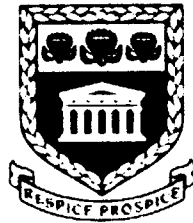


**UNIVERSITY OF THE WESTERN CAPE**

**Physiotherapy Department**



**RESEARCH DISSERTATION**

M.Sc. Physiotherapy

**DISSERTATION TOPIC:**

The Factors Influencing Functional Outcomes of Patients With Stroke  
Receiving Rehabilitation at a Sub-acute Rehabilitation Facility in the  
Western Cape

UNIVERSITY of the  
WESTERN CAPE  
2013

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**KEY WORDS:**

Stroke, factors influencing, functional outcomes, sub-acute rehabilitation facility



A research report submitted to the Faculty of Community of Health Sciences,  
University of the Western Cape, Cape Town, in fulfilment of the requirements for the  
degree of Master of Science in Physiotherapy.

UNIVERSITY OF  
WESTERN CAPE

**DECLARATION:**

I, Ryan Clive Groenewald, declare that this dissertation is my own work. It is being submitted for the degree of Master of Science in Physiotherapy at the University of the Western Cape, Cape Town. It has not been submitted before for any degree or examination at this or any other university.

---

Ryan Clive Groenewald

15<sup>th</sup> day of November, 2013.





**DEDICATION:**

To my wife, Michelle, for always believing in me

UNIVERSITY *of the*  
WESTERN CAPE

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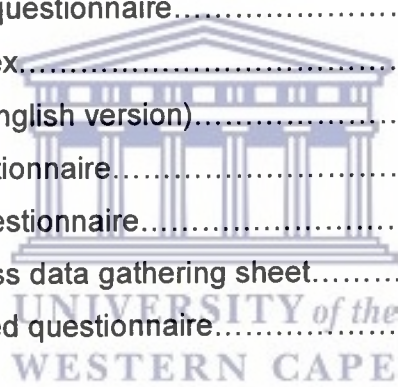
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## **LIST OF ABBREVIATIONS:**

ADL –	Activities of Daily Living
AHA –	American Heart Association
AIDS –	Acquired Immunodeficiency Syndrome
BADL –	Basic Activities of Daily Living
BI –	Barthel Index
BMH –	Booth Memorial Hospital
BP –	Blood Pressure
CCC –	Conradie Care Centre
CHC –	Community Health Centre
CTB –	Computer Tomography Brain
CVA –	Cerebrovascular Accident
CVD –	Cerebrovascular Disease
D/C –	Discharge
DALY –	Disability-adjusted Life Years
Dr –	Doctor
ERH –	Eerste River Hospital
EQ-5D –	Euro Quality of Life Questionnaire
EU –	European Union
FBH –	False Bay Hospital
FAM –	Functional Assessment Measure
FIM –	Functional Independence Measure
GFJ –	GF Jooste (Hospital)
GSH –	Groote Schuur Hospital
GU –	General Unit (Medical)
HIV –	Human Immunodeficiency Virus
HRQoL –	Health Related Quality of Life
HS –	Haemorrhagic Stroke
IADL –	Instrumental Activities of Daily Living
ICF –	International Classification of Functioning, Disability and Health
ICU –	Intensive Care Unit
IDT –	Interdisciplinary Team
IS –	Ischaemic Stroke

KBH –	Karl Bremer Hospital
LIFE-H –	Assessment of Life Habits
MBI –	Modified Barthel Index
MDT –	Multidisciplinary Team
NCD-	Non-communicable Disease
NHP –	Nottingham Health Profile
NIHSS –	National Institute of Health Stroke Scale
NINDS –	National Institute of Neurological Disorders & Stroke
NSA –	National Stroke Association
NSH –	New Somerset Hospital
O.T –	Occupational Therapy
OPD –	Out-patient Department
P.T –	Physiotherapy
QoL –	Quality of Life
SASPI –	Southern African Stroke Prevention Initiative
SF-36 –	Medical Outcomes Study Short Form
SLSR –	South London Stroke Register
SPSS 21 –	Statistical Package for the Social Sciences Version 21
S.T –	Speech Therapist
SU –	Stroke Unit (Specialised Rehabilitation)
SW –	Social Worker
TB –	Tuberculosis Bacillus
TIA –	Transient Ischemic Attack
tPa –	Tissue Plasminogen Activator
TSA –	The Salvation Army
UI –	Urinary Incontinence
UK –	United Kingdom
UWC –	University of the Western Cape
VAS –	Visual Analogue Scale
VHW –	Victoria Hospital Wynberg
WCPT –	World Confederation for Physical Therapy
WCRC –	Western Cape Rehabilitation Centre
WHO –	World Health Organisation



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## **ABSTRACT:**

### **BACKGROUND**

A great deal is known about stroke and its impact in high-income, developed countries, however this is not the case in developing countries, such as Sub-Saharan Africa. Stroke has been identified to be a major non-communicable disease (NCDs) reaching epidemic proportions in low-income, developing regions of the world. The estimates in the WHO global burden of disease update of 2004 places the burden from NCDs in South Africa as two to three times higher than that in developed countries. The rising of NCDs in South Africa, which mostly affects the quality of life of the working-age population and increases the healthcare expenses both at a personal and countrywide level, impacts on the workforce and productivity of the country.

There is much research regarding the factors influencing functional outcomes of individuals following a stroke at tertiary level or specialised rehabilitation institutions elsewhere in the world, where patients received intensive rehabilitation, however here in the South African public sector, where there are limited resources for intensive rehabilitation, only a few studies could be identified. Insufficient knowledge of the factors influencing functional outcome following a stroke in the South African context impacts negatively on the rehabilitation offered, as well as the rehabilitation programmes drawn up for the patients, as goal directed/focused treatment is based on guess work rather than evidence-based best practice.

Two factors, that have not been widely researched, but that have the potential to have a positive influence on functional outcome following a stroke are: 1) a family support network and 2) patient satisfaction. Limited literature is available on the family support network's relationship with functional outcomes and no literature could be identified on the patient's satisfaction in this regard.

## **AIM AND OBJECTIVES**

With the above in mind, the aim of this research study was to determine the factors influencing the functional outcomes of stroke patients receiving rehabilitation at a sub-acute, primary level in-patient rehabilitation facility in the Western Cape. The objectives of the study were to 1) identify the socio-demographic characteristics of each participant, including: age, gender, education level, employment status and history of stroke; 2) identify the medical factors involved with each participant, including: type and locality of stroke, aphasia, hypertension and Diabetes Mellitus; 3) determine the participant's functional level, perceived health related quality of life and perceived family support network; 4) determine the participant's perceived satisfaction level with rehabilitation; 5) identify the process of rehabilitation undergone by each participant, including: referral of participants to BMH, length of stay at BMH, intensity of each discipline of rehabilitation received at BMH, out-patient rehabilitation undergone during six months post discharge; and finally the most important objective of the study 6) to identify possible factors influencing the functional outcomes of the stroke participants. A particular focus was placed on identifying the influence of five factors, namely: 1) level of education, 2) perceived health related quality of life, 3) perceived family support, 4) perceived satisfaction, and 5) rehabilitation intensity.

## **METHODS**

This non-experimental study made use of a quantitative approach with a descriptive, observational, and longitudinal research design and took place at Booth Memorial Hospital (BMH) on 68 first time, acute stroke patients included into the study over a six month time period. Three measurement periods were use, which included admission, discharge and six month follow-up. The research instruments used to achieve the objectives of the study included: a socio-demographic questionnaire, an objective functional assessment in the form of the Barthel Index, a health related quality of life questionnaire in the form of the EQ-5D, a biopsychosocial questionnaires, including a perceived family support questionnaire and a perceived subjective satisfaction questionnaire, a rehabilitation process data gathering instrument, and finally a 'Use of Care' questionnaire.

## RESULTS

The relationships between the five factors being studied and the functional outcome of participants identified the following: A moderate statistically significant relationship ( $p = .02$ ) was noted for level of education, but only at six month follow-up; strong statistically significant results ( $p < .005$ ) were obtained for perceived health related quality of life and patient satisfaction at discharge and six month follow-up respectively; moderate and strong statistically significant differences were noted for perceived family support at discharge ( $p = .02$ ) and follow-up ( $p < .005$ ) respectively; and finally, rehabilitation intensity was identified to have had no statistically significant effect on the functional outcome of participants in this study. Subsequent findings of this study also identified that male participants had a higher functional state throughout the study measurement periods than females but the statistically significant difference between the genders in relation to function became progressively weaker over the three measurement periods from admission ( $p = .02$ ), to discharge ( $p = .046$ ) and at six month follow-up ( $p = .659$ ). Strong statistically significant differences were identified at discharge and six month follow-up for age group of participants in relation to functional outcome,  $p = .002$  and  $.004$  respectively.

Using the regression model, the findings of this study identified that perceived health related quality of life of participants was the strongest and most significant factor ( $p < .0001$ ) influencing the functional outcome of stroke participants at discharge and at six month follow-up respectively, accounting for 90.6% of the variance of function. For every one unit increase in quality of life, representing 1% on the VAS, there was a corresponding increase of .825 in function as measured by the Barthel Index.

## CONCLUSION

The findings of this study highlight the importance of a patient's subject feelings and perceptions toward their health, rehabilitation and family/societal standing in determining their functional outcome post-stroke, with this study suggesting higher perceived quality of life, family support and patient satisfaction with rehabilitation in individuals post-stroke correlated significantly with a higher functional outcome at discharge and at six months post discharge.

## CHAPTER ONE: INTRODUCTION

### 1.0 INTRODUCTION

This chapter begins with the background to the study, where stroke is defined and its global impact and burden are highlighted, with a particular focus on developing countries. In addition, the problem statement, research question, aim and objectives of the study will be highlighted. The chapter will then end with the outline of the chapters to follow.

### 1.1 BACKGROUND TO THE STUDY

Stroke or cerebrovascular accident (CVA), is defined by the World Health Organisation (WHO) as “rapidly developing clinical signs of focal (or global) disturbances of cerebral function, with symptoms lasting 24 hours or longer, or leading to death, with no apparent cause other than that of vascular origin” (WHO, 1988). WHO (2011) further identified that stroke is a condition in which there is an interruption of the blood supply to the brain, due to ischaemia or a haemorrhage of the blood vessel/s, which results in the loss of oxygen and nutrients to the brain and thus leads to neuronal damage. Jorgensen et al (2000) described this neuronal death as the basic damage following a stroke, which results in neurological impairment, functional disability, and frequently a reduction in quality of life.

Connor et al (2006) explained that a great deal is known about stroke and its impact in high-income, developed countries, however this is not the case in developing countries, such as Sub-Saharan Africa. In 2006, Lopez et al described stroke as a global pandemic, and by no means limited to western or high-income countries. About 85% of all stroke deaths were registered in low and middle-income countries, which also accounted for 87% of total years lost in terms of disability-adjusted life years (DALY), calculated worldwide as 72 million per year. WHO (2011) also identifies this global pandemic and added that the burden of stroke is placed on both the family and community. According to the WHO’s ‘10 leading causes of death in the world’, stroke was identified as the second most common cause of death worldwide (WHO 2013). In the World Health Report of 2002, an estimation of the global burden of cerebrovascular disease (CVD), including stroke, identified that two thirds of all stroke deaths occurred in developing regions of the world (WHO, 2002).



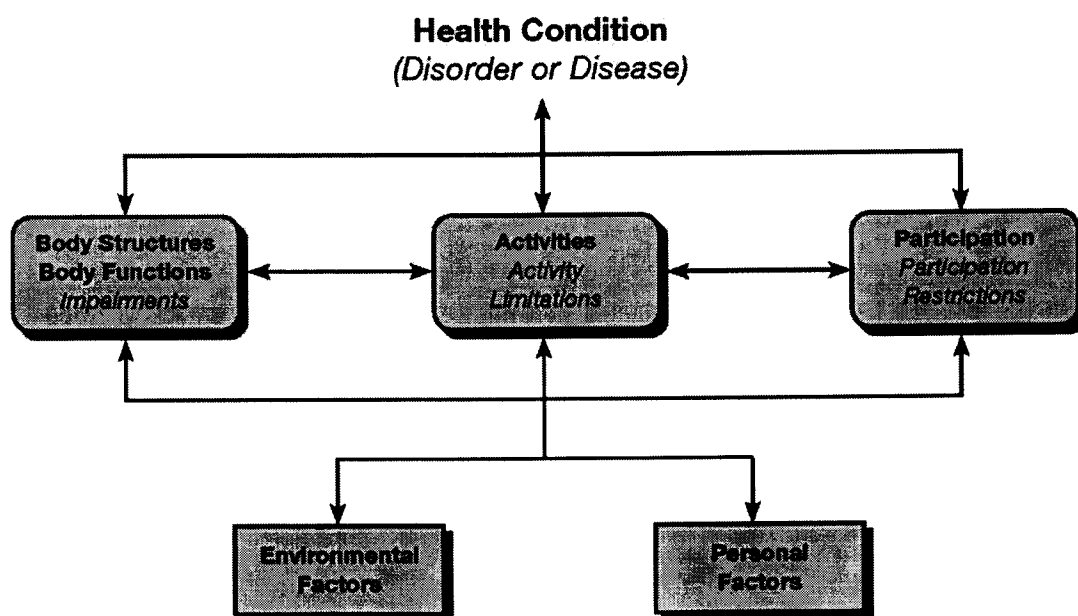
Househam (2010) further identified CVD (stroke), among others, to be a major non-communicable disease (NCD) reaching epidemic proportions in low-income, developing regions of the world. The estimates in the WHO global burden of disease update of 2004 places the burden from NCDs in South Africa as two to three times higher than that in developed countries (WHO, 2004). The rising of NCDs in South Africa, which mostly affects the quality of life of the working-age population and increases the health-care expenses both at a personal and countrywide level, impacts on the workforce and productivity of the country (Bradshaw et al, 2012). Househam (2010) recognised that the burden of NCDs in South Africa demonstrates a potential for a sustained rise in stroke incidence and therefore, significant investment in the health care system is justified.

Teasell et al (2008) recognised the implications of this expected rise in stroke incidence as significant, as the burden of the disability associated with stroke is high. Rehabilitation offers the opportunity to reduce this burden of disability, however given the resource-intensive nature of rehabilitation, it is imperative that it be utilised in a systematic and cost effective manner, in accordance with the best scientific evidence. Bagg et al (2002) identified that the increasing incidence of stroke, primarily in relation to the ageing population, means an increase in the demand for stroke rehabilitation services. Connor et al (2006) explained that, in order to effectively and efficiently use the available limited resources, one would need to know what the cost or economic burden of the disease is in terms of its impact on the health service directly, and on the individual, family and community, both directly and indirectly, financially, and psychosocially.

WHO (2001) reported that the impact of all health conditions and health related states, such as the impact of stroke on an individual, can be described using The International Classification of Functioning, Disability and Health (ICF) framework as it is a universal classification. The ICF is used to provide a 'unified and standard language and framework for the description of health and health related morbidity issues'. The ICF is divided into two domains: '1) body structures and function, and 2) activity and participation.' Function and disability are umbrella terms within the ICF, where functioning encompasses 'all body functions, activities and participation', and disability encompasses 'impairments, activity limitations and participation restrictions.'

The following terms, encompassed within the function and disability umbrellas, are defined by WHO (2001:10) as such: “Impairments are problems in the body function or structure such as a significant deviation or loss. Activity is the execution of a task or action by an individual and activity limitations are difficulties an individual may have executing certain tasks or actions. Participation is the involvement in a real life situation and participation restrictions are problems an individual may experience in involvement in these real life situations.” In addition, contextual factors such as environmental and personal factors are considered within the framework of the ICF. Joseph et al (2013) explained that the ICF framework acknowledges the context-specifics of an individual and the execution of functional tasks within a context, therefore it is imperative to have insight into factors that are predictive of functional outcome of individuals between different settings and various geographical areas in order to inform the rehabilitation process for a particular group of individuals.

The ICF can be used to classify measurements in relation to body functions, activities and participation and can furthermore be categorised as functional, relating to what the person can do, or as a disability, relating to what the person cannot do. The ICF model has no hierarchical direction but can be used and understood in any direction. The ICF can be used for various purposes, namely: as a statistical tool in collection and recording of data; as a research tool to measure outcomes and as a clinical tool in rehabilitation and outcome evaluation (WHO, 2001). Figure 1, can be used as an aid to assist with understanding the interactions between the components of the ICF.



**Figure 1: Interactions between the components of ICF (WHO, 2001)**

Using the ICF model to conceptualising stroke can be done in the following way: Stroke (as the health condition) has an effect on many of an individual's body structures and functions in terms of functional impairments and the individual may present clinically with one or more motor, sensory and/or cognitive deficit in isolation or as a combination of impairments (Duncan et al, 2005). These functional impairments, according to Jorgensen et al (2000) and Kelly-Hayes et al (1998), lead to certain activity limitations, which may include a loss of independence through the decreased ability to mobilise and/or the inability to continue normal activities of daily living (ADL). These activity limitations affect a stroke survivor's ability to participate in everyday life, known as participation restrictions, which could include the inability to work, socialise and be a productive member of society (Desrosiers et al, 2006).

In the available literature, a multitude of researchers over the years have identified numerous factors that influence the functional outcomes in individuals suffering from a stroke. These factors have many dynamics including person-specific factors, such as: age and gender; medical factors, such as: nature and severity of lesion; physical factors, such as: motor or sensory loss and cognitive deficits; psychosocial factors, such as: depression and quality of life; and rehabilitation factors, such as: early onset and intensity of rehabilitation to name a few (these concepts will be discussed in the Literature Review Chapter 2.4).

Scheepers et al (2008) concluded that more detailed knowledge on the precise course of recovery following a stroke would be of practical use to healthcare practitioners as this would enable them to develop a more differentiated prognosis and rehabilitation programme for the affected individuals so as to improve their functional outcomes.

## 1.2 PROBLEM STATEMENT

Working as a physiotherapist at Booth Memorial Hospital (BMH) for two years has shown the researcher that the need for holistic, patient-specific, non-generalised treatment programmes are extremely important. Due to the demand on acute beds in tertiary and district hospitals, the average length of stay per patient is only approximately 3 days and as a result, many patients are being discharged home prematurely. The major responsibility of relieving the Health Department's long-term health burden therefore falls onto the rehabilitation services. Secondary complications frequently develop as a result of other health service providers not referring patients appropriately, resulting in rehabilitation that is more costly, lengthier, and has poorer outcomes (Western Cape Department of Health, 2013).

According to the Western Cape Department of Health's (DOH) Comprehensive Service Plan for the Implementation of Health Care 2010, those patients who are admitted to step-down, sub-acute rehabilitation facilities are only given a short amount of time (six weeks) to gain functional independence before reintegration into their community (Western Cape Department of Health, 2007). As healthcare practitioners, we need to maximise the effectiveness of the time-frame given to allow for maximal functional outcomes for each patient. Aside from maximising the effectiveness of rehabilitation, family or care-givers need to be strongly considered in the overall scheme as the disabled individual becomes their responsibility once discharged from the rehabilitation facility. The disabled individuals put pressure on the wider community as a whole as more time and resources are required to ensure adequate care is given.

The family or care-givers deserve accurate and detailed information from the rehabilitation specialists at the healthcare facility regarding the stroke patient's likely

prognosis of functional recovery so as to best plan for the future of all stakeholders. Without this vital and necessary information, family or care-givers are alone and left in the dark regarding the patient's likely future functional outcomes. This could compound disability in a family and community that may already be stretched thin with available human and financial resources. In order to achieve maximum effectiveness of rehabilitation and reduce the overall burden of disability in the community, a better understanding is required of the role that certain factors play in influencing functional outcomes in stroke individuals in the context of South Africa.

There is much research regarding the factors influencing functional outcomes of individuals following a stroke at tertiary level or specialised rehabilitation institutions elsewhere in the world, where patients received intensive rehabilitation, as seen in studies done by Jehkonen et al (2006), Yannan et al (2003), and earlier studies conducted by David et al (1999) and Jorgensen et al (2000, 1996 and 1994) in The Copenhagen Stroke Study to name a few. However, here in the South African public sector, where there are limited resources for intensive rehabilitation, only a few studies, namely: Rouillard et al (2012) and Joseph et al (2013) were identified. Insufficient knowledge of the factors influencing functional outcome following a stroke in the South African context impacts negatively on the rehabilitation offered, as well as the rehabilitation programmes drawn up for the patients, as goal directed/focused treatment is based on guess work rather than evidence-based best practice.

Two factors that have the potential to have a positive influence on functional outcome following a stroke are: 1) a family support network, as seen in studies done by Halls (2008), Palmer et al (2003), and Naheed (2000) and 2) patient satisfaction. Limited literature is available on the family support network's relationship with functional outcomes and no literature could be identified by the researcher on the patient's satisfaction in this regard. Family support is a crucial factor in improvement of the neuropsychological problems of patients with stroke. Since patients with stroke are impaired by their physical and emotional problems, families have to play a consequential and supportive role to improve their condition and bring them back to near normalcy. Support should be adequately focused towards problem areas, i.e. physical or emotional support (Naheed, 2000).

These two factors, using minimal resources, could be identified to have an influence or not on the functional outcome of individuals following a stroke. A knowledge gap in the literature, especially in a South African context, has been clearly identified and needs to be filled. This study could add to the body of knowledge available locally and address the two variables (family support and patient satisfaction) that have not been researched widely.

### 1.3 RESEARCH QUESTION

What are the factors influencing the functional outcomes of patients with stroke receiving rehabilitation at a sub-acute, primary level in-patient rehabilitation facility in the Western Cape?

### 1.4 AIM

To determine the factors influencing the functional outcomes of patients with stroke receiving rehabilitation at a sub-acute, primary level in-patient rehabilitation facility in the Western Cape.



### 1.5 OBJECTIVES

1.5.1 Describe the socio-demographic characteristics of each participant, including:

- age, gender, education level, employment status and history of stroke

1.5.2 Describe the medical factors involved with each participant, including:

- type and locality of stroke, aphasia, hypertension and Diabetes Mellitus

1.5.3 Determine the participant's functional level, perceived health related quality of life and perceived family support network:

- on admission
- at discharge
- at six month follow-up

1.5.4 Determine the participant's perceived satisfaction level with rehabilitation:

- on discharge
- at six month follow-up

1.5.5 Describe the process of rehabilitation undergone by each participant, including:

- referral of participants to BMH
- length of stay at BMH
- intensity of each discipline of rehabilitation received at BMH
  - Including: Doctor
  - Physiotherapy
  - Occupational Therapy
  - Speech Therapy
  - Social Work
- out-patient rehabilitation undergone during six months post discharge

1.5.6 Describe possible factors influencing the functional outcomes of participants:

- at discharge
- at six month follow-up



## 1.6 OUTLINE OF CHAPTERS TO FOLLOW

Chapter one is the introduction to the study and describes the background, where stroke is defined and its global impact and burden are highlighted, with a particular focus on developing countries. In addition, the problem statement, research question, aim and objectives of the study are highlighted and the chapter ends with the outline of the chapters to follow.

Chapter two presents the literature review, divided into sub-sections, which include the following headings: epidemiology of stroke, disability post-stroke, stroke rehabilitation process, factors affecting the functional outcome of stroke and research instruments. Each sub-heading will then discuss, in detail, the most important information pertaining to the specific section of the chapter in order to give an overall, in-depth view of the study and its objectives. The chapter ends with a summary of the most important points.

Chapter three describes the methodology used in the current study, including the research setting, research design, study population and sampling, the measurement periods, the inclusion/exclusion criteria, the research instruments, validity and reliability, pilot study, data collection and data analysis. The chapter ends with the ethical considerations.

Chapter four presents the results based on the objectives of the study. The results obtained from the data gathered throughout the study over the measurement periods are presented through descriptive, univariate statistics and multivariate statistical analysis, with the aid of figures and tables. Objectives one through five are addressed using descriptive univariate analysis, while objective six is addressed using multivariate analysis. The chapter ends with a summary of the results.

Chapter five discusses the results obtained throughout the study, over the measurement periods, in order to address the research aim and objectives. The discussion surrounds the objectives of the study in the following five sub-sections: socio-demographics of participants, medical factors of participants, the functional state, perceived quality of life and perceived family support of participants, perceived satisfaction levels with rehabilitation, and finally the rehabilitation process factors. The factors that influenced the functional outcomes of the participants in this study are discussed under the relevant sub-section and the implications of these findings are highlighted.

Chapter six is the final chapter and includes the conclusion, which summarises the findings of the study with particular reference to the study objectives. In addition, the chapter also includes the significance and the limitations of the study and finally, ends with recommendations made based on the findings of this study.



## **CHAPTER TWO: LITERATURE REVIEW**

### **2.0 INTRODUCTION**

The purpose of this chapter is to identify and convey, from the available published literature, the most appropriate information to this study, to ensure that the study is as theoretically and clinically relevant as possible. According to Knopf (2006) a literature review should concisely summarise, from a set of relevant sources, the collective conclusions most pertinent to the research interests. It should evaluate the state of knowledge and identify areas of uncertainty or debate that cannot be resolved using the existing research because no one has yet considered it carefully. Therefore, using the literature review, areas in the available published literature that have been neglected will be identified, so as to justify the reason for further investigation through this research in order to fill the knowledge gap. The chapter is divided into sub-sections, which include the following headings: epidemiology of stroke, disability post-stroke, stroke rehabilitation process, factors affecting the functional outcome of stroke and research instruments. Each sub-heading will then discuss, in detail, the most important information pertaining to the specific section of the chapter in order to give an overall, in-depth view of the study and its objectives. The chapter will end off with a summary of the most important points.

### **2.1 EPIDEMIOLOGY OF STROKE**

Brachman (1996) defined epidemiology as the study of the determinants, occurrence, and distribution of health and disease in a defined population. In this study, the epidemiology of stroke will include the mortality, morbidity, incidence, prevalence, risk factors, and the burden of stroke. WHO (2004) approximated that 15 million people suffered from stroke each year and of those, 5 million died and another 5 million were left permanently disabled. Di Carlo (2009) acknowledged that stroke can be costly in many different forms, including from a human, family and societal perspective. The human cost can be seen as stroke is a leading cause of death and disability, with stroke ranking as the second most common cause of death in the world population. According to the American Heart Association (AHA) in 2003, the period of highest mortality is within thirty days post-stroke (AHA, 2009). Although there is a higher

incidence of stroke in males than in females, no difference in stroke mortality between men and women within each ethnic group was found by Ingall (2004), showing that stroke is non-discriminatory in its mortality.

The available figures from previous studies identify that the overall incidence of stroke is ever increasing. Strong et al (2007) identified an increase in the overall incidence of stroke to that reported by WHO (2004), which amounted globally to 16 million occurring annually each year, causing a total of 5.7 million deaths. This was explained by Bagg et al (2002) as being primarily in relation to the ageing population. Given that age is one of the most substantiated risk factors for stroke, the ageing of the world population implies a growing number of people at risk (Di Carlo, 2009). The WHO (2004) further identified that the ageing population will increase the prevalence of stroke and its associated burden.

Rosamond et al (2008) found that around the world, the majority of strokes (75%-89%) occurred in those over the age of 65. According to the World Development Report published in 1993 by Jamison et al (1993), the world population aged 60 and over in 1990 was 488 million and is projected to be 1.363 billion by 2030, showing an increase of 180%. In 1990, the developing (mainly low-to-middle income) countries (e.g. Sub-Saharan Africa) contained 58% of the world elderly, while in 2030 that is set to rise to two thirds or 66%. Brown et al (1996) identified the increasing incidence of stroke in relation to age, but added that a higher incidence is found in men and a higher prevalence is found in women because there are more women in the population over the age of 70 years. Rosamond et al (2008) clarified that, although men's stroke incidence rates may be greater than women's in younger individuals, this is not the case with older individuals.

In the South African context, Connor et al (2006) identified that stroke affects 243-300 per 100 000 of the South African population, resulting not only in long-term disability, but further impacting the patient, family and community, as well as leading to a dependency on others for assistance with everyday activities. Joseph et al (2013) acknowledged that stroke onset, in the Western Cape of South Africa, occurs at a much younger age than in persons in the developed world, which highlights the extended time these individuals have to live with the health condition.

