

# Healthcare Workers' Perspectives on the Utilization of the International HIV Dementia Scale for the Screening HIV-Associated Neurocognitive Disorders: A Qualitative Study at TASO Centres in Central and Southwestern Uganda

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**Introduction:** HIV-associated neurocognitive disorders (HAND) are becoming a significant public health concern in the continuum of human immune virus (HIV) treatment. These disorders range from subtle cognitive impairments to severe dementia. Despite many early-stage HAND cases being asymptomatic, healthcare workers (HCWs) rarely perform routine neurocognitive assessments. This leads to a high number of unrecognized cases and increases the risk of HAND among people living with HIV (PLWH).

**Material and Methods:** We aimed to explore HCWs' perspectives on integrating the International HIV Dementia Scale (IHDS) into routine care for screening HAND at The AIDS Support Organization (TASO) centres in central and southwestern Uganda.

**Results:** We conducted five focus group discussions with 37 HCWs from five TASO centres. Thematic analysis revealed eight key themes: 1) Impaired brain function, 2) Changes in activities of daily living, 3) Promotion of quality care perspectives, 4) Tool applicable and user-friendly, 5) Client increased self-awareness and self-confidence, 6) Integration of IHDS into routine HIV care, 7) Uncertainty about IHDS use, and 8) Continuous training for HCWs.

**Conclusion:** As PLWH enjoy longer and healthier lives, their risk for HAND increases, potentially affecting their quality of life. The use of the IHDS has raised awareness among HCWs and improved decision-making through cognitive assessments, emphasizing its value in PLWH. We recommend a prospective study to assess the long-term outcomes and efficacy of increased HAND screening. Furthermore, integrating a HAND screening module into the consolidated HIV guidelines is recommended to enhance its relevance.

**Keywords:** healthcare workers, HIV associated neurocognitive disorders, international HIV dementia scale, screening

## Introduction

The introduction of antiretroviral therapy (ART) marked a transformative moment in the perception of HIV/AIDS. It transformed the disease from a once fatal condition into a manageable long-term condition for many people living with HIV (PLWH).<sup>1</sup> While there has been extensive research on the impact of HIV on the brain and its consequence for neurological function<sup>2-5</sup> there remain significant challenges in translating these research findings into clinical practice.<sup>6</sup>

The availability of ART in the mid-1990s had a significant influence on HIV treatment, but its impact on preventing HIV-associated neurocognitive disorder remains unclear.<sup>7</sup> The persistent nature of HAND continues to make it a significant public health concern for PLWH despite the era of effective ART.<sup>8,9</sup>

As the lifespan of PLWH increases and they grow older, it is probable that the prevalence of cognitive difficulties will increase in the future.<sup>10</sup> This may be attributed to the interactive effects of chronic immune activation and the aging process on the central nervous system (CNS).<sup>11</sup>

HIV-associated neurocognitive disorder is defined as a spectrum of neurocognitive dysfunction based on its severity.<sup>12</sup> It is classified into three categories: asymptomatic neurocognitive impairment (ANI), which does not disrupt daily functioning, mild neurocognitive disorder (MND), causing slight interference with daily activities, and HIV-associated dementia (HAD), marked by substantial functional impairment.<sup>13</sup> The effects of HAND predominantly impacts cognitive functions including, memory, learning, complex attention, information processing, and executive functioning.<sup>14</sup> The spectrum of cognitive impairment can vary from minor difficulties to significant disruptions that affect daily functioning, mental well-being, and overall quality of life.<sup>4,12</sup> Studies indicate that a substantial portion of PLWH may experience a degree of neurocognitive decline at some point in their lives, with estimated prevalence rates ranging from 30% to 50%.<sup>13,15</sup> This could have significant implications for various aspects of life including engagement in daily activities, employment opportunities, and overall quality of life.<sup>16</sup>

Given the increasing life expectancies of PLWH,<sup>11</sup> it is realistic to receive appropriate services and support to manage the effects and repercussions of HAND on their daily functioning. Early detection of HAND is crucial worldwide, yet challenging due to lack of screening tools in clinical settings.<sup>17</sup> Sub-Saharan Africa, including Uganda, accounts for approximately 70% of the global HIV+ population, where HAND often remains undiagnosed due to inadequate assessments.<sup>6,18</sup> Therefore, screening using the International HIV Dementia Scale (IHDS), a tool developed and validated in urban Uganda is crucial.<sup>19</sup> The IHDS assesses memory recall, motor skills, and psychomotor speed.<sup>6,19</sup> Its culturally neutral design, enables an unbiased assessment of HAND across different communities distinguishing it from other neurocognitive assessments that may be affected by language and cultural nuances. This characteristic renders it a particularly useful tool in diverse settings. It has also been validated in different countries and languages<sup>19–21</sup> which underscores its exceptional utility. The IHDS is used in research globally,<sup>19,22</sup> due to its simplicity, which allows use by non-specialist staff in resource-limited countries like South Africa, Ethiopia, Nigeria, Malawi, and Kenya.<sup>17,23–26</sup> This indicates its effectiveness in identifying HAND across varied populations, regardless of geographic or urban disparities.

