

“I’m Just Forgetting and I Don’t Know Why”: Exploring How People Living With HIV-Associated Neurocognitive Disorder View, Manage, and Obtain Support for Their Cognitive Difficulties.

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Abstract

HIV-associated neurocognitive disorder (HAND) is common, but the lived experience of HAND is not well-understood. In this descriptive qualitative study, we explored how adults with HAND view, manage, and obtain support for cognitive difficulties. We interviewed 25 participants (20% female; median age = 51 years) who were diagnosed with HAND using neuropsychological assessment and a clinical interview. Semistructured interviews, co-developed with community members living with HIV, focused on how cognitive difficulties manifested and progressed, impacted well-being, and were discussed with others. We analyzed interview transcripts using a team-based, thematic approach. Participants described concentration, memory, and multitasking difficulties that fluctuated over time, as well as potential risk factors, management strategies, and psychosocial consequences. They reported they seldom discussed cognitive impairment with health care professionals, and that receiving a HAND diagnosis was validating, informative, yet somewhat disconcerting. Conversations between health care professionals and people living with HIV about HAND may provide opportunities for education, assessment, and support.

Keywords

HIV-associated neurocognitive disorder; HIV; cognitive impairment; patient–clinician communication; patient education; lived experience; descriptive qualitative research; Ontario; British Columbia

Introduction

HIV-associated neurocognitive disorder (HAND) is increasingly recognized as a concern among people living with HIV. HAND comprises three diagnostic categories, namely, asymptomatic neurocognitive impairment (ANI; characterized by mild cognitive impairments that do not interfere with daily functioning), HIV-associated mild neurocognitive disorder (MND; where cognitive impairments have a mild but noticeable or significant impact on daily functioning), and HIV-associated dementia (HAD; characterized by moderate to severe deficits that cause marked impairment in performing day-to-day tasks; Antinori et al., 2007). Despite the decline of HAD with the advent of HIV treatment (Heaton et al., 2011), milder forms of HAND remain common. Approximately 50% of people living with HIV are estimated to

experience HAND (Clifford & Ances, 2013; Woods et al., 2009), making it an important health condition to examine in the context of HIV.

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The clinical characteristics of HAND have been well-documented in neuropsychological studies (Cattie et al., 2012; Cysique, Maruff, & Brew, 2004; Gorman, Foley, Ettenhofer, Hinkin, & van Gorp, 2009; Woods, Moore, Weber, & Grant, 2009), which show that HAND may be associated with changes in learning, memory, attentional, and executive processes affecting health, quality of life, and work productivity (Doyle et al., 2012; Trépanier et al., 2005; Woods, Weber, Weisz, Twamley, & Grant, 2011). Despite clinical knowledge of the disorder, the lived experience of HAND has received little attention.

Two previous studies by Rourke and colleagues examined the lived experience of cognitive impairment in HIV: one with men and one with women (Gallagher et al., 2013; Hopcroft et al., 2013). Participants in both studies self-reported difficulties with attention, concentration, word-finding, and multitasking, and expressed ambivalence about the role of HIV in their cognitive challenges. Participants described that the severity of their cognitive difficulties fluctuated depending on their fatigue, stress levels, and depressive symptoms. Many participants noted resilient responses and optimistic attitudes regarding the daily challenges associated with their cognitive difficulties. They reported that friends with shared experience of cognitive impairment offered valuable psychosocial support. Some participants expressed concern about discrimination from friends and/or employers based on their cognitive difficulties.

Hopcroft et al. (2013) reported that certain triggers, including stress, anxiety, and feelings of depression, exacerbated the functional impact of participants' cognitive challenges. Men in this study indicated that older age was a protective factor affording them a relaxed outlook and reduced frustration in response to cognitive lapses. The authors recommended that triggers of worsened cognitive functioning be considered as candidate intervention/management targets. In their study of women living with HIV, Gallagher et al. (2013) suggested that conceptualizing cognitive impairment in HIV with a disability lens highlighted participation in parenting and work roles as central concerns of people living with the effects of HIV-related cognitive impairment. In both studies, Rourke and colleagues found participants endorsed consistent compensatory strategies, including to-do lists, planners, and calendars.

Thus, there is some emerging research that supports the utility of exploring the perspectives and experiences of people living with HIV and cognitive difficulties. Our aim was to build on this work to explore from the perspectives of men and women diagnosed with HAND how cognitive impairment affects health behaviors, interactions with health care professionals, and reactions to a neuropsychological assessment for a diagnosis of HAND, which included tailored performance feedback, recommendations, and resources.

Method

Design

This was a community-based, qualitative descriptive study consisting of semistructured interviews and team-based analysis of interview transcripts to identify codes, categories, and themes related to the lived experience of HAND (Vaismoradi, Turunen, & Bondas, 2013). Our research team included individuals living with HIV and HAND, clinicians, researchers, and students in the fields of rehabilitation, counseling, nursing, neuropsychology, social work, education, and clinical epidemiology. Six peer research associates (PRAs), community members living with HIV, were integral to the research process. We employed a community-based research approach to integrate the priorities, interests, and values of people living with HIV in our study (Israel, Schulz, Parker, & Becker, 1998; Minkler, 2005). Consistent with this approach, PRAs were involved throughout all stages of the study, including development of the interview guide, data analysis and interpretation, and knowledge translation and exchange. We obtained ethics approval at three institutional research ethics boards.

Participants and Recruitment

To be eligible to participate, volunteers had to be 20 to 75 years old with a prior HIV diagnosis, be in stable medical condition, speak English fluently with no hearing impairment, and be able to provide informed consent. Potential participants were excluded if they had active psychotic features (e.g., delusions and/or hallucinations). We used the Antinori et al. (2007) criteria for evaluation of HAND.

