Eliza Harris BSc

NEUROCOGNITIVE DISORDERS AND HIV.

Section A: A Thematic Synthesis Exploring the Lived Experience of People Living with HIV-Associated Cognitive Difficulties.

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Section B: The Validity of the Montreal Cognitive Assessment as a Screening Tool for Mild and Major Neurocognitive Impairment due to HIV

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A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
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CANTERBURY CHRIST CHURCH UNIVERSITY

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To my family and friends, for your love, understanding, and encouragement.

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Summary of Major Research Project

Section A

This literature review of the experiences of people living with HIV and cognitive difficulties used a meta-synthesis of 15 qualitative and mixed-methods studies. Thematic synthesis resulted in 5 themes and 19 subthemes. The themes included: ‘noticing cognitive changes’, ‘seeking an understanding’, ‘anger and shame’, ‘sense of loss’, and ‘adjustments to daily living’. The findings provide an initial understanding of the experiences of people living with HIV and cognitive difficulties, and how they manage these newfound difficulties. Limitations of the review are discussed, in addition to potential clinical and future research implications.

Section B

This major research project aimed to evaluate the suitability and validity of the Montreal Cognitive Assessment (MoCA) with the DSM-V criteria for cognitive impairment due to HIV. 86 participants were involved in the Receiver Operating Characteristic (ROC) analysis and several Spearman correlation analyses were conducted to explore the relationship between the MoCA subtests and the neuropsychological tests that measured specific cognitive domains/constructs. According to criteria defined in previous literature, the results of the ROC analysis area under the curve suggested that the MoCA is a suitable tool for identifying people with cognitive impairment due to HIV. Each of the MoCA subtests correlated with several of the neuropsychological tests measuring different cognitive constructs. The limitations of the study, and clinical and research implications are discussed.

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Eliza Harris BSc

Section A: A Systematic Review Exploring the Lived Experience of People Living with HIV and Cognitive Difficulties

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Abstract

Background and aim: Thanks to the development of effective treatment, HIV is now considered a chronic illness. People are now living longer on antiretroviral medication and living with HIV for decades. Although the prognosis has greatly improved for the health and life expectancy of people living with HIV, there continue to be complications, including HIV-associated neurocognitive disorder (HAND). This meta-synthesis aims to explore the experiences of people with HIV and cognitive difficulties and how they manage these conditions.

Method: A systematic literature search was conducted. 15 qualitative and mixed-method studies were included in the review, assessed for quality using the CASP criteria, and analysed using thematic analysis.

Results: The review resulted in five meta-themes and nineteen subthemes. These themes included details of people's experiences with cognitive difficulties and HIV, seeking to understand these cognitive changes, and their emotional and psychological responses to these new difficulties. The themes also expand on how people manage living with cognitive challenges, including how they adjust their daily lives and their social support.

Conclusions: The findings provide an initial understanding of some experiences of PLWHIV experiencing cognitive difficulties, including cognitive challenges, emotional and social impacts, and ways of coping. Limitations included the overrepresentation of Western samples and lack of author reflexivity in a majority of the selected studies. Future research and clinical practice implications are discussed.

Keywords: HIV, HAND, Cognitive Impairment, Meta-synthesis

Introduction

The human immunodeficiency virus (HIV) is a retrovirus that attacks the body's immune system, thus impairing the body's ability to fight off infections and illnesses (World Health Organisation, 2024; WHO). Without treatment, the immune system becomes progressively weaker, making individuals vulnerable to opportunistic infections which can become life-threatening. This progression can lead to the HIV infection advancing to acquired immunodeficiency syndrome (AIDS; The Well Project, 2023). Since the start of the HIV/AIDS pandemic, there have been approximately 40.4 million reported deaths worldwide (United Nations Programme on AIDS, 2023), with approximately 630000 people dying from HIV-related causes in 2023 (WHO, 2024).

Fortunately, since then there have been significant advances in the research and treatment of HIV. Antiretroviral therapy (ART) has been the recommended form of treatment since the mid-1990s and has significantly reduced mortality rates associated with HIV-related illnesses (Wing, 2017). With the continued development of effective ART, HIV is now considered a chronic condition (Deeks et al., 2013) and people living with HIV (PLWHIV) around the world are living longer than ever before (Teeraanachai et al., 2016).

Before the advent of ART, neurological problems were a common problem for people with HIV, with up to 50% of people experiencing severe cognitive impairments (Alford & Vera, 2018) and approximately 15-20% of people developing HIV-associated dementia (HAD; McArthur et al., 1993; Sacktor et al., 2001). Despite the widespread use of ART significantly reducing the prevalence of HAD and severe cognitive difficulties (Lindl et al., 2010), PLWHIV remain at higher risk of being diagnosed with dementia compared to people without HIV (Lam et al., 2021), and milder forms of cognitive impairment have become more common (Heaton et al., 2010; Saylor et al. 2016), often occurring at younger ages (Lam et al., 2021). These

cognitive difficulties significantly impact people's quality of life and psychological well-being (Elendu et al., 2023). The pathogenesis of HIV-associated cognitive impairments is presently unclear. Current hypotheses predominantly adopt the biomedical approach to explain how HIV may directly or indirectly affect the brain and impact cognitive function. Researchers have linked cognitive impairments in PLWHIV to premature ageing (Cohen et al., 2015), neuroinflammation caused by early infiltration of the virus in the central nervous system (Lindl et al., 2010) and ART toxicity (De Benedetto et al., 2020). Although the current approach to neurocognitive impairment is largely biomedical (Nicholson, 2020), there is value in utilising a more holistic approach such as the biopsychosocial model for dementia (Spector & Orrell, 2010). This incorporates psychological and social factors that affect cognitive health, for example depression and social isolation (Livingston et al., 2017; Spector & Orell, 2010) and can aid healthcare staff in providing a more holistic intervention, alongside medication, potentially further improving quality of life (Livingston et al., 2017).

Clinicians and researchers often refer to the cognitive impairments in PLWHIV as HAND (HIV-associated neurocognitive disorder). This term is commonly used throughout HIV research and can refer to the formal diagnostic criteria known as the 'Frascati criteria' for HIV-associated neurocognitive disorder (Antinori et al., 2007) or more broadly, the spectrum of cognitive difficulties associated with HIV (Elendu et al., 2023). Throughout this paper, the term HAND will refer to the latter, unless otherwise specified.

HAND typically includes difficulties in short-term memory, attention, and executive functioning (Woods et al., 2009), which can affect day-to-day functioning and mood (Aretouli & Brandt, 2010; Ma, 2020).

People with HAND face unique stressors, including those related to HIV as a chronic illness (Thompson et al., 1996), and cognitive impairment (Kulshreshtha et al., 2023). These

distinctive stressors may contribute to the reported poorer quality of life among individuals with HAND compared to those without HIV or cognitive challenges (Alford et al., 2022; Elendu et al., 2023).

To help the exploration and understanding of how PLWHIV and cognitive difficulties cope with these stressors, Lazarus and Folkman's theory of stress and coping (1984; Biggs et al., 2017) provides a useful framework. This theory, widely applied in HIV-related research (Moskowitz et al., 2009), proposes that individuals respond to a potential stressor by first, subjectively assessing the level of threat, and then evaluating the resources for coping available. This amount of stress experienced is determined by this transaction, rather than being a direct response to a stimulus. The theory further suggests that individuals adapt to threats, in this case, a chronic condition or change to cognitive function, by applying strategies, the effectiveness of which depends on the extent to which they reduce the perception of threat and improve emotional well-being. These strategies can be either problem-focused, which are the practical ways to tackle the problem directly, or emotion-focused, which are used to reduce the emotions or distress linked to the problem. The theory emphasises that coping is a dynamic process, as individuals reappraise the stressor over time and adapt accordingly, shifting between coping strategies.

PLWHIV continue to experience increased levels of stress even in the era of ART. Siegel and Schrimshaw (2005) observed that, contrary to expectations, women with HIV receiving ART were more likely to report several different stressors, including health-related stressors, indicating higher levels of perceived threat. To manage these stressors, PLWHIV who employed problem-focused coping strategies reported a better quality of life than those who used emotion-focused strategies such as avoidance (Coetzee & Spangenberg, 2003). Alternative emotion-focused strategies such as acceptance, social support, and cognitive reframing are beneficial for PLWHIV (Myint & Mash, 2008).

Although there has been limited literature using this theory with HAND, there are benefits to its application. The theory highlights the complex interplay between subjective appraisal of the cognitive symptoms or diagnosis, and the evaluation of the resources available to manage, which influence an individual's ability to adapt. Understanding the nuanced ways that PLWHIV perceive and manage cognitive difficulties can provide insights into the best forms of psychosocial support. It could be inferred that those who view cognitive challenges as a higher threat to their well-being or lifestyle, or those who do not perceive their coping resources as adequate, will experience higher levels of stress, thus negatively impacting their quality of life.

Quantitative reviews have found that PLWHIV and HAND have reported a lower quality of life (Alford et al., 2021; Elendu et al., 2023) and have higher rates of depression and anxiety (Elendu et al. 2023). The disability centrality model (Bishop, 2005) may offer an explanation for these findings, suggesting that quality of life is an outcome of psychosocial adaptability to disability. According to the model, individuals with a lower quality of life often perceive their disability as more central in their life. Bishop (2005) emphasises the importance of maintaining meaningful life roles, social connections, and meaningful activities to reduce psychological distress and enhance quality of life.

Both Lazarus and Folkman (1984) and Bishop (2005) stress the importance of coping strategies to reduce the impact of their cognitive difficulties on their lives, thus reducing the perception of the threat (Lazarus and Folkman, 1984) or shifting the focus of the problem and emphasising the person's strengths and finding fulfilment unrelated in areas to their disability (Bishop, 2005). Unfortunately, previous quantitative studies and reviews only provide a brief overview of associations between concepts and do not capture the intricacy and nuance of an individual's experiences, which is particularly relevant in the lives of PLWHIV and experiencing cognitive challenges. Qualitative research on people's experiences of HAND allows a platform for

PLWHIV to express their appraisals of their experiences, the difficulties they face, and the coping strategies and adjustments they have implemented. This can provide valuable insights to people who support PLWHIV, including healthcare professionals, carers, and service providers. To date, the qualitative literature in this area has not been reviewed.

Therefore, this paper aims to review the qualitative literature that has been published on PLWHIV's experience of cognitive difficulties. The research questions that guided this review were:

- What are the qualitative experiences of cognitive difficulties reported by PLWHIV?
- How do people manage these difficulties and the consequences of cognitive difficulties in the context of living with HIV?

Method

Review Design

This review followed the recommended methodological stages for a thematic review (Lachal et al., 2017). These stages are identifying a research question and the criteria, conducting the literature search and selecting the studies, quality assessing the studies, analysing the data, and finally, writing the review. To analyse the data, this review utilised a thematic synthesis approach, described by Thomas and Harden (2008). Thematic synthesis was decided upon as it allows for new interpretations from findings to be developed.

This review was registered with the International Prospective Register of Systematic Reviews prior to the extraction of the data (reference number CRD42024488378).

Literature Search

The search was pre-planned and terms were informed by preliminary searches on Google Scholar to evaluate the extent of the relevant literature and other reviews in this area. The formal searches were conducted across the electronic databases PsychInfo, CINAHL, Assia, and PubMed on the 30th November 2023. The search included literature from inception to November 2023. Synonyms were included using the Boolean operator 'OR', and categories of search terms were combined using the Boolean operator 'AND'. Table 1 summarises the search terms used for this review.

Table 1

Summary of search terms

Search Topic	Specific terms used
HIV	HIV or 'human immunodeficiency virus'
Cognitive difficulties	Disabilit* or 'episodic disability' or 'cognitive impairment' or 'cognitive dysfunction' or 'cognitive difficult*' or neurocognitive or 'cognitive disorder' or 'HIV associated dementia'
Qualitative	Qualitative or 'grounded theory' or 'thematic analysis' or 'interpretative phenomenological analysis' or experience* or 'focus group' or narrative or interview or 'mixed methods'

Study Selection

The electronic database search resulted in 2,397 references being identified. These were screened for eligibility. Table 2 outlines the inclusion and exclusion criteria used. The screening process consisted of removing duplicates, screening titles and abstracts, and finally reading the remaining full articles. A total of 15 papers were identified, and the bibliography for each was manually checked for any relevant studies. There were no further studies identified.

People who self-identified as having cognitive difficulties but did not have a formal diagnosis were included in this review. This was partly due to the qualitative literature on people's experiences of HAND being in relatively early stages, along with the ongoing debate about the validity of the Frascati criteria, which is the HAND criteria most frequently used in research (Nightingale et al., 2023).

As the aim of this review was specifically to explore the experiences of people with cognitive difficulties associated with HIV, it was decided to exclude those who had neurocognitive diagnoses which are not associated with HIV, or other neurological difficulties (e.g. neuropathy).

Table 2

Inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
Adult participants (age 18+)	PLWHIV with cognitive impairment acquired pre-HIV infection.
Participants were PLWHIV.	Studies focused on PLWHV and intellectual disabilities.
Studies that focus on cognitive difficulties in relation to HIV or have reported thematic findings of PLWHIV personal experience of cognitive difficulties in relation to their HIV diagnosis.	Case studies
Self-identified or formally diagnosed cognitive difficulties in the context of HIV	Studies focused on peripheral neuropathy in the context of HIV
Qualitative studies, or studies that include qualitative data.	
Studies published in peer-reviewed journal.	
Studies published in English	

Quality Appraisal

This review utilised the Critical Appraisal Skills Programme (CASP; 2018) framework for evaluating qualitative research. The CASP framework is used frequently in health-related research and endorsed by the Cochrane Qualitative and Implementation Methods Group (Long et al., 2020). A 'sensitivity analysis' was also conducted to judge the potential impact of quality on the review results (Thomas & Harden, 2008). This involved evaluating the studies that contributed to each theme to ensure that the studies rated with a lower quality rating were not major or sole contributors to a theme.

The CASP (2018) criteria consist of ten questions that evaluate the validity of the study, the results, and the value of the results. This included assessing the appropriateness of the methodology, design, recruitment strategy, and data analysis. The criteria also explore whether particular considerations were accounted for and mentioned, including ethical issues and researcher bias. If there was any uncertainty, the author brought this to a discussion in supervision.

Analysis

The thematic analysis consisted of three stages: coding all the data line-by-line in the selected studies; organising the codes into related concepts to create 'descriptive themes'; and using these to develop 'analytical themes' (Thomas & Harden, 2008). All the information in the 'results' section of the included studies was incorporated into the analysis (Thomas & Harden, 2008), except for the three studies which utilised a mixed method methodology, where only the qualitative data was included in the analysis.

The author completed line-by-line coding using NVivo software before grouping the 'free codes' together based on similarities. The analytical themes were created based on these groups

whilst considering the aims and research questions of this review. The analytical themes were brought to supervision and discussed. The quality appraisals were considered in relation to the analytical themes to ensure that there were no themes based solely on the studies that had poorer quality ratings.

Reflexive Statement

As with any qualitative analysis, there are risks of bias in interpreting findings (Berger, 2015), and this analysis was from the perspective of a white, female, trainee clinical psychologist. Before conducting the analysis, I reflected on my own professional and personal experiences of caring for people with cognitive impairments and working with people with HIV, considering how my assumptions could influence the interpretation of the data. For example, I was aware of my assumption that PLWHIV were stigmatised and historically they have been treated poorly by society, including healthcare services. I reflected on how this may lead me to focus on their struggles rather than their resilience and successes.

To reduce potential biases, an inductive coding approach was used to ensure that themes emerged from the data rather than being shaped by pre-existing assumptions (Nowell et al., 2017). In addition, regular supervision discussions helped develop and refine themes and challenge potential biases (Mohammed et al., 2016). For instance, I initially grouped all negative identity-related experiences under ‘Stigma’, assuming concerns about others’ perceptions reflected internalised self-perception. However, supervision helped me distinguish between external stigma and negative self-perception, allowing for a more nuanced understanding of how these factors influenced self-esteem and help-seeking.

Results

Overview of Included Studies

The PRISMA diagram is shown in Figure 1. Fifteen studies were included in this analysis, which are summarised in Table 3. Eight of the studies were qualitative or mixed methods studies that focused on PLWHIV's experience of cognitive difficulties, and five studies were qualitative or mixed methods which focused on PLWHIV's experience of disability and contained a theme or mention of people's experience of cognitive impairment. Two of the studies focused on the reaction and experience of receiving a probable diagnosis (Vance et al., 2019; Vance et al., 2020). It was not clear if these studies were linked or had some of the same participants, as these studies had many of the same authors and funders. Despite this, it was decided to include both studies as there were more participants in the 2020 study and each study contained different raw data (i.e. different quotes from participants).

One qualitative study that was included in this review focused on participants with AIDS Dementia Complex (now known as HAD; Gregory & Gibbs, 2002). Although this study was conducted in the early stages of ART and this diagnosis is now considered rare, it was included in this review. It was decided that including this data is still valuable and is related to the research question due to the sample being PLWHIV with severe cognitive impairment.

The aims of the studies were varied, with some being broad (e.g. to explore perspectives of people diagnosed with HAND; Terpstra et al., 2018) and others being more specific (e.g. explore the experiences of men aged 50 and older who self-identify as having HIV-associated neurocognitive challenges; Hopcroft et al., 2013). Six of the studies included in this review did not specifically aim to explore HAND, however, the results included quotes from PLWHIV regarding their experiences of cognitive challenges in the context of HIV (Akhtar et al., 2017;

Eaton et al., 2017; Hanass-Hancock et al., 2014; Hanass-Hancock 2019; O'Brien et al., 2019; Solomon et al., 2018). Three of the studies included people with a formal diagnosis of HAND (Alford et al., 2022; Gregory & Gibbs, 2002; Terpstra et al., 2018), two studies included participants who had self-identified cognitive challenges (Gallagher et al., 2012; Hopcroft et al., 2013), and one study did not specify how cognitive challenges were experienced or an inclusion criteria for this (Eaton et al., 2017). Two of the studies focused on responses to a 'probable' diagnosis, therefore, the participants in these studies had a 'probable' diagnosis of HAND (Vance et al., 2019; Vance et al., 2020). Cummins and colleagues' (2018) study was a mixed methods study whose participants were PLWHIV and included qualitative data related to PLWHIV who were experiencing cognitive difficulties which were included in the analysis.

The samples varied across the studies depending on the aims of the study, particularly age and gender. Most studies (n= 12) were conducted in high-income, Western countries (Canada, Australia, USA, England, and Ireland). One study was conducted in Zambia (Hanass-Hancock et al., 2019) and another in South Africa (Hanass-Hancock et al., 2014).

A majority of the studies (n=11) used one-to-one interviewing which were facilitated face-to-face or via telephone. Other data collection methods included a focus group (Vance et al., 2017) and specific open-ended questions that were asked as part of a study (Cummins et al., 2018; Vance et al., 2019; Vance et al., 2020). The data analysis was explained step by step in many of the studies (n=10) with a variety of analytical methods being referenced. Four studies described coding into themes in different variations, without mention of a specific analytical method, whilst two studies utilised grounded theory (Alford et al., 2022; Terpstra et al., 2018). Other analytical methods included the analytic induction method (Gregory & Gibbs, 2002), collaborative qualitative analysis (Hanass-Hancock et al., 2014), using the DEPICT model for analysis (Hanass-Hancock et al., 2019), content analytical framework (O'Brien et al., 2019), longitudinal analysis (Solomon et al., 2018), and conventional content analysis (Vance et al.,

2017). Only one study (Cummins et al., 2018) did not detail their qualitative analysis or reference an analytic method.

Figure 1
PRISMA diagram

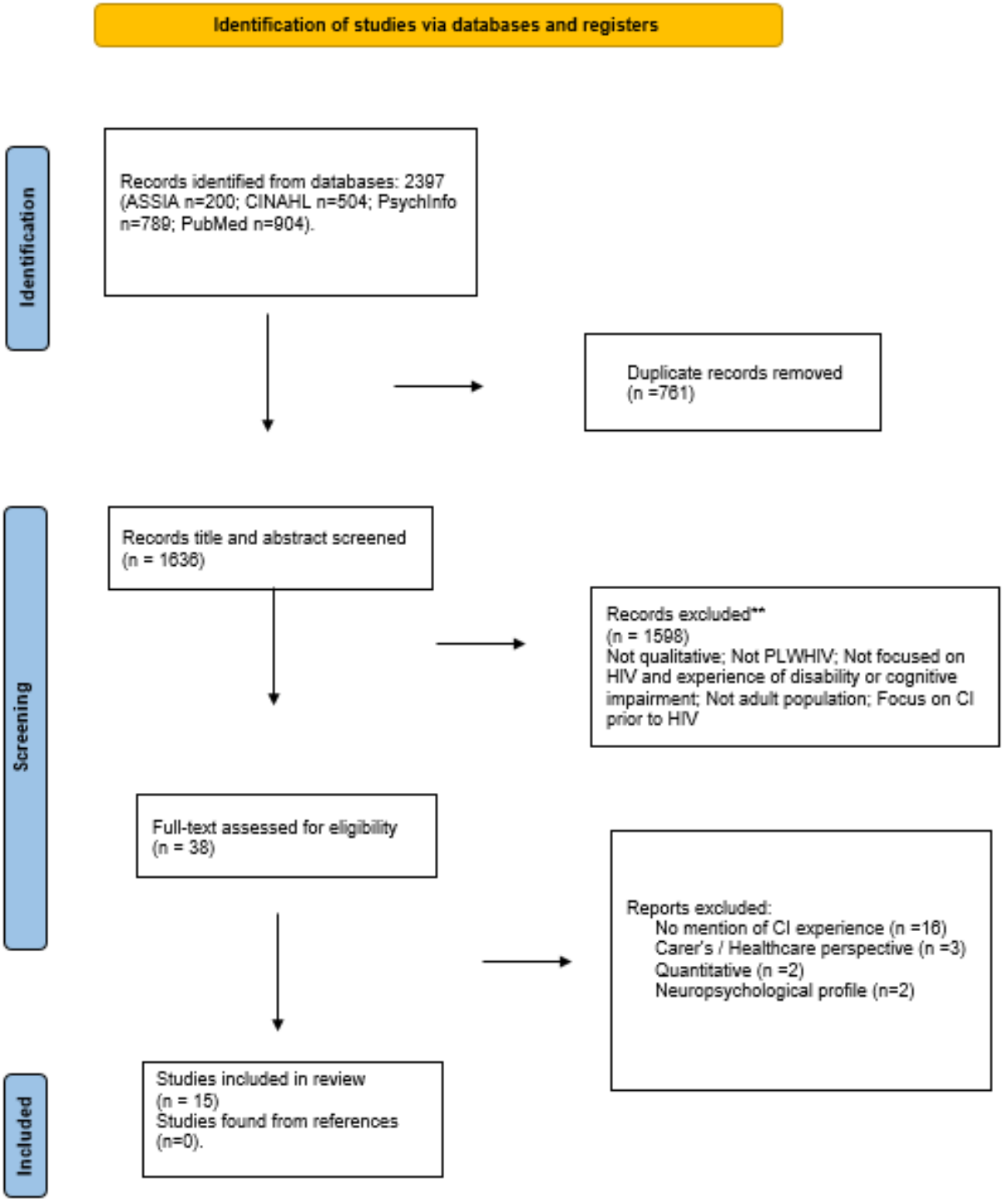

Table 3

Summary of Studies

Authors & Date	Title	Study Location	Aims & Research Questions	Participants	Design & Analysis
Akhtar et al., 2017	Experiences of women ageing with the human immunodeficiency virus	Ontario, Canada	To explore the experiences of older women living with HIV using the Episodic Disability Framework	10 women with HIV aged 51-62. No HAND criteria (not HAND specific. No demographics were given besides living situation.	Semi-structured interviews. Interview guide based on episodic disability framework (EDF). No specific analysis mentioned – thematic analysis steps explained.
Alford et al., 2022	"A fog that impacts everything": a qualitative study of health-related quality of life in people living with HIV who have cognitive impairment	South-East England (London, Brighton).	Understanding of Health-Related Quality of Life in PLWH with Cognitive Impairment.	18 men and 7 women with HIV and CI, aged between 38-80. CI defined by European AIDS Clinical Society of CI. Demographics given, participants were White British, Black African, Black Caribbean, White Other, and Black and White Mixed race.	Interviews, interview guides based on review of HRQoL literature and experiences of PLWHIV with CI. Grounded Theory

Cummins et al., 2018	Voices from Australia – concerns about HIV-associated neurocognitive disorder	New South Wales, Australia	Investigate if PLHIV in Australia had knowledge of HAND.	126 participants 116 male, 8 female, 2 transgender, age range 18->65.	Mixed methods, online survey with some open-ended questions. Analysis not specified
Eaton et al., 2017	The intersecting cognitive and aging needs of HIV-positive older adults: Implications for social work practice	Ontario Canada	What are the self-identified concerns of HIV+ older adults affected by HAND in Ontario? How have these concerns been addressed through existing programs and services from social workers? To what extent do participants understand the role of social workers?	20 people interviewed aged 50+ No specific demographics for those who were interviewed.	Mixed methods. Interview guide underpinned by community based framework. Not specified. Steps described thematic analysis.
Gallagher et al 2012	"It's a hidden issue": Exploring the experiences of women with HIV-associated neurocognitive challenges using the disability framework	Toronto, Canada	To explore the experiences of women living with self-identified HIV-associated neurocognitive challenges using WHO's ICF.	16 women with HIV-associated neurocognitive challenges (self-identified or formally diagnosed). Aged 21-62. Place of birth was reported, but not identified ethnicity.	Semi-structured interviews. Interview guide framed by the international classification of functioning, disability and health (ICF). Phenomenological design, theoretical analysis.