Nonetheless, the IHDS has limitations such as variability in sensitivity and specificity, and it does not detect all forms of neurocognitive impairments associated with HIV. Consequently, a comprehensive neuropsychological assessment is necessary for a definitive diagnosis as highlighted in some studies.<sup>15,27</sup> Previous studies on HAND screening have predominantly been conducted in research settings rather than clinical ones.<sup>7,13,18</sup> To address this discrepancy, our study sought to explore healthcare workers' perspectives regarding the utilization of the IHDS for routine HAND screening in HIV care settings.

## Materials and Methods

### Study Design

We conducted a descriptive qualitative study using Focus Group Discussions (FGDs) to gather in-depth insights into healthcare workers' perspectives on screening HAND with the International HIV Dementia Scale (IHDS). The discussions were guided by a focus group guide, allowing participants to openly and realistically express their opinions in a free-flowing conversation.

### Study Setting

The study was conducted at The AIDS Support Organization (TASO) centres located in central and southwestern Uganda. Established in 1987, TASO is Uganda's largest indigenous organization dedicated to providing comprehensive HIV/AIDS care and support for PLWH.<sup>28</sup> TASO supports the Ministry of Health by delivering a wide range of HIV/AIDS services national wide, including medical care, psychosocial support, and education on medication adherence, with particular focus on Antiretroviral Therapy (ART). To ensure a diverse representation of participants, we recruited participants from five different centres: Mbarara, Rukungiri, Entebbe, Mulago, and Masaka.

## Study Population and Sampling

The study included nurses, clinical officers, medical officers, and counselors, each playing a crucial role in the HIV care. Medical officers handle clinical and administrative tasks, clinical officers focus on patient care and refer cases, and nurses ensure patient safety and provide clinical support, while counselors offer emotional and psychological support and guidance.

At each centre, we selectively enrolled participants actively involved in client care, regardless of their specific roles, as all were trained in HAND screening using the IHDS and supported by the research team. We continued to enroll participants until no new information emerged from the discussions. Data saturation was achieved by the fifth focus group, aligning with Krueger<sup>29</sup> who suggested that three to six groups typically suffice to reach saturation.

## Ethical Consideration

The study was approved by ethics committees of Mbarara University of Science and Technology (MUST-REC) (Ref no. 27/10-16) and the National Council for Science and Technology (UNCST) (Ref no.HS2194). TASO's Institutional Review Board also granted permission, ensuring compliance with policies that protect participant rights and well-being. Procedures adhered to the 1964 Declaration of Helsinki guidelines. Participants gave written informed consent allowing for the anonymous reporting of their responses in the manuscript. Anonymity was maintained by using study identification numbers, storing consent forms separately, and securing all data with password protection.

## Data Collection Tools

We collected the socio-demographic data using a semi-structured questionnaire and conducted focus group discussions with open-ended questions. The focus group guide was developed by the author, informed by relevant literature and under the guidance of academic supervisors.

## Data Collection Procedure

We conducted five Focus Group Discussions (FGDs) between February and September 2021 across five different study sites with 37 participants, following the recommended group size of 6–8 by Krueger, Casey.<sup>29</sup> Medical coordinators at each site organized and coordinated all essential preparations and research assistants confirmed availability through phone calls prior to the sessions. The FGDs were held in English, lasted 60 to 90 minutes, and all participants provided written informed consent to join. Data collection was centered on the following key questions 1) could you please share your understanding of HIV-associated neurocognitive disorders? 2) Given the routine use of the International HIV Dementia Scale (IHDS) for screening HAND throughout this study period, what is your perception of this tool? 3) What are your thoughts on integrating this tool into routine HIV care for screening HAND? 4) What is your perspective on the feasibility of healthcare workers at TASO centres using IHDS to screen for HAND? 5) Could you share any additional knowledge or insights that might be important for us to understand before integrating HAND screening into routine HIV care?

During the data collection phase, evening debriefing meetings were conducted daily to assess data quality and resolve any issues, ensuring optimal data collection the next day. After obtaining written informed consent, focus group discussions were audio-recorded, with notes on nonverbal cues taken to augment the recordings. Participants' confidentiality was maintained using study identification numbers, and the discussions were held in secure rooms arranged by the medical coordinators at the TASO centres.

## Quality Control

The research assistants (RAs) were experienced in qualitative data collection and completed a five-day training program specific to this study, focusing on background knowledge, interviewing skills, and data probing to ensure data quality and credibility. We improved the credibility of our findings through prolonged focus group discussions that provided detailed data and deeper contextual understanding. Member checking verified data consistency and accuracy,<sup>30,31</sup> allowing participants to refine their responses. Cross-referencing preliminary findings with raw data furthered improved credibility.

