The influence of HIV on return to work in stroke survivors amongst a population in the eThekwini district, Kwazulu-Natal.

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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg in partial fulfilment of the requirements for the degree of Master of Science in Physiotherapy

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Declaration

I, Wesley Stephen Naidoo, declare that this research is my own work. It is being submitted for the degree of Master of Science in Physiotherapy at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

Signature of Candidate

On this 02nd day of October, 2021

Dedication

Firstly, all praise, glory, and honour be given to God the Father, Son, and Holy Spirit. This journey has been a tiresome one, but with the continuous plans He has for each one of us, I am indebted to the guidance and wisdom He has provided. To God be the Glory, now and forever always, Amen!

My parents, the late Mr. Stephen and Mrs. Meenakumari Naidoo. You both took on the tough task of raising me as your child and I am forever indebted to your love and care. Thank you for every ounce of the sacrifice made and support afforded, for I shall continue upholding our family name in the highest of esteem and prestige. I pray for continued happiness and prosperity in your lives. I love you both very much!

Before I completed this research report, my Dad, Mr. Stephen Naidoo, was called to be with our Lord and Saviour in late April 2020, to continue working in the Heavenly realm. He has left an indescribable legacy to continue with, to my mother Mrs. Meenakumari Naidoo, brother Mr. Bradlee Naidoo and myself. Dad, you truly are the only man on this Earth and lifetime I lay my life for. Please do return in the next lifetime as my Dad. We love you. This work is in memory of your unending desire to unite people with everlasting love and compassion. Have a blast in heaven with our dearly departed. Till we meet again Old Man!

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Abbreviations:

ADLs	Activities of Daily Living
AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-retroviral Therapy
ARV	Anti-retroviral
cART	Combined Antiretroviral Therapy
CNS	Central Nervous System
DALY	Disability Adjusted Life Years
DG	Disability Grant
HIV	Human Immunodeficiency Virus
FET	Further Education and Training
HRQoL	Health Related Quality of Life
IRIS	Immune Reconstitution Inflammatory Syndrome
PLHIV	People Living with Human Immunodeficiency Virus
QoL	Quality of Life
RTW	Return to Work
SA	South Africa
VZV	Varicella Zoster Virus
WHO	World Health Organization
YLD	Years Lived with Disability

Abstract

Background

Work is considered a life role. A return to work (RTW) process considers biopsychosocial factors together with the interaction of systems and stakeholders as determinants of work-related disabilities and participation. Stroke survivors often struggle to be or remain employed. As Human Immunodeficiency Virus (HIV) can increase the risk of stroke development, the economically active population are financially impacted from resultant disability. It is therefore paramount to ascertain the importance of quality of life (QoL) and economic outcomes amongst people living with HIV (PLHIV) contemplating a RTW. No study has explored the influence of HIV on RTW in stroke survivors.

Aim of the study:

To explore the influence of HIV in stroke survivors who either have or have not RTW.

Method

Twelve PLHIV who are stroke survivors with a history of employment prior to stroke onset were recruited from a hospital database of an antiretroviral/ human immunodeficiency (ARV/HIV) clinic to partake in a qualitative study. Using a phenomenological approach, data was collected using a demographic questionnaire and semi-structured interview. The semi-structured interview data was transcribed and analysed using an inductive thematic analysis. The study was conducted at a rehabilitation department of a regional hospital in the eThekwini district, Kwazulu-Natal.

Results

Two participants were in a pilot study with the remaining twelve participants in the main study. Participants were of a mean age of 39 years old, equally distributed as male to female and all were on ART. Only two participants were working at the time of the study. The physical and cognitive impacts resulting from the stroke sequalae largely affected their outlook on RTW. The engagement of healthcare services such as psychotherapy and counselling with other RTW enabling professionals provided a gateway to continued employment in the face of potential HIV disclosure at the workplace. An economically productive RTW process, which included the nullification of societal and work related barriers, is promoted by ART consideration, family support, the restoration and maintenance of employment benefits. Interestingly, the prosperity for

a better QoL and RTW via new job opportunities, mitigating the impact of one's altered health status on work suitability and an improved socioeconomic status were plausible.

Conclusion

Health education, especially at the workplace, would encourage a disclosure of both HIV status and ART use for HIV positive stroke surviving employees. Participants mentioned that employers should consider their employee's health to allow time away for medical care and still continue productivity at the workplace in their absence. Having a support structure including related support services, an opportunity to maintain employment and being empowered by RTW professionals can inform prospective employment decision-making processes which can minimize the negative effects of unemployment on the QoL of this population.

Keywords: HIV, stroke, return to work

CHAPTER 1

1. BACKGROUND AND NEED

1.1 **Introduction**

Return to work (RTW) can be defined as “the transition from unemployment to employment, whether full-time, part-time, sheltered, unstable or contract work“(Rueda *et al*., 2012). When a person is affected by a disease or disorder and forcefully removed from their occupational environment, an improvement in their health status is imperative to a proposed RTW (Peters *et al.*, 2012). It is considered fair to explore the outcomes of disease on work which is considered a life role (Peters *et al.*, 2012). For the purposes of this study, the return to paid work is a key milestone for many stroke survivors (Barker, 2006), as is maintaining employment for HIV positive persons. Unemployment not only isolates a person and reduces their quality of life but is a problem for governments and employers with the gravest concern being the economy (Clayton *et al.*, 2012).

The ongoing process of RTW takes into consideration biomedical, psychological and social factors as determinants of work disabilities and participation together with the interactions of many systems and stakeholders (Schwarz, Claros-Salinas and Streibelt, 2018). Employment is a domain stroke survivors are often not able to participate in (Naess *et al.*, 2004) with work disability being a major consequence of stroke especially at the participatory level (Arwert *et al.*, 2017). The need to understand the underlying aetiology and hence risk factors of stroke in people living with human immunodeficiency virus (PLHIV), particularly the younger and employable age groups is of paramount importance (Maredza, Bertram and Tollman, 2015). The increased risk of stroke development amongst working or employable age populations poses a serious threat to their livelihoods (Muka *et al.*, 2015). Amongst other suggested risk factors, Human Immunodeficiency Virus (HIV) is a predisposing factor to the development of stroke (Benjamin *et al.*, 2012). At an average of just below 40 years old, younger patients are very likely to be HIV-seropositive with the absence of common vascular risk factors such as diabetes and hypertension, hypercholesteremia, excessive alcohol intake, inactivity and smoking (Heikinheimo *et al.*, 2012).

Among the side effects of antiretroviral therapy (ART), factors of consideration amongst PLHIV returning to work are disease manifestations associated with repeated episodes of illness leading to physical and cognitive impairments and the fear of losing disability allowance (Braveman *et al.*,

2006; Gorman *et al.*, 2009). The coexistence of psychosocial and cognitive impairments, as well as a broad range of other neurological and sociodemographic factors, have been seen to affect the functional recovery of stroke survivors (Appelros, Stegmayr and Terént, 2009). These factors feed into the potential barriers of RTW including limited access to buildings and transport (Martin *et al.*, 2003), prejudice behaviour for being disabled (Treger *et al.*, 2007), lack of family support (Holmqvist, Kamwendo and Ivarsson, 2009) and workplace support with demotivation to RTW (van Velzen *et al.*, 2011). Due to their impairments and limitations, an employee unable to perform work-related activities may result in a premature and probable failure of RTW (Schwarz, Claros-Salinas and Streibelt, 2018).

Some factors thrive in unison such as being HIV positive and at risk of developing a stroke or being a stroke survivor. Work as highlighted is an integral part of one's livelihood. The growing epidemic of the relationship between HIV and surviving a stroke on RTW though needs further exploration. This study investigates the influence of HIV on stroke survivors returning to work in a region of a city in a province of South Africa which has a high prevalence and incidence rate of HIV.

1.2. Problem Statement

Employment is a multifaceted domain that culminates into an individual's quality of life (QoL). Unemployment has an undesirable effect on the individual, organisation and overall socioeconomic status of the geographical area. Despite more recent information available, the burden of stroke placed on an individual to a country, together with the effects of HIV, warrants much concern on its impact on RTW. To the author's knowledge, no study has explored the influence of HIV on RTW in stroke survivors.

1.3. Research Question

What is the influence of HIV on RTW in stroke survivors?

1.4. Aim of the study

To explore the influence of HIV on RTW in stroke survivors in the population of the eThekwini district, Kwazulu-Natal.

1.5. Objectives of the study

1.5.1. To describe the demographics and clinical characteristics of stroke survivors who are

HIV-positive in this population of the eThekwini district, Kwazulu-Natal.

1.5.2. To establish the rate of RTW of people with stroke who are HIV-positive in this population of the eThekwini district, Kwazulu-Natal.

1.5.3. To gain insight into reasons for RTW or not, in stroke survivors who are HIV-positive.

1.6. Significance of the study

Currently, there is a scarcity of evidence available on the influence of HIV on the RTW of stroke survivors. Work or employment is a part of a person's livelihood, which contributes to the overall shape of their QoL. The absence of work or being employed may jeopardize a person's productivity and livelihood holistically. Expanding the knowledge through this study to understand the influence of HIV on stroke survivors in a RTW process will improve holistic healthcare service delivery and the QoL of stroke survivors who live with HIV.

CHAPTER 2

2. LITERATURE REVIEW

2.1. Introduction

This literature review presents information on the definitions of HIV and stroke including its interaction on predisposing PLHIV to the risk of stroke development and eventual stroke incident. Additionally, an overview of the literature on the workplace and RTW processes of PLHIV and stroke survivors will be presented. An understanding of the influences on QoL and RTW efforts in PLHIV and stroke survivors was necessary to understand how PLHIV who survived a stroke endeavour to either RTW or participate in a RTW process.

To attain literature for inclusion in this literature review, the following databases were consulted: PubMed, EBSCO Host, Cochrane Collaboration, Scopus, PEDro, ClinicalKey and Google Scholar. The keywords used in literature searching included: HIV, stroke, HIV related stroke, incidence, prevalence, epidemiology, returning to work, return to occupation, managing at workplace, coping strategy, Africa, South Africa. The literature search was generally limited to articles that were less than ten years old.

2.2. Definition of Stroke

According to the World Health Organization (WHO), stroke is defined as “rapidly developing clinical signs of focal (at times global) disturbance of cerebral function lasting more than 24 hours or leading to death with no apparent cause other than that of vascular origin” (WHO, 1988). Bennett further distinguished this definition of stroke by the following:

> “[It] excludes neurological deficits from epidural and subdural haemorrhage, trauma, malignancy and infection-related cerebral haemorrhage or infarction, and transient ischaemic attacks characterized by brief episodes of focal loss of brain function of less than 24 hours and with no persistent deficit” (Bennett 2012, p.31).

In an ischaemic stroke, the cerebral ischaemia encountered can be either global or focal. There are cerebral areas supplied by specific arteries and a focal neurological deficit may suggest the location of the infarct. There are instances when a cerebrovascular accident may be ill-defined

or not result in a clearly delineated acute syndrome. This may result due to the distribution of the arteries involved, collateral circulation and variations in the region supplied by a particular artery (de Freitas and Bogousslavsky, 2005).

Cerebral haemorrhaging can be subdivided into intracerebral haemorrhaging (into brain parenchyma), intraventricular haemorrhaging (into the ventricle) and subarachnoid haemorrhaging (into the subarachnoid space). Amongst individuals less than 40 years of age, the causes of cerebral haemorrhaging may be a ruptured aneurysm, arterio-vascular malformation or illicit drug use. Hypertension is the predominant cause amongst individuals of between 40-69 years of age (Lawes *et al.*, 2004).

2.3. Epidemiology of stroke

The mean age of stroke survivors is known to be lower than sixty years of age in sub-Saharan countries (Kengne and Anderson, 2006) despite the need to work beyond the age of 65 years old due to the socioeconomic status and need to survive (Peters *et al.*, 2012). In sub-Saharan countries, the mean age of stroke survivors is much lower than what is documented elsewhere worldwide (Kengne and Anderson, 2006). Improper or incorrect documentation of stroke subtypes may be a reason for reported lower mean ages of sub-Saharan stroke survivors (Muli and Rhoda, 2013). The leading cardiovascular disease cause of death and disability in sub-Saharan Africa is stroke (Moran *et al.*, 2013).

In sub-Saharan Africa, two-thirds of all stroke deaths have occurred in low income and middle income countries (Feigin *et al.*, 2014; Behrouz and Gottesman, 2016). Similarly, they also experience the greatest burden of HIV worldwide (Luchuo and Nkoke, 2016). Stroke is increasing in low income and middle countries, and HIV, which is often prevalent in resource-poor regions, might add to this risk, although data remains very scarce (Benjamin *et al.*, 2012). Despite the high prevalence of HIV with other leading burdens such as violence and trauma, stroke is the eighth most important cause of years of life lost owing to illness and the ninth most important cause of disability in South Africa (SA) (Bryer *et al.*, 2010). It is estimated that the stroke burden by the year 2030, should current trends continue, will record approximately 20 million stroke related deaths and 70 million stroke survivors annually worldwide (Krishnamurthi *et al.*, 2013).

Studies of stroke done in Africa are primarily hospital-based case series (Onwuchekwa and Chinenye, 2010; Badry *et al.*, 2013). The data from such studies do not provide estimates of

prevalence or incidence because the population at risk is unknown (Owolabi et al., 2015). The incidence of patients who die quickly from stroke or those with mild stroke may not be captured leading to a skewed statistical perspective (Owolabi, 2011). However, an age standardized annual stroke incidence rate of up to 316 per 100 000 population, was revealed from community-based studies reviewed in Africa (Owolabi et al., 2015). The only community-based study on South African stroke prevalence rates showed that an age-standardized prevalence rate of 290 per 100000 people with a crude prevalence in rural SA of 300 per 100000 people (Connor, 2004). According to Bertram *et al.* (2013), approximately 75,000 strokes occur yearly in SA. An estimate of 33,500 strokes per year suggests that, despite comprising one-fifth of the total national population, rural SA, based on the 2007-2011 rural Agincourt study, bares approximately half of the stroke burden (Maredza, Bertram and Tollman, 2015). It is important to note that despite Agincourt sub-districts' socioeconomic status since 1994 improving, their reliance in social assistance grants remains a major source of income with a high labour migration rate (Collinson *et al.*, 2014).

Stroke survivors are the second and third largest contributors to disability adjusted life years (DALY) in developing and developed countries respectively (Vos *et al.*, 2015). Disability adjusted life years (DALY) are the sum of potential years of life lost due to premature death including years of life lost due to time lived in states of other than optimal health which may be loosely referred to as "disability". The years lived with disability (YLD) figure expresses the consequences of living with less than perfect health conditions (Mathers *et al.*, 2001).

One DALY lost is a one year loss of healthy life (Hong, 2011). In 2010, the DALY loss rate amongst all ages was 1821 per 100 000 person years in low and middle income countries and was twice as high as estimated rates for high-income countries (Feigin *et al.*, 2014). In SA, the DALY loss rate per 100 000 person years was estimated at 1570 (Feigin *et al.*, 2014). The rural Agincourt study estimated a DALY loss rate of 1552 per 100 000 person years, placing them in the upper range which suggested a significant burden due to stroke (Maredza, Bertram and Tollman, 2015). A previous study from 2008 highlighted that stroke in SA was responsible for 95 000 YLD annually (Bertram *et al.*, 2013).

2.4. What is HIV?

The human immunodeficiency virus is categorized under the genus Lentivirus which is found in Retroviridae family and subfamily Orthoretrovirinae (Luciw, 1996). Human Immunodeficiency

Virus is classified into the types 1 and 2 (HIV-1 and HIV-2) based on genetic characteristics and viral antigen differences. From epidemiological and phylogenetic analyses done, it was around 1920 to 1940 that HIV was first amongst the human population (Gao *et al.*, 1999; Sharp and Hahn, 2011; Faria *et al.*, 2014).

Through complex protein-protein interactions, the first virus particles are detectable. This occurs from the initial HIV attachment to CD4 positive cell right to integration into the host genome and release from the infected cell, spanning 12-24 hours. Infected T lymphocytes are eliminated with a half-life of two to four days from the blood of an HIV-infected person by cytotoxic HIV components, lysis of virus-producing cells or by cytotoxic T lymphocytes as a part of the immune response. With HIV infected T-helper cells lysed, there is a gradual decline of these cells observed. After a long-lasting HIV infection, the continuous loss of T helper lymphocytes results in immunodeficiency. The activation of long-lived cells which are HIV integrated like macrophages, astrocytes and memory T cells persists for several years resulting in infectious HIV particles being produced (Seitz, 2016).

Human Immunodeficiency Virus can lead to progressive cell-mediated immunodeficiency which results in an increased risk of opportunistic infections and death. With the CD4 count and viral load decreasing and increasing respectively, a person with HIV may become susceptible to opportunistic infections and possibly hospital admission (Weber *et al.*, 2000).

A day or two and within five to six days after HIV infection, can the infection be detected in regional lymphatic tissue and regional lymph nodes respectively (Maher *et al.*, 2005). Inclusive of the nervous system, HIV can be detected throughout the body after 10–14 days (Grivel *et al.*, 2007).

2.5. Neuropathophysiology of HIV

The pathophysiology of HIV on the nervous system for the purpose of this study was emphasized incorporating stroke which was defined in a preceding paragraph. Human Immunodeficiency Virus is associated with neurological complications or NeuroAIDS, which causes significant morbidity and mortality; stroke being one of the NeuroAIDS syndromes (Ovbiagele and Nath, 2011). Following infection, HIV breaches the blood-brain barrier and enters the central nervous system (CNS) through infected macrophages, a process aided by the cytokine monocyte chemoattractant protein1 (Eugenin *et al.*, 2006). Infected astrocytes and microglia as well as the neuronal damage which occurs via secondary effects of glial reaction and neurotoxic viral protein and cytokine

release, are due to the viral manifestation found within the CNS (Hesselgesser *et al.*, 1998; Kaul, Garden and Lipton, 2001; Kaul *et al.*, 2005). This phenomenon has been described as the "innocent bystander effect." "Innocent bystanders" are cells injured by immunologic reactions through an immune directed destruction of blood cells besides alloimmune and autoimmune cell lysis (Petz, 2006).

2.6. Epidemiology of HIV

At the end of 2018, an estimated 37.9 million people were living with HIV, of which 20.8 million were in eastern and southern Africa (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2019). From statistics taken in June 2019, only 24.5 million people are on anti-retroviral (ARV) treatment with a further 8.1 million people not knowing their HIV status globally. Of the total number of PLHIV on ARV treatment, 13.8 million are from eastern and southern Africa (UNAIDS, 2019). Approximately 7.9 million people of all ages (greater than 0 years) were living with HIV in SA in 2017. Human Immunodeficiency Virus prevalence among adults aged 15 to 49 years in SA is 20.6% (Human Science Research Council, 2017). The HIV prevalence rate amongst adults between 15 to 49 years of age varied geographically across South Africa, ranging from 12.6% in the Western Cape to 27% in KwaZulu-Natal (Human Science Research Council, 2017).

The annual number of new HIV infections globally continued to decline gradually in 2018 (UNAIDS, 2019) Statistics revealed as in the case with AIDS related mortality, that an appreciable decline in new HIV infections were amongst eastern and southern Africans, at 28%. Human Immunodeficiency Virus annual incidence among adults aged 15 to 49 years in South Africa is 0.79 percent. This corresponds to approximately 199,700 people newly infected with HIV aged 15 to 49 years in 2017 (Human Science Research Council, 2017).The largest reductions in annual HIV infections and Acquired Immune Deficiency Syndrome (AIDS) - related deaths have occurred in the region hardest hit by the epidemic - eastern and southern Africa (UNAID, 2019). Progress in the rest of the world, where HIV infections are predominantly among key populations such as sex workers, people who use drugs, gay men and other men who have sex with men, transgender people and prisoners—and their partners, is considerably slower (UNAIDS, 2019).

