Exploring the role of Social Work in supporting people affected by HIV-Associated Neurocognitive Disorder (HAND)

by

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A thesis submitted in conformity with the requirements for the degree of Master of Social Work
Factor-Inwentash Faculty of Social Work
University of Toronto

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Abstract

It is estimated that 50% of the 75,500 people living with HIV/AIDS in Canada will be affected by at least an asymptomatic form of HIV-Associated Neurocognitive Disorder (HAND). As the number of HIV-positive people over age 50 increases, social workers and other helping professionals need to adapt to meet people’s changing needs. Using a Participatory Action Research (PAR) framework, an explanatory sequential mixed-methods study was conducted to understand: a) concerns about living with HIV and changes in cognition; b) client knowledge and experience of social work; and c) gaps in current HIV-related programs and services related to cognitive health. Through a quantitative survey (n=108) and qualitative interviews (n=20), five key themes emerged regarding the duality of people’s perceptions and experiences, confusion about whether health issues were attributable to HIV or to aging, social work’s role as a necessary support service, and how knowledge and supports decrease stress and anxiety.
Acknowledgments

I benefited from the generous support of many individuals and organizations throughout the process of completing this thesis. Thank you to the Ontario HIV Treatment Network (OHTN) for funding this research project. Dr. Sean Rourke and Dr. Francisco Ibáñez-Carrasco from the OHTN provided support and guidance to this project from its conceptual stages through to completion. Thank you to ACT (the AIDS Committee of Toronto) for hosting this study.

Dr. Shelley Craig and Jocelyn Watchorn were incredible co-supervisors on this thesis. They were always available to debrief about the project and greatly contributed to the research team.

The other research team members – John McCullagh, Robert Wallace, Chantal Mukandoli, and David McClure – were a source of constant inspiration for me. They were passionate about the research project and worked diligently to meet high expectations and tight deadlines.

The Canadian Working Group on HIV and Rehabilitation (CWGHR), the Canadian AIDS Information Exchange (CATIE), and Casey House provided organizational support to the project in its early stages and remained supportive throughout the project’s timeline.

Thank you to Gabriela, my family, and my friends for their love and support throughout a busy two years.
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Chapter 1
Introduction

Purpose

The purpose of this research project was to engage people growing older with HIV in a mixed-method, Participatory Action Research (PAR) study to better understand how social workers can address concerns related to HIV, aging, and cognitive health.

This research study was funded by a provincially-allocated community-based research grant that seeks to fund “…scientifically rigorous, community relevant research that will have a short- to medium-term impact on those most affected by HIV in Ontario” (Ontario HIV Treatment Network, 2012, p. 2).

Research Questions

This study attempted to address a gap in service for people aging with HIV. To accomplish this, the author had to understand current cognitive health concerns and to what extent these concerns were addressed by existing services. Therefore, the study was designed to answer the following research questions:

1. What are the self-identified concerns of HIV-positive older adults affected by HAND in Ontario?
2. How have these concerns been addressed or not addressed through existing programs and services from social workers, hospitals and clinics, and community-based HIV organizations (CBOs or ASOs)?
3. To what extent do clients and community members understand the role of social workers, hospitals and clinics, and CBOs/ASOs?

Objectives and Goals

To try and answer the above research questions, this study had the following objectives:

1. To improve our understanding of the support service needs of HIV-positive older adults affected by or concerned about HIV-Associated Neurocognitive Disorder (HAND) in Ontario.
By exploring the challenges and barriers faced by HIV-positive older adults in Ontario and the services, both medical and community-based, currently available to address the self-identified needs of this population group, this project can inform the development of targeted support programming for HIV-positive older adults by social workers and organizations that serve people living with and affected by HIV/AIDS.

2. To increase the capacity of the research team to conduct community-based research for the aging population of people living with HIV.

This research project served as the author’s Master of Social Work (MSW) thesis and engaged four people living with HIV as peer researchers. By doing so, this project aimed to build the capacity of the research team to conduct further research into this priority population.

3. To create opportunities for knowledge transfer and exchange (KTE) between stakeholder groups about social work’s response to HIV and aging.

Social workers in Ontario have yet to comprehensively address issues related to HIV and aging. This research project aimed to initiate a client-centred response to the topic by gathering data directly from people most affected by HIV and aging in Ontario. Sharing the project findings through conferences, networks, written reports, social media, publications, etc. could create new partnership opportunities between stakeholders to address this issue.

### Rationale for the Study

This project originated as a result of interactions between service users and the author within the context of the author’s role at the AIDS Committee of Toronto (ACT), where the author coordinates group-based and individual interventions for people living with HIV. HIV-positive older adults were asking about support services within CBOs/ASOs that could provide emotional support, connection to medical treatment, and education regarding HAND.

An informal environmental scan was conducted in Winter 2014. From the author’s perspective at that time, CBOs/ASOs in Toronto were not offering programs and services focused on HAND in a consistent and comprehensive manner. Social workers and other service providers in CBOs/ASOs were certainly providing support to people affected by HAND, however the focus of their interventions was centred on living well with HIV and did not account for the unique challenges that a person affected by HAND may experience.
Organization of Thesis

This thesis is organized into the following chapters: (a) review of the literature; (b) methodology; (c) results; (d) discussion; (e) limitations; (f) conclusion; (g) references; and (h) appendices. Figures and tables have been included within the chapters to provide visual representations of the data. Where relevant, chapters have addressed the quantitative and qualitative aspects of this mixed-methods study as separate, sequential phases since the quantitative phase of data collection and analysis precluded the qualitative phase.
Chapter 2
Review of the Literature

HIV/AIDS and HAND

An estimated 75,500 Canadians were living with HIV at the end of 2014 (Chalacombe, 2015). Of this statistic, approximately 39,630 (53%) are men who have sex with other men (MSM) and 16,880 (22%) are women (Chalacombe, 2015). The largest proportions of new HIV diagnoses in Canada, since 1985, have been among people over the age of 30 and the proportions of new HIV diagnoses among people aged 40-49 and over 50 have been increasing since the beginning of the HIV epidemic (Public Health Agency of Canada, 2013). Neurocognitive impairment is a condition associated with HIV, with approximately 50% of all people living with HIV in Canada affected by at least an asymptomatic form of HIV-Associated Neurocognitive Disorder (HAND) (St. Michael’s Hospital, 2013). Previous studies have found that HIV-positive people who are aged 50-69 may be cognitively functioning similar to HIV-negative people aged 70-89 (Cohen, Seider, and Navia, 2015; Seider et al., 2014). Furthermore, epidemiological trends from the United States show that “HIV-infected adults over age 55 comprise the fastest-growing age group in the HIV-positive population, and advanced age at the time of seroconversion increases the risk for neurocognitive impairment” (Cohen, Seider, and Navia, 2015). In a systematic study of 96 people tested extensively throughout the first 12 months of their HIV infection, the majority of individuals were found to have HIV enter their nervous system at a median 77 days following HIV infection (Spudich, 2013). This initial HIV neuroinvasion was found to be largely asymptomatic and associated only with headaches (Spudich, 2013). Another cognitive health study of 347 participants with a mean age of 43 years old found that neurocognitive function declined faster among participants who had less education, were female, and who had a history of substance use or other comorbidities (Albert and Martin, 2014; Grant et al., 2014). HAND is defined as neurological disorders that cause cognitive impairment (Atkinson, 2010; Grant et al., 2014; Spudich, 2013). HAND is classified in three forms: Asymptomatic Neurocognitive Impairment (ANI), Mild Neurocognitive Disorder (MND), and HIV-Associated Dementia (HAD) (Grant et al., 2014). A person with ANI will likely not have any problems with daily functioning, however they will show impairment on neurocognitive testing (Grant et al., 2014; Spudich, 2013). MND is characterized by mild interference in a
person’s daily functioning, such as short-term memory loss (Grant et al., 2014; Spudich, 2013). HAD is diagnosed if an individual is significantly impaired in their ability to learn new information, maintain attention, and concentrate on tasks (Grant et al., 2014; Spudich, 2013). Medical research literature on HAND shows a shift from high rates of HAD to high rates of MND and the more common ANI (Grant et al., 2014). This shift is a result of the increased effectiveness of combination antiretroviral therapy (cART) compared to older HIV medications (Grant et al., 2014). ANI vastly increases the chances of further decline to cognitive functioning, resulting in a more serious prognosis, yet the early detection of ANI could lead to opportunities to delay such declines in cognition (Grant et al., 2014). The following quote summarizes the importance of an early HAND diagnosis:

Identifying that patients have a mild form of this condition is critical. Even mild neurocognitive problems can have a significant impact on a person’s everyday functioning, affecting [their] ability to take medications or ability to perform at work, and may also lead to more social isolation and withdrawal. (St. Michael’s Hospital, 2013).

Maintaining adherence to combined antiretroviral therapy (cART) is necessary to prevent HAND’S onset and progression (Grant et al., 2014). HIV medications, often referred to as cART, are designed to raise an individual’s CD4 count while lowering their viral load. The length of time between diagnosis and cART initiation also impacts the effect that HIV has on an individual’s cognition over time (Grant et al., 2014). If people recently diagnosed with HIV are immediately connected to care and start HIV treatment, this may lessen the effects of HAND (Grant et al., 2014). Only 43-52% of people living with HIV in Ontario are retained in care, i.e. attending regular appointments with a medical professional to ensure medication suitability and adherence (Hoe, 2015). Research has examined how care retention impacts adherence, with the finding that people retained in care are more likely to adhere to HIV medication than people not attending regular medical appointments (Marks, Crepaz, Senterfitt, and Janssen, 2005; Miller, Rosenberg, Rutstein, and Powers, 2007). HIV medications posed greater side effects to an individual’s cognition, among other issues, prior to the introduction of cART in 1997 (Grant et al., 2014).

In Canada, HAND is diagnosed by clinical neuropsychologists or other health professionals (e.g. doctors) (Grant et al., 2014; Rourke, Terpstra, and Ibáñez-Carrasco, 2015; Spudich, 2013). Testing for HAND involves a series of questions and psychometric tests that assess the individual’s processing speed, thinking, attention, and memory (Grant et al., 2014;
Clinicians rule out other causes of memory challenges like depression, substance use, and normal aging before concluding a diagnosis of HAND (Grant et al., 2014; Rourke, Terpstra, and Ibáñez-Carrasco, 2015; Spudich, 2013). Signs and symptoms of HAND can include: (a) difficulty concentrating; (b) struggling to learn new skills; (c) increased forgetfulness; (d) slowed reaction times; and (e) frequent confusion (Grant et al., 2014; Rourke, Terpstra, and Ibáñez-Carrasco, 2015; Spudich, 2013). A community leader in Canada’s HIV/AIDS movement described her experience with these symptoms in the following quote:

I also began to have difficulty finding words. It started with complex words. My brain would substitute another similar-sounding or simpler word. My sentences began to be filled with ‘thing’ or ‘stuff’ or ‘you know’. As it got worse, I forgot everyday words (Atkinson, 2010, p. 1).

HAND’s unique challenges further complicate the issues that people living with HIV already experience (Atkinson, 2010; Grant et al., 2014; Spudich, 2013). These challenges include: (a) increased anxiety about the long-term outcome of HAND; (b) difficulty adhering to medication; and (c) isolation caused by HAND-related stigma (Atkinson, 2010). One major concern of people growing older with HIV is that they will present a caregiver burden to their partner and family (Atkinson, 2010; Vance and Struzick, 2007). This concern is exacerbated when HAND is present as “…cognitive impairments decrease autonomy and increase the need for caregiver support…” (Vance and Struzick, 2007, p. 70). Studies have found that mild cognitive challenges can cause poor medication adherence (Hinkin et al., 2004; Vance and Struzick, 2007). Since the most effective treatment of HAND is HIV medications, poor medication adherence can lead to increased cognitive decline (Grant et al., 2014; Spudich, 2013; Vance and Struzick, 2007). Furthermore, HIV medications prevent the virus from progressing to AIDS so medication adherence is important for an individual’s overall life, not just their cognitive health (Vance and Struzick, 2007). Isolation caused by HAND-related stigma refers to a combination of ageism, i.e. discrimination against an individual because of their age, and HIV stigma (Atkinson, 2010; Vance and Struzick, 2007). Fear of embarrassment and discrimination can cause people affected by HAND to isolate themselves (Vance and Struzick, 2007). The community leader quoted above spoke about the effect of HAND-related stigma on her life:
As an AIDS activist, I used to speak in public regularly. Gradually, I began to shy away from those activities because it was embarrassing to be fumbling for words. I was acting like a stereotypical geriatric, not a 40-something lawyer. (Atkinson, 2010, p. 1).

### Social Determinants of Health

The social determinants of health influence the cognitive health of people living with HIV. These determinants include: (a) income and social status; (b) social support networks; (c) education; (d) employment/working conditions; (e) social environments; (f) physical environments and housing; (g) personal health practices and coping skills; (h) gender; and (i) culture (Public Health Agency of Canada, 2015).

Existing research shows that socio-economic factors, such as levels of education and literacy, impact the severity of HAND (Ryan, Baird, Mindt, Byrd, Monzones, and Morgello, 2005). Certain population groups could therefore be disproportionately affected, such as Hispanic and ACB (African, Caribbean, and Black) communities (Ryan, Baird, Mindt, Byrd, Monzones, and Morgello, 2005). A study of two hundred people affected by HAND in the United States found that non-Hispanic white participants had approximately 20% more years of education and 25-30% higher reading-grade level compared to their ACB and Hispanic counterparts (2005). The study found that these “reading/education discrepancies accounted for lower performance in all of the neuropsychological domains, whereas racial/ethnic minority status did not” (2005, p. 894).

For people living with HIV, adequate housing and gainful employment or meaningful volunteer opportunities have been proven to change self-perception from a person who is sick to one who is healthy (Trujillo, 2010). People living with HIV have identified working and volunteering as means to improve their self-esteem and feel like contributing members to society (Brooks and Klosinski, 1999; McReynolds, 2001; Trujillo, 2010). In previous studies, people who are currently working or actively volunteering have a lower prevalence of HAND compared to their unemployed counterparts (Fazeli et al., 2013). Inadequate housing among people living with HIV has caused them to stop taking cART compared to their adequately housed
counterparts (Kidder, Wolitski, Campsmith, & Nakamura, 2007; Quinn, Young, Thomas, Baldwin, and Paul, 2015).

Maintaining an active lifestyle by exercising regularly can increase an individual’s cognitive reserve and prevent the onset and progression of HAND (Fazeli et al., 2013). Similarly, the presence of other health and mental health issues can increase the prevalence and severity of HAND (Fazeli et al., 2013). These conditions can include: (a) mental health issues and concerns such as unmanageable stress or bipolar; (b) physical health issues such as cardiovascular disease or a traumatic brain injury; and (c) the use of cigarettes and other substances such as alcohol or marijuana (Fazeli et al., 2013). These complicating factors demonstrate the importance of understanding many dynamics within a person’s life when attempting to support improvements to their cognitive health.

