Patients' perceptions of barriers and facilitators influencing ability to return to work post-stroke

By:

Saleema Kriel

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Supervisor: Mrs. Gakeemah Inglis-Jassiem, MSc Physiotherapy, Physiotherapy Department, University of Stellenbosch

Co-supervisor: Dr Linzette Morris, PhD, Physiotherapy Department, University of Stellenbosch

Institution affiliation: Stellenbosch University

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DECLARATION

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Signature: Saleema Kriel **Date: April 2019**

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ABSTRACT

Introduction

Stroke is a neurological condition that impacts on the functional ability of the individual and affects participation in everyday activities, including returning to work. The various factors resulting from a stroke impacting the individual's ability to return to work is not fully clarified in the South African context. While there is literature in SA regarding physical disabilities which could affect the stroke patient's ability to return to work the patient's perceptions of these factors needs to be better understood. This study therefore addresses the patients' perceptions of barriers and potential facilitators affecting return to work post-stroke in the Western Cape.

Objective

The objective of this study was to better understand the patient's perception of barriers and facilitators affecting return to work post-stroke.

Methods

A qualitative retrospective study was conducted. Participants were recruited from the Delft, Elsies River and Bishop Lavis communities in the Western Cape Province, South Africa. The study included adult males and females from the age of 18, who had a stroke within the four years prior to data collection for this study, affecting their ability to engage in gainful employment. Various data collection tools were used during the course of this study, inclusive of the Modified Rankin scale (mRS), a self-developed sociodemographic questionnaire and Stroke Specific Quality of Life Scale (SS QoL Scale). Individual interviews were conducted with participants in the mentioned communities. Data from the sociodemographic form, mRS and SS-QoL were analysed using frequency tables and reported in tables. Atlas.ti. (Version 6.2.15; 2011) software was used to code and analyse the qualitative data from the interview transcriptions.

Results

A total of six participants participated in the interviews. An equal amount of males versus females were included. The age range of the participants was between 51 to 61 years, and one participant was 71 years old. All participants were involved in some form of employment before the onset of the stroke. Examples of this includes a builder/brick layer (n=2), domestic worker (n=1), textile machinist (n=1), repair/handy man (n=1) and managing a small goods

shop from their home (n=1). All of these occupations were physically demanding. None of the participants had returned to work at the time of the interviews. The barriers and potential facilitators identified were categorised into environmental and physical factors. Environmental barriers were identified to be due to weather, uneven terrain and transport difficulties. Physical barriers were identified to be due to functional difficulties, psychosocial factors and residual symptoms post-stroke. Potential environmental facilitators were identified to be transport and work ergonomics. Potential physical facilitators were related to greater functional abilities, positive psycho-social factors and good healthcare and/or rehabilitation.

Conclusion

Based on the results of this study, it can be concluded that return to work is influenced by several factors. These factors include the functional ability of the individual which is well supported in the literature, their environment, socio-economic status and their psychological well-being. It was however surprising to unravel the extent that the stroke participants' psychosocial well-being impacted on their perception of barriers and potential facilitators to return to work. Psychosocial factors were found to weigh heavily on an individual's return to work ability post-stroke. Based on the findings of this study, various recommendations can be made for rehabilitation, and for future studies.

OPSOMMING

Inleiding

'n Beroerte is 'n neurologiese toestand wat impak maak op 'n individu se funksionele vermoë en wat deelname aan alledaagse aktiwiteite, insluitent terugkeer werk toe, beïnvloed. Die verskeie faktore wat voortspruit uit `n beroerte en wat 'n individu se vermoë om terug te keer werk toe beïnvloed, word nie ten volle in die Suid-Afrikaanse konteks uitgeklaar nie. Alhoewel daar wel Suid-Afrikaanse literatuur is aangaande die fisiese gestremdhede wat die beroerte pasiënt se vermoë om terug te keer werk toe affekteer, moet die pasiënt se persepsie van hierdie faktore beter begryp word. Hierdie studie fokus dus op die pasiënt in die Wes Kaap se persepsie van hindernisse en fasiliteerders wat terugkeer werk toe na beroerte beïnvloed.

Oogmerk

Die doel van hierdie studie was om die pasiënt se persepsie van die hindernisse en fasiliteerders wat terugkeer werk toe na 'n beroerte beïnvloed, beter te verstaan.

Metodologie

'n Kwalitatiewe retrospektiewe studie was uitgevoer. Deelnemers is gewerf uit die Delft, Elsies Rivier en Bishop Lavis gemeenskappe in die Wes Kaap Provinsie, Suid-Afrika. Die studie het volwasse mans en vrouens oor die ouderdom van 18 jaar, wie in die afgelope vier jaar 'n beroerte gehad het, ingesluit. Die beroerte moes 'n invloed gehad het op hul vermoë om in winsgewende indiensneming betrokke te wees. Verskeie data-insamelingsinstrumente is in die loop van die studie gebruik, insluitend die Modified Rankin-skaal (mRS), 'n self-ontwikkelde sosiodemografiese vraelys en die Stroke Specific Quality of Life Scale (SS QoL Scale). Individuele onderhoude is met deelnemers in die bogenoemde gemeenskappe gevoer. Data vanuit die sosiodemografiese vraelys, mRS en SS-Qol is geanaliseer deur die gebruik van frekwensie tabelle en is met behulp van tabelle gerapporteer. Atlas.ti. (Weergawe 6.2.15; 2011) sagteware is gebruik om die kwalitatiewe data van die onderhoudstranskripsies te kodeer en te analiseer.

Resultate

In totaal het ses individue aan die onderhoude deelgeneem. ‘n Gelyke aantal mans en vrouens was ingesluit. Die ouderdomme van die deelnemers het tussen 51 en 61 jaar gewissel met een deelnemer wat 71 jaar oud was. Alle deelneemers get voor die beroerte gewerk. Voorbeelde hiervan sluit in 'n bouer / baksteenlaag (n = 2), huishulp (n = 1), tekstielwerktuigkundige (n = 1), herstel / handige man (n = 1) en bestuur 'n klein goederewinkel uit hul huis n = 1). Al hierdie beroepe was fisiek veeleisend. Nie een van die deelnemers het ten tyde van hul onderhoud al teruggekeer werk toe nie. Die hindernisse en potensiele fasiliteerders wat geïdentifiseer was, was gekategoriseer in omgewings faktore en fisiese faktore. Omgewings hindernisse wat geïdentifiseer was, was as gevolg van die weer, ongelyke terrein en vervoer probleme. Fisiese hindernisse wat geïdentifiseer was, was as gevolg van funksionele probleme, residuele gestremdhede en simptome na die beroerte, en sielkundige en sosiale faktore. Potensiale omgewings fasiliteerders wat geïdentifiseer was, was vervoer and werks ergonomika. Potensiale fisiese fasiliteerders was verwant aan beter funksionele vermoëns, positiewe psigo-sosiale faktore en goeie gesondheidsorg en/of rehabilitasie.

Gevolgtrekking

Gebaseer op die resultate van hierdie studie kan daar tot die gevolgtrekking gekom word dat terugkeer werk toe beïnvloed word deur verskeie faktore. Hierdie faktore sluit die funksionele vermoë van die individu, wat goed ondersteun word in die literatuur, in sowel as hul omgewing, sosio-ekonomise status en hul sielkundige welsyn. Die omvang van die impak wat deelnemers se psigososiale welsyn het op hul persepsie van die hindernisse en fasiliteerders om terug te keer werk toe, was egter verbasend. Daar is bevind dat psigososiale faktore swaar weeg op ‘n individu se vermoë om terug te keer werk toe na ‘n beroerte. Op grond van hierdie bevindinge van die studie kan verskeie aanbevelings gemaak word vir rehabilitasie en vir toekomstige studies.

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ABBREVIATIONS (order of appearance)

PWS	People/patient with stroke
SA	South Africa
ADL	Activities of daily living
RTW	Return to work
CNS	Central Nervous System
ICH	Intracranial Heamorrhage
SAH	Subarachnoid Heamorrhage
AHSA	American Heart and Stroke Association
DALY	Disability Adjusted Life years
NCD	Non communicable diseases
HIV	Human Immuno-deficiency virus
TB	Tuberculosis
CHC	Community Health centre
BL	Bishop Lavis
BLRC	Bishop Lavis Rehabilitation Centre
mRS	Modified Rankin scale
SS QoL	Stroke specific quality of llife
HRQoL	Health-related quality of life
CD	Compact Disc
DoH	Department of Health
HPT	Hypertension

Chapter 1

INTRODUCTION

According to the Heart and Stroke Foundation of South Africa (SA), a stroke occurs when the blood supply to the brain is interrupted. This could either be due to a blockage in the blood vessels, or due to a burst blood vessel (Heart and Stroke foundation of SA 2016). Stroke is one of the leading causes of disability and top three causes of death in SA (Statistics South Africa: Profiles of persons with disabilities 2014). According to the Heart and Stroke foundation of SA, ten people suffer a stroke in SA every hour. Given the prevalence of stroke, the economic burden of it is therefore high, especially in developing countries (Bonner et al 2015; Birabi et al 2012). This places a financial strain on the patient as well as on the family, since the occurrence of the stoke may have resulted in a loss of income. Stroke does however not only result in financial burden, but also places emotional and physical burden on those caring for the person with the stroke (Arwet et al 2017; Kusambiza-Kiingi et al 2017). Individuals have an 18% - 40% chance of reoccurrence of a stroke within the first five years of having their first stroke (Buenaflor et al 2017; Hardie et al 2005; Burn et al 1994), which signifies a potential increased future burden as well.

Stroke does not only result in physical impairments, but also affects the person's ability to participate in activities of daily living (ADL), to reintegrate in their community and their ability to return to gainful employment (Ntsiea et al 2015). After a stroke, individuals struggle to perform meaningful activities and participate in life roles within their context (Nasr et al 2016). Improvement in functional ability and returning to work has also been found to be an important component for the individuals' emotional well-being (Fride et al 2015; Hamzat 2014). However, the interaction between a person, their environment, and their resulting experience of disability, are still poorly understood (Pettersson et al 2012).

Return to work is noted to be an important aspect of an individual's wellbeing (Vestling et al 2003). Working gives an individual a sense of purpose and is viewed as a way to measure recovery post any disabling incident. The national disability prevalence rate in SA is 7,5% (Statistics South Africa: Profiles persons with disabilities 2014). Individuals with disabilities in SA often experience difficulty in accessing education and employment opportunities (Statistics South Africa: Profiles persons with disabilities 2014). This is especially concerning in the lower socio-economic areas of the country.

According to the literature found, the main barriers to prevent an individual from returning to work include not being able to mobilise independently; not being independent in their ADL;

the presence of ongoing fatigue and persistent pain; a poor social support system; environmental factors, specifically related to access to transport; their level of education and previous work experience. Other limiting factors identified were psychological factors like anxiety and depression, fear and their perception of the disability after stroke. In contrast, facilitators of returning to work post stroke included being able to mobilise independently; being able to perform ADL more independently; a positive perception of disability; and the support they received from their family, friends, community and potential employers (Coole et al 2013; Joseph et al 2013; Culler et al 2011; Lindstrom et al 2009). The attitude of a person with stroke and the ability of the individual to accept their disability are considered key facilitatory factors identified for returning to work (Culler et al 2011).

While there are many studies highlighting the functional limitations experienced by stroke survivors regarding return to work, there are only a few studies published focusing on the patient's own perception of the barriers and facilitators that accompany returning to work post-stroke. While various studies have been done in SA looking at return to work and/or assessing factors influencing return to work, an in-depth study looking at the patients' perceptions of barriers and facilitators to returning to work in the Western Cape, South Africa, has not yet been reported. The patients' perception of these factors is important when treating an individual with stroke and needs to be addressed during rehabilitation (Vestling et al 2013). Studies by both Medin et al (2006) and Ntsea et al (2015) indicated that return to work is influenced by other factors, not only physical recovery. It highlights the importance of the patients' self-efficacy and the support of others, again confirming the importance of understanding other more person-related factors affecting return to work. While there is literature in SA regarding physical disabilities which could affect the stroke patient's ability to return to work (Joseph et al 2013), one needs to also understand the factors from the patients' perspective (Culler et al 2011; Alaszewski et al 2007). Most studies done in SA posing similar questions have been conducted in the Gauteng province. The current study is therefore one of the first studies addressing the patients' perceptions of barriers and potential facilitators affecting return to work post stroke in the Western Cape, where contextual factors of a personal or environmental nature, may pose unique challenges.

Thesis overview

This thesis consists of six chapters. Chapter one introduces the main concepts for the current study. Chapter two reports on the findings of the literature review summarising the available literature found detailing the factors, both barriers and facilitators, affecting return

to work post stroke internationally and locally in SA. Chapter three describes the aims and objectives of the study, as well as methodology used to carry out the study. Chapter four, results, elaborates on the socio-demographic profile of the recruited participants along with the perceptions of these stroke participants expressed during the semi-structured interviews, supported by direct quotes. Chapter five elaborates and discusses these findings in more detail comparing it to the available literature. Chapter six, the final chapter includes the main conclusions, the limitations found during the study, as well as recommendations for future research and other stakeholders.

Chapter 2

LITERATURE REVIEW

2.1 Introduction

The following chapter presents an overview of the current literature found in relation to the reasons impacting a patient's ability to return to work post stroke. The purpose of this review was to explore the current available evidence associated with various key factors which influenced the ability of an individual post stroke when either returning or attempting to return to work.

The electronic databases searched during this review were: CINAHL, Cochrane, EBSCOHost, OTseeker, PEDro, PUBMed, ScienceDirect and Scopus. The following search terms and combinations of these terms were used during the search for relevant literature: *stroke, cerebrovascular accident, return to work, return to work after stroke, employment, vocation, job,* and *South Africa*. Terms were specifically focused on synonyms to work, for example vocation, occupation, employment, work and job. Cerebrovascular accident was also used in place of stroke.

2.2 Epidemiology of stroke

Stroke is classically characterized as a neurological deficit attributed to an acute focal injury of the central nervous system (CNS) by a vascular cause, including cerebral infarction, intracerebral haemorrhage (ICH), and subarachnoid haemorrhage (SAH) (American Heart and Stroke Association 2015). According to the American Heart and Stroke Association (AHSA), stroke affected 33 million people worldwide in 2010. Stroke is also the third cause of disability adjusted life years (DALY) in the world (World Health Organization 2011) and similarly to the United States, stroke is reported as the fifth leading cause of death in South Africa (Statistics South Africa 2004). Stroke results in more deaths in females, than in males (Bradshaw 2003). At least one in four people who suffer a stroke each year will have another stroke in their lifetime. Individuals have an 18% - 40% chance of reoccurrence of a stroke within the first five years of having the first stroke (Beunaflor et al 2017; Hardie et al 2005, Burn et al 1994). Although the true incidence and prevalence statistic for South Africa (SA) is yet to be reported in the literature, anecdotally the Heart and Stroke foundation of SA confirms that ten people suffer a stroke in SA almost every hour, which is an alarming rate.

Stroke is one of the most common non-communicable diseases (NCD) in SA. In 2010, the amount of deaths due to NCD was similar to the number of deaths due to HIV and TB

combined. This is disconcerting and the mortality rate ascribed to NCD is expected to continue to rise (Hoffman 2014). According to an editorial in the South African Medical Journal (2016), the World Health Organisation (WHO) has projected that in 2030, NCD will be the leading cause of death in Africa (Persistent burden from non-communicable diseases in South Africa needs strong action: South African Medical Journal 2016). The increase in NCD may be attributed to the following reasons: changing lifestyles and diet, inactivity, obesity and increased urbanisation of rural or indigenous populations (South African Medical Journal 2016; Heart and Stroke Foundation South Africa 2016). Other risk factors for stroke include hypertension, diabetes, obesity, history of coronary artery disease or myocardial infarction, and atrial fibrillation (Ntsekhe et al 2013; Norris et al 2012).

The ongoing burden of communicable diseases such as HIV has also contributed to a rise in the incidence of stroke in a younger population (Maredza et al 2015; Tollman et al 2008). In areas where the prevalence of HIV is high, there is a higher risk of stroke due to the risk factor of HIV (Heikinheimo et al 2012). Of concern is the projected impact that an increasing burden of stroke among young Africans can have on the country's middle-aged and elderly populations. With an increase in stroke-related HIV in the younger population, it will most likely increase the burden on the elderly who then become primary caregivers and providers for their children's offspring and family responsibilities (Connor et al 2005).

2.3 Impact of stroke on function

Stroke can result in both physical and cognitive impairments with varying severities. Given its impact on function, the occurrence of a stroke will affect the individual's quality of life and participation in everyday activities (Ntsiea et al 2015). People with stroke have reported being unable to participate in previously meaningful activities such as returning to work, social activities and domestic duties (Anderson et al 2011). The consequences of a stroke impact on different areas of a person's health and function. It does not only impact on physical abilities, but also results in the loss of independence and restrictions in participation, which negatively affects the emotional wellbeing of the person as well as their family (Rhoda 2012). Other factors that would impact on their everyday functioning are symptoms like fatigue, pain, swelling, stiffness and incontinence (Strickland 2014; Andersen et al 2012; Baumann et al 2012; Mukherjee et al 2006).

2.4 Burden of stroke on patients and caregivers

Stroke is a condition with high associated cost given the care and treatment required for recovery and reintegration (Maredza et al 2015). The outcome of a study conducted in Nigeria by Birabi et al (2012) showed that stroke results in a huge direct cost burden which is

unaffordable to the average stroke survivor increasing the need to return to work. Being financially independent was thought to assist with contributing to the financial responsibilities in the household for both the stroke survivor and their caregivers. Stroke survivors expressed the importance of working to earn money to live and to provide for their dependents (Harkte et al 2015; Harris 2014). Similarly, in India, economic burden of stroke is high as they do not receive financial compensation from governmental structures when disabled and due to the poor availability of healthcare services for chronic illness (Bonner et al 2015).

Stroke however does not only result in financial burden, but also emotional and physical burden on those caring for the person with the stroke. Stroke survivors who return to work, scored lower for depression and anxiety, were better able to perform their activities of daily living (ADL) and had a better quality of life, thereby reducing the requirements posed on their caregiver (Arwet et al 2017). Caregivers had difficulty with the following; physical strain from taking care of the stroke survivor, changes to their personal life goals and plans as well as witnessing the stroke survivors' behavioural changes (Kusambiza-Kiingi et al 2017).