Additionally, the researcher kept a reflexive journal documenting all research phases, maintaining objectivity and reducing bias to improve transparency and quality of the study.

The focus group guide was tested for clarity at the Immunosuppression Syndrome (ISS) Clinic, situated in a regional referral hospital in Mbarara district. The clinic has been operational with PEPFAR funding since 1998, serving as the hospital's outpatient HIV clinic and offering services similar to those at the study sites. Any issues or concerns that emerged during the pilot phase were thoroughly discussed and resolved before beginning data collection.

## Data Management and Analysis

Prior starting data analysis, we carefully reviewed the transcripts for accuracy. Detailed notes were typed after each interview to capture extensive content. For precise transcription, two transcriptionists were used, and both the author and academic supervisors confirmed the transcriptions' accuracy for analysis. The data were coded structurally and connected to the key questions using NVIVO 10.0. A code book was developed to cover all thematic areas from the interview guides and was checked for accuracy by team members. This was followed by generating coding reports for each code, which were used to create summaries that outlined the themes associated with each code. An independent researcher conducted the data analysis by reviewing audio recordings and corresponding transcripts, using the thematic analysis method as described by<sup>32</sup> This method was deemed most suitable for achieving the study objective due to its theoretical and epistemological flexibility. It allowed for the inclusion of various participant viewpoints concerning screening of HAND using IHDS. This approach facilitated the inclusion of diverse viewpoints on HAND screening with IHDS. During the familiarization phase, recurring themes were identified, coded, and analyzed to interpret emergent issues and derive insights that addressed the research questions.

## Results

### Sociodemographic Characteristics

Participant ages ranged from 20 to 55 years, with 1 to 25 years of experience in HIV-related work. Gender distribution was balanced at 49% male (n=18) and 51% female (n=19). Additionally, 62.2% were married, 44.5% had diplomas, and 37.8% were registered nurses. Detailed data is summarized in Table 1.

The analysis of participant responses generated eight themes concerning their understanding of HAND and their perception of using IHDS for HAND screening. We present our findings around these themes: Impaired brain function,

**Table 1** Demographic Characteristics

Variable	Frequency	Percentage
<b>Age in years</b>		
20–29	10	27.1
30–39	13	35.1
40–49	12	32.4
50–59	2	5.4
<b>Years of experience</b>		
1–4	13	35.1
5–9	7	18.9
10–14	8	21.6
15–19	7	18.9
20 and above	2	5.4

(Continued)

**Table 1** (Continued).

Variable	Frequency	Percentage
<b>Gender</b>		
Male	18	48.6
Female	19	51.4
<b>Marital status</b>		
Single	12	32.4
Married	23	62.2
Separated	2	5.4
<b>Qualifications</b>		
Certificate	5	13.6
Diploma	17	45.9
Degree	15	40.5
<b>Cadre</b>		
Enrolled Nurse	5	13.6
Registered Nurse	14	37.8
Clinical officer	4	10.8
Medical officer	3	8.1
Counselor	11	29.7

Change in activities of daily living, (3) Promotion of quality care perspectives, (4) Tool applicable and user-friendly, (5) Client increased self-awareness and self-confidence, (6) Integration of IHDS into routine HIV care, (7) Uncertainty about IHDS use, and Continuous training for healthcare workers.

To maintain the original context, we included representative quotes from participants to emphasize their responses. Each quote is marked with an FGD number, which specifies the study site, and a participant number to ensure anonymity. The FGD numbers are denoted as follows: 1 - Mbarara (MBR), 2 - Rukungiri (RUK), 3 - Entebbe, 4 - Mulago (MLG), and 5 - Masaka (MSK).

An overview of the emerging themes and subthemes is presented in [Table 2](#).

**Table 2** Emerged Themes and Subthemes

Themes	Subthemes
<b>Impaired brain function</b>	Neurodegenerative changes/ Alterations of brain function
	Multiple disorders of the brain
	Deterioration of brain function
<b>Change in activities of daily living</b>	Interference with performance of activities of daily life
	Inability to perform normal activities of daily life

(Continued)

**Table 2** (Continued).

Themes	Subthemes
<b>Promotion of quality care perspectives</b>	Early recognition of symptoms
	Discovery of subtle changes
	Improvement of psychosocial support
<b>Tool applicable and user-friendly</b>	Simple to use
	Brief and time saving
	User friendly / self-explanatory
<b>Client increased self-awareness and self confidence</b>	ART adherence following treatment plans
	Sense of care for one's own
	Bridges communication gap
<b>Integration of IHDS into routine HIV care</b>	Quick identification of dementia
	Beneficial to clients and cost effective
<b>Uncertainty about the IHDS use</b>	Negativity towards the IHDS tool
	System challenges
<b>Continuous training for healthcare workers</b>	Training and mentoring on tool use
	Inclusion of psychiatrist on the team

## Theme I: Impaired Brain Function

Participants described HAND as a neurodegenerative brain disorder characterized by symptoms such as memory loss and decreased psychomotor skills, or as a progressive cognitive decline with changes in behavior and deficiencies in concentration, memory, and attention.

