

HIV, Aging and Cognition: Implications for Social Workers and Social Service Workers

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HIV, Aging and Cognition

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Based on the findings of *Exploring the role of social work in supporting people affected by HIV-Associated Neurocognitive Disorder (HAND)*.

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Agenda

1. Background
2. Methods
3. Results
4. Discussion
5. Interaction!



Background

What is HIV-Associated Neurocognitive Disorder (HAND)?

HAND is defined as neurological disorders that cause cognitive impairment.

HAND is classified in three forms:

1. Asymptomatic Neurocognitive Impairment (ANI)
2. Mild Neurocognitive Disorder (MND)
3. HIV-Associated Dementia (HAD)



Background

- 75,000 Canadians living with HIV (Challacombe, 2014)
- Most aged 30+ and increasingly 40+ and 50+ (PHAC, 2013)
- 30-50% will be affected by HAND (St. Michael's Hospital, 2013)
- HIV enters nervous system within 1 year (Spudich, 2013)
- HIV medications can slow HAND (Grant et al, 2014)
- HAND causes anxiety, adherence challenges, stigma and isolation (Atkinson, 2010; Vance and Struzick, 2007)



Background

- Education & literacy impact HAND severity (Ryan et al, 2005)
- Housing & employment impact self, HAND severity, and medication adherence (Fazeli et al, 2013; Kidder et al, 2015; Trujillo, 2010)
- Other physical & mental health issues and substance use impact HAND severity (Fazeli et al, 2013)
- Active lifestyle & social support increases cognitive reserve (Fazeli et al, 2013)
- Increasing cognitive reserve slows cognitive aging and reduces dementia risk (Fazeli et al, 2013; Stern, 2013)



Background

- Absence of research literature concerning role of social work and social service work in supporting people affected by HAND
- Social workers, social service workers, and community-based HIV organizations (CBOs or ASOs) can help people living with HIV identify ways to increase their cognitive reserve, develop coping strategies for everyday life, and be a consistent contact for follow-up about brain health concerns. Such support could reduce anxiety, stigma, and isolation while increasing the overall health of people affected by HAND.



Methods

- Explanatory sequential mixed-methods design
- Informed by participatory action research (PAR)
- Peer researchers as equitable team members
- Purposive sampling + snowball sampling
- Phase one: Survey (n=108)
 - Data analysis: Descriptive statistics
- Phase two: Interviews (n=20)
 - Data analysis: Manifest and latent coding with three coders and a collaborative, iterative process to determine findings

