Return to Work After Stroke; Rate, Facilitators and Barriers in Buffalo City, South Africa

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Abstract

Background: Stroke is an alarming medical and public health problem globally. Effects of stroke are strongly linked to an increase in burden of care and loss in productivity. Literature shows that a large proportion of stroke survivors do not return to work (RTW).

Objectives: How many stroke survivors returned to work and what variables influence returning to work for stroke survivors in the Buffalo City Metropolitan Municipality (BCM), Eastern Cape, South Africa?

Methods: A descriptive, mixed methods study was conducted between March 2015 and March 2017. Quantitative data was collected from 40 participants. Demographic data, work history, and barriers and facilitators were identified with use of the *International Classification of Functioning, Disability and Health*. Qualitative data was collected from seven purposively selected participants using a semi-structured interview and was thematically analysed.

Results: Only 32% of participants successfully returned to work following their stroke. Those that returned to work had a low Modified Rankin Scale (mRS) and tended to have employment in white-collar work. Main barriers for returning to work that have been identified included: poor functional use of the affected arm and leg, poor memory, difficulty with speech and poor support and guidance from healthcare professionals and employers. Main facilitators included: dislike of being bored, financial needs to support one's self and family, enjoyment of work as well as supportive and understanding healthcare professionals and employers.

Conclusion: The RTW rate after stroke in BCM is low. Identification of goals and collaboration between all role players should commence at the earliest time possible, so as to begin the process of return to work.

Abstrak

Agtergrond: Beroerte is 'n kommerwekkende mediese en openbare gesondheidsprobleem wêreldwyd. Die effekte van beroerte word sterk gekoppel tot 'n toename in die las van sorg en verlies in produktiwiteit. Literatuur wys dat ‘n groot porsie van beroerte-oorlewendes nie terugkeer na die werk nie.

Objektief: Hoeveel beroerte-oorlewendes keer terug na werk en watter veranderlikes beïnvloed terugkeer na die werk vir beroerte-oorlewendes in die Buffalo City Metropolitaanse Munisipaliteit (BCM), Oos-Kaap, Suid-Afrika?

Metodes: 'n Beskrywende, gemengde metodes studie is uitgevoer tussen Maart 2015 en Maart 2017. Kwantitatiewe data is ingesamel van 40 deelnemers. Demografiese data, werkgeskiedenis en, met behulp van die *Internasionale Klassifikasie van Funksionering, Gestremdheid en Gesondheid*, is hindernisse en fasiliteerders geïdentifiseer. Kwalitatiewe data was versamel vanaf sewe doelgerigte geselekteerde deelnemers deur middel van 'n semi-gestruktureerde onderhoud en is tematies geanaliseer.

Bevindinge: Slegs 32% van die deelnemers het suksesvol terug gekeer na werk na hul beroete. Diegene wat terug gekeer het na die werk het 'n lae mRS gehad en was geneig om te werk in ‘n “wit boordjie” werk. Die belangrikste hindernisse geïdentifiseer vir terugkeer na werk, sluit in: swak funksionele gebruik van die angetaste arm en been, swak geheue, moeilike spraak en swak ondersteuning en leiding van gesondheidswerkers en werkgewers. Hooffasiliteerders sluit in: hou nie daarvan om verveeld te wees nie, finansiële behoeftes om self en familie te onderhou, werk genot, sowel as ondersteuning en begrip van gesondheidswerkers en werkgewers.

Gevolgtrekking: Die terugkeer na werk-koers ná beroerte in die BCM is laag. Identifikasie van doelstellings en samewerking tussen alle rolspelers moet so spoedig moontlik begin om sodoende die proses van terugkeer na werk te begin.

Introduction

Background

Stroke is an alarming medical and public health problem globally, but more so in lower income countries. One in six people worldwide will have a stroke in his or her lifetime, with Africa carrying a large and disproportionate burden of poor stroke outcomes (Akinyemi *et al.* 2015). In addition to having one of the highest stroke incident rates globally, the rate at which incidents are increasing is also very high in Africa (Owolabi *et al.* 2015). Effects of stroke go beyond the direct health impact; it is also strongly linked to an increased burden on families, caregivers and society, and to a loss in productivity (Akinyemi *et al.* 2015). This is having a detrimental impact on the emerging economies of Africa, including those of South Africa (Akinyemi *et al.* 2015).

The exact statistics for stroke in South Africa and particularily in the Eastern Cape are unknown. However, it has been documented in South Africa that stroke is the main cause of neuropsychological impairment in adults as well as a leading cause of illness and disability (Freeme & Casteleijn 2014; Ross & Deverell 2004). Together with this, studies have shown that there is an increased proportion of stroke survivors falling within the working-age group (Duff, Ntsiea & Mudzi 2014; O'Brien & Wolf 2010).

Unemployment levels in South Africa are high and levels of poverty are increasing (Statistics South Africa 2014). The Eastern Cape, one of the larger provinces in South Africa, is home to 12.8% of the national population; 70.6% of the provincial population live in poverty (Statistics South Africa 2014). In 2016, nationally, 1.2% of persons with a disability were employed (Department of Labour 2016), which was an improvement from the 2013 Figure of 0.9% but still below the 1.3% achieved in 2003 (Department of Labour 2014). The Department of Labour (2014) set the goal of

achieving 2% representation of persons with disability being employed by 2015, which has not been achieved.

Returning to work is one of the important outcome measures of post-stroke life satisfaction and participation (Duff *et al.* 2014; Giaquinto & Ring 2007; Hofgren *et al.* 2007). Many stroke survivors of working age wish to return to work (RTW) following stroke should they have sufficient support, accommodations, accessible environments and the functional capacity to do so (Hartke, Trierweiler & Bode, 2011). It is known from international literature (Hofgren *et al.* 2007; Trygged *et al.* 2011) and a regional South African study (Duff *et al.* 2014) that a large proportion of stroke survivors do not return to work and are reliant on others and/or their state for financial support (Duff *et al.* 2014). However, there is the potential for more than 50% of stroke survivors to return to work if their cognition is relatively unimpaired, they are able to walk, they were previously employed, are young, and have a "white-collar job" skill (Harris 2014).

Research problem

Except for the Gauteng study by Duff *et al.* (2014), there is minimal information available about the rate of RTW and what factors influence this in South Africa. With an increasing number of strokes occurring in a younger demographic, who are of working age, and the imperative to ensure employement opportunities for person's with disabilities (Department of Labour, 2014), information on returning to work post stroke from demographically diverse settings is required. The Eastern Cape Province is demographically very different from Gauteng with much higher levels of unemployment and poverty (Statistics South Africa 2017).

Research question

How many stroke survivors return to work and what variables influence the this in the Buffalo City Metropolitan Municipality (BCM), Eastern Cape, South Africa?

Contribution to the field

This study was developed with the hope that the end results might benefit current and future stroke survivors of working age, healthcare professionals, and the employers who are in day-to-day contact with the survivors. This study identified facilitators and hindrances experienced by stroke survivors in the RTW process. This information should, in a small way, assist in formulating suggestions on how to strengthen facilitators and minimise the hindrances to retuning to work after stroke.

Key Focus

To explore how many stroke survivors returned to workand what variables influence this for stroke survivors in the BCM, Eastern Cape, South Africa.

Research objectives

- To determine the number of stroke survivors who returned to work in the study setting between March 2015 and March 2017
- To explore the facilitators that influence RTW post stroke
- To explore the hindrances that influence RTW post stroke

Literature Review

Key words searched for:

Work; work AND quality of life; RTW after stroke OR cerebral vascular accident (CVA); stoke OR CVA in South Africa; factors influencing RTW following stroke OR CVA; stroke OR CVA AND poverty; stoke OR CVA AND economic burden; stroke/CVA AND rehabilitation; employment in South Africa; unemployment in

South Africa; employment AND disability; employment AND disability in South Africa.

Search Processes:

The following data bases were used to search for literature using the key words above: CINAHL, EBSCOhost; Google Scholar, MEDLINE, ProQuest, PubMed, SA ePublications as well as searching through SunLearn e-thesis and e-Wits Catalogue.

The definition and importance of work

The concept of work can be defined in many ways and for the purpose of this study it shall be defined as "tasks they (people) perform for some form of remuneration" (Van Deventer & Jordaan 2005: 693). A person can be self-employed or employed by an employer. Work may be categorised into formal and informal economic activities. Formal economic activity is regulated by the government and people working within the private and public sectors with contracts, stipulated salaries and benefits (Kay 2011; Ntsiea 2013). Informal economic activity is not regulated by government or the country's economy (International Labour Organisation 2007; Kay 2011). Income generation through informal economic activity does not necessarily require high levels of education, skills, technology, and capital (International Labour Office 2014) when compared with formal economic activity. Most people do not choose to work within the informal sector, but rather do so out of a need to survive and to have an/the opportunity to engage in income-generation (International Labour Office 2014).

Work is deemed as an important activity in an adult's life; it provides people with structure in their lives, an opportunity/opportunities for social interaction, recognised social status, a sense of belonging, and it promotes physical well-being (Billet 2005; Corr & Wilmer 2003; Gilworth, Phil, Sansam & Kent 2009; Vestling, Ramel & Iwarsson 2005) over and above the income generated. Work is also a means by which a person develops a sense of identity through the experiences, challenges, personal development and fulfilment achieved (Gilworth *et al.* 2009; Hartke *et al.* 2011; Vestling

et al. 2005). Work, regardless of status or payment level (Billet 2005), is strongly related to an improved perception of a person's quality of life and often only recognised as such, once the opportunity to work is lost.

Epidemiology of Stroke

The American Heart Association defines a stroke (not otherwise specified) as "an episode of acute neurological dysfunction presumed to be caused by ischemia or hemorrhage, persisting ≥24 hours or until death…" (Sacco, R.L., Kasner, S.E., Broderick, J.P., Caplan, L.R., Connors, J.J., Culebras, A., Elkind, M.S.V., George, M.G., *et al*. 2013). Strokes are one of the most devastating neurological conditions and are the leading cause of chronic disability globally (Connor, 2004; Johnson, Onuma, Owalabi & Sachdev 2016; Lindsay, Furie, Davis, Donnan & Norrving 2014; Mukherjee & Patil 2011) and in South Africa (Connor, Breyer, Meredith, Beukes, Dubb & Fritz 2005; Freeme *et al*. 2014; Maredza, Bertram, Gómez-Olivé & Tollman 2016). Studies have shown that there is a shift in trend in stroke outcomes; strokes are now less often fatal, but are a disabling condition when survived (Duff *et al*. 2014). Surviving a stroke does not only affect the physical aspects of a person, but also has a profound impact on all areas of a person's life (Baumann *et al*. 2012; Ross & Deverell 2004) including and not limited to their cognition, their emotional reactions, their perception, as well as on all their occupational performance areas i.e. personal management, work, social and leisure.

There was an approximate global incidence of 16.9 million strokes in 2010, of which 69% were in low- and middle-income countries (Feigin, *et al*. 2014). It is expected that by 2020 stroke will be the fourth highest cause of ongoing disease burden globally (El-hajj, Salameh & Rachidi 2016). Stroke, therefore, currently is and will continue to be a public health problem (Duff *et al*. 2014).

The prevalence rate of stroke in Africa is 963/100 000 with an incidence of 315/100 000 (Akinyemi *et al*. 2015). Every year there are 3.2 million Africans who suffer from a

stroke (Akinyemi *et al*. 2015) and the number is rising. Global burden of disease data reflects that between 1991(mean: 129.4/100 000) and 2010 (mean: 148.4/100 000) South Africa had an increase in age-standardised ischemic stroke of 5.2% (Owolabi *et al*. 2015). Urbanisation, lifestyle-changes and other socio-econimic factors couple with poor preventative and promotive education can be recognised as extenaiting factors for the increase in incidence, especially in individuals of a younger age(Owolabi *et al*. 2015)

Stroke has been identified a "catastrophic illness" in South Africa at the Joint World Congress on Stroke in 2006 (Culebras 2006). In South Africa, there were approximately an additional 75 000 new stroke cases during 2008 (Bertram *et al*. 2013). Maredza et al (2015) found that in 2011 at least 33 500 strokes occurred in rural South Africa and that the estimated annual occurrence of stroke is at least 30 000 in rural South Africa. Maredza et al (2015) therefore estimated the incidence for stroke to be 244/100 000 persons per year.

Historically, stroke is known to be a disease of late adulthood. However, incidents are increasing in younger adults (Brey & Wolf 2016; Feigin *et al*. 2014; Wolfenden & Grace 2015). Stroke in younger individuals (age <50) occur with an incidence of 6 to 20 per 100 000 people per year, while almost 5% of all strokes occur in persons younger than 45 years of age (Cotoi *et al*. 2016; Ntsiea, 2013). Thus there is an increasing proportion of stroke survivors who are of a working age (Duff *et al*. 2014; Hartke *et al*. 2011; O'Brien & Wolf 2010), and have many years before retirement.

Stroke and rate of retrun to work

Literature from studies done in the United States of America, the United Kingdom, Japan and Sweden have shown that the rates of RTW widely vary from 1% to 91% with variances occuring between countries as well as within the same country (Duff *et al*. 2014; Hofgren *et al*. 2007; Trygged *et al*. 2011). The wide range of RTW rates in the studies can be a result of different definitions of work used, varied age groups of

participants, nature and severity of the stroke and the type of rehabilitation received, cultural factors and disability compensation programmes (Duff *et al.* 2014). For example, participants are invited from different settings or databases, such as regional stroke studies or hospital-based studies, while other studies only have participants that have participated in vocational rehabilitation programmes (Wozniak & Kittner 2002). Harris (2014) conducted a systematic review of studies which featured stroke and RTW rates. The review compared and contrasted the studies' findings and presented the summarized data in table 1.