We recruited participants using purposive sampling from three sites, including a community-based organization with an HIV day health program, a community-based HIV specialty hospital, and a neuropsychology clinic at a large urban hospital. A clinical neuropsychologist informed clinicians at these sites how to identify signs of cognitive impairment associated with HAND when they recruited participants. To promote diversity in our sample, we asked clinicians to prioritize inviting individuals who varied in gender, age, racial/ethnic identity, and employment status. When they approached potential participants, clinicians provided an overview of the study and reviewed the contents of the consent form. Clinicians explained to potential participants that they would receive a HAND assessment (except for those previously assessed; see Research Procedure) involving tests of memory, attention, and thinking, and if they met criteria for HAND, they would be invited to participate in a qualitative interview. They described the consent process and obtained interested individuals' verbal consent to participate in the study and for their contact information to be forwarded to the research

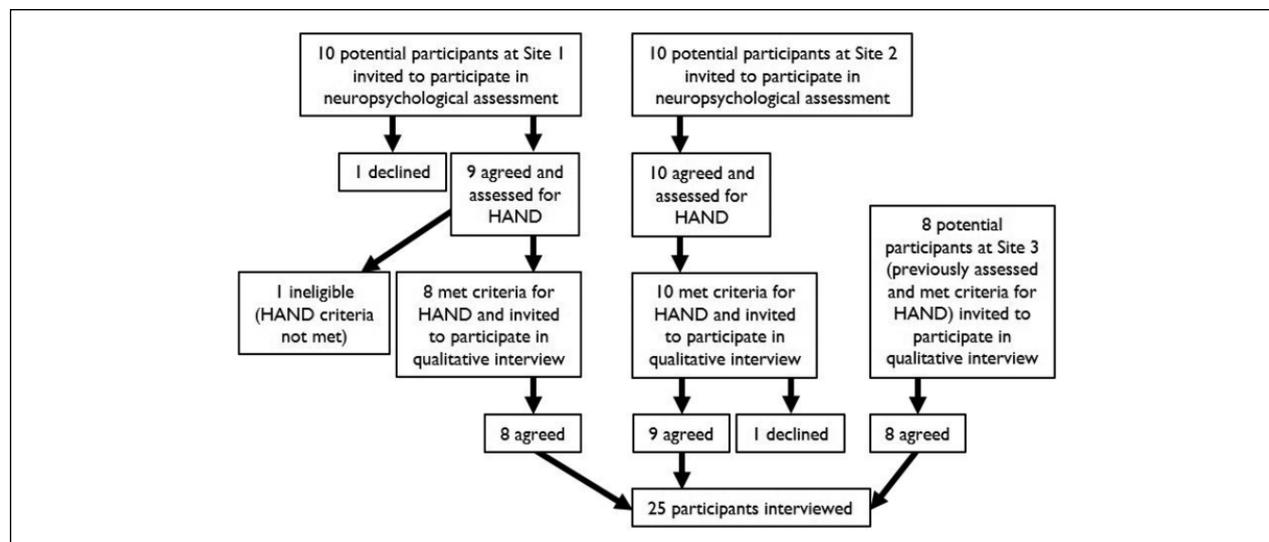


Figure 1. Participant recruitment flowchart.

Note. HAND = HIV-associated neurocognitive disorder.

coordinator. Clinicians provided potential participants with a copy of the consent form to review independently or with a trusted person before they met with the research coordinator. At the beginning of the first study visit, the research coordinator summarized the research project and procedures, detailed potential risks and benefits to participating in the study, and noted participants' right to withdraw from the study at any time. To help ensure participants were well-informed of these details, the research coordinator asked participants to describe their understanding of what they would be doing during each study visit and what the potential risks and benefits were to participating. The research coordinator then obtained participants' written informed consent and obtained ongoing verbal consent throughout the study.

Research Procedure

Participants recruited from one of three sites had, before the outset of this study, undergone a neuropsychological assessment for the diagnosis of HAND and a feedback session with a clinical neuropsychologist. Participants recruited from the other two sites completed the same assessment and a feedback session as part of this study. The trained research coordinator administered the standardized battery of neuropsychological tests (Supplementary File 1) and participants attended a feedback session with a clinical neuropsychologist and the research coordinator. During the feedback session, the clinical neuropsychologist summarized participants' relative strengths and weaknesses based on their neuropsychological test performance and indicated whether the pattern of results was consistent with clinical criteria for HAND. They also provided a list of resources

related to HIV-specific health information, emotional support, smoking cessation, and recreational programs in the community. Subsequently, the research coordinator invited participants who met criteria for HAND to participate in the qualitative interview. As prospective participants at the third site were previously diagnosed with HAND, they were invited to participate in the qualitative interview only. See Figure 1 for a flowchart of the recruitment process. For more details regarding the neuropsychological assessment and feedback session, see Supplementary File 1.

Qualitative interviews. We developed a semistructured qualitative interview guide based on previous literature (Gallagher et al., 2013; Hopcroft et al., 2013; O'Brien, Bayoumi, Strike, Young, & Davis, 2008) and guidance from PRAs. We later modified the guide according to emerging themes and issues that arose from our analysis of the first 10 interviews (see Supplementary File 2). Two team members, an experienced researcher living with HIV and the research coordinator, independently conducted the face-to-face interviews, which lasted 1 to 2 hours.

We asked participants to describe their cognitive difficulties and how these difficulties influenced their interactions with family, friends, and health care professionals. Questions focused on day-to-day challenges with memory, attention, and thinking; the trajectory of participants' cognitive capacities across days, months, and years; their effects on self-perception, mood, and resilience; and the social and health care support participants obtained for their cognitive difficulties. We also requested participants' input regarding their HAND diagnosis and feedback session.