Social supports can also increase cognitive reserve in people living with HIV (Fazeli et al., 2013). Increasing cognitive reserve, i.e. the brain’s resistance to cognitive decline, is important to slow cognitive aging and reduce dementia risk (Fazeli et al., 2013; Stern, 2012). In Toronto, where the study was based, HIV-specific professional social support can be accessed from hospitals and clinics, community-based HIV/AIDS service organizations (CBOs or ASOs), community centres, religious institutions, or from professionals in private practice. Types of HIV-specific professional social support include: (a) counselling; (b) case management; (c) support groups; (d) practical assistance programs, i.e. food programs, complementary therapy access, financial assistance, etc.; (e) educational workshops; (f) supportive housing; and (g) distribution of safe sex and harm reduction materials, i.e. condoms, sharps containers, etc. (Choi et al., 2015). Understanding how people connect to these supports and the barriers to service access would provide insight into how existing services can adapt to meet people’s cognitive needs.

The above determinants are impacted by an individual’s feelings of real or perceived exclusion from society, which in this context is complicated by the stigma associated with HIV/AIDS. Real or enacted social exclusion refers to prejudice and/or discrimination from others (Emlet et al., 2015). Perceived or anticipated social exclusion refers to an individual’s expectation of stigma or discrimination (Emlet et al., 2015). HIV stigma refers to prejudice and
discrimination against individuals that causes distress, social isolation, and mental health issues (Brennan, Emlet, and Eady, 2001; Emlet et al., 2015). For HIV-positive people over the age of 55, one study found that this determinant may be less of a concern compared to HIV-positive people under the age of 40 (Emlet et al., 2015) with the possible explanation that an individual’s resilience and protective factors (e.g. self-acceptance and self-compassion) increase with age (Emlet et al., 2015).

**Social Work and HAND**

There is a dearth in research literature concerning social work’s role in supporting people affected by HAND in Canada. In May 2014, the author searched PsycINFO and Social Work Abstract databases using keywords such as (social work*) and (HIV* or AIDS*) and (cognitive* or HAND*). One article from the United States focused on social work mitigating HAND risk factors (Vance and Struzick, 2007). This article was not based on a research study; instead, Vance and Struzick reviewed existing research on HAND and generalized social work interventions for dementia to discuss how social workers could potentially address issues related to HAND (2007).

Specialized social work support could be beneficial for people affected by HAND, as HIV-related social work interventions have been effective in normalizing people’s experiences, improving their psychosocial health, and advocating for social change (Gallo-Silver and Bimbi, 2012; White and Globerman, 2015). Social workers based in inter-professional hospital teams and in CBOs/ASOs are in a unique position to connect people affected by HAND to information, resources, and other people in similar situations (Gallo-Silver & Bimbi, 2012; Malowaniec, Rowe, Moreno, & Mould, 2001). Social work interventions could reduce HAND-related anxiety, stigma, and isolation while increasing the overall cognitive health of people affected by HAND.

Vance and Struzick hypothesized a social work model to support people affected by HAND, based on existing social work and dementia literature (2007). The model contains five sections: (a) assess need of client; (b) examine risk factors; (c) collaboratively determine type of intervention strategy; (d) deliver treatment/monitor adherence; and (e) assess outcomes and reassess (Vance and Struzick, 2007, p. 99). Section One: ‘assess needs of client’ contains three
steps: (a) social worker administration of the Mini Mental State Examination (MMSE), a simple questionnaire whereby a score of 90% or less indicates that cognitive impairments may be present; (b) asking the client directly about cognitive health concerns; (c) referring the client to a neuropsychologist, doctor, or other health professional who can administer tests for HAND (Vance and Struzick, 2007, p. 99). Section Two: ‘examine risk factors’ involves the following: (a) substance use; (b) poor nutrition; (c) social isolation; (d) lack of mental stimulation; (e) stress; (f) depression; (g) lack of exercise; (h) polypharmacy; and (i) poor medication regimen (Vance and Struzick, 2007, p. 99). Section Three: ‘collaboratively determine type of intervention strategy’ includes: (a) substance use treatment; (b) nutritional support; (c) depression treatment; (e) stress management; (f) stimulating activities; (g) cognitive remediation therapy, i.e. engaging in exercises such as memory training such as identifying mnemonic strategies; (h) medication adherence support; and (i) pharmaceutical follow-up (Vance and Struzick, 2007, p. 99). Section Four: ‘deliver treatment/monitor adherence’ is focused on monitoring the effects of the chosen intervention(s) over time (Vance and Struzick, 2007). Section Five: ‘assess outcomes and reassess’ has the client and social worker determine whether the treatment was effective and if not, which of the previous sections need to be repeated or modified (Vance and Struzick, 2007). This model of HAND-specific social work practice sounds promising, as it addresses many of the factors reviewed in the literature above. However, there is no evidence that people living with HIV had input into this model nor is there data that the model has been used in actual practice. Furthermore, the model was not based off of existing HAND social work services with Vance and Struzick noting that, to their knowledge, only one of their proposed interventions had been used with older adults living with HIV and this intervention was not delivered by social workers (Neundorfer, Camp, Skrajner, Malone, and Carr, 2004; Vance and Struzick, 2007, p. 64).

**Theoretical Approaches**

Systems theory and syndemic theory have often informed research and practice in the fields of HIV/AIDS and cognitive health due to their considerations of the impact of multiple, complex factors on people’s lives (Andretta, 2014; Polgar, 2013; Polgar and Ng, 2005; Wilson et al., 2014). Systems theory considers risks created by interrelated variables (Andretta, 2014; Polgar, 2013). This approach determines how these variables affect an overall outcome
(Andretta, 2014; Polgar, 2013). An example of this can be found in a recovery model for neural reconstruction that seeks to improve overall quality of life by understanding how: (a) patient variables, graft characteristics, and surgical protocols influence graft development; (b) graft development impacts a person’s interaction with simultaneous treatments, neurocognitive test performance, and clinical outcome measures; and (c) these variables impact an individual’s ability to complete activities of daily living, which is directly related to overall quality of life (Polgar, 2013; Polgar and Ng, 2005). Syndemic theory considers how epidemics, such as HIV/AIDS, continue because of the societal marginalization of communities that are disproportionately disadvantaged by the social determinants of health (Singer and Clair, 2003). HIV must be simultaneously addressed by medical and psychosocial interventions, according to syndemic theory, to reach an end to the epidemic (Singer and Clair, 2003; Wilson et al., 2014).

**Summary**

HAND is an issue that can affect many people living with HIV and social workers are in a unique position to provide specialized support services regarding HIV and aging. The acquisition of empirical data from people most affected by HAND will inform how social workers and other helping professionals provide support to people growing older with HIV/AIDS. As there is a dearth in existing literature regarding client engagement on this topic and on evidence-based HAND-specific social work interventions, people most affected by HAND need to be consulted regarding their needs and how social workers can support them before an intervention is piloted. A research study that seeks to engage people living with HIV over the age of 50 who are concerned about their cognitive health will address this research and service gap with the goal of utilizing the study’s findings to develop and improve social work interventions and community-based programs and services regarding HIV, HAND, and aging.
Chapter 3
Methodology

Overview

This study used an explanatory sequential mixed-methods research design informed by a participatory action research (PAR) framework to engage people over the age of 50 who are living with HIV (i.e. HIV-positive) and who are concerned about their cognitive health. Due to the dearth of research literature on social work support for people living with HIV and cognitive concerns, the research team decided on the study’s design as it “…involves a two-phase project in which the researcher collects quantitative data in the first phase, analyzes the results, and then uses the results to plan (or build on to) the second, qualitative phase” (Creswell, 2014, p. 224). Phase one of this research study was a quantitative survey that the research team developed to better understand the demographics, brain health concerns, and social work experiences of the sample (see Appendix 4). Phase two of the study was qualitative interviews of 20 survey participants, with questions developed based on analysis of the survey results (see Appendix 5). See below for more information on these two phases in quantitative and qualitative subsections.

Participatory Action Research (PAR)

This research project was underpinned by two philosophies: a) that PAR is an effective framework to engage and empower communities in determining their health-related needs; and b) that the inclusion of peer researchers in HIV/AIDS research (i.e. people living with HIV who identify with the subject being researched) are just as important, if not more important, than the inclusion of academic researchers and clinician-researchers.

The PAR framework permitted consideration of the history of HIV/AIDS, the larger societal factors, and rational thinking in the engagement of research participants on personal and community levels (Rubin and Babbie, 2008). PAR’s framework, at its base, “…[enables] researchers to work in partnership with communities in a manner that leads to action for change.” (Baum, MacDougall, and Smith, 2006, p. 854). With this research project, the author was inviting critique on his workplace (a community-based HIV organization) and his profession (social work). PAR was therefore integral for this project to be effective, as PAR permits
simultaneous action and reflection (Baum, MacDougall, and Smith, 2006). PAR also supports participants in viewing “…their situation as ‘an historical reality susceptible of transformation’ [instead of] ‘a dense, enveloping reality or a blind alley’. This transformative power is central to PAR” (Baum, MacDougall, and Smith, 2006, p. 856).

The author chose to integrate a PAR framework with the funder’s community-based research (CBR) framework because the two frameworks complement one another. PAR and CBR have been synthesized in recent research into the emerging framework of community-based participatory research (CBPR) (Flicker and Nixon, 2014; Marshall et al., 2012). This project aligned with its funder’s definition of CBR as it was hosted by a CBO/ASO, involved people living with HIV as decision-makers, and was responding to an existing gap in literature and practice (OHTN, 2012). PAR ensured that these CBR qualifiers were actively considered throughout the project, with regards to the equitable participation of peer researchers, the author, and his supervisors and to engaging key stakeholders throughout the duration of the project to encourage change (Baum, MacDougall, and Smith, 2006; Flicker and Nixon, 2014).

Including peer researchers as equitable research team members works to “…[address] issues of power and exclusion within researcher/community relationships…” (Greene et al., 2008, p. 361). Paid compensation, full involvement in the research process, and opportunities to determine their own capacity building needs are integral components to the successful engagement of peers in HIV research (Greene et al., 2008). Previous studies had encountered challenges regarding ‘tokenism’ (i.e. peers feeling that they are involved only for superficial purposes) and an inability to fully acknowledge the unique skills and abilities that peers contribute to a research team (Greene et al., 2008). To better understand the challenges faced by peer researchers, the author attended monthly OHTN webinars for the duration of the project. These webinars were part of a series titled “What’s hot with peer research associates in Canada?” and featured peer researchers talking about the benefits and challenges of their role.

**Peer Researchers**

In September 2014, the author sought to recruit five peer researchers to participate as equitable research team members and help with conceptualization. Research team recruitment
involved the author utilizing his professional networks to find five people living with HIV who had cognitive health concerns and who, possibly, had first-hand experience with HAND testing. In initial meetings with each peer researcher, the author expressed intention to develop this research study through a collaborative and participatory process from the early stages (e.g. funding and ethics approval) through to post-study activities (e.g. presentations and manuscripts). Five peers signed onto the project and worked with the author and his co-supervisors to determine the study design. One of the five peer researchers was only able to attend one meeting early on the process, and removed himself from the project shortly thereafter for personal reasons.

Of the four peer researchers that worked on this project from conceptualization through to completion, all four were over the age of fifty and living with HIV themselves. Three of the four had been screened for HAND previously, and all four expressed an understanding of social work and a need for the profession to focus specifically on HIV and cognitive health. Three of the four peers identified as white males and one identified as an African female. Two of the four peers had been educated as social workers and one was currently practicing as a registered social worker for an organization focused on LGBTQ health. The peer researchers were asked to provide input into all stages of the research study, with a focus on keeping the study accessible for people living with HIV. One recommendation that the peer researchers made was to promote the study using the title ‘HIV, Social Work, and Brain Health’. The peers recommended the use of the term ‘brain health’ instead of ‘cognitive health’ or ‘HAND’ as they felt it was an easier term to understand across culturally and linguistically diverse communities of people living with HIV.

The author worked with the peer researchers throughout their project to build their capacity in research. One of the four peers had worked as a peer researcher before; for the other three, this was their first peer research experience. Based on requests from the peer researchers, the author circulated articles and videos concerning HIV and cognitive health, conducting peer research, and study design throughout the duration of the research project. Additionally, the OHTN (the project’s funder) generously offered a 12-hour training to the peer researchers on how to conduct qualitative interviews prior to phase two of the research project. The training
agenda featured interactive sections on a) defining community-based research; b) learning how to talk about the study you represent; c) explaining this study’s rationale, methods, and goals; d) how to conduct a qualitative interview; and e) self care as a peer researcher.

Throughout both the quantitative and qualitative stages of data analysis, the author encouraged equitable collaboration between the entire research team (i.e. the author, his supervisors, and the peer researchers). A collaborative partnership was established early in the project, as the full research team met regularly starting at the project’s earliest stages (i.e. conceptualization and funding). This collaborative approach was undertaken to mitigate the challenges encountered in previous mixed-method studies that sought to engage peer researchers. These challenges included: a) research team members disagreeing on terminology; b) research team members with shorter-term engagement participating less than members who were engaged for a longer term; and c) misunderstanding of the data and project objectives from peer researchers (Fine and Toree, 2006; Westhues et al., 2008). Furthermore, the author attempted to follow best practice guidelines developed from recent PAR-informed literature, including: a) ensuring that peer researchers were appropriately compensated b) understanding team members’ unique social locations; and c) prioritizing the needs of the peer researchers in determining meeting agendas (Jacobs, 2010; Marshall et al., 2012).

**Sampling and Recruitment**

Purposive sampling was used in combination with snowball sampling for this research study. Recruitment was limited to Ontario due to funding guidelines. Purposive sampling was chosen as it was impossible to access a list of people living with HIV who were over the age of fifty and concerned about their cognitive health, so subjective information such as research team members’ contacts were used to identify social groups and organizations where the sample might be found (Neuman & Robson, 2009, p. 138). Snowball sampling greatly informed this process, as people within the organizations and groups that were initially identified referred the survey on to additional individuals, groups and organizations. The survey, available online and in paper at ACT’s office in downtown Toronto, were made available from May 8, 2015 to August 31, 2015 to ensure that sufficient time was provided for networked referrals. The following six primary recruitment sites were identified: (a) Canadian AIDS Treatment Information Exchange (CATIE);
(b) Canadian AIDS Society (CAS); (c) Ontario HIV Treatment Network (OHTN); (d) Toronto HIV/AIDS Network (THN); (e) AIDS Committee of Toronto (ACT); and (f) PositiveLite.com. These primary sites were chosen as ACT was the host organization, the OHTN was the funder, and CATIE, CAS, PositiveLite.com, and THN are all organizations that serve to centralize information regarding HIV. Figure 1 below presents a sociogram of referrals networks, with primary contacts marked by shaded circles and secondary contacts indicated by clear circles. Secondary contacts are listed to the best of the author’s knowledge, based on data collected and information shared from the authors’ networks. An individual’s participation is directly linked to the referral source in Figure 1 wherever possible.

