VALIDITY OF SCREENING TOOLS FOR ACTIVITY LIMITATION AND COGNITIVE DYSFUNCTION IN PATIENTS WITH HIV ASSOCIATED NEUROCOGNITIVE DISORDERS

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A dissertation submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in fulfilment of the requirements for the degree of Master of Science in Occupational Therapy.

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Declaration

I, Elizabeth Barbara Smith, declare that this dissertation is my own work. It is being submitted for the degree of Masters of Science in Occupational Therapy at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.

(Signature of candidate)

On this the 9th day of November 2020 in Leamington

Dedication

This dissertation is dedicated to those suffering from HIV Neurocognitive Disorders and the healthcare professionals who work tirelessly to provide the best possible service for them.

AND

To my Mother, my greatest cheerleader.

Acknowledgements

I would like to thank my supervisor, Professor Patricia de Witt, for challenging my thinking and developing me professionally and personally through this research process. I would also like to thank Dr Denise Franzsen for her knowledge of technology and statistics; your support has been invaluable.

I would like to thank my family and friends for their support in their individual and group capacity. I acknowledge the strength and perseverance given to me by my God, which frequently came in the form of my loved ones.

I would especially like to thank the clinic sites, staff and most importantly, the participants of this research.

Abstract

Introduction: Human Immunodeficiency Virus Neurocognitive Disorders (HIV NCD) are prevalent in South Africa. Human immunodeficiency virus associated neurocognitive disorder results in impairments in cognition and instrumental activities of daily living which can reduce quality of life. To effectively use limited health care resources, efficient and appropriate screening tools are needed to identify those who need a more comprehensive assessment and to guide care.

Methods: This study used a descriptive design to determine the efficacy and limitations of three screening tools used in tertiary clinics in Gauteng. The study occurred in two phases, each using a different methodology. In phase one, the quantitative strand, patient-participants were screened using the International HIV Dementia Scale (IHDS), Montreal Cognitive Assessment (MoCA) and World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0). The results were used to identify if those scoring 11 or below on the International HIV Dementia Scale, presented with cognitive dysfunction and activity limitations. These results were analysed using Spearman's correlation coefficient for correlation of the International HIV Dementia Scale, to the Montreal Cognitive Assessment and World Health Organization Disability Assessment Schedule 2.0, and their convergence analysed. In phase two, the qualitative strand, the perceptions and experiences of health professionals in the field, on the efficiency and efficacy of these three tools, were explored in group interviews.

Results: All 55 patient-participants, scoring 11 and below on the International HIV Dementia Scale, were found to have cognitive dysfunction and activity limitations, on the Montreal Cognitive Assessment and World Health Organization Disability Assessment Schedule 2.0, respectively. The cultural appropriateness of the Montreal Cognitive Assessment, and impact of mood and cognition on the World Health Organization Disability Assessment Schedule 2.0, for the cohort, was questioned in both phases of the study. The International HIV Dementia Scale total score was found to have clinically irrelevant correlations to the Montreal Cognitive Assessment and World Health Organization Disability Assessment Schedule 2.0 total scores, in the cohort. Therefore, these tools could not be used interchangeably

in the screening of human immunodeficiency virus associated neurocognitive disorders.

Conclusion: The screening tool administration should be standardised, and the results used with caution due to the limitations identified. Those with professional clinical reasoning should preferably use these tools. Further research is required to develop population appropriate screening tools, which will improve the efficiency and effectiveness of guiding care in human immunodeficency virus associated neurocognitive disorders.

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Nomenclature

Definition of Terms

Clade-C HIV: A subtype (clade) of HIV that is particularly prevalent in sub-Saharan Africa (Tyor et al., 2013).

Client factors: “Client factors are specific capacities, characteristics, or beliefs that reside within the person and that influence performance in occupations”(American Occupational Therapy Association, 2014:S7).

Community-based Rehabilitation: “A multisectoral approach working to improve the equalization of opportunities and social inclusion of people with disabilities while combating the perpetual cycle of poverty and disability. It is implemented through the combined efforts of people with disabilities, their families and communities, relevant government, education and healthcare sectors.” (World Health Organization, 2020).

Everyday function: The patient’s ability to perform cognitively related IADLs such as financial management (Antinori et al., 2007).

Occupational engagement: “Performance of occupations as the result of choice, motivation, and meaning within a supportive context and environment. Engagement includes objective and subjective aspects of clients’ experiences and involves the transactional interaction of the mind, body, and spirit.”(American Occupational Therapy Association, 2014:S4).

Occupational performance: “Act of doing and accomplishing a selected action, activity, or occupation that results from the dynamic transaction among the client, the context, and the activity.”(American Occupational Therapy Association, 2014:S43).

Occupations: “Daily life activities in which people engage. Occupations occur in context and are influenced by the interplay among client factors, performance skills, and performance patterns.” (American Occupational Therapy Association, 2014:S43).

Performance skills: “Goal-directed actions that are observable as small units of engagement in daily life occupations. They are learned and developed over time

and are situated in specific contexts and environments." (American Occupational Therapy Association, 2014:S43).

Task-Shifting: "Delegating tasks performed by physicians to staff with lower-level qualifications and ley-community workers." (Callaghan et al., 2010)

Abbreviations

ADLs: Activities of Daily Living

ANI: Asymptomatic Neurocognitive Impairment

ARV: Antiretroviral

CART: Combination Antiretroviral Therapy

CAT-rapid: Cognitive Assessment Tool rapid version

CD4: Cluster Differentiation 4

CIOMS: Council for International Organizations of Medical Sciences

CNS: Central Nervous System

DSM-5: Diagnostic and Statistical Manual of Mental Disorders Fifth Edition

EACS: European Aids Clinical Society

FDC: Fixed-Dose Combination

FDSR: National Framework and Strategy for Disability and Rehabilitation services

GAF: Global Assessment of Functioning

HAD: HIV-Associated Dementia

HDS: HIV Dementia Scale

HIV: Human Immunodeficiency-Virus

HIV NCD: Human Immunodeficiency Virus associated Neurocognitive Disorder

HIV+: Human Immunodeficiency Virus positive

HIV-: Human Immunodeficiency Virus negative

IADLs: Instrumental Activities of daily living

IHDS: International HIV Dementia Scale

MMSE: Mini-Mental State Examination

MND: Mild Neurocognitive Impairment

MoCA: Montreal Cognitive Assessment

NCD: Neurocognitive Disorder

OT: Occupational Therapy

OTPF-3: Occupational Therapy Practice Framework, Third Edition

RBANS: Repeatable Battery for Assessment of Neurological Status

ROC: Receiver Operating Characteristic

SES: Sequential Explanatory Strategy

SD: Standard Deviation

SMD: Severe Mental Disorder

SSQ: Simioni Symptom Questions

WHODAS 2.0: World Health Organization Disability Assessment Schedule 2.0

CHAPTER 1: INTRODUCTION

1.1 Introduction to Research

“In the era of widespread antiretroviral (ARV) therapy, people living with Human Immunodeficiency Virus (HIV) survive, however, this comes with new experiences of comorbidities and HIV-related disability posing new challenges to rehabilitation professionals and an already fragile health system in Southern Africa” (Chetty and Hanass-Hancock, 2016: p132). This statement by Chetty and Hanass-Hancock is particularly pertinent to South Africa, which has a high prevalence of HIV, but where the rollout of ARVs has increased life expectancy (Cornell et al., 2017). In 2018 it was estimated that 13.1% (7.72 million people) of the South African population (57.73 million people) were HIV positive, with 24% living in the Gauteng province where this study took place (Statistics South Africa, 2018).

A study by Liner, Ro and Robertson reported that while combination antiretroviral therapy (CART) has reduced the impact of HIV in terms of morbidity, severe forms of HIV dementia and neurocognitive dysfunction persists (Liner, Ro and Robertson, 2010). Recent research indicated that CART should be initiated early to protect the central nervous system (CNS) but stressed the impact of both HIV and ARVs on cognitive domains increasing the risk of dependence in daily activities (Liner et al., 2010). The increasing risk of dependence in daily activities is directly linked to the diagnostic criteria for levels of HIV associated Neurocognitive Disorders (HIV NCD) as described by Antinori et al. (2007) These diagnostic levels are divided into Asymptomatic Neurocognitive Impairment (ANI), Mild Neurocognitive Decline (MND), and HIV-Associated Dementia (HAD), known as the ‘Frascati Criteria’ (Antinori et al., 2007). Liner, Ro and Robertson (2010) stressed the importance of monitoring of the impact of HIV on Instrumental Activities of Daily Living (IADL). This specifically emphasised the importance of occupational therapys’ role alongside that of other health professionals. For CART to be initiated at the most effective point, it must be preceded by accurate and efficient screening and assessment of IADL and cognitive functioning as key diagnostic criteria.

According to Chetty and Hanass-Hancock (2016), well-resourced countries have developed public health approaches to HIV that include rehabilitation within the

framework of care to meet the specific health needs of the HIV population. South Africa lacks such an approach or framework, and there are few rehabilitation professionals and resources allocated in such facilities providing services to the HIV population (Chetty and Hanass-Hancock, 2016).

1.2 Statement of the Problem

The researcher was employed in one of two tertiary public health care facilities in Gauteng, South Africa that offered out-patient occupational therapy services to the HIV population with Neurocognitive Disorders (NCD) within the province. All patients referred to the HIV NCD clinic were screened using the International HIV Dementia Scale (IHDS) to facilitate service delivery and direct the nature of care in the clinic with limited human resources.

Based on the HIV Neurocognitive clinic records at the time of this research, 700 attendees were potentially requiring the services of a single occupational therapist. This high number of patients, to a single occupational therapist, demanded a rapid yet effective screening procedure to identify those patients most in need of referral to occupational therapy for comprehensive assessment and intervention.

Two additional screening tools were used in the clinic, in conjunction with the IHDS, to screen for cognitive dysfunction and activity limitations. These were the Montreal Cognitive Assessment (MoCA); and World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0), respectively. South African research has found the IHDS to be an appropriate screening instrument for HIV NCD in the South African population (Goodkin et al., 2014). While, the MoCA has been shown to have good sensitivity to HIV NCD in a South African study but poor specificity (Joska et al., 2016). The WHODAS 2.0 has been used internationally as it is aligned to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) and is the recommended functional capacity scale (Gold, 2014). The WHODAS 2.0 replaced the numerical scoring of the Global Assessment of Functioning (GAF) (Gold, 2014). The DSM-5 was used by the psychiatrist at the research site, as it lists psychiatric and medical diagnostics appropriate for the neuropsychiatric setting.

The MoCA and IHDS were routinely used as part of the screening at the research site, for phase one of this study. However, the WHODAS 2.0's domains were only

used by the research site's psychiatrist, to describe the everyday functioning of the patients, within the DSM-5. Thus, the WHODAS 2.0 questionnaire was not used to obtain the information reported under each domain by the psychiatrist.

Although these screening tools were used in the clinic setting to guide further assessment and intervention, it was unknown if these tools were effectively measuring cognition and activity limitations in the patients attending the clinic, identified with HIV NCD. It was also unknown if all screening tools efficiently and effectively established the need for further assessment, which was time-consuming, and therefore pertinent information in the resource-limited setting.

In a clinical setting which treated high numbers of vulnerable individuals with limited resources, it was vital to know that the resources available were being used to the greatest benefit possible. The unknown efficacy and efficiency of these tools meant that it was unknown whether the tools increased or decreased the challenges present in providing the patients with the care they require.

1.3 Purpose of the study

At the start of the study, it was assumed that what was needed was a single effective screening tool for people living with HIV NCD, which yielded efficient and accurate results and identified patients requiring occupational therapy, without further screening. This need was believed to be the first step to meeting the needs of this patient cohort in a constrained rehabilitation service.

The purpose of this study was to understand if the tools that were being used to screen for HIV NCD were providing accurate and efficient results in the screening of cognitive dysfunction and activity limitations, for referral to occupational therapy.

In order to understand the effectiveness of the tools, the study aimed to identify if the tools recognised cognitive and activity limitations, in patients with HIV NCD as identified by the IHDS. To understand the legitimacy of the MoCA and WHODAS 2.0 in the research setting, the convergent validity of these screening tools was evaluated to the IHDS. This evaluation assisted the researcher in understanding if all tools were required to effectively refer patients in need of further occupational therapy assessment for cognitive dysfunction and activity limitation.

This study also explored the assessing teams' perception of the screening tools used to guide care, how they were administered, their opinion of the efficacy of the tools, and the intervention needs of the patient based on the scores obtained.

Thus, the purpose of the study was twofold: the analysis of the screening tools, and to explore whether these screening tools were perceived to meet the teams' described needs, in terms of purpose, in a context with limited resources available to guide further assessment and intervention.

1.4 Research Question

This research aimed to answer two interrelated questions:

- Does screening with the MoCA and WHODAS 2.0 confirm areas of cognitive dysfunction and activity limitations in patients with HIV identified with NCD by a score of 11 or less on the IHDS?
- Do members of the team using the IHDS, MoCA and WHODAS 2.0 screening tools perceive these tools to meet the described purpose of guiding intervention and further care for patients with HIV NCD?

1.5 Aim of the study

The study aimed to determine the convergent validity of the MoCA and WHODAS 2.0 to the IHDS scores for patients with HIV identified with NCD by a score of 11 or less on the IHDS. The study also aimed to explore the perceptions of the assessing team about these screening tools, in guiding the care of patients with HIV NCD.

1.6 Objectives of the study

The study was completed in two parts.

Phase One: Objectives:

1. To determine the level of cognitive or activity limitations, on the MoCA and WHODAS 2.0, for patients identified with HIV NCD, by a score of 11 or less the on the IHDS.

2. To determine the convergence of the scores on the IHDS with the scores on the MoCA and WHODAS 2.0, for patients identified with HIV NCD, by a score of 11 or less on the IHDS.
3. To determine the convergent validity of the MoCA to the WHODAS 2.0 for patients identified with HIV NCD, by a score of 11 or less on the IHDS.

Phase Two: Objective:

Explore the perceptions of team members who assess patients with HIV NCD, as to the efficiency, effectiveness and limitations of the IHDS, MoCA and WHODAS 2.0 in guiding referral for further in-depth occupational therapy intervention at two clinics in Gauteng.

1.7 Justification

A limited number of studies have been carried out on the psychometric properties of the IHDS, MoCA and WHODAS 2.0 and none of these tools has been standardised for the South African HIV NCD population. The human resource limitations in HIV NCD clinics demand that the tools used for screening be fit for purpose, including the ability to identify when patients from this cohort require a comprehensive occupational therapy assessment and intervention.

Through understanding the convergence of the screening tools and the team members perceptions of the tools' usefulness, interdisciplinary teams will be able to manage referrals and resources more effectively, by referring to specific team members for assessment and treatment in areas of cognitive dysfunction and activity limitations. This understanding will result in an efficient inter-professional collaboration within the team and improved service delivery.

1.8 Structure of the dissertation

This dissertation has been structured into six chapters. The literature review in chapter 2 explores published works on; HIV NCD in South Africa, the screening tools for HIV NCD, both in South Africa and abroad to identify the gaps in knowledge of the tools and their importance in guiding referral for occupational therapy. The research methodology follows the literature review in chapter 3. The researcher then presents the results and discussion for the two phases of the study in chapters

4 and 5, respectively, followed by the conclusion and recommendations in chapter 6.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

The study centred on whether the screening tools used in two specialised HIV NCD clinics in Gauteng were effective and efficient in identifying cognitive and activity limitations in patients with HIV NCD.

The review investigated the literature on the reported challenges and limitations in South African healthcare concerning the assessment of and intervention for HIV NCD. Literature which outlined the characteristics of HIV NCD described what was found to be effective in the screening process for HIV NCD. Literature on the screening tools, and their utility and efficacy, both in South Africa and abroad were also searched to understand the known strengths and limitations of the screening tools being evaluated. This literature was reviewed to understand the research currently available and identify the gap in knowledge for the specific context, and referral process of patients accessing care at HIV NCD clinics to occupational therapy.

The search was mainly limited to studies published in the timeframe from 2007 until 2020, however seminal studies that fell outside of this timeframe were included. The search engines and databases used included: PubMed, Google Scholar, Wiley Online Library, Taylor & Francis Journals, Cochrane Library, Science Direct, Sage Journals Online, Sage Research Methods Core and SpringerLink. Searches for contextual management of HIV included keywords such as “HIV management South Africa”, “HIV interventions South Africa”. Searches for the screening of HIV NCD and its levels of characterisation included, “HIV cognitive decline South Africa”, “HIV Neurocognitive decline”, “HAND screening tools”, “assessment HIV cognitive impairment”. Literature specific to the screening tools was searched using “IHDS screening”, “International HIV Dementia Scale”, “MoCA HIV South Africa” “Montreal Cognitive Assessment HIV”, “WHODAS 2.0 and HIV”, “WHODAS 2.0 HIV South Africa”, “WHODAS 2.0 DSM 5”. Literature specific to occupational therapy guidelines for HIV NCD was searched using, “HIV cognitive disorders OT”, “OT

assessment HIV", "occupational therapy process HIV". Following these searches, the references of applicable articles were reviewed for further relevant literature.

The literature review was structured using a funnelled approach. The literature review began with the overall management of HIV NCD in South Africa, which reviewed the recommended and practised management strategies relative to the reported challenges and limitations of the South African context. This section was followed by the screening for HIV NCD, which reviewed reported requirements for effective and valid screening of HIV NCD, and the implementation of these in the South African context. Each of the three screening tools and their researched utility in the South African context, was also reviewed. Lastly, the review integrates screening into the occupational therapy process, analysing the relevance to occupational therapy practice.

2.2 Management of Human Immunodeficiency Virus Neurocognitive dysfunction in South Africa

Between 2001 and 2011, South Africa reported a decrease in new HIV infections by approximately 41%, but an increase in prevalence (UNAIDS, 2012). The increase in prevalence indicated the need to address the chronicity, which has resulted from people living longer with HIV and ageing (Hankins, 2013). The rise in chronic illness resulting from prolonged life expectancy due to HIV ARV treatment has increased the burden of care on the health system, with resource limitations impacting the public health care systems' ability to absorb this developing need for chronic management of those living with HIV (Chetty and Hanass-Hancock, 2016; Kautzky and Tollman, 2008). One of the challenges associated with chronic HIV is that of HIV NCD, which was found to be present in approximately up to 50% of people living longer with HIV (Heaton et al., 2010). In South Africa, approximately 90% of the HIV population has Clade-C HIV (Robertson et al., 2010). Heaps et al. (2012), reported that Clade-C infection causes neuronal damage, resulting in HIV NCD, specifically in a lower volume of white matter, thalamus, and overall grey matter in the Human Immunodeficiency Virus positive (HIV+) brain. South African studies have found varying percentages of the prevalence of HIV NCD among their cohorts. A study in KwaZulu-Natal of 146 HIV+ participants, reported a prevalence of 53% of participants with HIV NCD (Mogambery et al., 2017), a study conducted in Cape

Town in 2009 with 536 HIV+ participants found a 23% prevalence of HIV NCD (Joska et al., 2010), a study conducted in Cape Town in 2010 with 170 HIV+ participants found 76.47% of participants presenting with HIV NCD (25% HAD, 42% MND, 9% ANI) (Joska, Landon, et al., 2011). The prevalence of HIV NCD in the South African population indicated the need for effective management strategies to be implemented. Reports on the efficacy of management strategies for HIV NCD and HAD have been explored below.

In South Africa, the challenge of developing management strategies has been affected by the limitations present in public health service delivery and service access (Chetty and Hanass-Hancock, 2016). The limitations in public health service delivery include lack of trained staff, lack of resources and poor collaboration of treating professionals (Chetty and Hanass-Hancock, 2016; Kautzky and Tollman, 2008). The limitations in public health service access include: finances limiting access to services and transport costs limiting patients' ability to attend sessions (Chetty and Hanass-Hancock, 2016). Some authors have recommended that Community-based Rehabilitation (CBR) and task shifting approaches be used in developing effective management strategies for the identification of those in need of intervention (Chetty and Hanass-Hancock, 2016). However, concerns around the use of CBR in screening for HIV NCD have been raised by Robbins et al. (2011), who suggested that challenges such as limited resources, time and lack of qualified staff for supervision of community workers, may result in overestimated impairments. Should impairments be overestimated, this would increase referrals to the services, which are already over-burdened. The concerns of Robbins et al. (2011) concur with other studies which have indicated the importance of supervision and guidance of healthcare workers in task shifting approaches, to ensure adequate intervention (Schneider, Okello and Lehmann, 2016; Bennett et al., 2014) .

The findings reported above indicate the challenges present in South Africa in addressing the healthcare needs which arise with the management of chronic HIV care, including HIV NCD, which presents in up to 50% of people who are HIV+ (Joska et al., 2010; Joska, Landon, et al., 2011; Mogambery et al., 2017; Heaton et al., 2010). Underwood and Winston (2016), described a rigorous screening and assessment process for the effective management of cognitive decline associated with HIV. This process is not possible in the South African healthcare setting due to

the limitations described by Chetty and Hanass-Hancock (2016). These limitations led the researcher to the review of screening tools for HIV NCD that are being used, to better understand their effectiveness in guiding the referral, and care of patients accessing services for intervention in HIV NCD. This understanding could consequently be applied in CBR and task shifting approaches, which have been suggested in multiple areas of HIV intervention, as solutions to the limitations in resources experienced (Vermund, Sheldon and Sidat, 2015; Kautzky and Tollman, 2008; Chetty and Hanass-Hancock, 2016; Callaghan, Ford and Schneider, 2010).

Antinori et al. (2007), reported the importance of screening tools considering the population norms particularly; age, education, ethnicity and gender, as these influence the specificity of the tests in identifying HIV NCD. This view was supported by Morgan et al. (2008), who stressed the importance of specificity of screening tools for HIV NCD in understanding the effect on the mental function, along with the initiation of CNS-active drugs used in the intervention of HIV NCD. The combined findings of Morgan et al. (2008) and Antinori et al. (2007) have reinforced the importance of the screening tools used being not only specific to the impact of HIV on the body structures and functions but also specific to the context in which these tools are being used.

A Consensus Report of the Mind Exchange Group on HIV NCD in 2013, suggested that 6-12 monthly screening of mental functions and the impact on everyday function (such as IADLs) should take place in high-risk individuals, and 12-24 monthly in low-risk individuals (Antinori et al., 2013). This frequency of evaluation would require a valid standardised screening tool or outcome measure that can be used sequentially at these intervals to measure change. This requirement reinforced the importance of understanding the cognitive and activity limitations, as measured by the screening tools to ensure effective follow-up and timely referral to additional professional services for patients with HIV NCD to prevent deterioration. The effectiveness and efficiency of the screening tools are particularly important, given the limitations of patients and services in the clinic context in South Africa.

In the research clinic setting, the screening tools for HIV NCD patients which met the clinic's needs were considered to be: The International HIV Dementia Scale (IHDS), Montreal Cognitive Assessment (MoCA), and the World Health

Organization Disability Scale 2.0 (WHODAS 2.0). At the time this research was carried out, the National Framework and Strategy for Disability and Rehabilitation services 2015-2020 (FSDR) (South African National Department of Health, 2016) was being implemented. The FSDR identified the key issues to be addressed to create a comprehensive intervention model for persons living with a disability, including those living with HIV (Chetty and Hanass-Hancock, 2016). Despite the development of the rehabilitation framework for HIV, there was no standardised screening tool that had been validated for the South African population. As a result, clinicians at different public health service delivery sites were using different screening tools to those already mentioned. The use of different screening tools implied that each public health clinic was basing intervention strategies on different data, so there was no consistency or set protocol. The use of different screening approaches may be linked to a limited number of health professionals working with this cohort of patients, as well as insufficient clinical research limiting the evidence needed to develop and implement specific strategies (Vermund et al., 2015). Task-shifting approaches have been considered to alleviate the lack of qualified professionals but could perpetuate the lack of comprehensive screening and intervention programmes (Vermund et al., 2015). The 'best clinical practice' currently adhered to in public health clinics differs from that described by Underwood and Winston (2016), in that it is subjectively applied as opposed to following of a structured and standardised assessment process supported by evidence which was recommended (Underwood and Winston, 2016). However, the Mind Exchange Working Group described that different contexts and populations required unique screening tools and processes that were specific to their resources, and one set tool cannot be used across all contexts (Antinori et al., 2013). This report raised the question: without an evidence-informed standardised screening process specific to resources and context, can South Africa develop an effective intervention model?

2.3 Screening for Human Immunodeficiency Virus Neurocognitive Dysfunction

Cysique et al. (2010) published a screening algorithm for HIV NCD. Although not a South African study, it identified the value of an efficient and accurate screening for HIV NCD which would use human resources effectively and provide efficient access to necessary treatment for people with HIV NCD (Cysique et al., 2010).

The importance of an effective screening process was suggested by Cysique et al. (2010), due to the significant influence HIV NCD is known to have on patients' independence in daily activities, HIV dementia, and death which has been acknowledged in several other studies (Morgan et al., 2008; Kamminga et al., 2013; Heaton et al., 2010; Joska et al., 2016). This need for efficient and early intervention, achieved through accurate screening, has been identified due to the resource limitations impacting on the completion of a comprehensive assessment of neuropsychological deficits on all patients accessing care for HIV in clinical settings (Cysique et al., 2010; Heaton et al., 2010; Sacktor et al., 2005; Robbins et al., 2011; Joska et al., 2016). Therefore, effective, valid screening tools for HIV NCD are necessary to guide further care for those presenting with HIV NCD. These literature reports raised the question as to what is required for a screening tool to be effective and valid to guide further intervention?

South Africa, in particular, has a significant need to ensure valid, effective and time-efficient screening tools are available for HIV NCD identification. This need is specifically due to the lack of human and financial resources, lack of screening tools normed for the South African population and the knowledge that early identification, results in early intervention and better outcomes (Robbins et al., 2011; Joska et al., 2016). For screening tools to be effective in identifying the specific impact of HIV on the brain, they should; target domains that are known to be affected by HIV (Antinori et al., 2007), screen IADL function (Kamminga et al., 2013; Antinori et al., 2007), and be appropriate to the population profile (Antinori et al., 2007).

Before initiating screening to guide intervention in HIV NCD, it is essential to confirm that no pre-existing causes for cognitive decline are present (Rackstraw, 2011). This finding was also confirmed by the European Aids Clinical Society (EACS) Guidelines in 2015, which stated that severe psychiatric illness and drug abuse, amongst others, must be excluded before screening for HIV NCD (European AIDS Clinical Society, 2015). Screening must target the cognitive areas affected by HIV which include: attention; information processing; abstraction/executive functions; language; memory (learning, working memory, episodic memory, recall), motor and sensory-perceptual skills (Rackstraw, 2011; Antinori et al., 2007; Woods et al., 2009). Human Immunodeficiency Virus associated Neurocognitive Disorder has been understood to affect the brain subcortically, influencing psychomotor speed,

processing speed, executive functioning and memory (Valcour et al., 2011; Underwood and Winston, 2016). This finding would exclude screening tools such as the Mini-Mental state examination (MMSE), which is designed for cortical dementia screens (Underwood and Winston, 2016). However, due to the shifts in the clinical picture of HIV NCD and HIV Associated Dementia (HAD) since the widespread use of CART, it has been recommended that both cortical and subcortical screens be used (Joska et al., 2016; Valcour et al., 2011; Heaton et al., 2011). Therefore, a screening tool should be able to indicate limitations and deficits in these areas of mental function, specific to HIV NCD, to effectively guide referral for further assessment and intervention thus, using limited resources appropriately and optimally.

A comparison of five screening tools for HIV NCD was carried out in South Africa by Joska et al. (2016). These authors reviewed the IHDS, MoCA, MMSE, Simioni Symptom Questions (SSQ), and the Cognitive Assessment Tool rapid version (CAT-rapid) (Joska et al., 2016). It was found that the MMSE was not sensitive enough in detecting HIV NCD in the South African cohort and that none of the screening tools alone was adequate to screen for HIV NCD (Joska et al., 2016). The study found that the combination of the IHDS and CAT-rapid were most effective in screening for HIV NCD, and while the MoCA had good sensitivity, it had poor specificity (Joska et al., 2016). This study analysed the efficacy of screening tools being used in the screening of HIV NCD and HAD, providing the researcher with further understanding of properties of screening tools which could be potentially used across South Africa.

Although the number of new cases of HAD has reportedly decreased, this does not apply to the prevalence of HAD (Joska et al., 2016). The clinical presentation of neurocognitive decline is reported to be milder due to CART, but the prevalence remains high (Heaton et al., 2010; Cysique et al., 2010). This indicated the importance of screening for HIV NCD, especially to determine the level of severity of HIV NCD from Asymptomatic Neurocognitive Impairment (ANI) [level 1], Mild neurocognitive disorder (MND) [level 2], and HAD [level 3] (Antinori et al., 2007), known as the Frascati criteria (Rackstraw, 2011; Antinori et al., 2007). Both ANI and MND require a minimum of two of the cognitive areas to be affected, while the diagnosis of MND requires the presence of some impairment in everyday

functioning, specifically IADL impairment, due to neurocognitive decline (Antinori et al., 2007). This requirement supports the importance of screening for activity limitations in everyday functioning to guide further intervention and highlights the critical role of occupational therapy in the screening, assessment and treatment of HIV NCD.

'Everyday function' has been described in the Frascati criteria as 'the patient's ability to perform cognitively related IADLs such as financial management' (Antinori et al., 2007). A systematic review of the validity of HIV NCD screening tools, found the screening for IADL function to be lacking in the studies reviewed (Kamminga et al., 2013). Therefore these screening tools do not allow for categorising of the condition according to the Frascati criteria (Kamminga et al., 2013).

Performance-based screens of everyday function have been reported to be more effective than the self-report screens in identifying areas of everyday function that are impaired (Blackstone et al., 2012). However, self-report screens are more commonly used in clinical settings due to time constraints (Woods et al., 2009). Self-reports were found to be influenced by mood (Blackstone et al., 2012) and cognition (Thames et al., 2011). Individuals who are HIV+ and present with depressive symptoms have been found to over-report on everyday functional impairment, while those with cognitive impairment have been found to under-report (Thames et al., 2011). These results emphasise the importance of collecting background information and observing the patient, before carrying out self-report screens of everyday function, to determine the patient's ability to self-report activity limitation in daily function.

Moreover, Antinori et al. (2007) cautions that coexisting conditions may influence the interpretation of impairment in IADLs with HIV NCD. Coexisting conditions include substance abuse, unmanaged psychiatric illness and traumatic or acquired brain injury (Joska et al., 2016; Liner, Ro and Robertson, 2010; Antinori et al., 2013). Antinori et al. (2007) emphasised that the self-report for Activities of Daily Living (ADL) and IADL impairment should be relevant to the everyday life of the people being tested. The emphasis on relevance is essential when identifying appropriate screening tools for activity limitation in everyday function in the South African population, as many tools are developed in Europe and America. When such tools

are used in the South African setting, they do not account for cultural diversity and daily functioning expectations of the different groupings within the population.

A consensus report of the Mind Exchange Working Group stated that no single screening tool was suitable for all contexts (Antinori et al., 2013). They reiterated that the tool's appropriateness must be considered within the resources limitations of the setting, whether screening for HIV NCD or HAD, as well as the population characteristics for which the tool is used (Antinori et al., 2013). In a systematic review on the validity of cognitive screening tools for HIV NCD, it was recommended that rather than attempting to use a single screening tool, a screening procedure should be applied that would provide the best picture of the patient's problems and needs (Kamminga et al., 2013). Three key parts of this procedure that were recommended were; (i) to identify the degree of neurocognitive impairment using an appropriate screening tool, (ii) identify factors such as mood that could contribute to the neurocognitive impairment and, (iii) identify if the neurocognitive impairment affects IADL functioning (Kamminga et al., 2013). The reports of Antinori et al. (2013) and recommendations of Kamminga et al. (2013) support the aim of the researcher in understanding how the three screening tools are used in the research setting to guide care.

From the literature reported above, South Africa, requires an effective and efficient screening process with appropriate screening tools which identify the cognitive function impacted by HIV, the resulting influence on activity limitations and account for the context and norms of the population. The literature reports a lack of standardised and valid screening tools for HIV NCD, within the diverse South African population, to effectively guide care in resource-constrained contexts.

Literature on the specific screening tools used in the clinic was reviewed and is reported below, to understand the known benefits and limitations of these tools in guiding HIV NCD care, in South Africa.

2.3.1 International HIV Dementia Scale

The International HIV Dementia Scale (IHDS) was routinely used for all patients referred to the research clinic site. The IHDS was developed as a revision to the HIV Dementia Scale (HDS), as the HDS needed to be more cross-culturally appropriate (Sacktor et al., 2005). The HDS required formal western education, as

it used timed writing of the English alphabet (for the screening of psychomotor speed), and copying of a cube (for constructional praxis) (Sacktor et al., 2005). The IHDS removed the alphabetical writing item for assessing psychomotor speed and the cube copying item for constructional praxis, thus decreased the need of western education for completion of the screening (Sacktor et al., 2005).

The IHDS has been recommended as appropriate for resource-limited settings, as it can be carried out quickly by non-neurologists and does not require special tools to be completed (Sacktor et al., 2005). Evidence supports that the IHDS is a valid screen for HIV NCD in South Africa (Goodkin et al., 2014).

The IHDS has only three items which include; timed finger tapping (motor speed), timed alternating hand sequence (psychomotor speed), and short term verbal memory test of four items at two minutes (new learning/memory) (Sacktor et al., 2005). The administration of the items is described in chapter 3 (see 3.2.3.1).

A maximum of twelve points can be scored on this screening tool with ten or less, indicating the need for further evaluation of HIV dementia (Sacktor et al., 2005). The cut-off score of ten or less was chosen by Sacktor et al., (2005) as it achieved sensitivity in detecting HIV NCD of 80% of their research cohort, as required in a clinical setting. Although lower scores on the IHDS were found to correspond with increased cognitive impairment in their United States cohort, Sacktor et al. (2005) reported that the IHDS could not differentiate between the stages of HIV NCD. In a South African study in 2011, the IHDS total score showed differentiation between participants in their cohort with HAD, HIV NCD and ANI/no impairment (Joska, Westgarth-Taylor, et al., 2011). A South African study in 2014 used the IHDS to screen for HIV NCD on 70 HIV+ participants and concluded that the IHDS was a valid tool for this purpose but with a modified score of 10.5 (Goodkin et al., 2014). In their South African cohort, a score of 10.5 had a sensitivity of 80% and specificity of 60% in detecting HAD, and a sensitivity of 65% and specificity of 62% in detecting HIV NCD (Goodkin et al., 2014). The recommended cut-off score of 10 or less from Sacktor et al., (2005), yielded a lower sensitivity score of 70% in detecting HAD in South African cohort in the study by Goodkin et al. (2014).

In 2011, the validity of the IHDS within a neuropsychological battery was studied on 96 South African HIV+ experimental participants and 94 Human Immunodeficiency

Virus negative (HIV-) participants as the control group (Joska, Westgarth-Taylor, et al., 2011). A functional assessment was also carried out to categorise the participants in line with the Frascati Criteria for HIV NCD (Joska, Westgarth-Taylor, et al., 2011). These researchers reported that if the cut off was 10, the IHDS produced a sensitivity of 45% and a specificity of 79% in detecting HIV NCD, while a cut off of 11 yielded a sensitivity of 53% and specificity of 80% (Joska, Westgarth-Taylor, et al., 2011). Therefore, Joska, Westgarth-Taylor, et al. (2011), recommended a cut-off score of 11 to ensure a higher sensitivity and prevent missing cases. Thus, the researcher chose to use the cut-off of 11 as the inclusion criteria of participants in this study.

The results of five screening tools for HIV NCD were compared between a South African and United States cohort (Joska et al., 2016). The IHDS was found to have a fair sensitivity and good specificity for symptomatic HIV NCD (Joska et al., 2016). The same study found that when combined, the CAT-rapid and IHDS demonstrated improved results on the screening for any HIV NCD level when compared to the tools being performed in isolation; however, even this was not found to be optimal (Joska et al., 2016). The challenge of screening for the range of classifications within HIV NCD using only one screening tool has been reported in several other studies (Zipursky et al., 2013; Sacktor et al., 2005; Joska, Westgarth-Taylor, et al., 2011). Recommendations suggest the inclusion of executive functioning screens (Joska, Westgarth-Taylor, et al., 2011), screening of IADLs (Goodkin et al., 2014; Antinori et al., 2013) and screening for coexisting conditions (Joska et al., 2016; Antinori et al., 2013).

Therefore, the IHDS is considered a valid screening tool to identify potential HIV NCD in South Africa. However, the IHDS should not be the only tool used in the screening process to effectively guide care in HIV NCD. At the research site, the IHDS was routinely used in conjunction with the MoCA.

2.3.2 Montreal Cognitive Assessment (MoCA)

The MoCA was designed as a brief screening tool to identify mild cognitive impairment (Nasreddine et al., 2005). The MoCA was validated in Montreal, Canada, on a cohort of 93 participants with Alzheimer's disease and 90 healthy elderly participants in the control group (Nasreddine et al., 2005). The MoCA has

not been validated on a South African population. The effectiveness of the MoCA in identifying HIV NCD has been studied both in South Africa and abroad, with varied results in different cohorts (M. Janssen et al., 2015; Joska et al., 2016; Robbins et al., 2013; Hasbun et al., 2013; Jung Kim et al., 2016; Milanini et al., 2014; Koenig et al., 2016).

The MoCA consists of eight subtests which include thirteen tasks. Seven of the eight subtests are scored. The eight subtests include: (i) visuospatial/executive; (ii) naming; (iii) memory; (iv) attention; (v) language; (vi) abstraction; (vii) delayed recall; and (viii) orientation. The administration of the test is described in chapter 3 (see 3.2.3.2).

The MoCA has a total score of 30, with a cut-off point of 26. A score below 26 has been reported to indicate the need for further assessment of cognitive impairment. One point is added to the score if the person being screened has less than 12 years of formal education (Nasreddine et al., 2005).

Woods et al. (2009) published a review on the known cognitive deficits present in HIV NCD, specifically motor skills, processing speed, episodic memory, prospective memory, attention, working memory, executive function and verbal fluency. Of the specific cognitive deficits reported by Woods et al. (2009), the MoCA screens for executive function, attention and verbal fluency. Robbins et al. (2013) reported lower scores for visuospatial, executive, attention, working memory and list learning on the MoCA, in a South African HIV+ cohort, and confirmed this pattern had been observed in prior studies. In a systematic review on the use of the MoCA for HIV NCD, published in 2019, it was concluded that the MoCA was able to produce information that contributed to an HIV NCD diagnosis (Rosca et al., 2019). However, the accuracy with which the MoCA was able to support the diagnosis varied with cut-off points ranging from 22-27 (Rosca et al., 2019). The limitations reported in this review were the lack of variation in the demographics of study participants in terms of education, language and cultural backgrounds (Rosca et al., 2019). These limitations were a concern as MoCA performance is influenced by age, education level, language and culture (Carson et al., 2018). Koenig et al. (2016) found a significant positive association between the MoCA scores and ethnicity, education and employment status. It has been recommended that

normative data for the context was required to interpret the results accurately (Carson et al., 2018).

One South African study compared the Repeatable Battery for the Assessment of Neurological Status (RBANS) and the MoCA on 370 healthy participants of coloured ethnicity (Beath et al., 2018). The study concluded that the MoCA was fairly reliable for the population studied, when compared to the RBANS, but recommended modifications to specific domains and lowering of the cut-off score to 24 to reduce false-positives (Beath et al., 2018). Limited information on the demographics such as language, age and education level were available in the abstract, as the full paper was not published at the time of writing this review. This paper was the first to review the MoCA within the South African population to develop normative data (Beath et al., 2018). Due to the limited information provided in the abstract, the cut-off of 24 was not considered for use by the researcher in this current study.

Joska et al. (2016) found that the MoCA produced excellent sensitivity in their South African cohort but poor specificity for HAD, and good sensitivity but poor specificity for symptomatic HIV NCD. These findings differed from the systematic review of Rosca, Albarqouni and Simu, (2019) that highlighted the impact of context on performance on the MoCA. The cultural appropriateness of the MoCA has been raised as a limitation of efficacy in identifying HIV NCD in the South African population (Robbins et al., 2013). Robbins et al. (2013) used an adapted MoCA on a cohort of Xhosa speaking HIV+ and HIV – participants in South Africa. This adaptation was made to accommodate the low level of education and the first language of the target group, by adapting the verbal fluency task from phonetic to semantic fluency, and removing the sentence repetition task (Robbins et al., 2013). This adaptation reduced the language subtest to only one task. The total on the MoCA score was, therefore, adjusted to 28 (Robbins et al., 2013). When using the adapted version, floor effects across the cohort were noted in the cube drawing (executive subtest), naming (specifically rhinoceros), serial seven's (attention subtest), and the watch/ruler abstraction (abstraction subtest), suggesting that the difficulty in these subtests was not disease-related (Robbins et al., 2013). The HIV+ participants in the cohort performed worse overall in the visuospatial/executive, attention and naming subtests (Robbins et al., 2013). The strongest predictors of scores in this study were HIV status and level of education (Robbins et al., 2013).

Therefore, although the MoCA has been identified as an effective tool to support the diagnosis of HIV NCD (Rosca et al., 2019), the cultural appropriateness of the test and need for population norms are known to influence the accuracy of the results in detecting HIV NCD in the South African population (Robbins et al., 2013; Joska et al., 2016).

