

# **THE EFFECT OF HIV STATUS ON POST-STROKE OUTCOMES IN ACTIVITIES OF DAILY LIVING**

Hymeri Augustyn

A research report submitted to the Faculty of Health Sciences, School of Therapeutic Sciences, University of Witwatersrand, Johannesburg, in partial fulfilment of  
Masters of Science in Occupational Therapy

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## DECLARATION

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I, Hymeri Augustyn, declare that this thesis is my own work. It is being submitted for the degree of Masters of Science in Occupational Therapy in 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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Hymeri Augustyn

\_\_\_\_\_ day of \_\_\_\_\_, 2016

# PLAGIARISM DECLARATION

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## Postgraduate Office, Faculty of Health Sciences

Wits Medical School, 7 York Road, PARKTOWN, 2193, Johannesburg • Tel: (011) 717 2745 • Fax: (011) 717 2119 • e-mail: [healthpq@health.wits.ac.za](mailto:healthpq@health.wits.ac.za)

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## DEDICATION

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This thesis is dedicated to my mother and father for always believing in me.

## ABSTRACT

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The study conducted at Witrand Hospital in Potchefstroom explored the impact of HIV status on the outcome of stroke survivors. The ability to perform activities of daily living (ADLs) was assessed to determine the rate and nature of recovery of the HIV-positive and HIV-negative stroke survivors.

There was no difference in the rate and nature of recovery between the two groups upon admission and discharge. However, a difference in the rate and nature of recovery was noticed during the period from discharge to one month after discharge. The HIV-negative group showed more significant improvement as compared to the HIV-positive group, while the HIV-positive group showed a decline in their function over the period.

Because the sample size was small, generalisation of the results must be made with caution. Further investigation is needed to determine the reason the HIV-positive group had a decline in function during the month after discharge.

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## NOMENCLATURE

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**STROKE or CEREBROVASCULAR ACCIDENT** is characterised by a sudden onset of neurological deficits caused by a vascular injury to the brain. The vascular damage causes decreased supply of oxygen to the brain, resulting in brain tissue death or infarction (1) (2).

**OCCUPATION** includes the activities in which a person engages in everyday life. Occupations provide meaning, provide structure to living, and have cultural value. These activities include ADLs, work and leisure (3) (4).

**ACTIVITIES OF DAILY LIVING** are the activities in which people need to participate to take care of their bodies. These activities are essential for basic survival, health and wellbeing. Some of them include eating, dressing, washing, toileting, and functional mobility and is known as basic activities of daily living (BADL's). Instrumental activities of daily living (IADL's) support living within the home and community and is consist of more complex activities such as preparing food etc. (3).

**RISK FACTORS** can be divided into modifiable and unmodifiable risk factors. Unmodifiable factors include gender and age, whereas modifiable factors include hypertension, smoking and diet (5).

**OCCUPATIONAL PERFORMANCE** is the ability of an individual to perform purposeful daily activities (occupations) (4).

**HEMIPARESIS** is weakness or partial paralysis on one side of the body (1).

**HEMIPLEGIA** is paralysis on one side of the body (1).

**ANOSOGNOSIA** is the lack of awareness or denial of deficits as a result of brain damage (1).

**COMPENSATION STRATEGIES** is used by occupational therapists when functional recovery is not completely possible, the occupational therapist will teach the stroke survivor new techniques to perform for example, their activities of daily living (6).

## LIST OF ABBREVIATIONS

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<b>ADLs</b>	Activities of daily living
<b>AIDS</b>	Acquired immunodeficiency syndrome
<b>ARVs</b>	Antiretrovirals
<b>BI</b>	Bartell Index
<b>BMI</b>	Body Mass Index
<b>CDC</b>	Centre for Disease Control
<b>CNS</b>	Central nervous system
<b>CVA</b>	Cerebrovascular accident
<b>FIM</b>	Functional independence measure
<b>GBD</b>	Global Burden of Disease Study
<b>HAART</b>	Highly active antiretroviral therapy
<b>HIV</b>	Human immunodeficiency virus
<b>ICF</b>	International Classification of Functioning, Disability and Health framework
<b>RMM</b>	Rasch measurement model
<b>SADFM</b>	South African Database for Functional Medicine
<b>TB</b>	Tuberculosis
<b>WHO</b>	World Health Organisation

## CHAPTER 1: INTRODUCTION

---

### 1.1 Introduction to the study

A high proportion of the caseload of occupational therapists working in a rehabilitation setting is made up of stroke survivors (7). This is also true for the physical rehabilitation unit at Witrand Hospital, where this research was conducted. Occupational therapists play an important role in the rehabilitation of stroke survivors, where the focus of rehabilitation is to decrease the burden of care on caregivers and improve the stroke survivor's independence (2). This is important because of the often devastating consequences of a stroke on the stroke survivor and their caregivers, as well as the socioeconomic impact (2) (8). The consequences of having a stroke are greatest in low- and middle-income countries (8).

Stroke is the second leading cause of death worldwide, and the leading cause of acquired disability (9). Countries classified as having low and middle income, such as South Africa, have been found to have the largest burden of stroke, and account for the highest stroke mortality (85%) worldwide (10). The incidence of non-communicable disease is on the increase in both rural and urban areas across the globe, with hypertension, cardiovascular diseases and diabetes all predisposing factors for stroke, which has reached epidemic proportions in some lower income regions (10). Statistics South Africa reported that between 1999 and 2006, premature death as a result of stroke increased by 28% among people aged between 15 and 64 (11).

An investigation into the aetiology of stroke in patients younger than 45 years found that in Africa, 7% of patients presenting with stroke had no cardiovascular disease or other known predisposing factors. Stroke in this group is usually associated with human immunodeficiency virus (HIV) infection (11) (12). This is consistent with reports in literature that since the 1980s, there has been an increased risk of stroke in HIV-positive children and young adults (13) (14) (15). In addition, a study

conducted in Nigeria identified HIV as a risk for stroke, specifically in younger adults (16). It has also been reported that antiretroviral medication (ARVs) used to treat HIV cause atherosclerosis, which increases the risk for cardiovascular disease and other chronic diseases. Thus, a person infected with HIV has an increased risk of having a stroke (17) (18).

While South African research is predicting a marked reduction in new HIV infections over the next 30 years, particularly in the 15-49 age groups, older people presently affected with HIV are still at risk of stroke. It is estimated in the age group 50 years and older that the prevalence of stroke will increase from 9% to 17% as the introduction of ARVs has resulted in people infected with HIV living longer (17).

This trend has been noticed in patients with stroke referred to occupational therapists for rehabilitation, both in hospitals and primary healthcare facilities. The average age of stroke survivors in developed countries is 70 in men and 75 in women, whereas the average age of stroke survivors in sub-Saharan Africa is 50 for both men and woman. A study conducted in Gambia found that the mean age of stroke survivors was 58, about 10 to 15 years younger than stroke survivors in developed countries (8) (19).

Occupational therapists must understand and deal with the implications of differences in aetiology, age, illness progression and prognosis in stroke survivors (20). The focus of occupational therapy is on improving stroke survivor's independence and their ability to participate in ADLs or tasks that are orientated towards taking care of one's own body, like eating, grooming, dressing, bathing and toileting (21). This study will explore the impact of HIV on stroke survivors, which will assist in identifying possible implications for the rehabilitation of stroke survivors who are also HIV positive.

## **1.2 Research problem**

From clinical experience, the researcher has noted that stroke survivors who are HIV positive are more dependent in their ADLs on discharge or take longer to achieve the same level of independence compared to stroke survivors who are HIV

negative. This was unexpected, as literature indicates that HIV-positive stroke survivors are generally younger than HIV-negative stroke survivors, and that they do not usually have a history of hypertension, diabetes or cardiac disease. These conditions have been associated with poorer outcomes in stroke survivors, and therefore it would be expected that HIV positive stroke survivors have a better prognosis.

In planning an occupational therapy intervention programme, it is expected that younger stroke survivors would be more independent in their participation in ADLs, as age is one of the major factors that affects a person's ability to care for him/herself after a stroke (22). Age is reported to have a linear relationship on the outcome of stroke, with functional outcomes strongly relating to age and the severity of the stroke (23). Stroke survivors older than 64 have been found to need a significantly longer stay in hospital and tend to achieve lower levels of independence in their ADLs, resulting in them being more dependent on their caregivers at home after discharge.

There is very little research to provide evidence to understand the impact of HIV status on a stroke survivor's ability to participate in ADLs. Although there is literature that has shown that occupational therapy services improve ADL performance and overall quality of life for stroke survivors (24) (25) (26), relatively few studies have been conducted to identify specific challenges that therapists might encounter regarding the chronic health condition of HIV particularly related to stroke (27). No published studies could be found regarding the impact of HIV status on a stroke survivor's ability to participate in ADLs.

### **1.3 Purpose of the study**

The purpose of this research is to assist occupational therapists to plan effective and efficient occupational therapy interventions for stroke survivors by providing information regarding the effect of HIV on the rate and nature of recovery of stroke survivors specifically related to independent participation in ADL's.

#### **1.4 Research question**

Does the HIV status of a stroke survivor influence the rate and nature of recovery towards independent participation in ADLs?

#### **1.5 Aim of the study**

The aim of this study is to compare the difference between the rate and nature of recovery of stroke survivors who are HIV positive and HIV negative on admission to participate independently in ADLs at discharge and one month after discharge.

#### **1.6 Objectives of the study**

- To determine the ability of stroke survivors who are HIV positive to participate in ADLs on admission, at discharge, and one month after discharge.
- To determine the ability of stroke survivors who are HIV negative to participate in ADLs on admission, at discharge, and one month after discharge.
- To compare the ability of stroke survivors who are HIV positive and HIV negative to participate in ADLs on admission, at discharge, and one month after discharge in order to compare the rate and nature of change that occurred at each time period measured.

#### **1.7 Justification of the study**

Empirical evidence is needed to understand the collective impact of HIV status and stroke on a stroke survivor's rate of recovery and participation in ADLs so as to ensure appropriate and cost-effective service delivery. Literature indicates that 60% of HIV-negative stroke survivors are permanently dependent in some ADLs, including eating, grooming, dressing, bathing, toileting and mobility one year after suffering a stroke (21). Ninety percent of stroke survivors are independent with eating and toileting , between 59% and 68% need assistance with bathing and dressing one year after the stroke (1) (21).

As this research aims to provide scientific evidence for the rate and nature of recovery of HIV-positive and HIV-negative stroke survivors towards participating in ADLs, a typical South African hospital context gives occupational therapists a better idea of how to predict the rate and nature of recovery toward participation in ADLs, and provides information to plan for realistic outcomes. This would enable occupational therapists to realistically motivate for an extended hospital stay, if required, for patients who need more therapy which would ensure optimal ADL outcomes. This would also ensure that the HIV-positive stroke survivors are more independent in their ADLs when discharged, and therefore decrease the burden of care on the family (8). It would further assist occupational therapists to provide realistic treatment to these patients through appropriate goal setting, and caregiver training and support.

## CHAPTER 2: LITERATURE REVIEW

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### 2.1 Introduction to the literature review

Literature produced between 1994 and 2015 was used for this review, particularly local and international medical, rehabilitation- and occupational therapy-specific literature. Literature from 1994 was used because this is important, gold standard information regarding the rate and nature of stroke recovery. The following search engines and databases were used to collect pertinent literature: Google Scholar, ENSCO Host, CINAHL Plus, PUBmed, ScienceDirect, and Medline. The key words used to search for pertinent literature included: stroke, HIV, occupational therapy, rehabilitation, quality of life, and recovery.

This literature review includes a description, classification and epidemiology of stroke, as well as the rate and nature of recovery, specifically in performing ADLs, after a stroke. Literature pertaining to the description, classification, epidemiology of HIV/AIDS and its relation to stroke was also reviewed. As there is limited research on the manner in which HIV influences the rate and nature of recovery towards participating in ADLs after a stroke, literature pertaining to the impact of a stroke on the functional ability of a stroke survivor was reviewed first. This was done to get a better understanding of each topic separately, and then to draw conclusions on the impact of both conditions, when they occur simultaneously, on a person's ability to participate in ADLs. The burden of care of stroke and HIV on functional ability (specifically ADLs) and the community was also explored. Lastly, the role of occupational therapy in the rehabilitation of stroke survivors and people living with HIV/AIDS, and the outcome of therapy, is discussed.

### 2.2 Stroke and recovery of activities of daily living

#### 2.2.1 Introduction

Recent literature confirms that a stroke or a cerebrovascular accident (CVA) is characterised by a sudden onset of neurological deficits caused by a vascular injury

to the brain. Vascular damage is caused by decreased supply of oxygen to the brain, resulting in brain tissue death or infarction (1) (2).

Strokes are classified according to the mechanism and location of the vascular injury, and can be ischemic or haemorrhagic (1). Ischemic strokes are caused by a thrombosis or embolism that causes an occlusion of the cerebral vessels (1). Thrombotic occlusions in vessels are usually caused by atherosclerosis. Emboli are usually caused by dislodged platelets, cholesterol, or other material in the bloodstream (1).

Ischemic strokes are the most common, and represent approximately between 80% and 85% of all strokes, whereas haemorrhagic strokes account for between 15% and 20% of strokes (1) (2) (8) (28). Haemorrhagic strokes are caused by a rupture of the cerebral blood vessels, and are more severe than ischemic strokes. Bleeding can occur in the subarachnoid space or it can be intracerebral. Haemorrhages are usually caused by hypertension, arterio-venous malformation, or aneurysms (1) (28) (29).

Stroke symptoms vary, and are dependent on the location and extent of the lesion (1) (30). The majority of strokes occur in the anterior and posterior circulation of the brain (2). The most common manifestation of a stroke is hemiparesis or hemiplegia on the contralateral side to the lesion. Hemiparesis can be defined as weakness of one side of the body, and may cause only mild impairment to movement, whereas hemiplegia is paralysis of one side of the body, typically resulting in no or limited movement on the paralysed side (1) (2). The stroke survivor can also present with other specific symptoms depending on which hemisphere is affected. A stroke in the left hemisphere may result in right hemiparesis, aphasia, other communication deficits, and apraxia (1). A stroke in the right hemisphere may result in left hemiparesis, visual field deficits, spatial neglect, poor insight and judgment, and impulsivity (1).

Research is contradictory on the effect of the site of the lesion on outcomes. Some studies have reported no difference in the outcomes for stroke survivors with lesions in the left hemisphere as compared to the right hemisphere. However, there is some evidence that a stroke survivor with a lesion on the right might have a poorer prognosis (23), and this has been reported to be related to perceptual impairments,

anosognosia, and other cognitive impairments commonly associated with right-hemisphere lesions. These impairments have an influence on a stroke survivor's ability to regain function (1) (23) (31).

### **2.2.2 Risk factors for stroke**

Current research has reported an increased incidence of stroke risk factors in developing countries such as South Africa (32). These factors increase the burden of stroke in these low- and middle-income countries.

Risk factors can be divided in unmodifiable and modifiable risk factors. Unmodifiable risk factors include age, gender, socioeconomic status, race, and family history (5) (8). Modifiable risk factors include hypertension, smoking, obesity, diet, physical activity, diabetes, excessive alcohol use, psychosocial factors, hypercholesterolemia, atrial fibrillation, and prothrombotic factors (5) (8) (33). Of these risk factors, the most common are hypertension, smoking, obesity, diet, and lack of physical activity (33). The most common stroke risk factors reported in South Africa are hypertension (55%), excessive alcohol use (20%), diabetes (12%), and cigarette smoking (9%). When comparing international studies to South African studies, alcohol consumption appears to be a more prevalent risk factor (5) (8) (33).

Hypertension is a greater risk factor for haemorrhagic strokes, and is an important risk factor in persons younger than 45 years (33). This is a particular problem in South Africa, where 24.4% of the population is diagnosed with hypertension, and only 38% of those diagnosed adhere to their hypertension medication (5) (33).

Excessive alcohol use is the second-highest risk factor reported in South Africa. An alcohol intake of more than 30 drinks per month or binge drinking has been associated with an increased risk of stroke (33).

A significant correlation between diabetes and stroke has been reported in relevant literature. Diabetes is a risk factor in both the young and older age groups, but is more prevalent in persons older than 50 (5). Diabetes is a lifestyle related disease caused by obesity and physical inactivity, and has been associated with an increased

risk for ischemic strokes (33). An estimated 29% of South African men and 56% of South African women are obese (5). Although no association could be found between body mass index (BMI) and stroke, an increased waist-to-hip ratio has been reported to increase the risk of stroke (33), and recent research has found that the hip-to-waist ratio is a more accurate measure of obesity than BMI.

Smoking has been associated with an increased risk of stroke (33). Research has shown that when a person stops smoking, the risk of having a stroke reduces rapidly. Smoking has been more commonly associated with ischaemic strokes than haemorrhagic strokes (33).

Age remains the greatest unmodifiable risk factor associated with stroke. Hospital-based studies have found that the incidence of stroke in the younger age group (35-54 years) is higher in the sub-Saharan African population as compared to the same age group in developed countries (16). A study conducted in Nigeria found that the risk factors associated with stroke in younger adults (aged 45 and younger) differs slightly from the risk factors associated with stroke in older adults. The most common risk factors in younger adults are hypertension, smoking, hypercholesterolemia, cardiac disease, and HIV infection. HIV as a risk factor leading to stroke will be discussed in more detail later in the literature review (Section 2.3.4. Stroke in the HIV-positive population). Research also suggests that infarctions are also more common than haemorrhagic strokes in younger adults (16).

Another important unmodifiable risk factor is race. There is a clear difference in the distribution of stroke risk factors between races in South Africa. Black people have a higher risk of having a stroke than white people (5) (8). Hypertension is the most common risk factor among black people (59%), whereas dyslipidaemia (39%) is more common among white people (8). Smoking has been found to be higher risk factor among the mixed race population (44%) and the white population (42%) compared to the black population (21%) (8).

