Sexual function and quality of life in individuals post stroke: a cross sectional study in a public health-care setting in South Africa

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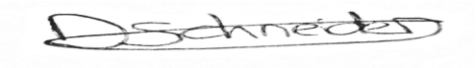
DECLARATION

I, Danielle Schneider, declare that the work contained in this research report is my own, except where otherwise indicated in the acknowledgement section.

This research report is being submitted to the University of the Witwatersrand, Johannesburg, South Africa for a degree of Masters in Adult Neurology Physiotherapy.

This work has not been submitted for any other degree or examination at this or any other university.



Danielle Schneider

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Date

ABSTRACT

Background

Sexual function is commonly affected post stroke because of physiological and psychological factors. The occurrence of sexual dysfunction post stroke has an effect on an individual's quality of life. Research on sexual function in the stroke population, especially in the South African context, is scarce. The aim of this study was to determine the factors associated with sexual function in an individual post stroke and the association with quality of life.

Method

This cross-sectional study took place at Thelle Mogoerane Regional Hospital and included 56 participants who had a stroke. The participant's level of disability was assessed with the Modified Rankin Scale (MRS). This was followed by administering the Stroke Specific Quality of Life scale (SSQOL) to assess quality of life, a questionnaire to obtain demographic information and information regarding sexual function in participants post stroke. Finally, the Changes in Sexual Functioning Questionnaire (CSFQ-14) was carried out to determine an individual's sexual function after stroke. Results were analysed with excel and using independent t tests, Chi squared tests, a 2-way ANOVA and correlation coefficients.

Results

The average age of the sample was 51,32 (SD= ±13,24) years. The sample was comprised of 32 (57,1%) males and 24 (42,9%) females. According to the CSFQ-14, majority of the study participants (n = 35, 62,5%) had sexual dysfunction after their stroke. No significant relationship was found between sex and sexual dysfunction (p=0,577). The factors associated with sexual dysfunction in individuals post stroke included age, disability, comorbidities, psychosocial factors such as self-esteem, role changes and depression. There was no significant interaction between level of disability and sexual dysfunction. Those with sexual dysfunction were found to have a lower mean SSQOL score (139.94 ± 33.89) than those without sexual dysfunction (149.76 ± 33.77). There was not a significant difference (p=0,298).

Conclusion

Sexual dysfunction is a common problem in individuals post stroke with majority of participants in this study experiencing sexual dysfunction since their stroke. There are many factors that are associated with an individual's sexual function post stroke namely pain, difficulty with positioning, self-esteem issues, lack of motivation and change in desire. Although there was not a significant relationship found between sexual dysfunction and quality of life in individual's post stroke, it is still an area of concern. Therefore, addressing sexual function in patients post stroke would be beneficial and including sexual rehabilitation as part of the rehabilitation protocol in individuals post stroke would be valuable.

Dedication

This research report is dedicated to all my patients who have had a stroke. I thank you for allowing me to accompany you on your journeys and for teaching me about the road to rehabilitation.

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LIST OF ABBREVIATIONS

ADL	Activities of daily living
cART	Combination antiretroviral therapy
CVA	Cerebrovascular accident
(DSM)-IV	The Diagnosis and Statistical Manual of Mental Disorders
ED	Erectile dysfunction
HIV	Human Immunodeficiency virus
HRQOL	Health related quality of life
ICF	The international classification of functioning, disability, and health
(ICD)-10	The International Classification of Diseases
IVR	Interactive voice response technology
LUTS	Lower urinary tract symptoms
MDT	Multidisciplinary team
MS	Multiple sclerosis
NIHSS	The National Institutes of Health Stroke Scale
PVMT	Pelvic floor muscle training
QOL	Quality of life
WHO	World Health Organisation

CHAPTER 1: INTRODUCTION AND SCOPE OF THE RESEARCH REPORT

1.1 Introduction

Stroke is one of the leading causes of death in the world and a major cause of disability globally (Bertram et al., 2013). Research shows that stroke results in more than five million deaths each year with majority of the mortalities occurring in low and middle income countries (Bertram et al., 2013; Connor et al., 2007). It is predicted that by 2030, there will be more than 20 million deaths each year due to stroke (Maredza et al., 2015). Moreover, the number of individuals in the world, who have had a stroke, are likely to increase to approximately 70 million if the current patterns continue (Maredza et al., 2015). This will increase the burden of disability worldwide as there will be an increased number of persons living with the consequences of stroke (Maredza et al., 2015). The World Health Organisation (WHO) has predicted that majority of strokes will affect people living in low and middle income countries (Connor et al., 2007; Mathers and Loncar, 2006). It is evident that non-communicable conditions such as stroke are on the rise in South Africa (Bertram et al., 2013). Research shows that people with a lower socioeconomic status are less likely to receive good quality acute based care and rehabilitation (Marshall et al., 2015).

The prevalence of stroke is increasing in the younger population (Bertram et al., 2013). A study by Kissela et al. (2012), shows that there was an increase in the percentage of strokes from 12.9% in 1993/1994 to 18.6% in 2005 in persons under 55 years of age. Thus, stroke is becoming a greater public health issue in South Africa as with a rise in stroke incidence in the younger population, there will be greater long term effects of stroke related disability (Bertram et al., 2013; Kissela et al., 2012).

The incidence of stroke is increasing in a younger age-group and cerebrovascular risk factors are high in South Africa (Bertram et al., 2013). South Africans have unhealthy lifestyle behaviours such as high salt diets, substance abuse, high stress levels as well as poor monitoring of individual health and poor adherence to medication, which are all stroke risk factors (Bertram et al., 2013). Hypertension, another significant risk factor of stroke, has a

high prevalence in South Africa at 24,4% with inadequate strategies in place to combat this and the other above mentioned risk factors in South Africa (Bertram et al., 2013). Human Immunodeficiency virus (HIV) is a risk factor for stroke in South Africa due to the virus itself and side effects of the combination antiretroviral therapy (cART) (Benjamin et al., 2012; Tipping et al., 2007).

Effects of stroke are multifaceted and affect a person physically, psychologically and socially, thereby impacting a person's quality of life (Nilsson et al., 2017). Quality of life can be described as the personal evaluation of an individual's life and wellbeing considering his or her value systems and environment (McDougall et al., 2010; Owiredu et al., 2015). The concept of health related quality of life is multifactorial involving the psychosocial, physical and environmental aspects of wellbeing (Donkor, 2018). Various outcome measures are available to assess an individual's health related quality of life such as The Short Form 36 Health Survey Questionnaire and EuroQOL (EQ-5D). Therapists addressing the rehabilitation of patients with stroke are encouraged to address patients according to the framework of the international classification of functioning, disability, and health (ICF) for a more holistic approach focusing on a person's wellbeing and therefore need to consider personal factors during rehabilitation such as age of the patient and what is meaningful for the patient. Sexuality and sexual function play a major role in a person's quality of life (Rosenbaum et al., 2014) and therefore addressing sexual function during rehabilitation is important especially in a younger population where sexual health is highly valued (Calabrò et al., 2011; Rosenbaum et al., 2014).

Research shows that sexual dysfunction occurs in as many as three quarters of individuals post stroke because of physiological and psychosocial factors (Akinpelu et al., 2013). Understanding how a stroke affects sexual function is complex as it is depends on the interaction between physiological mechanisms and psychological and social factors (Pistoia et al., 2006). Sexual function depends on the peripheral and central nervous systems working together and the hypothalamus and limbic system play an integral role in modulating sexual function (Pistoia et al., 2006; Zarayeneh and Sang Suh, 2017). The most common effects of sexual dysfunction post stroke include a lowered libido, a decrease in the frequency of sexual intercourse, poor erection and ejaculation in males and loss of vaginal lubrication in females, as well as a decline in the enjoyment of engaging in sexual activities (Tamam et al., 2008).

Factors such as pain, altered sensation, mobility issues and spasticity that are common in persons post stroke may result in sexual disability and act as physical barriers for optimal positioning during sexual activity (Kautz and Van Horn, 2017; Rosenbaum et al., 2014). Stroke related fatigue, premorbid comorbidities, such as hypertension, diabetes and cardiovascular issues and their medications also negatively affect sexual function (Calabrò et al., 2011; Ng et al., 2017). In addition to the physiological and physical factors, psychological and interpersonal factors will also impact sexual function post stroke (McGrath et al., 2019). These factors include low self-esteem, altered mood patterns, and depression which are commonly experienced by individuals after stroke (Rosenbaum et al., 2014). As a consequence of stroke, a person may experience a change in their identity and a change in the role they play in a relationship (Rosenbaum et al., 2014). Many individuals experience difficulty with the transition of the role from being a partner to a patient which negatively influences sexual wellness (Rosenbaum et al., 2014). Moreover, a stroke can lead to a person having impaired communication which influences intimate relationships (HoSook et al., 2011; Rosenbaum et al., 2014). Psychosocial factors including anxiety, fear of having another stroke, altered relationship with partners in addition to the physical factors mentioned above negatively influence sexual function in persons post stroke (Nilsson et al., 2017; Zarayeneh and Sang Suh, 2017).

It is evident that there is an effect in sexual function in individuals post stroke however therapists do not always address sexual function during rehabilitation (HoSook et al., 2011; Rosenbaum et al., 2014). Reasons for this may be due to inadequate knowledge or training of therapists regarding sexual function, therapists not recognising that sexual counselling is in their scope of practice or merely that therapists are awkward to engage with a taboo topic (Akinpelu et al., 2013; Kautz and Van Horn, 2017). Research however shows that patients' post stroke value sexual health and would like sexual rehabilitation to be included in their rehabilitation (McGrath et al., 2019). In a recent study, 81% of persons who had a stroke reported that they had inadequate knowledge and lack of information regarding sexual health (Stein et al., 2013). Literature shows survivors of stroke and their partners still believe myths regarding sexual health and are unaware that rehabilitation can positively influence sexual function and intimacy after stroke (Kautz and Van Horn, 2017). Furthermore, studies indicate that couples need reassurance that it is safe to engage in sexual activity after stroke (Kautz and Van Horn, 2017). In addition to providing education, physiotherapists along with occupational therapists can provide intervention specific to their scope of practice to improve bed mobility

and manage spasticity or pain for optimizing sexual positioning (Ng et al., 2017). Physiotherapy addresses the functional limitations and impairments contributing to sexual dysfunction and interventions for sexual rehabilitation including pain management, strengthening the pelvic floor musculature, improving general endurance and mobility as well as Pilates based exercises (Vajrala et al., 2020).

The provision of sexual health education is vital for individuals with disabilities and rehabilitation professionals are encouraged to advocate that their clients receive sufficient sexual health education (Kriofske Mainella and Smedema, 2021). The stroke population are a minority group when it comes to sexual health, rights and justice. It has been found that individuals living with disabilities are inadequately educated about sexual health topics. Furthermore even when sexual health education has taken place for persons with disabilities, social barriers limit the opportunities to socialise with potential romantic partners hindering the opportunity for a sexual life (Kriofske Mainella and Smedema, 2021).

1.2 Problem statement

There is minimal research on sexual function in the stroke population especially in the South African context. This limits members of the rehabilitation team, including physiotherapists, from addressing sexual function as part of the rehabilitation programme, despite the need for it. A study by HoSook et al., (2011), showed that a sexual rehabilitation programme significantly increased sexual satisfaction and the frequency of sexual activity in individuals post stroke. Benefits of sexual rehabilitation are evident in a recent study, where patients who received sexual rehabilitation post stroke had greater improvement in sexual health, reduced depression, anxiety and stress and well has improved in areas of overall functionality and independence (Vajrala et al., 2020). In order to address sexual function in rehabilitation, the impact of a stroke on a person's sexual function and the factors associated with a change in sexual function after stroke needs to be established. The results of this study will therefore determine the factors associated with sexual function in an individual post stroke and the association with quality of life. The findings of this study will thus provide therapists with information pertaining to addressing sexual function in rehabilitation.

1.3 Research question

What are the factors associated with sexual function in an individual post stroke and the association with quality of life?

1.3.1 Aim of the study

The aim of this research was to determine the factors associated with sexual function in an individual post stroke and the association with quality of life.

1.3.2 Objectives of the study

The objectives of this study were to determine:

1. An individual's sexual function post stroke.
2. The factors that are associated with an individual's sexual function post stroke.
3. The association of sexual function with the quality of life of an individual post stroke.

1.4 Significance of the study

When looking at the available research, there has been little research on sexual health or sexual function in individuals post stroke in low-income countries and no research has been done in this area in South Africa. As therapists, we aim for a patient-centred rehabilitation approach by addressing functional goals that are meaningful for the patient. Therapists therefore aim at getting a patient back to their highest possible level of independence to positively influence the patient's quality of life.

According to the literature, sexual function has a significant effect on a patient's quality of life and research shows that sexual health, and sexual function is affected post stroke (Akinpelu et al., 2013; Ng et al., 2017; Rosenbaum et al., 2014; Vajrala et al., 2020). Although this is evident in research, the area of sexual health and sexual function is one in which therapists currently do not play a significant role whether it is due to sexual health being a taboo topic or due to a

lack of knowledge and training in this field (Calabrò and Bramanti, 2014; Owiredu et al., 2015; Rosenbaum et al., 2014). Therapists, specifically working in a South African context, have a lack of training regarding how to approach and carry out sexual rehabilitation as part of a patient's rehabilitation. Thus, knowledge about how stroke impacts a patient's sexual function will be beneficial to therapists as there is a lack of awareness of what factors influences a person's sexual function after stroke and how sexual function impacts a person's quality of life (Rosenbaum et al., 2014). Therefore, this research will enhance therapists' knowledge regarding sexual rehabilitation for persons after stroke specifically in a South African context rather than relying on existing research done in other countries. Moreover, the results of this study will act as a platform for further studies to be done in this area with the aim of improving clinical practice.

1.5 Organisation of the research report

Figure 1.1 summarises the outline of the research report. The report is divided into six chapters including an introduction, literature review, methodology, results, discussion, and conclusion.

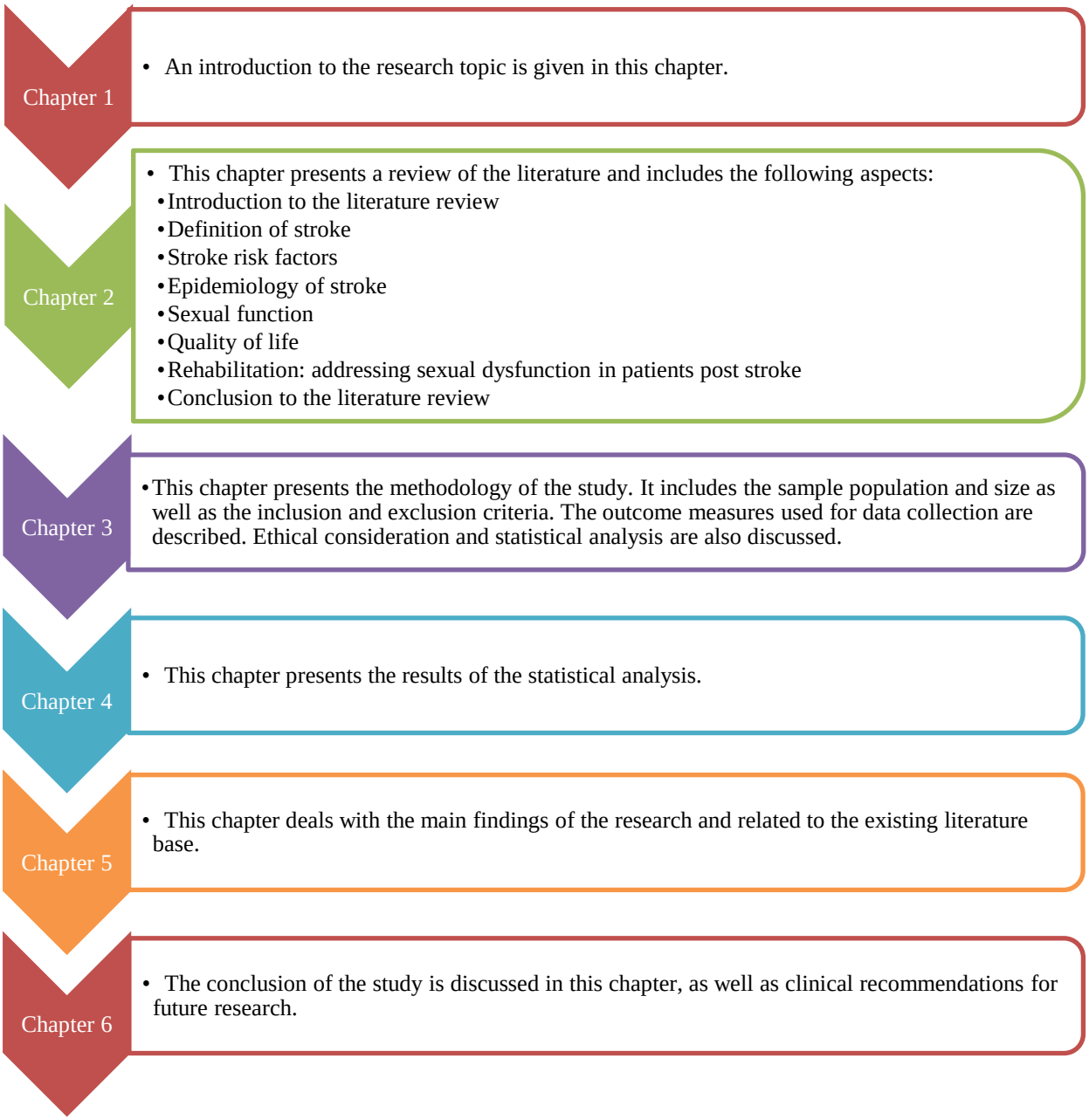

Figure 1.1: Organisation of the research report

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter reviews the current literature concerning sexual function and quality of life within the stroke population. Sexual function and the factors associated with sexual function in an individual post stroke will be discussed. This literature review will also describe how sexual function is affected in individuals post stroke. Moreover, the literature presented in this review will explain how sexual function affects quality of life, how stroke affects sexual function as well as how stroke impacts quality of life (QOL).

The evidence used in compiling this literature review was sourced from databases including CINAHL, PEDRO, PUBMED, EBSCO Host as well as Google Scholar. The keywords used to search for literature were stroke, sexual function, sexual dysfunction, QOL, stroke rehabilitation, sexual rehabilitation, intimacy. The literature search took place from January 2019 until October 2021 and included articles ranging from 1999 to 2021, except for a few studies from an earlier period (up to 1976) which addressed outcome measures and model development.

2.2 Definition of stroke

Cerebrovascular accident (CVA), commonly referred to as stroke, is defined as a neurological deficit caused by an acute injury to the central nervous system due to vascular origin (Sacco et al., 2013). The World Health Organisation defines stroke as “a clinical syndrome characterised by rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than of vascular origin” (World Health Organisation, 1980). The American Stroke Association for the 21st century have defined stroke as any sign of permanent brain, spinal cord or retinal cell death due to vascular causes which is based on the pathological or evidence-based imaging with or without the occurrence of clinical symptoms (Sacco et al., 2013). Transient ischaemic attack is a clinical syndrome that is characterised by focal neurological dysfunction lasting for less than 24 hours (Murphy and Werring, 2020).

Stroke is a significant contributing factor to death and disability worldwide (Sacco et al., 2013). Stroke is commonly classified into ischaemic and haemorrhagic stroke (Donkor, 2018). Ischaemic stroke occurs as a result of a disruption of the blood supply to an area of the brain (Donkor, 2018). A haemorrhagic stroke occurs due to a ruptured blood vessel (Donkor, 2018). Ischaemic stroke is commonly classified according to the Trial of Org 10172 in Acute Stroke Treatment classification system outlining the five main subtypes of cerebral ischaemia namely; large artery atherosclerosis, cardioembolic, small vessel occlusion, stroke of other determined aetiology and stroke of undetermined cause (Murphy and Werring, 2020). Haemorrhagic stroke includes intracerebral and subarachnoid haemorrhage (Donkor, 2018).

Ischaemic strokes account for approximately 80% of strokes and haemorrhagic stroke makes up about 20% of stroke events (Donkor, 2018). Interestingly, the proportions of stroke types is dependent on the population (Donkor, 2018). According to the first INTERSTROKE study that involved 22 countries, in Africa, ischaemic strokes accounted for 66% of stroke events and haemorrhagic strokes made up about 34% (Donkor, 2018). In contrast, in high income countries, the proportions of ischaemic and haemorrhagic stroke were about 91% and 9% respectively (Donkor, 2018). It is evident that ischaemic stroke is the main kind of stroke subtype in both the developed and developing world (Donkor, 2018).

The ICF is a helpful framework to describe the impact that stroke related disability has on an individual as stroke can affect an individual at the level of impairment, activity and participation (Rhoda et al., 2011). The major impairments post stroke include motor and sensory dysfunction as well as cognitive impairments (Gittins et al., 2021). Functional limitations post stroke include difficulties with activities of daily living such as grooming, dressing, eating, bathing and toileting as well as mobility limitations such as transfers, walking and stair climbing (Rhoda et al., 2011). A recent study by (Gittins et al., 2021) identified seven stroke impairment categories namely, patients with loss of consciousness, patients with motor, cognitive and sensory impairments, patients with motor and cognitive impairments, patients with motor and sensory impairments, those with only motor impairments, those with any non-motor impairments and patients with no impairments (Gittins et al., 2021). These categories form part of an impairment-based stroke classification system presented in this recent study (Gittins et al., 2021).

2.2.1 Stroke risk factors

Risk factors for stroke are commonly classified into modifiable and non-modifiable factors (Ranganai and Matizirofa, 2020). The modifiable risk factors are controllable and include hypertension, cholesterol problems, increased body mass index, physical inactivity and heart disease (Ranganai and Matizirofa, 2020). Non modifiable risk factors, which are uncontrollable, include age, gender, race and ethnicity as well as genetic predisposition of stroke (Ranganai and Matizirofa, 2020). In South Africa, the main factors for stroke risk include hypertension, HIV, obesity, physical inactivity, elevated cholesterol as well as an unhealthy diet (Benjamin et al., 2012; Wandai et al., 2017). These factors, as well as HIV, can also affect sexual health.

A significant risk factor for stroke particularly affecting younger individuals in lower income countries such as South Africa is HIV (Benjamin et al., 2012; Tipping et al., 2007). There is a high incidence of HIV in low income and middle-income countries thus increasing the risk for stroke (Benjamin et al., 2012). Both HIV and the side effects of cART can increase an individual's risk of stroke (Benjamin et al., 2012). Standard HIV treatment can contribute to stroke risk both directly; by speeding up atherosclerosis and indirectly; by increasing life expectancy whereby exposure to vascular risk factors such as diabetes, hypercholesterolaemia and hypertension will continue to increase and affect the aging HIV population (Benjamin et al., 2012).

People diagnosed with stroke who are also HIV positive are reportedly younger than individuals with stroke who do not have HIV (Benjamin et al., 2012). This could be as a result of the age of the population who are at a higher risk of contracting HIV or could be as a result that the causes of stroke in HIV is not dependent on typical vascular risk factors (Benjamin et al., 2012). A study by Ovbiagele and Nath (2011) assessed trends in the proportion of HIV infection among patients with stroke in the United States. The findings of this research showed that the median age for individuals with HIV who had had a stroke was 42,9 years in 1997 and 48,4 years in 2006 (Ovbiagele and Nath, 2011). Research done in a similar setting between 1997 and 2002 found that the median age of people with HIV who

had a stroke was 42 years (Ortiz et al., 2007). It is evident, that the occurrence of strokes affect a younger population in lower-income countries such as South Africa and Malawi (Heikinheimo et al., 2012; Tipping et al., 2007). For example, the median age of individuals with HIV who have strokes was 33,4 years in Cape Town South Africa in 2000 (Tipping et al., 2007) and 39,8 years in 2008 in Blantyre, Malawi (Heikinheimo et al., 2012). A possible explanation for this regional variation might be the use of cART, possibly because cART delays the time to stroke onset (Benjamin et al., 2012).

2.3 Epidemiology of stroke

2.3.1 Global epidemiology

Stroke is an increasing global healthcare challenge and is the leading cause of physical disability worldwide (Murphy and Werring, 2020). It is predicted that in the next 10 years, there will be 20 million deaths worldwide each year because of stroke (Maredza et al., 2015) and by 2030, there will be 70 million persons who have had a stroke globally (Maredza et al., 2015). Stroke is the second highest cause of mortality in middle to high income countries (Murphy and Werring, 2020). The incidence of stroke is 85-94 per 100 000 and is higher in adults over 75 years old with the incidence of stroke being 1151-1216 per 100 000 (Murphy and Werring, 2020). In 2016, there were 13.7 million new incident strokes globally (Saini et al., 2021). Data from 2010 to 2017 shows a significant increase in stroke incidence by 5.3% and prevalence by 19.3% (Saini et al., 2021). The majority of stroke related fatalities occur in low-income countries calculated as 85% of all stroke deaths (Murphy and Werring, 2020).

2.3.2 Epidemiology of stroke in Africa

The epidemiological data on stroke in Africa is scarce although according to estimates from the Global Burden of Disease model, stroke incidence appears to be increasing in Africa (Owolabi et al., 2018). Stroke has been estimated to be one of the main, non-communicable reasons of mortality and morbidity in Africa (Louw et al., 2020).

According to a systematic review by Adeloye (2014), 483 000 occurrences of stroke in persons aged 15 years or older were estimated in 2009 which is equivalent to 81.2/100 000 population. In 2009, there was an estimated 1.89 million persons above age 15 who had

suffered from a stroke with a prevalence of 317.3/100 000 population (Adeloye, 2014). Figures from this systematic review are indicative that there is an increasing burden of stroke in Africa (Adeloye, 2014). Statistics from 2013 show that there are 2.09 million stroke survivors, therefore a rise of 10.8% of stroke incidence and 9.6% of stroke survivors in Africa (Adeloye, 2014).

Africa has the highest burden of hypertension, which is the most common risk factor for stroke (Owolabi et al., 2018). Africa appears to have the greatest incidence, prevalence and case-related fatalities of stroke (Owolabi et al., 2018). In Africa, the standardised annual stroke incidence rates is roughly calculated to be up to 316 per 100 000, adjusted for age (Owolabi et al., 2018). In addition, the standardised prevalence rates of stroke in Africa, may be up to 981 per 100 000, adjusted for age (Owolabi et al., 2018).

2.3.3 Epidemiology of stroke in South Africa

In South Africa, stroke results in about 25 000 deaths each year (Maredza et al., 2015). In sub Saharan Africa, including South Africa, there is an increase in the burden of stroke (Ranganai and Matizirofa, 2020). This rising incidence of strokes will mean that more and more people will be living with disability resulting in an increased financial burden (Avan et al., 2019). Research shows that, after AIDS, HIV and heart disease, stroke is a major cause of death in South Africa (Bertram et al., 2013). Stroke is a major cause of mortality in South Africa and stroke is one of the ten major reasons for disability worldwide (Bradshaw et al., 2003).

A systematic review including three South African studies reported on the epidemiology of stroke in South Africa (Louw et al., 2020). The review reported that there was approximately 75 000 strokes occurring in South Africa each year with one third of strokes resulting in deaths within the first month (Louw et al., 2020). According to the systematic review, the projected burden of disease due to stroke was 564 000 disability adjusted life years (Louw et al., 2020). The Southern Africa Stroke Prevention Initiative that conducted a study in the Agincourt district in Mpumalanga found a crude prevalence of stroke of 300/100 000 in South Africa (Connor et al., 2007).

2.4 Sexual function

2.4.1 Definition of sexual function

The WHO defines sexual health as “a state of physical, emotional, mental and social wellbeing in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity” (World Health Organisation, 2006). The WHO further explains that “sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled” (World Health Organisation, 2006). According to The Global Advisory Board for Sexual Health and Wellbeing there are three vital elements comprising sexual health and wellbeing namely sexual health, sexual pleasure and sexual rights (Sladden et al., 2021). Sexual health looks at whether an individual is able to experience the emotional aspects of sex in addition to merely the physical experience of sex (Thomas and Thurston, 2016). Sexual function comprises more than merely sexual intercourse; it involves the complex interaction of the physical, psychological and behavioural systems (Monga et al., 1986)

2.4.2 Anatomy and physiology of sexual function

Sexual function occurs due to the complex interaction between the peripheral and central neural networks as well as the endocrine and the vascular systems (Pistoia et al., 2006; Stern et al., 2017). In addition to the vital roles that the anatomical and physiological systems play in sexual function, psychosocial factors have a fundamental influence on sexual function (Avasthi et al., 2017). These psychosocial factors include mental status, religious beliefs and socio-demographic conditions (Avasthi et al., 2017). Any problems with the functioning of the physiological and anatomical systems as well certain psychosocial influences can contribute to sexual dysfunction (Stern et al., 2017).

The major brain structures involved in sexual function include the prefrontal cortex, the anterior cingulate gyrus, the thalamus, the hypothalamus, the temporal and occipital lobes as well as the amygdala (Stern et al., 2017). The cerebral cortex is primarily responsible for initiating sexual arousal and orchestrating the cascade of sexual response (Thompson, 2011). The autonomic nervous system plays a fundamental role in sexual function and is controlled by subcortical structures including the hypothalamus, substantia nigra and limbic system (Pistoia et al., 2006).

Sexual function is controlled by the various systems and the involvement of the endocrine system is vital for effective sexual functioning (Stern et al., 2017). Hormones including testosterone, oestrogen, progesterone and oxytocin have positive effects on sexual function but the hormone prolactin has an inhibitory influence on sexual function (Stern et al., 2017). The neurotransmitters also seem to play a role in sexual function: serotonin has an inhibitory affect and potentially inhibits orgasm and dopamine and norepinephrine stimulate sexual function (Stern et al., 2017). Nitric oxide acts at a vascular level: in females it influences vaginal smooth muscle tone and vaginal lubrication (Stern et al., 2017). In males, nitric oxide allows for increased penile blood flow facilitating erection (Stern et al., 2017).

Risk factors of stroke such as underlying cardiovascular conditions, comorbidities such as diabetes or hypertension are classified as the primary causes of sexual dysfunction (Stratton et al., 2020). For example, vascular risk factors affect the functioning of smooth muscles cells in the genitals and cause endothelial dysfunction which contributes to sexual dysfunction (Park et al., 2015). Anti-hypertensive medications can also contribute to sexual dysfunction for example the cavernosal artery pressure is lowered consequentially leading to ED in males (Park et al., 2015).

2.4.3 Models of sexual function

There are various models of sexual response which describes the physical, physiological and emotional changes that the human body goes through in sexual activity (Basson, 2001). Most of the present sexual response cycle models incorporate the process of sexual desire, arousal and orgasm (Thomas and Thurston, 2016). The traditional cycle of sexual response proposed by Masters and Johnson in 1966 looks at a four stage linear model starting with excitement, followed by plateau, orgasm and finishing with a period of resolution (Stern et al., 2017; Thomas and Thurston, 2016).

In the first stage, excitement is characterised by physiological changes due to sexual arousal including an elevated blood pressure, rise in respiratory and heart rate as well as increased muscle tone (Basson, 2001). Females will experience increased vaginal lubrication and males will experience an erection (Basson, 2001). In the second phase, the plateau phase, there is continuation of these physiological responses (Basson, 2001). The peak of excitement is referred to as an orgasm which is defined as involuntary muscle contractions and a sense of euphoria (Basson, 2001). Resolution, the final phase, is where the body returns to baseline that is its pre-arousal state (Basson, 2001). Refer to figure 2.1 below which summarises this sexual response cycle by Masters and Johnson in 1966.

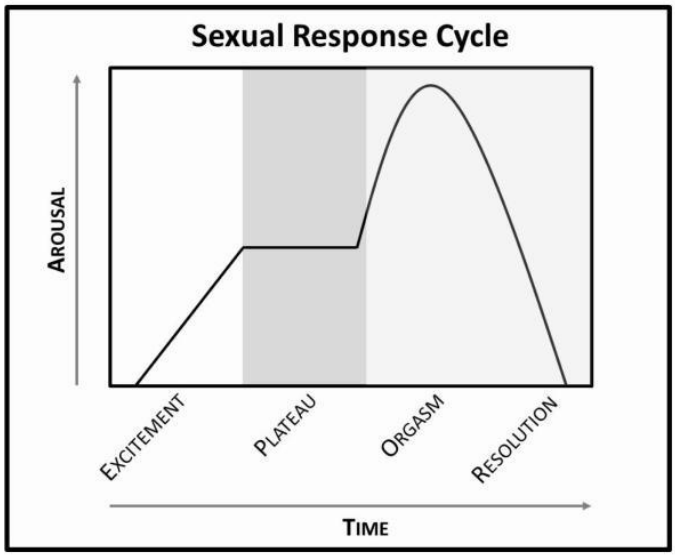

Figure 2.1: Maters-Johnson Model of Sexual Response (Thomas and Thurston, 2016)

The Kaplan model, consisted of three stages namely desire, excitement or arousal and orgasm (Stern et al., 2017). This model was modified from the traditional model by Masters and Johnson (Stern et al., 2017). Figure 2.2 illustrates the Masters-Johnson-Kaplan model of sexual response.

