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Community reintegration and satisfaction of survivors of stroke receiving physiotherapy services in the community health centres within the Johannesburg area

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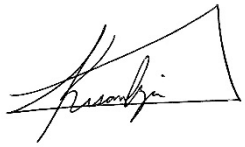
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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in fulfilment of the requirements for the degree of Master of Science in Physiotherapy (dissertation)

Johannesburg, 2016

Declaration

I, Adrian Kusambiza-Kiingi declare that this dissertation is my own work. It has been submitted for the degree of Master of Science in Physiotherapy at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.



_____ (Signature of candidate)

14th of October, 2016

Dedication

To my family, Audrey-Ann Kusambiza-Kiingi, Frederick Daniel Kusambiza-Kiingi and Margaret Ann Kusambiza-Kiingi, for being my pillars of support and motivating me to make this research a success.

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List of abbreviations

ADLs	Activities of Daily Living
CHCs	Community Healthcare Centres
CSI	Caregiver Strain Index
EQ-5D	EuroQoL
FLP	Functional Limitations Profile
FSQ	Family Strain Questionnaire
HRQOL	Health-Related Quality of Life
M-SCRIM	Maleka-Stroke Community Reintegration Measure
SIPSO	Subjective Index of Physical and Social Outcomes
RNLI	Reintegration to Normal Living Index
PHC	Primary Health Care
PTOPS	Physical Therapy Outpatient Satisfaction Survey
PTPSQ	Physical Therapy-Specific Patient Satisfaction Questionnaire
QoL	Quality of Life
SASPI	Southern African Stroke Prevention Initiative
SF-36	Medical Outcomes Study 36-item Short Form
SSQoL	Stroke Specific Quality of Life

Abstract

Background and aim of the study

The prevalence of stroke is high in South Africa. The average length of stay in hospital for stroke survivors in a tertiary hospital in Johannesburg is twelve days. Despite the benefits of early discharge from hospital for stroke survivors, early discharge from hospitals may lead to inadequate physiotherapy intervention for functional independence. This lack of independence would therefore lead to increased dependence on caregivers and lower levels of perceived and real community integration for survivors of stroke. When patients return to their homes, they require high levels of care. This care is often provided by family members or designated caregivers. These caregivers undergo high levels of strain that often lead to exhaustion and isolation. Patients at community health centres receive physiotherapy services on an outpatient basis and home visits are done when necessary. Literature on levels of community reintegration among stroke survivors within health centres in the Johannesburg area and their satisfaction with the physiotherapy services received is lacking. The aim of this study was to determine levels of community reintegration and satisfaction levels with physiotherapy of survivors of stroke in community healthcare centres in the Johannesburg area as well as to determine if there were any relationships between community reintegration and caregiver strain, quality of life and patient satisfaction with physiotherapy.

Method and procedures

This was a quantitative, cross-sectional study with questionnaires administered to stroke survivors and their caregivers at the community health centres in the Johannesburg area. Community reintegration was measured using the Maleka Stroke Community Reintegration Measure (M-SCRIM) and represented as frequencies and percentages as well as means and standard deviations. Caregiver strain was measured using the Caregiver Strain Index (CSI) and represented as frequencies and percentages. Quality of life was measured using the Stroke-Specific Quality of Life measure (SSQOL) represented as frequencies and percentages and satisfaction with physiotherapy services was measured using the Physical Therapy Patient Satisfaction Questionnaire (PTPSQ) and represented as medians and interquartile ranges. Correlations between M-SCRIM and CSI, M-SCRIM and SSQOL and M-SCRIM and PTPSQ were determined using Spearman's rank correlation coefficient.

Results

This study was conducted on 108 participants and 45 caregivers. The average age of the participants was 54 years (SD=12.73). Eighty five of the participants (78%) had achieved some form of community reintegration according to the M-SCRIM. Participants' lowest scores on the PTPSQ were for accuracy of bills, availability of parking and cost of physiotherapy. All the other questions scored a median of 100%. The mean score for SSQOL was 157 out of 245 (64%) with the highest score recorded at 235 out of 245 (96%) and the lowest score measured was 54 out of 245. Participants had some problems with each of the SSQOL domains. Forty five of the participants had caregivers. Twenty five (55%) of the 45 caregivers were strained according to the CSI. A positive correlation was found between the M-SCRIM and PTPSQ ($r = 0.27$, $p < 0.0001$) and the M-SCRIM and SSQOL ($r = 0.51$, $p < 0.0001$). A negative correlation was found between the M-SCRIM and CSI ($r = -0.37$, $p < 0.0001$).

Conclusion

Eighty five per cent of the stroke survivors in this study had some form of community reintegration and were generally satisfied with physiotherapy services. Their quality of life SSQOL was relatively low with the participants experiencing problems in every SSQOL domain. The majority of the caregivers were strained and survivors of stroke with higher community reintegration had less caregiver strain.

Key words: stroke, community, reintegration, satisfaction, physiotherapy, quality of life, caregiver strain

Key terms

Community reintegration

"Reorganization of physical, psychological and social characteristics of an individual into a harmonious whole so that one can resume a well-adjusted life after an incapacitating illness or trauma" (Dauphinee et al., 1987).

Patient satisfaction

Health care recipient's reaction to the important aspects of his/her experience with the health care service (Cleary and McNiel, 1988).

CHAPTER 1

1. INTRODUCTION

1.1 Background

The World Health Organization defines a stroke as rapidly developing clinical signs of focal or global disturbances of cerebral function, with symptoms lasting 24 hours or leading to death with no apparent cause other than vascular origin (WHO MONICA, 1988; Duncan et al., 2003; Sommerfield, 2004). Stroke is the most common life-threatening neurological disease affecting adults and it is the third most common cause of death in high income countries (Eaves, 2000; Langhorne et al., 2009).

According to Wolfe (2000), there are an estimated 4.5 million deaths and nine million survivors of stroke each year worldwide. Case fatality rates of stroke in sub-Saharan Africa are more than those in industrialised countries (Lemogoum et al., 2005). Two thirds of stroke deaths occur in low income and middle income regions of the world (Connor, 2008). It is predicted that by 2020, there will be 25 million deaths worldwide from stroke with 19 million of those coming from developing countries (Lemogoum et al., 2005). In Africa, 90% of haemorrhagic stroke survivors and more than 50% with ischaemic stroke are known to have hypertension (Mensah, 2008). The prevalence of stroke is high in South Africa (Thorogood et al., 2007). There are limited statistics specifically focused on the prevalence of stroke in South Africa. However, in a census carried out by the Southern African Stroke Prevention Initiative (SASPI) in 2001 in Limpopo, it was found that a crude prevalence of 300 people in every 100 000 suffer a stroke (Connor and Bryer, 2007). In South Africa, stroke contributes to 7.2% of all deaths and 7.9% of these deaths are in those people between the ages of 35 and 64 years (Rhoda et al., 2003; Wasserman et al., 2009). It is estimated that by 2023 there will be a 30% increase in the number of first-time stroke sufferers (Wolfe, 2000).

The effects of stroke may be motor, sensory, perceptual or cognitive deficits. These deficits, in addition to environmental and personal factors, create disability, hindering functional capability and decrease the potential of rehabilitation. Motor deficits are among the most common deficits that hinder a person's ability to complete their activities of daily living (ADLs) (Mercier, 2001; Langhorne et al., 2009). Eighty five per cent of survivors of strokes

suffer hemiparesis immediately after their infarct (Saposnik et al., 2010). These patients experience decreased health-related quality of life (QOL) (Geiger et al., 2001).

Even after a mild stroke, there are major effects on stroke survivor's ADLs and social roles (Rochette et al., 2007). A study by Mayo et al., (2002) showed that 50% of community-dwelling stroke survivors live with effects that put them at risk of diminished activity. Most survivors of stroke return home after being admitted into hospital with a subsequent rehabilitation programme (van den Heuvel et al., 2000). The number of survivors of stroke moving back to their community is growing (Mayo et al., 2002). Survivors of stroke also need to improve functional independence to facilitate their reintegration (Mayo et al., 2002). These stroke survivors need community health centres to continue rehabilitation to prevent their condition from deteriorating.

Rehabilitation is an on-going process of identifying problems and needs. These problems are then related to impaired body functions and structures, factors of the person, their environment and rehabilitation interventions (Stucki et al., 2002). Facilitating functional independence and community reintegration are major components of stroke management. It would therefore be logical that the sooner the patient can be discharged from the hospital, the sooner the process of reintegration can begin (Mayo et al., 2000). Survivors of stroke have been seen to have better compliance with therapy home programmes with early discharge from the hospital (Hillier et al., 2010).

The average length of stay in hospital for stroke survivors in a tertiary hospital in Johannesburg is twelve days (Mamabolo et al., 2009). Despite the benefits of early discharge from hospital for stroke survivors, early discharge from hospitals may lead to inadequate physiotherapy intervention aimed at improving functional independence (Hilton et al., 2013). This lack of independence would therefore lead to increased dependence on caregivers and lower levels of perceived community integration for survivors of stroke. Fifty per cent of survivors of stroke that return to their communities live with impairments that would not be manageable without the assistance of an able-bodied caregiver at home (Mayo et al., 2002).

Healthcare professionals involved in the rehabilitation of survivors of stroke are physiotherapists, speech therapists, occupational therapists, dieticians, rehabilitation doctors, psychologists and nurses. Rehabilitation can take place in various settings such as the in-patient

setting at a hospital or rehabilitation facility, out-patient setting at a community clinic and in the patient's home (Rhoda et al., 2009). Community healthcare centres provide services including preventative, promotative, curative and rehabilitative care. These centres, in most cases, are the first medical point of contact for survivors of stroke looking for care (Rhoda et al., 2003). For many survivors of stroke, community reintegration marks the end of their rehabilitation (Lord et al., 2005). The consequences of stroke also have an effect on the different dimensions of quality of life (QOL) (Carod-Artal et al., 2000).

Physiotherapy is an integral part of rehabilitation in various healthcare settings including community health centres and is concerned with solving a wide range of patient problems with regards to living at home with or without caregivers (Lord et al., 2005).

When patients return to their homes, they require high levels of care. This care is often supplied by family members or designated caregivers. These caregivers undergo unacceptably high levels of burden that often lead to exhaustion and isolation (Scholte op Reimer, 1998; Honea et al., 2008).

Patients at community health centres are seen on an outpatient basis and home visits are done when necessary. Literature on levels of community reintegration among stroke survivors within health centres in the Johannesburg area and their satisfaction with the physiotherapy services received has not been established, thus lacking.

1.2 Research questions

1.2.1 How satisfied were survivors of stroke in the community health centres in the Johannesburg area with the physiotherapy services and care received?

1.2.2 How well had these stroke survivors reintegrated back into their community?

1.2.3 What was the level of quality of life of the survivors of stroke receiving physiotherapy services?

1.2.4 What was the level of strain experienced by the caregivers of survivors of stroke in the community health centres within the Johannesburg area?

1.2.5 What relationship was found between levels of reintegration, caregiver strain, quality of life and patient satisfaction of these survivors of stroke?

1.3 Aim of the study

The aim of this study was to determine levels of community reintegration and satisfaction levels with physiotherapy of survivors of stroke in community healthcare centres (CHCs) in the Johannesburg area as well as to determine if there were any relationships between community reintegration and caregiver strain, quality of life and patient satisfaction with physiotherapy.

1.4 Objectives of the study

Primary objectives

1.4.1 To determine the level of community reintegration of survivors of stroke in their communities.

1.4.2 To establish the survivors of stroke satisfaction with the rehabilitation received at the community health centres within the Johannesburg area.

Secondary objectives

1.4.3 To establish the quality of life of survivors of stroke receiving physiotherapy services in the community health centres within the Johannesburg area.

1.4.4 To establish the level of strain experienced by caregivers of survivors of stroke in this study.

1.4.5 To determine correlations between reintegration and caregiver strain, reintegration and quality of life and reintegration and satisfaction with physiotherapy services

1.6 Significance of the study

It is important to establish levels of community reintegration in the CHCs in the Johannesburg area to give an overview of the stroke survivors in these areas. Community reintegration results will guide the focus of future rehabilitation sessions to ensure improvement in relating factors. The stroke survivors' satisfaction with physiotherapy services will serve as a gauge to assess whether treatment is adequate as well as give clues as to where the therapists in these areas can improve their services.

Caregiver strain results will allow therapists to be able to look out for specific concerns that caregivers have that may lead them to being strained once the patient returns home. Results of caregivers' levels of strain will allow health professionals in these areas to adjust their family home programmes to enable health professionals to develop programmes to help caregivers with factors that contribute the most towards their strain. Knowledge of the stroke survivors' levels of quality of life will give therapists an indication of whether more needs to be done with regards to addressing quality of life issues and to also prevent depression.

It is also important to establish the relationship between reintegration and quality of life to determine what needs to be focussed on in therapy to maximise quality of life as well as community reintegration. Establishing the relationship between community reintegration and satisfaction with physiotherapy will allow therapists to determine levels of satisfaction with therapy and adjust what is being done to maximise them. Establishing the relationship between community reintegration and caregiver strain will solidify the need for focus on community reintegration in therapy to prevent caregiver strain.

CHAPTER 2

2. LITERATURE REVIEW

2.1 Introduction

This literature review covers studies related to community reintegration of stroke survivors, their satisfaction with rehabilitation services received, their quality of life and the level of strain experienced by care givers of stroke survivors. Literature on stroke incidence and prevalence, risk factors of stroke, impairments and activity limitations after stroke is also reviewed in this chapter.

The literature search was conducted using the following sources: PubMed database, PeDRO and the Google scholar search engine. The following search words were used: stroke, community integration, satisfaction, quality of life, caregiver, rehabilitation, work. The literature was used to explore community reintegration, patient satisfaction with therapy, caregiver strain and quality of life. The literature was also used to make sure that the most valid and reliable methodology was chosen for the study.