Sample questions included the following: “Are the challenges you face with memory, attention, and thinking always there?” “How do difficulties with memory influence your self-confidence?” and “In what ways do challenges with memory, attention, or thinking affect your social life, such as the places you go or the people you spend time with?” Interviews were audio recorded and subsequently transcribed verbatim by a trained transcriptionist, with names, locations, and any other potentially identifiable information omitted. Only the transcriptionist, research coordinator, and principal investigator had access to the original transcripts.

We also administered a demographic questionnaire to obtain participants’ age, sex, education, recent employment history, medical history, social supports, and patterns of alcohol and drug use. We used information from the demographic questionnaire to characterize the study sample and provide information to support the HAND assessment to identify factors other than HIV that may influence neuropsychological functioning (i.e., age, education, medical history, and alcohol and drug use).

We compensated participants CAD\$40 for the neuropsychological assessment and CAD\$50 for the qualitative interview. Additional compensation for travel was provided for all study visits.

Involvement of PRAs. Six PRAs helped prepare the interview schedule, conduct qualitative data analysis, and prepare knowledge transfer and exchange materials. They completed four remunerated engagement and training sessions about research ethics, principles and practices in community-based research, qualitative data analysis methods (with a focus on coding data), and self-care. PRAs assessed the clarity and perceived relevance of the draft interview questions, read and coded blinded interview transcripts (independently and in groups with other members of the research team), and participated in two national research team meetings held in Toronto and Vancouver to identify initial codes and themes that emerged from the data. They also participated in a knowledge transfer event and helped prepare the research manuscripts.

Analysis

We adapted the DEPICT model (Dynamic reading, Engaged codebook development, Participatory coding, Inclusive reviewing and summarizing of categories, Collaborative analyzing, and Translating) to inform our team-based approach to qualitative analysis (Flicker & Nixon, 2014) and analyzed our data using grounded theoretical techniques (Corbin & Strauss, 1990). Each interview transcript (and its associated fieldnotes) was read by at least one researcher and one PRA. We circulated a sample of 10 transcribed and anonymized transcripts to team members for an initial reading to identify potential

Table 1. Participants’ Demographics ($N = 25$).

Characteristic	
Number of female participants	5 (20%)
Median age in years (IQR), range	51 (9.0), 35-72
Median years of education (IQR), range	13 (4.5), 0-16
Ethnicity (n , %)	
First Nations	8 (32)
Caucasian/White	8 (32)
African/Caribbean/Black	6 (24)
Latino/Hispanic	3 (12)
HAND diagnosis (n , %)	
ANI	1 (4)
MND	22 (88)
HAD	2 (8)
Employment status (n , %)	
Not currently employed	17 (68)
Employed part-time	3 (12)
Employed full-time	2 (8)
Student	2 (8)
Retired	1 (4)
Self-reported social support (n , %)	
Good support	9 (36)
Moderate support	8 (32)
Little support	2 (8)
Insufficient support	6 (24)

Note. IQR = inter-quartile range; HAND = HIV-associated neurocognitive disorder; ANI = asymptomatic neurocognitive impairment; MND = HIV-associated mild neurocognitive disorder; HAD = HIV-associated dementia.

codes, which we established collaboratively with all team members (including PRAs) during an initial in-person meeting. We used these codes to create a coding workbook for analyzing all subsequent interviews. In addition to de-identifying interview transcripts, we assigned transcripts for coding across regions and sites to further reduce the likelihood that readers, especially clinicians and PRAs, had any prior relationship with participants whose interviews were being read. After we established the descriptive codes, we grouped them into categories by theme and subsequently compared the text segments assigned to each category. At the second in-person meeting, team members reached a consensus regarding the general themes that emerged from the categories. Team members’ diverse perspectives, notably the PRAs’ lived experience of HAND and clinicians’ experience working with clients with HAND, enriched our interpretation.

Results

Twenty-five participants living with HAND (nine in Vancouver, 16 in Toronto) completed the qualitative interview and were included in the data analysis. See Table 1 for participant characteristics.

We identified five themes based on the interview codes and categories: (a) the natural history of participants' cognitive difficulties, including reported symptoms, their trajectory, and suspected risk factors (non-modifiable and modifiable); (b) participants' management strategies, categorized as compensatory (spontaneous and systematic) or remediation techniques; (c) the impact of cognitive impairment on participants' psychosocial well-being, including their emotional well-being and the role of stigma (felt stigma, self-stigma, and enacted stigma); (d) how cognitive challenges affect health and health care services (maintaining health behaviors and receiving health care support); and (e) how participants viewed and reacted to the HAND assessment process (receiving a HAND diagnosis, tailored feedback, and recommendations).

Natural History of Cognitive Difficulties

Participants described how their cognitive functioning manifested (cognitive symptoms), evolved over time (trajectory), and perceived risk factors (non-modifiable and modifiable) influencing their cognitive impairment.

Cognitive symptoms. Participants reported concentration, memory, and multitasking difficulties that interfered with activities at home, school, and work. Most participants noted frequent challenges recalling words, names, faces, details about past events, and/or important dates. Many described themselves as easily distracted, and noted they often initiated new activities before they finished others. A student in her late 40s with MND said, "Concentration is hard. Distraction is easy. So it's like I'm doing two or three things at one time . . . The problem is when I get the job done . . . I don't remember why I did it or where I put things." In addition to interfering with daily responsibilities, a few participants reported that cognitive impairment posed risks to their safety. For example, a man in his late 50s with MND and who had worked in construction recounted,

I lost my concentration and that's when things will start to fall apart . . . For instance I almost got—I was within the proximity of a concrete bucket that came down from a crane. I was within an arm's reach of the concrete bucket because I was having a discussion with my foreman . . . I didn't see it coming.