2.3.3 World Health Organization Disability Schedule 2.0 (WHODAS 2.0)

The categorisation of HIV NCD into MND and HAD requires the presence of mild and major dysfunction, respectively, in IADLs (Antinori et al., 2007). The areas in IADLs to be screened for dysfunction include but are not limited to; medication management, shopping, financial management, meal preparation, employment and driving (Antinori et al., 2007). The DSM-5 is the latest revision of the diagnostic classification system for mental disorders, which recommended the use of the WHODAS 2.0 for assessment of global functioning (Gold, 2014). The WHODAS 2.0 is a self-report, generic measure which aims to measure the impact of health on activity participation and is rooted in the International Classification of Function (ICF) (Üstün et al., 2010). The WHODAS 2.0 has been tested in 19 countries and is sensitive to activity participation in relation to health, regardless of the sociodemographic status of the individual (Üstün et al., 2010). The WHODAS 2.0 has been used with South African HIV+ cohorts to measure activity limitations (Kietrys et al., 2019; Hanass-Hancock, Myezwa and Carpenter, 2015; Myezwa et al., 2018). Self-report tools are considered appropriate in assisting in the diagnosis of HIV NCD in the absence of depression symptoms (Antinori et al., 2007). Objective assessment may be more useful when cognitive impairment has been identified (Antinori et al., 2007). No studies were identified by the researcher using the WHODAS 2.0 for screening in HIV NCD.

The WHODAS 2.0 requires the participant to consider their occupational behaviours within the period of the past 30 days and screens performance using self-reporting in six domains: understanding and communicating, getting around, self-care, getting along with others, life activities, and participation in society (Üstün et al., 2010). Each domain has several questions relating to the activities within that domain. The activities defined in the life activities domain, reflect that of IADLs, described by Antinori et al. (2007). The WHODAS 2.0 can be self-administered, interviewer-

administered or by proxy (Üstün et al., 2010). The domains and administration of the WHODAS 2.0 are described in chapter 3 (see 3.2.3.3).

The WHODAS 2.0 also explores the number of days out of 30 that difficulties in the above six domains were experienced, as well as the degree the difficulty impacted the person's activity participation; (i) they were totally unable to perform activities or (ii) they experienced reduced activity (Üstün et al., 2010).

The WHODAS 2.0 is a valid self-report scale, which has been tested across a variety of cultures and patient populations, maintaining consistency in reliability and item-response characteristics (Üstün et al., 2010). Reliability and validity of the WHODAS 2.0 have been examined in two international wave studies, which accounted for cultural and population variations (Üstün et al., 2010). The test-retest reliability of the WHODAS 2.0 was found to have an intra-class coefficient of 0.69–0.89 at item level; 0.93– 0.96 at domain level; and 0.98 overall (Üstün et al., 2010). The internal consistencies of the item-total correlations, using Cronbach's alphas, were found to range from acceptable to very good (Üstün et al., 2010). The WHODAS 2.0 was found to have concurrent validity with known instruments, such as the Functional Independence Measure, with high correlation in particular domains relevant to the measure (Üstün et al., 2010). Construct validity of the WHODAS 2.0 was reported in terms of the sensitivity to change, which was adequately sensitive and comparable to established measures (Üstün et al., 2010).

No known studies have used the WHODAS 2.0 in a screening battery to understand the activity limitations in a South African HIV NCD cohort. Three recent studies have used the WHODAS 2.0 to measure activity limitation and disability in South African cohorts who were HIV+ (Hanass-Hancock, Myezwa and Carpenter, 2015; Myezwa et al., 2018; Kietrys et al., 2019). Due to the limited ordinal scale and adapted scoring used in these studies (Hanass-Hancock, Myezwa and Carpenter, 2015; Myezwa et al., 2018), comparison to this study was limited. Myezwa et al. (2018) found that when ARV compliance increased, self-reported disability decreased. The presence of depression correlated with increased disability in all domains of the WHODAS 2.0 (Myezwa et al., 2018; Hanass-Hancock, Myezwa and Carpenter, 2015). Several studies concurred that screening functional deficits in persons with HIV NCD, who were classified as functionally impaired on the self-report, had more

symptoms of depression and a tendency to over-report dysfunction, as compared to results of performance-based testing (Blackstone et al., 2012; Thames et al., 2011; Obermeit et al., 2017). The researcher's inclusion criteria, therefore, required mood symptoms of participants to be medically stable.

Other than IADL limitation, as reported above, Blackstone et al. (2012) reported the 'gold standard' indicator of everyday function, in HIV NCD, to be employment status, as found in a cohort of 299 participants in a study in the United States of America (USA). Participants who were functionally impaired on performance-based measures were more likely to be unemployed than those who scored as functionally impaired on self-report (Blackstone et al., 2012). In the USA, the unemployment rate in December 2019 was 3.5% (United States Department of Labor: Bureau of Labor Statistics, 2020) while in South Africa, the unemployment rate in October 2019 was 29.1% (Statistics South Africa, 2019). The considerable difference in the unemployment rates affects the transferability of using employment as a gold standard indicator of everyday functional impairment in South Africa, although still a relevant factor for consideration. The WHODAS 2.0, contains a self-report on work, relating to difficulties experienced in work tasks (Üstün et al., 2010). The WHODAS 2.0 would, therefore, assist in identifying limitations in work activity, which has been identified as a valuable indicator of the influence of HIV NCD, by Blackstone et al. (2012).

Self-report has been accepted and is commonly used to identify the presence of activity limitations (Obermeit et al., 2017), to support the diagnosis of the categories of HIV NCD as per the Frascati Criteria, in the absence of depressive symptoms (Antinori et al., 2007). The efficacy and accuracy of self-report in supporting the diagnosis of HIV NCD has been studied concerning the cognitive impact of HIV NCD (Thames et al., 2011; Obermeit et al., 2017; Blackstone et al., 2012). Functional limitations in participants with MND are under-reported when self-report tools were used (Thames et al., 2011). Metacognition, an executive function, is required to self-appraise function and the influence of one's cognition (Obermeit et al., 2017). Human Immunodeficiency Virus is known to affect the frontal cortex and frontostriatal loops (Woods et al., 2009), which contributes to the challenges that people with HIV NCD experience, in metacognition of complex self-appraisal (Obermeit et al., 2017). The inflated self-report of dysfunction found in persons with

a depressed mood and the reduced self-reporting of dysfunction found with cognitive dysfunction, suggests that cases could be missed or mismanaged (Obermeit et al., 2017).

In summary, the WHODAS 2.0 is a self-report scale which is valid across varied sociodemographic status (Üstün et al., 2010), and has been used in South Africa to measure activities limitation in HIV+ cohorts (Myezwa et al., 2018; Hanass-Hancock, Myezwa and Carpenter, 2015). Self-report assessment can assist in the diagnosis of HIV NCD categories, in the absence of depressive symptoms (Antinori et al., 2007) but has presented with challenges of accuracy with impaired cognition in HIV NCD (Thames et al., 2011; Blackstone et al., 2012; Obermeit et al., 2017).

2.3.4 Integration into the Occupational Therapy Practice Framework: Domain and Process (3rd Edition)

Literature specific to screening within the occupational therapy process and HIV NCD was not found by the researcher, despite extensive searching. This identifies a specific gap in the literature to guide the identification of patients diagnosed with HIV NCD requiring a comprehensive occupational therapy assessment and future intervention, especially in resource-limited contexts. This gap limits the evidence for the efficacy of OT practice in HIV NCD. The researcher, therefore, has considered and reflected on how the screening of patients diagnosed with HIV NCD can be integrated into the Occupational Therapy Practice Framework: Domain and process (3rd ed.) (OTPF-3), as this is an international guide to the OT process in most contexts.

The practice of occupational therapy and the inter-related constructs that comprise quality practice are described in the OTPF-3 (American Occupational Therapy Association, 2014). The domain of occupational therapy practice delineates the areas in which occupational therapists are specifically skilled in carrying out the occupational therapy process (American Occupational Therapy Association, 2014). This process describes the actions taken by an occupational therapist in service delivery (American Occupational Therapy Association, 2014).

The domain of occupational therapy includes: Occupations, Client factors, Performance skills, Performance patterns and Contexts and Environments and can be seen in Table 2.1 (American Occupational Therapy Association, 2014).

Table 2.1 Aspects of the domain of occupational therapy.

OCCUPATIONS	CLIENT FACTORS	PERFORMANCE SKILLS	PERFORMANCE PATTERNS	CONTEXTS AND ENVIRONMENTS
Activities of daily living (ADLs)* Instrumental activities of daily living (IADLs) Rest and sleep Education Work Play Leisure Social participation	Values, beliefs, and spirituality Body functions Body structures	Motor skills Process skills Social interaction skills	Habits Routines Rituals Roles	Cultural Personal Physical Social Temporal Virtual

*Also referred to as *basic activities of daily living (BADLs)* or *personal activities of daily living (PADLs)*.

American Occupational Therapy Association (2014) 'Occupational Therapy Practice Framework: Domain & Process (3rd ed.)', American Journal of Occupational Therapy, 68(Supplementary 1: S4).

The IHDS and the MoCA are tools used to screen mental functions, as described in 2.3.1 and 2.3.2. Mental functions are classified as client factors in the OTPF-3 (American Occupational Therapy Association, 2014). The WHODAS 2.0 self-report tool that identifies the patient's perceived experience of difficulty in everyday life activities, classified as occupations in the OTPF-3 (American Occupational Therapy Association, 2014). In order to categorise the severity of HIV NCD, as discussed in 2.3, the degree of neurocognitive impairment and resulting impairment in everyday functions must be identified (Antinori et al., 2007). The Frascati Criteria specifically identify the sub-types of HIV NCD according to the degree of dysfunction in IADLs (Antinori et al., 2007), which form part of occupations as defined in the OTPF-3 (American Occupational Therapy Association, 2014). The impact of context on the appropriateness of the tools used for screening was highlighted by Antinori et al. (2007). These considerations require that screening tools consider the domain of context and environment in which they are used, which in this case refers to the cultural, personal and temporal contexts of the patients (American Occupational Therapy Association, 2014). Occupational therapists are skilled at evaluating the interrelatedness of the different aspects of the domain (American Occupational Therapy Association, 2014). This skill is essential when evaluating screening tools for patients for HIV NCD, as the complex dysfunction in mental functions

(neurocognitive impairments and resulting cognitive limitations) cause the dysfunction in occupations (IADLs).

The occupational therapy process includes evaluation, intervention and targeting outcomes (American Occupational Therapy Association, 2014), it does not, however, consider screening within this process. Earlier professional literature did consider screening to be a legitimate step in the occupational therapy process to decide if a person's difficulty fell within the occupational therapy domain of concern and if the problem was of sufficiently debilitating to warrant a comprehensive assessment especially in contexts with limited resources (Creek, 2008). In the human and financial resource-constrained context of the public health system in South Africa, prioritising patients according to need is critical in service delivery (Déry et al., 2019). In this context, the IHDS, MoCA and WHODAS 2.0 are screening tools to classify the extent of HIV NCD, which a patient has to (i) broadly identify those patients who are at risk of occupational dysfunction and need monitoring (ii) those who have sufficient dysfunction and need a comprehensive assessment and intervention. There is little literature on occupational therapy specific screening tools, although screening tools are widely used in many fields of service delivery in the health sector. Should a screening identify deteriorating or marked occupational dysfunction, then a more comprehensive occupational therapy assessment would be indicated.

In the evaluation process, the occupational therapist selects specific tools and occupations to measure the appropriate domains to understand their functionality and focus on the specific occupations that seem dysfunctional or affected (American Occupational Therapy Association, 2014). There are different types of evaluations, and thus evaluation tools and methods are selected for different purposes: to discriminate, predict function and evaluate outcomes (Millar Polgar, 2009). Using evaluation tools and methods to discriminate, assists in knowing who in a group has occupational dysfunction and will benefit from intervention, or different types of intervention (Millar Polgar, 2009). Using evaluation tools and methods to predict function helps the occupational therapist to understand the relationship between domains, for example: identifying that the patient has poor prospective memory (client factor) helps the therapist determine the relationship with difficulties managing medication (Millar Polgar, 2009). Using evaluation tools

and methods to evaluate outcomes can help understand the impact of the intervention on a single client, or when data is gathered, it can support practice (Millar Polgar, 2009).

When using specific standardised screening or evaluation tools, the tools must be effective for the purpose and appropriately inform the need for a more detailed assessment of the intervention aspect of the process. To ensure this, occupational therapists need to critique them (Millar Polgar, 2009). Aspects of critique include clinical utility, technical considerations, fair testing issues and external reviews (Millar Polgar, 2009).

The researcher has reviewed the screening tools used in this study, in the literature review section 2.3.1 through to 2.3.3. Through a critical review of the screening tools in clinical practice and review of the literature on screening for HIV NCD, the researcher identified that the interrelationship of the domains evaluated in the three screening tools is not adequately understood in the South African population.

In this study, the researcher aimed to establish if the screening tools being used are appropriate to predict function and if they can discriminate between those patients attending the clinic who required a further occupational therapy assessment to guide care. In this way, the researcher worked within the OTPF-3.

2.4 Summary

In the South African HIV+ population, HIV NCD is prevalent and specialised resources to treat this condition are limited; therefore, the context requires an effective screening process to guide further assessment and intervention. The IHDS has been found to be a valid screening tool for HIV NCD in South Africa but cannot stand alone in screening for the categories of HIV NCD. The MoCA has been found to be useful in identifying cognitive decline in HIV NCD, but the utility of the tool has been queried in the South African context. The WHODAS 2.0 has been found to be valid across varied contexts and has been used to understand the impact of HIV on everyday function in South Africa. The researcher aimed to understand if these tools are effective in predicting function and discriminate between those who require more in-depth assessment and those who would benefit from alternative management strategies. This aim is in line with the evaluation process of the OTPF-

3 and ensuring that the correct tools are selected and used to guide further care in HIV NCD.

CHAPTER 3 RESEARCH METHODOLOGY

3.1 Introduction

This research was done as a descriptive study with two phases. The initial quantitative phase examined the scores obtained on the three screening tools used with patients with HIV NCD, to determine if the MoCA and WHODAS 2.0 identified cognitive and activity limitations respectively, in patients scoring 11 and below on the IHDS. The second phase was informed by the first and used a qualitative design where the data was collected in group interviews with health professionals from two research sites, who utilised these screening tools regularly and with large numbers of patients with HIV NCD.

A descriptive design was used as the study aimed to describe and interpret the correlation between the screening tools already being used, and the professional's perceptions of these screening tools, without manipulation of any variables (Mertler, 2016). In this way, the researcher was able to describe and interpret if the existing screening tools differentiated the level of dysfunction that required referral to occupational therapy, as needed in the purpose of the study (see 1.3). The use of two phases allowed for the depth of interpretation of the quantitative results in phase one, through triangulation with perceptions of professionals in phase two. This depth was important in achieving the purpose of the study (see 1.3) and to answer the research question posed (see 1.4).

Thus, this chapter has been organised to report on the research methodology used in phase one, followed by phase two.

3.2 PHASE ONE

3.2.1 Research design

Phase one was the quantitative strand of the descriptive design explained above. This quantitative strand used a descriptive correlation methodology that examined the convergent validity of the MoCA and WHODAS 2.0, to the IHDS and each other. The quantitative design was appropriate as all the screening tools used quantitative

test results to determine the cognitive and activity limitations present, as measured by the MoCA and WHODAS 2.0, for participants scoring 11 or less on the IHDS. These scores were then used to determine the convergent validity of the MoCA and WHODAS 2.0, to the IHDS for participants identified with HIV NCD. Finally, the association between cognition and activity limitations was determined in the cohort through determining the convergent validity of the MoCA to the WHODAS 2.0. The association was determined to confirm if the MoCA and the WHODAS 2.0 were effective screening tools to identify the presence of cognitive and activity limitations in HIV NCD, to guide referral for further occupational therapy assessment and intervention.

3.2.2 Population and sample

The population for the study were people being treated for HIV NCD at an HIV Neuropsychiatry clinic. The sample was recruited using non-probability convenience sampling (Laerd Dissertation, 2012a).

The research site for phase one of the study was a busy outpatient clinic, based at a tertiary teaching hospital in Gauteng, South Africa. The multidisciplinary team at the clinic consisted of nursing staff, a medical officer, two psychiatrists, registrars in psychiatry and medical students. Referrals for specific interventions were made to departments such as psychology and occupational therapy by the clinic doctors based on the patient's screening results, as these departments had no full-time therapists in the clinic. The clinic was organised based on patients' health requirements related to their diagnosis. For example, patients with substance misuse/abuse comorbid to their neuropsychiatric diagnosis were seen on a specific clinic day. This was done to best use clinical resources for the needs of the target group. This organisation assisted the data collection process as potential participants, based on the inclusion criteria described below, attended the clinic on a specific day of the week between 09:00-13:00.

Given the resource limitations of the research setting and the inclusion criteria for the research participants, convenience sampling was an effective sampling technique. Convenience sampling allowed for ease of access to participants, where other limitations, such as a time-constrained busy clinic, were present (Laerd Dissertation, 2012a). Non-probability sampling was appropriate for this descriptive

study, to establish the convergent validity of three screening tools, for a specific group of people, which had not been previously established (Laerd Dissertation, 2012b). A known group sample, with a score of 11 and below on the IHDS, was considered most appropriate to establish the convergent validity of the tools in the specific group (Laerd Dissertation, 2012b). The sample recruited were those clinic attendees that had been clerked by the clinic doctor and had scored below 11 on the IHDS in the initial medical screening process. The score of 11 or below was the number used in the study to indicate that these patients required further screening for HIV NCD, as recommended by Joska, Westgarth-Taylor, et al. (2011) for the South African population (see 2.3.1). Patients recruited into the study were required to meet the following inclusion criteria.

Inclusion Criteria of patient-participants

HIV positive clinic attendees who:

- Were 18 years and older;
- Had scored 11 or below on the IHDS when assessed by the clinic doctor;
- Had been diagnosed with mood disorders but are stable on medication; and
- Compliant on ARV treatment.

Clinic attendees with any of the following exclusion criteria were not invited to participate in the study.

Exclusion Criteria of patient-participants

HIV positive clinic attendees who:

- Were actively psychotic;
- Had cognitive impairment due to traumatic brain injury; temporal lobe epilepsy; cerebrovascular incident; sexually transmitted infections, long term substance abuse.

The exclusion criteria aimed to prevent a skewed picture of the results from the screening tests, as the above cognitive impairments could present with a false positive on screening tests due to central nervous system damage by conditions other than the HIV and ARVs. The exclusion criteria were supported in a pragmatic approach to screening recommended by Joska et al. (2016) for resource-limited settings. These authors recommended excluding screening of patients with potential confounding conditions such as drug abuse, mental illness and biological

factors, including syphilis (Joska et al., 2016). The exclusion criteria were further supported by Goodkin et al. (2014), who indicated these competing causes of cognitive impairment in the population could result in false positives.

Those patients who met the inclusion criteria were informed of the research, given the information sheets approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand (Appendix A) and invited to participate. The researcher answered any questions the patients had around the research. The patients who chose to participate were given the consent form to complete (Appendix B). All patients invited to participate in the research agreed to participate.

3.2.2.1 Sample size

The sample size for this phase of the study was calculated using Cochrane's formula (Bartlett et al., 2001). Approximately 75 patients were seen at the clinic each week. In the eight weeks that data were collected, a total population of 600 patients was estimated. When patients were screened, approximately twelve patients per week met the inclusion criteria for the study. This provided a population of approximately 100 potential participants over the data collection period. A sample size of 55 patient-participants was required to be representative of the population if the margin of error was set at 5% according to Cochrane's formula.

3.2.3 Research Instruments

Patient-participants, in this study, all completed a demographic information form (Appendix C). Demographic information was collected on age, first and second language and the highest level of education obtained. Demographics on gender were retrieved from the MoCA. The time patient-participants had lived in South Africa was collected to identify the possibility of other clades of HIV being present in the cohort. The patient-participants were asked when they were first diagnosed, if they were on ARV's and if so, how long they had been on ARV's. This information allowed the researcher to ascertain the period between diagnosis and ARV treatment. Patient-participants were asked about co-morbid conditions and treatment for these. If the patient-participants were unable to answer any of these questions, the information was collected from their patient record. This information was used to understand the clinical picture of the cohort. The most recent CD4

count was collected from the patient-participants' records. The ARV regimen, period before initiation, and CD4 count are known to impact neurocognitive decline (Liner et al., 2010). Before the data collection, the patient-participants were asked if they had eaten breakfast before the attending clinic. This information was gathered to identify any other influences on performance in tests.

Data were then collected for all three of the following research instruments: IHDS, MoCA and WHODAS 2.0. For this study, the IHDS was only administered by the researcher if the clinic doctor had not tested the participant in the last six months. If the clinic doctors' completed IHDS scores were available in the patient-participants' clinic record, these were used. The MoCA and WHODAS 2.0 were administered by the researcher.

3.2.3.1 International HIV Dementia Scale (IHDS)

The IHDS (Appendix D) was routinely administered on admission to the clinic by the admitting doctor and again if the patient's condition indicated the need for a new evaluation.

The IHDS takes approximately five minutes to administer. It has been used in several studies in South Africa as a screening tool for HIV neurocognitive disorders (Goodkin et al., 2014; Joska et al., 2016; Joska, Westgarth-Taylor, et al., 2011). The tool is easy to administer and can be obtained at no cost, other than printing. It has an easily understood numerical scoring system. The IHDS does not require a trained examiner and does not require English proficiency (Antinori et al., 2013).

The IHDS is a useful screening tool for identification of those at risk of and with HIV dementia (Sacktor et al., 2005). The validity of the IHDS has been reported in literature through the sensitivity and specificity for the identification of HIV NCD, with no information on test-retest reliability or construct validity (Mwangala et al., 2019). Sacktor et al. (2005), established the IHDS as a valid international screening tool for HIV NCD. The IHDS was tested across a cohort in the United States of America, and in Uganda (Sacktor et al., 2005). A cut-off score of 10 was established to have sensitivity and specificity comparable to the Grooved Pegboard non-dominant hand test, a proven test for HIV dementia (Sacktor et al., 2005). Joska, Westgarth-Taylor, et al. (2011), established the validity of the IHDS in the South African population, using a Receiver Operating Characteristic (ROC) analysis. The study consisted of

a control group of 94 HIV – participants, and a test group of 96 HIV+ participants, who completed a full neuropsychological battery along with the IHDS (Joska, Westgarth-Taylor, et al., 2011). The IHDS discriminated well across the groups, when compared with the neuropsychological battery, with 53% sensitivity and 80% specificity when using a ROC analysis on a cut-off of 11 and below on the IHDS (Joska, Westgarth-Taylor, et al., 2011). Better sensitivity was achieved using a cut-off of 11 or less than that of 10 or less (Joska, Westgarth-Taylor, et al., 2011). The IHDS is an effective brief screening tool for HIV NCD in South Africa, although unable to adequately differentiate between categories described as 'Frascati Criteria' (Joska, Westgarth-Taylor, et al., 2011; Joska et al., 2016).

In this study, the administration and scoring guidelines for the IHDS screening test by N. Sacktor et al. of the Department of Neurology, Johns Hopkins University, Maryland were followed (Sacktor et al., 2005).

In this study, all patient-participants that did not have recent IHDS scores on file completed three subtests namely; timed finger tapping (motor speed), timed alternating hand sequence test (psychomotor speed), and recall of four items in a two minute period (memory recall) (Sacktor et al., 2005).

- During the timed Finger tapping subtest, the participant was required to place their non-dominant hand flat, fingers spread widely on the table. The participant was then asked to tap the first two fingers (index and middle finger) as quickly as possible with the number of taps made in five seconds counted, with a maximum score of four for fifteen taps. Eleven to fourteen taps in five seconds score 3 out of 4. Seven to ten taps in five seconds, scores 2out of 4. Three to six taps in five seconds, scores 1out of 4. Zero to two taps in five seconds, scores 0 out of 4.
- In the Alternating hand sequence subtest, the participant was asked to clench their hand in a fist with the fifth digit down on the table, place hand palm down flat on the table and then place the hand perpendicular to the table with the fifth digit on the table. This sequence was demonstrated twice before asking the participant to perform this. The number of sequences of the three movements was counted within a ten-second timeframe. A maximum score of 4 is obtained if 4 complete sequences are achieved in ten seconds. Three

sequences in ten seconds score 3 out of 4. Two sequences in ten seconds score 2 out of 4. One sequence in ten seconds scores 1 out of 4. Zero sequences in ten seconds, scores 0 out of 4.

- Memory recall subtest used a series of four words: dog, hat, bean, red, which are given at the beginning of the screening and had to be recalled verbally by the participant. After completing the motor and psychomotor subtests, the participant was requested to recall the four words. If the participant was unable to recall the words immediately, they were repeated. If the participant required prompts, category clues were used: animal (dog); clothing (hat); vegetable (bean); and colour (red). Words recalled spontaneously were given 1 point, and words requiring prompting scored 0.5 points.

The final IHDS score is calculated out of a maximum of twelve, with twelve indicating no need for further assessment for HIV dementia.

At the research site, IHDS scores of 10 or less were used by the clinic doctors as the indication to refer the patient for occupational therapy. However, for this research, scores of 11 or less were used as they are more sensitive in detecting forms of HIV NCD in the South African population, than a cut-off point of 10 (Joska, Westgarth-Taylor, et al., 2011; Joska et al., 2016).

3.2.3.2 Montreal Cognitive Assessment (MoCA)

At the research site, the MoCA (Appendix E) was also routinely administered by the clinic doctor on the admission of the patient to the clinic. If a MoCA score was already available in the patient record, from the referral source, the clinic doctor did not repeat it on admission to the clinic.

The MoCA is also a brief screening tool developed to detect mild cognitive impairment (Nasreddine et al., 2005), and can be used to track changes in cognition over time (Hasbun et al., 2013). The MoCA takes approximately fifteen minutes to administer. At the time of data collection (2017-2018), the MoCA was available to use free of charge, and no certification was required for administration. The developers had published guidelines on administration. The MoCA has been widely used to screen for cognitive impairment (Hasbun et al., 2013), however differing opinions as to its efficacy in detecting cognitive impairment in HIV infected individuals have been reported (Joska et al., 2016; Hasbun et al., 2013; Valcour et

al., 2011; M. A. M. Janssen et al., 2015; Robbins et al., 2013; Rosca, Albarqouni and Simu, 2019). Common challenges noted in the use of the MoCA in the South African population living with HIV, have been the cultural appropriateness of the test items (Robbins et al., 2013; Joska et al., 2016), and poor specificity of the MoCA in identifying HIV NCD both in South Africa and abroad (Joska et al., 2016; M. A. M. Janssen et al., 2015). No further psychometric properties of the MoCA in the South African population, specific to HIV NCD were found to be reported. Details on the sensitivity, specificity and known limitations of the MoCA, referenced above, can be found in the literature review (see 2.3.2).

The administration and scoring guidelines published by Nasreddine (2004), were followed in the administration of the MoCA for the study. The MoCA consists of eight subtests which include thirteen tasks. Seven of the eight subtests are scored. The eight subtests include: (i) visuospatial/executive; (ii) naming; (iii) memory; (iv) attention; (v) language; (vi) abstraction; (vii) delayed recall; and (viii) orientation.

- The visuospatial/executive subtest consists of 3 tasks, including an alternating trail making task (1 point), three-dimensional cube copy (1 point), and a clock drawing task (one point for contour, one for numbers, one for hands of the clock with total equal to 3 points) (Maximum total points= 5) (Nasreddine et al., 2005).
- The naming subtest has three images (lion, rhino and camel) which must be named (1 point per correctly named image, a maximum total of 3 points) (Nasreddine et al., 2005).
- The memory subtest is not scored. It has five nouns which are repeated over two trials and asked for a delayed recall after 5 minutes following completion of other subtests on the tool (0 points) (Nasreddine et al., 2005).
- The attention subtest has 3 tasks; 5 digits forwards and 3 digits backward (1 point per complete subset equal to a maximum of 2 points); ‘target detection’ through tapping (1 point is given if one or no errors are made); and serial seven subtraction (3 points if four or five subtraction are correct, 2 points if two or three subtractions are correct, 1 point if one subtraction is correct, and 0 if no subtractions are correct) (Maximum total points is 6 points) (Nasreddine et al., 2005).

- The language subtest consists of two tasks; verbal repetition of two complex sentences (1 point per sentence correctly repeated with a maximum of 2 points), and phonemic fluency using 'F' (1 point for eleven words or more in 60 seconds) (Maximum total points is 3) (Nasreddine et al., 2005).
- The abstraction subtest has one task which requires the abstraction of two concepts (1 point per correct abstraction with maximum total points is 2) (Nasreddine et al., 2005).
- The orientation subtest has one task asking orientation of date, month, day, year, place and city (1 point per correct response with a maximum total of 6 points) (Nasreddine et al., 2005).

The MoCA has a total score of 30, with a cut-off point of 26 (Nasreddine et al., 2005). A score below 26 indicates the need for further testing for cognitive impairment. One point is added to the score if the person being screened has less than 12 years of formal education (Nasreddine, 2004).

3.2.3.3 World Health Organization Disability Assessment Schedule 2.0 (2010) (WHODAS 2.0)

The DSM-5 was used to classify the diagnostic findings of the patients attending the research site clinics. The DSM-5 is the latest revision of the diagnostic classification system for mental disorders, which recommended the use of the WHODAS 2.0 for assessment of global functioning (Gold, 2014). The WHODAS 2.0 questionnaire was not used in the research sites, despite this recommendation. The WHODAS 2.0 is a self-report, generic measure which measured the impact of health on activity participation and was rooted in the International Classification of Function (ICF) (Üstün et al., 2010). The WHODAS 2.0 was used in this study as the everyday functional screening, as it was relevant to the research sites' diagnostic classification system, is linked to the ICF and obtained narratives on participants' experiences of activity participation.

Antinori et al. (2007) reported that self-report assessments of IADLs could assist in the diagnosis of HIV NCD in the absence of depressive symptoms. The WHODAS 2.0 has been used to understand the link between HIV and activity limitations in several studies in South Africa (Hanass-Hancock, Myezwa and Carpenter, 2015; Myezwa et al., 2018). The WHODAS 2.0 has been tested in 19 countries and is sensitive to activity participation in relation to health, regardless of the

sociodemographic status of the individual (Üstün et al., 2010). Detail of the known psychometric properties of the WHODAS 2.0 can be found in the literature review (see 2.3.3).

The WHODAS 2.0 requires the participant to consider their occupational behaviours within the past 30 days and screens performance using self-reporting in six domains: understanding and communicating, getting around, self-care, getting along with others, life activities, and participation in society (Üstün et al., 2010). Each domain has several questions relating to the activities within that domain. Responses to the questions are scaled from 1 (no difficulty) to 5 (extreme difficulty or unable to perform). These scaled responses are calculated onto a percentage of patient-experienced difficulty, with 100% being extreme difficulty or patient being unable to perform that activity. The summary score of the WHODAS 2.0 can be calculated through simple or complex scoring (Üstün et al., 2010). Simple scoring requires scores to be added up without weighting of individual items (Üstün et al., 2010). The simple scoring method is indicated for hand-scoring in a busy clinical setting and is not comparable across populations (Üstün et al., 2010). The complex scoring method is computerised scoring, which is based on item-response-theory (Üstün et al., 2010). The complex scoring weights items differently based on the level of difficulty of each item and can be used to compare across populations (Üstün et al., 2010). The researcher selected the complex scoring method due to the weighting of individual items and utility in population comparison. The WHODAS 2.0 also explored the number of days out of 30 that participants reported difficulties in the above six domains were present, as well as the degree the difficulty influenced their activity participation; (i) they were totally unable to perform activities or (ii) they experienced reduced activity (Üstün et al., 2010).

The 36-item interviewer-administered version was used to allow the researcher to control the environment (limiting distraction) and ensure the participants understood the questions in the WHODAS 2.0 (Appendix F). This version required the administrator to use two flashcards.

- Figure 3.1: Flashcard 1 described the meaning of health condition as well as difficulty in activity and reminded the participant to think only of the last 30 days (Üstün et al., 2010).

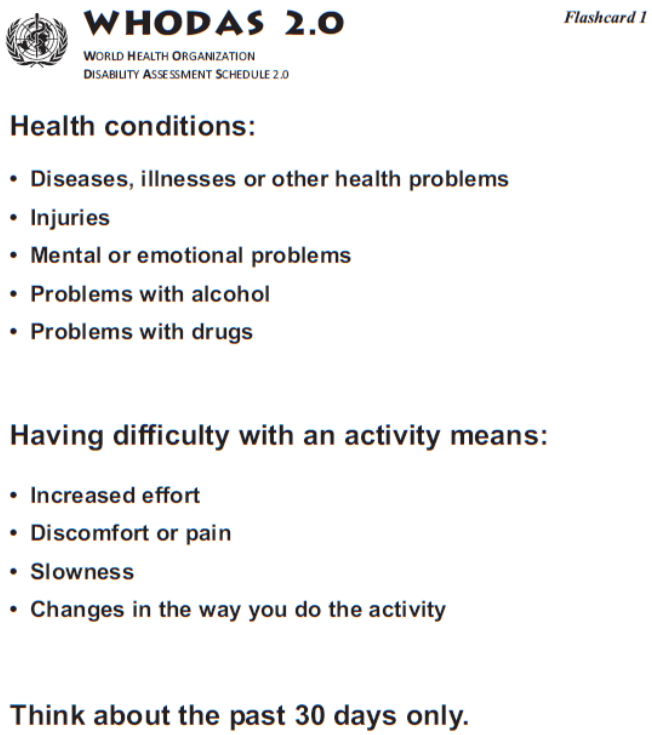

Figure 3.1 World Health Organization Disability Assessment Schedule, Flashcard 1.

Üstün, T. B. et al. (2010) Measuring Health and Disability Manual for WHO Disability Assessment Schedule. Edited by T. Utstun et al. World Health Organization. p109

- Figure 3.2: Flashcard 2 is a scale which indicates the levels of difficulty scaled from 1 (no difficulty) to 5 (extreme difficulty/unable to perform) (Üstün et al., 2010).

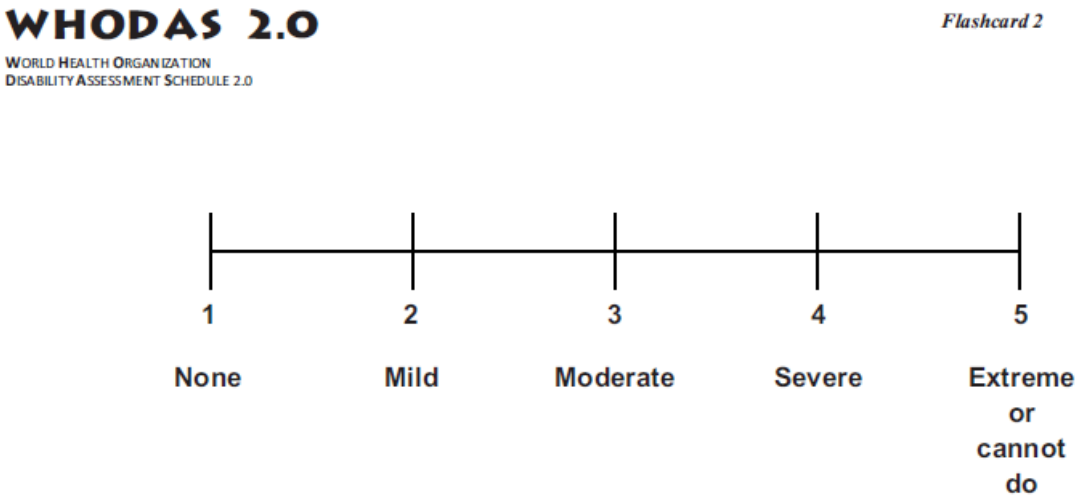

Figure 3.2 World Health Organization Disability Assessment Schedule 2.0, Flashcard 2.

Üstün, T. B. et al. (2010) Measuring Health and Disability Manual for WHO Disability Assessment Schedule. Edited by T. Utstun et al. World Health Organization. p111

These flashcards were created by the WHO Classification, Terminology and Standards Team and were provided in the Manual for WHO Disability Assessment Schedule (Üstün et al., 2010). To ensure that the researcher was competent to administer the WHODAS 2.0, she read the manual and completed the online user agreement to administer the WHODAS 2.0.

3.2.4 Research procedure

The researcher applied to the National Health Research Database (NHRD) before submitting the protocol to the university structures for approval.

Before the research was carried out at the clinic site, the researcher met with the Head of the Clinic and presented the protocol for consideration. Following the clinic head's verbal agreement, a letter formally requesting permission to carry out the research at the site was sent to the Head of Psychiatry at the hospital. The returned letter of permission can be found in Appendix G. After receiving the signed letter of permission from the Head of Psychiatry; the request to conduct the research was sent to the Medical Advisory Committee (MAC) of the site. The MAC granted permission; the signed letter of permission can be found in Appendix H.

Once permission was granted, the researcher conducted a planning visit to the research site and met with the clinic head to review the appropriate days and times for research to be conducted. The inclusion and exclusion criteria for the patient-participants were considered when planning suitable days for data collection. During the planning visit, the researcher discussed the booking timetable and clinic organisation with the clinic head and the nursing staff to ensure that the data collection would not interfere with the running of the clinic and patient's intervention.

At the research site data was collected on a Friday morning, as the head of this clinic indicated most patients that met the inclusion criteria attended on that day. So as not to interrupt the clinic's process and workflow, data were collected from 09:00-13:00. From 08:00-09:00, the researcher reviewed the clinic files for the previous IHDS scores. Based on the IHDS scores, clients were approached by the researcher and invited to participate in the study. If the client agreed to participate, a sticky note was put into their file for the treating doctor to ensure they were sent to the researcher following their consultation. New patients, who scored 11 or below on the IHDS, were also referred to the researcher, to be invited to participate in the research.

The researcher was given a private room in the clinic with a standard table and chairs to use while performing the screening tests on the patient-participants. The room had adequate lighting, airflow and ambient temperature for testing. The same room was used with all patient-participants seated at the table. The data collection took between 30 – 45 minutes, depending on the participant.

3.2.5 Ethical considerations

The protocol for this study was approved by the University of the Witwatersrand's Faculty of Health Science's Graduate Studies Committee and Human Ethics Research Committee (Medical) certificate M160954 (Appendix I). The information sheet (Appendix A) and consent forms (Appendix B) were included in the protocol submission to the Human and Ethics Research Committee (Medical), in line with items required to be included in protocol review (Council for International Organizations of Medical Sciences, 2016). Permission was obtained by the Head of Psychiatry and by the MAC of the research site as reported above. Permission was obtained in this way to work in conjunction with the relevant stakeholders to

manage any potential risks to the patients and service provision (Council for International Organizations of Medical Sciences, 2016).

The research sample was considered to be vulnerable concerning the stigmatisation of the HIV, potential for unemployment (as associated with HIV NCD activity limitation see 2.3.3), as well as the frailty and disability anticipated in those attending a neuropsychiatric clinic (Council for International Organizations of Medical Sciences, 2016). Research in vulnerable groups is only justified if it meets the needs of that particular group (World Medical Association, 2018). The research was specifically responsive to the needs of the resource-limited setting, as the researcher identified the need for the research to be carried out while working in a neuropsychiatric clinic setting (see 1.4). Responsiveness to the needs of the resource-limited setting was also in line with guideline 2 of the Council for International Organizations of Medical Sciences (CIOMS) International Ethical Guidelines for Health-related Research Involving Humans (Council for International Organizations of Medical Sciences, 2016). The research outcome aimed to benefit those attending such resource-limited settings in South Africa, through a better understanding of the efficacy of tools used to guide care in HIV NCD, therefore practising beneficence. To further the practice of beneficence, the results of this research will be made available to the professionals working in these settings to inform future practice, therefore benefiting the researched community (Council for International Organizations of Medical Sciences, 2016).

As described in the research procedure (see 3.3.4), the researcher worked in collaboration with clinic staff to prevent any disruption in service, minimising the risk of negatively impacting service provision, thus upholding the principle of beneficence in research (Council for International Organizations of Medical Sciences, 2016).

Each potential patient-participant was given a copy of the approved information sheet, which was available in English and Zulu (Appendix A) when they were invited to participate in the study. An expert in the Zulu language translated the information sheet from English to Zulu. The information sheet was translated back into English, to confirm the translation, by a separate individual. If the potential participant requested verbal explanation in Zulu, the supporting staff in the clinic had offered to

assist with translating from the researcher's English explanation. In this way, the researcher aimed to provide an appropriate opportunity for an understanding of the information provided. The researcher explained the research process, what was expected of them, that participation was entirely voluntary, and they could leave at any time without consequence. The researcher made it very clear to potential patient-participants that the research was not part of their treatment and would not assist or compromise their treatment in any way. The researcher answered any questions that potential patient-participants raised. The open communication allowed potential participants to make an informed decision as to whether they wished to participate or not, exercising autonomy and in keeping with the CIOMS essential information for informed consent (Council for International Organizations of Medical Sciences, 2016).

Once the research had been explained, the potential patient-participants were invited to participate in the study. If they agreed, they were given a consent form (Appendix B) which stated that they understood the information sheet, that their participation was voluntary, that no information that could identify them personally would be reported, and asked permission for the researcher to look at their file for their medication and viral load. All results from screening tools performed by the researcher were provided to the clinic doctor and recorded in the patients' clinic record to support the existing medical knowledge of the clinical picture of the participant. Providing results to the doctor supported the needs of the participants and thus adhered to the principle of justice (Gelling, 1999).