2.7. Causes of stroke in patients with HIV

Human Immunodeficiency Virus infection is known to cause endothelial dysfunction, resulting in a vasculopathy that can manifest in several forms (e.g. accelerated atherosclerosis and small vessel disease); in addition, opportunistic infections such as Varicella Zoster Virus (VZV), which

are more common in HIV infection, can also disrupt the vascular endothelium (Benjamin *et al.*, 2012). A breach in the protective barrier of the vascular endothelium may serve as the site, with progression, of vascular disease – a stroke in some cases. The occlusive thrombotic events are mediated by a cascade of events such as the recruitment of leucocytes, platelet adhesion and aggregation, blood clotting activation and the fibrinolysis derangement (Chi *et al.*, 2000; Kline and Sutliff, 2008). The vascular endothelium serves to prevent arterial wall inflammation, coagulation, remodelling and in some instances, a stroke (Chi *et al.*, 2000; Kline and Sutliff, 2008). Such dysfunction is the foundation of inflammatory process of atherosclerosis. There are similar effects of endothelial dysfunction which have been reported in HIV experimental models and persons with stroke (Chi *et al.*, 2000; Lo and Plutzky, 2012).

The mechanisms that may result in a consequential ischaemic or haemorrhagic stroke are listed below (Benjamin *et al.*, 2012):

- Coagulopathy

Deficiencies in protein C and protein S are sometimes associated with intracranial venous thrombosis, but rarely with arterial stroke in adults without HIV (Kenet *et al.*, 2010; Morris, Singh and Fisher, 2010). People living with Human Immunodeficiency Virus who have had a stroke have been identified having protein C and S deficiencies. It remains unclear if these deficiencies are primarily caused by the HIV infection or are secondary events (Benjamin *et al.*, 2012).

- Cardio-embolism

This accounts for 4–15% of ischaemic strokes in people with HIV (Hoffmann *et al.*, 2000; Mochan, Modi and Modi, 2003; Ortiz *et al.*, 2007). Human Immunodeficiency Virus-associated dilated cardiomyopathy is a frequently reported cause of cardiac disease. Cardio-embolism might be associated with opportunistic infection and have been attributed to HIV itself but the pathogenesis remains uncertain (Benjamin *et al.*, 2012).

- Opportunistic infections

There are some infections that are well established causes of stroke. Mycobacterium tuberculosis, syphilis, and VZV cause stroke in patients without HIV, but immunosuppression caused by HIV increases the susceptibility of acquiring or reactivating these infections which increases the risk of stroke (Timmermans and Carr, 2004; Gilden *et al.*, 2009; Lammie *et al.*, 2009).

2.8. The role of combined antiretroviral therapy in the pathogenesis of cerebrovascular disease and stroke

The overall success of combined antiretroviral therapy (cART) regimen can be applauded because of its ability to suppress viral replication without resistance, minus associated costs, which include toxicity, long-term adverse effects, drug interaction risk, and impact on the QoL (Ghosn *et al.*, 2018). All antiretroviral therapy (ART) guidelines over the past two decades have recommended cART initiation comprising two nucleoside or nucleotide reverse transcriptase inhibitors plus a third drug, which has either been a boosted protease inhibitor or a non-nucleoside reverse transcriptase inhibitor and an integrase inhibitor in the past decade (Ghosn *et al.*, 2018). Single-tablet regimens with three drugs are highly recommended as first-line therapy to optimise adherence and all are currently available (Ghosn *et al.*, 2018). It is a key determinant of treatment success and prevention of resistance (Ghosn *et al.*, 2018).

Combined antiretroviral therapy is postulated to cause direct tissue injury to arteries which results in a raised concentration of markers of endothelial dysfunction directly or indirectly through lipid modification (de Gaetano Donati *et al.*, 2003) although the relevance towards cerebrovascular disease remains uncertain. Evidence of long-term cART causing endothelial toxicity and vascular dysfunction is increasing (Corral *et al.*, 2009; Ross *et al.*, 2009). Although cART does reduce the virulence of HIV, it has little anti-inflammatory potential on the endothelium (Ross *et al.*, 2009). Viral loading may be considered a marker indicating the increased risk of stroke (Chow *et al.*, 2012). There are long- term endothelial and metabolic challenges that increase the risk of stroke development amongst PLHIV receiving cART despite their likelihood of a longer life. Further research is needed to assess the benefit and safety of acute stroke therapy and secondary stroke prevention in patients with HIV. Combined antiretroviral therapy undoubtedly has increased the lifespan of PLHIV (Heikinheimo *et al.*, 2012; Luchuo and Nkoke, 2016) but their increased risk of stroke in the long term, as a result of endothelial and metabolic side-effects remains a continuous topic for research.

A study has shown that the risk of stroke is great in the first six months after starting ART raising the possibility that ischemic stroke could be part of an Immune Reconstitution Inflammatory Syndrome (IRIS) (Heikinheimo *et al.*, 2012) . However, due to the sample size of the study being too small to firmly justify the conclusions reached, this is an area that requires further research (Heikinheimo *et al.*, 2012). IRIS is mentioned as the result of an overwhelming pathogen-specific, cell-mediated immune response which can arise from either through the unmasking of an occult

infection or a paradoxical deterioration following HIV treatment (Martin-Blondel *et al.*, 2011). The recovering immune response is thought to target persisting pathogen-derived antigens or, possibly, self-antigens, causing tissue damage (French, 2009)

In a case of stroke, this immune response may target antigens that arise from HIV-mediated tissue damage or HIV itself. Immunosuppression is a recognized risk factor for IRIS hence a plausible mechanism of stroke among those initiating ART (Heikinheimo *et al.*, 2012).

2.9. The challenge of HIV and stroke

Although the sudden onset of a focal neurological deficit is typical, atypical stroke presentations are common in the context of HIV infection—e.g., acute confusion, fever, acute loss of consciousness, and stepwise focal neurological presentation over hours to days (Sharfstein *et al.*, 2007; Bhagavati and Choi, 2008; Melica *et al.*, 2009). An atypical stroke presentation due to the possibility of HIV infection may highlight the importance of HIV screening as a precipitating factor towards the onset of stroke. (Bogorodskaya, Chow and Triant, 2019).

Cerebral infarcts are much more common than cerebral haemorrhage which follows the distribution seen in patients who are not HIV infected (Bogorodskaya, Chow and Triant, 2019). Interestingly, PLHIV who present with stroke are younger, with a mean age of 40 years, compared to patients who are not HIV infected (Ortiz *et al.*, 2007; Ances *et al.*, 2009; Benjamin *et al.*, 2012, 2017; Chow, 2014; Chow *et al.*, 2014; Carballo *et al.*, 2015; Edwards *et al.*, 2016; AbdelRazek *et al.*, 2018). Over 90% of HIV related strokes seen are ischaemic in nature based on in-hospital studies in sub-Saharan Africa (Mochan, Modi and Modi, 2005; Tipping *et al.*, 2006; Ortiz *et al.*, 2007).

With the advent of the HIV epidemic, stroke has become recognized as one of the significant causes of morbidity and mortality. As PLHIV survive and grow older, there shall be an increase in the likelihood of aging-related diseases such as stroke (Vinikoor *et al.*, 2013; Gutierrez *et al.*, 2016; Koethe *et al.*, 2016; Abdallah *et al.*, 2018). Stroke is one of the most common and resource intensive diseases (Krishnamurthi *et al.*, 2013; Feigin *et al.*, 2014) with the burden of stroke amongst PLHIV in sub-Saharan Africa expectantly increasing since over two-thirds of the HIV population lives in this region (Abdallah *et al.*, 2018).

2.10. The effect of HIV on Quality of life and return to work

“Quality of life is defined as an individual’s perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHOQOL-BREF 1996: p. 5). The domains of an individual’s life that are encompassed in QoL include “limitations in physical activities; problems with work or other daily activities; limitations resulting from pain; energy and tiredness; the effect of physical and emotional health on normal social activities; happiness, nervousness, and depression, and personal opinion of one’s health compared with that of one’s peers as well as the expectation of changes in health” (Hopman and Verner 2003, p. 34). Quality of life is a multifactorial and multidimensional concept of physical, psychological, and social functioning and well-being, and the impact of a disease and treatment on QoL is referred to as Health-related quality of life (HRQoL) (Leidy, Revicki and Genesté, 1999; Bowling, 2001; Guyatt *et al.*, 2007).

Degroote’s narrative review (Degroote, Vogelaers and Vandijck, 2014) included studies prior to July 2013 with data from high income countries that examined the determinants associated with HRQoL in PLHIV. Determinants of HRQoL in PLHIV were divided into four categories: sociodemographic, clinical, psychological and behavioural factors. The exact association between employment and HRQoL remains unproven but employment was a positive predictor for good physical health, three to four years post-employment (Degroote, Vogelaers and Vandijck, 2014). It is also worth noting that employment influenced both physical and mental health status with its effect on physical health 2-fold greater (Degroote, Vogelaers and Vandijck, 2014). A better overall (Schroecksnadel *et al.*, 2008), physical (Call *et al.*, 2000; Zinkernagel *et al.*, 2001; Préau *et al.*, 2007) and mental health status was associated with a better virological status but a lower mental health score (Préau *et al.*, 2007; Protopopescu *et al.*, 2007; Guaraldi *et al.*, 2008) with further disease progression and distress (Protopopescu *et al.*, 2007) can result from a poorer virological status. As symptom status was a strong predictor for HRQoL, lipodystrophy is a highly visible symptom with body image alteration either affecting physical and mental health (Murri *et al.*, 1997; Guaraldi *et al.*, 2008) or with self-esteem and social contacts of PLHIV also affected (Murri *et al.*, 1997). An active coping mechanism from the negative impact of depression on HRQoL (Kaplan *et al.*, 1995; Jia *et al.*, 2004; Holzemer *et al.*, 2009; Briongos Figuero *et al.*, 2011) and associated symptoms of anxiety (Bangsberg *et al.*, 2000; Bing *et al.*, 2001) which affects physical and mental health resulted in a better HRQoL. It is thought to be effective in reducing stress (Carroll, 2013) and consequential impact on mental health (Gibson *et al.*, 2011). Enhancing social support could minimize depressive symptoms which could improve mental health and HRQoL (Jia *et al.*, 2004). Further elaboration into emotional social support (e.g. empathy,

affection, care) and tangible social support (e.g. financial and material assistance) influences HRQoL in a positively and negative respectively (Friedland, Renwick and McColl, 1996). This distinctions based on people receiving tangible social support as a self-perception of being more ill hence decreasing HRQoL (Friedland, Renwick and McColl, 1996) with social support becoming more important at difficult times (Burgoyne and Renwick, 2004).

Disclosure of HIV diagnosis is a complex issue in daily living, with a considerable impact on the QoL of PLHIV (Préau *et al.*, 2017). In a longitudinal study approach spanning a ten year evolution, at least a quarter of the respondents with a low employment status and/ or educational status found it easier to disclose or discuss their HIV status with family (44%) and a new sexual partner (28%) since ART initiation (Préau *et al.*, 2017). It was hypothesized that with psychosocial interventions developing and medical follow-up appointments, PLHIV from a lower socioeconomic status are helped in their discussions about their seropositivity. Conversely, a higher socioeconomic status may perceive more stigma hence difficulty to speak about their seropositivity. A higher educational level may also predict greater knowledge of both disease and negative social impact surrounding PLHIV (Green, 1995; Simons, Groffen and Bosma, 2013). Identification of factors associated with the disclosure and discussion of one's HIV status (Jain *et al.*, 2013; Stangl *et al.*, 2013) may provide a basis for developing improved medical care.

Successful RTW or sustainability of employment in PLHIV depends not only on the co-operative employer-employee relationship but the availability of evidence based interventions to encourage and promote RTW (Robinson, Okpo and Mngoma, 2015). From the systematic review of interventions aimed at sustaining and improving employment in HIV positive persons, it was inconclusive to outline such intervention towards PLHIV and employment (Robinson, Okpo and Mngoma, 2015). Due to the non-reporting of follow-up outcome data post ART initiation at 6, 12, 18 and 24-month intervals, the vocational intervention study by Martin et al. (2012) was difficult to evaluate (Robinson, Okpo and Mngoma, 2015). Pharmacologically, no meta-analysis could be conducted due to the outcome measures and statistical methods within the studies (Bor *et al.*, 2012; Larson *et al.*, 2013) when comparing ART intervention in HIV-positive persons on employment status to a control group of healthy untreated participants. There were a significant decrease in employment six months prior to ART initiation and a surprisingly less likelihood to be employed as little as six months up to five years post ART initiation (Larson *et al.*, 2013; Linnemayr *et al.*, 2013; Nannungi, Wagner and Ghosh-Dastidar, 2013). There was a greater likelihood of employment for the ART group compared to pre-ART group (Linnemayr *et al.*, 2013) at a one

year follow up with a meta-analysis showing an increased likelihood for employment for those on ART (Linnemayr *et al.*, 2013; Nannungi, Wagner and Ghosh-Dastidar, 2013). Overall, the intervention effect due to different results between different comparisons that ART for HIV positive persons improving the ability to work and maintain employment is unclear (Robinson, Okpo and Mngoma, 2015). Thus far, ART does not fully restore work capacity in HIV positive persons compared to healthy individuals or full recovery of employment for the HIV positive index groups (Robinson, Okpo and Mngoma, 2015).

2.11. The effect of stroke on Quality of life and return to work

Stroke in younger adults is concerning as they are still part of the economically active population (Muli and Rhoda, 2013). The impact of stroke in younger adults and their families is great (Teasell, McRae and Finestone, 2000). Being one of a few sub-Saharan African study, Muli and Rhoda (2013) used the Short Form 36 (SF-36v2) questionnaire which determines QoL to investigate the QoL of young stroke adults in Kenya. The SF-36v2 is a validated generic health questionnaire for assessment of health status of adult patients in clinical trials (Kosinski *et al.*, 1999) with 35 items grouped into 8 multi-item health domains as QoL domains which are Physical functioning (PF) – limitations in physical activities because of health problems, Role physical (RP) – limitations in the usual role activities because of health problems, Bodily pain (BP), General health (GH), Vitality (VT) – energy and fatigue, Social functioning (SF) – limitations in social activities because of physical and emotional problems, Role emotional (RE) – limitations in usual role because of emotional problems and Mental health (MH). Subscale scores range from 0 to 100, with higher values representing better function/health status. Irrespective of the post-stroke onset duration, 161 young adults (between 15-49 years) of the mean age of stroke found in sub-Saharan Africa (Kengne and Anderson, 2006) were conveniently recruited, With 72% of their participants classified to be in the chronic stage of stroke (greater than eleven months), the VT domain was significantly scored highest but within the mean score for RP and BP domains. This means that they were not dissatisfied with their QoL in those domains compared to those less than eleven months post stroke onset. There was a significant association between occupation and PF, BP, GH and SF domains although 54% of this population was unemployed which may impact generalization across similar sociodemographic and socioeconomic populations (Muli and Rhoda, 2013). The underperformance of activities such as those which are vigorous, climbing stairs, walking various distances or engaging in activities which require bending, stooping or lifting and carrying are common in stroke survivors (Hartman-Maeir *et al.*, 2007) and have been associated with a lower QoL (King, 1996). People affected by stroke experienced more challenges with

physical functioning, psychological and emotional functioning and fulfilling previous roles (Muli and Rhoda, 2013). The long-term disability caused to a stroke survivor could lead to a significant decline in the level of functioning and deterioration of QoL (Opara and Jaracz, 2010).

The most severely affected areas of QoL experienced by people affected by stroke from Nigeria were physical (Owolabi, 2011; Akosile *et al.*, 2013; Muli and Rhoda, 2013), social and family (Akosile *et al.*, 2013), emotional (Enato, Yovwin and Ogunrin, 2012; Hamza *et al.*, 2014) and work-related domains (Akinpelu, Odetunde and Odole, 2012; Muli and Rhoda, 2013). This implied that the physical, social and emotional domains of QoL are all affected. Therefore, stroke severity (Owolabi, 2008, 2010, 2013; Gbiri, Akinpelu and Odole, 2010) and depression (Gbiri, Akinpelu and Odole, 2010; Abubakar and Isezuo, 2012; Gbiri and Akinpelu, 2012; Hamza *et al.*, 2014) are the important predictors of QoL with social (Owolabi, 2008) and spousal support (Gbiri, Akinpelu and Odole, 2010; Gbiri and Akinpelu, 2012) and cognitive function (Fatoye *et al.*, 2007) also predictive of QoL in people affected by stroke. In a South Africa based study, stroke survivors had a poor QoL due to a decreased level of community reintegration (Kusambiza-Kiingi, Maleka and Ntsiea, 2017) as the QoL was affected by the levels of physical impairment on functional outcomes and community reintegration (Carod-Artal *et al.*, 2000). This is mentioned as RTW was deemed a positive influence on the QoL in a group of South African stroke survivors (Ntsiea, Van Aswegen, Lord and Olorunju, 2015), which is a theme of struggle when a stroke survivor assessed their community reintegration and QoL (Kusambiza-Kiingi, Maleka and Ntsiea, 2017).

2.12. Determinants of return to work in people living with HIV

Employment can provide financial security, a social status, personal development, social relations, self-esteem and protection from the physical and psychosocial hazards brought on by ill-health, based on social determinants of health (Marmot *et al.*, 2008). Work is a wide concept that could be defined as paid work be it employed or self-employed or include voluntary and household work (Westerlind, Persson and Sunnerhagen, 2017).

Martin (2003) explored the relativity of workforce related concerns to workforce entry intent or simply the perceived obstacles to employment for unemployed PLHIV (Martin *et al.*, 2003). This study addressed the perceived obstacles concerning participants in part, on findings from studies regarding RTW efforts (Northwest AIDS Foundation (1997); Timmons and Fesko, 1997). A study further on reviewed the experiences of PLHIV attempting workforce re-entry while enrolled in a RTW program designed to assist in their efforts (Martin, Jillisa Steckart and Arns, 2006). Amongst

PLHIV who are disabled or unemployed, the greater the work related health concerns were, the less likelihood the consideration to RTW (Martin *et al.*, 2003) with more than 90% of 235 participants experiencing one or more employment barriers during participation in a RTW program (Martin, Jillisa Steckart and Arns, 2006). These barriers as listed from most to less common were physical health (61%), mental health (47%), job skill deficits including experience, education and language barrier (32%). lack of resource utilization such as transport, finance clothing and telephone (25%), motivation and attitude (19%), social problems including death, broken relationships and social support (16%), and cognitive deficits (16%) (Martin, Jillisa Steckart and Arns, 2006). The greater the amount of concern on possible loss of benefits or work related health would predict a greater estimated time to RTW (Martin *et al.*, 2003).

Nestled into a working model that is considered client-focused, four domains of influence exist guiding vocational decision making amongst PLHIV - medical, psychosocial, financial/legal and vocational (Goldblum and Kohlenberg 2005). The medical domain had the most significant effect when considering which factors are most influential on the shift from contemplation to consider work into actioning work integration (Conyers and Boomer, 2017). This can be considered a work-related health concern that emerged as a significant predictor of consideration to RTW. People living with HIV in Kenya and Zambia reported significant barriers to employment such as discrimination in hiring, loss of promotions and job termination because of HIV status (Sprague, Simon and Sprague, 2011). With improved health perception and reduced health distress, PLHIV are increasingly likely to not only consider work (e.g. contemplation) but to shift to higher levels of commitment (e.g. action) (Conyers and Boomer, 2017).

There was a lower level of concern over work-related health when RTW was considered (Martin *et al.*, 2003). The impact of psychosocial factors appeared to be more complex and more highly influenced by interactions with the other domains. Nevertheless, it is imperative to highlight the impact of reduced stigma and the increased mental health on the commitment to consider work when the psychosocial factors are considered (Conyers and Boomer, 2017).

Financial/legal domain has a direct impact on engagement in considering work. In comparison, as disability benefit loss and work-related health concerns increased, so did an estimated time to re-enter the workforce (Martin *et al.*, 2003; Conyers and Boomer, 2017). Concerns over the possible loss of benefits emerged as a predictor of estimated time to RTW along with work-related health concerns (Martin *et al.*, 2003). In some cases, working without access to health insurance

or adequate income may threaten the health and economic survival of PLHIV. Once financial risk hits a critical point, transition into action is necessary, possibly to meet basic survival needs (Conyers and Boomer, 2017). It is important to identify and quantify these areas of concern because these may become mediators of workforce entry attempts and successful workforce entry among PLHIV amongst other disabling illnesses (Martin *et al.*, 2003).