The Heart Disease and Stroke Statistics Update in 2008 explained that the risk of stroke occurrence increased with age, with the greatest risk for those over the age of 55. Warlow et al (2001) identified the conventional risk factors of stroke are divided into those we cannot influence (non-modifiable), such as: age, gender, family history and race; and those we can potentially influence (modifiable), such as: hypertension, Diabetes Mellitus, atrial fibrillation, smoking, hypercholesterolaemia, excessive alcohol intake, obesity, physical inactivity, and prothrombic factors. However, of the modifiable risk factors, hypertension was noted by Rosamond et al (2008) as the most powerful determinant of stroke risk. Salter et al (2012) explained that the risk of stroke increases proportionately as both increasing systolic and diastolic blood pressure (BP) increase. In the Framingham study conducted by Seshadri et al (2006) a graded increase in stroke risk was identified with an increase in BP and an example was made that the life time risk of stroke in a 65 year old woman with a BP of 120/80 mmHg is half that of a 65 year old woman with a BP of 140/90 mmHg. A greater understanding of the risk factors involved with stroke before its occurrence may help to improve the understanding of their effects on the functional outcome of the individuals after stroke (Ingall, 2004).

The burden of stroke has been highlighted in the 1900s by authors such as Silliman et al (1987) who identified the importance of understanding the social and functional consequences of stroke for patients and their families, whereby pressures to reduce lengths of hospital stay meant that patients were discharged from the hospital before much functional recovery had occurred, placing the burden of care on the family and community. Although this literature may be dated, it is still relevant today due to the same problems being faced as identified by the Western Cape Department of Health (2013). This burden of care and need of support for common daily activities by the stroke survivors directly impacts on the quality of life of patients and their families, frequently taking the role of caregivers. In a study done by Leys et al (2002), stroke was identified to have a compounding effect, whereby stroke is not limited only to affecting the physical and medical aspects of the individual but affecting the family dynamics and structure, as well as the community and society as a whole.

The burden of stroke also lies in the economic affect it has, as explained by Evers et al (2004) whereby the economic burden of stroke requires increasing attention for

more effective health care planning and resource allocation. In the developed country of the United States, the total direct and indirect cost of stroke for 2008 was estimated at \$65.5 billion. Direct costs, making up 67% of the total costs, included the cost of physicians and other health professionals, acute and long-term care and medication; whereas indirect costs, making up the remaining 33%, included loss of productivity resulting from morbidity and mortality (Rosamond et al, 2008). According to the European Cardiovascular Disease Statistics in 2008, EU countries' total annual cost of stroke was estimated at 27 billion Euros (Allender et al, 2008). In the UK alone, total societal costs are estimated at 8.9 billion Pounds per year (Saka et al, 2009). Unfortunately, this literature only focuses on the economic burden of stroke in first world countries, however the economic burden of stroke in the South African context could not be identified in any available literature for this research.

Di Carlo (2009) explained that it is essential to avoid the natural trend of increase in the human, economic and social burden of stroke by reducing the stroke frequency, stroke mortality and long-term disability through preventative measures, as well as evidence-based treatments. Connor et al (2006) acknowledged that accurately understanding the profile of stroke and the common causes within a population is vitally important to allow one necessary insight in order to plan appropriately and equip the health services to deal with the population-specific needs. Connor et al (2006) concluded by indicating the need for high quality, community-based stroke incidence studies with accurate assessments of stroke-type, sub-type, risk factors and causes, as well as long-term follow-up information, to help develop appropriate treatment and prevention strategies. This research study will aim to, among others, meet the need for long term follow-up information, to add to the body of stroke knowledge in the South African context.

## 2.2 DISABILITY POST-STROKE

The burden of stroke, explained by Saka et al (2009), does not only lie in the high mortality rate but the high long-term morbidity rate, leaving a significant number of survivors with moderate to severe chronic disabilities, who are then reliant on others to assist with daily activities. This concept was identified early in the study conducted by Wilkinson et al (1997) on 291 stroke sufferers included into the first ever South

London Stroke Register (SLSR) in 1989/1990, whereby 56% of participants had hemiparesis five years after the initial stroke; and 54% of participants who were assessed using the Barthel Index (BI) score at three months post-stroke were still in the same category after five years. However, caution must be taken when reporting these results as this study made use of the original BI of Mahoney and Barthel (1965) to assess function in individuals, which has been identified by Granger et al (1979) to be insensitive to change. This could therefore be the reason that patients were still assessed to be in the same category and not because no improvement in function had been achieved. Another reason for caution is that the SLSR had just been introduced and the methodological soundness of the results may be in question.

In 1990, participants in the Methodological Issues in Stroke Outcome Symposium determined that the nature of stroke recovery was complex and demanded clarification of its natural history and classification of the variable patterns of functional recovery. An improved understanding of stroke recovery was essential to limit the aforementioned long-term morbidity rate seen post-stroke in individuals (Gresham, 1990). From 1990-2000, scientist made outstanding progress in improving our understanding of stroke. However, the National Institute of Neurological Disorders and Stroke (NINDS) explained that, while this progress is acknowledged, the healthcare and research communities are keenly aware that the challenge to fully understand stroke is more urgent than ever (NINDS, 2013). Rouillard et al (2012) acknowledged that, in the South African context, little information is available on stroke survivor functioning, particularly at the level of activity limitations and participation restrictions.

As highlighted in Chapter One, disability and outcome in individuals post-stroke can be conceptualised using the ICF framework, to better understand the relationship between the disease and its effect on function and disability. This study will look specifically at the possible relationships between certain factors and how these factors affect the functional outcome of individuals. The factors in question include: level of education, stroke severity, perceived health related quality of life, perceived family support, perceived satisfaction with rehabilitation and rehabilitation intensity. This conceptualisation of disability will be done in terms of neurological deficits or impairments, activity limitations and participation restrictions as follows:

## 2.2.1 Neurological Impairments

As alluded to previously, Jorgensen et al (2000) described neurological impairment, functional disability and a reduction in quality of life as the result of the neuronal death following a stroke. Half of all stroke survivors are left with some degree of physical or cognitive impairments and the need for support for common daily activities directly impacts quality of life of patients and their relatives (Di Carlo, 2009).

Kelly-Hayes et al (1998) identified and described the potentially affected neurological domains post-stroke as follows: motor deficits, being the most prevalent of all deficits seen after a stroke, usually involves weakness of the face, arm or leg, alone or in various combinations. Sensory deficits, which may range from loss of primary sensations to more complex loss of perception. Visual deficits, which can include monocular visual loss, homonymous hemianopia, or cortical blindness. Language deficits, including dysphagia, which may present with disturbances in comprehension, naming, reception, fluency, reading or writing. Cognition deficits, which include impairments to memory, attention, orientation and construction. Finally, affect deficits, which may be present in the form of emotional lability or depression and tends to be observed in the months that follow the stroke, rather than during the acute event itself. However, Kelly Hayes et al (1998) concluded that the impairments alone do not define disability; there are many factors that determine function, including the influence of post-stroke rehabilitation training and physical and social environments to name a few.

A critical review done by Duncan et al (2005) found similar impairments to those identified by Kelly-Hayes et al (1998), but added that all the impairments could be seen in isolation or in combination following stroke and lead to difficulties with ADL, being activity limitations. This was confirmed in a study done by Lawrence et al (2001) on 1259 patients with stroke registered on the South London Stroke Register (SLSR), which found 6% of the patients had one to two impairments, 31.1% had three to five impairments, 50.6% had six to ten impairments and 10.6% had more than ten impairments post-stroke. The most common impairment identified was contra-lateral motor deficits of hemiplegia or hemiparesis (more so of the upper limb

than lower limb). The methodology of the SLSR, has been extensively described in previous research of Stewart et al (1999) and found to be methodologically sound.

In the well known and established Copenhagen Stroke Study, conducted by Jorgensen et al (2000), on 1197 random, completely unselected and consecutive patients with stroke in the acute stage who were admitted to a stroke specific unit, it was identified that neurological impairments following a stroke disables the individual in varying degrees, depending on the affected neurological domains. The initial stroke severity of the unselected sample was noted as 19% who had very severe strokes, 14% who had severe strokes, 26% who had moderate strokes, and 41% who had mild strokes. However all degrees of impairments affected the individual's ability to perform their activities of daily living (ADL).

### 2.2.2 Activity Limitations

Kelly-Hayes et al (1998) acknowledged that the basic activities of daily living (BADL) and the instrumental activities of daily living (IADL) are affected as a result of disability post-stroke and have an effect on the stroke patient's quality of life. The BADL includes basic self-care tasks, such as: feeding, grooming, dressing, bathing, toileting and mobility; whereas IADL includes higher functions, such as: work skills, religious activities, recreational activities, shopping, using transportation, preparing meals, handling finances and maintaining a household (Kelly-Hayes et al, 1998).

Hartman-Maeir et al (2007) conducted a study on 56 in-patients with stroke, with a mean age of approximately 58, at one year post onset. More than 50% of the sample required mild to moderate assistance with their BADL, however a large majority of the sample required full assistance with IADL, such as: meal preparation (77%), housekeeping (70%) and laundry (82%). Kelley-Hayes et al (1998) explained that independence with BADL would allow for a stroke patient to live at home with help from family or community providers for meals and other household tasks as needed; whereas independence in IADL allows for a stroke patient to be discharged home without dependency on others and to be a productive member of society.

In the same Copenhagen Stroke Study, conducted by Jorgensen et al (2000), the researchers identified that the ability to perform basic ADL is reduced in three out of four patients with stroke, with the abilities to transfer, dress and ambulate being most often affected. Jorgensen et al (1995) described ambulation as an essential part of daily physical activity but that 63% of stroke survivors have reduced ambulatory capacity post-stroke. Jorgensen et al (2000) further identified that impaired walking function greatly contributed to functional disability, and improvement in walking function was noted as the single goal most often stated by patients with stroke. Of the surviving patients seen in the Copenhagen Stroke Study, 66% achieved independent walking function after completed rehabilitation, with 22% left with no walking function at all. Danielsson et al (2012) explained that the high energy cost of walking affects the ability of a stroke patient to perform daily activities and participation, leading to a vicious cycle of physical inactivity.

### 2.2.3 Participation restrictions

Desrosiers et al (2002) explains that being able to walk, wash and dress (ADL) are not the only factors needed to resume a normal life post-stroke. Both reintegration into the community and readjustment to life post-stroke involves a number of factors beyond these basic functions of living. Jorgensen et al (2000) identified that the effects of impairments on activity result in the stroke sufferer being unable to participate in normal, everyday activities, such as: working and socialising. Desrosiers et al (2006) agreed with Jorgensen et al (2000) and further identified that many people suffering a stroke are not able to resume their previous role in life or engage in the various activities as they did previously, with the stroke distinctly restricting their participation in everyday life.

In a study done by Spitzer et al (2011) on 30 patients with stroke, where non-parametric correlation analyses quantified the presence and strength of the association between variables, it was identified that stroke survivors with cognitive impairments, even mild in severity, had significantly reduced participation in all ADL domains and by association, had participation restrictions. A previous study conducted by Leys et al (2002) to determine the three year outcome post-stroke of 287 young adults in France with ischaemic stroke, with an acceptable gender



distribution of 55.4% males and 44.6% females, identified that 4.2% of participants reported loss of employment and 7% reported divorce, despite apparent recovery. The study identified that it used one of the largest cohorts in young ischaemic stroke and that no participants were lost to follow-up. However, several limitations to the methodology were noted, including the study suffering from a bias in terms of recruitment, age and stroke type. Only participants admitted to the university hospital between the ages of 15 and 45 with an ischaemic stroke type were included in the study. Also, ethnicity could not be included due to the law of the country not allowing for any reference to a patient's ethnicity in their files. Although the findings obtained have some relevance in terms of post-stroke participation restrictions, these limitations may mean poor generalisability of the results to the general population.

The ICF framework identifies that participation is affected by contextual and personal factors of the individual sufferer (WHO, 2001). A study conducted by Desrosiers et al (2006) on stroke individuals over a four year period, using the Assessment of Life Habits (LIFE-H), found to be adequate in terms of reliability but less so with regards to validity (Salter et al, 2012), identified through multivariate analysis that the best predictors of long-term participation after stroke included age, co-morbidity, motor coordination and upper extremity ability. Fallahpour et al (2011) also acknowledged several studies that found age, gender, living environments, activity limitations and co-morbidity to be important predictors of participation in individuals post-stroke.

Most of the literature surrounding participation restrictions after stroke relates to studies done in developed, western countries, however more literature is becoming available in the non-western, developing world, as seen by the following South African studies of Maleka et al (2012), Rouillard et al (2012) and Mudzi et al (2013).

A qualitative study conducted by Maleka et al (2012) on people's experiences of living with stroke in low socio-economic areas of South Africa, identified that the sudden overwhelming transformation of a stroke caused not only a loss of meaningful activities and mobility, but social isolation, loss of role in the family and community, loss of hope, and was a threat to the livelihood of the stroke survivors. Maleka et al (2012) concluded the study by stating that the assessment of stroke survivors should include activity limitations and participation restrictions in order to

holistically rehabilitate and successfully reintegrate the patients back into their communities.

Rouillard et al (2012), conducted a study on 51 patients at a specialised rehabilitation facility (WCRC) in South Africa, on the functioning at six months post-stroke following discharge from in-patient rehabilitation, identified individual responses to questions addressing change in role of individuals post-stroke. The large majority of the sample reported that they were unable, or had a reduced ability, to participate in social and leisure activities (82.6%), work activities (60.8%) and family responsibilities (58.7%) respectively, with a further 37% reporting problems with relationships or feelings of isolation.

Finally, Mudzi et al (2013) conducted a study on 200 patients in South Africa aimed at identifying the community participation of patients twelve months post-stroke, found that patients with stroke struggled with interactions and had difficulties with community life and participating in recreation and leisure activities. Immediate family and societal attitudes were viewed as facilitators to community participation of stroke individuals, however friends, transportation services and social security services were viewed as barriers.

### 2.3 STROKE REHABILITATION PROCESS

The WHO defines rehabilitation of people with disabilities as a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. It provides disabled people with the tools they need to attain independence and self-determination (WHO, 2013). The Comprehensive Service Plan for the Implementation of Healthcare in the Western Cape further explained that rehabilitation is a goal orientated and time limited process (Western Cape Department of Health, 2007). Langhammer (2011) explained that rehabilitation has many different aspects and components that make it complex but holistic and beneficial to the patient if facilitated in the correct manner by all involved in the process.

Gresham et al (1995) found that in the absence of any curative therapy, rehabilitation is most commonly used to improve the quality of life of individuals after a stroke. Kwakkel (2006) explained that neurological rehabilitation is actually a special case of relearning to perform previously learned tasks in a different way by either using compensatory movement strategies or by adaptively recruiting alternative pathways.

The rehabilitation process starts at the individual's first point of entry into the health care system and continues along the continuum of care until the individual is re-integrated back into their community. The main goal of rehabilitation, carried out by a multidisciplinary team (MDT), is to enable individuals to return home with the highest possible level of functional independence (physical and psychological) and best possible quality of life, while reducing, as far as possible, the burden of care on family members and carers (Western Cape Department of Health, 2007). Dajpratham et al (2007) added to the main goal of rehabilitation management after a stroke, by including restoration of optimal social and vocational function to enable the patient to become a productive participant in the community. This takes into account the fact that stroke and the affected individuals are not one dimensional and many aspects of the patient need to be considered to ensure holistic rehabilitation.

Cifu et al (1999) explained that this holistic rehabilitation model can best be seen in an interdisciplinary rehabilitation setting, defined as one in which rehabilitation services are provided by diverse professionals who constitute an MDT, which communicates regularly and uses its varying expertise to work toward common goals. This model has been associated with improved functional outcome and quality of life, shorter length of stay, and decreased costs of treatment.

The Comprehensive Service Plan for the Implementation of Healthcare in 2010 defined the MDT as a wide variety of team members, such as medical professionals or physicians, nurses, physiotherapists, occupational therapists, speech and language therapists, and social workers amongst others, that are involved in the rehabilitation process of patients (Western Cape Department of Health, 2007). Davis et al (2011) agreed with the above definition but added that the patient and their family need inclusion to ensure the most holistic approach to rehabilitation possible.

The National Stroke Association (NSA, 2006) and National Institute of Neurological Disorders and Stroke (NINDS, 2011) briefly defined each discipline's role within the stroke rehabilitation MDT as follows: the physician specialises in diagnosis, treatment and rehabilitation of illnesses and has the primary responsibility of monitoring and managing the long-term care of the stroke patient's condition through their experience and the prescription of medication as required. The rehabilitation nurse provides assistance to the patient to manage their condition and any health problems that may occur post-stroke by issuing prescribed medication and helping the patient re-learn their ADL, such as: washing, dressing and feeding. The physiotherapist helps to improve the patient's functioning and overall mobility through individualised rehabilitation programmes. The occupational therapist helps patients to re-learn skills needed for performing self-directed activities and strategies to manage their ADL. The speech and language therapist helps patients re-learn communication skills and gives strategies to help with any swallowing difficulties that may have been experienced post-stroke. Finally, the social worker helps the patient and their family make decisions regarding their living arrangements post-stroke, through facilitating the process of goal setting and discharge planning in family meetings; and provides support services in the home environment through counselling to the patient and their families as required.



The World Confederation for Physical Therapy (WCPT) explained the physiotherapy aspect of rehabilitation more comprehensively, whereby physiotherapy provides services to individuals to develop, maintain and restore maximum movement and functional ability. This includes providing services in circumstances where movement and function are threatened by ageing, injury, disease or environmental factors. It is concerned with identifying and maximising quality of life and movement potential within the spheres of promotion, prevention, intervention, and rehabilitation. It involves the interaction between physiotherapist, patients, other healthcare professionals, families, care-givers, and the community in a process where movement potential is assessed and goals are agreed upon, using knowledge and skills unique to physiotherapists (WCPT, 2007).

Roth et al (1998) explained that rehabilitation is used widely to reduce the level of disability in stroke survivors and it relies on both remediation interventions designed

to reduce neurologic deficit and teaching compensatory techniques to enhance functional independence in the presence of neurological impairment. However, the effectiveness of rehabilitation has been difficult to measure due to the large quantity of factors that influence outcome after stroke. In a study conducted by Roth et al (1998), the effect of rehabilitation was identified as a potential factor influencing disability as patients who experienced neurological impairment reduction, and even those patients who did not, showed significant improvements in their functional performance levels, which suggests that rehabilitation favourably influences outcome, despite the extent of the change in the neurologic impairment.

A critical review of literature, done by Kwakkel et al (2004), identified two key elements that seem to determine the effectiveness of rehabilitation, the first being a beneficial effect of the intensity of therapy, with regards to the speed and degree of recovery; and the second involved therapeutic interventions that were task-specific, showing hardly any generalization. The available literature demonstrates that a task-specific therapy service versus a more generalised therapy is associated with improved functional outcome after stroke.

In particular to task-specific interventions, a pilot study done by Richards et al (1993) on task-specific therapy for optimisation of gait recovery in 27 patients with stroke in the acute stage, found that early-onset, intensive, task-specific physiotherapy demonstrated the greatest degree of gait recovery at three months. The researchers concluded that it was the task-specific nature of the therapy which contributed to this improvement, and not the intensity. Although this literature is dated and the study was only a pilot with a small sample, the recruitment of participants took twenty five months to identify suitable participants, indicating stringent inclusion and exclusion criteria and thus more sound results but poor generalisability. The authors acknowledged that further research was required but that the pilot study had made valuable discoveries.

Gresham (1986) found that, irrespective of the type and intensity of rehabilitation, the main pattern of functional recovery after a stroke is determined by certain unknown biological processes, often characterised as 'spontaneous neurological recovery'. A review article by Roth et al (1998), found that although stroke often resulted in some

degree of long-term impairment and disability, most patients experienced some natural recovery of neurological functioning and improvement in ability to perform ADL. Teasell et al (2009) identified that this spontaneous neurological recovery, defined as recovery of neurological impairments, occurs during the first three to six months, as a result of brain recovery and re-organisation.

Kwakkel et al (2004 and 2006) disagreed with Gresham (1986) on the main pattern of functional recovery and explained that functional recovery (referring to improvement of independence in ADL) is modifiable by interventions and is influenced by, but may occur independently of, neurological recovery. It was further stated that rehabilitation can facilitate the natural pattern of spontaneous recovery through intensive, task-specific and task-orientated training, but that functional recovery is dependent on the patient's motivation, ability to learn and family support as well as the quality and intensity of therapy.

In the Copenhagen Stroke Study, conducted by Jorgensen et al (2000), it was identified that the speed of functional recovery following a stroke is dependent on the initial stroke severity but that, in general, functional recovery was completed within three months of stroke onset. Of the patients, 95% had reached their best level of function within thirteen weeks post-stroke. Patients with a mild stroke recovered within two months, patients with a moderate stroke recovered within three months, patients with a severe stroke recovered within four months and patients with the most severe strokes recovered within five months from onset. As discussed previously, the Copenhagen Stroke Study is well known and established with sound methodology. However, it is important to recognise that results described in this study are for a sample that are in the ideal rehabilitation setting, whereby the participants were given the very best available treatment on a comprehensive, dedicated stroke unit throughout their rehabilitation. Therefore, as clinically sound as the results may be, they need to be reported with caution as this would not be the case in most rehabilitation settings, especially in a South African context.

Comprehensive stroke rehabilitation, at a dedicated and specialised stroke rehabilitation unit (SU), as opposed to a general unit (GU), consists of prevention and treatment of medical complications, allows for restoration of maximal independent

functioning, facilitation of psychosocial coping and adaptation by the patient and family, as well as promotion of community reintegration and enhancing quality of life for stroke survivors (Roth et al, 1998). Alberts et al (2000) identified that primary SUs reduce the number of survivors who depend on others for support either at home or in a health care facility. A point echoed by The Stroke Unit Trialists' Collaboration, in 2007, who further acknowledged that patients with stroke who received organised inpatient care in a SU were more likely to be alive, independent, and living at home one year post-stroke. Medifocus (2011) added that comprehensive stroke rehabilitation improves the functional abilities of stroke survivors, regardless of age or neurologic deficit, and decreases long-term care costs.

Kwakkel et al (1999) identified the differences in efficacy between a SU and GU as follows: mortality rates, ADL dependency and length of stay in hospital or at an institution were decreased in patients at SUs. However, multiple factors may contribute to the efficacy of care delivered at a SU, namely: better educated staff, better organisation of services and family integration, earlier implementation of rehabilitation services, and higher intensity of daily treatment during the early phase of stroke rehabilitation (Kwakkel et al, 1999). Brandstater et al (1987) and Roth et al (1998) further identified eight elements necessary for a successful comprehensive SU, namely: continuity of care, an experienced MDT, careful attention to comorbidities and complications in patients, early goal-directed treatment, systematic assessment of progress, education for patients and family, attention to psychosocial issues, and early comprehensive discharge planning.

However, in reality, often a stroke patient will require long-term management for the reduction of disability and functional recovery. Brainin et al (2004) explained that in the context of long-term improvements in stroke-related disabilities, rehabilitation should continue as long as objective improvement is observed; and that achieving and maintaining functional improvements requires cooperation and coordination between the healthcare services at the various levels. Cifu et al (1999) found that participation in out-patient, home health, and day rehabilitation programmes is strongly associated with improved functional outcome after stroke. Home health services are also associated with improved six month functional outcome when compared with day rehabilitation services. Davis et al (2011) further explained that

support services beyond primary care enhance coping and facilitate return to normal life, through providing flexibility and integration of social and medical services.

In conclusion of rehabilitation, Kwakkel et al, (2004) emphasised that each rehabilitation programme needs to be tailored to be patient-specific in order to maximise the effectiveness of the rehabilitation received. The challenge of the rehabilitation scientist is to improve the understanding of the various mechanisms that are involved in the outcome of functional recovery after stroke and define the restricted time window. Improved understanding of these processes would enable clinicians to define the optimal treatment goals within an individually tailored treatment programme and to develop new therapies that specifically interact with the processes of functional recovery and functional outcome.

## 2.4 FACTORS AFFECTING THE FUNCTIONAL OUTCOME OF STROKE

This section is the centre of the study and will focus on presenting the evolution of the factors that affect functional outcomes of stroke from earlier studies through to the latest available literature.

The issue of functional outcomes in stroke is a complex one. The ICF framework for classifying the consequences of disease at the levels of impairment (direct consequences of the disease process), activity limitation (reduction of functional activity) and participation restriction (problems experienced by individual in involvement) reflects this complexity. The framework emphasises that the focus of rehabilitation must change as the individual progresses through the various levels.

With the rising costs of stroke management and marked heterogeneity in stroke manifestation and recovery, Kwakkel et al (1996 and 1999) identified the importance of early, accurate and reliable prediction of outcome in stroke sufferers for the following three reasons: 1) to set realistic and attainable therapeutic goals; 2) to facilitate proper discharge planning; and 3) to anticipate the need for home adjustments and community support. Konig et al (2008) further identified that an early, simple, and reliable model to calculate the prognosis of likely outcome in patients with stroke is desirable and useful, for both clinical and research purposes.



Ashburn (1997) however acknowledged that, although frequently attempted during clinical practice and research, prediction of functional outcome is complex and often unreliable. Nearly all patients will receive some type of rehabilitation after a stroke and so predicting outcome, in reality, is predicting the combined effect of three issues, namely: 1) the natural recovery process; 2) the responsiveness to rehabilitation; and 3) the effectiveness of the treatment itself. In addition, the recovery process is multi-dimensional and characterised by individual variability (Ashburn, 1997). Dajpratham et al (2007) echoed Ashburn (1997) by emphasising that functional recovery in every individual is different and therefore it is difficult to predict outcome. Lincoln et al (1990) recognised that if predictions are to be used as a basis for the clinical management of patients, they must be very accurate for each individual and not just reveal patterns which apply only to groups of patients.

As early as the 1980s, researchers such as Jongbloed and Dombovy et al (1986) argued that certain subgroups of the stroke population may benefit more than others from specific, intensive rehabilitation services and that, in order to achieve the most efficient use of such services, it is important to identify predictors that discriminate between patients with stroke who have good and poor prognoses (Jongbloed, 1986). Dombovy et al (1986) identified the following predictors in patients with stroke as poor prognoses for effective rehabilitation to take place: decreased alertness, inattention, poor memory, inability to follow simple commands, hemi-neglect, significant associated medical problems, and language difficulties. Fang et al (2003) concurred with the concept identified by the two aforementioned researchers (Jongbloed and Dombovy) and stated that early prediction of functional recovery is an important factor in planning and utilising rehabilitation resources in clinical practice. Therefore, it is critical to evaluate the patient at stroke onset and to identify who will benefit from rehabilitation therapy.

Kwakkel et al (1996) conducted a critical review of the available literature and identified seventy eight prognostic studies, with a total of 16 149 patient with cerebrovascular disorders (CVD), surrounding the prediction of disability in stroke. Adherence to a number of key methodological criteria was required for the literature to be considered sound in its predictive and prognostic ability. These criteria included the following: reliability and validity of measurement instruments used to assess

dependent and independent variables, inclusion of an inception cohort, adequate and uniform end-point of observation, control for patient drop-out during the periods of observation, statistical testing of presumed relationship between dependent and independent variables, sufficient sample size in relation to the number of determinants, control for multicollinearity, specification of patient characteristics, description of interfering treatment effects during the period of observation, and cross-validation of the prediction model in a second independent group of patients. Of all the studies identified in the critical review, only three satisfied nine out of eleven criteria and ten satisfied eight out of eleven criteria with the following variables identified as the most valid predictors for functional recovery after stroke: stroke severity on admission, degree of motor paresis, urinary incontinence, age, level of consciousness 48 hours post-stroke, orientation in time and place, status following recurrent stroke, sitting balance and level of perceived social support.

Of particular importance to this research study is the level of perceived social support, identified by Kwakkel et al (1996), as a predictor of functional recovery. This concept was based on a study conducted by Glass et al (1993), on 46 patients with stroke who were followed over a six month time period. Significant differences were found across levels of social support in relation to functional status, with a three-way significant interaction between stroke severity, social support and functional outcome. As seen already by Kwakkel et al (1996) this study was identified as one of the best prognostic studies, showing strong indications that a high level of perceived social support may be associated with faster and better functional outcome after stroke, but limitations in sample size make it difficult to rule out other confounding factors.