Table 1 : Summary of research findings on RTW rates; adapted from Harris (2014)

Author	Country or location	Purpose of the study	Study population age range	Methodology/ Design	Rate of RTW description
Duff (2014)	South Africa	Not given	• 18-64 years	Not given	• 34%
Kauaranen (2013)	Finland	Assess cognitive severity of stroke as a barrier to RTW	• 18-65 years	Consecutive sampling (n=140)	• 41% 6 months post stroke
Peters (2013)	Nigeria	Determinants of RTW in Nigeria	• 24-90 years	Not given	• 55%
Andersen (2012)	Denmark	Fatigue as a factor for RTW	• <60 years	Cohort from prospective study (n=83)	• 53% in 1st year post stroke • 58% by 2nd year post stroke
Trygged (2011)	Sweden	To determine socioeconomic factors to predict RTW	• 40-59 years	Prospective cohort (n=7081)	• 69%

Author	Country or location	Purpose of the study	• Study population age range	Methodology/ Design	• Rate of RTW description
Hofgren (2010)	Sweden	Describe employment status after 1 year	≤65 years	Consecutive sampling (n=72)	18% in 1st year post stroke
Tanaka (2011)	Japan	To examine factors associated with early RTW	• Working age	Prospective cohort (n=335)	• 30% in 1st month
Saeki (2010)	Japan	Determinants of early RTW after stroke	• ≤65 years	Prospective cohort (n=253)	• 55% in first 400 days post stroke
O'Brien (2010)	United States	To assess work outcomes	• 30-65 years	Consecutive sampling (n=98)	• 56% 6 months post stroke
Busch (2009)	United Kingdom	Determinants for RTW in multi-ethnic urban population	• -	Cohort from prospective study (n=266)	• 35% in 1st year post stroke
Gabriele (2009)	Germany	Impact of subjective perception on RTW	• ≤64 years	Prospective longitudinal study (n=60)	• 26.7% in 1st year post stroke
Glozier (2008)	New Zealand	Determinants of psychiatric morbidity in younger adults and RTW after stroke	• ≥15 years	Cohort from prospective study (n=210)	• 53%

A study done by Duff in Johannesburg, South Africa found that 66.0% of stroke survivors (n=97) did not retrun to work after the stroke (Duff *et al*. 2014). Of the 34% that returned to work, 86.7% returned to the same job as before and 63.3% resumed fulltime employment (Duff *et al*. 2014). Duff (2014) deduced that either some employers were accommodating of their employees and/or recovery following the stroke was conducive for returning to work. The percentage of stroke survivors who

had their work adapted to suit their needs lead Duff to reason that the employers were accommodating. This belief that is in line with findings from Treger *et al*. (2007), who showed that 58% of stroke survivors' work demands were adapted to their individual needs.

A Canadian study by Mayo *et al*. (2002) and a South African study by Kusambiza-Kiingi, Maleka and Ntsiea (2017) revealed that stroke survivors generally struggle the most with the domain of work, while Edwards *et al*. (2006) showed decreased satisfaction in stroke survivors' ability to engage in productive pursuits such as work. Many reasons may contribute to these findings thus, in the context of this study, the International Classification of Functioning, Disability and Health (ICF) was used to explore factors facilitating the RTW for stroke survivors.

The International Classification of Functioning, Disability and Health (ICF)

The ICF is a universal and multi-purposive framework (Figure 1) in which health and health-related domains can be classified (World Health Organisation, 2002). These domains assist with describing changes in a person's body functions and structuresas well as assist in determining their capacity in a standard environment and their level of performance in their own environments (WHO, 2002) following a health-related occurrence. It further looks at environmental and personal factors that may influence a person's capacity and performance (WHO, 2002).

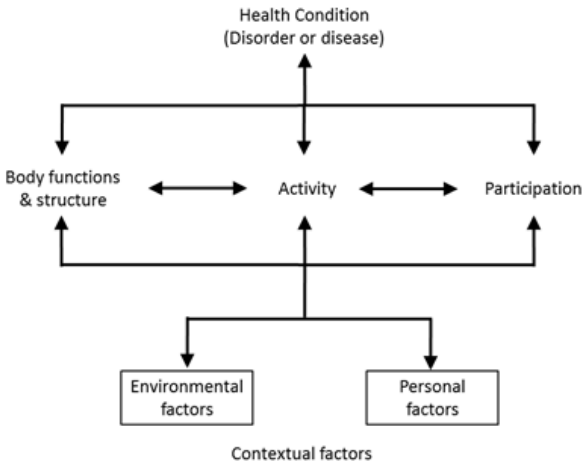

Figure 1: Diagrammatic presentation of the ICF (WHO, 2002)

The ICF provided the researcher with a framework to organise and analyse the data of perceived facilitators and barriers for returning to work by stroke survivors. The appendix to the questionnaire, on which the participants' perceived facilitators and barriers were recorded, was formulated using ICF second level domains under body functions and environmental factors as well as third level domain of activity and participation.

Factors that influence return to work following a stroke

Body function, activity and participation: Stroke severity and residual impairment are considered to be of the strongest predictors of RTW following a stroke (Balasooriya-Smeekens *et al.* 2016; Harris 2014; Wang *et al.* 2014). Stroke survivors with higher functional abilities (including but not limited to the ability to walk adequately and fairly intact cognition) and lower mRS scores have a greater likelihood of returning to work (Bonner *et al.* 2016; Gabriele & Renate 2009; Harris 2014; Wang *et al.* 2014) than those with more impairments. There is a general understanding in the literature that the extent and severity of the communicative (Duff *et al.* 2014; Hartke *et al.* 2011), cognitive (Duff *et al.* 2014; Hartke *et al.* 2011), physical and functional impairments (Duff *et al.* 2014; Hartke *et al.* 2011; Wang et al 2014), depression and fatigue (Duff *et al.* 2014) are predictive for RTW.

Cognitive impairment, especially coupled with an aphasia, is a poor prognostic factor for RTW (Gabriele & Renate 2009). Gilworth *et al.* (2009) found that persistent symptoms of the stroke (concentration and attention difficulties, irritability, headaches, memory difficulties and fatigue) are often barriers for returning to work. These impairments can be referred to as the invisible impairments of stroke and are often misunderstood by others (employers, healthcare professionals and family) and stroke survivors themselves (Balasooriya-Smeekens *et al.* 2016). Survivors can be perceived as being lazy, imagining problems, too sick and/or underperforming in their jobs as a result of these invisible impairments (Balasooriya-Smeekens *et al.* 2016).

Personal factors: In a systematic review by Wang *et al.* (2014) it was found that in most studies gender had no clear statistical relevance to RTW post stroke. However, some studies showed that women had an increased likelihood to return, whereas others showed that men had higher rates (Balasooriya-Smeekens *et al.* 2016). The systematic review further concluded that marital status or the side of stroke did not have a statistically significant impact on the rates of RTW (Wang *et al.* 2014).

There is no clear relationship between the rate of RTW and age (Gilworth *et al.* 2009), however recent research has linked younger age demographics at the time of the stroke with better RTW outcomes (Bonner *et al.* 2016; Harris 2014; Wang *et al.* 2014).

A survivor's premorbid type of work (skilled vs. unskilled) influences RTW rates (Duff *et al.* 2014; Hofgren, *et al.* 2007; Trygged, *et al.* 2011). Higher skilled workers (white-collar) have better RTW rates than unskilled or manual labour workers/employees (blue-collar) (Gilworth *et al.* 2009; Gabriele & Renate 2009; Harris 2014). The reason for this may be the nature and demands of the job. Blue-collar jobs tend to be more manual and physical in nature and, following a stroke, these tasks may be difficult to perform.

Education level and income have also been linked to RTW (Bonner *et al.* 2016; Harris 2014) as these often precede and result from the type of work a person engages in.

More often than not, the more educated the person, the more likely they would have a "skilled" and "admistrative" white-collar job, which results in a higher income and improved return to work rates. Those with lower levels of education tend to engage in blue-collar employment, which tend to have lower income levels and may be less flexible and have higher productivity expectations that may not be realistically attained or sustained by a stroke survivor (Bonner *et al.* 2016; Harris 2014).

The period of time a survivor has been working prior to the stroke can be a predictive factor. The longer the survivor has been working, coupled with a positive and supportive environment, the more likely it is that they will return (Balasooriya-Smeekens *et al.* 2016).

Psychological factors such as low self-esteem, stress and depression have been identified as barriers for RTW (Balasooriya-Smeekens *et al.* 2016; Duff *et al.* 2014; Wang *et al.* 2014). Whereas acceptance of impairment, self-motivation, positive self-perception and realistic goals have been seen as enablers for RTW (Balasooriya-Smeekens *et al.* 2016; Corr & Wilmer, 2003; Gilworth *et al.* 2009; Harris, 2014; Wang *et al.* 2014). Furthermore, Balasooriya-Smeekens *et al.* (2016) found that the survivors ability to adjust to their current level of functioning assisted with returning and remaining in the work environment.

The relationship between life satisfaction and prognosis for RTW are inter-dependent. Vestling et al and Hartke *et al.* (2011), have linked a better quality of life with better outcomes for RTW. Whereas, other studies report that stroke survivors who return have better perceptions of their quality of life and life satisfaction as well as fewer unmet needs (Gabriele & Renate, 2009; Hartke *et al.* 2011). Duff *et al.* (2014) found that stroke survivors who enjoyed their jobs and gained fulfilment were more likely to return. The challenges that their job provides and the personal development that they experience when participating in their job improves self-esteem and self-perception

as well as economic well-being (Gilworth *et al.* 2009). Duff *et al.* (2014) also found that two-thirds of their participants returned to work out of boredom.

Duff *et al.* (2014) found that the most common reason for returning to work was financial needs. A large percentage of the Stroke survivors in the study remained the main bread winner for their families following their stroke, despite not returning to work or earning an income. This was also found to be true in a study by Corr & Wilmer (2003). Gilworth *et al.* (2009) suggests that it is more challenging to return to work once a stroke survivor is dependent on non-work related income sources such as social grants and/or benefits.

Environmental factors: The access to rehabilitation services, especially that of vocational rehabilitation, can influence a person's ability to RTW (Balasooriya-Smeekens *et al.* 2016; Duff *et al.* 2014). Yet, vocational rehabilitation post stroke (both pre and post discharge) receives much less attention than functional exercises. South Africa is particular is known for experiencing a shortage of post-discharge rehabilitation services for patients using government facilities (Mayo *et al.* 2000; Rhoda *et al.* 2009; Kusambiza-Kiingi, Maleka & Ntsiea 2017). If minimal or no rehabilitation is received, a stroke survivor's skills might not be sufficiently retrained in the physical, cognitive or vocational domains for successful re-integration into the work place. Guidance from healthcare professionals can be seen as both a facilitator and a barrier to RTW. The medical professionals' view of the survivor is often limited to that of being the patient and may not take into account the larger social context of the survivor. Gilworth *et al.* (2009) discussed how medical advice on delaying returning to work may be misguided and could be seen as a barrier, as some survivors felt that they were ready to return before the time medically advised. Ongoing personalised support - medical, emotional, and informational - following discharge has been identified as a necessary factor in coping with residual impairments and facilitate the process of returning to work (Balasooriya-Smeekens *et al.* 2016; Gilworth *et al.* 2009). Returning to work at the earliest opportunity can be seen as an important step in the

recovery process (Gilworth *et al.* 2009) because the longer a survivor is absent from work, the more difficult it is to return.

Employers can be a facilitator or a barrier for returning to work. Enabling characteristics include: being flexible and supportive, an accepting and understanding attitude towards disability, understanding stroke-related challenges and providing accommodations (Balasooriya-Smeekens *et al.* 2016; Bonner *et al.* 2016). They could also hinder returning to work by being unsupportive, providing an extended leave of absence, having poor or limited knowledge and professionalism around disability in the work place, concerns around productivity, or outside perception of the company and the company's performance (Balasooriya-Smeekens *et al.* 2016; Giaquinto & Ring 2007). Gilworth *et al.* (2009) found that some stroke survivors who had taken early retirement felt that the processes leading to the decision were not clear and alternatives or possibilities were not fully explored. Furthermore, some felt that early retirement was pushed upon them.

In the study by Balasooriya-Smeekens *et al.* (2016), stroke survivors expressed how talking with their employer, Human Resources and Occupational Health services helped create a supportive environment as all parties involved have the same expectations and awareness of the survivors capabilities and challenges. This openness and transparency allowed for appropriate, reasonable accommodations to be implemented which included graded RTW processes, reduced working hours and other accommodations.

Lack of transport to the place of employment is an additional environmental factor that can prevent return to work (Duff *et al.* 2014). The nature of the resultant disability may prevent a person from accessing public transportation or independently using their own personal transportation (Balasooriya-Smeekens *et al.* 2016; Duff *et al.* 2014). Alternate arrangements may be costly in terms of finances, time, energy, and personnel.

High levels of support from family and friends can be an important and positive influence on a stroke survivor's ability to return to work (Bonner *et al.* 2016; Wang *et al.* 2014) and can also be associated with faster and increased range of functional improvement (Bonner *et al.* 2016).

Research methods and design

Design

This was a study of descriptive mixed methods design (Creswell 2003; Kroll, Neri & Miller 2005). The research was conducted in two sequential phases as described by Kroll, *et al.* (2005) and presented in Figure 2; Phase one being the quantitative phase and Phase two being the qualitative phase. In the quantitative phase, the number of stroke survivors that have returned to work and the variables that facilitated or hindered RTW was calculated. The qualitative aspect allowed the development of a more comprehensive picture of post stroke employment as well as the role of barriers and faciliators, as the participants provided rich contextual information.