Confidentiality of information of patient-participants was maintained through using participant numbers on all documents completed and stored for research purposes. No personal identifying data, such as name, identity number or address, were held by the researcher on any of the patient-participants. Hard copies of completed research tools and demographics sheets were kept behind a locked door, with electronic copies kept under password encryption. The hard and soft copies of data will be kept for six years if the research is unpublished and two years from publication if the research is published, as per the Health Professions Council of South Africa's General Ethical Guidelines for Health Researchers, published May 2018 (Health Professions Council of South Africa, 2008).

3.2.6 Data Analysis

In phase one, the researcher gathered ordinal data from patient-participants on both the demographics and the results of the screening tools. As the researcher did not make any assumptions on the probability curve of the data obtained and therefore, used a non-parametric procedure to analyse the data (Tomita, 2006b).

The demographic information collected from patient-participants (age, gender, languages spoken, education level, year of diagnosis of HIV, medication and other illnesses) were given a numerical value for ordinal, non-parametric analysis (Tomita, 2006a). Numerical values provided the researcher with percentage values to describe and understand the characteristics of the patient-participant cohort more effectively and interpret these findings in conjunction with the findings from the screening tools; therefore descriptive statistics were used (Tomita, 2006a).

The IHDS is scored from 0 to 12, with 12 being the maximum score. The MoCA is scored from 0 to 30 with 30 being the maximum score. The WHODAS 2.0 is scored in percentages of experienced difficulty with higher percentages indicating higher levels of difficulty experienced. The researcher interpreted the scores on the MoCA and WHODAS 2.0 in the cohort to determine if they reflected dysfunction in cognition and everyday functions, respectively, as indicated by the IHDS score of 11 or less. Due to the small sample size and distribution of the data, medians were used to describe the scores of the tests (Tomita, 2006a). The researcher tested for the covariance of the MoCA and WHODAS 2.0 to the IHDS and each other, aiming to understand if the total scores and subtest scores of the screening tools increased/decreased in the correlation. The researcher, therefore, selected the Spearman's correlation coefficient. When using Spearman's correlation coefficient, the strength of the correlation is classified as very low (below $r_s = 0.16$), weak to low (r_s=0.16-0.29), low to moderate (r_s =0.30-0.49), moderate (r_s =0.50-0.69), strong (r_s =0.70-0.89) and very strong (r_s = 0.90-1.00). Due to the WHODAS 2.0 increasing in score with the increased difficulty experienced in everyday function, a covariance to the IHDS and the MoCA would yield a negative score. A linear regression analysis was then used to understand the extent of correlation of the total scores on the screening tools, and whether the scores on the IHDS predicted those of the MoCA and WHODAS 2.0 (Tomita, 2006b).

Linear regression was used as the variables were continuous data, in the form of test performance. The linear relationship between the variables was tested and scatterplots indicating 95% predictive interval between the variables were created. The 95% prediction interval indicated an estimate of where an interval in a future observation, for a similar sample, will fall based with a certain probability, given what had already been observed this study (Coleman, 2018).

The r^2 value was used to determine the proportion of variance between the variables and analysed, according to Cohen's r classification (Cohen, 1988, 1992). The F value, of statistical significance of the regression model and the coefficients for the variables, were also calculated, to indicate overall if the model applied could statistically significantly predict one variable from the other (Laerd Statistics, 2018).

The normality of the regression residuals was established using Q-Q plots of every observed standardized residual value, against a standard normal distribution. The plots indicate the distributions are equal, only if the plot falls on or close to the line of normal distribution (Grace-Martin, 2020).

Data were checked for outliers using standard residuals and since not all outliers influence the regression analysis, and the influence of the outliers was determined using Cook's distance. These outliers would only have been eliminated if an observation with a value of Cook's distance was over 1 (Lane, 2018). The homoscedasticity of the data was assessed visually, by determining if clustering of data remained similar along the regression line (Lane, 2018).

3.3 PHASE TWO

Phase two was the qualitative phase of the two-phase descriptive design, used to understand and explain the results of the first phase. Phase two aimed to describe the experiences and perceptions of the assessing team members in using the three screening tools to guide care for the researched population in the Gauteng province. These perceptions were used to elaborate on the findings of phase one.

While this qualitative phase was valuable in the understanding of the results of phase one, it also served to explore the unexpected challenges experienced by the researcher when completing the screening tools with the patient-participants while collecting quantitative data. The qualitative phase also provided an opportunity to

explore how the assessing team members used the screening tools and the test results to guide health service delivery to the research population, and whether this was congruent with the results of the quantitative study in phase one. These issues were used to inform the questions planned to gather the data in the group interviews.

3.3.1 Research design

Phase two used a descriptive qualitative methodology to describe the experience and perceptions of the assessing team members in the two HIV NCD clinics in Gauteng.

The qualitative phase used the qualitative descriptive method to explore and describe the team members perceptions and experiences of the efficiency, effectiveness and limitations of the three screening tools (Colorafi and Evans, 2016). This phase aimed to explore how the team members used the three screening tools in determining the severity of cognitive dysfunction and activity limitations, as well as the need for and type of intervention required in the Gauteng population, living with HIV NCD.

The researcher used the descriptive qualitative method as it provided an appropriate low-inference approach to obtain information on experiences and perceptions of health professionals working in the field, on the three screening tools and their potential in guiding the service delivery to patients suffering from HIV NCD (Colorafi and Evans, 2016). To answer the research question and meet the single objective for phase two, a high inference approach such as grounded theory, would not have been useful, as this would have required interpretation of perceptions rather than the description (Colorafi and Evans, 2016). Due to the nature of high inference approach of qualitative methods such as grounded theory or phenomenology, they do not describe the direct experience of the participant and therefore were not appropriate to the research question and study aim (Sullivan-Bolyai et al., 2005). A qualitative descriptive methodology was able to identify essential information to review existing practice, as was required in this study (Sullivan-Bolyai et al., 2005).

Several factors informed the decision to use semi-structured formal field group interviews to collect data for phase two. These included the resource limitations of the clinics, typical engagement of a multi-disciplinary team, range of experiences

obtained, and the use of information from phase one to focus the group through semi-structured questions.

The use of a group interview, as opposed to in-depth individual interviews, was an efficient use of the resources and time in the clinics and limited disruption to the service. A formal group interview was used as this provided the opportunity for an arranged meeting time and place, which limited distraction and accommodated the busy schedules of participants within each clinic (Morgan et al., 2013). Accommodating the schedules of practitioner-participants was an important ethical consideration for the resource-limited settings, so as not to compromise the service provision.

A group interview was a typical engagement for the teams, who regularly attended team ward rounds, professional ward rounds and journal clubs together. This familiarity stimulated clinical discussion. The research question aimed to obtain a range of perceptions and experiences from team members and not to understand in-depth individual narratives. Therefore group interviews were more appropriate than in-depth individual interviews (DiCicco-Bloom and Crabtree, 2006).

The use of a semi-structured group interview provided the opportunity for prepared open-ended questions, based on findings in phase one, to be posed to the groups (Jamshed, 2014). Semi-structured group interviews provided the best use of time and allowed for comprehensive data to be collected on the team members perceptions of the tools and their efficacy in guiding care (Jamshed, 2014). Semi-structured group interviews were used as opposed to focus groups, as the focus group dynamic calls for in-depth analysis of the implicit and unconscious behaviour of the group, which was not required to answer the research question in this study (Smit and Cillers, 2006). The researcher was aware of the dynamics within the group; however, in keeping with the descriptive methodology, the clinical experiences and perceptions expressed were interpreted with low inference, at face value. Therefore the implicit analysis of the dynamics of a focus group was not required (Morgan et al., 2013).

3.3.2 Research context

Phase two of the research was carried out at the two neuropsychiatric clinics in Gauteng, South Africa.

The two clinics were similar in many regards. Both clinics were outpatient services which were explicitly tailored to HIV neuropsychiatry. The clinics both had a high patient turn over, with low staffing numbers. The clinics treated HIV, psychiatry and neuropsychiatry associated with HIV. The purpose of both clinics was to comprehensively treat HIV and related comorbid conditions, but not limited to, psychiatric and neuropsychiatric conditions. The clinics were based on the grounds of tertiary academic hospitals, which was in keeping with the specialist level of care required for the management of patients suffering from HIV NCD, attending these clinics.

Some differences included: Clinic one was based on the grounds of a large tertiary academic hospital, which was a general hospital servicing a large population, providing a wide range of healthcare from emergency and acute, to outpatient specialist care. Clinic two was based on the grounds of a specialist psychiatric hospital, which focused on the therapeutic rehabilitation of patients, providing medium-term inpatient and outpatient care for several weeks to months. As clinic one was based on hospital grounds, referrals for additional services occurred within the hospital context. Clinic 2, on the other hand, was situated in an affluent suburb far from the catchment area and referrals for additional services had to be sent to a neighbouring tertiary hospital, 8 kilometres from the clinic.

3.3.3 Population and sample

As there were only two HIV NCD clinics in Gauteng with limited human resources, the population was small, and data saturation was therefore not an appropriate analysis to guide sample size. For this reason, the model of information power was used to guide the sample size.

The model of information power suggests that the power of the information gathered from a sample is dependent on five items (Malterud et al., 2016). These five items are (i) the aim of the study, (ii) sample specificity, (iii) use of established theory, (iv) quality of dialogue, (v) analysis strategy (Malterud et al., 2016). The characteristics of each item indicate if a larger or smaller sample is required.

The aim of this study was narrow, as it aimed to understand if the assessing team members perceived the three screening tools to adequately identify patients with HIV NCD and direct the appropriate care. A narrow aim required a smaller sample

(Malterud et al., 2016). As this aim was specific, this also limited the number of potential participants required to provide sufficient information power (Malterud et al., 2016).

The sample specificity relates to the specificity of knowledge and experience of the participants in the sample (Malterud et al., 2016). A purposive sampling technique was used as the researcher required individuals with experience in and knowledge of assessment and intervention in HIV NCD in South Africa (Etikan et al., 2016). A purposive sampling technique was in line with the descriptive qualitative method used to gather the information, as it assisted the researcher to collect data from information-rich sources (Lambert and Lambert, 2012; Kim, Bradway and Sefcik, 2017). As there are only two HIV NCD clinics in the Gauteng Province, the population was small, and the total population sampling method was used (Etikan et al., 2016). The participants invited to participate in the study were health professionals working within these two clinic settings. They consisted of a neuropsychiatrist, neuropsychologist, psychiatrist and medical officers, all experienced and knowledgeable in working with the patient cohort and in the specific context. All staff were invited to participate in the study. As the population was divided across the two specialist clinics in Gauteng, one group interview was carried out at each clinic, to support access to participation. Having a variation in the professions of the participants, allowed for some varied experience for exploration in the data (Malterud et al., 2016). A smaller sample was appropriate as the participants held characteristics that were highly specific to the aim of the study, thus having higher information power (Malterud et al., 2016).

The use of established theory increases information power (Malterud et al., 2016). Established theory on how to effectively screen for HIV NCD and published work on the use of the screening tools in other countries, was available, but there was limited theory on the application of these in the South African context. Concerning the use of established theory, a larger sample would have been beneficial to provide sufficient information power (Malterud et al., 2016). However, phase one of this study built on the existing knowledge and provided a scaffold for the planning and analysis of phase two's questions and results (Malterud et al., 2016). In this way, phase one supported the information power for phase two.

The quality of the dialogue is dependent on the strength and clarity of communication between the researcher and the participants (Malterud et al., 2016). The researcher worked in a neuropsychiatric clinic setting and had experience and knowledge of HIV NCD cognitive and activity limitations, as well as the setting and could confidently approach the research content with the participants (Malterud et al., 2016). Although a novice to qualitative research, the researcher had experience and training in the running of groups, which allowed for confidence in establishing rapport within the participant groups and ability to manage dialogue (Malterud et al., 2016). The participants were professionals in the field and were able to effectively articulate their perceptions (Malterud et al., 2016). Thus, a larger sample size was not required to achieve adequate information power (Malterud et al., 2016).

The study used a case analysis. The specific case group was the practitioners who perform the screening tools in the two HIV NCD clinics. As this was a case study using thematic analysis to describe the perceptions of the participants, in an area with little previously published work, a smaller sample held sufficient information power to provide insight into these perceptions (Malterud et al., 2016).

Therefore, a purposive sampling technique with a small sample size held sufficient information power, according to the model of information power, to answer the research question and address the objective for phase two of the study.

3.3.4 Research procedure

3.3.4.1 Permission

Permission was received from the MAC of both sites (Appendix J) (Appendix H). Permission for staff to participate in phase two of the research was gained from the heads of both HIV NCD clinics in Gauteng. The researcher emailed the approved information sheets (Appendix K) to the head of each clinic to circulate to the potential participants inviting them to participate in the study.

When an agreement to participate was received from the team members, an appropriate date, time and venue for the group interviews were negotiated with each clinic head. These steps were in keeping with the process of planning formal group interviews (Morgan et al., 2013).

3.3.4.2 Preparation for the group interviews

Before the group interviews, the researcher prepared a set of questions, considering phase one's results, together with some prompts to guide the discussion. The preparation was to ensure similar issues were discussed in both groups and was in keeping with a semi-structured group interview data collection process (Jamshed, 2014). Questions on the psychometrics and appropriateness of the screening tools for the patient population were included, to explore the experiences and perceptions of the practitioner-participants in the administration of the screening tools (Appendix L). The researcher asked the practitioner-participants if they experienced patients to have particular challenges when completing the tools, to understand if there were common difficulties in the population, such as naming the rhinoceros in the MoCA.

3.3.4.3 Group interviews

At the beginning of each group interview, the researcher introduced herself and with the assistance of the approved information sheet for phase two (Appendix K), explained the research and answered any questions the participants had. The duration of the group interview was negotiated to be 60-90 minutes, and the nature of participation was explained. All participants were informed that their participation was voluntary, and they could leave at any point without consequence. It was also explained that due to the nature of the group interview, absolute confidentiality could not be ensured but no participant would be identified in the findings of the group interview. Demographic information was not collected on the practitioner-participants to protect confidentiality due to the small sample, and the number of clinics specialising in HIV NCD in Gauteng province.

Participants were asked to complete two consent forms, the first was for their participation in the group interview (Appendix M), and the second was for the audiotaping of the group interview (Appendix N).

The researcher created an open and relaxed climate within the groups. The relaxed climate was created to reduce the sanitised responses that one can receive from an overly structured environment (Lysack et al., 2006). The researcher introduced questions in a funnelled manner, with the first question opening the group to the topic of screening activity limitations and cognition in people living with HIV. The researcher then introduced the follow-up questions based on the research findings and experiences in phase one, to flow through the three screening tools used in the

research. Follow-up questions were used to gain an understanding of the experiences and perceptions of the practitioner-participants in using these screening tools to guide health care for those suffering from HIV NCD. In the group interviews, the researcher allowed the discussion to flow naturally, with the prepared questions and prompts only being used if the discussion did not identify the issues in the questions.

The groups were concluded with some discussion around the implications of the cognitive screening tool results for the activity limitations experienced by the people living with HIV NCD, and the overall value that the assessing teams perceive these tools bring into the intervention process.

3.3.5 Ethical considerations

The information sheet (Appendix K) for phase two was approved by the Human Ethics Research Committee (Medical) in the same procedure as explained in phase one (see 3.2.5). However, participants completed two consent forms, one for participation (Appendix M) and the second for the group interviews to be audio–recorded (Appendix N). Both consent forms were sent to participants before the group interview. Participants were informed that absolute confidentiality could not be assured in the group interviews. However, all participants were assured that the transcripts of the group interviews would be anonymised, and as no demographic information would be collected, no participant could be identified, since the population was so small.

Audio recordings and transcriptions have been kept password-protected. They will be stored electronically, for six years if research is unpublished and two years from the publication date, if research is published, as per Health Professions Council of South Africa's General Ethical Guidelines for Health Researchers, published May 2008 (Health Professions Council of South Africa, 2008).

3.3.6 Trustworthiness

The four components of trustworthiness were used to ensure the rigour of the qualitative data: Credibility, Transferability, Dependability and Confirmability (Thomas and Magilvy, 2011).

3.3.6.1 Credibility

To present an accurate description of the experiences and perceptions of the practitioner-participants, the researcher employed peer debriefing, triangulation, member checks, objective transcription service and prolonged exposure to the research context (Anney, 2014).

- Peer debriefing was achieved through guidance and review from an academic member of staff, with experience in qualitative research (Anney, 2014). Transcriptions, which had been anonymised, were provided to the peer examiner to guide and critically assess the presentation and analysis of the data (Krefting, 1991).
- Triangulation was achieved through using the two sources for data collection available and in carrying out two separate group interviews, one for each of the two HIV NCD clinics. This provided the researcher with the opportunity to identify areas of consensus, different perspectives and experiences of the participants, and where these were contradictory (Fusch and Ness, 2015). Triangulation was also achieved through the use of the quantitative results and observations from phase one being used to interpret and verify the perceptions and experiences expressed by the participants in qualitative data collection and analysis in phase two (Duffy, 1987).
- A member from each group was selected during qualitative data collection and agreed to participate in member checking (Thomas and Magilvy, 2011). The coding of the qualitative data was sent for member checking to the agreed member of each group. Sending the coding allowed members of the group to comment on and respond regarding the accuracy of captured information. Member checking also provided the researcher with the opportunity to identify any gaps in the codes or personal biases (Kornbluh, 2015). The member checking provided the researcher with the opportunity to reflect on the feedback and further analyse the data following feedback from members (Kornbluh, 2015).
- A professional objective transcriber was employed, to transcribe the audio-recordings. Professional transcription was done to ensure an unbiased verbatim account was transcribed from the audiotapes. The researcher reviewed the transcripts against the audiotapes to ensure that the

transcriptions were correct, and to gain a deeper understanding of the practitioner-participants expressed perceptions and experiences (FitzPatrick, 2019). The researcher then used both the transcripts and the audio recordings while coding, to strengthen the descriptive validity of the coding process (FitzPatrick, 2019).

- Prolonged exposure to the research context: The researcher was employed in the one research site for two years and therefore had prolonged exposure to the service. The researcher also spent 5 hours a week, for eight weeks, at the second research site during the data collection. Phase one's data collection provided the researcher with experience in completing the screening tools in the service delivery context of the practitioner-participants in phase two (Anney, 2014). This exposure to the context, informed the semi-structured interview questions, along with the findings of phase one.

3.3.6.2 Transferability

To determine the applicability of the results to other contexts and participants, the researcher provided thick and rich descriptions on the context and sampling (Thomas and Magilvy, 2011).

- The research contexts of phase two were described in terms of the location, patient turnover, type of care provided and access to referral services (see 3.3.2). Similarities and differences between the contexts were noted. The dense description of the research context allows for transferability to be determined (Krefting, 1991).
- The researcher used a purposive sampling technique to ensure adequate information power of the sample through increased sample specificity (Malterud et al., 2016) (see 3.3.3). The criteria for the specificity of the sample related to homogeneity in that all practitioner-participants were qualified healthcare professionals who had experience in screening, assessment and intervention of HIV NCD in a public healthcare setting. The criteria were heterogeneous in that the healthcare professionals had different specialities (e.g. neuropsychologist and medical officer), which provided a range of background knowledge and experience on the usefulness of the screening tools in HIV NCD. These similarities and differences between the recruited practitioner-participants ensured completeness of data (Elo et al.,

2014). Further details such as years of practice and where practitioners qualified were not collected due to the small intimate, professional community and the researchers aim to maintain the confidentiality of the participants.

3.3.6.3 Dependability

The researcher provided an audit trail through the steps described by Thomas and Magilvy (2011), and had peer analysis from her supervisor, throughout the process (Thomas and Magilvy, 2011).

- The audit trail: The two-fold purpose of the study was explicitly described (see 1.3) by the researcher (Thomas and Magilvy, 2011). A knowledgeable specific sample was recruited with sample characteristics and selection criteria described (see 3.3.3) (Thomas and Magilvy, 2011). The data collection process, including permission, preparation, and group interviews, were described (see 3.3.4) (Thomas and Magilvy, 2011). The thematic data reduction process, using an inductive approach with semantic analysis, was also detailed (see 3.3.7). The findings were summarised in a table, and the details of each of the themes, codes and sub-codes were further described using direct quotes from the practitioner-participants (see 5.4). The findings of phase two were discussed and interpreted in conjunction with the findings of phase one, as the qualitative phase (phase two) was used to add depth to the findings of phase one (see 5.6) (Thomas and Magilvy, 2011). Description of the research techniques and techniques for credibility have been communicated in chapter 3. Through following these steps of the audit trail, the researcher provided dependability of the findings (Thomas and Magilvy, 2011).
- Peer analysis was completed by the research supervisor throughout the trail described above. The supervisor scrutinised the process and challenged the assumptions of the researcher (Shenton, 2004). Peer analysis supported an honest and reflective approach to the study process (Anney, 2014).

3.3.6.4 Confirmability

The degree of confirmability of phase two was achieved through the dependability and triangulation strategies (Anney, 2014), as well as the use of direct quotations in the presentation of the findings (Bradshaw et al., 2017). The use of an audit trail and peer analysis, as described in 3.3.6.3, ensured dependability of the data and

supported confirmability (Anney, 2014). Triangulation of the data received between the two groups as well as with phase one of the study further supported the confirmability of the findings of phase two (Anney, 2014).

3.3.7 Data Analysis

A thematic analysis was used to analyse the data in phase two. Thematic analysis has been reported to be the preferred analysis in qualitative descriptive methodology (Kim et al., 2017). Thematic analysis was selected as it used a realist perspective, emphasised research context and used a non-linear process of analysis (Vaismoradi et al., 2013). The realist perspective provided by thematic analysis allowed the researcher to understand the experiences and perceptions of the participants within the realities of managing health care for HIV NCD in an under-resourced clinic in Gauteng within a middle-income country (Braun and Clarke, 2006). Thematic analysis was selected as opposed to content analysis, which is another popular descriptive analysis, as the researcher was not only interested in the frequency of the codes and did not want to remove meaning from the context (Vaismoradi et al., 2013). The researcher chose to use an inductive approach to identify themes within the data set from each group interview (Braun and Clarke, 2006). An inductive approach was more fitting to the nature of this study than a deductive approach, which uses previous theory to compare categories, as there was no pre-existing influential research on which to create a coding frame for the three screening tools in the South African context (Vaismoradi, Turunen and Bondas, 2013; Braun and Clarke, 2006). The level at which the themes were analysed was semantic, as the researcher was not looking for information beyond the expressed experiences and perceptions of the participants (Braun and Clarke, 2006).

The researcher followed the six phases of thematic analysis described by Braun and Clarke (2006). The six phases and how they were applied are reported below.

(i) In phase one, the researcher familiarised herself with the data through listening to the audiotapes and confirming the transcripts had been correctly transcribed. In this way, the data was read, re-read and revised audibly numerous times. During this initial phase, the researcher noted initial ideas on explicit themes.

(ii) In phase two, the researcher began coding the data set from each group interview. The researcher coded manually on the transcribed texts, taking note of contradictions and including these in the conceptualised codes.

(iii) In phase three, the researcher used colour coding and tabulation to sort and collate codes into broader themes. The researcher began to establish themes and categories through thematic tabulation.

(iv) In phase four, the researcher reviewed and refined the themes in each data set. This involved the collapsing and reconfiguring of codes within themes of each data set and collapsing the two data sets into one thematic table representing the data corpus. The researcher then re-coded and refined coding further to accurately represent the data corpus.

(v) In phase five, the researcher refined and defined the themes, collating them to the data and ensuring they were internally consistent. Themes were further merged when seen as having too much overlap. The researcher sent the thematic table for member checking in phase five of the analysis process. This was done to present data, to two group members, that was not overly complex and difficult to reflect upon, as this has been an identified challenge within member checking (Kornbluh, 2015).

(vi) In phase 6, the researcher prepared the writing up of the results of the group interviews. The write-up was prepared through identifying compelling extracts on which to report the theme, categories, sub-categories and codes. The write up further developed by analysing the data corpus of this phase of the study.

3.4 Conclusion

Chapter 3 described the methodology of the two-phased descriptive study carried out. The chapter explained how the design of the study of each of the two phases. Phase one was the quantitative strand of the study. Phase one used a descriptive correlation quantitative design to determine the convergent validity of the three screening tools and the extent to which they identified cognitive and activity limitations. This phase of the study was reported in terms of the study population, research instruments and research procedure. The results and discussion of phase one will be presented in chapter 4.

Phase two, which was the qualitative strand, used a descriptive qualitative design to determine the perceptions and experiences of health professional using these screening tools within health care delivery to HIV NCD patients, at two tertiary clinics in Gauteng, South Africa. The chapter described the research design, population, research procedure, trustworthiness strategies and data analysis that were used. The results and discussion of phase two will be reported in chapter 5.

The results of phases one and two will be described and discussed in relation to each other at the end of chapter 5.

CHAPTER 4 RESULTS AND DISCUSSION OF PHASE ONE

4.1 Introduction

This chapter, in keeping with the structure of this descriptive study with two phases, will report on the results of phase one of the study and then discuss the results.

Phase one of the study was a quantitative descriptive study which aimed to determine the convergent validity of the MoCA and WHODAS 2.0 to the IHDS scores, for patients with HIV identified with NCD by a score of 11 or less on the IHDS. The results section of this chapter reports first on the research sample and then on the results of the three objectives set for phase one of the study:

1. To determine the level of cognitive or activity limitations, on the MoCA and WHODAS 2.0, for patients identified with HIV NCD, by a score of 11 or less the on the IHDS.
2. To determine the convergence of the scores on the IHDS with the scores on the MoCA and WHODAS 2.0, for patients identified with HIV NCD, by a score of 11 or less on the IHDS.
3. To determine the convergent validity of the MoCA to the WHODAS 2.0 for patients identified with HIV NCD, by a score of 11 or less on the IHDS.

4.2. Phase one results

4.2.1 Introduction to the cohort

The sample consisted of 55 HIV+ patient-participants, admitted to the HIV NCD research site clinic, who scored below 11 on the IHDS. The demographics and medical history of the 55 patient-participants are presented below to describe the clinical picture of the cohort in phase one.

4.2.1.1 Demographics of participants

Table 4.1 records the demographic information of the sample (N=55). As can be seen from Table 4.1, the participants' ages ranged from 26 years to 64 years, with a mean age of 44 years. There were more females (n=45, 81%) than males and most participants reported that their home language was one of the indigenous

languages, with Zulu being the most frequently reported (n=23, 41.82%). However, 72.72% (n=40) of the participants indicated English as a second language. The formal education levels of the participants ranged from grade 4 to post matriculation. Of the 55 patient-participants, 50.9% (n=28) had a grade 11 or 12 education. Most participants in this sample were unemployed (n=48; .87.3%).

Table 4.1 Demographics of participants (N=55)

	Range	Percentage	Cumulative Percentage
Age	26-36 years	18.18	18.18
	37-47 years	46.64	61.82
	48-58 years	34.55	96.37
	59-69 years	3.64	100
		n	%
Gender	Male	10	18.18
	Female	45	81.82
Home Language	Zulu	23	41.82
	Tswana	10	18.18
	SeSotho	9	16.36
	Pedi	3	5.45
	Xhosa	6	10.91
	Venda	1	1.82
	Tsonga	1	1.82
	Afrikaans	2	3.64
Second Language	Zulu	9	16.36
	Tswana	1	1.82
	SeSotho	3	5.45
	Xhosa	1	1.82
	English	40	72.73
	Shangaan	1	1.82
Education level	Grade 4	1	1.82
	Grade 5	4	7.27
	Garde 6	1	1.82
	Grade 7	4	7.27
	Grade 8	5	9.09
	Grade 9	3	5.45
	Grade 10	7	12.73
	Grade 11	18	32.73
	Grade 12	10	18.18
	Post-Matric	1	1.82
	ABET	1	1.82
Employment status	Employed	7	12.73
	Unemployed	48	87.27
Nutrition	Breakfast eaten	38	69.09
	Breakfast not eaten	17	30.91

As eating breakfast has been reported to affect memory (Benton and Parker, 1998), the researcher ascertained from each patient-participant, whether they had eaten

breakfast, before the data collection. While n=38 patient-participants (69.09%) reported having eaten, 17 participants (30.9%) reported that they had not. Only eight patient-participants, 14.54% of those who had eaten, reported that they had had food before coming to the clinic, and 30 (54.6%) had had a meal provided by the clinic. This information described the socio-economic limitations of the patient-participants in managing their health, as well as potential external factors which may have influenced the scores of the cognitive tests.

4.2.1.2 Medical History

Table 4.2 records the medical history of the patient-participants (N=55). As can be seen from Table 4.2, the highest number of patient-participants were first diagnosed with HIV between 2009 and 2017 (n=28; 51%). The Cluster Differentiation 4 (CD4) count in the sample varied from 22 to 1384 with the mean of 479.4. However, the CD4 counts were not all recent to the data collection, and therefore could not be used in interpreting the results of the data. The initiation of antiretroviral (ARV's) treatment in this sample varied, with 28 participants (50.90%) who started ARV treatment between 3 months and 7 years prior to the time of data collection, and 25 participants (45.45%) who started treatment between 8 years and 15 years previously. The most frequently used ARV treatment was a fixed-dose combination (FDC), and for 39 patient-participants (70.91%) this was their primary treatment. Of the patient-participants, 25.45% were on a second ARV, with 16.36% on a third ARV treatment. Bipolar Disorder was found to be the most common coexisting condition, with 28 patient-participants diagnosed in the cohort (50.91%, n=28). This was followed by Hypertension (14.55%; n=8), Depression (12.73%; n=7), and Mood NOS (12.73%; n=7). Of the 55 patient-participants, 53 were on treatment for their illnesses (96.34% n=53). One patient-participant was not on treatment for their arthritis, and one patient-participant's medication list was unavailable to the researcher at the time of data collection.

Table 4.2 Medical History of the participants (N=55)

		n	%
Time since diagnosis	20 – 29 years	9	16.36
	10– 19 years	18	32.72
	1–9 years	28	50.9
ARV initiation	8 years-15 years before 2018	25	45.45
	3 months–7 years before 2018	28	50.90
	Unknown initiation date	2	3.64
ARV Treatment	FDC	39	70.91
	Aluvia	12	21.82
	Truvada	4	7.27
	3TC	1	1.82
	Lamzid	7	12.53
	HAART	5	9.09
	Efavirenz	1	1.82
	Dumiva	4	7.27
	Kaletra	1	1.82
	TDF	2	3.64
	Kivexa	1	1.82
	Atazanavir	1	1.82
Number of prescribed ARV's	One prescribed	55	100
	Two prescribed	14	25.45
	Three prescribed	9	16.36
Coexisting illnesses	Hypertension	8	14.55
	Asthma	1	1.82
	Diabetes	1	1.82
	COPD	1	1.82
	Arthritis	1	1.82
	Schizophrenia	3	5.45
	Psychosis GMC	6	10.91
	Schizoaffective	1	1.82
	Bipolar Disorder	28	50.91
	Depression	7	12.73
	Mood NOS	7	12.73
	Epilepsy*	2	3.64
Treatment for other illnesses	On treatment	53	96.34
	Not on treatment	1	1.82
	Unknown	1	1.82

*included in the study as evidence of only 1 episode, well-controlled

4.2.2 Objective 1 - The level of cognitive dysfunction and activity limitation for patients identified with human immunodeficiency virus neurocognitive disorder, on the International HIV Dementia Scale

Objective 1 was reported in the results using the descriptive statistics. The scores of the screening tools were converted and plotted onto a Gaussian curve, to analyse their standard deviation from the mean. Analysis of the standard deviation (SD) from the mean indicated the cognitive and activity limitations, in the cohort scoring 11 or less on the IHDS, as screened by the MoCA and WHODAS 2.0.

4.2.2.1 International HIV Dementia Scale (IHDS)

Table 4.3 reports the overall functioning of the 55 participants on the IHDS, considering a score of 11 or less was used to include patient-participants in the study. The total IHDS score for this sample had a median of 7.00, where the highest score could be 12, with a lower quartile of 5.50 and an upper quartile of 8.50. It can be noted from Table 4.3, that the motor speed and psychomotor speed subtests had a median of 2.00. These were lower than the memory recall subtest, with a median of 2.50, where both subtests had the highest possible score of 4.

Table 4.3 Median Scores for the International HIV Dementia Scale (N=55)

	Median	Lower Quartile	Upper Quartile	Possible highest score
IHDS Total score	7.00	5.50	8.50	12
Motor speed	2.00	1.00	3.00	4
Psychomotor speed	2.00	2.00	3.00	4
Memory recall	2.50	2.00	3.00	4

4.2.2.2 Montreal Cognitive Assessment

The cut-off score for further assessment on the MoCA is 26. As can be seen in Table 4.4 the sample group achieved a total median score of 20, out of a possible score of 30, with a lower quartile score of 15 and an upper quartile score of 23. All patient-participants were fully orientated, and all achieved the maximum score of 6 (Table 4.4). Delayed recall was the most problematic domain, with a lower quartile of 0, an upper quartile of 3 and a median of 2 (maximum possible score = 6). The language subtest was also problematic, with a lower quartile of 0, an upper quartile of 2 and a median of 1 (maximum possible score of 3).

Table 4.4 Median Scores for the Montreal Cognitive Assessment (N=55)

	Median	Lower Quartile	Upper Quartile	Possible highest score
MoCA total score	20.00	15.00	23.00	30
Executive subtest	3.00	2.00	3.00	5
Naming subtest	2.00	2.00	3.00	3
Attention subtest	4.00	2.00	5.00	6
Language subtest	1.00	0.00	2.00	3
Abstraction subtest	1.00	1.00	2.00	2
Delayed recall subtest	2.00	0.00	3.00	5
Orientation subtest	6.00	6.00	6.00	6

4.2.2.3 World Health Organization Disability Assessment Schedule 2.0

The WHODAS 2.0, looks at the difficulty experienced in daily living. Scores are self-scaled, ranging from no difficulty with specific tasks to extreme difficulty/unable to do. The domains which presented with the lowest percentages indicated the domains in which participants experienced the least difficulty. The domains which presented with the highest percentages indicated where participants experienced the greatest difficulty. The overall median percentage of difficulty experienced in daily life, reported for this sample, was 23.51%. The overall median percentage had a lower quartile at 14.72%, and an upper quartile at 31.63% (Table 4.5). The highest median percentage of 37.50%, was for the domain 'understanding and communicating'. 'Understanding and communicating' had a lower quartile percentage of 25% and an upper quartile of 45.83%. This domain included self-scaled scores on experiences of conversation, memory, attention, problem solving and learning in daily activity. The domain with the second-highest median percentage of difficulty was 'getting along with others' at 30%. 'Getting along with others' had a lower quartile of 20% and an upper quartile of 45%. This domain included self-scaled scores of dealing with people you do not know, maintaining relationships, making new friends and sexual activity. The domain with the third-highest median was that of 'participation in society', with 28.13% difficulty experienced. 'Participation in society' had a lower quartile of 18.75%, and an upper quartile of 46.88%. This domain included self-scaled scores of experiences of engaging in community activities, living with dignity, the emotional and financial impact of health condition, and the impact of health on family.

Table 4.5 Median Scores for the World Health Organization Disability Assessment Schedule 2.0 (N=55)

	Median (%)	Lower Quartile (%)	Upper Quartile (%)
WHODAS 2.0 total percentage difficulty	23.51	14.72	31.63
Understanding and communicating domain	37.50	25.00	45.83
Getting around domain	15.00	5.00	30.00
Self -care domain	6.25	0.00	12.50
Getting along with others domain	30.00	20.00	45.00
Life activities domain	12.50	6.25	18.75
Participation in society domain	28.13	18.75	46.88

While the domain 'getting around' had a median of 15%, with a lower quartile of 5%, and an upper quartile of 30%. The domain with the lowest median percentage, which indicated the least experience of difficulty, was self-care at 6.25%. Self-care had a lower quartile of 0% and an upper quartile of 12.50%. This domain includes experiences of difficulty in washing, dressing and toileting.

Table 4.6 Frequency and severity of difficulties reported in the World Health Organization Disability Assessment Schedule 2.0 (N=55)

	Median	Lower Quartile	Upper Quartile	Maximum number of days
Number of days difficulties present	15.00	5.00	30.00	30.00
Totally unable	3.00	0.00	5.00	30.00
Reduced activity	5.00	3.00	20.00	30.00

Table 4.6 showed the number of days that patient-participants experienced difficulties across all six domains in the last 30 days. Patient-participants reported experiencing difficulties with a median of 15 days, with a lower quartile of 5 and an upper quartile of 30. The patient-participants reported a median number of days of reduced activity at 5 days, with a lower quartile of 3 and an upper quartile of 20.

4.2.2.4 Indications of cognitive limitations on Montreal Cognitive Assessment and activity limitations on World Health Organization Disability Assessment Schedule 2.0

The scores for all patient-participants on the MoCA and WHODAS 2.0 fell below zero, except for one patient-participant, where their score which fell at a z score of 0.05 SD above the mean. A patient-participant scoring at this level would require monitoring, but further assessment is not indicated, based on this score.

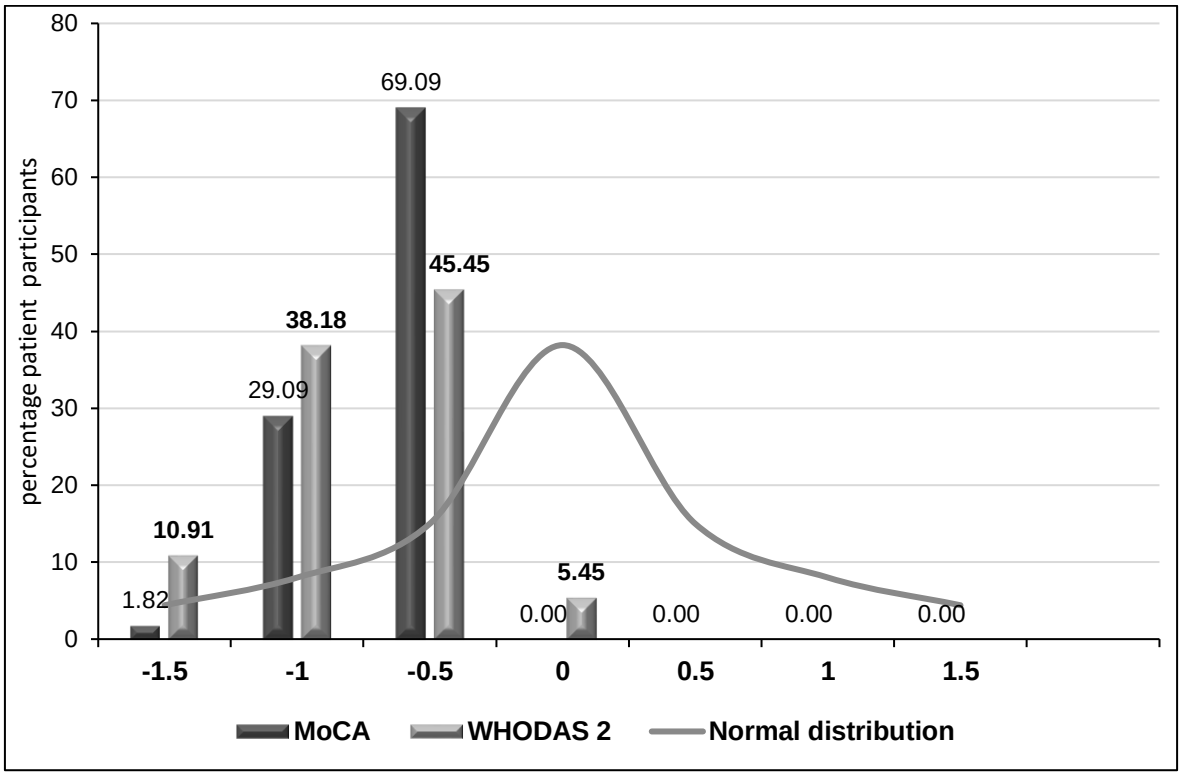

Figure 4.1 z-Scores for the Montreal Cognitive Assessment and World Health Organization Disability Assessment Schedule 2.0

Those patient-participants scoring at -1 SD from the mean, or below (Figure 4.1), had dysfunction which required a comprehensive occupational therapy assessment of cognition and activity limitations. Scores of between 11-17 on the MoCA fell at -1 SD from the mean. Scores of 10 and below on the MoCA calculated at -1.5 SD. Percentage of perceived difficulty on the WHODAS 2.0 from 20%-39% fell at -1 SD. Percentage of perceived difficulty of 40% or more fell at -1.5 SD. This result confirmed that all participants included in the study, who scored 11 or less on the IHDS, presented with cognitive dysfunction and activity limitations as screened by the MoCA and WHODAS 2.0, respectively.

4.2.3 Objective 2 - Convergence of the scores on the International HIV Dementia Scale with the Montreal Cognitive Assessment and the World Health Organization Disability Assessment Schedule 2.0 for patients identified with human immunodeficiency virus neurocognitive disorder, on the International HIV Dementia Scale

Objective 2 was addressed using Spearman's correlation coefficient, as the data were non-parametric, to understand the strength in the relationship of the IHDS to the MoCA (cognition) and WHODAS 2.0 (activity limitation). Regression analysis using the total scores, with prediction intervals, was completed on each of these correlations. Prediction intervals were used to understand if the IHDS predicted the cognitive dysfunction and activity limitations, identified by the MoCA and WHODAS 2.0, respectively.

Correlation of the IHDS, to the MoCA and WHODAS 2.0 in this patient-participant sample was done to explore the relationship of the IHDS to the MoCA and WHODAS 2.0 screening tools, to establish if they measured the same constructs. Understanding the relationship of these tools to the IHDS was important when screening for HIV NCD and identifying the need for further, more comprehensive assessment and intervention. The relationship was considered particularly concerning the classification of the severity of HIV NCD, as classification requires both cognitive and functional impact on daily activity (Antinori et al., 2007).