To participate in the online survey, participants needed to meet the following self-identified inclusion criteria: (a) HIV-positive; (b) over the age of 50; and (c) concerned about their cognitive health. The survey immediately ended for those who identified as younger than 50 and/or HIV-negative or who did not know their HIV status (see Appendix 4). Cognitive health concerns were assumed based on the participant’s willingness to participate in a survey about HIV and cognitive health where no incentive was offered. Research participants needed to be able to communicate in English or French and needed to be able to provide informed consent (see Appendices 4 and 6).

Recruitment for the follow-up interviews was connected to the survey. Survey participants received the invitation to provide contact information for an interview, separate from the survey itself. This aligns with the explanatory sequential mixed methods design of the research study, which aimed to use the qualitative sample as a means of describing the quantitative results (Creswell, 2014, p. 224).
The author established rapport with all potential interview participants through a series of phone, email, and in-person communications. These communications included gratitude for completing the survey, discussing the consent form (Appendix 6), scheduling the interview and determining participants’ pre-existing relationships with the peer researchers, and following up each interview with a debrief.
Quantitative Sample

Of the survey responses received (n=121), 89% (n=108) met inclusion criteria. 0.6% of responses were completed in French. The mean completion time was 00:15:33 with a mode of four to five minutes. Figure 2 displays the timeline of survey responses received and Figure 3 shows the age (first number) and percentage of responses received (second number). The data displayed in Figures 2 and 3 is based on the total number of responses received (n=121). The remaining figures and text in this section are based on the responses that met inclusion criteria (n=108), unless otherwise specified.

Figure 2: Survey response timeline

![Survey response timeline](image)

Figure 3: Age of survey respondents

![Age of survey respondents](image)
Gender, Sexual Orientation, Ethnicity, and Birthplace

Regarding gender, 88% of respondents identified as male with 12% female, in a question that included responses beyond the gender binary (e.g. trans female). For sexual orientation, 79.3% identified as gay with 12.3% heterosexual, 6.6% bisexual, and 2.8% queer. When asked about ethnicity, 83.6% identified as white/western European with 13.5% white/eastern European, 1.9% Caribbean, 1.9% Indigenous, 1.9% Hispanic/Latin American, and 1% South Asian. Of the respondents, 84.1% were born in Canada. For the 15.9% not born in Canada, most respondents were born in the United States with one or two people each born in Trinidad, the United Kingdom, Greece, New Zealand, Malaysia, Germany, Chile, and the Netherlands. For those not born in Canada, 57.1% moved to Canada before the age of 24.

Qualitative Sample

All of the interview participants (n=20) met inclusion criteria, as they had previously indicated when completing the survey. All interview participants requested an interview in English, when a French interview was also an option. Interview participants were provided with honourarium and transit tokens. Of the interview participants, 75% (n=15) identified as male and 25% (n=5) identified as female. The interviews were held between November 3, 2015 and November 30, 2015. Each peer researcher conducted four to six interviews and none of the peers conducted more than two interviews per day.

Data Collection

Quantitative Data Collection

The survey featured forty questions with up to twelve follow-up questions that displayed depending on participant responses (e.g. indicating that one was HIV-positive displayed a follow-up question asking for year of HIV diagnosis. The first page of the survey contained contact information for a member of the research team (see Appendix 4), should potential research participants have any questions or concerns. The survey questions were divided into five sections that attempted to address the study’s research questions.

Section One: ‘about yourself’ featured questions about participant gender, ethnicity, birthplace, employment status, average annual household income, highest level of education, and
housing situation. Options for gender included: (a) male; (b) female; (c) intersex; (d) two-spirit; (e) trans-man; (f) trans-woman; and (g) an open-ended other option. Sexual orientation could be defined as: (a) bisexual; (b) lesbian; (c) two-spirit; (d) queer; (e) gay; (f) straight/heterosexual; and (g) an open-ended other option. Participant ethnicity options were: (a) African; (b) Hispanic/Latin American; (c) Indigenous; (d) East Asian/Southeast Asian; (e) South Asian; (f) Middle Eastern/Arab; (g) Caribbean; (h) White/Eastern European; (i) White/Western European; and (j) an open-ended other option. Birthplace was asked as a dichotomous (i.e. yes, no) question of whether the participant was born in Canada, with open-ended follow-up questions of birth country and age of Canadian immigration if the respondent was born outside Canada. The question of employment status offered the following response options: (a) unemployed; (b) employed; (c) on disability (e.g. Ontario Disability Support Program, private disability); (d) retired; and (e) volunteer. If the respondent was unemployed and not volunteering, an open-ended question was asked concerning how long they have been out of the workforce. Average annual household income responses were: (a) under $5,000; (b) $5,000-$15,000; (c) $15,000-$25,000; (d) $25,000-$35,000; (e) $35,000-$45,000; and (f) over $50,000. The question about highest level of education could be answered with: (a) some primary school; (b) primary school; (c) some high school; (d) high school diploma/equivalency; (e) trade/vocational school; (f) some college/university; (g) college or university diploma/degree; (h) post-graduate masters/PhD; and (i) an open-ended other option. Participants could identify their housing situation as: (a) own; (b) renting – market rent; (c) renting – rent geared to income; (d) homeless; (e) shelter; (f) hotel/motel; (g) correctional institution; (h) hospital; (i) long term care; (j) temporary (e.g. couch surfing, staying with family/friends; and (k) an open-ended other option. A dichotomous response question (i.e. yes, no) followed asking if participants found their housing adequate with an open-ended question asking why if participants indicated that their housing was inadequate. These questions and their responses were duplicated from the questions asked at intake by all community-based HIV/AIDS service organizations (CBOs or ASOs) in Ontario, as standardized and monitored by the OHTN (OCHART, 2014). These questions were duplicated from OCHART with the aim of understanding participant demographics and of demonstrating transferability of findings to CBOs/ASOs in Ontario.

Section Two: ‘about living with HIV’ asked participants questions about their lowest and most recent CD4 counts, most recent viral load, and what HIV medications they are currently
using and have used in the past. Lowest and most recent CD4 counts had identical response options: (a) below 200; (b) 200–400; (c) 400–600; (d) 600–800; (e) 800–1000; (f) over 1000; and (g) don’t know. Most recent viral load could be indicated as: (a) undetectable; (b) 200–1000; (c) 40–200; (d) 200–1000; (e) over 1000; and (f) don’t know. Participants were asked a dichotomous response question (i.e. yes, no) about if they were taking HIV medications. If yes, they were asked an open-ended question as to when they started taking HIV medications. The response options for current and past HIV medications were identical and included: (a) aptivus; (b) atripla; (c) AZT; (d) celsentri; (e) combivir; (f) complera; (g) crixivan; (h) DDI; (i) D4T; (j) edurant; (k) fuzeon; (l) intelence; (m) isentress; (n) invirase; (o) kaletra; (p) kivexa; (q) norvir; (r) prezcobix; (s) prezista; (t) rescriptor; (u) retrovir; (v) reyataz; (w) stribild; (x) sustiva; (y) telzir; (z) tivicay; (aa) triumeq; (bb) trizivir; (cc) 3TC; (dd) truvada; (ee) viracept; (ff) viramune; (gg) viread; (hh) videx EC; (ii) zerit; (jj) zidovudine; (kk) don’t know; and (ll) an open-ended response option. The ranges for CD4 and viral load and the names of past and present HIV medications were based on information provided by the Canadian AIDS Treatment Information Exchange (CATIE), one of the organizations that provided organizational support to this study (CATIE, 2011). CATIE is a reliable source for updated and unbiased information about HIV/AIDS.

Section Three: ‘brain health concerns’ started with questions about: (a) smoking cigarettes; (b) substance use; (c) mental health concerns (e.g. anxiety, unmanageable stress, depression); (d) mental health issues (e.g. depression, bipolar); (e) physical health conditions; and (f) HAND testing, with dichotomous response options (i.e. yes, no, unsure) for each of these questions. If participants were tested for HAND, they were asked if the testing resulted in a diagnosis with dichotomous response options (i.e. yes, no, unsure). If participant were diagnosed with HAND, they were asked to select from the following diagnoses: (a) asymptomatic neurocognitive impairment (ANI); (b) mild neurocognitive disorder (MND); (c) HIV-associated dementia (HAD); and (d) don’t know. If participants were tested for HAND and not diagnosed, they were asked a dichotomous response question (i.e. yes, no) about whether the testing feedback suggested that there might be concerns about their brain health. Participants were then asked to select from a list of brain health concerns, the responses to which were developed from signs and symptoms of HAND indicated in the literature reviewed (Fazeli et al., 2013; Grant et al., 2014; Spudich, 2013). These responses included: (a) misplacing items; (b) completing daily living tasks; (c) maintaining attention; (d) difficulty remembering; (e) adhering to medication; (f)
Section Four: ‘supports’ asked about existing HIV-specific professional supports along with information about where these supports were accessed, how participants were connected with them, and barriers to service access. Possible responses were determined based on existing literature (Fazeli et al., 2013) and the research team’s knowledge of supports available for people living with HIV in Ontario. The question concerning who provides participants with HIV-related support contained the following response options: (a) no one; (b) friends; (c) family; (d) partner/spouse; (e) counsellor/therapist; (f) social worker; (g) medical professional (e.g. family doctor, specialist, naturopath, psychiatrist); and (h) an open-ended other option. Participants could indicate the following as where they accessed HIV-related support: (a) hospital; (b) AIDS service organization (e.g. AIDS Committee of Toronto); (c) community centre (e.g. the 519 Church Street Community Centre); (d) religious institutions (e.g. church, mosque, synagogue, temple, etc.); (e) social worker in private practice; (f) counsellor/therapist in private practice; (g) psychiatrist/psychologist; (h) none of the above; and (i) an open-ended other option. Participants were asked how they were connected to HIV-related supports with the following possible responses: (a) physician referral; (b) community referral; (c) self referral (i.e. internet search, word of mouth); (d) an open-ended response option; and (e) I do not access professional social supports around living with HIV. Regarding the type of HIV-related support that participants could access, response options were: (a) individual in-person (i.e. one-on-one); (b) support/therapy group in-person; (c) individual online (e.g. cyber counselling); (d) support/therapy group online; and (e) an open-ended other option. When asked if anything made
it difficult to access HIV-related supports, participants could indicate: (a) cost for transit; (b) services are not offered in my preferred language; (c) accessibility issues (e.g. wheelchair); (d) health challenges; (e) confidentiality concerns; (f) time of day that services are offered; (g) child care/child minding needs; (h) waitlist to access services; and (i) an open-ended other option. Participants were then asked dichotomous response questions (i.e. yes, no) about if they talk about brain health with their service provider and if yes, if their service provider has referred them to HAND testing. This was followed by another dichotomous response question (i.e. yes, no) as to whether participants had tried to get help about brain health and been unable to. If yes, participants were asked to explain as an open-ended response. The final question in this section asked dichotomously (i.e. yes, no) if overall support has been helpful for participants with the option to provide open-ended comments.

Section Five: ‘gaps in programs and services for HIV and brain health’ contained open-ended questions asking participants how CBOs/ASOs, social workers, and hospitals could support them with regards to HIV and brain health along with a question asking if these organizations had the capacity to provide adequate support. Since funding and study feasibility allowed for only twenty survey respondents to attend an interview, these questions sought to gather some qualitative data from the entire sample.

Upon completion of the survey, participants had the option of providing their contact information to attend an interview by either completing a separate online survey or by completing a tear-away page of the hard copy survey, which was then deposited into a separate box. Hard copy surveys were entered into FluidSurveys by the research team for the purpose of data analysis.

**Qualitative Data Collection**

Interview data was collected in-person and over the phone by the peer researchers. Interview length ranged from 00:27:50 to 01:22:02 with a mean length of 01:00:15. Thirteen interviews were conducted in-person with twelve occurring at ACT and one occurring at a long-term care facility. Seven phone interviews were conducted due to the participant residing outside of the Greater Toronto Area (GTA) (e.g. Windsor, Ontario). All interviews were audio-recorded
and an external company transcribed the recordings. The process used to develop the interview questions can be found in the data analysis section below and the full interview question set can be found in Appendix 5.

**Informed Consent**

**Quantitative Phase**

Participants were asked to read information regarding inclusion criteria, survey length, confidentiality, how results would be shared, and contact information to ask questions (see Appendix 4). They then had to answer a mandatory dichotomous response question (i.e. yes, no) asking if they consented to participate in the survey.

**Qualitative Phase**

As this project was centred on cognitive health, there was a risk that potential participants could be cognitively impaired to the point of not being able to provide informed consent. Two measures were employed to mitigate this risk: a) a consent process was added into the survey (see below informed consent section and Appendix 4); and b) prior to participating in the interview, the author asked each participant some simple questions at the end of the consent process to determine that the participant showed appreciation and understanding to consent to research.

**Ethical Issues**

The possibility of risk to research participants was manageable but present. The University of Toronto’s HIV/AIDS Research Ethics Board, who approved this research study, classify risk as physical, psychological, social, and legal (University of Toronto, 2015, p. 5). Physical risk was not present in the study. Psychological risk, social risk, and legal risk were present in the study.

Research participants were at psychological risk of discomfort, anxiety, and/or unease about the content of the research project (HIV and cognitive health). At the start of each interview, the peer researcher asked the participant a question regarding possible discomfort felt
during the survey stage. Following each interview, the author debriefed with the research participant and offered an opportunity to discuss any discomfort. Research participants were provided with information related to relevant counselling and support services and a brochure titled *Things to Keep in Mind when Living with HIV and Changes in Cognition* (see Appendix 7). The project’s funder, the Ontario HIV Treatment Network (OHTN), developed this brochure.

Since peer researchers conducted the interviews, research participants were at social risk of disclosing their HIV status and other personal information to someone who may know them socially and/or in other contexts. It was explained to participants that the author and his co-supervisors would have access to all research data while each peer researcher would only have access to the identity (i.e. given name) of the people that they were personally interviewing. When the author contacted each participant to schedule an interview, he shared the names of the peer researchers. Each participant was scheduled with a peer researcher whose name they did not recognize. In the rare instance where a participant recognized the names of all four peer researchers, the participant was given the choice of who to interview with. Additionally, all four peer researchers signed binding confidentiality agreements with the AIDS Committee of Toronto (the host agency). The potential exposure of sensitive information and our confidentiality measures were detailed in the consent form (see above section and Appendix 6).

For legal risk, research participants were informed of the standard limits of confidentiality during informed consent (see Appendix 6). This included disclosure of harm to self or others, neglect and/or abuse of a minor, and abuse by a regulated health professional. None of the research participants disclosed a situation that constituted a duty to breach confidentiality.

