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VALIDITY OF THE HIV DISABILITY QUESTIONNAIRE FOR PEOPLE LIVING WITH HUMAN IMMUNODEFICIENCY VIRUS IN SOUTH AFRICA

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

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DECLARATION

I, Adetunji Abiodun ADELEKE, declare that this dissertation is my own work. It is being submitted for the degree of Masters of Science at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

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…07……………….day of ……October……………., 2016

DEDICATION

This thesis is dedicated to my parents, Mr ADELEKE Idris and Mrs ADELEKE Ibiyemi, the patients who made this study possible and their families who suffer with them in their illness.

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Keep on walking…

ABSTRACT

Background and purpose

Disability in people living with human immunodeficiency virus (HIV) has become a major health problem especially in HIV endemic countries like South Africa. In this study we determined the validity and reliability of the first specific disability assessment instrument for people living with HIV, the HIV Disability Questionnaire (HDQ).

Methodology

Adults living with HIV were recruited from hospital clinics and AIDS service organizations in South Africa. A demographic questionnaire and HDQ paired with two reference measures were administered. To assess construct validity, factor analysis, convergent and divergent validity and level of disability against known group variables were determined. Cronbach's alpha was established to determine reliability of the HDQ.

Results

Of the 498 participants, the majority were females (68.27%) and were taking antiretroviral therapy (100%). Majority of the participants were black (95.18%) and have a median age of 41 years. Confirmatory factor analyses indicated goodness of fit similar to that previously shown for the HDQ, with the hypotheses for convergent and divergent validity and known group variables being accepted. Internal consistency was good with Cronbach's alpha values above 0.7 for all domains on the HDQ.

Conclusions

The HDQ demonstrates a variable degree of construct validity and internal consistency when administered to adults living with HIV in South Africa.

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DEFINITION OF TERMS

Disability

A disability is a function or condition judged to be significantly impaired relative to the usual standard of a group or individual. The term is used to refer to individual functioning, including sensory impairment, physical impairment, intellectual impairment, mental illness, cognitive impairment, and various types of chronic disease. Disability as defined by the International Classification of Functioning, Disability and Health (ICF) "umbrella term for these impairments, as well as activity limitations and participation restrictions" (WHO, 2001).

Activity Limitation

The execution of a task or action by an individual is defined as activity and difficulty at the individual level is considered an activity limitation(WHO, 2001).

Participation restriction

Involvement in a life situation is defined as participation and difficulty at the societal level is considered as participation restriction(WHO, 2001).

Uncertainty

Uncertainty associated with disabilities has been defined as the perception that one lacks the ability to predict, explain, or establish meaning of illness-related circumstances (Brashers, 2001; Mishel, 1988).

Episodic

Episodic disabilities are long-term conditions that are characterized by periods of good health alternated by periods of disability or illness. These periods may vary in length, severity and predictability from one person to another (O'Brien et al., 2008).

Validity

Validity is the degree to which a research study/instrument measures what it intends to measure (Gravetter & Forzano, 2009).

Construct validity

"Is the degree to which a test measures what it claims to be measuring and refers to the degree to which inferences can legitimately be made from the operationalisations to the theoretical constructs on which those operationalisations were based." (Gravetter & Forzano, 2009).

Factor Analysis

This is a type of statistical method used to show the variability among observed, correlated variables in terms of a potentially lower number of unobserved variables called factors (Kielhofner, 2006).

Confirmatory Factor Analysis

Structural equation modelling that focuses mainly with measurement models which is the relationship between latent variables and observed measures (Brown, 2015).

Convergent Validity

This can be defined as a parameter which measures the degree to which two measures of constructs that theoretically should be related are in fact related (Kielhofner, 2006).

Divergent Validity

This is also known as discriminant validity and it’s a parameter which measures the degree to which constructs that should have no relationship do, in fact, not have any relationship (Kielhofner, 2006).

Reliability

Reliability is the consistency of results when the experiment is replicated under the same conditions (Kielhofner, 2006).

ABBREVIATIONS

AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral therapy or treatment
CES-D	Centre for Epidemiologic Studies Depression Scale
COPE	Coping with Problems Experienced
DALY	Disability adjusted life years
FIM	Functional Independence Measure
HIV	Human immunodeficiency virus
HDQ	HIV Disability Questionnaire
HRQoL	Health related quality of life
ICF	International Classification of Functioning, Disability and Health
KMO	Kaiser-Mayer-Olkin
MOS-SSS	Medical Outcomes Study Social Support Survey
PLWHIV	People living with human immunodeficiency virus
QoL	quality of life
RMSEA	Root Mean Square Error of Approximation
SF-36	Medical Outcomes Short Form Health Survey
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV and AIDS
WHO	World Health Organisation
WHODAS 2.0	World Health Organisation Disability Assessment Scale-2
WHOQOL	World Health Organization Quality of Life Instruments (100 and BREF)

CHAPTER 1: INTRODUCTION

1.1 BACKGROUND AND NEED

Since the advent of antiretroviral treatment or therapy (ART), people living with human immunodeficiency virus (PLWHIV) have experienced extended survival rates, but this has been accompanied by physical, psychological and socio-cultural challenges (Nixon, Hanass-Hancock, Whiteside, Barnett, 2011). Studies have stated that these challenges occur in the early stage and continue through the stages of the disease (Banks, Zuurmond, Ferrand, & Kuper, 2015; Hannass-Hancock, Myezwa, & Carpenter, 2015; Rusch, Nixon, Schilder, Braitstein, Chan, & Hogg, 2004; Deeks, Lewin, & Havlir, 2013).

The incidence and prevalence rate of HIV infection is a significant problem in sub-Saharan Africa, as 23.5 million people are living with HIV in this region (UNAIDS, 2012). Only Botswana, Swaziland and Lesotho have a higher prevalence rate of HIV infection than South Africa (SA) (WHO, 2010). Furthermore, SA is reported to have the highest number of PLWHIV (UNAIDS, 2012).

Literature indicates that the challenges PLWHIV face may be due to the health related consequences of the condition and may be as a result of the disease itself, side effects of the medications or concurrent health conditions (Rusch, et al., 2004). The challenges can vary from emotional disturbance related to dealing with the diagnosis to the social effect of the diagnosis including isolation and stigma. Physical and/or emotional discomfort is also associated with the progression of the disease, all of which can interfere with day-to-day functioning (Ezeamama, Woolfork, Guwatudde, Bagenda, Manabe, Fawzi, et al., 2016).

O'Brien, Bayoumi, Strike, Young, & Davis. (2008) report that these health related challenges in PLWHIV can be referred to as "disability". This disability includes challenges resulting in impairments, activity limitations and participation restrictions in the individual's everyday life based on the International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001; O'Brien, Bayoumi, Strike, Young, & Davis. 2008; O'Brien, Solomon, Bergin, O'Dea, Stratford Iku, et al., 2015): This was confirmed by a study on PLWHIV, carried out by Rusch, et al. in British Columbia in 2004. They reported high levels of activity limitations and participation restrictions were experienced by between 80.6% and 93.2% of PLWHIV respectively (Rusch et al., 2004). However, this study was somewhat limited due to the homogenous nature of its participants.

It was shown in South Africa that just under half the participants of a cohort of 1042 adults taking ART, in a study by Hanass-Hancock et al. (2015), presented with one or more activity limitation when assessed by the World Health Organisation Disability Assessment Scale-2 (WHODAS 2.0). Of these participants, 35% had limitations that were considered as the onset of disability (Hanass-Hancock, et al., 2015). It is important that assessments that include other aspects of disability are validated on this population to indicate the extent of disability present in PLWHIV as these findings have implications for rehabilitation of these disabilities. It was estimated in June 2015, that 6.19 million people in South Africa were living with HIV and if 35% of this population present with limitations then rehabilitation services may be needed for 2.17 million (Stats SA, 2015). It is, therefore, important to have valid assessment instruments of disability in this population so that the extent and level of disability can be determined for the planning of adequate rehabilitation services.

This will also allow rehabilitation professionals including occupational therapists, to understand and address disability related to activity limitations, and participation restrictions in PLWHIV. The need to define and establish the role of rehabilitation in general and occupational therapy in particular in addressing these aspects in HIV care was emphasised by Hanass-Hancock et al. (2015). In order to achieve this, assessment of disability which specifically considers PLWHIV and that has been validated in a developing country like South Africa is needed.

O'Brien et al. (2008) contributed to understanding the specific disability experienced by PLWHIV when they developed the Episodic Framework on which they based assessment of disability in this population. This framework considered the fluctuating health related challenges faced by those living with HIV and included the component of uncertainty about the future as part of disability (O'Brien et al., 2008). Four types of "uncertainty" specific to living with HIV after starting antiretroviral therapy have been described. These include (a) feelings of hope as a result of improved immunological functioning; (b) anxiety as a result of role changes between ill-health and health (c) interpersonal relations, including stigmatisation; and, (d) reassessment of life (Brashers, Neidig, Cardillo, Dobbs, Russell, & Haas, 1999).

Based on this understanding of disability in PLWHIV O'Brien et al. developed an assessment specifically for individuals living with HIV, the HIV Disability Questionnaire (HDQ) in 2014. The HDQ is a 70 item questionnaire, with 6 domains which assess the disabilities in PLWHIV on 3 scales namely, the presence, severity and episodic scales (O'Brien, Solomon, & Bayoumi, 2014). The HDQ was developed from the episodic disability framework and it conceptualizes disability into 4 categories which include impairments, activity limitations, participation restrictions and uncertainty (O'Brien, Solomon & Bayoumi, 2014).

This instrument's validity and reliability have been tested in Canada and Ireland based on known group variables related to disability in PLWHIV such as age and concurrent health conditions. Convergences to activity limitations and participation restrictions assessment instruments and divergence from quality of life assessment instruments were also established. An individual's quality of life, is affected by HIV and may deteriorate as the disease progresses (Burgoyne & Saunders., 2001; Ezeamama et al., 2016). As O'Brien Solomon, Bergin, O'Dea, Stratford, Iku, & Bayoumi. (2015) point out quality of life assessment instruments consider constructs outside the scope of disability, however, they include the meaning of social relationships and "personal goals, values, and expectations" (O'Brien et al., 2015)

The convergent validity, divergent validity and confirmatory factor analysis of the HDQ is limited to samples in developed countries, thus making the generalisability of these findings to other populations difficult (O'Brien, et al., 2015). It is unknown if the HDQ is valid in identifying disability in PLWHIV in developed countries where the incidence of HIV is greater and the disease is more prevalent in females. Current co-morbid conditions are also more likely to be related to Tuberculosis (TB) and diarrhoea as well as access to medical care and medication which may be limited (Shisana, Rehle, Simbayi, Zuma, Jooste, Zungu, et a. 2014; Tun, Okal, Schenk, Esantsi, Mutale, Kyeremaa, et al. 2016; Sarfo, Sarfo, Norman, Phillips, Bedu-Addo & Chadwick, 2014).

1.2. STATEMENT OF PROBLEM

Studies on disability related activity limitations and participation restrictions in PLWHIV and more importantly in occupational therapy are limited (Hanass-Hancock, et al., 2015). Studies on disability in terms of impairments, activity limitations and participation restrictions in PLWHIV in South Africa have used generic disability assessments and at present, there is only one assessment of disability specifically developed for use with PLWHIV receiving ART, the HIV Disability Questionnaire (HDQ). The HDQ has only been validated in first world developed countries like Canada and Ireland (O'Brien, et al., 2015) although the highest incidence of HIV is in sub-Saharan Africa. (UNAIDS, 2012). There is a need to validate this instrument in developing countries and in the African context so that reliable data on disability related activity limitations and participation restrictions of PLWHIV can inform the development of appropriate services to address the health and well-being of these individuals.

1.3. PURPOSE OF THE STUDY

The purpose of the study was therefore to confirm the validity and reliability of the HDQ for a sample of PLWHIV accessing ART in Johannesburg Metro South Africa. The study is focused on a selected sample in South Africa which is a developing country. According to Stats SA, (2015), the population of PLWHIV who are accessing available ART in South Africa is the highest in the world necessitating the need to have a valid assessment tool to conceptualize the disabilities experienced by this population.

1.4 AIMS AND OBJECTIVES OF THE STUDY

The aim of this study was to determine the selected aspects of validity and reliability of the HIV Disability Questionnaire (HDQ) on a sample of PLWHIV in Johannesburg.

Objectives

1. To confirm the domains represents a single construct of the HDQ on the sample of persons living with HIV in Johannesburg Metro, to confirm if HDQ measures what it is supposed to measure.

2. To determine the convergent validity of the HDQ by testing hypotheses based on the convergence with the World Health Organisation Disability Assessment Scale (WHODAS-2) on a sample of persons with HIV living in Johannesburg
3. To determine the divergent validity of the HDQ by testing hypotheses based on the divergence with the Medical Outcomes Study Social Support Survey (MOS-SSS) on a sample of persons with HIV living in Johannesburg
4. To confirm the known group validity by comparing the level of disability assessed by the HDQ scores to known demographic and medical variables.
5. To determine the reliability of the HDQ in terms of internal consistency in the sample of PLWHIV IN Johannesburg.

1.5 THE HYPOTHESES FOR CONSTRUCT VALIDITY

1.5.1 Convergent and Divergent Validity Hypotheses

In the absence of any gold reference measures for assessing disability and quality of live in PLWHIV reference assessment instruments developed for use with people living with chronic health conditions were chosen. These assessment instruments, the WHODAS 2 and MOS-SSS have been validated on large samples (Üstün 2010, Gjesfjeld, Greeno, & Kim, 2007; Sherbourne & Stewart, 1991).

1.5.1.1 Convergent validity

It was hypothesized that the total HDQ presence, severity and episodic scores of all the domain scores would have a positive high to moderate correlation with the total score of the WHODAS 2.0 since the two reference assessment instruments measure the same construct which are the three domains (impairments, activity limitations, and participation restrictions) of disabilities.

It was hypothesised that the:

- The impairment domains on the HDQ Domain 1: physical symptoms and Domain 2: cognitive symptoms have a positive high to moderate correlation with mobility and cognitive domains on the WHODAS 2.0 respectively.

- The domains on the HDQ representing participation restrictions Domain 4: uncertainty, Domain 5: difficulties with day to day activities and Domain 6: challenges with social participation scores have a positive high to moderate correlation with participation restrictions domain on the WHODAS 2.0. Domain 5: difficulties with day to day activities correlate moderately with activity 1 and 2 domains on the WHODAS 2.
- The HDQ Domain 6: challenges with social participation scores have a positive high to moderate correlation with the getting along with people's domain of the WHODAS 2.0

1.5.2 Divergent hypotheses

It was hypothesized that the total HDQ presence, severity and episodic nature would have a low correlation with the total score of the MOS-SS which assesses the social quality of life constructs which are not congruent with the construct of disability assessed by the HDQ.

1.5.2 Known Group Hypotheses

The HDQ was developed to assess disability in an aging group of PLWHIV with concurrent health conditions, who had been receiving ART over a period of time and who were no longer employed. It was hypothesised that the HDQ would assess different levels of severity and /or the presence of disability which would differ significantly for the known group variables of age, concurrent health conditions, length of time on ART and employment status.

1.6 SETTING OF THE STUDY

The project was conducted at four different hospitals in Johannesburg namely: The Wits Donald Gordon Medical Centre, Helen Joseph Hospital, Chris Hani Baragwanath Hospital, and the Johannesburg Health District. Several factors influenced choosing these hospitals for the study, some of which are the intended generalisability of this study to the South African population, the sample size and also the accessibility to participants.

Wits Donald Gordon Medical Centre which is the first private teaching hospital in South Africa was included as it represented people living with HIV from a high socioeconomic status that were easily accessible. The HIV clinic forms part of the University of the Witwatersrand academic complex as do the clinics at Helen Joseph Hospital and Chris Hani Baragwanath Academic Hospital.

Themba Lethu Clinic at Helen Joseph Hospital, Gauteng was selected as a research site as it is the largest national antiretroviral roll-out site in South Africa, and has been active since 2004 (Right to Care, 2010). The clinic is a part of the Medicine Department of Helen Joseph Hospital and Right to Care. Right to Care is a non profit organisation that provides prevention, care, and treatment for individuals living with HIV and associated diseases (Right to Care, 2010). More than 24,000 clients have been treated at this clinic, of which 14,000 patients have been initiated on ART (Right to Care, 2010). Patients from across Gauteng and from outside the province are served by this clinic due to the clinic's high quality of care (Right to Care, 2010). Nthabiseng Thuthuzela HIV/AIDS Clinic at Chris Hani Baragwanath Academic Hospital is a government/public facility. It is a provincial primary health care facility that provides TB and HIV-related treatment, support services and care. The clinic has a client base of more than 5000 PLWHIV on ART from across Gauteng and outside the province. Participants attending outpatient clinics in the Johannesburg Health District in Hillbrow from a small informal drug rehabilitation group were also invited to participate in this study.

1.6. JUSTIFICATION FOR THIS STUDY

Studies by Hanass-Hancock, Regondi, van Egeraat, & Nixon, S, (2013) Hanass-Hancock et al. (2015), Hanass-Hancock, Misselhorn, Carpenter, Myezwa, (2016), Myezwa Buchalla, Jelsma & Stewart (2011) and Myezwa, Stewart, Musenge & Nesara (2009) and Rusch et al. (2004) have not only contributed to the understanding of disabilities experienced by PLWHIV but they have also revealed the need to have a valid assessment tool to measure these disabilities (Hanass-Hancock et al., 2013.2015, 206, Myezwa 2011,2009). The result of this study will indicate the validity and reliability of the HDQ developed to identify disability in PLWHIV, for a sample of PLWHIV receiving ART in South Africa. The level of disability in the sample used in this study confirmed research about impairments, activity limitations and possible disability affecting day-to-day activities and will also give more insight or knowledge on the missing component in lives of PLWHIV in a developing country.

The HDQ is the first HIV disability assessment tool to measure the uncertainties and episodic nature of disabilities experienced by PLWHIV. These concepts which are influenced by employment status, financial security, stigma and discrimination and length of time receiving ART which are perceived to be on high rise in sub-Saharan Africa and most especially South Africa (Abrefa-Gyan, Cornelius, & Okundaye, 2016; Govender, Fried, Birch, Chimbindi, & Cleary, 2015; Hanass-Hancock Myezwa & Carpenter, 2015a). Validating the tool in Johannesburg Metro area, South Africa will provide a basis for validation of the instrument in other African countries. The result of the study will also provide information to inform policy and research as well as support planning and implementation of rehabilitation programmes for HIV sufferers.

1.7 OUTLINE OF THE THESIS

Chapter 1 - Introduction

Chapter 1 introduces the concept of disability specific to PLWHIV. The need to assess disability in PLWHIV and to validate the HIV Disability Questionnaire (HDQ) was also introduced. The statement of the problem indicated a lack of studies on disability in HIV in developing countries including South Africa, measured by an assessment specifically designed for PLWHIV. The objectives of the study were set out as well as the main aim to determine the validity and reliability of the HDQ. The layout of the rest of the study was also introduced.

Chapter 2: Literature Review

Chapter 2 contains a review of the literature relevant to the aims and objectives of the study. This literature is classified into two sections: literature related to disabilities, living with HIV and the effect of HIV on health and literature related to the assessment of disabilities in persons with HIV. Activity limitations, participation restrictions and quality of life are reviewed in detail in the first section of this chapter while construct validity, convergent and divergent validity, confirmatory factor analysis and reliability of the HIV disability questionnaire is discussed in detail in the second section of this chapter. This chapter also reviews gaps in the literature that this study explored.

Chapter 3 : Methodology

This chapter discusses the empirical methodology adopted in this study. This involves discussion of the types of study and general design, choice of the study site and population, selection of samples and sample size, and measurement instruments. The research procedure which entails the languages used in data collection, training of research assistants and pre-testing of research instruments were also discussed. The data collection procedure is presented. This entails recruiting of participants according to ethical guidelines followed by administering of the questionnaires at the research sites. Data processing methods and data analysis plans are also presented.

Chapter 4 : Results

This chapter presents the results of the demographic characteristics of the study participants including age, gender, marital status and children, education, employment and disability grants as well as medical factors including CD4 counts, viral load, and WHO clinical staging were reported. The other sections of this chapter present the factor analysis and convergent and divergent validity of the HDQ against two reference assessment instruments, the difference in the level of disabilities experienced by participants in this study and known group variables were also reported.

Chapter 5 : Discussions and Limitations

This chapter is an overview of the findings of each objective of the study. It contains a detailed explanation of the study results according to aims and objectives of the study. Relevant literature was used to explain the outcome of this study which includes the demographic and medical outcomes, the validity and reliability of the HDQ and disabilities relevant to activity limitations and participations restrictions. Limitations were also drawn from the study which may have impacted on the outcomes in validating the HDQ for people living with HIV in South Africa.

Chapter 6 : Conclusion and Recommendations

This chapter summarizes the study and the conclusions drawn from the outcome of the study on the validity of the HDQ. Several recommendations were made based on questions that remained unanswered for further studies in specific areas such as the validity of the observed high occurrence of episodic disabilities in PLWHIV in South Africa.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

The literature review was carried out to provide information on the expected outcome of this study which aims to provide the first known valid assessment tool for the measurement of disability in PLWHIV in SA and it has two main sections. The first section deals with presentation of literature related to disability and living with HIV as well as the prevalence, types and impact of disabilities in PLWHIV in South Africa. The second section explores the validity and reliability of the HIV disability questionnaire (HDQ) by providing information on previous validation and reliability study, the limitations, the methodology used, and the outcomes. This is done to provide information on the expected outcome of this study which aims to provide the first known valid assessment tool for the measurement of disability in PLWHIV in South Africa.

The following path was adopted to identify relevant literature for this chapter. Various research portals were accessed for journal and articles related to this study some of which are Clinical Key, Cochrane Reviews, Google Scholar, Pubmed, Science Direct, Scopus, Springer, Pedro Database and Wiley Interscience. Moreover, some websites were visited to gather more detailed and related information, some of which are Centre for Disease Control, Google, South African National AIDS Control, Medical Research Council, UNAIDS, World Health Organisation, and Canadian Working Group on HIV and Rehabilitation. Finally, review of textbooks and journals, research publications and abstract were also carried out to obtain more explanatory information on this research study. The key terms used for the search were HIV, disability, activity limitation, participation restriction, quality of life, HIV disability questionnaire, validity, reliability, WHODAS, medical outcome study social support survey.

2.2 SECTION 1: DISABILITY, LIVING WITH HIV AND THE EFFECT OF HUMAN IMMUNODEFICIENCY VIRUS ON HEALTH

South Africa is facing a transition in health characterized by an escalation of free public access to antiretroviral treatment while the need for managing chronic infection as a result of the HIV persists. An increase in the prevalence of and disability exists in people living with the infection.

2.2.1 Prevalence and Incidence Rates of HIV in South Africa

The high prevalence of HIV in South Africa presents a significant problem for this country as according to UNAIDS, South Africa is reported to have the highest population of PLWHIV in the world (UNAIDS, 2014).

Table 2.1: Human immunodeficiency virus Prevalence Estimates and Number of population living with Human immunodeficiency virus in South Africa (2002 – 2015)

Year	Prevalence				Incidence	HIV population (Millions)
	Women 15-49 (years)	Adults 15-49 (years)	Youth 15-24 (years)	Total population	Adults 15-49 (years)	
2002	16,69	14.50	6.75	8.8	1.65	4.02
2003	16.85	14.58	6.35	9.0	1.63	4.14
2004	16.93	14.62	6.07	9.1	1.65	4.25
2005	17.01	14.65	5.91	9.2	1.67	4.35
2006	17.22	14.82	5.82	9.4	1.65	4.51
2007	17.52	15.10	5.76	9.7	1.58	4.71
2008	17.81	15.39	5.71	10.0	1.50	4.93
2009	18.09	15.66	5.69	10.2	1.43	5.13
2010	18.29	15.87	5.70	10.4	1.38	5.32
2011	18.42	16.01	5.64	10.6	1.34	5.48
2012	18.53	16.14	5.61	10.7	1.31	5.65
2013	18.67	16.29	5.60	10.9	1.28	5.83
2014	18.85	16.46	5.59	11.1	1.23	6.02
2015	18.99	16.59	5.59	11.2	1.22	6.19

(Source: Stats SA, 2015)

Table 2.1 reveals the growth in the population living with HIV from 4.02 million in 2002 to 6.89 million people in 2015 (Stats SA, 2015). The South African National HIV Prevalence, Incidence and Behaviour Survey conducted in 2012 indicate that increased access to ART, which nearly doubled between 2008 and 2012, has resulted in higher numbers of PLWHIV living in the community. This and the incidence in the form of new infections accounts for the increased prevalence of HIV.

The South African National HIV Prevalence, Incidence, and Behaviour Survey revealed that the HIV incidence rate, is still a concern, with new cases of HIV infection recorded in 2013 at 340,000 with a range of 310 000 to 370,000. The prevalence and incidence of HIV must be considered separately and although the prevalence of HIV has increased according to Stats SA, (2015) the incidence of HIV in South Africa has gradually reduced over the period 2002-2015. The incidence is also still an issue with SA, reported to have the highest number of HIV infections (UNAIDS, 2012). The population of people living with HIV is 6,300,000 with a range of 6,000,000 to 6,500,000 (Granich, Williams, & Montaner, 2015). According to Stats SA, (2015), higher incidence of HIV is present among women between the ages of 15-49 when compared to men of the same age bracket (Stats SA, 2015). About 17% of reproductive woman in South Africa are HIV positive.

Younger females aged 15-24 years showed a decline in HIV incidence (Stats SA, 2015). This survey and reports by the Statistician General in 2015 reported a decline from 5.3 % to 2.1% in 2002-2005 and 2008-2012 in this age group (Stats SA, 2015). This indicates a marked reduction of about 60% in HIV incidence in younger women, which may bode well for lower prevalence rates in the future et al, 2014). This confirms the changing nature of the prevalence and incidence of HIV since the introduction of ART which is reflected in research showing a change in the health and mortality patterns over the last 15 years.

2.2.2 Changing Health and Mortality Patterns in Individuals Living with Human Immunodeficiency Virus on Antiretroviral Therapy

Human immunodeficiency virus disease has now been described as a chronic disease that is episodic in nature, within the present anti-retroviral therapy (ART) era, instead of a terminal disease which it was regarded as before the introduction of ART (Nixon & Cott, 2000). This perceived change in the status of HIV has also brought about changes in needs related to living with a chronic condition, population, causes of death, disabilities and secondary complications of the illness in PLWHIV. The prevalence and causes of death in PLWHIV between the pre-ART era and this current ART era have changed. This was further explored by Palella Jr, Baker, Moorman, Chmiel, Wood, Brooks, et al. (2006) and Granich, Gupta, Hersh, Williams, Montaner, Young, et al. (2013). Palella Jr et al. (2006) recruited 6945 participants with HIV through a prospective, multicentre, observational cohort study followed for a median of 39.2 months and reported a decline in death rate from 7.0/100 person-years of observation in 1996 to 1.3 death/100 person years in 2004. This study also further revealed that although the AIDS related death rate reduced, non-AIDS related deaths increased proportionally from 13.1 percent in 1996 to 42.5 percent in 2004 where the most frequent were cardiovascular disease, pulmonary disease; hepatic and non-AIDS malignancy.

From 1995-2013, ART has prevented 4.8 million deaths in southern Africa and 7.6 million AIDS related death worldwide (UNAIDS, 2014). Granich et al. (2013) examined the HIV prevalence and annual AIDS death ratio in South Africa between 1990 and 2013 by using the United Nations Programme on HIV/AIDS (UNAIDS). They reported that South Africa has the second leading AIDS related death after Nigeria with 200,000 deaths related to AIDS and an uncertainty bound of 170,000 to 220,000 000. They also revealed that 30 in every 1000 people living with HIV dies from AIDS related causes (Granich et al., 2015).

A study on changing causes of death and mortality rates for PLWHIV in Southern Alberta was carried out by Krentz, Kliewer & Gill (2005). They recruited 1987 participants through a database search of primary care information for causes of death in patients documented to have had HIV between 1984-2003. They reported violence (3%), suicide (7%), cardiovascular disease (16%), hepatic disease (16%), non-HIV malignancies (19%) and drug overuse as the major causes of non-AIDS related deaths (Krentz et al., 2005).

Sarfo et al. (2014) in their study at various clinics and hospitals in Ghana examined the co-morbid illnesses experienced by PLWHIV and classified them into two groups, AIDS defining and non AIDS defining events. They recruited 4039 participants, starting ART between 2004 and 2010. They reported 28.83 deaths per 1000 persons during the years in which they followed up on participantswith 681 AIDS defining events were recorded per 1000 persons during these years of which TB and diarrhoea were the most common at 176(26.3%) and 155(22.8%) respectively. Fourty one non-AIDS defining events were recorded With cerebrovascular events 10(0.3%) and hepatic events 20(0.5%) being the most frequent (Sarfo et al., 2014).