Tables 4.7-4.9 show that no strong correlations were found between the IHDS and the MoCA or the WHODAS 2.0 screening tools using Spearman's Correlation Co-efficient but moderate [r_s range 0.50-0.69] and low to moderate [r_s range 0.30-0.49] correlations are reported below, along with the regression analysis for the association between the total score on each screening tool.

4.2.3.1 Correlation between neurocognition on the International HIV Dementia Scale and cognition on the Montreal Cognitive Assessment

Correlations between the IHDS and the MoCA, examined the relationship between the two cognitive screening tools used in the HIV NCD clinic in Gauteng, to screen for cognitive deficits associated with HIV NCD in patients attending this clinic. Table 4.7 shows a moderate correlation was found between the total scores of the IHDS and the MoCA, with an r-value of 0.53 with a p-value of <0.05.

Table 4.7 shows a low to moderate correlation was found between the total score of the MoCA and the motor speed subtest of the IHDS with r_s= 0.49 and psychomotor speed subtest of r_s=0.40. A low to moderate correlation was found between the total score of the IHDS and the Language subtest r_s=0.46 and Delayed recall r_s=0.48 subtests of the MoCA. The Motor speed subtest of the IHDS reported a low to moderate correlation to Naming (r_s =0.39), Language (r_s =0.42) and Delayed recall (r_s =0.39) subtests of the MoCA. The Psychomotor speed subtest of the IHDS, correlated with low to moderate correlation to the Language subtest (r_s = 0.44) of the MoCA.

Table 4.7 Correlations between the Montreal Cognitive Assessment and the International HIV Dementia Scale

	IHDS Total score	Motor speed Subtest	Psychomotor speed Subtest	Memory recall Subtest
	r_s			
MoCA Total score	**0.53***	**0.49***	**0.40***	0.11
Executive Subtest	0.18	0.28	0.17	-0.11
Naming Subtest	**0.41***	**0.39***	0.26	0.07
Attention Subtest	0.23	0.21	0.17	0.03
Language Subtest	**0.46***	**0.42***	**0.44***	0.00
Abstraction Subtest	0.06	0.11	-0.02	0.05
Delayed recall Subtest	**0.48***	**0.39***	0.34	0.22
Orientation Subtest	0.30	0.37	0.17	-0.02

***Significance p≤ 0.05**

Three negative correlations were found: one between the Executive subtest of the MoCA and the Memory recall subtest on the IHDS (r_s = -.011), the second between the Abstraction subtest of the MoCA and the Psychomotor speed subtest on the IHDS (r_s = -0.02), and the third between the Orientation subtest of the MoCA and the Memory recall subtest of the IHDS (r_s = -0.02). The strength of these negative correlations was, however, very low. All these correlations were significant at p=0.05. There was no correlation between the Memory recall subtest on the IHDS, to any of the MoCA subtests (see Table 4.7).

The coefficient of determination r^2 indicated that 25 % of the variation on the total scores of the IHDS could be accounted for by variation on the total scores of the MoCA (Appendix O). Although the slope and intercept in the linear regression were

significant (F=17,60; p=0,0001), the results were scattered and only a quarter of the IHDS total score was accounted for by the total score on the MOCA. This indicated that the correlation was significant but did not explain the variability in the dependent variable (MoCA) (Frost, 2020). According to Cohen's r, this meant a small effect with little clinical relevance, in terms of the association between variables measured by the two tests (Cohen, 1988). The scatter plot (Figure 4.2) displayed homoscedasticity, which indicated the variances in the data remained similar along the line of best fit (Laerd Statistics, 2018). A residual Q-Q plot was created using the data (Appendix O) which showed the residuals of the regression followed a normal distribution, within the range of scores in the cohort, with a small number of outliers (Grace-Martin, 2020) (Appendix O). The outliers were analysed using Cook's Distance. No outliers were removed, as the Cook's distances were all less than 1 (Appendix O) (Lane, 2018).

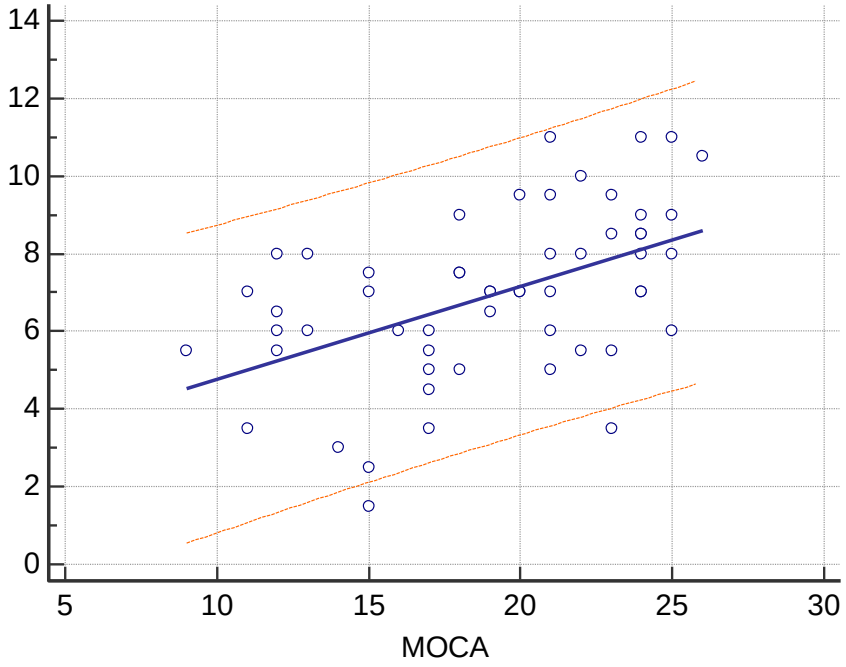

Figure 4.2 Scatter plot with prediction intervals for the Montreal Cognitive Assessment and the International HIV Dementia Scale

4.2.3.2 Correlation between neurocognition on the International HIV Dementia Scale and activity limitation on the World Health Organization Disability Assessment Schedule 2.0

The correlations between the IHDS and the WHODAS 2.0 were negative, as seen in Table 4.8 and Table 4.9, indicating a high score on one test correlated to a low score on the other. The negative correlations were due to the WHODAS 2.0 scores representing the increased presence of difficulty by increased percentage, while the IHDS scores indicate increased difficulty with lower scores. As can be seen in Table 4.8, the total scores of the IHDS and the WHODAS 2.0 have a very low correlation (r_S= -0 14).

Table 4.8 Correlations between the World Health Organization Disability Assessment Schedule 2.0 domains and the International HIV Dementia Scale

	IHDS Total score	Motor speed Subtest	Psychomotor speed Subtest	Memory Recall Subtest
	r_s			
WHODAS 2.0 Total score	-0.14	-0.12	0.02	-0.10
Understanding and communicating Domain	-0.20	-0.18	-0.08	-0.11
Getting around Domain	-0.05	0.00	0.02	-0.12
Self-care Domain	-0.18	-0.22	-0.03	-0.02
Getting along with others Domain	-0.07	-0.11	0.09	-0.01
Life activities Domain	**-0.36***	-0.29	-0.22	-0.13
Participation in society Domain	-0.07	-0.04	-0.00	-0.12

***Significance p≤ 0.05**

The WHODAS 2.0 'Life Activities' domain (Table 4.8) had a low to moderate correlation with the total score of the IHDS (r= -0.36). The 'Life Activities' domain of the WHODAS 2.0 was found to have weak to low correlations to the 'Motor speed' subtest (r_s = -0.29) and the psychomotor speed subtest (r_s = -0.22).

Table 4.9 Correlations between the World Health Organization Disability Assessment Schedule 2.0 presenting difficulty on overall daily activity and the International HIV Dementia Scale

	IHDS Total score	Motor speed Subtest	Psychomotor speed Subtest	Memory Recall Subtest
	r_s			
Number of days difficulties present	**-0.39***	-0.26	**-0.30***	-0.15
Totally unable	-0.19	-0.19	-0.14	-0.03
Reduced activity	-0.20	-0.21	-0.03	-0.08

***Significance p≤ 0.05**

A low to moderate correlation was found between the number of days where difficulties were reportedly present on the WHODAS 2.0 and the overall score of the IHDS with r_s= 0.39 (Table 4.9). A low to moderate correlation between the number of days difficulties were present and the Psychomotor speed subtest of the IHDS, with r_s = -0.30, was also found. All these correlations were significant at p=0.05.

The coefficient of determination r^2 indicated that 0 % of the variation of the total scores on the IHDS was accounted for by variation on the total scores of the WHODAS 2.0. The linear regression analysis (Figure 4.3) showed that the total scores on the IHDS were not associated with the total scores on the WHODAS 2.0. The slope and the intercept were found to have no significance (F= 0,28; p=0,598) (Appendix O). The scatter plot (Figure 4.3) displayed heteroscedasticity, which indicated the variances in the data did not remain similar along the line of best fit (Laerd Statistics, 2018).

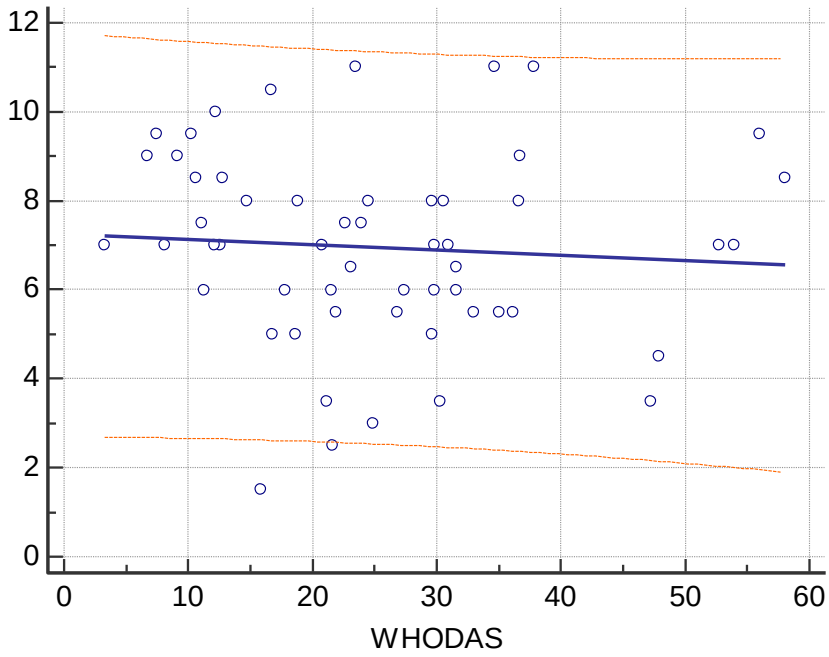

Figure 4.3 Scatter plot with prediction intervals for the World Health Organization Disability Assessment Schedule 2.0 and the International HIV Dementia Scale

A residual Q-Q plot was created using the data (Appendix O) which showed the residuals of the regression followed a normal distribution, within the range of scores in the sample, with a small number of outliers (Grace-Martin, 2020) (Appendix O). The outliers were analysed using Cook's Distance. No outliers were removed, as the Cook's distances were all less than 1 (Appendix O) (Lane, 2018).

4.2.4 Objective 3 - Convergent Validity of the Montreal Cognitive Assessment to the World Health Organization Disability Assessment Schedule 2.0, for patients identified with human immunodeficiency virus neurocognitive disorder, on the International HIV Dementia Scale

Objective 3 was addressed using Spearman's correlation coefficient to understand the strength of the relationship of the MoCA (cognition) to the WHODAS 2.0 (activity limitation). A regression analysis using the total scores, with prediction intervals, was completed on these correlations. The prediction intervals were used to understand if the cognitive dysfunction identified on the MoCA predicted the activity limitations, identified on the WHODAS 2.0, in this cohort.

The correlation of the MoCA to WHODAS 2.0 in this patient-participant sample was done to explore the association of cognition and activity limitation, as measured by these tools, to establish if they measured the same constructs. Understanding the

relationship between the MoCA and the WHODAS 2.0 was necessary as these tools had been used to screen cognitive dysfunction and activity limitation to guide further occupational therapy assessment and intervention (see 1.3).

Table 4.10 Correlations between the Montreal Cognitive Assessment and World Health Organization Disability Assessment Schedule 2.0

	MoCA Total score	Executive Subtest	Naming Subtest	Attention Subtest	Language Subtest	Abstraction Subtest	Delayed recall Subtest	Orientation Subtest
	r							
WHODAS: total score	**-0.40***	-0.19	-0.28	-0.20	-0.08	-0.29	**-0.46***	**-0.35***
Understanding and communicating Domain	-0.23	-0.16	-0.21	-0.15	-0.03	-0.17	-0.24	-0.12
Getting around Domain	**-0.36***	-0.21	-0.17	-0.22	-0.03	-0.29	**-0.39***	-0.22
Self-care Domain	**-0.36***	-0.21	-0.17	-0.14	-0.19	-0.24	**-0.40***	**-0.39***
Getting along with others Domain	-0.20	-0.09	-0.23	-0.06	-0.01	-0.18	-0.24	-0.23
Life activities Domain	**-0.54***	-0.21	**-0.31***	-0.28	**-0.42***	-0.26	**-0.55***	-0.24
Participation in society Domain	-0.26	-0.08	-0.08	-0.23	0.07	-0.27	-0.26	-0.35

***Significance p≤ 0.05**

The correlation between the MoCA and WHODAS 2.0 was considered particularly regarding the classification of the severity HIV NCD, as this classification required both cognitive dysfunction and limitations in daily activities (Antinori et al., 2007).

The correlations between the MoCA total scores and the WHODAS 2.0 total scores were negative, as was found with the correlations of the IHDS and the WHODAS 2.0. The negative correlations indicated that achieving a high score on one test correlated with achieving a low score on the other. As described previously, this is due to the scoring on WHODAS 2.0, which represented increased difficulty by increased percentage, while the MoCA scoring indicated increased difficulty with lower scores.

From Table 4.10 and Table 4.11, the WHODAS 2.0 and the MoCA total scores were found to have a low to moderate correlation of r_s =-0.40 with a p-value=0.05. The total score of the MoCA, showed a moderate correlation with the 'Life activities' domain of the WHODAS 2.0, with r_s=-0.54. A low to moderate correlation was found

between the MoCA total score and the ‘Getting around’ (r_s=-0.36), and ‘Self-care’ (r_s=-0.36) domains on the WHODAS 2.0.

The WHODAS 2.0 total score had a low to moderate correlation with the ‘Delayed recall’ (r_s=-0.46) and ‘Orientation’ (r_s=-0.35) subtests on the MoCA.

The subtests on the MoCA, which had the highest correlation with the WHODAS 2.0 domains, were the ‘Delayed recall’ and ‘Orientation’ subtests. The ‘Delayed recall’ subtest on the MoCA correlated with a low to moderate correlation to ‘Getting around’ (r_s=-0.39), and ‘Self-care’ (r_s=-0.40) domains of the WHODAS 2.0. The ‘Delayed recall’ subtest of the MoCA had a moderate correlation to the ‘Life activities’ (r_s= -0.55) domain of the WHODAS 2.0. The ‘Orientation’ subtest on the MoCA had a low to moderate correlation with the ‘Self-care’ (r_s=-0.39), and ‘Participation in Society’ domains on the WHODAS 2.0.

The ‘Life activities’ domain on the WHODAS 2.0 had the highest number of low to moderate and moderate correlations with subtests on the MoCA. The ‘Life activities’ domain correlated with low to moderate correlation to the ‘Naming’ (r_s=-0.31) and ‘Language’ (r_s=-0.42) subtests on the MoCA. The ‘Life activities’ domain on the WHODAS 2.0 had a moderate correlation with the ‘Delayed recall’ subtest on the MoCA (r_s=-0.55).

The MoCA’s ‘Executive’ subtest recorded between a very low and weak to low correlation to all domains of the WHODAS 2.0, with the r-value varying between -0.09 and -0.21. The ‘Attention’ and ‘Abstraction’ subtests on the MoCA, did not correlate with the WHODAS 2.0 in any domains higher than a weak to low correlation. Similarly, the domains of ‘Understanding and communicating’ and ‘Getting along with others’, on the WHODAS 2.0, did not correlate with the MoCA total score or subtests higher than a weak to low correlation.

Table 4.11 Correlations between the Montreal Cognitive Assessment and World Health Organization Disability Assessment Schedule 2.0 presenting difficulty on overall daily activity

	MoCA Total score	Executive Subtest	Naming Subtest	Attention Subtest	Language Subtest	Abstraction Subtest	Delayed recall Subtest	Orientation Subtest
	r							
Number of days difficulties present	**-0.34***	-0.10	-0.29	-0.14	-0.15	-0.16	**-0.40***	-0.29
Totally unable	-0.09	0.15	-0.09	-0.09	0.07	0.04	-0.22	-0.19
Reduced activity	**-0.31***	-0.10	**-0.35***	-0.07	-0.09	-0.28	**-0.38***	**-0.37***

***Significance p≤ 0.05**

The WHODAS 2.0 item relating to the number of days participants reported difficulty (Table 4.11), was found to have a low to moderate correlation with the total score of the MoCA (r_s =-0.34). A low to moderate correlation was also found between the number of days difficulty was reported and the 'Delayed recall' subtest (r_s= -0.40), as well as the 'Orientation' subtest (r_s= -0.29) of the MoCA. The 'Reduced activity' item on the WHODAS 2.0 was also found to have a low to moderate correlation to the total MoCA score (r_s=-0.31) as well as the 'Naming' (r_s=-0.35), the 'Delayed recall' (r_s=-0.38) and 'Orientation' subtests (r_s=-0.37).

The coefficient of determination r^2 indicated that 17% of the variation on the total score of the WHODAS 2.0, was accounted for by variation of the total score on the MoCA. Although the slope and intercept in the linear regression were significant (F=11,0803; P=0,0016), there were scattered results, and only 17% of the total score obtained on the WHODAS 2.0 was accounted for on the MoCA total score. This indicated that the correlation was significant but did not explain the variability in the dependent variable (MoCA) (Frost, 2020). According to Cohen's r, this meant a small effect with little clinical relevance, in terms of the association between variables measured by the two tests (Cohen, 1988). The scatter plot (Figure 4.4) displayed heteroscedasticity, which indicated the variances in the data did not remain similar along the line of best fit (Laerd Statistics, 2018). A residual Q-Q plot was created using the data (Appendix O), which showed the residuals of the regression had more clustering on the higher scores of the WHODAS 2.0, with a small number of outliers (Grace-Martin, 2020) (Appendix O). The outliers were analysed using Cook's Distance. No outliers were removed, as the Cook's distances were all less than 1 (Appendix O) (Lane, 2018).

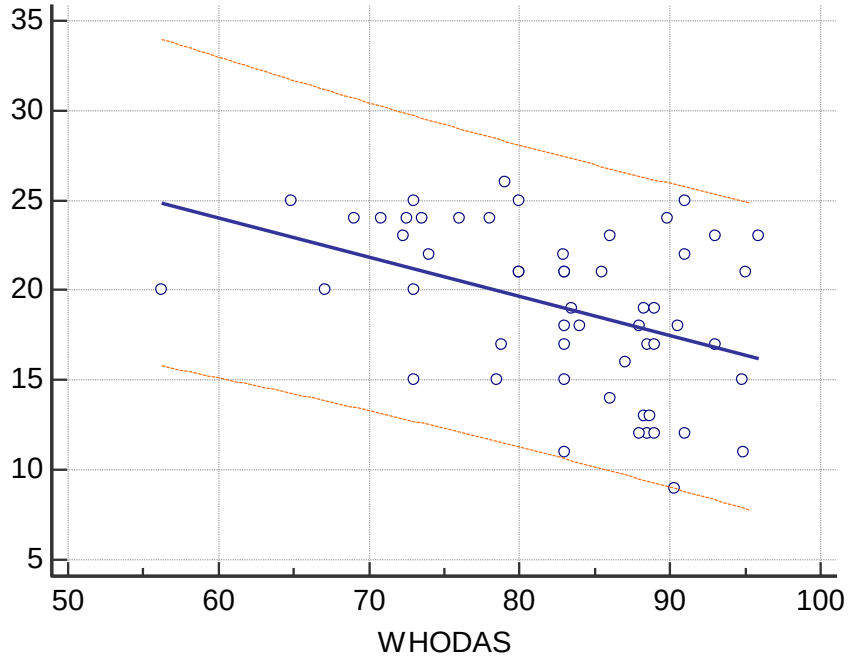

Figure 4.4 Scatter plot with prediction intervals for Montreal Cognitive Assessment and World Health Organization Disability Assessment Schedule 2.0

4.2.5 Summary

Sections 4.1 and 4.2 in chapter 4 presented the quantitative results of phase one of the research.

Concerning objective one, the results indicated that 54 of 55 patient-participants, with IHDS scores of 11 and below, were found to have cognitive and activity limitations as screened by the MoCA and WHODAS 2.0 (Figure 4.1). The z-scores of the 54 patient-participants calculated for the MoCA and WHODAS 2.0 fell below zero. The results of the MoCA presented as z-scores indicated that 69.09% of patient-participants required monitoring for cognition, as they fell at -0.05 SD from the mean. The remaining 30.91% of patient-participants, had scores on the MoCA, that fell at -1 SD from the mean and below. MoCA scores at -1 SD below the mean required further occupational therapy assessment and intervention for cognition. The WHODAS 2.0 results, indicated that 50.9% of the patient-participants required monitoring for activity limitations, falling at -0.05 SD from the mean. The 49.09% of patient-participants whose z-scores fell at -1SD from the mean and below, required further assessment and intervention for activity limitations.

The second objective was to determine the convergence of the IHDS scores, to the MoCA and the WHODAS 2.0 scores, for patients identified with HIV NCD, by a score of 11 or less on the IHDS. The residuals for the IHDS and the MoCA were normally distributed, and only 25% of the variation on the IHDS total score was accounted for by the MoCA total score. According to Cohen's r, 25% was a small effect size and was not clinically relevant.

It was found that the IHDS total score had no convergence to the WHODAS 2.0 total score, with 0% of the variation on IHDS total score accounted for by the total score on the WHODAS 2.0.

Spearman's correlation coefficient was used to understand the relationship between the subtests on the IHDS and the MoCA. The strongest correlation found between the IHDS and the MoCA was between the total scores of the screening tools. When analysing the subtest correlations, the strongest correlations were low to moderate. Spearman's correlation coefficient was also used to understand the relationship between the IHDS subtests and the WHODAS 2.0 domains. The domain of 'Life Activities' was the only domain found to have a low to moderate correlation to the IHDS total score.

The third objective was to determine the convergent validity of the MoCA to the WHODAS 2.0 for patients identified with HIV NCD, by a score of 11 or less on the IHDS. Completion of a linear regression analysis found only 17% of the variation in the MoCA total score was accounted for by the total score on the WHODAS 2.0. According to Cohen's r, 17% of the accounted variation was not clinically relevant.

Spearman's correlation coefficient was used to analyse the correlation between the subtests of the MoCA and the domains of the WHODAS 2.0. The strongest correlation, which was moderate, was found between the total score of the MoCA and the domain of 'Life Activities' on the WHODAS 2.0.

Therefore, the findings confirmed that patient-participants, who scored below 11 on the IHDS, required further occupational therapy monitoring and assessment for cognitive and activity limitations. The convergent validity between the IHDS total score and the MoCA total score was of little clinical relevance, as identified by the variation, according to Cohen's r. There was no convergent validity between the IHDS total score and the WHODAS 2.0 total score, indicating these tests screen

different concepts in patients identified with HIV NCD on the IHDS. Therefore, these screening tools cannot be used interchangeably.

The relationship between cognition and activity limitation, as measured by the MoCA and the WHODAS 2.0, was found to have little clinical relevance according to Cohen's r. There was little clinical relevance in the association of the variables they screen, as only 17% of the variation on the WHODAS 2.0 total score (activity limitations) was accounted for by cognitive function screened by the MoCA total score.

4.3 Phase one Discussion

4.3.1 Introduction

Phase one of the research questioned if screening with the MoCA and WHODAS 2.0, confirmed areas of cognitive and activity limitation within patients who have HIV identified with NCD, on the IHDS. The discussion will initially consider the sample characteristics and the appropriateness of the sample for the study. The results discussion, pertinent to phase one's three objectives, will follow the sample discussions. The limitations of the study and the implications of these for the results will then be discussed.

4.3.2 The sample

The 55 participants in the study attended an HIV neuropsychiatry clinic in Gauteng, South Africa. All patient-participants in the sample scored 11 or below on the IHDS, which indicated either ANI or MND presence. The mean age of the 55 patient-participants was 44 years, with the highest percentage falling into the 25-45 year age group, which is consistent with the age band in which HIV infections are highest in South Africa (Allinder and Fleischman, 2019). When the age of the sample was compared to other South African studies, which reported on ages of participants with HIV NCD, the patient-participants in this study fell into a similar age group. The reported mean age of participants with ANI/MND was 31.5 years (Goodkin et al., 2014), with that for ANI being 40 years and MND 46 years (Joska et al., 2016). One study reported ANI and MND in younger patients at 20.18 years and 22 years respectively (Joska, Westgarth-Taylor, et al., 2011) but no patients participants younger than 26 participated in the current study. Research has reported that age

was not significantly associated with IHDS score (Joska, Westgarth-Taylor, et al., 2011) and the differentiation of HIV NCD categories (ANI/MND) (Goodkin et al., 2014).

A higher percentage of females has been a common characteristic reported in studies on HIV NCD in South Africa (Joska et al., 2016; Goodkin et al., 2014; Joska, Westgarth-Taylor, et al., 2011). The percentage of female participants reported in other studies were 62.8% (Joska et al., 2016), 79.2% (Joska, Westgarth-Taylor, et al., 2011) and 81% (Goodkin et al., 2014). Therefore, this characteristic of the sample, at 81.81%, was congruent with previous research of this population.

The employment statistics indicated that 87.27% were unemployed. The percentage of unemployed patient-participants in the current study was 87.27%, with 96.36% being of employment age. Employment status has been found to be a gold-standard indicator for an everyday functioning decline in HIV NCD (Blackstone et al., 2012). The context of the population in the Blackstone et al. (2012) study was considerably different to that of the context of the current study, as it was completed in the USA, with a reported unemployment rate of 3.5% in 2019 (United States Department of Labor: Bureau of Labor Statistics, 2020). The official unemployment rate in South Africa in September 2019 was 29.1% (Statistics South Africa, 2019). Therefore, this gold-standard indicator cannot be applied to this cohort. The percentage of unemployed patient-participants in this cohort was, however, considerably higher than the percentage reported by Myezwa et al. (2018). Myezwa et al. (2018) researched disability and health in a large cohort of HIV+ people in South Africa, but not specifically to HIV NCD, and reported 58.3% of their cohort earned an income. The 58.3% reported in the Myezwa et al. (2018) cohort was significantly higher than the 12.73% in this sample. Although the gold-standard indicator of unemployment may not be directly transferrable, given the difference in contextual challenges, the percentage of unemployed patient-participants in this sample was higher than the official unemployment rate in South Africa. Therefore, the high percentage of unemployed patient-participants in this cohort may be indicative of dysfunction associated with HIV NCD. The 45.57% difference in employment between the two cohorts may also be accounted for in disability grants, which were considered as income in the Myezwa et al. (2018) study; however, this data was not collected in this study's cohort.

Only 32.73% of patient-participants had completed 11 years of formal education, and 18.18% had completed 12 years. The median for the education level of the sample was grade 11, with 45.45% of the sample having a grade 10 or less. The median level of education was congruent with other studies completed on HIV+ cohorts in South Africa, particularly relating to HIV NCD (Joska, Westgarth-Taylor, et al., 2011; Joska et al., 2016; Robbins et al., 2013). Years of formal education completed in these cohorts, were a median of 11 (Joska et al., 2016), a mean of 10.51 (Robbins et al., 2013) and a mean of 10.05 (Joska, Westgarth-Taylor, et al., 2011). Years of education have been found to predict scores of both the IHDS (Joska, Westgarth-Taylor, et al., 2011) and the MoCA (Robbins et al., 2013) in South African studies on HIV NCD. Joska, Westgarth-Taylor, et al. (2011) found that the level of education predicted lower total IHDS scores only in HIV-negative participants. Robbins et al. (2013) found the level of education to be a significant predictor MoCA performance in their South African cohort, above that of HIV status. Human immunodeficiency virus-positive status was found to predict lower total scores, on the MoCA, as did lower levels of education (Robbins et al., 2013). The effect of the level of education on the MoCA scores questions the MoCA's sensitivity and specificity for HIV NCD, in a cohort which 18.18% had completed 12 years of education.

Most patient-participants in the sample had been diagnosed with HIV between 1-9 years prior to the study, with the median at 9 years. Myezwa et al. (2018) reported a significant association between the duration of HIV infection and the WHODAS 2.0's measured disability. Further to this, they found greater reported disability on the WHODAS 2.0 in participants who had been diagnosed 9 years before their study (Myezwa et al., 2018). The patient-participant cohort of this study, all scored 11 or below on the IHDS indicating neurocognitive decline associated with HIV, and possible cognitive dysfunction and activity limitations as screened by the MoCA and WHODAS 2.0, respectively. Therefore, the median of 9 years since diagnosis in this cohort, corresponds with findings of Myezwa et al. (2018) indicating greater disability with increased duration since diagnosis.

All patient-participants in this study were on an ARV regime. Fixed-Dose Combination (FDC) was the most frequently prescribed ARV with 70.91% on FDC. The most frequent treatment with FDC was congruent with the South African Health

Department's roll-out plan of April 2013, with FDC as the first-line treatment for HIV (Government Communication and Information System, 2020). The FDC, roll-out by the South African Department of Health, was a combination of tenofovir (TDF), emtricitabine (FTC) and efavirenz (EFV) (Government Communication and Information System, 2020). The use of EFV has been associated with neuropsychiatric side effects and worsened neurocognitive function (Dalwadi et al., 2018). Neuropsychiatric side effects associated with EFV include but are not limited to: mania, anxiety, agitation, dizziness, depression, psychosis, impaired concentration, abnormal dreams and insomnia (Dalwadi et al., 2018). The neuropsychiatric symptoms have been reported to continue for two years into the use of EFV in approximately 6% of patients, including symptoms of depression and mania (Dalwadi et al., 2018). Literature has indicated that long term EFV use worsens cognitive function and may increase the prevalence of HIV NCD, particularly in asymptomatic HIV (Dalwadi et al., 2018). The literature on EFV suggested that caution should be taken in initiating EFV in patients with mental illness, as they may be at higher risk of developing neuropsychiatric side effects associated with EFV (Gaida et al., 2016). The use of FDC in 70.91% of the patient-participants, was contrary to reports in the literature, particularly considering that 100% of the patient-participants had HIV NCD and 50.91% were diagnosed with Bipolar disorder.

The most common co-existing condition in the patient-participant sample was Bipolar Disorder (50.91%). Bipolar Disorder was followed by hypertension (14.55%), Depression (12.73%) and Mood NOS (12.73%). All patient-participants were stable on medication for these conditions, as per inclusion criteria. Of the studies on HIV NCD in South Africa, only one reported on the mental health status of their cohort, with no similarities to this sample (Robbins et al., 2013). All the patient-participants in this cohort were registered patients of an HIV neuropsychiatry clinic, no South African studies were found by the researcher that have taken place in this specific context. The nature of the research site would indicate a higher number of patients with common and severe mental disorders than the overall HIV+ population in South Africa. Therefore, the sample's high percentage of Bipolar Disorder may have been the result of the nature of the clinic, as well as the day on which the researcher gathered data, as described in Chapter 3 (see 3.2.2). The

clinic attendees on the day data were gathered were considered by the psychiatrist in charge to be medically well managed, in terms of HIV and co-existing conditions.

Bipolar Disorder is categorised as a Severe Mental Disorder (SMD), along with Schizophrenia and Major Depressive Disorder (MDD) with psychosis (Jonsson et al., 2013). Bipolar Disorder was found to be the most common co-existing condition in the patient-participant cohort (50.91%). Jonsson et al. (2013), reported the prevalence of HIV in persons with SMD's to be between 2.6%-59.3% in sub-Saharan Africa, and the prevalence of SMD in the HIV positive population to be up to 15%. The percentage of the sample with SMDs is similar to the prevalence of HIV in SMD. However, this cannot be confirmed as data on date of diagnosis of co-existing conditions was not collected. The percentage of patient-participants with Bipolar Disorder in the sample was not an expected reflection of the wider HIV NCD population in South Africa and was likely to be specific to the research context.

In a prospective study on a South African HIV+ cohort, Brennan et al. (2018) reported hypertension in over 20% of their cohort on the initiation of ARV treatment. While on ARV treatment, 13% of the Brennan et al. (2018) cohort developed hypertension. Data on the onset of co-existing conditions in the patient-participants in this study was not gathered. However, the prevalence of hypertension in the current study's cohort (14.55%) fell between the prevalence and incidence rates described by Brennan et al. (2018).

The prevalence of depression in people who are HIV+ and on ARV treatment in sub-Saharan Africa has been estimated between 9%-32% (Bernard et al., 2017). In a more recent study conducted on 662 HIV+ participants in South Africa, a depression prevalence rate of 53.8% was found (Van Coppenhagen and Duvenage, 2019). Van Coppenhagen and Duvenage (2019), reported that none of the participants in their study, who were identified as depressed, were on treatment for depression. In this current study the diagnosis of depression in the patient-participant sample at 12.73%, fell within the low estimated range for Sub-Saharan Africa and was considerably lower than that of the South African study by Van Coppenhagen and Duvenage (2019). This difference may be specific to the research context, as well as the day on which data were collected in the clinic.

There were no reported prevalence rates found of Mood NOS in an HIV+ population in South Africa in the literature. The prevalence of Mood NOS (12.73%) in the patient-participant cohort may be due to the research site and the patient profile of the clinic. The prevalence rate of Mood NOS in this cohort is, therefore, not a reflection of the HIV+ population in South Africa.

The sample's demographic characteristics and medical information, presented with similarities to previous studies carried out in this population, as well as differences. The similarities included age, a predominantly female sample, with a median of a grade 11 level of formal education. The sample was predominantly treated with FDC, congruent with the ARV roll-out of the Department of Health in 2013. The use of the EFV component of FDC raises some concern, as it has been reported to result in neuropsychiatric side effects and cognitive decline. The differences included this sample presenting with higher rates of unemployment than HIV+ population studies not specific to HIV NCD, as well as higher rates of SMD's. The unemployment rate in the patient-participants was higher than the national unemployment rate and may be a consequence of HIV NCD, as all patient-participants scored below 11 on the IHDS, which indicated a neurocognitive decline. The higher rate of SMD's may be due to the specific patient-population of the research site, as this was a neuropsychiatric clinic.

4.3.3 Level of cognitive or activity limitations for patients identified with a score of 11 or less on the International HIV Dementia Scale

In Phase one, the first objective of the study was to determine the level of cognitive dysfunction or activity limitations, on the MoCA and WHODAS 2.0, for patients identified with HIV NCD, by a score of 11 or less the on the IHDS.

This section will discuss the results of the IHDS, MoCA and WHODAS 2.0 in terms of the level of cognitive and activity limitations, on those who scored 11 or less on the IHDS.

4.3.3.1 International HIV Dementia Scale

All 55 patient-participants scored below 11 on the IHDS, as per the inclusion criteria. Based on the median total score of 7 in the sample and an upper quartile of 8.5, disturbance in neurocognition was identified across the sample indicating the presence of HIV NCD. Goodkin et al. (2014) reported a mean total score on the

IHDS of 7.2 in their cohort correlated with HAD, and that a mean total score of 8.75 correlated with ANI/MND. The IHDS total scores reported by Joska, Westgarth-Taylor, et al. (2011) were higher than those reported by Goodkin et al. (2014). Joska, Westgarth-Taylor, et al. (2011) reported mean total score, in their cohort, on the IHDS with HAD at 9.69, MND at 10.23 and ANI at 10.92.

The patient-participants results on the IHDS presented with a median score of 2, out of a possible 4, in both the motor speed subtest and psychomotor speed subtest. The psychomotor speed subtest's median was found to be the same as the lower quartile score. The psychomotor subtest score has been found to be low in HIV NCD, in similar cohorts (Goodkin et al., 2014; Joska, Westgarth-Taylor, et al., 2011). Slowed movement and slowed information processing are known prominent features of HIV NCD, with psychomotor slowing being a central deficit associated with damage to the frontostriatal circuits (Woods et al., 2009).

The IHDS total scores of the patient-participants were consistent with other South African studies, on cohorts with HIV NCD. Therefore, the cohort presented with disturbances in neurocognitive function. Neurocognitive dysfunction was expected with a cut-off score of 11 and below on the IHDS.

4.3.3.2 Montreal Cognitive Assessment

All patient-participants scored below the 26-cut-off score, with a median total score of 20, lower quartile of 15 and upper quartile of 23, out of a highest possible score of 30. Based on the 26-cut-off score, cognitive deficits were present in all patient-participants in the cohort. Only one study on the utility of the MoCA in HIV NCD was found in a South African cohort (Robbins et al., 2013). In that study, the total score was reduced to 28, after removing the sentence repetition task in the language subtest, as it was considered inappropriate for the cohort (Robbins et al., 2013). In their cohort, Robbins et al. (2013) found a mean total score of 18.62. Considering the reduction of 2 points from the score, this was similar to the median score in the patient-participants in phase one. In their cohort, Robbins et al. (2013) found that education was a more significant predictor of the MoCA score than HIV status.

The language subtest of the MoCA was considered problematic by Robbins et al. (2013). This concern was based on the fact that the primary language of their cohort was not English, and their cohort had low levels of education (Robbins et al., 2013).

The language subtest was found to be similarly problematic in this study's cohort, with a median score of 1, a lower quartile of 0 and an upper quartile of 2 out of a possible score of 3. Similar to the reasoning for the adaptation of this subtest by Robbins et al. (2013), none of the patient-participants in this study had English as a primary language, and only 18.18% had completed 12 years of formal education. Therefore, the cohort's challenges on this subtest may not reflect the impact of HIV NCD.

The delayed recall subtest was found to have the greatest deficit in the current cohort. The delayed recall subtest was found to have a median score of 2, with a lower quartile of 0 and an upper quartile of 3, out of a possible 5. Difficulty in the delayed recall subtest was expected in HIV NCD, as episodic memory difficulty is prevalent in HIV and can be assessed through list learning (Woods et al., 2009) [as completed in the delayed recall subtest of the MoCA]. Considerably lower scores on the delayed recall subtest were found by Robbins et al. (2013) in their HIV+ group when compared to their HIV- control group. Robbins et al. (2013) reported this to be an established pattern in research. Therefore, the delayed recall subtest deficits noted in the cohort were consistent with the decline associated with HIV NCD.

The IHDS executive subtest results in the cohort, had a median score of 3, a lower quartile of 2 and an upper quartile of 3, out of a possible 5. Difficulty in the executive subtest was expected in the cohort as HIV NCD is associated with executive dysfunction (Woods et al., 2009). A further difficulty in executive function was noted, as seen in the abstraction subtest, with a median score of 1 and a lower quartile of 1, out of a possible score of 2. The cohort's difficulty in these subtests was consistent with findings by Robbins et al. (2013). Robbins et al. (2013) found that their HIV+ cohort had significantly lower scores on the executive and visuospatial tasks when compared to their HIV- cohort. However, floor effects have been noted by Robbins et al. (2013) in the cube copy and watch/ruler abstraction tasks. The cube copy in the visuospatial/executive subtest, and the watch-ruler task in the abstraction subtest, were found to be problematic across both the HIV+ and HIV- cohorts in the Robbins et al. (2013) study. Robbins et al. (2013), speculated that this might be due to lack of educational opportunities across both HIV+ and HIV- cohorts. These speculations were consistent with the demographics of the patient-participant cohort in this study, with only 18.18% having 12 years of formal

education. Although the executive/visuospatial and abstraction subtests indicate deficits consistent with those expected in HIV NCD, two tasks (cube copy and watch/ruler abstraction) in the subtests have presented with floor effects in a similar cohort (Robbins et al., 2013). The floor effects may have influenced the specificity with which the tool was able to identify disturbances due to HIV NCD in the cohort, resulting in false low scores on these subtests.

The attention subtest results in the cohort, presented with a median score of 4, a lower quartile score of 2 and an upper quartile score of 5, out of a possible 6. Attention deficits are expected in HIV NCD and could be linked to increased frontoparietal activation (Woods et al., 2009). Attention and executive function deficits have been found to be strong predictors for IADL dependence. Similar deficits were noted by Robbins et al. (2013) in the HIV+ cohort using the MoCA. The serial seven subtraction task, of the attention subtest, was the most challenging for the patient-participants and has been found to have floor effects (Robbins et al., 2013). Although this form of mental manipulation would be challenging in HIV NCD, Robbins et al. (2013) suggested the floor effect on this task of the subtest may have been due to low levels of education in their cohorts. This suggestion was consistent with the patient-participant cohort with 18.18% who had completed 12 years of formal education. Therefore, although the attention subtest identified deficits known to be affected by HIV, this score may have been influenced by the level of education of the patient-participants as well.

The cohorts IHDS naming subtest results had a median score of 2, a lower quartile of 2 and an upper quartile of 3, out of a possible score of 3. These results did not identify a significant deficit in the cohort and were not an expected deficit in HIV NCD. However, of interest during the administration of this subtest, the cohort found the rhinoceros was challenging to name. This challenge was consistent with the findings of Robbins et al. (2013) in a similar cohort. The naming difficulty was suspected to be due to a lack of educational opportunity in the cohort (Robbins et al., 2013). This report from Robbins et al. (2013) suggested that the scores on this subtest may not have been specific to HIV NCD in the cohort.