### **2.2.3 Epidemiology of stroke**

Stroke is the fourth-leading cause of mortality worldwide, and one of the top 10 causes of disability (8). Low- and middle-income countries account for 85% of the worldwide stroke mortality (33). Studies over the past four decades have established that the incidence of stroke in low- and middle-income countries is increasing compared to the 42% decrease in incidence in high-income countries (32). A decrease in stroke mortality has been reported worldwide, with the number of stroke survivors increasing (32). This increase in the numbers of stroke survivors has resulted in an increase in the burden of care on families, caretakers, and the health system (8).

The World Health Organisation (WHO) has studied the incidence rates of stroke all over the world, and has reported on the incidence of stroke in the Africa E region, which includes South Africa. Overall, the incidence of stroke was found to be lower in South Africa than in other countries in the region, but the incidence of stroke in the younger age groups was higher (34).

In 2013, cerebrovascular diseases accounted for 4.9% (22 463) of deaths in South Africa, and was the fourth-leading cause of mortality (35). In 2007, there were reported to be 350 000 stroke survivors in South Africa (34). Thus the prevalence of stroke in South Africa is approximately 300 people out of 100 000 (2).

South Africa's North West province, where this study was conducted, has an estimated population of 3.5 million, 6.8% of the country's total population. In 2013, cerebrovascular disease was the sixth leading cause of mortality in North West, and accounted for 4.6% (1 644) of deaths (35).

### **2.2.4 The burden of stroke**

According to South Africa's department of health, the country is experiencing a quadruple burden of disease caused by the increase in chronic diseases, HIV/AIDS, an maternal and child health issues and injuries (34). Stroke is the leading cause of disability among adults, and it is expected that the prevalence of stroke survivors will increase further due to better medical services (36) (37).

Traditionally, stroke has been considered an older person's disease. However, research has found that low- and middle-income countries have a greater proportion of stroke survivors younger than 75 than those older than 75 (8) (32). A 2010 Global Burden of Disease (GBD) study reported an increase in the incidence of stroke in people younger than 20 and in adults aged between 20 and 64 (32). Studies have highlighted that when stroke survivors are younger, there is an added financial burden on an already strained health system and an increased burden on caregivers because these stroke survivors need care and social support for a much longer periods of time (9) (38). The younger the stroke survivor, the greater the financial impact on the family and the economy, because they are in the economically active age band. In 1991, a study was conducted in South Africa to determine the economic burden of stroke survivors. It found that cardiovascular diseases (including stroke, ischemic heart disease, peripheral vascular disease and thromboembolic conditions) cost South Africa up to R5 billion a year. When this cost was adjusted to 2011 rand values, the annual cost was estimated to be as much as R16 billion. This estimation is even higher today as a result of a higher incidence of stroke (34).

Many people who survive a first stroke have inadequate access to health services for acute stroke treatment, rehabilitation and stroke prevention programmes, resulting in stroke survivors not achieving expected outcomes in relation to independence and quality of life (32) (39). In the rural areas of South Africa admission after suffering a stroke is dependent on the severity of the stroke. The more severe the stroke the more likely the stroke survivor will be admitted to the hospital (8). The average length of stay of stroke survivors in hospitals has also decrease from 14 days in 1998 to only seven days in 2002. This affects the outcome of stroke survivors greatly (8).

In South Africa the caregivers of stroke survivors are mostly family members and friends who are untrained. The burden on the caregivers is increasing due to the stroke survivors being discharge before they reach their full functional ability due to the shortening of length of stay in hospitals. Because of the early discharge of the stroke survivors there is a big responsibility to the care givers to improve the stroke survivor's functional ability at home. The poor accessibility of health services makes this very difficult (8).

### **2.2.5 Rate and nature of recovery of activities of daily living following stroke**

Stroke recovery is heterogeneous, and depends on the nature and severity of the stroke (21) (40). On average, stroke survivors are the most dependent (75%) in their ADLs immediately after the stroke (41). A stroke survivor's dependence decreases to 58% one week after the stroke, and their dependence further decreases to 9% after six months (41). The initial severity of disability and the amount of function that recovers in the first three to 10 days after the onset of the stroke is an important indicator for their outcomes after six months (40). The rate of recovery can be characterised by the largest improvements occurring during the first weeks after the stroke, decreasing in the post-acute phase to three months after the stroke, after which the improvements start to plateau until six months after the stroke (40). The early recovery after the stroke can be attributed to spontaneous neurological recovery (40). Research has found that after six months, between 5% and 10% of stroke survivors will have further improvement in their ADLs and upper and lower limb function, although a decline in activity participation was found in between 15% and 25% of stroke survivors (40) (6).

As a result of motor, cognitive and perceptual impairments, stroke survivors experience significant restrictions in several functional areas such as ADLs, household tasks, and social and recreational activities (21). After rehabilitation, 28% of stroke survivors are moderately to severely dependent in performing their ADLs, 26% have mild impairments, and only 46% become independent (1).

Research has also identified a pattern in recovery, where survivors become more capable of performing their ADLs. More complex skills such as dressing take longer to improve compared to activities such as grooming, where compensation strategies can be applied more easily (40). It was found 96% of stroke survivors are independent in eating one year after their stroke, and 64% are independent with grooming, but only 32% are independent with upper limb dressing and 42% with lower limb dressing. However, 93% of stroke survivors were found to be independent with toileting one year after the stroke (21).

Impaired upper limb function was present in 85% of all stroke survivors one year after the stroke, and was found to persist in between 55% and 75% of stroke survivors (22). Long-term disability after a stroke includes hemiparesis (50%), impaired mobility (30%), impaired ability to perform ADLs (26%), aphasia (19%), and symptoms of depression (35%) (22).

### **2.2.6 Predictors of functional recovery following a stroke**

Research has identified some predictors to assist clinicians to determine the prognosis for the return of function for stroke survivors. The length of time before any improvement takes place after a stroke can be an indication of the severity of the cerebral damage that has occurred. Research suggests that a poor outcome can be expected if the lower limb does not regain any function within the first two weeks, and the upper limb after four weeks (2) (42). Factors reported to predict functional recovery of stroke survivors negatively include advanced age, a history of previous strokes, urinary incontinence, persistent visiospatial deficits, cognitive impairments, post-stroke depression, severity of motor deficits, and major hemispheric syndrome (22). Other predictors that can also lead to a poorer prognosis are the presence of a coexisting disease such as HIV, poor balance and severe aphasia (42).

## **2.3 Human immunodeficiency virus and recovery of competence in activities of daily living**

### **2.3.1 Introduction**

The symptoms of HIV were first described in 1981 by Masur *et al.* in the United States. Acquired immunodeficiency syndrome (AIDS) was officially defined in 1993 by the Centre for Disease Control and Prevention (CDC) in the US. These two conditions are regarded as a pandemic that affects populations and countries around the world (43).

Human immunodeficiency virus is a retrovirus that results in a gradual decline of the immune system. After the virus enters the body, it overwhelms the CD4 lymphocytes (CD4<sup>+</sup>T), the cells responsible for protecting the body against viruses (43).

Within the first four weeks of being infected with HIV, a person may experience flu-like symptoms. With time, the person's immune system becomes depleted and unable to protect the body against infections. It can take up to 12 years for HIV to develop into AIDS. It is reported that only 10% of people living with HIV progress to AIDS within the first three years after infection. With the progression of HIV, the occurrence of opportunistic diseases increases and the infected person begins to experience cognitive, motor and psychosocial impairments. As soon as two weeks after infection, the virus can cross the blood-brain barrier and enter the central nervous system. This is thought to be the cause of cognitive impairments in HIV-positive people, as 50% of HIV positive people are reported to present with cognitive impairments and dementia before death, although a decline in the prevalence of HIV-associated dementia has been observed since the introduction of ARVs (44). Cognitive symptoms include impaired memory and concentration, slow processing of information, impaired ability to learn, and reduced executive functioning (43) (45). Motor impairments include weakness and incoordination, while psychosocial symptoms include irritability and depression (43). All of these symptoms have an effect on a person's ability to perform their ADLs.

Classification of the different stages of HIV/AIDS is based on CD4 count and specific medical impairments that predetermine progressive loss of function (46). There are two different methods to classify HIV/AIDS as it progress through the different stages. One classification system was developed by the WHO, and the other by the CDC. The WHO clinical staging system for HIV/AIDS was developed in 1990, and provides clinical parameters to guide clinical decision-making for the management of HIV/AIDS patients. The staging criteria have been regularly revised as new information has become available. The clinical disease classification developed by the CDC is based on immunological parameters (CD4 counts). This clinical staging system for HIV/AIDS is more commonly used in regions with limited resources (47). Table 2.3.1 illustrates the revised WHO clinical staging of HIV/AIDS for adults and adolescents, and Table 2.3.2 illustrates the clinical disease classification developed

by the CDC, which shows CD4 levels in relation to the severity of immune suppression.

**Table 2.3.1: Revised WHO clinical staging of HIV/AIDS for adults and adolescents** (taken from the interim WHO clinical staging of HIV and AIDS case definition for surveillance document, page 11-12) (47)

<b>Primary HIV infection</b>
Asymptomatic Acute retroviral syndrome
<b>Clinical stage 1</b>
Asymptomatic Persistent generalised lymphadenopathy
<b>Clinical stage 2</b>
Moderate unexplained weight loss (<10% of presumed or measured body weight) Recurrent respiratory tract infections Herpes zoster Angular cheilitis Recurrent oral ulceration Papular pruritic eruption Seborrhoeic dermatitis Fungal nail infections of finger
<b>Clinical stage 3</b>
<b><i>Conditions where a presumptive diagnosis can be made on the basis of clinical signs or simple investigations:</i></b>  Severe weight loss (>10% of presumed or measured body weight) Unexplained chronic diarrhoea for longer than one month Unexplained persistent fever (intermittent or constant for longer than a month) Oral candidiasis Oral hairy leukoplakia Pulmonary tuberculosis (TB) diagnoses in the past two years Severe presumed bacterial infection (such as pneumonia, emphysema, pyomyositis, bone or joint infection, meningitis, bacteraemia) Acute necrotising ulcerative stomatitis, gingivitis or periodontitis  <b><i>Conditions where confirmatory diagnostic testing is necessary:</i></b> Unexplained anaemia (<8g/dl), and neutropenia (<500/mm <sup>3</sup> ) and or thrombocytopenia (<50 000/mm <sup>3</sup> ) for more than one month
<b>Clinical stage 4</b>
<b><i>Conditions where a presumptive diagnosis can be made on the basis of clinical signs or simple investigations:</i></b>  HIV wasting syndrome Pneumocystis pneumonia

<p style="text-align: center;">                     Recurrent severe or radiological bacterial pneumonia                      Chronic herpes simplex infection (orolabial, genital or anorectal for more than one month)                      Oesophageal candidiasis                      Extrapulmonary TB                      Kaposi's sarcoma                      Central nervous system (CNS) toxoplasmosis                      HIV encephalopathy  <b>Conditions where confirmatory diagnostic testing is necessary:</b>                      Extrapulmonary cryptococcosis including meningitis                      Disseminated non-tuberculosis mycobacteria infection                      Progressive multifocal leukoencephalopathy                      Candida of trachea, bronchi or lungs                      Cryptosporidiosis                      Isosporiasis                      Visceral herpes simplex infection                      Cytomegalovirus, infection (such as histoplasmosis, coccidiomycosis, penicilliosis)                      Any disseminated mycosis (such as histoplasmosis, coccidiomycosis, penicilliosis)                      Recurrent non-typhoidal salmonella septicaemia                      Lymphoma (cerebral or B cell non-Hodgkin)                      Invasive cervical carcinoma                      Visceral leishmaniasis                 </p>
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**Table 2.3.2: Clinical disease classification developed by the CDC** (taken from the interim WHO clinical staging of HIV and AIDS case definition for surveillance document, page 15) (47)

Classification	CD4 count
Not significant immune suppression	>500/mm <sup>3</sup>
Mild immune suppression	350-499/mm <sup>3</sup>
Advanced immune suppression	<200/mm <sup>3</sup>

At first HIV/AIDS was seen as a terminal diagnosis, but with medical advances the life expectancy of people living with HIV/AIDS has drastically improved, and it is now regarded as a chronic disease. Quality of life of HIV and AIDS sufferers greatly depends on the consistent availability of medical resources and support, and access to treatment (43).

### 2.3.2 Epidemiology of HIV

At the end of 2013, it was estimated that there were approximately 35 million people living with HIV worldwide (48). Globally, new HIV infections declined by 38% between

2001 and 2013, but there are still 2.1 million new HIV infections worldwide per year (48). The increase in the number of people living with HIV is a result of new HIV infections and the positive effect of antiretroviral treatment, which has increased life expectancy. The current estimate is that 4 million (0.8%) adults between the ages of 15 and 49 are living with HIV (48). The sub-Saharan Africa region accounts for approximately 69% of people affected with HIV worldwide (10), and South Africa accounts for 18% of the total global population of people living with HIV (48) .

In 2012, there were 6.4 million people living with HIV in South Africa, 31.2% of who are receiving ARVs. This percentage has increased from 16.6% in 2008 (49). The prevalence of HIV remains higher in females than men, with the highest prevalence in the 30-34 age group in females (36%) and the 35-39 age group in males (28.8%). Black people have a higher prevalence of HIV compared to other race groups, they account for 15% of the people living with HIV in South Africa. The highest prevalence of HIV is found in people living in informal residential areas. North West province has the fourth-highest prevalence of HIV in South Africa, accounting for 13.3% of people living with HIV in the country (49).

In 2013, HIV accounted 23 124 deaths in South Africa. It was the third-leading cause of morbidity for males in South Africa, accounting for 4.9% (11 643) of all deaths by natural causes in 2013 (35). In the female population, HIV accounted for 5.3% (11 481) deaths, and was the fourth-leading cause of morbidity as a result of natural causes (35).

### **2.3.3 The burden of HIV**

Literature suggests that whereas people living with HIV previously needed assistance with basic ADLs, they now need more assistance with instrumental ADLs. Research has found that only 12% of people living with HIV/AIDS need assistance with basic ADLs, where 55% needs assistance with instrumental ADLs (43) (46). People living with HIV frequently experience cognitive and physical impairments, but the onset and severity of these impairments vary from person to person. With the progression of the disease neurological changes predispose a person living with HIV to psychological

impairments. Some of these psychological impairments include prolonged depression, impaired memory, concentration and attention, anxiety and reduced motivation and drive (50) (43). The most frequent impairments experienced are fatigue, anxiety, impaired concentration, muscle aches, and depression. Fatigue is one of the symptoms that causes impairments in mobility, basic ADLs and instrumental ADLs, but mostly with more vigorous activities, resulting in sufferers being unable to work and fulfil their roles, and ultimately leading to them withdrawing from social activities (46) (51).

### **2.3.4 Stroke in the HIV-positive population**

Stroke has been reported in HIV-positive people from as early as 1980, when it was noted that there was a high incidence of stroke in HIV-positive children and young adults without the classic risk factors of stroke. A study on AIDS patients noted that many were found to have had ischemic strokes on autopsy, but that the majority of these strokes were undiagnosed when the patient was alive (29).

HIV infection can potentially increase the risk of stroke, as can the use of ARVs, which are known to cause vascular damage. It is important to understand the extent to which HIV infection contributes to increased risk for stroke, especially in regions with high HIV prevalence such as South Africa (13).

With the introduction of ARVs in 1996, it was noted that the prevalence of neurological infections and tumours such as CNS lymphomas declined in the HIV-positive population, resulting in an increase in life expectancy (52). However it was noted that after two years of continually using ARVs, HIV-positive patients started to develop atherosclerosis, as well as an increase in myocardial infarctions and ischemic strokes (29).

Clinically, it was important to determine whether the HIV or ARVs, or both, contributed to the development of atherosclerosis and increased the risk for strokes and myocardial infarctions in the HIV-positive population. Research established that HIV can be seen as an independent predictor for stroke, particularly in the younger population because other risk factors for stroke are not that common in this group (53). Risk factors for stroke among the HIV-positive population may differ from the

unaffected population, and the effects of HIV and ARV medication must always be considered (13) (54).

The exact influence HIV plays in increasing risk factors for stroke is not yet fully understood. Recent studies have shown that HIV infects the endothelium and alters cerebrovascular functioning. These changes are thought to increase the risk for stroke. Other causes of stroke associated with HIV have also been identified and include tumours, coagulopathies and opportunistic infections. Some research suggests that there is also a relationship between CD4 count and strokes, as people living with HIV usually present with CVAs when their CD4 count is below 200 (52). ARVs have been associated with an increased risk of ischemic strokes as they accelerate atherosclerosis and metabolic syndrome (13) (54).

#### **2.4 Characteristics of stroke in HIV-positive stroke survivors**

It is reported that stroke survivors who are HIV positive are typically younger than stroke survivors who are HIV negative. In developed countries, the median age of HIV-positive stroke survivors is 42 years, whereas the median age of HIV-positive stroke survivors in developing countries is 39 years. One hypothesis to explain the difference in median age of HIV-positive stroke survivors is the earlier identification of the illness and introduction of ARVs in developed countries (13).

Clinical descriptions and neurological deficits of stroke survivors who are HIV positive and negative are reported to be the same. However, HIV-positive stroke survivors often have atypical symptoms such as acute confusion, fever, and acute loss of consciousness (13).

Ischemic strokes are more common in the HIV-positive population, and can be connected with more than 90% of HIV-associated strokes. The incidence of ischemic strokes in this population is 5.27 per 1 000 people compared to 3.75 in the HIV-negative population (29). The subtypes of stroke common in the HIV-positive population include lacunar strokes, partial anterior circulation strokes, and total anterior circulation strokes (13).