This literature review was written following this format:

2.2 Incidence and prevalence of stroke

2.3 Risk factors related to stroke

2.4 Impairments and activity limitations post stroke

2.5 Community reintegration post stroke

2.6 Return to work post stroke

2.7 Social reintegration post stroke

2.8 Services for stroke survivors (hospital, clinic and community)

2.9 Stroke survivors' satisfaction with physiotherapy services

2.10 Factors that influence patient satisfaction with physiotherapy

2.11 Quality of life of stroke survivors

2.12 Factors that influence quality of life post stroke

2.13 Caregiver strain index (for caregivers of stroke survivors)

2.14 Factors that influence caregiver strain

2.15 Review of outcome measures

2.16 Summary of the literature review

2.2 Incidence and prevalence of stroke

Vascular disease is a major cause of mortality and morbidity around the world (Thorogood et al., 2007; Ferrarello et al., 2011). With regards to worldwide deaths, stroke is the second most cause (Connor et al., 2005). Stroke is the third most common cause of death in high income countries (Langhorne et al., 2009). Death within the first year has been estimated in between 15% and 25% of survivors of stroke (Carod-Artal et al., 2000). Eighty per cent of all deaths related to stroke happen in developing countries (Lemogoum et al., 2005). It is the most common life-threatening neurological disease affecting adults (Eaves, 2000). The socio-economic effect of stroke worldwide is considerable (Wolfe, 2000). Reoccurrence of stroke happens in between five per cent and 14% of survivors of stroke (Carod-Artal et al., 2000). Stroke reoccurrence is high among survivors of a first stroke with 50% of these reoccurrences leading to permanent disability (Lemogoum et al., 2005; Connor et al., 2005; Dearle, 2009). The high incidence of stroke can be related to lack of health resources and uncontrolled risk factors like hypertension and diabetes mellitus (Lemogoum et al., 2005).

According to Wolfe (2000), there are an estimated 4.5 million deaths and nine million survivors of stroke each year worldwide. In South Africa, stroke contributes to 7.2% of all deaths and 7.9% of deaths in those people between the ages of 35 and 64 years old (Rhoda et al., 2003; Wasserman et al., 2009). There is a crude prevalence of 300 people in every 100 000 suffer a stroke (Connor and Bryer, 2007). Similarities can be seen in the prevalence of stroke between South Africa and high-income countries (Maleka et al., 2012; Connor, 2007).

2.3 Risk factors related to stroke

Stroke is closely linked to lifestyle diseases such as coronary diseases and diabetes as well as the increased mortality rate associated with these conditions (Langhammer et al., 2014). This means that in addition to physical and cognitive impairment following a stroke, survivors of stroke may also suffer from secondary effects following inactivity such as decreased physical capacity which will lead to greater levels of dependency and a shortened life expectancy (Langhammer et al., 2014). Long-term therapy that also focuses on changes to lifestyle is also important in the management of stroke (Langhammer et al., 2014).

High blood pressure affects 42% of the population in rural Southern Africa (Thorogood, 2007). Cholesterol affects about 25% of this population (Thorogood, 2007). Movements to decrease the incidence of stroke globally are focused on public health efforts (Lemogoum et al., 2005).

These population-based strategies are focused on lowering the risk factors thus decreasing the incidence of stroke (Lemogoum et al., 2005; Langhammer et al., 2014). Factors that have led to high incidences of stroke in sub-Saharan Africa are related to high salt intake, increased frequency of meals, physical inactivity (which increases a person's risk of stroke by 50%), the way meals are prepared, use of tobacco (high prevalence of smoking in children between the ages of 13 and 15 in sub-Saharan Africa which was measured at 33% in South Africa) and general lack of awareness of stroke (Lemogoum et al., 2005). Physical activity as well as a diet high in fruits and vegetables and low in saturated fats are recommended in the prevention of stroke (Greenlund et al., 2002). Stroke is seen as one of the top risk factors for older patients getting a fracture after a fall and activities that promote mobility and fitness are important in the prevention of such events (Eng et al., 2003).

Although hypertensive treatment at community clinics in South Africa is free, 75.8% of patients with high blood pressure do not take medication (Thorogood, 2007). Hypertension is a major risk factor for stroke in South Africa (Hale et al., 1998). Poor control of hypertension can be attributed to inadequate follow-up owing to financial difficulties (Hale et al., 1998). A further consideration may be the lack of knowledge surround a stroke and its causes (Hale et al., 1998). Prevention of hypertension is paramount in the prevention of stroke (Hale et al., 1998). Education is the main role of primary healthcare in the prevention of stroke (Hale et al., 1998). Professionals at all healthcare levels need to reinforce that the control of such risk factors will lead to the prevention of stroke (Hale et al., 1998). A study by Rhoda and Hendry (2003) in South Africa made a recommendation for the implementation of aggressive health education programmes geared at health professionals and the community.

2.4 Impairments and activity limitations post stroke

Stroke frequently causes persistent neurological damage that results in diminished activity and participation restriction (Sveen et al., 1999). Impairments following a stroke can be characterised as positive features, negative features and adaptive features (Sommerfield et al., 2004). Positive features include adopting abnormal postures as well as the presence of spasticity (Sommerfield et al., 2004). Negative features include the loss of muscle strength and loss of dexterity (Eng et al., 2003; Sommerfield et al., 2004). Adaptive changes include physiological, mechanical and functional changes to the soft tissue in the body (Sommerfield et al., 2004).

A common impairment for survivors of stroke is hemiplegia. Eighty per cent of these survivors of stroke have motor impairments on the contralateral side (Sommerfield et al., 2004). Functional recovery rarely progresses past the first year post stroke (Eng, 2003). Motor recovery plateaus six months post stroke (Krakauer, 2006). Seventy per cent to eighty per cent of survivors of stroke suffer from some form of upper extremity impairment (Pang et al., 2006). Long-term disability often includes involvement of the upper limb in survivor of strokes list of impairments (Lo et al., 2010). Many of these survivors of stroke do not regain functional use of this arm and this leads to problems while engaging in ADLs and engagement in community life (Pang et al., 2006). Other common impairments resulting from stroke include perceptual deficits, pain, spasticity, poor balance, sensory loss and impaired cognition, aphasia, loss of vision and increased energy expenditure during activities of daily living (ADL) (Sommerfield et al., 2004; Kluding et al., 2009; Mamabolo et al., 2009; Wolfenden et al., 2009). Together, deficits in these body functions limit survivors of strokes ability to take part in daily activities (Kluding et al., 2009; Mamabolo et al., 2009). A great number of survivors of stroke have activity limitations because of these impairments (Gebruers et al., 2010). Evaluation of the effect of these impairments on activities of daily living is imperative in the rehabilitation process (Sveen et al., 1999). The main goal of rehabilitation post stroke should be to ensure that the survivor of stroke has meaningful activities and participation in their community (Hillier et al., 2010).

In a study by Langhammer et al., (2008), deterioration in ADLs and motor function were noted in survivors of stroke after one year. Activity limitations that have been seen to effect a person's ability to participate in ADLs include ability to walk and functional balance (Kluding et al., 2009). Other common activities that survivors of stroke have trouble with include brushing of teeth, dressing, writing and drinking (Gebruers et al., 2010). The number of survivors of stroke in South Africa requiring assistance with at least one ADL is at the level of first world countries (Connor et al., 2004). Forty per cent to sixty per cent of survivors of stroke will regain functional independence in ADLs and mobility between the third and tenth month following a stroke (Ferrarello et al., 2011). When this level of independence is reached in these survivors of stroke, it is rarely maintained and functional independence slowly starts to decrease over time (Ferrarello et al., 2011).

2.5 Community reintegration post stroke

Rehabilitation in the hospital versus in the community cannot be viewed in isolation as it is in the community that the survivors of stroke tests what they have learned in the hospital (Schmidt et al., 1986). The success of the rehabilitation process is measured by the level of function that a survivor of stroke has once they return to their community (Schmidt et al., 1986). Reintegration into normal living is defined as "Reorganization of physical, psychological and social characteristics of an individual into a harmonious whole so that one can resume a well-adjusted life after an incapacitating illness or trauma" (Dauphinee et al., 1987). The four divisions of integration are physical integration, functional integration, social integration and societal integration (Karlsudd, 2007).

A large part of stroke rehabilitation is aimed at community reintegration. According to Mayo et al. (2000), early discharge from hospital would result in higher levels of community reintegration of survivors of stroke. According to Mamabolo et al. (2009) the average stay of a survivor of stroke in Chris Hani Baragwanath, a government hospital in South Africa, is twelve days. These patients are discharged from hospital quite early and one could say that they are discharged before they reach functional independence (Mamabolo et al., 2009). To ensure early discharge leads to community reintegration, survivors of stroke need to be discharged with a plan for continued intervention in their home setting or as a rehabilitation outpatient (Mayo et al., 2000).

Thirty nine per cent to sixty five per cent of survivors of stroke report problems with activity limitations and participation restrictions that are related to their community reintegration (Pang et al., 2007). There has been a link found between physical function after stroke and satisfaction with levels of community integration (Pang et al., 2007). Many survivors of stroke have low levels of community integration following discharge from hospital. Another factor that affects community reintegration is self-efficacy. This concept is defined as a survivor of stroke's judgement of his/her ability to complete all their ADLs (Pang et al., 2007). An example of this would be the stroke survivor's confidence in the ability to maintain their standing balance while completing an activity (Pang et al., 2007). Low self-efficacy leads to a self-imposed decrease in the survivor of stroke's level of activity which may lead to decreased levels of community reintegration (Pang et al., 2007).

Physical disability is an indicator for the level of community integration amongst survivors of stroke (Murtezani et al, 2009). Survivors of stroke with severe physical disabilities have lower ADL outcomes and subsequently lower levels of community integration (Murtezani et al, 2009). Increasing functional independence can lead to rehabilitation professionals expecting a higher level of reintegration in their patient's ADLs and social roles (Bourdeau et al., 2008).

2.6 Return to work post stroke

Work can be defined as "continuing occupation in the production of supplies and services for payment" which can be done on a part-time or full-time basis (Wolfenden et al., 2009). It can also be broadly defined as unpaid work in the home or family enterprise, paid work for another entity or informal economy or as self-employment (World Health Organization, 2011). As stroke usually occurs later in life, goals that are related to vocation are rarely focussed on (Vestling et al., 2003). Vocational rehabilitation aims include promoting employment opportunities for survivors of stroke in the open labour market (Kuoppala et al., 2008). Although incidence of stroke has a strong link to increasing age, young people can also experience stroke (Treger et al., 2007). Roughly 20% of all survivors of stroke are below the age of 65 (Medin et al., 2006). Up to 12% of first strokes happen in patients under the age of 45 (Varona et al., 2004).

Younger survivors of stroke are not only faced with impairments and difficulties in executing basic ADLs, but also in participating in extended tasks such as returning to work (Treger et al., 2007). Stroke is rarely understood for the range of impairments experienced by the younger survivors of stroke (Wolfenden et al., 2009). Younger, higher functioning survivors of stroke are more likely to want to return to work (Wolfenden et al., 2009). Rehabilitation for survivors under this age may be more complex as there may be a possible return to the workplace (Medin et al., 2006). These survivors may be responsible for other family members (Medin et al., 2006). Loss of employment post stroke has financial implications on the individual and the society as there is a loss in productivity (Medin et al., 2006). It has also been shown that well-being, self-worth, social identity and satisfaction levels are increased when there is a return to work following a stroke (Medin et al., 2006; Wolfenden et al., 2009). This indicates a need for well-developed rehabilitation programmes for return to work (Medin et al., 2006).

Use of the biomedical approach in stroke rehabilitation has shown to be sufficient enough to get survivors of stroke back on their feet, but not enough to facilitate a return to work (Medin

et al., 2006; Treger et al., 2007; Wolfenden et al., 2009). In a study by Medin et al. (2006), informants reported that the hospital rehabilitation programme aimed primarily at restoring bodily function and a return to ADLs rather than a return to the workplace.

Indicators related to readiness to return to work are vast (Saeki et al., 1993; Vestling et al., 2003; Medin et al., 2006). Some of these indicators include the survivor of strokes age, profession, side of hemiparesis, hemisphere of lesion, cognitive impairments, apraxia and muscle strength (Saeki et al., 1993; Vestling et al., 2003). The rehabilitation process, employer, social structure and personal factors are factors that influence a survivor of stroke's ability to return to work (Medin et al., 2006). These survivors of stroke require support from the employer, social support as well as motivation to aid their return to work (Medin et al., 2006). External factors that may limit return to work are architectural barriers, lack of appropriate transportation, a poor local economy and stereotypes against disabled people (Treger et al., 2007). Return to work following surviving a stroke reflects social restoration (Saeki et al., 1993).

2.7 Social reintegration post stroke

It is important for health professionals and the families of the survivor of stroke to identify with social activities they will be able to resume when they return home (Schepers et al., 2005). Domains that encompass the social concept can fall under family, work and leisure spheres (Schepers et al., 2005). Factors that have an effect on social reintegration of survivors of stroke include age, urinary incontinence post-stroke, depression and physical and intellectual impairments (Schepers et al., 2005). It is important to note that diminished activity levels can lead to social isolation and this can incur further health problems for the survivor of stroke (Hartman-Maeir et al., 2007).

2.8 Services for stroke survivors (hospital, clinic and community)

Rehabilitation is the process with the objective of making it possible for people with impairments or activity limitations to become more functionally independent. Rehabilitation can be defined as "measures required for coping with functional consequences of a disease, defect or trauma" (Kuoppala et al., 2008).

"For some people with disabilities, rehabilitation is essential to being able to participate in education, the labour market, and civic life. Rehabilitation is always voluntary, and some

individuals may require support with decision-making about rehabilitation choices. In all cases, rehabilitation should help to empower a person with a disability and his or her family" (WHO, 2011).

A comprehensive stroke health-care service includes continuous care that takes place in a variety of settings and involves various members of a multidisciplinary team (Anderson et al., 1995). These settings include the acute hospital, inpatient care or nursing facility, the patients home or as an outpatient at a hospital or community health-care centre (CHC) (Gresham et al., 1995). Acute management of stroke that includes intensive stroke unit care and functional exercise has been seen to be beneficial (Langhammer et al., 2008). Early admission to a hospital following a stroke leads to faster stabilization of the survivor of stroke's condition as well as speedy access to the appropriate treatment (Anderson et al., 2000). Having said this, there is heavy reliance on hospitals for this acute management while access to community based rehabilitation facilities remains limited (Anderson et al., 2000).