More recent research in high income countries shows that 50% of non AIDS deaths are due to cancer and cardiovascular disease as PLWHIV have a 50% higher risk for myocardial infarctions (Simmons, Ciancio, Kall,, Rice & Delpech., 2013). In developing countries like South Africa TB is a major cause of death thus countries in Africa show a different picture with non AIDS deaths (Maartens, Celum, & Lewin., 2014). Because of stigma AIDS related deaths are under reported so there is no clear picture of AIDS related deaths and those that are non AIDS related (Parker & Aggleton, 2003)

However, since the advent of ART and free public access to other HIV medications in South Africa, HIV is no longer viewed as a terminal illness but rather as a chronic disorder that is episodic in nature. Therefore, the life expectancy of PLHIV is now between 35.49-43.60 years for men and 34.09-41.88 for women (Bhaskaran, Mussini, Antinori, Walker, Dorrucci, Sabin, et al., 2008; Johnson, Mossong, Dorrington, Schomaker, Hoffmann et al., 2013; Palella Jr et al., 2006; UNAIDS, 2013).

The provision of ART, especially in South Africa, remains controversial due to the cost burden on the state with 42% (40%-44%) of the people living with HIV receiving medication for the disease (Granich et al., 2015). Provision of ART is presently based on the South African Antiretroviral Guidelines updated in 2013. These guidelines are based on the studies that have been carried out on when PLWHIV should start ART. The When to Start Consortium (2009); Hammer, Eron, Reiss, Schooley, Thompson, Walmsleyet et al. (2008) and South African Antiretroviral Guidelines updated in 2013 all indicated a CD4 count of about 350 cells/millimetre cube as a level to introduce the treatment. The South African Antiretroviral Guidelines updated in 2013 also suggested that irrespective of the level of CD4 count, people with all types of TB, pregnant women and breastfeeding mothers, as well as those at WHO stage 3 and 4, are eligible to start ART. Breastfeeding mothers, patients with low CD4 count less than 200 cells/microlitre, patients with TB/HIV comorbidities with CD4 count less than 50 cells/microlitre, and patients with stage 4 irrespective of CD4 level require fast tracking (i.e. ART initiation within seven days of being eligible) (South African Antiretroviral Treatment Guidelines, 2013). The introduction of ART even at these late stages of HIV has significantly reduced the mortality rate, but it has been revealed a relative increase in the non-AIDS related death rate.

Access to medication, health behaviour and adherence to medication still remains a problem among PLWHIV particularly in South Africa. Defaulting and poor access to ART was explored by Govender et al. (2015). They studied social assistance through disability grants and recruited 1200 patients on ART from which data was collected through an exit interview in two rural and two urban health sub district in four provinces in South Africa. The participants in their study in a context of chronic poverty and high unemployment revealed that paying for transport fees to get to the facilities was a barrier to accessing medication and adherence to medication (Govender et al., 2015). They found that while temporary disability grants are provided for PLWHIV with CD4 count less than 200 cells/microlitre and who cannot work because of a mental or physical disability, the administrative process for accessing disability grant was perceived as unnecessarily onerous by participants due to the poor knowledge of the administrative process among the health workers (Govender et al., 2015).

In their study, 463 participants that were receiving the grant, 4.54% reported missing clinic while 9.72% reported missing medication dosages. Of the 804 participants that are not receiving the grant, 5.86% were reported as missing clinic visits while 16.10% were reported to be missing medication dosages. Their study provided evidence that grants provided for livelihood in impoverished PLWHIV as well as contributing to slightly better access to treatment and that discontinuation of a grant may result in deterioration of health and disability in these patients (Govender et al., 2015).

Woolgar & Mayers (2014) carried out a study on benefits and adherence to treatment related to disability grants for PLWHIV in an informal settlement in

Western Cape. They showed that most participants in their study valued their health and remained adherent to ART even when their temporary disability grant was discontinued. It was reported that health professionals felt that patients exaggerated their disability status and defaulted on medicine in order to retain their grants, while patients reported they were denied grants due to the lack of health professionals understanding of disability related to HIV (Woolgar & Mayers 2014, Simchowitz 2004).

This revealed the need for health care providers to be aware of increasing incidence of conditions and disabilities related to living with HIV so as to screen, monitor, and treat such conditions (Hsue, Squires, Bolger, Capili, Mensah et al., 2008). In terms of disability resulting from impairments, activity limitations, participation restrictions and decreased quality of life the need for valid measures of disability in PLWHIV in South Africa should be a priority.

2.2.3 Activity limitations and participation restrictions of persons living with Human Immunodeficiency Virus

The incidence and prevalence rates of HIV in South Africa do not sufficiently reveal the disability and health challenges facing PLWHIV. Disability, as stated by Convention on Rights of Persons with Disability, is a long-term impairment in physical, sensory, mental, and intellectual abilities which when in interaction with barriers limit their full and productive participation in society as others of their equal. This definition emphasizes not only the symptoms and diagnosis of the medical conditions but also the social and environmental conditions that contribute to the construct of disability (Vereinte Nationen, 2014). Disability has been conceptualised into three main categories: impairments, activity limitation, and participation restrictions, by the International Classification of Disability and Health (ICF) in order to understand disablement and the consequences of disease (Weltgesundheitsorganisation, 2001). The ICF obtained its strength not just from focusing on the biomedical concerns which centres on symptom and diagnosis but also on the social concern which focuses on how the biomedical challenges affect people’s lives and livelihood (WHO 2001). The ICF has therefore been useful as a framework through which disability related to HIV has been viewed since 1990 in Canada (Nixon & Cott, 2000; Worthington Myers, O’Brien, Nixon & Cockerill, 2005); Canada Working Group on HIV and Rehabilitation, 2011). However, using this same framework for conceptualising HIV in developing countries has only begun in the last 10 years.

Activity limitation can be defined as the difficulties an individual may experience in executing activities (Üstün 2010). Another presentation of activity limitation is limitation experienced for a long time in performing usual day-to-day activities due to health problems (WHO, 2001). Activity limitations present in many different ways. These include limitations in self-care (bathing, grooming, toileting, eating and staying by oneself for few days), understanding and communication (learning new tasks, analysing and finding solutions to problems in day-to-day life) and physical activity (e.g. standing for two hours, walking up ten steps, carrying a ten pound object) (Weltgesundheitsorganisation, 2001). There are also limitations in engaging in recreation or social activities (e.g. visiting friends, sewing, going shopping, going to the cinemas, reading) with no assistance from a caregiver, another person or assistive equipment (WHO, 2001).

Participation in daily activities may be defined as the ability to take part in society in terms of education, employment, and civic, social and family role participation as well as leisure in both environmental and socio-cultural context (Kindig, 2008; WHO, 2001). Any disturbance in participation was referred to as Handicap by the WHO in 1980, but recently, has been replaced with participation restriction (WHO, 2001).

The extended lifespan of PLWHIV has had an accompanying and corresponding increase in challenges in everyday activities which present as activity limitations and participation (Palella Jr et al., 2006). Myezwa et al. (2009) conducted a study using the ICF checklist on a sample of HIV-positive inpatients admitted to Chris Hani Baragwanath Hospital in Johannesburg, South Africa as a means of assessing the impairments, activity limitations and participation restrictions in patients living with HIV. They reported a high level of disablement among 80 HIV-positive inpatients and 45 HIV- positive outpatients (Myezwa et al., 2009). Activity limitations were found to be experienced by up to 35.5% of the population of PLWHIV even with free public access to ART (Govender et al., 2015; Hanass-Hancock et al., 2015; South African Antiretroviral Treatment Guidelines, 2013).

More recently Myezwa et al. (2011) compared data from four different cross-sectional studies that had applied the ICF. Three of these studies were carried out in South Africa and the last one in Brazil.The studies revealed issues across all groups including problems with sleep and weight maintenance (50%, 92/185), emotional functioning (49%, 185) and drive and energy (45%, 83/185) (Myezwa et al., 2011). Based on the results of this study, some participants reported pain as a major problem while some that have limited access to ART reported functional mobility as a problem (Myezwa et al., 2011). Gaidhane, Zahiruddin, Waghmare, Zodpey, Goyal, & Johrapurkar, (2008) also used the ICF to examine self-care in people living with HIV by recruiting 194 participants at a tertiary care hospital in rural India. They discovered more than 60% of the participant's experience one or more impairments in self-care (Gaidhane et al., 2008). This evidence points to the spectrum of disability, and it’s significant impact on activity limitations and participation in society but provides no information on health related quality of life (HRQoL) and how it is affecting PLWHIV on ART. Health related quality of life is related specifically to the impact of the person’s health status on their quality of life and participation in activities and society (Ferrans, 2005).

2.2.4. Health-related quality of life in persons with HIV

The WHO defines health as a state of mental, social and physical well-being and not just the absence of an illness or disease. A number of researchers, for example, McCall (1975), Myers (1987), Davidson and Cotter (1991), O’Brien and Ayidya (1991), Grayson and Young (1994), Diener and Suh (1997), Turksever and Atalik (2001) have studied on QoL and revealed that there are two dimensions to this concept; environmental and psychological dimensions. Grayson and Young (1994) showed that there seems to be an agreement that in defining quality of life, there are two fundamental sets of processes operating. The psychological component relates to gratification with life otherwise called individual or personal QoL, life satisfaction, or subjective well-being.The second environmental component is related to external conditions which trigger the internal mechanism otherwise called urban QoL, environmental QoL, community QoL, or quality of place. Since QoL is a broad concept, it is often argued that in defining it, these two dimensions should be considered.

The WHO definition of HRQoL supports the same components including the individuals understanding of their life roles and position in the context systems in which they live in relation to their expectations, goals, standards, and concerns (Hoffman, Wai, Thomas, Levin, O’Brien & Goldman 1992). This is a complex and multi-faceted concept affected by the person’s psychological state, physical health, and social relationships affecting their level of independence, personal relationships and ability to interact within their environments (Hoffman et al., 1992). In PLWHIV HRQoL was affected by the introduction of ART due to the change of the condition from terminal to chronic (Mutabazi-Mwesigire, Katamba, Martin, Seeley & Wu, 2015). The challenges presented by this included the marked uncertainties PLWHIV faced for their future with feelings of hope but having to deal with social stigma, barriers to employment and other health related issues (Rusch et al., 2004).

Measuring HRQoL is probably the most subjective assessment in health practice in persons with chronic conditions as it reveals their perspective of the burden of the disease (Ramond-Roquin, Haggerty, Lambert, Almirall & Fortin, 2016). Furthermore, HRQoL has been evaluated in relation to many chronic conditions including chronic pain, multiple sclerosis, pancreatitis, chronic heart failure and primary hypertension and measures are not specific to one condition. The measurement of HRQoL is further complicated by the differences in these conditions which result in different impairments. With regards to HIV, and the advent of antiretroviral therapy, it is undoubtedly important to consider the HRQoL of patients with the HIV infection and the impact of the ART (Perez Baño, Ruz, Jimenez, Prados et al., 2005).

2.2.4.1 Measurement of HRQoL

Health related QoL in PLWHIV has been studied in the past few years by several researchers with many different instruments. These include instruments developed for the medical outcome study (MOS) and the instrument developed at Stanford University for the AIDS time-oriented Health outcome study, the Quality of Well-Being Scale (Kaplan et al., 1984), the HIV Overview of Problems Evaluation System (HOPES), and the Functional Assessment of Human Immunodeficiency Virus Infection (FAHI) (Cella McCain, Peterman, Mo, & Wolen, 1996). Studies cited above have shown a marked reduction in HRQoL for PLWHIV, but little information is available on the reliability and validity of these assessment tools when used with PLWHIV in resource limited environments.

In 2008, O’Brien et al developed a conceptual framework and an assessment tool for disability related specifically to living with HIV which encompasses activity limitations, participation restrictions and HRQoL. The framework considers the “day-to-day health related consequences of HIV” which in their framework is conceptualised as disability. The authors felt the strength of the Episodic Disability Framework would be useful for clinicians, researchers and policy makers to understand the dimensions of HIV-related disability and the need for flexible policies in relation to grants and work.

For PLWHIV the framework assists in explaining the experience of disability to health and care providers and can provide opportunities to develop strategies that may help with disability episodes over time. However, the framework was developed on an English speaking urban population who agreed to participate in the study which may have limited the perspective of disability. The severity of the participants’ HIV was also not analysed in relation to their disability. Testing to improve this and assess which aspects of the frame affect other groups needs to be carried out (O’Brien et al., 2008).

2.3 DISABILITY IN PERSONS LIVING WITH HIV

The real burden of HIV can be viewed in the light of disability-adjusted-life-years (DALY) which measures the “ years of life lost due to time lived in a state of less than full health”. It is thus to the sum total of years a person has been living with a disability (Bradshaw et al., 2003). According to the WHO (2009), HIV accounts for above 40 percent of the DALYs in South Africa in the year 2004. In light of this high prevalence of DALYs in PLWHIV, the provision of rehabilitation services to prevent and address disabilities in PLWHIV on ART or any other HIV medication has become an important consideration in HIV management.

In order to measure disability in PLWHIV O’Brien et al (2015) based on their conceptual framework, developed an assessment instrument, the HDQ specifically for this population. The framework using a qualitative study identified three concepts related to disability in PLWHIV namely the constructs of impairments, activity limitations and participation restrictions (O’Brien et al., 2008). These concepts include (1) episodic disability where fluctuations in the dimensions of disability on a daily basis and over the persons life present challenges in everyday activities, (2) contextual factors which may add to or reduce the dimensions of disability and (3) triggers or life events that result in major episodes of disability (O’Brien et al., 2008 O’Brien, Davis, Strike, Young & Bayoumi, 2009). Each concept will be considered individually in the next section.

2.3.1 Dimensions of Episodic Disability

Health related problems in PLWHIV may occur in episodes and may fluctuate from day to day or over months and years. The initial concept in the framework was an Episodic Disability Framework consisting of four dimensions (O’Brien et al., 2008). The four dimensions of episodic disability were labelled based on the language preferred by participants living with HIV and the development of the framework was based on concepts in the ICF (O’Brien et al., 2008). The dimensions include (1) difficulties in carrying out activities of daily living which is similar to activity limitations, disability, and functional limitations, (2) impairment and symptoms which are synonymous to disablement at the level of body part, function and structure and (3) difficulties with social inclusion which are synonymous with handicap, disability and participation restrictions (O’Brien et al., 2008). The fourth dimension added was that of uncertainty which considered worry and stress about the future due to the episodic nature of the condition. This was also sometimes associated with anxiety and depression (O’Brien et al., 2009).

These four dimensions of disabilities are somewhat linked; that is the challenges in one or more of the dimensions is associated with the experience of another (O’Brien et al., 2008).

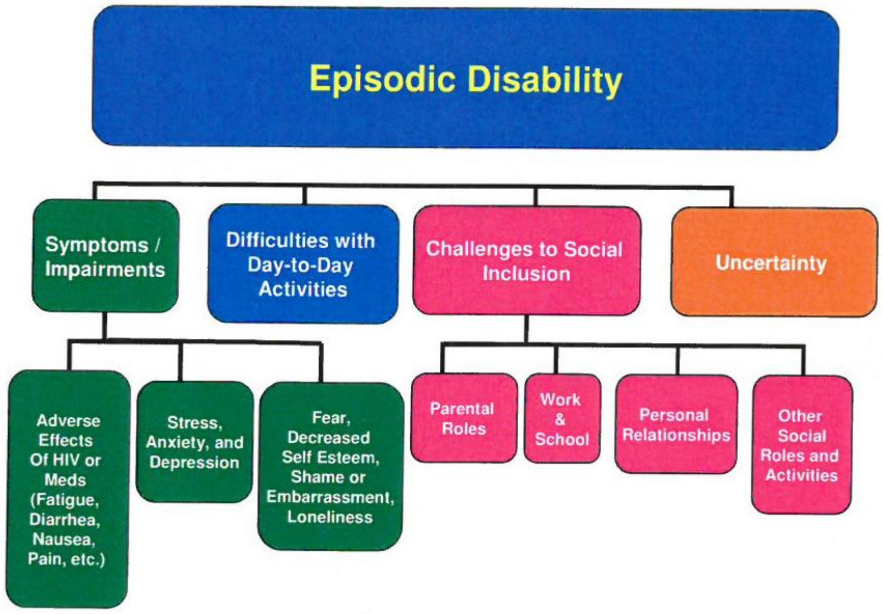

Figure 2.1 - Conceptual framework for episodic disability. O'Brien et al. (2008)

O'Brien et al. (2008) reported that the episodic difficulties may fluctuate over the course of the day or the course of living with the infection over months and years.

2.3.1.1. Symptoms and Impairments

It has been revealed that disabilities experienced by people on ART may be as a result of the infection itself, side effects of the medication and other opportunistic infections (Nixon, Forman, Hanass-Hancock, Mac-Seing, Munyanukato et al., 2011a; Rusch et al., 2004). Several immunodeficiency complications associated with inflammation have been observed by many researchers as an effect of the progression of the infection in people on long term ART calling for intense management of this disease and other disabilities (Hanass-Hancock et al., 2015; Myezwa et al., 2011; Nixon et al., 2011a; O'Brien et al., 2008; Rusch et al., 2004).

In their study on disability in PLWHIV Rusch et al. (2004) found a third of participants had up to 10 multiple impairments and 91% of participants reporting at least one impairment. The participants CD4 counts were related to the number and type of impairments seen (Rusch et al., 2004). The most common impairment reported by 78.2% of participants were psychosocial and cognitive problems related to mental body functions. This finding was supported by the findings of sensory impairment by Hanass-Hancock et al., (2015) and Myezwa et al. (2009). Neuromuscular impairment was experienced by 49.5% of participants with other medical impairments being reported by 81% of participants admitted to hospitals. Pain of varying degrees was a problem for more than three-quarters of the participants (Myezwa et al., 2009). Similar findings were reported in a second study by Myezwa et al. (2011) where impairments were associated with a high level of activity limitations and difficulties with day to day activities.

2.3.1.2 Difficulties with day to day activities

Rusch et al. (2004) and Hannass-Hancock et al. (2015) researched activity limitations experienced by PLWHIV in different studies. Rusch et al. (2004) recruited 762 participants which was equivalent to 50.5% of PLWHIV in British Columbia through an anonymous survey sent out by email (Hanass-Hancock et al., 2015; Rusch et al., 2004). They reported on activity limitations and participation restrictions in 80.6% (607) of the participants with sexual activities, vigorous and moderate activities and household chores been most frequently reported disabilities (Rusch et al., 2004).

In their study activity limitations were associated with CD4 count levels and reported 87.8% of the participants with a CD4 level below 200 cells/microlitre showed some limitations in activities (Rusch et al., 2004). Slightly fewer participants 77.4% in the group with CD4 counts between 200-500 cells/microlitre also reported some limitations in day to day activities while only 76.5% in the group with CD4 counts above 500 cells/microlitre reported some limitations. Using adjusted odds ratios of in mental function (18.71), laundry (8.41) and household chores (4.12) for those with CD4 level below 200 cells/ microlitre it was inferred that the participants with lower CD4 counts presented with more activity limitations as all odds ratio for those with CD4 level above 200 cells/ microlitre were below 4.32(Rusch et al., 2004).

Activity limitation in people living with HIV was further investigated by Hanass-Hancock et al., (2015) by recruiting cohort of people (n=1042) who had been on ART for six months or longer in a semi-urban public hospital in South Africa. They used the WHODAS 2.0 as their assessment instrument and also used a weighted score of two or more on the WHODAS 2.0 as an indicator of limitations (Hanass-

Hancock et al., 2015). Their results showed that 50.19% of the participants had no limitation whatsoever, 14.20% had a weighted score of 1 on the WHODAS 2.0, 14.88% had a weighted score of 2 and a weighted score of 3 on WHODAS 2.0 was reported by 8.16% of the participants, while 12.57% of the participants reported a score of 4 or higher (Hanass-Hancock et al., 2015). While Rusch et al. (2004) and Hanass-Hancock et al. (2015) have mapped out the activity limitations in PLWHIV they found that these limitations may be associated with the high percentage of PLWHIV on ART who presented with depression in their studies.

The results of the study by Rusch et al. (2004) needs to be interpreted with caution however as the sample under-represented people who are injection drug users, homeless, aboriginals and females and did not represent the people of other races apart from the Caucasians. The study by Hanass-Hancock et al. (2015) was also limited in that they did not map out specifically the types of activity limitations being experienced by the PLWHIV as they only classified limitations based on the six domains on the WHODAS 2.0 which include life activity, getting along, mobility, cognition, participation and self-care. Therefore there is a need for a more detailed study in a diverse population of PLWHIV.

2.3.1.3 Challenges in Social inclusion

The third dimension under episodic disability is challenges with social inclusion in the framework. Research by Rusch et al., (2004) based on the ICF framework explored the relationship between the different dimensions of disability, revealed that all activity limitations and impairments have a relationship with social role restriction. Their study indicated that the social role restriction had a very strong relationship with mental body functions (Rusch et al., 2004). Adjusted odds ratios in their study showed social role restriction were significantly related to impairments and activity limitations, most strongly to limitations in using the toilet followed by financial matters (Rusch et al., 2004).

O’Brien et al. (2014), also echoed the correlation (r=0.88) between the social role restriction and mental-emotional challenges, which also supported the study by Rusch et al. (2004). Challenges to social inclusion according to the episodic disability framework have four components: personal relationships, parental roles, work and school and other social roles and activities (O’Brien et al., 2008). Stigma and discrimination is another variable that has posed a challenge to social inclusion that has been studied extensively by many researchers some of which are Eyles, Lee, & Birch (2014), Brittain Mellins, Phillips, Zerbe, Abrams, Myer et al. (2016), Chollier Tomkinson, & Philibert (2016) and Patel, Srivastava, Sharma, & Moitra (2016). Patel et al. (2016) in examining stigma and social inclusion, recruited 30 PLWHIV in tertiary care in Surat city in the Indian state of Gujarat where 36.7% of the participants reported stigma and discrimination and about 44% reported practice of health care providers taking extra precautions while providing treatment (Patel et al., 2016). Brittain et al. (2016) reported in their study on social support, stigma and antenatal depression in HIV-Infected pregnant woman in South Africa finding that social support and stigma are interrelated and associated with depressive symptoms. A high level of stigma was discovered to have a moderate relationship with depression score and social support with no association observed between social support and depression scores (Brittain et al., 2016) .

2.3.1.4 Uncertainty

This domain of episodic disability has been described as a source of fear, anxiety, emotional distress and depression for people living with HIV. With the continuous increase in public access to ART, PLWHIV have extended survival rates and are hence faced with new uncertainties as they plan to live rather than avoid death (O'Brien et al., 2008). A high population of PLWHIV will have to reconstruct their identities not as a person living with a deadly disease but a chronic one and also renegotiate their life priorities (Brashers, Neidig, Cardillo, Dobbs, Russell, & Haas., 1999; Hanass-Hancock et al., 2015; Nixon et al., 2011; O'Brien et al., 2008). Brashers et al. (1999) define uncertainty to be the "individual's inability to give meaning to illness when outcomes are unpredictable and when the disease and its treatments and symptoms of care are highly complex, lacking information and ambiguous" this shows that the uncertainty with any chronic illness is as difficult as the impending death (Brashers et al., 1999:501).

Mishel's Uncertainty in Illness Trajectory, conceptualizes uncertainty as the interpersonal, social and emotional unknowns associated with illness progression, diagnosis, and long term prognosis (Mishel, 1990). O’Brien et al. (2008) conducted a study to determine uncertainty in PLWHIV and discovered sources of uncertainty similar to that reported by Mishel. (1990) and Brashers et al. (1999) even though they did not try to find out if the participant could understand their illness unlike Brashers et al. (1999) they found out that participants in their studies could understand and communicate their uncertainty (O’Brien et al., 2008).

2.3.2 Contextual Factors and Triggers of Disability

The other two concepts of the framework developed by O’Brien et al. (2008) are contextual factors and triggers of disability.(O’Brien et al., 2008)

2.3.2.1 Contextual Factors

Contextual factors are regarded as the health related challenges in relation to the features that altered their experiences (O’Brien et al., 2008). Two groups of contextual factors have been identified in the ICF. In 2008, O’Brien et al. describe these factors in relation to PLWHIV with each having two subcategories namely extrinsic: social support and stigma; intrinsic contextual factors: personal attributes and living strategies.

Extrinsic contextual factors are stigma and social support. O’Brien et al. (2008) stated that stigma results from discrimination from family, friends, employer, work colleagues, employers and health care providers due to the HIV status of people, ethno-cultural background, their sexual orientation, exacerbated disability, employment status and gender(O’Brien et al., 2008). They also stated that social support includes emotional and practical support received from family, friends, pets or partners and community; support from policy and programmes and personnel and health care support services. When these factors are considered from an HIV perspective the implications may be broader than for other chronic conditions and this was accommodated in the development of the HDQ particularly in terms of stigma and family and community support which is experienced internationally (O’Brien et al., 2008).

Intrinsic factors include personal attributes and living strategies (O’Brien et al., 2008). Non-modifiable characteristics are co-morbid illness inherent to an individual and age (O’Brien et al., 2008). Living strategies are attitudes, behaviours, and beliefs people adopts in order to live with HIV and other opportunistic infections (O’Brien et al., 2008). These includes seeking and maintaining a sense of control over life and the illness, seeking communication with others, developing and adopting beliefs and attitudes to manage living with HIV and blocking HIV out of mind (O’Brien et al., 2008). The strength of the use of these contextual factors in the assessment of disability in PLWHIV is that context can be linked to both disability and the episodic nature of the disability that occurs with HIV. This offers a new perspective on the intrinsic factors by offering a “foundation from which to build strategies to mitigate episodes of disability experienced by adults living with HIV” (O’Brien et al., 2009:10).

2.3.2.2 Triggers of Disability

Triggers for disability are life changing events which affect the person living with HIV that may result in impairments, activity limitations or participation restrictions (O’Brien et al., 2008a). Four examples of disability triggers included: receiving an HIV diagnosis; experiencing a serious illness; suffering a loss of others and starting or changing antiretroviral medications (O’Brien et al., 2008).

The view of disability as conceptualised by O’Brien et al.(2008) for PLWHIV emphasises the provision of rehabilitation services, to prevent and address impairments, activity limitations, participation restrictions in PLWHIV on ART or any other HIV medication (O’Brien et al., 2008). This is an important consideration in HIV management. Chetty and Hanass-Hancock in 2016 emphasised the need for decentralised rehabilitation services and concerns about the lack of major therapeutic disciplines like occupational therapy and the speech and language therapy services in this field of practice. (Chetty and Hanass-Hancock 2016)

One of the major concerns in the rehabilitation field is to identify and validate assessment tools for disability in PLWHIV so that the prevalence and severity of disability in this population can be recognised and adequate interventions provided. This is also essential if effective services are to be delivered to this population.

2.4 SECTION 2: ASSESSMENT OF DISABILITY IN PERSONS WITH HIV

Both demographic information and standardised assessments are required to complete a full assessment of disability in PLWHIV. The demographic factors that are associated with disability in PLWHIV are reviewed first.

2.4.1 Demographic Factors

Demographic factors are known to be associated with HIV and disability (Hanass-Hancock, 2015; Myezwa et al., 2009; Rusch et al., 2004). These include old age, low socioeconomic status, gender, educational level, and white ethnicity. In middle and low income countries, social support such as family support, support from friend and community at large are also revealed to be positively associated with activity level, social role inclusion and quality of life (Bauman Reis, Sallis, Wells, Loos & Martin, 2012). In sub-Saharan Africa industrialisation often results to growth in cities, leading to informal settlements that may lead to regression in health (BeLue Okoror, Iwelunmor, Taylor, Degboe, Agyemang,& Ogedegbe., 2009). This result was further confirmed in research done in Khayelitsha by Belue et al. (2008), SA. Khayelitsha is a partial informal settlement in the Western Cape. The researchers noted that the inability to depend on a partner and lack of portable water in the home had the strongest association with perceived stress (BeLue et al., 2008). Transport and mobility stress often occurs in informal settlements (BeLue et al., 2009, 2008). It is therefore to be expected that environmental factors such as accessibility (transport, distance, and mobility) are associated with activity level, social role participation, and quality of life in individuals living in low- and middle income countries (Bauman et al., 2012).

2.4.2 Assessment tools

While many tools used for assessment of disabilities in PLWHIV for example WHODAS 2.0 and MOS-SSS, had been developed before the era of ART which has changed the course of HIV from a terminal disease to a chronic illness (Palella Jr et al., 2006) other recently developed assessment tools for example the HIV specific HRQoL questionnaire focuses on employment and social relationships (Duracinsky, Herrmann, Berzins, Armstrong, Kohli, Le Coeur, et al., 2012a;

Duracinsky, Lalanne, Le Coeur, Herrmann, Berzins, Armstrong et al., 2012b) are now available. The scope of these tools such as values, goals and expectation goes beyond the scope of disability and the tools were not developed to evaluate the episodic nature of the disability experienced by PLWHIV.