2.5 Return to work post stroke

A major factor identified for subjective well-being and life satisfaction among people with stroke was returning to work (Vestling et al 2003). People with stroke felt that returning to work demonstrated recovery post stroke, but also noted that the value and meaning of returning to work was based on their past experiences (Alaszewski et al 2007). The participants in the study done by Alaszewski et al (2007) valued work and felt that working had benefits in terms of financial resources, alleviating boredom, and providing social status, which in turn motivated them to return to work. For others, however, work-related stress was a causative factor for their stroke. So while return to work was a participation goal, they were hesitant to return to their former stressful work environment (Alaszewski et al 2007). For some of these participants, return to work also acted as an indicator to pre-stroke normality and rapid return to work was equated to a quick recovery from the incident. They perceived returning to pre-morbid employment would also limit the significant impact of the stroke on their personal life.

The term gainful employment refers to being able to gain something by being employed. This may not necessarily be in monetary value, but can also be a sense of purpose, independence and/or emotional fulfillment. Vestling et al (2003), indicates that returning to work after a stroke is a major factor for subjective well-being and life satisfaction after stroke. In order to return to work, an individual must be independent in basic self-care function (Hackett et al 2012; Saeki et al 2010) and display basic cognitive abilities (Ntsiea et al 2015;

Coole 2013). Improvement in a person with stroke's functional ability and returning to work are considered important facilitatory factors that improve participation and reintegration in their community again (Fride et al 2015; Hamzat et al 2014). Return to work in this study does therefore not only mean returning to monetary gain, but to any form of work.

Return to work rates for people with stroke varied in all the sourced literature. There is currently no specific percentage one can apply to a person with strokes' probability of returning to work, irrespective of the country (Arwert et al 2017; Harkte et al 2015; Harris 2014; Coole 2013). The return to work rate post stroke varied in different studies. According to review done by Treger et al (2007) of 16 different studies, the return to work rate varied between 19% and 79%. Return to work was supported by a high level of education, having a professional job and being younger than 65 years of age (Bonner et al 2015; Treger et al 2007). Currently there is no national or census data available on the re-employment of people with stroke in SA as a whole, only in selected provinces of the country. A study done in Gauteng, reports a return to work rate of 34% (Duff et al 2014). The current unemployment in SA may however impact on return to work rates (Statistics South Africa 2011). While a definite return to work rate after stroke could not be confirmed, research did indicate a significant difference in recovery between a developing country like SA and a developed county like Germany post rehabilitation (Rhoda 2014). This could be attributed to the level of resources in a developed country versus a developing country as there was no significant difference found in the therapy services.

2.6 Resultant stroke impairments and its impact on return to work

2.6.1. Physical impairments

In a study done by Hartke et al (2015), the presence of physical impairments were found to be the most important factor influencing the patient's ability to return to work post stroke.

- Mobility

The ability to walk was noted as a strong predictor of return to work in more than one article (Hirotaka et al 2014; Vestling et al 2003). Mobility was however not only affected by the action of walking, but also by the speed of walking **(**Allen et al 2011). In a study done by Ntsiea et al (2013), poor walking speed was further confirmed to affect return to work.

- Activities of daily living

Impaired ADL were also found to be a significant predictor of return to work (Hannerz et al 2012). A study conducted in Jerusalem confirmed the importance for the individual of being able to participate in ADL. It highlighted specifically the dissatisfaction felt when an individual's level of function and ability to participate in these activities were affected (Hartman-Maeir et al 2007). Examples of ADL's affected after a stroke are activities like bathing, grooming, dressing and feeding (Joseph et al 2013). Due to the importance people with stroke attach to their independence, therapists are encouraged to identify, assess and treat the underlying impairments and functional limitations which influence their ability to participate in these daily activities.

2.6.2 Fatigue

Post stroke fatigue was noted to be an independent factor in not being able to return to work (Andersen et al 2012). It was recorded as the second highest impairment barrier to return to work in one study (Hartke et al 2015) and it was also found to decrease the likelihood of return to work despite the amount of time that had elapsed since the occurrence of the stroke in another (Kauranen et al 2013). Fatigue was also reported as one of the biggest concerns for individuals who have returned to work, by both the individual and the employer (Bonner et al 2015; Coole et al 2013).

2.6.3 Cognitive fallout

Hartke et al (2015) identified cognitive function as the third highest factor influencing return to work. In a study comparing various factors between stroke patients who have returned to work and those that have not, it was found that returning to work in fact increased the cognitive function of these individuals significantly, probably due to the stimulation and cognitive requirements of managing a daily workload (Fride et al 2015). Cognitive function was also found to play a role in overall life satisfaction (Baumann et al 2012).

- ***Language and speech***

Other factors identified to be predictors of return to work was the absence of aphasia and attention dysfunction (Harris 2014) as well as apraxia, which positively impacted on returning to employment (Saeki et al 1995).

- Memory and concentration

A study conducted in Luxembourg measured life satisfaction two years post stroke (Baumann et al 2012). In this study, impaired memory function was noted as one of the contributors to life satisfaction.

2.6.4 Psychosocial factors

Various psychological factors associated with stoke have also been linked to successful re-employment post incident. Stroke survivors are at risk of depression, anxiety, changes in identity and potential for social isolation (Mukherjee 2006). Another study reported that life satisfaction was associated with feelings, sleep, emotion, cognition and pain (Baumann et al 2012). It confirms that if intervention is aimed at factors affecting the individual's quality of life, it will improve their life satisfaction. Findings from these studies indicate that life satisfaction may be less influenced by physical impairments than other more personal, social and psychological issues. This supports the study done by Hirotaka et al (2014) which found that there is a considerable lack of non-medical factors that affect the likelihood of returning to work post stroke (Hirotaka et al 2014). This study suggests further investigation into support from the family and workplace, as well as the families wish for the person to return to work.

Having a more positive attitude and receiving external support were associated with an increased likelihood to return to work (Lindstrom et al 2009). Good social support was confirmed as a significant factor for return to work in a study done by Harris (2014). A study done in the United Kingdom highlighted the importance of the individual accepting their stroke related problems and adapting their behaviour and attitudes post incident which led to greater social participation post stroke. The importance of being able to accept the limitations of the stroke and take control of their situation was further highlighted in a study done by Medin et al (2006). This coping ability to adapt seems to be an important characteristic in managing challenges with everyday activities, but was also proven to be an important facilitatory quality when returning to work (Coole et al 2013).

Depression was another common consequence resulting from people who had not returned to work post stroke (Mukherjee et al 2006; Arwet et al 2017). According to literature, the onset of depression was not necessarily related to the time that elapsed since the stroke (Arwet et al 2017; Treger et al 2007). It was therefore important to be aware of the possible presents and impact of depression on the individual (Arwet et al 2017; Fride 2015; Vestling et al 2003; Treger et al 2007). Depression may impact on the individuals' perception of the

stroke. Literature confirms that a negative perception of their illness will reduce the chances of going back to work (Harris 2014).

Fear of worsening physical disability was also found to be a common reason for not returning to work (McLean 2007). This was not only reported as a concern by the individual who suffered the stroke, but also by the potential employer (Coole et al 2013). The fear of worsening the physical disability by returning to work, was a concern and could impact on an employer's willingness to re-employ a stroke survivor.

A study investigated the perceived and experienced restrictions in participation and autonomy among adult survivors of stroke in Ghana (Amosun et al 2013). Despite receiving different forms of rehabilitation, these stroke participants in Ghana did not only experience restrictions in outdoor mobility, but also engaging in paid employment, participating in family- and social activities. They also perceived that their participation in education and training, paid or voluntary work, helping and financially supporting others, was greatly impacted by the stroke. Amosun et al (2013) subsequently advocated for the inclusion of these vocational factors during stroke rehabilitation.

Rehabilitation should therefore be focused on what is most meaningful to the person following their stroke. Healthcare professionals need to explore what the stroke survivor wants to do, what they perceive to be barriers and what skills and supportive networks are needed to reach a productive activity outcome level (Woodman et al 2014). Rehabilitation is too often focused mainly on impairments and not on all aspects that will prepare the individual for returning to work. It is therefore important for therapists to be aware of the above mentioned factors during rehabilitation (Medin et al 2006).

2.7 Income and education

Income and education were also noted as independent predictors of return to work in the study done by Trygged et al (2011). Individuals who achieved higher levels of education and earned more were found to have an increased probability of returning to work (Peters 2013; Trygged 2011; McLean 2007). Earning a higher income also potentially allows the person with stroke access to the appropriate care sooner. A more advanced education was linked to improved cognitive function and ability to perform a role that was more sedentary in nature (Joseph 2014). Higher income earners may have a better chance of work tasks being adjusted in the workplace in comparison with more manual and physically demanding tasks applicable to lower income earners. The physical impairments therefore do not impact that significantly on their work performance (Peters et al 2013; Trygged et al 2011). In a study

done by Larsen et al (2016), it was confirmed that majority of people with stroke who had returned to work, were working adjusted hours. Adjustments of working hours and tasks have been found to be more feasible in the sedentary/administrative roles (Larsen et al 2016).

2.8 Types of employment

Joseph et al (2013) highlighted that skilled workers were more successful in return to work given their job requirements and work environment. This author also noted that individuals from low socioeconomic backgrounds had more difficulty retuning work than people from higher socioeconomic backgrounds. Low socioeconomic status has also been found to influence the individual's functional status and ability to return to work (Glader et al 2017).

Being a white collar worker, working in the public sector and/or being self-employed were determinants for higher life satisfaction and subjective well-being (Vestling 2003; Peters 2013) and promoted return to work (Saeki et al 1995). Variables which predicted economic hardship after a stroke were identified to be the female gender, hazardous alcohol consumption, manual occupations and lack of health insurance (Essue et al 2012).

In a study done by Culler (2011), stroke patients identified factors affecting employment to be neurological, social, personal and environmental. While vocational specialists held similar opinions, they also felt that being realistic in vocational goals were important (Culler et al 2011). Employers however noted that the disability was not the limiting factor, but felt that their ability to meet the essential job requirements were of greater importance (Culler et al 2011).

Assessing return to work is therefore considered as one of the important indicators of successful rehabilitation. Possible alternative employment options also need to be evaluated when returning to work (Treger et al 2007).

2.9 Role of employer in re-employment of people with stroke

While it is possible to return to work with some limitations, this will impact on the individual's performance and may require that various accommodations be implemented by the employer which may become costly (Coole et al 2013). Furthermore, their residual disabilities were not the only indicator for return to work. Individuals post stroke that had sympathetic managers or colleagues who understood and recognized their difficulties and took action to amend them, felt that this helped to build their confidence, overcome

difficulties and work successfully (Alaszewski et al 2007). According to Coole et al (2013), employers face complex emotional and practical issues when helping an employee return to work after a stroke. Some of these concerns raised by employers included how stroke may impact the individual's capacity to work; how he may be perceived by his colleagues; how to address the employee should there be any concerns; the employees' awareness of his limitations considering that some employees returned to soon. The involvement of a healthcare professional to facilitate the return to work process is therefore advocated (Culler et al 2011).

This was confirmed in another study looking at the varying perceptions of the person with stroke, a vocational specialist and employers during reintegration back into the workplace (Culler et al 2011). Stroke participants complained of the physical and environmental challenges which affected their ability to return to work. Examples of these included walking from the garage to the office, opening doors, fatigue and cognitive problems. However, they identified that having a supportive employer assisted them in returning to work as they seemed to understand the limitations of the person with stroke and showed empathy towards their condition (Culler et al 2011). The employer in contrast emphasized the importance of meeting the job requirements and functions and felt that the employee's disability did not play role. Other concerns expressed by the employer included reliability in the workplace and external factors like transport. The vocational specialist in Culler et al (2011) indicated that physical impairments were the easiest to address when returning to work, compared to other factors like poor insight and poor motivation, views similar to that expressed by the employer. This displays the importance of understanding the patient's perception of factors facilitating or impeding return to work post stoke and highlights the importance of addressing these expressed needs during rehabilitation (Vestling et al 2013).

It was also found that workability assessments and workplace visits were effective in facilitating return to work for stroke survivors. Employers and people with stroke expressed the need to have the support of the healthcare provider, either doctor or therapist to support and educate them during this time (Coole et al 2013). Workability assessments were found to be effective in facilitating return to work in SA as it adequately prepared both the employer and the person with stroke for successful return to work (Ntsiea et al 2015). While a study done by Baldwin et al in 2011 questions whether there is enough evidence to support the use of various rehabilitation programs to increase return to work rates amongst stroke survivors, studies done by Ntsiea et al (2015); Coole et al (2013) and Culler et al (2011) highlights the benefits of return to work interventions.

2.10 Conclusion

Returning to work after the occurrence of a stroke is seen as an important factor of ones well-being (Vestling et al 2003) and can be considered as proof that the person has recovered post stroke (Medin et al 2006). Understanding the influencing factors can therefore be considered as equally important as this will affect the outcome of interactions with a person with stroke in a social, rehabilitative and employment environment. In order to address barriers to returning to work, it is therefore important to understand and assess the patients' perception of their condition (Harris 2014). While there are many studies highlighting the functional limitations experienced by person with stroke, there are only a few studies published focusing on the patient's perception of factors impacting return to work post-stroke. Of all the articles reviewed and discussed above, a small amount of articles specifically discussed the perceptions mentioned by the person with stroke.

Based on the review of the available literature, a gap has been identified specifically addressing the patients' perceptions of factors which either facilitate or act as barriers to return to work post stroke. The patients' perceptions of these factors are important when treating an individual with stroke and needs to be addressed during rehabilitation (Vestling et al 2013). Studies by both Medin et al (2006) and Ntsea et al (2015) indicate that re-employment post stroke is influenced by other factors, not only physical recovery. It highlights the importance of the patients' self-efficacy and the support of others, again confirming the importance of understanding other factors affecting successful return to work. While there is literature in SA regarding the physical disabilities which could affect the stroke patient's ability to return to work (Joseph 2013), one needs to also understand the factors from the patients' perspective which affects their reintegration into the workplace (Culler 2011; Alaszewski et al 2007). While a similar study has been conducted in the Gauteng Province, due to the difference in the unemployment rate noted to be 25.7% in Gauteng and 18.5% in the Western Cape, as well as the differences in the profile of the residents in terms of education, culture and demographics (Statistics South Africa 2011), further investigation is required in the Western Cape. This study therefore focused on the patients' perception of factors facilitating and/or acting as barriers when returning to work post-stroke in the Western Cape Province in SA.

The following chapter elaborates on the specific research question and objectives of this study along with a detailed description of the methods employed to reach these objectives.

Chapter 3

METHODS

The following chapter describes the methods used during the study. The procedures were piloted prior to the principal study. The various outcome measures, data collection tools and procedures employed during the study are described. Description of the data analysis is provided in this chapter including how themes were identified from transcribed interview data.

3.1 Research question

What are the perceptions of people with stroke (PWS) regarding barriers and facilitators that influence their ability to return to work?

3.2 Study aim & objectives

The study aimed to identify the perceptions of people with stroke (PWS) regarding facilitators and barriers influencing their ability to return to work. PWS were recruited from the Delft, Elsies River and Bishop Lavis communities in the Western Cape Province, South Africa.

The primary objectives of this study were therefore to:

3.2.1. Determine which key factors PWS perceived as barriers to successfully returning to previous employment or an alternative occupation.

3.2.2. Determine which key factors PWS perceived as facilitators to successfully returning to previous employment or an alternative occupation.

3.2.3. Determine the functional, social and emotional well-being of PWS.

3.3 Study design

A qualitative retrospective study was conducted. This method was used as we needed to explore and gain an understanding of the various factors affecting a person's ability to return to work after stroke. This included exploration of their opinions and motivations. Individual interviews were conducted where PWS were asked to reflect on past experiences in order to gain an understanding of the various factors affecting their ability to return to work.

An Interpretive paradigm was used during this study given the subjective nature of the study design. This approach supports the idea that one's reality is influenced by multiple social realities. It supports that no perception can be wrong, but is rather a construct of one's reality and that truth is context dependant.

3.4 Study setting

Participants were recruited from Bishop Lavis (residential area within Matroosfontein), Elsies River and Delft communities in Cape Town, Western Cape Province, South Africa. According to statistics South Africa (Statistics South Africa 2011), the unemployment rate for these communities average around 40.9 %. The unemployment rate for the Cape Town Metropolis was 23.9%. Bishop Lavis totals a population of 77,121 people, of which 90.9 % included the coloured population, 7.0 % the black African population and 2.1% consisting of the Indian/Asian and white population, with 81.6% being Afrikaans speaking. Elsies River totals a population of 42,479 people, of which 91.4 % included the coloured population, 6.8% the black African population and 1.8% consisting of the Indian/Asian and white population. A total of 77.4% were Afrikaans speaking. Delft totals a population of 152,030 people, of which 51.5 % included the coloured population, 46.2 % the black African population and 2.2% consisting of the Indian/Asian and white population, with 77.4% being Afrikaans speaking (Statistics South Africa 2011). According to the census data, an average of 10% of people living in these communities were not earning any income. These areas are designated as poorer socio-economic communities and people living there tend to fall in the lower income brackets.

3.5 Recruitment sites

Target areas included Delft, Bishop Lavis (BL) and Elsies River communities. These three areas are geographically adjacent to and fell within the service catchment area of Tygerberg Academic Hospital, which is one of the tertiary healthcare institutions within the City of Cape Town Metropole. Due to time & resource constraints, and the scope of this Masters study, other tertiary healthcare institutions in the City of Cape Town Metropole could not be included. The resultant limitations of this restriction will be further discussed in Chapter 6.

3.6 Population

The targeted population for this study includes PWS of different racial groups, both male and female, residing in Delft, Bishop Lavis (BL) and Elsies River communities. These potential participants may or may not have completed rehabilitation after their stroke. In terms of

employment, they may or may not have returned to work or attempted to return to work at the time of the study.

3.7 Sample

Purposive sampling method was used during this study. These specific target areas were selected given its geographical area. All participants had to have been working before the onset of the first stroke.

The sample for the study included male and female adults with stroke residing in the above mentioned areas and who attended the community stroke groups at the local day hospital or community-based rehabilitation centres situated in these areas.

3.7.1 Inclusion criteria:

The study included adult males and females from the ages of 18, who suffered a first stroke within the last four years prior to the commencement of data collection and individuals who were working at the time of the stroke. Individuals who were previously employed and had intentions of working in the future, potentially returning to their previous employment were included in this study. Individuals who were able to speak English, Afrikaans and isiXhosa; and who were permanent residents of South Africa (SA), were included. Individuals with stroke who were currently attending or had previously attended an outpatient clinic, community health centre or community stroke group(s), or underwent a period of inpatient rehabilitation were eligible to participate in this study.