Participants suggested that there are persistent inconveniences caused by difficulties with concentration, memory, and multitasking that interfered with efficiency and fulfilling daily responsibilities, as well as potential dangers.

Trajectory. When asked to consider how their cognitive functioning had changed over time, most participants

reported a decline in their cognitive functioning compared to months and years prior. Considering the trajectory of his cognitive difficulties over many years, a man who was in retirement and diagnosed with MND stated, "I think there's been a general . . . degradation may be too strong a word, but decline in that capacity." A middle-aged man with MND who was working part-time explained, "at first [my cognitive impairment] was pretty bad, but it's . . . leveled off." In contrast, another participant diagnosed with MND said his cognitive functioning was not "any worse than it has been over the years." Despite meeting criteria for HAND, not all participants claimed they noticed changes in their cognitive functioning since their HIV diagnosis.

Participants made statements about differences in their cognitive functioning "then" versus "now." A woman in her late 40s who was seeking employment at the time of her interview asserted, "I used to be a smart person until I [got] this illness [HIV]." Others cited a decline in specific cognitive domains; for instance, a middle-aged man who was discussing his responsibilities at work said,

[W]hen I'm writing out an order, everything is written down there. But I used to rely on my memory to remember . . . now I'm relying more on our manual or catalogue, which has all of those details written down and I just have to go back and check.

Participants also reported short-term fluctuations in their cognitive capacities. An older participant with MND described day-to-day fluctuations in his cognitive functioning that he referred to as "good days" and "bad days." He explained,

[On a good day] I function well. I don't forget a lot of things. I make social arrangements and do things with people. A bad day is where it might be that same scenario, but I start to forget little things and then I get upset that I forgot and I get into a bit of a spiral there. The first is still the most common.

Non-modifiable risk factors. Participants in this study speculated about causes of their cognitive impairment outside their control, including normal aging, long-standing psychiatric and/or intellectual conditions (e.g., attention-deficit hyperactivity disorder, learning disabilities), past substance use, and HIV.

Although most participants considered their cognitive impairment to be best explained by factors other than HIV, they often cited a combination of factors that included HIV. A student with MND noted, "Well I didn't realize it was a big problem until recently. I thought it was just me aging. I thought it was just a lot of stress causing it. So I wasn't talking to my doctor about it." This participant's reference to stress mirrored comments from several participants that both stable and dynamic factors influenced their cognitive functioning.

Modifiable risk factors. Participants perceived that factors beyond their control, such as HIV medications, stressful thoughts and events, sleep, and mood, also influenced their cognitive status. As an older man with MND explained, “I’ve been on meds for over two years now and I noticed, you know, I’m struggling to find words and things like that . . . the impact of just medication itself on peoples’ cognitive abilities . . . especially the intense nature of the medications.” Other participants suggested some, but not all, HIV medications may have hindered their cognitive capacities. A woman diagnosed with MND said,

I wanted to talk with my HIV doctor . . . maybe if she can change my medication maybe I’ll be better. Maybe my memory will improve. Yeah, I still have to talk with her about it because I don’t know the cause—if it’s due to medication or it’s HIV.

Participants recollected ruminative negative thoughts about their cognitive difficulties that increased their subjective stress and worsened their ability to think and remember. An older man in retirement reflected, “I find that there’s a vicious circle. Like [one] afternoon I was getting more preoccupied and concerned with what I was forgetting and it was increasing the stresses I was feeling.” Participants also recalled stressful life events that caused abrupt and significant cognitive problems. A woman diagnosed with ANI said,

[O]ne lady, she yelled at me because [while I was in a movie theatre] I didn’t pick up the phone . . . She started yelling at me and cursing. After that I didn’t know where I [was]. I was completely lost and it was dark on me. I asked the ladies who were there . . . where are we and did we watch the movie? I was completely lost. I asked them to “take me home because I don’t know where I am and I don’t know the way to my house.”

Thus, in addition to the inherent stress of experiencing cognitive difficulties, participants reported that external stressors had a significant disruptive effect on their cognitive status.

Participants also identified poor sleep as a modifiable risk factor that influenced cognition. For example, a man in his mid-30s who was diagnosed with MND said,

I don’t sleep well . . . I only sleep for three hours and then I will be up until morning. I cannot sleep like eight straight hours or six straight hours, only three or four. So I don’t know if that [influences] my memory too. I think so.

Many participants reported a link between their past experiences of low mood with cognitive dysfunction. A man in his early 60s with MND asserted, “There’s a strong correlation between mood—between emotions and the intellect . . . my experience [of] emotions provide almost like a fertilizer for the intellect.”

Participants noticed ongoing fluctuations in the severity of their cognitive difficulties, and attributed the changes to a variety of modifiable risk factors such as HIV medication, stress, lack of sleep, and mood.

Management Strategies

Participants reported mental and behavioral strategies used to manage their cognitive difficulties, including compensatory and remediation approaches (Cicerone et al., 2011).

Compensatory strategies

Spontaneous. Many participants reported spontaneous compensatory responses to daily hassles attributable to cognitive impairment, including solution-focused and trial-and-error approaches. One participant summarized his response to such hassles as, “I know I can do this - let’s rethink about what worked and what didn’t work that [other] time that I can utilize for this time. That’s the best way; it’s turning it around.”