Dombovy et al (1986) recognised that the presence of a caring and able spouse may be one of the most significant positive factors in the outcome of rehabilitation, along with other social and economic factors. Naheed (2000) acknowledged that the basic component of any society is home, where we feel protected and esteemed. In a home, family works as a functional unit, each person having separate roles with diversified functions, but all work together for a desired outcome. The relationship between family members is powerful and accounts for a considerable degree of human behaviour, emotions, values and attitudes. Each member contributes in one

way or another and is influenced by the behaviour of other members; particularly in situations where a member of the family undergoes an abrupt, life alarming outbreak of a disease. A stroke patient's better prognosis is dependent on the amount of care and social support given by the family members. As well as the family support, it was shown that a positive attitude from the family towards the stroke patient results in improvements in the patient's overall condition. Furthermore, a distressing event, such as a stroke, becomes less stressful if one enjoys the support of close-knitted family organisations. Family relations, if positive, will provide aid in overcoming the consequences of the stressful event. At the same time, the negative impacts of the ailment can be buffered by a relaxed, healthy, positive attitude and by the comfort and aid provided by supportive family members (Naheed, 2000).

In contrast, perceived lack of social support by the patient towards family or caregivers was associated significantly with depression, and depressed patients were identified by Naheed (2000) to have had a longer duration of illness. Therefore, socially isolated patients may be at particular risk for poor outcome post-stroke. A study conducted by Korpelainen et al (1999) recognised that psychosocial factors play a crucial role in determining activity and satisfaction in individuals after stroke, and their influence can be even stronger than that of medical factors.

As crucial as psychosocial factors may be in determining functional outcome of individuals post-stroke, one cannot ignore the magnitude of available literature indicating the importance of the medical factors involved in the outcome. Kwakkel et al (2004) explained that, even though the functional outcome of patients with stroke is heterogeneous by nature and individual recovery patterns differ, a strong mathematical regularity has been found in patients' functional recovery. The final outcome in patients with stroke is largely determined within a limited time window of four weeks post-stroke. Patients showing greater improvements within the first few weeks post-stroke reach higher plateaus at six months than those with later Barthel Index (BI) improvements. Cifu et al (1999) also identified this limited time frame and added that early onset of rehabilitation interventions, within three to thirty days post-stroke, together with increased intensity of rehabilitation was strongly associated with improved functional outcome following stroke. Conversely, decreased functional

abilities in the first few weeks post-stroke correlated strongly with decreased discharge-to-home rate and outcomes at discharge and up to six months follow-up.

A systematic review done by Counsell et al (2001), which included studies up until 1997, found that the methodologies of most prognostic models for stroke recovery was poor, with none of them being recommended for clinical practice or research. Since then, further validated prognostic models by Baird et al (2001) and Johnston et al (2003) have been developed but require imaging equipment not available to patients in all settings. Models by Counsell et al (2002) and Wiemar et al (2002), which were validated and found to be successful, use two simple clinical variables, namely: age and neurological impairment, as measured by National Institute of Health Stroke Scale (NIHSS) assessed within six hours of stroke (Konig et al, 2008).

According to Ingall et al (2004), the two strongest predictors of outcome for all stroke types in all patients are age and severity of stroke at onset, with the likelihood of having a favourable outcome decreased with increasing age and severity respectively. Marini et al (2004) identified the fact that older stroke survivors not only have more severe stroke deficits on admission when compared with younger stroke survivors, they also recover more slowly. A general agreement was found by Nedeltchev et al (2005) that young adults have better chances of surviving a stroke than older individuals, however the majority of survivors have emotional, social or physical sequelae that impair their quality of life post-stroke. A study conducted by Leys et al (2002), seen in the Literature Review Chapter 2.2 previously, also identified that functional outcome was reported as favourable in most studies conducted in young patients who survived an ischaemic stroke, with 94% of young stroke survivors gaining independence.

In a prospective study by Bagg et al (2002) on 561 participants, age showed a significant but small effect on the functional outcome of participants. Due to the small variation in outcome, age has an insignificant clinical impact. The researcher therefore cautioned that, in view of strong evidence of the effectiveness of intensive stroke rehabilitation units, the impact of age on functional outcomes must be clearly identified before embracing a system that denies access to rehabilitation units based on age alone. Teasell et al (2009), also identified the small but significant effect of

age on the speed and completeness of recovery, but recognised that because older patients with stroke do recover, albeit at a slower rate, age in and of itself is a poor predictor of functional recovery after stroke.

In another study conducted by Black-Schaffer et al (2004) on 979 patients with stroke, it was identified that patients with advancing age and severe functional impairment on admission correlated with lesser improvement by discharge but that for patients with a higher admission functional level, age made no difference to the degree of improvement achieved. Black-Schaffer et al (2004) also recognised that, although the rate of recovery is greater in younger individuals, the older survivors may achieve the same level of independence in basic mobility and ADL when they are given more time. This study was conducted at a long-term acute care rehabilitation hospital, where patients who are admitted are required to be within a strict diagnostic category. These requirements result in a majority of the patients being more medically complex, having lower functional levels and longer lengths of stay than would normally be found in the general acute hospital. Therefore, generalisability of these results may be affected. In conclusion, Black-Schaffer et al (2004) found that, although literature is not in agreement on the influence of age on stroke functional outcomes, the literature does agree that functional level on admission to rehabilitation is an important predictor of discharge functional level. This is most likely due to admission functional level being related to stroke severity.

In a critical review of 78 quantitative and qualitative studies done by Daniel et al (2009), stroke severity was identified as the most robust predictor of return to work, although the process of returning to work is extremely individual and can be affected by a number of factors. Those who are not able to return to work after a stroke have greater levels of unmet needs and poor psychosocial outcomes. Factors that enable successful return to work include: provision of vocationally directed rehabilitation, employer flexibility, social benefits and support from family or co-workers.

Jorgensen (1996) identified stroke severity as the most important factor in both neurological and functional recovery. Garraway et al (1981 and 1985) first proposed the concept of three bands of patients with stroke based on stroke severity, followed by Stineman et al (1998) who more definitively defined each band as follows: the first

“upper” band included patients with mild strokes, having a motor Functional Independence Measure (FIM) >62 at time of rehabilitation admission and required less than two weeks to recover. The second “middle” band included conscious patients with moderately severe stroke, with a motor FIM score of between 38-62. These patients are best managed in a comprehensive, well-staffed and intensive rehabilitation unit and make the most benefit from rehabilitation. The last, “lower” band included unconscious patients with the most severe strokes, having a motor FIM <37. They are unlikely to achieve functional independence, regardless of treatment, unless the patient is young in age and has a long length of stay.

Mamabolo (2012) identified that patients with stroke had limited functional independence at discharge from the hospital but functional levels improved post discharge, where a hospital stay of more than six weeks increased the probability of attaining functional independence. Jorgensen et al (2000) explained that the length of stay of an individual at a facility depends on a variety of factors, such as: stroke severity, co-morbidity, social conditions, family support and availability of nursing homes. Black-Schaffer et al (2004) agreed that length of stay is sensitive to a variety of non-medical factors, but added that rehabilitation team culture played its role too, as higher goals may be set for younger patients and they may be kept longer in order to achieve these goals. In the study conducted by Black-Schaffer et al (2004), there was a highly significant relationship with the youngest patients staying longer, on average 66.7 days compared to 43.7 days for the oldest patients. The common pathway for slowly improving patients with stroke is to be discharged to a skilled nursing rehabilitation facility before their recovery is complete. A study conducted by Ng et al (2005), added that a shorter length of stay and an interrupted rehabilitation stay were associated with lower discharge functional levels when using the FIM scores and total FIM.

Andersen et al (2009) explained that outcomes post-stroke are determined, not only by the initial severity of the stroke, but also by the nature or classification of the lesion as well. However, comparisons between haemorrhagic stroke (HS) and ischaemic stroke (IS), in respect to prognostic determinants, were hampered by the disproportionate distribution of the two types of stroke, with IS being about ten times more frequent than HS, as seen in a study conducted by Andersen et al (2009) on

39 484 patients from a Danish stroke registry to compare haemorrhagic and ischaemic stroke, whereby 89.9% were ischaemic and 10.1% were haemorrhagic. Andersen et al (2009) did however find that HS was more severe than IS and was associated with a higher mortality risk than IS. Haematoma expansions, oedema formation and intra-ventricular haemorrhage leading to increased intracranial pressure are likely contributors to the acute excess mortality. The strength of this study lies in the large sample, no limitation on age, gender or stroke severity, and the fact that survival data was captured for all patients, except for <0.2% who were lost to follow-up. There were however, some limitations to the study with regard to missing data. Due to the nationwide registration of patients in such a large quantity, 34% of the participants had to be excluded from analysis as a result. Although survival and mortality rates were well recorded, no information with regards to treatment and interventions are available, which may have had an effect on the survival rates.

Research done by Scheepers et al (2008) agreed with that of Andersen et al (2009) by identifying that from twelve to twenty six weeks post-stroke, patients with cerebral infarction statistically showed significantly faster increase in BI scores compared to patients with intracerebral haemorrhage. Also, the time window for recovery was more restricted with intracerebral haemorrhage. An increase in ADL independence was found up until ten weeks post-stroke in patients with haemorrhage, whereas patients with infarction showed recovery up until twenty six weeks post-stroke.

In an earlier critical review by Jongbloed (1986), still cited by later studies (Kwakkel et al, 1996), on 33 prognostic studies done, six key determinants were identified that successfully predicted functional outcome post-stroke. They included: stroke severity on admission, age of patient, status following previous strokes (baseline of function), urinary and bowel incontinence as well as visuo-spatial deficits. This critical review gives a good indication of the possible factors that may determine functional outcome post-stroke but suffers from many limitations, namely: the fact that the review was done many years ago and the studies that were examined had many differences in patient samples, research settings, timing of measurements and observations of function and length of stay of each research group; therefore the findings should be considered carefully before any clinical decisions are made.

According to Ween et al (1996) urinary incontinence (UI) correlated negatively with outcome after stroke, both functionally and with regards to the long-term well-being of stroke survivors. Jorgensen et al (2000) confirmed that urinary and faecal incontinence after stroke are important both prognostically and socially for patients and for caregivers. UI after stroke implies a poor prognosis, and persisting UI increases the burden on caregivers and is socially stigmatising.

Counsell et al (2001) recognised other negative predictors of stroke outcome at the time of stroke onset, which included the previously mentioned decreased level of consciousness, but added increased blood glucose level. A high blood glucose level is associated with increased lactate production in ischemic brain tissue, which is associated with a larger final infarct volume. Jorgensen et al (1994) and Toni et al (1992) also found that increased blood glucose on admission was related to poor outcome in stroke survivors and they needed a longer time to recover their function post-stroke. Reith et al (1996) added that spontaneous body temperature on admission is also a strong independent outcome predictor with a 1°C increase in body temperature relating to a two times greater risk of a poor outcome.

Naheed (2000) found that aphasia in left hemisphere patients with stroke indicated a more severe stroke, resulting in greater physical disability and social handicap in the long-term outcome. A study done by Fang et al (2003) showed that aphasia, as well as a serious decrease in cognitive function, affects the functional recovery of patients after stroke, and added that the reason could be due to the fact that patients with aphasia and cognitive fallouts could not follow the guidance of rehabilitation therapists. However, this study was limited in the fact that there was an obvious imbalance between the number of participants in the experiment group (50) and the control group (78) due to participants being lost to follow-up or dropping out of the study.

Gialanella et al (2003) confirmed that disabilities after stroke, such as aphasia and unilateral neglect, were associated with limited functional recovery and poor functional outcome. In a review done by Jehkonen et al (2006), several authors confirmed that the presence of neglect predicted poor functional outcome and an



inability to manage ADL after stroke. However, some of those studies indicated that neglect is an independent predictor of poor functional outcome, while others reported that neglect has an impact on functional outcome only in connection with other factors. Stineman et al (1998) disagreed on the effects of aphasia on functional outcomes by adding that, although a left hemisphere stroke patient demonstrated more severe expressive and receptive language disorders, recovery patterns in physical disabilities were remarkably similar across all stroke impairments.

According to Naheed (2000), a number of personal attributes such as age, socio-economic status and educational level have been found to be related to stroke functional outcome and management later on. A well-educated patient will understand the true reality of the disease and react towards it in a mature manner, and an educated family of the patient will be capable of understanding the instructions and adopt corrective measures to improve the situation. Dombovy et al (1986) identified that education of patient and family members post-stroke may be equally as important as the actual rehabilitation of the patient. However, a study conducted by Mudzi et al (2012), on the effect of carer education on the functional abilities of patients with stroke, identified that carer education alone did not result in significant improvements in patients' functional abilities and that the carers required more support to enable them to positively influence the patient's outcomes post-stroke.

One important note is that level of education, essentially literacy, is not the same as health literacy. Health literacy, is defined by Weiss et al (2007) as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions". Glassman (2013) acknowledged too that health literacy is not simply the ability to read. It requires a complex group of reading, listening, analytical, and decision-making skills, as well as the ability to apply these skills to healthcare situations. Weiss et al (2007) identified, in the American Medical Association report, that poor health literacy was a stronger predictor of a person's health than age, income, employment status, education level, and race.

A direct relationship between education and health was identified by Cutler (2007), where better educated individuals showed more positive health outcomes. This association remains substantial and significant even after controlling for job characteristics, income, and family background. Cutler (2007) explained that the mechanisms by which education influences health outcomes are complex and are likely to include interrelationships between demographic and family background, greater resources associated with higher levels of education, a learned appreciation for the importance of good health behaviours, and one's social networks.

#### Summary of section:

The issue surrounding prediction of functional outcomes in stroke is a complex one. Certain subgroups of the stroke population may benefit more than others from specific, intensive rehabilitation services and in order to achieve the most efficient use of such services, it is important to identify the predictors that discriminate between the stroke population. From an earlier study by Jongbloed (1986), factors that were identified to have an effect on functional outcomes post-stroke included: stroke severity on admission, age of patient, status following previous strokes (baseline of function), urinary and bowel incontinence as well as visuo-spatial deficits. Jorgensen et al (2000) confirmed that urinary and faecal incontinence after stroke are important prognostically. Jorgensen (1996), Ingall et al (2004), and Daniel et al (2009) identified stroke severity as the most robust predictor of functional outcome and more particularly, return to work. Kwakkel et al (2004) recognised that patients showing greater improvements within the first few weeks post-stroke reached higher plateaus at six months than those with later BI improvements. Toni et al (1992), Jorgensen et al (1994) and Counsell et al (2001) identified that an increased blood glucose level on admission was related to poorer outcome in stroke survivors. Gialanella et al (2003) confirmed that aphasia and unilateral neglect were associated with limited functional recovery and poor functional outcome. According to Naheed (2000), a number of personal attributes, including socio-economic status and educational level were found to be related to stroke functional outcome.

From the critical review by Kwakkel et al (1996), stroke severity on admission, degree of motor paresis, urinary incontinence, age, level of consciousness 48 hours post-stroke, orientation in time and place, status following recurrent stroke, sitting

balance and level of perceived social support were identified as the most significant predictors of functional outcome. Of particular importance to this research study is the level of perceived social support, identified by Kwakkel et al (1996) in a study by Glass et al (1993), whereby significant differences were found across the various levels of social support in relation to functional outcome. Naheed (2000) explained that a stroke patient's prognosis for better functional outcome is dependent upon the amount of care and social support given by the family members. As well as the family support, it was shown that a positive attitude from the family towards the stroke patient results in improvements in the patient's overall condition.

## 2.5 RESEARCH INSTRUMENTS

This study will make use of seven research instruments altogether as part of the data collection process. The tools include: 1) a socio-demographic questionnaire, 2) an objective functional outcome assessment in the form of the latest Barthel Index, 3) a health related quality of life questionnaire in the form of the EQ-5D, two biopsychosocial questionnaires assessing 4) perceived family support and 5) perceived satisfaction levels with rehabilitation, 6) a rehabilitation process data gathering instrument and finally, 7) a 'Use of Care' questionnaire to collect rehabilitation data relating to the six months post discharge from BMH.

1. Socio-demographic close-ended questionnaire (Administered on admission):  
This instrument was used to collect data relating to the socio-demographic status of each participant, including: age, gender, ethnicity, level of education, employment status and any family history of stroke. The researcher adapted a questionnaire previously used in a study by Rhoda (2010), which investigated the rehabilitation of patients with stroke admitted to a Community Health Centre (CHC) in the Western Cape. The adaptations included changing of formatting and removal of certain questions that were duplicated in other questionnaires or were not appropriate for this specific study and setting, such as: date of stroke onset, date of admission to rehabilitation facility, classification of type of stroke, risk factors, and who the primary caregiver was. Validity and reliability of this instrument in relation to this research study was determined using the methods described in Methodology Chapter 3.7.1.

## 2. Barthel Index (Administered on admission, discharge and follow-up):

The Barthel Index (BI) is an ordinal scale for the functional assessment of disability that has been widely used in stroke outcome research, as seen by Kasner (2006). It is an index that is used to quantify the ability of a patient, with neuromuscular or musculoskeletal disorders, to independently carry out their functions or ADL. Originally developed by Mahoney and Barthel (1965), the BI consists of ten common ADL, eight of which represent activities related to personal care, including: feeding, bathing, grooming, dressing, bladder/bowel control, toileting and transfers, and two related to mobility and ability to manage stairs, overall yielding a score between 0-20.

However, the original BI was identified by Granger et al (1979) to be insensitive to change and having arbitrary scores. Granger et al (1979) therefore modified the BI to include 10 points per variable, with a total of 100, to improve the sensitivity of the outcome scale, and found it to be reliable and consistent with other stroke evaluations. A higher BI score, achieved by the individual being tested, correlates to a greater degree of functional independence of the individual (Granger et al, 1979).

According to Granger et al (1979), a BI score of 85 usually corresponds to independence with minimal assistance, and further proposed a 60/61 split, when using the BI, as the threshold between dependence and independence with regard to functional abilities. Sulter et al (1999) identified that a BI score of  $\geq 60$  meant, in practical terms, that most patients were independent for essential personal care, such as: mobility, eating, sphincter control and personal toileting. However, this sum score for the BI of  $\geq 60$  has not been adopted as a standardised cut-off, as explained by Salter et al (2012), who further explained that there seems to be little agreement regarding classifications derived from the BI score.

Sulter et al (1999) identified that, although the BI is the most commonly used scale for assessing ADL, the criteria for classifying patients with favourable outcome varied substantially from trial to trial, with a variety of sum scores from  $\geq 50$  to  $\geq 95$  being used and chosen arbitrarily without being validated. Few studies have been conducted on the clinical relevance of the sum scores, however Kay et al (1997) and Dennis et al (1997) found that a score of  $< 85$  corresponded to a state in which patients reported needing help in performing activities of daily living, with a sensitivity

of 94% to 95% and a specificity of 80% to 86%. Sulter et al (1999) concluded that, as no consensus can currently be reached trying to define favourable outcome, it may be easier to focus on that which defines poor outcome. Sulter et al (1999) suggested that the definition of poor outcome should be if any of the following occurred: death, institutionalisation due to stroke or a BI <60.

Loewen et al (1988) found the intertester and intratester reliability for the BI to be highly acceptable. A systematic review and meta-analysis by Duffy et al (2013), identified the BI as having excellent inter-rater reliability for standard administration after stroke and despite limitations within the studies surrounding modest sample sizes, clinical heterogeneity and variable methodological quality, the BI was found to be an appropriate functional outcome measure for stroke trials and practice.

Teasell et al (2004) identified several advantages of the BI, including the fact that: it is easy to administer, does not require formal training, takes little time to complete, and its widespread familiarity contributes to its interpretability. Salter et al (2012) agreed that the main advantage of the BI is its simplicity and ease of administration and added that the BI's reliance on information collected during functional examination enhances its convenience and cost effectiveness. Salter et al (2012) further explained that the BI has been widely used across a variety of settings without a significant decrease in reliability or validity.

A study conducted by Hobart et al (2001), compared the psychometric properties of the BI with newer and lengthier scales, namely: the Functional Independence Measure (FIM) and The Functional Assessment Measure (FAM), in patients undergoing rehabilitation. It was found that all three rating scales demonstrated equivalent reliability and validity in measuring physical disability, and were similarly responsive to change. Therefore, Hobart et al (2001) suggested that the newer and more extensive rating scales offered few advantages over the more practical and economical BI.

Scheepers et al (2006) explained that longitudinal studies not only required measures that are reliable and valid, but also responsive, with responsiveness being defined as the ability of a measure to detect changes over time. Scheepers et al

(2006) further identified several studies that measured the responsiveness of the BI, FIM total and FIM motor and no differences were found between these measurements in terms of their responsiveness. However, in a study conducted on the effect sizes of the BI and the FIM, scores were smaller for the chronic phase than for the sub-acute phase, indicating that both measures detected fewer changes for the period between six to twelve months post-stroke. One possible reason for the small effect could be the ceiling effects found for the BI and FIM scores in the chronic phase. In the rehabilitation phase, the rehabilitation process particularly focuses on recovery of self-care and mobility, however in the chronic phase, after discharge home, this focus shifts to the resumption of activities in family and social life. However, since the BI is the shortest measure, as well as the easiest to use and requiring no special training, it is given preference for the sub-acute phase (Scheepers et al, 2006). As this study is not focused on the effects of factors occurring in the chronic stage, and the fact that all data is gathered within the six months post-stroke, the ceiling effect of the BI is not of any concern to the researcher. However, it is noted as a possible limitation to the tool.

Mahoney and Barthel (1965) identified several guidelines for the use of the BI, which allow for the administration of the instrument through best available evidence. This includes asking the nurses and the patient's friends and relatives about the patient's performance, which means direct testing is not required. This allows for non-direct testing, through telephonic conversations, in the case of participants who are unable to be physically present for a follow-up.

Based on these above findings and due to the simplicity and generic nature, as well as the ease of administration, high responsiveness rate and appropriateness of the BI tool, it was chosen as the preferred tool to be used to determine functional outcome in the sample being observed in this study.

The following Table 2.5.1.1 demonstrates the reliability, validity and responsiveness of the measurement tools in comparison with each other.

**Table 2.5.1.1 – Comparison of BI and FIM instruments (Salter et al, 2012)**

Tools:	Reliability		Validity		Responsiveness		
	Rigor	Results	Rigor	Results	Rigor	Results	Floor/Ceiling
BI	+++	+++ (TR)	+++	+++	+++	++	Varied
		+++ (IO)					
		+++ (IC)					
FIM	+++	+++ (TR)	+++	+++	+++	++	Varied
		+++ (IO)					
		+++ (IC)					

**NOTE:** +++=Excellent; ++=Adequate; +=Poor; TR=Test re-test; IC= internal consistency; IO = Interobserver; varied (re. floor/ceiling effects; mixed results)

3. EQ-5D - Quality of life (Administered on admission, discharge and follow-up):  
 The EQ-5D, developed by the EuroQol Group (1990), is a standardised measure of health status, consisting of two parts, the EQ-5D descriptive system and the EQ-5D visual analogue scale (VAS). The descriptive system comprises of the following five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has three levels: 1 = no problems, 2 = some problems and 3 = severe problems. The participant is asked to indicate his/her health state, on a specific day, by ticking in the box against the most appropriate statement applicable to the respondent at that present moment in each of the five dimensions. Each decision results in a one digit number, between 1 and 3, expressing the level selected for that dimension. The digits for the five dimensions can be combined into a five digit combination describing the respondent's perceived overall health state. 11111 being the best possible outcome and 33333 being the worst possible outcome. Theoretically, there are 243 such possible combinations. The EQ-5D VAS records the respondent's self-rated health on a vertical, visual analogue scale where the endpoints are labelled 'Best imaginable health state' at the top marked by 100 and 'Worst imaginable health state' at the bottom marked by 0.

The EQ-5D, as an instrument for measuring health status, has been found to be feasible, reliable and valid (Ravens-Sieberer et al, 2010). Cheung et al (2009) identified several advantages of this questionnaire, including: its simplicity and generic nature, allowing it to be applicable to a variety of conditions, and the fact that it is cognitively undemanding and only takes a few minutes to complete. Cheung et al (2009) further stated that the EQ-5D information or data can be used as a

quantitative health outcome measure. Salter et al (2012) added to the advantages of the EQ-5D by indicating the responsiveness of the tool, found to be 80% by Dorman et al (1997), 80% to 86% by Dorman et al (1998) and 92.5% by Barton et al (2008).

Salter et al (2012) explained the feasibility of the EQ-5D with regards to the fact that, even though, the EQ-5D was originally designed as a self-completion questionnaire, it can also be administered as a postal or telephonic survey or in face-to face interview as required. It requires no specialised training to administer and the scale and supporting information are readily available. A limitation of the EQ-5D is the fact that higher reports of missing data were found in the EQ-5D, when using the tool in an elderly population, than for the Nottingham Health Profile (NHP) or the Medical Outcomes Study Short Form (SF-36). However, its simplicity and brevity remain an advantage for use with stroke survivors (Salter et al, 2012).

The EQ-5D was compared to the SF-36 and the NHP for use in this particular study and the following was identified: The Medical Outcomes Study Short Form (SF-36) was identified by Salter et al (2012) as a generic health survey created to assess health status in the general population. Several limitations of the SF-36 were identified, including high rates of missing data reported among older patients when using the self-completed form of administration, with reports by Andersen et al (1999) of only one in every five patients being able to complete the form when administering it through face-to-face interviews. Salter et al (2012) identified that older respondents felt that the questions asked were aimed at younger people and participants expressed concern at the relevance of certain questions. Salter et al (2012) further identified that, although the tool is considered simple, it takes about ten minutes to complete. Permission needs to be obtained from the Medical Outcomes Trust who oversee the standardised administration of the SF-36. The use of the scale scores and summary represent a loss of information and therefore a decrease in the potential clinical interpretability.

The Nottingham Health Profile (NHP) was explained by Salter et al (2012) to be a brief, subjective measure of perceived health encompassing social and personal effects of illness. The NHP was however identified by Bowling (1997) and Ebrahim et al (1986), to be a somewhat limited measure as it does not assess many areas of



concern for a stroke patient, such as: sensory deficits, incontinence, eating problems, intellectual abilities or financial difficulty. Bowling (1997) concluded that the NHP was not suited for the general stroke population.

Based on these above findings and due to the simplicity and generic nature, as well as the ease of administration, high responsiveness rate and appropriateness of the EQ-5D tool, it was chosen as the preferred tool to be used to determine perceived health status in the sample being observed in this study.

The following Table 2.5.2.1 demonstrates the reliability, validity and responsiveness of the measurement tools in comparison with each other.

**Table 2.5.2.1 - Comparison of EQ-5D, SF-36 and NHP instruments (Salter et al, 2012)**

Tools:	Reliability		Validity		Responsiveness		
	Rigor	Results	Rigor	Results	Floor	Results	Floor/Ceiling
EQ-5D	+	++ (TR) ++ (IO)	+++	++	+	++	Varied
SF-36	+++	++ (TR) ++ (IC)	+++	+++	++	+++	+
NHP	+++	+++ (TR) +++ (IC)	+++	++	+	n/a	= (ceiling)

**NOTE:** +++=Excellent; ++=Adequate; +=Poor; n/a- not applicable; TR=Test re-test; IC= internal consistency; IO = Interobserver; varied (re. floor/ceiling effects; mixed results)

4. Perceived family support (Administered on admission, discharge and follow-up)  
A family support questionnaire appropriate for this study could not be identified using the available literature and resources. Subsequently, a self-developed closed-ended questionnaire was developed for specific use in this study.

The questionnaire consisted of nine yes/no questions that were aimed at providing information and insight into the participant's perceived family support in their home environment. Depending on the participants' perception of their family support, the respondent indicated either 'yes' or 'no' to each statement with a positive answer marked as a point. Each positive answer was counted to give a numerical total out of nine, with nine being the highest and correlating with the best possible perceived family support. The intervals used to determine perceived family support were as

follows: 1-3 = poor perceived family support, 4-6 = moderate perceived family support and finally, 7-9 = good perceived family support. Validity and reliability of this instrument in relation to this research study was determined using the various methods described in Methodology Chapter 3.7.1.