3.7.2 Exclusion criteria:

Individuals already receiving social grants and who were unable to work pre-morbidly due to non-stroke conditions, as well as PWS presenting with aphasia were excluded from this study. The presence of aphasia may affect one's ability to actively participate and to comfortably express perceptions and opinion on reasons for not being able to return to work and were therefore excluded. Individuals who were not residents of SA, would present with different sociodemographic backgrounds, and potentially received different treatment or rehabilitation to those residing in SA, and therefore were also excluded from this study. Their perceptions or reasons for not finding employment may have been different to SA residents.

3.8 Recruitment method

Once ethical approval was obtained to conduct research in the three communities, the facility managers of the community healthcare and/or rehabilitation centres were contacted to obtain permission to advertise the study and recruit potential participants from their

respective centres. Telephonic and electronic contact was made with the facility managers. Successful contact was only made with Elsies River community health centre (CHC), Bishop Lavis rehabilitation centre (BLRC) and BL day hospital. Multiple attempts to contact the facility manager at Delft day hospital were unsuccessful. Further recruitment at Delft day hospital was therefore terminated.

Notices were placed at the healthcare facilities in Bishop Lavis and Elsies River after permission was granted by the respective facility managers (Appendix 10 [a] and [b]). As notices were placed in public areas such as waiting rooms at these healthcare facilities, it sought to not only target PWS attending rehabilitation and/or for other healthcare needs, but also those who had completed stroke rehabilitation, those working already and those who had not returned to work. Notices would have also been seen by family members and friends of PWS who could pass the information on to potential participants. The public display of notices at these healthcare facilities would have facilitated that potentially a greater number of people in the target population could be informed.

Additionally, the principal researcher contacted the community stroke groups in Elsies River and Bishop Lavis areas to inform PWS attending these stroke groups about the research project. Successful communication was only made with the Bishop Lavis stroke group. A brief talk was given at this stroke group to inform the PWS of this study and to attempt recruitment from their membership. This strategy was carried out on two different days (once by the principal researcher and once by the trained research assistant) to optimise contact with all group members in the event of non-attendance on a particular day. The BL stroke group members were also asked to inform other PWS in their community about the study. The second talk was done two months after the first as the response to the first talk was very poor. Stroke group members were informed that the principal researcher could be contacted telephonically if they or others that were interested in the study had any queries regarding participation.

Recruitment and data collection took place over the span of nine months, after permission was granted by the facility managers.

3.9 Research assistants

Two research assistants, a physiotherapist to assist with recruitment and a healthcare worker proficient in speaking isi-Xhosa to assist with interviews, were identified and thoroughly briefed regarding the study and the objectives thereof. Even though a research assistant was identified to assist with the interviews of potential participants who spoke Xhosa only, their services were not utilised during the study period as all the participants

were able to speak English and Afrikaans. The principal researcher was therefore able to conduct all the interviews as she was proficient in both these languages.

3.10 Data collection tools

Various data collection tools were used during the course of this study. In order to determine the current condition of the participants identified to partake in the study, the Modified Rankin scale (mRS) was used. During the interview, a self-developed questionnaire was used to determine the sociodemographic characteristics of the participants.

The Stroke Specific Quality of Life Scale was used to assess their level of functioning after the stroke and how it affected their well-being. An interview schedule was employed during individual interviews to ascertain the perspectives of participants on the factors affecting return to work after stroke.

3.10.1 Modified Rankin scale (mRS)

The mRS was used to determine the baseline of function of each participant during the initial screening assessment over the telephone, as well as at the recruitment site when it was identified that the individual would be participating in the study. This scale assesses the degree of disability in patients who had a stroke via a scoring system, with zero being no disability and five indicating constant care for all needs. During the interview, the level of disability initially reported by the participant was verified using this scale (Appendix 7).

3.10.2 Self-developed sociodemographic questionnaire

This questionnaire was developed by the principal researcher and aimed to identify the sociodemographic details of the participants involved in the study (Appendix 6).

3.10.3 Interview schedule

The interview schedule was developed by the principal researcher based on information found in similar research (Bonner 2016; Hartke 2015; Harris 2014; Medin et al 2006). It was used as a guide during the interview to facilitate the flow of the interview and to ensure that the relevant questions were asked (Appendix 6).

For the purpose of the principal study, both the self-developed sociodemographic questionnaire and interview schedule formed the basis of the interview.

3.10.4 Stroke Specific Quality of Life Scale (SS QoL Scale)

The SS QoL scale was used during the interview to determine the participants' functional, social and emotional well-being after the stroke (Appendix 9). This is a self-report outcome measure used to assess quality of life in stroke patients. It consists of a 5-point rating scale and addresses various issues, namely functional abilities, emotional and social aspects which may have been impacted by the stroke. It assists in determining the participants' health-related quality of life. The higher the score, the better the participants' functional, social and emotional well-being after the stroke. It is a reliable and valid instrument for measuring self-reported health-related quality of life (HRQoL) (Hsueh 2011). According to the article by Hsueh (2011), the construct validity of the 12-domain SS-QOL is well supported for measuring HRQoL in ischemic stroke patients. It has been recommended that the 12-domain version of the SS-QOL be used for capturing multiple impacts of stroke as well as overall HRQoL status on the basis of patients' perspectives (Hsueh 2011).

3.11 Study Procedure

3.11.1 Pilot Study

A pilot study was conducted with one participant. This participant was 57 years old who suffered a left sided stroke. He previously worked as a builder and stopped working due to the onset for the stroke. He was married at the time of the interview. The sociodemographic form, interview schedule and outcome measurement tools were used to trial the planned procedures. The principal researcher made minor adjustments to the timing and flow of the questions based on her experiences during the piloting of procedures.

3.11.2 Principal study

All PWS residing in the Bishop Lavis and Elsies River communities fitting the inclusion criteria who attended the rehabilitation, healthcare centres and community stroke groups, and who consented to participate in the study, were recruited.

a) Responses after recruitment

One patient responded to the notices placed at Elsies River CHC. Zero patients responded to the notices placed at Bishop Lavis day hospital. After the first talk done by the research assistant at BLRC, three people expressed interest in participating in the study. After the second talk, 12 patients expressed interest in participating in the study. Two of these patients were included in the original three that had contacted the researcher after the first talk.

b) Sample

A total of 15 participants met the inclusion and exclusion criteria and were identified as potential participants to take part in the study. Of this 15, only eight participants consented and took part in the interviews. Four potential participants were not contactable after more than three attempts and communication with them was then ceased. Even though potential participants provided contact numbers at the initial information and recruitment talk at the stroke group, which were confirmed with their folder records at the stroke group, they remained unreachable. One participant experienced transport challenges a few times and could not reach the venue for the interview, while another participant was not able to stay after the stroke group for the planned interview due to dependency on transport from other group members.

During the course of the interview, it was established that two participants 0005 and participant 0003 did not meet the inclusion criteria for the study. Once of these participants attended the stroke group, and referred to having a stroke in the initial conversation at the day hospital, but admitted to not actually have a stroke at the interview. He had injured his back at work, resulting in the inability to use his lower limbs and being wheelchair bound. The other participant initially reported having a stroke in 2013, however, during the interview, it was established that she actually had the stroke much earlier in 2003. These participants could therefore not be included in the main study analysis as they did no longer met the inclusion criteria.

c) Interview Procedure

Individual interviews were conducted with six participants who consented to take part. Participants either made contact via text message, telephone call or instant messaging after seeing the notices at the community centre or after the talks at the stroke group. A number of participants were also contacted by the principal researcher who provided their mobile number after the talk at the stroke groups.

Once identified, the participant was contacted telephonically by the principal researcher. Their language preference was attained on the telephone as well as a brief assessment of their functional ability using the MRS. The place and time of the interview was established and confirmed. Individual interviews were held in the mentioned communities at the healthcare facilities after the stroke groups and/or at the local library. These venues were selected as they were easily accessible to the participants.

Participants were informed of privacy and confidentiality of their identity during the study and interview sessions. After the researcher had introduced herself, the participant information leaflet and consent form was explained to the participant, and they were asked to sign in order to give their consent to participate in the study. The participant information leaflet and consent form was explained to the participants in the language of their choice. Only two participants preferred English while the other four participants preferred Afrikaans as the medium for the interview. Most of the participants were accompanied by a family member or friend due to mobility impairments. These caregivers stayed for the interview or waited in a separate area for the interview to be completed.

Each interview lasted approximately 30 to 45 minutes. Each participant was allocated a unique identity number before the interview commenced. The interviews were recorded using a digital recorder. The recorder was turned on and the participant was then referred to by the allocated number and not addressed by name or surname in order to preserve the identity of the participant. Upon completion of the interview, the participant and his family member or friend were thanked for attending and for their participation. The interview was closed off. Each participant was given a small gift inclusive of fruit and a bottle of water.

3.12 Data management and analysis

Upon completion of interviews, the recordings were sent to a professional transcriptionist to be transcribed. These recordings were then saved onto a CD for safe-keeping. The transcriptions and sociodemographic data collected were read several times to understand and become familiar with the interviews. The data derived from these interview transcriptions, the sociodemographic form, SS-QoL and mRS was then analyzed. Data from the sociodemographic form, mRS and SS-QoL were analyzed using frequency tables and reported in tables using Microsoft Excel (MS Excel 2010).

Atlas.ti. (Version 6.2.15; 2011) software was used to analyze the qualitative data from the interview transcriptions by coding the transcribed data. Inductive analysis of the data was applied as the researcher used the data to guide her on the relevant themes that emerged from the data. The conceptual framework was therefore derived from the themes which emerged. The coding themes were then checked and verified by the two independent reviewers to confirm that the codes used were correct and consistently identified. Based on consensus discussions, some changes were made to the coding themes. After further analysis of the coded data via inductive analysis, common themes emerged. These themes were then grouped together to identify the common perceptions expressed by the participants. These perceptions formed the subheadings for the content in the results chapter.

3.13 Ethical considerations

Ethical approval for this study was granted by the Health Research Ethics Committee (HREC) of Stellenbosch University, South Africa (HREC Reference No. S15/10/253). Ethical clearance was also obtained from the Department of Health (DoH) prior to the commencement of the study (Appendix 4, 5, 6) to conduct research at healthcare facilities in the Bishop Lavis, Elsies River and Delft communities. Once approval was granted, the facility managers of the community health centres in these three communities were contacted to gain permission to advertise the study and recruit potential participants from their respective centres.

The participant information leaflet and consent form was explained to each potential participant. Participants were asked to provide written informed consent before participating in this study. All the participants who attended the interview sessions agreed to participate in the study and were able to sign the form themselves.

Participants were encouraged to freely communicate during the interview. They were informed that their participation was voluntary and they could withdraw from the study at any time. Participants were further informed that all information shared with the research team would remain confidential and that there would be no reference to their name or details during data analysis and publication of this study.

Interviews were conducted at the community library or at the outpatient department where the stroke group was held, whichever setting was most convenient for the participant to access. Interviews were conducted in a quiet space within the community library/outpatient department. Upon the initial telephone screening, the location for the interview was confirmed with the participant.

The participants were also informed that the study did not present any risks of physical harm to any of the participants. Open ended questions were asked during the interview to encourage honest participation from the participants.

Upon completion of the research project, findings of this study will be forwarded to the physiotherapist at the stroke groups. These findings can then be shared with the patients attending the stroke groups.

3.14 Trustworthiness of the study

In order to support the trustworthiness of this study, the following concepts have been explored. These are credibility, dependability, conformability and transferability.

3.14.1 Credibility

Researchers must ensure that the findings of the study is represented and described accurately. Semi Structured interviews were conducted and member checking was carried out verbally throughout the interviews to ensure descriptions and experiences expressed by participants were correctly understood by the researcher.

3.14.2 Dependability

Dependability refers to the consistency of the research process during data collection, analysis and interpretation of the findings. This was ensured in the study by using the same data collection tools, self-developed standardised coding system and interview format for all interviews. The findings of the mRS scale and SS QoL also assisted the researcher in identifying the consistency of the information given by the participants.

3.14.3 Conformability

Conformability refers to the concept of objectivity, to ensure that the findings (accuracy, relevance, meaning) of the research as far as possible that of the participants and not of the researcher to eliminate bias. This concept was displayed in this study by the keeping of an audit trail and checking of themes that emerged with a second reviewer.

3.14.4 Transferability

Transferability refers to the potential for findings can be generalized or transferred to other settings or groups. The findings discussed in this study relates to other research used to prepare and compile the interview schedule.

The next chapter will expand on the sociodemographic profile of stroke participants and the results of the interviews conducted by the principal researcher.

Chapter 4

RESULTS

4.1 Introduction

This chapter outlines the results found during this study. It includes the demographic details of the participants, findings of their functional abilities as well as the qualitative data from the semi-structured interviews.

4.2 Sociodemographic details of the sample

Of the 15 participants that were screened for inclusion, eight participants consented and took part in the interviews. During the interviews two participants were found not to meet the inclusion criteria. The interviews of these two participants have therefore not been included in the final analysis below.

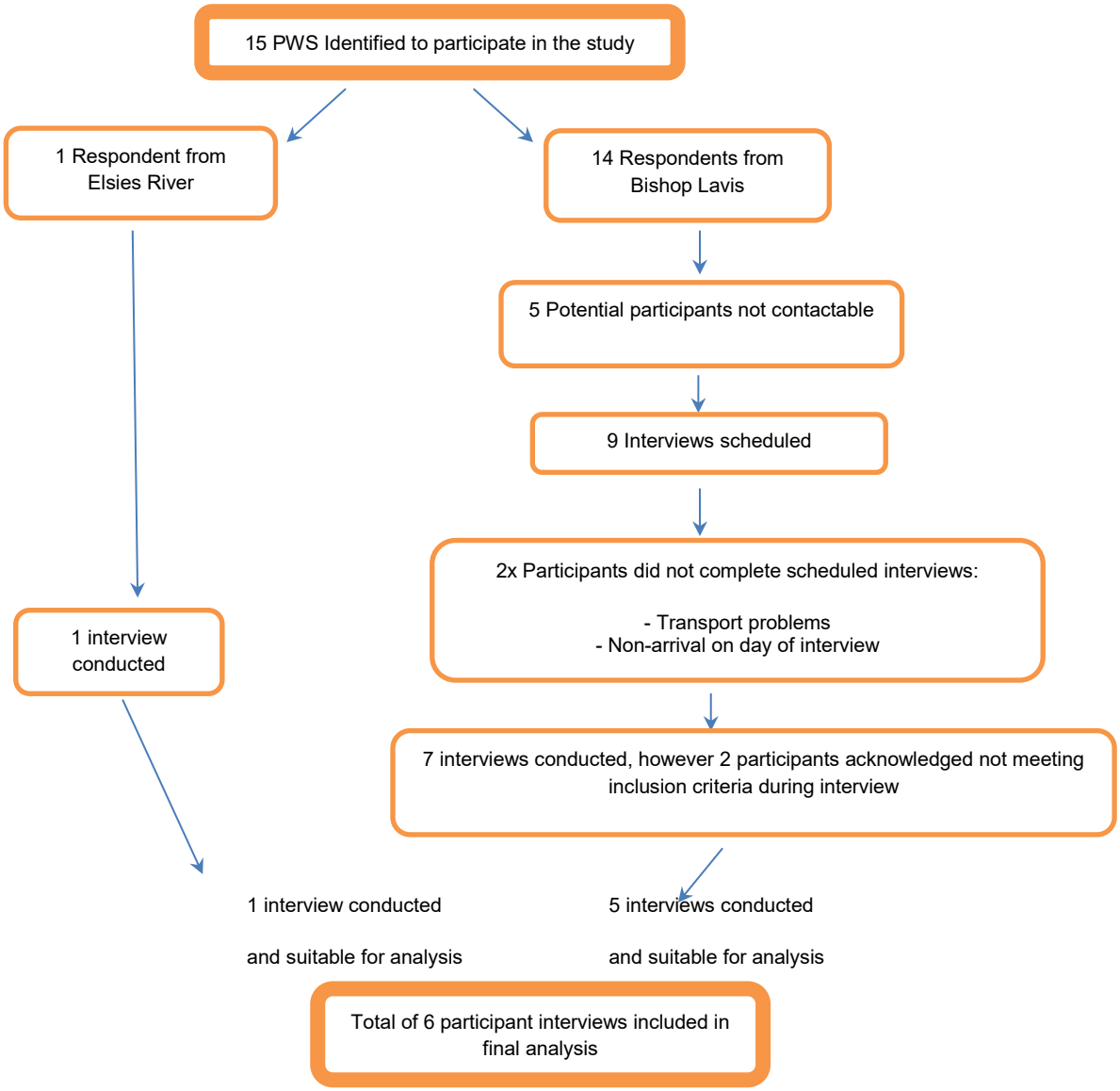

Figure 1: Flow diagram of participant recruitment

All participants' attended the community stroke group in the area they resided in. There were an equal amount of women and men in this sample with a median age of 58 (71-51) for the sample (Table 1). The education level of participants varied between having a grade seven level of education (n=1) to an undergraduate diploma (n=1). Two participants could not remember their highest education level. None of the participants were employed at the time of the interview, but all had participated in some form of employment before the stroke. The types of employment the participants previously participated in varied between formal and informal employment. Some were employed in the open labour market and others were self-employed. Examples of previous employment for the participants in this study was a builder/brick layer (n=2), domestic workers which included cleaning houses for income (n=1), textile machinist (n=1), repair/handy man (n=1) and managing a small goods shop from their home (n=1). All of these occupations were physically demanding and required good physical ability and mobility. None of the participants' reported receiving a disability grant.

Table 1: Socio-demographic details of participants included in the study

Participant ID	Area	Age (years)	Gender	Occurrence of recent stroke (months)	No. of strokes suffered	Affected side	Marital Status	No. of Dep.	Employment
0001	Elsies River	57	M	12	2	L	Married	3	Builder/ brick layer
0002	Bishop Lavis	52	M	24	1	R	Single	1	TV repair man
0004	Bishop Lavis	56	F	36	1	L	Widowed	3	House shop
0006	Bishop Lavis	61	F	24	1	R	Single	0	Domestic Worker
0007	Bishop Lavis	71	M	24	>3	L	Married	4	Builder/ brick layer
0008	Bishop Lavis	51	F	36	2	R	Married	2	Machinist

M: Male; F: Female; L: Left; R: Right; Y: Yes; N: No

The researcher enquired about the participant's source and amount of income during the interviews. However, as none of the participants had returned to work, they were not comfortable providing this information as they would then need to provide the income of their spouse or family member caring for them. For ethical reasons, the researcher did not persist that this information be provided.