Systematic. In addition to solution-focused and trial-and-error reactions, participants described systematic strategies, such as using paper-based and electronic aids for planning, scheduling, and reminders. One participant in her late 40s diagnosed with MND explained, “I will plan what I want to do for the next day. I always like to plan my stuff. I don’t have a lot of stuff to plan but that’s what helps me get through the day.” In terms of processing and retaining information, another participant said she used patterns to enhance her attention and organization, like arranging materials “alphabetically, by numbers, or by color.”

Participants indicated that physically salient prompts, reminders, and instructions to aid in day-to-day tasks were an asset. For example, two participants reported that remembering their daily schedule was easiest when they transcribed their schedule on a small notepad or piece of paper they stored in their pockets. One of these participants described,

I have to put things in place to remember. So sometimes I write it down and I have it in my pocket and I say to myself okay now when I go home I have to empty out my pockets. So I know that when I empty out my pocket and paper that I write on I’m going to remember that I wrote on that paper. Instantly I open it. But I have to put a lot of stuff in place in order to remember things.

Comparing paper-based and electronic scheduling strategies, a man in his early 50s with MND said,

I keep [a sheet] with me because as appointments come up I can write them right in. I just find doing it through the smart phone is a little more difficult. I did try using that app

because I could link it up to alarms and whatnot. But it just wasn't working and I'm a technology smart person and I find it frustrating.

However, some participants relied primarily on electronic aids. A middle-aged man with MND said, "I have calendar reminders and stuff. Whenever I bring my bike I have to ping it [track its location using GPS] because I've left my bike and not remembered where the bike was before, that kind of stuff."

Remediation strategies. Participants reported engaging in activities that may have helped maintain or improve their level of cognitive functioning, such as mental exercises, maintaining a healthy diet, physical exercise, and mindfulness. In terms of mental exercises, a man with severe cognitive impairment explained, "If someone says a word and I don't get it . . . I say it a couple times until my vocabulary gets bigger and bigger." Another participant with MND suggested that "trying to eat as health[y] as [he] possibly can" benefited his cognitive function. Regarding physical exercise, a man in his late 40s with MND said, "Well, I think I find that, you know, like exercise, a walk, the fresh air . . . getting some air into your lungs, wakes you up and gets your brain going." Finally, a man of the same age reflected, "I meditate quite a bit. I think that is probably the thing that helps me most." Most participants outlined one or more activities they engaged in that may have been considered remedial for brain health.

Psychosocial Well-Being

Participants described several impacts of HAND on psychosocial well-being, including their emotional well-being and stigma, and positive and negative dimensions of social connectedness.

Emotional well-being. Many participants reported that experiences of frustration, embarrassment, and worry associated with cognitive difficulties and potential decline, were common for them. A participant in his late 40s diagnosed with MND stated, "[Y]ou get kind of frustrated and pissed off at yourself because you forgot." Referring to his memory difficulties at work, one participant disclosed,

[Not remembering is] embarrassing for me because you know I would get frustrated because I couldn't remember and I didn't want to ask [my supervisor] again because he was so tired of people being around him and not remembering. I don't know if he had a lot of [employees] that were positive or whatnot.

Another participant explained, "There are times when I notice [my cognitive difficulties] more than others . . .

[for example,] in a situation where it can be embarrassing to forget something." Frequent worries were also reported, such as one participant who said he worried that "blinking" and having "intervals in [his] conversation" signaled cognitive decline. However, worry may have been a motivating factor for one participant who said, "I worry about [my memory getting worse] . . . That's why I try to read every day so that my memory won't get so bad and then I try to do [cognitively challenging] games. That helps me a lot too."

Stigma. In addition to the frustrations, embarrassment, and worries participants described, they also noted problems related to stigma of cognitive impairment. Participants in this study described dimensions of stigma, including felt stigma, self-stigma, and enacted stigma (Corrigan, Larson, & Ruesch, 2009; Gray, 2002), regarding cognitive impairment and HIV that affected them in social and work settings.

Felt stigma. Several participants reported not speaking up or asking for help when their cognitive difficulties caused problems because they were concerned others would judge them negatively. For example, a man with MND stated that when he lost track of conversations, he "put [on] a brave face . . . [and] a big smile" and "laugh so they [wouldn't] know" he was experiencing cognitive difficulties.

Self-stigma. Some participants made critical self-judgments about their cognitive status and how it could impact their futures. A woman diagnosed with ANI said,

I don't want to get dementia. If I do and people know this already, if I do, I'm going to take myself out because like who wants to sit around watching somebody lose your mind. I think that's very selfish of people and I don't like to do that.

Other participants made similar comments, such as a woman with MND who said, "I don't even want to see myself becoming dependent on people or even my kids to have to take care of me or having to remain on social assistance."

However, some demonstrated contrasting perspectives, such as a man with MND who asserted,

Like, am I going to be like you see people on TV and whatnot going through dementia and whatnot? I think if I've got the right team that will work with me then it won't be as . . . You know if I notice a big difference, yes, I will definitely put my hand up and ask for help.

Enacted stigma. Participants described criticism they had received from others in response to their attentional and memory lapses. A man with MND said his children

think, “When dad forgets, he’s stupid.” A woman in her early 50s with MND recalled,

[M]y daughter criticized me about the way, you know, I behave. I behave like I’m not in my sound mind or I can’t remember things. They treat me like I’m not competent enough to be with their children alone or for me to take them out . . . It’s not like I’m out with the kids on the subway and then suddenly I remember “Oh, you’re with me.” That doesn’t happen.

