

**IMPACT OF CAREGIVER EDUCATION ON STROKE SURVIVORS AND THEIR  
CAREGIVERS.**

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A thesis submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in  
fulfilment of the requirements for the degree of Doctor of Philosophy

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## DECLARATION

I, Witness Mudzi declare that this research report is my own work. It is being submitted for the degree of Doctor of Philosophy 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)

-----day of -----, 2010.

## **DEDICATION**

To my son (Russell Nyasha) for being the driving force for my will to live and make this work a success.

## **ABSTRACT**

Despite the improvements that have been made in health care over the years, stroke remains a serious public health problem in low, middle and high-income countries. Post-stroke, there are many consequences that manifest and these include mortality, morbidity and socioeconomic, affecting not only the stroke survivor but also the caregiver. These consequences are felt hardest in low and middle-income countries because they are the least able to deal with health related setbacks to development. Pressure for beds and the need to reduce hospitalisation related costs have resulted in early discharge home of patients culminating in caregivers playing a more significant role post-stroke.

The role played by caregivers has of late received much attention and is well documented in high-income regions. Informal caregivers are particularly important in low resourced settings. Caregivers play an important role in the rehabilitation process of the stroke survivor. The discharge home of patients with stroke to unprepared caregivers is associated with burden or strain, which negatively affects the quality of life of not only the caregiver but the stroke survivor as well. The effect of a structured, individualised caregiver training programme on patients with stroke and their carers has not been established in sub-Saharan Africa in general and South Africa in particular.

With this in mind, the aim of the study was to establish the impact of caregiver education on the morbidity of the stroke survivors and on the quality of life of the stroke survivors and their carers. The specific objectives of the study were to establish the: physiotherapy caregiver education programmes and associated content in use for managing patients with stroke at Chris Hani Baragwanath hospital, effect of caregiver education on the mobility of the stroke survivors, effect of caregiver education on the health related quality of life of the stroke survivor and the caregivers, effect of caregiver education on the ability of the stroke survivor to socialise and participate in community issues and also the patient and caregiver characteristics associated with caregiver strain post-stroke.

To achieve the first objective, a self designed questionnaire was used to establish the physiotherapy caregiver education programmes and associated content in use for managing patients with stroke at Chris Hani Baragwanath hospital from the physiotherapists at the hospital. For the rest of the objectives, a stratified randomised controlled trial using concealed allocation with a broad entry and blinded outcome assessment at baseline, three, six and 12 months was used for data collection. The participants for the study were first time ischaemic patients with stroke admitted to Chris Hani Baragwanath hospital, Soweto, Johannesburg, South Africa. A total of 200 patients and their caregivers

participated in the study. These were randomly assigned to either the control group or the experimental group. The caregivers in the experimental group were subjected to an individualised training programme just prior to discharge of the patient with stroke and at the three month follow up. The assessor was blinded to the group allocation of the patients and caregivers until after completion of the study.

From the study, the one-year case fatality was 38%. The mean hospital length of stay for patients with stroke was six days and the average number of physiotherapy contacts for the stroke survivors was one. The content of the rehabilitation programme of patients post-stroke was well structured and appropriate at Chris Hani Baragwanath. However, there was no caregiver involvement or training during in-patient rehabilitation. The barriers to caregiver involvement included perceived high workload by therapists, short hospital length of stay, poor referral systems between clinicians and therapists of patients post-stroke and caregivers being unavailable during working hours for training purposes.

Using the Barthel Index (BI) scores, 78% of the patients were functionally dependent at 12 months post discharge. None of the patients were fully independent in mobility and stair climbing. The experimental group had better mean BI scores at the three and 12 month follow up periods ( $p = 0.01$  and  $p = 0.05$  respectively) when compared to the control group. Caregiver education had the effect of improving the BI scores by one and 0.7 at the three and 12 months follow ups respectively. However, the functional abilities of the patients from both groups were still low at 12 months with averages of 13.3 and 12.6 for the experimental and control groups respectively (out of a possible 20).

The overall patient mobility scores as measured on the Rivermead Mobility Index were low over the study period with averages of 9.1 and 8.5 for the experimental and control group respectively (out of a possible 15). However, the experimental group had slightly better Rivermead Mobility Index (RMI) scores, which were not statistically significant. Caregiver education had the effect of reducing the risk of death by 27% relative to that occurring among the control group patients.

The health related quality of life of the stroke survivors was generally poor over the study period. The baseline means from their EQ-5D scores (for health related quality of life) were 42.4 and 43.7 for the control and experimental groups respectively, which rose to 67 and 68.8 at 12 months respectively post discharge. Caregiver education had the effect of improving patients' EQ-5D scores by a factor of three and this was only at 12 months.

The caregivers' quality of life generally declined over the 12 months of the study period (more in the control group than the experimental group) from averages of 92 and 93 at three months (for the control and experimental groups respectively) to 83 and 86 (respectively) at 12 months. However, the experimental group had better mean EQ-5D scores (health related quality of life) than the control group ( $p = 0.001$ ). Caregiver education had the effect of improving EQ-5D scores by factors of 3.4 and 3.6 at the six and twelve month follow up period.

The ability to socialise and participate in community issues was poor. None of the participants could carry out single and multiple tasks without assistance at 12 months post discharge. More than 87% of the patients had mild to moderate difficulty with walking at 12 months post discharge and they were all unable to lift and carry objects, have fine hand use and move around with equipment without assistance. None of the patients was able to carry out domestic activities without any difficulty and consequently they could not prepare meals and do housework without assistance from helpers.

All of the participants had mild to moderate and severe to complete difficulty in basic interpersonal interactions, complex interpersonal interactions and formal relationships. They all had mild to moderate difficulty engaging in recreation and leisure activities while 27% of the control group and 25% of the experimental group had severe to complete difficulty with community life at 12 months post discharge.

The design, construction and building products and technology for both public and private use were cited as barriers to community participation. More than 50% of the patients also cited friends as being barriers to community participation but acquaintances, colleagues, neighbours and community members were cited as being facilitators together with personal care providers (caregivers). Transport services, systems and policies were also cited as barriers by more than 80% of the participants. Caregiver education did not seem to influence patients' ability to participate in community issues given the similarities in percentages between the control and experimental groups.

At three months post discharge, 89% of the caregivers in the control group and 92% of those in the experimental group were strained from caregiving duties. However, these percentages declined to 78% and 43% respectively at 12 months, showing the effectiveness of caregiver education. Caregiver education had the effect of reducing strain by a factor of 2.6 at 12 months.

The patient characteristics that were associated with caregiver strain were the dependency levels in transfers, mobility, dressing, bathing, poor activities of daily living scores, patient anxiety/depression,

pain and poor perceived health state. The only caregiver characteristic that influenced caregiver strain was the level of education.

The reduced hospital length of stay, pressure for beds and possibly inadequate rehabilitation personnel levels means that its possible that some caregivers are not adequately trained to meet patient needs, although this needs to be confirmed with further controlled research. The current pressure on in-patient services at Chris Hani Baragwanath hospital is resulting in suboptimal exposure to rehabilitation of patients post-stroke. There is insufficient organised caregiver education at present. Structured individualised caregiver training has the effect of positively influencing the health related quality of life of the patients especially at six and 12 months post discharge.

Caregivers for patients with stroke suffer from physical, financial and psychological problems, which negatively affect their health related quality of life. Currently, high levels of caregiver strain persist post-stroke. Caregiver education however has the effect of reducing the decline in caregiver health related quality of life over time.

Caregiver training did not positively influence patient mobility and this is most probably because the patients had very low or poor functional ability levels at discharge from hospital. However, structured and individualised caregiver training has the effect of improving patients' quality of life and can help reduce deaths among stroke survivors.

The patient ability to socialise and participate in community issues post-stroke is currently poor. This mainly stems from the poor functional ability levels, which necessitate dependency on caregivers. Compounding the low functional ability levels are the transport systems, services and policies, attitudes of friends and the design, construction and building products and technology for both public and private use, which are barriers to community participation.

The high patient dependency levels result in caregivers being highly strained. The patient characteristics that influence caregiver strain are dependence in transfers, grooming, mobility, dressing, poor activities of daily living, patient anxiety/depression, pain and poor perceived health state (health related quality of life). The only caregiver characteristic that was associated with caregiver strain is the level of education.

The early discharge home with little caregiver training calls for provision of community rehabilitation services preferably through domiciliary visits. Caregivers of patients with stroke should be assessed and treated for depression given its high prevalence among this cohort.

The referral system between the local community health centres and the discharging hospital need to be strengthened to ensure access to rehabilitation by all patients post discharge from hospital. The referral to social workers during in-patient and out-patient rehabilitation also need to be strengthened to ensure processing of social grants to alleviate financial strain as is appropriate.

Caregiver strain is a complex and multifaceted problem with no single causation or solution. As a result, further research is needed to establish the reasons for poor rehabilitation service provision post-stroke for patients and caregivers and find solutions to these. It is important to explore different methods of caregiver education programmes so that the method that yields the best results for both patients and caregivers can be established in our setting and internationally.

**Key words:** Stroke, Caregiver, Physiotherapy, Rehabilitation, Quality of life, Burden of caregiving.



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## **ABBREVIATIONS USED**

AIDS – Acquired Immunodeficiency Syndrome

BI – Barthel Index

CG – Control Group

CHBH – Chris Hani Baragwanath hospital

CONSORT – Consolidated Standards of Reporting Trials

CSI – Caregiver Strain Index

CT – Computerised Tomography

DALYs – Disability Adjusted Life Years

EG – Experimental Group

EQ-5D – The European Quality of Life Scale

FIM – Functional Independence Measure

HIV – Human Immunodeficiency Virus

ICC – Intraclass Coefficient

ICF – International Classification of Functioning, Disability and Health

ICIDH – The International Classification of Impairment, Disabilities and Handicaps

LACI – Lacunar Circulation Infarction

MRI – Magnetic Resonance Imaging

MRMI – Modified Rivermead Mobility Index

OCSP – Oxfordshire Community Stroke Project

PACI – Partial Anterior Circulation Infarction

RMI – Rivermead Mobility Index

SF-36 – The Medical Outcomes Study 36-Item Short Form

TACI – Total Anterior Circulation Infarction

TOAST – Trial of ORG 10172 in Acute Stroke Treatment

USA – United States of America

VAS – Visual Analogue Scale

WHO – World Health Organisation

# CHAPTER 1

## 1. INTRODUCTION

### 1.1 Background and Need

Stroke is a well-documented public health problem in low, middle and high-income countries. It is considered the fourth leading cause of global mortality (Lopez et al., 2006a). Stroke has also been shown to be among the top ten leading causes of disability worldwide (Lopez et al., 2006a, Murray and Lopez, 1997) and including amongst black people in South Africa (Disler et al., 1986). It is reported to be among the top four causes of death in South Africa (Bradshaw et al., 2002a). The prevalence of stroke survivors needing help with activities of daily living in South Africa following a stroke is almost the same as in high income countries (Connor et al., 2004). Other than the devastating effects of human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS), neurological disability(stroke included) has been singled out as the most important healthcare challenge of the next few decades (Pomeroy and Tallis, 2002; Connor et al., 2004).

Following stroke, more than 60% of survivors will need help with activities of daily living when at home (Connor et al. 2004) and it is mostly provided by informal caregivers (Dewey et al., 2002). The caregiver is usually either a close relative or a spouse and is affected by the patient's illness from the onset. Both formal and informal caregivers play an important role in the support of disabled stroke survivors at home (Wilkinson et al., 1997). In poorly resourced settings, early discharge with home based rehabilitation continued by the caregiver is an attractive option.

The increase in financial constraints on the healthcare system (Anderson et al., 1995) and in addition to that, pressure for beds (Putterill et al., 1984a) has prompted a shift from institutional care to community care. In the previous decade, patients with stroke were hospitalised for up to two weeks at Chris Hani Baragwanath Hospital (CHBH), an urban hospital in Soweto, South Africa and were then discharged home (Hale, 2002). This saw caregivers playing a more dominant role in patient management especially in the post-hospital period. More often than not patients with stroke are sent home prematurely to a family that has to cope with the changed individual without any prior training on how to manage the patient and with very little or no supported care (Hankey, 2004; Hale, 2002).

Caregivers have emerged as integral to the improvement in quality of life and survival of stroke victims as they adapt to the subsequent impairment (Pomeroy and Tallis 2002). They are recognized as one of

the most important components of community care for survivors of stroke (Twigg, 1998). Caregiver involvement helps to reduce the risk of another stroke, reduce post-stroke complications, improve function after a stroke, help achieve the highest possible functional recovery and in the process improve community integration (Kalra et al., 2004; Hankey, 2004; Han and Haley, 1999). Post-stroke disability and depression (among other variables), are correlated with low quality of life (Carod-Artal et al., 2000). Caregivers play a leading role in helping stroke survivors cope with these emerging problems. Mayo et al. (2000) and Glass et al. (1993) also concur that supported discharge of patients with stroke (caregiver/relative involvement) leads to better physical health and improves community integration. The patients with stroke in Soweto, South Africa have limited rehabilitative support and do not have the supported early discharge programmes found in developed countries that are described in the literature (Hale, 2002).

Despite caregivers being responsible for disabled patients with stroke at home, they receive little or no training for their care-giving role (Kalra et al., 2004). Some research done in high-income countries has shown that caregiver training in basic skills of moving and handling, facilitation of activities of daily living and simple nursing tasks reduces the burden of care and increases the quality of life of patients and caregivers (Kalra et al., 2004, Patel et al., 2004). Caregiver training has also been shown to be cost effective for the health system (Patel et al., 2004). Caregiver education was also seen to help improve the functional abilities of disabled people (not specifically stroke survivors) in a study done in the Cape Flats of Cape Town South Africa (Futter, 1996). The education process to prepare patients with stroke and their carers for the challenges of transition to home and the stroke recovery process should start in the acute rehabilitation phase of the stroke survivor (Flick, 1999).

The only South African study that investigated long-term effects of stroke rehabilitation was the one by Hale et al., (1999). Their study found that stroke survivors were troubled by shoulder and knee pain, inability to walk outside the home, difficulty with transfers, as well as by washing and dressing difficulties. A general lack of understanding of stroke in patients with stroke was also demonstrated. However, the impact of caregiver education on both the stroke survivor and the caregiver in South Africa remains largely unknown. The same study (Hale, 2002) suggested empowerment of caregivers and families as one of the strategies that should be used when managing stroke survivors.

Other than the obvious impact that stroke has on the survivor, the burden of caring for a stroke survivor has been associated with disruption of both the integrity of families and quality of life of the caregivers themselves (Anderson et al., 1995; Bugge et al., 1999; Hankey, 2004). In their endeavour to improve

the quality of life of the stroke survivor, caregivers experience a significant burden, which if excessive can lead to breakdown in the support provided (Anderson et al., 1995). Depression is common among stroke survivors' caregivers (Flick, 1999; Han and Haley, 1999, Putterill et al., 1984b).

It is because of this burden, which can be socially profound, that caregivers deserve attention in their own right as part of the various rehabilitation interventions designed to reduce the handicap following stroke (Anderson et al., 1995). Despite the presence of community services such as district nursing, domiciliary care, day centres and hospitals in high-income countries, stroke groups and respite care, the needs of caregivers remain largely unmet (Anderson et al., 1995). This was further reiterated by Bugge et al. (1999) who noted inadequate provision and usage of caregivers' support services as contributory factors to increased caregiver strain. The level of caregiver strain and the preparedness of the caregivers for the caregiving role in low-income countries, South Africa included, are unknown. Physiotherapists involved with the management of stroke survivors in South Africa point out that healthcare education is a cornerstone for service delivery and that it is supposed to be aimed at clients, caregivers, the public, and community health workers (Hale, 2002).

In South Africa economic constraints have hampered the development of sufficient community based support services (Putterill et al., 1984a and Hale et al., 1998). There is therefore very little respite for the carer who will be carrying the burden of care of the stroke survivor. Despite their key role, the carer is often an ignored member of the health care team (Putterill et al., 1984b). A study from Cape Town, South Africa, showed that preparation of carers for looking after stroke survivors is deficient (Putterill et al., 1984b). In Hale's 2002 study, caregivers indicated a feeling of inadequacy when dealing with transfers from bed to chair, walking, washing, dressing and communication of stroke survivors. They also wanted to be given information on what to do in the event of another stroke, recommended dietary changes, handling of a patient with stroke and how to reduce dependence of stroke survivors. So despite whatever training, if any, they were given in the hospitals, the caregivers for stroke survivors in Soweto felt inadequately prepared for their care giving roles.

Following discharge, stroke survivors and their carers are still besieged by numerous problems and continue to be in need of medical and social assistance. Caregivers are thought to be important but in practice, in low resourced areas like Soweto, may be the only source of care and rehabilitation available to patients with stroke exacerbated by economic forces, HIV that result in high demand for beds and therefore early if not premature discharge. In theory it would be helpful to educate carers and

they have said that they want this (Hale, 2002) but that it is not clear whether this would make any difference to quality of life or long-term outcome.

## **1.2 Problem Statement**

Caregivers are playing a more and more significant role in not only the prevention of another stroke event by encouraging improvements in lifestyle risk factors such as diet and smoking, ensuring adherence to medication and clinic attendance among other measures, but also by helping stroke survivors cope with the resultant impairment, which consequently positively affects their quality of life and preventing complications of stroke such as pressure sores, urinary tract infections. The preparedness of caregivers for the care-giving role for stroke survivors in Soweto was shown to be inadequate (Hale, 2002).

The impact of a structured and focused caregiver education might have on stroke survivors and their caregivers remains largely unknown in South Africa and Sub-Saharan Africa. Some studies done in high-income countries (Blake et al., 2003; Bugge et al., 1999; Lincoln et al., 2003; Mant et al., 2000; Rodgers et al., 2001) only investigated the role of caregivers in stroke survivors without 'tailor made' caregiver training. Only one study examined tailored 'hands-on' training of caregivers (Kalra et al., 2004 and Patel et al., 2004) but we cannot extrapolate the results as suitable for Africa. This is mainly because there are social and cultural differences which in turn inform the medical/health phenomena; making it difficult to superimpose research findings from high-income countries onto low- and middle-income countries (Gallagher-Thompson et al., 2000). Friends and relatives (carers) may provide well meaning but incorrect information to the patient (Rosman, 1987) emphasising the need for proper training of carers in looking after the stroke survivor.

The methods of providing information to patients with stroke and carers being used in the clinical setting are inadequate (Rodgers et al., 2001). The existing support structures for care given in Sub-Saharan Africa (South Africa included) are also largely unexplored. Hale (2002) pointed out the need for a different service delivery approach for patients with stroke at CHBH, one that would provide acute in-patient care followed by a supportive home programme. This study hopes to try out one such approach by having tailored 'hands-on' training of the caregivers, in order to explore how good a method this is to best utilise the caregivers to get optimal rehabilitation outcomes following a stroke with less strain on the caregivers. It is quite clear from the literature that how best to utilise caregivers without overstraining them remains a challenge not just for South Africa but also throughout the whole



world. Though Hale's 2002 study investigated the long-term outcome of stroke survivors and showed several problems for both the survivors and the carers, the study did not include the education of caregivers during patients' hospitalisation. This study hopes to assess the impact of a structured tailored 'hands-on' caregiver education programme (individualised to the needs of each patient and caregiver) on both the stroke survivors and their carers.

### **1.3 Aim of the Study**

To establish the impact of caregiver education on the morbidity of stroke survivors and on the quality of life of the stroke survivors and their caregivers.

#### **1.3.1 Objectives of the study:**

- To establish what physiotherapy caregiver education programmes and associated content was in use for managing patients with stroke at Chris Hani Baragwanath hospital.
- To establish the effect caregiver education has on mobility of the stroke survivors:

This included establishing the effect of caregiver education on the stroke survivor's:

- bed mobility
- sitting to standing
- transfers
- stair climbing and descending (when possible/safe)
- walking on even ground
- walking on uneven ground (when possible/safe)
- running (when possible/safe)

- To establish the effect caregiver education has on the quality of life of the stroke survivors:

This included establishing the effect of caregiver education on the stroke survivor's assessment of their:

- general mobility

- general self care ability
- ability to carry out day to day activities
- pain or discomfort
- anxiety or depression
- where applicable, rating of their perceived state of health on a visual analogue scale of 0 to 100.

This included establishing the effect of caregiver education on the patients' perceived health related quality of life

- To establish the effect caregiver education has on the quality of life of the caregivers:

This included establishing the effect of caregiver education on the caregivers':

- general mobility
- general self care ability
- ability to carry out day to day activities
- pain or discomfort
- anxiety or depression
- where applicable, rating of one's perceived state of health on a visual analogue scale of 0 to 100.

This included establishing the effect of caregiver education on the caregiver's perceived health related quality of life

- To establish the effect caregiver education has on the ability of the stroke survivor to socialise and participate in community issues:

This included establishing the stroke survivor's:

- extent of general participation restriction
- extent of general activity limitation
- extent of personal relationships and interactions limitation
- extent of community, social and civic life activity limitation

and establishing how these are impacted on.

- To establish patient characteristics associated with caregiver strain following a stroke:

This included:

- documenting the stroke survivor 's degree of dependence or independence in:
  - bowel and bladder management
  - grooming
  - toilet use
  - feeding
  - transfer
  - mobility
  - bathing
  - dressing
- establishing the stroke survivor 's stroke subtype
- establishing the stroke survivor 's affected hemisphere

and establishing whether these factors were associated with caregiver strain.

- To establish caregiver characteristics associated with caregiver strain following a stroke

This included documenting:

- amount of time spent care giving
- amount of help received from relatives
- financial independence of caregiver
- level of education of the caregiver
- gender of caregiver
- age of caregiver
- type of accommodation used (own house or renting)

and establishing whether any of these factors were associated with caregiver strain.

## **1.4 Significance of Study**

Resources for rehabilitation are limited in the public health care system in South Africa and as such the need for effective and inexpensive realistic rehabilitation programmes aimed at improving the quality of

life and community integration of stroke survivors cannot be overemphasised (Hale et al., 1998). Caregiver participation in the post hospitalisation era of stroke survivors plays a crucial role in their ability to deal with the resultant disability and impairment. Programmes that provide caregiver education on stroke recovery, the adjustment process, physical assistant skills, and community resources should be in place during the entire rehabilitation process (Flick, 1999).

The long-term outcome of stroke survivors in Soweto (South Africa) is plagued by shoulder pain, mobility problems, lack of knowledge on stroke, poor financial status and a general dependency (Hale, 2002). The impact of an enhanced and structured caregiver education might have on stroke survivors and the caregivers in a low resourced urban setting like Soweto remains largely unknown. This study aimed to assess whether a programme of education for caregivers improves outcome for stroke survivors and caregivers, and hopefully provide information that could be used to improve the quality of lives of both the stroke survivors and the caregivers elsewhere.

At the present time, there is no “best practice” for the rehabilitation needs of stroke survivors in South Africa as shown by the divergent views by stroke experts in the country on how to manage stroke survivors (Hale 2002). Although this study will not produce a best practice method for physiotherapy in the management of patients with stroke, it is hoped that it will also contribute towards the establishment of best practice guidelines for the training of caregivers of stroke survivors in the country.

### **1.5 General Outline of the Thesis:**

The general outline of the thesis is outlined below:

Chapter 2: Literature Review

Chapter 3: Instrumentation and Outcome Measures

Chapter 4: Methodology

Chapter 5: Results

Chapter 6: Discussion

Chapter 6: Conclusion and recommendations

## **CHAPTER 2**

### **2. LITERATURE REVIEW**

#### **2.1 Introduction**

Despite the improvements that have been made in health care, stroke remains a serious public health problem in low, middle and high-income countries. The role played by caregivers in stroke survivors has of late received tremendous attention and is well documented in high-income regions (Johansson et al., 2003; Smith et al., 2004b; Visser-Meilly et al., 2005; Ski and O'Connell, 2007). Despite there being considerable literature, there is very little (if any at all) evidence from low and middle-income countries, in Africa as a continent and in particular in South Africa, regarding the welfare of caregivers post-stroke. Though inferences can be made from the available literature (mainly from high income countries) these inferences are of limited value as it has been shown that even within the same geographical block (in this case Europe), there can exist differences as regards risk of stroke and death from stroke (Wolfe et al., 2000). Stroke continues to be among the leading causes of the global burden of disease and accounts for a large percentage of disability seen worldwide and even among black people in South Africa. As stated by Connor et al. (2004), more than 60% of stroke survivors will need help with activities of daily living when at home and this help is mostly provided by informal caregivers (Dewey et al., 2002). The training and education of caregivers on how best to look after the stroke survivors to positively impact on their quality of life (both the stroke survivor and the carer) thus becomes very important.

This section of the thesis describes the literature that helped give an in depth view of the study objectives. The aim of this review is to describe the magnitude of the problem of stroke, its influence on stroke survivors and their carers and the role of rehabilitation and caregiver education in all this. To help with this endeavour literature was sought using search engines that included the Cochrane Database, Pubmed, Medline, the Cirrie website, the Pedro Database and hand searching journals.

A brief explanation is given on the definition of stroke followed by the prevalence and incidence of stroke to help shed light on the magnitude of the problems of stroke. A brief review of the risk factors associated with subsequent stroke episodes is outlined, as this was deemed important in the population being studied. The study involved stroke survivors who are still at risk of having another stroke episode and hence those factors likely to contribute towards another episode are explored in the review. HIV

and poverty have also been closely linked with stroke events and hence these are touched on in the review. The study population comprised of stroke survivors and their carers from Soweto (Johannesburg, South Africa) whose majority of inhabitants belong to a low socioeconomic bracket, which again justifies the review of literature on poverty and stroke.

The different stroke types and subtypes have been shown to result in different mortality and morbidity outcomes. With this in mind, a brief review was done on the stroke types and subtypes including their influence on functional outcomes. The consequences of stroke that is, its mortality, morbidity and socioeconomic consequences (including effect on health related quality of life) are also described. One effective way to negate these effects is rehabilitation, which includes physiotherapy. With this in mind, a review on the impact of rehabilitation with specific reference to the impact on health related quality of life was done. Working closely with the rehabilitation personnel and quite crucial to the post-stroke survival of the stroke victim are the caregivers, as such, the role of the caregivers post-stroke is discussed.

During the care giving process, there is a certain amount of associated. This was also reviewed with particular attention being paid to the factors that have been shown to be associated with an increased burden of care giving. For effective care giving, one can only assume that the caregivers need education on what needs to be done when at home with the stroke survivor. The role of physiotherapists in this endeavour is thus also explored in the review.

## **2.2 Definition of Stroke**

The World Health Organisation (WHO) defines stroke as “rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death with no apparent cause other than of vascular origin” (WHO MONICA Project, 1988). de Jong et al. (2003) also used the same definition in their study that described stroke subtypes and mortality. For the purposes of this study, the WHO definition was adopted since it is also in line with the stroke clinical definition used in South African hospitals (South African Medical Association, 2000). Because there should be vascular involvement for a diagnosis of stroke to be made, stroke can also be called a cerebrovascular accident.

## 2.3 Prevalence and Incidence of Stroke.

Stroke prevalence studies are very difficult to do and most of the ones that are done have inaccuracies as they may fail to identify those patients who die and those who recover completely (Connor and Bryer, 2005; Bonita et al., 1997). Stroke was considered to be the sixth leading cause of death in 1997 (Murray and Lopez, 1997) but is now thought to be the fourth leading cause of the global burden of disease (Lopez et al., 2006a). An age standardised stroke prevalence of 833 per 100 000 people was established in New Zealand (Bonita et al., 1997), 100 per 100 000 people in France, 124 per 100 000 in the United Kingdom and 136 per 100 000 people in Germany (Wolfe et al., 2000). In the United States of America, approximately 700 000 Americans have a new or recurrent stroke each year (American Heart Association, 2003).

It was however interesting to note that the study by Lopez et al. (2006a) did not have stroke in the top ten causes of burden of disease for sub-Saharan Africa. The top ten causes of mortality for sub-Saharan Africa largely included poverty related diseases such as malaria, diarrhoeal disease, tuberculosis and protein-energy malnutrition (Lopez et al., 2006a). The absence of stroke in the top ten causes of the burden of disease could have been brought about because of the poor data systems existent in most sub-Saharan countries, particularly for causes of death (Lopez et al., 2006a). It could also be because sub-Saharan Africa is currently undergoing an epidemiological transition with aging of the population and increasing exposure to lifestyle risk factors and consequent non-communicable, particularly vascular, disease (Connor, 2007). In South Africa, stroke is believed to be among the top four causes of death (Bradshaw et al., 2002).

Most studies related to stroke in sub-Saharan Africa are hospital based, with a large number of them being retrospective case-note reviews and this creates a dearth of literature on the incidence, prevalence or outcome of stroke (Walker, 1994). A recent study in South Africa found a high prevalence of hypertension and postulated that South Africa is facing the challenge of an emerging epidemic of vascular disease (Thorogood et al., 2007).

The average age of patients affected by stroke was found to be 70 years in men and 75 years in women with more than half of all strokes occurring in people over 75 years (Feigin et al., 2003). Feigin et al.'s 2003 study was a review of population-based studies of incidence, prevalence, mortality and case fatality of stroke and included countries from the Americas, Europe, Asia and Australia. In Chile, stroke affects mainly the elderly with the mean age for patients with stroke being around 66.4 years

(Lavados et al., 2007). The results from these studies are different from those in Africa and South Africa in particular. The average age for those patients who sustained a stroke is younger than 50 years of age in sub-Saharan Africa (Seedat, 2006). A study done in Gambia (Africa) found that the mean age of patients with stroke was 58 years, which was about 10-15 years younger than patients with stroke in developed countries (Walker et al., 2003). A current review of available data seem to suggest that the prevalence of stroke in sub-Saharan Africa is less than half that found in high-income countries (Connor et al., 2007a). Connor et al. (2007a) in a systematic review of studies done in sub-Saharan Africa looking at stroke mortality, prevalence, incidence and case fatality, showed that the prevalence of stroke in sub-Saharan Africa was less than half that found in high-income regions but disabling stroke prevalence could be as high as in high-income countries. The lack of community based incidence studies in sub-Saharan Africa means that the incidence of stroke in sub-Saharan Africa remains largely unknown (Feigin et al., 2003).

Lemogoum et al. (2005) state that stroke is an emerging leading cause of preventable death and disability in adults in sub-Saharan Africa. In an editorial, Seedat (2006) also agrees that stroke from hypertension remains a major public health problem in sub-Saharan Africa. To add weight to this, Mathers and Loncar (2006), project that stroke will be the third leading cause of death in low-income countries by the year 2030.

Stroke has also been shown to be among the top ten leading causes of disability worldwide (Murray and Lopez, 1997) and amongst black people in South Africa (Disler et al, 1986). It is believed to be among the top four causes of death in South Africa (Bradshaw et al., 2002b) and in most societies (Lopez et al., 2006a). Wolfe et al. (2002) found that blacks are at a greater risk of stroke than whites are. Wolfe et al. (2002)'s study was done in South London (United Kingdom). The study established that the black population was at increased risk of stroke and most subtypes of stroke but these did not result in significant differences in survival. The authors acknowledge that the reasons for the differences in risk between the two populations (white and black) are unclear but point out that differences in socioeconomic status seemed to play a significant independent part. Along similar lines, Lawrence et al.'s 2001 study also showed that blacks had higher age and sex-adjusted rates of disability in ischaemic stroke but had impairment rates similar to those of whites. Their study however did not provide any explanation for the trends observed.

There appear to be gender differences in the prevalence of stroke in some studies. Boix et al. (2006) found that more women who are Spanish suffered from stroke than men despite there being more men



in the study population. In contrast, a study done in New Zealand found that stroke affected more men than women and was seen to have an overall prevalence rate of 4.6 per 1000 people (of those who made an incomplete recovery) (Bonita et al., 1997). These findings were strengthened by Appelros et al. (2009) who from a review of studies from five continents found that stroke is 33% more likely to occur in males than in females and was 41% more prevalent among men than women. It was however interesting to note that the study by Connor et al. (2004) in a rural area in South Africa did not find any differences in the prevalence between males and females after age standardisation. The reasons for the lower rates of stroke in women than men include possible genetic differences, the positive effects of oestrogen on cerebral circulation in females (Krause et al., 2006) and the lower blood pressure values persistent in women (Wiinberg et al., 1995).

## **2.4 Risk Factors for Stroke**

The main risk factors for stroke are known and agreed upon world over. This section discusses the importance of these risk factors when someone already has a stroke (risk for a secondary stroke). A significant number of people (between 7 and 16%) have a recurrence of stroke within one year of the initial stroke and the number increases with time (Fukuda et al., 2009; Hankey et al., 1998). Risk factors for stroke fall into two main categories, modifiable and non-modifiable risk factors. The conventional or non-modifiable risk factors include age, gender, family history, socioeconomic status and race and those that can be influenced include hypertension, diabetes mellitus, atrial fibrillation, smoking, hypercholesterolaemia, excessive alcohol intake, obesity, physical inactivity and prothrombotic factors (Warlow et al., 2001). The most common risk factor for stroke world over seems to be hypertension. It was found to be the commonest risk factor for stroke in India (62%) followed by diabetes (38%) and smoking (28%) (Kaul et al., 2000). Similar trends were found by Ng et al. (2007) who established that hypertension was the commonest risk factor at 70.6%, with diabetes mellitus accounting for 19.7%.

At least 7% of all patients with a history of a transient ischaemic attack (TIA) or stroke will have a recurrent event each year (Carter et al., 2007; Hankey and Warlow, 1999). Hankey et al. (2002) and Dennis et al. (1990) established stroke or TIA to be the most important risk factors for recurrent stroke resulting in about 30% of the people who have had a stroke having another stroke within five years, with half of the strokes occurring within six months to a year of the initial stroke event. This figure could be higher in sub-Saharan Africa where accessibility of health services and antihypertensive drugs in particular remain an enormous challenge (Thorogood et al., 2007)

In South Africa, hypertension (55%) was confirmed to be the commonest risk factor and it was highest in the black population (Connor et al., 2005). In a more recent paper, Thorogood et al. (2007) also confirmed that there is a high prevalence of hypertension (42%) in a rural South African population while Hoffman (1998) established a prevalence of 31% for hypertension and 19% for smoking. It is believed that the increasing level of urbanisation among black people predisposes them to the development of hypertension (Steyn et al., 1991). By virtue of hypertension being found to be the most important risk factor, the presence of hypertension after a stroke becomes a major concern in stroke survivors. Patients with stroke thus need to have their blood pressure checked regularly and they should be consistently taking their medication. However as stated by Walker (1994) and Thorogood et al. (2007), compliance with antihypertensive treatment in Africa is a major problem. If there is poor compliance with prescribed medicine, this can predispose the patients with stroke to another stroke, which can result in either more disability or death. The World Health Organisation (WHO) acknowledges that the majority of deaths as a result of stroke occur in developing countries (WHO, 2002).

de Jong et al. (2003) found that diabetes, advanced age and stroke subtype are independent predictors of 30-day case fatalities. Lavados et al. (2007) describe hypertension as being the commonest risk factor for stroke. A large number of patients with stroke and with hypertension as the causative agent still have high blood pressure showing low levels of secondary prevention (Connor et al., 2007a).

The influence of race on stroke occurrence is well-documented world over. There is a higher stroke risk in black people than in white people (Heuschmann et al., 2008). This followed a study done in the United Kingdom where stroke statistics between 1995 and 2004 were analysed. Black people are at an increased risk of stroke and this translates into differences in mortality between whites and blacks (Wolfe et al., 2002). Wolfe et al.'s 2002 study was done in an area populated with predominantly black people in London. Lemogoun et al. (2005) goes further to say that the emerging stroke epidemic in sub-Saharan Africa and other developing countries is a consequence of the adoption of poor lifestyles such as an unhealthy diet, tobacco use and sedentary habits that are largely fuelled by urbanisation, globalisation and industrialisation.

In South Africa, there are clear differences in the distribution of the risk factors between races. As stated by Connor et al. (2005), hypertension is commonest in the black population (59%) while dyslipidaemia (37%) is more common among the white population who are ten times more likely to have dyslipidaemia than blacks are. Smoking is found to be much higher among the mixed race

population (44%) and the white population (42%) than the black population (21%). Despite these results having limitations in terms of the sampling methods employed (acknowledged by the authors) which included the sample not being representative in a statistical sense, it does give real insight into the distribution of risk factors for first time stroke and also recurrent stroke in South Africa. The other risk factors that were found to be associated with stroke include diabetes mellitus (12%), cigarette smoking (9%) and alcohol use (20%) (Connor et al., 2004). Similar results were also found in other studies that showed that the other stroke risk factors include diabetes mellitus (3 – 10%), cigarette smoking (15 – 28%) previous stroke or transient ischaemic attack (2 – 7%) (Rosman, 1986; Joubert, 1991).

In their review titled “New Evidence for Stroke Prevention” Straus et al. (2002) state that the secondary prevention strategies are antihypertensive therapy, use of statins (for cholesterol), warfarin (for non-rheumatic atrial fibrillation), antiplatelet therapy, carotid endarterectomy (for stenosis) and cessation of smoking. Among the secondary prevention strategies mentioned here, it is worth noting that the importance of maintaining physical activity was not mentioned. Physical activity has been seen to help reduce blood pressure and thus can be a very useful method of preventing another stroke (Sharman and Stowasser, 2009; Fagard and Cornelissen, 2007; Asmar et al., 2007; Wolf et al., 1999). Engaging in physical activity and dietary change can help lower future risk of stroke and is related to better health related quality of life among people with stroke (Greenlund et al., 2002).

In South Africa, treatment at community clinics including drug prescription are free but despite this the majority of people with high blood pressure (75.8%) are not on any treatment (Thorogood et al., 2007). This obviously puts these people at great risk of sustaining a stroke. Some of the reasons why such a high number of people are not getting and taking their antihypertensive medication from clinics include difficulties with people getting to clinics (transport issues), difficulties with drug supplies as well as problems with equipment within the clinics (SASPI Team, 2004; Khan et al., 2005). As stated by Hale et al. (1998), prevention of hypertension is of paramount importance in South Africa and hence one of the crucial roles of primary health care in the prevention of stroke is therefore education.

### **2.4.1 Poverty and Stroke**

In their editorial titled: “Stroke prevention in poor countries; Time for action”, Bonita and Beaglehole (2007) state that stroke is a cause of poverty and that stroke is caused by poverty. This statement is relevant given the fact that following stroke there can be loss of productivity, which can be a precursor

to poverty. On the other hand, the presence of poverty precipitates the risk factors for stroke thus facilitating stroke development. There is much research that has shown that people with a low socioeconomic status experience higher stroke mortality than those with a high socioeconomic status (Jakovljevic et al., 2001; Lostao et al., 2001; Hart et al., 2000; Smith et al., 1998; Kunst et al., 1998).

Logie (1993) succinctly stated that the more economically people are advantaged, the healthier they are and that the narrower the gap between rich and the poor, the better the health of the whole population. The socioeconomic status was found to be a significant factor in the difference in prevalence of untreated hypertension between blacks and whites in the United States of America (Bell et al., 2004). One of the most talked about issues in the last two to three decades is market oriented health sector reform where user fees are charged. As stated by Whitehead et al. (2001), the introduction of user fees (as requested by the World Bank as a condition for developing countries to access loans) for public services and the growth of out of pocket expenses such as transport costs can constitute a major economic trap especially for middle-income and low-income countries. Whitehead et al. (2001) accurately argue that the introduction of user fees affects the poorest of the poor the most. The ordinary assumption in this case would be that patients with stroke who are poor are not able to access the health care system timeously and hence may need help with activities of daily living much more than if they had received proper medical and rehabilitation care.

It is largely agreed that poverty results in ill health (Parmely, 2000; Morris, 1986; Shaw and Griffin, 1995; Bonita and Beaglehole, 2007). Unfortunately, patients with conditions such as stroke are the ones that are hit hardest. As stated by Bonita and Beaglehole (2007), the poor found in mainly low- and middle-income countries are increasingly affected by stroke because of changing population exposures to risk factors and most importantly due to the high costs of medical care involved. They go on to state that the costs of on-going rehabilitation and care that is largely undertaken by family members, further impoverishes the family. This agrees with Bravata et al.'s 2005 statement that socioeconomic status may influence not only stroke incidence but outcome as well.

The risk factors for stroke are the same for low-income, middle-income and high-income countries and as such, the methods of stroke prevention can be generic. However, poverty associated constraints particularly in low-income countries, need to be taken into consideration. If the response to stroke and other chronic diseases is not scaled up in low- and middle-income countries, the health and economic consequences of stroke will continue to devastate the poor (Bonita and Beagleton 2007). Though South Africa is considered to be a middle-income country, it is rated amongst those countries with the most

extreme disparities in wealth in the world with 52% of households living in poverty in 1996 (Bradsaw and Steyn, 2001).

In the rural areas, admission following stroke depends on the severity of the stroke, the more severe the stroke, the better the chances of being admitted (Poungvarin,1998). However the current pressure for beds and the ever escalating hospital costs (Putterill et al., 1984b; Anderson et al., 1995) has seen the number of hospitalisation days coming down from a mean of 14 days in 1998 (Hale et al.,1998) to around seven days for patients with medical conditions in 2002 (Reid et al., 2005). This further affects outcome in patients with poor socioeconomic backgrounds. Socioeconomic status affects outcome independently of stroke severity (Zhou et al., 2006; Arrich et al., 2005).

In addition to the increased risk for stroke associated with low socioeconomic status, persons with low socioeconomic status have excess rates of morbidity and mortality following stroke (Jakovljevic et al., 2001). This is further strengthened by Weir et al. (2005)'s finding that there is an inverse gradient in disability after stroke, with patients from the most deprived areas significantly more likely to be dead or dependent than patients from affluent areas

#### **2.4.2 HIV/AIDS and Stroke**

HIV/AIDS was established as the fourth leading cause of the burden of disease globally in 2001 and was the leading cause in sub-Saharan Africa (Lopez et al., 2006b). It is well known that HIV/AIDS has decimated sub-Saharan Africa. Despite sub-Saharan Africa comprising only 10% of the world's population, it contains nearly two-thirds of all people living with HIV/AIDS (UNAIDS, 2008). The prevalence of HIV among adult medical hospital admissions in South Africa was found to have jumped from 4% to 35% over a twelve-year period affecting health services at various levels (Reid et al., 2005). The same study also found that the average length of hospital stay decreased by 28% over the same study period while there was not a corresponding increase in the number of medical beds or medical and nursing staffing levels. The study found the average hospital length of stay of patients was 7.7 days among adult medical hospital admissions.

Increased HIV infections may result in patients with other conditions receiving inadequate care as patients compete for scarce resources (Abegunde et al., 2007, Colvin et al., 2001). This may also be true for those patients admitted to hospital with stroke. The reduced hospital length of stay may mean

that patients now have very little time to receive rehabilitation (including physiotherapy), and hence may be discharged home in a very dependent state.

The HIV pandemic has created an atypical picture for most commonly known neurological problems, stroke included. HIV has been established as an independent risk factor for stroke (Cole et al., 2004). Cole et al. (2004) state that HIV/AIDS accounts for an adjusted relative risk of 13.7 (95% confidence interval [CI], 6.1 to 30.8) for ischaemic stroke and 25.5 (95% CI, 11.2 to 58.0) for intracerebral haemorrhage. This has seen, for example, stroke moving from being largely an adult disease to being a disease of the young as well. The erratic recovery that is associated with HIV/AIDS and stroke has also changed the complexion of stroke as we used to know it.

Despite reported increases of young HIV positive patients with stroke by clinicians, there are no real statistics about the influence of HIV/AIDS on stroke in South Africa (Connor and Bryer, 2005). The impact of HIV/AIDS is greatest in young adults which may be the reason why only 2% of patients with stroke in the SASPI stroke prevalence study were suspected of being HIV positive (Connor et al., 2004).

The full impact of HIV/AIDS on stroke is still to be fully established, not just in South Africa but world over. What makes this a critical issue for South Africa is that it is a country where there is a high prevalence of HIV/AIDS, in fact the largest epidemic in the world with an estimated 5.7 million people living with HIV (UNAIDS, 2008). This high number of people living with HIV/AIDS means that many families will lose their parents. Southern Africa accounted for 38% of all the AIDS deaths in 2007 (UNAIDS, 2008). This sees grandparents playing parental roles and may add further stress to their already fragile bodies due to ageing. This is the age group that has the greatest risk for stroke and vascular disease and this further compounds the situation (Connor and Bryer, 2005). Another aspect that is worth mentioning is that some of the caregivers might have HIV/AIDS themselves and that on its own is an added stress (Black et al., 1994).

## **2.5 Classification of Stroke**

Stroke generally is a syndrome that presents with various pathological conditions that are not very easy to distinguish clinically (Allen, 1983). Lawlor et al. (2002) concur that there are uncertainties in the diagnosis of stroke subtypes, which could actually affect the available statistics on stroke deaths. Understanding the various stroke subtypes is very important for a country like South Africa, which can

be considered to be undergoing a health transition. Stroke subtypes change with time (Connor and Bryer, 2005) and this has implications as regards management strategies and resource allocation. The understanding of stroke subtypes is also important to help explain the expected recovery patterns for patients following stroke.

There are two main types of stroke, namely haemorrhagic and ischaemic stroke. Haemorrhagic stroke accounts for 15 – 20% while ischaemic stroke accounts for 80 – 85% of all strokes (Elkind, 2003). However Tsiskaridze et al. (2004) found that there were more patients with haemorrhagic than ischaemic stroke in Georgia and thought that geographical and lifestyle variations could help explain the differences in the ratios of the two stroke types that were noted.

The proportion of strokes in sub-Saharan Africa is higher than in high-income regions but it has not been shown whether cerebral haemorrhage or haemorrhagic stroke outnumbers ischaemic stroke. (Connor et al., 2009; Connor, 2007; Walker et al., 2003; Wiredu and Nyame, 2001). However hypertension is the commonest risk factor and this is believed to be because there is less risk of dyslipidaemia in sub-Saharan Africa compared to hypertension (Connor et al., 2005; Thorogood et al, 2007).

Haemorrhagic stroke can further be subdivided into intracerebral and subarachnoid haemorrhage. However, for the purposes of this study, the focus will mainly be on the ischaemic stroke subtypes and not the haemorrhagic subtypes. Distinguishing between an ischaemic and a haemorrhagic stroke with accuracy requires either a Magnetic Resonance Image (MRI) or a Computerised Tomography (CT) scan. Ischaemic stroke can be classified by clinical ischaemic stroke subtype or into aetiopathological types. The two that are commonly used the world over are the Trial of ORG 10172 in Acute Stroke Treatment (TOAST) criteria and the Oxfordshire Community Stroke Project (OCSP).

These two classification systems have many similarities but the main difference is that TOAST (Adams et al., 1993) uses aetiology as the basis for classification while OCSP (Bamford et al., 1991) uses clinical presentation as the basis for classification.

### **a) The Trial of ORG 10172 in Acute Stroke Treatment (TOAST) Classification System**

This system was first described by Adams et al. (1993) and uses five main categories for the classification of ischaemic stroke, namely large artery atherosclerosis, cardioembolism, small vessel occlusion, stroke of other determined aetiology and stroke of undetermined aetiology. They found it to be easy to use and also to have good interobserver agreement. It should however be noted that the TOAST is an expensive and extensive investigation which is seldom used available in low resourced areas like the ones we have in public hospitals in sub-Saharan Africa and in particular South Africa (Connor et al., 2009; Connor, 2007). This classification system will not be discussed in detail since it was not useful for this study.

### **b) The Oxfordshire Community Stroke Project (OCSP) Classification System**

Bamford et al. (1991) suggested this system of classification. This was after they assessed 675 cases of first ever stroke encountered over five years. This system was seen to have good interobserver reliability (Bamford et al., 1991). The patient's clinical history and physical examination findings play an important role in the classification process. The classification system uses four main subtypes to classify stroke syndromes. When the stroke is confirmed an infarct the terms are used to classify ischaemic stroke subtypes. . The four subtypes are:

#### **i) Lacunar Circulation Syndrome/Infarcts (LACI)**

Lacunar infarcts are small, deep, not cortical, infarcts usually within the distribution of a small, perforating artery. The signs and symptoms include:

- Pure motor stroke
- pure sensory stroke
- Sensorimotor
- or less commonly
- ataxic hemiparesis
- isolated dysarthria
- clumsy hand syndrome

(Bamford et al., 1991)



However, it is important to note that for it to be diagnosed as a lacunar infarct, there should not be an accompanying aphasia, neglect or visual impairment, that is cortical signs (Aerden et al., 2004).

## **ii) Posterior Circulation Syndrome/Infarcts (POCI)**

This is confirmed by definite brain stem signs, which include:

- ipsilateral cranial nerve palsy with contralateral motor and/or sensory deficit
- bilateral motor and/or sensory deficit
- disorder of conjugate eye movement
- cerebellar dysfunction without ipsilateral long tract deficit (i.e. ataxic hemiparesis)
- isolated homonymous visual field defect
- homonymous hemianopia

(Bamford et al., 1991)

This stroke subtype always occurs without aphasia, neglect, loss of consciousness and visual field defects or other higher cortical functions signs. It usually has an overall good functional outcome.

## **iii) Total Anterior Circulation Syndrome/Infarcts (TACI)**

This is confirmed by the presence all of the following:

- hemiparesis and hemi-sensory loss (motor and sensory loss of at least two areas of the face, arm and leg)
- homonymous hemianopia
- cortical dysfunction such as neglect (visual-spatial disorder), dysphasia

With this subtype, there is a negligible chance of a good functional outcome (Lawrence et al., 2001; Bamford et al., 1991) and there can be high mortality rates (Carter et al., 2007; Lawrence et al., 2001). It occurs as a result of occlusion of the internal carotid artery or main-stem middle cerebral artery affecting both the deep and superficial territories. Total anterior infarction can usually assumed if the level of consciousness is impaired and testing of higher cerebral function and visual fields is therefore impossible (Bamford et al., 1991).

#### **iv) Partial Anterior Circulation Syndrome/Infarcts (PACI)**

This type of lesion results from more restricted cortical infarcts due to occlusion of the upper division of the middle cerebral artery (when there is usually no visual field deficit) and the lower division of the middle cerebral artery (when the motor/sensory deficit is often negligible) in addition to individual branch occlusions.

Partial anterior circulation infarction is implicated if there are:

- any two of the three components of the TACI syndrome
- higher cerebral dysfunction alone
- motor/sensory deficit more restricted than those classified as LACI e.g. confined to one limb, or to face and hand but not to the whole arm.

(Bamford et al., 1991).

Patients with partial anterior circulation infarction usually have a prognosis intermediate between those with total anterior circulation infarcts (worse) and those with lacunar infarcts (better). (Bamford et al., 1991).

The OCSF received support from some authors (Pittock et al., 2003; Aerden et al., 2004). Pittock et al. (2003) stated that it was easy to apply without specialist neurologic training. This means that as long as one works in the medical field and is familiar with the presentation of patients with stroke, one can easily learn how to classify patients using this classification system. It is however still important to have a computerised tomography (CT) or magnetic resonance imaging (MRI) scan to confirm the pathology of stroke before any classification can be done. However Aerden et al. (2004) pointed out that the OCSF assessment was problematic in critically ill patients since the ability to isolate the affected body parts with accuracy is largely diminished. The assessment is difficult with scanning the only option and prognosis is dependent on the critical illness rather than the stroke.

As already highlighted, stroke subtypes have an influence on outcome post-stroke. In addition, the actual stroke types also have an important influence on outcome following stroke and this is explained in detail in the next section.

## 2.5.1 Functional Outcome for Ischaemic and Haemorrhagic Strokes

Haemorrhagic strokes are associated with a higher risk of fatality than cerebral infarction strokes (Andersen et al., 2009; Bamford et al., 1990; Caplan, 1992; Qureshi et al., 2001). However as established by Paolucci et al. (2003), patients who survive with intracerebral haemorrhage may have a better prognosis if there are no other powerful mitigating prognostic factors. This better neurological and functional prognosis is believed to be due to better neurological recovery (Paolucci et al., 2003), probably as the haematoma resolves. Paolucci et al. (2003) cautioned against generalisation of their findings as their study was not population based. The increased risk of fatality from haemorrhagic stroke is time-dependent with the risk disappearing three months post-stroke (Andersen et al., 2009)

Bamford et al. (1990) also established that cerebral infarction results in better survival rates but less functional ability when compared with haemorrhagic stroke. Their study established that one year post-stroke, 23% of those with cerebral infarction were dead and 65% of the survivors were functionally independent. For intracerebral haemorrhage 62% were dead and 68% of the survivors were functionally independent while for subarachnoid haemorrhage 48% were dead and 76% of the survivors were functionally independent. These figures clearly show higher deaths rates among patients with stroke from haemorrhage compared to those from an infarction but also better functional outcomes from those who survive the haemorrhagic stroke. This could be due to the extent of associated brain damage, which in a survivable haemorrhage is probably less than that in an ischaemic stroke with a similar presentation at onset.

Similar results to those by Bamford et al. (1990) were established by Kelly et al. (2003). Their study comprising 1064 cases with the majority of the cases having cerebral infarction (871) established that patients with cerebral infarction had better functional abilities (better Functional Independence Measure scores) at admission than those with haemorrhagic stroke. They however established that, in the long term, patients with haemorrhagic stroke made significantly better recovery than those with cerebral infarction even though the patients had the same severity when looking at the resulting disability from stroke at admission. The sample size for patients with haemorrhagic stroke was smaller compared to that for cerebral infarction.

It is therefore clear that mortality rates are higher following haemorrhagic stroke than ischaemic stroke in the short term but prognosis is better following haemorrhagic stroke than ischaemic stroke in the long

term. In addition to these specific outcomes for the main stroke subtypes, there are general consequences of stroke, which are presented in the following section.

## **2.6 Consequences of Stroke**

Following stroke, there are many consequences that manifest and these include mortality, morbidity and socioeconomic. Chronic diseases, stroke included, are on the rise and they have a substantial effect on health and economic welfare (Abegunde et al., 2007). The consequences of stroke will be felt hardest in low-income and middle-income countries because they are the least able to deal with a health related setback to development (Abegunde et al., 2007). The general effects of stroke are reviewed below.

### **2.6.1 Mortality, Case Fatality and Morbidity Consequences from Stroke**

Following stroke, survival is the most important outcome. It is however well documented that stroke results in high mortality and morbidity. The mortality and morbidity rates vary from continent to continent, from region to region and from country to country (Ali et al., 2009; Wolfe et al., 2000). For example, stroke mortality is approximately five times higher in Eastern Europe when compared with Western Europe (Stegmayr et al., 2000). Stroke is considered the third most common cause of death in the United Kingdom (Wolfe, 2000). It should however be noted there has been a general decrease in mortality trends in some of the high-income countries (Goldacre et al., 2008; Rothwell et al., 2004). Goldacre et al. (2008) report that stroke mortality in England halved between 1979 and 2004. The decrease in mortality rates is attributed to stroke prevention strategies and stroke care, as well as falling stroke incidence as demonstrated in the Oxford vascular study (Rothwell et al., 2004). They however caution that data on stroke mortality is still strewn with inaccuracies especially if stroke is considered as only the underlying cause of death, which grossly underestimates the population "burden" of stroke as a cause of death. Harmsen et al.'s 2009 study in Sweden however found no recent change in stroke incidence and mortality when they studied data compiled between 1987 and 2006 though this study was based on registration data rather than on data from an 'ideal' community based stroke incidence as in the Oxford study.

It has been established that age-adjusted stroke mortality in adults in sub-Saharan Africa seems to be similar to that in high-income countries (Connor et al., 2007b). As stated by Connor et al. (2007), the lack of accurate longitudinal data from the various regions within the sub-Saharan block remains a

challenge for the production of accurate data on mortality in sub-Saharan Africa. Stroke is believed to be the fifth leading cause of death in both low- and middle-income countries and high-income countries in adults between the ages of 15 and 59 years (Mathers et al., 2006). The same study established stroke as a distant seventh leading cause of death in sub-Saharan Africa with HIV/AIDS being the leading cause of death. Overall, when all age groups are considered, stroke is the second commonest cause of death in both low- and middle-income countries and high-income countries (Mathers et al., 2006; Lopez et al., 2006b).

Stroke is said to be responsible for about 5.7 million deaths each year with the majority of these deaths occurring in low-income and middle-income countries (Strong et al., 2007). In a follow up study, de Jong et al. (2003) found that about 36% of patients with stroke died. Their study also showed that high age, diabetes and stroke subtype (atherothrombotic infarct and cardioembolic infarct) were independent predictors of 30-day case fatalities. Similarly, Mihalka et al. (2001) also found the overall 30-day case fatality in patients with stroke to be 23.3%, but it was as high as 36.8% among those patients with stroke who were treated at home. This study was done in West Ukraine and involved a relatively small sample size of only 352 stroke cases.

Lawlor et al.'s 2002 study on secular trends in mortality by stroke subtype in the 20<sup>th</sup> century found that deaths from stroke could be as high as 60% but pointed out that differences in diagnostic criteria could account for the inconsistencies in epidemiological studies on stroke. In South Africa, mortality from stroke increases with age and is higher in males than females over 35 years of age (Khan and Tollman, 1999). The study also concluded that death from stroke accounted for about 10.3% of deaths in the 35-65 year age group. These findings are similar to those by Norman et al. (2007) who stated that in 2000 high blood pressure caused 46 888 (9%) deaths in South Africa. However, one needs to take into account the problems with compilation of statistics (largely incomplete and hospital based and hence under reporting could be an issue) and how they can affect the accuracy of the data (Connor et al., 2007b). In a South African burden of disease study, Bradshaw et al. (2002a and 2002b) established that stroke was among the top five causes of deaths and was even more important (among the top three) in most provinces. These figures could have changed by now given the problem of HIV/AIDS that is also gripping the country. These figures are however higher when compared to the figures that come from high-income countries.

In a systematic review, hospital case fatality studies for sub-Saharan Africa were shown to be around 30% in one month (Connor et al., 2007a). This agrees with the findings by Rosman (1986) and Joubert

(1991) who established that the 30-day case fatality was between 33% and 35% in Zimbabwe and South Africa. However higher rates have been established elsewhere; in Gambia the 30-day case fatality was shown to be 46% while the one-year case fatality was 62% (Garbusinski et al., 2005). In a study done in the United Kingdom, Bamford et al. (1991) found the overall 30-day case fatality rate to be 19% with cerebral infarction accounting for 10%, intracerebral haemorrhage accounting for 50% and that for subarachnoid haemorrhage being 46%. High case fatality rates are indicative of inadequacies in medical care, rehabilitation and prevention strategies (Garbusinski et al., 2005).

Disability is very common in patients with stroke (Stephens et al., 2005). Stroke is responsible for the loss of 38.5% of disability adjusted life years (DALYs) in males and 43.0% in females in South Africa (Norman et al., 2007). Stroke (26.1%) was also established to be among the top three causes of disability in the Cape Peninsula, specifically in the Nyanga district of South Africa (Disler et al., 1986). This study was conducted in a predominantly black residential area and so gives insight into the influence of stroke on disability amongst black South Africans. However it is important also to realise that the area that was studied (Nyanga) is relatively small and so may have underrepresented the actual prevalence of disability from stroke among black South Africans.

The prevalence of stroke survivors in rural South Africa is 243 per 100 000 and of these, 66% needed help with at least one activity of daily living (Connor et al., 2004). This study did not include the whole of South Africa but illustrates prevalence levels in one province of South Africa (Limpopo). It however gives insight into the magnitude of the problem among the black population in South Africa. The prevalence of disabling stroke in sub-Saharan Africa seems to be the same as that for high-income countries (Connor et al., 2004; Connor et al., 2007a). Thorogood et al. (2007) in their conclusion to a cross-sectional study of vascular risk factors in a rural South African population agreed with the popularly held view that sub-Saharan Africa is following the predicted path towards an epidemic of vascular disease.

Mortality following stroke can vary depending on the stroke type and subtype (de Jong et al., 2003). However as stated by Lawlor et al. (2002) the aetiological factors that account for the differences in secular trends between cerebral haemorrhage and both cerebral infarct and coronary heart disease are not very clear though the early life risk factors associated with them seem to be important. Gender seems to have an effect on mortality post-stroke. More females (18184) than males (13 930) die of stroke in South Africa (Bradshaw et al., 2003). The higher mortality rates in females is a complex issue. Generally females live longer and age is a risk factor for stroke so although men are more likely to have

a stroke, because woman outnumber men, the prevalence of stroke and mortality associated with stroke is likely to be higher in woman (Connor, 2007). The overall age-standardised mortality rate for stroke in South Africa was 124.9/100 000 according to the burden of disease estimates done in 2000 (Bradshaw et al., 2003).

It is however interesting to note that there is a general decrease in mortality from stroke (Islam et al., 2008; Heuschmann et al., 2008) in high-income countries an occurrence attributed to decreasing risk rather than improving survival (Islam et al., 2008). This can therefore be said to mean that if resources are put in to managing the risk factors for stroke, the mortality from stroke can be curtailed substantially.

The stroke mortality rates in black people are higher than in white people (Gillum, 1999). This is important to note because this study population is largely black. While there is a general decrease in stroke mortality in high-income countries, this was not the case among the black population in the United States of America (USA) where they actually increased by more than 8% between 1992 and 1996 (Gillum, 1999). The reason for the differences in mortality rates between whites and blacks were largely unknown. What is clear though is the fact that blacks who have adopted western life styles (due to either immigration or normal economic development) have higher rates of stroke mortality (Gillum, 1999). The added weight of morbidity and mortality from stroke results in various socioeconomic consequences.

### **2.6.2 Socioeconomic Consequences of Stroke**

Socioeconomic factors are naturally very complex and they have a strong influence on stroke risk factors and standards of care and consequently on functional outcome post-stroke (Cox et al., 2006). In developing countries (Africa included) 80% of the population stays in the rural areas which means that factors like lack of resources and cultural practices, limit access to stroke services (Poungvarin, 1998). Very little is known about the socioeconomic impact of stroke in South Africa (Connor and Bryer, 2005). However, what is known is that in most countries, the poorest people have the highest risk of developing chronic diseases (stroke included) and that they are the least able to cope with the resulting financial consequences (Suhrccke et al., 2006).

Stroke is found to have estimated lifetime costs per patients of between US\$59 800 and US\$230 000 (Caro et al., 2000), while the American Heart Association (1998) estimated the direct costs of stroke,

including costs for hospital and acute rehabilitation admission, nursing home care, physician and other health professionals' services, drugs, home health care and durable medical equipment to be around \$28.3 billion. In a study looking at the burden and costs of chronic diseases in low-income and middle-income countries, Abegunde et al. (2007) estimated that US\$84 billion of economic production will be lost from heart disease, stroke and diabetes between 2006 and 2015. The American Heart Association (2003) estimates the annual indirect costs of stroke attributable to lost patient wages and productivity to be \$16 billion. This has huge economic implications not just on the afflicted patient but also on the patient's family and the health care system.

Hospital costs are some of the major socioeconomic concerns following stroke. According to van Exel et al. (2003), the determinants for hospital costs following stroke depend on the length of stay in hospital. The age of the patient (older than 75 years) and marital status (living alone) are found to result in substantially higher costs (van Exel et al., 2003). Hospital length of stay is in turn found to be determined by the severity of the stroke, death from stroke in the acute phase, and also waiting lists for placement in nursing homes. In addition to that, socioeconomic status may contribute towards ethnic disparities in stroke incidence and outcomes (Bravata et al., 2005), further fuelling the socioeconomic disparities that may be observed post-stroke.

The need for caregiver help increases with the severity of the stroke (Hickenbottom et al., 2002). Hickenbottom et al. (2002)'s study showed that the yearly care giving costs ranged from \$3 500 to \$8 2000. One however needs to note that these figures could be much higher now since the study was done in 2001. With loss of employment and inability to return to work with rates ranging from 0% to 100% (Daniel et al., 2009), means the family of the person with a stroke comes under severe financial pressure.

Stroke has been shown to cause social problems. The social problems that can arise from stroke include social isolation, decreased community involvement, disruption of family function, poor motivation, dependency and also loss of control (Daniel et al., 2009; Goldberg, 1991). Some of the factors that contribute towards the isolation being referred to here are physical disability and incontinence. Fear of having an accident in public in as far as incontinence is concerned will result in the stroke survivor choosing to stay indoors instead of socialising with others. The deterioration in ability to engage in social activities among stroke survivors ranges from 15% to 79% (Daniel et al., 2009). Over time, caregiver burden can decrease as carers adopt coping strategies but harmony in the



relationship (between the stroke survivors and their spouses) and social relations decrease (Visser-Meily et al., 2009).

Following stroke, sexual dysfunction and dissatisfaction with sexual life are common in stroke survivors and their spouses ( Forsberg-Warleby et al., 2001; Angeleri et al., 1993; Korpelainen et al., 1999). The sexual problems that patients with stroke complain of include libido, coital frequency, sexual arousal (including erectile and orgasmic ability and vaginal lubrication) and sexual satisfaction (Korpelainen et al., 1999).

Social support in the form of social relationships is of paramount importance if one is to survive the long-term effects of stroke (Lynch et al., 2008). The ability to return to work is often compromised following stroke, which inadvertently affects the financial independence of not just the stroke survivor but also the family especially if the stroke survivor was the main breadwinner prior to the stroke. The inability to return to meaningful employment can be there despite meaningful functional recovery (Hommel et al., 2009). This therefore means that stroke survivors will require meaningful social and financial support for them to be able to lead a reasonable life. The socioeconomic consequences of stroke in South Africa are unknown (Connor and Bryer, 2005). The combined effects of morbidity and socioeconomic consequences of stroke affect not only the stroke survivor but also the caregiver's quality of life, which will now be explored.

### **2.6.3 Stroke effects on Quality of Life**

There is no universally accepted definition of quality of life and neither is there an agreement on how the term should be defined and conceptualised in research (Kranciukaite and Rastenyte, 2006). One definition that is well known and commonly used is the one that was provided for health related quality of life by the WHO (1948). They described health related quality of life as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity". However, as stated by Salter et al.(2008), there is not one universally accepted definition of health-related quality of life. The WHO further defined "quality of life" as "An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns". It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment" (WHO, 1995).

It is generally agreed that when measuring quality of life there should be at least four dimensions assessed which are namely: physical, functional, psychological and social health (de Haan et al., 1993). Within these, "the physical health dimension refers primarily to disease-related and treatment-related symptoms. Functional health comprises self-care, mobility, and physical activity level, as well as the capacity to carry out various roles in relation to family and work. Cognitive functioning, emotional status (especially post-stroke depression) and general perceptions of health, well being, life satisfaction, and happiness are the central components of the psychological life domain. Social functioning includes "the assessment of qualitative and quantitative aspects of social contacts and interactions" (de Haan et al., 1993).

If one survives a stroke and undergoes a successful rehabilitation programme that on its own is not enough to be considered as a good outcome, we need to know the health related quality of life of the concerned individual (Tengs et al., 2001; Niemi et al., 1988).

The concept of "quality of life" post-stroke still require much attention and effort in developing countries mainly because the resources that are required are normally an issue (Pongvarin, 1998). To ensure better quality of life for the stroke survivor, there is a need for team effort involving many people including the patient, and importantly the carer. (Pongvarin, 1998).

There appear to be racial differences to the effects on quality of life post-stroke. Black people tend to have worse disability in the short term than white people (Lawrence et al., 2001; Horner et al., 1991) and the reasons for this disparity have not yet been established. This then translates into poorer perceived quality of life amongst black people.

### **2.6.3.1 Quality of life for the stroke survivor**

Following stroke, at least 50% of stroke survivors will be left with some disability (Ashburn, 1997; Bonita et al, 1997), a similar trend that was also found in rural South Africa (Connor et al., 2004). This therefore can be translated to mean that the quality of life post-stroke is not ideal. Many studies have been done which show that patients experience a reduction in quality of life post-stroke (Duncan et al., 1997; Hackett et al., 2000; Williams et al., 1999). Many factors have a bearing on the perceived quality of life following stroke and these factors influence various spheres of the stroke survivor's life. Some of these are highlighted below:

The presence of depression in the stroke survivor is one of the determinants of their quality of life post-stroke (Carod-Artal and Egido, 2009; Pan et al., 2008; Jonsson et al., 2005; Carod-Artal et al., 2000; Kauhanen et al., 2000; Suenkeler et al., 2002; Mackenzie and Chang, 2002; King, 1996). The depression seems to be a determinant of quality of life both in the short term and in the long term (Mackenzie and Chang, 2002; Sturm et al., 2004). This could be linked to the fact that by then the stroke survivor will be more realistic about the expected recovery and disability post-stroke. Depression is therefore an important aspect to assess during the hospitalisation period so that corrective interventions can be started early (Naess et al., 2006; Mackenzie and Chang, 2002).

Poor social support has also been shown to be linked to poor quality of life post-stroke (Carod-Artal and Egido, 2009; Markus, 2004; Mackenzie and Chang, 2001). This is believed to be influenced by the functional and cognitive state as well as the subjective needs of the individual stroke survivor (Mackenzie and Chang, 2002) making involvement of the family in the rehabilitation of the afflicted individual from early on very important. The poor quality of life in the long term for stroke survivors as a consequence of poor social support could also be linked to the inability to maintain or re-establish social ties (Astrom et al., 1992). Closely linked to the family support is marital status and its effect on quality of life. Being unmarried was found to have a negative influence on quality of life (Naess et al., 2006) a finding that is in contradiction to that by Kauhanen et al. (2000). One can only assume that the presence of a spouse can mean better social support although this is not always guaranteed. It is however important to note that family support on its own is not enough, societal support is also important if stroke survivors are to have an acceptable level of quality of life (Angeleri et al., 1993).

Functional ability of the stroke survivor is a strong predictor of the patient's perceived quality of life post-stroke (Naess et al., 2006; Nichols-Larsen et al., 2005; Mackenzie and Chang, 2002; Yoon, 1997). As stated by Tengs et al. (2001), stroke severity defined by the resulting morbidity should be the primary factor influencing quality of life post-stroke. Dependency in activities of daily living negatively influences quality of life. The dependency in activities of daily living has been linked to physical functioning and the general domains of quality of life (King, 1996). The functional ability is also an important predictor of a patient's ability to return to work and quality of life is positively linked to the possibility of going back to work (Gabriele and Renate, 2009). It was interesting to note from Gabriele and Renate (2009)'s study that having returned to work was not related to an increased level of quality of life in patients with stroke. Closely linked to the issue of physical functioning is fatigue, which is established to have a negative influence on quality of life (Naess et al., 2006). This influence from fatigue can be independent

of depression. It is important to note that there are cases where patients have reported reduced quality of life despite having regained high levels of functioning (Duncan et al., 1997) suggesting that there are other factors that influence quality of life post-stroke other than functional ability.

Gender seems to play an important part in determining the quality of life post-stroke. Women seem to have strokes later in life but have poorer functional outcomes (Appelros et al., 2009; Fukuda et al., 2009; Gargano and Reeves, 2007; Angeleri et al., 1993). An inability to function independently is linked to poor perceived quality of life by stroke survivors (Gargano and Reeves, 2007; Naess et al., 2006). The differences in quality of life between men and women cannot be explained by females' greater age at stroke onset or any demographic and clinical characteristics (Gargano and Reeves, 2007). This means that at the moment there is no explanation as to why women have poorer quality of life post-stroke compared to men.

The older the individual at the time of the stroke the poorer the quality of life post-stroke and the greater the deterioration in quality of life over time (Niemi et al., 1988). This is most likely due to the increase in disability and health related problems that come with old age (Niemi et al., 1988).

One way of ensuring better functional outcomes for patients with stroke and hence better health related quality of life is using organised care for patients with stroke (Cochrane Library, 2005; van Exel et al., 2003; Indredavik et al., 1998) and this can be done without the need for an extra budget (van Exel et al., 2003). Organised stroke care involves the setting up of dedicated units for the care and rehabilitation of the stroke survivor instead of utilising general wards (Indredavik et al., 1998). In South Africa, the government has agreed to the stroke unit concept and intends to ensure that each province has a stroke unit (Connor and Bryer, 2005). Apart from these efforts of organised care, an important player is the caregiver and hence their quality of life must be explored.

