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# Caregivers' perceived enablers of and barriers to adherence to home exercise programmes in stroke survivors

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# Caregivers' perceived enablers of and barriers to adherence to home exercise programmes in stroke survivors

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

Johannesburg, 2017

## Declaration

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

 (Signature of candidate)

20th day of June (month) 2017

**DEDICATION**

To my loving parents Leon and Monica Scorrano who always belief in me.

**ACKNOWLEDGEMENTS**

1. To the University of the Witwatersrand Ethics Committee and School of Therapeutic Sciences assessor committee for approving my research.
2. My supervisors, Dr V. Ntsiea and Prof D. Maleka for your support, encouragement and assistance.
3. The management of Witrand Hospital for allowing me to base my study at their hospital.
4. My husband Herman Terblanche, thank you for walking this journey with me and for all your patience and continuous support.
5. All my friends and family, thank you for your encouragement and support.
6. To the Lord God, all the glory – Grace and blessings in abundance.

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## LIST OF ABBREVIATIONS

| | |
|---|---|
| ADLs | Activities of daily living |
| BI | Barthel Index |
| GBD | Global burden of disease |
| WHO | World health organisation |

**ABSTRACT**

**Background and Purpose:**

One of the leading causes of neurological disability that cause a remarkable functional impairment is stroke. In stroke rehabilitation, the goal is to discharge patients at their optimal functional independent level. This level of independence is not always reached on discharge due to decreased length of stay and a high demand for beds. In addition, community based rehabilitation services in South Africa are poorly developed and inadequate. This leads to early discharge and rehabilitation goals that are not reached.

Adherence to physiotherapy home programmes is unsatisfactory and it is a big obstacle faced by physiotherapists. Patients do not reach their rehabilitation goals and desired outcomes because they fail to continue and to adhere to home programmes. Factors associated with adherence vary considerably among individuals. Various enablers of and barriers to adherence to home exercise programmes and participation in rehabilitation and physical activity are found in literature.

Because the desired outcomes for stroke survivors are not met on hospital discharge they rely upon caregivers to assist them not only with activities of daily living but also with the continuation of the rehabilitation process through home exercise programmes. Thus, adherence to home exercise programmes in not only affected by the stroke survivors' beliefs and attitudes but also by those of the caregiver, as they play an essential role post-stroke and in the rehabilitation process.

To the researcher's knowledge no studies on factors that influence adherence to home exercise programmes in stroke survivors from a caregivers' perspective have been conducted in South Africa and more specifically the North West province of South Africa. The aim of this study was to establish caregivers' perceived enablers and barriers of adherence to home exercise programmes in stroke survivors. There were three main objectives: i) to establish the demographic profile of the stroke survivors and their caregivers ii) to establish the caregivers' perceived enablers of adherence to home exercise programmes iii) to establish the caregivers' perceived barriers of adherence to home exercise programmes.

**Methodology:**

This was a qualitative study design using in-depth caregiver interviews. Ethical clearance was applied for at the University of the Witwatersrand and permission was also obtained from hospital management where the study took place before the commencement of the research project.

Interviews were conducted with the caregivers of patients discharged from the hospital where the study took place, who met the inclusion criteria. The interviews took place at the hospital three months post discharge. Verbal and written consent was obtained from all the stroke survivors and caregivers for participation and audio recording of the interviews. The researcher collected all the demographic data from the stroke survivors including BI score.

The in-depth interview was conducted by the researcher using an interview schedule. The interview was informal, with open- ended questions, carried out in a conversational style in the participants' choice of language Afrikaans, English or Setswana. Initially the interview started with structured questions and probing questions followed as necessary for more information or clarification thereof. Audio records and field notes were made during the interview by the researcher. The audio records were transcribed and translated word for word afterwards by the researcher. The data was analysed by the researcher and a second analyser using the general inductive approach and consisted of five main steps.

**Results:**

Seven interviews were conducted. The average age of the stroke survivors was 55.8 (±15.03) years, four were female and three were male, five had right sided strokes and two left sided. The average BI score was 47.1%. The average age of the caregivers was 47.8 years (±13.96) years, five were female and two were male all of them were closely related family members. Three were unemployed, two self-employed, one employed and one a pensioner.

The most common enablers of adherence to home exercise programmes are: self –motivation, external motivation from friends and family, daily routine, spirituality, carers' 'attitudes and desire' and knowledge.

The most common barriers of adherence to home exercise programmes are: general health issues, other responsibilities, lack of family and social support, caregiver burden and stress, low self-efficacy and mood, and fear of falling.

**Conclusion:**

It is evident from this study that adherence to home exercise programmes is multifactorial and does not only relate to the stroke survivor alone. Caregivers have a lot of responsibilities and experience emotional strain and burden and this has an influence on stroke survivors' adherence to home exercise programmes as they rely upon caregivers for assistance. When addressing adherence both the stroke survivor and the caregivers needs to be considered. Being aware of the potential enablers and barriers of adherence to home exercise programmes can give health care professionals insight in how to optimise adherence and possibly improve functional ability and the quality of life of stroke survivors.

**Key word:** stroke, adherence, home exercise programmes, enablers, barriers, factors influencing adherence, caregivers' perspective

# CHAPTER 1

## 1.1 BACKGROUND

This chapter will provide an overview of the study including the background to indicate the need for the study, problem statement, the aim of the study, the objectives as well as the significance of the study.

## 1.2 Introduction

One of the leading causes of neurological disability that causes remarkable functional impairments is stroke (Jurkiewicz et al., 2011; Tiedemann et al., 2012). Physiotherapists are responsible for prescription, promotion and education of patients about the importance and value of exercises as it relates to optimal physical function, wellness and quality of life (Forkan et al., 2006). In stroke rehabilitation, the goal is to discharge patients at their optimal functional independent level (Ogwumike et al., 2014). This level of independence is not always reached on discharge due to decreased length of stay and a high demand for beds in government hospitals. In addition, community based rehabilitation services in South Africa are poorly developed and inadequate (Hale et al., 1996; Rhoda et al., 2006; Mudzi, 2009; Mudzi et al., 2012c). This leads to early discharge and rehabilitation goals that are not reached. Sometimes patients are sent home without rehabilitation and they receive no intervention once they are at home. Adherence to physiotherapy home programmes is unsatisfactory and it is a big obstacle faced by physiotherapists. Patients do not reach their rehabilitation goals and desired outcomes because they fail to continue and to adhere to home programmes (Sluijs et al., 1993; Merrill, 1994; Ogwumike et al., 2014).

Successful rehabilitation outcomes depend on the effectiveness of treatment and the extent to which a patient complies with the treatment regime (Ogwumike et al., 2014). The terms compliance and adherence are sometimes used synonymously but are actually not the same. Compliance has been defined as “the extent to which a person’s behaviour in terms of taking medication, following diets or executing other lifestyle changes matches with the prescribed medical or health advice” (Cameron, 1996 pg. 244; Horn et al., 2005). Compliance is also regarded as when the patient does what they are told or advised to do (Merrill, 1994). The term ‘non-compliance’ implies a lack of patient involvement and therefore the use of it is declining. Adherence is defined as “the extent to which the patient’s behaviour matches agreed recommendations from the prescriber (Horne et al., 2005). It has been adopted by many as an alternative to compliance, in an attempt to emphasise that the patient is free to decide whether to adhere to the recommendations and that failure to do so should not be a

reason to blame the patient. Adherence adds to the definition of compliance by emphasising the need for agreement (Horne et al., 2005). The term adherence will be used for the purpose of this study as it allows the patient to influence the decision making.

According to literature the following factors influence adherence: discomfort (Jurkiewicz, 2011; Ogwumike, 2014), personal barriers for example little time, forgetfulness and exercise not being part of their daily routine (Sluijs et al., 1993; Jurkiewicz, 201;1 Ogwumike, 2014), patient therapist relationship and dependence on physiotherapists, lack of knowledge and understanding of home programmes (Sluijs et al., 1993; Cameron, 1996; Ogwumike, 2014), characteristics of the illness, whether the illness is acute or chronic regarded as serious and the degree of disability caused by it, when the illness is perceived as serious and more severe with greater disability adherence increases (Sluijs et al., 1993), patients' beliefs and attitudes, lack of family support, lack of social interaction and isolation (Sluijs et al., 1993; Cameron, 1996) as well as lack of motivation and musculoskeletal problems such as pain and poor endurance (Jack et al., 2010; Jurkiewicz, 2011). There is no relationship between age, sex, race and education to adherence with home programmes (Sluijs et al., 1993).

As mentioned earlier, decreased length of stay and high demand for beds in government settings leads to early discharge before patients reach their optimal functional independence level. Therefore, caregivers are relied upon to assist them not only with activities of daily living (ADLs), but also with the continuation of the rehabilitation process through home exercise programmes (Mudzi et al., 2012c). Thus, adherence to home exercise programmes is not only affected by the stroke survivors' beliefs and attitudes but also by those of the caregiver, as they play an essential role post-stroke and in the rehabilitation process.

Health care professionals are responsible to give adequate information to families and stroke survivors regarding their condition. According to literature stroke survivors, their families and carers are unsatisfied with the information given and this can contribute to poorer outcome as uninformed patients are less satisfied and therefore more likely to not adhere to advice and treatment (Rogers, 2001).

Treatment outcomes and function is negatively affected by non-adherence with home exercise programmes as it can lead to long term disabilities, poor quality of life and preventable disease progression (Ogwumike et al., 2014). According to William (2009) caring for a stroke survivor has a great burden and high demands on caregivers and influences both their physical and emotional wellbeing. Interventions need to be directed towards both the stroke survivor and

the carer to improve the recovery and quality of life of the stroke survivor, but also to sustain the carer's own health and wellbeing (Forster et al., 2013).

The importance of adherence to treatment and home exercise programmes cannot be overemphasised. Identifying the enablers and barriers of adherence to home exercise programmes may give insight that can be used to increase the positive effect of the enablers and reduce the negative effect of the barriers. This will optimise adherence and lead to continuous improvement, functional independence and better quality of life.

### 1.3 Problem statement

Stroke survivors do not reach their optimal functional independence level and rely on caregivers who play an essential role in the rehabilitation process and the continuation of therapy after discharge through a home exercise programme. Studies were conducted to look at adherence to home programmes in a wide variety of conditions and it was found to be poor (Sluijs et al., 1993; Forkan et al., 2006; Medina-Mirapeix et al., 2009). None of these studies looked at adherence from a caregivers' perspective and all of the findings were based on the patients. To the researcher's knowledge no studies on perceived enablers and barriers of adherence to home exercise programmes in stroke survivors from a caregivers' perspective have been conducted in South Africa and more specifically the North West province of South Africa.

### 1.4 Research Question

What are the caregivers' perceived enablers and barriers of adherence to home exercise programmes in stroke survivors?

### 1.5 Aim of the Study

To establish caregivers' perceived enablers and barriers of adherence to home exercise programmes in stroke survivors.

### 1.6 Objectives of the study

1.6.1 To establish demographic profile of the stroke survivors and their caregivers.

1.6.2 To establish the caregivers' perceived enablers of adherence to home exercise programmes.

1.6.3 To establish the caregivers' perceived barriers of adherence to home exercise programmes.

### 1.7 Significance of the study

The established enablers and barriers of adherence to home exercise programmes may assist physiotherapists, as well as other allied health professionals to:

- Identify patients at risk for non-adherence.
- Suggest methods to reduce the negative impact of the barriers and increase the positive impact of the enablers.
- Adapt home exercise programmes and family training to optimise adherence.
- Offer the necessary support required by stroke survivors and caregivers.

If adherence is maximised, stroke survivors will have better functional outcomes due to the ongoing rehabilitation process (Ogwumike et al., 2014).

## CHAPTER 2

## 2. LITERATURE REVIEW

This chapter will provide an overview of the literature related to the study objectives. It includes the definition and epidemiology of stroke, the impact of stroke, stroke rehabilitation in general, adherence to physiotherapy and home exercise programmes, enablers and barriers of adherence to physiotherapy, the role of caregivers in rehabilitation, the effect of caregiving on caregivers and interventions available for caregivers.

### 2.1 Introduction

One of the leading causes of disability that cause a remarkable functional impairment is stroke (Jurkiewicz et al., 2011; Tiedemann et al., 2012). Optimal recovery post stroke involves complex rehabilitation which is individualised according to stroke survivors needs. Recovery post-stroke is a lengthy process with neurological recovery occurring 1-3 months post stroke and functional recovery 4-6 months post stroke (Schaechter, 2004). Rehabilitation interventions that speed up recovery and aim to reduce long term disability have a major impact on the individual and the burden of the disease (Galvin et al., 2009).

One of the key interventions in interdisciplinary stroke rehabilitation is physiotherapy (Veerbeek et al., 2014). Physiotherapists are responsible for prescription, promotion and education of patients about the importance and value of exercises as it relates to optimal physical function, wellness and quality of life (Forkan et al., 2006). In stroke rehabilitation, the goal is to discharge patients at their optimal functional independent level (Ogwumike et al., 2014). This level of independence is not always reached on discharge due to decreased length of stay and a high demand for beds. In addition, community based rehabilitation services in South Africa are poorly developed and inadequate (Hale et al., 1996; Rhoda et al., 2006; Mudzi, 2009; Mudzi et al., 2012c). This leads to early discharge and rehabilitation goals that are not reached. Sometimes patients are sent home without rehabilitation and they receive no intervention once they are at home.

Because the desired outcomes of stroke survivors are not met, they rely on caregivers not only to assist them with activities of daily living (ADLs), but also with continuation of the rehabilitation process through home exercise programmes (Mudzi et al., 2012c). Thus, adherence to home exercise programmes is not only affected by the stroke survivors' beliefs and attitudes but also by those of the caregiver, as they play an essential role post-stroke and in the rehabilitation process (Mudzi et al., 2012c).

The involvement of caregivers and family members in the rehabilitation of stroke survivors maximises the effect of the rehabilitation. It allows for carry over outside the formal physiotherapy practice giving stroke survivors the opportunity for informal practise in their home environment. It reduces fear, improves handling skills and assists in coping (Galvin et al., 2009). Through this the gains and improvement from the initial rehabilitation are more effectively maintained. This is required to avoid long term disabilities, poor quality of life and preventable disease progression which occur as a result of non-adherence. Non-adherence with home exercise programs will negatively affect treatment outcomes and function (Ogwumike et al., 2014).

This literature review was done using the following search engines and databases: Google Scholar, Pubmed, EBSCO Host (Medline, Academic Search Complete, CINAHL Plus, Education Research Complete, ERIC, Global Health, Health Source: Nursing/Academic Edition, SocINDEX). The following search words were used: adherence, non-adherence, compliance, non-compliance, caregivers, family members, home exercise programmes, enablers, barriers, enablers, motivators, stroke survivors, epidemiology, perspectives, perceptions, impact of stroke, interventions, caregiver burden, caregiver strain, role of caregiver-s, role of families. These enabled the researcher to gain an in-depth view of the literature related to this study.

**2.2 Definition and Epidemiology of stroke**

The World Health Organisation (WHO) defines stroke as “rapidly developing clinical signs of focal, or at times global disturbance of cerebral function, lasting more than 24 hours or leading to death with no apparent cause other than a vascular origin” (WHO, 2002). A lack of oxygen and nutrients cause damage to brain tissue, post stroke (WHO, 2002).

Stroke is a major cause of long term disability and one of the top 10 leading causes of disability (Feigin et al., 2003; Lopez et al., 2006) and the second leading cause of death worldwide (Lozano et al., 2012). The prevalence of stroke in South Africa is as high as that of high income countries (Connor, 2004). Stroke is now being recognised as an important cause of death and disability in low income countries (Connor, 2004; Lopez et al., 2006) with the burden increasing (Adeloye, 2014).

The number of people affected by stroke increases yearly since 1990 (Krishnamurthi et al., 2013). The number of people who become disabled as a result of stroke and deaths related to stroke are also increasing (Krishnamurthi et al., 2013). In 2005, 16 million new cases of stroke and 62 million stroke survivors were estimated globally with 9.7% accounting for all

global deaths (WHO, 2004; Strong et al., 2007). Stroke was responsible for 5.3 million deaths or 1 in 10 deaths world-wide in 2010 (Krishnamurthi et al., 2013). It is estimated that by 2030, there will be 23 million new stroke cases, 7.8 million stroke deaths and 70 million stroke survivors worldwide (WHO, 2004; Strong et al., 2007; Maredza et al., 2015).