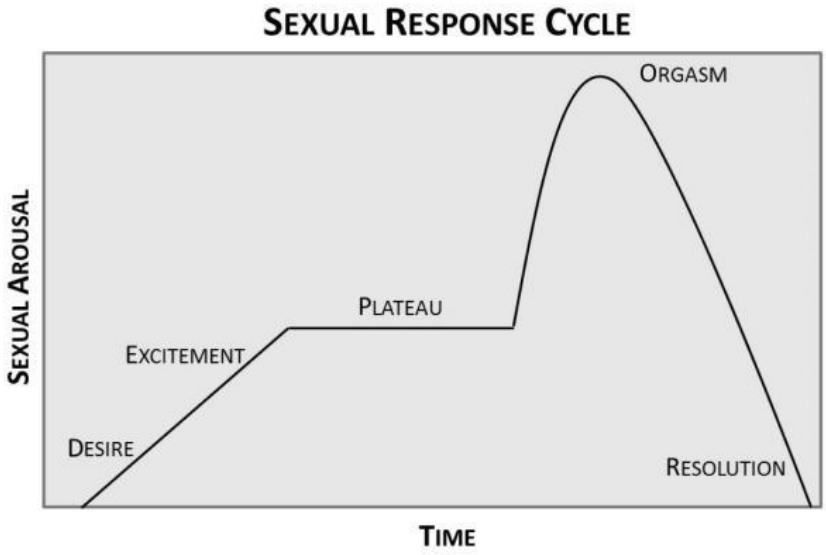

Figure 2.2: The Masters-Johnson-Kaplan Model (Thomas and Thurston, 2016)

The more recent, Basson model of sexual response describes sexual response as a cycle (Thomas and Thurston, 2016). See figure 3 below which illustrates the Basson model. This circular process begins with sexual neutrality, followed by sexual arousal and desire as a response to sexual stimuli which are processed in the limbic centres of the brain (Basson, 2001). In contrast to the Masters-Johnson- Kaplan model, where desire leads to arousal, sexual stimuli usually precedes physical arousal (Thomas and Thurston, 2016). Physical and emotional satisfaction, recognised by emotional intimacy is the outcome of sexual activity which is followed by a period of sexual neutrality, hence a circular model of sexual response (Basson, 2001; Thomas and Thurston, 2016). Any problem within any stage in the sexual response cycle will lead to sexual dysfunction (Basson, 2001). In individuals post stroke, sexual function may be impaired at any stage of this sexual response cycle. For example, the stage of sexual arousal and desire can be affected by sensory impairments post stroke because the processing of sensation of sexual stimuli is impaired.

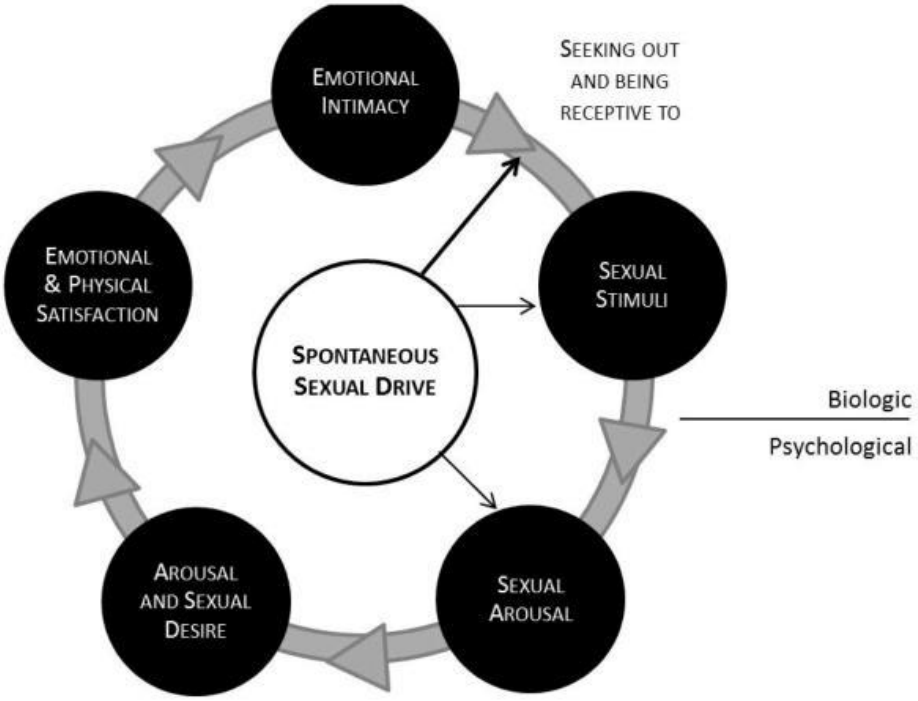

Figure 2.3: Basson Model of Female Sexual Response (Thomas and Thurston, 2016)

2.5.1 Definition of sexual dysfunction

Sexual dysfunction has a significant impact on a person regarding their mood, interpersonal relations and quality of life (Domingo et al., 2018). In males, sexual dysfunction is usually marked by a decline in sexual desire and erectile dysfunction (Thompson., 2011). In females, sexual dysfunction typically consists of reduced arousal, problems with orgasm as well as sexual pain (Thompson., 2011). The four primary groupings of sexual dysfunction include disorders of sexual desire, disorders of arousal, disorders of orgasm and sexual pain (Hatzimouratidis and Hatzichristou, 2007).

There are various classification systems used to define sexual dysfunction including The International Classification of Diseases (ICD)-10 by the WHO, and the Diagnosis and Statistical Manual of Mental Disorders (DSM)-IV provided by the American Psychiatric Association (Hatzimouratidis and Hatzichristou, 2007). The ICD-10 classification of sexual

dysfunction is based on how an individual is able to participate in a sexual relationship and it uses categories which are divided into organic and non-organic dysfunctions (Hatzimouratidis and Hatzichristou, 2007). The DSM-IV includes a chapter describing sexual disorders and dysfunctions including problems with orgasm, pain during sexual intercourse, an exaggerated sexual response cycle or a strong disgust of sexual activity (Hatzimouratidis and Hatzichristou, 2007).

2.5.2 Epidemiology of sexual dysfunction

In the general population, roughly 40-45% of females and 20-30% of males experience at least one sexual dysfunction (Thompson., 2011). In the United States, it is estimated that 43% of females and 31% of males experience sexual dysfunction (Stern et al., 2017). Sexual dysfunction is associated with emotional and physical problems (Stern et al., 2017). Among males, premature ejaculation is the most common sexual dysfunction (Avasthi et al., 2017).

The common risk factors for sexual dysfunction include general health, psychological disorders, demographic and social factors (Stern et al., 2017). Female gender, co-existing medical or psychiatric conditions and older age are all risk factors for sexual dysfunction (Stern et al., 2017).

2.5.3 Assessing sexual dysfunction

In order to address and manage problems with sexual function, an accurate diagnosis and comprehensive assessment of sexual function is required (Park et al., 2015). The sexual process is a psychobiological response and therefore aspects such as the environment, emotions, self-image, and sexual preferences must also be included in the assessment of sexual dysfunction (Grover and Shouan, 2020). Factors such as age, physical health and the presence of psychiatric comorbidities must also be considered (Grover and Shouan, 2020). Rating scales should be used as a supplement to a detailed history taking and holistic assessment (Grover and Shouan, 2020). The current instruments available to assess sexual function are a product of Masters and Johnson's and later Kaplan's models of the sexual response cycle, which focus on the phases of desire, arousal, orgasm and resolution

(DeRogatis, 2008; Thomas and Thurston, 2016). Concerning the sexual response cycle, dysfunction can occur in any or numerous phases of the cycle, and the diagnosis is usually made without defining the aetiology of sexual dysfunction (DeRogatis, 2008). The existing instruments to evaluate sexual function provide scores on domains comparable to the key phases of the sexual response cycle (DeRogatis, 2008). The outcome measures aim to evaluate an individual's perception of the quality of sexual activities during each phase, and the person's satisfaction with these experiences (DeRogatis, 2008). Many of the contemporary assessment tools also provide an overall score, which is indicative of the individual's overall quality of sexual functioning (DeRogatis, 2008). The Changes in Sexual Function Questionnaire (CSFQ-14) is a popular tool to measure sexual functioning (Keller et al., 2006). The CSFQ-14 has been extensively validated for clinical use and may be particularly beneficial in community practice (Keller et al., 2006). This tool is valuable when comparing males and females as it has sex specific, parallel assessments of sexual function regarding five areas namely pleasure, sexual desire/frequency, sexual desire/interest, arousal/excitement, and orgasm/completion (Keller et al., 2006). Most of the outcome measures summarised in Table 2.1, which has been taken from DeRogatis (2008), have been developed within the context of clinical research however it is valuable to adopt these instruments in the clinical setting (DeRogatis, 2008). These tools have sound psychometric properties and are reliable and valid instruments (DeRogatis, 2008). All the tools presented in Figure 2.4, can be administered in less than 20 minutes (DeRogatis, 2008).

Inventory name	*Modality/ gender*	*No. of items*	*Adminis- tration time*	*Domains*
Arizona sexual experience scale (ASEX)	SR/male and female	5	<10 min	Drive, arousal, penile erection/vaginal lubrication, orgasm, satisfaction
Center for Marital and Sexual Health Sexual Functioning questionnaire (CMASH-SFQ)	SR/male and partner	21	<15 min	Sexual frequency, sexual satisfaction, orgasm, erectile function
Derogatis interview for sexual functioning (DISF-SR)	CI and SR/male and female	25	<15 min	Cognition, arousal, behavior, orgasm, drive/relationship, overall total score
Female sexual function index (FSFI)	SR/female only	19	15 min	Desire, arousal, lubrication, orgasm, satisfaction, pain
Index of premature ejaculation	SR/male only	10	<10 min	Sexual satisfaction, control, distress
International index of erectile function (IIEF)	SR/male only	15	<15 min	Erectile function, orgasm, desire, intercourse satisfaction, overall total score
Profile of female sexual function (PFSF)	SR/female only	37	<20 min	Desire, arousal, orgasm, pleasure, concerns, responsiveness, self-image
Sexual function questionnaire (SFQ)	SR/female only	26	<15 min	Desire, arousal–sensation, arousal–lubrication, enjoyment, orgasm, dyspareunia, partner relationship, overall total score
Sexual interest and desire inventory	CI	13	<15 min	Overall total score
Short scale to measure female sexual functioning (SPEQ)	SR/female only	9	<5 min	Feelings for partner, sexual responsivity, sexual frequency, libido, dyspareunia, partner problems
Female sexual distress scale (FSDS/FSDS-R)	SR/female only	12/13	<5 min	Unidimensional scale measuring sexually related personal distress. 'R' version has an additional desire item

Figure 2.4: Properties of 10 measures of the quality of sexual function (DeRogatis, 2008)

2.5.4 Sexual function post stroke

Research shows that sexual dysfunction is prevalent in the neurological population. For example, in the multiple sclerosis (MS) population, research shows that the average prevalence of sexual dysfunction is 40 to 80 percent in women and 50 to 90 percent in males (Domingo et al., 2018). Among males with MS, the common problems of sexual dysfunction include erectile dysfunction, problems with orgasm, sensory changes in the genital area as well as reduced libido (Domingo et al., 2018). In females with MS, the major complaints include lack of vaginal lubrication and numbness in the genitals (Domingo et al., 2018). The incidence rate for erectile dysfunction (ED) is 25-30 cases per thousand person years and increases with age as does the prevalence of sexual dysfunction (Lewis et al., 2004). Erectile dysfunction is a common occurrence in males post stroke, affecting approximately 48 to 62% of these patients. In addition, males with lower urinary tract symptoms (LUTS) are at risk of urinary incontinence during sexual activity which negatively affects sexual life (Tibaek et al., 2015).

Sexual dysfunction is common in the stroke population, with 57-75% of stroke survivors experiencing some kind of sexual dysfunction (Thompson., 2011). Sexual dysfunction commonly occurs in individuals post stroke irrespective of the severity of stroke with prevalence being between 20 and 75% (Oyewole et al., 2017a). According to Akinpelu et al., (2013), as many as three quarters of individuals experience issues with sexual function post stroke. In a Nigerian cohort of individuals post stroke, there was a decline in libido and frequency of engaging in sexual intercourse with a prevalence more than 70% (Oyewole et al., 2017a). The prevalence of problems with orgasm, erection and ejaculation was more than 60% amongst the Nigerian stroke survivors (Oyewole et al., 2017a). Moreover, research conducted among Nigerian stroke survivors found that sexual function is affected post stroke as a result of old age, depression and psychological influences (Akinpelu et al., 2013).

A study by Korpelainen et al., (1999), found that 49% of persons post stroke and 31% of spouses of individuals post stroke were unhappy with their sexual life post stroke. Furthermore, 33% of persons post stroke and 27% of their spouses reported no participation in sexual intercourse after the stroke (Korpelainen et al., 1999; Seymour and Wolf, 2014). Sexual problems occurring after stroke were identified in this study; 75% of male stroke survivors experienced ED and 46% of the females in the study had problems with vaginal

lubrication post stroke (Korpelainen et al., 1999; Seymour and Wolf, 2014). According to various studies, there was a considerable decrease in satisfaction and desire in individuals post stroke (Seymour and Wolf, 2014). In a study by Choi-Kwon and Kim (2002), 65% of their sample had reduced coital frequency three months post stroke and this only improved to 49% two years after stroke (Seymour and Wolf, 2014).

According to research by Akinpelu et al. (2013), 95% percent of participants (ages ranging from 28 to 79 years old) experienced at least one problem with sexual function. A decline in coital frequency and reduced libido were the most commonly reported problems with sexual function and were reported by more than 70% of participants (Akinpelu et al., 2013). Other types of sexual dysfunction reported were problems with ejaculation, erection and orgasm which were reported as troublesome by more than 60% of participants. (Akinpelu et al., 2013). It is noteworthy, that ED particularly affected males who were in the older age group (Akinpelu et al., 2013). Furthermore, the individuals experiencing sexual dysfunction reported that factors such as QOL, general attitude to sex, depression and ability to express sexual feelings significantly influenced sexual dysfunction (Akinpelu et al., 2013).

The common complications of sexual dysfunction are problems with ejaculation and impotence in males and loss of vaginal lubrication and problems with sexual arousal and orgasms in females (Park et al., 2015). It is evident that sexual dysfunction is more common following neurological conditions and sexual dysfunction is commonly experienced by persons with physical disabilities (Yilmaz et al., 2017). A significant consequence of stroke is problems with sexual function, which negatively impacts a person's QOL (Kautz and Van Horn, 2017; Oyewole et al., 2017a; Pistoia et al., 2006). Sexual dysfunction, including a reduction in coital frequency, lowered libido and sexual dissatisfaction, occurred in almost half of the post-stroke population even in instances of patients exhibiting mild or no physical disability (Park et al., 2015).

Sexual dysfunction is multifactorial and is influenced by psychological, social, physical, physiological and demographic factors (McGrath et al., 2019; Yilmaz et al., 2017). There are various factors contributing to sexual dysfunction and these can be categorised into primary, secondary, and tertiary causes (Stratton et al., 2020). The primary causes of sexual dysfunction are due to the effects of the brain lesion itself, for example erection and ejaculation issues in males and reduced vaginal lubrication in females (Akinpelu et al., 2013; McGrath et al., 2019). Pre-existing comorbidities such as cardiovascular conditions or diabetes as well as the side effects of medications are also classified as primary issues of

sexual dysfunction (McGrath et al., 2019; Stratton et al., 2020). Vascular risk factors may contribute to sexual dysfunction via damaged smooth muscle cells in the genitals and via endothelial dysfunction (Park et al., 2015). The presence of diabetes, hypertension, dyslipidaemia and obesity are risk factors for ED in males post stroke (Park et al., 2015). Certain medications can result in adverse side effects such as impaired sexual function. An example of such medications are anti-hypertensives which can affect erections by lowering the cavernosal artery pressure (Park et al., 2015). Also, a common side effect of anti-depressants, which are frequently prescribed to stroke survivors, is sexual dysfunction (Park et al., 2015). The secondary causes of sexual dysfunction relate to the sequelae of stroke (Stratton et al., 2020). Examples of the secondary causes affecting sexual function include sensory and/or motor impairments, pain, abnormal tone and bladder and bowel dysfunction (Stratton et al., 2020).

The tertiary causes of sexual dysfunction are complex and include altered cognition, personality changes, and psychological and behavioural problems (Stratton et al., 2020). According to Akinpelu et al., (2013), psychological factors are the primary reasons for a deterioration in sexual function in individuals post stroke. These psychological factors are broad and may include issues with self-esteem, depression, anxiety, stress and fear of recurrence of stroke (McGrath et al., 2019). Other tertiary problems contributing to sexual dysfunction are the changes experienced by individuals with regards to their perceived roles in relationships for example, the transition from a sexual partner to a patient (Stratton et al., 2020). Many individuals struggle with the shift of the role from being a partner to a patient after their stroke, which affects sexual wellbeing (Rosenbaum et al., 2014). The tertiary causes of sexual dysfunction extend to involve the partners of stroke survivors (Stratton et al., 2020). Patients' partners experience feelings of anxiety, trepidation, fear of relapse and reduced excitation which negatively impacts sexual function (Stratton et al., 2020). In a narrative review by Rosenbaum et al., (2014), partners of stroke survivors reported that changes in their sexual relationship had less to do with the loss of the physical aspects of sexual function and were more due to identity changes and transition in roles in a relationship. Partners also indicated that they experienced grieving and a sense of loss for the previous state of their relationship (Rosenbaum et al., 2014). In addition, the cognitive and behavioural issues that are classified as tertiary causes of sexual dysfunction include problems with judgement, memory problems and emotional lability (Stratton et al., 2020). Patients may also experience impairments with speech and communication difficulties after a

stroke which can negatively impact the intimacy in a relationship (HoSook et al., 2011; Rosenbaum et al., 2014).

In summary, there are various non-lesion factors that can contribute to post-stroke sexual dysfunction that include physical deficits, psychological factors, sociodemographic factors (Park et al., 2015). Physical deficits refer to hemiparesis, impaired sensation and spasticity which may affect positioning and mobility thus negatively affecting sexual function (Park et al., 2015). Research by Sjögren and Fugl-Meyer, (1982) assessed 110 post-stroke patients with the aim of understanding the impact that disability and dependence in activities of daily living (ADL) has on sexual health. Approximately 75% of the patients had reduced coital frequency post stroke and this reduction in intercourse frequency was positively correlated to the level of physical disability and degree of dependence in ADL (Sjögren and Fugl-Meyer, 1982). Weakness, loss of limb dexterity and fatigue can contribute to sexual dysfunction in stroke survivors (Park et al., 2015). Other physical impairments which may affect sexual function include pseudobulbar palsy, drooling, and bladder and bowel dysfunction (Park et al., 2015). Overactive bladder is commonly experienced by individuals post stroke and not only negatively impacts their QOL but also is associated with sexual dysfunction (Itoh et al., 2013).

Psychological factors may affect sexual functioning more than the physical deficits in post-stroke individuals (Park et al., 2015). This is often seen amongst individuals who have minor physical disability yet experience a decline in sexual function post stroke (Park et al., 2015). Depression, anxiety, fear, and mental fatigue significantly impact sexual function (Park et al., 2015). Patients post stroke who experienced sexual dysfunction exhibit significantly more symptoms of depression (Kimura et al., 2001). Research has shown that depression is more likely the contributing factor to sexual dysfunction post stroke than the stroke lesion (Park et al., 2015). Fear is another psychological factor that contributes to problems with sexual function (Park et al., 2015). Fear of stroke reoccurrence is discussed in the literature as another factor negatively affecting sexual function (Park et al., 2015). Fear experienced by the partners of stroke survivors contributed significantly to a decline in sexual activity which was evident from research done, that evaluated sexual changes in 62 stroke survivors (Giaquinto et al., 2003). Majority of the patients' partners experienced fear including fear of relapse, anguish and in some cases shock to face a naked partner with a disability, which played a strong role in the decline of sexual function (Giaquinto et al., 2003; Park et al.,

2015). Thus both partners in a sexual relationship can contribute to sexual dysfunction (Park et al., 2015). Partners of stroke survivors who have cognitive and emotional deficits as well as sensorimotor impairments post stroke experience higher dissatisfaction with their sexual lives particularly one year after the stroke (Forsberg-Wärleby et al., 2004).

It is evident from the literature that age and/or gender is not directly correlated with sexual dysfunction (Kimura et al., 2001; Korpelainen et al., 1999; Park et al., 2015). There is also no clear correlation between the occurrence of sexual dysfunction and marital status, relationship duration and level of education (Korpelainen et al., 1999; Park et al., 2015). An individual's premorbid sexual life is an important indicator of sexual life after the stroke (Hawton, 1984; Park et al., 2015). In a study by Hawton, (1984), fifty men who had moderate to severe strokes were interviewed six months post stroke regarding their sexual adjustment. It was determined that the frequency that a couple were sexually active prior to the stroke was largely predictable of whether a couple had resumed sexual activity post stroke rather than factors such as the patient's age or level of physical disability (Hawton, 1984). Although this research is not current, its findings are valuable and there is not more recent literature that refutes this.

Sexual dysfunction is commonly experienced by individuals post stroke however it is an under-recognized complication and is often under-addressed by health care professionals although sexual health is a fundamental part of QOL (Park et al., 2015). Sexual health is regarded as a very personal and private topic and is not recognised as an integral part of post-stroke rehabilitation (Nilsson et al., 2017).

2.6 Quality of life

2.6.1 Definition of quality of life

The WHO QOL group defined QOL as an "individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns" (The WHOQOL Group, 1998, p.551). Quality of life is described as a person's perception of their general wellbeing and is associated with an individual's "physical health, psychological state, personal beliefs, social relationships and their relationships to salient features of their environment" (World Health Organization, 1997).

In simple terms, QOL can be understood as the personal appraisal of the overall nature of an individual's life (McDougall et al., 2010). Quality of life has multiple dimensions that involve physical, psychological and social aspects of an individual's wellbeing (Owiredu et al., 2015).

The WHO categorizes QOL into four key areas including: environmental, physical, psychological, and social relationships (McDougall et al., 2010). When understanding QOL according to the ICF, QOL falls under the domain of functioning (Teixeira-Salmela et al., 2009). QOL comprises both health and non-health related aspects and it encompasses environmental and personal factors which fits into the domains of the ICF.

The closely related concept of health related quality of life (HRQOL), is an important patient-centred outcome that involves the physical, psychological and social feelings of wellbeing (Donkor, 2018). The concept of HRQOL evaluates the complex impact that disease and disability has on an individual's life (Donkor, 2018). There are various HRQOL outcome measures that exist and are helpful tools to identify the areas of need in individual (Donkor, 2018). Generic measures of HRQOL such as The Short Form 36 Health Survey Questionnaire and EuroQOL (EQ-5D), assess HRQOL across populations of different diseases (Donkor, 2018). Specific outcome measures are more valid, responsive, and sensitive in assessing HRQOL in a specific population or for a specific disease for example the SSQOL in the stroke population.

2.6.2 Stroke and quality of life

A stroke can result in physical and psychological impairments, compromising an individual's functional independence and negatively impacting a person's QOL (Lo Buono et al., 2017). Stroke morbidity is the primary cause of reduced independence and poor QOL among adults (Calabrò et al., 2011). Moreover, stroke related disability causes reduced QOL among the post stroke population (Lin et al., 2011). The more severe an individual's disability, the lower their QOL is (Lin et al., 2011). The sequelae of stroke including the social, cognitive and physical impairments negatively impacts an individual's QOL (Lo Buono et al., 2017). Quality of life is an important domain for assessment in stroke survivors and will assess the impact that the physical, social, emotional and cognitive consequences have on an individual's QOL post stroke (Muus et al., 2007).

The disability and morbidity encountered by individuals post stroke reduces the QOL of stroke survivors (Lin et al., 2011). Stroke-related disability has a profound impact on an individual's HRQOL (Donkor, 2018). Therefore, a key goal of stroke neuro-rehabilitation is to improve an individual's functional status and improve the QOL of stroke survivors (Lin et al., 2011).

There are various outcome measures that are patient-centered, sensitive and valid in assessing the HRQOL in the stroke population (Donkor, 2018). These measures include the Niemi QoL scale, Stroke Impact Scale (SIS), Stroke and Aphasia Quality of Life Scale -39 (SAQoL-39), Newcastle Stroke-Specific Quality of Life Measure (NEWSQOL), Stroke-Specific Quality of Life Scale (SSQOL), and the Health Related Quality of Life in Stroke Patients (HRQoLISP) (Donkor, 2018). In a review outlining the advantages and disadvantages of QOL measures used in stroke research, the Niemi QoL scale satisfied major criteria including evidence of reliability, validity and responsiveness (Buck et al., 2000). Another tool, the SIS has adequate psychometric properties in patients with mild to moderate stroke severity (Richardson et al., 2016). Many measures assessing the QOL after stroke are generic instruments such as the well-being scale or the Short-Form-36 which are not as sensitive to assess the specific effects of a disease such as stroke on an individual's QOL (Mahmoodi et al., 2015). The SSQOL scale is commonly used and has been validated for the stroke population (Boosman et al., 2010) and because it is a specific scale to assess QOL post stroke, it is significantly more valid and sensitive in comparison to generic instruments (Mahmoodi et al., 2015). There is good test-retest reliability (Lin et al., 2011) and the SS-QOL scale has excellent internal reliability with Cronbach's alpha coefficients falling between 0.80 and 0.92 (Boosman et al., 2010; Lin et al., 2011).

Various studies investigating stroke and QOL, show that the factors contributing to HRQOL include depression, functional status, age, presence of comorbidities, time since stroke, social class, support structure and caregiver characteristics (Donkor, 2018). In a study based in Ghana, the identified domains impacting HRQOL were the psychological, cognitive and physical domains (Donkor, 2018). Similar findings were apparent in a Nigerian study, where the physical, psychological, cognitive and social interaction domains were the areas of HRQOL that were most affected by stroke (Donkor, 2018).

2.6.3 Sexual function and quality of life

Sexual health contributes significantly to human relationships and may enhance a person's QOL (Owiredu et al., 2015; Park et al., 2015; Rosenbaum et al., 2014). It is evident from many studies, that adequate sexual functioning enables individuals to experience a sense of physical, social, and psychological wellbeing (Oyewole et al., 2017a; Vajrala et al., 2020). Human sexuality is significant in maintaining relationships and the feelings of being an integral part of society (Cybulski et al., 2018). Adequate sexual life is important for wellbeing in adulthood and sexual identity is linked closely with self-esteem (Cybulski et al., 2018). If sexual issues arise, self-esteem, social relationships and mental health can be affected (Cybulski et al., 2018).

A study based in Ghana investigated the prevalence of sexual dysfunction and its impact on QOL amongst individuals living with physical disability (Owiredu et al., 2015). People living with physical disability may experience frustration and anxiety and these emotions may worsen or lead to sexual dysfunction (Owiredu et al., 2015). Sexual dysfunction negatively affects the QOL of the individual living with a physical disability and the QOL of their sexual partner (Owiredu et al., 2015). In this study, the prevalence of sexual dysfunction amongst persons with physical disability was 64,4% in males and 65,7% in females (Owiredu et al., 2015). The major areas of sexual dysfunction amongst females were anorgasmia, non-communication and avoidance of sexual interactions whilst the typical sexual problems experienced by males were infrequency, premature ejaculation and decreased sexual satisfaction (Owiredu et al., 2015). Infrequency, a common sexual problem identified amongst males, could be due to unavailability of sexual partners either because of perceptions of available female partners or due to the limitation placed on males by societal perceptions resulting in a lack of self- esteem and poor confidence hindering their sexual health (Owiredu et al., 2015). This research shows that sexual dysfunction was associated with a lower QOL in individuals with physical disabilities which may be exacerbated by society's negative views on sexual health amongst persons with physical disability (Owiredu et al., 2015). Sexual dysfunction and poor sexual satisfaction can negatively impact QOL (Owiredu et al., 2015). Participants were assessed using the Golombok Rust Inventory of Sexual Satisfaction (GRISS) questionnaire and the Sexual Quality of Life questionnaire (SQoL) (Owiredu et al., 2015). In this study, males with sexual disability had a significantly lower sexual QOL compared to females with physical disability (Owiredu et al., 2015).

McCabe and Taleporos, (2003) assessed the association between physical disability and sexual depression, sexual esteem, sexual satisfaction, and frequency of sexual activity in 1196 participants. There were 448 participants who were able-bodied and 748 participants who had a physical disability with the participants' age ranging from 18 to 69 years (McCabe and Taleporos, 2003). A disability survey was used to determine the severity of disability subjectively, the severity of disability objectively and the duration of disability (McCabe and Taleporos, 2003). The findings revealed that the more severe the physical disability, the lower the individual's self-esteem, the poorer the sexual satisfaction and the worse the sexual depression experienced by the individual (McCabe and Taleporos, 2003). In addition, the results demonstrated that persons with more severe physical disabilities engage in sexual activities less frequently (McCabe and Taleporos, 2003). This study also concluded that females with physical disabilities experienced a more positive outlook towards their sexual health compared to males with physical disabilities (McCabe and Taleporos, 2003). Males living with disabilities may experience the feeling of failure regarding sexual performance which has an emasculating effect on these individuals, negatively impacting their QOL (McCabe and Taleporos, 2003). Other findings are that the longer an individual had lived with a physical disability, the more positive their attitudes were about their sexual wellbeing (McCabe and Taleporos, 2003). It is evident that physical disability can lead to negative emotions in many individuals including a misleading belief system that people with disabilities are less sexually desirable than an able-bodied individual and that living with a disability can significantly limit ones sexual expression (McCabe and Taleporos, 2003). These feelings are destructive to an individual's self-esteem and can negatively impact one's QOL (McCabe and Taleporos, 2003).

A qualitative study investigating the perspectives and experiences regarding sexual issues encountered by individuals post stroke suggested that sexual life is a vital part of stroke recovery (Schmitz and Finkelstein, 2010). Issues with sexual functioning that arise post stroke are experienced by both the stroke survivors and their partners as a sense of loss (Schmitz and Finkelstein, 2010). Sexual dysfunction cannot merely be seen as a physical impairment as a result of the stroke but must be understood as a complex function affected by biopsychosocial factors (Schmitz and Finkelstein, 2010). Sexual problems occur as a result of the complex interaction between physiological, psychological, and social factors and therefore these problems can affect a person's psychological wellbeing and impact one's QOL (Schmitz and Finkelstein, 2010).

One of the major concerns identified by stroke survivors and their partners is the changes in roles that couples experience which is often as a coping mechanism to deal with the impact of stroke (Schmitz and Finkelstein, 2010). Role identity changes often occur within a relationship where the partner takes on a caregiver role which affects sexual confidence, sexual interest and desirability for both individuals (Schmitz and Finkelstein, 2010). There is added stress in a relationship, affecting sexual relations which has been associated with a negative impact on QOL in both stroke survivors and their partners (Schmitz and Finkelstein, 2010).

2.7 Sexual rehabilitation

2.7.1 Addressing sexual function in patients post stroke

Sexual activity must be carefully considered in patients post stroke and sexual counselling is essential to optimise QOL similar to that pre-stroke (Giaquinto et al., 2003). Sexual intervention, sexual counselling and sexual education are imperative in post-stroke rehabilitation and are considered a necessity for improving QOL (Prior et al., 2019). A WHO report states that addressing sexual health is to a large extent, culturally determined, influenced by gender constructs and religion (Vikan et al., 2019). According to the WHO, the disconnect between patients' desires to address their sexual concerns and the services actually provided by health care providers emphasizes that sexual counselling is an area that requires urgent attention (Vikan et al., 2019). In a recent study by Vikan et al., (2019), sexual health policies at nine specialized stroke rehabilitation centres were investigated. Four out of the nine rehabilitation centres scored low on having a sexual health policy in stroke rehabilitation (Vikan et al., 2019). The findings of this study stresses the importance of implementing sexual health policies at stroke rehabilitation centres (Vikan et al., 2019).