### **2.6.3.2 Quality of Life for the stroke caregiver**

In their endeavour to improve the quality of life of the stroke survivor, caregivers experience a significant burden that if excessive can lead to a breakdown in the support provided (Anderson et al., 1995). The long-term effects of care giving for stroke survivors include complaints of restraints in social life, uncertainty about care needs, constant worries, feelings of the burdens of responsibility and an increased prevalence in depression among stroke caregivers (de Freitas et al., 2005). The burden of

caring for a stroke survivor is associated with disruptions of both the integrity of families and quality of life of the caregivers themselves (Anderson et al., 1995; Bugge et al., 1999; Hankey, 2004). Closer to home, patients with stroke in Soweto (Johannesburg, South Africa) were shown to have limited rehabilitative support post discharge and not the supported early discharge programmes described in the literature (Hale, 2002). This means that domiciliary visits or community physiotherapy is not as effective as it should be in reaching all stroke survivors at home.

One of the reasons why carers have reduced quality of life is that the caregiver's social life is limited by care giving duties (Jaffe and Blackley, 2000). Jaffe and Blackley (2000) reported that caregivers find it hard to justify spending money or taking time away from the care-receiver to get involved in activities that are more social. Similarly, it has been observed that the chronic burden of psychological, social, physical, and financial stress coupled with the erosion of precious family and leisure time, poor recognition and support can negatively affect the caregiver's quality of life (Larson et al., 2005; White et al., 2003; Dewey et al., 2002; Scholte op Reimer, 1998a; Dennis et al., 1998).

Caring for a stroke survivor with communication difficulties is also associated with reduced health related quality of life (White et al., 2003). This mainly stems from the increased decision making duties for the stroke survivor since they are not in a position to speak for themselves. This coupled with the stroke survivor's reduced functional status negatively affects the caregiver's quality of life (Jonsson et al., 2005).

Caregivers reported worse quality of life than patients regarding emotional and mental factors and the explanation for this was that in the process of care-giving, caregivers take up most of those factors (emotional and mental) that would otherwise have bothered the patients themselves and that negatively affect their own quality of life (Jonsson et al., 2005). If uncontrolled, this can put caregivers at risk of dying. Caregivers who report caregiver strain are more likely to die compared to non-caregiving controls (Schulz and Beach, 1999).

The quality of life of the caregiver is interlinked to their caregiver burden, which will be expounded on under 2.8. The patient's ability to participate actively in community activities following stroke is very important if they are to live a meaningful life. In their endeavour to achieve meaningful participation, many factors interfere with the process and these will be reviewed in the next section.

## **2.6.4 Activity Limitation and Participation in the Community Post-stroke**

The WHO describes participation as “involvement in life situations” (WHO, 2001). They go on further to say that the definition of participation brings in the concept of involvement. It is important to note that participation is affected by environmental and personal factors. More than 80% of patients with mild stroke can achieve maximum improvements in activities of daily living function within three weeks (Jorgensen et al., 1995). Consequently, the measurement of only activities of daily living in this subgroup becomes inadequate to give the full extent of the impact of stroke according to the International Classification of Functioning, Disability and Health (ICF) model. These individuals may still have limitations in physical functioning, instrumental activities of daily living and participation (Jorgensen et al., 1995).

Patients with stroke generally function better in activities of daily living than they do in social activities/interactions (Schmidt et al., 1986). However, patients with stroke living with another adult demonstrate a lower degree of functioning in activities of daily living, but have better community participation (Schmidt et al., 1986). The adult carer will do most of the activities of daily living for the patient and thus not give them an opportunity to practice. Community participation will improve, because the adult carer is able to assist the patient with transfers and moving from one facility to another.

Accessibility of community facilities is found to be one of the predictors of social integration of patients with stroke (Belanger et al., 1988). Thus, if the facilities are not accessible, it becomes less likely that the patient will integrate into the community. This also affects compliance with medication, as indicated by Hale et al. (1999), who established that medication non-compliance is largely due to financial and transportation difficulties in attending clinics.

Following stroke, the attainment of independent community ambulation is a challenging rehabilitation goal (Lord et al., 2008). If patients do not have adequate ambulatory ability this directly affect their ability to participate in the community (Taylor et al., 2006). About 66% of patients with stroke who are in the community need help with at least one activity of daily living (Connor et al., 2004). One can easily extrapolate from this that the ability of the patients to participate in community activities is compromised by their dependency on other individuals to carry out activities of daily living. Similar findings were found in Canada where it was reported that almost 50% of the community dwelling stroke population

live with disability to the extent that if there is no full time and able-bodied caregiver at home, they also require help with activities of daily living (Mayo et al., 2002).

Environmental and social interaction health related quality of life may decrease post-stroke affecting the ability of the patient to re-integrate into community life (Kwok et al., 2006; Hartman-Maeir et al., 2007). This is mainly as a result of physical complaints such as pain in the joints post-stroke (Kwok et al., 2006; Hale et al., 1999). Equally important is the role of environmental factors in determining the extent to which an individual will be able to participate in community activities post-stroke (Schneidert et al., 2003).

Gait speeds measured in the clinic can overestimate the actual ambulatory ability of patients with stroke when they are in the community (Taylor et al., 2006). Their study revealed that even those patients with stroke that said they could “regularly access the community” in fact could not complete a simple trip involving a visit to a supermarket and a chemist. Equipping patients with stroke with the skills necessary for them to be able to negotiate the various terrains that they meet in the community is still a big challenge for rehabilitation professionals (Taylor et al., 2006). Along similar lines it has been established that community physiotherapy treatment has no effect on patients’ activities of daily living, social activity, anxiety, depression, and number of falls, or on emotional stress of carers (Green et al., 2002). Their study showed that community physiotherapy for patients with mobility problems one year after stroke leads to significant, but clinically small improvements in mobility and gait speed, which is not sustained when treatment ends.

As stated by Ilse et al. (2008), the patients’ functional and activity level play an important role in predicting caregiver strain during the sub-acute phase while the participation level becomes more important over time. This just goes to emphasise the importance of assessing the participatory level of patients post-stroke if one is to have a complete picture of the caregiving burden. The participatory domains often affected for the caregiver are personal relationships, employment and recreation (Rochette et al., 2007). Literature is awash with information on the positive influence of rehabilitation on patients post-stroke. The impact of rehabilitation on patients with stroke is reviewed in the next section.

## **2.7 Impact of Rehabilitation on Patients with Stroke**

The goal of rehabilitation following stroke is to improve the patients’ functional ability and enhance their integration back into the community. Rehabilitation can be part of the management of stroke survivors

either when still in hospital or as out-patients. The emotional and physical challenges that are faced by the patient following stroke are essential determinants of the successful rehabilitation after discharge from the acute setting to home (Aprile et al., 2008; Dorsey and Vaca, 1998). An improved functional ability is associated with an improved perceived health-related quality of life (Carod-Artal and Egido, 2009). Following stroke, proper management during the acute period will result in less disability and a less negative impact on the healthcare sector and society (McNaughton et al., 2005).

It has been shown that provision of rehabilitation improves the quality of life of the stroke survivor and their carers (Kalra et al., 2004; Patel et al., 2004). Rehabilitation improves both the physical as well as the social function of patients post-stroke, but repeated cycles of treatment are needed to maintain the level of improvement patients reach (Aprile et al., 2008; Studenski et al., 2005; Hopman and Verner, 2003). Aprile et al.'s 2008 study was fairly large, with 66 patients being enrolled for the study. However, the study would have yielded even stronger results if they had done a randomised control trial. Physiotherapy is part of the rehabilitation stroke survivors receive in hospital and it has been shown to have positive effects on functional abilities in patients with stroke (van Peppen et al., 2004). If rehabilitation is provided early, it can result in reduced hospital length of stay and improved functional outcome (Hayes and Carroll, 1986). It should however be noted that the effects of rehabilitation are found to be short lived (six months post discharge), post the rehabilitation period (Hopman and Verner, 2003) suggesting the need to continue with rehabilitation for some time post rehabilitation to enable maintenance of or improvement of gained functional abilities. However, despite all this, patients with stroke appear to have a relatively good quality of life six years post-stroke even in the presence of significant physical disability (Hackett et al., 2000).

The functional outcome of a patient following stroke depends among other things on the quality of rehabilitation the patient receives, the timing of the treatment and the amount of time spent in rehabilitation (Paolucci et al., 2000; Horn et al., 2005; Maulden et al., 2005). Though length of stay in hospital is considered important, the actual time of hospitalisation required to enable effective rehabilitation is not clear. There is a wide range of hospital length of stay in patients with stroke. The average hospital length of stay at Chris Hani Baragwanath Hospital (CHBH) in South Africa was found to be about 14 days (Hale, 2002) in 2002. Another study reported the hospital length of stay for patients with stroke to be 30 – 34 days in South Africa, Australia and Finland (Green et al., 2005). It should however be noted that Green et al.'s 2005 study sample consisted of patients with stroke who were in the sub-acute to chronic stage and for the South African sample were from private hospitals. The



average length of hospital stay for patients with stroke in high-income countries varies from 28 to 34 days (van Exel et al., 2003; van Straten et al., 1997).

It also important to note that the standard of stroke rehabilitation varies from country to country and with this comes the availability of resources for not just acute care but also rehabilitation, all of which have an influence on the functional outcome and survival rate of the stroke survivor (Dennis and Langhorne and 1998). It is quite clear that many studies have shown the effectiveness of rehabilitation in improving the quality of life of people with stroke and linked to that is the fact that physiotherapy improves several aspects of the patient's health following stroke. One of the cornerstones of the rehabilitation process of patients with stroke is the involvement of caregivers.

## **2.8 Role of Caregivers Post-stroke**

Being a caregiver means being responsible for someone else's welfare. There are two types of caregivers, formal and informal caregivers. Formal caregivers are the trained caregivers with professional qualifications for that kind of work and usually are paid for services rendered. On the other hand, informal caregivers are not paid or trained by statutory bodies (Smith et al., 2004b; Low et al., 1999). Informal caregivers refer to family members such as spouses or their offspring or friends who take the role of looking after someone when they are afflicted with some ailment (Anderson et al., 1995; Wade et al., 1986). For this study, the caregivers involved were informal caregivers and as such, the literature review will focus on this group of carers. Informal caregivers are the cornerstone for the development and implementation of community care policies (Simon et al., 2009).

Post-stroke, informal carers have an indispensable role to play and their ability to fulfil this role is crucial for the survival of stroke survivors when at home (Ski and O'Connell, 2007). The number of informal caregivers is increasing (Johansson et al., 2003; Visser-Meilly et al., 2005a) as more and more patients are discharged home without achieving full functional ability during hospitalisation. World-over the health care delivery system is shortening the hospital length of stay without giving full community services as there is a general shift from in-patient to out-patient rehabilitation and rehabilitation at the patient's home at times (Anderson et al., 2000). This therefore places the caring responsibility on the shoulders of the immediate family members and friends who are largely untrained and are therefore informal caregivers.

The use of informal carers is universal but in poorly resourced settings such as sub-Saharan Africa where accessibility of health services remain an enormous challenge (Thorogood et al., 2007), early discharge with home based rehabilitation being continued by the caregiver is an attractive option. Early supported discharge for people with stroke can provide a cost effective alternative to usual care (Teng et al., 2003). The need to cut hospital costs and pressure for beds has seen patients being discharged home post-stroke before they are functionally independent. This has resulted in caregivers being integral to the improvement in quality of life and survival of stroke victims as they adapt to the subsequent impairment (Smith et al., 2004b; Pomeroy and Tallis, 2002; Anderson, 1988). The majority of the caregivers for patients with stroke are family members and friends who are usually not professionally trained for this role and hence constitute what is termed informal caregiving (Smith et al., 2004b). The same applies to the South African setting where from personal experience in the hospitals, the majority of the caregivers are informal caregivers (either relatives or friends of the patient with stroke).

Caregiver involvement is believed to help lower the risk of another stroke, reduce post-stroke complications, improve function after a stroke, help achieve the highest possible functional recovery and in the process improve community integration (Hankey, 2004; Kalra et al., 2004; Han and Haley, 1999). If these goals are met, this results in improved quality of life of not only the stroke survivor but that of the carer as well (Adams, 2003). Informal caregivers are important for the promotion of both successful health outcomes in the stroke survivor and for the cost effective use of health and social services post-stroke (Low et al., 1999).

It is the responsibility of government to stimulate generation of information to reduce the risk of chronic diseases and in ensuring access to preventative and treatment services, especially for poor people (Abegunde et al., 2007). However as stated by van Gijn and Dennis (1998), very little information about the nature of stroke, its cause, management and likely prognosis tends to be given to patients and their carers. This results in a situation where more often than not patients with stroke are sent home prematurely to a family that has to cope with the changed individual without any prior training on how to manage the patient or with very little or no supported care (Smith et al., 2004b; Hankey, 2004; Hale, 2002; Kalra et al., 2004).

Caregivers more often than not are responsible for taking care of the patient with stroke after discharge. They play a very important supporting role in the rehabilitation process and it is believed that this role will increase with the "growing trend of providing stroke rehabilitation in survivors' own homes once they

have been discharged from hospital" (Low et al., 1999). Care giving duties can involve administering medicines, assisting with physiotherapy exercises and performing medical procedures with little or no training (Henderson, 1998). The presence of the informal caregivers allows the stroke survivor to be in the community instead of a nursing home (Hancock and Jarvis, 1994). It is however important to realise that it is the early period at home after return from hospital and rehabilitation, that feelings of desolation and isolation are usually the strongest among carers (van Gijn and Dennis, 1998; Smith et al., 2004b). In their efforts to ensure that the person with stroke is taken care of, the impact of that process on the caregivers often results in a burden that can negatively affect the well-being of the caregivers.

## **2.9 Burden of Care Giving for Stroke Survivors**

Pressure for beds (Colvin et al., 2001; Gilks et al., 1998; Putterill et al., 1984a) and limited resources (Veenstra and Oyier, 2006; Anderson et al., 1995) have led to a shift from institutional care to community care for patients with stroke. The need to reform the health delivery system and cutting costs at the same time has also been attributed to the increase in informal caregivers for both acute and chronic diseases (Rosenberg and James, 1994)

Connor et al. (2004) found that in rural South Africa, the percentage of people needing help with activities of daily living was very high (66%). This places a large burden on the family particularly the one in the family doing the care giving duties, the rest of the family and the community to some extent. It has been shown that women are the main informal caregivers and when women do care giving duties it is considered an extension of their domestic responsibilities (Henderson, 1998). This results in increased workloads for the caregiver, a role that often does not receive recognition. Caregivers find the care-giving role to be stressful (Draper and Brocklehurst, 2007).

In their endeavour to improve the quality of life of the stroke survivor, caregivers experience a significant burden, which if excessive can lead to a breakdown in the support provided (Smith et al., 2004b; Anderson et al., 1995). Caregiver burden can be divided into objective and subjective burden (Han and Haley, 1999; Montgomery et al., 1985). Objective burden refers to the time spent on care giving, the tasks involved during the care giving process and the possible financial constraints that may arise. Subjective burden refers to the physical, psychological, social and emotional impact caregivers experience during the execution of their care giving duties. As already stated before, the long-term effects of care giving for stroke survivors include complaints of restraints in social life, uncertainty about care needs, constant worries, feelings of heavy responsibility and an increased prevalence in

depression among stroke caregivers (de Freitas et al., 2005). The burden of caring for a stroke survivor has been associated with a disruption of both the integrity of families and quality of life of the caregivers themselves (Anderson et al., 1995; Bugge et al., 1999; Hankey, 2004; Smith et al., 2004b).

Care giving often results in caregivers not being able to socialise (Smith et al., 2004b). Carers often cannot find support to allow them to take breaks and may end up not being able to respond to invitations to leave the house e.g. for parties or even just for social calls. Carers only have quality time when patients they are caring for are in bed, but they are usually too tired to make good use of this time (Smith et al., 2004b). As stated by Jaffe and Blackley (2000), caregivers find it difficult to justify spending money or taking time away from the care-receiver, for social activities. Although Jaffe and Blackley's 2000 study was done in rural Canada, the socioeconomic status of the group they studied has many similarities with this study's population. Their study established that one of the reasons for caregivers' inability to socialise was limited financial and social resources. It is not known how much of an influence this has in a South African setting.

The prevalence of emotional disorders, which include depression and anxiety among caregivers of stroke survivors, ranges from 20 to 55% (Simon et al., 2009; Anderson et al., 1995; Carnwath and Johnson, 1987; Dennis et al., 1998; Wade et al., 1986). To add weight to this, relatively recent studies have also established anxiety and depression as being common in patients with stroke and their caregivers thereby influencing the care giving burden (Smith et al., 2007; Jonsson et al., 2005; Berg et al., 2005; Forsberg-Warleby et al., 2004; Smith et al., 2004b). The major problem for family caregivers is that they fail to recognise characteristic behaviours they commonly associate with the survivor before the stroke and it is that change in the person with a stroke that results in stress for the caregivers (Grant, 1996). The most commonly reported behaviour changes in patients post-stroke are frustration and quickness to anger often emanating from loss of activity or role in the family/workplace or lower levels of recovery than anticipated (Smith et al., 2004b). This leaves the caregiver feeling overwhelmed and frustrated with the caring responsibility.

Pierce et al. (2006) established that caregivers struggled with balancing their own activities and care giving duties. This was found to be especially problematic when the care giving duties increased or the caregiver resumed their own normal duties. Although their study was done on a small sample, it managed to establish that the top three factors that compounded care giving were less independence by the stroke survivor, having to deal with emotions and living with the resultant physical limitations. Carers for people with stroke appear to be more stressed than previously thought (Smith et al., 2004a).

In the caregiving process, a number of factors can influence the burden that caregivers experience and these are reviewed next.

### **2.9.1 Factors influencing burden of care giving**

There are many factors that influence caregiver burden. Informal caregivers do not choose to be caregivers (Jaffe and Blackley, 2000). They often become caregivers because there is no one else to do the care-giving job other than themselves and also because socially and culturally it is as a way of maintaining human relations and usual social activities (Jullamate et al., 2007). The fact that some people are caregivers due to forced circumstances means that they are doing so less wholeheartedly and hence being alone becomes a source of dissatisfaction for themselves. Care giving often interferes with the patient's ability to socialise and that becomes a source of caregiver strain (Smith et al., 2004b). Many caregivers neglect their own health in order to satisfy the needs of the chronically ill relative/family member and by doing so become subjected to severe stress (Onega, 2008)

It is well known that family interactions, functions, and routines will change in response to the stroke survivor's presence in the family (Crosato and Leipert, 2006). What makes the whole business of care giving more complicated is that informal caregivers aim to meet the needs of the dependent stroke survivor while at the same time adjusting vocationally, socially, and emotionally to the sudden change in their own lifestyle (Hankey, 2004). Hankey (2004) further states that carers need to be motivated, enthusiastic, physically fit, psychologically sound, emotionally robust, financially resourceful, adequately informed, trained, and skilled for them to cope with care giving duties. Shortfalls in any of these areas can result in caregiver strain or burn out.

Long hours of care giving have also been seen to be associated with reported caregiver strain (Jaffe and Blackley, 2000; Bugge et al., 1999). This usually affects those caregivers who do not have family support. If family members are involved in care giving, time is freed for the caregiver to socialise and by being able to do so, the caregiver burden is lessened (Simon et al., 2008). The amount of time needed to look after an individual will vary and is dependent on many factors. Some of these include the degree of disability (Gosman-Hedstrom et al., 2008; Pinquart and Sorenson, 2003,) with which the patient presents as well as the relationship and degree of closeness of the caregiver to the care-receiver. The actual duration of the care-giving role is however found not to have an effect on caregiver strain as those caregivers who had been looking after a relative for a long time experienced the same strain as new caregivers (van den Heuvel et al., 2001). These findings seem to agree with Blake et al.'s 2003

findings, which showed that the number of caregivers who are stressed only rose from 39% at three months to 40% at six months adding weight to the suggestion that care giving strain remains relatively high over time. Caregiving stress does appear to increase over time (Simon et al., 2009). This is thought to be linked to the persistence of poor physical abilities by the patients with stroke and the resultant loss of hope of the situation improving, by the caregivers.

Stroke severity is found to be associated with increased care giving strain (Carod-Artal and Egido, 2009; Simon et al., 2008; Gosman-Hedstrom et al., 2008; Bugge et al., 1999). This is mainly because the persistent neurological deficits dictate that the stroke survivor relies more on outside help being provided by the caregivers. This can be the case despite patients themselves having a better sense of wellbeing as regards their quality of life in the long term (Jonsson et al., 2005). This is attributed to the acceptance of disability by the stroke survivor while at the same time the caregiver helps more. Patient physical deficits are also associated with caregiver burden among patients with stroke (Choi-Kwon et al., 2005; Blake et al., 2003; Blake and Lincoln, 2000). These physical deficits are closely linked to the neurological deficits with which patients present. Stroke severity is also linked to the negative perception about the future that caregivers of patients with stroke have, which inadvertently affects the carers' psychological wellbeing (Forsberg-Waleby et al., 2001).

Working outside of the home and doubling as a caregiver has been perceived as leading to increased caregiver burden (Jaffe and Blackley, 2000). As stated by Jaffe and Blackley (2000), combining work and care -giving often means less sleep and no social life. The act of balancing work and care -giving is a very difficult one for most working caregivers. These caregivers also have personal lives which suffer as a consequence, for example it was noted that women caregivers retired from their work to enable them to provide more time to their loved ones (Jaffe and Blackley, 2000). This not only can increase the financial burden for the family but can also generate animosity towards the individual being cared for and consequently a feeling of caregiver strain (Crosato and Leipert, 2006). Bugge et al. (1999) concurred with these statements when they showed that both time spent helping the patient and time with the patient were associated with caregiver strain. They went on to postulate that the caregivers under the greatest strain are those who actually have to set aside specific time to provide care (i.e. those who are normally not with the patient and have to create time to fit the caring duties into an already busy schedule).

Unemployment is also a factor that negatively influences care-giving burden (Choi-Kwon et al., 2005). The unemployment in this case can be of either the patient or the caregiver. Although unemployment

was found to be a factor influencing care-giving burden, economic status was not found to be an influencing factor.

The HIV/AIDS pandemic has created a situation where it is now quite probable that the caregiver for someone with stroke might be someone who is suffering from HIV/AIDS in sub-Saharan Africa. It is a well-known fact that the presence of HIV/AIDS results in poor health and even reduced physical ability (van As et al., 2009; Voss et al., 2007; Rusch et al., 2004), which in turn affects one's capacity to look after the individual with stroke. It is reported that caregivers feel that their health deteriorates as a result of the care giving role (Draper and Brocklehurst, 2007; Jaffe and Blackley, 2000). It therefore makes sense to assume that the presence of HIV/AIDS in the individual giving care to someone can lead to further deterioration of their own health (the carer) thereby making the caregiving task very difficult. Caregivers who report poor health have increased caregiver strain (Bugge et al., 1999). van den Heuvel et al. (2001) found in their study on risk factors for burn-out in caregivers for patients with stroke, that caregivers in good physical health experience less strain from care giving. The common problems experienced by caregivers include headaches, chronic back pain, depression and emotional and physical exhaustion (Jaffe and Blackney, 2000). It was however shown that the caregiver's perceived health was linked to their level of family support and employment outside the home (Jaffe and Blackley, 2000). In contrast to these findings, Choi-Kwon et al. (2005) did not find the caregiver's physical health to be correlated with the care-giving burden.

Other factors that can be associated with increased caregiver strain include feelings of guilt, resentment, impatience and fear (Edwards, 2006). This includes the fear that another stroke will occur, fear that the stroke survivor might fail to accept the resulting disability, fear that the survivor might need nursing home placement and the fear of being abandoned by family members and friends (Edwards, 2006). As Dorsey and Vaca (1998) put it, it can also be called the "fear of the unknown". The resentment that caregivers for patients with stroke have, can be directed towards the patient because of the care-giving burden.

Being a young caregiver is found to be associated with increased strain (van den Heuvel et al., 2001) a finding that is also supported by Periard and Ames's 1993 study. A possible explanation for this finding is believed to be the fact that younger caregivers often have other obligations such as work and children in addition to caring for a relative.

The majority of caregivers for patients with stroke are females (Bugge et al., 1999; van den Heuvel et al., 2001; Jonsson et al., 2005; McCullagh et al., 2005) and being female is found to be a factor associated with increased strain (Carod-Artal and Egido, 2009; Choi-Kwon et al., 2005; Chiou et al., 2005). This again can be attributed to the multiple family responsibilities, including at times, work responsibilities that women have in addition to caring for the individual with stroke. Female caregivers are also shown to be susceptible to increased strain early on when compared to their male counterparts but in the long term, the levels of stress are equal in both men and women (Choi-Kwon et al., 2005).

The presence of aphasia, dysarthria and cognitive dysfunction in the patient with stroke is found to be associated with increased caregiver strain (Draper and Brocklehurst., 2007; Choi-Kwon et al., 2005). The existence of communication problems between the caregiver and the patient with stroke could be the source of the care giving strain in this case. If the patient cannot verbalise what they want or need help with, this naturally means that the caregiver has to be around them more often and will have great difficulty trying to understand what they need help with. The loss or impairment of the ability to communicate is frustrating and devastating to both the stroke survivor and the caregiver with possible consequences that include fear, feelings of hopelessness and depression (Hickey, 2001).

Anxiety has been established as a very important factor affecting caregiver burden (Carod-Artal and Egido, 2009; Choi-Kwon et al., 2005; Thommessen et al., 2001; Dennis et al., 1998). Once the caregiver feels anxious, depression usually follows and the most likely scenario is that they will feel much strain in their care giving duties. It is also established that carer mood is the most important factor associated with care giving strain when caring for patients with stroke (Blake and Lincoln, 2000). To add weight to these findings, McCullagh et al.'s 2005 study also established that patient and caregiver anxiety rather than levels of disability, age, gender or support from family or social services is responsible for the amount of caregiver burden experienced in the immediate aftermath of stroke, though this decreases with time and other determinants become more prominent. Not all factors negatively influence caregiver burden, some positively influence the burden of caregiving for patients with stroke.



## **2.9.2 Factors that can positively influence the caregiving experience**

Though caring for an individual with stroke can be associated with care giving strain, at times it can be a rewarding experience (Hankey, 2004). This is usually the case when the caregiver is well supported not only by family members and friends but also by health care providers.

Another important contributor to a positive care-giving experience is an understanding of their own ability to cope and how this can influence their caregiver stress (Hodgson et al., 1996). This means that such carers are more mentally prepared for the care-giving experience. Stress increases over time, especially when the caregiver needs are not met. Provision of adequate information (especially those addressing the behavioural and emotional aspects of care giving), the need for skills in the aspects of care, and support in the case management can help create an environment where the caregiver feels rewarded with the care giving experience (Crosato and Leipert, 2006).

Positive coping strategies that include self-control skills also contribute towards less reporting of psychiatric symptoms among caregivers when compared to those who use passive avoidance strategies (Matson, 1994). Positive coping strategies include remaining positive, adapting to change, comparing their situation to others who are worse off, changing their employment status, humour and switching off (O'Connell and Baker, 2004). In addition to practising positive coping strategies, it has also been shown that other services such as post-discharge support, counselling, further information about stroke and practical help all contribute immensely towards the long-term quality of health of caregivers (Greveson and James, 1991).

Bugge et al. (1999) established that male patients with stroke less neurological impairment and continence within the first seven days of stroke are associated with less caregiver strain. Patient and caregiver anxiety are also established to be independent determinants of caregiver strain at three months (McCullagh et al., 2005). McCullagh et al. (2005) go further to say that at one year, family support becomes an important determinant of caregiver strain. This helps to support findings that show that caregiver strain is multifactorial in origin and requires greater analysis and assessment for better prevention and management strategies to be implemented.

The relationship of the caregiver to the patient is a determinant of caregiver strain (van Excel et al., 2004). Their study established that the number of care-giving hours per day increased for non-spousal

caregivers compared with spousal caregivers. This was explained by the fact that non-spousal caregivers have a virtually different life outside the stroke survivor's one and yet they have to try and 'marry the two'. They may also have their own family commitments and this makes the whole caregiving process very difficult for them. However, use of family support was shown to be one of the coping strategies that was successfully used by caregivers (O'Connell and Baker, 2004).

An understanding of the emotional and physical challenges that are faced by the individual who has had a stroke are essential determinants of successful rehabilitation for someone now at home. A well-supported environment for the caregiver seem to be able to help alleviate the care-giving burden when looking after an individual with stroke (Low et al., 1999). Poor follow-up procedures post discharge and the lack of rehabilitation when the stroke survivor goes home are some of the major concerns for caregivers (Ski and O'Connell, 2007). One of the ways through which the burden of caregiving can be alleviated is through the education of the caregivers.

## **2.10 Education of Caregivers**

One of the essential goals of primary health care is prevention of stroke and for this education of everyone involved plays a major role. Health education in general terms, is directed at the healthy individuals and is aimed at the maintenance of health (Verhaak and van Busschbach, 1988). The education can however also be extended to the sick so that they can know about their disease condition, prognosis, treatment, what they should or should not do. Patient education can be defined as " a planned experience that uses a combination of methods such as teaching, counselling and behaviour modification techniques to influence a patient's knowledge and health behaviour" (Schrieber and Colley, 2004). Health education is practiced world over and is of importance in the prevention of primary and secondary stroke.

In low-income countries, the priority should be education of the public and of health care providers about the preventable nature of stroke as well as about the warning signs and symptoms of the disease (Poungvarin,1998). Equally important in all this is the education of the carers not only about the above but also about how to look after the patient with stroke effectively so as to mitigate against the adverse stroke effects on the quality of life of the caregiver and the patient.

Health education is essential when treating hypertensive patients (Flaherty et al., 2004). In as much as teaching caregivers is important, the patient needs to be educated on the entire concept of

hypertension, especially as regards the possible resultant effect of stroke from uncontrolled blood pressure (Al Shafae et al., 2006; Lemogoun et al., 2005, Flaherty et al., 2004). However, in relatively old studies it was revealed that patients with stroke's knowledge of hypertension and its causal relationship is suboptimal (Flaherty et al., 2004; Hale et al., 1997). These findings are also strengthened by Bogoshi et al. (2003) who stated that in South Africa, 79% of those who were hypertensive and 64% of those who had a stroke indicated that they did not know that they were at risk of a stroke. Hale et al (1997) concluded that patients needed more education regarding hypertension and its consequences. Pancioli et al. (1998) concurred with Hale et al.'s 1997 findings that people with self reported risk factors for stroke are largely unaware of their increased risk and also that the population at greatest risk for stroke, namely the very elderly, are the least knowledgeable about stroke warning signs and risk factors. Pancioli et al.'s 1998 study was conducted via telephone and hence no verification of the actual cases (people who claimed to have stroke risk factors) could be done and this can be cited as a weakness of the study.

Kalra et al. (2004) and Patel et al. (2004) showed that training the caregiver for people with stroke benefits not only the patient but also the caregiver and the community through positive effects on quality of life. The needs of the stroke survivor are often multiple and include help with physical activities, nursing activities, communication, psychological and emotional support, and social reintegration into society for which a caregiver is very important (Visser-Meilly et al, 2004). This can result in a deterioration of the caregiver's health status, social life and well-being (Low et al., 1999, Wyller et al., 2003). Identification of the factors that can help identify caregivers at risk of adverse outcomes can be reduced by caregiver training (McCullagh et al., 2005).

van den Heuvel et al. (2001) suggested that caregiver education should cover self-efficacy, stimulate caregivers to use the coping strategy "confronting", and teaching them how to mobilise social support in a way that is satisfactory to them. The caregivers need to be equipped with information on how best to help the stroke survivor. van den Heuvel et al.'s 2001 study showed that if caregivers know how to make time for themselves, their hobbies, and their social life and know where to ask for support, they experience less strain, further highlighting the importance of comprehensive education of the caregivers. They argued further that it was knowledge about how effective they could be in their caregiving duties, which was more important than knowledge about patient care. It is important that patients with stroke, their families and caregivers be educated in the importance of incorporating the patient back into the family unit (Dorsey and Vaca, 1998).

The education of the patient and the caregiver does not always result in improved perceived health status (Rodgers et al., 1999). The education programme may improve carers' knowledge about stroke and its consequences but it may fail to provide them with positive solutions to their problems hence the lack of improvement in perceived health status (Rodgers et al., 1999). This however can be alleviated through proper family caregiver education (Houts et al., 1996). The method of instruction used to impart education to either the patient or the caregiver plays an important role in the effectiveness of the education process.

### **2.10.1 Methods, content and requirements of caregiver education**

#### **a) Introduction**

This section describes the methods, content, and requirements of caregiver education that should be in place for it to be an effective programme. The specific theories of education are not reviewed since that was beyond the scope of this review. In some cases, excerpts are borrowed from patient education and are applied to caregiver education and vice-versa. Because of the nature of the review being undertaken, some of the relevant literature that was reviewed is fairly old but is still of value.

#### **b) Methods, content and requirements of caregiver education**

An effective education programme should impact on the patient or patient's family (Dent, 2000). The problem of ineffective education is closely associated with non-adherence of the taught programme (Kerssens et al., 1999). The method of instruction that is chosen to impart knowledge to caregivers must be effective. With this in mind, Schure et al. (2006) compared the effectiveness of two methods of caregiver education, a group support programme and a home visiting programme for family caregivers of patients with stroke. They concluded that each method had its own supporters. They concluded that the type of intervention should be caregiver specific. The caregivers who preferred the group programme were the ones who were burdened, lived with a more psychologically handicapped relative, were using active coping strategies more frequently, or lived in a region, which is considered to be more sociable.

A good educational programme for caregivers should:

- be based on “learning by doing” Schurgers (1996). This means that caregivers should be given an opportunity to have “hands on training” of what would be expected of them when at home with the patient.
- have a multidimensional approach to assessing and dealing with problems and should be used with an emphasis on emotions, information and coping (Visser-Meily et al., 2005). The caregiver-training programme should be tailor made to individuals so that their coping ability with the caregiving duties can be enhanced (Visser-Meily et al., 2005; Dent, 2000). One of the recommendations by Visser-Meily et al. (2005) was that more emphasis should be placed on individualised needs of the caregivers instead of offering a pre-structured programme.
- balance the negative and positive aspects of the participants’ experiences (Weitzner et al., 2000). One way of ensuring this particular requirement is to individualise training of the caregivers so that caregivers are given adequate time to address their needs.
- for group work, be targeted at participants who share certain characteristics (Goodman, 1991). The caregivers should share certain common attributes such as the socioeconomic background. This encourages a sense of belonging and cooperation among the caregivers, providing support to one another in the process.
- contain a combination of education and counselling (Evans et al., 1988). This should be done depending on the caregiver needs.
- have a predetermined number of sessions and implementation intervals with a standardised training programme, a flexible component incorporating individualised themes based on participants’ priorities and problem areas (Patterson et al., 2000). As already explained, the training should be tailor made to the individual needs of each patient. The aspects to be covered during training can be drawn from a standardised training manual but adapted to individual needs.

Any caregiver education should address all possible barriers to the education process. The common caregiver education barriers are impaired vision or hearing, cognitive problems, too complicated language for the patient/caregiver and group or peer influences (Swezey and Swezey, 1976). Others include the content of the educational material (Dent, 2000; Oladepo et al., 1996) and the ability to be mobile for those in the community and availability of time (Oladepo et al., 1996)

The intervention strategies for caregiver education should be timed appropriately (Cameron and Gignac, 2008). Cameron and Gignac (2008) propose five stages that caregivers for patients with stroke undergo and what needs to be done as part of the caregiver education process at each stage.

Table 2.1 below highlights the stages caregivers go through according to Cameron and Gignac (2008).

**Table 2.1:** The stages caregivers go through post-stroke

Phase	Time	Setting	Care Focus	Caregiver support needs	Caregiver outcomes
Event/Diagnosis	Acute phase of illness Short duration	Acute care hospital	Professional care Diagnosis and survival of event Family care Concern for survival	Information – diagnosis, prognosis and current treatment Emotional – someone to talk to	Knowledge – survival/prognosis Enhanced decision making Emotional distress
Stabilisation	Soon after patient stabilisation Short duration	Acute care hospital	Professional care Patient has stabilised Specific patient training Uncertainty about the future	Information – cause of event Emotional someone to talk to Training – initial training to assist with activities of daily living and rehab	Information outcomes – awareness about cause Emotional distress
Preparation	Before patient goes home Short to moderate duration	Acute care hospital/Rehabilitation Facility	Professional care Discharge/in-patient rehabilitation Safety in activities of daily living Secondary prevention Family care Care needs Concern from caregiver on ability to meet care needs	Information – access to community resources Emotional – mounting anxiety and uncertainty Training – new activities of daily skills and rehab	Knowledge – community resources Caregiving confidence/self efficacy Emotional distress Anxiety Perceived social support
Implementation	Few months after discharge home	Home	Professional care Adaptation to community living Community services Medications Family care Learning caregiving Realises personal costs of caregiving	Information – everyday management of ongoing activities Information – potential impact of caregiving Emotional – fear and anxiety Training – support for caregiving Appraisal - feedback	Improved self efficacy Use of community services Emotional distress Psychological well being
Adaptation	After a period of adjustment at home	Home	Professional care Community integration Secondary prevention Caregiver becomes more confident with caregiving duties Personal consequences of caregiving set in Focus on future personal and caregiving needs	Information and training Information – work and community options Information – future needs Emotional – support from support groups Emotional – relationship changes Appraisal - feedback	Patient community integration Perceived social support Decrease in emotional distress Increase in psychological well-being Increased participation in valued activities

Taken and adapted from Cameron and Gignac (2008)

It is quite clear from the above table that for effective implementation of a caregiver education programme, adequate hospitalisation time with access to the caregiver(s) is of paramount importance.

In a review on intervention studies for caregivers of stroke survivors, Visser-Meily et al., (2005b) acknowledge that there does not seem to be a superior method for caregiver education for patients with stroke, making effectiveness of information provision difficult to conclude on. The studies that have been done on caregiver interventions utilised many periods post-stroke, ranging from a few days post-stroke to one year post-stroke (see examples from Table 2.2 below).

The information needs of patients and carers is not being met and it may not be possible to meet the patients' and carers' desire for information especially about recovery and prognosis (Wiles et al., 1998). Provision of verbal information to patients is very important but has the major handicap that patients tend to forget (Dent, 2000; Ley, 1989). This can be done either through face-to-face interactions or via the telephone (Dent, 2000). One way of getting around this problem is to provide written information, which is valued by patients and carers (Lomer and McLellan, 1987). However, this method may not be appropriate if the patients and caregivers have low educational levels, which may affect either reading ability or their understanding (Dent, 2000; Gunn, 1993).

A combination of written and verbal information of the two methods has more advantages than the two methods separately. Information provision should be tailor made to the individual for it to have the most impact and not generalised to all patients (Wiles et al., 1998). This can be done by having general information from which specifics are chosen to fit the needs of the carer of the patient.

Group meetings can also be used as an education session (Dent, 2000). This has the advantage of group support. With more advances in technology, this has even gone further to include the use of chat rooms over the internet (Dent, 2000). Future and to some extent current methods of teaching will also utilise electronic mail (e-mail) (Dent, 2000)

In any teaching situation, reflective thinking/listening plays an important role in the understanding of the taught material (Gance-Cleveland, 2007; Pask, 1976) and facilitates the transfer of "classroom knowledge" into clinical practice (Wong, 1979). An open therapist-patient/caregiver relationship encourages dialogue, action and reflection on progress and steers clear of unrealistic expectations and misunderstandings (Trede, 2000).

An effective caregiver/patient education programme should take cultural cues into consideration for it to be accepted and avoid unnecessary embarrassment to both the patient and the recipient (Dent, 2000). All cultures and ethnic groups have a system of health beliefs that they use to explain how illness

occurs, is treated and who should be involved in doing this (Chachkes and Christ, 1996). Patient/caregiver education should take note of such beliefs and should not be authoritarian but rather family centred (Gance-Cleveland, 2007).

It is important that the roles of the patient and the family be explained during the education process to ensure continuity of treatment as well as patient progress (Lange, 1989). Once patient/caregiver education has taken place, recall can be enhanced by testing them through a checklist (Webber et al., 2001). There doesn't seem to be agreement in the literature on the format of caregiver education or even the content of what should be covered during the training sessions.

A summary of some of the methods that have been used in caregiver education to date is given in the following table.

**Table 2.2:** Summary of some of the methods that have been used in caregiver education

<b>Intervention</b>	<b>Authors</b>	<b>Duration</b>	<b>Time post-stroke</b>	<b>Author Conclusions</b>
Seminar	Braithwaite and McGown, 1993	2 hours	~ 4 years	Emotional state of caregiver did not influence learning Older caregivers less informed
Counselling	Dennis et al., 1997	Less than 5 client contacts	Within 30 days	Carers in treatment group less depressed
Seminar/class	Evans et al., 1988	1 hour	Third week in hospital	Both education and counselling effective, combined results better
Telephone intervention	Grant , 1999 and Grant et al., 2002		2 days before discharge	Reduced depression Positive-solving skills No differences in burden
Small group education	Rodgers et al., 1999	1 hour	5 - 9 days	Improved carer knowledge but not perceived health status
Tailor made home programme	Teng et al., 2003		< 28 days	Reduced burden of caregiving

From the above information, it is evident that that there is no agreed way of conducting caregiver education. The time needed to impart an education programme is dependent on patient/caregiver



needs if one is to take the tailor made home programme route. Generally, the education should happen in the early days post-stroke. Tailor made home programmes seem to be more effective in reducing the burden of caregiving. Physiotherapists, along with all other rehabilitation and health personnel play an important role in the education of caregivers. The role of physiotherapists in particular is expounded on in the following section.

### **2.10.2 Role of physiotherapists in caregiver education**

Patient education is defined as “a planned learning experience that uses a combination of methods such as teaching, counselling and behaviour modification techniques to influence a patient’s knowledge and health behaviour” (Schreiber and Colley, 2004). In its essence and most recognisable form, health education is directed at healthy individuals and it is concerned with the maintenance of health (Verhaak and van Busschbach, 1988). It is however equally important or even more so in those who may have fallen sick or those who will be taking care of them and in doing so run the risk of falling sick as well (Verhaak and van Busschbach, 1988).

Health-care practitioners are an important source of information for preventative health and encouragement from them, can have a positive impact on healthy life style practices (Cameron and Gignac, 2008; Greenlund et al., 2002). Following stroke, patients need information on prognosis and also on health-related quality of life issues to empower them to make informed decisions as regards employment and vocation in general (Naess et al., 2006). Caregivers also require information to enable them to provide care to patients with stroke. Health care providers have an important role to play in maintaining carers’ quality of life since they are often the first port of call for many stroke carers (Low et al., 1999).

This applies to physiotherapists as well. The amount of time physiotherapists spend with patients post-stroke make them ideal health care professionals to impart knowledge to the carers on what needs to be done to maintain their quality of life once they start staying and looking after the person with stroke. The major shortcoming with rehabilitation services as far as carers for stroke survivors are concerned include insufficient provision of information covering the following areas: post discharge service needs, carers’ domiciliary support, the provision of aids and adaptations (Pound et al., 1993).

## 2.11 Summary of Literature Review

The prevalence of stroke is increasing world over and will continue to increase as people live longer. There however seem to be a general decrease in stroke mortality especially in high-income countries. In low-income countries that are considered to be undergoing epidemiological transition it is anticipated that stroke will reach epidemic proportions in the near future. The pressures for beds and economic constraints have seen the length of hospital stay for patients afflicted with stroke getting shorter and shorter. This has seen an increase in the role being played by caregivers post-stroke, the majority of whom are informal caregivers. The reduced hospital stay means inadequate time for preparation by would be caregivers for the caregiving role. Caregiving for patients with stroke is associated with a reduction in health status, social life and well-being of the caregivers. Though there is agreement on the programmes that need to be put in place to equip caregivers with the required knowledge for care giving, none has yet proved to be ideal. Health care providers, physiotherapists included, have a role to play in this regard. There is a need for more studies that evaluate the effectiveness of health interventions on carers' quality of life using standardised measures with either longitudinal or randomised control design or both (preferably) to improve the strength of the results.

## CHAPTER 3

### 3. INSTRUMENTATION and OUTCOME MEASURES

#### 3.1 Introduction

This chapter describes the instruments that were used for the data collection process including (where applicable) the justification as to why they were chosen. The instruments are linked to the appropriate objectives.

#### 3.2 Instrumentation and Outcome Measures

##### 3.2.1 For objective 1, *“To establish the physiotherapy caregiver education programmes and content currently in use when managing patients with stroke at Chris Hani Baragwanath hospital”.*

This information was collected through a self-administered questionnaire completed by the physiotherapists working in the adult neurology department at Chris Hani Baragwanath Hospital.

For this purpose, a questionnaire with open-ended questions was designed (see appendix J). Open-ended questions were opted for in order to leave room for the therapists to give as much information as they could on the subject areas that were being explored. This option was also taken because this part of the study was necessary to gather baseline assessment information but was not fundamental to the actual study.

#### i) **The Physiotherapist Questionnaire:**

##### a) General Description

The questions required the physiotherapists to give a full but brief description of how they managed a patient with stroke (practice and **not theory**) from admission until discharge. The emphasis was placed on what was actually happening and not the ideal way of managing patients. They were then asked to explain what they believed to be the role of a caregiver in the management of patients with stroke.

The next questions on the questionnaire sought to elicit information on how the therapists involved caregivers during the management of patients with stroke. The physiotherapists were also asked to rate

themselves on how effective they thought they were in involving caregivers in the management of patients with stroke. Lastly the questions required the therapists to give an account of what they perceived to be the challenges/constraints that they faced in their endeavour to involve caregivers in the management of patients with stroke.

b) Content Validity

Content validity of the questionnaire was established by giving the questionnaire to two experts in stroke rehabilitation for their input given the intended objectives. Minor adjustments were made to the wording of the questionnaire as per the recommendation of the experts (see pilot study results in results section, Chapter 5).

The questionnaire was then piloted on four physiotherapists from another hospital to test the clarity of the questions. No adjustments were made to the questionnaire after this as the physiotherapists concurred that the questions were clear.

**3.2.2 For objective 2, “To establish the effect caregiver education has on the mobility of stroke survivors”:**

To establish the patients’ functional mobility levels at the time of discharge following their stroke and at subsequent follow up assessment; the Rivermead Mobility Index (RMI) was used for data collection in conjunction with information that was also obtained using the Barthel Index.

**The Rivermead Mobility Index (RMI):**

a) General Description and History of the Rivermead Mobility Index (RMI)

The RMI was developed from the Rivermead Motor Assessment by Collen et al. (1991b). The focus of this instrument is on body mobility. The RMI consists of 14 questions and one direct observation. The RMI covers a range of activities that assess how mobile the patient is from bed mobility to running. It was developed to measure mobility in patients with stroke and head injury. If the patient is unable to perform the aspect of mobility they score a 0, if they are able to perform it independently they score 1 and the values are added. This allows for a total out of 15. If they score 15/15, they are deemed to be completely functional as far as their mobility is concerned.

A further development was made from the RMI in the form of the Modified RMI (MRMI) by Lennon and Johnson (2000). They collapsed the number of test items on the scale from 15 to eight as a way of trying to improve its effectiveness in measuring change following patient treatment. They also changed the scoring from a two-point to a six-point scale. This scale was however only tested in acute (hospitalised) patients and is thus not well used in an out-patient population. It has been suggested in the literature that the MRMI is more responsive due to its 6-point scoring system as opposed to the dichotomous scoring of the RMI (Hsueh et al., 2003).

#### b) Validity and Reliability of the RMI

The RMI was shown to be a valid tool for assessing mobility in patients with stroke (Antonucci et al, 2002.) It was also shown to be reliable to a limit of 2 points out of 15 (Collen et al, 1991b). A coefficient of reproducibility of greater than 0.9 was also established (Hsieh et al, 2000) while Green et al. (2001) found a mean difference and reliability coefficient of 0.3 +/- 2.2 showing that the RMI is a valid and responsive instrument when measuring mobility in patients with stroke. Although the sample size was relatively small (38 patients) in Hsieh et al.'s 2000 study, their study showed that the RMI was a valid instrument.

Lennon and Johnson's 2000 study on the MRMI found that it was responsive to change (effect size =1.15) had test-retest reliability ( $r = 0.731$ ), inter-rater reliability (Intraclass coefficient (ICC) = 0.98) and good internal consistency (Cronbach's alpha = 0.93) showing that it had good to excellent validity and reliability, regardless of the experience of the testers.

The original RMI (Rivermead Mobility Index) was shown to be valid and reliable in a study by Chen et al. (2007). The standard error of measurement (SEM) and smallest real differences (SRDs) were used to determine the absolute reliability of the RMI. SEM is used to quantify the "threshold that indicates a real improvement (beyond measurement error) for a group of individuals and SRD represents the threshold indicating a real improvement for a single individual". Thus the lower the scores the more reliable the measure. The RMI scored 0.8 and 2.2 respectively. As such, this study found the RMI to have absolute reliability. Relative reliability was also shown in this study with an Intraclass Coefficient (ICC) of 0.96.

c) Why the RMI?

As stated by Collen et al. (1991b), the RMI is short, simple and clinically relevant and can be used either at home or in a hospital. Given that most of the follow up assessments were going to happen outside the hospital environment, this instrument was thus deemed appropriate for use in this study. The MRMI was not considered because it has not been extensively used in an out-patient population of those with stroke. As stated by Forlander and Bohannon (1999) in their review on the use of the RMI in research, the RMI possesses characteristics desirable in measurement scales and thus warrants broader application in research. For this study, because of the good information on the validity and reliability of the RMI, and its ease of availability and application, a decision was made to use it for data collection.

**3.2.3 For objective 3, “To establish the effect caregiver education has on the quality of life of stroke survivors”:**

Generally speaking, assessing quality of life involves describing and measuring the impact of different conditions on people’s daily lives, taking into account the physical, emotional and social functions of the concerned individual (Health Economics Unit, 2001). According to the Health Economics Unit (2001), when this concept is applied to measuring the impact of diseases and treatments on people’s daily lives and their ability to function it is then called ‘health related quality of life’. The quality of life that was measured in this study was the ‘health related quality of life’. It is however important to note that as stated by Salter et al. (2008), there is no single accepted definition of health related quality of life.

Quality of life measures can either be generic (used to assess the impact of any disease process or treatment) or they can be disease specific, that is designed to assess treatments and disease processes of a specific condition (Guyatt et al., 1993). Quality of life is better measured when inferred from both objective functioning and subjective wellbeing. Quality of life measures allow evaluation of the effect of interventions from the patient’s perspective.

For this study, the instrument of choice for measuring the health related quality of life was the European Quality of Life Scale-5D (EQ-5D). The EuroQol (EQ-5D) questionnaire was used as an outcome measure for quality of life of both the caregivers and the patients.

## **The EQ-5D**

### a) General Description and History of the EQ-5D

A multidisciplinary team of European researchers (the EuroQol Group) concurrently developed the EQ-5D in five different languages (The EuroQol Group, 1990). It was developed to be self-administered and short enough to enable use with other instruments. The EQ-5D is an internationally developed, generic index used to measure health related quality of life (The EuroQol Group, 1990; The EuroQoL Group, 2004).

It is a self-administered two-part questionnaire though it may be administered either by a questionnaire for self-completion with mild to moderate stroke or by interview in patients with significant motor deficits (Dorman et al., 1997). The first part consists of five categories addressing mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each category has three descriptive statements that define the level of difficulty for that particular area. The participant chooses a statement that best describes how they fair in that particular section. Each statement chosen is then given a numerical rating corresponding to the statement's level of difficulty: 1 = some or no problems, 2 = moderate problems, 3 = extreme problems. These ratings are then combined such that each combination of choices creates a five-digit expression of a health state, classifying respondents into 1 of 243 distinct health states.

The second part of the EQ-5D has a visual analogue scale (VAS) that has values ranging from 0 (worst imaginable) to 100 (best possible) to measure the patient's perception of their state of health.

### b) Validity and Reliability of the EQ-5D

The EQ-5D has been shown to be a valid and reliable measure of health related quality of life (Dorman et al, 1997). In the South African context, the EQ-5D is available in Afrikaans, English, Sesotho, Xhosa and Zulu, however no information could be found on the validity and reliability of the EQ-5D in the Afrikaans, Sesotho and Zulu languages. Its Xhosa version has been found to be valid and reliable (Jelsma et al, 2004).

The EQ-5D produced fairly good inter-rater agreements with Kappa values of 0.05 to 0.64 when an interview-based administration was done (Finch et al., 2002). The individual items of the EQ-5D gave

varying degrees of agreement with mobility, 0.48; self-care, 0.62; usual activities, 0.37; pain 0.30; anxiety/depression, 0.05. According to Finch et al. (2002), this showed a moderate agreement for mobility, substantial agreement for self-care, fair agreement for usual activities, fair agreement for pain and a slight agreement for anxiety/depression item. A three-week test-retest reliability of the EQ-5D in a group of patients who had a stroke produced  $\kappa$  coefficients that ranged from 0.63 to 0.80 for the five dimensions and 0.86 for the VAS section suggesting excellent reproducibility (Dorman et al., 1998). Two-week test-test reliability estimates were also found to be high by Hurst et al. (1997) with ICCs of 0.85 and 0.78 for the VAS and the weighted index score.

c) Why the EQ-5D?

There are many quality of life outcome measures that can be used which include the Medical Outcomes Study 36-Item Short Form (SF-36) health survey, the Nottingham Health Profile (NHP), the Sickness Impact Profile (SIP), the Quality of Well-Being (QWB) Scale and the Health Utilities Index (HUI) among many others. Instruments that measure quality of life differ in whether they are generic or specific. Generic health related quality of life instruments can be applied across all diseases or conditions, medical interventions or even populations while specific health related instruments are made to be specific to particular interventions or for specific populations (Patrick and Deyo, 1989). The SF-36 is one of the most commonly used health status questionnaires. It comprises of 36 items that were selected from the Medical Outcomes Study . It belongs to the health profile section of generic instruments for measuring quality of life. The SF-36 has been shown to a valid and reliable instrument for measuring quality of life though this was in a population of patients with osteoarthritis (Kantz et al., 1992).

There are no uniformly 'worst' or 'best' performing instruments when it comes to measuring quality of life (Coons et al., 2000).The EQ-5D instrument was chosen for use in this study because it is an easy to use generic measure of health related quality of life (EuroQol Group, 1990). It is also important to note that the EQ-5D is designed to characterise an individual's current health status and the results obtained from this instrument can be used for health-economic evaluation with less time being needed for its administration. The EQ-5D is also simple to use, valid, responsive to change and sufficient for group comparisons (Hurst et al., 1997). In as much as the SF-36 is also a good generic instrument that can be used for measuring quality of life, it does not have these qualities. To add to this both the EQ-5D and the SF-36 have acceptable and qualitatively similar test-retest reliability and both can be used for assessing health related quality of life outcomes in patients after stroke (Dorman et al., 1998). The ease of application, availability (available from the EQ-5D group free of charge) and less time required for



administration led to the EQ-5D being chosen as the instrument to measure health related quality of life in this study.

### **3.2.4 For objective 4, “To establish the effect caregiver education has on the quality of life of the caregivers”:**

The EQ-5D was used together with the Caregiver Strain Index (CSI). The Caregiver Strain Index was used as an additional outcome measure. The CSI consists of 13 questions that address the impact of care giving on the carer’s life. It has been shown to have construct validity (Robinson, 1983). It has been used to measure care-giving strain in spouses of patients with stroke (Blake et al, 2003).

#### **The Caregiver Strain Index (CSI)**

##### a) General Description and History of the CSI

The CSI was developed by Robinson in 1983 and is very popular in stroke research. It is a brief and easily administered tool and it is the most commonly used scale to measure care-giving burden (Visser-Meily, 2004). The CSI consists of 13 items that are posed to the caregiver as questions. The caregiver has to answer ‘yes’ or ‘no’. A ‘no’ is given a value of ‘0’ while a ‘yes’ is given a value of ‘1’. The CSI is then computed by summing ‘0’ (no) and ‘1’ (yes) responses to give a total out of 13, in other words the total score is the number of yes answers. This then simply means that the CSI scores range from 0 to 13. Positive responses to seven or more items on the index indicate a greater level of stress (Robinson, 1983).

##### b) Validity and Reliability of the CSI

The CSI was established to have good internal reliability with a coefficient of 0.86 (Robinson, 1983) a score that was slightly bettered by the Modified Caregiver Strain Index (MCSI) which scored 0.88 (Thornton and Travis, 2003). The reproducibility of the CSI was found to be very good (0.93; 95% confidence interval 0.84 – 0.97) with better responsiveness than the Caregiver Reaction Assessment (CRA) (Post et al., 2007).

##### c) Why the CSI?

Just like most other instruments, modified versions of the CSI have also been produced. One such version is The Modified Caregiver Strain Index (MCSI), which still assesses 13 aspects of physical health, family finances, social interactions, time demands and employment (Thornton and Travis, 2003). There are also other scales that can be used to measure caregiver burden such as the Sense of

Competence Questionnaire (SCQ) (Scholte op Reimer et al., 1998b), Caregivers' Burden Scale (CBS) (Elmstahl et al., 1996), Relatives' Stress Scale (RSS) (Draper et al., 1992), Burden Interview (BI) (Schulz et al., 1988) and Caregiver Reaction Assessment (CRA) (Given et al., 1992). However, as stated by van Exel et al. (2004), when the CSI was compared to the CRA and the SCQ on caregivers of patients with stroke, it was found that the CSI was a better instrument because it was easy to use and resulted in fewer missing values. The evidence for clinical validity was also strongest for the CSI based on associations between higher burden scores and patients' disability, and patients' and caregivers' poor level of health related quality of life (van Exel et al., 2004).

The CSI can be used to assess caregiver burden in individuals of any age who have assumed the role of caregiver for an older adult (Sullivan, 2002). It is a brief, easily administered instrument (Sullivan, 2002). The CSI is the most commonly used scale for measuring caregiver burden (Visser-Meily et al., 2004). As stated by Visser-Meily et al. (2004), no measure for caregiver burden has proven superiority above others. The CSI was chosen for this study because of its good validity and reliability, ease of access and also the fact that it requires less time to administer. Studies done on caregivers of patients with stroke have also recommended the CSI as the instrument of choice for assessing the burden of informal caregivers (van Exel et al., 2004, Post et al., 2007).

### **3.2.5 For objective 5, *"To establish the effect caregiver education has on the ability of the stroke survivor to socialise and participate in community issues"*:**

The International Classification of Functioning, Disability and Health (ICF) checklist was used to help answer this objective. The ICF framework has three components:

- i) Body functions and structures- this component includes physiologic and anatomical parts. In these, the loss or variation/deviation from normal body function and structures are referred to as "impairments".
- ii) Activity- this includes task execution by the individual. Limitations in activity are difficulties an individual could have in executing "activities"
- iii) Participation- this includes involvement in everyday situations. Therefore, "participation" restrictions are challenges people may experience with such involvement".

(WHO, 2001).

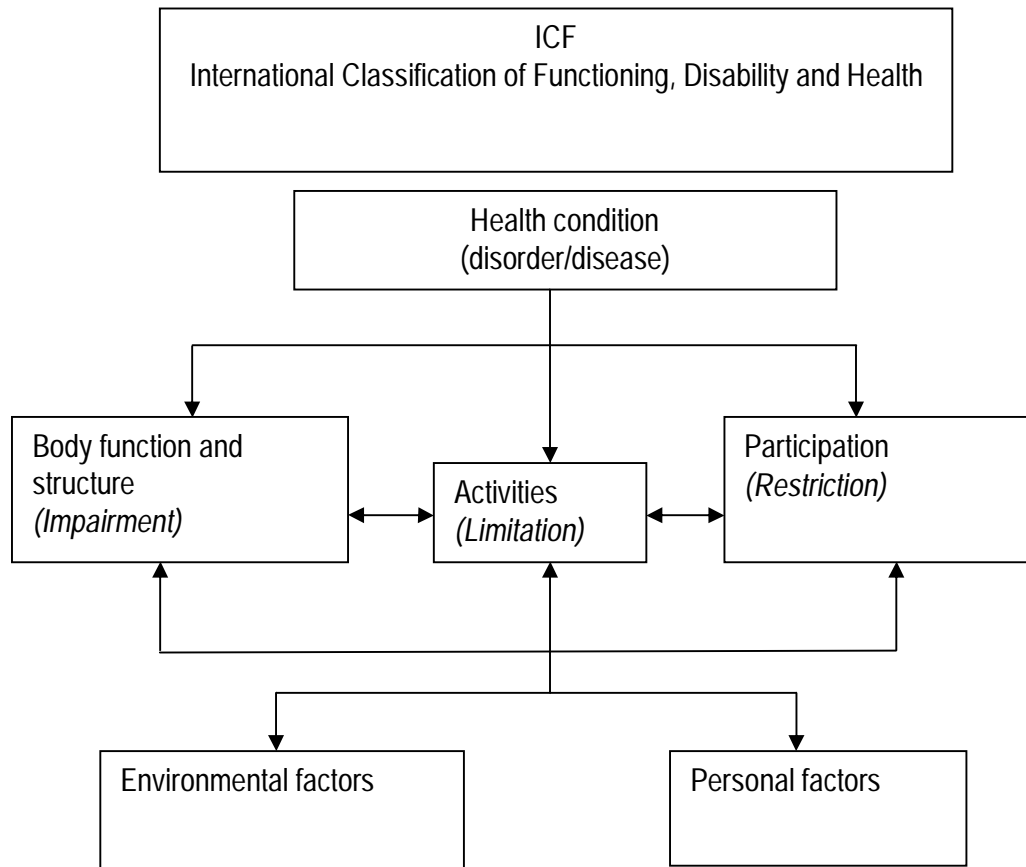
The participation section addresses general capacity and restriction to participation, interpersonal relationships and interactions and also community, social and civic participation. This part of the ICF was important for this study so as to measure this aspect for patients with stroke post discharge from hospital. Independent community ambulation is a challenging rehabilitation goal and affects the patients' ability to participate in the community (Lord et al., 2008). This makes the assessment of this aspect of the patients' lives post-stroke very important.

a) General Description and History of the ICF

The International Classification of Functioning, Disability and Health (ICF) checklist provides a standard language and a universal and globally accepted framework and classification that comprehensively address human experiences in relation to functioning and health. The first classification of disability, the International Classification of Impairment, Disabilities and Handicaps (ICIDH) was published and released for trials only in 1980 (WHO, 1980). The ICIDH did not manage to get approval from the World Health Assembly as an official WHO classification mainly because of the criticism it received over the negative terminology such as handicap and also for not taking into account the role of the environment in its model. As a response to this, the WHO developed the ICF, which was then endorsed by the World Health Organisation (WHO) in 2001 as a modification or improvement of the ICIDH (WHO, 2001). The change from the ICIDH to the ICF meant that the WHO was moving from a biomedical model to a bio-psycho-social model. Use of the ICF enables the international community to communicate in a common language using common terminology enabling better understanding and comparison of research outcomes within and across patient populations (Geertzen, 2008; WHO, 2001).

The ICF framework components described above can be represented in a flow diagram to show how they are interlinked as shown below:

Figure 3.1 below illustrates the ICF framework.



**Figure 3.1:** ICF framework adopted from WHO (2001)

The ICF allows one to measure how an individual fares when involving capacity to do an activity and actual performance. Capacity refers to what one can do under the best circumstances and performance refers to what one can actually do in day-to-day life (Geertzen, 2008). The ICF has both positive and negative terms to reflect both capacity and difficulty (WHO, 1999). The positive terms are body structure and function, activity, and participation while the negative terms are impairments, activity limitations and participation restrictions. It has the potential to provide coding for the various items on the different measures commonly used in the health field that would enable the characterisation of specific functional problems of individuals (Ustun et al., 2003, Finger et al., 2006). From the main ICF an ICF core set for stroke was developed (Stier-Jarmer et al., 2005, Ewert et al., 2005)

b) Validity and Reliability of the ICF

The validation process of the ICF is an ongoing development in which all the evidence gathered during its implementation will be integrated (Cieza and Stucki, 2008). The fact that the ICF was borne out of a worldwide comprehensive consensus process over several years arguably gives it a degree of validity. Two focus groups of patients with rheumatoid arthritis (RA) managed to confirm the entire ICF core set for RA suggesting that it is a robust and all inclusive instrument (Coenen et al., 2006). In patients with stroke, the methods that are used for reporting specific measurement qualities of outcome for the participation section of the ICF were found to be inconsistent (Salter et al., 2005). Salter et al. (2005) go on further to say that the responsiveness of the measures has not been well documented and hence care should be taken when reporting the strength of the measurements. However, other studies have found the ICF to have exhaustiveness/width because it was shown to be able to cover all aspects of the patient experience (Kirchberger et al., 2007a; Kirchberger et al., 2007b)

The inter-rater agreement of two physiotherapists who administered the ICF and the Extended ICF Core Set for Stroke was fairly poor with observed agreement being 51% with Kappa = 0.41 (Starrost et al., 2008). These results were not found to be related to rater confidence or the physiotherapists' areas of core competence.

c) Why the ICF?

The ICF places the notion of health and disability in a new light. It 'mainstreams' the experience of disability and recognises it as a universal human experience (WHO, 2009). This suggests that the ICF has the capacity to describe fully how well or badly an individual is faring while in the community following stroke. The ICF has been used in measuring activity and participation of patients with stroke when they are in the community with very good applicability and ability to highlight the problematic areas (Mayo et al., 2002). There are many scales that have been developed to try and measure the degree of community integration/participation following stroke such as the Community Integration Questionnaire, the Perceived Handicap Questionnaire, the London Handicap Scale but none of these is as comprehensive as the ICF making it the natural choice to help answer this study objective in patients with stroke. The ICF is considered to follow a universal model instead of a minority one and this provides worldwide cultural applicability (Cieza and Stucki, 2008). In addition to this as pointed out by Jelsma (2009), utilisation of the ICF in developing countries must be encouraged. The ICF was therefore the instrument of choice for this objective.

### **3.2.6 For objective 6, “To establish patient characteristics associated with increased caregiver strain following a stroke”:**

This information was captured largely as part of the demographic data of the patient in addition to the data that were collected from the Barthel Index (BI), RMI and the EQ-5D.

#### **Patient Demographic Questionnaire**

##### a) General Description

The patient demographic questionnaire collected information that included the stroke survivors' degree of functional independence, type of stroke, the affected hemisphere and financial independence (See Appendices B and C).

##### b) Validity and Reliability

The questionnaire was checked for content validity and repeatability (test-retest). The content validity was checked by giving the questionnaire to experts in the field of physiotherapy neurology for their input given the intended objectives. Minor modifications were made to the questionnaire following the meeting with experts. The questionnaire was then piloted on patients with stroke to get further input on the clarity of the questions and also to check its repeatability (see pilot study results section, Chapter 5).

The Barthel Index (BI) was used to gather information on the patient's functional independence in activities of daily living.

#### **The Barthel Index**

##### a) General Description and History of the Barthel Index (BI)

The Barthel Index (BI) was used to gather information on the patient's functional independence in activities of daily living. The 10-item BI was published in 1965 by Mahoney and Barthel to measure functional independence specifically directed at the personal and domestic activities of daily living. It has 10 questions, which address bowel and bladder management, grooming, toilet use, feeding,

transfers, mobility, bathing and dressing. The values assigned to each item are based on time and amount of actual physical assistance required if a patient is unable to perform the activity (Mahoney and Barthel, 1965). The total score for the original BI was 100 and the higher the score, the better the functional ability of the patient.

In most studies, a score of 50 or more was used to define favourable outcome (Sulter et al., 1999). However, as shown by Sulter et al. (1999), a score of 60 was a pivotal point as patients moved from assisted independence to dependence. Similar scoring methods were used elsewhere where 60% was the cut off between independence and more marked dependence, 40% or below indicated severe dependence while 20% or below reflected total dependence (Granger et al. (1979), Finch et al., 2002)

It is however important to note that the original BI as put forward by Mahoney and Barthel (1965) has since been substantially modified. For example, the BI that was developed by Collin and his colleagues (1988) consists of a maximum score of 20. This BI variation (the Collin 20 point) has been shown to be completely valid, reliable, appropriate and clinically significant (Collin et al., 1988).

In another attempt to modify further the original BI, the 5-item BI was developed (Hobart and Thompson, 2001). This was however shown to have lower internal consistency than the 10-item BI did and had considerable floor effects in the initial stages of rehabilitation (Hsueh et. al., 2002).

#### b) Validity and Reliability of the BI

Data management is considered to be of high quality if it meets the requirements of reliability, internal consistency and validity. As stated by Sharrack et al. (1999), an assessment tool should be scientifically sound in terms of three basic psychometric properties: reliability, validity, and responsiveness. A study by Hsueh et al. (2001) found the BI able to meet all these requirements. Green et al. (2001) found that measurements of basic activities of daily living and mobility using the BI was very reliable post-stroke.

In a study investigating the test-retest reliability of the BI, Green et al. (2001) found that the mean difference between testing was only 0.4 and a reliability coefficient of 2.0 was found - indicating good reliability with little bias. In a study comparing BI and the Functional Independence Measure (FIM), Hsueh et al. (2001) found that the BI was in no way inferior to the motor subscale of the FIM and, in fact, was preferable to the FIM in measuring activities of daily living in that it took less time and was less complicated. These sentiments were later strengthened by Houlden et al.'s 2006 study findings that

showed that the FIM scores did not have any advantage over the BI in evaluating change during early patient rehabilitation.

van der Putten et al.'s 1999 study concurred with these findings in a study aimed at comparing the appropriateness and responsiveness of the FIM and BI when used to assess patients with stroke and multiple sclerosis. One of the major criticisms of the BI has always been the accusation that it has a "ceiling effect". However Salter et al.'s 2005 study showed that the BI had good responsiveness with only a noteworthy ceiling effect of 27% being seen post discharge from rehabilitation facilities. Their study also found the BI to have excellent test- retest (regardless of the skill of the rater) and inter-observer reliability as well as excellent internal consistency.

c) Why the BI?

The BI and Functional Independence Measure (FIM) are observer-rated generic measures (not specific to a disease/condition) of activity used in studies examining functional recovery following stroke rehabilitation. The FIM was developed in 1986 in response to the perceived shortcomings of the BI, which was considered too simple and unresponsive (Granger et al., 1986). Availability and cost issues result in the BI being used more often than the FIM in clinical trials (Sangha et al., 2005).

The BI and FIM are recommended for group comparison studies and not for individual patient's decision-making (Hobart et al., 2001). D'Olhaberriague et al. (1996) established that the interobserver agreement of the BI is greater than that of the Rankin score and that the BI was the more reliable disability scale. Non-medical personnel can use the BI reliably, as established by Schlote et al. (2004) implying that it is very user friendly. Collin et al. (1988) also found no difference in the results of the BI when using four different methods of obtaining the score (i.e. self-reporting, asking a trained nurse, and separate testing by two skilled observers).

For this study, the BI was chosen as the instrument for collection of data on patients' functional abilities because it was found to be used more often than the FIM and the BI was cited in studies that were of superior quality (Sangha et al., 2005). There is also a trend in that the BI is used in studies that are more recent especially if they originate in Europe (Sangha et al., 2005). The BI was also chosen because it is easy to apply and has been well-validated (Green et al., 2001 and Collin et al., 1988).



### **3.2.7 For objective 7, “To establish caregiver characteristics associated with increased caregiver strain following a stroke”.**

This information for this objective was largely collected through a questionnaire (caregiver demographic questionnaire, Appendix D) that gathered the demographic data for the caregiver in addition to that gathered from the EQ-5D.

#### **Caregiver Demographic Questionnaire**

##### a) General Description

The information that was captured with this questionnaire included the amount of time spent care giving, amount of help received from relatives, number of family members staying with caregiver and stroke survivor, financial independence of caregiver, level of education of the caregiver, gender of caregiver and age of caregiver. The type of accommodation used (own house or renting) by caregiver and patient was also recorded.