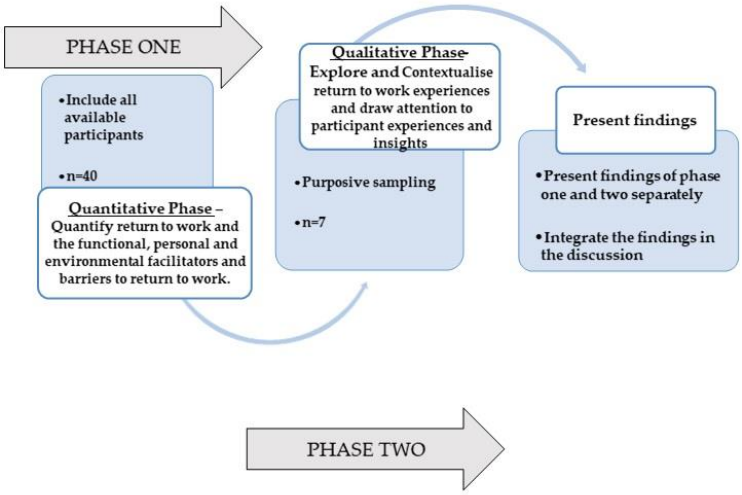

Figure 2: Diagrammatic representation of the sequential mixed methods study design.

Setting

The study was done in the BCM (see Figure 3) in the Eastern Cape Province. This included urban, peri-urban and rural catchment areas. The population ranges from the impoverished, through blue-collar workers to white-collar workers and spanned across all races. The main languages spoken are isiXhosa (76.9%) and English (10.7%) with the remainder of the official languages accounting for the difference (12%)(Statistics South Africa, 2011).

Figure 3: Map of Buffalo City Metropolitan Municipality (Buffalo City Metropolitan Municipality 2017)

The picture of employment statistics of the Eastern Cape as a province together with the specific statistics of the BCM (Statistics South Africa, 2017) are represented in Tables 2 and 3.

Table 2.:Employment information of the working age (15-64) population in the Eastern Cape and Buffalo City Municipality (Statistics South Africa, 2017)

Jan-March 2017		Population (15-64 years)	Labour Force	Employed	Unemployed	Not economically active	Discouraged	Other	Unemployment rate	Employed/population ratio (Absorption)	Labour force participation Rate
	Thousands	Percentage (%)									
Eastern Cape	Official	4 178	2 126	1 442	684	2 052	370	1 682	32,20	34,50	50,90
	Expanded	4 178	2 555	1 442	1 113	1 623	-	-	43,60	34,50	61,10
Buffalo City Municipality	Official	506	365	257	107	141	5	136	29.5	50.80	50.8
	Expanded	506	381	257	123	125	-	-	32.4	72.10	75.3

Procedure

Phase one: Quantitative Phase

The study population was identified, and contact details sourced, from three tertiary level hospitals in the area – two government funded hospitals and one private healthcare facility. As shown in Figure 4, persons of working age (18 to 64 years), who lived in BCM, suffered a stroke between 01 January 2012 and 31 December 2015, and accessed one of the three healthcare facilities were included in the study.

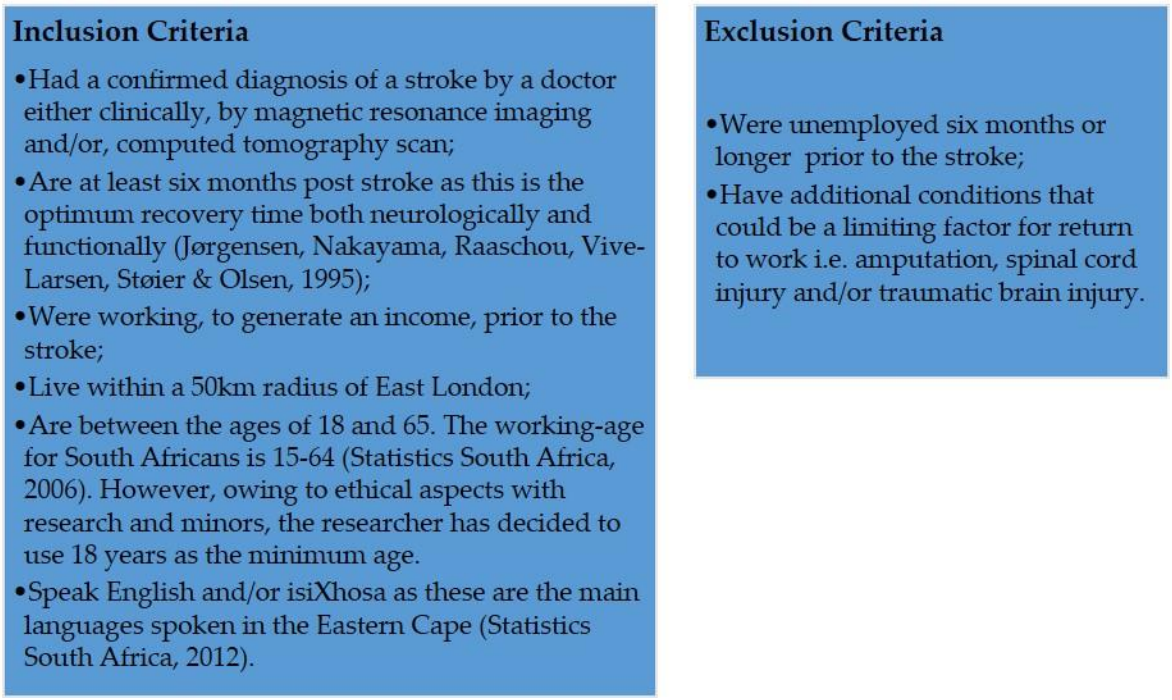

Figure 4: Study inclusion and exclusion criteria

A total of 251 people were identified. A sample size of 75 or more was required to allow for inferential analysis. However, of the 251 people, 211 did not/could not participate in the study due to the reasons presented in Figure 5. A total of 40 potential participants remained and participated in the study. As a result of having a small size of the sample group descriptive analyisis was used.

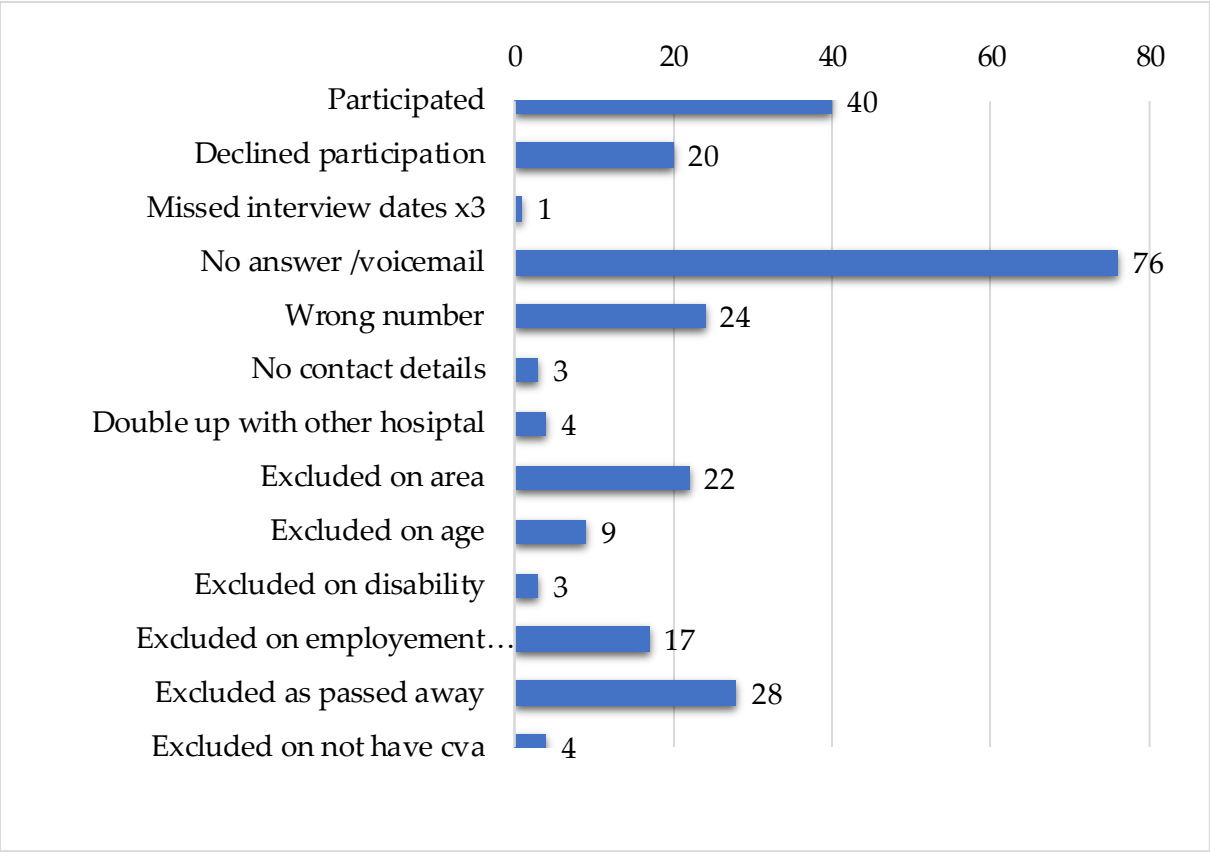

Figure 5: Graphical representation of people included and excluded (N=251)

Quantitative data was collected using a self-developed, structured questionnaire (see Appendix 3). The questionnaire was based on one used in a similar study conducted by Duff *et al*. (2014). The main difference between the two questionnaires was the use of the International Classification of Functioning, Disability and Health (ICF) as framework (WHO, 2002) in the current study, to provide an overarching structure for questions on facilitating and inhibiting variables for returning to work.

The questionnaire comprised of the following six sections:

- Section A -Demographic and medical data;
- Section B - Financial and work history;
- Section C – Determining factors for successful RTW (administered only if participant has successfully returned to work);

- Section D – Determining factors for having stopped working after initially returning to work (administered only if participant had initially returned to work but had since stopped);
- Section E – Determining factors for not returning to work (administered only if participant had not returned to work in any way) and;
- Section F, the Modified Rankin Scale (Wilson, Hareendran, Grant, Baird, Schulz, Muir & Bone, 2002) - Determining the participants' level of functioning at the time of the study.

Sections A, B and F were completed with all participants, while sections C, D and, E were completed with those fitting the relevant past and current work status.

The content validity of the questionnaire was determined by a reference group of peers who had neuro-rehabilitation and/or vocational rehabilitation experience. Further changes to the questionnaire were made during the training of translators, who were first language isiXhosa speaking individuals. These changes ensured plain language English that eased verbal translation to isiXhosa during the interviews. The questionnaire was further refined following the pilot study, which was conducted with a participant not included in the research.

Data was collected between March 2015 and March 2017 by the researcher, an occupational therapist, assisted by two translators. The two translators received training, signed confidentiality forms and contributed to the finalisation of data collection tools.The researcher administered the questionairres as part of the the first interviews and, when necessary, the translators verbally translated the questions and the answers. Translation of the direct questions was standardised, however should further explanation of the questions was needed the translators translated as required by the situation. mRS scores were determined through observation by the researcher and self/proxy reporting of the level of assistance the participant requires in performing their occupations. Participants were interviewed in their homes.

The researcher captured the data using Microsoft Office Excel. Data was mainly categorical in nature and descriptive analysis was done with assistance from a statistician. Due to the small size of the sample, no inferential analysis was done.

Phase two: Qualitative phase

Following Phase one of the study, seven participants were identified using purposive sampling (Carter, Lubinsky, Domholdt & Domholdt, 2011) to participate in Phase two based on their expression and richness of their experiences of the return to work process. Of the seven participants: two had successfully returned to work, one had attempted to return to work, but had since stopped, and four did not return.

Data was collected through semi-structured interviews, with the guidance of an interview schedule (see appendix 4), by the researcher with the assistance of one of the two translators (when necessary). The translator who assisted during the interviews was consistent. The translator translated the questions ask by the researcher, the answers from the participant and translated additional explanation of the questions provided by the researcher. The interviews were carried out at the participants' homes and lasted 15-40 minutes, depending on the amount of information that the participant shared. The interviews were voice recorded with verbal permission from participants. Data saturation was achieved with the seven interviews.

The voice recordings were transcribed by the researcher (English recordings) and an isiXhosa academic (isiXhosa recordings). The transcribed isiXhosa recordings were translated into written English by a volunteer who is proficient in both spoken and written English and isiXhosa.

Thematic analysis (Guest, MacQueen & Namey, 2012) was applied to identify and describe the implicit and explicit factors that impacted return to work. Codes were

identified and then collated into emerging themes. The researcher and one supervisor analysed the data separately and reached a consensus on themes in order to enhance the credibility of the findings.

Ethical considerations

Participation in the study was voluntary and participants were asked to sign a written informed consent following an explanation of the study in their language of preference (see Appendices 1 & 2). This informed consent, when necessary, was verbally translated into isiXhosa by the translator. Special consideration was given to determine the participants' competency for making an informed decision. Where participants did not have the competence, the primary caregiver gave written informed consent on their behalf, and either written or verbal assent from the participant was obtained. Participants and caregivers were informed about confidentiality, that the researcher or translator would not divulge any personal information and that their identities would be kept confidential. Approval for this study was obtained from the Committee for Human Research at Stellenbosch University (S14/10/216). Further approval to carry out the research and gather names and contact details was obtained from the Department of Health, Eastern Cape, as well as from the research committee or CEO's of the hospitals.

Results

Phase one

Demographic and medical details

Forty stroke survivors comprising of 18 (45%) men and 22 (55%) women with a mean age of 49.65 (SD= 9.644) years participated in the study. Additional socio-demographic and medical characteristics of the participants are represented in Table 4.

Table 4: Socio-demographic and medical characteristics of the participants

		Total (n)	Percentage (%)
Age	18-29	2	5
	30-39	4	10
	40-49	13	32,5
	50-59	17	42,5
	60-65	4	10
Gender	Men	18	45
	Women	22	55
Marital status	Not married	10	25
	Married	20	50
	Divorced	4	10
	Separated	1	2,5
	Widowed	5	12,5
Highest level of education	Post graduate degree	1	2,5
	Undergraduate degree	3	7,5
	Diploma	10	25
	Grade 12 or equivalent	11	27,5
	Up to grade 9	11	27,5
	Up to grade 7	2	5
	> grade 7	1	2,5
	No formal schooling	1	2,5

		Total (n)	Percentage (%)
Side of weakness	Right	20	50
	Left	20	50
Period since stroke	6-8 months	2	5
	9-11 months	1	2,5
	12-17 months	7	17,5
	18-24 months	10	25
	>24 months	20	50
Had previous stroke	yes	17	42,5
	no	23	57,5
Other medical conditions	yes	33	82,5
	no	7	17,5

Modified Rankin Scale (mRS) scores showed that 22 (55%) participants fell in the range of no disability to slight disability, while (4) 10% had moderate to severe or severe disability (Figure 6).