The management of sexual dysfunction is complex and multifaceted. In order to address sexual dysfunction effectively, a multi-disciplinary team approach is required (Stratton et al., 2020). There are various types of interventions to address sexual dysfunction, including pharmacological and non-pharmacological interventions for males and females (Stratton et al., 2020). A review conducted by Ng et al., (2020), assessed the effectiveness of interventions to reduce problems with sexual function after stroke as well as to evaluate any adverse effects

associated with these interventions. The findings concluded that pharmaceutical intervention such as sertraline to treat premature ejaculation in males needs further testing (Ng et al., 2020). Non-pharmacological interventions for males include the usage of mechanical devices such as penile implants and vacuum pumps, or lubricants in females; educational support such as counselling and physical rehabilitation such as physiotherapy for bed mobility or pelvic floor strengthening (Stratton et al., 2020). The current evidence supporting structured sexual rehabilitation and pelvic floor physiotherapy to address sexual dysfunction post stroke is scarce (Ng et al., 2020).

The goals of sexual rehabilitation post stroke are to evaluate sexual problems, provide educational material on sexual concerns, and facilitate return to sexual activity (Stratton et al., 2020). Sexual rehabilitation is patient-centred and is tailored according to individual needs as well as being functionally orientated (Stratton et al., 2020). A major part of sexual rehabilitation is counselling which can address issues with sexual performance, issues with medication and medical comorbidities that can affect sexual function as well as other interpersonal factors (Stratton et al., 2020). Sexual rehabilitation including counselling can take place in a group setting or can be done one-on-one and can make use of various methods such as visual or oral information, written or audio-visual materials or practical training (Stratton et al., 2020).

A study by Hamam et al., (2013), aimed to identify the availability and accessibility of printable education materials online regarding sexual concerns post stroke. Nine printable educational materials were identified covering similar content including: problems experienced post stroke, suggested solutions to these problems and reassurance to stroke survivors and their partners (Hamam et al., 2013). There was a lack of content covering solutions and reassurance and the available content was general and not evidence-based (Hamam et al., 2013). The study concluded that educational materials on return to sex after stroke may be a beneficial resources for health-care professionals, patients post stroke and their partners (Hamam et al., 2013). The authors highlight that the educational content should cover information for partners, information on a variety of sexual activities such as masturbation and be accessible and relevant for a wider population including single individuals and people in same-sex relationships (Hamam et al., 2013).

2.7.2 Barriers to including sexual rehabilitation in the stroke rehabilitation

Patients with neurological conditions commonly experience sexual problems however addressing sexual dysfunction is poorly addressed in clinical practice (Owiredu et al., 2015). Individuals post stroke who receive rehabilitation, are often not provided with sexual rehabilitation as a component of the rehabilitation programme (McGrath et al., 2019; Rosenbaum et al., 2014). There are various reasons for this including: sexuality and sexual function are viewed as taboo topics, therapists are uncomfortable broaching sexual function, as well as a lack of therapists' knowledge and training in this field (HoSook et al., 2011; Kautz and Van Horn, 2017; McGrath et al., 2019; Rosenbaum et al., 2014). An individual's unique beliefs, concern for offending the patient, awkwardness and the understanding that it is other professionals' scope were barriers to sexual rehabilitation (Hamam et al., 2013; Prior et al., 2019). In addition, lack of hospital policy, unhelpful mindsets of staff and societal views such as people with disabilities are asexual, are significant barriers to sexual rehabilitation (Vikan et al., 2019).

Time limitations and lack of information and resources are also obstacles encountered by therapists regarding addressing sexual function during rehabilitation (McGrath et al., 2019; Rosenbaum et al., 2014). The provision of sexual rehabilitation services is scarce (Kautz and Van Horn, 2017); this is evident from the statistics of the 2012 Australian National Stroke Audit Rehabilitation Service Report where only 17 percent of patients post stroke had information on sexual health provided to them (Ng et al., 2017).

According to research by Schmitz and Finkelstein (2010), there are unmet rehabilitation needs regarding sexual problems and concerns. Most participants in their study reported that they lacked the opportunity to broach the topic of sexual function throughout the rehabilitation process (Schmitz and Finkelstein, 2010). Results from a pilot study conducted by McLaughlin and Cregan in Ireland found that although the majority of rehabilitation staff had been questioned by their patients for guidance on problems with sexual health during rehabilitation, most patients had received no sexual rehabilitation during their stroke rehabilitation (McLaughlin and Cregan, 2005). A recent study by Prior et al., (2019), investigated the current methods for presenting educational content on post stroke sexual activity as well as sought to identify the perceived gaps in sexual rehabilitation from the patients' perspectives. The findings from this study that included 183 post stroke patients in

Tasmania, Australia showed that although 30% of participants requested to obtain additional information associated with post stroke sexual activity, only 8,2 % of participants had received this (Prior et al., 2019). In addition, the results showed that the most preferable method of receiving information on sexual activity was from a doctor in a private discussion with or without their partner present (Prior et al., 2019). This study stresses that education and post-stroke sexual activity information is inconsistent and does not meet the needs of patients within major Tasmanian hospitals (Prior et al., 2019).

2.7.3 Sexual rehabilitation

A commonly used model to address sexual problems encountered by persons with chronic illnesses and disabilities is the Permission, Limited Information, Specific Suggestions, and Intensive Therapy model (PLISSIT) (Khakbazan, 2016). This model, originally described by Annon in 1974, is a useful tool for healthcare professionals to address sexual problems and helps to guide sexual counselling for individuals post stroke (Annon, 1976; Kautz and Van Horn, 2017). The information discussing the PLISSIT model in Annon's work is still relevant and comprehensive compared to more recent literature (Annon, 1976). The PLISSIT model uses a patient-centred approach and is a guideline for healthcare professionals to assess a patient's sexual concerns and plan a four-stage framework for sexual intervention (Annon, 1976; Khakbazan, 2016).

The four steps of this model are:

- Permission. This refers to "giving the patient permission" to maintain their sexual traditions and to continue being sexually active as well as to encourage the patient to share their sexual concerns. This first phase is fundamental in reducing the patient's concerns and anxiety (Khakbazan, 2016).
- Limited Information. This phase provides patients with factual information directly relating to their sexual issues mentioned in the first phase (Annon, 1976). It may include anatomical and physiological information about sexual functioning (Khakbazan, 2016).
- Specific Suggestions: This phase enables patients to make behavioural changes specific to their sexual goals and provides patients with practical exercises, strategies,

and recommendations to address sexual problems for example to alter sexual positions or take medication (Annon, 1976; Khakbazan, 2016).

- Intensive Therapy. In the case where sexual problems could not be addressed in the initial three stages, intensive therapy is indicated whereby referral to specialists is required as greater skills, training and knowledge is required (Khakbazan, 2016; Taylor and Davis, 2007).

The PLISSIT model is beneficial in resolving an individual's sexual problems by using the first three phases of the model. An extension of the original PLISSIT model, the Ex-PLISSIT model emphasises that at each stage "permission giving" is vital whereby the focus must be on normalizing sexuality (Taylor and Davis, 2007).

A study by Song et al., (2011), demonstrated that a post stroke, sexual rehabilitation programme for patients and their partners, significantly increased their sexual satisfaction and frequency of sexual activity but did not have an impact on sexual knowledge. The intervention programme suggested in this study can be used as a guideline for sexual rehabilitation for patients post stroke (Song et al., 2011). The sexual rehabilitation programme was reviewed and modified by nursing professors, one rehabilitation medicine professor and a neurology head nurse (Song et al., 2011). The contents of the programme include information regarding changes in sexual life post stroke; general information regarding a healthy sexual life; counselling on fears regarding sexual life after a stroke; discussing tips and strategies to minimise potential sexual dysfunction post stroke; and presenting common questions and answers regarding sexual function post stroke. This post-stroke intervention programme can be administered to patients and their partners as a guideline for resuming a healthy sexual life upon discharge (Song et al., 2011). There are various limitations of this study. This study only provides information on the effects of a once-off sexual rehabilitation intervention programme and therefore it would be beneficial for further research to evaluate the effectiveness of repeated application of this programme on an out-patient basis (Song et al., 2011). Another weakness is that this study only evaluated the short term effect of a sexual rehabilitation intervention programme and it would be beneficial for further research to look at the long term impact of such a programme (Song et al., 2011). In addition, the study has a small sample size of 46 participants which limits its general applicability (Song et al., 2011). There were strengths of this study including that there were no significant differences found between the participants in the control and

experimental groups regarding general characteristics ensuring no effect on the outcome variables (Song et al., 2011). The results of this study were statistically significant regarding the second and third hypotheses (Song et al., 2011). The mean sexual satisfaction score in the experimental group for patients and their spouses who were provided with a sexual rehabilitation intervention programme was significantly higher than that in the control group (Song et al., 2011). The results were also statistically significant and supported the third hypothesis, that patients and their spouses who received sexual rehabilitation would have a higher sexual activity frequency than those who were not provided with a sexual rehabilitation intervention programme (Song et al., 2011). In addition, the frequency of sexual intercourse in the experimental group was also significantly higher than that in the control group (Song et al., 2011).

A cross-sectional study by Meesters et al., (2020) looked at the long term relational and sexual functioning for patients post stroke who previously received sexual counselling during their rehabilitation. The sexual counselling that participants received during their rehabilitation was based on the understanding of the classification developed by Pieters et al., (2018) and are approaches commonly used in sexual rehabilitation in the Netherlands (Meesters et al., 2020). The classification includes six areas of sexual difficulties which are regularly experienced by patients, namely: problems with sexual functioning, a change in the sexual experience, disturbed intimacy in a relationship, practical difficulties which negatively impact sexual pleasure, difficulties adapting to physical limitations in sexual activities, and difficulties that young individuals encounter with regard to courtship, dating and sexual health (Meesters et al., 2020).

Sexual counselling, to address the above areas, is based on the principles of adaptation, compensation and acceptance (Meesters et al., 2020; Pieters et al., 2018). Adaptation refers to the changes that individuals with chronic health conditions must apply to the basic areas of life such as intimacy and sexual wellbeing (Meesters et al., 2020). Sexual counselling prepares and supports patients for adapting in their intimate relationships for example addressing the fear of the re-occurrence of stroke during sexual activities (Meesters et al., 2020). Compensation refers to the strategies and materials that are shared with patients and their partners during sexual rehabilitation to assist with practical challenges that patients may encounter in an intimate relationship when adaptations are inadequate to optimise sexual health (Meesters et al., 2020). Examples of compensatory devices used to aid sexual

satisfaction and make sexual experiences possible and more pleasurable, include vibrators, incontinence materials and supportive cushioning for positioning (Meesters et al., 2020). The last principle described by Pieters et al., (2018) is acceptance which is considered a prerequisite for working on adaptation and compensation. Counselling plays a major role in facilitating patients with the process of accepting the major consequences that come with a chronic health condition specifically regarding sexual dysfunction (Meesters et al., 2020; Pieters et al., 2018).

The findings of this research show that patients who received sexual counselling during their rehabilitation post stroke experience high relational satisfaction in the long term after stroke, despite experiencing sexual dysfunction and dissatisfaction with their sexual life that is, 63% of the males and 44% of the female participants (Meesters et al., 2020). Another noteworthy finding of this study was that relational satisfaction and sexual satisfaction are strongly related to each other (Meesters et al., 2020). Previous research has not specifically included patients who have received sexual counselling after stroke and interestingly, results of this study show that patients still report sexual dysfunction and dissatisfaction with sexual life in the longer term post stroke despite receiving sexual rehabilitation post stroke (Meesters et al., 2020). Although interesting, there are various limitations of this study such as the low response rate which can potentially result in a selection bias and affect the generalizability of the results (Meesters et al., 2020). It is also suggested that questionnaires were completed more by patients who experience sexual dysfunction (Meesters et al., 2020). Another limitation of this study is that the questionnaire was only completed once-off, therefore it is impossible to infer changes over time or infer causal relationships from the results (Meesters et al., 2020). In addition, the outcome measure used to assess sexual functioning, the Eleven Questions about Sexual Functioning (ESF men and ESF woman), was not validated to be used for the current purpose in the study population (Meesters et al., 2020). This study was only conducted in one western European country which is a limitation as there are significant cultural differences regarding sexual health and the role of sexual rehabilitation post stroke between countries and therefore it is difficult to understand if the study findings translate cross-culturally (Meesters et al., 2020). The findings of this research imply that continued assessment of sexual functioning and satisfaction with sexual life is beneficial after stroke rehabilitation even when sexual counselling was included as stroke-related complications may persist or appear over time (Meesters et al., 2020).

A systematic review conducted by Auger et al., (2021), describes the best available literature supporting effective interventions used in post stroke rehabilitation of sexual function. This systematic review recommends clinically relevant approaches that can be used by health care professionals during the rehabilitation of patients post stroke (Auger et al., 2021). This review showed that majority of the research previously conducted in this field has focused on interventions targeting the individual post stroke but stresses that interventions focusing on the environment in a multimodal approach can also be beneficial (Auger et al., 2021). Eight studies were included in this review (Auger et al., 2021). Structured sexual rehabilitation programmes based on the PLISST model and pelvic floor muscle training had the best evidence-based interventions for use by allied health professionals (Auger et al., 2021). Two studies focused on the role of the physical therapist in sexual rehabilitation including pelvic floor muscle training and training patients in improving physical functioning for sexual activities such as bed mobility and positioning (Auger et al., 2021). Four of the intervention studies presented the impact of a structured sexual rehabilitation programme (Auger et al., 2021). One study was a case of interdisciplinary sexual rehabilitation and one study was the implementation of a systematic sexuality-relation discussion (Auger et al., 2021). Two of the studies assessed the effectiveness of a specific intervention, namely training the pelvic floor musculature and a retreat for couples post stroke (Auger et al., 2021).

This systematic review had various limitations including the risk of potential bias in each of the studies analysed (Auger et al., 2021). For example, this review included studies with a level of evidence four such as a case study (Auger et al., 2021). Despite these limitations, this research had numerous strengths in particular that is was conducted following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Auger et al., 2021). A librarian accredited with The American Library Association (ALA) was involved throughout the systematic review to ensure an extensive search strategy (Auger et al., 2021). In addition, there was blinded data collection as well as data extraction was done according to the Oxford Centre for Evidence-based. Medicine (OCEBM) and the Template for Intervention Description and Replication (TIDieR), which attests to the quality of the data included and its clinical relevance and research benefits (Auger et al., 2021). Moreover, this is a unique study as it is the only systematic review of its kind and therefore despite its limitations, this research has provided beneficial and relevant insight into sexual dysfunction post stroke.

The overall results of each of the studies described in this review are as follows. Intervention should be customised to the stage of sexual rehabilitation, for example in the acute stage, written documentation should be the focus as the initial period post stroke is overwhelming for the patient (Auger et al., 2021). In the rehabilitation setting, documentation should also be offered to the patient for example in the form of informative pamphlets (Auger et al., 2021). During inpatient rehabilitation, it is suggested that a structured programme taking place the week before discharge, in the form of a one-time 30-45 minute individual consultation based on the PLISTT model (Auger et al., 2021). In the outpatient setting, structured sexual rehabilitation programmes are also recommended including pelvic floor muscle training, skill development and sexual counselling to facilitate patients' abilities to engage in sexual activities (Auger et al., 2021). For the community setting, once off interventions, for example a couples' retreat, could be beneficial at enhancing intimacy in a relationship and promote a couples' sexual wellbeing (Auger et al., 2021) This systematic review confirms the importance of further research in the area of sexual rehabilitation post stroke with a focus on the environment and not only the individual (Auger et al., 2021).

2.7.4 The role of the multidisciplinary team in sexual rehabilitation

Health care professionals including nurses, speech therapists, occupational therapists, social workers, psychologists and physiotherapists play a vital role in sexual rehabilitation (Nilsson et al., 2017; Rosenbaum et al., 2014). Allied healthcare professionals should include sexual rehabilitation in their scope specific practice to aid patients in sexual function (Kautz and Van Horn, 2017; Ng et al., 2017). For example speech therapists retraining function in patients with dyspraxia for kissing, nurses to assist with bladder and bowel programmes, and physiotherapists to assist with mobility and to assist with positioning of patients, which all will influence effective sexual functioning (Ng et al., 2017).

A study by Rosenbaum et al., (2014), emphasises the importance of addressing sexual function in patients post stroke. The findings of this narrative review are limited because only 27 articles were included in this review (Rosenbaum et al., 2014). Other weaknesses of this review includes that there were no specifications on study design for the trials included and there was no standard for the quality of trial methodologies included (Rosenbaum et al., 2014). Strengths of this review however are that the literature is fairly recent, from 2012, and specific keywords were used in the search (Rosenbaum et al., 2014).

Research conducted by Pieters et al., (2018), looks at a training programme specifically designed for professionals working in rehabilitation as part of a multidisciplinary team. The training aims to facilitate an environment in which sexual health issues can be addressed (Pieters et al., 2018). The study uses a pre-test-post-test design to assess the impact of the training given to six teams in the Netherlands (Pieters et al., 2018). The knowledge and comfort levels of the rehabilitation staff significantly increased after the training, demonstrating that rehabilitation professionals can benefit from a tailor made training programme on sexual healthcare (Pieters et al., 2018). Another valuable finding from this study is the importance of defining roles and responsibilities amongst members of the multidisciplinary team (MDT) which aids integrating sexual health into rehabilitation (Pieters et al., 2018). This study does however have limitations, in particular, the absence of a control group, the lack of data from a patient's perspective and a limited option to generalize the results to a specific chronic condition or physical disability (Pieters et al., 2018).

Despite these weaknesses, the study had beneficial recommendations. In particular, training a MDT on sexual health improves the knowledge of healthcare professionals to approach sexual health issues, the roles of MDT members should be clearly defined concerning sexual health rehabilitation, institutional policies regarding sexual rehabilitation should be put in place, and the effectiveness of the sexual health training programme should be guided by patients' experiences (Pieters et al., 2018). Health care professionals continue to be challenged in the area of addressing sexual health amongst the rehabilitation patient population, whether it being due to a long-standing taboo or an oversight, but patients are at risk of developing chronic sexual problems (Pieters et al., 2018). Therefore, it is the responsibility of health care professionals to adequately educate themselves in the area of sexual health and be able to recognize poor communication that hinders sexual rehabilitation (Pieters et al., 2018).

2.7.5 The role of physiotherapy in sexual rehabilitation

Sexual rehabilitation has positive effects for patients regarding the regularity of sexual activity and sexual satisfaction (HoSook et al., 2011). A recent study by Vajrala et al., (2020), examined the effect of a structured physiotherapy and counselling programme on sexual health in individuals post stroke. The physiotherapy intervention for sexual rehabilitation consisted of pelvic floor muscle training (PFMT), Pilates-based exercises, general endurance

exercises, bed mobility exercises as well as functional electrical stimulation (FES) of the bulbocavernosus muscle (Vajrala et al., 2020). The motivation behind using FES in sexual rehabilitation is to stimulate nerves and muscles, for example in the Bulbocavernosus muscle which will facilitate erection in males (Vajrala et al., 2020). Functional electrical stimulation of the pelvic floor muscles will promote blood flow to the penis and stimulate muscles in the area to provide pressure on the penile veins during sexual activity to enable sustaining an erection (Vajrala et al., 2020). Vaginal electrical stimulation has proven effective in improving the sexual health of women with pelvic floor dysfunction (Aydın et al., 2015) and functional electrical stimulation is a beneficial technique in females with sexual dysfunction for example in those experiencing vaginismus (Yaraghi et al., 2019).

Kegel exercises are considered the first-line therapy for patients who experience symptoms such as pelvic floor weakness and urinary incontinence. Kegel exercises aim to strengthen the pelvic floor musculature including the levator ani, and coccygeus muscles which play a crucial role in supporting the pelvic organs (Huang and Chang, 2021). There is currently no set protocol for PFMT, but the focus is that patients should contract the pelvic floor muscles rather than the abdominal, gluteal, or inner thigh muscles (Huang and Chang, 2021). These exercise are popularly recommended by clinicians as they have few side effects and can be tailor made to suit the individual's needs (Huang and Chang, 2021). Kegel exercises are used in sexual rehabilitation. In females, Kegel exercises aim to reduce pain during sexual intercourse by facilitating vaginal muscle relaxation (Vajrala et al., 2020). Furthermore , Kegel exercises promote blood flow to the pelvic floor muscles and increase lubrication to the vagina which facilitates more comfortable penetration during sexual intercourse (Vajrala et al., 2020).

A study by Tibaek et al., (2015) assessed the effect of PFMT on erectile function as an indicator of sexual health in males with LUTS post stroke. Thirty-one participants were randomized to a treatment or control group, the participants in the treatment group received a 12-week programme of PFMT. The small sample size in this study was a major weakness (Tibaek et al., 2015). Another weakness of this study is that there was a large amount of data missing from the control group which reduces the internal validity of the study due to potential selection bias (Tibaek et al., 2015). In addition, the long term effects were defined by the results obtained at a six month follow which may have been premature (Tibaek et al., 2015). Another limitation of this study is the validity of the International Index of Erectile

Function (IIEF-5) questionnaire as the pre-test data was changed from three months to one month (Tibaek et al., 2015). There was also the chance of a placebo effect in this study which is another limitation (Tibaek et al., 2015). The results showed that PFMT may have short and long term effects on erectile function in males with LUTS post stroke although results were not statistically significant (Tibaek et al., 2015). Although this research had various limitations, the results of this trial showed that PFMT was associated with a improved erectile function in men with LUTS after stroke and has clinical relevance namely, PFMT appeared well tolerated, with low drop-out rate, there was a high session attendance, and no reported adverse events (Tibaek et al., 2015). It is believed that this study is the first randomised controlled trial evaluating the effect of PFMT measured on erectile function in men with LUTS after stroke (Tibaek et al., 2015) and thus still adds value to the field of sexual rehabilitation post stroke.

2.8. Conclusion to the literature review

Sexual health is an integral part of normal life and has a significant impact on a person's QOL. There is considerable research that recognizes that problems with sexual function commonly arise post stroke. Sexual dysfunction affects as many as three quarters of individuals post stroke (Akinpelu et al., 2013). The causes of sexual dysfunction are multifactorial and are related to physical, physiological and psychosocial reasons (Rosenbaum et al., 2014). The areas of sexual dysfunction most commonly affected in individuals post stroke are lowered libido, decreased vaginal lubrication and orgasmic dysfunction in females, ED and poor ejaculation in males and a decline in the frequency and enjoyment of engaging in sexual activities (Akinpelu et al., 2013; Tamam et al., 2008; Vajrala et al., 2020).

Research shows that the prevalence of stroke is on the rise in South Africa and is becoming a significant public health care issue in South Africa particularly affecting the younger population (Bertram et al., 2013; Kissela et al., 2012). Therefore, there is a rising need for adequate and accessible information regarding sexual function post stroke in South Africa and there is a major need for sexual rehabilitation post stroke. It is evident that online information about sexual function post stroke is insufficient, very general and not evidence based (Rosenbaum et al., 2014). There is scarcity in the literature to fairly support the

possible benefit or risk to guide clinical practice regarding sexual rehabilitation (Ng et al., 2020). The literature however shows that stroke survivors value sexual health and would like sexual function to be addressed during their post stroke rehabilitation (McGrath et al., 2019). The MDT plays a major role in sexual rehabilitation according to their scope of practice, for example the psychologist addresses psychosocial issues, the speech therapist addresses communication barriers and physiotherapists assist with functional limitations in order to facilitate more effective sexual functioning (Kautz and Van Horn, 2017; Ng et al., 2017).

Stroke morbidity and stroke-related disability has a significant effect on an individual's QOL. The literature reveals that sexual function, which is commonly affected in stroke survivors, can significantly impact a person's QOL and affect an individual's general wellbeing (Owiredu et al., 2015; Park et al., 2015; Rosenbaum et al., 2014). It is evident from research, that sexual dysfunction is associated with a poorer QOL.

Reasons that sexual health is an under-addressed issue in post stroke rehabilitation are vast and includes that health care professionals lack knowledge, experience, and training in this area (Akinpelu et al., 2013; Kautz and Van Horn, 2017). Despite the knowledge that sexual dysfunction is a common occurrence amongst stroke survivors and their partners, there is inadequate effort to address this problem in post-stroke rehabilitation (Rosenbaum et al., 2014).

In conclusion, sexual health should be addressed by health care professionals in the acute stages of post stroke rehabilitation (Rosenbaum et al., 2014). A collaborative approach is required from professionals to address sexual health in patients after stroke and the multidisciplinary team should work together with sexologists to provide effective sexual rehabilitation addressing all aspects of sexual dysfunction (Rosenbaum et al., 2014).

CHAPTER 3: METHODOLOGY

This chapter describes the methods and instrumentation used for the data collection. It also describes the study sample, process of data collection and data analysis.

3.1 Type of study

This was a quantitative cross-sectional study.

The participants were assessed once-off and numerous variables were assessed at once.

3.2 Participants

3.2.1 Source of participants

Participants for the study were recruited from the outpatient department of the physiotherapy department at Thelle Mogoerane Regional Hospital. This hospital is a government hospital situated in Vosloorus, Johannesburg. The hospital offers inpatient and outpatient neurological rehabilitation services.

3.2.2 Sample selection

Information about patient numbers was collected by counting how many new outpatients were booked for the neurology physiotherapy outpatient department in 2017 and 2018. A total of 121 outpatients arrived for their outpatient appointments in 2017 and 154 patients arrived for their outpatient appointments in 2018. Therefore, the average number of outpatients booked for the first time over the two years was 138. Using a confidence interval of 10 and a 95% confidence level, a sample size of 57 participants was required, for the study, based on an average number of outpatients booked yearly (138) (Raosoft.com, 2004).

3.2.2.1 Inclusion criteria

Participants were included in the study if they:

- had a confirmed CVA
- were between three months and 24 months post stroke
- were reportedly sexually active prior to having a stroke
- were aged between 18 to 75 years old
- had scored at least 24 out of 30 in the Mini-Mental State Examination (MMSE) or 17 out of 22 on the Adult Lifestyles and Function Interview (ALFI) version of the MMSE (Roccaforte et al., 1992)

3.2.2.2 Exclusion criteria

Participants were excluded from the study if they:

- had more than one CVA
- had previous sexual dysfunction
- had communication problems (i.e. severe aphasia or dysarthria) as confirmed by a speech therapist and scored lower than 24 out of 30 in the Mini-Mental State Examination or less than 17 out of 22 on the ALFI-MMSE (Roccaforte et al., 1992).

3.3 Instrumentation and outcome measures

3.3.1.1 Mini- Mental State Examination (MMSE)

This test has been used as a screening tool of cognitive impairment and has been widely used in the stroke population (Bour et al., 2010; Toglia et al., 2011). It comprises of seven cognitive domains consisting of 11 questions or simple tasks. The domains include orientation to time, orientation to place, three-word registration, attention and calculation, three-word recall, language and visual construction (Toglia et al., 2011). A score of less than 24 out of 30 is indicative of cognitive impairment (Dick et al., 1984). In a study by Toglia et al. (2011), the internal consistency of the tool indicated a Cronbach alpha of 0.60. Refer to appendix VII for an example of the tool.

3.3.1.2 Adult Lifestyles and Function Interview (ALFI)-Mini- Mental State Examination (MMSE)

This is a 22- point version of the MMSE that can be used telephonically. It has omitted 8 items of the original MMSE that could not be administered telephonically (as visual cues/ face-face assessment are required for those items). Roccaforte et al., (1992), assessed the validity of the ALFI-MMSE in a study of 100 geriatric outpatients. Correlations between phone and face-to-face versions of the MMSE were excellent (Pearson's r = 0.85). Sensitivity of 67% and specificity of 100% were reported in a population of elderly, community-dwelling individuals. This was similar to the sensitivity (68%) and specificity (100%) reported for screening with the traditional MMSE (Carlew et al., 2020; Kennedy et al., 2014; Newkirk et al., 2004; Roccaforte et al., 1992). Refer to appendix VIII to view the measure.

3.3.2 The Stroke Specific Quality of Life questionnaire (SS-QOL)

This tool based on patient reported outcomes has been used to assess a patient's quality of life after having a stroke. This tool has been used widely in the stroke population and has been validated for use in patients with ischaemic strokes, subarachnoid haemorrhage and intracerebral haemorrhage (Boosman et al., 2010). It has been used to look at the HRQOL of an individual over 12 domains made up of a further 49 items ranked using Likert scales (Teixeira-Salmela et al., 2009). A higher score is indicative of a better HRQOL (Teixeira-Salmela et al., 2009). The SS-QOL is an appropriate tool as it relates to the components of the ICF and thus encourages a patient-centred rehabilitation approach (Lin et al., 2011). Each domain has adequate validity and sensitivity as well as adequate internal consistency (Lin et al., 2011; Teixeira-Salmela et al., 2009). All domains of the SS-QOL have demonstrated excellent internal reliability (Cronbach alpha value = 0.73) (Williams et al., 1999). Most domains of the SS-QOL scale were responsive to change with a standardized effect size >0.4 (Williams et al., 1999). Moreover, there is good test-retest reliability (Lin et al., 2011) and the SS-QOL scale has excellent internal reliability with Cronbach's alpha coefficients falling between 0.80 and 0.92 (Boosman et al., 2010; Lin et al., 2011). The SS-QOL scale is comprehensive and enables clinicians to understand the impact that a stroke has on an individual's quality of life in order to develop appropriate treatment regimens that are patient specific (Lin et al., 2011; Teixeira-Salmela et al., 2009). Research by Williams et al., (2001),

looked at the validity of telephone administration of the SS-QOL. The study concluded that telephonic administration of the SS-QOL is accurate and unbiased (Williams et al., 2001). Refer to appendix X to view this tool.

3.3.3 The Modified Rankin Scale (MRS)

This tool is a seven level clinician-reported measure that has been used to establish the degree of disability and functional independence of a person after stroke (Nunn et al., 2016). This tool has been used widely in stroke research (Quinn et al., 2009; Wilson J. T. Lindsay et al., 2005). It is a reliable and valid tool for randomised clinical trials (Nunn et al., 2016). The administrator of the tool gives the participant a score from zero; no symptoms; with scores ascending in the severity of level of disability to a score of six; in the case of the patient being dead. In studies, the participant was scored according to the best fitting description of the participant's level of disability. The intra-rater reliability is excellent with a kappa value of 0.81 (Wilson et al., 2005). Inter-rater reliability is moderate improves with structured interviews (kappa value of 0.56 versus 0.78) (Banks and Marotta, 2007) The MRS has demonstrated strong test-re-test reliability (k=0.81 to 0.95) (Banks and Marotta, 2007).

The MRS has been validated for use telephonically (Chen et al., n.d.; Janssen et al., 2010; Savio et al., 2013). A study by (Savio et al., 2013) showed that a telephone assessment of stroke disability with the MRS is reliable in comparison to face to face assessment. Most patients received the same score by the two methods and there was excellent agreement by the two methods. Another study by Janssen et al., (2010) used the MRS in telephone interviews and showed that the MRS used telephonically has a good agreement with face-to-face assessment and is reliable to use in a clinical trial. Refer to appendix IX for the MRS.

3.3.4 The Changes in Sexual Functioning Questionnaire (CSFQ-14):

The CSFQ-14 is an outcome measure that has been used in studies to measure sexual functioning. This tool is easy and quick to administer and is suitable to use in community settings (Keller et al., 2006). The questionnaire uses Likert scales to aid a person in self-evaluation of their sexual health and potential problems with sexual function (Keller et al., 2006). Using this questionnaire is considered to be easier than conducting an interview on a taboo topic (Keller et al., 2006). This questionnaire has been used as an assessment of sexual function in patients post stroke (Ng et al., 2017; Oyewole et al., 2017a; Sansom et al., 2015).

The tool has good construct validity and good internal reliability with the Cronbach's alpha coefficient for the total score of the CSFQ-14 calculated as 0.90 and 0.89 for the female and male versions respectively demonstrating a high internal consistency (Bobes, M. P. Gonzalez, F. Rico-Vill, 2000; Keller et al., 2006). The CSFQ-14 has assessments specific to males and females, and is therefore beneficial when comparing problems with sexual function in different sexes (Keller et al., 2006). The first question in the CSFQ-14 relies on the participant comparing their current sexual life to before their stroke, thus participants who were not sexually active prior to the stroke were excluded from the study. No research that has used this measurement tool has been harmful to the participants (Keller et al., 2006).

According to a study by Dunn et al., (2007), the CSFQ-14 was valid to obtain data using interactive voice response technology (IVR). This study concluded that IVR assessment of sexual dysfunction on the CSFQ-14 was highly correlated with previously validated paper-and-pencil assessment. The overall correlation between the paper and IVR CSFQ-14 total score was $r = 0.96$ ($p < .0001$). Similarly, high correlations were found between paper and IVR assessment methods on the individual CSFQ-14 subscales.