4.3 Stroke risk factors

The participants presented with medical conditions commonly associated with stroke. All presented with the modifiable risk factor of hypertension (HPT). The majority of the participants presented with up to three risk factors, e.g. HPT, hypercholesterolemia and heart disease as described in figure 2.

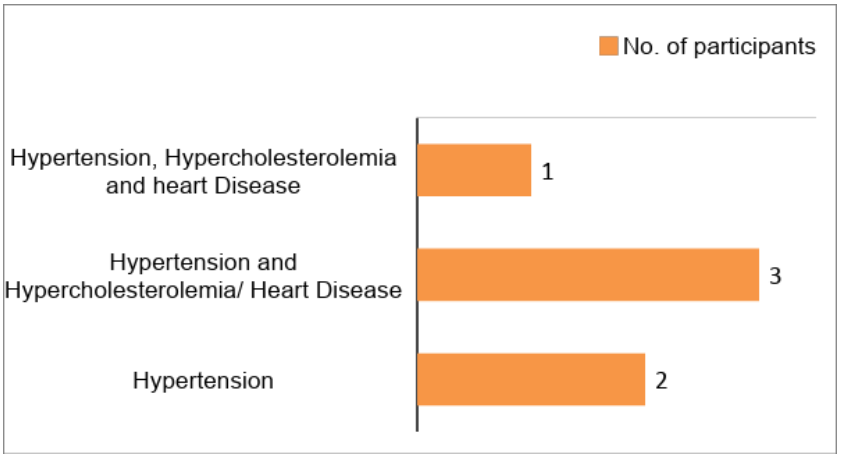

Figure 2: Self-reported risk factors

4.4 Functional limitations post stroke

Participants had varying levels of function post stroke. This is described using the Modified Rankin Scale (mRS) and self-reported information obtained during the individual interviews.

4.4.1 Level of function post stroke

The mRS scale was used to evaluate the participants' level of function at the time of the interview as shown in figure 3. The majority of the participants still presented with numerous impairments as a result of the stroke with higher mRS scores. These impairments will be described further below.

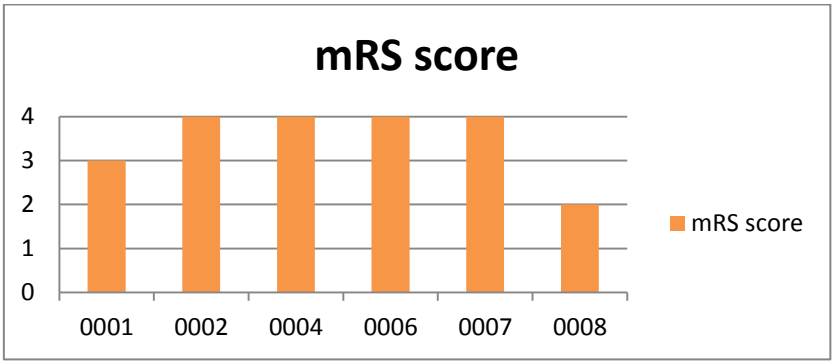

Figure 3: The mRS scores for participants

4.4.2 Limitations related to mobility and activities of daily living (ADL)

Although participants were mobile and used mobility assistive devices like walking sticks, most of them indicated that they preferred using wheelchairs when leaving the house and

entering the community. Half of the participants chose to use a wheelchair on the day of their interviews. They expressed feeling safer or more stable using a wheelchair than any of their other assistive devices like a crutch or quadropod.

Only one participant was independent in mobility and activities of daily living (ADL). All other participants required assistance, either from a family member or caregiver, or assistive devices for mobility and ADL. These activities of daily living specifically related to tasks such as eating, dressing, food preparation and walking.

4.5 Pain post stroke

All of the participants who participated in the study expressed the presence of pain after the stroke. A specific question highlighting the presence of pain was asked during the interview. Pain was generally reported on the side affected by the stroke, and often came on with movement. One participant however expressed pain in her chest, not related to the stroke.
The impact of pain on the participants functional abilities have been further unpacked in the section below.

4.6 Medical management and rehabilitation post stroke

4.6.1 Medical management

Two out of the six participants received treatment from a tertiary level hospital after the stroke. The rest of the participants only received medical management from a day hospital (primary level care) and no referral was made to other levels, i.e. secondary or tertiary hospitals. The specific content or details of their early medical care after the stroke was beyond the scope of this study.

4.6.2 Rehabilitation

All participants, except one, were referred to the rehabilitation group within one year of having the stroke. All participants were referred to individual as well as to group therapy. All participants were referred to a physiotherapist initially. Four of the six participants were referred to a physiotherapist and either an occupational therapist or speech therapist. Two of the six participants were referred to all three therapists initially.

4.7 Health-related quality of life post stroke

This Stroke Specific Quality of Life Scale (SS QoL Scale) was used during the interviews to determine the participants' health-related quality of life in terms of their functional, social and emotional well-being after the stroke. The SS QoI therefore proved to be an appropriate

instrument to measure these components. The total average score of participants was approximately 115 (range 97- 153). The higher the score, the better the person's functioning.

Functional aspects evaluated by the SS QoI include mobility, language, self-care, upper extremity function and vision. The table below illustrates the average and range of scores for these functional aspects.

Table 2: SS QoI Scale scores – Functional aspects

	Language n=6	Mobility n=6	Self - Care n=6	Upper extremity function n=6	Vision n=6
Mean score	10.33	11.66	11.50	11.66	11.66
Range	(8 - 12)	(9 - 23)	(9 - 25)	(5 - 25)	(7 - 15)
Maximum achievable score	25	30	25	25	15

Social aspects evaluated by the SS QoI include family roles, personality, social roles and work/ productivity. The table below illustrates the scores for these social aspects. The participants' ability to be productive and family roles were most affected.

Table 3: SS QoI Scale scores – Social aspects

	Family roles n=6	Personality n=6	Social roles n=6	Work/ Productivity n=6
Mean score	6.17	9.17	10.17	6.67
Range	(5 - 8)	(5 - 12)	(8 - 12)	(4 - 11)
Maximum achievable score	15	15	25	15

Aspects of emotional well-being evaluated by the SS QoI included energy, mood and thinking. The table below illustrates the scores for these aspects of emotional well-being. Participants' energy levels and ability to concentrate and remember things (Thinking) was mostly affected after the stroke.

Table 4: SS QoI Scale scores – Emotional aspects

	Energy	Mood	Thinking
Mean score	5.50	12.83	8.00
Range	(3 -7)	(11 - 17)	(3 - 12)
Maximum achievable score	15	25	15

4.8 Factors affecting return to work in this sample of PWS

During the participant interviews there were clear themes that emerged which participants identified as either a barrier or facilitator to return to work. These are described below and have been divided into either environmental or physical factors. As all the participants did not return to work at the time of this study, the factors have been further divided into that which participants considered were clear barriers, but also that which they perceived may have positively influenced returning to work. These perceived positive factors are also reported below.

4.8.1 Barriers to return to work

Clear barriers were reported by the participants during the interviews, which in their opinion prevented them from returning to work. These were either attributed to environmental or physical factors.

Each category has been divided into sub categories highlighted during the interviews along with supporting direct quotes from the participants.

4.8.1.1 Environmental barriers

Clear environmental barriers were reported by the participants during the interviews, which in their opinion prevented them from returning to work. The following section discusses these barriers in detail with the supporting quotes from participants attached. The categories have been described in the flow diagram below.

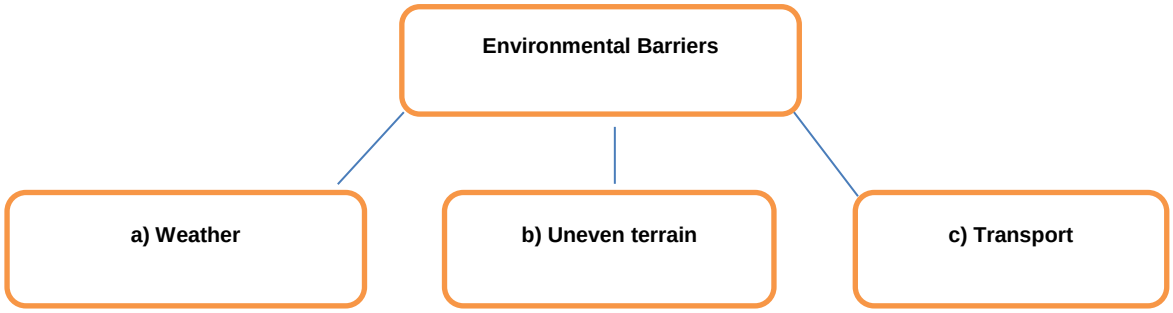

Figure 4: Flow diagrams of Environmental Barriers

a) Weather

The weather was reported to impact their independence. Windy weather, for example would result in the participant requiring more support than usual.

"Interviewee: If the wind is bad. And I need to go to the shop, then I don't use the crutch. I use that one. Researcher: Okay, it is a bit more stable? Interviewee: Yes, and I bought sugar during the week and so on." (P0002, 194,198)

b) Uneven terrain

Uneven terrain was observed as a limiting factor, particularly when participants went outside of their home environment. Most participants reported needing assistance when leaving the house. Specific reference was also made to fear of falling.

"The only time when I take a crutch is when I go out of the, at the gate

But what I am very particular of is that I don't fall."

(P0007, 237:237, 257:257)

"Yes, I can walk. I can, but not far. I'm too afraid to walk down the road or go to the shop or whatever, just in case something happens with me." (P0001, 15:19)

c) Transport

Some participants were assisted by a community member to get to the interview venue as they did not feel comfortable coming on their own. Participants reported that if they did not have a family member or friend who was able to accompany them to a venue, then they would have to pay a community member to accompany them. They reported that this could become very costly. Accessibility to public transport was also noted to be difficult due to their remaining physical impairments after the stroke.

"Researcher: Okay because I was talking to some of the other people and they say that they get charged to push, people charge them to push their wheelchair. Interviewee: Yes that is a fact. Researcher: Even if it's family. Interviewee: That's a fact. It happens yes." (P0007, 324:327)

4.8.1.2 Physical barriers

Clear physical barriers were reported by the participants during the interviews, which in their opinion prevented them from returning to work. The following section describes these barriers in detail under the categories of function, symptoms, psychological, social and management. Psychological factors have been associated with physical barriers given its potential impact on the participants' physical abilities.

Each category has been divided into sub categories as described in the flow diagram below. Supporting quotes from the interviews are used to highlight participant perceptions related to these categories.

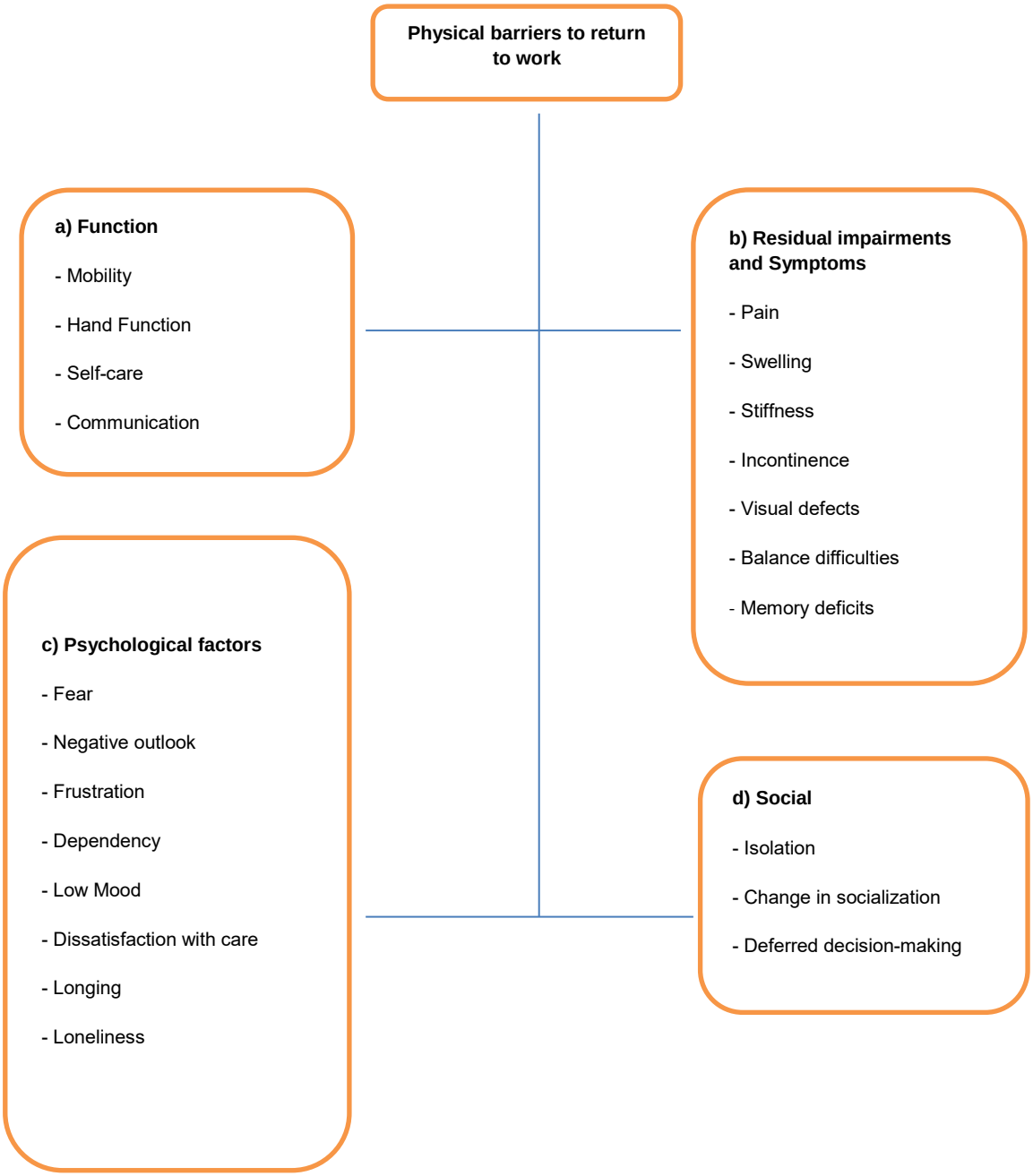

Figure 5: Flow diagram of Physical barriers

a) Function

Function-related barriers refer to the tangible activity limitations identified by participants during the interviews. These factors were also visibly identifiable by the researcher when engaging with the participants during the interviews. These function-related barriers have been divided into challenges with mobility, hand function, self-care and communication.

- **Mobility**

Problems with mobility were reported by most of the participants. Many of them used assistive devices on a daily basis to assist with getting from one point to the next. Crutches was the most common assistive device used to assist with mobility, however participants also used wheelchairs for outdoor mobility, or when long periods of walking may be required, for example going to the shop for grocery shopping.

"I can walk, but with a crutch." (P0002, 101:102)

"Interviewee: I go everywhere with the crutch. Just to get around. Researcher: And can you walk for a small distances without the crutch? Interviewee: No. Researcher: Okay. Do you use the crutch at home. Interviewee: Yes. Researcher: And if you go to any other place? Interviewee: Yes. Researcher: Okay. Are you able to go to the shop? Interviewee: I go to the shop with my wheelchair." (P0004, 083:096)

- **Hand function**

Most participants suffered from impaired hand function. For most of them, the arm was affected more severely than the leg after the stroke.

"The arm and the leg yes, and the eye. At this moment, the arm,

Now I can't write with my hand then I get tired [laugh]."

(P0004, 031:034, 148)

"

"Can't work yes. Because my right hand is the hand I used to fix televisions, to work with wires I can't do anything now." (P0002, 009:012)

- **Self-care**

Not being dependent in their basic function of ADL was identified as a limitation by many of the participants. ADL mentioned included preparing food, eating and chewing, washing and dressing. This was reported to affect their contribution in their family. If they were able to perform these tasks again, as reported by some of these participants, it not only allowed them to play a more active role in addressing family needs but also gave them a sense of independence and self-worth.

"You know why? Because when my wife and my children come from work, then usually the food is finished, I can't even peel a potato or slice an onion or whatever, dice onions. I can't do nothing for myself because in other words, if I feel like an egg, I fry an egg. I must ask her to do it, because I usually do it myself." (P0001, 63:65)

"Another thing is, I can't eat everything, because if I eat then I bite my… my lip." (P0001, 081:081)

"I actually struggle with, I could not eat that time. I used to eat with my right hand. Now I cannot eat with my right hand. I eat with my left hand. To hold my spoon and fork to get it to my mouth." (P0002, 234:240)

- **Communication**

It was evident from the interviews that the ability to communicate was affected for most of the participants after the stroke. This could either be due to their inability to speak, or to formulate a complete sentence. While this had improved for some participants, it had not improved for all. Some participants were still struggling with various aspects of their communication.

"Interviewee: I could talk, but not so well. Researcher: Okay. Was it difficulty to get the words out? Interviewee: It was difficult, I could talk, but not properly. Researcher: Okay. Just so that I understand, you knew what you wanted to say, but couldn't get the words out? Interviewee: Yes, I couldn't say them properly." (P0004, 062:066)

This was particularly evident for one of the participants whose family member accompanied them to the interview. Whilst the participant attempted to answer the researcher's questions, most were answered (verbally) by the family member and then verified by the participant.

b) Residual impairments and symptoms post stroke

Participants still experienced various symptoms despite the time that had elapsed since the stroke. These symptoms were noted to negatively impact their everyday function. Below is a list of symptoms expressed by the participants, along with the substantiating quotes.

- **Pain**

As previously noted pain was reported by all participants generally present on the side of the stroke and brought on by movement. This often resulted in limiting freedom of movement on the painful side.

"Yes, sometimes when I stretch it. The pain is actually here. Look here, it is here in the arm and here also. Here it is also in the joint, If I lift the leg, it is painful." (P0002, 154, 158)

" Researcher: Okay. At this stage, do you have any pain on the affected side? Interviewee: Just here behind my back. Researcher: By the shoulder? Interviewee: No, just here, here.. Researcher: Okay. On the top? Interviewee: Yes here.. This along with the arm.. Researcher: Okay. So there is not pain in the leg? Interviewee: No, but by the knee." (P0004, 113:123)

"Oh yes. Oh yes. In my leg and in my arm." (P0007, 138:141)

- **Swelling**.

Swelling of the limbs was reported by a participant, specifically in the feet and during longer periods of standing or walking.

"The foot swells sometimes, if she walks, then her foot turns like this, and also struggles with the foot that swells." (P0006, 144:144)

- **Stiffness**

Stiffness in the lower limbs was another musculoskeletal symptom reported. This affected the ease with which certain movements could be performed. It is unclear if this stiffness was related to swelling or the presence of increased tone.

