A qualitative study of the lived experience of HIV-associated neurocognitive disorder HAND
HEADS UP!

• **Background**: HIV-associated neurocognitive disorder (HAND) is common, but the lived experience of HAND is not well-understood.

• **Objectives**: to describe the lived experience of living with HAND; how adults with HAND view, manage, and obtain support for cognitive difficulties.

• **Methods and Activities**: Mixed neuropsychological screening and semi-structured interviews of 25 participants, co-developed with community members living with HIV.
Analysis and Results:

• We analyzed interview transcripts using a team-based, thematic approach (across provinces to avoid residual disclosure).
• Peer Researchers participated in analysis, interpretation and KTE
• Participants described concentration, memory, and multitasking difficulties that fluctuated over time, as well as potential risk factors, management strategies, and psychosocial consequences.
• Participants reported seldom discussing cognitive impairment with health care professionals, HR, and others, receiving a HAND diagnosis was validating, informative, yet somewhat disconcerting.
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• Knowledge, Transfer and Exchange: 2 manuscripts (one in preparation), 2 conference posters, 2 clinical brochures prepared by patients now in use in Toronto, Vancouver (Brighton, Sussex, UK clinic), catalyst for two sister projects at CAMH and ACT, 1 operating grant in preparation for the CIHR CBR Fall competition.

Tips for Healthcare Providers

1. Recognize that HIV-associated neurocognitive disorder (HAND) affects memory, attention, and other thinking skills.

2. Help your patients understand that HAND is linked to behaviors such as missing appointments, forgetting doses of medication, forgetting names, etc.

3. Clarify the distinction between HAND and dementia (e.g., Alzheimer’s disease) with your patients in order to help alleviate anxiety and uncertainty about possible having dementia.

4. Use complaints of memory, attention, and other thinking difficulties (e.g., missed appointments and medication doses, word-finding difficulties, attention lapses) as conversation starters about HIV and brain health/HAND.

5. Recognize that patients living with HIV employ both adaptive (e.g., focusing on one task at a time) and maladaptive (e.g., use of substances) strategies to cope with cognitive difficulties, and empower patients to choose more adaptive options.

6. Work in partnership with patients to identify cognitive challenges and potential coping or management strategies—they will likely be more effective the more specific they are (e.g., working out a specific strategy to remind patients to take medications such as keeping them medications on the kitchen table or writing a reminder note on the bathroom mirror rather than just suggesting patients use memory reminders).

7. Help patients identify solutions tailored to their strengths; the tech-savvy might want to use electronic reminders, alarms, and calendars; visual learners might want to use large paper calendars in a central location such as the fridge for appointments and reminders.

8. Connect and refer patients with cognitive difficulties to rehabilitation programs (e.g., occupational therapy) in public health and community-based programs.

9. Emphasize the importance of healthy living: reducing substance use, eating a nutritious diet, getting adequate sleep, keeping regular sleeping patterns, and engaging in regular exercise tailored to their abilities and financial means.

10. Help patients with cognitive difficulties by optimizing reminders within your practice (e.g., setting phone or email reminders for appointments, providing handouts of important information, having large font plain language forms/information brochures).

11. Recognize that having cognitive symptoms can be very distressing and it may be important to assess for related mood and anxiety symptoms.

Resources

For information about HIV and HAND:

Canadian AIDS Treatment Information Exchange (CATIE)
http://www.catie.ca/fact-sheets/other-health-conditions/hiv-and-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.

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

For further information:

HIV neurobehavioral Research Centre (U.S.)
https://hnrc.hivresearch.ucsd.edu

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

Always talk to your physician and other health care providers!

Tips to keep in mind
HIV-associated neurocognitive disorder

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