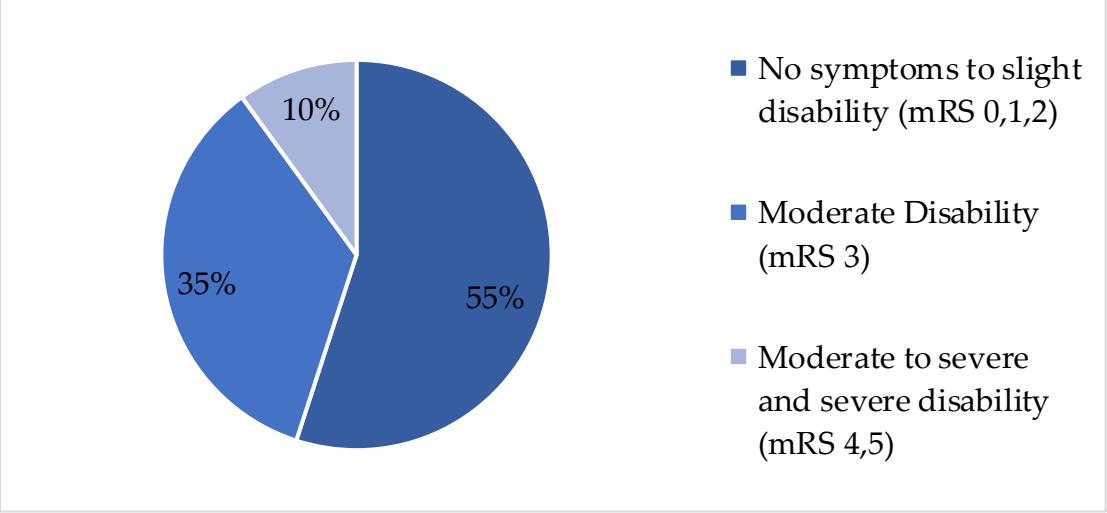

Figure 6: Participants mRS scores

Financial and work type details prior to suffering a stroke

Figure 7 shows that most participants (25%) were employed as professionals in fields such as nursing, education, information technology (I.T.) and engineering. This was followed by 17.5% working as plant and machine operators, 15% working as clerks and a further 15% working in elementary occupations which includes but are not limited to domestic cleaner, office cleaner and general labourer.

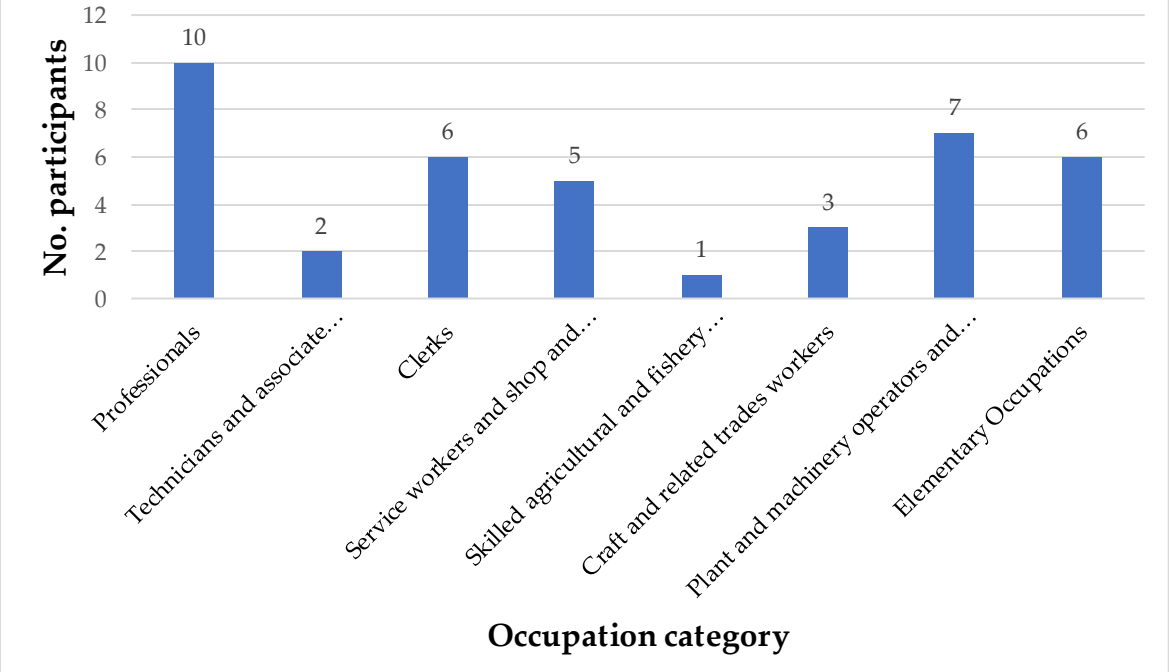

Figure 7: Classification of Occupations of the participants before the stroke in accordance South African Classification of Occupations (n = 40) (Statistics South Africa, 2012a)

Return to work

Of the 40 participants, 13 (32.5%) returned to work, 3 (7.5%) initially returned to work, but have since stopped due to challenges experienced in the work place (Figure 8). None of the participants who are currently not working have engaged in any other form of alternative income generation. Seventeen (63%) of the participants are receiving a form of disability benefit (state or private) and 10 (37%) of those, who were previously working and were either the sole or joint bread winner for the

family, are no longer able to financially support themselves nor contribute to their families finances. The type of profession showed no trends, but white-collar (61.5%) versus blue-collar (38.5%) work was associated with successful return to work. All those that returned to work had a monthly income of R5 000 or greater. Gender (45.5% of women versus 16.7% of men were working), age (42.1% of those younger than 50 where working while 23.8% of those over 50 were working) and higher levels of education (69.2% with grade 12 or above were working versus 59.2% of those with less that grade 12 were working) also seemed to have a favourable impact on being employed.

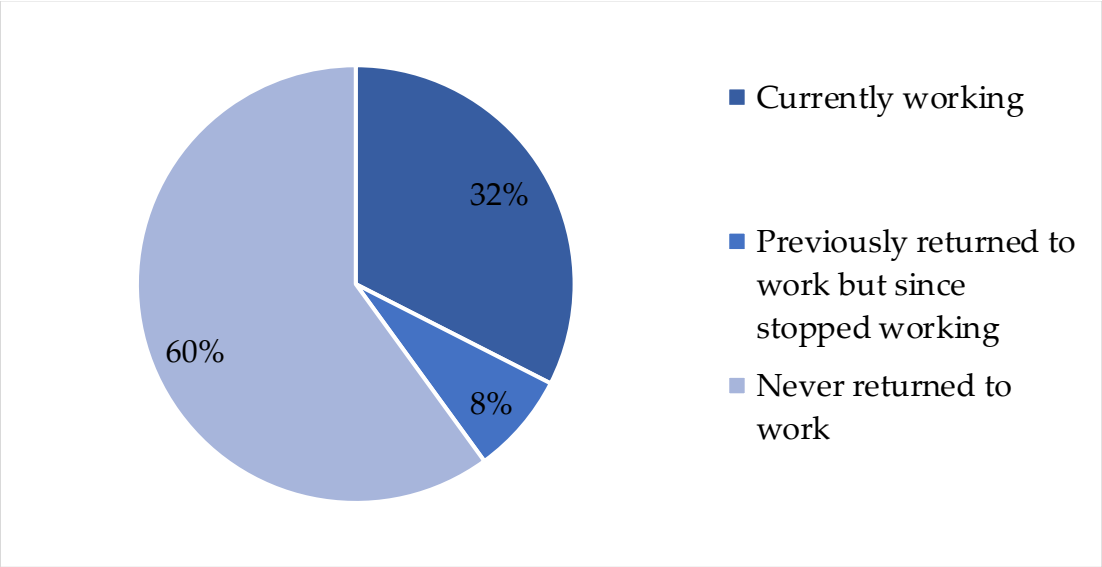

Figure 8: Rate of return to work.

Table 5 shows that all the participants (n=13) who have successfully returned to work had a mRS score of 0 (no symptoms) or 1 (no significant disability). The participants that went back to work, but who have subsequently stopped (n=3) all scored 2 (slight disability) on the mRS. Of those who did not return to work, six had scores of 2 and eighteen had scores ranging from 3 to 5 on the MRS.

Table 5: mRS scores compared to return to work status (n=40)

	No significant disability (mRS 0,1,2)	Moderate to severe disability (mRS 3, 4, 5)	Total
Successfully returned to work	13	0	13
Returned to work, but have since stopped	3	0	3
Never returned to work	6	18	24

Phase one - Barriers to return to work

For those participants that had previously returned to work (n=3), but have since stopped, the main barriers (Figure 9) for successful work reintegration were poor use of the affected arm and other environmental barriers e.g one participant was offered an alternative job and, following resignation, the new job offer fell through and another participant felt that he was a burden for his family and co-workers. The main barriers for not returning to work at all (n=24) were all impairment related. Other perceived barriers included: following doctor's recommendations, poor balance, fear of falling, stress of being moved to an alternate work place and insufficient funds for a return-to-driving assessment for a self-employed taxi driver.

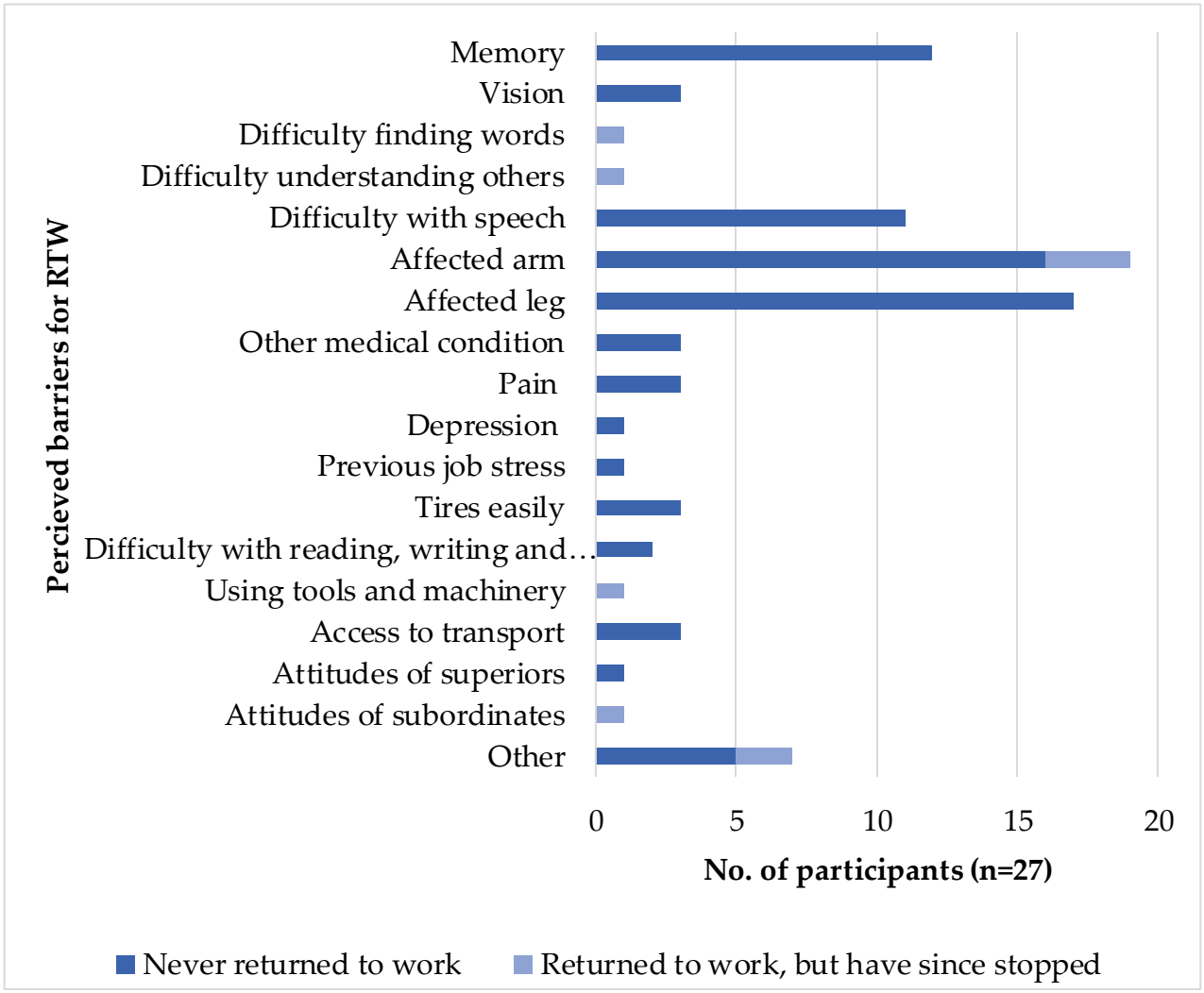

Figure 9: Perceived barriers for return to work (n=27)

Phase one – Facilitators for return to work

As seen in Figure 10, boredom, followed by financial needs and the enjoyment of work were the motivating factors for participants to return to work. The "other" reasons specified include: the ability to drive, the ability to walk - even if it is with mild limp - and the drive to provide a better life for the family than the participant had growing up.