The burden of stroke in Africa is high and still increasing (Adeloye, 2014). In a systematic review and meta-analysis of the incidence and prevalence of stroke in Africa in 2014 by Adeloye there was a crude incident rate of 112.9 per 100 000 person years from community-based studies compared to 77.4 from hospital based studies. There is over a 100% increase in stroke cases and stroke survivors recorded between 1990-2010 according to the 2014 Global Burden of Disease (GBD) estimates by Feigin and colleagues. In 2009 in Africa there were over 483 000 new cases of stroke among people aged 15 years or more with an incidence rate of 81.21/100 000 person years (Adeloye, 2014). There were also an estimated number of 1.89 million stroke survivors in Africa among people aged 15 years or more with a prevalence rate of 317.3/100 000 population (Adeloye, 2014).

It was reported in 2004 that 8% of all first ever strokes occur in Africa and 5% of over 30 million stroke survivors worldwide were in Africa (WHO, 2004; Strong et al., 2007). Overall stroke mortality at one month is about 30% in Africa and this is much higher compared to the 20% in the rest of the world (Connor et al., 2007).

Dramatic epidemiological changes are experienced by rural South Africa due to the increase in non-communicable diseases (Maredza et al., 2015). The incidence of stroke in the entire rural South African population of approximately 13 million people were 33 500 strokes occurring in 2011. This gives a crude incidence rate of 259 cases per 100 000 person years (Maredza et al., 2015). In 2013, the incidence of stroke in South Africa was 75 000 strokes per year (Bertram et al., 2013). Furthermore 25 000 deaths occur annually due to stroke in South Africa and it is responsible for 95 000 years lived with disability (Bertram et al., 2013). The observed crude mortality rate was 114 per 100 000 person years in 2007-2011 (Maredza et al., 2015). In north west province of South Africa, where the current study was conducted, stroke accounts for 5-6% of deaths being one of the leading causes of death in the age group 45-59 years and 60 years and older (Shutte et al., 2012). Schutte (2012), in their incident based study, found a high incidence of key stroke risk factors in rural North West province of South Africa. This has potential to increase the burden of stroke in low income countries.

### 2.3 Impact of stroke and service provision

Stroke has a major impact on both the individual and the community. Initially during the acute phase post stroke, the following common impairments occur: motor function (50-83%), cognitive function (50%), urinary incontinence (40-50%), dysphagia (45%), aphasia (23%), and dysphasia (36%) (Paul et al., 2007). Incomplete recovery occurs in half of all stroke survivors and assistance with activities of daily living is required by half of them (Truelson et al., 2006; Wasserman et al., 2009). The most debilitating and persistent impairments seen post stroke are deficits in upper and lower limb function. Poor recovery of ADLs and mobility are due to gross and fine motor impairments as well as general balance impairments that occur in 80% of all stroke survivors (Chouhan and Kumar, 2012).

A study by Green and colleagues in 2005, compared rehabilitation practices in three countries: Australia, Finland and South Africa. Data were used from private hospitals in South Africa and public hospitals in Australia and Finland. A difference in age distribution of stroke survivors across countries was found. In South Africa, stroke survivors were much younger compared to Australia. South African stroke survivors were also admitted and discharged with lower functional levels. In some cases, the functional levels were poorer on discharge compared to those of Australian and Finland patients on admission. In South Africa, most stroke survivors had to stay with family or friends and far more patients died during rehabilitation. In Australia and Finland, the focus was on early intervention and patients received inpatient and outpatient rehabilitation services. Rehabilitation usually started immediately after the acute episode.

In South Africa patients receive minimal therapy interventions in hospital. The average length of stay in tertiary hospitals for a stroke patient is six days (Mudzi, 2009). A study by Hale and colleagues in 2002 indicated that the average length of stay at the Chris Hani Baragwanath hospital which is a government hospital in South Africa was 14 days. Green et al. (2005) found an average stay of 30-34 days for stroke survivors in the South African sample from private hospitals. In high income countries, the average length of stay varies between 28-34 days (Van Straten et al., 1997; Van Exel et al., 2003). Hospital length of stay is shortening worldwide. Therefore, patients have limited functional independence on discharge and remain limited in their participation in family and community activities (Maleka et al., 2012).

Community-based rehabilitation services are poorly developed, inadequate and inaccessible (Hale et al., 1996; Rhoda et al., 2006; Mudzi, 2009). Thus, the burden of care of stroke survivors is on relatives and family members. In poorly resourced areas home based rehabilitation that is continued by caregivers after early discharge is an attractive option (Mudzi, 2009). Therefore, caregiver involvement and training during in-patient and out-patient

rehabilitation may be an affordable and effective way of improving stroke survivors' outcome and quality of life and overcoming the challenges regarding resources, both human and financial (Mudzi, 2009).

### 2.4 Stroke rehabilitation

Stroke results in physical impairment. Therefore, there is a need for interventions that aim to speed up recovery and to reduce long term disability in order to address both the individual and social burden of the illness (Galvin et al., 2009). Rehabilitation includes all measures that aim to reduce the impact of the disability on an individual in order to enable him or her to achieve independence, social integration, better quality of life and self-actualisation (Rhoda et al., 2006).

Exercise intervention is one of the major components of stroke rehabilitation. It aims to minimise the effect of the brain tissue damage and optimise re-learning (Galvin et al., 2009). Physiotherapy assists with further improvement, maintaining function, reduce impairments, improve general physical fitness and promote self-management (Karingen et al., 2011; Olaleye et al., 2012). Through structured exercise programmes as part of stroke rehabilitation, physiotherapists also aim to prevent disability and to improve and optimise physical functioning and help stroke survivors regain pre-stroke functional level (Ogwumike et al., 2014).

During the first six months following a stroke the major functional improvements are seen, but functional improvement is still experienced even as the disease moves into a more chronic phase (Karingen et al., 2011). Therefore, stroke rehabilitation is a continuous process and will be needed for years following the incident and sometimes even lifelong (Karingen et al., 2011; MacDonald et al., 2013). Literature suggests that improvement in functional activities as well as ADLs is enhanced with more intensive exercise (Galvin et al., 2009; Lohse et al., 2014). Improvements in behavioural function are associated with large quantities of practice which leads to cortical reorganisation. This can be linked to the neural changes and recovery of function and learning post stroke (Lohse et al., 2014). Lohse et al. (2014) found a positive dose-response relationship in a meta-analysis looking at the time spend in therapy and therapy outcomes.

Additional physiotherapy will lead to added financial constraints, therefore other ways of increasing physiotherapy and exercise dose need to be looked at. One suggestion is that physiotherapist needs to develop strategies to ensure that the patients and caregivers take full responsibility for their own therapy and exercises (Galvin et al., 2009). Patients need to

take active part in their rehabilitation by managing their own home exercise programmes (Karingen et al., 2011).

As the goal of stroke rehabilitation is to discharge patients at their optimal functional independent level or as community dwelling individual, effective treatment as well as patients' adherence to prescribed exercises are two vital components to achieve this. Interventions will only be beneficial and rehabilitation programmes successful if patients adhere to it and therefore better treatment outcomes are associated with adherence (Ogwumike et al., 2014).

### 2.5 Adherence to physiotherapy

Literature on adherence to home exercise programmes in stroke survivors is limited. In general, adherence to home programmes for physiotherapy is unsatisfactory and it is a big obstacle faced by physiotherapists. Patients do not reach their rehabilitation goals and desired outcomes because they fail to continue and to adhere to home programme post discharge (Sluijs et al., 1993; Merrill, 1994; Ogwumike et al., 2014). Thus, stroke survivors deteriorate and initial functional gains from physiotherapy in hospital are lost post discharge. In resource constrained countries like South Africa with a high demand for beds and decreased length of stay with limited government rehabilitation services, outpatient physiotherapy services are important, but attendance is poor (Ntamo et al., 2013).

Factors related to poor attendance of outpatient physiotherapy as reported by Ntamo et al. (2013) studying a rural hospital in South Africa were mostly socio economic. Transport (including taxi drivers who refused to transport patients with wheelchairs), traveling costs, and geographic distribution were on top of the list. Patients lived in rural areas far from clinics and hospitals, 27% of the participants resided in areas over 100km from the hospital. Lack of or the absence of caregivers was another reason for poor attendance. Some stroke survivors relied on grandchildren for assistance with ADLs and these grandchildren had to attend school during the day. Insensitive public transport systems especially taxi drivers who refuse to transport patients with wheelchairs remains a problem for those that cannot afford private transport. Poor resources and the availability of equipment in some institutions including a lack of therapists as well as bad attitudes from hospital staff were also reported (Ntamo et al., 2013).

Non-adherence leads to inadequate participation in home exercise programmes, increased the strain on caregivers, decreased productivity, increased financial burden, increased health care costs due to secondary complications, waste of resources and has a negative effect on treatment outcomes (Karingen et al., 2011; Ogwumike et al., 2014). It also has a negative

effect on the health system, therapeutic efficacy, attenuates optimal clinical benefits and can lead to preventable disease progression, poor quality of life and even death. In a young or middle age population, it can lead to loss of productive years due to the long-term disability, and in elderly functional independence and quality of life will be negatively affected by non-adherence (Ogwumike et al., 2014). There is a need for interventions to improve adherence. Adherence has to be addressed in order for stroke survivors to realise their full potential. Physiotherapists are challenged to find ways of encouraging realistic expectations and adjustment to disability (Karingen et al., 2011).

With effective strategies that aim to minimise stroke related disability, not only health costs will be minimised but quality of life will be improved. There is evidence that structured exercise programmes do enhance physical functioning in stroke survivors, but the effectiveness depends on ongoing adherence which remains a barrier (Tiedemann et al., 2012).

### 2.6 Adherence to home exercise programmes

According to literature the following factors influence adherence: discomfort (Jurkiewicz, 2011; Ogwumike 2014) personal barriers for example little time, forgetfulness and exercise not being part of their daily routine (Sluijs, 1993; Jurkiewicz, 2011; Ogwumike, 2014); patient therapist relationship and dependency on physiotherapists; lack of knowledge and understanding of home programmes (Sluijs et al., 1993; Cameron, 1996; Chan et al., 2010; Ogwumike, 2014); characteristics of the illness, whether the illness is acute or chronic, regarded as serious and the degree of disability caused by the illness; patients' beliefs and attitudes; lack of family support; lack of social interaction and isolation (Sluijs, et al., 1993; Cameron, 1996; Chan et al., 2010); lack of motivation; and musculoskeletal issues such as pain and poor endurance (Chan et al., 2010; Jack et al., 2010; Jurkiewicz, 2011). When the illness is perceived as serious and more severe with greater disability, adherence increases (Sluijs, 1993). There is no relationship between age (Sluijs et al., 1993; Chan et al., 2010), sex, race and education to adherence with home programmes (Sluijs, et al., 1993). Characteristics of the patient, their illness, the prescribed regimen and the treatment provider are important component associated with adherence (Sluijs, et al., 1993; Chan et al., 2010). Factors that affect adherence can further be divided into three components (Olaleye et al., 2012): Internal and personal factors, relational and experiential factors, and external factors.

<u>Internal and personal factors:</u>

These relates to personal and health beliefs, beliefs and hope with regards to recovery, the role and outcome of exercise, hope, motivation, expectation, self-will and determination, mood and state of mind as well as physical impairments (Olaleye et al., 2012).

Relationship between patients' beliefs, attitudes and adherence:

Patients' beliefs and attitudes determine adherence. Those with a strong belief that their health and illness dependents on their own behaviour are more likely to adhere. These patients use an internal locus of control. Those using an external locus of control are more likely to not adhere (Sluijs, et al., 1993). Feelings of hope and disease progression are important factors that influence motivation and participants' attitude towards physical activity (Elsworth et al., 2009). There is a need for disease considerations and to know how responsive physical problems are to change as this can influence participants' faith in exercise (Elsworth et al., 2009).

Adherence related to the characteristics of the illness:

When the illness causes disability, patients perceive it as more serious and adherence increases in these cases. During acute illnesses adherence is also rated higher compared to chronic illnesses. This might be due to the expected recovery from acute illnesses that motivated them to follow through and adhere with specific prescribed regimens (Sluijs, et al., 1993).

Non-adherence is associated with discomfort, barriers, helplessness and dependency (Sluijs, et al., 1993; Ogwumike et al., 2014). Decreased exercise adherence is seen in those with the perception that exercises will not help much or when they perceive specific barriers to exercise (Sluijs, et al., 1993). The most important barriers are pain, lack of time, exercise not fitting into their day, lack of motivation, forgetfulness, difficulty in doing exercises and the need for physical assistance (Sluijs, et al., 1993; Ogwumike et al., 2014). Participation is also affected by patients' mood and their desire to improve. Low mood and depression are usually related to poor adherence and those with a positive mind set are more likely to adhere (Olaleye et al., 2012).

When considering the outcome or effect of exercise, those with positive outcomes experience feelings of hope and encouragement which motivates them to be optimistic about their health and recovery. Negative outcomes are discouraging and damping their hopes. When they have positive experiences, they feel the exercises are helping and have the potential to make an improvement. Positive outcomes are therefore associated with an increase in adherence whereas negative outcomes promote non-adherence (Olaleye et al., 2012).

Relational/experiential factors

This is about relationships with others including family, friends and colleagues as well as the support received from them. Another important relationship is the patient therapist relationship

(Chan et al., 2010; Olaleye et al., 2012). In developing countries family support in hospital and post discharge are essential for survival and quality of life (Idowu et al., 2015). Family support is an important motivating factor (Karingen et al., 2011; Olaleye et al., 2012).

Different strategies are used to assist patients to adjust to their disabilities as this is part of the goal of stroke rehabilitation. These strategies include support groups, psychological counselling, family/peers support and medication (Olaleye et al., 2012). In a study by Olaleye et al. (2012), participants reported that the positive attitude and the provision of adequate information from the physiotherapist had a positive influence on their participation. Positive relationships have been shown to increase patients' attendance to appointments and exercise.

Health care professionals are responsible to give adequate information to families and stroke survivors regarding their condition. According to literature stroke survivors, their families and carers are unsatisfied with the information given and this can contribute to poorer outcome as uninformed patients are less satisfied and therefore more likely to not adhere to advice and treatment (Rogers, 2001).

Health care providers play an important role in supervision as well as giving instructions. Prolonged supervision with regular follow-ups and feedback on progression and efforts improves adherence (Sluijs et al., 1993; Chan et al., 2010). Exercises need to be linked with the patients' own ideas and perceptions to enhance adherence (Sluijs et al., 1993). The relationship between the patient and the health care provider is also an important factor. Close relationships lead to satisfaction and adherence (Sluijs et al., 1993; Chan et al., 2010; Olaleye et al., 2012). Knowledgeable support is an important factor. Fitness professionals and physiotherapist should have the necessary knowledge on the conditions and how to treat them effectively as this has a huge impact on patients' trust and confidence in them. Support from physiotherapist is integral for effective transitioning from rehabilitation setting, usually hospitals and clinics to community settings, home and/or fitness centres (Elsworth et al., 2009).

Physiotherapist need to be clear about their expectations with regards to exercises, rehabilitation goals and their satisfaction as stroke survivors have high expectations about their recovery. Stroke survivors reported that positive relationships and attitudes with physiotherapist as well as the provision of adequate information from their physiotherapist influenced their participation (Olaleye et al., 2012). Physiotherapists' visual, verbal and overall explanation quality has a strong effect on the patients' performance of home exercises (Chan et al., 2010). Therefore, goal planning is an essential part of rehabilitation (Olaleye et al.,

2012). Health care professional should never underestimate patients' knowledge, they should always be aware of the specific conditions and exercise response before they meet patients this will give them confidence in prescription and aid trust in the relationship (Elsworth et al., 2009).

Positive feedback is an important factor that can motivate patients to exercise. They want to know if the physiotherapists are satisfied and if they progress. Monitoring patient and acknowledging their demand and ideas are also strong motivators (Sluijs et al., 1993).

External factors

These relate to the following: characteristics, structure and content of the exercise programme, exercise equipment, exercise information provision and knowledge, financial and transportation issues as well as faith in God (Olaleye et al., 2012).

A study by Chan and colleague in 2010 identified that the complexity of home exercise programmes influence adherence and identified the number of exercises, the complexity of the exercises and the level of fatigue experienced during exercises as factors that have an influence on adherence (Chan et al., 2010). When considering exercise programmes the following factors are important to enhance adherence convenient regimes that are individualised and fit into daily routines (Sluijs et al., 1993): Programmes should be challenging and interesting, and linked to patients' goals (Olaleye et al., 2012). Clear instructions should be given with clear rationale to prevent misinterpretation and non-compliance (Sluijs, et al., 1993). The exercise programme should be monitored, reviewed and progress should be noted. (Olaleye et al., 2012). Physiotherapist should assist patient with realistic expectations helping them to plan outpatient services and treatment (Karingen et al., 2011).