##### b) Validity and Reliability of the Caregiver Demographic Questionnaire

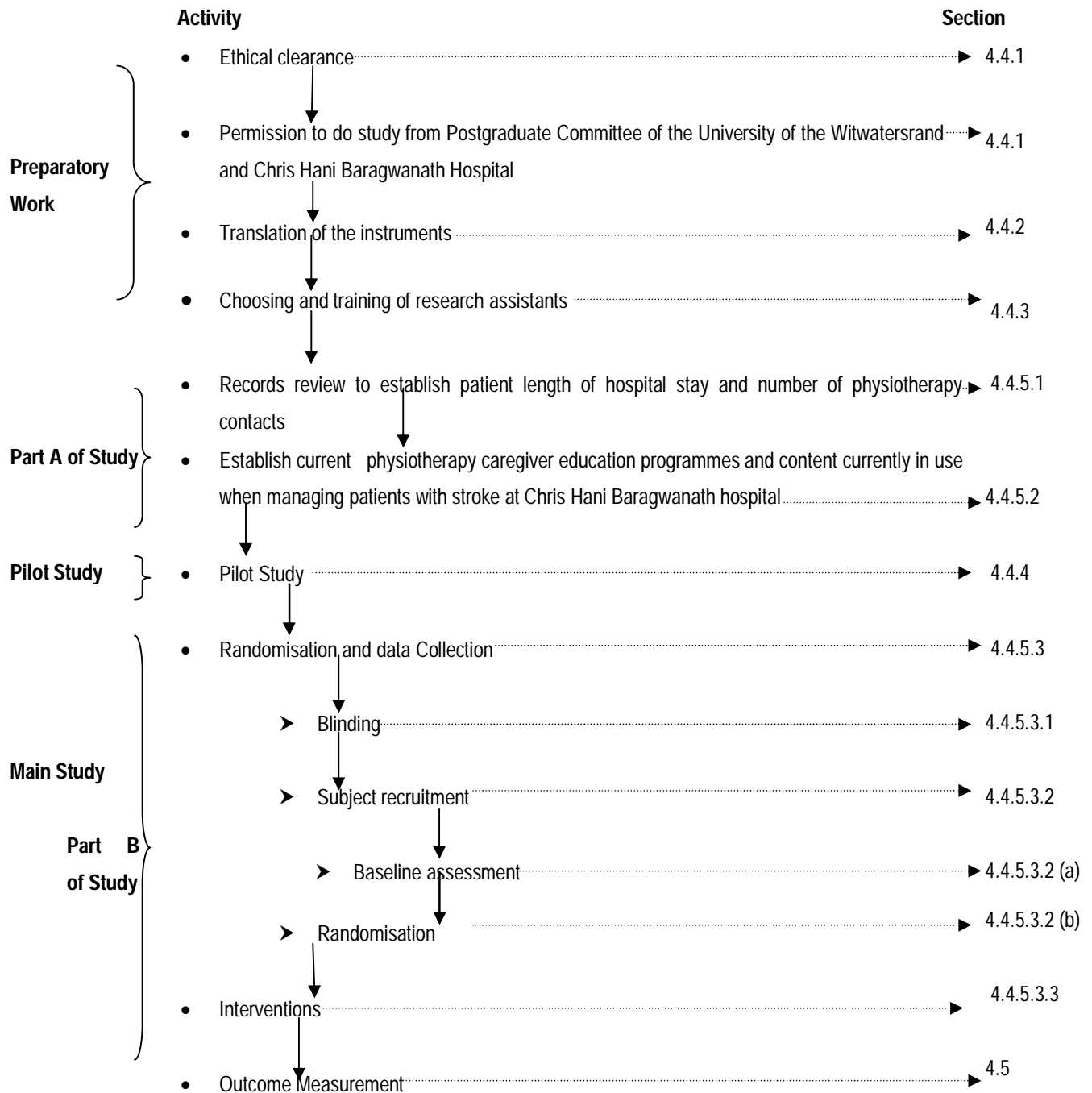
The questionnaire was checked for content validity and repeatability (test-retest). The content validity was checked by giving the questionnaire to experts in the field of neurology for their input given the intended objectives. Minor modifications were made to the questionnaire following the meeting with experts. The questionnaire was then piloted on patients with stroke to get further input on the clarity of the questions and also to check its repeatability (see pilot study results section, Chapter 5).

# CHAPTER 4

## 4. METHODOLOGY

### 4.1 Introduction

This chapter explains the procedure that was followed when obtaining data for the study. The method employed to analyse the data is also explained. The design of the study was as shown in the flow diagram below.



**Figure 4.1:** Methodology flow diagram

## 4.2 Study Design

A stratified randomised controlled trial using concealed allocation with a broad entry and blinded outcome assessment at three months, six months and one year after randomisation was used. Concealed allocation was done to ensure randomisation while blinded outcome assessment was necessary to avoid bias. The stratification was necessary to ensure appropriate representation of the stroke subgroups so that results could be generalised to the stroke population.

## 4.3 Subjects

### 4.3.1 Source of subjects

Stroke survivors from Chris Hani Baragwanath Hospital (CHBH) participated in the study. The hospital caters mainly for the surrounding largely black population of Soweto, in Johannesburg, South Africa. It is considered the world's largest hospital, occupying 173 acres with 3200 beds. It is also a tertiary referral centre and one of the University of the Witwatersrand teaching hospitals (Tshukutsoane and Scribante, 2008). The caregivers of the stroke survivors were also residents of Soweto.

### 4.3.2 Sample Size

From a statistical calculation, a sample of 200 patients with stroke and caregivers (100 per group) had 80% power to detect a difference in means of 1.0 assuming that the common standard deviation was 2.5 using a two-group t-test with a 0.05 two-sided significance level using the Barthel Index as the main outcome measure. However, for the Caregiver Strain Index, EuroQol (EQ5D) questionnaire, Rivermead Mobility Index and the ICF checklist this sample size yielded power in excess of 90%.

#### 4.3.2.1 Inclusion Criteria

##### a) Patients

Patients with stroke were included in the study when they met the following criteria:

- a confirmed diagnosis of any of the ischaemic strokes subtypes and were 18 years of age and above.
- both male and female patients
- resident in Soweto.
- independent in activities of daily living before the stroke
- medically and neurologically stable at the time of baseline assessment

- expected to return home with some form of residual disability which would make them need supervision or physical assistance for core activities of daily living
- had someone willing to look after them post discharge (a caregiver) who fulfilled the required inclusion and exclusion criteria.

b) Caregivers

The people who were to be responsible for looking after the person with stroke were included in the study if they:

- were 18 years and above.
- were willing to provide support to the person with stroke after discharge.
- did not have a disability that made them require help with activities of daily living as well.
- were a resident of Soweto (for ease of follow up).

#### 4.3.2.2 Exclusion Criteria

a) Patients

Patients with stroke were excluded from the study if they:

- had a haemorrhagic stroke.
- had a transient ischaemic attack.
- were experiencing a second or recurrent stroke (might have previous exposure to education, likely to have pre-existing disability, and as misdiagnosis of stroke is common in those who have had a prior stroke).
- were medically unstable or had a life threatening pathology.
- were discharged within 24 hours of admission to hospital (before the physiotherapy team had time to assess them)
- lived outside the study area (Soweto).
- did not have a caregiver who would help look after them after discharge.

b) Caregivers

Caregivers were excluded from the study if they:

- were less than 18 years of age.
- were not willing to participate in the study.
- were not in a position to provide support to the patient after discharge.
- were professional caregivers (would have had prior exposure to education).

The patient was excluded from the study if the caregiver did not meet the inclusion criteria and there was nobody else from the family or close to the patient who could meet the inclusion criteria.

## **4.4 Procedure**

The instruments that were used for the data collection are described in detail in Chapter 3: "Instrumentation and Outcome Measures". These instruments are the Barthel Index (BI), the Rivermead Mobility Index (RMI), the Caregiver Strain Index (CSI), part two of the International Classification of Functioning, Disability and Health (ICF) checklist, the EuroQol (EQ-5D) questionnaire and self-designed questionnaires to capture demographic details of the patients and caregivers. Below is the procedure that was used for the data collection.

### **4.4.1 Ethical Considerations:**

The following ethical practices were taken into consideration during the data collection process:

- Informed consent was sought at all times from the participants including the physiotherapists, patients and the caregivers.
- If either the patient or the caregiver declined to participate in the study, they were not considered for further participation in the study.
- In the case of patients who were aphasic, consent was sought from the immediate caregiver or responsible relative of the patient.
- The information that was collected was kept confidential at all times and was used only for the purposes of the study.
- Ethical clearance for the project was sought and granted from the Committee for Research on Human Subjects of the University of the Witwatersrand (ethical clearance number M050328; Appendix AP).

Permission to do the study was also sought and granted from the Head of the Physiotherapy Department and Chief Executive Officer of Chris Hani Baragwanath Hospital (see Appendix AQ and AR).

While permission was being sought from these various bodies, the translations for the instruments into languages that are commonly spoken in the Johannesburg metropolitan area was undertaken.

### **4.4.2 Translation of Instruments**

To enable availability of the research instruments to the participants in a language that was familiar and comfortable to them (in terms of understanding), the demographic questionnaires (for both the patients

and their caregivers), the BI, RMI, CSI, EQ-5D and ICF were made available in English, isiZulu and Sesotho language versions.

The original English instruments were translated into the two versions (isiZulu and Sesotho) with the help of language experts. Different people from the same translation service department were then given the translated documents to translate back into English.

The back translation process was done to ensure consistency and to prevent loss of meaning during the translation process. To reconcile any differences that may have arisen during the translation process, a meeting was then held with people fluent (two for each language) in the three languages and the few differences that appeared between the original and back translated versions were reconciled by looking at the vernacular versions and obtaining consensus on the translation (Beaton et al., 2000).

The few differences in translation that were seen were deemed to have arisen from those words that did not have ready meanings in the vernacular language and these are further explained in the pilot study.

### **4.4.3 Choosing and training of research assistants**

To facilitate the data collection process, research assistants were needed. The function of the research assistants involved identification of participants, concealed randomised allocation of participants into the two main groups for the study and training of the caregivers who were in the experimental group. The role of the researcher was to train the research assistants as well as to collect all data from baseline assessment to assessment 12 months post-stroke. The researcher was blinded to the training and group allocation of the patients and caregivers until after the data collection process was completed. The completed assessment forms were also kept by the first research assistant (involved in initial identification and screening assessment for inclusion into the study) so as to reduce potential bias from the researcher during subsequent assessments.

#### **4.4.3.1 The Research Assistants**

Successful rehabilitation of patients with stroke requires a multidisciplinary approach with each member of the rehabilitation team playing an active role as is required by the way in which the patient presents.

With this in mind, the research assistants were drawn from physiotherapists, occupational therapists and physiotherapy assistants.

The following were needed as research assistants for the data collection process:

a) Three Physiotherapists

Three physiotherapists were needed for the data collection process. One was involved with the initial identification and screening assessment of patients to see if they met the inclusion criteria and to seek the patients' consent to taking part in the study. Once that was done, the name of the patient was given to the second physiotherapist who performed concealed stratified random allocation of the patients. The names of those who were in the experimental group were then given to the third physiotherapist who was responsible for the training of the caregivers. The third physiotherapist and the researcher did not have access to the list showing the allocation of the patients.

b) One Occupational Therapist

The occupational therapist was involved with the training of caregivers who belonged to the experimental group. The third physiotherapist who was responsible for the training of the caregivers worked in conjunction with the occupational therapist.

c) One Physiotherapy Assistant

The physiotherapy assistant's function was to help with screening of patients for inclusion into the study as well as helping with translations during the data collection process as required.

The ability to converse in at least two of the three languages was a requirement to qualify as an assistant for this study. This was necessary to make both the data collection process and the training of caregivers as understandable and relevant to the participants as was possible.

#### **4.4.3.2 Training of the Assistants**

The assistants were trained for the data collection process in an afternoon workshop after they had agreed to help with the data collection. The assistants were specifically trained in the following:

a) Screening of the patients and caregivers

The assistants were made aware of the inclusion and exclusion criteria for both the patients and caregivers. They were also given information and training on the different classifications of stroke subtypes to aid understanding of the research process that needed to be followed in general and specifically the stratified random allocation of patients.

b) Training of the caregivers

The research assistants who were involved with the training of the caregivers were then briefed on how to train the caregivers in the experimental group. This training process involved both a theoretical component and a practical session on aspects such as lifting techniques, handling of the hemiplegic shoulder, facilitation techniques to aid with the re-training of mobility and any other activities of daily living needing attention (see Appendix AO for outline of training manual).

The training of research assistants also covered information on stroke related problems and their prevention; such as management/prevention of pressure sores, importance of positioning, gait facilitation and sexuality issues. A theoretical revision of the definition of stroke, its causes, consequences, prevention and management options (including physiotherapy and occupational therapy) was also given (see Appendix AO for outline of training manual). To ensure that the research assistants understood the training process, the researcher observed them training caregivers during a pilot study run.

#### **4.4.4 Pilot Study**

A pilot study was conducted in preparation for the main study.

a) **Purpose of the Pilot Study**

The purpose of the pilot study was to:



- i) test the methodological process and establish if there were any unforeseen circumstances that could hamper the data collection process.
- ii) establish clarity of the questionnaires and instruments used by both the physiotherapists and patients and to make adjustments as necessary.
- iii) establish the amount of time it would take to administer the questionnaires and instruments.
- iv) establish the average time it would take to run a training session for those caregivers in the experimental group.
- v) establish the intra-rater reliability of the self-designed questionnaires, the CSI, EQ-5D, RMI and ICF instruments.
- vi) to familiarise the research assistants with the data collection process.
- vii) establish the average number of patient physiotherapy contacts for patients with stroke prior to discharge.

## **b) Methodology of the Pilot Study**

### **i) Questionnaire for the Physiotherapists**

To check understanding of the questions in the questionnaire that was developed to establish the current content of caregiver education programmes and the barriers to the interaction between physiotherapists and caregivers, questionnaires were administered to four physiotherapists from another hospital in Johannesburg. The questionnaires were given to the therapists in the morning for them to complete and comment on any questions they felt were not very clear as well as the amount of time it took to complete them. The completed questionnaires were then collected in the afternoon of the same day.

### **ii) Administration of the questionnaires and instruments to the patients and caregivers**

The patient demographic questionnaire and measuring instruments were administered to ten patients who fitted the inclusion criteria at Chris Hani Baragwanath hospital. Completion of the questionnaire and instruments was simultaneously done by the researcher and an assistant in-order to establish inter-rater reliability. In order to establish intra-rater reliability of the researcher and the research assistant, the same questionnaires and instruments were administered five to seven days later (depending on availability of the caregiver). The measuring instruments that were administered to the patients were the patient demographic questionnaire, BI, RMI, EQ-5D and the ICF. The EQ-5D was self administered

while the rest of the instruments were interviewer administered. For patients who were aphasic, some of the information was collected from the caregivers.

The caregivers for the ten patients had the caregiver demographic questionnaire, the CSI and the EQ-5D administered. The EQ-5D and the demographic questionnaire were self administered while the CSI was interviewer administered. Assistance was given during the completion of the instruments as was necessary.

iii) Training of the caregivers

After completion of the questionnaires, the caregivers of five of the ten patients identified for the pilot study were trained in how they could help the patient when at home to aid recovery. The other five caregivers could not make it to the training session due to various commitments elsewhere. The training was done by the two research assistants who were to be involved in the caregiver education , a physiotherapist and an occupational therapist. The training involved individualised programmes that were specific to the needs of the patients for whom they would be caring.

iv) Review of patient records to establish number of physiotherapy contacts

The records of patients who had been admitted for stroke -related illnesses were retrieved and reviewed if they had been admitted to Chris Hani Baragwanath Hospital from the 1<sup>st</sup> of March 2005 to the 31<sup>st</sup> of October 2005. Hundred files of patients admitted with a diagnosis of stroke were accessed. Only those records of patients who were discharged home after admission were reviewed. The information that was retrieved was on the number of physiotherapy contacts (contact between the patient and the physiotherapist) during in-patient hospital stay.

#### **4.4.5 Main Study**

##### **4.4.5.1 Part A: Records Review for Patient Hospital Length of Stay and Number of Physiotherapy Contacts**

The records of patients who had been admitted for stroke -related illnesses were retrieved and reviewed if they had been admitted to Chris Hani Baragwanath Hospital from the 1<sup>st</sup> of March 2005 to the 31<sup>st</sup> of October 2005. Files of patients who had been admitted with a diagnosis of stroke were accessed until a total of 100 were obtained. Only those records of patients who were discharged home

after admission were reviewed. The information on patient length of hospital stay and the number of physiotherapy contacts (contact between the patient and the physiotherapist) during in-patient hospital stay was retrieved from the files.

#### **4.4.5.2 Part A: Establishing the Current Caregiver Education Programme in Place at Chris Hani Baragwanath Hospital (CHBH)**

Part one of the study involved establishing the current caregiver education programme (and its content) being used at CHBH. For this, the physiotherapists' understanding of the role of the caregiver in managing patients with stroke, the physiotherapists' thoughts on their effectiveness in involving caregivers in managing patients with stroke, the content of the physiotherapists' caregiver training programmes and lastly the barriers to caregiver involvement in managing patients with stroke were established using a self administered open ended questionnaire (Appendix J).

The questionnaire was hand delivered to the physiotherapists who were working in the neurology department of CHBH physiotherapy department. The therapists who consented to take part in the study were given three days to complete the questionnaire after which the forms were collected by the researcher.

An information sheet explaining the purpose of the study and the fact that the physiotherapists were not obliged to take part in the study was given together with the questionnaire. It was also explained to them that by completing the questionnaire they were consenting to taking part in the study.

#### **4.4.5.3 Part B: Randomisation and Data Collection – Patients and Caregivers**

##### **4.4.5.3.1 Blinding**

A computer generated random number sheet was produced with blinding of the researcher and the researcher did not have access to it until after data collection. The research assistant who was involved with the allocation of patients and caregivers into the two groups for the study was not involved with the assessment or training of the participants and this allocation was with the blinding of the researcher and the research assistants responsible for caregiver training. Once randomisation was completed, the names of the patients in the experimental group were given to the research assistant responsible for caregiver training. The allocation into groups and training of the caregivers was done with blinding of

the researcher. The second training of caregivers, which was provided at three months depending on the needs of the caregiver, was done with blinding of the researcher.

#### **4.4.5.3.2 Subject recruitment**

To attain the required sample size for the study, all consecutive patients with ischaemic stroke and their caregivers fitting the inclusion criteria were approached by either the researcher or the research assistant for their permission and initial screening for inclusion into the study until the sample size was reached. Patients were approached when they were in the medical wards after admissions for suspected and confirmed diagnosis of ischaemic stroke. A detailed explanation was given to the patients about the study purpose and requirements, and information sheets were handed out to aid with the explanations. Once this was done, informed consent was then sought from the patient. It was only after this that the details of the caregiver were obtained from the patient. The same procedure was then followed with the caregiver. The caregivers were approached either during the hospital visiting time or via the telephone to seek their permission for inclusion into the study and to set up times when they could come and sign the consent forms. For inclusion into the study, both the patient and the caregiver needed to agree to participate in the study.

The diagnosis of stroke was confirmed by CT scan/MRI and the classification of the stroke subtype was done by the neurologist in the ward. The stroke subtype classification that was used followed the Oxfordshire Community Stroke Project (OCSP) classification system as was proposed by Bamford et al. (1991). Once suitability for inclusion into the study had been ascertained, the name of the patient was given to the research assistant responsible for the randomisation.

##### **a) Baseline Assessment**

On attainment of informed consent, a baseline assessment was then done on both the patient and the caregiver by the researcher. The information that was sought from the patients included the demographic data, cause of stroke, stroke subtype, resultant neurological deficits, caregiver availability and relationship. For the caregivers the information that was sought was demographic data including employment status.

The baseline assessment was done before randomisation and during the hospitalisation period. The medical stability of the patient was verified during baseline assessment. Once deemed stable enough and within a day or two before discharge the BI, RMI and EQ-5D were then administered to the patients

while the EQ-5D was administered to the caregivers. In the event of the patient having speech problems and not being able to provide some of the information required for the data collection process, the caregiver was asked to provide the information (Sneeuw et al, 1997).

b) Randomisation

Blocked stratified randomisations with concealed allocations were then done after the baseline assessments. The stratification was done for the research sample of 200 patients following the percentages that were proposed by Bamford et al. (1991) for ischaemic stroke subtypes. The randomisation was thus done within each stroke subtype.

There are four ischaemic stroke subtypes according to the Oxfordshire Community Stroke Project Classification (OCSP) by Bamford et al. (1991). Although the study by Bamford et al. (1991) was done on a different continent (Europe) because of the lack of similar data from Africa, the percentages for the stroke subtypes that they established were adopted for this study.

Table 4.1 below shows the distribution of the percentages that were used in the randomisation process according to stroke subtype.

**Table 4.1:** Percentage distribution of the stroke subtypes

<b>Infarction Stroke Subtype</b>	<b>Percentage</b>
Total Anterior Circulation Infarct	17%
Partial Anterior Circulation Infarct	34%
Posterior Circulation Infarct	24%
Lacunar Circulation Infarct	25%

(Adopted from Bamford et al. 1991)

These percentages were then used to justify the stratifications for the randomisation process.

Once the patient had been assessed (baseline assessment), they were then randomised into either the control or experimental group using computer generated stratified random numbers. The group allocations, either control or experimental, were put into envelopes marked 1 to 200. The envelopes were then handed to the patients by the research assistant responsible for the randomisation process, ensuring concealed allocation of subjects.

#### **4.4.5.3.3 Interventions:**

##### **a) Control Group**

All the patients and caregivers in the control group (group 1) received the standard existing rehabilitation stroke care as was currently being undertaken at CHBH at the time of the study. In other words, the usual way of handling patients with stroke at discharge from CHBH and how the caregivers were involved in that process was followed (see Chapter 5 for the description of the standard practice).

##### **b) Experimental Group**

###### **i) Initial Intervention for stroke survivors and their caregivers**

All the patients with stroke in the experimental group received the standard and existing rehabilitation stroke care as was currently being done at CHBH.

In addition to the above, all the caregivers in this group received “hands-on” training in lifting and handling techniques, back care, facilitation of mobility and transfers, continence, assistance with activities of daily living and communication. Included were information on stroke related problems and their prevention, management/prevention of pressure sores, continence, positioning, gait facilitation and sexuality as was indicated by the condition of the patient they would be looking after post discharge.

The caregivers also received information on stroke; that is its definition, causes, consequences, prevention and management options (including physiotherapy and occupational therapy). They were also encouraged to have their stroke survivors (patients) attend nursing and therapy activities (mobility, transfers and activities of daily living training) during hospitalisation and after discharge wherever possible. Advice on the available community services such as stroke aid groups and out-patient rehabilitation services was also provided.

This training was given as a 45-minute training session just before discharge home of the patient. The training was specific to the individual patient needs for whom the caregiver would be responsible. It involved a practical component where the caregivers were expected to demonstrate the taught exercises.

## **ii) Subsequent Intervention for caregivers**

The training assistant visited the patients at three months as part of the follow up assessment. This was to check the general wellbeing of the patient and the caregiver and depending upon either need or upon request, a subsequent training session for the caregivers was provided only to those belonging to the experimental group.

This subsequent training was provided at a local clinic, home or hospital, whichever was most appropriate and convenient for the caregiver. The same content as for the initial training was covered but was once again tailor made to suit the current requirements of the person with stroke and those of the caregiver. Again, this lasted for 45 minutes.

## **4.5 Outcome Measures**

The baseline assessments were done just before discharge for both the patient and the caregiver. After that, follow up assessments were done at 3, 6 and 12 months post discharge.

The follow up assessments were mainly done at home or any convenient place and wherever possible were done separately for patients and caregivers.

In the few instances where patients were unable to complete questionnaires due to speech problems, caregivers were allowed to help by providing information. Instruments were made available in English, isiZulu and Sesotho as explained in the "Instrumentation and Outcomes" chapter (Chapter 3).

## **4.6 Data Analysis**

To help deduce meaning from the data, descriptive statistics were used to analyse the data especially for the demographic information and assessment of patient community participation. The means and standard deviations of the various data categories were calculated as was appropriate for the demographic variables of the patients and the caregivers e.g. for age, Rivermead Mobility scores, Barthel Index scores and quality of life scores. The chi-square test (and where appropriate the Fischer's exact test as well) were used to compare most of the demographic data such as patient and caregiver age, marital status, side of body affected, gender and their effects on variables that included functional ability, mobility and quality of life. The comparisons between the experimental and control group involving continuous data were done using the independent *t* test. Regression tests using an analysis of

variance (ANOVA) were also used to establish the influence of the different factors from the assessment tools on the quality of life of the stroke survivor.

Logistic regressions were used to estimate odds ratios comparing the caregiver measurements to the stroke survivors. The data obtained from the Barthel Index, Rivermead Mobility Index and ICF checklist provided a degree of independence or dependence of the stroke survivor and their impact on the caregiver's strain and quality of life was ascertained. Where appropriate, change scores were used for data analysis. The data analysis was done using both "intention to treat" and "per protocol" analyses. However, the discussion is centered on the "intention to treat" analysis, which was the preferred model for data analysis as recommended by the Consolidated Standards of Reporting Trials (CONSORT) agreement (Altman et al., 2001). All statistics were calculated using STATA version 11.1. The significance level was set at  $p \leq 0.05$ .



## CHAPTER 5

### 5. RESULTS

#### 5.1 Introduction

The results of the pilot and main study are presented in this chapter using descriptive statistics, tables and graphs and where appropriate statistical tests. The results that are presented are those that were obtained using the “intention to treat” analysis. “Intention to treat” analysis is the recommended method for data analysis when reporting randomised trials (Altman et al., 2001). The results for the per protocol analysis are given as an appendix (see Appendix A). There are different schools of thought on how to deal with missing data, that is to impute or not to impute and if you are imputing how to impute the data and these are acknowledged. However, for this study, no data were imputed as that would have distorted the study findings especially given the fact that caregiver data were also necessary for data analysis. Missing data should not be imputed using 0 (zero) for this can create confusion especially if the variable being investigated could have a value of zero (Robson, 2002). Comparisons would have been inappropriate if data were imputed for caregivers who were not followed up when the patients they cared for died. The actual presence of the patients was required to establish the effect on the caregiver.

#### 5.2 Pilot Study Results

##### a) Results of the pilot study

###### i) Administration of questionnaire to the physiotherapists

The physiotherapists reported that it took on average 10 minutes to complete the questionnaire. They did not report any ambiguous questions in the questionnaire.

###### ii) Administration of questionnaire and instruments to patients and caregivers

It took on average 40 minutes to complete and administer all the instruments and questionnaires to both the patient and caregiver. If any interpretation (translation) of the instruments was needed the data collection process took as much as one and a half-hours. The interpretation was necessitated by situations where the patient or caregiver was not able to read any of the languages that were available. This was mainly because of low educational levels among the participants. To mitigate against this, the instruments were also made available in two vernacular languages, isiZulu and Sesotho.

The ICF proved to be relatively difficult to administer with the main problem being that it was a relatively long section and not easy to understand or distinguish sections for most of the

patients/caregivers. As a result, more time was needed to complete the ICF section. In addition to that, the ICF was also made available in isiZulu and Sesotho. The rest of the instruments were clear and easy to administer to both patients and caregivers.

iii) Training of the caregivers

The training of the caregivers was seen to take on average 45 minutes depending on the number of items that needed to be covered for the concerned individual(s). It was also noted that getting a number of caregivers to arrive at the same time for the training session was going to be a challenge.

**b) Implications of the results of the pilot study on the main study**

The pilot study results showed that there was a need to budget for adequate time for the training sessions since they were most likely going to be done on an individual basis and not in groups as was initially envisaged. The study also showed that more time needed to be set aside for the administration of instruments in cases where an interpreter was required. Minor adjustments needed to be made to the self-designed questionnaires since they were largely understood. The adjustments that were made were as follows:

- i) Receiving benefit/grant was added to question 3 (on patient demographic questionnaire) and question 2 (on caregiver demographic questionnaire) that sought to establish the employment status of the patients and the caregivers

Lastly, it was quite clear that even for those instruments which the patients or caregivers were supposed to complete on their own (self-administered), time needed to be created to ensure the availability of the researcher during the completion process in case they had questions that needed an immediate response.

### **5.3 Validity and Reliability of Instruments**

a) Patient Demographic Questionnaire

The patient demographic questionnaire had good intra-rater reliability with a Spearman's correlation coefficient of 0.98.

b) Rivermead Mobility Index

The Rivermead mobility index had good intra-rater reliability with a Spearman's correlation coefficient of 0.96.

c) EQ-5D

The EQ-5D had good intra-rater reliability with a Spearman's correlation coefficient of 0.89.

d) Caregiver Strain Index

The Caregiver Strain Index had good intra-rater reliability with a Spearman's correlation coefficient of 0.86.

e) ICF

The ICF had fairly good intra-rater reliability with a Spearman's correlation coefficient of 0.61.

f) Caregiver Demographic Questionnaire

The caregiver demographic questionnaire had good intra-rater reliability with a Spearman's correlation coefficient of 0.99.

### 5.4 The average number of physiotherapy contacts prior to discharge

Two hundred and twenty records of patients with a diagnosis of stroke at admission were reviewed and of these, 100 met the inclusion criteria. The remainder either died prior to discharge or did not have a confirmed diagnosis of stroke after admission. Figure 5.1 below shows the distribution of the number of physiotherapy contacts for the reviewed files.

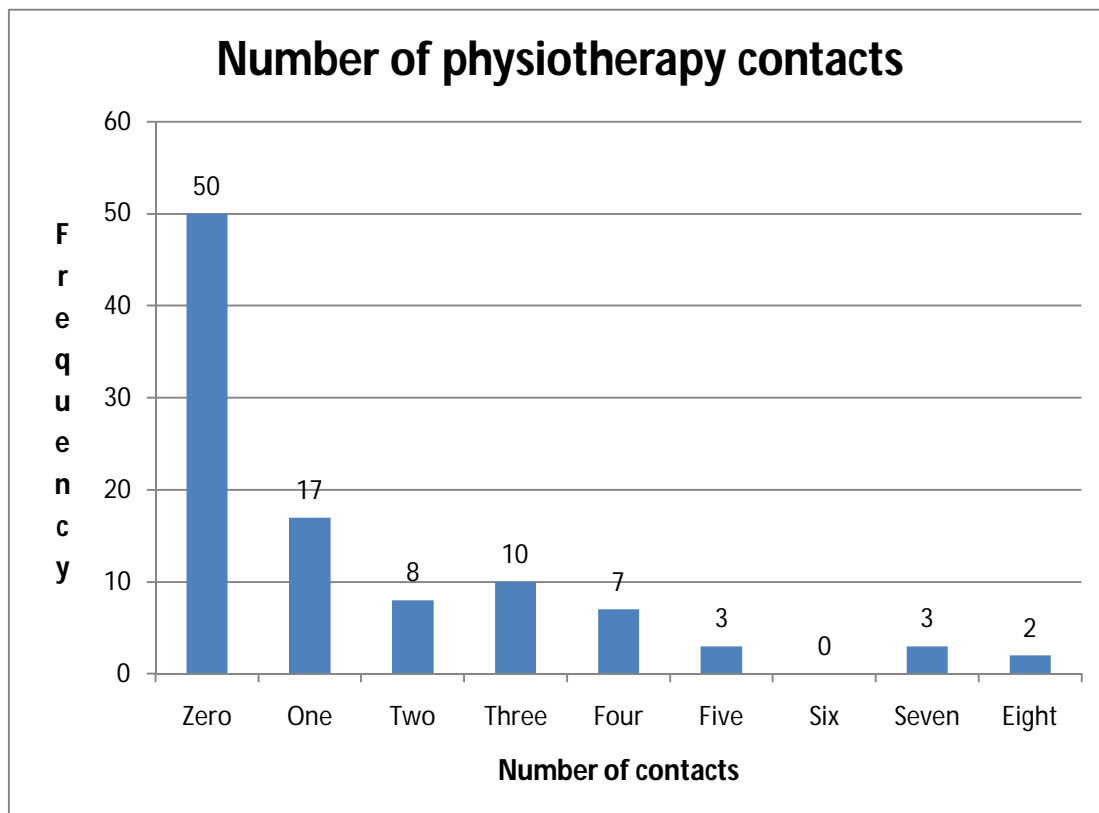
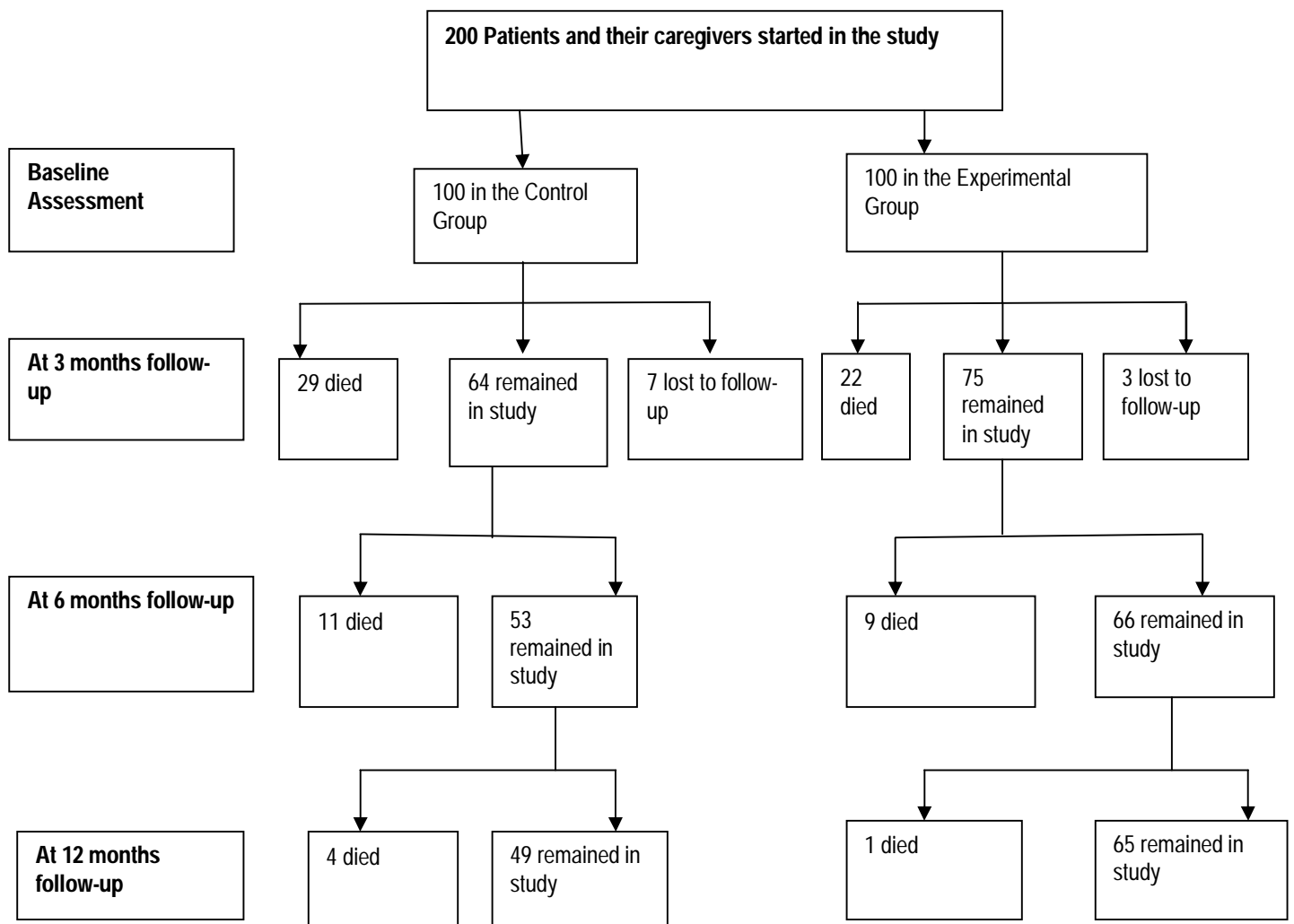


Figure 5.1: Number of physiotherapy contacts during in-patient stay (n = 100)

A review of 100 records of confirmed patients with stroke showed that on average patients with stroke received one physiotherapy contact during their in-patient stay.

### 5.1 Participant retention and outcome

The sample size for the study was 200 patients with stroke and their caregivers. There were 100 patients and caregivers in each of the two groups, the control and the experimental groups. The distribution of the study sample over the one-year study period is shown in Figure 5.2 below.



**Figure 5.2:** The distribution of the study sample over the one-year study period

Thirty-eight percent of the patients died during the one-year period with the majority of the patients (25.5%) dying within three months post discharge. Ten patients could not be found at the 3-month follow-up. The patients could not be found because the addresses that they had provided at the

hospital prior to discharge were incorrect and they did not have cell phone or land line telephone numbers on which they could be tracked. They also did not have any other contactable relatives with whom we could check their whereabouts. Thus, only 5% of the sample could not be traced.

## 5.2 Equality of the study groups at baseline

The differences between the study groups at baseline were checked using a two-sample t test with equal variances and the results are shown in Table 5.1 below.

**Table 5.1:** The differences between the study groups at baseline

<b>Characteristic</b>	<b>Difference</b>	<b>t-value</b>	<b>p value</b>
Patient age	2.06	1.28	0.20
BI Total	-0.09	-0.28	0.48
RMI Total	-0.34	-1.75	0.80
Patient Perceived Health State (EQ-5D)	-1.25	-0.84	0.20
Caregiver age	-1.16	-0.63	0.53

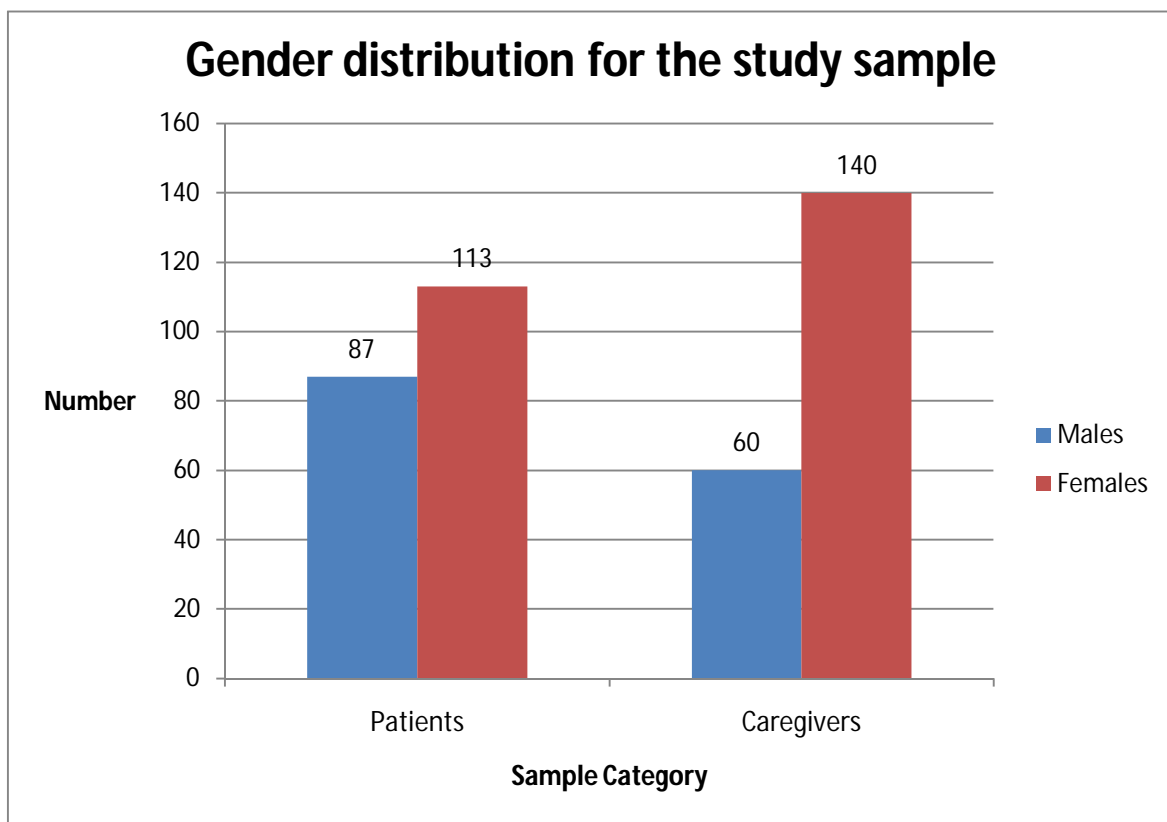
The differences between the study groups' major variables at baseline were not statistically significant when tested at the 0.05 level of significance.

## 5.3 Demographics of the Study Sample

This section gives the results for the demographics of the study sample (both patients and caregivers as is appropriate) which cover gender, stroke subtype, age, level of education, employment status, marital status, relationship of caregiver to patient, availability of the caregiver and the home environment.

**a) Gender distribution for the study sample**

The gender distribution of the patients and caregiver for the study sample is shown in Figure 5.3 below.



**Figure 5.3:** The gender distribution of the study sample (n = 200)

There were more females than males in both the patients and the caregivers.

The gender distribution of the patients study sample by stroke subtype is shown in Figure 5.4 below.

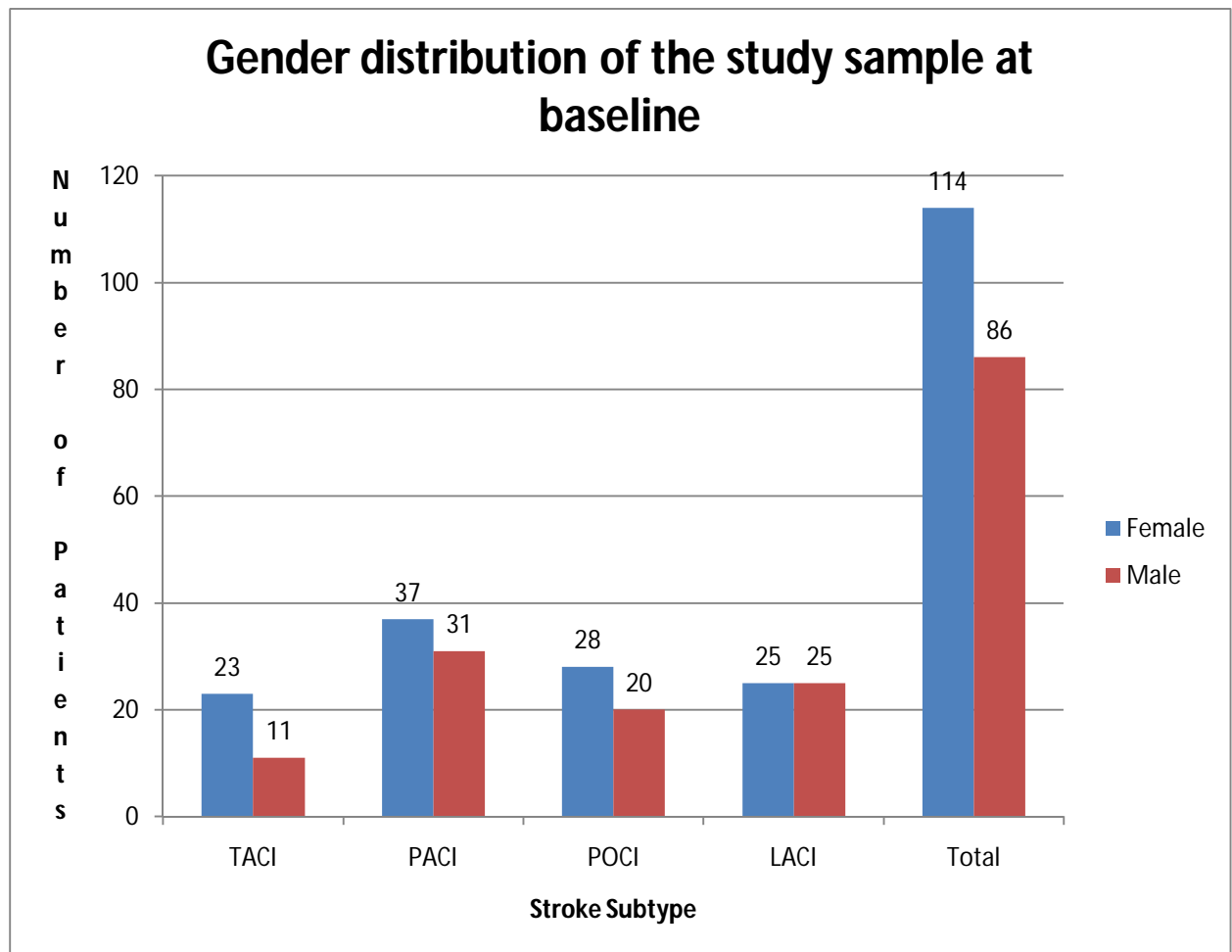
**Key:**

TACI= Total Anterior Circulation Infarction

PACI = Partial Anterior Circulation Infarction

POCI= Posterior Circulation Infarction

LACI = Lacunar Circulation Infarction



**Figure 5.4:** Gender distribution of the patients study sample by stroke subtype at baseline assessment (n = 200)

There were more females in the patient study sample (57%) than males (43%) and there was a generally similar trend within the stroke subtypes except for lacunar infarcts where the gender distribution was equal.

**b) Distribution of the patients study sample by stroke subtype**

The gender distribution of the patients' study sample by stroke subtype and side of body affected at baseline assessment is shown in Table 5.2 below.

**Table 5.2:** Gender distribution of the patients by stroke subtype and side of body affected (n = 200)

Gender	Total	Side of body affected	TACI		PACI		POCI		LACI		Total	Overall Total	
			CG n	EG n	CG n	EG n	CG n	EG n	CG n	EG n		CG n(%)	EG n(%)
Male	87(43.5)	Left Hemiplegia	4	3	9	9	6	7	9	7	28(14)	26(13)	54(27)
		Right Hemiplegia	1	3	8	5	3	4	4	5	16(8)	17(8.5)	33(16.5)
Female	113 (56.6)	Left Hemiplegia	7	3	6	11	10	8	7	5	30(15)	27(13.5)	57(28.5)
		Right Hemiplegia	5	8	11	9	5	5	5	8	26(13)	30(15)	56(28)
Total			17	17	34	34	24	24	25	25	100(50)	100(50)	200(100)

CG = control group and EG=experimental group

There were more females with right hemiplegia (28%) than males (16.5%), a trend that was seen in most of the stroke subtype groups.



**c) Age distribution of the patients and caregivers at baseline.**

The age distribution of the study sample is shown in Table 5.3 below.

**Table 5.3:** The age distribution of the patients at baseline (n = 200)

**Key:**

TACI= Total Anterior Circulation Infarction  
PACI = Partial Anterior Circulation Infarction  
POCI= Posterior Circulation Infarction  
LACI = Lacunar Circulation Infarction

<b>Age</b>	<b>Male n(%)</b>	<b>Female n(%)</b>	<b>TACI n(%)</b>	<b>PACI n(%)</b>	<b>POCI n(%)</b>	<b>LACI n(%)</b>	<b>Total n(%)</b>
≤20 years	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
21 – 30 years	0(0)	2(1)	0(0)	2(1)	0(0)	0(0)	1(0.5)
31 – 40 years	14(7)	10(5)	1(0.5)	13(6.5)	4(2)	6(3)	23(11.5)
41- 50 years	32(16)	35(17.5)	10(5)	19(9.5)	18(9)	20(10)	67(33.5)
51 – 60 years	19(9.5)	36(18)	11(5.5)	18(9)	11(5.5)	15(7.5)	48(24)
61 – 70 years	18(9)	21(10.5)	8(4)	11(5.5)	12(6)	8(4)	46(23)
71 – 80 years	3(1.5)	8(4)	2(1)	5(2.5)	3(1.5)	1(1.5)	12(6)
≥81 years	1(0.5)	1(0.5)	2(1)	0(0)	0(0)	0(0)	2(1)
Total	87(43.5)	113(56.5)	34(17)	68(34)	48(24)	50(25)	200(100)
Minimum Age	31	28	39	28	34	33	28
Mean Age	52.1	54.1	57.4	52.1	53.8	51.3	53.2
Maximum Age	87	82	87	78	74	71	87
Std. Deviation	11.4	11.4	11.8	12.4	10.8	9.7	11.4

The 41 – 50 year old age group had the highest percentage of patients (33.5%) and the mean age for the patient study group was 53.2 years.

The age distribution of the caregivers for the study sample at baseline is shown in Table 5.4 below.

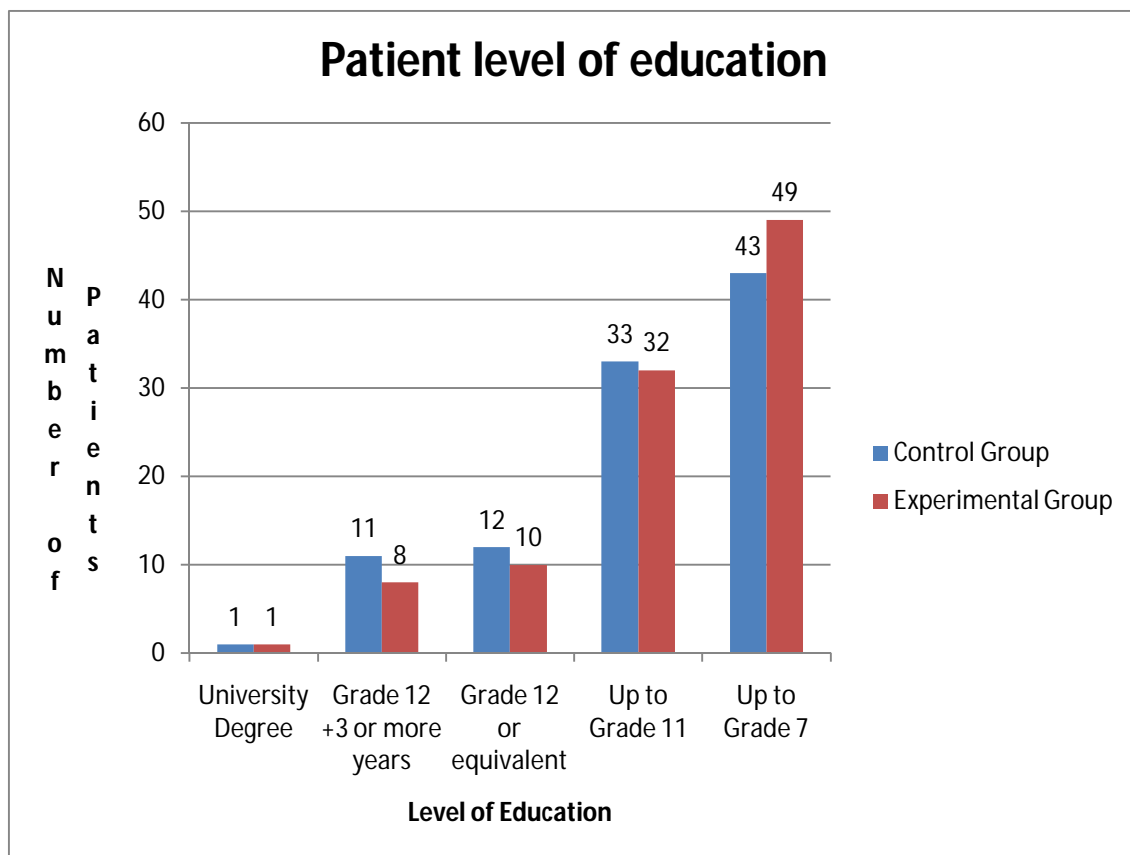
**Table 5.4:** Age distribution of the caregivers at baseline (n = 200)

Age	Control Group (n = 100)			Experimental Group (n = 100)			Total/ Overall
	Male n(%)	Female n(%)	Total n(%)	Male n(%)	Female n(%)	Total n(%)	
≤20 years	0(0)	1(0.5)	1(0.5)	0(0)	3(1.5)	3(1.5)	4(2)
21 – 30 years	10(5)	25(12.5)	35(17.5)	6(3)	18(9)	24(12)	59(29.5)
31 – 40 years	3(1.5)	18(9)	21(10.5)	7(3.5)	26(13)	33(16.5)	54(27)
41- 50 years	8(4)	20(10)	28(14)	3(1.5)	16(8)	19(9.5)	47(23.5)
51 – 60 years	5(2.5)	5(2.5)	10(5)	7(3.5)	3(1.5)	10(5)	20(10)
61 – 70 years	3(1.5)	0(0)	3(1.5)	7(3.5)	4(2)	11(5.5)	14(7)
71 – 80 years	1(0.5)	1(0.5)	2(1)	0(0)	0(0)	0(0)	0(0)
≥81 years	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
Total	30(15)	70(35)	100(50)	30(15)	70(35)	100(50)	200(100)
Minimum Age	21	20	20	21	19	19	19
Mean Age	42.8	37.4	39	47.4	37.1	40.2	39.6
Maximum Age	72	72	72	70	68	70	72
Standard Deviation	15.4	10.8	2.5	15.7	11.4	2.7	1.8

The highest percentage of the caregivers (58.5%) were younger than 41 years of age.

#### d) Educational level of the patients and caregivers

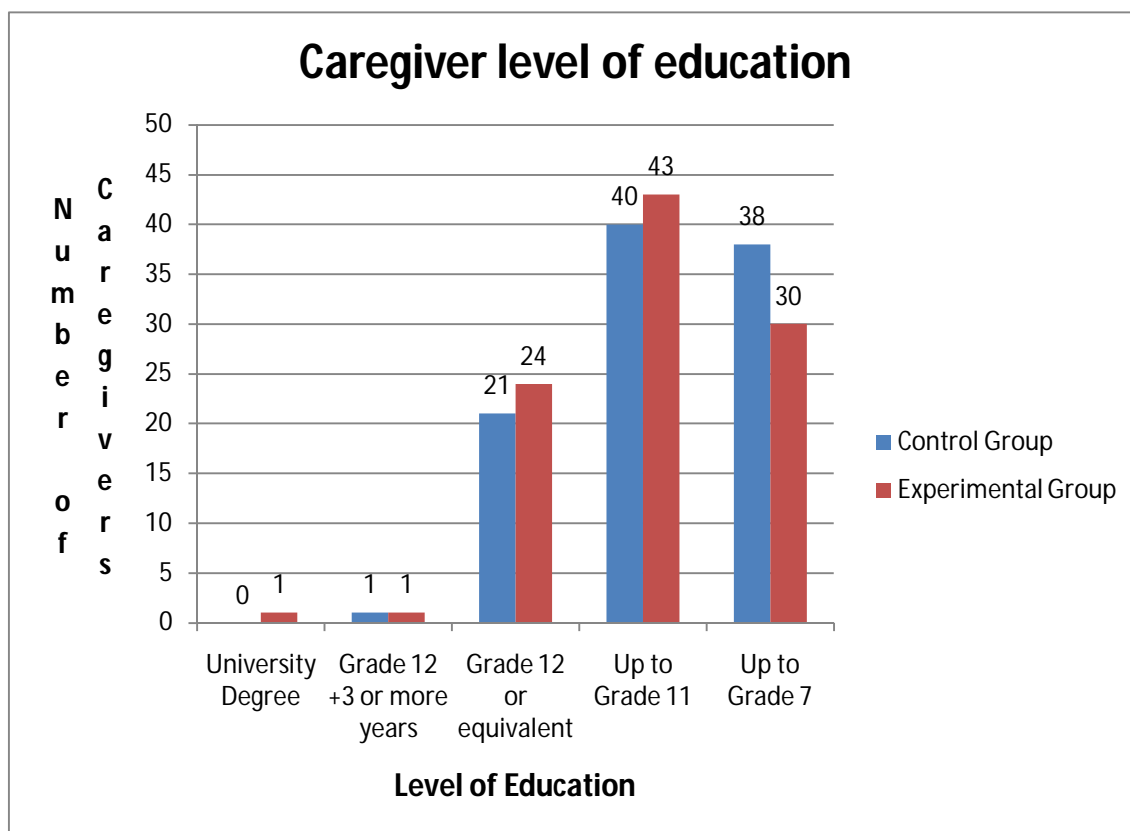
The education level of the patients is shown in Figure 5.5 below.



**Figure 5.5:** The patient level of education (n = 200)

The highest percentage of the patients (46%) had attained “up to Grade 7” level of education and hence can be classified as having received a low level of education. The distribution of educational levels between the two groups was almost even.

The distribution of the education level for the caregivers is shown in Figure 5.6 below.

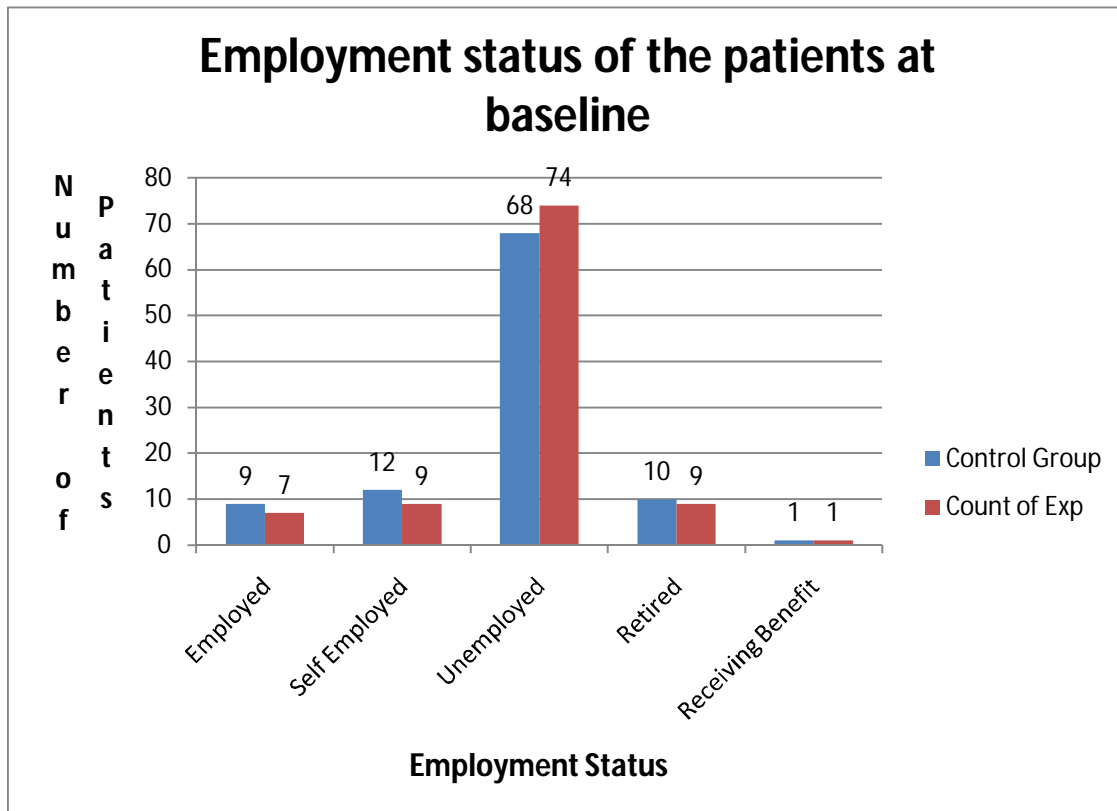


**Figure 5.6:** The caregiver level of education (n = 200)

The highest percentage of the caregivers (41.5%) had completed up to Grade 11 level of education. A fairly high number (34%) had completed up to Grade 7 level of education. All the caregivers were not gainfully employed at the time of the study.

### e) Employment status of patients and caregivers

The employment status of the patients at baseline is shown in Figure 5.7 below.

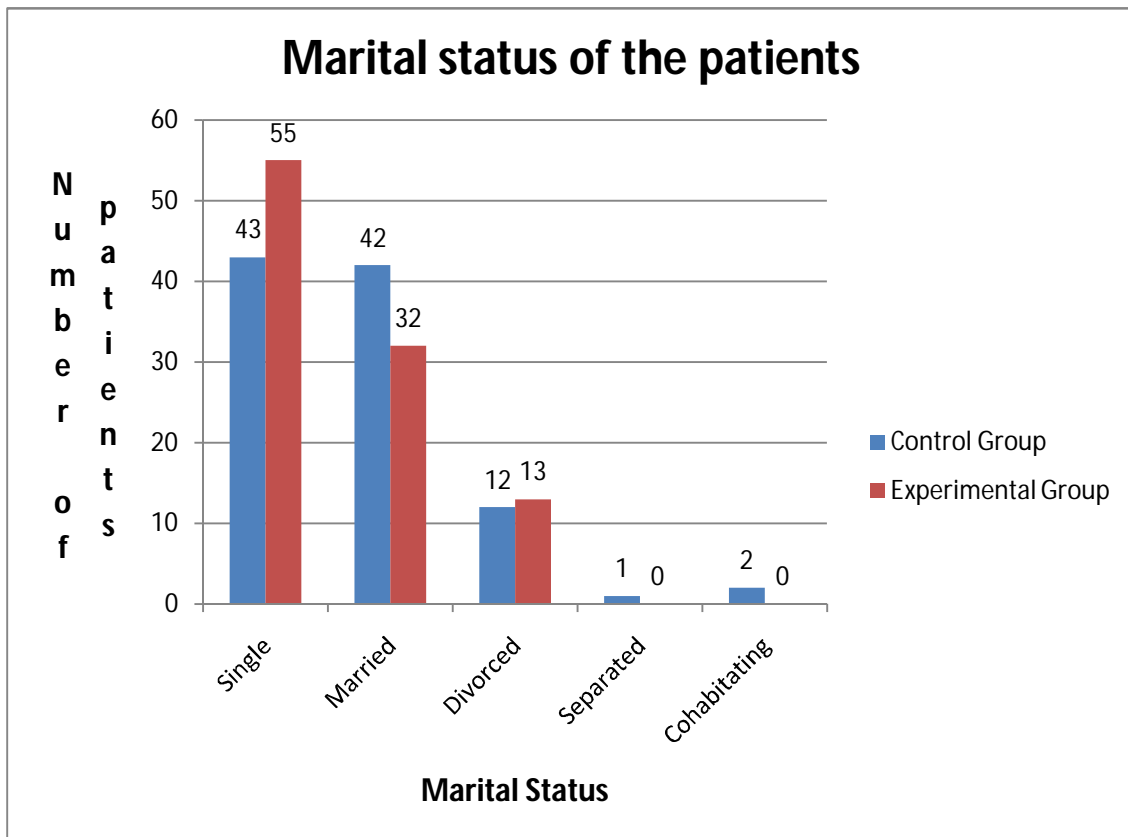


**Figure 5.7:** Patient employment status at baseline (n = 200)

A high percentage of the patients 71% (142) were unemployed.

**f) Marital status of the patients**

The distribution of the marital status of the patients for the study sample is shown in Figure 5.8 below.

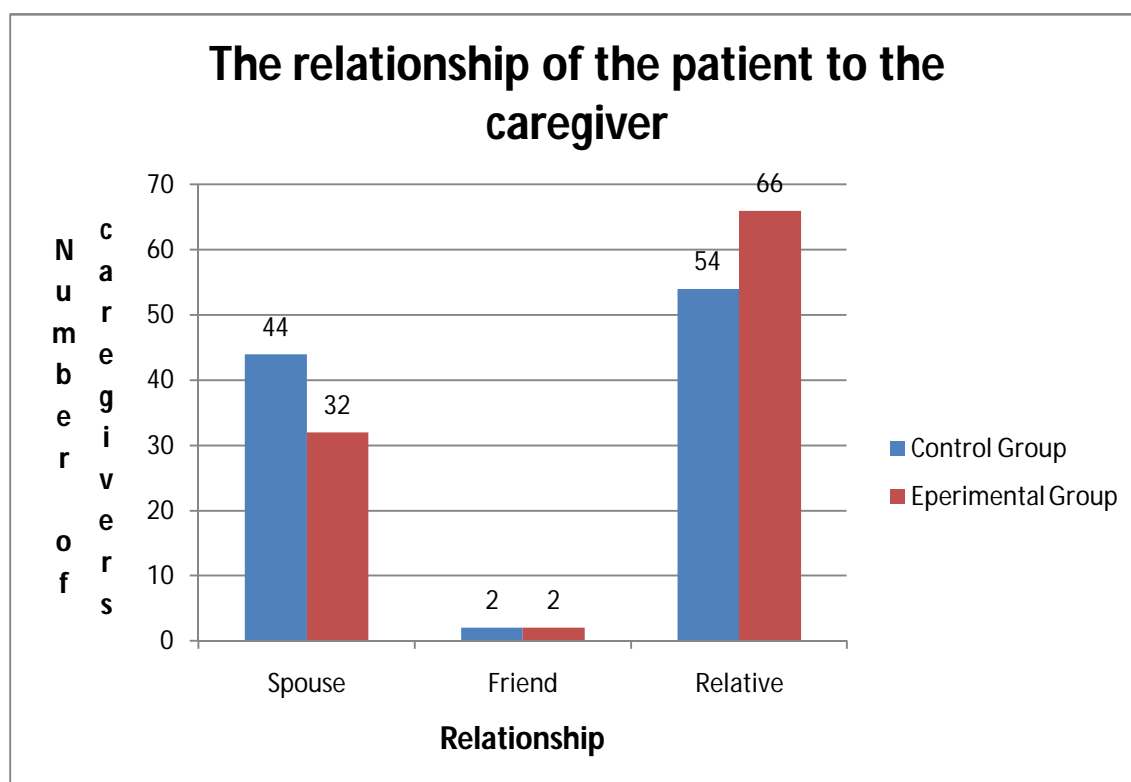


**Figure 5.8:** The patient marital status distribution (n = 200)

The highest percentage of the patients (49%) were single followed by 37% who were married. There were more single people (55) in the experimental group compared to the control group (43).

**g) The relationship of the patient to the caregiver**

Figure 5.9 below shows the distribution of the relationship of the patients to the caregivers for the study sample.

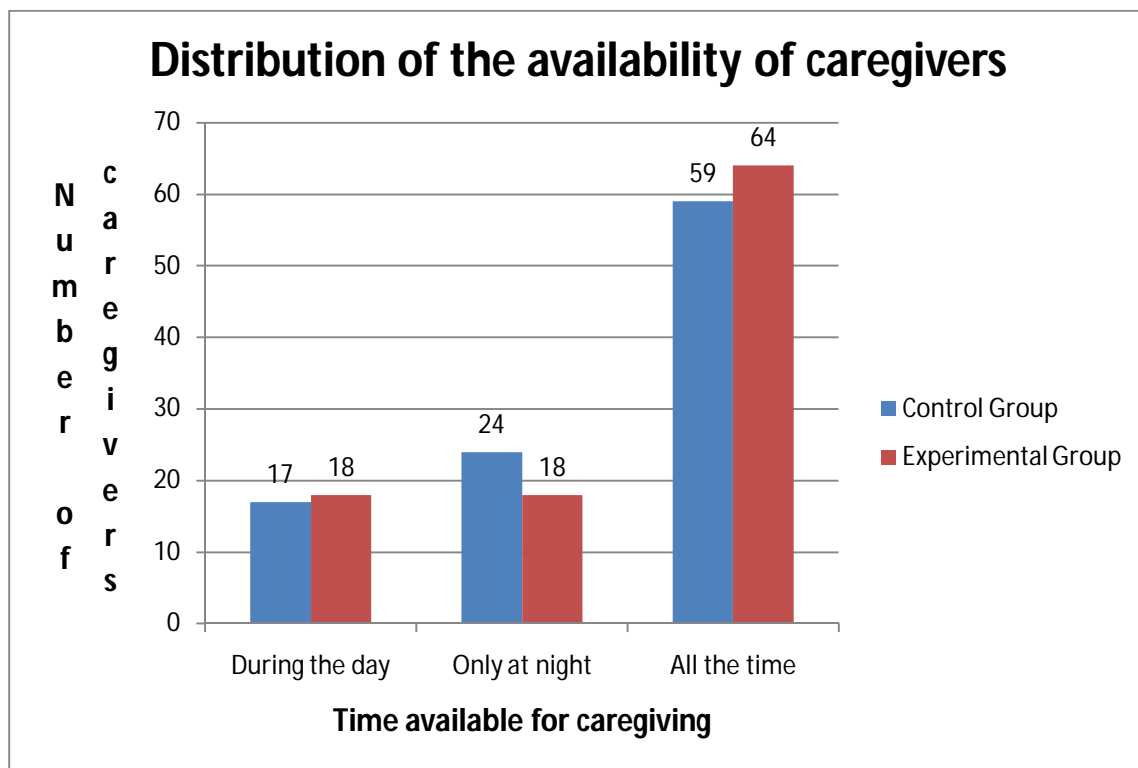


**Figure 5.9:** The distribution of the relationship of the patient to the carer (n = 200)

The highest percentage of the patients (50%) were cared for by relatives followed by 48% who were care for by spouses.

### h) Availability of the caregiver for caregiving duties

Figure 5. 10 below shows the distribution of the availability of caregivers for the study sample



**Figure 5.10:** The distribution of the availability of caregivers (n = 200)

The highest percentage of the caregivers (61.5%) were available all the time for care-giving duties.



**i) Home Environment for the patients**

Table 5.5 below shows a summary of the home environment for the patients.

**Table 5.5:** Patient home environment (n = 200)

<b>Home Environment</b>	<b>Study Group</b>	<b>No n(%)</b>	<b>Yes n(%)</b>
Running water	Control	3(1.5)	97(48.5)
	Experimental	7(3.5)	93(46.5)
Electricity	Control	3(1.5)	97(48.5)
	Experimental	7(3.5)	93(46.5)
Toilet inside	Control	58(29)	42(21)
	Experimental	49(24.5)	51(25.5)
Own bed	Control	100(50)	100(50)
	Experimental	100(50)	100(50)
Even ground	Control	58(29)	42(21)
	Experimental	49(24.5)	51(25.5)
Stairs	Control	100(50)	0(0)
	Experimental	100(50)	0(0)

The above percentages were calculated using 200 as the base (total sample for the patients).

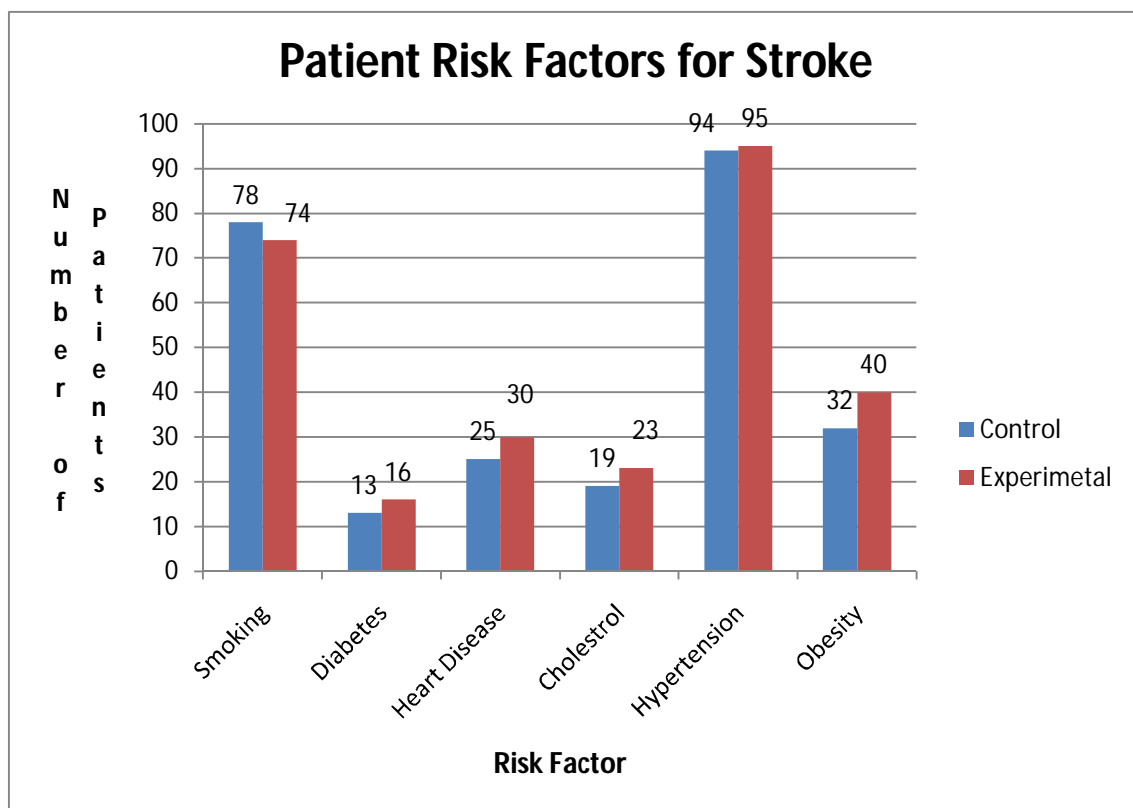
The majority of the patients (>90%) had running water, electricity and own beds. None of the houses had stairs.