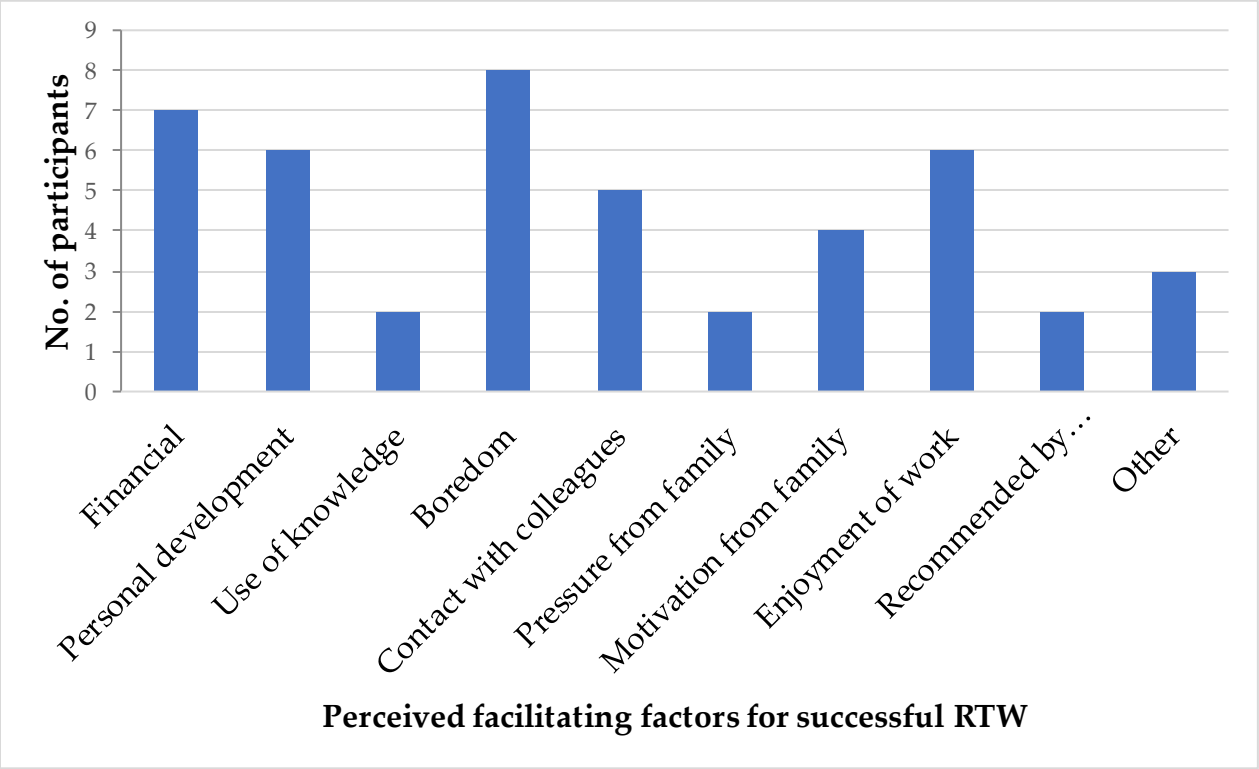

Figure 10: Facilitators for successful return to work (n = 13)

Phase two

The background information of the seven participants of Phase two is presented in table 6.

Table 6: Demographic information of participants in Phase two

Participant	**R89**	**R108**	**C2**	**C4**	**F15**	**F16**	**F109**
Pseudonym	**Fezeka**	**Busisiwe**	**Cebisa**	**Langa**	**Adam**	**Zodwa**	**Khule**
Age	56	50	36	33	41	37	40
Gender	Woman	Woman	Woman	Man	Man	Woman	Woman
Highest level of education	Grade 12 or equivalent	Grade 12 or equivalent	Post high school diploma	Grade 12 or equivalent	Up to grade 9	Grade 12 or equivalent	Grade 12 or equivalent
Monetary income	>R20 001	>R20 001	<R1500	<R1500	R1501-R5000	R10 001- 15 000	<R1500
Type of work	Professional – Land administrative officer	Clerk – Personal assistant to district director in the department of education	Service, shop and market sales workers - Health and beauty therapist	Elementary occupation – Casual manual labourer	Service, shop and market sales workers - Site manager for aa security company	Clerk – HR administration clerk for Sassa	Elementary occupation – Domestic worker
Employment group for study	Never returned to work	Returned to work	Returned to work, but has since stopped	Returned to work, but have since stopped	Never returned to work	Returned to work	Never returned to work

*Pseudonyms have been used to protect the identities of the participants

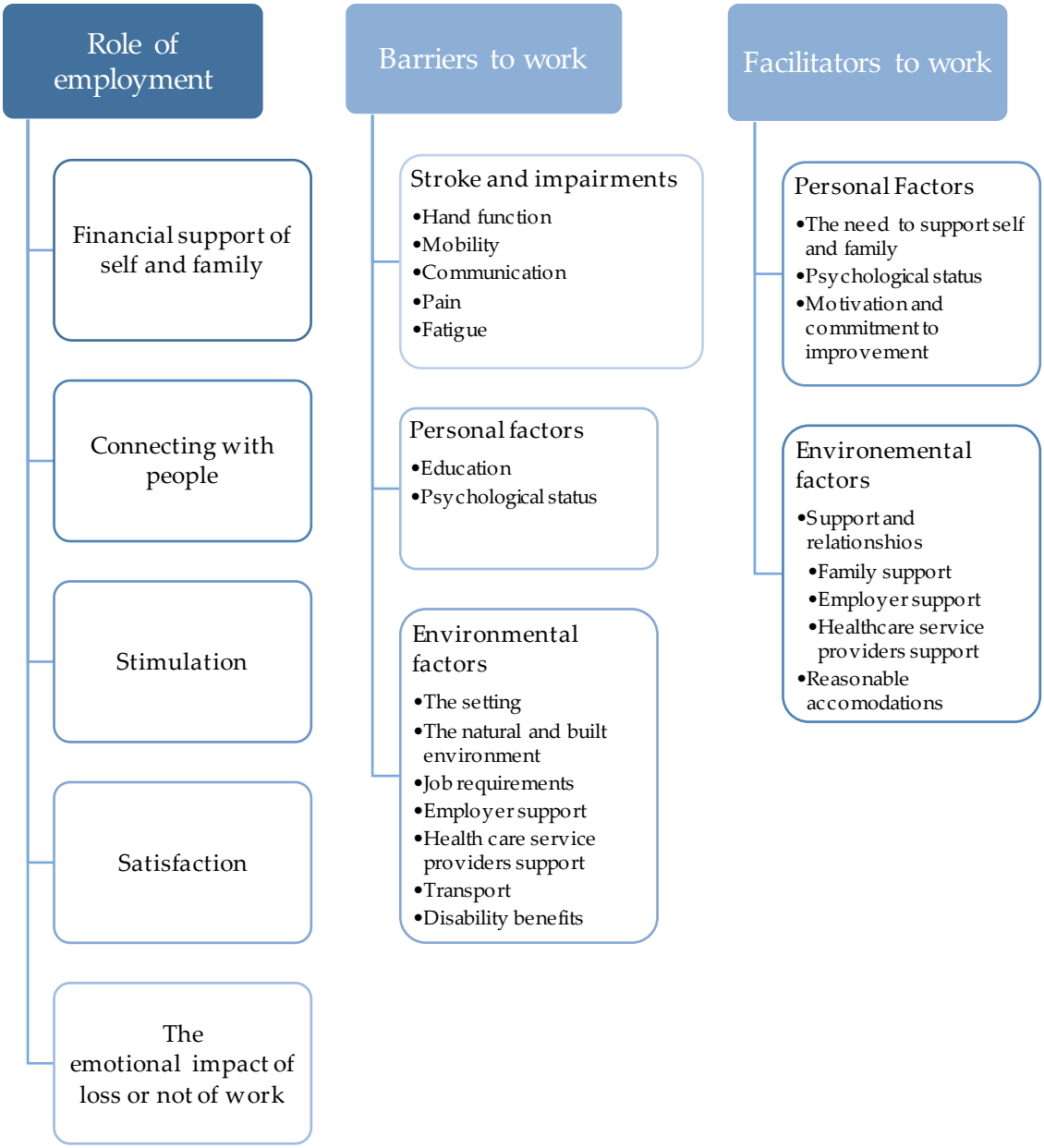

Figure 11: Themes and sub-themes that emerged from the data

Three main themes were identified: role of work; barriers to RTW and; facilitators for RTW. Each of these themes has sub-themes as shown in Figure 11.

Theme 1: Role of work

Employment played an important role in the lives of participants. Sub-themes ranged from securing an income to supporting self and family, the opportunity to connect with a wide number of people, the stimulation it provides and the satisfaction derived from it or the feelings associated with the loss of work.

Financial support of self and family: Work allowed participants to earn money and meet financial obligations.

> Langa: "I loved work- making my own money." (M, 33, stopped employment)

Cebisa expanded on this and explained that earning her own money supported her independence:

> Cebisa: "…to like take care of myself. I was born being an independent person. I love to do things on my own. I don't like to rely on other people." (W, 36, stopped employment)

The narratives also reflect the strong motivation provided by a desire to provide for the needs of families and especially minor children.

> Langa: "It's because I have a child, you know… and I want to support her…" (M, 33, stopped employment)
>
> Zodwa: "I'm living comfortably with my child, if I wasn't working my child wouldn't be living the lifestyle she is living now." (W, 37, returned to employment)
>
> Adam: "…what makes working important is like I can bring home my salary every month, you know. Let my wife and my kids have money." (M, 41, never returned to employment)

To connect with people: The social aspect of being employed and connecting with others appeared to give a sense of purpose and satisfaction not only in the work place, but in overall life satisfaction. Participants spoke of it with enjoyment, passion and enthusiasm.

> Cebisa: "I love helping other people. Making other people smile. I love it!" (W, 36, stopped employment)
>
> Fezeka: "To … interact with people [*pause*] rural people are so very very nice and kind. People in the bundus, in the rondavels are very very kind. I'm telling you. I… like to, to work with people outside, yes, very much." (W, 56, never returned to employment)
>
> Adam: "I enjoy working with people… I'm actually a peoples' person, let me say that …just to socialise with other people…" (M, 41, never returned to employment)

Satisfaction: Work has a strong relationship with life satisfaction (Alaszewski *et al*. 2007; Duff *et al*. 2014; Wang *et al*. 2014), as work can often provide enriching experiences and challenges that promote personal development and fulfilment (Vestling *et al*. 2005). This satisfaction is seen in participants' enthusiasm about their jobs.

> Fezeka: [*Smiling*] "Yoh! I like I liked it so much! I liked my work so much. Yoh! I used to enjoy it very much. I'm telling you. I loved my work so much.... [*laughs*]... really, I loved my work too much." (W, 56, never returned to employment)

> Langa: "I enjoyed because I was doing something that fulfilled me." (M, 33, stopped employment)

Stimulation: Work provides opportunities for people to be intellectually and socially stimulated and provides a sense of day-to-day purpose (Alaszewski *et al*. 2007; Duff *et al*. 2014).

> Fezeka: "I don't want to be stuck in one place doing nothing. I want to move about and meet other people... [*pause*]... and share ideas with other people." (W, 56, never returned to employment)

The emotional impact of loss of work: Loss of work can lead to a loss of identity, fear of not being able to provide for oneself or family and boredom (Alaszewski *et al*. 2007) as Langa expressed so clearly.

> Langa: "I am heartbroken because I can no longer work ... I was heartbroken. I was now in despair because I did not know how I was going to earn a living ... I just lost faith and I never knew what to do. I had lost faith in ever working again." (M, 33, stopped employment)

Whereas, returning to work provided a sense of overcoming the stroke and provided purpose in life.

> Zodwa: "It [work] is very important because if I didn't work because of this stroke or if I was medically boarded I would be dead now ... coming back to work did me good, it gave me a reason to wake up." (W, 37, returned to employment)

Thus, participants from all three groups felt that it would be important for them to return to work.

> Adam: "Oh, I would freakin' jump through the roof man - (*laughs*) - Yah, will jump through the roof if I could go back…" (M, 41, never returned to employment)

> Busisiwe: "I was looking forward to going back to work… I wanted to be at work again…To see if I can cope and try my best." (W, 50, successfully returned to employment)

Even if they have some apprehension about the process.

> Langa: "I would be happy [to go back to work] and I would be nervous at the same time …" (M, 33, stopped employment)

Theme 2: Barriers to work

Three sub-themes emerged under barriers to RTW. These were: The stroke and its impairments, personal factors and environmental factors.

The stroke and its impairments: Participants described how physical, cognitive and communicative impairments limited or prevented their re-entry into work. On a physical level the paralysis caused by the stroke, such as loss of hand and arm dexterity, created challenges.

> Fezeka: "No, this arm is so stubborn very very stubborn this one … very stubborn. It can only do do this, [*makes a crude fist and wriggles fingers in a flexed position*] this movement a bit, can move a bit, like this. But, it can't go up and down, up and down." (W, 56, never returned to employment)

Cebisa expands on the importance of work speed and bilateral hand function in certain jobs.

> Cebisa: "But the only thing I was typing, so I'm using, using only one side…you are slow, 'cause you know that when you are typing you have to use both hands… [*raised voice volume*]… 'cause I- if I didn't have stroke. If I had two hands [*pause*], I'll be in so many hotels by now. Or I'll be doing massages by now… [*lowers voice volume*] In hospitality, you have to

> work fast. So if you have one hand, how are you going to work fast? It's not as if you can't work at all, but, they want you to work fast." (W, 36, stopped employment)

The paraplegia also hampers mobility which can be a barrier for RTW, especially if the job is physical in nature and/or requires one to move around or access different environments.

> Adam: "Yeh, that I can't walk properly you know. I can't walk fast." (M, 41, never returned to employment)

The ability to communicate is an important function in every-day life and work therefore communication impairments prevented return to work.

> Adam: "… as you can hear me speak now, I don't speak properly, neh. Because this side, the li… my lips here and my tongue is, its feeling a bit stiff." (M, 41, never returned to employment)

> Fezeka: "Yes. But I… I don't think there's any chance of me going back to work now [*sigh*] at all. Because talking is a challenge to me." (W, 56, never returned to employment)

Zodwa viewed returning to work as a therapeutic tool for improving her communication.