Transportation and financial issues relate more to adherence of outpatient physiotherapy services (Olaleye et al., 2012). Unemployment is a big problem in South Africa (Ntamo et al., 2013). These together with stroke survivors that lose their jobs prematurely cause them to rely on caregivers who are usually family members for financial support. This places an increased financial burden on caregivers. They rely on a few outpatient sessions that public hospitals offer them, if they are able to afford transport. The services are inadequate to meet their needs due to shortage of resources and the patients are usually unable to afford additional services of a physiotherapist or other exercise services such as fitness clubs (Idowu et al., 2015). Public transport is also an obstacle with taxi drivers usually refusing to transport patients with wheelchairs. Patients are reluctant to use public hospitals close to them and prefer to go to

institutions where they were treated initially due to inadequate services and poor resources and equipment (Ntamo et al., 2013).

A lack of time to go for therapy was also reported by self-employed patients. The fear of losing their jobs and income prevent them from attending as they are the breadwinners (Ntamo et al., 2013). In a study by Elsworth et al, (2009) stroke survivors reported that they feel that exercise is an important and effective way of preventing physical deterioration. They experienced facilities and environments as barriers, accessibility were the major issue, fees and cost, the lack of support from professionals and fear of doing exercises incorrectly were also, mentioned. The challenges faced with the attendance of outpatient services give us insight into perceived barriers which further emphasise the need for alternative programmes. Home exercise programmes is such an option but will only be effective if they adhere to it.

Throughout rehabilitation patients receive a lot of information and they may not always be ready to receive this information. Patients experience different emotions from shock and grief and thus they need to process and re-orientate themselves to varying degree. All of this can have an influence on their participation in rehabilitation depending on the situation they experience (Karingen et al., 2011).

In order to achieve patient adherence to long term rehabilitation therapies, therapist needs to facilitate empowerment. Empowerment makes use of patients own experiences and knowledge to improve independence and participation. Empowerment gives patients self-responsibility with regards to their rehabilitation. Health care professionals facilitate participation and independence while the patient has an obligation to actively participate and implement the rehabilitation goals. Therefore, there is an increased demand for accountability and joint decision making which are important factors (Karingen et al., 2011).

Patients depend on physiotherapists for goal setting and even when they are involved in goal setting process they still depend on physiotherapist to carry them out. They have the expectation of “being rehabilitated”. A lack of knowledge of their own responsibilities during rehabilitation is experienced. Patients are passive some may know their rights but not their responsibilities. Other factors that influence adherence or empowerment of patients are; follow up, use of a multi professional team, carryover of exercise to home environment and ADLs, individual information and rehabilitation plans, patient awareness of their own responsibilities, personal values, grief process, family support and the clarification of roles (Karingen et al., 2011).

Spirituality and faith in God is an important coping mechanism and hope for recovery in patients with chronic disabilities and stroke. Spirituality gives patient hope and meaning to life and helps them to adjust to their disabilities. Faith in God as well as patient therapist relationship influenced both internal and personal characteristics of the participants external locus of control influencing internal and personal characteristics (hope, beliefs, motivation, determination) and therefore their participation (Olaleye et al., 2012).

### 2.7 Enablers of adherence to physiotherapy

From literature, the following factors are important enablers of adherence to physiotherapy: patients' knowledge with regards to their condition and self-management, enjoyment of the exercise programme and support (Elsworth et al., 2009; Olaleye et al., 2012). Support can be divided into emotional, physical and informational (Elsworth et al., 2009). Emotional support from friends, family, support groups and counselling helps stroke survivors to adjust to their disability (Karingen et al., 2011; Olaleye et al., 2012). Other factors that motivate stroke survivors to adhere are a positive outcome and positive experience in doing exercises, their belief and faith in God. Information provision from physiotherapists and goal planning are also essential. Other important factors are the availability of equipment and resources together with planned activities (Olaleye et al., 2012).

To ensure that stroke survivors participate in their home exercise programmes the financial and transportation issues needs to be addressed and family, friends and work based support needs to be promoted (Olaleye et al., 2012). Knowledge about patient's life and experiences can assist in joint decision making which may enable adherence (Karingen et al., 2011).

A systematic review by MacDonald et al. (2013) suggested stroke survivors' engagement in rehabilitation programmes as one variable that may impact on rehabilitation outcomes. Engagement can be demonstrated through body language and non-verbal actions as well as attendance, adherence, working alliance, disclosure and active participation in session. Increased levels of engagement in rehabilitation have been associated with enhanced adherence, attendance, functional improvements during inpatient and outpatient rehabilitation and reduced levels of depression (MacDonald et al., 2013).

Knowledge of factors that may help or hinder adherence may have an effect on adherence. The systematic review by MacDonald et al. (2013) identified seven themes: Goal setting, therapeutic connection, personalised rehabilitation, paternalism versus independence, patient centred practice, knowledge as well as feedback and achievement.

Goal setting was most effective when stroke survivors were actively involved in the process and when goals were based on mutual understanding, interaction and negotiation. Patients' engagement was also influenced by physiotherapist's manner, the support they provided and how they were involved in the rehabilitation process (Maclean et al., 2000). Individualised and personalised therapy programmes, rehabilitation interventions and environments play an enormous role in patient engagement. The level to which a person involves themselves in the rehabilitation depends on the level of familiarity and the perceived importance of rehabilitation (Proot et al., 2007). Rehabilitation needs to be meaningful and functional to avoid disengagement (Proot et al., 2000). Autonomy enhances motivation and the level of autonomy directly influences engagement. Patient centred practises, joint decision making, respecting patient choices and services that are structured around patient's needs, interest, goals and choices, not only empower and encourage them but also improves autonomy and participation in rehabilitation. Education and providing adequate information about stroke and the reasoning for rehabilitation choices may encourage patients to take on a more central role in rehabilitation. Motivation and participation can further be enhanced by providing feedback and using positive reinforcement (MacDonald et al., 2013).

### 2.8 Barriers of adherence to physiotherapy

There is a decline in physical activity among stroke survivors compared to the general population. This leads to sedentary lifestyle and functional decline (Rimmer et al., 2008; Mulligan et al., 2012). It remains a challenge for physiotherapist to increase participation in physical activity (Rimmer et al., 2008).

Although we focus on adherence to home exercise programmes any barrier that relates to physical activity may also influence and apply to our focus of home exercise programmes. Personal, physical and environmental barriers were identified in a systematic review by Mulligan et al. (2012) of barriers in physical activity experienced by people with chronic neurological conditions including stroke. Personal barriers include increase in age, belief that physical activity has no positive benefit and low self-efficacy to exercise. Physical barriers referred to impairments in body structures and function either from the neurological conditions itself or as a secondary condition. The impairments were a lack of energy, fatigue, poor general health, uncoordinated movement, poor balance and impaired vision, pain, depression, increased body mass index and cognitive dysfunction. Environmental barriers referrers more to physical and social environment but this relates more to recreational activities and will not necessarily have a negative effect on adherence to home exercise programme. Physical environmental barriers were a lack of available, accessible and affordable transport, difficulty in accessing assistance or support. Social environmental barriers include a lack of

expectations to be physically active and a lack of support when doing so. Staff members at recreational facilities have insufficient knowledge of the needs of people with disability to offer suitable assistance and support.

In order to promote physical activity health care professionals should eliminate barriers. Therefore, it is important to have sufficient knowledge of the barriers in order to identify those (Rimmer et al., 2008). The five most common barriers identified by Rimmer et al. (2008) were: Cost of programmes, lack of transportation, lack of awareness and knowledge of fitness centres and available programmes, lack of knowledge on how or where to exercise. Other barriers were lack of energy and motivation, not feeling comfortable to train in a facility, health concerns, exercises are difficult, lack of time and interest and concerns that exercise will worsen their condition. Knowing these barriers to physical activity will assist health care professional in the development of home or community based exercise programmes (Rimmer et al., 2008). Identifying and removing the personal and environmental barriers may aid in the effective tailoring of programmes to the individual needs of stroke survivors and their environment. This will enhance the likelihood that they will adhere and successfully participate.

### 2.9 Role of caregivers in rehabilitation

Stroke causes sudden changes on family roles that create stress for family members as well as stroke survivors (Galvin et al., 2009). It is a traumatic, complex and life changing experience (Lutz et al., 2010). The psychosocial impact of stroke extends to family members and informal caregivers (Grant et al., 2004; Rigby et al., 2009).

As mentioned earlier, decreased length of stay and high demand for beds in government settings leads to early discharge when patients have not yet reached their optimal functional independence level (Mudzi et al., 2012c; Ntamo et al., 2013). Hospital length of stay is shortening worldwide (Anderson, 2000). There is a general shift of care from inpatient to out-patient rehabilitation and rehabilitation at home (Anderson, 2000; Schure et al., 2006). Because of this, there will be an increased need for care of stroke survivors at home and a greater need for family members to be caregivers (Schure et al., 2006).

Therefore, caregivers are relied upon to assist them not only with activities of daily living, but also with the continuation of the rehabilitation process through home exercise programmes (Mudzi et al., 2012c; Ntamo et al., 2013). Thus, adherence to home exercise programmes is not only affected by the stroke survivors' beliefs and attitudes but also by those of the caregiver, as they play an essential role post-stroke and in the rehabilitation process.

Being a caregiver comes with great responsibility as it requires someone to be responsible for someone else's life. Caregivers can be informal or formal. Formal caregivers refer to those that are trained to be caregivers with professional qualifications and they are usually paid for their work and services (Mudzi, 2009). Informal caregivers are not qualified, trained or paid. It refers to those that are not part of the formal community support service. They are usually friends and family that provide task-orientated assistance. It is acknowledged that they play a vital role in the care of stroke survivors, but usually this is not without consequence (Dewey et al., 2002).

Eighty percent of stroke survivors return to the community post stroke, relying on family members for emotional, informational and instrumental support for activities of daily living (Han et al., 1999; Grant et al., 2004). Post stroke, family members have to assist and deal with mobility related problems, difficulties with self-care and communication, but also cognitive impairment, emotional problems, behavioural and personality changes as a result of the stroke (Han et al., 1999; Grant et al., 2004; Forster et al., 2013). The support caregivers give to stroke survivors plays an important role in their recovery but also determines whether they can stay outside rehabilitation care and reintegrate into the community (Han et al., 1999; Choi-Kwon et al., 2009; Rigby et al., 2009), but this comes with a substantial personal cost.

The availability of nursing homes and societal support for patients with stroke is poor in developing countries compared to United States (Choi-Kwon et al., 2009). This increases the responsibility and burden of untrained family members to be informal caregivers. With a rapidly ageing population there will be an increase in number of people affected by stroke over the years (Dewey et al., 2002; Green, 2005). The prevalence of stroke survivors will increase as a result of more effective treatments and a decline in mortality (Schure et al., 2006). This will further increase the burden on informal caregivers.

In 2006, in the United States, there were 44 million adults that provided unpaid informal care to adults living with disabilities in the community (Lutz et al., 2010). In a study by Dewey et al. (2002) in Melbourne, 69% of stroke survivors with a first ever stroke received informal care from relatives or friends three months post stroke. Two thirds of the primary caregivers were women, in 53% of the cases it was either the wife or the daughter. Care is provided during family or leisure time. In Netherlands 50 000 to 60 000 family members act as caregivers for stroke survivors at home, most of them being female spouses (Schure et al., 2006).

In South Africa, there is a substantial increase in palliative care cases over the last 10 years as a result of the burgeoning HIV/AIDS pandemic. In rural and disadvantaged communities

the prevalence of chronic and debilitating disease has a huge influence on care services. South Africa compared to high income countries has unique factors to consider that influence caregiving (Uren et al., 2012). In addition to the high prevalence of HIV/AIDS (Uren et al., 2012), there are high rates of unemployment and poverty (Olaleye et al., 2012; Uren et al., 2012). Due to circumstances and conditions caregivers are not always intrinsically self-motivated to become caregivers and therefore have a greater risk of strain in terms of the obligation and distress that comes with the experience (Uren et al., 2012).

Caregivers play a crucial role in the survival of stroke survivors at home. Their duties range from administering medication, assisting with activities of daily living, mobility, home exercise programmes to performing medical procedures without training. They play an important supportive role in the rehabilitation process. The involvement of caregivers assists in lowering the risk for another stroke, it decreases the post stroke complications, aids in improving function post stroke, helps stroke survivors to achieve the highest possible functional independence and recovery and assist in community integration (Mudzi, 2009).

Family members have to cope with other responsibilities besides caregiving. Some are employed and have to quit their jobs or reduce working hours. They are expected to make significant changes in their everyday lives and routines to accommodate stroke survivors or to assume responsibilities that were previously performed by stroke survivors. They need to coordinate stroke survivor's lives, arrange appointments, negotiate with other family members and clarify caretaking roles and challenges. Stroke survivor's needs are always priority and leads to caregivers being restricted. They neglect their own social activities and relationships with other friends and family members. Their own physical health deteriorates due to tiredness, fatigue and inadequate rest. Due to multiple roles and responsibilities they experience a loss of independence (Grant et al., 2009).

Therefore, interventions need to be directed towards both the stroke survivor and the carer to improve the recovery and quality of life of the stroke survivor, but also to sustain the carer's own health and wellbeing (William, 2009; Forster et al., 2013). Therefore, adherence to home exercise programmes may lead to physical improvement for the stroke survivors and better quality of life. This will in return decrease the burden of caregiving and reduce negative health effects of caring on caregivers.

### 2.10 Caregiver burden and strain

Caregivers quality of life is influenced by stroke survivors' physical ability, their cognitive and behavioural problems, mobility, the carers own health and psychological status and the

strength and quality of the relationship between the stroke survivor and the caregiver (Lutz et al., 2010). There is a positive correlation between improvements in functional level and quality of life of caregivers (Lutz et al., 2010; Hilton et al., 2013).

Caregivers are the backbone of the service provided to surviving stroke survivors. It has been reported that 30% of caregivers are under considerable strain three years post stroke and 21% after five years (Bugge et al., 1999). Rigby et al. (2009) reported that 25% of caregivers were under significant burden at one month post stroke, 28% at three months and 37% at six months. A South African based study by Hilton et al. (2013) found that 77% of caregivers were severely strained 6-36 months post discharge. This could be due to the greater functional dependence of stroke survivors.

Caregiver burden refers to the load carried by caregivers that comes from adopting to the caregiver role. It can be divided into a subjective and objective burden. Subjectively referring to the social, emotional and psychological impact of caring and objectively referring to the physical assistance provided during caregiving tasks, time spent on caregiving, caregiving tasks performed and possible financial problems (Van Exel et al., 2004; Rigby et al., 2009). Patient factors have an effect on caregivers' health and well-being, but family problems may have a negative effect on stroke survivors' recovery. Therefore, caregivers have an effect on stroke survivors' recovery, but stroke survivors also have an effect on caregiver strain (Bugge et al., 1999). Healthy and supportive families optimise stroke recovery. Less activity limitations are experienced by those living at home compared to those in institutional care. As mentioned earlier family support together with caregivers are important factors to enable stroke survivors to remain in the community (Rigby et al., 2009).

Caring for a stroke survivor has a great burden and high demands on caregivers and influences both their physical and emotional wellbeing (Forster et al., 2013). As a result of caregiving, caregivers experience adverse health which has also been linked to high rates of depression, anxiety, cardiovascular disease, general ill-health and mortality. This leads to poor quality of life for the carer and restrains in social activities (Rigby et al., 2009). Caregivers' health is linked to stroke survivors' recovery in physical, emotional and cognitive domains. Recovery also depends on families' ability to provide emotional and instrumental support and assistance (Lutz et al., 2010).

Impairment in motor and cognitive function, increased dependency and the inability to perform activities increases the caregiver burden and high levels of emotional strain from looking after the stroke survivors (Paul et al., 2007). Emotional problems experienced by stroke survivors

leads to additional strain. Caregiver burden differs among cultures and societies depending on familyism and individualism (Choi-Kwon et al., 2009).

An overwhelming sense of burden is experienced by family caregivers. This burden is associated with caregiver depression. Predicting factors of depression and increased burden are stroke survivors' functional level and the amount and type of caregiver tasks. An increase in stroke severity and stroke related problems further increase the risk for caregiver depression. Emotional distress is further increased by task difficulty, low self-esteem and if tasks are very time consuming. This leads to negative caregiver outcome and challenges in managing finances, managing behaviours and providing emotional support (Lutz et al., 2010).