"If I put my foot down and stand up then it pulls stiff, then it takes a few minutes to come right". (P0002,159:162)

- **Incontinence**

Whilst only mentioned by one participant, not being able to control her bladder was a limiting factor to leaving the house. This participant still experienced issues of incontinence despite the length of time that has elapsed since the stroke.

"I have a very weak bladder. In the lounge, I will be sitting and then I can't feel that I need to pee. But I will stand up and the pee will run out." (P0004 168:172)

- **Visual defects**

Some participants reported deterioration in their vision after the stroke. If they however suffered from a visual impairment before the onset of the stroke, this was worsened after the stroke.

"It tears a lot and I can't see very well. It constantly feels like there is something in my eyes.

Yes, because I can't see properly." (P0004, 039:042; 182:182)

"Not the speech, but I think it affected the eyesight, not that much but it affected that." (P0007, 095:095)

- **Balance difficulties**

Participants did not specifically mention that their balance was affected during the interviews, however it was the observation of the researcher that participants experienced difficulty with balance during the interview. This was also attributed to the requirement of an assistive device by most of the participants.

"I can manage that because if anything happens I have got the benches to hold on to. You know. But I practice to use not the crutch. But what I am very particular of is that I don't fall." (P0007, 255:257)

- **Memory deficits**

Various participants reported still experiencing ongoing challenges with memory and recall. Some had managed to figure out alternative methods to manage this such as using the reminder function on their cellular phone.

"No, I don't think I will. I don't have any problems with my arms and legs, but I still have difficulty with my memory. That is why I don't think I will go back to work. I can walk on my own, but my biggest problem is my memory." (P0008, 081:081)

"[laughing] You see, these are all the things I do, because I forget. That's all the effects of the stroke. Forgetfulness. I put it on my reminders." (P0007, 283:289)

- **Fatigue**

A common symptom reported by many of the participants was the presence of fatigue after the stroke. They particularly expressed struggling with lower energy levels after the incident. This affected their ability to perform many ADL and walking longer distances. For some participants, this remained a limiting factor and they continue to tire quickly. While they perceived the fatigue improving over time, they felt that their energy levels had not returned to pre-morbid levels yet.

"Family member: No, she did get very tired. No, it is still the same. She gets tired very quickly." (P0006, 215:223)

"Interviewee: I was very tired yes. I slept a lot. I was after therapy. I was always very tired.

Researcher: And now, if you walk around in the house, do you feel very tired? Interviewee: Yes. Researcher: Is it getting better? Can you walk a bit longer? Interviewee: Yes, a little bit." (P0004, 137:144; 149:156)

"I can make my own food, I can dress myself, clean. But I can only do a little at a time because I get tired." (P0008, 085:085)

c) Psychological factors

The psychological factors depicted below refer to the discouraging emotions or feelings expressed by the participant or observed by the researcher during the interviews. They were identified by the participants as limiting factors, i.e. barriers to returning to work.

- **Fear**

Fear was expressed by a number of the participants. This emotion was expressed in relation to the reoccurrence of a stroke as well as challenges they experienced after the current stroke. A sense of anxiety was also observed by the participants when speaking about the fears.

i) Fear of re-occurrence of stroke

Participants expressed the fear of experiencing another stroke, specifically the participants who already had more than one stroke. They feared not only death, but being more severely impaired than after the initial stroke.

"And I tell you that really shook me. And I had three in my sleep. Slight ones but I mean think of the possibility of losing my life. Because there is no help, my wife is sleeping, you know and other help, everybody is sleeping, so. (P0007, 223:225)

ii) Fear of falling

Other participants expressed the fear of falling during walking and moving around. This was considered a limiting factor when outside of their home environment.

"*I'm too afraid to walk down the road or go to the shop or whatever, just in case something happens to me" (P0001, 19:19)*.

"But what I am very particular of is that I don't fall." (P0007, 257:257)

iii) Fear of further harm

Given their residual impairments, participants expressed concern for enduring further injury as a result of these impairments.

"Researcher: Okay. And can you make tea, or is it difficult. Interviewee: No, I am scared I will burn myself." (P0004, 219:220)

- **Negative outlook**

During the interviews with few participants, their outlook towards many current aspects of their lives was negative. This included their functional ability, and/or rehabilitation, and/or their interaction with others.

"Because my friend was here this morning, he asked me hey, do you have job, I said to him you can see, I can't do nothing. I said I can only sit there and supervise them what to do." (P0001, 49:51)

"The stroke groups? Okay, I…at the moment they give me physio, but at the stroke group they just… because I did ask them for the physio for my hand, but… and my… my foot. But in the stroke group it's like, like oh you know, like what can I say, like in a crèche or whatever, they throw a ball or whatever it is. Yes, I need a physio for my hand." (P0001, 032:037)

- **Frustration**

Many participants expressed the emotion of frustration during the interviews. This was generally related to the initial onset of the stroke and their sudden lack of independence. However, for some participants, frustration remained a reality whilst carrying out their daily activities.

"Yes, yes, because I… I can't sit here at home the whole time, because I'm only sitting at home doing nothing. That's it yes because I… I get frustrated to sit at home." "Now I'm frustrated, I can't do nothing,." (P0001, 049:051)

- **Dependency**

All of the participants were dependant on a family or community member for at least one basic activity of daily life. Due to this, some participants admitted to not taking the initiative to do things themselves. A sense of frustration was however observed from family members during the interviews, when assisting with activities that the participants could have done themselves.

"No, I can't do anything. Family member: If I see she is struggling, then I will help her. Interviewee: Then I can dress. Yes, they bring my food to the bed. Family member: Yes she can eat on her own." (P0006, 092:097, 105, 108)

- **Low mood**

Low mood was reported by all of the participants after the occurrence of the stroke. This was reported to be due to the functional limitations that they experienced post stroke. Some of these participants reported that their mood improved along with improvements in their abilities and independence. This was further confirmed by various family members that accompanied participants to the interview sessions. For others however, they still felt negatively about the stroke and their current loss of independence.

"I did feel very down, because if I wanted to do something for myself, I couldn't do it". (P0004, 184:184)

'I feel okay, but....Not so good." (P0006, 234:237)

- **Dissatisfaction with care**

The medical care received immediately after the stroke, as well as ongoing interventions seemed to have a significant impact on the participants' views and feelings around the treatment they were currently receiving. For participants who had negative experiences of medical care initially, continued to hold this negative opinion of their current care. They felt that their needs were not being met during therapy and that they were not being listened to.

"The stroke groups? Okay, I…at the moment they give me physio, but at the stroke group they just… because I did ask them for the physio for my hand, but… and my… my foot. But in the stroke group it's like, like oh you know, like what can I say, like in a crèche or whatever, they throw a ball or whatever it is. Yes, I need a physio for my hand." (P0001, 032:037)

- **Longing**

A sense of longing was felt during the interview with some of the participants. This did not only relate this to their need to return to work, but also to their need to return to their previous function and hobbies before the stroke.

"Yes, plus I got pigeons, I didn't even see my pigeons for the past 8 or 10 months because the loft is right up on top by the door, you climb up a ladder. So I can't go in." (P0001, 041,043)

"Because sometimes I… if I don't get a work then I sometimes move around with the bicycle and look for work like cutting grass and that stuff. I can do nothing." (P0001, 051:059)

"Because my goal is to walk from my house to therapy [laugh]. I always walked yes. Researcher: Okay, and were you very busy? Interviewee: Yes." (P0004, 278:286)

- **Loneliness**

During the interviews with some of the participants, loneliness was apparent by the statements that they made, as below.

"I always want to be alone at home. I don't want to go out to visit people. No, I stay at home." (P0004, 194:198)

But for others, the sense of loneliness came through during the interview conversation by the things they did not elaborate on, or did not answer fully. It was the avoidance of the topic that led the researcher to believe that the feeling of loneliness was present in their everyday lives. For one participant, despite staying with three other people, no reference was made to them during the interview for example.

d) Social factors

- **Isolation**

Isolation from friends and family members was reported during the interviews. This did not seem to be due to discrimination from others as none of the participants reported being treated differently. The reason for this could not be articulated by the participants.

"I always want to be alone at home. I don't want to go out to visit people. No, I stay at home." (P0004, 194:198)

- **Change is socialization**

It was reported by some participants and confirmed by their family members that their interaction with others changed since the occurrence of the stroke. The reason for this was not established.

"Yes, she used to talk a lot. She was a joke with everyone [laugh]. She used to joke a lot. But she doesn't joke anymore. We used to laugh a lot for her."

(P0006, 190:200)

- **Deferred decision- making**

During an interview, the following was noted by a participant:

"The doctor didn't say that I was fit to go back to work. But it doesn't bother me. I first want to get better, then I will think about going back to work." (P0008, 067:069)

For all other interviews conducted, no other participants had made reference to requiring confirmation from the doctor before returning to work, despite all having physical limitations. This participant was the only participant where no physical limitations were reported. Whilst the participant did later mention that additional improvement in abilities was still needed, the exact nature and extent of the improvement could not be articulated. This participant appeared to require validation by the treating physician, before being comfortable to return to work again.

4.8.2 Perceived potential facilitators to return to work

None of the participants who took part in the study had returned to work. The potential facilitators reported below are therefore factors that the participants perceived could or may have assisted them in returning to work.

4.8.2.1 Potential environmental facilitators

Very few participants reported on environmental factors that could have assisted them in returning to work during the interviews. This could be due to the fact that none of them had returned to work at the time of the interviews. The following environmental facilitators are

therefore based on a combination of the opinions expressed during the interviews, as well as the observation of the researcher which could result in potential facilitators to returning to work. The various potential facilitators are further discussed with supporting quotes from participants. These potential facilitators are described in the flow diagram below.

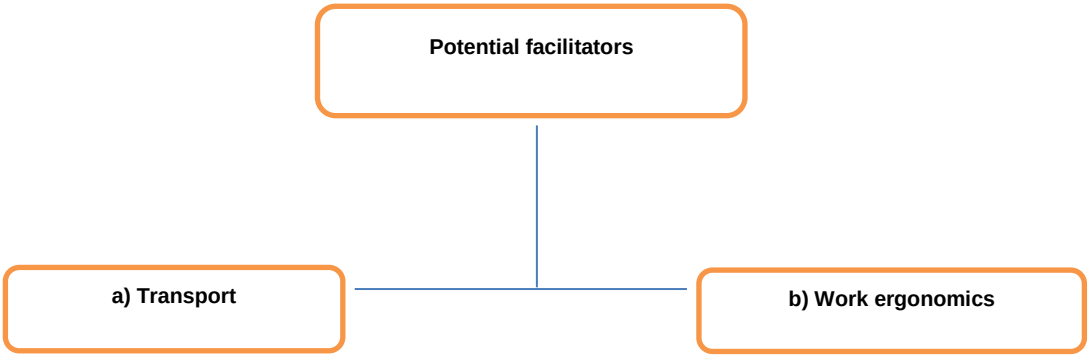

Figure 6: Flow diagram of potential environmental facilitators

a) Transport

Participants highlighted that having access to transport, specifically private transport, improved their ability to interact and connect with peers, access healthcare services and move within their community.

"Like when we leave here, we go to the shop, Shoprite and when we are finished there, I phone my cousin and she comes to pick me up and she drops me and my wife at home" (P0007, 355:356)

"You know the one cousin that takes me to church, I go to Tygerberg for check up on the pacemaker. I used to go every six months and then every nine months but now it is extended to once a year. And I phone her to make an appointment to take me there. And she drops me at the hospital at five o'clock in the morning, without asking me a cent. And she refuses if I offer her some money. So I get, and then I have got another cousin living close by here who picks me every Wednesday for the rehabilitation centre and fetches me there every day, every Wednesday." (P0007, 321:323)

b) Work ergonomics

The ergonomic set-up of the work environment was reported as something that needed to be considered before they would be able to return to work. Alternatively, some participants reported that they previously mainly worked in a seated position and therefore felt it would still be possible after the stroke, even in a wheelchair.

"Researcher: And when you were working, did you work on a table, or did you sit and work. Interviewee: I use to sit and work. Researcher: Sit? Interviewee: By a table."

(P0002, 163:166)

4.8.2.2 Potential physical facilitators

Given that none of the participants had returned to work, factors which the participants felt could have assisted in their return to work are discussed below. The following are therefore factors that the participants think could have assisted them in returning to work.

The potential physical factors identified have been divided into sub categories of (a) function, (b) psychological and social factors, (c) impairments or symptoms as well as (d) continued management, described in the flow diagram below. Each sub category will be explained with supporting direct quotes from participants.

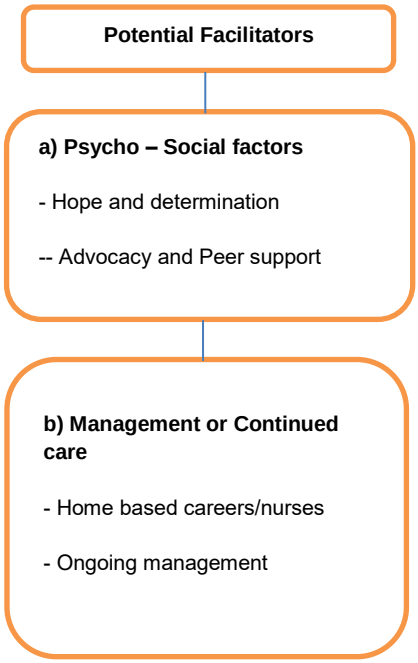

Figure 7: Flow diagram of the potential facilitators

a) Positive psycho-social factors

The psychological factors depicted below refer to the optimistic emotions or feelings expressed by the participant. Despite the occurrence of the stroke and the residual impairments, some participants still had a positive outlook towards the stroke experience and their view of the future.

- **Hope and determination**

Some participants acknowledged that they would not be able to return to their previous work but were hopeful about alternative future employment options. The quote below depicts the ideas of a participant going through a cycle of self-reflection to explore alternative job options he felt may still be achievable.

Researcher: Would you like to go back to some kind of work if you can? Interviewer: You know lady I was thinking about this, especially with my situation, I am thinking of doing what I used to do before. Not particularly building, but a lot of other things like working in the yard, you know making garden. I was also a salesman for a very long time you know. After I have completed my study as a bricklayer, I have been in sales, I have been in management too. (P0007, 162/165)

- **Advocacy and Peer support**

Some participants mentioned that they were now able to use their experience with the stroke and its consequences to educate others by sharing their experiences.

"My family helped and supported me a lot. Now I can help other people in the same situation." (P0008, 093:093)

"Because I know what it is to suffer from strokes and I want to help wherever I can". (P0007, 201:201)

One participant spontaneously used his knowledge and experiences after the stroke to educate and assist others with strokes in his community. He was providing education on management of risk factors such as hypertension and helping others understand its importance in preventing the re- or occurrence of a stroke.

"Thank you. Quite a lot of people speak to me about hypertension, I have seen a lady the other day and they discovered at the doctor or the day hospital that her blood pressure was so high, that it shook me in bed you know, because mine was never that high. And she didn't have a stroke and I had to talk to her about how to go about things before she gets a stroke." (P0007, 195:195)

"And I am about to help a lady who is sitting in a wheelchair and she has had a stroke two and a half years before mine and she is still sitting in a wheelchair. And when I told her and her husband how many strokes I have, they couldn't believe it and I told them the problem is you hardly attended the rehabilitation centre. You know and if they did, because I can tell you now when I went to the rehabilitation centre, I saw them, she was only coming very occasionally and I know her for many years already. She is a, a professional receptionist, you know but I can tell you, the woman can't, she can't speak, she can understand what you are saying, and she is actually wheelchair ridden. You know and I am busy with her.

Because I know what it is to suffer from strokes and I want to help wherever I can. I think they are trying to educate people at the rehabilitation centre to have lessons with people who suffer from hypertension and you know chronic illnesses. Before they get a stroke. That is correct and I am telling you I am looking forward to that because I don't want you to suffer a stroke. No, no, no, if it can be prevented with the greatest of pleasure." (P0007, 199:205)

b) Management or Continued care

Participants continued to receive medical care after the occurrence of the stroke. This included one or more of the following: home based care either by healthcare workers or nurses, medical follow-up appointments and monitoring of risk factors, regular attendance of the stroke rehabilitation group and continuing with a home based exercise programme.

- **Home based careers/nurses**

Some participants reported that home based carers/nurses came to assist them at home with some of the daily tasks that they were not able to perform independently yet as well as therapy**.**

"I can't wash myself. That's why the nurses come to wash me. (P0002, 172)

"…they come to the house to give her therapy." (P0006, 117:120)

- **Ongoing management**

Many participants continued to attend the day hospital for ongoing monitoring of associated risk factors. This included collection of medication and monitoring of hypertension, diabetes and cholesterol markers.

"I was thinking, I am seeing the day hospital next week Thursday and I want them to check up how the cholesterol is, is it healed or you know." (P0007, 129)

4.9 Summary of results

In this chapter the sociodemographic profile of stroke participants and findings of the interviews have been presented. A total of six interviews were performed. Hypertension was the most common risk factor presenting in all of the participants. Participants presented with varying levels of function post stroke assessed by using the mRS and SS QoI tools. None of the participants had returned to work at the time of the interviews. During the interviews, barriers and potential facilitators to returning to work were identified. The barriers and potential facilitators are divided into two categories, namely environmental and physical factors. Environmental barriers were identified to be due to weather, uneven terrain and transport difficulties. Physical barriers were identified to be due to functional difficulties, residual impairments and symptoms post stroke, psychological and social factors. Potential

environmental facilitators were identified to be transport and work ergonomics. Potential physical facilitators were however difficult to establish given that none of the participants were able to return to work.

The next chapter will discuss these findings and contrast it to the available literature.

Chapter 5

DISCUSSION

In this chapter, the qualitative themes reported in the previous chapters are compared and contrasted with the literature, in order to describe and understand the perceived facilitators and barriers to returning to work post stroke from the patient's perspective.

The discussion will be focused on the demographic outline of the participants, as well as their functional, social and emotional well-being. It will also highlight the key factors individuals perceived as potential facilitators and barriers to returning to their previous employment or an alternative employment.

5.1. Psychosocial demographics of people with stroke and employment

This section discusses the demographic details of the participants who took part in the study with correlation to the literature found.

During the initial screening, eight persons with strokes were identified for the interviews. During the interviews it was discovered that two persons with strokes did not meet the inclusion criteria. The reasons for the misunderstanding regarding the inclusion criteria were not identified during the study. It is however the researcher's opinion that this may have been due to cognitive impairment post stroke that was not apparent during the initial screening.