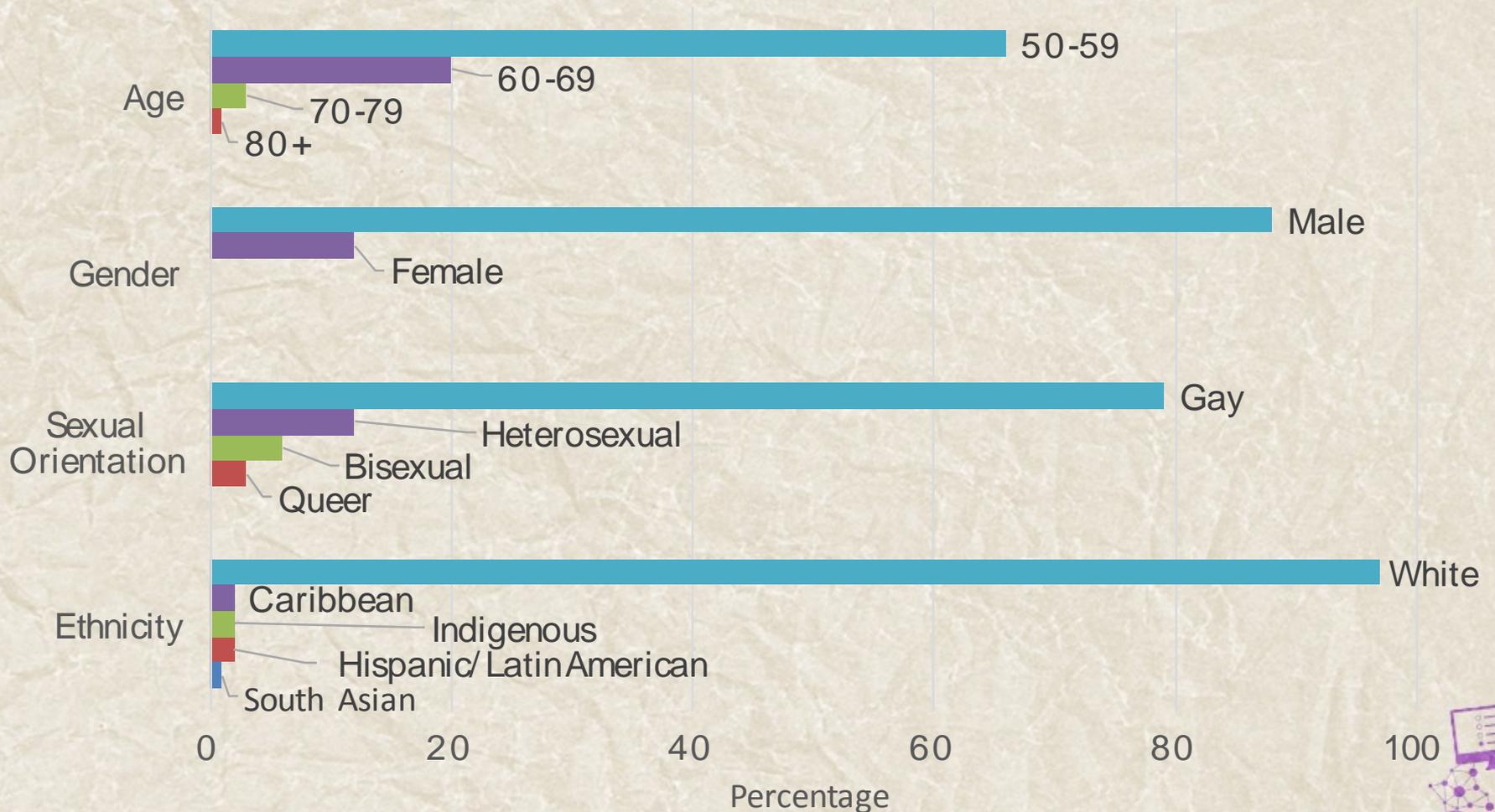


Research Questions

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?