Family members reported the following stroke related patient problems during caring: mood disturbances, anxiety and depression, memory problems, needing help with dressing and bowel-related difficulties, transportation, other sensory and motor problems, difficulty walking and stair climbing, problems with vision, hearing and communication (William et al., 2009).

These problems can be risk factors for caregiver depression (William et al., 2009) and anxiety (Bugge et al., 1999) and may have a negative impact on patients or hamper rehabilitation and therefore it is important to understand them (Han et al., 1999; William et al., 2009). Stroke survivors' depressive symptoms are worsened by depression in stroke caregivers. Caregiver depression has a negative effect on the social rehabilitation and integration of stroke survivors (Han et al., 1999). If these issues are not this may increase the risk of nursing home placement of patients and institutionalisation of caregivers (William et al., 2009). Caregiver burden and strain increases with time and is most striking during the early post stroke phase (Bugge et al., 1999).

Other factors related to caregiver burden and depression are:

- hours of caregiving
- caregiver social support
- caregiver age
- caregiver education
- caregivers' physical health
- caregiver depression
- stroke survivors' disability
- stroke survivors' depression – dealing with anger and mood
- stroke survivors fatigue

- stroke survivors cognitive function
- high economic burden

(Han et al., 1999; Choi-Kwon et al., 2009; Rigby et al., 2009)

Time spent helping stroke survivors was associated with increase strain (Bugge et al., 1999; Choi-Kwon et al., 2009; Rigby et al., 2009), especially during the first six months post stroke. Strain is higher in those that have to set time aside in an already busy schedule to help and assist stroke survivors (Bugge et al., 1999).

Patient characteristics have an effect on caregiver burden. Although no consistent factors were found in the study by Bugge et al. (2005), stroke severity appeared to be associated with increased strain. Different caregiver factors such as depression, strain, burden and psychological wellbeing might be associated with different patient factors. Changes to family life, personal plans and the confining nature of caregiving are factors reported by caregivers to increase strain (Bugge et al., 1999).

A lack of socio-emotional support and social acknowledgement leads to increased feelings of entrapment and depression caregivers are unsatisfied with their own performance as a caregiver and with their relationships during these times. There is a loss of time for self and a loss of privacy. This leads to increased caregiver burden and depression (Choi-Kwon et al., 2009).

Social support is shown to increase stroke survivors' emotional well-being and influencing depression associated with chronic life changing illnesses. Social support may be a buffering factor not only to the stroke survivor but also the caregiver (Choi-Kwon et al., 2009).
Family involvement may reduce high levels of caregiver burden (Galvin et al., 2009; Rigby et al., 2009) by reducing the fear caregivers experience to cope at home (Galvin et al., 2009).

Therefore education, providing adequate information about the nature, cause and consequences of stroke is very important (Grant et al., 2004; Galvin et al., 2009).
A systematic review by Greenwood (2007) investigated factors associated with carer outcome and found the following:

> Carer factors – psychological characteristics, self-efficacy, coping strategies, self-esteem and mastery, other factors associated with the psychological characteristics of carers were burden, vitality and bother, poor physical health of carer also relates to their physical health. Other carer demographic characteristics were gender,

employment status, finances having a low household income, being a daughter in law and having a family with young children.

Stroke survivor factors – impairments, disability and dependency were associated with the following carer outcomes: Emotional well-being, burden, quality of life, life satisfaction, stress, strain and psychosocial health of caregivers, stroke survivors' mood, emotional wellbeing, and behavioural changes.

Family factors – referred to family functioning, family life events, family hardiness and disharmony in the relationship.

Other factors included provision of informal care, formal support, belonging and tangible support. Family support was associated with better quality of life, informal support was associated with lower burden and tangible support improved psychosocial health. Increased burden was associated with poorer health-related quality of life.

**2.11 Family involvement**

A study done by Galvin et al. (2009) looked at the views of family members of stroke survivors with regards to their role in physiotherapy and in the delivery of additional exercises post stroke. Family involvement was not practised routinely and ranged from 21-36%. The findings did however indicate that the family members are willing to be involved and to assist with exercises in the home environment. Literature supports the benefits of family involvement in the rehabilitation process as it maximises the effect and outcome of rehabilitation by allowing additional practise of activities outside the therapy setting at home, maximising learning and supporting carry over to the home environment. Initial rehabilitation is also better maintained this way. Involving the family in the process can assist them to cope by improve their handling skills.

Physiotherapists reported that a lack of interest, motivation and availability of family members are some of the limiting factors in family involvement (Galvin et al., 2009). Stroke has been referred to as a family dilemma (Mackenzie et al., 2012). There is proof that family support results in more effective rehabilitation and has a buffering effect on psychological and social problems (Mackenzie et al., 2012). The initial gains in rehabilitation are more effectively maintained in families that are healthy and involved in the rehabilitation process and home exercise programmes (Greenwood et al., 2007).

## 2.12 Interventions for caregivers

Family caregivers do not choose their role but become caregivers as a consequence of their kinship with stroke survivors. Therefore, caregivers are not always aware of their specific role as a caregiver. They are in need of support to prevent social isolation and burnout (Schure et al., 2006).

There are interventions developed to alleviate the negative effect of caregiving and to meet the needs of informal caregivers. Several studies have been conducted on interventions and the following have been found to have a positive outcome: Web-based interventions for social support, home tele-health interventions, telephone interventions focusing on problem solving skills, telephone support groups, training interventions involving family members and caregivers in the rehabilitation process, allowing them to attend session, providing information about stroke and involving them in discharge plans, training in basic caregiving skills as well as prevention and management of stroke related problems (Lutz et al., 2010).

There is a need to create an environment for caregivers where the caregiver can feel rewarded. Caregivers need to be provided with adequate information and the necessary skills in all aspects of caring. Their emotional and behavioural challenges also need to be addressed. When caregivers' needs are not met stress increase over time (Crosato et al., 2006).

The transition from inpatient care and therapy to having little or no assistance at home also needs intervention. There is a lack of formal support post discharge and stroke survivors and families feel that they have to figure things out for themselves at home. They feel abandoned once they leave hospital and not part of the discharge planning process (Lutz et al., 2010).
Understanding the problems families and caregivers experience and their needs will enable us to develop high-quality home exercises programmes that are comprehensive and informative (Grant et al., 2004). A study by Mudzi (2009) indicated the need for more structured caregiver education programmes and good support structures in South Africa. In his study, caregiver training improved perceived quality of life of stroke survivors at six and twelve months post discharge. Education may lead to a better understanding of stroke survivors' needs and abilities and thus may improve caregivers' own caring abilities (Mudzi, 2009).

In an intervention study that aimed to counsel and educate family caregivers of stroke survivors it was indicated that knowledge about patient care, self-efficacy, the use of coping strategies and social support had positive effects (Schure et al., 2006). Knowledge and coping

are thought to buffer the impact of stressors and therefore important for caregivers' wellbeing (Schure et al., 2006; Greenwood et al., 2007).

The provision of information and the use of positive coping strategies improve the ability of caregivers to cope (Schure et al., 2006; Greenwood et al., 2007). Caregivers need to apply the coping strategies which include remaining positive, adapting to change, comparing situation to others who are worse off, changing their employment status, humour and switching off (O'Connell et al., 2004). In addition to this, other strategies and services should also be offered to caregivers. These include post discharge support, counselling, provision of information about stroke, skill training and practical help. This will contribute to the long term quality of life of stroke survivors (Crosato et al., 2006). Counselling programmes appear to have the best outcome in minimising family caregivers' stress (Schure et al., 2006).

As the burden of care giving increases due to psychological impairments in stroke survivors there is a greater need for contact with fellow caregivers and for outside support (Schure et al., 2006). Contact with fellow caregivers or support groups have a positive effect on caregivers' emotional wellbeing. Identifying with people in similar circumstances give them the opportunity to generate information on how to cope better which then positively impacts on their own problem solving skills (Schure et al., 2006).

In a study by Schure (2006), they compare the effectiveness of a group support program and a home visiting programme and both interventions showed to be helpful and feasible. The group support programme offered more emotional and information support that were helpful. The study indicated that those who preferred this type of intervention were burdened, made use of coping strategies often and were caring for a more psychologically impaired patient.

### 2.13 Positive aspects of caregiving

Despite the high burden, physical and emotional strain that comes with caregiving, caregivers reported that caring can be rewarding for them. It helps them to appreciate life more and improves their relationship with the care recipients (Han et al., 1999; Rigby et al., 2009; Mackenzie et al., 2012). The benefits of caring also include helping them to cope in stressful situations (William et al., 2009). Good support structures are essential not only provided by family and friends but also by health care providers (Mudzi, 2009).

Positive aspect and experiences of caregiving are firstly improved recovery and progress of stroke survivors (Mackenzie et al., 2012). The smallest amount of improvement and recovery gives caregivers a sense of pride. Other aspects were feeling appreciated, strengthened

relationships and increased self-esteem (Greenwood et al., 2009; Mackenzie et al., 2012). Feeling needed and appreciated by stroke survivors and the community gives caregivers a source of satisfaction. These experiences with associated with different coping strategies. Problem- focussed and emotion-focussed coping strategies together with psychological resources are commonly used in order to cope with uncertainties. Other strategies used is to cope is to live day by day (Greenwood et al., 2009; Mackenzie et al., 2012), comparing their situation with others who are worse off, and using humour. Caring gives caregivers meaning and purpose in life. It makes them appreciate life more, realising what is important and what really matters makes the carer a better person. It gives them the opportunity to learn new skills, manage difficult situations which all contribute to a feeling of mastery that increased their self-esteem and gives them inner strength (Mackenzie et al., 2012).

Positive and negative aspect of caregiving give us a more balanced look at the whole caregiver experience and this can help us to sustain and support caregivers better. As health professionals, we can help caregivers to be aware of their contribution to the rehabilitation process. Appropriate support, services and interventions can be offered (Mackenzie et al., 2012). In order to equip and better advise stroke survivors, families and caregivers we need to understand the barriers and enablers of physical activity and more specifically home exercise programmes in order to enhance participation (Billinger et al., 2014).

### 2.14 Conclusion

From the literature, it is evident that adherence to home exercise programmes in stroke survivors who are discharged from hospital while not functioning on an optimal functional independent level and rely on caregivers is a multifactorial problem. When addressing adherence one needs to consider both the stroke survivors and the caregivers. Adherence is not only influenced by the stroke survivors' personal barriers, physical impairments and emotional problems but also by the caregivers. Caregivers are under high physical and emotional strain. If the caregiver is under strain and stress it definitely reflects on their caring abilities and can also influence adherence to home exercise programmes as stroke survivors are in need of their assistance. Informal caregivers have many responsibilities and they need to "juggle" everything in order to get to everything and cope. If stroke survivors are fully dependent assisting them with ADLs might be time consuming and exercise programmes might be neglected.

Most common barriers are the following patient-related factors which include fatigue, lack of interest and motivation, depression, lack of self-efficacy, negative beliefs and attitudes towards exercise and fear of falling, another stroke or adverse events, practical reasons may

include lack of support from family and friends and lack of availability of resources, lack of transportation, poor accessibility and costs. Other potential barriers are health problems, physical impairments, embarrassment and a lack of knowledge with regards to the condition itself but also on how to do exercises and the potential benefits (Billinger et al., 2014). Family and social support, the desire to get better and participate in daily activities, the resumption of driving, improving overall health and wellness, improving functional abilities and reducing musculoskeletal issues are among the most common enablers of adherence (Billinger et al., 2014).

Treatment outcomes and function are negatively affected by non-adherence with home exercise programmes as it can lead to long term disabilities, poor quality of life and preventable disease progression (Ogwumike et al., 2014). The importance of adherence to treatment and home programmes cannot be overemphasised. Identifying the enablers and barriers of adherence to home exercise programmes may give insight that can be used to increase the positive effect of the enablers and reduce the negative effect of the barriers. This will optimise adherence and lead to continuous improvement, functional independence and better quality of life.

## CHAPTER 3

## 3. METHODOLOGY

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

### 3.1 Study design

This was a qualitative study design using in-depth caregiver interviews (DiCicco-Bloom et al., 2006; Cresswell, 2009; Turner, 2010).

### 3.2 Study population

The caregivers (the individual identified by the family who accepted the responsibility of taking care of the stroke survivor whether it is a family member or a qualified person for example a nurse, assistant nurse or trained carer) of stroke survivors meeting the inclusion criteria, discharged from the hospital where the study was conducted between April 2015 –July 2016.

### 3.3 Study sample

Purposeful sampling was used to recruit participants. It is commonly used in qualitative research the purpose is to obtain a rich in-depth understanding of the research question by participants who relate to the research question (Creswell 2009). The researcher screened stroke survivors on discharge from hospital to identify those who functioned on a dependent level and met the inclusion criteria. The caregivers of the stroke survivors who gave consent for participation were then recruited for the study. The interviews continued until data saturation was reached.

In the rehabilitation unit where patients were recruited, it is standard that all stroke survivors, their family and caregivers who are available on discharge receive education, training and an individualised hard copy home exercise programme according to stroke survivors needs. All stroke survivors have a follow-up session one month post discharge to meet with the multi-professional team in a combined setting to monitor progress. Physiotherapists and other allied health professionals may book follow up appointment prior to this date and thereafter if they wish to. The purpose of this study was not to test the effectiveness of the training received or the home exercise programmes but to identify barriers to and enablers of adherence to home exercise programmes from a caregivers' perspective. Therefore, the home exercise programmes were not standardised for the study and the follow up contact sessions were not monitored.

### 3.4 Inclusion and exclusion criteria

Inclusion Criteria:

- Caregivers of all stroke survivors regardless of the stroke survivors age
- Confirmed stroke diagnoses regardless of time since stroke
- Caregivers of stroke survivors with a Barthel Index (BI) score between 0 – 80% (to exclude stroke survivors who did not need assistance with home exercise programme). A score of 85% indicate independence with minimal assistance (Sulter et al., 1999) and a score of 90% is the turning point where a person is independent and help is not required (Uyttenboogaart et al., 2005).

Exclusion Criteria:

Any other conditions other than stroke that may cause functional limitations.

### 3.5 Instrumentation

The following instruments were used for the data collection.

3.5.1 Demographic questionnaire (Appendix E) was developed to obtain the demographic details of the participants and stroke survivors in order to establish the characteristics of all stroke survivors and caregivers. The following were covered in this questionnaire: age; gender; age; relationship; highest level of education, occupation, language, date of stroke, side of hemiplegia and BI score.

3.5.2 Barthel Index (Appendix F) to establish the stroke survivors' functional ability. This was done in order to determine their level of dependence and inclusion in the study.

The BI was developed to measure functional independence in personal care and mobility. It is a reliable measure used during rehabilitation to predict length of hospital stay, estimate prognosis, and to anticipate discharge outcomes (Green et al., 2001).

A BI score of at least 60% indicates that a person is independent for vital care, such as moving around unassisted, sphincter control, and eating in addition to personal toileting (Sulter et al., 1999). BI score between 0 – 80% indicated that stroke survivors did not need assistance with home exercise programmes and could be excluded. A score of 85% indicate independence with minimal assistance (Sulter et al., 1999) and a score of 90% is the turning point where a person is independent and help is not required (Uyttenboogaart et al., 2005).

3.5.3 Schedule of interview questions (Appendix G) to determine the perceived enablers and barriers of adherence to home exercise programmes in strokes survivors from a

caregivers' perspective. Two structured research questions were developed by the researcher. A discussion with stroke rehabilitation therapists was held to validate the content of the structured questions. Therapist who attended the discussion were one physiotherapists, one occupational therapists and one speech and language therapist all working in the field of neurological rehabilitation. The questions were validated against the aim and objective of the study. To improve clarity, the questions were rephrased.

The two main questions were:

a) Please tell me what do you think are the enablers of adherence to home exercise programmes?

b) Please tell me what do you think are the barriers to adherence to home exercise programmes?

**3.6 Data collection**

Data was collected by the researcher using in-depth caregiver interviews and continued until data saturation was reached. Data was considered saturated when no new information was surfacing during subsequent interviews (Strauss and Corbin, 1990; Polgar and Thomas, 2008). The point of saturation is normally dependent on the issue being investigated, the experience of the researcher and the objectives of the study (Trigg et al., 2000). The researcher was involved in the rehabilitation of three of the stroke survivors and had no relationship with the other four.

The caregivers of patients discharged from the hospital where the study took place, who met the inclusion and exclusion criteria after screening, were invited for an interview. The interview took place at the hospital three months post discharge. The transport fees for the participants to come to the interview were covered by the researcher. The researcher made alternative arrangements to meet at a place of convenience for the participants that were unable to come to the hospital.