The prevalence of stroke was previously associated with the older generation. However, it is affecting the younger generation in more recent years as well. This is related to the rising increase of HIV in the younger population (Birabi et al 2012; Joubert 1991). This is a concerning factor for the South African economy as it will increase the burden of financial obligations on the older generation. While a great deal of education has been done in SA regarding HIV (Human Immunodeficiency Virus) and consequences around non-adherence to treatment, ongoing education is still required to emphasize the probability and risk of developing secondary conditions of HIV such as stroke.

According to the South African Labour Guide, there is no statutory retirement age applicable to all employees (Labour Guide 2018). However, the typical average retirement age ranges from 60 to 65 years of age. Ages of the participants included in this study ranged from 51 – 61, however one participant was over the age of 65. The findings of his interview were still

included in the results as despite his age, he continued to express the willingness to partake in gainful employment. Despite the ages of the participants, there is still a chance that they could return to some form of gainful employment. Taking into account the average retirement age according to the SA Labour Guide, many individuals continue to work even after they have reached their retirement age, due to the current economy and increasing financial cost of daily expenses
(https://www.iol.co.za/personal-finance/retirement-may-have-to-be-retired).

Literature indicates that females are at higher risk of developing and/or dying of a stroke than males (Connor et al 2005). Recently, households have shifted from a male headed household to equal share in providing specifically in the African and Coloured population in SA (Statistics South Africa 2014/2015). In addition to the increased financial contribution of the female gender, women remain the primary caregivers in the family (Maredza et al 2015; Kamal et al 2009). The increased risk of prevalence of stroke in the female population will therefore increase the burden of both financial and caregiver strain for families. Even though this statistic was not observed in the current study due to the equal distribution of males and females in the sample, all of these participants did not return to work in this study. Further investigation is therefore needed to understand the influence of gender in relation to return to work in SA post stroke. The findings of this kind of study would be important to understand influencing factors which could be addressed during treatment and rehabilitation.

Participants were recruited from Bishop Lavis and Elsies River areas. Both communities are classified as low socioeconomic areas in SA (Statistics South Africa 2011). Studies done by Joseph et al (2014) and Glader et al (2017), noted that stroke survivors from low socioeconomic backgrounds had more difficulty returning to work than stroke survivors from higher socioeconomic backgrounds. This was linked to various factors such as the quality of care that they received post stroke, their educational level and ability to be reskilled, as well as their employment experience.

Findings of studies done in developed countries cannot be applied directly to a developing country like SA as the socio-economic and cultural context would be different. Developing countries face different challenges to developed countries. The burden of disease in a developing country like SA is higher than in a developed country. This can be attributed to the quality and availability of healthcare. Access to vocational training or job opportunities and efficient public transport remains a challenge for people in developing countries. This can in turn impact on their access to healthcare, as well as employment. In developing

countries, individuals do not have access to proper education and in rural SA, continue to face challenges preventing them from completing their full schooling career (Ramdass 2009). Unemployment and the unavailability of jobs continue to be a challenge in developing countries. This creates room for further discussion as there may also be a correlation between managing financial situations of the country to make sufficient resources available, for example in the healthcare system which in turn may improve the country's unemployment rate. Lastly, poverty continues to be a big challenge in developing countries. Poverty refers to basic human needs not being met which includes access to clean and usable water, food security, education and so forth (Studies in Poverty and Inequality Institute South Africa 2007; Definitions of poverty: World Bank Group 2018). The difficulties found in these studies are similar to that found in the current study, example difficulties include access to transport and adequate healthcare for people with strokes.

All participants in this study presented with the risk factor of Hypertension (HPT). The majority of the participants presented with up to three risk factors, i.e. HPT, hypercholesterolemia and heart disease. According to the literature (Ntsekhe et al 2013; Norris et al 2012), hypertension is the most frequent risk factor in stroke patients. This was confirmed in the SASPI study done in rural SA (Southern Africa Stroke Prevention Initiative 2004). It is therefore important that patients with hypertension be educated about the risk factors associated with not controlling this condition adequately. Treatment and counselling have been implemented routinely in state healthcare facilities for persons diagnosed with HIV. The same or a similar form of counselling might be beneficial for patients that have been diagnosed with hypertension to fully understand the risks related to non-adherence to treatment for their condition.

According to the National Stroke Association of America, a stroke survivor has a 40% chance of reoccurrence of a stroke within the first five years after the first stroke. This is an alarming statistic as it translates to at least one in four people who suffer a stroke each year having another stroke in their lifetime. The Heart and Stroke foundation of SA confirms that ten people suffer a stroke in SA every hour. This further highlights the importance of managing associated risk factors (Buenaflor et al 2017). In the current study, only one participant emphasised the importance for managing the risk factors related to stroke, specifically hypertension. This is concerning considering that half of the participants in our study had suffered more than one stroke. It is therefore important that the risk of another stroke, and how to prevent this, be adequately explained by all healthcare providers to ensure that the individual fully understands the impact of non-adherence to treatment and making more informed lifestyle choices in future.

5.2. Functional related factors affecting employment

Most participants in the current study reported on residual physical impairments after the stroke. This affected their mobility as well as their ability to perform basic ADL. Based on these interviews, physical challenges therefore ranked very highly as a limiting factor for returning to previous employment. This has been well established in the literature as a big contributor to preventing people from participating in their communities and returning to work (Hamzat 2014; Tanaka et al 2013). Participants perceived that their physical inabilities would affect their ability to perform their jobs as effectively and efficiently as before. One participant specifically noted that he would not be able to return to his previous job as a repair man as he was not able to use both his hands. For other participants, for whom mobility was an important part of the previous occupation i.e. a builder or domestic worker, difficulty in walking could have had an impact on their ability to perform these roles.

The intensity and frequency of rehabilitation in the public health sector in SA is often limited due to resources (Kahonde et al 2010; Rhoda 2010). It would therefore be crucial to identify the functional needs of stroke patients so that rehabilitation can be focused on improving the functional abilities which will allow the individual to be as independent in their home and community environment as possible. In addition to this, focus should also be placed on requirements for returning to a previous vocational role. It is interesting to note that none of the participants in this study underwent vocational rehabilitation or similar programmes. According to Ntsiea et al (2015), vocational rehabilitation has been reported to be an important factor in equipping individuals when returning to work. These authors concluded that workability assessments specifically were effective in facilitating return to work in SA (Ntsiea et al 2015). However, due to the current limited resources available at community healthcare clinics as described in the study done by Rhoda et al (2010), receiving therapy related to vocational intervention and/or rehabilitation in the Western Cape Province may be very limited. Vocational intervention and/or rehabilitation does not necessarily refer to costly physical intervention or rehabilitation, it can also be in the form of providing the appropriate support to the employer and work colleagues (Coole et al 2013). This is yet another area of rehabilitation for stroke survivors who have the potential to return to work, which needs to be explored in the SA context.

Mobility, and specifically, walking independently was mentioned by most of the participants as a functional limitation after the stroke. While this was not emphasized by all the participants as a limiting factor to return to work, it did limit their ability to fulfil their basic and

participation needs like going to the shop independently. The inability to walk will also impede their ability to access public transport. It may also limit their ability to access their work environments independently. Reference was made by one of the interviewees to the inability to negotiate stairs. Should stairs be a requirement to access her work environment, she would have difficulty doing so. In a study done in Italy (Singam et al 2015), difficulty in walking was identified as one of the biggest limiting factors to returning to work. Walking should therefore be a key clinical indicator for discharge from inpatient rehabilitation when the patients' goal and progress during rehabilitation supports returning to work and if their future employment requires this level of mobility.

All of the participants reported some form of limitation in their ADL. Not being able to perform their basic ADL would impact on their level of independence and confidence. It would also affect their ability to prepare for work and indirectly impact on their ability to return to and sustain gainful employment. The importance of focusing on participation in ADL during rehabilitation has therefore been identified in the study done by Vestling (2003), as this was noted as an important factor in subjective well-being and life satisfaction. It was also found to be a significant factor influencing return to work (Hackett et al 2012; Satoru et al 2010). In SA the prevalence of people needing help with at least one activity of daily living was higher than in a developed country like New Zealand (Connor et al 2004). This is a significant finding because it indicates that continued assistance from the family, or caregiver is required despite receiving stroke rehabilitation. It further suggests that additional investigation is required into the reasons for the difference in dependence after a stroke in developing versus developed countries. It would be important to address the limitations experienced by the individual when performing basic ADL during the rehabilitation phase post stroke to maximise their chances of re-employment.

5.3. Associated impairments and symptoms after stroke

During the interviews, some symptoms mentioned by the participants were not directly linked to return to work at the time of the interview. However in previous literature, the influence of these impairments on everyday function, and impact on return to work, has been reported. A concerning impairment noted by a participant was the presence of incontinence. While incontinence was not directly linked to return to work for this participant, a study done by Strickland (2014), confirmed that incontinence gave rise to feelings of embarrassment and shame. These are similar emotions to the emotions expressed by the participant in the current study. It would therefore be important to understand how incontinence would affect the individual's ability to return to gainful employment. The in-depth understanding of the

effects of incontinence in post stroke patients have not been explored in the literature and further studies on this is required.

Many of the participants also reported the presence of various symptoms like fatigue, pain, swelling in the extremities and joint stiffness, and its impact on their everyday functional abilities and emotional well-being. These symptoms have been reported to influence the patient's psycho-emotional well-being and independence (Andersen et al 2012; Baumann 2012; Mukherjee 2006); and therefore would have a direct relation to their capacity to return to work.

Pain was a common symptom reported by all participants. While pain was not directly associated with the inability to return to work, it was reported as a limiting factor to performing everyday activities. Pain was reported in joints involved in dynamic activities and therefore affected basic movement like walking or sitting for a brief period. Various studies have also highlighted the correlation between pain as a limiting factor to ADL (Baumann et al 2012). There is therefore a need for further research to be done in order to understand the impact of pain on one's ability to return to work post stroke in SA. This should be explored by further research.

Similarly to pain, fatigue or feeling "very tired" was not directly associated during this study with difficulty in returning to work but was mentioned by more than one participant as something that limits participation in normal daily activities. Given its effect on everyday activities, one could argue that it would also affect ability to sustain a full day of activity, or working, irrespective of the nature of the occupation. Returning to work in a labour intensive occupation may therefore also not be sustainable for extended periods of time. This is supported by various studies and is noted to be a barrier to return to work (Hartke et al 2015; Harris 2014; Andersen et al 2012). In these studies, fatigue was rated as one of the greatest factors preventing return to work post stroke. This is not an area which has been greatly explored, especially in the SA context. There is however a definite need to understand the impact of fatigue on the capacity of individuals with stroke to sustain a full day of work, which needs further investigation.

Based on the finding of this study, in comparison with the literature, both fatigue and pain post stroke needs further investigation to understand its impact on return to work.

5.4 Psychological factors that affect return to work post stroke

According to the literature, a very important reason for people having difficulties at work was due to so-called invisible impairments. If impairments of stroke were more visible, it was usually easier for other people as well as the person with stroke themselves to understand or have empathy for these difficulties. The understanding and knowledge of stroke and stroke-related impairments are very important so that the individual is treated appropriately (Balasooriya-Smeekens et al 2016). Invisible impairments include psychological and cognitive deficits such as concentration, memory and personality changes. Therapeutic intervention should be focused not only on treating the physical impairments, but include treatment of the above-mentioned impairments as well. Counselling which provide the stroke survivor, their caregiver/s and potential employer the tools to deal with these factors, are therefore equally important. This will result in an employer and or caregiver being more empathetic towards the needs of the person with stroke. It will also result in the identification of realistic expectations; the person with stroke will have a better idea of what they can and cannot do, which will result in better acceptance of their current physical and vocational situations (Balasooriya-Smeekens et al 2016). Providing adequate education to the person with a stroke, caregiver and the employer, as well as ensuring that the various parties understand the impact of the stroke, is very important to address during various phases of recovery and the process of reintegration.

An example of an invisible factor highlighted during the interviews in this study would be the fear of falling or reoccurrence of another stroke. The fear of falling can be expected for those that still present with residual mobility impairments and balance dysfunction. The fear of falling can also be identified as a limiting factor should they not be willing to participate in various aspects of rehabilitation were the chance of falling is evident to them. Therapists therefore need to take this into consideration during their rehabilitation intervention. Should the fear of falling be identified during rehabilitation, the therapist may have to increase the amount of assurance and motivation offered to the patient during rehabilitation, and be cognisant of the effect of reducing the physical support to the patient.

Given that half of these participants suffered more than one stroke, the importance of understanding the risk factors which could lead to the reoccurrence of another stroke needs to be adequately addressed during their recovery. A participant reported that due to the education he received from the rehabilitation therapist regarding the risk factors for preventing another stroke, he is now able to educate fellow community members on preventive measures for stroke. This highlights the importance of providing education by the rehabilitation therapist, thereby empowering the person who has been affected by the stroke.

Campaigns like “Act FAST” (Health Promotion Agency 2018) can be used to educate the community about early signs of a stroke and assist in facilitating earlier management with the intention of reducing its severity.

It is also evident that while most of the participants seemed to have come to terms with their medical and functional condition, there still seemed to be some degree of frustration given their functional limitations and experience of pain. This was most apparent in participants whose basic ADL remained affected. Once a participant was able to care for themselves, they seemed to have accepted their condition more easily. In a study done by Woodman et al (2014), it was found that the ability of the person to accept their stroke related impairments resulted in adapted attitude and behaviour. This acceptance and adaptability were influential in their social participation (Woodman et al 2014). It is therefore important that the goals set during rehabilitation and recovery is realistic and achievable, and has been adequately discussed and understood between the patient and the healthcare provider.

It was also noted that when participants were determined, and resilient, they were able to cope better and their attitudes towards their current abilities and future was very positive. These attributes may also assist them with the tools they need to return to work, however this would need to be further explored.

Other psychosocial feelings mentioned during this study related to frustration, dependency, loneliness and longing. One participant specifically mentioned that he cannot go to his budgie loft as before. This was something he was able to do regularly and is now not able to do since his stroke. This gave rise to feelings of frustration. The need to be alone, as well as reduced participation in previous activities was also reported by participants and/or their family member accompanying them to the interview since the occurrence of the stroke. Further investigation is therefore required to establish the effect these factors will have should the patient attempt to return to work.

Low mood and poor motivation for recovery are common emotions expressed by individuals who are not be able to accept their disabling health condition. This was also apparent in the current study. Accepting their condition means that they accept that improvement to the extent that their function returns to premorbid levels, is unlikely (Woodman et al 2014). One participant in particular seemed to have difficulty in accepting his limited recovery, even after two years and voiced his discontent with post stroke rehabilitation, especially the amount and effectiveness of said therapy.

It was also found in this study that despite having similar functional abilities, the participants' perception of their abilities differed due to the above mentioned factors. A study done by Harris (2014) also indicated the strong influence one's perception of illness has on your ability to return to work. In contrast to this, a study done by Bonner et al (2015) indicates that psychological factors do not play as significant a role in return to work. While the findings of the current study could not be directly linked to successful return to work, there remains a need in the SA context to further explore the influence and impact of these various psychological factors on the stroke person's ability to return to work.

5.5. Impact of support systems

There did not seem to be a relationship between the support available to the participant in relation to their attitude in this study. Some of the participants were accompanied by a family member during the interview. Despite assuming that having a family member present can affect the nature or willingness of participants to engage in the interviews, this did not seem to be the case during the current study. The presence of a family member enriched the interviews as they were able to validate some of the information given by the participant. One of the participants had a good support system as his wife also took part in the interview and helped to verify some of his responses. Despite the support from his family, he however continued to express negative feelings and attitude toward rehabilitation and future recovery.

Another participant referred to receiving help from community nurses that attended to his medical and self-care needs a few times per week. While his support was not noted to be from a family member or friend, he could rely on the community nurses to meet his basic needs. Although beyond the scope of the current study, one may argue that this additional resource reduced the burden of care for his primary caregivers. This further confirms the importance and benefits of having a support system, irrespective of the source (Lindstrom et al 2009). There is a vast amount of literature to validate the importance of a good support system, as referenced in the literature review chapter. Support is not only provided by a family member or friend, but can also be provided by the community, employer, colleagues and from members of the treating healthcare team (Ntsiea et al 2015; Harris 2014; Woodman et al 2014; Amosun et al 2013; Coole et al 2013; Culler et al 2011; Lindstrom et al 2009). Support is not only limited to emotional support, but could also be in the form of physical support, example reasonable accommodation, allowing time off work for hospital visits, therapy sessions and so forth. In contrary to this, a study done in India found that social support does not impact on return to work (Bonner et al 2015). However, in India, family support is a very important part of their culture and is therefore not a variable that can be easily measured or distinguished. These study findings can therefore not easily be

compared to SA due to the vast cultural differences between these two countries as well as the diversity in the social norms of family units in the SA population.

5.6. Rehabilitation post stroke

Rehabilitation was frequently mentioned during the course of the interviews. The impact rehabilitation had on their recovery and well-being was mentioned often during interviews when reporting on experiences after the stroke, as well as their attitudes and overall level of motivation. Rehabilitation seemed to have a positive impact on most of the participants' emotional well-being. Rehabilitation was also viewed as a reason to "get out of the house" and "something to do", giving the stroke survivor a sense of purpose. It is therefore important for therapists to understand the far reaching impact and influence rehabilitation has for the recipient of the treatment.

Five out of the six participants taking part in the study resided in the same area and attended the same stroke group. It was interesting to note the varied opinions participants related regarding their experience of rehabilitation received. The rehabilitation, expectations of the patient and the relationship with the therapists treating the patients also seemed to have an impact on their view and attitude towards the rehabilitation centre and experience as well as acceptance of the stroke. When a participant's expectations for recovery had not materialised, they showed a negative attitude towards rehabilitation. Participants who had a good relationship with the therapist, seemed to look forward to going to therapy. Once again, emphasizing the importance of setting realistic expectations; understanding the impact and influence of rehabilitation; as well as the importance of the patients' understanding and acceptance of residual limitations after stroke. These are important components which need to be addressed during the patient's recovery journey and progress during rehabilitation.

Despite positive attitudes expressed by most of the participants to returning to work, it is interesting to note that none of the participants were referred or participated in vocational rehabilitation programmes. According to Ntsiea et al (2015), vocational rehabilitation is considered an important factor in equipping an individual when returning to work. Workability assessments were found to be effective in facilitating return to work in the SA context (Ntsiea et al 2015). Another study by Culler et al (2011) emphasized the importance of support required from the rehabilitation therapist for both the stroke survivor and the potential employer (Culler 2011). By increasing the support to the stroke survivor and employer, the chance of sustainable employment is greater as support is offered throughout the return to work process. However, a study done by Baldwin et al (2011) indicates that there is not enough evidence to support or refute the use of specific rehabilitation programs to increase return to work rate amongst stroke survivors. In another study done in Washington,

individuals who suffered a stroke were returning to work even in the absence of specific rehabilitation (O' Brien 2010). This leaves room for further investigation and understanding the value of vocational rehabilitation as well as workability assessments, particularly in the SA context.