Gregory & Gibbs 2002	AIDS dementia complex: the perception of loss of functional ability.	New South Wales, Australia	Investigate issues of concern to clients with ADC.	4 men with a medical diagnosis of AIDS Dementia Complex. Ages not disclosed	Narrative Approach. Semi-structured interviews. Analytic induction method
Hanass-Hancock et al 2014	"When I was no longer able to see and walk, that is when I was affected most": experiences of disability in people living with HIV in South Africa	KwaZulut Natal, South Africa	Explore the experience of adults living with HIV and on ART in regards to impairments, activity limitations, and participation restrictions.	19 participants 10 women 9 men. Aged 20-54.	Descriptive, qualitative design. ICF-guided data collection and analysis. In-depth interviews. Collaborative qualitative analysis method (Jackson, 2008).
Hanass-Hancock et al 2019	Perspectives on ART adherence among Zambian adults living with HIV: insights raised using HIV-related disability frameworks	Lusaka, Zambia	To understand if and how health challenges and functional limitations impact treatment adherence among Zambian women and men on ART over time.	35 participants 18 women 17 men Ages 21-56 Ethnicity not stated	Qualitative longitudinal study. Qualitative interviews. Interview guide structured by ICF and EDF. Thematic content analysis and DEPICT method

Hopcroft et al., 2013	"My body's a 50-year old but my brain is definitely an 85-year-old": exploring the experiences of men ageing with HIV-associated neurocognitive challenges	Toronto, Canada	Explore the experiences of men aged 50 and older who self-identify as having HIV-associated neurocognitive challenges, particularly perceptions from the Episodic Disability Framework.	12 men aged 55-62 years. Self-identified and formally diagnosed cognitive impairment.	Semi-structured interviews. Interview guide based on EDF. Thematic analysis.
O'Brien et al., 2019	Cross-cultural applicability of the episodic disability framework with adults living with HIV in Ireland: a qualitative study	Dulin, Ireland	To describe the applicability of the episodic disability framework among adults living with HIV in Ireland	12 adults, 3 women 9 men. Aged 36-71. Participants were White Irish, Black or African, or Irish Italian.	Semi-structured interviews guided by EDF. Content analytical techniques.
Solomon et al., 2018	Qualitative longitudinal study of episodic disability experiences of older women living with HIV in Ontario, Canada	Ontario, Canada	To examine the disability experiences of older women living with HIV over time.	10 women aged 51-61 years.	Semi-structured interviews at 5-month intervals. Thematic analysis

Terpstra et al., 2018	"I'm Just Forgetting and I don't know why": Exploring how people living with HIV-Associated Neurocognitive Disorder view, manage, and obtain support for their cognitive difficulties	Vancouver & Toronto, Canada	To explore the perspectives of men and women diagnosed with HAND How cognitive impairment affects health behaviours, interactions with HCP, and reactions to neuropsychological assessment for a diagnosis of HAND.	25 participants diagnosed with HAND according to Frascati criteria. 5 female, 20 male. Participants were First Nations, White, African/ Caribbean / Black.	Semi-structured interviews. Interview guide. Grounded theory.
Vance et al., 2017	Perceptions of brain health and cognition in older African Americans and Caucasians with HIV: A focus group study	Alabama, USA	To investigate what type of cognitive complaints do older people with HIV self-report and what do they know about how to improve brain health and cognition.	30 adults with HIV and self-identify at least one cognitive problem. 13 women 17 men Aged 51-64 Participants were African American and White.	Focus groups, determined by ethnicity and gender. Content analysis

Vance et al., 2019	Informing adults with HIV of cognitive performance deficits indicative of HIV-Associated Neurocognitive Disorder	Alabama, USA.	Describe the reactions of PWH upon being informed of a possible diagnosis of HAND and concerns about this diagnosis.	85 participants living with HIV 27 women, 58 men Participants were African American, White, and Hispanic.	2 open-ended questions asked 6-8 weeks after assessment. Thematic/content analysis.
Vance et al., 2020	Reactions to a Probable Diagnosis of HIV-Associated Neurocognitive Disorder: A content analysis	Not specified. America	To assess the reactions of PLWH who were informed of being diagnosed with HAND or borderline HAND	139 participants with HIV, aged between 40-70. 55 women, 84 men African Americans, White, and Native American.	2 open ended questions asked 2-3 months after assessment. Content analysis

Quality Evaluation

Each research paper was assessed using the CASP (2018) criteria. A brief colour-coded synopsis of the quality appraisal can be seen in Table 4. Appendix 1 shows a more detailed evaluation of the studies.

Aims, Method and Design

All of the studies included in this review gave a clear statement of the aims. Qualitative designs were deemed appropriate in relation to all of the aims. Those that only partially met the criteria did not justify why the design was chosen. The lack of justification may be explained by the word limitations enforced by some publications.

Sampling

Eight studies met the criteria for sampling, five papers met this criteria partially as they did not specify where participants were recruited from or the inclusion or exclusion criteria were not specified or justified. Eaton and colleagues (2017) was the only paper to not meet this criteria, as it only referenced the sampling techniques used and did not explain which organisations were used for recruitment.

Although not specifically mentioned in the CASP, seven studies gave very limited demographical information, and eight studies did not report the ethnicity of their participants. This may have been done for anonymity, however, it could limit the interpretations in further reviews if comparisons between ethnicities were to be considered. Having little information on the characteristics of the sample also limits the conclusions that can be made regarding the transferability of findings across populations.

Data collection

The most frequent data collection method was via semi-structured interviews (n=11), although only a few gave details as to why this method was deemed most appropriate (n=3). Almost half of the studies referenced an interview guide (n=7) and most studies gave a clear explanation of how the interview guide was developed, or which framework influenced the interview guide. One study used focus groups for data collection, however, it did not justify the reason for this (Vance et al., 2017).

The studies that partially met the criteria did not justify their design or the framework that they used to inform the interview.

Reflexivity and ethical issues

Author reflexivity was the most common unmet criteria, which is particularly important for the development and interpretation of qualitative research and data (Stahl & King, 2020). There was one study where bias was a particular concern (O'Brien et al., 2019). There were some concerns regarding the study's data analysis, as both the data collection and analysis were conducted by a single researcher. This approach could introduce unintended bias, particularly since the study aimed to review the cross-cultural applicability of a framework the researcher had contributed to developing.

Potential ethical issues were rarely explicitly mentioned; however, four studies referred to the capacity of participants (Alford et al., 2022; Gregory & Gibbs, 2002; Gallagher et al., 2012; Hopcroft et al., 2013), and seven studies explicitly mentioned that informed consent was obtained. Studies that did not meet the criteria did not mention whether ethical approval was sought or any other ethical considerations.

Data analysis and findings

Ten of the studies gave clear steps of how data was analysed, and how multiple researchers were involved in the analysis. Several of the studies did not reference the specific approach or type of analysis used. All the studies provided an adequate amount of raw data in their results section, although two studies did not specify which participant said each quote (Hopcroft et al., 2013; Vance et al., 2017), therefore it is not clear if the quotes are from different participants. Findings were mostly clear and discussed in relation to the aims and the current literature. Only two studies explicitly discussed credibility (Akhtar et al., 2017; Gregory & Gibbs, 2022). The studies that only partially met these criteria missed the limitations of the studies or did not adequately discuss the results in relation to current literature.

Summary

The aims of all the studies were clear and qualitative methodology was deemed appropriate. There was an adequate number of quotes used in each of the studies and most of the findings were clear. The main concerns were regarding the reflexivity of the researchers as only two of the studies explicitly mentioned this in the report (Akhtar et al., 2017; Gregory & Gibbs, 2002). This is a common finding in qualitative research (Olmos-Vega et al., 2022) and may be due to word constraints imposed by journals or due to uncertainty surrounding reflexivity in qualitative research (Olmos-Vega et al., 2022).

Table 4
Quality evaluation of selected studies

	Studies														
CASP Criteria	Akhtar et al., 2017	Alford et al., 2022	Cummins et al., 2018	Eaton et al., 2017	Gallagher et al., 2012	Gregory & Gibbs., 2002	Hanass-Hancock et al., 2014	Hanass-Hancock et al., 2019	Hopcroft et al., 2018	O'Brien et al., 2019	Terpstra et al., 2018	Solomon et al., 2018	Vance et al., 2017	Vance et al., 2019	Vance et al., 2020
Aims															
Method															
Design															
Sample															
Data collection															
Reflexivity															
Ethical considerations															
Data Analysis															
Clear findings															

Key: Green - criteria met, Orange – criteria partially met, Red – criteria not met.

Thematic Analysis

The analysis resulted in five themes and nineteen subthemes, which are summarised in Table 5, along with quotes from the studies. Each of these themes and associated subthemes will be discussed in turn.

Noticing Cognitive Changes

Memory Loss

Twelve studies described the symptoms of cognitive impairment that PLWHIV had noticed in their everyday life. The most common observation was having difficulties with memory and forgetfulness, often described as the first indicator (Gallagher et al., 2012). This mainly affected people's short-term memory (Eaton et al., 2017; Gallagher et al., 2012), with many reporting difficulties with remembering words, names, past events and misplacing objects (Gallagher et al., 2012; Terpstra et al., 2018; Vance et al., 2017). Some PLWHIV noticed these changes in their memory as they now relied on practical strategies they did not previously have to use (Hopcroft et al 2013; O'Brien et al., 2019; Terpstra et al., 2018). Participants with HAD reported no changes or difficulties with their memory (Gregory & Gibbs, 2002), despite requiring supported accommodation and having a diagnosis of dementia. This change may indicate a change in insight if cognitive impairment deteriorates further.

Forgetfulness caused some participants to be in high-risk situations. One individual reported forgetting to turn off kitchen appliances (Gallagher et al., 2012), and another expressed confusion whilst they were driving (Vance et al., 2017). A frequently reported risk was forgetting to take medication and attend medical appointments (Hanass-Hancock et al., 2019; O'Brien et al., 2019; Solomon et al., 2018; Terpstra et al., 2018).

Poor Concentration

Another common observation was increased difficulty with concentration. This had a negative impact on people's ability to focus whilst at work (Alford et al., 2022; Gallagher et al., 2012), and affected social situations (Akhtar et al., 2017; Gallagher et al., 2012; Hopcroft et al., 2013). Poor concentration was linked to difficulties with multitasking which made work tasks and social situations more strenuous for those affected (Alford et al., 2022; Hopcroft et al., 2013; Gallagher et al., 2012). One participant stated his difficulties in concentration had led him to be in a dangerous situation whilst working on a construction site (Terpstra et al., 2018).

Mental Fatigue

Fatigue was described in two studies, which participants described as a symptom of its own, whilst others thought of fatigue as a secondary symptom due to the amount of energy and effort it takes to compensate for their cognitive difficulties (Gallagher et al., 2012). Participants found that fatigue also worsens other cognitive symptoms (Gallagher et al., 2012; Hopcroft et al., 2013).

Uncertainty of the Cause

Many participants questioned whether these cognitive changes were caused by HIV, or whether there may be other explanations. Many queried whether it was the natural course of ageing (Eaton et al., 2017; Gallagher et al., 2012; Hopcroft et al., 2013; O'Brien et al., 2019; Vance et al., 2017), due to the long-term effects of taking anti-retroviral medication (Eaton et al., 2017; Terpstra et al., 2018; Vance et al., 2020), or other factors, such as not getting enough sleep (Terpstra et al., 2018), or the menopause (Gallagher et al., 2012). Despite seven studies reporting this uncertainty, there was no further exploration of the emotional or psychological impact.

Table 5
Themes and Subthemes

Theme	Subtheme	Contributing Studies	Example Quotes & Statements
Noticing Cognitive Changes	Memory loss	Alford et al., 2022 Eaton et al., 2017 Gallagher et al., 2012 Gregory & Gibbs 2002 Hanass-Hancock et al., 2014 Hanass-Hancock et al., 2019 Hopcroft et al., 2013 O'Brien et al., 2019 Solomon et al., 2014 Terpstra et al., 2018 Vance et al., 2017	"Take your meds. Yeah, I have forgotten…I still forget what I'm going to do." (Solomon et al., 2018) "I can be driving . ''Where am I going?'' Sometimes I have to pull over and regroup. It's really scary." (Vance et al., 2017) "ADC is supposed to affect your memory, but my memory is now excellent" (Gregory & Gibbs, 2002)
	Poor concentration	Akhtar et al., 2017 Alford et al., 2022 Gallagher et al., 2012 Hopcroft et a., 2013 O'Brien et al., 2019 Solomon et al., 2014 Terpstra et al., 2018 Vance et al., 2017	"I can't concentrate… I can't multitask. Like, I can't even talk on the phone and do something else" (Akhtar et al., 2017) "…like a mild hangover in the morning…I just felt that I had to try that extra bit hard…to concentrate a bit harder…" (O'Brien et al., 2019)

Mental fatigue	Gallagher et al., 2012 Hopcroft et al., 2013	"By 2 to 3 in the afternoon I'm pretty well pooped. I'm tired and I can't retain information, [or] make a good decision" (Hopcroft et al., 2013). "[After] three or four hours of [a] meeting, I began to feel almost brain dead. So I just felt physically and mentally exhausted from feeling bombarded by a lot of information I couldn't really understand. So I really just felt like I just want to go home and go to bed." (Gallagher et al., 2012)
Uncertainty of cause	Eaton et al., 2017 Gallagher et al., 2012 Hopcroft et al., 2013 O'Brien et al., 2019 Terpstra et al., 2018 Vance et al., 2017	"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?" (Eaton et al., 2017) "I have no idea right now. All I have is questions [about the cause of my neurocognitive challenges]. I don't know... I don't want to jump to conclusions, but I'm looking at it in terms that I don't really know a lot about it. Could it be age? Could it be dementia that's HIV-related?" (Hopcroft et al., 2013).

Seeking an Understanding	Barriers to seeking support	Eaton et al., 2017 Terpstra et al., 2018	"… and that's why I originally didn't even 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" (Eaton et al., 2017) "Well I didn't realize it was a big problem until recently. I thought it was just me ageing. I thought it was just a lot of stress causing it. So I wasn't talking to my doctor about it." (Terpstra et al., 2018).
	Mixed feelings to diagnosis	Terpstra et al., 2018 Vance et al., 2019 Vance et al., 2020	"Astonished, astounded. My first reaction was to research cognition and think of ways to improve on my speed and abilities." (Vance et al., 2019) "[It is] good to know it's not me not trying hard enough." (Vance et al., 2020)
	Professional support to understand the diagnosis	Alford et al., 2022 Terpstra et al., 2018	"[The feedback] made me more positive in a way, that, you know what, I'm not stupid" (Terpstra et al., 2018).

Anger and Shame	Frustration and embarrassment	Alford et al., 2022 Terpstra et al., 2018	"Sometimes it gets very hard and bad because you are round and round on the same thing, you get frustrated and anxious about what you have done or what things you are supposed to do on that day" (Alford et al., 2022) "[Not remembering is] embarrassing for me because you know I would get frustrated because I couldn't remember and I didn't want to ask [my supervisor] again because he was so tired of people being around him and not remembering. I don't know if he had a lot of [employees] that were positive or whatnot." (Terpstra et al., 2018)
	Negative self-perception	Alford et al., 2022 Hopcroft et al., 2013 Terpstra et al., 2018	…referring to themselves using derogatory language, such as "the village idiot", "useless", "worthless" and "stupid" (Alford et al., 2022) "I used to be a smart person, until I [got] this illness [HIV]". (Terpstra et al., 2018)

	Stigma experiences and worries	Alford et al., 2022 Eaton et al., 2017 Gallagher et al., 2012 Hanass-Hancock et al., 2014 Hopcroft et al., 2013 Terpstra et al., 2018	". . .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." (Eaton et al., 2017) "I even realise that maybe to them I'm like - stupid to them" (Hanass-Hancock et al., 2014).
Sense of Loss	Changes in daily living	Akhtar et al., 2022 Alford et al., 2022 Cummins et al., 2018 Gallagher et al., 2012	"Quality of life I would think is (to) do things and get out…which I don't do really anymore, I'll be honest…I'd go up [to bed] at 3 o'clock, put the TV on, watch that with the dogs…that's my choice, I don't have to, but it's just easier that way." (Alford et al., 2022) "All of these affect [cognitive difficulties] my day to day living issues as well as ability to work well in employment" (Cummins et al., 2018)

Changes in relationships	Alford et al., 2022 Gregory & Gibbs, 2002 Gallagher et al., 2012 Terpstra et al., 2018	"You end up slowly getting rid of them [friends]…you start to put distance because…it's like not wanting to meet people" (Gallagher et al., 2012) "My father was coming every day to see me in hospital ... and after 2 and a half months he sort of said, 'No. I can't cope with this. I can't cope with you, I can't cope with what you're going through.' And I don't think he knew what I was going through." (Gregory & Gibbs, 2002)
Low Mood	Alford et al., 2022 Gallagher et al., 2012 Hopcroft et al., 2013 Terpstra et al., 2018	"It isn't something that's easy [CI]…It doesn't make you a very happy person. And happiness depends on everything…on the state of your mind being able to cope with life, it's just always there" (Alford et al., 2022) "I didn't actually come to terms with the underlying causes of my depression until about 5 or 6 years ago. But then I started to get really serious psychiatric help and I take antidepressants." (Gallagher et al., 2012)

	Uncertainty about the future	Alford et al., 2022 Cummins et al., 2018 Eaton et al., 2017 Gallagher et al., 2012 Hopcroft et al., 2013 Terpstra et al., 2018	"I would rather go before any long-term, visibly embarrassing traits develop..." (Cummins et al., 2018) "I am concerned I won't be able to take care of myself." (Vance et al., 2020)
Adjustments to daily life	Practical strategies	Alford et al., 2022 Gallagher et al., 2012 Hanass-Hancock et al., 2019 Hopcroft et al., 2013 Solomon et al., 2014 O'Brien et al., 2019 Terpstra et al., 2018 Vance et al., 2017	"[regarding medication] what I used is this small phone, you can set the alarm." (Hanass-Hancock et al., 2019). "Oh, for me, I try to write it down and organize things, try and have it organized, put stuff in a certain spot where I know where it is. My important messages and things I need to remember, I write it down" (Vance et al., 2017)
	Proactive Strategies	Alford et al., 2022 Terpstra et al., 2018	"I do mindfulness and some yoga now, which I think makes me more present with my memory problems so I'm going to forget things less…" (Alford et al., 2022) "I worry about [my memory getting worse] That's why I try to read every day so that my memory won't get so bad and then I try to do [cognitively challenging] games. That helps me a lot too." (Terpstra et al., 2018)

Prioritising what is important	Gallagher et al., 2012 Hopcroft et al., 2013	"You prioritize whatever in life is important to you. So, you prioritize how you spend your time, [and] do the things that you want to be doing" (Hopcroft et al., 2013)
Finding a purpose & remaining optimistic	Alford et al., 2022 Gallagher et al., 2012 Terpstra et al., 2018	"I thank god for work…I think work have been really good at supporting me mentally" (Alford et al., 2022) "I have a reason to live. I always say that if I didn't have children there was no purpose of life. I wouldn't think I would be living now. I have kids to take care of." (Gallagher et al., 2012) "My life is not over. These things that I enjoyed before I can still do and enjoy." (Gallagher et al., 2012) "I know I can do this - let's rethink about what worked and what didn't work that [other] time that I can utilize for this time. That's the best way; it's turning it around." (Terpstra et al., 2018)

Personal Support	Alford et al., 2022 Hopcroft et al., 2013 Terpstra et al., 2018	“I’m well supported, it makes a huge difference to everything” (Alford et al., 2022) “So we’re all in the same boat. It’s almost a joke when we’re all out together” (Hopcroft et al., 2018)

Seeking an Understanding

Barriers to seeking support

For some PLWHIV who had observed cognitive changes, there were barriers to seeking professional support. Some found it difficult to broach the subject with their doctors or other healthcare professionals due to the fear of stigma of their HIV status (Alford et al., 2022) or the stigma of having cognitive difficulties (Eaton et al., 2017). Other individuals considered it a manageable issue that was not serious enough to discuss with their doctor (Hanass-Hancock et al., 2019; Terpstra et al., 2018).

Mixed reactions to the diagnosis

Those who had sought out support and were given a diagnosis of HAND (or a probable diagnosis) had mixed emotional responses. Most PLWHIV were relieved to find that there was an explanation for their cognitive difficulties, and it was not due to their lack of effort or intelligence (Terpstra et al, 2018; Vance et al., 2019; Vance et al., 2020). This may explain why some people were thankful to know their diagnosis (Terpstra et al., 2018; Vance et al., 2019; Vance et al., 2020). Others were surprised and shocked by the diagnosis (Terpstra et al., 2018; Vance et al., 2019; Vance et al., 2020), and one individual refuted it (Vance et al., 2020). These responses of shock or denial appeared to be more likely if the participant had no prior concerns regarding their cognitive health (Vance et al., 2020). Some PLWHIV expressed feelings of anxiety, sadness, fear, and confusion (Terpstra et al., 2018; Vance et al., 2019; Vance et al., 2020), whilst other people reported no concern or emotional response (Vance et al., 2019; Vance et al., 2020). Many also expressed a desire to learn more about the diagnosis and what can help improve symptoms or stop further deterioration (Vance et al., 2019; Vance et al., 2020).