With regard to benefits, interview participants received thirty dollars honorarium and two tokens for public transportation. Additionally, this research project responded to a lack of specialized social work services for older adults affected by HAND. This study should lead to more evidence-based practice in this area alongside increased community knowledge about the issue. As there is a dearth of research in this area, the project will expand the body of knowledge for social work support for the research participants.
Confidentiality

The author and his co-supervisors were bound by their professional affiliation in the Ontario College of Social Workers and Social Service Workers (OCSWSSW) to protect the confidentiality of research participants (2008). The peer researchers, as mentioned above, signed a binding confidentiality agreement with the host agency to maintain the confidentiality of research participants. Research participants were assigned a code for their audio-recorded interview, with the author storing the code key in a locked filing cabinet. Transcript Divas, an external transcription company whose confidentiality policies were approved by the University of Toronto’s HIV/AIDS Research Ethics Board, transcribed the interviews. The use of Transcript Divas was explained to research participants in the consent form (Appendix 6).

Interview recordings were permanently deleted once transcription was complete and the transcription was verified as correct. Transcripts will be kept digitally for seven years, until November 2022, at which point they will be destroyed. Consent forms will be stored in a locked filing cabinet at the host agency, separate from any other research data related to this project, and will also be destroyed in November 2022. This conforms with the University of Toronto’s Data Security Standards for Personally Identifiable and Other Confidential Data in Research (2008).

Data Analysis

Two stages of data analysis were employed, as described in more detail below. The quantitative data was analyzed using descriptive statistics by the research team with the purpose of developing the qualitative questions. The qualitative data was analyzed using manifest and latent coding by three coders followed by a full team collaboration to determine overall findings.

Quantitative Data Analysis

Given this study’s explanatory sequential mixed methods design, the qualitative data would be used to describe or expand upon the quantitative data. As such, the author planned to apply the following approach to data analysis:

The quantitative and qualitative databases are analyzed separately in this approach. The quantitative results are then used to plan the qualitative follow-up. One important area is that the quantitative results cannot only inform the sampling procedure but it can also
point toward the types of qualitative questions to ask participants in the second phase. These questions...are general and open-ended. (Creswell, 2014, p. 224-5).

The author exported the survey results from FluidSurveys into Microsoft Excel and assigned each qualifying survey response a unique identifier from S001 to S108. The author then ran frequency distributions on the quantitative results to develop descriptive statistics (Neuman and Robson, 2009). These descriptive statistics were then used to create a series of visual representations such as bar graphs and pie charts similar to the figures presented in the quantitative results section below (Neuman and Robson, 2009). The descriptive statistics were sent to the research team, who had two weeks to review the results with the intent of developing interview questions. When the author met with the research team, the separate analyses were discussed regarding what each team member found to be significant about the survey results. The research team collaboratively determined to focus the interview questions on six topic areas: (a) feedback about the survey; (b) HIV and the social determinants of health; (c) mental health; (d) cognitive health; (e) HAND screening/testing; and (f) the role of social work and CBOs/ASOs. These topic areas would provide additional insight into answering the study’s research questions and they aligned with the study’s objectives and information contained in the background above.

**Qualitative Data Analysis**

The author assigned each transcript a unique identifier from I01 to I20. Content analysis was then employed whereby NVivo software was used to systematically code participant responses (Neuman and Robson, 2009). The author initially employed manifest coding, noting how often certain words were used (Neuman and Robson, 2009). Participants had varying definitions of common terms, so manifest coding risked losing the connotation within the responses (Neuman and Robson, 2009). The author then used latent coding, or semantic analysis, throughout this process to determine the underlying meaning of participant responses (Neuman and Robson, 2009). As the peer researchers had each conducted four to six of the twenty interviews, the author was concerned that the peer researchers would be biased towards their set of interviews. To mitigate this concern, the second stage of data analysis employed an iterative process whereby the author and his two co-supervisors, none of whom had conducted any interviews, separately used NVivo software to analyze the interview data over a period of two months from December 2015 to February 2016. Each coder assigned a category, or node, to each
participant response. These categories had broad titles such as ‘mental health’ or the ‘social determinants of health’. The coders then created subcategories within each node, to represent differences of opinion on the category’s subject matter. Most often, this meant separating responses into positive perceptions and negative perceptions. From there, each coder generated visual representations of these categories and subcategories to consider how respondents felt about the broad topic areas. Each coder identified four or five interconnected themes that sought to answer the study’s research question and selected two or three direct quotes from participants that supported each theme. The author and his co-supervisors then met with the peer researchers on February 16, 2016. In this meeting, each coder shared their findings and the peer researchers provided insight into whether or not these findings concurred with the participant responses from the four to six interviews that each peer researcher conducted. Following two hours of discussion, five interconnected themes were agreed upon.
Chapter 4
Results

Quantitative Results

Employment Status

Figure 4 displays respondent employment status and Figure 5 details how long those who are unemployed and not volunteering have been out of the workforce. One respondent has been out of the workforce for 58 years and is not included in Figure 5.

Figure 4: Employment status of survey respondents
Education, Income, and Housing

Among the participants, 66.1% have completed a college diploma or university degree. 31.7% of respondents have an annual household income over $50,000 with 45.2% at less than $25,000. Figures 6 and 7 show responses related to housing.

Figure 6: Housing situation of survey respondents

- Market Rent: 41.00%
- Rent Geared to Income: 23.60%
- Own: 33%
- Temporary: 2.30%
Figure 7: Do survey respondents find their housing adequate?

![Pie chart showing 82.90% Yes and 17.10% No.](image)

CD4, Viral Load, and HIV Medications

When asked about viral load, which indicates how much HIV is in a millilitre of blood, 89.6% of respondents stated they were undetectable (commonly accepted as less than 40 copies of HIV per millilitre of blood) with 1.9% at 40-200, 0.9% at 200-1000, 2.8% over 1000 and 4.7% unknown. Participants identified their lowest or nadir CD4 count and their most recent CD4 count; higher counts indicate that HIV is significantly compromising a person’s immune system. Figure 8 displays these results.

Figure 8: Lowest (nadir) and most recent CD4 counts of survey respondents

![Bar chart showing CD4 counts distribution.](image)
From the survey, 97.2% of respondents are taking HIV medications and 2.8% are not. Figure 9 shows when respondents started taking HIV medications (one person responded with “cocktail” which is not included) and Figure 10 shows which HIV medications, past and current, have been used by respondents (Aptivus and Prezcoxbix were listed as survey options but received no responses. Thalidomide, Amprenavir, and DDC all received single responses from separate respondents as other past HIV medications and are not included).

**Figure 9: When did survey respondents start taking HIV medications?**

![Figure 9: When did survey respondents start taking HIV medications?](image)

**Figure 10: Past and current HIV medications taken by survey respondents**

![Figure 10: Past and current HIV medications taken by survey respondents](image)
Concerns about HAND and HAND Testing

Table 1 displays the results of questions about respondent health and behaviours that can be complicated by HIV and cognitive concerns.

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you exercise regularly?</td>
<td>54.7%</td>
<td>45.3%</td>
<td>N/A</td>
</tr>
<tr>
<td>Do you smoke cigarettes?</td>
<td>27.1%</td>
<td>72.9%</td>
<td>N/A</td>
</tr>
<tr>
<td>Do you use substances that could impact your brain health? (e.g. alcohol, cocaine, crystal meth, injection drugs, marijuana)</td>
<td>51.4%</td>
<td>47.7%</td>
<td>0.9%</td>
</tr>
<tr>
<td>Are you currently experiencing mental health concerns? (e.g. anxiety, unmanageable stress, depression)</td>
<td>53.8%</td>
<td>38.7%</td>
<td>7.5%</td>
</tr>
<tr>
<td>Have you ever been diagnosed with a mental health issue that could impact brain health? (e.g. depression, bipolar)</td>
<td>53.8%</td>
<td>43.4%</td>
<td>2.8%</td>
</tr>
<tr>
<td>Have you ever been diagnosed with a health issue, aside from HIV, that could impact brain health? (e.g. cardiovascular disease, MS, diabetes, traumatic brain injury)</td>
<td>30.8%</td>
<td>61.5%</td>
<td>7.7%</td>
</tr>
</tbody>
</table>

Among the respondents, 25.5% had been screened or tested for HAND, with 60.4% never attending a test and 14.2% unsure if they had been tested. Of those tested, 51.9% were diagnosed with HAND with 33.3% not diagnosed and 14.8% unsure. Figure 11 displays the form of HAND that respondents had been diagnosed with.
Figure 11: What form of HAND were survey respondents diagnosed with?

Participants indicated that 55.6% of those that were tested and not diagnosed felt concerned about their brain health based on feedback received following the test. Figure 12 identifies what concerns all respondents had about their brain health. Figure 13 shows how respondents react to these concerns. The x axis responses are condensed from the survey response options, which are listed above in data collection.

Figure 12: Survey respondents’ concerns about their brain health.

- **64.1%** Difficulty remembering
- **64.1%** Remembering the names of people you’ve just met
- **51.5%** Feeling emotionally overwhelmed
- **51.5%** Procrastinating or putting off tasks more than usual
- **50.5%** Maintaining attention
- **46.6%** Finding words
- **43.7%** Misplacing items
- **34%** Expressing yourself clearly
- **32%** Remembering the names of people you’ve known for a long time
- **29.1%** Making decisions
- **25.2%** Multitasking
- **22.3%** Completing daily living tasks
- **21.4%** Keeping social plans
- **21.4%** Active employment
- **21.4%** Following verbal instructions
- **21.4%** Doing simple math in my head
- **18.4%** Solving problems
- **16.5%** Adhering to medication
- **15.5%** Predicting the consequences of my decisions
- **14.6%** Calculating a tip at a restaurant
- **10.7%** Reading a map / understanding directions
- **8.7%** Following written instructions
- **3.9%** Inappropriate dress/attire
Current supports

In responding to the multi-answer question of ‘who provides you with support around living with HIV?’, 78.1% indicated that a medical professional supports them with 48.6% friends, 31.4% counsellor/therapist, 24.8% family, 24.8% partner/spouse, 19% social worker, and 8.6% of participants indicating that no one provided them with HIV-specific support. 4.8% of respondents wrote in ‘peer support’ as an open-ended response to this question. Figure 14 indicates where respondents currently access professional social supports for HIV.

Figure 14: Where survey respondents access HIV professional social supports
When asked how they were connected to HIV-specific professional social supports, 43.4% of respondents were referred by their physician, 37.4% referred themselves, 17.1% were referred by a member of their community, and 26.3% indicated that they do not access HIV-specific supports. Among those who do access such supports, 79.5% have used individual in-person supports, 55.7% have attended a support/therapy group in-person, 8% have attended a support/therapy group online, and 5.7% have accessed individual online support (i.e. online counselling).

Respondents identified barriers to accessing service as a waitlist (30.6%), confidentiality concerns (29.2%), cost for transit (26.4%), time of day (25%), health challenges (22.2%), language (2.8%) and accessibility (1.4%). Overall, 55.3% identified HIV-specific support received as helpful and 44.7% identified the support as not helpful.

Among the respondents, 46% identified that they talk about cognitive health with their service provider whereas 54% do not. For those that do discuss cognitive health, 31.8% have been referred to HAND screening/testing by their service provider and 68.2% have not. Overall, 82.8% of respondents were able to get help concerning cognitive health when they tried and 17.2% were not able to.

**Role of Social Workers, Hospitals, and CBOs/ASOs**

Table 2 and the text below show responses to separate open-ended questions on the role of CBOs/ASOs, hospitals, and social workers concerning HIV and brain health support.

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes (%)</th>
<th>No (%)</th>
<th>Unknown (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can CBOs/ASOs support you? (n=63)</td>
<td>79.4%</td>
<td>12.7%</td>
<td>7.9%</td>
</tr>
<tr>
<td>Can hospitals support you? (n=52)</td>
<td>73.1%</td>
<td>11.5%</td>
<td>15.4%</td>
</tr>
<tr>
<td>Can social workers support you? (n=52)</td>
<td>69.2%</td>
<td>15.4%</td>
<td>15.4%</td>
</tr>
</tbody>
</table>
Regarding specific supports from CBOs/ASOs, more than half of respondents requested group support and computer stations for brain training programs, with the remainder offering general statements such as “anything”. One participant said the following:

Computer Stations that are individual, self-contained, quiet, with no audio or visual distractions so client could perform Brain-Training Software Exercises (e.g. ‘Luminosity’). Facilitated Peer-Support Groups for [people living with HIV] with a known diagnosis of HAND to discuss the impacts of diminishing brain functions on their lives, partners, families, friends lives. Support Groups for partners/family/friends dealing with someone who has HAND. (S106, 50-59 years old, male, white/eastern European).

Most of the respondents who did not want support from CBOs/ASOs or who did not know what support these organizations could offer responded with general statements such as “none” or “haven’t a clue”. One participant responded with this answer: “I consider myself to be an AIDS survivor and over the past 20 + years have lost faith in ASOs willingness to provide meaningful and appropriate services.” (S107, 50-59 years old, male, white/western European).

For hospitals, over half of the respondents that requested support were seeking client-centred clinical care and testing for HAND. A respondent summarized this, saying “scientifically proven testing and counselling/advice based, on test results, on ways to obtain improvements to brain fitness.” (S065, 60-69 years old, female, white/Canadian). Similar to the CBO/ASO question above, most people who did not want hospitals supporting them or did not know how hospitals could support responded with statements such as “I have no idea?” and “none”. A respondent said that “currently, my health team does not do any pro-active monitoring for problems that may be slowly affecting me.” (S054, 50-59 years old, male, white/western European).

Concerning social workers, most survey respondents requested emotional support, information provision, service navigation, and referrals for HAND testing. One respondent asked for a “resource center for brain health challenges (glossary/HAND info/services for help with brain health/examples of vocabulary to discuss with doctors” (S075, 50-59 years old, female, white/western European). Another respondent said the following:

Social Work run programmes aimed at [people living with HIV] with a diagnosis of mild-moderate HAND, and their significant others/family/friends/supports to ‘educate’ about HAND, advocate for services on behalf of clients, provide emotional support through talk therapy, home visits. Discuss implications of Public Trustees, POA for Finances,
accessing Legal Aid for Clients in need, i.e. become an ‘Advocate’, or ‘Navigator’ for the client as they move through the medico-legal-social-community landscape. (S106, 50-59 years old, male, white/eastern European).

The general comments stating that support was not needed or unknown from social workers was more specific than the comments stated above for CBOs/ASOs and hospitals. Most of these respondents replied with a variation on the response “I don’t deal with social workers”. Two participants questioned the scope and qualifications of social workers, with one stating “do social workers take care of this and everything else? Really? I would prefer someone not to raise my expectations?” (S008, 50-59 years old, male, Hispanic/Latin American) and another stating “Are Social Workers qualified in the field of dementia and memory loss. How can Social Workers deal with loss in all aspects..death, economic status, loss of friends and ostrasizing [sic] by family. Assist in making of wills, DNR, Powers of Attorneys.” (S018, 60-69 years old, male, white/western European).