Patient stay in hospital following a stroke has decreased so much so that rehabilitation is often incomplete upon discharge (Duncan et al., 2003; Langhammer et al., 2008). Edwards et al., (2006) found that thirty five per cent of survivors of stroke were discharged home with no post-acute rehabilitation services. Eighty seven per cent of the survivors of stroke in this study experienced residual symptoms following discharge (Wolfenden et al., 2009).

In order to maintain physical function, survivors of stroke need to do as much physical activity as the general population (Langhammer et al., 2014). Such activity is limited for survivors of stroke with moderate to severe disability (Langhammer et al., 2014). This lack of physical activity can often be devastating to persons with already limited physical capabilities post stroke (Langhammer et al., 2014). Physiotherapists and occupational therapists have been seen as the health professionals that facilitate motor recovery in survivors of stroke (Galvin et al., 2011).

Early supported discharge home from an inpatient setting has positive benefits compared to prolonged hospital stay (Hillier et al., 2010). Survivors of stroke have been seen to have better compliance with therapy when it is done in the home setting whereas the physiological outcomes are better when therapy is done in an inpatient setting (Hillier et al., 2010). As the population grows older, more and more people are having strokes. More of these survivors are

making it passed the acute phase therefore more stroke survivors are returning to their communities (Mayo et al., 2002). This means that more stroke survivors will seek community-based services to prevent further deterioration of their condition and to improve their functional capabilities (Mayo et al., 2002).
Continued therapy past this subacute phase may increase improvements experienced by the survivor of stroke (Duncan et al., 2003; Mamabolo et al., 2009). Care for a survivor of stroke occurs in various settings (Gresham et al., 1995). It is common to find gaps in the survivor of stroke's care when moving from setting to setting and it is therefore vital that proper hand over and referral is done between placements (Gresham et al., 1995).

South Africa has adopted the primary health-care approach as the most appropriate strategy to meet its health-care needs (Rhoda et al., 2003). A district health system is in place to meet the healthcare needs of each province (Rhoda et al., 2003). At least one community healthcare centre is present in each of these districts (Rhoda et al., 2003). CHCs provide services that range from preventative and promotative services to curative and rehabilitative services (Rhoda et al., 2003).

The provincial government of the Western Cape (2007) has designated CHCs as low-intensity rehabilitation facilities. These facilities often have to manage survivors of stroke in the acute phase (Rhoda et al., 2009). The results of a study by Rhoda et al. (2009) revealed that there is a lack of therapy services to provide rehabilitation to survivors of stroke at the CHCs in the Western Cape. The findings in this study also suggest that the amount of time spent on physiotherapy, occupational therapy and speech therapy was low either as a result of the lack of services or an inability to access the CHCs (Rhoda et al., 2009).

A major determinant of successful rehabilitation is ensuring that there is not only good management of the survivor of strokes residual impairment, but also in taking into consideration the social and physical environment that the survivor of stroke is going into (Anderson et al., 1995; Hillier et al., 2010). The key to improving prevention of stroke is to increase the awareness of health professionals as well as the public (Connor et al., 2005). A rehabilitation centre may not take the survivor of stroke's real world situations into account and is not seen as the ideal surrogate environment for their environmental needs (Hillier et al., 2010). This situation may result in the patient leaving the rehabilitation centre with unmet needs. These unmet needs can lead to increased levels of physical and financial strain to the

survivor of strokes family and may lead to increased utilization of healthcare services through an increased number of hospitalisations (Hillier et al., 2010).

Benefits of home-based care include it being cost-effective (Anderson et al., 2000; Hillier et al., 2010). Home-based care allows the survivor of stroke to have a greater say in the decision making (Hillier et al., 2010). Decreased inpatient stay is also seen as a benefit of home-based care (Anderson et al., 2000; Hillier et al., 2010). This decreased hospital stay means that survivors of stroke have a decreased chance of getting iatrogenic illnesses and distress from prolonged hospital stay (Anderson et al., 2000). Most survivors of stroke choose home-based treatment as their preferred method of care (Hillier et al., 2010). A reduction in carer strain is also seen as a benefit of home-based care (Hillier et al., 2010). Further benefits of home-based therapy are that it is more convenient, more comfortable for the survivor of stroke and their family and home-based care gives an opportunity for the entire household to have a greater understanding of the therapy (Hillier et al., 2010). The carer also has more confidence to carry out the therapy (Hillier et al., 2010).

Some of the negative implications of home-based care noted by health professionals include safety of the members of staff, time spent travelling and poor ergonomics in the survivor of strokes home setting (Hillier et al., 2010). These concerns aside, survivors would have greater benefit from home-based care (Hillier et al., 2010). Home-based rehabilitation post-discharge results in a more functional recovery post stroke (Mamabolo et al., 2009).

2.9 Stroke survivors' satisfaction with physiotherapy services

Most patients admitted into hospital with a stroke receive physiotherapy, but a clear view on the impact of treatment has not emerged (Pound et al., 1994). A previous study revealed that 85% of survivors of stroke were satisfied with physiotherapy, but only 46% felt that they had received enough rehabilitation (Pound et al., 1994). Initially survivors of stroke are encouraged to have high hopes of recovery, but they often get disillusioned when they do not see these levels of recovery (Pound et al., 1994). The significance of patient satisfaction is that survivors of stroke are more likely to adhere to exercise programmes when they are satisfied with the physiotherapy service (Hush et al., 2010).

Patient-centred care is seen as an important factor in good health service delivery (Hush et al., 2010). As the competition in the healthcare industry increases, being able to measure

satisfaction with physiotherapy becomes more important (Beattie et al., 2002). Patient satisfaction is being used more to gauge the quality of healthcare services (Monin et al., 2002; Hush et al., 2010). Patients who have a higher level of satisfaction are more likely to continue with physiotherapy treatments and adhere to the physiotherapist treatment plans (Beattie et al., 2002). An aspect of patient satisfaction includes patient-practitioner relationship, which refers to the health professional's ability to communicate, the health professional's personality as well as their competence in their field (Beattie et al., 2002). Other aspects include accessibility of services, continuity of care, costs related to the service and the state of the facility where the service is carried out (Beattie et al., 2002). The health professional's personality and the process of care are most important aspects with regards to patient satisfaction with physiotherapy (Hush et al., 2010).

2.10 Factors that influence patient satisfaction with physiotherapy

A factor affecting patient satisfaction is that a physiotherapy visit is longer than a routine visit to a medical practitioner (Monin et al., 2002). These sessions require high levels of physical contact and active participation from the person making use of the service (Monin et al., 2002). Other factors that influence patient satisfaction with physiotherapy are the pain levels experienced with physiotherapy treatment and that a visit to the physiotherapist may be seen as physically taxing (Monin et al., 2002). The outcome of physiotherapy care is not a predictor for the level of satisfaction experienced by a person making use of that service (Hush et al., 2010).

2.11 Quality of life of stroke survivors

Quality of life is defined as "individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (Sturm et al., 2004, page 2340). Quality of life has been described as need satisfaction, health-related subjective experiences and perceived psychosocial and physical well-being (de Haan et al., 1993; Kauhanen et al., 2000; Lynch et al., 2008). The impact of stroke on health related QOL is multi-faceted (Owolabi et al., 2009).

2.12 Factors that influence quality of life post stroke

Quality of life for survivors of stroke is measured over four dimensions. Physical, psychological, functional and social dimensions (Carod-Artal et al., 2000; de Haan et al., 1993). Physical dimensions refer to symptoms and effects related to stroke (Carod-Artal et al., 2000).

The psychological dimension relates to cognitive and emotional functions related to stroke (Carod-Artal et al., 2000). The functional dimension relates to the survivor of stroke's ability to complete their ADLs (Carod-Artal et al., 2000). The social dimension relates to the survivor of stroke's family and general social situation (Carod-Artal et al., 2000; de Haan et al., 1993). Increased levels of physical impairment following a stroke may lead to decreased quality of life (Carod-Artal et al., 2000). Survivors of stroke that present with few physical impairments can also have decreased quality of life. Psychological status is just as important as physical status when looking at stroke-related quality of life (Carod-Artal et al., 2000). Most quality of life instruments have information that is collected using a questionnaire or interview. Survivors of stroke with cognitive or difficulties with speech are often left out of QOL assessments in stroke outcome studies (Carod-Artal et al., 2000).

Survivors of stroke may experience emotional lability and mood disturbances that contribute to increased levels of anxiety, depression and frustration at their limitations (Wolfenden et al., 2009). Depression post stroke is a risk factor for diminished levels of QOL even with survivors of stroke who have minor deficits (Kauhanen et al., 2000). This depression is thought to impact on the functional recovery of stroke in addition to leaving the survivor of stroke with decreased levels of QOL (O'Connell et al., 2001). Knowledge on the impact of marital status on QOL is limited (Kauhanen et al., 2000).

Survivors of stroke have looked to prayer as a way of mediating the impact of the effects of stroke (Robinson-Smith, 2002). Prayer serves to increase survivors of stroke's self-efficacy as well as allowing them to build up internal resources (Robinson-Smith, 2002). It also assists survivors of stroke to work against the stressors affecting them post stroke. Robinson-Smith et al. (2000) found that survivors of stroke used prayer to instil self-confidence. The participants in this study who used prayer and reported a moderately high personal faith in God had higher QOL than those who reported little personal faith in God (Robinson-Smith, 2002). These investigators recognised that prayer is an important coping strategy used by some survivors of stroke (Robinson-Smith, 2002).

2.13 Caregiver strain index (for caregivers of stroke survivors)

Rehabilitation has focused its efforts of reducing disability as well as institutionalisation and this has led to increasing numbers of survivors of stroke being managed at home (McCullagh et al., 2005). Fifty per cent of survivors of stroke that return to their communities live with

effects that would not be manageable without the assistance of an able-bodied caregiver at home (Mayo, 2002). These caregivers determine whether the survivor of stroke will manage in their community without the need of a rehabilitation facility (Han et al., 1999). This care is usually provided in a nursing home, hostel or the home of the survivor of stroke. Increased assistance to care for the survivor of stroke may come from allied health professionals, community nurses and social services, but the bulk of the caregiving will be done by an informal caregiver or family member (Hankey, 2004).

When survivors of stroke are discharged into the community, they are still reliant on a caregiver and this can increase the strain on the survivor's family (Mamabolo et al., 2009). The caregiver's ability to adjust to the task of taking care of the survivor of stroke has an effect on the survivor of stroke's quality of life (Han et al., 1999). Sixty six per cent of survivors of stroke require assistance with at least one ADL after discharge (Mamabolo et al., 2009).

2.14 Factors that influence caregiver strain

Carers of survivors of stroke have to manage physical and cognitive impairments as well as behavioural and emotional problems (van den Heuvel et al., 2000; Dennis et al., 1998). Problems that caregivers have to contend with include difficulties in mobility, self-care for the survivor of stroke, communication, depression and personality changes (Han et al., 1999). Some carers cope well in these situations while others do not (van den Heuvel et al., 2000). Caregivers of survivors of stroke need to be motivated, enthusiastic, physically fit, psychologically sound, emotionally robust, financially resourceful and adequately trained (Hankey, 2004). There is often very little time between the stroke, hospitalisation and discharge for caregivers to acquire all these skills (Hankey, 2004).

People who care for survivors of stroke may experience strain (Blake et al., 2003). These caregivers may present as being anxious, depressed or limited in their social activities (Dennis et al., 1998). A lower quality of life was found among caregivers of survivors of stroke in addition to an increased prevalence in depression (De Freitas et al., 2005). Long-term caregivers for survivors of stroke also report uncertainty about care needs and feeling of heavy responsibility (De Freitas et al., 2005). Early detection of these individuals would allow for targeted help that may reduce the amount of strain that these carers experience (Blake et al., 2003). According to Greveson et al., (1991) 30% of caregivers were under considerable strain after three years and Wilkinson et al. (1997) reported that 21% of carers experience this strain

after five years of caring for a survivor of stroke (Bugge et al., 1999). Spouses of survivors of stroke are more susceptible to symptoms of depression from adopting the role as caregiver (Dennis et al., 1998).

2.15 Review of outcome measures

Information discussed below also includes outcome measures not used in the study to show that other outcome measures were considered during the choosing process.

2.15.1 Community reintegration

The M-SCRIM was developed in 2010 and measures levels of community reintegration of stroke survivors. This measure has an urban and rural version. For the purpose of this study, the urban version was used. This measure was found to be reliable and valid for stroke survivors in urban townships Johannesburg area. The urban version had 40 items that are spread over the following six domains namely, ADL and self-care, social interaction and relationship, home and family responsibilities, social interaction, extended family responsibilities and work and education. The urban version of the M-SCRIM was scored out of 112. Total scores were multiplied by 100% with a higher percentage score implying a higher level of community reintegration (Maleka, 2010). The M-SCRIM had good internal consistency with a Cronbach alpha coefficient of 0.95. The M-SCRIM was compared to the Subjective Index of Physical and Social Outcomes (SIPSO) to determine construct validity. A very high and positive correlation was found between the two outcome measures. The M-SCRIM was a reliable and valid tool for measuring stroke-specific levels of reintegration for survivors of stroke living in low socio-economic areas (Maleka, 2010).

The Subjective Index of Physical and Social Outcome (SIPSO) is a ten-item, self-administered questionnaire with proven validity and reliability (Trigg et al., 2000). This questionnaire addresses quantitative and qualitative aspects of activities. It has an intraclass correlation coefficient of 0.96 (Trigg et al., 2000). Construct validity was confirmed through significant correlations with the six subsections of the Functional Limitations Profile (FLP) and Reintegration to Normal Living Index (RNLI) (Trigg et al., 2000).

The M-SCRIM was chosen due to its high Cronbach alpha coefficient of 0.95 as well as its urban version's relation to the reality of an urban community in South Africa. It also has elements in it that relate directly to the social circumstances that were faced in the communities

in the areas surrounding Johannesburg not found in other questionnaires such as attending traditional events and being able to collect water from a source outside of the participants dwelling.

2.15.2 Caregiver strain

The Caregiver Strain Index (CSI) measured the subjective caregiver load of ill or disabled patients. The measure consisted of 13 yes/no items. These items were employment, financial, physical, and social and time (Sullivan, 2002). A total score above seven indicated that the caregiver was strained (Robinson, 1983). The CSI was found to have an internal consistency reliability of $\alpha = 0.86$. Construct validity was supported by correlations with physical and emotional health of the caregiver as well as subjective views of the caregiving situation (Sullivan, 2002).