Other instruments such as the Brief-Coping with Problems Experienced (COPE), HIV stigma scale, the Centre for Epidemiological Studies Depression Scale and the HIV Symptom Index have been used in relation to determining disability in PLWHIV. Assessment tools that have been used in research to assess activity limitations and HRQoL of PLWHIV include the WHODAS 2.0 and MOS-SSS and the HDQ developed specifically to be used with PLWHIV.

2.4.2.1 World Health Organization Disability Assessment Schedule (WHODAS 2.0)

This is a generic, practical assessment instrument that measures health and disability in a clinical practise or at a population level (Üstün, 2010). WHODAS 2.0 conceptualise functioning into six domains, cognition (understanding and communicating), mobility (moving and getting around), self-care (dressing, eating, hygiene and staying alone), getting along (interactions with other people), life activities (work, leisure, domestic activities and school), and participation (participation in society and community activities) (Üstün, 2010).

Many measures of disability have already been published; they are sometimes regarded as functioning measures and health status measures (Üstün, 2010). Aspects that make WHODAS 2.0 different are (1) direct link to the ICF as it covers ICF domains and applies to all diseases (2) cross-cultural comparability, (3) psychometric properties and (4) ease of use and availability (Üstün, 2010). Reliability and validity of the WHODAS 2.0 have been carried out in different geographical representations of WHO regions (taking into account cultural and linguistic variation) some of which are Nigeria, United States of America, Greece, and Luxemburg to mention a few. The assessment tool has good construct validity with confirmatory factor indicating that the six domains are independent of each other. Test-retest reliability is adequate concurrent validity to Medical Outcomes Study's 36-Item Health Survey (SF-36), the Functional Independence Measure (FIM), World Health Organization Quality of Life Instruments (WHOQOL-100 and

WHOQOL-BREF), in different populations. The internal consistency is between 0.94 and 0.98 for the various domains (Üstün, 2010).

Different versions of the WHODAS 2.0 exist, and these include three 36 item versions (interview-administered, self-administered, and proxy-administered), three 12 item versions (interview-administered, self-administered, and proxy-administered) and one 12+24 item version in interview format (Üstün, 2010). Scoring of the WHODAS 2.0 both the short and full versions involves two basic options: simple and complex scoring (Üstün, 2010). The simple scoring system involves summing of the assigned numbers to the item on the questionnaire (1), 'none' (2), 'mild' (3), 'moderate' (4), severe (5), extreme while the complex scoring method takes into account multiple levels of difficulty for each WHODAS 2.0 item, therefore, allowing analysis that makes use of the full information of the response categories for comparative analysis subpopulation and population at large (Üstün, 2010).

Handling missing data within WHODAS 2.0 involves two approaches: simple and complex approach (Üstün, 2010). The simple approach varies based on the version of WHODAS 2.0. For the 12 item short Version, when one item is missing, the mean of other items is used to assign a score to the missing item. When working with WHODAS 2.0 full version, if a participant is not working and has given a response to 32 items, the score can be used as it is and then compared with that of the 36 item version. The Complex approach is used when working with large data sets where more than one or more than two items are missing in the 12 item and 36 item versions respectively (Üstün, 2010).

2.4.2.2 Medical Outcome Study Social Support Survey (MOS-SSS)

The MOS-SSS is a brief, self administered, multidimensional questionnaire developed to assess social support in a medical outcome study (Sherbourne & Stewart, 1991). The MOS-SSS contains 19 functional support items, arranged in a 5-point linkert type scale, closely related to different dimension of social support: (1) information support (guidance, advice, information, or feedback- 4 questions) (2) affection support (affection and expression of love-3 Questions) (3) positive social interaction (affection and expression of love- 3 questions) (4) tangible support (provision of behavioural assistance, medical aid- 4 questions) and (5) emotional support (Sherbourne & Stewart, 1991).

Five answer options are available for every question on the assessment tool: ‘none of the time,’ ‘a little of the time,’ ‘some of the time,’ most of the time,’ and ‘all of the time’. In addition to social support, the MOS-SSS have two items that evaluate social network (number of relatives and close friends) (Sherbourne & Stewart, 1991). The MOS-SSS has 3 different versions: 18, 12 and 4 items versions and score on each scale is calculated as a percentage of the maximum score possible in that dimension (Gjesfjeld et al., 2007; Sherbourne & Stewart, 1991).

Various studies have been carried out to determine the reliability and validity of MOS-SSS. According to Sherbourne et al. (1991) the MOS-SSS has a high internal consistency (Cronbach’s alpha = 0.97 and sufficient test- retest reliability α=0.78). Soares et al. (2012) assessed the psychometric properties of the MOS-SSS Brazilian Portuguese version in a survivors of Hodgkin’s lymphoma (HL) and reported that item-correlated person correlation coefficient between items and their dimension range from 0.57 to 0.76, internal consistency assessed using Cronbach’s alpha was 0.95 for the overall scale and varying from 0.78 to 0.87 for the 5 subscales. In addition, an exploratory factor analysis yielded a 3- factor solution, positive social interaction, aggregating affection, and informational and emotional dimensions of social support (Soares et al., 2012).

2.4.2.3 HIV Disability Questionnaire

This questionnaire was developed by O’Brien et al. (2014) specifically to assess the disabilities of PLWHIV in view of the extended life span and aging in this population. Persons living with HIV are experiencing episodes of illness and wellness associated with adverse effect of the antiretroviral therapy, the disease itself and other opportunistic infections (Gaidhane et al., 2008; Weiss et al., 2010; Willard et al., 2009). In light of this, disability has become as important as mortality in this population (Üstün, 2010).

Developed by O’Brien et al. the HDQ is a self-administered questionnaire that assesses the nature of disability experienced by PLWHIV on three scales namely severity, presence and episodic scales. The HIV disability questionnaire is the first HIV specific disability measure to be developed based on a conceptual framework that examines disability experienced by PLWHIV (O'Brien et al., 2014). O'Brien et al., (2015) developed the HDQ to assess disability in men from an urban area who had been living with HIV and taking ART. The assessment was validated on participants with concurrent health conditions who were not working.

The internal consistency, construct validity, and test-retest reliability of this new HIV specific questionnaire was further investigated by O'Brien et al. (2015) in an international study on PLWHIV in Ireland and Canada. The sample consisted of 235 adults (18 years and older) living with HIV recruited from hospital clinics, and AIDS services organisation and administering the HDQ with seven other reference measures namely; WHODAS 2.0, SF-36, MOS-SSS, HIV Symptoms Index, HIV Stigma Scale, COPE, Centre for Epidemiologic Studies Depression Scale (CES-D). O'Brien et al. (2015) calculated the HDQ disability presence, severity, episodic scores (scored from 0-100). They reported a Cronbach's alpha score of between 0.97 and 0.96 for the severity and episodic scales in Canadian and Irish studies respectively.

Construct validity was assessed using 40 a priori hypotheses of correlations confirming both convergent validity and divergent validity with the seven reference instruments mentioned above. Of these 32 (80%) were supported in the Canadian study and 22 (55%) were supported for the Ireland participants (O'Brien et al., 2015). Test-retest reliability ranges from ICC values of 0.80 to 0.89.

O'Brien et al. (2015) concluded that the HDQ is valid and reliable in Canada and Ireland. There were significant differences in the presence, severity and episodic scales for the two countries due to known group demographic and medical variables in the two samples. The participants in Ireland differed from those in Canada in that they were younger, they had fewer concurrent health conditions and approximately 50% were employed. The median time since diagnosis with HIV of the Canadian sample was also eight years earlier than that of the Irish sample so the Canadian participants had been living with HIV for much longer.

The developers of The HDQ stated that the results of this validity study cannot be generalised as the study was completed in resource rich countries necessitating a validation study of the HDQ in a resource limited environment such as Such Africa.

2.5 CONCLUSION

Human immunodeficiency virus infection is a significant health related issue in SA, with prevalence high in both genders between the ages of 15-49 and more common among women. With local ART initiation guidelines now being aligned with those recommended internationally, the mortality rate in PLWHIV could be reduced with a corresponding increase in the number of PLWHIV developing disability. Disability rate in PLWHIV has already been reported to be high in PLWHIV in South Africa. Both national and international data has revealed that impairment; activity limitation and participation restriction in PLWHIV may be related with a corresponding decline in quality of life. In light of the need for rehabilitation services to prevent, control and manage disabilities in PLWHIV as the burden related to HIV is greater in South Africa than in other parts of the world. The HDQ was develop but requires validity and reliability in a resources limited country.

CHAPTER 3: METHODOLOGY

3.1 INTRODUCTION

In this chapter, the empirical research methodology is presented including the study design, study population and criteria for selection of participants in the study. Ethical considerations and data collections tools, data methods and data analysis are also presented.

3.2 TYPE OF STUDY AND GENERAL DESIGN

A quantitative, descriptive, cross-sectional research design was used. This is a study design that aims to provide data on a selected sample of the population of PLWHIV. It is a suitable design for this observational study where variables will not be manipulated but instead, some feature of the sample, such the presence, severity and episodic nature of disability in PLWHIV will be described (Kielhofner, 2006). A cross-sectional study compares persons at a single point in time. This is a quantitative descriptive study as the relationships between variables will also be compared.

The validity of the HDQ for the South African sample were also determined using a correlation study design. The convergent and divergent validity of the HDQ with other instruments assessing activity limitations and quality of life were determined.

3. 3. STUDY SITES AND POPULATION

3.3.1 Study sites

Four study sites were chosen because of various factors. Some of the factors were to provide diversity in the sample and supported the intended generalisability of this study by including hospitals from the suburban, and townships areas to reflect not just the distribution of disability between the different socioeconomic groups but also the racial distribution of HIV and accompanying disabilities. The vicinity of all sites which was within a 20km radius of the University of the Witwatersrand Education Campus based on convenience sampling for the researcher in terms of transport. Helen Joseph Hospital (Themba Lethu Clinic) and Chris Hani Baragwanath Hospital (Nthabiseng Thuthuzela Clinic) and the Donald Gordon Medical Centre and a fourth site involved individuals associated with a drug rehabilitation support group were the sites where participants were recruited (see Chapter 1).

3.3.2 Population

The participants in this study were adults with HIV who have been on ART for six months or longer. People living with HIV who attended Helen Joseph Hospitals (Themba Lethu Clinic), Chris Hani Baragwanath Hospital (Nthabiseng Thuthuzela Clinic), an informal drug rehabilitation support group and Donald Gordon Medical Centre between June and July 2016 was included in this study.

3.3.3 Sample selection

The sample was conveniently selected among individuals living with HIV, on ART, living in Johannesburg Metro, South Africa.

3.3.4. Inclusion criteria:

Participants had to be

- Adults (18 years and above)
- Persons with HIV and on antiretroviral medication for six months or longer
- Must be able to answer self-report questionnaires independently or in an assisted interview format

3.3.5 Sample size

The sites used to recruit participants, provide services to approximately 11,000 individuals and according to Cochrane's formula for a survey sample size of a minimum of 400 participants, would provide a statistically representative sample of this population, with an acceptable error at 5% (p=0.05) for the categorical data used in this study (Barlett et al., 2001). This sample size was also adequate for the factor analysis where a suggested 3-6 subjects-to-variables ratio recommended by Arrindell & van der Ende (1985) indicating a sample size of 350 with a ratio of 5:1 should be included for the 70 items on the HDQ. The sample was larger than the minimum sample of 250 they recommended (Arrindell & van der Ende 1985). The choice of approximately 5 participants per item on the HDQ was used as the ratio of 2:1 – 5:1 is reported more often in the literature (25.8%) in PsychINFO articles than any other ratio (Costello, A& Osborne 2005).

The sample size was adequate for the convergent and divergent validity of the HDQ as based on the sample size calculation used by O'Brien et al (2015) in which they required weak correlations of 0.3 to show significant divergence between the HDQ and Medical Outcomes Study Social Support MOS-SSS) at a power of 90%.

3.4. ASSESSMENT INSTRUMENTS

The following instruments were used: a demographic questionnaire, HDQ and WHODAS 2.0 to assess activity limitations and participation restrictions and the, MOS-SSS to assess quality of life related to social support.

3.4.1 Demographic questionnaire

A demographic and medical history questionnaire was developed by the researcher (Appendix A) and in view of the demographic factors affected by HIV reviewed in the literature the following variables were added to the demographic questionnaire: questions pertaining to age, sex, marital status for information regarding support, comorbidities, current employment status, monthly income and/or grants received by participants; housing environment for an estimation of size of housing and transport.

The questionnaire consisted of fourteen questions in two categories: personal background and medical history. Questions to assess variables such as age, gender, marital status and the number of children they have were presented first. The highest level of education and employment status was also established.

The questionnaire was piloted for content validity by giving it, together with the study aims and objectives, to two professors of medicine with academic and clinic experiences in HIV populations for review. Their suggestions and comments were implemented and minor adjustments made accordingly.

Three questions were added indicating if the participants are receiving the disability grants or not, confirming the period since the antiretroviral therapy was initiated and the recording of the participants' viral load.

Information about illnesses, surgery, CD4 counts, viral load and length of time on ART was confirmed where possible by reviewing the participants' clinic files. Participants were asked to give permission for the file to be consulted if it was available.

3.4.2 HIV Disability Questionnaire (HDQ)

The HDQ is a 69 item questionnaire which comprises of six domains: physical, cognitive, mental and emotional health symptoms and impairments, difficulty with activities of daily living, barriers to social participation, and uncertainty (Appendix B).

Table 3.1 Structure of the HIV Disability Questionnaire

Domain	Physical symptoms and impairments	Cognitive symptoms and impairments	Mental and emotional health symptoms and impairments	Uncertainty (or worry about the future)	Difficulty with day-to-day activities	Challenges to taking part in social and community life
	1	2	3	4	5	6
Number of items	20 items	3 items	11 items	14 items	9 items	12 items

Item 70 on the HDQ allows for the PLWHIV to report whether they are having a good or bad day at the time they filled out the questionnaire (O'Brien et al., 2015).

The HDQ measures the presence, severity and episodic nature of disability experienced by PLWHIV and scores from these measures are transformed to a score of a linear range of 0-100. The HDQ was developed on a five point Likert type scale from 0-4.

The HDQ is scored from the Linkert scale in three different methods to determine the presence, severity and episodic nature of disability

Scoring:

a. Presence scale

For the presence scores, the results of each domain of the HDQ is scored by give 0 (not present) where PLWHIV indicates no disability and 1(present) where PLWHIV indicates disability against each item irrespective of severity. The presence of disability score is calculated by determining the number of items where disability is marked present against the total number of items answered and multiplied by 100.

b. Severity Score

For the severity scores, each domain score is added up based on the score from 0 to 4 calculated by dividing the total possible score for that domain which is the number of items answered multiplied by four which is the highest possible score for any item. The final score is multiplied it by 100. The total severity score is calculated by summing the total domain scores and dividing it by the total number of domains which is six.

c. Episodic scale

The HDQ episodic scale has a Yes or No option for each of the 69 items on the scale. The episodic nature of disability score is calculated by determining the number of yes responses indicating fluctuation in disability which are divided by the total number of responses and multiplied by 100.

Each of the six domains of the HDQ is scored separately for each scale and then a total score for each scale was calculated by summing the total scores of these domains and dividing it by the total number of domains, thus resulting in three different scale results for the HDQ.

3.4.3 World Health Organisation Disability Assessment Scale (WHODAS-2)

The WHODAS-2 contains 36 items that assess disability in six domains (Appendix C).

Table 3.2 Structure of the World Health Organisation Disability Assessment Scale

Domain	Mobility	Cognition	Self care	Getting along with people	Life activities (domestic, leisure, work and school)	Participation in society

	1	2	3	4	5	6
Number of items	6 items	5 items	4 items	5 items	8 items	8 items

Scores range from 0-100, where 0 indicates an absence of disability across all domains while 100 shows full disability (WHO, 2001). The WHODAS 2 has validity and reliability for individuals with chronic conditions (Kemmler et al., 2003).

A complex scoring approach is utilised for the WHODAS 2.0 based on item response theory (IRT) (Üstün, 2010). Each item on the WHODAS 2.0 was coded as “none”, “mild”, “moderate”, “severe” and “extreme” separately the summary score was determined by differentially weighting the items and the levels of severity.

The scoring uses three steps:

Step 1- summing of recorded items scores in each domain

Step 2- summing of all the six domains

Step 3- converting the summary scores into a score ranging from 0-100

The WHODAS 2.0 therefore has a domain specific score for each six domains: mobility, self-care, cognition, getting along, life activities (household and work) and participation restrictions as well as a total score.

3.6.4 Medical Outcomes Study Social Support Survey (MOS-SSS)

This MOS-SSS assessment tool contains 20 items which focuses on assistance, companionship or other types of support availability when needed (Appendix D). Scores on this assessment instrument also range from 0-100 with 0 indicating no available support when needed and 100 indicating assistance is always available when needed. This tool shows construct validity and reliability when used with PLWHIV (Sherbourne, et al., 1991).

Table 3.3 Structure of the Medical Outcomes Study Social Support Survey

Domain	Emotional and informational support	Tangible support	Affectionate support	Positive social interactions
	1	2	3	4

Number of items	8 items	4 items	3 items	3 items
	items 3, 4, 8, 9 13, 16, 17, and 19	items 2, 5, 12 and 15	items 6, 10, and 20	items 7, 11, and 18

An additional item, item 14 is scored alone. A complex scoring method was used for the MOS-SSS. The scores for each of these items are converted to a score of metric range from 0-100 by dividing the total scores by the maximum possible score and dividing by 100.

To calculate each domains scores, item scores were summed and divided by the total number of items in the domains while the total MOS-SSS score was calculated by adding the total domain scores and dividing it by the total number of domains.

3.5 LANGUAGE USED IN DATA COLLECTION AND TRAINING OF RESEARCH ASSISTANTS

3.5.1 Language review

South Africa has 11 official languages: Afrikaans, English, isiNdebele, isiXhosa, isiZulu, Sesotho sa Leboa, Setswana, siSwati, Tshivenda and Xitsonga. The *lingua franca* of the country is English, due to it being the language of business, media and politics (Stats SA, 2011). Most frequently spoken languages at the study sites, where this research was conducted in Gauteng province are isiZulu (19.8%), English (13%), Afrikaans (12.4%) and Sesotho (11.6%) (Stats SA, 2011).

According to Ballington et al. (2012) and Wood, Hanrahan, Coetzee, Koekemoer & Brooke, (2010) in two unpublished PhD theses from the University of the Witwatersrand subjects in research studies in Gauteng province, prefer to provide information in English and very rarely select to provide information in their home language (Ballington et al., 2012; Wood et al., 2010). Therefore, data capturing forms, information sheets and consent forms were kept in English.

However the possibility did exist that patients at the clinics even though they might speak some English would not be comfortable reading and completing self-report questionnaires unassisted in English. Therefore, research assistants fluent in isiZulu which is commonly spoken in Gauteng Province were recruited to assist participants with understanding questions on the self-report questionnaires used in this study. They also explained the contents of the information sheets and the consent forms to participants who did not read or understand written English.

3.7 RESEARCH PROCEDURE

The project was submitted to the University of the Witwatersrand's Human Research Ethics Committee (HREC), and ethical clearance was granted (clearance certificate M160407 (Appendix E)

The project was approved by the Faculty of Health Sciences of the University of the Witwatersrand Permission to conduct the project at The Wits Donald Gordon Medical Centre (May 2016), Helen Joseph Hospital (June 30) and Chris Hani Baragwanath Hospital (July 2016) was received from the hospital management followed by consultation with the medical manager of the clinics for written permissions (Appendix F). The participants associated with the drug rehabilitation group who attended Hillbrow Clinic were approached on an individual basis

Before data collection was started, four research assistants were recruited and trained to assist with translation and reading of the questionnaire for participants who needed help in understanding the questions. Adequate training was given to the research assistants so they did not expand on question but delivered the exact question.

Times that were suitable to the clinic were determined with the mangers for data collection to take place and arrangements were made for the staff at the clinic to recruit patients into the study as requested by the ethics committee.

3.7.1 Training of research assistants

Four research assistants were recruited for this study, two of whom assisted with data collection at the Themba Lethu Clinic, and another two who assisted with data collection at the Nthabiseng Thuthuzela Clinic. Two of these assistants were students at the University of the Witwatersrand while the other two were students at the University of Johannesburg.

All the research assistants were recruited for their language skills as they were fluent in English and isiZulu. One research assistant could also speak eight other South African official languages fluently including (isiZulu, Tsonga, Tswana, Venda, Ndebele, Xhosa, Swazi, and Northern Sotho) and another was fluent in isiXhosa.

Training sessions were held with the research assistants and the study aims and objective were discussed with them and their role in assisting with data collection was explained. They were provided with a document with the most important facts to remember when assisting participants to complete the questionnaires. The four assistants were also made familiar with the consent forms and information documents. The data capturing forms, consent forms and information documents were translated into isiZulu verbally by each research assistant which was recorded by the researcher. The recorded translated information was given to two researchers who are PhD students at the Department of Public Health University of the Witwatersrand and who understand isiZulu with the English version. They translated the information back into English and identified the best verbal translations of the questions and information sheet. The research assistants were provided with a copy of these verbal translations to listen to and follow during data collection.

3.7.2 Pre-Testing of research instruments

The research instruments were pre- tested for a week prior to the collection of data followed by an update of the demographic questionnaire. The questionnaires were pre- tested with 10 individuals (HIV status unknown) five of whom are fluent in English and five who were not. The aim was to assess the feasibility, the simplicity, the deficits and the weakness of the demographic questionnaire before it was finally implemented in the study as well as determine the time it took to complete all four research instruments with and without assistance. This pre-test was carried out with the research assistants and this helped them get familiar with the administration and interpretation of some of the questionnaires.

3.7.1 DATA COLLECTION PROCEDURES

The directors of the HIV clinics at the hospitals were consulted. Verbal permission was received to use a room at the clinic for data collection and for staff to recruit patients for the study. Participants were approached by the clinic staff and provided with an information sheet (Appendix G) so they could understand the purpose of the study. They were asked to sign informed consent (Appendix H). This was followed by administration of the self-report questionnaires in the following order:

- Demographic questionnaire.
- HIV Disability Questionnaire.
- The two reference questionnaires: The WHODAS 2.0 and the then the MOS-SSS.

Participants were asked by the researcher to complete the questionnaires themselves if possible or to request the help of a research assistant for translation. Participants were moved to a quiet area in the clinics at a table to complete the questionnaires by themselves or with the help of a researcher.

3.7.3 Data processing methods and data analysis plans

The researcher closely supervised the research assistants during data collection. The researcher also checked some of the questionnaires to identify omitted fields. Missing data was collected immediately while participants were still available. Four questionnaires were eliminated because two of the participants did not meet the inclusion criteria and two were excluded because more than 10% of the data was missing. Data was cleaned and put onto an Excel spreadsheet (2007) and analysed using Stata 13 and Statistic v 12.

3.7.4 Data management

Data was entered onto Excel spreadsheets on completion of data collection. Scores for the HDQ were calculated so that the scores for the presence, severity and episodic scales were reflected as a score out of a total of 100. The score for the WHODAS 2.0 and the MOS-SSS which is an equivalent of the total severity score of the HDQ was also converted into a metric score ranging from 0-100 for easy interpretation and correlation with those of the HDQ.

3.8 ETHICAL CONSIDERATION DURING THIS STUDY

Project particulars were explained to participants by four research assistants during recruitment, and participants were provided with an information sheet to confirm the requirements of the study. They were asked to sign two informed consent sheets, one to participate in the research and another one to give permission for their file to be accessed for information on CD4 counts and viral load. The information document (Appendix G) and consent forms (Appendix H). Participants' names collected on the informed consent sheets were kept separate from data-capturing forms to ensure anonymity. During data collection and analysis study participants' names were used for identification purposes. Consultations with participants were held in a private room in the clinic to ensure privacy and the same procedure was repeated for all participants to ensure standardisation.

3.8.1 Consent

Informed consent was sought from the participants before the questionnaires were administered. Participants were informed of the voluntary nature of the study and that they could withdraw from the study at any time if they so wished without affecting their medical treatment or any other benefit.

3.8.2 Confidentiality

The data collection procedures took place in five rooms two at the Themba Lethu clinic, and three at both the Nthabiseng Thuthuzela Clinic and the Donald Gordon Family Medicine Clinic. Individuals associated with the drug rehabilitation programme were provided with questionnaires and completed them at home and returned them in a blank file to the researcher. No names were used at Themba Lethu Clinic, Hillbrow Clinic and Donald Gordon Clinic, but names were collected at Nthabiseng Thuthuzela Clinic for specific file identification alone and were not included in the data capturing form.

3.8.3 Non-maleficence

The principles of non-maleficence were applied in this study by ensuring that the information was not used to harm the participants in anyway and the benefits that the study will have for the University of the Witwatersrand, the community and the participants is in terms of knowledge.

3.9 DATA ANALYSIS

3.9.1 Demographic data

Data was analysed using descriptive analysis involving frequency, and percentages for the demographic and medical history data. Data for demographics that were described included age, education, marital status and number of children as well as CD4 counts, viral load concurrent medical conditions and period of time they have been on medication.

Descriptive results were used to analyse the results of the HDQ, WHODAS-2 and the MOS-SSS for the sample of 498 participants. Median scores were presented as the data were ordinal in nature and not normally distributed to describe the disability for the participants on the HDQ, WHODAS-2 and the quality of life of the participants on the MOS-SSS. Mean and standard deviation for the scores were also presented as some median scores were 0 and the means were included to indicate that some participants indicated disability on the presence, severity and episodic scales for these domains.

3.9.2 Construct analysis of the HDQ

The Kaiser-Mayer-Olkin (KMO) test of sampling adequacy and the Bartlett's tests of sphericity were used to confirm the data were adequate for a factor analysis. A principal component factor analysis with varimax rotation was used to confirm the a priori factor structure as found by O'Brien et al. (2014) for the domains on the HDQ using factor loadings. Eigen values were set at 1 and factor loadings were set at 0.30.

A confirmatory factor analysis of the HDQ was published by O'Brien et al. (2014) using maximum likelihood analysis and Root Mean Square Error of Approximation (RMSEA). The same parameters were used in a confirmatory factor analysis on the severity data of the HDQ for the sample in this study.

3.9.3 Convergent and divergent validity

The scores on the WHODAS -2 which measures the same constructs of activity limitations and participation restrictions as the HDQ was correlated with the severity scores on the HDQ to determine convergent validity. The MOS-SSS which measures quality of life which has been shown previously to be a construct divergent to disability related activity limitations and participation restrictions was correlated with the HDQ to determine divergent validity. Spearman's correlation coefficients were used as the scales are ordinal scales. The correlations were interpreted according to the following criteria (Tomita, Mann, Fraas, & Stanton, 2004).

0 - 0.29	no correlation
0.30 – 0.39	A weak correlation
0.40 – 0.59	A moderate correlation
0.60 – 0.79	A strong correlation
0.80 – 1.00	Excellent

3.9.4 Construct validity based on known group variables

Construct validity was determined by comparing the known group variables for the participants against demographic and medical factors. The level of disability was determined on the HDQ severity score. A score of 0 was considered as no disability, a score of 1-24 was considered as mild disability, a score of 25-50 was considered as moderate disability and a score of 50+ was considered a severe disability. The frequency of the different levels of disability related to activity limitations and participation restrictions were calculated for the sample in this study.

Based on the hypotheses the demographic and medical factors were analysed for each level of disability related to determine if there was any difference for these factors for the groups with no, mild, moderate or severe disability.

3.9.5 Reliability

Since the HDQ is a self-report questionnaire no interrater reliability needed to be established. The internal consistency was determined for the domain and total scores with 0.70 being set as an adequate level of consistency (Tavakol & Dennick, 2011).

CHAPTER 4: RESULTS

4.1 INTRODUCTION

This chapter presents the results of the demographics of the participants as well as medical information related to HIV and analysis to determine the validity of the HDQ for the sample in this study. Psychometric properties of the HDQ, and also the validity and reliability of the HDQ was also reported in this chapter.

4.2 DEMOGRAPHIC AND MEDICAL INFORMATION OF THE PARTICIPANTS

Demographic information of the population of this study would be described to form a basis for the discussion of the population in this study.

4.2.1 Age, gender and population group

There was an unequal distribution according to gender with 158 (31.73%) of participants being males and 340 (68.27%) female (Figure 4.1).