2.13. Determinants of return to work in stroke survivors

Resuming work is an important indicator of recovery for young stroke survivors (Alaszewski *et al.*, 2007) and has a significant impact on subjective well-being and life satisfaction (Vestling, Tufvesson and Iwarsson, 2003). In young people [defined as an individual between 18 and 64 years old (Edwards *et al.*, 2018)], the years of unemployment means loss of work and productivity which is an economic burden to society (Persson, Ferraz-Nunes and Karlberg, 2012) and contributes to an economic burden of stroke (Saka, Mcguire and Wolfe, 2009). A stroke survivor is encouraged and supported in being an active participant during their individualized RTW process by collaborating with the employer and public authorities (Vestling, Ramel and Iwarsson, 2013). Their RTW process facilitated by mutual respect, trust, recognition including supervisory support and comradery creates the gateway to feeling secure and receptive (Schwarz, Claros-Salinas and Streibelt, 2018).

Meeting the minimum requirements of work demands after stroke as compared to before stroke is stressful. The constant availability towards customers, patients or colleagues in a competitive work environment, with irregular work inflow and lack of control over it; creates stress (Palstam, Törnbom and Sunnerhagen, 2018). An underestimation of a stroke survivor's impairments and limitations can result in a premature and failed RTW. An overestimation can result in a decision not to RTW (Schwarz, Claros-Salinas and Streibelt, 2018). Having a strong work role, job satisfaction and continuous passion are facilitators to RTW coupled with high motivation and determination as important factors in a RTW process (Schwarz, Claros-Salinas and Streibelt, 2018). When impairments and stress-related symptoms endure, managing the demands of work becomes an isolated struggle (Palstam, Törnbom and Sunnerhagen, 2018). In many African countries, the inclusion of stroke patients aged 65 and above in the workforce illustrates the plight of people in African countries. They are forced to work until retiring due to frailty (Peters *et al.*, 2012). Participants RTW with a significant association to functional status and post stroke duration as predictors of RTW following stroke. In the absence of, or with slight disability and a stroke onset of greater than one year ago, there was a higher chance of RTW (Peters *et al.*, 2012). There

must be consideration to the social and infrastructural differences between a developing country with severely disabled people due to stroke RTW (Saeki and Toyonaga, 2010), and a developed country with less to no severely disabled people due to stroke RTW who have access to buildings with ramps and escalators for wheelchair access (Saeki and Toyonaga, 2010). Another stark difference was the unavailability of specialized sub-acute and long term rehabilitation centres where engagement with intensive therapy services post in-patient discharge, which may mark a less likelihood of RTW within the first year post stroke onset (Saeki *et al.*, 1995; Wozniak *et al.*, 1999; Peters *et al.*, 2012).

Edwards et al. (2018) derived from a systematic review of 28 quantitative studies and one qualitative study globally with an average age of participants ranging from 37 to 55 years, that the median frequency of RTW after stroke increase with time (Edwards *et al.*, 2018). From the studies reviewed, it was found that 41% of participants RTW between 0 and six months, 53% at one year, 56% at 18 months and 66% between two and four years after stroke. The most commonly reported predictors of RTW in stroke survivors were greater independence in activities of daily living (Vestling, Tufvesson and Iwarsson, 2003; Saeki and Toyonaga, 2010; Tanaka, Toyonaga and Hashimoto, 2011, 2014; Hackett *et al.*, 2012; Waje-Andreassen *et al.*, 2013; Ntsiea, Van Aswegen, Lord and Olorunju S, 2015; Bonner *et al.*, 2016), better cognitive ability (Vestling, Tufvesson and Iwarsson, 2003; Hofgren *et al.*, 2007; Kauranen *et al.*, 2013; Waje-Andreassen *et al.*, 2013; Tanaka, Toyonaga and Hashimoto, 2014; Ntsiea, Van Aswegen, Lord and Olorunju S, 2015) fewer neurological deficits (Saeki and Hachisuka, 2004; Hofgren *et al.*, 2007; Saeki and Toyonaga, 2010; Tanaka, Toyonaga and Hashimoto, 2014; Ntsiea, Van Aswegen, Lord and Olorunju S, 2015) and employment in an office or professional setting which can be referred to as white-collar type jobs (Saeki and Hachisuka, 2004; Tanaka, Toyonaga and Hashimoto, 2011, 2014; Bonner *et al.*, 2016). Blue-collar workers have decreased rates of RTW even though there have been no specific occupations identified that are predictive of RTW trends (Brey and Wolf, 2014; Bonner *et al.*, 2016; Chang *et al.*, 2016; Van Patten *et al.*, 2016). There were some studies which used varying definitions of RTW which included studying (Hofgren *et al.*, 2007; Andersen *et al.*, 2012) or specifically return to full-time work (Waje-Andreassen *et al.*, 2013; Stefanovic Budimkic *et al.*, 2016) and such variations may have contributed to the variation in reported frequencies and predictors of RTW. Although the male gender was reported as a predictor of RTW after stroke, the studies sampled mostly male participants (Saeki and Toyonaga, 2010; Hackett *et al.*, 2012; Waje-Andreassen *et al.*, 2013). Stroke severity using the National Institute of Health Stroke Scale and functional disability using the Modified Rankin Scale were a consistent

predictor (Saeki *et al.*, 2016; Van Patten *et al.*, 2016; Westerlind, Persson and Sunnerhagen, 2017) and an important determinant (Bonner *et al.*, 2016) of stroke survivors' RTW.

Despite Edwards et al. (2018) extensive review of quantitative research, the value and personal significance of work may be more important factors influencing RTW than residual disability and may not have been captured by the single qualitative study reviewed (Alaszewski *et al.*, 2007). Motivational factors for RTW included the monotonous "sick person" label, having a strong work ethic and identity, restoring a normal and meaningful daily activity as well as the pursuit for economic stability (Palstam, Törnbom and Sunnerhagen, 2018). In the experiences of thirteen participants' RTW and maintaining work seven to eight years after stroke, stroke survivors:

- Struggled with impairments in the RTW process.
- Were uncertain about the consequences of stroke, and prognosis of recovery raised worries about the future, including work life.
- Had mixed feelings of worry and grief about the RTW process over lost functions but also acceptance and gratitude for being able to work (Palstam, Törnbom and Sunnerhagen, 2018).

Post-stroke depression is associated with lower RTW rates at longer periods post-stroke (Arwert *et al.*, 2017; van der Kemp *et al.*, 2019). The success of the RTW process for a stroke survivor was influenced by factors of the workplace and existing rehabilitation services. Induced impairments in body structures and functions limit the ability to perform work-related activities and meet job demands. Secretively, minor impairments persist as key barriers to RTW after stroke with examples including fatigue, exhaustion, tiredness, and weakness (Schwarz, Claros-Salinas and Streibelt, 2018). Maintaining work is a continuous struggle many years after a stroke, using coping strategies successfully are dependent on each individual's work situation, which employer support also has an impact on (van der Kemp *et al.*, 2019).

2.14. Stigma and discrimination of people living with HIV at the workplace

The need for privacy (Fesko, 2001; Escovitz and Donegan 2005) substantiated being absent from work due to a change in health status (Fesko, 2001; Brooks *et al.*, 2004; Degroote *et al.*, 2014) and placing trust in colleagues and employers (Anderson *et al.*, 2008) are found to be important aspects for PLHIV deciding to disclose their HIV status. When not supported by supervisors and colleagues, a sustainable work environment seems painstaking to maintain. This means an isolated struggle enduring impairments and stress-related symptoms while exceeding their limits to manage work demands (Palstam, Törnbom and Sunnerhagen, 2018).

The workplace serves as an important location of economic activity, on which individuals depend for social and individual development, and often for their very survival (Sprague and Dickinson, 2008). People living with HIV and those working with HIV-affected communities agree that despite the workplace being an important setting to address stigma and discrimination, it continues (Sprague, Simon and Sprague, 2011). Stigma refers to "prejudicial attitudes and behaviours that view some people as less valuable than others because of some quality of who they are (e.g. their gender, race, belief, culture, sexual orientation, behaviour, work, HIV status or other characteristics)" (Non-governmental organisation(NGO) Delegation to the UNAIDS programme co-ordinating boards (PCB), 2010). Discrimination refers to laws, policies or practices that disadvantage people because of who they are (e.g. their gender, race, culture, sexual orientation, behaviour, work, HIV status or other characteristics) (Non-governmental organisation(NGO) Delegation to the UNAIDS programme co-ordinating boards (PCB), 2010).

The PLHIV Stigma Index is a tool that measures and detects changing trends concerning stigma and discrimination experienced by PLHIV. As a community research and advocacy initiative, it documents how PLHIV experience stigma and discrimination (Dos Santos *et al.*, 2014) and evaluate efforts to address such stigma and discrimination in PLHIV (Stackpool-Moore *et al.*, 2013). By using a single outcome measurement tool, it builds an evidence base to make it possible to compare data across countries (Stackpool-Moore *et al.*, 2013). Compared to other world regions, African respondents reported a smaller proportion of HIV related stigma and discrimination. However, there is a variable percentage of respondents by African sub regions, of particular forms of HIV stigma or employment discrimination (Sprague, Simon and Sprague, 2011). From the UNAIDS PCB delegation survey of 213 African respondents. Eastern African respondents reported the highest proportion of experiencing forced disclosure at the workplace (38%), exclusion at the workplace (43%) and loss of employment (56%) (Non-governmental organisation(NGO) Delegation to the UNAIDS programme co-ordinating boards (PCB), 2010). Compared to other sub regions in Africa however, Eastern African respondents may be sensitized to this problem or made more aware of the extent employment discrimination based on HIV status in their locations (Sprague, Simon and Sprague, 2011). For the purposes of this study, the proportion of Southern African respondents reported experiencing forced disclosure at the workplace (19%), exclusion at the workplace (28%) and loss of employment (29%) (Sprague, Simon and Sprague, 2011). This indicates from a general view that the workplace in Africa also, remains a site where HIV related stigma and discrimination persist.

People who experienced HIV-related discrimination have an increased risk of employment loss (Dray-Spira *et al.*, 2008). Based on their HIV status from 40% of PLHIV in both Kenya and Zambia, more than two-thirds (71%) of Kenyans and over half (55%) of Zambian respondents reported that their job termination was either entirely because of their HIV status or that of HIV status and some other reason (Sprague, Simon and Sprague, 2011). This illustrated further evidence of HIV related employment discrimination.

2.15. Disclosure of HIV status in the workplace

The fear of stigma and social exclusion are important reasons for nondisclosure of HIV status (Adeoye-Agboola *et al.*, 2016). Limited disclosure (to only one, or a few colleagues) can be an important strategy to avoid stigma (Anderson *et al.*, 2008). Ethnicity (Emlet, 2006; Elford *et al.*, 2008; Rodger *et al.*, 2010), disease duration and the number of years with HIV (Conyers and Boomer 2005; Emlet, 2006) and a higher position in an organization or non-manual work (Conyers and Boomer 2005; Degroote *et al.*, 2014) were found to be associated with the level of disclosure exercised amongst the workforce which incorporates employers and colleagues.

The need to be accommodated and supported at work has been emphasized (Fesko, 2001; Escovitz and Donegan 2005). Living with openness and transparency (Degroote *et al.*, 2014), personal acceptance of HIV status (Fesko, 2001) and being accepted without prejudice (Wagener *et al.*, 2017) were descriptions of personal reasons allied to decision-making on disclosure. One study concluded that the perceived irrelevance of the HIV status for work was important for the decision not to disclose (Wagener *et al.*, 2014). The closer the relationship, the more willing PLHIV were to inform others of their HIV status with the highest levels of perceived discriminatory reactions coming from, amongst others, co-workers and employers (Dos Santos *et al.*, 2014). The disclosure of one's HIV status in view of ART successfully suppressing its manifestation, has become less urgent as is its influence on the ability to work (Wagener *et al.*, 2017).

2.16. Conclusion

This literature review emphasized how employment forms one of the integral components of QoL. An improvement to one's health status amplifies the prospect of RTW (Peters *et al.*, 2012). It is rather well documented that despite declining incidental rates particularly in eastern and southern Africa (UNAIDS 2019), the complexity that the HIV epidemic poses in the risk of cerebrovascular disease development requires continuous research. The unparalleled burden of curbing the HIV

epidemic engulfs the resources needed to address other pertinent health conditions or diseases. The debilitating effects of a stroke are documented to be an expensive, resource-demanding condition to combat (Krishnamurthi *et al.*, 2013; Feigin *et al.*, 2014; Vos *et al.*, 2015).

Despite the advent of, and need for early initiation on ART (Cohen *et al.*, 2011; Lundgren *et al.*, 2015) and later on, cART to effectively manage PLHIV (Ghosn *et al.*, 2018), there remains very little to co-manage the impending stroke risk and detrimental effects towards employment. There are similarities documented between the factors that influence the QoL in PLHIV and stroke survivors. There are interesting, intuitive factors invested into the determinants of PLHIV and stroke survivors RTW which are complex but similarly inter-related. People living with HIV and stroke survivors have varying two-folded needs to satisfy their overall plight e.g. the need for physical health (Conyers and Boomer, 2017; Palstam, Törnbom and Sunnerhagen, 2018). The continuous “taboo” plaguing the stigmatized PLHIV continues to manifest even at the workplace (Sprague, Simon and Sprague, 2011). Such a struggle is shared by a stroke survivor, who even if coping strategies are adopted, finds it a continuous struggle (van der Kemp *et al.*, 2019).

Identifying and capturing the experiences of stroke survivors who are HIV positive towards RTW, was important. No study presently exists to better understand how stroke survivors who are HIV positive perceive their unique quest to either RTW or be involved in a RTW process. Delving into their experience will hopefully better inform what unique and/ or similar factors are encountered in SA compared to other parts of the world. These factors will either inform the promotion or inhibition of the opportunity to not only improve their status of employment but QoL (WHOQOL-BREF 1996).

CHAPTER 3

METHODOLOGY

3.1 Introduction

This chapter presents the methodology used to collect and analyse data for this study. Information on the criteria for participants to be included in the study, where they were recruited from and the sample size determination are provided. The study design, including the instruments used for data collection, with the procedures followed to conduct the research study is presented. The ethical issues that were followed in the procedures are also discussed.

3.2. Study Design

This was a qualitative study with a phenomenological approach using a demographic questionnaire and a semi-structured interview. Phenomenology is a powerful research strategy well suited to exploring challenging problems in health profession education (Neubauer, Witkop and Varpio, 2019).

3.3. Source of participants

The participants were recruited from an ARV/ HIV clinic as well as computerized databases at Addington Hospital, a regional hospital based at South Beach, Durban, which is a part of the eThekwini District, Kwazulu-Natal.

3.4. Sample size

Researchers affirmed that acceptable data saturation is determined when no new data, themes or coding are available and there can be a replication of the study (Guest, Bunce and Johnson, 2006; O'Reilly and Parker, 2012; Walker, 2012). Data saturation may be attained from a minimum of six participants (Guest, Bunce and Johnson, 2006) but a determinant is data richness and not thickness (Dibley, 2011). Furthermore, the more information that a sample holds, the lower the number of participants needed (Malterud, Siersma and Guassora, 2016).

Due to the stagnant recruitment of prospective participants, a convenience sampling was employed (Coole *et al.*, 2013) with the use of an electronic computerized database at Addington Hospital, a regional hospital in the eThekwini District, Kwazulu-Natal. The database from the ARV/ HIV clinic at the hospital had approximately 1714 patients that attended the clinic. From this

database with the relevant medical history data which was captured and drawn from, 110 prospective participants were selected as it was recorded that they had a neurologic manifestation. A further 76 prospective participants were excluded because there was no indication of a first incident of stroke. During telephonic contacting of the remaining 34 prospective participants with five had already demised with a further five not meeting the inclusion criteria due to incorrect diagnosis captured, seven prospective participants could not be contacted due to incorrect contact details, two were out of the Kwazulu-Natal province/ relocated at the time of study and one participant refused to participate. Therefore fourteen participants were eventually recruited. Two prospective participants were used in the pilot study with the remaining twelve participants used in the main study.

3.5. Sample selection

The sample consisted of stroke survivors who were HIV positive and had a history of employment.

3.5.1. Inclusion Criteria

- First incident of stroke
- HIV positive on ART
- Employed up until time of stroke
- Confirmed diagnosis of stroke according to WHO (WHO 1988)
- At least six months post-stroke (Gilworth *et al.*, 2009)

3.5.2. Exclusion Criteria

- Pensioners
- Patients with aphasia
- HIV status unknown

3.6. Instrumentation

There were two instruments used to satisfy the objectives of the research study: a demographic questionnaire and an interview schedule. To facilitate a smooth and consistent data collecting process, the demographic questionnaire built a profile of the studied population in respect to their personal information, related medical information, economic and employment status, type of work and mode of transport to work. Questionnaires were available to participants in English or isiZulu depending on their preference (Refer to Appendix A for English and Appendix B for isiZulu). The semi-structured interview followed (Refer to Appendix C for English and Appendix D for isiZulu),

which collected data about prospective participants detailing events leading up to and beyond their first incident of stroke as well as how stroke, HIV and ART adherence affected their life in a RTW scenario. Participants chose their preferred interview language of either English or isiZulu.

3.7. Procedure

3.7.1. Pilot study

3.7.1.1. Objective:

The objective of the pilot study was for the researcher and research assistant to familiarise themselves with the assessment tools, to establish clarity, appropriateness and ambiguity of the demographic questionnaire and semi-structured interviews as well as the duration of the semi-structured interview.

3.7.1.2. Methodology:

The pilot study was conducted in June 2018 with two participants randomly selected from the eventual recruitment list of 14 prospective participants. The two participants were a 39-year-old male who was previously a combi driver in the taxi industry and a 40-year-old female who was previously a domestic worker. The participants participated in the research study with their preferred language considered i.e. isiZulu. Each participant received an information sheet that outlined the proposed study. They consented to participate in the study. Two separate consent forms were signed: one for participation in the study (Refer to Appendix E for English and Appendix F for isiZulu) with the other for use of a digital voice recorder for the semi-structured interviews (Refer to Appendix G for English and Appendix H for isiZulu). The demographic questionnaire was administered first and completed with the assistance of the researcher and research assistant. Thereafter the semi-structured interview followed with the research assistant with the researcher present. Unfortunately, due to unforeseen background interference from construction work at the study site, one of the two interviews could not be analysed. The interview with the male participant was not rescheduled. Despite this shortcoming and challenge, field notes were taken from both instances of the questionnaires completed and interviews conducted which were valuable in consideration towards the main study.

3.7.1.3. Training to conduct interviews

The research assistant, who conducted the interviews, had sociolinguistic competence (Squires, 2008) in isiZulu. The researcher was also present at the interviews to ensure a smooth flow of the interviewing process essentially and also provide advice should the research assistant need guidance as the interview evolved.

Before the pilot study commenced, the research assistant was given an English version of the scheduled questions for the semi-structured interviews. It was then followed by an isiZulu version of the same document which the research assistant familiarised themselves with. An independent bilingual colleague with sociolinguistic competence in isiZulu translated the data collection instrumentation from English to isiZulu. A second independent bilingual colleague with sociolinguistic competence in isiZulu with the research assistant reviewed the isiZulu translation independently. Their comments and corrections were returned to the original translator for incorporation. This process helped to ensure the accuracy and clarity of the isiZulu version of all items used in this study (Martin *et al.*, 2003). The research assistant was educated extensively about the study and its proposed outcomes. The researcher demonstrated bracketing to eliminate any potential bias emanating from his knowledge, beliefs, values and experiences in order to accurately describe participant's life experiences (Chan, Fung and Chien, 2013). The research assistant was also encouraged not to introduce his knowledge, beliefs, values and experiences during the data collection process. If there was any clarity required by the research assistant during the research collection process, the researcher was present throughout to liaise with and continue in a most smooth and efficient manner.