Qualitative Results

Survey feedback

The first section of interview questions was focused on feedback from the survey, particularly asking how participants heard about the survey and what interested them about the survey. Most respondents heard about the survey through a partner organization’s newsletter or email (see Figure 1 above). Some respondents spoke about their personal experiences with cognitive health concerns as the motivation for completing the survey. One interviewee said “Because I’m beginning to lose my memory at times. Unexpectedly I’ll miss words that I want to identify something with” (I07, 70-79 years old, male, white/Canadian) and another responded with the following:

Well basically because I’ve been diagnosed with HAND. And it’s been bothering me and now it’s escalating where whenever I’ve got these foggy days I find that now it’s linking to depression. I don’t know if one goes with – I’ve never been depressed in my life and now I’m getting more and more depressed where I had to seek help actually. (I14, 50-59 years old, male, French Canadian).

Other participants indicated that they felt proactive by completing the survey, with one person saying “…brain health is becoming more and more a subject that people are discussing and I
understand that it can creep up on you when you least expect it and so I’m really curious to see, to get involved in the study.” (I15, 60-69 years old, male, white/Canadian).

**HIV and the Social Determinants of Health**

Questions about HIV and the social determinants of health (e.g. housing, smoking, employment) comprised the second section of interview questions. When asked the broad question of how HIV has affected your life, with probes about treatment and employment decisions, some respondents identified how an HIV diagnosis was the starting point for community action and engagement. The following response is an example of this:

…It has caused me to very interested in HIV research. So I work in that area now, and I am on boards and areas related to research. And I participate as a volunteer in a number of community advisory committees and stuff like that. So it affects my activity because I’m interested in being on top of where the thinking is moving around health matters for those that are HIV positive. (I02, 50-59 years old, female, white/Canadian).

Other participants found HIV to be of concern, but manageable overall. One participant said “It could be anything else. It could be – I find it’s better than getting cancer, or something like that. You know what I mean? It’s manageable. It’s sort of like a – it’s a nuisance, if anything.” (I6, 50-59 years old, female, white/Canadian). Many respondents had been HIV-positive or over twenty years and spoke about how HIV had changed over that time. One person replied with “I think that I didn’t expect to live therefore I didn’t do things…I was very intimidated about disclosure so I quite frankly, it took me so much time to approach anybody that I didn’t have much of a sex life.” (I13, male, 50-59 years old, white/Canadian). Regarding employment, people identified that HIV had caused interruptions in their career plans. A participant said “[HIV has] led to I guess if we’ll say careers in the like four or five years at a stretch because of unemployment in between a lot of it based on pretty severe depression.” (I13, 50-59 years old, male, white/Canadian). Over half of interview participants stated that they do not smoke cigarettes, with some of them having never smoked.

**Mental Health**

The third section of the interview contained questions on mental health. Participants had started talking about mental health concerns and issues, predominantly depression, in the two
previous sections as illustrated in some of the quotes above. When asked about how HIV and brain health concerns have affected their mental health, participants provided a variety of responses. One person said:

Well at first it was manic depressive, I would go – I would be really, really low, low, low and then something good would happen and I would be ecstatic. And then I went through this a couple of times and at the time I was seeing an analyst at [Mount Sinai Hospital] and I said you know what, this rollercoaster is making me crazy because it’s just the two extremes. (I20, 60-69 years old, male, white/Canadian).

For some participants, mental health issues were present, however they did not make a direct link to HIV and brain health. A respondent said that “I have medication for panic attacks and I’m bipolar. I have post-traumatic stress, borderline personality disorder…it’s more about the medication you take and losing your balance and falling….” (I04, 50-59 years old, female, white/Canadian).

**Cognitive Health**

Participant responses were varied when asked about their cognitive health concerns and supports, the fourth interview section. Some participants were self-identifying supports for their brain health concerns, because they didn’t think that their doctor or psychiatrist could help with this issue. An example of this:

Well there’s this thing called, company called Brain Booster. And I’m going to try it. It’s a reputable supplement company and I want to see what happens. It can’t do any harm, I know that. So if it’ll make my brain a little – even if it doesn’t get worse as fast, anything that would help. But inevitably, I know there’s nothing you can do that we know about medically, that I’m aware of anyway. (I07, 70-79 years old, male, white/Canadian).

Many participants have independently developed coping strategies for brain health concerns, such as “…I have my keys on a chain attached to my pants, that was, that drove me nuts till I finally learned, yeah, you’ve got to keep your keys attached to your pants.” (I08, 60-69 years old male, white/Canadian). Most participants tend to rely on their HIV-positive friends for support concerning HIV and brain health, either connecting with one or two close friends or with a group of friends. One participant described this type of friendship thusly:
So it’s not a physical but it’s a brother love type or thing that it’s a mentor because we understand exactly I feel not that we are one stone, don’t get me wrong. But as all my friends, the few, who I can discuss any of these issues. For me, [he] will remain the person who knows exactly where I’m coming from, where I’m aiming, what I’m going through, my struggle because his are pretty similar. (I11, 50-59 years old, male, French Canadian).

Other people mentioned a strong bond with their doctor, who they have been seeing for over a decade and who they feel comfortable talking about HIV and brain health concerns with. Exercise was also a topic of discussion in this section, as participants identified that it was helpful to helping them through difficult times. One respondent stated “what does exercise mean to me? Oh they’re very important. Yeah, I had very bad periods in my life, but every time I had bad, bad, bad – like bad periods – the gym would get me through it.” (I10, 50-59 years old, male, Hispanic/Latin American).

**HAND Testing**

The fifth interview section was focused on the testing and screening of HAND. One of our survey questions asked if being tested for HAND caused distress, even if the test result was negative. For some participants, there was a feeling of inadequacy following a HAND test. One person said the following:

I can’t remember things. My short-term memory is not very good. My long-term memory is fine. And I did a [HAND test] with lots of different tests and everything. And I left – and it was a full day. And I left there feeling inadequate because I couldn’t remember how to – a lot of things. (I09, 50-59 years old, male, white/Canadian).

Most participants reported a positive experience being tested at St. Michael’s Hospital in downtown Toronto, where a team of scientists and doctors are committed to screening, diagnosing, and treating HAND. When participants were tested for HAND outside of Toronto, however, their experiences were not as positive. One participant recounted the following:

Yeah, HAND test and apparently, according to the person who conducted the HAND test, I, pardon me, I failed miserably so. Which gave me a bit of concern again, you know, because I thought wow, I didn’t realize that I had these limitations, you know? It was by, the doctor had a visiting specialist who conducted these tests…and she said I’m going to
a quick test on you. She says this isn’t the full test, this is just a precede version of the test, and she didn’t give me my results right then and there. The doctor told me what happened…in the subsequent visit, but I was quite surprised at the result, because I didn’t realize that I had this issue or problem. (I12, 60-69 years old, male, white/Canadian).

Some participants identified that this research project was the first time they had heard about HAND and were unaware of how to be assessed for HIV-related cognitive issues.

**Role of Social Workers, Hospitals, and CBOs/ASOs**

The sixth and final interview category explored the role of social workers, hospitals and CBOs/ASOs by asking participants about the professional support they received for HIV outside of the doctor’s office, and how these professional supports might be able to address brain health concerns. Some participants requested counselling therapy, social support, and practical assistance from social workers and CBOs/ASOs. One participant said the following:

Yes, I’ve used [ASOs]. I’ve picked up vitamins there…food bank I’ve used…noticing today on the board that they have some socials for women with AIDS and I marked some down because I’m thinking maybe to come socialize…just talk therapy I guess. I mean, that’s – I don’t have a social worker. (I19, 60-69 years old, female, white/Canadian).

Other respondents were more specific about how social work and CBOs/ASOs could provide HAND-related support. An example of this is the following response:

Well, I certainly think [ASOs] can have those education sessions where they bring in experts to talk about, what are the newest developments in HAND, what are they finding in HAND research – that’s education and information. But I would like to see more around applications towards the individual that is suffering from HAND and what programs could be put in place for them. Things like maybe brain…well, the testing, setting up or facilitating testing for people who haven’t been tested, re-testing to see progression or regression of those who have been tested. So I guess that would just sort of, you know not only just be through your family doctor but I think there should be a role through ASOs, maybe even having – I don’t know – groups or software, like I noticed people coming here to use the computers and maybe they could have those brain function software programs on computers, a special quiet area where it can be done.
Yeah, or software that could be accessed on the website so people who can’t make it out of their homes can access it that way. (I18, 50-59 years old, male, white/Canadian).

Being able to share brain health concerns with social workers and other helping professionals without being labelled or judged was of great importance for participants. One person stated that “and that’s why I originally didn’t event want to come to the table to talk about my brain health because I figured okay they’re going to…say somebody’s got a cognitive brain issue okay there’s somehow less of a person. And I didn’t want to do that to myself…I have to learn to deal with it better, yeah. And I think the social workers have to do that too.” (I15, 60-69 years old, male, white/Canadian).

**Key Themes**

The following five interconnected themes emerged from the quantitative and qualitative data collected throughout this research project.

**Theme 1: You lay in bed and you think to yourself, you’re just not happy, you’re not happy at all**

With 53.8% of survey respondents currently experiencing a mental health concern (e.g. anxiety, unmanageable stress, depression), the impact of mental health on the lives of the sample was apparent prior to the interviews. In the interviews, people described how: (a) mental health issues, most commonly depression; (b) stigma and discrimination, both self-imposed and from others; (c) fear of the future; (d) confusion on where to access supports; (e) treatment fatigue; and (f) financial stressors contributed to negatively impact respondents’ overall health and wellbeing. The full quote from this theme’s heading is as follows:

> But it can be very – it has been depressing sometimes. You know, you lay in bed and you think to yourself, you’re just not happy, you’re not happy at all. And I don’t want that to have access to the types of medications I have, whether that would create a scariness around will I think about that? How far do I go with this thinking process? I’m depressed so am I thinking about death or how far am I going with this before I try to pull away from it or try to redirect myself somehow? So, it can be a little bit nerve wracking that way. I don’t know what the levels should be ‘cause I’m not a counsellor or whatever. But I’m pretty secure in myself. I like myself. I think that makes a difference because I’m
okay with me, you know? Maybe other people aren’t but I don’t give a shit I’m happy with me and I like doing the things I’m doing. And being part of the community and that kind of stuff has always been a pleasure for me. But there are times when you have really low periods. (I01, 50-59 years old, male, white/Canadian).

Aging was also a factor in participants’ self-perceptions, as shown in the following quote:

I don’t want to be one of those couch potatoes or a person in a wheelchair, I don’t. I was always afraid of growing old. I wanted to die at 50. When I was a kid I said I want to die at 50 and I won’t be burden to anybody. I don’t want to waste away…the thought of withering away to, you know, a sick, needy person that people have to strain yourself to take care of, because I don’t have family. So that scares me (I04, 50-59 years old, female, white/Canadian).

A participant who had been diagnosed with HAND stated that “When it comes to the HAND part I find that I’m more alone that if low, no support that it’s and I’m more, it’s like what HIV was in the late eighties, mid-eighties to nineties it’s like what’s going to happen now?” (I14, 50-59 years old, male, French Canadian).

Theme 2: I’m pretty secure in myself. I like myself. I think that makes a difference

This theme’s heading is pulled from the same quote used for the first theme’s heading, and demonstrates the duality of perception and experience that the sample felt with regards to their life, HIV, and brain health. From the survey, 35.6% of respondents stated that family and friends were a source of support for HIV and brain health concerns. Interviewees echoed this statement, providing detail on how participants have been developing their own coping strategies to deal with brain health concerns. For many participants, they identified thriving when objectively they may seem to be socially isolated. This independent attitude appears to have been partly developed from years when helping professionals were not adequately addressing HIV/AIDS, so people had to discover their own resiliencies and ways to live. As one person said, “I came from the era where you couldn’t guarantee the doctor would know anything. I sort of read everything I could get my hands on and continued on almost to the point of an obsessive point at best so I can talk most doctors under the table” (I13, male, 50-59 years old, white/Canadian). This resilient approach is also demonstrated in the following response:
Well you go through this – once you’ve hit the brick wall a couple of times you – there has to be a certain level, you have to accept where you are because if you don’t it’s going to completely frustrating continually, you’re never going to get anywhere. And so you sort of accept a mean that you’re now in and whether that’s good bad, it’s the mean that you’re in (I20, 60-69 years old, male, white/Canadian).

One respondent said that “I know what depression is, I know what triggers it for me. I know how to deal with it to come out of it. I try to maintain a positive outlook and keep busy, I do not sit and mope.” (I03, 50-59 years old, male, white/Canadian). Another participant stated the following: “It’s to be able to refocus myself at those moments, assess the situation and trying to figure out what else I could do to get out of it. So I’m not saying I’m exempt [from depression]. I feel, I feel it when it’s coming. I try not to get too deep in it…” (I11, 50-59 years old, male, French Canadian).

**Theme 3: Is it aging or is it HIV?**

Participants’ perception of themselves and their fears and anxieties concerning cognitive health were frequently centred around uncertainty regarding what issues HIV is causing and what issues can be attributed to the aging process. This question arose from participants during discussion on cognitive health, life with HIV, and coping strategies. Participants indicated that this question affected their overall health, how they perceive their experiences, their sense of what is real, and their reactions to new issues and concerns. One interviewee summed up this theme with the following response:

My doubts about the brain fluids is – it’s just, is it aging? Being old? Or is it the HIV that affected it? Or was it the medication of the HIV? I don’t know. But nobody knows. I think it’s normal, at a certain point, to start having troubles. At 58, 60. Everybody does, so being HIV is probably worse, but you deal with it. (I10, 50-59 years old, male, Hispanic/Latin American).

Another participant expressed this same theme, saying “Every time I get something and I say…’do you think this has any relation to the HIV?’ and [my partner says] ‘well, you know, you are aging and you are HIV.’” (I08, 60-69 years old, male, white/Canadian). A third interviewee echoed these concerns, saying “Like how do I know which…what is actually
because of the HIV, or is it just normal due course for aging, you know? Like, what do I need to expect, you know?” (I12, 60-69 years old, male, white/Canadian).

For social workers, this theme is important because it addresses a central tension in the experience of the sample. It may be helpful to support clients in working through questions regarding aging and HIV.

**Theme 4: Social workers are the meat and potatoes**

Participants had a variety of opinions on how social workers could provide them with support, and on defining social work’s role overall. People mentioned that social workers could be counsellors, housing workers, disability support workers, case managers, system navigators, resource and referral providers, generalists, and specialists. The heading for this theme was pulled from an interview response that encapsulated the sentiment that many respondents were sharing about social work. The response is as follows:

Well I’ve never dealt with psychiatrists before except like my first visit last week so I think it would be unfair for me to make any kind of statement. But social workers I find are more, what’s a good expression? Meat and potatoes. Right down there and they probably are more understanding and can link you to different resources. (I14, 50-59 years old, male, French Canadian).