## **2.5 Causes of stroke in the HIV-positive population**

The aetiology of strokes in HIV-positive patients can be directly or indirectly attributed to HIV. Secondary causes of strokes in HIV-positive patients include mass lesions (toxoplasmosis and primary CNS lymphoma), increased use of illicit drugs, and vasculitis caused by opportunistic infections (encephalitis, syphilis, tuberculosis and cryptococcus). Research has found evidence of HIV causing small and medium vessel vasculopathy, which can be a direct cause of a stroke (52). There is some evidence indicating that both HIV infection and highly active antiretroviral therapy (HAART) are associated with increased risk of stroke and myocardial infarctions (55) (56).

HIV-associated vasculopathy is an abnormality of the cerebral blood vessels caused directly or indirectly by HIV. These abnormalities can cause the formation of aneurysms (intracranial or extracranial), vasculitis, and accelerated atherosclerosis, which can increase the risk of having a stroke. Opportunistic infections include tuberculosis, meningitis, varicella zoster virus and neoplasia. These can lead to lymphoma in cerebral blood vessels, endocarditis, HIV-associated cardiac dysfunction and ischaemic heart disease, and are linked to the occurrence of strokes (13).

There is not a lot of information available on how or whether HIV affects the outcome of stroke recovery. A retrospective study conducted in South Africa found no statistical difference in functional outcome between stroke survivors who are HIV negative and those who are HIV positive on discharge after receiving rehabilitation from a multidisciplinary team (50). However, there is no information available on the long-term effects of HIV on stroke recovery.

## **2.6 The role of occupational therapy in neurological rehabilitation**

Occupational therapists use outcome measures to determine the effectiveness of rehabilitation, and measure the baseline performance before rehabilitation commences and the occupational performance ability at discharge (57). The role of

occupational therapists in the rehabilitation of stroke survivors is to improve impaired performance skills in order to improve clients' occupational performance, (2).

### **2.6.1 Outcome measures used in rehabilitation**

Outcome measures frequently used by occupational therapists in a rehabilitation setting are the Bartel Index (BI) and the Functional Independence Measure (FIM) (57).

The BI is an outcome measure using a ratings scale to measure the activity limitations of patients with impaired body functions and structures. The BI is used to assess stroke survivors' baseline abilities at the start of therapy to quantify functional changes during and after rehabilitation. This outcome measure can also be used to predict the length of hospital stay (58) (59) (60). The BI consists of 10 items: feeding, bathing, grooming, dressing, bowel management, bladder management, toileting, mobility, stair climbing, and transfers. There are different scoring systems for the BI: one uses scores ranging from 0 (fully dependent) to 100 (fully independent) (60). Thus, scores of 0-20 indicate total dependency, 21-60 indicate severe dependency, 61-90 indicate moderate dependency, and 91-99 slight dependency. The BI is not very sensitive to changes in stroke survivors with mild or nearly recovered strokes, and does not account for the environmental adaptations needed to complete tasks (58) (60).

The FIM, on the other hand, is an outcome measure that records the severity of disability instead of impairment, and is based on the International Classification of Functioning, Disability and Health framework (ICF). A 7-point scale (ranging from total assistance to complete independence) is used to rate a stroke survivor's level of disability (61). The FIM is used to determine burden of care, and to evaluate the effectiveness and outcome of rehabilitation (62) (63). Training is needed to use this outcome measure effectively, and it can be used on a wide range of patients with neurological impairments (61). The FIM was developed and standardised in North America. A study conducted in Sweden found that it does not have good cross-cultural validity. One explanation for this can be cultural and environmental differences across countries (64).

Although these outcome measures are widely used internationally, neither of them is standardised for South Africa, but the South African Database for Functional Medicine (SADFM) is. The SADFM is an evidence-based reporting framework that can be used to convert patients' functional abilities into quantifiable data, making it possible for clinicians to measure improvement. This data can be used to direct rehabilitation, monitor progress, and measure outcomes (61). The SADFM consist of six measurement tools that are designed to measure a patient's functionality in different healthcare settings such as acute hospitals, sub-acute facilities, community-based facilities, and so on. Like the FIM, it is based on the ICF framework developed by the WHO. One measurement scale of the SADFM relates to the activity participation section of the ICF, and can be used to measure stroke survivors' ability to take care of themselves. This beta measurement tool is designed for use in sub-acute and non-acute healthcare settings, and consists of 18 items, 13 of which are within the physical domain, and five within the cognitive domain. The 13 physical items consist of eating, grooming, bathing, upper limb dressing, lower limb dressing, toileting, bladder management, bowel management, transfers (from bed to chair, wheelchair, toilet, tub or shower), and locomotion (walking, wheelchair, stairs); while the five cognitive items include comprehension, expression, social interaction, problem solving, and memory. A stroke survivor's functional ability is scored using a seven-point scale. Table 2.6.1 describes the definition of each point of the scale for the beta measurement tool.

**Table 2.6.1: Beta measurement tool scoring (61)**

Score	Description
1	The subject does not assist at all. They are completely dependent on one or two therapists to complete the task.
2	The subject tries to assist, but provides less than half of the effort (25%-49%). One therapist is required to complete the task.
3	The subject performs 50%-75% of the task, but still requires the help form one therapist.
4	The subject requires incidental hands-on help only. They perform >75% of the task.
5	The subject requires supervision, cuing and/or setting up to complete the task.
6	The subject requires extra time or uses an assistive device.
7	The subject is fully independent.

## **2.6.2 Rehabilitation of stroke survivors**

Stroke survivors in Witrand Hospital receive treatment from a variety of medical professionals during the rehabilitation process. The multidisciplinary team usually consist of occupational therapists, physiotherapists, speech and language therapists, medical doctors, nurses, dieticians, and psychologists. There is evidence that a multidisciplinary approach in the rehabilitation of stroke survivors decreases the length of stay in hospital, as well as mortality (2) (24).

### **2.6.2.1 Role of occupational therapy in the rehabilitation of stroke survivors**

Stroke rehabilitation is goal orientated and focuses on improving a stroke survivor's independence. The focus is on improving physical and cognitive deficits. Stroke rehabilitation aims to decrease the burden on caregivers by helping stroke survivors to become as independent as possible (1) (38). This is achieved through remediation and the development of skills, compensatory techniques, activity modification and assistive devices or environmental accommodations or modifications.

Occupational therapy is based on an understanding of the importance of everyday activities to a stroke survivor's health and wellbeing. Success in occupations is central in redeveloping a stroke survivor's identity, sense of competence, and sense of meaning and purpose. Suffering a stroke has a marked influence on a person's ability to participate in ADLs (21).

During therapy, occupational therapists use occupation as an end or as a means. Occupational therapy is client centred, and differs depending on the stroke survivor's context and needs. Treatment might include remedial and compensatory strategies to attempt to reduce disability and impairments (1).

Occupational therapists aim to ensure that stroke survivors reach their highest level of independence by improving their ADLs (1) (2). Visual-perceptual and cognitive deficits are also addressed through the use of functional tasks or compensatory

strategies (1) (2). For stroke survivors to use their affected upper limbs spontaneously while doing ADLs, the occupational therapist will aim to improve stroke survivors' postural control and control of movement, muscle strength, and endurance of the affected upper limb (1) (2). Stroke survivors and their caregivers are also taught management techniques to prevent pain and other secondary mechanical or physiological restrictions to their movement (1) (2). Occupational therapists also aim for the stroke survivor to gain competence in tasks and activities to resume roles or assume new meaningful roles in the community (including return to home and work) (1) (2). They use clinical reasoning together with occupational therapy predictors to predict a stroke survivor's prognosis to determine the most suitable and effective treatment plan (2). When a stroke survivor has a positive prognosis for functional recovery, rehabilitation focuses on improving deficits, but if the prognosis for functional recovery is not good, the occupational therapist will focus on teaching the stroke survivor and caregivers techniques to compensate for their deficits (6) (37).

According to research, the level of independence in ADLs is directly linked to quality of life (61) (65). It has been found that stroke survivors who are more dependent in ADLs have a lower quality of life compared to those who are more independent (1) (61) (65). Occupational therapy aims to engage stroke survivors in meaningful and purposeful activities to facilitate independence in all occupational performance areas.

### **2.6.3 Occupational therapy for people living with HIV/AIDS**

Previously, HIV/AIDS was classified as a short-term terminal illness, but it has been reclassified as chronic condition as a result of medical advances. Consequently, more emphasis needs to be placed on the rehabilitation of people living with HIV/AIDS to ensure that their health, ability to continue participating in ADLs, and quality of life is being maintained (43) (46). Stroke is the leading cause of disability among adults, and it is expected that the prevalence of stroke survivors will increase further due to better medical services (36) (37).

The main focus of occupational therapy for people living with HIV/AIDS is to ensure occupational competence through rehabilitation. During the early stages of HIV, it is important for an infected person to maintain or establish routines, habits and behaviours that ensure the maintenance of health (43). Symptoms caused by the virus or medication might result in challenges at work, self-care, and other occupations. It is important that occupational therapy focuses on assisting the person living with HIV in preserving or adapting the roles that are important to them (43). With the progression of the disease, the person will experience periods of ill health, and during these periods, occupational therapists can assist with accommodations and adaptations to work tasks, ADLs, and leisure activities (43). Some of the symptoms that can influence the ability of people living with HIV to perform their occupational roles are sensory impairments, weakness, incoordination, and impaired memory. Occupational therapists can assist with environmental adaptations, adaptive strategies, or assistive devices (43).

## **2.7 Effectiveness of occupational therapy in neurological rehabilitation**

A systematic review of randomised trials indicated that stroke survivors who receive occupational therapy are more independent in their ADLs than stroke survivors who do not receive occupational therapy (25). Studies also suggest that stroke survivors who receive early intervention have more favourable ADL and neuromuscular outcomes. High intensity therapy is more favourable for improvement, but improvement in motor and cognitive deficits does not necessarily lead to the improvement of ADLs (1) (66).

Although there is evidence that occupational therapy is effective in the rehabilitation of stroke survivors, measuring the effect is problematic, as it is difficult to distinguish between recovery resulting from rehabilitation and spontaneous recovery, especially as the population of stroke survivors is diverse (1).

There is very little literature available to determine the effectiveness of occupational therapy in the rehabilitation of people living with HIV/AIDS. The little literature there is reflects the experience of people living with HIV/AIDS, and suggests occupational

therapists can assist most in the development of programmes and services to maintain or improve occupational performance (43).

## **2.8 Conclusion**

Stroke is the leading cause for disability and the prevalence of stroke is increasing due to improved medical services(36) (37). The prevalence of the risk factors for stroke are increasing in South Africa. The most common stroke risk factors reported in South Africa are hypertension, excessive alcohol use, diabetes mellitus and cigarette smoking. Age remains the greatest unmodifiable risk factor associated with stroke. The rate and nature of recovery can be characterised by the largest improvements occurring during the first weeks post-stroke decreasing in the post-acute phase to three months post-stroke, three to six months the improvements start to plateau (40).

Although the number of people diagnosed with HIV is decreasing each year, the prevalence of HIV is still increasing. This can be explained by the fact that the life expectancy of people living with HIV has increased since the introduction of ARVs.

It has been reported that HIV increases the risk for stroke, especially in the younger population. As a consequence, younger HIV-positive stroke survivors create an increased burden for caregivers, as they need to look after stroke survivors for longer. It also has a greater impact on the economy because of the increased and protracted cost burden, and increased length of unemployment rates as a result of disability.

Although there is a lot of literature available on the rate and nature of recovery of stroke survivors, very little information is available on the impact of HIV on the rate and nature of recovery of stroke survivors. While there is evidence that occupational therapy is effective in the rehabilitation of stroke survivors, measuring the effect is problematic, as it is difficult to distinguish between recovery as a result of rehabilitation and spontaneous recovery, especially as the population of stroke survivors is so diverse (1). However, a systematic review of randomised trials

indicated that stroke survivors who receive occupational therapy are more independent in their ADLs than stroke survivors who do not receive occupational therapy (25).

Identifying the impact of HIV on the rate and nature of stroke recovery can assist occupational therapist to direct their goal setting and the rehabilitation process.

## CHAPTER 3: METHODOLOGY

### 3.1 Introduction

This chapter describes the methodology used to achieve the aim of the study, which is to compare the rate and nature of recovery of independence in ADL participation between stroke survivors who are HIV-positive and those who are HIV-negative on admission, at discharge, and one month after discharge.

### 3.2 Study design

A quantitative, descriptive, comparative research design was used to determine the relationship between the rate and nature of recovery of a sample of stroke survivors who were HIV negative and a sample who were HIV positive (67). The research process is illustrated in Figure 3.2.1

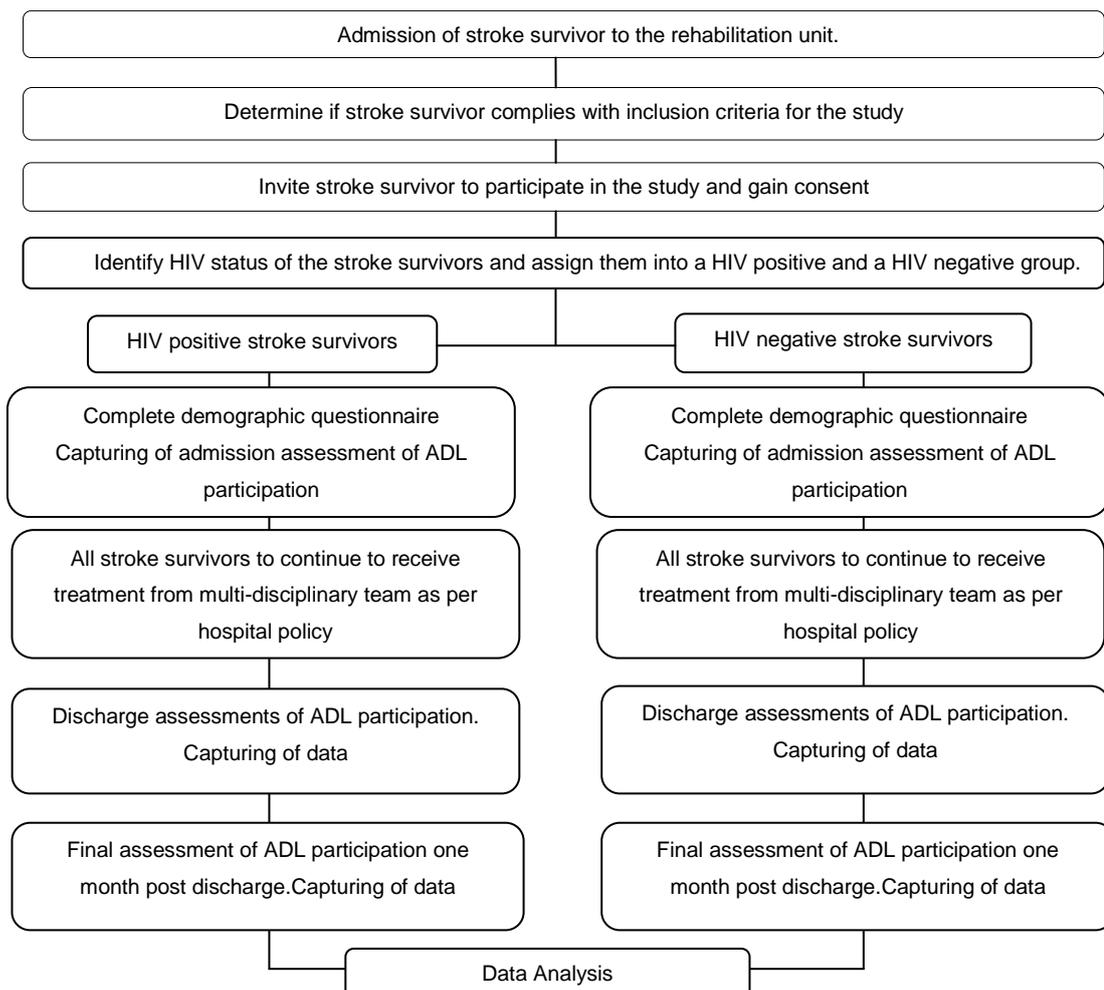


Figure 3.2 1. Flow diagram illustrating the research process

Descriptive data were used to describe the characteristics of the two samples, as well as the similarities and differences between the two groups in terms of the rate and nature of recovery in ADL participation (67). The ADL participation data of the HIV-negative group and the HIV-positive group were then compared with each other. Information within each group was also compared.

### **3.3 Research context**

The research was conducted at Witrand Hospital in Potchefstroom, North West province, South Africa. The province accounts for 6.8% of the country's population. In 2013, cerebrovascular disease was the sixth-leading cause of mortality in the province, and accounted for 4.6% (1644) of deaths in the region (35).

Witrand Hospital is primarily a specialised psychiatric hospital, but also has a physical rehabilitation unit on the premises. The unit consists of 15 beds dedicated to the rehabilitation of patients diagnosed with spinal cord injuries, head injuries or stroke. Stroke survivors are admitted to the unit regardless of their HIV status. This unit is the only one of its kind in the province, and it provides services to both private and public sector patients.

Rehabilitation services are delivered by a team comprising professionals in disciplines such as occupational therapy, physiotherapy, speech and language therapy, and psychology, as well as dieticians, social workers, medical doctors and nursing staff.

### **3.4 Study population**

The study population consisted of all first stroke survivors referred for occupational therapy following admission to the hospital's physical rehabilitation unit between March 2014 and March 2015.