## 5.4 Stroke Risk Factors and Subtypes, Deaths and Hospital Length of Stay

The following sections detail the results for stroke risk factors that were present in the patient study sample, the deaths that occurred among the patients (including comparisons of those who died and those who survived) and also the CHBH hospital length of stay for patients with stroke.

### a) Patient risk factors for stroke

The distribution of the risk factors for stroke that were present in the patients is shown in Figure 5.11 below.



**Figure 5.11:** Patient risk factors for stroke (n = 200)

The commonest risk factor for stroke was hypertension (94.5%), followed by smoking (76%) and obesity (36%).

**b) Description of those who died during the study period.**

The distribution of those who died during the study period is shown in Table 5.6 below.

**Table 5.6:** The distribution of those who died in the study by stroke subtype (n = 76)

Stroke Subtype	Time period of death	Control Group (n = 44)	Experimental Group (n = 32)	Total (n = 76)	Total death (within subtype) n(%)	Death % of study sample %
Total Anterior Circulation Infarct (TACI) (n = 34)	At 3 months	12(35.3)	6(17.7)	18(52.9)	24(70.6)	12
	At 6 months	2(5.9)	2(5.9)	4(11.8)		
	At 12 months	1(2.9)	1(2.9)	2(5.9)		
Partial Anterior Circulation Infarct (PACI) (n = 68)	At 3 months	10(14.7)	9(13.2)	19(27.9)	28(41.2)	14
	At 6 months	5(7.4)	3(4.4)	8(11.8)		
	At 12 months	1(1.5)	0(0)	1(1.5)		
Posterior Circulation Infarct (POCI) (n = 48)	At 3 months	3(6.3)	2(4.2)	5(10.4)	9(18.8)	4.5
	At 6 months	2(4.2)	1(2.1)	3(6.3)		
	At 12 months	1(2.1)	0(0)	1(2.1)		
Lacunar Circulation Infarct (LACI) (n = 50)	At 3 months	4(8)	5(10)	9(18)	15(30)	7.5
	At 6 months	2(4)	3(6)	5(10)		
	At 12 months	1(2)	0(0)	1(2)		
Total		44(58)	32(42)	76(100)		38

Overall, most of the deaths (14%) occurred within the PACI stroke subtype. Within each subtype however, the analysis revealed that TACI had the highest percentage of deaths (70.6%).

**c) The distribution of those who died by BI, RMI and EQ-5D scores at baseline**

The distribution by BI, RMI and EQ-5D scores at baseline of those who died are shown in Table 5.7 below.

**Table 5.7:** The distribution of those who died by BI, RMI and EQ-5D scores at baseline

<b>Parameter</b>	<b>Control Group (n = 44)</b>	<b>Experimental Group (n = 32)</b>	<b>Overall (n = 76)</b>
<b>Age</b>			
Mean	58.5	49.3	54.6
Minimum	33	31	31
Maximum	87	68	87
St. Deviation	13.4	11.5	13.3
<b>RMI Total Score</b>			
Mean	3.2	3.3	3.2
Minimum	1	1	1
Maximum	7	6	7
St. Deviation	1.2	1.3	1.3
<b>BI Total Score</b>			
Mean	5.3	5.1	5.2
Minimum	2	2	2
Maximum	10	11	11
St. Deviation	2.2	2.5	2.4
<b>EQ-5D VAS Score</b>			
Mean	41.5	40.9	41.3
Minimum	20	20	20
Maximum	65	80	80
St. Deviation	9.4	10.7	9.9

The patients who died had on average low total BI and RMI scores (5.2 and 3.2 respectively)

**d) Differences between those who died and those who survived:**

The differences between those who died and those who survived are shown in Table 5.8 below.

**Table 5.8:** Differences between those patients who died and those who survived

	<b>Survived (n = 114)</b>	<b>Died (n = 76)</b>	<b>p value</b>
<b>Patient Age</b>			
Mean	52.2	54.6	
Standard Error	1	1.5	0.08
Standard Deviation	10.1	13.3	
95% Confidence Interval	50.3 – 54	51.6 – 57.6	
<b>BI Total</b>			
Mean	6.6	5.2	
Standard Error	0.2	0.3	< 0.001
Standard Deviation	2.3	2.4	
95% Confidence Interval	6.2 – 7	4.7 – 5.7	
<b>RMI Total</b>			
Mean	3.6	3.2	
Standard Error	0.1	0.1	0.03
Standard Deviation	1.4	1.3	
95% Confidence Interval	3.3 - 3.9	2.9 – 3.5	
<b>EQ-5D VAS Scores</b>			
Mean	44.1	41.3	
Standard Error	1	1.1	0.03
Standard Deviation	10.7	9.9	
95% Confidence Interval	42.1 – 46.1	39 – 43.5	

The patients who died had lower BI, RMI and EQ-5D scores than those who survived with  $p < 0.001$ ,  $p = 0.03$  and  $p = 0.03$  respectively.

### e) The effect of caregiver education on death

The effects of caregiver education on the deaths from the study sample are shown in Table 5.9 below.

**Table 5.9:** Summary statistics of effect of caregiver on death

Measure	Formula/calculation	Effect	95% Confidence Intervals
Risk in Control Group		$44/100 = 0.44 = 44\%$	
Risk in Experimental Group		$32/100 = 0.32 = 32\%$	
Absolute Risk Reduction	Risk Difference	$0.44 - 0.32 = 0.12 = 12\%$	0.02 – 0.22
Relative Risk	Experimental/Control	$0.32/0.44 = 0.73 = 73\%$	
Relative Risk Reduction	$1 - \text{Relative Risk} \times 100$	$(1 - 0.73) \times 100 = 27\%$	
Number needed to treat	Inverse of absolute risk reduction	$1/0.12 = 8$	5 – 50

Caregiver training reduced the risk of death by 27% relative to that occurring among the control group patients. From the number needed to treat, one patient death was prevented for every eight caregivers trained.

### a) Patient hospital length of stay

The distribution of the hospital length of stay is shown in the table below.

**Table 5.10:** Summary of hospital length of stay statistics (n = 100)

Length of Hospital Stay (in days) Statistics	
Mean	6
Median	6
Mode	4
Standard Deviation	4
Minimum	1
Maximum	18

The mean hospital length of stay following stroke was 6 days.

## **5.5 The caregiver education programmes and content currently in use when managing patients with stroke at Chris Hani Baragwanath hospital.**

The results in this section help to answer objective one, which aimed to establish the physiotherapy caregiver education programmes and content currently in use when managing patients with stroke at Chris Hani Baragwanath hospital.

There were three physiotherapists working in the Chris Hani Baragwanath hospital neurology physiotherapy department at the time of the study. Of these, two consented to take part in the study.

### **a) Results of the general stroke management protocols used by physiotherapists**

Generally, comprehensive and appropriate management plans were used. The areas that were reported to be covered during rehabilitation of patients with stroke were:

A thorough assessment of the patient covering the following aspects:

- Bed mobility.
- Sitting balance.
- Upper limb re-education.
- Higher-level mobility activities that include facilitation and retraining of sit to stand, standing balance and gait.

### **b) Perceived role of the caregiver by physiotherapists**

The following were suggested as roles of the caregiver following a stroke:

- To assist the patient with activities of daily living.
- To assist with rehabilitation at home.
- To ensure patients keep appointments.
- To ensure that patients avoid/reduce stroke risk factors.
- To help patient understand their condition.
- To help patient integration into society.
- To motivate patient to be responsible for their own rehabilitation.

**c) Extent of caregiver involvement in the patient management process**

- Currently the physiotherapists teach caregivers the necessary aspects of treatment for patients only when patients start coming as out-patients, there is no involvement of caregivers during in-patient rehabilitation.
- The caregiving teaching during out- patient rehabilitation is done through:
  - demonstrations to the caregiver by the therapists.
  - hands on demonstration by the caregivers of the taught skills.

**d) Current content of caregiver training (that is what is covered only when patients come as out-patients)**

- Education on patient condition.
- Teaching treatment/handling techniques to the caregivers – specifically positioning and lifting.

**e) Self rating of the physiotherapists on their effectiveness in caregiver involvement**

- The therapists rated themselves as being “Moderately Effective” and concurred that more could still be done.

**f) Challenges/constraints to caregiver involvement in patient management**

The challenges physiotherapists gave, for their inability to involve caregivers during in-patient rehabilitation included:

- A heavy workload making it impossible to create time for caregivers.
- Caregivers being unavailable for training during normal working hours due to other commitments.



The challenges physiotherapists gave for their inability to involve effectively caregivers during out-patient rehabilitation included:

- Some caregivers are too old and are not able to help patients with stroke.
- A lack of money for stroke survivors and their carers hinders out-patient physiotherapy attendance, as they cannot afford the taxi fares to the hospital.
- Caregivers complain of being overwhelmed by the responsibility of looking after someone who has sustained a stroke.
- Different caregivers accompanying patients on different days when they come for their appointments as out-patients hence more time required to train each one.

## **5.6 Patient Functional Ability as Measured by the Barthel Index**

The results for the patients' activities of daily living functional ability as measured by the Barthel Index are presented in this section. These results were important to help establish the impact of caregiver education on the patients with stroke's mobility and quality of life post-stroke (objectives two and three). The information was also important for objective five, which sought to establish the effect of caregiver education on the ability of the stroke survivor to socialise and participate in community issues.

### **a) Patient Barthel Index scores and comparisons between groups**

A summary of patient ability to carry out activities of daily living over the study period as measured by the Barthel Index is shown in Table 5.11 below. The table is in three parts that cover three pages. The first two pages show the patient BI scores for the two groups from baseline to 12 months including measurements at three and six months.

**Table 5.11:** Summary of patient ability to carry out activities of daily living

Item Score	Baseline		3 Months		6 Months		12 Months	
	Control (n = 100) n(%)	Experimental (n = 100) n(%)	Control (n = 64) n(%)	Experimental (n = 75) n(%)	Control (n = 53) n(%)	Experimental (n = 66) n(%)	Control (n = 49) n(%)	Experimental (n = 65) n(%)
<b>BI-Bowel</b>								
0	1(1)	1(1)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
1	52(52)	58(58)	10(15.6)	8(10.7)	0(0)	1(1.5)	0(0)	0(0)
2	47(47)	41(41)	54(84.4)	67(89.3)	53(100)	65(98.5)	49(100)	65(100)
<b>BI-Bladder</b>								
0	40(40)	42(42)	1(1.6)	1(1.3)	0(0)	0(0)	0(0)	0(0)
1	32(32)	29(29)	30(46.9)	36(48)	0(0)	2(3)	0(0)	0(0)
2	28(28)	29(29)	33(51.6)	38(50.7)	53(100)	64(97)	49(100)	65(100)
<b>BI-Grooming</b>								
0	27(27)	30(30)	2(3.1)	2(2.7)	0(0)	0(0)	0(0)	0(0)
1	73(73)	70(70)	62(96.9)	73(97.3)	53(100)	66(100)	49(100)	65(100)
<b>BI-Toilet use</b>								
0	60(60)	39(39)	9(14.1)	1(1.3)	0(0)	0(0)	0(0)	0(0)
1	40(40)	61(61)	51(79.7)	68(90.7)	45(84.5)	59(89.4)	41(83.7)	57(87.7)
2	0(0)	0(0)	4(6.3)	6(8)	6(11.3)	7(10.6)	8(16.3)	8(12.3)
<b>BI-Feeding</b>								
0	26(26)	23(23)	10(15.6)	2(2.7)	1(1.9)	0(0)	0(0)	0(0)
1	74(74)	77(77)	39(60.9)	49(65.3)	34(64.2)	38(57.6)	29(59.2)	32(49.2)
2	0(0)	0(0)	15(23.4)	24(32)	18(34)	28(42.4)	20(40.8)	33(50.8)

Item Score	Baseline		3 Months		6 Months		12 Months	
	Control (n = 100) n(%)	Experimental (n = 100) n(%)	Control (n = 64) n(%)	Experimental (n = 75) n(%)	Control (n = 53) n(%)	Experimental (n = 66) n(%)	Control (n = 49) n(%)	Experimental (n = 65) n(%)
<b>BI-Transfer</b>								
0	34(34)	33(33)	13(20.3)	7(9.3)	2(3.8)	0(0)	0(0)	0(0)
1	66(66)	64(64)	48(75)	58(77.3)	39(73.6)	50(75.8)	25(51)	24(36.9)
2	0(0)	3(3)	3(4.7)	10(13.3)	12(22.6)	15(22.7)	24(49)	40(61.5)
3	0(0)	0(0)	0(0)	0(0)	0(0)	1(1.5)	0(0)	1(1.5)
<b>BI-Mobility</b>								
0	38(38)	36(36)	15(23.4)	11(14.7)	3(5.7)	1(1.5)	0(0)	0(0)
1	61(61)	61(61)	49(76.6)	55(73.3)	42(79.2)	48(72.7)	39(79.6)	42(64.6)
2	1(1)	3(3)	0(0)	9(12)	8(15.1)	17(25.8)	10(20.4)	23(35.4)
3	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
<b>BI-Dressing</b>								
0	64(64)	62(62)	21(32.8)	16(21.3)	7(13.2)	2(3)	2(4.1)	1(1.5)
1	36(36)	38(38)	43(67.2)	59(78.7)	44(83)	58(87.9)	29(59.2)	35(53.8)
2	0(0)	0(0)	0(0)	0(0)	2(3.8)	6(9.1)	18(36.7)	29(44.6)
<b>BI-Stairs</b>								
0	100(100)	98(98)	64(100)	73(97.3)	51(96.2)	62(93.9)	35(71.4)	41(63.1)
1	0(0)	2(2)	0(0)	2(2.7)	2(3.8)	4(6.1)	14(28.6)	24(36.9)
2	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
<b>BI-Bathing</b>								
0	99(99)	96(96)	59(92.2)	67(89.3)	45(84.9)	52(78.8)	13(26.5)	9(13.8)
1	1(1)	4(4)	5(7.8)	8(10.7)	8(15.1)	14(21.2)	36(73.5)	56(86.2)

Item Score	Baseline		3 Months		6 Months		12 Months	
	Control (n = 100)	Experimental (n = 100)	Control (n = 64)	Experimental (n = 75)	Control (n = 53)	Experimental (n = 66)	Control (n = 49)	Experimental (n = 65)
<b>Total BI Score</b>								
Mean	6.1	6.2	8.7	9.7	10.8	11.3	12.6	13.3
Minimum	2	2	2	3	6	7	9	10
Maximum	11	13	14	16	17	19	17	19
St. Dev	2.4	2.5	2.7	2.3	1.9	2.1	2.3	2.1
25th percentile	5	5	7	9	10	10	11	11
50th percentile	5.5	5	9	9	10	11	12	14
75th percentile	10	10	11	12	11	12	15	15

None of the patients in the study sample was fully independent in mobility and stairs climbing. Generally, the BI total mean scores improved over the study period but they were relatively higher for the experimental group than the control group (see page 134).

The frequency distribution of the functional levels of the patients of the study sample is shown in Table 5.12 below.

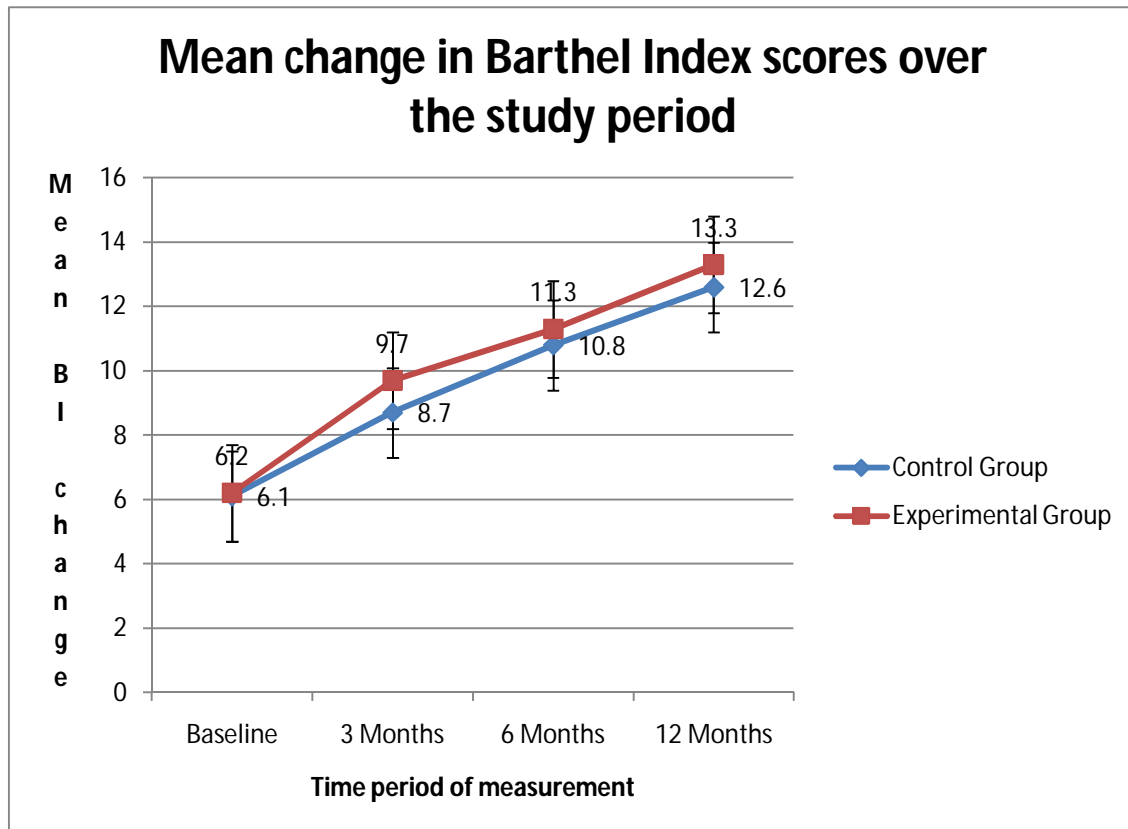
**Table 5.12:** The frequency distribution of the functional levels of the patients

Time period of measurement	Total Barthel Index Score	Control Group n(%)	Experimental Group n(%)	Total n(%)
3 Months	≤11	100(100)	99(99)	199(99.5)
	≥12	0(0)	1(1)	1(0.5)
6 Months	≤11	61(95.3)	67(89.3)	128(92.1)
	≥12	3(4.7)	8(10.7)	11(7.9)
12 Months	≤11	45(84.9)	48(72.7)	93(78.2)
	≥12	8(15.1)	18(27.3)	26(21.8)

Patients who scored 12 and above ( $\geq 60\%$ ) on the BI were considered to be functional while those who scored less than 12 ( $< 60\%$ ) were considered to be dependent.

Only one patient was functionally independent at the 3 months follow up period. The number of functionally independent patients went up over the study period but only 26(21.8%) were functionally independent at the 12 months follow up period.

The distributions of the Barthel Index mean scores are shown in Figure 5.12 below.



**Figure 5.12:** Mean BI scores over the 12 months period.

There was a general increase in patients' BI mean scores over the study period. Overall, the patients in the experimental group had better BI mean scores than the control group ( $p = 0.001$ ).

The two sample t-test statistical results of the BI mean difference in change between the groups at the various measurement points are shown in Table 5.13 below. The p-values that are given are for the one tailed t test.

**Table 5.13:** The two-sample t test statistical results of the BI mean difference in change between the two groups.

<b>Period</b>	<b>Mean Experimental Group</b>	<b>Mean Control Group</b>	<b>Mean difference</b>	<b>St. Error</b>	<b>95% CI</b>	<b>p value</b>
<b>Baseline</b>	6.2	6.1	0.1	0.3	-0.8 – 0.6	0.40
<b>3 Months</b>	9.7	8.7	1	0.4	-1.8 – (-0.5)	0.01
<b>6 Months</b>	11.3	10.8	0.5	0.4	-1.3 – 0.2	0.08
<b>12 Months</b>	13.3	12.6	0.7	0.4	-1.5 – 0.1	0.05

Mean difference = mean (experimental group) – mean (control group) which is the treatment effect.

The differences of the BI mean change between the two groups' measurements were not statistically significant at baseline and at six months. The experimental group however had a better mean score than the control group at three months ( $p = 0.01$ ) and at 12 months ( $p = 0.05$ ) at the 0.05 level of significance. The patient BI scores improved over time but overall they were still poor. Caregiver education had the effect of improving the BI scores by an average of one and 0.7 at three and 12 months respectively.

## 5.7 The effect of caregiver education on the mobility of the stroke survivors.

This section presents the results for patient mobility as measured by the Rivermead Mobility Index from baseline to 12 months, including comparisons of the mean scores for the control and experimental groups. These results help answer objective two, which sought to establish the effect of caregiver education on the mobility of stroke survivors.

The distribution of the patients' mobility abilities as measured by the Rivermead Mobility index over the study period are shown in Table 5.14 below. The table is presented in three parts spanning over three pages.

**Table 5.14:** The Rivermead Mobility Index scores for the patients over the study period.

Item score	Baseline		3 Months		6 Months		12 Months	
	Control (n = 100) n(%)	Experimental (n = 100) n(%)	Control (n = 64) n(%)	Experimental (n = 75) n(%)	Control (n = 53) n(%)	Experimental (n = 66) n(%)	Control (n = 49) n(%)	Experimental (n = 65) n(%)
<b>Turn in bed</b>	100(100)	100(100)	64(100)	75(100)	53(100)	66(100)	49(100)	65(100)
<b>Ly-sitting</b>	99(99)	99(99)	64(100)	74(98.7)	53(100)	66(100)	49(100)	65(100)
<b>Sitting balance</b>	80(80)	84(84)	61(95.3)	74(98.7)	53(100)	66(100)	49(100)	65(100)
<b>Sit – standing</b>	27(27)	35(35)	50(78.1)	70(93.3)	52(98.1)	65(98.5)	47(95.9)	65(100)
<b>Standing unsupported</b>	13(13)	22(22)	21(32.8)	32(42.7)	48(90.6)	62(93.9)	47(95.9)	65(100)
<b>Transfer</b>	12(12)	19(19)	16(25)	26(34.7)	45(84.9)	60(90.9)	46(93.9)	64(98.5)



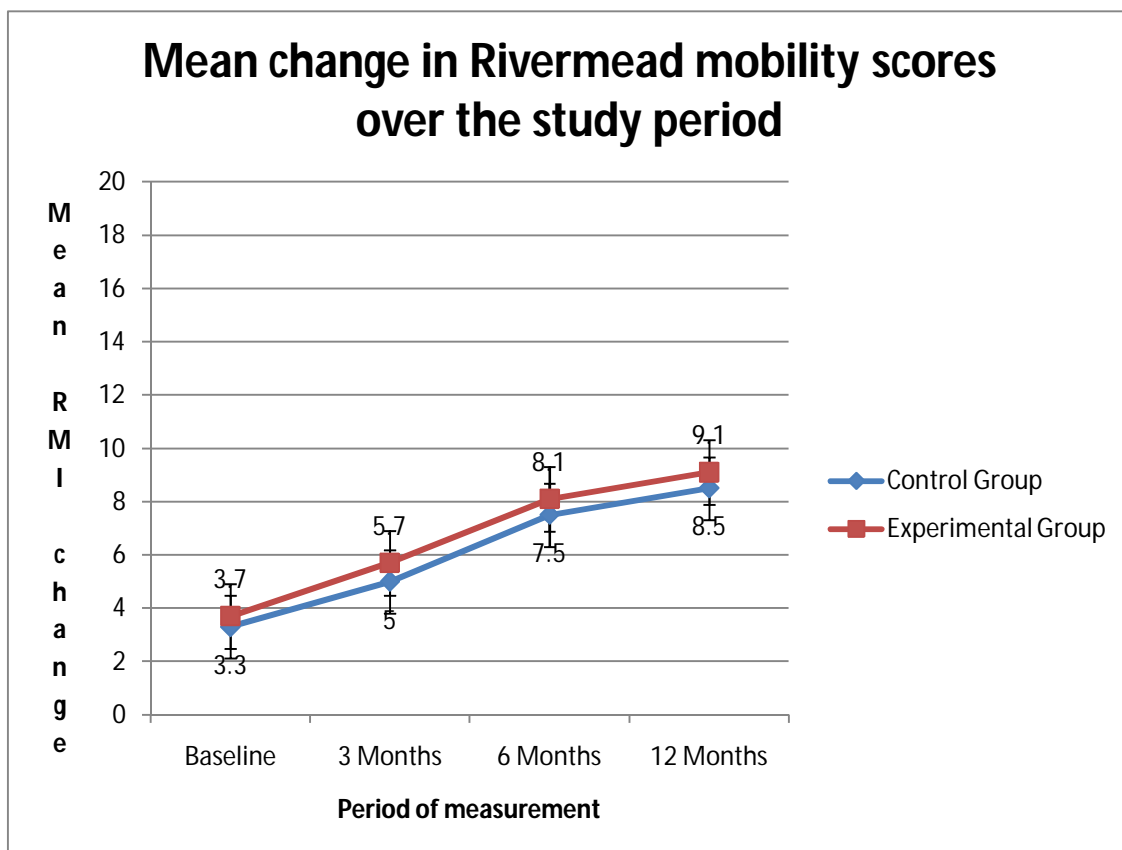
Item score	Baseline		3 Months		6 Months		12 Months	
	Control (n = 100) n(%)	Experimental (n = 100) n(%)	Control (n = 64) n(%)	Experimental (n = 75) n(%)	Control (n = 53) n(%)	Experimental (n = 66) n(%)	Control (n = 49) n(%)	Experimental (n = 65) n(%)
<b>Walking inside with aid</b>	1(1)	2(2)	2(3.1)	10(13.3)	8(15.1)	17(25.8)	10(20.4)	23(35.4)
<b>Stairs</b>	0(0)	0(0)	0(0)	0(0)	2(3.8)	4(6.1)	14(28.6)	24(36.9)
<b>Walk outside even ground</b>	0(0)	0(0)	0(0)	4(5.3)	4(7.5)	8(12.1)	3(6.1)	5(7.7)
<b>Walking inside no aid</b>	0(0)	0(0)	0(0)	5(6.7)	5(9.4)	13(19.7)	8(16.3)	15(23.1)
<b>Pick objects up from floor</b>	0(0)	0(0)	6(9.4)	11(14.7)	12(22.6)	15(22.7)	14(28.6)	18(27.7)
<b>Walking outside uneven ground</b>	0(0)	0(0)	0(0)	4(5.3)	4(7.5)	8(12.1)	3(6.1)	5(7.7)
<b>Bathing</b>	0(0)	0(0)	9(14.1)	18(24)	14(26.4)	24(36.4)	18(36.7)	29(44.6)
<b>Steps</b>	0(0)	0(0)	0(0)	0(0)	0(0)	2(3)	0(0)	2(3.1)
<b>Running</b>	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)

Item score	Baseline		3 Months		6 Months		12 Months	
	Control (n = 100)	Experimental (n = 100)	Control (n = 64)	Experimental (n = 75)	Control (n = 53)	Experimental (n = 66)	Control (n = 49)	Experimental (n = 65)
<b>Total RMI Score</b>								
<b>Mean</b>	3.3	3.7	5.0	5.7	7.6	8.1	8.5	9.1
<b>Minimum</b>	1	1	2	1	3	3	3	5
<b>Maximum</b>	7	10	12	12	13	14	13	14
<b>St. Dev</b>	1.2	1.5	2.6	2.9	2.5	2.5	2.5	2.0
<b>25th percentile</b>	3	3	4	4	6	7	7	8
<b>50th percentile</b>	3	3	4	4	7	7	8	8
<b>75th percentile</b>	4	4	6	7	9	9	10	10

For the Rivermead Mobility Index, the higher the score the better the mobility ability of the patient. Patient mobility increases as the scores increase.

All the patients were able to turn in bed just before discharge home with only three (1,5%) able to walk inside the hospital with an aid. However at 12 months follow up 87.7% of the survivors (79.6% in the control group and 93.8% in the experimental group) were able to walk inside the house with an aid. The patients' mobility generally increased over the one-year follow up period with the mean total Rivermead Mobility index score improving from 3.3 and 3.7 at baseline to 8.5 and 9.1 at 12 months for the control and experimental groups respectively. Overall, the patient mobility scores were very low.

The analysis results for the Rivermead mobility index mean scores are shown in Figure 5.13 below.



**Figure 5.13:** Mean RMI scores over the 12 months period.

There was a general increase in the patients' RMI scores but they were still low. Overall, the experimental group patients had better mean mobility scores than those in the control group ( $p = 0.001$ ).

The statistical test results of the mean change between the groups at the various measurement points are shown in Table 5.15 below.

**Table 5.15:** The statistical test results of the mean RMI change between the two groups.

<b>Period</b>	<b>Mean Score Experimental Group</b>	<b>Mean Score Control Group</b>	<b>Mean difference</b>	<b>St. Error</b>	<b>95% CI</b>	<b>p value</b>
<b>Baseline</b>	3.7	3.3	0.3	0.2	-0.7 – 0.0	0.80
<b>3 Months</b>	5.8	5.0	0.7	0.5	-1.7 – 0.2	0.06
<b>6 Months</b>	8.1	7.6	0.5	0.5	-1.4 – 0.4	0.14
<b>12 Months</b>	9.1	8.5	0.6	0.4	-1.4 – 0.2	0.08

Mean difference = mean (experimental group) – mean (control group) which is the treatment effect.

The differences of the RMI mean change between the two groups at the four points of measurement were not statistically significant.

## 5.8 The effect of caregiver education on the quality of life of the stroke survivors.

The results in this section help answer objective three, which sought to establish the effect of caregiver education on the stroke survivors' quality of life. A summary of the measurements for the patients from baseline to 12 months is given with comparisons of the effect on the control and experimental groups.

The perceived health related quality of life measurements for the patients from baseline to 12 months are shown in Table 5.16 below.

**Table 5.16:** Perceived health related quality of life measurements for the patients over the study period.

Item score	Baseline		3 Months		6 Months		12 Months	
	Control (n = 100) n(%)	Experimental (n = 100) n(%)	Control (n = 64) n(%)	Experimental (n = 75) n(%)	Control (n = 53) n(%)	Experimental (n = 66) n(%)	Control (n = 49) n(%)	Experimental (n = 65) n(%)
<b>Mobility</b>								
No problems	0(0)	0(0)	0(0)	0(0)	0(0)	1(1.5)	0(0)	1(1.5)
Some problems	98(98)	96(96)	64(100)	73(97.3)	53(100)	64(97)	49(100)	62(95.4)
Confined to bed	2(2)	4(4)	0(0)	2(2.7)	0(0)	1(1.5)	0(0)	2(3.1)
<b>Self Care</b>								
No problems	0(0)	0(0)	0(0)	1(1.3)	0(0)	1(1.5)	0(0)	1(1.5)
Some problems	94(94)	97(97)	63(98.4)	70(93.3)	52(98.1)	62(93.9)	48(98)	61(93.9)
Unable	6(6)	3(3)	1(1.6)	4(5.3)	1(1.9)	3(4.5)	1(2)	3(4.6)
<b>Usual Activities</b>								
No problems	0(0)	0(0)	0(0)	0(0)	0(0)	2(3)	1(2)	2(3.1)
Some problems	99(99)	96(96)	64(100)	73(97.3)	53(100)	63(95.5)	48(98)	62(95.4)
Unable	1(1)	4(4)	0(0)	2(2.7)	0(0)	1(1.5)	0(0)	1(1.5)

Item score	Baseline		3 Months		6 Months		12 Months	
	Control (n = 100) n(%)	Experimental (n = 100) n(%)	Control (n = 64) n(%)	Experimental (n = 75) n(%)	Control (n = 53) n(%)	Experimental (n = 66) n(%)	Control (n = 49) n(%)	Experimental (n = 65) n(%)
<b>Pain/Discomfort</b>								
No pain	31(31)	30(30)	33(51.6)	43(57.3)	34(64.2)	48(72.7)	10(20.4)	12(18.5)
Moderate pain	60(60)	68(68)	26(40.6)	30(40)	18(34)	17(25.8)	39(79.6)	53(81.5)
Extreme pain	9(9)	2(2)	5(7.8)	2(2.7)	1(1.9)	1(1.5)	0(0)	0(0)
<b>Anxiety/Depression</b>								
Not anxious	4(4)	1(1)	5(7.8)	4(5.3)	8(15.1)	9(13.6)	8(16.3)	14(21.5)
Moderately anxious	50(50)	55(55)	44(68.8)	58(77.3)	39(73.6)	50(75.6)	36(73.5)	40(61.5)
Extremely anxious	46(46)	44(44)	15(23.4)	13(17.3)	6(11.3)	7(10.6)	5(10.2)	5(7.7)
<b>General health over last 12 months</b>								
Better	0(0)	0(0)	2(3.1)	2(2.7)	3(5.7)	6(9.1)	6(12.2)	7(10.8)
Same	2(2)	3(3)	23(35.9)	25(33.3)	21(39.6)	21(38.8)	16(32.7)	21(32.3)
Worse	98(98)	97(97)	39(60.9)	48(64)	29(54.7)	39(59.1)	27(55.1)	37(56.9)

Item score	Baseline		3 Months		6 Months		12 Months	
	Control (n = 100)	Experimental (n = 100)	Control (n = 64)	Experimental (n = 75)	Control (n = 53)	Experimental (n = 66)	Control (n = 49)	Experimental (n = 65)
<b>VAS Score</b>								
Mean	42.4	43.7	50.5	52.4	60.5	63.5	67.0	68.8
Minimum	20	20	20	30	30	45	40	40
Maximum	80	90	80	90	80	90	90	95
St. Dev	9.5	11.4	10.4	10.6	9.5	8.4	11	10.6
25th percentile	40	40	45	45	60	60	60	60
50th percentile	40	40	50	50	60	60	70	70
75th percentile	50	50	60	60	65	65	75	75

More than 90% of the patients reported having some self-care, usual activity and mobility problems throughout the study period. The mean VAS scores for the patients generally improved over the 12 months period for both groups.

The results of the effect of caregiver education on the health related quality of life of the patients is shown below.

Figure 5.14 below shows the mean change in patient quality of life over the study period.

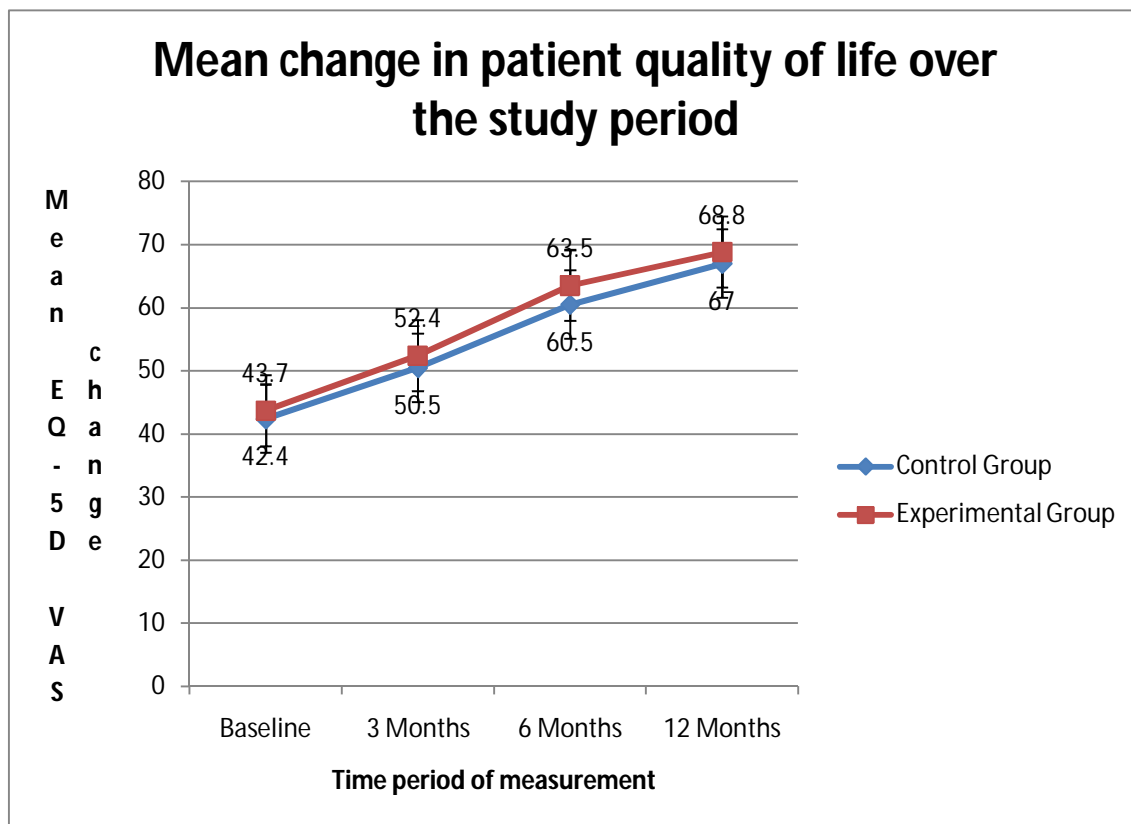


Figure 5.14: Mean change in patient quality of life (EQ-5D VAS scores).

There was a general increase in the patients' mean perceived health related quality of life. Overall, the patients in the experimental group had better mean scores than the control group ( $p = 0.01$ ).



The statistical test results of the mean change between the groups at the various measurement points are shown in Table 5.17 below.

**Table 5.17:** The statistical test results of the mean patient EQ-5D VAS scores change between the two groups.

<b>Period</b>	<b>Mean Score Experimental Group</b>	<b>Mean Score Control Group</b>	<b>Mean difference</b>	<b>St. Error</b>	<b>95% CI</b>	<b>p value</b>
<b>Baseline</b>	43.7	42.4	1.3	1.5	-4.2 – 1.7	0.20
<b>3 Months</b>	52.4	50.6	1.8	1.8	-5.4 – 1.7	0.15
<b>6 Months</b>	63.5	60.5	3.0	1.6	-6.3 – 0.2	0.03
<b>12 Months</b>	68.9	67.0	1.9	2.0	-5.8 – 2.2	0.19

Mean difference = mean (experimental group) – mean (control group) which is the treatment effect.

The differences of the EQ-5D VAS mean change between the two groups at the four points of measurement were not statistically significant except at the 6 months period where the experimental group patients had better mean scores ( $p = 0.03$ ). At 6 months caregiver education had the effect of improving patients' EQ-5D VAS score by 3 and this was a clinically significant change.

### **5.9 The effect of caregiver education on the quality of life of the caregivers.**

This section presents the results that help answer objective four, which sought to establish the effect of caregiver education on the quality of life of the caregivers. The first section is a summary of the EQ-5D scores for both groups (control and experimental) over the twelve months followed by the comparisons between the two groups.

The perceived health related quality of life measurements for the caregivers from baseline to 12 months are shown in Table 5.18 below. The table is presented in two parts (over two pages) with the second page highlighting the summary statistics for the EQ-5D VAS scores for the control and experimental groups over the 12 months period.

**Table 5.18:** Perceived health related quality of life measurements for the caregivers over the study period.

Item score	3 Months		6 Months		12 Months	
	Control (n = 64) n(%)	Experimental (n = 75) n(%)	Control (n = 53) n(%)	Experimental (n = 66) n(%)	Control (n = 49) n(%)	Experimental (n = 65) n(%)
<b>Mobility</b>						
No problems	64(100)	75(100)	53(100)	66(100)	49(100)	65(100)
Some problems	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
Confined to bed	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
<b>Self Care</b>						
No problems	64(100)	75(100)	53(100)	66(100)	49(100)	65(100)
Some problems	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
Unable	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
<b>Usual Activities</b>						
No problems	64(100)	75(100)	53(100)	66(100)	49(100)	65(100)
Some problems	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
Unable	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
<b>Pain/Discomfort</b>						
No pain	58(90.6)	69(92)	40(75.5)	53(80.3)	19(38.8)	26(40)
Moderate pain	6(9.4)	5(6.7)	13(24.5)	12(18.2)	28(57.1)	35(53.8)
Extreme pain	0(0)	1(1.3)	0(0)	1(1.5)	2(4.1)	4(6.2)
<b>Anxiety/Depression</b>						
Not anxious	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
Moderately anxious	51(79.7)	60(80)	40(75.5)	57(86.4)	8(16.3)	13(20)
Extremely anxious	13(20.3)	15(20)	13(24.5)	9(13.6)	41(83.7)	52(80)
<b>General health over last 12 months</b>						
Better	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
Same	60(93.8)	73(97.3)	49(92.5)	64(97)	43(87.8)	59(90.8)
Worse	4(6.3)	2(2.7)	4(7.5)	2(3)	6(12.2)	6(9.2)

Item score	3 Months		6 Months		12 Months	
	Control (n = 64)	Experimental (n = 75)	Control (n = 53)	Experimental (n = 66)	Control (n = 49)	Experimental (n = 65)
<b>VAS Score</b>						
Mean	92.3	93.3	88.6	92	82.8	86.3
Minimum	75	70	70	65	70	65
Maximum	100	100	100	100	95	95
St. Dev	5.3	5.6	6.3	5.6	7.4	7.4
25th percentile	90	90	85	90	75	80
50th percentile	95	95	90	95	80	90
75th percentile	95	95	95	95	90	95

The major areas of complaint from the caregivers were pain/discomfort and anxiety/depression. At 12 months 63 (55,3%) of the caregivers (28 (57.1%) from the control group and 35 (55.4%) from the experimental group) complained of moderate pain while 93 (81.6%) of the caregivers (41 (83.7%) from the control group and 52 (80%) from the experimental group) complained of being extremely anxiously.

The results of the effect of caregiver education on the health related quality of life of the caregivers is shown below.

Figure 5.15 below shows the mean change in caregiver quality of life over the study period.

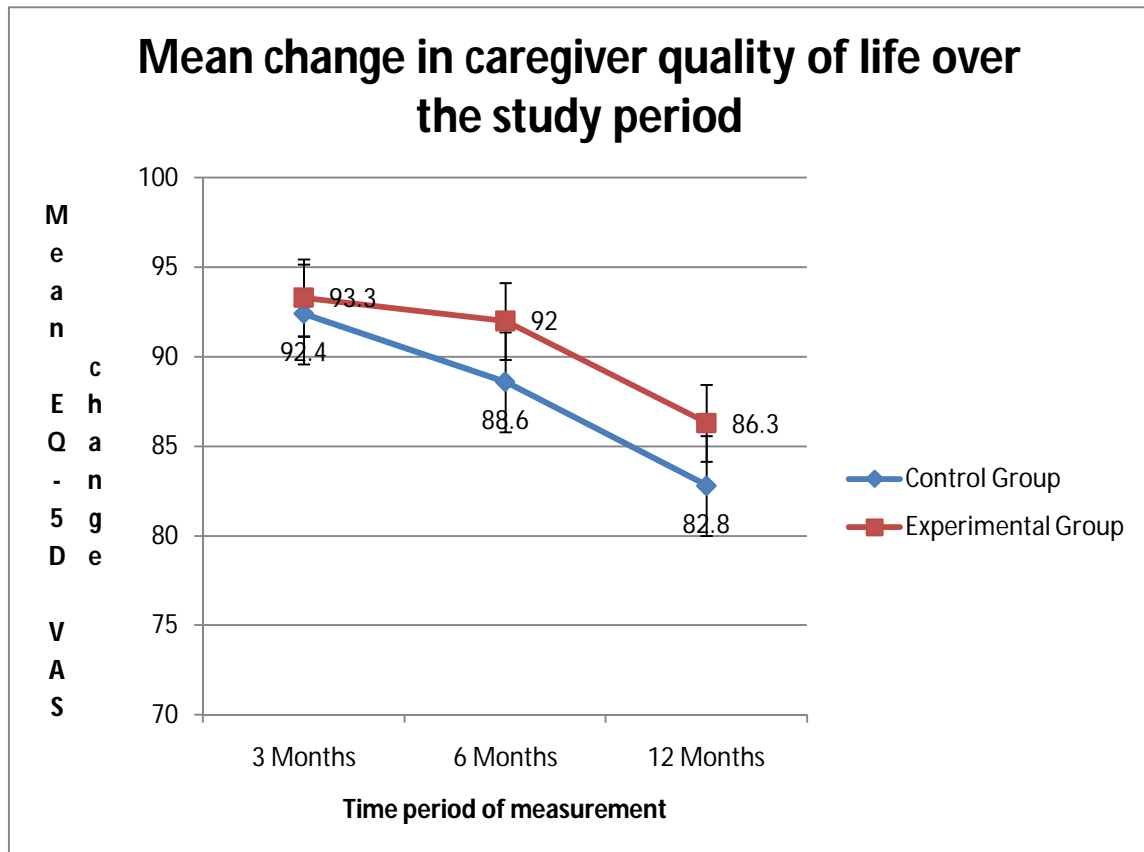


Figure 5.15: Mean change in caregiver quality of life (EQ-5D VAS scores)

There was a general decline in the caregivers' mean perceived health related quality of life. Overall, the experimental group caregivers had better mean EQ-5D scores than the control group ( $p = 0.001$ )

The statistical test results of the mean change between the groups at the various measurement points are shown in Table 5.19 below.

**Table 5.19:** The statistical test results of the mean caregiver EQ-5D VAS scores change between the two groups.

Period	Mean Score Experimental Group	Mean Score Control Group	Mean difference	St. Error	95% CI	p value
3 Months	93.3	92.3	1	1	-2.8 – 0.9	0.15
6 Months	92	88.6	3.4	1.1	-5.6 – (-1.2)	0.001
12 Months	86.3	82.8	3.6	1.4	-6.3 – (-0.8)	0.006

Mean difference = mean (experimental group) – mean (control group) which is the treatment effect.

The differences of the EQ-5D VAS mean change between the two groups at 6 months and 12 months was statistically significant with  $p = 0.001$  and  $p = 0.006$  respectively in favour of the experimental group. Caregiver education had the effect of improving caregivers' EQ-5D VAS by 3.4 and 3.6 at 6 and 12 months between groups respectively and this was a clinically meaningful change. However, overall quality of life declined over the 12 months.

## 5.10 The effect of caregiver education on the ability of the stroke survivor to socialise and participate in community issues.

This section presents the results for objective five, which sought to establish the effect of caregiver education on the stroke survivor's ability to socialise and participate in community issues. A summary of the patients' ability to socialise and participate in the community from three months to 12 months is given including the environmental factors that were barriers or facilitators to the patients' ability to socialise and participate in community issues.

### a) Extent of general participation restriction

For this section, results that showed significant findings are highlighted. According to the ICF, *the performance qualifier* assesses the patient's current ability to perform activities while *the capacity qualifier* assesses the patient's ability to carry out activities without any form of assistance. It is therefore expected that in some cases it may be more difficult for patients to do activities without assistance.

For the purposes of data analysis, the qualifiers were coded as follows:

0 = No difficulty - was left as a stand-alone category.

1 = Mild difficulty and 2 = Moderate difficulty were combined into one category which is the mild to moderate difficulty.

3 = Severe difficulty and 4 = complete difficulty were combined into one category which is the severe to complete difficulty.

The extent of general participation restriction for the patients is shown in Table 5.20 below.

**Table 5.20:** Extent of general participation restriction

		<b>d210 Undertaking Single Task</b>				<b>d220 Undertaking Multiple Tasks</b>			
		<b>Performance Qualifier</b>		<b>Capacity Qualifier</b>		<b>Performance Qualifier</b>		<b>Capacity Qualifier</b>	
		Control	Experimental	Control	Experimental	Control	Experimental	Control	Experimental
		Group	Group	Group	Group	Group	Group	Group	Group
		n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
3 Months (Control Group n = 64) (Experimental Group n = 75)	No difficulty	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
	Mild to Moderate difficulty	38(59.4)	42(56)	26(40.6)	0(0)	8(12.5)	4(5.3)	0(0)	0(0)
	Severe to complete difficulty	26(40.6)	33(44)	38(59.4)	75(100)	56(87.5)	71(94.7)	64(100)	75(100)
6 Months (Control Group n = 53) (Experimental Group n = 66)	No difficulty	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
	Mild to Moderate difficulty	16(30.2)	12(18.2)	16(30.2)	0(0)	3(5.7)	5(7.6)	0(0)	0(0)
	Severe to complete difficulty	37(69.8)	54(81.8)	37(69.8)	66(100)	50(94.3)	61(92.4)	53(100)	66(100)
12 Months (Control Group n = 49) (Experimental Group n = 65)	No difficulty	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
	Mild to Moderate difficulty	22(44.9)	31(47.7)	0(0)	0(0)	23(46.9)	30(46.2)	0(0)	0(0)
	Severe to complete difficulty	27(55.1)	34(52.3)	49(100)	65(100)	26(53.1)	35(53.8)	49(100)	65(100)

At the three months follow up, 40.6% of the control group and 44% of the experimental group patients had severe to complete difficulty in undertaking single tasks while more than 87% had severe to complete difficulty in performing multiple tasks. No participants (100%) could carry out single and multiple tasks without assistance at the end of 12 months.

The extent of mobility performance and activity limitation for the patients is shown in table 5.21 below.

**Table 5.21:** The extent of mobility performance and activity limitation

		d430 Lifting and carrying objects				d440 Fine hand use				d450 Walking				d465 Moving around using equipment			
		Performance Qualifier		Capacity Qualifier		Performance Qualifier		Capacity Qualifier		Performance Qualifier		Capacity Qualifier		Performance Qualifier		Capacity Qualifier	
		CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG
		n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
3 Months	No difficulty	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	
(Control Group n = 64)	Mild to Moderate difficulty	14(21.9)	13(17.3)	0(0)	0(0)	31(48.4)	30(40)	0(0)	0(0)	13(20.3)	13(17.3)	0(0)	0(0)	64(100)	75(100)	64(100)	75(100)
(Experimental Group n = 75)	Severe to complete difficulty	50(78.1)	62(82.7)	75(100)	75(100)	33(51.6)	45(60)	64(100)	75(100)	51(79.7)	62(82.7)	64(100)	75(100)	0(0)	0(0)	0(0)	0(0)



		d430 Lifting and carrying objects				d440 Fine hand use				d450 Walking				d465 Moving around using equipment			
		Performance Qualifier		Capacity Qualifier		Performance Qualifier		Capacity Qualifier		Performance Qualifier		Capacity Qualifier		Performance Qualifier		Capacity Qualifier	
		CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG
		n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
6 Months	No difficulty	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	
(Control Group n = 53)	Mild to Moderate difficulty	21(39.6)	32(49.2)	0(0)	0(0)	34(64.2)	38(58.5)	0(0)	0(0)	21(39.6)	32(49.2)	0(0)	0(0)	53(100)	66(100)	0(0)	0(0)
(Experimental Group n = 65)	Severe to complete difficulty	32(60.4)	34(50.8)	53(100)	66(100)	19(35.8)	28(41.5)	53(100)	66(100)	32(60.4)	34(50.8)	53(100)	66(100)	0(0)	0(0)	53(100)	66(100)
12 Months	No difficulty	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	
(Control Group n = 49)	Mild to Moderate difficulty	43(87.8)	61(93.8)	0(0)	0(0)	43(87.8)	61(93.8)	0(0)	0(0)	43(87.8)	61(93.8)	0(0)	0(0)	49(100)	65(100)	0(0)	0(0)
(Experimental Group n = 65)	Severe to complete difficulty	6(12.2)	4(6.2)	49(100)	65(100)	6(12.2)	4(6.2)	49(100)	65(100)	6(12.2)	4(6.2)	49(100)	65(100)	0(0)	0(0)	49(100)	65(100)

At 3 months, 79.7% of the control group and 82.7% of the experimental group had severe to complete difficulty with walking but these percentages decreased to 12.2% and 6.2% respectively at twelve months but with more than 87% still having mild to moderate difficulty with walking. All the participants indicated an inability to lift and carry objects, have fine hand use and move around with equipment without assistance (capacity).

## b) Extent of general activity limitation

The extent of general participation restriction in domestic activities for the patients is shown in Table 5.22 below.

**Table 5.22:** Extent of general participation restriction in domestic activities

		<b>d620 Acquisition of goods and services</b>				<b>d630 Preparation of meals</b>				<b>d640 Doing housework</b>				<b>d660 Assisting others</b>			
		Performance Qualifier		Capacity Qualifier		Performance Qualifier		Capacity Qualifier		Performance Qualifier		Capacity Qualifier		Performance Qualifier		Capacity Qualifier	
		CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG
		n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
3 Months	No difficulty	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
(Control Group n = 64)	Mild to Moderate difficulty	34(53.1)	36(48)	0(0)	0(0)	34(53.1)	36(48)	0(0)	0(0)	34(53.1)	36(48)	0(0)	0(0)	25(39.1)	35(46.7)	0(0)	0(0)
(Experimental Group n = 75)	Severe to complete difficulty	30(46.9)	39(52)	64(100)	75(100)	30(46.9)	39(52)	64(100)	75(100)	30(46.9)	39(52)	64(100)	75(100)	39(60.9)	40(53.3)	64(100)	75(100)
6 Months	No difficulty	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
(Control Group n = 53)	Mild to Moderate difficulty	40(75.5)	60(90.9)	0(0)	0(0)	40(75.5)	60(90.9)	0(0)	0(0)	40(75.5)	60(90.9)	0(0)	0(0)	21(39.6)	32(48.5)	0(0)	0(0)
(Experimental Group n = 66)	Severe to complete difficulty	13(24.5)	6(9.1)	53(100)	66(100)	13(24.5)	6(9.1)	53(100)	66(100)	13(24.5)	6(9.1)	53(100)	66(100)	32(60.4)	34(51.5)	53(100)	66(100)

		<b>d620 Acquisition of goods and services</b>				<b>d630 Preparation of meals</b>				<b>d640 Doing housework</b>				<b>d660 Assisting others</b>			
		Performance Qualifier		Capacity Qualifier		Performance Qualifier		Capacity Qualifier		Performance Qualifier		Capacity Qualifier		Performance Qualifier		Capacity Qualifier	
		CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG
		n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
12 Months	No difficulty	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
(Control Group n = 49)	Mild to Moderate difficulty	49(100)	65(100)	0(0)	0(0)	49(100)	65(100)	0(0)	0(0)	49(100)	65(100)	0(0)	0(0)	44(89.8)	61(92.4)	0(0)	0(0)
(Experimental Group n = 65)	Severe to complete difficulty	0(0)	0(0)	49(100)	65(100)	0(0)	0(0)	49(100)	65(100)	0(0)	0(0)	49(100)	65(100)	5(10.2)	4(7.8)	49(100)	65(100)

None of the participants was able to carry out domestic activities without any difficulty. They were not able to acquire goods and services, prepare meals, do housework or assist others without assistance from helpers (capacity).

### c) Extent of personal relationships and interactions participation and limitation

The distribution of the extent of personal relationships and interactions participation and limitation of patients is shown in the following table, which is in two parts, that is Part (a) and (b).

**Table 5.23a:** The extent of interpersonal interactions and relationships of the patients

		<b>d710 Basic interpersonal interactions</b>		<b>d720 Complex interpersonal interactions</b>		<b>d730 Relating with strangers</b>				<b>d740 Formal Relationships</b>						
		Performance Qualifier		Capacity Qualifier		Performance Qualifier		Capacity Qualifier		Performance Qualifier		Capacity Qualifier				
		CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG			
		n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)			
3 Months	No difficulty	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
(Control Group n = 64)	Mild to Moderate difficulty	38(59.4)	43(57.3)	18(28.1)	17(22.7)	64(100)	75(100)	0(0)	0(0)	64(100)	75(100)	0(0)	0(0)	64(100)	75(100)	0(0)
(Experimental Group n = 75)	Severe to complete difficulty	26(40.6)	32(42.7)	46(71.9)	58(77.3)	0(0)	0(0)	64(100)	75(100)	0(0)	0(0)	64(100)	75(100)	0(0)	0(0)	64(100)
6 Months	No difficulty	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
(Control Group n = 53)	Mild to Moderate difficulty	16(30.2)	11(16.7)	13(24.5)	6(9.1)	53(100)	66(100)	0(0)	0(0)	53(100)	66(100)	0(0)	0(0)	53(100)	66(100)	0(0)
(Experimental Group n = 66)	Severe to complete difficulty	37(69.8)	55(83.3)	40(75.5)	60(90.9)	0(0)	0(0)	53(100)	66(100)	0(0)	0(0)	53(100)	66(100)	0(0)	0(0)	53(100)
12 Months	No difficulty	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
(Control Group n = 49)	Mild to Moderate difficulty	23(46.9)	32(49.2)	0(0)	0(0)	49(100)	65(100)	0(0)	0(0)	49(100)	65(100)	0(0)	0(0)	49(100)	65(100)	0(0)
(Experimental Group n = 65)	Severe to complete difficulty	26(53.1)	33(50.8)	49(100)	65(100)	0(0)	0(0)	49(100)	65(100)	0(0)	0(0)	49(100)	65(100)	0(0)	0(0)	49(100)

All the participants had mild to moderate and severe to complete difficulty in basic interpersonal interactions, complex interpersonal interactions, ability to relate to strangers and formal relationships throughout the study period.

**Table 5.23b:** The extent of interpersonal interactions and relationships of the patients

		<b>d750 Informal social relationships</b>				<b>d760 Family relationships</b>				<b>d770 Intimate relationships</b>			
		Performance Qualifier		Capacity Qualifier		Performance Qualifier		Capacity Qualifier		Performance Qualifier		Capacity Qualifier	
		CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG
		n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
<b>3 Months</b>	No difficulty	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
(Control Group n = 64)	Mild to Moderate difficulty	52(81.3)	53(70.7)	0(0)	0(0)	43(67.2)	52(69.3)	0(0)	0(0)	5(7.8)	9(12)	0(0)	0(0)
(Experimental Group n = 75)	Severe to complete difficulty	12(18.7)	22(29.3)	64(100)	75(100)	21(32.8)	23(30.7)	64(100)	75(100)	59(92.2)	66(88)	64(100)	75(100)
<b>6 Months</b>	No difficulty	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
(Control Group n = 53)	Mild to Moderate difficulty	53(100)	66(100)	0(0)	0(0)	34(66)	38(57.6)	0(0)	0(0)	18(34)	27(40.9)	0(0)	0(0)
(Experimental Group n = 66)	Severe to complete difficulty	0(0)	0(0)	53(100)	66(100)	19(34)	28(42.4)	53(100)	66(100)	35(66)	39(59.1)	53(100)	66(100)
<b>12 Months</b>	No difficulty	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
(Control Group n = 49)	Mild to Moderate difficulty	49(100)	65(100)	0(0)	0(0)	44(89.8)	61(93.8)	0(0)	0(0)	21(42.9)	29(44.6)	0(0)	0(0)
(Experimental Group n = 65)	Severe to complete difficulty	0(0)	0(0)	49(100)	65(100)	5(10.2)	4(6.2)	49(100)	65(100)	28(57.1)	36(55.4)	49(100)	65(100)

All the participants had mild to moderate and severe to complete difficulty in informal social relationships, family relationships and intimate relationships throughout the study period.

**d) Extent of community, social and civic life activity participation and limitation**

The extent of patient activity participation and limitation in community, social and civic life is shown in Table 5.24 below.

**Table 5.24:** The extent of patient activity participation and limitation in community, social and civic life

			d910 Community Life				d920 Recreation and leisure				d930 Religion and spirituality				d940 Political Life and citizenship			
			Performance Qualifier		Capacity Qualifier		Performance Qualifier		Capacity Qualifier		Performance Qualifier		Capacity Qualifier		Performance Qualifier		Capacity Qualifier	
			CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG
			n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
3 Months	No difficulty		0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
(Control Group n = 64)	Mild to Moderate		38(59.4)	52(69.3)	0(0)	0(0)	64(100)	75(100)	0(0)	0(0)	64(100)	75(100)	0(0)	0(0)	33(51.6)	28(37.3)	0(0)	0(0)
(Experimental Group n = 75)	Severe to complete	difficulty	26(40.6)	23(30.7)	64(100)	75(100)	0(0)	0(0)	64(100)	75(100)	0(0)	0(0)	64(100)	75(100)	31(48.4)	47(62.7)	64(100)	75(100)
6 Months	No difficulty		0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
(Control Group n = 53)	Mild to Moderate		25(47.2)	29(54.7)	0(0)	0(0)	53(100)	66(100)	0(0)	0(0)	53(100)	66(100)	0(0)	0(0)	50(94.3)	65(98.5)	0(0)	0(0)
(Experimental Group n = 66)	Severe to complete	difficulty	28(52.8)	37(45.3)	53(100)	66(100)	0(0)	0(0)	53(100)	66(100)	0(0)	0(0)	53(100)	66(100)	3(5.7)	1(1.5)	53(100)	66(100)
12 Months	No difficulty		0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
(Control Group n = 49)	Mild to Moderate		36(73.5)	49(75.4)	0(0)	0(0)	49(100)	65(100)	0(0)	0(0)	49(100)	65(100)	0(0)	0(0)	28(57.1)	39(60)	0(0)	0(0)
(Experimental Group n = 65)	Severe to complete	difficulty	13(26.5)	16(24.6)	49(100)	65(100)	0(0)	0(0)	49(100)	65(100)	0(0)	0(0)	49(100)	65(100)	21(42.9)	26(40)	49(100)	65(100)

At 12 months 26.5% of the control group and 24.6% of the experimental group still had severe to complete difficulty with community life while all the participants (100%) had mild to moderate difficulty with recreation and leisure activities.

**e) The environmental factors that influenced the patient ability to function in the community**

For the purposes of data analysis, the qualifiers were coded as follows:

0 = No barriers or facilitator was left as a stand-alone category.

1 = Mild barriers and 2 = Moderate barriers were combined into one category which is the mild to moderate barriers.

3 = Severe barriers and 4 = Complete barriers were combined into one category which is the severe to complete barriers.

1 = Mild facilitator and 2 = Moderate facilitator were combined into one category which is the mild to moderate facilitator.

3 = Severe facilitator and 4 = Complete facilitator were combined into one category which is the severe to complete facilitator.

The products and technology environmental factors that influenced the patient's ability to function in the community are shown in Table 5.25 below.

**Table 5.25:** The “products and technology” environmental factors that influenced the patient ability to function in the community

		e150 Design, construction and building products and technology (public use).				e155 Design, construction and building products and technology (private use).			
		Barrier		Facilitator		Barrier		Facilitator	
		CG	EG	CG	EG	CG	EG	CG	EG
		n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
3 Months	No Barrier/facilitator	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
(Control Group n = 64)	Mild to Moderate Barrier/Facilitator	41(64.1)	49(65.3)	0(0)	0(0)	51(83.6)	62(82.7)	0(0)	0(0)
(Experimental Group n = 75)	Severe to complete Barrier/Facilitator	23(35.9)	26(34.5)	0(0)	0(0)	13(16.4)	13(17.3)	0(0)	0(0)
6 Months	No Barrier/facilitator	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
(Control Group n = 53)	Mild to Moderate Barrier/Facilitator	22(41.5)	33(50)	0(0)	0(0)	32(60.4)	34(51.5)	0(0)	0(0)
(Experimental Group n = 66)	Severe to complete Barrier/Facilitator	31(58.5)	33(50)	0(0)	0(0)	21(39.6)	32(48.2)	0(0)	0(0)
12 Months	No Barrier/facilitator	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
(Control Group n = 49)	Mild to Moderate Barrier/Facilitator	29(59.2)	36(55.4)	0(0)	0(0)	2(4.1)	4(6.2)	0(0)	0(0)
(Experimental Group n = 65)	Severe to complete Barrier/Facilitator	20(40.8)	29(44.6)	0(0)	0(0)	47(95.9)	61(93.8)	0(0)	0(0)

The design, construction and building products and technology of buildings for both public and private use were considered as being mild to moderate and severe to complete barriers.

The support and relationships environmental factors that influenced the patient ability to function in the community are shown in Table 5.26 below.



**Table 5.26:** The “support and relationships” environmental factors that influenced the patient’s ability to function in the community

		<b>e310 Immediate family</b>				<b>e320 Friends</b>				<b>e325 Acquaintances, peers, colleagues, neighbours and community members</b>				<b>e340 Personal care providers and personal assistants</b>			
		<b>Barrier</b>		<b>Facilitator</b>		<b>Barrier</b>		<b>Facilitator</b>		<b>Barrier</b>		<b>Facilitator</b>		<b>Barrier</b>		<b>Facilitator</b>	
		CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG
		n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
3 Months	No Barrier/facilitator	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
(Control Group n = 64)	Mild to Moderate Barrier/Facilitator	0(0)	0(0)	56(87.5)	71(94.7)	35(54.7)	48(64)	29(45.3)	27(36)	35(54.7)	48(64)	21(32.8)	23(30.7)	0(0)	0(0)	35(54.7)	48(64)
(Experimental Group n = 75)	Severe to complete Barrier/Facilitator	0(0)	0(0)	8(12.5)	4(5.3)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	8(12.5)	4(5.3)	0(0)	0(0)	29(45.3)	27(36)
6 Months	No Barrier/facilitator	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
(Control Group n = 53)	Mild to Moderate Barrier/Facilitator	0(0)	0(0)	50(94.3)	61(92.4)	31(58.5)	33(50)	22(41.5)	33(50)	31(92.4)	33(50)	19(35.8)	28(42.4)	0(0)	0(0)	31(58.5)	33(50)
(Experimental Group n = 66)	Severe to complete Barrier/Facilitator	0(0)	0(0)	3(5.7)	5(7.6)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	3(5.7)	5(7.6)	0(0)	0(0)	22(41.5)	33(50)
12 Months	No Barrier/facilitator	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
(Control Group n = 49)	Mild to Moderate Barrier/Facilitator	0(0)	0(0)	26(53.1)	33(50.8)	29(59.2)	36(55.4)	20(40.8)	29(44.6)	20(40.8)	29(44.6)	6(12.2)	4(6.2)	0(0)	0(0)	20(40.8)	29(44.6)
(Experimental Group n = 65)	Severe to complete Barrier/Facilitator	0(0)	0(0)	23(46.9)	32(49.2)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	23(46.9)	32(49.2)	0(0)	0(0)	29(59.2)	36(55.4)

The support of the immediate family and that of personal care providers and assistants was seen as being a facilitator to activity participation. However, greater than 50% of the patients saw the support of friends as being barriers for the duration of the study, indicating a lack of support from this group. Acquaintances, peers, colleagues, neighbours and community members were also largely seen as being facilitators to activity participation..

The attitudes environmental factors that influenced the patients' ability to function in the community are shown in Table 5.27 below.

**Table 5.27:** The “attitudes” environmental factors that influenced the patient’s ability to function in the community

		e410 Individual attitudes of immediate family members				e420 Individual attitudes of friends				e440 Individual attitudes of personal care providers and personal assistants				e460 Societal attitudes			
		Barrier		Facilitator		Barrier		Facilitator		Barrier		Facilitator		Barrier		Facilitator	
		CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG
		n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
3 Months	No Barrier/facilitator	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
(Control Group n = 64)	Mild to Moderate Barrier/Facilitator	0(0)	0(0)	35(54.5)	48(64)	35(54.5)	48(64)	29(45.3)	27(36)	35(54.5)	48(64)	0(0)	0(0)	0(0)	0(0)	64(100)	75(100)
(Experimental Group n = 75)	Severe to complete Barrier/Facilitator	0(0)	0(0)	29(45.3)	27(36)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	29(45.3)	27(36)	0(0)	0(0)	0(0)	0(0)
6 Months (Control Group n = 53)	No Barrier/facilitator	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
(Experimental Group n = 66)	Mild to Moderate Barrier/Facilitator	0(0)	0(0)	31(58.5)	33(50)	31(58.5)	33(50)	0(0)	0(0)	0(0)	0(0)	31(58.5)	33(50)	0(0)	0(0)	53(100)	66(100)
	Severe to complete Barrier/Facilitator	0(0)	0(0)	22(41.5)	33(50)	0(0)	0(0)	22(41.5)	33(50)	0(0)	0(0)	22(41.5)	33(50)	0(0)	0(0)	0(0)	0(0)

		e410 Individual attitudes of immediate family members				e420 Individual attitudes of friends				e440 Individual attitudes of personal care providers and personal assistants				e460 Societal attitudes			
		Barrier		Facilitator		Barrier		Facilitator		Barrier		Facilitator		Barrier		Facilitator	
		CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG
		n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
12 Months	No Barrier/facilitator	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
(Control Group n = 49	Mild to Moderate Barrier/Facilitator	0(0)	0(0)	20(40.8)	29(44.6)	20(40.8)	29(44.6)	0(0)	0(0)	0(0)	0(0)	20(44.6)	29(44.6)	0(0)	0(0)	49(100)	65(100)
(Experimental Group n = 65)	Severe to complete Barrier/Facilitator	0(0)	0(0)	29(59.2)	36(55.4)	0(0)	0(0)	29(59.2)	36(55.4)	0(0)	0(0)	29(59.2)	36(55.4)	0(0)	0(0)	0(0)	0(0)

The individual attitudes of the immediate family members were viewed as being largely facilitators while that of friends were more or less equally divided between barriers and facilitators over the study period. The attitudes of personal care providers and assistants were also viewed as being largely facilitators.

The services, systems and policies factors that influenced the patient ability to function in the community are shown in Table 5.28 below.

**Table 5.28:** The “services, systems and policies” factors that influenced the patient ability to function in the community

		e525 Housing services and policies				e540 Transportation services, systems and policies				e570 Social security services, systems and policies				e575 General social support services, systems and policies			
		Barrier		Facilitator		Barrier		Facilitator		Barrier		Facilitator		Barrier		Facilitator	
		CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG	CG	EG
		n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
3 Months	No Barrier/facilitator	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
(Control Group n = 64)	Mild to Moderate Barrier/Facilitator	56(87.5)	63(84)	0(0)	0(0)	52(81.3)	64(85.3)	0(0)	0(0)	64(100)	75(100)	0(0)	0(0)	31(48.4)	35(46.7)	0(0)	0(0)
(Experimental Group n = 75)	Severe to complete Barrier/Facilitator	8(12.5)	12(16)	0(0)	0(0)	12(18.8)	11(14.7)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	33(51.6)	40(53.3)	0(0)	0(0)
6 Months	No Barrier/facilitator	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
(Control Group n = 53)	Mild to Moderate Barrier/Facilitator	50(94.3)	61(92.4)	0(0)	0(0)	53(100)	66(100)	0(0)	0(0)	53(100)	66(100)	0(0)	0(0)	34(64.2)	38(57.6)	0(0)	0(0)
(Experimental Group n = 66)	Severe to complete Barrier/Facilitator	3(5.7)	5(7.6)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	19(35.8)	28(42.4)	0(0)	0(0)
12 Months	No Barrier/facilitator	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)
(Control Group n = 49)	Mild to Moderate Barrier/Facilitator	26(53.1)	33(50.8)	0(0)	0(0)	49(100)	65(100)	0(0)	0(0)	49(100)	65(100)	0(0)	0(0)	43(87.8)	61(93.8)	0(0)	0(0)
(Experimental Group n = 65)	Severe to complete Barrier/Facilitator	23(46.9)	32(49.2)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	6(12.2)	4(6.2)	0(0)	0(0)

All the participants viewed the social security services and systems and policies as mild to moderate barriers and the general social security services and systems and policies as mild to complete barriers to their extent of participation in the community. Greater than 80% cited the transportation services, systems and policies as being a mild to moderate barrier. Housing policies were also considered as a mild to complete barrier.