Another participant stated the following:

I think there’s a role for social workers because of the study of especially the family dynamics and interpersonal dynamics. And also they’ve been working in ASOs alongside other people since the beginning of this disease…the social worker that I had that came into deal with my illness and helping me deal with my family or helping them come to terms with it, you know, was of great benefit, and also helping my partner and I kind of work together (I18, 50-59 years old, male, white/Canadian).

One participant compared social workers to other helping professionals, stating that:

And I worked with psychiatrists, psychologists, social workers. The most effective people working with the patients were always the social workers…because they look at life from the point of view of the person living it. How they live in a society, rather than as a person who’s got an illness or an ailment or something. They look at the whole person. A
more holistic point of view. So just generally, better generalists and specialists in what they do (I07, 70-79 years old, male, white/Canadian).

Social work’s role in CBOs/ASOs was not especially clear to some participants. Most of these participants were uncertain about the overall role of CBOs/ASOs in general. One participant was unaware that his counsellor at a CBO/ASO was a registered social worker.

**Theme 5: Increasing knowledge and support decreases anxiety and stress**

Among the survey respondents, 82.8% were able to get help concerning cognitive health when they attempted to. There was a prevailing sentiment that ‘knowledge is power’ from the interviewees who felt educated about HAND and that ‘I feel comfortable and reassured’ from the interview participants who have existing supports for their HIV and brain health concerns. In contrast, participants who did not know about HAND and who were not supported concerning HIV and brain health felt anxious and stressed about the future. One participant summed up this theme in the following response:

Right and that’s where I think the supports are needed that when, you know, shit happens you’ve got someone that you can depend on to try and explain it to you in a way that you understand or give you choices of how to either resolve what may be happening…what’s available to you to keep you sane and healthy. (I01, 50-59 years old, male, white/Canadian).

Overall, participants found that discussing HIV and brain health concerns was more helpful than not addressing the issue. Another participant stated the following:

And the other thing is that there’s these groups that are sponsored by ACT called Living with HIV and I’ve gone to three of them…and I found that really, really useful because one of the problems with HIV and like finding or found out I’m not alone in this is feelings of isolation. Because it took me a long time to get to the point where I was willing to admit that I had it to anybody else out there. And I’m glad that I’ve gone over that hump because now it doesn’t bother me (I15, 60-69 years old, male, white/Canadian).
Chapter 5
Discussion

HAND Concerns

The first research question asked about the self-identified brain health concerns of HIV-positive older adults affected by HAND. With 108 qualifying survey responses and 20 in-depth interviews, the topic of HAND and relevant supports is one that people growing older with HIV in Toronto seem to identify as a priority issue. Among the survey respondents, 60.4% (n=65) had never been tested for HAND and 14.2% (n=15) were uncertain if they had been tested. Given that: (a) 51.9% of survey respondents who tested for HAND were diagnosed; (b) 50% of people living with HIV will be affected by HAND (St. Michael’s Hospital, 2014); (c) HAND can present in the first year of living with HIV (Spudich, 2013); and (d) HAND can be treated effectively in its early stages (Grant et al., 2014), it is important that people living with HIV are connected to HAND testing. The quantitative sample expressed numerous concerns about their cognitive health headlined by: (a) difficulty remembering (64.1%); (b) remembering the names of people they’ve just met (64.1%); (c) feeling emotionally overwhelmed (51.5%); (d) procrastinating or putting off tasks more than usual (51.5%); and (e) maintaining attention. The qualitative sample explained that the question of ‘is it aging or is it HIV?’ exacerbated these cognitive health concerns, causing more anxiety and stress. The above concerns are all signs and symptoms of HAND (Grant et al., 2014; Rourke, Terpstra, and Ibáñez-Carrasco, 2015; Spudich, 2013). Testing and treatment for HAND combined with social work support could alleviate these concerns among people living with HIV. Existing literature has found that asymptomatic neurocognitive impairment (ANI) is the most common form of HAND (Grant et al., 2014). However, 64.2% of survey participants diagnosed with HAND had a more severe form of HIV-related cognitive impairment. This is significant as the more severe forms cause disruption to activities of daily living (Fazeli et al., 2013; Grant et al., 2014) which can be interpreted to mean that people living with HIV are not seeking HAND tests until their cognitive decline has reached a stage where it is difficult to contain through treatment and coping strategies (Fazeli et al., 2013; Grant et al., 2014). This is a problem as the progression of HAND can significantly lower an individual’s quality of life and can cause increased anxiety and stress in couples and families due to caregiver burden (Fazeli et al., 2013; Vance and Struzick, 2007). The importance of testing
early for HAND is two-fold: (a) cognitive testing prior to a diagnosis of impairment develops a baseline for the individual, which can vary based on factors such as education and housing that marginalized population subgroups are disproportionately disadvantaged by (Ryan, Baird, Mindt, Byrd, Monzones, and Morgello, 2005); and (b) the impact of HAND, when diagnosed in its asymptomatic stage, can be slowed and possibly reversed through HIV treatment (cART) and through lifestyle changes and additional supports for health and mental health (Fazeli et al., 2013; Grant et al., 2014).

Current Supports

The second research question asked about the extent to which current supports such as social workers, hospitals and clinics, and CBOs/ASOs are addressing brain health concerns for people living with HIV over the age of 50. CBOs/ASOs noted a 25% increase in clients aged over 55 in 2013 with this age group comprising 13% of total clients in Ontario’s CBOs/ASOs (OCHART, 2014). It is significant that, overall, the quantitative sample was engaged in their HIV care with 97.2% of respondents currently taking HIV medications and 89.6% identifying that their viral load was currently undetectable. The qualitative sample explained the value of this engagement, noting that their doctor and local CBO/ASO had been sources of consistent support for many years. Adherence to HIV medications and an undetectable viral load greatly contribute towards the prevention of HAND (Fazeli et al., 2013; Grant et al., 2014) and are indicators that the majority of survey respondents are retained in HIV care (Hoe, 2015).

Considering that the many brain health concerns that this sample raised despite the apparent absence of the HAND risk factor of HIV treatment noncompliance, there could be greater concern and cognitive challenges among the estimated 40-48% of people living with HIV in Ontario who may not be taking HIV medications (Hoe, 2015). As 48.1% of survey respondents indicated that they access a CBO/ASO and given that recruitment was largely conducted by a network of community-based HIV organizations in Ontario, it is likely that the majority of participants are further engaged in their HIV care through service access at CBOs and ASOs. Despite the high levels of engagement that participants have with their doctors and local CBO/ASO and their numerous cognitive health concerns, 74.5% of the quantitative sample have not been tested for HAND. Such a disconnect could be explained by the stigma associated with identifying changes in cognition. The qualitative sample supported this explanation, expressing
concern that they would be viewed as ‘incompetent’ or ‘less of a person’ by service providers if
they discussed cognitive challenges and concerns. Another possible explanation for low testing
rates could be a lack of knowledge among service providers regarding HAND. This explanation
is supported by the author’s informal environmental scan, which found that Ontario HIV service
providers were not addressing HAND-specific concerns. Therefore, the author concludes that:
(a) people are not talking about cognitive issues with service providers at Ontario’s CBOs/ASOs;
and/or (b) service providers at CBOs/ASOs in Ontario do not know about options for HAND
prevention, testing, and treatment.

**Implications for Social Work Practice**

The third research question asked about how people living with HIV understand the role
of social workers, hospitals and clinics, and CBOs/ASOs. Survey participants are already
connected to these supports, predominantly through their doctor (78.1%), CBO/ASO (48.1%),
and counsellor/therapist (31.4%). The majority of participants agree that CBOs/ASOs (79.4%),
hospitals (73.1%), and social workers (69.2%) can support them with their cognitive health.
These findings are significant as the sample already understands service provider roles in a
personal context since the sample currently accesses helping professionals for support. This
finding means that social workers on family health teams, in hospitals, in community
organizations, and in private practice are well positioned to connect people living with HIV to
HAND testing. Based on qualitative participant responses, social workers are positioned to
utilize the therapeutic alliance with clients to follow-up with them about HAND testing
experiences and to help clients identify coping strategies and opportunities to improve their
cognitive reserves (e.g. exercise, volunteering) (Fazeli et al., 2013; Vance and Struzick, 2007).
However, 44.7% of survey respondents indicated that their overall HIV-specific support had not
been helpful for them with 54% not discussing brain health concerns with their service providers.
This finding is difficult to interpret as the word ‘helpful’ was not defined. Respondents stated
that social workers must take a holistic view in providing such support by recognizing the many
complicating factors in participants’ lives. Additionally, a clear statement was made that social
workers and other helping professionals should not label them as ‘incompetent’ or ‘less of a
person’ for needing support and/or having brain health concerns. These statements mean that
participants consider their lives to be complex and that a top-down approach to service delivery
may not address all of their health and mental health needs. Social workers and the organizations they work for can improve upon how they describe their role to clients and other stakeholders during intake and assessment. Balancing an assessment of the client’s suitability for services with the opportunity for clients to assess whether a service will be helpful, using tools such as professional codes of ethics and encouraging questions, could lead to increased client satisfaction. Based on participant response, Vance and Struzick’s (2007) model of social work support for people affected by HAND could be implemented if the participants’ conditions just discussed are adhered to.

**Implications for Research**

This project demonstrated a need for more psychosocial research regarding HIV and aging, especially in the fields of mental health and cognitive health. Recruiting a larger sample with greater standardization in quantitative measures would provide more reliable, generalizable data on the supports necessary for people to address HIV and brain health concerns. We may be able to better understand the relationship between HIV treatment adherence and cognitive health concerns by asking participants more about their housing status, education, literacy level, HIV medication adherence, and comorbidities such as substance use and mental health issues. These social determinants of health have all been found to impact HAND onset and progression, especially among racial and ethnic population subgroups (Ryan, Baird, Mindt, Byrd, Monzones, and Morgello, 2005; Trujillo, 2010). Although 66.1% of participants had completed a post-secondary degree, the sample still had numerous brain health concerns. This is significant when considering the potential cognitive concerns that people without a post-secondary education may experience. Over half of participants had mental health concerns and were using substances that are known to negatively impact cognitive health (Fazeli et al., 2013). Exercise and physical activity are highly effective strategies to enhance cognitive health and overall wellbeing (Fazeli et al., 2013). Approximately half of survey participants identified exercising regularly (54.7%), however regularity was not defined in the survey question. Interview participants detailed the positive effects that exercise had on their lives. This is significant as an active lifestyle is a coping strategy that people can independently integrate into their daily lives if the means are available (e.g. nearby gym, finances, etc.) to improve their mental health and cognitive health. I interpret the research findings and literature reviewed as indication that care retention (i.e.
adhering to medications, attending regular medical appointments, and accessing social work support) may result in the following: (a) slower cognitive decline and improved cognition in people living with HIV compared to those not retained in care; and (b) better overall health and mental health outcomes in people living with HIV compared to those not retained in care. These two hypothesized causes could be tested in further research.
Chapter 6
Limitations

Validity

The use of an explanatory sequential mixed methods approach can compromise validity as the researchers cannot follow up on all aspects of the quantitative results (Creswell, 2014, p. 225). An example of this is that interview participants were not asked specific questions about their past and present HIV medication. Since only 20 of the 108 survey participants that met inclusion criteria were interviewed, there were certainly some perspectives that were not expanded upon in the second stage of data collection.

Sampling

Another limitation of this study is that the sample was largely homogenous. From the survey, 88% (n=95) of respondents were male; 79.3% (n=85) identified as gay; and 97.1% (n=104) identified their ethnicity as white. Ethnicity was a multi-answer question and some respondents identified with both white and another ethnicity, however none of these other ethnicities accounted for more than 2% of survey respondents.

Generalization

The survey sample can be compared to the demographics of people living with HIV who are accessing CBOs/ASOs in Ontario, as questions matched those asked at intake (OCHART, 2014). However, the lack of standardized measures in addressing cognitive health and mental health makes the findings difficult to generalize beyond the scope of Ontario or more accurately, downtown Toronto.
Chapter 7
Conclusion

Significance

Support for HAND has not been previously addressed in social work research literature. As the population of people living with HIV in Canada grows older, cognitive concerns were become a higher priority for clients seeking social work support. Additionally, this project increased the research capacity of the author and of the four peer researchers.

Results

The duality of personal experience among the sample, i.e. that people can have both moments of strength and weakness, is an important consideration for social workers and other helping professionals. This consideration works against the threat of pathologizing clients as unhealthy or perpetually in need of support. The finding that the question of ‘is it aging or is it HIV?’ is significant as it addresses a key uncertainty that is causing anxiety and stress among people living with HIV. Finally, participant-identified usefulness of social work and CBOs/ASOs combined with reduced stress and anxiety as a result of increased knowledge and support is important for service providers, policy makers, and organizational administrators to consider when reviewing current programs and services and identifying new opportunities.

Implications

This topic area would benefit from a more heterogeneous, standardized quantitative study that sought to understand these issues among a larger, more diverse group of people living with HIV over the age of fifty. That future study combined with this study’s findings could provide the information needed to pilot evidence-based programs and services to support the cognitive and mental health of people aging with HIV.
References


Appendices

Appendix 1: Funding Offer

March 25, 2015

Mr. Andrew Eaton
399 Church St.
4th Floor
Toronto, ON
M5B2J6

Dear Andrew,

Thank you for the re-submission of your OHTN Community-Based Research & Evaluation Fund grant entitled "Exploring the role of Social Work in supporting people affected by HIV-Associated Neurocognitive Disorder (HAND)" and for the thoughtful changes made by your team to address the reviewers comments.

Following the review of this re-submission, we are pleased to advise you that your proposal has been recommended for funding.

Enclosed are two forms that must be completed and returned to the OHTN before any funds can be released – the Offer of a Community-Based Research & Evaluation Fund grant, and the Grant Accountability Agreement. Please e-mail or fax the completed and signed forms to the attention of Lydia Makoroka (scan to lmakoroka@ohtn.on.ca or fax to 416-640-4245) as soon as possible.

As a condition of funding, you are required to submit final and financial reports as stated in the offer. You may also be asked to submit an abstract for presentation of your project and its findings at a future OHTN Research Conference.

Congratulations on the success of your application and best wishes for the completion of your project.