3.7.2. Implications of pilot study

Some questions were constructed inappropriately which caused either ambiguity or confusion in both participants' responses. Table 3.1 highlights the challenges and corrections made from the demographic questionnaire.

Table 3.1. Challenges and Corrections made from the demographic questionnaire

Challenges from demographic questionnaire	Corrections made to demographic questionnaire (See Appendix A and B)
• Place of residence with a choice of "sharing"	• Expanded wording to include "sharing with family/ friends"
• "Side of dominance" not understood	• Changed to "dominant hand"

• Attaining information about interactions with other health workers and when, as a stroke survivor.	• Illustrated using a table with different health care occupations commonly known to a stroke survivor and if interacted, when.
• Not able to answer questions set when attaining related medical history.	• Added an alternative statement to original question which read: “Do you take any tablets at home every day? If yes, what is it for?”
• Unsure when asked if they received disability benefits	• Modified question to ask if they had received disability benefits from other sources
• The employer’s involvement in a RTW process	• Modified question to attain whether there was anyone who advised them on accommodation or RTW and the process thereof.

During the interviews, some questions were phrased inappropriately which caused confusion and ambiguity which affected the responses. These challenges and corrections made to address them are presented in Table 3.2.

Table 3.2. Challenges and corrections made to semi-structured interview

Challenges from semi-structured interview	Corrections made to semi-structured interview (See Appendix C and D)
• The events leading up to the stroke had too many leading shorter questions.	• Modified the question to establish the onset of the participant’s stroke so that they should share their experience more comfortable and avoided too many leading shorter questions.
• Unable to appropriately explain the effects of HIV on the participant’s life.	• Rephrased the question to invite the participant to share the impacts it had in all aspects of their life.

• Inconsistent answers when asked about the location of work from home.	• Modified the question so that the participant could answer either describing by distance or time taken.
• The participant's opinion of the impact of each or both conditions (HIV and stroke) had on their current state been answered inconsistently.	• Modified the question so that the participant was allowed to think with reasons, the impact HIV and/or stroke or neither had on him/her.

Other minor flaws which needed to be corrected to continue the main study were:

- The inclusion of a question to investigate the participant's workforce involvement in assisting him/her throughout the returning to work process or life thereof.
- The inclusion of a question about the availability and suitability of a potential job or career path in their current state, with reason.
- Not to deviate from the semi-structured interview schedule as this results in a loss of coherence and a disjointed interview.
- Not to lead the participant with suggestive phrases, but to use an example to assist the participant in understanding the meaning of the question thus allowing them to respond appropriately.

3.7.3 Main study

3.7.3.1. Recruitment

Posters and reminders were placed around the HIV/ AIDS Clinic to remind the staff of the research and recruitment process. Daily, the principal researcher would also go to the administrative office of the HIV/ AIDS clinic and check in on any success of recruitment as well as potential participants from the day's list of scheduled patients. However after almost two months, due to the stagnant rate of recruitment, a convenient sampling was undertaken. The twelve prospective participants came to the hospital on an agreeable date and time with the researcher (and research assistant if necessary due to language preference) and participated in the study. Each participant was scheduled on a different day i.e. only one participant at a time on a single day.

3.7.3.2. Data collection procedure

An information sheet about the study was provided in the preferred language of the participant i.e. isiZulu or English, and participants were allowed to ask questions. When the participant

understood the information provided about the study, they signed consent to participate and consent for the interview to be audio recorded. Nine demographic questionnaire and semi-structured interview were conducted at the Department of Physiotherapy (with three in the Department of Occupational Therapy, during times of unexpected hospital construction) at Addington Hospital during August 2018 till October 2018. The demographic questionnaire gathered data such as age, gender, race, education, dwelling, related medical information about HIV, stroke and other illnesses including health worker services attained, economic status relating to their financial responsibilities and benefits received and finally knowledge of accommodation to returning to work and current RTW status. From our literature review, we endeavoured to learn about the participant's ART status and holistic service utilization to add to our discussion on potentially discoverable phenomena. The questionnaire was administered in the preferred language i.e. isiZulu or English, with assistance rendered and completed by either the research assistant or principal researcher respectively. Once completed in their preferred language, the semi-structured interview began, being digitally voice recorded in a noise-reduced environment. Upon the participant's request, four participants requested that the interview be conducted in isiZulu to enable an expressive platform, which was led by the research assistant with the researcher present. The interview started by asking the participant to talk about something important to them hence started with "the stroke onset" followed by "the HIV and ARV onset" and coherently bringing in the work aspect (Taylor and Bogdan, 1998). The demographic questionnaire took an average of five minutes to complete and the semi-structured interview lasted between 16-61 minutes.

The study adhered to principles of participatory research and of equal power and respect between the interviewer and participant, for example, by training interviewers to sit next to participants and to strive to make the experience an empowering one for the participant. No member checking was done but this point is noted by the researcher for future research. All participants were thanked for their participation in the study and were referred to appropriate local organizations if the interviewer determined that they required specific support after the interview.

The interview extracted the most explicit information possible about the influence of HIV on stroke survivors returning to work including the management received after their stroke, coping mechanisms implemented outside the health facility, transportation modes to and from work, reasons for current RTW status, personal feelings over returning to work or not and any other related information they felt necessary to disclose. Privacy was maintained for each participant

throughout the research study and data collection. Participants were compensated fully for their transportation to the research study site for the sole purpose of the research study. Upon completion of the research study, each participant signed an acknowledgment of participation in the research study before being compensated.

3.8. Ethical Considerations

Ethical approval was obtained from the Human Research Ethics Committee (Medical) of the University of the Witwatersrand (Refer to Appendix I). The research was conducted with permission from the National Health Research Division who after redirecting to the Provincial Health Research Committee in the Kwazulu-Natal Department of Health, advised to attain permission from management at various proposed health institutions. The research site viz. Addington Hospital, Durban, granted formal permission to conduct the research study (Refer to Appendix J). The management of the Physiotherapy and Occupational Therapy departments were consulted and permission obtained to use their facility to conduct the study. Participants were informed on the purpose of the study and the confidentiality of all information before a written consent was obtained in their preferred language (English or isiZulu). They also consented to the use of a digital voice recorder for the proposed semi-structured interview. All medical data relevant to this research study were kept confidential and anonymous.

3.9. Data management

The demographic questionnaire was completed in a prescribed user-friendly Microsoft Word document on a single page document which was printed on both sides. There was a total of 21 questions: 18 questions with a single choice made – applicable to the participant, of which four questions required an elaboration of not greater than two words to the appropriate choice made; and three other questions which required answering the question with no greater than three words. The questionnaire hardcopy was kept by the researcher before the information was electronically transferred to a Microsoft Excel spreadsheet file. There were four different sheets created in this file that captured the personal information, related medical information, economic status and employment status of the participants. All files were saved onto external hard drives as well as on computer data storage known as cloud storage to have data readily available, accessible and in order to eliminate a potential threat to data tampering or loss. Access to these files was password protected.

The semi-structured interviews were recorded using a digital voice recorder of a cellular device. Thereafter, it was saved onto a computer device – laptop, external hard drives as well as on computer cloud storage to have data readily available, accessible and eliminate a potential threat to data tampering or loss. Access to these files was also password protected. The interviews were sent electronically to two reputable cross language transcribing companies. The English interviews were transcribed verbatim and the isiZulu interviews were translated and transcribed verbatim but needed to be logical and sensible to an English-speaking reader. The interviews were transcribed verbatim by an independently dedicated transcriber for consistency (Twinn, 1997) and conceptual congruency (Twinn, 1997; Larkin, Dierckx de Casterlé and Schotsmans, 2007). The independently dedicated transcriber sent through verbatim transcriptions. Field notes and reflective journaling were done by the researcher for English spoken interviews and collaboratively with the research assistant for isiZulu spoken interviews. This content ensured that the data collected was better understood. The researcher printed out all 12 semi-structured transcribed interviews for data analysis.

3.10. Data Analysis

Information from the demographic questionnaires was analysed using frequency and percentage distributions. The following data were reported: age as a mean with ranges; gender, race, education, place of residence, ART, stroke-affected side, dominant hand, treatment from health workers, illnesses/ co-morbidities, financial roles when diagnosed with HIV and then stroke, disability grant, disability benefits, current work status, occupation, return to previous job, education of RTW process and future work status as modes.

The interviews were analysed using an inductive thematic analysis. The transcripts were initially browsed through with relevant statements highlighted from the first impression for familiarisation. A line by line analysis followed with labels provided for relevant statements. Labels thereafter were pinned onto large display paper. Data were clustered to seek the development of codes. There was a constant comparing of all transcripts to ensure optimal and thorough coding development (Gilworth *et al.*, 2009). Data were independently coded by the researcher and at least one other independent individual (VN) including peer-debriefing and coding consistency checking by two other independent individuals (SC and KS) who ensured the credibility of the analysis. The independent reviewers had experience and knowledge of primarily qualitative research analysis. The relevant quotations were attached to the coding done. These quotations and codes were put into an electronic spreadsheet of a workbook on Microsoft Excel. Once coding

was done, categories and sub-categories were developed and collapsed into eventual themes. The codes, sub-categories and categories were interconnected to understand relevant contributions to the eventual themes formed. The coding, sub-categories, categories, and themes were captured onto another electronic spreadsheet on a Microsoft Excel document. An array of finalized themes emerged from the categories that reflected and fulfilled the purpose of the research study.

3.11. Conclusion

This chapter outlined how the research study was conducted, illustrating the steps involved in participant selection, the method together with instruments used to collect data as well as the approach used in analysing the collected data. The next chapter details the results from the analysis process, describing the findings of the research study.

CHAPTER 4

4. RESULTS

4.1. Introduction

No study to date had explored the RTW efforts or engagement in a RTW process, of a stroke survivor who is HIV positive. The results of this chapter are presented concerning what the influence of HIV is on RTW in stroke survivors. The study sought to describe the demographics and clinical characteristics, establish the rate of RTW and gain insight into reasons for RTW or not, in stroke survivors who are HIV positive in this population of the eThekwini district, Kwazulu-Natal. The results are presented according to each study objective with codes and themes derived from the inductive thematic analysis. A qualitative study design using a phenomenological approach was adopted with data collected using a demographic questionnaire and a semi-structured interview.

An outline of this results chapter is provided, as follows:

4.2. Demographics and clinical characteristics of the participants
4.3. The effects of stroke sequelae on various life roles
4.4. Relevance of HIV status in RTW scenario
4.5. ART considerations
4.6. Socioeconomic factors
4.7. Societal factors
4.8. Future QoL and RTW prospects
4.9. Conclusion

4.2. Demographic and clinical characteristics of the participants

The demographic data of the twelve participants are presented with the use of five tables for profile building of this study population as follows: Personal information, related medical information, economic status, employment status and type of work and mode of transport to work. Personal information of the study participants is presented in Table 4.1.

Table 4.1. Personal information of the participants from the demographic questionnaire

Personal information	Number of study participants (N = 12) (n = %)
Age (Years):	
Mean (Range)	39 years (29-54)
Gender:	
Male/ Female	6 / 6 (50/50)
Race:	
Black	12 (100)
Education:	
Intermediate Phase	1 (8.3)
Senior Phase	1 (8.3)
Further Education and Training Phase	8 (66.6)
Tertiary Level	2 (16.6)
Residence:	
Owned	2 (16.6)
Rented	2 (16.6)
Shared with family/ friends	8 (66.6)

Twelve individuals participated with a mean age of 39 years old (range 29 – 54 years). Only two participants attained a level of tertiary education. Residency was shared with family or friends in 66.6% of participants. Table 4.2 presents the related medical information of the study participants.

Table 4.2. Related medical information of the participants from the demographic questionnaire.

Medical information	Number of study participants (N = 12) (n = %)
On Antiretroviral treatment (ART):	
Yes	12 (100)
Weaker side of body:	
Left	9 (74.7)
Right	3 (24.9)
Dominant side of body:	
Left	2 (16.6)
Right	10 (83.3)
Receiving treatment following stroke from:	
Medical doctor	10 (83.3)
Physiotherapist	11 (91.6)
Occupational Therapist	3 (24.9)
Speech and Language Pathologist	1 (8.3)
Audiologist	1 (8.3)
Social Worker	3 (24.9)

Dietician	2 (16.6)
Counsellor	2 (16.6)
Traditional Healer	2 (16.6)
Medical conditions known about:	
Hypertension	3 (24.9)
Hepatic conditions	2 (16.6)
Asthma	1 (8.3)

All study participants were initiated on ART. Within 6 months post stroke onset, 83.3% and 91.6% of participants were treated by medical doctors and physiotherapists respectively. Table 4.3 presents the economic status of the study participants.

Table 4.3. Economic status of participants from the demographic questionnaire

Economic status	Number of study participants (N = 12) (n = %)
Financial role when diagnosed with HIV:	
Sole breadwinner	7 (58.1)
Breadwinner/ contributing	4 (33.2)
Dependent	1 (8.3)
Financial role when diagnosed with stroke:	
Sole breadwinner	5 (41.5)
Breadwinner/ contributing	5 (41.5)
Dependent	2 (16.6)
Receiving a DG?	
Yes	4 (33.2)
No	8 (66.6)
If No, have they applied to receive a DG?	
Yes	3 (24.9)
No	4 (33.2)
Pending	1 (8.3)
Received any benefit from private insurance?	
Yes	2 (16.6)
No	7 (58.1)
Never heard of such	3 (24.9)

A majority of participants at the time of positive HIV diagnosis (91.6%) and stroke (83.3%) were financially involved in their households. Eight of the participants (66.6%) are not earning a state disability grant with half of them not having applied. Only two participants (16.6%) received funds

from a private insurance scheme. The employment status of the study participants is presented in Table 4.4.

Table 4.4. Employment status of the participants from the demographic questionnaire

Employment status	Number of study participants (N = 12) (n = %)
Participant currently working?	
Yes	2 (16.6)
No	10 (83.3)
Participant attempted returning to previous job?	
Yes	4 (33.3)
No	8 (66.6)
Did anyone help them understand being accommodated RTW?	
Yes	4 (33.3)
No	8 (66.6)
If Yes, who was it?	
Healthcare workers	4 (33.3)
Preference of employment status:	
Continue to work	6 (50)
Seek another job	6 (50)

Following the stroke with the confirmed HIV diagnosis and initiation on ARV therapy, only two participants (16.6%) held a form of employment, with four participants (33.3%) having attempted to RTW. Participants were aided in understanding a RTW process by health care professionals only. An equal ratio of 6:6 participants (50%:50%) desired to either continue to work or seek another job. Table 4.5 summarizes the study participants' type of work and mode of transported used to work

Table 4.5. Participants' type of work and mode of transport used to work

Participant	Job Title	Job Description	Mode of Transport to work
A	Kitchen assistant	Cooking various dishes	Private as passenger

B	Customer service agent	Attending to network and client-related queries	Public
C	General cleaner	Mopped and dusted (shop keeping)	Public
D	Machine operator	Planned and manufactured radiators	Public
E	Recruitment agency supervisor	Administrative tasks including paymaster duties	Public and private
F	Domestic worker	Housekeeping duties and aftercare of children	Stayed at workplace
G	Enrolled nursing assistant	Medical related care for patients in hospital	Public
H	Combi conductor	Co-ordinating trips and collecting fares	Public
I	Construction worker	Transporting mixed mortar and bricks	Private as passenger
J	Front desk receptionist	Recorded occupancy and payments at lodge	Stayed at workplace
K	Pool pump installer	All activities involved in installing home-built pools	Public
L	Financial advisor	Undertaking and underwriting insurance policies	Public and private

Eight participants (66.6%) engaged in work that involved physically demanding tasks whilst the remaining four participants (33.3%) engaged in a physical but more cognitively demanding work which involved diverse work tasks. Eight participants (66.6%) engaged the use of public transport to work (i.e. taxi, bus and train OR road and rail). Two participants (16.6%) incurred no transportation costs as both lived at their employment sites.

Table 4.6. Themes, categories and subcategories developed from inductive analysis of information collected from interviews with study participants

Themes	Categories	Subcategories
1. The effects of stroke sequelae on various life roles	a. Physical impact	a. Ability to use transport. Independence in Activities of Daily Living (ADL) performance. The effects of stroke sequelae causing upper limb impairments to ADLs. The effects of stroke sequelae causing lower limb impairments to ADLs. The effects of physical stroke sequelae on occupational tasks.
	b. Cognitive impact	b. Effect on participant's cognition. The effect of cognitive stroke sequalae on occupational tasks.
2. Relevance of HIV status in RTW scenario	a. Psychotherapy and counselling	a. Fear created by lack of knowledge regarding the HIV threat to life. Continued employment following HIV disclosure
	b. Engagement with RTW professionals	b. Time off to continue treatment
3. ART considerations	a. Fear of adverse effects	a. Continued ART adherence. Defaulting ART regime.
	b. Promoting longevity of life with continued ART	b. A lifeline towards a continued livelihood.

4. Economic factors	a. Positive economic productivity b. Negative economic productivity	a. To maintain employment. Restore prior employment benefits b. Employer's negative attitude. Lack of support during RTW process. Undesirable workplace accommodation.
5. Societal factors	a. Barrier to an acceptable QoL b. Family support	a. Social stigma. b. Family support structure towards RTW efforts.
6. Future QoL and RTW prospects	a. Promoting a better QoL b. Realistic goal setting towards new job opportunities	a. An improved outlook through employment. b. Impact of altered health status on work stability. Benefits of returning to economic productivity.

The participants were asked about events leading up to and beyond their first-ever stroke experience as well as how stroke, HIV and ART adherence affected their life. Developed themes related to the effects of stroke sequelae on various life roles and relevance of HIV status in RTW scenario, illustrated in Table 4.6, are elaborated on in 4.3.

4.3. Theme 1: The effects of stroke sequelae on various life roles

The resultant stroke sequelae affected the participants' activity and participation levels:

> *"My life is not the same as before now, sometimes I think that maybe it would have been better if the stroke would have just killed me, because now the quality of life has deteriorated, I sometimes have the feeling of just wanting to be isolated and stay alone." Participant H*

Listed in the next subsection are the categories and subcategories that were linked to the theme with the respective quotations:

4.3.1. Physical impact

Each participant individualized their diverse physical sequelae following their respective stroke event. To elaborate on the changes during the stroke, eleven participants experienced physical changes. These impairments influenced the following: -

Ability to use transport:

"Especially the transport was a problem. I could not jump into the taxi by myself. I relied on people to pick me up now there is a queue… All the stuff. It was a problem. Sometimes I could not even be able to jump into the car because I was weak" Participant G

"The biggest challenge was boarding a taxi. I had to be carried so that I could get on." Participant E

Independence in ADL performance:

"If I need to relieve myself, I could not even go to the toilet by myself. I had to find someone who could assist me." Participant D

"It made me feel very bad. I'm a big man and asking my mother to bath me. That was very bad." Participant E

"Physical, I can't do a lot of things on my own. I can't do my washing. I can't do my children's washing. I have to depend on things around the house... It's those things and you push yourself to do better but you don't like it, you end up leaving it." Participant L

"Yes, I can go to the shops but sometimes I use a bar to walk and then come right again." Participant J

"Can't sweep the floor, can't make the bed. Peeling the vegetables, can't cook nicely." Participant J

"I could not walk. I had to stop working. I had to stop even running. I used to run. I used to play soccer. I stopped working. I stopped to support my child because now I am not working." Participant G

The effects of physical stroke sequelae on occupational tasks

Two participants shared the view that the resultant stroke sequelae stifled their prospects in life with specific reference to the importance of work

"If I didn't have a stroke, I would be working and doing everything for myself."
Participant A

"I still believe that if I didn't have the stroke I would still be working or maybe got promoted."
Participant B

The work performance following stroke left most participants doubtful of being productive in their respective fields of work.

