

# HEADSUP!

## HEADS UP! Results of a qualitative study of the lived experience of HIV-associated neurocognitive disorder

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### BACKGROUND

Little is known about how individuals with HIV-associated neurocognitive disorder (HAND) view, cope with, and manage changes in memory, attention and thinking.

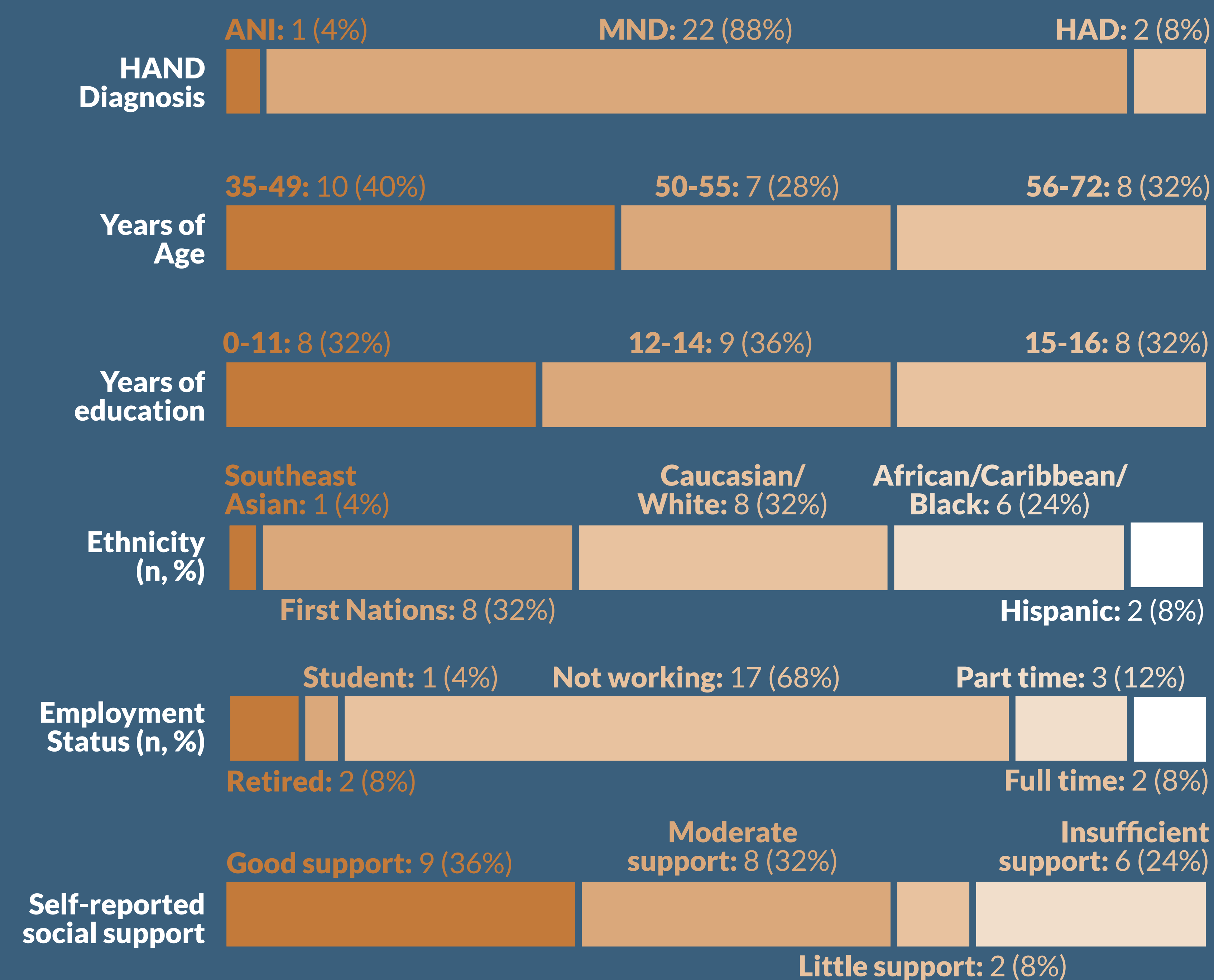
### PURPOSE

To explore the experience of HAND among those who receive HIV care and support services at Casey House, St. Michael's Hospital (Toronto) and The Dr. Peter Centre (Vancouver), including the trajectory and consequences of HAND as well as coping strategies.

### METHODS

**Study design.** We conducted a cross-sectional qualitative study using face-to-face interviews to explore the experience of living with HAND.

**Participants and procedures.** Twenty-five adults received neuropsychological testing for HAND and participated in a feedback session with a Clinical Neuropsychologist before participating in a 1.5-hour semi-structured interview about the lived experience of HAND.



**Interview schedule.** Questions prepared by study investigators and trained peer researchers focused on: (1) the trajectory of HAND; (2) HAND's effects on self-confidence, mood and resilience; and (3) the role of HAND in interactions with friends, family and healthcare providers.

**Analysis.** Transcribed interviews were coded and summarized by teams of at least two, including peer researchers.

### RESULTS

The themes derived from HEADS UP! interviews included (1) the lived experience and emotional impact of cognitive impairment, (2) strategies used to cope with cognitive impairment, (3) outcomes of the HAND assessment de-briefing with a clinical neuropsychologist, and (4) interactions with healthcare providers and caregivers about HAND.

Participants described experiencing confusion, anxiety and frustration as a result of their cognitive impairment, as well as fear of losing their identity and living with the stigma of cognitive challenges added to HIV.

Other consequences of HAND included material losses (e.g., misplaced cheques), missed appointments, and medication dosage errors or misses.

Participants reported a wide range of HAND-related strategies, including de-cluttering one's space, seeking memory-aid support from friends and healthcare providers about appointments or personal memories, and long-term use of substances to increase attention or achieve forgetfulness.

Strategies for managing cognitive impairment varied according to participants' strengths; those who were tech-savvy used technology for reminders, alarms, appointments, and important dates.

Visual learners kept reminders and appointments on bulletin boards and/or large calendars. Participants described helpful in-the-moment tactics such as "laughing it off" (using humour to cover/dismiss symptoms).

When speaking about the HAND assessment feedback session with a clinical neuropsychologist, many participants expressed relief at not having severe cognitive impairment and/or a neurological condition such as Alzheimer's disease or other dementia. However, participants expressed uncertainty about the future regarding the progression/prognosis of their cognitive impairment and what supports will be needed.

Participants reported that their greatest supports were healthcare providers and intimate partners (although families could be harsh on participants' forgetfulness or lack of attention and sharpness) and yet they reported having few explicit conversations about their cognitive functioning as a potential HIV symptom. With regard to health systems, there were systemic gaps in patient-support reported by participants, such as healthcare providers/their administrative support not calling to remind participants about important appointments.

### DISCUSSION

Our results greatly enrich the current clinical literature, which predominantly focuses on the psychometric measurement of HAND presented in the clinical literature. These results can help bring awareness of HAND into healthcare interactions: people living with HIV or healthcare providers can use examples of tactics and strategies to start conversations about HAND. Key messages about living with HAND should be tailored to specific audiences, including tips for both healthcare providers and people living with HIV.

**COI Disclosure:** I have no conflicts of interest.

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