Results: Participants



Results: Brain Health Concerns

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



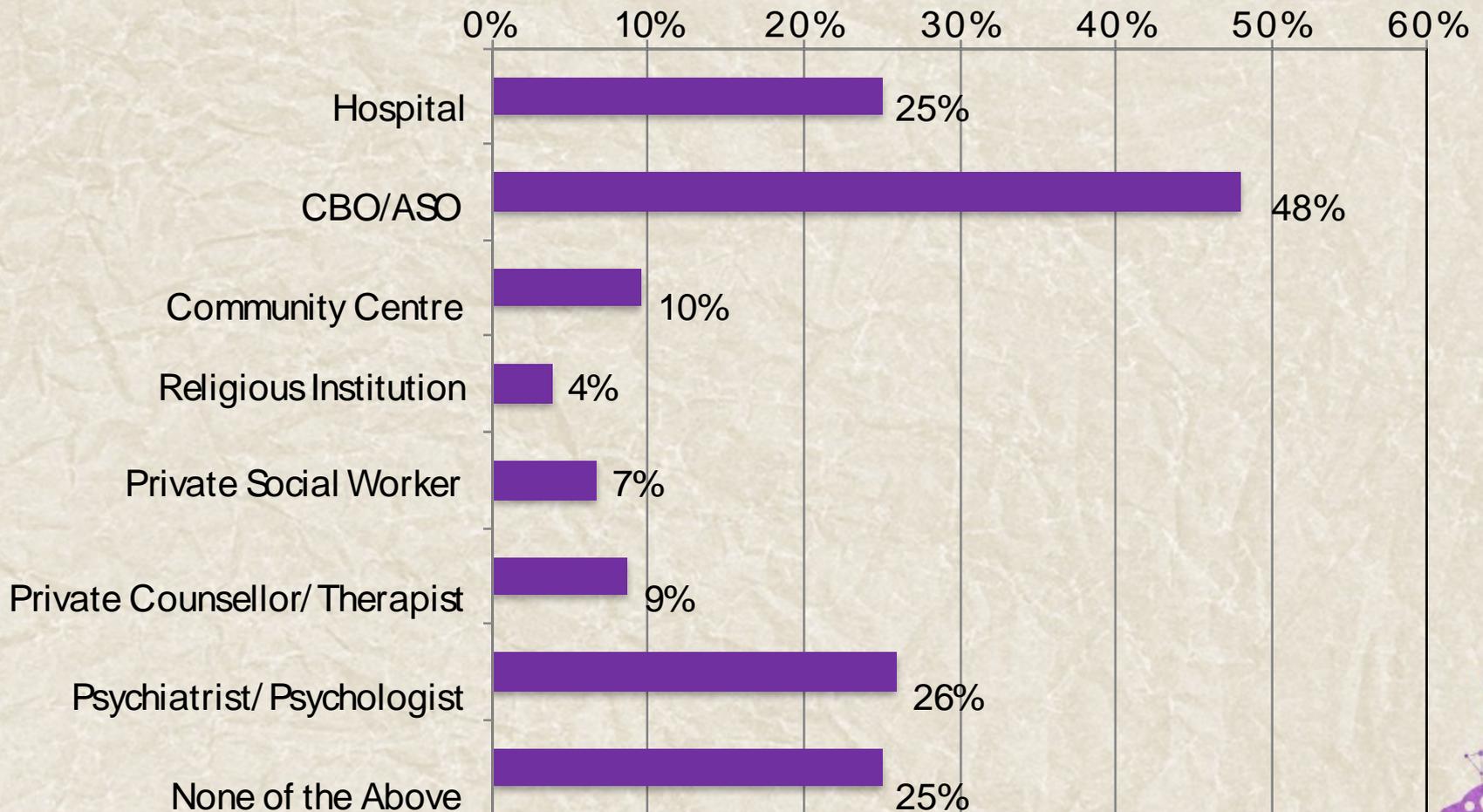
Results: Brain Health Concerns

Table 1			
Factors impacting brain health			
Question	Yes	No	Unknown
Do you exercise regularly?	54.7%	45.3%	N/A
Do you smoke cigarettes?	27.1%	72.9%	N/A
Do you use substances that could impact your brain health? (e.g. alcohol, cocaine, crystal meth, injection drugs, marijuana)	51.4%	47.7%	0.9%
Are you currently experiencing mental health concerns? (e.g. anxiety, unmanageable stress, depression)	53.8%	38.7%	7.5%
Have you ever been diagnosed with a mental health issue that could impact brain health? (e.g. depression, bipolar)	53.8%	43.4%	2.8%
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)	30.8%	61.5%	7.7%



Results: Current Supports

Where do participants access HIV-specific supports?



Results: Current Supports

1. Do survey respondents talk about brain health with service providers?
 - 46% yes; 54% no
2. If yes, have respondents been referred for HAND screening?
 - 31.8% yes; 68.2% no
3. Have respondents ever tried to get brain health help and been unable to?
 - 82.8% no; 17.2% yes



Results: Role of SW & SSW

Table 2

Can CBOs/ASOs, hospitals, and social workers provide support for HIV and brain health?

Question	Yes	No	Unknown
Can CBOs/ASOs support you? (n=63)	79.4%	12.7%	7.9%
Can hospitals support you? (n=52)	73.1%	11.5%	15.4%
Can social workers support you? (n=52)	69.2%	15.4%	15.4%



Results: Role of SW & SSW

“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 towardsthe 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).



Results: Role of SW & SSW

“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.” (S10 6, 50-59 years old, male, white/eastern European).



Results: Role of SW & SSW

“Do social workers take care of this and everything else? Really? I would prefer someone not to raise my expectations” (S0 0 8, 50 -59 years old, male, Hispanic/Latin American)

“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.” (S0 18, 60 -69 years old, male, white/western European)



Results: Role of SW & SSW

“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).



Social determinants of health associated with greater cognitive reserves: many are within an individual's control

- Social supports which can provide an antidote to real and perceived stigma
- Management of mental health issues such as chronic stress, anxiety and depression
- Literacy and educational levels
- Adult occupation
- Life style issues such as exercise
- Housing –people in better housing are more medication compliant



Our study findings show that clients are motivated:

- 54.7% exercise
- 48.6% get support from family and friends
- 24.8% get support from partners/spouse
- 24.8% get support from family
- 72.9% are non-smokers



The flip side..There are some BUTS:

- 43.5% do not exercise
- 51.4% do not get support from friends
- 75.2% do not get support from family
- 24.8% get support from a partner or spouse which may indicate the number who are single
- While just under 60% worry about their cognitive health, only 46% talk to their service providers and only 31.8% of these were referred for testing. This may also reflect resourcing issues outside of Toronto



Themes from the qualitative data

- Participants struggled to separate what is HAND and what is a normal part of the aging process
 - Impact:
 - Fear and uncertainty about the future, particularly anxiety over what is a symptom to worry about and what is not
- Participants are resilient, independent and cope, but often at a cost
 - A common sense of being on their own to deal with:
 - Anxiety
 - Depression
 - Participants often struggled alone with their fears rather than reach out for support
 - Fear of aging alone



Themes

- Knowledge reduces anxiety and stress. Those who discussed brain health concerns experienced less anxiety and stress about the future
- The role of Social Workers and Social Service Workers was not well understood and many did not know their service provider's professional identity. However, for those who did, social workers were seen as:
 - “Meat and potatoes” i.e. brokers between clients and resources
 - Holistic in their approach
 - Knowledgeable about interpersonal dynamics