"The reason I didn't go back to work is that I need to use this affected hand in most times and after using it I don't sleep when I get home. I get pains the whole night." Participant H

"No one, besides that he told me that when his conductor is off or on weekends, he will call me but until now he hasn't called me. Now when I think I see that the competition is high between the drivers' other conductors are fast and they make more money. So maybe I'm the reason we make less money. Because I work slow." Participant H

"Because sometimes you have to escort the patients to other hospitals... Now you are going to be running and pushing the stretchers alone. You see. I saw now I am not managing because the load was too much. Then I told them that I am a hazard to myself and also to the patients." Participant G

"My work relied heavily on me using my hands, feet and applying my mind. I often made use of a ruler, a measuring tape, a ball pen and I was required to think all the time. So, I had to think about my wellbeing. I could not operate a press with my feet and I could not operate the machine with my hands because the stroke had an impact on their functioning." Participant D

"Everyone had their own expertise and each one got a share of the earnings based on their contribution to the project… The impact of the stroke on my left side is the reason I have not been able to continue working." Participant K

4.3.2. Cognitive impact

There were fewer participants who shared their experiences of cognitive effects impairments due to the stroke. Their experiences confirmed the diverse effects of stroke sequelae especially on the cognitive functions, which may be an aspect overlooked and undervalued.

Effect on participant's cognition

Two participants experienced cognitive changes that occurred during the time of their first-ever stroke:

> *"I cannot remember if I fell asleep or fainted. I just remember being woken up by a man who tried to get me back on top of the bed, but did not succeed because I was not able to assist him by lifting myself. I felt like I was dreaming, but then I noticed who it was." Participant K.*

> *"I told my sister that no I'm not feeling good. I had to go sleep. Then from after 11:00, I can't remember. Honestly nothing till the day I woke up and that was that." Participant L.*

After the stroke event, the memory difficulties challenged especially their survival and affected their QoL:

> *"I have the challenges now, that I forget a lot of things" Participant H*

> *"Mentally it's the forgetting part, it just frustrates you. Sometimes you say something and you forget it. Emotionally draining" Participant L*

The effect of cognitive stroke sequelae on occupational tasks

Participant L mentioned that her employer was motivational with the hope that she would RTW. However, her resignation seemed inevitable as she reflected and realized that the current job demands and versatile work-related tasks do not align with her residual abilities. Her salary scale was majorly commission-driven:

> *"Because I can't walk and I can't talk properly… That is the reason. I can't talk. My job was to interact with the client, so now I can't talk… I understand the advisors work so you see my office there's no admin. There's no work that will make you sit down and do. I have to go out and make money". Participant L*

As a combi conductor, one of participant H's work tasks was to handle transportation fares which were affected and together with his communication difficulty was a social deterrent. This caused him to behave inappropriately which impacted on his occupational relationships albeit personal relationships:

> *"Sometimes there's a problem with counting the money and sometimes give passengers wrong change, when I count, I mix calculations and forget the amounts of change that I need to give back… When I talk, I also drool and that causes trouble between me and the passengers because some of them laugh and then I end up feeling like I should just say bad things to them."*

4.4. Theme 2: Relevance of HIV status in RTW scenario

When participants were asked to delve into their experiences of a RTW process bearing in mind their HIV status, most responses illustrated a realistic and simplistic plea to be valued as part of the workforce.

4.4.1. Psychotherapy and Counselling

The coherence of psychotherapy and counselling as well as engagement with similar people invoked an acceptance of one's HIV status. This acceptance may positively influence the different constructs of life including work. One must guard against the adoption of sympathy and its negative contribution to a suboptimal QoL:

> *"So I've been exposed to family with HIV and AIDS I kind of knew about it even though I thought it was far from me because of the behaviour that I had, even now I still can't believe that I have this kind of disease…I managed to get over it because I attended a lot of what is called? Psychologist, counselling. They even referred me here and I've been attending up until I felt like I'm fine now." Participant B*

> *"I know a lot about HIV. I have studied about HIV and I also get HIV counselling." Participant A*

<u>Fear created by lack of knowledge regarding the HIV threat to life</u>

A potential threat when accepting one's HIV status is to withdraw oneself away from attaining an acceptable QoL, closing the window on an opportunity to improve on it. This particular threat existed in a participant whose occupation was the healthcare industry:

"It is because now I will have to try keep myself from lots of things. Keep myself away. So now I am just isolating myself… So now I was afraid that now I am going to die. That was the most fear I used to have. So now my life is actually affected like that. I knew I was going to die. When you know since you have got this now you are going to die."
Participant G

Continued employment following HIV disclosure

The assurance that treatment adherence should be understood and accommodated at the workplace was elaborated on by participants:

"Because there are situations where you have to collect your medication or when you work overtime you might miss your time to take medication or like in construction maybe in the days where you are doing a concrete and the guys decide that they won't take lunch to push the job, so the employer must be aware that you need to eat so you can take your medication." Participant I

"At first I told the uncle (driver) that in a month I have to fetch my medication but didn't tell what is it for. As time went on, I ended up telling him because sometimes the date to get medication will fall on a Friday because we cannot go to the clinic on Saturday, maybe it's on a Friday and it's the busy day or the month end is on a Monday." Participant H

"I think it is important because when I need to go collect medication, I will have to inform my employer of my whereabouts." Participant K

"They really need to know that on a certain date I will not be coming to work because I must collect my medication. He will at least know where I am instead of assuming that I am absent from work." Participant A

4.4.2. Engaging with RTW enabling professionals

Time off to continue treatment visits

Rehabilitation had been mentioned in two participants' cases to have brought a renewed perspective on their recovery. This can precipitate further engagement with RTW enabling professionals:

"After I worked with a physio. I picked up and started walking. Yes, it was for a couple of months." Participant E.

"*They (the doctors) said maybe it's going to subside on its own. I should continue attending physiotherapist and on the 19th, 20th I got discharged and I've been coming back for physio, physio… but I told them (the family who wanted the participant to return to them to aid in maintaining and improving livelihood) I can't come back right away because I was still attending physio I will come back after my recovery." Participant B.*

4.5. Theme 3: ART considerations

When advocating towards the acceptance of one's HIV status, it is an invitation to consider an acceptance towards improved overall health. The consideration of ART may be seen as a journey that should be well navigated.

4.5.1. Fear of adverse effects

A participant blamed her adherence to ART for the stroke onset which affected her livelihood:

Participant J – "I will say both"; Interviewer – "Why do you say both?" Participant J – "Because since I was taking medication, I became like this".

<u>Continued ART adherence</u>

The feared side effects of continued treatment adherence resulted in doubt regarding the regimen of ART. However, participants continued faithfully as they returned to an acceptable health status:

"The first few times it makes you dizzy but right now, it is okay. I am now used to them." Participant E

"At first it changed my life because at some point I was too big (gained weight) and I was confused and it was like I was a fool, and then thing went back to normal." Participant F

"Nothing much at first it was like I'm going to lose my mind, now I'm better." Participant J

<u>Defaulting ART regimes</u>

Defaulting ART led to eventual hospitalization. The adverse effects following defaulted ART regimes served as motivation towards treatment continuity:

"When I started ARV, it was Atrozia. Atrozia was ok. Then it got finished, then they gave us Odimion, (ok) it was ok, then it got finished and they gave us Trippers. That one makes you see flames. I stopped it until I was sick." Participant L

"Following year, I got tired .it wasn't even a year and I felt like I don't want that medication anymore and then I stopped. I didn't go to get medication for about 3 months. I wasn't sick because even at that time they were telling me I will get sick, I wasn't sick. I was still fine. I didn't want to take it but now I can see that it is helping me a lot because the time I was here in hospital they told me that the CD4 count is over 1000." Participant B

4.5.2. Promoting longevity of life with continued ART

A lifeline towards a continued livelihood

Taking ART was seen to improve the longevity of life. It restored life despite not returning to one's former life:

"I won't say it's the same but I'm alive but I can say it has put it back to normal. I'm not that weak now, I take my pills accordingly, even though it will not go back to the way it was before (my life) but they are helping me." Participant I

"All I can do is focus on my treatment and make sure that it does not progress further because I cannot stop it. Therefore, there is life if you adhere to treatment." Participant D

"I need to continue taking my pills maybe my life will continue and then do what the doctor told me to do." Participant H

The rate of RTW, reasons for RTW and not RTW of people with stroke who are HIV positive in this study

Out of four participants who embarked on a RTW process, two participants RTW with only one participant being able to maintain their previous employment. The sole participant who RTW captured her needs to survive. The desire to be economically productive in view that there was no support system and fear of the employers dismissing her based on her health status was justifiable to a forced RTW.

4.6. Theme 4: Economic factors

Work is known to be an imperative construct in a person's QoL and HRQoL which should include the economic variable. There is a need to promote economic productivity as one nullifies the negative influences to such progression.

4.6.1. Positive economic productivity

To maintain employment

The need to protect one's job by maintaining a good working relationship is critical. The following participant's responses highlight a simple consideration for their colleagues to plan for their absence or time off.

> *"I think it's important because he needs to understand that when you are absent, he is aware about your reason to be absent. Your reason to be absent so he can make arrangements for your replacement and work smooth the next day." Participant H*

Restore prior employment benefits

The majority of the responses were favourable towards seeking a new job. Only one participant had the desire to improve his breadwinner status by restoring his prior employment benefits. It could afford him an opportunity to improve his recovery and QoL:

> *"Medical aid can provide me with a motorised wheelchair kind of. Also, so that I can be faster in getting accommodation maybe nearby, you see. Because I do stuff. I cook at home when I am alone." Participant G.*

4.6.2. Negative economic productivity

Employer's negative attitudes

Upon overhearing her employers speak when she was hospitalized for the stroke suffered, she feared the possibility of being unfairly dismissed:

> *"They were going to fire me. Because I heard that the time, I was in hospital they wanted to fire me, because of the stroke." Participant J*

The potential loss of business for the employer was prioritized over considering the employee's length of service hence the attempt to RTW was disregarded

> *"I worked at that company for about thirteen to fifteen years. To be honest, the employer only likes you while you are still fit to perform your duties… You must push his production*

so that he can get what he wants from you. He is not worrying about your life." Participant D

A participant was told she is sick and not fit to RTW. Her employer advised her to regularly check her blood pressure and monitor her condition. This did not encourage and motivate the participant towards a definitive RTW plan or process to follow:

"It was just that I was told that they can't take me back because I won't be able to work properly because I still had this problem, I should stay at home until I have recovered fully… I can say no help they could offer me, just that they said I should go to the clinic to check my BP, and I went there it was normal." Participant F

The potential job loss was a great risk as the employer would have felt that the potentially decreasing productivity level jeopardized their business:

"I would never tell him about my HIV status. As I mentioned earlier, my employer said he need me to work in order to increase production. Most employers think that once you are infected with HIV and you are on treatment, then it is the end of the road for you." Participant D

The key point mentioned from reserving the right to disclose to their employer was the lack of relevance to the productivity of their job performance:

"Because it is not about what are you having. It is not important what are you having. What is important is that do you do your job as you are expected and go home." Participant G

"No, I don't think it has anything to do with your work… The status has nothing to do with who you are and what you do." Participant L

<u>Lack of support during RTW process</u>

Without a support structure to depend on during a time of illness and transitioning phase before RTW, the recovery phase may only be a brief period of time as there is an emphasis on RTW:

Participant: "I don't have any family who is going to support me." Q2 c follow on) "Ok, so it's just the money you needed to survive?" Participant: "Yes"
Interviewer with Participant J

Disclosing their HIV status may result in prejudiced behaviour towards them

"It's confidential at the end of the day so it's still privacy. I don't think it's important. Some people they can't wait to destroy you with such information" Participant B

"If they are well informed, then there is no problem. The problem is when you disclose to people who do not understand. They start to discriminate you and treat you bad. That is a problem." Participant D

Undesirable workplace accommodation

A pivotal point during the return to work integration program, is being able for the workplace to accommodate the affected individual and vice versa. The need to have a collaborative effort from both the affected employee via consultation with the relevant workplace stakeholders, is emphasized as a priority.

Participant J felt she was accommodated when she RTW by accepting the working conditions. She did not question or ask for a consultation with her employers as her need to survive through continuous employment was prioritized:

"It's not easy but I can't just do nothing, because I'm working night time." Participant J

Amongst other participants, such as Participant E, he was demoted and subsequently left work due to the lack of communication from his employers when he was replaced. He felt demotivated despite being allowed to RTW to a rank lower than his previous post.

"Because I was replaced. It was head office; they could get someone to replace me because I was not around… I thought by asking they will send me back to the head office… but they said no I could not."

There was no service compromise during participant G's RTW but he felt he could have been alternatively accommodated for his stroke sequelae. He felt he was insensitively handled as he was hastily boarded off due to medical reasons:

"They just came to me that your medical boarding has been approved. But they never came and try to analyse exactly what is it and how they can assist… and you know what I was turned down by this story that you can never work for the … since you took medical boarding, or you can never work in this section." Participant G

The employer's inability to accommodate Participant I to RTW overshadowed his efforts to RTW:

"It was the decision of the … company owner that I won't be able to fit on the kind of the job that is done there. And I wasn't registered, it was a temporal job. He told me that If he had another light job that I could do he would have offered me that job but he doesn't have anything light to do and also his work is periodical…he tried to explain to me, he said if he had registered employees he would have kept me to clean the light things but the cleaning there is difficult, like loading sand into a bakkie, you use a spade, it would be difficult to put me back." Participant I

Return to economic productivity of a stroke survivor who is HIV positive

The following two themes, societal factors and future QoL and RTW prospects highlight the profile of a stroke survivor who is HIV positive willing to return to economic productivity in this population. Listed and elaborated on are codes developed that were most common and worth mentioning as RTW related information. This information interplayed with their QoL and refocused a RTW effort as a return to economic productivity.

4.7. Theme 5: Societal factors

In literature reviewed, despite continuous quantification required, societal factors are sound contributors to potentiate an acceptable QoL inclusive of work as part of that construct.

4.7.1. Barrier to an acceptable QoL

Social Stigma

Some of the participants reported discrimination due to their altered health status. Enduring a stigma from any societal belonging is difficult especially when this stigma extends itself to engulf the independence that once defined a person's livelihood.

"It's difficult because when you are sick there's that stigma…They speculate that it's because of a certain disease or condition, but I eventually accepted." Participant I

"Socially, yes. Some of my friends now they just stood away from me. Since now I'm not as normal as I used to and active as I was. I lost lots of friends, girlfriends all that stuff they learnt to distance themselves from me." Participant G

"I still do have my own car. I can't drive it now. I can't walk, I can't do anything and it pains to see someone taking advantage of your things because you are just seating there, you can't do anything you are just looking, and you can't do anything about it." Participant L

The importance of societal support encourages a stroke survivor who is HIV positive to persevere returning to economic productivity but their stroke sequelae rewarded them with much despair:

"Some say I must study to be a cashier. That course is very expensive. Some are negative. They say I will not work anywhere because I use one hand." Participant A

"Those words that I can't pronounce clearly or correct, screaming South Beach Point, South Beach Point now there's that thing that now when I talk I also drool and that causes trouble between me and the passengers because some of them laugh and then I end up feeling like I should just say bad things to them, and I also feel like they take me for a fool the way they act," Participant H

Participant H, however, responded with much thought provocation that endurance and tolerance to society be exercised for one's own job satisfaction because work is an important life role to safeguard. He believed it would improve job performance through self-reflection on their interaction with society:

"As you understand your family you must understand other people, as this person entered the car and said some words towards you it doesn't mean that you must take that personally, understand that, them jumping into the taxi helps you, if they didn't get into your taxi you wouldn't be happy,"

4.7.2. Family support

Family support structure towards RTW efforts:

Participants were assisted by immediate and extended family members through financial, moral, caregiving and QoL support. The support of their family towards a new job comforted the loss or decline of a productive livelihood and established QoL.

"We have a family business. They knew what I was doing before. So, we had difficulties in our business. They took me and said I do that and the business is doing very well." Participant E

"It is my little sister. She always tells me to send my CV if there are any vacancies." Participant A

"The only person who seems to show any concern about me going back to work is my wife. She always tells me that I should make a quick recovery so that I may go back to work or go find employment elsewhere." Participant D

"Yes, but currently I'm doing a business so I don't mind with me not going back to work. My brother said I'm a good person to venture into the business." Participant C

4.8. Theme 6: Future QoL and RTW prospects

4.8.1. Promoting a better QoL

An improved outlook through employment

Using the opportunity to get into a new job setting was seen as a form of health promotion towards a positive prognosis of the participant's condition:

"Where I am right now, it helps me a lot because I can do some exercising instead of sitting at home and doing nothing. It helped me a lot." Participant E

"When you get a new job, you will experience new challenges. I believe that in life you must have challenges. For me life will be boring if life has no challenges… But if I can get a new job that will challenge me, I will be very happy." Participant D

4.8.2. Realistic goal setting towards new job opportunities

Impact of altered health status on work suitability

Post stroke, the residual abilities guided realistic goal setting on the suitability of work sought:

"Every job out there is designed for me, I think. Unless if it is a job that requires physical strength. Every type of work suits me. I can do it. If they ask me to manufacture a car, I will tell them what I need to make that car. That job I can do as well. I can even work at a call centre. I can talk to people." Participant D

"I think being a security guard would suit someone with the same condition as me because you are not required to do any heavy lifting." Participant K

Two participants further mentioned that their health status once improved would determine their ability to seek better job opportunities:

> *"Maybe when I get better. I would like to have a job. Another job… so I can be able to do things for myself not asking anybody else." Participant C*

> *Interviewer: "How do you feel about finding a new job?" Participant L: "That I would do when I feel better… Because I'm not going back to my old job."*

Benefits of returning to economic productivity

The need for an improved socioeconomic status was highlighted as a renewed lease on life from attaining economic productivity through a new job.

> *"I think I would be happy for a new job and it will improve my life even at home… supporting my family at the most. Because now I'm depending on my uncles who have better jobs at the moment and the kids need transport money to school and a lot of other thing." Participant I*

> *"I would be helpful because this grant money is not enough. I have a lot… My children must eat, you know food is expensive these days, get new clothes and we should travel to collect ARVs. So, transport is another expense." Participant A*

> *"Maybe I can go and visit home." (Home is East London from Durban, has not visited for a few years due to unfair demands from job type and remuneration) Participant J*

4.9. Conclusion

Via an inductive process of data analysis, the results of this research study presented HIV positive stroke survivors' involvement in a RTW process. Beyond the knowledge gained about their demographic and clinical characteristics, their experiences in a RTW process or contemplation with an emphasis in seeking economic productivity by RTW and the snapshots of a better QoL, set in motion an informed and tangible approach to explore RTW efforts. The next chapter sheds light on phenomena common as well as unique to PLHIV who are also stroke survivors.

CHAPTER 5

DISCUSSION

5.1. Introduction

This research study investigated the influence of HIV on stroke survivors' RTW in a population of the eThekwini district, Kwazulu-Natal. It was conducted to determine the demographics and clinical characteristics, establish the rate of RTW and gain insight into the reasons for either RTW or not of stroke survivors who are HIV positive in this population of the eThekwini district, Kwazulu-Natal. Data were collected by means of a demographic questionnaire and semi structured interview that were administered to 12 participants recruited at a regional hospital in Durban. The interview method of data collection was preferred because phenomena can be derived from several individual experiences to develop a deeper understanding about the features of a phenomenon (Moustakas, 1994; Creswell, 2007). Studying the experiences and meaning of a disease aids in exploring personal and sensitive themes. As the significance of this study outlined, such exploration can help identify potentially modifiable factors to improve health care (Wright, Holcombe and Salmon, 2004). Descriptive statistics of the demographic questionnaire together with thematic analysis using an inductive approach to the data transcribed from the semi structured interviews were presented.

5.2. Demographics and clinical characteristics of the participants

The mean age of this study population was similar to the populations studied in previous works of stroke survivors who are infected with HIV (Ortiz *et al.*, 2007; Chow *et al.*, 2012; Heikinheimo *et al.*, 2012; Benjamin *et al.*, 2014; Edwards *et al.*, 2018; AbdelRazek *et al.*, 2018). Only 25% of the study population developed a stroke within a year deeming IRIS and associated vascular endothelial pathological changes a possibility but requiring further research. This is similar to a study by Heikeinheimo (2012). As the remaining population developed a stroke beyond a year post ART initiation, regular medical screening of people living with HIV (PLHIV) to evaluate the risk of stroke development or other side effects may be considered.