### Neurodegenerative Changes/ Alterations of Brain Function

Participants' views on HAND ranged from being a brain disorder affecting memory and movement to a condition impacting nerve function across the body.

“...is when the brain undergoes distortion due to HIV infection; leading to impairment of memory, psychomotor skills, and the motor functions. This disruption results in a disorder within the brain...” (FDG 4 034 – MLG, FGD 2 005- RUK)

“...once the HIV virus enters the brain, it alters the functions of the nerves which interferes with the rest of the body causing a disorder”. (FDG 4 033 – MLG, FGD 5 021- MSK)

### Multiple Brain Disorders

Other participants described HAND as a group of brain disorders that significantly affect the central nervous system, detailed as follows:

“...it is a collection of disorders due to HIV infection that disturb the central nervous system especially the brain that coordinates movement and memory”. (FDG 3 040 – EBB; FGD 4 032- MLG)

### Deterioration of Brain Function

Participants considered HAND as a progressive cognitive decline causing impaired brain function, behavior changes, reduced concentration, memory problems, and attention deficits, illustrated by the following statement:

“...HIV associated neuro-cognitive disorders progressively reduce the brain function... ..may be associated with behavior changes and decline in cognitive function including trouble with concentration, memory and attention” (FGD 1 011 – MBR, FGD 4 035-MLG)

## Theme 2: Change in Activities of Daily Living

Activities of daily living (ADLs) are essential for personal well-being, with inadequate performance leading to poor hygiene, malnutrition, and other health issues. HAND can impair cognitive functions necessary for daily tasks like medication management, personal hygiene, and decision making ultimately impacting the well-being of PLWH.

### Disturbance in Performing Activities of Daily Living

Participants reported that HAND results from the effects of HIV on the brain, significantly interferes with daily activities like mobility, medication adherence, planning and personal hygiene, as exemplified in their statements:

“...the disorder is associated with reduced concentration, changes in speech, and disruptions in sleep patterns, forgetfulness, and slowed movements. Over time, the brain’s functions gradually weaken, leading to an overall slowing down of the body, which interferes with everyday activities...” (FGD 4 032 – MLG)

“...the disorder affects brain functions which disrupt the day to day life by slowing down daily activities such as decision making and personal care...”(FGD 2 005 – RUK, FGD 5 025 –MSK)

### Decreased Ability to Carry Out Activities of Daily Living

Participants noted that when the virus affects brain cells, clients can experience issues with concentration, memory, speech, and movement, leading to decline in functionality and daily challenges. This cognitive deterioration hampers routine tasks, lowers confidence, and often results in clients suffering silently, as highlighted in the excerpts below:

“...the brain, being highly impacted, hinders the body’s ability to move and respond to instructions efficiently..., sometimes clients may exhibit changes in mood and behavior silently affecting their personal confidence in everyday life (FGD 5029 – MSK, FGD 4 032 MLG)

“...when the brain is affected, numerous parts of the body get impacted... leading to altered speech, and a person who used to walk properly may become slow due to damage to sensory nerves. The whole body system becomes distorted and disorderly and person may suffer in silence, unsure of how to deal with these changes...” (FGD 4 035 – MLG, FGD 1 013 - MBR)

## Theme 3: Promotion of Quality Care Perspectives

Prioritizing quality care is essential for protecting health outcomes of clients. A streamlined approach to provide quality care is key in enhancing the wellbeing and functionality of people living with HIV.

### Early Recognition of Symptoms

Most participants agreed on the necessity of screening all clients for HAND, regardless of their general immunity levels. They highlighted that early detection could enable more effective interventions, ultimately enhancing health outcomes.