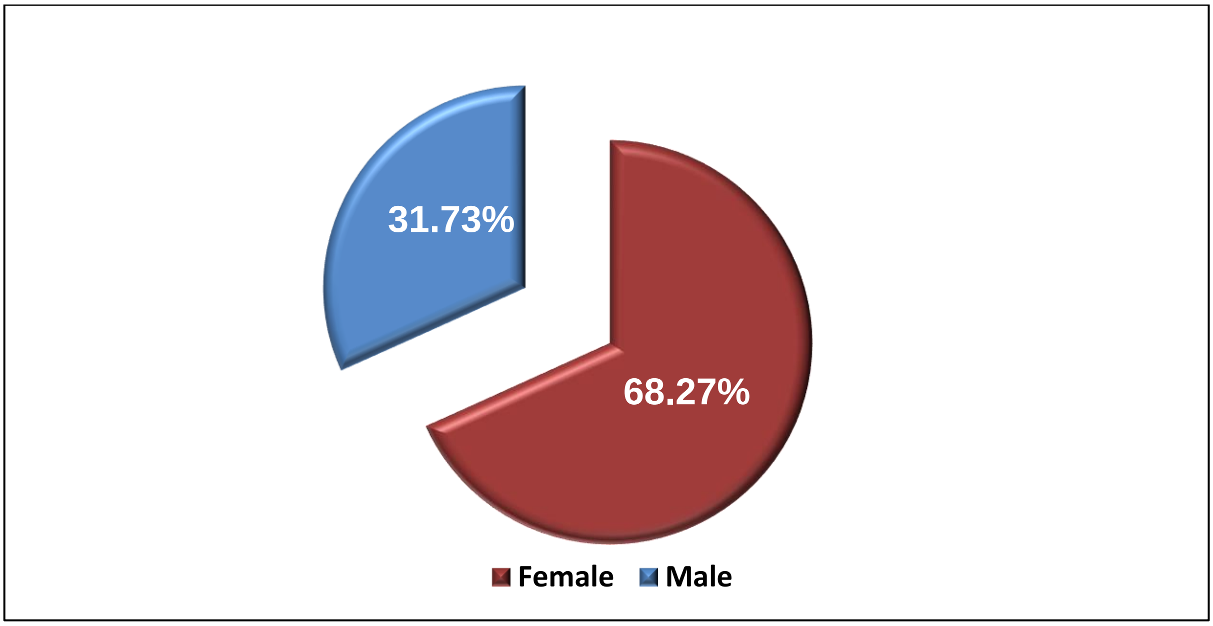

Figure 4.1 Gender distribution of participants (n=498)

Table 4.1 Indicates that the age of participants in the study was concentrated between 30 years old and 49 years old (72.89%) Age distribution showed that most of the participants (90.16%) were above 30 years.

Table 4.1 Age and population group (n=498)

	n (%)
Age	
20-30	49 (89.87)
30-39	198 (39.91)
40-49	165 (33.26)
50-59	69 (13.91)
60+	15 (3.02)
Population group	
Black	474 (95.18)
Indian	1 (0.2)
Coloured	8 (1.61)
White	15 (3.01)

Analysis of race according to population grouping revealed that most of the participants were Black, while the smallest number were Indian (0.2%) with Coloureds and Whites making up the 3.01% and 1.61%of the sample respectively.

4.2.2 Martial status and children

There were 240 single participants in this study accounting for 48.19% of the sample and 182 were married making up 36.55% of the sample. A divorced, widowed and separated status was also reported under the remaining 14.50% of the participants. Few participants (5.42%) had more than four children with majority of the study population having between one to four children 410 (82.33%). Sixty one (12.25%) reported having no children.

Table 4.2 Martial Status and number of children (n-498)

	n (%)
Marital status	
Single	240 (48.19)
Married	182 (36.55)
Other status	70 (14.50)
Children	
1-4 children	410 (82.33)
More than 4 children	27 (5.42)
No children	61 (12.25)

4.2.3 Education, Employment and Disability grants

For this study, the highest level of educational falls between participants with matric and some tertiary education (247, 49.60%). Those with Grade 11 and below including some participants with no education made up 42.97% of the sample. Lowest percentage of participants had (37, 7.43%) bachelors and other degrees (Table 4.3).

Table 4.3 Education and Employment status (n=498)

	n (%)
Highest level of Education	
None to Grade 11	213 (42.97)
Matric and some tertiary education	247 (49.60)
Degree	37 (7.43)
Employment status	
Employed	307 (61.65)
Unemployed	191 (38.35)
Disability grants	
No grant	479 (96.18)
Receive a grant	19 (3.82)

Among this population, there are more patients (307, 61.65%) that are employed while unemployed participants accounted for 191 (38.35%) of the sample

Disability grants were received by 19 (3.82%) of the participants (Table 3).

4.3 MEDICAL INFORMATION

4.3.1 WHO HIV stage, CD4 count and viral load

Participants were divided into groups according to the World Health Organization Stage distribution for HIV. From Table 4.4 it is noted that 148 (65.49%) of the total study population have a WHO stage of 1 as indicated by the case file review. While 32(14.16%) have a WHO stage of 3, 29(12.83%) have a WHO stage of 2 with a small percentage of participants 17 (7.52%) at WHO stage of 4. A number of patients 272 (54.6%) did not have this information in their files (Table 4.4).

Table 4.4 World Health Organisation HIV stage, CD4 counts and viral load (n=498)

	n%
WHO Stage	
WHO Stage 1	148 (65.49%)
WHO Stage 2	29 (12.83)
WHO Stage 3	32 (14.16%)
WHO Stage 4	17 (7.52%)
CD4 Count	
< 200 cells/microliter	52 (10.44)
201-349 cells/microlitre	137 (27.51)
350-500 cells/microlitre	121 (24.30
>500cells/microlitre	188 (37.75)
Viral Load	
Undetectable viral load	231 (47.23)
Detectable viral load	258 (52.76)

A small percentage of participants (10.44%) presented with a CD4 count below 200 cells/microlitre. Further analysis revealed that although 89.76% of the study participants has a CD4 counts above 200 cells/microlitre, a similar percentage had a CD4 count between 201-349 cells/microlitre, and between 350-500 cells/microlitre while just over a third (37.75%) had a CD4 count above 500 cells/microlitre (Table 4.4). A greater percentage of female participants had higher CD4 counts than male participants. A similar finding was seen for the undetectable viral load which was found in a higher percentage of female participants (52.23%) when compared to the male participants (36.19%). In the total group the percentage of participants with detectable and undetectable viral load was similar with slightly more participants (52.76%) having a detectable viral load.

4.3.2 Concurrent Health Conditions

The majority of the participants (70%) did not indicate any incidence of concurrent health conditions. The number of concurrent health conditions reported by each participant was important as the higher the number of concurrent health conditions may be related to their disability (O'Brien et al., 2008) and this is represented in Table 4.5.

Table 4.5 incidence of concurrent health conditions in the participants (n=498)

Number of Concurrent Health Conditions	n (%)
0	349 (70.0)
1	99 (19.8)
2	29 (5.8)
3	12 (2.4)
4	4 (0.8)
5	3 (0.6)
6 and 7	1 (0.2)

The type of concurrent health conditions was aslo recorded and of the 149 (30%) participants who did report concurrent health conditions, the most common concurrent health conditions reported were hypertension (31.5%), Tuberculosis, muscle and joint pain and kidney infections and kidney failure (10.1%), headaches, flu and Castleman's flu as well as diabetes (9.39%). Other concurrent health conditions reported by between 5.6% and 3.36% of participants include pulmonary disease, Lipodystrophy, ulcers, diarrhoea and cancer. A very small number of participants (2.0%) reported debilitation conditions including loss of sight, hearing, stroke as well as depression as concurrent to their HIV diagnosis.

4.3.3 Medication

Figure 4.2 shows that majority of the study participants (52.01%) have been on ART for a period of more than 5 years, while 35.74% have been on ART for period ranging from 1 to 5 years. A small percentage (12.25%) has been on ART for a period ranging from 6 months to 1 year.

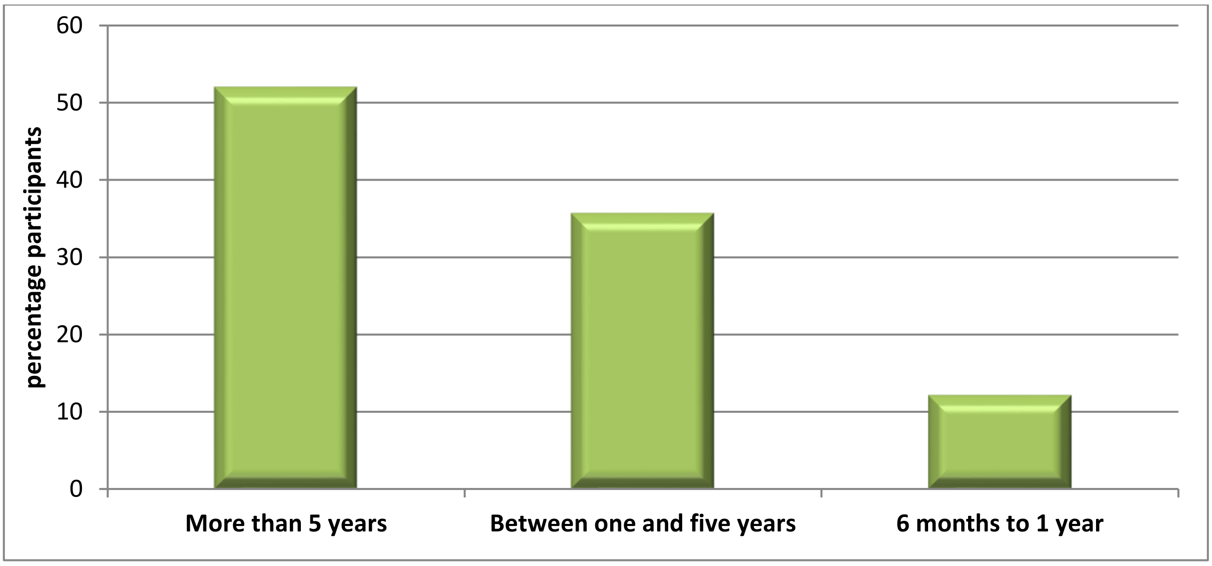

Figure 4.2 Length of time participants have been taking antiretroviral medication (n=498)

4.4 THE HIV DISABILITY QUESTIONNAIRE

The results for the presence, severity and episodic nature scales for the participants were determined**.** The HDQ is divided into three scales which consider the presence of disability, the severity of disability and the episodic nature of disability as a percentage of the sample. For the HDQ, median scores were used as the data were not normally distributed and as was confirmed by the differences in the median and mean scores. Median scores also accommodated the ordinal nature of the data. Means and SD were presented to accommodate median score of 0 in some domains indicating that mild disability was found for these domains in this study on the HDQ.

4.4.1 Scales of the HIV Disability Questionnaire

4.4.1.1. Presence of Disability

The median scores indicate that the presence of disability in the participants ranged between the different domains on the HDQ.

Table 4.6 The scores for the domains and totals for presence of disability on the HIV Disability Questionnaire (n=498)

Total group (n=498)	Mean (SD)	Median	Lower 1st quartile - Upper 3rd Quartiles	Difference in mean and median scores
Total Score Presence	28.99 (22.86)	24.63	10.14, 42.02	4.36
Domain 1: Physical Symptoms	26.99 (9.81)	28.01	18.87, 23.69	-1.02
Domain 2: Cognitive Symptoms	21.28 (8.40)	21.28	20.08, 28.18	0
Domain 3: Mental and Emotional Health Symptoms	28.11 (9.49)	27.71	18.87, 35.14	0.4
Domain 4: Uncertainty	44.85 (11.18)	44.67	39.15, 53.01	0.18
Domain 5: Difficulties with day to day activities	15.26 (10.68)	12.65	9.43, 9.07	2.61
Domain 6: Challenges to taking part in Social and Community Life	24.83(10.79)	20.28	16.46, 30.32	4.55

The lowest score was obtained for Domain 5: difficulty with day to day activities indicating a low presence of disability in this domain and the highest score of

44.67 was for Domain 4: uncertainty. The score for all other domains were similar with a total presence score of 24.63.

4.4.1.2 Severity of Disability

Table 4.7 shows the severity of disability domain scores for the HDQ. As for presence Domain 4: Uncertainty had the highest median at 21.42. The median score for some domains were 0 for the severity reported by participants for Domain 2: cognitive symptoms and Domain 5: difficulty with day to day activities. The mean scores indicated the presence of mild severity in these two domains. The severity in other domains was reported as less than a score of 10 with the total severity score at 10.14.

Table 4.7 The scores for the domains and totals for severity of disability on the HIV Disability Questionnaire (n=489)

Total group (n=498)	**Mean (SD)**	**Median**	**Lower 1st quartile - Upper 3rd Quartiles**	**Difference in mean and median scores**
Total Score Severity	14.72 (13.86)	10.14	4.34,20.66	4.58
Domain 1: Physical Symptoms	11.75 (11.97)	8.75	3.75, 16.25	3
Domain 2: Cognitive Symptoms	8.40 (15.26)	0.00	0.00, 8.33	8.4
Domain 3: Mental and Emotional Health Symptoms	14.23 (19.05)	6.81	0.00, 20.45	7.42
Domain 4: Uncertainty	27.19 (24.35)	21.42	7.14, 42.85	5.77
Domain 5: Difficulties with day to day activities	7.04 (13.10)	0.00	0.00, 8.33	7.04
Domain 6: Challenges to taking part in Social and Community Life	12.81 (16.86)	6.25	0.00, 18.75	6.56

4.4.1.3 Episodic Nature of Disability

The median scores indicated that the episodic nature of disability in the participants occurred in all the domains on the HDQ. As for presence of disability the lowest score was obtained for Domain 5: difficulty with day to day activities indicating a low fluctuation day to day in this domain and the highest score of 33.63 was for Domain 4: uncertainty. The score for all other domains were similar with a total presence score of 15.94.

Table 4.8 The scores for the domains and totals for episodic nature of disability on the HIV Disability Questionnaire

Total group (n=498)	**Mean (SD)**	**Median**	**Lower 1st quartile - Upper 3rd Quartiles**	**Difference in mean and median scores**
Total Score Episodic	22.16 (21.64)	15.94	5.79, 26.10	6.22
Domain 1: Physical Symptoms	21.43 (7.10)	22.89	17.07,19.08	-1.46
Domain 2: Cognitive Symptoms	16.87 (2.21)	16.87	14.66, 27.11	0
Domain 3: Mental and Emotional Health Symptoms	22.42 (7.04)	22.29	15.69, 39.5	0.13
Domain 4: Uncertainty	33.48 (8.77)	33.63	28.71, 39.56	-0.15
Domain 5: Difficulties with day to day activities	12.70 (5.36)	12.45	8.23, 16.06	0.25
Domain 6: Challenges to taking part in Social and Community Life	18.07 (7.16)	15.07	13.05, 21.89	3

When question 70 on the HDQ was analysed 437 (87.7%) of participants reported the day on which they were assessed was a good day and only 12.3 % reported having a bad day.

4.5 VALIDITY AND RELIABILITY OF THE HIV DISABILITY QUESTIONNAIRE FOR A SOUTH AFRICAN SAMPLE

The validity of the HDQ for the South African sample in this study was determined by completing a factor analysis on the data for the presence, severity and episodic disability scale results. More so, the convergent validity for disability related to activity limitations and participation restrictions and divergent validity to a quality of life measure was also reported. Reliability was assessed by determining internal consistency of the HDQ.

4.5.1 Factor Analysis of the HIV Disability Questionnaire

Before the principal component factor analysis and a pattern matrix were completed on the scores for the severity scale to establish the adequacy of the data factor analysis was determined using the HDQ severity scale. The score of Kaiser-Mayer-Olkin (KMO) test of the adequacy of the sample for the HDQ was 0.93 which is at an acceptable level. Bartlett's test of sphericity also reached significance of $p \leq 0.001$ which indicates the data were suitable for structure detection and should reveal distinct factors.

The pattern matrix from a principal component factor analysis on the scores for the severity scale was completed with varimax rotation that indicated that the six domains or dimensions of the HDQ were perserved for four of the six domains for the sample in this study. Most items loaded sufficiently (0.3) except item 19 (hearing), item 64 (I find it hard to talk with others about my illness, even my family and friends), 67 (I find it hard to start new, intimate, sexual relationships living with HIV.), 68 (I tend to isolate myself from others because I am HIV positive).

Six items from domain 5 (difficulties with day to day activities) loaded with Domain 6 (challenges to taking part in social and community life). Three items under Domain 6 (challenges to taking part in social and community life) loaded under Domain 4 (uncertainty). The six domains all had Eigen values above one which account for 49.6% of the variance (Appendix I).

Two approaches in a confirmatory factor analysis were used to determine the goodness of fit of the domain in HDQ for the sample in this study. All standardised factor loadings presented in red in Appendix I indicate that all items should be included in the model but the Chi-squared value for the confirmatory factor analysis on the severity scores of the HDQ showed a significant difference in the fit between the patterns observed in the matrix and the domains specified ($p \leq 0.001$).

The goodness of fit of the domains described in the HDQ severity scale was further tested using RMSEA based on a maximum likelihood method of estimation suggested for assessment instruments with a large number of items but a small number of factors for data that is not normally distributed (Mislevy, 1986). Table 4.9 indicates that the RMSEA estimate fell below 0.05 supporting an acceptable fit for the domains on the HDQ severity scale.

Table 4.9 Results Confirmatory Factor Analysis – Goodness of Fit

Chi-Square Statistic	Steiger-Lind RMSEA
Chi-Square Statistic: = 4314.57	Point Estimate: 0.042
Degrees of Freedom: 2276 p-value: ≤ 0.001	>Lower 90% Bound: 0.0406 >Upper 90% Bound: 0.0444

The factor analysis does indicate differences for some items in two of the domains on the HDQ for the South African sample with a number of items indicating that items previously under day to day activities fit better into social inclusion and uncertainly constructs.

4.5.2 Convergent and Divergent Validity

The HDQ results for severity of disability reflecting activity limitations and participation restrictions were correlated with the results on two reference measures namely the WHODAS2 and the MOS-SSS.

4.5.2.1 Convergent Validity -World Health Organisation Disability Assessment Scale -2

Table 4.10 shows the disabilities reported by participants in this study on the WHODAS 2.0. The difference in the mean and median scores indicates that the data were not normally distributed for this sample. Six of the domains had a median score of 0 but the mean indicated disability scores between 11.65 and

5.74 for these domains as some participants reported a problem in cognition, mobility, getting along with people and life activities.

The total disability median score was 2.38 with median scores of 0 for all domains indicating no impairments and activity limitations which could be considered as the onset of disability (Hanass-Hancock, et al., 2015). A higher score was obtained for participation in society where disability median score of 4.17 was obtained (Table 4.10).

Table 4.10 Scores for the domains and total score on the World Health Organisation Disability Assessment scale -2 (n=498)

Total group (n=498)	Mean (SD)	Median	Lower 1st quartile - Upper 3rd Quartiles	Difference in mean and median scores
Total Score	9.97(15.66)	2.83	0.00, 12.20	7.14
Domain 1: Cognition	10.16(17.33)	0.00	0.00,15.00	10.16
Domain 2: Mobility	10.33(19.18)	0.00	0.00, 12.50	10.33
Domain 3: Self care	5.74(16.48)	0.00	0.00, 16.47	5.74
Domain 4: Getting Along with people	11.65(19.34)	0.00	0.00, 16.67	11.65
Domain 5A: Life Activities (Domestic)	8.84(19.19)	0.00	0.00, 10.00	8.84
Domain 5B: Life Activities (School/work)	7.99(18.18)	0.00	0.00, 0.00	7.99
Domain 6: Participation in society	14.91(20.66)	4.17	0.00, 20.66	10.74

Convergent validity of the HDQ was assessed with the WHODAS -2 as both tests purport to measure the same constructs related to impairments, activity limitations and participation restrictions. Table 4.11 shows the correlations between the HDQ and WHODAS 2.0.

Table 4.11 Correlations between the domains of the HIV Disability Questionnaire and World Health Organisation Disability Assessment -2

WHODAS-2	**Domain 1: Cognition**	**Domain 2: Mobility**	**Domain 3: Self care**	**Domain 4: Getting Along**	**Domain 5A: Life Activities 1**	**Domain 5B: Life Activities 2**	**Domain 6 Participation in society**	**Total Score**
HDQ	rho							
Domain 1: Physical Symptoms	0.39*	**0.41***	0.32*	**0.41***	0.34*	0.33*	0.37*	**0.44***
Domain 2: Cognitive Symptoms	**0.48***	0.33*	0.29*	0.31*	0.31*	0.33*	0.32*	0.36*
Domain 3: Mental and Emotional Health Symptoms	**0.41***	0.33*	0.31*	**0.42***	0.34*	0.34*	**0.45***	**0.45***
Domain 4: Uncertainty	**0.41***	0.32*	0.24*	**0.44***	0.32*	0.32*	**0.50***	**0.48***
Domain 5: Difficulties with day to day activities	**0.45***	**0.43***	0.38*	0.39*	**0.42***	**0.41***	**0.41***	**0.45***
Domain 6: Challenges to Social and community inclusion	**0.45***	0.38	0.32*	**0.53***	**0.40***	0.39*	**0.56***	**0.55***
Total score for Disability Presence	**0.52***	**0.46***	0.39*	**0.55***	**0.44***	**0.42***	**0.58***	**0.60****
Total Score for Disability Severity	**0.49***	**0.42***	0.34*	**0.51***	**0.40***	0.39*	**0.53***	**0.56***
Total score episodic disability	0.36*	0.38*	0.26*	0.33*	0.36*	0.34*	0.37*	**0.43***

Significance p≤ 0.05*
p≤ 0.01**

As hypothesised the total severity, presence and episodic scores of the HDQ have a moderate correlation with the WHODAS 2.0 total score.

All the correlations were significant and all the domain scores of the HDQ with the exception of Domain 2 Cognitive symptoms also correlated moderately with the total score of the WHODAS 2.0. There was a strong correlation between the total score of the WHODAS-2 and presence of disability on the HDQ.

For the impairment domains, Domain 1 (physical symptoms) of the HDQ had a significant and moderate correlation (0.41) with the Domain 2 (mobility) on the WHODAS 2.0. Domain 2 (cognitive symptoms) on the HDQ had a moderate correlation (0.48) which was significant with Domain 1 (cognitive systems) of the WHODAS 2.0. These correlations were all significant at the $p \leq 0.05$ level but only those presented showed moderate positive correlations indicating scores that were high on the HDQ were also high for the WHODAS-2 and vice versa.

One domain related to impairment Domain 3 of HDQ: mental and emotional health symptoms, and two domains related to activity limitations and participation restrictions Domain 4: uncertainty and Domain 6: challenges social and community inclusion, had a moderate correlation (0.45, 0.50; and 0.56 respectively) with participation in society on the WHODAS 2.0. Domain 5 of the HDQ (difficulties with day to day activities) correlated significantly with Domain 5A (life activities 1) (0.42), Domain 5B (life activities 2) (0.41) and Domain 6: (participation restrictions) (0.41) of the WHODAS 2.0. The self care domain 3 on the WHODAS -2 had a low correlation with all scores on the HDQ.

4.5.2.2 Medical Outcomes Study Social Support Survey

Table 4.12 shows that participants in the study had a total score of 88.16 in social quality of life. Most scores were high indicating the little loss of QoL with domain 3 (affection support) median score indicating no loss of QoL. The mean score however indicated some participants did have a lower QoL for this domain. The differences between the means and median scores indicate the data were not normally distributed.

Table 4.12 The scores for the domains and totals on the Medical Outcomes Study Social Support Survey (MOS-SSS) (n=489)

	Mean (SD)	**Median**	**Lower 1st quartile - Upper 3rd Quartiles**	**Difference in mean and median scores**
Total score	78.73 (24.18)	88.16	24.18,100.00	-9.43
Domain 1: Emotional and informational support	78.02 (24.96)	87.50	60.00,100.00	-9.48
Domain 2: Tangible support	75.73 (26.62)	80.00	55.00,100.00	-4.27
Domain 3: Affection support	82.32 (24.19)	100	66.66,100.00	-17.68
Domain 4: Positive social interaction	80.21 (25.29)	93.34	66.66,100.00	-13.13
Question 14	25.92 (9.33)	33.33	20.00,33.33	2.61

Divergent validity was confirmed by correlating the scores for the HDQ with those on the MOSS-SSS. It was hypothesised that these test measure two different constructs and no correlations would be found for the domains and total scores on the tests.

While a small number of the correlations were significant at the p ≤0.05 level Table 4.13 shows a negative weak correlation between all the scores for the HDQ and MOS-SSS for the domains and total scores for the two tests. This indicated these tests measure two different constructs and that the HDQ does not assess components of quality of life related to social support.

Table 4.13 Correlations between the domains of the HIV Disability Questionnaire and the Medical Outcomes Study Social Support Survey

MOS-SSS	**Domain 1: Emotional and informational support**	**Domain 2: Tangible support**	**Domain 3: Affection support**	**Domain 4: Positive social interaction**	**Question 14**	**Total Score**
HDQ			**Rho**			
Domain 1: Physical Symptoms	-0.15	-0.13	-0.14	-0.15	-0.15	-0.15
Domain 2: Cognitive Symptoms	-0.17	-0.16	-0.19	-0.16	-0.17	-0.18
Domain 3: Mental and Emotional Health Symptoms	-0.27	-0.23	-0.26	-0.26	-0.25	-0.26
Domain 4: Uncertainty	-0.28*	-0.24	-0.23	-0.23	-0.22	-0.26
Domain 5: Difficulties with day to day activities	-0.19	-0.15	-0.18	-0.17	-0.16	-0.19
Domain 6: Challenges to Social and community inclusion	-0.34*	-0.30*	-0.31*	-0.33*	-0.31*	-0.33*
Total score for Disability Presence	-0.32*	-0.29*	-0.29*	-0.29*	-0.29*	-0.04
Total Score for Disability Severity	-0.29*	-0.25	-0.26	-0.26	-0.25	-0.05
Total score episodic disability	-0.29*	-0.15	-0.15	-0.14	-0.14	0.01

Significance $p \leq 0.05$*
$p \leq 0.01$**

4.6 LEVELS OF DISABILITY AND KNOWN GROUP VARIABLES

The severity, presence and episodic nature of disability as assessed by the HDQ were considered for the participants in this study. Over half of the participants presented with a mild disability both in levels severity (53.41%) presence (52.40%) and levels of episodic nature of disabilities (56.82%). A floor effect with 5% of participants reporting no presence of disability was found for the HDQ with no ceiling effect as no participant achieved a score of a 100 for presence or severity of disability. (Table 4.14)

Table 4.14 Frequency table for Levels of severity, presence and episodic nature of disability

	Levels of severity of disability n (%)		**Levels of presence of disability n (%)**		**Levels of episodic nature of disability n (%)**
No disability	55 (11.04)	No disability	23 (4.61)	No change in last week	55 (11,04)
Mild disability	266 (53.41)	Mild disability in less than 25% of items	261 (52.40	Change in last week in less than 25% of items	283 (56.82)
Moderate disability	114 (22.89)	Moderate disability in less than 50% of items	135 (27.10)	Change in last week in less than 50% of items	104 (20.88)
Severe disability	63 (12.65)	Severe disability in more than 50% of items	79 (15.86	Change in last week in more than 50% of items	56 (11.24)

All the known group demographic and medical variables assessed on the participants were compared to the severity and presence of disability as measured by the HDQ. The level of disability where the known group medical variables or the demographic variables differed significantly as hypothesised in Chapter 1 will be presented in this section.

4.6.1. Severity of Disability

4.6.1.1 Number of concurrent Health Conditions

The number of concurrent health conditions the participants reported differed significantly depending on the severity of their level of disability (Figure 4.4). A large percentage (22.22%) of those with four to seven concurrent health conditions reports having severe disability as oppose 2.01% of those with no concurrent health condition.

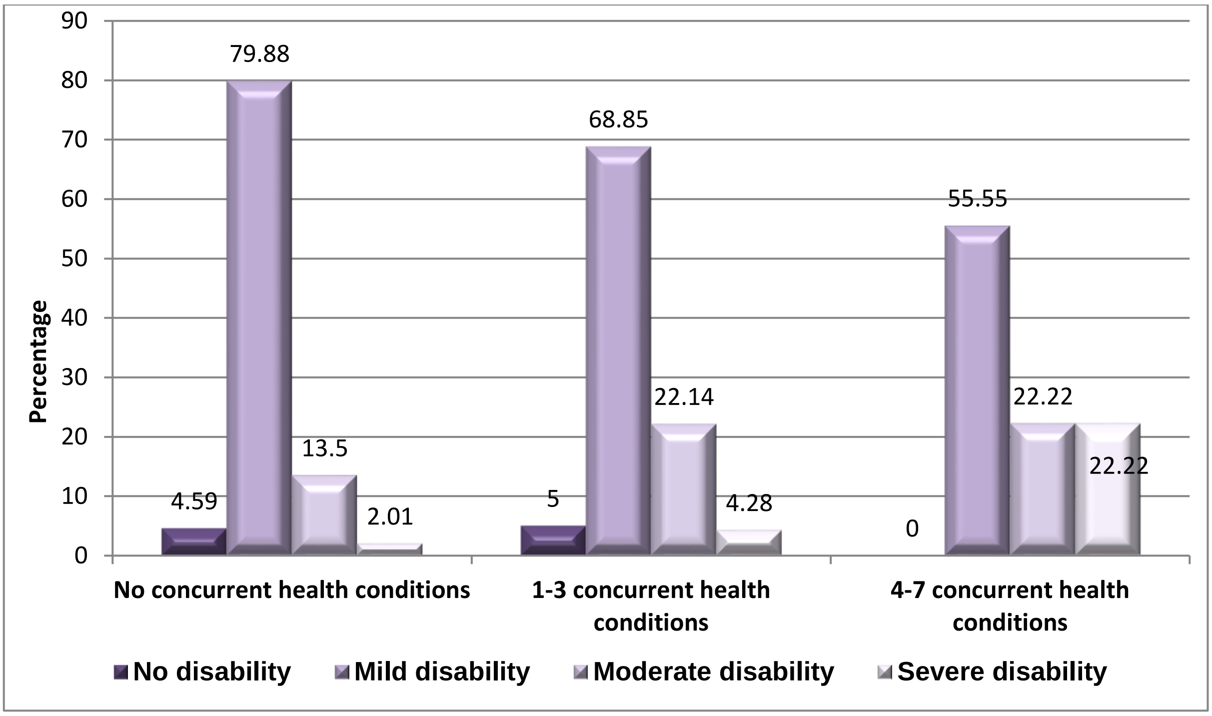

Figure 4.4 Comparison of the percentage of number of concurrent health conditions reported by participants according to the severity of their level of disability (p=0.027)

More so, 4.49% of those with no concurrent health condition also indicated no disability while none of those with 4-7 concurrent health condition report any disability. Figure 4.4 indicates that as the number of concurrent health conditions increased significantly so did the percentage of participants with a moderate and severe disability (p=0.027).