Sincerely yours,

Sean B. Rourke, Ph.D.
Scientific and Executive Director

/end Offer of a CBR Fund Grant; Review Summary; Grant Accountability Agreement;

cc: Dr. Jon Salsberg, Chair, CBR Review Committee
Ms. Jocelyn Watchorn, Co-Principal Investigator
Dr. Shelley Craig, Co-Principal Investigator, Factor-Inwentash Faculty of Social Work
Mr. Pieter Huisman, Director of Operations, ACT
Appendix 2: Ethics Approval and Amendment Approval

PROTOCOL REFERENCE # 31509

April 29, 2015

Dr. / Mr. / Ms. Community Researcher and Ms Jocelyn Watchorn
SPECIAL - COMMUNITY-BASED RESEARCH DIVN OF V-P RESEARCH

Mr. Andrew Eaton
SPECIAL - COMMUNITY-BASED RESEARCH DIVN OF V-P RESEARCH

Dear Dr. / Mr. / Ms. Community Researcher, Ms Jocelyn Watchorn, Mr. Andrew Eaton,

Re: Your research protocol entitled, "Exploring the role of social work in supporting people affected by HIV-Associated Neurocognitive Disorder (HAND)"

<table>
<thead>
<tr>
<th>ETHICS APPROVAL</th>
<th>Original Approval Date: April 29, 2015</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Expiry Date: April 28, 2016</td>
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<td>Continuing Review Level: 1</td>
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We are writing to advise you that the HIV Research Ethics Board (REB) has granted approval to the above-named research protocol, for a period of **one year**. Ongoing research under this protocol must be renewed prior to the expiry date.

Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation. Any adverse or unanticipated events in the research should be reported to the Office of Research Ethics as soon as possible.

Please ensure that you submit an Annual Renewal Form or a Study Completion Report 15 to 30 days prior to the expiry date of your current ethics approval. Note that annual renewals for studies cannot be accepted more than 30 days prior to the date of expiry.

If your research is funded by a third party, please contact the assigned Research Funding Officer in Research Services to ensure that your funds are released.

Best wishes for the successful completion of your research.

Yours sincerely,
Dear Dr. / Mr. / Ms. Community Researcher, Ms. Jocelyn Watchorn, Mr. Andrew Eaton,

Re: Your research protocol entitled, "Exploring the role of social work in supporting people affected by HIV-Associated Neurocognitive Disorder (HAND)"

We are writing to advise you that a member of the HIV Research Ethics Board (REB) has granted approval to an amendment (Received October 9, 2015) to the above-referenced research protocol under the REB's delegated review process. This amendment approval letter only applies to what was outlined in the request form under section 5.a) or otherwise marked in the revised protocol.

**Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation. Any adverse or unanticipated events should be reported to the Office of Research Ethics as soon as possible.**

Best wishes for the successful completion of your research.

Yours sincerely,
Appendix 3 – Survey Recruitment Flyers

ARE YOU OVER THE AGE OF 50 AND LIVING WITH HIV?

The AIDS Committee of Toronto (ACT) and the Factor-Inwentash Faculty of Social Work at the University of Toronto are conducting research into the role of social work in supporting people living with HIV who are over the age of 50 and concerned about their brain health.

We have developed a survey that will ask you questions about your demographics, brain health concerns, current supports, and gaps in programs and services for HIV and brain health. Your responses will be anonymous and confidential.

Your participation may help to improve or develop programs and services for people aging with HIV.

The survey can be found online at: fluidsurveys.com/s/hiv-brain-health

or come to ACT’s 4th floor reception area to complete a paper copy.

This project has received approval from the University of Toronto HIV Research Ethics Board.

If you have any concerns or questions about ethical issues related to this study, please contact:

University of Toronto Research Ethics Board: ethics.review@utoronto.ca or phone 416-946-3273

Funded by The Ontario HIV Treatment Network (OHTN).
AVEZ-VOUS PLUS DE 50 ANS ET VIVANT AVEC LE VIH?

Le AIDS Committee of Toronto (ACT) et de la faculté de travail social Factor-Inwentash de l’Université de Toronto étudions le rôle du travail social pour aider les personnes vivant avec le VIH qui sont âgés de plus de 50 et préoccupés par la santé cognitive.

Nous avons développé une enquête qui vous poser des questions sur vos données démographiques, les préoccupations de santé cognitives, supports, et les lacunes dans les programmes et services pour le VIH et la santé cognitive. Cette enquête est confidentielle et anonyme.

Votre apport dans cette enquête nous aidera à fournir de l’information aux programmes et services pour les personnes vieillissantes vivant avec le VIH.

L’enquête peut être trouvé à ACT ou en ligne à :
fluidsurveys.com/s/hiv-brain-health

ou venir au 4ème zone de réception au sol de l’ACT pour compléter une copie papier.

Ce projet a reçu l’approbation de l’Université de Toronto Comité d’éthique de recherche sur le VIH.

Si vous avez des questions ou des préoccupations au sujet de questions éthiques liées à cette étude, s’il vous plaît contacter :

University of Toronto Research Ethics Board:
thics.review@utoronto.ca
ou phone 416-946-3273

Financé par le Réseau ontarien de traitement du VIH (L’OHTN).
Appendix 4: Survey Questions

HIV and Brain Health Survey

This survey was designed to learn about the support service experiences of people over the age of 50 that are living with HIV and concerned about their brain health. We are a team of service providers, researchers, and people living with HIV from the AIDS Committee of Toronto (ACT) and the Factor-Inwentash Faculty of Social Work at the University of Toronto. Your input in this survey will help inform programs and services for people aging with HIV. This survey is one part of a research project that will also involve qualitative interviews. Your survey responses will be used to help the research team develop the qualitative interview questions.

This survey will take about 15 minutes to complete and is confidential and anonymous.

Do you have to answer every question?
You do not have to answer every question

Confidentiality
Paper surveys will be collected and stored at ACT, in a locked cabinet, until survey responses are entered into a digital database. Once entered, paper surveys will be shredded. The digital database will be saved as an encrypted file on a password protected computer at ACT. Results from the survey will be summarized, and any personally identifying information shared by survey respondents will be removed.

How will we share the survey results?
Results will be analyzed and used to develop a report that will be available in Spring 2016. We will also share what we learn from this survey with other AIDS service organizations and interested survey participants. This way the information you share can enable other organizations to provide programs and services that respond to your priorities, concerns, and strengths.

This survey will be available to complete until August 31, 2015.

You can complete the survey on-line through Fluid Surveys: http://www.fluidsurveys.com/s/hiv-brain-health

Alternatively, you can complete the attached survey and return it by:

• Fax to: 416-340-8224
• Email to: aeaton@acttoronto.org
• Mail to/Bring to: ACT, 399 Church Street, 4th Floor, Toronto, Ontario M5B 2J6

If you have any questions about this survey, please contact Andrew Eaton at (416) 340-8484, ext. 283 / aeaton@acttoronto.org or University of Toronto Human Research Ethics Program at (416) 946-3608.

Do you consent to participate in this survey?
☐ Yes ☐ No
1. What is your HIV status?
   □ HIV+ □ HIV- □ Unknown

If you are living with HIV, in what year were you diagnosed? ____________________

2. What is your age?
   □ 19 years or under □ 50-59 years
   □ 20-29 years □ 60-69 years
   □ 30-39 years □ 70-79 years
   □ 40-49 years □ 80 years and over

*Please note: You are eligible to complete this survey if you are HIV+ and over the age of 50.*

Please tell us about yourself:

1. How do you identify your gender?
   □ Male □ Female □ Intersex □ Two-spirit
   □ Trans-man □ Trans-woman □ Other (please specify)__________________________

2. How would you define your sexual orientation?
   □ Bisexual □ Lesbian □ Two-Spirit □ Queer
   □ Gay □ Straight/Heterosexual □ Other (please specify)__________________________

3. How would you define your ethnicity?
   □ African □ Hispanic/Latin American □ Indigenous □ East Asian/Southeast Asian
   □ South Asian □ Middle Eastern/Arab □ Caribbean □ White/Eastern European
   □ White/Western European □ Other (please specify)__________________________

4. Were you born in Canada?
   □ Yes □ No
   If no, where were you born? (country) _________________________________
   If no, when did you move to Canada? (age) _______________________________

5. What is your employment status?
   □ Unemployed □ Employed □ On Disability (examples: ODSP, private disability)
   □ Retired □ Volunteer

If unemployed/not volunteering, how long have you been out of the workforce? ________
6. What is your average annual household income?

- Under $5,000
- $5,000 – $15,000
- $15,000 – $25,000
- $25,000 – $35,000
- $35,000 – $50,000
- Over $50,000

7. What is your highest level of education?

- Some Primary School
- Primary School
- Some High School
- High School Diploma/Equivalency (GED)
- Trade/Vocational School
- Some college/university
- College or University Diploma/Degree
- Post-Graduate Masters/PhD
- Other (please specify) ____________________________

8. What is your housing situation?

- Own
- Renting – Market Rent
- Renting – Rent Geared to Income
- Homeless
- Shelter
- Hotel/Motel
- Correctional Institution
- Hospital
- Long Term Care
- Temporary (couch surfing, staying with family/friends)
- Other (please specify) ____________________________

9. Do you find your housing adequate?  □ Yes  □ No

   If no, why not? ____________________________

10. Do you exercise regularly?  □ Yes  □ No

Please tell us about living with HIV:

1. What has your lowest CD4 count been? (i.e. nadir CD4)

   - Below 200
   - 200-400
   - 400-600
   - Don’t Know
   - 600-800
   - 800-1000
   - Over 1000

2. What was your most recent CD4 count?

   - Below 200
   - 200-400
   - 400-600
   - Don’t Know
   - 600-800
   - 800-1000
   - Over 1000

3. What was your most recent viral load?

   - Undetectable
   - 40-200
   - Don’t Know
   - 200-1000
   - 400-600
   - Over 1000
   - Don’t Know
4. Are you taking HIV medications?  □ Yes  □ No
   If yes, when did you start taking HIV medications? ______________

5. What HIV medication(s) are you currently taking? (please select all that apply)
   □ Aptivus  □ Atripla  □ AZT  □ Celsentri  □ Complera
   □ Crixivan  □ DDI  □ D4T  □ Edurant  □ Fuzeon  □ Intelence
   □ Isentress  □ Invirase  □ Kaletra  □ Kivexa  □ Norvir  □ Prezobix
   □ Prezista  □ Rescriptor  □ Retrovir  □ Reyataz  □ Stribild  □ Sustiva
   □ Telzir  □ Tivicay  □ Triumeq  □ Trizivir  □ 3TC  □ Truvada
   □ Viracept  □ Viramune  □ Viread  □ Videx EC  □ Zerit  □ Ziagen
   □ Don’t Know  □ Other (please specify) _______________________

6. What HIV medication(s) have you taken in the past? (please select all that apply)
   □ Aptivus  □ Atripla  □ AZT  □ Celsentri  □ Complera
   □ Crixivan  □ DDI  □ D4T  □ Edurant  □ Fuzeon  □ Intelence
   □ Isentress  □ Invirase  □ Kaletra  □ Kivexa  □ Norvir  □ Prezobix
   □ Prezista  □ Rescriptor  □ Retrovir  □ Reyataz  □ Stribild  □ Sustiva
   □ Telzir  □ Tivicay  □ Triumeq  □ Trizivir  □ 3TC  □ Truvada
   □ Viracept  □ Viramune  □ Viread  □ Videx EC  □ Zerit  □ Ziagen
   □ Don’t Know  □ Other (please specify) _______________________

Brain Health Concerns:

1. Do you smoke cigarettes?  □ Yes  □ No
2. Do you use substances that could impact your brain health?  □ Yes  □ No
   □ Don’t Know
   (examples: alcohol, cocaine, crystal meth, injection drugs, marijuana)
3. Are you currently experiencing mental health concerns?  □ Yes  □ No
   □ Don’t Know
   (examples: anxiety, unmanageable stress, depression)
4. Have you ever been diagnosed with a mental health issue that could impact brain health?
   (examples: depression, bipolar)  □ Yes  □ No  □ Don’t Know
5. Have you ever been diagnosed with a health condition, besides HIV, that could impact brain health?
   (examples: tertiary syphilis, MS, traumatic brain injury)  □ Yes  □ No  □ Don’t Know
6. Have you ever been screened/tested for an HIV-Associated Neurocognitive Disorder (HAND)?

☐ Yes  ☐ No  ☐ Don’t Know

If yes, did the screening/testing result in a diagnosis of HAND?  ☐ Yes  ☐ No  ☐ Don’t Know

If yes, what form of HAND were you diagnosed with?
☐ Asymptomatic Neurocognitive Impairment (ANI)  ☐ Mild Neurocognitive Disorder (MND)
☐ HIV-Associated Dementia (HAD)  ☐ Don’t Know

If no, were you given feedback that suggested there might be concerns about your brain health?
☐ Yes  ☐ No

7. What concerns you about your brain health? (please check all that apply)
☐ Misplacing items  ☐ Completing daily living tasks
☐ Maintaining attention  ☐ Difficulty remembering
☐ Adhering to medication  ☐ Reading a map/understanding directions
☐ Active employment  ☐ Procrastinating or putting off tasks more than usual
☐ Making decisions  ☐ Predicting the consequences of my decisions
☐ Following written instructions  ☐ Following verbal instructions
☐ Doing simple math in my head  ☐ Calculating a tip at a restaurant
☐ Multitasking  ☐ Expressing yourself clearly
☐ Solving problems  ☐ Remembering names of people you’ve just met
☐ Keeping social plans  ☐ Remembering names of people you’ve known for a long time
☐ Finding words  ☐ Feeling emotionally overwhelmed
☐ Inappropriate dress/attire  ☐ Other (Please specify) ____________________________

8. How do you react to concerns about your brain health?
☐ I get worried / I feel stressed out
☐ I talk to family/friends about my concerns
☐ I talk to professional supports (example: social worker) about my concerns
☐ I turn to my faith/personal belief system
☐ Other (please specify) ____________________________

Supports:

1. Who provides you with support around living with HIV? (please check all that apply)
☐ No One  ☐ Friends  ☐ Family  ☐ Partner/Spouse  ☐ Counsellor/Therapist
☐ Social Worker  ☐ Medical professional (family doctor, specialist, naturopath, psychiatrist)
☐ Other (please specify) ____________________________
2. Where do you currently access professional social supports around living with HIV?
   (please check all that apply)
   □ Hospital
   □ AIDS Service Organization (example: AIDS Committee of Toronto)
   □ Community Centre (example: The 519 Church Street Community Centre)
   □ Religious Institution (examples: church, mosque, synagogue, temple, etc.)
   □ Social Worker in private practice
   □ Counsellor/Therapist in private practice
   □ Psychiatrist/Psychologist
   □ None of the above
   □ Other (please specify) ________________________________

3. How did you get connected to professional social supports around living with HIV?
   (please check all that apply)
   □ Physician Referral
   □ Community Referral
   □ Self Referral (i.e. internet search, word of mouth)
   □ Other (please specify) ________________________________
   □ I do not access professional social supports around living with HIV

4. What type of professional social supports around living with HIV have you accessed?
   (please check all that apply)
   □ Individual in-person (i.e. one-on-one)
   □ Support/Therapy Group in-person
   □ Individual online (example: cyber counselling)
   □ Support/Therapy Group online
   □ Other (please specify) ________________________________

5. Is there anything that has made it difficult for you to access professional social supports around living with HIV? (please check all that apply)
   □ Cost for transit
   □ Services are not offered in my preferred language
   □ Accessibility issues (eg. wheelchair)
   □ Health challenges
   □ Confidentiality concerns
   □ Time of day that services are offered
   □ Child care/Child minding needs
   □ Waitlist to access services
   □ Other (please specify) ________________________________

6. When you access support, do you talk about brain health with your service provider?
   □ Yes    □ No
If yes, has your service provider referred you to HAND screening/testing?
☐ Yes  ☐ No

7. Have you ever tried to get help about brain health and been unable to?
☐ Yes  ☐ No

If yes, please explain:

8. Overall, has the support you have received been helpful for you?
☐ Yes  ☐ No

Comments?