Support to Understand Diagnosis

Receiving detailed feedback and support after the neuropsychological testing for HAND reduced participants' worries and it was encouraging to hear about their strengths, as well as their difficulties, improving their self-esteem (Terpstra et al., 2018). It was important that the results were explained and did not include too much jargon, which could leave people feeling confused (Terpstra et al, 2018). Learning more about HAND also improved people's understanding and outlook about the diagnosis (Terpstra et al., 2018). Those who reported that they did not receive adequate feedback after the testing reported feelings of failure or worry (Eaton et al., 2018).

Anger and Shame

Frustration and Embarrassment

Several participants described feelings of "frustration" and "embarrassment" when they struggled to remember things or to concentration (Alford et al., 2022; Hopcroft et al., 2013; Terpstra et al., 2018), particularly when in work or social situations. Examples given that evoke frustration and embarrassment were word-finding difficulties, challenges in expressing themselves, and having to ask the same thing again from a colleague (Alford et al., 2022; Terpstra et al., 2018). This was upsetting and could lead to increased anxiety in these situations (Alford et al., 2022).

Negative Self-Perception

These feelings were linked to feeling "useless" in one study (Alford et al., 2022). Studies also found that some participants would use derogatory or self-stigmatising language to describe themselves now, due to their cognitive difficulties, and compare themselves to how they were before (Alford et al., 2022; Terpstra et al., 2018). This may contribute to some of the reported changes in self-esteem and changes in personal roles due to their difficulties with memory and

attention (Alford et al., 2022; Hopcroft et al., 2013). Alford and colleagues (2022) reported that negative self-perception caused people to become quieter and more reserved due to their perceived shame of their difficulties. Conversely, people who retained a sense of 'normality', such as maintaining employment with suitable adaptations or finding volunteer work, were reported to have more positive self-perception (Alford et al., 2022; Hopcroft et al., 2013).

Stigma Experiences and Worries

As well as self-stigma, PLWHIV reported experiencing stigma around HIV and cognitive impairment from others, including loved ones (Gallagher et al., 2012). Participants were also worried about potential stigma, raising concerns that others may consider them "stupid" or treat them differently due to their cognitive challenges (Eaton et al., 2017; Hanass-Hancock et al., 2014). Some people experienced judgement and criticism from their family members because of their forgetfulness (Terpstra et al., 2018). One participant highlighted the need for society to be more understanding of people with cognitive difficulties, instead of labelling them with a diagnosis which leads to being stigmatised (Gallagher et al., 2012).

Sense of Loss

Changes in Daily Living

There were many ways in which their cognitive challenges affected people's everyday lives. PLWHIV reported the changes in their employment, including changing job roles, reducing workload, and losing their job (Akhtar et al., 2017; Gallagher et al., 2012), along with difficulties finding employment (Alford et al., 2022). Symptom progression, in two cases, had led to a suspension of their driving licence (Solomon et al., 2014).

Cognitive difficulties also lead to a reduction in recreational activities, such as watching films, reading, going on holidays, and seeing friends (Alford et al., 2022; Hopcroft et al., 2013).

PLWHIV reported increased stress in leaving the house, and often preferred to stay at home (Alford et al., 2022).

Changes in Relationships

Reduction in outside activities, including community participation led to many PLWHIV and cognitive difficulties to feel lonely and isolated (Gallagher et al., 2012). Others reported that they had withdrawn from previous social circles due to concerns about their ability to cope with others' social demands and worries about experiencing judgment due to their forgetfulness or difficulties concentrating (Alford et al., 2022). As well as maintaining relationships, people felt that their cognitive challenges prevented them from being able to form relationships with others (Terpstra et al., 2018).

Whilst many were concerned with their ability to cope with others, PLWHIV with more severe stages of HAND experienced their family reducing contact as they struggled to come to terms with his dementia diagnosis (Gregory & Gibbs, 2002).

Low Mood

Feelings of depression were also attributed to forgetfulness (Hopcroft et al., 2013), as well as more general "mental health difficulties" which began or have increased since their cognitive difficulties (Alford et al., 2022; Hopcroft et al., 2013). Low mood was a common experience, mentioned explicitly in five studies, though some studies did not specify whether participants considered this to be due to cognitive difficulties, or other stressors (Gallagher et al., 2012; Hopcroft et al., 2013). Gallagher and colleagues (2012) reported that all their participants described feelings of "depression".

Uncertainty about the Future

In addition to the low mood in response to their newfound challenges, many found themselves questioning and mourning for the future they had planned. Participants from several studies

raised concerns about the trajectory and progression of their cognitive difficulties. A frequent fear reported by participants was losing the ability to look after themselves independently, thus being a "burden" to their loved ones (Cummins et al., 2018; Eaton et al., 2017; Terpstra et al., 2018; Vance et al., 2019), whilst those without close family relationships were worried about who will support them if their cognition deteriorates (Eaton et al., 2017; Gallagher et al., 2012). Some were concerned about what they would forget if their memory were to deteriorate, expressing fears of forgetting their family members or forgetting themselves (Alford et al., 2022; Terpstra et al., 2018).

Adjustments and Coping

Practical Strategies

To support themselves with their daily challenges and cognitive changes, many PLWHIV devised strategies and aids to help them with their cognitive difficulties. These included paper-based reminders such as notes, lists, calendars, and diaries (Alford et al., 2022; Gallagher et al., 2012; Hopcroft et al., 2013; O'Brien et al., 2019; Terpstra et al., 2018; Vance et al., 2017) which supported people to maintain their independence and carry out their everyday tasks successfully (Alford et al., 2022; Gallagher et al., 2012). Electronic reminders were also a useful tool, with people using their phones to create alarms (Alford et al., 2022; Gallagher et al., 2012; Hanass-Hancock et al., 2019), which aided with medication adherence (Hanass-Hancock et al., 2019).

Proactive Strategies

In addition to practical strategies to aid with independence and cognitive difficulties, PLWHIV also reported engaging in some pre-emptive approaches to help with their brain health. These included mindfulness and meditation, yoga, exercise, and brain training (Alford et al., 2022; Terpstra et al., 2018), as well as lifestyle changes such as reducing alcohol consumption, eating

a healthy diet, and doing volunteer work (Alford et al., 2022; Terpstra et al., 2018). Implementing these changes was reported to decrease anxiety and worry regarding future cognitive decline and increase hope (Alford et al., 2022).

Establishing Priorities

Participants also described other purposeful lifestyle adjustments, including prioritising what is important (Hopcroft et al., 2013). Some participants described how they purposefully reduced their workload and involvement in extracurricular activities (Gallagher et al., 2012) or their social circle (Hopcroft et al., 2013) to prioritise relationships and activities that are important to them. This reduced the feeling of being overwhelmed some participants felt in their lives with their cognitive challenges (Hopcroft et al., 2013).

Finding a Purpose and Remaining Optimistic

Certain personal priorities gave many participants a sense of purpose and meaning in their lives, which helped them cope with these changes. Those who were still able to work reported that their jobs helped them cope with their difficulties and built their self-esteem (Alford et al., 2022; Gallagher et al., 2012). Mothers also reported that being a parent gave them purpose and helped them cope with their difficulties, contrary to what women without children predicted (Gallagher et al., 2012).

Along with having a sense of purpose, other participants explained the value of remaining optimistic in the face of adversity. In two studies, participants stressed the importance of maintaining a "positive outlook", saying that it assists them to continue to partake in things they enjoy (Gallagher et al., 2012). Some participants explained that their experiences with HIV and hardships made them resilient, an attribute that helped them cope with their cognitive difficulties (Alford et al., 2022). Several participants counted themselves as "lucky" despite their current difficulties, as they remembered the friends that they had lost to HIV (Alford et al., 2022). Maintaining a positive attitude was more difficult for younger participants with a

recent HIV diagnosis, which in turn had a negative impact on their cognitive functioning (Gallagher et al., 2012).

Support from Others

Having social connections and support was perceived as contributing to PLWHIV having a positive outlook and perceptions of coping. Supportive colleagues helped some participants cope and improved their wellbeing (Alford et al., 2022), and having support from others made a "huge difference to everything" (Alford et al., 2022). Friends and family provided practical support by reminding individuals about appointments (Terpstra et al., 2018), along with emotional support from people who are accepting (Alford et al., 2022; Gallagher et al., 2012). Religion, faith and a spiritual community were also sources of support, and reduced feelings of isolation and increased hope (Alford et al., 2022; Gallagher et al., 2012).

Many participants found solace in having relationships with people who understood their difficulties. Having support from others with HIV who are going through similar experiences was a positive experience for many, to talk about and even find humour in their experiences (Hopcroft et al., 2013; Terpstra et al., 2018).

PLWHIV with good support systems stressed the importance of the relationships (Hopcroft et al., 2013) and were less likely to socially withdraw (Alford et al., 2022).

Discussion

This review aimed to explore people's experiences of living with HIV and cognitive difficulties and to understand how they cope these challenges. This review included 15 studies which had reported PLWHIV's experiences of cognitive difficulties, of which 13 were qualitative and 2 had a mixed method design. The selected studies either had a primary focus on cognitive difficulties in HIV, or included quotes reflecting the experiences of PLWHIV and cognitive impairments, but cognitive difficulties were not the main focus of the research.

This discussion will provide an overview of the results of this review, in the context of the aims of the review, the current literature, and the limitations and future implications.

Summary of Findings

PLWHIV who reported difficulties with cognition described changes in memory, concentration, and increased fatigue. This is in concordance with quantitative literature and the cognitive profiles of HAND (Heaton et al., 2010; Lawler et al., 2011). These difficulties with memory and concentration can pose significant risks for PLWHIV, including problems with remembering to take medication. Taking medication consistently is crucial, as inconsistent ART can lead to the viral load increasing, heightening the risk of opportunistic infections due to a depleted immune system (El-Sadr et al., 2006). Additionally, inconsistent ART use can contribute to the development of drug resistance (WHO, 2022). Other physical risks due to memory difficulties were highlighted in this review, such as forgetting to turn off kitchen stoves or impacting one's ability to drive.

Despite the increased challenges reported, PLWHIV acknowledged some barriers to seeking support from healthcare professionals. These barriers included fear of stigma, relating to both HIV and cognitive impairments. Although advancements have been made in HIV treatment and epidemiology, stigma remains a persistent issue, including in healthcare settings (Wagner

et al., 2016), which this review identified as a continued fear. PLWHIV have reported experiencing explicit discrimination due to their HIV status which has discouraged them from seeking support from healthcare services (Zhou, 2009). Negative past experiences from healthcare professionals may deter PLWHIV from seeking both medical and psychological care (Nguyen et al., 2019), potentially worsening well-being and limiting resources for coping with cognitive and emotional challenges. Furthermore, others did not seek professional support as they related their difficulties to ageing or thought that it was something that they could manage on their own. These barriers to seeking support highlight the importance of healthcare professionals regularly enquiring about cognitive functioning with PLWHIV, along with routine screening for people who have concerns regarding their cognition. Care should be taken when selecting appropriate screening tools, as some popular screening tools do not have the sensitivity or specificity in the detection of HAND (Vastag et al., 2022).

Vance and colleagues raised the ethical dilemmas associated with diagnosing HAND, questioning its usefulness and the potential for harm (Vance et al., 2019; Vance et al., 2020). However, this review found that many people felt a sense of relief upon receiving a diagnosis and expressed gratitude when professionals listened to their concerns (Vance et al., 2019). The benefit and importance of neurocognitive assessment feedback was emphasised and appeared to help people accept their difficulties (Alford et al., 2022), and increase self-esteem (Terpstra et al., 2018). It may be that having a better understanding of their difficulties reduces the negative appraisal of their difficulties, thus increasing the individual's perception of their ability to cope (Lazarus & Folkman, 1984). Acceptance has also been identified as an effective emotion-focused strategy (Myint & Mash, 2008). This should be the first step for healthcare professionals in supporting PLWHIV and HAND to cope with the changes and their psychological well-being.

Several coping strategies for PLWHIV and HAND were identified in this review. Lazarus and Folkman's theory (1984) suggests that people utilise problem-based and emotional-based coping strategies when adjusting to, and managing, stress. Although none of the studies within this review specifically focused on coping strategies, a variety of problem-based and emotional-based coping strategies were described by participants and appeared to be used in tandem. The strategies identified in this review primarily involved techniques to manage symptoms of cognitive difficulties rather than addressing HAND-related impairment and anxiety. For example, problem-focused strategies included having external memory aids, such as diaries, calendars, post-it notes, or alarms. It is promising that people are implementing these strategies at the early stages of their difficulties, as this may be more difficult to implement if their cognition were to decline further (Ross et al., 2022).

Other problem-focused strategies included prioritising relationships and what is important in life by adapting social and work responsibilities. Reordering priorities and finding a purpose have been suggested to be two coping processes which aid positive emotions (Folkman, 2008). Social withdrawal was identified as a strategy to reduce feelings of overwhelm for some PLWHIV, however, literature suggests that this may have a more negative impact on psychological well-being for PLWHIV (Basavaraj et al., 2010). Although it may have its benefits, social withdrawal could be one contributing factor to the reported loneliness which participants reported in this review (Gallagher et al., 2012).

Having support from loved ones and people from the HIV community was important to people experiencing HAND. Using humour as a coping strategy, and having emotional and practical support from family, friends, and other PLWHIV appeared to be a way of managing negative emotions and appraisals. Having social circles gave PLWHIV a purpose, and participants reported their roles as mothers (Gallagher et al., 2012) or employment roles (Alford et al., 2022), gave them meaning in their lives that are unrelated to their health conditions and were

beneficial to their well-being. Having a purpose or meaning has been reported as an important value for people with chronic conditions (Duggleby et al., 2012). This may support Bishop's (2005) centrality of disability theory that building a self-concept or having important roles that are separate from the disability can improve quality of life and reduce the dominance of the disability in a person's life. Having an optimistic outlook, despite the difficulties, was seen as another important way to cope, which has been seen in other chronic illnesses (Hurt et al., 2013; Duggleby et al., 2012). Some PLWHIV also noted that despite their ongoing health difficulties, including cognitive difficulties, their experiences of losing loved ones to HIV in the epidemic made them feel lucky to have survived (Alford et al., 2022).

Although some people reported optimism and increased quality of life due to their life roles and meaningful activities, depression or low mood were frequently reported by PLWHIV and cognitive difficulties. Depression is the most common psychiatric comorbidity for PLWHIV (Nanni et al., 2014), which may be exacerbated by cognitive challenges. HAND was associated with reducing self-esteem and reported feelings of loss. Understanding the psychological experiences of people with HAND may also help inform psychological treatment.

Limitations

The sampling of the studies within this review had notable limitations. In general, the sample sizes were small, and the studies were conducted in Western countries with some studies not reporting the ethnicity of the sample. Given that HIV, cognitive difficulties and HAND are global issues, and many PWLHIV live in non-Western countries, this limitation affects the transferability of these findings to diverse populations.

The studies in this review also included various ages, genders, and ethnic backgrounds, and there are likely to be significant differences in PLWHIV's experiences of cognitive difficulties when considering age, gender and ethnicity. This review gives an overview of PLWHIV's experiences, however, the limited reporting of participant demographics and the limited

number of qualitative studies focusing on PLWHIV experiences of HAND reduces the interpretations that can be made across the population, particularly in terms of intersectionality. Many of the studies included in this review did not adequately consider the researcher's role in the study, which raises concerns about the credibility of the results. This is a common issue with qualitative research (Olmos-Vega et al., 2022), however, should be carefully considered whilst conducting research, particularly with influence in creating the interview guide and analysing the results.

Implications for Clinical Practice

Despite the limitations of the generalisability and credibility of the data, this review has provided an overview of the rich data produced by PLWHIV and their experiences of cognitive difficulties. This may benefit carers, support services, healthcare providers and systems to understand their experiences and how they can best support people experiencing HAND.

Some studies highlighted the barriers for PLWHIV to seek professional support for their cognitive difficulties, including fear of stigma (Alford et al., 2022). Literature has also found a lack of knowledge surrounding HAND in both PLWHIV and healthcare professionals (Munsami et al., 2020). Raising awareness of HAND to both healthcare professionals and PLWHIV could increase the support for people experiencing HAND. It is also the responsibility of healthcare providers and healthcare professionals to provide a safe space for PLWHIV to discuss their HIV status and health concerns, which can be developed by adopting a non-judgemental stance (Chambers et al., 2015).

Some of the studies in this review highlighted the benefit of having a feedback session after the assessment. Services that conduct diagnostic assessments should provide suitable feedback on the assessment results and post-diagnostic support, which may aid with the individual’s adaptation to their challenges and, in the long-term, support their wellbeing.

Implications for Future Research

To have a further understanding of how people with HAND are coping and how healthcare professionals can best support them with adapting to their difficulties, it would be beneficial for future research to focus on the psychological impact of HAND and further exploration of specific strategies PLWHIV implement to help them cope with their difficulties. The studies included in this review largely reported adaptive coping strategies, although this may not be fully representative of the population (Banerjee et al., 2021), therefore, future research could explore strategies used in more detail.

As previously discussed, it is the role of healthcare professionals to enquire about any cognitive changes to allow space for PLWHIV to discuss any concerns regarding their cognition. This review outlined some of the barriers to seeking professional support, including worries about stigma. By starting the conversation, healthcare professionals can further assess those with concerns, using suitable screening tools that have validity in identifying HAND. Future research should evaluate which screening tools are most suitable when identifying people with HAND, to ensure it has a suitable sensitivity and specificity for this diagnosis. This will help individuals with HAND receive the appropriate psychological, emotional, and social support to manage their difficulties, which have been touched upon in this review.

As aforementioned, HIV and HAND occur worldwide. As much of the current research focuses on Western countries, it would be beneficial for future research to explore how HAND is experienced by people of different ethnicities, socioeconomic backgrounds, and genders. This could give further insight into the differences between these groups.

People with cognitive impairment can have differing opinions from their loved ones about the amount of support that they need (McIlvane et al., 2008), similar to those with more severe cognitive difficulties in HIV (Gregory & Gibbs, 2002). Comparing the perspectives of people

with a formal diagnosis of HAND and their loved ones may provide further insight into the experiences of PLWHIV and the support that they require.

Conclusion

The findings of this literature review provide an initial overview of the experiences of PLWHIV and cognitive difficulties. It gives insight into the cognitive changes that people experience and how these have affected their everyday lives and emotional well-being. Although no studies focused on coping strategies, PLWHIV experiencing cognitive challenges described the many ways they manage their newfound difficulties. The experiences described in this review provide valuable insight to carers, healthcare providers, and services who care for PLWHIV and are at increased risk of cognitive impairments. The qualitative research in this area is still in the early stages, and further research would be beneficial.

References

Akhtar, N. F., Garcha, R. K., & Solomon, P. (2017). Experiences of women aging with the human immunodeficiency virus: A qualitative study. *Canadian Journal of Occupational Therapy*, *84*(4–5), 253–261. https://doi.org/10.1177/0008417417722574

Alford, K., Daley, S., Banerjee, S., Hamlyn, E., Trotman, D., & Vera, J. H. (2022). "A fog that impacts everything": a qualitative study of health-related quality of life in people living with HIV who have cognitive impairment. *Quality of Life Research*, *31*(10), 3019–3030. https://doi.org/10.1007/s11136-022-03150-x

Alford, K., Daley, S., Banerjee, S., & Vera, J. H. (2021). Quality of life in people living with HIV-associated neurocognitive disorder: A scoping review study. *PLOS ONE*, *16*(5), e0251944. https://doi.org/10.1371/journal.pone.0251944

Alford, K., & Vera, J. H. (2018). Cognitive Impairment in people living with HIV in the ART era: A Review. *British Medical Bulletin*, *127*(1), 55–68. https://doi.org/10.1093/bmb/ldy019

Antinori, A., Arendt, G., Becker, J. T., Brew, B. J., Byrd, D. A., Cherner, M., Clifford, D. B., Cinque, P., Epstein, L. G., Goodkin, K., Gisslen, M., Grant, I., Heaton, R. K., Joseph, J., Marder, K., Marra, C. M., McArthur, J. C., Nunn, M., Price, R. W., . . . Wojna, V. E. (2007). Updated research nosology for HIV-associated neurocognitive disorders. Neurology, 69(18), 1789–1799. https://doi.org/10.1212/01.wnl.0000287431.88658.8b

Aretouli, E., & Brandt, J. (2010). Everyday functioning in mild cognitive impairment and its relationship with executive cognition. International Journal of Geriatric Psychiatry, 25(3), 224–233. https://doi.org/10.1002/gps.2325

Banerjee, N., Goodman, Z. T., McIntosh, R. C., & Ironson, G. (2021). Cognition, coping, and psychological distress in HIV. *AIDS and Behavior*, *26*(4), 1074–1083. https://doi.org/10.1007/s10461-021-03462-y

Basavaraj, K., Navya, M., & Rashmi, R. (2010). Quality of life in HIV/AIDS. Indian Journal of Sexually Transmitted Diseases and AIDS, 31(2), 75. https://doi.org/10.4103/0253-7184.74971

Berger, R. (2013). Now I see it, now I don't: researcher's position and reflexivity in qualitative research. Qualitative Research, 15(2), 219–234. https://doi.org/10.1177/1468794112468475

Biggs, A., Brough, P., & Drummond, S. (2017). Lazarus and Folkman's Psychological Stress and Coping Theory. The Handbook of Stress and Health: A Guide to Research and Practice, First Edition, 349–364. https://doi.org/10.1002/9781118993811.ch21

Bishop, M. (2005). Quality of life and psychosocial adaptation to chronic illness and disability. Rehabilitation Counseling Bulletin, 48(4), 219–231. https://doi.org/10.1177/00343552050480040301

Coetzee, M., & Spangenberg, J. (2003). Coping styles and quality of life in people with HIV/AIDS: a review. journals.ufs.ac.za. https://doi.org/10.38140/aa.v35i2.797

Cohen, R. A., Seider, T. R., & Navia, B. (2015). HIV effects on age-associated neurocognitive dysfunction: premature cognitive aging or neurodegenerative disease? Alzheimer's Research & Therapy, 7(1). https://doi.org/10.1186/s13195-015-0123-4

Collini, P., & Mawson, R. L. (2022). A new era of HIV care for age-associated multimorbidity. Current Opinion in Infectious Diseases, 36(1), 9–14. https://doi.org/10.1097/qco.0000000000000890

Cummins, D. D., Waters, D., Aggar, C., Crawford, D., Fethney, J., & O'Connor, C. (2018). Voices from Australia– concerns about HIV associated neurocognitive disorder. *AIDS Care*, *30*(5), 609–617. https://doi.org/10.1080/09540121.2018.1426826

Critical Appraisal Skills Programme (CASP) (2018). CASP Qualitative Checklist. Retrieved from https://casp-uk.net/casp-tools-checklists/