Social connectedness. HAND also influenced social well-being through its influence on social connectedness. Many described friends or family as a source of shared experience and practical support. A man in his mid-50s diagnosed with MND said, “I’m surrounded with people [living with HIV], so they relate to me and I relate to them . . . we look out for each other right, which is a good thing.” Another participant stated that he and his friends would “laugh about [their] cognitive difficulties” because they were all “going through the same process.” Similarly, one participant reported that his wife helped him cope with his memory difficulties by “laugh[ing] about [his forgetfulness]” in a light-hearted manner.

Participants provided several examples of how their friends helped them manage their cognitive challenges. A man with MND described,

[For] important things like appointments, I rely on my friend. He’s got a chart for me, he’s got a calendar. He’s very practical in what he does, which I admire him for . . . I kind of trust him. He’s got a couple of files with my name on it. Important papers that I’m going to lose or I don’t want to lose, I give it to him. It’s in my file.

Other participants described feeling that their cognitive impairment prevented them from forming and maintaining friendships, which reduced their self-esteem. A man in his early 60s diagnosed with MND noted, “It’s just people talk to me and I lose interest, no eye contact. One time I did that to my friend who was standing there. I was just staring at him. Sometimes I don’t feel adequate . . . because I’m losing friends and stuff.”

Thus, while many participants found significant others and friends helpful for coping with cognitive impairment, some asserted the impairments jeopardized their social networks.

Health and Health Care Services

Maintaining health behaviors. Many participants recollected missing or forgetting meals, medication, and medical appointments. As one participant with MND described, “I had an appointment, a hearing test, a while ago . . . It took me three times before I could get in to see

the doctor. I kept forgetting the appointments, even though I had a reminder.” Another with MND said, “My memory problems interfere with my remembering to take pills, for example, and my remembering to eat.” Most participants recalled one or more instances when their cognitive difficulties interfered with their health behaviors.

Health care support. Several participants in our study recalled receiving valuable support from community-based health care professionals, especially with medical appointment reminders. For instance, a man diagnosed with MND said, “I didn’t miss any of [the Hepatitis C specialist’s] appointments because [the support staff] . . . will call me that morning for a reminder.” Another recounted a health care support staff member helping him “repair damage” done with a medical specialist when multiple appointments were missed.

Participants often indicated they rarely discussed their cognitive difficulties with their primary care physicians and HIV specialists. When asked if he had spoken to a health care professional about his cognitive challenges, a man with MND responded, “I don’t think so, no. That’s sort of something I’ve always thought I’d have to take on myself.” Those who reported having the conversations about cognitive difficulties indicated that the conversations were limited. As a man in his late 40s recounted, “[M]y family doctor . . . might be the only person I would have talked to about memory, but nothing extensive or anything.” Alternatively, another man with MND recalled saying to his health care professional, “I have . . . lost some valuable things and I don’t know why . . . I just want to know if it’s HIV.”

Some participants reported concern and guilt about how their missed appointments were interpreted or handled by their health care professionals. For example, a man in his early 50s with MND asserted, “the doctor is not going to put up with no-shows.” A woman with MND explained,

If I forget about my doctor’s appointment I feel bad. It’s like I did it intentionally like I didn’t want to go to the doctor. I make sure that I go straight away and tell them that you know what I forgot that I had appointment at this time, that’s why I’m here. Rather than calling them that I forgot my appointment. So they can see me physically.

Other participants asserted that appointment attendance should be a shared responsibility between patients and health care professionals. As a woman with ANI said, “I get frustrated because, it’s like, you’ve got to be at this appointment and we’re not going to chase you down for this appointment. He gets like that and it’s a conflict sometimes.”

Overall, participants emphasized that community-based health care professionals offered valuable support to help them manage their cognitive impairment, and that they infrequently raised concerns about cognitive functions with their primary care physicians or HIV specialists. Furthermore, participants described worries and frustrations about missing medical appointments, especially specialist appointments.

HAND Diagnosis and Feedback

Reaction to HAND diagnosis. Participants' responses to receiving a diagnosis of HAND varied. Several participants reported that a diagnosis of ANI or MND relieved their anxiety and concerns of having dementia. For example, when we asked a woman with ANI what she found most helpful during the neuropsychological assessment and feedback session, she said, "[The feedback session] relieved a lot of things that were on my mind . . . one of my worst fears is having dementia." A man in his early 60s with MND stated that he appreciated receiving an explanation for his cognitive difficulties and the knowledge that his memory was not "disappearing for no reason." However, some participants found the diagnosis disconcerting. A woman diagnosed with MND was surprised but accepted that she met criteria for HAND. She said,

It was scary to know, scary to find out for me in a way . . . It just kind of shocked me. But I have to realize now I have to accept it, because you know, I am getting older and I know there's going to be some issues down the line for me forgetting and stuff because that's the way it is. It kind of opened my eyes a little bit.

In contrast, a man diagnosed with MND said, "I just don't want to accept that I'm suffering memory loss." Thus, some participants who had pre-existing concerns about their cognitive functioning found the assessment and diagnosis provided relief, whereas those who reported little or no knowledge of their impairments experienced some shock and difficulty coming to terms with the new diagnosis.

Receiving HAND assessment results and recommendations. In addition to their HAND diagnosis, the clinical neuropsychologist gave participants tailored feedback regarding their relative strengths and weaknesses on the cognitive tests, as well as educational information about the causes, clinical characteristics, and management of HAND. During the qualitative interviews, we asked participants to comment on what they perceived to be the benefits and drawbacks of the tailored assessment feedback and related resources. Speaking generally about the feedback meeting, a middle-aged man diagnosed with MND reported,

Well, like, it wasn't fun, right, talking about these issues—but, you know, I don't usually talk about things at all with other doctors. It gave me an opportunity to put this out there and just see the reaction. I got good feedback. I'd say it was a very worthwhile experience.