**f) The environmental factors that were associated with the extent of activity limitations:**

Table 5.29 below shows the association between environmental factors and the factors they influenced. This table is presented over the next three pages.

**Table 5.29:** The association between environmental factors and activities of daily living

<b>Domains</b>	<b>Environmental Factors</b>	<b>r value*</b>
d175 Solving Problems	e150 Public buildings design and construction	0.7
	e225 Climate	-0.9
	e310 Support of friends	0.9
	e325 Support of acquaintances, peers, colleagues, neighbours and community members	
	e355 Support from health professionals	0.9
	e410 Individual attitudes of immediate family members	0.9
	e420 Individual attitudes of friends	0.9
	e440 Individual attitudes of personal care providers and assistants	0.9
d120 Undertaking a single task	e355 Support from health professionals	-0.7
	e360 Support from health related professionals	-0.7
	e450 Individual attitudes of health professionals	-0.7
	e455 Individual attitude of health related professionals	-0.7
	e575 General social support services, systems and policies	0.7
	e310 Support of immediate family	-0.99
d220 Undertaking multiple tasks	e325 Support of acquaintances, peers, colleagues, neighbours and community members	-0.7
	e355 Support from health professionals	-0.8
	e360 Support from health related professionals	-0.99
	e455 Individual attitude of health related professionals	-0.99
	e460 Societal attitudes	-0.99
	e465 Societal norms, practices and ideologies	-0.99

\*Only those factors with high correlations, that is 'r' values greater than or equal to 0.6 were chosen for display in the results section. All these correlations were statistically significant with  $p < 0.001$ .

<b>Domains</b>	<b>Environmental Factors</b>	<b>r value*</b>
d430 Lifting and carrying goods	e120 For personal indoor and outdoor mobility and transportation	0.6
	e125 Products for communication	0.7
	e150 Public buildings design and construction	0.7
	e155 Private buildings design and construction	-0.6
	e310 Support of friends	0.6
	e360 Support from health related professionals	0.6
	e410 Individual attitudes of immediate family members	0.6
	e420 Individual attitudes of friends	0.6
d450 Walking	e525 Housing services, systems and policies	0.7
	e575 General social support services, systems and policies	0.7
	e325 Support of acquaintances, peers, colleagues, neighbours and community members	0.6
	e575 General social support services, systems and policies	-0.6
	e590 Labour and employment services, systems and policies	-0.7
	e150 Public buildings design and construction	0.7
	e155 Private buildings design and construction	0.7
	e310 Support of friends	0.98
d465 Moving around using equipment	e325 Support of acquaintances, peers, colleagues, neighbours and community members	0.98
	e340 Support of personal care providers and personal assistants	0.9
	e590 Labour and employment services, systems and policies	-0.7
	e310 Support of immediate family	-0.7
	e460 Societal attitudes	-0.7
d470 Using transportation	e465 Societal norms, practices and ideologies	-0.7
	e340 Support of personal care providers and personal assistants	0.8
d510 Washing oneself	e575 General social support services, systems and policies	-0.9

<b>Domains</b>	<b>Environmental Factors</b>	<b>r value *</b>
d640 Doing housework	e325 Support of acquaintances, peers, colleagues, neighbours and community members	0.6
	e590 Labour and employment services, systems and policies	-0.6
d740 Formal relationships	e310 Support of immediate family	-0.7
	e460 Societal attitudes	-0.7
	e465 Societal norms, practices and ideologies	-0.7
	e525 Housing services, systems and policies	-0.7
	e575 General social support services, systems and policies	-0.7
	e590 Labour and employment services, systems and policies	-0.8
d760 Family relationships	e320 Support of friends	0.6
	e340 Support of personal care providers and personal assistants	0.6
	e410 Individual attitudes of immediate family members	0.6
	e420 Individual attitudes of friends	0.6
	e440 Individual attitudes of personal care providers and assistants	0.6
	e525 Housing services, systems and policies	0.8
	e540 Transportation services, systems and policies	0.7
	e575 General social support services, systems and policies	-0.9
e590 Labour and employment services, systems and policies	-0.9	
d770 Intimate relationships	e320 Support of friends	0.6
	e340 Support of personal care providers and personal assistants	0.6
	e440 Individual attitudes of personal care providers and assistants	0.6
	e450 Individual attitudes of health professionals	0.6
	e455 Individual attitude of health related professionals	0.6

\*Only those factors with high correlations, that is 'r' values greater than or equal to 0.6 were chosen for display in the results section. All these correlations were statistically significant with  $p < 0.001$ .

The support and attitudes of immediate family, friends, acquaintances, peers, colleagues, personal care providers and personal assistants were the environmental factors largely associated with the extent to which patients were able to carry out activities.

## 5.11 The patient characteristics associated with caregiver strain post stroke.

This section presents the results that helped answer objective six, which sought to establish patient characteristics associated with caregiver strain following a stroke. The first section outlines the general caregiver strain trends for the caregivers over the 12 months period and the statistical differences between the control and experimental groups. This is then followed by the univariate regression analysis results detailing those factors that were associated with caregiver strain.

### 5.11.1 Summary of Caregiver Strain among the Caregivers

The general caregiver strain trend for the study sample is shown in Table 5.30 below which is presented in two parts over two pages.

**Table 5.30:** General caregiver strain trend of the study sample.

Item Score	3 Months				6 Months				12 Months			
	Control (n = 64)		Experimental (n = 75)		Control (n = 53)		Experimental (n = 66)		Control (n = 49)		Experimental (n = 65)	
	no.	%	no.	%	no.	%	no.	%	no.	%	no.	%
Sleep disturbed	27	42.2	50	66.7	16	30.2	37	56.1	23	46.9	42	64.6
Inconvenience	38	59.4	35	46.7	37	69.8	29	43.9	34	69.4	24	36.9
Physical strain	63	98.4	71	94.7	53	100	63	95.5	40	81.6	35	53.8
Confining	59	92.2	66	88	50	94.3	58	87.9	47	95.9	50	76.9
Family adjustments	56	87.5	63	84	49	92.5	57	86.4	46	93.9	53	81.5
Changes in personal plans	56	87.5	59	78.7	51	96.2	56	84.8	44	89.8	46	70.8
Demands on time	57	89.1	69	92	50	94.3	65	98.5	36	73.5	28	43.1
Emotional adjustments	42	65.6	60	80	24	45.3	33	50	25	51	17	26.2
Behaviour upsetting	3	4.7	7	9.3	36	67.9	21	31.8	4	8.2	5	7.7



Item Score	3 Months				6 Months				12 Months			
	Control (n = 64)		Experimental (n = 75)		Control (n = 53)		Experimental (n = 66)		Control (n = 49)		Experimental (n = 65)	
	no.	%	no.	%	no.	%	no.	%	no.	%	no.	%
Personality change upsetting	35	54.7	54	72	51	96.2	54	81.8	47	95.9	54	83.1
Work adjustments	55	85.9	56	74.7	48	90.6	54	81.8	36	73.5	21	32.3
Financial strain	59	92.2	71	94.7	50	94.3	65	98.5	46	93.9	62	95.4
Feel overwhelmed	13	20.3	18	24	4	7.5	12	18.2	23	46.9	16	24.6
<b>CSI Total Score</b>												
Mean	8.8		9.1		9.8		9.2		9.3		6.7	
Minimum	3		3		2		5		2		2	
Maximum	12		13		11		12		12		12	
St. Dev	1.6		1.7		1.6		1.6		2.7		2.7	
25th percentile	8		9		10		9		8		5	
50th percentile	9		10		11		10		10		6	
75th percentile	10		10		11		10		11		9	

The major areas that contributed towards caregivers' strain were feelings of caregiving causing physical strain, feeling of being confined, having to make family adjustments, the personality changes in the patient and the financial strain resulting from the stroke. The CSI total mean scores for both groups generally increased from three months to six months and came down slightly at 12 months for the control group (from 9.8 to 9.3) and decreased for the experimental group (from 9.2 to 6.7).

The frequency of caregiver strain among the caregivers over the study period is shown in Table 5.31 below.

**Table 5.31:** Frequency of caregiver strain

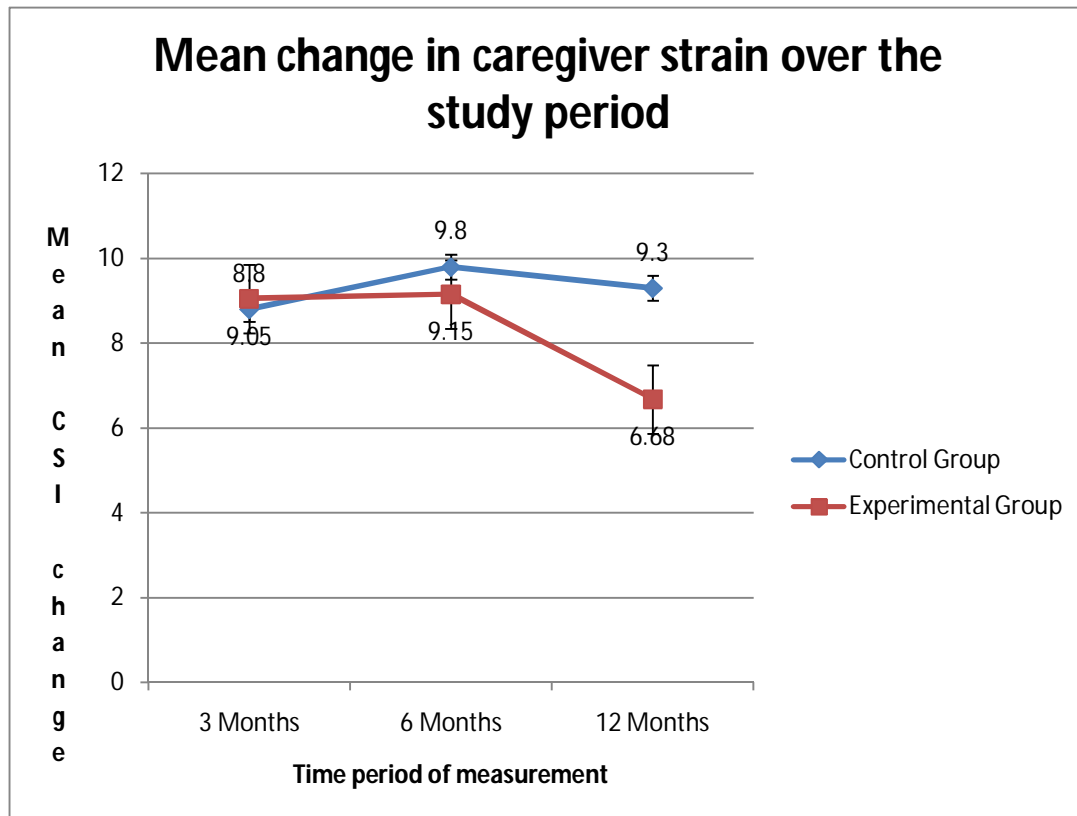
Time period of measurement	Caregiver Strain Index	Control Group n(%)	Experimental Group n(%)	Total n(%)
3 Months	≤6	7(10.9)	6(8)	13(9.35)
	≥7	57(89.1)	69(92)	126(90.7)
6 Months	≤6	2(3.8)	6(9.1)	8(6.7)
	≥7	51(96.2)	60(90.9)	111(93.3)
12 Months	≤6	11(22.4)	37(56.9)	48(42.1)
	≥7	38(77.6)	28(43.1)	56(57.9)

According to the scoring of the Caregiver Strain Index, those who scored  $\geq 7$  are considered to be strained while those who score less than 7 are considered not strained. The higher the score, the more strained the caregivers are and the lower the score, the better the outcome.

More than 90% of the study sample was strained at three and six months follow up. At the 12 month follow up, there were more strained caregivers in the control group (77.6%) than in the experimental group (43.1%).

The results of the effect of caregiver education on caregiver strain are shown below.

Figure 5.16 below shows the mean change in caregiver strain over the study period.



**Figure 5.16:** Mean change in caregiver strain

Caregiver strain rose between three months and six months and then significantly declined in the experimental group and marginally in the control group. The within group mean CSI change for the control group was statistically significant at between 3 and 6 months ( $p = 0.02$ ) while for the experimental group it was statistically significant at between 3 and 12 months and between 6 and 12 months ( $p < 0.001$ ).

The statistical test results of the mean caregiver strain index change between the control and experimental groups at the various measurement points are shown in Table 5.32 below.

**Table 5.32:** The mean caregiver strain change of the control and experimental groups.

Period	Mean Score Experimental Group	Mean Score Control Group	Mean difference	St. Error	95% CI	p value
3 Months	9.1	8.8	0.3	0.3	-0.8 – 0.3	0.18
6 Months	9.2	9.8	-0.6	0.3	0.1 – 1.2	0.01
12 Months	6.7	9.3	-2.6	0.5	1.6 – 3.6	< 0.001

Mean difference = mean (experimental group) – mean (control group) which is the treatment effect.

The differences of the CSI mean change between the two groups at six months and 12 months was statistically significant with the experimental group scoring lower mean CSI scores than the control group ( $p = 0.01$  and  $< 0.001$  respectively for the 6 and 12 months assessments). Caregiver education had the effect of reducing caregiving stress by 2.6 at 12 months and this was a clinically significant change.

### 5.11.2 Patient characteristics associated with caregiver strain

The univariate regression analysis results for patient factors influencing caregiver strain are given in this section. In the table below, the coefficients are given in reference to the constant and so will be above or below the reference by the given coefficient value. Though a multivariate analysis was done, it was decided against displaying the results to reduce type I errors emanating from “over analysis” of the data. The univariate analysis results were considered adequate to answer the objective.

**Table 5.33:** Patient characteristics associated with caregiver strain

<b>Factor</b>	<b>Coefficient</b>	<b>Std. Error</b>	<b>Exp(beta)</b>	<b>p-value</b>	<b>95%CI</b>
<b>Stroke subtype</b>					
Total Anterior Circulatory Infarction	Reference = 8.1			-	-
Partial Anterior Circulatory Infarct	0.6	0.8	1.8	0.14	0.8 – 4.2
Posterior Circulatory Infarct	1	1.1	2.6	0.02	1.2 – 6
Lacunar Circulatory Infarct	0.6	0.8	1.9	0.13	0.8 – 4.4
<b>BI Transfer</b>					
Unable	Reference = 8.5	-	-	-	-
Major help	0.8	1.1	2.3	0.07	0.9 – 5.7
Minor help	-1.1	0.2	0.3	0.03	0.1 – 0.9
Independent	-1	0.6	0.4	0.51	0.0 – 7.4
<b>BI Mobility</b>					
Immobile	Reference = 8.7			-	-
Wheelchair dependent	0.4	0.6	1.4	0.38	0.6 – 3.3
Walks with help	-1.1	0.2	0.3	0.02	0.1 – 0.9
Independent	-			-	-
<b>BI Dressing</b>					
Dependent	Reference = 9			-	-
Needs help	0.1	0.4	1.1	0.68	0.6 – 2.2
Independent	-2.2	0.04	0.1	<0.001	0.0 – 0.2

Factor	Coefficient	Std. Error	Exp(beta)	p-value	95%CI
<b>BI Bathing</b>					
Dependent	Reference = 9.3			-	-
Independent	-1.5	0.1	0.2	<0.001	0.1 – 0.4
<b>BI Total</b>	-0.2	0.03	0.8	<0.001	0.7 – 0.9
<b>RMI Total</b>	-0.1	0.03	0.9	0.001	0.8 – 1
<b>EQ-5D Usual Activities</b>					
No problems	Reference = 6.8			-	-
Some problems	2	7.1	7.1	0.05	1 – 50.8
Unable	3	28.5	19.1	0.05	1 – 358.7
<b>EQ-5D Pain/Discomfort</b>					
No pain/discomfort	Reference = 9.1			-	-
Moderate pain/discomfort	-0.7	0.1	0.5	0.002	0.3 – 0.8
Extreme pain/discomfort	-0.2	0.6	0.8	0.77	0.2 – 3.5
<b>EQ-5D Anxiety/Depression</b>					
Not anxious/depressed	Reference = 7.8			-	-
Moderately anxious/depressed	1.2	1.1	3.2	0.001	1.6 – 6.4
Extremely anxious/depressed	1	1.2	2.7	0.03	1.1 – 6.3
<b>EQ-5D General Perceived Health State</b>					
Better	Reference = 7.5			-	-
Much the same	1.8	3	6.3	<0.001	2.5 – 15.9
Worse	1.1	1.4	3	0.02	1.2 – 7.4
<b>EQ-5D VAS Perceived Health State</b>	-0.04	0.09	1	<0.001	0.9 – 1

The caregivers of those patients who needed minor help with transfers had on average 1.1 less caregiving strain than those caregivers for patients who were unable to transfer ( $p = 0.03$ ; OR = 0.3). The caregivers of those patients who walked with help had on average 1.1 less caregiver strain than those caregivers for patients who were immobile ( $p = 0.02$ ; OR = 0.3). As the BI total score increases by one unit, it has the impact of reducing the CSI total score by 0.2 ( $p = 0.001$ ; OR = 0.8) and as the RMI total score increases by one unit, it has the impact of reducing the CSI total by 0.1 ( $p = 0.001$ ; OR = 0.9). As the EQ-5D VAS score increases by one unit, it has the impact of reducing the CSI total score by 0.04 ( $p < 0.001$ ; OR = 1).

## 5.12 The caregiver characteristics associated with caregiver strain

In this section, the caregiver characteristics that influenced caregiver strain are presented. Caregiver characteristics associated with caregiver strain are shown in Table 5.34 below.

**Table 5.34:** Caregiver characteristics associated with caregiver strain

Factor	Coefficient	Std. Error	Exp(beta)	p-value	95%CI
<b>Level of education</b>					
University degree	Reference = 10			-	-
Grade 12 + 3 or more years	-			-	-
Grade 12 or equivalent	-1.2	0.1	0.3	0.02	0.1 – 0.8
Up to Grade 11	-1.4	0.1	0.3	0.002	0.1 – 0.6
Up to Grade 7	-1.2	0.1	0.3	0.008	0.1 – 0.7

The only caregiver factor that seemed to influence caregiver strain was level of education. The caregivers of those patients who had gone to school up to Grade 11 had on average 1.4 less caregiver strain than those caregivers who had a university degree ( $p = .0002$ ; OR = 0.3).

The results for the objectives of the study were presented in this chapter. These results will now be discussed in the next chapter: Chapter 6: Discussion.

## CHAPTER 6

### 6. DISCUSSION

#### 6.1 Introduction

This chapter will discuss the results that were obtained from this study. The discussion will include the following subheadings: Caregiver education programmes and content currently in use at Chris Hani Baragwanath hospital; the effect of caregiver education on mobility of the stroke survivors; the effect of caregiver education on the quality of life of the stroke survivors; the effect of caregiver education on the quality of life of the caregivers; the effect of caregiver education on the ability of the stroke survivors to socialise and participate in community issues; the patient characteristics associated with caregiver strain following stroke; the caregiver characteristics associated with caregiver strain following stroke and the sample size, selection and demographics.

#### **6.2 The caregiver education programmes and content currently in use when managing patients with stroke at Chris Hani Baragwanath hospital (CHBH).**

At CHBH, patients with stroke have a very short in-patient stay and have limited contact with a physiotherapist. Although the rehabilitation itself was well structured, there was no involvement of caregivers during in-patient rehabilitation. The major barriers to caregiver involvement in the rehabilitation of patients with stroke include a heavy patient load for the physiotherapists and limited available time during working hours for caregivers to come for training.

Patient length of hospital stay is one of the determinants of functional outcome following stroke. It is however also the major determinant of direct cost for stroke care (Jorgensen et al., 1997). In this study, the average length of hospital stay of patients with stroke was shorter than that found in a previous study at the same hospital (14 days (Hale, 2002) to about 6 days). The average length of stay for patients with stroke has thus been greatly reduced. This can be explained in part, by the increase in pressure for beds in hospitals due to the HIV/AIDS pandemic, which has resulted in increased patient loads (Gilks et al., 1998, Colvin et al., 2001, Reid et al., 2005, Veenstra and Oyier, 2006). This increased patient load results in patients being discharged home as soon as



their medical status allows irrespective of their functional status. This compares poorly with the average length of stay in high-income countries such as the Netherlands and United Kingdom where it is around 28-34 days (Green et al., 2005). In addition, high-income countries have acute rehabilitation units where patients with stroke are admitted while in South Africa there are very few such public facilities and CHBH does not have a specific stroke rehabilitation unit. Unlike the setting in most high-income countries where the majority of patients who require rehabilitation are admitted to stroke units, the majority of patients at CHBH and many other public tertiary hospitals in South Africa go home after discharge from the acute medical wards. There is overwhelming evidence of the effectiveness of stroke units to not only improve functional outcomes post-stroke but also a reduction in mortality (Stroke Unit Trialists' Collaboration, 2007; Schwamm et al., 2005; Krespi et al., 2003; Langhorne and Duncan, 2001; Kalra et al., 2000; Sinha and Warburton, 2000; Indredavik et al., 1999; Indredavik et al., 1998). There is controversial evidence on the costs involved in running stroke units with some studies finding no additional costs while some acknowledge the better results come at increased costs (Moodie et al., 2006; Patel et al., 2004). Overall, however, one cannot ignore the effectiveness of dedicated stroke units on functional outcomes and survival rates from published studies.

The short length of hospital stay for patients with stroke has implications for the number of physiotherapy contacts patients receive before discharge. A shorter hospital stay increases the likelihood of patients being discharged home without receiving sufficient, if any physiotherapy. The mean number of physiotherapy contacts for patients found during a record review prior to this main study was one. This compares poorly with the average number of contacts in the United States where patients receive physiotherapy for an average of 13.6 days during an average length of stay of 18.7 days (Jette et al., 2005). Following a stroke, the first two to five days after admission are used to ensure that the patient with a stroke is medically stable. This situation gives an average of one day for physiotherapists to provide treatment to patients with a stroke at CHBH. The result is that patients are discharged home with very little physiotherapy (or rehabilitation in general). These findings tend to agree with Green et al.'s 2005 findings which showed that patients with a stroke in South Africa were discharged with lower functional status than Finnish and Australian patients had on admission. Inadequate rehabilitation and poor functional status at discharge results in patients going home to unprepared caregivers with the potential of placing an enormous burden on them.

The patient's functional status is one of the determinants of quality of life in patients with stroke and their caregivers (Jonsson et al., 2005). It is disheartening to note that it is claimed that in South Africa, there is insufficient focus on early intervention and early rehabilitation of patients with stroke and that rehabilitation sometimes occurs quite a long time after the initial acute episode (Green et al., 2005). It should however be borne in mind that a longer length of hospital stay does not necessarily translate into better functional outcomes for patients with stroke as other factors such as experience and the competence of therapists, intensity of treatment, length of treatment and even patient motivation to participate in the treatment have a significant impact on outcome (McNaughton et al., 2005). The assessment of physiotherapy contacts was potentially limited as no assessment was done on the influence of stroke severity or subtype on the poor number of physiotherapy contacts and some physiotherapists may not have recorded their treatment contacts in the medical notes, though to do so is standard good practice.

Interestingly none of the physiotherapists in this study mentioned the need to involve caregivers during the in-patient rehabilitation process of the survivors of stroke in their general management protocols of patients with stroke. They were however able to describe the role of the caregiver. They stated that the caregiver role included assisting the patient with activities of daily living, rehabilitation at home, keeping medical appointments, avoidance/reduction of stroke risk factors, understanding of their condition, integration into society and encouraging them to take responsibility for their own rehabilitation. Of course, in this situation, physiotherapists were not interacting with the caregivers during in-patient hospital time and so no training of caregivers happens before patients are discharged home. Caregiver training is currently only offered to those caregivers who can manage/afford to accompany patients with stroke when they return for physiotherapy treatment as out-patients. In this regard, the therapists rated themselves as being moderately effective in involving caregivers in out-patient treatment and concurred that there was room for improvement.

In general, there currently is no structured way of teaching caregivers how to look after patients with stroke post-discharge at CHBH. The education of patients who are able to come as out-patients at CHBH is specific to each patient and mainly revolves around teaching caregivers how to

continue with patient rehabilitation at home as well as teaching caregivers how to protect themselves during lifting of patients. This caregiver training is done through observation of therapists treating patients as well as asking caregivers to demonstrate taught treatment ideas. There is clearly less emphasis on risk factor knowledge, importance of taking medication, warning signs of stroke, consequences of a stroke and the prevention and management options of a stroke.

In the hospital setting for this study, therapists seldom if ever interacted with caregivers during the in-patient stay, and few stroke survivors are able to return as out-patients, thereby limiting the potential for rehabilitation and caregiver training. CHBH caters mainly for an economically disadvantaged population from the surrounding Soweto area. As is typical of similar populations, many patients cannot afford the required bus fare to commute to the hospital or community health centre for treatment as out-patients and the quality of health care is thus worse for the poor (Bradshaw and Steyn, 2001). The inability of the therapists to interact with caregivers during the in-patient hospital period following stroke can also be attributed to inadequate funding of the health care sector. The cuts to health care funding are reducing the time health care professionals have to interact with the families (Cameron and Gignac, 2008).

This study identified several barriers to caregiver training during a patient with stroke's hospital stay. These included a heavy workload for physiotherapists, making it impossible for them to create time for caregivers and lack of caregiver availability for training during normal working hours due to their other commitments. Though the physiotherapists stated that they interact with caregivers during out-patient rehabilitation of patients with stroke, they suggested further barriers to this interaction. These included some caregivers being too old and so unable to help look after the patient with a stroke, poor financial resources, being overwhelmed with responsibility and different caregivers taking turns to accompany patients for out-patient physiotherapy. This latter barrier could be because of the demanding nature of accompanying a patient to a physiotherapy session in terms of time and monetary commitment. This results in poor continuity of care, duplication of training and insufficient reinforcement of training.

The physiotherapists also reported that caregivers feel overwhelmed by the responsibility of looking after patients. Caregiving has been associated with increased depression and family

constraints (Anderson et al., 1995; Han and Haley, 1999; Flick, 1999, Putterill et al., 1984b). Factors that add to the caregiver burden include financial difficulties, and personal, often age related physical limitations. Stroke in high-income regions of the world typically affects the elderly, but in populations in transition like South Africa stroke affects younger individuals (Connor et al., 2007a).

Better organisation of services and family integration (through education of the caregivers) coupled with early implementation of rehabilitation can be useful in ensuring better outcomes in stroke rehabilitation (Fjaertoft et al., 2003, Walker et al., 2003, Fjaertoft et al., 2005). Training relatives and caregivers (supported discharge) to help with rehabilitation could help reduce morbidity and mortality following stroke (Fjaertoft et al., 2003, Langhorne et al., 2005, Langhorne and Holmqvist 2007). This early supported discharge system should be supplemented with out-patient care for patients through either out-patient visits or domiciliary visits. Ideally, caregivers should attend therapy sessions and should be encouraged to participate in the management of their relatives from the beginning to enable the setting of realistic goals for the rehabilitation of the stroke survivor.

Many populations such as ours in a low-resourced urban South African setting are undergoing epidemiological transition with a resulting increase in the incidence of stroke expected (Connor et al., 2007b) and yet are exposed to an enormous burden of HIV/AIDS which has resulted in an unprecedented burden on hospital beds (Karim et al., 2009). This burden drives the early discharge of patients with stroke from hospital and results in inadequate contact with physiotherapists. Stroke units, in-patient rehabilitation facilities, and long-term care facilities are lacking in the public sector of South Africa and are unlikely to become commonplace in the near future. This places a greater responsibility on relatives and family members of stroke survivors to act as caregivers. Though South Africa is considered a middle-income country in terms of its economy, it has health outcomes that fare worse than those in many lower income countries (Coovadia et al., 2009). Given the limitation of resources, both human and financial, in-patient and out-patient caregiver training in rehabilitation may provide an affordable and effective way of improving stroke survivor function and survival.

### **6.3 The effect of caregiver education on mobility of the stroke survivors.**

One of the most important aims of rehabilitation following stroke is to improve patients' functional ability. A major contributor towards the realisation of this important rehabilitation goal is improved patient mobility (Langhorne et al., 2009; van Peppen et al., 2004). Physiotherapy is one of the components of rehabilitation and it improves mobility post-stroke (Naess et al, 20006). The patients in this study sample had very low mobility levels at discharge from hospital as indicated by their low RMI scores at the baseline assessment. The control group had a mean RMI score of 3.3 and the experimental group 3.7 at baseline and the RMI scores rose in both groups over the study period with the difference between the two groups being largely clinically insignificant except at three months post discharge where the experimental group had better RMI scores. These scores are very low and signify a high degree of dependency in the patients. The higher the RMI scores, the higher the mobility of the patient and the reverse is true (Collen et al., 1991a).

Patients were only able to carry out low-level mobility activities such as rolling in bed and coming from lying to sitting at discharge from hospital (baseline) while at 12 months 80% of the control group and 94% of the experimental group were able to walk inside their houses with aids. These percentages were low for patient ability to walk outside on uneven ground, with only 25% of the control group and 23% of the experimental group being able to do so at 12 months post discharge. The patients who belonged to the experimental group improved their RMI scores by an average score of 0.7, which was moderately clinically significant. One can only postulate that maybe the patients cared for by the trained caregivers were exercised a little more than those who were cared for by untrained caregivers and hence the slightly better outcome. This outcome could also be attributed to increased confidence with the mobilisation process by the caregivers.

The poor RMI mobility scores of the patients also agree with the finding of low BI mobility scores. At the 12 months assessment period, 80% of the control group and 65% of the experimental group were wheelchair dependent with only 20% and 35% (respectively) being able to walk with the help of one person. It is clear from the above statistics that patients were physically poor and were very dependent on their caregivers for functional activities. This could be attributed to the larger percentage of women in this study group. Women generally tend to have worse outcomes post-stroke than men (Di Carlo et al., 2003; Kelly-Hayes et al., 2003; Niewada et al., 2005; Paolucci et

al., 2006). This could also be interpreted to mean that caregiver education did not have much of an impact on patients' physical functioning. This agrees with Barskova and Wilz (2007)'s finding that patients' physical function recovery is not affected by their partners (carers) but rather that it is the patients' locomotor difficulties that influence their partner's health.

The lack of clinically significant changes in the two groups' mobility abilities could be attributed to the low scores they had at discharge and lack of ongoing out-patient rehabilitation. Though it was not part of this study, it was noted during the follow up interviews that the majority (greater than 70%) of the subjects were not receiving out-patient rehabilitation. As one patient put it, *"I do not have the money to go to the clinic or the hospital for physiotherapy sessions; it costs R200 to travel to and from the hospital by metered taxi as the normal taxis will not take me with my wheelchair"*. If the patients had gone for rehabilitation after their early discharge from hospital, they would have benefited. Training and exercise programmes have value in stroke rehabilitation (Ramas et al., 2007). They have been shown to result in improved patient functional abilities and quality of life (Kalra et al., 2004; McNaughton et al., 2005; Aprile et al., 2008). The finding of patient inability to attend out-patient rehabilitation agrees with Kengne and Anderson (2006)'s statement that *"there is poor access of patients to rehabilitation services and little information available on functional recovery of patients after stroke in sub-Saharan Africa"*.

The low mobility scores also meant that patients could not fend for themselves and accordingly the caregivers were also not able to work so that they could provide care to the stroke survivors almost all the time. All the caregivers in this study were not gainfully employed at the time of the study. This sentiment agrees with the observed trend that the majority of the patients saw general social support services, systems and policies as barriers to their ability to function in the community. This argument is further strengthened by the fact that all the patients were not gainfully employed and the majority of the patients (greater than 96%) were not receiving social grants despite qualifying for them post-stroke. The reasons for not receiving social grants were attributed to two things: lack of knowledge of the application process and secondly the inability to get to the nearest social welfare centres to do the applications. Even for those few who were receiving social grants, the money was used to sustain the whole family and the priorities of the patient were bottom of the list.

As one caregiver put it: *"we cannot take her to the local clinic for physiotherapy and resupply of medicines because the money is not enough, we need to buy food"*.

Walking exercises are very physically demanding and as such the caregivers may not have let the patients practice enough when at home, resulting in clinically insignificant differences between the two groups. Despite the general increase in mobility among the patients over the year, they still struggled with higher mobility tasks such as stair climbing and running with none of the participants being able to do the latter. The fact that the majority of the patients did not attend out-patient rehabilitation did not help as well. Early discharge combined with home rehabilitation help promote motor and functional gains that happen through natural recovery and rehabilitation to a greater degree of higher level function and satisfaction with community reintegration (Mayo et al., 2000). This then eventually translates into better physical health for the patient. The role of out-patient rehabilitation, either at home or at the clinic/hospital can thus not be overemphasised.

These results further strengthen the need for the provision of out-patient rehabilitation to patients post-stroke. Clearly, the need is there and this can be done through domiciliary visits. The government has already introduced compulsory community physiotherapy service for all undergraduate students qualifying in the health sector (physiotherapy and occupational therapy included) as part of the drive to strengthen primary health care (Mohamed, 2005). Primary health care is aimed at making the health care system easily accessible and affordable to people in the communities in which they reside (Dennil, 1995). What is required is strengthening of the structures that are already in place. It was obvious from the interactions with patients that they were not being seen at home if they were not able to get to the clinic. Despite the lack of financial resources to enable them to travel to local health centres, it also showed inadequate referral to local community rehabilitation personnel or possibly lack of resources to enable them to see patients outside the clinic where they are based. The reasons for this require further investigation. These findings agree with Coovadia et al. (2009)'s statement that despite South Africa's large economy, it belongs in the category of poorly resourced countries and that there is still inequitable distribution of resources especially between the private and public health sectors.

It is also quite evident that accessibility to the disability grant system needs to be improved so that patients post-stroke can have some form of income that will help them travel to local health centres for collection of their medicines as well as receiving or continuing with rehabilitation. As seen from this study, all the patients regarded the social security services, systems and policies as being either mild to moderate or severe to complete barriers to their ability to function in the community. However, it should not be assumed that access to the grant system will translate to improved ability to access health centres, as this is dependent on many other factors such as the needs of the immediate and extended families and the attitude and care of the personal care providers and assistants. The attitudes of the personal care providers and assistants were perceived as being facilitators. However, the high level of caregiving burden seen among the caregivers could in the end cause negative attitudes given the continued low level functional abilities of the patients and their continued reliance on caregivers for activities of daily living (Jaffe and Blackley, 2000; Larson et al., 2005)

The improvements in mobility that were noted in both groups over the one-year period, point largely to natural recovery since the majority of the patients were not receiving out-patient rehabilitation. One can only postulate that if the patients had received rehabilitation for longer periods, they would have improved not only much faster but also much more in their mobility. Physiotherapy has been shown to be effective in improving patient mobility in many studies (Naess et al., 2006; Studenski et al., 2005; Hopman and Verner, 2003). It is clear from this study that improving patients' mobility should not be left to the caregivers alone. Not only is it physically demanding, but also the clinical expertise required to do so may not be easy for patients and caregivers to understand during educational sessions. Hence the need for out-patient or domiciliary rehabilitation.

#### **6.4 The effect of caregiver education on the quality of life of the stroke survivors.**

The patients in both groups reported very low perceived health status at discharge from hospital with a mean of 42 for the control group and 44 for the experimental group. At the end of one-year post-stroke, the patients' mean EQ-5D visual analogue scale scores improved to 67 and 69 for the control group and the experimental group respectively. Though the mean scores improved, they



were still not high. The explanation for the low perceived health related quality of life scores by the patients could be attributed to the low functional and mobility levels they had throughout the study period. This finding is similar to that by Rodgers et al. (1999) where a comprehensive stroke education programme did not result in improved patient perceived health status. This finding also raises the question of content, timing, delivery and duration of the training programme that was given in this study. Was the training enough to improve quality of life, was it timed right for maximum effect? These questions warrant further investigation. Although some aspects that were assessed showed improvements, it is still important to consider other ways of imparting this knowledge to the caregivers and establish the method, content and duration of training that would produce the best results. The results however contradict those by Hackett et al. (2000) who found that the health related quality of life post-stroke was relatively good for most patients in their study. The major difference between Hackett et al.'s cohort of patients and the one for this study was that they studied patients six years post-stroke while this study covered the first year post-stroke. It is therefore possible that after a longer period, the patients in this study could have better functional abilities and hence better health related quality of life scores.

It was however interesting to note that caregiver education seemed to improve the perceived health related quality of life scores for the patients with the EQ-5D scores improving by three at the six months follow up period. One can only postulate that this was because education of the caregivers left them with a better understanding of the patients, which might have resulted in improved caring ability for the patients, which would then translate, to better-perceived health related quality of life. Though the patient EQ-5D scores decreased slightly at 12 months, caregiver training had the effect of improving the patients' perceived quality of life by almost "two". The decline in EQ-5D scores observed could be attributed to the realisation of poor expected functional outcomes and prognosis by the patients, which could have lowered their expectations and resultantly the perceived quality of life.

The major areas of concern of the patients were mobility, self-care and ability to carry out usual activities with more than 93% of the patients from either group having some problems or being unable to carry out these activities. This agrees with the low functional and mobility levels that these patients demonstrated at all four assessment periods. The overall mean BI score of the

patients at baseline assessment was 6.1 (30.5%). This compares poorly to that of patients from Belgium where the mean BI score at admission was 40% (Ilse et al., 2008) or those from Sweden which were 92.2% at baseline and 94.4% at 12 months (Larson et al., 2005). This adds weight to Green et al. (2005)'s finding that the majority of patients from South Africa have worse functional outcomes at discharge than patients from Finland and New Zealand have at admission to hospital. This could possibly point to differences in pre-stroke levels of physical and functional abilities. It is quite clear that the ability to move and carry out functional activities has a huge bearing on the patients' perceived health related quality of life. Functional ability has been established to be a strong predictor of patients' perceived quality of life post-stroke (Naess et al., 2006; Nichols-Larsen et al., 2005; Bluvol and Ford-Gilboe, 2003). The low functional levels mean that patients will be dependent on caregivers for them to be able to carry out activities of daily living. The increased dependence on caregivers for activities of daily living alone can also contribute towards poor perceived health related quality of life. However as reported by Duncan et al. (1997), there are cases when patients report reduced quality of life despite high levels of functioning indicating the effect of factors other than functional levels. The low socioeconomic status of this cohort of patients could have contributed towards the poor functional outcomes noted. Patients residing in deprived areas are significantly more likely to die soon after the stroke or be dependent, than patients from affluent areas (Weir et al., 2005)

The number of patients who complained of pain rose over the one-year period from 60% and 68% for the control group and experimental group respectively at baseline to 80% and 82% respectively. These percentages compare fairly well to those of studies done elsewhere. Widar et al. (2002) found that in a cohort of patients with stroke, 63% complained of moderate pain while 37% complained of severe pain. This finding of pain being a common complaint among patients post-stroke agrees with Hale et al. (1999) 's findings where it was reported that stroke survivors in Soweto, South Africa, are troubled by shoulder and knee pain, inability to walk outside the home, transfers, as well as washing and dressing difficulties. Widar et al. (2002) strengthen these findings when they state that upper limb use and walking were the activities most affected by pain. The findings from this study confirm that nothing much has changed as far as the patient complaints about pain are concerned since Hale et al. (1999) performed their study. Though this study did not explore the source and sites of the pain, the percentages of the patients who complained of pain

were high. One therefore cannot rule out pain being a significant factor towards the diminished functional abilities of this cohort of patients.

Anxiety/depression also increased in this cohort from around 50% at baseline to more than 61% at 12 months. Depression has been established as a determinant of quality of life of stroke survivors post-stroke (Carod-Artal and Egido, 2009; Pan et al., 2008; Naess et al., 2006; Jonsson et al., 2005). The worsening of the patients' anxiety/depression state could be attributed to the fact that patients become more realistic about the expected recovery with time and when that happens, they get depressed/anxious. It should also be regarded as a possibility that as the patients gradually adapt to their acquired handicap from the stroke, it could actually be more demanding for the caregiver resulting in the increased anxiety/depression. Depression is a treatable condition and as such should be assessed and managed in patients with stroke. Post-stroke depression following an ischaemic stroke increases the risk of mortality (Williams et al., 2004).

The fairly poor quality of life in this cohort of patients can possibly be attributed again to the predominance of females in the study sample. Females are less likely to achieve independence in activities of daily living post-stroke (Gargano and Reeves, 2007) and their rehabilitation prognostic results are poor (Paolucci et al., 2006). The reasons for the differences in functional outcome and response to rehabilitation between men and women have not been fully understood to date. One possible explanation is the reduction in physical strength with age, which is more significant in women than in men (Sinaki et al., 2001). It has also been reported that women are open to asking for help while men often disguise their need for help and this could result in the misconception that they are doing better than females (Aberg, 2005). In addition, Rodgers et al. (1999) established that a stroke education programme could improve the patient and carer's knowledge about stroke but not necessarily their perceived health state and psychological outcomes. They point to the possible adverse effect of increased knowledge. If patients and carers become more knowledgeable about their condition and the possible prognosis, they can be more realistic about the expected prognosis and this can negatively affect their perceived health related quality of life.

One of the possible explanations for the poor quality of life scores in this cohort of patients is the fact that they had a very low mean hospital length of stay (6 days) and did not receive adequate

out-patient rehabilitation. Hospital length of stay was found to be significantly correlated with quality of life post-stroke (Mackenzie and Chang, 2002). One can assume that a longer hospital length of stay enables the rehabilitation therapists to treat the patient and make reasonable functional progress. Physiotherapy improves functional outcome post-stroke (van Peppen et al., 2004) and it is provided as part of rehabilitation post-stroke. If patients had stayed in hospital for longer periods and had received rehabilitation, it is possible that they could have attained better functional levels than the ones reported here. The timing and intensity of rehabilitation therapies following stroke is of paramount importance (Dombovy, 2004; Teasell and Kalra, 2005). The brain is primed for maximum neuroplasticity in the first three months post-stroke, and rehabilitation should also be maximised during that period (Schaechter, 2004; Hayes and Carroll, 1986).

The poor functional ability of patients with stroke established in this study and the resultant poor quality of life agree with Connor et al.'s 2004 study findings that the major problem in rural South Africa for patients post-stroke, is disability. This emphasises the need for early treatment and rehabilitation, which is currently compromised by the early discharge home from hospitals to unprepared caregivers. Early supported discharge is no more or less expensive for patients with greater functional limitations post-stroke (Teng et al., 2003) and so can easily be implemented in a low resource setting like the one we have in this study area.

### **6.5 The effect of caregiver education on the quality of life of the caregivers.**

Caregivers from both the experimental and control groups started with high levels of health related quality of life, which came down over the one-year period. The decline in the caregiver quality of life was much steeper in the control group than in the experimental group. The results also showed that caregiver education had the effect of improving caregivers' EQ-5D visual analogue scores by more than three at the six and 12 months follow up period. This can be interpreted to mean that caregiver education positively affected the caregiver's quality of life though there were many other factors working against those gains. The need for support of the caregivers has been echoed by other authors over time (Angeleri et al., 1993). Early discharge of patients negatively affects the rehabilitation process and places increased and unrealistic demands on the carers (Ski and O'Connell, 2007). The caregivers are expected to perform some difficult caregiving tasks that include administering drugs, assisting with physiotherapy exercises with very little if any training at

all (Jaffe and Blackley, 2000). This cohort of caregivers was no exception. The early discharge home of patients with little or no physiotherapy meant that patients were discharged home to untrained caregivers, negatively influencing their health related quality of life. However, training of the caregivers has the effect of reducing the rate of decline in quality of life over time compared to those who are not trained as seen from this study.

The major area of concern for the caregivers was anxiety/depression with the percentages for extremely anxious/depressed caregivers rising from 20% at three months for the control and experimental groups to 84% and 80% respectively at 12 months. These percentages at 12 months are much higher than has been reported elsewhere (Simon et al., 2009; Smith et al., 2007; Berg et al., 2005; Anderson et al., 1995; Carnwath and Johnson, 1987). Anxiety/depression is an important determinant of low quality of life (Kauhanen et al., 2000). The anxiety could have arisen from the lack of tangible progress among the patients' functional abilities. Most of the patients (56%) were still wheelchair dependent for mobility at 12 months post-stroke. This meant that the caregivers were expected to continue caring for patients and the high levels of anxiety/depression could have negatively contributed towards their perceived health related quality of life (Smith et al., 2007; Berg et al., 2005; Smith et al., 2004b). Caregiving for patients with stroke causes greater strain than caregiving for patients with other neurological problems (Chow et al., 2007).

Another source of stress for caregivers is the change in personality that caregivers observe in the stroke survivor (Grant et al., 1996). This was cited by 96% of the control group and 83% of the experimental group as being a contributory factor to the caregiving stress that they exhibited. What is interesting to note is that the change in the patient's personality became more and more of an issue for the caregivers over time, starting at 55% for the control group and 72% for the experimental group at three months to the levels stated for 12 months. The increase in the percentages of caregivers who reported the change in personality of the patient as a source of stress points to the waning of tolerance over time. It is possible that initially the caregivers are more tolerant of the change in personality and are also hopeful that it will get better over time. The lack of change over time diminishes that hope and hence the tolerance. The change in personality of the patient requires that the caregivers make adjustments in their treatment and interactions with the concerned individual. The adjustment is usually through 'enduring effects on the self'

(Buschenfeld et al., 2009). The "enduring effects on self" then predispose these individuals to severe stress. Though a higher percentage of the caregivers in the experimental group cited personality change as a stressor at three months (72%) than the control group (55%) the percentages had been reversed by the six months follow up period, a trend that was maintained at 12 months. This meant that the caregivers in the experimental group were slightly better at coping with the changes in personality in the end than were those in the control group. This could be attributed to a better understanding of the reasons for the change in personality by the caregivers. If the caregivers understand why patients behave the way they do post-stroke, it has the effect of improving their ability to cope with the change in personality. The slightly better functional abilities of the patients cared for by the trained caregivers could also have made it easier for the caregivers to cope with the personality changes.

The complaints of moderate pain among caregivers increased from 9% and 7% at three months for the control and experimental groups respectively to 57% and 54% respectively at 12 months. Jaffe and Blackney (2000) also found complaints of pain to be common among caregivers of patients with stroke. Pain greatly contributes towards poor health related quality of life (Widar et al., 2003). The pain could have been because of increased physical strain on the body from the physical efforts that were required to help move these highly dependent patients. As seen from the patient mobility scores, they were highly dependent on their caregivers. Results from the BI transfer subsection show that at six months post-stroke, only 23% of the control and experimental groups needed minor help with transfers with the rest either needing major help or not being able to do so completely. This high dependency meant the patients could only move from one position to another with caregiver assistance, a physically demanding activity on the caregivers, which could have been a precursor to the pain they complained about. Caregivers who report poor health have been seen to be suffering from caregiver burnout (van den Heuvel et al., 2001). The caregivers in this study sample may be at risk of having caregiver burnout above the levels previously observed, given the low levels of functional ability observed at 12 months post-stroke and the potential resultant increase in complaints of pain by caregivers.

At three and six months post-stroke more than 90% of the caregivers were stressed while at 12 months 78% of the control group and 43% of the experimental group were stressed. This is much

higher compared to findings elsewhere (Berg et al., 2005). They established caregiver stress prevalence rates of between 30% and 33% in Finland. The major sources of stress for the caregivers were the physical strain from the caregiving, feelings of being confined, having to make family adjustments and financial strain because of the stroke. The low functional levels of the patients meant that a lot of physical effort was required to help them carry out activities of daily living and to move them when at home. Physical strain has been identified as one of the reasons for increased caregiver strain elsewhere (Visser-Meily et al., 2009; Larson et al., 2005; White et al., 2003; Scholte op Reimer, 1998a; Dennis et al., 1998). More than 95% of the study sample complained that caregiving caused them physical strain at the three and six months follow up periods. The percentages however decreased at 12 months with 82% from the control group and 54% from the experimental group complaining of being physically strained from caregiving duties. It can be concluded that the reason for the high percentages of physical strain that were experienced at three and six months were mainly due to the low physical abilities of the patients resulting in caregivers having to put in a lot physical effort and hence the physical strain. The reduction in the physical strain complaint percentages at 12 months can be attributed to the improvements the patients had made by then and also the fact that caregivers would have devised ways to deal with the physical demands of caregiving. This is even more profound when one considers the decline in percentage in the experimental group, which came down by 45% from 98% at three months to 54% at 12 months, which can be attributed to the positive effects of caregiver education in the long term.

The feelings of being confined or restrained in their social life as a contributing factor to caregiver stress by caregivers of patients with stroke have been established in previous studies (Visser-Meily et al., 2009; Lynch et al., 2008; de Freitas et al., 2005; Smith et al., 2004b; Jaffe and Blackley, 2000). The high level of dependency of the patients in this study sample meant that caregivers' social life was limited. They could not leave the patient unattended fearing something might happen in their absence as one caregiver put it *"I cannot afford to visit friends these days because he needs me to be around most of the time, I would not be able to forgive myself if something were to happen to him in my absence"*. This is supported by the finding that more than 78% of the caregiver study sample had to adjust their personal plans while more than 80% had to make family adjustments at the three, six and 12-month follow up periods. This points to a strong sense of dedication to caregiving duties and at times this can lead to poor quality of life of the caregiver

(Larson et al., 2005; White et al., 2003; Scholte op Reimer, 1998a). Social dysfunctioning post-stroke has also been established (Hommel et al., 2009). Their study however cautions against the possibility that patients may have overestimated their social dysfunctioning. Caregiving duties for patients with stroke result in caregivers having less time to socialise with family and friends, and less time for recreational activities negatively influences caregivers' quality of life (White et al., 2004).

Financial strain was reported by more than 92% of the study sample of caregivers from three months to 12 months, a finding similar to that by Jaffe and Blackney (2000). Financial strain has been identified as a predictor of quality of life in patients post-stroke (King, 1996). This finding has been reported before though from the patients' perspective in a study done in the same area (Hale et al, 1999). Despite South Africa being regarded as a middle-income country, it is one of those countries with the most extreme disparities in wealth distribution in the world (Bradshaw and Steyn, 2001). Their report suggested that 52% of households were living in poverty in 1996, suggesting that many in this cohort of patients could have belonged to that subset. The individuals who had a stroke could no longer contribute financially to the financial needs of the family and the caregivers were curtailed in their ability to contribute financially to the family needs for they were required to be around the patient for longer periods given their low functional levels. This then resulted in the caregivers feeling the stress arising from their financial shortcomings. The fact that the majority of the patients (greater than 96%) were not receiving social grants did not alleviate the situation. As stated by Parmley (2000), of about 4.4 billion people that reside in low-income countries, about 60% lack access to sanitation while 20% lack access to health care of any kind. This strengthens the argument that poverty is a common feature in low-income countries and this cohort of patients were no exception. The financial difficulties also impacted on patients' ability to commute (Hale et al., 1999), negatively influencing their quality of life. Social services have a big role to play in patients post-stroke. This finding is not unique to this cohort of patients. Wackerbarth and Johnson (2002) found that caregivers of patients with stroke needed legal and financial information in addition to support. Though not explored in detail, it was quite clear that the majority of the patients and caregivers were not aware of how they could access disability grants post-stroke. The financial shortcomings of both the patients and caregivers meant that it was difficult to



have group programmes especially at follow-ups or have them come back to the hospital out-patients and so follow ups were consequently done at the patients' homes.

Caregiver education had the effect of reducing caregiver stress by 3 at 12 months, a clinically significant change. This agrees with findings elsewhere (Kalra et al., 2004; Patel et al., 2004). The question that begs to be answered would be how this was achieved despite the low functional levels of the patients. One can only conclude that the trained caregivers were able to cope with the caregiving duties much better than the untrained ones most likely pointing to effectiveness of caregiver training in that respect. This ability to cope better with caregiving duties could have resulted in the slightly better mean EQ-5D VAS scores for health related quality of life. It is however evident that caregiving does take its toll on caregivers from both sets of groups (control and experimental) over time but with slightly better stress outcomes for the trained caregiving group. White et al. (2003) established similar findings; they found that during the second year of caregiving post-stroke, poorer caregiver physical health was associated with diminished quality of life.

It is important to note that the caregiving burden is not a static concept; burden develops over time and changes depend on many variables affecting both the patient and the caregiver. Caregiver education had the effect of reducing caregiver burden in the long term when compared to controls. Caregiver education is not only a form of social support but also empowers caregivers with a sense of control over their caregiving duties. This however does not diminish the importance of social support as has been established (White et al., 2004). Currently patients are being discharged home to unprepared caregivers in our setting. This is despite the finding that a lack of caregiver preparedness is associated with increased risk of depression post-stroke (Grant et al., 2004).

### **6.6 The effect of caregiver education on the ability of the stroke survivors to socialise and participate in the community.**

The patients had problems with undertaking single and multiple tasks. At 12 months, 53% of the control group and 54% of the experimental group had severe to complete performance difficulty in undertaking multiple tasks with 55% and 52% respectively having severe to complete performance difficulty with undertaking single tasks. All the patients were dependent on their caregivers for

single and multiple tasks as shown by all patients not being able to do any tasks without help. To add weight to this argument was the fact that the ability to undertake a single task was strongly negatively correlated with the support of immediate family ( $r = -0.99$ ), support from health professionals ( $r = -0.8$ ) while for multiple tasks societal attitudes, support from health professionals and individual attitude of health related professionals were all strongly negatively correlated ( $r = -0.99$ ). In other words, the inability to undertake a single task was associated with an increased need for help from the immediate family while poor support from health professionals and poor attitudes from health related professionals were associated with an increased inability to carry out tasks. The patient dependency on outside help can be explained by the poor functional levels that the patients exhibited throughout the study period. A score of 60% is the cut off between independence and more marked dependence, 40% or below indicates severe dependence while 20% or below reflects total dependence (Granger et al. (1979), Finch et al., 2002). The mean BI scores at 12 months for the patients in this study were 63% and 67% for the control and experimental groups respectively and they were 54% and 57% respectively at the six months follow up period. At six months follow up, 92% of the patients were dependent according to the BI scores while 78% were dependent at 12 months. It is quite clear from these figures that the majority of the patients had dependence scores for most of the study period. Low BI scores negatively affect patient's ability to do activities and participate in the community (Wee and Lysaght, 2009). The dependence they had, stemmed from their poor physical condition as depicted by the low BI and RMI scores. The poor BI scores can be attributed to stroke severity as well as the early discharge from hospital, which meant that the patients received little to no rehabilitation before discharge. The lack of out-patient rehabilitation, physiotherapy included also meant that patients had to rely solely on caregivers and natural recovery for any functional improvements. Rehabilitation has been shown to improve not only the quality of life of the carers, but of the stroke survivors as well (Kalra et al., 2004; Patel et al., 2004).

In agreement with the mobility and activity of daily living abilities, the patients demonstrated mild to moderate and severe to complete difficulty with lifting and carrying of objects, fine hand use, walking and moving around using equipment in the community. To reinforce their dependence on their caregivers, the patients had severe to complete difficulty to carry the above-mentioned activities without assistance (capacity). The ability to lift and carry objects was positively correlated

with support of friends and health related professionals ( $r = 0.6$ ) and individual attitudes of the immediate family and friends ( $r = 0.6$ ) again showing their dependency on outside help for them to be able to carry out functional activities. Walking in the community was also positively correlated with the support of friends ( $r = 0.98$ ) and negatively correlated with labour and employment services, systems and policies ( $r = -0.7$ ). This can be explained through the implications of the financial situation on the patients. Inadequate finances meant an inability to get to the local clinic or to go back to CHBH for out-patient rehabilitation. The financial situation was compounded by the lack of access to social grants and also the inability of the caregivers to engage in gainful employment activities. The financial concerns were raised by both patients and caregivers during follow up assessments.

Low physically functioning patients have role limitations and are very limited in their social functioning (Naess et al., 2006). The improvements that were noted in mobility and activities of daily living ability over the one-year period were not enough to allow patients to function independently in the community. The patients were still largely wheelchair dependent. Patient ability to ambulate in the community can easily be overestimated especially if they have a walking speed of less than 0.8m/s in the hospital gym (Taylor et al., 2006). Gait speed on its own is not a good predictor of community ambulation as many other factors come into play (van de Port et al., 2007a). As stated by Lord et al. (2008), independent community ambulation is a challenging goal. It appears as if the same trends observed in 1986 by Disler et al. persist today. In their study, they found that stroke was the largest cause of disability (23.7%) and that the majority of the patients with disability that they saw had problems with locomotion. Hale et al. (1999) also found that patients in Soweto struggled with gait while in the community, and recommends that safe walking must be ensured before discharge. A recent systematic review showed that gait oriented training interventions have a significantly positive effect on both gait speed and walking distance (van de Port et al., 2007b). This again points towards the positive effects that could be gained by these patients from rehabilitation therapies.

Due to their low functioning levels, the patients in this study had severe to complete difficulty in preparing meals, doing housework and assisting others. These are all physical activities, which can be quite demanding on the body. The fact that the patients struggled with locomotion means that

any other activity that required them to move and execute a task at the same time would have been almost “mission impossible”. Post-stroke patients who use a walking aid have poor balance and less social participation than their age matched counterparts walking unaided (Hamzat and Kobiri, 2008). The patients in this study were largely wheelchair dependent and one can only extrapolate that their social participation would be heavily compromised.

Generally more patients in the control group than the experimental group had severe to complete difficulty in carrying out the above listed mobility subcomponents at both the 6 and 12 months follow up periods suggesting that caregiver education might have positively contributed towards their mobility in the community. It should however be noted that the ICF data were collected mainly from patient interviews and as such they may have overestimated their ability to perform mobility activities. This was shown to be the case when patients post-stroke could not make a simple trip to the shops and back despite reporting being able to do so (Taylor et al., 2006). Patient community participation could be higher mainly because of the help they receive from the caregivers (Schmidt et al., 1986). This seemed to have been the case in this study if one considers that all the patients in the study sample had severe to complete difficulty in carrying out the mobility subcomponents under discussion when undertaken without help from their personal caregivers and assistants. However, this finding agrees to some extent with that of Lord et al. (2004). Their study established that almost 33% of the patients with stroke in the community were not able to get out into the community unsupervised and this was despite 74.6% of the subjects having said that “getting out and about” in the community was essential or very important. One however needs to appreciate the fact that the patients in Lord et al.’s study were receiving physiotherapy and some of them had recovered well enough not to need further physiotherapy. This scenario makes the findings in this study understandable for it highlights how complex the issue of ambulation in the community really is. For example, one would want to know the influence of cognitive deficits (which are common post-stroke) on gait performance.

As regards the extent of personal interactions and relationships for patients in the community, all the patients demonstrated some degree of difficulty with basic interpersonal and complex interpersonal interactions, relating to strangers, formal and informal relationships and, family and intimate relationships. The majority of the patients expressed mild to moderate difficulty for the

performance qualifier and complete dependence on the caregivers as demonstrated by their severe to moderate difficulty for the same activities when without assistance (capacity qualifier). The high number of patients having problems with personal interactions and relationships agrees with the finding by Hommel et al. (2009) who established that 78% of their study sample complained of social dysfunctioning despite having good functional abilities. The patients in this cohort did not have good functional abilities, they were very low functioning and this can possibly explain the reported inability to socialise. The poor physical ability of the patients meant that they had to rely on their caregivers for the execution of day-to-day activities.

Patients struggled with community, social and civic life activity participation. They again showed mild to moderate and severe to complete difficulty with community life, recreation and leisure ability, religion and spirituality. Caregiver education seemed to have the effect of reducing the number of patients with severe to complete difficulty when compared to those in the control group when it came to the performance qualifier. Both sets of patients however again showed complete dependence on their caregivers for all of them (100%) had severe to complete difficulty with the same activities when they were without assistance. This again agrees with the limited improvements that were noted in patients' functional abilities over the study period. Similar problems with socialisation were established in a previous study in the same geographical location with similar patients (Hale et al., 1999). Hale et al (1999) reported that patients post-stroke received very few visitors and only two could visit their neighbours. Higher social participation is associated with better physical function and vitality in patients post-stroke (Jonsson et al., 2005). Poor physical function can also result in complaints of emotional stress from the caregivers. These psychosocial factors are important in the prediction of quality of life (Mackenzie and Chang, 2002).

Individuals' participation in their society depends on the outcome of the interaction between their personal characteristics and the environment in which they operate. It is thus important to note that patients had issues with accessibility of both public and private buildings and caregiver education did not seem to have influenced accessibility in any way given the similarities in the percentages between the control and experimental groups. The accessibility issues around the private buildings (mainly their homes) pertained to the terrain outside the houses and the size of some of the rooms in which the patients were staying. As one patient put it: *"I wish I could move around a little bit*

*more to socialise with my friends but the ground is so uneven that I find it difficult to wheel myself to anywhere*". Another patient also complained about the amount of space saying, *"the space is so small that I cannot manoeuvre my wheelchair in here and that limits my ability to help myself quite considerably"*. Patients also complained that they found it difficult to access some of the places in their communities like shopping malls, local supermarkets and shops mainly because of transport problems to these places and the terrain for the local shops. Accessibility of community facilities is one of the predictors of social integration of patients post-stroke (Belanger et al., 1988). It therefore goes without question that the level of community integration for this group of patients post-stroke is low.

The patients saw the immediate family and personal care providers and assistants as being largely facilitators. Again, this agrees with the finding that the patients were largely dependent in activities of daily living and demonstrated severe to complete difficulty in carrying out activities without help. Stroke survivors get help from their caregivers regardless of their functional abilities (Gosman-Hedstrom et al., 2008). What was interesting was the rise in percentages of those who thought the immediate family were severe to complete facilitators from 12.5% and 5.3% at three months follow up for the control and experimental groups to 46.9% and 49.2% respectively at 12 months. This could be due to one of two things; firstly, it could be a signal that the patients appreciated the role of the caregivers more as time went by or secondly, it could signal an increased dependency on the caregivers, which would be a worrying sign. One would expect that as patients regain some of their functional abilities, they would rely less on the caregivers for carrying out activities of daily living. However, one needs to take note of the fact that although the patients' functional abilities generally improved over time; they did not do so to satisfactory levels at the end of the 12 months of the study.

Patients regarded their friends as being barriers (more than 50%) to their ability to participate in the community. One of the consequences of stroke is limitation of social participation (Daniel et al., 2009). The major concern for the patients seemed to have been the fact that they could no longer *"hang out"* with their friends as they used to do before the stroke and the visits from the friends had diminished. To quote one patient, *"ever since I came back from the hospital, my friends have hardly been here to spend some time with me, it is as if I have stopped existing for them and that*

*pains me a lot*". One can explain this through the limited functional abilities that the patients exhibited. Going out with them (the patients) would have meant a lot of physical work for the friends and so they opted out. One can only speculate that if the patients were more functional, their friends would have found it a lot easier to spend time with them.

The above scenario is strengthened further by the finding that at 12 months more than 40% of the patients thought that their friends' attitudes were mild to moderate barriers to their ability to function in the community. They were however happy with the attitudes of the immediate family members, the personal providers and society care. The patients found the general population to be helpful, as one patient put it: *"The public is very understanding, when they see me coming, they either offer to help or they give way which helps with my mobility to some extent"*. However, the same could not be said about their friends. This is supported by the finding that more than 46% of both the control and experimental groups perceived acquaintances, peers, colleagues, neighbours and community members as facilitators to community participation. There wasn't much difference in the percentages for these two groups of patients, 47% for the control group and 49% for the experimental group. The almost similar percentages could be as a result of the almost similar functional levels between these two groups of patients and hence similar demands for help with activities of daily living when at home..

One major source of concern for the patients was the availability of housing and accessibility of social grants (the disability grant to be exact). All participants considered the housing services and policies to be either mild to moderate or severe to complete barriers. Poor housing conditions and environmental factors, poverty and its deep effects on body and spirit, poor education and low literacy are greater causes of poor health than racially biased medical care (Green, 2003). The patients wished to have access to better housing and to quote one patient *"The government needs to give priority to people with disabilities when it comes to housing. If I was staying in a better house, I am quite sure I would be able to participate in the community more"*. The issue of social grants was also problematic for most patients who are from a low socioeconomic level. People of low socio-economic status have worse health and are most likely to receive a disability pension (Treger et al., 2007). Patients complained that they did not have the means to go to the social welfare offices to make the necessary grant applications while in a few cases they were not even

aware that they actually qualified to receive disability grants. This cohort of patients were not employed and so would have benefited from social grants. As stated by Bonita and Beaglehole (2007) in an editorial, "stroke is a cause of poverty and is caused by poverty". Patients who are able to go back to meaningful employment post-stroke report better health related quality of life (Niemi et al., 1988). The inaccessibility of social grants by persons with stroke also points towards coordination problems with the rehabilitation team. It questions the strength of the hospital interdepartmental referral system especially between the ward, physiotherapists, occupational therapists, speech therapists and the social workers, the latter being responsible for processing the applications. As stated by Lincoln (1994), clearly, coordinated rehabilitation is lacking.

It was worrying to note that 100% of the patients viewed transport services, systems and policies as being mild to moderate barriers. This stemmed mainly from the fact that if patients were using a wheelchair for mobility, they would then be asked to pay for themselves and then the wheelchair as well in taxis. In some cases they were not allowed onto the taxi making the ability to move around very limited. As one patient put it, *"Being in a wheelchair is like a curse, you are being punished for being disabled, the taxi either does not stop for you or if it does, then you have to pay for yourself, the person helping you and the wheelchair making the whole business of moving around pretty expensive"*. It is therefore quite clear that the transport and financial problems that patients have when in the community are major sources of limitation to community participation. Transportation problems among patients with stroke were raised in an earlier study (Hale et al, 1999) and they appear to be still a major concern today. This limits patients' ability to move around and may even have contributed towards their inability to attend out-patient rehabilitation.

### **6.7 The patient characteristics associated with caregiver strain following stroke.**

More than 90% of the caregiver study sample showed caregiver strain at three and six months follow up. Though the percentages of those strained came down at the 12 months follow up to 58% (with 78% for the control group and 43% for the experimental group), the percentages of strained caregivers were still quite high. This is much higher compared to, for example, the 33% that was found by Ilse et al. (2008) and 29% that was found by van Excel et al. (2004). Though the prevalence of caregiver strain was fairly high in Simon et al. (2009)'s study (37 – 54%), it was still



lower than the values obtained in this study. The reason for the difference could lie in the population differences of both the stroke survivors and the carers. Ilse et al. (2008)'s study was done in Belgium, a high-income country while South Africa is considered a low to middle-income country. Furthermore, this study sample is largely a low socioeconomic group. Caregiver education had the effect of reducing caregiving stress by 2.6 at 12 months and this was a clinically significant change. It meant that the trained caregivers were better equipped to execute the caregiving duties resulting in the decline in caregiving burden experienced.

The patient characteristics associated with caregiver strain mainly hinged around the level of dependency/independency that the patients had. The higher the level of independency, the less the caregiver strain the caregivers had and the reverse is true (Visser-Meily et al., 2009). Patient physical deficits are associated with caregiver stress (Ilse et al., 2008; Choi-Kwon et al., 2005; Blake et al., 2003; Blake and Lincoln, 2000). The patient physical deficits are linked to the neurological deficits with which they manifest. The patient physical deficits influenced what the patient needed help with, which was namely help with transfers, mobility, dressing and bathing, as seen by poor BI and RMI total scores.

The major areas that contributed towards caregivers strain were feelings of caregiving causing physical strain, feelings of being confined, having to make family adjustments, the personality changes in the patient and the financial strain resulting from the stroke (between 63% and 97%). Though the same factors were established in Belgium, the percentages are very different with a range of 37 – 50% for the same factors (Ilse et al., 2008). The only difference was on “feelings of being overwhelmed” which were surprisingly quite low in this study, ranging between 13% and 36%. The reason for the low percentage on feelings of being overwhelmed could lie in the cultural differences between the two study populations. In African culture, it is considered impolite to complain publicly about the burden of looking after an ill relative and so the response to this question could have been masked (Alston and McCowan, 1995). The inability of the stroke survivor to provide social support to the caregiver like they did pre-stroke could also be a factor influencing the strain on the carer (White et al., 2004). Reduced functional ability could mean that the patient's ability to engage in social activities with the carer like they used to do before the stroke could be severely diminished and that would translate into increased strain of the caregiver.

The CSI total mean scores for both groups generally increased from 3 months to 6 months and came down slightly at 12 months for the control group (from 9.8 to 9.3) and came down significantly for the experimental group (from 9.2 to 6.7). The reductions in the caregiver strain at 12 months in both groups could point to an increased ability to cope with caregiving duties or possibly an improvement in the patients' physical conditions as seen by the corresponding improvements in patients' BI and RMI scores. The reductions in caregiver strain levels over time agree with Visser-Meily et al.'s 2009 findings. This can be attributed to adaptations to the caregiving role. It is clear from the differences in reductions in caregiver burden between the control and experimental groups that caregiver education leads to better adaptation to the caregiving role and hence less strain in the long term.

The caregivers of patients who needed minor help with transfers had on average 1.1 less caregiver strain than those who were not able to transfer at all ( $\exp(\beta) = 0.3$ ; CI 0.1 – 0.9) or in other words, they were 70 percent less likely to be strained. At 12 months, 51% of the control group and 36.9% of the experimental still required major help with transfers added to 49% and 61.5% respectively who needed minor help with transfers. These percentages agree with the high percentages (greater than 70%) of wheelchair dependent patients at 12 months. If the patients were still that dependent on caregivers for transfers at 12 months, it comes as no surprise that the ability to do transfers was one of the factors that influenced caregiver stress. Helping with transfers is a physically demanding exercise again supporting the high complaints of physical strain that came from the caregivers.

Reinforcing the importance of patient physical ability was the finding that the caregivers of those patients who needed help with walking had on average 1.1 less caregiver strain than those caregivers for patients who were immobile ( $\exp(\beta) = 0.2$ ; CI 0.1 – 0.9). Put in other words, the caregivers of patients who needed help with walking were 80% less likely to be stressed than those for patients who were immobile. As already established the majority of the patients were wheelchair dependent and so largely relied on their caregivers for mobility. The physical frailties of the patients were also confirmed by their very low walking ability scores on the RMI. Only 20.4% of

the control group and 35.4% of the experimental group could walk inside the house with help and these are very low percentages.

Overall, the degree of independency in activities of daily living was also found to be a factor that influenced caregiver strain. Every unit increase of the BI score had the effect of reducing the caregiver strain index total by 0.2 (exp (beta) = 0.8; CI 0.7 – 0.9). The degree of dependency is strongly linked to the physical abilities of the patients as already explained. The BI mean scores of 12.6 and 13.3 for the control and experimental groups at 12 months shows that patients were quite dependent on their caregivers one year after the stroke. Using the BI classification of dependency/independency 27.3% of the control group and 21.8% for the experimental group had greater than 60% and so were considered to be in the independent group. This compares poorly to the 65% reported by Wolfe et al. (2000). The low BI scores also meant that patients were not able to do their usual activities and this negatively affected caregiver stress levels. This was strengthened by the finding that caregivers for patients who had some problems with or were unable to do usual activities had on average two and three (respectively) more caregivers stress than those caregivers for patients who had no problems with usual activities. The high dependency of the patients demonstrated in this sample could also possibly be explained by the fact that the majority of the study sample was women. Women are more severely ill post-stroke and tend to have worse outcomes than men (Appelros et al., 2009; Fukuda et al., 2009; Roquer et al., 2003)

The patients' mobility scores were generally low as measured by the RMI, agreeing with the BI subset for mobility that the cohort of patients for this study were very low functioning. The caregivers in the experimental group had on average 0.8 less strain than the caregivers for the patients in the control group ( $p < 0.001$ ; CI -1.3 – (-0.4)). As the RMI total scores increased by one, this reduced the caregiver stress index total by 0.1 (exp (beta) = 0.03; CI 0.8 – 1). It is therefore safe to conclude that the higher the mobility ability of the patient, the better the caregivers would fare as they would had less strain. The finding that level of mobility influences caregiver strain agrees with the outcomes from other studies (Rigby et al., 2009; Ilse et al., 2008; Choi-Kwon et al., 2005)

The patients' perceived health state (EQ5D VAS score) was also a determinant of caregiver strain. The patient mean scores were relatively low, from around 42 at three months to about 67 at 12 months. As the EQ-5D VAS score increased by one unit, it had the impact of reducing the CSI total score by 0.04 ( $p < 0.001$ ; exp (beta) = 1; CI 0.9 - 1). The impact of patients' perceived health state on caregiver strain has also been established elsewhere (van Excel et al., 2004; van Excel et al., 2005). If patients feel they are not doing well health wise, that feeling is communicated to the caregiver in one way or the other and that could negatively influence the caregiver's strain as they may start doubting the effectiveness of their own caregiving role.

