knowledge about HIV-associated neurocognitive challenges using available resources should also take priority.

The interpersonal strategies included directly providing practical assistance, information, counseling, and/or referrals to PLWH experiencing neurocognitive problems. In general, these strategies have been discussed in previous academic literature,³³ but to date, little discourse specific to providers utilizing them to support PLWH experiencing neurocognitive decline has been published.²² The provision of practical assistance, information, counseling, referrals, and other support services catered to the specific needs of clients is at the core of the work of ASOs,³⁴ so it came as no surprise that it turned out that our participants utilized them as interpersonal strategies to support clients struggling with neurocognitive challenges. These strategies have been recognized and supported by ASO funders and networks,^{34,35} but unfortunately, details on how to customize them as strategies to systematically address neurocognitive challenges are yet to be cultivated and implemented.

Similar to the intra- and interpersonal strategies, the organizational strategies employed by the participants are consistent with those discussed in previous literature as strategies utilized in the HIV sector to address other problems related to HIV. Efforts to create support groups dedicated to the needs of specific clients infected and affected by HIV,³⁶⁻³⁸ build and sustain partnerships to share limited resources, and strengthen the capacity of community responses to HIV/AIDS,³⁹⁻⁴¹ and advocate for greater access to local primary care, social support, and mental health services, as well as services with expertise and experience working with PLWH,⁴² have been sanctioned by researchers, knowledge users, and community advocates. These findings suggest that in recent years, providers with different qualifications, levels of knowledge on HAND, job titles, and lengths of service in the HIV sector have intuitively used evidence-informed strategies known to be of value for addressing non-HAND-related issues to support PLWH experiencing neurocognitive impairment.

Although participants shared that they were able to find ways to support PLWH experiencing neurocognitive challenges, the findings of this study clearly points to the need to empirically investigate the effectiveness of the strategies that were discussed in this article as they pertain to addressing HAND and other causes of neurocognitive challenges, preferably through the lens of McLeroy and colleagues' *socio-ecological model*.²⁸ This article adds important knowledge to academic literature by drawing attention to strategies with considerable potential for addressing HAND and supporting PLWH with neurocognitive difficulties in the future. However, it is important to recognize its limitations. In particular, the possible significance of distinguishing strategies to specifically address HAND from strategies to address HIV-associated neurocognitive challenges resulting from other causes was not explicitly covered in this article. Additionally, the client populations served by the study participants typically did not include HIV-positive youth and transgender individuals. As such, strategies to deliver relevant services to these specific subpopulations may need to be considered in future studies and papers.

Conclusion

In order to fully harness the potential of the strategies described by our participants to successfully address neurocognitive difficulties, empirical investigation of their effectiveness as they pertain to addressing HAND and other causes of neurocognitive challenges needs to be conducted. Further studies, programs, and policies are needed to develop and tailor these strategies to the specific needs, circumstances, and capacities of providers in the HIV sector. Collectively, such efforts will enable community-based service providers to more effectively support PLWH with neurocognitive problems.

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