The family strain questionnaire (FSQ) is a family strain questionnaire with four sections. The first captures demographic information such as age, education, employment, and marital status of the caregiver, their relationship with the patient, and the composition of the family. The second is a brief interview relating to the patient's condition, leisure time activities, and socioeconomic resources. The third is two multiple choice questions concerning the caregiver's perception of the psychosocial distress suffered by him/her and his/her patient as a result of the disease/condition. The last section is 47 dichotomous items assessing family strain, family relationships and knowledge about the disease. Test-retest reliability showed a Cronbach value of $\alpha = 0.92$.

The CSI was chosen as most articles in the literature use the CSI as the primary measure when investigating caregiver strain (Blake et al., 2003; Bugge et al., 1999; Mudzi, 2010). The modified caregiver index, a version subsequent to the CSI, has slightly better internal consistency reliability of $\alpha = 0.9$ (Thornton et al., 2003). The modified CSI is also an easy way of detecting strain in informal caregivers (Thornton et al., 2003). Despite this fact, the original CSI was chosen as there are more articles to compare with when discussing the findings. The CSI was chosen over the FSQ as it is shorter and allows caregiver strain to be assessed in a more quantitative manner.

2.15.3 Quality of Life scale

An ideal health-related QoL measure should be rigorous, valid, reliable, patient-centred, responsive, precise, acceptable, appropriate, and interpretable and must cover all measurable domains of life and functioning (Owolabi et al., 2009).

The Stroke Specific Quality of Life scale is a Likert scale that was split into 12 domains with statements namely; energy, family, roles, language, mobility, mood, personality, self-care, social roles, thinking, upper extremity function, vision and work/productivity. The SSQOL was found to be a valid and reliable measure of health related quality of life (Williams et al., 1999). The SSQOL had good internal consistency (α = 0.81 - 0.94), construct validity and responsiveness to change for the 12 subscales (Muus et al., 2007; Lin et al, 2011).

The EuroQoL (EQ-5D) is a generic health index comprised of a five part questionnaire and a visual-analogue self-rating scale (Hurst, 1997). EQ-5D demonstrated moderate to high correlations with measures of impairment and high correlations with disability measures (Hurst, 1997).

EQ-5D essentially consists of two pages - the EQ-5D descriptive system (page two) and the EQ visual analogue scale (page three) (Hurst, 1997). The EQ-5D descriptive system comprises of mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has three levels: no problems, some problems, severe problems. The respondent is asked to indicate their health state by ticking in the box against the most appropriate statement in each dimensions (Hurst, 1997). This decision results in a one-digit number expressing the level selected for that dimension. The digits for five dimensions can be combined in a five- digit number describing the respondent's health state. It should be noted that the numerals one-three have no arithmetic properties in the scale and should not be used as a cardinal score (Hurst, 1997).The EQ visual analogue scale records the respondent's self-rated health on a vertical scale where the endpoints are labelled 'Best imaginable health state' and 'worst imaginable health state'. This information can be used as a quantitative measure of health outcome as judged by the individual respondents (Hurst, 1997).

The SSQOL was chosen as instead of giving three different scores as the EQ-5D does, having one score would allow for simplified correlation investigations between the SSQOL and M-SCRIM as per this study objectives discussed above.

2.15.4 Patient satisfaction with physiotherapy services

Satisfaction questionnaires allow healthcare providers to monitor and evaluate the outcome of care (Goldstein et al., 2000). They also allow healthcare providers to predict patient behaviour on the basis that patient satisfaction with the service has some form of influence on outcomes of therapy (Goldstein et al., 2000). Also, these questionnaires allow healthcare providers to adjust and develop strategies to improve outcomes of care (Goldstein et al., 2000). Based on the number of physiotherapy satisfaction questionnaires available, it is apparent that physiotherapists have recognised the importance of getting feedback from patients (Goldstein et al., 2000).

The Physiotherapy-Specific Patient Satisfaction Questionnaire was a Likert scale questionnaire comprised of 26 points with the first six asking about demographic data as well as site of injury and the other 20 questions relating to satisfaction with the physiotherapy service offered. Participants had five choices for each question ranging from "strongly disagree" to "strongly agree" and a sixth choice if they felt they had no experience with that item. The scores were totalled with higher numbers meaning higher levels of patient satisfaction with the physiotherapy service they received. There was a small section at the end of the questionnaire to allow for additional comments. The PTPSQ has a Cronbach α coefficient of 0.99. The questionnaire was shown to yield reliable measurements as well as have content, construct and concurrent validity (Goldstein et al., 2000).

Correlations between "would recommend to family and friends" (question 22), "would return to this facility for physical therapy in the future" (question 23), and "overall satisfaction with the physical therapy experience" (question 26) are the determinants of concurrent validity. The correlations for question 22 and the summary score is $r = 0.95$ ($P< 0.01$), question 23 and the summary score is $r =5.96$ ($P< 0.01$) and question 26 and the summary score is $r = 0.96$ ($P<.01$). These correlations indicate a high level of agreement between the summary score and each of the criterion variables. Issues found with the PTPSQ were that some patients were not always able to accurately recall the entire process of care and therapists that showed good 'bedside manner' may have had inflated scores (Goldstein et al., 2000).

The Physical Therapy Outpatient Satisfaction Survey (PTOPS) is a 34-question, five-point Likert scale (Roush and Sonstroem, 1999). There are ten questions related to enhancers, ten related to detractors, seven related to location and seven related to cost (Roush and Sonstroem,

1999). Enhancers and location are positive scales, i.e. higher scores indicate greater satisfaction; Detractors and Cost are negative scales, i.e. higher scores indicate less satisfaction (Roush and Sonstroem, 1999).

The PTPSQ was chosen for this study. Although the questionnaire had items that were related to bills and parking space, things not generally found at the healthcare facilities in the Johannesburg area, it was very comprehensive although lengthy as well as providing a space for comments that would help enrich the discussion of this study by allowing the researcher to capture data that might not have been directly related to the question.

2.16 Summary of the literature review

This literature review was done to determine the current situation with regards to the factors that contribute to a survivor of strokes' community reintegration. Some of these include impairments, activity limitations and expectations with regards to their new social roles, ability to return to work and the need for a caregiver. The literature shows that community reintegration is affected by involvement of the survivor of stroke's family and whether or not the treatments shown in a rehabilitation facility can be translated into treatment at the survivor of stroke's home environment. The literature also shows that survivors of stroke that are more functionally independent have a higher quality of life. One other thing that can be noted is that survivor of stroke's satisfaction with physiotherapy does not always correspond with levels of functional independence. Survivors of stroke that have low levels of functional independence might have had high levels of satisfaction with physiotherapy.

This study was designed to determine levels of community reintegration of survivors of stroke using the M-SCRIM. The M-SCRIM has a very high and positive correlation with the SIPSO. The M-SCRIM was used due to its specificity to the South African setting.

Quality of life was measured using the SSQOL. SSQOL was chosen as instead of giving three different scores as the EQ-5D does, having one score would allow for simplified correlation investigations between the SSQOL and M-SCRIM as per the objectives discussed.

Satisfaction with physiotherapy was assessed using the PTPSQ. Although the questionnaire had items that were related to bills and parking space, things not generally found at the healthcare facilities in the Johannesburg area, it was very comprehensive although lengthy as

well as providing a space for comments that would help enrich the discussion of this study by allowing the researcher to capture data that might not have been directly related to the question.

Level of strain felt by the stroke survivors' caregivers was assessed using the CSI. The CSI was chosen as most articles in the literature use the CSI as the primary measure when investigating caregiver strain.

The study was also designed to see if a relationship exists between community reintegration and caregiver strain, quality of life and satisfaction with physiotherapy. The methods used to investigate this will be discussed in the next chapter.

CHAPTER 3

3. METHODOLOGY

3.1 Introduction

This chapter serves to explain the study methodology as well as the outcome measures and procedure used in this study. The study population and data analysis is also described in this chapter.

3.2 Study Design

This study was a quantitative, cross-sectional study.

3.3 Study participants

3.3.1 Source of participants

Survivors of stroke were recruited from four community health centres in areas around Johannesburg. These four centres are community health centres that offered physiotherapy as part of their rehabilitation service at the time of the study.

3.3.2 Sample size

The combined average monthly population of survivors of stroke at the five health centres over three months was calculated to be 150. One hundred and fifty patients was an accurate representation of the patient numbers at the community health centres in the Johannesburg area. According to Bartlett et al. (2001), the number of participants needed to accurately represent the views of the population under study was 108. This figure was calculated at a confidence interval of 95 per cent with 0.005 reliability (Bartlett et al., 2001). It was assumed that the patients would each come to the clinic with a caregiver. According to a confidence interval of 0.9, a sample size of 92 caregivers was required to get meaningful data.

3.3.3 Inclusion criteria

- Survivors of stroke that were considered for the study were male or female and over the age of 18. These survivors of stroke needed to have been treated by a physiotherapist as an outpatient or on a home-visit basis from any of the study sites.
- Survivors of stroke that were able to give verbal or written consent to take part in this study
- Survivors of stroke where the stroke is older than six months, but no older than four years.
- The primary caregiver was defined as the person who spends the most time compared to any other individual in the household caring for the survivor of stroke. Survivors of stroke were not required to have primary caregivers present to be included in the study

3.3.4 Exclusion criteria

- Participants who had survived more than one stroke
- Survivors of stroke that presented with receptive aphasia

3.4 Outcome measures

3.4.1 The Maleka Stroke Community Reintegration Measure (M-SCRIM); See Appendix A, is a community reintegration questionnaire with an urban and rural version. The urban version has 40 items that are spread over six domains.

3.4.2 Physical Therapy Patient Satisfaction Questionnaire (PTPSQ); See Appendix B, a Likert scale questionnaire comprised of 26 points with the first six asking about demographic data as well as site of injury and the other 20 questions relating to satisfaction with the physiotherapy service offered.

3.4.3 Stroke Specific Quality of Life Scale (SSQOL); See Appendix C, is a Likert scale that was split into 12 domains with statements namely; energy, family, roles, language, mobility, mood, personality, self-care, social roles, thinking, upper extremity function, vision and work/productivity.

3.4.4 Caregiver Strain Index (CSI); See Appendix D, has thirteen questions that determine whether a caregiver is strained. Answering yes to seven or more questions indicates that the caregiver is strained.

3.4.5 Demographic data sheet; See Appendix E, has items including gender, physical address, race, stroke survivor's currents occupation, date of administration of the questionnaire, date of birth, age, marital status, whether a caregiver is present, level of education, side of the body affected by stroke and date of stroke.

The questionnaires were not translated into other languages because the researcher and assistants were able to speak the relevant languages.

3.5 Procedure

3.5.1 Pilot study

Ethical clearance for both the pilot and main studies was obtained prior to commencement of the pilot study (See Appendix F) and was granted. Requests for approval to conduct the study at four health centres in the Johannesburg area were sent to the Administrative Director of Johannesburg Metro District (see Appendix G) and permission was granted. A pilot study was conducted at one of these health centres to assess the feasibility of conducting the study. A sample of convenience was chosen as the primary purpose of the pilot study was to determine the feasibility of the study. The CHC chosen was the one where the researcher was working full-time. Five participants were entered into the pilot study. These five participants were treated as outpatients at the facility previously and met the inclusion criteria. These five participants had caregivers and all five participants had the M-SCRIM, PTPSQ, CSI and SSQOL administered to them to determine and problems that may be encountered in the main study. PTPSQ was done by the researcher so as to minimise the influence on participants' feedback. Researcher was present for all the data collection except for the PTPSQ conducted at the placement that the researcher worked. The researcher found that the questionnaires took between 25 and 35 minutes to complete. The researcher collected the information from all five participants with the research assistant administering the PTPSQ and it was decided that the researcher would collect the information in the main study with the research assistants present. Inter rater reliability was not established as the inter rater reliability scores established for the outcome measures that were chosen was high. There was no need to change the methodology

for the main study and this meant that the participants from the pilot study were included in the main study.

3.5.2 Main study

Consent was obtained from participants that met the inclusion criteria and demographic data was collected. Files at each clinic were checked regularly for stroke participants that met the criteria by the physiotherapists working at each clinic. Participants were contacted telephonically or through the weekly stroke groups to set appointments at the clinic. Home visits were done where the participants could not make it to the clinic. All participants completed the M-SCRIM (see Appendix A) and SSQOL (see Appendix C). If care-givers were present, they were assessed using the Caregiver Strain Index (see Appendix D). PTPSQ (see Appendix B) was administered to each participant by the researcher to determine satisfaction with the physiotherapy service. The Demographic data sheet was completed by all participants (see Appendix E)

One research assistant at each facility helped to gather the information from the participants as they were familiar with the setting. Assistants were trained in administering of the questionnaires by the researcher to ensure inter-rater reliability. These assistance were all physiotherapists that had been working at these facilities for a minimum of one year. These research assistants organised the times that the participants will be at the clinic. Arrangements were made to ensure that there was an assistant available that spoke the participant's home language.

The researcher maintained reliability by training the research assistants at the same time. Questions were asked to each participant and caregiver in the same manner. The primary researcher met the research assistants once a month for discussions regarding progress and any difficulties experienced while administering the questionnaires.

3.6 Ethical considerations

Ethical clearance was granted by the University of the Witwatersrand committee for research on human subjects in 2014: Clearance number M1404452 (See Appendix F).

Participants were given an information letter (see Appendix H) that explained the procedure. Both participants (see Appendix I) and caregivers (see Appendix J) were asked to complete a consent form prior to administering the questionnaires.

The participants of the study were not forced to volunteer information and were given the option of withdrawing from the study at any time.

Participants remained anonymous when the findings were presented. The information gathered was added to these stroke survivor's existing rehabilitation files within the various physiotherapy departments.

All participants' personal details (demographics, disabilities, scores, outcome measures) were only accessed by the observers.