4.6.1.1 Employment

Figure 4.5 indicates there was a significant difference (p=0.019) in the percentage of participants employed when the severity of disability was considered with 80% percent of the participants experiencing severe disability been unemployed. A higher percentage of the unemployment was also found for those with moderate disability (19.9% vs. 13.7%).

Figure 4.5 clearly indicates the effect of the severity of disability on employment as assessed by the HDQ.

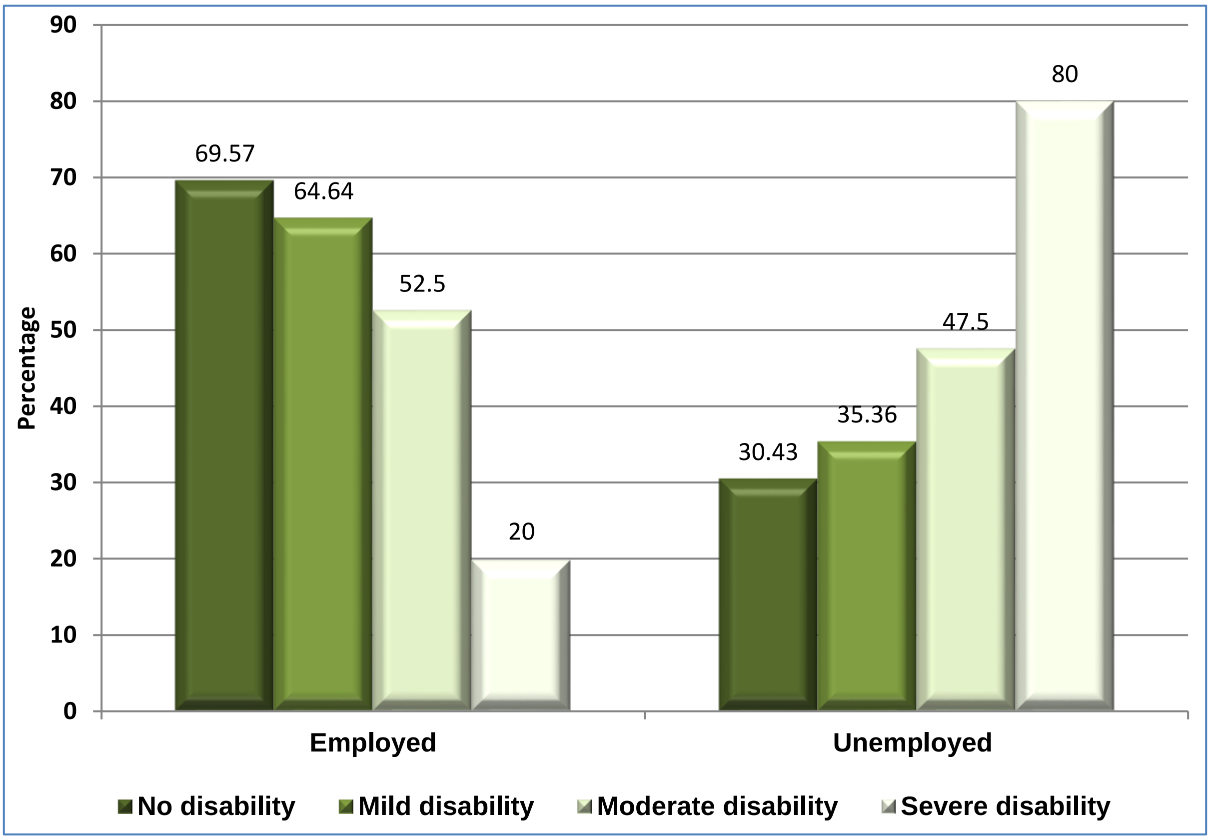

Figure 4.5 Percentage employed and unemployed participants according to the severity of their level of disability (p=0.019)

4.6.2 Presence of disability

4.6.2.1 Age

The presence of disability was significantly affected by age (p=0.049) as none (0.00%) of people between the ages of 50-59 experienced no disability and almost 19% of those experiencing severe disabilities fall into this group as opposed to younger participant (20-30 years) where just 10% present with severe disabilities (Table 4.17).

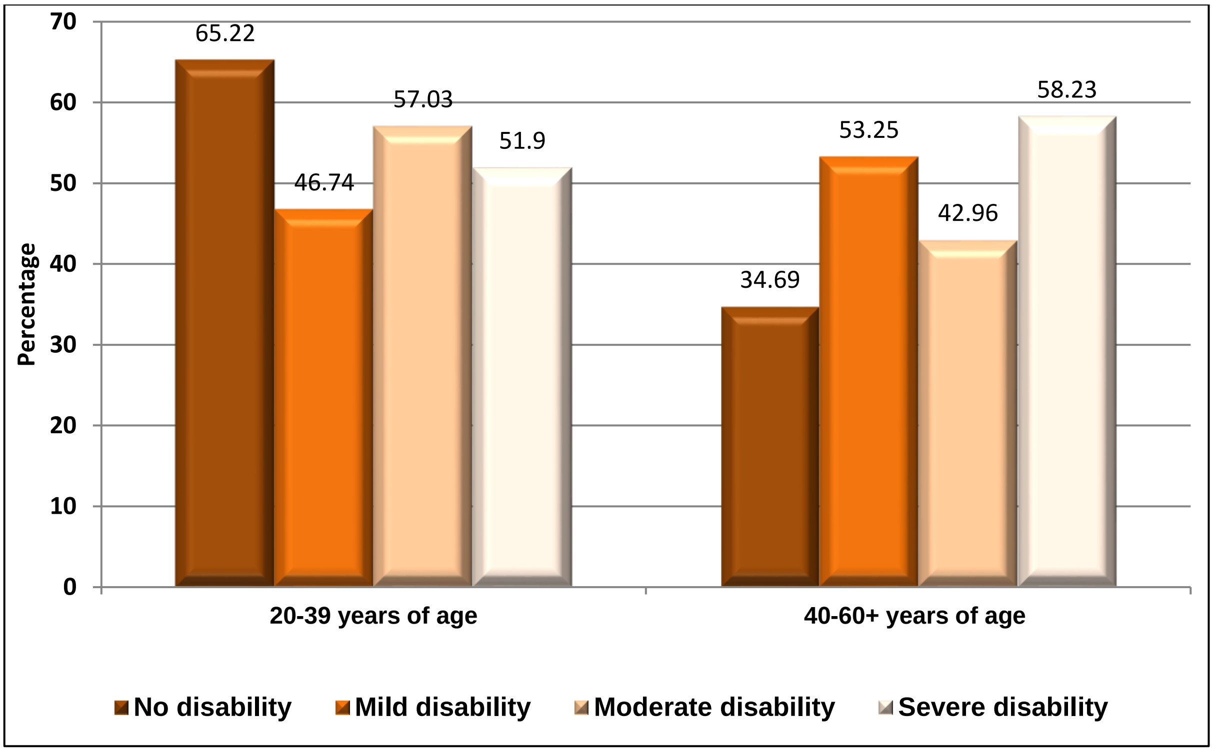

Figure 4.6 Comparison of the older and younger participants according to the level of presence of disability (p=0.049).

Although the difference across age groups differed with a smaller percentage of the older age group (40 to 60+ years) having disability in between 25-50% of items Figure 4.5 indicates the higher percentage of this older age group has a higher presence of disability.

4.6.3 Length of time on antiretroviral therapy

A significant difference (p=0.003) was revealed between the length of time participants have been on medications and level of disability presence (Table 4.18).

Majority (59.49%) of the participants experiencing severe disability have been on medication for more than 5 years only 3.9% of the people who have been on medication for more than 5 years also indicate no presence of disability in all domains of the HDQ.

Figure 4.6 indicates the increase in the presence of disability in more than for participants that have been on ART for more than 5 years.

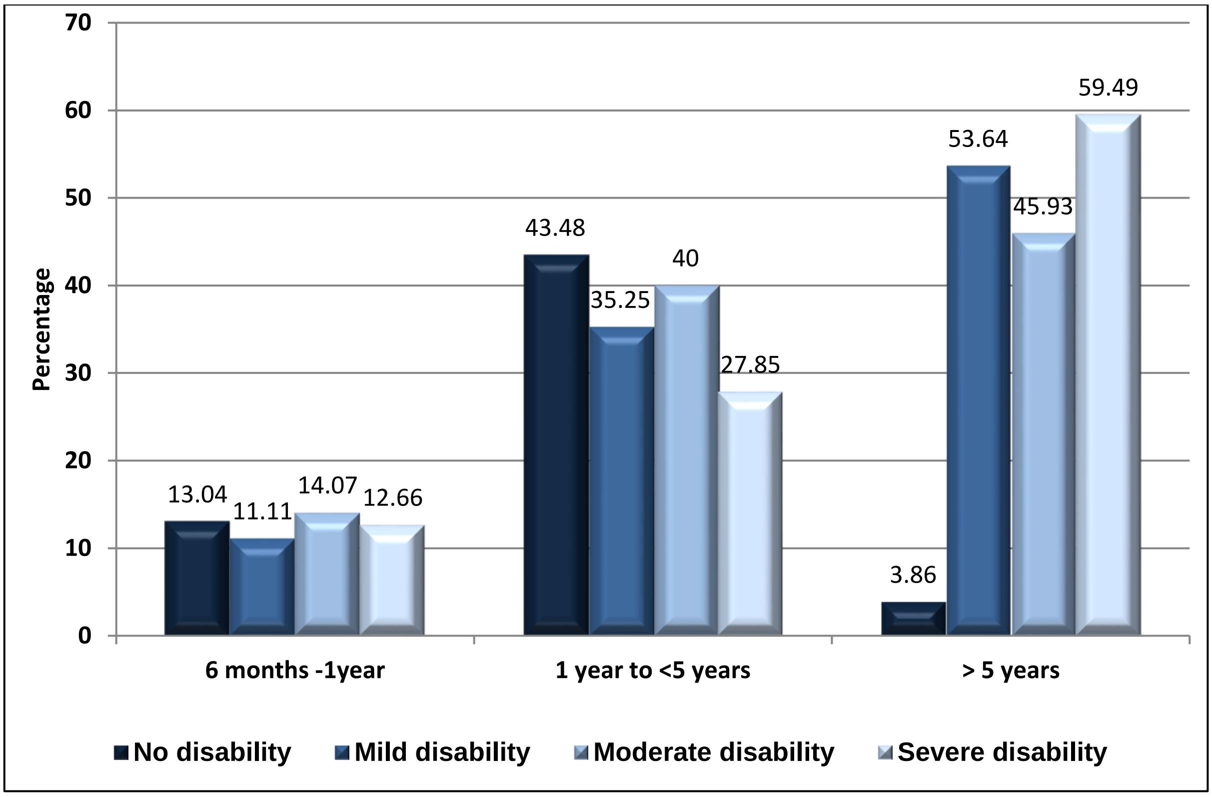

Figure 4.7 Percentage of participants according to the presence of disability and the length of time they having been taking antiretroviral medication (p=0.003).

4.6.2.3 Employment status in relation to presence of disability

A significant difference (p=0.002) was observed between employment and disability presence. This is illustrated in figure 4.8 below as 73.9% of the participants experiencing no disability are employed as compared to 26.07% for the unemployed. A higher percentage (56.96%) of those experiencing severe disabilities also reported being unemployed.

Figure 4.7 indicates clearly that the level of the presence of disability as assessed by the HDQ was significantly different for the participants that were employed and unemployed.

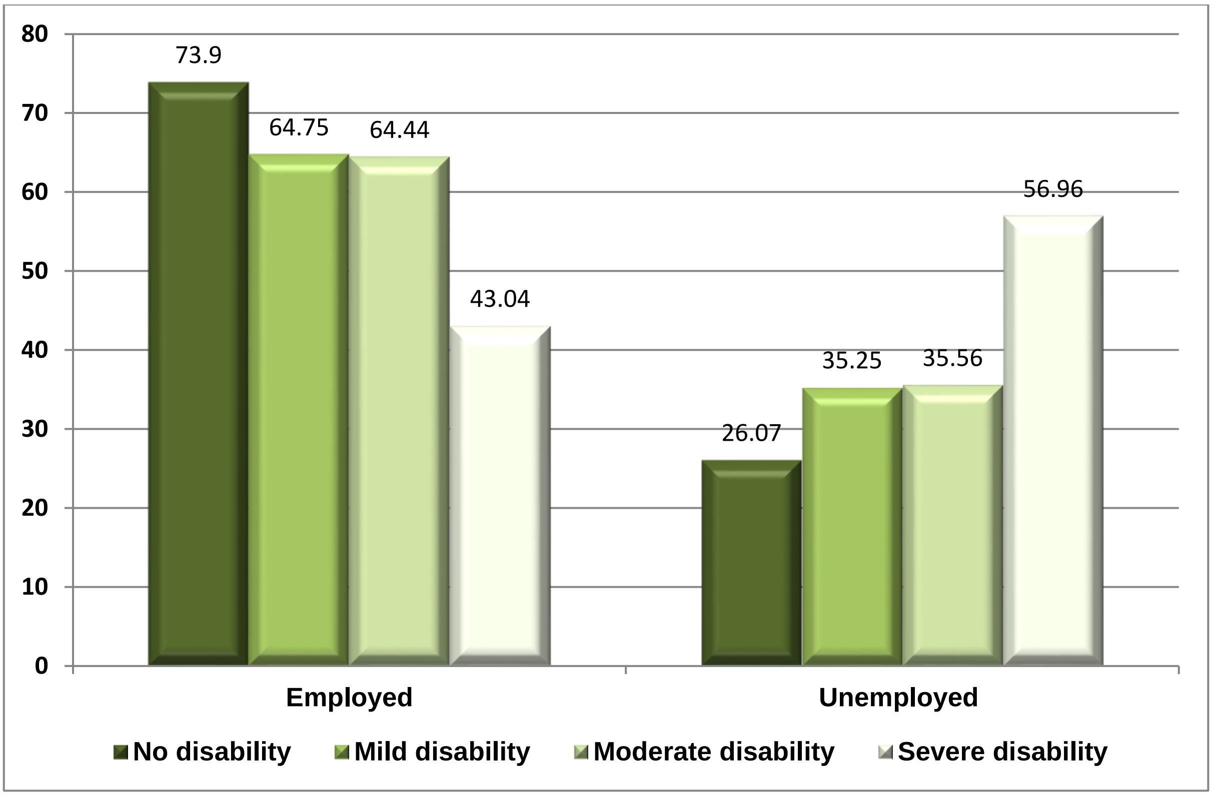

Figure 4.8 Comparison of the percentage employed and unemployed participants according to the presence of disability (p=0.002)

The hypotheses that the level of the severity and presence of disability would differ significantly for the known group variables of age, concurrent health conditions, length of time on ART and employment were accepted for this study. These findings support the construct validity of the HDQ in identifying different levels of disability in terms of other known group variables specifically associated with HIV.

4.7 RELIABILITY OF THE HIV DISABILITY QUESTIONNAIRE (HDQ)

The internal consistency of the domains on the HDQ was assessed. It was found that for the sample of participants in this study that the consistency of the scores was high above the acceptable level of 0.70 (Table 20).

Table 4.20 Cronbach's Alpha scores for the HIV Disability Questionnaire (n=498)

HDQ score	HDQ severity score	HDQ episodic score	HDQ presence score	Items(n)
	Cronbach's alpha			
Physical	0.93	0.87	0.83	20
Cognitive	0.93	0.88	0.85	3
Mental-Emotional	0.92	0.85	0.79	11
Uncertainty	0.93	0.87	0.79	14
Difficulty with day-to-day activities	0.93	0.86	0.77	9
Challenges to social inclusion	0.93	0.87	0.81	12
HDQ total (all items)	0.92			69

4.8 SUMMARY OF RESULTS

The aim of this study was to determine the validity (convergent and divergent) and internal consistent reliability of the HDQ. The construct validity of the HDQ was determined through confirmatory factor analysis. For the confirmatory factor analysis, goodness of fit was shown through Steiger-Lind RMSEA statistics which indicated that all items assessed one construct, disability.

The convergent validity was confirmed by the moderate correlation of the a priori hypotheses between the HDQ and the WHODAS 2.0 while divergent validity was confirmed by 100 percent lack of correlation between the total severity score of the HDQ and its domains and the MOS-SSS. Known group hypothesis was also developed and supported by the results as level and presence of disability differ significantly for age, concurrent health conditions, length of time on ART and employment.

CHAPTER 5: DISCUSSION

5.1 INTRODUCTION

This chapter presents an overview of the study's findings for each objective in three parts. The first part discusses the demographic and medical factors of the participants of the study. The second part of this chapter explores the validity and reliability of the HIV disability questionnaire, while the third part discusses activity limitations, participation restrictions and social support in a sample of PLWHIV in Johannesburg Metro. Potential areas of study to be pursued beyond this study were also discussed.

5.2 RESPONSE RATE

A research population of 1436 participants who are adults and attending an HIV clinic in Johannesburg Metro area were approached. Only 502 gave consent to participate in this study giving a response rate of 35.9%. Of these participants, four HDQ were declared invalid because they did not meet the inclusion criteria and also because more than 10% of the information was missing.

The response rate of this study was lower than the response rate of similar studies by Myezwa et al, (2009). Both of these studies were carried out in South Africa. One possible reason may be due to research fatigue on the part of the participants as most of them reported filling the WHODAS 2.0 before. Three of the four study sites are in University of Witwatersrand teaching hospitals, which are regular centres for different forms of research and sites for data collection.

More so, respondent burden, convenience and length of time required to complete the questionnaire are some other factors that contribute to this low response rate as literature suggest that people are less likely to agree to take part in a survey that is longer because of the increased inconvenience (Collins et al., 1988). This was evident as many participants who didn't take part in the study gave this reason. Lack of cash incentives in this study is another contributing factor to this low response rate, many studies report offering participants material incentives for participating increases response rate (Singer et al., 2000). This was particularly true at Chris Hani Baragwanath Hospital where cash incentives were being requested by participants as previous studies had offered such incentives. This was supported by Singer et al. (1999) who reported that cash incentives have been more effective than any other types of incentives.

5.3 DEMOGRAPHICS AND MEDICAL INFORMATION

Basic demographic characteristics included in the study were age, sex, marital status, race and the number of children they have. Socioeconomic information recorded includes their highest level of education, current employment, and disability grant information. Some clinical outcomes were also recorded during the data collection, which included CD4 counts, viral load information and date of initiation of ART.

5.3.1 Demographics

The mean age of the study participants was 41 years with the majority of participants between 30 and 49 years (Table 4.1). This was similar to the mean age reported in another disability study with PLWHIV on ART in South Africa with mean 38 years. These results reflected those reported by the Human Sciences Research Council (HSRC) in their HIV prevalence survey (Shisana, et al., 2014).

The proportion of female participants in this study was 68.27% (Figure 4.1) which is similar to other studies in South Africa and other African countries where percentage of female to males with HIV is approximately two-thirds to one-third. This concurs with HIV statistics for South Africa and is supported by studies in which the percentage of females ranges from 60.3% to 79% (Chetty & Hanass-Hancock, 2016; Hanass-Hancock, et al., 2015; Mugisha, et al., 2016; Narsai, et al., 2016). Therefore it can be accepted that the age and gender distributions in this study are reflective of the trends for PLWHIV in South Africa.

The distribution of race for the participants in this study was congruent with the prevalence reported by the HSRC for PLHIV exposed to ART, according to population group, ninety-five percent of participants were Black with 5% of participants from the Indian, Coloured and White population groups which is similar to the 4% reported by the HSRC (Shisana, et al., 2014).

The majority of participants were single (Table 4.2) and approximately 20% more male than female participants were married. Being married has been associated with lower incidence of HIV infection for males. This was supported by the HSRC survey where relationship between marital status and HIV incidence was lowest at 0.6% compared to single individuals who had more than one sexual partner in a year where the incidence was 2.4% (Shisana, Risher, Celentano, Zungu, Rehle, et al 2016). In a study by Pitpitan, Kalichman, Eaton, Sikkema, Watt, et al. (2016) on men's behaviours being a predictor for women's risk for HIV/AIDS, they reported that only 27.1% of participants participating in drinking and unprotected sex were married. This supports the findings that single individuals are more are at risk for HIV infection (Pitpitan et al., 2016).

A high proportion of the participants (82.33%) have between one and four children with 85% of the female participants having children. Some participants are single parents as a high percentage of participants who have children indicated they were single.

More than half of the study participants have matric and some tertiary education. Although not supported by this study, knowledge about the prevention of HIV has been found to be significantly better in participants with a higher level of education (matric to some tertiary education) when compared with those without any formal education. This may explain the lower proportion (7.4%) of the participants with degree in this study. Another explanation for this low prevalence in people with a degree is because this group may be able to afford private health care thus could be treated elsewhere.

Hargreaves, Morison, Chege, Rutenburg, Kahindo, et al. (2015) found discernible trends or correlations between education, socioeconomic status and HIV prevalence in young individuals and HIV prevalence in South Africa and Eastern Africa (Hargreaves, et al., 2015). Those from lower socioeconomic circumstances are more likely to take part in risky sexual behaviour and are less likely to be tested and present with a higher prevalence of HIV (Wabiri & Taffa, 2013).

Two-thirds of the participants in this study were either employed (full-time or part-time) or attending school. More participants in this study reported being employed than the 49% reported in a similar study on disability in PLWHIV on ART by

Hanass-Hancock, et al. in 2015 (Hanass-Hancock, et al., 2015). The employment rate reflected that for Gauteng province in 2016 however (Statistics SA, 2016).

With 57.03% of the study participants having a level of education above matric, it can be assumed that most of the participants have some insight and knowledge about HIV as well as having access to treatment. This raises the question whether this sample is biased as it does not include those who are not being tested and accessing treatment for HIV since only 48% of PLWHIV in South Africa are accessing ART (UNAID, 2016). It is not clear whether this missing population is more poorly educated, have a lower socioeconomic status and have less access to health care.

Contrary to the findings of Govender et al. (2015) none of the participants in this study were receiving disability grants, although 10.44% of the participants in this study qualified for these grants as they had a CD4 of <200 cells/microlitre. Knowing the threshold level of the participants income would have better explained if any participants, even with CD4 count <200 cells/microlitre qualified for a temporary disability grant. Govender et al. (2015) reported that people living with HIV deliberately refuse to adhere to ART to lower their CD4 count so they can have access to disability grants. Nearly 90% of participants in this study had CD4 counts higher than 200 cells/microlitre, indicating they might have been more aware of the side effects of non-adherence to their HIV medications than requiring state assistance in the form of a small disability grant although this needs further investigation. (Govender et al.,2015).

This finding may have been affected by the relatively high employment rate found for study with the 3.8% of study participants receiving permanent disability grants being similar to that reported by Hanass-Hancock, et al.(2015), Those receiving grants had been diagnosed with other permanent disability such as blindness.

5.3.2 Medical Information

Clinical outcomes such as length of time participants have been on ART and occurrence of opportunistic infections are important indicators of disease progression and response to treatment. plasma HIV-1 viral load, WHO clinical stage, and CD4 counts are some of the important indicators for monitoring and evaluating the prognosis of HIV and the possibility of developing disabilities in people living with HIV.

More than 50% of the participants WHO stages were missing in the case files and this information could not be inferred from the CD4 count or viral load as the HIV clinical staging was based on clinical finding and diagnosis and no other medical information. For those participants where the WHO stage was indicated the majority (65.5%) were in stage 1 which indicated that they are asymptomatic for concurrent health conditions (World Health Organisation, 2007).

The CD4 counts staging use in this study was based on the WHO immunosuppression staging of disease. The proportion of the participants with CD4 counts higher than 200cell/microlitre was very high (89.6%) which is similar to results from other studies in South Africa (Centres for Disease Control and Prevention, 1999).

It has been physiologically shown that females, either HIV negative or positive, have a higher CD4+ T-lymphocyte (CD4) count compared to males (vom Steeg & Klein, 2016) . Small but significant, this study showed a higher CD4 count for females than males. A study by Maskew, Brennan, Westreich, McNamara, MacPhail &, Fox. (2013) at the Themba Lethu Clinic where some data for this study was collected, confirmed the gender differences in the CD4 count. They attribute this to men only accessing treatment at a later stage in disease with lower CD4 counts (Maskew et al., 2013).

In this study, about half (47.2%) (Table 4.4) of the participants had an undetectable viral load with females having a higher (52.2%) undetectable viral load. These results are similar to those in other studies in South Africa and better than those reported for other African countries where access to ART is limited (Tun, et al., 2016). The higher percentage of females with undetectable viral load and higher CD4 counts is congruent with studies in sub-Saharan Africa due to reduced adherence in men (El-Khatib, Katzenstein, Marrone, Laher, Mohapi et al., 2011) with men generally having a higher risk of viral infection (Kipp, Alibhai, Saunders, Senthilselvan, Kaler, et al 2010).

The undetectable viral load for the participants in this study was lower than the nearly 90% of participants reported with undetectable viral load in relation to the validation and use of the HDQ in developed countries. This may be explained by the late provision of ART to the participants in this study. Most participants would only have been started on ART when they had a CD4 < 200 cells/microlitre as this was the policy of the Department of Health prior to 2016. Research indicates that patients who start ART at this stage may not achieve adequate CD4 counts or undetectable viral load over a five year period and are more likely to be compromised in terms of their health (Ferrer, Curto, Esteve, Miro, Tural, et al., 2015).

In this study, participants reported 48 different concurrent health conditions with 30% reporting having one or more condition. This was less than the 40% reported by Hanass-Hancock et al. (2015) in their study of PLWHIV on ART in South Africa (Hanass-Hancock, et al., 2015). Opportunistic infections occur commonly in patients with HIV/AIDS due to lowered immune responses. However, the study found that 20.68% of the HIV/AIDS patients have one type of opportunistic infection while 4.7% experience two types; it was observed that the majority of the HIV/AIDS patients do not experience any opportunistic infections (73.98%). This may be due to the fact that the participants in this study are attending a clinic and have access to ART. They have also been taking ART for a relatively short time compared to those in studies on validity of the HDQ in developed countries (O’Brien et al., 2015). High blood pressure was the most reported concurrent health condition by about a quarter of the participants which was similar to that report by Canadian participants living with HIV, assessed for disability on the HDQ (O’Brien et al., 2015). The percentage of participants who reported other health conditions was much lower than reported in Canada and Ireland in the validity and reliability study of the HDQ (O’Brien et al., 2015). Tuberculosis which has reached epidemic proportions in relation to HIV infection in South Africa was reported by just fewer than 10% of participants. This is congruent with the drop in TB rates in PLWHIV on ART and the increased cure rate reported in South Africa from 2011 (World Health Organisation, 2013).

Half of the study participants (52.0%) have been on ART for a period more than 5 years which reflects the roll out of ART in South Africa between 2004 and 2011 (World Health Organisation, 2013). There were only a small percentage of participants (12.3%) who have been on ART for a period less than a year reflecting the lower incidence 1.22 of new infections in the age group assessed for this study (Table 2.1) (Stats SA, 2015).

5.4 VALIDITY AND RELIABILITY OF THE HIV DISABILITY QUESTIONNAIRE

The aim of this study was to investigate the validity of the HDQ in PLWHIV in a developing country. In line with validity studies previously completed on the HDQ, a factor analysis, concurrent validity for the severity of disability and divergent validity in terms of quality of life were established. The internal consistency of the three scales on the HDQ was determined.

5.4.1 Factor analysis

Factor analysis was used to determine the fit of the data assessed in the South African sample to the hypothesised domains of disability measured by the HDQ. On rotated principal extraction of factors, the impairment domains for physical symptoms, cognitive symptoms and mental and emotional symptoms all loaded on the a priori factors as expected. On Domain 4: uncertainty, all expected items loaded as well as three items under challenges of social and community inclusion which also loaded in this factor. These items relate to social isolation and deal with aspects of discussion about the condition with family and friends as well as starting new sexual relationships. It is not clear why in this sample these items should load into the uncertainty domains as they appear to deal with social inclusion. This aspect would need further investigation.