5.7. Employment characteristics

All of the previous occupations mentioned by the participants are classified as physical in nature according to the International Standard Classification of Occupations (ISCO). Majority of the participants had also not completed a grade 12 education. Studies show that higher education levels increase the stroke patient's chances of returning to work as it is associated with improved cognitive function; of better suited accommodations in the workplace; and available roles requiring less physical function (Peters et al 2013; Trygged et al 2011; McLean 2007).

None of the participants were working at the time of the interview. Some of them did express the desire and need to go back to work but this was not specific to returning to their previous role or job. Given the physical nature of their pre-morbid occupations, returning to their previous role with their current limitations would have been difficult or not possible for some. Given the high unemployment rate is SA, the chances of finding new employment in SA remains extremely limited (Statistics South Africa 2011). Despite the mandated disability quota system for employers in SA (Schneider et al n.d), many unskilled or so-called blue collar workers are less likely to resume employment. This system tends to be more applicable to companies who offer permanent employment opportunities. Taking into account the education of the participants involved in the current study, as well as the nature of their previous employment, the disability quota initiative may therefore not be applicable or support their need to resume work. While the intention of this initiative is to include persons with disabilities into the employment sector by requiring that all companies employ a certain amount of persons with disabilities, it does not include all areas and types of employment. This can be linked to various studies comparing return to work in blue collar versus white collar workers. It was confirmed that white collar workers had a better chance of returning to work than blue collar workers (Vestling et al 2003; Saeki et al 1995). This could be associated with white collar workers often having higher levels of education (Chang et al 2016), as well as better practices put into place for accommodations in the work place for those in higher income jobs (Larsen et al 2016). The nature of healthcare received may also be different in high income earners versus lower income earners. This can be associated with the current healthcare system in SA. Resources in the public healthcare system of SA are often very limited, especially in lower socioeconomic and rural areas. This therefore may

influence the availability of accessible, comprehensive and quality care and treatment provided to individuals with stroke in these poorer communities. Further investigation into the impact of healthcare received post stroke in the public versus private healthcare sectors may facilitate a better understanding on its impact on return to work outcomes post stroke.

5.8. Impact of transport barriers to return to work post stroke

Despite that interviews were conducted in an accessible facility, namely community library and healthcare facilities, there were some individuals that were not able to attend as they did not have access to transport, or they were dependent on others for transport and were therefore not able to stay for an interview. Participants reported that if they did not have a family member or friend who was able to accompany them to a venue, they would have to pay another community member to escort them. They reported that this could become very costly considering already limited resources. Given that none of the participants' were working at the time of the study, not being able to afford transport could affect their ability to look for work, to go for interviews and it may even deter them from accepting a job that is not within close distance to where they resided. Similarly, should any form of training be required to allow them to return to work, not having access to transport could be a further deterrent. Access to transport was highlighted in a study done by Nicholson et al (2013), confirming that poor access to transport is one of the major barriers faced every day for people with stroke. Transportation services are either not accessible or not affordable for individuals with stroke (Cawood & Visagie 2015; Nicholson et al 2013; Rhoda 2012). The current public transport system in SA is not reliable which further impacts on the individual's ability to arrive punctually at his place of work or for job interviews. In addition to unreliability, the public transport vehicles are not easily accessible for persons with physical disabilities and pose safety risks (Nicholson et al 2013; Rhoda 2012). Alternative transport measures therefore have to be sought which often have long waiting lists, or are very costly. "Dial-a-ride" is a well-known transportation service offered to persons with disabilities in the Western Cape Province. Despite the fact that the purpose of the transportation service is to provide transport to persons with disabilities, long waiting lists also exist in order to use this service; the cost of this service is on the rise; and it is often noted not to be reliable by users. In the City of Cape Town, Western Cape, the new public bus services (MyCiti buses) are slightly more accessible to transport people with disabilities. However, only limited areas of Cape Town are serviced by these upgraded buses. Various organisation like the Department of Health, Department of Transport and Public Works need to take this into consideration and collaborate in order to address the limitations faced regarding transport for persons with disabilities and its impact on their ability to access essential services.

5.9 Summary of discussion chapter

This chapter discussed the key perceptions of a few people with stroke from the Elsies and Bishop Lavis communities which impacted their ability to return to work. Barriers to return to work post stroke from the perspective of employers and other prognostic physical outcomes are well documented in international literature. However, many of the personal and environmental factors that affect resuming gainful employment remain unclear and require further investigation in the SA context.

The ability to regain as much independence in mobility and ADL was found to be a very important aspect associated with either returning or not returning to work. This is supported by the findings of the current study. Accepting the outcome of the stroke and the residual impairments are also important factors influencing return to work. While this was not directly associated with return to work in this study, it was evident during the interviews and is supported by the literature. Rehabilitation, ongoing support and education were also found to play an important role in the person with strokes' emotional and social well-being. A positive experience of rehabilitation services, and/or ongoing support and education was found to empower the individual and was associated with a positive perception of their condition. Access to transport was found to impact the individual's access to their environment. This is supported in the literature. Further understanding of the impact of transport on return to work needs to be investigated in the SA context. The nature of the individual's previous employment and education was found to play an important role in returning to employment.

The current study highlights some of the unique and predominantly psychosocial factors that people with stroke in less resourced communities face in their recovery journey after the incident towards full participation and reintegration. These above-mentioned key insights provide motivation for further studies as well as recommendations for clinicians which can be included during rehabilitation of a person with stroke. While there is a substantial amount of literature to discuss the impact of psychological factors, they are mainly from international studies. Given the diverse cultures in SA, there is a need for future research to investigate these factors to better understand the patients' perception of factors affecting return to work post stroke. This newfound understanding will facilitate recommendations to clinicians to address these factors during rehabilitation of a person with stroke.

The next chapter will elaborate on these recommendations for all stakeholders. Various limitations to the study were identified and will also be unpacked in the next chapter.

Chapter 6:

CONCLUSION, RECOMMENDATIONS AND LIMITATIONS TO THE STUDY

6.1 Conclusion

The current thesis is the first study to report on patients' perceptions of barriers and potential facilitators to returning to work post stroke in low socioeconomic areas of the Western Cape, South Africa. Based on the findings of this study, it can be concluded that return to work is influenced by various factors. These factors include the functional ability of the individual, their environment and their psychological well-being. It was however surprising to unravel the extent that the participants' psychosocial well-being had on their perception of barriers and potential facilitators to return to work.

Psychosocial aspects weigh heavily on an individual's return to work ability post stroke. These psychosocial aspects can either work as a facilitator or a barrier when looking at return to work. The main psychosocial factors identified in this study related to the motivation and attitude of the individual and their perception of their abilities and environment. Another aspect which was found to affect the return to work of patients with strokes was environmental factors like transport. Difficulty in finding transport does not only affect the ability of those with strokes to access their work environment, but also to access rehabilitation or healthcare treatment. The functional ability of the individual also affected their ability to return to work. However, it was not only the physical function of the individual, but also the physical symptoms experienced as a result of the stroke. Fatigue and pain were the most common symptoms reported by the participants and impacted greatly on their ability to sustain activity for a full day. These findings emphasize the importance of being aware of and addressing these influencing factors during treatment from the acute through to rehabilitation phases of stroke patients.

6.2 Recommendations

The following recommendations can be made based on the findings of this study.

6.2.1 Recommendations for treatment

Based on the finding of this study, the following recommendations can be made for treatment and rehabilitation of patients with strokes in SA:

6.2.1.1 Recommendations for holistic treatment

This study confirms the importance of having a holistic approach towards the treatment of a stroke patient. Treatment and rehabilitation should include adequately addressing the psychosocial aspects affecting the stroke survivor's ability to return to work, along with the environmental and physical factors. This would require an interdisciplinary team approach, inclusive of a psychologist and social worker, during both in-patient and out-patient treatment. It has also highlighted the significance of a supportive employer in facilitating the return to work process.

6.2.1.2 Recommendation for health promotion and education regarding treatment of risk factors

As mentioned several times throughout this study, the chance of reoccurrence of a stroke is high. The importance of managing risk factors is therefore essential during the acute and long term treatment and recovery of the person with stroke. This includes ongoing education by all healthcare professionals involved in providing care to the person with stroke, i.e. rehabilitation therapists, nurses and doctors at the community health centres where the individual may attend for their chronic medication, as well as community healthcare workers.

6.2.1.3 Recommendation for focused rehabilitation

It is important that the personal and vocational needs of the patient be identified during rehabilitation. This will enable the healthcare professional and the patient to establish realistic goals for rehabilitation. For some individuals, independence in ADL might be of most importance, for others being able to return to gainful employment may be a priority. None of the participants in this study received vocational rehabilitation. For some of the participants vocational rehabilitation may have given them the tools to find alternative employment. Vocational rehabilitation does not only refer to costly therapeutic interventions, but also identifying and facilitating interaction between the stroke survivor and the employer.

Setting realistic goals may also assist the individual to accept their disability, thereby improving their overall perception of their condition, attitude and motivation.

6.2.2 Recommendations for future and/or similar studies

Based on the findings of this study, the following recommendations can be made for future and/or similar studies in SA:

6.2.2.1 Socioeconomic status and return to work

Given that SA is a developing country with a high unemployment rate, a further study could investigate the correlation between the unemployment rate and current socioeconomic status of persons with stroke in SA. A similar study may look at the unique factors prevalent in different provinces in SA, to ascertain which of these should be addressed by healthcare structures and policy makers within that province. A greater understanding of the impact of low socioeconomic status on return to work is needed in SA due to the high levels of poverty and limited education opportunities for people with disabilities.

6.2.2.2 Impact of post stroke fatigue and pain on return to work

Associated symptoms like pain and fatigue were noted by several participants during the interviews and were supported by literature. A study focused on the impact of post stroke pain and fatigue in therefore required in the South African context, to understand the impact these factors have on the individuals' ability to return to work in SA.

6.2.2.3 Factors impacting return to work in different ages

The sample size for this study was very small, and all the participants were above the age of 50. A further study is therefore needed to understand the patients' perceptions of barriers and potential facilitators to return to work post stroke in a bigger sample of varying ages, especially the growing number of younger individuals with stroke including those with the double burden of stroke and HIV.

6.2.2.4 Follow on study investigating factors affecting return to work post stroke

In the current sample, none of the participants had returned to work. Facilitators identified during the interviews were therefore noted to be potential facilitators as they could not be directly associated with return to work. Further investigation is therefore needed to compare facilitators and barriers for people that have, and have not gone back to work in the Western Cape, specifically from low socioeconomic societies.

6.3 Limitations of the current study

Limitations to this study included its small sample size, poor contactability of participant and facility managers as well as access to transport. These have been further discussed below and suggestions have been given on how to mitigate them in future studies.

6.3.1 Sample size

This study only included the results of six participants. Coincidently, three were males and three were females. Ages of five of the participants ranged from 51 to 61 years, with one participant being 71 years of age. Due the small sample size, results related to gender could not be extrapolated. Due to the age of the participants, the findings of the study cannot be applied to the younger or middle age generation either. It is likely that the findings may have been different if younger individuals with stroke were included. Given the above, the findings of the study remains unique to older persons with stroke from the recruitment areas and cannot be generalised to all stroke populations. It does however provide some insights into the challenges faced by these participants and offer a base for further studies.

Suggestion to increase sample size

To increase participation in this study, the following additional steps could have been taken:

- Awareness could have been raised in other community establishments, for example shopping mall, religious dwellings which could increase the participation for those that are no longer attending the stroke group, and/or have returned to work.
- Contacting acute rehabilitation centres in the area and private healthcare centres could have been done. For this study, recruitment was limited to CHC due to the time and resource constraints experienced by the researcher. This should be taken into account for future studies as increasing the areas recruited from may assist in increasing the participants taking part in the study.
- Additional/other sampling techniques, example snowballing to recruit addition participants could have been used.
- Accessing the CHC statistics for relevant time period to identify all the people who presented for stroke rehabilitation and stroke treatment could have been employed.

6.3.2 Contactability

Poor contactability of participants, therapists and facility managers is also noted as a limitation to this study. Difficulty was experienced when trying to contact the facility managers, therapists and most importantly the potential participants.

6.3.2.1 Facility managers

After approval was received from the Department of Health, the researcher contacted the facility managers at the three community health centers originally identified. The researcher was however only able to make successful contact with two of the facility managers and the third facility was therefore not included in the main study. Should the third area have been

included, additional factors may have been identified that could have expanded the current findings.

6.3.2.2 Therapists

The researcher was only able to make successful contact with the therapists of one of the recruitment areas identified for this study. This then resulted in the majority of the participants residing in the same area and receiving rehabilitation by the same therapists. This may have influenced the findings of the study given that the rehabilitation received, environment and community of most of the participants were alike. The limited participation by therapists could have been due to availability of their time, in relation to demands of their job.

6.3.2.3 Participants

Most of the participants involved in this study were recruited at community stroke groups. Participants or family members provided their contact details. The contact details provided were also confirmed with their details on file in their hospital records. Despite this, there were still patients who were not contactable due to incorrect or discontinued telephone or cellular numbers. It is also likely that limited resources affected potential participants from purchasing data for cellular phones to contact the principal investigator. This limitation significantly impacted on the amount of patients that eventually were recruited to participate in the study. The researcher had asked some of the participants to stay after the therapy sessions for the interviews, but they verbalized that their transport could only pick them up at a certain time and was therefore not able to stay later.

Suggestion to improve contactability

To increase the contactability of the facility managers, therapists and participants, the following additional steps could have been taken:

- Visiting of sites to ascertain facility manager and therapist contact details when telephonic and email correspondence was not successful should have been done.
- A “missed call” to the participant’s phone immediately after the contact number was given to the researcher to verify the number straightaway should have been done.

6.3.3 Transport

Another limitation to the study was access to transport for participants to reach the interview site. Despite that interviews were conducted in an accessible facility, namely community libraries and healthcare facilities, there were some individuals that were still not able to attend the interviews. These participants did not have access to transport, or were dependent on others for transport; and were therefore not able to stay for an interview after their rehabilitation or therapy session. This was confirmed to be the reason for two of the potential participants not being able to partake in the interviews. This impacted on the amount of participants in this study.

Suggestion to improve transport

To improve the accessibility to the interview venues, the following could have been untaken:

- Interviews could have been conducted at the participant's house
- Researcher could have assisted with transport costs to get the participants to the interview sites, or back home from the rehabilitation centers after the interview.

6.3.4 Data Saturation limitations for this study

Data saturation is a tool used during the research project for the researcher to determine when the research can be terminated. In this study, data collection was terminated when the researcher no longer received response from potential participants to partake in the study.

The limitations experienced during this study, could have been addressed by the researcher should this information have been available prior to seeking approval to access the facilities and conducting of the interviews. These limitations should be considered and addressed for similar studies conducted in the future.

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APPENDICES

Appendix 1: Letter to Department of Health

Mrs S Kriel
102 10th Street
Kensington
7405
Cape Town

Date: 18 May 2016

Dear Sir/Madam

Ethics No: S15/10/253

Re: Permission to conduct Masters Study at Bishop Lavis, Elsies River and Delf communities.

I am currently doing my Master's degree at the University of Stellenbosch. My study will focus on the patients' perceptions of factors which either assist or act as barriers to return to work post-stroke. I would therefore like to request permission to conduct this study in the Bishop Lavis, Elsies River and Delft communities.

The study will be conducted via individual interviews with participants in the area. It will be a qualitative study and no interventions will be used.

Thank you

Yours in Health,

Saleema Kriel
HPSCA no: PT0096954

Appendix 2: Approval letter: Ethics

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

Approval Notice
Response to Modifications:- (New Application)

12-May-2016
Kriel, Saleema S

Ethics Reference #: S15/10/253
Title: Patients' perceptions of barriers and facilitators influencing ability to return to work post stroke.

Dear Mrs Saleema Kriel,

The **Response to Modifications - *(New Application)*** received on **12-Apr-2016**, was reviewed by members of **Health Research Ethics Committee 2** via Expedited review procedures on **12-May-2016** and was approved.
Please note the following information about your approved research protocol:

Protocol Approval Period: **12-May-2016 -11-May-2017**

Please remember to use your **protocol number** (**S15/10/253**) on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:
Please note a template of the progress report is obtainable on www.sun.ac.za/nhs and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.
Translation of the consent document to the language applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372
Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Helene Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics

approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.
For standard HREC forms and documents please visit: www.sun.ac.za/rds

If you have any questions or need further assistance, please contact the HREC office at .

Included Documents:
20160425 MOD Cover letter
Investigator declarations
Protocol
CV L Morris
Checklist
20160425 MOD Protocol
Application form
Protocol Synopsis
CV G Inglis-Jassiem
CV S Kriel
Application form_signature page

Sincerely,

Francis Masiye
HREC Coordinator
Health Research Ethics Committee 2

Appendix 3: Amendment letter: Ethics

UNIVERSITEIT STELLENBOSCH UNIVERSITY

Amendment Approval Letter

12/12/2018

Project ID: 4771

Ethics Reference #: S15/10/253

Title: Patients' perceptions of barriers and facilitators influencing ability to return to work post stroke

Dear Mrs Saleema Kriel,

Your amendment request dated 15 November 2018 refers.

The Health Research Ethics Committee (HREC) reviewed and approved the amended documentation through an expedited review process.

The following amendments were reviewed and approved:

1. Amended protocol dated 15 November 2018
2. Amendment to the inclusion criteria to include adult males and females from the ages of 18, who suffered a first stroke within the last four years prior to the commencement of data collection and individuals who were working at the time of the stroke.

Where to submit any documentation

Kindly note that the HREC uses an electronic ethics review management system, *Infonetica*, to manage ethics applications and ethics review process. To submit any documentation to HREC, please click on the following link: https://applyethics.sun.ac.za.

Please remember to use your **Project ID [4771]** and ethics reference number **[S15/10/253]** on any documents or correspondence with the HREC concerning your research protocol.

National Health Research Ethics Council (NHREC) Registration Numbers: REC-130408-012 for HREC1 and REC-230208-010 for HREC2

Federal Wide Assurance Number: 00001372

Institutional Review Board (IRB) Number: IRB0005240 for HREC1

Institutional Review Board (IRB) Number: IRB0005239 for HREC2

The Health Research Ethics Committee complies with the SA National Health Act No. 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki and the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles, Structures and Processes 2015 (Department of Health).