3.7 Data analysis

Descriptive statistics were used and represented as percentages, means and standard deviations. Depending on the distribution of data, the Pearson's product moment correlation coefficient or Spearman's rank correlation coefficient would be used to establish correlations between reintegration and caregiver strain, reintegration and quality of life and reintegration and satisfaction with physiotherapy services. Summary of data analysis for each objective is presented in Table 3.1

Table 3.1 Summary of data analysis for each objective

Objective	Outcome measure	Type of data	Statistical test
To determine the level of community reintegration of survivors of stroke in their communities.	M-SCRIM	Categorical data (total scores) Continuous data (domain scores)	Frequencies and percentages Mean and standard deviation
To establish the survivors of stroke satisfaction with the rehabilitation received at the community health centres within the Johannesburg area.	PTPSQ	Continuous data	Median and Interquartile range
To establish the quality of life of survivors of stroke receiving physiotherapy services in the community health centres within the Johannesburg area?	SSQOL	Continuous data	Mean and standard deviation
To establish the level of strain experienced by caregivers of survivors of stroke in this study.	CSI	Categorical	Frequencies and percentages
To determine correlations between reintegration and caregiver strain, reintegration and quality of life and reintegration and satisfaction with physiotherapy services	M-SCRIM CSI SSQOL PTPSQ		Spearman's rank correlation coefficient

Results of this study are presented in the next chapter.

CHAPTER 4

4. RESULTS

4.1 Introduction

The objectives of this study were to: determine the level of community reintegration of survivors of stroke in their communities; establish the stroke survivors' satisfaction with the rehabilitation received at the community health centres within the Johannesburg area; establish the quality of life of stroke survivors receiving physiotherapy services in the community health centres within the Johannesburg area; establish the level of strain experienced by caregivers of stroke survivors in this study and determine correlations between reintegration and caregiver strain, reintegration and quality of life and reintegration and satisfaction with physiotherapy services. A description of the sample and demographic data related to the participants will be presented before discussing the results specific to each objective.

4.2 Distribution of study sample

Distribution of the study sample is presented in Figure 4.1.

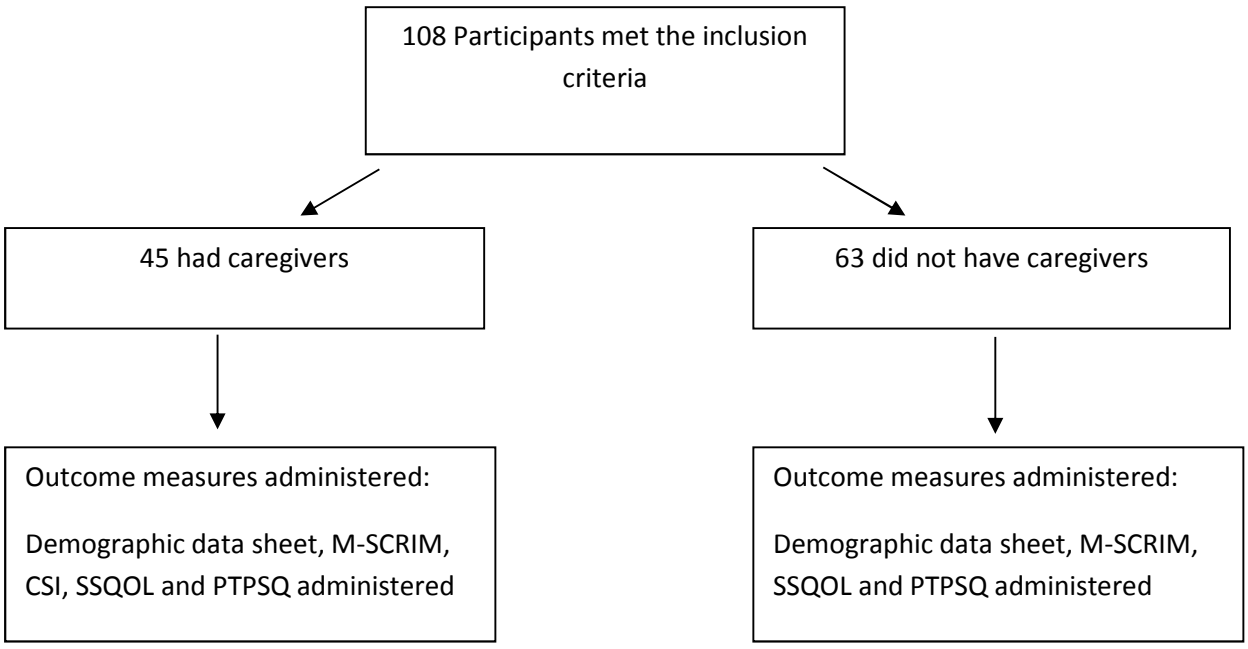


Figure 4.1 Distribution of the study sample

Hundred and eight participants met the inclusion criteria and they were all included in this study. Forty two per cent of the 108 stroke survivors had caregivers and the CSI was administered to these caregivers.

4.3 Demographic information

The mean age of participants in the study was 54 years (SD = 12.73). The youngest participant was 20 years old and the oldest participant was 79 years old. Fifty seven of the participants came from Alexandra township, two from Diepsloot, eight from Mofolo, 19 from Hillbrow and 22 from Chiawelo (n=108). The average space of time between the dates of the participant's stroke to the date of administering the questionnaire was 26 months (SD = 10.24).

Demographic information of the study participants is shown in the Table 4.1.

Table 4.1 Demographic information of the study participants (n = 108)

Participant characteristics	n (%)
Gender	
Male	48 (44)
Female	60 (56)
Race	
Black	100 (93)
Coloured	3 (2.7)
Asian	4 (3.7)
Other	1 (0.6)
Marital status	
Single	37 (34.3)
Married	55 (50.9)
Divorced	5 (4.6)
Widow(er)	11 (10.2)
Employment status	
Employed	32 (30)
Unemployed	59 (55)
Pensioner	31 (28)
Education	
No education	8 (7.4)
Completed primary school	8 (7.4)
High school without matric	71 (65.7)
Matriculated	15 (13.9)
Tertiary education	6 (5.6)
Affected side	
Left	57 (53)
Right	51 (47)

There were more females (56%) than males (44%) in the study sample. The majority of the participants (65.7%) left high school without completing matric. The number of stroke survivors with left hemiplegia was almost equal to those with right hemiplegia (53% and 47% respectively).

4.4 Stroke survivors' level of community reintegration

The mean total score for the M-SCRIM was 70 out of 112 (SD= 22.94). The highest score measured was 112 out of 112 and the lowest score measured was 17 out of 112.

Results of the level of stroke survivors' level of community reintegration are presented in Table 4.2.

Table 4.2 Level of stroke survivors' community reintegration (M-SCRIM scores)

Level of integration	M-SCRIM bracket	Per centage n (%)
No integration	0% - 40%	23 (21.3)
Minimal integration	41% - 59%	23 (21.3)
Moderate integration	60% - 79%	32 (29.6)
Full integration	80% and above	30 (27.8)

Fifty eight per cent of the stroke survivors had moderate to full integration and 21% had no community integration. Twenty one per cent of the survivors of stroke were minimally integrated into the community.

The M-SCRIM domain scores are shown in Table 4.3.

Table 4.3 M-SCRIM domain scores (n = 108)

Domain (total domain score)	**Mean** ± SD
ADL and self-care (48)	36 **±** 11.9
Social interaction and relationship (20)	10 **±** 5.2
Home/Family responsibilities and appearance (19)	9 **±** 6.5
Social interactions (13)	9 **±** 2.5
Extended family responsibilities (6)	2 **±** 1.4
Work and education (6)	2 **±** 2.3

SD = Standard deviation

When viewed as a percentage of each total domain score, 'ADL and self-care' (36 out of 48) and then 'Social interactions' (nine out of 13) have the highest scores among the participants in this study. Areas that participants struggled with the most were extended family responsibilities and work and education which both had a mean score of two out of six.

4.5. Patient satisfaction levels

The mean score for patient satisfaction with physical therapy was 92% (SD=9.17).

The data for the PTPSQ was skewed and thus median scores and interquartile ranges (IQR) were calculated. This resulted in the PTPSQ values presented in Table 4.4.

Table 4.4 PTPSQ individual question scores

Question (Total score: 5 for each question)	Median (IQR)
My privacy was respected	5 (5 to 5)
Physical therapist was courteous	5 (5 to 5)
Staff members were courteous	5 (4 to 5)
Clinic scheduled appointments at convenient times	5 (4 to 5)
Satisfied with treatment by physical therapist	5 (5 to 5)
My first physiotherapy appointment was organised quickly	5 (4 to 5)
Easy to schedule visits after my first appointment	5 (4 to 5)
I was seen promptly when I arrived for treatment	5 (4 to 5)
The location of the facility was convenient for me	5 (4 to 5)
My bills were accurate	0 (0 to 0)
I was satisfied with the services offered by my physical therapist	5 (4 to 5)
Parking was available for me	0 (0 to 0)
The physiotherapist understood my condition	5 (5 to 5)
The instructions my physiotherapist gave me were helpful	5 (4 to 5)
I was satisfied with the overall quality of my physiotherapy care	5 (4 to 5)
I would recommend this facility to my family or friends	5 (5 to 5)
I would return to this facility if I required physiotherapy in the future	5 (4 to 5)
The cost of physiotherapy was reasonable	0 (0 to 0)
If I had to, I would pay for these physiotherapy services myself	5 (2.75 to 5)
Overall, I was satisfied with my experience with physiotherapy	5 (5 to 5)

IQR = Interquartile range

Participants' lowest scores were for accuracy of bills, availability of parking and cost of physiotherapy. All the other questions scored a median of 100%.

4.6 Quality of life

The mean total for the SSQOL for all 108 stroke survivors in this study was 157 out of 245 (64%) (SD= 23.16) the highest score was 235 out of 245 (96%) and the lowest score measured was 54 out of 245. Mean scores and standard deviations for the SSQOL domains are presented in Table 4.5.

Table 4.5 SSQOL domain scores (n=108)

Domain (245)	Mean ± SD	% Score
Energy (15)	8 ± 4.41	53%
Family Role (15)	9 ± 4.22	60%
Language (25)	19 ± 6.85	76%
Mobility (30)	18 ± 8.56	60%
Mood (25)	15 ± 7.05	60%
Personality (15)	9 ± 4.1	60%
Self-care (25)	16 ± 7.74	64%
Social roles (25)	14 ± 6.98	56%
Thinking (15)	11 ± 3.93	73%
Upper extremity function (25)	16 ± 7.34	64%
Vision (15)	12 ± 3.95	80%
Work/Productivity (15)	9 ± 4.77	60%

According to the scores of the SSQOL, participants showed some problems in each of the domains. Participants had lowest scores for the energy domain and highest scores for the vision and language domains.

4.7 Level of strain experienced by caregivers

Caregivers with a CSI score of more than or equal to 7 are considered to be strained. Of the 45 caregivers in this study, 25 (55%) had a score more than or equal to 7 meaning that they were strained and 20 (45%) had a score less than 7, were not strained. The number of caregivers that replied "yes" and "no" to any of the domains are shown in table 4.6.

Table 4.6 CSI domain scores (n=45)

Domain	Yes n (%)	No n (%)
Caregiver experiences sleep disturbance	10 (22)	35 (78)
It is an inconvenience	19 (42)	26 (58)
It is a physical strain	21 (47)	24 (53)
It is Confining	19 (42)	26 (58)
There have been family adjustments	24 (53)	21 (47)
There have been changes in personal plans	21 (47)	24 (53)
There have been other demands on my time	20 (44)	25 (56)
There have been emotional adjustments	20 (44)	25 (56)
Some behaviour is upsetting	14 (31)	31 (69)
It is upsetting to find xxxx has changed so much from his/her former self	21 (47)	24 (53)
There have been work adjustments	10 (22)	35 (78)
It is a financial strain	17 (38)	28 (62)
Feeling completely overwhelmed	14 (31)	31 (69)

The domains that the caregivers struggle with most are the fact that taking care of the survivor of stroke is a physical strain, they feel like there have been many changes to their personal plans, family adjustments and that the caregiver is upset to see that the survivors' behaviour has changed since the stroke. Sleep disturbances and work adjustments seem to be the least affected items.

4.8 Correlation between community reintegration and caregiver strain index, stroke survivors' quality of life and patients' satisfaction

The data from the M-SCRIM was skewed (Std. Dev. = 22.94) as per the sktest done on the Stata statistical software and therefore Spearman's coefficient was used to determine correlation between M-SCRIM and CSI, M-SCRIM and SSQOL and M-SCRIM and PTPSQ.

Table 4.7 Correlation between community reintegration and caregiver strain index, stroke survivors' quality of life and patients' satisfaction

Correlation investigated	Correlation value	P value	Summary of correlation
M-SCRIM and PTPSQ	0.2745	(P<0.0001)	Weak positive correlation
M-SCRIM and SSQOL	0.5190	(P<0.0001)	Moderate positive correlation
M-SCRIM and CSI	-0.3707	(P<0.0001)	Weak negative correlation

A positive correlation is seen between M-SCRIM and SSQOL showing better QOL in participants with higher levels of reintegration. There is a weak positive relationship between M-SCRIM and PTPSQ showing a higher level of satisfaction with physiotherapy in participants with higher levels of community reintegration. A weak negative correlation exists between the M-SCRIM and CSI indicating that caregivers of participants with higher levels of integration have lower levels of strain.

4.9 Summary of results

One hundred and eight participants met the inclusion criteria and they were all included in this study. Forty two per cent of the 108 stroke survivors had caregivers and the CSI was administered to these caregivers. The mean age of participants in the study was 54 years (SD = 12.73). The youngest participant was 20 years old and the oldest participant was 79 years old. Fifty seven of the participants came from Alexandra township, two came from Diepsloot, eight from Mofolo, 19 from Hillbrow and 22 from Chiawelo (n=108). The average space of time between the dates of the participant's stroke to the date of administering the questionnaire was 26 months.

There were more females (56%) than males (44%) in the study sample with the majority of the participants (65.7%), having left high school without completing matric. The number of stroke survivors with left hemiplegia was almost equal to those with right hemiplegia (53% and 47% respectively).

Fifty eight per cent of the stroke survivors had moderate to full integration and 21% had no community integration. Twenty one per cent of the survivors of stroke were minimally integrated into the community. The mean total score for the M-SCRIM was 70 out of 112 (SD= 22.94). The highest score measured in the M-SCRIM was 112 out of 112 and the lowest score measured was 17 out of 112. When viewed as a percentage of the total domain score, "ADL and self-care" and then "Social interactions" have the highest scores among the participants in this study.