Verbal and written consent was obtained from all the stroke survivors and caregivers for participation and audio recording of the interviews (See Appendix B-D) after the information sheet (Appendix A) had been read to the participants. The researcher collected all the demographic data (Appendix E) from the stroke survivors including BI score (See Appendix F). The interview was conducted by the researcher using an interview schedule (See Appendix G).

The interview was informal, with open- ended questions, carried out in a conversational style in the participants' choice of language Afrikaans, English or Setswana. A Setswana translator was trained prior to the study by the researcher on the specific research topic and interview questions as Setswana is the most common language of the province where the study was conducted. However, the translator was never used during the interviews as all of the participants' choice of language were either English or Afrikaans. If any other languages were requested the researcher was willing to find a translator for that specific language. Initially the interview started with structured questions and probing questions followed as necessary for more information or clarification thereof. Audio records and field notes were made during the interview by the researcher. The length of each interview was determined by the first two interviews and ranged between 20 – 30 minutes per interview. The caregiver was given the opportunity to listen to the audio tape directly after the interview and make corrections where necessary if needed. The audio records were transcribed, translated word for word and manually coded afterwards by the researcher.

### 3.7 Pilot study

The first two interviews served as the pilot study. After the first two interviews the questions were reviewed as well as the interview process. This was done to identify any flaws, shortcomings, limitations and weaknesses regarding the interview process, open-ended questions and the use of a translator. No problems were identified and there was no need for changes. The data obtained during these two interviews were included in the study

### 3.8 Data analysis

The data was analysed by the researcher and a second analyser (a therapist who was familiar with the different approaches and methods of qualitative studies, but impartial to views of the study) using the general inductive approach and consisted of six main steps (Thomas, 2006).

#### Step 1 - Transcription

All the audio recorded interviews were transcribed, translated and electronically captured. This was done by the researcher.

#### Step 2 – Preparation of raw data

The transcribed data was formatted into a common format and printed.

#### Step 3 – Content analysis

The content analysis consisted of four sub steps:

***Step 3.1 – Systematic reading***

*Systematic reading of the raw data to identify and understand the themes that emerged from the text.*

***Step 3.2 – Create categories***

*In this step categories and themes were manually identified and defined.*

***Step 3.3 – Overlapping coded and uncoded text***

*Some of the text may not be relevant and therefore was not included into categories and some of it can be applied to more than one category. Identified which of it can be excluded and which can be applied to more than one category.*

***Step 3.4– Refinement and revision of categories***

*Here some of the categories were combined and sub categories were formed.*

**Step 4 – Second Analyser**

Data was analysed by a second person/research assistant to ensure the trustworthiness. The same steps described in Step 3 were followed.

**Step 5 - Finalisation**

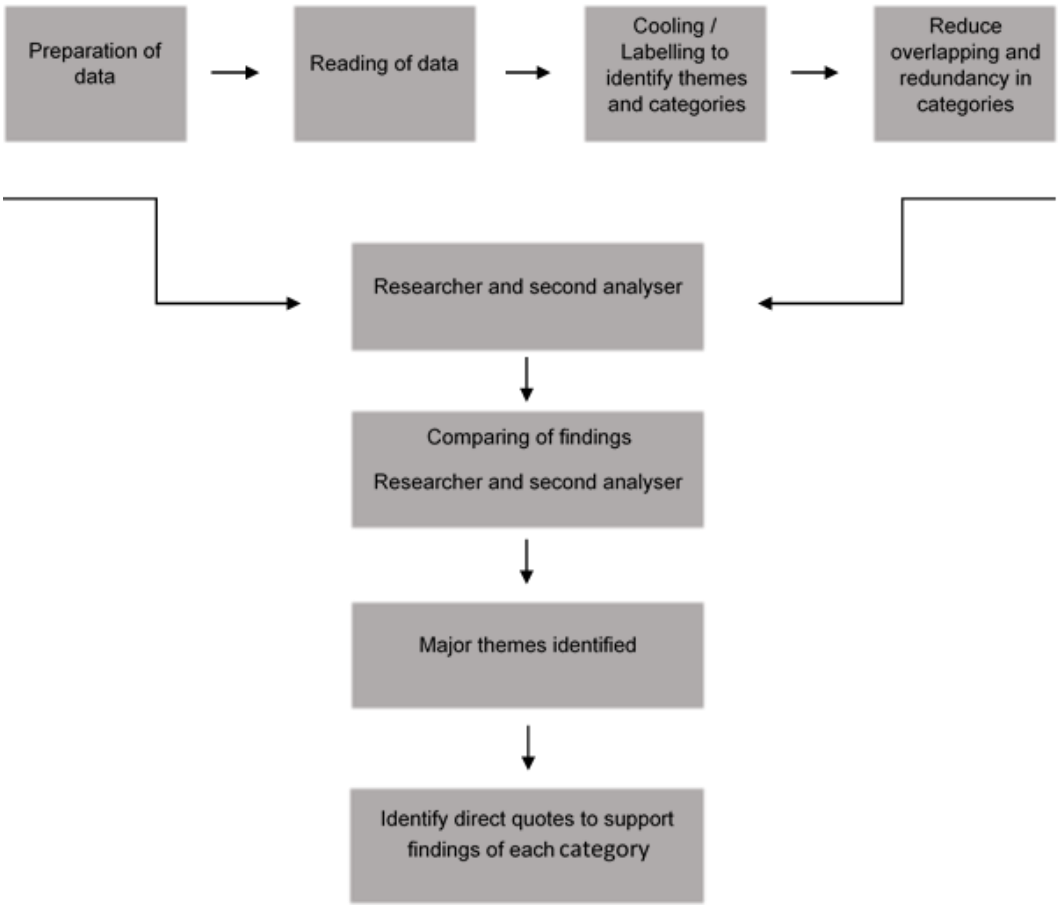
The researcher and therapist's codes and categories were compared and similarity established before formulation and interpretation of themes for trustworthiness. This process also dealt with the researcher's potential biases and assumptions and thus ensured confirmability.

**Step 6 – Identification of direct quotes**

Identification of direct quotes to support the finding of each theme in order to answer the research question.

Credibility was ensured by capturing detailed descriptions of the perceived barriers and enablers of adherence to home exercise programmes and by transcribing voice recordings verbatim to capture each narrative. Transferability was ensured by providing a detailed description of the study methods and findings.

**Figure 3.1 Analysing process**




### 3.9 Ethical considerations

Approval and clearance was obtained from the following parties:

- The Human Research Ethics Committee of the University of the Witwatersrand (Clearance number: M150152)
- Senior management of the hospital where the study will be done
- Informed consent will be sought from the stroke survivors and the caregivers

Verbal and written consent was obtained from the stroke survivors as well as their caregivers to allow the caregivers to give information about them. Participants were informed in writing that participation is voluntary and confidential and that they can withdraw at any stage without penalty. They were also informed that they can decline to answer any question during the interview process. The research objectives and data collection process were given to the participants in writing. Confidentiality was ensured by not mentioning the participants' names. A numbering system was used for the interviews and the audio records were transcribed by the researcher herself. All the audio records as well as the transcribed data will be stored

according to the ethical guidelines of the HPCSA for two years in case of publication and for six years in the absence of publication (Health Professional Counsel of South Africa, 2008) where after it will be destroyed. Only the researcher and the second analyser had access to it.

# CHAPTER 4

# 4. RESULTS

## 4.1. Introduction

This chapter presents the results of the qualitative study of the perceived enablers and barriers of adherence to home exercise programmes in stroke survivors from a caregiver's perspective. The chapter will present the demographic profile of the stroke survivors and their caregivers and the themes that emerged from the in-depth interviews.

### 4.2.1 Demographic profile of stroke survivors

The demographic profile of the stroke survivors is presented in Table 4.1. Out of the seven stroke survivors who were included in the study four were female and three males. Their ages ranged between 32-76 years with an average age of 55.8 (±15.03) years. The relationship with the caregiver indicated that all of them were closely related family members. Four of the stroke survivors were employed prior to the stroke, two were pensioners and one unemployed. The majority suffered a left sided stroke with only two being right sided. The BI score ranged between 20-70% with an average score of 47.1%.

### 4.2.2 Demographic profile of caregivers

The demographic profile of the caregivers is presented in Table 4.1. Out of the seven participants the majority was female with only two male participants. Ages ranged between 26-65 years with an average age of 47.8 (±13.96) years. All of the caregivers were closely related family members. Three of the caregivers were employed, three were unemployed and one was a pensioner.

**Table 4.1 Demographic profile of the caregivers and stroke survivors**

| | Caregiver | | Stroke Survivor | | |
|---|---|---|---|---|---|
| **Interview** | **Occupation** | ***HLE** | **Occupation** | ***HLE** | ****Relationship** |
| 1 | Unemployed | Grade 12 | Lecturer | Tertiary | Sister |
| 2 | Self-employed | Grade 12 | Pensioner | Grade 10 | Daughter |
| 3 | Pensioner | Grade 10 | Pensioner | Grade 10 | Wife |
| 4 | Counsellor | Grade 12 | Unemployed | Grade 12 | Daughter |
| 5 | Unemployed | Grade 8 | Driver | Grade 7 | Wife |
| 6 | Self-employed | Grade 12 | **PA | Diploma | Father |
| 7 | Unemployed | Grade 10 | General Worker | Grade 6 | Husband |
| | **Mean (SD)** | **Range** | **Mean (SD)** | **Range** | |
| Ave (years) | 47.8 (13.9) | 26-65 | 55.8 (15.0) | 32-76 | |
| ***BI/100 | | | 47.1 | 20-70 | |
| Time since incident (Days) | | | 150.1 | 123-208 | |
| | **n** | **%** | **n** | **%** | |
| **Gender** | | | | | |
| Male | 5 | 71.4 | 4 | 57.1 | |
| Female | 2 | 28.6 | 3 | 42.9 | |
| **Side of stroke** | | | | | |
| Left | | | 2 | 28.6 | |
| Right | | | 5 | 71.4 | |

*Highest level of education (HLE); **Personal Assistant (PA); ***Barthel activities of daily living index (BI);

****Relationship of caregiver to stroke survivor; SD: Standard deviation

### 4.3.1 Caregivers' perceived enablers of adherence to home exercise programmes

An open-ended question was asked during each interview to determine the caregivers' perceived enablers of adherence to home exercise programmes in stroke survivors. The answers were coded and categorised into common themes. Twenty themes emerged from the interviews and were categorised into five categories. These categories are: motivation, routine, spirituality, carers' 'attitudes and desire' and knowledge.

**A) Motivation**

This category can be sub-divided into self-motivation and external motivation from friends and family.

a) Self-motivation

Caregivers reported that most of the stroke survivors are self-motivated and have a desire to get better and do things for themselves again. They are also externally driven to return to work and to drive again. The quotations below illustrate the self-motivation sub-division (the number represents the interview participant):

> *"He wants to be strong. He wants to get out of bed, out of the wheelchair" (5)*
>
> *"He doesn't want me to help him, he wants to walk by himself, do everything for himself" (5)*
>
> *"So that she can get better and start working again." (4)*
>
> *"He has a car. He wants to drive the car." (5)*
>
> *"He wants to live like the other people, he doesn't want to live this life." (5)*
>
> *"She just wants to get better, rest this year and start over next year." (6)*

b) External motivation

Motivation by friends and family are an important enabler according to caregiver. Continuous encouragement, support, love, keeping the stroke survivor company and re-assurance was mentioned. The quotes below illustrate the external motivation subdivision:

> *"I would motivate her and talk nicely to her" (1)*
>
> *"We tell him continuously, you know, he is going to get stronger and he will walk again and he will be able to do everything for himself, which motivates him" (2)*

*"We support her, make sure that she is alright. She doesn't feel lonely. Make sure, that she knows that we care about her." (4)*

*"We support her very much, we show that we love her and that she is not alone in her disability. We tell her that she is going to be fine." (4)*

The importance of social interaction - friends visiting the stroke survivors as well as people from church was also mentioned as illustrated by the quotes below.

*"Our pastor once visiting her, he came with the church members" (4)*

*"Yes most of the time to be motivated is just to keep her company you see, must get some friends and those people that were in church" (7)*

**B) Routine**

Having a specific daily routine and schedule was mentioned by five participants as an important enabler. As illustrated by the following quote: "If you don't work according to a program or routine it won't work, you won't be able to get to it. Really. You really need to stick with it, a time for this and a time for that. Otherwise you won't manage." (3)

Knowing when to do what and having a specific time for exercises enabled them to adhere to the home exercise programme.

*"It is part of your daily routine" (3)*

*As caregivers described their daily routine they mentioned a specific time for exercises.*

*"In the morning she wake up neh, then I bath her, then she do the exercises," (4)*

*"When he finished bathing, we do his exercises…" (3)*

*"I start with the exercises, if we do something else we get tired. So we start with it." (5)*

*"Sometimes I do exercises twice a day in the morning just after breakfast tablets everything is fine then she relax a little bit then we can start during the day after lunch after eating relax then we take it again." (7)*

Unexpected guest that interrupts stroke survivors' daily routine was a cause of non-adherence.

*You know if it's a specific time that he needs to do something and then people come to visit and the children come." (3)*

*"Anyone comes at any time, so one will still be here then the next one comes. Then one goes and the next one sit down. And so it continuous, you understand, you make coffee, do this, do that, prepare food, you just don't get to everything." (3)*

It appears that those who had a specific time for exercise were more likely to adhere to the home exercise programme.

**C) Spirituality**

Spirituality and faith in God was mentioned by four participants, although not all elaborated on it. Their faith and belief in God allows them to stay strong and keeps them going. This is illustrated by the following quote:

*"…I don't think we would have been able to get through this without our Heavenly Father" (6) "He is absolutely in control here." (6)*

Reading the Bible and listening to gospel music had a positive effect on their mood.

*"We just put on spiritual music and take two to three verses and it does really motivate her." (1)*

**D) Carers attitudes and desires**

In most of the interviews carers expressed their desire for stroke survivors to get better. The following quotes illustrate carers' attitudes and desires:

*"I want her to get better" (4)*

*"we want him to be strong and get better soon." (5)*

*"we want her healthy again" (6)*

They want stroke survivors to improve and also acknowledge that they know exercises are good for them.

*"Actually they do really help out…" (1)*

The caregivers are prepared and willing to assist with home exercises.

*"But we are trying very hard to make sure, that she is doing the exercises, so that she can get better." (4)*

*"I am prepared to help her with that cause I make it possible for her every day to get the training." (7)*

**E) Knowledge**

In order to adhere to exercises one has to know what to do and how to do it. Two of the caregivers said that the family education and training received from the rehabilitation unit enabled them to continue the rehabilitation at home. The importance of correct handling skills was also mentioned. The quote below illustrate the theme of knowledge:

> *"Training for me is of vital importance. If we didn't have this rehabilitation unit, I don't know. And the people who are trained to work with her, psychologically and the exercises. We wouldn't have progressed this fast." (6)*

### 4.3.2 Caregivers perceived barriers of adherence to home exercise programmes

An open-ended question was asked during each interview to determine the barriers of adherence to home exercise programmes in stroke survivors from a caregiver's perspective. The answers were coded and categorised into common themes. Nineteen themes emerged from the interviews and were categorised into six categories. These categories are: general health issues, other responsibilities, lack of family and social support, caregiver burden and stress, low self-efficacy and mood, fear of falling.