“...assessment helped in identifying hidden symptoms that were not initially recognized during routine interactions. This improved care for timely medical treatment and referrals for further management before the client is severely demented” (FGD 4 031 – MLG, FGD 3 041- EBB, FGD 1 011 -MBR, FGD 3 043- EBB, FGD 1 013- MBR)

“...routine screening enabled us to recognize clients with brain impairment that we had never noticed before as we used to wait for clinical signs to become apparent”. (FGD 1 013 – MBR, FGD 3 042 - EBB, FGD 5 026 – MSK)

“...clients disclosed symptoms they had never mentioned before during the usual interactions. We also identified numerous concerns that were previously unknown which guided us in providing comprehensive interventions at the individual, family or community level” (FGD 5 025- MSK, FGD 3 043 – EBB, FGD 5 020-MSK)

### Uncover Subtle Brain Changes

Participants emphasized the importance of using IHDS for HAND screening to identify symptoms that are commonly missed in routine HIV care, noting that subtle signs of dementia can go unnoticed, as illustrated in the following quote:

“...the tool revealed blind spots that impact clients’ adherence to medications, bringing to light signs and symptoms that were previously unknown and not identified during routine care” (FGD 2 001- RUK, FGD 1 012 MBR, FGD 4 034 MLG, FGD 5 021 MSK)

### Improve Psychosocial Support

Utilization of IHDS for HAND screening underscored the significance of psychosocial support within routine HIV care, as detailed below:

...the screening process improved psycho- social support by addressing a previously overlooked issue. In the past clients would miss their appointments and be blamed, while in reality, they could not remember their appointment days. This tool has enabled us to refocus our approach and provide more dedicated support to these clients. (FGD 1 012 – MBR, FGD 4 033 – MLG, FGD 2 010- RUK)

## Theme 4: Tool Applicable and User-Friendly

The International HIV Dementia Scale (IHDS) is the tool used for identifying HAND. It is quick, simple, cost-effective, and known for its user-friendliness. Its integration in clinical settings like the TASO centre will provide a supportive approach to care for PLWH.

### Simple to Use

Some participants described the International HIV Dementia Scale as a simple tool that clients appreciated during the screening exercise, as stated in the following excerpt:

“...the IHDS is a simple tool, as you screen clients may smile despite their situations, it is like you are playing a game...very interesting as you try to identify a disorder...” (FGD 5 029 – MSK, FGD 2 003 – RUK, FGD 5 021 MSK, FGD 4 035-MLG)

### Brief and Time Saving

Other participants noted that the IHDS was precise and efficient, taking only a short time to complete the screening and successfully identify the disorder as exemplified in the following quotes:

“...the tool is not time consuming and provides immediate results” (FGD 3 040 – EBB, FGD 5 028, 020 – MSK)

“...the tool is faster and enables you assess many clients in a short time in contrast to the mental state examination which takes longer to complete for each individual client...” (FGD 2 006 – RUK, FGD 1 014 MBR, FGD 3 042 – EBB)

### User Friendly and Self-Explanatory

Participants mentioned that the tool’s clarity and simplicity ensured clients faced no difficulties in answering technical questions, as stated below:

“unlike other tools that necessitate complex learning, the IHDS is easy to use, with appropriate training. Its user-friendly design disregards the need for extensive technical knowledge”. (FGD 1 012 – MBR, FGD 3 041-EBB, FGD 1 016 - MBR)

## Theme 5: Clients Increased Self-Awareness and Self-Confidence

After the HAND screening exercise, clients showed increased awareness of their cognitive state. They gained a deeper understanding of their health challenges which improved their confidence in managing themselves.

### Adherence to ART Based on Treatment Plans

Participants reported that clients enjoyed the screening exercise and were able to recall forgotten information. As clients recognized the connection between the exercise and the brain, they planned strategies for consistent medication adherence, as highlighted in the following quotes:

“...so, you mean I’ve reached this point with my memory? No wonder I’ve been forgetting taking my pills on time... ummm...I have a plan to avoid missing my medication in the future.... whenever I play with my fingers that will be the time to swallow my medicine”. (FGD 2 003 – RUK, FGD 1 013 – MBR)

“...continuing to play with their hands could act as a prompt for maintaining medical adherence. ...whenever they engage in the exercise, it could serve as a signal to remind them to take their medicine at that moment...”. (FGD 3 040 – EBB)

### Sense of Care for One’s Own Health

Participants expressed that the HAND screening exercise had the potential to empower clients to exercise their inherent right to self-manage and maintain their health, as stated in the following excerpt:

“...the tool cautions clients to be watchful after noticing that they have forgotten what they have been told within a short period of time, ...as a result they gain a sense of control and improved self- management of their health...”(FGD 5 023, 020 – MSK, FGD 1 016 – MBR)

### Bridges Communication Gap

Participants noted that using IHDS for HAND screening significantly improved communication with their clients. The interactive nature of the exercise encouraged clients to actively participate and freely express their concerns, as illustrated by the following quotes:

“...use of this tool significantly improved our interactions with clients... we charted with them during the screening process, which encouraged active client participation leading to a greater acceptance of their existing situation and a better understanding of the importance of seeking support...”. (FGD 5 021 –MSK, FGD 4 032 – MLG)

“...the tool facilitates clients in sharing their stories and experiences during the screening process...., as they do so, they open up and recognize the presence of an issue that requires attention and resolution...”. (FGD 2 005 - RUK, FGD 5 029 – MSK)

“...when I initially began screening this client, he appeared visibly unhappy ... as he actively engaged with the tool, he brightened up and became more excited. This tool encourages interactivity and fosters positive client engagement...”. (FGD 5 028 –MSK)

## Theme 6: Integration of IHDS into Routine HIV Care

Participants highlighted the importance of integrating IHDS into routine care, noting that early screening can identify HAND symptoms at their onset, providing significant support for neurocognitive functioning in PLWH.