The IHDS orientation subtest had the highest score in the cohort, as 100% of the patient-participants scored 6/6 on the subtest. The intact orientation of the cohort

was congruent with the expected stability of co-existing severe mental disorders. This result was similar to Robbins et al. (2013), who found the mean score of 5.69 for the orientation subtest to be the same across their HIV+ and HIV- cohorts.

The appropriateness of the language subtest to the cohort is questionable, as none of the patient-participants had English as their home language. Specific tasks which were challenging across the cohort such as the Necker cube, serial seven subtraction, watch/ruler abstraction and rhinoceros naming have presented with floor effects in another South African study (Robbins et al., 2013). Therefore, although the MoCA identified cognitive dysfunction in the cohort, the extent to which this is due to HIV NCD is unclear. The extent to which the IHDS identified cognitive dysfunction from HIV NCD lacks clarity because of the possible impact of cultural inappropriateness (specifically language and cultural commonality of objects used in memory and naming subtests) and effect of level of education, on the results. These identified limitations in the use of the MoCA for HIV NCD in South African population were supported by the findings of Joska et al. (2016), who found the MoCA to have poor specificity for HIV NCD in their cohort.

4.3.3.3 World Health Organization Disability Assessment Schedule 2.0

The median total score for the patient-participants on the WHODAS 2.0 was 23.51%, with a lower quartile of 14.72% and an upper quartile of 31.63%. When compared to the population norms of the WHODAS 2.0 IRT-based score (Üstün et al., 2010: 43), the cohort median total score fell within the 80th percentile. This percentile indicated high levels of experienced difficulty in daily living in the cohort when compared to population norms. Studies on HIV and disability have been concluded on a South African sample using the WHODAS 2.0, however comparison to these studies has been limited due to the representation of scoring (Hanass-Hancock, Myezwa and Carpenter, 2015; Myezwa et al., 2018). No studies using the WHODAS 2.0 on a South African population with HIV NCD were found for comparison to this study.

The highest median score of 37.50% was for the domain ‘understanding and communicating’, with a lower quartile percentage of 25%, and an upper quartile of 45.83%. These results were expected as the cohort experienced neurocognitive decline, based on the IHDS cut-off score of 11 and below. This domain reported on the patient-participants’ experiences of conversation, memory, attention, problem

solving and learning in daily activity. The highest median score in this domain corresponds with known cognitive dysfunction associated with HIV NCD, specifically executive function, memory and attention (Woods et al., 2009). Deficits in attention, memory and executive function in HIV NCD have been found to be strongly linked to activity limitations (Woods et al., 2009). This domain had the third-highest difficulty in the Myezwa et al. (2018) cohort. The median score of 37.5% in this cohort was 4.5% higher than that of Myezwa et al. (2018), who reported a mean of 33%, where the cohort was not specific to HIV NCD.

The domain with the second-highest median percentage of difficulty in this cohort was 'getting along with others' at 30%, with a lower quartile of 20%, and an upper quartile of 45%. Challenges with interpersonal relationships are not specific to functional decline in HIV NCD, as outlined by the 'Frascati Criteria' (Antinori et al., 2007) and was an unexpected result. Although an unexpected result, social problem solving requires executive function (known to be impaired in HIV NCD) and social cognition which have been reported to have a close association (Anderson et al., 2013). Executive function and social cognition involve the frontal networks of the brain (Anderson et al., 2013). As frontostriatal circuits are known to be compromised by HIV NCD (Woods et al., 2009), this may have impacted on the patient-participants experienced difficulties in 'getting along with others'. For this association to be confirmed, research on the specific impact of HIV NCD on social cognition is needed. Social cognition deficits have been reported in patients with euthymic Bipolar Disorder, particularly in Theory of Mind (mentalising) and facial recognition (Samame et al., 2012). As 50.91% of the cohort had co-morbid Bipolar Disorder, this may have impacted the high median percentage of difficulty in 'getting along with others'. 'Getting along with others' domain presented with difficulty of only 16.5% in the Myezwa et al. (2018) cohort. 'Getting along with others' was the only domain which presented as significantly lower (by 34.41%) in the Myezwa et al. (2018) cohort than the cohort in this current study. The presence of HIV NCD and SMD was the notable difference in the cohort in the current study, to that of Myezwa et al. (2018).

The domain with the third-highest median score was 'participation in society', with a median score of 28.13% difficulty experienced, with a lower quartile of 18.75% and an upper quartile of 46.88%. In a South African study on disability in HIV, the

domain of ‘participation in society’ was found to have the greatest difficulty in the cohort, with a mean percentage of difficulty of 40.2% (Myezwa et al., 2018). The domain of ‘participation in society’ includes engaging in community activities, emotional and financial impact of health condition and living with dignity (Üstün et al., 2010). In a study comparing HIV-related stigma from 2004 – 2016 in South Africa, it was found that community stigma had increased over this period (Visser, 2018). Community stigma refers to how the community perceives and responds to HIV and the person with HIV in particular (Visser, 2018). This stigma may increase the difficulty of engaging in community activities, increase the emotional impact of the health condition and therefore increase the experienced difficulty of living with dignity. Human immunodeficiency virus neurocognitive disorder has been found to be associated with unemployment in MND and HAD (Antinori et al., 2007) (Heaton et al., 2004). These reports were congruent with the findings in the cohort whom all scored under 11 on the IHDS, indicating the presence of HIV NCD with 87.27% unemployed. The cohort’s challenge of unemployment may be reflected in the experienced difficulty with the financial impact of the health condition in the domain of ‘participation in society’.

The domain ‘getting around’ had a median of 15%, with a lower quartile, was 5% and an upper quartile of 30%. This domain examined difficulty in standing for ten minutes, standing up from sitting, leaving the house and walking a long distance such as one kilometre. In the current study, 7.27% of patient-participants had co-existing illnesses that may have resulted in physical difficulty in mobility, such as standing up and walking long distances. Difficulty in ‘getting around’ may also be influenced by the psychomotor slowing present in HIV NCD (Woods et al., 2009). Psychomotor slowing was present in the current study cohort, as seen in the results of the IHDS. Psychomotor slowing may also have affected the patient-participants experienced difficulty in standing up from sitting and walking long distances. Myezwa et al. (2018) reported a mean difficulty of 37.8% in the domain of ‘getting around’ in their cohort. The mean in the Myezwa et al. (2018) cohort was 22.8% higher than the median reported perceived difficulty in the cohort in this study.

The WHODAS 2.0 domain of ‘Life activities’ presented with a median score of 12.5%, a lower quartile of 6.25% and an upper quartile of 18.75%. The median percentage of difficulty perceived in this cohort was 20.4% lower than the mean

percentage of difficulty (32.9%) reported by Myezwa et al. (2018), in their cohort. This difference was an unexpected result, as the domain of 'Life activities' includes difficulty in IADLs, which is characteristic of HIV NCD (Antinori et al., 2007). However, this finding may be attributed to the cognitive difficulties present in the cohort, impairing their metacognitive ability to self-report on aspects such as 'doing household tasks well'. Cognitive deficits due to HIV NCD, have been found to result in lower self-reported difficulty in everyday functioning (Thames et al., 2011). Gandhi et al. (2011) found that lower scores in self-reported difficulties in IADLs correlated with more severe forms of HIV NCD. Therefore, the cognitive deficits present in the cohort due to HIV NCD may have resulted in the lower than expected self-report of difficulty in the domain of 'Life activities'. Lower self-reported scores would limit the assessor's ability to effectively identify deficits associated with HIV NCD. Less impact on IADLs has been associated with milder forms of HIV NCD (Antinori et al., 2007). Therefore, lower self-reported scores in this domain may reduce referral for further occupational therapy intervention.

The domain with the lowest median percentage, indicating least experience of difficulty, was self-care at 6.25%, with a lower quartile of 0%, and an upper quartile of 12.50%. This domain included experiences of difficulty in washing, dressing and toileting (Antinori et al., 2007). This result was expected, as none of the participants in the cohort presented with physical limitations which would impact on the ability to complete these tasks. In relation to cognition, activities such as washing, dressing and toileting are habituated tasks which do not require executive functions, known to be impaired in HIV NCD such as problem-solving, to be completed. This domain does not explore higher-order self-care skills such as routinising self-care or planning self-care appropriately for specific weather or events. These questions would require more use of executive function and prospective memory known to be impaired in HIV NCD (Woods et al., 2009).

Across the domains on the WHODAS 2.0, the perceived difficulty from the Myezwa et al. (2018) cohort was higher than the perceived difficulty of the cohort in this study on all but two domains. The exceptions were a substantially lower score in 'getting along with others' and a mildly lower score in 'understanding and communicating' which have been discussed above. Myezwa et al. (2018) reported increased disability with depressive symptoms in their cohort. Symptoms of depression have

been found to increase the self-report of deficits in everyday function (Blackstone et al., 2012). The patient-participants in phase one of the study were all stable on medication for mood disorders, as per inclusion criteria. As they did not present with acute mood symptoms, this may have reduced self-report of difficulties in domains when compared to results of the Myezwa et al. (2018) study. The influence of impaired cognition on lowering scores on self-report (Chiao et al., 2013; Thames et al., 2011; Shirazi et al., 2017), may also have resulted in the cohort in this study under-reporting difficulties when compared to the cohort of Myezwa et al. (2018). Therefore, the higher perceived percentage of difficulty reported by Myezwa et al. (2018), when compared to the cohort in this study, may have been due to depressive symptoms in their cohort. The perceived percentage of difficulty may have been lower in the cohort in this study, due to cognitive impairment associated with HIV NCD limiting judgement and self-awareness for accurate self-report.

The number of days the difficulties were present out of 30, was reported with a median of 15 days, a lower quartile of 5 days, and an upper quartile of 30 days. This was a crude result as it does not refer to a specific difficulty but all domains. However, this result suggested that the cohort had difficulty in carrying out everyday activities with a median of 50% of a month, and up to 100%. This result showed the frequency of daily challenges faced by the cohort in activity limitations associated with HIV NCD.

The WHODAS 2.0 identified activity limitations in the cohort. As expected, the domain of ‘understanding and communicating’ presented with the highest experienced difficulty. It was unexpected that the domain of ‘getting along with others’ had the second-highest median percentage of difficulty. This result may have been due to the impact of HIV NCD on the frontostriatal circuits limiting executive function and social cognition, but research would be required to confirm this association. Difficulty experienced in ‘participation in society’ highlighted the potential impact of community stigma on patient-participants. It was unexpected that the domain of ‘Life activities’ presented with a lower percentage of experienced difficulty in the cohort, due to the characteristic decline in IADLs associated with HIV NCD. This result was thought to be due to the cognitive impairment in HIV NCD limiting self-awareness, and therefore self-report on ‘how well’ an IADL was completed. When compared to results from a South African study using the

WHODAS 2.0 in HIV, the perceived percentage of difficulty in this cohort may have been lower due to the presence of HIV NCD, and the absence of acute depressive symptoms.

4.3.3.4 Conclusion of Objective one

The results of the IHDS, MoCA and WHODAS 2.0 were discussed above in relation to objective one.

The results of the IHDS of the patient-participants in this study were consistent with other South African studies that had used the IHDS to identify HIV NCD. Therefore, the cohort presented with disturbances in neurocognitive functioning expected in HIV NCD.

The results of the MoCA, based on the 26-cut-off, indicated that all patient-participants had cognitive dysfunction. Of the patient-participants, 30.91% needed a referral for further occupational therapy assessment for cognitive dysfunction, while 69.09% required monitoring and maintenance intervention. Due to the reported bearing of education, language, and context on the results of the MoCA, the specificity of these results, to identify the cognitive impact of HIV NCD, is questionable. These identified limitations of the tool in the cohort may result in unnecessary referral and false-positive results for others being tested.

The WHODAS 2.0 median score for the cohort, fell within the 80th percentile of the population norms. This result indicated that activity limitations as measure by the WHODAS 2.0 were present in the cohort. Of the patient-participants, 49.09% would require a further occupational therapy assessment and intervention for activities limitations, as a result of HIV NCD. Further performance-based assessments would be required to establish the severity of dysfunction, due to the reported impact of cognitive dysfunction on self-report. The impact of cognition on the self-reported percentage of difficulty may result in late referral for further occupational therapy assessment and intervention, which would be detrimental to the patients' health care.

The results of the MoCA and WHODAS 2.0, therefore, showed cognitive and activity limitations, respectively, as based on scores of 11 or less on the IHDS. Therefore, the need for further occupational therapy intervention for cognitive and activities limitation was identified in the cohort. However, the efficacy of the tools in identifying

cognitive and activity limitation in HIV NCD is questionable. The questionable efficacy may result in over or under referral when using the MoCA and WHODAS 2.0, in people suffering from HIV NCD.

4.3.4 Convergent validity of the International HIV Dementia Scale to the Montreal Cognitive Assessment and the World Health Organization Disability Assessment Schedule 2.0, in patients identified with human immunodeficiency virus neurocognitive disorder on the International HIV Dementia Scale

Phase one's second objective was to determine the convergence of scores on the IHDS, with the scores on the MoCA and WHODAS 2.0, for patients with HIV NCD, by a score of 11 or less on the IHDS. The discussion below elaborates on the convergence of the IHDS to the two screening tools for cognition and activity limitations.

4.3.4.1 Association between neurocognition scores on the International HIV Dementia Scale and cognition scores on the Montreal Cognitive Assessment

The IHDS and the MoCA were found to have a moderate correlation using Spearman's correlation coefficient on the total scores, and a significant F-value but a low coefficient of determination (r^2) on the regression analysis. It was found that only 25% of the variation on the total score on the MoCA could be accounted for by the total score on the IHDS and according to Cohen's r, this had little clinical significance. Therefore, the HIV NCD measured by the IHDS cannot be used to identify or predict cognitive dysfunction, as measured by the MoCA, in this cohort of patients.

These findings were supported by Joska et al. (2016) who found the IHDS had poor sensitivity but good specificity for HIV NCD, while the MoCA had poor specificity and good sensitivity. These findings suggested that the MoCA may over-identify cognitive dysfunction and as concluded by Joska et al. (2016), neither of these screening tools alone was adequate to screen for HIV NCD. The poor specificity of the MoCA was confirmed, in identifying HIV NCD for the South African population, due to challenges of cultural appropriateness, language, and education related to the tool (Robbins et al., 2013). The poor specificity must be considered when interpreting the correlations between the IHDS and MoCA total scores and subtest scores, which are discussed below.

The IHDS total score was found to have weak to low correlation with the executive/visuospatial, attention and abstraction subtests on the MoCA, in the cohort. These subtests were also found to have a poor correlation with the motor speed, psychomotor speed and memory subtests of the IHDS in the patient-participant cohort. Human Immunodeficiency Virus Neurocognitive Disorder is known to present with disturbances in executive function and attention (Woods et al., 2009). As the IHDS has been validated for use in identifying the presence of HIV NCD, in the South African population (Joska, Westgarth-Taylor, et al., 2011), the poor correlation of these subtests to the IHDS total score was unexpected. This result suggested that the subtests are not measuring the same constructs. This finding was supported by the recommendation in some studies that the IHDS be administered with executive function screening tools to improve specificity and sensitivity to HIV NCD (Joska et al., 2016).

The poor correlation may also be explained by the findings of Robbins et al. (2013), who reported the visuospatial/executive (particularly cube copy), attention (particularly serial 7's), and abstraction (particularly watch/ruler abstraction) subtests to have floor effects in their study, across their cohorts of HIV+ and HIV- participants. The floor effects were reported to be due to the level of formal education and lack of education opportunities in their cohort, as well as cultural inappropriateness of some items in the test (Robbins et al., 2013). This finding was similar to the patient-participant cohort in this study, as only 18.18% had completed 12 years of formal education.

The IHDS total score presented with a low to moderate correlation to the naming subtest of the MoCA in the patient-participant group (r_s=0.41). A low to moderate correlation was also found between the IHDS motor speed subtest (r_s=0.39) and the MoCA naming subtest. This finding was unexpected as difficulty with naming had not been reported as specific to HIV NCD. The low to moderate correlation may be due to the floor effect noted by Robbins et al. (2013) across their HIV+ and HIV- cohort in this subtest. Robbins et al. (2013), found that their cohort had a specific challenge with the naming of the rhinoceros. This challenge was similarly observed during administration of the MoCA by the researcher in this study.

The IHDS total score was found to have a low to moderate correlation to the language subtest of the MoCA in the patient-participants (r_s=0.46). A low to moderate correlation of the motor speed subtest (r_s=0.42), and the psychomotor speed subtest (r_s=0.44) to the language subtest of the MoCA was also found. The language subtest of the MoCA consists of sentence repetition and fluency tasks (Nasreddine et al., 2005). Verbal fluency has been found to be influenced by HIV NCD and damage to frontostriatal circuits, although action fluency has been found to have greater predictive value for IADL deficit in HIV NCD (Woods et al., 2009). Therefore, it was expected that the language subtest of the MoCA would correlate to the IHDS scores in the cohort. The appropriateness of the language subtest in the MoCA, to the South African population, has been questioned by Robbins et al. (2013), due to the requirement of English which is not the first language of most citizens. Specific to the verbal fluency task, the use of phonemic fluency could not be translated into the home language of their cohort and was adapted to semantic fluency (Robbins et al., 2013). This challenge was similar to the cohort demographics in this study, as none of the patient-participants had English as their home language. This report, combined with the cohort's language demographics suggested that poor results in the language subtest may not have been due to HIV NCD but rather an inappropriate item for the cohort, within the screening tool.

A low to moderate correlation of the IHDS total score and MoCA subtest of delayed recall (r_s=0.48) was found in the patient-participant group. This result was expected as list learning is known to be impaired in HIV NCD (Woods et al., 2009). A low to moderate correlation of the delayed recall subtest of the MoCA was also found to the motor speed subtest (r_s=0.39), and psychomotor speed (r_s=0.34) subtest of the IHDS. Unexpectedly the memory subtest of the IHDS had a weak to low correlation to the delayed recall subtest of the MoCA (r_s=0.22). The IHDS gives three words for repetition, followed by two brief motor tasks before the recall of the three words (Sacktor et al., 2005). The MoCA list learning consists of five words and is followed by the attention, language and abstraction subtests (Nasreddine et al., 2005). The severity of the impairment in working memory in HIV NCD is known to be related to the complexity of the attentional task which has been found to increase frontoparietal activation (Woods et al., 2009). The MoCA increases the attentional requirement as it has five words and is followed by attention and executive function

tasks before the list recall. The attentional requirement may result in a greater difficulty in completing the delayed recall of the MoCA, when compared to that of the IHDS, resulting in a poor correlation between these two subtests.

The IHDS total scores were found to have a low to moderate correlation with the orientation subtest on the MoCA (r_s=0.30). A low to moderate correlation was also found between the motor speed subtest of the IHDS and orientation subtest of the MoCA (r_s=0.37). Weak to low and very low correlations were found between the psychomotor speed subtest (r_s=0.17), memory recall subtest (r_s=-0.02) and the orientation subtest on the MoCA. All patient-participants scored 6 out of 6 in the orientation subtest of the MoCA. This result was expected as all patient-participants, per inclusion criteria, were stable and did not present with conditions such as delirium, which may result in disorientation.

4.3.4.2 Association between neurocognition scores on the International HIV Dementia Scale and activity limitation measured by the World Health Organization Disability Assessment Schedule 2.0

The total score of the IHDS and the total score of the WHODAS 2.0 were found to have very low correlation (r_s=-0.14), using Spearman's correlation coefficient. The linear regression showed no association between these screening tools, and 0% of the variation on the total score of the IHDS, could be accounted for by the total score of the WHODAS 2.0. This finding indicated that the effect of HIV NCD on activity limitation could not be deduced from the IHDS score. This finding was consistent with reports of similar studies using the IHDS, which have recommended the use of functional screens to accompany the IHDS when screening for HIV NCD (Kamminga et al., 2013; Goodkin et al., 2014).

When considering the low correlations of the subtests of the IHDS and the WHODAS 2.0, a low to moderate correlation was found between the IHDS total score and the domain of 'Life Activities' the WHODAS 2.0 (r_s=-0.36). This stronger correlation was expected, as the domain of 'Life Activities' asks for self-report on IADLs. This correlation was therefore in line with the 'Frascati Criteria' for the classification of HIV NCD, as it showed a correlation between the IHDS score and difficulties experienced in IADL function, in the study cohort. This domain presented with a lower than expected median percentage of difficulty for HIV NCD, in the study cohort, and when compared to a South African HIV+ cohort (Myezwa et al., 2018).

This difference may be due to the influence of cognitive dysfunction associated with HIV NCD on self-report (Thames et al., 2011). Therefore, changes in percentages in this domain should be carefully monitored when screening individuals suffering from HIV NCD, as this could indicate changes in the progression of the condition.

The IHDS total score, as well as the IHDS psychomotor speed score, were found to have a low to moderate correlation with the self-reported number of days of difficulty in carrying out their day to day activities reported by all patient-participants. This correlation was of importance as psychomotor speed impairment has been found to be a predictor of cognitive impairment, and HIV associated dementia (Kinuthia et al., 2016). The slowing of the psychomotor speed is a predictor of the disease progression (Kinuthia et al., 2016), which may explain the relationship between the IHDS total score, IHDS psychomotor speed score, and the number of days the participants report difficulty carrying out their day to day activities on the WHODAS 2.0. This result was expected when understanding the predictive nature of psychomotor speed. This correlation must be noted with caution in patients who do not present with well-managed mood and affect, as this may lead to an over-report of difficulties, as found in a number of studies when reviewing self-report of activity limitations in HIV (Blackstone et al., 2012; Obermeit et al., 2017). In the current study, only patients with mood disorders who were considered stable and compliant with their medical management, by the psychiatrist in charge, were included.

The IHDS was found to have a weak to low correlation with the domain of 'Understanding and Communicating' on the WHODAS 2.0 (r_s=-0.20). This domain covers an individual's ability to concentrate, problem-solve, remember important daily tasks, understand what others say, start and maintain a conversation (Üstün et al., 2010). Therefore, self-report on a broader range of cognitive functions was covered by the domain of 'Understanding and Communicating' than that of the IHDS. The ability to problem-solve, concentrate, learning something new and remember to do important tasks are known to be impaired in HIV NCD (Woods et al., 2009). Therefore, it was expected that the IHDS would have a stronger correlation to this domain. The strength of the correlation may have been impacted by questions on communication, such as starting and maintaining a conversation and understanding what people say, as these are not specific to cognitive

dysfunction in HIV NCD, and these underlying constructs are not screened in the IHDS.

The poor correlation between the IHDS total score and subtest scores, and WHODAS 2.0 total score and domains, indicated that the IHDS could not be used to deduce activity limitation in everyday functioning. This finding supported reports that the IHDS should be accompanied by a functional screen, to identify the need for further assessment and intervention (Kamminga et al., 2013; Goodkin et al., 2014). The low to moderate correlation between the IHDS total score and domain of 'Life activities', on the WHODAS 2.0, is a valuable finding. It identified a correlation between the neurocognitive disturbance identified by the IHDS and IADL limitation expected as per the 'Frascati criteria' for the classification of HIV NCD.

4.3.4.3 Conclusion of Objective 2

Only 25% of the variability of the total scores of the IHDS accounted for the variability of the total scores of the MoCA, which, according to Cohen's r, had little clinical relevance. This finding was supported by Joska et al. (2016), who reported that an executive screening tool should be used in conjunction with the IHDS to improve its sensitivity and specificity in screening for HIV NCD. The use of the MoCA as an additional screening tool should be considered with the findings of Robbins et al. (2013), noting concerns around the appropriateness of the MoCA for the South African population in measuring the cognitive impact of HIV NCD.

The IHDS and WHODAS 2.0 total scores were found to have a very low correlation, and 0% of the variability in the total scores of the IHDS accounted for the variability in the total scores of the WHODAS 2.0. This finding indicated that activity limitation could not be identified or predicted from the IHDS scores, in the cohort selected for this study. This finding was supported by recommendations that the IHDS should be completed in conjunction with a screening of everyday function, in order to use the 'Frascati criteria' classification for HIV NCD (Antinori et al., 2007; Kamminga et al., 2013; Goodkin et al., 2014).

In this study cohort, neither the MoCA nor the WHODAS 2.0, presented with clinically relevant convergence, to the IHDS with scores of 11 or less.

4.3.5 Convergent validity of the Montreal Cognitive Assessment to the World Health Organization Disability Assessment Schedule 2.0, in patients identified with human immunodeficiency virus neurocognitive disorder, on the International HIV Dementia Scale

Phase one's third objective aimed to determine the convergent validity of the MoCA to the WHODAS 2.0 for patients identified with HIV NCD, by a score of 11 or less on the IHDS. The discussion below draws on observations made on demographic information, to understand the convergent validity of the MoCA (cognitive limitation) and the WHODAS 2.0 (activity limitation).

4.3.5.1 Association of cognition scores on the Montreal Cognitive Assessment and activity limitations measured by the World Health Organization Disability Assessment Schedule 2.0

The MoCA and WHODAS 2.0 total scores, were found to have a low to moderate correlation (r_s=-0.40) in the cohort, using Spearman's correlation coefficient. In the linear regression, only 17% of the variation on the WHODAS 2.0 was accounted for by the variation in the MoCA scores. According to Cohen's r, this provides a small effect size with little clinical relevance. Therefore, the cognition measured by the MoCA cannot be used to identify or predict activity limitations measured by the WHODAS 2.0. This finding was congruent with recommendations of Antinori et al. (2007) that a screen of everyday function (activity limitations) should be carried out in conjunction with a cognitive screen, to effectively identify the severity of HIV NCD. The residuals for the linear regression did not follow a normal distribution. The heteroscedasticity of the plot indicated a clustering of higher scores for the WHODAS 2.0. This clustering may be accounted for by the conversion of WHODAS 2.0 scores to percentages, rather than a standard score. The WHODAS 2.0 is also a self-report tool and the correlation of patient report scores, to therapist scores on screening tools such as the MoCA, may affect the outcome (Abma et al., 2016). Therefore, the results should be interpreted with caution.

The interpretation of the subtest and domain correlations are discussed below, relating to the MoCA, and possible rationale for higher scores in specific domains of the WHODAS 2.0. Two moderate correlations were found: the first between the MoCA total score and the domain of 'Life activities' on the WHODAS 2.0 (r_s=-0.54), the second between the IHDS delayed recall subtest and the WHODAS 2.0 'Life activities' domain (r_s=-0.55). The correlation between the IHDS total score and 'Life

activities' domain was an expected relationship, as cognitive decline and IADL dysfunction are specific to the classification of HIV NCD as per the 'Frascati Criteria' (Antinori et al., 2007). Therefore, the domain of 'Life activities' should be monitored for change, if administering the WHODAS 2.0 for the screening of HIV NCD everyday function (activity limitations).

The delayed recall subtest on the MoCA was found to have a low to moderate correlation (r_s=-0.46) to the WHODAS 2.0 total score, and moderate correlation (r_s=-0.55) to the domain of 'Life activities', in the cohort. These correlations were expected, as low scores on the list learning aspect of the delayed recall subtest have been found to be a pattern of performance in HIV NCD (Heaton et al., 2011), and in a South African study on the utility of the MoCA in HIV NCD, by Robbins et al. (2013). Disturbance in memory has been found to be strongly associated with deficits in IADLs, such as employment and household management (Woods et al., 2009), as reported on in the 'Life activities' domain (Üstün et al., 2010). This reported association was also congruent with the high unemployment percentage (87.27%) of the cohort. This correlation supported the substantial contribution of the 'Life activities' domain of the WHODAS 2.0, and its relationship to the deficits noted in the IHDS and MoCA, in line with the classification of HIV NCD.

The executive/visuospatial, attention, and abstraction subtests of the MoCA, were found to have weak to low and very low correlations with the WHODAS 2.0 total percentage and domains. This result was unexpected, as executive function and attention are known to be impaired in HIV NCD and have a strong association with dysfunction in IADLs and activity limitations (Woods et al., 2009). These subtests have been found to be inappropriate to the South African population, due to cultural inappropriateness and requirement for formal education (Robbins et al., 2013). Weak to low and very low correlations were also found between the IHDS total score and executive/visuospatial, attention, and abstraction subtests of the MoCA, in the study cohort. The findings of Robbins et al. (2013) may explain the weak correlation between the results of these subtests, and the domains of the WHODAS 2.0, in the cohort.

Low to moderate correlations have also been found with the MoCA subtests of naming and language, to the domain of 'Life activities' in the WHODAS 2.0. This

result was expected, as verbal fluency has been found to be a modest predictor of activity limitation, while action fluency has been found to be five times more sensitive (Woods et al., 2009). This correlation should also be considered in light of the queried cultural appropriateness of these subtests, for the South African population, by Robbins et al. (2013).

The orientation subtest of the MoCA was found to have low to moderate correlations with the WHODAS 2.0 total percentage (r_s=-0.35), the 'Self-care' domain (r_s=-0.39) and the 'Participation in society' domain (r_s=-0.35), in the cohort. These correlations indicated the relationship between orientation to person, place and time and engagement in daily activity. Poor orientation could limit one's ability to effectively participate in society, as defined by the domain in the WHODAS 2.0, such as attending community gatherings or doing activities for relaxation and pleasure (Üstün et al., 2010). If an individual were disorientated, their ability to attend a gathering at a specific time and place would be affected. Poor orientation could have negative consequences for the self-care tasks, described in the WHODAS 2.0, such as washing, dressing, eating, and staying alone for a few days (Üstün et al., 2010). If an individual were disorientated, their ability to orientate to time and place to complete these tasks appropriately would be impaired. It was unexpected that the orientation subtest of the MoCA had a very low correlation to the domain of 'Understanding and communicating', on the WHODAS 2.0, as orientation would be required for problem-solving, learning something new and remembering to do important things.

The MoCA total score had a low to moderate correlation to 'The number of days difficulties were present' (r_s=-0.34), and 'Reduced activity' (r_s=-0.31) on the WHODAS 2.0, in the study cohort. Low to moderate correlations were also found between the delayed recall subtest and 'Number of days difficulties were present' (r_s=-0.40), and 'Reduced activity' (r_s=-0.38). These correlations indicated that the cognitive dysfunction experienced by the patient-participants influenced the frequency with which they experienced challenges in daily activity, and needed to reduce engagement in activities. This finding would stand to reason, as the greater challenge one has in completing a task satisfactorily, the less motivation they would express in initiating a new task, resulting in reduced activity. A low to moderate correlation was also found between the IHDS total score (r_s=-0.39), IHDS

psychomotor speed subtest (r_s=-0.30) and the 'Number of days difficulties were present' on the WHODAS 2.0, in the cohort. These correlations showed a trend in the relationship between cognitive limitations identified in the IHDS and MoCA, and the frequency with which activity limitations presented.

The implications of these findings indicated that, although the WHODAS 2.0 did not account for variability on the MoCA in the study cohort, there are valuable correlations between subtests and domains. These correlations have highlighted the domain of 'Life activities' on the WHODAS 2.0 and 'number of days difficulty was present'. This finding was congruent with the pattern described by Antinori et al. (2007), of dysfunction in daily activities associated with levels of HIV NCD. The correlation of the 'Life activities' domain, which also included questions on work, has further been supported in the demographics of the participants, with 87.27% of participants being unemployed (see 4.5.2). This correlation combined with cohort demographics was congruent with findings which reported unemployment to be a significant consequence of HIV NCD (Blackstone et al., 2012; Cattie et al., 2012; Gandhi et al., 2011). This finding suggested a potential clinical use from the domain of 'Life activities', indicating that further occupational therapy assessment would be beneficial, namely IADL and vocational.

4.3.5.2 Conclusion of Objective 3

The total percentage of perceived difficulty of the WHODAS 2.0 was not found to have a strong correlation with the MoCA total score. The MoCA was found to account for only 17% of the variation in the WHODAS 2.0, with a small clinically irrelevant effect size.

The analysis identified valuable correlations between some cognitive subtests of the MoCA and activities domains on the WHODAS 2.0, when considered in relation to previous studies, for the screening of HIV NCD. A moderate correlation was found between the WHODAS 2.0 'Life activities' domain and the MoCA total score. This correlation indicated an association to be considered when screening for HIV NCD, in terms of the 'Frascati Criteria' (Antinori et al., 2007). This correlation suggested that patient-participants presenting with cognitive limitation on the MoCA would benefit from further assessment and possibly intervention from occupational therapy, in IADLs.

Other moderate correlations to be considered were that of the delayed recall subtest of the MoCA, with the WHODAS 2.0 total score, and 'Life activities' domain. These were congruent with previous studies, in the pattern of HIV NCD, which reported the predictive value of list learning and memory, on everyday functioning in HIV NCD. Therefore, this subtest may be valuable in identifying risk for activity limitations, in the screening of HIV NCD.

This analysis has also identified the lack of correlation and potential impact of inappropriate subtests, ineffectively identifying those in need of further assessment, for both cognitive and activity limitation. Overall, the WHODAS 2.0 adequately identified correlation between limitations in cognition (measured by the MoCA) and IADLs. Therefore, the WHODAS 2.0 would be an appropriate self-screen tool for the initial screen of activity limitation in HIV NCD. The use of the WHODAS 2.0 should, however, be considered in line with the impact of mood and cognition (see 4.3.3.3).

4.3.6 Limitations

The results of this research should be viewed with caution, due to the lack of previous research using the WHODAS 2.0 as a self-report in HIV NCD and lack of full neuropsychological and functional testing in the cohort.

There was no previous research for comparison, on the efficacy of the WHODAS 2.0 in the screening of HIV NCD with cognitive decline, at the time of writing up the study. Studies have been carried out using the WHODAS 2.0 in the South African context to understand activity limitations of HIV, but these results had not been compared with levels of cognitive function, or specifically HIV NCD. The scores in these studies had been adapted, limiting the comparison to the cohorts (Myezwa et al., 2018; Hanass-Hancock, Myezwa and Carpenter, 2015). The limitation in comparison restricted the researcher in cross-referencing findings specific to the context.

The research was limited, as no full neuropsychological and functional testing had been carried out on the study cohort, for comparison with the results of the tests. The lack of full neuropsychological testing was characteristic of the resource limitations of setting and supported the purpose of the study.

4.4 Conclusion of Phase one

Phase one of the study aimed to ascertain whether the MoCA and WHODAS 2.0 confirmed areas of cognitive dysfunction and activity limitations in patients with HIV NCD, identified by a score of 11 or less on the IHDS. It was found that 98.8% of the patient-participant group had z-scores on both the MoCA and the WHODAS 2.0, 1 SD below the mean or less (figure 4.1). This result indicated that all patient-participants scoring 11 or less on the IHDS, presented with cognitive dysfunction and activity limitations, as measured by the MoCA and WHODAS 2.0.

Although the MoCA identified cognitive dysfunction in the patient-participants, it should be considered with the low specificity to HIV NCD, and reports of cultural inappropriateness of specific MoCA subtests for patients with HIV NCD in South Africa. The inappropriate subtests included the executive/visuospatial, naming, language, attention, and abstraction subtests (Robbins et al., 2013). The low specificity to HIV NCD in the context may result in over-identification of cognitive dysfunction. The over-identification may result in a higher number of referrals for intervention than necessary.

While the WHODAS 2.0 identified activity limitation in the cohort, the results of the WHODAS 2.0, should be considered in conjunction with the impact of symptomatic low mood increasing self-report of dysfunction (Blackstone et al., 2012; Thames et al., 2011), and poor cognition decreasing self-report of dysfunction (Thames et al., 2011; Chiao et al., 2013).

The convergence of the IHDS total score had little clinical relevance to the MoCA total score and no clinical relevance to the WHODAS 2.0 total score, indicating these tools cannot be used interchangeably in the screening of HIV NCD.

The usefulness of these screening tools for patients with HIV NCD is further explored in Chapter 5, concerning the perspectives of the team members who administer and refer patients for further intervention. Phase two was included to address concerns regarding the potential effect of the MoCAs cultural inappropriateness, the impact of cognitive dysfunction on a self-report screening tool such as the WHODAS 2.0, and the overall efficacy of the tools for screening HIV NCD, in the South African population.

CHAPTER 5 RESULTS AND DISCUSSION PHASE TWO

5.1 Introduction

This chapter reports on and discusses the findings of the qualitative phase of the two-phased descriptive design of this study. The objective of phase two was to explore the perceptions of the team members, who assess HIV NCD, as to the efficiency, effectiveness and limitations of the IHDS, MoCA and WHODAS 2.0, in guiding referral for further in-depth occupational therapy intervention, at two clinics in Gauteng.

This phase aimed to provide a descriptive and detailed account of the participants' experiences of using these screening tools to add richness and depth to the quantitative findings of phase one.

5.2 Sample

There were five practitioner-participants, from a potential six, who agreed to participate in the study. All the practitioner-participants were qualified health professionals and were employed at one of the two HIV NCD clinics in Gauteng. Therefore, they were experienced at screening HIV patients for NCD using the screening tools being examined. The range of health professionals in the sample included a neuropsychiatrist, neuropsychologist, psychiatrist, and two medical officers.

Two group interviews were conducted, one at each clinic, consisting of two and three practitioner-participants, respectively. The practitioner-participants from Clinic 1 had considerable experience in working in the neuropsychiatric clinic specific to HIV NCD but did not have higher qualifications in the field. In contrast, two of the three practitioner-participants at Clinic 2 had additional qualifications in the field.

Since the population was small, and participants could easily be identified, no further demographic data on the practitioner-participants were collected.

5.3 The group interviews

The group interviews were similar in terms of venue, duration and group procedure; however, the climate in the two groups was different. The one group of practitioner-participants appeared time-pressured, ill-prepared for the group interview, and the climate was tangibly tense with one dominant participant. This group lasted 40 minutes and was not repeated or postponed, as time pressure was a constant challenge in the setting. The other group of practitioner-participants was prepared and engaged intently for the duration of the group (55 minutes). The climate in this group was calm and relaxed, with each member allowing others to freely express their experiences and perceptions. This difference in climate between the group interviews had some impact on the nature and manner in which data was collected and in providing thick and rich data for analysis.

5.4 Findings

As can be seen in Table 5.1, a single theme 'Screening to guide care in HIV NCD' emerged from the data. The theme arose from the perception that all practitioner-participants held around the value of the screening tools to guide the intervention of HIV NCD client. The importance of early, rapid diagnosis and focused intervention was perceived to be linked to the use of the screening tools.

> *"We want to act in the quickest time possible…to diagnose them as early as possible" [P 3].*

One member linked the importance of the screening tools directly to pick up on challenges which impacted on the patient's daily activities which may affect intervention strategies saying,

> *"…we have patients that have cognitive decline, so that has implications [for] them remembering their appointments, remembering to take their medications…if we don't screen for that, it becomes a problem in the long run." [P 2].*

Table 5.1 Practitioner-participant's experiences of using screening tools to guide care for HIV neurocognitive disorders

Theme	Categories	Sub-categories	Codes
Screening to guide care in HIV NCD	Purpose of screening?	To identify activity limitations and cognitive problems	Objectively versus subjectively
			To benchmark for progress and decline
			To determine impact of illness
			To direct intervention
			Assisting in early diagnosis for intervention
	How screening is done	Learning from experience	To merge patient history with test results
			To gain test competence
			To determine test preference
			To use standardised scores
		Helping patients succeed	By changing questions
			By Prompting
			By Translating
	How fit are the screening tools for purpose?	The South African patient cohort	Poor relevance to context and home language
			Not testing HIV Clade-C specific impact
			Subtests requiring formal education
		HIV NCD clinic context	With few hands and high workload
			With limited intervention options and resources
		Complexity of cases	Skews test results

Table 5.1 also reports the three categories that emerged from this theme, namely, 'the purpose of screening', 'how screening is done' and 'how fit are the tools for purpose'. Each of the identified categories, sub-categories and codes, will now be discussed.

5.4.1 Purpose of screening

Practitioner-participants described the screening tools as the 'backbone' with the primary purpose being to guide the care needed by the HIV NCD patients at the clinic, especially for guiding the activity and cognitive intervention, something they

put ‘emphasis on’ at both clinics. The group interviewees expressed consensus regarding the perception that these screening tools were viewed as the ‘backbone’ of the clinic. This perception was reflected in the sub-category: ‘Identifying activity limitation and cognitive problems’ which was expressed as the fundamental purpose of screening.

The practitioner-participants described that screening tools supported them to objectively understand what patients identified as difficulties,

> *“…to objectively look at the impairments that the patient [has and] then subjectively complain about” [P4].*

This objectivity, obtained from the screening tools, was perceived to provide the practitioner-participants with a benchmark from which to review the impact of interventions: improvement or potential decline,

> *“…to have that baseline that we can have [to guide] interventions and then monitor progress.” [P4].*

The practitioner-participants described that the screening tests were not only used to benchmark intervention but also to direct further intervention so

> *“…that we know what we are dealing with…” [P3],*

> *“Where we are going to rehabilitate and how we are going to rehabilitate, and what the recommendations [are] going to be as a result” [P5].*

Lastly, the perceived purpose of the screening was to support practitioners understanding of the impact of the illness on the patients,

> *“…to categorise…how serious is it from mild to severe…” [P3].*

5.4.1.1 Activity and cognitive screening

The practitioner-participants agreed that from their experience, the screening tools were central to guiding their care of activity limitations and cognitive difficulties of patients referred to the clinic in saying,

> *“…one of the mistakes that I think we make in general in…HIV medicine is [that] we just concentrate on the ARV’s and people being biologically suppressed…we forget about the functional [activity] side of things, the*

cognitive side of things. So, I think …in our clinic [it is] one of the things that we'll always try and emphasise on." [P2].