**A) General health issues**

General complaints from the stroke survivors like not feeling well, tiredness, pain and stiffness, swelling, nausea and dizziness were common reasons for not adhering to home exercise programmes. Some of the responses were as follow:

> *"Like my hand is sore, I am feeling this and this" (1)*
>
> *"He will just wake up one morning and then he is nauseous and dizzy" (3)*
>
> *"Sometimes she doesn't want to do it, she tells us she is tired." (4)*

**B) Other responsibilities**

All of the caregivers were closely related family members. During the discussion of other responsibilities in the interviews it was evident that there is not always time for exercise. Caregivers are responsible for their own families, they need to continue with normal house chores, washing, cooking, and cleaning with an added responsibility of taking care of the stroke survivor. Some of them even have to combine all of this with work. Others were unemployed and had to find a job and go for interviews. One caregiver volunteered at a local

old age home helping the elderly and another one had her own business. The quotes below illustrate the theme of other responsibilities:

> *"I need to wash dishes, clean the house, dish up for everybody, wash those dishes while they just sitting there doing nothing." (1)*

> *"I always tell her it's now getting to much for me, because I also have a kid a six year old, I don't even give my son attention that much, because of now the situation" (1)*

> *"Most of the times early morning you get up go to work, then you come back, during the day my mother looks after him but she's also old so she can't really help him with the exercises. Then you come in the afternoon to exercises him, then he is too tired or it's too hot or his not up to it, so you can't do it regularly." (2)*

> *"You have to cook, because he has to eat, you just came home, so there you are there are not really time for it (exercise). Now you have to prepare food then you have to eat then you have to start with something else, you are busy all the time." (3)*

> *"Sometimes I have to go for interview for work because I am still looking for work" (7)*

**C) Lack of family and social support**

There is a lack of family as well as social support from friends or family members visiting. In most of the cases other family members were not involved at all. In none of the interviews the caregivers mentioned other family members visiting them. The only times when they assisted was when called for help. The quotes below illustrate the lack of family and social support:

> *"I am the only person that does that to her, that's why I am saying I am the only link if I were to decide like the other day I had an interview then I had to go and work I could see it torn her apart that I had to go and work, so I am the only person plus our mother we are not that close to our mother, so I am the only link." (1)*

> *"Yes but, they are actually just there to help when I call them to quickly come and help me. They stay close but they are not always with us." (2)*

> *"They are not visiting regularly, but I tell him leave those people, he should just be happy that I am here with him." (5)*

**D) Caregiver burden and stress**

Caregivers experience physical and emotional burden and stress. Increased responsibilities, pressure from family members that results in conflict, stroke survivors becoming dependent on caregivers, they neglect their own families and responsibilities that cause further burden and stress. The quotes below illustrate the caregivers' burden and stress:

Physical burden refers to inability to handle or assist stroke survivor due to their own health issues or stroke survivors increased body mass index like one carer expressed

> *"they are not easy because she's big" (4).*
>
> *"Sometimes if I help him my back hurts." (5)*

Stroke survivors become dependent on caregivers to help them and assist them and prefer caregivers' assistance above those of other family members.

> *"whenever I am not home she stresses a lot, she feels, it's as if she feels I am taking in a lot so sometimes she feels like I don't want to do it or that I am tired now of doing it. That times she feels I am gone for ever, as I am not she always needs me to be there it's like as if I am not there she can't survive and have always taught her that it is not like you can't survive, you gonna be fine" (1)*
>
> *"She doesn't even ask her kids to help her, she'll say it's better when it is me doing it." (1)*
>
> *This leads to further conflict between the caregiver and children. So you understand it is a barrier between me and the kids, (1)*

Another caregiver experienced conflict with the stroke survivors' children.

> *"Yes, enough pressure. They give me trouble all the time about everything, I do this wrong, I give the wrong medication and then I do this and then I do that. It has been like this ever since he started rehab, all the time. He can sense it. He can sense the tension." (3)*

Caregivers have increased responsibilities that cause them to feel overwhelmed.

> *"Like everything you, you, you." (1)*
>
> *"If I come home at night, I have to fight because he is not eating, I have to fight with him because he is not exercising, I have to fight with him because he is rude to my mother, I am always the one fighting, it's always me." (2)*
>
> *"I was brave to say I will handle it, but it's getting to me." (3)*

*I think the big issue is the children, they find fault with everything I do, I just try my best to help him and to keep him happy, but with them nothing is right, you understand?" (3)*

**E) Low self-efficacy and mood**

Stroke survivors have low self-efficacy they feel helpless and frustrated with their abilities. This is illustrated by the quotes below:

*"Some days he will say he is in everyone's way and it will be better if he dies." (2)*

*"I think it is very bad for him, he can't do anything for himself, in the beginning he got very dispirited." (3)*

*"It's her health the way she looks at herself, I'm not well and now at home." (1)*

*"If he sees people outside, then he says, eish, if I can only walk like that man" (5)*

Mood wise, depression is a big barrier to adherence. Caregivers expressed that stroke survivors experience different emotions that all relate to depression. They will just get up angry, refuse to talk to anyone, sleep a lot, be irritated, scream and refuse to exercise for no specific reason. This is illustrated by the following quotes:

*"Sometimes she gets up angry and she doesn't want to do anything." (4)*

*"But on days that she is depressed she doesn't want to do anything she gets irritated, she screams a lot, she doesn't have that patience on those days that she is depressed." (1)*

One also mentioned blame shifting where the patient blamed the caregivers and family members in this case for his physical abilities and inabilities.

*"He can be very depressed at times he will just be angry for the world because he can't walk and then it's our fault, because we don't exercise him, he could have walked and be stronger long ago, but we don't care about him we don't give him attention." (2)*

**F) Fear of falling**

Stroke survivors have a fear of falling and therefore don't want to perform exercises. One caregiver also experienced a fear of the stroke survivor falling and that she will not be able to help him. This is illustrated by the quotes below:

*"She is scared maybe she's going to fall" (1)*

*"Then she walks on her own, a little bit but with anxiety, because her hand will sweat and close tightly..." (6)*

*"I am still scared that he is going to fall, and how am I going to prevent that, I am too weak." (2)*

**G) Lack of knowledge**

Lack of knowledge was identified as a potential barrier. One caregiver expressed lack of knowledge on how to handle the stroke survivor and how to do the exercises. Another one experienced difficulty with some of the exercises and how to do them correctly. This may indicate a need for more information and better training.

*"The therapists are professionals and they know how to help him we don't know it makes it very, very difficult." (2)*

*"We don't know how to do it. We do it different. Then he will tell you, you don't do it correct, I am not going to do it." (2)*

### 4.4 Summary of results

The average age of the stroke survivors was 55.8 years, four were female and three were male, five had right sided strokes and two left sided. The average BI score was 47.1%. The average age of the caregivers was 47.8 years, five were female and two were male all of them were closely related family members. Three were unemployed, two self-employed, one employed and one a pensioner.

The most common enablers of adherence to home exercise programmes are: self –motivation, external motivation from friends and family, daily routine, spirituality, carers' 'attitudes and desire' and knowledge.

The most common barriers of adherence to home exercise programmes are general health issues, other responsibilities, lack of family and social support, caregiver burden and stress, low self-efficacy and mood, fear of falling and lack of knowledge.

The results will be discussed in the next chapter.

# CHAPTER 5

# 5. DISCUSSION

## 5.1. Introduction

Adherence to home exercise programmes is poor. Factors associated with adherence vary considerably among individuals (Karingen et al., 2011). Various enablers and barriers to adherence to home exercise programmes and participation in rehabilitation and physical activity are found in literature. The aim of this research report was to establish caregivers' perceived enablers and barriers of adherence to home exercise programmes in stroke survivors. There were three main objectives: i) to establish the demographic profile of the stroke survivors and their caregivers ii) to establish the caregivers' perceived enablers of adherence to home exercise programmes iii) to establish the caregivers' perceived barriers of adherence to home exercise programmes. In this chapter, the findings from the results chapter will be discussed and compared to previous work in order to determine similarities and differences between this study and those found in the literature.

## 5.2. Demographic profile of stroke survivors

There were slightly more females than males in the study. Out of the seven stroke survivors who were included in the study four were female and three males. In a review conducted by Connor et al. (2007) they reported that in South Africa the prevalence of stroke for men was 281 per 100 000 (200–362), and in women 315 per 100 000 (243–387) over the age of 15 years. A study by Mudzi et al. (2012a) also had more female than male participants in their study. The ages of stroke survivors ranged between 32-76 years with an average age of 55.8 years. In the North West province of South Africa, where the current study was conducted, stroke accounts for 5-6% of deaths being one of the leading causes of death in the age group 45-59 years and 60 years and older (Shutte et al., 2012). The average age is less than 65 years. This is in line with a review conducted by Connor et al. (2007) that reported that stroke incidence is higher in those younger than the age of 65 in Sub Saharan Africa. Other studies conducted by Mudzi et al. (2012a) and Connor et al. (2009) had an average age of 53 and 51 years respectively. In another study by Mudzi (2009) the average age was 53.2 years. The educational level of the stroke survivors is in keeping with the literature. The majority had an educational level below grade 12. Mudzi et al. (2012c), also found that 78% of their study population had an educational level below grade 12.

In this study, the employment rate was much higher. Four of the stroke survivors were employed prior to the stroke, two were pensioners and one unemployed compared to Mudzi

et al. (2012c) who found 71% were unemployed. The majority suffered a left sided stroke with only two being right sided. A study by Kara et al. (2015) also found more left than right sided strokes. Fink et al. (2008) reported that there is no difference in functional outcome of stroke survivors with left sided stroke and those with right sided stroke. The side of the stroke has no influence on stroke survivors' ability to perform activities of daily living (Rexroth et al., 2005). The BI score ranged between 20-70% with an average score of 47.1%. A study by Green et al. (2005) found that South African stroke survivors are admitted and discharged with lower functional levels. Mudzi et al. (2012a), also found a low BI score in the majority of the patients. In another study by Mudzi et al. (2012c), the majority of the stroke survivors had a dependency score throughout the study at six months 92% and twelve months 78%. This negatively affects stroke survivors' ability to perform activities.

### 5.3 Demographic profile of the caregivers

There were more female than male caregivers in the study. Out of the seven participants four were female with only three male participants. This is in line with studies by Kara et al., (2015); Mudzi, (2009) and Haley et al. (2009) who also had more female than male caregivers. There is a traditional assumption that females are available for caregiving and this may explain the high number of female caregivers (Jaffe et al., 2000). Caregivers' ages ranged between 26-65 years with an average age of 47.8 years. A study by Mudzi (2009), caregivers' ages ranged between 41-50 years. The average age in the study of Kara et al. (2015) was 45.6 years. The average age of caregivers' in our study is similar to other South African based studies as mentioned.

All of the caregivers in our study were closely related family members. The burden of care is more and more on stroke survivors' relatives and family members (Green et al., 2005; Mudzi et al., 2012c). Home based rehabilitation that is provided by caregivers especially in poorly developed areas after early discharge, is becoming a more attractive option (Mudzi et al., 2012c). In a study by Dewey et al. (2002) in Melbourne, 69% of stroke survivors with a first ever stroke received informal care from relatives or friends three months post stroke. Uren et al. (2012) reported that care was provided by either the wife or the daughter during family or leisure time. This can be a burden to the caregiver as can be seen in this study with three of the caregivers employed, three unemployed but going for interviews and one was a pensioner. Caregivers have to take on the caregiving role despite existing responsibilities (Jaffe et al., 2000).

Four (57%) of the caregivers had an educational level of grade 12 and three (43%) less than grade 12. In Mudzi (2009)'s study, 41.5% completed up to grade 11 and 34% completed grade

seven. A study by Haley et al. (2009) reported higher educational levels 25% completed high school, 7% less than high school and 67% had college graduate. Our findings are in line with those of Mudzi (2009) which was also a South African based study.

### 5.4 Caregivers' perceived enablers of adherence to home exercise programmes

#### A) Motivation

Self-motivation and external motivation were the most common enablers mentioned by caregiver. Motivation is a frequently used concept, though poorly understood and also reported as an important determinant of rehabilitation outcome (Maclean et al., 2000). Motivation is usually attributed to patients based on their demeanour whether they are proactive or passive (proactivity is associated with motivation and passivity with a lack of motivation) and adherence to rehabilitation (adherence was seen as indicative of motivation, non-adherence as a lack of motivation) (Maclean et al., 2000). These criteria have blurred boundaries. Personal as well as social factors are determinants of motivation (Maclean et al., 2000).

In literature, a lack of motivation is more commonly reported as a barrier in those that tend to not adhere (Sluijs et al., 1993; Forkan et al., 2003; Chan et al., 2010; Jack et al., 2010; Jurkiewicz, 2011). Caregivers in the study by Grant et al. (2004), reported a lack of motivation from stroke survivors' one month post stroke. Our findings are in line with the findings of Elsworth et al. (2009) who indicated that motivation is an important facilitator of adherence. Caregivers in our study mentioned that stroke survivors had an external desire to do things for themselves and a desire to get better, return to work and drive again. In a study by Olaleye et al. (2012) the desire to get better was also mentioned as a factor that influenced the participation of those with a positive mind set who are more likely to adhere.

Good social support is seen as essential to maintain patient motivation (Maclean et al., 2000). Motivation by friends and family was mentioned as an important enabler by caregivers in this study. Emotional support from friends, family, support groups and counselling helps stroke survivors to adjust to their disability (Karingen et al., 2011; Olaleye et al., 2012). Recovery also depends on families' ability to provide emotional and instrumental support and assistance (Lutz et al., 2010).

Stroke has been referred to as a family dilemma (Mackenzie et al., 2012). There is proof that family support results in more effective rehabilitation and has a buffering effect on psychological and social problems (Mackenzie et al., 2012). The initial gains in rehabilitation

are more effectively maintained in families that are healthy and involved in the rehabilitation process and home exercise programmes (Greenwood et al., 2007).

From our study, it is evident that stroke survivors seek continuous encouragement, support, love, company and re-assurance. Positive affect and encouragement from family and friends are perceived enablers of physical activity (Nicholson et al., 2014). Karingen et al. (2011) reported that family support services are a motivating factor to adherence.

**B) Routine**

Having a specific routine was an important enabler of adherence to home exercise programmes as expressed by one caregiver *"If you don't work according to a program or routine it won't work, you won't be able to get to it. Really. You really need to stick with it, a time for this and a time for that. Otherwise you won't manage." (3)*

Stroke has a direct effect on family and social life. In family life, caring for a stroke survivor causes disruptions and changes in daily routines (Northcott et al., 2016). Caregivers have other responsibilities besides caregiving in order to manage everything from household chores, caregiving, own families and children to home exercise programmes and unexpected visitors. Thus, caregivers and stroke survivors have to plan and set goals.

Literature on the importance or benefits of having a daily routine is limited. In a study by Greenwood et al. (2010) caregivers identified the importance of scheduling activities and planning in advance. It is valuable to ensure that journeys and for example shopping trips are easier and more enjoyable. One family reported that a worked-out routine helped them as a family to better cope and assist each other. These are all strategies that can increase caregivers' autonomy and independence.

A study by Olaleye et al. (2012) looked at perceived factors that affected participation in outpatient stroke physiotherapy exercises in Nigeria. In this study, the importance of planned activities was also mentioned as a facilitator of participation. In other studies barriers such as exercise not fitting into or being part of their daily routine and little time to exercise was reported (Sluijs et al., 1993; Ogwumike et al., 2014).

Grant et al. (2004) suggested that strategies that assist caregivers to make the first few weeks of caregiving easier need to be implemented during the recovery process. These strategies should aim to make the carers feel comfortable and should encourage stroke survivors'

independence. They suggested having a schedule avoiding overlapping, allowing more time for ADLs and laying out clothes the night before.

According to these findings a daily routine and planned activities may have benefits in coping for caregivers of stroke survivors.

**C) Spirituality**

Spirituality and faith in God was another enabler of adherence to home exercise programmes according to caregivers. Religion and spirituality are linked to positive physical and mental health outcomes (Johnstone et al., 2007). Stroke survivors' belief and faith in God was found to be a source of hope for recovery (Maleka et al., 2012; Olaleye et al., 2012). Spirituality is an important coping mechanism for people with chronic disability such as stroke, traumatic brain injury, spinal cord injury and cerebral palsy (Johnstone et al., 2007). Individuals with chronic disabilities may expect to live for years after the onset of their injury or disease. Religion serves as a coping mechanism. Their faith in God gives them hope and helps them to cope with their disability and giving them something to look forward to. Spirituality and religion helps people with disability to adjust to their impairments, gives them meaning to life and help them to establish new life goals (Schulz 2005; Johnstone et al., 2007).

Individuals experiencing more disabling conditions of increased severity may tend to engage more in religious activities. The specific way or mechanism by which religion assists in adjusting to disability is relatively unimportant. Individuals have their own personal faith and religious practices, and that is all that matters (Johnstone et al., 2007).

**D) Carers attitudes and desires**

Carers' attitudes and desires are also reported by caregivers as an enabler of adherence to home exercise programmes. What was evident from the interviews was the willingness of caregivers to assist stroke survivors as well as their desire for them to improve.

Literature specific on the willingness of caregivers in their caregiver role as well as their desire for stroke survivors to improve is limited according to the researchers' knowledge. Literature supports the benefits and positive aspects of caregiving (Greenwood et al., 2009; Haley et al., 2009).