The mean score for patient satisfaction with physical therapy was 92% (SD=9.17). Participants' lowest scores in the PTPSQ were for accuracy of bills, availability of parking and cost of physiotherapy services. The rest of the items had a 100 score for each items.

The mean total for the SSQOL for all 108 stroke survivors in this study was 157 out of 245 (SD= 23.16) where the highest score was 235 out of 245 and the lowest score was 54 out of 245. According to the scores of the SSQOL, participants showed some problems in each of the domains. Participants had lowest scores for the energy domain and highest scores for the vision and language domains.

Twenty five (55%) of the caregivers had a score more than seven meaning that they were strained and 20 (45%) had a score less than 7 (not strained). The domains that the caregivers struggled with the most were physical strain, many changes to their personal plans and seeing that the survivors' behaviour has changed since the stroke. Sleep disturbances and work adjustments seem to be the least affected domains.

There was a positive correlation between M-SCRIM and SSQOL showing better QOL in participants with higher levels of reintegration. There was a weak positive relationship between M-SCRIM and PTPSQ showing a higher level of satisfaction with physiotherapy in participants with higher levels of community reintegration. The correlation between the M-SCRIM and CSI was weak and negative indicating that caregivers of stroke survivors with higher levels of community reintegration had lower levels of strain.

The results is discussed in the next chapter.

CHAPTER 5

5. DISCUSSION

5.1 Introduction

The aim of this study was to determine levels of community reintegration and satisfaction levels with physiotherapy of survivors of stroke in CHCs in the Johannesburg area as well as to determine if there were any relationships between community reintegration and caregiver strain, quality of life and patient satisfaction with physiotherapy. The findings are discussed in full below.

5.2 Demographic information of the study sample

The original sample size recommended for this study was 108 survivors of stroke and 92 caregivers of which only the number of survivors of stroke was realised. Of these 108 survivors of stroke, 45 (42%) had caregivers. In a study by Ntsiea et al. (2014), 93% of the participants had caregivers. This figure far exceeds the number in this study. Fifty per cent of survivors of stroke have impairments that require the assistance of an able-bodied caregiver (Mayo et al., 2002). One of the inclusion criteria in Ntsiea et al. (2014) was that the survivor's stroke needed to be less than eight weeks old at the time of baseline assessment. The lower need for caregivers in this study may have been because the participants were assessed six months or later post-stroke and would not have needed as much assistance with ADLs as in the study by Ntsiea et al. (2014).

There were more females (56%) compared to male (44%) survivors of stroke in the study. A study by Schneider et al. (2003) consisted of 61% female survivors of stroke. This is similar to the gender distribution found in this study. A study by Mamabolo et al. (2009) also had more female survivors of stroke (60%) than males. Bugge et al. (1999) also showed a higher number of females with stroke. Women go through longer hospital stay and remain more disabled than men (Roquer et al., 2003). Women also have a higher lifetime risk of stroke than men do (Petrea et al., 2009). This is due to women having a higher life expectancy and their increased level of disability after stroke (Petrea et al., 2009). This may be the reason for higher numbers of females in this study as they would make up a larger number of the patients trying to access healthcare services.

The mean age for the participants was 54 years with the youngest participant being 20 years old and the oldest being 79 years old. Ntsiea et al's (2014) mean stroke age was 45 years, Duff et al's (2014) mean stroke age was 51 years and Hilton et al's (2013) mean stroke age was 56 years. In a study by Schneider et al. (2003), the age range of stroke survivors was 18 to 95 years old with a mean age of 61 years. Studies by Bugge et al. (1999) and Duncan et al. (2003) both had 70 years as the mean age for the stroke survivors in their study. Pang et al. (2003) had a mean age of 65 years. These studies were conducted in more developed countries where patients have better healthcare services and education about the risk factors for stroke. Studies by Ntsiea et al., (2014) Duff et al., (2014) and Hilton et al., (2013) all took place in South Africa and are similar to the ages found in this study. There is a shift to more of the younger population having stroke (Wolf et al., 2009). South Africa is a developing country where a reason for younger strokes may be the lack of awareness around hypertension and other risk factors related to stroke (Hale et al., 1998), especially with the pandemic of HIV/AIDS in Sub-Saharan Africa. Neurological involvement in stroke patients is common (Mochan et al., 2003). Stroke in patients with HIV is owed to vascular abnormalities, coagulation disorders and cardio-embolic disease (Mochan et al., 2005).

The majority of the participants (65.7%) had an incomplete high school education. This figure was followed by those who had completed matric or had some form of tertiary education (19.5%). In studies by Ntsiea et al. (2014) and Duff et al. (2014) the majority of the participants completed matric or had some form of tertiary education. In a study by Mamabolo et al. (2009) the majority of the participants had a primary school education or less. It must be noted that most of the participants from the study by Mamabolo et al. (2009) and this study come from the same geographic areas/settings. Higher education levels are paramount to increased levels of work and work-readiness (Harvey, 2000). More than 50 per cent of the participants in a study by Schneider et al. (2003) had more than a high school education.

Participants in this study and those in the study by Mamabolo et al. (2009) were from government facilities which are mostly used by people of low socio-economic status, less pay and relatively lower education levels. Studies by Duff et al. (2014) and Ntsiea et al. (2014) focused on participants that were working prior to their stroke and this may have been a reason for their participants having higher levels of education even though some of the participants in these two studies were from private healthcare settings.

According to the results, only 18 participants (17%) were employed at the time of the questionnaire administration while 59 (55%) participants were unemployed. Most participants in the study by Mudzi's (2010) were unemployed (71%). A study by Duff et al. (2014) had an unemployment figure of 51% which is similar to the level of unemployment in this study. National unemployment in South Africa is 38% (Klasen and Woolard, 2009). Figures in all three of these studies are higher than the national figure for unemployment. We can assume that the scores in these three studies would be higher than the national average at the time due to the presence of disability in the participants.

The number of participants in this study with left hemiplegia was 57 (53%) while 51 participants had right hemiplegia. The Ntsiea et al. (2014) and Duncan et al. (2003) samples showed similar numbers of left and right sided hemiplegia. There seems to be no differences in the number of left versus right sided stroke.

5.3 Community reintegration post stroke

Fifty seven per cent of the stroke survivors had moderate to full integration and 21% had no community integration. In a study by Pang et al. (2007), only 11% of the participants were satisfied with the levels of community reintegration when the Reintegration to Normal Living Index (RNLI) was used. Pang et al. (2007) had a study sample of 63 community-dwelling participants above the age of 50 with chronic stroke older than one year. These participants were originally enrolled in a clinical intervention trial to evaluate the effects of an exercise program. One can say that Pang et al. (2007) had low numbers of participants that had satisfactory levels of integration compared to this study where reintegration was experienced by more than half of the participants. The participants in the study by Pang et al. (2007) were assessed more than one year post-stroke while this study's survivors of stroke were assessed from six months post stroke to four years post stroke. Both studies were done on chronic stroke participants, but because participants in the Pang et al. (2007) study may have been much older, this may have included participants whose functional ability has deteriorated many years after their stroke. Patients unable to maintain their activity levels after stroke may lead to deterioration in their condition (Langhammer et al., 2014). Pang et al. (2007) also experienced low levels of self-efficacy in their study whereas self-efficacy or ability to manage ADLs was the one domain in this study that had the lowest complaints. This low number of complaints

with regards to managing ADLs may be the reason for higher levels of reintegration in this study but also patient in Africa have to get on with life in very hostile environments, therefore there is no time for complacency and complaints.

Participants experienced some difficulty in all domains with ADLs and self-care and social interaction showing the least amount of difficulty. In a study by Mayo et al., (2002), 77% of the participants did not struggle with basic ADLs. This finding matches the findings in this study. Participants in the study by Mayo et al., (2002) were assessed at six months after stroke which is within the timeframe as the participants as this study. A reason for this domain having the best scores may be because inpatient rehabilitation is centred on acute management of stroke through using functional exercises (Duncan et al., 2003; Langhammer et al., 2008). Edward et al. (2006) also found that participants scored well with the ADL domain in the RNLI, but struggled in the other domains. This focus on self-efficacy or ability to complete ADLs in therapy results in a higher ADL score (Pang et al., 2007). Focus on this domain in therapy would mean incomplete rehabilitation of other areas in other domains in the M-SCRIM.

Work and education was one of the domains that the participants of this study struggled with the most with a mean score of two (±=2.3). Participants in a study by Mayo (2002) struggled most with a meaningful activity to fill the day. Vocational rehabilitation after stroke is not as much of a priority as stroke usually occurs later in life and this may be a reason why participants in both studies struggled with this domain (Vestling et al., 2003). Participants in a study by Edward et al. (2006) showed decreased satisfaction in their ability to engage in productive pursuits such as work and volunteer activities as well as their ability to travel and participate in leisure and recreational pursuits. This finding is similar to the one in this study. A reason for low scores with the work and education domain of the MCRIM in this study may be that most participants already had low levels of education or were unemployed before they had their stroke and had no intention of going back to work or school nor volunteering in community related projects (unpaid employment).

5.4 Patient satisfaction with physiotherapy services

The mean score for patient satisfaction with physiotherapy was 92% (SD=9.17). A study by Beattie et al. (2005) showed that 71.2% of their study participants were satisfied with physiotherapy. In the study by Beattie et al. (2005), 1502 participants were assessed with the MedRisk instrument for measuring patient satisfaction with physical therapy care. When

patient's expectations of care are exceeded, levels of satisfaction are high. Patients may view the physiotherapy services offered at community healthcare centres as inferior as there is heavy reliance on hospitals for this acute management while access to community based rehabilitation facilities is limited (Anderson et al., 2000). These participants may not have been expecting to encounter physiotherapy services at a community level due to scarcity of this service and this may have exceeded the participant's expectations of healthcare.

Participants' lowest scores were for accuracy of bills, availability of parking and treatment prices. Participants may have viewed this item as the travel costs they may have incurred or the type of transport used to get to the facility. This information cannot be confirmed and another study in this setting is required to verify this information. In a study by Lord et al. (2004), participants that complained of a difficulty using public transport were those participants that relied on others for public transport. In the context of this study, participants of this study did not need parking as they were using public transport therefore the question related to the availability of parking was irrelevant. In a study of patient satisfaction with physiotherapy by Beattie et al. (2005), cost of therapy was the one item that scored poorly. In the case of Beattie (2005) it may have been related to the cost of therapy being high whereas in this study the low scores might be due to the fact that participants received free healthcare services and felt this question was irrelevant. The pilot study would not have picked this up as only five participants were interviewed.

The parking item on this questionnaire received a median score of 0 (IQR = 0 to 0). Participants may have viewed this item as the place where their public transport drops them off or where their private taxi parks in relation to the facility. Parking may have been answered poorly as with the context in this low socioeconomic community, many of the patients that come to these primary healthcare facilities use public transport. This is a limitation and another study in this setting would be required to verify this information.

Scheduling another appointment after the initial one scored 5 (IQR = 4 to 5). Anderson (2007) did a cross-sectional survey on a convenience sample of 5,030 patients who rated their doctors on a web-based survey developed to collect detailed information on patient experiences with healthcare. The survey included self-reported information on wait times, time spent with doctor, and patient satisfaction. Anderson's study (2007) reported that long waiting times produced low levels of participant satisfaction. After initial treatment, patients in the primary

healthcare facilities in the study setting generally expressed that the duration between first and second appointments is large. It seems that this did not affect the way the participants in this study answered the question.

"I was seen promptly when I arrived for treatment" scored 5 (4 to 5) on the PTPSQ. A study by Anderson et al. (2007) suggested that it is the amount of time spent with the health practitioner and not the waiting time that determines the patients' level of satisfaction with the primary healthcare service. According to Anderson et al. (2007), this score is not as important as time spent in therapy in determining patient satisfaction and therefore should not matter. In addition to this, the primary healthcare (PHC) setting operates differently to the hospital setting in that in a hospital, a patient is required to line up to collect their file before treatment whereas in a PHC setting a patient is given an appointment beforehand and is only required to be at the rehabilitation department at the time specified. The waiting time for physiotherapy treatment can therefore be viewed as decreased in comparison to the rest of the clinic.

5.5 Quality of life post stroke

The mean total for the SSQOL for all 108 stroke survivors in this study was 157 out of 245 (± 23.16), the highest score was 235 out of 245 and the lowest score was 54 out of 245. In a study by Ntsiea et al. (2014), the mean total for the SSQOL was 219 with a minimum of 151 and maximum of 245. Every domain scored higher in Ntsiea's (2014) study compared to this study. It must be noted that in the study by Ntsiea et al. (2014), the SSQOL was done at eight weeks, three and six months post stroke while in this study, the SSQOL was done a minimum of six months post stroke. According to Ahlsiö et al. (1984), ADL function improved during follow up assessments, but QOL did not. In a study by Niemi et al. (1988), 83% of the sample population had decreased QOL four years after stroke. This time period also applies to the current study as it used the four year mark as the cut off point for inclusion into the study.

Participants had lowest scores for the energy domain in this study. A study by Ntsiea et al. (2014) also used the SSQOL to determine HRQOL between an Intervention group and control group. The sample consisted of eighty stroke survivors between 18 and 60 years who were employed at the time of stroke onset The intervention group and control group both scored 13 out of 15. The mean score for the energy domain for this study was eight. The energy domain scores in this study may have been lower than the scores by Ntsiea et al. (2014) because employment prior to stroke was not an inclusion criteria. Survivors of stroke suffer from

reduced levels of physical activity, deconditioning and further physical deterioration (Hurkmans et al., 2011).

Participants reported problems with all domains including self-care, social roles and work/productivity. These figures are all lower than the levels found for these domains by Ntsiea et al. (2014). A study by Hopman and Verner (2003) reported health-related quality of life using the Medical outcomes study 36-item short form (SF-36) on 85 rehabilitation patients at a hospital. In Hopman and Verner's (2003) study patients reported decline in domains related to their independence, usefulness, self-care and socialising that were as a result of comorbid conditions, reduced energy levels, limited social life, and unrealistic expectations of recovery post stroke. Deficits in these areas are similar for the domains in the SSQOL results in this study.