The five codes identified the practitioner-participants' view of the value of using the screening tools, which contributed to guiding the care of the HIV NCD patients seen at the clinic.

The first code identified was that the screening tools enabled them to **objectively versus subjectively** evaluate the patients and their problems. Practitioner-participant 4 stated that from his perspective the importance of the screening was

"…to objectively look at the impairments that the patient [has] then subjectively will complain about…subjective symptoms [can] be translated into objective scores in terms of deficits that are in domains of functioning.".

This view was supported by practitioner-participant 1 who stated,

"you [think you] know the patient before testing is done, you have a certain expectation of them doing this test, only to find that they're not coping that well, and I am quite surprised by what they can't do…".

The group interviewees perceptions of the purpose and value of the objective score obtained held similarities and differences. The similarities emphasised the importance of the objective score concerning the patients subjective reporting of their difficulties. The differences emphasised their inaccurate expectation of the patients' performance before completing the screening test. Another practitioner-participant highlighted the importance of the objective scoring to guide referral,

"…if we don't screen for that [cognitive decline] it becomes a problem in the long run." [P2]

The practitioner-participants frequently highlighted the value of the screening tests to provide **'a benchmark for progress and decline'**.

"…to have then that baseline that we can have interventions and then monitor progress according to, things that are standardised or well… easy to interpret." [P4].

"And then with HIV obviously [you have] to assess how far they have declined" [P1].

The frequency of this rescreening was also emphasised.

> *"So with my …patients I do it every three to six months, just to see if what we are doing in the groups and stuff is working [P5], "…when we have intervention then we can maybe compare." [P4].*

Another practitioner-participant reported a different frequency of rescreening.

> *"…we still try and do it once a year." [P2].*

While practitioner-participant 1 challenged the value of the screening tools for monitoring.

> *"…I mean as a monitoring tool like what are you trying to get out of this. "I don't see the point of monitoring… it takes too much of time" [P1].*

This difference in view was perceived to be related to the lack of human resources.

> *"…maybe the challenge we face is that we don't have neuropsychologists because ideally…we've identified a memory problem then they should go for more in-depth memory tests, but we can't afford to do that because we don't have the resources" [P1].*

Although the practitioner-participants expressed similar views on the value placed on the screening tools effectiveness to identify and benchmark cognitive function in patients with HIV NCD, the limitation of human resources created limitations in the frequency at which screening tests were repeated and used for monitoring of the patient's condition.

The practitioner-participants perceived that the screening tools assisted in determining the '**impact of illness'**. They perceived the screening tools assisted them to know,

> *"How serious it is from mild to severe, we want to pick that up.…to ensure we know what we are dealing with" [P3]. We have "[to] identify the severity of the virus on the brain or on functionality and then where it's affecting the brain …" [P5].*

> *"…But the other thing is to also categorize them, so we want to find categories. How serious is it from mild to severe, we want to pick that up." [P3]*

Activity limitations, as seen in test behaviour, was also viewed as valuable in terms of categorising the severity of illness.

> *"In the MoCA, if you can be quite vigilant when the patient is doing it, it can also give you other things, about their…like how they manage a task, which is quite nice in terms of how you would look at intervention for that person." [P4].*

This statement highlights that in using the screening tools to determine activity limitations and cognitive ability, both the scores and the patient's test behaviour added value to practitioner's understanding of a patient and the impact of his illness on his activity limitations.

Practitioner-participants were also of the view that the use of the screening tools assisted them to '**direct intervention'** as the screening tests identified problem areas and the impact of illness. Thus, the practitioner-participants perceived that the screening tools helped guide the health care for patients more effectively and efficiently.

> *"It [the screening] shows that something's wrong…and they can do further testing and refer to that appropriately." [P1].*

Some practitioner-participants experienced that the screening tools allowed them:

> *"…to see how dysfunctional they [patients] are as a result of the virus, and then what interventions we're doing to either [supress] that degenerative process or to kind of allow them to work or study…without compromising their ability at all." [P5].*

These views indicated that the practitioner-participants are using the screening tests to guide care by directing the immediate intervention and further referral, emphasising:

> *"what interventions we're doing" [P5] and "…early referral" [P3]*

for additional services including occupational therapy.

'Assists in early diagnosis for intervention' was the final sub-code in category one**.** Practitioner-participants emphatically stressed that based on evidence, the most important clinical outcome was that:

"we want to act [in] the quickest time possible…the earlier we diagnose it, the better outcome we're going to get" and repeated, "So, again, I just feel that the earlier I do it, the better, studies have shown that this is the case as well" [P3].

In summary, it was the perception and experience of the five practitioner-participants that the screening tools were essential in the HIV NCD clinics to identify and benchmark activity limitations and cognitive problems early in this cohort of patients. Practitioner-participants perceived and experienced the tools to be essential to guide and monitor intervention, as well as referral for more comprehensive assessments. Although the lack of human resources challenged how services were delivered, and patient intervention was monitored.

5.4.2 How screening is done

'**How screening is done',** the second category in this theme, was frequently raised in discussion, as a perceived consideration to the value and efficacy of the screening tools to guide care in HIV NCD. 'How screening is done' was perceived to be an important issue as the reliability, validity of the screening tools and accuracy of the scoring, had important implications for their usefulness in guiding care for HIV NCD patients.

"…although it's not valid [I use it] just for my own purposes…it's just what you're trying to get out of it and what you are trying to do with the result." [P1].

The three screening tools are standardised and thus need to be executed and scored in a standardised manner. Therefore, they should be used in a manner that is,

"absolutely standardised [and users] do not deviate from standardisation at all" [P5].

Two sub-categories emerged from the data, 'Learn from experience' and 'Helping patients succeed'. The practitioner-participants described both similar and diverse opinions as they identified among reflected on their experiences as to the effectiveness, efficiency, and limitations of how screening was done.

5.4.2.1 Learn from experience

Practitioner-participants reported that no formal process was required at the time of the study to learn the administration and scoring of the screening tools. The tools were learnt from a colleague or were self-taught from an instruction manual. Most practitioner-participants acknowledged that when they were first taught or learnt the screening tool, they performed them in a standardised manner but reported that:

> *"…this changes once practitioners become more experienced and are able to draw more from the screening tools than what is provided by the score, and when, I think you come to my level [of experience], it's definitely not standardised…" [P4].*

So, with experience, assessors:

> *"…learn the nuances of it" and "then as they become more familiar with the assessment as they become more familiar with the neurocognitive domains of function and HIV then [this] allows them to deviate." [P5].*

While this was a concern for all practitioner-participants, some placed more emphasis on this than others.

The practitioner-participants expressed the importance of **'merging patient history with test results'**.

> *"…premorbid problems the patient might have, are quite important…We need to know where the patient was before [P3]" "…if their remote memory is really shocking, I also kind of look at …[if] they are premorbid learning impaired." [P4].*

These statements indicated how the practitioner-participants learn from experience, that a patient may be scoring poorly on a test, but coexisting illnesses are commonly present and must also be accounted for in the clinic patient group. The tools' effectiveness to guide care in HIV NCD, therefore depended on comprehensive history taking and the experience of the practitioner to create a clinical picture. The clinical picture created then informed the practitioner of implications for test performance. These statements expressed the value the practitioner-participant placed on understanding the background of the patient and the needs of the patient in guiding care. This understanding of patients' history was viewed as vital in

understanding the results of the screening tools to most effectively guide care in HIV NCD.

Competence in using the screening tools emerged as a strong code. '**Test competence**' was perceived to play a role in the skill and experience of the tester and how test results were interpreted in the light of performance, as well as patient test behaviour and contextual demands. Practitioner-participant 4 reported:

> *"With MoCA, the way we roll it out, it's quite standardised…if you look how the patient does on the test, it can maybe cue you towards what deficit [the patient has]" "…If someone is aware of the neuropsychiatry around the HIV…If you observe the patient you can get a lot of information that can add value (to) MoCA".*

In the MoCA Visuospatial/Executive subtest,

> *"…in terms of the executive component…you can visually see the motor slowness, but it's not a timed test." [P4]*

Participant 3, based on their experience, felt:

> *"…clinical skills matter because you are able to understand what's going on…and investigate further".*

The practitioner-participants indicated they learn from experience, and this '**determines test preference**' for one or other of different screening tests. These preferences were expressed as both individual and contextual, based on their experiences and expectations of the screening tools.

> *"…I am very bias towards the IHDS…it's only becoming more evident that it's actually very good" [P3].*

This perception was supported by practitioner-participant 2, who perceived that the IHDS did not need to be modified as:

> *"…it really covers most of the things you expect in HIV neurocognitive disorders…it's really straight forward."*

However, this same practitioner-participant still indicated a preference for the MoCA in terms of its efficiency,

"I just do the MoCA" [P2].

Practitioner-participant 2 explained, in his experience, he preferred using the MoCA alone due to time limits in their work context. To complete both the IHDS and the MoCA, was not practical:

> *"…because doing both of them that's like twenty minutes...if we are busy on Friday's I don't have that luxury…" [P2] "I choose the MoCA because of what it will give me, at least there's more domains…" [P2].*

The limitation of time to conduct screening tools was supported by practitioner-participant 1:

> *"…tools like the IHDS that may be less time-consuming…I seriously struggle with time."*

Some practitioner-participants' preference was based on their knowledge of what was being specifically screened with each tool. Practitioner-participant 5 stated that:

> *"…knowing what the impact is of HIV on the brain and knowing that there is calcification in the basal ganglia, then you know that a test like [the MoCA] will work. But [when a patient] also has incredibly slow processing speed and working memory difficulties, I don't think the MoCA assesses [this] very well…".*

This perceived limitation was supported by practitioner-participant 4,

> *"…you can visually see the motor slowness, but it's [the MoCA] not a timed test…which then didn't add value in terms of specificity for HIV."*

Although practitioner-participants expressed a preference for specific screening tests, the reasoning behind their selection of tests differed.

The group interviewees' experience was that **standardised scores** needed to be used with discretion, concerning their interpreted expectation of the patients' needs as well as their limitation in resources:

> *"…it depends on the patients' circumstances…some patients just need to know medication…and that basic functioning [basic activities]. Other patients*

are working, so we need to give them skills…[so] they can cope with their work environment." [P1].

This perception acknowledged that the patients' expected needs influenced how the subtest scores were interpreted and thus, how they were used to guide care. Practitioner-participant 1 also acknowledged that resource limitations might constrain care in various clinics.

"…everyone's not going to be referred...because of all the limitations" [P1].

How the screening tools' scoring was used, and especially cut-offs were viewed differently by other practitioner-participants.

"…cut off's are quite standardised…when they're 24 [referring to MoCA] we know they need more testing, but I think on the individual subsections, the domains that they cover then sometimes when you pick up deficits. What I like to do is look at other bedside cognitive testing to validate [the result] or to give it more power..." [P4].

One participant perceived this to be particularly important as:

"…two patients might have a score of less than 24, and then you realise that they are deficit in different areas …so, at that, the MoCA points actually to exactly where the deficit is… [so you can] do further testing for the referral…" [P3].

Practitioner-participant 5, added that from her experience:

"…trying to condense your entire neurocognitive functioning into a score…it's never going to help you…in a lot of cases we'll see somebody with a score of 28 and there is still functional impairment [activity limitations]."

This statement highlighted the practitioner-participants' experiences that the scores on screening tools do not necessarily identify activity limitations and neither does knowledge of the patient:

"…some patients I don't think they'd be able to [perform well in the test] and they prove you wrong" [P1].

The above two statements, of practitioner-participants one and five, implied that the screening tool results and activity limitations presentation do not always correspond, which has some implication for a referral to a service like occupational therapy.

How the standardised scores of the screening tools were analysed and used to interpret the test performance were also discussed. Most practitioner-participants agreed that standardised scores are:

> *"…a very generalised clue" [P5],*

Moreover, the subtests indicate where the deficits are. The practitioner-participants perceived, from experience, that these scores should be supported by the observation of the patient's behaviour.

> *"… you should be able to observe what it means" [P5].*

The practitioner-participants stressed the importance of experience and clinical knowledge and that these assisted interpretations. However, it was acknowledged that these should not influence the way the test was administered due to the standardisation process:

> *"you're compromising the validity of the assessment" [P5].*

And when,

> *"you play around with the test to get more value from it…I think that like skews it" [P4].*

These statements acknowledged that changing the way a test is administrated can impact on the psychometrics affecting the validity and reliability of the test.

In summary, the category of 'learning from experience' highlighted practitioner-participants' experiences and perceptions of 'merging patient history with test results' to ensure they were identifying deficits related to current presentation; 'test competence' which comes with experience allows more effective use of the screening tests, but with standardised use of the tests one can still have effective results for further intervention; 'test preference' showed that preference of test was based on context, knowledge and available resources; and practitioner-participants used 'standardised scores' with discretion taking into account the result on specific subtests.

5.4.2.2 Helping patients succeed

All practitioner-participants reported changing items within the screening tests, to assist patients to succeed:

> *"You've got to just tweak it a little to make them understand…" [P1]*

and,

> *"…In terms of the attentional subset, I don't do the five forwards because actually, you need a minimum of seven. So, I up that to seven and score that to seven." [P4]. "…I like to prompt them…[P1]".*

Three codes emerged within this category: 'changing questions', 'prompting' and 'translating'. These codes will be explored below in terms of 'helping patients succeed' and the effect this has on the efficiency and effectiveness of the screening tools to guide care in HIV NCD.

'**Change questions'** was frequently reported by the practitioner-participants, especially when administering the MoCA. Changing of questions was often associated with the delayed recall of words in MoCA, which practitioner-participants felt they were modifying for context:

> *"…tweak it a little bit and some of the words like velvet and daisy, I don't think some of them know what it is." [P1].*

Practitioner-participant 4 also stated:

> *"we do modify…if I can see a patient has a low-ish education…I won't use things like daisy…I'd use tree." "Yes, the validity of this test then is in question because now I've changed components, but for me, I'm trying to get a kind of sense in my head clinically, 'does this patient have memory?' So, I'm not going to give them things where I know it's going to prejudice the score".*

The most changes reported were to the delayed recall and attentional subtests:

> *"…the memory first trial…I can sometimes give it to them five times." [P4], "…I do incorporate a colour always and a part of the body…words in the MoCA are a little more complicated than that." [P4],"… I think they [IHDS and MoCA memory subtests] do correlate." [P4] "…I think with the memory, if*

English is your second, third, fourth language, things like 'velvet' and 'daisy' are like a little bit bizarre." [P5].

These statements were supported by practitioner-participant 1:

"…if you don't know the word you are not going to remember it…"

Practitioner-participants motivated that changing of the questions on the memory subtest was to compensate for the language and ensure the patient was being tested on memory and not their ability to understand English, and therefore helping the patient to succeed.

'**Prompting**' was also reported to be used in the MoCA to help patients succeed. The prompting was particularly noted in the naming, language and attention subtests of the MoCA. Practitioner-participant 1 reported that in the naming subtest on the MoCA, the camel image was often problematic:

"I like prompt them to say there's a cigarette (referring to Camel brand cigarettes) or something like that you know".

It was one practitioner-participants view that:

"they struggle because of how the picture is drawn." [P1]

While practitioner-participant 4 stated that:

"one big criticism of the MoCA in our setting is the actual pictures…our population like may not identify [with picture content]."

Practitioner-participant 1 referred to the memory subtest in the MoCA:

"I have tried other things like simple things in the room like chair, window…all basic so its things they know…because (if) you don't know the word you're not going to remember it…it's a language issue".

The attentional subtest was also discussed in terms of prompting:

"…I say one/two/three backwards is three/two/one…" [P1].

In practitioner-participant 2's experience:

"they don't understand."

‘**Translating**’ of terms was another way reported in ‘helping the patients succeed’, either by the tester doing the translation or having a translator.

> *“I don’t speak any of the local languages…so translation is very important for me, [and] for my patients.” [P3].*

While practitioner-participants agreed with these challenges, the influence of translation on the psychometrics of the tests was stressed:

> *“…I will say the instruction, which is like a sentence, then whoever is translating will say a paragraph...you are getting a score, but it’s not a valid score…” [P5].*

‘How screening is done’ explored how the practitioner-participants administered the screening tools based on their learnt experience and wanting to help the patients succeed. Practitioner-participants reported that through learning from their own experience, they merged the comprehensive patient history with test results for an effective referral. Experience in administering the screening tools was reported to improve test competence and what practitioner-participants were able to extract from the screening tools. Practitioner-participants reported developing a preference for different screening tools through their experience of administering these. The practitioner-participants indicated that through learnt experience, standardised scores were used with discretion when guiding further care. The practitioner-participants modified the MoCA based on their experience and perceived needs of the population, as found in the category of ‘helping patients succeed’. Modifications to help the patients were achieved through changing questions, prompting and translating the MoCA. Practitioner-participants acknowledged that modifications influenced the validity of the screening tools but reported that the modifications were necessary for their patients understanding.

5.4.3 How fit are the tools for purpose?

This category emerged from discussions and was accompanied by high emotion, particularly related to the challenges faced by the practitioner-participants when using the screening tests. Practitioner-participant 3 said:

> *“…it’s a whole PhD by itself...”,*

to determine how effective the tests are for screening and guiding patients' intervention in the public sector HIV NCD clinic context in South Africa.

This category emerged from concerns from the practitioner-participants as to whether the screening tools they heavily rely on, are fit for purpose and context. Three sub-categories were identified under 'How fit are the tools for purpose?', these include 'The South African patient cohort', 'HIV NCD clinic context' and 'complex cases'. These sub-categories will be explored below to further understand the tools' effectiveness and limitations, from the perspective and experience of the practitioner-participants.

5.4.3.1 The South African patient cohort

The context of the HIV NCD clinics is financially and human resource-constrained, and this has been found to be a common challenge across public sector clinics in treating the high number of patients who have HIV (Robbins *et al.*, 2011; Chetty and Hanass-Hancock, 2016). It has been reported that there are few culturally appropriate and validated screening tools for HIV NCD for the South African population (Robbins et al., 2011). Practitioner-participant 4's view was that:

> *"…we take all these tools from overseas where it's not even tested or not researched here, and then we start applying them? ...that already, we fall short when we are using them."*

Three codes were identified within this sub-category. Two of the three codes, in the 'South African patient cohort' sub-category, were discussed with high frequency. These codes were 'poor relevance to context and home language' and 'subtests requiring formal education'. The code 'not testing HIV Clade-C specific impact' was identified by one practitioner-participant and was included due to the specific nature of the opinion concerning the South African cohort. This sub-category specifically explored the limitations experienced by the practitioner-participants in administering the screening tools in an HIV NCD clinic in South Africa. The limitations were predominantly focused on the use of MoCA.

'Poor relevance to context and home language' was a significant limitation to 'how fit the screening tools are for purpose', particularly the MoCA, as language is used throughout the tool. The perceived impact of language in the MoCA was not only regarding the subtests but also the administration instructions, the concern that:

"…they [the patients] don't understand" [P2],

often because:

"the language as well it's a bit tricky. You need to describe for them…because I noticed there was…two words that practically had almost the same meaning in the language and you had to now call someone that really speaks the language to explain specifically which one you are referring to." [P3].

Some of the subtests were highlighted as having limited relevance to context and home languages such as the naming, language, and memory subtests. The naming subtest required the patient to identify and name images which are more familiar in our context:

"…the latest version has pictures that maybe our population may not identify [with]" "They need to put snake, a chicken" [P4]

Practitioner-participant 3 agreed:

"the camel is quite...[difficult]."

The language subtest was also perceived as a contextual limitation and within the clinic patients' home languages spoken:

"…verbal fluency in South Africa in general…is a huge problem. So, "name the number of words in one minute that begin with the letter 'f',' if English is not your first language, it is so hard." [P5].

Practitioner-participant 2 agreed as he perceived:

"the fluency, because I think it has to do with… [P2]"

"…language [P1]".

The language difficulty was perceived to be the reason practitioner-participants modified aspects of the screening tools to help the patient succeed. These modifications extended into the memory subtest:

"…where you have to apply language and memory, they struggle a lot with that in MoCA." [P3] "…[if] you don't know the word you're not going to remember it" [P1].

‘Subtests requiring formal education’

Many practitioner-participants perceived that the visuospatial/executive, abstraction and attention (serial 7 subtraction) subtests of the MoCA require some level of formal education, which many patients do not have. Practitioner-participant 4 believed that:

> *“...the cube is learnt, like lots of people in first world education systems will learn how to draw the cube, but lots of people in our setting don’t. This doesn’t necessarily mean they have visuospatial issues.”*

It was also stated that:

> *“… the abstraction” [P4]*

test also required some formal education. However, it was also thought that not only formal education might be required for:

> *“the abstraction but that [it] could be more…I don’t know if it’s understanding or a cognitive problem…” [P1].*

The mathematics component of the attention subtest was also thought to be challenging for patients that lacked formal education:

> *“…numbers yes. So, remember most of our patients are not educated, so that’s going to be a little tricky one... subtract backwards, they struggle a little bit.” [P3].*

Practitioner-participant 2 reported how he modified the question:

> *“…what I sometimes do then is try and use some of these things in their day to day functioning like ‘so if you go to the shop’…and some of them are able to do that arithmetic.”.*

Thus, there was some agreement that in light of these limitations and the modifications made by the tester to overcome these challenges, may indicate that this screening tool was not completely fit for purpose in the HIV NCD clinic context and the patient cohort.

The fact that the screening tools were ‘**Not testing HIV Clade-C specific impact**’ was discussed regarding the differences in the nature of memory screening between

the IHDS and the MoCA. The practitioner-participants concluded that the IHDS memory testing was not the best fit for the Clade-C HIV impact on the brain, which practitioner-participant 5 explained,

> *"…our (the South African) Clade of HIV has a different neuro-psych profile to overseas…we would [need to] look more at a working memory because of the nature of the way the virus attacks the brain."*

This statement highlighted the importance of the screening tools being appropriate to the symptom profile seen in the strain of HIV commonly found in the South African population.

> *"The IHDS is just looking at holding onto the memory and then here (referring to MoCA) the attention subtest is actually doing something with the numbers that you are holding in your mind" [P4].*

Practitioner-participants 4 and 5 agreed that the MoCA was a better reflection of Clade-C HIV memory deficits when compared to the IHDS,

> *"the MoCA" [P5].*

These perceptions perhaps supported the idea this subtest should be modified due to not having enough digits to assess accurately:

> *"five is actually the lowest average, so you should be able to do seven minimum" [P5].*

The reported limitation that the attention subtest does not thoroughly screen working memory deficits suggested that additional modifications are needed to develop the tools to be fit for purpose. Modifications to the executive subtest were also suggested to improve the fit for purpose:

> *"…in terms of the trails…the problem with that is that yes you can visually see the motor slowness, but it's not a timed test…in terms of specificity for HIV…we [are] looking at processing…if you observe you would have to report it, but it doesn't add to the scores." [P4].*

This report suggested that the screening tools were not the best fit for the patient cohort and modifications to the tools (specifically the MoCA) would improve their fit for the South African patient cohort. This report also suggests that specific clinical

knowledge and experience was required to accurately interpret the result of the screening tools for this specific patient cohort.

5.4.3.2 HIV NCD clinic context

How fit the screening tools were for purpose, was strongly linked to their contextual appropriateness. As previously stated, the context had some influence on the tester's preference of which screening tool they use:

> *"I think the MoCA on its own …it's fine because you don't want to make it longer than it is, then we won't be able to do it because we have lots of clients to see." [P2].*

Thus, the patient load in the clinic limited the practitioners from completing a battery of screening tools which would be more beneficial to the patients, due to time limitations:

> *"I still want to use other tests…remember what we said earlier, combining [IHDS and CAT-rapid] also increases sensitivity." [P3].*

'Few hands and high workload' were experienced as a limitation in deciding which screening tools best fit the purpose of the clinic.

Participant 1 reported:

> *"I seriously struggle with time and in the busy clinic. The whole story is its difficult to do this...I mean it is not like I'm trying to take shortcuts…I just take the main, main, main domains"*

to direct care. Practitioner-participant 2 supported this experience, saying:

> *"I just do the MoCA…because doing both of them (IHDS and MoCA) that's like twenty minutes…I don't have that luxury."*

Therefore, practitioner-participants were not able to complete more than one screening tool due to the limitation of 'few hands high workload'. The 'few hands and high workload' also impacted on the use of screening tools for the ongoing monitoring of intervention in the clinic context:

"…(patients) who've been known to us for a while I don't see the point in monitoring with them. If I want [more information] I do the IHDS because it's quicker for me. This (MoCA) takes like too much of time." [P1].

The WHODAS 2.0 is time-consuming and had to be administered differently from the standardised manner because of time limitation. It takes more time as:

"…they [the patients] are still asked about the rating scale querying 'is this is impaired', 'this is not impaired' [so assessors] don't give the actual questionnaire to the patient…because again you'd have to sit down with them and go through each thing with them explaining, and I mean that would take like an hour maybe an hour and 30 minutes."[P2].

So, while the WHODAS 2.0 may be fit for purpose in guiding care for activity limitations in HIV NCD, it failed in terms of the resource limitations of the clinic context.

'Limited intervention options and resources' have been experienced as a severe challenge in a variety of public health contexts, but especially in the HIV NCD clinic, limiting intervention options.

"In an ideal world obviously, you would want to refer them immediately, but we don't have that luxury." [P5].

The interventions that should facilitate essential health for these patients were limited by resource constraints.

"The challenge that we face is that we don't have neuropsychologists because ideally after the MoCA and we've identified a memory problem then they should go for more in-depth memory tests, but we can't afford to do that because we don't have the resources."[P2]. "Even in the private sector, we are struggling with the low number of clinicians to people…in terms of cognitive rehabilitation." [P5].

The practitioner-participants also indicated that access to resources was also limited by:

"where are you staying, how convenient is [it] to come [to therapy], is there therapy closer to them [patients]…" [P3].

Practitioner-participants reported two different approaches had been adopted to provide more patients care; these include ‘stratification’, and ‘home programmes’.

‘Stratification’ aimed to use all available resources effectively, following screening:

> *“we have to be also a little bit clever about how we stratify. Who [which patients] gets access to the actual physical person [health professional] versus other tiers…If it’s a very mild cognitive problem, you may want to roll out other things….At the moment I think people access services when they are quite severe, and then we refer only when we actually feel that they might benefit. We also kind of look at the person, are they working, other factors…” [P4]. “I’d refer for intervention only when I feel that the patient will benefit from the intervention…if they’re working or want to work.” [P1].*

Participant 2 agreed that the ‘stratification’ for referral was an effective approach:

> *“…I think it all depends…on the patient’s circumstances…some patients just need to know their medication…other patients are working, so we need to give them skills.”*

The ‘stratified’ approaches used, described the need for referral as based on the daily activities needs and expectations of the patients rather than the scores of the screening tools. This stratified approach linked to the ‘use of standardised scores with discretion’.

The home programme approach, although a good strategy, had only been used in a limited way due to staff shortages.

> *“…If a patient can only come once a month or if they can’t make the groups or whatever, then I make them a workbook and then they just take their workbook home.” [P5].*

This strategy was also used:

> *“if it’s a very mild cognitive deficit. You may want to roll out other things like more workbooks that they can remember and exercises.” [P4].*

It was acknowledged that home programmes required skilled practitioners to compile these, in relation to the deficits identified on the screening tools, and results

of any other assessments carried out, to identify the expected outcomes and contents of the cognitive programme.

5.4.3.3 Complexity of cases

Participant 1 explained the complexity of patients attending the tertiary level clinics:

> *"…that condition the patient comes in with [neuropsychiatric conditions] …compounds their functional ability just as much [as HIV NCD] …we need to obviously take it into consideration from that point of view regardless of the HIV.".*

This statement described the complexity of the patients presenting at the two tertiary-level HIV NCD clinics. The statement expressed the impact of the complexity of patients' health concerns and needs on the effectiveness and efficiency of the tools for purpose. These complex cases were perceived to, 'Skew test results', impacting on the effectiveness of the tools.

'Skews test results' was noted as a challenge in the complex cases assessed by all practitioner-participants, with all three screening tools. This code was described in terms of pre-morbid conditions (developmental and psychiatric), phase of co-existing psychiatric illness and the complexities related to testing everyday activity performance with cognitive decline resulting from HIV NCD. The complexity was reported by practitioner-participant 1 in terms of the phase of illness of the client:

> *"…we need to know when it was taken (referring to MoCA score) and at what phase of illness…what the MSE (Mental State Examination) is, there may be their psychiatric functioning at that time…some patients have shocking scores when they are in the ward, and after discharge, it's a different story."*

This perception was supported by practitioner-participant 5, who stated:

> *"…as long as they're not delirious or psychotic or anything that would preclude them from benefitting from the rehabilitation…".*

Skewing of results was not only expressed concerning the cognitive screening but also the WHODAS 2.0 and the influence complex cases have on the patients' ability to effectively complete a self- scaled tool:

"…as long as they [are] still coping with their activities of daily living, it's very difficult for the patients to come in and report that…so I would say self-report, it [is] no not the best" [P3].

This statement described the difficulty patients might have with judgement of their difficulties which influences the effectiveness of the tool for purpose. This statement was expanded on in terms of the cognitive complexities of HIV NCD:

"…particularly with dementia, I wouldn't trust a self-report." [P5].

Practitioner-participant 1 also explained their perceived limitations with this in relation to HIV NCD, saying:

"…physical things they may be able to answer correctly they can get dressed…but some of these things like can you get all the work done you need to…they do have a very false sense of what they can do."

Practitioner-participant 4 referred to comorbid psychiatric illness and the impact on self-scaled scoring saying:

"would you trust this (referring to WHODAS 2.0 self-report) like for a depressed person?".

A further concern about the influence of co-existing psychiatric illnesses was reported:

"…a delusional patient might give you false scores here (referring to the WHODAS 2.0 self-report)."[P4]

Therefore, it was expressed that the complexity of the condition itself, pre-morbid and co-existing conditions skew the results of the screening tools, particularly in self-report, limiting the effectiveness of the tools for purpose. It was further expressed that this limitation, in turn, created an increased need for referrals, to professionals within the team who can objectively test these areas more specifically:

"OT will adapt their assessment to what the patient does on a day to day basis which then gives us a very good indication of where they are, what they are able to do…" [P2]

as opposed to a self-report such as the WHODAS 2.0.

5.5 Summary

The findings of phase two were presented in the form of a table. The table was developed using thematic analysis of the two group interviews where the perceptions of practitioner-participants as to the efficiency, effectiveness and limitations of the IHDS, MoCA and WHODAS 2.0 in guiding referral for further in-depth occupational therapy intervention for people living with HIV NCD attending clinics in Gauteng, were discussed.

In the category 'Purpose of screening', the practitioner-participants described the tools to be efficient in guiding care in terms of the impact of illness, supporting in directing intervention and assisting in early diagnosis for intervention, in providing a benchmark for decline and supporting objective versus subjective evaluation of clients. Using the screening tools to benchmark decline was limited by the time available to monitor for change.

The category of 'How screening is done' explored 'learning from experience' and 'helping patients succeed'. Merging the patents' history and test competence, assisted in gaining a better understanding of the patients' performance on the screening tool. The preference of tests was based on knowledge of HIV NCD symptoms as well as time limitations. Standardised scores were reported to be a generalised result used in conjunction with clinical reasoning and observation during the administration of the tool. The practitioner-participants did not experience the cognitive tests to translate into activity limitations. In the sub-category of 'Helping patients succeed' the practitioner-participants reported to change questions, prompt patients and translate the tools, specifically the MoCA. The questions were adapted to the context in terms of language, culture and level of formal education, and these modifications affected the scores' validity.

In the category of 'How good the tools are for purpose', tools were described to have particular limitations in the South African patient cohort. The poor 'relevance to context and home language' was perceived to be specifically related to the MoCA naming, language, and memory subtests. These subtests were modified in 'helping the patients succeed.' The 'requirement for formal education' on the executive/visuospatial, abstraction and attention subtests was perceived to be inappropriate for the clinic context and cohort of patients. The memory subtest on

the MoCA, although reported to be limited by the language, was reported to be more appropriate to Clade-C HIV than the IHDS memory subtest. The 'HIV NCD clinic context' was reported to be limited by human resources which impacted on how the tools were administered and availability of interventions following screening. The complexity of cases presenting in the tertiary clinic was reported to 'skew test results' making the clinical picture unclear. The complexities were experienced to be co-existing psychiatric illness and the impact of cognitive disturbance on self-report.

The findings of phase two will be discussed in relation to the results of phase one in the following discussion. This was done to understand how the described experiences of the assessing team members on the effectiveness, efficiency and limitations of the tools support or contradict those of the quantitative results in phase one.

5.6 Discussion

5.6.1 Introduction

As described above phase two of the study explored the perceptions of assessing team members as to the efficiency, effectiveness and limitations of the IHDS, MoCA and WHODAS 2.0 in guiding referral for further in-depth occupational therapy intervention for people living with HIV NCD, attending two clinics in Gauteng.

The characteristics of the sample will be discussed first. The sample discussion will be followed by a discussion of the findings presented above in chapter 5, as per objective two of the study (see 1.6). The findings of phase two will be compared to phase one's findings and relevant research.

5.6.2 The sample

The total population sampling for this study was small (N=6). Five out of a potential six practitioners participated in the study. Due to the small sample size, only the professional designation of practitioner-participants was collected to support anonymity. The practitioner-participant group consisted of a range of health professionals including a neuropsychiatrist, neuropsychologist, psychiatrist and two medical officers, all of whom had experience in HIV NCD assessment using the screening tools under review to guide intervention.

The limited number of health professionals experienced in HIV NCD was in line with the reported challenges in treating the chronicity of HIV in South Africa (Robbins et al., 2011). Therefore, within this limitation in the population, the sample had the necessary training and experience with the HIV NCD population to provide rich data for phase two.

The sample used a case analysis of the practitioners who performed the screening tools in the two HIV NCD clinics, in Gauteng. As the sample size was small, it was only possible to run two group interviews. Two group interviews were conducted as opposed to one larger group, as this worked best for the scheduling of the participants within their resource limitations, which was an important ethical consideration. As the research question for this phase was narrow, the small specific sample was able to provide adequate information power (Malterud et al., 2016). The quality of the dialogue in the groups was good, and the researcher was able to recognise and respond to the differences in group climate to maintain rapport among the interviewees in both group interviews (Malterud et al., 2016). The focused dialogue of the semi-structured group interviews further supported information power, as it allowed for clear communication and limited ambiguity (Malterud et al., 2016). The practitioner-participants' knowledge of established theory on HIV NCD and the requirements for effective assessment, expressed and applied to the questions, supported the information power of the sample (Malterud et al., 2016). For further detail on the information power of the sample, see 3.3.3.

5.6.3 Phase two objective

The perceptions of practitioner-participants as to the efficiency, effectiveness and limitations of the IHDS, MoCA and WHODAS 2.0 in guiding referral for further in-depth occupational therapy intervention will be discussed below. The discussion will be structured by reporting the perceptions which were and were not consistent with phase one's findings and literature.

5.6.3.1 Perceptions consistent with Phase one results and literature

The perceptions of the practitioner-participants that were consistent with phase one of the study and with literature will be presented in four subsections. These will cover the perceptions of the usefulness of the screening tools; the efficiency,

effectiveness, and limitations of the three screening tools, and the limitations of the clinic context.

5.6.3.1.1 Usefulness and limitations of the screening tools

The practitioner-participants described the screening tools as essential, 'the backbone' in guiding care in HIV NCD. The perceptions and experiences of the practitioner-participants were that the tools assisted in directing care, provided an objective measure, assisted in early diagnosis, benchmarking and monitoring change. The practitioner-participants' experience in the usefulness of comprehensive clinical history, together with the standardised scores, will also be discussed.

The perception that the screening tools are useful in directing intervention was consistent with the findings of phase one of this study. All patient-participants who scored 11 and below on the IHDS, which was the referral cut-off, were found to have MoCA and WHODAS 2.0 scores, which indicated the need for further assessment and intervention. This finding was also consistent with the study by Cysique et al. (2010), who reported the importance of effective screening to guide further intervention in HIV NCD. Cysique et al. (2010) further reported that practitioners might overlook those in need of further assessment and intervention without the use of effective screening tools. The Cysique et al. (2010) report was consistent with the practitioner-participants' perceptions that the screening tools provided an objective measure of cognitive and activity limitation, and that the screening tools assisted in early diagnosis. This perception was also consistent with reports that the CNS is one of the first areas targeted by HIV, and therefore should be assessed within six months of diagnosis with HIV (Antinori et al., 2013; Valcour et al., 2011).

The practitioner-participants perceived that the screening tools assisted in benchmarking their patients for both monitoring and decline. This perception was consistent with the recommendations of The Mind Exchange Working Group (Antinori et al., 2013). The working group described that screening should take place before the initiation of CART to establish a baseline, and should be used to monitor change (Antinori et al., 2013). The working group further recommended that screening tools be used to monitor high-risk patients 6-12 monthly and lower-risk patients 12-24 monthly (Antinori et al., 2013). This recommendation supported the described monitoring carried out by some of the practitioner-participants, who

repeated the screens 3-6 monthly with patients attending active rehabilitation, while those who were lower-risk and required monitoring were reportedly screened annually. The usefulness of regular monitoring was, however, perceived to be limited by some practitioner-participants, due to the limitation of qualified practitioners to carry out further assessment and intervention. This perception was consistent with other studies reporting challenges in managing chronicity of HIV and screening for HIV NCD in resource-limited settings (Chetty and Hanass-Hancock, 2016; Robbins et al., 2011).

The practitioner-participants described the importance of combining the results of the screening tools with a comprehensive patient history. This report was consistent with literature which suggested that certain conditions may contribute to neurocognitive impairment as well as increase the risk factors of patients, influencing how care should be provided (Joska et al., 2016; Antinori et al., 2013).

The practitioner-participants described the standardised scores to be useful in identifying cognitive and activity limitation. However, they also experienced the standardised scores to be less effective than the results of subtests. The practitioner-participants' experience that the subtests gave more information on specific HIV NCD deficits was supported by phase one's findings, specific to activity limitation. A stronger correlation to the IHDS was found to the 'Life Activities' domain when compared to the correlation of the IHDS and WHODAS 2.0 total scores. Stronger correlations were also found between the MoCA subtests and WHODAS 2.0 domains when compared to their total scores. One exception to this was the correlation between the IHDS and the MoCA total scores, which was stronger than the correlation of their subtests. This exception may be due to the MoCA subtest limitations for the South African population, as described below.

The practitioner-participants' described experience and perception of the screening tools usefulness were, therefore, consistent with the literature and phase one of this study.

The practitioner-participants did, however, also describe perceived limitations of the usefulness of the screening tools. These limitations were specific to the tools and their specific service delivery context. The perceived limitations will be discussed

below in regarding the effectiveness, efficiency and limitations of each screening tool and the clinic context.

5.6.3.1.2 Perceptions of the efficiency, effectiveness and limitations of the International HIV Dementia Scale

The practitioner-participants described the IHDS as effective and efficient for the patients in their context. These perceptions were consistent with the purpose of the tools' development as being rapid and cross-cultural (Sacktor et al., 2005). This finding was consistent with literature which suggested the IHDS is a valid, brief screening tool for HIV NCD in South Africa (Joska, Westgarth-Taylor, et al., 2011; Goodkin et al., 2014). The practitioner-participants experienced two limitations in the use of the IHDS. The first limitation experienced was the need to have a second cognitive screen to support the findings of the IHDS. This experienced limitation was consistent with the findings of Joska et al. (2016), who reported that the combination of the CAT-rapid and the IHDS improved the sensitivity and the specificity of identifying HIV NCD. This experienced limitation was also consistent with phase one's findings, which identified a poor correlation between the IHDS and MoCA executive function subtests. Phase one's finding agreed with the findings of Joska et al. (2016) that further executive function screening was required together with the IHDS.

The second limitation perceived by one practitioner-participant was the memory subtest of the IHDS. The practitioner-participant reported that the Clade-C strain of HIV typically found in South Africa damages working memory, which was consistent with literature (Rao et al., 2013). The memory subtest of the IHDS was designed to test new learning (Sacktor et al., 2005), which is also known to be affected in HIV NCD (Woods et al., 2009). Therefore, the perception that the IHDS does not screen for working memory was consistent with the literature. However, the extent to which this limits the identification of HIV NCD is unknown.

Therefore, the practitioner-participants' perceptions that the IHDS is efficient, and effective, with minimal limitation in screening HIV NCD in the clinic patient cohort, was consistent with phase one's findings and the literature.

5.6.3.1.3 Perceptions of the efficiency, effectiveness and limitations of the Montreal Cognitive Assessment

The MoCA was perceived to be effective in screening as it provides a greater number of subtests to guide care. The practitioner-participants, however, perceived the limitations of the MoCA in the clinic context to be substantial. The perceived limitations included inappropriateness of subtests to culture, language and the requirement for formal education.

The MoCA was perceived to be effective in guiding further referral as it provided a more specific direction for referral, as there are more domains to consider. This perception was consistent with literature that the MoCA was beneficial in identifying the range of deficits present in HIV NCD (Valcour et al., 2011). Although, a later study found that the MoCA did not improve the sensitivity and specificity of the IHDS, as expected (Joska et al., 2016). The finding of Joska et al. (2016) may be due to the limitations of the MoCA perceived by the practitioner-participants, with their specific patient cohort. The practitioner-participants perceived the naming subtest to be inappropriate to the cultural context of their patients. This perception was also found to be consistent with the findings of Robbins et al. (2013), who found the rhinoceros image was often confused with a hippopotamus, in their cohort. This limitation was also consistent with the experience of the researcher in phase one of this study when using the MoCA to collect data. The naming subtest was found to have a lower quartile range of 2 and an upper quartile range of 2 out of a total score of 3. Therefore, the perception of inappropriate images for cultural context was consistent with phase one's findings and the literature.