The total CSFQ-14 score can be calculated by adding up the values of the responses for all 14 items of the questionnaire. Scores for the subscales of sexual desire/frequency, sexual desire/interest, sexual pleasure, sexual arousal/excitement, and sexual orgasm/completion are calculated by adding up the values of items that correspond to the specific subscales as outlined in the instruction manual. The instructions of the CSFQ-14 explain how to determine if sexual dysfunction is present according to sex-specific scoring protocols. The instruction manual provides specific cut-off points for each of the subscales and if an individual obtains a score at or below the cut-off points on any of the subscales, it is indicative of sexual dysfunction. Cut-off points for the total CSFQ-14 score are given; for example, if a male obtains a total CSFQ-14 score of 47,0 or less, or if a female obtains a total CSFQ-14 score of 41,0 or less, it is indicative that sexual dysfunction is present. Refer to appendix XII for the outcome measure.

3.3.5 Questionnaire

This questionnaire was developed to establish the demographic factors of patients as well as factors, both clinical and psychological, affecting return to sexual function post stroke. The

CSFQ-14 does not look at psychosocial factors, demographics as well as other factors mentioned in the literature, and therefore using this tool alone was not sufficient in answering the research question to its entirety. The questionnaire specifically asks about the participants' experience of sexual activity, thus being sexually active prior to the stroke was a criterion for inclusion in the study. If an individual was not sexually active prior to their stroke, the participant would be unable to effectively assess if his or her sexual function was affected in any way post stroke if one did not have a reference for comparison. Refer to appendix XI to review the questionnaire.

3.4 Procedure

3.4.1 Pilot study

3.4.1.1 Aim

The aim of the pilot study was to ascertain the face validity of the questionnaire, to train a research assistant as well as check the amount of time it would take to administer the outcome measures in the study.

3.4.1.2 Objectives

The objectives of the pilot study were to:

1. Ascertain the face validity of the questionnaire
2. Train a research assistant as an interpreter:
    - Train an assistant as an interpreter for certain words in the outcome measures that participants in the study may have had difficulty understanding.
    - Train a research assistant on the purpose of the research
    - Train a research assistant in the various outcome measures
    - Train a research assistant how the interviews were to be conducted.
3. Check the amount of time it would take to administer the outcome measures in the study.

3.4.1.3 Methodology

The questionnaire was developed based on content from the literature. The questionnaire was reviewed by four experts in the field for face validity. Thereafter, permission was requested and granted from TMRH to conduct the pilot study. Outpatients known to TMRH rehabilitation unit who met the inclusion criteria were invited to participate in the pilot study.

The pilot study was conducted using 10% of the main study's sample size therefore included six participants. If there were no changes made to the questionnaire after the pilot study, data collected from the pilot study was included in the main study.

To check for intra-rater reliability of the questionnaire, the questionnaire was administered through an interview and then repeated five to ten days later to the same participant. The research assistant was present during this process to assist with interpreting words where necessary. Thereafter, the primary researcher and research assistant conducted the pilot study following the same methodology of the main study by carrying out the outcome measures (MMSE, MRS, SSQOL, the questionnaire and the CSFQ-14) through interviewer-administered methods, except for the MRS which the researcher completed. The purpose of this was to establish how long the study would take for completing the outcome measures for each participant. There was one primary researcher who administered all outcome measures independently but if help was required in interpreting words or phrases, the research assistant was available to assist.

3.4.1.4 Results and implications of the pilot study

The questionnaire that was developed based on the content from the literature was reviewed by four experts in the field for face validity. The table below indicates the feedback from the four experts in the field and the responses to the feedback to make necessary changes to the questionnaire.

Table 2.2: Feedback of experts regarding the questionnaire for the pilot study

Person validating content		**Feedback /Suggestion**	**Response**

K. Mashola (Physiotherapist MSc Physiotherapy: Neurorehabilitation physiotherapist Physiotherapy lecturer, previously worked in women's health)	1	First start by asking the participants if they are having sexual intercourse or not, before you ask them when they began after the stroke	In section B, added part A and Part B to question 1: • Part A: Have you had sexual intercourse since your stroke? Yes/ No?
	2	Reword question 1, "What is the time interval between the time of your stroke and resuming having sexual intercourse?" to make it as layman as possible	If yes (to question 1a), How long after the stroke did you start having sexual intercourse?
	3	For question 2, for data analysis purposes, number the "if yes" part of the question	The question will be numbered: 2.1) If yes –indicate your level of pain on the VAS below and highlight on the body chart below where your pain is
	4	Question 2 should be three-fold instead of two-fold (it currently only asks the severity of the pain on the VAS and not also how pain affects the sex life)	For this questionnaire, it is not a concern how the pain affects the sex life- as this becomes qualitative in nature
	5	Questions 3,4,5,6 and 7, only have yes/no answers. If the reasons behind the possible yes answers are required, add text boxes underneath the yes/no so that the participant can specify the reasons why they answer yes. If the reasons are not required, then you can leave the questions as is.	There is no need to further elaborate on the answers
T. Cohen (occupational therapist- works in neurorehabilitation and runs sexual function groups)	6	In section A, for question 10e, write out CVS in full	CVS problems will be written as cardiovascular system problems
	7	In section A, for question 10- ask whether participant has had more than one stroke	It is part of the exclusion criteria that participants will be

			excluded from the study if they have had more than one CVA therefore adding this question is irrelevant
	8	In section B, for question 9d instead of lack of desire word this as “changes in desire (yes/no)” If yes, then specify if there is a lack of desire or increased desire as sometimes patients will have an increase in desire depending on the location of the stroke	9d) Change of desire? Yes/No, If yes: Lack of desire? Yes/No Increased desire? Yes/No
	9	In section B, for question 9, add cognitive difficulties as a problem	This is not necessary as participants will have scored at least 24 out of 30 in the Mini-Mental State Examination.
	10	In section B, for question 9, add erectile dysfunction (males) and decreased sensitivity (females)? Yes/ No	This is covered in the CSFQ-14 and therefore does not need to be included in this questionnaire
Dr D. Breedt (Psychologist and director of Charis psychological services working in sexual rehabilitation, columnist for sexology and spinal cord injuries for the rolling Inspiration Magazine	11	Include a question of whether the patient is/was in fact sexually active	This is a similar comment to the feedback from Ms Mashola- It has been addressed (see 1 above). In section B, added part A and Part B to question 1: • Part A: Have you had sexual intercourse since your stroke? Yes/ No?
	12	Include either low mood or depression but not both as it speaks to similar areas. My suggestion is to use “low mood” as it is less judgemental and more likely to elicit a truthful answer.	I will include both. The term "depression” is more widely spoken about compared to low mood and therefore to avoid confusion both low mood and depression will be included
	13	Consider adding in a separate question about increased or decreased sex drive as that is	This has been addressed as it is a

		also sometimes affected either by physical or emotional factors. I know you asked whether there is less desire, but the assumption is there that it has decreased, but it can also increase.	similar comment to point 8 Question 9 in section B will read as follows. 9d) Change of desire? Yes/No, If yes: Lack of desire? Yes/No Increased desire? Yes/No
	14	Under 9.g. in section B, the term "unwell" can be ambiguous (physically/emotionally unwell) and therefore skew the results. Consider rephrasing to clarify this.	9g) feeling physically unwell? Yes/No
Dr Corlia Brandt (PHD Physiotherapy, Women's Health Physiotherapist, and lecturer)	15	Include a question about whether the participant suffers from lower back pain or sacroiliac joint pain	This would be addressed in Section A, question 2 where the participant is asked to indicate their pain on a body chart
	16	A participant may have general pain just due to increased pelvic floor muscle tone; how will the participant know if the pain is associated with the stroke - as it might not be?	The participant will indicate their pain on the body chart. If the participant has previously seen a healthcare professional for pelvic floor pain or hypertonicity it will be indicated in the last question; 10B
	17	Include a question on whether the participant had urinary tract infections or other vaginal infections	In section a 10i: Other, e.g., Urinary tract infections or vaginal infections _____, Please specify
	18	Include a question somewhere on whether the participant knows that there is treatment available as this lack of knowledge may influence their fear/thoughts/anxiety Also assess whether the participant has seen a psychologist/other medical profession for their potential problem	Question 10 added to section B: 10A) Are you aware that there are health care professionals who help with sexual dysfunction? Yes/No 10B) Have you asked for help from a health

			care professional Yes/No. If No, why?

3.4.1.5 Conclusion of the pilot study

Regarding the intra-rater reliability of the questionnaire, for all 6 participants who were involved in the pilot studies, the answers remained the same when the questionnaire was administered 5-10 days after originally asking the questions.

The interview took between 45 minutes and 1 hour to complete. The time to administer the outcome measures was found to be reasonable according to the researcher, research assistant and participants. The process of the interviews ran smoothly, and no problems were encountered during administering the interviews.

The pilot study was effective in training the research assistant to become familiar with the outcome measures used and he was able to be the interpreter and explain any queries to the participants.

3.4.2 Main study

Permission to conduct the study was requested from the necessary authorities at TMRH by hand delivering a letter of request that explained the purpose of the study (see appendix IV). Upon receiving approval and permission being granted, potential participants were approached and informed about the study, when they visited the allied department at TMRH. The participants were thereafter contacted telephonically to schedule an appointment at TMRH. The potential participant was initially screened for any cognitive impairments using the MMSE. The score of the MMSE determined whether the individual was included or excluded from the study. If the participant was not included in the study, they continued with usual therapy. If the participant was included in the study, the researcher obtained written consent after giving over the information sheet and clarifying any questions. Thereafter, the

MRS was completed by the researcher. This was followed by administering the SSQOL scale, the questionnaire, and the CSFQ-14. The research assistant was available to assist with interpreting words when needed. The interviews took place in the physiotherapy neurology gym where there was sufficient privacy for the participant to answer the questions comfortably.

Data collection started prior to the initial lockdown and the Coronavirus pandemic, but because of various challenges of the Coronavirus (COVID) pandemic, which impacted on South Africa from March 2020 onwards, data collection became challenging. Many potential participants who were invited to participate in the study did not want to come into Thelle Mogoerane Regional Hospital to be interviewed face to face as they reported that they were uncomfortable to come into the hospital unnecessarily and potentially be exposed to COVID. Other potential participants had moved back home, sometimes out of Gauteng, due to loss of employment because of the COVID pandemic. In addition, compliance to outpatient appointments at the hospital became poor. Taking the above into consideration, I reapplied for ethical clearance to carry out data collection telephonically with participants who were not able to be interviewed face to face. This enabled data collection to continue while ensuring that no participants were unnecessarily exposed to COVID or who were no longer able to travel due to lockdown restrictions. Refer to the ethics reapplication letter in appendix II.

The process of screening for participants and inviting potential participants to participate in the study remained the same. Participants were still given the option to meet at the hospital for a face-to-face interview but if they preferred a telephonic interview than I scheduled an appropriate time with the participant to do the interview telephonically. All outcome measures remained the same regardless of whether the interview was face to face or telephonic. With regards to the screening tool, The Mini Mental State Examination (MMSE), instead, the Adult Lifestyles and Function Interview (ALFI) version was used. Consent to participate in the telephonic interview was obtained as follows:

- If the patient had access to email: they could sign the consent form and send the consent form back via email

- If patients had access to WhatsApp: a WhatsApp requesting consent was sent and a reply from the participant giving consent was received. I then took a screenshot of this WhatsApp for record purposes

- If WhatsApp was not an option, I obtained consent via SMS

- Alternatively, the patient was voice recorded over the phone giving verbal consent to participate in the study

Prior to obtaining consent, the study was explained thoroughly to the participant and any questions were answered.

3.5 Ethical considerations

Ethical approval and clearance were obtained from the Human Research Ethics Committee at the University of the Witwatersrand prior to initiating research (see appendix I for the ethics clearance certificate). Ethical clearance was re-applied for in May 2021 and ethical approval and clearance was obtained from the Human Research Ethics Committee at the University of the Witwatersrand for the option of doing some interviews telephonically (see appendix III for the new ethics clearance certificate). In addition, permission was obtained from the necessary authorities at TMRH before starting the research (see appendix IV). All data collected throughout the study was kept safe and confidential and was only used for the purpose of this research. Results from the study will be disclosed to the participants at the end of the study by contacting the participants and making the research available to the participants via a publication.

The appointments were done on a one-on-one basis with the participant and research assistant ensuring the participant's privacy. The participants were able to withdraw from the study at any point with no negative consequences. In the situation whereby it was evident that the participant was experiencing dysfunction, the participant was referred to the psychologist and medical doctor, as per the availability of staff members trained in sexual rehabilitation as the study site. Participants gave written consent to participate in the study. Information about the study, including informing participants that a research assistant would be present was clarified in addition to issuing the participants an information sheet. The research assistant was available to read the information sheet to participants in the case of illiteracy or provide explanation when required. Transportation costs of the participants were covered.

3.6 Data analysis

An appropriate software package such as SPSS (Version 26) and Microsoft excel (Windows version 11) was used to organise and analyse the data. In order to determine normality, histograms were run on all the variables. In addition, Kolmogorov Smirnov tests and Shapiro-Wilk tests were to determine the normality of the dependant variables. Pearson Correlations and Chi-Squared correlation tests were used. The significance levels used were alpha of 0.05. The r value interpretations were used as part of the analysis, or the Cohens criteria were used.

Table 3.2: Data Analysis

Objective	Variables	Types of data	Statistical Tests
1) To determine an individual's sexual function post stroke. **Outcome Measure:** CSFQ-14	Independent-stroke Dependent-sexual function	Binary – Nominal data	**Frequency & Averages:** Looks at what proportion of individuals of the sample have sexual dysfunction post stroke *Note, the CSFQ-14 instruction manual was followed to assess whether sexual dysfunction was present for participants. Cut-off points indicating sexual dysfunction are as follows: for a male a total CSFQ-14 score of 47,0 or less, for a female, a total CSFQ score of 41,0 or less (see appendix XII) **Pearson Chi-Square Tests:** Looks at the subscales of the CSFQ-14 for males and females
2) To determine the factors that are associated with an individual's sexual function post stroke. **Outcome Measure:** Questionnaire & MRS	Independent-Factors Dependent-Sexual dysfunction	Categorical – Nominal & Ordinal data	**Chi-square**: Looks at how the various factors are associated with sexual function. It will relate sexual dysfunction to the various factors determined by using the questionnaire. **2-way ANOVA:** • Looks at the between subject effects, looking at the interaction between sexual function and sex. • Looks at the interaction between level of disability, sexual function, and sex
3) To determine the association of sexual function on the quality of life of an individual post stroke **Outcome Measure:** SS-QOL	Independent-Sexual Function Dependent-Quality of life	Nominal	**2 -Way ANOVA:** Looks at whether there is an interaction between sexual function (score of CSFQ-14) and quality of life (SSQOL) and sex.

3.7 Conclusion of the methodology

This chapter has presented the study design, objectives, sample size and inclusion and exclusion criteria of the study sample. The procedure and method of both the pilot study and main study have been described. This chapter has presented the various outcome measures that have been used in the study. In addition, data collection, data recording and statistical analysis have been presented. The results of the statistical analysis are presented in Chapter 4.

CHAPTER 4: RESULTS

4.1 Introduction

This chapter presents the results of the study and gives an overview of the profile of the participants. The objectives of this study were to determine an individual's sexual function post stroke, to determine the factors that are associated with an individual's sexual function post stroke as well as to determine the association of sexual function with the quality of life of an individual post stroke. The results are presented as follows:

- 4.2 profile of the study sample
- 4.3 descriptive statistics of sexual function
- 4.4 descriptive statistics of the MRS
- 4.5 descriptive statistics of the SSQOL Scale
- 4.6 Inferential statistics of the association between level of disability and sexual function
- 4.7 Inferential statistics of the association between sexual function and QOL.

4.2 The profile of the study sample

A total of 56 individuals post stroke participated in the study. Initially, 57 individuals were invited to participate in the study and were included. Upon data cleaning, one person was excluded due to erroneous data capturing thus resulting in a total sample size of 56. An attempt to still include the participant was made by trying to contact the participant to clarify missing information but unfortunately the participant had passed away since the initial assessment. The statistician was consulted and due to the normal distribution of the data, the decision was made to exclude the participant and to continue the data analysis with a sample size of 56 (100%).

Nineteen (33,9%) of the 56 participants were interviewed telephonically and the remainder (n=37; 66,1%) were interviewed face to face. Table 4.1, and Figure 4.1 show the demographics of the participants in the study.

Table 4.1: Demographic profile of the study sample (n=56)

Demographics		Number of participants n=56 (%)
Sex	Male	32 (57,1)
	Female	24 (42,9)
Relationship status	Single	6 (10,7)
	Married	34 (60,7)
	Live-in partner	10 (17,9)
	Widowed	4 (7,1)
	Divorced	1 (1,8)
	Other	1 (1,8)
Level of education	Before finishing primary school	2 (3,6)
	Finished primary school	16 (28,6)
	Finished high school	33 (58,9)
	University graduate	5 (8,9)
Hand dominance	Right	54 (96,4)
	Left	2 (3,6)
Side of hemiparesis	Right	22 (39,3)
	Left	33 (58,9)
	Hemiparesis resolved	1 (1,8)

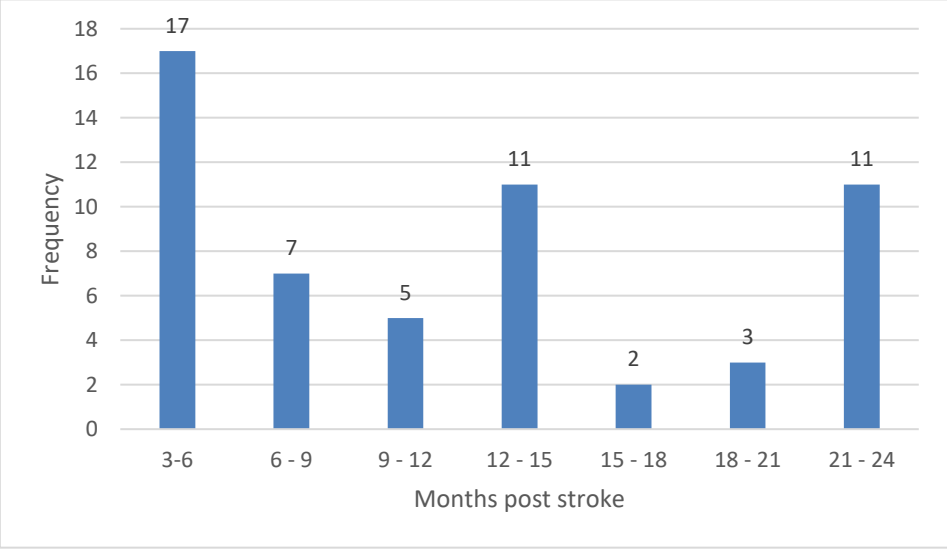

Figure 4.1: Time since stroke

The average age of the sample was 51,32 (SD =±13,24) years with the youngest participant being 19 years old and the oldest participant being 73 years old. The sample was comprised of 32 (57,1%) males and 24 (42,9%) females. The participants were from a range of relationship statuses including single, married, live-in partners, widowed, divorced and other. Most participants in the sample were married (n=34; 60,7%) and 17,9% (n=10) of the sample had a live-in partner. Most of the study sample (n=33; 58,9%) had at least a high school education and only a small percentage (n= 5; 8,9%) of the study sample had a university degree. Most participants (n=33; 58,9%) had left hemiparesis while 39,3% (n=22) of the sample had right hemiparesis. One participant's hemiplegia had resolved completely. Almost all participants were right hand dominant (n=54; 96,4%). Figure 4.2 shows that most participants (n=17; 30,4 %) were three to six months post stroke at the time of data collection. Only two participants (3,6%) were within 15 to 18 months post stroke. The mean amount of time that had passed since stroke and the time meeting with the participant for data collection was 11,39 months (SD =±7,09).

Table 4.2 shows the co-morbidities with which the patients in this study sample presented. A single patient could have more than one co-morbidity.

Table 4.2: Co-morbidities of the study population (n=56)

Comorbidity	Frequency of participants presenting with comorbidity n=56 (%)	Frequency of participants in which comorbidity was controlled
HIV	14 (25,0)	14 (100,0)
Hypertension	39 (69,6)	37 (94,9)
Diabetes	17 (30,4)	16 (94,1)
Epilepsy	1 (1,8)	1 (100,0)
Cardiovascular condition	3 (5,4)	3 (100,0)
Arthritis	1 (1,8)	1 (100,0)
Respiratory condition	0 (0,0)	0 (0,0)
Depression	1 (1,8)	1 (100,0)
Asthma	1 (1,8)	1 (100,0)

Comorbidity	Frequency of participants presenting with comorbidity n=56 (%)	Frequency of participants in which comorbidity was controlled
Bladder and/or bowel problem	1 (1,8)	0 (0,0)
Bladder issue	1 (1,8)	0 (0,0)
Cholesterol problem	3 (5,4)	1 (100,0)
Gout	1 (1,8)	1 (100,0)
Low blood pressure	1 (1,8)	1 (100,0)
Renal disease	1 (1,8)	1 (100,0)
Constipation	1 (1,8)	0 (100,0)

The most common comorbidity in the study population was hypertension (n=39; 69,6%) and 94,9% (n=37) of the hypertensive participants were on treatment to control it. Seventeen individuals (30,4%) of the study sample had diabetes and 14 participants (25%) of the participants had HIV. Sixteen (94,1 %) of the 17 individuals who had diabetes reported that they were on treatment. All 14 (100%) of the participants with HIV were on ART.

Figure 4.2 describes the pain experienced by participants post stroke, rated according to the visual analogue scale.

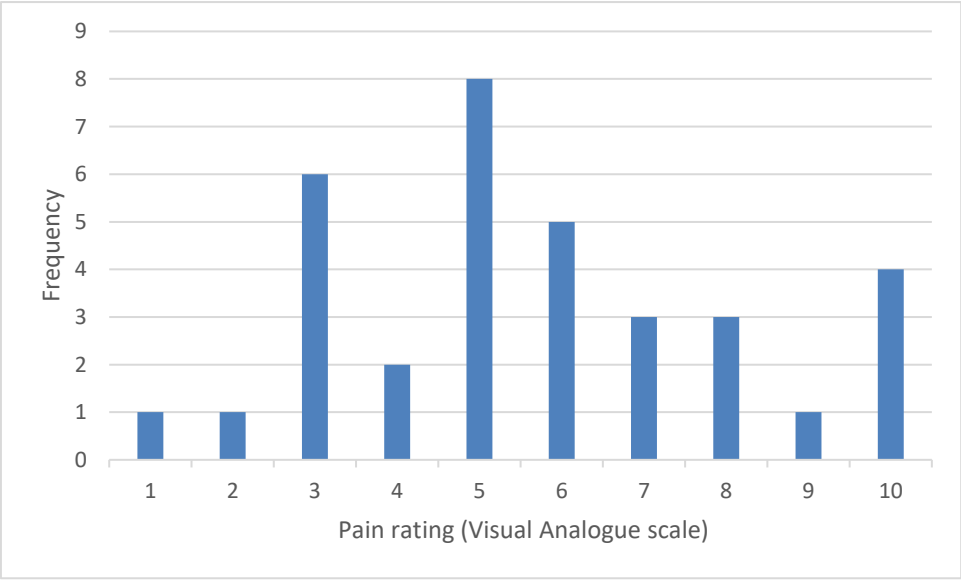

Figure 4.2: The pain rating of study sample

The pain rating scale had a mean of 5,68 (SD =±2.43). Most of the sample reported a pain level of five out of a possible 10 (n=8; 14.3%). The highest pain level of 10 out of a possible 10 was reported by 7.1% (n=4) of the study sample.

4.3 Descriptive statistics of sexual function

The questionnaire was used to determine various factors that were associated with sexual function post stroke. Figures 4.3-4.4.6 describe these factors.

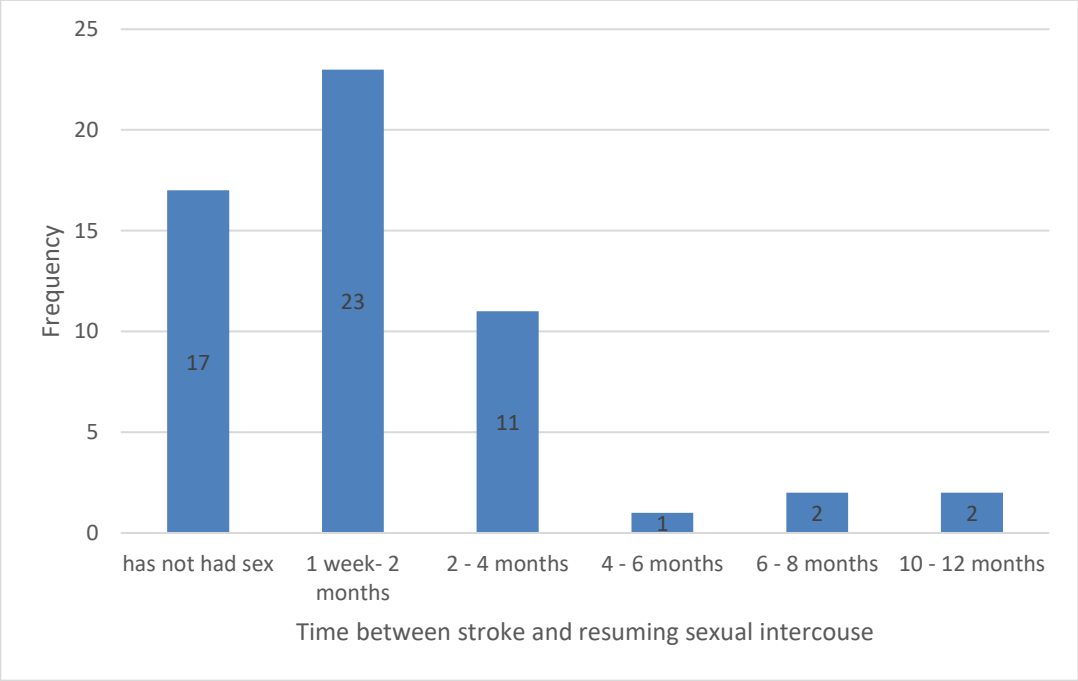

Figure 4.3: The time between stroke and resuming sexual intercourse for the study population (n=56)

Seventeen participants (30,4%) had not had sexual intercourse since their stroke at the time that the questionnaire was done. Of the participants that had resumed sexual intercourse after their stroke, most participants (n=23; 41,1%) had sexual intercourse between one week and two months after the stroke. Eleven participants (19,4%) had sexual intercourse within two to four months after their stroke. Data was recorded in excel for each question and the mean was calculated. The average time waited by the 39 participants (69,6%) to have sexual intercourse after their stroke was 2,7 months (SD =±2,82). Data was regrouped into two-monthly time intervals for visual representation.

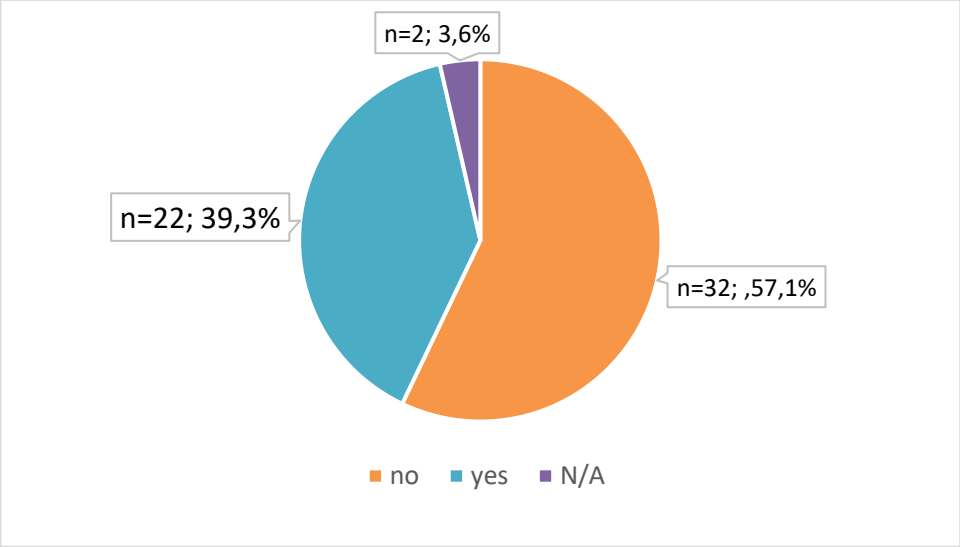

Figure 4.4.1: Does pain affect your current sex life?

Pain was reported by 39,3 % of the study sample (n=22) as a factor that affects one's sex life in comparison to 57,1% of the study sample (n=32) who reported that pain did not affect one's current sex life.

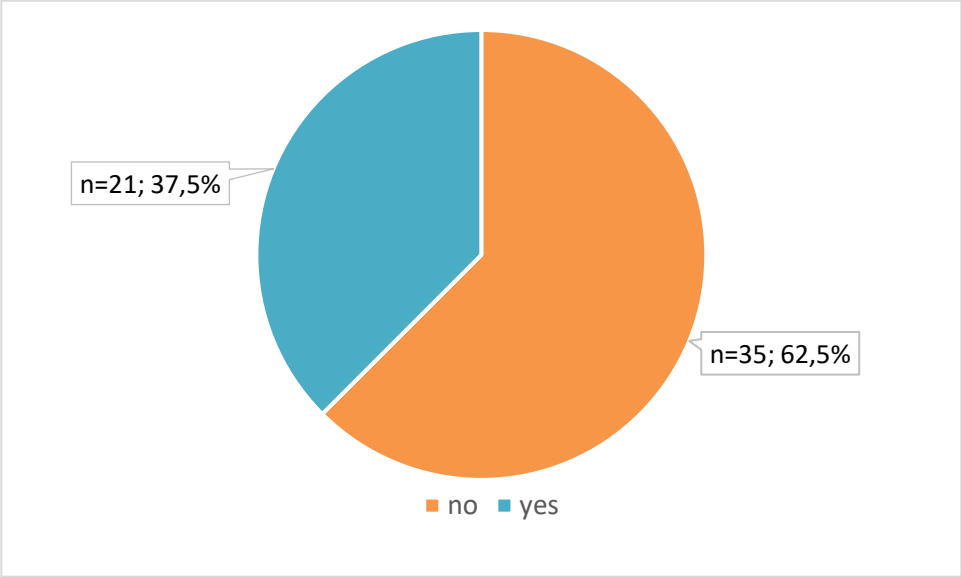

Figure 4.4.2: Are you afraid that you will experience increased pain during sex?

There was a greater number of participants (n=35; 62,5%) that reported not being afraid of increased pain during sex.

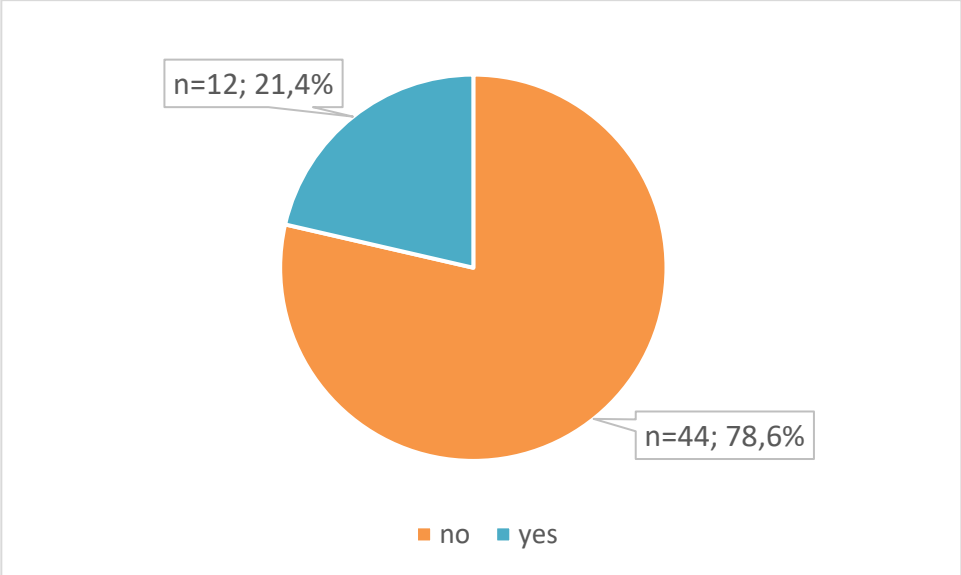

Figure 4.4.3: Are you anxious/scared that you will have another stroke during sexual activity?

Only 12 of the participants, that is, 21,4% of the study sample feared having another stroke during sexual activity.