Benefits from caregiving may be an important psychological resource for caregivers. The ability of caregivers to find benefits in stressful situations is seen as a beneficial form of coping rather than denial (Haley et al., 2009). Positive aspects of caregiving reported are a greater

appreciation for life, improvement in relationship with the care recipients (Han et al., 1999; Haley et al., 2009; Rigby et al., 2009; Mackenzie et al., 2012), improved recovery and progress of stroke survivors (Mackenzie et al., 2012). The smallest amount of improvement and recovery gives caregivers a sense of pride (Greenwood et al., 2009). Satisfaction reported by caregivers includes feeling good about caregiving: caregiving gives them a sense of fulfilment, satisfaction, it made them realise what is important, enjoy helping stroke survivors, and increase their self-esteem (Greenwood et al., 2009; Mackenzie et al., 2012).

Positive approaches are used as a buffer and strategy to help caregivers to overcome some of the stresses and challenges of caregiving as well as negative experiences such as uncertainty (Mackenzie et al., 2012).

A study done by Galvin et al. (2009) looked at the views of family members of stroke survivors with regards to their role in physiotherapy and in the delivery of additional exercises post stroke. The findings indicate that the family members are willing to be involved and to assist with exercises in the home environment. Literature supports the benefits of family involvement in the rehabilitation process as it maximises the effect and outcome of rehabilitation.

Caring gives caregivers meaning and purpose in life. It makes them appreciate life more, realising what is important and what really matters and makes the carer a better person. It gives them the opportunity to learn new skills, manage difficult situations which all contribute to a feeling of mastery that increased their self-esteem and gives them inner strength (Mackenzie et al., 2012).

**E) Knowledge**

Knowledge with regards to home exercise programmes was perceived as both an enabler and a barrier to adherence to home exercise programmes. Caregivers in this study focus more on the positive aspects of knowledge and the training received as opposed to other studies where they focused primarily on lack of knowledge (Elsworth et al., 2009; Greenwood et al., 2009; Karingen et al., 2011; Mc Donald et al., 2013). This may be due to the therapists' attitude. In a study by Olaleye et al. (2012), participants reported that the positive attitude and the provision of adequate information from the physiotherapist had a positive influence on their participation.

Caregivers in this study did indicate the need for more knowledge. In order to adhere to exercises one has to know what to do and how to do it. Health care professionals are responsible to give adequate information to families and stroke survivors regarding their

condition (Rogers, 2001). Caregivers need to be provided with adequate information and the necessary skills in all aspects of caring (Crosato et al., 2006). Family education and training enables caregivers to assist stroke survivors to continue with rehabilitation at home (Rogers, 2001).

In a study by White et al. (2002), timely information and advice had great value for caregivers and guidance from health care professionals was also an important facilitator. Caregivers in this study were very specific with regards to the value of hands-on training to help them prepare for their role as caregivers. They identified a need for collaboration with families and caregivers in order to assist and support them with undertaking the role as caregivers.

### 5.5 Caregivers' perceived barriers of adherence to home exercise programmes

#### A) General health issues

The following physical complaints were common reasons for non-adherence as mentioned by caregivers in our study: not feeling well, tiredness, pain and stiffness and other less common reasons like swelling, nausea and dizziness. General complaints like these are common reasons for non-adherence found in literature. A study by Ogwumike et al. (2014) found a negative correlation between pain, fatigue and adherence to home exercise programmes. Pain and discomfort was reported as a barrier to adherence in a study by Sluijs et al. (1993). Chan et al. (2010); Billinger et al. (2014) and Nicholson et al. (2014) also identified pain and fatigue as barriers to physical activity in stroke survivors. Physical symptoms are also reported by other researchers (Grant et al., 2004; Jack et al., 2010; Jurkiewicz, 2011). A study by Forkan et al. (2006) on adherence to home exercise in older adults with balance impairments found changes in health status as a primary reason for non-adherence.

#### B) Other responsibilities

Other responsibilities were a big barrier in adherence to home exercise programmes according to caregivers. Other responsibilities besides caregiving are time constraining and cause them to neglect certain aspects of caregiving in this case adherence to home exercise programmes. During the discussion of other responsibilities in the interviews it was evident that there is not always time for exercise. Caregivers have other responsibilities beside the role as caregiver. Those responsibilities include their own families, continuing with normal house chores, washing, cooking, cleaning and being employed. As mentioned by one caregiver: "I need to wash dishes, clean the house, dish up for everybody, and wash those dishes while they just sitting there doing nothing." (1)

All of the caregivers in this study were closely related family members and are therefore referred to as informal caregivers. Informal caregivers are usually friends and family that provide task-orientated assistance without formal training. It is acknowledged that they play a vital role in the care of stroke survivors, but usually this is not without consequence (Dewey et al., 2002).

Caregivers have to take on the caregiving role despite existing responsibilities. Together with caregiving duties female caregivers have to continue with household chores including cooking, shopping, cleaning and laundry (Jaffe et al., 2000). They are expected to make significant changes in their everyday lives and routines to accommodate stroke survivors or to assume responsibilities that were previously performed by stroke survivors. Caregivers have inadequate time to do caregiving tasks and manage stroke survivors' physical symptoms (Grant et al., 2004).

Post stroke, family members have to assist and deal with mobility related problems, difficulties with self-care and communication, but also cognitive impairment, emotional problems, behavioural and personality changes as a result of the stroke (Han et al., 1999; Grant et al., 2004; Forster et al., 2013). Caregiver duties range from administering medication, assisting with ADLs, mobility, home exercise programmes to performing medical procedures without training. They play an important supportive role in the rehabilitation process. It decreases the post stroke complications, aids in improving function post stroke, helps stroke survivors to achieve the highest possible functional independence and recovery and assist in community integration (Mudzi, 2009). A study by Grant et al., (2004) reported that within the first week of caregiving caregivers felt overwhelmed, helpless and frustrated attempting to manage simultaneous work, household tasks and caregiving responsibilities.

The role of caregivers and the responsibilities caregiving adds to their everyday life will take up significant time in their day. Caregivers may therefore neglect certain tasks and responsibilities especially those that are not priority for them or time consuming. Assisting stroke survivors with home exercise programmes might be one of those tasks that are neglected resulting in non-adherence and affecting stroke survivors' functional outcome and quality of life.

**C) Lack of family and social support**

A lack of family and social support was another barrier reported by caregivers in adherence to home exercises programmes. Caregivers reported that there was a lack of involvement of other family members. They did not receive any assistance. Not only did the caregiver lack

support from other family members but the stroke survivors also suffered. They rarely went out and social support from friends was minimal.

Stroke has a direct effect on family and social life. In family life stroke is causing disruptions in family relationships, lost roles, changes in daily routines, reduced family activities and dealing with strong negative emotions. Stroke also has a negative effect on friends and social life making it difficult to maintain relationships and friendships, reduce social activity, loss of friends and result in isolation and loneliness (Northcott et al., 2016). With this in mind the experiences of the caregivers as reported in our study are therefore expected and not something new. Contrary to our finding Northcott et al. (2016) found that despite the reduction in most indicators of social support post stroke for example contact with friends and participation in social activities stroke survivors' perception of feeling supported remained stable.

It can be that the caregivers' perception of what they observed in our study differs from those of the stroke survivors and that they may actually seek support and therefore feel that the stroke survivors also do as they spend most of their time together.

Reasons for the reduction in social activities and participation is because of perceived barriers which includes physical disability, communication difficulties, fatigue, relocation, lack of access, internal barriers and negative emotions and the stigmatising attitudes of others (Northcott et al., 2016).

Social support can increase adherence (Chan et al., 2010). Participants in this study received a lot of support to do exercises from friends and family close to them. A lack of family support and encouragement (Billinger et al., 2014; Idowu et al., 2015) as well as other social support are barriers to physical activity. Social support is shown to increase stroke survivors' emotional well-being and influences depression associated with chronic life changing illnesses (Choi-Kwon et al., 2009). Social support may be a buffering factor not only to the stroke survivor but also the caregiver (Choi-Kwon et al., 2009).

Valuable support functions as perceived by stroke survivors includes: the need for emotional support, they want to feel valued and loved, encouraged, know that others belief in them, accepted, reassured and constancy knowing someone is there for them; receiving tangible support in a way that fostered independence, sense of control and social participation; social companionship humour, distraction, quality time with friends and family and being able to contribute or maintain roles (Northcott et al., 2016).

Caregiving leads to a loss of autonomy and independence in caregivers (Greenwood et al., 2010). Caregivers experience a lack of freedom and time for themselves due to stroke survivors' dependency on them and they feel trapped at home (Greenwood et al., 2009). Out of clinical experience and working with caregivers, a lack of social support and assistance from friends and family lead to a reduction in social participation and activities for caregivers because they feel that they cannot leave stroke survivors alone. Limited social activities result in caregivers being depressed. There is a strong relationship between positive social interaction and depression. Therefore, it is evident that social support has a major influence on the strain and burden experienced by caregivers of stroke survivors (Cumming et al., 2008).

The management of caregivers own emotional feelings and responses are undervalued. Carers have a need for emotional support (Greenwood et al., 2009). Family support is associated with better quality of life in caregivers compared to social service support (Greenwood et al., 2007). If caregivers are not looked after emotionally it will have a negative effect on the way they assist and take care of stroke survivors. There is a stage during rehabilitation that stroke survivors are still fully dependent for assistance and completely rely on caregivers to help them. Emotionally and unsupported caregivers will not be able to offer proper assistance with home exercise programmes during these times and this will have a negative effect on adherence and may lead to non-adherence.

**D) Caregiver burden and stress**

Caregivers reported that the emotional and physical burden of caregiving together with stroke survivors' dependency on them as a barrier of adherence to home exercise programmes.

Household responsibilities and the unfamiliarity of the caregiver role are overwhelming. This result in family caregivers experiencing feelings of frustration, helplessness, being overwhelmed, struggling to manage simultaneous work, household tasks and caregiving responsibilities as well as a loss of independence (Grant et al., 2004).

The prevalence of caregiver strain as reported by Haley et al. (2009) is as follows: 44% had no strain, 41.33% some strain and 14.67% a lot of strain. The prevalence of caregiver burden as reported by Bugge et al. (1999) at one, three and six months were 25%, 28% and 37% respectively. Caregivers under the greatest strain are those that have to fit caring into an already busy programme which requires setting a side time for caring because they are not constantly with the stroke survivor (Bugge et al., 1999).

Behavioural, cognitive and emotional problems experienced by stroke survivors have a significant impact on caregivers' feelings and on their ability to manage other caregiving problems (Grant et al., 2004; Haley et al., 2009; Rigby et al., 2009). Other characteristics associated with caregiver burden are the number of caregiving tasks and the amount of time spend caregiving (Rigby et al., 2009). Changes to family life, changes to personal plans and the confining nature of caregiving also increase caregiver burden (Bugge et al., 1999). Caregiver strain is not only associated with caregiving task alone but also due to the changes that occur in their own established routines and patterns of daily living. Usual roles, routines and responsibilities facilitate adaptation and provide comfort because of their familiarity (Grant et al., 2004). Physical disability and stroke survivors' behaviour are the main reasons for caregivers' frustration, aggravation, sadness, disappointment, impatience, hurt and upset. Negative feelings are internalised and have a negative effect on caregiving abilities (Grant et al., 2004).

Caregiver training has the potential to alleviate caregiver burden (Rigby et al., 2009). Caregivers are often reluctant stating that it is their responsibility to take care of the stroke survivor and if the role was reversed the stroke survivor would have done the same for them. Therefore, they are not always willing to ask for assistance from friends and family or health care professional (Grant et al., 2004). Often caregivers want to share the responsibility of caregiving but do not want to lose control over the situation (Grant et al., 2004).

Caregiver dependency was reported by caregivers as a barrier. Stroke survivors become dependent on caregivers to help them and assist them and prefer caregivers' assistance above those of other family members. Stroke survivors required constant physical attention due to impairment in motor and cognitive function which increases dependency due to the inability to perform activities. Some stroke survivors are impulsive and not aware of their limitations and thus cannot be left alone (Greenwood et al., 2010). This make caregivers feel "trapped" at home, isolated and increases the caregiver burden and levels of emotional strain from looking after the stroke survivors (Greenwood et al., 2009; Greenwood et al., 2010; Paul et al., 2007). Dependency on caregivers together with impairment and disability are associated with caregiver outcome and have an effect on the emotional well-being of caregivers, caregiver burden, quality of life, stress, strain, life satisfaction and psychological health (Greenwood et al., 2007). Stroke survivors' functional dependence is associated with depression in caregivers (Rigby et al., 2009). Increased burden and strain experienced by caregivers as a result of the challenges of caregiving will have a negative effect on caregivers' abilities. This will influence their ability to assist stroke survivors with home exercise programmes and may influence adherence or result in non-adherence.

Caregivers reported that they have their own health problems that they also have to attend to and that caring added extra strain on their own health. As a result of caregiving, caregivers experience adverse health (Rigby et al., 2009). According to literature little is known about the effect of caregiving on carers' physical health, but it is as important as their emotional health (Han et al., 1999). Physical burden experienced by caregivers in this study may relate more to the lack of knowledge in handling skills that was mentioned by a few of the participants rather than reduced physical health.

Caregivers' health is linked to stroke survivors' recovery in physical, emotional and cognitive domains. Recovery also depends on families' ability to provide emotional and instrumental support and assistance (Lutz et al., 2010). Caregiver depression has a negative effect on the social rehabilitation and integration of stroke survivors (Bugge et al., 1999; Han et al., 1999).

**E) Low self-efficacy and mood**

Caregivers experienced stroke survivors' low self-efficacy and mood as a barrier to adherence of home exercise programmes. According to them stroke survivors experience emotions of helplessness, frustration, irritation and anger and depression and blame caregivers and family members for their physical inabilities. These experiences are supported by finding of Grant et al. (2004) who did a study on the experiences of caregivers in caregiving following the first month post discharge. In this study they reported the following: mood swings, emotional changes, and a lack of motivation, depression, anger outbursts, stroke survivors wanting to stay alone when it is not safe, and yelling and cursing as common problems experienced in the first four weeks. This leads to feelings of sadness, frustration, impatience and disappointment in caregivers especially when stroke survivors have a lack of motivation.

Self-efficacy is a construct derived from the Social Cognitive Theory by Bandura (Bandura 1997). Self-efficacy beliefs can determine self-motivation, how people feel, think and behave with regards to their health. Self-efficacy has an influence on motivation and health behaviours. It determines the goals people set, how much effort they put into achieving those goals, and their resilience when faced with difficulties or failure (Bandura 1997). In stroke rehabilitation, self-efficacy is a determinant of mobility gains and functional improvement. Physical impairments and psychological factors have an influence on each other and are therefore essential for the understanding of disability. Negative affect which includes feeling of frustration, pain fatigue or a fear of falling are common barriers (Nicholson et al., 2014).

Stroke survivors may have a lack in confidence in the prescribed exercises and think that it will not benefit their health or recovery or they may lack confidence in their ability to perform

the exercises thinking that they might not be able to perform the exercises (Nicholson et al., 2014). Patients' beliefs and attitudes determine adherence and those with a strong belief that their health and illness dependents on their own behaviour adhere more. Thus, use an internal locus of control (Sluijs, et al., 1993). Whereas those that lack confidence in their ability refers more to self-efficacy (Nicholson et al., 2014). Low self-efficacy was a common restriction in Nicholson et al. (2014)'s study. Stroke survivors lack control over their abilities and physical activity and feel that they are not capable. There is evidence that people who belief their own capability are more motivated to be physically active (Nicholson et al., 2014). Negative emotions have an effect on self-efficacy which affect the ability to act or perform and can therefore influence adherence.

A depressed mood is common post stroke and is associated with poor functional outcome (Willey et al., 2010). Mood disorders post stroke focus largely on depression. The prevalence of post stroke depression is between 20-50% and persist three to six months post stroke. A third of stroke survivors develop post-stroke depression and one quarter develops post-stroke anxiety (Cambell Burton et al., 2013; Hacket et al., 2005).

A systematic review by Cambell et al. (2013) established that anxiety disorders occurred in approximately 20-25% of patients at any time after stroke. Hacket et al. (2005) reported 33% of all stroke survivors experienced depression. In Barker-Collo (2007)'s study the prevalence rate of moderate to severe depression and anxiety was 22.8% and 21.1% respectively. There is a greater likelihood to experience depression and anxiety after a stroke compared to the general population. Willey et al. (2010) reported mood disturbance in 40.9% of the sample within 7-10 days post-stroke. Those that reported a depressive mood within the first week were also more likely to be severely disabled at 24 months post stroke. Depression may have a negative effect on adherence and stroke survivors' ability and willingness to engage in exercises.