The mean score for social roles (14 out of 20) and work/productivity (9 out of 15) domains showed that participants had problems with these domains. These scores were lower than the ones found in the study by Ntsiea et al. (2014). Participants experienced problems with having a meaningful activity post-stroke. Patients returning to work post stroke have positive impacts on their QOL (Ntsiea et al., 2014) and looking at the high levels of unemployment in this study, this statement holds true as there are high levels of unemployment in this study with problems experienced in the social roles and work/productivity domain.

5.6 Caregiver strain

Of the 45 caregivers in this study, 25 (55%) had a score ≥ 7 meaning that they were strained and 20 (45%) had a score less than 7 (not strained). This figure of strained caregivers is higher than the Blake et al. (2003) study in which 40% of the caregivers were found to be strained after six months. The study by Blake et al. (2003) assessed 116 patients three and six months post stroke. Figures of strain found in Ilse et al. (2008) and Bugge et al. (1999) were 33% and 37% at six months. The study by Ilse et al. (2008) assessed 90 patients and their caregivers at two, four and six months post stroke. The study by Bugge et al. (1999) measured caregiver strain at one, three and six months post stroke. A study by McCullagh (2005) assessed caregiver strain of 232 caregivers of hospital patients. This study showed caregiver strain levels decreased between the three and 12-month period. Ilse and Bugge et al.'s figures of strain are low compared to the one in this study, but figures of caregiver strain measured in the Mudzi (2010) and Hilton et al. (2013)' studies were much higher than this study with 90 per cent and

77 per cent strained caregivers respectively. Mudzi's (2010) study was conducted on 200 hospital in-patients and their caregivers in the Johannesburg area while Hilton et al. (2013)' study assessed 35 participants in clinics and hospitals in the Johannesburg area. This would suggest that figures of caregiver strain vary widely. On closer inspection, the first studies mentioned were done in middle to high socioeconomic settings. Hilton et al.'s (2013) study included participants between six and 36 months post-stroke while Mudzi's (2010) did not state how long participants had their stroke for. In the study by Hilton et al. (2013), the caregivers of the survivors of stroke were assessed earlier on than the caregivers in this study. This extended period may have resulted in the caregivers being able to come up with more coping mechanisms for caring for the survivor of stroke thus meaning they would be less strained. The study by Mudzi (2010) focused more on participants that required a caregiver for core ADLs whereas participants included in this study did not need to have a caregiver. This study as well as the study done by Mudzi (2010) and Hilton et al. (2013) were done in low socioeconomic settings. People living in these settings may already have had some form of financial or physical strain prior to the stroke. The stroke in addition to the pre-existing strain would have made it easier for caregivers to feel strain.

The domains that the caregivers struggle with most are taking care of the survivor of stroke is a physical strain, they feel like there have been many changes to their personal plans and that the caregiver is upset to see that the survivors' behaviour has changed since the stroke. Mudzi's (2010) study shows physical strain, feeling of being confined, having to make family adjustments, the personality changes in the patient and the financial strain to be the items of most concern to the caregivers. Bugge et al's (1999) study showed that changes to plans, feeling of being confined and family adjustments to be the biggest concerns. These two studies differ from the current study except with regards to physical strain. Hale et al. (1998) did a study in South Africa where a lack of knowledge surrounding hypertension, stroke and its impairments was a consideration. This lack of knowledge may be a reason that caregivers were unprepared to deal with the physical strain of taking care of a survivor of stroke as well as being overwhelmed by the behavioural changes that come with having a stroke. Another reason that the caregivers may have had high complaints of physical strain was because data was collected after a minimum of six months post-stroke. After assisting with ADLs and transfers after this length of time there is no doubt that it would take a toll on the body of the caregiver.

5.7 Relationship between community reintegration and caregiver strain index, stroke survivors' quality of life and patients' satisfaction with physiotherapy services

There was a positive correlation between M-SCRIM and SSQOL which shows that as community reintegration improves, so does the survivor of strokes' quality of life. The M-SCRIM had a mean score of 10 for the social roles and interactions domain which is out of 20. The SSQOL scores for social roles and family roles showed that participants struggled with this domain. Quality of life is affected by levels of physical impairment which affects functional outcomes and community reintegration (Carod-Artal et al., 2000). Activities of daily living and self-care had a mean score of 36 out of 48 in the M-SCRIM while participants showed problems in self-care in the SSQOL. Another factor that negatively affects community reintegration is the inability to complete ADLs (Pang et al., 2007). According to the M-SCRIM, participants in this study had few problems with their ADLs. This further shows why there is a relationship between the M-SCRIM and SSQOL in this study.

There was a weak positive relationship between M-SCRIM and PTPSQ showing a higher level of satisfaction with physiotherapy in participants with higher levels of community reintegration. Pound et al. (1994) stated that better levels of integration did not necessarily lead to high levels of satisfaction, but led to better adherence to exercise programmes (Hush et al., 2010). This may have meant the participant identified with or trusted the healthcare facility more and this would have led to higher levels of exercise adherence which would improve their functional ability and eventually lead to better community reintegration.

There was a negative correlation between community reintegration and levels of caregiver strain. Hillier et al. (2010) suggests that patients that return home with lower levels of reintegration are more of a physical and financial burden on their family and this holds true in this study as this study showed physical strain and financial strain as factors that contributed to caregiver's levels of strain. This confirms the fact that community reintegration has a negative correlation to caregiver strain.

Personal and behavioural changes in the participants were reported as reasons for strain in the CSI. A study by Mudzi (2010) also found the same changes to be reasons for caregiver strain. Personal mechanical and behavioural changes (Sommerfield, 2004) are worsened by patients being discharged from hospital with lower functional outcomes According to Sveen et al. (1999). This statement means that the survivors of stroke in this study may have been more

reliant on their caregivers for support. This increased burden would lead to a larger level of caregiver strain (Han et al., 1999). This statement agrees with the findings in this study that community reintegration has a negative relationship with caregiver strain.

5.8 Limitations of the study

- The study would have had more informative data had more information regarding the caregiver's demographics been assessed. The only information available was whether the survivor of stroke had a caregiver, whether the caregiver was strained or not and the various topics that strained the caregiver.
- The employment situation for the survivors of stroke before the stroke versus after the stroke is unclear. This information would have enriched the data as return to work is an important topic when talking about community reintegration.
- Not all the participants had files at the facilities and date of stroke may therefore be inaccurate as the researcher only had patient's self-reported date of stroke.
- Participant safety during physiotherapy sessions with regards to precautions by the therapist, signage and on-site security was one dimension that was not investigated by the PTPSQ. This factor may have played a role in getting a more accurate idea of whether the participants were satisfied with the overall physiotherapy experience.
- Lack of clarity regarding costs of therapy as well as understanding of what was meant by the question related to parking in the PTPSQ may have made the results of the PTPSQ less accurate.
- The time-frame post stroke was wide: six months to four years. This was done to ensure the required number of participants would have been assessed in the given time. This may have influenced the findings of this study

5.9 Conclusion

- This study is similar to the literature in that not all patients are reintegrated into their community. Reasons for this may be that they have problems with ADLs, fail to return to meaningful tasks in the community such as work or they have a lack of social interaction. This decreased level of integration leads to decreased quality of life for survivors of stroke.
- The decreased QOL and level of community reintegration experienced by these survivors of stroke leads to increased burden on the caregivers for financial, physical and emotional support and this can lead to caregiver strain. Comparisons with literature

showed differences in levels of caregiver strain in the different settings. Decreased reliance on caregivers for support may have resulted in less strain.

- This study established a negative relationship between levels of caregiver strain and community reintegration. Although the survivors of stroke may not have fully reintegrated into the community, they may experience high levels of satisfaction with the physiotherapy service. This study established a positive relationship between levels of community reintegration and satisfaction with physiotherapy. The results from this study show that there may be a need to use a satisfaction questionnaire that doesn't focus on the monetary aspect of healthcare as the facilities examined in this study were all free, government services. The question related to cost may need to be modified such so that it reflects the costs that may have been incurred by a patient accessing healthcare at this level. The question related to parking may need to be modified so that it reflects the modes of transport used by most patients in this setting.

The Chapter below concludes the findings of this study.

CHAPTER 6

6.1 CONCLUSION

This conclusion is based on the results and discussion around the objectives of this study which included determining the levels community reintegration, patient satisfaction with physiotherapy, quality of life and caregiver strain levels as well as investigating any relationships between reintegration, satisfaction with physiotherapy, quality of life and caregiver strain.

- Eighty five of the participants (79%) had achieved some form of community reintegration.
- Participant scores for the PTPSQ were high as most scored four or five on the Likert scale. The only low mean scores were related to parking availability and bill accuracy possibly due to lack of understanding of this question as services at PHC level are free and the context of the study setting is one where most patients rely on public transport.
- The mean score for SSQOL was 157 out of 245 with the highest score recorded at 235. This score was relatively lower when compared with another study even when domain-specific comparisons were made.
- Twenty five (55%) of the 45 caregivers were strained. This figure was comparable with other studies that ranged from 33% to 90% of caregivers strained.
- A positive relationship exists between reintegration levels post stroke and patient satisfaction with physiotherapy and between reintegration levels and quality of life after a stroke. A negative relationship exists between reintegration levels and levels of caregiver strain.

6.2 RECOMMENDATIONS

6.2.1 Clinical recommendations

- Better screening and referral to dietician at an inpatient and outpatient level may assist to address the low energy levels experienced by survivors of stroke.
- Caregivers who are strained would require more caregiver training. In addition to this, caregiver expectations need to be set while the survivor of stroke is still an inpatient so that they are aware of the possibilities before they are sent home with the patient. Physical strain was the main complaint from caregivers in this study. Proper lifting and

transfer techniques need to be demonstrated to caregivers possibly in the form of an ergonomics class. Pain relieving modalities should also be shown to caregivers so that they are able to self-manage muscle injuries they acquire from caring for a survivor of stroke.

- A support group for caregivers led by a social worker or psychologist in conjunction with rehabilitation therapists may reduce caregiver strain post stroke.
- Another way of ensuring better transfer of skills is to implement more rigid protocols for discharge reports from inpatient to outpatient care and outpatient to home-based care.

6.2.2 Recommendations for future research

- Conduct this research in the other districts that surround the Johannesburg Metro. This may lead to more information that can assist in the adjustment health professionals' interventions to improve reintegration post stroke
- Further studies in South Africa should use the M-SCRIM to evaluate community reintegration as it is more suited to the communities that are in the country. Studies done with this outcome measure in provinces in South Africa will yield results that are more comparable.
- If further studies are done to evaluate survivors of stroke and their caregivers them more demographic information should be gathered to get a more enriched depiction of the survivor of strokes' and their caregivers.

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APPENDICES
APPENDIX A; Maleka Stroke Community Reintegration Measure

INSTRUCTIONS TO THE PATIENTS

The therapist will read the items concerning your community reintegration following stroke to you (patient and/or caregiver), please respond appropriately.

At end of the interview the therapist will give, you feedback regarding your community reintegration and discuss the way forward regarding your rehabilitation.

INSTRUCTIONS TO THE ASSESSOR

Explain the purpose of administering the MSCRIM to the patient and the caregiver: to assess community reintegration following stroke in order to plan on improving or maintaining it.

Administer the MSCRIM, in case of a patient not able to communicate the caregiver must be interviewed.

Start with demographic information and state whether this is baseline or follow up assessment.
At the end of the interview, add points for each domain and calculate the total score for the patient.
Interpret and provide feedback for the patient by placing the patient's score on the scale below.

Cut off points:

- 80% and above means full reintegration
- 79%-60% moderate reintegration
- 59%-41% minimal reintegration
- 40%-0% no reintegration

Discuss the way forward regarding the patient's rehabilitation goals to improve community reintegration with the patient and caregiver. The setting of rehabilitation goals should be guided by the domain(s) and item(s) that the patient obtained by the lowest scores.

THE ENGLISH VERSION OF THE MSCRIM URBAN SETTING VERSION

Domain 1: ADL AND SELF CARE

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to get up and out of bed in the morning?				
2 Are you able to pour water into a kettle/basin?				
3 Are you able to wash yourself?				
4 Are you able to dress yourself?				
5 Are you able to feed yourself?				
6 Are you able to drink from a cup or glass?				
7 Are you able to move around uneven/hilly areas?				
8 Are you able to move around in your home?				
9 Are you able to move around in your yard?				
10 Are you able to move around in your community?				
11 Are you able to collect water from the river/communal tap?				
12 Are you able to carry heavy object(s) for example shopping bags (2-3)?				
13 Are you able to get to the clinic/hospital to collect your medication or for rehabilitation/nursing/ medical help?				
14 Are you able to use the same transport you used before the stroke?				
15 Are you able to do an activity for self enjoyment or relaxation such as to listen to a radio or watch TV or read a book/ bible/magazine/newspaper?				
16 Are you able to get out of the house to go shopping in town or going out with friends or watch a soccer match at a stadium?				

Domain 2: SOCIAL INTERACTIONS AND RELATIONSHIP

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to work in your garden or fields?				
2 Are you able to attend social events in your community such as funerals, parties or weddings?				
3 Are you able to attend burial society, social club meetings and other structures meeting or meetings called by the chief/councilor in your community?				
4 Are you able to carry out your community roles e.g. singing in the choir, helping at the local school, digging of a grave, community leadership, preaching or evangelizing to people or burying your congregants,?				
5 Are you able to attend religious, spiritual and other religious related activities e.g. bible studies, home cell meetings, prayer meetings?				
6 Are you able to do a physical activity such as playing any sport?				
7 How satisfied are you with your interaction with other people?	Not Satisfied (0)		Satisfied (1)	Very satisfied (2)

Domain 3: HOME/FAMILY RESPONSIBILITIES AND APPEARANCE

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to clean your house and yard i.e. sweep, pick up papers and/or mudding the floors with cow dung?				
2 Are you able to cook and prepare meals for your family?				
3 Are you able to clean the area and utensils used for preparing meals?				
4 Are you able to wash the clothes?				
5 Are you able to hang the clothes on a washing line or are you able to dry your clothes the way you have always done?				
6 How satisfied are you with your appearance in the public?	Not Satisfied (0)		Satisfied (1)	Very satisfied (2)
7 How satisfied are you with your ability to physically assist someone?	Not Satisfied (0)		Satisfied (1)	Very satisfied (2)

Domain 4: SOCIAL INTERACTIONS

1 How satisfied are you with your visiting other people and them visiting you?	Not Satisfied (0)	Satisfied (1)	Very satisfied (2)	
2 How satisfied are you with help and support that you receive from your family and friends?	Not Satisfied (0)	Satisfied (1)	Very satisfied (2)	
3 How satisfied are you with your ability to solve family and friend's problems	Not Satisfied (0)	Satisfied (1)	Very satisfied (2)	
4 Are your friends and family assisting you with your travelling needs?	No (0)	Yes, but rarely (1)	Yes, sometimes (2)	Yes, always (3)
5 Are you able to remember things told and events easily?	Not at all (0)	To some extent (1)	To a full extent (2)	
6 Are you able to make decisions regarding your life and family issues?	Not at all (0)	To some extent (1)	To a full extent (2)	

Domain 5: EXTENDED FAMILY RESPONSIBILITIES

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to take care of your livestock (if you have) e.g. feed your dogs or herd/tend your cattle/ goats, including milking?				
2 Are you able to teach children home keeping tasks e.g. cultural/traditional cooking, and mudding with cow dung?				