More than 80% of the participants during either the onset of stroke or HIV diagnosis were breadwinners. An individual's financial status relative to survival is considered a determinant of work consideration (Conyers and Boomer, 2017). The participants' livelihood by virtue of their altered health status may well have been jeopardized resulting from the sudden loss of

employment that burdens society (Persson, Ferraz-Nunes and Karlberg, 2012). The economic burden of the participants may have been alleviated if they either earned a state dependent disability grant (DG) or attracted disability benefits from an insurance holding. No literature was found to inform the author of stroke survivors' accessibility to DG in SA but PLHIV provided they meet the prescribed, objective criteria (SECTION27) do receive state aided DG amongst other acceptable populations to relieve poverty and protect economic shock (Brockerhoff, 2011). Provided that there is equality in the formal processes and accessibility of DG applications would the relief and protection be felt for the vulnerable populations (Govender *et al.*, 2015) which should include HIV positive stroke survivors. Only a third of the study participants and two others earned a state dependent DG or private disability benefit respectively. A small number of the participants formerly worked in developed workplace establishments whilst others for small to medium business enterprises. As part of an employee's remunerative package, the provision of disability insurances may not be a necessity. Further on, this fringe benefit may not be affordable for the employer. Introducing affordable disability insurances for employers to partake in also, is worth considering. During a transitional phase of RTW consideration which may include alternative job seeking, the provision of economic support to maintain an acceptable QoL and HRQoL alleviates the affected employee's stress and burden on society (Saka, Mcguire and Wolfe, 2009).

5.3. Return to economic productivity of a stroke survivor who is HIV positive

The realistic goal setting towards work suitability influenced the need for vocational rehabilitation due to the impact of an affected employee's altered health status. Only two participants had tertiary level education, but the researcher is unaware of their qualification achieved as it was not a question asked in the demographic questionnaire. For stroke survivors, the significance of educational status remains largely debatable (Vestling, Ramel and Iwarsson, 2005; Hackett *et al.*, 2012; Larsen *et al.*, 2016) but inclusive of other dependent variables such as white collar jobs, it may indicate a RTW opportunity for them (Peters *et al.*, 2012). It may differ across other similar populations studied in different geographical locations that their educational level may guide work accommodation through work trials or suitable job opportunities through vocational decision making (Maaijwee *et al.*, 2014). A higher education level indeed increased the likelihood of RTW in different geographical locations (Vestling et al., 2003; Lindström et al., 2009; Peters et al., 2012; Chang et al., 2016) which is considered a part of an employee behavioural intervention incorporating training and work trials (Clayton *et al.*, 2012). A higher education level, clearly defined career path and work experience (Culler *et al.*, 2011) may pave a road in the likelihood of RTW which through appropriate vocational rehabilitation also encourage an early RTW (Chang

et al., 2016). A worthwhile resolve would be to accommodate the affected employee returning to work with skills development from their previous or similar job roles or a modified job. The comprehensive length of time to evaluate the success of a work trial especially in a similar or modified job post is necessary. Due to the unknown reason for educational lapses with lower cognitive capabilities and lack of occupational skill level (Vestling, Tufvesson and Iwarsson, 2003; Hofgren *et al.*, 2007; Kauranen *et al.*, 2013), the restoration of prior, equal remuneration is debatable. The question posed is based on the comparative meaning of work (Westerlind, Persson and Sunnerhagen, 2017) to RTW (Rueda *et al.*, 2012). Was the decision to RTW or seek a new job opportunity to restore prior employment benefits or restore breadwinner status for these participants?

The studied population were largely defeated when thoughts of RTW and workplace integration were presented. Despite a handful of participants attempting to RTW and even fewer *making the cut,* the difficulty of transitioning from healthcare to a workforce is acknowledged (Brannigan *et al.*, 2017). A few of the participants mentioned the benefit of societal support enhancing their RTW process (Vestling, Ramel and Iwarsson, 2013), as they desired to return to economic productivity. Work trials provide important information to bring insight into the RTW process. With the aid of an adjustment period which includes recovery time, an attempt could be made by stroke survivors to RTW (Brannigan *et al.*, 2017). A graded RTW approach with the inclusion of work adaptations or possibly entering different job types can enhance the RTW initiative and work sustainability following stroke (Gilworth *et al.*, 2009; Brannigan *et al.*, 2017; Schwarz, Claros-Salinas and Streibelt, 2018). The studied population emphasized the physical impairments following stroke as a foremost deterrent to RTW which Vestling (2013) called on to spearhead a work trial as part of the RTW process. Their difficulties in overcoming the various stroke sequelae with the need to maintain their ART regime unprejudiced at the workplace, is worth investigating. It could be seen as a part of a graded RTW approach inclusive of a work trial, both within this district and the greater boundaries of South Africa. These initiatives may need to continue after RTW as hidden problems could only appear several month post RTW (Culler *et al.*, 2011). To the author's knowledge, no research is available to support RTW initiatives and facilitations in stroke survivors who are HIV positive. In the African context, there was only one study that showed benefit in RTW facilitations amongst stroke survivors (Ntsiea, Van Aswegen, Lord and Olorunju, 2015).

Considered a newfound disability at the workplace (Arwert *et al.*, 2017), participants' physical and lesser yet notable cognitive impairments challenged their workplace participation (Naess *et al.*,

2004; Arwert *et al.*, 2017). Stroke survivors' physical and cognitive impairments negatively influenced ADLs which made RTW difficult. One abstract but strong view was a participant whose inability to use transport was identified as a need for work contemplation. This barrier to RTW (Treger *et al.*, 2007) can therefore be linked to a work-related health concern (Martin *et al.*, 2003). It is not clear why this RTW barrier was poorly identified since there were nine other participants who accessed transport to work. E-hailing services such as Uber, Taxify and others can be considered an accommodative RTW strategy. Due to the exponential rise in personalized transportation service as suggested which may result in non-affordability, employers may consider either a payable travel subsidy or incorporate it in-house as an employment-based fringe benefit.

Apart from the exclusion of HIV positive aphasic stroke survivors in this study, it is not clear why other healthcare services were poorly recruited to address residual stroke sequelae. A reason for the high consultation rate of participants with medical doctors is suggested to be follow-up visits to review a patient's prognosis. Physiotherapists are primary healthcare providers during a patient's stroke onset and subsequent hospital admission and upon discharge from in-patient care (Geerars et al. 2021). This may possibly be the explanation for an even higher consultation rate with physiotherapists. There was only one participant who emphasized the impact of her resultant cognitive and communicative impairments on her variably skilled occupational tasks. It is speculative that due to the lower number of white-collar occupations in the sampled population, there was greater emphasis placed on the physical abilities which dampened emphasis on the cognitive and communicative abilities to RTW. The interaction of multi-morbidities on HIV positive stroke survivors RTW was not a part of this study's objectives or reviewed in any background literature. From data collected via the demographic questionnaire, we noted a low representation or reporting of only three co-morbidities i.e. Asthma, Hepatic-related conditions and Hypertension. During the semi-structured interview, there was no mention or responses of such interaction with the participant's resultant stroke, HIV or ART in their RTW effort. A greater sample size may shed light to the potential impact of multi-morbidity on HIV positive stroke survivors' need to be supported by both suitable RTW enabling healthcare and non-healthcare professionals. It may be plausible that this oversight warrants future investigation into the inter-relational associations that may inform or dissolve specific, relevant stakeholder intervention and communal initiatives.

Despite the varying degrees of physical and cognitive capabilities needed amongst blue and white-collar occupations, there is an undeniable need to satisfy all domains of QoL. It is well

documented that in both PLHIV and stroke survivors, a person's highest level of QoL and HRQoL illuminated the viability and realism of work. A greater independence in ADLs (Vestling, Tufvesson and Iwarsson, 2003; Saeki and Toyonaga, 2010; Tanaka, Toyonaga and Hashimoto, 2011, 2014; Hackett *et al.*, 2012; Waje-Andreassen *et al.*, 2013; Ntsiea, Van Aswegen, Lord and Olorunju S, 2015; Bonner *et al.*, 2016) may promote the higher level of QoL and functioning to avoid work related disability at the very least (Opara and Jaracz, 2010; Schwarz, Claros-Salinas and Streibelt, 2018).

From results shown in Table 4.4 it was concluded that there was an equal ratio of participants who desired to RTW to their previously held job to those whose ambition was to seek a new job. From the equal ratio of participants, it is noted that the participants' consideration could have been better informed. The consideration is substantiated on four participants who were in some way, which was not explored in this study, guided by healthcare professionals on a RTW process. Out-of-hospital consultations with other healthcare professionals are dependent on referrals from those with an appreciable knowledge of holistic stroke care management. Improving the holistic stroke care management healthcare providers render to enable a RTW process is continuously advisable. The training may include improved identification and appropriate referral to other suitable RTW enabling healthcare and non-healthcare professionals. Like PLHIV that increase their level of work consideration by reducing health distress (Conyers and Boomer, 2017), stroke survivors similarly would benefit. This is a reminder of the resourcefully demanding reply needed to the multitude of effects on various life roles due to stroke (Krishnamurthi *et al.*, 2013; Feigin *et al.*, 2014; Vos *et al.*, 2015). The evidence from this study suggests that there should be engagement with RTW professionals to address the HRQoL determinants. This suggestion is implied as the RTW process is holistic and that the relationship of QoL and RTW through previous research and from this study is that to be of a hand in glove type.

A participant's lack of social support led to his poorer social well-being which is a deterrent to QoL. As with another participant, their subsequent RTW contemplation was negatively fuelled and only because of her socioeconomic status did the sole participant force her RTW. The question of a consultative RTW process echoed in those participants who were unsuccessful at efforts to RTW. The sole participant who returned to their previously employment may have preferred to avoid a consultative RTW process. This was due to the fear of becoming economically unproductive, compromising their livelihood based on the altered health status. For two other participants, it may have benefitted them to have a consultative RTW process. They desired to

be accommodated at the workplace. The undesirable workplace accommodation these two participants faced in their quest to restore their prior employment benefits, were common. In one of the two latter participants, he felt he recovered adequately to assume a change in his job description. A work trial may have benefitted him. The use of ART may have improved his, self-reported, QoL and RTW productivity levels over time which promoted his overall urge to RTW. The desire to restore his prior employment benefits would have positively influenced his medical prognosis viz. with a medical aid. Being medically boarded eliminated the possibility of re-entering the workforce (Martin *et al.*, 2012; Conyers and Boomer, 2017). The other participants, who desired to RTW by looking for new job opportunities, were ambitious to restore a breadwinner status (Palstam, Törnbom and Sunnerhagen, 2018). The desire to seek a new job opportunity does not guarantee prior employment benefits restored, but from this study population, it may be a search for work to minimize the negative effect on their QoL. This revised mission to seek a new job opportunity seemed to be more tangible due to the prospective benefits compared to their previously known employment benefits. An overall support system therefore may encourage a better QoL (Owolabi, 2008) and HRQoL (Murri *et al.*, 2003; Ruiz Perez *et al.*, 2005; Briongos Figuero *et al.*, 2011; George *et al.*, 2016). Social well-being may be viewed as a non-clinical factor of RTW contemplation. The sole participant who returned to work, lacked a support system. Combined with the prejudicial behaviour of her employer due to her altered health status, the fear of losing her job was exacerbated. The lack of social and family support as Owolabi (2010) and Akosile (2013) suggested, jeopardized her work status. Although it was not an objective of this study, participants viewed a support system integral to the restoration of prior employment benefits or a breadwinner status for those seeking new job opportunities. A holistic support system during the RTW process which includes both a non-clinical and clinical component will be beneficial in the RTW programme, preventing a misinterpretation of one's ability towards either a premature RTW or overestimating an eventual non-RTW.

Study participants mentioned that a positive, economically productive work environment to maintain employment after HIV status disclosure is challenging. Some participants felt there was no need to disclose because of its irrelevance to job performance (Wagener *et al.*, 2014) and fear of workplace discrimination. Disclosure of one’s HIV status is reported to be a barrier to PLHIV RTW (Fesko, 2001; Brooks *et al.*, 2004; Anderson *et al.*, 2008; Degroote *et al.*, 2014). Some of the participants accepted their HIV status even though it did not restore their former livelihood particularly one participant who was even thankful for being alive. This personal acceptance (Degroote *et al.*, 2014) together with the potential positive effects on RTW productivity through

ART adherence (Robinson, Okpo and Mngoma, 2015) ought to excite the affected employee to disclose their HIV status. An adherence to ART for some participants who accepted their continued livelihood suppressed the need to disclose their HIV status (Wagener *et al.*, 2017). If health education and ART considerations positively influence the workplace, then it could stimulate a positive economic productivity at the workplace including the affected employee. It allows employees to disclose both HIV status and ART regime to continue and maintain employment. This could through ART bring longevity of life as employers and the workplace support the RTW process. Education at the workplace can stamp out negative employer attitudes that may cloud their perceptions of affected employee's productivity level which as it was already mentioned is a primary concern in a workplace. This will encourage better workplace accommodation as well as retaining affected employees (Robinson, Okpo and Mngoma, 2015).

Participants shared their experiences of side effects from ART adherence which affected their QoL. The altered health status should warrant continuation with healthcare needs. The continued ART adherence despite residual stroke sequelae can prevent related side effects that may lead to unnecessary medical consultations, hospital admissions and an overall negative QoL which may extend the time away from engaging in work. Participants who wished to practice ART adherence by requesting time away from work to attend to their healthcare needs may minimize the negative effect on workplace productivity. There is evidence from Sub-Saharan African research done which showed that ART adherence from as early as a month post HIV diagnosis resulted in a decrease of absenteeism and conversely an increase in work productivity and performance (Beard, Feeley and Rosen, 2009). The responses echoed their conscious and caring effort to collaborate with employers to ensure continued workplace productivity which subsequently sustained their employment through a strengthening workplace relationship. A challenge may be to mitigate the flattering, initial treatment optimism in the early stages of ART regimes being adhered to, with longer term treatment fatigue (Beard, Feeley and Rosen, 2009).

A workplace environment devoid of support from supervisors, colleagues and managers is toxic to the relationship with affected employees. These employees struggle therefore to sustain employment (Palstam, Törnbom and Sunnerhagen, 2018). Introducing effective health education with an overall involvement of all stakeholders in the workplace can harness the ideal workplace environment illustrated through the works of Palstam (2018). Awareness initiatives, incentivized where possible, such as regular in-house trainings and guest speaker talks amongst the workforce, and work support groups towards employment wellness programmes can ramp up the

prevention of prejudicial and stereotypical behaviour found in HIV affected populations at the workplace (Dos Santos *et al.*, 2014; Odek, Glendinning and Charalambous, 2014). The refreshed view to disclose an ART regime with HIV status through health education at the workplace should alleviate HIV related discrimination and stigmatization. The promotion of a collaborative RTW process therefore ensures transparency between employers and affected employees through an enhanced consultative RTW process (Vestling, Tufvesson and Iwarsson, 2003). With caution, despite the positivity created, a potentially disempowering reality is the consideration for consequential stroke sequelae in this and future, similar studied populations.

5.4. Conclusion

Participants expressed their desire for continued employment or to engage in productive employment that would either improve or maintain an acceptable socioeconomic status. Their health related, work related and societal factors influenced their decisions made and outcomes that followed. This research study raised further exploration into economic productivity that HIV positive stroke survivors navigated through. The final chapter to follow concludes with limitations and suggestions for future research, that which can be made from this research study.

CHAPTER 6

6.1. Conclusion

This research study sought to determine the influence of HIV on RTW in stroke survivors in a region of the eThekwini district, Kwazulu-Natal. Unemployment severely impacts a person's QoL in which their health status dictates potential change to employment or extent of their disability. In cases of HIV infections, the presentation of stroke can be atypical which makes the resultant sequelae unpredictable. Even with cART that is known to suppress the HIV replication, it comes with the risk of predisposing a user to the development of stroke. An extremely integral component for a PLHIV who has had a stroke is being able to resume work but also for the workplace to accommodate him or her or accomplish their previous work tasks. This would satisfy the work demands.

This study illustrated the consequences suffered from the stroke to HIV positive participants. The altered health status called for concerns related to their financial status, the need for vocational rehabilitation and viewing transportation as a consideration to address in the RTW process. Their HIV diagnosis and status thereafter spurred on a movement of health education especially at the workplace to alleviate discrimination and a fear of stigma. This initiative would promote a collaborative RTW process between all stakeholders including the affected employee at the workplace. The disclosure of HIV status with increased motivation to disclose their use of cART would be advantageous in continuing their need for medical care and time away from work and ensure employers plan for their absence and maintain productivity.

Having a support structure and maintaining employment post HIV and ART disclosure stimulates positive economical productivity. A consideration to train RTW enabling professionals will inform better decision making and realistic goal setting towards a RTW or seeking a new job opportunity for HIV positive stroke survivors. In minimizing the negative effects of unemployment by restoring a QoL, the desire to RTW can be viewed by one restoring their prior employment benefits. Despite a weaker finding in the study, this is worth mentioning as it reinforces the need for vocational rehabilitation and work trials with other social determinants in RTW amongst HIV positive stroke survivors.

6.2. Limitations

The researcher was unable to recruit participants from other proposed institutional sites as the sites did not respond to permission sought to conduct the study. The results thereof may be homogenous but given the choice of semi structured interviews conducted, it captured a fair representation of thoughts and experiences from those of the same geographical location. The definition of RTW compared to returning to a work environment in this study seemed to be ambiguous. The inclusion criteria stipulated “up until the time of stroke” with the demographic questionnaire reporting a 50% split in those participants desiring to RTW and those participants seeking a new job opportunity. The author investigated RTW to a previous occupation. The analysis accounted for those wishing to return to economic productivity in view that a high percentage of them were breadwinners. The perspectives of stakeholders in the RTW process were not accounted for as it was not an objective of the study. In the analysis, the barriers encountered by those who attempted to RTW were mentioned. Based on the demographic questionnaire, the equal split of those choosing another job over RTW means that it is important to explore these perspectives to better inform the RTW process or seek proper closure.

6.3. Recommendations

Findings highlighted the need to investigate non-clinical factors such as education at the workplace in respect to HIV and ART disclosure and its contribution towards the overall RTW process may be worthwhile. An extension of this may involve a longitudinal study to investigate the contribution of RTW enabling professionals and other support services for PLHIV who are also stroke survivors, towards the attainment and sustainment of work using QoL as a possible outcome measurement. The definition of work and RTW used in this study was limited to the concept of self-employment. In the South African context, escalating and alarming unemployment rates may warrant the exploration of self-employment or attaining skill sets towards entrepreneurship as a beneficial alternative for HIV positive stroke survivors. This may bring an attainment of economic productivity, reclaiming a livelihood and sense of purpose. There would be a need for access to other associated health facilities' databases to recruit a wider sample size which would improve the ability to generalize findings in this specific population. A snowball sampling strategy could attract a greater sample size given the possible knowledge of other client relationships or connections established through ongoing medical care and/or as supportive structures. The data saturation reached however brought a rich and meaningful account of these participants’ lives which shed light on a novel topic.

From the analysis and discussion of the data collected in this research study, the conclusions reached illustrated that HIV positive stroke survivors indeed require further exploration into their RTW processes. The author found that despite no other literature found to date exploring the RTW process of HIV positive stroke survivors, the need for a multi-disciplinary approach to be further diversified may benefit the affected individual. For a Physiotherapist specifically, this additional information and the global plethora of other relevant research will inform and improve perspectives to advocate a universal RTW approach. Ultimately, an individual's QoL remains tentative, until an affected individual seeks closure on their remaining value to a workforce and livelihood.