> Zodwa: "Yes, I had a problem with my speech, I couldn't speak properly… now I'm talking clearly … my speech has improved… going back to work helped a lot." (W, 37, returned to employment)

In addition to impairments related to muscle function, the stroke also caused pain that limited the ability to work.

> Fezeka: "Yoh, lower back pain and the waist. It's killing me.. [*Sigh*] that's why I can't work any anymore now…" (W, 56, never returned to employment)

Finally, post-stroke fatigue, characterised by feeling endlessly exhausted or tired, a lack of energy and drive and difficulty engaging in routine activities (Flinn & Stube 2010) hampered return to work.

> Khule: "I always feel tired … I do want to work but the body doesn't want to." (W, 40, never returned to employment)

Personal factors: Two personal factors were identified as sub-themes under barriers to returning to work which are educational level and psychosocial status.

Cebisa felt that her educational level negatively impacted her ability to return to work following her stroke.

> Cebisa: "Uhm, I didn't finish my, ah, my diploma so I end up only getting a certificate in hospitality…most of those places they want diploma not certificate." (W, 36, stopped employment)

The other personal factor related to participants` psychosocial status. The psychosocial impact of a stroke is complex, it can manifest in a variety of ways and can have a long standing impact on a person's perception of themselves and their environment (Kirkevold, Bronken, Martinsen & Kvigne, 2012). Langa expresses the hopelessness he felt about the uncertainty of his return to work prognosis.

> Langa: "I just lost faith and I never knew what to do. I had lost faith in ever working again… I was heartbroken… I was now in despair because I did not know how I was going to earn a living." (M, 33, stopped employment)

Environmental factors: Different cities in South Africa provide different work opportunities. Cebisa found that living in a smaller city limited her opportunities in the hospitality industry.

> Cebisa: "… here in East London, it's not that big. Like you can be a supervisor in housekeeping … even in kitchen. Can be a supervisor, but, it, it's rare that you find supervisors in the kitchen, here in the East London … Other places like, Jo'burg, Cape Town- can be a concierge. And there is, err- even only one place that I've seen a bell boy, in East London. So, how can you be a concierge in East London?" (W, 36, stopped employment)

Similarly, Langa, who is skilled in fitting and turning, thought that he could return to that type of work, but that getting work in this field in East London would be a challenge owing to job scarcity.

> Langa: Yes, I can do it with one hand 'cause most of the time fitting and turning- fitting and turning you use things to measure things and you can do it with one hand … No, I didn't [look for work in this field] because jobs are scarce in that field." (M, 33, stopped employment)

The natural and built environment also created challenges. Although having successfully returned to employment, Busisiwe could not fully participate in her job as she found access to buildings in the community to be poor.

> Busisiwe: "I don't attend meetings in some halls because they are not accessible." (W, 50, successfully returned to employment)

These challenges are sometimes exacerbated by the nature of the job, as seen here in Fezeka's case.

> Fezeka: "Most of the time I was a … field worker. We needed to go out to the field [walk around the sites]. To demarcate sites for people that side … But now I can't do that anymore." (W, 56, never returned to employment)

Other participants also believed that the demands of their previous work were not in-line with their abilities following their stroke.

> Langa: "I thought it for myself, because I could see my arm; I cannot use it anymore. And I thought no I cannot do any work [manual labour]." (M, 33, stopped employment)

> Adam: "Like if I'm going to work. … It's up and down- you must be active; you know … it's not an arse job … Like run around, you know. Go there. Go there. Go sort this one out. Go sort that one out. Sort that problem out." (M, 41, never returned to employment)

Participants linked poor support from employers to poor return to work. Adam and his wife showed hurt and anger towards the employer and the lack of support they received.

> Adam's wife: "… I mean, even his own boss didn't bother seeing to him when he had a stroke… We have never heard from him again, to this day."
>
> Adam: "My … boss don't didn't care. You know, when I had a stroke, they didn't care… And they didn't support me- Not at all." (M, 41, never returned to employment)

Fezeka also expressed despair and frustration with not having employer support, "transparency", and information, especially with regards to her disability payments and livelihood.

> Fezeka: My other problem… they just stop … my payment. Stopped it, just like that, I haven't been, haven't been paid for three months now…but previously they put me on sick leave, with full pay…at the end of August, they stopped my payment… just like that. Then... then they gave a letter of ill retirement … That is what is worrying me. They never explained … to me what is going on. I never … given a chance at all ... No! Not at all! Not at all! … That's why I am worried." (W, 56, never returned to employment)

She felt her manager showed apathy.

> Fezeka: "I think she understand you know, but she does not care [employer; her situation] … They [manager] just come when you have to fill in some forms. Incapacity leave forms… Yes, even this one [colleague from work], she came here to drop off my letters…" (W, 56, never returned to employment)

Her exacerbation of the situation was clearly summed up in her wish for knowing what was happening.

> Fezeka: "They don't, they don't tell you what is going to happen, after. Transparency *[in exasperation]* not there. Transparency is not there at all. That's all I can say, if only they could be transparent you know?" (W, 56, never returned to employment)

It is strange to perceive healthcare professionals as being barriers to work, as they are facilitators of healing and promoters of good health. However, it has been noted in literature and during the interview process that health care professionals' lack of addressing the subject, their uncertainty of, and incongruity between professionals on a stroke survivors' capacity for return to work can be seen as barriers.

> Adam's wife: " … no one really spoke to us and said anything about when and if he recovers, what he will be able to do… the specialist just said to me there was nothing they can do. He must just go home and see day-to-day … nothing was ever told or said to us that this would be the necessary steps to do, or take for him to get back into work and stuff like that."

Langa felt that it is necerssary for the issue of RTW to be addressed by healthcare professionals.

> Langa: "I enquired [from healthcare professionals] about going back to work but they said they did not know how long my healing process would take and I should carry on with my exercises, I will be ok… No they didn't ask about my goals … it worried me very much because I did not know what to do … how was I going to earn a living?" (M, 33, stopped employment)

Zodwa was given two contradicting recommendations by medical doctors in a short period of time.

> Zodwa: "My first attending doctor initially didn't want me to go back to work … I had a problem with my speech, I couldn't speak properly. The doctor thought my speech I wouldn't get better … She [participant's sister] didn't accept the first doctor's opinion because I was too young to stop working … at least that one [the doctor providing the second opinion] was positive." (W, 37, returned to employment)

Transportation can be a barrier for successful RTW, especially in South Africa where there are challenges with the public transport system (Duff, Ntsiea & Mudzi, 2012). Private transportation may not be readily accessible owing to personal impairments preventing them from returning to driving or family members' (who could assist with transportation) own personal commitments. This dilemma was experienced by Busisiwe, who previously drove and had the ability to access public transport. Following her stroke, she became reliant on her daughter, but this posed a challenge as her daughter had her own commitments.

> Busisiwe: "*[pause]*…The challenge I am having is that, is that, is that of driving because ah… like my daughter now he's he's has got a part-time job in Beacon Bay neh; so I have to wait.

> It's the trans, yah, it's the, it's the transport yah [even while being employed]." (W, 50, successfully returned to employment)

So, despite having successfully returned to work, transportation is a barrier that she faces daily.

Disability benefits are generally perceived to be a positive thing following disability, as the person does not lose an income entirely. However, receiving a disability benefit can be seen as a double edged sword, as in Khule's case, there was no exploration or attempt to return to work as she was receiving an income in the form of a grant.

> "No because I get paid- grant now … I didn't attempt going back." (W, 40, never returned to employment)

Theme 3: Facilitators to employment

The facilitators for RTW fell into two ICF groupings, namely personal and environmental factors.

Personal Factors: The need to support self and family can be a strong driving factor for returning to paid employment.

> Zodwa: "It was because of my young child I thought she was too young … I- ah- I thought of him – oo eh – [*becomes emotional*]." (W, 37, returned to employment)

Langa, expressed a deep desire to return to paid employment as he needs to provide for his young daughter.

> Langa: "… I'm wanting to support little girl …" (M, 33, stopped employment)

Positive attitudes and good psychological well-being have been seen as positive predictors for RTW (Andersen, Christensen, Kirkevold & Johnsen, 2012). This is exemplified by Busisiwe.

> Busisiwe: "Even myself … I am positive about my situation … The first thing is to accept your disability… And you must also help yourself." (W, 50, successfully returned to employment)

Cebisa had a positive attitude and belief in herself, despite having stopped working, she was still looking for opportunities to return to the working environment. She stated that she felt that she could hold her own, especially in the hospitality industry where her passion lies.

> Cebisa: "When you are a receptionist, you are the face of the business." Researcher: "And do you feel that you could be the face of the business?" Cebisa: "[*laughs*] Yeh, yeh. Because I know that I can sell- I can, I can sell. I can make sales up. That's one thing I am sure of for myself, when it comes to selling the- the place that I'm working for." (W, 36, stopped employment)

One's motivation and commitment to recovery could facilitate the RTW process.

> Busisiwe: "I was committed to my rehabilitation… I was committed to my therapy … Then you must work on it. You must … if you are in the Rehab, you must do what you are told what to do, because there everybody is trying to help you. And you must also help yourself." (W, 50, successfully returned to employment)

Environmental factors : Supportive relationships, whether personal or professional, are important for a stroke survivor's ability to face the challenges that are resultant of the stroke (Hartke *et al*. 2011). In the study family support was a strong factor in the successful return to work for Zodwa and Busisiwe.

> Zodwa: "My sister. She didn't accept the first doctor's opinion because she thought I was too young to stop working. My sister, my niece … everything I needed, they were supportive … my mother, everybody was there." (W, 37, returned to employment)

> Busisiwe: "Oh gosh, my children, yoh, they are very supportive. My mother, yah, my family." (W, 50, successfully returned to employment)

Busisiwe placed great emphasis on the support that she received from her employer. She also highlighted the importance of her colleagues' understanding of her capabilities and difficulties experienced when carrying out her job duties.

> Busisiwe: "Yah, my boss. He was so supportive… and colleagues, they are VERY [*with strong emphasis*] they are very supportive. Even now … My work was quite understanding… even in my new place … My boss advised me to … get a transfer. He assisted me to getting a transfer to East London." (W, 50, successfully returned to employment)

Zodwa also acknowledged the importance of employer and colleague support in her successful work reintegration.

> Zodwa: "So right now I do not have a problem because everyone knows that I had a stroke, and ah, that's why ah, I`m in the position that I am in right now. So I don't have any problems with it. It's like everyone understands my situation … They were so kind. Everyone in my section wanted me back, basically everybody wanted me to come back [to work]. It was nice, everybody was very supportive." (W, 37, returned to employment)

Despite, having since stopped working, Cebisa acknowledged the efforts of a previous employer in trying to assist her with employment prospects.

> Cebisa: "Oh shame, big time. 'cause even at court he was the one who sent me. No- despite that you were, that you had a stroke. You can still go. Yep … [*pause*]… my ex-boss – my ex-boss the person who, the person that hired me when in court – my ex-boss [same person as above] asked her to help me out … if I can do anything so I can get back to massages." (W, 36, stopped employment)

Healthcare professionals, with understanding and positive attitudes towards stroke outcomes of a stroke survivor, can have a positive impact on a survivor's potential for returning to employment. This was the case with Zodwa.

> Zodwa: "My first attending doctor initially didn't want me to go back to work… Then I went to the second Doctor. At least that one wa-wa- was positive." (W, 37, returned to employment)

Busisiwe also acknowledged that the good prognostic information provided by the healthcare professionals motivated her on her path to successful work re-integration.

> Busisiwe: "Oh, I was told I had a good potential to go to work." (W, 50, successfully returned to employment)

Zodwa and Busisiwe needed accommodations at work, which were provided. Without the support and understanding of their employers and healthcare professionals in making the appropriate adjustments, successful re-integration may have not been achievable.

> Zodwa: "I still work at HR, like before but right now I do not work as much as I used to work. Now I am doing like minor works in terms of capturing things…" Researcher: "Who made the recommendation for you to go onto the lighter duties?" Zodwa: "My supervisor and my, my doctor … I didn't have a problem [with the changes] as long as I was going back to work." (W, 37, returned to employment)

> Busisiwe: "[at the Bhisho office] I was assisted with some of my job because I- I don't have speed as I used to be, before I got stroke … Yes, it [work load] is been reduced slightly...Then, yah, in July my boss advised me to … get a transfer. He assisted me to getting a transfer to East London [This accommodation stopped the need for her to travel to another town every day for work] … I attend therapy two, twice a week. I got to work first, then in the afternoon…I got released for therapy." (W, 50, successfully returned to employment)

Discussion

Thirty-two percent of the study participants returned to work, which is close to the thirty-four percent that returned to work in the study by Duff *et al*. (2014). However, this falls below the return to work rate (55%) in Nigeria (Harris 2014). Despite South Africa being a developing country and the high rate of unemployment in the Eastern Cape (Statistics South Africa 2012b), the RTW rate was higher than the rates found in the studies conducted by Hofgren in Sweden(18% RTW), Tanaka in Japan (30% RTW) and Gabriele in Germany (26.7% RTW) (Harris 2014). However, 68% of participants were unemployed. This is much higher than the expanded unemployment rate of 32.4% of the BCM (Statistics South Africa 2012). As such, disability remains an underrepresented category of persons within the workforce.

The current results, both quantitative and qualitative, concurred with previous study findings (Bonner *et al*. 2016; Gabriele & Renate 2009; Harris 2014; Wang *et al*. 2014)

that poor functional abilities post stroke negatively impact RTW rates. In general, the more impaired the functional abilities of stroke survivors, the lower the RTW rates. In this study, all the participants who successfully returned to work had mRS scores that were indicative of no to minimal disability. Poor functional use of the affected arm, hand, and/or leg, difficulty with mobility, challenges with memory and speech impairments were listed as barriers for return to work by current study participants. This reflected the findings of Duff *et al.* (2014), Gabriele & Renate (2009) and Gilworth *et al.* (2009).