### **3.5 Study sample**

Total population sampling was used as the number of first stroke survivors admitted to Witrand Hospital in a year is small. Between March 2013 and August 2013, 42 stroke survivors were admitted to the rehabilitation unit at this Hospital. This number includes stroke survivors who had their first strokes and those who have suffered previous strokes. Of the 42, 11 were HIV positive (26%). All the stroke survivors admitted to the rehabilitation unit at Witrand Hospital who met the inclusion criteria and agreed to participate in the study were included.

- The inclusion criteria were male or female first stroke survivors between the ages of 20 and 99 years, both HIV positive and HIV negative, admitted to the unit, and who were referred for rehabilitation.
- Stroke survivors were excluded from the study if they had suffered a previous stroke or the stroke was associated with a secondary diagnosis (such as spinal cord injuries, head injuries, tumours, dementia, or encephalopathy).
- The stroke diagnosis was confirmed by a medical doctor from the referring hospital.
- It is a routine hospital requirement for all patients admitted to undergo an HIV test. The hospital HIV counsellors obtained the necessary consent from the stroke survivors or their families before doing the HIV test, and gave the routine counselling. If a stroke survivor refused the HIV test, they were excluded from the study. The results of the tests were kept in envelopes in the stroke survivors' files to ensure confidentiality.

### **3.6 Data collection tools**

The data for the study were collected using a demographic questionnaire and the SADFM database.

#### **3.6.1 Demographic questionnaire**

A demographic questionnaire was developed by the researcher for the purpose of this study. The questionnaire included the stroke survivor's age, race, diagnosis (subtype of stroke), HIV status, co-morbid conditions, level of education, and occupation. A copy of the questionnaire can be found in Appendix G. The research

assistant collected the demographic information to ensure that the researcher remained blinded to the HIV status of the stroke survivors.

### **3.6.2 South African Database for Functional Medicine**

The SADFM (Appendix J) was used to collect the data relating to ADL participation at three points during this study (on admission, discharge, and one month after discharge).

The SADFM is an evidence-based reporting tool developed from the International Classification of Functional Disability & Health Framework (ICF) (61). The SADFM consists of six measurement tools. The first tool is the alpha measuring tool, which measures a person's ability to maintain the functioning of their bodily organs and systems. This tool is commonly used in acute settings. Second is the beta measuring tool, which is commonly used in sub-acute settings to measure a person's ability to care for themselves and the amount of assistance they need. The gamma tool measures a person's ability to live independently. The delta tool measures a person's cognitive functions. The fifth tool is the omega tool, which is used for people receiving palliative care. The last tool, the pressure ulcer healing tool, is used for wound care (61).

As this study focused on a stroke survivor's ability to participate in ADLs, the beta measurement tool was used to collect the data. It measures a person's ability to participate in self-care activities, and the assistance that person requires. Regular scoring records a stroke survivor's progression or regression during these activities over time (61). The beta measurement tool is an outcome measurement tool used routinely in the physical rehabilitation unit to assist therapists to measure the outcomes of the intervention of stroke survivors, and monitor their progress and need for direct care (61).

The beta tool's internal consistency was tested by calculating the Cronbach Alpha coefficient. The internal consistency for admission scores was 0.96 and on discharge it was 0.98, indicating a high to very high internal consistency (61). Using the Rasch measurement model (RMM), the beta measurement tool obtained significant person reliability and item reliability values. The beta subscales are reported to have good

levels of accuracy and predictability. For self-care (eating, dressing and grooming), the Rasch measurement is 0.97/-0.95, and for toileting it is 0.99/-0.93 (61) (69). The Rasch model can be used to determine the internal consistency and reliability of a set of items. The Rasch model requires the data to fit the measurement tool and not the other way around – for example, if the scale scores of a certain measurement tool do not vary between different groups in contrast to other statistical techniques, such as item response theory. It can also be used to determine whether a measurement tool has equal interval-level properties (69) (70).

This study used the beta measurement tool because it enabled the researcher to convert a stroke survivor's ability to participate in ADLs into quantifiable ordinal data.

### **3.7 Data collection process**

A research assistant, one of the physiotherapists working in the unit, was used throughout the study to assist with data collection. She had three years of work experience, and was trained before the research commenced. Training included the explanation of the purpose of the study, the recruitment of participants to the study using the approved information sheet, how to collect the data using the demographic questionnaire, and how to assign the research subjects into the two groups.

The research assistant approached each stroke survivor who met the inclusion requirements (see section 3.5 for the inclusion criteria) for the study on admission. She invited stroke survivors to participate in the research study, used the information sheet (Appendices A and B) to explain the study to the stroke survivors, and obtained the necessary consent (Appendix C). Consent was either given by the stroke survivor themselves, or, if they were unable to give consent due to severe cognitive impairments, the research assistant informed the caregiver of the study (Appendix D) and obtained consent from the stroke survivor's family (Appendix E). If the research assistant was unable to obtain consent from the stroke survivor's family, consent was given by the chief executive of Witrand Hospital (Appendix E).

The research assistant collected the required demographic information (Appendix G) from the patients' hospital records, and captured it on the demographic questionnaire for each patient. The demographic questionnaire included the HIV status of the stroke survivor, and the research assistant used the stroke survivors' HIV status to assign them to the two groups. This ensured that the researcher remained blinded to the HIV status of the stroke survivors.

The researcher, who had received training to ensure the correct use of the SADM beta measurement tool, collected the data. This ensured consistency and thus that the data collected at admission, at discharge, and one month after discharge was valid and reliable.

The first two assessments were completed in the rehabilitation unit. The stroke survivors were observed during their daily routine in the unit for eating, grooming, dressing, toileting, and bathing. The last assessments were completed during the stroke survivors' routine one-month follow-up appointment. A score ranging from one to seven was then awarded to their performance, depending on the scoring protocol. This data were captured on a data collection form, a copy of which can be found in Appendix I.

All the stroke survivors who participated in the study received therapy from the multi-professional team as per the hospital policy, including occupational therapy. Although treatment is individualised for each patient, hospital policy (Appendix K) gives guidelines to therapists. One of the aspects addressed by the occupational therapy programme was ADL participation, including eating, grooming, bathing, toileting, and upper and lower limb dressing. The researcher provided therapy to some of the stroke survivors.

On discharge, the caregivers of the stroke survivors routinely received some training regarding the physical handling of the stroke survivor, how to assist them during ADL activities (according to the stroke survivors' abilities), and were provided with general information on precautions, positioning, and so on. The stroke survivors also received a date for their routine one-month follow-up appointments on the day they were discharged.

Demographic information was kept separate from the data gathered using the beta measurement tool until the end of the study to ensure the researcher remained blind to the patients' HIV status.

### **3.8 Ethical considerations**

Ethical clearance was granted by the Human Research Ethics Committee (Medical) for the University of the Witwatersrand, clearance number M130934 (Appendix L). Consent to conduct the study was also granted by Witrand Hospital and the North West department of health (Appendix M).

The information sheet (Appendices A and B) presented to the participants highlighted certain key ethical issues. Participation in the study was voluntary. The stroke survivor could withdraw from the study at any time without any complications. All information remained confidential. The stroke survivor's confidentiality and anonymity was ensured throughout the study by not writing their name on the demographic questionnaire or the ADL participation data collection form. Each demographic questionnaire and data collection form was allocated a number for capturing and analysis purposes using a participant information sheet (Appendices F) to ensure the demographic information and the data from the three assessments could be linked after all the data was collected.

### **3.9 Data analysis**

All data were captured on two Microsoft Excel spread sheets: one for the HIV-positive group and another for the HIV-negative group.

The researcher used descriptive statistics to describe the demography of the two groups using means, modes, ranges and percentages. As data was not evenly distributed, medians and quartile ranges were used to record central tendencies. The HIV-negative and HIV-positive groups' demographic information were compared to using nonparametric statistics because of the small sample size (20 in the HIV-positive group and 12 in the HIV-negative group) (71) (72). Confidence intervals were

used to determine the difference between the two means(73). When analysing the demographic information of the study sample, the Fisher's exact test was used for the groups that had less than five participants to determine if there were significant differences between the demographic variables of the two groups (71) (72). Differences were determined in age, race, diagnosis, comorbidities, level of education, and occupation.

The three SADFM beta data ratings for each subject were also recorded to determine differences between the rate and nature of recovery of the HIV-positive group and the HIV-negative group. Nonparametric statistics were used to compare the ADL participation of the two groups as a result of the small sample sizes (71) (72). The Mann-Whitney U test was used to compare the ordinal data to establish significant differences between the two groups negative group) (71) (72).

Comparisons were investigated within the two groups over the three assessment periods. The Friedman ANOVA test and Kendall's Coefficient of Concordance were also used. These are also nonparametric tests used to determine significant differences within the groups over the three assessments periods (71) (72).

Effect size was used to quantify the size of the difference between two groups at the three periods to determine whether there was a clinically relevant difference between the two groups, and was determined using Cohen's *d* (71) (72). The HIV-negative and HIV-positive groups were compared to determine whether there was a difference between the rate and nature of recovery in the two groups.

## CHAPTER 4: RESULTS

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### 4.1 Introduction

The results of this study are reported in two parts. The demographic characteristics of the participants are reported first. Then the ADL participation of the stroke survivors, as measured on the beta measurement tool of the SADFM at the three intervals, are reported in accordance with the first objective: to determine the ability of stroke survivors who are HIV-positive to participate independently in ADLs on admission, at discharge, and one month after discharge. This is followed by the second objective: to determine the ability of stroke survivors who are HIV-negative to participate in ADLs on admission, at discharge, and one month after discharge. Finally the ADL performance of the two groups is compared as set out in the third objective: to compare the ability of stroke survivors who are HIV-positive and HIV-negative to participate in dependently in ADLs on admission, at discharge, and one month after discharge so as to determine the change in the rate and nature of recovery at each interval.

### 4.2 Demographic characteristics of the stroke survivors

The study sample consisted of 32 stroke survivors: 20 HIV negative and 12 HIV positive.

In the HIV-positive group, there were three stroke survivors who did not attend their last assessment. Their data were still included in the study, and therefore the study sample of the HIV-positive group conducted on admission and discharge was 12, whereas the study sample at the one month after discharge was 9.

#### 4.2.1 Age of sample

Figure 4.2.1 illustrates the age distribution between the two groups. The mode of the age band of the HIV-negative group was 50-59 (n = 9), and in the HIV-positive group it was 40-49 (n = 6).

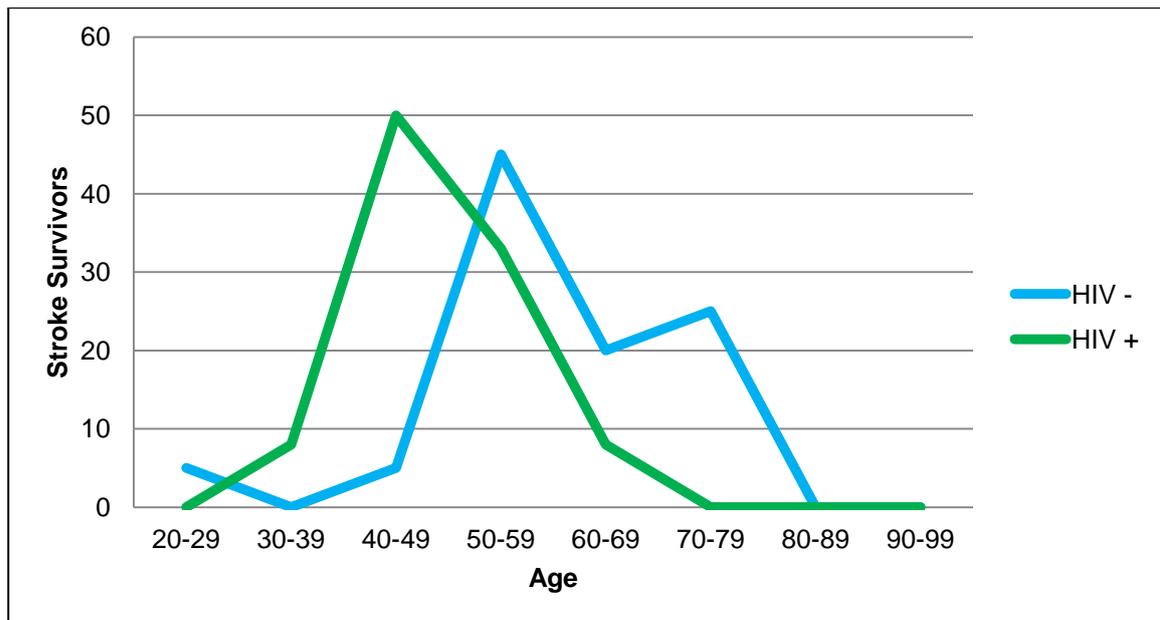


Figure 4.2.1. Age distribution between the two study groups

There was a statistically significant difference between the ages of the HIV-negative and the HIV-positive group, where  $p=0.001$ , suggesting that HIV-positive stroke survivors are younger than HIV-negative stroke survivors.

#### 4.2.2 Gender of sample

The HIV-negative group consisted of 75% males ( $n=15$ ) and 25% females ( $n=5$ ), whereas the HIV-positive population was 50% males ( $n=6$ ) and 50% females ( $n=6$ ). There is a statistically significant difference between the gender of the HIV-positive and HIV-negative group  $p=0.014$ .

#### 4.2.3 Race distribution within the sample

Figure 4.2.2 illustrates the racial distribution within the study sample. In the HIV-negative group, 65% were black ( $n=13$ ), 25% white ( $n=5$ ), and 10% coloured ( $n=2$ ). The racial distribution in the HIV-positive group was 50% black ( $n=6$ ) and 50% white ( $n=6$ ). There was no statistical difference in racial distribution between the HIV-negative and HIV-positive group.

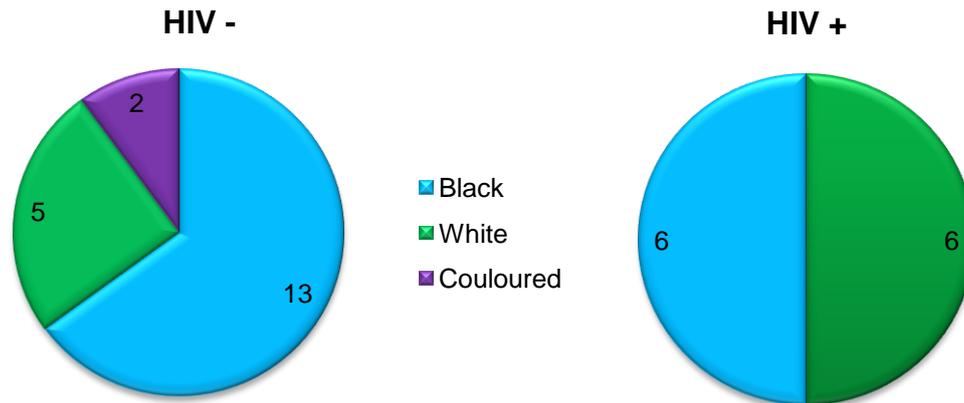


Figure 4.2.2. Race distribution of the two groups

#### 4.2.4 Educational status of the sample

In the HIV-negative group (n=20), 5% of the participants had a degree (n=1), 25% had no schooling (n=5), 30% had primary school as their highest level of education (n=6), and 40% had a diploma (n=8). In the HIV-positive group (n=12), 8% had a diploma (n=1), 42% had primary school as their highest level of education (n=5), and 50% had high school as their highest level of education (n=6).

#### 4.2.5 Work status of participants in the sample

In the HIV-negative group (n=20), 5% were domestic workers (n=1), 10% were administration workers (n=2), 30% were manual workers (n=6), and 55% had no current employment (n=11), either being unemployed or on pension. In the HIV-positive group (n=12), 8% were mineworkers (n=1), 8% were domestic workers (n=1), 17% were administrative workers (n=2), 25% were manual labourers (n=3), and 41% were unemployed (n=5).

#### 4.2.6 Types of stroke

Of the stroke survivors in the total sample (n = 32), 34% (n=11) suffered a haemorrhagic stroke and 66% an infarct (n=21). In the HIV-negative group (n=20), 25% suffered a haemorrhagic stroke (n=5) and 75% suffered an infarct stroke (n=15), as shown in Figure 4.2.3. In the HIV-positive group, an equal number suffered infarct and haemorrhagic strokes. Although more stroke survivors in the HIV-positive group

had haemorrhagic strokes, there was no statistical difference ( $p=0.250$ ) between the groups.

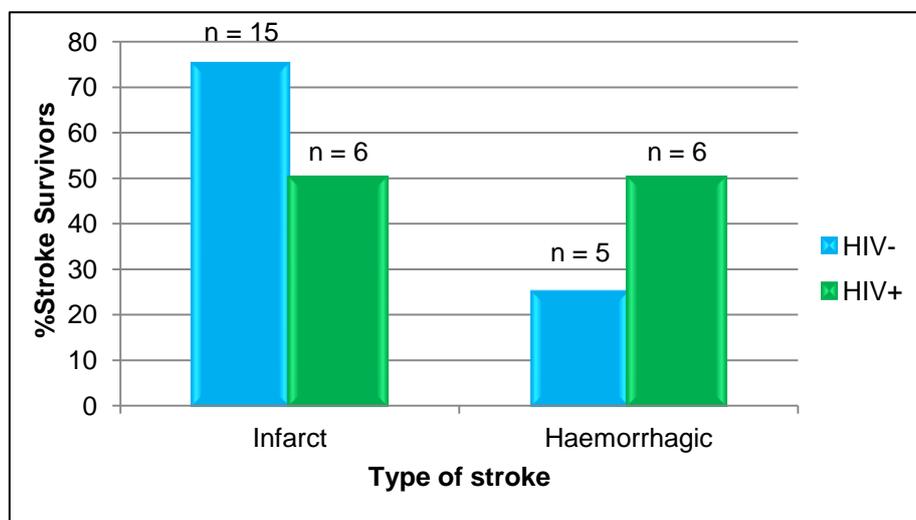


Figure 4.2.3. Stroke types within the study sample

Of the 32 stroke survivors within the total sample, 47% had a left hemispheric lesion (n=15) and 53% had a right hemispheric lesion (n=17). In the HIV-negative group, 45% had a right hemispheric lesion (n=9) and 55% had a left hemispheric lesion (n=11). In the HIV-positive group, 33%(n=4) had a left hemispheric lesion and 66% (n=8) had a right hemispheric lesion. Although there was no statistical difference between the HIV-negative and the HIV-positive groups ( $p=0.231$ ), there appears to be a trend of a higher prevalence of right hemispheric lesions in the HIV-positive group.