In Domain 5: difficulties with day to day activities, the activities related to occupational performance areas such as personal and instrumental activities of daily living and leisure appear to load with other instrumental activities of daily living, work and social activities in Domain 6: challenges with social and community inclusion. For this study it appears that the inability to complete grooming, leisure, household chores, use transport and manage finaces do load with care of others, work activities and social activites, indicating that these occupational performance skills load with social and community participation. There is therefore no clear differentiation for these items which could be considered activity limitations on the HDQ from participant restrictions for the sample in this study.

These results may be due to differences in the sample used for this study which differed in age, length of time on ART, gender distribution and employment status when compared to that reported in the Canadian study (O'Brien et al in 2014), Participants in this study may have seen personal and instrumental activities of daily living as important in supporting their ability to work and integrate socially. These aspects should be investigated further in validating the HDQ for developing counties and according to various known group variables.

Overall in the confirmatory factor analysis and the maximum likelihood method indicated that the all items load under 6 factors indicating the HDQ measures had a single construct of disability. The other results for the goodness of fit reflect those reported by O'Brien et al in 2014. The lack of fit as indicated by the significant result for the chi-squared test, in this case, can also be over inflated by the large sample size as in the study by O'Brien et al (2014) is not as important as the significant RMSEA results, which in this case, showed an acceptable fit as did the fit for each item (O'Brien et al 2014). Thus the model with six domains was accepted as valid for the South African sample (Table.4.14) as the relationships between 6 domains in the HDQ was still similar although the items in the domains would need to be reviewed and investigated further for different populations.

5.4.2 Convergent and divergent validity

Convergent validity of the HDQ was tested by correlating it with the WHODAS 2.0 and divergence was tested with the MOS-SSS which considers the quality of life related to social support which was not the intention of the HDQ.

The four convergent validity correlation hypotheses were supported by the South African participants. The first hypothesis that the total severity, presence and episodic nature of disability scores, as well as all the domain scores of the HDQ, will correlate moderately with the total score of the WHODAS 2.0 was supported with moderate to strong positive correlations which were significant at $p \leq 0.05$. This hypothesis was developed based on the fact that the two disability assessment tools was developed to measure impairments, activity limitations and participation restrictions in related domains of disability. The WHODAS 2 has previously been used to assess disability in PLWHIV in South Africa in a diverse sample and was found to identify activity limitations and participation restrictions in 49.9% of PLWHIV (Hanass-Hancock, et al., 2015). The median scores of 0 obtained indicate that over 50% of the participants in this study also reported no activity limitations and participation restrictions for most domains on the WHODAS 2 in agreement with this finding (Table 4.10). Hanass-Hancock, et al. (2015) also indicated that 35% of their participants scored 3 or 4 on items on the WHODAS-2 were considered as severe enough to indicate the onset of disability, with a slightly greater percentage of participants in this study (43%) scoring 3 or 4 on items on the HDQ which could be considered as onset of moderate or severe disability by (Table 11).

The only exception for this hypothesis was for Domain 2: cognition symptoms score of the HDQ which however, had a weak correlation with the total WHODAS 2 score. This may reflect the small number of items (3) in this domain on the HDQ as compared to the 6 in the WHODAS 2.

The second hypothesis that Domain 2: cognition symptoms on the HDQ would correlate moderately with the equivalent impairment domain for cognition on the WHODAS 2.0 was accepted. A similar finding for physical symptoms of the HDQ and mobility on the WHODAS 2 indicate these domains consider similar constructs and can be considered valid for the HDQ. The third symptom domain on the HDQ for mental and emotional impairment is not reflected as a separate domain on the WHODAS 2 but did correlate moderately with the domain for cognition on the WHODAS 2.0. This correlation was supported by Hanass-Hancock et al.(2015) in their study in South Africa where they found a correlation between depression and cognition in PLWHIV (Hanass-Hancock, et al., 2015).

The domains on the HDQ representing participation restrictions in the form of challenges to social and community inclusion, as proposed in the third hypothesis had positive moderate correlations above 0.5 with Domain 6: participation in society on the WHODAS 2.0. This indicates that the HDQ was measuring participation in society similar to that assessed by the WHODAS-2.

A fourth hypothesis that the domain of social and community inclusion on the HDQ and getting along with others on the WHODAS 2 would be moderately convergent was proposed as both contain similar items involving but not limited to how much participants has been emotionally affected by their health condition, how much they spent on their health condition and how much of a problem they have in joining community services. This hypothesis was accepted (Table 4.11).

Similar moderate correlations for Domain 6: participation in society as well as Domain 4: getting along with people, on the WHODAS 2.0 were found for Domain 4: Uncertainty on the HDQ. Although uncertainty is a unique construct assessed on the HDQ with no corresponding domain on the WHODAS 2.0, the definition of uncertainty indicated it does have components related to emotion and social inclusion (Brashers, et al., 1999). Hanass-Hancock, et al. (2015) also found components related to emotion and social inclusion were related to participation restrictions in PLWHIV (Hanass-Hancock, et al., 2015).

All of the domains on the HDQ had a weak correlation with the self-care domain on the WHODAS 2 as no domain on the HDQ considers personal activities of daily living exclusively but rather difficulty in day to day activities which correlated moderately with Domain 5: Life Activities on the WHODAS-2. These domains appear to cover activity limitations but they also correlate moderately with the domains indicating participation restrictions thus indicating a link between these two constructs in both assessments.

Divergence from quality of life social support constructs was hypothesised, and the total domain scores of the HDQ did have weak negative correlations with the MOS-SSS scores (Table 4.13). This hypothesis was accepted proving the constructs assessed by these assessment instruments differ. The MOS-SSS like the WHODAS was developed for use with people living with a chronic health condition but not specifically developed for PLWHIV. The MOS-SSS evaluates coping by looking for and getting help from others for emotional support for the adverse effects of chronic illness which is a different construct to disability in chronic illness.

These results were similar to those reported by O’Brien et al (2015) in their study on the psychometric properties and the construct validity of the HDQ. The convergent and divergent validity of the HDQ reported by O’Brien et al (2014) were confirmed for the sample in this study indicating the HDQ does therefore, assess disability as defined by O’Brien et al. (2008) when compared to reference measures.

5.4.3 Known Group Hypotheses

The known group hypotheses proposed for this study were based on those proposed by O’Brien et al. (2015) that disability in PLWHIV is related to age and concurrent health conditions. Two further hypotheses based on known group variables that differed significantly between the participants assessed by O’Brien et al. (2015) in their studies in Canada and Ireland were employment status and length of time on ART. These hypotheses were tested and were supported by this study in the South African population. Although comparing the known group variables for the South African sample with those reported for the Canadian and Irish study it was clear that lower median scores were obtained for the length of time on ART and the number of concurrent health conditions. While the average age of the participants was similar to that for the participants in Ireland and younger than those in Canada, more to the participants in South Africa were employed. In discussing the known group variables reference will be made to the previous validity studies for the HDQ in Canada and Ireland.

5.4.3.1 Age, concurrent health conditions and length of time on antiretroviral

The concept of physical symptoms and impairments is particularly relevant to aging with HIV, whereby older adults tend to have been living with the disease for a longer time thereby developing more comorbidities. The levels of disability were analysed according to the scores on the domains with those scoring 50 or more considered as having moderate to severe disability. The result of this study reveal that the majority of older participants experience mild to severe disability, a result similar to that revealed by Guaraldi Prakash, Moecklinghoff & Stellbrink., 2014 who stated that chronic inflammations, frailty and increased morbidity is related to aging due to decline in ability of the body tissue to renew and repair themselves. This process is accelerated in HIV positive individuals resulting in high level of disabilities in this population (Guaraldi et al., 2014).

Based on the known group factors O’Brien et al. (2015) had already found a significantly higher level of disability on all the scales for all domains, and the three total scores between the older participants in Canada and those in Ireland. The age of participants in this study was similar to that reported for Ireland. The lower scores for all domains and total scores for the presence of disability found in the South African sample does not appear to be related strongly to age under 50 years which supports the study by Guaraldi et al. (2014). They revealed a higher rate of concurrent health conditions in older participants with the newly calculated life expectancy of 75 years in the HIV-positive men who have sex with men living in a developed country. This results in them experiencing higher levels of concurrent health conditions which includes, but is not limited to headaches, fatigue, diarrhoea, fever, and shortness of breath.

This concept is supported by this study where the majority of the participants is 98.84%, are over 50 years of age and have experienced some form of disability ranging from mild, moderate to severe in relation to the number of reported concurrent health conditions. This result can be accepted as a true picture of HIV in people above the age of 50 years.

It is likely that concurrent health conditions play a larger role in the presence of disability as there was a significant difference between this variable reported by participants in this study. This is also reflected in the study by O’Brien et al. (2015) where participants in Canada with significantly higher scores for the presence of disability also had significantly more concurrent health conditions.

An increase in the levels of severity of disability in this study was found for the length of time participants had been receiving ART. Participants who had been on ART for longer had more severe disability. This finding was supported by the lower levels of severity for all domains on the HDQ found for the South African sample when compared to the results from Canada and Ireland. This is the known group variables that differ from the previous studies using the HDQ. In Canada, the median year of diagnosis was 1999 with approximately 40% being diagnosed before 1996. In Ireland, the median year of diagnosis was 2003 and although not reported the participants in these cohorts have probably been on ART for much longer than the participants in this study.

The participants assessed by the HDQ in Ireland with the significantly lower severity of disability had received ART for an average of 7 years. Based on the roll out of ART in South Africa which started in 2004, 80% reached clinics and those in need with a resultant increase in life expectancy between 2009 and 2011. Thus the participants in the South African sample can be assumed to have received ART for a shorter period of mostly seven to eight years (Johnson, 2012; World Health Organisation, 2013).

5.4.3.2 Employment

The HDQ was developed to assess disability in PLWHIV who were no longer employed. The results of this study indicated a significant difference in the level of the presence and severity of disability as assessed by the HDQ and the employment status of the participants. Those with more severe disability are significantly less likely to be employed. This is supported by Elzi, Conen, Patzen, Fehr, Cavassini, Calmy et al. (2016) in their study on Ability to Work and Employment Rates in (HIV)-1-Infected Individuals Receiving Combination Antiretroviral Therapy. This study revealed that employment rate increased by 46.4% after a year of antiretroviral treatment among 947 individuals unable to work at baseline, thus indicating exposure to ART reduces the severity of disability and increases employment rate accordingly (Elzi et al., 2016).

This study demonstrated that a population-based sample of people living with HIV in South Africa has been experiencing lower levels of disability than reported for samples in developed counties (O'Brien, et al., 2014). The majority of participants (80.3%) in this study experienced mild disability. This is similar to results by (Rusch et al., 2004) where they reported some activity limitations in 80.6% of their study participants

The results for the participants in this study were similar to those reported by O’Brien et al. (2015) in that uncertainty scored as being the most common disability as well as being the most severe disability. This confirms the importance of including this construct in the HDQ in the assessment of disability in PLWHIV (O’Brien et al., 2015). The concept of uncertainty is particularly relevant to unemployment and financial uncertainty, aging with HIV, whereby older adults may worry about their source of health challenges transition to retirement or job security living with HIV health providers’ knowledge and skills; appropriate long-term housing and who will care for them as they age living with HIV (Solomon, O'Brien, Wilkins & Gervais, 2014).

5.4.3.3 The presence, severity and episodic nature of disability

Based on the Episodic Framework described by O'Brien et al (2015) the presence, severity and episodic nature of disability in the South African sample was considered. The HDQ was initially developed to test older PLWHIV who had more severe disability; therefore, for some items and domains for the sample in this study median scores of 0 were obtained, indicating no disability as the participants were younger and had milder disability which may have had an effect on the validity of the HDQ . This indicates the HDQ may not discriminate ability in a sample with demographic and medical factors representative of PLWHIV in developing countries.

The presence of disability for physical, cognitive, mental and emotional health symptoms all scored at a similar level. In comparison, the studies in Ireland where more disability was reported for mental and emotional health symptoms. The lowest score was for difficulties with day to day activities for this study and was also reflected in the lowest score in the Canadian and Irish studies. This indicates similarity in the domains where disability is likely to be found in PLWHIV, confirming the HDQ reflects similar proportions for of the presence of disability in the various domains for the sample in this study. The one domain, mental and emotional health symptoms which exhibited presence of no disability in this study, differed when compared to the Canadian study where this domain reached a median of 100. This finding confirms the ability of the HDQ to differentiate between groups which were not comparible in terms of employment status, concurrent health conditions and lenth of time on ART. The finding may have also been influenced by the small number of items in this domain which did not identify mental and emotional symptoms in the sample in this study. This is troublesome as Hanass-Hancock et al. (2016) found this aspect to be of great concern in PLWHIV in their study in terms of disability (Hanass-Hancock et al., 2016). These aspects may not be adequately assessed by the HDQ and need further investigation.

There was one marked difference for the HDQ in the South African sample. Higher episodic scores with the exception of physical symptoms was reported by the participants in this study than those reported by O'Brien et al., (2015) in the Canadian and Irish studies. People live more with uncertainty in low resourced countries even if not HIV positive and this may impact more on those living with HIV. Participants may have reported more fluctuation in all aspects of their lives, more frequent bad days or changes in past week in all health challenges on the HDQ than participants in other studies because of less access to resources (Hanass-Hancock, 2009).

This may be experienced under uncertainty in terms of concern about health due to aspects like accessing health care. It has been revealed that poor financial circumstances and reliance on public transport mean that patients cannot always keep appointments (Harris, et al., 2011). Receiving treatment at some clinics requires the entire day, especially in large HIV clinics with long cues as these clinics serve thousands of patients. This requires time off work and since all participants were assessed on the day they were at clinic for a check up may reflect renewed uncertainty about their medical results which are checked on that day. Stockouts of ART are also a reality in some clinics which means participants may not be sure that their medication will be available when they need it (Doctors Without Borders (MSF), 2016; the Rural Doctors Association of Southern Africa (RuDASA), 2016 and the Rural Health Advocacy Project (RHAP), 2016).

Participants may experience more episodic fluctuations in their health challenges due to the socioeconomic and social circumstance in which they live. Coping with everyday activities in under resourced circumstances may be difficult in terms of accessing adequate nutrition, community support and employers that are understanding of time needed off work. (AIDS Foundation South Africa, 2016). This is an aspect of the HDQ that needs further investigation.

5.4.4 Internal Consistency

The internal consistency of the HDQ was compared to that established in other studies using the HDQ. The HDQ severity, episodic domains scale scores and total scores met pre-specified criteria for internal consistency reliability. This is a result similar to the previous study by O’Brien et al. (2015) in which they also determined the internal consistency reliability of the HDQ in developed countries (Canada and Ireland). The Cronbach’s alpha severity scores of the HDQ are better for the South African population than the Irish and Canadian population living with HIV as the scores only range between 0.92 to 0.93, while for Canadian participants it ranges from 0.87 to 0.93 and 0.84 to 0.92 for Irish participants. The higher internal consistency Cronbach's alpha scores for this study may reflect some duplication of content in the items with redundancy of items. These results may reflect the loading of items on different factors in the HDQ for this sample making some items redundant (Streiner, 2003).

5.5 LIMITATIONS OF THE STUDY

Only PLWHIV receiving ART were included in the study, and although this may have biased the sample as approximately only half of the PLWHIV in South Africa are accessing ART (Stats SA, 2015), it alleviated the necessity of establishing whether potential participants are living with HIV. The reality is in a low resourced developing country like South Africa with a high prevalence of HIV. Not all PLWHIV will have access to ART but approximately half of the PLWHIV in South Africa are now accessing ART, reflecting an increase of nearly 2 million as compared to 2002. Due to changes in health policy, the number of individuals being provided with ART continues to rise yearly (Stats SA, 2015).

Data on medical issues was difficult to obtain as medical information like WHO clinical staging and viral loads were missing in the case file.

Research fatigue could have been a problem which resulted in patients at the clinic refusing to participate as they had already completed questionnaires in other studies. However, this did not affect the sample size nor does it affect the generalisability of the results as the participants represent the population of people living with HIV in Johannesburg and Soweto, South Africa.

Assessment of the interpretability of the HDQ scores is important to understanding the meaning of the HDQ scores both for the health care providers and the patients as this will help to identify services, program and interventions that will reduce disabilities and increase overall wellness.

The HDQ was initially developed for assessing disabilities in men living with HIV in urban areas and taking ART, living with concurrent health conditions and unemployment. In light of this, the HDQ in this study was with different known group variables in comparison to the Canadian samples as this study included more women and employed participants, of whom the majority are not experiencing any concurrent health conditions and on ART.

While this is the first HDQ validity study in a developing country, the transcultural validity of the HDQ is unknown and may affect the generalisability of this finding in other developing countries in that this limitation restricts our goals of generalizing these findings to South Africa.

The study used a convenient sample and participants were not randomly selected. Findings from this study also under-represent young people living with HIV in South Africa. More so, people living with disabilities such as deafness, blindness, and psychiatric illness were under-represented in this study. These limitations therefore may affect the acceptability of these results as a true picture of validity of the HDQ and disabilities associated with HIV in this population.

Despite these limitations, this study is an important step in statistically establishing the validity and reliability of the HDQ in developing countries. It also adds to the existing knowledge on the global impact of HIV on activity limitations, participations, restrictions and quality of life in relationships with social support in developing and low resource countries. Furthermore, this study has been able to reveal the importance of including uncertainty as a domain of disabilities in PLWHIV as this is the first study to explore HIV from episodic disability framework in a developing country, thereby revealing more areas where services, programs and interventions are needed to reduce disabilities and increase quality of life in PLWHIV.

5.6 METHODOLOGICAL STRENGTHS OF THE STUDY

Rigour in terms of data collection and missing data were followed in this study as was the training of research assistants. The research assistants were familiar with all the assessment tools and were able to assist participants who they guided through the self-report questionnaires if necessary. This ensured that the participants understood the questions, increasing their ability to report on their impairments, activity limitations and participation restrictions which make up the construct of O’Brien et al (2014) as well as their QoL in the language of their choice (O’Brien et al 2014).

According to the COSMIN checklist the following were included in the study in relation to hypothesis testing, validity and reliability.

The percentage of missing data was minimised by checking the questionnaires before the participants leave the research site. Two questionnaires were eliminated from the study because the participants have been on ART for less than 6 months and the other two were excluded because more than 10% of the items and/or domains were missing.

The sample size was justified for survey sampling as well as factor analysis and convergent validity and the sample was larger than that calculated as necessary for the study. Hypotheses for convergent validity were determined based on priori factors from research by O'Brien et al (2014).

The direction and magnitude of correlations was presented in the data analysis, and results with the reference assessment tools and their measurement properties as well as the convergent and divergent described in the literature review and methodology.

The construct validity of the HDQ was assessed using factor analysis and was shown to consist of six factors, and measure of the construct of disability as described by O'Brien et al. (2014). The factor analysis indicated six factors for this study which showed discrepancies within the domains in the HDQ as described by O'Brien et al. (2014). Items on the HDQ were appropriate for the age, gender and urban sample in this study and the assessment is specifically designed for PLWHIV (O'Brien et al., 2014).

The criteria for internal consistency were met although the internal consistency for each domain was not calculated.

5.7 CONCLUSION

The demographics for the sample were shown to match others reported for PLWHIV in South Africa. The validity and reliability of the HDQ was determined for this sample which differed in terms of demographic factors and medical history from other samples of PLWHIV on which the HDQ had been validated.

The findings in the factor analysis indicate that the construct validity HDQ may be affected by these differences and support the importance of establishing validity of assessment tolls on different populations.

For assessments to be valid they should provide scores that have the same meaning across different populations. They must be evaluated for differences in scoring and for factors that may differ from the original population on which the assessment was developed. While the language and self-report nature of the questionnaire was accommodated in this study to make the test accessible to participants by training research assistants to assist with administration of the test, other factors appear to have played a role in structure of the assessment which may affect interpretation and identification of disability in different domains on the HDQ. Thus before recommending the HDQ as a valid test for South African PLWHIV, particularly in light of 0 scores for some domains on the severity scale, further investigation into participants' perceptions of the presence and severity of their disability as well as the episodic nature of their disability needs to be completed.

The HDQ appears to measure the construct of disability in PLWHIV as defined by O'Brien et al. (2014) and shown in the confirmatory factor analysis and convergent and divergent correlation studies. The levels of disability assessed by the HDQ were also associated with known group factors in the South African sample indicating that the assessment is responsive to mils, moderate and severe disability levels (O'Brien et al., 2014).

Based on the measurement of the construct of disability the internal consistency was established for the HDQ. The deficiency which may be related to the high Cronbach's alpha scores for this aspect, however, may bring the relevance of all items into question.

CHAPTER 6: CONCLUSION

6.1 CONCLUSION

The aim of this study was to determine the validity of an assessment instrument, the HDQ for a sample of PLWHIV in South Africa. The HDQ had been researched in developed countries by O'Brien, et al. (2015) but not in South Africa and many other low resource countries where the presentation of HIV differs in a low resourced health system and economy (Stats SA, 2015). The selection of a convenient sample of 498 participants in clinics in Johannesburg resulted in a sample that differed in gender, age, length of time on ART, the number of concurrent health conditions and employment rates from those used to test the validity of the HDQ previously.

The HDQ validity was tested using factor analysis, convergent and divergent validity as well as whether known group hypotheses were supported by the levels of disability assessed in the South African sample.

The principal component analysis results supported those found previously for the HDQ except for the domains related to activity limitations or difficulty with day to day activities where items loaded in the domain related to participation restrictions or challenges with social and community inclusion. Some items related to participation restrictions also loaded into the domain or uncertainty. These differences may have been related to the known group variables such as employment status and the number of concurrent health conditions that differ between this sample and that assessed by O'Brien et al. (2014) when she validated the HDQ in Canada (O'Brien et al., 2014).

Confirmatory factor analysis in this study indicated an acceptable goodness of fit for the framework used for identifying the construct of disability in the South African sample. The maximum likelihood ratio also confirmed that the factors loaded on one construct – that of disability. Therefore, the HDQ can be accepted as a tool which measures disability in PLWHIV in the South African sample. This was confirmed by the convergence to scores on a reference assessment instrument which assesses activity limitations and participation restrictions, the WHODAS 2. Divergent validity from assessment MOS-SSS indicated that the

HDQ assessed disability and not social support. It can therefore be accepted that the HDQ is a valid assessment instrument for the overall evaluation of disability according to the Episodic Framework developed by O'Brien et al. (2008) in PLWHIV in South Africa.

The HDQ was also found to be assessing different levels of disability when these were compared to known group variables related to HIV. Although there were more female participants in this study, this did not affect the level of disability. Other known factors such as the number of concurrent health conditions and shorter time on ART was congruent with the lower presence and severity of disability found in the South African sample. The level of severity and presence of disability was also significantly different in PLWHIV who were employed and unemployed, confirming the validity of the test to identify higher levels of disability in those who are no longer able to work.

When the domains and episodic nature of disability were considered some differences were found between those reported previously in the HDQ in developed countries and those found for the sample of PLWHIV in South Africa. The principal component factor loading structure of the HDQ was found to fit the six domains of the HDQ with the exception of Domain 5; difficulties with day to day activities which loaded with Domain 6 Challenges in social inclusion. These two domains can be considered to assess occupational performance related to participation restrictions and this finding may reflect those found for the episodic nature of disability.

These findings may be related to the effects of living in low resourced circumstances where participants encounter difficulties in accessing health care and coping with a chronic illness may be affected by socioeconomic or social circumstances. The validity of the HDQ in assessing participation restrictions in a low resourced country as well as the added burden placed on those living with HIV in a developing country such as South Africa needs further investigation.

The research study did consider the validity of the first HIV specific disability instrument for use in South Africa. In addition, the study contributed to the known literature related to the socio-demographic profile of those individuals and also the effect of this profile on disability in those living with HIV in Gauteng Province.

6.1 RECOMMENDATIONS

The research project highlighted several areas where research is still needed, particularly in relation to mental and emotional symptoms, participation restrictions as well as the episodic nature of disability in PLWHIV. This study reported a higher occurrence of episodic disability in PLWHIV in South Africa when compared with other studies in Canada and Ireland, more studies are needed to confirm this observation.

The current research participants could be followed up longitudinally for a longer period to determine the validity of the HDQ in identifying the change in disability in PLWHIV over time in one context.

It is recommended that all South Africa clinics computerise the medical records to minimise missing medical information.

The length of the HDQ was one of the reasons why some participants did not participate as they complained it is extended and would take a lot of their time. Further revision of this instrument may include a short-form version to encourage patient participation in future studies and enhance intended feasibility of the HDQ in clinical settings.

Changes in disabilities over time and effectiveness of interventions, especially in low resource and HIV endemic countries, needs to be examined by exploring additional psychometric assessment of responsiveness of the HDQ as this study involves participants at one time only.

6.2.1 Clinical Recommendations

Patients attending HIV clinics should be routinely assessed for disability. The assessments used in this study were all self-report assessments which the patients needed assistance to complete. Therefore, if an assessment such as the HDQ is used it will probably have to be with assistance from a therapist or therapy technician.

Those identified with mild disability should be included in preventive programmes so as to be maintained at this level. The patients with moderate to extreme disability should receive appropriate rehabilitation to assist with maintenance of independence and resolution of impairments and participation restrictions if possible.

In conclusion, it appears that the HDQ is an appropriate assessment to determine disability in PLWHIV in South Africa as this presents the best option currently for the assessment of disability related to impairments, activity limitations and participation restrictions for this population which should be assessed by rehabilitation services.

There are some reservations about the validity and reliability of the HDQ for this sample and therefore it is recommended that further analysis of the HDQ results of this study are completed using Rasch analysis before the HDQ is used in the clinical setting in South Africa due to some discrepancies in the factor analysis found for this study. Convergence of the HDQ results could also be made with assessment tools that measure occupational performance in activities, and participation such as the Activity Participation Outcome Measure (APOM) by Casteleijn and Graham, (2012) to confirm the results on the self-report of disability.

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APPENDIX A DEMOGRAPHIC QUESTIONNAIRE

Please answer these questions by marking one line.

1. Gender: _____ 0) Male _____ 1) Female

2. Years of age: _____

3. In which group do you mostly place yourself?

_____ 1) Black _____ 4) Caucasian/White

_____ 2) Coloured _____ 5) Indian

_____ 3) Asian _____ 6) Other _________________

4. What is your CD4 count level______________________________________?

5. What is your current marital status?

_____ 1) Single (never married) _____ 4) Widowed

_____ 2) Married _____ 5) Divorced

_____ 3) In committed relationship _____ 6) Separated

______7) Complicated

6. Do you have any children? _____ 0) No _____ 1) Yes (including step or adopted)

7. How many children? _____

8. How far did you go in school?

_____ 1) Less than Grade 10 _____ 5) Bachelor's degree

_____ 2) Completed Grade 10 _____ 6) Master's degree

_____ 3) Matric _____ 7) Ph.D., .

_____ 4) Some tertiary qualification _____ 8) Other _________________

9. Current employment:

_____ 1) Employed full time or more _____ 4) In school full time

_____ 2) Employed part-time _____ 5) Homemaker _____ 6) Unemployed

_____ 3) Self-employed _____ 7) Retired or disabled

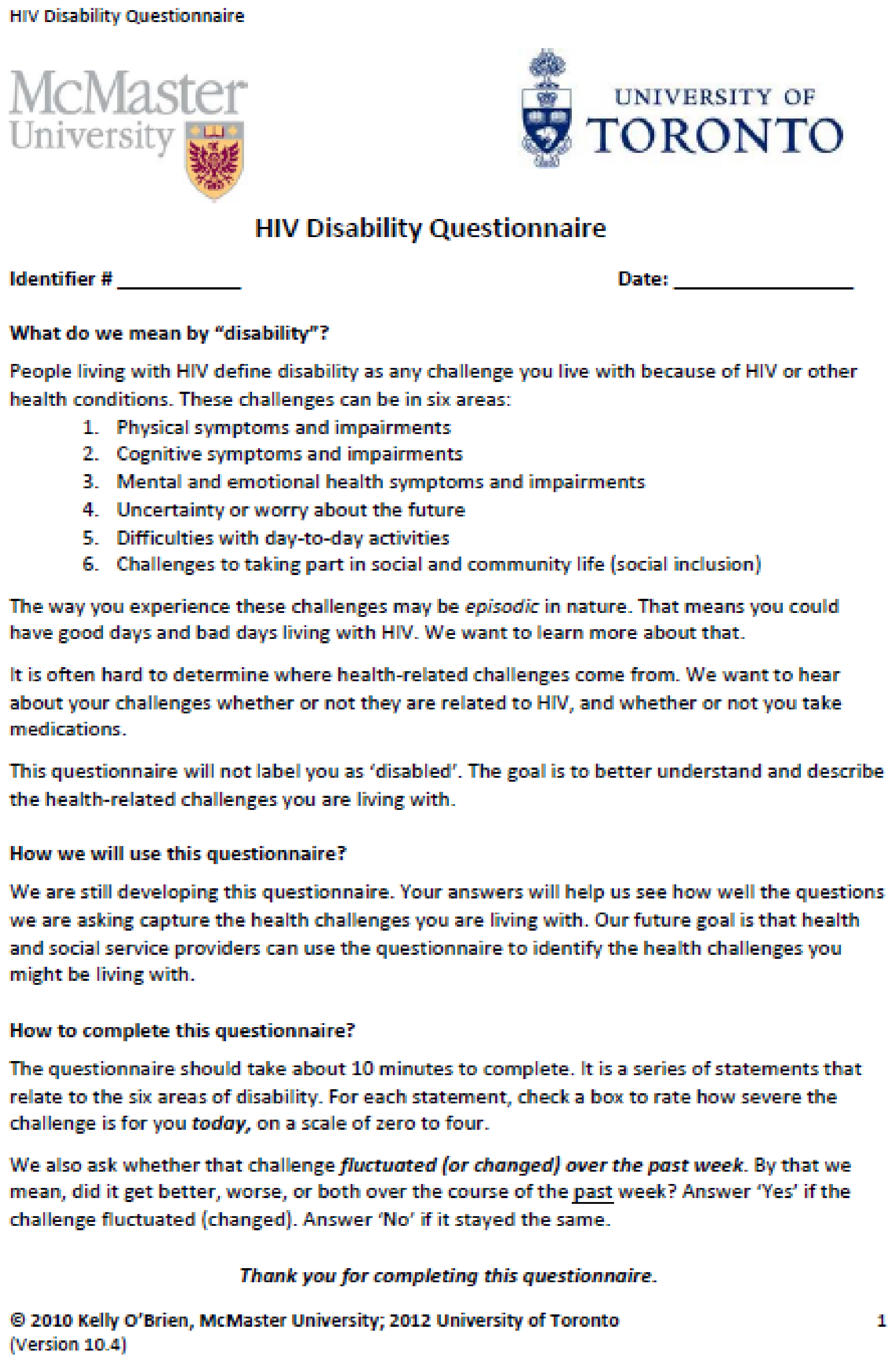
10 Are you currently receiving a disability grant ___________-

11. How long have you been on antiretroviral treatments___________________?

12. Please list any current medical problem(s) that you have:

____

APPENDIX B HIV DISABILITY QUESTIONNAIRE



HIV Disability Questionnaire

McMaster University

UNIVERSITY OF TORONTO

HIV Disability Questionnaire

Identifier # ___________ **Date:** ______________

What do we mean by "disability"?