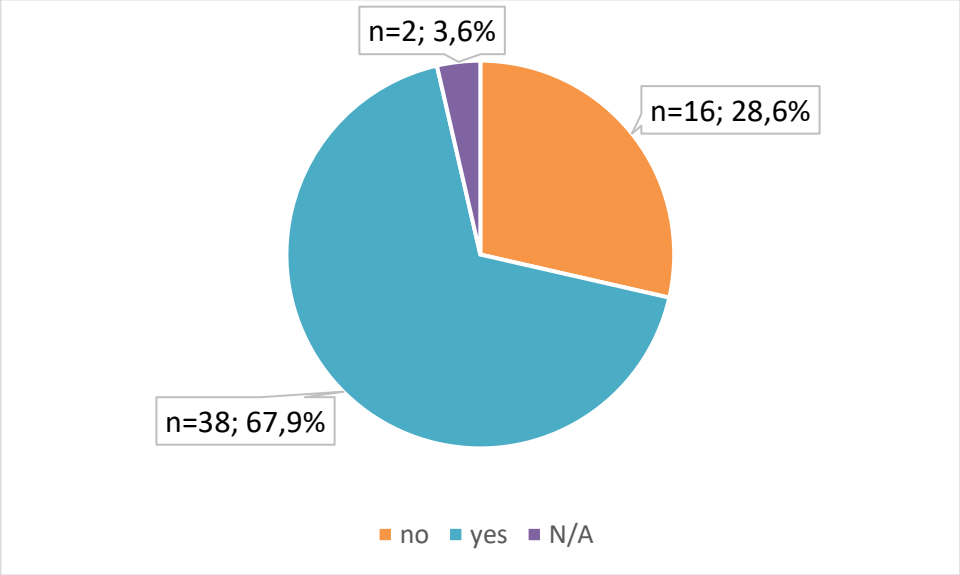

Figure 4.4.4: Are you unable to find a comfortable position for sex after your stroke?

More than half (n=38; 67,9%) of the participants reported problems with finding a comfortable position for sex after their stroke.

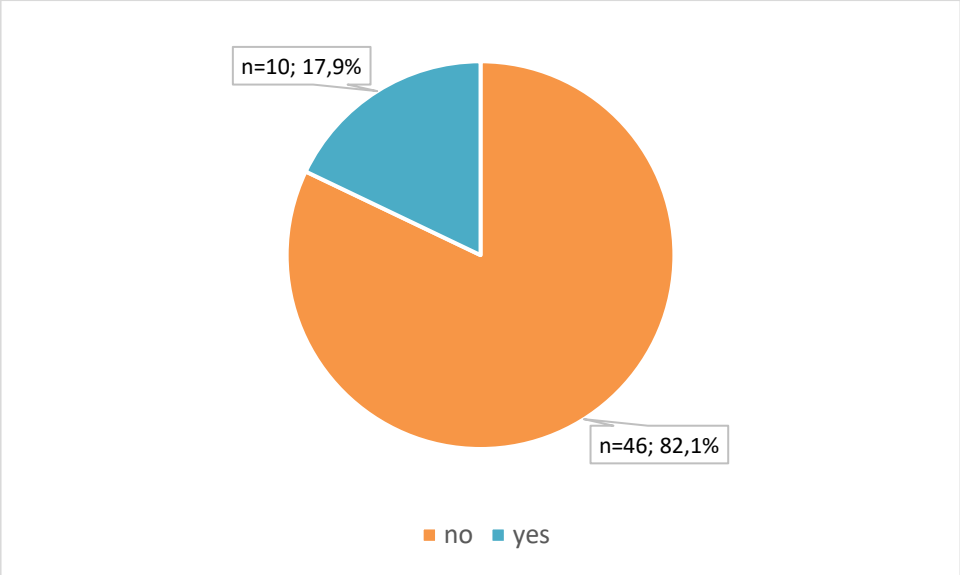

Figure 4.4.5: Are you afraid of having sex because of incontinence?

Most participants (n=46; 82,1%) reported that they were not afraid of having sex because of incontinence although this was a concern of 10 of the participants (17,9%).

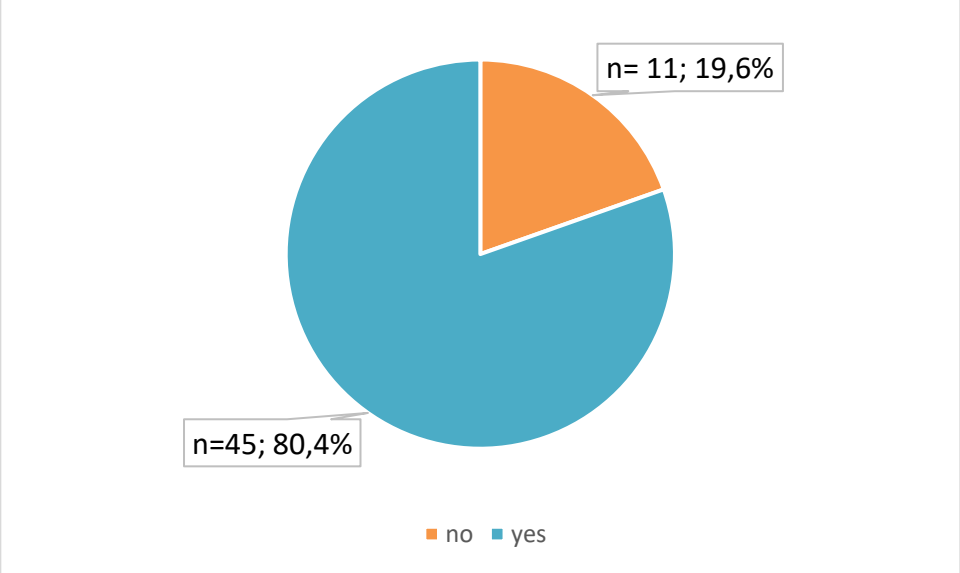

Figure 4.4.6: Are you able to discuss sexuality with your partner?

Majority of participants (n=45; 80,4%) reported that they were able to discuss sexuality with their partner.

The questionnaire also asked participants questions about other potential barriers regarding sexual function following the stroke. Table 4.3.1 shows the participants' perceptions of their partners' outlook to return to sex after stroke and Table 4.3.2 shows the participants' personal beliefs regarding what factors affect their sex life post stroke.

Table 4.3.1: The participants' perceptions of their partners' outlook to return to sex after stroke. (n=56)

Participant's perception of partner's outlook being a barrier to sex		**Number of participants n (%)**
Partner fearful of causing participant another stroke	No	38 (67,9)
	Yes	18 (32,1)
Partner fearful of causing participant pain	No	32 (57,1)
	Yes	24 (42,9)
Partner finds participant unattractive	No	39 (69,6)
	Yes	17 (30,4)
Difficulty balancing roles between being a sexual partner and caregiver	No	32 (57,1)
	Yes	24 (42,9)

Table 4.3.2: Personal beliefs regarding what factors affect participants' sex life post stroke. (n=56)

Personal beliefs regarding what factors affect participants' sex life post stroke.		Number of participants n (%)
Poor self esteem	No	29 (51,8)
	Yes	27 (48,2)
	n/a	0 (0,0)
Depression	No	25 (44,6)
	Yes	31 (55,4)
	n/a	0 (0,0)
Change of desire	No	20 (35,7)
	Yes	35 (62,5)
	n/a	1 (1,8)
Lack of desire	No	13 (23,2)
	Yes	36 (64,3)
	n/a	7 (12,5)
Increased desire	No	45 (80,4)
	Yes	2 (3,6)
	n/a	9 (16,1)
Lack of motivation	No	19 (33,9)
	Yes	36 (64,3)
	n/a	0 (0,0)
Tiredness/fatigue	No	24 (42,9)
	Yes	32 (57,1)
	n/a	0 (0,0)
Feeling physically unwell	No	32 (57,1)
	Yes	24 (42,9)
	n/a	0 (0,0)

Regarding participants' perceptions, 18 participants (32,1%) believed that their partners were afraid to cause the participant another stroke because of sex. Twenty-four participants (42,9%) believed that their partners were afraid of causing them pain during sexual intercourse. Most of the participants (64,3%) reported that they had a lack of desire and a lack of motivation to engage in sexual intercourse post stroke. It is noteworthy that 27 individuals (48,2%) reported poor self-esteem which they believe is a factor affecting their sex life after stroke.

The awareness of participants regarding availability of help to address sexual dysfunction was also assessed and is shown in Figure 4.5.

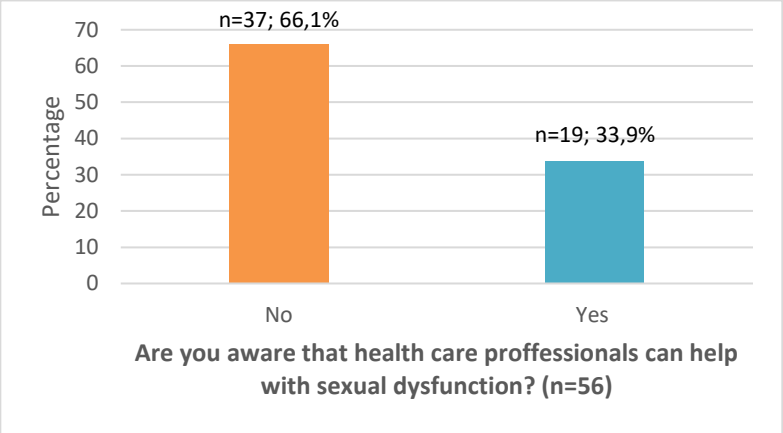

Figure 4.5: Awareness of health care professionals' ability to address sexual dysfunction (n=56)

Majority of the sample (n=37; 66,1%) did not know that health care professionals can help with sexual dysfunction.

Table 4.4 shows the results of the sexual functioning of the participants post stroke as determined by the CSFQ-14 outcome measure.

Table 4.4: A description of sexual function post stroke according to the CSFQ-14 (n=56)

			Mean	SD±	Range	Subscale cut-off values (Clayton et al., 1997)
Sex	**Male (n=32)**	Pleasure	2.22*	1.39	1-5	4,0
		Desire/Frequency	5.97*	2,15	2-10	8,0
		Desire/Interest	8.84*	2.86	3-15	11,0
		Arousal/excitement	9,03*	3.33	3-15	13,0
		Orgasm/completion	8.59*	4.10	3-15	13,0
		CSFQ-14_Total	**44.19***	**11.17**	**14-70**	**47,0**
	Female (n=24)	Pleasure	2.46*	1.38	1-5	4,0
		Desire/Frequency	4.62*	1.61	2-10	6,0
		Desire/Interest	7,00*	2.30	3-15	9,0
		Arousal/excitement	7.71*	3.11	3-15	12,0
		Orgasm/completion	7.58*	4.15	3-15	11,0
		CSFQ-14_Total	**36.25***	**10.58**	**14-70**	**41,0**
Overall (Male and female) (n=56)		Pleasure	2.32	1,38	**	**
		Desire/frequency	5.39	2,03		
		Desire/interest	8,05	2,77		
		Arousal/excitement	8.46	3,28		
		Orgasm/completion	8.16	4,12		
		CSFQ-14 Total	**40.79**	**11,53**		

*Indicates sexual dysfunction

** no range and no cut-off scores in CSFQ-14 manual for overall score

According to the scoring protocol of the CSFQ-14, the total CSFQ-14 cut-off score for females is 41,0 (range: 14 to 70). The female sample in this study had a mean of 36,25 (SD =±10,58) thus falling below the cut-off score indicative of sexual dysfunction. The cut-off score for males for the total CSFQ-14 score is 47,0. The male sample in this study had a mean of 44,19 (SD =±11,17) which is below the cut-off scores indicating sexual dysfunction.

According to the CSFQ-14 cut-off scores, the mean for the female sample fell below the cut-off points for all five categories: sexual desire/frequency, sexual desire/interest, sexual pleasure, sexual arousal/excitement, and sexual orgasm/completion, therefore indicative of sexual dysfunction in all areas. Similarly for the male sample, the means for each subscale fell below the cut-off score of the CSFQ-14 therefore indicating sexual dysfunction in all five areas.

Figure 4.6.1 to Figure 4.6.5 illustrates the distribution of scores for each of the subscales of the CSFQ-14; namely pleasure, desire/frequency, desire/interest, arousal, and orgasm/completion.

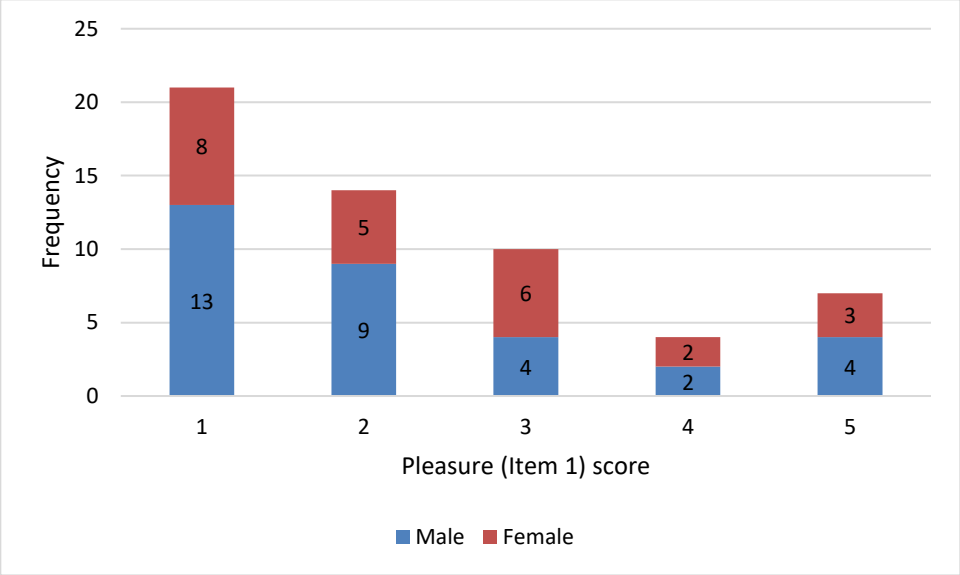

Figure 4.6.1: The distribution of CSFQ-14 scores for sexual pleasure for the study population (n=56)

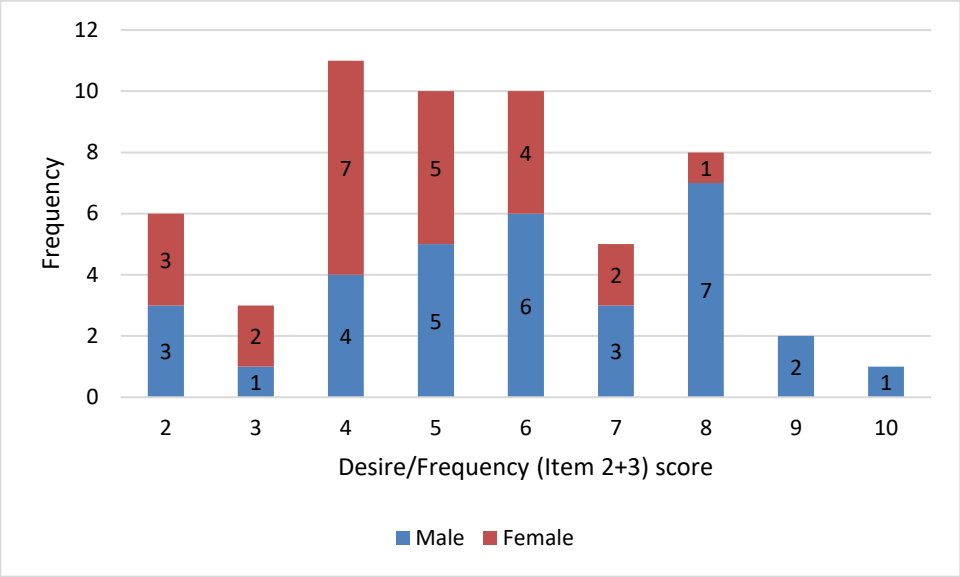

Figure 4.6.2: The distribution of CSFQ scores for sexual desire/frequency for the study population (n=56)

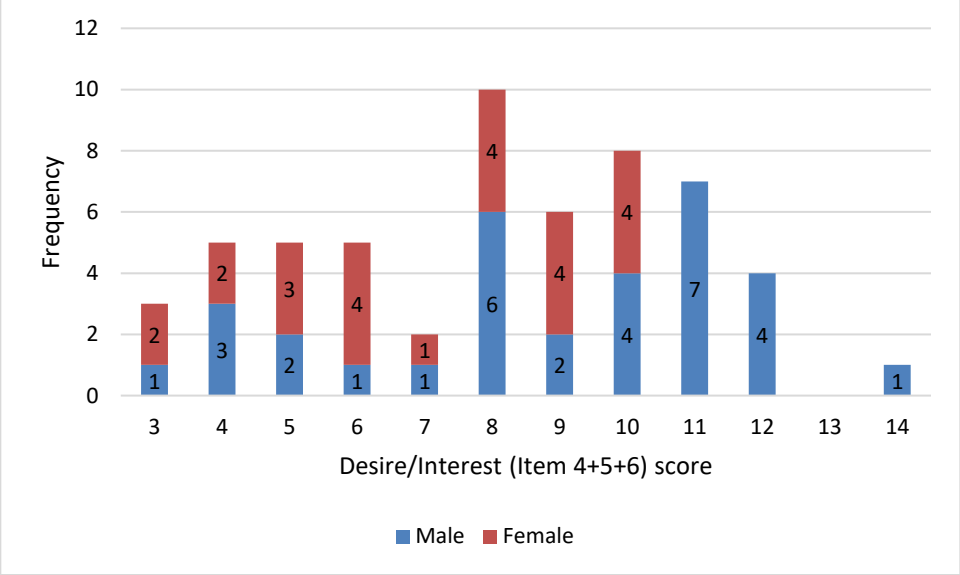

Figure 4.6.3: The distribution of CSFQ-14 scores for sexual desire/interest for the study population (n=56)

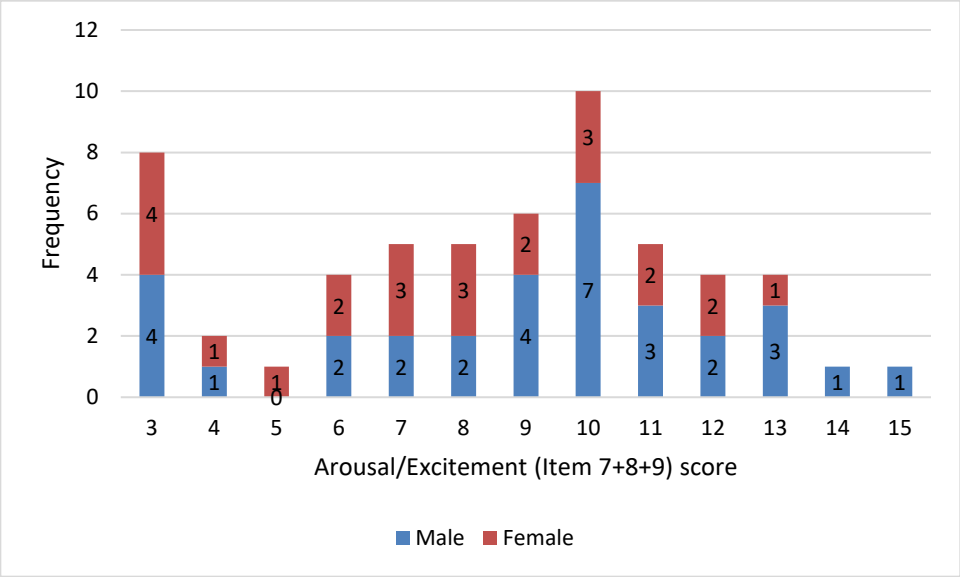

Figure 4.6.4: The distribution of CSFQ-14 scores for sexual arousal/excitement for the study population (n=56)

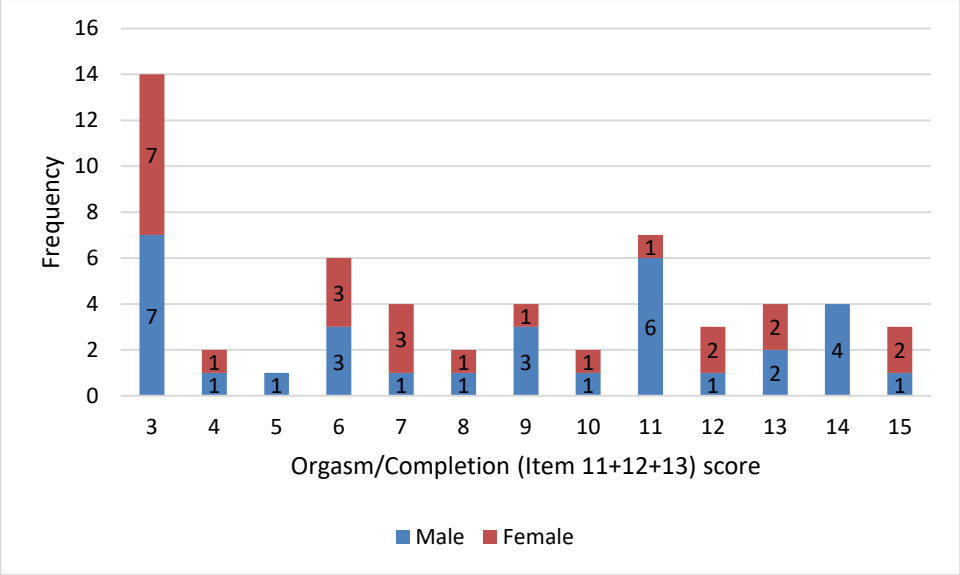

Figure 4.6.5: The distribution of CSFQ-14 scores for orgasm/completion for the study population (n=56)

Most of the sample, n=21 (37,5%), reported a response of one out of a possible five for pleasure indicating that they had no enjoyment or pleasure regarding their current sexual life, while 14 (25%) participants scored a 3 for the subscale of orgasm/completion which is the lowest possible score for this subscale indicating dysfunction regarding orgasm/completion.

Figure 4.7 shows the frequency of participants in the study who have sexual dysfunction and those who do not have sexual dysfunction according the CSFQ-14.

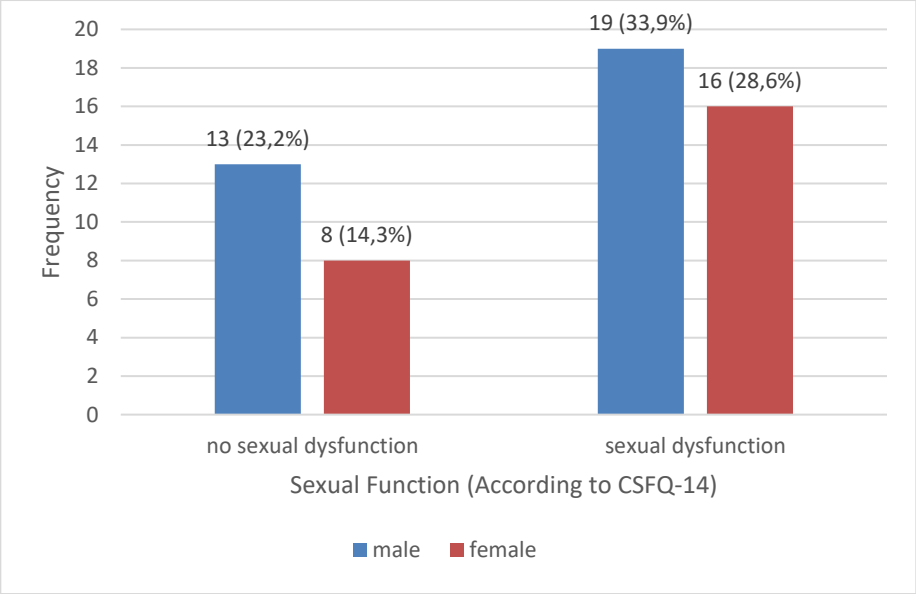

Figure 4.7: The distribution of participants with sexual dysfunction versus those with no sexual dysfunction based on the CSFQ-14

According to the CSFQ-14, 35 participants (62,5%) had sexual dysfunction and 21 participants (37,5%) had no sexual dysfunction. Of the participants who had sexual dysfunction 19 participants (33,9%) were males and 16 participants (28,6%) were females therefore more males experienced sexual dysfunction than females. Thirteen (23,2%) males as compared to 8 (14,3%) of females had no sexual dysfunction.

A chi squared test of significance revealed that there is no significant relationship between sex and sexual dysfunction ($X^2_{1,56} = 0.311$; $p = 0.577$).

Figure 4.8 shows the number of participants with sexual dysfunction and those without sexual dysfunction categorised according to their ages.

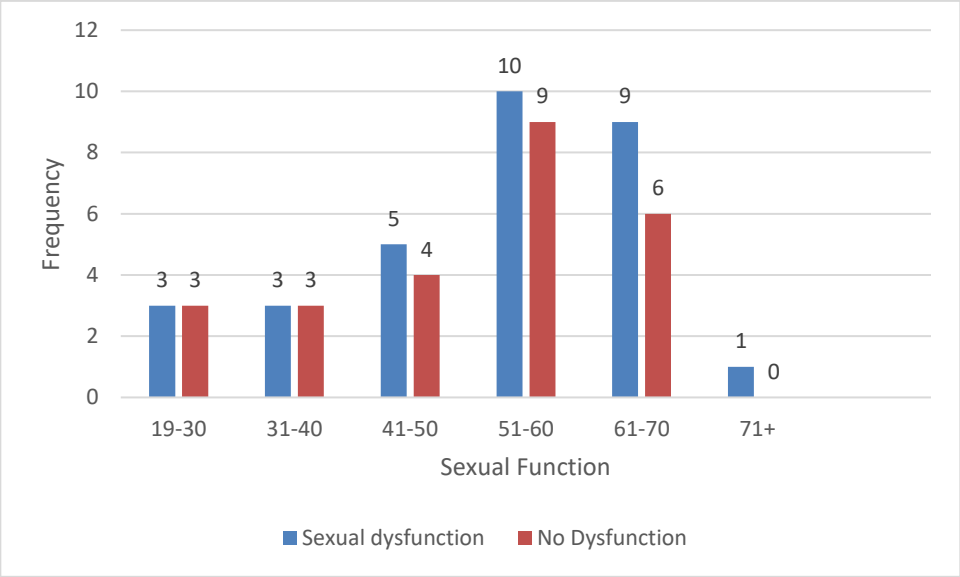

Figure 4.8: The distribution of sexual function and sexual dysfunction according to age categories

Most participants in the study were between 51 to 60 years of age. Generally, as age increases, the frequency of sexual dysfunction increases. Of the sample with sexual dysfunction, 20 participants (64,5%) of the sample were older than 51 years. It is noted that there is only one participant older than 70 years and although this participant has sexual dysfunction, no real inferences can be drawn from the small sample.

Table 4.5 shows the frequencies of participants with sexual dysfunction and of those with no sexual dysfunction for the various subscales of sexual function according to the CSFQ-14 namely, pleasure, desire/frequency, desire/interest, arousal/excitement, orgasm/completion as well as the total score of the CSFQ-14.

Table 4.5: The frequencies of participants with and without sexual dysfunction for the subscales of the CSFQ-14 (n=56)

		Sex		Total
		Male	Female	
		N (%)	N (%)	N (%)
Sexual Pleasure	No dysfunction	4 (7,1)	3 (5,4)	7 (12,5)
	Dysfunction	28 (50,0)	21 (37,5)	49 (87,5)
Sexual Desire/Frequency	No dysfunction	3 (5,4)	3 (5,4)	6 (10,7)
	Dysfunction	29 (51,8)	21 (37,5)	50 (89,3)
Sexual Desire/Interest	No dysfunction	5 (8,9)	4 (7.1)	9 (16,1)
	Dysfunction	27 (48,2)	20 (35,7)	47 (83,9)
Sexual Arousal/ Excitement	No dysfunction	2 (3,6)	1 (1,8)	3 (5,4)
	Dysfunction	30 (53,6)	23 (41,1)	53 (94,6)
Sexual Orgasm/Completion	No dysfunction	5 (8,9)	6 (10,7)	11 (19,6)
	Dysfunction	27 (48,2)	18 (32,1)	45 (80,4)
Total CSFQ-14 Score	No dysfunction	13 (23,2)	8 (14,3)	21 (37,5)
	Dysfunction	19 (33,9)	16 (28,6)	35 (62,5)

For each subscale of sexual function, more participants had dysfunction compared to no dysfunction. For example, 89,3% (n=50) of participants experienced dysfunction for sexual desire/frequency. For sexual arousal/excitement, majority of participants (n= 53; 94,6%) had dysfunction in this area. Regarding sexual pleasure, 49 participants (87,5%) had dysfunction.

Table 4.6 shows the Pearson Chi Square tests to determine whether there was a significant difference between males and females with regards to subscales of sexual dysfunction for pleasure, desire, interest, arousal, orgasm, or total sexual functioning according to the CSFQ-14.

Table 4.6: Pearson Chi-Square Tests of subscales of sexual dysfunction for males and female

		Sex
Pleasure Dysfunction	Chi-square	.000
	Df	1
	Sig.	***1.000[a]***
Desire/Frequency Dysfunction	Chi-square	.140
	Df	1
	Sig.	***.708[a]***
Desire/Interest Dysfunction	Chi-square	.011
	Df	1
	Sig.	***.916[a]***
Arousal/Excitement Dysfunction	Chi-square	.117
	Df	1
	Sig.	***.732[a]***
Orgasm/Completion Dysfunction	Chi-square	.764
	Df	1
	Sig.	***.382[a]***
Total CSFQ-14 Dysfunction	Chi-square	.311
	Df	1
	Sig.	.577

Results are based on non-empty rows and columns in each innermost sub table.

a. More than 20% of cells in this sub table have expected cell counts less than 5. Chi-square results may be invalid.

There were no significant differences between males and females with regards to levels of sexual dysfunction for pleasure, desire, interest, arousal, orgasm, or total sexual functioning according to the CSFQ-14.

Table 4.7 shows the mean scores of the CSFQ-14 according to sex distribution.

Table 4.7: The mean scores of the CSFQ-14 for male and female participants

Sex	Sexual Dysfunction	Mean	Std. Deviation	N (56)
Male	no sexual dysfunction	54.31	5.51	13
	Sex dysfunction	37.26	8.39	19
	Total	44.19	11.17	32
Female	no sexual dysfunction	48.00	4.78	8
	Sexual dysfunction	30.38	7.10	16
	Total	36.25	10.58	24
Total	no sex dysfunction	51.90	5.99	21
	Sex dysfunction	34.11	8.46	35
	Total	40.79	11.53	56

The mean CSFQ-14 score for males with sexual dysfunction was 37,26 (SD =±8,39). The mean CSFQ-14 score for the female participants with sexual dysfunction was 30,38 (SD =±7,10).

Figure 4.9 shows a visual representation of the means of the total CSFQ-14 scores for males and females in the study sample.

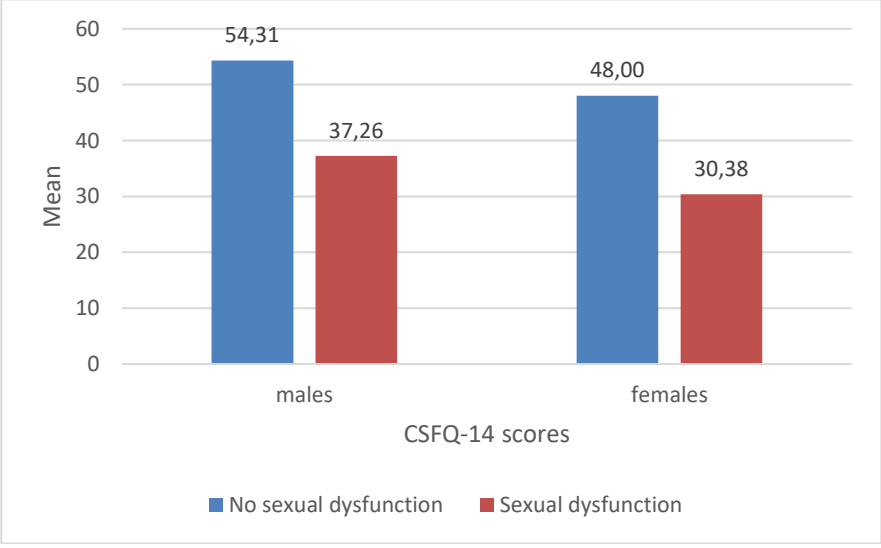

Figure 4.9: The mean CSFQ-14 scores for male and female participants

Males with sexual dysfunction obtained a mean CSFQ-14 score that was 31,39% lower relative to those that did not exhibit sexual dysfunction. Similarly, female participants with sexual dysfunction obtained a mean CSFQ-14 score that was 36,71% lower relative to those without sexual dysfunction. The male participants' mean CSFQ-14 score of 45,7 was 2,77% lower relative to the cut-off of 47 indicating sexual dysfunction. For females, the mean CSFQ-14 score was 39,19 which is 4,41% lower than the female cut off score of 41 indicative of sexual dysfunction.