The specific subsections of the EQ-5D that were predictors of determinants of caregiver strain were inability to do usual activities, having moderate pain/discomfort and being anxious/depressed. The caregivers for patients who were moderately anxious/depressed and extremely anxious/depressed had on average 1.2 (exp (beta) = 3.2; CI 1.6 – 6.4) and 1 (exp (beta) = 2.7; CI 1.1 – 6.3) (respectively) more stress than those caregivers for patients who were not anxious or depressed. A similar positive association was also established by McCullagh et al. (2005). If patients are anxious/depressed, it has the effect of negatively affecting the well-being of the caregivers as they may start doubting their own capability in helping the stroke survivor. That feeling of not being able to help adequately or the feeling of helplessness can be a major contributor towards the complaints of caregiver strain (Houts et al., 1996).

McNaughton et al. (2001) recommended that intervention studies for patients with stroke should take into account the stroke type, however, in this study, the stroke subtype was not found to be a factor influencing caregiver strain. Whatever effects might have been, could possibly have been diluted by the similarity in low functional levels of the study sample.

In this study, the patient's age was not a predictor of caregiver strain, a finding similar to that of McCullagh et al. (2005). One possible explanation could be that this was a relatively homogeneous group with a fairly low mean age, which again could have diluted the influence of age in the study.

## **6.8 The caregiver characteristics associated with caregiver strain following a stroke**

The only caregiver characteristic that was associated with caregiver stress was level of education. The caregivers of those patients who had gone to school up to Grade 11 had on average 1.4 less caregiver strain than those caregivers whose caregivers had a university degree ( $p = 0.002$ ;  $\exp(\beta) = 0.3$ ; CI 0.1 – 0.6). The reason why those with more education were more stressed could be that their understanding of the patients' clinical change and prospects was better and more realistic. The negative effect of higher education was also established by Larson et al. (2005). It is postulated that in addition to having other duties to do other than caregiving, the more educated caregivers have access to information and so are more informed about possible prognosis and also the negative consequences of the stroke. This then might result in their having poorer perceived quality of life than that of the less educated caregivers (Larson et al., 2005).

No other caregiver characteristics were found to be associated with caregiver strain. This finding largely agrees with that by Ilse et al. (2008) which also found no caregiver characteristics associated with caregiver strain. Other studies found caregiver age to be associated with caregiver strain. Van den Heuvel et al. (2001) found that younger caregivers experienced more strain than older ones while Dennis et al. (1998) found the opposite, with older caregivers experiencing more strain. Again, the influence of age could have failed to be an influence in this study due to the homogeneity of the study sample, which was largely made up of younger caregivers.

Caregiver gender was not found to be a predictor of caregiver strain in this study contrary to findings from other studies that established that female caregivers were more strained (Scholte op Reimer et al., 1998a). However, the finding that caregiver gender is not a predictor agrees with findings from previous studies (van den Heuvel et al., 2001, Forsberg-Warleby et al., 2001). It is not clear why there are conflicting findings on this particular demographic factor.

The caregiver's general health as measured by the EQ-5D was not found to be associated with caregiver strain. Similar findings were established elsewhere (van den Heuvel et al., 2001). However, some studies have found caregiver's general health to be associated with caregiver strain (Bugge et al., 1999; Blake and Lincoln, 2000). This creates a confusing picture and thus calls

for further investigation. The fact that many of the caregivers in this study population were young (mean age 39.6 years) could also be taken to mean that they were still in their prime physical health and hence poor health was not associated with increased caregiver strain. It could also be true that caregivers' perceptions of their health are dependent on many other variables some of which may not have been explored in this study, making it difficult to establish a simple relationship between caregiver strain and their perceived health status.

### **6.9 Sample: size, selection and demographics**

The sample size of 200 patients and their caregivers (with 100 in each group) was adequate for the study and had more than 80% power to detect change when using the BI, RMI, EQ-5D and the CSI. There were no significant differences between the two groups at baseline suggesting that randomisation was effective in ensuring equality between the two groups.

There were more female (56.5%) than male (43.5%) patients in the study group. This agrees with findings in other studies where it was shown that more females suffer from stroke compared to males (Ilse et al., 2008; Correia et al., 2004). Overall, there were more patients with left hemiplegia (56%) than those with right hemiplegia. It is not clear why more female than male patients were in the study, the opposite of which has been established in other studies (Boix et al., 2006). However, one cannot rule out the possibility of genetics playing a part in this. The sex differences between men and women are related to steroid hormones (Reeves et al., 2008). It was established that cerebrovascular reactivity is quite good in premenopausal women while postmenopausal women have poorer responses than age matched men suggesting an important role for oestrogen in the occurrence of stroke in older women (Matteis et al., 1998).

As far as the patient age distribution of the study sample is concerned, one can conclude that this was generally a young population with a mean age of 53.2 years (standard deviation 11.4). This mean age is much lower compared to those from other countries, for example the mean for patients with stroke is 67.3 years in Belgium (Ilse et al., 2008) and over 70 years in most high-income countries (Feigin et al., 2003). This supports Lemogoum et al. (2005)'s statement that stroke occurs at much earlier ages in sub-Saharan Africa compared to high-income countries. A fairly high prevalence of stroke among young people has been established before (Hoffman, 2001).

Hoffman's 2001 study established that 25% of the study sample comprised of patients aged between 15 and 49 years.

The low mean age for the study sample also confirms what the literature says about South Africa being in the middle of a health transition (Connor et al., 2007b). The increase in economic and demographic development in developing countries has resulted in a shift from diseases caused by poverty, toward chronic non-communicable, lifestyle-related diseases (Reid and Thrift, 2005). The majority of the patients (33.5%) were in the 41 – 50 year age group. It confirms that life style diseases are increasing as people move away from traditional lifestyles and their diet and lifestyle changes in accordance to the "westernisation" of their way of life. As hypertension, smoking and obesity increase with less physical activity, more and more people will fall victim to stroke. There were more women than men in those aged 51 years and above, a finding that agrees with that reached by Reeves et al. (2008). Reeves et al. (2008) conclude in their review that with increasing age, more black women than men suffer from stroke, becoming almost three times higher in those aged 85 years or older.

The caregivers were largely females (70%) with the most of them (59%) being less than 41 years of age. This agrees with the literature in that females usually form the bulk of caregivers when a family member falls sick (Bluval and Ford-Gilboe, 2003; Jaffe and Blackley, 2000). Societal and family norms dictate that women are 'natural caregivers' (Bluval and Ford-Gilboe, 2003), pressure which on its own can also contribute towards caregiver strain. The reason for the mean age of the caregivers being less than that of the patients (39.6 years compared to 53.2 years) could be that some of the caregivers were siblings to the patients. The spouses who made up a significant number of the caregivers could also have lowered the mean age since it is more common for the female spouse to be younger than the male spouse.

The patients in the study had low levels of education with 46% of them having attained "up to Grade 7" level of education. This can be attributed to the apartheid era policies where equality, even in education, was not a priority (Coovadia et al., 2009). The educational levels between the two groups (control and experimental) were largely equal with very minor variances. The caregivers had slightly better educational levels than the patients with the majority of them having

attained “up to Grade 11” level of education compared to 33% of the patients at the same educational level. The slight improvements in the level of education among the caregivers can be ascribed to the different age groups. The caregivers were on average much younger than the patients, with mean age 39.6 years compared to 53.2 years. This therefore means that the caregivers would have benefitted more from the strides made in education just prior to and since the advent of democracy in South Africa. The poor/low educational levels are synonymous with low socioeconomic status (Green, 2003). Socioeconomic status may contribute to ethnic disparities not only in stroke incidence but also in stroke outcome (Bravata et al., 2005). This therefore can be taken to mean that the low socioeconomic status of the patients in this study contributed towards their low functional abilities. If they were better off socioeconomically, they could have afforded out-patient rehabilitation, which maybe would have improved their functional abilities.

In line with the low educational levels that the patients had, the majority of the patients (71%) were not gainfully employed at the time of their stroke while all the caregivers were unemployed at baseline assessment. A similar finding was established before in the same geographical location (Hale et al, 1999). The difference between Hale et al. (1999) and this study’s findings is that their cohort of patients comprised largely of pensioners receiving grants which was not the case in this study where the majority were not employed prior to the stroke. The low level of education meant that the patients most probably did not have any skills training that would make them marketable to any potential employers. As for the caregivers, one can only assume that the fact that they were unemployed was one of the criteria for being chosen as a caregiver by the family. The family would have to look at those who were not employed and so could afford to be with the patient as was required for caregiving duties.

It was interesting to note that quite a number of the patients (49%) were single. It was however quite apparent during the data collection process that some of those who said they were single were in fact cohabitating. Because most of the patients were single, the majority of the caregivers were also relatives (50%). This, to some extent, points to the strength of the family unit among this particular set of families. To strengthen this point, the majority of the caregivers (62%) were available for caregiving duties all the time. The finding of relatives making up the bulk of caregivers following stroke was also found to be the same in Belgium (Ilse et al., 2008).



The majority of the patients (95%) had running water and electricity while 47% had “even ground” outside the home. The fact that 54% of the patients had uneven ground outside leads one to conclude the presence of major mobility problems for the patients, the majority of whom (greater than 70%) were wheelchair dependent at 12 months. This would also be a major source of physical strain for the caregivers as they would have to push the patients to wherever they wished to go.

In agreement with previous study findings from South Africa, hypertension (95%) and smoking (76%) were the most common risk factors for stroke among the study population (Thorogood et al., 2007; Lavados et al., 2007; Connor et al., 2005; Hoffman, 1998; Steyn et al., 1992). This adds weight to the statement that as the population adopts more and more western life styles, the country is in danger of a “stroke explosion” in the near future as these lifestyle changes begin to take their toll (Thorogood et al., 2007). The finding of hypertension, smoking and obesity (36%) being the commonest risk factors in this study population agrees with findings from other countries (Kaul et al., 2000; Centres for Disease Control and Prevention, 2005; Pancioli et al., 1998) Obesity has been established as a significant problem in urban black females in sub-Saharan Africa (Walker, 1994). Soweto, where the patients in this study resided, is an urban setting and hence the fairly common problem of obesity. Cigarette smoking doubles the risk of stroke (Bhat et al., 2008). All these three are modifiable risk factors. It therefore highlights the importance of health education so that these risk factors can be reduced in the community (Lemogoum et al., 2005). Declines in the incidence of stroke have been noted in high-income countries. This decline has been attributed to a decrease in risk rather than improving survival (Islam et al., 2008), further highlighting the importance of educating the general populace on stroke risk factors. Improvements in stroke prevention and the care post-stroke can result in decreased stroke mortality (Goldacre et al., 2008).

The high percentage of deaths in this cohort of patients with stroke confirms Strong et al. (2007)'s statement that of the 5.7 million deaths from stroke each year, the majority occur in low-income and middle-income countries. It was interesting to note that most of the deaths occurred in the Total Anterior Circulation Infarction (TACI) with 71% of this subset dying during the study period. The lowest percentage deaths occurred in the Posterior Circulation Infarct group where 19% of the

subset died. The reason why there was such a high death rate among the TACI group is that the resultant neurological deficits are most dense in this group (Lawrence et al., 2001). This means that the patients with this type of stroke suffer the most grave physical deficits, will be more dependent on caregivers, and will also be more susceptible to diseases such as chest infections (due to the reduced mobility ability) and hence the high death rate. This is supported by the finding that those who died had on average lower BI, RMI and EQ-5D VAS scores than those who survived. The majority of the deaths (61%) occurred within the first three months post discharge. This agrees with Ilse et al. (2008) who (though much lower deaths were recorded) reported that the only deaths they had in their study (2%) died before the fourth month follow-ups. This could be attributed to the high prevalence of bed rest complications during the acute period of stroke mainly as a result of immobility (Lawrence et al., 2001).

Lacunar infarcts had the lowest mortality in this study agreeing with similar findings from the Netherlands (de Jong et al., 2003). This could be because lacunar infarcts result in the least severe neurological deficits (with no cortical higher function involvement) among the infarction stroke subtypes and consequently the patients have better functional outcomes hence the reduction in deaths in this population. The high death rate in this study population could also be because the study sample comprised of patients with a low socioeconomic status. Individuals with a low socioeconomic status have higher stroke mortality than those with a high socioeconomic status (Jakovljevic et al., 2001; Hart et al., 2000). The percentage of those who died over one year (38%) agrees with the one-year case fatality reported by Wolfe (1996) which was between 34 and 41%. It should however be noted that the percentages provided by Wolfe (1996) refer to the overall rate for all forms of stroke types while for this study it was only from stroke arising from infarctions. Matenga (1997) also put the one case fatality from stroke in Zimbabwe at more than 30%, agreeing to a large extent with the findings of this study. The reported one year case fatality rate of 38% in this study is however much lower than that reported from another African country, Gambia, which was 62% (Garbusinski et al., 2005). This could be viewed to suggest better medical care of patients with stroke in South compared to those in Gambia. The possible impact of HIV/AIDS (though not part of this study) on the reported deaths cannot be ignored. Sub-Saharan Africa remains the world's most seriously affected region with AIDS the leading cause of death with South Africa having the largest number of HIV infections in the world (UNAIDS, 2008).

Caregiver education had the effect of reducing the risk of death by 27%, relative to that occurring in the control group patients. If we can reduce the risk of death by any percentage among our patients, that is a worthwhile activity. From the number needed to treat, one patient death was prevented for every eight caregivers trained. It is therefore quite clear that caregiver education has a significant effect on the reduction of patient deaths post-stroke. This can be explained by the fact that trained caregivers are more confident in moving patients and general care of the patient (Yeung et al., 2007; Houts et al., 1996; ) thereby minimising the onset of complications of bed rest especially among a group of low functioning patients as was the case in this sample. The improved caring ability by the caregivers translates into better outcomes as far as death is concerned post-stroke.

## **CHAPTER 7**

### **7. CONCLUSION AND RECOMMENDATIONS**

#### **7.1 Introduction**

This chapter summarises the findings from the study with particular reference to the study objectives and also provides recommendations on lessons learnt and research that if done will contribute to further understanding and improvements of patient caregiver interactions post-stroke.

#### **7.2 Conclusion**

- The reduced hospital length of stay, pressure for beds and possibly inadequate staff levels means that patients are being discharged home to untrained caregivers. Currently, caregiver therapist interaction during the patient's hospital stay is non-existent, resulting in patients being sent home to untrained caregivers. This has the effect of negatively impacting on the quality of life of both the caregiver and the stroke survivor.
- Though patient mobility generally improves over time, it does not improve to satisfactory levels. Caregiver training did not result in much patient mobility improvements during the study period mainly because of the very low mobility levels patients exhibited at baseline assessment.
- Structured caregiver training positively impacted on patients' health related quality of life, especially at six and 12 months post discharge.
- If caregiver education could help prevent one patient death for every eight caregivers trained, one can only extrapolate that early supported discharge can help reduce risk of death or dependency.
- Caregivers for patients with stroke suffer from physical, psychological and financial problems which negatively affects their quality of life. The study however showed that

caregiver training has the effect of significantly reducing the decline in caregiver quality of life over time.

- The current high levels of caregiver strain shows that the current system is not working and a more structured caregiver education programme with good support structures for post discharge care should be put in place to help alleviate the burden of caregiving. The results however, show that caregiver training has the effect of significantly reducing caregiver stress due to better ability to cope with the caregiving duties.
- The patient ability to socialise and participate in community issues is currently poor. This is mainly affected by the patients' poor levels of functional ability, which causes them to be dependent on caregivers for execution of activities of daily living. Caregiver education did not influence patient ability to socialise and participate in community issues. Transport systems, services and policies, attitudes of friends and the design, construction and building products and technology for both public and private use were perceived as barriers to community participation.
- The patient characteristics that influence caregiver strain are patient dependency in grooming, mobility, dressing, bathing, poor activities of daily ability, and patient anxiety/depression, pain and poor perceived health state.
- The caregiver characteristic associated with caregiver strain is only the level of education. Caregivers with a university degree are more strained than those with lower levels of education.

### **7.3 Recommendations**

The recommendations from the study are in two parts, first for clinicians and secondly for further research.

#### **7.3.1 For the clinicians**

- Caregiver training needs to be treated as a priority if we are to help patients survive in the community post-stroke.

- The majority of patients are being discharged home with very low functional levels to unprepared caregivers resulting in them being very low functioning one-year post-stroke. Community physiotherapy including domiciliary visits needs to be strengthened to ensure continuation of rehabilitation post discharge from the hospital.
- An unacceptably high number of the caregivers are strained from caregiving with depression/anxiety being one of the major causes. Depression is treatable and hence early diagnosis with proper management of those diagnosed with it is important.
- The referral system between the discharging hospital and the local community health centre needs to be strengthened to ensure that all patients have access to rehabilitation post discharge from hospital.
- Referral to social workers needs to be strengthened to ensure that disability grant applications are made before the patient is discharged home or the local social workers (in the community) need to be notified when a patient is discharged to their area.
- One way of combating the problem of early discharge with little rehabilitation might be the creation of stroke units that focus on the medical care and rehabilitation of patients with stroke.

### **7.3.2 For further research**

- It is important to establish the reasons behind the inability of rehabilitation to reach those people who cannot afford to go to the local health centres
- The required patient to staff levels for effective rehabilitation during in-patient physiotherapy needs to be investigated to improve health delivery to patients post-stroke.

- There is no agreement in the literature on the best method for caregiver education at the moment, it would be important to try out the effectiveness of different methods of caregiver training and see which one would best suit our country.
- Effects of caregiver education should be investigated looking at specific types of caregivers e.g. spouse versus other family members and see if there are differences.
- Professional counselling for caregivers of patients with stroke should be added and its effect on caregiver stress levels measured.
- In our setting where length of stay is very short, and resources are limited, it remains to be seen whether stroke units are cost effective, though morbidity and mortality will almost certainly be reduced and so studies should be done in that regard.
- Further studies should be done, specifically looking at the role of personality and individual efficacy in caregiver strain for those caring for persons with stroke.

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Zhou G, Liu X, Xu G, Liu X, Zhang R, Zhu W 2006 The effect of socioeconomic status on three year mortality after first ever ischemic stroke in Nanjing, China. *BMC Public Health* 6: 227. DOI: 10.1186/1471-2458-6-227.

## LIST OF APPENDICES

### Appendix A

#### Per Protocol Analysis Results

##### Introduction:

The results obtained using the per protocol analysis are shown in the following pages. These comprised of data that were obtained from the patients and the caregivers who were alive or present at the end of the study and were assessed on time.

The numbers in both groups were as follows: Control group – 49 patients and 49 caregivers: Experimental Group – 65 patients and 65 caregivers.

#### 5.18: Patient Functional Ability as Measured by the Barthel Index

The distribution of the Barthel Index mean scores are shown in in Figure 5.17 below.

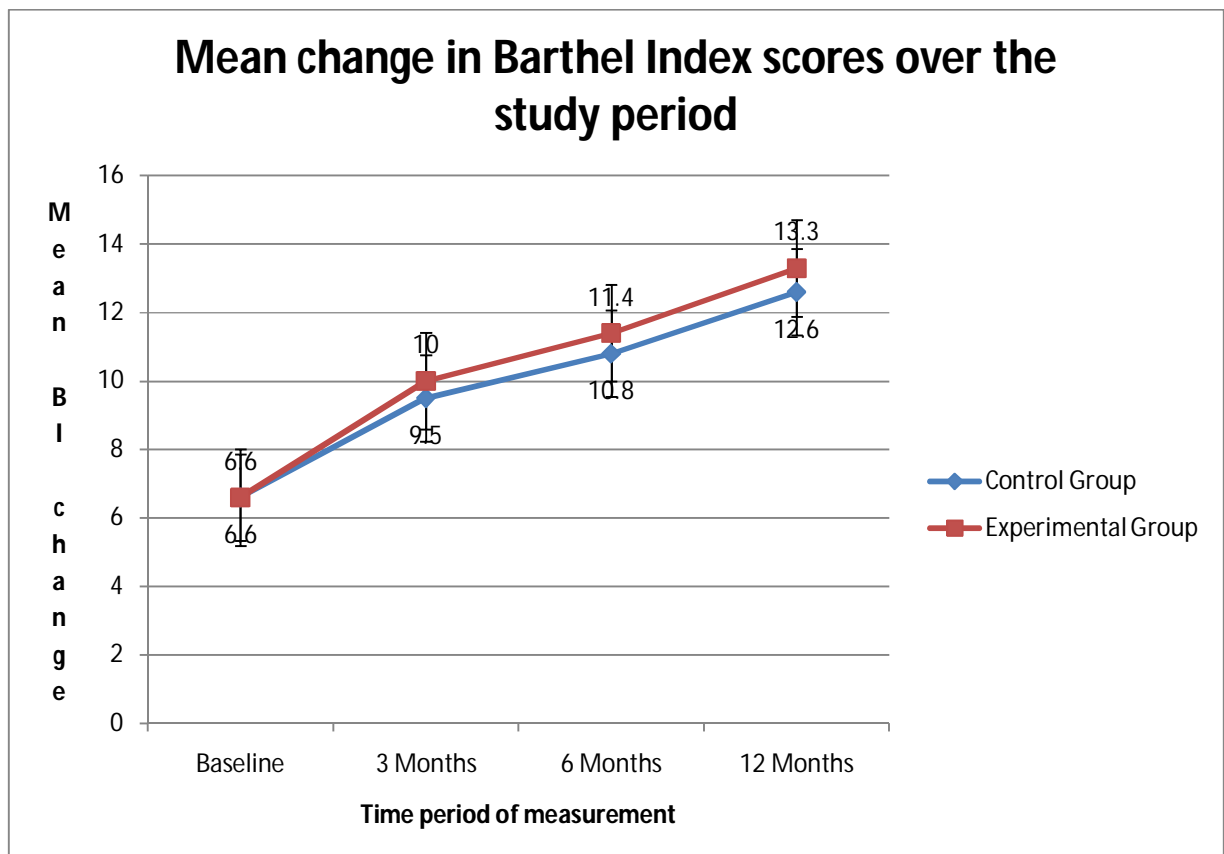


Figure 5.17: Mean BI scores over the 12 months period.



There was a general increase in patients' BI mean scores over the study period. The BI mean difference between the two groups was not statistically significant with  $p = 0.08$

The two-sample t test statistical results of the BI mean difference in change between the two groups are shown in Table 5.35 below. The p-values that are given are for the one tailed t test.

**Table 5.35:** The two-sample t test statistical results of the BI mean difference in change between the two groups.

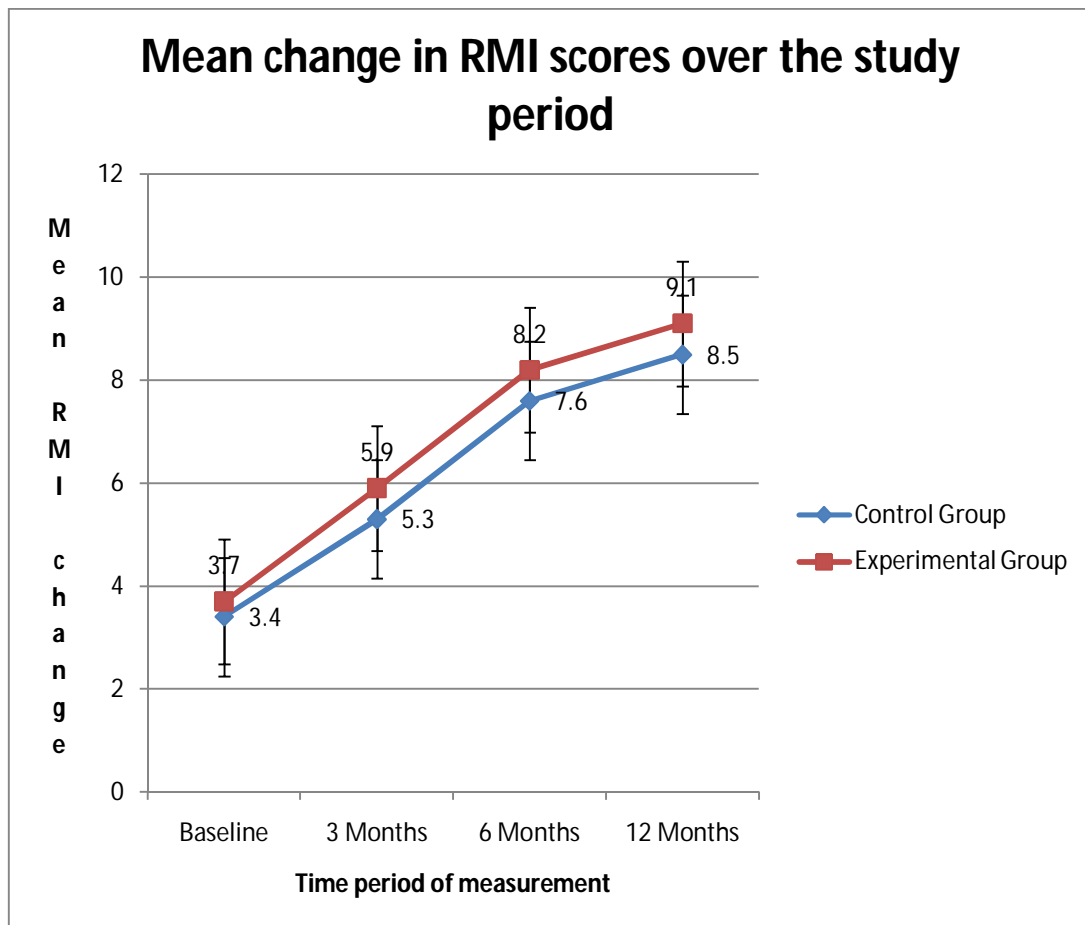
Period	Mean Score Experimental Group	Mean Score Control Group	Mean score difference	Std. Error	95% CI	p value
<b>Baseline</b>	6.6	6.6	-0.1	0.5	-0.8 – 0.9	0.54
<b>3 Months</b>	10	9.5	0.5	0.4	-1.2 – 0.2	0.1
<b>6 Months</b>	11.4	10.8	0.6	0.4	-1.3 – 0.1	0.05
<b>12 Months</b>	13.3	12.6	0.7	0.4	-1.5 – 0.1	0.05

Mean difference = mean (experimental group) – mean (control group).

The differences of the BI mean change between the two groups' measurements were not statistically at baseline and 3 months ( $p = 0.5$  and  $0.1$  respectively) but were significant at 6 months and 12 months at the  $0.05$  level of significance.

### **5.19 The effect of caregiver education on the mobility of the stroke survivors.**

The analysis results for the Rivermead mobility index mean scores are shown in Figure 5.18 below.



**Figure 5.18:** Mean RMI scores over the 12 months period.

There was a general increase in the patients' RMI scores. The experimental group had better mean RMI scores than the control group ( $p = 0.03$ ).

The statistical test results of the mean change between the groups at the various measurement points are shown in Table 5.36 below.

**Table 5.36:** The statistical test results of the mean change between the two groups.

<b>Period</b>	<b>Mean Score Experimental Group</b>	<b>Mean Score Control Group</b>	<b>Mean difference</b>	<b>St. Error</b>	<b>95% CI</b>	<b>p value</b>
<b>Baseline</b>	3.8	3.4	0.4	0.3	-0.9 – 0.1	0.08
<b>3 Months</b>	5.9	5.3	0.6	0.5	-1.7 – 0.5	0.13
<b>6 Months</b>	8.2	7.6	0.6	0.5	-1.5 – 0.3	0.11
<b>12 Months</b>	9.1	8.5	0.6	0.4	-1.4 – 0.2	0.08

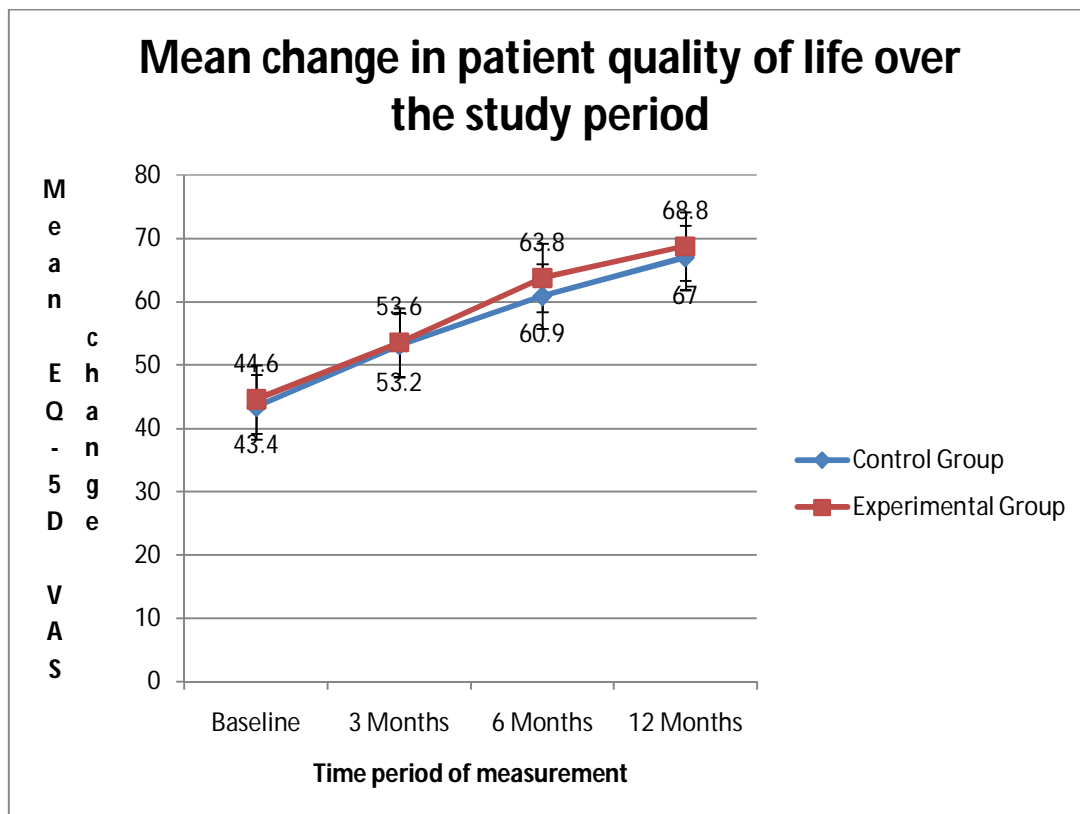
Mean difference = mean (experimental group) – mean (control group).

The differences of the RMI mean change between the two groups at the four points of measurement were not statistically significant.

## 5.20 The effect of caregiver education on the quality of life of the stroke survivors.

The analysis results for the effect of caregiver education on the health related quality of life of the patients are shown below.

Figure 5.19 below shows the mean change in patient quality of life over the study period.



**Figure 5.19:** Mean change in patient quality of life (EQ-5D VAS scores).

There was a general increase in the patients' mean perceived health related quality of life. The patients in the experimental group did not have statistically better mean scores than the control group ( $p = 0.11$ ).

The statistical test results of the mean change between the groups at the various measurement points are shown in Table 5.37 below.

**Table 5.37:** The statistical test results of the mean patient EQ-5D VAS scores change between the two groups.

<b>Period</b>	<b>Mean Score Experimental Group</b>	<b>Mean Score Control Group</b>	<b>Mean difference</b>	<b>St. Error</b>	<b>95% CI</b>	<b>p value</b>
<b>Baseline</b>	44.6	43.4	1.3	2.0	-5.3 – 2.8	0.27
<b>3 Months</b>	53.6	53.2	0.5	1.9	-4.1 – 3.2	0.40
<b>6 Months</b>	63.8	60.9	2.9	1.6	-6 – 0.3	0.03
<b>12 Months</b>	68.9	67	1.8	2.0	-5.8 – 2.2	0.19

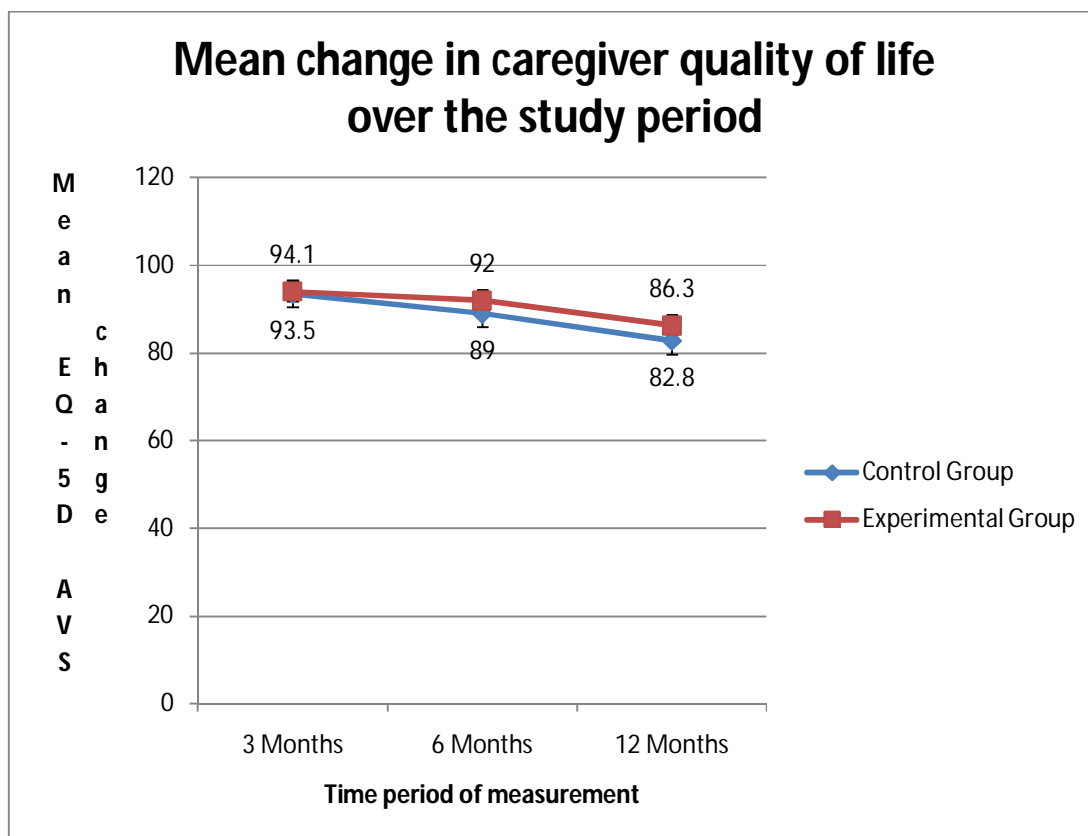
Mean difference = mean (experimental group) – mean (control group).

The differences of the EQ-5D VAS mean change between the two groups at the four points of measurement were not statistically significant except at the 6 months period where the experimental group patients had better mean score ( $p = 0.04$ ).

### 5.21 The effect of caregiver education on the quality of life of the caregivers.

The per protocol analysis results for the effect of caregiver education on the health related quality of life of the caregivers are shown below.

Figure 5.20 below shows the mean change in caregiver quality of life over the study period.



**Figure 5.20:** Mean change in caregiver quality of life (EQ-5D VAS scores).

There was a general decline in the caregivers' mean perceived health related quality of life.

The statistical test results of the mean change between the groups at the various measurement points are shown in Table 5.38 below.

**Table 5.38:** The statistical test results of the mean caregiver EQ-5D VAS scores change between the two groups.

<b>Period</b>	<b>Mean Score Experimental Group</b>	<b>Mean Score Control Group</b>	<b>Mean difference</b>	<b>St. Error</b>	<b>95% CI</b>	<b>p value</b>
3 Months	94.1	93.5	0.61	0.9	-2.3 – 1.1	0.25
6 Months	92.2	89	3.2	.10	-5.4 – (-1)	0.001
12 Months	86.3	82.8	3.5	1.4	-6.3 – (-0.8)	0.001

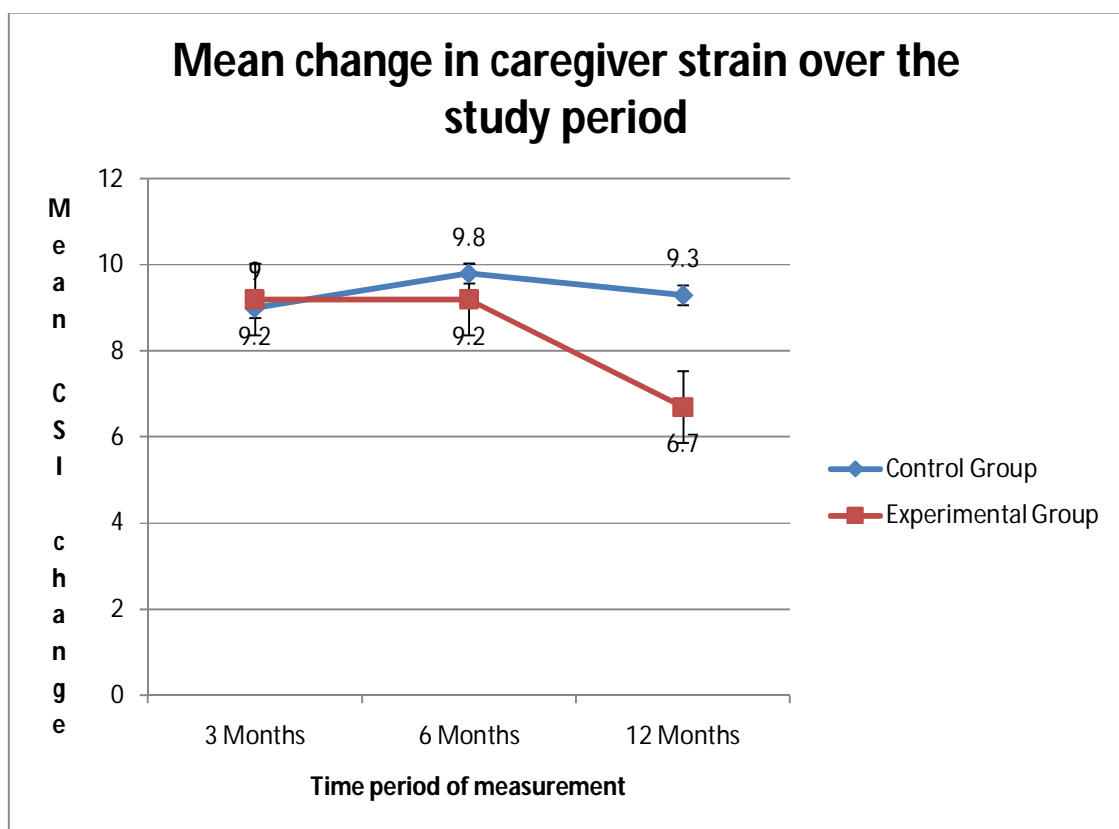
Mean difference = mean (experimental group) – mean (control group).

The differences of the EQ-5D VAS mean change between the two groups at 6months and 12 months was statistically significant with p =0.001 and 0.001 respectively.

### 5.22 Patient characteristics associated with caregiver strain.

The distribution of caregiver strain over the study period is shown in Figure 5.21 below.

Figure 5.21 below shows the mean change in caregiver strain over the study period.



**Figure 5.21:** Mean change in caregiver strain

Caregiver strain rose between 3 months and six months in the control group and then significantly declined in the caregiver group and marginally in the control group.



The statistical test results of the mean change between the groups at the various measurement points are shown in Table 5.39 below.

**Table 5.39:** The statistical test results of the mean caregiver strain change between the two groups.

<b>Period</b>	<b>Mean Score Experimental Group</b>	<b>Mean Score Control Group</b>	<b>Mean difference</b>	<b>St. Error</b>	<b>95% CI</b>	<b>p value</b>
3 Months	9.2	9	0.2	0.2	-0.7 – 0.3	0.19
6 Months	9.2	9.8	-0.6	0.3	0.1 – 1.3	0.01
12 Months	6.7	9.3	-2.6	0.5	1.6 – 3.6	< 0.001

Mean difference = mean (experimental group) – mean (control group).

NB: With the CSI scores, the lower the score, the better the outcome.

The differences of the CSI mean change between the two groups at 6months and 12 months was statistically significant with the experimental group scoring lower mean CSI scores than the control group with (p =0.01 and <0.001 respectively for the 6 and 12 months periods). At 12 months, caregiver education had effect of reducing caregiver strain by 2.6.

### 5.22.1 Patient characteristics associated with caregiver strain

The univariate analysis results of factors influencing caregiver strain are shown below.

**Table 5.40:** Univariate regression analysis of factors influencing caregiver strain – per protocol analysis.

Factor	Coefficient	Std. Error	Exp(beta)	p-value	95%CI
<b>Stroke subtype</b>					
Total Anterior Circulatory Infarction	Reference = 8.4	-	-	-	-
Partial Anterior Circulatory Infarct	0.5	0.8	1.6	0.29	0.7 – 3.9
Posterior Circulatory Infarct	0.6	0.8	1.8	0.18	0.7 – 4.5
Lacunar Circulatory Infarct	0.3	0.6	1.3	0.55	0.5 – 3.3
<b>BI Transfer</b>					
Unable	Reference = 9.1	-	-	-	-
Major help	0.2	1.0	1.3	0.75	0.3 – 5.6
Minor help	-1.7	0.1	0.2	0.03	0.0 – 0.9
Independent	-1.6	0.3	0.2	0.31	0.0 – 4.7
<b>BI Mobility</b>					
Immobile	Reference = 9.1	-	-	-	-
Wheelchair dependent	-0.1	0.5	0.9	0.9	0.3 – 2.9
Walks with help	-1.6	0.1	0.2	0.01	0.1 – 0.7
Independent	-	-	-	-	-
<b>BI Dressing</b>					
Dependent	Reference = 9.6	-	-	-	-
Needs help	-0.5	0.2	0.6	0.2	0.3 – 1.4
Independent	-2.9	0.02	0.1	<0.001	0.0 – 0.1

Factor	Coefficient	Std. Error	Exp(beta)	p-value	95%CI
<b>BI Bathing</b>					
Dependent	Reference = 9.4	-	-	-	-
Independent	-1.7	0.04	0.2	<0.001	0.1 – 0.3
<b>BI Total</b> (against Control Group)	-1.6	0.03	0.7	<0.001	0.6 – 0.7
<b>RMI Total</b> (against control group)	-0.1	0.03	0.8	<0.001	0.8 – 0.9
<b>EQ-5D Usual Activities</b>					
No problems	Reference = 7.6	-	-	-	-
Some problems	2	7.3	7.4	0.04	1.1 – 52.1
Unable	3	28.1	19.1	0.05	1.1 – 345.9
<b>EQ-5D Pain/Discomfort</b>					
No pain/discomfort	Reference = 9.1	-	-	-	-
Moderate pain/discomfort	-0.7	0.1	0.5	0.004	0.3 – 0.8
Extreme pain/discomfort	-0.11	1	0.9	0.91	0.1 – 7.8
<b>EQ-5D Anxiety/Depression</b>					
Not anxious/depressed	Reference = 7.7	-	-	-	-
Moderately anxious/depressed	1.2	1.2	3.4	<0.001	1.7 – 6.6
Extremely anxious/depressed	1.4	2	4.1	0.005	1.5 – 10.8
<b>EQ-5D General Perceived Health</b>					
<b>State</b>	Reference = 7.5	-	-	-	-
Better	1.8	2.9	6.1	<0.001	2.4 – 15.4
Much the same	1.2	1.5	3.4	0.007	1.4 – 8.2
Worse					
<b>EQ-5D VAS Perceived Health State</b>	-0.04	0.09	1	<0.001	0.9 – 1

The caregivers of those patients who needed minor help with transfers had on average 1.7 less caregiving strain than those caregivers for patients who were unable to transfer ( $p = 0.03$ ; OR = 0.2). The caregivers of those patients who walked with help had on average 1.6 less caregiver strain than those caregivers for patients who were immobile ( $p = 0.01$ ; OR = 0.2). As the BI total score increases by one unit, it has the impact of reducing the CSI total score by 1.6 ( $p < 0.001$ ; OR = 0.7) and as the RMI total score increases by one unit, it has the impact of reducing the CSI total by 0.1 ( $p < 0.001$ ; OR = 0.8). As the EQ-5D VAS score increases by one unit, it has the impact of reducing the CSI total score by 0.04 ( $p < 0.001$ ; OR = 1).

### 5.23 The caregiver characteristics associated with caregiver strain

The caregiver characteristics that influenced caregiver strain are shown in the table below.

**Table 5.41:** Caregiver characteristics associated with caregiver strain

Factor	Coefficient	Std. Error	Exp(beta)	p-value	95%CI
<b>Level of education</b>					
University degree	Reference = 10		-	-	-
Grade 12 + 3 or more years	-				
Grade 12 or equivalent	-1.2	0.2	0.6	0.01	0.1 – 0.7
Up to Grade 11	-1.3	0.2	0.6	<0.001	0.1 – 0.6
Up to Grade 7	-1.1	0.2	0.6	0.01	0.1 – 0.8

The only caregiver factor that seemed to be influencing caregiver strain was level of education. The caregivers of those patients who had gone to school up to Grade 11 had on average 1.3 less caregiver strain than those caregivers who had a university degree ( $p < .0001$ ; OR = 0.6).

## Appendix B

### INITIAL QUESTIONNAIRE FOR PATIENT'S DEMOGRAPHIC DATA

Name: ..... Date:.....

Date of Birth: ..... Age:.....

Address:.....

.....

.....

Date of stroke:.....

Date of admission:.....

#### 1. Type of stroke:

1.1 First time stroke?  YES  NO

1.2 Side of body affected:  Left  Right

1.3 Type of stroke:  Haemorrhagic  Infarct

1.3.1 Ischaemic Stroke Subtype  Total Anterior Infarct  
 Partial Anterior Infarct  
 Posterior Infarct  
 Lacunar Infarcts

2. Gender:  Male  Female

#### 3. Employment status at time of stroke:

- Employed  
 Self Employed  
 Unemployed  
 Retired  
 Receiving Benefit/Grant  
 Other: Specify.....

#### 4. Marital status:

- Single  
 Married

- Divorced
- Separated
- Cohabiting
- Other: Specify .....

5. Caregiver Situation:

- Lives alone (No Carer)
- Carer present during day
- Carer present only at night
- Carer present all the time

6. Relationship to Carer

- Spouse
- Friend
- Relative
- Neighbour
- Other: Specify.....

6 Completed Education Level:

- University degree
- Grade 12 + 3 or more years
- Grade 12 or equivalent
- Up to grade 11
- Up to grade 7

8. Check List of Risk factors:

- | YES                      | NO  |
|--------------------------|---|
| <input type="checkbox"/> | <input type="checkbox"/> Smoking: Specify number per day .....                      |
| <input type="checkbox"/> | <input type="checkbox"/> Diabetes   |
| <input type="checkbox"/> | <input type="checkbox"/> Heart Disease  |
| <input type="checkbox"/> | <input type="checkbox"/> Hyperlipidaemia/ cholesterol                               |
| <input type="checkbox"/> | <input type="checkbox"/> Hypertension   |
| <input type="checkbox"/> | <input type="checkbox"/> Overweight (BMI 25 – 29.9) Height.....Weight..... BMI..... |

Other: Specify.....

**9. Pre-morbid Functional Status**

- Independent in all activities of daily living
- Needed assistance with activities of daily living
- Other: Specify.....

**10. Baseline Patient Assessment:**

- |  |             |                              |                             |
|--|-------------|------------------------------|-----------------------------|
| <u>Continence:</u>                                 | Bladder:    | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
|  | Bowels:     | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| <u>Major Language Deficit (Can't talk at all):</u> |             | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| <u>Major Cognitive Deficit:</u>                    |             | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| <u>Major Perceptual Deficit:</u>                   |             | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Additional complications present?                  | Cardiac:    | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
|  | Pulmonary:  | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Additional neurological impairment present?        | Epilepsy:   | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
|  | Head Injury | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Any clinical evidence of immuno-suppression        |             | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

## Appendix C

### SUBSEQUENT QUESTIONNAIRE FOR PATIENT'S DEMOGRAPHIC DATA (At 3, 6 and 12 months post discharge)

Name: ..... Date:.....

Date of Birth: ..... Age: .....

Address:.....

.....

.....

Date of stroke:.....

Date of admission:.....

#### 1. Type of stroke:

1.1 First time stroke?  YES  NO

1.2 Side of body affected:  Left  Right

1.3 Type of stroke:  Haemorrhagic  Infarct

1.3.1 Ischaemic Stroke Subtype  Total Anterior Infarct

Partial Anterior Infarct

Posterior Infarct

Lacunar Infarcts

2. Gender:  Male  Female

#### 3. Financial and Employment status :

3.1 has your financial situation changed as a result of your stroke:

Yes  No

3.2 Do you receive any financial support?  Yes  No

If yes, please specify:

Disability grant

Pension

UIF (unemployment)

Other: Specify.....

3.3 Employment Information

Employed

Self Employed



- Unemployed
- Retired
- Receiving Benefit
- Other: Specify.....

4. Marital Status:

- Single
- Married
- Divorced
- Separated
- Cohabiting
- Other: Specify .....

5. Caregiver Situation:

- Lives alone (No Carer)
- Carer present during day
- Carer present only at night
- Carer present all the time

6. Relationship to Carer

- Spouse
- Friend
- Relative
- Neighbour
- Other: Specify.....

7. Accommodation Situation and Home Environment:

- Own house
- Renting
- Informal settlement
- Running water
- Electricity
- Inside toilet

- Outside toilet
- Own bed
- Even ground (outside)
- Uneven ground (outside)
- Has stairs
- Has no stairs
- Other: Specify.....

**8. Knowledge of Risk Factors:**

- |                          |  |
|--------------------------|--|
| YES                      | NO   |
| <input type="checkbox"/> | <input type="checkbox"/> Smoking: Specify number per day ..... |
| <input type="checkbox"/> | <input type="checkbox"/> Diabetes                              |
| <input type="checkbox"/> | <input type="checkbox"/> Heart Disease                         |
| <input type="checkbox"/> | <input type="checkbox"/> Hyperlipidaemia/ cholesterol          |
| <input type="checkbox"/> | <input type="checkbox"/> Hypertension                          |
| <input type="checkbox"/> | <input type="checkbox"/> Overweight/Obese (BMI of >25)         |
| <input type="checkbox"/> | <input type="checkbox"/> Other: Specify.....                   |

**9. Subsequent Patient Assessment:**

- |   |             |                              |                             |
|---|-------------|------------------------------|-----------------------------|
| <u>Continence:</u>                          | Bladder:    | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
|   | Bowels:     | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| <u>Major Language Deficit:</u>              |             | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| <u>Major Cognitive Deficit:</u>             |             | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| <u>Major Perceptual Deficit:</u>            |             | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Additional complications present?           | Cardiac:    | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
|   | Pulmonary:  | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Additional neurological impairment present? | Epilepsy:   | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
|   | Head Injury | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Any clinical evidence of immuno-suppression |             | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

10. Five main problems (if any) being experienced:

- i).....
- ii).....
- iii).....
- iv).....
- v).....

## Appendix D

### INITIAL AND SUBSEQUENT QUESTIONNAIRE FOR CAREGIVER'S DEMOGRAPHIC DATA

Name: ..... Date:.....

Date of Birth: ..... Age: .....

Address:.....

.....

1. Gender:  Male  Female

2. Employment status:

- Employed
- Self Employed
- Unemployed
- Retired
- Receiving Benefit
- Other: Specify.....

3. Marital status:  Single

- Married
- Divorced
- Separated
- Cohabiting
- Other: Specify .....

4. Family Situation:

- Lives alone (No other family members)
- Lives with children: Give number.....
- Lives with other adults: Give number .....
- Receives help from other members of the family in caregiving

5. Completed Education Level:

- University degree
- Grade 12 + 3 or more years

- Grade 12 or equivalent
- Up to grade 11
- Up to grade 7

**6. Accommodation Information**

- Own house
- Renting
- Informal settlement

**7. Home environment**

- |  |  |
|--|--|
| <input type="checkbox"/> Running water         | <input type="checkbox"/> Uneven ground (outside) |
| <input type="checkbox"/> Electricity           | <input type="checkbox"/> Has stairs              |
| <input type="checkbox"/> Inside toilet         | <input type="checkbox"/> Has no stairs           |
| <input type="checkbox"/> Outside toilet        | <input type="checkbox"/> Other:                  |
| <input type="checkbox"/> Own bed               | Specify.....                                     |
| <input type="checkbox"/> Even ground (outside) |  |

**8. Knowledge of Stroke Risk factors:**

- | YES                      | NO  |
|--------------------------|---|
| <input type="checkbox"/> | <input type="checkbox"/> Smoking                      |
| <input type="checkbox"/> | <input type="checkbox"/> Diabetes                     |
| <input type="checkbox"/> | <input type="checkbox"/> Heart Disease                |
| <input type="checkbox"/> | <input type="checkbox"/> Hyperlipidaemia/ cholesterol |
| <input type="checkbox"/> | <input type="checkbox"/> Hypertension                 |
| <input type="checkbox"/> | <input type="checkbox"/> Overweight                   |
| <input type="checkbox"/> | Other: Specify.....                                   |

**Appendix E**

**BARTHEL ACTIVITIES OF DAILY LIVING INDEX**

*Bowels* 0 = incontinent (or needs to be given enema)  
 1 = occasional accident (once a week)  
 2 = continent

*Bladder* 0 = incontinent, or catheterised and unable to manage alone  
 1 = occasional accident (maximum once per 24 hours)  
 2 = continent

<i>Grooming</i>	0 = needs help with personal care 1 = independent face/ hair/ teeth/ shaving (implements provided)
<i>Toilet use</i>	0 = dependent 1 = needs some help, but can do something alone 2 = independent (on and off, dressing, wiping)
<i>Feeding</i>	0 = unable 1 = needs help cutting, spreading butter, etc. 2 = independent
<i>Transfer (bed to chair and back)</i>	0 = unable, no sitting balance 1 = major help (one or two people, physical) 2 = minor help (verbal or physical) 3 = independent
<i>Mobility</i>	0 = immobile 1 = wheelchair dependent, including corners 2 = walks with help of one person (verbal or physical) 3 = independent (but may use any aid; for example, stick)
<i>Dressing</i>	0 = dependent 1 = needs help but can do about half unaided 2 = independent (including buttons, zips, laces, etc.)
<i>Stairs</i>	0 = unable 1 = needs help (verbal, physical, carrying aid) 2 = independent
<i>Bathing</i>	0 = dependent 1 = independent (or in shower)
total	0-20

## Appendix F

### RIVERMEAD MOBILITY INDEX

Instructions:

The patient is asked the following 15 questions and observed (for item 5). A score of 1 is given for each yes answer. Note that most require independence from personal help, but method is otherwise unimportant.

Q	Question	Yes	No
1	Turning over in bed Do you turn over from your back to your side without help		
2	Lying to Sitting From lying in bed, do you get up to sit on the edge of the bed on your own without holding on for 10 seconds		
3	Sitting balance Do you sit on the edge of the bed without holding on for 10 seconds		
4	Sitting to standing Do you stand (from any chair) in less than 15 seconds, and stand there for 15 seconds (using hands, and with an aid if necessary)?		
5	Standing unsupported Observe standing for 10 seconds without any aid or support		
6	Transfer Do you manage to move e.g. from bed to chair and back without help?		
7	Walking inside, with an aid if needed Do you walk 10m, with an aid or furniture if necessary, but no standby help?		
8	Stairs Do you manage a flight of stairs without help?		
9	<i>Walking outside (even ground)</i> Do you walk around outside, on pavements without help?		
10	Walking inside, with no aid Do you walk 10m inside with no calliper, splint, aid or use furniture, and no stand-by help?		
11	Picking off floor If you drop something on the floor, do you manage to walk 5m, pick it then walk back?		
12	<i>Walking outside (uneven ground)</i> Do you walk over uneven ground (grass, gravel, dirt etc) without help?		
13	Bathing Do you get in/out of bath or shower unsupervised and wash self?		
14	Up and down four steps Do you manage to go up and down four steps with no rail and without help, but using an aid if necessary?		
15	Running Do you run 10m without limping in 4 seconds (fast walk is acceptable)?		

**Total...../15**

## Appendix G

### THE EuroQol (Eq-5D) Health Questionnaire (South African English Version)

By placing a tick in one box in each group below, please indicate which statements best describe your own state of health TODAY.

#### Mobility

- I have no problems in walking about
- I have some problems in walking about
- I am confined to bed

#### Self-Care

- I have no problems with self-care
- I have some problems washing or dressing myself
- I am unable to wash or dress myself

#### Usual Activities (*e.g. work, study, housework, family or leisure activities*)

- I have no problems with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities

#### Pain/Discomfort

- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

#### Anxiety/Depression

- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed



Compared with my general level of health over the past 12 months, my state of health today is:

- Better  PLEASE TICK  
Much the same  ONE  
Worse  BOX

To help people say how good or bad their state of health is, we have drawn a scale on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale, in your opinion, how good or bad your own health is today. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your state of health is today.

**Your own  
state of health  
today**

Best  
imaginable  
state of health

100

90

80

70

60

50

40

30

20

10

0

Worst  
imaginable  
state of health

## Appendix H

### THE CAREGIVER STRAIN INDEX

Score: 'Yes' = 1  
'No' = 0

"I am going to read a list of things which other people have found to be difficult in helping with after someone comes home from hospital." (or)

"I am going to read a list of things which other people have found to be difficult when helping someone who has an illness.'

"Would you please tell me whether any of these apply to you? (give examples)

---

- Sleep is disturbed (e.g. because.....is in and out of bed or wanders around at night).
- It is inconvenient (e.g. because helping takes so much time or it's a long drive over to help).
- It is a physical strain (e.g. because of lifting in and out of the chair; effort or concentration is required).
- It is confining (e.g. helping restricts time, or cannot go visiting).
- There have been family adjustments (e.g. because helping has disrupted routine; there has been no privacy).
- There have been changes in personal plans (e.g. had to turn down job; could not go on vacation/ holiday).
- There have been other demands on my time (e.g. from other family members).
- There have been emotional adjustments (e.g. because of severe argument).
- Some behaviour is upsetting (e.g. because of incontinence;..... Has trouble remembering things; or ..... accuses people of taking things).
- It is upsetting to find ..... has changed so much from his/ her former self (e.g. he/ she is a different person than he/ she used to be).
- There have been work adjustments (e.g. because of having to take time off).
- It is a financial strain.
- Feeling completely overwhelmed (e.g. because of worry about .....; concerns about how you will manage).
- /13 Total**

## Appendix I

### THE ICF CHECK LIST

# ICF CHECKLIST

## *Version 2.1a, Clinician Form*

### **for International Classification of Functioning, Disability and Health**

*This is a checklist of major categories of the International Classification of Functioning, Disability and Health (ICF)*

*of the World Health Organisation. The ICF Checklist is a practical tool to elicit and record information on the*

*functioning and disability of an individual. This information can be summarized for case records (for example, in*

*clinical practice or social work). The checklist should be used along with the ICF or ICF Pocket version.*

**H 1.** When completing this checklist, use all information available. Please check those used:

**[1] written records [2] primary respondent [3] other informants [4] direct observation**

*If medical and diagnostic information is not available it is suggested to complete*

*appendix 1: Brief Health Information (p 9-10) which can be completed by the respondent.*

**H 2. Date** \_\_\_/\_\_\_/\_\_\_ **H 3. Case ID** \_\_, \_\_\_\_, \_\_ **H 4. Participant No.** \_\_\_\_, \_\_\_\_, \_\_

---

*Day Month Year CE or CS Case No. 1<sup>st</sup> or 2<sup>nd</sup> Evaluate FTC Site Participant*

#### **A. DEMOGRAPHIC INFORMATION**

**A.1 NAME (optional)** First \_\_\_\_\_ FAMILY \_\_\_\_\_

**A.2 SEX** (1)  Female (2)  Male

**A.3 DATE OF BIRTH** \_\_/\_\_/\_\_ (date/month/year)

**A.4 ADDRESS (optional)**

**A.5 YEARS OF FORMAL EDUCATION** \_\_

**A.6 CURRENT MARITAL STATUS:** (Check only one that is most applicable)

(1) Never married  (4) Divorced

(2) Currently Married  (5) Widowed

(3) Separated  (6) Cohabiting

**A.7 CURRENT OCCUPATION** (Select the single best option)

(1) Paid employment  (6) Retired

(2) Self-employed  (7) Unemployed (health reason)

(3) Non-paid work, such as volunteer/charity  (8) Unemployed (other reason)

(4) Student  (9) Other

(5) Keeping house/House-maker  (please specify) \_\_\_\_\_

**A.8 MEDICAL DIAGNOSIS of existing Main Health Conditions, if possible give ICD Codes.**

1. No Medical Condition exists

2. .... ICD code: \_\_. \_\_. \_\_. \_\_.

3. .... ICD code: \_\_. \_\_. \_\_. \_\_.

4. .... ICD code: \_\_. \_\_. \_\_. \_\_.

5. A Health Condition (disease, disorder, injury) exists, however its nature or diagnosis is not known

## **PART 2: ACTIVITY LIMITATIONS & PARTICIPATION**

### **RESTRICTION**

□ *Activity is the execution of a task or action by an individual.. Participation is involvement in a life situation.*

□ *Activity limitations are difficulties an individual may have in executing activities. Participation restrictions are problems an individual may have in involvement in life situations.*

*The Performance qualifier describes what an individual does in his or her current environment. Because the current environment brings in the societal context, performance can also be understood as "involvement in a life situation"*

*or "the lived experience" of people in the actual context in which they live. This context includes the environmental factors – all aspects of the physical, social and attitudinal world that can be coded using the Environmental Factors.*

*The Capacity qualifier describes an individual's ability to execute a task or an action. This construct indicates the highest probable level of functioning that a person may reach in a given domain at a given moment. To assess the full ability of the individual, one would need to have a "standardized" environment to neutralize the varying impact of different environments on the ability of the individual. As standardized environment may be: (a) an actual environment commonly used for capacity assessment in test settings; or (b) where this is not possible, a hypothetical environment a uniform impact.*

**Note:** Use Appendix 2 if needed to elicit information on the Activities and Participation of the individual

<b>First Qualifier: Performance extent of participation restriction</b>	<b>Second Qualifier: Capacity (without assistance) Extent of Activity limitation</b>
<b>0</b> No difficulty <b>1</b> Mild difficulty <b>2</b> Moderate difficulty <b>3</b> Severe difficulty <b>4</b> Complete difficulty <b>8</b> Not specified <b>9</b> Not applicable	<b>0</b> No difficulty <b>1</b> Mild difficulty <b>2</b> Moderate difficulty <b>3</b> Severe difficulty <b>4</b> Complete difficulty <b>8</b> Not specified <b>9</b> Not applicable

<b>Short List of A&amp;P domains</b>	<b>Performance Qualifier</b>	<b>Capacity Qualifier</b>
<b>d1. LEARNING AND APPLYING KNOWLEDGE</b>		
<b>d110</b> Watching		
<b>d115</b> Listening		
<b>d140</b> Learning to read		
<b>d145</b> Learning to write		
<b>d150</b> Learning to calculate ( <i>arithmetic</i> )		
<b>d175</b> Solving problems		
<b>d2. GENERAL TASKS AND DEMANDS</b>		
<b>d210</b> Undertaking a single task		
<b>d220</b> Undertaking multiple tasks		
<b>d3. COMMUNICATION</b>		
<b>d310</b> Communicating with -- receiving -- spoken messages		
<b>d315</b> Communicating with -- receiving -- non-verbal messages		
<b>d330</b> Speaking		
<b>d335</b> Producing non-verbal messages		
<b>d350</b> Conversation		

<i>Short List of A&amp;P domains</i>	Performance qualifier	Capacity qualifier
<b>d4. MOBILITY</b>		
<b>d430</b> Lifting and carrying objects		
<b>d440</b> Fine hand use ( <i>picking up, grasping</i> )		
<b>d450</b> Walking		
<b>d465</b> Moving around using equipment ( <i>wheelchair, skates, etc.</i> )		
<b>d470</b> Using transportation ( <i>car, bus, train, plane, etc.</i> )		
<b>d475</b> Driving (riding bicycle and <i>motorbike, driving car, etc.</i> )		
<b>d5. SELF CARE</b>		
<b>d510</b> Washing oneself ( <i>bathing, drying, washing hands, etc</i> )		
<b>d520</b> Caring for body parts ( <i>brushing teeth, shaving, grooming, etc.</i> )		
<b>d530</b> Toileting		
<b>d540</b> Dressing		
<b>d550</b> Eating		
<b>d560</b> Drinking		
<b>d570</b> Looking after one`s health		
<b>d6. DOMESTIC LIFE</b>		
<b>d620</b> Acquisition of goods and services ( <i>shopping, etc.</i> )		
<b>d630</b> Preparation of meals ( <i>cooking etc.</i> )		
<b>d640</b> Doing housework ( <i>cleaning house, washing dishes laundry, ironing, etc.</i> )		
<b>d660</b> Assisting others		
<b>d7. INTERPERSONAL INTERACTIONS AND RELATIONSHIPS</b>		
<b>d710</b> Basic interpersonal interactions		
<b>d720</b> Complex interpersonal interactions		
<b>d730</b> Relating with strangers		
<b>d740</b> Formal relationships		
<b>d750</b> Informal social relationships		
<b>d760</b> Family relationships		
<b>d770</b> Intimate relationships		
<b>d8. MAJOR LIFE AREAS</b>		
<b>d810</b> Informal education		
<b>d820</b> School education		
<b>d830</b> Higher education		
<b>d850</b> Remunerative employment		
<b>d860</b> Basic economic transactions		
<b>d870</b> Economic self-sufficiency		
<b>d9. COMMUNITY, SOCIAL AND CIVIC LIFE</b>		
<b>d910</b> Community Life		
<b>d920</b> Recreation and leisure		
<b>d930</b> Religion and spirituality		
<b>d940</b> Human rights		
<b>d950</b> Political life and citizenship		

**ANY OTHER ACTIVITY AND PARTICIPATION**

## **PART 3: ENVIRONMENTAL FACTORS**

□ *Environmental factors* make up the physical, social and attitudinal environment in which people live and conduct their lives.

<b>Qualifier in environment:</b>	<b>0</b> No barriers	<b>0</b> No facilitator
<b>Barriers or facilitator</b>	<b>1</b> Mild barriers	<b>+1</b> Mild facilitator
	<b>2</b> Moderate barriers	<b>+2</b> Moderate facilitator
	<b>3</b> Severe barriers	<b>+3</b> Substantial facilitator
	<b>4</b> Complete barriers	<b>+4</b> Complete facilitator

<b><i>Short List of Environment</i></b>	<b><i>Qualifier barrier or facilitator</i></b>
<b>e1. PRODUCTS AND TECHNOLOGY</b>	
<b>e110</b> For personal consumption ( <i>food, medicines</i> )	
<b>e115</b> For personal use in daily living	
<b>e120</b> For personal indoor and outdoor mobility and transportation	
<b>e125</b> Products for communication	
<b>e150</b> Design, construction and building products and technology of buildings for public use	
<b>e155</b> Design, construction and building products and technology of buildings for private use	
<b>e2. NATURAL ENVIRONMENT AND HUMAN MADE CHANGES TO ENVIRONMENT</b>	
<b>e225</b> Climate	
<b>e240</b> Light	
<b>e250</b> Sound	
<b>e3. SUPPORT AND RELATIONSHIPS</b>	
<b>e310</b> Immediate family	
<b>e320</b> Friends	
<b>e325</b> Acquaintances, peers, colleagues, neighbours and community members	
<b>e330</b> People in position of authority	
<b>e340</b> Personal care providers and personal assistants	
<b>e355</b> Health professionals	
<b>e360</b> Health related professionals	
<b>e4. ATTITUDES</b>	
<b>e410</b> Individual attitudes of immediate family members	
<b>e420</b> Individual attitudes of friends	
<b>e440</b> Individual attitudes of personal care providers and personal assistants	
<b>e450</b> Individual attitudes of health professionals	
<b>e455</b> Individual attitudes of health related professionals	
<b>e460</b> Societal attitudes	
<b>e465</b> Social norms, practices and ideologies	
<b>E5. SERVICES, SYSTEMS AND POLICIES</b>	
<b>e525</b> Housing services, systems and policies	
<b>e535</b> Communication services, systems and policies	
<b>e540</b> Transportation services, systems and policies	
<b>e550</b> Legal services, systems and policies	
<b>e570</b> Social security, services, systems and policies	
<b>e575</b> General social support services, systems and policies	
<b>e580</b> Health services, systems and policies	
<b>e585</b> Education and training services, systems and policies	
<b>e590</b> Labour and employment services, systems and policies	
<b>ANY OTHER ENVIRONMENTAL FACTORS</b>	

**Appendix 1:**

**BRIEF HEALTH INFORMATION**

Self Report                       Clinician Administered

X.1 Height : \_\_\_/\_\_\_/\_\_\_ cm (or inches)

X.2 Weight: \_\_\_/\_\_\_/\_\_\_ kg (or pounds)

X.3 Dominant Hand (prior to health condition): Left  Right  Both hands equally

X.4 How do you rate your physical health in the past month?  
Very good       Good       Moderate       Bad       Very bad

X.5 How do you rate your mental and emotional health in the past month?  
Very good       Good       Moderate       Bad       Very bad

X.6 Do you currently have any disease(s) or disorder(s) ?  
 NO                                       YES  
If YES, please specify:\_\_\_\_\_

X.7 Did you ever have any significant injuries that had an impact on your level of functioning?  
 NO                                       YES  
If YES, please specify \_\_\_\_\_

X.8 Have you been hospitalized in the last year?  
 NO                                       YES  
If YES, please specify reason(s) and for how long?  
1. \_\_\_\_\_; \_\_\_\_ . \_\_\_\_ . \_\_\_\_ days  
2. \_\_\_\_\_; \_\_\_\_ . \_\_\_\_ . \_\_\_\_ days  
3. \_\_\_\_\_; \_\_\_\_ . \_\_\_\_ . \_\_\_\_ days

X.9 Are you taking any medication ( either prescribed or over the counter)?  
 NO                                       YES  
If YES, please specify major medications  
1. \_\_\_\_\_  
2. \_\_\_\_\_  
3. \_\_\_\_\_

**X.10** Do you smoke?

NO

YES

**X.11** Do you consume alcohol or drugs?

NO

YES

*If YES, please specify average daily quantity*

Tobacco: \_\_\_\_\_

Alcohol: \_\_\_\_\_

Drugs: \_\_\_\_\_

**X.12** Do you use any assistive device such as glasses, hearing aid, wheelchair, etc.?

NO

YES

*If YES, please specify*

---

**X.13** Do you have any person assisting you with your self care, shopping or other daily activities?

NO

YES

*If YES, please specify person and assistance they provide*

---

**X.14** Are you receiving any kind of treatment for your health?

NO

YES

*If YES, please specify:*

---

**X.15** Additional significant information on your past and present health:

---

—

---

**X.16** IN THE PAST MONTH, have you cut back (i.e. reduced) your usual activities or work because of your *health condition?* (a disease, injury, emotional reasons or alcohol or drug use)

NO

YES If yes, how many days? \_\_\_\_\_

**X.17** IN THE PAST MONTH, have you been totally unable to carry out your usual activities or work because of your *health condition?* (a disease, injury, emotional reasons or alcohol or drug use)

NO

YES If yes, how many days? \_\_\_\_\_



## **Appendix 2:**

### **GENERAL QUESTIONS FOR PARTICIPATION & ACTIVITIES**

*The following probes are proposed as a guide to help the examiner when interviewing the respondent about problems in functioning and life activities, in terms of the distinction between capacity and performance. Take into account all personal information known about the respondent and ask any additional probes as necessary. Probes should be rephrased as open-ended questions if necessary to elicit greater information.*

*Under each domain there are two kinds of probes:*

*The first probe tries to get the respondent to focus on his or her **capacity** to do a task or action, and in particular to focus on limitations in capacity that are **inherent or intrinsic features of the person** themselves. These limitations should be direct manifestations of the respondent's health state, without the assistance. By **assistance** we mean the help of another person, or assistance provided by an adapted or specially designed tool or vehicle, or any form of environmental modification to a room, home, workplace and so on. The level of capacity should be judged relative to that normally expected of the person, or the person's capacity before they acquired their health condition.*

*The second probe focuses on the respondent's **actual performance** of a task or action in the person's actual situation or surroundings, and elicits information about the effects of environmental barriers or facilitators. It is important to emphasize that you are only interested in the extent of difficulty the respondent has in doing things, **assuming that they want to do them**. Not doing something is irrelevant if the person chooses not to do it.*

---

#### **I. Mobility** (Capacity)

(1) In your present state of health, how much difficulty do you have walking long distances (such as a kilometer or more) without assistance?