### Quick Identification of Dementia

Participants reported that using IHDS for HAND screening helped identify early signs of dementia in clients and found its integration into their practice easy and quick, as highlighted in the following statements:

“...the tool was an eye opener for quickly identifying dementia in our clients... It was fast and easy which enabled provision of comprehensive HIV care, considering its integration will be a brilliant idea ...” (FGD 5 020 –MSK, FGD 1 011 – MBR)

“...since the tool is not time consuming and easily recognizes subcortical dementia, we could easily incorporate it in our day to day work in HIV care...” (FGD 3 042 - EBB, FGD 1 011- MBR, and FGD 5 021- MSK)

### Beneficial and Cost Effective

Participants noted that using the IHDS screening tool into clinical settings would enable early monitoring of cognitive function to prevent dementia. Additionally, educating clients about HAND and mitigation strategies could improve health outcomes and optimize resource allocation, as explained in the following statements:

“...integrating this tool into HIV care will serve as a preventive measure against progression to dementia. Since treating dementia after its onset can be challenging and expensive, early screening can significantly improve the chances of effective intervention...” (FGD 5 029 – MSK, FGD 4 037 – MLG)

”integrating this tool into the HIV care package is essential to prevent missing the diagnosis, ...it is very beneficial to both the clients and the healthcare team” (FGD 4 030 – MLG, FGD 5 020 – MSK)

“...if this tool is integrated into the ministry of health HIV management protocols, it will enhance the care provided to our clients, consequently influencing the allocation of resources...” (FGD 1 013 –MBR, FGD 2 003 – RUK)

## Theme 7: Uncertainty About IHDS Use

Participants noted that some healthcare workers were hesitant to use the IHDS for HAND screening, possibly due factors like limited time, heavy workloads, demanding tasks, lack of expertise, and unclear referral process within the system.

### Negativity Towards the Use of IHDS Tool

Although most participants found the IHDS screening quick and simple, some expressed concerns and reluctance about its integration, as illustrated by the following quotes:

“utilizing IHDS during every visit might not be feasible, given the need to complete the HIV ART card (the blue card), and simultaneously conducting the screening..., this could be too much and could potentially pose challenges”. (FGD 4 032- MLG)

“using IHDS on clients takes up considerable time often requiring several attempts for clients to complete it accurately as they often struggle to do it correctly. it can be quite inconvenient and time consuming” (FGD 4 03, 30 – MLG)

“...IHDS requires plenty of time demonstrating to the clients...you give much time to allow them practice... yet actually, you have more other clients waiting...”. (FGD 2 005 –RUK, FGD 4 032, 037 – MLG)

“we already have numerous tools to document as part of clinical assessments, and the inclusion of IHDS will only add to the workload and prolong clinical work, leading to more clients waiting in corridors...” (FGD 4 037 – MLG)

### System Challenges

Participants expressed concerns about the current infrastructure that hinders clients’ access to referred mental health services. They pointed out that transportation costs frequently prevent clients from accessing the services they were referred to, as explained in the following statements:

“when you screen and identify that the client is not well or experiencing dementia, the point of referral is not clear and even those who are referred do not receive the necessary services because there is no one available to attend to them. This is a disappointing and demoralizing situation” (FGD 5 021, 029 – MSK, FGD 4 030 – MLG)

“it is impractical to follow up on a client’s referral unless there is an established communication system in place with a designated contact person”. (FGD 2 009 - RUK, FGD 5 030 – MSK)

## Theme 8: Continuing Training for Healthcare Workers

Training and mentorship in using IHDS for HAND screening are essential for maintaining good standards in HIV care, underscoring the need for continuing education for healthcare workers. Healthcare workers must be well-informed to effectively support and discuss HAND with their clients, understanding their supportive role as a team.