De Benedetto, I., Trunfio, M., Guastamacchia, G., Bonora, S., & Calcagno, A. (2020). A review of the potential mechanisms of neuronal toxicity associated with antiretroviral drugs. Journal of Neurovirology, 26(5), 642–651. https://doi.org/10.1007/s13365-020-00874-9

Deeks, S. G., Lewin, S. R., & Havlir, D. V. (2013). The end of AIDS: HIV infection as a chronic disease. *The Lancet*, *382*(9903), 1525–1533. https://doi.org/10.1016/s0140-6736(13)61809-7

Duggleby, W., Hicks, D., Nekolaichuk, C., Holtslander, L., Williams, A., Chambers, T., & Eby, J. (2012). Hope, older adults, and chronic illness: a metasynthesis of qualitative research. *Journal of Advanced Nursing*, *68*(6), 1211–1223. https://doi.org/10.1111/j.1365-2648.2011.05919.x

Eaton, A., Craig, S. L., & Wallace, R. (2017). The intersecting cognitive and aging needs of HIV-positive older adults: Implications for social work practice. *Social Work in Health Care*, *56*(8), 733–747. https://doi.org/10.1080/00981389.2017.1339759

Elendu, C., Aguocha, C. M., Okeke, C., Okoro, C. A., & Peterson, J. C. (2023). HIV-related neurocognitive disorders: Diagnosis, Treatment, and Mental Health Implications: A Review. *Medicine*, *102*(43), e35652. https://doi.org/10.1097/md.0000000000035652

El-Sadr, W., Lundgren, J. D., Neaton, J. D., Gordin, F. M., Abrams, D. I., Arduino, R. C., Babiker, A., Burman, W. J., Clumeck, N., Cohen, C., Cohn, D. V., Cooper, D. A., Darbyshire, J., Emery, S., Fätkenheuer, G., Gazzard, B., Grund, B., Hoy, J., Klingman,

K. L., . . . Rappoport, C. (2006). CD4+ Count–Guided interruption of antiretroviral treatment. *The New England Journal of Medicine*, *355*(22), 2283–2296. https://doi.org/10.1056/nejmoa062360

Folkman, S. (2008). The case for positive emotions in the stress process. Anxiety Stress & Coping, 21(1), 3–14. https://doi.org/10.1080/10615800701740457

Gallagher, S., BíRó, S., Creamer, E. K., Della Rossa, E., Collins, E., Rourke, S. B., & Nixon, S. (2012). "It's a Hidden Issue": Exploring the experiences of women with HIV-associated neurocognitive challenges using a disability framework. *Disability and Rehabilitation*, *35*(1), 36–46. https://doi.org/10.3109/09638288.2012.687029

Gregory, K., & Gibbs, D. (2002). AIDS dementia complex: the perception of loss of functional ability. *British Journal of Occupational Therapy*, *65*(11), 509–514. https://doi.org/10.1177/030802260206501105

Hanass-Hancock, J., Bond, V., Solomon, P., Cameron, C., Maimbolwa, M., Menon, J. A., & Nixon, S. (2019). Perspectives on ART adherence among Zambian adults living with HIV: insights raised using HIV-related disability frameworks. *AIDS Care*, *32*(5), 623–629. https://doi.org/10.1080/09540121.2019.1653441

Hanass-Hancock, J., Myezwa, H., Nixon, S., & Gibbs, A. (2014). "When I was no longer able to see and walk, that is when I was affected most": experiences of disability in people living with HIV in South Africa. *Disability and Rehabilitation*, *37*(22), 2051–2060. https://doi.org/10.3109/09638288.2014.993432

Heaton, R. K., Clifford, D. B., Franklin Jr, D. R., Woods, S. P., Ake, C., Vaida, F., & Charter Group. (2010). HIV-associated neurocognitive disorders persist in the era of potent antiretroviral therapy: CHARTER Study. *Neurology*, *75*(23), 2087-2096.

Hopcroft, L., Bester, L., Clément, D., Quigley, A., Sachdeva, M., Rourke, S. B., & Nixon, S. (2013). "My body's a 50 year-old but my brain is definitely an 85 year-old": exploring

the experiences of men ageing with HIV-associated neurocognitive challenges. *Journal of the International AIDS Society*, *16*(1). https://doi.org/10.7448/ias.16.1.18506

Hurt, C. S., Burn, D. J., Hindle, J. V., Samuel, M., Wilson, K., & Brown, R. G. (2013). Thinking positively about chronic illness: An exploration of optimism, illness perceptions and well-being in patients with Parkinson's disease. *British Journal of Health Psychology*, *19*(2), 363–379. https://doi.org/10.1111/bjhp.12043

Kulshreshtha, A., Alonso, Á., McClure, L. A., Hajjar, I., Manly, J. J., & Judd, S. E. (2023). Association of stress with cognitive function among older black and white US adults. *JAMA Network Open*, *6*(3), e231860. https://doi.org/10.1001/jamanetworkopen.2023.1860

Lachal, J., Révah-Levy, A., Orri, M., & Moro, M. R. (2017). Metasynthesis: an original method to synthesize qualitative literature in psychiatry. *Frontiers in Psychiatry*, *8*. https://doi.org/10.3389/fpsyt.2017.00269

Lam, J. O., Lee, C., Gilsanz, P., Hou, C. E., Leyden, W. A., Satre, D. D., Flamm, J., Towner, W., Horberg, M. A., & Silverberg, M. J. (2021). Comparison of dementia incidence and prevalence between individuals with and without HIV infection in primary care from 2000 to 2016. *AIDS*, *36*(3), 437–445. https://doi.org/10.1097/qad.0000000000003134

Lawler, K., Jeremiah, K., Mosepele, M., Ratcliffe, S. J., Cherry, C. L., Seloilwe, E., & Steenhoff, A. P. (2011). Neurobehavioral effects in HIV-Positive individuals receiving highly active antiretroviral therapy (HAART) in Gaborone, Botswana. *PLOS ONE*, *6*(2), e17233. https://doi.org/10.1371/journal.pone.0017233

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. Springer publishing company.

Lindl, K. A., Marks, D. R., Kolson, D. L., & Jordan-Sciutto, K. L. (2010). HIV-Associated Neurocognitive Disorder: Pathogenesis and therapeutic opportunities. Journal of

Neuroimmune Pharmacology, 5(3), 294–309. https://doi.org/10.1007/s11481-010-9205-z

Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D., Ballard, C., Banerjee, S., Burns, A., Cohen-Mansfield, J., Cooper, C., Fox, N., Gitlin, L. N., Howard, R., Kales, H. C., Larson, E. B., Ritchie, K., Rockwood, K., Sampson, E. L., Mukadam, N. (2017). Dementia prevention, intervention, and care. The Lancet, 390(10113), 2673–2734. https://doi.org/10.1016/s0140-6736(17)31363-6

Long, H., French, D. P., & Brooks, J. (2020). Optimising the value of the critical appraisal skills programme (CASP) tool for quality appraisal in qualitative evidence synthesis. *Research Methods in Medicine & Health Sciences*, *1*(1), 31–42. https://doi.org/10.1177/2632084320947559

Ma, L. (2020). Depression, anxiety, and apathy in mild Cognitive Impairment: Current Perspectives. Frontiers in Aging Neuroscience, 12. https://doi.org/10.3389/fnagi.2020.00009

McArthur, J. C., Hoover, D. R., Bacellar, H., Miller, E. N., Cohen, B. A., Becker, J. T., Graham, N. M., McArthur, J. C., Selnes, O. A., Jacobson, L. P., Visscher, B. R., Concha, M., & Saah, A. J. (1993). Dementia in AIDS patients. *Neurology*, *43*(11), 2245. https://doi.org/10.1212/wnl.43.11.2245

McIlvane, J. M., Popa, M. A., Robinson, B. E., Houseweart, K., & Haley, W. E. (2008). Perceptions of illness, coping, and well-being in persons with mild cognitive impairment and their care partners. *Alzheimer Disease & Associated Disorders*, *22*(3), 284–292. https://doi.org/10.1097/wad.0b013e318169d714

Mohammed, M. A., Moles, R. J., & Chen, T. F. (2016). Meta-synthesis of qualitative research: the challenges and opportunities. International Journal of Clinical Pharmacy. https://doi.org/10.1007/s11096-016-0289-2

Moskowitz, J. T., Hult, J. R., Bussolari, C., & Acree, M. (2009). What works in coping with HIV? A meta-analysis with implications for coping with serious illness. *Psychological Bulletin*, *135*(1), 121–141. https://doi.org/10.1037/a0014210

Myint, T., & Mash, B. (2008). Coping strategies and social support after receiving HIV-positive results at a South African district hospital. *SAMJ: South African Medical Journal*, *98*(4), 276-277.

Nanni, M. G., Caruso, R., Mitchell, A. J., Meggiolaro, E., & Grassi, L. (2014). Depression in HIV Infected Patients: a Review. *Current Psychiatry Reports*, *17*(1). https://doi.org/10.1007/s11920-014-0530-4

Nicholson, L. (2020) Achieving person-centred dementia care through a bio-psychosocial model. *Nursing Times* [online]; 117: 1, 50-53.

Nightingale, S., Ances, B. M., Cinque, P., Dravid, A., Dreyer, A. J., Gisslén, M., Joska, J. A., Kwasa, J., Meyer, A., Mpongo, N., Nakasujja, N., Pebody, R., Pozniak, A., Price, R. W., Sandford, C., Saylor, D., Thomas, K. G. F., Underwood, J., Vera, J. H., & Winston, A. (2023). Cognitive impairment in people living with HIV: consensus recommendations for a new approach. *Nature Reviews Neurology*, *19*(7), 424–433. https://doi.org/10.1038/s41582-023-00813-2

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis. International Journal of Qualitative Methods, 16(1). https://doi.org/10.1177/1609406917733847

O'Brien, K. K., Bergin, C., Solomon, P., O'Dea, S., Forde, C., & Vajravelu, S. (2019). Cross-cultural applicability of the episodic disability framework with adults living with HIV in Ireland: a qualitative study. *Disability and Rehabilitation*, *43*(2), 229–240. https://doi.org/10.1080/09638288.2019.1621395

Olmos-Vega, F. M., Stalmeijer, R. E., Varpio, L., & Kahlke, R. (2022). A practical guide to reflexivity in qualitative research: AMEE Guide No. 149. Medical Teacher, 45(3), 241–251. https://doi.org/10.1080/0142159x.2022.2057287

Ross, S. D., Hofbauer, L. M., & Rodriguez, F. S. (2022). Coping strategies for memory problems in everyday life of people with cognitive impairment and older adults: A systematic review. *International Journal of Geriatric Psychiatry*, *37*(5). https://doi.org/10.1002/gps.5701

Sacktor, N., Lyles, R. H., Skolasky, R. L., Kleeberger, C. A., Selnes, O. A., Miller, E. N., Becker, J. T., Cohen, B. A., & McArthur, J. C. (2001). HIV-associated neurologic disease incidence changes: *Neurology*, *56*(2), 257–260. https://doi.org/10.1212/wnl.56.2.257

Saylor, D., Dickens, A. M., Sacktor, N., Haughey, N. J., Slusher, B. S., Pletnikov, M., Mankowski, J. L., Brown, A., Volsky, D. J., & McArthur, J. C. (2016). HIV-associated neurocognitive disorder — pathogenesis and prospects for treatment. *Nature Reviews Neurology*, *12*(4), 234–248. https://doi.org/10.1038/nrneurol.2016.27

Siegel, K., & Schrimshaw, E. W. (2005). Stress, appraisal, and coping: a comparison of HIV-infected women in the pre-HAART and HAART eras. Journal of Psychosomatic Research, 58(3), 225–233. https://doi.org/10.1016/j.jpsychores.2004.09.002

Solomon, P., O'Brien, K. K., Nixon, S., Letts, L., Baxter, L., & Gervais, N. (2018). Qualitative longitudinal study of episodic disability experiences of older women living with HIV in Ontario, Canada. *BMJ Open*, *8*(4), e021507. https://doi.org/10.1136/bmjopen-2018-021507

Spector, A., & Orrell, M. (2010). Using a biopsychosocial model of dementia as a tool to guide clinical practice. International Psychogeriatrics, 22(6), 957–965. https://doi.org/10.1017/s1041610210000840

Stahl, N. A., & King, J. R. (2020). Expanding approaches for research: Understanding and using trustworthiness in qualitative research. *Journal of Developmental Education*, *44*(1), 26-28.

Teeraananchai, S., Kerr, S. J., Amin, J., Ruxrungtham, K., & Law, M. (2016). Life expectancy of HIV-positive people after starting combination antiretroviral therapy: a meta-analysis. *HIV Medicine*, *18*(4), 256–266. https://doi.org/10.1111/hiv.12421

Terpstra, A. R., Worthington, C., Ibàñez-Carrasco, F., O'Brien, K. K., Yamamoto, A., Carusone, S. C., Turje, R. B., McDougall, P., Granger, W. J., Thompson, V. C., DeSousa, M., Creal, L., Rae, A., Medina, C., Morley, E., & Rourke, S. B. (2018). "I'm just forgetting and I don't know why": Exploring how people living with HIV-Associated Neurocognitive Disorder view, manage, and obtain support for their cognitive difficulties. *Qualitative Health Research*, *28*(6), 859–872. https://doi.org/10.1177/1049732318761364

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8*(1). https://doi.org/10.1186/1471-2288-8-45

Thompson, S. C., Nanni, C., & Levine, A. M. (1996). The stressors and stress of being HIV-positive. *AIDS Care*, *8*(1), 5–14. https://doi.org/10.1080/09540129650125957

United Nations Programme on AIDS (UNAIDS; 2023) *Global HIV & AIDS statistics — Fact sheet*. unaids.org. https://www.unaids.org/en/resources/fact-sheet

Vance, D. E., Gakumo, C. A., Childs, G., Enah, C., & Fazeli, P. L. (2017). Perceptions of brain health and cognition in older African Americans and Caucasians with HIV: a focus group study. *Journal of the Association of Nurses in AIDS Care*, *28*(6), 862–876. https://doi.org/10.1016/j.jana.2017.07.006

Vance, D. E., Jensen, M., Tende, F., Walker, T. J., Robinson, J., Diehl, D., Fogger, S. A., & Fazeli, P. L. (2019). Informing adults with HIV of cognitive performance deficits indicative of HIV-Associated Neurocognitive Disorder: a content analysis. *Journal of Psychosocial Nursing and Mental Health Services*, *57*(12), 48–55. https://doi.org/10.3928/02793695-20190821-03

Vance, D. E., Robinson, J., Walker, T. J., Tende, F., Bradley, B., Diehl, D., McKie, P., & Fazeli, P. L. (2020). Reactions to a probable diagnosis of HIV-Associated Neurocognitive Disorder: a content analysis. *Journal of the Association of Nurses in AIDS Care*, *31*(3), 279–289. https://doi.org/10.1097/jnc.0000000000000120

Vastag, Z., Fira-Mlădinescu, O., & Roşca, E. C. (2022). HIV-Associated Neurocognitive Disorder (HAND): Obstacles to early neuropsychological diagnosis. *International Journal of General Medicine*, *Volume 15*, 4079–4090. https://doi.org/10.2147/ijgm.s295859

Wagner, A. C., McShane, K., Hart, T. A., & Margolese, S. (2016). A focus group qualitative study of HIV stigma in the Canadian healthcare system. *Canadian Journal of Human Sexuality*, *25*(1), 61–71. https://doi.org/10.3138/cjhs.251-a6

The Well Project (2023, September 23). *What are HIV & AIDS?*. https://www.thewellproject.org/hiv-information/what-are-hiv-aids

Wing, E. J. (2017). The aging population with HIV infection. *Transactions of the American Clinical and Climatological Association*, *128*, 131.

Woods, S. P., Moore, D. J., Weber, E., & Grant, I. (2009). Cognitive Neuropsychology of HIV-Associated Neurocognitive Disorders. Neuropsychology Review, 19(2), 152–168. https://doi.org/10.1007/s11065-009-9102-5

World Health Organization (WHO), (2022) *HIV drug resistance*. (2022). who.int. https://www.who.int/news-room/fact-sheets/detail/hiv-drug-resistance

World Health Organization: (WHO), (2024, July 22). HIV and AIDS. https://www.who.int/news-room/fact-sheets/detail/hiv-aids

Eliza Harris BSc

Section B: The Validity of the Montreal Cognitive Assessment as a Screening Tool for Mild and Major Neurocognitive Impairment due to HIV

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SALOMONS INSTITUTE
CANTERBURY CHRIST CHURCH UNIVERSITY

Abstract

Introduction & Aim: With the development of effective treatment, HIV is now considered a chronic condition. The effects of living with long-term HIV are now being researched, as it continues to increase the risk of certain health conditions, including cognitive impairment. Early diagnosis of cognitive impairment is beneficial to help understand newfound difficulties and gain support, therefore screening for cognitive impairment due to HIV is a value. This study aims to evaluate the validity of one particular screening tool, the Montreal Cognitive Assessment (MoCA) with the DSM-V criteria for cognitive impairment due to HIV.

Method & Analysis: The study had 86 participants who had completed the MoCA and a further clinical assessment, including neuropsychological testing. A Receiver Operating Characteristic (ROC) analysis was used to assess the suitability of the MoCA as a screening tool for this population, and a correlation analysis was conducted to evaluate the construct validity of the MoCA subscales.

Results: The ROC analysis produced an area under the curve of 0.83. The Youden's Index led to a threshold of 24.5/30 for the MoCA for an optimal cut-off between sensitivity and specificity. Each MoCA subtest correlated with several subtests that measured different cognitive domains.

Discussion: This study highlights the ethical implications of screening tools within healthcare services. Further research evaluating other potential screening tools would benefit services to ascertain the most sensitive and specific screening tool for neurocognitive disorder due to HIV.

Terminology

This research paper focuses on diagnostic criteria for neurocognitive difficulties. It is important to note that terms *disorder* and *impairment,* while widely used in the literature and clinical practice, can be problematic. These terms can imply that the difficulty lies with the individual, without fully acknowledging the broader systemic and environmental factors that may contribute to these challenges (Wakefield, 2007). These terms were nevertheless adopted in this report as it is the language that is generally used in the literature and most understood by the readership this report hopes to impact.

The term HIV-associated neurocognitive disorder (HAND) can refer to specific diagnostic criteria for cognitive impairments related to HIV (Antinori et al., 2007), or it can refer to a spectrum of cognitive impairments that are associated with HIV (Elendu et al., 2023), ranging from mild cognitive impairment to dementia. For the purposes of this paper, the latter definition of HAND will be used unless otherwise specified.

Introduction

The human immunodeficiency virus (HIV) is a virus that damages key cells in the immune system, weakening the body's ability to protect itself against infections and disease progression (World Health Organisation [WHO], 2024). When an individual's immune system is weakened, they become more vulnerable to opportunistic infections, cancers, or other conditions (Morris, 2020) which can be detrimental to their health and can ultimately be life threatening (Jones et al., 1999). There are three stages of HIV disease, with the most advanced stage being acquired immune deficiency syndrome (AIDS) which is when their CD4 count drops to a certain level, or sufferers have a specific opportunistic infection (Center for Disease Control and Prevention, 2023). Since the start of the HIV epidemic in the 1980s, approximately 42.3 million people have died from AIDS-related illnesses (UNAIDS, 2024).

Fortunately, over the past four decades, there have been drastic improvements to the prognosis for people infected with HIV due to the advances in research and the development of antiretroviral treatment (ART; Palmisano & Vella, 2011). ART consists of a group of antiretroviral drugs that suppress the viral load by preventing the virus from replicating (Myhre & Sifris, 2023). Thanks to ART, HIV is now considered a chronic condition rather than a terminal diagnosis (Elbirt et al., 2015), and there has been a significant reduction in the rates of HIV developing into AIDS (May et al., 2014).

Since the development of effective ART, the focus for healthcare professionals has changed from treating infections due to the depletion of the immune system, to managing the long-term complications of HIV and strong medication (Elbirt et al., 2015). Notably, HIV-associated neurocognitive disorder (HAND) has become an increasingly recognised complication for PLWHIV who are receiving ART (Elendu et al., 2023).

Before the discovery of effective treatment, HAND was observed in up to 50% of people with late-stage HIV (Alford et al., 2018). For those affected, the most severe form, HIV-associated

dementia (HAD) was reported in 15-20% of cases (McArthur et al., 1993; Sacktor et al., 2001). HAD is a progressive subcortical dementia characterised by impairments in cognitive, motor, and behavioural functions (Brew & Chan, 2014). Fortunately, ART has reduced the severity of neurocognitive challenges for people living with HIV (PWLHIV), however, the prevalence of the milder forms of HAND has increased (Heaton et al., 2010; Saylor et al. 2016). In the ART era, the cognitive difficulties experienced by those with HAND typically include poor concentration, impairments in memory and difficulties with executive functions (Woods et al., 2009). Attentional difficulties may manifest as problems with concentration and holding information in mind, while memory deficits can affect the ability to recall past events or learn new information (Sanmarti et al., 2014) Executive dysfunctions, including difficulties in organising, planning and problem-solving may also be prominent in those with HAND (Sanmarti et al., 2014). Caution should be taken when assessing for HAND, as cognitive difficulties may also stem from other factors such as medication side effects (Reust, 2011), fatigue (Campbell et al., 2022) or low mood (Rubin & Maki, 2019) can impact cognitive function in PLWHIV. These are distinct from HAND as they are not from the direct neurological impact of HIV. Therefore, it is essential to consider these contextual considerations when assessing cognitive impairment in PLWHIV, given the range of factors that may contribute to cognitive difficulties.

Cognitive difficulties are associated with lower quality of life for PLWHIV (Tozzi et al., 2003) and can pose a significant risk to people's physical and mental health. Qualitative studies with PLWHIV have highlighted possible explanations for this, including cognitive difficulties contributing to unplanned changes in employment (Hopcroft et al., 2013), increased isolation (Gallagher et al., 2012), reduction in recreational activities (Alford et al., 2021) and difficulties performing activities of daily living which subsequently harm individuals' sense of independence (Alford et al., 2022). Experiencing changes in several areas of life is associated

with a loss of sense of self (Alford et al., 2022), and many report that their cognitive impairment has reduced their self-esteem (Alford et al., 2022). In addition, many PLWHIV have described the emotional impact of their cognitive changes, including feelings of frustration and embarrassment when they struggle to remember or concentrate (Alford et al., 2022; Hopcroft et al., 2013; Terpstra et al., 2018) and increased low mood due to their cognitive difficulties (Hopcroft et al., 2013). Along with the impact on emotional well-being, cognitive impairment is linked to individuals forgetting to take their ART medication regularly (Ettenhofer et al., 2010), which could have severe consequences on their physical health.

The quality of life for individuals with chronic conditions is thought to be influenced by how the perceived challenges of the condition impact daily life (Bishop, 2005). Bishop's (2005) model incorporates psychosocial adaptation to chronic conditions with perceived quality of life, offering a holistic perspective on the individual's experience. It proposes that the distress a person feels regarding their disability is shaped by how dominant the difficulties are in a person's day-to-day life and activities. Early detection of cognitive impairments can provide an opportunity for individuals to receive appropriate rehabilitation, practical adaptations and psychological support. These interventions may help lessen the perceived impact of the cognitive challenges on daily life, thus potentially decreasing psychological distress. With the right support from healthcare professionals and the use of suitable rehabilitation models, individuals may develop new ways of coping with their newfound difficulties and reduce their interference with their day-to-day life (Livneh & Parker, 2005). This, in turn, may improve their illness perception and thus quality of life (Guzmán et al., 2020). Given the significant impact of mild cognitive difficulties on PLWHIV, early detection is crucial to provide the necessary support for both their cognitive difficulties and the emotional impact.