As noted above, many participants had not previously discussed their cognitive concerns with health care professionals. For this participant, as well as others, disclosing to a health care professional that he was experiencing cognitive difficulties, having his cognitive functioning assessed, and receiving feedback about his cognitive status were of significant benefit. As noted earlier, several participants explained that the clinical neuropsychologist validated their concerns about cognitive impairment and confirmed for them that their cognitive challenges were worthy of attention from a health care professional. A man diagnosed with MND reported feeling as though "somebody was actually paying attention to what we were going through."

Participants also reported that the meeting with the neuropsychologist increased their self-esteem. When she reflected on the neuropsychologist's feedback regarding cognitive tests she performed well on, a woman with ANI noted, "[The feedback] made me more positive in a way, that, you know what, I'm not stupid." Thus, participants indicated that positive feedback was a source of increased confidence and encouragement when receiving a HAND diagnosis.

Participants reported some limitations of the assessment feedback session, like the technical terms used to describe cognitive capacities. A woman diagnosed with MND explained,

I just didn't understand [the results of the assessment]. I didn't know what she meant by [problem solving] . . . She said five things. Problem solving, speed, something like that and there's something wrong my fingers, the tips, which I believe is true, and I forget the other two.

In summary, participants found that once they disclosed their cognitive challenges to a health care professional, had their suspected impairments confirmed, and received encouraging personalized feedback about their cognitive test results, they felt relieved and validated.

Discussion

This study extends our previous research exploring the experiences of men and women living with HIV and cognitive impairment. To our knowledge, this is the first study to investigate how individuals view and react to an assessment for the diagnosis of HAND and interactions between people living with HIV and their loved ones and health care providers about their cognitive difficulties.

Participants in this study described concentration, memory, and multitasking difficulties, which were consistent with previous qualitative (Gallagher et al., 2013; Hopcroft et al., 2013) and clinical (Hinkin, Castellon, & Hardy, 2000; Murji et al., 2003; Rourke, Halman, & Bassel, 1999; Tozzi et al., 2007; Woods et al., 2009) studies of cognitive function in people living with HIV. These clinical studies showed that individuals living with HIV tend to exhibit impairment on tests of sustained and complex attention (which may relate to concentration and multitasking, respectively; Hinkin et al., 2000; Woods et al., 2009) and memory, relative to age- and education-matched controls.

Building on the coping strategies previously outlined by Gallagher et al. (2013) and Hopcroft et al. (2013), we found that participants described using compensatory and remediation strategies consistent with their personal preferences and expertise. Individuals less comfortable with technology reported using paper notebooks and calendars to record appointments and important dates, while others found assistive technologies helpful for managing their schedules. Reviewing and planning daily schedules was a helpful strategy reported by some participants and has been shown to be potentially useful in the context of HAND (Cattie et al., 2012) and other cognitive disorders (Cicerone et al., 2011). Participants in this study underscored the benefits of exercise and mindfulness for cognitive functioning, activities which may help address cognitive impairment in HIV (Dufour et al., 2013; Fazeli et al., 2015; Zeidan, Johnson, Diamond, David, & Goolkasian, 2010).

Aligning with previous reports (Gallagher et al., 2013; Hopcroft et al., 2013), we found that negative emotional reactions to cognitive challenges (Carter, Rourke, Murji, Shore, & Rourke, 2003), especially frustration, embarrassment, and worry, were commonly endorsed. Participants expressed self-critical and potentially self-stigmatizing emotional reactions to their cognitive difficulties suggested they may have felt “at fault” for them. However, they also reported adaptive psychological reactions, such as laughter with friends and partners. Individuals living with HIV who report more negative psychological reactions to cognitive challenges may benefit from psychosocial interventions that incorporate friends and family to foster shared understanding and social support.

Notably, past research suggests that HIV stigma can be a barrier to conversations with family, friends, and health care professionals about health problems and behaviors (McDonald, Slavin, Pitts, & Elliott, 2016). Accordingly, participants in this study provided examples of felt stigma that prevented them from talking about cognitive difficulties with employers and friends. However, women in Gallagher et al.’s (2013) study reported positive

experiences after disclosing their cognitive impairment to their employers. Furthermore, disclosure of cognitive impairment to an employer or appropriate educational advisor may facilitate workplace or academic accommodations. Interventions aimed at improving communication and increasing knowledge about cognitive and related functional difficulties associated with HIV among family, friends, health care professionals, employers, and/or academic advisors (as well as the potential advantages, disadvantages, and procedures of disclosing a cognitive disability) may help individuals living with HAND overcome stigma (Von Ah, Storey, Jansen, & Allen, 2013).

Our results also highlight that prospective memory (i.e., “remembering to remember”) may be a key issue affecting medication adherence and medical appointment attendance for individuals living with HAND. Missed appointments are costly (Mitchell & Selmes, 2007) and associated with poorer maintenance of an undetectable viral load (Berg et al., 2005). Consequently, evidence-based strategies that target prospective memory may improve medical appointment attendance, medication adherence, and maintenance of health-promoting habits and routines for HIV-positive patients with cognitive impairment (Ellis & Jenkins, 2012). Furthermore, reminders for appointments, taking medications, and other health behaviors can be tailored according to patients’ preferences and use of various technologies, such as alarms, email, text messages, and phone calls (Finkelstein, Liu, Jani, Rosenthal, & Poghosyan, 2013).