The practitioner-participants perceived that the attention subtest (particularly serial sevens), the Necker cube, and the abstraction subtest, were inappropriate for their patients due to the requirement for formal education. This perception was also reported in the literature as a concern regarding the MoCA for the South African population. Robbins et al. (2013), found education to be a significant predictor of performance on the MoCA, in their South African cohort. Floor effects were found on the cube copy, abstraction and attention subtests across their HIV+ and HIV- cohort (Robbins et al., 2013). Robbins et al. (2013) reported that this was due to the low level of formal education in their cohort, consistent with the perceptions of the practitioner-participants and demographics of phase one's sample.

Language was perceived to be a limitation in the MoCA, both in the overall administration and specific subtests, for the South African HIV NCD population. The overall administration was described by the practitioner-participants to 'sometimes require translation'. Specific subtests that were perceived to be impacted by language were the words in the memory subtest (list learning) and the language subtest's verbal fluency. These perceptions were consistent with the Robbins et al. (2013) study, who adapted the MoCA by administering it in their cohorts' primary language and adapting the verbal fluency task to a semantic fluency task.

The practitioner-participants also described adapting the MoCA to accommodate for their perceived limitations of the tool. They changed questions, prompted patients, and translated the tool or the instructions. The practitioner-participants were aware of the psychometric implications for the results. Despite the psychometric implications, they perceived this to be better than ineffectively screening patients. They perceived these limitations were due to the use of screening tools which have not been developed or standardised for their population. This view was consistent with the literature, which reported a lack of validated screening tools for HIV NCD in the South African population (Robbins et al., 2011). This limitation impacts further assessment and intervention for the HIV NCD patient population in South Africa (Robbins et al., 2011).

Therefore, the perceptions of the practitioner-participants, that the MoCA was an effective tool was contradictory to the significant limitations for their patients due to cultural appropriateness, language and requirement of formal education. This finding was consistent with the literature and phase one's results. These perceived limitations resulted in the modification of both the screening tool and its administration, which affected the tool's psychometric properties. Therefore, the MoCA was considered as not entirely appropriate for use in this context and cohort. An adapted, validated version should be explored further to the work of Robbins et al. (2013), as this may be more appropriate in guiding care.

5.6.3.1.4 Perceptions of the efficiency, effectiveness and limitations of the World Health Organization Disability Assessment Schedule 2.0

The practitioner-participants reported the WHODAS 2.0 as having limited effectiveness concerning the complexity of their patients' illness and poor efficiency, which limited use in the clinic context. The effectiveness of the WHODAS 2.0, as a

self-scaled score, was perceived to be inadequate for HIV NCD, due to the cognitive decline. This perception was supported by literature that the cognitive decline associated with HIV NCD results in under-reporting of everyday dysfunction (activity limitations) (Thames et al., 2011; Chiao et al., 2013). This perception was also consistent with phase one of this study, which found the percentage of reported difficulty was lower in phase one's cohort when compared to an HIV+ South African cohort without HIV NCD (Myezwa et al., 2018).

The WHODAS 2.0 effectiveness was also perceived to be poor by the practitioner-participants, in the presence of symptoms of depression. Again, this was consistent with the literature, which suggested that patients with depression over-report activity limitation (Blackstone et al., 2012; Thames et al., 2011).

The practitioner-participants described having limited experience in carrying out the WHODAS 2.0 interview. They did not use the self-scaled tool; they only described activity limitation within the domains of the WHODAS 2.0, due to the inefficiency of the tool which included the time needed to explain the content and rating scale. This described inefficiency was consistent with the experience of the researcher, in phase one of the study. The need to adapt the tool due to inefficiency was consistent with the needs described in other clinic contexts, that provided services for HIV NCD in South Africa, due to the resource limitations (Robbins et al., 2011; Chetty and Hanass-Hancock, 2016). These described contextual limitations will be discussed further in section 5.6.3.1.5.

Therefore, the practitioner-participants perceived limitations concerning the WHODAS 2.0 effectiveness and efficiency in the clinic context, and clinic cohort were consistent with literature and phase one's findings.

5.6.3.1.5 Limitations of the clinic context

The clinic context was experienced by the practitioner-participants to create limitations in the screening tools' effectiveness. These limitations were specifically perceived regarding the high number of patients, the low number of professionals, limited referral opportunities and complexity of cases seen in the clinics.

The practitioner-participants described having a low number of experienced professionals to assess and provide intervention in their cohort, which influenced how the practitioners were able to use the screening tools, which tools they chose

to use and how the tools were administered. The practitioner-participants stressed the importance of the competence of testers in getting the most out of the tools.

The limitations experienced by the practitioner-participants and results described in phase one were consistent with the literature, which described limitations of screening for HIV NCD in South Africa. Robbins et al. (2011) reported that South Africa had shortages of qualified professionals to screen, assess and provide intervention for HIV NCD. This shortage prevents an adequate understanding of prevalence, incidence and effective intervention for people suffering from HIV NCD (Robbins et al., 2011). The time shortage also influenced which tools were used and how these tools were used. This knock-on effect compounded the problem described in the literature, as without consistency in the use of screening tools, understanding of prevalence and incidence ratings, a comparison of interventions cannot be achieved. The resource limitations were exacerbated by the lack of appropriate and valid screens which are effective and efficient for this South African cohort (Robbins et al., 2011). Effective and efficient screening tools could support implementations of more effective screening strategies that would not require expert training to be administered (Robbins et al., 2011). Therefore, the experience described by the practitioner-participants was consistent with the literature and the problem statement (see 1.2) and purpose (see 1.3) of this study.

The practitioner-participants described the limited opportunity for referral following screening. The limited referral opportunity resulted in using standardised scores with discretion, based on clinical reasoning, to identify those patients most in need of intervention. The experience of the lack of referral opportunities was consistent with reports in the literature regarding a limitation in the number of experienced practitioners who can complete further assessment, and intervention, in South Africa (Robbins et al., 2011; Chetty and Hanass-Hancock, 2016). It was also perceived that the referral, for further assessment and intervention, was influenced by the patients' context and resources to access services regularly. Chetty and Hanass-Hancock (2016) reported similar findings and suggested that patients experienced serious barriers in accessing services including transportation, financial limitations, physical access and inadequate treating team interaction.

These challenges raised questions of an ethical nature, in meeting the needs of the patients suffering from the chronic outcomes of HIV. Should valid and appropriate screening tools be developed, how would this affect clinical implications for further assessment and intervention? Therefore, the limitation of low numbers of practitioners and patients' limitations in accessing services has both clinical and ethical implications for the cohort.

The practitioner-participants had implemented strategies in an attempt to mitigate these implications, such as stratification and home programmes. These strategies, however, still left high numbers of patients without intervention from professions, such as occupational therapy, which limited access to interventions that could improve quality of life. Similar strategies have been suggested by Chetty and Hanass-Hancock (2016). These included task-shifting to trained lay-personnel, delivering community-based rehabilitation, and outreach services (Chetty and Hanass-Hancock, 2016).

The complexity of the health conditions that present in the clinic patients limited the use of strategies such as task-shifting, as the level of medical complexity required tertiary level screening and assessment. However, strategies such as community-based rehabilitation and outreach may be effective, following screening and assessment in tertiary clinic settings. This suggestion was supported by the results of phase one, which indicated that, based on the MoCA scores of patient-participants, 69% would benefit from monitoring and maintenance services for cognitive function. A large percentage of the cohort could be appropriate for community-based rehabilitation programmes for maintenance of cognition, compensation for activity limitation and the promotion of quality of life.

Therefore, the limitations experienced and perceived by the practitioner-participants in the clinic context were consistent with the literature. Phase one's findings supported the suggestion for implementation of strategies for intervention in those patients who may not require in-depth intervention at a tertiary clinic setting.

5.6.3.2 Perceptions inconsistent with phase one results and literature

The practitioner-participants' perceptions and experiences were found to mostly correspond with literature and the findings of phase one, except for two perceptions. These inconsistent perceptions were that the MoCA and IHDS memory subtests

screened the same component of memory and that the screening tools identified the severity of illness.

When discussing the memory subtests, several practitioner-participants perceived that the IHDS and MoCA memory subtests screened the same aspect of memory, but with the MoCA subtest being just a little bit more complex. This perception was inconsistent with phase one's findings. The IHDS memory subtest was found to have a weak to low and very low correlation with all MoCA subtests, and the WHODAS 2.0, including the memory subtest of the MoCA. This finding may support the perception of one practitioner-participant, who stated that the South African clade of HIV has a different profile of memory to that which is screened by the IHDS.

Another inconsistency was found in the perception that the IHDS scores assisted in categorising the patients' severity of HIV NCD. This perception was inconsistent with literature on the IHDS, which reported that the IHDS score cannot categorise HIV NCD in terms of ANI, MND and HAD, according to the 'Frascati criteria', as it does not have a measure of everyday function [activity limitation] (Goodkin et al., 2014). This perception was also inconsistent with findings that the IHDS specificity and sensitivity, in the South African population, requires the addition of an executive screening tool to improve the result (Joska et al., 2016). Moreover, this was inconsistent with the perception of another practitioner-participant who stated in their experience; activity limitations were sometimes present with adequate scores in cognitive screens.

Therefore, the practitioner-participants' perceptions were inconsistent with literature and phase one of the study on two issues. The practitioner-participants' inconsistent perceptions were not corroborated by other practitioner-participants and were perceptions of individuals as opposed to the whole group.

5.6.4 Limitations of Phase Two

Phase two was limited in the collection of demographics, although the experience and range of health professionals enabled rich data.

The collection of demographics was limited by the small sample size, and a small number of specialised clinics in the region, which resulted in the opportunity for practitioner-participants to be identified if demographic data were collected. The

limited demographics may have implications for the description of the sample, and therefore replication of the study. However, this limitation did not constrain the analysis of the perceptions and experiences of the practitioner-participants. Due to the consistencies found between the data collected, literature and phase one's results, this limitation may not have impacted the interpretation significantly.

5.6.5 Conclusion of Phase Two

Phase two consisted of two formal semi-structured group interviews, run with five healthcare professionals experienced in screening, assessing and treating of patients with HIV NCD, in the tertiary clinic context. Much of the data collected was consistent with the literature and phase one's findings, which highlighted the influence of context on the effectiveness of the screening tools.

The tools have been found to be effective in identifying cognitive dysfunction and activity limitations. However, they were found to lack specificity due to cultural inappropriateness, language barriers, requirements for formal education, the influence of depressive symptoms, and inherent cognitive decline skewing the result of the screening tools. These limitations increase the requirement for skilled and experienced practitioners, who can interpret test-related behavioural observations to complete screening tools. The modifications made to the screening tools to assist patient performance impacted the validity of the tools and resulted in subjective discrepancy in the interpretation of the performance on the tools used to guide intervention. This finding reinforced the requirement for appropriate tools to be investigated either through adaptation of existing tools or development of new screening tools, appropriate to the context.

The lack of human resources for further intervention resulted in limited numbers of patients receiving health promotion and preventative intervention which could improve quality of life and reduce the burden of disease (The 4th International Conference on Health Promotion, 1997). The perceptions and experiences of the practitioner-participants, consistent with service challenges in literature, raise questions around the ethical considerations for HIV NCD intervention in the South African population.

CHAPTER 6 CONCLUSIONS AND RECOMMENDATIONS

6.1 Main findings of the research

This research aimed to answer two inter-related questions. The main findings of these questions will be presented sequentially.

The first research question pertained to phase one of the study. This phase aimed to identify if screening with the MoCA and WHODAS 2.0 confirmed areas of cognitive dysfunction and activity limitation in patients with HIV, identified with NCD, by a score of 11 or less on the IHDS.

The results indicated that all patient-participants who scored 11, or below, on the IHDS had cognitive dysfunction and activity limitations, as measured by the MoCA and WHODAS 2.0, respectively. Of the patient-participants who scored 11 or below on the IHDS, 30.91% required further assessment and intervention based on the scores of the MoCA, while 49.09% required further assessment and intervention for activity limitations, based on the WHODAS 2.0 scores.

The IHDS and MoCA total scores were found to have a moderate correlation. However, according to Cohen's r, the correlation had a small effect size and was not clinically relevant. The low clinical relevance of the correlations found between the total scores and subtest scores must also be considered with the limitations of the MoCA in the South African population, as described in the literature (Robbins et al., 2013).

The IHDS and WHODAS 2.0 total scores were found to have very low correlation, indicating that activity limitations cannot be deduced from the score of the IHDS. Therefore, the scores of the IHDS are not sufficient to identify activity limitation and require additional screening of everyday function.

The MoCA was found to have a low to moderate correlation with the WHODAS 2.0. However, this correlation should be viewed with circumspection, considering that the effect size was small, according to Cohen's r, with little clinical relevance. Although there was a small effect size of the correlation of the total scores, there

were valuable correlations found between subtests and domains, particularly 'Life activities' on the WHODAS 2.0. The moderate correlation of the 'Life activities' domain to the MoCA total score, was consistent with the pattern of HIV NCD described in the 'Frascati criteria' (Antinori et al., 2007). The moderate correlation should be used with caution, however, given the reported cultural and language concerns and the requirement of formal education, of the MoCA, reducing the specificity of results relative to HIV NCD patients in the study cohort. This moderate correlation should also be used with caution in HIV NCD, given the findings of reduced self-report of activities limitation with cognitive decline (Thames et al., 2011). This inaccuracy could result in an unnecessary referral or no referral at all.

The small clinical effect size, according to Cohen's r, of the MoCA and the WHODAS 2.0 total scores to the IHDS total score suggested that a single screening tool was not sufficient to identify cognitive dysfunction and activity limitation in the cohort. This finding was consistent with the literature on the screening of HIV NCD (Joska et al., 2016) and categorisation of HIV NCD (Antinori et al., 2007).

The median result of the patient-participants fell within the 80th percentile of the population norms, which suggested that the WHODAS 2.0 sufficiently identified those patient-participants with activity limitation. However, the WHODAS 2.0 results in the patient-participants with HIV NCD, in this study, were found to be lower than those of a South African HIV+ cohort without HIV NCD. This finding may be due to the impact of cognitive decline, causing under-reporting of activity limitation. The under-reporting of cognitive decline limits the accuracy of the WHODAS 2.0 as a self-report screen, in accurately identifying activity limitation and thus the need for further occupational therapy assessment and intervention. However, despite this concern, this study suggests that the WHODAS 2.0 is sufficiently accurate to identify activity limitation but should be used with the knowledge of its limitation in cognitive decline.

The second research question asked if the team members perceived the three screening tools to meet their described purpose of guiding intervention and further care in HIV NCD. The perception of the team members was found to be consistent with the literature and phase one of the study. The described MoCA limitations and time needed to administer the WHODAS 2.0 exceeded that of the effectiveness of

the tools in the clinic context. Therefore, the screening tools were not found to be sufficiently accurate to guide care in terms of their construct and the contextual limitations of the clinics. Despite the limitations of the tools, the practitioner-participants still described the tools as the 'backbone' in guiding care in HIV NCD, as they did not have other, more appropriate screening tools available.

6.2 Clinical implications

The clinical implication of the study's results indicates that the results of the MoCA and WHODAS 2.0 cannot be taken at face value. Should these tools be used for screening in this patient population, they should be used with an understanding of the tools' limitations in the population. Patients with scores of below 11 on the IHDS and 20% perceived difficulty, or more, on the WHODAS 2.0, should be referred for further occupational therapy assessment and intervention. Patients scoring 11 on the IHDS should be monitored 6-12 monthly for any change in scores. These patients should be monitored using the WHODAS 2.0, with specific attention to any change in score on the domain of 'Life activities'.

6.3 Recommendations

6.3.1 Clinical

Due to the limitations of the screening tools for this population, testers are required to have considerable knowledge of the screening tools, their psychometric properties and test mechanics. Testers are also required to have sound clinical judgement to observe patient's behaviour, listen to patient histories and complaints and triangulate these, to assist in interpreting the results and make a decision on further health care.

Despite the limitations of the screening tools studied, it is likely that they will continue to be used for the screening of HIV NCD until some more appropriate screening tools are available. However, they should not be carried out by unqualified community workers, as has been recommended in task shifting, to alleviate the burden in healthcare settings. If community workers carried out the MoCA and WHODAS 2.0 without specific clinical judgement, this might result in over-referral for cognition and under-referral for activity limitation. This result would add to the

burden of under-resourced specialist clinics and limit referral to occupational therapy services for appropriate health care.

New guidelines on the MoCA administration have been developed, which require online training and registration to be completed, before using the tool. Although this might improve the standard administration of the tool by health professionals, it may not influence the described tendency to deviate from the standard administration procedure when one gains experience with the tool. The need for this online training, certification and associated cost would further limit the use of the tool in community settings, due to resource limitations. Similar concerns around the impact of the new certification process, have been expressed in literature (Borson et al., 2019). The new requirement could increase the MoCA limitations of effectiveness in the clinic context for this patient population.

This study, and others reported in the literature, have found the MoCA to have clinical limitations due to the inappropriateness of some subtests to context, language and requirement for formal education, resulting in false low scores.

It is recommended that the three screening tools explored in this study should all be used with caution, given the construct and contextual limitations, with the HIV NCD population in South Africa. The strengths and limitations of the tools in guiding care in HIV NCD need to be clearly understood before tools are used. The tools should be used as a screening and should not be the only assessment procedure. The lack of appropriate and sufficient human resources for intervention, when indicated by the results of the screening tools, is a serious concern for the health, occupational performance and well-being of this population, and is of ethical concern. Intervention for cognitive dysfunction and activity limitation, with the universal health care services, should be considered with using a primary health care approach, such as outreach and community-based intervention services. This approach would alleviate the burden on tertiary clinics and would support tertiary prevention, health and well-being and maintenance of activity performance in a vulnerable and chronically ill population.

6.3.2 Research

It is recommended that in support of task shifting, it would be beneficial to carry out further research on the comparison of the results on completion of the screens

between different healthcare professionals and community-based rehabilitation workers. This research could further develop an understanding of the influence of clinical judgment on the effectiveness of the tools in guiding further care.

The most essential research would be in the development of an appropriate tool that could identify HIV NCD within the South African population. This research would enable those without trained clinical judgement to effectively carry out the screen, thus alleviating pressure on the healthcare system and improving the service provided to the patients.

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APPENDIX A

Information Sheet regarding proposed research participation

Clinic Attendees

Title: Validity of Screening Tools for Activity Limitation and Cognitive Dysfunction in Patients with HIV Associated Neurocognitive Disorders

*****Please note that if you need help to understand this information, ask and we will get you an interpreter*****

Dear: Clinic Attendee

Thank you for thinking about being part of this research project. I hope that this information will answer any questions you might have about the research and what your part to play is in the research.

My Name is Elizabeth Smith. I am an Occupational Therapist (OT) performing research at Luthando Clinic. I care about the results of your visits to the clinic and want to improve the quality of services to you, the clinic attendees.

I would appreciate your valuable part in this research, and this is how you can help:

- *What is the research about?*
  During my work at a clinic I have seen that many attendees' struggle to come for lots of assessments, such as OT. This has been found as a problem due to financial limitations and we want to make your opportunities to access health care better. This research is looking at how we can help to make important assessments quicker, as well as making sure we are using the best assessments for your needs. We are specifically looking at assessments that help us understand your memory and attention and how your illness has affected these areas and the areas of your everyday living. Your involvement in this research will help us gather the information we need to make this process better and hopefully be used to provide better treatment within your needs.

- *What will you be asked to do, and how long will this take?*
  When you visit the doctor for your regular appointment, the doctor will decide based on your complaints whether or not assessment of memory and attention will be needed. If you need more assessment, you are part of the group that can help with the study. The doctor will then perform a screening test on these problems called the MOCA (Montreal Cognitive Assessment). Based on your scores on the MOCA you will be requested to do two more tests, the IHDS and the WHODAS 2.0. These tests will happen on the same day by the researcher. The IHDS is the International HIV Dementia Scale, and looks at the areas of the brain affected by HIV. The WHODAS 2.0 is the third assessment, which looks at how you are coping with your activities every day, when thinking about your illness. This will take approximately 20 minutes.

  In total the three tests will take about 20-30 minutes. This will be done at the clinic, during your regular appointment and will not require any extra transport cost.

- *Is there any risk or benefit for you?*

  No one will be able to recognise you specifically in the research information as no names or identifying information will be used on research papers. Your confidentiality (no one will know who you are) will be kept at all times in research documents. The assessments are not known to have any bad side effects.

  We will use this data at the clinic to help us put clinic attendees into the right treatment. This will help us to see the attendees in the clinic who need extra help in areas that have perhaps been overlooked due to limited access to the team help.

- *Do you have to be a part of this research?*
  No, you will not be forced in any way to let the researcher to use the scores from your assessments. AND, you are still welcome to have the assessments done even if you don't want your scores to be used. This is your choice to help us collect this information.

- *Will you get your scores back?*
  Yes, the team members will give the information to your Doctor for your next visit. They will make sure that your Doctor gives you all the options on available treatment at the clinic if a problem is found. You will then be able to make a choice on how you want to go forward with the information from the tests. Please remember that the research is only on the assessments scores and will not involve any information on your treatment at this time. BUT treatment within the clinic is offered as normal.

Now that you have all the information, if you wish to let us to use your scores, please fill in the consent form provided. You are welcome to ask the researcher any questions you have.

You may also contact the HREC should you have any complaints or queries about the research. The contact details are found below:

- Chairperson: peter.cleaton-jones1@wits.ac.za

- Administrators: Ms Zanele Ndlovu/ Mr Rhulani Mkansi/ Mr Lebo Moeng
  Tel 011 717 2700/2656/1234/1252

  Email: HREC-Medical.ResearchOffice@wits.ac.za

Thank you

Ishidi lwazi mayelana no ucwaningo ukubamba iqhaza labahambi emtholampilo

Bathandekayo: abahamba umtholampilo

Ngiyabonga ngokubamba ighaza ukuba inqenye Yale iphrojekthi, ngiyathemba ukuthi le minininingwane ezo phendula kungaphi imibuzo ungabanayo ngalo cwaningo futhi enye ingxenye ozokuyidlana kulo cwaningo

Igama lami NGU Elizabeth Smith.ngigu meluleki emsebenzi, ngiyenza umcwaningo e Luthando Clinic.ngiyakhathazeka ngo mphumela yenu yokuvakasha e mtholampilo futhi ngifuna ukuqeda ngezinga le isevisi eya kini bahambi Bo mtholampilo

Ngithanda ukunibonga nokubaluleka ngokuba ingxenye yalo cwaningo, unga siza ngalendlela le:

- ***Ucwaningo lungani?***

  Ngesikhathi ngisebenza e mtholampilo ngibone ukuthi ababekhonaa bahluleka ukuza kuzo hlolwa,nje ngo meluleki emsebenzi lokhu ku tholwe kuyinkinga ye mali,thina sifuna ukuni yenzela o belula bokuti nithole impilo kanye no mtholampilo o kangcono,ucwaningo lona lu beka izindlela esingayi sebenzisa ukusiza nokubaluleka bokuhlolwa ngokushesha.sibeka ukuhlolwa nokuthembisa ukuthi esikwenzayo sisebenza okungcono kakhulu nge zidingo zenu,sibheke kakhulu ku cwaningo elizoqedisa thina ukuzwisisa isikhubuzo no kuqaphela nokuthi ukugula kwakho ku kuthinte kanjani empilweni yakho ya mihla,ukuziqaza kulo cwaningo kuzonqedisa thina u ku hlanganisa u lwazi sidinga o kwenza inqubo lena kangcono,futhi sithemba ukuthi sizo sejenziswa ukuhlinzeka kangcono ukwelashwa ngaphakathi kwi isidingo sakho

- ***Lokho ozokubuzwa, nokuthi lokhu kuzothatha isikhathi esingakanani?***

  Lapho uvakashela udokotela ngukuqokwa kwakho ukuya okujwayelekile,udokotela uzokhipha isinqumo ukuya ngezikhalazo ukuthi yebo noma cha ukuhlolwa kwe inkumbulo kanye noku qaphela kuzodingek,o ma o dinga ukuhlolwa,uyiqenye ye bandla eli zoqedisa ngezifundo,udokotela uzo yenza ukuhlolwa lokuhlola kulezi izinga ezibizwa nge **MOCA**(ukuya ngezikolo zenu kwi **MOCA**),uzo qelwa ukwenza izivivinyo ezimbili

ngaphezulu e **IHDS** ne **WHODAS 2.0** lezi zivivinyo zizo kwenzeka ngosuku olufanayo ku mcwaningi,E IHDS yiyona ngamazwe ngamazwe(INTERNATIONAL HIV DEMENTIA SCALE) futhi o bukeka kwizindawo yobuchopho obatintekayo kwi HIV e WHODAS 2.0 e ye sithathu ku cwaningo e beka indlela o bhekana ngayo nayo imisebenzi yakho nsuku zonke,o ma oqabanga ngokugula kwakho,lokhu kuzo thatha isikhathi esingango 20 imizuzu,inani lezintathu kuzothatha esikhathi esingango 20-30 imizuzu lokhu kuzokwenziwa emtholampilo ngesikhathi sakho esivamile futhi ngeke kudinge izindleko ezengeziwe zemali

- ***Ingabe kukhona ingozi noma inzuzo kuwe***

Akekho oyokwazi ukubona wena ngokuqondile owcaningeni ulwazi lomthengisi njengoba kungekho amagama noma ulwazi lokuhlonza izosetshenziselwa e phepheni akekho ozokukwazi ukuthiungubani,izogcinwa kuma dokhumenti ocwaningo ukuhlolwa azaziwa ukuba nemiphumela e mibe,sizosebenzisa imininingwane yase mtholampilo ukuqedisa thina kanye nokuhi sisize sibeke abahlala emtholampilo ukuya emplilweni efanele lokhu kuzosiza ukubona abahambele emtholampilo abadinga usizo kwezinye izindawo ngenxa ye boxane bokufinyelela ukusiza ithimba

- ***Kufanele o be khona ingxenye yalolu cwaningo***

  Cha, ngeke o phoqelwe nganoma iyiphi indlela ukuvumela umthengisi ukusebenzisa umphumela kusuka ekuhloleni kwakho, futhi uvumekile ukuze ube noku hlolwa.kwenziwe uma ungafuni ukuthi ka sejenziswe umphumela wakho, lokhu kungokwakho ukukhetha kusisa siqoqe ulwazi

- ***Uzothola isikolo sakho emuva***

Yebo,amalungu eqembu azonikeza ulwazi ku dokotela ngokulandelayo,ukuze u dotokela wakho akuphe izinketho kwi ukwelaswha e mtholampilo umangabe inkinga e khona,u zo khetha ukuthi o zo sebenza kanjani ngo lwazi kusukela ekuhlolweni,khumbula ukuthi ucwaningo e le kohlolwa isikolo ngeke iphathe,izibandla kanye noma yiluphi ulwazi ekwelapheni kwakho ngalesi sikhathi kodwa ukulashwa e mtholampilo kunikezwa njengokuvamile.

Manje lokho unayo yonke imininingwane, uma ufisa ukuvumela sisebenzise amaphuzu akho ngicela o gcwalise I formu lokuvuma wamukelekile ukubuza ucwaningo noma yimiphi imibuzo unayo

Ungasefuthi o xhomane ne **HREC,** uma onalokukhononda noma imibuzo, ongaxhumana no:

- Chairperson:peter.cleaton-jones1@wits.ac.za
- Administrators:Ms Zanele Ndlovu/Mr Rhulani Mkansi/Mr Lebo Moeng

Tel: 011 717 2700/2556/1234/1252
Email:HREC-Medical.ReseachOffice@wits.ac.za

Ngiyabonga

.

APPENDIX B

Informed Consent form

Clinic Attendees

I _____- have read, or have had explained to me in my first language the participant information sheet and I understand the participant information sheet.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this negatively impacting on any assessment or treatment opportunities. I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any research reports on this study.

I agree to take part by allowing the researcher to use my scores from the assessments done. I agree to allow the researcher to look at my file to see what medication I am taking and what my viral load is.

Participant's name:

Signature: Date:

APPENDIX C

For research use

Participant Number:

Demographic information of Research Participant

Please provide the following information. Should you require assistance, please don't hesitate to ask.

<table>
<tr><td rowspan="2">1.Age:</td><td>2.First language:</td><td rowspan="2">3.What is your highest level of education? (EG: Standard 7)</td></tr>
<tr><td>2.1 Other Languages:</td></tr>
<tr><td colspan="3">4.Please indicate how long you have lived in South Africa:</td></tr>
<tr><td>5. When were you first diagnosed with HIV?</td><td colspan="2">6. Do you have any other illnesses other than HIV? Please specify</td></tr>
<tr><td>7. Are you on ARV Treatment?</td><td>8. Are your other illnesses medically treated?</td><td>9. If so, what medications are you taking?</td></tr>
<tr><td>7.1 If so, how long?

7.2 What ARV treatment are you currently on?</td><td rowspan="2">11. Please tell us if you have eaten breakfast this morning?</td><td rowspan="2">11.1 If so, what did you eat?</td></tr>
<tr><td>10. CD4 Count:</td></tr>
</table>

Thank you for your information.

APPENDIX D

International HIV Dementia Scale (IHDS)

Memory-Registration – Give four words to recall (dog, hat, bean, red) – 1 second to say each. Then ask the patient all four words after you have said them. Repeat words if the patient does not recall them all immediately. Tell the patient you will ask for recall of the words again a bit later.

1. Motor Speed: Have the patient tap the first two fingers of the non-dominant hand as widely and as quickly as possible.
   4 = 15 in 5 seconds
   3 = 11-14 in 5 seconds
   2 = 7-10 in 5 seconds
   1 = 3-6 in 5 seconds
   0 = 0-2 in 5 seconds

   ____

2. Psychomotor Speed: Have the patient perform the following movements with the non-dominant hand as quickly as possible: 1) Clench hand in fist on flat surface. 2) Put hand flat on surface with palm down. 3) Put hand perpendicular to flat surface on the side of the 5th digit. Demonstrate and have patient perform twice for practice.
   4 = 4 sequences in 10 seconds
   3 = 3 sequences in 10 seconds
   2 = 2 sequences in 10 seconds
   1 = 1 sequence in 10 seconds
   0 = unable to perform

   ____

3. Memory-Recall: Ask the patient to recall the four words. For words not recalled, prompt with a semantic clue as follows: animal (dog); piece of clothing (hat); vegetable (bean); color (red).
   Give 1 point for each word spontaneously recalled.
   Give 0.5 points for each correct answer after prompting
   Maximum – 4 points.

   ____

Total International HIV Dementia Scale Score: This is the sum of the scores on items 1-3. The maximum possible score is 12 points. A patient with a score of ≤ 10 should be evaluated further for possible dementia.

____

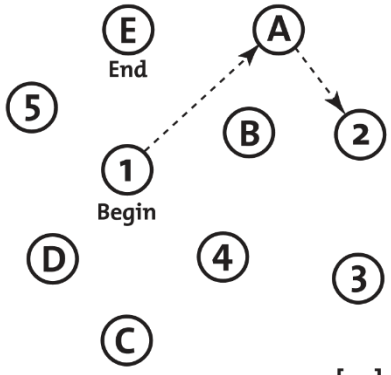
N. Sacktor, et.al.
Department of Neurology
Johns Hopkins University
Baltimore, Maryland
International HIV Dementia Scale.

APPENDIX E

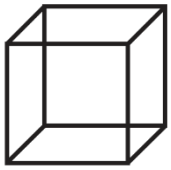
MONTREAL COGNITIVE ASSESSMENT (MOCA)

Education :
Sex :
Date of birth :
DATE :

VISUOSPATIAL / EXECUTIVE



Copy cube



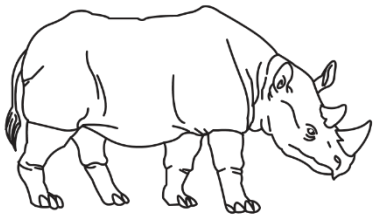
[ ] [ ]

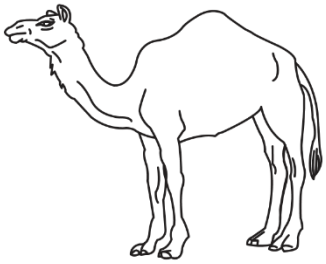
Draw CLOCK (Ten past eleven)
(3 points)

[ ] Contour [ ] Numbers [ ] Hands

POINTS __/5

NAMING





[ ] [ ] [ ] __/3

MEMORY

Read list of words, subject must repeat them. Do 2 trials. Do a recall after 5 minutes.

	FACE	VELVET	CHURCH	DAISY	RED
1st trial					
2nd trial					

No points

ATTENTION

Read list of digits (1 digit/ sec.). Subject has to repeat them in the forward order [ ] 2 1 8 5 4

Subject has to repeat them in the backward order [ ] 7 4 2 __/2

Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors

[ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B __/1

Serial 7 subtraction starting at 100 [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65

4 or 5 correct subtractions: **3 pts**, 2 or 3 correct: **2 pts**, 1 correct: **1 pt**, 0 correct: **0 pt** __/3

LANGUAGE

Repeat : I only know that John is the one to help today. [ ]

The cat always hid under the couch when dogs were in the room. [ ] __/2

Fluency / Name maximum number of words in one minute that begin with the letter F [ ] _____ (N ≥ 11 words) __/1

ABSTRACTION

Similarity between e.g. banana - orange = fruit [ ] train – bicycle [ ] watch - ruler __/2

DELAYED RECALL

	Has to recall words WITH NO CUE	FACE	VELVET	CHURCH	DAISY	RED	Points for UNCUED recall only
		[ ]	[ ]	[ ]	[ ]	[ ]	__/5
Optional	Category cue						
	Multiple choice cue						

ORIENTATION

[ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City __/6

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www.mocatest.org

Normal ≥ 26 / 30

TOTAL __/30

Add 1 point if ≤ 12 yr edu

APPENDIX F

WHODAS 2.0

WORLD HEALTH ORGANIZATION
DISABILITY ASSESSMENT SCHEDULE 2.0

36-item version, interviewer-administered

Introduction

This instrument was developed by the WHO *Classification, Terminology and Standards* team, within the framework of the WHO/National Institutes of Health (NIH) Joint Project on Assessment and Classification of Disability.

Before using this instrument, interviewers must be trained using the manual *Measuring Health and Disability: Manual for WHO Disability Assessment Schedule – WHODAS 2.0* (WHO 2010), which includes an interview guide and other training material.

The versions of the interview available are as follows:

- 36-item – Interviewer-administered[a]
- 36-item – Self-administered
- 36-item – Proxy-administered[b]
- 12-item – Interviewer-administered[c]
- 12-item – Self-administered
- 12-item – Proxy-administered
- 12+24-item – Interviewer-administered

[a] A computerized version of the interview (*iShell*) is available for computer-assisted interviews or for data entry

[b] Relatives, friends or caretakers

[c] The 12-item version explains 81% of the variance of the more detailed 36-item version

For more details of the versions please refer to the WHODAS 2.0 manual *Measuring Health and Disability: Manual for WHO Disability Assessment Schedule – WHODAS 2.0* (WHO 2010).

Permission to translate this instrument into any language should be obtained from WHO, and all translations should be prepared according to the WHO translation guidelines, as detailed in the accompanying manual.

For additional information, please visit www.who.int/whodas or contact:

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WHODAS 2.0

WORLD HEALTH ORGANIZATION
DISABILITY ASSESSMENT SCHEDULE 2.0

36
Interview

This questionnaire contains the interviewer-administered 36-item version of WHODAS 2.0.

Instructions to the interviewer are written in bold and italics – do not read these aloud.

Text for the respondent to hear is written in

standard print in blue.

Read this text aloud.

Section 1 Face sheet

Complete items F1–F5 before starting each interview				
F1	Respondent identity number			
F2	Interviewer identity number			
F3	Assessment time point (1, 2, etc.)			
F4	Interview date	_____ day	_____ month	_____ year
F5	Living situation at time of interview (circle only one)	Independent in community		1
		Assisted living		2
		Hospitalized		3

Section 2 Demographic and background information

This interview has been developed by the World Health Organization (WHO) to better understand the difficulties people may have due to their health conditions. The information that you provide in this interview is confidential and will be used only for research. The interview will take 15–20 minutes to complete.

For respondents from the general population (not the clinical population) say:

Even if you are healthy and have no difficulties, I need to ask all of the questions so that the survey is complete.

I will start with some background questions.

A1	***Record sex as observed***	Female	1
		Male	2
A2	How old are you now?	_____ years	
A3	How many years in all did you spend studying in school, college or university?	_____ years	
A4	What is your current marital status? ***(Select the single best option)***	Never married	1
		Currently married	2
		Separated	3
		Divorced	4
		Widowed	5
		Cohabiting	6
A5	Which describes your main work status best? ***(Select the single best option)***	Paid work	1
		Self employed, such as own your business or farming	2
		Non-paid work, such as volunteer or charity	3
		Student	4
		Keeping house/ homemaker	5
		Retired	6
		Unemployed (health reasons)	7
		Unemployed (other reasons)	8
		Other (specify)_____ _____	9

Section 3 Preamble

Say to respondent:

The interview is about difficulties people have because of health conditions.

Hand flashcard #1 to respondent and say:

By health condition I mean diseases or illnesses, or other health problems that may be short or long lasting; injuries; mental or emotional problems; and problems with alcohol or drugs.

Remember to keep all of your health problems in mind as you answer the questions. When I ask you about difficulties in doing an activity think about …

Point to flashcard #1 and explain that "difficulty with an activity" means:

- Increased effort
- Discomfort or pain
- Slowness
- Changes in the way you do the activity.

Say to respondent:

When answering, I'd like you to think back over the past 30 days. I would also like you to answer these questions thinking about how much difficulty you have had, on average, over the past 30 days, while doing the activity as you usually do it.

Hand flashcard #2 to respondent and say:

Use this scale when responding.

Read the scale aloud:

None, mild, moderate, severe, extreme or cannot do.

Ensure that the respondent can easily see flashcards #1 and #2 throughout the interview

Section 4 Domain reviews

Domain 1 Cognition

I am now going to ask some questions about understanding and communicating.

Show flashcards #1 and #2 to respondent

In the past 30 days, how much difficulty did you have in:		None	Mild	Moderate	Severe	Extreme or cannot do
D1.1	Concentrating on doing something for ten minutes?	1	2	3	4	5
D1.2	Remembering to do important things?	1	2	3	4	5
D1.3	Analysing and finding solutions to problems in day-to-day life?	1	2	3	4	5
D1.4	Learning a new task, for example, learning how to get to a new place?	1	2	3	4	5
D1.5	Generally understanding what people say?	1	2	3	4	5
D1.6	Starting and maintaining a conversation?	1	2	3	4	5

Domain 2 Mobility

I am now going to ask you about difficulties in getting around.

Show flashcards #1 and #2

In the past 30 days, how much difficulty did you have in:		None	Mild	Moderate	Severe	Extreme or cannot do
D2.1	Standing for long periods such as 30 minutes?	1	2	3	4	5
D2.2	Standing up from sitting down?	1	2	3	4	5
D2.3	Moving around inside your home?	1	2	3	4	5
D2.4	Getting out of your home?	1	2	3	4	5
D2.5	Walking a long distance such as a kilometre [or equivalent]?	1	2	3	4	5

Please continue to next page...

Domain 3 Self-care

I am now going to ask you about difficulties in taking care of yourself.

Show flashcards #1 and #2

In the past 30 days, how much difficulty did you have in:		None	Mild	Moderate	Severe	Extreme or cannot do
D3.1	Washing your whole body?	1	2	3	4	5
D3.2	Getting dressed?	1	2	3	4	5
D3.3	Eating?	1	2	3	4	5
D3.4	Staying by yourself for a few days?	1	2	3	4	5

Domain 4 Getting along with people

I am now going to ask you about difficulties in getting along with people. Please remember that I am asking only about difficulties that are due to health problems. By this I mean diseases or illnesses, injuries, mental or emotional problems and problems with alcohol or drugs.

Show flashcards #1 and #2

In the past 30 days, how much difficulty did you have in:		None	Mild	Moderate	Severe	Extreme or cannot do
D4.1	Dealing with people you do not know?	1	2	3	4	5
D4.2	Maintaining a friendship?	1	2	3	4	5
D4.3	Getting along with people who are close to you?	1	2	3	4	5
D4.4	Making new friends?	1	2	3	4	5
D4.5	Sexual activities?	1	2	3	4	5

Please continue to next page...

Domain 5 Life activities

5(1) Household activities

I am now going to ask you about activities involved in maintaining your household, and in caring for the people who you live with or are close to. These activities include cooking, cleaning, shopping, caring for others and caring for your belongings.

Show flashcards #1 and #2

Because of your health condition, in the past 30 days, how much difficulty did you have in:		None	Mild	Moderate	Severe	Extreme or cannot do
D5.1	Taking care of your household responsibilities?	1	2	3	4	5
D5.2	Doing your most important household tasks well?	1	2	3	4	5
D5.3	Getting all the household work done that you needed to do?	1	2	3	4	5
D5.4	Getting your household work done as quickly as needed?	1	2	3	4	5

If any of the responses to D5.2–D5.5 are rated greater than none (coded as "1"), ask:

D5.01	In the past 30 days, on how many days did you reduce or completely miss household work because of your health condition?	***Record number of days*** ____

If respondent works (paid, non-paid, self-employed) or goes to school, complete questions D5.5–D5.10 on the next page. Otherwise, skip to D6.1 on the following page.

5(2) Work or school activities

Now I will ask some questions about your work or school activities.