Stroke is a life changing event and thus depressive symptoms could be reactive in nature (Willey et al., 2010). Anxiety and depression occur mostly during early stage after a stroke. This is also the time frame in which most of the intense rehabilitation is offered. Negative emotions and depression during these times will influence stroke survivors' engagement in exercises. In some cases, early hospital discharge may result in stroke survivors being at home during this stage and therefore adherence to home exercise programmes might be negatively affected. Emotional difficulties will have an influence on recovery (Barker-Collo, 2007; Hacket et al., 2005). Depression and anxiety have an impact on stroke survivors' ability to fully take part in rehabilitation. Depression may cause a lack of motivation and stroke

survivors will not push themselves during therapy sessions especially physical exercises and those with anxiety may experience a fear of falling and will refuse to attempt to walk without assistance despite reassurance (Barker-Collo, 2007). This can also be carried over to the home environment with the performance of home exercise programmes. Early recognition of symptoms is important as is treatable, however the necessary support should be offered to optimise recovery (Barker-Collo, 2007; Hacket et al., 2005).

**F) Fear of falling**

Fear of falling was one of the less common barriers reported by caregivers of adherence to home exercise programmes. Caregivers fear to leave stroke survivors without supervision or completely alone because they fear that they will fall. Caregivers fear that the prescribed exercises will cause them to fall, or that they will not be able to assist them when they fall during exercises. Stroke survivors also experience fear of falling and therefore don't want to do exercises alone and depend on caregivers for assistance.

Caregivers in a study by Grant et al. (2014) reported safety concerns as the main problem experienced during the first month post stroke. These included a fear of falling. The characteristics of the problem shifted over the time frame of the study as the caregiver gained more confidence and the stroke survivors physical functioning improved.

A common consequence of fear of falling is noted in older adults who have not fallen as a predictor of future falls (Delbaere et al., 2004). Stroke survivors have impairments and activity limitations that put them at risk for falling. Stroke survivors have approximately twice the risk of falling compared to aged match controls. They remain a high-risk population for the first few months post discharge home (Jørgensen et al., 2002). The fear of falling from both the caregiver as well as stroke survivors' perspective leads to a reduction in performance of physical activities, which cause them to lose muscle strength, postural control abilities, and they begin to have lessened functional abilities while walking or performing ADLs, thereby worsening their fear of falling, and the cycle continues (Delbaere et al., 2004).

In a study by Da Silva et al. (2014) all of the survivors reported that they had sustained at least one fall since the time of their stroke, with 50% sustaining an injury from a fall. Assuring the safety of stroke survivors remain big concern for caregivers. Stroke survivors' weakness, impaired judgement and memory predispose them to falls and other accidents (Grant et al 2004). Fear of falling may have a negative effect on adherence to home exercise programmes. Both the caregiver and stroke survivor experience this fear and it may prevent engaging in

certain activities or performing exercises where there is a potential risk for falling. This will ultimately result in non-adherence.

**G) Lack of knowledge**

There was a lack of information with regards to knowledge identified which could have a negative effect on adherence and was perceived as a barrier. Some of the caregivers in our study indicated that they did not receive information on how to handle stroke survivors or how to perform exercises correctly. According to literature stroke survivors, their families and carers are unsatisfied with the information given and this can contribute to poorer outcome as uninformed patients are less satisfied and therefore more likely to not adhere to advice and treatment (Rogers, 2001). Billinger et al. (2014) also identified lack of knowledge on how to exercise and where to exercises as barriers to physical activity in stroke survivors.

Literature provides evidence of a lack of knowledge reported by caregivers and stroke survivors (Elsworth et al., 2009; Greenwood et al., 2009; Karingen et al., 2011; Mc Donald et al., 2013), stroke survivors lack knowledge of their own responsibilities to participate in rehabilitation (Karingen et al., 2011). Literature also indicated the need for information and training specifically tailored to individual needs of stroke survivors (Greenwood et al., 2009; Olaleye et al., 2012).

A lack of knowledge and information results in feelings of anxiety in stroke survivors. They feel afraid to take part in rehabilitation (McDonald et al., 2013). Without this preparation for the caregiver role caregivers experience fear and uncertainty (Cameron et al., 2013). Clear instructions should be given with clear rationale to prevent misinterpretation and non-adherence (Sluijs et al., 1993). The exercise programme should be monitored, reviewed and progress should be noted (Olaleye et al., 2012). Physiotherapist should assist patient with realistic expectations helping them to plan outpatient services and treatment (Karingen et al., 2011).

In an intervention study that aimed to counsel and educate family caregivers of stroke survivors it was indicated that knowledge about patient care, self-efficacy, the use of coping strategies and social support had positive effects (Schure et al., 2006). Knowledge and coping are thought to buffer the impact of stressors and therefore important for caregivers' wellbeing (Schure et al., 2006; Greenwood et al., 2007; Rigby et al., 2009).

### 5.6 Conclusion of discussion

This study identified the most common enablers and barriers of adherence to home exercise programmes of stroke survivors from a caregiver's perspective. Findings of this study correlates with the existing body of literature on adherence of stroke survivors and the problems and challenges experienced by caregivers. Motivation, routine, spirituality, caregivers' attitude and desire and knowledge were reported as enablers. General health issues, other responsibilities, lack of family and social support, caregiver burden and stress, low self-efficacy and mood, fear of falling and a lack of knowledge were reported as barriers of adherence to home exercise programmes.

# CHAPTER 6

# 6. CONCLUSION

## 6.1 Introduction

This chapter summarises the findings with particular reference to the objectives of the study. It also includes the limitations of the study and recommendations for clinicians and further research.

## 6.2 Conclusion of the study

The objectives of the study were: i) to establish demographic profile of the stroke survivors and their caregivers ii) to establish the caregivers' perceived enablers of adherence to home exercise programmes iii) to establish the caregivers' perceived barriers of adherence to home exercise programmes.

The average age of the stroke survivors was 55.8 (±15.03) years the majority were females with a right sided stroke. The average BI score was 47.1%. The majority of the caregivers were females and closely related family members with an average age of 47.8 (±13.96) years.

Caregivers reported the following enablers of home exercise programmes: Self and external motivation (emotional support from friend and family), having a specific routine enabled them to balance all the aspects of caregiving and to get to everything. Spirituality and faith in God was an important coping mechanism for stroke survivors which enabled them to have hope. Caregivers' attitude and desire was expressed in their willingness to assist stroke survivors and their desire for them to improve and recover. Lastly knowledge was an important enabler focusing on information given as well as the value of education and training of caregivers to prepare them to handle stroke survivors.

The most common barriers of adherence to home exercise programmes according to caregivers were general health issues which mostly included pain and fatigue, other responsibilities of caregivers were a barrier as caregiving comes with great responsibility, added tasks and activities and the interruptions of everyday life and responsibilities. A lack of family and social support has a negative effect on adherence and influenced both the stroke survivor and the caregivers' emotional well-being, caregiver burden and stress, stroke survivors' low self-efficacy and mood, fear of falling from both the caregivers and the stroke survivors themselves were also mentioned as barriers of adherence to home exercise programmes.

From this study, it is evident that adherence to home exercise programmes is multifactorial and does not only relate to the stroke survivor alone. Caregivers have a lot of responsibilities and experience emotional strain and burden and this has an influence on stroke survivors' adherence to home exercise programmes as they rely upon caregivers for assistance. When addressing adherence both the stroke survivor and the caregivers needs to be considered. Being aware of the potential enablers and barriers of adherence to home exercise programmes can give health care professionals insight in how to optimise adherence and possibly improve functional ability and the quality of life of stroke survivors.

### 6.3 Limitations of the study

Findings of this study are from a particular rehabilitation unit in South Africa based on a specific stroke population and can therefore not be generalised. Further research will be useful to determine if our findings can be generalised to other stroke units and stroke populations in South Africa.

Follow up contact sessions with physiotherapist post discharge were not monitored. Frequent follow ups with therapist and family members could have influenced adherence as they may have received more information and or guidance with regards to home exercise programmes.

### 6.4 Recommendations

#### 6.4.1 For the clinician

Clinically therapist needs to be aware of the enablers of and barriers to adherence to home exercise programmes in order to optimise adherence. Clinical facilities should review their family/caregiver training and education. The enablers of and barriers to adherence to home exercise programmes should be incorporated and attended to during these sessions providing appropriate information and the necessary skills to families and caregivers. Clinicians need to identify relevant socio-economic factors as potential barriers and address this by referring caregivers, family members and stroke survivors for assistance at appropriate facilities and departments for example social work and psychology. Home exercise programmes should be structured in such a way that it optimise adherence. The following aspects should be considered when developing a home exercise programme: The enablers and barriers of adherence to home exercise programmes, programmes should be individualised and linked to patients' goals. There should be clear instructions on how to perform exercise as well as repetition to prevent miss interpretation. It should fit into their daily routine. Home exercise programmes should be monitored and reviewed. Findings of this study should be made

available to the clinical facility where the study was conducted to improve their family education and training.

### 6.4.2 For further research

Further qualitative and quantitative research on the enablers and barriers of adherence to home exercise programmes from a caregiver's perspective needs to be explored especially in South Africa and other developing countries where social circumstances differ. There is a need for further investigation into psychosocial and socioeconomic factors that are potential barriers to adherence to home exercise programmes. Further research is needed to test strategies that reduce the negative impact of the barriers and increase the positive aspects of the enablers. There is a need to test caregiver education programmes on stroke caregivers and the effect it will have on the barriers and enablers of adherence to home exercise programmes.

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**Appendix A**

**Information document**

**Study title:** Caregivers' perspective of enablers and barriers of adherence to home exercise programmes in stroke survivors

Good day, I am Maryke Scorrano an MSc Physiotherapy student at the University of Witwatersrand.

I am conducting a research study on the enablers and barriers that influence adherence to home exercise programmes in stroke survivors from a caregiver's perspective. Research is just the process to learn the answer to a question. In this study, we want to know what the enablers and barriers are that result in patients not adhering to home exercise programmes, as rehabilitation is an ongoing process which starts in hospital but continue after discharge at home.

I am inviting you to take part in this research study. The study will consist of an interview with you as the caregiver regarding your family members adherence to their home exercise programme, if they agree upon it. Consent will be obtained from them to allow you to give this information regarding them. If you agree to participate I will arrange a time for an interview with you three months post discharge at the hospital I will cover your transport costs to get to the hospital. The interview will be 30-45 minutes and audio recorded if you agree upon it.

The purpose of the study will be to identify the enablers and barriers which will assist physiotherapists, as well as other allied health professionals to identify patients at risks for non-adherence and find possible methods to reduce non-adherence. It can also assist therapist in adapting home exercise programmes and family training to optimise adherence. If adherence is maximised stroke survivors will have better functional outcomes and independence due to the ongoing rehabilitation process.

Participation in the research is voluntary and you may refuse to participate or withdraw at any time without penalty. You are also allowed to participate without being audio recorded. Participation in the research study will have no financial implication. Feedback from the research will be available on request.

Efforts will be made to keep personal information confidential. No names will be mentioned and I will make sure that all personal information and the audio record of the interview is kept in a secure locked place and only I will have access to it. Absolute confidentiality cannot be guaranteed. Personal information may be disclosed if required by law.

CONTACT INFORMATION
Should you require more information please contact Miss M. Scorrano (researcher) at 018 294 9100 or Dr V. Ntsiea (research supervisor) at 011 717 2015. Should there be any ethical queries about the research please feel free to contact the Human Research Ethics Committee (HREC) chairman Prof P Cleaton-Jones at 011 717 1234

Regards,
Maryke Scorrano

**Appendix B**

**Informed consent stroke survivor**

I, the undersigned_____ (full name and surname) have read through the information provided about the research study and declare that I fully understand the content thereof. I give permission to my caregiver to participate and give information about me to the researcher.

Signature_____ signed at _____on the _____ day of _____ 2015

**Appendix C**

**Informed consent for audio records**

I, the undersigned_____ (full name and surname) agree to be

□ Audio recorded

□ Not audio recorded

during the interview.

Signature_____ signed at _____on the _____ day of _____ 2015

**Appendix D**

**Informed consent Caregiver**

I, the undersigned_____ (full name and surname) have read through the information provided about the research study and declare that I fully understand the content thereof.

Signature_____ signed at _____on the _____ day of _____ 2015

**Appendix E**

**Demographic data**

Demographic details: Stroke survivor and their caregiver

Interview number: ……..

| | CAREGIVER | STROKE SURVIVOR |
|---|---|---|
| Gender | | |
| Age | | |
| Relationship | | |
| Highest level of education | | |
| Occupation | | |
| Language | | |
| Date of stroke | | |
| Side of hemiplegia | | |
| Barthel index score | | |

## Appendix F

## Barthel Index

**THE BARTHEL INDEX**

**Patient Name**: _____
**Rater Name:** _____
**Date:** _____

| Activity | Score |
|---|---|
| **FEEDING**<br>0 = unable<br>5 = needs help cutting, spreading butter, etc., or requires modified diet<br>10 = independent | _____ |
| **BATHING**<br>0 = dependent<br>5 = independent (or in shower) | _____ |
| **GROOMING**<br>0 = needs to help with personal care<br>5 = independent face/hair/teeth/shaving (implements provided) | _____ |
| **DRESSING**<br>0 = dependent<br>5 = needs help but can do about half unaided<br>10 = independent (including buttons, zips, laces, etc.) | _____ |
| **BOWELS**<br>0 = incontinent (or needs to be given enemas)<br>5 = occasional accident<br>10 = continent | _____ |
| **BLADDER**<br>0 = incontinent, or catheterized and unable to manage alone<br>5 = occasional accident<br>10 = continent | _____ |
| **TOILET USE**<br>0 = dependent<br>5 = needs some help, but can do something alone<br>10 = independent (on and off, dressing, wiping) | _____ |
| **TRANSFERS (BED TO CHAIR AND BACK)**<br>0 = unable, no sitting balance<br>5 = major help (one or two people, physical), can sit<br>10 = minor help (verbal or physical)<br>15 = independent | _____ |
| **MOBILITY (ON LEVEL SURFACES)**<br>0 = immobile or < 50 yards<br>5 = wheelchair independent, including corners, > 50 yards<br>10 = walks with help of one person (verbal or physical) > 50 yards<br>15 = independent (but may use any aid; for example, stick) > 50 yards | _____ |
| **STAIRS**<br>0 = unable<br>5 = needs help (verbal, physical, carrying aid)<br>10 = independent | _____ |
| **TOTAL (0–100):** | _____ |

*Provided by the Internet Stroke Center — www.strokecenter.org*

**Appendix G**

**Schedule of interview questions**

a) Please tell me what do you think are the enablers of adherence to home exercise programmes?

b) Please tell me what do you think are the barriers to adherence to home exercise programmes?

The researcher will thank the participants and give them the opportunity to listen to the audio tape and correct where necessary.

The researcher will explain the next step and the rest of the research procedure. Tell them that they might be interviewed again or called to come back if necessary after the analysis if more information is required.

**Appendix H**
**Clearance certificate**

R14/49 Miss Maryke Scorrano

## HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

## CLEARANCE CERTIFICATE NO. M150152

| | |
|---|---|
| **NAME: (Principal Investigator)** | Miss Maryke Scorrano |
| **DEPARTMENT:** | Physiotherapy<br>Witrand Hospital |
| **PROJECT TITLE:** | Caregivers' Perspective of Enablers and Barriers of Adherence to Home Excercise Programmes in Stroke Survivors |
| **DATE CONSIDERED:** | 30/01/2015 |
| **DECISION:** | Approved unconditionally |
| **CONDITIONS:** | |
| **SUPERVISOR:** | Dr MV Ntsiea and Dr MED Maleka |
| **APPROVED BY:** | Professor P Cleaton-Jones, Chairperson, HREC (Medical) |
| **DATE OF APPROVAL:** | 04/03/2015 |

**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 research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**.

Principal Investigator Signature Date

**PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES**

**Appendix I**

**Turnitin report**

turnitin

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**Caregivers' perceived enablers and barriers of adherence to home exercise programmes in stroke survivors**

Maryke Scorrano

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

Johannesburg, 2017

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## Maryke Scorrano MSc Research Report

ORIGINALITY REPORT

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22 February 2017

The Chairperson
Graduate Studies Committee
University of the Witwatersrand
Faculty of Health Sciences

Dear Professor Papathanasopoulos

**Re: Turnitin score of 20% for Maryke Scorrano Research Report**
**MSc Physiotherapy: Student No. 927587**

Ms Maryke Scorrano is a MSc Physiotherapy student in our Department. She has just received her Turnitin score in preparation for submission of her research report for examination. I have read the detailed Turnitin report and can confirm that most of the areas that are highlighted in the document are not content related. It is mainly to do with instrumentation which uses common terminology and general research and stroke terms.

**Dr Veronica Ntsiea**
**Supervisor**