People living with HIV define disability as any challenge you live with because of HIV or other health conditions. These challenges can be in six areas:

1. Physical symptoms and impairments
2. Cognitive symptoms and impairments
3. Mental and emotional health symptoms and impairments
4. Uncertainty or worry about the future
5. Difficulties with day-to-day activities
6. Challenges to taking part in social and community life (social inclusion)

The way you experience these challenges may be *episodic* in nature. That means you could have good days and bad days living with HIV. We want to learn more about that.

It is often hard to determine where health-related challenges come from. We want to hear about your challenges whether or not they are related to HIV, and whether or not you take medications.

This questionnaire will not label you as 'disabled'. The goal is to better understand and describe the health-related challenges you are living with.

How we will use this questionnaire?

We are still developing this questionnaire. Your answers will help us see how well the questions we are asking capture the health challenges you are living with. Our future goal is that health and social service providers can use the questionnaire to identify the health challenges you might be living with.

How to complete this questionnaire?

The questionnaire should take about 10 minutes to complete. It is a series of statements that relate to the six areas of disability. For each statement, check a box to rate how severe the challenge is for you ***today***, on a scale of zero to four.

We also ask whether that challenge ***fluctuated (or changed) over the past week***. By that we mean, did it get better, worse, or both over the course of the past week? Answer 'Yes' if the challenge fluctuated (changed). Answer 'No' if it stayed the same.

Thank you for completing this questionnaire.

(Version 10.4)

Section 1: Physical Symptoms and Impairments (20 items)

Item #	Statement	A) Check the box that describes how you are feeling **today**.					B) Has this challenge fluctuated (or changed) **over the past week**?	
1	I feel fatigued (or tired) when doing my usual activities.	Not at all ☐ (0)	Slightly ☐ (1)	Moderately ☐ (2)	Very ☐ (3)	Extremely ☐ (4)	Yes ☐ (1)	No ☐ (0)
2	I have diarrhea.	Not at all ☐ (0)	A little ☐ (1)	A moderate amount ☐ (2)	Very much ☐ (3)	An extreme amount ☐ (4)	Yes ☐ (1)	No ☐ (0)
3	I feel nauseous.	Not at all ☐ (0)	Slightly ☐ (1)	Moderately ☐ (2)	Very ☐ (3)	Extremely ☐ (4)	Yes ☐ (1)	No ☐ (0)
4	I have headaches.	Not at all ☐ (0)	A little ☐ (1)	A moderate amount ☐ (2)	Very much ☐ (3)	An extreme amount ☐ (4)	Yes ☐ (1)	No ☐ (0)
5	I have numbness or tingling in my hands.	Not at all ☐ (0)	A little ☐ (1)	A moderate amount ☐ (2)	Very much ☐ (3)	An extreme amount ☐ (4)	Yes ☐ (1)	No ☐ (0)
6	I have numbness or tingling in my feet.	Not at all ☐ (0)	A little ☐ (1)	A moderate amount ☐ (2)	Very much ☐ (3)	An extreme amount ☐ (4)	Yes ☐ (1)	No ☐ (0)

Item #	Statement	A) Check the box that describes how you are feeling **today**.					B) Has this challenge fluctuated (or changed) **over the past week**?	
7	I have aches or pains.	Not at all ☐ (0)	A little ☐ (1)	A moderate amount ☐ (2)	Very much ☐ (3)	An extreme amount ☐ (4)	Yes ☐ (1)	No ☐ (0)
8	I have trouble swallowing food.	None at all ☐ (0)	A little trouble ☐ (1)	A moderate amount of trouble ☐ (2)	Very much trouble ☐ (3)	Extreme trouble ☐ (4)	Yes ☐ (1)	No ☐ (0)
9	I have less desire to have sex (decreased libido).	Not at all ☐ (0)	A little less ☐ (1)	Somewhat less ☐ (2)	Much less ☐ (3)	No desire at all ☐ (4)	Yes ☐ (1)	No ☐ (0)
10	I have shortness of breath.	Not at all ☐ (0)	A little ☐ (1)	A moderate amount ☐ (2)	Very much ☐ (3)	An extreme amount ☐ (4)	Yes ☐ (1)	No ☐ (0)
11	I have fever, chills, or sweats.	Not at all ☐ (0)	A little ☐ (1)	A moderate amount ☐ (2)	Very much ☐ (3)	An extreme amount ☐ (4)	Yes ☐ (1)	No ☐ (0)
12	I feel weakness in my muscles.	Not at all ☐ (0)	Slightly ☐ (1)	Moderately ☐ (2)	Very ☐ (3)	Extremely ☐ (4)	Yes ☐ (1)	No ☐ (0)

Item #	Statement	A) Check the box that describes how you are feeling today.					B) Has this challenge fluctuated (or changed) over the past week?	
13	I have muscle cramps.	Not at all ☐ (0)	A little ☐ (1)	A moderate amount ☐ (2)	Very much ☐ (3)	An extreme amount ☐ (4)	Yes ☐ (1)	No ☐ (0)
14	I have stomach cramps.	Not at all ☐ (0)	A little ☐ (1)	A moderate amount ☐ (2)	Very much ☐ (3)	An extreme amount ☐ (4)	Yes ☐ (1)	No ☐ (0)
15	I am unintentionally losing weight.	Not at all ☐ (0)	Slightly ☐ (1)	Moderately ☐ (2)	Very much ☐ (3)	Extremely ☐ (4)	Yes ☐ (1)	No ☐ (0)
16	I lack an appetite for food.	Not at all ☐ (0)	A little ☐ (1)	Moderate lack of appetite ☐ (2)	Serious lack of appetite ☐ (3)	Extreme lack of appetite ☐ (4)	Yes ☐ (1)	No ☐ (0)
17	I have trouble sleeping.	None at all ☐ (0)	A little trouble ☐ (1)	A moderate amount of trouble ☐ (2)	Very much trouble ☐ (3)	Extreme trouble ☐ (4)	Yes ☐ (1)	No ☐ (0)
18	I have problems with my vision.	Not at all ☐ (0)	A little ☐ (1)	Moderate problems ☐ (2)	Serious problems ☐ (3)	Extreme problems ☐ (4)	Yes ☐ (1)	No ☐ (0)

Item #	Statement	A) Check the box that describes how you are feeling today.					B) Has this challenge fluctuated (or changed) over the past week?	
19	I have problems with my hearing.	Not at all ☐ (0)	A little ☐ (1)	Moderate problems ☐ (2)	Serious problems ☐ (3)	Extreme problems ☐ (4)	Yes ☐ (1)	No ☐ (0)
20	I feel dizzy.	Not at all ☐ (0)	A little ☐ (1)	Moderately ☐ (2)	Very much ☐ (3)	Extremely ☐ (4)	Yes ☐ (1)	No ☐ (0)

Section 2: Cognitive Symptoms and Impairments (3 items)

Item #	Statement	A) Check the box that describes how you are feeling today.					B) Has this challenge fluctuated (or changed) over the past week?	
21	I have trouble remembering things like appointments and when to take my medication.	None at all ☐ (0)	A little trouble ☐ (1)	A moderate amount of trouble ☐ (2)	Very much trouble ☐ (3)	Extreme trouble ☐ (4)	Yes ☐ (1)	No ☐ (0)
22	I have trouble thinking clearly.	None at all ☐ (0)	A little trouble ☐ (1)	A moderate amount of trouble ☐ (2)	Very much trouble ☐ (3)	Extreme trouble ☐ (4)	Yes ☐ (1)	No ☐ (0)

Item #	Statement	A) Check the box that describes how you are feeling today.					B) Has this challenge fluctuated (or changed) over the past week?	
23	I have trouble concentrating.	None at all ☐ (0)	A little trouble ☐ (1)	A moderate amount of trouble ☐ (2)	Very much trouble ☐ (3)	Extreme trouble ☐ (4)	Yes ☐ (1)	No ☐ (0)

Section 3: Mental and Emotional Health Symptoms and Impairments (11 items)

Item #	Statement	A) Check the box that describes how you are feeling today.					B) Has this challenge fluctuated (or changed) over the past week?	
24	I feel anxious.	Not at all ☐ (0)	Slightly ☐ (1)	Moderately ☐ (2)	Very ☐ (3)	Extremely ☐ (4)	Yes ☐ (1)	No ☐ (0)
25	I feel sad, down, or depressed.	Not at all ☐ (0)	Slightly ☐ (1)	Moderately ☐ (2)	Very ☐ (3)	Extremely ☐ (4)	Yes ☐ (1)	No ☐ (0)
26	I am afraid for my future.	Not at all ☐ (0)	Slightly ☐ (1)	Moderately ☐ (2)	Very ☐ (3)	Extremely ☐ (4)	Yes ☐ (1)	No ☐ (0)
27	I lack confidence around others.	Not at all ☐ (0)	Slightly ☐ (1)	Moderately ☐ (2)	Very ☐ (3)	Extremely ☐ (4)	Yes ☐ (1)	No ☐ (0)

Item #	Statement	A) Check the box that describes how you are feeling today.					B) Has this challenge fluctuated (or changed) over the past week?	
28	I am uncomfortable with how my body looks.	Not at all ☐ (0)	Slightly ☐ (1)	Moderately uncomfortable ☐ (2)	Very ☐ (3)	Extremely ☐ (4)	Yes ☐ (1)	No ☐ (0)
29	I feel isolated even when I'm around others. In other words, I feel that I don't belong.	Not at all ☐ (0)	Slightly ☐ (1)	Moderately ☐ (2)	Very ☐ (3)	Extremely ☐ (4)	Yes ☐ (1)	No ☐ (0)
30	I feel embarrassed around others.	Not at all ☐ (0)	Slightly ☐ (1)	Moderately ☐ (2)	Very ☐ (3)	Extremely ☐ (4)	Yes ☐ (1)	No ☐ (0)
31	I feel guilty.	Not at all ☐ (0)	Slightly ☐ (1)	Moderately ☐ (2)	Very ☐ (3)	Extremely ☐ (4)	Yes ☐ (1)	No ☐ (0)
32	I feel lonely.	Not at all ☐ (0)	Slightly ☐ (1)	Moderately ☐ (2)	Very ☐ (3)	Extremely ☐ (4)	Yes ☐ (1)	No ☐ (0)
33	I feel discouraged about my future life options.	Not at all ☐ (0)	Slightly ☐ (1)	Moderately ☐ (2)	Very ☐ (3)	Extremely ☐ (4)	Yes ☐ (1)	No ☐ (0)
34	I feel 'shut out' by my friends or family.	Not at all ☐ (0)	Slightly ☐ (1)	Moderately ☐ (2)	Very ☐ (3)	Extremely ☐ (4)	Yes ☐ (1)	No ☐ (0)

Section 4: Uncertainty or Worry about the Future (14 items)

Item #	Statement	A) Check the box that describes how you are feeling <u>today</u>.					B) Has this challenge fluctuated (or changed) <u>over the past week</u>?	
35	I worry about my future health living with HIV.	Not at all ☐ (0)	A little ☐ (1)	Somewhat ☐ (2)	Very much ☐ (3)	A lot ☐ (4)	Yes ☐ (1)	No ☐ (0)
36	I worry about my lab test results such as my CD4 count and viral load.	Not at all ☐ (0)	A little ☐ (1)	Somewhat ☐ (2)	Very much ☐ (3)	A lot ☐ (4)	Yes ☐ (1)	No ☐ (0)
37	I worry about having a serious illness.	Not at all ☐ (0)	A little ☐ (1)	Somewhat ☐ (2)	Very much ☐ (3)	A lot ☐ (4)	Yes ☐ (1)	No ☐ (0)
38	I worry about what the outcome of my next illness might be.	Not at all ☐ (0)	A little ☐ (1)	Somewhat ☐ (2)	Very much ☐ (3)	A lot ☐ (4)	Yes ☐ (1)	No ☐ (0)
39	I worry about the side effects of HIV treatments.	Not at all ☐ (0)	A little ☐ (1)	Somewhat ☐ (2)	Very much ☐ (3)	A lot ☐ (4)	Yes ☐ (1)	No ☐ (0)
40	I worry about my income or financial security living with HIV.	Not at all ☐ (0)	A little ☐ (1)	Somewhat ☐ (2)	Very much ☐ (3)	A lot ☐ (4)	Yes ☐ (1)	No ☐ (0)
41	I worry what might happen to my family and friends if I have an episode of illness.	Not at all ☐ (0)	A little ☐ (1)	Somewhat ☐ (2)	Very much ☐ (3)	A lot ☐ (4)	Yes ☐ (1)	No ☐ (0)

Item #	Statement	A) Check the box that describes how you are feeling <u>today</u>.					B) Has this challenge fluctuated (or changed) <u>over the past week</u>?	
42	I worry about being able to remain in the workforce or return to the workforce.	Not at all or Not applicable ☐ (0)	A little ☐ (1)	Somewhat ☐ (2)	Very much ☐ (3)	A lot ☐ (4)	Yes ☐ (1)	No ☐ (0)
43	I worry about dying.	Not at all ☐ (0)	A little ☐ (1)	Somewhat ☐ (2)	Very much ☐ (3)	A lot ☐ (4)	Yes ☐ (1)	No ☐ (0)
44	I worry about my bodily appearance.	Not at all ☐ (0)	A little ☐ (1)	Somewhat ☐ (2)	Very much ☐ (3)	A lot ☐ (4)	Yes ☐ (1)	No ☐ (0)
45	I worry about the legal issues of telling others about my HIV status.	Not at all ☐ (0)	A little ☐ (1)	Somewhat ☐ (2)	Very much ☐ (3)	A lot ☐ (4)	Yes ☐ (1)	No ☐ (0)
46	I worry about what others would think of me if they knew I was HIV positive.	Not at all ☐ (0)	A little ☐ (1)	Somewhat ☐ (2)	Very much ☐ (3)	A lot ☐ (4)	Yes ☐ (1)	No ☐ (0)
47	I worry about transmitting HIV to others.	Not at all ☐ (0)	A little ☐ (1)	Somewhat ☐ (2)	Very much ☐ (3)	A lot ☐ (4)	Yes ☐ (1)	No ☐ (0)

Item #	**Statement**	**A) Check the box that describes how you are feeling <u>today</u>.**					**B) Has this challenge fluctuated (or changed) <u>over the past week</u>?**	
48	I have put certain life decisions on hold (such as buying a house, returning to work or school, or starting a family) because of my uncertainty living with HIV.	No ☐ (0)	Very few things ☐ (1)	Some things ☐ (2)	Most things ☐ (3)	Everything ☐ (4)	Yes ☐ (1)	No ☐ (0)

Section 5: Difficulties with Day-to-Day Activities (9 items)

Item #	**Statement**	**A) Check the box that describes how you are feeling <u>today</u>.**					**B) Has this challenge fluctuated (or changed) <u>over the past week</u>?**	
49	I am unsteady on my feet.	Not at all ☐ (0)	Slightly ☐ (1)	Moderately ☐ (2)	Very ☐ (3)	Extremely ☐ (4)	Yes ☐ (1)	No ☐ (0)
50	I have trouble walking.	Not at all ☐ (0)	A little trouble ☐ (1)	A moderate amount of trouble ☐ (2)	A lot of trouble ☐ (3)	I cannot walk ☐ (4)	Yes ☐ (1)	No ☐ (0)
51	I have trouble climbing stairs.	Not at all ☐ (0)	A little trouble ☐ (1)	A moderate amount of trouble ☐ (2)	A lot of trouble ☐ (3)	I can't do this ☐ (4)	Yes ☐ (1)	No ☐ (0)

Item #	**Statement**	**A) Check the box that describes how you are feeling <u>today</u>.**					**B) Has this challenge fluctuated (or changed) <u>over the past week</u>?**	
52	I have trouble with daily activities such as eating, bathing, grooming, or dressing.	Not at all ☐ (0)	A little trouble ☐ (1)	A moderate amount of trouble ☐ (2)	A lot of trouble ☐ (3)	I can't do this ☐ (4)	Yes ☐ (1)	No ☐ (0)
53	I have trouble doing household chores such as cleaning, doing dishes, laundry, and cooking.	Not at all ☐ (0)	A little trouble ☐ (1)	A moderate amount of trouble ☐ (2)	A lot of trouble ☐ (3)	I can't do this ☐ (4)	Yes ☐ (1)	No ☐ (0)
54	I have trouble taking part in leisure or recreational activities, such as exercise or dancing.	Not at all ☐ (0)	A little trouble ☐ (1)	A moderate amount of trouble ☐ (2)	A lot of trouble ☐ (3)	I can't do this ☐ (4)	Yes ☐ (1)	No ☐ (0)
55	I have trouble getting out to do errands such as grocery shopping, banking, or doctor's appointments.	Not at all ☐ (0)	A little trouble ☐ (1)	A moderate amount of trouble ☐ (2)	A lot of trouble ☐ (3)	I can't do this ☐ (4)	Yes ☐ (1)	No ☐ (0)
56	I have trouble keeping track of my finances.	Not at all ☐ (0)	A little trouble ☐ (1)	A moderate amount of trouble ☐ (2)	A lot of trouble ☐ (3)	I can't do this ☐ (4)	Yes ☐ (1)	No ☐ (0)

Item #	**Statement**	**A) Check the box that describes how you are feeling today.**					**B) Has this challenge fluctuated (or changed) over the past week?**	
57	I have trouble getting around, such as driving or taking public transportation.	Not at all ☐ (0)	A little trouble ☐ (1)	A moderate amount of trouble ☐ (2)	A lot of trouble ☐ (3)	I can't do this ☐ (4)	Yes ☐ (1)	No ☐ (0)

Section 6: Challenges to Taking Part in Social and Community Life (Social Inclusion) (12 items)

Item #	**Statement**	**A) Check the box that describes how you are feeling today.**					**B) Has this challenge fluctuated (or changed) over the past week?**	
58	I find it hard to meet the needs of those I care for (such as children, parents, grandparents, partners, or pets).	Not at all or Not applicable ☐ (0)	A little hard ☐ (1)	Moderately hard ☐ (2)	Really hard ☐ (3)	I can't do it ☐ (4)	Yes ☐ (1)	No ☐ (0)
59	I find it hard to fulfill my role as a family or community member living with HIV.	Not hard at all ☐ (0)	A little hard ☐ (1)	Moderately hard ☐ (2)	Really hard ☐ (3)	I can't do it ☐ (4)	Yes ☐ (1)	No ☐ (0)
60	I feel cut off from my friends, networks, ethnic or religious communities.	Not at all ☐ (0)	A little ☐ (1)	Moderately ☐ (2)	Very much ☐ (3)	Extremely ☐ (4)	Yes ☐ (1)	No ☐ (0)

Item #	**Statement**	**A) Check the box that describes how you are feeling today.**					**B) Has this challenge fluctuated (or changed) over the past week?**	
61	My illness prevents me from doing volunteer or paid work or going to school.	Not at all ☐ (0)	Slightly ☐ (1)	Moderately ☐ (2)	Very much ☐ (3)	Completely ☐ (4)	Yes ☐ (1)	No ☐ (0)
62	I feel that my work performance is limited because of my illness.	Not at all or Not applicable ☐ (0)	Slightly ☐ (1)	Moderately ☐ (2)	Very much ☐ (3)	Extremely limited ☐ (4)	Yes ☐ (1)	No ☐ (0)
63	I struggle to maintain safe and stable housing living with HIV.	Not at all ☐ (0)	A little ☐ (1)	Moderately ☐ (2)	Very much ☐ (3)	Extremely ☐ (4)	Yes ☐ (1)	No ☐ (0)
64	I find it hard to talk with others about my illness, even my family and friends.	Not hard at all ☐ (0)	A little hard ☐ (1)	Moderately hard ☐ (2)	Really hard ☐ (3)	I can't do it ☐ (4)	Yes ☐ (1)	No ☐ (0)
65	I find it hard to ask others for help when I go through an episode of illness.	Not hard at all ☐ (0)	A little hard ☐ (1)	Moderately hard ☐ (2)	Really hard ☐ (3)	I can't do it ☐ (4)	Yes ☐ (1)	No ☐ (0)
66	I find it hard to start new friendships living with HIV.	Not hard at all ☐ (0)	A little hard ☐ (1)	Moderately hard ☐ (2)	Really hard ☐ (3)	I can't do it ☐ (4)	Yes ☐ (1)	No ☐ (0)

APPENDIX C WORLD HEALTH ORGANISATION DISABILITY ASSESSMENT SCALE (WHODAS-2)

In the past 30 days, how much difficulty did you have in:						
Understanding and communicating						
D1.1	Concentrating on doing something for ten minutes?	None	Mild	Moderate	Severe	Extreme or cannot do
D1.2	Remembering to do important things?	None	Mild	Moderate	Severe	Extreme or cannot do
D1.3	Analysing and finding solutions to Problems in day-to-day life?	None	Mild	Moderate	Severe	Extreme or cannot do
D1.4	Learning a new task, for example, learning how to get to a new place?	None	Mild	Moderate	Severe	Extreme or cannot do
D1.5	Generally understanding what people say?	None	Mild	Moderate	Severe	Extreme or cannot do
D1.6	Starting and maintaining a conversation?	None	Mild	Moderate	Severe	Extreme or cannot do
Getting around						
D2.1	Standing for long periods such as 30 minutes?	None	Mild	Moderate	Severe	Extreme or cannot do
D2.2	Standing up from sitting down?	None	Mild	Moderate	Severe	Extreme or cannot do
D2.3	Moving around inside your home?	None	Mild	Moderate	Severe	Extreme or cannot do
D2.4	Getting out of your home?	None	Mild	Moderate	Severe	Extreme or cannot do
D2.5	Walking a long distance such as a kilometre[or equivalent]?	None	Mild	Moderate	Severe	Extreme or cannot do

In the past 30 days, how much difficulty did you have in:						
Self-care						
D3.1	Washing your whole body?	None	Mild	Moderate	Severe	Extreme or cannot do
D3.2	Getting dressed?	None	Mild	Moderate	Severe	Extreme or cannot do
D3.3	Eating?	None	Mild	Moderate	Severe	Extreme or cannot do
D3.4	Staying by yourself for a few days?	None	Mild	Moderate	Severe	Extreme or cannot do
Getting along with people						
D4.1	Dealing with people you do not know?	None	Mild	Moderate	Severe	Extreme or cannot do
D4.2	Maintaining a friendship?	None	Mild	Moderate	Severe	Extreme or cannot do
D4.3	Getting along with people who are close to you?	None	Mild	Moderate	Severe	Extreme or cannot do
D4.4	Making new friends?	None	Mild	Moderate	Severe	Extreme or cannot do
D4.5	Sexual activities?	None	Mild	Moderate	Severe	Extreme or cannot do
Life activities						
D5.1	Taking care of your household Responsibilities?	None	Mild	Moderate	Severe	Extreme or cannot do
D5.2	Doing most important household tasks well?	None	Mild	Moderate	Severe	Extreme or cannot do
D5.3	Getting all the household work done that you needed to do?	None	Mild	Moderate	Severe	Extreme or cannot do
D5.4	Getting your household work done as quickly as needed?	None	Mild	Moderate	Severe	Extreme or cannot do

If you work (paid, non-paid, self-employed) or go to school, complete questions D5.5 -D5.8, below. Otherwise, skip to D6.1.

Because of your health condition, in the past 30 days, how much difficulty did you have in:						
D5.5	Your day-to-day work/school?	None	Mild	Moderate	Severe	Extreme or cannot do
D5.6	Doing your most important work/school tasks well?	None	Mild	Moderate	Severe	Extreme or cannot do
D5.7	Getting all the work done that you need to do?	None	Mild	Moderate	Severe	Extreme or cannot do
D5.8	Getting your work done as quickly as needed?	None	Mild	Moderate	Severe	Extreme or cannot do

Participation in society						
In the past 30 days:						
D6.1	How much of a problem did you have in joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?	None	Mild	Moderate	Severe	Extreme or cannot do
D6.2	How much of a problem did you have because of barriers or hindrances in the world around you?	None	Mild	Moderate	Severe	Extreme or cannot do
D6.3	How much of a problem did you have living with dignity because of the attitudes and actions of others?	None	Mild	Moderate	Severe	Extreme or cannot do
D6.4	How much time did you spend on your health condition, or	None	Mild	Moderate	Severe	Extreme or cannot do

	its consequences?					
D6.5	How much have you been emotionally affected by your health condition?	None	Mild	Moderate	Severe	Extreme or cannot do
D6.6	How much has your health been a drain on the financial resources of you or your family?	None	Mild	Moderate	Severe	Extreme or cannot do
D6.7	How much of a problem did your family have because of your health problems?	None	Mild	Moderate	Severe	Extreme or cannot do
D6.8	How much of a problem did you have in doing things by yourself for relaxation or Pleasure?	None	Mild	Moderate	Severe	Extreme or cannot do

	Overall, in the past 30 days, how many days were these difficulties present?	***Record number of days ____***
	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 ____***
	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 ____***

APPENDIX D MEDICAL OUTCOMES STUDY SOCIAL SUPPORT SURVEY (MOS-SSS)

1.0 About how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is on your mind)?

Write in number of close friends and
close relatives:

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to YOU if you need it?

(Circle One Number on Each Line)

		None Of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
2.0	Someone to help you if you were confined to bed	1	2	3	4	5
3.0	Someone you can count ***on*** to listen to you when you need to talk	1	2	3	4	5
4.0	Someone to give you good advice about a crisis	1	2	3	4	5
5.0	Someone to take you to the doctor if you needed it	1	2	3	4	5
6.0	Someone who shows you love and affection	1	2	3	4	5
7.0	Someone to have a good time with	1	2	3	4	5
8.0	Someone to give you information to help you understand a situation	1	2	3	4	5
9.0	Someone to confide in or talk to about yourself or your problems	1	2	3	4	5
10	Someone who hugs you	1	2	3	4	5
11	Someone to get together with for relaxation	1	2	3	4	5
12	Someone to prepare your meals if you were unable to do it yourself	1	2	3	4	5

13	Someone whose advice you really want	1	2	3	4	5
14	Someone to do things with to help you get your mind off things	1	2	3	4	5
15	Someone to help with daily chores if you were sick	1	2	3	4	5
16	Someone to share your most private worries and fears with	1	2	3	4	5
17	Someone to turn to for suggestions about how to deal with a personal problem	1	2	3	4	5
18	Someone to do something enjoyable with	1	2	3	4	5
19	Someone who understands your problems	1	2	3	4	5
20	Someone to love and make you feel wanted	1	2	3	4	5

APPENDIX E ETHICS CLEARANCE CERTIFICATE

R14/49 Mr Adentunji Abiodun Adeleke and Rulaine Smith

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M160407

NAME: **(Principal Investigator)**	Mr Adentunji Abiodun Adeleke and Rulaine Smith
DEPARTMENT:	Occupational Therapy Wits Donald Gordon Medical Centre Isando, Bedforview, Yeoville, Berea and Malvern Clinics in Johannesburg
PROJECT TITLE:	Activity Limitations Participation Restrictions and Quality of Life in Patients with Human Immunodeficiency Virus
DATE CONSIDERED:	06/05/2016
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Denise Franzsen
APPROVED BY:	Professor P. Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	15/06/2016

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 10004,10th floor, Senate House/2nd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand. I/We fully understand the 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 review in April and will therefore be due in the month of April each year.