#### 5. Perceived satisfaction (Administered at discharge and follow-up)

A satisfaction questionnaire appropriate for this study could not be identified using the available literature and resources. Subsequently, a self-developed closed-ended questionnaire was developed for specific use in this study.

The questionnaire consisted of 16 statements that were aimed at providing information and insight into the perceived satisfaction levels of the participant with rehabilitation services that they were involved with during their stay at BMH. The participants then chose from one of six options available in the key that they perceived to best describe each statement. The key was structured as follows: 1 = Strongly agree, 2 = Agree, 3 = Neither agree nor disagree, 4 = Disagree, 5 = Strongly disagree or 6 = I have no opinion on the matter. Each question therefore had a numerical answer attached to it, which was then added up to give a total score out of 96, with 16 being the lowest possible total score. For statistical analysis purposes, the total scores of each individual were then divided by the total number of questions in the questionnaire (16) to give a final score of between 1 and 6, which then correlated with the above key to give an overall final answer of perceived satisfaction with rehabilitation (personal communication with Prof. R. Madsen, 2013).

The intervals used to determine final scores were as follows:  $<1.49 = 1$  (excellent),  $1.5 - 2.49 = 2$  (Good),  $2.5 - 3.49 = 3$  (satisfactory),  $3.5 - 4.49 = 4$  (unsatisfactory),  $4.5 - 5.49 = 5$  (poor), and  $>5.5 = 6$  (extremely poor). Lower total initial scores equated to lower final scores, which correlated with higher perceived satisfaction levels. (E.g.  $16 = 1 = \text{Strongly Agree} = \text{excellent perceived satisfaction with rehabilitation services}$ ). Validity and reliability of this instrument in relation to this research study was determined using the various methods described in Methodology Chapter 3.7.1.

6. Rehabilitation process (Administered at discharge):

A rehabilitation process data gathering instrument appropriate for this study could not be identified using the available literature and resources. Subsequently, a self-developed objective data gathering instrument was developed for specific use in this study. It was used to document all the data gathered by each discipline seen by the participant. The instrument included a medical section and a rehabilitation section. The medical section included information pertaining to: the referral hospital's details, the length of stay at Booth Memorial Hospital (BMH), classification of stroke type, locality of stroke, and finally whether the participant suffered from any form of aphasia or hypertension and/or diabetes mellitus. The rehabilitation section included information related to the frequency, duration and overall intensity of treatment and rehabilitation undergone by each participant at BMH. All data was gathered solely by the researcher from the rehabilitation notes in the patient's personal file. Validity and reliability of this instrument in relation to this research study was determined using the various methods described in Methodology Chapter 3.7.1.

7. 'Use of Care' questionnaire (Administered at follow-up):

This questionnaire, developed by Rhoda (2010), was adjusted to focus the questions directly to this study's target population. It was used to ascertain the type, frequency and intensity of rehabilitation undergone by the sample during the six months post discharge from BMH, which could have influenced their functional outcomes. It also aimed to find out reasons behind non-attendance at out-patient rehabilitation and how the participants have been managing in their current living environment with regards to care and mobility. Thirteen questions make up the questionnaire, however if no rehabilitation was undertaken during the six months post discharge, questions 2 and 3 were not completed by the participants. This questionnaire has been used in previous research and found to be valid but unreliable (Rhoda, 2010). Validity and reliability of this instrument in relation to this research study was determined using the various methods described in Methodology Chapter 3.7.1.

## 2.6 SUMMARY OF CHAPTER

The purpose of this chapter was to identify and convey, from the available published literature, the most appropriate information to this study, to ensure that the study is as theoretically and clinically relevant as possible. This chapter firstly spoke of the epidemiology of stroke, including the mortality, morbidity, incidence, prevalence, risk factors and burden of stroke. Secondly, disability post-stroke, which highlighted through the ICF framework, the neurological impairments, activity limitations and participation restrictions post-stroke. Thirdly, the stroke rehabilitation process was discussed, which concluded with the concept that each rehabilitation programme needs to be tailored to be patient-specific in order to maximise its effectiveness. Fourthly, the centre of the study focussed on the factors influencing the functional outcomes of stroke from early literature through to more recent available literature. Finally, the chapter ended with the description of the research instruments that were used in this research study.



## CHAPTER THREE: METHODOLOGY

### 3.0 INTRODUCTION

The methodology chapter describes the research setting, research design, study population and sampling, the measurement periods, the inclusion/exclusion criteria, the research instruments, validity and reliability, pilot study, data collection and data analysis and finally, the chapter will end off with the ethical considerations. As far as possible, this study attempted to meet the criteria outlined by Kwakkel et al (1996) in their critical review for determination of valid prognostic research in stroke functional outcome, seen in the Literature Review Chapter 2.4. Further information regarding meeting the aforementioned criteria is detailed in a few of the following headings.

### 3.1 RESEARCH SETTING

The study was conducted at Booth Memorial Hospital (BMH) in Oranjezicht, Cape Town, South Africa. BMH is a 120 bed sub-acute, primary level, low intensity in-patient rehabilitation healthcare facility run by The Salvation Army (TSA). BMH offers patients, with a wide variety of conditions (mainly neurological and orthopaedic), interdisciplinary rehabilitation for a period of six weeks.

In the Cape Metropole area, there are various levels of rehabilitation (in- and out-patient) services offered through facility-based and community-based services. Within the facility-based rehabilitation service, there is tertiary level rehabilitation, such as Groote Schuur Hospital (GSH) and Tygerberg Hospital (TBH) aimed at providing individuals with ICU/high-care and acute stage management of conditions. Then there is primary (step-down) level rehabilitation, such as Booth Memorial Hospital (BMH) and Conradie Care Centre (CCC), aimed at low intensity rehabilitation for acute and sub-acute patients. Finally, there is secondary level rehabilitation, such as Western Cape Rehabilitation Centre (WCRC), aimed at individuals with a more permanent type of disability needing high intensity rehabilitation, over an extended period of time. Within the community-based rehabilitation, services such as the community clinics, community health centres (CHCs), home based care (HBC) and out-patient department (OPD) services at

tertiary and district level hospitals are available (Western Cape Department of Health, 2007). The participants included in this study were only examined at the primary (step-down) level of rehabilitation (BMH) and at a CBS level at six month follow-up.

The rehabilitation services offered at BMH include: full time day and night time nurses, who attend to the monitoring and assistance of the patients, with regards to their medication, ADL and general care throughout their stay; a doctor, who manages the medical aspect of rehabilitation for each patient with regards to assessments, monitoring of condition and prescribing of medication; two full-time physiotherapists, who manage the physical side of rehabilitation with regards to assessments and treatment of each patient with the aim of reducing overall disability and return of independence; a half-day occupational therapist with a half-day occupational therapy assistant, who assess and manage treatments of each patient appropriately according to the occupational therapy principles, with a focus on treatment of the upper limbs and return of independence in relation to ADL; a sessional speech and language therapist who works three half-days per week and manages the communication and swallowing aspect of rehabilitation of each patient; and a social worker, who manages the social aspect and reintegration of each patient into the community. The rehabilitation services are focused on being holistic and aimed at minimising functional impairments, activity limitations and participation restrictions, to facilitate the reintegration of patients into their homes and community.

### 3.2 RESEARCH DESIGN

This non-experimental study made use of a quantitative approach with a descriptive, observational, and longitudinal research design. The quantitative approach was employed to identify any possible relationships between various variables and to come to a conclusion regarding the factors that are likely to have an influence on the functional outcomes of patients with stroke. Given (2008) explained that the objective of quantitative research is to develop and employ mathematical models, theories and/or hypotheses pertaining to phenomena.

Domholdt (2000) explained that non-experimental research does not involve any manipulation of variables and further explained that descriptive research enables the

researcher to control the data collected for the purpose of describing a phenomenon. Most descriptive studies include many different variables and as there are no presumptions of cause or effect, the distinction between independent and dependent variables are not usually made in the report (Domholdt, 2000).

The observational aspect of the study, described by Mann (2003), is one in which no intervention is made. In the case of this study, the researcher observed as the participants went through the normal rehabilitation process at the rehabilitation setting, with no experimentation done, not intervening in any way. A major advantage of an observational study, identified in a study done by Leys et al (2002), is that the study can evaluate patients in conditions as close as possible to true life and it can include all consecutive patients admitted during the study period.

The longitudinal aspect of the study was used as the participants were studied over an extended period of time. Domholdt (2000) identified that a study is longitudinal in design when the sample is measured and described several times over an extended period. Cherry (2007) also explained the benefits of this type of research is that it allows one to observe changes over a period of time and allows the researcher to discover relationships between various variables.

These study designs were chosen as they have been used before in similar research studies (Rouillard et al, 2012 and Joseph et al, 2013) and were identified as the most suitable to determine the factors influencing functional outcomes of individuals affected by stroke admitted to a sub-acute, primary level rehabilitation healthcare facility over an unspecified, extended time frame.

### 3.3 STUDY POPULATION AND SAMPLING

This research study made use of non-probability, convenience, consecutive sampling with an inception cohort. Domholdt (2000) explained that non-probability sampling is distinguished by the absence of randomisation and is widely used in physiotherapy research, mainly when limited funding is available. The selection of participants for this study was left to the researcher and there was no attempt at randomness. Convenience sampling involves the use of readily available subjects,

where consecutive sampling (a form of convenience sampling) is used in prospective studies when all subjects who meet the criteria are placed in the study until a specified number of subjects is collected, or in the case of this study, a specified time frame has passed (Domholdt, 2000). Consecutive subjects, who met the inclusion criteria, were included in the study sample as they were admitted to the hospital, until their six month follow-up was concluded.

In a study measuring outcomes, the ideal sample size is based on a statistical basis, whereby a minimum of ten subjects would be required per factor/predictor being identified (Hier et al and Sackett et al, 1991 and Kwakkel et al, 1996). This study aimed to identify the effect of five factors, therefore 50 participants would be required (see Annexure A). A review of the previously admitted patients to BMH was necessary to identify the time frame necessary for the study. The review found that a possible ten participants per month could be included into the study. However, to address attrition, which is common in longitudinal studies, the researcher aimed to recruit 60 participants overall and therefore, a six month time period was identified as adequate for the admission of participants into the study.

For statistical purposes, all data collected from participants on admission was analysed in the study to describe their functional baseline. However, patients who passed away during their six week stay at BMH were subsequently excluded from further analysis on discharge and at the six month follow-up. Patients who passed away during the six months post discharge from BMH were included in the discharge analysis but were excluded from the six month follow-up analysis. This was done to allow for the maximum number of full data sets in the study at the given measurement periods. Furthermore, the participants assessed to have receptive aphasia on admission were excluded from the analysis of the questionnaires over the measurement periods as full data set could not be obtained. Specifications of participant withdrawal/exclusion from this study was identified for control of patient drop out, identified by Kwakkel et al (1996), as necessary to prevent a biased outcome of results.



### 3.4 MEASUREMENT PERIODS

The measurement periods were decided upon by firstly taking into consideration the inception cohort, which as identified by Kwakkel et al (1999) required all participant's first measurement to be done as soon as possible after stroke onset, therefore on admission to BMH. Secondly, the discharge measurement period was decided upon by the six week programme in place at BMH for all patients. The six month post discharge follow-up measurement period for participants was decided upon by taking into consideration the available literature (Kwakkel et al, 1996).

### 3.5 INCLUSION/EXCLUSION CRITERIA

#### 3.5.1 Inclusion Criteria-

The individuals included in this study were all acute or sub-acute patients with stroke who were admitted to BMH for the purpose of rehabilitation. Patients in the acute or sub-acute phase of the stroke include those who have had their stroke less than six months prior to their inclusion into the study (Korner-Bitensky et al, 2011).

#### 3.5.2 Exclusion Criteria-

The individuals excluded from this study were all those who refused consent or where the individual's guardians (in the case of those who were unable to make independent decisions) refused consent. Furthermore, patients with stroke who had additional medical conditions (e.g. amputation, fracture, HIV/AIDS, TB), that may influence the participant's functional outcomes or impact negatively on the individual's subjective perceived satisfaction levels or perceived health related quality of life were excluded.

### 3.6 RESEARCH INSTRUMENTS

This study made use of seven instruments altogether as part of the data collection process. The tools included: 1) A socio-demographic questionnaire, which was used to collect data relating to the socio-demographic status of each participant, including: age, gender, ethnicity, level of education, employment status and any family history of stroke. 2) An objective functional assessment in the form of the Barthel Index, which is an index that is used to quantify the ability of a patient to independently carry

out their functions or ADL. 3) A health related quality of life questionnaire in the form of the EQ-5D, which is a standardised measure of health status. Biopsychosocial questionnaires, which included: 4) a perceived family support questionnaire aimed at providing insight into the participant's perceived family support structure; and 5) a perceived subjective satisfaction questionnaire aimed at providing information and insight into the perceived satisfaction levels of the participant with rehabilitation services received. 6) A rehabilitation process data gathering instrument, which was used to document all the relevant rehabilitation data. Finally, 7) a 'Use of Care' questionnaire to collect rehabilitation data relating to the six months post discharge from BMH. For a more comprehensive description of each research instrument used in this study, see Chapter 2.5.

### 3.7 VALIDITY AND RELIABILITY

As part of this research study, the researcher aimed to prove the validity and reliability of the research instruments used in the study. The appropriate approach for determining an instrument's reliability depends on the type of instrument (Domholdt, 2000). The instruments used in this research study are within the self-report and observational categories, which allow for the following simple methods to be used when determining reliability: test-retest, interrater reliability and internal consistency.

#### 3.7.1 Reliability and validity of each instrument used in this research:

The test retest method, one of the simplest ways of testing the stability and reliability of an instrument (Shuttleworth, 2009), was conducted by issuing the instruments to five pilot study participants and then, two weeks later, following-up by re-issuing the questionnaires again and comparing the results. The variables being tested for during the pilot study did not change throughout the process and all the responses given in the test retest were of a similar nature, therefore the research instruments were identified as reliable. No formal statistical tests were conducted to obtain these results, it was determined by viewing the responses.

However, Domholdt (2000) explains that, as observational measurements require only a human instrument with systematic knowledge of what to observe, determining

the reliability of these measurements are linked to determining intrarater reliability. Intrarater reliability refers to the consistency with which one rater assigns scores to a single set of responses on two separate occasions. Domholdt (2000) further explained that interrater reliability refers to the consistency of performance among different raters or judges assigning scores to the same objects or responses. Intrarater reliability and content validity of the research instruments used in this study was determined using the test retest method, which involved asking rehabilitation staff working in a similar rehabilitation centre, Conradie Care Centre (CCC), to review the questionnaires. All instruments were found to be valid and reliable as they measured what they intended to.

The research instruments used in this study were tested for internal consistency by using the Cronbach's Alpha coefficient and Inter-Item mean statistic. The Cronbach's Alpha coefficient for the Barthel Index over all three measurement periods was noted as 0.883 with a mean Inter-Item correlation of 0.714. The Cronbach's Alpha coefficient for the EQ-5D over all three measurement periods was noted as 0.916, with a mean Inter-Item correlation 0.42. The Cronbach's Alpha coefficient for the perceived family support questionnaire over the three measurement periods was noted as 0.799, with a mean Inter-Item correlation of 0.578. Finally, the Cronbach's Alpha coefficient for the perceived satisfaction questionnaire over the two measurement periods was 0.971, with a mean Inter-Item correlation of 0.943. Therefore, all the Cronbach's Alpha coefficients for the research instruments used in this study were found to have very good internal consistency reliability.

### 3.8 PILOT STUDY

A pilot study was conducted by the researcher and included five participants from BMH, who were selected according to the inclusion/exclusion criteria of the study. The sample size of the pilot study is acknowledged as a limitation in Chapter 6.3. The pilot study was done to test logistics and gather information regarding appropriateness of measurement instruments used, so as to improve the quality and efficiency of the main study (Altman et al, 2006). It aimed to refine the research tools, and in so doing, improve the quality of the data retrieved from the participants (Katzenellenbogen et al, 1997). The participants were then excluded from the main

study to prevent any exposure bias that may have been present. The pilot study proved successful as it indicated the general length of time that was required to complete each questionnaire and allowed the researcher to become more familiar with the research instruments, therefore no changes to the measurement instruments were recorded for the main study.

### 3.9 DATA COLLECTION

After ethical clearance had been obtained from UWC and permission had been granted by Booth Memorial Hospital (BMH), all acute and sub-acute patients with stroke admitted to BMH, for the specific reason of rehabilitation, were available to be a part of the main study. The majority of patients with stroke being referred to BMH are in the acute to sub-acute phase (within three weeks post-stroke). The researcher had access to the BMH patient register, which was updated by the hospital and viewed daily by the researcher to assess for any possible new recruits to the study. The researcher had access to the participants at all times during their stay at BMH and was able to observe and record all the necessary data.

Each individual (or their guardian in the case where the individual was unable to consent to or comprehend the study) who met the inclusion criteria for the research study was invited to participate in the study after the aim of the study was explained to them. They were given an information sheet (see Annexure B) and a consent form (see Annexure C) prior to any administration of forms and questionnaires. The information sheet detailed the study and the exact expectations of each individual during their involvement with the research. Only once informed consent had been given, were the questionnaires administered in the form of a structured interview, in the physiotherapy gym at a time that was suitable to the participant. This was done by the researcher, to ensure there were no difficulties experienced by participants in this process.

Individuals who were included in the study were then issued, within two days of their arrival at BMH, with the socio-demographic questionnaire (see Annexure D), the perceived family support questionnaire (see Annexure G) and the EQ-5D questionnaire (see Annexure F), and then the Barthel Index (BI) functional level

assessment (see Annexure E) was carried out by the researcher through observations of functional tasks given to the participant in the physiotherapy gym and subjective questioning of the participant and staff.

Their rehabilitation regimes were strictly documented and monitored by all therapists involved in the individual's rehabilitation throughout their stay at BMH. At the end of the participant's rehabilitation, within two days of their discharge date, the rehabilitation process was documented on the data gathering instrument (see Annexure I), by the researcher, using the data gathered from the patient's hospital file. The perceived satisfaction level questionnaire (see Annexure H) was administered, along with the repeat of the EQ-5D and perceived family support questionnaires, which were again completed through a structured interview and finally, the functional level BI was again assessed.

Participants were then assessed again, after six months post discharge at their follow-up, within a window period of seven working days, using the BI functional level assessment. The 'Use of Care' questionnaire (see Annexure J) was administered for the first time, along with the repeat of the EQ-5D, perceived satisfaction level and perceived family support questionnaires. The six month follow-up data was collected at a place suitable for the patient. Transport arrangements were made if the participants were willing to return to BMH or alternatively, if it was not possible for the participants to return, they were contacted telephonically by the researcher and interviews were conducted over the phone with the participants and their family.

Carr et al (2001) found that studies which compared telephonic and face-to-face interviews showed that telephonic interviews produced data that was "at least comparable in quality" to that of data attained by face-to-face interviews. Leys et al (2002) found no significant differences between patients examined at a neurologic visit and those followed-up by telephonic interviews. Della Pietra et al (2011) identified several studies that found agreement between telephonic assessments versus face-to-face assessments using the BI, with the study conducted by Della Pietra et al (2011) further identifying the validity and reliability of telephonic assessments when using the BI. The EuroQol Group identified telephonic interviews as an alternative to face-to-face administration of the EQ-5D (Cheung et al, 2009).

Description of any additional treatment effects during the period of observation, including paramedical and medical interventions, are required as the additional treatments are also a potential confounder for discovering discriminants for functional recovery after stroke (Kwakkel et al, 1996). However, no confounding paramedical or non-medical interventions were noted for any of the participants during their stay at BMH or during six months post discharge.

Only the researcher collected the data to prevent any possible outside bias or misinterpretation of data that may have influenced the outcome of the research. All dates of assessments and questionnaire completion were captured for the purpose of data analysis.

### 3.10 DATA ANALYSIS

All the data collected from the participants in this study was captured initially on Microsoft Excel 2007 and then imported into SPSS 21. The data analysis was managed in five phases: In the first phase, exploratory data analysis was conducted through graphical display, as recommended by Katzenellenbogen et al (1997). This enabled the researcher to review the shape of data distributions.

The second phase entailed a correlation matrix in which all demographic variables were correlated with the outcome variable to determine whether there were any variables that needed to be considered as potential covariates in the subsequent analysis. This control was conducted for multicollinearity, regarded as sufficient if the multivariate analysis of the relation between an outcome variable and two or more independent variables is partialled out for interaction (Kwakkel et al, 1996).

The third phase entailed univariate analysis in which one variable is explored at a time (Indrayan, 2008). Though the combined result of several univariate analyses may be very different from the result obtained by simultaneous consideration of these variables. Pallant (2011) recommended that the descriptive univariate phase of data analysis has a number of uses, including: describing the characteristics of the sample, checking the variables for any violation of the assumptions underlying the statistical techniques to be addressed in the research questions, and to address

specific research questions. In this analysis, the purpose of univariate analyses was to support the initial findings of phase one in terms of the extent to which the data met the assumptions of inferential statistics e.g. normal distribution, homogeneity of variance and heteroskedasticity (Wilcox et al, 2004). From this it emerged that not all data was normally distributed and necessitated the exploration of non-parametric statistics. Furthermore, the researcher was able to test if the data supported the proposed univariate and multivariate analyses. The results of univariate analyses are summarised per measuring instrument and along the demographic variables.

In the fourth phase, mean differences between admission and discharge, as well as follow-up were assessed using the Kruskal-Wallis test which is the non-parametric equivalent of the dependent t-test. Significance was tested at a level 0.05% alpha level (Kwakkel et al, 1996). However, in interpreting the findings of these tests, the decision-making was not purely based on statistical significance, as null findings may still have clinical significance (Katzenellenbogen et al, 1997).

In the fifth phase, predictive relationships were tested for using multiple regression analysis. Multiple regression is considered appropriate since it allows predictor variables to compete with one another to determine which offers the most unique explanation of the variance as evidenced by the semi-partial coefficients (Wilcox, 2012). This analysis incorporated the general linear model to control for the non-normal distribution of scores (Gray, 2009). Two sets of regression analyses were conducted. The first model tested whether the predictor variables (perceived satisfaction level, family support and health related quality of life) could significantly explain the variance on function (BI) at discharge. The second analysis was conducted to determine whether the BI was a function of the predictor variables at follow-up. This analysis was conducted using the enter methods in two steps. In the first step, the same model was used as at discharge for consistency and in the second step, education was added as a predictor since it was identified as a potential covariate in earlier analyses. This allowed for the same model to be tested at discharge and follow-up. All models and beta coefficients were tested for significance at an alpha level below 0.05.

### 3.11 ETHICAL CONSIDERATIONS

Ethical clearance and permission to conduct this study was obtained from the University of the Western Cape's Faculty of Community and Health Sciences Higher Degrees Committee, the Senate Research Grant and Study Leave Committee, from the Western Cape Department of Health and finally from the BMH Administrator, Lieutenant Colonel Malcolm R. Forster.

Confidentiality of all participants, whether included or excluded from the study, was ensured by not disclosing any information to unauthorised parties. The use of password-protected computerised files, as well as identification coding on information gathered, was used. The participant's name was not included on the collected data (except for the demographic information). A code was placed on the questionnaires and other collected data, through the use of an identification key, which only the researcher was able to link relevant information to the participant's identity, and only the researcher had access to the identification key. All included participants got full disclosure regarding the aims, objectives and purpose of the research study.

Written informed consent was obtained from the participants or the participant's guardian and they were given the right to refuse participation in the study without question. Participants in the study had the right to, at any point in time, withdraw from the study without repercussions (refusal of treatment or stigmatisation from the therapists). Results of the study will be made available to the relevant parties upon completion. Any necessary referrals for participants or family members were handled as the need arose.



## CHAPTER FOUR: RESULTS

### 4.0 INTRODUCTION

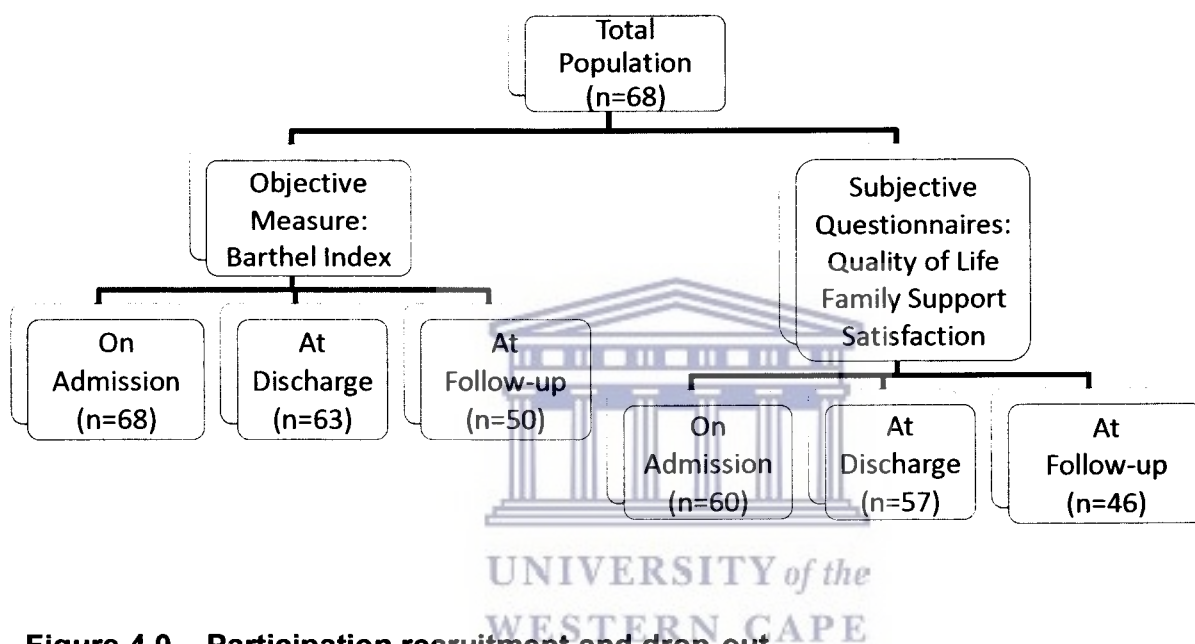
Based on the objectives of the study, the results obtained from the data gathered throughout the main study at the various measurement periods will be presented through descriptive, univariate statistics and multivariate statistical analysis, with the aid of figures and tables. Objectives 1 through 5, namely: identifying the participants 1) socio-demographic characteristics, 2) medical factors, 3) functional level, perceived health related quality of life, perceived family support network, 4) perceived satisfaction level with rehabilitation and 5) the process of rehabilitation undergone by each participant, were addressed using descriptive univariate analysis. Objective 6, namely: identifying possible factors influencing the functional outcomes of participants were identified using multivariate analysis. Each section will correspond with the objective number. This chapter will end off with a summary of the results.

Participant recruitment and drop-out throughout study:

From the total participants (n=68) in the sample, there was a total of 16.2% (n=11) deaths throughout the study. Of the eleven participants who passed away, 45.5% (n=5) passed away during their rehabilitation stay at BMH and 54.5% (n=6) before the six month follow-up. Approximately 10% (n=7) of participants could not be contacted after their discharge from BMH for their six month follow-up assessment and as such were lost to follow-up. As a full data set could not be completed for each of these participants, they were excluded from the analysis of the objective BI, as well as the subjective health related quality of life, family support and satisfaction with rehabilitation questionnaires over the relevant measurement periods.

Furthermore, in addition to the exclusion of the participants who passed away or were lost to follow-up, another 11.8% (n=8) of participants were excluded from the analysis of the subjective EQ-5D perceived health, perceived family support and perceived satisfaction with rehabilitation questionnaires due to the presence of receptive aphasia and hence an incomplete data set. This exclusion of participants

with cognitive and language deficits from the sample is justified as it is in alignment with previous research of a similar nature by Rouillard et al (2012) and Joseph et al (2013). While all 68 participant's socio-demographic information was analysed, the exclusions only allowed for a total sample of 60 eligible participants to be analysed on admission, 57 participants at discharge and 46 participants at six month follow-up for the three afore mentioned subjective questionnaires (See Figure 4.0 below).