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Appendix A

DEMOGRAPHIC QUESTIONAIRE

Please tick the appropriate box (√)

Personal Information:

1. Age: ☐
2. Gender: Male ☐ Female ☐
3. Race: Black ☐ White ☐ Colored ☐ Indian ☐ Other ☐
4. Education: No school ☐ Foundation phase (Grade R-3) ☐
   Intermediate phase (Grade 4-6) ☐ Senior phase (Grade 7-9) ☐
   FET phase (Grade 10-12) ☐ Tertiary ☐
5. Is the place you staying at:
   Owned ☐ Rented ☐ Shared with family/ friends ☐

Related medical information:

6. When were you diagnosed with HIV?
   _____ (month and year)
7. Have you started ARV (antiretroviral) treatment? Yes ☐ No ☐
   If yes, when? _____ (month and year)
8. When did you have the stroke?
   _____ (month and year)
9. Which side of your body is weaker? Left ☐ Right ☐
10. Which is your dominant hand? Left ☐ Right ☐
11. Following your stroke, did you receive treatment from the following health workers and when?

Health Worker	Yes	No	When?
Medical Doctor			
Physiotherapist			
Occupational Therapist			
Speech and Language Pathologist			
Audiologist			
Social Worker			
Dietician			

Any other? Yes ☐ No ☐

If yes, list who? _____

12. Do you have any of the following illnesses/ Do you take any tablets at home? If yes, what is it for?
    - -Hypertension/ High blood pressure? ☐
    - -Diabetes Mellitus/ High blood sugar? ☐
    - -High Cholesterol? ☐
    - -Heart conditions? ☐
    - -Vascular conditions? ☐
    - - Any other medical conditions not listed:

    Please list: _____

Economic status:

13. What was your financial role when you were diagnosed with HIV?

    Sole breadwinner ☐ A breadwinner/ contributing ☐
    Dependent ☐ Not contributing ☐

14. What was your financial role when you had the stroke?

    Sole breadwinner ☐ A breadwinner/ contributing ☐
    Dependent ☐ Not contributing ☐

15. Are you receiving a disability grant? Yes ☐ No ☐

    If no, have you applied? Yes ☐ No ☐

16. Have you received any disability benefit from a private insurance company?

    Yes ☐ No ☐ Pending ☐ Never heard of such ☐

Employment status:

17. Are you currently working? Yes ☐ No ☐

18. What was/is your occupation?

    _____

19. Did you return at any point to your previous job? Yes ☐ No ☐

20. Did anyone help you to understand how you can be accommodated at your workplace e.g. a doctor at the hospital, a therapist, someone you worked with etc.?

    Yes ☐ No ☐ If yes, who was it? _____

21. Would you: Continue to work ☐ Resign ☐

Prefer to seek another job ☐

Appendix B

Inani labantu abazobuzwa

Imininingwane egondene nawe:

1. Iminyaka: ☐
2. Ubulili: Indoda ☐ Isifazane ☐
3. Uhlanga: Unsundu ☐ Umlungu ☐ Ikhaladi ☐ Shaniya ☐ Okunye ☐
4. Imfundo: Inani lezikole ☐ Amabanga aphasi ☐
   Amabanga amanje ☐ Amabanga aphakeme ☐
   Ezamakhono ☐ Ekugogoda ☐
5. Indawo ohlala kuyo:
   Ingeyaho ☐ Uqashile ☐ Uhlala nomuntu ☐

Okunye kwempilo nokuhlanganise isifo sohlangothi

6. Sikuqale nini sifo sohlangothi?
   _____
7. Iliphi uhlangothi lomzimba olulula? Sonxele ☐ Esokudla ☐
8. Iliphi uhlangothi lomzimba olusebenzayo kakhulu? Sonxele ☐ Esokudla ☐
9. Uke uhambele isikhungu sokuhlomulisa ngezempilo? Yebo ☐ Cha ☐
10. Unazo ezinye izifo kwezingezansi?

- Isifo senhliziya?
- Isifo sikashukela?
- Cholesterol?
- Inkinga yenhiliziyo?
  Uma uthi yebo, chaza kabanzi? _____
- Vascular problems?

Uma uthi yebo, chaza kabanzi? _____

- Zikhona ezinye izifo ezingabalwanga?
  _____

11. Uqale nini ukuba nesandulela ngculazi?
    _____
12. Usuqalile ukudla imishangaze yakho? Yebo ☐ Cha ☐
    Uma uthi yebo, nini? _____

Isimo somnotho

13. Iliphi ihlandla obukulo lomnotho ngaphambi kokulinyazwa uhlangothi?

    Ubuzimele wena ☐ Ubuwondla ekhaya ☐
    Ubuziphilisa ☐ Ubungakhiphi lutho ☐

14. Iliphi ihlandla obukulo lomnotho ngephambi kokuba nesandulela ngculazi?

    Ubuzimele wena ☐ Ubuwondla ekhaya ☐
    Ubuziphilisa ☐ Ubungakhiphi lutho ☐

15. Ubesebenza muphi msebenzi?
    _____

16. Ubuyithola imali yokukhubazeka? Yebo ☐ Cha ☐ Ubuphila ngayo ☐

17. Ubuyithola imali yokungakwazi ukuzenzela isibonelo ngemali yomshwalense noma yasemsebenzini?

    Yebo ☐ Cha ☐ Ubuphila ngayo ☐

18. Sikhona isimo sakuphoqa ukuthi ukubuyele emsebenzini walkudala?
    Yebo ☐ Cha ☐

19. Uyasebenza okwamanje? Yebo ☐ Cha ☐

20. Uma impendulo yakho ku yebo kumbuzo ongenhla nyathanda?
    Ukuqhubeka nomsebenzi ☐ Ukusula ☐ Udinga omunye umsebenzi ☐

21. Bayishitsha impilo noma wajwale isimo? Yebo ☐ Cha ☐

Appendix C

Interview Questions

1.

a. You had the stroke in (mention from questionnaire). Tell us what happened?

b. Can you remember what difficulties you had before the stroke?

c. Can you remember what difficulties you had after the stroke?

d. How has the stroke affected your life?

e. How has HIV affected your life?

f. **(If on treatment)** How has the ARV treatment affected your life?

2.

a. Briefly, describe your work.

~~b.~~ How far was it from your home to work? How did you travel to work and home?

c. Why/why not have you returned to work?

d. Do you think HIV, stroke or both brought you to this point? Why?

e. What challenges have you encountered RTW? How have these been addressed?

f. How did your employer accommodate your RTW? [lighter/alternate work, asking them, their responses]

g. Who else at your workplace assisted in trying to accommodate or help you through your difficult times or return to work or finding a new job? Tell us what did they do for you?

h. Who else in your life assisted in trying to accommodate or help you through your difficult times or return to work or finding a new job? Tell us what did they do for you?

i. Did you reveal your status to your employer? Why/ Why not?

j. Is it important to reveal your status to your employer? Why?

k. How do you feel about returning to work? Why?

l. How do you feel about finding a new job? Why?

m. Is there a job available for you? If NO, why? If YES, what job do you think is available for you and why?

n. What do you believe are factors that could facilitate and promote someone similar RTW? Why?

o. What do you believe are factors that could be obstacles that affect someone similar RTW? Why?

3. Is there anything, related to your stroke and returning to work, that you want to talk about?

Appendix D

Ingxoxo yemibuzo

1. Ngicela ungitshele kabanzi ngesifo sohlangothi.
    a) Sikuqale nini sifo sohlangothi futhi siqale kanjani?
    b) Ungakhumbula ukuthi buphi ubunzima obuhlangabezana nabo ungakabi ne sifo sohlangothi? Ngaphambi kokuthi ube naso ibuphi ubunzima ohlangabezane nabo?
    c) Ukuba nesifo sohlangothi kukuphathe kanjani empilweni?
    d) Ukuba nesandulela ngculaza kukuphatha kanjani empilweni?
    e) (**Uma udla imishanguzo**) Ukudla imishanguzo ye ARV kuyishitsha kanjani mpilo yakho?
2. Ngicela ungitshele ngesimo emsebenzini
    a) Ngicela ungichazele ngomsebenzi wakho?
    b) Lingakanani ibanga usuka ekhaya uya emsebenzini futhi uhamba ngani uma uya emsebenzini?
    c) Kungani ungakabuyelanga emsebenzini?
    d) Ucabanga ukuthi isifo sohlangothi kanye nesandulela ngculazi ikona ukwenze ukuthi ume kulesi simio? Ngobani?
    e) Izphi izingqinamba ohlangabezane nazo ukubuyela emsebenzini? Baku chazela kanjani ngalokho?
    f) Umqasi wakho wakuhlanganisa kanjani ne ukubuyela emsebenzini? [bakuxegisela/nomunye umsebenzi, ngokubabuza, impendulo zabo]
    g) Wavela obala ngesimo sakho sempilo kumqashi? Kungani ungakwenzanga lokho?
    h) Ngabe kubalulekile ukuveza isimo sakho sempilo kumqashi wakho? Ngobani?
    i) Uzizwa kanjani ngokubuyela emsebenzini? Ngobani?
    j) Uzizwa kanjani ngokuthola umsebenzi omusha? Ngobani?
    k) Ikuphi okholelwa ukuthi ikona okunga lula futhi kube nomthelela komunye ofa nokubuyela emsebenzini? Ngobani?
    l) Ikuphi okholwa ukuthi kungaba izithiyo ezinganomthelela komunye ofana ne ukubuyela emsebenzini? Ngobani?
3. Ngabe kukhona okunye, okuhlangene nesifo sohlangothi nokubuyela emsenenzini, ofuna ukukhuluma ngakh?

Appendix E

Informed Consent

I, (full name and surname), _____, give permission to Wesley Naidoo and his appointed research assistants to include me in their study to find out the influence of HIV on returning to work in stroke survivors amongst a population in the eThekwini district, Kwazulu-Natal. I also consent to participate in their research study by answering the demographic questionnaire and being involved in an interview.

I understand the reasons for this research study being done. I know that:

- I can leave the research study at any time if I want to do so.
- The information I give will be treated as confidential.
- I will not be paid for participating in this research study.
- The questionnaire and interview will last no longer than one hour.
- Participation in this research study will purely be for the purpose of this study.

Name of participant: _____

Signature: _____

Date: _____

Name of researcher/research assistant: _____

Signature: _____

Date: _____

Appendix F

Ukwaziswa ngemvume

Mina (igama eliphelele nesibongo) _____ nginika imvume ku Wesley Naidoo ngokuqokwa kwakhe nomsizi wakhe ukuthi babekucwaningo lokwazi kabanzi ngengqinamba zokwenza abantu aphila ngogawulayo noma abahlaselwa isifo sohlangothi ukuthi babuyele emsebenzini. Ngizimisele ukubamba iqhaza kuqhazi kucwaningo nakwinhlolokhono no0kuphendula imibuzo.

Ngiyazizwa izizathu zokwenza lokucwaningo:

- Ngingalushiya ucwaningo noma nini mangithanda.
- Ulwazi engininika loans ngicela lube imfihlo.
- Ngeke ngikhokhelwe ukubamba iqhaza kucwaningo.
- Imibuzo nenhlolokhono ngeke idlule e-Horeni.
- Ukubamba iqhaza kulolucwaningo lokufunda kuzocacisa umthelela walokhu kululekwa.

Igama lobambi iqhaza: _____

Sayina lapa: _____

Usuku: _____

Igama lophethe ucwaningo/ umlekeli: _____

Sayina lapha: _____

Usuku: _____

Appendix G

Informed Consent – Audio Recording

I, (full name and surname), _____, give permission to Wesley Naidoo and any of his appointed research assistants to interview me in their study to find out the influence of HIV on returning to stroke survivors amongst a population in the eThekwini district, Kwazulu-Natal, with the use of a voice recorder.

I understand the reasons for this research study being done. I know that:

- I can leave the research study at any time if I want to do so.
- The information I give will be treated as confidential.
- I will not be paid for participating in this research study.
- The interview will last between 30-45 minutes.
- Participation in this research study will purely be for the purpose of this study.

Name of participant: _____
Signature: _____
Date: _____

Name of researcher/research assistant: _____
Signature: _____
Date: _____

Appendix H

Waziswa ngemvume-yomsindo wokuqopha

Mina (igama eliphelele nesibongo) _____ nginika imvume ku Wesley Naidoo ngokuqokwa kwakhe nomsizi wakhe ukuthi babekucwaningo lokwazi kabanzi ngengqinamba zokwenza abantu aphila ngogawulayo noma abahlaselwa isifo sohlangothi ukuthi babuyele emsebenzini. Ngizimisele ukubamba iqhaza kuqhazi kucwaningo nakwinhlolokhono nokuphendula imibuzo.

Ngiyazizwa izizathu zokwenza lokucwaningo:

- Ngingalushiya ucwaningo noma nini mangithanda.
- Ulwazi engininika lona ngicela lube imfihlo.
- Ngeke ngikhokhelwe ukubamba iqhaza kucwaningo.
- Inhlolokhono ngeke ibe ngaphasi kuka 30-45 yemizuzu.
- Ukubamba iqhaza kulolucwaningo lokufunda kuzocacisa umthelela walokhu kululekwa.

Igama lobambi iqhaza: _____

Sayina lapa: _____

Usuku: _____

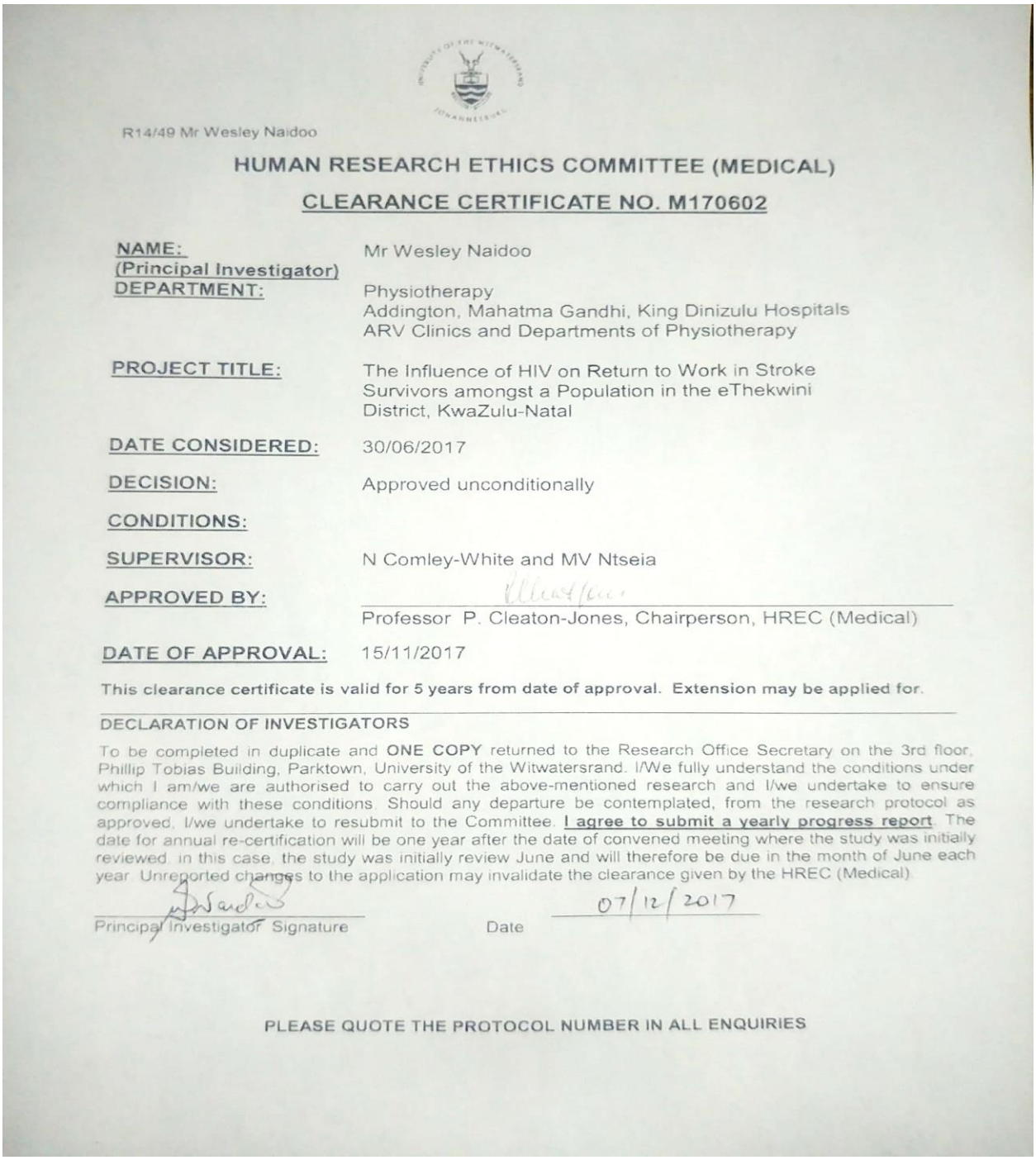
Igama lophethe ucwaningo/ umlekeli: _____

Sayina lapha: _____

Usuku: _____

Appendix I

Human Research and Ethics Committee (HREC) clearance



R14/49 Mr Wesley Naidoo

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M170602

NAME: (Principal Investigator)	Mr Wesley Naidoo
DEPARTMENT:	Physiotherapy Addington, Mahatma Gandhi, King Dinizulu Hospitals ARV Clinics and Departments of Physiotherapy
PROJECT TITLE:	The Influence of HIV on Return to Work in Stroke Survivors amongst a Population in the eThekwini District, KwaZulu-Natal
DATE CONSIDERED:	30/06/2017
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	N Comley-White and MV Ntseia
APPROVED BY:	Professor P. Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	15/11/2017

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on the 3rd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand. I/We fully understand the conditions under which I am/we are authorised to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. in this case, the study was initially review June and will therefore be due in the month of June each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

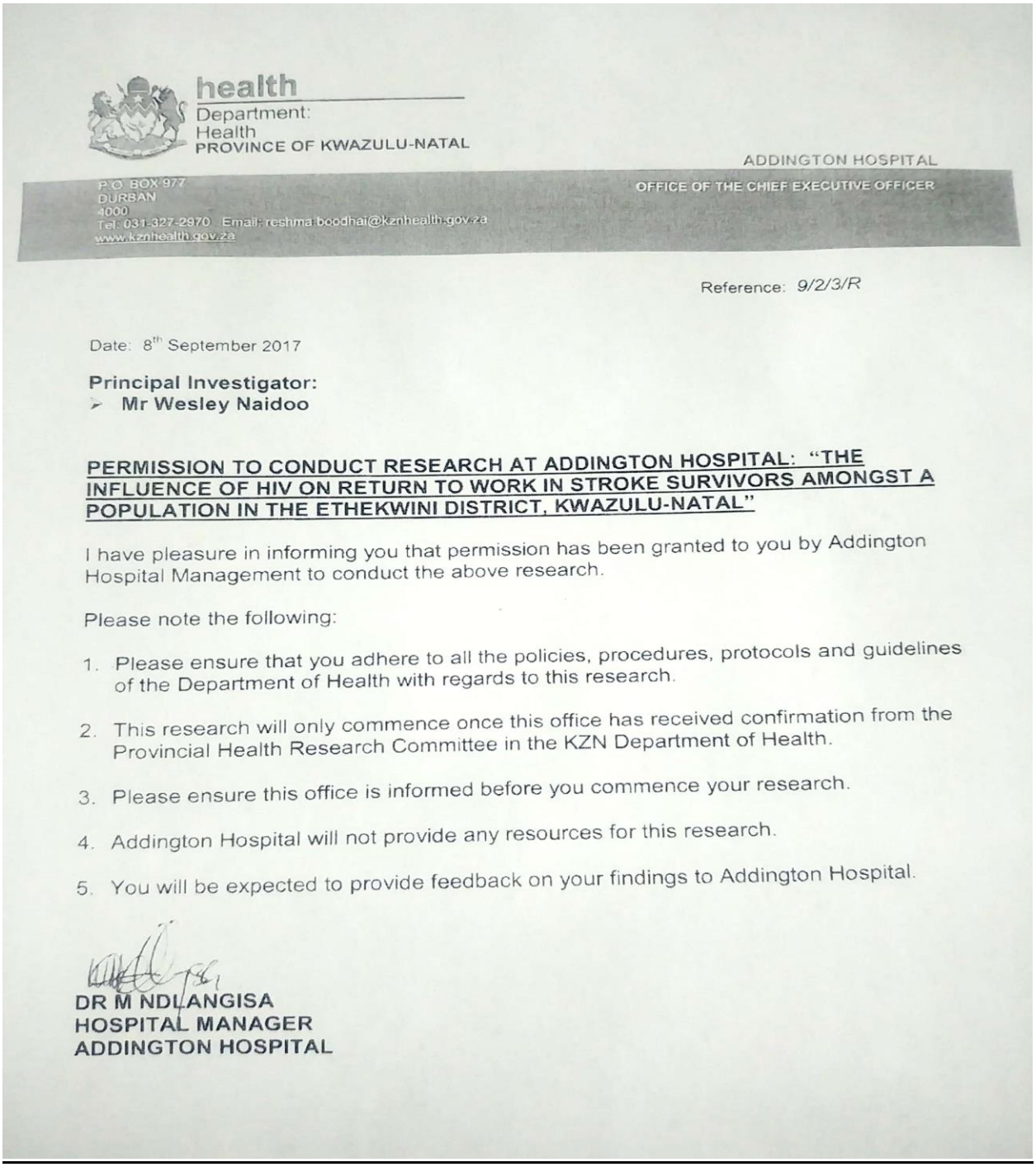
Principal Investigator Signature

Date 07/12/2017

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix J

Permission letter from research site



health
Department:
Health
PROVINCE OF KWAZULU-NATAL

ADDINGTON HOSPITAL
OFFICE OF THE CHIEF EXECUTIVE OFFICER

P.O. BOX 977
DURBAN
4000
Tel: 031-327-2970 Email: reshma.boodhai@kznhealth.gov.za
www.kznhealth.gov.za

Reference: 9/2/3/R

Date: 8th September 2017

Principal Investigator:
- **Mr Wesley Naidoo**

PERMISSION TO CONDUCT RESEARCH AT ADDINGTON HOSPITAL: "THE INFLUENCE OF HIV ON RETURN TO WORK IN STROKE SURVIVORS AMONGST A POPULATION IN THE ETHEKWINI DISTRICT, KWAZULU-NATAL"

I have pleasure in informing you that permission has been granted to you by Addington Hospital Management to conduct the above research.