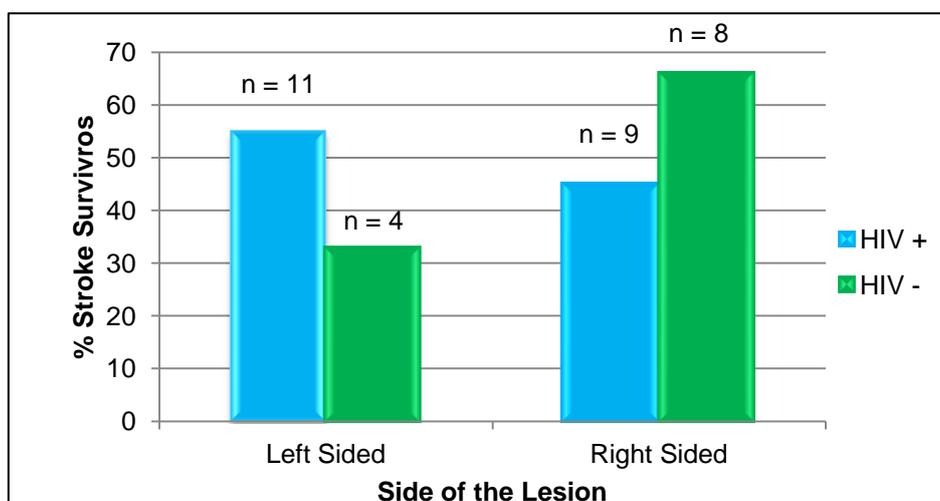


Figure 4.2.4 Hemispheric lesions within the study sample

#### 4.2.7 Risk factors

The majority of stroke survivors in the total sample (69%) had hypertension as a risk factor ( $n = 22$ ). Figure 4.2.4 illustrates the distribution of risk factors within the two groups. In the HIV-negative group, the risk factors with the lowest prevalence were being overweight with 15% ( $n=3$ ) and diabetes with 15% ( $n=3$ ). The most prevalent risk factor in this group was hypertension, and accounted for 85% of the risk factor in this group ( $n=17$ ). In the HIV-positive group, the risk factor with the lowest prevalence was other risk factors, which accounted for 17% ( $n=2$ ); diabetes and being overweight both accounted for 25% ( $n=3$ ), and hypertension was the highest risk factor, accounting for 43% ( $n=5$ ). No statistical difference was found between the two groups, but smoking ( $p = 0.696$ ), being overweight ( $p = 0.647$ ) and diabetes ( $p = 0.647$ ) were more prevalent in the HIV-positive group

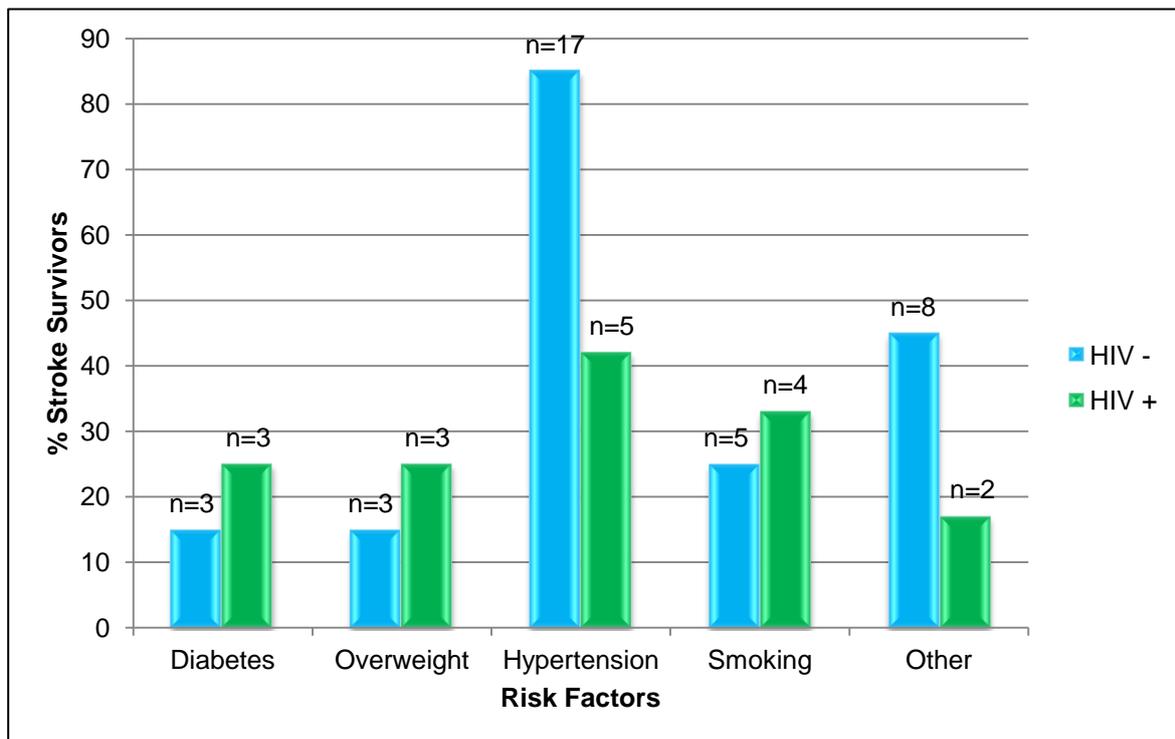


Figure 4.2.5 Distribution of risk factors between the study sample

#### 4.2 Rate and nature of recovery of HIV-positive stroke survivors

Table 4.2 illustrates the median and minimum and maximum scores of the HIV-positive group on admission, discharge, and one month after discharge. On admission, the HIV-positive group needed the most assistance with toileting and the least assistance with eating. All the scores improved from admission to discharge.

On discharge, the HIV-positive group still needed the most assistance with toileting and the least assistance with upper limb dressing. One month after discharge, the HIV-positive group needed the most assistance with washing and the least assistance with toileting. There was a decrease in the mean score in all ADLs in this group.

**Table 4.2. The scores of the HIV positive group over the three periods**

	<b>HIV-positive stroke survivors on admission (n=12)</b>	<b>HIV-positive stroke survivors on discharge (n=12)</b>	<b>HIV-positive stroke survivors one month after discharge (n=9)</b>
	<b>Mean score on admission (minimum and maximum score)</b>	<b>Mean score on discharge (minimum and maximum score)</b>	<b>Mean score one month after discharge (minimum and maximum score)</b>
<b>Eating</b>	4.33 (2.00 – 5.00)	6.08 (3.00 – 7.00)	4.58 (0.00 – 7.00)
<b>Grooming</b>	3.25 (2.00 – 5.00)	5.50 (3.00 – 7.00)	4.33 (0.00 – 7.00)
<b>Upper limb dressing</b>	3.00 (1.00 – 6.00)	5.50 (3.00 – 7.00)	4.50 (0.00 – 7.00)
<b>Lower limb dressing</b>	2.66 (1.00 – 6.00)	5.33 (2.00 – 7.00)	4.08 (0.00 – 7.00)
<b>Washing</b>	2.41 (1.00 – 5.00)	4.66 (2.00 – 7.00)	3.66 (0.00 – 7.00)
<b>Toileting</b>	2.25 (1.00 – 5.00)	4.91 (1.00 – 7.00)	4.08 (0.00 – 7.00)

### **4.3 Rate and nature of recovery of HIV-negative stroke survivors**

Table 4.3 illustrates the median and minimum and maximum scores of the HIV-negative group on admission, discharge, and one month after discharge. On discharge, the HIV-negative group needed the most assistance with washing and the least assistance with toileting. All scores continued to improve from admission, although there was a slight decrease in scores in upper limb dressing from discharge to one month after discharge. On discharge, the HIV-negative group still needed the most assistance with washing and the least with eating. The HIV-negative group

needed the most assistance with washing and the least assistance with eating one month after discharge.

**Table 4.3.: The scores of the HIV negative group over the three periods**

	<b>HIV-negative stroke survivors on admission (n=20)</b>	<b>HIV-negative stroke survivors on discharge (n=20)</b>	<b>HIV-negative stroke survivors one month after discharge (n=20)</b>
	<b>Mean score on admission (minimum and maximum score)</b>	<b>Mean score on discharge (minimum and maximum score)</b>	<b>Mean score one month post discharge (minimum and maximum score)</b>
<b>Eating</b>	4.10 (2.00 – 7.00)	5.65 (3.00 – 7.00)	6.15 (3.00 – 7.00)
<b>Grooming</b>	3.00 (1.00 – 5.00)	5.05 (2.00 – 7.00)	5.80 (2.00 – 7.00)
<b>Upper limb dressing</b>	2.45 (1.00 – 5.00)	5.40 (2.00 – 7.00)	5.25 (1.00 – 7.00)
<b>Lower limb dressing</b>	2.30 (1.00 – 5.00)	5.05 (1.00 – 7.00)	5.45 (1.00 – 7.00)
<b>Washing</b>	2.15 (1.00 – 5.00)	4.05 (2.00 – 7.00)	4.45 (1.00 – 7.00)
<b>Toileting</b>	2.20 (1.00 – 5.00)	4.75 (1.00 – 7.00)	5.20 (1.00 – 7.00)

#### **4.4 Comparison of the scores of the HIV-positive and HIV-negative groups**

##### **4.4.1 Activities of daily living scores on admission**

Table 4.4 illustrates the mean admission scores in the ADLs of the HIV-negative and HIV-positive groups. It can be seen that the scores of both groups are similar, but that the HIV-positive group scored 0.5 higher on two of the ADL variables. When the admission scores of the HIV-positive and HIV-negative groups were compared, no statistical difference was found between them.

##### **4.4.2 Activities of daily living scores on discharge**

Table 4.4 illustrates the ADL scores of the two groups at discharge. Again, the scores are very similar, but the HIV-positive group scored 0.5 higher on all scores except

washing. There was no statistical significant difference between the scores of the HIV-negative and HIV-positive groups on discharge.

#### **4.4.3 Activities of daily living scores one month after discharge**

Table 4.4 illustrates the scores of the two groups one month after discharge. In this case, the HIV-negative group scored higher on four variables: 05 on eating, 1 on dressing, 1.5 on grooming, and 2 on toileting. However, this was also not significantly statistically different.

There was a statistically significant improvement in both groups in the ability to participate in all ADLs when the admission scores were compared to their scores at discharge. Table 4.4 illustrates the *p* values of each ADL for the different groups.

#### **4.5 Rate and nature of change in activities of daily living scores over time**

There was a statistical significant improvement in HIV-negative group's ability to participate in all ADLs when the admission scores were compared to their scores at one month after discharge. When the scores of the HIV-positive group were compared on admission and one month after discharge, there was only a statistically significant improvement found in toileting. Table 4.5 illustrates the *p* values of each ADL for the different groups.

When the two groups' scores on discharge and one month after discharge were compared, the HIV-negative group showed a statistically significant improvement in grooming. There was no statistically significant improvement in the other items. Table 4.6 illustrates the *p* values of each ADL for the different groups.

When the improvement of the two groups was compared between discharge and one month after discharge, more improvement was noted in the HIV-negative group. This improvement was statistically significant, as illustrated in Table 4.6.

Table 4.7 illustrates the effect size and confidence intervals between the two groups through a comparison of their improvement between admission and one month after discharge, although there was again no statistically significant difference.

The improvement in the two groups was also compared on discharge and one month after discharge. More improvement was noted in the HIV-negative group during this period. This difference was statistically significant, as illustrated in Table 4.7.

#### **4.6 Conclusion**

Demographic details were collected for the different groups to determine the integrity of the sample. This is discussed in detail in Chapter 5. On admission, the HIV-positive group needed assistance with all of their ADLs. There was an improvement in all their ADL scores between admission and discharge. However, one month after discharge, there was a decline in all scores in the HIV-positive group. The HIV-negative group also needed assistance with all of their ADLs on admission, and also showed improvement in all their scores between admission and discharge. This group also showed more improvement one month after discharged, although there was a slight decrease in scores for upper limb dressing. No statistically significant difference was found between the two groups between admission and discharge. When the two groups' ability to perform ADLs one month after discharge were compared, statistically significant differences were noted, the most significant being the rate and nature of change in the two groups. These findings are discussed in detail in Chapter 5.

Table 4.4 Comparison of scores between the two groups over the three periods

	Admission			Discharge			One month after discharge		
	HIV positive (n=12)	HIV negative (n=20)	<i>p</i> value (Mann-Whitney U test)	HIV positive (n=12)	HIV negative (n=20)	<i>p</i> value (Mann-Whitney U test)	HIV negative (n=20)	HIV positive (n=9)	<i>p</i> value (Mann-Whitney U test)
	Mean score (minimum and maximum score)	Mean score (minimum and maximum score)		Mean score (minimum and maximum score)	Mean score (minimum and maximum score)		Mean score (minimum and maximum)	Mean score (minimum and maximum)	
<b>Eating</b>	4.33 (2.00 – 5.00)	4.10 (2.00 – 7.00)	0.27	6.08 (3.00 – 7.00)	5.65 (3.00 – 7.00)	0.24	6.15 (3.00 – 7.00)	4.58 (0.00 – 7.00)	0.23
<b>Grooming</b>	3.25 (2.00 – 5.00)	3.00 (1.00 – 5.00)	0.57	5.50 (3.00 – 7.00)	5.05 (2.00 – 7.00)	0.42	5.80 (2.00 – 7.00)	4.33 (0.00 – 7.00)	0.22
<b>Upper limb dressing</b>	3.00 (1.00 – 6.00)	2.45 (1.00 – 5.00)	0.29	5.50 (3.00 – 7.00)	5.40 (2.00 – 7.00)	0.73	5.25 (1.00 – 7.00)	4.50 (0.00 – 7.00)	0.73
<b>Lower limb dressing</b>	2.66 (1.00 – 6.00)	2.30 (1.00 – 5.00)	0.75	5.33 (2.00 – 7.00)	5.05 (1.00 – 7.00)	0.48	5.45 (1.00 – 7.00)	4.08 (0.00 – 7.00)	0.28
<b>Washing</b>	2.41 (1.00 – 5.00)	2.15 (1.00 – 5.00)	0.53	4.66 (2.00 – 7.00)	4.05 (2.00 – 7.00)	0.33	4.45 (1.00 – 7.00)	3.66 (0.00 – 7.00)	0.47
<b>Toileting</b>	2.25 (1.00 – 5.00)	2.20 (1.00 – 5.00)	0.86	4.91 (1.00 – 7.00)	4.75 (1.00 – 7.00)	0.84	5.20 (1.00 – 7.00)	4.08 (0.00 – 7.00)	0.33

Table 4.5 Rate and nature of change in ADL scores on admission and one month post discharge

		HIV negative		HIV positive	
		Scores on admission and one month after discharge ( <i>p</i> value)	Mean on admission and one month after discharge (minimum and maximum scores)	Scores on admission and one month after discharge ( <i>p</i> value)	Mean on admission and one month after discharge (minimum and maximum scores)
-Comparison between HIV-positive and HIV-negative groups on admission and one month after discharge	Eating	0.000	4.10 (2.00 – 7.00)	0.959	4.33 (2.00 – 5.00)
			6.15 (3.00 – 7.00)		4.58 (0.00 – 7.00)
	Grooming	0.000	3.00 (1.00 – 5.00)	0.230	3.25 (2.00 – 5.00)
			5.80 (2.00 – 7.00)		4.33 (0.00 – 7.00)
	Upper limb dressing	0.000	2.45 (1.00 – 5.00)	0.109	3.00 (1.00 – 6.00)
			5.25 (2.00 – 7.00)		4.50 (0.00 – 7.00)
	Lower limb dressing	0.000	2.30 (1.00 – 5.00)	0.091	2.66 (1.00 – 6.00)
			5.45 (1.00 – 7.00)		4.08 (1.00 – 7.00)
	Washing	0.000	2.15 (1.00 – 5.00)	0.114	2.41 (1.00 – 5.00)
			4.45 (1.00 – 7.00)		3.66 (1.00 – 7.00)
	Toileting	0.000	2.20 (1.00 – 5.00)	0.029	2.25 (1.00 – 5.00)
			5.20 (1.00 – 7.00)		4.08 (1.00 – 7.00)

Table 4.6. Rate and nature of change in ADL scores from discharge to one month post discharge