(2) How does this compare with someone, just like yourself only without your health condition?

(Or: "...than you had before you developed your health problem or had the accident?)

(Performance)

(1) In your present surroundings, how much of a problem do you actually have in walking long distances (such as a kilometer or more)?

(2) Is this problem walking made worse, or better, by your actual surroundings?

(3) Is your capacity to walk long distances without assistance more or less than what you actually do in your present surroundings?

## **II. Self Care**

(Capacity)

- (1) In your present state of health, how much difficulty do you have washing yourself, without assistance?
- (2) How does this compare with someone, just like yourself only without your health condition?  
(Or: "...than you had before you developed your health problem or had the accident?)

(Performance)

- (1) In your own home, how much of a problem do you actually have washing yourself?
- (2) Is this problem made worse, or better, by the way your home is set up or the specially adapted tools you use?
- (3) Is your capacity to wash yourself without assistance more or less than what you actually do in your present surroundings?

## **III. Domestic Life**

(Capacity)

- (1) In your present state of health, how much difficulty do you have cleaning the floor of your where you live, without assistance?
- (2) How does this compare with someone, just like yourself only without your health condition?  
(Or: "...than you had before you developed your health problem or had the accident?)

(Performance)

- (1) In your own home, how much of a problem do you actually have cleaning the floor?
- (2) Is this problem made worse, or better, by the way your home is set up or the specially adapted tools you use?
- (3) Is your capacity to clean your floor without assistance more or less than what you actually do in your present surroundings?

#### **IV. Interpersonal Interactions**

(Capacity)

(1) In your present state of health, how much difficulty do you have making new friends, without assistance?

(2) How does this compare with someone, just like yourself only without your health condition?

(Or: "...than you had before you developed your health problem or had the accident?)  
(Performance)

(1) In your present situation, how much of a problem do you actually have making friends?

(2) Is this problem making friends made worse, or better, by anything (or anyone) in your surroundings?

(3) Is your capacity to make friends, without assistance, more or less than what you actually do in your present surroundings?

#### **V. Major Life Areas**

(Capacity)

(1) In your present state of health, how much difficulty do you have getting done all the work you need to do for your job, without assistance?

(2) How does this compare with someone, just like yourself only without your health condition?

(Or: "...than you had before you developed your health problem or had the accident?)  
(Performance)

(1) In your present surroundings, how much of a problem do you actually have getting done all the work you need to do for your job?

(2) Is this problem fulfilling your job requirements made worse, or better, by the way the work environment is set up or the specially adapted tools you use?

(3) Is your capacity to do your job, without assistance, more or less than what you actually do in your present surroundings?

**ICF Checklist** © World Health Organization, September 2001. Page 13

## **VI. Community, Social and Civic Life**

(Capacity)

(1) In your present state of health, how much difficulty do you have participating in community gatherings, festivals or other local events, without assistance?

(2) How does this compare with someone, just like yourself only without your health condition?

(Or: "...than you had before you developed your health problem or had the accident?)

(Performance)

(1) In your community, how much of a problem do you actually have participating in community gatherings, festivals or other local events?

(2) Is this problem made worse, or better, by the way your community is arranged or the specially adapted tools, vehicles or whatever you use?

(3) Is your capacity to participate in community events, without assistance, more or less than what you actually do in your present surroundings?

## Appendix J

### QUESTIONNAIRE TO ESTABLISH CURRENT CAREGIVER TRAINING PRACTICES

1. In your own words, give a brief outline of how you manage a patient with stroke (practice and **NOT** theory) from admission till discharge

i.....  
.....  
.....

ii.....  
.....  
.....

iii.....  
.....  
.....

iv.....  
.....  
.....

v.....  
.....  
.....

vi.....  
.....  
.....

vii.....  
.....  
.....

viii.....  
.....  
.....

ix.....  
.....  
.....

2. Explain what you think the role of a caregiver is in stroke management

i.....  
.....  
.....  
.....

ii.....  
.....  
.....

iii.....  
.....  
.....

iv.....  
.....  
.....  
.....

v.....  
.....  
.....

3. In your department how do you involve caregivers in stroke management?

i.....  
.....  
.....

ii.....  
.....  
.....

iii.....  
.....  
.....

iv.....  
.....  
.....

v.....  
.....  
.....

4. How effective do you think you are as a department in involving caregivers in stroke management?

Choose your answer by ticking appropriate answer from options given below.

Not Effective       Moderately Effective       Very Effective

Not Sure

Other Criterion and explanation:

-----  
-----  
-----  
-----

5. What are challenges/constraints do you face in caregiver involvement in stroke management?

i.....  
.....  
.....

ii.....  
.....  
.....

iii.....  
.....  
.....

iv.....  
.....  
.....

v.....  
.....  
.....

## Appendix K : INFORMATION SHEET FOR PATIENTS

Dear Patient

My name is Witness Mudzi. I am a lecturer in the physiotherapy department at the University of the Witwatersrand. I am doing a study to find out what is the best way to train people who look after a person with a stroke (caregivers) so that they can do so with less difficulty. The study also looks at how well the person with a stroke and the caregiver cope at home.

I got your name from the ward to which you were admitted following your stroke. If you agree to take part in this study you will be assigned to **one** of two groups. You will be assigned to one of the two groups by choosing a marked envelope that will contain information about the group that you will belong to. Agreeing to take part in the study means agreeing to the following (depending on the group to which you are assigned).

### Group 1 (Control Group)

If assigned to Group 1, you will receive normal training for coping with your stroke like is done at the hospital. Your caregiver will be trained to look after you in the manner normally done at the hospital by the hospital staff. You will then be interviewed while still in the hospital and after discharge at 3, 6 and 12 months (at home or at the nearest clinic or hospital). The interviews will be looking at how well you walk, cope with the usual things you do at home and your satisfaction with life in general.

### Group 2 (Experimental Group)

If assigned to Group 2, you will receive normal training for coping with your stroke like is done at the hospital. Your caregiver will be trained to look after you in the manner normally done at the hospital by the hospital staff. In addition to the normal training given in the hospital your caregiver will also be given a more formal and structured training. The training will include "hands-on" training on helping you move from chair to bed, walk, prevent bed sores and manage your bowel and bladder well. Included will also be information on the causes of a stroke and how to prevent another stroke. You will then be interviewed while still in the hospital and after discharge at 3, 6 and 12 months (at home or at the nearest clinic or hospital). The interviews will be looking at how well you walk, cope with the usual things you do at home and your satisfaction with life in general.

If in Group 2, the training your caregiver will receive will be for between 30 and 45 minutes. This will be done when you are still in hospital. Those caregivers who feel need more time will be given the time they require for them to grasp the information being given.

For either group, please note that you are not obliged to take part in this study, it is voluntary. You will not be paid for agreeing to take part in the study. You can leave the study any time that you wish. Refusal to take part in the study will not affect your treatment in hospital or any other treatment sessions after discharge in any way.

I hope this study will help us come up with the best way of training caregivers of patients with stroke so that they can get better with less difficulty on the caregivers.

If you need to get in touch with me at any given moment please use the details provided below.  
Thank you for your help

Witness Mudzi (Mr.)  
Physiotherapy Department  
University of the Witwatersrand.

Phone Number : 072 858 2942 (Cell)  
: 011 717 3716 (Work)



## Appendix L: INFORMATION SHEET FOR CAREGIVERS

Dear Caregiver

My name is Witness Mudzi. I am a lecturer in the physiotherapy department at the University of the Witwatersrand. I am doing a study to find out what is the best way to train people who look after a person with a stroke (caregivers) so that they can do so with less difficulty.. The study also looks at how well the person with a stroke and the caregiver cope at home.

I got your name from..... who identified you as the person who will be looking after them when they are discharged from hospital where they are currently receiving treatment for stroke. If you agree to take part in this study you will be assigned to **one** of two groups. You will be assigned to the group that the person who identified you as their caregiver belongs to. This was done by asking them (the patient) to choose a marked envelope that contained information about the group that they belong to. Agreeing to take part in the study means agreeing to the following (depending on the group to which you are assigned).

### Group 1 (Control Group)

You will receive the normal training and information that is done and given at the hospital. You will then be interviewed while the patient is still in hospital and after patient discharge at 3, 6 and 12 months (at home or at the nearest clinic or hospital, whichever is convenient for you). The interviews will be looking at how well you are coping with looking after the person with the stroke and your general satisfaction with life.

### Group 2 (Experimental Group)

You will receive the normal training and information that is done and given at the hospital. In addition to the normal training given in the hospital you will then be given a more formal and structured training. The training will include "hands-on" training on how you can help the person with a stroke to move from chair to bed, walk, prevent bed sores and to manage their bowel and bladder. You will also be given information on the causes of a stroke and how to prevent another stroke. You will be interviewed while the patient is still in the hospital and after the patient is discharged at 3, 6 and 12 months (at home or at the nearest clinic or hospital). The interviews will be looking at how well you are coping with looking after the person with the stroke and your general satisfaction with life.

If in Group 2, the training you will receive will be for between 30 and 45 minutes. This will be done when the patient is still in hospital. Those who feel need more time will be given the time they require for them to grasp the information being given.

For either group, please note that you are not obliged to take part in this study, it is voluntary. You will not be paid for agreeing to take part in the study. You can leave the study any time that you wish. Refusal to take part in the study will not affect you in any way. Your refusal to take part will also not affect your relative (the patient)'s treatment in hospital or any other subsequent treatment sessions after their discharge in any way.

I hope this study will help us come up with the best way of training caregivers of patients with stroke so that they can get better with less difficulty on the caregivers.

If you need to get in touch with me at any given moment please use the details provided below.  
Thank you for your help

Witness Mudzi (Mr.)  
Physiotherapy Department  
University of the Witwatersrand.

Phone Number : 072 858 2942 (Cell)  
: 011 717 3716 (Work)

## Appendix M

### CONSENT FORM FOR CARE GIVERS

I ..... have read the information sheet and agree to take part in the study being conducted by Mr. W. Mudzi. By signing this form (if in group 2, experimental group) I am agreeing to be given additional training on how to look after my relative who had a stroke. I am also agreeing (for group 1 and 2) to be interviewed about 4 times (when my relative is still in hospital and at 3, 6, and 12 months after discharge from hospital) on how well I will be coping with looking after my relative with stroke and general satisfaction with life.

I understand that there are no monetary rewards for my participation and that I am not obliged to take part and can withdraw from the study at any time. I also understand that this will not affect the medical treatment of my family member (relative) in any way.

Signed:.....

Witness:.....

Date:.....

## Appendix N

### CONSENT FORM FOR PATIENTS

I ..... have read the information sheet and agree to take part in the study being conducted by Mr. W. Mudzi. By signing this form I am agreeing to being interviewed about 4 times (in hospital and at 3, 6, and 12 months after my discharge from hospital) on how well I will be coping at home and my satisfaction with life in general. I am also agreeing to provide the name of the person who will be looking after me following discharge so that they can be asked to join the research if they want.

I understand that there are no monetary rewards for my participation and that I am not obliged to take part and can withdraw from the study at any given time. I also understand that this will not affect my medical treatment in any way and refusal to participate will not prejudice me in any way.

Signed:.....

Witness:.....

Date:.....

## Appendix O

### INFORMATION SHEET FOR PHYSIOTHERAPISTS

Dear Colleagues

My name is Witness Mudzi. I am a lecturer in the physiotherapy department at the University of the Witwatersrand. I am doing a study to find out what is the best way to train people who look after a person with a stroke (caregivers) so that they can do so with less difficulty. The study also looks at how well the person with a stroke and the caregiver cope at home.

I got your name through the Physiotherapy Head of Department. As part of the study, I need to find out what is currently being done as regards training of caregivers on how to look after patients with stroke in the hospital. This information will be used to see areas, which we can improve on and also identify the problems encountered when trying to teach caregivers how to look after their relatives suffering from stroke.

All you will need to do is answer questions on the current programme being used in the department (if it is there) and maybe identify some of the problems that make teaching relatives of stroke survivors how to look after the stroke survivors difficult.

You are not obliged to take part in this study, it is voluntary. You will not be paid for agreeing to take part in the study. Refusal to take part in the study will not affect you in any way.

I hope this study will help us come up with the best way of training caregivers of patients with stroke so that they can get better with less difficulty on the caregivers.

If you need to get in touch with me at any given moment please use the details provided below.  
Thank you for your help

Witness Mudzi (Mr.)  
Physiotherapy Department  
University of the Witwatersrand.

Phone Number : 072 858 2942 (Cell)  
: 011 717 3716 (Work)

## Appendix P

### CONSENT FORM FOR PHYSIOTHERAPISTS

I ..... have read the information sheet and agree to take part in the study being conducted by Mr. W. Mudzi. By signing this form I am agreeing to being interviewed on the current status of teaching of caregivers how to look after their relatives suffering from stroke.

I understand that there are no monetary rewards for my participation and that I am not obliged to take part and can withdraw from the study at any given time.

Signed:.....

Witness:.....

Date:.....

## Appendix Q

### INITIAL QUESTIONNAIRE FOR PATIENT'S DEMOGRAPHIC DATA- isiZulu Version

#### IPHEPHA LEMIBUZO LOKUQALA LEMININGWANE YEZIGULI EPATHELENE NALA ZIHLALA KHONA

Igama: .....Usuku:.....  
Usuku lokuzalwa: ..... Ubudala: .....  
Ikheli:.....  
.....  
.....  
Usuku lwe-stroke:.....  
Usuku lokulaliswa:.....

1. Uhlobo lwe-stroke:

- 1.1 I-stroke sokuqala?  YEBO  CHA
- 1.2 Uhlangothi lomzimba oluthintekayo:  Kwesokhohlo  Kwesokudla
- 1.3 Uhlobo lwe-stroke:
- Lokuqhunyelwa umthambo/Haemorrhagic
- Lokuvimbeleka kwegazi emithanjeni/Infarct

1.3.1 Uhlotshana lwe-stroke esidalwa ukuphazamiseka kokuhamba kwegazi/Ischaemic Stroke Subtype

- Ukufelwa yizicubu kwanganeno okuphelele/Total Anterior Infarct
- Ukufelwa yizicubu kwanganeno okuyingxenywe/Partial Anterior Infarct
- Ukufelwa yizicubu zangemuva/Posterior Infarct
- Ukufa lwezicubu okudalwa yimbobo/Lacunar Infarcts

2. Ubulili:  Owesilisa  Owesimame

3. Isimo sokusebenza ngenkathi ka nhlangothi:

- Bengisebenza

- Bengizisebenza mina
- Bengingasebenzi
- Bengimpeshile
- Bengemukela isondlo/isibonelelo
- Okunye: Balula.....

4. Isimo sokushada:

- Angishadile
- Ngishadile
- Ngehlukanisile
- Sihlala ngokhlukana
- Ngikipitile
- Okunye: Balula .....

5. Imibandela yokunakekelwa:

- Ngihlala ngedwa (Anginamnakekeli)
- Umnakekeli uba khona emini
- Umnakekeli uba khona ngokuhlwa kuphela
- Umnakekeli uba khona sonke isikhathi

6. Ubudlelwano nomnakekeli

- Umlingani
- Umngane
- Isihlobo
- Umakhelwane
- Okunye: Balula.....

7. Izinga lemfundo ephothuliwe:

- Iziqu zaseNyuvesi
- Isigaba 12 + 3 noma eminye iminyaka ngaphezulu
- Isigaba 12 kumbe okuthi kakufane naso
- Ngifike kusigaba 11
- Ngifike kusigaba 7

8. Uhla lwamaphuzu obucayi:

YEBO CHA

- Ngiyabhema: Shono inani ngosuku .....
- isifo sikaShukela
- Isifo senhliziyo
- i-Hyperlipidaemia/ cholesterol
- i-I-Hypertension
- Ngikhuluphele (BMI 25 – 29.9) Ubude.....Isisindo..... BMI.....
- Okunye: Balula.....

9. Isimo sokuzenzela ngaphambi kokugogwa ukugula (Premorbid functional status)

- Uyazenzela konke okwenziwayo mayelana nempilo yansuku zonke (ama ADL)
- Udinga ukusizwa ngokwenziwa mayelana nempilo yansuku zonke (ADL)
- Okunye: Balula.....

10. Ukuhlolwa okuyisisekelo kwesiguli (Baseline Patient Assessment):

Ukulawula ukuzikhulula:

Isinye:  Yebo  Cha

Amathumbu:  Yebo  Cha

Ukukhubazeka okukhulu kokukhuluma (Angikwazi nhlobo ukukhuluma):  Yebo  Cha

Ukukhubazeka okukhulu komqondo:  Yebo  Cha

Ukukhubazeka okukhulu kokubona:  Yebo  Cha

Ezinye izigulo ezikhona ngaphezu kwalezi?



INhliziyo:  Yebo  Cha

Amaphaphu:  Yebo

Cha

Ezinye izigulo zemizwa ezikhona ngaphezu kwalezi?

Isithuthwane:  Yebo  Cha

Ukulimala ekhanda  Yebo  Cha

Noma ibuphi ubufakazi bokungelapheki:

Yebo  Cha

## Appendix R

### SUBSEQUENT QUESTIONNAIRE FOR PATIENT'S DEMOGRAPHIC DATA

(At 3, 6 and 12 months post discharge) - isiZulu Version

#### UHLA LWEMIBUZO OLULANDELAYO OLUPHATHELENE NEMININGWANE YALA KUHLALA KHONA ISIGULI

(Emva kwezinyanga ezi 3, 6 ne 12 sidedelwe)

Igama: ..... Usuku:.....

Usuku lokuzalwa: ..... Ubudala: .....

Ikheli:.....

.....

.....

Usuku lwe-stroke:.....

Usuku lokulaliswa:.....

#### 1. Uhlobo lwe-stroke:

1.1 I-stroke sokuqala?  YEBO  CHA

1.2 Uhlangothi lomzimba oluthintekayo:  Kwesokhohlo  Kwesokudla

1.3 Uhlobo lwe-stroke:

Sokuqhunyelwa yimithambo/Haemorrhagic

Sokufelwa yizicubu/Infarct

#### 1.3.1 Uhlotshana lwe-stroke esidalwa ukuphazamiseka kokuhamba kwegazi/ Ischaemic Stroke Subtype

Ukufelwa yizicubu kwanganeno okuphelele/Total Anterior Infarct

Ukufelwa yizicubu kwanganeno okuyingxenye/Partial Anterior Infarct

Ukufelwa yizicubu zangemuva/Posterior Infarct

Ukufa lwezicubu okudalwa yimbobo/Lacunar Infarcts

2. Ubulili:  Owesilisa  Owesimame

#### 3. Isimo sezimali nesokusebenza :

3.1 Kungabe isimo sakho sezimali sesishintshile yini ngenxa yokuphathwa kwakho yi- stroke:

Yebo  Cha

3.2 Kungabe uyaluthola usekelo lwezimali?  Yebo  Cha

Uma uthu yebo, siza ucacise:

Isondlo sokukhubazeka

- Umhlalaphansi
- UIF (isondlo sabangasasebenzi)
- Okunye: Balula.....

3.3 Imininingwane yokusebenza

- Ngiyasebenza
- Ngiyazisebenza
- Bengingasebenzi
- Ngimpeshile
- Ngemukela isondlo/isibonelelo
- Okunye:  
Balula.....

4. Isimo sokushada:

- Angishadile
- Ngishadile
- Ngehlukanisile
- Sesihlala ngokhlukana
- Ngikipitile
- Okunye: Balula .....

5. Isimo sokunakekelwa:

- Uhlala yedwa (Akanaye umnakekeli)
- Umnakekeli uba khona emini
- Umnakekeli uba khona ngokuhlwa kuphela
- Umnakekeli uba khona sonke isikhathi

6. Ubudlelwano nomnakekeli

- Umlingani
- Umngane
- Isihlobo
- Umakhelwane
- Okunye:  
Balula.....

7. Isimo mayelana nala uhlala khona nesasekhaya:

- Umuzi wakho
  - Uqashile
  - Kusemjondolo
  - Kunamanzi agelezayo
  - Kunogesi
  - Kunendlu yangasese engaphakathi
  - Kunendlu yangasese engaphandle
  - Nginombhede wami
  - Umhlaba uyalingana (egcekeni)
  - Umhlaba awulingani (egcekeni)
  - Kunezitebhiso
  - Akunazitebhiso
  - Okunye:
- Balula.....

8. Ulwazi lwamaphuzu obucayi:

YEBO CHA

- Ukubhema: Shono inani ngosuku .....
- Isifo sikashukela
- Isifo senhliziyo
- Hyperlipidaemia/ cholesterol
- I-Hypertension
- Nginesisindo esikhulu/Ngikhuluphele (BMI ka >25)
- Okunye: Balula.....

9. Ukuhlolwa kwesiguli kokulandela:

- Ukulawula ukuzikhulula: Isinye:  Yebo  Cha  
 Amathumbu:  Yebo  Cha  
Ukukhubazeka okukhulu ngokolimi:  Yebo  Cha  
Ukukhubazeka okukhulu komqondo:  Yebo  Cha  
Ukukhubazeka okukhulu kokubona:  Yebo  Cha  
 Ezinye izigulo ezikhona ngaphezu kwalezi?  
 Ihhliziyo:  Yebo  Cha  
 Amaphaphu:  Yebo  Cha  
 Ezinye izigulo zemizwa ezikhona ngaphezu kwalezi?  
 Isithuthwane:  Yebo  Cha  
 Ukulimala ekhanda:  Yebo  Cha  
 Noma ibuphi ubufakazi bokungelapheki:  Yebo  Cha

10. Izingqinamba ezinhlanu ezimqoka (uma zikhona) ohlangabezana nazo:

- i).....  
 ii).....  
 iii).....  
 iv).....  
 v).....

## Appendix S

### INITIAL AND SUBSEQUENT QUESTIONNAIRE FOR CAREGIVER'S DEMOGRAPHIC DATA - isiZulu Version

#### UHLA LWEMIBUZO LOKUQALA NOLOKULANDELISA OLUPHATHELENE NEMININGWANE YALA KUHLALA KHONA UMNAKEKELI

Igama: ..... Usuku:.....  
Usuku lokuzalwa: ..... Ubudala: .....  
Ikheli:.....

1. Ubulili:  Owesilisa  Owesimame

2. Isimo somsebenzi:

- Ngiyasebenza
- Ngiyazisebenza
- Bengingasebenzi
- Ngimpeshile
- Ngemukela isondlo/isibonelelo
- Okunye: Balula.....

3. Isimo sokushada:

- Angishadile
- Ngishadile
- Ngehlukanisile
- Sesihlala ngokhlukana
- Ngikipitile
- Okunye: Balula .....

4. Isimo sasemndenini:

- Uhlala wedwa (Awekho amanye amalungu omndeni)
- Uhlala nezingane : nikeza inani.....
- Uhlala nabanye abadala : nikeza inani .....
- Usizwa amanye amalungu omndeni ngonakekelo

5. Izinga lemfundo ephothuliwe:

- Iziqu zaseNyuvesi
- Isigaba 12 + eminye iminyaka emi 3
- Isigaba 12 kumbe okunye okuthi akulinganiswe naye

- Ngize ngafika kusigaba 11
- Ngize ngafika kusigaba 7

8. Imininingwane ngendawo yokuhlala

- Umuzi wakho
- Uqashile
- Kusemjondolo

9. Umumo wendawo yasekhaya

- Kunamanzi agelezayo
- Kunogesi
- Kunendlu yangasese engaphakathi
- Kunendlu yangasese engaphandle
- Nginombhede wami
- Umhlaba uyalingana (egcekeni)
- Umhlaba awulingani (egcekeni)
- Kunezitebhiso
- Akunazitebhiso
- Okunye: Balula.....

8. Ulwazi ngamaphuzu abucayi kwi-stroke:

YEBO CHA

- Ukubhema
- Isifo sikashukela
- Isifo senhliziyo
- i-Hyperlipidaemia/ cholesterol
- I-Hypertension

- Ukukhuluphala  
 Okunye: Balula.....

## **Appendix T** **Barthel Index – isiZulu Version**

### **i-INDEKSI KA- BARTHEL YOKWENZA OKUHAMBISANA NEMPILO YANSUKU ZONKE (I-ADL)**

*Amathumbu*      0 = ukuhluleka ukuzilawula (kumbe udinga ukuchathwa)  
                         1 = ingozi ethe gqwa (kanye ngesonto)  
                         2 = uyakwazi ukuzilawula

*Isinye*            0 = uyehluleka ukuzilawula, kumbe usebenzisa ikhathetha futhi awukwazi ukuzenzela  
                         uwedwa  
                         1 = ingozi ethe gqwa (akudluli kusikhawu esisodwa emahoreni angama 24)  
                         2 = uyakwazi ukuzilawula



- Ukuzicwala*      0 = udinga usizo ngokuzilungisa  
1 = uyazilungisa ubuso/izinwele/amazinyo/ukushefa (iziilungisi zihlinzekiwe)
- Ukusebenzisa indlu yangasese*  
0 = udinga ukwelekelwa  
1 = udinga ukwelekelwa okuthize, kodwa kukhona okwazi ukuzenzela ngokwakho  
2 = awudingi ukwelekelwa (kuyaguqu-guquka, ukuziqokisa, ukuzesula)
- Ukuzifunza*      0 = awukwazi  
1 = udinga usizo ukusika, ukugcoba ibhotela, etc.  
2 = awudingi ukwelekelwa
- Ukuzithutha (kusuka embhedeni kuya esihlalweni nokubuya)*  
0 = awukwazi, angikwazi ukuzihlalela  
1 = Kudingakala usizo olukhulu (lomuntu oyedwa kumbe ababili, izikhwepha)  
2 = Kudingakala usizo oluncane (ngenkulumo kumbe ngezikhwepha)  
3 = awudingi ukwelekelwa
- Ukunyakaza*      0 = akunyakazeki  
1 = udinga usizo lwesihlalo esihambayo, kumbandakanya amajika  
2 = uhamba ngokwelekelwa umuntu oyedwa (ngenkulumo kumbe ngezikhwepha)  
3 = awudingi ukwelekelwa (kepha ungayisebenzisa noma iyiphi insiza; isibonelo, dondolo)
- Ukugqoka*      0 = udinga ukwelekelwa  
1 = udinga usizo kepha uyakwazi ukugqoka isigamu ngaphandle kosizo  
2 = awudingi ukwelekelwa (kumbandakanya izinkinobho, awoziphu, imichilo, njalo njalo.)
- Izitebhiso*      0 = awukwazi  
1 = udinga usizo (ngenkulumo, ngezikhwepha, nosizo lokuthwalwa)  
2 = awudingi ukwelekelwa
- Ukuzigeza*      0 = udinga ukwelekelwa  
1 = awudingi ukwelekelwa (kumbe eshaweni)
- sekukonke 0-20 **Total...../20**

## Appendix U

### RIVERMEAD MOBILITY INDEX – isiZulu Version

#### i-INDEKSI YASE RIVERMEAD YOKUNYAKAZA

**Imiyalelo:** Isiguli sibuzwa imibuzo eyi 15 bese siqashelwa (kwenzwelwa uhlamvu 5). Uma impendulo kungu yebo kunikezwa iphuzu lika 1. Qaphela ukuthi eminingi idinga umuntu angaleklelwa, kepha indlela yokwenza kayimqoka kangako.

Q	Umbuzo	Yebo	Cha
1	Ukuguquka embhedeni Kungabe uyaguquka ulele ngomhlane uguqukele ecaleni ngaphandle kosizo		
2	Ukuvuka uhlale kade ulele Uma klade ulele embhedeni, uyavuka uzisondelele kunqenqema lombhede ungabambelele kuze kuphele imizuzwana eyi 10		
3	Ukuzimelela uhlezi Kungabe uyahlala onqenqemi lombhede ngaphandle kokubambelela kuphele imizuzwana eyi 10		
4	Ukuhlala kade umile Uyasukuma kade uhlezi (kunoma isiphi isihlalo) ngaphansi kwemizuzwana eyi 15, bese uma lapho imizuzwana eyi 15 (usebenzisa izndla, noma insiza uma kunesidingo)?		
5	Ukuma ungesekelwe lutho Ume imizuzwana eyi 10 ngaphandle kwensiza kumbe usekelo		
6	Ukuthutha Kungabe uyakwazi ukuzisukela e.g. embhedeni uye esihlalweni ngaphandle kokusizwa?		
7	Ukuhamba ngaphakathi, ngenzisa uma kunesidingo Uyawuhamba u- 10m, ngenzisa kumbe ngefenisha uma kunesidingo, kepha ngaphandle kosizo oluhlala lucuphele lokho?		
8	Izitebhiso Uyakwazi ukukhuphuka izitebhiso ngaphandle kosizo?		
9	<i>Ukuhamba ngaphandle (even ground)</i> Kungabe uhamba around outside, on pavements ngaphandle kosizo?		
10	Ukuhamba ngaphakathi, ngaphandle kwensiza Kungabe uhamba 10m ngaphandle kwe-calliper, udondolo kumbe ifenisha, kumbe usizo oluhlala lucuphile?		
11	Ukucosha phansi Uma uwisa utho phansi, kungabe uyakwazi ukuhamba 5m, uyicoshe bese uphinda emuva futhi?		
12	<i>Ukuhamba ngaphandle (kwiphansi elingalingani)</i> Kungabe uhamba kwiohansi elingalingani (utshani, inhlabathi, obhuqwini nokunye etc) ngaphandle kosizo?		
13	Ukuzigeza Uyangena/uphume ebhavini kumbe eshaweni ungabhekwe muntu futhi uzigeze?		
14	Ukwenyuka wehle izitebhiso ezine Uyakwazi ukwenyuka wehle izitebhiso ezine ezingenasibambelelo futhi ngaphandle kosizo, kepha usebenzisa insiza uma kunesidingo?		
15	Ukugijima Kungabe uyawugijima u 10m ngaphandle kokuxhuga ngemizuzwana emi 4 (ukuhamba usheshe nakho kwemukelekile)?		

Total...../15

Isimo sempilo  
esihle kakhulu  
ongasicabanga

100

## Appendix V

### The EuroQol (Eq-5D) Health Questionnaire (South African isiZulu Version)

Ngokufaka uphawu ebhokisini elilodwa kulelo nalelo qoqo elingezansi, sicela ukhombise ukuthi yisiphi isitatimende esichaza kahle kakhulu isimo sempilo yakho namhlanje.

#### Ukuhamba/ukunyakaza

Anginazinkinga ukuzihambahambela

Nginezinkinga ezithile ukuzihambahambela

Ngihlala ngisembhedeni/ngisocansini

#### Ukuzinakekela

Anginazinkinga ngokuzinakekela

Nginezinkinga ezithile zokuzigeza noma ukuzigqokisa

Angikwazi ukuzigeza noma ukuzigqokisa

**Imisebenzi ejwayelekile** (*isibonelo: ukusebenza, ukutadisha, umsebenzi wasendlini, imisebenzi yomndeni noma eyokungcebeleka*)

Anginazinkinga ukwenza imisebenzi yami eyejwayelekile

Nginezinkinga ezithile ukwenza imisebenzi yami eyejwayelekile

Angikwazi ukwenza imisebenzi yami eyejwayelekile

#### Izinhlungu/ukungaphatheki kahle

Anginazinhlungu noma ukungaphatheki kahle

Nginezinhlungu noma ukungaphatheki kahle okulingene nje

Nginobuhlungu obedlulele nokungaphatheki kahle

#### Ixhala/ukudangala

Anginalo ixhala noma ukudangala

Nginexhala noma ukudangala okulingene nje

Nginexhala nokudangala ngokweqile

90

80

70

60

50

40

30

20

10

0

Isimo sempilo  
esimbi kakhulu  
ongasicabanga

Ukuze sisize abantu basho ukuthi isimo sempilo yabo sihle noma sibi kangakanani, sidwebe isikali (esifana netemometha)okuqoshwe kuso isimo esihle kakhulu ongase usicabange sabekwa ku 100 naleso esibi kakhulu saba ku- 0.

Singathanda ukuba ukhombise kulesi sikali ukuthi yinhle noma yimbi kangakanani impilo yakho namhlanje, ngokwakho ukubona. Siza wenze lokhu ngokudweba umugqa osuka ebhokisini ngezansi uye kunoma yiliphi izinga esikalini elikhombisa ukuthi sihle noma sibi kangakanani isimo sempilo yakho namhlanje.

**Isimo sakho**

**Sempilo  
namhlanje**

Ngenxa yokuba izimpendulo azaziwa ukuthi zivela kobani, kuzosisiza ukuqonda izimpendulo zakho kangcono uma singaba neminingwane ngalowo nalowo muntu njengoba izoqoqwa ngale mibuzo elandelayo.

1. Sewake wahlangabezana nokugula okukhulu? Yebo Qha *Sicela ufake Uphawu Emabhokisini afanele*
  - kuwena uqobo lwakho*
  - emndenini wakho*
  - ekunakekeleni abanye*
  
2. Uneminyaka emingaki?
  
3. Ngabe: Ungowesilisa Ungowesifazane *sicela ufake uphawu ebhokisini elifanele*
  -
  
4. Ngabe:
  - uyabhema njengamanje*  SICELA UFAKE UPHAWU
  - wawubhema*  EBHOKISINI ELIFANELE
  - awukaze ubheme*
  
5. Uyasebenza manje, noma wake wasebenza kwezempilo noma kwezenhlalakahle? Yebo Qha SICELA UFAKE UPHAWU EBHOKISINI ELIFANELE
  -
  
- Uma kunjalo, kusiphi isikhundla?.....
  
6. Yikuphi kulokhu okulandelayo okuwuchaza kahle umsebenzi okuyiwonawona owenzayo?
  - Uqashiwe noma uyazisebenza*  SICELA UFAKE UPHAWU
  - Sewathatha umhlalaphansi*  EBHOKISINI ELIFANELE
  - Umsebenzi wasendlini*
  - ungumfundi*
  - ufuna umsebenzi*
  - okunye (siza ubalule)*  .....
  
7. Wafunda wagcina kuliphi ibanga? Yebo Qha SICELA UFAKE UPHAWU EBHOKISINI ELIFANELE
  -
  
8. Unazo iziqu zezemfundo noma okulingana nazo okungulwazi lobungcweti? Yebo Qha SICELA UFAKE UPHAWU EBHOKISINI ELIFANELE
  -
  
9. Uma uyazi ikhodi yeposi lakho, ungasiza ngokuyibhala lapha

## Appendix W

### THE CAREGIVER STRAIN INDEX – isiZulu Version

#### I-NDEKSI YOKUGQILAZEKA KOMNAKEKELI

Iphuzu: 'Yebo' = 1 'Cha' = 0

"Ngizofunda uhla lwezinto abanye abantu abaye bazithole kunzima ukusiza ngazo emveni kokuba umuntu ebuyele ekhaya ekade esesibhedlela." (noma)

"Ngizofunda uhla lwezinto abanye abantu abaye bazithole zinzima lapho belekelela onesigulo."

"Ngicela ukuba ungitshele ukuthi kuyenzeka yini lokhu kuwe? (nikeza izibonelo)

- 
- Ukuphazamiseka kokulala (e.g. ngoba.....ude ephuma engena embhedeni kumbe eyaluzab busuku).
  - Akumnandi (e.g. ngoba ukusiza kuthatha isikhathi esiningi kumbe ngishayela ibanga elide uma ngizosiza).
  - Kuyangikhandla emzimbeni (e.g. ngenxa yokuphakamisa ngibuye ngibeke umuntu esihlalweni; kudingeka amandla nokugxila).
  - Kuyavalelana (e.g. ukusiza kungincisha isikhathi, kumbe angikwazi ukuvakasha).
  - Kuye kwaba nezinguquko emndenini (e.g. ngoba ukusiza kuye kwaphazamisa uhlelo oluvamile; akukho ngasese).
  - Kube nezinguquko kuzinhlelo eziqondene nabantu (e.g. kuye kwafanela ngingqabe umsebenzi; kangikwazanga ukuya ekhefini/eholidini).
  - Kuye kwaba nezinye izimfuno ngesikhathi sami (e.g. kwamanye amalungu omndeni).
  - Kuye kwaba khona izinguquko ngemizwa (e.g. ngenxa yokuhilizisana okukhulu).
  - Okunye ukwenza kuphathana kabi (e.g. ngenxa yokungakwazi ukulawula ukuzikhulula;..... Uyakhohlwa; kumbe ..... ubeka abantu amacala okuthatha izinto ezithize).
  - Kuyangikhuba ukubona u ..... eseshintshe kangaka kwebengimazi eyikho (e.g. usengomunye umuntu).
  - Kuye kwadingeka ngenze izinguquko emsebenzini (e.g. ngoba kufanele ngithathe isikhathi ngingasebenzi).
  - Kuyagqilaza ngakwezezimali.
  - Ngizithola ngigubuzelekile impela (e.g. ngoba ngikhathazekile ngo .....; ngenxa yokuhlala ngicabanga ukuthi uzozenzela kanjani izinto).
  - /13 Sekukonke

## Appendix X

### THE ICF CHECK LIST – isiZulu Version

#### Uhlu lokuhlunga (ICF Checklist)

##### *Ihumusho 2.1a oluyifomu yocwaningo*

esetshenziswa emhlabeni wonke ukuhlunga ukusebenza, ukukhubazeka nesimo sempilo yomuntu.

Lokhu kuwuhlu lokuhlunga izigaba ezinkulu zomhlala wonke, ekuhlungeni ukusebenza, ukukhubazeka nesimo sempilo yomuntu (ICF), enhlanganweni yomhlaba ebhekelele isimo sempilo ebizwa ngokuthi yi-World Health Organisation (WHO). Lolu luhlu luyisikhali esisiza kakhulu ekucubunguleni nasekuqopheni ulwazi, olumayelana nokusebenza nokukhubazeka kwalowo nalowo muntu ngamunye. Lolu lwazi lungaqoqwa lusetshenziswe kubantu ngokwehlukana (njengasekuphileni kwabantu nakwenhlalakahle) Lolu luhlu lungasetshenziswa luhambisane nohlu lokuhlunga (ICF) noma i-ICF Pocket Version.

Uma ugcwalisa lolu lezi zinhl, sebenzisa lonke ulwazi noma imininingwane ekhona: Qaphelisa lolu lwazi olusetshenzisiwe: [1] okuqoshwe phansi [2] umphenduli wokuqala [3]omunye onolwazi ngubuzwayo [4] ulwazi ozitholele lona

Uma umhlalo wezokwelapha ungekho uyelulekwa ukuthi uqedele ukugcwalisa ngokuthi usebenzise isixhumelo/ isijobelele 1: Ulwazi olufingqiwe ngempilo (ikhasi 9 -10) okungagcwaliswa ngumphenduli.

H2. Usuku \_\_\_/\_\_\_/\_\_\_ Usuku inyanga unyaka H3 Inombolo yokwenziwe \_\_\_/\_\_\_/\_\_\_  
CE or CS case no. Ukuhlola kokuqala noma kwesibili  
H4. Inombolo obambe iqhaza \_\_\_/\_\_\_/\_\_\_  
FTC Site Obambe iqhaza

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### **INGXENYE 2 UKUGQINDEKA KOKUSEBENZA NOKUBAMBA IQHAZA OKUNGAPHELELE**

- Ukusebenza: Ukwenza umsebenzi komuntu othile, Ukubamba iqhaza ukuba nesandla uma kwenziwa okuthile ekuphileni.
- Ukungqindeka kokusebenzi: wubunzima ekufezeni umsebenzi, Ukubamba iqhaza okungaphelele yinkinga umuntu ahlangani nayo eyenza ukuthi angabi nesandla uma kwenziwa umsebenzi nasekuphileni

Okuchaza ukusebenza okwenziwa kusho ukuchaza okwenziwa ngothile endaweni nasesimeni esiphila kusona. Ngenxa yokuthi isimo esiphila kusona sibandakanya impilo yomphakathi abahlala nawo. Ukwenza kungachazwa "njengokubalwa ekuqhubekeni kwesimo sempilo. "noma" "amava okuphila." kwabantu lapho bephila khona. Lesi simo sifaka phakathi nesimo senhlalo esikungezungezile kuwo wonke amacala (aspects) okuphila; ngokwenyama, enhlalweni nasendleleni okubhekwa ngayoizinto ezingabalwa njengezinto eziithinta isimo sezenhlalo.

Okuchazwa yizinga lokusebenza kusho ukuchaza ukukwazi komuntu ukufeza indima ethile noma izinga lokwenza okuthile. Lokhu kuchazwa noma kukhomba izinga eliphakeme umuntu angase afinyelele kulo ekufezeni indima ayinikwe (ayibekelwe) esikhathini esithile. Ukuze ukwazi ukufaka esilinganisweni ngokuphelele, udinga isikali esiqoqele ndawonye zonke izimo ezenza umehluko lapha nalaphaya emandleni alowo osebenza leyo ndima. Isilinganiso esifaka konke singaba (a) yisimo lesi esejwayelekile esiyisikali sokuhlola isimo; noma (b) uma loku kungenakwenzeka, kwakhiwa yisimo esicishe sisebenze ngokufaka konke.

**Qaphela:** Sebenzisa isengezo 2, uma kudingekile ukuthi uthole ulwazi ngokusebenza nangokuzibandakanya. Komuntu

<b>Ukuchaza kokuqala kokusebenza Izinga lokungapheleli ukubamba iqhaza.</b>	<b>Ukuchaza kwesibili: Izinga (engasizwa) lokungqindeka lokusebenza.</b>
0. Akunabunzima 1. Buncane ubunzima 2. Akunzima kakhulu 3. Kunzima kakhulu 4. Kunzima kuyilitshe 8. Akuchazisisiwe 9. Kakudingeki.	0. Akunabunzima 1. Buncane ubunzima 2. Akunzima kakhulu 3. Kunzima kakhulu 4. Kunzima kuyilitshe 8. Akuchazisisiwe 9. Kakudingeki

<b>Uhla olufishane lokusebenza nokubamba iqhaza</b>	<b>Ukuchaza Ukwenza</b>	<b>Ukuchaza izinga</b>
<b>d1. UKUFUNDA NOKUSEBENZISA ULWAZI</b>		
<b>d110</b> Ukubhekisa		
<b>d115</b> Ukulalela		
<b>d140</b> Ukuzifundisa umbhalo		
<b>d145</b> Ukuzifundisa ukubhala		
<b>d150</b> Ukuzifundisa ukubala		
<b>d170</b> Ukuxazulula izinkinga		
<b>d.2. IMISEBENZI EYEJWAYELEKILE NOKUKHANDLEKA</b>		
<b>d210</b> Ukuthawala umsebenzi owodwa		
<b>d220</b> Ukuthwala imisebenzi eminingi		
<b>d.3. UKUXHUMANA</b>		
<b>d310</b> Ukuxhumana-ukwamukela-umbiko owethulwe ngomlomo		
<b>d315</b> Ukuxhumana-ukwamukela- umbiko ongethuliwe ngomlomo		
<b>d330</b> Ukukhuluma		
<b>d335</b> Ukudlulisa umlayezo ongethuliwe ngomlomo		
<b>d350</b> Ingxoxo		
<b>d4. UMNAYAKAZO</b>		
d430 Ukufukula nokuthwala izinto		
d440 Ukusebenzisa isandla (ukucosha nokubamba)		
d450 Ukuhamba		
d465 Ukuhambahamba ngosizo lwezinto (ukuhamba ngesihlalo samasondo nokunye)		
d470 Ukusebenzi isithuthi (imoto, ibhasi, indiza, isitimela nokunye)		
<b>d5. UKUZINAKA</b>		
<b>d510</b> Ukugeza (ukuhlamba, ukuzesula, ukuhlamba izandla nokunye)		
<b>d520</b> Ukunaka izitho zomzimba (ukuxubha amazinyo, ukushefa nokulungisa ikhanda)		
<b>d530</b> Ukuzikhulula		
<b>d540</b> Ukwembatha		
<b>d550</b> Ukudla		
<b>d560</b> Ukuphuza		
<b>d570</b> Ukunakekela impilo yonke		
<b>d6. IMPILO YASEKHAYA</b>		
<b>d620</b> Ukuqoqa impahla nokuyinakekela (ukuthenga nokunye)		
<b>d630</b> Ukwenza ukudla (ukupheka nokunye)		
<b>d640</b> Ukusebenza endlini (ukuhlaza indlu, izitsha, izingubo nokunye)		
<b>d660</b> Ukusiza abanye		
<b>d7. UKUBHOBOKELANA UKWAKHA UBUHLOBO NOKUSEBENZISANA</b>		



<b>d710</b> Ukuxoxisana okulula		
<b>d720</b> Ukuxhumana okujulile		
<b>d730</b> Ukuxhumana nongabazi		
<b>d740</b> Ukwazana kahle		
<b>d750</b> Ukwazana ngokuhlangana nje		
<b>d760</b> Ubuhlobo basemndenini		
<b>d770</b> Ubuhlobo bezithandani		
<b>d8. IZIGABA EZIBALULEKILE ZEMPILO</b>		
<b>d810</b> Imfundo okungesiyo yasesikoleni		
<b>d820</b> Imfundo yasesikol'eni		
<b>d830</b> Imfundo ephakemeyo		
<b>d850</b> Umsebenzi okuholelayo		
<b>d860</b> Ukuqondisisa okulula ngomnotho		
<b>d870</b> Ukuzimela ngokomnotho		
<b>d9. UMPHAKATHI, UKUHLALISANA NEMPUCUKO</b>		
<b>d910</b> Impilo emphakathini.		
<b>d920</b> Ukudlala nokuzijabulisa		
<b>d930</b> Inkolo nezomoya		
<b>d940</b> Amalungelo esintu		
<b>d950</b> Ezepolitiki nezezakhamuzi		
<b>EMINYE IMISEBENZI NOKUBAMBA IQHAZA</b>		

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**INGXENYE 3: AMAPHUZU NGENDAWO OPHILA KUYO**

- ***Amaphuzu ngendawo ophila kuyo. Isimo sokomzinba, ukuhlungana kwabantu nendlela abathatha ngayo izinto konke kwakha isimo esikhuthaza indlela yokuphila.***

***Incazelo ngendawo noma endaweni:  
Izivimbelo noma okukhuthazayo***

- |                         |                            |
|-------------------------|----------------------------|
| 0. Azikho izivimbelo    | 0. Azikho izikuthazo       |
| 1. Zincane izivimbelo   | +1. Zincane izinkuthazo.   |
| 2. Kazinzima izivimbelo | +2. Kazinzima izinkuthazo. |
| 3. Zinzima izivimbelo   | +3. Zanile izinkuthazo.    |
| 4. Zivalile izivimbelo  | +4. Ziningi izinkuthazo    |

<b><i>Uhlu olufushane ngendawo nesimo senhlalo ohleli kuyo</i></b>	
<b>e1. UMKHIQIZO NOBUCIKO</b>	
e110 Okusetshenziswa nguwe (ukudla, nemithi)	
e115 Okusetshenziswa nguwe empilweni yansuku zonke	
e120 Okusetshenziswa nguwe ngaphakathi nangaphandle ekuhambeni nasekuthutheni	
e125 Imikhiqizo yezokuxhumana	
e150 Ukuhlela, ukwakha nokuhlunganisa ezobuciko nokwakhela umphakathi	
e155 Ukuhlela ukwakha nokuxhuma ezobuciko nokwakhela abathile	
<b>e2. EZEMVELO EZISIZUNGEZILE NEZINGUQUKO EZENZWE NGABANTU</b>	
e225 Isimo sezulu	
e240 Ukukhanya	
e250 Umsindo	
<b>e3. UKUXHASANA NOBUHLOBO</b>	
e310 Umndeni	
e320 Abangane	
e325 Abangane, ontanga, ozakwethu, omakhelwane nomphakathi	
e330 Abantu abayiziphathimandla	
e340 Abakunakekelayo nabangani bakho	
e355 Abaqeqeshelwe ezempilo	
e360 Abaqeqeshiwe ngokwezempilo	
<b>e4. INDLELA ENIBHEKANA NGAYO ABANYE</b>	
e410 Indlela ababhekana ngayo abomndeni	
e420 Indlela ababhekana ngayo abangani	
e440 Indlela ababhekana ngayo abasizi nababelekelelayo	
e450 Indlela ababhekana ngayo abaqeqeshwa bezempilo	
e455 Indlela ababhekana ngayo abaphathelane nezempilo	
e460 Iningi labahlali linjani	
e465 Baphila mpiloni, abakwenzayo nendlela abacabanga ngayo	
<b>e5. AMASEVISI, IZINHLELO NEMIGOMO</b>	
e525 Amasevisi asemakhaya, izinhlelo nemigomo	
e535 Amasevisi ezokuxhumana, izinhlelo nemigomo	
e540 Ezokuthutha indlela nemigomo.	
e550 Ezomthetho indlela nemigomo.	
e570 Ezokuphepha komphakathi indlela nemigomo	
e580 Ezempilo indlela nemigomo.	
e585 Imfundo nokuqeqeshwa, izinhlelo nemigomo	
e590 Ezomsebenzi nokuqeqeshwa, indlela nemigomo	
<b>AMANYE AMAPHUZU ANGABA KHONA MAYELANA NENHLALO OKUHLALWA PHAKATHI KWAYO</b>	

## Isengezo 2:

### IMIBUZO NGOKUBAMBA IQHAZA NOKUSEBENZA.

Iziqondiso ezilandelayo (izindlela zokufuna ulwazi) zenzelwe ukuba zikuhole zikuqondise, zikusize (njengohlolayo), ukuxoxisana nomuntu lowo ngezinkinga ekusebenzeni naseqhubekeni nempilo, uma sibheka umehluko phakathi kwamazinga okusebenza nokwenza okuthile. Ubheke lonke ulwazi onalo ngomuntu lowo, wenezele imibuzo elula uma kudingekile ukuze uthole ulwazi oluninigi.

Phansi kwalelo nalelo qoqo kukhona izinhlobo ezimbili zemibuzo.

Umbuzo wokuqala uzama ukuthola ophendulayo ukuba abheke **amandla akhe okwenza** umsebenzi, kakhulu abheke kulokho okumngqindela khona amandla Lezi zinto ezimvimbayo kungaba **azalwe nazo noma ezidalwa azithathe kwabanye**. Lokhu kungqindeka kuchaza izimo sempilo yomuntu, ngaphandle kokuncediswa. **Ngoncedo**, sisho usizo lomunye umuntu, noma usizo lwalezo zinto ezilungiselwe lokho, noma izimo ezindlini, ikhaya, endaweni yokusebenza njalonzalo. Izinga lamandla lihlulelwa ngalokho okungalindeleka kumuntu lowo, noma amandla ayenawo ingakaxhwalali impilo yakhe.

Umbuzo wesibili ubheke kumphenduli **nokwenza kwakhe**, phansi kwesimo nendawo akuyo, ukuze kutholakale ulwazi ngokwenzekayo kuye okudalwa yizinto ezimvimbayo noma ezimkhuthazayo. Kubalulekile ukugcizelela ukuthi wena ubheke ukuthi ubunzima bungakanani uma umuntu lowo enza izinto ezithile, **sithatha ngobuthi ufuna ukukwenza lokho**. Ukungenzi akusho lutho nxa umuntu ekhetha kanjalo.

#### I. Ukuhamba.

##### (Amandla okwenza)

- (1) Esimeni okuso sempilo kulesi sikhathi, kunzima kangakanani ukuhamba ibanga elide (okungaba ngangekilomitha noma ngaphezulu) ngaphandle kosizo?
- (2) Lobu bunzima bungakanani uma ubuqhathanisa nomuntu ongaguli njengawe?  
(noma: " \_ \_ \_ ungakaguli noma ulimale)?

##### (Ukwenza)

- (1) Endaweni ohlala kuyo manje, bungakanani ubunzima obutholayo ekuhambeni ibanga elide (ngangekilomitha noma ngaphezulu)?
- (2) Ngase kube lobu bunzima bokuhamba bukhuliswa noma buba ngcono benziwa yisimo sendawo okuyo?
- (3) Ngabe amandla okuhamba amabanga amade, ngaphandle kosizo, makhulu noma mancane kunokuba kwenzeka esimeni sendawo okuyo?

## II. Ukuzinaka

### (Amandla okwenza)

- (1) Esimeni sempilo okuso, kunzima kangakanani ukuzigeza ngaphandle kosizo?
- (2) Lobu bunzima bungakanani uma ubuqhathanisa nomuntu ongaguli njengawe?

(noma: " \_ \_ \_ ungakaguli noma ulimale)?

### (Ukwenza)

- (1) Ekhaya kwakho unenkinga engakanani uma uzigeza?
- (2) Ngabe le nkinga iba nkulu noma iba ngcono ngendlela ikhaya lakho elakhiwe ngayo, noma yenziwa yizinto ozisebenzisayo ezilungele lokho?
- (3) Ngabe amandla okuzigeza ngaphandle kosizo makhulu noma mancane kunokuba kwenzeka esimeni sendawo okuyo manje?

## III: Impilo yasekhaya

### (Amandla okwenza)

- (1) Ezimeni sempilo okuso, kunzima kangakanani ukuhlanza indawo phansi endaweni ohlala kuyo, ngaphandle kosizo?
- (2) Lobu bunzima bungakanani uma ubuqhathanisa nomuntu ongaguli njengawe?

(noma: " \_ \_ \_ ungakaguli noma ulimale)?

### (Ukwenza)

- (1) Ekhaya kunzima ukuhlanza iphansi, ingakanani inkinga?
- (2) Ngabe inkinga yinkulu noma ingcono, kwenziwa yindlela ikhaya elakhiwe ngayo noma kwenziwa yizinto osebenza ngazo?
- (3) Ngabe amandla ukuhlanza indawo yakho ngaphandle kosizo, makhulu noma mancane kunokuba kwenzeka esimeni sendawo ohlala kuyo?

## IV: Ukuxhumana nabantu

### (Amandla okwenza)

- (1) Esimeni okuso sempilo, kunzima kangakanani ukuthola abangane abasha ngaphandle kosizo?
- (2) Lobu bunzima bungakanani uma ubuqhathanisa nomuntu ongaguli njengawe?

(noma: " \_ \_ \_ ungakaguli noma ulimale)?

**(Ukwenza)**

- (1) Esimeni sempilo okusona manje, kunzima kangakanani ukuthola abangane?
- (2) Inkinga yokuthola abangane iba yimbi noma iba ngcomo ngenxa yokuthile ( noma othile) endaweni ohlala kuyo?
- (3) Ngabe amandla okuthola abangane ngaphandle kosizo, makhulu noma mancane kunokuba kwenzeka esimeni sendawo ohlala kuyo.

**V: Okubalulekile kakhulu empilweni**

**(Amandla okwenza)**

- (1) Esimeni okuso sempilo, kunzima kangakanani ukwenza wonke umsebenzi owaqashelwe wona ngaphandle kosizo?
- (2) Lobu bunzima bungakanani uma ubuqhathanisa nomuntu ongaguli njengawe?  
(noma: " \_ \_ \_ ungakaguli noma ulimale)?

**(Ukwenza)**

- (1) Esimeni sendawo okuyo, ingakanani inkinga yokwenza umsebenzi owaqashelwe wona?
- (2) Kule nkinga yokufeza izidingo zomsebenzoi owaqashelwe, ngabe kambe kuba kubi noma kuba ngcono ngenxa yendlela okuhlelwa ngayo noma izinto zokusebenza ezilungele ukuba uzisebenzise ngayo?
- (3) Ngabe amandla okwenza umsebenzi, ungasizwa muntu, makhulu noma mancane kunokuba kwenzeka lapho uhlezi khona?

**VI. UMPHAKATHI, UKUHLALISANA NOKUZIPHATHA (AMANDLA)**

- (1) Esimeni sempilo okuso, kunzima kangakanani ukwethamela imibuthwano yomphakathi, imigidi nokunye okunjalo ngaphandle kosizo?
- (2) Lobu bunzima bungakanani uma ubuqhathanisa nomuntu ongaguli njengawe?  
(noma: " \_ \_ \_ ungakaguli noma ulimale)?

**(Ukwenza)**

- (1) Emphakathini, angakanani inkinga yokwethamela imibuthano yomphakathi, imigidi nokunye?
- (2) Ngabe le nkinga ibayimbi noma iba ngcono ngenxa yokuhlela komphakathi noma izinto zokusebenza, ezokuhamba nokunye?
- (3) Ngabe ukwethamela kwakho imibuthano ngaphandle kosizo, kuningi noma kuncane kunokuba kwenzeka lapho uhlala khona?

## Appendix Y

### INFORMATION SHEET FOR PATIENTS – isiZulu version

#### ISAZISO KWIZIGULI.

Sawubona siguli

Igama lami ngingu Witness Mudzi, ngifundisa eWits university. Ngenza ucwaningo lokuthola indlela engcono yokukuqeqesha abantu abanakekela iziguli ze-stroke, ukuze kubelula ukunakekela abantu abaphethwe yistroke. Lolucwaningo luzobheka nokuthi umuntu ophethwe yi-stroke nomnakekeli wakhe bayakhona yini ukumelana nobunzima ekhaya.

Igama lakho ngilithole ewodini obulele kuyo emva kokushaywa yi-stroke. Uma ungathanda ukuba yingxenyeye yalolucwaningo uzofakwa kwelilodwa kumaqembu amabili esinawo. Iziguli zikhethiswa amaqembu ngokuthi zikhethwe izimvilophu, izimvilophu lezi-ke yizona ezishoyo ukuthi umuntu uya kuliiphi iqembu. Ukuba yingxenyeye yocwaningo kusho ukuvumelana nalokho okudingeka eqenjini lakho.

Iqembu lokuqala (.....)

Uma useqenjini lokuqala, uzothola uqeqesho nolwazi esibhedlela. Umuntu okunakekelayo ekhaya uzothola uqeqesho ngendlela okumele akunakekele ngayo. Uzobe sewuvivinywa ngalolulwazi noqeqesho owaluthola, ezikhathini ezihlukene, Kanje: usasesibhedlela noma sewuphumile (emva kwezinyanga eziwu3, 6, 12 usuphumile esibhedlela). Loku kuzokwenzelwa ekhaya noma esibhedlela noma eklinic esondelene nawe, unokuzikhethela indawo ovumelana nayo. Imibuzo izobheka ukuthi uyakhona yini ukubhekana nezinsalelo zempilo (ukuthi uhamba kanjani, uyakhona yini ukwenza umsebenzi wasekhaya, nokuthi uthozile yini ngemusa)

Iqembu lesibili(

Uma useqenjini lesibili, uzothola uqeqesho nolwazi esibhedlela. Umuntu okunakekelayo ekhaya uzothola uqeqesho ngendlela okumele akunakekele ngayo. Ngaphezu kwalokho umnakekeli uzothola uqeqesho oluhlelekile. Uzothola ithuba loku-(practisa) ukususa umuntu onestroke embhedeni umyise esihlalweni, ukumhambisa, nokuvimbela izilonda zokulala. Uzobe sewuvivinywa ngalolulwazi noqeqesho owaluthola, ezikhathini ezihlukene, Kanje: usasesibhedlela noma sewuphumile (emva kwezinyanga eziwu3, 6, 12 usuphumile esibhedlela). Loku kuzokwenzelwa ekhaya noma esibhedlela noma eklinic esondelene nawe, unokuzikhethela indawo ovumelana nayo. Imibuzo izobheka ukuthi uyakhona yini ukubhekana nezinsalelo zempilo (ukuthi uhamba kanjani, uyakhona yini ukwenza umsebenzi wasekhaya, nokuthi uthozile yini ngemusa).

Uma useqenjini lesibili, uqeqesho luzothatha imizuzu engu-30 kuya ku-45. Isikhathi singandiswa uma kunesidingo ukuze abantu babuzisise kahle ngabakufundile. Uqeqesho luzokwenziwa isiguli sisasesibhedlela.

Emaqenjini womabili, awuphoqelekanga ukuba yingxenyeye yalolucwango. Awuzokukhokhelwa ngokuba yingxenyeye yalokhu. Uvumelekile ukuyekela noma yinini. Ukuyeka angeke kukuhlukumeze nalutho, angeke futhi kuvimbele umuntu omnakekelayo amathuba okuthola usizo nokunakekelwa esibhedlela, esasesibhedlela noma esephumile.

Ngiyathemba lolucwaningo luzosisiza sithole indlela okuyiyonayona yokuqeqesha abantu abanakekela iziguli-ezinstroke, ngaphandle kobunzima.

Ungaxhumana nami noma yinini. Izinombolo zingezansi. Ngiyabonga ngosizo lwakho.

Witness Mudzi (Mnz.)  
Physiotherapy Department  
Wits university

ucingo: 072 858 2942 (cell)  
: 011 717 3716 (yomsebenzi)

## Appendix Z

### INFORMATION SHEET FOR CAREGIVERS - isiZulu Version

#### ISAZISO KWABANAKEKELA ABAGULAYO

Mnakekeli wesiguli

Igama lami ngingu Witness Mudzi, ngifundisa eWits university. Ngenza ucwaningo lokuthola indlela engcono yokukuqeqesha abantu abanakekela iziguli ze-stroke, ukuze kubelula ukunakekela abantu abaphethwe yi-stroke. Lolucwaningo luzobheka nokuthi umuntu ophethwe yi-stroke nomnakekeli wakhe bayakhona yini ukumelana nobunzima ekhaya.

Igama lakho ngilithole ku.....ongitshela ukuthi uzobe umnakekela uma esephumile esibhedlela. Uma ungathanda ukuba yingxenye yalolucwaningo uzofakwa kwelilodwa kumaqembu amabili esinawo. Uzofakwa eqenjini lapho isiguli sakho sikhona. Iziguli zakhethiswa amaqembu ngokuthi zikhethwe izimvilophu, izimvilophu lezi-ke yizona ebezisho ukuthi umuntu uya kuliphil iqembu. Ukuba yingxenye yocwaningo kusho ukuvumelana nalokho okudingeka eqenjini lakho.

Iqembu lokuqala (.....)

Uzothola uqeqesho nolwazi esibhedlela. Uzobe sewubuzwa uvivinywa ngalolulwazi noqeqesho owaluthola, ezikhathini ezihlukene. Uzobuzwa isiguli sisasesibhedlela noma sesiphumile (emva kwezinyanga eziwu3, 6, 12 isiguli siphumile esibhedlela). Loku kuzokwenzelwa ekhaya noma esibhedlela noma eklinic esondelene nawe, unokuzikhethela indawo ovumelana nayo. Imibuzo izobheka ukuthi uyakhona yini ukubhekana nomuntu ogulayo.

Iqembu lesibili

Uzothola uqeqesho nolwazi esibhedlela. Ngaphezu kokufundiswa uzothola uqeqesho oluhlelekile. Uzothola ithuba loku- (practiza) ukususa umuntu onestroke esihlalweni umyise embhedeni, ukumhambisa, ukuvikela izilonda zokulala, nokunakekela ukusebenza kwesingezansi. Uzofundiswa ngezinto ezidala i-stroke nokuthi ungasivikela kanjani. Uzobuzwa isiguli sisasesibhedlela noma sesiphumile (emva kwezinyanga eziwu3, 6, 12 isiguli siphumile esibhedlela). Loku kuzokwenzelwa ekhaya noma esibhedlela noma eklinic esondelene nawe, unokuzikhethela indawo ovumelana nayo. Imibuzo izobheka ukuthi uyakhona yini ukubhekana nomuntu ogulayo.

Uma useqenjini lesibili, uqeqesho luzothatha imizuzu engu-30 kuya ku-45. Isikhathi singandiswa uma kunesidingo ukuze abantu babuzisise kahle ngabakufundile. Uqeqesho luzokwenziwa isiguli sisasesibhedlela.

Emaqenjini womabili, awuphoqelekanga ukuba yingxenye yalolucwango. Awuzukukhokhelwa ngokuba yingxenye yalokhu. Uvumelekile ukuyekela noma yinini. Ukuyeka angeke kukuhlukumeze nalutho, angeke futhi kuvimbele umuntu omnakekelayo amathuba okuthola usizo nokunakekelwa esibhedlela, esasesibhedlela noma esephumile.

Ngiyathemba lolucwaningo luzosisiza sithole indlela okuyiyonayona yokuqeqesha abantu abanakekela iziguli-ezinstroke, ngaphandle kobunzima.

Ungaxhumana nami noma yinini. Izinombolo zingezansi. Ngiyabonga ngosizo lwakho.

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## Appendix AA

### CONSENT FORM FOR CARE GIVERS - isiZulu Version

#### I-FOMU YESIVUMELWANO YABANAKEKELI BEZIGULI

Mina .....ngifundile isaziso futhi ngizimisele ukuba yingxenywe yocwaningo olwenziwa wu Mnz. W. Mudzi. Ngokusayina lefomu ngiyavuma ukunikwa uqeqesho lokubhekelela umhlobo wami one-stroke. Ngiyavuma (ngokuba kwiqembu lokuqala noma lesibili) ukuvivinywa noma ukubuzwa izikhathi eziwu-4 (ngesikhathi isihlobo sami sisesibhedlela nangemva kwezinyanga eziwu3, 6,12 emva kokukhishwa esibhedlela) ngokuthi ngiqhuba kanjani ekunakekeleni isiguli sami.

Ngiyaqonda ukuthi angizukukhokhelwa ngokwenza lokhu futhi angiphoqiwe ukuba yingxenywe yalokhu. Ukuba yingxenywe yalolucwaningo noma ukungabi yingxenywe akuzukushintsha indlela isihlobo sami esinakekelwa ngayo lapha esibhedlela.

Sayina.....

Ufakazi.....

Usuku.....



## Appendix AB

### CONSENT FORM FOR PATIENTS - isiZulu Version

#### IFOMU YESIVUMELWANO NEZIGULI

Mina .....ngifundile isaziso futhi ngizimisele ukuba yingxenywe yocwaningo olwenziwa wu Mnz. W. Mudzi. Ngokusayina lefomu ngiyavuma ngiyavuma (ngokuba kwiqembu lokuqala noma lesibili) ukuvivinywa noma ukubuzwa izikhathi ezivuwu-4 (ngesikhathi ngisisesibhedlela nangemva kwezinyanga ezivuwu3, 6,12 emva kokukhishwa esibhedlela) ngokuthi ngibhekana kanjani nezinsalelo zokugula ekhaya. Ngizoletha negama lozonginakekela ekhaya ukuze abe yingxenywe yaloluhlelo uma ethanda.

Ngiyaqonda ukuthi angizukukhokhelwa ngokwenza lokhu futhi angiphqiwe ukuba yingxenywe yalokhu. Ukuba yingxenywe yalolucwaningo noma ukungabi yingxenywe akuzukushintsha indlela engizonakekelwa ngayo lapha esibhedlela .

Sayina.....

Ufakazi.....

Usuku.....

## Appendix AC

### INITIAL QUESTIONNAIRE FOR PATIENT'S DEMOGRAPHIC DATA – SeSotho Version

#### LETHATHAMA LA PELE LA DIPOTSO LA DINTLHA TSA MAEMO A BOPHELO A MOKUDI

Lebitso: .....Letsatsi:.....

Letsatsi la Tlhaho: ..... Dilemo: .....

Aterese:.....

.....

Letsatsi la setrouku:.....

Letsatsi la ho amohelwa sepetele:.....

#### 1. Mofuta wa setrouku:

- 1.1 Na ke setrouku sa kgetlo la pele?  EE  TJHEE
- 1.2 Lehlakore la mmele le amehileng:  Le letshehadi  Le letona
- 1.3 Mofuta wa setrouku:  Sa ho tswa madi  Sa sebaka se senyane

- 1.3.1 Mofutanyana wa Setrouku wa Ischaemic  Setrouku se Feletseng sa Kapele  
 Setrouku sa Karolwana e Kapele  
 Setrouku sa Karolo e Kamorao  
 Setrouku se etsang ho Phobela

2. Bong:  E motona  E motshehadi

#### 3. Maemo a mosebetsi ka nako ya setrouku:

- O a sebetsa  
 O a itshebetsa  
 Ha o sebetse  
 O behile meja/ o pensheneng  
 O fumana Thuso  
 E nngwe: Hlalosa.....

#### 4. Maemo a lenyalo:

- Ha ke a nyala/nyalwa  
 Ke nyetse/nyetswe

- Re kgaotse lenyalo
- Re arohane
- Re phela mmoho
- E nngwe:

Hlalosa.....

**5. Maemo a Mohlokamedi:**

- Ke dula ke le mong (Ha ho Mohlokamedi)
- Mohlokamedi o teng motsheare
- Mohlokamedi o teng bosiu feela
- Mohlokamedi o teng ka dinako tsohle

**6. Kamano le Mohlokamedi**

- Molekane ka lenyalo
- Motswalle
- Wa leloko
- Moahisani
- E nngwe: Hlalosa.....

**7. Bohato bo Phethilweng ba Thuto:**

- Dikri ya Yunivesithi
- Kereiti ya 12 + 3 kapa dilemo tse ka hadimo
- Kereiti ya 12 kapa lengolo le lekanang le yona
- Ho fihlela ho kereiti ya 11
- Ho fihlela ho kereiti ya 7

**8. Lenaneo la ho Lekola mabaka a Kotsi:**

- |                          |   |
|--------------------------|---|
| EE                       | TJHEE   |
| <input type="checkbox"/> | <input type="checkbox"/> Ho tsuba: Hlalosa palo ka letsatsi.....                            |
| <input type="checkbox"/> | <input type="checkbox"/> Lefu la Tswekere   |
| <input type="checkbox"/> | <input type="checkbox"/> Lefu la Pelo   |
| <input type="checkbox"/> | <input type="checkbox"/> Kholestorole (Hyperlipidaemia/ cholesterol)                        |
| <input type="checkbox"/> | <input type="checkbox"/> Kgatele e hodimo ya madi   |
| <input type="checkbox"/> | <input type="checkbox"/> Boima bo fetisisang (BMI 25 – 29.9) Bolele.....Boima..... BMI..... |

E nngwe: Hlalosa.....

**9. Boemo bo Neng bo Sebetsa Pele o Kula**

Ho ikemela ho di-ADL tsohle

O hloka thuso ho di-ADL

E nngwe: Hlalosa.....