Table 4.8 describes the interaction between sexual function and sex by means of the 2-way ANOVA test.

Table 4.8: A 2-way ANOVA test of between-subject effects, looking at the interaction between sexual function and sex

Source	Type III Sum of Squares	Df	Mean Square	F	Sig.	Partial Eta Squared
Model	97917.797[a]	4	24479.449	500.326	.000	.975
Sex	549.213	1	549.213	***11.225***	***.002***	.178
Sexual Dysfunction	3791.071	1	3791.071	***77.484***	***.000***	.598
Sex * Sexual Dysfunction	1.063	1	1.063	***.022***	***.883***	.000
Error	2544.203	52	48.927			
Total	100462.000	56				

a. R Squared = .975 (Adjusted R Squared = .973)

The 2-way ANOVA revealed significant effects for sex and sexual dysfunction. In other words, males and females had significant differences with regards to their CSFQ-14 scores ($F_{1,52}$=11,225; p=0.002). Furthermore, 97% of the variance in CSFQ-14 scores was accounted for by sex and sexual dysfunction which indicates a strong relationship between these factors and CSFQ-14 scores.

4.4 Descriptive statistics of the Modified Rankin Scale (MRS)

Figure 4.10 shows the distribution of scores obtained by participants on the MRS measuring the level of disability of the participants.

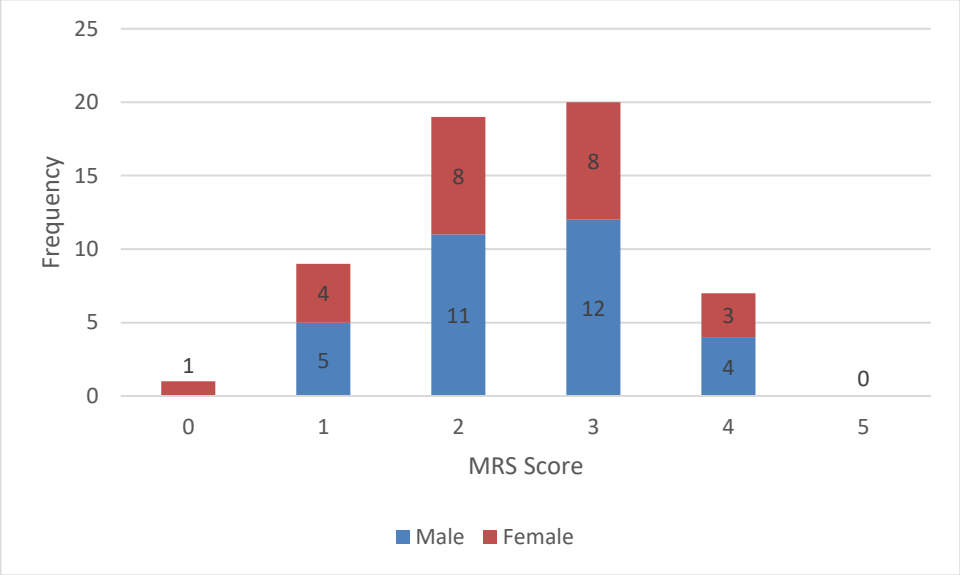

Figure 4.10: The frequency of scores on the Modified Rankin Scale (MRS) for the study population (n=56)

Most participants (n=39; 69.6%) in the sample obtained a score of two or three on the MRS indicating slight disability (unable to perform all previous activities but able to look after own affairs without assistance) and moderate disability (requires some help but able to walk without assistance) respectively. Only one participant obtained a score of zero therefore according to the MRS, had no symptoms at all. The data had a normal distribution with a minimum of zero and a maximum of four.

Table 4.9 shows the mean scores of the MRS values for males and females with and without sexual dysfunction.

Table 4.9: The mean scores on the Modified Rankin Scale (MRS) for the study population (n=56)

Sex	Sexual Function	Mean MRS Score	Std. Deviation	N (56)
Male	No sexual dysfunction	2.23	0.73	13
	Sexual dysfunction	2.63	1.01	19
	Total	**2.47**	**0.92**	**32**
Female	No sexual dysfunction	2.25	0.89	8
	Sexual dysfunction	2.37	1.15	16
	Total	**2.33**	**1.05**	**24**
Total	No sexual dysfunction	2.24	0.77	21
	Sexual dysfunction	2.51	1.07	35
	Total	**2.41**	**0.97**	**56**

The mean of the study sample for the MRS was 2,41 (SD =± 0,97). The mean score of the male participants for the MRS was 2,47 (SD =±0,92). The mean score of the female participants for the MRS was 2,33 (SD =±1,05). The mean MRS score of participants with sexual dysfunction (n=35) is 2,51 (SD =± 1,07) compared to the MRS score of those with no sexual dysfunction (n=21) which is 2,24. (SD =±0,77). Those with sexual dysfunction had higher (2.51 ± 1,07) mean MRS scores than those without sexual dysfunction (2.24 ± 0,77). There was however no significant difference regarding the MRS scores for those with and without sexual dysfunction (p =0,306).

4.5 Descriptive statistics of the SSQOL scale

Table 4.10 describes the QOL of the participants in the study according to the SSQOL scale.

Table 4.10: Quality of life of the study sample (n=56)

QOL Subscales (245)	Minimum Score	Maximum Score	Mean (SD±)	Percentage Score (%)
Energy (15)	3	15	6,36 (3,24)	42
Family roles (15)	3	15	6,62 (3,15)	44
Language (25)	5	25	17,29 (7,37)	69
Mobility (30)	6	30	16,13 (6,59)	54
Mood (25)	5	25	14,41 (5,68)	58
Personality (15)	3	15	7,21 (3,84)	48
Self-care (25)	5	25	18,45 (5,32)	74
Social roles (25)	5	20	8,09 (3,47)	32
Thinking (15)	3	15	9,79 (4,12)	65
Upper extremity function (25)	8	25	18,54 (5,90)	74
Vision (15)	4	15	13,39 (2,76)	89
Work / Productivity (15)	3	15	7,36 (4,12)	49
Total Score (245)	**66**	**222**	**143,62 (33,88)**	**59**

The mean of the total score of the SSQOL was 143,62 (SD =± 33,88), indicating that QOL is affected in the study sample. The minimum score obtained was 66 with a maximum score of 222 with a higher score indicating a better QOL. According to the scores of the SSQOL, participants showed some issues in each of the domains. Participants had the lowest scores for the social roles domain and had the highest scores for the vision domain.

4.6 Inferential statistics of the association between level of disability and sexual function

Table 4.11 shows a 2-way ANOVA test of between- subjects effects, looking at the interaction between level of disability (MRS), sexual dysfunction and sex.

Table 4.11: Results of a 2-way ANOVA test of the interaction between level of disability, sexual dysfunction, and sex.

Source	Type III Sum of Squares	Df	Mean Square	F	Sig.	Partial Eta Squared
Model	327.021[a]	4	81.755	85.062	0.000	.867
Sex	.178	1	.178	***0.185***	***0.669***	.004
Sexual Dysfunction	.872	1	.872	***0.907***	***0.345***	.017
Sex *Sexual Dysfunction	.240	1	.240	***0.250***	***0.619***	.005
Error	49.979	52	.961			
Total	377.000	56				

a. R Squared = .867 (Adjusted R Squared = .857)

Neither sex, nor sexual dysfunction or even the interaction between sex and sexual dysfunction on MRS were significant. This indicates that there were no significant differences between males and females with regards to disability, and no significant differences between those with or without sexual dysfunction with regards to their physical ability. Despite this lack of significance, there are still mean differences. When there is no sexual dysfunction present, both males and females have similar scores on the MRS. However, when there is sexual dysfunction present, then males score higher on the MRS. Finally, 85% of the variance in MRS scores is accounted for by sex, sexual dysfunction and the interaction which is very high which indicates a strong relationship between sex, sexual dysfunction, and disability.

4.7 Inferential statistics of the association between sexual function and QOL

Table 4.12 shows the SSQOL scores between the participants with sexual dysfunction and those with no sexual dysfunction.

Table 4.12: The mean scores on the SSQOL for the study population (n=56)

SSQOL Scores	Sexual Function	Mean	Std. Deviation	N (56)
Total	Sexual dysfunction	139.94	33,89	35
	No sexual dysfunction	149.76	33.78	21
	Total	**143,62**	**33,88**	**56**
Male	Sexual dysfunction	142.32	37,16	19
	No sexual dysfunction	162,77	32,38	13
	Total	**150,63**	**36,22**	**32**
Female	Sexual dysfunction	137,13	30,52	16
	No sexual dysfunction	128,63	25,25	8
	Total	**134,29**	**28,60**	**24**

Those with sexual dysfunction were found to have a lower mean SSQOL score (139.94 ± 33.89) than those without sexual dysfunction (149.76 ± 33.77). There was no significant difference however between those with and without sexual dysfunction regarding SSQOL scores (p=0,298).

Table 4.13 is a summary of the 2-way ANOVA test that describes the interaction between QOL, sexual dysfunction and sex.

Table 4.13: A 2-way ANOVA test of between- subjects effects, looking at the interaction between quality of life (SSQOL), sexual dysfunction and sex.

Source	Type III Sum of Squares	Df	Mean Square	F	Sig.	Partial Eta Squared
Model	1162448.962[a]	4	290612.241	270.492	.000	.954
Sex	4880.054	1	4880.054	***4.542***	***.038***	.080
Sexual_Dysfunction	450.663	1	450.663	***.419***	***.520***	.008
Sex * Sexual_Dysfunction	2644.029	1	2644.029	***2.461***	***.123***	.045
Error	55868.038	52	1074.385			
Total	1218317.000	56				
a. R Squared = .954 (Adjusted R Squared = .951)						

The 2-way ANOVA revealed a significant effect for sex ($F_{1,52}$=4.542; p=0.038) indicating significant differences between males and females with regards to their QOL. In total, males had a SSQOL score of 150,0 while females had a score of 134,2 indicating males had better QOL than females. Although no significant interaction was present, there were still mean differences. When no sexual dysfunction was present, males and females reported very different QOL scores, with males reporting higher QOL than females, however when there was sexual dysfunction, the scores for males and females were much closer. Finally, 95% of the variance in QOL scores is accounted for by sex, sexual dysfunction, and the interaction. This interaction is very high and indicates a strong relationship between sex, sexual dysfunction, and QOL.

CHAPTER 5: DISCUSSION

5.1 Introduction

The aim of this study was to determine the factors associated with sexual function in an individual post stroke and the association with quality of life. The objectives were to determine an individual's sexual function post stroke, to determine the factors that are associated with an individual's sexual function post stroke and to determine the association of sexual function with the quality of life of an individual post stroke. This chapter will discuss the main findings of the research in relation to the literature and will address the study objectives. This chapter will be presented as follows:

5.2 The profile of the study participants
5.3 Sexual function post stroke
5.4 Factors associated with sexual function post stroke
5.5 Association of sexual function and quality of life of an individual post stroke

5.2 Profile of the study participants

A total of 56 participants were involved in this study who were between 3 months and 24 months post stroke.

5.2.1 Sex and Age

Individuals included in the study were between 19 and 73 years old. The mean age of the sample was 51,3 (SD =± 13,24) years. This mean age was comparable to the mean age of 51,4 (SD =±11,0) years in a Dutch study by Meesters et al., (2020) and the mean age of 55,2 (SD =± 10,8) years in a Nigerian study (Akinpelu et al., 2013), both of which addressed sexual function post stroke. This is close to the age group of individuals who had a stroke, reported in research by Ovbiagele and Nath

(2011) with a median age of 42,9 years in 1997 and 48,4 years in 2006 in the United States. The median age of people with HIV who had a stroke in a similar setting between 1997 and 2002 was 42 years old (Ortiz et al., 2007). According to the literature, strokes more commonly affect a younger population in lower-income countries such as South Africa (Heikinheimo et al., 2012; Tipping et al., 2007). It is hypothesised that individuals who have had a stroke in developing countries are on average 15 years younger than individuals who have had a stroke in developed countries (Vajrala et al., 2020). The median age of individuals with HIV who have strokes was 33,4 years in Cape Town South Africa in 2000 (Tipping et al., 2007) and 39,8 years in 2008 in Blantyre, Malawi (Heikinheimo et al., 2012). The mean age of the study sample is higher (51,32 years) and this may be due to an outlier amongst the participants (73-year-old) affecting the distribution of the data. Another possible explanation for the older age group in this sample is due to the regional variation with regards to the use of cART, perhaps because cART delays the time to stroke onset (Benjamin et al., 2012). This would be applicable to 25% of the population in this study who were HIV positive and were receiving cART.

In a study by Vajrala et al. (2020), which looked at the effect of sexual rehabilitation in post-stroke patients, the mean age of male participants was 41,5 years and female participants was 41,2 years which is only about a decade younger than the mean age of participants in this study (51,32 years). A recent study carried out in the Congo, that aimed to improve the sexual management of stroke survivors, has a similar mean age of stroke survivors that is 52, 9 years with limits of 20 and 73 years , comparable to the age range in my study of 19 to 73 years old (Diatewa et al., 2021). The mean age of participants across 16 studies as part of a systematic review was 58, 46 years (Dusenbury et al., 2017).

The age of 50 years and younger is recognised as the sexually active phase and therefore participants in this study are close to this sexually active age-group (Vajrala et al., 2020). This highlights the significant need of sexual rehabilitation as many individuals post-stroke fell within the sexually active age group. A study by Oyewole et al., (2017) assessed the prevalence of sexual dysfunction of 121 stroke survivors with a mean age of 62,6 (SD =±11,2 years) thus even in an older post stroke population, it is important to address sexual function.

In a study by Ng et al., (2017) the mean age of participants was 63 years with the youngest patient being 19 and the oldest 95 years of age. Sexual rehabilitation is therefore important in persons of all age groups. It is interesting that 40 of the 68 (58,8 %) participants reported not having sexual intercourse for at least five years before their stroke but they were still sexually active regarding the broader definition of sexuality including masturbation , sexual desires and sexual thoughts (Ng et al., 2017). This shows that one must consider the broader definition of sexuality and not just address issues with sexual intercourse. The criteria to participate in the research included being sexually active prior to the stroke. This potentially excluded potential participants for example those who do not have a sexual partner but were still sexually active regarding masturbation and other sexual activities besides intercourse.

The study sample was comprised of male and female participants. Majority of the study participants were male (57,1%). Although a small sample size (n=56), the sex make-up of this sample is in line with literature. In a study by Meesters et al., (2020), just over half (53%) of the study sample were males. Research shows that in terms of stroke incidence, males younger than 45 years' experience a higher incidence of ischaemic stroke and poorer functional recovery compared to females in the same age category (Gibson and Attwood, 2016). Between the ages of 45 to 54 years, there is an increased incidence of ischaemic stroke occurring in females. This may be due to the onset of menopause and hormonal changes in conjunction with a risk of obesity and metabolic syndrome contributing to increased stroke risk (Gibson and Attwood, 2016; Roy-O'Reilly and McCullough, 2018). From 55 years onwards, the incidence of stroke is comparable in males and females until the age of 85 years where females are at a higher risk of ischaemic stroke (Gibson and Attwood, 2016; Roy-O'Reilly and McCullough, 2018).

A study that examined the effectiveness of a sexual rehabilitation intervention programme regarding sexual knowledge and satisfaction in addition to frequency of sexual activity one month post stroke was conducted by HoSook et al., (2011) in South Korea. Most of the study participants with strokes were male (82,6%) compared to 17,4% who were female. This ratio suggests that males are more inclined to reactivate their sexual function than women. Similarly, in research about sexual rehabilitation amongst individuals with spinal cord injuries, more than 70% of participants were males although the incidence rate of spinal cord injury is similar amongst men and women in South Korea (HoSook et al., 2011). This suggests that Korea is still heavily influenced by a primarily male dominant culture with a more passive role of female sexual health (HoSook et al., 2011).

In this research, there are more male participants which could also suggest that males were more interested in sexual function post stroke and thus more males agreed to participate in the study. The South African culture may also influence this ratio. According to Meyer (2017), masculinity and manhood is confirmed by having sexual relations especially in peri-urban areas of South Africa where men establish their masculinity amongst peers by seeking sexual partners.

In a systematic review that examined the determinants of sexual function and dysfunction in males and females post stroke, the majority of participants were males (n= 1702, 90%) (Dusenbury et al., 2017). Only 10% of the studies in this systematic review included women and therefore more research in this area that focuses on the female population is required in order to gain further understanding of sexual concerns and sexual function in women post stroke (Dusenbury et al., 2017). The male to female ratio of participants in this study are more equal which is helpful to reflect the sex-specific issues with sexual function and QOL.

5.2.2 Relationship status

In this study, 60,7% of participants were married compared to 10,7% of participants who were single. Similarly, in a study by Liu et al., (2018) the majority of patients in the study were married (89,9%) compared to unmarried patients (10,1%). According to this research, there was no significant difference in history of stroke, and hypertension between the two groups (Liu et al., 2018). In research by Meesters et al., (2020), 29% of the study participants were single. The literature regarding relationship status and sexual function amongst stroke survivors is scarce and more research evaluating this would be beneficial. It would be valuable to gain more knowledge about how stroke affects dating life for single individuals.

In this study, the questionnaire first established the relationship status of the participant. This was important as later it was asked whether the participant was able to discuss sexuality with his or her partner and whether his or her partner was unwilling to have sex for various reasons. Although not evaluated in this study, it would be beneficial in future research to assess if there was an association between the relationship status and return to sexual function post stroke. For example, a married individual in a steady relationship may be more willing to participate in sexual rehabilitation after

their partner's stroke compared to a single individual's partner who may not invest in this process and rather decided to not pursue the sexual relationship with their partner after his or her stroke.

5.2.3 Comorbidities

The comorbidity statistics in this study shows that 69,6% of the participants had hypertension, 25% of the sample had HIV and 30,4% of participants had diabetes. These statistics are in line with South Africa's main risk factors for stroke (Wandai et al., 2017).

Human immunodeficiency virus is a significant risk factor for stroke especially affecting the younger age group and is common in lower income countries such as South Africa (Benjamin et al., 2012; Tipping et al., 2007). A total of 14 participants, 25% of the study sample had HIV. In addition to HIV, cART is also a risk factor for stroke (Benjamin et al., 2012) and this is interesting when looking at the participants in this study with HIV, where all 14 participants in the study with HIV were on cART.

According to stroke Wajngarten and Silva (2019), hypertension is the most common risk factor for stroke, based on findings from 30 studies, and hypertension has been noted in about 64% of patients with stroke (Wajngarten and Silva, 2019). This is very similar to the results of this study with 69,6% (n=39) of the study sample having hypertension. Most of the participants (n=37; 94,9%) with hypertension were on medication.

The findings of this study show that diabetes affected 30,4% (n= 17) of the participants. This is in line with the statistics in the literature, that is, approximately one-third of all individuals with stroke have diabetes (Lau et al., 2019). Diabetes is a highly prevalent comorbidity in patients with stroke and is associated with poorer stroke outcomes compared to individuals without diabetes (Lau et al., 2019). In a meta-analysis of 39 studies (n=359,783), the estimated prevalence of diabetes was 28% with the rate being higher in ischaemic (33%) compared to haemorrhagic stroke (26%) (Lau et al., 2019).

Multiple comorbidities are associated with sexual dysfunction in males and females (Polland et al., 2018). Clinically this is important, as sexual rehabilitation post stroke may be complicated by underlying medical conditions and if sexual rehabilitation is not done in conjunction with medical intervention, it may be ineffective. For example, the side effects of chronic medication may lead to

ED in males or problems with vaginal lubrication in females (Polland et al., 2018). In this study, participants were excluded if they experienced sexual dysfunction prior to their stroke. In the public health care setting, many individuals are formerly diagnosed with comorbidities such as hypertension after their stroke and chronic medication is initiated. Therefore, some participants' sexual dysfunction may not only be due to the stroke but also can occur because of the medication they are taking to manage their comorbidities. Therefore, participants' comorbidities and medication were established. It would be valuable for future research to analyse this further.

5.3 Sexual function post stroke

This section will address the first objective of the study, that is, to determine an individual's sexual function post stroke.

In this study, 62,5% (n=35) of the participants were found to have sexual dysfunction post stroke. These findings are consistent with the literature which reports that 57-75% of individuals experience sexual dysfunction post stroke. This study's findings are also in line with research by Oyewole et al., (2017), that states that sexual dysfunction has prevalence between 20% and 75% and occurs irrespective of the severity of stroke. A study done in Brazil, that assessed sexual function and QOL of persons post stroke, found that the prevalence of sexual dysfunction was 60,0% and 77,7% in females and males respectively (Pereira et al., 2017).

According to the CSFQ-14, the mean score for the male sample for the category of desire/frequency was 5,97 (SD =±2,15) indicating sexual dysfunction. The female sample also had sexual dysfunction for this category indicated by a mean score of 4,62 (SD =±1,61). The category of sexual desire/ frequency looked at how frequently an individual engages in sexual activity and how often the individual desires to engage in sexual activity. These findings are comparable to the findings of Choi-Kwon and Kim (2002), where 65% of their sample had reduced coital frequency three months post stroke (Choi-Kwon and Kim, 2002; Seymour and Wolf, 2014). Additionally, 33% of individuals reported no participation in sexual intercourse after the stroke (Korpelainen et al., 1999; Seymour and Wolf, 2014).

The category of pleasure in the CSFQ-14 is measured by how enjoyable or pleasurable one's sexual life is currently. In this study, male participants scored a mean value of 2,22 (SD =±1,39) and females obtained a mean score of 2,46 (SD = ±1,38), both of which fell below the cut-off values for the category of pleasure indicating sexual dysfunction for pleasure. These results are consistent with findings of a study by Korpelainen et al., (1999), where 49% of persons post stroke and 31% of spouses of individuals post stroke were unsatisfied with their sexual life after stroke. Similarly, in research by Meesters et al., (2020), more than half the participants (54%) reported that they were very unsatisfied sexually.

According to a study by (Korpelainen et al., 1999) , sexual dysfunction was present among stroke survivors with 46% of females in the study having reduced vaginal lubrication and 75% of males experiencing ED post stroke. The results of my study are in line with the above findings. The female participants in this study scored a mean of 7,71 (SD =±3,11) for arousal/excitement which fell below the cut-off value for this category indicating dysfunction in this area. For female sexual arousal/ excitement, the presence of adequate vaginal lubrication during sexual activity was a factor to determine if there was sexual dysfunction for this category. For male participants, questions on erectile function are used in the CSFQ-14 to determine whether males experience dysfunction in arousal/excitement. Males obtained a mean of 9,03 (SD =±3,33) for this category falling below the subscale cut-off value and therefore had dysfunction with arousal and erection which is in line with research by Korpelainen et al., (1999) and Seymour and Wolf, (2014). In addition, a recent study by Dai et al., (2020), showed that ED occurred in 77,8% of males after ischaemic stroke.

Research by Akinpelu et al. (2013), showed that 95% percent of participants (ages 28 – 79 years old), a similar age-group to my study, experienced at least one problem with sexual function. The most commonly reported sexual dysfunctions were reduced libido and reduced coital frequency which were experienced by more than 70% of participants (Akinpelu et al., 2013). Sexual problems such as reduced coital frequency and reduced libido are also problems found amongst the participants in my study. For example, both the males and females scored below the cut-off values for the category of desire/interest on the CSFQ-14 suggesting issues with libido. Moreover, 64,3% of participants reported a lack of desire and 64,3 % of participants reported a lack of motivation which were reported as major factors affecting their sex life post stroke. In a Nigerian cohort of individuals, there was reduced libido and coital frequency with a prevalence more than 70% (Oyewole et al., 2017a). The prevalence of problems with orgasm, erection and ejaculation was more than 60% amongst the

Nigerian stroke survivors (Oyewole et al., 2017a). These findings are similar to the findings in my study.

According to Akinpelu et al., (2013), types of sexual dysfunction reported were problems with ejaculation and orgasm which were reported as troublesome by more than 60% of participants. (Akinpelu et al., 2013). This is seen in the findings of my study where the mean score (8,59, SD =±4,10) for orgasm/completion was below the cut-off value indicating sexual dysfunction in this area and problems with ejaculation.

An important finding in my study is that 17 participants (30,4%) had not had sexual intercourse since their stroke at the time that the questionnaire was done which was a minimum of three months post stroke. This is an interesting finding as all these participants were sexually active prior to their stroke. At TMRH, there is currently no sexual rehabilitation offered and one wonders whether the lack of sexual rehabilitation post stroke affects the return to sexual intercourse post stroke.

It is an interesting finding that majority of the sample (n=37; 66,1%) did not know that health care professionals can help with sexual dysfunction. This will leave individuals feeling helpless and anxious about return to sexual activity post stroke. According to the WHO, there is a disconnect between patients' desires to discuss sexual health post stroke and the services available to address sexual concerns post stroke (Vikan et al., 2019). There is an urgent need for improving the provision of sexual training in this cohort (Vikan et al., 2019). It is evident from literature (Vikan et al., 2019) and my study that there is a lack of knowledge around accessibility to sexual rehabilitation post stroke. According to (Gianotten et al., 2006), majority of healthcare professionals find the sexual issues of their patients difficult to address. Rehabilitation professionals feel they lack the necessary skills, knowledge and training to address sexual issues with their patients (Akinpelu et al., 2013; Gianotten et al., 2006; Kautz and Van Horn, 2017). As patients lack the knowledge and experience inadequate information regarding sexual health post stroke (Stein et al., 2013), healthcare professionals have the responsibility to promote awareness, share knowledge, make information accessible and implement sexual rehabilitation protocols into stroke rehabilitation.

It is necessary to look at research on sexual rehabilitation in the general population and apply the principles to patients experiencing sexual dysfunction post stroke. Research shows that aerobic exercise can help improve ED and pelvic floor physiotherapists can treat sexual pain disorders such as vaginismus to mitigate sexual dysfunction (Gopal et al., 2021). Physiotherapy interventions including

muscle retraining exercises, manual therapy, electrical stimulation, biofeedback and counselling can help address sexual dysfunction (Gopal et al., 2021). The literature supports that physical activity improves mental health and lowers the rate of depression and anxiety which helps target the psychological aspects of sexual dysfunction (Gopal et al., 2021).

5.4 Factors associated with sexual function post stroke

This section will address the second study objective, that is, to determine the factors that are associated with an individual's sexual function post stroke.

5.4.1 Age

The mean age of participants in this study was 51,32 (SD =±13,24) years with the youngest participant being 19 years old and the oldest participant being 73 years old. It is seen that the presence of sexual dysfunction increases with an increase in age. Majority of the study sample with sexual dysfunction were older than 51 years. This finding is supported by other literature that shows a decline in sexual function with an increase in age (Oyewole et al., 2017a).

For example, research by Oyewole et al (2017), shows that an increase in one -year in age increased the odds of having sexual dysfunction by 6,7% among stroke survivors. In males, the level of testosterone decreases every year between the ages of 40 and 70 years which can lead to ED, reduced sexual satisfaction and frequency (Oyewole et al., 2017a). Sexual problems arise in females during menopause (Oyewole et al., 2017a), a natural progression of ageing.

In this study, it can be suggested that the reason for sexual dysfunction occurring post stroke is due to other factors besides for age as the participants were only included in the research if they had no previous sexual dysfunction. It would be beneficial, however, for future research to investigate whether stoke impacts sexual health more in older individuals. For example, research looking at whether age influences sexual rehabilitation or sexual recovery.

5.4.2 Sex

In the study, of the 35 participants who had sexual dysfunction 19 participants (33,9%) were males and 16 participants (28,6%) were females therefore more males experienced sexual dysfunction than females. This difference is not however statistically significant (p=0,577).

This finding is in disagreement with research by Oyewole et al., (2017), that found females post stroke were seven times more likely to have sexual dysfunction compared to males post stroke. These results suggest the need of assessing females for sexual dysfunction post stroke and the importance of implanting female-specific sexual rehabilitation interventions post stroke (Oyewole et al., 2017a). This discrepancy between gender and sexual function may be due to the following: the study sample may include older participants therefore it is likely that most female participants were peri-menopausal accounting for the increased prevalence of sexual dysfunction amongst females (Oyewole et al., 2017a). Moreover, the cultural and religious beliefs must be considered amongst the Nigerian population in this study, that is, females may fear rejection or divorce if they complain about sex-related matters as well as may keep sexual matters privately as discussing such matters is seen as a sign of promiscuity in Nigerian women (Oyewole et al., 2017a).

5.4.3 Comorbidities

The most common comorbidity in the study population was hypertension (n=39; 69,6%). Regarding hypertension and sexual functioning, research shows that anti-hypertensive medication is significantly associated with ED (Bener et al., 2008). In this study, 30 male participants (53,6%) had dysfunction for the arousal and erection subscale of the CSFQ-14 indicating ED. This is an interesting finding as there were many hypertensive participants taking antihypertensive treatment which could contribute to ED in addition to the stroke leading to ED.

Seventeen individuals (30,4%) of the study sample had diabetes. The literature shows that comorbidities such as hypertension and diabetes can affect sexual function among individuals post stroke (Oyewole et al., 2017a). In research by Oyewole et al., (2017), 95% of the participants post

stroke presented with global disability, with 19% having diabetes and 73% of the sample having hypertension which could have influenced the high prevalence of sexual dysfunction in this study (Oyewole et al., 2017a). Medication taken for diabetes is significantly associated with ED (Bener et al., 2008). Research looking at how many males post stroke had ED compared to how many diabetic males post stroke had ED would be informative.

Another potential factor contributing to sexual dysfunction amongst people with stroke is HIV. In this study, 14 participants (25%) of the participants had HIV with 100% of these individuals on cART. Research shows that sexual dysfunctions are common among males with HIV for example loss of libido, ejaculatory disorders and ED which is the most frequent sexual problem in this population with a prevalence of 30-50% even in males younger than 40 years (De Vincentis et al., 2021). The factors associated with sexual problems in persons with HIV can include the infection itself, HIV stigma, fear of virus transmission and self-esteem issues (De Vincentis et al., 2021). Amongst the female population with HIV, sexual dysfunction is also common and usually due to psychosocial factors (Moshfeghy et al., 2021). As many individuals with stroke are HIV positive, it is necessary to address sexual dysfunction in this context holistically therefore considering HIV and sexual wellness.

5.4.4 Disability level

The mean of the study sample for the MRS was 2,41 (SD =±0,97). The mean MRS score of participants with sexual dysfunction (n=35) is 2,51 (SD =±1,07) compared to the MRS score of those with no sexual dysfunction (n=21) which is 2,24 (SD =±0,77). Those with sexual dysfunction had higher (2,51 ± 1,07) mean MRS scores than those without sexual dysfunction (2,24 ± 0,77) indicating a greater level of disability and a higher level of dependence amongst the group of participants with sexual dysfunction compared to those without sexual dysfunction. This difference in MRS scores between individuals with and without sexual dysfunction however is not significant.

Findings from a study by Akinpelu et al., (2013), showed that there was no significant difference between motor function and those with sexual dysfunction and those without sexual dysfunction. Results from my study also showed no significant association between level of disability and sexual function. It was hypothesized that the more severe one's disability, the more likely the presence of sexual dysfunction. In my study however, most participants had a similar level of disability as

determined by the MRS and future research could aim to assess different severities of disabilities post stroke and the association with sexual function post stroke to further understand if a relationship exists between disability and sexual function. Similarly in research conducted by Buzzelli et al., (1997) and Choi-Kwon and Kim, (2002), it was found that motor disability post stroke had no effect on sexual activities after stroke. This study looked at post stroke emotional incontinence and sexual activity changes in the subacute and chronic stage of stroke (Choi-Kwon and Kim, 2002). Participants with severe motor impairment reported low coital frequency while participants with a low Barthel Index score (ability of an individual to perform self-care) had a reduced libido three months post stroke (Choi-Kwon and Kim, 2002). At a two-year follow up, severe motor dysfunction after stroke was related to reduced sex drive, coital frequency and erectile function (Choi-Kwon and Kim, 2002). In summary this study findings that motor dysfunction post stroke was significantly related to sexual activity changes is in line with findings from this study although insignificant.

Even when taking sex into account, there was no significant difference in MRS scores for participants with and without sexual dysfunction. There were also no significant differences between males and females regarding disability, and no significant differences between those with or without sexual dysfunction with regards to their physical ability, despite this lack of significance, there are still mean differences. When there is no sexual dysfunction present, both males and females have similar scores on the MRS. However, when there is sexual dysfunction present, then males score higher on the MRS indicative of a greater level of disability however this was not significant.