		HIV negative		HIV positive	
		Scores on discharge and one month after discharge (p value)	Mean on discharge and one month after discharge (minimum and maximum scores)	Scores on admission and one month after discharge (p value)	Mean on discharge and one month after discharge (minimum and maximum scores)
<b>-Comparison between HIV-positive and HIV-negative groups on discharge and one month after discharge</b>	<b>Eating</b>	0.132	5.65 (3.00 – 7.00)	0.176	6.08 (3.00 – 7.00)
			6.15 (3.00 – 7.00)		4.58 (1.00 – 7.00)
	<b>Grooming</b>	<b>0.020</b>	5.05 (2.00 – 7.00)	0.332	5.50 (3.00 – 7.00)
			5.80 (2.00 – 7.00)		4.33 (1.00 – 7.00)
	<b>Upper limb dressing</b>	0.722	5.40 (2.00 – 7.00)	0.367	5.50 (3.00 – 7.00)
			5.25 (2.00 – 7.00)		4.50 (0.00 – 7.00)
	<b>Lower limb dressing</b>	0.463	5.05 (1.00 – 7.00)	0.150	5.33 (2.00 – 7.00)
			5.45 (1.00 – 7.00)		4.08 (1.00 – 7.00)
	<b>Washing</b>	0.378	4.05 (2.00 – 7.00)	0.248	4.66 (2.00 – 7.00)
			4.45 (1.00 – 7.00)		3.66 (1.00 – 7.00)
	<b>Toileting</b>	0.248	4.75 (1.00 – 7.00)	0.441	4.91 (1.00 – 7.00)
			5.20 (1.00 – 7.00)		4.08 (1.00 – 7.00)

Table 4.7: Effect size and confidence intervals between the two groups

	Admission to one month after discharge		Admission to discharge		Discharge to one month after discharge	
	Effect size (Cohen's <i>d</i> )	Confidence intervals	Effect size (Cohen's <i>d</i> )	Confidence intervals	Effect size (Cohen's <i>d</i> )	Confidence intervals
<b>Eating</b>	<b>1.72</b>	0.26 – 3.18	-0.2	-0.93 – 0.53	<b>1.83</b>	0.28 – 3.38
<b>Grooming</b>	<b>1.69</b>	0.32 – 3.06	-0.2	-1.03 – 0.63	<b>1.75</b>	0.21 – 3.29
<b>Upper limb dressing</b>	<b>1.25</b>	-0.44 – 2.94	0.45	-0.64 – 1.54	<b>2.25</b>	0.75 – 3.75
<b>Lower limb dressing</b>	<b>1.71</b>	0.02 – 3.40	0.09	-1.14 – 1.32	<b>1.40</b>	-0.18 – 2.98
<b>Washing</b>	<b>1.19</b>	-0.36 – 2.74	- 0.35	-1.31 – 0.61	<b>1.25</b>	-1.10 – 3.60
<b>Toileting</b>	<b>1.34</b>	-0.27 - 2.95	-0.11	-1.29 – 1.07	<b>1.00</b>	-0.68 – 2.68

## CHAPTER 5: DISCUSSION

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### 5.1 Introduction

The discussion aims to comment on the findings and compare them to other studies. The findings will be considered in relation to a clinical setting, and suggestions will be made on how these findings may be used by occupational therapists treating such patients' demographic characteristics will be discussed to determine the integrity of the sample and then the rate and nature of recovery of the HIV-positive and HIV-negative group will be considered and discussed separately. Finally, the rate and nature of the two groups will be compared to discuss the difference in the rate and nature of recovery, and the possible implications of this on the rehabilitation of HIV-positive stroke survivors.

### 5.2 Demographic characteristics of the stroke survivors

The study sample consisted of 32 stroke survivors: 20 HIV-negative and 12 HIV-positive stroke survivors. The study sample was collected over a period of one year, and not six months as initially planned. The reason for this was that fewer than expected HIV-positive stroke survivors were admitted to the unit during this time, and some of the HIV-positive stroke survivors were excluded from the study because they did not meet the inclusion criteria. This correlates with the referral pattern of the unit. More HIV-negative stroke survivors were admitted to the unit than HIV-positive stroke survivors. The ratio of HIV negative to HIV positive patients compared well with another study conducted at Witrand Hospital which showed more HIV negative stroke survivors compared to HIV positive stroke survivors (50). Even though the two groups were not of equal size, the study sample was still representative of the population of stroke survivors at Witrand Hospital.

The HIV-positive group was about 10 years younger than the HIV-negative group. This is in keeping with other studies. A study conducted in 2006 in the United States found that HIV-positive stroke survivors had a median age of 48.4, and a South

African study found the median age of HIV-positive stroke survivors to be even younger at 33.4 (13). In sub-Saharan Africa, the incidence of stroke is higher in the younger age group (35-54) (16). The highest incident of stroke in this study group was in the 40-49 age range in the HIV-positive group, and 50-59 in the HIV-negative group.

Of the total sample for this study, there were more male stroke survivors than female stroke survivors. Other research showed similar results, where the prevalence of stroke was higher in males than females (50). The HIV-negative group followed the same trend, with the group consisting of more males than females. The study sample of another study conducted at Witrand Hospital had the same findings, and also found that there were more females than males in the HIV-positive group (50). However, there was no difference in gender spread in the HIV-positive group in this study. This was interesting because it was expected that there would be more female stroke survivors in this group as literature indicates that the prevalence of HIV is higher in females in sub-Saharan Africa (48). A reason for this could be the small sample size of this study and the referral pattern of the hospital for the duration of the study.

In the total sample for this study, there were more black stroke survivors than white stroke survivors. This was the case in the HIV-negative group, and correlates with other research that shows stroke is more prevalent in black people than white people (5) (8). One of the reasons for this is the fact that hypertension is more prevalent among black people (8). The HIV-positive group had the same number of black and white stroke survivors. Despite this, there was no statistically significant difference between the racial distribution in the two groups in this study. This unexpected because the incidence of HIV and stroke in the black population is higher than in other race groups (49). A previous study conducted at Witrand Hospital also had more black stroke survivors in the HIV-negative group, but there were only black stroke survivors in the HIV-positive group even though the study had a larger sample (50).

More stroke survivors were employed in the HIV-negative group than in the HIV-positive group. The majority of stroke survivors in both groups were unemployed. In

the HIV-negative group 55% had no current employment and in the HIV-positive group 41% were unemployed. These figures included stroke survivors not currently employed, as well as those on pension. The unemployment figures are higher than the unemployment rate of the North West province of 25.2% this can be explained by the progressed age of the stroke survivors. The unemployment rate for the North West province in 2014 was 25.2% (74).

Literature reports that ischaemic strokes have a higher prevalence than haemorrhagic strokes (1) (2) (8) (28). The prevalence of ischaemic strokes is even higher in the HIV-positive population. The incidence of ischemic strokes is 5.75 per 1000 people in the HIV-positive population compared to 3.75 in the HIV-negative population (1) (29). In this study sample, there was no statistically significant difference between the different types of strokes in the HIV-positive and HIV-negative groups. The reason for this might be that ischaemic strokes were more prevalent in both groups.

In the total sample, more stroke survivors had suffered a right hemispheric lesion. However, in the HIV-negative group, more stroke survivors had left hemispheric lesions. There was no statistically significant difference between the two groups regarding the hemispheric side of the lesion. The HIV-positive group had a higher prevalence of right hemisphere strokes. This might have an influence on the prognosis of this group as there is research indicating that a right-sided lesion might have a poorer prognosis (23). Impaired perceptual and cognitive impairments resulting from these strokes influence the ability of a stroke survivor to learn compensatory techniques and improve their functional ability to perform ADLs.

In both groups, hypertension was the most prevalent risk factor. Hypertension was also found to be the most prevalent risk factor in other studies conducted in South Africa, where the prevalence of hypertension in stroke survivors was 55% (5) (8) (33). When the prevalence of hypertension was compared to another study conducted at Witrand Hospital, it was higher in the sample of this study: the prevalence of hypertension in the previous study was 34.8% in the HIV-positive group compared to 85% in this study (50). In the previous study, in the HIV-negative

group, 31.4% of stroke survivors were diagnosed with hypertension compared to 43% in this study (50).

HIV can be seen as an independent predictor for stroke (53). Risk factors for stroke among the HIV positive population may differ from the non-affected population, and the effects of HIV and ARV medication must always be considered (13) (54). Some difference in the risk profile of the two groups would have been expected, but there was no statistically significant difference between the HIV-positive and the HIV-negative groups in this study. There was, however a higher prevalence of smoking, obesity and diabetes in the HIV-positive group.

### **5.3 Rate and nature of recovery of HIV-positive stroke survivors**

It is important for occupational therapists to have a good understanding of the rate and nature of recovery of stroke as this has an influence on treatment. This will assist the occupational therapist in choosing treatment goals, and will enable the occupational therapist to determine the stroke survivors' prognosis, which might influence the type of therapy (rehabilitative or compensatory), the length of stay in hospital, and whether the stroke survivor will continue treatment after discharge or only receive a home treatment programme.

On admission, this group needed physical assistance from someone with all their ADLs (based on their SADFM scores), particularly with lower limb dressing, washing and toileting, as they were able to do less than 50% of these tasks independently. This was expected, and is consistent with the researcher's clinical experience and literature, which also demonstrates that one week after experiencing a stroke, a stroke survivor is usually 58% dependent (41). A study conducted at Witrand Hospital that also used the SADFM, looked at the combined scores of HIV-positive stroke survivors on admission, but did not separate the scores. In this study the stroke survivors also needed more than 50% assistance with their ADLs on admission to the rehabilitation unit (50).

On discharge, the stroke survivors still needed physical assistance (based on their SADFM scores), although there was improvement in all the different ADL activities

between admission and discharge. They needed the most assistance with toileting and washing, and the least assistance with eating. This correlates well with literature, which indicates that more complex skills takes longer to improve (40). The rate and nature of recovery of the HIV-positive stroke survivors seems to be the same during this period, when compared to the HIV-negative group.

One month after discharge the HIV-positive stroke survivors' showed a decreased ability to perform their ADLs independently as they needed more assistance with their ADLs compared to their ability on discharge. There was a decline in their performance for all ADL activities except toileting, in which all of the stroke survivors were independent. These findings were unexpected, as some improvement was still expected. The recovery of stroke survivors is characterised by the most improvement during the first three months after the stroke, and between three and six months, improvement starts to plateau (40). A more spontaneous recovery was also expected, because the HIV-positive group was younger and should have greater neural plasticity. Younger age is seen as an indicator for good prognosis (40).

There was a trend indicating right hemispheric lesions to be more prevalent in the HIV-positive group. Evidence is found in literature indicating that a stroke survivor with a right-sided lesion might have a poorer prognosis (23). This poorer outcome has been reported to be related to perceptual and cognitive impairments influencing a stroke survivor's ability to relearn and regain function (1) (23) (31). There is some evidence indicating a decline in activity participation of between 15% and 25% of stroke survivors (6) (40), but this evidence is based on HIV-negative stroke survivors.

There appears to be a difference in the rate and nature of recovery between HIV-positive and HIV-negative stroke survivors, specifically one month after discharge. One possible explanation for this is that the recovery of HIV-positive stroke survivors plateaus earlier, although more research is needed to confirm this. Another aspect that must be considered to try to explain this finding is to look at the CD4 count of the stroke survivors and how this influences their ability to perform ADLs. Occupational therapists need to take this into consideration when they plan to discharge HIV-positive stroke survivors. Family support for the stroke survivors is hugely important, and they might need more regular follow-ups. It is also very important to train their

families on how to implement the home programme to try to maintain the stroke survivors' level of function after discharge, or to assist with further improvement.

#### **5.4 Rate and nature of recovery of HIV-negative stroke survivors**

On admission, the stroke survivors in the HIV-negative group needed assistance with all their ADL activities, particularly with upper and lower limb dressing and toileting. They were only able to do less than 50% of these tasks according to the SADFM scores.

On discharge, these stroke survivors still needed assistance with washing and toileting, but they were able to complete more than 75% of the tasks independently. With the rest of the ADLs, they only needed setting up, cueing or supervision. There was improvement in all of their ADLs between admission and discharge.

There was further improvement in all their ADLs between discharge and one month after discharge, except for upper limb dressing. They also still needed assistance with washing (they were able to do 75% of the task independently).

This correlates with other research regarding the pattern of recovery for participation in ADLs. More complex activities such as dressing take longer to improve than activities for which it is easier to apply compensatory strategies, such as grooming (40). A stroke survivor's dependence decreases to 58% one week after suffering a stroke, and their dependence further decreases to just 9% after six months (41).

The HIV-negative group also presented with more left hemispheric lesions, which generally have a better prognosis than right hemispheric lesions. The rate and nature of the recovery of the HIV-negative group correlates well with other studies

#### **5.5 Comparison of the rate and nature of recovery between the HIV-positive and HIV-negative groups**

The rate and nature of recovery can be directly linked to the ability of the stroke survivor to participate in ADL's. By comparing the rate and nature of recovery

between the two groups a conclusion can be made regarding the influence HIV has on the stroke survivor's ability to participate in ADL's. This will now be discussed further.

When the admission scores of the HIV-positive and HIV-negative groups were compared, there was no statistically significant difference between the scores. This indicates that the ability of stroke survivors to perform ADLs was the same in both groups. The severity of cerebral damage can be used to determine the prognosis for the recovery on admission (2) (42). Based on this it can be assumed that differences in scores that were derived during the study cannot be attributed to the initial severity.

There was also no statistically significant difference between the scores of the HIV-positive and HIV-negative groups on discharge. The rate and nature of HIV-positive and HIV-negative groups between admission and discharge remained the same. An important factor that needs to be investigated, but that was not part of this study is the length of stay of the stroke survivors in the rehabilitation unit. However, the previous study conducted at Witrand Hospital found no statistically significant difference in the length of stay between HIV-positive and HIV-negative stroke survivors (50).

There was a statistically significant difference between admission scores and discharge scores in both the HIV-positive and HIV-negative groups, indicating that there was improvement in both groups. This improvement can be attributed to spontaneous neurological recovery as a result of neuroplasticity (40), and the therapy stroke survivors received during their admission. A systematic review of randomised trials indicated that stroke survivors who received occupational therapy were more independent in their ADLs than stroke survivors who did not receive occupational therapy (25). Studies also suggest that stroke survivors who receive early intervention have more favourable ADL outcomes (1) (66).

More improvement was noted in the HIV-negative group during the period between discharge and one month after discharge than in the HIV-positive group. There is no definitive explanation for this, but HIV is seen as an indicator for poor prognosis in

stroke patients (42). One aspect that needs to be investigated is the relationship between the CD4 count of the stroke survivors and their recovery. The presence of HIV-associated dementia, which would affect their cognitive functioning, may also lead to impaired recovery. It is reported that 50% of HIV-positive stroke survivors have cognitive impairments (44), which include impaired memory and concentration, slow processing of information, impaired ability to learn, and impaired executive functioning (43) (45). These impairments are very likely to affect an HIV-positive stroke survivor's ability to perform ADLs and participate in rehabilitation. The presence of HIV might also cause the stroke survivors to plateau in their improvement sooner than stroke survivors who are HIV-negative. Again further research is necessary to investigate this.

It might also be possible that the hospital environment is more conducive for stroke survivors' recovery than a home environment, as their families may not encourage independence but rather assist them with all of their ADLs. This aspect also requires further investigation.

Another explanation for the poorer performance in the HIV positive group may be the trend in the HIV-positive group indicating a higher prevalence of right hemispheric lesions. There is some evidence indicating that stroke survivors with a right-sided lesion might have a poorer prognosis (23). This has been reported to be related to perceptual impairments, anosognosia, and other cognitive impairments commonly associated with right hemisphere lesions. These impairments have an influence on a stroke survivor's ability to regain function (23).

## **5.6 Limitations of the study**

The sample size of the study was small and therefore generalisation of the results must be made with caution. The study was also limited to only one hospital. A study using stroke survivors from different hospitals and with a bigger sample would provide more definitive results.

A difference between the two groups was noticed after discharge. There is limited research available regarding the effect of HIV on the rate and nature of stroke

recovery and the outcome of ADLs, further investigation are necessary to investigate this further.

The relationship between CD4 count and ADL performance was not included in the study. HIV associated dementia was also not considered during this study. Both these aspects might have an influence on the rate and nature of recovery of the HIV positive stroke survivors.

## CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS

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### 6.1 Conclusions

It is important for occupational therapists to note that, according to this study, there is no difference between the rate and nature of recovery between HIV-positive and HIV-negative stroke survivors between admission and discharge. The clinical implication of this is that the treatment of HIV-positive stroke survivors does not need to be different than the treatment of HIV-negative stroke survivors. HIV-positive stroke survivors might have more cognitive and perceptual impairments than HIV-negative stroke survivors, but improvement was still noted as a result of spontaneous recovery through neuralplasticity and the therapy they received.

The biggest difference between the groups is noticeable after discharge. Discharge planning is important for this group. More regular follow-ups might be needed for these stroke survivors, and accordingly, it is recommended that they be included in an outpatient treatment programme. Family training is essential to ensure that the family is able to implement the home treatment programme to further improve the stroke survivors' functioning, or to maintain their current functioning.

### 6.2 Recommendations

The same study with a larger sample size and the same number of stroke survivors in both groups would provide more definitive results.

Further investigation is also needed to determine why the HIV-positive group had a decline in function one month after discharge. More detailed information is also needed about possible factors influencing prognosis, such as CD4 count and presence of HIV-associated dementia. The post-discharge assessment can also be extended to three months to a year to provide more comprehensive information on stroke survivors' abilities to participate in ADLs after suffering a stroke.

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## Appendix A: Information sheet for participants (HIV-negative)

### Occupational Therapy

School of Therapeutic Sciences • Faculty of Health Sciences • 7 York Road, Parktown 2192, South Africa  
Tel: +27 11 717-3701 • Fax: +27 11 717-3709 • E-mail: denise.franzsen@wits.ac.za



### INFORMATION SHEET FOR PARTICIPANT (HIV Negative)

#### TITLE OF THE STUDY:

**The effect of HIV status on outcomes post-stroke in the participation in activities of daily living**

Hello,

I am Hymeri Augustyn an MSc Occupational Therapy student at the University of Witwatersrand.