**10. Tekolo ya Motheo ya Mokudi:**

Ho itshwara /itaola: Senya:  Ee  Tjhee

Mala:  Ee  Tjhee

Kgaello e Matla ya Puo (Ha tsebe ho bua ho hang):  Ee  Tjhee

Kgaello e Matla ya Kutlwisiso:  Ee  Tjhee

Kgaello e Matla ya Pono:  Ee  Tjhee

Na ho na le ditharahano tse eketsehileng tse teng?

Tsa pelo:  Ee  Tjhee

Tsa matshwafo:  Ee  Tjhee

Na ho na le ditshitiso tse eketsehileng tse teng tsa methapo ya kutlo?

Lefu la ho wa:  Ee  Tjhee

Kotsi ya hloohong  Ee  Tjhee

Bopaki bofe le bofe ba tleneniki ba kगतello ya boitshireletso  Ee  Tjhee

## Appendix AD

### SUBSEQUENT QUESTIONNAIRE FOR PATIENT'S DEMOGRAPHIC DATA (At 3, 6 and 12 months post discharge) – SeSotho Version

#### LETHATHAMA LE HLAHLAMANG LA DIPOTSO LA DINTLHA TSA MAEMO A BOPHELO A MOKUDI (Dikgweding tse 3, 6 le tse 12 ka mora ho lokollwa)

Lebitso: .....Letsatsi:.....

Letsatsi la Tlhaho: ..... Dilemo: .....

Aterese:.....

.....

Letsatsi la setrouku:.....

Letsatsi la ho amohelwa sepetele:.....

#### 1. Mofuta wa setrouku:

1.1 Na ke setrouku sa kgetlo la pele?  EE  TJHEE

1.2 Lehlakore la mmele le amehileng:  Le letshehadi  Le letona

1.3 Mofuta wa setrouku:  Sa ho tswa madi  Sa sebaka se senyane

- 1.3.1 Mofutanyana wa Setrouku wa Ischaemic  Setrouku se Feletseng sa Kapele  
 Setrouku sa Karolwana e Kapele  
 Setrouku sa Karolo e Kamorao  
 Setrouku se etsang ho Phobela

2. Bong:  E motona  E motshehadi

#### 3. Maemo a Ditjhelete le a Mosebetsi:

3.1 Na maemo a hao a ditjhelete a fetohile ka lebaka la setrouku sa hao:  Ee  
 Tjhee

3.2 Na ho na le tshehetso efe kapa efe ya ditjhelete eo o e fumanang?  Ee  
 Tjhee

Ha karabo e le ee, thusa o hlalose:

Thuso ya ho hloka boitekanelo

Penshene

Inshoreense ya ho Hloka Mosebetsi (UIF)

E nngwe: Hlalosa.....

3.3 Tlhahisoleseding ka mosebetsi

- O a sebetsa
- O a itshebetsa
- Ha o sebetse
- O behile meja/ o pensheneng
- O fumana Thuso
- E nngwe: Hlalosa.....

4. Maemo a lenyalo:

- Ha ke a nyala/nyalwa
- Ke nyetse/nyetswe
- Ke kgaotse lenyalo
- Re arohane
- Re phela mmoho
- E nngwe:

Hlalosa.....

5. Maemo a Mohlokamedi:

- Ke dula ke le mong (Ha ho Mohlokamedi)
- Mohlokamedi o teng motsheare
- Mohlokamedi o teng bosiu feela
- Mohlokamedi o teng ka dinako tsohle

6. Kamano le Mohlokamedi

- Molekane ka lenyalo
- Motswalle
- Wa leloko
- Moahisani
- E nngwe: Hlalosa.....

7. Maemo a Bodulo le Tikoloho ya Lehae:

- Ntlo ya hao
- O hirile
- Ntlo e sa tlwaelehang (Mokhukhu)
- Metsi a pompo

- Motlakase
- Ntlwana e ka hara ntlo
- Ntlwana e ka ntle
- Bethe ya hao
- Lebala le tsitsitseng (ka ntle)
- Lebala le matsutlatsutla (ka ntle)
- Ho na le ditepisi (mehato)
- Ha ho ditepisi (mehato)
- E nngwe: Hlalosa.....

8. Tsebo ya Dintlha tse Kotsi:

EE TJHEE

- Ho tsuba: Hlalosa palo ka letsatsi.....
- Lefu la tswekere
- Lefu la Pelo
- Kholestorole (Hyperlipidaemia/ cholesterol)
- Kgatello e hodimo ya madi
- Boima bo fetisisang/Ho nona (BMI of >25)
- E nngwe: Hlalosa.....

9. Tekolo e Hlahlamang ya Mokudi:

Ho itshwara /itaola: Senya:  Ee  Tjhee

Mala:  Ee  Tjhee

Kgaello e Matla ya Puo:  Ee  Tjhee

Kgaello e Matla ya Kutlwisiso:  Ee  Tjhee

Kgaello e Matla ya Pono:  Ee  Tjhee

Na ho na le ditharahano tse eketsehileng tse teng?

Tsa pelo:  Ee  Tjhee

Tsa matshwafo:  Ee  Tjhee

Na ho na le diitshiso tse eketsehileng tse teng tsa methapo ya kutlo?

Lefu la ho wa:  Ee  Tjhee  
Kotsi ya hloohong  Ee  Tjhee  
Bopaki bofe le bofe ba tleneniki ba kgaello ya boitshireletso  Ee  Tjhee

10. Mathata a mahlano a matla (ha a le teng) ao o bileng le boiphihlelo ba ona:

- i).....
- ii).....
- iii).....
- iv).....
- v)**.....



## Appendix AE

### INITIAL AND SUBSEQUENT QUESTIONNAIRE FOR CAREGIVER'S DEMOGRAPHIC DATA – SeSotho Version

#### LETHATHAMA LA PELE LE LE HLAHLAMANG LA DIPOTSO TSA MOHLOKOMEDI LA DINTLHA TSA MAEMO A BOPHELO

Lebitso: ..... Letsatsi:.....

Letsatsi la Tlhaho: ..... Dilemo: .....

Aterese:.....

.....

1. Bong:  E motona  E motshehadi

2. Maemo a mosebetsi:  O a sebetsa  
 O a itshebetsa  
 Ha o sebetse  
 O behile meja/ o pensheneng  
 O fumana Thuso  
 E nngwe:  
Hlalosa.....

3. Maemo a lenyalo:  Ha ke a nyala/nyalwa  
 Ke nyetse/nyetswe  
 Ke kgaotse lenyalo  
 Re arohane  
 Re phela mmoho  
 E nngwe:  
Hlalosa.....

4. Maemo a Lelapa:  
 O phela a le mong (Ha ho ditho tse ding tsa lelapa)  
 O dula le bana: Neha palo .....  
 O dula le batho ba bang ba baholo: Neha palo .....  
 O fumana thuso ho ditho tse ding tsa lelapa mabapi le tlhokomelo

5. Bohato bo Phethilweng ba Thuto:  
 Dikri ya Yunivesithi  
 Kereiti ya 12 + 3 kapa dilemo tse ka hadimo

- Kereiti ya 12 kapa lengolo le lekanang le yona
- Ho fihlela ho kereiti ya 11
- Ho fihlela ho kereiti ya 7

**10. Tlhahisoleseding ka Bodulo**

- Ntlo ya hao
- O hirile
- Ntlo e sa tlwaelehang (Mokhukhu)

**11. Tikoloho ya lehae**

- |  |   |
|--|---|
| <input type="checkbox"/> Metsi a pompo                   | <input type="checkbox"/> Lebala le matsutlatsutla (ka ntle) |
| <input type="checkbox"/> Motlakase                       | <input type="checkbox"/> Ho na le ditepisi (mehato)         |
| <input type="checkbox"/> Ntlwana e ka hara ntlo          | <input type="checkbox"/> Ha ho ditepisi (mehato)            |
| <input type="checkbox"/> Ntlwana e ka ntle               | <input type="checkbox"/> E nngwe:                           |
| <input type="checkbox"/> Bethe ya hao                    | Hlalosa.....  |
| <input type="checkbox"/> Lebala le tsitsitseng (ka ntle) |   |

**8. Tsebo ya Dintlha tse Kotsi tsa Setrouku:**

EE TJHEE

- Ho tsuba:
- Lefu la tswekere
- Lefu la Pelo
- Kholestorole (Hyperlipidaemia/ cholesterol)
- Kgateello e hodimo ya madi
- Boima bo fetisisang
- E nngwe: Hlalosa.....

**Appendix AF**

**BARTHEL ADL INDEX – SeSotho Version**

LENANE LA BARTHEL ADL

*Mala:* 0 = ho sitwa ho itshwara / ho itaola ( o hloka ho nehwa sepeiti /lehlaka)  
 1 = kotsi ka mohlomong (ha nngwe ka beke)  
 2 = ho itshwara / itaola

*Senya:* 0 = ho sitwa ho itshwara, kapa o kentswe lelana mme ha o kgone ho le sebedisa o le mong

1 = kotsi ka mohlomong (boholo ha nngwe dihoreng tse 24)  
2 = ho itshwara / itaola

*Ho itlhwekisa* 0 = o hloka thuso ya ho itlhwekisa  
1 = o ikemetse mabapi le sefahleho/ moriri/ meno/ ho kuta ditedu (ha ho nehelanwe ka disebediswa)

*Ho sebedisa ntlwana* 0 = o tshepetse  
1 = o hloka thuso e itseng, empa o ka etsa ntho e itseng o le mong  
2 = o ikemetse (ka nako tse ding, ho tena, ho itlhakola (fefa)

*Ho ja* 0 = ha o kgone  
1 = o hloka thuso ya ho seha, ho tlotsa sereledi, jj.  
2 = o ikemetse

*Ho fetisetsa (ho tloha betheng ho ya setulong le ho kgutlela)*  
0 = ha o kgone, ha ho tekatekano ya ho dula  
1 = thuso e kgolo (motho a le mong kapa ba babedi, matla)  
2 = thuso e nyane (ya ho bua kapa matla)  
3 = o ikemetse

*Ho tsamaya* 0 = ha o kgone ho tsamaya  
1 = o tshepetse ho setulo sa ho tsamaya, ho kenyeletsa dihuku  
2 = o tsamaya ka thuso ya motho a le mong (ka puo kapa matla)  
3 = o ikemetse (empa o ka sebedisa sesebediswa sa thuso (aid) sefe kapa sefe; mohlala, seikokotlelo)

*Ho tena /apara* 0 = o tshepetse  
1 = o hloka thuso empa o ka etsa halofo ya ho tena o sa thuswa  
2 = o ikemetse (ho kenyeletsa dikonopo, diziphu, maqhwele, jj.)

*Ditepisi (mehato)* 0 = ha o kgone  
1 = o hloka thuso (ka puo, matla, thuso ya ho rwala)  
2 = o ikemetse

*Ho tola* 0 = o tshepetse  
1 = o ikemetse (kapa ka shawareng)

paloyohle 0-20 **Total...../20**

## Appendix AG

### RIVERMEAD MOBILITY INDEX – SeSotho Version

#### LENANE LA HO TSAMAYA LA RIVERMEAD

**Ditaelo:** Mokudi o botswa dipotso tse latelang tse 15 mme a hlokomelwe (bakeng sa ntlha ya 5). Ho neha ntlha e le 1 bakeng sa karabo ka nngwe e reng ee. Hlokomela hore bongata bo hloka boikemelo ba hore motho a se ke a thuswa empa mokgwa ha se ntho ya bohlokwa.

Potso	Ee	Tjhee
Ho fetoha betheng O fetoha ho tloha mokokotlong wa hao ho ya lehlakoreng la hao ntle le thuso		
Ho paqama ho ya ho Ho dula Ho tloha ho paqameng betheng, na o a phahama o dule ntlheng ya bethe ka bowena ntle le ho itshwarella metsotswana e 10		
Tekatekano ya ho dula Na o dula ntlheng ya bethe ntle le ho itshwarella metsotswana e 10		
<i>Ho tloha kemong ya ho ema ho ya ho ya ho dula</i> Na o a ema (ho tloha setulong sefe kapa sefe) nakong e ka tlase ho metsotswana e 15, le ho ema moo metsotswana e 15 (o sebedisa matsoho, mmoho le sesebediswa se thusang ha ho hlokeha)?		
Ho ema o sa tshehetswa Hlokomela ho ema ka metsotswana e 10 ntle le sesebediswa sefe kapa sefe sa thuso kapa tshehetso		
Ho fetisetsa Na o kgona ho sisinyeha, mohlala, ho tloha betheng ho ya setulong le ho kgutlela ntle le thuso?		
Ho tsamaya ka hare, ka sesebediswa sa thuso ha ho hlokeha Na o tsamaya 10m, ka sesebediswa sa thuso kapa fenetjhara ha ho hlokeha, empa ho se na thuso e haufi?		
Ditepisi (mehato) Na o kgona ho hlwa bophahamo a ditepisi ntle le thuso?		
<i>Ho tsamaya ka ntle (lebaleng le tsitsitseng)</i> Na o tsamaya o potoloha ka ntle, hodima ditselana tsa mokato?		
Ho tsamaya ka hare, ntle le thuso Na o tsamaya 10m ka hare ntle le ditshehetso tsa maoto, settlami sa lesapo, sesebediswa sa thuso kapa tshebediso ya fenetjhara, mme ho se thuso e haufi?		
<i>Ho thonaka ntho e fatshe</i> Ha o diha ntho e itseng fatshe, o a kgona ho tsamaya 5m, o e thonake mme o kgutlele morao?		
<i>Ho tsamaya ka ntle (lebaleng le matsutlatsutla)</i> Na o tsamaya lebaleng le matsutlatsutla (la jwang, kerabole, dithole jj) ntle le thuso?		
Ho tola Na o a kena / o tswa bateng kapa shawareng o sa lebellwa mme o itlhatswe?		
Ho nyoloha le ho theoha ditepising tse nne Na o a kgona ho nyoloha le ho theoha ditepising tse nne tse se nang boitshwarello ba ditshepe mme ntle le thuso, empa o sebedisa sesebediswa sa thuso ha ho hlokeha?		
Ho matha Na o kgona ho matha 10m ntle le ho hlotsa ka metsotswana e 4 (ho tsamaya ka potlako ho amohelehile)?		

paloyohle 0-15 **Total...../15**

## Appendix AH

### THE EuroQol (Eq-5D) Health Questionnaire (South African SeSotho Version)

#### Lethethama la Dipotso tsa Bophelo tsa EuroQol (Eq-5D) (Phatlalatso ya Senyese mane ya Afrika Borwa)

Ka ho beha letshwao le bokoseng le le leng ho sehlopha ka seng se ka tlase, thusa o bontshe hore ke polelo efe e hlalosing ka botlalo maemo ao e leng a hao a bophelo KAJENO.

#### Ho tsamaya

- Ha ke na mathata a ho tsamatsamaya
- Ke na le mathata a itseng a ho tsamatsamaya
- Ke dula betheng ka dinako tsohle

#### Ho itlhokomela

- Ha ke na mathata a ho itlhokomela
- Ke na le mathata a itseng a ho itlhatswa kapa ho itentsha
- Ha ke kgone ho itlhatswa kapa ho itentsha

#### Mesebetsi ya Tlwaelo (*mohlala, mosebetsi, ho ithuta, mosebetsi wa lapeng, lelapa kapa mesebetsi ya boithabiso*)

- Ha ke na mathata a ho phetha mesebetsi ya ka ya tlwaelo
- Ke na le mathata a itseng a ho phetha mesebetsi ya ka ya tlwaelo
- Ha ke kgone ho phetha mesebetsi ya ka ya tlwaelo

#### Bohloko /Makukuno

- Ha ke na bohloko kapa makukuno
- Ke na le bohloko kapa makukuno a mahareng
- Ke na bohloko kapa makukuno a fetisisang

#### Tshabo/ Ho Tepella

- Ha ke na tshabo kapa ho tepella
- Ke na le tshabo kapa ho tepella ho mahareng
- Ke na le tshabo kapa ho tepella ho fetisisang

Maemo a matle ka  
ho fetisisa a  
bophelo

Ha ho bapiswa ka bophara

le bophahamo ba bophelo ba ka  
dikgweding tse 12 tse fetileng.  
maemo a bophelo ba ka kajeno a:

- |                   |                          |                 |
|-------------------|--------------------------|-----------------|
| A Matle           | <input type="checkbox"/> | THUSA O TSHWAYE |
| A batla a tshwana | <input type="checkbox"/> | LEBOKOSE        |
| A Mabe            | <input type="checkbox"/> | LE LE LENG      |

Ho thusa batho ho bolela hore maemo a bona a bophelo a matle kapa a mabe hakae, re radile sekala moo boemo bo botle ka ho fetisisa boo o ka bo nahanang bo tshauwe ka 100 mme boemo bo bobele ha ka ho fetisisa boo o ka bo nahanang bo tshauwe ka 0.

Re ka rata hore o bontshe sekaleng sena, hore bophelo ba hao bo botle kapa bo bobele hakae kajeno. Thusa etsa hona ka ho seha mola ho tloha lebokoseng le ka tlase ho ya fihla ntlheng efe kapa efe sekaleng e bontshang hore maemo a bophelo a matle kapa a mabe hakae kajeno.

**Maemo a hao a  
bophelo a kajeno**



Maemo a mabe ka  
ho fetisisa a  
bophelo

## Appendix A1

### THE CAREGIVER STRAIN INDEX – SeSotho Version

#### LENANE LA HO IMELWA HA MOHLOKOMEDI

Ntlha: 'Ee' = 1 'Tjhee' = 0

"Ke tla bala lenaneo la dintho tseo batho ba bang ba fumaneng ho le boima ho thusa ha motho e mong a fihla hae ho tswa sepetele." Kapa:

"Ke tla bala lenaneo la dintho tseo batho ba bang ba fumaneng ho le boima ho thusa ha motho e mong a ena le bokulo."

"Na o ka thusa o mpoelle ha le efe ya tsena e sebetsa ho wena? (neha mehlala)

---

- Boroko bo a sitiseha (mohlala, hobane ..... o kena a etswa betheng kapa o solla hohle bosiu).
- Ke tshitiso (mohlala, hobane ho thusa ho nka nako e ngata kapa o kganna sebaka se selelele ho ya thusa).
- Ho a kgathatsa mmeleng (mohlala, hobane ho phahamisa le ho beha le ho theola setulong; ho hlokeha boiteko kapa tsepamiso ya maikutlo).
- Ho a kgoka (mohlala, ho thusa ho notla nako, kapa ha o kgone ho tjhaka).
- Ho bile le diphetoho tse etsuwang lapeng (mohlala, hobane ho thusa ho ferekantse tlwaelo; ha ho boinotshi (bophelo boo e leng ba hao).
- Ho bile le diphetoho mererong ya botho (mohlala, ho tlameha ho tlohela mosebetsi; ha o kgone ho ya phomolong).
- Ho bile le ditseko tse ding nakong ya ka (mohlala, tse tswang ho ditho tse ding tsa lelapa)
- Ho bile le diphetoho tsa kameho ya maikutlo (mohlala, ka baka la phehisano e matla).
- Boitshwaro bo bong bo a kgathatsa (mohlala, hobane ho hloka boitaolo; ..... O na le bothata ba ho hopola dintho; kapa .....o qosa batho ka ho nka dintho).
- Ho a kgathatsa ho fumana hore ..... o fetohile haholo ho boyena ba pele (mohlala, ke motho ya fapaneng ho eo a neng a atisa ho ba yena).
- Ho bile le diphetoho mosebetsing (mohlala, ka lebaka la ho nka nako ya ho ba siyo mosebetsing).
- Ho a imela ka ditjhelete.
- Ho ikutlwa o okametswe ka botlalo (mohlala, ka lebaka la ho tshwenyeha ka ....; ngongoreho ya hore o tla kgona jwang).
- /13 Paloyohle

## Appendix AJ

### THE ICF CHECK LIST - SeSotho Version

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## LENANEO LA HO LEKOLA LA ICF

### Phatlalatsa 2.1a, Foromo ya Setsebi sa Tleleniki

#### bakeng sa Tlhophiso ya Matjhaba ya ho Sebetsa ( ho Hloka Boitekanelo le Bophelo

Lena ke lenaneo la ho lekola la dikarolo tsa sehlooho tsa Tlhophiso ya Matjhaba ya ho Sebetsa, ho Hloka Boitekanelo le Bophelo (ICF)

la Mokgatlo wa Lefatshe wa Bophelo. Lenaneo la ho Lekola la ICF ke sesebediswa se sebetsang sa ho qolla le ho ngola rekoto ya tlhahisoleseding mabapi le ho sebetsa le ho hloka boitekanelo ha motho. Tlhahisoleseding ena e ka kgutsufatswa bakeng sa direkoto tsa diketsahalo (ho etsa mohlala, tshebetsong ya tleleniki kapa mosebetsi wa bodulo). Lenaneo la ho lekola le lokela ho sebediswa mmoho le ICF kapa phatlalatsa ya Pokotho ya ICF.

H 1. Ha o tlatsa lenaneo lena la ho lekola, sebedisa tlhahisoleseding yohle e fumanehang. Thusa o lekole tseo tse sebedisitsweng:

**[1] direkoto tse ngotsweng [2] moarabi ya ka sehloohong [3] ba bang batsebisi [4] tlhokomelo e tobileng**

Ha tlhahisoleseding ya bongaka le e bontshang bokulo e sa fumanehe ho eletswa hore ho tlatswe

sehlomathiso 1: Tlhahisoleseding e Kgutshwane ya Bophelo (maqephe 9-10) e ka tlatswang ke moarabi.

**H 2. Letsatsi** \_\_\_ / \_\_\_ / \_\_\_ **H 3. ID ya Ketsahalo** \_\_ , \_\_\_ , \_\_\_ **H 4. Nomoro ya Monka-karolo.** \_\_\_  
\_\_\_ / \_\_\_ / \_\_\_

### **KAROLO 2: MEEDI YA TSHISINYEHO LE THIBELO YA HO NKA KAROLO**

☐ Tshisinyeho ke phethahatso ya mosebetsi kapa tshebetso ya motho. Ho nka karolo ke ho ba le seabo ho maemo a bophelo.

☐ Meedi ya tshisinyeho ke mathata ao motho a ka bang le ona phethahatsong ya ditshisinyeho. Dithibelo tsa ho nka karolo kemathata ao motho a ka bang le ona ha a na le seabo maemong a bophelo.

Lehlalosi la ho Phetha tshebetso le hlalosa ntho e etsuwang ke motho tikolohong ya hae ya jwale. Hobane tikoloho ya jwale e kenyeletsa boemo ba bodulo, ho phetha tshebetso hape ho ka utlwisiswa jwalo ka "ho ba le seabo maemong a bophelo"

kapa "boiphihlelo bo phelwang" ba batho boemong ba nnete boo ba phelang ho bona. Boemo bona bo kenyeletsa mabaka a tikoloho – maemo ohle a tlhaho, a bodulo le tihadimo ya lefatshe a ka nehwa khoutu ho sebediswa Mabaka a Tikoloho.

Lehlalosi la Bokgoni le hlalosa bokgoni ba motho ba ho phethahatsa mosebetsi kapa tshebetso. Sebopeliso sena se bontsha bophahamo bo hodimodimo ba ho sebetsa boo motho a ka bo fihlellang sebakeng se nehlanweng ka nako eo. Ho lekola bokgoni bo feletseng ba motho, motho a ka hloka ho ba le tikoloho e "maemong" ho lekalekanya sefutho se fetofetohang sa diitkoloho tse fapaneng ho bokgoni ba motho. Jwalo ka ha tikoloho e maemong e ka ba: (a) tikoloho ya nnete, e tlwaelehileng e sebediswang ho lekola bokgoni tlhahlobong ya maemo a tikoloho; kapa (b) moo ho kgonehang, tikoloho ya boiqapelo e nang le sefutho se tshwanang.

**Hlokomela:** Sebedisa Sehlomathiso 2 ha ho hlokeha ho ntsha tlhahisoleseding ka Ditshisinyeho le Ho Nka Karolo ha motho



<b>Lehlalosi la Pele: Boholo ba ho phetha tshebetso ya thibelo ya ho nka karolo</b>	<b>Lehlalosi la Bobedi: Bokgoni (ntle le thuso) Boholo ba moedi wa Tshisinyeho</b>
<b>0</b> Ha ho bothata <b>1</b> Bothata bo bonyane <b>2</b> Bothata bo mahareng <b>3</b> Bothata bo matla <b>4</b> Bothata bo feletseng <b>8</b> Ha e a hlahoswa <b>9</b> Ha e sebetse	<b>0</b> Ha ho bothata <b>1</b> Bothata bo bonyane <b>2</b> Bothata bo mahareng <b>3</b> Bothata bo matla <b>4</b> Bothata bo feletseng <b>8</b> Ha e a hlahoswa <b>9</b> Ha e sebetse

### ***Lenaneo le Lekgutshwane la dibaka tsa Tshisinyeho (A) le ho Nka Karolo (P)***

	<b><i>Lehlalosi la phethahaso</i></b>	<b><i>Lehlalosi la bokgoni</i></b>
<b>d1. HO ITHUTA LE HO SEBEDISA TSEBO</b>		
<b>d110</b> Ho bohela		
<b>d115</b> Ho mamela		
<b>d140</b> Ho ithuta ho bala		
<b>d145</b> Ho ithuta ho ngola		
<b>d150</b> Ho ithuta ho bala dipalo ( <i>dipalo</i> )		
<b>d175</b> Ho rarolla diqaka		
<b>d2. MESEBETSI LE DITSEKO KA BOPHARA</b>		
<b>d210</b> Ho etsa mosebetsi o le mong		
<b>d220</b> Ho etsa mosebetsi e mengata		
<b>d3. KGOKAHANO</b>		
<b>d310</b> Kgokahano le – ho fumana –melaetsa e buuwang		
<b>d310</b> Kgokahano le – ho fumana –melaetsa e seng ya molomo		
<b>d330</b> Ho bua		
<b>d335</b> Ho hlahisa melaetsa e seng ya molomo		
<b>d350</b> Puisano		

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### ***Lenaneo le Lekgutshwane la dibaka tsa Tshisinyeho (A) le ho Nka Karolo (P)***

<b>d4. HO TSAMAYA</b>	<b><i>Lehlalosi la phethahatso</i></b>	<b><i>Lehlalosi la bokgoni</i></b>
<b>d430</b> Ho phahamisa le ho tshwara dintho		
<b>d440</b> Ho sebedisa letsoho hantle ( <i>ho thonaka, ho tshwara</i> )		
<b>d450</b> Ho tsamaya		
<b>d465</b> Ho potoloha o sebedisa sesebediswa ( <i>setulo se tsamayang, di-skeiti, jj.</i> )		
<b>d470</b> Ho sebedisa dipalangwang ( <i>koloi, bese, terene, sefofane, jj.</i> )		
<b>d475</b> Ho kganna ( <i>ho palama baesekele le sethuthuthu, ho kganna koloi, jj.</i> )		

<b>d5. HO ITLHOKOMELA</b>		
<b>d510</b> Ho itlhatswa ( <i>ho tola, ho itlhakola, ho hlatswa matsoho, jj.</i> )		
<b>d520</b> Ho hlokomela diitho tsa mmele ( <i>ho hlatswa meno, ho kuta ditedu, ho apara hantle, jj.</i> )		
<b>d530</b> Ho ya ntlwaneng		
<b>d540</b> Ho tena diaparo		
<b>d550</b> Ho ja		
<b>d560</b> Ho nwa		
<b>d570</b> Ho baballa bophelo ba hao		
<b>d6. BOPHELO BA LAPENG</b>		
<b>d620</b> Ho fumana thepa le ditshebetso ( <i>ho reka, jj.</i> )		
<b>d630</b> Ho lokisa dijo ( <i>ho pheha, jj.</i> )		
<b>d640</b> Ho etsa mosebetsi wa ntlo ( <i>ho hlwekisa ntlo, ho hlatswa dijana, diaparo, ho aena, jj.</i> )		
<b>d660</b> Ho thusa ba bang		
<b>d7. TSHEBEDISANO PAKENG TSA BATHO LE DIKAMANO</b>		
<b>d710</b> Tshebedisano tsa sethatho pakeng tsa batho		
<b>d720</b> Ditshebedisano tse rarahaneng pakeng tsa batho		
<b>d730</b> Kamano le baditjhaba		
<b>d740</b> Dikamano tse tlwaelehileng		
<b>d750</b> Dikamano tse sa tlwaelehang tsa bodulo		
<b>d760</b> Dikamano tsa lelapa		
<b>d770</b> Dikamano tsa lerato		
<b>d8. DIBAKA TSE MATLA TSA BOPHELO</b>		
<b>d810</b> Thuto e sa tlwaelehang		
<b>d820</b> Thuto ya sekolong		
<b>d830</b> Thuto e phahameng		
<b>d850</b> Mosebetsi o nang le moputso		
<b>d860</b> Thekisetsano tsa motheo tsa moruo		
<b>d870</b> Ho ikgona ho tsa moruo		
<b>d9. BOPHELO BA MOTSE, BA BODULO LE BA BOAHI</b>		
<b>d910</b> Bophelo ba Motse		
<b>d920</b> Boithabiso le boiketlo		
<b>d930</b> Tumelo le borapedi		
<b>d940</b> Ditokelo tsa botho		
<b>d950</b> Bophelo ba dipolotiki le boahi		

**TSHISINYEHO EFE KAPA EFE E NNGWE LE HO NKA KAROLO**

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## **KAROLO 3: MABAKA A TIKOLOHO**

▣ *Mabaka a tikoloho a bopa sebaka, bodulo le tshadimo ya lefatshe ya moo batho ba phelang teng le mokgwa oo ba tsamaisang bophelo ba bona.*

**Lehlalosi ho tikoloho: 0** Ha ho mekwallo **0** Ha ho mohlophisi

**Mekwallo kapa mohlophisi 1** Mekwallo e bonolo +1 Mohlophisi ya bonolo

**2** Mekwallo e mahareng +2 Mohlophisi ya mahareng

**3** Mekwallo e matla +3 Mohlophisi ya bonahalang

**4** Mekwallo e feletseng +4 Mohlophisi ya feletseng

<b>Lenaneo le Lekgutshwane la Tikoloho</b>	<b>Lehlalosi mokwallo kapa mohlophisi</b>
<b>e1. DIHLAHISWA LE THEKNOLOJI</b>	
<b>e110</b> Bakeng sa tshebediso ka bowena ( <i>dijo, meriana</i> )	
<b>e115</b> Bakeng sa tshebediso ya hao ya ka mehla	
<b>e120</b> Bakeng sa tshebediso ya hao ya kantle le kahare ya ho tsamaya le ya dipalangwang	
<b>e125</b> Dihlahiswa tsa kgokahano	
<b>e150</b> Dihlahiswa tsa ho rala, ho aha le meaho le theknoloji ya meaho ya ho sebediswa ke setjhaba	
<b>e150</b> Dihlahiswa tsa ho rala, ho aha le meaho le theknoloji ya meaho ya ho sebediswa ke ba poraefete	
<b>e2. TIKOLOHO YA TLHAHO LE DIPHETOHO TSE ENTSWENG KE BATHO HO TIKOLOHO</b>	
<b>e225</b> Maemo a lehodimo	
<b>e240</b> Kganya	
<b>e250</b> Modumo	
<b>e3. TSHEHETSO LE DIKAMANO</b>	
<b>e310</b> Lelapa le haufi-ufi	
<b>e320</b> Metswalle	
<b>e325</b> Ba tsebanang, dithaka, bomphato, baahisani le diho tsa motse	
<b>e330</b> Batho ba okametseng	
<b>e340</b> Ba nehelanang ka tlhokomelo ya motho le bathusi ba bowena	
<b>e355</b> Ditsebi tsa bophelo	
<b>e360</b> Ditsebi tse amanang le tsa bophelo	
<b>e4. MAEMO</b>	
<b>e410</b> Maemo a motho a diho tse haufi-ufi tsa lelapa	
<b>e420</b> Maemo a motho a metswalle	
<b>e440</b> Maemo a motho a ba nehelanang ka kgathallo ya botho le bathusi ba motho	
<b>e450</b> Maemo a motho a ditsebi tsa bophelo	
<b>e455</b> Maemo a motho a ditsebi tse amanang le tsa bophelo	
<b>e460</b> Maemo a tsa bodulo	
<b>e465</b> Mekgwa ya bodulo, ditlwaelo le ditumelo	
<b>E5. DITSHEBELETSO, DITSHEBETSO LA MAANO</b>	
<b>e525</b> Ditshebeletso, ditshebetso le maano a matlo	
<b>e535</b> Ditshebeletso, ditshebetso le maano a kgokano	
<b>e540</b> Ditshebeletso, ditshebetso le maano a dipalangwang	
<b>e550</b> Ditshebeletso, ditshebetso le maano a molao	
<b>e570</b> Ditshebeletso, ditshebetso le maano a tshireletso ya bodulo	
<b>e575</b> Ditshebeletso, ditshebetso le maano tshetso ya bodulo	
<b>e580</b> Ditshebeletso, ditshebetso le maano a tsa bophelo	
<b>e585</b> Ditshebeletso, ditshebetso le maano a thuto le thupelo	
<b>e590</b> Ditshebeletso, ditshebetso le maano a mesebetsi le khiro	
<b>MABAKA AFE KAPA AFE A MANG A TIKOLOHO</b>	

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## Sehlomathiso 2:

### DIPOTSO KA BOPHARA MABAPI LE HO NKA KAROLO LE DITSHISINYEHO

Dipotso tse latelang tse fuputsang di hlahiswa jwalo ka tataiso ya mohlalobi ha a buisana le moarabi mabapi le mathata a ho sebetsa le ditshisinyeho tsa bophelo, ho ya ka boikgetho pakeng tsa bokgoni le tshebetso, Ho elwa hloko tlhahisoleseding yohle ya botho e tsejwang mabapi le moarabi le ho botsa dipotso tse fuputsang dife kapa dife tse eketsehileng ho ya ka moo ho hlokehang. Dipotso tse fuputsang di lokela ho botjwa hape jwalo ka dipotso tse bulehileng ha ho hlokeha hore di hlahise tlhahisoleseding e ngata le ho feta.

Tlase sebaka ka seng ho na le mofuta e mmedi ya dipotso tse fuputsang:

Potso ya pele e fuputsang e leka hore moarabi a tobe ho **bokgoni** ba hae ba ho etsa mosebetsi kapa tshisinyeho, mme ka ho ikgethang a tobe ho meedi ya bokgoni eo e leng **dipontsho tse mading kapa tsa tlhaho tsa motho** ka boyena. Meedi ena e lokela ho ba dipheho tse totobetseng tsa maemo a bophelo ba moarabi, ntle le thuso. Ka **thuso** re bolela thuso e tswang ho motho e mong, kapa thuso e nehelwang ka sesebediswa kapa koloi e lokiseditsweng kapa e bopilweng ka ho ikgethang, kapa le ofe mofuta wa phetolo ya tikoloho ya phapusi, lehae, sebaka sa mosebetsi jwalo jwalo. Bophahamo ba bokgoni bo lokela ho ahlolwa ka ho nyalana le bo lebelletsweng ka tlwaelo ho motho, kapa bokgoni ba motho pele a fumana maemo a bona a bophelo.

Potso ya bobedi e fuputsang e lokela ho toba ho **phethahatso ya nnete** ya mosebetsi kapa tshisinyeho ya Moarabi maemong a nnete a motho kapa tse mo potileng, mme e hlahise tlhahisoleseding mabapi le dipheho tsa mekwallo ya tikoloho kapa tsa bahlophisi. Ke ntho ya bohlokwa ho matlafatsa hore o na le thahasello feela ho boholo ba mathata ao moarabi a nang le ona ho etsa dintho **ha ho hakannngwa hore o batla ho**

**di etsa.** Ho se etse letho ha ho bolele letho ha motho a kgetha ho se e else.

#### I. Ho tsamaya

(Bokgoni)

(1) Maemong a hao a jwale a bophelo, o na le bothata bo bokae ba ho tsamaya sebaka se selelele (se kang kilomita kapa ho feta) ntle le thuso?

(2) Hona o ho bapisa jwang le motho e mong, ya tshwanang le wena hantle a hloka feela maemo a hao a bophelo?

(Kapa: "...ho na le ka moo o neng o le ka teng pele o hlaselwa ke tsietsi ya hao ya bophelo kapa o hlalhelwa ke kotsi?)

(Ho phetha tshebetso)

(1) Sebakeng se o potapotileng ha jwale, o na le bothata bo bokae ba nnete ba ho tsamaya sebaka se selelele (se kang kilomita kapa ho feta)?

(2) Na bothata bona ba ho tsamaya bo a mpefala, kapa ho ntlafala, ke sebaka sa hao se o potapotileng e le ka nnete?

(3) Na bokgoni ba hao ba ho tsamaya dibaka tse telele ntle le thuso bo feta kapa bo ka kwano ho na le

ka moo o etsang ka teng e le ka nnete sebakeng sa hao se o potileng?

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#### II. Ho itlhokomela

(Bokgoni)

(1) Maemong a hao a jwale a bophelo, o na le bothata bo bokae ba ho itlhatswa ntle le thuso?

(2) Hona o ho bapisa jwang le motho e mong, ya tshwanang le wena hantle a hloka feela

maemo a hao a bophelo?

Kapa: "...ho na le ka moo o neng o le ka teng pele o hlaselwa ke tsietsi ya hao ya bophelo kapa o hlalhelwa ke kotsi?)"

(Ho phetha tshebetso)

(1) Lehaeng la hao, o na le bothata bo bokae ba nnete ba ho ithatswa?

(2) Na bothata bona bo a mpefala, kapa bo a ntlafala, ho ya ka moo ntlo ya hao emeng ka teng kapa sesebediswa

tse lokisitsweng ka ho ikgetha tseo o di sebedisang?

(3) Na bokgoni ba hao ba ho ithatswa ntle le thuso bo feta kapa bo ka kwano ho na le ka moo o etsang ka teng e le ka nnete sebakeng sa hao se o potileng?

### **III. Bophelo ba Lapeng**

(Bokgoni)

(1) Maemong a hao a jwale a bophelo, o na le bothata bo bokae ba ho hlwekisa fuluru ya moo o dulang, ntle le thuso?

(2) Hona o ho bapisa jwang le motho e mong, ya tshwanang le wena hantle a hloka feela maemo a hao a bophelo?

Kapa: "...ho na le ka moo o neng o le ka teng pele o hlaselwa ke tsietsi ya hao ya bophelo kapa o hlalhelwa ke kotsi?)"

(Ho phetha tshebetso)

(1) Lehaeng la hao, o na le bothata bo bokae ba nnete ba ho hlwekisa fuluru?

(2) Na bothata bona bo a mpefala, kapa bo a ntlafala, ho ya ka moo ntlo ya hao emeng ka teng kapa disebediswa

tse lokisitsweng ka ho ikgetha tseo o di sebedisang?

(3) Na bokgoni ba hao ba ho hlwekisa fuluru ntle le thuso bo feta kapa bo ka kwano ho na le ka moo o etsang ka teng e le ka nnete sebakeng sa hao se o potileng?

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### **IV. Tshebedisano Pakeng tsa Batho**

(Bokgoni)

(1) Maemong a hao a jwale a bophelo, o na le bothata bo bokae ba ho etsa metswalle, ntle le thuso?

(2) Hona o ho bapisa jwang le motho e mong, ya tshwanang le wena hantle a hloka feela maemo a hao a bophelo?

Kapa: "...ho na le ka moo o neng o le ka teng pele o hlaselwa ke tsietsi ya hao ya bophelo kapa o hlalhelwa ke kotsi?)"

(Ho phetha tshebetso)

(1) Maemong a hao a jwale, o na le bothata bo bokae ba nnete ba ho etsa metswalle?

(2) Na bothata bona bo etsa ho fumana metswalle ho mpefale, kapa ho ntlafale ka ntho efe kapa efe (kapa le mang feela) sebakeng se o potapotileng?

(3) Na bokgoni ba hao ba ho etsa metswealle, ntle le thuso bo feta kapa bo ka kwano ho na le ka moo o etsang ka teng e le ka nnete sebakeng sa hao se o potileng?

### **V. Dikarolo tse Matla tsa Bophelo**

(Bokgoni)

(1) Maemong a hao a jwale a bophelo, o na le bothata bo bokae ba ho phetha mosebetsi kaofela o hlohang ho o etsa bakeng sa mosebetsi wa hao, ntle le thuso?

(2) Hona o ho bapisa jwang le motho e mong, ya tshwanang le wena hantle a hloka feela maemo a hao a bophelo?

Kapa: "...ho na le ka moo o neng o le ka teng pele o hlaselwa ke tsietsi ya hao ya bophelo kapa o hlahelwa ke kotsi?)"

(Ho phetha tshebetso)

(1) Sebakeng se o potapotileng ha jwale, o na le bothata bo bokae ba nnete ba ho etsa mosebetsi kaofela o hlokang o phethwe ho etsa mosebetsi wa hao?

(2) Na bothata bona ba ho kgotsofatsa ditlhoko tsa mosebetsi wa hao bo a mpefala, kapa bo a ntlafala, ke mokgwa oo

tikoloho ya mosebetsi e emeng ka wona kapa disebediswa tse lokisitsweng ka ho ikgetha tseo o di sebedisang?

(3) Na bokgoni ba hao ba ho etsa mosebetsi wa hao, ntle le thuso, bo feta kapa bo ka kwano ho na le

ka moo o etsang ka teng e le ka nnete sebakeng sa hao se o potileng?

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## **VI. Bophelo ba Motse, ba Bodulo le ba Boahi**

(Bokgoni)

(1) Maemong a hao a jwale a bophelo, o na le bothata bo bokae ba ho nka karolo diphuthehong tsa motse, meketeng kapa diketsahalong tse ding tsa lehae, ntle le thuso?

(2) Hona o ho bapisa jwang le motho e mong, ya tshwanang le wena hantle a hloka feela maemo a hao a bophelo?

Kapa: "...ho na le ka moo o neng o le ka teng pele o hlaselwa ke tsietsi ya hao ya bophelo kapa o hlahelwa ke kotsi?)"

(Ho phetha tshebetso)

(1) Motseng wa heno, o na le bothata bo bokae ba nnete ba ho nka karolo diphuthehong tsa motse, meketeng kapa diketsahalong tse ding tsa lehae?

(2) Na tsietsi ena e mpefetse, kapa e ntlafetse, ke mokgwa oo motse wa heno o hlophisitsweng ka teng kapa

disebediswa tse lokisitsweng ka ho ikgetha, dikoloi kapa le eng eo o e sebedisang?

(3) Na bokgoni ba ho nka karolo diketsahalong tsa motse, ntle le thuso, di ka hodimo kapa ka kwano

ho ka moo o etsang ka teng e le ka nnete sebakeng sa hao se o potileng?

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## Appendix AK INFORMATION SHEET FOR PATIENTS – SeSotho Version

### LENWGALE LA HLAHISO LESEDING HO MOLWETSIMOKUDI

Mokudi yo a ratehang

*Lebitso la ka ke Witness Mudzi. Ke morutabana mo lefapheng la physiotherapy Unibesithing ya Witwatersrand. Ke etsa dipatlisiso ho fumana tsela e ntle ka ho fitisisa ya ho ruta batho ba ba hlokomelang motho ya shweleng lehlakore (bahlokomedi ba mokudi)) hore ba tsebe ho etsa mosebetsi ha bobebe/bonolo. Dipatlisiso tsena di sheba le hore mokudi le motho eo a mo hlokomelang ba kgona jwang ha ba le hae.*

Ke thotse lebitso la hao kamoreng ye o neng o robetse ho yona sepetlela ha o ne o shwa lehlakore. Ha o dumela ho nka karolo dipatlisisong tsena o tla tsenywa sehlopheng se le seng ho tse pedi. O tla Kenywa ho se seng sa dihlopha tsena ka ho nka sephuthelwana moo o tla tholang hlahiso leseding ka sehlopha se o leng ho sona. Ho dumela ho nka karolo dipatlisisong tsena ho ra hore o dumelelana le tse latelang (Ho ya le hore o mo sehlopheng se feng).

#### Sehlopha 1 (Sehlopha sa ho laola)

Ha o kentswe mo sehlopheng 1, o tla thola thupello e tlwaelehileng ya ha o shwele lehlakore ho tswana le eo e tholang sepetlele. Mohlokomedi wa hao o tla rupellwa ho ho hlokomela ka tsela eo ho tswaetsweng ho etswa sepetlela ke basebetsi ba sepetlela. O tla botswa dipotso o sa le sepetlela le ka moraho ha hore o tswa sepetlela mo kgweding tse 3, 6 le 12 (hae kapa kliniking ye haufi kapa sepetlela). Dipotso di tla be di shebane le hore o tsamaya jwang, o kgona jwang ho etsa ntho tse o tswaetsweng ho di etsa hae le ho kgotsofalela ha hao bophelo ka kakaretso.

#### Sehlopha 2 (sehlopha sa dipatlisiso)

Ha o kentswe sehlopheng 2, o tla thola thupello e tlwaelehileng ya ha o shwele lehlakore ho tswana le eo e tholang sepetlele. Mohlokomedi wa hao o tla rupellwa ho ho hlokomela ka tsela eo ho tswaetsweng ho etswa sepetlela ke basebetsi ba sepetlela. Hodimo ha thupello e tlwaelehileng ya sepetlela mohlokomedi wa hao o tla thola thupello e keneletseng e beakantsweng hantle. Thuto yena e tla kenyeletsa ho rutwa ka "tshebediso ya matsoho" hore o ka thusa jwang motho ya shweleng lehlakore ho tloha setulong ho ya beteng, ho tsamaya, ho thibela dintho tse tswang letlalong ha o robetse nako e telele le ho ba thusa ka ho ithoma mantle le moroto. O tla fiwa hlahiso leseding ka dilo tse etsang hore motho a shwe lehlakore le hore o ka thibela jwang ho shwa lehlakore hape. O tla botswa dipotso ha o sa le sepetlela le ha o lokolotswe sepetlela mo kgweding ya 3, 6 le 12 (Hae kapa kliniking ya haufi kapa sepetlela). Dipotso di tla be di shebile hore o tsamaya hantle ha kanakang, o kgona jwang ho etsa dintho tse o tswaetsweng ho di etsa hae le ho kgotsofalela ha hao bophelo ka kakaretso.

Ha o le sehlopheng 2, thuto e mohlokomedi wa hao a tla e tholang e tla ba mahareng a metsotso e 30 le 45. Se se tla etswa ha o a sa le sepetlela. Bahlokomedi bao ba bonang hore ba hloka nako e fetang ena ba tla fiwa nako eo ba e hlohang hore ba kgone ho utlwisisa hlahiso leseding eo ba e fiwang.

Ho sa kgathalitse hore o sehlopheng sefeng, hle tseba hore ha o tobelle/hapeletse hore nka karolo dipatlisisong tsena, o na le boikgethelo. O ka se lefiwe/patelwe ho nka karolo dipatlisisong tsena. O ka tlohela nako efe kapa efe ha o batla. Ho hana ho nka karolo dipatlisisong tsena ha ho no ama kalafi ya hao sepetlela kapa kalafi efe kapa efe eo a tla e fumanang moraho ha ho tswa sepetlela.

Ke tshepa hore dipatlisiso tsena di tla re thusa hore re thole tsela e ntle ka ho fetisisa ya ho ruta bahlokomedi ba bakudi ba shweleng lehlakore hore bakudi ba shweleng lehlakore ba be kaone ntle le ho imetsa bahlokomedi.

Ha o hloka ho ikopanya le nna ka nako efe kapa efe, hle sebedisa dinomoro tse mo tlase.

Ke lebohlang thuso ya hao.

Witness Mudzi (Mr.)  
Lefapha la Physiotherapy  
Unibesithi ya Witwatersrand

Nomoro ya mohala : 072 858 2942 (Cell)  
: 011 717 3716 (Mosebetsi)

## Appendix AL

### CONSENT FORM FOR PATIENTS – SeSotho Version

#### LENGWALO LA HO DUMELA HO NKA KAROLO LA MOKUDI

Nna ..... ke badile lengwalo la hlahiso leseding ebile ke dumela ho nka karolo mo dipatlisisong tse etswang ke Mr. W. Mudzi. Ka ho saena foromo ena ke dumela hore ke tla botswa dipotso makgethlo a 4 (sepetlela le kgwedi tse 3, 6, le 12 moraho ha hore ke tswa sepetlela) hore ho tholwe hore ke kgona jwang ko hae le ho kgotsofalela bophelo ha ka, ka kakaretso. Ke dumela hape le ho nehelana ka lebitso la motho eo a tla nhlokomelang ha ke tswa sepetlela, hore ba tsebo kopjwa/kgopelwa hore ba nke karolo dipatlisisong tsena ha eba ba batla.

Ke utlisisa hore ha ke no lefiwa ha ke nka karolo le hore ha ke pateletsehe ho nka rarolo ebile nka ikgohele moraho mo dipatlisisong nako efe kapa efe ha ke batla. Ke utlwisisa hape le hore sena ha se no ama kalafi ya ka ka tsela efe kapa efe le hore ho hana haka ha ho na ho mpea maemong a mabe ka tsela efe kapa efe

Saenilwe:.....

Paki:.....

Letsatsi:.....



## APPENDIX AM

### INFORMATION SHEET FOR CAREGIVERS – SeSotho Version

#### LENWGALE LA HLAHISO LESEding HO BAHLOKOMEDI BA MOLWETSI/MOKUDI

Mohlokomedi wa molwetsi yo a ratehang

*Lebitso la ka ke Witness Mudzi. Ke morutabana mo lefapheng la physiotherapy Unibesithing ya Witwatersrand. Ke etsa dipatlisiso ho fumana tsela e ntle ka ho fitisisa ya ho ruta batho ba ba hlokomelang motho ya shweleng lehlakore (bahlokomedi ba mokudi)) hore ba tsebe ho etsa mosebetsi ha bobebe/bonolo. Dipatlisiso tsena di sheba le hore mokudi le motho eo a mo hlokomelang ba kgona jwang ha ba le hae.*

Ke thotse bitso la hao ho ..... Yo a kgethileng wena hoba motho yo a tla mo hlokomelang ha a lokolotswe ho tswa sepetlela moo ba fumanang kalafi ya ho shwa lehlakore. Ha o dumela ho nka karolo dipatlisisong tsena, o tla tsenywa mo sehlopheng se le seng ho tse pedi. O tla tsenywa mo sehlopheng se motho eo a ho kgethileng ho ba mohlakomedi a leng ho sona. Sena se entswe ka ho ba kopa(mokudi) hore ba kgethe sephuthelwana se tshwailweng se nang le hlahiso lesedi ka sehlopha se ba leng ho sona. Ho dumela ho nka karolo dipatlisisong tsena ho ra hore o dumelelana le tse latelang (Ho ya le hore o mo sehlopheng se feng).

#### Sehlopha 1 (Sehlopha sa ho laola)

O tla thola thuto le hlahiso leseding e tlwaelehleng ya sepetlela. O tla botsiswa dipotso ha mokudi a sa le sepetlela le ha a lokolotswe sepetlela mo kgweding ya 3, 6 le 12 (Hae kapa kliniking ya haufi kapa sepetlela, efe kapa efe e leng bonolo ho wena). Dipotso di tla be di shebile hore o kgona jwang ho hlokomela mokudi le ho kgotsofalela ha hao bophelo ka kakaretso.

#### Sehlopha 2 (sehlopha sa dipatlisiso)

O tla thola thuto le hlahiso leseding e tlwaelehleng ya sepetlela. Hodimo ha thuto le hlahiso leseding ye tlwaelehleng ya sepetlela o tla thola thuto e keneletseng e beakantsweng hantle. Thuto ena e tla kenyeletsa ho rutwa ka "tshebediso ya matsoho" hore o ka thusa jwang motho ya shweleng lehlakore ho tloha setulong ho ya beteng, ho tsamaya, ho thibela dintho tsa letlalo tse tswang ha o robetse nako e telele, le ho ba thusa ka ho ithoma mantle le moroto. O tla fiwa hlahiso leseding ka dilo tse etsang hore motho a shwe lehlakore le hore o ka thibela jwang ho shwa lehlakore hape. O tla botswa dipotso ha mokudi a sa le sepetlela le ha a lokolotswe sepetlela mo kgweding ya 3, 6 le 12 (Hae kapa kliniking ya haufi kapa sepetlela, efe kapa efe e leng bonolo ho wena). Dipotso di tla be di shebile hore o kgona jwang ho hlokomela mokudi le ho kgotsofalela ha hao bophelo ka kakaretso.

Ha o le sehlopheng 2, thuto eo o tla e tholang e tla ba mahareng a metsotso e 30 le 45. Se se tla etswa ha mokudi a sa le sepetlela. Bao ba bonang hore ba hloka nako e fetang ena ba tla fiwa nako eo ba e hlokanang hore ba kgone ho utlwisisa hlahiso leseding eo ba e fiwang.

Ho sa kgathalatshe hore o sehlopheng sefeng, hle tseba hore ha o tobellwe/hapeletsehe ho nka karolo dipatlisisong tsena, o na le boikgethelo. O ka se lefiwe/patelwe ho nka karolo dipatlisisong tsena. O ka tlohela nako efe kapa efe ha o batla. Ho hana ho nka karolo dipatlisisong tsena ha ho no ama bophelo bja hao ka tsela efe kapa efe. Ho hana ho nka karolo dipatlisisong tsena ha ho no ama kalafi ya leloko la hao (mokudi) sepetlela kapa kalafi efe kapa efe eo a tla e fumanang moraho ha ho tswa sepetlela.

Ke tshepa hore dipatlisiso tsena di tla re thusa hore re thole tsela e ntle ka ho fetisisa ya ho ruta bahlokomedi ba bakudi ba shweleng lehlakore hore bakudi ba shweleng lehlakore ba be kaone ntle le ho imetsa bahlokomedi.

Ha o hloka ho ikopanya le nna ka nako efe kapa efe, hle sebedisa dinomoro tse mo tlase.  
Ke lebohang thuso ya hao.

Witness Mudzi (Mr.)  
Lefapha la Physiotherapy  
Unibesithi ya Witwatersrand.

Nomoro ya mohala : 072 858 2942 (Cell)  
: 011 717 3716 (Mosebetsi)

## Appendix AN

### CONSENT FORM FOR CARE GIVERS – SeSotho Version

#### **LENGWALO LA HO DUMELA HO NKA KAROLO LA BAHLOKOMEDI BA MOKUDI**

Nna ..... ke badile lengwalo la hlahiso leseding ebile ke dumela ho nka karolo mo dipatlisisong tse etswang ke Mr. W. Mudzi. Ka ho saena foromo ena (ha ke le sehlopheng 2, sehlopha sa dipatlisiso) Ke dumela ho fiwa thupelo e keneletseng ya hore ke hlokomele jwang leloko la lelapa le shweleng lehlakore. Ke dumela hape (sehlopha 1 le 2) ho botswa dipotso makgehlo a 4 (ha mokudi a nse a le sepetlela le kweding tse 3, 6, le 12 moraho ha hore a tswe sepetlela) hore ho tholwe hore ke kgona jwang ho hlokomela mokudi ya shweleng lehlakore le ho kgotsofalela bophelo ka kakaretso.

Ke utlisisa hore ha ke no lefiwa ha ke nka karolo le hore ha ke pateletsehe ho nka karolo ebile nka ikgohela moraho mo dipatlisisong nako efe kapa efe ha ke batla. Ke utlwisisa hape le hore sena ha se no ama kalafi ya leloko la ka la lelapa ka tsela efe kapa efe.

Saenilwe:.....

Paki:.....

Letsatsi:.....

## Appendix AO

### Training Manual for Research Assistants

#### Caregiver Education/Training

The caregiver education will focus on the following aspects:

**a) Definition of a stroke:**

- Can also called a "cerebrovascular accident" or CVA
- Occurs when blood vessels carrying oxygen and other nutrients to a specific part of the brain suddenly burst or become blocked.
- The problem with blood circulation cuts off the oxygen supply and brain cells begin to die.

**b) Causes of a stroke:**

Strokes fall into several major categories, based on whether the disrupted blood supply is caused by a blocked blood vessel (also known as an ischemic stroke) or a hemorrhage. Since each type of stroke has a different type of treatment, it is very important for the physician to determine the cause of the stroke, as well as the location, as quickly as possible.

**i) Risk Factors That Can Be Changed**

- hypertension (high blood pressure)
- smoking
- heart disease
- high cholesterol level
- excess alcohol intake
- obesity
- sedentary lifestyle
- diabetes
- elevated hematocrit (increase in red blood cells)
- use of oral contraceptives (especially for women who smoke)
- stress
- 

**ii) Risk Factors That Cannot Be Changed**

- age
- sex
- race
- family or individual history of stroke or TIA

**c) Warning signs of a stroke:**

- Your physician may identify certain signs that indicate you are at risk for stroke.
- Or, your body may warn you by the appearance of one or more of the symptoms listed below:
  - ▲ Sudden weakness, numbness or paralysis of the face, arm or leg (especially on one side of the body)
  - ▲ Loss of speech or trouble talking or understanding language
  - ▲ Sudden loss of vision, particularly in only one eye
  - ▲ Sudden, severe headache with no apparent cause
  - ▲ Unexplained dizziness, loss of balance or coordination (especially if associated with any of the above symptoms)

**d) Consequences of a stroke:**

- Different areas of the brain control different bodily functions.
  - When certain brain cells are not able to function due to stroke, the parts of the body controlled by those cells are also unable to function.
  - For instance, if the left hemisphere of the brain is damaged, most of the effects will occur on the right side of the body.
- i) On the patient:
- ▲ hemiparesis (paralysis on one side of the body)
  - ▲ aphasia (the loss of ability to speak or to understand language)
  - ▲ spatial-perceptual deficits
  - ▲ learning difficulties
  - ▲ memory loss
  - ▲ behavioral/emotional changes
  - ▲ loss of motor skills - inability to do activities of daily living such as feeding, bathing, dressing
  - ▲ loss of sensation
  - ▲ confusion
  - ▲ inability to walk
  - ▲ inability to go to work
  - ▲ problem with knowing how to do things one normally does
  - ▲ emotional problems from failure to accept disability and a feeling of helplessness
  - ▲ possible death from complications
- ii) On the carers:
- ▲ Change of social schedules while trying to accommodate patient
  - ▲ May even have to quit work
  - ▲ Will have little time to socialise and interact with other family and friends
  - ▲ Can be emotionally and physically draining

NB: Important to highlight that patient is a changed somebody following a stroke and family should be prepared to deal with that.

e) **Prevention and Management Options Following a Stroke**

i) **Prevention:**

o **Regular Medical Check-ups**

- ▲ To allow monitoring of above said risk factors
- ▲ Risk factors such as heart disease, high blood pressure, and elevated blood cholesterol must be monitored by your physician on a regular basis.

o **Control Blood Pressure**

- ▲ High blood pressure (hypertension) is the single most important risk factor for stroke.
- ▲ Even mild hypertension, if not adequately treated, increases stroke risk.
- ▲ Hypertension is often called the “silent killer” because there may be no obvious symptoms.
- ▲ It is important to check your blood pressure regularly.
- ▲ Controlling blood pressure, whether by a low-sodium diet, weight control, stress management and/or medication will reduce your risk of stroke.
- ▲ Remember: medication to control hypertension is effective only if taken on a regular basis, so it is important to follow your physician’s instructions.

o **Stop Smoking**

- ▲ Studies confirm that smokers have a higher risk of stroke, regardless of other factors such as age, high blood pressure, or heart disease.
- ▲ The risk declines dramatically within a few years of stopping smoking.

o **Treat Heart Disease**

- ▲ A variety of heart conditions, including irregular heart rhythms (atrial fibrillation), heart attacks and heart valve disorders, can cause stroke.
- ▲ Treatment of these disorders can reduce stroke risk.

o **Improve Diet**

- ▲ Consumption of foods high in fat, cholesterol and salt increases the risk for stroke.
- ▲ The following recommendations are among the most important for stroke prevention.
- ▲ Ask your doctor for more help in identifying dietary culprits and making appropriate substitutions.
  - **Avoid excess fat:**
    - High intakes of fat, particularly saturated fat, and cholesterol may contribute to atherosclerosis, which is associated with stroke.
    - Dietary fat and cholesterol may be reduced by limiting fat or oil added in cooking, trimming fat and skin from meats and poultry, using low-fat or non-fat dairy products, broiling and baking foods rather than frying, and limiting eggs to no more than three a week.
  - **Avoid excess sodium:**
    - Excess sodium in the diet is linked to hypertension.
    - Table salt is the primary source of dietary sodium.
    - Try to eat fresh food whenever possible.
  - **Limit alcohol intake:**

- Individuals who drink alcoholic beverages (more than two drinks per day) have an increased risk of stroke.
  - For heavy drinkers, the risk of stroke increases further
- **Maintain a Healthy Weight**
  - ▲ Being overweight strains the heart and blood vessels and is associated with high blood pressure.
  - ▲ Obesity also predisposes a person to heart disease and diabetes, both of which increase the risk for stroke.
  - ▲ Keeping your weight to recommended levels for your height and build is a prudent preventive measure.
- **Exercise Regularly**
  - ▲ The percentage of fat in our bodies tends to increase with age.
  - ▲ Regular exercise helps keep this increase to a minimum.
  - ▲ There appears to be an inverse relationship between exercise and arterial blockage from fat , i.e., more exercise is linked to lower levels of artery blockade from fat
- **Treat Diabetes**
  - ▲ The association between diabetes and increased stroke risk seems to be related to the circulatory problems caused by diabetes.
  - ▲ Good control of diabetes appears to reduce the cardiovascular complications of the disease.
- **Reduce Stress**
  - ▲ Because stress may increase blood pressure, it is linked indirectly to stroke risk.
  - ▲ A one-time stressful event rarely causes a stroke, but long-term unresolved stress can contribute to high blood pressure.
  - ▲ Stress management, including relaxation techniques, biofeedback, exercise and counseling, appear to be useful in the treatment of high blood pressure, thus lowering the risk of stroke.
- **Use of Oral Contraceptives**
  - ▲ Oral contraceptives, especially those with high estrogen content, appear to increase the risk of blood clots, including clots that cause stroke, especially in women over age 30.
  - ▲ The risk is even higher in women who smoke.
  - ▲ Consult your physician for advice regarding alternative methods of birth control if you have stroke risk factors and are currently using oral contraceptives.
- **Post-menopausal Estrogen Use**
  - ▲ Recent studies have shown that post-menopausal estrogen replacement is associated with a small increase in the risk of stroke.

**ii) Management following a stroke:**

- If cause is high blood pressure – importance of taking medication to control blood pressure
- Physiotherapy
  - Helps with:
    - Bed mobility
    - Mobility out of bed ( in the house and outside) – ( Transfers and Gait)
    - Regaining of strength
- Occupational Therapy
  - Helps with:
    - Teaching how to do all transfers
    - Teaching how to do the various activities of daily living e.g. wash, dress, eat, home management
    - Ways of coping with disability when doing various chores
    - Regaining movement particularly in the upper limb
    - Cognition
    - perceptual
- Speech Therapy
  - Helps with speech if one has problems understanding speech or speaking.
  - Helps with swallowing
- **All the caregivers in this group will receive “hands-on” training in:**
  - lifting and handling techniques
    - ▲ Protecting the hemiplegic shoulder
    - ▲ Protecting own backs
    - ▲ Giving patient enough time to try out any movement before offering help
    - ▲ Trying facilitation of movement as opposed to doing it for the patient
    - Include rolling, lying to sitting, sitting balance, sitting to standing, standing balance, and wherever possible gait.
  - back care
    - ▲ keep back straight
    - ▲ use hips and knees to bend when lifting
    - ▲ never lift and twist back, rather use feet to turn
    - ▲ if patient too big ask for help with lifting
  - Shoulder care
    - ▲ Shoulder extremely vulnerable following a stroke
    - ▲ Do not pull weak arm or shoulder when doing transfers
    - ▲ Always support weak shoulder during transfers
    - ▲ Position shoulder in retraction when in side lying on affected shoulder
    - ▲ Keep arm supported when sitting in chair or wheelchair at home

- facilitation of mobility and transfers
  - ▲ patient should be given time to practice all movements and not be helped with all activities
  - ▲ when helping with any movement, patient should be an active participant and not a passive recipient
  - ▲ important to know potential of patient and avoid frustrations
  
- continence
  - ▲ pelvic floor muscles weaken following a stroke
  - ▲ this can result in uncontrolled passing out of urine and stool
  - ▲ one way to help regain normal function is doing pelvic floor muscles exercise e.g.
    - pelvic tilt exercise
    - resisted adduction
    - tightening of gluteals and related pelvic floor muscles when urinating (trying to stop urine mid stream)
    - eating food high in fibre for good bowel movement
    - Having regular and consistent times for bowel emptying
    - Drinking adequate fluids (greater than 1.5 litres per day)
  
- Assistance with activities of daily living and communication.
  - ▲ Patient will need help with some if not all activities of daily living they used to do before the stroke
  - ▲ Patient may need assistive devices for help with activities of daily living
  - ▲ Whatever activity that they do, they should be given an opportunity to try before being helped
  - ▲ All movement should involve active participation from the patient
  - ▲ As regards communication:
    - Be patient when they are trying to speak
    - Speak slowly and repeat self
    - Can use a bit of sign language or demonstrations to improve understanding
    - Do not apportion blame for patient's failure to speak clearly or understanding what you are saying
    - Go for speech therapy with patient
  
- **Included will also be information on:**
  - stroke related problems and their prevention
    - ◆ emotional stress
      - ▲ from frustrations with disability and inability to be self reliant
      - ▲ can be prevented by providing family support
      - ▲ can also seek professional counselling from psychologists
    - ◆ incontinence
      - ▲ from weak pelvic floor muscles



- ▲ can also occur due to inability to walk to the toilet
    - ▲ patient may not be able to communicate need to visit the toilet
    - ▲ above pelvic floor exercises and improving communication as described above can help prevent these problems
- ◆ pressure sores
  - ▲ mainly caused by sitting or lying in one place for long periods (unrelieved pressure)
  - ▲ compounded by poor circulation and paralysis
  - ▲ can be prevented by:
    - regular turning of patient when in bed ~ after every 2 hours
    - regular pressure relieving when in wheelchair after every 15 – 30 minutes
    - encouragement of mobilisation as taught by your physiotherapist
    - proper positioning when in wheelchair or bed – bony areas not touching
- ◆ hemineglect
  - ▲ lack of awareness of the affected side
  - ▲ caused by a number of things, among them loss of vision on side with stroke
  - ▲ perceptual problems can also compound the hemineglect
- ◆ contractures
  - ▲ caused mainly by lack of movement in a joint for a long period
  - ▲ results from mainly from muscle shortening
  - ▲ usually accompanied by bone deformities if uncorrected for long periods
  - ▲ can be prevented by:
    - doing regular passive movements and stretches
    - proper positioning when in bed and when in wheelchair
- ◆ painful shoulder
  - ▲ caused by trauma to the shoulder which can be due to:
    - incorrect way of doing passive movements to the shoulder
    - pulling of shoulder during transfers when walking patient
    - poor positioning of shoulder
    - increased muscle tone
  - ▲ May be prevented by:
    - Correct handling during transfers or when mobilising patient
    - Correct positioning when in bed or wheelchair
    - Doing maintenance passive movements
- management/prevention of pressure sores
  - ▲ Occurs from unrelieved pressure as described before
  - ▲ Prevention is also as before
  - ▲ Management of a pressure sores:

- Remove pressure from pressure sore immediately
      - Seek medical attention urgently
      - Try and establish cause of pressure sore to avoid future event.
  - positioning
    - ▲ important for:
      - maintaining proper muscle length
      - prevention of pressure sores
      - avoidance of choking when feeding
      - exacerbation of abnormal patterns
    - ▲ Keep muscles in a lengthened position
    - ▲ Use the sitting or half sitting position for feeding
    - ▲
  - gait facilitation
    - ▲ depending on the physiotherapist's instructions patient must be helped to walk as is appropriate
    - ▲ Safe use of walking aid
  - sexuality.
    - ▲ Usually not a problem if patient is psychologically prepared
    - ▲ Might require reversal of roles if paralysis interfering a lot
    - ▲ Lack of endurance could also affect performance
    - ▲ If problematic, see a psychologist.
- They will also be encouraged to have their stroke survivors attend nursing and therapy activities (mobility, transfers and activities of daily living) during hospitalisation and after discharge where possible.
  - Advice on available community services such as stroke aid groups will be provided
    - ▲ In Soweto the following provide continued care in physiotherapy, Occupational Therapy and Speech Therapy:
      - ◆ Chiawelo Clinic
      - ◆ Mofolo Clinic
      - ◆ Zola Clinic
    - ▲ Social services and benefits
  - This will be given as a 45 minute (to be confirmed during pilot studies) training session before discharge of the patient.

## Appendix AP

### Ethical Clearance Certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

R14/49 Mudzi

CLEARANCE CERTIFICATE

PROTOCOL NUMBER M050328

PROJECT

Impact of Caregiver Education on Stroke Survivors and Their Caregivers

INVESTIGATORS

Mr W Mudzi

DEPARTMENT

Physiotherapy

DATE CONSIDERED

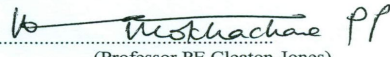
05.04.01

DECISION OF THE COMMITTEE\*

Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 05.05.10

CHAIRPERSON   
(Professor PE Cleaton-Jones)

\*Guidelines for written 'informed consent' attached where applicable

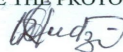
cc: Supervisor : Dr A Stewart

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10005, 10th Floor, Senate House, University.

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES



## Appendix AQ

### Letter of Permission to Access Patient Records at Chris Hani Baragwanath Hospital



CHRIS HANI BARAGWANATH HOSPITAL

MS. G. M. BOGOSHI  
SENIOR CLINICAL EXECUTIVE  
PO BERTSHAM  
2013  
Tel (011) 933 8154/9154  
Fax (011) 938 8161  
e-mail: gmbogoshi@webmail.co.za

*Caring is our Mission*

26 January 2005

Dr. E. Bondarenko  
Chief Executive Officer  
Chris Hani Baragwanath Hospital  
P.O. Bertsham  
2013

Dear Dr. Bondarenko

**RE: ACCES TO PATIENT'S RECORDS**

Enclosed find a request to access patient's records for Mr. Witness Mudzi in partial fulfillment for his PhD study.

It would be appreciated if his request could be granted to ensure completion of his studies. Patient affairs will be contacted to ensure that protocol for access to medical records is adhered to.

Recommended / not recommended

*Bogoshi*  
.....  
**Mrs. G.M. Bogoshi**  
**Senior Clinical Executive**

Recommended / not recommended / Recommended with amendments

*Singh 2006/01/27*  
.....  
**Dr. A. Manning**  
**Director: Clinical Services**

Approved / not approved / Approved with amendments

*Provided it is not interfere with day to day work of the archives Dept.*  
*ee Bond*  
.....  
**Dr. E. Bondarenko**  
**Chief Executive Officer**

*2.02.06.*

# Appendix AR

## Letter of Permission to Conduct Research at Chris Hani Baragwanath Hospital



Gauteng Department of Health

CHRIS HANI BARAGWANATH HOSPITAL

### PERMISSION FOR RESEARCH

DATE: 25/07/2005

NAME OF RESEARCH WORKER: WITNESS MUZZI

TITLE OF RESEARCH PROJECT IMPACT OF CAREGIVER

EDUCATION ON STROKE SURVIVORS AND THEIR CARERS

OBJECTIVES OF STUDY (Briefly or include a protocol): \_\_\_\_\_

See Protocol.

METHODOLOGY (Briefly or include a protocol): \_\_\_\_\_

See Protocol.

CONFIDENTIALITY OF PATIENTS MAINTAINED: Yes

COSTS TO THE HOSPITAL: None

APPROVAL OF HEAD OF DEPARTMENT: Yes

APPROVAL OF CRHS OF WITS UNIVERSITY: Yes

SUPERINTENDENT PERMISSION:

Signature: [Signature] Date: 25 July 2005

Subject to any restrictions: No financial implications to the institution.