Implications for practice

- Social Workers and Social Service Workers carry many roles:
 - Counsellors
 - Case managers and service brokers
 - Educators
 - Advocates
- Given that many do not understand the roles of Social Workers and Social Service Workers, it is important that we educate our clients about what we do and how we can help them
- Dimensions of practice impacting on reduction of barriers and engaging clients in service:
 - Practical assistance
 - Clinical and counselling



Operate from within an anti-oppression framework

- Recognize the ways in which clients are marginalized and support their empowerment. Oppression operates both systemically and at the psychological level. Reducing barriers and enhancing access requires that we apply this framework at both the social and the psychological levels. It applies as much to the removal of barriers at the practical level of case management as to the ways we engage clients who are struggling on a psychological level



Practical skills

- Knowledge of community resources particularly with respect to social determinants of health is key given their relationship with cognitive health
 - Housing
 - Income supports
 - Social and group programs which can reduce isolation and counter the sense of being alone
 - Mental health services
 - Employment opportunities, both paid and unpaid
- Advocacy skills designed to help clients navigate complex systems associated with all of these determinants of health
- Advocacy regarding the need for services aimed at supporting the cognitive reserve. In this way, advocacy is key to the facilitation of service access



Clinical issues: strategies for engagement

- Qualitative data shows that clients who talk about their brain health concerns feel better than those who don't. Quantitative data shows that clients may well not raise these issues with their service providers. It is therefore important to be comfortable raising these issues with clients. It is also critical to be knowledgeable about HIV brain health and resources to:
 - Recognize (not diagnose) possible manifestations of HAND
 - Normalize client fears
 - Provide appropriate education about brain health issues
 - Increase the likelihood that clients will access testing where possible
 - Access and/or help clients access other resources in the community and online e.g. brain fitness programs



Clinical issues: strategies for engagement

- Maintaining a balance between supporting client independence and resolve while encouraging the possibility of exploring more relational coping strategies is critical. Clients very often struggle on their own, but we know those who are less isolated have better outcomes. This may involve teaching clients social skills, assertiveness and exploring obstacles to reaching out
- A characteristic impact of social stigmatization and isolation is shame. It is the psychological mechanism of oppression. Learning to recognize and respond to it is crucial in responding to issues related to depression and social isolation in particular. Shame may well be a factor in preventing clients from talking to their care providers and familial/support networks. Shame acts as a barrier to accessing services. Reducing shame enhances the capacity to access them.



Signs and symptoms of shame

- Self-blame narratives
- Self-talk organized around themes of not mattering, being alone or inversely, intense anger and defensiveness at not feeling valued
- Clients paralysed by shame and the effects of stigmatization are often unable to access service: it becomes a critical barrier



Helping clients deal with shame

- Strategies for helping clients deal with shame include:
 - Using the therapeutic alliance to engender a felt sense of safety
 - Normalizing the experience of shame as a response to stigma
 - Supporting self-advocacy and social action as coping responses to stigma
 - Identifying the signs that clients may be in a shame state e.g. narrative themes, posture and responding with empathy
 - Helping clients recognize when they are feeling shame and helping clients develop strategies (e.g. mindfulness) which are useful in learning to identify shame triggers as well as the self talk/scripts (“nobody cares about me,” “I don’t matter to people,” “I’m on my own”) and cognitive distortions associated with shame (e.g. generalizations, all or nothing thinking)



Helping clients deal with shame

- Teaching self-compassion, self care and self soothing strategies
- Teaching interpersonal skills around eliciting support
- For those who experience shame through protective anger, try to explore underlying feelings and teach alternative ways of navigating them. Confrontation is not helpful



Helping clients learn strategies of emotional regulation

- Supporting clients in the exploration of their fears about their cognitive health, about the future, about aging and aging alone without undermining their ability to manage on their own. Involves teaching clients the skills of emotional self-management to facilitate taking action
- Related skills:
 - Recognizing when a client is either overwhelmed by negative emotion or shut down emotionally. In either case, higher cognitive functions are offline and clients need to be brought back into awareness of sensory information about what is happening in the moment
 - Titrating emotional arousal as difficult emotions such as fear and shame are explored – knowing when to explore and when to back away from intense emotion
 - Teaching the same emotional management strategies useful in working with shame i.e. grounding techniques, mindfulness practice, self talk
 - Encouraging clients to explore accessing more interpersonal avenues of support through MI techniques, coaching



Summary

Social Workers and Social Service Workers can reduce barriers to service by:

1. Helping clients better understand the multiple roles social workers and social service workers carry and the ways they can help them access services
2. Understanding the client's experience, particularly the ways in which marginalization create both internal and external barriers to accessing service
3. Using knowledge of the client's experience to help them overcome the shaming effects of stigmatization and the experience of fear so that they can better challenge the barriers confronting them. This is key to enhancing access
4. Utilizing the therapeutic alliance to refer to and follow-up about HAND testing



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