To provide PLWHIV with the appropriate support, professionals need to identify whether they are experiencing cognitive difficulties related to HIV, which is not always straightforward. The

"gold standard" for this is an extensive assessment, which includes a comprehensive battery of neuropsychological testing (Nightingale et al., 2023). Unfortunately, a full battery of neuropsychological assessments can be costly, take extensive time, and require specialist input from a clinical neuropsychologist with experience working with PLWHIV (Robinson-Papp et al., 2009). Therefore, is it not viable to regularly facilitate a full neuropsychological assessment with every PLWHIV at risk of cognitive impairment within the NHS. Thus, cognitive screening tools are important instruments to identify individuals who require further testing and must be evaluated for their suitability for specific conditions.

Several cognitive screening tools have been evaluated for their effectiveness in detecting HAND. These include the Montreal cognitive assessment (MoCA; Nasreddine et al., 2005; Fazeli et al., 2017), the international HIV dementia scale (Sacktor et al., 2005; Haddow et al., 2013), and the Mini-mental state examination (Folstein et al., 1983; Milanini et al., 2016). As HAND tends to cause mild cognitive impairment in PLWHIV, it is crucial that the screening tools being used are sufficiently able to identify mild impairment, and not only more severe forms of impairment. Although the international HIV dementia scale (Sacktor et al., 2005) was developed to screen for HAND, it is more appropriate for identifying severe forms of HAND and is not suitable for the milder forms of cognitive impairment (Mind Exchange Working Group, 2013).

Research found the MoCA to be a more sensitive screening tool for mild cognitive impairment and less prone to ceiling effects when compared to the mini-mental state examination (Jia et al., 2021; Milanini et al., 2014). As the MoCA has greater sensitivity for identifying people with mild cognitive difficulties, it could be a more effective screening tool for identifying people with neurocognitive disorders due to HIV.

The MoCA is a widely recognised, free cognitive screening tool, which has been translated into over 100 different languages. There has been a substantial amount of research evaluating

its reliability and validity across various populations and conditions, as detailed on the MoCA website (www.mocacognition.com). It aims to cover several cognitive domains, including memory, attention, and executive functions (Nasreddine, 2005), which are cognitive functions affected by HAND.

Previous research on the validity of the MoCA in identifying the diagnosis of HAND has yielded mixed results. Studies have indicated that the MoCA borders on poor to fair ability in identifying those with HAND (Fazeli et al., 2017; Janssen et al., 2014; Kim et al., 2016; Koeing et al., 2016; Milanini et al., 2014; Overton et al., 2013), according to the guidelines outlined by Li and He (2018). These studies all utilised the Frascati criteria to diagnose HAND (Antinori et al., 2007), which are the most commonly used criteria in both research and clinical practice (Ferretti et al, 2017; Nightingale et al., 2023). Table 1 shows a summary of the Frascati criteria. In recent years, the Frascati criteria have faced criticism from researchers and clinicians, who argue that it overestimates the prevalence of HAND within the HIV population (Gisslén et al., 2011; Nightingale et al., 2021). Gisslén and colleagues (2011) suggest that this is due to the lenient threshold of one standard deviation below appropriate norms to define cognitive impairment. Critics have also pointed out the criteria's overreliance on neuropsychological test scores for the diagnosis of HAND, failing to account for contextual factors that are known to influence these test results such as education, socioeconomic background, and comorbidities such as mood (Nightingale et a., 2021). It has been suggested that up to a third of healthy individuals score one standard deviation below the demographically adjusted norms on neuropsychological tests (Binder et al., 2009), raising concerns about this threshold potentially leading to a high false-positive rate (Nightingale et al., 2021). This emphasises the importance of contextualising neuropsychological test results and adopting a multidisciplinary approach to diagnosing neurocognitive impairments, as recommended by various guidelines for HIV-associated cognitive impairments (European AIDS Clinical Society [EACS], 2015; Mind

Exchange Working Group, 2013). Given the growing doubts about the clinical relevance of the Frascati criteria, there is a need for alternative diagnostic criteria that can be applied to both research and clinical settings (Nightingale et al., 2023).

Alternative criteria that can be used clinically are the Diagnostic and Statistical Manual of Mental Disorders (5^{th} edition; DSM-V) criteria for mild or major cognitive impairments associated with HIV (American Psychiatric Association [APA], 2013). These criteria differ from the Frascati criteria in several ways, shown in Table 1.

Table 1

The Frascati and DSM-V Criteria for Cognitive Impairment in PLWHIV

	Frascati Criteria (Antinori et al., 2007)	DSM-V Criteria for Neurocognitive Disorder (NCD) (APA, 2013)
Severity levels	Has 3 severity levels; 1. Asymptomatic Neurocognitive Impairment (ANI), 2. Mild Neurocognitive Disorder (MCD), 3. HIV Associated Dementia (HAD).	Has 2 severity levels: 1. Mild Neurocognitive Disorder 2. Major Neurocognitive Disorder
Threshold Criteria	**ANI** – falling one standard deviation (SD) below the mean of demographically adjusted normative scores in 2 cognitive domains. No subjective concerns are required. **MCD** – Same as ANI, but cognitive impairments interfere with 2 or more daily activities.	**Mild NCD** - "typically lies in the 1-2 SD range" – although this is not a formal threshold. The criteria focus on cognitive decline from the previous level of performance in one or more cognitive domains. Mild NCD does not interfere with capacity for independence, but greater effort or compensatory strategies may be required.
	HAD – test performance falling at least 2 SDs below the demographically normative mean and severe interference with daily living.	**Major NCD -** "typically falls two or more SD below appropriate norms" in one or more cognitive domains. This is a suggested threshold and is not a formal threshold to be used. These cognitive impairments must interfere with independence for everyday activities.
	There is no mention of clinical judgment in the criteria. Has more reliance on the population's "norms". Uses age-education-appropriate norms.	Criteria state that decline is based on objective assessment falling below the "expected level" or "previous level", suggesting clinical judgment and premorbid estimations. Both mild and major cognitive impairments require some subjective concerns from service users or someone who knows them.

The DSM-V criteria do not have a formal threshold for neuropsychological test scores within the criteria, although it does have a suggested threshold which it acknowledges must be interpreted with caution (APA, 2013). The criteria also recommend a more extensive assessment, such as serum HIV testing, neuroimaging, and a lumbar puncture to confirm diagnosis (APA, 2013). This is supported by diagnostic guidelines for cognitive impairment in PLWHIV (EACS, 2015; Exchange Working Group, 2013). Alford and colleagues (2019) emphasized the need for a holistic assessment which includes neuropsychological testing, but as part of a wider assessment. Otherwise, without the contextual interpretation of neuropsychological test results and further medical testing, the DSM-V criteria can suffer the same limitations as the Frascati criteria (Tierney et al., 2017).

There has been no research published evaluating the MoCA as a screening tool for the DSM-V criteria for neurocognitive disorders due to HIV. Consequently, the current study aimed to evaluate the sensitivity (the test's ability to correctly identify those with the condition) and specificity (the test's ability to correctly identify those without the condition) of the MoCA in screening for cognitive impairment in PLWHIV, as defined by the DSM-V criteria. A second aim of the study is to evaluate whether there is a correlation between the cognitive domains being measured in the MoCA and cognitive domains being measured by the tests used in a neuropsychological battery. This will evaluate whether the items in the MoCA and neuropsychological test battery measure the same cognitive domains (convergent validity), and whether MoCA subtests are distinct in measuring their intended constructs without significant overlap with unrelated domains (discriminant validity). Clarke-Carter (2024) recommends using correlation analysis to assess both convergent and discriminant validity, which supports the approach taken in this study.

By evaluating this screening tool, the hope was that the study would provide evidence for the appropriate use of the MoCA in screening for neurocognitive disorders due to HIV, aligning

with the NHS value *'commitment to quality of care'* (Department of Health, 2023). The aim was to evaluate whether the MoCA is sensitive and specific enough to identify people with mild or major cognitive impairment due to HIV. This will allow services to provide individuals who have been identified by the screening tool with further testing and support them with their difficulties, with the hope to *'improve lives'* (Department of Health, 2023) of the patients who are under their care.

Method

Design

The study had a cross-sectional design, and used both secondary and newly collected data.

Participants

The sample consisted of 86 participants, distributed between two subgroups.

The first subsample comprised 81 archival test scores. These participants completed the MoCA and neuropsychological testing as part of their routine assessment at a specialist service. Before gaining access to the archival data, there was a concern that it would include few or no participants who scored within the 'normal' range on the MoCA but had still undergone neuropsychological testing, as the service was purportedly using the MoCA as a screening tool to decide whether to undertake further testing. To address this, it was planned to supplement the archival data with a second subsample comprising neuropsychological data collected specifically for this study from participants who scored within the "normal" range on the MoCA, (i.e. 26 or above).

Initially, it was estimated that 25-30 people would need to be recruited to account for the possibility of false negatives, however, as 22 people had scored 26 or above and also completed further neuropsychological testing, the number of additional recruits needed was lowered to five to ten.

Subsample two consisted of five participants recruited from the HIV clinic in Southeast England. Healthcare professionals from the clinic identified participants who were PLWHIV and reported no concerns with cognitive function. The healthcare professional used their clinical judgement and knowledge of the service user to assess whether the potential participant would be suitable and unlikely to experience distress during the assessment process. Table 2 identifies the inclusion and exclusion criteria for the study.

Table 2

Inclusion and exclusion criteria

Subsample	Inclusion Criteria	Exclusion Criteria
Subsample One	Adults aged 18+ who had a diagnosis of HIV. Completed a MoCA test Completed the neuropsychological assessment as part of their care within an HIV memory service.	Individuals who were suspected to have a learning disability in their premorbid screening. Any neuropsychological assessments that were administered by a translator, as this compromises the standardisation of the assessments.
Subsample Two	Adults aged 18+ who had a diagnosis of HIV. A MoCA score of 26/30 or above. Had read and understood the participant form, the potential risks of participating, and consented to participate Who have a level of English deemed appropriate by the clinician to understand and complete the neuropsychological assessments.	Individuals who were suspected to have a learning disability in their premorbid screening.

Diagnosis of Neurocognitive Disorder

To assess for neurocognitive disorder due to HIV, subsample one received a full clinical assessment. The neuropsychological testing is one part of the wider assessment. If neuropsychological test scores were approximately 1.5 or more standard deviations below the estimated premorbid ability, this may flag a potential neurocognitive impairment. The scores are contextualised with information from other assessments, such as clinical history, information from an informant, medical test results (for example, a brain scan, blood tests, or lumbar puncture results), and demographic factors that may influence neuropsychological test scores. The subjective concerns regarding cognitive changes were also taken into account whilst interpreting the neuropsychological test scores.

A multidisciplinary team were involved in the assessment for subsample one, with a clinical neuropsychologist overseeing the interpretation of all the neuropsychological testing.

For subsample two, the participants had no subjective concerns regarding their cognitive function. A trainee clinical psychologist administered the neuropsychological testing under the supervision of the clinical neuropsychologist in the service. There were no indicators of a need for further testing within subsample two.

Measures

All participants completed the MoCA plus a battery of neuropsychological tests. The first subsample had completed this as part of a routine assessment by a clinical neuropsychologist, clinical psychologist, or an assistant psychologist under the supervision of the clinical neuropsychologist. The second subsample completed the same battery of neuropsychological tests which was facilitated by the trainee clinical psychologist. This battery was assembled by the service based on research and best practice guidelines. The measures were used to test

specific cognitive domains that have been observed to be affected in PLWHIV and cognitive impairment.

The neuropsychological battery consists of the following tests:

Montreal Cognitive Assessment (MoCA)

The MoCA is a 10-question pen-and-paper screening tool which aims to assess for mild cognitive impairment (Nasreddine, 2005). The test gives a total score out of 30, with a lower score suggesting cognitive impairment. Typically, a score of 26 or above indicates 'normal' cognitive functioning (Nasreddine, 2005). The test also provides subscale scores for attention (0-5), delayed memory (0-5), language (0-3), visuospatial and executive function (0-5), conceptual thinking (0-2) and orientation (0-6). The MoCA has good construct validity (Freitas et al., 2011; Vogel et al., 2015) and good internal reliability ($\alpha = 0.92$; Julayanont & Nasreddine, 2016). At the clinic, the MoCA is typically administered by a nurse or other trained professional before being referred to the memory clinic by a nurse or other trained professional. The earliest recorded MoCA was in August 2016 and the most recent was July 2024.

Depression, Anxiety and Stress Scale (DASS-21)

The DASS-21 (Lovibond & Lovibond, 1995) is a self-report scale that aims to measure depression, anxiety and stress. It has good internal reliability (Depression $\alpha = 0.94$, Anxiety $\alpha = 0.90$, Stress $\alpha = 0.93$) and construct validity (Crawford & Henry, 2003). This is incorporated in the neuropsychological battery as mood and stress are known to impact neuropsychological assessments and cognitive functioning (Muñoz-Moreno et al., 2021). Therefore, it is important to understand each individual's emotional state to inform the assessment.

Test of Premorbid Functioning (ToPF)

The ToPF (Weschler, 2009) is a word reading test consisting of 70 phonetically irregular words and is designed to estimate pre-morbid cognitive and memory functioning. This is used in clinical settings to have an informed estimate of an individual's previous cognitive ability (Weschler, 2009). ToPF aims to identify a broader range of IQ by testing word reading, which is more resilient to cognitive impairment and brain injury (Joseph et al., 2019). Weschler (2009) has reported good concurrent validity and internal reliability ($\alpha = 0.95$).

The ToPF provides a standard score (M = 100; SD = 15) for the estimation of premorbid IQ and memory abilities.

Repeatable Battery of the Assessment of Neuropsychological Status (RBANS)

The RBANS (Randolph, 1998) is a brief test which consists of 12 subtests that measure attention, language, visuospatial abilities, immediate memory, and delayed memory. Raw scores from each domain are converted to age-based standard scores (M = 100; SD = 15) and percentile scores, providing a domain-specific index score. The domain-specific indexes are attention, immediate memory, visuospatial, language, and delayed memory. The sum of the index scores is then converted to an overall standard score.

It has good internal reliability ($\alpha = 0.94$; Randolph, 1998) and demonstrated good accuracy and sensitivity in identifying mild cognitive impairments (Karantzoulis et al., 2013) as well as positive results for early identification of HAND in PLWHIV (Costaggiu et al., 2020). Table 3 shows a list of the subtests in the RBANS and the cognitive domain indexes.

Table 3

RBANS Subtest, Task, and the Domain Specific Indexes

Subtest	Task	Domain-Specific Index
List learning	Immediate recall of 10 words	Immediate Memory
Story Memory	Recall of a story consisting of 12 items	Immediate Memory
Figure Copy	Draw an exact copy of a complex figure whilst looking at the figure	Visuospatial perception
Line Orientation	Match the orientation and angle of two lines from a set of 11	Visuospatial perception
Picture Naming	Name 10 pictures	Language
Semantic Fluency	Name as many fruits and vegetables as possible within one minute	Language
Digit Span	Immediate recall of a string of numbers which increase by one digit each time.	Attention
Coding	Copy symbols to corresponding numbers within a time limit using a key provided	Attention
List Recall	Delayed recall of list of words which were given at the start of the test	Delayed Memory
List Recognition	Asked to identify which words from a new list were on the list at the start of the test.	Delayed Memory
Story Recall	Delayed recall of the story from the start of the test.	Delayed Memory
Figure Recall	Delayed recall of the figure seen at the figure copy	Delayed Memory

Colour-Word Interference Task (taken from Delis-Kaplans Executive Functioning System (D'KEFS)

The colour-word inference task (Delis et al., 2001) is a test to assess the executive functions of inhibition and switching. There are four trials within this task, which are outlined in Table 4. This subtest has good construct validity (Swanson, 2005).

Table 4

DKEFS Colour-Word Inference Trials

Trial	Task
Trial 1 – colour naming trial	The participant is presented with a page of coloured squares (blue, green, red). The participant is asked to name the colours as fast as they can.
Trial 2 – word reading trial	The page consists of the words 'blue', 'green' and 'red' written in black ink. The participant is asked to read the words as fast as they can.
Trial 3 – inhibition trial	The participant is shown a page which consists of the words 'blue', 'green', and 'red' which are written in incongruent coloured ink. The participant is asked to say the colour of the ink, not the word, as fast as they can.
Trial 4 – inhibition / switching trial	The participant is shown a page which consists of the words 'blue', 'green', and 'red' which are written in incongruent coloured ink. Some of the words are in a box. The participant is asked to say the colour of the ink, unless the word is in a box, then they should read the word. They are asked to do this as fast as they can.

Each trial is timed, and the time is converted into a standard score based on age range. These standard scores were converted into percentiles using the psychometric conversion table (Appendix 2).

Mazes Test (taken from Neuropsychological Assessment Battery; NAB)

The Mazes test (Stern & White, 2003) assesses the executive functions of planning and problem-solving. It is a pen-and-paper task where the individual is asked to draw a continuous line from the start to the end of three mazes, which increases in difficulty. This test has been found to have good construct validity (Zgaljardic & Temple, 2010).

Trail-Making

The trail-making task (Army Individual Test Battery, 1944) was designed to measure visual scanning and switching (Pérez-Parra & Restrepo-De-Mejia, 2023). The timed test has two parts: in the first part, the participant is asked to draw a line to connect consecutive numbers, the second part, the participant is asked to draw a line to connect alternative numbers and letters (one to A, A to two, two to B, B to three etc.) Trail-making tasks have good internal reliability (α =0.86; Wagner et al., 2011).

The time taken to complete the trail-making task is converted into a z-score. For this study, the z-score was then converted into a percentile score using a psychometric conversion table (Appendix 2).

Procedures

For subsample one, the participant scores were all secondary data. The data was collated into an anonymised dataset by the assistant psychologist from the care team. This dataset included an anonymised participant number, age at the time of testing, gender, individual MoCA scores, and raw and percentile scores for each of the neuropsychological subtests.

For the second subsample, participants were invited to participate in the study by a staff member at an HIV clinic. If they were interested in participating, they were asked to read a participant information sheet (PIS; Appendix 3). The PIS received feedback from the Terrence Higgins Trust (a charity for PLWHIV) support group to ensure it was accessible and included client-sensitive language. The feedback stated that it was appropriate, although it was quite lengthy. The research team attempted to reduce the information as much as possible without leaving necessary material out. Consenting participants were encouraged to take the information sheet home to think about and were given the option to take a PIS without the mention of HIV if preferred (Appendix 4). If they agreed to participate and consented, either their contact details were given to the research team, or they emailed their interest to a member of the research team. The trainee clinical psychologist contacted the participants to confirm that they understood the study and the potential risks and to answer any questions. Verbal consent was sought before organising a date for the neuropsychological testing. The participant met with the trainee clinical psychologist to complete the battery of tests. Prior to the testing, the participant was asked to sign a consent form. The battery of tests included the measures outlined above and took approximately 60-90 minutes. All participants were reminded of their right to pause for a break or withdraw at any time. Once the testing was complete, the active participation in the study had ended. Each participant in subsample two received a £10 voucher. The results of the neuropsychological tests were anonymised and input into the dataset. The scores were also uploaded to the participant's health records by a member of the care team.

Ethical Considerations

The study received ethical approval from an NHS research ethics committee (Appendix 6). The research team ensured that ethical considerations were continually thought about and discussed throughout the study.

For subsample one, information governance was an important consideration. The assistant psychologist from the care team collated and anonymised the archival data from service users who completed the neuropsychological battery as part of their care. This allowed personal and confidential information to be limited to only those who were in the care team and not within the wider research team. This procedure followed the guidance of the health research authority, which states that patient data can be used and does not require patient consent if the data is anonymised by the care team (Health Research Authority, n.d.).

For subsample two, the research team obtained verbal and written consent prior to participating. The research team also considered the potential impacts of neuropsychological testing. The testing can be a long process, which some find frustrating, tiring, or boring. As healthcare professionals who knew the potential participants were involved in the recruitment process, they were asked to use their knowledge of the service user and their clinical judgement to assess whether they would find the battery of tests distressing. To reduce distress during the testing, participants could pause the testing at any point or withdraw from testing completely. If the participant's neuropsychological test scores indicated that there were any concerns, the participant's information would be passed onto the specialist memory clinic for further clinical investigation. There were no indications of any neuropsychological impairment during the testing of the 5 recruited participants.

As the participants each completed a mood measure, there was the possibility that participants could disclose emotional distress. It was planned that the service's clinical procedures would be followed if this were to occur, including signposting to appropriate support or seeking immediate support if there was a significant, or imminent risk. In practice, there were no concerns identified in subsample two, therefore, no signposting or immediate support was necessary.

All the participant information was stored securely on NHS Microsoft OneDrive, as agreed by the sponsor and NHS ethics.

Data Analysis

A receiver operating characteristic (ROC) analysis was conducted to evaluate the performance of the MoCA in identifying whether a person had a cognitive impairment according to the DSM-V criteria for mild or major cognitive impairment due with HIV. ROC analysis aims to evaluate the accuracy of a diagnostic test and looks at the sensitivity and specificity at all possible test cut-offs (Mandrekar, 2010). Table 5 shows the guidelines outlined by Li and He (2018) which were used to interpret the results of the area under the ROC curve.

Table 5

Interpretations of the area under the curve (Li & He, 2018)

Area Under the Curve Value	Interpretation
≥ 0.9	Test is considered excellent
0.8-0.9	Test is considered good
0.7-0.8	Test is considered fair
0.6-0.7	Test is considered poor
Below 0.6	Test does not have discriminatory ability.

If the area under the curve is 0.6 or below, the test is not suitable as a measure to determine whether a person has a cognitive impairment or not. The Statistical Package for the Social Sciences (SPSS) was used to conduct this analysis.

For the second aim of this study, Spearman's correlation was used to identify whether there was a relationship between the scores of the MoCA subscales and the scores of the neuropsychological tests assessing the same cognitive domain. The scores from both

subsamples were converted to percentiles using normative data to allow for comparison between tests. Given that some of the data was not normally distributed, Spearman's test was used. SPSS was used to conduct this analysis.

Table 6 shows the cognitive domains outlined in the MoCA, the MoCA questions that make up this cognitive domain, and the neuropsychological battery assessing the same domain.

Table 6

Cognitive Domains Tested by MoCA and Neuropsychological Testing

Cognitive Domain	MoCA question	Neuropsychological battery score
Attention (/6)	Digit Span Letter A tapping Serial 7 subtractions	RBANS Attention Index
Delayed Memory (/5)	Delayed Word recall	RBANS Delayed Memory Index
Visuospatial / Executive Function (/5)	Copy a picture of a cube Clock Drawing	RBANS Visuospatial Index
	Trail Making	Trail Making test part B NAB Mazes DKEFS Colour Word Inferencing – Inhibition Condition
Language (/3)	Picture Naming Sentence Repetition Verbal Fluency	RBANS Language Index

Results for Aim One: ROC Analysis

Participants

Initial estimations from the clinical psychologist at the specialist clinic indicated that there were approximately 110 individuals who had completed the full neuropsychological battery of tests. This minimum sample size (n=110) would allow for the detection of an area under the curve (AUC) of 0.679 (assuming the ratio of positive cases / total sample size was 0.7; Lu, 2021). After further examination of the anonymised archival data and deletion of the participants without a MoCA score reported, the final sample size was smaller than anticipated (n=86). This sample size allowed for sufficient power (0.80) to detect an AUC of 0.724 (assuming ratio of positive cases was 0.72).