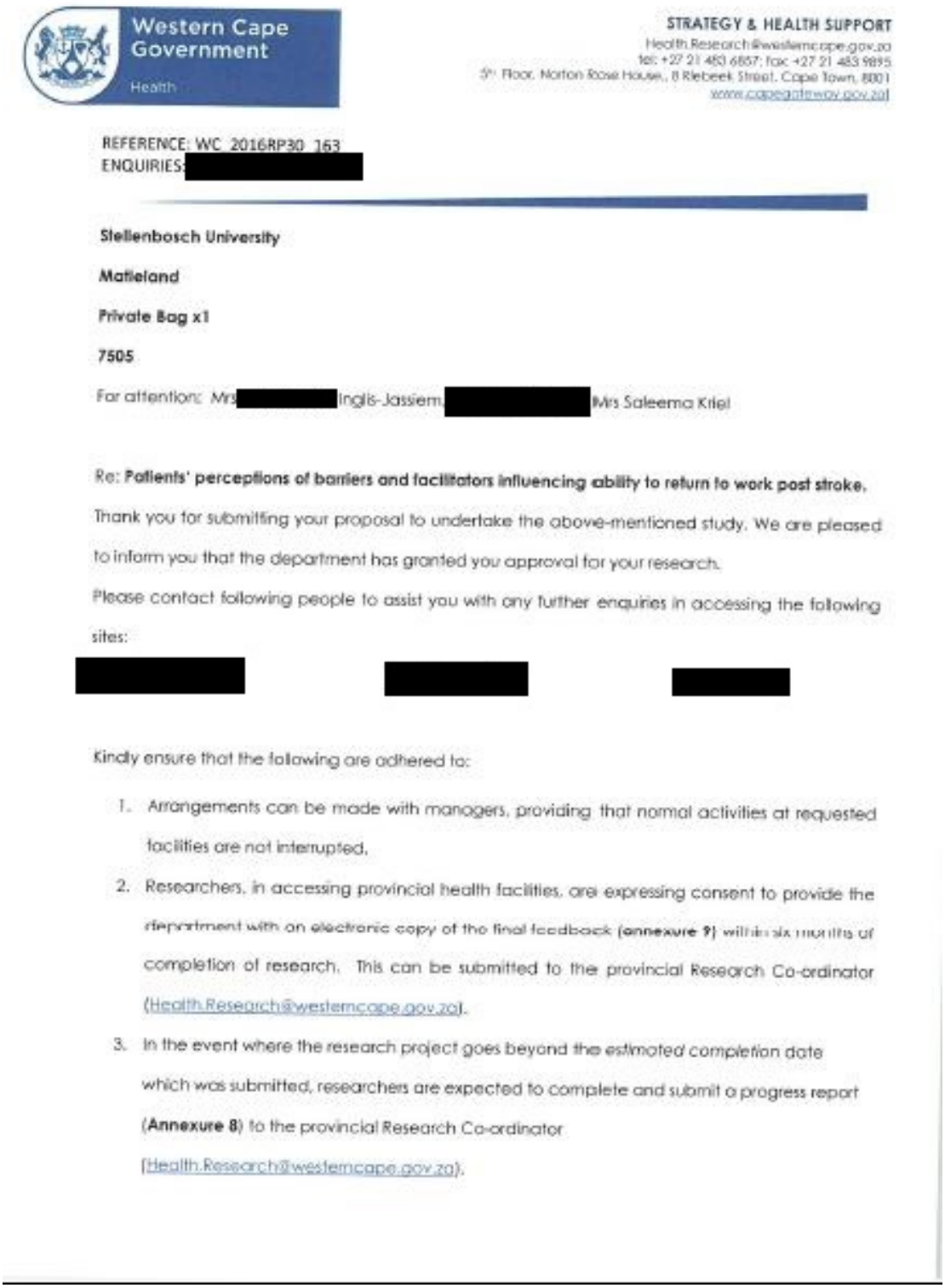
Yours sincerely,

Francis Masiye,

HREC Coordinator,

Health Research Ethics Committee 2 (HREC 2).

Appendix 4: Approval letter – Bishop Lavis



Western Cape Government
Health

STRATEGY & HEALTH SUPPORT
Health.Research@westerncape.gov.za
tel: +27 21 483 6857; fax: +27 21 483 9895
5th Floor, Norton Rose House, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: WC_2016RP30_163
ENQUIRIES: [redacted]

Stellenbosch University

Matieland

Private Bag x1

7505

For attention: Mrs [redacted] Inglis-Jassiem [redacted] Mrs Saleema Kriel

Re: **Patients' perceptions of barriers and facilitators influencing ability to return to work post stroke.**

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.

Please contact following people to assist you with any further enquiries in accessing the following sites:

[redacted] [redacted] [redacted]

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
3. In the event where the research project goes beyond the estimated completion date which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

4. The reference number above should be quoted in all future correspondence.

Yours sincerely

[redacted]

DIRECTOR: HEALTH IMPACT ASSESSMENT

DATE: 18 / 10 / 2016.

CC [redacted]

DIRECTOR: [redacted]

Appendix 5: Approval letter – Elsies River

Western Cape Government
Health

STRATEGY & HEALTH SUPPORT
Health.Research@westerncape.gov.za
tel: +27 21 483 6857; fax: +27 21 483 9895
5th Floor, Norton Rose House, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: WC_2016RP30_163
ENQUIRIES: [redacted]

Stellenbosch University

Matieland

Private Bag x1

7505

For attention: Mrs [redacted] Inglis-Jassiem [redacted], Mrs Saleema Kriel

Re: **Patients' perceptions of barriers and facilitators influencing ability to return to work post stroke.**

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.

Please contact following people to assist you with any further enquiries in accessing the following sites:

[redacted] [redacted] [redacted]

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
3. In the event where the research project goes beyond the estimated completion date which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
4. The reference number above should be quoted in all future correspondence.

Yours sincerely

[redacted]

DIRECTOR: HEALTH IMPACT ASSESSMENT

DATE: 9/9/2016.

CC [redacted] DIRECTOR: [redacted]

Appendix 6: Approval letter – Delft

STRATEGY & HEALTH SUPPORT
Health.Research@westerncape.gov.za
tel: +27 21 483 6857; fax: +27 21 483 9895
5th Floor, Norton Rose House, 8 Riebeek Street, Cape Town, 8001
www.capegatewway.gov.za

REFERENCE: WC_2016RP30_163
ENQUIRIES: [redacted]

Stellenbosch University

Matieland

Private Bag x1

7505

For attention: Mrs [redacted] Inglis-Jassiem [redacted] Mrs Saleema Kriel

Re: **Patients' perceptions of barriers and facilitators influencing ability to return to work post stroke.**

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.

Please contact following people to assist you with any further enquiries in accessing the following sites:

[redacted] [redacted] [redacted]

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
3. In the event where the research project goes beyond the estimated completion date which was submitted, researchers are expected to complete and submit a progress report

(**Annexure 8**) to the provincial Research Co-ordinator

(Health.Research@westerncape.gov.za).

4. The reference number above should be quoted in all future correspondence.

Yours sincerely

[redacted]

DIRECTOR: HEALTH IMPACT ASSESSMENT

DATE: 22/9/2016.

CC [redacted] **DIRECTOR:** [redacted]

Appendix 7: Socio-demographic form and Interview schedule

(Please complete each section and mark with X where appropriate)

Date: _____ **Code:**

Site:

BASIC INFORMATION SHEET

Thank you for agreeing to participate in this study. Below are some basic questions for you to complete. All the information will be used for research purposes only and no personal information will be shared.

1. Your Information:

Name: _____

Age: _____

Date of Birth: _____

Gender: **F / M**

Marital status:

Single □ Married □ Divorced □ Other: _____

What is your highest level of schooling/education:

None □ Grade 7 □ Grade 12 □ Diploma □ Degree □

Other: _____

Do you have any dependants: Y / N

If yes, how many? _____

Income:

No income	Between R1 and R5000	Between R5000 and R10000	Above R10000

On which date did your stroke occur: _____

Which side of your body was affected by the stroke: Left / Right

What functional abilities was affected by the stroke: _____

_____

What kind of medical treatment did you have after your stroke:

- **Where you treated by your General Practitioner (GP): Y / N**
- **Were you treated by a traditional healer: Y/ N**
- **Did you go to hospital? Y / N**
- **Other:** _____

Were you admitted for rehabilitation: Y / N

If yes, how long after you had the stroke did you start rehabilitation:

0 – 1 yrs□ 1 - 2 yrs□ 2 – 3 yrs □ 3 – 4 yrs□ 4 – 5 yrs□

More than 5 yrs□

Which of the following rehabilitation specialists did you see?

A) Physiotherapist
B) Occupational Therapist
C) Speech Therapist
D) Social worker
E) Other

Did rehabilitation improve your functional abilities? Y / N

Has your doctor said that you are able to return to work? Y/N

If yes, how long after you had the stroke did the doctor say you can return to work?

0 – 6 wks□ 6 wks – 3 mnths□ 3 – 6 mnths□ 6 – 18 mnths□ 18 – 24 mnths□

Besides the stroke, do you have any other medical conditions?

Diabetes (sugar): Y / N Hypertension: Y / N Cholesterol Y / N

Heart Disease: Y / N Respiratory conditions, like Asthma: Y / N

Arthritis: Y / N. If yes, please confirm area involved _____

Other (please include all previous injuries/surgeries)

_____

_____

2. Pain:
Do you experience any pain since the stroke Y / N

Does the pain impact on your ability to perform work related tasks? Y / N

3. Employment Information:
Were you working before the stroke? Y / N

If yes, what kind of work were you doing? _____

Were you in Fulltime/Part-time/Casual employment? _____

Are you currently back at work? Y / N

Where are you currently working? _____

Are you in Fulltime/Part-time/Casual employment?

If not your previous job, what is your current job? _____

How long after your stroke did you RTW? _____

If you have returned to work, what helped you when returning to work?

- Did you experience any challenges?
- How do you feel about your current job?
- How do you get along with your colleagues?
- Have any changes been made to assist you?
- How does your family feel about you returning to work?

If you did not return to work, do you feel you would be able to go back to work? Y / N

- If you have not returned to work, in your opinion, why have you not returned to work?
- Is there anything you can think of that would have helped you return to work?
- Would you like to return to work? If so what have you found when looking for work?
- Is there anything you can think of that would help you to find work?

THANK YOU ☺

Appendix 8: Modified Rankin Scale

Modified Rankin Scale

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 = Moderate 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

*van Swieten, J. C., Koudstaal, P. J., Visser, M. C., Schouten, H. J., van Gijn, J. (1988). Interobserver agreement for the assessment of handicap in stroke patients. *Stroke*, 19, 604-607.

Modified Rankin Scale-Structured Interview (MRS-SI)

0 = No symptoms at all; no limitations and no symptoms.

1 = No significant disability; symptoms present but not other limitations. Question: Does the person have difficulty reading or writing, difficulty speaking or finding the right word, problems with balance or coordination, visual problems, numbness (face, arms, legs, hands, feet), loss of movement (face, arms, legs, hands, feet), difficulty with swallowing, or other symptom resulting from stroke?

2 = Slight disability; limitations in participation in usual social roles, but independent for ADL. Questions: Has there been a change in the person's ability to work or look after others if these were roles before stroke? Has there been a change in the person's ability to participate in previous social and leisure activities? Has the person had problems with relationships or become isolated?

3 = Moderate disability; need for assistance with some instrumental ADL but not basic ADL. Question: Is assistance essential for preparing a simple meal, doing household chores, looking after money, shopping, or travelling locally?

4 = Moderately severe disability; need for assistance with some basic ADL, but not requiring constant care. Question: Is assistance essential for eating, using the toilet, daily hygiene, or walking?

5 = Severe disability; someone needs to be available at all times; care may be provided by either a trained or an untrained caregiver. Question: Does the person require constant care?

*Wilson, L. J. T., Harendran, A., Grant, M., Baird, T., Schultz, U. G. R., Muir, K. W., Bone, I. (2002). Improving the assessment of outcomes in stroke: Use of a structured interview to assign grades on the Modified Rankin Scale. *Stroke*, 33, 2243-2246.

Appendix 9: Stroke Specific Quality of Life Scale (SS-QoL)

Stroke Specific Quality of Life Scale (SS-QOL)

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 10 (a): Notice to be placed in community centres (English)

Have you or a family member had a

Stroke?

I am a Masters student at the University of Stellenbosch conducting a study to determine the factors, both positive and negative, people experience after having stroke when returning or trying to return to work.

If you, a family member or friend has suffered a stroke and are interested in participating in this study, please contact me, Saleema Kriel on xxxxx.

Are you:

- *Between the ages of 18 and 65, and suffered a first stroke within the last 2 years.*
- *Are you a permanent resident of South Africa (SA),*

Then you are a candidate for this study.

With this information we hope to identify the factors that people with stroke in South Africa think affect their ability to return to work.

This information could be incorporated into the management of a stroke survivor to equip them when attempting to return to work. It will give the rehabilitation specialists insight into various factors which stroke survivors may face when returning to work, some of which could be addressed during rehabilitation.

Your participation in this study is voluntary.

Appendix 10 (b): Notice to be placed in community centres (Afrikaans)

Het u of ‘n familielid

‘n Beroerte

Gehad?

Ek is ‘n student van die Universiteit van Stellenbosch. My navorsing is op die positiewe and negatiewe effekte van beroerte op ‘n persoon se vermoë om te werk.

As U of ‘n familielid ‘n beroerte gehad het en wil deel neem, skakel/ whatsapp/ please call me op **061 806 6735** of stuur ‘n epos na saleemahendricks@gmial.com.

Is jy:

- *Tussen die ouderdom van 18 en 65, en het ‘n beroerte gehad in die laaste 2 jaar.*
- *Bly permanent in Suid Afirka (RSA),*

Dan is jy ‘n kandidaat vir hierdie navorsing.

Met hierdie inligting hoop ons om die faktore te identifiseer wat mense met beroerte dink hulle vermoë om terug te keer na werk, beïnvloed.

Hierdie inligting kan opgeneem word in die bestuur van ‘n beroerte-oorlewende om hulle toe te rus wanneer hulle probeer om terug te keer na die werk.

U deelname is vrywillig.

Appendix 11: Participant Information Leaflet and Consent Form

TITLE OF THE RESEARCH PROJECT: Patients' perceptions of barriers and facilitators influencing ability to return to work post stroke

REFERENCE NUMBER: Pending

PRINCIPAL INVESTIGATOR: Saleema Kriel

ADDRESS:
Physiotherapy Division
Faculty of Medicine and Health Sciences
Stellenbosch University
Francie van Zijl Drive; Tygerberg; Cape Town; 8000
South Africa

CONTACT NUMBER: 061 806 6735

Dear Participant

My name is Saleema Kriel and I am doing my Master's degree at the University of Stellenbosch. I would like to invite you to participate in a research project. This research project will focus on patients' opinions, after they have had a stroke, on things which would either help them to return to work, or make returning to work difficult.

Please take some time to read the information in this letter, . Please feel free to ask any questions about anything that you do not fully understand. It is very important that you clearly understand what this project is about and how you could be involved. Your participation in this project is completely voluntary and you do not have to participate if you do not want to. If you say no, this will not affect you negatively in any way. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee (HREC) at Stellenbosch University** and will follow accepted and applicable National and International ethical guidelines , including those of the International Declaration of Helsinki October 2008.

What is this research study all about?

The aim of this study is to understand patients' opinions of things they have experienced, which have played a part in their ability to return to work after they have had a stroke. These factors will help us to understand what has helped people return to work, and what has made it difficult to go back to work.

The study will be conducted at the Delft, Elsies River and Bishop Lavis communities. We would like about 20 people to take part in the study.

Individual interviews will be held, at a place most convenient for you. In the interviews, we will discuss the reasons that have either helped you to return to work, or made it difficult to return to work. Your opinions will be recorded on a recorder and in writing. This information will then be put together and used to identify which factors helped you return to work, and which factors made it difficult to return to work. If a direct statement made by one of the people participating in the study is used in the report, the name of this person will not be mentioned. They will be referred to as "participant 1, or 2", and so on.

Why have you been invited to take part?

You have been asked to take part if:

- You have suffered a stroke and are between the ages of 18 and 65 years.
- You had a first stroke within the last 2 years.
- You were working before the stroke or are planning to start working.
- You permanently live in South Africa.
- You are currently going for treatment or have already gone for treatment of the stroke at a hospital or clinic, community health centre or stroke groups, or

What will your responsibilities be?

If you agree to take part, you will be asked to give your opinion on what issues or challenges you faced when you returned to work, or when you tried to return to work. You will also be asked to give your opinion on the things that helped you to return to work if you have returned to work.

Will you benefit from taking part in this research?

This research will help to understand the things which patients experience after having a stroke, when they try to return to work. Once these are identified, some of them can hopefully be worked on during rehabilitation to better prepare patients if they want to return to work.

Are there in risks involved in you taking part in this research?

No medicines or treatment is used during this study and there are therefore no risks when taking part in this study.

Who will have access to your medical records?

All information collected during the study will be treated as confidential and protected. If any direct comments from the people who take part are used, the person will not be identified. Only the researcher will have access to specific information. The recorded information will be typed out but no names will be given on the recorded information. The completed report will be published in a medical journal.

Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study but your transport and meal costs will be covered for the study visit. There will be no costs involved for you, if you do take part.

Is there anything else that you should know or do?

You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed.

You will receive a copy of this information and consent form for your own records.

If you are willing to participate in this study please sign the attached Declaration of Consent and hand it to the investigator.

Yours sincerely

Saleema Kriel
Principal Investigator

Declaration by participant

By signing below, I ……..…….. agree to take part in a research study entitled **……..**
.

I declare that:

- I have read the attached information leaflet and it is written in a language that I can clearly understand.
- I have had a chance to ask questions and all my questions have been properly answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be negatively affected in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the process that I agree to.

Signed at (*place*) .....…..…….. On (*date*) ……...…….. 2009.

.....

Signature of participant

Declaration by investigator

I *(name)* ……..…… declare that:

- I explained the information in this document to ……..
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (If an interpreter is used then the interpreter must sign the declaration below.

Signed at (*place*) .....…..…….. on (*date*) ……...…….. 2010.

....
Signature of investigator **Signature of witness**

Declaration by interpreter

I *(name)* ……..…… declare that:

- I assisted the investigator (name) ……. to explain the information in this document to (name of participant) ……..…….. using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) .....…..…….. on (*date*) ……...……..2010

....

Signature of interpreter **Signature of witness**