I am conducting a study that will aim to provide evidence for the assumption based on clinical experience that HIV status in stroke survivors affects their progress. The stroke survivor's ability to perform activities of daily living (ADLs) will be assessed and the data collected will then be compared according to their HIV status. This will enable therapists to be able to motivate to extend hospital stay in order for the stroke survivor to receive more therapy to ensure that they are more independent in their ADLs when discharge to decrease the burden on the family. It can also assist therapists with treatment of these patients through goal setting and caregiver training.

I am inviting you to take part in the study as part of a control group of stroke survivors because of your negative HIV status. Your participation means that you will be asked to complete a questionnaire about your personal details and I will be assessing your ability to perform activities of daily living. These activities include eating, grooming, bathing, dressing and toileting which will be observed in occupational therapy.

These activities will be assessed on admission, at discharge and one month after discharge. The assessment one month after discharge will take place on the same day of your follow up appointment at the hospital.

Each assessment will take approximately 30 minutes.

Participation in the research will have no financial implications for you. Confidentiality will be ensured as your name will not be used on any data collection sheets. I will make sure that all personal information is kept in a secure locked place and only I will have access to the data. Your identity and information will remain confidential.



Participation in the research is voluntary and refusal to participate or withdrawal at any time will have no implications and will not affect your treatment and therapy in any way.

Feedback from the research will be available on request.

## **CONTACT INFORMATION**

Should you require more information Please contact Miss H Augustyn (researcher) at 018 294 9100 or Prof P de Witt (research supervisor) at 011 717 3701

Should there be any ethical queries about the research please feel free to contact the Human Research Ethics Committee (HREC) Chairman Prof P Cleaton-Jones at 011 7171234

Regards

Hymeri Augustyn

## Appendix B: Information sheet for participants (HIV-positive)

### Occupational Therapy

School of Therapeutic Sciences • Faculty of Health Sciences • 7 York Road, Parktown 2192, South Africa  
Tel: +27 11 717-3701 • Fax: +27 11 717-3709 • E-mail: denise.franzsen@wits.ac.za



### INFORMATION SHEET FOR PARTICIPANT (HIV POSITIVE)

#### TITLE OF THE STUDY:

**The effect of HIV status on outcomes post-stroke in the participation in activities of daily living**

Hello,

I am Hymeri Augustyn an MSc Occupational Therapy student at the University of Witwatersrand.

I am conducting a study that aims to understand the effect of HIV status on stroke survivors progress. The stroke survivor's ability to perform activities of daily living (ADLs) will be assessed and the data collected will then be compared according to their HIV status.

I am inviting you to take part in the study as part of a group of stroke survivors because of your HIV status. The benefit of this study is that it may enable therapists to be able to motivate to extend hospital stay in order for you to receive more therapy to ensure that you are more independent in your ADLs when discharge so your family does not have to help you as much. It can also assist therapists with your treatment through goal setting and caregiver training.

Your participation means that you will be asked to complete a questionnaire about your personal details and I will be assessing your ability to perform activities of daily living. These activities include eating, grooming, bathing, dressing and toileting which will be observed in occupational therapy.

These activities will be assessed on admission, at discharge and one month after discharge. The assessment one month after discharge will take place on the same day of your follow up appointment at the hospital.

Each assessment will take approximately 30 minutes.



Participation in the research will have no financial implications for you. Confidentiality will be ensured as your name will not be used on any data collection sheets. I will make sure that all personal information is kept in a secure locked place and only I will have access to the data. Your identity and information will remain confidential.

Participation in the research is voluntary and refusal to participate or withdrawal at any time will have no implications and will not affect your treatment and therapy in any way.

Feedback from the research will be available on request.

**CONTACT INFORMATION**

Should you require more information Please contact Miss H Augustyn (researcher) at 018 294 9100 or Prof P de Witt (research supervisor) at 011 717 3701

Should there be any ethical queries about the research please feel free to contact the Human Research Ethics Committee (HREC) Chairman Prof P Cleaton-Jones at 011 7171234

Regards

Hymeri Augustyn

## Appendix C: Informed consent for participant

### Occupational Therapy

School of Therapeutic Sciences • Faculty of Health Sciences • 7 York Road, Parktown 2192, South Africa  
Tel: +27 11 717-3701 • Fax: +27 11 717-3709 • E-mail: denise.franzsen@wits.ac.za



### INFORMED CONSENT FOR PARTICIPANT

I, the undersigned \_\_\_\_\_ (full name and surname)  
have read through the information provided about the research study and declare that  
I fully understand the content thereof.

Signature of the participant/caregiver: \_\_\_\_\_

Signed at \_\_\_\_\_ on the \_\_\_\_\_  
day of \_\_\_\_\_ 2014.



## Appendix D: Information sheet for caregivers

### Occupational Therapy

School of Therapeutic Sciences • Faculty of Health Sciences • 7 York Road, Parktown 2192, South Africa  
Tel: +27 11 717-3701 • Fax: +27 11 717-3709 • E-mail: denise.franzsen@wits.ac.za



I

## INFORMATION SHEET FOR CAREGIVER

### TITLE OF THE STUDY:

**The effect of HIV status on outcomes post-stroke in the participation in activities of daily living**

Hello,

I am Hymeri Augustyn an MSc Occupational Therapy student at the University of Witwatersrand.

I am conducting a study that aims to understand the effect of HIV status on stroke survivors progress. I am inviting you and your family member to take part in the study which will assist other stroke survivors who may be HIV positive. In the study your family member's ability to perform activities of daily living (ADLs) will be assessed.

The purpose of the study is to enable therapists to motivate to extend hospital stay if the stroke survivors progress more slowly and need to receive more therapy to ensure that they are more independent in their ADLs when discharge to decrease the burden on the family. It can also assist therapists with treatment of these patients through goal setting and caregiver training.

If you agree to participate it means that you will be asked to complete a questionnaire about your family member's personal details and you will be giving me permission to assess your family member's ability to perform activities of daily living. These activities include eating, grooming, bathing, dressing and toileting which will be observed in occupational therapy.

These activities will be assessed on admission, at discharge and one month after discharge. The assessment one month after discharge will take place on the same day of your family member's follow up appointment at the hospital. Each assessment will take approximately 30 minutes.



Participation in the research will have no financial implications for your family member. Confidentiality will be ensured by not using a name on any data collection sheets. I will make sure that all personal information is kept in a secure locked place and only I will have access to the data. The identity and information of your family member will remain confidential.

Participation in the research is voluntary and refusal to participate or withdrawal at any time will have no implications and will not affect your family member's treatment and therapy in any way. Feedback from the research will be available on request.

## **CONTACT INFORMATION**

Should you require more information Please contact Miss H Augustyn (researcher) at 018 294 9100 or Prof P de Witt (research supervisor) at 011 717 3701 Should there be any ethical queries about the research please feel free to contact the Human Research Ethics Committee (HREC) Chairman Prof P Cleaton-Jones at 0117171234

Regards

Hymeri Augustyn

## Appendix E: Informed consent for caregivers/CEO Witrand Hospital

### Occupational Therapy

School of Therapeutic Sciences • Faculty of Health Sciences • 7 York Road, Parktown 2192, South Africa  
Tel: +27 11 717-3701 • Fax: +27 11 717-3709 • E-mail: denise.franzsen@wits.ac.za



### INFORMED CONSENT FOR CAREGIVER/CEO WITRAND HOSPITAL

I, the undersigned \_\_\_\_\_ (full name and surname)  
have read through the information provided about the research study and declare that  
I fully understand the content thereof.

Signature of the participant/caregiver: \_\_\_\_\_

Signed at \_\_\_\_\_ on the \_\_\_\_\_  
day of \_\_\_\_\_ 2013.



## Appendix F: Participant information

Code \_\_\_\_\_

Name and  
Surname:

Hospital  
Number:

Date of Birth:

## Appendix G: Demographic questionnaire

Code \_\_\_\_\_

Date \_\_\_\_\_

Age:	20-29	30-39	40-49	50-59	60-69	70-80
------	-------	-------	-------	-------	-------	-------

Gender	Male	Female
--------	------	--------

Race:	Black	White	Coloured	Other
-------	-------	-------	----------	-------

HIV Status:	Positive	Negative
-------------	----------	----------

Diagnosis:	Infarct	Haemorrhage
------------	---------	-------------

Right Hemisphere	Left Hemisphere
------------------	-----------------

Co Morbidities:	Diabetes
	Overweight
	Hypertension
	Smoking
	Other

Level of Education:	No Schooling	Primary	High School
	Diploma	Degree	Other

Occupation:	Domestic	Administrative	Manual Labour
	Mine	Other	

**Appendix H: Data capturing sheet (Demographical information)**

Age		Race		Gender		Diagnosis		Diagnosis2		Risk Factors		Level of Education		Occupation	
20-29	1	Black	1	Male	1	Infarct	1	L Hemisphere	1	Diabetes	1	No Schooling	1	Domestic	1
30-39	2	White	2	Female	2	Haemorrhage	2	R Hemisphere	2	Overweight	2	Primary	2	Administrative	2
40-49	3	Coloured	3							Hypertension	3	High School	3	Manual Labour	3
50-59	4	Other	4							Smoking	4	Diploma	4	Mine	4
60-69	5									Other	5	Degree	5	Other	5
70-79	6											Other	6		
80-89	7														
90-99	8														

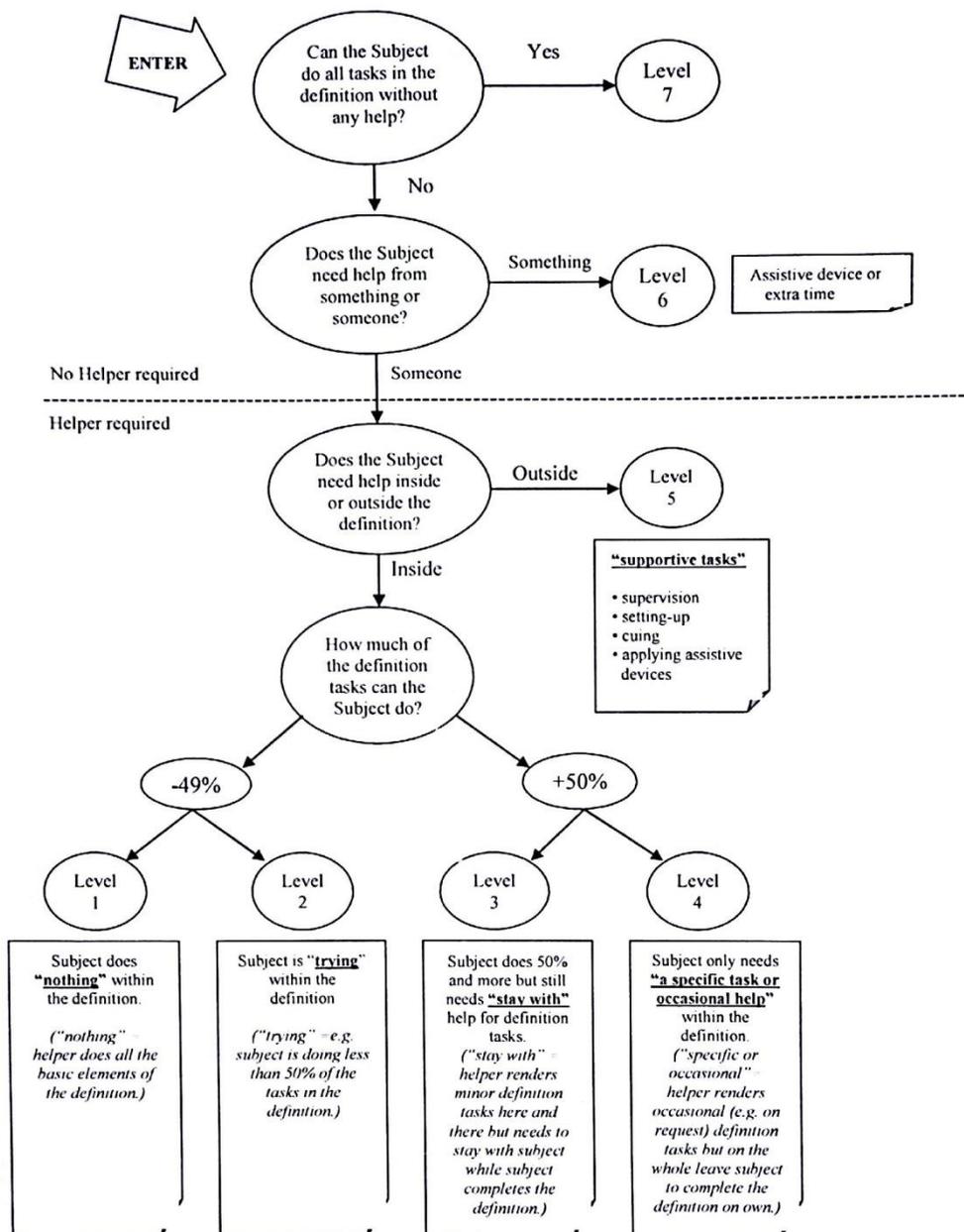
Appendix I: Data capturing sheet ( ADL assessments)

Assessment 1	Eating	1	2	3	4	5	6	7
	Grooming	1	2	3	4	5	6	7
	Dressing UL	1	2	3	4	5	6	7
	Dressing LL	1	2	3	4	5	6	7
	Washing	1	2	3	4	5	6	7
	Toileting	1	2	3	4	5	6	7
Assessment 2	Eating	1	2	3	4	5	6	7
	Grooming	1	2	3	4	5	6	7
	Dressing UL	1	2	3	4	5	6	7
	Dressing LL	1	2	3	4	5	6	7
	Washing	1	2	3	4	5	6	7
	Toileting	1	2	3	4	5	6	7
Assessment 3	Eating	1	2	3	4	5	6	7
	Grooming	1	2	3	4	5	6	7
	Dressing UL	1	2	3	4	5	6	7
	Dressing LL	1	2	3	4	5	6	7
	Washing	1	2	3	4	5	6	7
	Toileting	1	2	3	4	5	6	7

## Appendix J: SADFM – Beta tool

### General description of the $\beta$ BETA Instrument

**DEFINITION:** *The definition consists of the basic elements required to complete the task.*



**General Rules:**

1. If any of the definitions require the help of 2 helpers = score 1
2. If in doubt about the score = score the lowest
3. Always score actual performance, not potential performance.

Appendix K: Treatment policy



**health**  
 Department of  
**Health**  
 North West Province  
 REPUBLIC OF SOUTH AFRICA



02 Deppe Street Dassierand Potchefstroom 2520  
 Tel: 018 2949100  
 Fax: 018 2947069  
 Enquiries: Mrs. N.L. Mocwaledi-Senyane  
 Email: nmocwaledi@nwpg.gov.za

**WITRAND HOSPITAL**

Witrand Hospital: Office of the Chief Executive Officer

4/04/2014

**STROKE REHABILITATION - POST STROKE**

Author	<i>Compiled &amp; Reviewed by: R. Laubscher / S. du Plooy</i>
Review Date	April 2017
Description	Policy on Stroke Rehabilitation – Post stroke
Coverage	Physical Rehabilitation and Medicine Unit (Clinical / Nursing Department)
Policy / SOP number	<b>GENERIC HOSPITAL POLICY NO: GHP 23/2014 (REHAB) VOL. 5, 2014</b> (This policy replace GHP 19/2012, 03/10/2012, 23/2012)

### 1. POLICY STATEMENT

A short guideline on post stroke rehabilitation

### 2. RATIONALE

The rehabilitation of patients post stroke often poses specific challenges to the rehab team.

The attached give some guidance to the MPT on most frequent disabilities post stroke for rehab planning purposes. Specific interventions will be individualized by the therapists in the individual plans based on specific goals

### 3. GUIDELINE

\*A stroke or "brain attack" occurs when brain cells die because of inadequate blood flow. When blood flow is interrupted, brain cells are robbed of vital supplies of oxygen and nutrients. About 80 percent of strokes are caused by the blockage of an artery in the neck or brain; the remainder is caused by a burst blood vessel in the brain that causes bleeding into or around the brain.

\*\*Functions compromised when a specific region of the brain is damaged by stroke can sometimes be taken over by other parts of the brain. This ability to adapt and change is known as plasticity.

#### What is post-stroke rehabilitation?

Rehabilitation helps stroke survivors relearn skills that are lost when part of the brain is damaged. For example, these skills can include coordinating leg movements in order to walk or carrying out the steps involved in any complex activity. Rehabilitation also teaches survivors new ways of performing tasks to circumvent or compensate for any residual disabilities. Patients may need to learn how to bathe and dress using only one hand, or how to communicate effectively when their ability to use language has been compromised. There is a strong consensus among rehabilitation experts that the most important element in any rehabilitation program is carefully directed, well-focused, repetitive practice - the same kind of practice used by all people when they learn a new skill, such as playing the piano or pitching a baseball.

Rehabilitative therapy begins in the acute-care hospital after the patient's medical condition has been stabilized, often within 24 to 48 hours after the stroke. The first steps involve promoting independent movement because many patients are paralyzed or seriously weakened. Patients are prompted to change positions frequently while lying in bed and to engage in passive or active range-of-motion exercises to strengthen their stroke-impaired limbs. ("Passive" range-of-motion exercises are those in which the therapist actively helps the patient move a limb repeatedly, whereas "active" exercises are performed by the patient with no physical assistance from the therapist.) Patients progress from sitting up and transferring between the bed and a chair to standing, bearing their own weight, and walking, with or without assistance. ~~Rehabilitation nurses and therapists help patients perform progressively more complex and demanding tasks, such as bathing, dressing, and using a toilet, and they encourage patients to begin using their stroke-impaired limbs while engaging in those tasks. Beginning to reacquire the ability to carry out these basic activities of daily living represents the first stage in a stroke survivor's return to functional independence.~~

#### What disabilities can result from a stroke?

The types and degrees of disability that follow a stroke depend upon which area of the brain is damaged. Generally, stroke can cause five types of disabilities: paralysis or problems controlling movement; sensory disturbances including pain; problems using or understanding language; problems with thinking and memory; and emotional disturbances.