In total, there were 86 participants included in the analysis. The majority of the participants were male (n=74). The mean age of participants was 55.98 years old (SD=9.44), ranging from 37 to 86 years old. Twenty-five participants scored 26 or over on the MoCA, which was the current cut-off being used by the service. Fifty-nine of the participants received a diagnosis of either mild or major cognitive impairment after an extensive clinical assessment, including neuropsychological testing. Table 7 shows the demographic and clinical characteristics that were collected for this sample.

Table 7
Sample characteristics

Sample	Female	Male	Age (M)	No impairment	Diagnosis of mild cognitive impairment	Diagnosis of major cognitive impairment
Subsample One	11	68	56.35	19	52	10
Subsample Two	1	4	52.4	5	0	0
Total Sample	12 (13.95%)	74 (86.05%)	55.98	24 (27.91%)	52 (60.47%)	10 (11.62%)

ROC Analysis

The ability of the MoCA to identify whether a person has a cognitive impairment or not was in the "good" range (AUC=0.83), (95% CI, CI= 0.754 to 0.920, p=<.001). Figure 2 shows the ROC curve. Table 8 shows the sensitivity and specificity of the MoCA at different cut-off points according to the coordinates of the ROC curve. The Youden's index was calculated for each of the cut-off scores. The cut-off score of 24.5 produced the highest Youden's index (0.566).

Figure 1

ROC curve

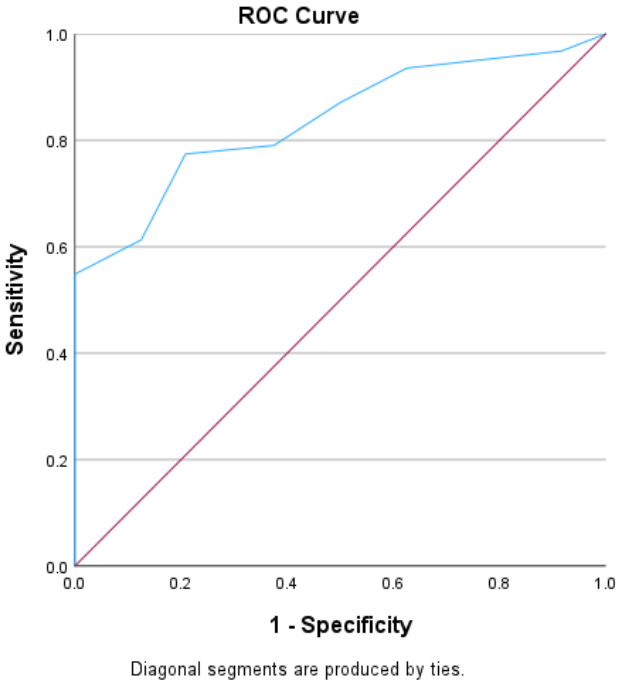

Table 8

Sensitivity and Specificity of Different Cut-Off Points

Cut-off score of MoCA	Sensitivity	1 - Specificity
17.5	.126	.000
18.5	.177	.000
19.5	.226	.000
20.5	.258	.000
21.5	.387	.000
22.5	.548	.000
23.5	.613	.125
24.5	.774	.208
25.5	.790	.375
26.5	.871	.500
27.5	.935	.625
28.5	.968	.917
29.5	.984	.958

Results for Aim 2: Spearman's Correlation

Participants

The participants included in the analysis of aim one were also included in the analysis of aim two. Two of the participants did not have their MoCA subscale scores and could not be included in the analysis, therefore the total number of participants was 84.

The missing data from subsample one is summarised in Table 9. The missing data was due to the participant not completing the subtest, the index score not being calculated due to missing subtests, or the data not being recorded in the patient records.

Table 9

Missing Data from Correlation Analysis

Subscale	Total Number of Participants	Missing Data
MoCA Visuospatial / Executive Function Score	84	0
MoCA Naming Score	84	0
MoCA Language Score	84	0
MoCA Abstraction Score	84	0
MoCA Delayed Recall Score	84	0
RBANS Visuospatial Index Score	83	1
RBANS Language Index Score	84	0
RBANS Attention Index Score	82	2
RBANS Delayed Memory Index Score	84	0
Trail B Score	82	2
NAB Mazes Score	82	2
DKEFS Inhibition Score	74	10

Spearman's Correlation Analysis

In the following tables, the subtests in bold represent the test measuring the same cognitive domain as the MoCA subscale.

Table 10 shows the results of the Spearman's correlation analysis between the MoCA attention subtest score and the neuropsychological test scores. The MoCA attention subtest score had a significant relationship with seven of the eight subtests, ranging from small to medium effect size (Field, 2013). In this sample, the strongest relationship was with the RBANS immediate memory index score.

Table 10

Spearman's Correlations between MoCA Attention Subscale and Neuropsychological Test Scores

	Correlation Coefficient	Confidence Interval	P value	Number of participants
RBANS Attention	.272*	.052 to .467	.013	82
RBANS Delayed Memory	.363**	.155 to .540	<.001	84
RBANS Immediate Memory	.390**	.186 to .563	<.001	84
RBANS Language	.277*	.060 to .496	.011	84
RBANS Visuospatial	.389**	.183 to .562	<.001	83
DKEFS Inhibition	.240*	.005 to .450	.040	74
Mazes	.155	-.070 to .366	.163	82
Trail B task	.485**	.294 to .639	<.001	82

** Correlation is significant at the 0.05 level*

*** Correlation is significant at the 0.01 level*

Correlations are reported for the MoCA subscale raw score X and for each neuropsychological test (percentiles from normative table).

Table 11 shows the results of the Spearman's correlation analysis between the MoCA delayed recall subtest score and the neuropsychological test scores. The MoCA delayed recall subtest score had a significant relationship with six of the eight subtests, ranging from small to large effect size (Field, 2013). In this sample, the strongest relationship was with the RBANS delayed memory index score.

Table 11

Spearman's Correlations Between MoCA Delayed Recall and Neuropsychological Test Scores

	Correlation Coefficient	Confidence Interval	P value	Number of participants
RBANS Attention	.160	-.066 to .370	.151	82
RBANS Delayed	.510**	.372 to .657	<.001	84
Memory				
RBANS Immediate	.346**	.137 to .527	<.001	84
Memory				
RBANS Language	.279*	.063 to .471	.010	84
RBANS Visuospatial	.378**	.170 to .553	<.001	83
DKEFS Inhibition	.137	-.102 to .360	.246	74
Mazes	.422**	.220 to .590	<.001	82
Trail B task	.338*	.124 to .521	.002	82

** Correlation is significant at the 0.05 level*

*** Correlation is significant at the 0.01 level*

Correlations are reported for the MoCA subscale raw score X each neuropsychological test (percentiles from normative table).

Table 12 shows the results of the Spearman's correlation analysis between the MoCA language subtest score and the neuropsychological test scores. The MoCA language subtest score had a significant relationship with five of the eight subtests, ranging from small to medium effect size (Field, 2013). In this sample, the strongest relationship was with the RBANS attention index score.

Table 12

Spearman's Correlations between MoCA Language and Neuropsychological Test Scores

	Correlation Coefficient	Confidence Interval	P value	Number of participants
RBANS Attention	.330*	.116 to .515	.043	82
RBANS Delayed Memory	.258*	.040 to .453	.018	84
RBANS Immediate Memory	.222*	.001 to .422	.043	84
RBANS Language	.321*	.108 to .506	.003	84
RBANS Visuospatial	.155	-.069 to .365	.161	83
DKEFS	.444	-.148 to .319	.090	74
Mazes	.272*	.052 to .467	.013	82
Trail B	.176	-.049 to .384	.114	82

** Correlation is significant at the 0.05 level*

*** Correlation is significant at the 0.01 level*

Correlations are reported for the MoCA subscale raw score X each neuropsychological test (percentiles from normative table).

Table 13 shows the results of the Spearman's correlation analysis between the MoCA visuospatial and executive function subtest score and the neuropsychological test scores. The

MoCA visuospatial and executive function subtest score had a significant relationship with seven of the eight subtests, ranging from small to large effect size (Field, 2013). In this sample, the strongest relationship was with the trail-making condition B score.

Table 13

Spearman's Correlations between MoCA Visuospatial and Executive Function and Neuropsychological Test Scores

	Correlation Coefficient	Confidence Interval	P value	Number of participants
RBANS Attention	.251*	.029 to .449	0.23	82
RBANS Delayed Memory	.393**	.189 to .564	<.001	84
RBANS Immediate Memory	.430**	.232 to .594	<.001	84
RBANS Language	.264*	.047 to .458	.015	84
RBANS Visuospatial	.297**	.081 to .487	.006	83
DKEFS Inhibition	.137	-.102 to .360	.245	74
Mazes	.431**	.229 to .596	<.001	82
Trail B task	.552**	.375 to .690	<.001	82

** Correlation is significant at the 0.05 level*

*** Correlation is significant at the 0.01 level*

Correlations are reported for the MoCA subscale raw score X each neuropsychological test (percentiles from normative table).

Discussion

This study aimed to evaluate the validity of the MoCA as a screening tool for neurocognitive disorder due to HIV, using the DSM-V criteria. The study's second aim was to evaluate the convergent and discriminant validity between the MoCA subtest scores and a selection of neuropsychological tests for this population.

The primary findings were that the MoCA was a suitable screening tool for identifying PLWHIV who met the neurocognitive disorder diagnostic criteria at least according to the criteria defined by Li and He (2018). Previous studies evaluating the MoCA using the Frascati criteria for HAND reported a lower area under the curve, suggesting it was bordering on acceptable and poor discrimination between people with and without HAND (Fazeli et al., 2017; Janssen et al., 2015; Koenig et al., 2015; Ku et al., 2014; Overton et al., 2013). One potential explanation for the differences in these results is the Frascati criteria's threshold of one standard deviation, which as discussed in the introduction, may be too lenient. This can be problematic as this result can be seen in healthy individuals (Binder et al., 2009) and it relies on the normative test data being an accurate depiction of the clinical population (Nightingale et al., 2014). Gisslén and colleagues (2011) suggest that the cut-off of one standard deviation may lead to false positives and, thus an unrepresentative prevalence of cognitive impairment in the population. Given the subtle nature of asymptomatic neurocognitive impairment, it is unlikely that there is a screening tool that could achieve sufficient sensitivity and specificity to reliably identify this diagnosis (Joska et al., 2018). The reliance on one form of testing and a lower cut-off for diagnosis with neuropsychological testing may have reduced the diagnostic accuracy of the MoCA for the Frascati criteria compared to the DSM-V criteria. Participants who received a diagnosis had a full clinical assessment, including multidisciplinary input, medical assessments, and the consideration of contextual factors when interpreting

neuropsychological test results as recommended for neurocognitive assessments (EACS, 2015; Mind Exchange Working Group, 2013).

Notably, the area under the curve result aligns more closely with prior research evaluating the MoCA for mild cognitive impairments caused by other conditions, such as Parkinson's or Alzheimer's. These studies reported the MoCA to have good discrimination abilities between people with and without mild cognitive impairment, with AUC values ranging from 0.85 to 0.88 (Ciesielska et al., 2016; Dalrymple-Alford et al., 2010; Freitas et al., 2013). This may reflect the similarities in the DSM-V criteria and other mild cognitive impairment criteria.

The ROC analysis also provided sensitivity and specificity estimates for a range of cut-offs for the MoCA. There are several ways to determine the most appropriate cut-off point (Habibzadeh et al., 2016), and as with every screening tool, there must be a compromise between sensitivity and specificity. One of the most common ways to identify the optimal cut-off point is using the Youden's Index (Çorbacıoğlu & Aksel, 2023). This index combines sensitivity and specificity for each score, identifying where both metrics meet their peak (Çorbacıoğlu & Aksel, 2023; Schisterman et al., 2007). The Youden's Index ranges from zero to one, with zero indicating no diagnostic ability and one indicating perfect sensitivity and specificity (Çorbacıoğlu & Aksel, 2023). In this study, a score of 24.5 yielded the highest Youden's Index (0.566), providing a sensitivity of 77% and a specificity of 79%. Hence, a cut-off of 24 or below would correctly identify 77% of people with HAND, and 79% of people who do not have HAND would score 25 or above and therefore not be identified for further testing. This score does not quite reach the desired trade-off of sensitivity ≥80% and specificity ≥60%, which is frequently used in research for cognitive screening tools (Stolwyk et al., 2014). The score of 25.5 is closer to this desired cut-off (sensitivity 79%, specificity 62.5%). Compared to prior research using the Frascati criteria, the cut-off falls within the range suggested by previous studies, which ranged from 22 to 26 (Fazeli et al., 2017; Janssen et al., 2015; Koenig et al., 2015; Ku et al.,

2016; Overton et al., 2013). These studies, however, tended to have lower levels of sensitivity and specificity with these cut-offs.

No screening tool is perfect, and there is always a risk of false negatives, where individuals with the condition go undetected, and false positives, where individuals without the condition are mistakenly flagged for further testing. This trade-off is evident in this analysis, which estimates that if a cut-off of 24 is used then approximately 23% of people with HAND will not be identified for further testing, potentially delaying their diagnosis. Additionally, approximately 21% of people will be incorrectly identified as needing further testing, which could cause potential anxiety and stress for individuals, and be costly for some services. When selecting the most appropriate cut-off, services should consider their specific circumstances and values to determine a balance of sensitivity and specificity. Services can have limited resources, making procedures such as neuropsychological testing expensive and time-consuming, which highlights the importance of specificity. This must be compared to the costs of missing individuals who score over the cut-off, and thus will not be identified for further testing, however, meet the criteria for a cognitive impairment. This can delay treatment and could negatively impact the psychological and emotional well-being of an individual.

This study also evaluated the convergent and discriminant validity of the MoCA subscale scores and the scores from a battery of neuropsychological tests. This involved assessing the relationships between the MoCA subscale scores with more in-depth tests which aim to measure the same cognitive construct/domain, as well as between the different cognitive constructs.

The MoCA aims to test eight cognitive domains: attention, delayed recall, language, visuospatial and executive function, abstraction, naming, and orientation (Nasreddine, 2005). The neurocognitive battery included several different neuropsychological tests which explored these cognitive domains in more depth. The strength of the correlation coefficient was

determined using criteria defined by Field (2013). It was found that each of the MoCA subscale scores had significant positive relationships with several subscales from the neuropsychological battery of tests.

Theoretically, one would expect the MoCA attention subscale to have a positive correlation with the RBANS attention index score (Mirsky, 2018). The results were partially in agreement with this expectation. Within this sample, the MoCA attention subscale had a significant moderate association with the RBANS immediate memory index score, RBANS visuospatial index score, RBANS delayed memory Index score, and the trail-making B score. It has a weak association with the RBANS attention index score, RBANS language score, and the colour-word inference inhibition score from the DKEFS. Neuropsychologists have reported difficulties in measuring attention, as many tasks that measure attention also require other abilities (Manly et al., 2013), which may impact the results. It is surprising, however, that the attention subscale in the MoCA did not have a stronger relationship with the RBANS attention scale. Theorists have suggested that attention utilises different systems for distinct attentional functions (Manly et al., 2013). These different functions are considered to include focus, execute, sustain, encode, and shift. These elements of attention are thought to be supported by different regions of the brain. Therefore, it may be that the MoCA attention subscale measures a different element of attention to the RBANS attention index, and the subtests that have a stronger relationship with the MoCA attention subscale may be assessing similar elements of attention.

As would be expected, the MoCA delayed recall subscale had the strongest association with the RBANS delayed memory index in this sample, which was a positive, moderate relationship. This MoCA subscale also had some significant weak to moderate associations with several of the subscales from the neurocognitive battery of tests, which suggests that it may not be very specific at measuring delayed memory within this sample. Similarly, the MoCA language

subscale had a significant weak to moderate relationship with several of the subtest scores, including RBANS immediate memory index, RBANS visuospatial index, RBANS delayed memory index, and the mazes subtest. The strongest relationship was a moderate effect size with the RBANS attention index, and the second strongest was with the RBANS language index score. Whilst attention is a construct that is required in several of the subtests, it would be expected for the strongest relationship to be with the RBANS language index as they aim to measure the same construct.

The MoCA's visuospatial and executive function subscale aims to measure two cognitive domains. Four subtests in the battery aimed to measure either visuospatial ability or executive function: RBANS visuospatial index, the trail-making B condition (switching and visual scanning), the mazes task (planning), and the DKEFS colour-word inference inhibition task (inhibition and switching). Therefore, we would expect this MoCA subscale to have the strongest relationship with these subtests. The MoCA subtest score correlated significantly with seven of the eight subtests. The strongest relationship was with the trail-making B task, which demonstrated a large effect size. This result was expected, as the MoCA contains a shortened version of this task to assess executive function. In contrast, there was only a small correlation between this MoCA subscale score and the RBANS visuospatial index. Criticism of the scoring criteria for the RBANS visuospatial tests, which are considered somewhat subjective and possibly unreliable (Duff et al., 2007) may account for the weak relationship between the two. Surprisingly, the only subtest that did not have a significant relationship with the MoCA visuospatial and executive function subscale was the DKEFS colour-word inference inhibition score. Given that both subtests assess the executive function of switching, it would be expected for these two scores to be correlated. There are two possible explanations for this. Firstly, this MoCA subscale consists of three tasks, only one of which measures executive function (the trail-making task), whilst the other two measure visuospatial ability. The limited

emphasis on executive function may have led to this lack of significance between the two. Secondly, the DKEFS subtest had ten fewer participant scores, which reduced the statistical power and potentially prevented the detection of a small correlation.

Overall, the results of the correlational analysis were not as would theoretically be expected. For this sample, the MoCA subscales were not very specific in the cognitive domains they aimed to measure as each subscale correlated with several subtests measuring different cognitive domains. Therefore, it would not be recommended to draw definitive conclusions regarding an individual's ability in specific cognitive domains based on their subscale score on the MoCA domains. If an individual's cognitive strengths and difficulties needed to be mapped, further testing would be necessary. As the MoCA is a brief screening tool, it is designed to be short and therefore is unlikely to fully evaluate all aspects of a cognitive domain. Whilst this is useful for detecting general cognitive difficulties, it is unlikely to provide enough detail to fully evaluate an individual's strengths and challenges and is not intended to replace a comprehensive neuropsychological assessment (Cullen et al., 2006).

Limitations

There were several limitations to this study. Firstly, the large majority of the sample were male (86%), and all were fluent in English, which limits the generalisability of the results. In the UK, 68% of PLWHIV accessing HIV care were male (UK HIV Statistics, n.d.). The estimated percentage of men living with HIV worldwide is 47% (UNAIDS, 2024), and with higher percentage of women and girls having HIV in eastern and southern Africa (UNAIDS, 2024). Therefore, broader national and international use of the MoCA as a screening tool for PLWHIV remains to be determined, including MoCA tests in other languages. Whilst one of the study's significant strengths is the use of a clinical sample, a limitation of this study is the lack of control of some extraneous variables. For example, although the tests are standardised and have

scoring manuals, the testing was administered and scored by several different clinicians, which may have resulted in different scoring standards for some of the tests.

Despite the limitations, this study has made a valuable contribution to research for PLWHIV and HAND as it is the first study to explore the validity of a screening tool for the DSM-V criteria of HAND. Additionally, it is the first study evaluating the MoCA for PLWHIV using a clinical sample, which used both neuropsychological test scores and further medical investigations to diagnose HAND.

Implications for Future Research

To further these findings, future research should explore the validity of the MoCA in other countries and a more diverse population. The cultural sensitivity of the DSM-V criteria for HAND should also be investigated further. Furthermore, as there are currently no other studies evaluating screening tools for the DSM-V criteria of HAND, researchers should also evaluate the validity of other cognitive screening tools with the DSM-V criteria of HAND which could help ascertain which screening tool has the best diagnostic accuracy for this criteria and population.

Clinical Implications

There are important ethical issues regarding screening tools and their use within services. As aforementioned in the introduction, preferably, all individuals would have a full clinical assessment, including a neuropsychological battery, to assess for cognitive impairment. Due to the financial costs, extensive time required, and need for specialist input (Mitrushina, 2009), this is rarely viable in public services. Screening tools, such as the MoCA, have the potential to cause harm to individuals by falsely identifying a need for further testing, or by not identifying individuals with the condition they are being screened for (WHO, 2020). Harm from screening tools can often be overlooked when compared to the benefits (Petticrew et al.,

2001), however, it is critical for services to consider the stress and anxiety that the tests can cause (WHO, 2020), as well as the potential risks for individuals who require further testing but are not identified by the screening tool. Therefore, if specific cut-off criteria were to be decided by a service, they must weigh the benefits and costs of the use, whilst ensuring they are incorporating their own values and ethics (WHO, 2020). A potential way to increase the sensitivity is by professionals who administer the screening tool taking a brief history from the individual, noting clinical observations whilst undertaking the screening test, and assessing their self-report of cognitive function (Mitrushina, 2009). This, with the results, may provide a more detailed screening assessment and could identify those who have a cognitive impairment but score above the service's cut-off criteria. This may, however, require a neuropsychological specialist to administer the screening tool, which may not be viable in some services.

The MoCA was designed to be a brief cognitive screening tool to identify individuals who need further testing. The test takes approximately 10 minutes to facilitate, and therefore can only partially assess some of the constructs it aims to measure, lacking the scope required for a comprehensive evaluation. When compared to a gold standard battery of tests, the cognitive domains being tested by the MoCA do not appear to be very specific and correlate with several different cognitive domains. This may be adequate for a brief screening tool, however, it highlights the importance of more in-depth testing and the limitations of the MoCA. Many services, both nationally and internationally, have limited resources impacting the ability for these services to provide regular neuropsychological testing and further medical testing which are recommended when diagnosing HAND (American Psychiatry Association, 2013), there is a need for brief and free tests that are accurate in diagnosing conditions such as HAND. This is a complex problem, and although this study may support the MoCA being used as a screening tool, it is not recommended to use the MoCA as a diagnostic tool for this population.

Conclusion

According to the criteria set out by Li and He (2018), the results from this study suggest that the MoCA is a suitable screening tool for identifying those who have mild or major neurocognitive disorder due to HIV, and those who do not. However, deciding on a cut-off score raises important ethical issues regarding the sensitivity of the screening tool. Whilst the MoCA subscale scores did all have a relationship with the scores of the neuropsychological test measuring the same cognitive domains, it also had significant, and sometimes stronger, relationships with other domains. This suggests that whilst the MoCA does measure these domains, it may not be very specific for this population, and therefore clinicians should refrain from making conclusions regarding individual subscale scores and an individual's cognitive difficulties. This also highlights the importance of using the MoCA as a screening tool, and not as a diagnostic tool as it does not replace the need for more in-depth neuropsychological assessment.