Wang *et al.* (2014) concluded from a systematic review of the literature that gender had no statistical impact on RTW. In this study, being a women showed more favourable outcomes for RTW. As in previous studies, age, higher education levels, income level and white-collar jobs were positive prognostic factors for return to work (Bonner et al. 2016; Gabriele & Renate 2009; Gilworth et al. 2009; Harris 2014; Hofgren *et al.* 2007; Trygged et al. 2011).

The qualitative results showed that psychosocial factors such as mental state, attitude, self-esteem, motivation and acceptance of disability had an impact on stroke survivors' RTW journey. As Duff *et al.* (2014) and Balasooriya-Smeekens *et al.* (2016) have found, low mental state, poor self-esteem and poor acceptance of disability can be barriers to RTW. Whereas the opposite is true should the stroke survivor have a positive attitude, strong motivation and acceptance of their disability (Balasooriya-Smeekens *et al.* 2016; Corr & Wilmer 2003; Gilworth *et al.* 2009; Harris 2014; Wang *et al.* 2014).

Environmental factors such as support systems (family, employer and healthcare professionals), accessibility of the workplace (natural and built environment) and transportation have been identified as potential barriers to RTW in literature (Balasooriya-Smeekens *et al.* 2016; Duff *et al.* 2014;Giaquinto & Ring 2007; Gilworth *et al.* 2009). These barriers also emerged as themes in the qualitative phase of this

study, but were not recognised and identified in the quantitative phase. This may be because these barriers are less overt and obvious to participants when compared to the physical impairments of stroke. This could also be a result of people viewing disability within the context of the medical model, where it is seen as the sum of the impairments of the body rather than examining the contribution of environmental factors (physical and social) to disability.

Lack of employer support or guidance from healthcare professionals also emerged strongly as barriers during the semi-structured interviews, whereas they were not apparent in the quantitative data. Employers have an important role to play in the RTW process. Without their understanding and empathy the process of work re-integration might be more challenging as they might be less likely to be flexible, to implement reasonable accommodations and to try and understand the person's challenges. Open, transparent communication is important to build trust between employer and employee as well as to empower the employee to be a part of the decision making process regarding return to work. Poor professionalism of the employer and inappropriate supply of extended sick leave with minimal discussion were found to be barriers for RTW in this study and in previous studies (Balasooriya-Smeekens *et al.* 2016; Giaquinto & Ring 2007). It is key for employers to understand these factors as anatgonising persons with disabilities, contributing to the poor outcome of RTW and underrepresentation of disabled persons within the workplace.

From the perspectives of participants, medical advice and rehabilitation following a stroke appeared to focus on the impairments and functional exercises rather than ongoing support for return to work and vocational training programmes. The findings again reflect those of previous studies (Balasooriya-Smeekens *et al.* 2016; Duff *et al.* 2014). This may be due to a shortage of staff and/or a shortage of vocational rehabilitation programmes in South Africa (Kusambiza-Kiingi *et al.* 2017; Mayo *et al.* 2002; Rhoda *et al.* 2009). It might also be the result of a lack of knowledge

on RTW with a disability on the side of health care service providers (Gilworth *et al.* 2009).

Limited access to transportation (personal and public) was found to be a barrier in the study by Duff *et al.* (2014), owing to the nature of the impairments and resultant disability. This was not identified as a main barrier in the current study, however, during the in-depth interviews one participant drew attention to this challenge.

Boredom or lack of stimulation, financial pressures, personal development and the enjoyment of work have been identified as strong facilitators for successful return to work. This is similar to conclusions by Alaszewski *et al.* (2007), Duff *et al.* (2014) and Wang *et al.* (2014). Gilworth *et al.* (2009) further explain that personal development gained through work has a positive influence on self-esteem, self-perception and overall economic well-being. This rationalisation was echoed by the participants who had successfully returned to work. They also felt returning to work had a positive result on their overall recovery.

Having knowledge and acceptance of one's disability has been shown to be a good prognostic factor for RTW (Gilworth *et al.* 2009). Participants verbalised the importance of this during Phase two. Motivation and commitment to one's recovery was highlighted by participants as important both before and after returning to work. Similar assertions are made by Seibers (2013) who states that a chance of future happiness for people with disabilities lies in the conception of the self that is not based on the past, but on the present and the future by embracing what the body has and will become relative to the demands on it. Thus, accepting the disability as a positive identity and benefitting from the knowledge embodied in it creates a better chance of happiness and health.

Social support systems (family, employer and healthcare professionals) are valuable facilitators for return to work (Balasooriya-Smeekens *et al.* 2016; Bonner *et al.* 2016; Duff *et al.* 2014; Wang *et al.* 2014) and cannot be underestimated. The value of

support from family and the need to care for minor children has also been identified in this study. Support from the employer is a strong facilitating factor regarding their understanding of the nature of impairments, a positive and professional attitude to disability, flexibility and allowing appropriate reasonable accommodations (Balasooriya-Smeekens *et al.* 2016; Bonner *et al.* 2016; Duff *et al.* 2014). This positive support and the appropriate reasonable accommodations implemented facilitated successful work re-integration of participants. Understanding and ongoing support from healthcare professionals, and their positive attitudes towards stroke outcomes are two important facilitating factors for RTW (Balasooriya-Smeekens *et al.* 2016; Gilworth *et al.* 2009). Without this understanding and support, returning to work may not have been possible for some participants. Miller *et al.* (2010) states that the holistic, collaborative and comprehensive approach of the rehabilitation team is the cornerstone of stroke rehabilitation; further highlighting that the patient and their family/caregiver are the central team members for the rehabilitation journey. From this study and the study by Duff *et al.* (2014), it is evident that more emphasis needs to be placed on cohesive and collaborative working of the rehabilitation team in the South African context. Role players (including the employer) should be identified early and involved from the outset of the rehabilitation journey. There needs to be clear lines of communication and a collaboratively agreed upon plan.

Similarly to the findings of Billet (2005); Corr & Wilmer (2003); Gilworth *et al.* (2009) and Vestling *et al.* (2005) , participants found value in working through the social interaction with people, the stimulation a job provided and the satisfaction gained from engaging in their work-based duties. However, the ability to financially support oneself and their family was the strongest factor as to why work was important. Losing the ability to work can be devastating (Gabriele & Renate 2009; Gilworth *et al.* 2009) and this was clearly expressed by some of the participants. The fear of not being able to provide for oneself and family, the loss of identity, and

boredom explained by Alaszewski *et al.* (2007) are similar to the fears experienced by current participants.

Study limitations

The limitations to the study include:

- It was difficult to acquire the names of potential participants and a complete list of the study population could not be compiled.
- Contact details were not always complete or current in the hospital files. 100 of the 251 potential participants for Phase one could not be traced or contacted.
- Most of the participants accessed private healthcare services. This may be due to having medical insurance as a result of employment and many potential participants from state hospitals could have been either unemployed or did not meet the age inclusion criteria.
- The Phase one sample size was too small to do inferential analysis. This small sample, in addition to the number of potential participants that could not be traced, also limits the generalisability of the results; those who did participate might not be representative of the larger population.
- The questionnaire was not tested for reliability and concurrent validity.
- During the qualitative phase, the translator paraphrased at times rather than directly translating, therefore applying his subjectivity to the interview. This may have impacted the line of questioning by the researcher during the interview.

Recommendations

There needs to be a greater focus on increasing RTW after stroke; not only in BCM but in South Africa. The following recommendations are therefore made:

- The Department of Health and the private health sector should improve overall access to general rehabilitation programmes in the acute setting following stroke with focus on functional capacity, and facilitation of participation in life roles.
- Healthcare facilities (public and private sector) should consider including supportive outpatient vocational rehabilitation programmes post stroke as well as on the job support to explore the effect of mentorship on the integration of employees with disabilities post stroke as participants identified lack of support as a main barrier.
- Therapists should be encouraged to focus more of their attention on providing appropriate RTW education to patients and liaise with the treating medical doctor and the employer with regards to sick leave and medical boarding.
- Rehabilitation therapists need to advocate for and support their patient until successful reintegration into work as this is the end goal of rehabilitation.
- There is a need for therapists specialising in vocational rehabilitation to provide education on RTW to healthcare professionals on creating supportive environments and making recommendations based on functional capacity evaluation and not only based on impairment.
- There is a need to provide education on RTW to employers with focus on their role within the RTW process, vocational rehabilitation, graded work re-entry programmes and the need for reasonable accommodations.
- More intensive education should be provided to the patient and their family/primary caregiver on the disability grant application process as 37% of those who were not working did not receive a disability grant. Therapists are encouraged to form productive working partnerships with the Department of Social Development to help facilitate this process.
- Although South Africa has policies and legislation in place for employment of persons with disabilities, there is still a great need for education (to people,

employers and stakeholders) on how these policies and the legislation can be practically and economically implemented. There also needs to be more stringent monitoring and better motivators for employers. Employers need to situate disability as a social justice issue and interrogate the systems and practices that are antagonistic to persons with disabilities as revealed in this study. Of equal importance is the need for senior management in the workplace to facilitate an accepting culture that incorporates disability.

- Similar studies should be conducted in other provinces in South Africa so that a national perspective can be obtained.

Conclusion

The RTW rate is poor and needs to improve, especially within the South African economic context. More attention must be focused on improving functional capacity, especially that of one-handed techniques and alternative mobility solutions during the acute phase of rehabilitation. In addition, communication and collaboration between all role players should commence at the earliest time possible, so as to forge a plan and begin the process of returning to work. It is important to have the patient, their family, the employer and the healthcare professionals working together as a supportive unit, as the theme of support was identified as a strong facilitator.

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Appendix 1.

PARTICIPANT INFORMATION SHEET AND CONSENT FORM FOR PARTICIPANTS
(Stroke survivors)

Return to Work after Stroke; Rate, Facilitators and Barriers in Buffalo City, South Africa

Reference Number: S14/10/216

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I, Stacey Patterson, am an Occupational Therapist working at a neurological rehabilitation centre. I am currently carrying out a research project on the factors that influence the return to work of stroke survivors in the East London and surrounding areas of the Eastern Cape, South Africa.

I would like to invite you to participate in a study that looks at the factors that influence your ability to return to work following your stroke. In order to decide if you would like to participate in this study, you should understand its risks and benefits in order to be able to make an informed choice. I will, to the best of my ability, try to ensure that all your questions have been answered before you agree to participate.

WHAT IS THE PURPOSE OF THIS STUDY?

This research project is part of a course work Master's Degree through the Department of Rehabilitation Studies, at Stellenbosch University in the Western Cape.

I have chosen to do research to answer my question of "How many stroke survivors return to work following a stroke and what are the factors that influence this?" In this study, I shall be looking at the following:

The number (%) of stroke survivors participating in the study that return to work in the East London and surrounding areas of the Eastern Cape, South Africa

What factors influence these stroke survivors ability to return to work post stroke in the East London and surrounding areas of the Eastern Cape, South Africa

Through this study, I hope to achieve a better understanding into the different factors that influence your ability to return or not return to work. By doing so, I seek to allow stroke survivors, their employers and the rehabilitation staff to better be informed about these factors and to use this information to ease the return to work processes.

WHAT DOES THIS STUDY INVOLVE FOR YOU?

The research study aims to involve seventy-five participants in the first phase and, six participants selected from Phase one to participate in Phase two.

If you agree to participate in this study, it will involve myself, as the researcher, and a research assistant meeting you at a place and time that suits you. I will ask you some questions, and complete a ten page questionnaire. This should take forty-five minutes to one hour of your time.

All of the questionnaires will be administered by myself and/or the research assistant, so there will always be a person available to you should you have any questions or do not understand what is being asked of you. We will give you plenty of time to answer each of the questions. A family member, friend or caregiver may be present to help you, if you feel this is needed.

The study will likely be a once off visit by me and/or the research assistant to each of the 75 participants however, you may be asked to participate in the second phase of the study later in the year. Should you be invited to participate in the second phase, I will contact you telephonically and request your participation. You may at this point, decline participation in the second phase.

If you agree to participate in the second phase of this study, it will once again involve myself, the researcher, and a research assistant meeting you at a place and time of your and/or your primary caregiver's convenience. This meeting will be pre-determined telephonically beforehand. I will conduct a short interview with you, which involves me asking you about your experiences in returning to work or not returning to work after having your stroke. This should take one to one-and-a-half hours of your time.

WHAT HAPPENS NEXT?

Should you decide to take part in the study, you will be asked to sign a consent form. You will be given a copy of this information sheet for your own records.

DOES MY PARTICIPATION IN THIS STUDY INVOLVE ANY PHYSICAL RISK?

There will be no direct risk to you and/or your family in taking part in this study. Should you feel unsettled by the emotions experienced in the interview processes, I will make a referral to your local counselling services if you wish. There will be no cost incurred by you or your family.

The benefits of taking part in this study, is that you are participating in a study that can help improve the return to work process for yourself and those whom have suffered a stroke in South Africa. The researcher, however, does not promise any payment or job opportunities following your participation in the study.

WHO WILL RECEIVE THE RESULTS OF THIS STUDY?

Your name and any other identifying information will not be recorded in this study, but rather you will be assigned a reference number. Information from this study that may be presented or published will never identify you and/or your family or primary caregiver.

The results will be shared with Stellenbosch University, the private rehabilitation unit, the private practices and organizations from which your name was in their data bases.

On completion of the study, results will be made available to you, should you wish to know them. These results will then be sent by delivery of your choice- email, fax or postage.

CAN I WITHDRAW FROM THE STUDY?

Your participation in this study is voluntary and there is no pressure on you to take part. At any point, should you feel uncomfortable or are unhappy in any way during the interview, in either phase; you are entitled to ask to withdraw. No penalty will be incurred by you should you chose to withdraw, and no hard feelings will be held by me, the researcher, towards you in any way.

CONFIDENTIALITY

Every effort will be made by me, the researcher, to keep all documentation, which shows your name and answers to the questionnaire and the interview, confidential. No answers or personal information will be disclosed to anyone other than myself, the research assistants and the statistician, unless required by law.