A study by Yilmaz et al., (2017), aimed to investigate the sexual changes in females with stroke and determine the factors linked to these changes. The Female Sexual Function Inventory (FSFI) was the main outcome measure to measure sexual function and was used alongside the National Institutes of Health Stroke Scale (NIHSS) to determine the stroke severity, and the MRS to determine level of dependence and degree of disability (Yilmaz et al., 2017). The results of the study showed that the higher the dependence level of the patient (as determined by the MRS), the lower the FSFI score and the more severe the stroke (according to the NIHSS), the lower the FSFI score (Yilmaz et al., 2017) . These results show that stroke severity and dependence levels are important indicators of sexual dysfunction in female stroke survivors (Yilmaz et al., 2017). These findings are in line with this study, although not significant, regarding the mean differences, that is those with sexual dysfunction had higher mean MRS scores than those without sexual dysfunction indicating a greater level of disability amongst the participants with sexual dysfunction.

A study by Kimura et al., (2001), reported that physical disability is an important influencer of sexual function post stroke. Individuals with sexual dysfunction after stroke, had more impaired activities of daily living compared to those individuals without sexual dysfunction (Kimura et al., 2001). This study by Kimura et al., (2001) specifically looked at ADL which is not assessed by the MRS, therefore it looked at disability under different activity limitations thus is not directly comparable to the results from my study. Research by Choi-Kwon and Kim, (2002), shows that participants with severe motor impairment and low Barthel Index scores had reduced libido at three months post stroke.

The issue of positioning affecting sexual function is seen in this study, where 67,90 % of the participants reported that they were unable to find a comfortable position for sex after their stroke. This issue is also reported in other studies where physical impairments and limitations with mobility because of stroke lead to difficulties in sexual positioning during intercourse (Hawton, 1984; Kimura et al., 2001; Schmitz and Finkelstein, 2010; Yilmaz et al., 2017). These include muscle weakness, spasticity and pain, which were seen to negatively affect sexual function particularly regarding positioning for sexual activities (Hawton, 1984; Kimura et al., 2001; Schmitz and Finkelstein, 2010; Yilmaz et al., 2017).

Healthcare professionals, especially physiotherapists and occupational therapists, should address the physical impairments that affect positioning during sexual activities (Ziegler, 1999). The physiotherapist is responsible for helping the patient improve motor function, flexibility, balance, coordination, general mobility, and endurance which will facilitate more enjoyable sexual relations (Ziegler, 1999). The occupational therapist's role includes analysis of activity limitations and helping with adaptations to overcome barriers (Ziegler, 1999). For example, for patients with hemiplegia, the individual can lie on their affected side enabling the unaffected arm to touch his or her partner (Ziegler, 1999). Another recommended position is for the individual to lie in supine and the partner lie on top where the partner is encouraged to touch areas of the body where sensation in intact (Ziegler, 1999). For females that experience spasticity in the hip adductors, penetration may be affected (Ziegler, 1999). In these cases, a position of rear vaginal entry or lying at a right angle to her partner is recommended (Ziegler, 1999). The use of assistive devices such as handles attached to the headboard along with pillows to support and aid positioning are helpful (Ziegler, 1999).

In this study, 39,3 % of participants reported that pain affects their sex life and 37,5% of participants were afraid that they would experience increased pain during sex. The presence of pain and fear of pain during sexual activities affects sexual function amongst stroke survivors and QOL of these individuals.

Muscle weakness and spasticity are impairments affecting sexual activities in individuals post stroke. This study did not specifically look at muscle weakness and spasticity however and it would be beneficial for future research to assess which physical impairments related to stroke affect sexual function in order to adequately address sexual dysfunction.

5.4.5 Psychosocial factors

In this study, the questionnaire was used to identify which factors the participants believed affected their sex lives post stroke.

5.4.5.1 Poor self esteem

Poor self-esteem was reported by 48,2% of the participants as a factor affecting their sex life post stroke. Anecdotally, participants reported that the anxiety of reduced sexual performance post stroke caused low self-esteem and frustration in their sexual relations. State self-esteem is described as the part of a person's feeling of self-worth that can be influenced by a particular situation of stress such as stroke (Chang and Mackenzie, 1998). This study sample comprised of 152 patients who had a stroke and results showed that the degree of state self-esteem was also a predictor of functional outcome of persons after stroke (Chang and Mackenzie, 1998). Poor self-esteem can arise because of the physical impairments post stroke which were reported by some participants in the study. There were 17 participants (30,4%) that felt their partner's found them unattractive since the stroke which was a factor negatively affecting their sex lives. This perception of being unattractive to one's partner can impact self-esteem and be a factor affecting sexual function and QOL post stroke as seen in research by Finger, (1993).

According to Finger (1993), a common consequence of being unable to perform sexually results in reduced self-esteem. Therefore, not only does self-esteem affect sexual function post stroke, but sexual dysfunction affects self-esteem, resulting in a vicious cycle. In addition, McCabe and Taleporos, (2003) suggested that individuals living with physical disabilities experience many social barriers and sexual barriers which often leads to lowered self-esteem.

Self-esteem issues in males can cause the individual to feel less manly after the stroke (Finger, 1993). In his research, Finger (1993, pp. 50) states that "a man who has lost his perceived virility in life will often view himself as being sexually impotent as well". Females also associate sexuality with their physical appearance and changes to appearance post stroke can lead to negative self- image and lead to feeling sexually unappealing (Finger, 1993). An individual's partner or spouse may also experience similar perceptions and find their affected partner sexually unattractive post stroke (Finger, 1993).

Results from a study by Diatewa et al., (2021), shows that reduced self-esteem was experienced by 30,6 % of the study sample and sadness was felt by 41,7% of stroke survivors (Diatewa et al., 2021). It is important to consider psychological factors as causes of sexual dysfunction and the inclusion of psychologists in the MDT is imperative in sexual rehabilitation. Reduced self-esteem post stroke can lead to feelings of isolation and rejection with reduced sexual opportunities (Keppel and Crowe, 2000).

A study by Keppel and Crowe, (2000) assessed the effects of stroke on body-image and self-esteem of 40 participants with a mean age of 36,7 years. This study's findings showed that body-image was significantly negatively affected post stroke, and this was associated with a significant negative impact on self-esteem (Keppel and Crowe, 2000). Horne et al., (2014) describes self-esteem as a major foundation of confidence and that poor self-esteem and therefore lack of confidence is common after stroke. Poor self-esteem leads to psychological distress and has been associated with loss of self-identity and reduced social interactions which are likely to negatively affect health outcomes and functional independence in individuals after stroke (Horne et al., 2014). Identifying strategies to improve confidence after a stroke was highlighted as one of the top ten research priorities following stroke (Pollock et al., 2012).

5.4.5.2 Depression

Depression was reported by 55,5% of the study sample as a psychological factor affecting sexual function post stroke. Depression may lead to symptoms of sexual dysfunction, including ED, decreased libido, and anorgasmia (Calabrò et al., 2011; Ziegler, 1999). Mood disorders, such as depression and anxiety commonly occur after a stroke, and therefore can result in sexual dysfunction associated with depression post stroke (Calabrò et al., 2011). Sexual health is influenced by mental wellbeing and as depression is common amongst stroke survivors, altered mental health can negatively impact sexual health. It may also be a vicious cycle as the more depressed one may feel, the worse sexual health may be which in turn can lead to feelings of depression. This is supported by literature, for example individuals with ejaculation dysfunction and sexual dissatisfaction had significantly higher scores of depression compared to the scores of those without dysfunction (Kimura et al., 2001; Korpelainen et al., 1999).

Research shows that depression is one of the most common psychological consequences occurring during the acute stage post stroke and it may be experienced for a short period or be long lasting significantly affecting QOL after stroke (Keppel and Crowe, 2000). Depression can hinder function and affect the progression of rehabilitation in patients post stroke (Ziegler, 1999). Individuals post stroke experience feelings of poor self-worth which can lead to depression, thus rehabilitation post stroke should address this through psychological intervention (Keppel and Crowe, 2000).

Moreover, post stroke patients are commonly treated for depression using psychotropic drugs which are known to potentially cause sexual dysfunction (Calabrò et al., 2011). Sexual rehabilitation post stroke needs to be holistic and focus on the psychosocial factors associated with sexual health in addition to physical rehabilitation as depression was reported by more than half of the study sample experiencing sexual dysfunction.

5.4.5.3 Fear/ Anxiety

The feelings of anxiety and fear are commonly described in the literature as psychological factors affecting sexual function.

Fear of stroke reoccurrence due to sexual activity was reported by 12 of the participants in my study (21,4% of the study sample). This fear should be addressed during the early stages of stroke rehabilitation as addressing personal or communal beliefs and superstitions about what is safe or not safe post stroke can prevent common misperceptions and positively impact QOL in stroke survivors.

Not only do the individuals who have had a stroke experience feeling of fear, but their partners also experience these feelings which can affect sexual relations. For example, 18 participants (32,10%) believed that their partners felt scared to cause their partner pain during sex after their stroke which also impacts sexual health. Although pain and incontinence are physical impairments contributing to sexual dysfunction, the fear of such factors must be considered when addressing sexual dysfunction. In this study, 10 of the participants (17,9 %) reported fear of having sexual relations because of incontinence and 21 participants (37,5 %) feared increased pain during sex.

An interesting finding from this study is that 69,6% of participants had engaged in sexual intercourse since their stroke. This is comparable to findings of (Diatewa et al., 2021), where 60% of stroke survivors in their study had resumed sexual intercourse since their stroke. Reasons identified by the participants for not resuming sexual relations post stroke included the fear of stroke recurrence and fear of failure of sexual intercourse (Diatewa et al., 2021). These factors associated with sexual function post stroke were also reported amongst participants in this research. For example, 21,40% of individuals reported fear of stroke recurrence because of sexual activity.

One participant explained that his sexual life has been affected post stroke, because of feeling too weak to engage in sexual relations and moreover scared that sexual activities will make him weaker and take away his energy which he needs for “healing”. He has avoided engaging in sexual relations as this may slow down his recovery.

It is evident that fear is a problem in this sample which is also seen in the literature and is something that can be addressed in sexual rehabilitation early on to help manage expectations and patient and partners’ perceptions of return to sexual function post stroke.

5.4.5.4 Lack of desire

In addition, lack of desire was reported by 64,3% of participants, as a factor affecting sex life post stroke. This is in line with literature which reports that the frequency of persons post stroke who experience reduced sexual desire varies from 26% to 79% (Diatewa et al., 2021; Kimura et al., 2001;

Korpelainen et al., 1999; Monga et al., 1986). This is a significant finding that can guide therapists planning a sexual rehabilitation programme. Diatewa et al., (2021) looked at the frequencies of sexual disorders after a first stroke and identified the factors associated with sexual disorders. In this study, the overall frequency of participants post stroke that experienced decreased sexual desire was 50% which also is in line with the literature (Diatewa et al., 2021). The most predominant sexual disorder identified amongst the female participants post stroke in this study was decreased sexual desire with 100% of the female sample experiencing reduced sexual desire post stroke (Diatewa et al., 2021) which reflects other literature that states that decreased desire is the most prominent sexual problem is women regardless of disability (Kautz and Van Horn, 2017). Therefore, sex should be considered when looking at such factors post stroke.

Sexual desire dysfunctions sometimes referred to as issues with libido are defined as diminished feeling of sexual interest or desire, reduced or absent sexual thoughts or fantasies which goes beyond the normally expected decrease in sexual interest that occurs with aging and relationship durations (Hatzimouratidis and Hatzichristou, 2007; Lewis et al., 2004). The ICD-10 classification system of sexual dysfunction defines a lack of sexual desire as a loss of sexual desire that is the main problem not secondary to other sexual difficulties (Hatzimouratidis and Hatzichristou, 2007).

Sexual desire can be affected by psychological factors such as depression and fear of a recurrent stroke (Calabrò et al., 2011). In males, diabetes is a comorbidity that has been associated with a greater prevalence of issues with sexual desire (Lewis et al., 2004) and because many stroke survivors have diabetes, future research could consider if it is the comorbidity such as diabetes or the stroke affecting sexual desire. Increasing age is another factor affecting sexual desire that could be looked at in future research. For example, whether an older sample of stroke survivors experience more issues with sexual desire compared to a younger sample. It is apparent from the literature that reduced sexual desire increases with age for example approximately 10% of females under 49 years old have a low level of desire with the prevalence increasing to 22% in women ages 50-65 years and again increasing to 47% in the 66-74 year-old age group (Lewis et al., 2004). Therefore, the impact that aging has on sexual desire must be considered when looking at sexual desire in individuals after stroke.

Neurological rehabilitation should address sexual desire dysfunctions and typical recommendations to help increase sexual desire include the following: improving and maintaining personal hygiene and

grooming to feel sexually attractive and desirable, to communicate sexual desire through touch and to include ADL that improve general wellbeing (Kautz and Van Horn, 2017).

5.4.5.5 Relationship with sexual partners

Moreover, 30,4% of stroke survivors in the study, believed that their partners found the participant unattractive post stroke. In research by Diatewa et al., (2021), hesitation and physical aversion felt by the partner were reported as factors affecting sexual life post stroke. It would be interesting for future research to look at partners' perspectives regarding sexual function.

In this study, majority of participants (80,4%) reported that they were able to discuss sexuality with their partner. The participants in this study may have been more open, communicative, and willing and thus reflect a sample that were open to participate in this study with such a sensitive and personal topic. This is not consistent with the literature where it has been reported that 77,8% of stroke survivors and 60% of their partners experienced problems with verbal and non-verbal communication about sexual problems and had psychological problems (Diatewa et al., 2021). Reasons for a decrease in communication within couples is usually due to anxiety and literature reports that sexual health post stroke is usually a subject that is not discussed even between the couple (Diatewa et al., 2021).

Although majority of participants in this study did not have an issue with communication with their partner regarding sexual health, communication, either verbal or non-verbal, may have been too superficial and not effective at enhancing sexual performance. For example, communication workshops during sexual rehabilitation should guide couples in communicating how to sexually please one's partner with various physical limitations since one's stroke.

During data collection, a participant reported that due to his stroke, he feels weak and is scared his wife will view him as weak and unmanly as he will be weak during sex. This again speaks to the cultural beliefs of strength and effective sexual performance affecting masculinity and the issues of self-esteem that may arise post stroke (Meyer, 2017). It is evident that the changed attitude of spouses or partners towards their partner who had a stroke, has an important influence on intimacy (Keppel and Crowe, 2000). It is more likely that a decline in sexual activity is associated with individuals who have unrealistic attitudes or those who are overprotective and perceive their partner to be more childlike because of the stroke (Keppel and Crowe, 2000).

From the above findings, it is vital to include the patient's partner in sexual rehabilitation. (Auger et al., 2021; Stead and White, 2019). Stead and White, (2019) describe a programme, an Aphasia Couples Retreat, that facilitates discussions and addressed the major issues related to intimacy post stroke. This programme is run by members of the MDT including psychologists, speech therapists and occupational therapists (Stead and White, 2019). The current literature suggests the following strategies to target the current gaps in care around intimacy and sexual rehabilitation for couples including initiating a discussion about intimacy and providing resources about sexual rehabilitation in early stages of rehabilitation, to train professionals on how to improve communication with couples on topics such as intimacy as well as to create events to foster platforms for support systems and connections within the caregiver community as a support (Stead and White, 2019).

In a relationship, where a member of a couple has a neurological injury, the partner usually assumes the role of the caregiver and the patient becomes the care recipient with daily life becoming dominated by medical management and home care duties (Stead and White, 2019). The previously mutual, romantic relationship transforms into a caregiver and care receiver relationship with the loss of intimacy negatively impacting the psychological states of both partners (Stead and White, 2019). The decrease of intimate and sexual relations forms part of an individual's sense of loss and grief that is experienced by a partner caring for a spouse (Stead and White, 2019).

A study by (Kitzmüller and Ervik, 2015) interviewed 12 females spouses of stroke-affected partners to further understand the influence that s stroke has on the female spouses' sexual relationship with their disabled partner after the stroke. The interviews highlighted four main problems that affected the relationship namely: they were married to a stranger; the shift from partner to caregiver; sexual health wrapped in silence and a void to live with (Kitzmüller and Ervik, 2015). The salient findings from this research included that when couples were educated on strategies that improve communication about intimacy, the potential to improve intimacy was increased and couples experienced less embarrassment (Kitzmüller and Ervik, 2015).

5.5 Association of sexual function and quality of life of an individual post stroke

This section will address the third objective of the study, that is, to determine the association of sexual function and quality of life of an individual post stroke.

The SSQOL scale was used to determine the QOL of individuals post stroke in this study. For the difference between QOL, when comparing those with and without sexual dysfunction, no significant differences were found ($t_{54} = -1.05$; $p = 0.30$). Those with sexual dysfunction were found to have a lower QOL score (139,94 ± 33,89) than those without sexual dysfunction (149,76 ± 33,77) out of a possible score of 245. Both groups obtained poor overall scores on the SSQOL indicating that QOL is affected in individuals post stroke. These findings are in line with the literature. It, however, would be beneficial to assess QOL over a specific period which was one limitation of this study as a cross-sectional study. The mean of the total score of the SSQOL was 143,62 (SD =± 33,88) with a minimum score obtained of 66 and a maximum score of 222 with a higher score indicating a better QOL. In research by (Ntsiea et al., 2015), participants had a better QOL according to the SSQOL scale where the mean total score for the SSQOL was 219 with a minimum score of 151 and a maximum of 245. It is worth noting that in the study by Ntsiea et al., (2015), the SSQOL scale was carried out at eight weeks, three and six months post stroke compared to my study where the SSQOL scale was conducted at a minimum of three months post stroke. In addition, in the study by Ntsiea et al., (2015), participants were excluded if they had a Barthel index score of less than 12 out of 20 indicating dependence in ADLs whereas participants of any level of dependence were included in my study which could affect the SSQOL score as level of dependence in ADLs post stroke could influence QOL post stroke.

There were significant differences between males and females with regards to their QOL. In total, males had a SSQOL score of 150,0 while females had a score of 134,2 indicating males had better QOL than females. Although no significant interaction was present, there were still mean differences. When no sexual dysfunction was present, males and females reported very different QOL scores, with males reporting higher QOL than females, however when there was sexual dysfunction, the scores for males and females were much closer. The finding in my study, that females had a poorer QOL than males post stroke is in line with many studies (Bushnell et al., 2014; Franzén-Dahlin and Laska, 2012; Gargano and Reeves, 2007; Gray et al., 2007; Reeves et al., 2008). Research by Bushnell et al.,

(2014), that looked at QOL differences between 1370 participants with stroke or transient ischaemic attack at three and 12 months post discharge found that women have worse QOL than men up to 12 months after stroke even when adjusting for variables such as stroke severity and disability. According to Reeves et al., (2008), the causes for the sex differences in QOL needs further research but some explanations include that compared with men, women are usually older, have poorer premorbid function with more comorbidities, less social support and are more likely to be widowed. Although these are suggested explanations for the differences in QOL between males and females after stroke, most studies have adjusted for these factors such as age and comorbidities and therefore these factors do not adequately elucidate this common finding (Reeves et al., 2008).

It is seen that there are many outcome measures available to assess QOL which makes comparing QOL amongst different studies challenging. In a study by Akinpelu et al., (2013), the QOL of participants was also assessed using the SS-QOL scale. Participants had a mean QOL score of 181,0 ± 30,5 which is indicative of a better QOL than the participants in this study (Akinpelu et al., 2013). Participants with sexual dysfunction in erection, ejaculation and sexual dissatisfaction had significantly higher QOL scores, in contrast to what one would hypothesise (Akinpelu et al., 2013). This could be due to the cultural tendency of Nigerians to not assume negative traits to themselves which may have influenced the participant's answering of the SS-QOL scale (Akinpelu et al., 2013). This may also be seen amongst the South African participants in the current study. The research in this topic is still scarce and it was difficult to come across more research that looked at this.

The literature around the topics of sexual function and QOL is scarce. A study by Owiredu et al., (2015), aimed to determine the prevalence of sexual dysfunction and its impact on the QOL among persons with physical disability in Ghana. The findings show that sexual dysfunction was associated with a lower QOL for persons with disability, however it is noted that this issue may be worse when considering the negative societal perceptions regarding sexual health in persons with disability (Owiredu et al., 2015). The mean sexual quality of life (SQOL) score was slightly higher in the females. The study concluded that the prevalence of sexual dysfunction amongst persons with physical disability is 64.4% in males and 65.7% in females. Generally, the physically disabled women in this study had a significantly better sexual quality of life than physically disabled men. In conclusion, poor sexual function with low sexual satisfaction are risk factors for poor QOL (Owiredu et al., 2015).

It can be understood that people with more severe physical disabilities had lower self-esteem, lowered sexual satisfaction, engages in sexual activities less frequently and are generally more depressed than individuals without disabilities (McCabe and Taleporos, 2003). In Nigerian culture, sexual health is viewed as personal and therefore sexual issues should not be discussed openly (Oyewole et al., 2017b). This is even more so amongst the female population where talking about sexuality is often judged as a sign of promiscuity (Oyewole et al., 2017b). In this study, all of the female stroke survivors experienced sexual dysfunction which may be due to a lack of previous opportunity to open up about sexual health without being chastised (Oyewole et al., 2017b).

In a study investigating HRQOL in relation to disability and sexual function, 95% of the participants had moderate to severe disability and low sexual function (86,8%) (Oyewole et al., 2017a). The HRQOL was negatively impacted by an individual's disability but not by sexual function despite the direct correlation between sexual function and HRQOL (Oyewole et al., 2017a). Similarly, in the current study, there was no significant differences found when comparing QOL of participants with and without sexual dysfunction even when accounting for sex differences.

A study in Brazil assessed the sexual function of stroke survivors and compared the QOL and functional independence among sexually active and sexually inactive individuals post stroke (Pereira et al., 2017). Regarding the QOL, individuals who had no active sex life had poorer scores for QOL compared with those individuals who were sexually active (Pereira et al., 2017). These findings correspond with my study where individuals with sexual dysfunction have a lower QOL score compared to those individuals without sexual dysfunction.

5.6 Limitations

- The CSFQ-14 outcome measure, although used in other stroke research does not account for the effects of hemiplegia or language impairments in patients with stroke (Ng et al., 2017). There is no assessment tool for sexual function that is currently available that has been validated for the stroke population and the development of a stroke -specific outcome measure for assessing sexual function is needed. The CSFQ-14 was used in other stroke research and was the most appropriate outcome measure to use in this study.

- This study had a cross-sectional design which does not allow for evaluation of how sexual functioning and QOL related to sexual function changes over the course of stroke recovery.
- The study's inclusion criteria looked at individuals who were reportedly sexually active prior to their stroke. This inclusion criterion did not however define "sexually active" and did not specify if participants' sexual lives were in any way affected prior to stroke which could have impacted post stroke sexual function. For example, a participant may have reported to be sexually active prior to their stroke even if they had an issue (for example reduced libido) prior to their stroke. Therefore, their baseline status of sexual function could have been more clearly defined.
- The sample was from one study site (a large, urban hospital) and thus results are not generalizable to the whole country, nor globally, especially considering the variations in cultural and societal norms for sexual health.
- Most participants had an MRS score of 2 or 3 that is, slight, or moderate disability. It would be beneficial to look at a wider variety of disability levels to determine if disability level in fact affects sexual function post stroke.
- The study broached very personal topics. The fact that the primary researcher was from a different cultural background to most of the participants could have influenced the results due to participants not answering truthfully due to the feeling of being unable to relate culturally to the researcher. This was addressed by the researcher establishing a professional rapport with each participant prior to starting the interview and reassuring the participant that the highest level of confidentially will be maintained throughout ensuring the participant felt comfortable knowing their privacy was of utmost importance. The researcher also took time to explain the need for more research in the area of sexual health post stroke in a South African context. For interviews where participants required an interpreter, the research assistant was present, and he was trained during the pilot study on the sensitivity of the research subject and how to conduct himself in a professional manner throughout the interview to make participants feel comfortable with reassuring the participants that all confidentially will be followed. Moreover, due to the quantitative type of study, worthwhile, personal insights and details could have been missed and future studies would benefit from a mixed methodology study design.

5.7 Strengths

- The study used well validated and reliable outcome measures to assess sexual function and QOL of the participants. The standardised outcome measures utilised in this study are easily accessible and can be used in a rehabilitation setting with patients or in future research. In order to validate the questionnaire, a pilot study was conducted prior to data collection.
- Participants were not excluded based on language barriers as a research assistant was trained as an interpreter and available to assist with conducting interviews which allowed for a wider sample.
- To the best of the researcher's knowledge, this study is the first known to research in South Africa to assess sexual function of individuals post stroke. This study is a start at addressing the paucity of literature regarding the impact that a stroke has on intimate relationships and sexual functioning and will act as a platform for further research in this area. In addition, this study will hopefully encourage healthcare professionals working in neurorehabilitation to become more informed about sexual rehabilitation in patients after stroke specifically in a South African context.
- The study's inclusion criteria specified that participants were at least three months post stroke which ensured participants' sufficient time to readjust after the stroke and resume sexual relations.

CHAPTER 6: CONCLUSION AND RECCOMMENDATIONS FOR FUTURE RESEARCH

6.1 Conclusion

This study aimed to determine the factors associated with sexual function in an individual post stroke and the association with quality of life. The objectives were to determine an individual's sexual function post stroke and to determine the factors that are associated with an individual's sexual function post stroke. The final objective was to determine the association of sexual function with the quality of life of an individual post stroke. This cross-sectional study was carried out at TMRH. The data collection consisted of the researcher completing the MRS and then administering the SSQOL scale, the questionnaire, and the CSFQ-14.

The results show that majority of the participants were found to have sexual dysfunction post stroke. For each subscale of sexual function, namely sexual desire/frequency, sexual desire/interest, sexual pleasure, sexual arousal/excitement, and sexual orgasm/completion, more participants had dysfunction compared to no dysfunction. Both male and female participants obtained CSFQ-14 mean scores indicative of sexual dysfunction for the overall score and for all the CSFQ-14 subscales as above.

The factors impacting an individual's sexual function post stroke included: pain, fear of incontinence during sexual activity, difficulty with positioning for sexual activity, anxiety of having another stroke during sexual activity. Personal factors associated with an individual's sexual function post stroke included poor self-esteem, depression, change of desire, lack of motivation, fatigue and feeling physically unwell. The participants' perceptions of their partners also were factors associated with sexual function post stroke such as fear of causing the individual pain or another stroke, partner finding individual unattractive, and role changes. Another factor was age with the trend indicating that the older the individual the more likely sexual dysfunction was present although this finding was not significant. Regarding sex, there was no significant differences between males and females with regards to sexual dysfunction. The level of disability was another factor impacting sexual function but the interaction between sexual dysfunction on MRS was not significant.

Regarding the association between sexual function and QOL, those with sexual dysfunction were found to have a lower mean SSQOL score than those without sexual dysfunction however no significant difference was found.

As sexual function is an important aspect of QOL, sexual rehabilitation should be an integral part of post stroke rehabilitation that is offered to patients and their partners. Majority of the participants in the study population did not know that healthcare professionals can help with sexual dysfunction after stroke. The MDT, including physiotherapists, occupational therapists, psychologists, and speech therapists, should have adequate training and knowledge to address sexual health and sexual function post stroke. Furthermore, members of the MDT should collaborate with sexual medicine specialists in addressing sexual health in post stroke rehabilitation.

6.2 Recommendations

6.2.1 Clinical recommendations

- Training of the MDT should be done to ensure that professionals are well-equipped to deal with issues regarding sexual health and sexual functioning in individuals post stroke. The MDT should include sexologists and psychologists to address sexual functioning holistically.
- Efforts should be put into ensuring that individuals who have had a stroke have access to sexual rehabilitation regarding information on the sexual changes in patients post stroke as well as on where to access sexual rehabilitation. Sexual training and education programmes should be included in in-patient and out-patient rehabilitation.
- Sexual rehabilitation should also be offered to partners of individuals post stroke or in the form of couples training. This will help to manage expectations of the patient and partners' regarding the return to sexual function post stroke.

6.2.2 Recommendations for future research

- Currently this is the only study looking at sexual function in individuals post stroke conducted in South Africa. It is recommended that for future research is done in this area looking at the changes in sexual functioning post stroke, assessing the knowledge and skills of professionals working in stroke rehabilitation regarding sexual training and education specifically in the public health care setting in South Africa.
- It is recommended that research of a qualitative nature is done, for both areas of stroke survivors and rehabilitation professions, to gain more insight into the personal experiences of changes in sexual function post stroke and the barriers and facilitators to the provision of sexual rehabilitation in a South African context.
- It is recommended that research on sexual function post stroke is also carried out in the private sector and to other settings for example in the rural sector to make results more generalizable to the wider South African population and other cultural backgrounds.
- Research to develop a stroke specific tool to assess sexual function is recommended. There is no assessment tool for sexual function that is currently available that has been validated for the stroke population and the development of a stroke -specific outcome measure for assessing sexual function is needed.
- Future research in this area should assess whether severity of disability post stroke is a factor influencing sexual function post stroke. Therefore, research should include participants with a wider range of severity of disability as most participants in this study had a similar level of disability as determined by the MRS. Moreover, future research could assess which physical impairments related to stroke affect sexual function which will help address sexual dysfunction.
- It would be beneficial for future research to look at partners' perspectives regarding sexual function post stroke.

CHAPTER 7: REFERENCE LIST

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CHAPTER 8: APPENDICES

Appendix I – Ethical Clearance Certificate Original

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

Office of the Deputy Vice-Chancellor (Research & Post Graduate Affairs)

TO: Ms D Schneider
School of Therapeutic Sciences
Department of Physiotherapy
Medical School
University

E-mail: Danipantan@gmail.com

CC: Supervisor: Ms N Comley-White <Nicolette.Comley-White@wits.ac.za>
and <HREC-Medical.ResearchOffice@wits.ac.za>

FROM: Iain Burns
Human Research Ethics Committee (Medical)
Tel: 011 717 1252

E-mail: Iain.Burns@wits.ac.za

DATE: 2019/10/14

REF: *R14/49*

PROTOCOL NO: **M190634** *(This is your ethics application study reference number. Please quote this reference number in all correspondence relating to this study)*

PROJECT TITLE: *Sexual function and quality of life in individuals post stroke: A cross sectional study in a public health-care setting in South Africa*

Please find attached the Clearance Certificate for the above project. I hope it goes well and that an article in a recognized publication comes out of it. This will reflect well on your professional standing and contribute to the Government funding of the University.

MSWorks2000/Iain0007/Clearscan.wps

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

R14/49 Ms D Schneider

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M190634

NAME: (Principal Investigator)	Ms D Schneider
DEPARTMENT:	School of Therapeutic Sciences Department of Physiotherapy Medical School University
PROJECT TITLE:	Sexual function and quality of life in individuals post stroke: A cross sectional study in a public health-care setting in South Africa
DATE CONSIDERED:	2019/06/28
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Ms N Comley-White
APPROVED BY:	Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	2019/10/14

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, Johannesburg.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to submit details to the Committee. I **agree to submit a yearly progress report**. When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in **June** and will therefore reports and re-certification will be due early 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 _____

PLEASE QUOTE THE CLEARANCE CERTIFICATE NUMBER IN ALL ENQUIRIES

Appendix II- Letter of request for reapplication to ethics

18/05/2021

Good day Mr Burns,

I hope this email finds you well.

I have attached my protocol for my Masters research report in physiotherapy which was given ethical clearance in October 2019. Please find attached my ethical clearance certificate (M190634) for my study titled "Sexual function and quality of life in individuals post stroke: a cross sectional study in a public health-care setting in South Africa".

I started with data collection prior to lockdown and the COVID pandemic, but because of the Covid pandemic, I am struggling to complete data collection. Many potential participants who I have invited to participate in the study do not want to come into Thelle Mogoerane Regional Hospital to be interviewed and complete the questionnaires as they have reported they are anxious and uncomfortable to come into the hospital unnecessarily and potentially be exposed to COVID.

Other potential participants have moved back home due to loss of employment because of the COVID pandemic. In addition, compliance to outpatient appointments at the hospital has been poor.

Considering the above, I would like to request ethical clearance to carry out some of the data collection telephonically. This will enable me to continue with my data collection and ensure that no participants are unnecessarily exposed to COVID.

Please note, that when inviting potential participants to the study, I will give them the option to meet at the hospital as originally described in my protocol but if they would prefer a telephonic interview than I could schedule an appropriate time with the patient to do the interview telephonically.

As my study is not qualitative in nature, face to face interviews are not essential as facial expressions and body language will not add any value to the data collection.