### Training and Mentoring on Tool Use

Some participants emphasized the importance of training and mentoring healthcare workers to effectively use IHDS in HAND screening. Ensuring consistent knowledge across all staff will streamline the process and ensure accurate identification of HAND, as shown in the following statements:

”providing training and mentorship to all staff in the use of IHDS is necessary as it will empower us to consistently assess many clients within a short period of time”. (FGD 2 005 – RUK)

”everyone will need some training to effectively and confidently use the IHDS, and this applies not only to healthcare workers, but also to individuals who engage with clients, including expert clients in communities”. (FGD 4 034 – MLG)

“...to achieve successful integration of IHDS, staff members will require mentorship, particularly those working in special clinics caring for clients with poor adherence...” (FGD 2 010, 008, 007 – RUK, FGD 1 014 – MBR)

### Inclusion of a Psychiatrist in the Team

All participants agreed that adding a psychiatrist to the team would help overcome some challenges clients face when accessing the referral facility. These include transportation costs, long waits without services, and absence from work, as illustrated in the following excerpts:

“psychiatrists should be part of the team and care for clients with dementia directly at the centres, instead of referring them. The referral process can be stressful for clients and sometimes poses a risk of loss to follow-up”. (FGD 2 003 – RUK, FGD 1 011- MBR, FGD 5 026 – MSK, FGD 3 043 – EBBE)

## Discussion

This study is one of few to explore the healthcare workers' perspectives on using IHDS to screen for HAND in routine clinical settings. While IHDS has been used in several studies,<sup>7,13,18</sup> to detect HAND, focused literature on healthcare workers' views remains scarce. Notably, routine healthcare often fail to address the progressive neurocognitive changes in clients living longer with HIV.<sup>33</sup> Early detection is crucial for providing tailored care to PLWH grappling with HAND. However, the recommended method for diagnosing HAND requires comprehensive neuropsychological testing, which is time-intensive, costly, and depends on trained personnel, the resources that often scarce in settings like TASO.

User-friendly tools like the IHDS are designed to detect HAND and identify clients who may necessitate further assessment. However, healthcare workers often struggle with selecting appropriate screening tools due to unclear guidelines. The IHDS targets subcortical brain regions commonly affected by HAND,<sup>34</sup> meets essential feasibility requirements for clinical settings. It can be administered easily as an outpatient procedure without specialized equipment or proficiency in English. Although recommended to take 2 to 3 minutes<sup>19</sup> it requires 3 to 5 minutes in practice as observed in our study. This makes IHDS useful in resource- limited settings like TASO. Findings were organized into specific thematic themes to clarify understanding.

### Impaired Brain Function

Clients may experience memory lapses, slower cognitive processing, and difficulty managing daily tasks. This is indicative varied symptoms such as motor skill deterioration, behavioral changes like apathy, and cognitive impairments including memory deficits.<sup>16,27</sup> Early detection of HAND is complicated by subtle, asymptomatic brain changes that may occur before ART initiation.<sup>35</sup> These changes may emerge from HIV-related brain damage that occurs before the initiation of ART. If untreated, these changes can lead to severe outcomes, with varying progression rates.<sup>2</sup>

### Change in Activities of Daily Living

Even minor changes in daily activities can significantly challenge PLWH, affecting tasks like managing finances, following instructions, remembering important details.<sup>36</sup> Those with unmanaged HAND may find daily functioning and treatment adherence difficult.<sup>37</sup> Although advances in antiretroviral therapies have reduced neurocognitive decline, disruptive symptoms still threaten PLWH's independence.<sup>24</sup> Research shows that neurocognitive disorders can impair memory and complicate daily tasks.<sup>38,39</sup> Similarly, those employed may encounter safety risks and poor performance, which could lead to injuries and job loss.<sup>40</sup> Therefore, screening for HAND is crucial due to its significant impact on behavior and functional capabilities.<sup>41</sup>

### Promotion of Quality Care Perspectives

Optimal care for PLWH should include routine HAND screening during every visit, irrespective of their immune status. It is essential that healthcare workers are proficient with the IHDS to conduct effective HAND screening.<sup>37</sup> Research by Molinaro, Sacktor, Nakigozi, Aggrey, Batte, Kisakye, Myanja, Nakasujja, Robertson, WAWER,<sup>42</sup> supports IHDS'

effectiveness across diverse populations. Furthermore, a study in Tanzania by Okere, Meta, Maokola, Martelli, van Praag, Nanche, Gomez, Pozniak, Rinke de Wit, de Klerk<sup>43</sup> underscores the necessity of high-quality, WHO-supported, client-centered HIV programs, emphasizing the importance of psychological support. This support is vital for improving psychological adjustment, coping mechanisms, and therapy adherence,<sup>40,44,45</sup> and helps those with HAND improve in cognitive functions, self-care, and overall well-being.

## Tool Applicable and User-Friendly

Regular screening using IHDS allows early HAND detection before clients exhibit subjective complaints.<sup>42</sup> The IHDS is culturally neutral, suitable for diverse environments and particularly beneficial in resource-limited countries like Uganda with varied cultures and languages.<sup>19</sup> Its simplicity enabled non-neurological staff to use it effectively in countries such as Nigeria, Ethiopia, South Africa, Malawi and Botswana.<sup>17,24–26,46</sup> Although not a substitute for comprehensive neuropsychological assessments,<sup>34</sup> the IHDS efficiently identifies clients with HAND, enabling referrals for further evaluation. Thus its user-friendly proved practical for use in TASO centres in our study.