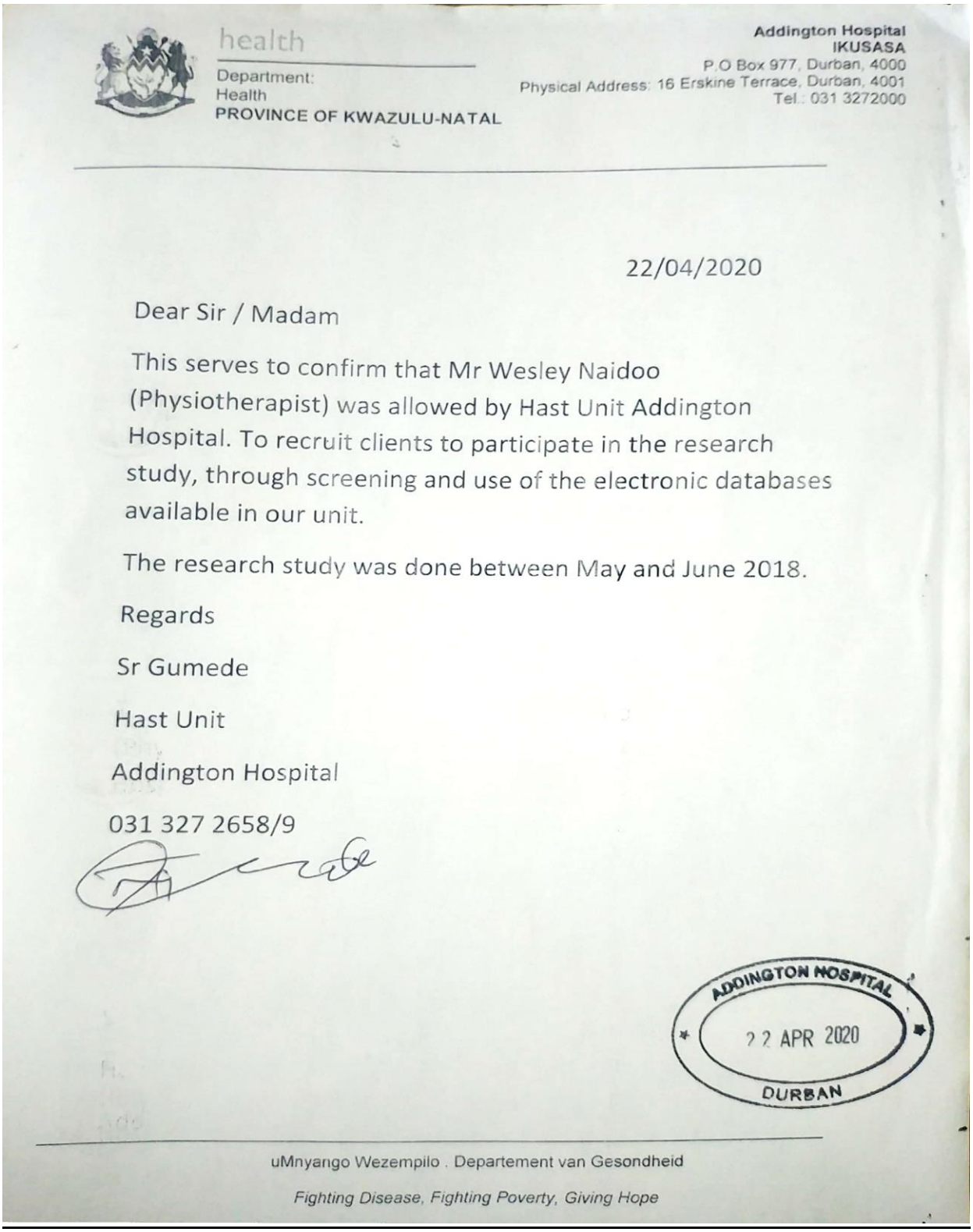
Please note the following:

1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. This research will only commence once this office has received confirmation from the Provincial Health Research Committee in the KZN Department of Health.
3. Please ensure this office is informed before you commence your research.
4. Addington Hospital will not provide any resources for this research.
5. You will be expected to provide feedback on your findings to Addington Hospital.

DR M NDLANGISA
HOSPITAL MANAGER
ADDINGTON HOSPITAL

Appendix K

Permission letter to access patient records from HIV/AIDS clinic (Addington Hospital)



health

Department:
Health
PROVINCE OF KWAZULU-NATAL

Addington Hospital
IKUSASA
P.O Box 977, Durban, 4000
Physical Address: 16 Erskine Terrace, Durban, 4001
Tel.: 031 3272000

22/04/2020

Dear Sir / Madam

This serves to confirm that Mr Wesley Naidoo (Physiotherapist) was allowed by Hast Unit Addington Hospital. To recruit clients to participate in the research study, through screening and use of the electronic databases available in our unit.

The research study was done between May and June 2018.

Regards

Sr Gumede

Hast Unit

Addington Hospital

031 327 2658/9

ADDINGTON HOSPITAL
22 APR 2020
DURBAN

uMnyango Wezempilo . Departement van Gesondheid

Fighting Disease, Fighting Poverty, Giving Hope

Appendix L

Postgraduate office acceptance letter

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Private Bag 3 Wits, 2050
Fax: 027117172119
Tel: 02711 7172076

Reference: Mrs Sandra Benn
E-mail: sandra.benn@wits.ac.za

10 January 2018
Person No: 1480636
PAG

Mr W Naidoo
36 Edgebury Road
Eastbury
Phoenix
4068
South Africa

Dear Mr Naidoo

Master of Science in Physiotherapy: Approval of Title

We have pleasure in advising that your proposal entitled *The influence of HIV on return to work in stroke survivors amongst a population in the eThekwini district, Kwazulu-Natal* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

Appendix M

Information Document

Hello,

My name is Wesley Naidoo, and I am a student at the University of the Witwatersrand. I am doing a research study on the influence of HIV in returning to work (RTW) amongst stroke survivors. Research is just the process to learn the answer to a question. In this study I want to learn from your experiences after surviving a stroke and how it has affected you either RTW or not. I also want to understand your reasons keeping in mind your HIV status, positive or negative.

It is important that you read and understand what is involved. Please do not hesitate to ask me if you need clarity on any issue. If I find potentially distinct differences in reasons that affect people living with stroke returning to work accounting for their HIV as well, it will assist us, health professionals, to modify and devise means to improve our service delivery to such patients. It also will help the employees or patients and employers to create an environment that can accommodate for a successful RTW. This will decrease the increasing burden and need for disability support from public and private resources.

The research study consists of two parts. The first part is a demographic questionnaire in your preferred language i.e. isiZulu or English. This questionnaire is to be completed by you or by either a caregiver after explanation by the research assistant or principal researcher. The questionnaire will build your profile in preparation for the interview to follow, which is part two. The profile consists of your demographic data, your past medical history including your stroke experience and economic status. The questionnaire should not take you a maximum of 10 minutes to complete. The interview that follows will be done in your preferred language i.e. isiZulu or English. 20 questions shall be asked. The interview would take us between 30-45 minutes to complete. I would like to know about your experiences following your known HIV status and the stroke, your working/employment history, personal feelings towards either RTW or not or finding a new job and anything else you wish to speak about relating to the topic of the research study.

Risks

There is no risk to yourself or your family by participating in this research study. No additional cost will be incurred by you or your family when involved in this research study.

Benefits

You will not benefit directly from participating in this study. Indirectly, however, your participation will assist in adding to the growing amount of knowledge, improving the type and quality of management received by people like yourself to access means of sustaining your well-being as best possibly available to probable RTW.

Reimbursements

You will not be paid for participating in this study, but if you are required to travel solely for the purpose of the study, your transport costs will be reimbursed adequately.

Participation is voluntary, and you may withdraw at any time should you wish to do so. You may discontinue participation at any time without penalty or loss of benefits to which you are entitled.

Confidentiality: Efforts will be made to keep personal information confidential. Absolute confidentiality cannot be guaranteed. Personal information may be disclosed if required by law. Ethical clearance to conduct this research has been granted by the University of the Witwatersrand committee for research on human subjects (medical). If you have any complaints regarding how the researcher conducted themselves or the interview or their treatment towards you, you may contact the chairperson of this committee, Prof Cleaton-Jones at Peter.Cleaton-Jones1@wits.ac.za, or committee administrators: Ms. Zanele Ndlovu/ Mr. Rulani Mkansi/ Mr Lebo Moeng at 011 717 2700/ 2656/ 1234/ 1252 or email at HREC-Medical.ResearchOffice@wits.ac.za.

Thank you very much.
Wesley

Contact details of researcher:
Wesley Naidoo, Physiotherapist
Department of Physiotherapy
031 – 327 2345/ 076 771 5716

Appendix N

Imininingwane yolwazi

Sanibona

Igama lami ngingu Wesley Naidoo, ngingumfundi emfundweni ephakeme yase Witwatersrand. Ngenza izifundo zokucubungula kabanzi ngokubuyela emsebenzini emva kwesifo sohlangothi nesandulela isimo sengculazi uma usubuyela emsenzini (RTW) phakathi kwabantu abaphila nesifo sohlangothi ukucubungula kabanzi ngokuba ufunde ukuphendula imibuzo. Kulokhu kufunda engikwenzayo ngifuna ukwazi ngolwazi lwakho ngemuva kokuba uphathwe uhlangothi nokuthi kuphazamise ukubuyela emsebenzini noma cha. Ngifuna futhi ukwazi ngezizathu ezibangela ukuthi isimo sakho sengculazi sihlale simukelela noma singamukeleki.

Kubalulekile futhi ukuthi ufunde futhi uzwe kahle kuthi kuqhubekani, ngicela ukuthi ungangabazi ukuba ungibuze uma ufuna uchazeleke kahle noma ngayiphi nkinga. Okungafani ngezizathu zokuthinta abantu abaphila nesifo sohlangothi futhi bezobuyela emsenzini, futhi kubhekwa nesimo sakho sengculazi kuzosisiza thina abezimpilo emsebenzini.

Kusho ukwenza kahle emsebenzini wethu ezigulini. Kuyabasiza futhi ukwazi abasebenzi Kanye neziguli nabaqashi benze isimo esisodala impumelelo ukubuyela emsebenzini lokho kuzonciphisa ukwanda komthwalo kanye nezidingo zokunakekela kwezinto ezidingwayo kanye nokunye okuzimele.

Ukuthola kabanzi ngento kuhlukene kabili. Okokuqala ukubuzwa ngemibuzo ngolimi lwakho isiZulu noma isiNgisi.lemibuzo kumele iphendulwe noma igcwaliswe nguwena noma umlekeleli wakho, emva kokuthola kabanzi kumsizi noma umphathi wakho. Imibuzo kufanele ivezwe ulwazi olungcono. Imibuzo kufanele iveze ubuwena obulungisela imibuzo ezolandela okuyigaba sesibili. Isimo sakho sakhiwe ulwazi olutholakale, isimo sempilo esidlule kanye nesimo sokufa uhlangothi kanye nesimo sezezimali. Imibuzo akufanele ithathe isikhathi esingaphezulu kwemizuzu eyishumi ukuyigcwalisa. Ukuhlolwa kwakho okulandelayo kuzokwenziwa ngolwimi lwesizulu noma lwesingisi, kunemibuzo ecishe ibe amashumi nanye, ezobuzwa kuzothatha imizuzu eyishumi nantathu kuya kweyishumi nane ukuphendula imibuzo ukuze iphele.

Ngifisa ukwazi mayelana nolwazi lwakho olunzulu nge sandulela ngculazi kanye nesifo sohlangothi, emsebenzini wakho noma lapho uqashiwe khona kanye nemizwa yakho nge ukubuyela emsebenzini noma ukungatholi umsebenzi noma yini ofuna ukukhuluma ngayo ethintene nesihloko sokufunda ngokuhlolisisa.

Risk – Ingozi

Ayikho ingozi kuwe nase mndenini wakho ngokuhlanganyela ngokufuna ulwazi kabanzi. Akukho mali ezofakwa bese uyahlukumezeka wena nomndeni wakho uma uhlanganyela kulolucwaningo ngokuthola ulwazi.

Benefits – Ongasizakala Ngakho

Angeke uzikale ngqo kulokhu kuzihlanganisa ngalokukufunda kodwa uzosizakala ngenye indlela, ukuzihlanganisa kwakho kuzosiza ekwandiseni ulwazi nokwenza kube ngcono lolohlobo kanye nobuhle bokuziphatha obutholwa umuntu onjengawe. Okuthola imininingwane ezokwenza ukuba uphila kahle ukunokwenzeka inokutholakala ukubuyela emsebenzini

Reimbursement – Izindleko

Angeke ukhokhelwe ngokuzihlanganyela kulokhu kufunda kodwa uma kufanele ukuba uhambe wedwa ngenxa yalokukufundiswa, izindleko zokugibela ezanele. Ukuhlanganyela kulokhu kuwukuzikhethela kanti ungayeka noma nini uma ufuna uqhubeke ngaphandle kokuba uhlawuliswe noma ulahlekelwe ukuba usizakale kulokhu okufanele.

Imizamo izokwenziwa ukugcina imininingwane yakho iyimfihlo siyaqiniseka angeke inikwe kwabanye. Imininingwane ingavezwa uma idingwa umthetho.

Confidentiality – Imfihlo: Ukucacisele kokuyikho ukuze kuqhubeke lokukuhlowa kunikwe ikomidi yase University yase Witwatersrand ilungelo lokuklola impilo yomuntu.

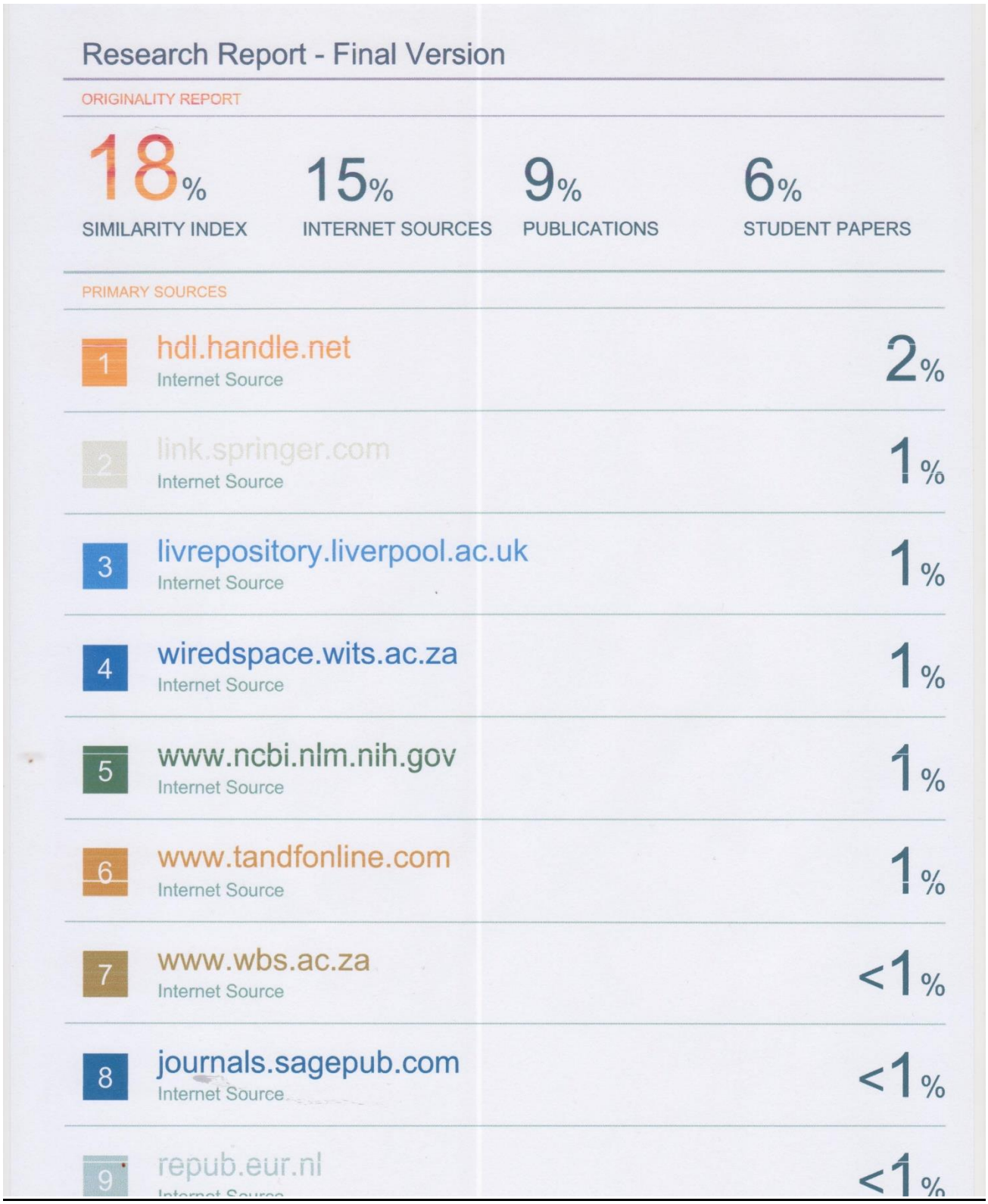
Uma kunento ongayithandi mayelana nokuziphatha kwalaba abahlolisisayo noma emibuzweni yokwelashwa kwakho, ungathinta umphathi sihlalo waleli komidi u- Prof Cleaton Jones ku Peter, Peter.Cleaton-Jones1@wits.ac.za, noma Committee Administrator: Ms Zanele Ndlovu/ Mr Rulani Mkansi/ Mr Lebo Moeng ku – 011-7172 700/2656/1234/12520 noma email at HREC-Medical.Research Office @wits.ac.za.

Ngiyabonga.
Wesley

Imininingwane yokuxhumana nomcwaningi
Wesley Naidoo (Physiotherapist)
Umnyango waka (Physiotherapy)
031 – 327 2345/ 076 771 5716

Appendix O

Turnitin Report:



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