*Paralysis or problems controlling movement (motor control)*

Paralysis is one of the most common disabilities resulting from stroke. The paralysis is usually on the side of the body opposite the side of the brain damaged by stroke, and may affect the face, an arm, a leg, or the entire side of the body. This one-sided paralysis is called *hemiplegia* (one-sided weakness is called *hemiparesis*). Stroke patients with hemiparesis or hemiplegia may have difficulty with everyday activities such as walking or grasping objects. Some stroke patients have problems with swallowing, called *dysphasia*, due to damage to the part of the brain that controls the muscles for swallowing. Damage to a lower part of the brain, the cerebellum, can affect the body's ability to coordinate movement, a disability called *ataxia*, leading to problems with body posture, walking, and balance.

*Sensory disturbances including pain*

Stroke patients may lose the ability to feel touch, pain, temperature, or position. Sensory deficits may also hinder the ability to recognize objects that patients are holding and can even be severe enough to cause loss of recognition of one's own limb. Some stroke patients experience pain, numbness or odd sensations of tingling or prickling in paralyzed or weakened limbs, a condition known as *paresthesia*.

Stroke survivors frequently have a variety of chronic pain syndromes resulting from stroke-induced damage to the nervous system (neuropathic pain). Patients who have a seriously weakened or paralyzed arm commonly experience moderate to severe pain that radiates outward from the shoulder. Most often, the pain results from a joint becoming immobilized due to lack of movement and the tendons and ligaments around the joint become fixed in one position. This is commonly called a "frozen" joint; "passive" movement at the joint in a paralyzed limb is essential to prevent painful "freezing" and to allow easy movement if and when voluntary motor strength returns. In some stroke patients, pathways for sensation in the brain are damaged, causing the transmission of false signals that result in the sensation of pain in a limb or side of the body that has the sensory deficit. The most common of these pain syndromes is called "thalamic pain syndrome," which can be difficult to treat even with medications.

The loss of urinary continence is fairly common immediately after a stroke and often results from a combination of sensory and motor deficits. Stroke survivors may lose the ability to sense the need to urinate or the ability to control muscles of the bladder. Some may lack enough mobility to reach a toilet in time. Loss of bowel control or constipation may also occur. Permanent incontinence after a stroke is uncommon. But even a temporary loss of bowel or bladder control can be emotionally difficult for stroke survivors.

*Problems using or understanding language (aphasia)*

At least one-fourth of all stroke survivors experience language impairments, involving the ability to speak, write, and understand spoken and written language. A stroke-induced injury to any of the brain's language-control centers can severely impair verbal communication. Damage to a language center located on the dominant side of the brain, known as Broca's area, causes *expressive aphasia*. People with this type of aphasia have difficulty conveying their thoughts through words or writing. They lose the ability to speak the words they are thinking and to put words together in coherent, grammatically correct sentences. In contrast, damage to a language center located in a rear portion of the brain, called Wernicke's area, results in *receptive aphasia*. ~~People with this condition have difficulty understanding spoken or written language and often have incoherent speech. Although they can form grammatically correct sentences, their utterances are often devoid of meaning. The most severe form of aphasia, *global aphasia*, is caused by extensive damage to several areas involved in language function. People with global aphasia lose nearly all their linguistic abilities; they can neither understand language nor use it to convey thought. A less severe form of aphasia, called *anomic* or *amnesic aphasia*, occurs when there is only a minimal amount of brain damage; its effects are often quite subtle. People with anomic aphasia may simply selectively forget interrelated groups of words, such as the names of people or particular kinds of objects.~~

*Problems with thinking and memory*

Stroke can cause damage to parts of the brain responsible for memory, learning, and awareness. Stroke survivors may have dramatically shortened attention spans or may experience deficits in short-term memory. Individuals also may lose their ability to make plans, comprehend meaning, learn new tasks, or engage in other complex mental activities. Two fairly common deficits resulting from stroke are *anosognosia*, an inability to acknowledge the reality of the physical impairments resulting from stroke, and *neglect*, the loss of the ability to respond to objects or sensory stimuli located on one side of the body, usually the stroke-impaired side. Stroke survivors who develop apraxia lose their ability to plan the steps involved in a complex task and to carry the steps out in the proper sequence. Stroke survivors with apraxia may also have problems following a set of instructions. Apraxia appears to be caused by a disruption of the subtle connections that exist between thought and action.

*Emotional disturbances*

Many people who survive a stroke feel fear, anxiety, frustration, anger, sadness, and a sense of grief for their physical and mental losses. These feelings are a natural response to the psychological trauma of stroke. Some emotional disturbances and personality changes are caused by the physical effects of brain damage. Clinical depression, which is a sense of hopelessness that disrupts an individual's ability to function, appears to be the emotional disorder most commonly experienced by stroke survivors. Signs of clinical depression include sleep disturbances, a radical change in eating patterns that may lead to sudden weight loss or gain, lethargy, social withdrawal, irritability, fatigue, self-loathing, and suicidal thoughts. Post-stroke depression can be treated with antidepressant medications and psychological counseling.

**What medical professionals specialize in post-stroke rehabilitation?**

Post-stroke rehabilitation involves physicians; rehabilitation nurses; physical, occupational, recreational, speech-language, and vocational therapists; and mental health professionals.

*Physicians*

Physicians have the primary responsibility for managing and coordinating the long-term care of stroke survivors, including recommending which rehabilitation programs will best address individual needs. Physicians are also responsible for caring for the stroke survivor's general health and providing guidance aimed at preventing a second stroke, such as controlling high blood pressure or diabetes and eliminating risk factors such as cigarette smoking, excessive weight, a high-cholesterol diet, and high alcohol consumption.

Neurologists usually lead acute-care stroke teams and direct patient care during hospitalization. They sometimes remain in charge of long-term rehabilitation. However, physicians trained in other specialties often assume responsibility after the acute stage has passed, including *physiatrists*, who specialize in physical medicine and rehabilitation.

*Rehabilitation nurses*

Nurses specializing in rehabilitation help survivors relearn how to carry out the basic activities of daily living. They also educate survivors about routine health care, such as how to follow a medication schedule, how to care for the skin, how to manage transfers between a bed and a wheelchair, and special needs for people with diabetes. Rehabilitation nurses also work with survivors to reduce risk factors that may lead to a second stroke, and provide training for caregivers.

Nurses are closely involved in helping stroke survivors manage personal care issues, such as bathing and controlling incontinence. Most stroke survivors regain their ability to maintain continence, often with the help of strategies learned during rehabilitation. These strategies include strengthening pelvic muscles through special exercises and following a timed voiding schedule. If problems with incontinence continue, nurses can help caregivers learn to insert and manage catheters and to take special hygienic measures to prevent other incontinence-related health problems from developing.

### *Physical therapists*

Physical therapists specialize in treating disabilities related to motor and sensory impairments. They are trained in all aspects of anatomy and physiology related to normal function, with an emphasis on movement. They assess the stroke survivor's strength, endurance, range of motion, gait abnormalities, and sensory deficits to design individualized rehabilitation programs aimed at regaining control over motor functions.

Physical therapists help survivors regain the use of stroke-impaired limbs, teach compensatory strategies to reduce the effect of remaining deficits, and establish ongoing exercise programs to help people retain their newly learned skills. Disabled people tend to avoid using impaired limbs, a behavior called *learned non-use*. However, the repetitive use of impaired limbs encourages brain *plasticity* and helps reduce disabilities.

Strategies used by physical therapists to encourage the use of impaired limbs include selective sensory stimulation such as tapping or stroking, active and passive range-of-motion exercises, and temporary restraint of healthy limbs while practicing motor tasks. Some physical therapists may use a new technology, *transcutaneous electrical nerve stimulation (TENS)*, that encourages brain reorganization and recovery of function. TENS involves using a small probe that generates an electrical current to stimulate nerve activity in stroke-impaired limbs.

In general, physical therapy emphasizes practicing isolated movements, repeatedly changing from one kind of movement to another, and rehearsing complex movements that require a great deal of coordination and balance, such as walking up or down stairs or moving safely between obstacles. People too weak to bear their own weight can still practice repetitive movements during hydrotherapy (in which water provides sensory stimulation as well as weight support) or while being partially supported by a harness. A recent trend in physical therapy emphasizes the effectiveness of engaging in goal-directed activities, such as playing games, to promote coordination. Physical therapists frequently employ selective sensory stimulation to encourage use of impaired limbs and to help survivors with neglect regain awareness of stimuli on the neglected side of the body.

### *Occupational and recreational therapists*

Like physical therapists, occupational therapists are concerned with improving motor abilities. They help survivors relearn motor skills needed for performing self-directed activities-*occupations*-such as housecleaning, gardening, and practicing arts and crafts. Therapists can teach some survivors how to adapt to driving and provide on-road training. They often teach people to divide a complex activity into its component parts, practice each part, and then perform the whole sequence of actions. This strategy can improve coordination and may help people with apraxia relearn how to carry out planned actions.

Occupational therapists also teach people how to develop compensatory strategies and how to change elements of their environment that limit goal-directed activities. For example, people with the use of only one hand can substitute Velcro closures for buttons on clothing. Occupational therapists also help stroke survivors learn how to use assistive devices, such as canes, walkers, or wheelchairs. Finally, many occupational therapists teach people how to make changes in their homes to increase safety, remove barriers, and facilitate physical functioning, such as installing grab bars in bathrooms.

Recreational therapists help people with a variety of disabilities to develop and use their leisure time to enhance their health, independence, and quality of life.

### *Speech-language pathologists*

Speech-language pathologists help stroke survivors with aphasia relearn how to use language or develop alternative means of communication. They also help people improve their ability to swallow.

Many specialized therapeutic techniques have been developed to assist people with aphasia. Some forms of short-term therapy can improve comprehension rapidly. Intensive exercises such as repeating the therapist's words, practicing following directions, and doing reading or writing exercises form the cornerstone of language rehabilitation. Conversational coaching and rehearsal, as well as the development of prompts or cues to help people remember specific words, are sometimes beneficial. Speech-language pathologists also help stroke survivors develop strategies for circumventing language disabilities. These strategies can include the use of symbol boards or sign language. Recent advances in computer technology have spurred the development of new types of equipment to enhance communication.

Speech-language pathologists use noninvasive imaging techniques to study swallowing patterns of stroke survivors and identify the exact source of their impairment. Difficulties with swallowing have many possible causes, including a delayed swallowing reflex, an inability to manipulate food with the tongue, or an inability to detect food remaining lodged in the cheeks after swallowing. When the cause has been pinpointed, speech-language pathologists work with the individual to devise strategies to overcome or minimize the deficit. Sometimes, simply changing body position and improving posture during eating can bring about improvement. The texture of foods can be modified to make swallowing easier; for example, thin liquids, which often cause choking, can be thickened. Changing eating habits by taking small bites and chewing slowly can also help alleviate dysphasia.

#### *Vocational therapists*

Approximately one-fourth of all strokes occur in people between the ages of 45 and 65. For most people in this age group, returning to work is a major concern. Vocational therapists perform many of the same functions that ordinary career counselors do. They can help people with residual disabilities identify vocational strengths and develop résumés that highlight those strengths. They also can help identify potential employers, assist in specific job searches, and provide referrals to stroke vocational rehabilitation agencies.

Most important, vocational therapists educate disabled individuals about their rights and protections as defined by the Americans with Disabilities Act of 1990. This law requires employers to make "reasonable accommodations" for disabled employees. Vocational therapists frequently act as mediators between employers and employees to negotiate the provision of reasonable accommodations in the workplace.

#### **Where can a stroke patient get rehabilitation?**

Rehabilitation should begin as soon as a stroke patient is stable, often within 24 to 48 hours after a stroke. This first stage of rehabilitation usually occurs within an acute-care hospital. At the time of discharge from the hospital, the stroke patient and family coordinate with hospital social workers to locate a suitable living arrangement. Many stroke survivors return home, but some move into some type of medical facility.

#### *Inpatient rehabilitation units*

Inpatient facilities may be freestanding or part of larger hospital complexes. Patients stay in the facility, usually for 2 to 3 weeks, and engage in a coordinated, intensive program of rehabilitation. Such programs often involve at least 3 hours of active therapy a day, 5 or 6 days a week. Inpatient facilities offer a comprehensive range of medical services, including full-time physician supervision and access to the full range of therapists specializing in post-stroke rehabilitation.

#### *Outpatient units*

Outpatient facilities are often part of a larger hospital complex and provide access to physicians and the full range of therapists specializing in stroke rehabilitation. Patients typically spend several hours, often 3 days each week, at the facility taking part in coordinated therapy sessions and return home at night. Comprehensive outpatient facilities frequently offer treatment programs as intense as those of inpatient facilities, but they also can offer less demanding regimens, depending on the patient's physical capacity.

*Nursing facilities*

Rehabilitative services available at nursing facilities are more variable than are those at inpatient and outpatient units. Skilled nursing facilities usually place a greater emphasis on rehabilitation, whereas traditional nursing homes emphasize residential care. In addition, fewer hours of therapy are offered compared to outpatient and inpatient rehabilitation units.

*Home-based rehabilitation programs*

Home rehabilitation allows for great flexibility so that patients can tailor their program of rehabilitation and follow individual schedules. Stroke survivors may participate in an intensive level of therapy several hours per week or follow a less demanding regimen. These arrangements are often best suited for people who lack transportation or require treatment by only one type of rehabilitation therapist. Patients dependent on Medicare coverage for their rehabilitation must meet Medicare's "homebound" requirements to qualify for such services; at this time lack of transportation is not a valid reason for home therapy. The major disadvantage of home-based rehabilitation programs is the lack of specialized equipment. However, undergoing treatment at home gives people the advantage of practicing skills and developing compensatory strategies in the context of their own living environment.

**What research is being done?**

The National Institute of Neurological Disorders and Stroke (NINDS), a component of the Federal Government's National Institutes of Health (NIH), has primary responsibility for sponsoring research on disorders of the brain and nervous system, including the acute phase of stroke and the restoration of function after stroke. The NINDS also supports research on ways to enhance repair and regeneration of the central nervous system. Scientists funded by the NINDS are studying how the brain responds to experience or adapts to injury by reorganizing its functions (plasticity) by using noninvasive imaging technologies to map patterns of biological activity inside the brain. Other NINDS-sponsored scientists are looking at brain reorganization after stroke and determining whether specific rehabilitative techniques, such as constraint-induced movement therapy and transcranial magnetic stimulation, can stimulate brain plasticity, thereby improving motor function and decreasing disability. Other scientists are experimenting with implantation of neural stem cells, to see if these cells may be able to replace the cells that died as a result of a stroke.

*Compiled by: Dr. T.G.K Oosthuizen*

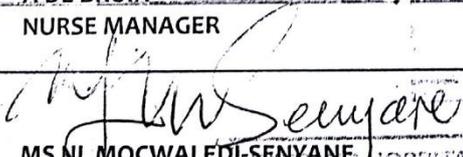
*Reviewed by: S. Du Plooy and Dr. R. Laubscher*



**A DE BRUIN**  
NURSE MANAGER



**T.G.K OOSTHUIZEN**  
SENIOR MANAGER MEDICAL SERVICES



**MS NL MOCWALEDI-SENYANE**  
HOSPITAL CEO

2014-04-07

## Appendix L: Ethical clearance certificate



R14/49 Ms Hymeri Augustyn

### HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

#### CLEARANCE CERTIFICATE NO. M130934

**NAME:** Ms Hymeri Augustyn  
**(Principal Investigator)**

**DEPARTMENT:** Occupational Therapy  
Witrand Hospital, Potchefstroom, North West

**PROJECT TITLE:** The Effect of HIV Status on Outcomes Post Strike  
in the Participation in Activities of Daily Living

**DATE CONSIDERED:** 27/09/2013

**DECISION:** Approved unconditionally

**CONDITIONS:**

**SUPERVISOR:** Prof P de Witt

**APPROVED BY:**   
\_\_\_\_\_  
Professor PE Cleaton-Jones, Chairperson, HREC (Medical)

**DATE OF APPROVAL:** 13/11/2013

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 Secretary in Room 10004, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report.**

\_\_\_\_\_  
Principal Investigator Signature

\_\_\_\_\_  
Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

## Appendix M: Permission Letter



### **POLICY, PLANNING, RESEARCH, MONITORING AND EVALUATION**

**To** : Ms H Augustyn

**From** : Policy, Planning, Research, Monitoring & Evaluation

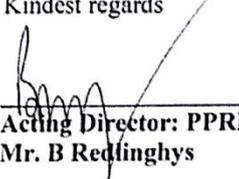
**Subject** : Approval Letter- The effect of HIV status on outcomes post stroke in the participation of activities of daily living

#### **Purpose**

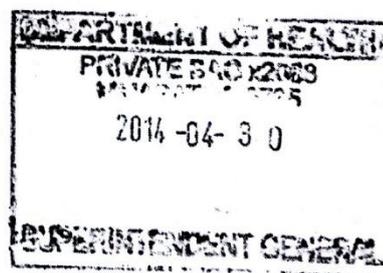
To inform the researcher that permission to undertake the above mentioned study has been granted by the North West Department of Health. The researcher is expected to arrange in advance with the chosen districts or facilities, and issue this letter as prove that permission has been granted by the provincial office.

Upon completion, the department expects to receive a final research report from the researcher.

Kindest regards

  
Acting Director: PPRM&E  
Mr. B Redlinghys

30/4/16  
Date



Healthy Living for All

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