**Figure 4.0 – Participation recruitment and drop-out**

#### 4.1 SOCIO-DEMOGRAPHICS OF PARTICIPANTS

##### 4.1.1 Age and gender

A total of 68 participants were recruited into the study. On admission, the sample included 44.1% (n=30) males and 55.9% (n=38) females. The mean age of the sample was 63.69 (SD +/-12.18) years old. The oldest participant included in the study was an 88 year old female and the youngest participant being a 32 year old male.

#### 4.1.2 Participants according to age group

The sample was divided into six groups according to their age, in terms of decades, for the purpose of analyses in this study. The age groups were: 30-39, 40-49, 50-59, 60-69, 70-79 and 80-89. The majority of 36.8% (n=25) participants were in the 60-69 age group. For a further breakdown of age group distribution in sample, see Table 4.1.2 below.

**Table 4.1.2 – Participants according to age group**

Age Groups	Frequency % (Number)
30-39	3.3 (1)
40-49	11.8 (8)
50-59	18.4 (13)
60-69	36.8 (25)
70-79	16.7 (12)
80-89	13.2 (9)
<b>Total:</b>	<b>100 (68)</b>

#### 4.1.3 Age group and gender distribution

Of the 30 males in the study, the majority of 40% (n=12) were between the ages of 60 to 69. This too was identified with the 38 females, as the majority 34.2% (n=13) were also in the 60 to 69 age group. A further breakdown of the participant age groups in relation to gender distribution is illustrated in Table 4.1.3 below.

**Table 4.1.3 – Participant age groups in relation to gender distribution**

Age Groups	Males % (Number)	Females % (Number)
30-39	3.3 (1)	0 (0)
40-49	10 (3)	13.2 (5)
50-59	20 (6)	18.4 (7)
60-69	40 (12)	34.2 (13)
70-79	16.7 (5)	18.4 (7)
80-89	10 (3)	15.8 (6)
<b>Total</b>	<b>100 (30)</b>	<b>100 (38)</b>

#### 4.1.4 Education

Of the sample in the study, the majority of 63.2% (n=43) participants had between a Grade 8 and Grade 12 level of education, and only 1.5% (n=1) had a tertiary degree. For a further breakdown of the education level of the sample, see Table 4.1.4 below.

**Table 4.1.4 – Participant education level**

Education Level	Frequency % (Number)
None	5.9 (4)
<Grade 8	29.4 (20)
Grade 8 – 12	63.2 (43)
Tertiary	1.5 (1)
Total	100 (68)

#### 4.1.5 Employment Status

The employment status of the vast majority of participants in the sample amounted to 61.8% (n=42) who were pensioners (over the age of 60). For the employment status of all participants in the sample, see Table 4.1.5 below.

**Table 4.1.5 – Participant employment status**

Employment Status	Frequency % (Number)
Pensioners	61.8 (42)
Unemployed	25 (17)
Employed	12.2 (9)
Total	100 (68)

#### 4.1.6 Family History of Stroke

The majority of 61.8% (n=42) participants claimed no family history of stroke, with 38.2% (n=26) participants claiming there was.

## 4.2 MEDICAL FACTORS OF PARTICIPANTS

### 4.2.1 Type of CVA

The majority of 58.82% (n=40) of participants suffered an infarction, while 13.24% (n=9) of participants suffered a haemorrhagic stroke. Approximately 28% (n=19) of participants were still awaiting Computer Tomography brain (CTB) scans when they were admitted to BMH and therefore, the type of stroke was not known at the time of data collection for this study.

### 4.2.2 Aphasia

Of the 68 participants in the sample, approximately 23.5% (n=16) suffered from a type of aphasic complication. Of those 16 participants, 50% (n=8) experienced complications of expressive aphasia only, 43.75% (n=7) experienced global aphasia (both expressive and receptive aphasia), and 6.25% (n=1) experienced complications of receptive aphasia only.

### 4.2.3 Hemisphere Affected

Based on the side of the body affected by the stroke in the sample, the locality of the stroke could be identified. A slight majority of 51.5% (n=35) of participants had a left sided infarction or lesion, with 48.5% (n=33) of participants having a right sided infarction or lesion.

### 4.2.4 Hypertension and Diabetes Mellitus

Of the total 68 participants, 80.9% (n=55) of participants suffered from hypertension, 30.9% (n=21) of participants suffered from either type of Diabetes Mellitus and 27.9% (n=19) of participants suffered from both hypertension and Diabetes Mellitus. Only 16.2% (n=11) of participants were not diagnosed as having either of these risk factors for stroke. These were the only risk factors documented for the purpose of this study.

### 4.3 FUNCTIONAL AND PERCEIVED HEALTH STATE OF PARTICIPANTS

#### 4.3.1 Functional state of participants

The descriptive statistics of the functional state of all eligible participants of the sample in terms of the Barthel Index (BI) at the various measurement periods can be seen in Table 4.3.1.1 below.

**Table 4.3.1.1 – Barthel Index of sample over measurement periods**

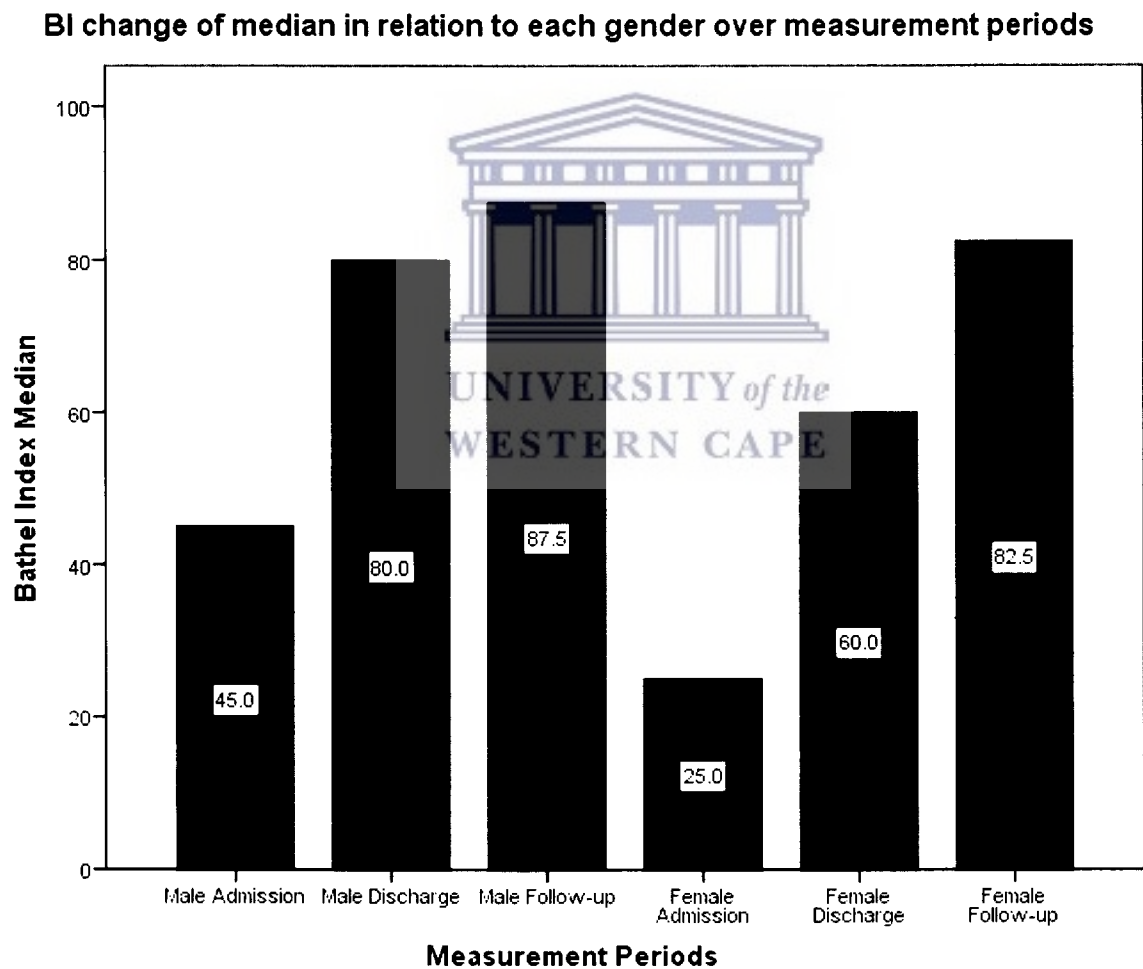
Descriptives	Admission BI	Discharge BI	Follow-up BI
Participants (Number)	68	69	90
Median	35	75	85
Percentiles 25	10	50	67.5
50	35	75	85
75	60	90	90
Minimum	0	0	0
Maximum	85	100	100

The BI changes of the sample seen throughout the measurement periods within the study show a change in median of 40 from admission to discharge, and a further change of 10 from discharge to six months follow-up, amounting to a total change in median of 50 from admission to six months follow-up for all participants of sample. For multivariate analysis of the BI over the various measurement periods, see 4.6.1. The researcher further broke down the BI scores into gender distribution over the three measurement periods. See Table 4.3.1.2 below.

**Table 4.3.1.2 - BI scores in relation to gender distribution over measurement periods**

Descriptives	Males			Females		
	Admission	Discharge	Follow-up	Admission	Discharge	Follow-up
Participants (Number)	30	28	20	38	35	30
Median	45	80	87.5	25	60	82.5
Percentiles 25	30	65	75	5	30	58.75
50	45	80	87.5	25	60	82.5
75	60	90	90	45	85	95

For all male participants, a change in median of 35 from admission to discharge was identified, and a further change of 7.5 from discharge to six months follow-up, amounting to a total change in median of 42.5 from admission to six months follow-up. For all female participants, a change in median of 35 from admission to discharge was identified, and a further change of 22.5 from discharge to six months follow-up, amounting to a total change in median of 57.5 from admission to six months follow-up. For a visual representation of the BI changes in median over measurement periods in relation to gender distribution, see Figure 4.3.1 below. For multivariate analysis of the BI in relation to gender distribution see 4.6.6.



**Figure 4.3.1 – BI change of median in relation to gender distribution**

### 4.3.2 Perceived health state of participants

#### 4.3.2.1 Perceived health related Quality of Life EQ-5D – Descriptive System

Data obtained through the EQ-5D descriptive system for perceived health related quality of life of the sample over the measurement periods is presented in Table 4.3.2.1 below.

**Table 4.3.2.1 – Participants' perceived quality of life over measurement periods**

Measurement Periods:	Quality of Life Categories:	Participants Response %		
		No Problems/ None	Some Problems/ Moderate	Unable/ Extreme
Admission	Mobility	1.7	48.3	50
	Self Care	10	53.3	36.7
	Usual Activities	5	38.3	56.7
	Pain/Discomfort	48.3	45	6.7
	Anxiety/Depression	33.3	50	16.7
Discharge	Mobility	33.3	40	26.7
	Self Care	17.5	40	42.5
	Usual Activities	17.5	30	52.5
	Pain/Discomfort	75.4	21	3.5
	Anxiety/Depression	64.8	28	7.2
Follow-up	Mobility	58.7	28.3	13
	Self Care	47.8	47.8	4.3
	Usual Activities	37	52.2	10.9
	Pain/Discomfort	78.3	19.6	2.2
	Anxiety/Depression	84.8	13	2.2

(Number of participants: On admission = 60, at discharge = 57 and at follow-up = 46)

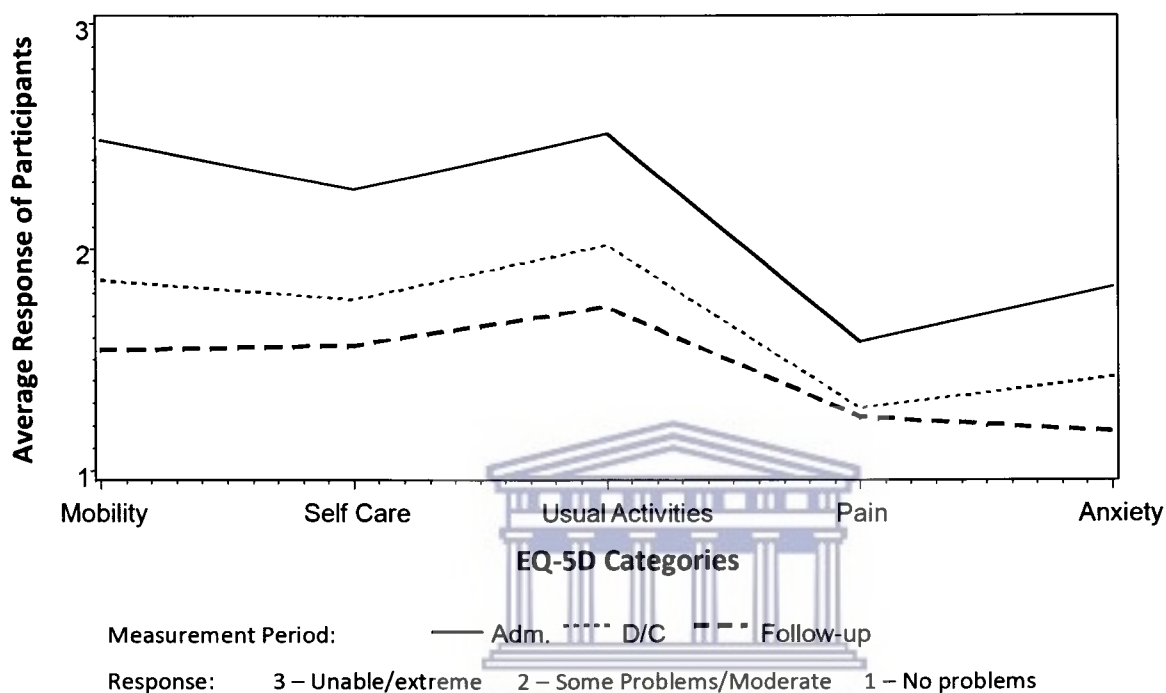
The overall mode for responses to each category of the EQ-5D descriptive system, except 'Pain/Discomfort', changed from admission through to six month follow-up.

On admission, the mode for each category was identified as 3 2 3 1 2, which refers to a perceived inability to mobilise, some problems experienced with caring for self, a perceived inability to carry out usual activities, as well as no pain/discomfort experienced and moderate anxiety/depression. On discharge, the mode for each category was identified as 2 2 2 1 1, referring to some perceived problems experienced with mobilising, caring for self and carrying out usual activities, as well as experiencing no pain/discomfort or anxiety/depression. At follow-up, the mode for each category was identified as 1 1 2 1 1, which refers to no perceived problems experienced with mobilising or caring for self, some perceived problems experienced with carrying out usual activities, as well as experiencing no pain/discomfort and no anxiety/depression.



The change in average response (mode) by the sample for the EQ-5D descriptive system over each measurement period can be seen in Figure 4.3.2.1 below.

**Average response of participants for each EQ-5D category over measurement periods**



**Figure 4.3.2.1 - Change in response to EQ-5D over measurement periods**

#### 4.3.2.2 Perceived health related Quality of Life EQ-5D – Visual Analogue Scale

The descriptive statistics for the EQ-5D VAS perceived health state of all eligible participants at the various measurement periods can be seen in Table 4.3.2.2 below.

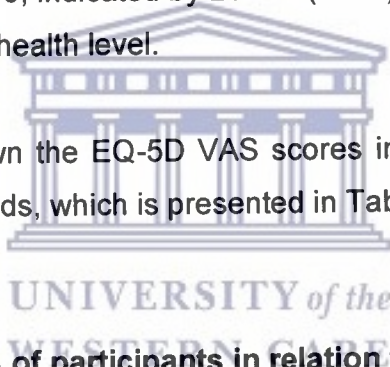
**Table 4.3.2.2 - EQ-5D VAS change in median over the measurement periods**

Descriptives	Admission VAS	Discharge VAS	Follow-up VAS
Participants (Number)	60	57	46
Median	30	60	80
Percentiles 25	20	50	60
50	30	60	80
75	50	75	90
Minimum	10	10	30
Maximum	80	90	100

The EQ-5D VAS changes seen throughout the measurement periods for all participants of the sample show a change in median of 30 from admission to discharge, and a further change of 20 from discharge to six month follow-up, amounting to a total change in median of 50 from admission to six month follow-up for the sample. For multivariate analysis of the EQ-5D VAS, see 4.6.2.

Based on the responses to the EQ-5D VAS over the three measurement periods, the following was identified as the overall mode of perceived health state of the sample for the respective observational period: On admission – 10 out of a possible 100, indicated by 18.3% (n=11) of participants, which referred to an extremely poor self-rated health level. On discharge – 70 out of a possible 100, indicated by 22.8% (n=13) of participants, which referred to a good self-rated health level. At six month follow-up – 90 out of a possible 100, indicated by 23.9% (n=11) of participants, which referred to an excellent self-rated health level.

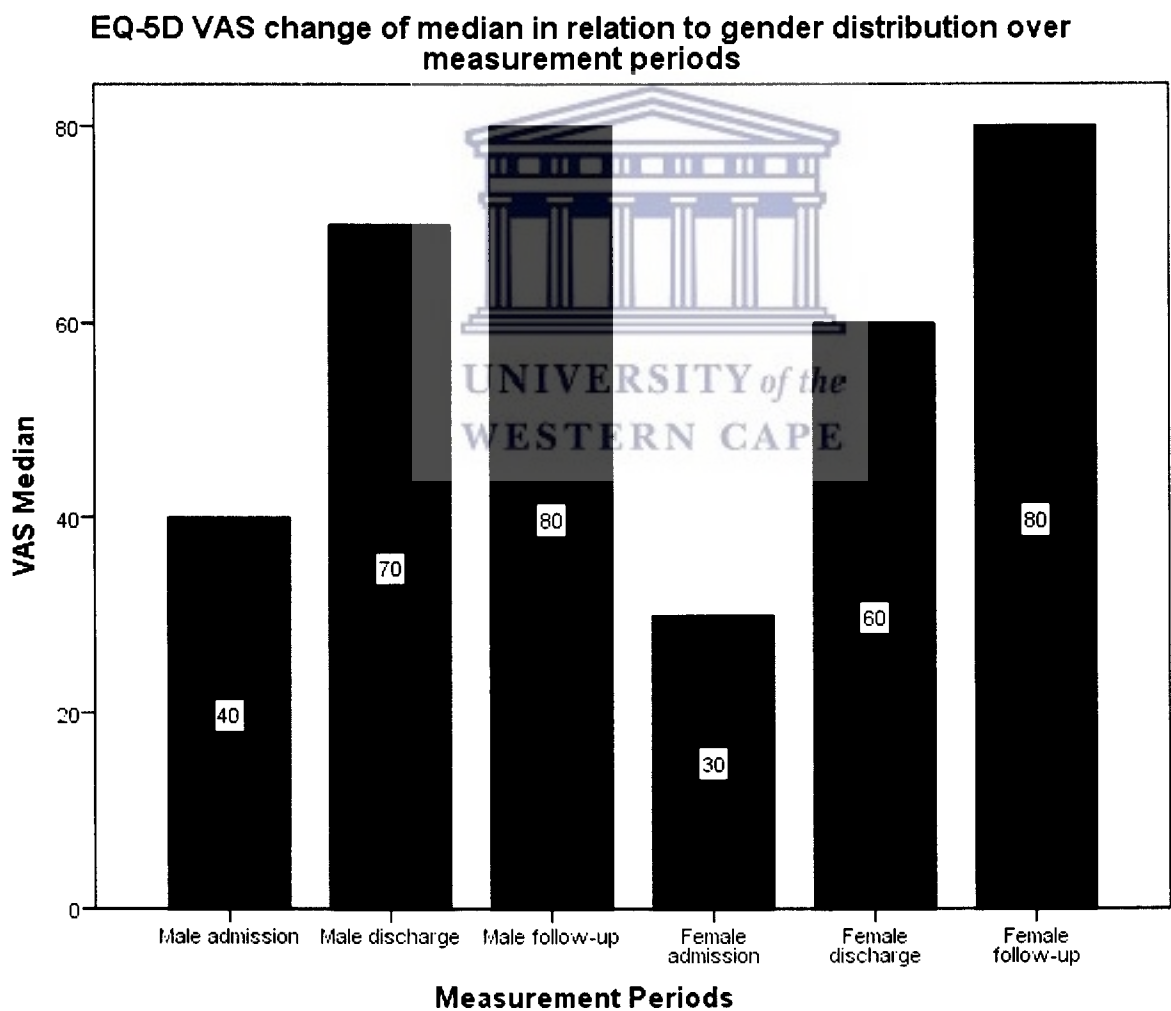
The researcher further broke down the EQ-5D VAS scores into gender distribution over the three measurement periods, which is presented in Table 4.3.2.3 below.



**Table 4.3.2.3 - EQ-5D VAS scores of participants in relation to gender distribution**

Descriptives	Males			Females		
	Admission	Discharge	Follow-up	Admission	Discharge	Follow-up
Participants (Number)	28	26	19	32	31	27
Median	40	70	80	30	60	80
Percentiles 25	20	60	70	12.5	40	60
50	40	70	80	30	60	80
75	50	72.5	90	50	80	90

In conclusion of the EQ-5D VAS, changes seen throughout the measurement periods for all male participants is noted as follows: change in median of 30 from admission to discharge, and a further change of 10 from discharge to six months follow-up, amounting to a total change in median of 40 from admission to six months follow-up. The EQ-5D VAS changes seen throughout the measurement periods for all female participants is noted as follows: a change in median of 30 from admission to discharge, and a further change of 20 from discharge to six months follow-up, amounting to a total change in median of 50 from admission to six months follow-up. For a visual representation of EQ-5D VAS perceived health state change of median in relation to gender distribution over measurement periods, Figure 4.3.2.2 below.



**Figure 4.3.2.2 – EQ-5D VAS change of median in relation to gender distribution**

### 4.3.3 Perceived family support

The measurement periods for the perceived family support of the sample yielded the following descriptive statistical results, presented in Table 4.3.3.1 below.

**Table 4.3.3.1 - Perceived family support over measurement periods**

Descriptives	Family Support		
	Admission	Discharge	Follow-up
Participants (Number)	60	57	46
Median	8	8	8
Percentiles 25	6	7	7
50	8	8	8
75	8	9	9
Minimum	0	0	1
Maximum	9	9	9

The measurement periods of all eligible participants in the sample for the perceived family support on admission, discharge and at follow-up yielded a median score of 8 across all three periods, showing no change in median from admission to six month follow-up. For multivariate analysis of perceived family support, see 4.6.3.

The researcher further broke down the perceived family support into gender distribution over the three measurement periods and identified the following, presented in Table 4.3.3.2 below.

**Table 4.3.3.2 - Perceived family support in relation to gender distribution**

Descriptives	Males			Females		
	Admission	Discharge	Follow-up	Admission	Discharge	Follow-up
Participants (Number)	28	26	19	32	31	27
Median	7.5	8.5	9	8	8	8
Percentiles 25	7	7	7	6	6	7
50	7.5	8.5	9	8	8	8
75	8	9	9	8	8	9

In conclusion of the perceived family support changes seen throughout the measurement periods within the study for gender distribution, male participants had a change in median of 1 from admission to discharge, and a further change of 0.5 from discharge to six month follow-up, amounting to a total change in median of 1.5 from admission to six month follow-up. Female participants showed no change in median from admission to six months follow-up.

#### 4.4 PERCEIVED SATISFACTION LEVEL WITH REHABILITATION

Perceived satisfaction of rehabilitation by the sample over the measurement periods yielded the following descriptive statistical results, presented in Table 4.4.1 below.

**Table 4.4.1 – Perceived satisfaction levels over measurement periods**

Descriptives	Satisfaction Level	
	Discharge	Follow-up
Participants (Number)	57	46
Median	1	1
Percentiles 25	1	1
50	1	1
75	1	1
Standard Deviation	0.18626	0.18884
Minimum	1	1
Maximum	2	2

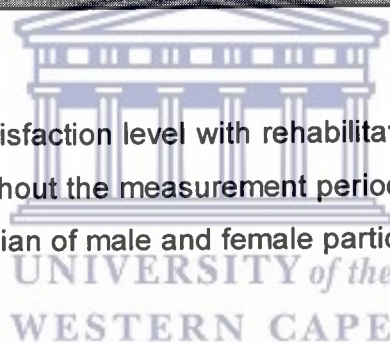
The most commonly noted result for perceived satisfaction with rehabilitation at discharge and follow-up by the eligible sample was 1 out of a possible 6, indicated by 80.7% (n=46) and 78.3% (n=36) participants respectively, which referred to an excellent perceived satisfaction level at discharge and six months follow-up. In conclusion of the change seen throughout the measurement periods, there was no change to note in median from discharge to six months follow-up. For the multivariate analysis of perceived satisfaction, see 4.6.4.

The researcher further broke down the perceived satisfaction of rehabilitation into gender distribution over the three measurement periods and identified the following, presented in Table 4.4.2 below.

**Table 4.4.2 - Perceived satisfaction levels in relation to gender distribution**

Descriptives	Males		Females	
	Discharge	Follow-up	Discharge	Follow-up
Participants (Number)	26	19	31	27
Median	1	1	1	1
Percentiles 25	1	1	1	1
50	1	1	1	1
75	1	1	1	1
Std. Deviation	0.18755	0.13159	0.18784	0.22269

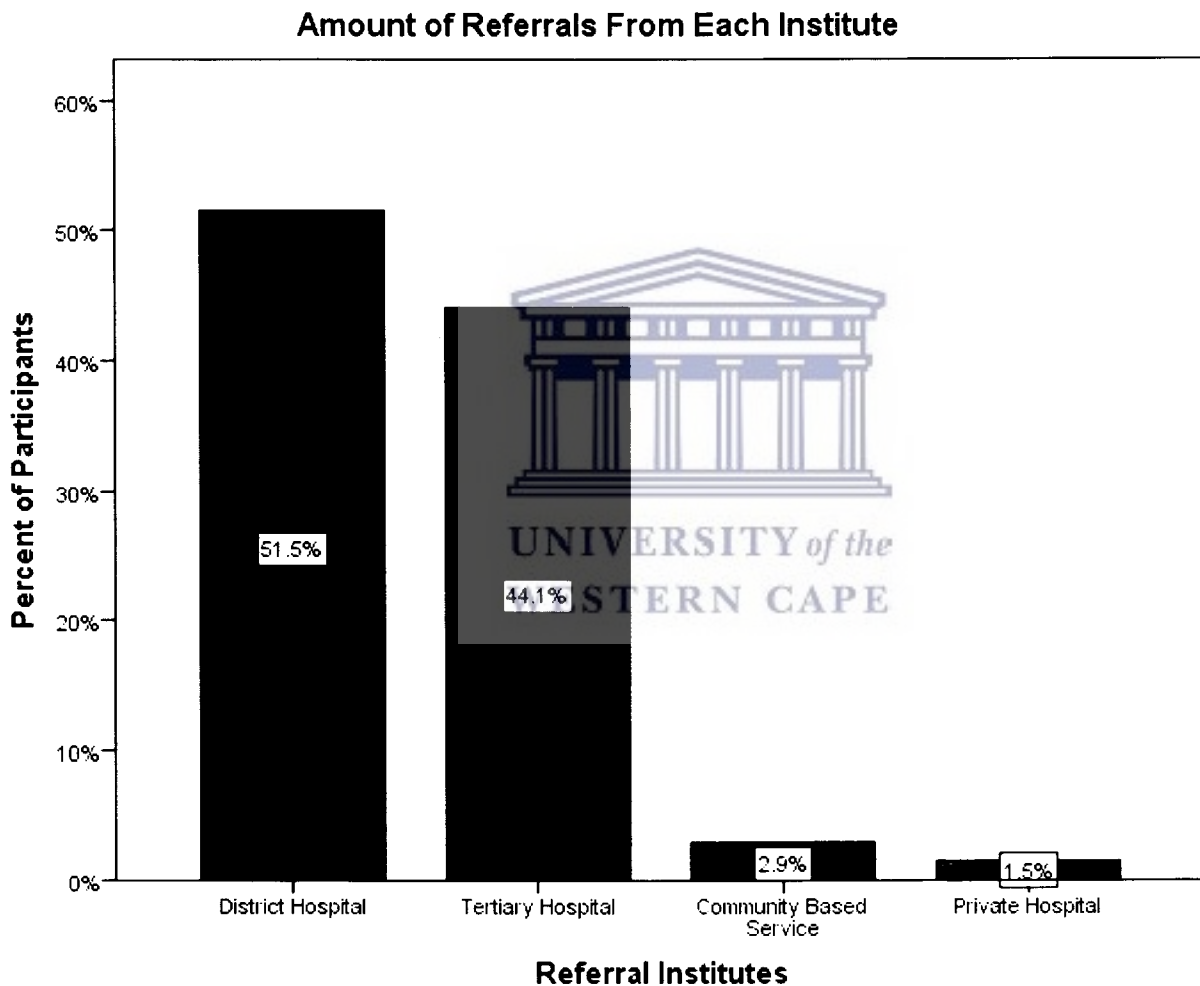
In conclusion of the perceived satisfaction level with rehabilitation change in relation to gender distribution seen throughout the measurement periods within the study: no changes were noted in either median of male and female participants from discharge to six month follow-up.