References

Alford, K., Banerjee, S., Nixon, E., O'Brien, C., Pounds, O., Butler, A., Elphick, C., Henshaw, P., Anderson, S., & Vera, J. H. (2019). Assessment and Management of HIV-Associated Cognitive Impairment: Experience from a Multidisciplinary Memory Service for People Living with HIV. *Brain Sciences*, *9*(2), 37. https://doi.org/10.3390/brainsci9020037

Alford, K., & Vera, J. H. (2018). Cognitive Impairment in people living with HIV in the ART era: A Review. *British Medical Bulletin*, *127*(1), 55–68. https://doi.org/10.1093/bmb/ldy019

Alford, K., Daley, S., Banerjee, S., & Vera, J. H. (2021). Quality of life in people living with HIV-associated neurocognitive disorder: A scoping review study. *PLOS ONE*, *16*(5), e0251944. https://doi.org/10.1371/journal.pone.0251944

Alford, K., Daley, S., Banerjee, S., Hamlyn, E., Trotman, D., & Vera, J. H. (2022). "A fog that impacts everything": a qualitative study of health-related quality of life in people living with HIV who have cognitive impairment. *Quality of Life Research*, *31*(10), 3019–3030. https://doi.org/10.1007/s11136-022-03150-x

American Psychiatric Association. (2013). Neurocognitive Disorders. In *Diagnostic and statistical manual of mental disorders* (5th ed., text rev.) 10.1176/appi.ajp.2013.13020179

Antinori, A., Arendt, G., Becker, J. T., Brew, B. J., Byrd, D. A., Cherner, M., Clifford, D. B., Cinque, P., Epstein, L. G., Goodkin, K., Gisslen, M., Grant, I., Heaton, R. K., Joseph, J., Marder, K., Marra, C. M., McArthur, J. C., Nunn, M., Price, R. W., Wojna, V. E. (2007). Updated research nosology for HIV-associated neurocognitive disorders. Neurology, 69(18), 1789–1799. https://doi.org/10.1212/01.wnl.0000287431.88658.8b

Army Individual Test Battery. (1944). Manual of directions and scoring. Washington, DC: War Department, Adjutant General's Office.

Binder, L. M., Iverson, G. L., & Brooks, B. L. (2009). To Err is Human: "Abnormal" Neuropsychological Scores and Variability are Common in Healthy Adults. Archives of Clinical Neuropsychology, 24(1), 31–46. https://doi.org/10.1093/arclin/acn001

Bishop, M. (2005). Quality of life and psychosocial adaptation to chronic illness and disability. Rehabilitation Counseling Bulletin, 48(4), 219–231. https://doi.org/10.1177/00343552050480040301

Brew, B. J., & Chan, P. (2014). Update on HIV Dementia and HIV-Associated Neurocognitive Disorders. Current Neurology and Neuroscience Reports, 14(8). https://doi.org/10.1007/s11910-014-0468-2

Campbell, L. M., Sun-Suslow, N., Heaton, A., Heaton, R. K., Ellis, R. J., Moore, D. J., & Moore, R. C. (2022). Fatigue is associated with worse cognitive and everyday functioning in older persons with HIV. AIDS, 36(6), 763–772. https://doi.org/10.1097/qad.0000000000003162

Center for Disease Control and Prevention (2023) AIDS - health, United States. https://www.cdc.gov/nchs/hus/sources-definitions/aids.htm

Ciesielska, N., Sokołowski, R., Mazur, E., Podhorecka, M., Polak-Szabela, A., & Kędziora-Kornatowska, K. (2016). Is the Montreal Cognitive Assessment (MoCA) test better suited than the Mini-Mental State Examination (MMSE) in mild cognitive impairment (MCI) detection among people aged over 60? Meta-analysis. Psychiatria Polska, 50(5), 1039–1052. https://doi.org/10.12740/pp/45368

Çorbacıoğlu, Ş. K., & Aksel, G. (2023). Receiver operating characteristic curve analysis in diagnostic accuracy studies: A guide to interpreting the area under the curve value. Turkish Journal of Emergency Medicine, 23(4), 195–198. https://doi.org/10.4103/tjem.tjem_182_23

Costaggiu, D., Pinna, E., Serchisu, L., Barcellona, D., Piano, P., Ortu, F., Marongiu, F., & Mandas, A. (2020). The Repeatable Battery for the Assessment of Neuropsychological Status as a screening strategy for HIV-Associated Neurocognitive Disorders. AIDS Care, 33(3), 357–363. https://doi.org/10.1080/09540121.2020.1742859

Crawford, J. R., & Henry, J. D. (2003). The Depression Anxiety Stress Scales (DASS): Normative data and latent structure in a large non-clinical sample. British Journal of Clinical Psychology, 42(2), 111–131. https://doi.org/10.1348/014466503321903544

Cullen, B., O'Neill, B., Evans, J. J., Coen, R. F., & Lawlor, B. A. (2006). A review of screening tests for cognitive impairment. Journal of Neurology Neurosurgery & Psychiatry, 78(8), 790–799. https://doi.org/10.1136/jnnp.2006.095414

Dalrymple-Alford, J., MacAskill, Nakas, C., Livingston, L., Graham, C., Crucian, G., Melzer, T., Kirwan, J., Keenan, R., Wells, S., Porter, R., Watts, R., & Anderson, T. (2010). The MOCA. Neurology, 75(19), 1717–1725. https://doi.org/10.1212/wnl.0b013e3181fc29c9

Delis, D.C., Kaplan, E., & Kramer, J.H. (2001). The Delis-Kaplan Executive Function System. San Antonio: The Psychological Corporation.

Department of Health. (2023). The NHS Constitution for England. The Department of Health and Social Care. https://www.gov.uk/government/publications/the-nhs-constitution-for-england/thenhs-constitution-for-england

Duff, K., Leber, W. R., Patton, D. E., Schoenberg, M. R., Mold, J. W., Scott, J. G., & Adams, R. L. (2007). Modified scoring criteria for the RBANS figures. Applied Neuropsychology, 14(2), 73–83. https://doi.org/10.1080/09084280701319805

Elbirt, D. M., Mahlab-Guri, K., Bazalel-Rosenberg, S., Attali, M., & Asher, I. (2015). HIV-associated neurocognitive disorders (HAND). Isr. Med. Assoc. J, 17, 54.

Elendu, C., Aguocha, C. M., Okeke, C., Okoro, C. A., & Peterson, J. C. (2023). HIV-related neurocognitive disorders: Diagnosis, Treatment, and Mental Health Implications: A Review. *Medicine*, *102*(43), e35652. https://doi.org/10.1097/md.0000000000035652

Ettenhofer, M. L., Foley, J., Castellon, S. A., & Hinkin, C. H. (2010). Reciprocal prediction of medication adherence and neurocognition in HIV/AIDS. *Neurology*, *74*(15), 1217–1222. https://doi.org/10.1212/wnl.0b013e3181d8c1ca

Fazeli, P. L., Casaletto, K. B., Paolillo, E., Moore, R. C., Moore, D. J., & Group, N. T. H. (2017). Screening for neurocognitive impairment in HIV-positive adults aged 50 years and older: Montreal Cognitive Assessment relates to self-reported and clinician-rated everyday functioning. Journal of Clinical and Experimental Neuropsychology, 39(9), 842–853. https://doi.org/10.1080/13803395.2016.1273319

Ferretti, F., Mora-Peris, B., Underwood, J., Waldman, A., Everitt, A., & Winston, A. (2017). Cognitive impairment in a clinical setting. JAIDS Journal of Acquired Immune Deficiency Syndromes, 77(1), e10–e13. https://doi.org/10.1097/qai.0000000000001547

Folstein, M. F., Robins, L. N., & Helzer, J. E. (1983). The Mini-Mental State Examination. Archives of General Psychiatry, 40(7), 812. https://doi.org/10.1001/archpsyc.1983.01790060110016

Field, A. (2013). *Discovering statistics using IBM SPSS statistics* (4th ed.). SAGE Publications.

Freitas, S., Simões, M. R., Marôco, J., Alves, L. B., & Santana, I. (2011). Construct validity of the Montreal Cognitive Assessment (MOCA). *Journal of the International Neuropsychological Society (Print)*, *18*(2), 242–250. https://doi.org/10.1017/s1355617711001573

Gallagher, S., BíRó, S., Creamer, E. K., Della Rossa, E., Collins, E., Rourke, S. B., & Nixon, S. (2012). "It's a Hidden Issue": Exploring the experiences of women with HIV-associated neurocognitive challenges using a disability framework. *Disability and Rehabilitation*, *35*(1), 36–46. https://doi.org/10.3109/09638288.2012.687029

Gisslén, M., Price, R. W., & Nilsson, S. (2011). The definition of HIV-associated neurocognitive disorders: are we overestimating the real prevalence? BMC Infectious Diseases, 11(1). https://doi.org/10.1186/1471-2334-11-356

Guzmán, A., Gillanders, D., Stevenson, A., & Ross, K. (2020). Psychosocial adjustment to Mild Cognitive Impairment: The role of illness perceptions, cognitive fusion and cognitive impairment. *Dementia*, *20*(2), 464–484. https://doi.org/10.1177/1471301219893862

Haddow, L., Floyd, S., Copas, A., & Gilson, R. (2013). A systematic review of the screening accuracy of the HIV dementia scale and international HIV dementia scale. *PLOS ONE*, *8*(4), e61826. https://doi.org/10.1371/journal.pone.0061826

Habibzadeh, F., Habibzadeh, P., & Yadollahie, M. (2016). On determining the most appropriate test cut-off value: the case of tests with continuous results. Biochemia Medica, 297–307. https://doi.org/10.11613/bm.2016.034

Health Research Authority (n.d.) Guidance for using patient data. https://www.hra.nhs.uk/covid-19-research/guidance-using-patient-data/

Heaton, R. K., Clifford, D. B., Franklin Jr, D. R., Woods, S. P., Ake, C., Vaida, F., & Charter Group. (2010). HIV-associated neurocognitive disorders persist in the era of potent antiretroviral therapy: CHARTER Study. *Neurology*, *75*(23), 2087-2096.

Homack, S., Lee, D., & Riccio, C. A. (2005). Test Review: Delis-Kaplan Executive Function System. Journal of Clinical and Experimental Neuropsychology, 27(5), 599–609. https://doi.org/10.1080/13803390490918444

Hopcroft, L., Bester, L., Clément, D., Quigley, A., Sachdeva, M., Rourke, S. B., & Nixon, S. (2013). "My body's a 50 year-old but my brain is definitely an 85 year-old": exploring the experiences of men ageing with HIV-associated neurocognitive challenges. *Journal of the International AIDS Society*, *16*(1). https://doi.org/10.7448/ias.16.1.18506

Janssen, M. a. M., Bosch, M., Koopmans, P. P., & Kessels, R. P. C. (2015). Validity of the Montreal Cognitive Assessment and the HIV Dementia Scale in the assessment of cognitive impairment in HIV-1 infected patients. Journal of NeuroVirology, 21(4), 383–390. https://doi.org/10.1007/s13365-015-0324-4

Jia, X., Wang, Z., Huang, F., Su, C., Du, W., Jiang, H., Wang, H., Wang, J., Wang, F., Su, W., Xiao, H., Wang, Y., & Zhang, B. (2021). A comparison of the Mini-Mental State Examination (MMSE) with the Montreal Cognitive Assessment (MoCA) for mild cognitive impairment screening in Chinese middle-aged and older population: a cross-sectional study. *BMC Psychiatry*, *21*(1). https://doi.org/10.1186/s12888-021-03495-6

Jones, J. L., Hanson, D. L., Dworkin, M. S., Alderton, D. L., Fleming, P. L., Kaplan, J. E., & Ward, J. (1999). Surveillance for AIDS-defining opportunistic illnesses, 1992–1997. *Archives of Dermatology*, *135*(8), 897-902.

Joseph, A. L. C., Lippa, S. M., McNally, S. M., Garcia, K. M., Leary, J. B., Dsurney, J., & Chan, L. (2019). Estimating premorbid intelligence in persons with traumatic brain injury: an examination of the Test of Premorbid Functioning. Applied Neuropsychology: Adult, 28(5), 535–543. https://doi.org/10.1080/23279095.2019.1661247

Joska, J. A., Witten, J., Thomas, K. G., Robertson, C., Casson-Crook, M., Roosa, H., Creighton, J., Lyons, J., McArthur, J., & Sacktor, N. C. (2016). A comparison of five brief screening tools for HIV-Associated neurocognitive disorders in the USA and South Africa. AIDS and Behavior, 20(8), 1621–1631. https://doi.org/10.1007/s10461-016-1316-y

Julayanont, P., & Nasreddine, Z. S. (2016). Montreal Cognitive Assessment (MOCA): Concept and Clinical review. In Springer eBooks (pp. 139–195). https://doi.org/10.1007/978-3-319-44775-9_7

Karantzoulis, S., Novitski, J., Gold, M., & Randolph, C. (2013). The Repeatable Battery for the Assessment of Neuropsychological Status (RBANS): Utility in Detection and Characterization of Mild Cognitive Impairment due to Alzheimer's Disease. *Archives of Clinical Neuropsychology*, *28*(8), 837–844. https://doi.org/10.1093/arclin/act057

Kim, W. J., Ku, N. S., Lee, Y., Ahn, J. Y., Kim, S. B., Ahn, H., Hong, K., Song, J. Y., Cheong, H. J., Kim, W. J., Kim, J. M., Namkoong, K., Choi, J. Y., & Kim, E. (2015). Utility of the Montreal Cognitive Assessment (MoCA) and its subset in HIV-associated neurocognitive disorder (HAND) screening. Journal of Psychosomatic Research, 80, 53–57. https://doi.org/10.1016/j.jpsychores.2015.11.006

Koenig, N., Fujiwara, E., Gill, M. J., & Power, C. (2015). Montreal Cognitive Assessment Performance in HIV/AIDS: Impact of Systemic Factors. Canadian Journal of Neurological Sciences / Journal Canadien Des Sciences Neurologiques, 43(1), 157–162. https://doi.org/10.1017/cjn.2015.306

Ku, N., Lee, Y., Ahn, J., Song, J., Kim, M., Kim, S., Jeong, S., Hong, K., Kim, E., Han, S., Song, J., Cheong, H., Song, Y., Kim, W., Kim, J., Smith, D., & Choi, J. (2014). HIV-associated neurocognitive disorder in HIV-infected Koreans: the Korean NeuroAIDS Project. HIV Medicine, 15(8), 470–477. https://doi.org/10.1111/hiv.12137

Li, F., & He, H. (2018). Assessing the accuracy of diagnostic tests. PubMed, 30(3), 207–212. https://doi.org/10.11919/j.issn.1002-0829.218052

Livneh, H., & Parker, R. M. (2005). Psychological adaptation to disability: Perspectives from chaos and complexity theory. Rehabilitation Counseling Bulletin, 49(1), 17-28.

Lovibond, S. H., & Lovibond, P. F. (1995). Depression anxiety stress scales. *Psychological Assessment*.

Lu, G. (2021) "Sample Size Formulas For Estimating Areas Under the Receiver Operating Characteristic Curves With Precision and Assurance". Electronic Thesis and Dissertation Repository. 8045. https://ir.lib.uwo.ca/etd/8045

Mandrekar, J. N. (2010). Receiver operating characteristic curve in diagnostic test assessment. Journal of Thoracic Oncology, 5(9), 1315–1316. https://doi.org/10.1097/jto.0b013e3181ec173d

Manly, T., Fish, J., & Mattingley, J. B. (2013). Visuo-spatial and attentional disorders. In L. H. Goldstein & J. E. McNeil (Eds.), *Clinical neuropsychology: A practical guide to assessment and management for clinicians* (2nd ed., pp. 261–291). Wiley Blackwell.

May, M. T., Gompels, M., Delpech, V., Porter, K., Orkin, C., Kegg, S., Hay, P., Johnson, M., Palfreeman, A., Gilson, R., Chadwick, D., Martin, F., Hill, T., Walsh, J., Post, F., Fisher, M., Ainsworth, J., Jose, S., Leen, C., Sabin, C. (2014). Impact on life expectancy of HIV-1 positive individuals of CD4+ cell count and viral load response to antiretroviral therapy. *AIDS*, *28*(8), 1193–1202. https://doi.org/10.1097/qad.0000000000000243

McArthur, J. C., Hoover, D. R., Bacellar, H., Miller, E. N., Cohen, B. A., Becker, J. T., Graham, N. M., McArthur, J. C., Selnes, O. A., Jacobson, L. P., Visscher, B. R., Concha, M., & Saah, A. J. (1993). Dementia in AIDS patients. *Neurology*, *43*(11), 2245. https://doi.org/10.1212/wnl.43.11.2245

Milanini, B., Ciccarelli, N., Fabbiani, M., Baldonero, E., Limiti, S., Gagliardini, R., Borghetti, A., D'Avino, A., Mondi, A., Colafigli, M., Cauda, R., & Di Giambenedetto, S. (2016). Neuropsychological screening tools in Italian HIV+ patients: a comparison of Montreal Cognitive Assessment (MoCA) and Mini Mental State Examination (MMSE). The Clinical Neuropsychologist, 30(sup1), 1457–1468. https://doi.org/10.1080/13854046.2016.1183048

Milanini, B., Wendelken, L. A., Esmaeili-Firidouni, P., Chartier, M., Crouch, P., & Valcour, V. (2014). The Montreal Cognitive Assessment to screen for cognitive impairment in HIV patients older than 60 years. JAIDS Journal of Acquired Immune Deficiency Syndromes, 67(1), 67–70. https://doi.org/10.1097/qai.0000000000000220

Mind Exchange Working Group, Antinori, A., Arendt, G., Grant, I., Letendre, S., Chair, ... & Drapato, A. W. (2013). Assessment, diagnosis, and treatment of HIV-associated neurocognitive disorder: a consensus report of the mind exchange program. *Clinical Infectious Diseases*, *56*(7), 1004-1017. https://doi.org/10.1093/cid/cis975

Mirsky, A. F. (2018). The neuropsychology of attention: Elements of a complex behavior. *Integrating theory and practice in clinical neuropsychology*, 75-92.

Mitrushina, M. (2009). Cognitive screening methods. *Neuropsychological assessment of neuropsychiatric and neuromedical disorders*, 101-126.

Morris, S. Y. (2020). *Opportunistic infections in HIV*. Healthline. https://www.healthline.com/health/hiv-aids/opportunistic-infections

Muñoz-Moreno, J. A., Cysique, L. A., & Rourke, S. B. (2021). Neuropsychiatric Disorders, Emotional Disturbances, and Their Associations with HIV-Associated Neurocognitive Disorder. In *Current topics in behavioral neurosciences* (pp. 347–366). https://doi.org/10.1007/7854_2021_233

Myhre, J. & Sifris, J. M. (2023). *How antiretroviral therapy works for HIV*. Verywell Health. https://www.verywellhealth.com/antiretroviral-therapy-5216107

Nasreddine, Z. S., Phillips, N. A., Bédirian, V., Charbonneau, S., Whitehead, V., Collin, I., Cummings, J. L., & Chertkow, H. (2005). The Montreal Cognitive Assessment, MOCA: a brief screening tool for mild cognitive impairment. *Journal of the American Geriatrics Society*, *53*(4), 695–699. https://doi.org/10.1111/j.1532-5415.2005.53221.x

Nightingale, S., Winston, A., Letendre, S., Michael, B. D., McArthur, J. C., Khoo, S., & Solomon, T. (2014). Controversies in HIV-associated neurocognitive disorders. *The Lancet Neurology*, *13*(11), 1139-1151.

Nightingale, S., Dreyer, A. J., Saylor, D., Gisslén, M., Winston, A., & Joska, J. A. (2021). Moving on from HAND: why we need new criteria for cognitive impairment in persons living with human immunodeficiency virus and a proposed way forward. *Clinical Infectious Diseases*, *73*(6), 1113-1118.

Nightingale, S., Ances, B., Cinque, P., Dravid, A., Dreyer, A. J., Gisslén, M., & Winston, A. (2023). Cognitive impairment in people living with HIV: consensus recommendations for a new approach. *Nature Reviews Neurology*, *19*(7), 424-433.

Overton, E. T., Azad, T. D., Parker, N., Shaw, D. D., Frain, J., Spitz, T., Westerhaus, E., Paul, R., Clifford, D. B., & Ances, B. M. (2013). The Alzheimer's disease-8 and Montreal Cognitive Assessment as screening tools for neurocognitive impairment in HIV-infected persons. Journal of NeuroVirology, 19(1), 109–116. https://doi.org/10.1007/s13365-012-0147-5

Palmisano, L., & Vella, S. (2011). A brief history of antiretroviral therapy of HIV infection: success and challenges. *DOAJ (DOAJ: Directory of Open Access Journals)*, *47*(1), 44–48. https://doi.org/10.4415/ann_11_01_10

Pérez-Parra, J. E., & Restrepo-De-Mejía, F. (2023). The Trail Making Test (part B) is associated with working memory: A concurrent validity study. Applied Neuropsychology Adult, 1–9. https://doi.org/10.1080/23279095.2023.2171793

Petticrew, M., Sowden, A., & Lister-Sharp, D. (2001). False-Negative Results in Screening Programs. International Journal of Technology Assessment in Health Care, 17(2), 164–170. https://doi.org/10.1017/s0266462300105021

Randolph, C., Tierney, M. C., Mohr, E., & Chase, T. N. (1998). The Repeatable Battery for the Assessment of Neuropsychological Status (RBANS): Preliminary Clinical Validity. Journal of Clinical and Experimental Neuropsychology, 20(3), 310–319. https://doi.org/10.1076/jcen.20.3.310.823

Reust, C. E. (2011). Common adverse effects of antiretroviral therapy for HIV disease. PubMed, 83(12), 1443–1451. https://pubmed.ncbi.nlm.nih.gov/21671545

Robinson-Papp, J., Elliott, K. J., & Simpson, D. M. (2009). HIV-related neurocognitive impairment in the HAART era. Current HIV/AIDS Reports, 6(3), 146–152. https://doi.org/10.1007/s11904-009-0020-1

Rubin, L. H., & Maki, P. M. (2019). HIV, depression, and cognitive impairment in the era of effective antiretroviral therapy. Current HIV/AIDS Reports, 16(1), 82–95. https://doi.org/10.1007/s11904-019-00421-0

Sacktor, N., Lyles, R. H., Skolasky, R. L., Kleeberger, C. A., Selnes, O. A., Miller, E. N., Becker, J. T., Cohen, B. A., & McArthur, J. C. (2001). HIV-associated neurologic disease incidence changes: *Neurology*, *56*(2), 257–260. https://doi.org/10.1212/wnl.56.2.257

Sacktor, N. C., Wong, M., Nakasujja, N., Skolasky, R. L., Selnes, O. A., Musisi, S., ... & Katabira, E. (2005). The International HIV Dementia Scale: a new rapid screening test for HIV dementia. *Aids*, *19*(13), 1367-1374. 10.1097/01.aids.0000180790.77379.3a

Sandel, N., Emami, K., Tedaldi, E., Fischer, T., & Minniti, N. (2015). Neuropsychological domains: executive functions C-35 Construct Validity of NAB Mazes and Relationship with CD4+ T-cell Nadirs in an Urban HIV+ Cohort. *Archives of Clinical Neuropsychology*, *30*(6), 575.3-576. https://doi.org/10.1093/arclin/acv047.237

Sanmarti, M., Ibáñez, L., Huertas, S., Badenes, D., Dalmau, D., Slevin, M., ... & Jaen, A. (2014). HIV-associated neurocognitive disorders. *Journal of molecular psychiatry*, *2*, 1-10.