Show flashcards #1 and #2

Because of your health condition, in the past 30 days how much difficulty did you have in:		None	Mild	Moderate	Severe	Extreme or cannot do
D5.5	Your day-to-day work/school?	1	2	3	4	5
D5.6	Doing your most important work/school tasks well?	1	2	3	4	5
D5.7	Getting all the work done that you need to do?	1	2	3	4	5
D5.8	Getting your work done as quickly as needed?	1	2	3	4	5
D5.9	Have you had to work at a lower level because of a health condition?				No	1
					Yes	2
D5.10	Did you earn less money as the result of a health condition?				No	1
					Yes	2

If any of D5.5–D5.8 are rated greater than none (coded as "1"), ask:

D5.02	In the past 30 days, on how many days did you miss work for half a day or more because of your health condition?	***Record number of days*** ____

Please continue to next page...

Domain 6 Participation

Now, I am going to ask you about your participation in society and the impact of your health problems on you and your family. Some of these questions may involve problems that go beyond the past 30 days, however in answering, please focus on the past 30 days. Again, I remind you to answer these questions while thinking about health problems: physical, mental or emotional, alcohol or drug related.

Show flashcards #1 and #2

In the past 30 days:		None	Mild	Moderate	Severe	Extreme or cannot do
D6.1	How much of a problem did you have joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?	1	2	3	4	5
D6.2	How much of a problem did you have because of barriers or hindrances in the world around you?	1	2	3	4	5
D6.3	How much of a problem did you have living with dignity because of the attitudes and actions of others?	1	2	3	4	5
D6.4	How much time did you spend on your health condition or its consequences?	1	2	3	4	5
D6.5	How much have you been emotionally affected by your health condition?	1	2	3	4	5
D6.6	How much has your health been a drain on the financial resources of you or your family?	1	2	3	4	5
D6.7	How much of a problem did your family have because of your health problems?	1	2	3	4	5
D6.8	How much of a problem did you have in doing things by yourself for relaxation or pleasure?	1	2	3	4	5

H1	Overall, in the past 30 days, how many days were these difficulties present?	***Record number of days*** ____
H2	In the past 30 days, for how many days were you totally unable to carry out your usual activities or work because of any health condition?	***Record number of days*** ____
H3	In the past 30 days, not counting the days that you were totally unable, for how many days did you cut back or reduce your usual activities or work because of any health condition?	***Record number of days*** ____

This concludes the interview. Thank you for participating.

APPENDIX G

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Department of Occupational Therapy
Wits Education Campus

School of Therapeutic Sciences, Faculty of Health Sciences, 7 York Road, Parktown, 2193, South Africa
Tel: +27 11 717 3701 | Fax: +27 717 3709 | Email: leilane.bogoshi@wits.ac.za | www.wits.ac.za

DATE: September 2017

TO: Prof. Jeenah
Head of Psychiatry,
Chris Hani Baragwaneth Academic Hospital
E-mail: yasmien.jeenah@wits.ac.za

Re: Request for permission to perform research at Chris Hani Baragwaneth Hospital, Luthando Clinic

Dear Prof Jeenah,

My name is Elizabeth Smith, I am an Occupational Therapist. I am currently enrolled as a Masters student at the University of the Witwatersrand, student number: 350981.

During my work at Lufuno Neuropsychiatry Clinic (2014-2017), I have identified a need for further research into the screening and assessment process of HIV Neurocognitive decline, in order to improve service delivery, in access as well as quality. The research is titled: Validity of Screening Tools for Activity Limitation and Cognitive Dysfunction in Patients with HIV Associated Neurocognitive Disorders.

Unfortunately my data collection has proved difficult at Lufuno Clinic, and I am at a concerning point regarding time and numbers collected. Myself and my supervisor (Prof. de Witt), have met with Dr. Sibandze who is satisfied with the research taking place at Luthando Clinic. He mentioned a few concerns regarding process and population within the protocol, as it was based on the process used within Lufuno Clinic. We are happy to make these minor adjustments and collect our data from zero at Luthando. I have not made these adjustments to the protocol as yet, as I wanted to submit the protocol as approved by the Wits Human Ethics Research Committee (HREC). We will make the adjustments as agreed upon by the CHBAH Research board and inform the Wits Medical Research committee

about change site of data collection. The most important of these concerns raised by Dr. Sibandze being that the doctor at Luthando does not perfom the IHDS but rather the MOCA as per Luthando's process. This will mean that the researcher will perform this screening.

Attached please find the letter of permission signed by Dr. Sibandze, the protocol as approved by the Wits Medical Ethics Research Committee, approval from the HREC, as well as appendices of the protocol. I am requesting that you give permission for this research to be carried out at Luthando Clinic.

Kind Regards,

Smith

Elizabeth Smith
BScOT(WITS)
OT0084263
Student: 350981

PERMISSION TO CONDUCT RESEARCH

I F.Y. Jeenah hereby give permission for the project entitled Validity of Screening Tools for Activity Limitation and Cognitive Dysfunction in Luthando Patients with HIV Associated Neurocognitive Disorders to be completed at Lufuno Clinic at Chris Hani Baragwaneth Academic Hospital. - provided no staff member time for the research. collect the data

Signed

Date 19/09/2017

APPENDIX H

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

MEDICAL ADVISORY COMMITTEE
CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL

PERMISSION TO CONDUCT RESEARCH

Date: 29 Sept 2017

TITLE OF PROJECT: Validity of screening tools for activity limitation and cognitive dysfunction in patients with HIV associated neurocognitive disorders

UNIVERSITY: Witwatersrand

Principal Investigator: E Smith

Department: Occupational Therapy

Supervisor (If relevant): P de Witt

Permission Head Department (where research conducted): yes

Date of start of proposed study: Sept 2017
Date of completion of data collection: Dec 2020

The Medical Advisory Committee recommends that the said research be conducted at Chris Hani Baragwanath Hospital. The CEO /management of Chris Hani Baragwanath Hospital is accordingly informed and the study is subject to:-

- Permission having been granted by the Human Research Ethics Committee of the University of the Witwatersrand.
- the Hospital will not incur extra costs as a result of the research being conducted on its patients within the hospital
- the MAC will be informed of any serious adverse events as soon as they occur
- permission is granted for the duration of the Ethics Committee approval.

.....
Recommended
(On behalf of the MAC)
Date: 29 September 2017

.....
Approved/Not Approved
Hospital Management
Date: 03/10/17

APPENDIX I

R14/49 Miss Elizabeth Smith

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M160954

NAME: (Principal Investigator)	Miss Elizabeth Smith
DEPARTMENT:	Occupational Therapy Tara The H. Moross Hospital - Lufuno Neuropsychiatry Clinic
PROJECT TITLE:	Validity of Screening Tools for Activity Limitation and Cognitive Dysfunction in Patients with HIV Associated Neurocognitive Disorders
DATE CONSIDERED:	30/09/2016
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Prof Patricia De Witt
APPROVED BY:	Professor P Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	25/01/2017

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 301, Third Floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in September and will therefore be due in the month of September each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Ms E Smith

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M160954

NAME: (Principal Investigator)	Ms E Smith
DEPARTMENT:	School of Therapeutic Sciences Department of Occupational Therapy University
PROJECT TITLE:	Validity of screening tools for activity limitation and cognitive dysfunction in patients with HIV-associated neurocognitive disorders
DATE CONSIDERED:	30/09/2016
DECISION:	Approved unconditionally
CONDITIONS:	Certificate re-issed on 15 January 2018 - study now to be conducted at Chris Hani Baragwanath Academic Hospital
SUPERVISOR:	Professor P De Witt
APPROVED BY:	CB Penny Professor CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	25/01/2017 (original approval date)

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on 3rd floor, Phillip V Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

I/We fully understand the conditions under which I am/we are authorised to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to resubmit to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. in this case, the study was initially reviewed in **September** and will therefore be due in the month of **September** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Smith

Principal Investigator Signature

Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX J

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH
TARA the H. Moross Centre
Private Bag X7
RANDBURG 2125
(011) 535-3000
(011) 535-3026

29 November 2016

For attention: **Dr Madigoe and Dr Otieno**

Dear Doctors

Re: Application by Ms Elizabeth Smith to do research at Tara Hospital

I hereby request permission for Ms Elizabeth Smith to conduct research at Tara Hospital. Ms Smith is an Occupational Therapist working at Tara H. Moross Centre for Lufuno Neuropsychiatry Clinic, staff number 26692945 and currently enrolled as a Masters student at the University of the Witwatersrand, student number: 350981.

The title of her research is: "Validity of screening tools for activity limitation and cognitive dysfunction in patients with HIV associated neurocognitive disorders".

During her work at Lufuno, she has identified a need for further research into the screening and assessment process, in order to improve service delivery in access as well as quality.

According to her protocol she will use scores from tests currently being used in the clinic to screen patients with HIV associated neurocognitve dysfunction. The patients will be adequately informed about the research and will be asked to participate in the research. Should they wish to decline, this will not impact their assessment or treatment negatively. These are tests that already being performed and will not require further resources from the hospital. The research has the potential to improve the clinics current screening and assessment process as well as improve the quality of the service offered by the clinic.

Ms Smith has applied to the Human Research Ethics Committee (Medical) at the University of Witwatersrand for ethical clearance and they require permission from Tara Hospital before they can issue a clearance certificate.

The application was discussed at the recent Tara Research Meeting. Some concerns were raised around whose responsibility performing the screening tests would be. Ms Smith corrected the protocol as well as the ethics certificate submission.

.....

Date: 29.11.2016

Dr Ronelle Price-Hughes

Chairperson- Tara Research Committee

Recommended/Not Recommended

.....

Dr Thebe Madigoe

Clinical Head

Date: 29/11/16

Approved/Not Approved

..... Subject to Ethics approval

Dr Florence Otieno

CEO

Date: 29/11/16

APPENDIX K

Information Sheet regarding proposed research participation

Referring team members working in Neuropsychiatry

Title: Validity of screening tools for occupational performance in patients with HIV neurocognitive decline

Dear: Potential participant

Thank you for considering being involved in this research project. I hope that this information will answer any questions you might have about the research and your role in the process.

My Name is Elizabeth Smith. I am an Occupational Therapist (OT). I care about the outcomes of our assessment and treatment at clinic level and am hoping that through this research project I can help to develop improvement in assessment from the team as a whole, working toward the same goal.

I would appreciate your valuable input into this research, and this is how you can help:

- *What is the research about?*
  During my work at Lufuno Neuropsychiatry clinic I have seen that many attendees' struggles to come for assessment with multiple team members, such as OT. This has been found as a restriction due to financial limitations and we want to make their opportunities to access health care better. This research is looking at how we can help to make much needed assessments quicker, as well as making sure we are using the best assessments for the attendees needs. We are specifically looking at assessments that help us understand the cognitive processes that arise from HIV and how the illness has impacted on these cognitive areas and the areas of everyday living. Your involvement in this research will help us gather the information we need to make this process better, by assisting the researcher in understanding the main goal of the referring doctor. It will assist us in understanding the depth of assessment expected from the referring doctor and hopefully assist in refining the assessments performed by the allied staff, specifically OT.

- *What will you be required to do, and how long will this take?*
  You will be asked to participate in a group interview discussion, regarding your reasons and expectations when referring patients with HIV for further assessment in OT. This will be arranged at a time that will not impact on your treatment, and at a location that best fits the needs of the group. The group interview will take approximately 2 hours. After which the researcher will compile an understanding of themes that arise from the discussion and may contact you for confirmation of the analysed points.
- *Is there any risk or benefit for you?*

  No one will be able to recognise you specifically in the research information as no names or identifying information will be used on research documents. Your confidentiality will be kept at all times in research documents. The group interviews are not known to have any adverse side effects.

  Due to the fact that the research will be done in discussion groups, we cannot completely ensure confidentiality. No names of professionals will be used in the research documentation. The groups will be voice recorded for the purposes of analysis. These recordings will however, not be made public and will only be used for the purposes of research data collection.

  We will use this data at Lufuno clinic to help us put the necessary attendees into appropriate treatment. This will help us to recognise and identify the attendees in the clinic who need extra help in areas that have perhaps been overlooked due to limited access to the team intervention. This will mean that the information you provide will help the team to understand the needs of referrals and outcomes expected from these. This will assist in developing an improvement in communication and retrieval of necessary information from the team. We hope that our collection of this information and developed understanding will be used in other clinics to improve their assessments for patients with possible HIV dementia, thus positively impacting your team work and assessment in your setting.

- *Do you have to be a part of this research?*
  No, you will not be forced in any way to attend the group interview. This is your choice to help us collect this information.

- *Will you get information back?*
  Yes, you will be allowed access to the results once the researcher has analysed the findings, you are welcome to contact and request the identified outcomes. You may also read the research once it is completed.

Now that you have all the information, if you wish to attend the group interview, please fill in the consent form provided. You are welcome to ask the researcher any questions you may still have.

You may also contact the HREC should you have any complaints or queries about the research. The contact details are found below:

- Chairperson: peter.cleaton-jones1@wits.ac.za

- Administrators: Ms Zanele Ndlovu/ Mr Rhulani Mkansi/ Mr Lebo Moeng
  Tel 011 717 2700/2656/1234/1252

  Email: HREC-Medical.ResearchOffice@wits.ac.za

Thank you for your consideration!

APPENDIX L

Preparation for Group interviews

Questions to be used as needed

- From your experience and understanding what is the importance of functional testing and cognitive screening in HIV-NCD?
- Do you think the scores on the MOCA/IHDS are indicative of a certain functional capacity?
    - Are there certain questions/areas you think indicate deficits more than others? Or questions you think are less effective in testing?
    - Are there any areas of the MOCA/IHDS that you think are not appropriate for the SA population?
- Do you feel that there are any important areas in the MOCA that are not raising issues needed to be screened for in HIV- NCD?
- Do you translate any of the questions in the MOCA when testing?
- Literature reports the importance of the mechanics and psychometric value of testing. When training registrars to perform tests such as the MOCA and IHDS are these trained?
    - Specifically, in light of inter-rater reliability, test retest reliability…etc
    - How regularly do you repeat the testing?
- From your experience, does the IHDS give a good indication of possible underlying deficits that may impact function? Discuss…
- Do you feel that medication is the most effective form of treatment for cognitive and resulting functional deficits in HIV NCD?
    - At what point do you refer for further therapeutic intervention?
- What is your experience with the WHODAS 2.0, as it is considered to be the functional screening for the DSM 5 criteria?
- Have you found it to be an effective representation of expected deficits from cognitive screening?
- Would you consider the clients perception of their function to be the most effective measure of function, in light of possible cognitive impairments being screened for in this population?
- Do the results and treatment achieved from this screening validate for you the time spent on the testing?
- What are your expectations from therapeutic intervention for clients?
    - At Asympotmatic NCD
    - Mild NCD
    - HAND

APPENDIX M

Consent form

Referring Team members working in Neuropsychiatry- Group interviews

I _____- have read, or have had explained to me in my first language the participant information sheet and I understand the participant information sheet.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any research reports on this study.
I agree to take part by allowing the researcher to use my opinions and thoughts on topics discussed in the group interview for research purposes.

Participant's name:

Signature: Date:

APPENDIX N

Consent form

Referring Team members working in Neuropsychiatry-Group Interviews Voice Recording

I _____- have read, or have had explained to me in my first language the participant information sheet and I understand the participant information sheet. I agree to allow the researcher to voice record my discussion in the group interview.

I understand that my opinions and discussions will be recorded for the researcher to utilize in the processing of information gathered during my participation in the group interviews. I understand that these recordings will not be made accessible to the general public and are for use in analysis process of the research.
I agree to take part by allowing the researcher to voice record my opinions and thoughts on topics discussed in the group interview for research purposes.

Participant's name:

Signature: Date:

APPENDIX O

REGRESSION RESULTS:

IHDS vs MoCA

Dependent Y	IHDS
Independent X	MOCA

Least squares regression

Sample size	55
Coefficient of determination R^2	0,2493
Residual standard deviation	1,8912

Regression Equation

y = 2,3903 + 0,2388 x

Parameter	Coefficient	Std. Error	95% CI	t	P
Intercept	2,3903	1,1132	0,1576 to 4,6231	2,1473	0,0364
Slope	0,2388	0,05692	0,1246 to 0,3530	4,1954	0,0001

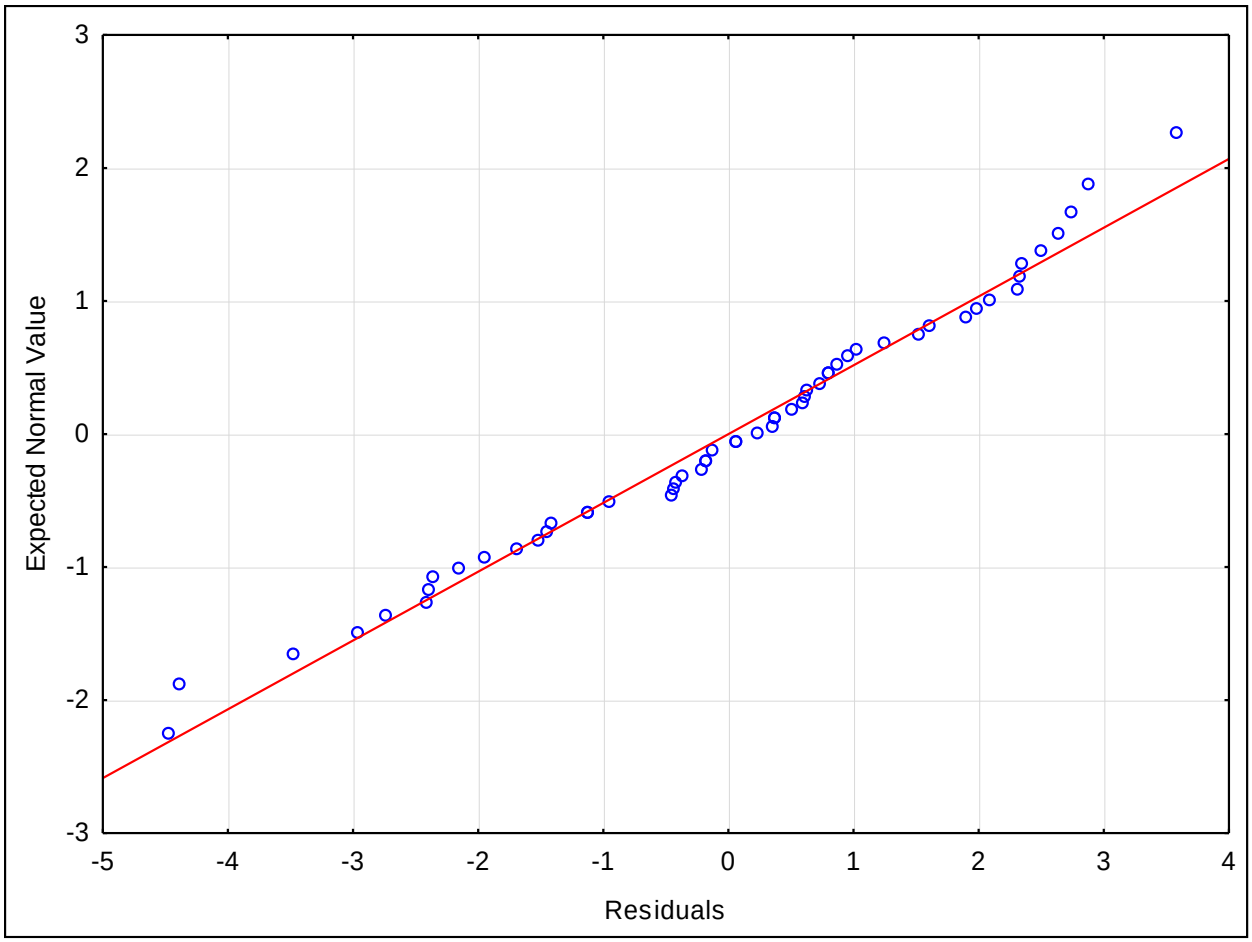
Analysis of Variance

Source	DF	Sum of Squares	Mean Square
Regression	1	62,9564	62,9564
Residual	53	189,5708	3,5768

F-ratio	17,6013
Significance level	P=0,0001

Residual Q-Q plot

The residuals of the regression follow a normal distribution with a small number of outliers.



Standard residuals

The standard residuals indicate two outliers as seen on the residual plot

Case	Standard Residuals -5. -4. -3. ±2. 3. 4. 5.	Outliers Standard Residual	Outliers Std.Err. Pred.Val
24	. . . *| . . .	-2,31	0,340
42	. . . * | . . .	-2,36	0,343
Minimum	. . . * | . . .	-2,36	0,340
Maximum	. . . *| . . .	-2,31	0,343
Mean	. . . *| . . .	-2,34	0,341
Median	. . . *| . . .	-2,34	0,341

Cook’s distance

The influence of the outliers was accessed using Cook’s distance. They were not removed since Cook’s distance values were all less than 1.

Cook's distances Case ,000 . . . . . ,098	Cook's Distances:Sorted Cook's Distance
42 . . . | . . *	0,098488
24 . . . | . . * .	0,092970
7 . . . | . * . .	0,075569
15 . . . | * . . .	0,059370
29 . . . | * . . .	0,054431
35 . . . |* . . .	0,050945
4 . . . * . . .	0,049885
40 . . . * . . .	0,049435
53 . . . *| . . .	0,046766
41 . . . * | . . .	0,043534
47 . . . * | . . .	0,040906
13 . . .* | . . .	0,035656
2 . . *. | . . .	0,028945
32 . . *. | . . .	0,027900
8 . * . | . . .	0,015047
26 . * . | . . .	0,014866
22 . * . | . . .	0,013890
19 . *. . | . . .	0,012656
5 . *. . | . . .	0,012191
36 . *. . | . . .	0,011489
12 . * . . | . . .	0,007939
1 . * . . | . . .	0,007738
45 . * . . | . . .	0,007738
52 . * . . | . . .	0,006741
49 . * . . | . . .	0,006252
37 . * . . | . . .	0,005555
21 . * . . | . . .	0,005199
34 . * . . | . . .	0,004744
54 .* . . | . . .	0,003195
55 .* . . | . . .	0,002894
39 .* . . | . . .	0,002028
27 .* . . | . . .	0,001843
46 .* . . | . . .	0,001831
6 .* . . | . . .	0,001831
20 .* . . | . . .	0,001120
33 .* . . | . . .	0,001016
10 .* . . | . . .	0,000880
3 .* . . | . . .	0,000880
30 .* . . | . . .	0,000649
18 .* . . | . . .	0,000597
9 .* . . | . . .	0,000520
16 .* . . | . . .	0,000488
50 .* . . | . . .	0,000482
23 .* . . | . . .	0,000175
28 .* . . | . . .	0,000091
14 .* . . | . . .	0,000077
31 .* . . | . . .	0,000077

Cook's distances Case ,000 . . . . . ,098	Cook's Distances:Sorted Cook's Distance
44 .* . . | . . .	0,000014
11 .* . . | . . .	0,000014
Minimum .* . . | . . .	0,000014
Maximum . . . | . . *	0,098488
Mean . .* . | . . .	0,018650
Median . * . . | . . .	0,007738

IHDS vs WHODAS

Dependent Y	IHDS
Independent X	WHODAS

Least squares regression

Sample size	55
Coefficient of determination R^2	0,005255
Residual standard deviation	2,1771

Regression Equation

y = 7,2366 + -0,01188 x

Parameter	Coefficient	Std. Error	95% CI	t	P
Intercept	7,2366	0,6389	5,9551 to 8,5181	11,3265	<0,0001
Slope	-0,01188	0,02245	-0,05690 to 0,03315	-0,5291	0,5989

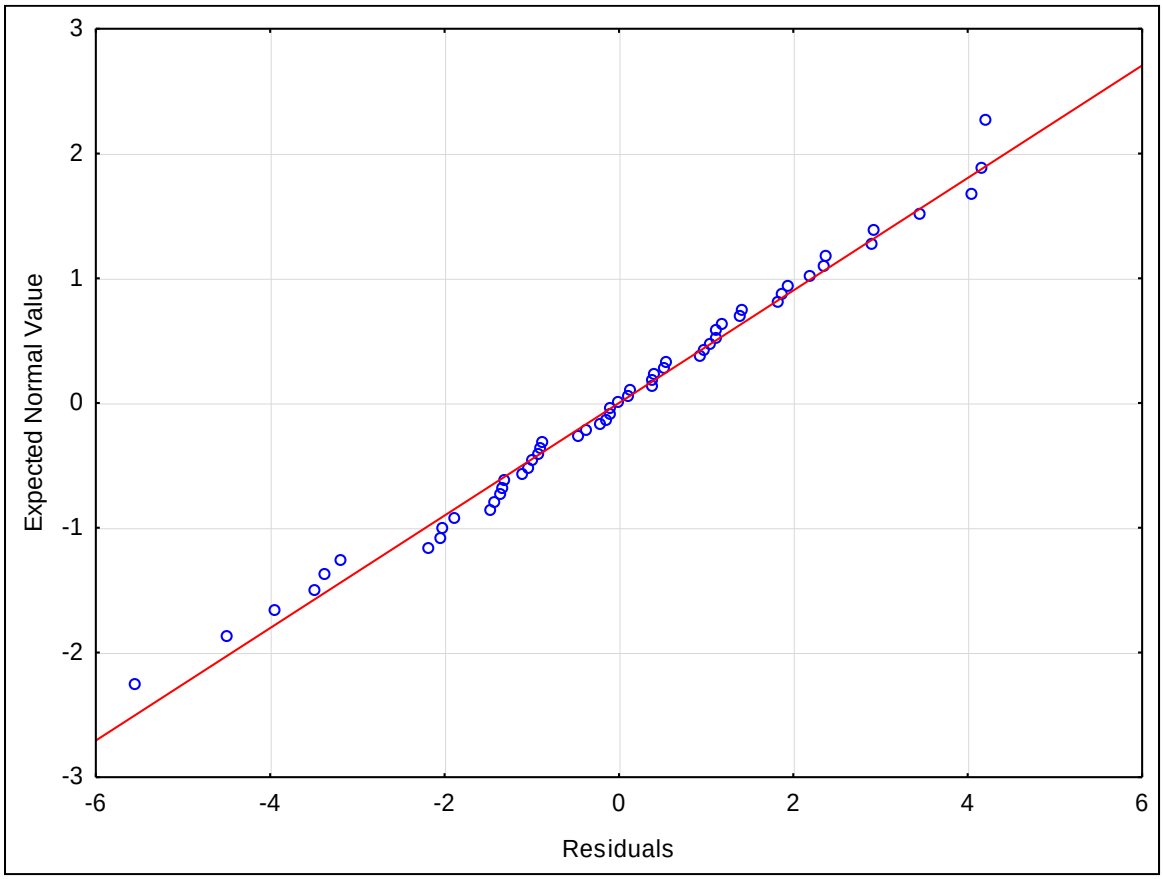
Analysis of Variance

Source	DF	Sum of Squares	Mean Square
Regression	1	1,3270	1,3270
Residual	53	251,2003	4,7396

F-ratio	0,2800
Significance level	P=0,5989

Residual Q-Q plot

The residuals of the regression follow a normal distribution with a small number of outliers.



Standard residuals

The standard residuals indicate four outliers as seen on the residual plot

Case	Standard Residuals -5. -4. -3. ±2. 3. 4. 5.	Standard Residual: Outliers Residual
15	. . . * . . .	-4,43099
29	. . . |* . . .	4,40228
35	. . . |* . . .	4,35229
42	. . . * | . . .	-5,61845
Minimum	. . . * | . . .	-5,61845
Maximum	. . . |* . . .	4,40228
Mean	. . . |* . . .	-0,32372
Median	. . . |* . . .	-0,03935

Cook’s distance

The influence of the outliers was accessed using Cook’s distance. They were not removed since Cook’s distance values were all less than 1.

Cook's distances Case ,000 . . . . . ,082	Cook's Distances: Sorted Cook's Distance
42 . . . | . . *	0,081978
29 . . . | . . * .	0,078025
35 . . . | . *. .	0,065697
22 . . . | . * . .	0,062712
24 . . . | * . . .	0,047116
15 . . . * . . .	0,039965
8 . . . *| . . .	0,037399
14 . . . * | . . .	0,036081
47 . . . * | . . .	0,033702
53 . . . * | . . .	0,033631
27 . . . * | . . .	0,032986
17 . . . * | . . .	0,032091
32 . . .* | . . .	0,030479
13 . . .* | . . .	0,028649
19 . . *. | . . .	0,024716
2 . . *. | . . .	0,023961
54 . . *. | . . .	0,022925
26 . . * . | . . .	0,021446
5 . . * . | . . .	0,021041
34 . .* . | . . .	0,016104
52 . *. . | . . .	0,011184
43 . *. . | . . .	0,009621
41 . *. . | . . .	0,009114
12 . * . . | . . .	0,008344
16 . * . . | . . .	0,007917
3 . * . . | . . .	0,006846
10 . * . . | . . .	0,005619
7 . * . . | . . .	0,005010
18 . * . . | . . .	0,004851
4 . * . . | . . .	0,004835
38 . * . . | . . .	0,004684
55 . * . . | . . .	0,004394
51 . * . . | . . .	0,004192
48 . * . . | . . .	0,003960
20 . * . . | . . .	0,003079
49 .* . . | . . .	0,002538
1 .* . . | . . .	0,002176
40 .* . . | . . .	0,002098
21 .* . . | . . .	0,002041
33 .* . . | . . .	0,002028
28 .* . . | . . .	0,002026
30 .* . . | . . .	0,001764
23 .* . . | . . .	0,001482
37 .* . . | . . .	0,001468
39 .* . . | . . .	0,001463
46 .* . . | . . .	0,000773

Cook's distances Case ,000 . . . . ,082	Cook's Distances: Sorted Cook's Distance
6 .* . . | . . .	0,000659
31 .* . . | . . .	0,000606
45 .* . . | . . .	0,000503
50 .* . . | . . .	0,000344
44 .* . . | . . .	0,000321
11 .* . . | . . .	0,000244
36 .* . . | . . .	0,000117
25 .* . . | . . .	0,000103
9 .* . . | . . .	0,000010
Minimum .* . . | . . .	0,000010
Maximum . . . | . . *	0,081978
Mean . .* . | . . .	0,016129
Median . * . . | . . .	0,005010

MoCA vs WHODAS

Dependent Y	MOCA
Independent X	WHODAS

Least squares regression

Sample size	55
Coefficient of determination R^2	0,1729
Residual standard deviation	4,1506

Regression Equation

y = 37,1740 + -0,2189 x

Parameter	Coefficient	Std. Error	95% CI	t	P
Intercept	37,1740	5,4775	26,1875 to 48,1606	6,7866	<0,0001
Slope	-0,2189	0,06575	-0,3507 to -0,08699	-3,3287	0,0016

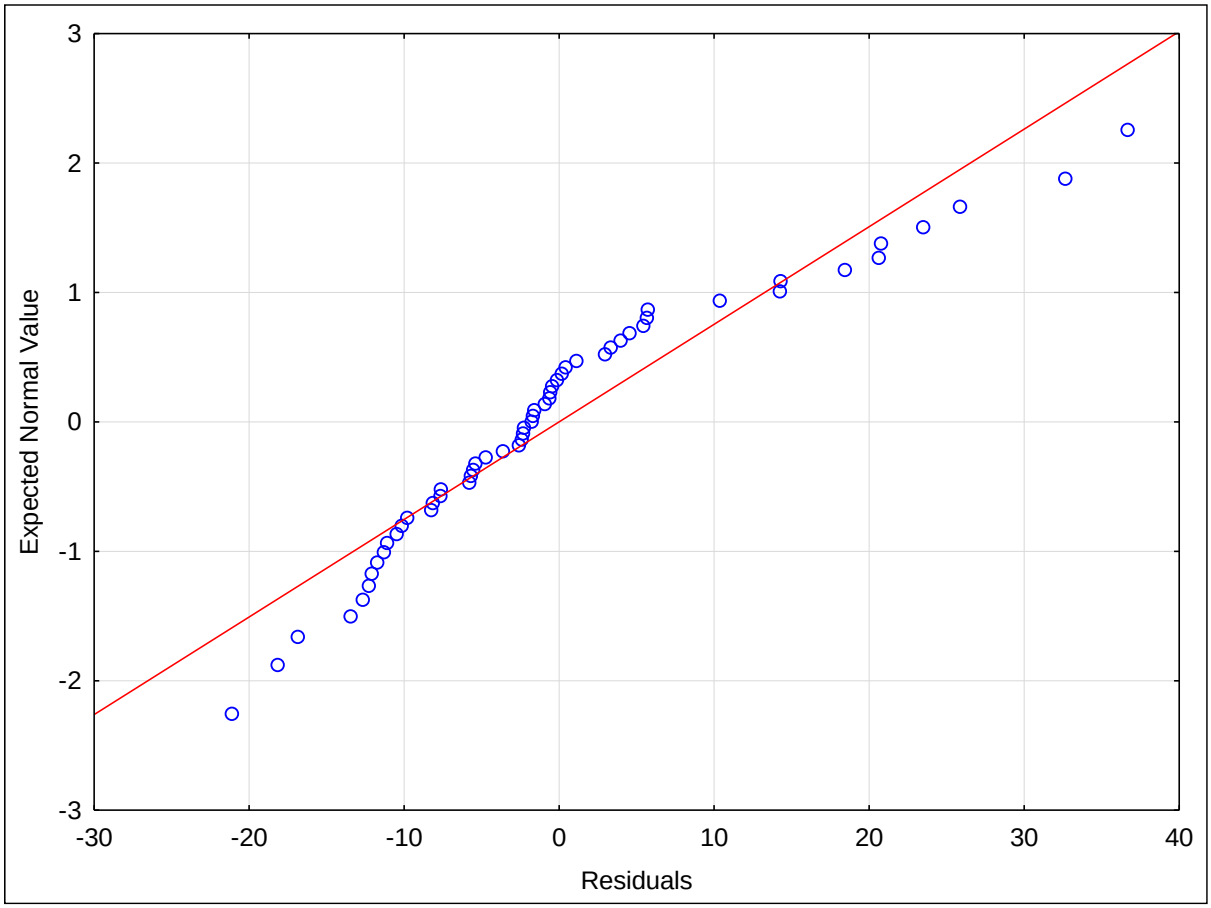
Analysis of Variance

Source	DF	Sum of Squares	Mean Square
Regression	1	190,8825	190,8825
Residual	53	913,0447	17,2273

F-ratio	11,0803
Significance level	P=0,0016

Residual Q-Q plot

The residuals of the regression show some deviation from a normal distribution with a no outliers.



Standard residuals

The standard residuals indicate no outliers as seen on the residual plot

Case	Standard Residuals -5.	-4.	-3.	±2.	3.	4.	5.	Standard Residual: MOCA (Data Spread sheet 13.4) Outliers		
								Standard Pred. v.	Standard Residual	Std.Err. Pred.Val
Minimum	.	.	.	*	.	.	.	-0,864826	-2,02632	0,742851
Maximum	.	.	.	*	.	.	.	-0,864826	-2,02632	0,742851
Mean	.	.	.	*	.	.	.	-0,864826	-2,02632	0,742851
Median	.	.	.	*	.	.	.	-0,864826	-2,02632	0,742851

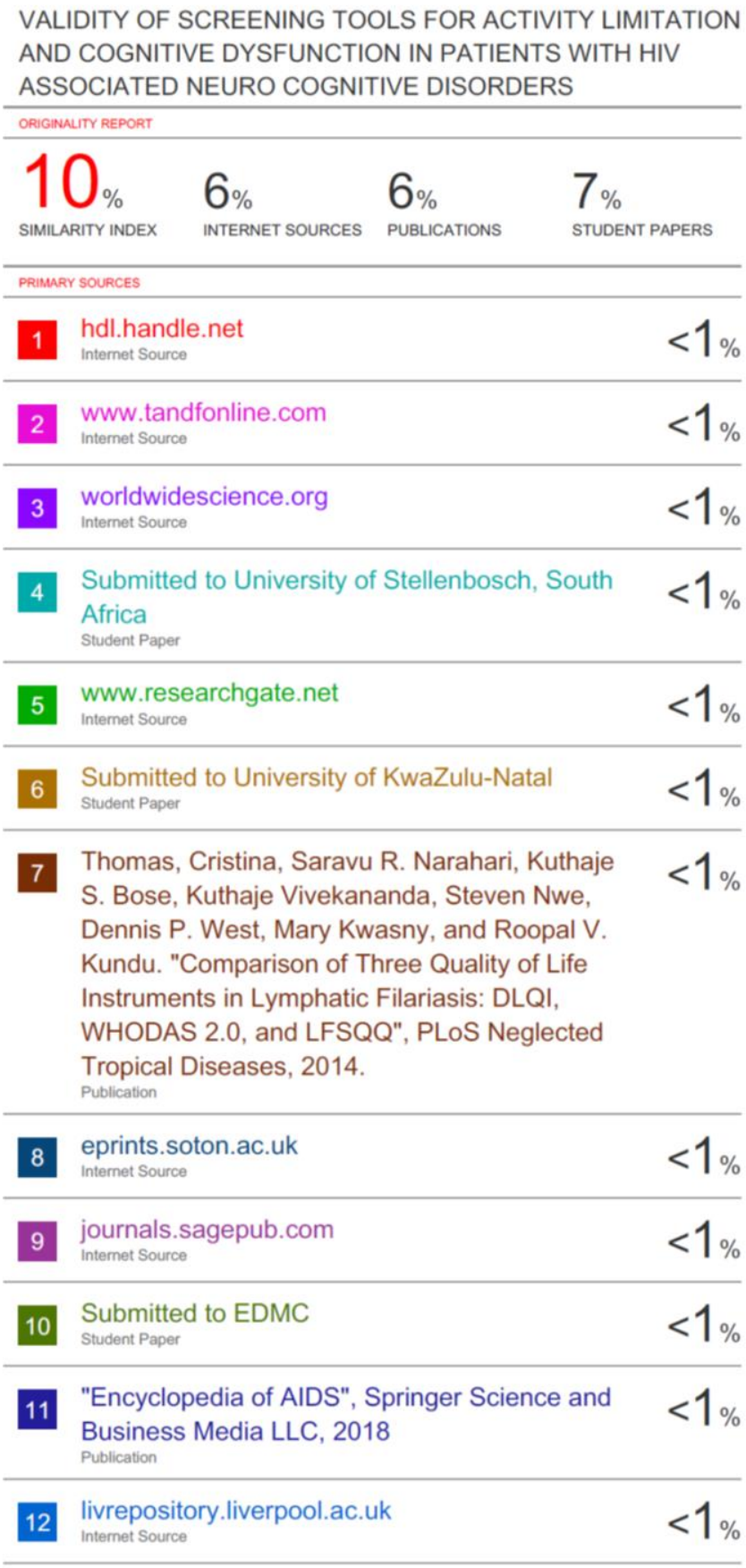
Cook’s distance

All Cook’s distance values were all less than 1.

Case	Cook's distances ,000 . . . . . ,210	Cook's Distances Sorted
		Cook's Distance
14	. . . | . . *	0,210138
27	. . . * | . . .	0,092890
38	. . * | . . .	0,070186
29	. . *. | . . .	0,064928
24	. . * . | . . .	0,053282
36	. . * . | . . .	0,051842
40	. . * . | . . .	0,051659
35	. .* . | . . .	0,039178
22	. .* . | . . .	0,038203
2	. * . | . . .	0,035115
18	. * . | . . .	0,029932
25	. *. . | . . .	0,027485
7	. *. . | . . .	0,026944
37	. *. . | . . .	0,026451
13	. *. . | . . .	0,024906
16	. *. . | . . .	0,024362
41	. * . . | . . .	0,019528
39	. * . . | . . .	0,018546
4	. * . . | . . .	0,018377
33	. * . . | . . .	0,017429
42	. * . . | . . .	0,017416
8	. * . . | . . .	0,017132
54	. * . . | . . .	0,014479
48	. * . . | . . .	0,013495
53	. * . . | . . .	0,011826
28	. * . . | . . .	0,011174
10	. * . . | . . .	0,011089
45	. * . . | . . .	0,010750
3	. * . . | . . .	0,010436
34	. * . . | . . .	0,009586
15	. * . . | . . .	0,008797
1	. * . . | . . .	0,008226
52	.* . . | . . .	0,005813
51	.* . . | . . .	0,004829
19	.* . . | . . .	0,004015
20	.* . . | . . .	0,003880
21	.* . . | . . .	0,003551
23	.* . . | . . .	0,003103
30	.* . . | . . .	0,002208
9	.* . . | . . .	0,002173
47	.* . . | . . .	0,002173
31	.* . . | . . .	0,001934
44	.* . . | . . .	0,001443
17	.* . . | . . .	0,001243
43	.* . . | . . .	0,001092
49	.* . . | . . .	0,001092

Case	Cook's distances ,000 . . . . . ,210	Cook's Distances Sorted Cook's Distance
11	.* . . | . . .	0,001037
6	.* . . | . . .	0,000556
32	.* . . | . . .	0,000517
55	.* . . | . . .	0,000409
26	.* . . | . . .	0,000408
46	.* . . | . . .	0,000347
5	.* . . | . . .	0,000045
50	.* . . | . . .	0,000006
12	.* . . | . . .	0,000006
Minimum	.* . . | . . .	0,000006
Maximum	. . . | . . *	0,210138
Mean	. * . . | . . .	0,020503
Median	. * . . | . . .	0,010750

APPENDIX P



VALIDITY OF SCREENING TOOLS FOR ACTIVITY LIMITATION AND COGNITIVE DYSFUNCTION IN PATIENTS WITH HIV ASSOCIATED NEURO COGNITIVE DISORDERS

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