## 4.5 REHABILITATION PROCESS FACTORS

### 4.5.1 Referral of participants to BMH

All participants of the sample included in this study were admitted to BMH from various hospitals with the majority of 51.5% (n=35) of participants coming from the surrounding district hospitals. The referrals of all participants are presented in Figure 4.5.1 below.



**Figure 4.5.1 – Percentage of participants referred per referral institution**

#### 4.5.2 Length of stay of participants

The descriptive statistical results for length of stay of sample at BMH are presented in Table 4.5.2 below.

**Table 4.5.2 - Length of stay of sample at BMH (n=63)**

Descriptives	Length of Stay
Mean	35.8
Standard Deviation	9.51
Minimum stay	12
Maximum stay	49
Range	37

#### 4.5.3 Rehabilitation services received

The sample for the following figures excludes all those participants (n=5) who passed away during their stay at BMH, as well as those patients who were not referred for the specific discipline.

All information and descriptive statistical analysis of frequency and duration of the disciplines seen by the sample during their stay at BMH is presented in Table 4.5.3 below.

With a focus on rehabilitation specific interventions, the researcher focused solely on rehabilitation specific disciplines (including the physiotherapist, occupational therapist and speech therapist) to gain the most accurate possible understanding of the effect of rehabilitation on the functional outcomes. The mean average for the total frequency of rehabilitation sessions received by the participants, yielded 17.1 times per participant (standard deviation = 9.57) and an overall duration of 610 minutes of rehabilitation specific time (standard deviation = 366.26) for each individual throughout their stay at BMH. This equates to an overall mean average intensity of 35.8 minutes per rehabilitation session per participant for all rehabilitation specific disciplines combined (standard deviation = 3.26).



Table 4.5.3 – Rehabilitation services received by participants during stay at BMH

	Disciplines Seen											
	Doctor		Physiotherapist		Occupational Therapist		Speech Therapist		Social Worker			
	Freq.	Duration (min)	Freq.	Duration (min)	Freq.	Duration (min)	Freq.	Duration (min)	Freq.	Duration (min)	Freq.	Duration (min)
Participant (Number)	63	63	63	63	58	58	45	45	17	17		
Mean	5.29	32.94	9.78	293.33	5.41	237.41	3.22	137.33	1.24	20		
Mode	4	25	8	240	1	90	2	90	1	20		
Std. Deviation	1.670	9.573	5.256	157.685	4.337	197.667	2.430	114.324	0.562	6.374		
Minimum	2	15	1	30	1	30	1	30	1	10		
Maximum	9	50	23	690	19	855	12	540	3	30		
Range	7	35	22	660	18	825	11	510	2	20		

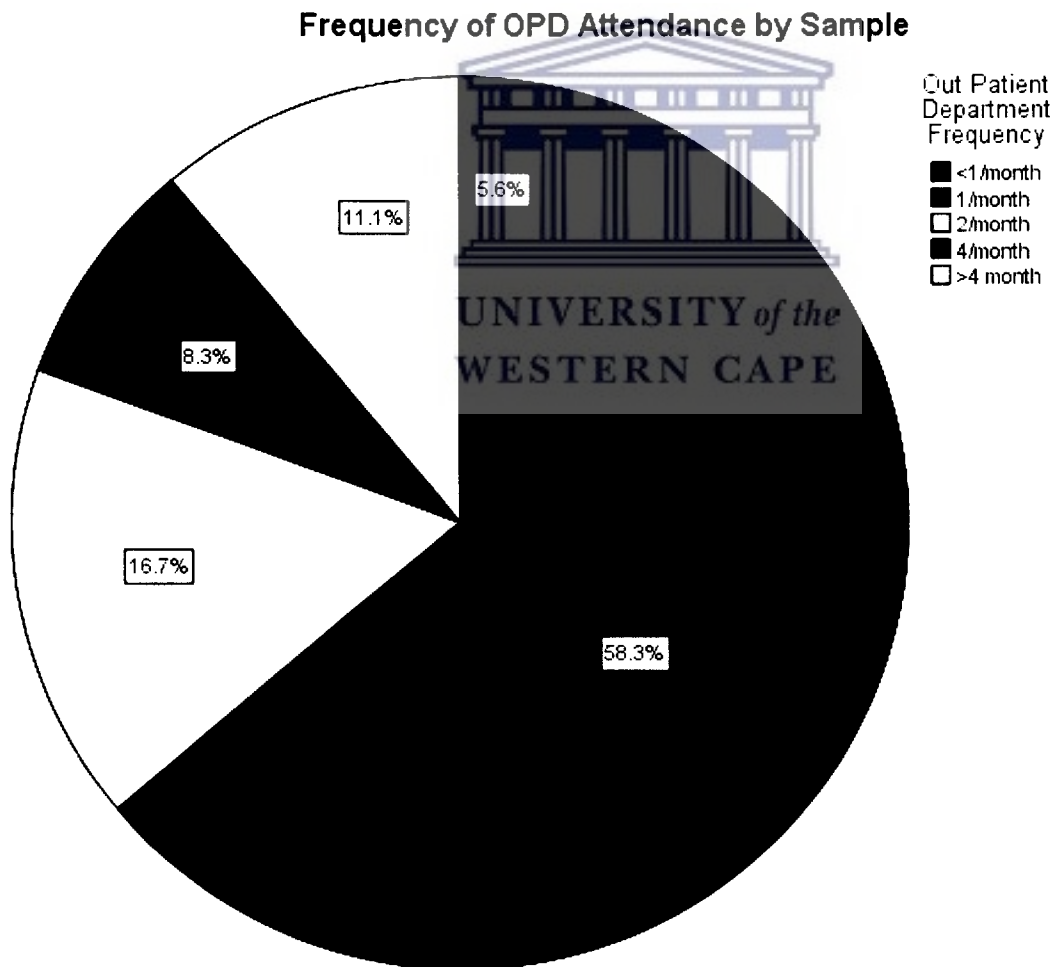
#### 4.5.4 'Use of Care' in six months post discharge

The only measurement period for the "Use of Care" follow-up was done at six month follow-up with all eligible participants, amounting to 50.

##### 4.5.4.1 Out-Patient Department Rehabilitation (OPD)

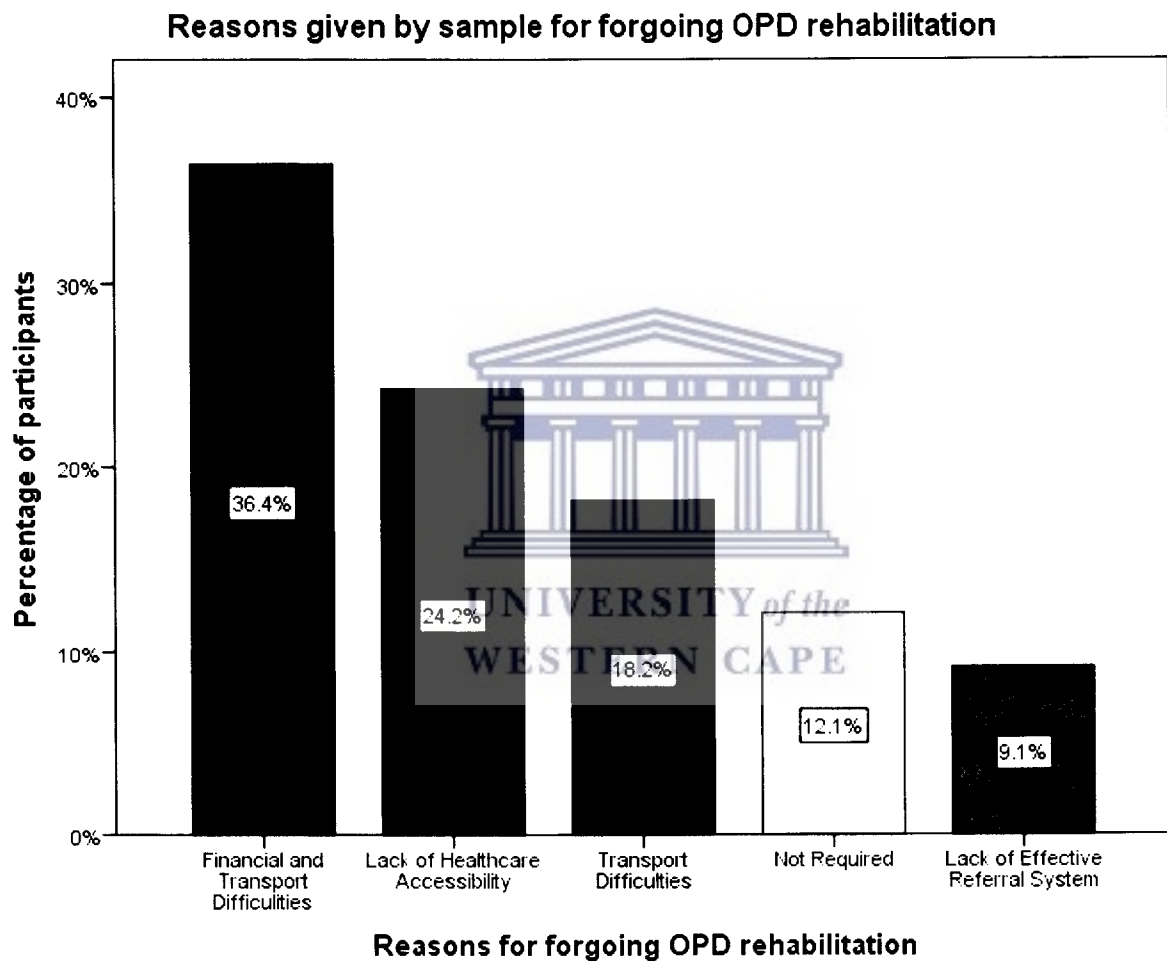
A large majority of 72% (n=36) of participants had attended OPD rehabilitation during the six months post discharge from BMH, whereas 28% (n=14) of participants chose not to or were unable to attend OPD rehabilitation.

Of the 72% of participants who attended OPD rehabilitation, a majority of 58.3% (n=21) participants went once a month. For a visual representation of the all frequencies of OPD attendance by the sample, see Figure 4.5.4.1(a) below.



**Figure 4.5.4.1(a) – Frequency of OPD attendance for the sample (n=36)**

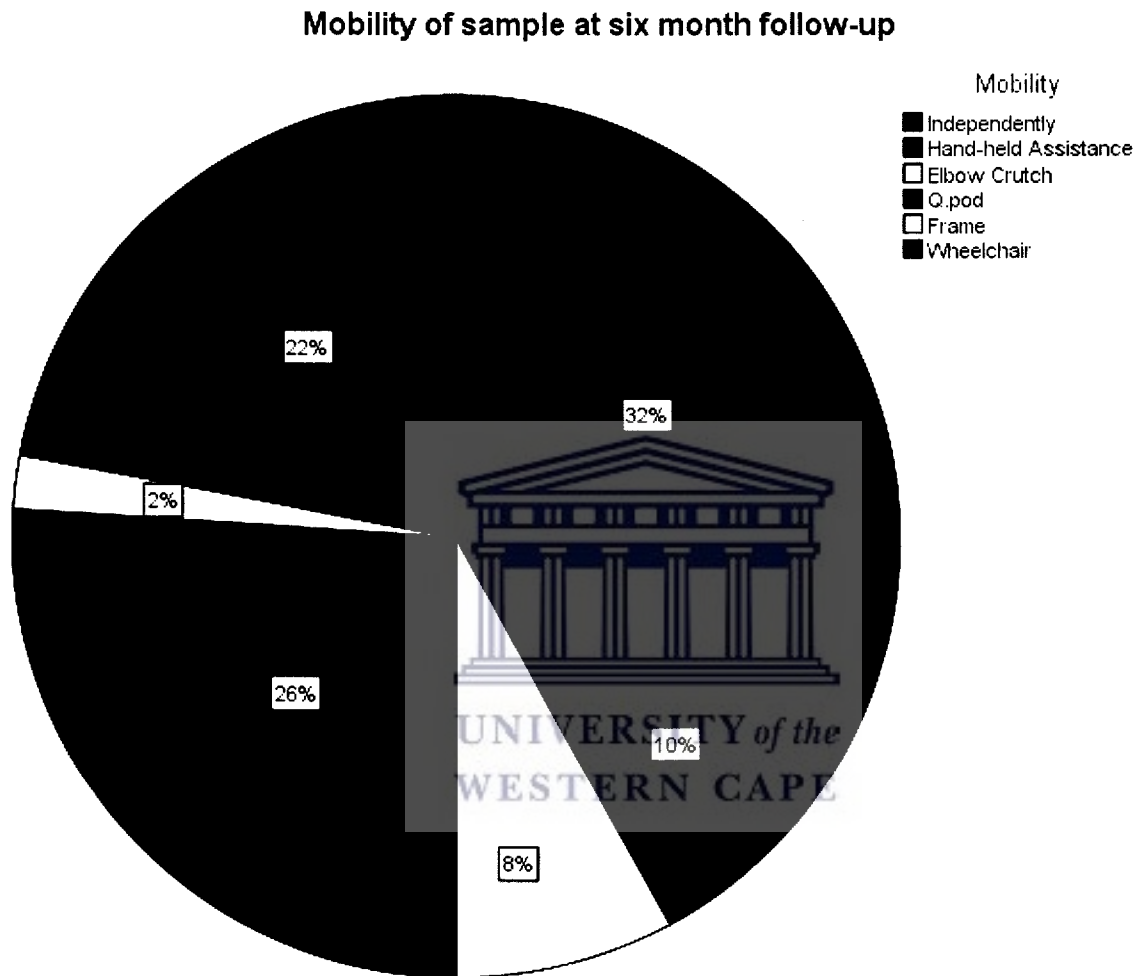
Several reasons for not going to OPD rehabilitation more often or forgoing rehabilitation all together was given by 66% (n=33) of participants or their family members. The majority of 36.4% (n=12) of participants identified financial and transport difficulties as the main reason. For a visual representation of all the reasons for forgoing OPD rehabilitation given by the sample, see Figure 4.5.4.1(b) below.



**Figure 4.5.4.1(b) – Reasons for forgoing OPD rehabilitation (n=33)**

#### 4.5.4.2 Mobilisation

Of the participants who identified that they were able to mobilise, 32% (n=16) could manage independently of walking aids and/or assistance at the six month follow-up. The mobility of the entire sample is presented in Figure 4.5.4.2 below.



**Figure 4.5.4.2 - Mobility of sample at follow-up (n=50)**

#### 4.5.4.3 Living environment

The majority of 86% (n=43) of participants were still living in the same house as before their stroke. However, 8% (n=4) were living in an alternative home and 6% (n=3) were living in a care facility.

The reasons for the changes in living environment for the seven participants were identified as: 57.1% (n=4) of families or caregivers could not manage the needs of the participant in their home environment and 42.9% (n=3) indicated that there was no one to care for the participant during the day or night.

## 4.6 FACTORS INFLUENCING FUNCTIONAL OUTCOME OF STROKE

### 4.6.1 Barthel Index (BI)

The results of the Friedman Test on the BI functional scores of the sample indicated a statistically significant difference across the three measurement periods, admission, discharge and follow-up, ( $n=50$ ) Chi Squared = 81.05 and  $p= .0001$ . Inspection of the median (Md) values reflected an increase in functional state from admission (Md = 35) to discharge (Md = 70) to six month follow-up (Md = 85).

Follow-up post-hoc tests on the significance within the three measurement periods, involved use of Wilcoxon Signed Rank Test. The Wilcoxon Signed Rank Test revealed statistically significant increases in the BI functional state scores across all three periods following rehabilitation, from admission to discharge ( $z= -6.691$ ,  $p< .005$ ), from admission to follow-up ( $z= -5.839$ ,  $p< .005$ ) and from discharge to follow-up ( $z= -4.384$ ,  $p< .005$ ).

### 4.6.2 EQ-5D VAS

The results of the Friedman Test on EQ-5D VAS perceived health state scores of the sample indicated a statistically significant difference across the three measurement periods, admission, discharge and follow-up ( $n=46$ ) Chi Squared = 85.21 and  $p= .0001$ . Inspection of the median values showed an increase in perceived health state from admission (Md = 32.5) to discharge (Md = 65) as well as follow-up (Md = 80).

Follow-up post-hoc tests on the significance within the three measurement periods, involved use of Wilcoxon Signed Rank Test. The Wilcoxon Signed Rank Test revealed statistically significant increases in the EQ-5D VAS perceived health state scores across all three periods following rehabilitation, from admission to discharge ( $z= -6.436$ ,  $p< .005$ ), from admission to follow-up ( $z= -5.926$ ,  $p< .005$ ) and from discharge to follow-up ( $z= -5.018$ ,  $p< .005$ ).

### 4.6.3 Family Support

The results of the Friedman Test on perceived family support scores of the sample indicated a statistically significant difference across the three measurement periods, admission, discharge and follow-up ( $n=46$ ) Chi Squared = 10.48 and  $p= .005$ . Inspection of the median values showed no difference in perceived family support

from admission (Md = 8) to discharge (Md = 8) and at follow-up (Md = 8). However, looking at the mean rank over the three time periods, an increase in perceived family support is apparent over time, from admission (Mn rank = 1.76) to discharge (Mn rank = 2.09) and finally to follow-up (Mn rank = 2.15).

Follow-up post-hoc tests on the significance within the three measurement periods, involved use of Wilcoxon Signed Rank Test. The Wilcoxon Signed Rank Test revealed statistically significant increases in the perceived family support scores from admission to discharge ( $z = -2.289$ ,  $p = .022$ ), but not from admission to follow-up ( $z = -1.666$ ,  $p = .096$ ) and not from discharge to follow-up ( $z = -.213$ ,  $p = .831$ ).

#### 4.6.4 Perceived satisfaction

The results of the Friedman Test on perceived satisfaction scores of the sample indicated no statistical significant difference across the two measurement periods, discharge and follow-up ( $n=46$ ) Chi Squared = 1.000 and  $p = .317$ .

#### 4.6.5 Spearman Rho correlation coefficients

4.6.5.1 The relationship between the BI of the sample over the three measurement periods was investigated and a strong positive correlation between the three variables was identified, with admission BI and discharge BI  $\rho = .83$  and  $p < .005$ , admission BI and follow-up BI  $\rho = .67$  and  $p < .005$ , and discharge BI and follow-up BI  $\rho = .78$  and  $p < .005$ .

4.6.5.2 The relationship between the level of education of the sample and the BI was investigated and no significant difference at discharge was identified for the correlation between the two variables, with  $\rho = -.06$  and  $p = .62$ . However, a moderate negative correlation and statistically significant difference was identified between the two variables at six month follow-up,  $\rho = -.32$  and  $p = .02$ .

4.6.5.3 The relationship between the perceived health related quality of life of the sample and the BI was investigated on discharge and at follow-up. All categories within the EQ-5D descriptive system showed a strong negative correlation and strong statistically significant difference on the BI over both discharge and follow-up measurement periods, except for "Pain/Discomfort" at follow-up. See Table 4.6.5.3 below for results.

**Table 4.6.5.3 – The relationship between perceived quality of life and the BI**

Measurement Periods		Perceived Quality of Life					
		Mobility	Self Care	Usual Activities	Pain/Discomfort	Anxiety/Depression	VAS
Discharge	Number	57	57	57	57	57	57
	Rho	-.78	-.78	-.72	-.49	-.67	-.81
	P value	<.005	<.005	<.005	<.005	<.005	<.005
Follow-up	Number	46	46	46	46	46	46
	Rho	-.83	-.81	-.77	-.16	-.51	-.92
	P value	<.005	<.005	<.005	.28	<.005	<.005

4.6.5.4 The relationship between the perceived family support of the sample and the BI was investigated and a moderate positive correlation between the two variables was identified at discharge, with a moderate statistical significant difference  $\rho = .31$  and  $p = .02$ , and at six months follow-up with a very strong statistically significant difference  $\rho = .47$  and  $p < .005$ .

4.6.5.5 The relationship between the perceived satisfaction levels with rehabilitation of the sample and the BI was investigated and a moderate negative correlation between the two variables was identified at discharge  $\rho = -.48$ , and a strong negative correlation was identified at follow-up  $\rho = -.56$ , with both periods showing strong statistically significant results,  $p < .005$  respectively.

4.6.5.6 The relationship between the total rehabilitation intensity of the sample and the BI was investigated and no significant difference was identified for the correlation between the two variables at discharge and follow-up,  $\rho = -.05$  and  $p = .73$  and  $\rho = -.04$  and  $p = .76$  respectively.

#### 4.6.6 Gender distribution in relation to Barthel Index

A Mann-Whitney U Test revealed a moderate significant difference in the admission BI of males (Md = 45, n=30) and females (Md = 25, n=38),  $U= 382.500$ ,  $z= -2.323$ ,  $p= .02$ ; a weak but significant difference in the discharge BI of males (Md = 80, n=28) and females (Md = 60, n=35),  $U= 346.500$ ,  $z= -1.992$ ,  $p= .046$  and no significant difference in the follow-up BI of males (Md = 87.5, n=20) and females (Md = 82.5, n=30),  $U= 278.000$ ,  $z= -.441$ ,  $p= .659$ .

#### 4.6.7 Age groups in relation to Barthel Index

The Kruskal-Wallis H Test revealed strong statistical significant differences for the BI in relation to the age groups of the sample at discharge and follow-up with Chi-Squared = 18.863 and 17.584 respectively, and  $p= .002$  and  $p= .004$  respectively, over the measurement periods. See Table 4.6.7.1 below for a full illustration of the change in median of the sample in the age groups over the measurement periods.

**Table 4.6.7.1 - Change in BI median for age groups over measurement periods**

Age Group	Discharge BI	Follow-up BI
30-39 Number	1	1
Median	95	95
40-49 Number	7	6
Median	90	92.5
50-59 Number	13	9
Median	75	90
60-69 Number	23	21
Median	75	90
70-79 Number	11	8
Median	45	40
80-89 Number	8	5
Median	47.5	85
Totals Number	63	50
Median	75	85
Chi-Square	18.863	17.584
P-Value	.002	.004



#### 4.6.8 Multiple regression analysis

**Table 4.6.8.1 - Regression analysis of patient variables regressed onto BI at discharge**

Variable	R <sup>2</sup>	F	p <sup>1</sup>	b	p <sup>2</sup>
Model 1	.778	61.934	.000*		
Quality of life (VAS)				.874	.000*
Family Support				.105	
Satisfaction with rehab				-.094	.215

From the above table, the model significantly ( $p^1$ ) explained 77,8% of the variance ( $R^2$ ) on function at discharge. In this model, perceived health related quality of life emerged as a significant predictor ( $p^2 < .000$ ) controlling for family support and satisfaction with rehabilitation. For every one unit increase in quality of life, representing 1% on the VAS, there was a corresponding .874 increase in function as measured by the BI.

Since the model in Table 4.6.8.1 tested significantly, the regression at follow-up was conducted in two steps. The first step duplicated the significant model at discharge and the second step added education as a demographic variable that correlated significantly with the outcome variable, which had to be considered as a covariant.

**Table 4.6.8.2 - Regression analysis of patient variables regressed onto BI at follow-up**

Variable	R <sup>2</sup>	F	p <sup>1</sup>	B	p <sup>2</sup>
Model 1	.899	123.534	.000*		
Quality of life (VAS)				.831	.000*
Family Support				.090	.151
Satisfaction with rehab				-.105	.074

Variable	R <sup>2</sup>	F	p <sup>1</sup>	B	p <sup>2</sup>
Model 2	.906	99.012	.000*		
Quality of life (VAS)				.825	.000*
Family Support				-.097	.182
Satisfaction with rehab				.088	.090 <sup>a</sup>
Education				-.090	.069

<sup>a</sup> Excluded from the model

From the table above, both regression models tested significant and explained 89.9% and 90.6% of the variance on function. The significant increase in explanation in the second model makes it the preferred model for explaining the Barthel Index

scores as a function of the identified predictors at follow-up. In the second model, however, satisfaction with rehabilitation was excluded as a predictor since it did not significantly add unique explanation to the model.

In this model, perceived health related quality of life (VAS) emerged as a significant predictor of function ( $p < .000$ ) controlling for family support and education. For every one unit increase in quality of life, there was a corresponding increase of .825 in function as measured by the Barthel Index.

#### 4.7 SUMMARY OF RESULTS

Of the total 68 participants in the sample, approximately 16% died throughout the study, with approximately 10% lost to follow-up after discharge. To summarise the results, an average participant (using majorities) in this study would be as follows:

A 63.69 year old female (~56%) pensioner (~62%), having an education level between Grade 8 and Grade 12 (~63%), who suffered an infarction (~59%) affecting the left hemisphere (51.5%) and also suffered from hypertension (~81%), who was referred to BMH from a district hospital (51.5%). The length of stay at BMH was approximately 34 days and a mean intensity of approximately 36 minutes per rehabilitation session was had. At six month follow-up, 86% of participants were occupying the same house as before the stroke, with 32% managing to mobilise independently, 58% attending OPD rehabilitation once per month, and ~36% indicating that financial and transport difficulties were the main reasons for not attending OPD rehabilitation more often.

The median BI of the sample on admission was 35, with the median for males at 45 and females at 25; however, the median BI at six month follow-up was 85, with males at 87.5 and females at 82.5, only representing a difference of 5. The median EQ-5D VAS of the sample on admission was 30, with males at 40 and females at 30; however, median VAS at six month follow-up was 80, with both males and females at 80 respectively. The median score of the sample for the perceived family support over all measurement periods was 8, equating to excellent perceived family support. Males showed a positive change in their median family support score from admission at 7.5 to follow-up at 9, while females remained constant at 8. All participants over

the measurement periods remained constant in their satisfaction of rehabilitation with scores of 1, equating to excellent perceived satisfaction with rehabilitation.

The BI, EQ-5D VAS and perceived family support showed statistically significant changes ( $p < .005$ ) over the three measurement periods. No such significant changes were identified for perceived satisfaction over the two measurement periods.

The Spearman Rho correlation tests identified relationships between functional outcome and the following variables: A moderate negative correlation and moderate statistically significant relationship ( $p = .02$ ) was noted for education, but only at six month follow-up. Strong statistically significant results ( $p < .005$ ) were obtained for perceived health related quality of life at discharge and six month follow-up respectively. Moderate and strong statistically significant differences were noted for perceived family support at discharge ( $p = .02$ ) and follow-up ( $p < .005$ ) respectively. Strong statistically significant differences ( $p < .005$ ) were noted with satisfaction levels at discharge and follow-up respectively. Rehabilitation intensity had no effect on functional outcomes in this study.

Male participants had a higher functional state throughout the study measurement periods but the statistically significant difference between the genders in relation to function became progressively weaker over the three measurement periods from admission ( $p = .02$ ), to discharge ( $p = .046$ ) and at six month follow-up ( $p = .659$ ). Strong statistically significant differences were identified at discharge and six month follow-up for age group of participants in relation to functional outcome,  $p = .002$  and  $.004$  respectively.