Domain 6: WORK AND EDUCATION

Item	No (0)	Able with major help (1)	Able with minor help (2)	Able with no help (3)
1 Are you able to go back to work (paid or volunteer)?				
2 Are you able to attend school or training programmes (including adult education) in or out of your community?				

APPENDIX B; Physiotherapy-specific Patient Satisfaction Questionnaire

Please place an X in the appropriate box to indicate your rating, or answer the descriptive questions on the appropriate line. Any additional comments you wish to make are welcome; write in the "Comments" section at the end of the questionnaire, or attach additional pages if you require more space. Please return the questionnaire to us at your earliest convenience.

Thank you very much for your feedback!

Physical Therapy Patient Satisfaction Questionnaire

Descriptive Questions

1. Your age _____ Years

2. Your sex ☐ Male ☐ Female

3. How did you learn about this facility? *(Check all that apply.)*
☐ Physician ☐ Insurance company recommendation
☐ Friend ☐ Former patient
☐ Telephone book ☐ Other, please indicate _____

4. Was this your first experience with physical therapy? ☐ Yes ☐ No

5. Was this your first experience with this facility? ☐ Yes ☐ No

6. Please check the location of the problem for which you received physical therapy. *(Check all that apply.)*
☐ Neck ☐ Hip
☐ Lower back ☐ Foot
☐ Shoulder ☐ Hand
☐ Elbow ☐ Knee
☐ Other, please indicate _____

Please rate your degree of satisfaction with each of the following statements. *(1=strongly disagree, 2=disagree, 3=neither agree nor disagree, 4=agree, 5=strongly agree. Please check 9 if you have no opinion on the subject.)*

		Strongly Disagree 1	Disagree 2	Neither Agree nor Disagree 3	Agree 4	Strongly Agree 5	No Exp. w/ Item 9
7.	My privacy was respected during my physical therapy care.	☐	☐	☐	☐	☐	☐
8.	My physical therapist was courteous.	☐	☐	☐	☐	☐	☐
9.	All other staff members were courteous.	☐	☐	☐	☐	☐	☐
10.	The clinic scheduled appointments at convenient times.	☐	☐	☐	☐	☐	☐
11.	I was satisfied with the treatment provided by my physical therapist.	☐	☐	☐	☐	☐	☐
12.	My first visit for physical therapy was scheduled quickly.	☐	☐	☐	☐	☐	☐
13.	It was easy to schedule visits after my first appointment.	☐	☐	☐	☐	☐	☐
14.	I was seen promptly when I arrived for treatment.	☐	☐	☐	☐	☐	☐
15.	The location of the facility was convenient for me.	☐	☐	☐	☐	☐	☐
16.	My bills were accurate.	☐	☐	☐	☐	☐	☐
17.	I was satisfied with the services provided by my physical therapist assistant(s).	☐	☐	☐	☐	☐	☐
18.	Parking was available for me.	☐	☐	☐	☐	☐	☐
19.	My physical therapist understood my problem or condition.	☐	☐	☐	☐	☐	☐
20.	The instructions my physical therapist gave me were helpful.	☐	☐	☐	☐	☐	☐
21.	I was satisfied with the overall quality of my physical therapy care.	☐	☐	☐	☐	☐	☐
22.	I would recommend this facility to family or friends.	☐	☐	☐	☐	☐	☐
23.	I would return to this facility if I required physical therapy care in the future.	☐	☐	☐	☐	☐	☐
24.	The cost of the physical therapy treatment received was reasonable.	☐	☐	☐	☐	☐	☐
25.	If I had to, I would pay for these physical therapy services myself.	☐	☐	☐	☐	☐	☐
26.	Overall, I was satisfied with my experience with physical therapy.	☐	☐	☐	☐	☐	☐

APPENDIX C; Stroke Specific Quality of Life

Stroke Specific Quality of Life Scale (SS-QOL)

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

Energy

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

Family Roles

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

Language

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

Mobility

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

Mood

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

Personality

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

Self Care

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

Social Roles

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

Thinking

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

Upper Extremity Function

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

Vision

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

Work/Productivity

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

TOTAL SCORE ____

Reference

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

APPENDIX D; Caregiver Strain Index

The Caregiver Strain Index: I am going to read a list of things that other people have found to be difficult. Would you tell me if any of these apply to you? (Give examples)

	Yes=1	No=0
Sleep is disturbed (e.g., because _____is in and out of bed or wanders around at night)		
It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help)		
It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)		
It is confining (e.g., helping restricts free time or cannot go visiting)		
There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy)		
There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation)		
There have been other demands on my time (e.g., from other family members)		
There have been emotional adjustments (e.g., because of severe arguments)		
Some behavior is upsetting (e.g., because of incontinence; _____has trouble remembering things; or _____accuses people of taking things)		
It is upsetting to find_____ has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be)		
There have been work adjustments (e.g., because of having to take time off)		
It is a financial strain		
Feeling completely overwhelmed (e.g., because of worry about _____; concerns about how you will manage)		
TOTAL SCORE (Count yes responses. Any positive answer may indicate a need for intervention in that area. A score of 7 or higher indicates a high level of stress.)		

Robinson, B. (1983). Validation of a Caregiver Strain Index. Journal of Gerontology. 38:344-348. Copyright (c) The Gerontological Society of America. Reproduced by permission of the publisher.

APPENDIX E; Demographic Data Sheet

Demographic data sheet

STUDY TITLE: Community reintegration of survivors of stroke receiving physiotherapy services in the community health centres within the Johannesburg area

Filled out by (mark with an X):

Researcher	Participant	Caregiver

Gender	
Physical address	
Race	
Current occupation	
Date of assessment	
Date of birth	
Age	
Marital status	
Do you have a caregiver?	
Level of education	
Affected side	
Date of stroke	

APPENDIX F; Ethical Clearance Certificate

M140452

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M140452

NAME: (Principal Investigator)	Mr Adrian Kusambiza-Kiingi et al
DEPARTMENT:	Physiotherapy Hillbrow Rehabilitation, Alexandra, Chiawelo and Mofolo Rehabilitation Clinics
PROJECT TITLE:	Community Reintegration of Survivors of Stroke receiving Physiotherapy Services in the Community Health Centres within Johannesburg Area
DATE CONSIDERED:	25/04/2014
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Dr D Maleka
APPROVED BY:	Professor PE Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 06/06/2014

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

DECLARATION OF INVESTIGATORS

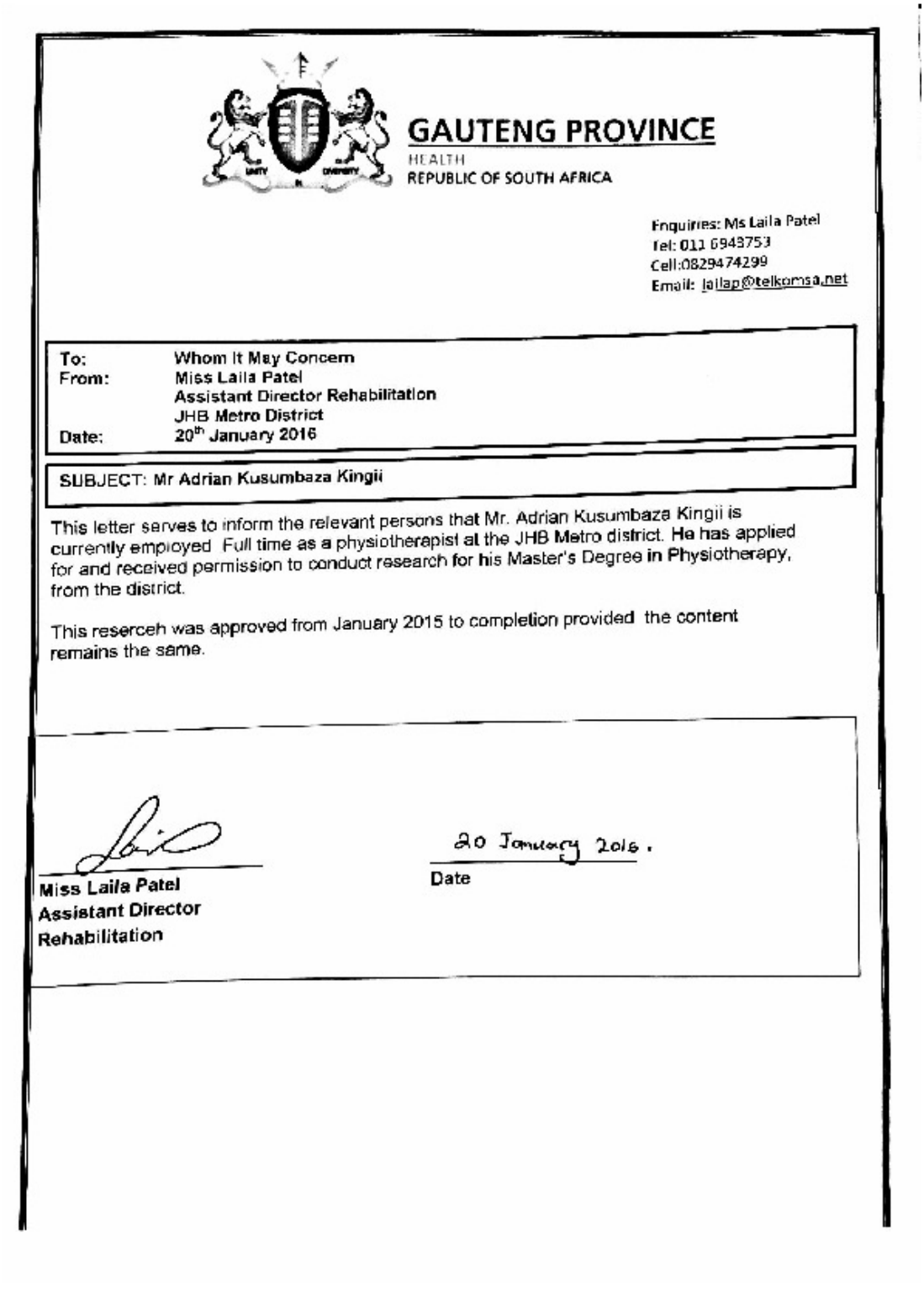
To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House University.

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

Principal Investigator Signature M140452Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX G; Permission Letter to Carry Out Research from Johannesburg Metro



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Enquiries: Ms Laila Patel
Tel: 011 6943753
Cell:0829474299
Email: lailap@telkomsa.net

To:	Whom It May Concern
From:	Miss Laila Patel Assistant Director Rehabilitation JHB Metro District
Date:	20th January 2016

SUBJECT: Mr Adrian Kusumbaza Kingii

This letter serves to inform the relevant persons that Mr. Adrian Kusumbaza Kingii is currently employed Full time as a physiotherapist at the JHB Metro district. He has applied for and received permission to conduct research for his Master's Degree in Physiotherapy, from the district.

This reserceh was approved from January 2015 to completion provided the content remains the same.

Miss Laila Patel
Assistant Director
Rehabilitation

20 January 2016.
Date

APPENDIX H; Information Document

Community reintegration of survivors of stroke receiving physiotherapy services in the community health centres within the Johannesburg area

I, Adrian Kusambiza, am doing research on community integration. Research is where we ask questions to find out new information. Community reintegration is how well people fit back into their community after they've been taken out of it.

I'm inviting you to take part in this study. The study is going to involve answering four questionnaires. The study will begin in June 2014. We are surveying participants' views on community reintegration following a stroke, levels of strain experienced by the participant's caregivers, quality of life and satisfaction levels with the physiotherapy service. There will be a total of 108 people in the study. These other participants will be from four community health centres in the Johannesburg area.

Participants will only be asked to answer questions and will not be at risk of bodily harm. There are no direct benefits of being a part of this study. The study will help us see how satisfied survivors of stroke and their caregivers are with the physiotherapy service offered at the community health centre. The study will also help us better understand whether survivors of stroke fit back into their community and it will show us whether participants feel the treatments we give them are helping them.

Participants will not be forced to take part in the study and can choose to withdraw from the study at any time.

If participants are asked to come to the clinic on days when they are not receiving any treatment from the clinic, they will be reimbursed for their taxi fare.

Efforts will be made to keep personal information confidential. When the information is presented at the end of the study, participants will remain anonymous.

Contact details of researcher/s – for further information, contact Adrian Kusambiza on 074 605 7063 or at silas@live.co.za

Contact details of REC administrator and chair – Professor Cleaton-Jones 011 717 1234

APPENDIX I; Informed Consent Sheet for Participant

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I consent voluntarily to participate as a participant in this research.

Print Name of Participant_____

Signature of Participant _____

Date _____
Day/month/year

Statement by the researcher/person taking consent
I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:
1. Demographic data will be collected
2. Four questionnaires will be administered

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Print Name of Researcher/person taking the consent_____

Signature of Researcher /person taking the consent_____

Date _____
Day/month/year

APPENDIX J; Informed Consent Sheet for Caregiver

The primary caregiver is the caregiver that spends the most time caring for the survivor of stroke.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I consent voluntarily to participate as a participant in this research.

Print Name of Participant_____

Signature of Participant _____

Date _____
Day/month/year

Statement by the researcher/person taking consent
I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:
1. Caregiver strain will be administered with the primary caregiver

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Print Name of Researcher/person taking the consent_____

Signature of Researcher /person taking the consent_____

Date _____
Day/month/year