A novel finding in this study, and contribution to the literature, was that conducting a comprehensive, “gold standard” neurocognitive assessment for the diagnosis of HAND, particularly ANI and MND, and sharing the results and implications of the assessment with participants, was favorably received and an important intervention to reduce worry and rumination. Furthermore, conducting a clinical interview was helpful for assessing the potential contributions of developmental or other comorbidities to participants’ cognitive status. The assessment and feedback process appeared to validate participants’ struggles with cognitive impairment and alleviate their fears of dementia (and specifically Alzheimer’s disease). Feedback from participants in this study suggested that specific worries about cognitive decline and dementia, as well as uncertainty about the existence of cognitive impairment, were areas of concern that may need more attention. These concerns may be addressed in part by more targeted patient education and practical strategies to cope with and manage cognitive difficulties.

Experiences with the HAND assessment and feedback session suggest that additional and longer term support following a diagnosis of HAND such as counseling or peer support may also help reduce fears, facilitate acceptance of the diagnosis, and increase self-efficacy and

confidence. Furthermore, based on our study participants' feedback, using more accessible language, limiting feedback to key assessment results and recommendations, and providing written handouts summarizing information about cognitive impairment and HIV may be helpful for educating individuals diagnosed with HAND.

A noteworthy finding was the role(s) of health care professionals in supporting individuals with HIV and cognitive impairment. Specifically, health care professionals in community-based settings (e.g., support workers) were reported to provide valuable support for participants' cognitive difficulties, such as reminders of medical appointments. However, participants indicated that they had minimal discussions about their cognitive functioning with primary care physicians and HIV specialists. There are likely many reasons for this communication gap. For example, clinical guidelines for HIV assessment and treatment of HAND were only recently developed (The Mind Exchange Working Group et al., 2012) and there are few accessible continuing medical education opportunities to increase knowledge base. Moreover, the access to and resources for formal neurocognitive assessment of HAND are lacking, and there is only modest evidence for the effectiveness of current screening tools available to assess for the neurocognitive impairments associated with HIV (Zipursky et al., 2013). Participants' expressed perceptions that the roles of their primary care physicians and HIV specialists may not necessarily include the scope of helping to assess and address cognitive impairment may be another contributing factor. Providing health care professionals with key messages and resources they can share with their patients about how HIV can affect the brain, and empowering individuals living with HIV with knowledge to bring to their physicians to begin those conversations, may be useful starting points for addressing the functional and psychological consequences of HAND (Malaspina et al., 2011). Furthermore, remaining informed about emerging research on the potential association or link between HAND and Alzheimer's disease, particularly findings from prospective studies, may help health care professionals deliver up-to-date and accurate information to their patients about their relative risk for Alzheimer's disease, which may alleviate worries that the mild cognitive impairments they experience are signaling an insidious "dementia" syndrome (Brew, Pemberton, Blennow, Wallin, & Hagberg, 2005). To date, there is mixed evidence regarding neuropathological similarities between HIV and Alzheimer's disease, but previous studies suggest that both similarities and major differences exist (Brew et al., 2005; Esiri, Biddolph, & Morris, 1998).

Particularly for milder forms of cognitive difficulties, there are still ways that health care professionals can help to mitigate their potentially adverse effects (Eshkoor,

Hamid, Mun, & Ng, 2015). However, the development or identification of brief screening tools for HAND is necessary to increase access to cognitive screening (Borson et al., 2013; Morley et al., 2015) and identify those who may benefit from further assessment and/or intervention (Borson et al., 2013; Joska et al., 2016; Morley et al., 2015; Zipursky et al., 2013). Recent work by Robbins et al. (2018) with second-generation cognitive screening instruments for HAND show promise in having better sensitivity and specificity for identifying those at risk for HAND who need more detailed follow-up and support.

This was an exploratory study limited to urban Canadian contexts with predominantly men with Mild Neurocognitive Disorder classification of HAND. Although a comparison of the experiences of participants living in urban versus rural areas was beyond the scope of this study, there may be additional and distinct experiences of HAND for individuals who may have limited or no access to neuropsychological services not captured in this study. Furthermore, because of our limited sample, we did not examine differences by sex, ethnicity, and age, and these factors should be explored in future studies. A large proportion of participants were not working, and we did not explore employment as a factor in the lives of those with HAND. Moreover, our interview schedule did not include a question about impaired motor function, a concern raised by participants in previous qualitative studies on HAND (Gallagher et al., 2013). The lived experience of HAND for individuals not seeking care from HIV-specific facilities and those unaware of or unmotivated to identify their cognitive impairment was not captured here and also deserves attention in future studies. Overall, research is needed to explore the lived experience of HAND across a wider range of impairment, for people living in rural communities, among those who are employed or studying full-time, and using a recruitment strategy that includes individuals with HAND who are not accessing HIV-specific care.

In this study, participants expressed not only relief and validation but also shock and doubt, in response to their HAND diagnosis. They reported that their partners and close friends help them cope with their cognitive difficulties, and past reluctance to share their concerns about cognitive impairment with their health care providers. Much like participants in previous studies of the lived experience of cognitive impairment in HIV (Gallagher et al., 2013; Hopcroft et al., 2013), our participants reported concentration, multitasking, and memory difficulties that varied in degree depending on factors such as stress, sleep, and mood, and produced negative emotional reactions including frustration, embarrassment, and worry. Participants described paper-based and electronic aids they used to compensate for their memory difficulties and activities like exercise and mindfulness that improved their concentration and memory.

In conclusion, individuals with HIV may benefit from open discussions with health care professionals about HAND, including patient education, suggestions for managing and coping with cognitive challenges, and opportunities for neuropsychological assessment and feedback. Health care professionals may benefit from education about HAND and strategies for initiating helpful conversations about cognitive symptoms and impairments with people living with HIV.

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Supplemental Material

Supplementary material for this article is available online.

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