Using the regression model for the variables being studied in this population, perceived health related quality of life (VAS) emerged as the most significant predictor of functional outcome for the participants in this study. For every one unit increase in quality of life, representing 1% on the VAS, there was a corresponding increase of  $.825$  in function as measured by the Barthel Index.

## **CHAPTER FIVE: DISCUSSION**

### **5.0 INTRODUCTION**

This study aimed to identify the factors influencing the functional outcomes of patients with stroke receiving rehabilitation at a sub-acute, step-down rehabilitation facility in the Western Cape. This chapter will therefore discuss the results obtained from the data gathered throughout the study, over the various assessment periods, in order to address the research aim and objectives. The discussion will surround the objectives of the study in the following five sub-sections: 1) socio-demographics of participants, 2) medical factors of participants, 3) the functional state, perceived quality of life and perceived family support of participants, 4) perceived satisfaction levels with rehabilitation, and 5) rehabilitation process factors. The factors that influenced the functional outcomes of the participants in this study will be discussed within each relevant section. For ease of reading, each section corresponds to the relevant objective number. Using available and relevant local and international literature, each sub-section will attempt to highlight the possible reasons for the obtained results in this study. Relationships identified in previous research, as well as possible new relationships, will be reported on.

This discussion will make particular reference to two recent, similar stroke studies conducted in South Africa at the Western Cape Rehabilitation Centre (WCRC), namely by Rouillard et al (2012) and Joseph et al (2013), as they most closely correspond with the context, aims and objectives of this study.

### **5.1 SOCIO-DEMOGRAPHICS OF PARTICIPANTS**

The findings of this study identified that the majority of 55.9% of the stroke participants were female, which coincides with that of other local and international literature. A South African study, conducted by Mudzi (2010) at Chris Hani Baragwanath Hospital in Johannesburg, identified 56.5% of the 200 stroke participants as female. Furthermore, the Southern African Stroke Prevention Initiative (SASPI) acknowledged that the prevalence of stroke was reported as higher in females than in males (Thorogood et al, 2004). Internationally, of the stroke survivors identified in America, 60% were reported as female by the Heart Disease

and Stroke Statistics - 2009 Update (American Heart Association, 2009). To understand the implications for this finding, we need to understand the role each gender plays in society. The World Development Report of 2012 identified the main role for men in society as one of primary income-earner and breadwinner in the family. In all the developing countries in which the study was conducted (including South Africa), income generation for the family was the first and most likely mentioned definition of a man's role in the family and of a good husband. Females are viewed as having a greater household and care giving role. With these views in mind, the more females who are disabled by stroke, not only results in a great burden of disability in the community, but also means there are less households and families who have the support and care of their wives or mothers, which only compounds the effect of stroke further.

The mean age of the sample for this study was identified to be 63.69 years old, whereby the highest number of participants (36.8%) were in the 60-69 year age group and 61.8% of the participants were recorded as pensioners. The implication for this finding is that the majority of participants in this study were already pensioners at onset of stroke and therefore were no longer earning an income through active work. This fact means that there was a decreased financial burden on the participants and community as the participants did not lose income through loss of work years and have the additional financial burden of care post-stroke. However, as identified by Hassan et al (2011), South Africa has few residential facilities, which means that many patients with severe disabilities are discharged into the care of families, often without support and follow-up. A lack of community support services and financial pressures contribute to a double loss of income as family members give up work to care for the stroke survivor.

The mean age identified in this study does not correspond with that of other studies of a similar nature, namely by Rouillard et al (2012) and Joseph et al (2013), whereby the mean age of the participants was reported to be 51.9 and 52.95 years old respectively. Hospital-based studies in South Africa have identified that stroke incidence is higher among the 35-54 year old age group (Connor et al, 2006). The higher than expected mean age of participants in this research study could be attributed to the fact that the sample population was much less exclusive than that of the two aforementioned studies, both of which were conducted at a specialised

rehabilitation facility, where more younger stroke individuals are accepted due to the high intensity rehabilitation offered. A wider spectrum of patients, in terms of age and stroke severity, are admitted to BMH due to less stringent admission criteria and therefore, the findings of those two studies may not be a true reflection of the stroke population as a whole with regards to the mean age of patients with stroke in South Africa. However, in the previously mentioned study conducted by Mudzi (2010), the mean age of the participants was identified to be 53.2 years old, with a majority of 33.5% of participants in the 41-50 year old age group. This study has a much greater generalisability of findings due to the large sample size and sample population. One possible reason for the mean age of this research study not coinciding with that of other South African research is that BMH may be viewed, by referring hospitals, as a low functioning geriatric care facility that is more accepting of older patients with a poorer prognosis of recovery, thereby decreasing the generalisability of the findings to the South African stroke population.

The correlation test done to identify the relationship between the level of education and functional outcome at discharge indicated that education played no significant role ( $p = .62$ ) in determining the functional outcome of the participants during the acute rehabilitation phase. However, unexpectedly at six month follow-up, a moderate negative correlation ( $Rho = -.32$ ) and moderate statistically significant relationship ( $p = .02$ ) was identified, which indicated that the lower the education level of the participant was, the higher the functional outcome would be at the six month follow-up. A possible explanation for the lack of significant effect during hospitalisation is that the participants relied heavily on the therapist for understanding during their rehabilitation sessions and therefore, the level of education had little influence on the functional outcome of the participants in this study. No explanation could be given for the finding at six month follow-up as these findings do not coincide with those found in a study conducted by Putman et al (2007) on 419 consecutive patients with stroke to determine the effects of socio-economic status on functional and motor recovery after stroke. Education level was identified as a significant determinant of functional recovery during in-patient rehabilitation but after discharge, education level was not a significant factor. However, this study was limited by the fact that, as a result of subject exclusion from the study, the scores were an overestimation of the total sample of patients with stroke. Putman et al (2007) also identified that education level, as an indicator for

socio-economic status, may be influenced by the age distribution in the sample, with older patients with stroke having a lower educational attainment than their younger counterparts.

## 5.2 MEDICAL FACTORS OF PARTICIPANTS

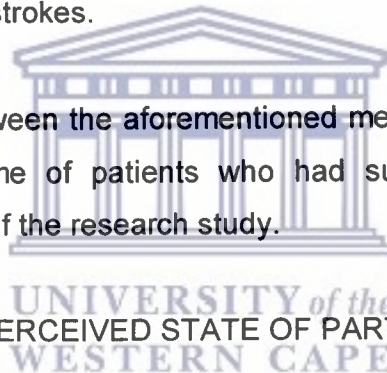
Approximately 10% of the participants suffered from either global or receptive aphasia, which limited their response to questionnaires and subsequently, the participants were excluded from the subjective analysis section of the study. This finding coincides with that of Rouillard et al (2012), whereby approximately 5% of the participants were excluded from the subjective EQ-5D analysis as a result of said language deficits. The implication of this finding is that there are a number of stroke survivors who may struggle with communication between themselves, staff and family members, which may affect their quality of life. Kitzmuller (2012) acknowledged that mutual understanding between a stroke patient and family members was threatened as they experienced considerable obstacles to communication with aphasia being the worst. These participants with aphasia will require intensive ongoing speech therapy to prevent the language and cognitive deficit from severely affecting the patient's quality of life and functional outcome potential. Therefore, speech therapists are noted as an important part of the rehabilitation process and team.

The laterality of stroke in the sample of this study was evenly spread with 51.5% suffering a left sided stroke, while the rest suffered a right sided stroke. This finding closely corresponds with that of Joseph et al (2013) and Rouillard et al (2012), whereby 50.75% and 56.5% of participants respectively suffered from a left sided lesion. Bendok et al (2011) reported that several studies, which investigated the effect of stroke laterality on functional outcome, identified that a difference in risk and prognosis attributable to laterality of stroke, either affecting the dominant or non-dominant hemisphere, had not been found.

A large majority of 80.9% of participants in this study suffered from the co-morbidity and risk factor for stroke, hypertension, while only 30.9% of participants suffered from Diabetes Mellitus. These findings of a high percentage of stroke individuals suffering from hypertension and a low percentage suffering from Diabetes Mellitus

coincides with the findings of Ng et al (2007) who established that hypertension was the most common risk factor in stroke at 70.6%, with Diabetes Mellitus only occurring in 19.7%. Further evidence is noted in the Heart Disease and Stroke Statistics – 2009 Update whereby, of the 80 million people who suffered from a Cardiovascular Disease (CVD), 73.6 million (92%) suffered from hypertension and only 17 million people (~21.5%) suffered from Diabetes Mellitus (American Heart Association, 2009). In a South African context, in the aforementioned SASPI study of stroke prevalence in rural South Africans, hypertension was identified as the most common risk factor affecting 71% of stroke sufferers, with only 12% being affected by Diabetes Mellitus (Thorogood et al, 2004). With hypertension being associated as a main risk factor in stroke, the risk of recurrent strokes are dramatically increased. The National Stroke Association (2013) explained the importance of controlling blood pressure in patients who have already had a stroke, so as to reduce their risk and prevent the occurrence of further strokes.

No correlation or relationship between the aforementioned medical factors and their effects on the functional outcome of patients who had suffered a stroke was identified as this was not a focus of the research study.



### 5.3 THE FUNCTIONAL AND PERCEIVED STATE OF PARTICIPANTS

5.3.1 The findings of this study for the functional state of participants indicate that on admission, the Barthel Index (BI) median score for all participants was 35. This does not coincide with the findings of Rouillard et al (2012) and Joseph et al (2013), whereby the admission BI scores of the participants were 50 (median) and 58.85 (mean) respectively. This indicates that the participants in the BMH study were much less functional on admission than those who participated in the studies conducted at the specialised rehabilitation facility (WCRC). Again, this could be explained by the stringent admission criteria at WCRC, whereby only patient's with the best possible rehabilitation potential are accepted. By discharge, the participants in this study recorded a median BI score of 75, which was closer to that of Joseph et al (2013), who reported a discharge mean BI of 81.59. The findings for the change in median of 40 points for this BMH study and the change in mean of 22.74 for Joseph et al (2013), from admission to discharge, indicates that the participants at BMH showed a greater recovery of function from admission to discharge. The greater



recovery can be explained by the fact that, although participants with a lower BI score on admission are less functionally independent to start with, they have more room for functional improvement than those with a higher admission BI. At six month follow-up, the median BI score of the participants in this BMH study was reported as 85, which is only slightly less than the median BI score found by Rouillard et al (2012) at their six month follow-up, reported as 90. Rouillard et al (2012) further identified that their median score of 90 at six month follow-up was similar to that of European studies, with a median range between 85 and 100. Therefore, the findings in this study for the follow-up BI score are corroborated by that of other similar studies in South Africa and abroad.

Kay et al (1997) and Dennis et al (1997) found that a BI score of <85 corresponded to a state in which patients reported needing help in performing activities of daily living. Therefore, the median BI score of 75 at discharge implies that the participants required assistance from care-givers for their activities of living at the time of reintroduction into the community. However, the median BI score of 85 at six month follow-up indicates that the participants were, for the most part, independent in their essential activities of daily living, such as feeding, washing, dressing and toileting, but that assistance would still be required with mobility. This finding implies that the burden of care for care-givers of stroke survivors lessen over a period of time. However, in the study conducted by Rouillard et al (2012), at the six month follow-up, 56% of the care-givers of stroke survivors still indicated a high level of strain, which included financial strain and work adjustments.

A total median change on the BI of 50 points from admission to six month follow-up was identified in this study, as opposed to the median change of 40 points found by Rouillard et al (2012). This could be explained by the lower admission median BI in this study of 35 as opposed to the median identified by Rouillard et al (2012) of 50. The Friedman Test on the median BI scores of all the participants throughout the measurement periods in this study showed statistically significant improvements from admission to discharge and from discharge to six month follow-up, with  $p < .005$  respectively. Joseph et al (2013) also identified a significant statistical difference between the participants' admission and discharge mean BI scores ( $p < .01$ ), implying that the participants from both studies showed significant functional improvements during their rehabilitation at the respective facilities.

Once the BI data was divided into each gender, the BI scores for the participants could be identified in terms of gender distribution. The median BI score for males reflected a score of 45 on admission, with females only at 25, a difference of 20 points indicating that males had a higher admission functional state than females post-stroke. At discharge, a similar picture is shown where males reflected a median BI score of 80, with females only at 60, again a difference of 20 points indicating that males had a higher discharge functional state than females as well. However, at six month follow-up, a different picture was evident whereby, although males still reflected a higher follow-up median BI score of 87.5, it was only 5 points more than the females with a score of 82.5. These findings are corroborated by Paolucci et al (2006), in a study conducted on 440 first ever ischaemic patients with stroke over an eight week period, which identified that the female sex was a mildly unfavourable prognostic factor in rehabilitation following a stroke, as the functional outcome was found to be better in males upon discharge, especially in higher independence of ADL's and stair climbing (Paolucci et al, 2006). However, care must be taken in reading into these results as only ischaemic strokes were included in the sample and the sample was not population-based, which may affect the generalisability of the results to this study.



In a study conducted by Lai et al (2005) on 459 acute and sub-acute patients with stroke, six months post-stroke, females were less likely than men to be functionally independent, even after controlling for age, pre-stroke physical functioning, stroke severity and depressive status at baseline. One possible explanation could be the ceiling effect of the BI, well documented by many researchers, such as Quinn et al (2011), whereby the BI is limited in its responsiveness to change, especially in the chronic setting. Quinn et al (2011) explained that the weakness of BI is that it is not sensitive enough to change at extremes of ability, which makes the scale less discriminating in patients with severe or minor stroke events. For longer-term assessment, where patients may progress to a high functional level, BI on its own is unlikely to be sufficiently sensitive and should be replaced or used along with other scales.

Change of the median BI score of 35 for both males and females from admission to discharge indicated that both male and female participants improved functionally at

the same rate. However, the variation in change of median BI for males of only 7.5 and females of 22.5 during the period of discharge to six month follow-up indicated that, although males still had a higher functional state than females six months post discharge, females showed a greater functional improvement than their male counterparts during this period. The results of the Mann-Whitney U test for gender in relation to functional outcome identified that, although males had a higher admission, discharge and follow-up median BI than females, the statistical significance between the genders decreased from a moderate significance on admission ( $p = .02$ ) to a weak significance at discharge ( $p = .046$ ) and to no significance at six month follow-up ( $p = .659$ ). These findings show that, although the male participants had a higher BI median throughout the measurement periods, male and female participants had an equal functional recovery rate from admission to discharge, but females showed a greater improvement in function over the final measurement period. The implication for this finding is that, although the female gender may be a mildly unfavourable predictor of functional outcome on admission, due to the rate of functional recovery for female stroke survivors, they should be afforded every rehabilitation opportunity that male stroke survivors are throughout the rehabilitation process.

5.3.2 The findings of this study for the perceived health state of participants indicated that on admission, the most problems experienced by the participants were in mobility, reported by 98.3%; with the least problems experienced in pain and discomfort, reported by 61.7% of participants. At discharge, the most problems experienced were in usual activities, reported by 82.5% of participants; with the least problems still experienced in pain and discomfort, reported by 24.6% of participants. Finally, at six month follow-up, the most problems experienced were still in usual activities, reported by 63.1% of participants; with the least problems experienced in anxiety and depression, reported by 15.2% of participants. This finding of usual activities being the most affected in participants six months post-stroke is in correlation with the finding of Rouillard et al (2012) in their study, which found that the ability to perform usual activities was most affected at six month follow-up, reported by 61% of participants. Rouillard et al (2012) further identified at six month follow-up that 52% of participants still reported problems with mobility. This finding is slightly higher than that found in this study, whereby 41.3% of participants reported problems.

A link can be made between the participants' functional ability at discharge (75) and six months post discharge (85) with their responses to the quality of life questionnaire. The most problems experienced by the participants at discharge and at six month follow-up were with carrying out their usual activities, reported by 82.5% and 63.1% of participants respectively. In the study conducted by Rouillard et al (2012), whereby the median BI at six month follow-up was 90, the large majority of the sample reported that they were unable, or had a reduced ability, to participate in social and leisure activities, work activities and family responsibilities respectively, with a further 37% reporting problems with relationships or feelings of isolation. The study conducted by Mudzi et al (2013) identified that patients with stroke struggled with interactions and had difficulties with community life and participating in recreation and leisure activities twelve months post-stroke. These findings imply that a high percentage of stroke survivors still experienced problems with usual activities and participation in everyday life long after the stroke onset and that the follow-up OPD rehabilitation sessions at the community-based services should be focused more on limiting participation restrictions than solely on functional gains.

The five categories of the EQ-5D showed majority changes by the participants throughout the three measurement periods. In the first category, being mobility, the majority of 50% of participants identified a perceived "inability" to mobilise on admission but by six month follow-up, the majority of 58.7% of participants perceived "no problems" experienced. The second category of self-care showed that 53.3% of participants identified "some problems" experienced on admission but by six month follow-up, 47.8% of participants were split between "no problems" and "some problems" experienced. The third category of usual activities identified that 56.7% of participants reported a perceived "inability" to perform their usual activities on admission but by six month follow-up, 52.2% reported only "some problems" were experienced. The fourth category, being pain and discomfort, identified on admission that 48.3% of participants reported "no problems" were experienced and by six month follow-up, that majority increased to 78.3% of participants. The fifth and final category of anxiety and depression found that 50% of participants reported a "moderate" level of anxiety and depression on admission, but by six month follow-up, 84.8% reported "no problems" were experienced.

These findings reflect an improvement in each of the five categories of perceived mobility, self-care, usual activities, pain and discomfort, and anxiety and depression throughout the rehabilitation process. This improvement could be explained by the positive influence of the rehabilitation process, as identified by Kwakkel et al (2004 and 2006), which would allow for a gain in confidence of the stroke individual's own ability to recover post-stroke and allow for an improved perception of their ability to cope functionally. Kwakkel et al (2004 and 2006) further explained that, although the rehabilitation process facilitates this neurological recovery post-stroke, most recovery is dependent on the individual's own motivation. Mudzi (2010) explained that depression or lack of motivation, in the short-term and long-term, is a determinant of health related quality of life and should be assessed early in the hospitalisation phase to be adequately and effectively managed.

A study conducted by Mudzi (2010) on 200 patients with stroke and their care-givers at Chris Hani Baragwanath Hospital (CHBH) identified, using the EQ-5D, that the responses of the majority of participants, in both the control and experimental groups, remained in the "some problems/moderate" category throughout the 12 month duration of the study. The two groups having almost identical responses for each category implies that the "education and training" done with the care-givers of the experimental group had little to no effect on the perceived health related quality of life of the patients with stroke. This finding, together with that of this BMH study, indicates that the rehabilitation process undergone by patients with stroke at a rehabilitation centre, by trained rehabilitation professionals has a positive effect on health related quality of life. A concept echoed by Naess et al (2006), who identified that intensive physiotherapy had the potential for important improvement in health related quality of life after stroke. The implication for these findings is that one cannot underestimate the value of trained healthcare professionals, in a rehabilitation specific centre, for the improvement of a patient's function and quality of life.

The findings of this study for the perceived health state of participants, using the EQ-5D visual analogue system (VAS), indicated that the median score improved significantly ( $p < .005$ ) from admission (30) to discharge (60) and again to six month follow-up (80). Rouillard et al (2012) only reported on the median VAS score of perceived health state at six month follow-up for their participants, which was 70. Rouillard et al (2012) further reported this median was similar to that of the CERISE

project (70) in European rehabilitation centres at the same measurement point. In the study conducted by Mudzi (2010), the six month VAS of both groups studied was reported to be 60. Therefore, the VAS median identified in this research study does not coincide with those mentioned by Rouillard et al (2012) or that of Mudzi (2010) as it is higher. This finding however, could be explained by looking at the differences in the study design and the rehabilitation input received, whereby the participants included in the study by Rouillard et al (2012) received little to no further contact with healthcare services post discharge and in the study conducted by Mudzi (2010), the participant's post discharge rehabilitation was not documented. As such, it is likely the participant's perception of their health state would show less improvement as a result of less rehabilitation input and functional change post discharge from the rehabilitation setting. This concept become clear as we look at the individual responses and the link between quality of life and function.

A look at the individual responses by the participants to the VAS identified that, on admission, 18.3% of participants indicated an extremely poor perceived health state of 10 out of 100, but by discharge 22.8% reported a much higher score of 70, and at six month follow-up, 23.9% of participants reported a score of 90. This finding indicates that the most change in perceived health occurred during the period of admission to discharge. This finding can be explained by the fact that perceived health related quality of life is directly linked with functional ability, as seen in studies conducted by Chan et al (2009) and Kim et al (1997), and due to the fact that most return of functional ability for 95% of stroke individuals occurs during the initial few weeks post-stroke, while the individual is still in hospital (Jorgensen et al, 2000).

This concept of perceived health related quality of life being directly linked to functional ability and outcome corresponds with the findings of this research study, whereby the correlation test done to identify the relationship between perceived health related quality of life EQ-5D descriptive system and the functional outcome of participants, identified strong negative correlations (ranging from  $Rho = -.49$  to  $-.81$ ) and strong statistically significant relationships ( $p < .005$ ) at discharge and follow-up. This finding together with the strong positive correlation at discharge ( $Rho = .81$ ) and follow-up ( $Rho = .92$ ) and strong statistically significant relationship ( $p < .005$ ) obtained between the EQ-5D VAS and functional outcome indicated that, higher perceived quality of life resulted in higher functional outcomes for the participants.

Using multiple regression analysis, the major finding of this study, confirmed this concept and identified perceived health related quality of life (VAS) as the strongest, most significant predictor ( $p < .000$ ) of functional outcome at discharge and at six month follow-up respectively, accounting for 90.6% of the variance on function; where, for every one unit increase in quality of life (VAS), there was a corresponding increase of .825 in function as measured by the Barthel Index.

5.3.3 The findings of this study for the perceived family support, showed that the median scores of all participants remained the same from admission through to six month follow-up. However, the Friedman Test used the mean family support scores of all the participants in this study and reflected statistically significant improvements from admission to discharge and to six month follow-up ( $p < .005$ ).

To gain a more in-depth understanding of this finding, the researcher divided the family support data in relation to gender distribution so as to understand the data more completely. The median family support score for males reflected a score of 7.5 on admission, with females slightly higher at 8, a difference of 0.5 points indicating that females have a slightly higher perceived sense of family support on admission than males post-stroke. At discharge however, a different picture is evident with males reflecting a median family support score of 8.5, with females remaining at 8, again a difference of 0.5 points but in the opposite direction indicating that males have a slightly higher perceived sense of family support at discharge than females. Change of the median family support score of 1 for males and no change for females from admission to discharge indicated that only male participants had a change in their perceived sense of family support during this period. At six month follow-up, a similar picture to the discharge period is evident. Male participants reflected a higher median family support score of 9, whereas the female participants remained at 8. The variation in change of median for males of 0.5 and no change in females during the period discharge to six month follow-up, indicated that only the male participants perceived a sense of increasing family support. The fact that females remained constant in their perceived family support throughout the measurement periods could possibly be due to females being more secure in the family support network than males. Males may, incorrectly, identify a sense of less family support initially but come to realise, perhaps due to visits from family during their hospital stay and a

strong family connection at home once discharged, that they do in fact have a good support network.

The correlation test done to identify the relationship between family support and functional outcome of the participants identified a moderate positive correlation ( $Rho = .31$ ) and statistically significant ( $p = .02$ ) relationship at discharge and a strong correlation ( $Rho = .47$ ) and statistically significant ( $p < .005$ ) relationship at follow-up respectively. These findings indicated that perceived family support played a significant role in determining the functional outcomes of the participants, however more so during the six months post discharge. This is understandable as family support structures are more evident once the patient is discharged into their community. Mudzi (2010) identified that poor family support has been linked to poor quality of life post-stroke and closely linked to family support is marital status and its effect on quality of life. A study conducted by Naess et al (2006) on 190 experimental participants reported that being unmarried was found to have a negative influence on quality of life and functional independence of stroke survivors. However, this study was focused on young (15-45 years old) stroke survivors and with only an ischaemic stroke sub-type, therefore affecting the generalisability of the finding.

The implication for this finding is evident, if the rehabilitation process does not already include the family or care-giver in the education and rehabilitation of the stroke individual, especially if the patient is male, then more family involvement in rehabilitation throughout their recovery will improve the patient's perception of their family support, and in so doing positively influence the stroke individual's quality of life and functional outcome.

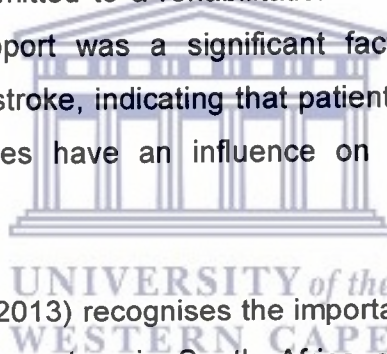
#### 5.4 PERCEIVED SATISFACTION LEVEL WITH REHABILITATION

The findings of this study showed that a large majority of participants, on admission (80.7%) and at six month follow-up (78.3%), indicated a score of 1 out of a possible 6 on their satisfaction with rehabilitation questionnaire, which referred to an excellent perceived satisfaction level with the rehabilitation process. Even when the researcher divided the satisfaction data in relation to gender distribution to more completely understand the finding for both male and female participants, the score of 1 out of 6 was still reported at discharge and six month follow-up respectively. This



finding indicates that perceived satisfaction with rehabilitation at BMH was the same for all participants at discharge and follow-up.

The correlation test done to identify the relationship between perceived satisfaction with rehabilitation and functional outcome of participants identified a strong statistically significant relationship ( $p < .005$ ) with moderate ( $Rho = -.48$ ) and strong ( $Rho = -.56$ ) negative correlations, over the discharge and follow-up measurement periods respectively. This indicates that perceived satisfaction of rehabilitation played a role in determining functional outcomes of the participants, more so post discharge. No available literature specifically on the relationship between the level of patient satisfaction with rehabilitation and functional outcome of patients with stroke could be identified and thus no comparisons could be made with this particular study. However, in a longitudinal study conducted by Chang et al (1998) on 152 patients with stroke in the acute stage admitted to a rehabilitation hospital, it was identified that satisfaction with social support was a significant factor in contributing to functioning at three months post-stroke, indicating that patient satisfaction, although not specific to rehabilitation, does have an influence on a patient's functional outcome.



The Western Cape Government (2013) recognises the importance of the experience of patients within the healthcare system in South Africa and indicated, in their Healthcare Plan for 2030, that quality of care and patient satisfaction with healthcare services will be an important aspect to achieve. Illness can cause anxiety and fear in patients, and it is important to recognise that patient perspectives are dependent on their values, beliefs and culture, and are informed by family, friends and community. These factors influence health-seeking behaviour, adherence to healthcare advice and interventions and self-care. The focus of health reform in the Western Cape for 2030 will therefore be on patient experiences and outcomes, whereby the organisation of care will have a patient perspective instead of an organisational perspective. This will require patients to be treated with dignity and respect, to be listened to and provided with information that they can understand, and to be involved and empowered in making informed choices to determining their treatment options. The healthcare professionals will be required to manage their patients holistically, by locating the illness within a broader personhood, family and community context, while also understanding the socio-economic and other

contextual factors involved. The Western Cape Government (2013) further identified that a patient-centred approach, built on a relationship of trust, leads to increased patient compliance, improved quality of care and patient satisfaction and, ultimately, better health outcomes. In the Annual Performance Plan 2013/14-2015/16, one of the Department of Health's medium-term strategic goals is to strengthen the health system's effectiveness in by focusing on reengineering primary healthcare and improving patient care and satisfaction through the implementation of the National Health Insurance and strengthening of health information systems (Department of Health, 2013).