Saylor, D., Dickens, A. M., Sacktor, N., Haughey, N. J., Slusher, B. S., Pletnikov, M., Mankowski, J. L., Brown, A., Volsky, D. J., & McArthur, J. C. (2016). HIV-associated neurocognitive disorder — pathogenesis and prospects for treatment. *Nature Reviews Neurology*, *12*(4), 234–248. https://doi.org/10.1038/nrneurol.2016.27

Schisterman, E. F., Faraggi, D., Reiser, B., & Hu, J. (2007). Youden Index and the optimal threshold for markers with mass at zero. Statistics in Medicine, 27(2), 297–315. https://doi.org/10.1002/sim.2993

Stern, R. A., & White, T. (2003). NAB, Neuropsychological Assessment Battery: Administration, scoring, and interpretation manual. Lutz: Psychological Assessment Resources.

Stolwyk, R. J., O'Neill, M. H., McKay, A. J., & Wong, D. K. (2014). Are cognitive screening tools sensitive and specific enough for use after stroke? Stroke, 45(10), 3129–3134. https://doi.org/10.1161/strokeaha.114.004232

Swanson, J. (2005). The Delis-Kaplan Executive Function System. Canadian Journal of School Psychology, 20(1–2), 117–128. https://doi.org/10.1177/0829573506295469

Terpstra, A. R., Worthington, C., Ibàñez-Carrasco, F., O'Brien, K. K., Yamamoto, A., Carusone, S. C., Turje, R. B., McDougall, P., Granger, W. J., Thompson, V. C., DeSousa, M., Creal, L., Rae, A., Medina, C., Morley, E., & Rourke, S. B. (2018). "I'm just forgetting and I don't know why": Exploring how people living with HIV-Associated Neurocognitive Disorder view, manage, and obtain support for their cognitive difficulties. *Qualitative Health Research, 28*(6), 859–872. https://doi.org/10.1177/1049732318761364

Tierney, S. M., Sheppard, D. P., Kordovski, V. M., Faytell, M. P., Avci, G., & Woods, S. P. (2017). A comparison of the sensitivity, stability, and reliability of three diagnostic schemes for HIV-associated neurocognitive disorders. *Journal of NeuroVirology*, *23*(3), 404–421. https://doi.org/10.1007/s13365-016-0510-z

Tozzi, V., Balestra, P., Galgani, S., Murri, R., Bellagamba, R., Narciso, P., Antinori, A., Giulianelli, M., Tosi, G., Costa, M., Sampaolesi, A., Fantoni, M., Noto, P., Ippolito, G., & Wu, A. W. (2003). Neurocognitive Performance and Quality of Life in Patients

with HIV Infection. *AIDS Research and Human Retroviruses*, *19*(8), 643–652. https://doi.org/10.1089/088922203322280856

UNAIDS. (2024). Global HIV statistics [Report]. https://www.unaids.org/sites/default/files/media_asset/UNAIDS_FactSheet_en.pdf

UK HIV Statistics | National AIDS Trust. (n.d.). https://www.nat.org.uk/about-hiv/hiv-statistics#:~:text=36.4%25%20were%20women.-,Ethnicity,and%2028.4%25%20were%20Black%20African.

World Health Organisation: (WHO) (2020). Screening programmes: a short guide. In https://iris.who.int/. https://iris.who.int/bitstream/handle/10665/330829/9789289054782-eng.pdf

World Health Organization: (WHO), (2024, July 22). HIV and AIDS. https://www.who.int/news-room/fact-sheets/detail/hiv-aids

HIV and AIDS. https://www.who.int/news-room/fact-sheets/detail/hiv-aids

Wagner, S., Helmreich, I., Dahmen, N., Lieb, K., & Tadic, A. (2011). Reliability of three alternate forms of the trail making tests A and B. Archives of Clinical Neuropsychology, 26(4), 314–321. https://doi.org/10.1093/arclin/acr024

Wakefield, J. C. (2007). The concept of mental disorder: diagnostic implications of the harmful dysfunction analysis. PubMed, 6(3), 149–156. https://pubmed.ncbi.nlm.nih.gov/18188432

Wechsler, D. (2009). Test of premorbid functioning: UK edition: London: Pearson Press

Woods, S. P., Moore, D. J., Weber, E., & Grant, I. (2009). Cognitive Neuropsychology of HIV-Associated Neurocognitive Disorders. *Neuropsychology Review*, *19*(2), 152–168. https://doi.org/10.1007/s11065-009-9102

Zgaljardic, D. J., & Temple, R. O. (2010). Neuropsychological Assessment Battery (NAB): Performance in a Sample of Patients with Moderate-to-Severe Traumatic Brain

Injury. Applied Neuropsychology, 17(4), 283–288.

https://doi.org/10.1080/09084282.2010.525118

Section C

Appendix 1

Quality Appraisal

Appraisal Criteria	Akhtar et al., 207	Alford et al., 2022	Cummins et al., 2018	Eaton et al., 2017	Gallagher et al., 2012	Gregory & Gibbs, 2002	Hanass-Hancock et al., 2014	Hanass-Hancock et al., 2019	Hopcroft et al., 2018	O'Brien et al., 2019	Terpstra et al., 2018	Solomon et al., 2018	Vance et al., 2017	Vance et al., 2019	Vance et al., 2020
Was there a clear statement of the aims of the study?	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Was a qualitative methodology appropriate?	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Was the research design appropriate to address the aims of the research?	**Yes** Explanation of methodological design and justification why it was chosen.	**Partial** Explained methodology design, did not justify why this was used.	**Partial** Justification of the questions asked in survey, no clear justification for why qualitative aspect.	**Yes** Justification of why mixed-methods was chosen. No specific qualitative design specified.	**Yes** Qualitative methodological design specified and justified.	**Yes** Design specified and justified.	**Yes** Explanation of how and why the ICF was used. No design specified.	**Partial** Only states "qualitative longitudinal" – no justification or explanation further than this.	**Yes** Explanation of framework used (EDF) and for qualitative design.	**Yes** Explanation of why qualitative descriptive design used.	**Partial** Appropriate design method, but this was not justified.	**Yes** Discussed the design and how it worked over time. No explicit naming of the design	**Partial** Appropriate use of focus groups and qualitative design – however no mention of the design method.	**Yes** Discussed why qualitative responses were important for research.	**Partial** Qualitative design appropriate. No methodological design specified or justified.
Was the recruitment strategy appropriate	**Partial** Explanation on how participant	**Yes** Clear description of	**Yes** Explanation on why	**No/Unknown** Sampling method	**Yes** Explained how the participant	**Yes** Explained how participant	**Yes** Explained how participant	**Partial** Appropriate sample. Explanati	**Yes** Explained how participant	**Yes** Explained why sampling	**Yes** Did not specify why these	**Partial** Does not specify where or	**Yes** Sample were participant	**Yes** Explained how sample	**Partial**

to the aims of the research?	s were recruited, and justification of criteria. Not explicitly specified why these participants were the most appropriate and very limited demographics of participants.	recruitment. No clear explanation why these participants were most appropriate. Gave age, ethnicity, and other demographic information.	some were excluded	named. Not clear where recruitment took place, vague mention of "network" or how interviewees were selected. No mention of inclusion / exclusion criteria.	s were selected and the inclusion and exclusion criteria were explained. Limited demographics on sample.	s were selected. No demographic data given (no ages, no ethnicity). Small sample size.	s were selected and how they considered diversity	on of how sites of recruitment were chosen. Did not explain how participants were selected from the sites – just that it was purposive sampling dependent on 3 criteria.	s were contacted. Did not specify why some did not choose to participate	method was used and why particular demo-graphics sought. Did not discuss why some people chose not to take part.	participants were most relevant. Promoted diversity in sample.	how many "community organisations". No justification for inclusion criteria.	for the aim, inclusion and exclusion criteria were justified. No justification for choice of ethnicities (e.g. not including other global majority groups).	was recruited. Demographics of sample reported. Justified exclusion criteria.	
Was the data collected in a way that addressed the research issue?	**Yes** Framework for interviews justified. Clear explanation of data collection. Form clear.	**Yes** Setting was justified and clear how data was collected. Clear interview guide and how this was created.	**Partial** Clear how data was collected. No justification for survey.	**Partial** Clear how data was collected. The form of data was not clear.	**Yes** Clear data collection, by who, and form of data was clear. Setting not justified.	**Yes** Clear how data was collected and the form of the data.	**Yes** Clear how data was collected, by whom, and how the interview guide was developed. Clear form of data.	**Partial** Form of data clear. Unsure how data was collected – whether structured or semi-structured interviews. No details of questions in guide.	**Yes** Clear how data was collected and use of interview guide. Form of data was clear. Setting not justified.	**Yes** Justified method of data collection. Data saturation mentioned in discussion.	**Yes** Clear how the data was collected and how the guide was later modified. Form of data was clear.	**Yes** Explained how longitudinal design worked for data collection & framework for interviews.	**Partial** Clear how data was gathered, but no justification for use of focus groups. Form of data was clear and saturation discussed.	**Yes** Explained how data was collected and what the questions were. Form of data mentioned.	**Partial** Short and vague explanation of data collection
Has the relationship between researcher and participant been adequately considered?	**Yes** Section on trustworthiness and how risks of potential biases were reduced.	**No** Roles of research team made explicit, but were not reflected upon. No mention of how	**No** Although the researcher did not interview, there was no mention of how the questions were	**Partial** Discussed peer researchers and why they were used.	**Partial** Discussed roles in the research team and specified that two team members coded the transcript	**Yes** Bracketing discussed, and further explanation of trustworthiness and credibility.	**No** No reflexivity discussed.	**No** No reflexivity discussed. Mentions diverse team for analysis, but does not specify.	**No** No reflexivity discussed.	**No** No reflexivity discussed.	**Partial** Roles of the research team discussed and included peer research associates. Did not	**No** No mention of the roles within the research team. The team member who	**No** No mention of reflexivity	**No** No mention of reflexivity.	**No** No mention of reflexivity

		any potential bias was reduced.	devised or how they were involved in qualitative analysis		who had not conducted interviews. Roles of co-supervisors were not reflected on.						reflexively discuss how these could impact.	conducted the interviews did not develop the research question. Discussed EBE involvement.			
Have ethical issues been taken into consideration?	**Partial** Ethical approval sought. Interviewer was experienced in working with vulnerable people. No mention of informed consent.	**Partial** Discussed informed consent and involved consultant's view on capacity to consent. No mention of ethical approval.	**Yes** Ethical approval sought, consent was explained on the survey, data was anonymised	**Partial** Ethical approval obtained. No mention of consent or potential ethical issues or consent.	**Yes** Ethical approval sought. Mention of capacity. No mention of potential ethical risks.	**Yes** Ethical approval sought and explanation of ethical considerations for consent described. Some mention of other ethical considerations.	**Yes** Ethical approval sought. Small mention of informed consent	**Yes** Ethical approval sought. Informed consent mentioned.	**Yes** Some mention of ethical approval and consent. No mention of potential ethical risks.	**Partial** Mention of ethical approval sought, but no mention of consent. Explains use of 1:1 interviews due to sensitive nature, but no other potential ethical issues discussed.	**Yes** Mention of ethical approval sought. Did not specify the ethical risks, but did note that the risks were discussed with potential participants and how informed consent was obtained.	**No** No mention of ethical approval, and no discussion of issues raised by the study. Did mention that interviewer had experience of conducting interviews with vulnerable populations.	**Yes** Ethical approval sought, consent and anonymity in group discussed. No mention of the effects of the study during or after.	**Yes** Ethical approval was sought, and consent was mentioned. Discussed ethical considerations of diagnosis in the introduction, however, did not explain how these were considered in the study.	**Yes** Ethical approval sought, ethics of diagnosis mentioned in the introduction, and participants with concerns able to call researcher. Not justification of receiving a probable diagnosis by letter. Did offer support if concerned.
Was the data analysis sufficiently rigorous?	**Yes** Good explanation of how the analysis was conducted.	**Yes** Good explanation of analysis, and by who. Team-	**No** Only reports the qualitative themes in the results section. No mention	**Yes** Explanation of steps the analysis. No formal analysis specified.	**Yes** Explanation of steps of the analysis. No analysis method	**Partial** Brief explanation of method. Considered	**Yes** Team analysed data. Steps of analysis explained. Analysis stated.	**Yes** Analysis method was named and explained. Some quotes	**Partial** Good explanation of how the analysis, specified the analysis	**Partial** Good explanation of the data analysis. The researcher who	**Yes** Gave step-by-step analysis, and included the team in the	**Yes** Gave step-by-step details of analysis. Involved whole research team.	**Yes** Gave detailed description of the analysis. Did not examine	**Yes** Gave short description of steps. Used two independent coders.	**Partial** 2 coders were used, gave brief steps about how data was analysed.

	No specific analysis mentioned.	based analysis.	of how these themes were analysed, by who.		was specified. Used team members who did not conduct interviews to code.	researchers role. Not specified steps and who conducted analysis.		provided – not many for the number of participants and length of study. Researcher role not examined	used. No reflexivity from researcher Not clear how the longitudinal aspect was considered in analysis.	conducted the interviews also did the analysis, which was not discussed.	analysis process.	Did not reflect on own role or potential bias.	researcher influence.		No reflexivity and explanation was brief.
Is there a clear statement of findings?	**Yes** Findings were explicit and a lot of raw data was provided. Results were discussed in relation to research question and current literature. Limitations were discussed.	**Yes** Clear, explicit findings. Provided a lot of raw data for each theme. Findings discussed in context of wider literature and study aims. Limitations were discussed. No mention of credibility.	**Partial** Findings were explicit, however, there was not much discussion on the qualitative data within the study an the interpretation that can be made	**Yes** Clear explicit findings, discussed in relation to research questions and existing literature. Some mention of credibility (peer researchers).	**Yes** Clear explicit findings, provided raw data. Discussed findings in relation to aims and current literature. Limitations acknowledged. No mention of credibility.	**Yes** Clear explicit findings, provided raw data. Discussed findings in relation to aims and current research.	**Partial** Explicit reporting of findings and good amount of quotes provided. Limitations were not discussed.	**Partial** Not clear the longitudinal changes. Limitations not adequately explored. Credibility not discussed.	**Yes** Clear statement of findings, discussed generalisability and limitations.	**Partial** Findings were explicit. Findings were discussed in context of current literature. Not clear in arguments against and little mention of credibility.	**Yes** Findings were explicit, and discussed in context of other current literature. Limitations discussed.	**Partial** Findings were explicit. No discussion of credibility. Limited discussion in relation to context of current literature.	**Partial** Findings were explicit in context of the aims. Strengths and limitations discussed. No discussion of creditability and limited discussion in relation to current literature.	**Yes** Findings were explicit and relevant literature discussed. Clinical implications and limitations mentioned.	**Yes** Findings were explicit. Clear argument for and against, and results were in context with aim. No credibility discussed.

Appendix 2

Psychometric Conversion Table

Removed for electronic submission

Appendix 3

Full Participant Information Sheet

[redacted]

Information about the research
(FULL INFORMATION SHEET)

Is the Montreal Cognitive Assessment a Valid Screening Tool for Mild Neurocognitive Disorder in People living with HIV?

Hello. My name is Eliza Harris and I am a trainee clinical psychologist at Canterbury Christ Church University. I am working with [redacted] and we would like to invite you to take part in a research study. Before you decide whether to take part, it is important that you understand why the research is being done and what it would involve for you.

What is the purpose of the study?

We want to explore whether the Montreal Cognitive Assessment (MoCA) is a good tool for identifying between people living with HIV who have memory problems and people living with HIV who do not have memory problems. This will help services understand whether the MoCA is a good tool to identify whether a person needs further testing for their mental processing.

It is important to make sure that assessment tools are suitable for different populations to ensure that individuals who might benefit from further support or assessment are being identified early and that the correct care and treatment can be offered.

Why have I been invited?

You have been invited as you have attended the [redacted] and did not report any problems with your mental processes, or you scored above 26 on the MoCA which suggests you are not having any problems and therefore do not need further testing on memory and thinking.

To evaluate whether the MoCA is a good assessment tool, we need 30 people who have scored over 26 on the MoCA. We would need these 30 people to come to the [redacted] at the [redacted] to meet with a researcher and complete some tests on memory and thinking.

Do I have to take part?

No, you do not have to take part. It is up to you to decide whether to join the study. If you agree to take part you are free to withdraw at any time, you do not need to give a reason. This would not affect the standard of care you receive from [redacted] or any other NHS provider.

What will happen to me if I take part?

If you agree to take part, we will organise a date for you to attend the [redacted] at the [redacted] s part of the

[redacted]

[redacted] When you come to the clinic, we will ask you to complete a series of tests with the researcher. These tests will look at different mental processes such as attention and memory. These tests will take approximately 60-90 minutes to complete. These tests include:

- A questionnaire that will ask questions about your mood. This will take approximately 5 minutes to complete.
- Reading a list of different words, which will take approximately 5-10 minutes.
- A series of memory tests looking at different types of memory. This includes repeating words and phrases, and copying images, among other, similar memory tasks. This will take approximately 30 minutes.
- A memory task involving repeating numbers, which will take approximately 5 minutes.
- A verbal task involving thinking of items from a particular category for a set amount of time. This will take approximately 5 minutes.
- A task involving switching between naming words and colours of words. This will take approximately 5 minutes.
- A dot-to-dot task, which will take approximately 5 minutes.
- A timed paper maze task, which will take approximately 2 minutes.

You may also be asked to complete the screening tool if you have not already done so, which will take approximately 10 minutes.

Some of these tests will be timed, whilst others may not. You may decline any of the tests or questionnaires at any time if you do not wish to complete them. Throughout your time in the study, you will have the support from the researcher.
Once you have completed the tests, your scores will be added to a database that is held by the clinicians who work for the clinic. A member of staff from the clinic will be adding your scores to this database.

Expenses and payments

As a thank you for your participation, all participants who come for testing will be offered the option of receiving a £10 gift voucher. To redeem this voucher, your email address would need to be passed to the university finance team. No other personal information will be passed to this team.

What are the possible disadvantages and risks of taking part?

It is possible that the tests may show that you are having some problems with your memory, or other thinking process. This is unlikely, but not impossible. If this is the case, a clinician from the [redacted] will be informed and you will be invited back for further investigations and support.

Although it is uncommon, some people can find the testing quite difficult and therefore can become quite upset. If you become upset by the testing at any point, you may take a break or the testing can be stopped. Generally, people do not become distressed by the testing and can sometimes enjoy the tests. If you think that it is likely that these tests will cause you distress or upset, it may not be suitable for you to participate in this study.

Some people can find the testing experience quite tiring. We will offer you regular breaks in between the subtests if you find yourself getting tired.

[redacted]

There is a questionnaire which asks about your mood. This will be scored after the testing has been completed. If there are any concerns raised in the responses to the questionnaire, the researcher will inform your direct care team at the Lawson Unit to offer you further support.

What are the possible benefits of taking part?

Although we cannot promise that the study will directly benefit you, the information we get from this study will help improve the treatment and assessment of people living with HIV who are experiencing problems with their mental processes. It will help improve the current tools being used by many services and provide evidence as to whether this is a useful tool.

What will happen if I don't want to carry on with the study?

You may withdraw from the study at any time. This includes withdrawing before, during, or after the testing. As well as withdrawing from participating in the study, you can withdraw your data from the study up to two weeks after you complete the tests. After this time, it is likely that your scores have already been used in the analysis.

If you would like to withdraw from participating in the study, and/or request the removal of your data from the study, you can email Eliza Harris e.harris13@nhs.net to request this.

Withdrawing from the study will not impact any aspect of your care with any services within [redacted] or any other NHS service.

Who is in the research team?

The research team is made up of:

Dr Clara O'Brien – Chief Investigator
Dr Fergal Jones – Researcher & Statistician
Eliza Harris – Researcher
Chloe Seikus - Researcher

If you agree to participate, you will meet with Eliza Harris or Chloe Seikus to complete your assessment.

Concerns and Complaints

You can raise a complaint to Eliza Harris (researcher) by emailing her e.harris13@nhs.net. If you remain dissatisfied and wish to complain formally, you can do this by contacting Professor Margie Callanan, Director of Salomons Institute for Applied Psychology, Salomons Institute for Applied Psychology, Margie.callanan@canterbury.ac.uk.

You may also email the Health Research Authority with any complaints that you have regarding this research complaints@hra.nhs.uk.

[redacted]

Will information from or about me taking part in the study be kept confidential?

Yes, we will follow ethical and legal practices and all information about you will be handled in confidence.

Your data will be collected during the testing process and input into the [redacted] by a member of the care team. All information which is collected from or about you during the course of the research will be kept strictly confidential. The people who have access to this information will be yourself, the [redacted]. Any information about you which leaves [redacted] will have your name and any identifiable information removed so that you cannot be recognised.

The test scores will also be added to your medical records.

What will happen to the results of the research study?

The results from the study will be written up in the form of a research paper and there is hope that they may be published in a journal. There will be no personal information of any of the participants in this study, therefore no participants will be identifiable from the publication.

As this project is part of a Doctoral qualification, this study will also be written up as a thesis.

A leaflet or poster will be made with a summary of the study and the results. These will be displayed [redacted]

Who is sponsoring and funding the research?

[redacted] is sponsoring this study.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by NHS Research Ethics Committee.

Further information and contact details

If you would like to speak to someone and find out more about the study or if you have any questions, you can email e.harris13@nhs.net and she will get back to you as soon as possible.

If you are dissatisfied with any of the study and wish to complain and you do not feel comfortable bringing this to Eliza, please email complaints@hra.nhs.uk.

GDPR Statement

In this research study, we will use personal information from you that you have given us. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study.

[redacted]

This information will include your name, date of birth and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?
You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team
- by sending an email to [redacted]

Appendix 5

Participant Consent Form

[redacted]

Ethics approval number: 318899
Version number: 5
Participant Identification number for this study:

CONSENT FORM

Is the Montreal Cognitive Assessment a Valid Screening Tool for Mild Neurocognitive Disorder?

Name of Chief Investigator: Dr. Clara O'Brien
Name of Researcher: Eliza Harris

Please initial box

1. I confirm that I have read and understand the full information sheet (version 5.0, dated 22/02/24) for the above study. I have had the opportunity to consider the information, and ask questions and these have been answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. I can withdraw by contacting the study team (email on the information sheet). ☐

3. I understand that I can choose to withdraw my data from the study within 2 weeks from the date I completed the memory testing. ☐

4. I understand that the data from this study may be looked at by the sponsor [redacted] for auditing purposes. ☐

5. I agree to take part in the above study. ☐

6. I would like to receive an email with a summary of the results* ☐

*If you initialled this box, please provide your email address:

_____

Name of Participant_____ Date_____

Signature _____

Name of Clinician _____ Date_____

Signature _____

Each individual who chooses to consent to their information being included in the study will have signed two consent forms, one which is held by the research team and another which the participant will be asked to sign and keep for their own records.

Appendix 6

REC Approval Letter

Removed for electronic submission