The Research Ethics Committee may need to see personal details during the course of the study, and if the research is published they may need to disclose certain information; but you will first be contacted and this will be discussed before anything should happen.

Should you have any questions please feel free to contact me, Stacey Louise Patterson, through the contact details below. You may also contact the Stellenbosch University Human Science Research Ethics Committee with any concerns or complaints you may have regarding this study.

Researcher: Stacey Louise Patterson
Telephone (work): 043 742 0723
Cell Number: 083 305 9059
Email: stacey.l.patterson@gmail.com

Stellenbosch University Human and Social Sciences Research Ethics Committee

Tel: +27 21 938 9677
Fax: +27 21 938 9855
Email: **ethics@sun.ac.za**
Postal address: PO Box 19063
Tygerberg
7505
Cape Town
South Africa

Appendix 2.

Declaration of the participant

By signing below, I ……..……..…….(participant) agree to take part in a research study entitled "From the working class: Factors that influence return to work of Stroke Survivors in the East London and surrounding areas of the Eastern Cape, South Africa."

I declare that:

- I have read or had read to me this information and assent/consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurized to take part.
- I may choose to leave the study at any time and will not be penalized or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

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

…… ……

Signature of participant **Signature of witness**

Assertion by participant (if unable to give consent)

By signing below, I ……..……. agree to take part in a research study entitled "From the working class: Factors that influence return to work of Stroke Survivors in the East London and surrounding areas of the Eastern Cape, South Africa."

I assent that:

- I have read or had read to me this information and assent/consent form and it is written in a language with which I am fluent and comfortable.

- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurized to take part.
- I may choose to leave the study at any time and will not be penalized or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

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

…… ……

Signature of participant **Signature of witness**

Declaration of the primary caregiver of the participant (If participant is unable to give consent)

By signing below, I ……..……..…….(primary caregiver) agree to ……..……..(participant) to take part in a research study entitled "From the working class: Factors that influence return to work of Stroke Survivors in the East London and surrounding areas of the Eastern Cape, South Africa."

I declare that:

- I have read or had read to me this information and assent/consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurized to take part.
- I may choose to leave the study at any time and will not be penalized or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

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

....
Signature of participant **Signature of witness**

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*) ……...……...

....
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 isiXhosa.
- 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*) ……...……..

....

Signature of interpreter **Signature of witness**

Appendix 3.

Sample group

Factors That Influence Return To Work After Stroke.

Questionnaire

SECTION A: DEMOGRAPHIC AND MEDICAL DETAILS

1) Participants number:……

2) Age:……

3) Gender: Male ☐ Female ☐

4) Race: Asian ☐ Black ☐ Coloured ☐ White ☐

5) Marital status: Not Married ☐ Married ☐ Divorced ☐ Separated ☐
Widowed ☐ Living together ☐ Other ☐

6) How far did you go with your education?
Post Graduate Degree ☐ Undergraduate university Degree ☐
Diploma ☐ Grade 12 or equivalent ☐ Up to grade 9 ☐
Up to grade 7 ☐ >Grade 7 ☐ No formal schooling ☐
Other:……

7) Side of hemiplegia (weakness): Right ☐ Left ☐ Both: ☐

8) Date of stroke: ……

9) Period of time since stroke: 6-8 months ☐ 9-11months ☐ 12-17 months ☐
18-24 months ☐ >24months ☐

10) Have you had a previous stroke?
Yes☐ No☐
If yes, when?……

11) Do you have any other medical conditions?
Yes☐ No☐
a) Hypertension: ☐

b) Diabetes: ☐

c) Epilepsy: ☐

d) Headaches: ☐

e) Fatigue: ☐

f) Depression: ☐

g) Arthritis: ☐

Other:……

SECTION B: FINANCIAL AND EMPLOYMENT HISTORY

12) What is your present monthly personal income?

<R1500☐ R1501-R5000☐R5001-R10 000☐ R10 001-R15 000☐

R15 001-R20 000☐ >R20 001☐

13) Are you currently working?

Yes☐ No☐

If you answered YES, when did you return back to work?

……

If you answered NO, do you have any other form of income generating activity?

Yes☐ No☐

If you answered yes, what do you do to generate an income or money?

……

14) Before your stroke, were you the main source of income for your family?

Yes☐ No☐ If no, why?

……

a. If Yes, are you still the main source of income for your family?

Yes☐ No☐

If no, where is this income coming from? ……

15) Prior to your stroke, did you work:

In the formal employment sector as a permanent/ part-time employee or business owner ☐ or

Did you work as a casual labourer ☐ or

Did you generate your own income through outside of the formal employment sector ☐

……

……

16) Where you self-employed (formal or informal) or employed by others before the stroke?

Self-employed ☐ Employed by others ☐

17) What work did you do to earn money before you had your stroke?

……

……

……

18) If you were formally employed by a company or a person at the time of your stroke, did you receive sick leave?

Yes ☐ No ☐

If yes, for how long ……

If yes, were you paid Yes ☐ No ☐

19) Are you currently receiving any disability benefit? (private or governmental)

Yes ☐ No ☐

If yes, please specify……

Only ask questions 20-22 if the person has returned to work then proceed to section C; if they are not working ask from question 23. If they answered yes, complete the section and proceed to section D. If they answered no at 23, stop asking questions on this page and proceed to section E.

20) If you are working, then did you return to your previous paying job or income generating activity?

Yes☐ No☐

If you answered YES;

a) Has what you were doing before the stroke now changed after the stroke?

Yes ☐ No ☐

b) Were there any changes to the buildings (inside or outside) to accommodate your needs?

Yes ☐ No ☐

21) If you returned to work, then are you working full day or half-day or shifts?

Full day ☐ Half day ☐ Shift work ☐

22) How many days in a week are you working?.....

23) Are you happy in your current job?

Yes ☐ No ☐

Why?.....

24) If you are currently not working, had you previously returned to work after your stroke?

Yes ☐ No ☐

If you answered YES, please answer below.

a) How long after your stroke did you return to work? .....

b) How long did you work before stopping ?.....

c) Did you return to your previous job?

Yes ☐ No ☐

If you answered NO, please specify change of job and why?

.....

.....

d) If you initially returned to your previous job then, were your job duties changed at all ?

Yes ☐ No ☐

e) Was your physical work environment changed to accommodate you? (whether it was the previous employment or new employment)

Yes ☐ No ☐

If you answered YES, was it suitable?

Yes ☐ No ☐

f) Were you working full day or half day or shift?

Full day ☐ Half day ☐ Shift ☐

g) How many days in a week were you working?……

h) Did you enjoy your most recent job?

Yes ☐ No ☐ Why?……

SECTION C : INFLUENCING FACTORS FOR RETURNING TO WORK

Only complete if the participant returned to work.

25) What were your reasons for returning to work? You may give as many reasons as you can think of. *(Data collector should record all reasons mentioned)*

……

……

……

……

……

……

……

……

26) Of all the reasons you listed above, which are the main three reasons why you chose to go back to work in order of importance?

i. ……..

ii. ……..

iii. ……..

SECTION D: INFLUENCING FACTORS FOR STOPPING WORK

Only complete if the participant returned to work and then stopped.

27) Please list the reasons that caused you to stop working. You may give as many reasons as you can think of *(Data collector should only record those mentioned)*

……

……

……

……

……

……

……

……

……

28) Of all the reasons you listed above, which are the main three reasons that contributed most to your stopping work following your stroke? Please list in order of importance

i. ……

ii. ……

iii. ……

SECTION E: INFLUENCING FACTORS FOR NOT RETURNING TO WORK

Only complete if the participant never returned to work.

29) Please list the factors below that caused you to stop working. You may give as many reasons as you can think of. *(Data collector should only record those mentioned)*

……

……

……

……

……

……

……

……

……

30) Of all the reasons you listed above, which are the main three reasons contributed most to you not returning to work after your stroke? Please list in order of importance

i. ……...

ii. ……..

iii. ……...

APPENDIX: FACTOR LIST FOR SECTIONS C,D,E

a) Body Functions factors

- Poor memory ☐
- Poor concentration ☐
- Difficulty with thinking skills (higher order cognition) ☐
- Difficulty with vision ☐
- Difficulty with hearing ☐
- Difficulty with finding words (Expressive aphasia) ☐
- Difficulty understanding others (Receptive problems) ☐
- Difficulty with speech and speech clarity ☐
- Poor use of affected arm (writing, carrying, etc.) ☐
- Poor use of affected leg ☐
- Difficulty with going to the toilet or incontinence ☐
- Other medical related conditions ☐
- Pain ☐

b) Psychosocial factors

- Demotivated/ No desire ☐
- Boredom ☐
- Depressed ☐
- Anxiety / Fear of returning to work ☐
- Fear of superiors/colleagues/subordinates perceptions ☐
- Previous job related stresses ☐

c) Activity and participation factors

- Difficulty getting ready for work on time ☐
- Difficulty getting to work on time ☐
- Tire easily during the day ☐
- Difficulty with reading/writing /basic calculations ☐
- Difficulty with doing simple tasks required in the job ☐
- Difficulty doing complex tasks required in the job ☐
- Difficulty with completing all tasks required of me in time ☐
- Difficulty using the tools/machinery needed for my job ☐

- Difficulty with meeting my job requirements ☐
- Difficulty moving around my work environment effectively ☐
- Difficulty with the physical demands of the job ☐
- Difficulty with forming and maintaining formal relationships with superiors, colleagues and/or subordinates ☐
- Unable to be accommodated in the work place ☐
- No suitable position available in the work place ☐
- Previous employer would not rehire ☐

d) Economic factors

- Financially unnecessary (self-sufficient) ☐
- Receiving a government disability grant ☐
- Receiving a disability benefit payments ☐
- Taken early pension ☐
- Medically boarded ☐
- Still on paid sick leave ☐
- Still on temporary incapacity leave ☐

e) Environmental Factors

- Inability to access transport ☐
- Poor access to assistive devices for mobility ☐
- Poor access to assistive devices for communication ☐
- Outdoor work environment has poor physical accessibility ☐
- Indoor work environment has poor physical accessibility ☐
- Attitudes of superiors in the work environment ☐
- Attitudes of colleagues in the work environment ☐
- Attitudes of subordinates in the work environment ☐
- Did not know about employment and disability policies ☐

f) Other

- Did not know that you could return to work ☐
- Do not know your rights as a disabled person and your rights with regards to return to work ☐

Appendix 4

SECTION F: MODIFIED RANKIN SCALE (Wilson, L. J. T. Harendran, A. Grant, M. Baird, T. Schultz, U. G. R. Muir, K. W. Bone, I. 2002)

The Interviewer is to select the most appropriate description.

√	Scale	Description	Questions
	0	**No symptoms at all**; no limitations and no symptoms.	
	1	**No significant disability**; symptoms present but no other limitations	As a result of the stroke, does the participant have difficulty with: Reading and writing Speaking or finding the right word Balance and coordination Visual problems Numbness (face, arms, hands, legs, feet) Swallowing Other
	2	**Slight disability**; limitations in participation in usual social roles, but independent for ADL	As a result of the stroke has there been a change in the person's ability to: Work or look after others Participate in previous social and leisure activities Has the participant had problems with relationships and/or has become isolated since the stroke?
	3	**Moderate disability**; need for assistance with some instrumental ADL but not basic ADL	As a result of the stroke,is assistance essential for preparing a simple meal, doing household chores, looking after money, shopping, or traveling locally?
	4	**Moderately severe disability**; need for assistance with some basic ADL, but not requiring constant care.	As a result of the stroke, 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	As a result of the stroke, does the person require constant care?

Appendix 5

FACTORS THAT INFLUENCE THE RATE RETURN TO WORK AFTER STROKE.

General Questions

- What work were you doing before your stroke? Please give details on requirements and duties.
- Did you enjoy you're the job you had before your stroke? Were you satisfied? Reasons.
- Is work important to you? Reasons.
- What were you told about your ability to return to work after having your stroke? (in detail)
- Do you understand your rights as a person with a disability in the work environment?

If returned to work

- Tell me about your experience of being employed.
- What are the difficulties did you experience?
- What has helped you or made the experience easier
- Please tell me about the people that helped you with your attempt to return to work. What role did the play?
- Are you currently happy with where you are in terms of your work? Please explain

If returned to work and then stopped

- Tell me about your experience being employed
- What are the difficulties did you experience?
- What helped you or made the experience easier
- Please tell me about the people that helped you with your attempt to return to work. What role did the play?
- I see the reasons for your stopping working, how did this affect you?
- Did you ask for assistance or accommodations in the work place at the time?
- Would you like to be working? Reasons
- Are you happy about your work status and why?

If never returned to work

- Would you like to be working? Reasons
- What stops you from being working?
- Did you ever get offered assistance to return to work in any manner?
- Did you try return to work? Why was it unsuccessful?
- Are you happy about your work status and why?

Appendix 6

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Approved with Stipulations
New Application

20-Nov-2014
Patterson, Stacey SL

Ethics Reference #: S14/10/216

Title: **From a working class: Factors that influence the return to work of stroke survivors in the East London area of the Eastern Cape, South Africa.**

Dear Miss Stacey Patterson,

The **New Application** received on 15-Oct-2014, was reviewed by members of **Health Research Ethics Committee 2** via Expedited review procedures on **06-Nov-2014**.

Please note the following information about your approved research protocol:

Protocol Approval Period: **20-Nov-2014 -20-Nov-2015**

The Stipulations of your ethics approval are as follows:
1. Please provide information in the informed consent form (ICF) and protocol regarding compensation of the study participants for their time and efforts to participate in this study.

Please remember to use your **protocol number** (S14/10/216) 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/rds 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 219389156.

Appendix 7

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
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Ethics Letter

23-Mar-2015

Ethics Reference #: S14/10/216
Title: From a working class: Factors that influence the return to work of stroke survivors in the East London area of the Eastern Cape, South Africa.

Dear Miss Stacey Patterson,

Stipulated documents are in order.

If you have any queries or need further help, please contact the REC Office 219389207.

Sincerely,

REC Coordinator
Mertrude Davids
Health Research Ethics Committee 2