__________________________ ______________________

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX F ACCESS LETTER REQUESTING PERMISSION TO CONDUCT RESEARCH

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 I Fax: +27 717 3709 I Email: leilane.bogoshi@wits.ac.za I www.wits.ac.za

23.5.2016

To Whom it May Concern,

……..

Dear Sir/Ma.

REQUEST FOR PERMISSION TO CONDUCT RESEARCH

S**tudy title: VALIDITY OF THE HIV DISABILITY QUESTIONNAIRE FOR PATIENTS WITH HUMAN IMMUNODEFICIENCY VIRUS IN SOUTH AFRICA**

I, Adetunji Abiodun Adeleke am a registered Master's student in the Department of occupational therapy at the University of Witwatersrand. My supervisor is Mrs. Denise Franzsen and my associate supervisor is Mrs. Rulaine Smith

The proposed topic of my research is activity limitations, participation restrictions and quality of life in patients with human immunodeficiency virus. The objectives of the study are:

a. Determine the content validity and convergent validity of the HDQ with the World Health Organisation Disability Assessment Scale (WHODAS-2) and the divergent validity with the Medical Outcomes Study Social Support Survey (MOS-SSS) on a sample of persons with HIV living in Johannesburg.
b. To determine the reliability in terms of internal consistency of the HDQ on the South African sample.

c. Determine the activity limitations, performance restrictions and quality of life on a sample of persons with HIV living in Johannesburg using the HDQ.

d. Determine the relationship between the level of activity limitations, performance restrictions, and quality of life of PLWHIV.

e. Investigate the effects of operating variables (demographic and medical factors) on the activity limitations, participation restrictions and quality of life in comparison to results published in Canadian and Irish studies using the HDQ.

The research would involve people living with HIV filling in three self administered questionnaires once off. This can be done at the clinic while they are waiting for treatment.. An assistant will be available to assist them if they need help understanding the questions. All questions will concern the activities they do on a daily basis as well as some basic demographic and medical information. The patients' names will not be recorded on any forms.

I am hereby seeking your consent to allow me to use your clinic for this study. To assist you in reaching a decision, I have attached to this letter:

A copy of an ethical clearance certificate issued by the University

(a) A copy the research protocol which I intend using in my research

Should you require any further information, please do not hesitate to contact me or my supervisor. Our contact details are as follows:

1. Adeleke Adetunji Abiodun

Tel. 0848869572 email. a.adetunji12@hotmail.com

1. Mrs. Denise Franzsen or Mrs. Rulaine Smith

Wits OT Dept, 7 York Rd., Parktown 2193,Email. denise.franzsen@wits ac.za. Tel.0117173701

Your permission to conduct this study will be greatly appreciated. If you agree please sign the attached permission form.

Yours sincerely,

PERMISSION TO CONDUCT RESEARCH

I _______________ the manager of the Clinic give permission for the study entitled : ACTIVITY LIMITATIONS, PARTICIPATION RESTRICTIONS AND QUALITY OF LIFE IN PATIENTS WITH HUMAN IMMUNODEFICIENCY VIRUS to be conducted in this clinic.

Signature _____________________________

Name ___________________________

Date __________________________

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

MEDICAL ADVISORY COMMITTEE
CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL

PERMISSION TO CONDUCT RESEARCH

Date: 24 June 2016

TITLE OF PROJECT: Activity limitations, participation restrictions and quality of life in patients with human immunodeficiency virus

UNIVERSITY: Witwatersrand

Principal Investigator: A Adeleke

Department: Occupational Therapy

Supervisor (If relevant): D Franzen

Permission Head Department (where research conducted): Not yet

Date of start of proposed study: June 2016
Date of completion of data collection: Dec 2018

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: 24 June 2016

....
Approved/Not Approved
Hospital Management
Date: 28/06/16

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Gauteng Department of Health
Helen Joseph Hospital
Enquiries: Dr. M.R. Billa
Chief Executive Officer
Tel :(011) 489-0306/1087
Fax :(011) 726-5425
E mail: Raymond.Billa@gauteng.gov.za
30 June 2016

Dr.M.R.Billa
Chief Executive Officer
Helen Joseph Hospital

Dear Dr.Billa

STUDY: Activity limitations, participation restrictions and quality of life in patients with human immunodeficiency virus

RESEARCHER: A. Adeleke

The above was discussed at the Research Committee Meeting. We recommend that permission be granted for Helen Joseph Hospital to be used as a site for the above research. However, since this is a research project involving voluntary participation. We cannot guarantee participation of individuals/patients.

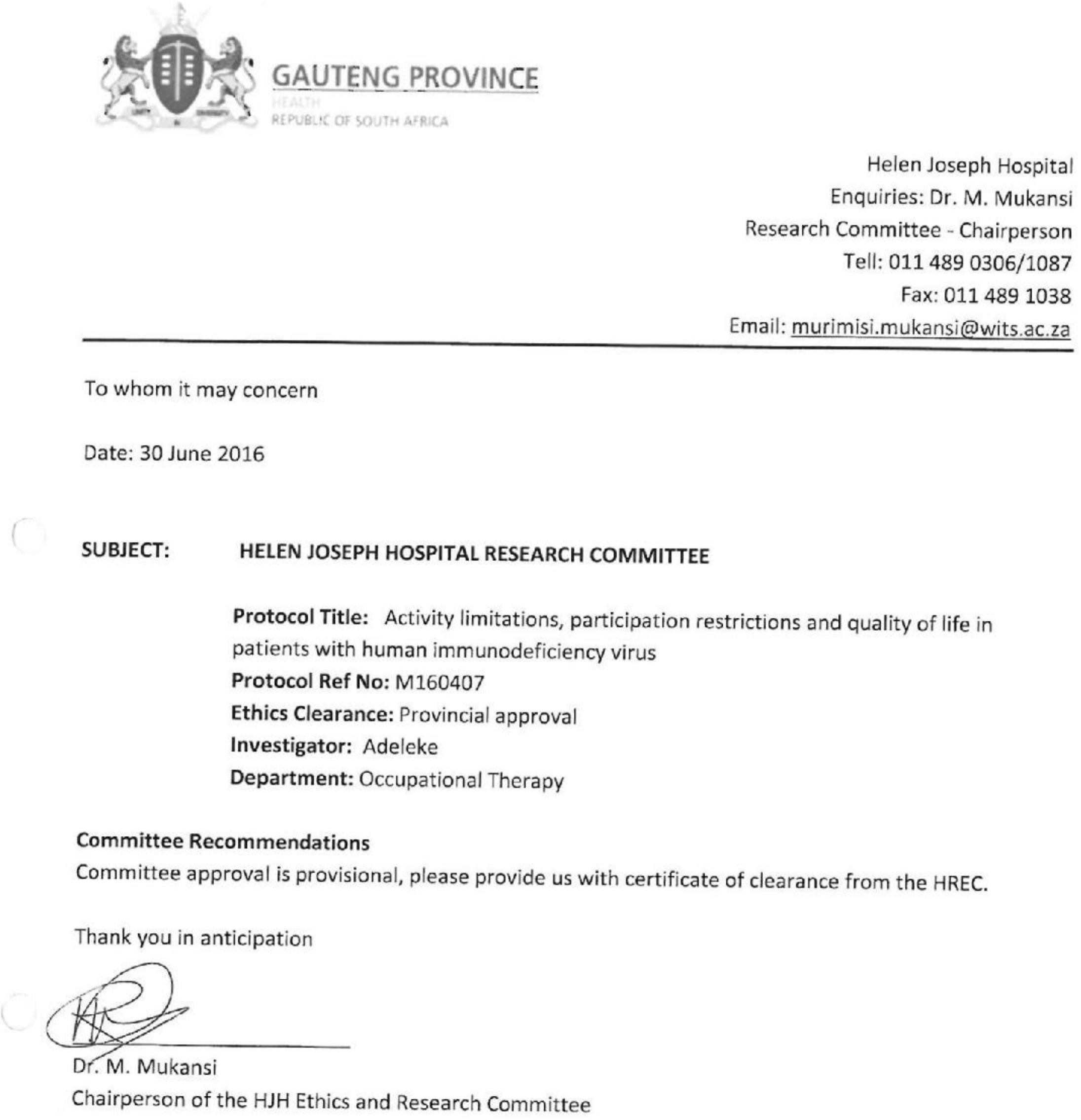
Upon completion of the study, a copy thereof should be submitted to Helen Joseph Hospital.

Thank you

DR. Murimisi Mukansi
CHAIRPERSON
DATE:

Approved

DR. M.R. BILLA
CHIEF EXECUTIVE OFFICER
DATE: 30.06.2016



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Helen Joseph Hospital
Enquiries: Dr. M. Mukansi
Research Committee - Chairperson
Tell: 011 489 0306/1087
Fax: 011 489 1038
Email: murimisi.mukansi@wits.ac.za

To whom it may concern

Date: 30 June 2016

SUBJECT: **HELEN JOSEPH HOSPITAL RESEARCH COMMITTEE**

Protocol Title: Activity limitations, participation restrictions and quality of life in patients with human immunodeficiency virus
Protocol Ref No: M160407
Ethics Clearance: Provincial approval
Investigator: Adeleke
Department: Occupational Therapy

Committee Recommendations
Committee approval is provisional, please provide us with certificate of clearance from the HREC.

Thank you in anticipation

Dr. M. Mukansi
Chairperson of the HJH Ethics and Research Committee

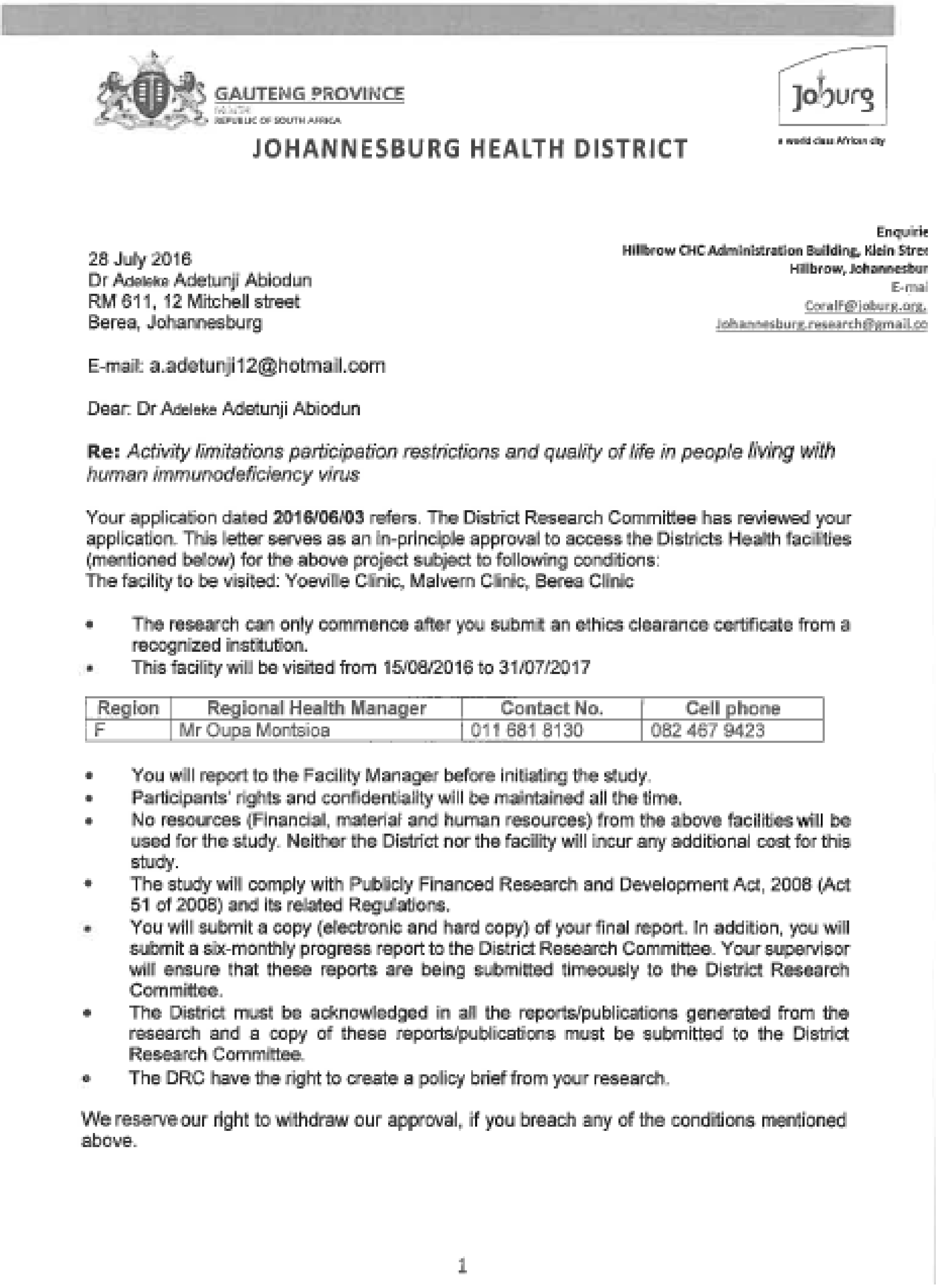
PERMISSION TO CONDUCT RESEARCH

I Gail Ashford the manager of the Wits DGMC Clinic give permission for the study entitled : ACTIVITY LIMITATIONS, PARTICIPATION RESTRICTIONS AND QUALITY OF LIFE IN PATIENTS WITH HUMAN IMMUNODEFICIENCY VIRUS to be conducted in this clinic.

Signature

Name G Ashford

Date 25·5·16



GAUTENG PROVINCE
REPUBLIC OF SOUTH AFRICA

JOHANNESBURG HEALTH DISTRICT

Joburg
a world class African city

Enquirie
Hillbrow CHC Administration Building, Klein Stre
Hillbrow, Johannesbur
E-mai
CoralF@joburg.org.
Johannesburg.research@gmail.co

28 July 2016
Dr Adeleke Adetunji Abiodun
RM 611, 12 Mitchell street
Berea, Johannesburg

E-mail: a.adetunji12@hotmail.com

Dear: Dr Adeleke Adetunji Abiodun

Re: *Activity limitations participation restrictions and quality of life in people living with human immunodeficiency virus*

Your application dated **2016/06/03** refers. The District Research Committee has reviewed your application. This letter serves as an in-principle approval to access the Districts Health facilities (mentioned below) for the above project subject to following conditions:
The facility to be visited: Yoeville Clinic, Malvern Clinic, Berea Clinic

- The research can only commence after you submit an ethics clearance certificate from a recognized institution.
- This facility will be visited from 15/08/2016 to 31/07/2017

Region	Regional Health Manager	Contact No.	Cell phone
F	Mr Oupa Montsioa	011 681 8130	082 467 9423

- You will report to the Facility Manager before initiating the study.
- Participants' rights and confidentiality will be maintained all the time.
- No resources (Financial, material and human resources) from the above facilities will be used for the study. Neither the District nor the facility will incur any additional cost for this study.
- The study will comply with Publicly Financed Research and Development Act, 2008 (Act 51 of 2008) and its related Regulations.
- You will submit a copy (electronic and hard copy) of your final report. In addition, you will submit a six-monthly progress report to the District Research Committee. Your supervisor will ensure that these reports are being submitted timeously to the District Research Committee.
- The District must be acknowledged in all the reports/publications generated from the research and a copy of these reports/publications must be submitted to the District Research Committee.
- The DRC have the right to create a policy brief from your research.

We reserve our right to withdraw our approval, if you breach any of the conditions mentioned above.

APPENDIX G INFORMATION DOCUMENT FOR PARTICIPANTS

Study title: VALIDITY OF THE HIV DISABILITY QUESTIONNAIRE FOR PATIENTS WITH HUMAN IMMUNODEFICIENCY VIRUS IN SOUTH AFRICA

****

Good day

Introduction:

I, Mr. Adetunji Abiodun, Adeleke a master's student at the University of the Witwatersrand, am doing a research on activity limitations, participation restrictions and quality of life in people living with HIV in Johannesburg.

In this study we want to learn more about the challenges you face in your daily activities with the use of questionnaires. This is a study involving research (one-time assessment with the questionnaires) this not routine care and this is been done to reduce the level of disability in this society and validate the HIV disability questionnaire (HDQ).

Invitation to participate: We are inviting you to take part in a research study that aims to check if the HDQ can be used with people in South Africa and help to provide answers to assist in reducing disability among people living with HIV.

What is involved in the study – You will be required to complete answers on questionnaires about your daily activities and any problems you have doing these at one time only. Your involvement in this research will include filling in the questionnaires with help of an assistant if you need it while at the clinic. The questionnaires will include some personal information but will be anonymous as your name will not be required on any form. The other questions which will take 25 to 30 minutes to complete will have questions about every day activities at home, work and social activities. Some of the questions that would be asked also includes aspects of mobility, self care, how much support do you receive from people when needed. One of the questions is about your CD4 count. Please sign permission to obtain this information from your file.

Please let me know if you need assistance with translating the questions of filling them in. There is someone helping me that can translate questions into the language you are familiar with and assist you. If you need help a quite private place will be organised so you are not overheard but it may take longer, up to 40 minutes to complete the questionnaire.

Risks of being involved in the study. There are no risks in being involved in the study And no direct benefits to you. It is hoped that the study will assist in setting up appropriate services for people living with HIV. If you feel distressed by some of the questions and wish to discuss this with someone you will be provided with the contact details of a psychologist or occupational therapists you can contact if you wish to follow up on this.

Participation is voluntary, and if you don't want to take part this will not affect your treatment in any way. You can also stop taking part at any time without any consequence or penalty loss of benefits to which you are otherwise entitled.

Confidentiality: Efforts will be made to keep personal information confidential and no material that can identify you personally will be used in the research. All records will be destroyed after six years according to HPCSA regulations or after the study is published.

Organizations that may inspect and/or copy this research records for quality assurance and data analysis include groups such as the Research Ethics Committee.

Feedback from the study will be available on request.

Contact details of researcher.

2. Adeleke Adetunji Abiodun

Tel. 0848869572 email. a.adetunji12@hotmail.com

Supervisors

3. Mrs. Denise Franzsen

Wits OT Dept, 7 York Rd., Parktown 2193, Email. denise.franzsen@wits ac.za. Tel.0117173701

4. **Mrs. Rulaine Smith**

Wits OT Dept, 7 York Rd., Parktown 2193, Email. rulaine.smith@wits.ac.za. Tel. 0117173701

Contact details of HREC administrator and chair – for reporting of complaints / problems. Please contact

Chairperson of the ethics committee Prof P Cleaton-Jones at Zanele Ndlovu@wits.ac.za or 011-717-1234

If you agree to take part please sign the consent form on the next page

Regards

APPENDIX H INFORMED CONSENT FORM

If you need an INTERPRETER, please tell us.

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 affecting my medical care. I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.

I agree to take part in the study

Participant's name:

Signature: Date:

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name:

Signature: Date:

PERMISSION TO ACCESS FILE

If you need an INTERPRETER, please tell us.

I ________________________________- agrre that the researcher may access my CD4 count from my file.

Participant’s name:

Signature: Date:

APPENDIX I FACTOR ANALYSIS

FACTOR ANALYSIS PATTEN MATRIX - HIV DISABILITY QUESTIONNAIRE SEVERITY SCALE

Pattern Matrix[a]

	Variable	Factor Loadings (Varimax normalized) (HDQ severity) Extraction: Principal components (Marked loadings are >.300000)					
		Factor 1	Factor 2	Factor 4	Factor 4	Factor 5	Factor 6
Physical Domain (1)	HDQ1	0.44					
	HDQ2	0.33					
	HDQ3	0.58					
	HDQ4	0.57					
	HDQ5	0.37					
	HDQ6	0.36					
	HDQ7	0.58					
	HDQ8	0.37					
	HDQ9	0.37					
	HDQ10	0.37					
	HDQ11	0.62					
	HDQ12	0.58					
	HDQ13	0.65					
	HDQ14	0.56					
	HDQ15	0.34					
	HDQ16	0.51					
	HDQ17	0.39					
	HDQ18	0.45					
	HDQ19	0.13					
	HDQ20	0.51					
Cognitive Domain (2)	HDQ21		0.44				
	HDQ22		0.55				
	HDQ23		0.56				
Mental and Emotional Domain (3)	HDQ24			0.38			
	HDQ25			0.49			
	HDQ26			0.39			
	HDQ27			0.63			
	HDQ28			0.36			
	HDQ29			0.77			
	HDQ30			0.76			
	HDQ31			0.68			
	HDQ32			0.64			
	HDQ33			0.64			
	HDQ34			0.61			
Uncertainty (4)	HDQ35				0.64		
	HDQ36				0.55		
	HDQ37				0.73		
	HDQ38				0.72		
	HDQ39				0.69		
	HDQ40				0.65		
	HDQ41				0.65		
	HDQ42				0.48		
	HDQ43				0.63		

	HDQ44				0.53		
	HDQ45				0.67		
	HDQ46				0.68		
	HDQ47				0.58		
	HDQ48				0.33		
Difficulties with day to day activities (5)	HDQ49					0.65	
	HDQ50					0.74	
	HDQ51					0.70	
	HDQ52					0.11	0.74
	HDQ53					0.17	0.73
	HDQ54					0.22	0.68
	HDQ55					0.14	0.72
	HDQ56					0.10	0.43
	HDQ57					0.18	0.74
Challenges to Taking Part in Social and Community Life (6)	HDQ58						0.53
	HDQ59						0.53
	HDQ60						0.43
	HDQ61						0.62
	HDQ62						0.57
	HDQ63						0.53
	HDQ64				0.57		0.27
	HDQ65						0.33
	HDQ66						0.35
	HDQ67				0.52		0.12
	HDQ68				0.36		0.27
	HDQ69						0.45
	Expl.Var	6.24	Factor	6.79	Factor	3.29	0.27

MAXIMUM LIKELIHOOD FACTORS

Variable	Factor Loadings (Unrotated) (HDQ severity) Extraction: Maximum likelihood factors (Marked loadings are >.300000)					
	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6
HDQ1	-0.44	-0.12	-0.10	0.20	-0.14	0.01
HDQ2	-0.25	0.01	0.05	0.15	-0.20	-0.04
HDQ3	-0.44	-0.15	-0.03	0.24	-0.27	0.01
HDQ4	-0.45	-0.13	-0.20	0.25	-0.19	0.09
HDQ5	-0.41	-0.20	-0.23	0.12	-0.02	0.18
HDQ6	-0.42	-0.21	-0.34	0.13	-0.06	0.10
HDQ7	-0.54	-0.27	-0.13	0.22	-0.14	0.16
HDQ8	-0.25	-0.17	0.04	0.10	-0.17	0.02
HDQ9	-0.35	-0.02	-0.14	0.12	-0.15	0.08
HDQ10	-0.43	-0.23	-0.07	0.13	-0.14	-0.05
HDQ11	-0.45	-0.14	-0.06	0.28	-0.23	0.12
HDQ12	-0.63	-0.19	-0.08	0.26	-0.14	0.10
HDQ13	-0.47	-0.18	-0.17	0.26	-0.22	0.27
HDQ14	-0.38	-0.11	-0.10	0.24	-0.22	0.08
HDQ15	-0.38	0.07	0.00	0.26	-0.04	-0.04
HDQ16	-0.30	-0.06	0.05	0.28	-0.24	-0.01
HDQ17	-0.51	-0.02	-0.08	0.20	-0.06	0.04

Variable	Factor Loadings (Unrotated) (HDQ severity) Extraction: Maximum likelihood factors (Marked loadings are >.300000)					
	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6
HDQ18	-0.32	-0.10	-0.15	0.28	-0.15	0.12
HDQ19	-0.17	-0.02	-0.09	0.12	-0.04	-0.02
HDQ20	-0.54	-0.18	-0.03	0.17	-0.14	0.09
HDQ21	-0.44	-0.12	-0.10	0.20	-0.14	0.01
HDQ22	-0.25	0.01	0.05	0.15	-0.20	-0.04
HDQ23	-0.44	-0.15	-0.03	0.24	-0.27	0.01
HDQ24	-0.45	-0.13	-0.20	0.25	-0.19	0.09
HDQ25	-0.41	-0.20	-0.23	0.12	-0.02	0.18
HDQ26	-0.42	-0.21	-0.34	0.13	-0.06	0.10
HDQ27	-0.54	-0.27	-0.13	0.22	-0.14	0.16
HDQ28	-0.25	-0.17	0.04	0.10	-0.17	0.02
HDQ29	-0.35	-0.02	-0.14	0.12	-0.15	0.08
HDQ30	-0.43	-0.23	-0.07	0.13	-0.14	-0.05
HDQ31	-0.45	-0.14	-0.06	0.28	-0.23	0.12
HDQ32	-0.63	-0.19	-0.08	0.26	-0.14	0.10
HDQ33	-0.47	-0.18	-0.17	0.26	-0.22	0.27
HDQ34	-0.38	-0.11	-0.10	0.24	-0.22	0.08
HDQ35	-0.38	0.07	0.00	0.26	-0.04	-0.04
HDQ36	-0.30	-0.06	0.05	0.28	-0.24	-0.01
HDQ37	-0.51	-0.02	-0.08	0.20	-0.06	0.04
HDQ38	-0.32	-0.10	-0.15	0.28	-0.15	0.12
HDQ39	-0.17	-0.02	-0.09	0.12	-0.04	-0.02
HDQ40	-0.54	-0.18	-0.03	0.17	-0.14	0.09
HDQ41	-0.39	-0.13	-0.09	0.22	-0.16	-0.06
HDQ42	-0.51	-0.08	-0.03	0.33	-0.13	-0.14
HDQ43	-0.45	-0.12	-0.12	0.26	-0.04	-0.17
HDQ44	-0.47	0.03	-0.13	0.17	0.09	-0.01
HDQ45	-0.65	0.12	-0.04	0.22	0.01	-0.02
HDQ46	-0.69	0.20	-0.14	0.09	-0.02	-0.05
HDQ47	-0.63	0.18	0.20	0.10	0.17	-0.03
HDQ48	-0.50	-0.06	-0.02	0.03	0.09	0.10
HDQ49	-0.71	0.13	0.21	0.17	0.36	0.03
HDQ50	-0.67	0.12	0.24	0.17	0.33	0.02
HDQ51	-0.65	0.15	0.05	0.12	0.31	0.03
HDQ52	-0.70	0.19	0.04	0.24	0.16	-0.08
HDQ53	-0.75	0.24	0.05	0.16	0.17	-0.13
HDQ54	-0.61	0.15	0.10	0.22	0.18	-0.06
HDQ55	-0.72	0.35	-0.12	-0.03	-0.01	-0.09
HDQ56	-0.63	0.26	-0.16	-0.01	-0.02	-0.14
HDQ57	-0.67	0.25	-0.34	-0.26	-0.05	-0.18
HDQ58	-0.64	0.21	-0.35	-0.29	-0.09	-0.22
HDQ59	-0.67	0.24	-0.20	-0.16	-0.10	-0.03
HDQ60	-0.61	0.24	-0.19	-0.05	-0.11	-0.13
HDQ61	-0.58	0.24	-0.24	-0.12	-0.06	-0.12
HDQ62	-0.49	0.12	-0.10	-0.13	0.08	-0.14
HDQ63	-0.63	0.26	-0.12	-0.14	0.00	0.01
HDQ64	-0.68	0.10	-0.06	-0.15	0.03	0.10
HDQ65	-0.54	0.43	0.00	-0.17	-0.03	0.28
HDQ66	-0.54	0.41	-0.01	-0.21	-0.06	0.33
HDQ67	-0.35	0.26	-0.22	-0.18	0.03	0.02
HDQ68	-0.56	0.03	0.18	-0.01	-0.11	-0.12
HDQ69	-0.49	-0.42	-0.30	-0.11	0.13	0.04

Eigenvalues for HIV Disability Questionnaire

Value	Eigenvalues (HDQ severity) Extraction: Principal components			
	Eigenvalue	% Total variance	Cumulative Eigenvalue	Cumulative %
1	20.90982	30.30408	20.90982	30.30408
2	4.54613	6.58860	25.45595	36.89268
3	3.06093	4.43614	28.51688	41.32882
4	2.30469	3.34014	30.82158	44.66895
5	1.91226	2.77139	32.73384	47.44035
6	1.64144	2.37889	34.37528	49.81924