## Clients Increased Self-Awareness and Self-Confidence

After HAND screening, increased client awareness led to better health management and medication adherence.<sup>47</sup> This is supported by research from Heaton, Clifford, Franklin, Woods, Ake, Vaida, Ellis, Letendre, Marcotte, Atkinson,<sup>12</sup> which indicates that self-confidence enhances health management in PLWH. The screening process also improved communication between healthcare workers and clients, encouraging active participation and better understanding of medication schedules. Consistent adherence to ART is essential to prevent HAND progression and optimize health outcomes,<sup>48</sup> as HAND can compromise treatment adherence if clients are unaware of their cognitive decline.<sup>27</sup> Although severe HAND is uncommon, 40–50% of PLWH, struggle with maintaining adherence necessary for robust immune function.<sup>49,50</sup> Cognitive improvements depend on long-term adherence,<sup>16,51</sup> and factors like HIV infection,<sup>52</sup> ART toxicity,<sup>53</sup> and aging<sup>10</sup> potentially accelerating virus progression and HAND onset, especially when clients cannot advocate for their self-care rights.

## Integration of IHDS into Routine HIV Care

The World Health Organization (WHO) 2016 guidelines recommend routine screening of mental disorders in PLWH to improve health outcomes and ART adherence.<sup>54</sup> Using the IHDS to screen for HAND is crucial, as individuals may be unaware of their cognitive decline. Yet, WHO guidelines do not specify the preferred screening methods or frequency.<sup>55</sup> Screening tools should be quick and simple for everyday clinical use, providing immediate feedback to addresses client concerns and discuss lifestyle changes to boost well-being. While the IHDS is easy to and integrates well into routine HIV care, it has limitations in differentiating stages of neurocognitive impairment<sup>56</sup> and can lead to frequent HAND misdiagnoses,<sup>23</sup> due to its preliminary screening nature, which can lead to false positives.

## Uncertainty About the International HIV Dementia Scale (IHDS) Use

This study found that using the IHDS to screen for HAND is time-consuming, causing long wait times and client dissatisfaction due multiple practices before assessments. Its regular use burdens healthcare workers with extra paperwork and shifts care from client-focused to task-focused in line with a study by Manongi et al.<sup>57</sup> Morley et al<sup>58</sup> noted that time constraints and lack of expertise hinder effective HAND screening. The referral system also limits access to mental health services for clients with HAND, often leaving them without sufficient psychiatric support and inconsistent care at the referral centres. This highlights the need for proper integration of the IHDS within a well-resourced and structured healthcare system.

## Continuous Education for Healthcare Workers

The study underscores the necessity of continuous education for healthcare workers to remain current with the latest practices in HIV care and ensure better outcomes.<sup>59</sup> Fletcher<sup>56</sup> highlights the value of training to update skills, promote positive behaviors, and address care disparities. Training should cover HAND classification, symptoms, and screening, to prepare healthcare workers for effective HAND identification and referrals.<sup>60</sup> As PLWH age and struggle with multiple

health conditions potentially causing brain damage, HAND emerges as a key public health concern, requiring prompt screening and interventions to avert cognitive decline.<sup>15</sup> This underlines the continued need for training to enable healthcare workers detect HAND early and provide effective care in line with the TASO model. The lack of on-site psychiatric services for PLWH with HAND stresses the need for direct psychiatric care.<sup>23</sup> Labrague, McEnroe-Petite, Papathanasiou, Edet, Arulappan,<sup>60</sup> also emphasize continual education to improve healthcare workers' knowledge and support for clients.

## Study Strengths and Limitations

The strength of this study comes from its diverse and multidisciplinary team, including nurses, clinical officers, medical officers, and counselors, which enriched the findings. Using IHDS raised awareness about an often overlooked condition among PLWH, highlighting the importance of HAND screening during routine HIV care.

However, the study has notable limitations. It used IHDS as a screening tool rather than a diagnostic instrument, which might require further comprehensive neuropsychological assessments to confirm HAND. Additionally, the findings are mainly applicable to PLWH at TASO centers, a significant yet under-studied group, suggesting that results from the IHDS should be interpreted with caution.

## Conclusion

This study is the first to explore healthcare workers' perspectives on using the IHDS for screening HAND at TASO centres. As PLWH live longer, the risk of developing HAND increases, impacting their quality of life. The findings enable healthcare workers make more informed decisions regarding clients' cognitive health, and emphasize the need for continuous training to integrate HAND screening into HIV guidelines. We recommend a prospective study to assess the long-term outcomes of increased HAND screening and further research on the IHDS's clinical utility for both HIV-positive and HIV-negative populations to enhance its effectiveness and relevance.

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## Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

## Disclosure

The authors declare no competing interests in this work.

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