The Changes in Sexual Functioning Questionnaire (CSFQ-14) is one of the major outcome measures used in my study. According to a study by Dunn et al., (2007), the CSFQ-14 was valid to obtain data using interactive voice response technology (IVR). This study concluded that IVR assessment of sexual dysfunction on the CSFQ-14 was highly correlated with previously validated paper-and-pencil assessment. The overall correlation between the paper and IVR CSFQ-14 total score was $r = 0.96$ ($p < .0001$). Similarly, high correlations were found between paper and IVR assessment methods on the individual CSFQ-14 subscales.

The Stroke Specific Quality of Life Scale (SS-QOL) is another outcome measure that I use in my research. Research by Linda S et al., (2000), looked at the validity of telephone administration of the SS-QOL. The study concluded that telephonic administration of the SS-QOL is accurate and unbiased (Williams Linda S et al., 2000).

The Modified Rankin Scale (MRS) has been validated for use telephonically (Chen et al., n.d.; Janssen et al., 2010; Savio et al., 2013). *A study by Savio et al., (2013) showed that a telephone assessment of stroke disability with the MRS is reliable in comparison to face to face assessment. Most patients received the same score by the two methods and there was excellent agreement by the two methods. Another study by* (Janssen et al., 2010) *used the MRS in telephone interviews and showed that the MRS used telephonically has a good agreement with face-to-face assessment and can be used reliably in the setting of a clinical trial.*

With regards to the screening tool-The Mini Mental State Examination (MMSE), I will use the Adult Lifestyles and Function Interview (ALFI) version. This is a 22- point version of the MMSE and it has omitted 8 items of the original MMSE that could not be administered telephonically (as visual cues/ face-face assessment are required for those items). Roccaforte et al. (1992) assessed the validity of the ALFI-MMSE in a study of 100 geriatric outpatients. Correlations between phone and face-to-face versions of the MMSE were excellent (Pearson's r = 0.85). Sensitivity of 67% and specificity of 100% were reported in a population of elderly, community-dwelling individuals. This was similar to the sensitivity (68%) and specificity (100%) reported for screening with the traditional MMSE (Carlew et al., 2020; Kennedy et al., 2014; Newkirk et al., 2004; Roccaforte et al., 1992).

I will obtain consent from the participants as follows:

- *If the patient has access to email-they can sign the consent form and send the consent form back via email*

- *If patients have access to WhatsApp- I will send them a WhatsApp requesting consent and receive a reply from the participant giving consent. I will then screenshot this WhatsApp for record purposes*

- *If WhatsApp is not an option, I will obtain consent via SMS*

- *Alternatively, I will record the patient telephonically giving verbal consent to participate in the study*

Prior to obtaining consent, the study will be explained thoroughly to the participant and any questions will be answered or clarifications will be made.

I have discussed the above with my supervisor Mrs Nicolette Comley-White.

Please can you let me know if the above changes would be fine to go ahead with in terms of ethical considerations? I am happy to answer any further queries or concerns that you might have.

Thanks very much
Kind regards,
Danielle Schneider
072 631 8101

Appendix III- Ethical Clearance Certificate (2)

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG	HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

2021/05/27

Ms D Schneider
School of Therapeutic Sciences
Department of Physiotherapy
Medical School
University

Sent by e-mail to: Danipantan@gmail.com

Dear Ms Schneider

Re: **Protocol Ref No:** M190634
Protocol Title: *Sexual function and quality of life in individuals post stroke: A cross sectional study in a public health-care setting in South Africa*
Principal Investigator: Ms D Schneider

Thank you for your e-mail of 2021/05/18.

I confirm that we have noted and approve of your proposal to conduct some of your interviews by telephone, when participants are unwilling or unable to meet you for face-to-face interviews.

Thank you for keeping us informed.

Yours Sincerely

J. Burns
.....
Mr I Burns
For the Human Research Ethics Committee (Medical)

CB Penny
.....
Dr CB Penny, Chairperson, Human Research Ethics Committee (Medical)

Appendix IV- Consent from Thelle Mogoerane Regional Hospital

Consent from Thelle Mogerane Regional Hospital

Mrs Danielle Schneider
Unit 13 Silvamonte Village
Silvamonte 2192
072 631 8101
Danipantan@gmail.com
28/05/19

To whom it may concern

Permission letter: Research at Thelle Mogoerane Regional Hospital

I am a physiotherapist and have been employed at Thelle Mogoerane Regional Hospital since 2017. I am currently studying a Master of Science in Physiotherapy by coursework specialising in Adult Neurology at the University of the Witwatersrand. As part of the degree, I am required to perform a research report.

The topic of my study is: "Sexual function and quality of life in individuals post stroke: A cross sectional study in a public health-care setting in South Africa. In this study, I aim to determine the factors associated with sexual dysfunction in an individual post stroke and the association with quality of life. In order to achieve this aim, the following objectives will be included.

To determine:

1) An individual's sexual function post stroke.
2) The factors that are associated with an individual's sexual function post stroke.
3) The association of sexual function with the quality of life of an individual post stroke.

Currently, there has been little research on sexuality or sexual function in individuals post stroke in developing countries and no research has been done in this area in South Africa. According to the literature, sexuality and sexual function has a significant effect on a patient's quality of life and research shows that sexuality and sexual function is affected post stroke. Although this is evident in research, the area of sexuality and sexual function is one in which therapists currently do not play a significant role whether it is due to sexuality being a taboo topic or due to a lack of knowledge and training in this field. Therapists, specifically working in a South African context, have a lack of training regarding how to approach and carry out sexual rehabilitation as part of a patient's rehabilitation. Thus, knowledge about how stroke impacts a patient's sexual function will be beneficial to therapists as there is a lack of awareness of what factors influences a person's sexual function after stroke and how sexual function impacts a person's quality of life. Therefore research in this area will enhance therapists' knowledge regarding sexual rehabilitation for persons after stroke specifically in a South African context rather than relying on existing research done in other countries. Moreover this study will act as a platform for further studies to be done in this area with the aim of improving clinical practice. This study will therefore have significant carryover and be of benefit to therapists and patients and hopefully allow us to improve the rehabilitation of patients with stroke in our country and enhance their quality of life.

This letter serves to ask permission for me to conduct the study at Thelle Mogoerane Regional Hospital in the outpatient Physiotherapy Adult Neurology Department. Outpatients who fulfil the inclusion criteria and agree to participate in the study will sign consent after receiving an information sheet and I will arrange a time to meet with them. I will assess the level of disability of the participant using The Modified Rankin Scale. Thereafter, I will

administer various interview based outcome measures including the Stoke Specific Quality of Life scale, the questionnaire and the Change in Sexual Functioning Questionnaire. Administering all outcome measures will not take more than one hour.

All ethical considerations will be strictly adhered to. Ethical approval and clearance will be applied for and obtained from the Human Research Ethics Committee at the University of the Witwatersrand prior to initiating research. In addition permission from the necessary authorities at Thelle Mogoerane Regional Hospital will be obtained before starting the research. All data collected throughout the study will be confidential, kept safe and will only be used for the purpose of this research. Participants will remain anonymous. Results from the study will be disclosed to the participants. The appointments will be done on a one-on-one basis with the participant and research assistant ensuring the participant's privacy. There is no risk to the participants partaking in this study and the participants may withdraw from the study at any point. Participants will give written consent to partake in the study. Information about the study including informing participants that a research assistant will be present, will be clarified in addition to issuing the participants an information sheet. Transportation costs of the participants will be covered.

There will be no extra cost incurred to the hospital as a result of the research being conducted at Thelle Mogoerane Regional Hospital.

If you have any further questions or issues in this regard please feel free to contact me on the details provided above.

I appreciate you taking the time to read this letter

Kind regards

Danielle Schneider
BSc Physiotherapy

HOD Physiotherapy: _____

Recommended/not recommended

Signature: _____ Date: 28/05/2019

Clinical manager: _____

Supported/not supported

Signature: _____ Date: 29/05/2019

CEO: _____ MOHAKA MM

Approved/~~not approved~~

Signature: _____ Date: 29/05/2019

Appendix V- Information Sheet

Information Sheet

Dear Sir/Madam

Thank you for taking the time to read this.

I, Danielle Schneider, am doing a research study as part of my physiotherapy masters degree. The study will look at the factors associated with sexual function in an individual after stroke and how it is associated with quality of life. Research is a way in which we are able to answer questions and gain more knowledge in certain areas. My study is called: "Sexual function and quality of life in individuals post stroke: a cross sectional study in a public health-care setting in South Africa".

Why am I doing this study?

In this study, I am hoping to learn more about what factors are associated with sexual function in individuals post stroke. Research has shown that sexual problems occur in many people after having a stroke due to various reasons. Research also shows that sexual function plays an important role in a person's quality of life.

This is an important study because there is little research on sexual function in people after having a stroke especially in South Africa. This limits members of the rehabilitation team, including physiotherapists, from addressing sexual function during rehabilitation, despite the need for it. The information gained from this study will allow us as physiotherapists to better understand how a stroke affects a person's sexual function and quality of life. It will also show why it is important to include sexual function in the rehabilitation of patients after stroke.

Who will be able to participate in this study?

Male and female individuals, aged between 18 years and 75 years old who have had a stroke will be invited to participate. Individuals will be included if they are between three months and 24 months post stroke, but will not be included if they have had more than one stroke. Persons who were sexually active before stroke will be able to participate but will not be included if they had previous sexual dysfunction.

What does the study involve?

This is a cross sectional study which means that whoever participates in the study will only be seen once for the purposes of the study. The appointment will take place in the physiotherapy outpatient department at Thelle Mogoerane Regional Hospital. I will first assess your level of disability using a tool called the Modified Rankin Scale. Afterwards you will be asked questions in three spoken questionnaires including the Stroke Specific Quality of Life Scale, a questionnaire, and the changes in sexual functioning questionnaire. The whole process should not take longer than one hour.

Participation in the study is voluntary and if you decide not to participate in the study, there will be no disadvantage to you in any way and you will not lose any benefits that you are usually entitled to. You are free to withdraw from the study at any time without any consequences. If you decide to participate in the study, your transportation costs to the hospital will be covered if you are coming specifically for the research study appointment.

What are the benefits or risks involved in this study?

There is no risk to you participating in this study. There will be no direct benefit for you taking part in this study but the results will be shared with you at the end of the study. You will not get any payment from this study.

How will your privacy be protected in this study?

All the information collected throughout the study will be confidential, kept safe and will only be used for this research. Your name will not be used (you will be anonymous) throughout the study as I will give a number to each participant and your name will only be written on the consent form. In order to ensure your privacy, the appointments will be done on a one-on-one basis in a private setting with myself, and a research assistant to assist with interpretation where needed.

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg. This Committee is responsible to safeguard the rights and dignity of all humans who agree to participate in a research project and the integrity of the research.

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

You are also free to contact my supervisor, Mrs Nicolette Comley-White at nicolette.comley-white@wits.ac.za or on 011 717 3725.

If you have any questions or concerns regarding this study or require any more information about this study, please feel free to contact me on my details mentioned below.

Many Thanks

Danielle Schneider

BSc Physiotherapy

072 631 8101

Danipantan@gmail.com

Appendix VI- Consent Form

Study Title: Sexual function and quality of life in individuals post stroke: a cross sectional study in a public health-care setting in South Africa

I, _____, consent to participate in the study conducted by Danielle Schneider. I have received an information sheet and understand the purpose of the study and processes involved in the study. I was given time to read the information sheet or had the information sheet read to me. I have been given time to ask any questions and clarify any concerns regarding the study. I am aware that I have been invited to participate in the study and it is my choice to take part in the study. I fully understand that I can withdraw from the study at any point without any consequences. I understand that there is no direct benefit of partaking in the study and my participation is voluntary. I have been given contact details, listed below and understand that I am free to speak to any of these contacts regarding the study.

My signature below indicates my consent.

Participant signature:_____ Date:_____

Researcher Signature:_____ Date:_____

Contact details:

Danielle Schneider, Principal Investigator, telephone number: 072 631 8101, or by e-mail at Danipantan@gmail.com

Nicolette Comley-White, Supervisor, on telephone no: 011 717 3702, or by e-mail at Nicolette.Comley-White@wits.ac.za

Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za.

Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

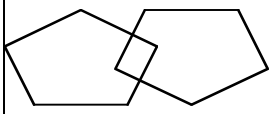
Appendix VII- MMSE

Mini-Mental State Examination (MMSE)

Patient's Name:_____ Date: _____

Instructions: Score one point for each correct response within each question or activity.

Maximum Score	Patient's Score	Questions
5		"What is the year? Season? Date? Day? Month?"
5		"Where are we now? State? County? Town/city? Hospital? Floor?"
3		The examiner names three unrelated objects clearly and slowly, then the instructor asks the patient to name all three of them. The patient's response is used for scoring. The examiner repeats them until patient learns all of them, if possible.
5		"I would like you to count backward from 100 by sevens." (93, 86, 79, 72, 65, …) Alternative: "Spell WORLD backwards." (D-L-R-O-W)
3		"Earlier I told you the names of three things. Can you tell me what those were?"
2		Show the patient two simple objects, such as a wristwatch and a pencil, and ask the patient to name them.
1		"Repeat the phrase: 'No ifs, ands, or buts.'"
3		"Take the paper in your right hand, fold it in half, and put it on the floor." (The examiner gives the patient a piece of blank paper.)
1		"Please read this and do what it says." (Written instruction is "Close your eyes.")
1		"Make up and write a sentence about anything." (This sentence must contain a noun and a verb.)

1		“Please copy this picture.” (The examiner gives the patient a blank piece of paper and asks him/her to draw the symbol below. All 10 angles must be present and two must intersect.) 
30		TOTAL

Interpretation of the MMSE:

Method	Score	Interpretation
Single Cutoff	<24	Abnormal
Range	<21	Increased odds of dementia
	>25	Decreased odds of dementia
Education	21	Abnormal for 8th grade education
	<23	Abnormal for high school education
	<24	Abnormal for college education
Severity	24-30	No cognitive impairment
	18-23	Mild cognitive impairment
	0-17	Severe cognitive impairment

Interpretation of MMSE Scores:

Score	Degree of Impairment	Formal Psychometric Assessment	Day-to-Day Functioning
25-30	Questionably significant	If clinical signs of cognitive impairment are present, formal assessment of cognition may be valuable.	May have clinically significant but mild deficits. Likely to affect only most demanding activities of daily living.
20-25 **See investigations Needed below**	Mild	Formal assessment may be helpful to better determine pattern and extent of deficits.	Significant effect. May require some supervision, support and assistance.
10-20	Moderate	Formal assessment may be helpful if there are specific clinical indications.	Clear impairment. May require 24-hour supervision.
0-10	Severe	Patient not likely to be testable.	Marked impairment. Likely to require 24-hour supervision and assistance with ADL.

Investigations- MSU, FBC, Vit B12, Renal profile, Thyroid function, Vit D, Iron, Folate, VDRL, HBA1C, Bone profile

Source:

- Folstein MF, Folstein SE, McHugh PR: "Mini-mental state: A practical method for grading the cognitive state of patients for the clinician." *J Psychiatr Res* 1975;12:189-198.

Appendix VIII- ALFI MMSE

Maximum Score	Patient's Score	Questions
5		"What is the year? Season? Date? Day? Month?"
4		"Where are we now? State? County? Town/city? Hospital?
3		The examiner names three unrelated objects clearly and slowly, then the instructor asks the patient to name all three of them. The patient's response is used for scoring. The examiner repeats them until patient learns all of them, if possible.
5		"I would like you to count backward from 100 by sevens." (93, 86, 79, 72, 65, …) Alternative: "Spell WORLD backwards." (D-L-R-O-W)
3		"Earlier I told you the names of three things. Can you tell me what those were?"
1		Tell me, what is the thing called that you are speaking into as you talk to me?
1		"Repeat the phrase: 'No ifs, ands, or buts.'"
22		TOTAL

Appendix IX- MRS

Modified Rankin Scale

Patient Number: _____

RANKIN Rater Name: _____

SCALE (MRS) Date: _____

Score Description

0	No symptoms at all
1	No significant disability despite symptoms; able to carry out all usual duties and activities
2	Slight disability; unable to carry out all previous activities, but able to look after own affairs without assistance
3	Moderate disability; requiring some help, but able to walk without assistance
4	Moderately severe disability; unable to walk without assistance and unable to attend to own bodily needs without assistance
5	Severe disability; bedridden, incontinent and requiring constant nursing care and attention
6	Dead

TOTAL (0–6): _____

Appendix X- SSQOL

Stroke Specific Quality of Life Scale (SS-QOL)

Patient Number:_____ Date:_____

Scoring: each item shall be scored with the following key	
Total help - Couldn't do it at all - Strongly agree	1
A lot of help - A lot of trouble - Moderately agree	2
Some help - Some trouble - Neither agree nor disagree	3
A little help - A little trouble - Moderately disagree	4
No help needed - No trouble at all - Strongly disagree	5

Energy

1. I felt tired most of the time. ___
2. I had to stop and rest during the day. ___
3. I was too tired to do what I wanted to do. ___

Family Roles

1. I didn't join in activities just for fun with my family. ___
2. I felt I was a burden to my family. ___
3. My physical condition interfered with my personal life. ___

Language

1. Did you have trouble speaking? For example, get stuck, stutter, stammer, or slur your words? ___
2. Did you have trouble speaking clearly enough to use the telephone? ___
3. Did other people have trouble in understanding what you said? ___
4. Did you have trouble finding the word you wanted to say? ___
5. Did you have to repeat yourself so others could understand you? ___

Mobility

1. Did you have trouble walking? (If patient can't walk, go to question 4 and score questions 2-3 as 1.) ___
2. Did you lose your balance when bending over to or reaching for something? ___
3. Did you have trouble climbing stairs? ___
4. Did you have to stop and rest more than you would like when walking or using a wheelchair? ___
5. Did you have trouble with standing? ___
6. Did you have trouble getting out of a chair ___

Mood

1. I was discouraged about my future. ____
2. I wasn't interested in other people or activities. ____
3. I felt withdrawn from other people. ____
4. I had little confidence in myself. ____
5. I was not interested in food. ____

Personality

1. I was irritable. ____
2. I was inpatient with others. ____
3. My personality has changed. ____

Self Care

1. Did you need help preparing food? ____
2. Did you need help eating? For example, cutting food or preparing food? ____
3. Did you need help getting dressed? For example, putting on socks or shoes, buttoning buttons, or zipping? ____
4. Did you need help taking a bath or a shower? ____
5. Did you need help to use the toilet? ____

Social Roles

1. I didn't go out as often as I would like. ____
2. I did my hobbies and recreation for shorter periods of time than I would like. ____
3. I didn't see as many of my friends as I would like. ____
4. I had sex less often than I would like. ____
5. My physical condition interfered with my social life. ____

Thinking

1. It was hard for me to concentrate. ____
2. I had trouble remembering things. ____
3. I had to write things down to remember them. ____

Upper Extremity Function

1. Did you have trouble writing or typing?	___
2. Did you have trouble putting on socks?	___
3. Did you have trouble buttoning buttons?	___
4. Did you have trouble zipping a zipper?	___
5. Did you have trouble opening a jar?	___

Vision

1. Did you have trouble seeing the television well enough to enjoy a show?	___
2. Did you have trouble reaching things because of poor eyesight?	___
3. Did you have trouble seeing things off to one side?	___

Work/Productivity

1. Did you have trouble doing daily work around the house?	___
2. Did you have trouble finishing jobs that you started?	___
3. Did you have trouble doing the work you used to do?	___
TOTAL SCORE	___

Reference

Williams LS, Weinberger M, Harris LE, Clark DO, Biller J. Development of a stroke-specific quality of life scale. Stroke 1999 Jul;30(7):1362-9.

Appendix XI- The Questionnaire

Section A: Demographics

1) Patient number: _____
2) Age: _____
3) Gender: Male / Female/ Other
4) Relationship status: Married, Single, Divorced, Widowed, Live-in partner, other
5) Level of education: Before graduating primary school, graduated from primary school, graduated from high school, graduated from university
6) Date of stroke: _____
7) Time period since stroke: _____
8) Side of hemiplegia: Left or right
9) Hand dominance: Left or right
10) Comorbidities/ Medical conditions and if the patient is on medication for them (controlled):
    a) HIV: Yes/No _____Controlled: Yes/No
    b) Hypertension: Yes/ No _____Controlled: Yes/No
    c) Diabetes: Yes/ No _____Controlled: Yes/No
    d) Epilepsy: Yes/ No _____Controlled: Yes/No
    e) Cardiovascular problems: Yes/ No_____ Controlled: Yes/No
    f) Arthritis: Yes/ No _____Controlled: Yes/No
    g) Respiratory conditions: Yes/ No _____Controlled: Yes/No
    h) Depression: Yes/ No _____Controlled: Yes/No
    i) Other (e.g. urinary tract infections/ vaginal infections).
    Please specify:
    _____Controlled: Yes/No

11) Medication patient takes:

Medication	Dosage	Frequency

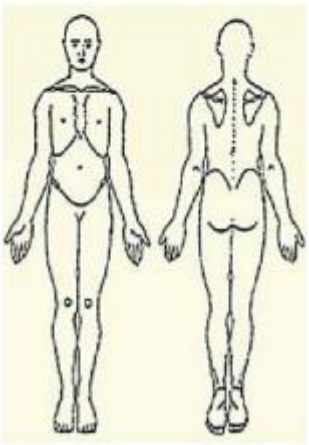
Section B:

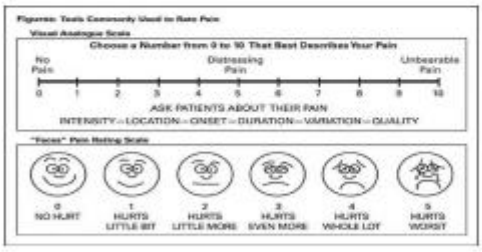
1a) Have you had sexual intercourse since your stroke? _____Yes/ No

1b) If yes, how long after the stroke did you start having sexual intercourse?_____

2a) Have you developed pain since your stroke? _____Yes/ No

2b) If yes, indicate your level of pain on the VAS below and highlight on the body chart below where your pain is:





2c) Does this pain affect your current sex life? _____ Yes/ No

3) Are you afraid that you will experience increased pain during sex? _____Yes/No

4) Are you anxious or scared that you will have another stroke during sexual activity? __Yes/No

5) Are you unable to find a comfortable position for sex after your stroke? _____Yes/No

6) Are you afraid of having sex because of incontinence (the risk of poor bladder and/or bowel control during sex)? _____Yes/No

7) Are you able to discuss sexuality with your partner? _____Yes/No

8) Do you think that your partner is now unwilling to have sex because of?

a) Fear of causing another stroke: Yes/No

b) Fear of causing you pain: Yes/No

c) Finds you unattractive: Yes/No

d) Difficulty in balancing the role between partner and carer: Yes/No

e) Other, please specify_____

9) Is your sex life currently affected by?

a) Poor self-esteem? Yes/No

b) Depression/ Low mood? Yes/ No

c) Change of desire? Yes/No. If yes:

c.1) Lack of desire? Yes/No

c.2) Increased desire? Yes/No

d) Lack of motivation? Yes/No

e) Tiredness/ fatigue? Yes/No

f) Feeling physically unwell? Yes/No

g) Other, please specify: _____

10a) Are you aware that there are health care professionals who can help with sexual dysfunction? _____Yes/No

10b) If yes, have you asked for help from a health care professional? _____Yes/No

10c) If No why? _____

Appendix XII- CSFQ-14

Changes in Sexual Functioning Questionnaire (CSFQ-F-C)

Patient Number: _____ Date: _____

NOTE: This is a questionnaire about sexual activity and sexual function. By sexual activity, we mean sexual intercourse, masturbation, sexual fantasies and other activity.

1. Compared with the most enjoyable it has ever been, how enjoyable or pleasurable is your sexual life right now?
☐ 1-No enjoyment or pleasure
☐ 2-Little enjoyment or pleasure
☐ 3-Some enjoyment or pleasure
☐ 4-Much enjoyment or pleasure
☐ 5-Great enjoyment or pleasure

2. How frequently do you engage in sexual activity (sexual intercourse, masturbation, etc.) now?
☐ 1-Never
☐ 2-Rarely (once a month or less)
☐ 3-Sometimes (more than once a month, up to twice a week)
☐ 4-Often (more than twice a week)
☐ 5-Every day

3. How often do you desire to engage in sexual activity?
☐ 1-Never
☐ 2-Rarely (once a month or less)
☐ 3-Sometimes (more than once a month, up to twice a week)
☐ 4-Often (more than twice a week)
☐ 5-Every day

4. How frequently do you engage in sexual thoughts (thinking about sex, sexual fantasies) now?
☐ 1-Never
☐ 2-Rarely (once a month or less)
☐ 3-Sometimes (more than once a month, up to twice a week)
☐ 4-Often (more than twice a week)
☐ 5-Every day

5. Do you enjoy books, movies, music or artwork with sexual content?
☐ 1-Never
☐ 2-Rarely (once a month or less)
☐ 3-Sometimes (more than once a month, up to twice a week)
☐ 4-Often (more than twice a week)
☐ 5-Every day

6. How much pleasure or enjoyment do you get from thinking about and fantasizing about sex?
☐ 1-No enjoyment or pleasure
☐ 2-Little enjoyment or pleasure
☐ 3-Some enjoyment or pleasure
☐ 4-Much enjoyment or pleasure
☐ 5-Great enjoyment or pleasure

7. How often do you become sexually aroused?
☐ 1-Never
☐ 2-Rarely (once a month or less)
☐ 3-Sometimes (more than once a month, up to twice a week)
☐ 4-Often (more than twice a week)
☐ 5-Every day

8. Are you easily aroused?
☐ 1-Never
☐ 2-Rarely (much less than half the time)
☐ 3-Sometimes (about half the time)
☐ 4-Often (much more than half the time)
☐ 5-Always

9. Do you have adequate vaginal lubrication during sexual activity?
☐ 1-Never
☐ 2-Rarely (much less than half the time)
☐ 3-Sometimes (about half the time)
☐ 4-Often (much more than half the time)
☐ 5-Always

10. How often do you become aroused and then lose interest?
☐ 5-Never
☐ 4-Rarely (much less than half the time)
☐ 3-Sometimes (about half the time)
☐ 2-Often (much more than half the time)
☐ 1-Always

11. How often do you experience an orgasm?
☐ 1-Never
☐ 2-Rarely (much less than half the time)
☐ 3-Sometimes (about half the time)
☐ 4-Often (much more than half the time)
☐ 5-Always

12. Are you able to have an orgasm when you want to?
☐ 1-Never
☐ 2-Rarely (much less than half the time)
☐ 3-Sometimes (about half the time)
☐ 4-Often (much more than half the time)
☐ 5-Always

13. How much pleasure or enjoyment do you get from your orgasms?
☐ 1-No enjoyment or pleasure
☐ 2-Little enjoyment or pleasure
☐ 3-Some enjoyment or pleasure
☐ 4-Much enjoyment or pleasure
☐ 5-Great enjoyment or pleasure

14. How often do you have painful orgasm?
☐ 5-Never
☐ 4-Rarely (once a month or less)
☐ 3-Sometimes (more than once a month, up to twice a week)
☐ 2-Often (more than twice a week)
☐ 1-Every day

____ = Pleasure (Item 1)
____ = Desire/Frequency (Item 2 + Item 3)
____ = Desire/Interest (Item 4 + Item 5 + Item 6)
____ = Arousal/Excitement (Item 7 + Item 8 + Item 9)
____ = Orgasm/Completion (Item 11 + Item 12 + Item 13)
____ = Total CSFQ Score (Items 1 to 14)

Changes in Sexual Functioning Questionnaire (CSFQ-M-C)

Patient Number: _____ Date: _____

NOTE: This is a questionnaire about sexual activity and sexual function. By sexual activity, we mean sexual intercourse, masturbation, sexual fantasies and other activity.

1. Compared with the most enjoyable it has ever been, how enjoyable or pleasurable is your sexual life right now?
☐ 1-No enjoyment or pleasure
☐ 2-Little enjoyment or pleasure
☐ 3-Some enjoyment or pleasure
☐ 4-Much enjoyment or pleasure
☐ 5-Great enjoyment or pleasure

2. How frequently do you engage in sexual activity (sexual intercourse, masturbation, etc.) now?
☐ 1-Never
☐ 2-Rarely (once a month or less)
☐ 3-Sometimes (more than once a month, up to twice a week)
☐ 4-Often (more than twice a week)
☐ 5-Every day

3. How often do you desire to engage in sexual activity?
☐ 1-Never
☐ 2-Rarely (once a month or less)
☐ 3-Sometimes (more than once a month, up to twice a week)
☐ 4-Often (more than twice a week)
☐ 5-Every day

4. How frequently do you engage in sexual thoughts (thinking about sex, sexual fantasies) now?
☐ 1-Never
☐ 2-Rarely (once a month or less)
☐ 3-Sometimes (more than once a month, up to twice a week)
☐ 4-Often (more than twice a week)
☐ 5-Every day

5. Do you enjoy books, movies, music or artwork with sexual content?
☐ 1-Never
☐ 2-Rarely (once a month or less)
☐ 3-Sometimes (more than once a month, up to twice a week)
☐ 4-Often (more than twice a week)
☐ 5-Every day

6. How much pleasure or enjoyment do you get from thinking about and fantasizing about sex?
☐ 1-No enjoyment or pleasure
☐ 2-Little enjoyment or pleasure
☐ 3-Some enjoyment or pleasure
☐ 4-Much enjoyment or pleasure
☐ 5-Great enjoyment or pleasure

7. How often do you have an erection related or unrelated to sexual activity?
☐ 1-Never
☐ 2-Rarely (once a month or less)
☐ 3-Sometimes (more than once a month, up to twice a week)
☐ 4-Often (more than twice a week)
☐ 5-Every day

8. Do you get an erection easily?
☐ 1-Never
☐ 2-Rarely (much less than half the time)
☐ 3-Sometimes (about half the time)
☐ 4-Often (much more than half the time)
☐ 5-Always

9. Are you able to maintain an erection?
☐ 1-Never
☐ 2-Rarely (much less than half the time)
☐ 3-Sometimes (about half the time)
☐ 4-Often (much more than half the time)
☐ 5-Always

10. How often do you experience painful, prolonged erections?
☐ 5-Never
☐ 4-Rarely (once a month or less)
☐ 3-Sometimes (more than once a month, up to twice a week)
☐ 2-Often (more than twice a week)
☐ 1-Every day

11. How often do you have an ejaculation?
☐ 1-Never
☐ 2-Rarely (once a month or less)
☐ 3-Sometimes (more than once a month, up to twice a week)
☐ 4-Often (more than twice a week)
☐ 5-Every day

12. Are you able to ejaculate when you want to?
☐ 1-Never
☐ 2-Rarely (much less than half the time)
☐ 3-Sometimes (about half the time)
☐ 4-Often (much more than half the time)
☐ 5-Always

13. How much pleasure or enjoyment do you get from your orgasms?
☐ 1-No enjoyment or pleasure
☐ 2-Little enjoyment or pleasure
☐ 3-Some enjoyment or pleasure
☐ 4-Much enjoyment or pleasure
☐ 5-Great enjoyment or pleasure

14. How often do you have painful orgasm?
☐ 5-Never
☐ 4-Rarely (once a month or less)
☐ 3-Sometimes (more than once a month, up to twice a week)
☐ 2-Often (more than twice a week)
☐ 1-Every day

____ = Pleasure (Item 1)
____ = Desire/Frequency (Item 2 + Item 3)
____ = Desire/Interest (Item 4 + Item 5 + Item 6)
____ = Arousal/Erection (Item 7 + Item 8 + Item 9)
____ = Orgasm/Ejaculation (Item 11 + Item 12 + Item 13)
____ = **Total CSFQ Score** (Items 1 to 14)

Scoring for CSFQ-F-C: (Female Clinical Version)

If the female patient obtains a score at or below the following cut-off points* on any of these scales, it is indicative of sexual dysfunction:

Total CSFQ score:	41.0 (range: 14 to 70)
Sexual Desire/Frequency score:	6.0 (range: 2 to 10)
Sexual Desire/Interest:	9.0 (range: 3 to 15)
Sexual Pleasure:	4.0 (range: 1 to 5)
Sexual Arousal/Excitement:	12.0 (range: 3 to 15)
Sexual Orgasm/Completion:	11.0 (range: 3 to 15)

Scoring for CSFQ-M-C: (Male Clinical Version)

If the male patient obtains a score at or below the following cut-off points* on any of these scales, it is indicative of sexual dysfunction:

Total CSFQ score:	47.0 (range: 14 to 70)
Sexual Desire/Frequency score:	8.0 (range: 2 to 10)
Sexual Desire/Interest:	11.0 (range: 3 to 15)
Sexual Pleasure:	4.0 (range: 1 to 5)
Sexual Arousal/Excitement:	13.0 (range: 3 to 15)
Sexual Orgasm/Completion:	13.0 (range: 3 to 15)