Gaps in Programs and Services for HIV and Brain Health:

1. What types of support and/or specific programs and services would you like to receive regarding HIV and Brain Health from AIDS Service Organizations? (example: AIDS Committee of Toronto)

2. What types of support and/or specific programs and services would you like to receive regarding HIV and Brain Health from Social Workers?

3. What types of support and/or specific programs and services would you like to receive regarding HIV and Brain Health from hospitals?

4. Do you feel that the above-mentioned organizations adequately support your concerns regarding HIV and Brain Health? Please explain.

5. Is there anything else you’d like to share with us?
Thank you for completing the HIV and Brain Health Survey.

Would you like to participate in a one-on-one qualitative interview, to tell us more about your experiences and concerns related to HIV and brain health? If so, please provide your contact information below. Your contact information cannot be connected to your survey answers, which are anonymous and confidential. Please detach this page and place in the box labeled “Contact Information”. Please place the completed survey in the separate box labeled “Completed Surveys”. Compensation will be provided for your time during the interview. Interviews will be scheduled and conducted in Fall 2015 (October/November)

Name: ____________________________________________

Phone Number: __________________________________

Can we leave a voicemail?  ☐Yes  ☐No

Email: ____________________________________________

Address:
________________________________________________________________________________________
____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

Thank You
Appendix 5: Qualitative Interview Questions

Exploring the role of Social Work in supporting people affected by HIV-Associated Neurocognitive Disorder (HAND)

Qualitative Interview Schedule

Participation in the Research Study

How did you find out about the HIV & Brain Health Survey, that you completed as the first stage of this research study?

Probe What interested you about the survey?

What issues did the survey raise for you, if any at all?

Probe How did you feel about the survey?

HIV and the Social Determinants of Health:

How has living with HIV affected your life?

Probes What major life events or big decisions have you navigated in living with HIV (examples: treatment, employment)? Can you say something about what it was like to have to make those decisions? Describe how you have engaged with your HIV care.

How has your experience living with HIV changed over time?

Probes How do you feel now compared to when you were first diagnosed? What has changed in your life with regards to living with HIV?

Can you talk a bit about how you experience your housing situation? (examples: house, apartment, etc.)

Probe What would you change about your living situation, if anything?

What has your experience been like with regards to smoking?

Probes Are you currently smoking or have you smoked in the past? What are the reasons behind your decisions regarding smoking?
How do you feel about the aging process?

**Probes** Do you experience any discomfort or anxiety? Are your feelings about aging connected to financial, emotional, and/or physical health concerns? If so, how so?

**Mental Health:**

What concerns do you have about your mental health or about managing stress, anxiety and depression, if any at all?

**Probe** Have you been assessed for a mental illness? What was that experience like?

How do your concerns about your brain health affect your overall mental health, if at all?

**Probes** How is your mood affected on a daily basis? Do you notice changes in your mood depending on certain thoughts/events/behaviours? How do you feel on a daily basis?

**Cognitive Health:**

What is it about your brain functioning that concerns you?

**Probes** How have you responded to each area of concern? Example: if the person replies “I’m concerned about my memory”, you could ask: How have you tried to improve your memory, if at all? How do you prioritize, plan, and/or make decisions about improving your memory, if at all?

How did you first identify a problem or concern about your brain health?

**Probes** Who do you talk to about your health and wellbeing? When did you become concerned about your brain health? Did you notice these changes on your own?

How have you tried to improve your memory, if at all?

**Probe** Do you have specific concerns about your brain health that you’re trying to work on? (examples: remembering the names of people you’ve just met, multitasking)

Who have you approached for support about your brain health?

**Probe** Examples: friends, family, social workers, doctors, etc.
How have you reacted or do you think you would react if someone challenged your memory of an event?

What have people’s reactions been when you’ve talked about your brain health?

Probes What would encourage you to talk to others about your brain health? How have these reactions affected you, if at all?

Have you considered exercise as a strategy for managing mental and cognitive health issues?

Probes What does exercise mean to you? How do your exercise, if at all?

HAND screening/testing:

What do you know about screening or testing for HIV-Associated Neurocognitive Disorders (HAND)?

Probes Has anyone ever mentioned HAND screening/testing to you? Have you ever seen a presentation or written material on HAND? Have you consulted a professional (example: neuropsychologist) about HAND?

If participant has been screened/tested for HAND: A) What was your screening/testing experience like?

Probes How were you referred? OR How did you find out about HAND screening/testing? Did you go back for your test results? How did it feel to receive feedback about your brain health? Did the screening/testing process raise your concerns, lower your concerns, or have no effect?

If participant has not been screened/tested for HAND: B) What has gotten in the way of getting screened/tested, if anything?

Probe How do you feel about the possibility of HAND screening/testing?

Role of Social Work & AIDS Service Organizations (ASO):

What kind of support have you received outside of the doctor’s office, with respect to living with HIV?

Probes Past and present supports (examples: ASO, social workers, peer support, friends, family, religious or faith-based, other organizations?) How have you felt about the support you’ve
received, past and present? Did the quality of support differ depending on whether the support was provided by ASO or non-ASO professionals? If so, how so?

Can you say something about how you think social workers can help that might be similar to different from other health professionals (examples: doctors, psychiatrists, psychologists)?

**Probes** How can social workers support people living with HIV who are concerned about their brain health? What has your experience been like accessing social workers? What supports do you access from social workers, if at all?

What do you think AIDS Service Organizations do? (examples: AIDS Committee of Toronto - ACT Toronto People with AIDS Foundation – PWA)

**Probes** What ASO’s have you accessed? What services have you accessed from those ASO’s?
Appendix 6: Consent Form

Exploring the Role of Social Work in Supporting People Affected by HIV-Associated Neurocognitive Disorder (HAND)

Consent to Participate in a Research Study

Project Team
Andrew Eaton (AIDS Committee of Toronto) 416-340-8484 ext. 283
Jocelyn Watchorn (AIDS Committee of Toronto) 416-340-8484 ext. 248
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Robert Wallace (Community Member) 416-340-8484 ext. 407
Chantal Mukandoli (Community Member) 416-340-8484 ext. 407
David McClure (Community Member) 416-340-8484 ext. 407

You are consenting to participate in a research study that will gather information about the support service needs of older adults living with HIV/AIDS who are concerned about cognitive health, i.e. are affected by HIV-Associated Neurocognitive Disorder (HAND). There are two groups of people involved in this study: the research team members and the project participants.

As a project participant, your participation will involve:
- Completing an hour-long qualitative interview to discuss your lived experience with HIV and what support services you would like to have provided to you by social workers

Where will my information be kept?
Paper copies of any notes taken throughout this project and the questionnaires will be stored in a locked cabinet at ACT. Consent forms will be stored in a separate locked cabinet at ACT, away from research data. Digital files of the audio-recorded interview and will be saved as encrypted files on password protected computers at ACT. The audio-recorded interviews will be transcribed by Transcript Divas Canada, an external transcription company. All other documents and digital files will be accessible only to the research team.

Any paper notes or questionnaires will be stored for about a year (the length of the research project), at which point they will be shredded. Digital files as well as the consent forms will be stored for 7 years, and will then be destroyed (deleted or shredded). The interview recordings will be destroyed (i.e. permanently deleted) immediately after they have been transcribed and the transcription has been verified as correct.

Confidentiality
We will not disclose any information that can be used to identify you. You will not be identified by name in any documents related to this research, and any identifying information you provide will be deleted or changed in order to protect your identity.

Potential Benefits of the Research
You will have the opportunity to participate in a research study to address a gap in service. Findings from this research may be helpful in developing or improving programs and services for people living with and affected by HIV.

Potential Risks or Discomforts
You will be meeting face-to-face and sharing information and experiences during the interview. The
interviewer and all members of the research team have signed binding confidentiality agreements. The interviewer and all members of the research team do have a duty to break confidentiality in the following circumstances: 1) when there is an immediate risk of harm to yourself or others; 2) when required by law (subpoena); 3) when there is abuse, harm or neglect to a child under the age of 16, as outlined in the Child and Family Services Act; and 4) when you report abuse by a regulated healthcare professional. Research team members will have a duty to report if such information is shared by research participants during the course of your involvement in the project.

During the interview, you may be triggered or made upset by some of the topics that are discussed. If this happens, please let the interviewer or another member of the research team know. Counselling support will available to you should you require it.

**How will I learn about the study results?**

This project will be completed by Winter 2016. Results from the project will be written up in and be available publically on the ACT website, or by request at the ACT offices, beginning in Spring 2016. You have the option of providing your contact information to personally receive the findings of this project. Research team members will also present the findings at appropriate conferences and community forums.

**Payment for participation**

You will receive honoraria to compensate you for your time according to the following schedule:

- $30 for completing the one-hour interview

You will also receive 2 TTC tokens for completing the interview.

**Participation and Withdrawal from the Research**

You can choose whether or not to participate in this project. Participants are free to withdraw from the project at any time.

There will be no penalty if you choose to withdraw. Information that you shared during the course of the project can be removed from the research data.

**Rights of Project Participants**

If you have any questions regarding your rights as a project participant, please contact the Office of Research Ethics at the University of Toronto at ethics.review@utoronto.ca or phone 416-946-3273.

I understand the information provided to me for the project titled *Exploring the Role of Social Work in Supporting People Affected by HIV-Associated Neurocognitive Disorder (HAND)*. My questions have been answered to my satisfaction and I agree to participate in this project. I have been offered a copy of this form.

Participant signature                                                                 Date

Signature of research team member                                                                 Date

☐ Participant accepted and received a copy of the signed consent form
☐ Participant did not accept a copy of the signed consent form.
Diagnosed with HAND? What to do?
Antiretroviral therapy is the most effective known treatment for HAND (HIV-Associated Neurocognitive Disorder). Starting treatment early and choosing HIV treatments that are good at controlling the virus (getting it undetectable and increasing your CD4) can help to address HAND. Your doctor will help you decide which treatment is right for you.

It’s also important to diagnose and treat any other conditions that affect memory, attention, and thinking, such as anxiety, depression or substance use.

Will I still be able to work if I have HAND?
Your ability to work will depend on the types of cognitive impairments you have and the demands of your job. It’s easier to compensate for some impairments than others, and employers may be able to modify tasks to make them more manageable. Talk to your doctor and your employer.

Good for the heart? Good for the brain.
Exercise, healthy eating, getting a good sleep, and managing stress with activities such as meditation or yoga are just a few examples of everyday activities that can improve your memory, thinking, and brain health.

10 Ways to Stay Sharp
1. Write down “to-do” items in a notebook or on sticky notes.
2. Keep an electronic calendar, diary planner or wall calendar and set reminders.
3. Break down large tasks into a series of smaller tasks and tackle one task at a time.
4. Minimize interruptions and distractions (e.g., multi-tasking; loud TV in the background).
5. Take frequent breaks.
6. Organize and de-clutter your home or workspace.
7. Develop a routine for meals, medication, exercise, etc.
8. Increase your fitness (e.g., exercise more within your abilities).
9. Decrease your stress (e.g., practice yoga or meditation at a community centre).
10. Identify someone in your life who can help you to remember special dates and appointments.

Resources
For information about HIV and HAND:
Canadian AIDS Treatment Information Exchange (CATIE)
http://www.catie.ca/
fact-sheets/other-health-conditions/hiv-aids-brain

A Mind of Her Own
Long-term survivor Maggie Atkinson adds cognitive problems to her list of HIV-related issues. Here she takes a walk down memory lane and shares what she’s learned about protecting her brain.
http://www.aids2000.ca/
postmarket/winter-2000/mind-her-own

For information about the HEADS UP Study:
http://www.
endneuropathology.ca/brain-heart

For further information:
HIV Neurobehavioral Research Centre (U.S.)
https://hivneuroresearch.ucsf.edu

For general information about HIV, contact your local AIDS service organization:
https://aids.org

Always talk to your physician and other health care providers.

ATTENTION: MEMORY, WORD-FINDING THINGS TO KEEP IN MIND WHEN LIVING WITH HIV AND CHANGES IN COGNITION

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HIV and Your Brain

Good brain health helps us process words and tasks efficiently, feel sharp-minded, be good problem-solvers, pay attention to people and things we value, and remember important names and dates.

HIV can affect the brain and have a negative impact on cognition, which is the ability to focus on tasks, remember names and events, and think as fast as we can when making choices. The virus can cause HIV-Associated Neurocognitive Disorder or HAND, which slows cognition, making it harder to pay attention, find words or remember things.

About 30-50% of people with HIV will experience cognitive changes over their lifetime. Now that most people with HIV are taking highly active antiretroviral therapy, most will develop one of the rarer forms of HAND. Before antiretroviral therapy, more people developed more severe forms of dementia but that is not very rare.

What are the symptoms and signs of HAND?

HAND causes problems with attention, thinking or remembering that can interfere with daily tasks and responsibilities. Symptoms and signs can include:

- New problems with attention or concentrating (e.g., when reading or watching a movie)
- More struggles learning new skills (e.g., a new computer program at work)
- Increased forgetfulness (e.g., trouble remembering appointments or to take medication)
- Increased trouble planning and organizing events, tasks (e.g., difficulty managing finances, organizing meals)
- Trouble finding the right words when speaking or writing
- Slowed thinking and slowed reaction time
- "Foggy" confusion or trouble thinking clearly

These symptoms and signs can also be particular concerns if they are new or seem to be getting worse over time.

How is HAND diagnosed?

Because the effects of HAND are slowly felt, they can go undetected. Doctors and other HIV care providers may not always ask people living with HIV about issues with memory, thinking and attention. However, it is important to detect HAND as early as possible, so an effective support and treatment plan can be developed. If you are concerned that HIV may be affecting your brain, let a good idea to mention any symptoms to your healthcare provider.

The best way to get screened and assessed for HAND in Canada is to be referred to a clinical neuropsychologist or other health professionals with training in neuropsychological assessment and knowledge of HAND. Diagnosing HAND involves administering a series of questions and psychological tests that assess processing speed, thinking, attention and memory. Before diagnosing HAND, it is important to rule out other causes of difficulties with memory, attention and thinking such as depression, substance use or normal aging.