## 5.5 REHABILITATION PROCESS FACTORS

The findings of this study showed that the majority of participant referrals (51.5%) came from surrounding district hospitals. This is due to the vast number of district hospitals in the surrounding Metropole area that is serviced by BMH, with only two tertiary institutes currently available. However, even though there are only two tertiary institutes in the Metropolitan area, these institutes accounted for 44.1% of participant referrals. Only a small portion of the sample (2.9%) were referred by community-based services (CBS) and only 1.5% from private hospitals. The reason for the low numbers being referred to BMH from CBS is due to the continuum of care referral pathway, whereby patients are normally referred from a tertiary or district institute to a step-down facility and only then referred to CBS. Once a patient is discharged to the community, they are managed by CBS and are generally not readmitted into a step-down facility. Also, the reason for the low number of private hospital referrals is due to the fact that BMH is a facility that sees predominantly non-medical aid, government funded patients. Only once a patient's medical aid cover has expired would they then be admitted to BMH.

The mean length of stay for the participants in this research study was approximately 34 days (SD= 9.51). This finding does not coincide with the other South African studies mentioned, with Rouillard et al (2012) and Joseph et al (2013) reporting a mean length of stay for the participants at WCRC of 62 days and approximately 52 days respectively. The reason for this large discrepancy in length of stay between the studies could be due to the service procedures and policies of each facility and the fact that pressure to discharge patients at a rehabilitation facility like WCRC is

not as high as it is at government facilities such as BMH and Conradie Care Centre, implying there is a higher turnover of patients requiring primary level, lower intensity rehabilitation before being discharged into their community. A higher pressure to discharge patients in these facilities results in less admission time in hospital, which equates to less in-patient rehabilitation time and thus, lower functional independence gained by the patients before being discharged into their community. Unfortunately, this pressure will not be eliminated, but can be more effectively managed through 1) effective referral systems for patients along the continuum of care pathway, whereby patients are discharge to the most appropriate rehabilitation levels for their specific needs and 2) efficient use of human and financial resources at these levels.

The findings for this study for the rehabilitation process identified the overall mean intensity of approximately 36 minutes for each rehabilitation session. The participants were seen most frequently by physiotherapy during their stay at BMH, approximately ten times, in comparison to occupational and speech therapy, at approximately five and three times respectively. The difference in frequencies could be attributed to the staff make-up, with physiotherapy having two full time physiotherapists, occupational therapy having two half-day staff members and speech therapy only one sessional staff member. This finding coincides with that of Rhoda et al (2009) who identified, at the six month follow-up assessment period at community health clinics (CHC), that physiotherapy was the therapeutic service most frequently received by patients with stroke (approximately 58%) and speech therapy the least received (8%). Rhoda et al (2009) also identified the decreased number of therapy sessions could be linked to availability of therapy staff or the therapists' large patient-load at the CHC. As identified earlier regarding the importance of communication, aphasia plays an influential role in determining quality of life of patients with stroke, not to mention the negative influence being unable to swallow effectively and requiring a nasogastric tube for feeding has on a patient. As speech therapy is not viewed as being a functional therapy (with regards to mobility and ADL), it is possible that it gets less recognition of importance in rehabilitation, but only to the detriment of the patients. Speech therapy needs to be given equal resources (both human and financial) to limit the cognitive burden on patients with stroke and to improve their quality of life and satisfaction.

The correlation test done to identify the relationship between rehabilitation intensity and functional outcome indicated no correlation or significant difference at discharge ( $p = .73$ ) and follow-up ( $p = .76$ ) respectively. This finding does not coincide with that of other literature. An earlier research synthesis of nine controlled studies by Kwakkel et al (1997), with a total sample size of 1051 patients, identified a small but statistically significant ( $p = .05$ ) intensity-effect relationship in the rehabilitation of patients with stroke, whereby higher intensities of rehabilitation resulted in improvements in ADL, as well as neuromuscular and functional outcome. However, generalisability of this finding is difficult, due to the low methodological quality of the included studies. A more recent study by Hu et al (2010), on 154 patients with stroke in the acute stage, identified that rehabilitation commencement time and intensity, after adjusting for functional status and stroke severity, remained an important predictor of stroke functional outcome.

The findings of this study indicated that a large majority of participants (72%) attended out-patient department (OPD) rehabilitation at CBS during the six months post discharge. However, of this majority who attended, 58.3% could only attend once per month. The main reason given by the majority of participants (36.4%) why they could not attend OPD rehabilitation more often was due to financial and transport difficulties. Patients could either not afford to pay for transport to the CBS and/or they did not have any access to transport options. A study done by Rouillard et al (2012) identified that most participants received little input after discharge, with only approximately 9% of participants receiving >6 OPD rehabilitation treatment sessions and 10% receiving no further contact with healthcare services at all. Rhoda et al (2009) identified an earlier Western Cape study, conducted by Whitelaw et al (1994), which revealed that patients with stroke could not attend follow-up rehabilitation sessions due to a lack of transport to access the community rehabilitation centres. The public transport infrastructure in South Africa is unfortunately not geared to accommodate all the disabled people who require transport to and from their CHC for follow-up appointments and rehabilitation treatment sessions. Rouillard et al (2012) explained that difficulties in community mobility are exacerbated by environmental barriers, such as unfavourable terrain and local public transport that are not geared to persons with disability. Often, the transport services that are in place are either too expensive for the average South

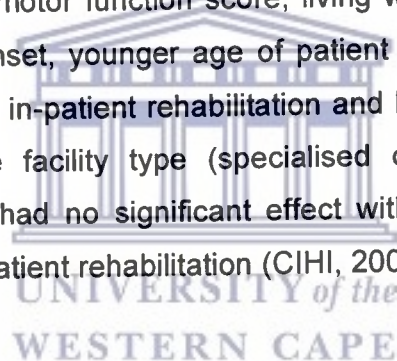
African to afford or they are fully booked, leaving the patients little choice but to forego their appointments and rehabilitation.

The findings of this study indicated that 32% of participants were able to mobilise independently of any walking aids or assistance at six month follow-up, while 46% required some form of assistance to mobilise and 22% were not able to mobilise at all. This finding is only slightly less than that achieved in the study conducted by Rouillard et al (2012), who identified, at six month follow-up, that 52% of participants required some form of assistance with mobility. However, these findings were not in correspondence with that of Jorgensen et al (1995).

The well established Copenhagen Study, conducted by Jorgensen et al (1995) on 804 consecutive patients with stroke in the acute stage attempted to identify the time course and degree of recovery of walking function after stroke. It was identified at the end of rehabilitation (mean length of stay of 35 days) that, of the participants who had no independent walking function on admission, 34% of the survivors achieved independent walking function at discharge. Jorgensen et al (1995) further identified that initial walking function was impaired in two out of three patients with acute stroke, however recovery of walking function occurred in 95% of the patients within the first 11 weeks after stroke. This study included a large, unselected number of patients with stroke in the acute stage with the population being community-based, and all participants were evaluated serially from the time of acute admission to death or end of rehabilitation.

A study conducted by Viosca et al (2005) on 41 consecutive patients with stroke in the acute stage, with a mean length of stay of 23 days in a district hospital rehabilitation facility and a further twelve month follow-up period, disagreed with the time course set forward by Jorgensen et al (1995). Viosca et al (2005) reported improvement in walking capacity of participants throughout their follow-up process of twelve months post-stroke. Indicating that prediction of recovery in mobility, and function in general, post-stroke is not a simple task and can be influenced by the study outcome measures and designs used. Therefore, the clinical implication for this finding is that rehabilitation should continue for as long as objective improvement is noted, whether in-hospital or at CBS rehabilitation.

The findings of this study showed that the majority of participants (86%) returned to their previous residential address post discharge, with 14% of participants placed in a care facility or alternative home due to the families or care-givers either being unavailable to care for the participant during the day or night, or being unable to manage the needs of the participant post-stroke. This finding is higher than that of Putman et al (2009) in a study conducted on 532 consecutive patients with stroke in four European rehabilitation centres, which identified that at six month follow-up, between 66% - 76% of patients were discharged home, with between 5% - 19% representing the amount who were institutionalised. However, the findings of this research study did coincide with that of a study conducted by the Canadian Institute for Health Information (CIHI, 2009) on 3752 patients with stroke, whereby 85% of all stroke rehabilitation participants included in the analysis were discharged home. The factors that were specifically associated with an increased chance of discharge home were: a higher admission motor function score, living with a spouse or other family member prior to stroke onset, younger age of patient (<65), unilateral body involvement, earlier admission to in-patient rehabilitation and being male. One point to note in contrast is that the facility type (specialised or generalised stroke rehabilitation unit) in this study had no significant effect with regard to discharge outcome of participants after in-patient rehabilitation (CIHI, 2009).



## CHAPTER SIX: CONCLUSION

### 6.0 INTRODUCTION

This chapter will summarise the findings of the entire study, with particular reference to the study objectives, and provide a conclusion to the results and discussions of the previous chapters. It will also include the significance and the limitations of the study and finally, the chapter will end off with recommendations that are based on the findings of this study.

### 6.1 CONCLUSION

This study aimed to identify whether certain factors, including the participants' level of education, perceived health related quality of life, perceived family support, perceived satisfaction with rehabilitation, and rehabilitation intensity, were factors that influenced their functional outcome post-stroke at discharge and at six months post discharge. Particular interest was placed on the influence of the stroke individual's family support and patient satisfaction, as identified in Chapter One. The findings of this study identified that perceived health related quality of life of participants is the strongest and most significant factor ( $p < .000$ ) influencing the functional outcome of stroke participants at discharge and at six month follow-up respectively, accounting for 90.6% of the variance of function. The subsequent findings of this study also suggest that perceived family support of the participants had a moderate statistically significant influence ( $p = .02$ ) on functional outcome of participants at discharge and a stronger significant influence ( $p < .005$ ) post discharge; with perceived satisfaction with rehabilitation identified to have had a strong statistically significant influence on the functional outcomes of participants at discharge and follow-up,  $p < .005$  respectively. These findings highlight the importance of a patient's subject feelings and perceptions toward their health, rehabilitation and family/societal standing in determining their functional outcome post-stroke, with this study suggesting higher perceived quality of life, family support and satisfaction with rehabilitation in individuals post-stroke correlated significantly with a higher functional outcome at discharge and at six months post discharge.

## 6.2 SIGNIFICANCE OF THE STUDY

This study aimed to provide preliminary information regarding the biopsychosocial and rehabilitation factors that had an influence on the functional outcomes of patients with stroke in a sub-acute, primary level rehabilitation facility so as to provide information to healthcare professionals, in a South African context, on what possible areas of the rehabilitation process requires more attention when rehabilitating these patients to allow for maximal functional outcomes and patient independence to be obtained. The areas that require more attention have been identified as patient quality of life, family support and satisfaction with rehabilitation, which all significantly influence functional outcome post-stroke. Although not a specific aim of this study, the researcher managed to adhere to ten of the eleven requirements set forward by Kwakkel et al (1996) for effective prognostic research studies, thus improving the quality of the findings due to methodological soundness. The criteria that was not adhered to was cross-validation of the prediction model, which will be further discussed in the limitations section below.

## 6.3 LIMITATIONS TO THE STUDY

Several limitations to the study were identified by the researcher with the most obvious limitation being the small overall sample size. Although determined to be effective for this research study, the sample size had an effect on the distribution of the variables being studied, and therefore influenced which statistical tests could be performed on the data captured. Only non-parametric tests were used as a result of non-normal distributions of the variables. Pallant (2011) explained that parametric tests are more stringent with assumptions and are more powerful than their non-parametric counterparts, therefore as only non-parametric tests could be performed in this research study, the findings are somewhat less powerful. The small sample size was as a result of the exclusion of certain cases due to death of participants, participants being lost to follow-up and due to the presence of receptive aphasia, influencing the participant's ability to report back and give vital information to the researcher. Domholdt (2000) explained that mortality of participants in a study can be a potential threat to internal validity as deaths leave the researcher with a very different sample by the end of the study. The amount of participants lost to follow-up was attributed to the six month follow-up period post discharge, during which no contact was made and many contact numbers were no longer in service.



The researcher did not make use of an intention to treat analysis, as the participants who died or were lost to follow-up were excluded altogether from the analysis. This is noted by the researcher as a limitation as it could have influenced the results.

Cross-validation of the prediction model onto an independent sample, identified by Kwakkel et al (1996), was not an objective of this study and thus was not conducted. However, the researcher does recognise the importance of cross-validation in research of this nature, and therefore noted this as a possible limitation to the study.

The clinical management and rehabilitation of a number of the participants included in this study was conducted by the researcher himself, as he was their assigned physiotherapist. The researcher acknowledges that this may have caused bias and thus has noted it as a limitation.

The researcher is also aware of a general limitation to observational studies, which is that the researcher has no control over the composition of the control group and therefore cannot randomise the allocation of individuals. This can create bias, and can also mask cause and effect relationships or, alternatively, suggest correlations where there are none, known as error in research (Shuttleworth, 2009).

Due to the fact that non-probability sampling was used, the researcher identified that an exclusion bias may have occurred due to non-randomisation of the sample, which in this case places a limit on how much information the study sample can provide about the stroke population as a whole.

Another limitation identified by the researcher is that of the pilot study, as mentioned in the Methodology Chapter 3.8, where only five participants were used. Ideally, a minimum of 10% of the total sample size required for the main study should be attained in the pilot study, therefore a minimum of six participants should have been included.

A limitation identified by a participant in the study was that the family support questionnaire focused only on the perceived family support aspect rather than social support in general. In doing so, the researcher may have inadvertently excluded an important aspect, as certain participants may only have a social support network

and/or may feel more support socially than in their family environment. For those particular participants, that social support structure may provide the necessary support they require to improve quality of life sufficiently to improve functional outcome post-stroke.

Generalisation of the findings in this research study may be difficult due to several factors, one of which includes the fact that this was not a population-based study. The participants included in this study were only selected from one step-down, primary rehabilitation facility in Cape Town and were therefore not representative of the stroke population as a whole. Also, the mean age of participants in this study sample did not coincide with that of other South African research by Mudzi (2010), Rouillard et al (2012) and Joseph et al (2013), indicating again that the sample was not a true representation of the South African stroke population.

#### 6.4 RECOMMENDATIONS

Based on the findings of this study, the following recommendations can be:

##### Policies

- Healthcare facilities should have policies in place that positively influence the patient's overall experience and satisfaction within the healthcare system in South Africa, along the continuum of care, to improve the quality of care and to lessen the burden of the disease on the individual.
- The public transport infrastructure in South Africa needs to be geared more to meet the needs of disabled individuals, to allow for more appointments and rehabilitation sessions at community-based services to be met.
- With the high amount of people suffering from hypertension, greater awareness and education strategies should be implemented to control blood pressure and reduce the risk of stroke occurrence.

##### Rehabilitation

- During rehabilitation of stroke individuals, a higher emphasis should be placed on their subjective perception of their condition and situation, including the health related quality of life, family support and satisfaction levels.

- More focus should also be placed on limiting participation restrictions than on functional gain alone, to allow for a greater ability to manage with usual activities once patient has been discharge from the rehabilitation setting.
- Families and care-givers should be included as far as possible in the rehabilitation process, without hindering the therapist and patient, but allowing for the stroke survivor to perceive a strong family support structure.

#### Future Research

- Cross validation of prediction models on an independent group of participants should be included in the aim of the study so as to improve the methodological soundness and quality of the results obtained.
- Pilot studies conducted should include a minimum of 10% of total participants required for the main study to be viewed as statistically relevant and useful.
- The sample included in a study of this nature should be randomised to eliminate an exclusion bias from occurring; and should be community-based to be more inclusive of the stroke population as a whole, which would allow for better generalisability of the findings.
- It was not an objective of this study, but further research should be done into each category of the EQ-5D descriptive system to identify the effect each has on the functional outcomes of patients with stroke more conclusively.

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## **ANNEXURE A**

### **FACTORS INFLUENCING FUNCTIONAL OUTCOMES TO BE RESEARCHED**

1. Level of education
2. Perceived health related quality of life
3. Perceived family support
4. Perceived satisfaction with rehabilitation
5. Rehabilitation intensity



**ANNEXURE B**  
**INFORMATION SHEET**

**Project Title:** The Factors Influencing Functional Outcomes of Stroke Patients Receiving Rehabilitation at a Sub-acute Rehabilitation Facility in the Western Cape.

**What is this study about?**

This is a research project being conducted by Ryan Clive Groenewald, of the University of the Western Cape. We are inviting you to participate in this research project because you, as a patient suffering from a stroke, fulfil the requirements to make this study possible. The purpose of this research project is to provide preliminary information to health care workers regarding the factors that have an influence on the functional outcomes of patients with stroke in a sub-acute primary level rehabilitation facility, so as to obtain maximal functional outcomes and patient independence.

**What will I be asked to do if I agree to participate?**

You will be asked to complete several short questionnaires, on admission, at discharge and again at six months follow-up, with the aid of the researcher. These questionnaires will include information on demographics, health related quality of life, satisfaction level and family support. Your rehabilitation process will also be monitored by your therapists and documented by the researcher. All the research, as far as possible, will be conducted at Booth Memorial Hospital (BMH). The study length will include the duration of rehabilitation while at BMH and a follow-up appointment six months post discharge.

**Would my participation in this study be kept confidential?**

We will do our best to keep your personal information confidential. To help protect your confidentiality, whether included or excluded from the study, no information will be disclosed to any unauthorized parties. The use of password-protected computerized files, as well as identification coding on information gathered, will be used. Your name will not be included on the collected data (except for the demographic information). A code will be placed on the questionnaires and other collected data, through the use of an identification key, the researcher will be able to link your relevant information to your identity, and only the researcher will have access to the identification key. If we write a report or article about this research project, your identity will be protected to the maximum extent possible.

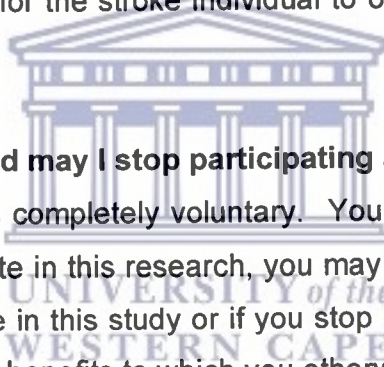
In accordance with legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authorities information that comes to our attention concerning potential harm to you or others.

**What are the risks of this research?**

There are no known risks associated with participating in this research project.

**What are the benefits of this research?**

This research is not designed to help you personally, but the results may help the investigator learn more about the factors that influence the functional outcomes of stroke individuals. We hope that, in the future, other people might benefit from this study through improved understanding of this subject. With the correct knowledge and research data, treatment regimes could be drawn up that focus rehabilitation in the correct area and in the correct manner, allowing for the stroke individual to obtain maximal functional outcomes and independence.



**Do I have to be in this research and may I stop participating at any time?**

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

**Is any assistance available if I am negatively affected by participating in this study?**

No assistance has currently been made available, but should you require counselling or other assistance, it will be provided.

**What if I have questions?**

This research is being conducted by Ryan Clive Groenewald of the physiotherapy department at the University of the Western Cape with the assistance of supervisor Professor Anthea Rhoda. If you have any questions about the research study itself, please contact Ryan Clive Groenewald at: Booth Memorial Hospital 32 Prince Street, Oranjezicht, 8001, 021 465 4846 or by email at: [ryang@boothhosp.org](mailto:ryang@boothhosp.org).

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Head of Department: Professor Jose Frantz

Dean of the Faculty of Community and Health Sciences: Professor R. Mpofu

University of the Western Cape

Private Bag X17

Bellville 7535

This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.

Research Registration Number:

11/5/15



**ANNEXURE C**

**INFORMED CONSENT FORM**

**Title of Research Project:**

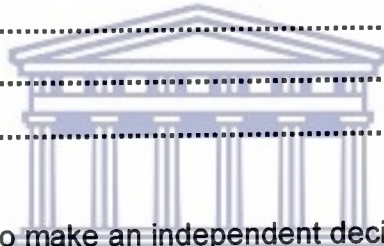
The Factors Influencing Functional Outcomes of Stroke Patients Receiving Rehabilitation at a Sub-acute Rehabilitation Facility in the Western Cape.

The study has been described to me in language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

**Participant's name**.....

**Participant's code**.....

**Participant's signature**.....



In the event the patient is unable to make an independent decision:

**Name of legal guardian/representative of patient**.....

**Guardian/Representative's signature**.....

**Witness**.....

**Date**.....

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

**Study Coordinator's Name: Professor A. Rhoda**

**University of the Western Cape**

**Private Bag X17, Belville 7535**

**Telephone: (021) 959 2542**

**Email: arhoda@uwc.ac.za**



**ANNEXURE D**

PATIENT CODE: \_\_\_\_\_

DATE: \_\_\_\_\_

**SOCIO-DEMOGRAPHIC DATA**

**STRICTLY CONFIDENTIAL!!!!**

**PATIENT NAME:**

**FOLDER NUMBER:**

**GENDER:**

**DATE OF BIRTH:**

**RACE:**

(included to assess equality of services)

**ADDRESS**

**CONTACT NUMBER:**

**HIGHEST QUALIFICATION/  
LEVEL OF EDUCATION:**

**EMPLOYMENT STATUS:**

**OCCUPATION:**

**HISTORY OF STROKE:**

<b>FAMILY:</b>	<b>PREVIOUS:</b>
----------------	------------------



**ANNEXURE E**

**THE  
BARTHEL  
INDEX**

**Patient Name:** \_\_\_\_\_

**Rater Name:** \_\_\_\_\_

**Date:** \_\_\_\_\_

**Activity** \_\_\_\_\_ **Score** \_\_\_\_\_

**FEEDING**

- 0 = unable
- 5 = needs help cutting, spreading butter, etc., or requires modified diet
- 10 = independent

\_\_\_\_\_

**BATHING**

- 0 = dependent
- 5 = independent (or in shower)

\_\_\_\_\_

**GROOMING**

- 0 = needs to help with personal care
- 5 = independent face/hair/teeth/shaving (implements provided)

\_\_\_\_\_

**DRESSING**

- 0 = dependent
- 5 = needs help but can do about half unaided
- 10 = independent (including buttons, zips, laces, etc.)

\_\_\_\_\_

**BOWELS**

- 0 = incontinent (or needs to be given enemas)
- 5 = occasional accident
- 10 = continent

\_\_\_\_\_

**BLADDER**

- 0 = incontinent, or catheterized and unable to manage alone
- 5 = occasional accident
- 10 = continent

\_\_\_\_\_

**TOILET USE**

- 0 = dependent
- 5 = needs some help, but can do something alone
- 10 = independent (on and off, dressing, wiping)

\_\_\_\_\_

**TRANSFERS (BED TO CHAIR AND BACK)**

- 0 = unable, no sitting balance
- 5 = major help (one or two people, physical), can sit
- 10 = minor help (verbal or physical)
- 15 = independent

\_\_\_\_\_

**MOBILITY (ON LEVEL SURFACES)**

- 0 = immobile or < 50 yards
- 5 = wheelchair independent, including corners, > 50 yards
- 10 = walks with help of one person (verbal or physical) > 50 yards
- 15 = independent (but may use any aid; for example, stick) > 50 yards

\_\_\_\_\_

**STAIRS**

- 0 = unable
- 5 = needs help (verbal, physical, carrying aid)
- 10 = independent

\_\_\_\_\_

**TOTAL (0-100):** \_\_\_\_\_

## The Barthel ADL Index: Guidelines

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1. The index should be used as a record of what a patient does, not as a record of what a patient could do.
2. The main aim is to establish degree of independence from any help, physical or verbal, however minor and for whatever reason.
3. The need for supervision renders the patient not independent.
4. A patient's performance should be established using the best available evidence. Asking the patient, friends/relatives and nurses are the usual sources, but direct observation and common sense are also important. However direct testing is not needed.
5. Usually the patient's performance over the preceding 24-48 hours is important, but occasionally longer periods will be relevant.
6. Middle categories imply that the patient supplies over 50 per cent of the effort.
7. Use of aids to be independent is allowed.

## References

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Mahoney FI, Barthel D. "Functional evaluation: the Barthel Index." *Maryland State Med Journal* 1965;14:56-61. Used with permission.

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## ANNEXURE F

### EQ-5D DESCRIPTIVE SYSTEM

**Figure 1: EQ-5D (UK English version)**

By placing a tick in one box in each group below, please indicate which statements best describe your own health state 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

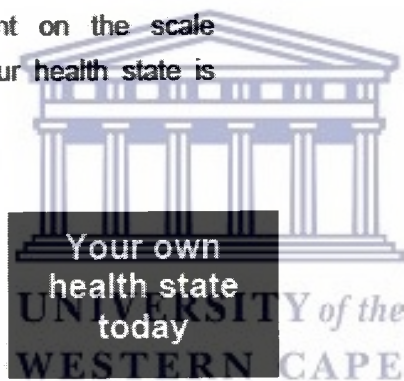
#### **Anxiety/Depression**

- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed

## EQ-5D VISUAL ANALOGUE SCALE (VAS)

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) 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 how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.



Best  
imaginable  
health state

100

90

80

70

60

50

40

30

20

10

0

Worst  
imaginable  
health state

## ANNEXURE G

PATIENT CODE: \_\_\_\_\_

DATE: \_\_\_\_\_

**FAMILY SUPPORT DATA**

**STRICTLY CONFIDENTIAL!!!!**

<u>Questions:</u>	<u>YES</u>	<u>NO</u>
1. Do you have a spouse?		
2. Do you have children?		
3. Do you feel your spouse, children or other family members will be supportive in their care of you?		
4. Do you feel you are in regular contact with your spouse, children and relatives?		
5. Do you feel like you are able to ask your family for assistance if it is needed?		
6. Do you feel there is someone in your family that you can confide in and with whom you can freely discuss any problems?		
7. Do you feel as if your problem/condition has negatively affected your relationships with family members?		
8. Do you feel as if you are a burden on your family?		
9. Do you feel you have the support of your family members, whatever the need may be?		

## ANNEXURE H

PATIENT CODE: \_\_\_\_\_

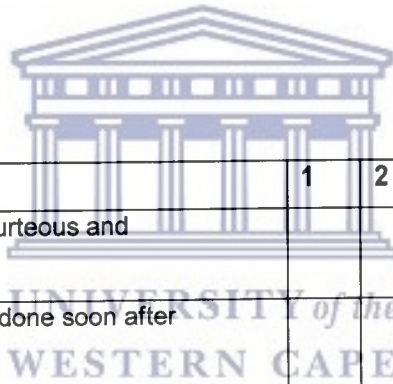
DATE: \_\_\_\_\_

### SATISFACTION DATA

### STRICTLY CONFIDENTIAL!!!!

Please rate your degree of satisfaction with each of the following statements...

- 1 = Strongly agree
- 2 = Agree
- 3 = Neither agree nor disagree
- 4 = Disagree
- 5 = Strongly disagree
- 6 = I have no opinion on the matter



Questions:	1	2	3	4	5	6
I was treated in a friendly, respectful, courteous and professional manner by all the staff						
My initial assessments for therapy were done soon after admission						
The therapy staff introduced themselves and made me feel comfortable						
My assessment and treatment was done in a language that was understandable to me						
The option to refuse therapy was available to me at all times						
My dignity and right to privacy was respected during therapy						
I had opportunities to discuss my concerns with the therapists						
My therapists understood my problem or condition						
The instructions my therapists gave me were helpful						
I was seen frequently enough during my admission						
I feel the time I had with the therapists was adequate						
My environment/surroundings were conducive to my recovery						
I was satisfied with the overall quality of the treatment/services						
I am pleased with the outcome of my therapy						
I would recommend this facility to family or friends in need						
I would return to this facility for therapy if it were necessary						

## ANNEXURE J

PATIENT CODE: \_\_\_\_\_

DATE: \_\_\_\_\_



**STRICTLY CONFIDENTIAL!!!!**

1. Have you attended any further rehabilitation in the past 6 months after your discharge from Booth Memorial Hospital? (If no, continue to question 4).

Yes	
No	

2. Which of the following health care professionals have you seen over the past 6 months?

Physiotherapist	
Occupational Therapist	
Speech/Language therapist	
Social worker	
Dietician	
Psychologist	
Nurse	
Traditional Healer	
Community Rehabilitation worker	
Home-based Carer	
Medical Doctor	
Specialist	
Self-help group/ stroke group	



3. How many times have you undergone rehabilitation in the last 6 months?

Once a month	
Twice a month	
Three times a month	
Four times a month	
More than Four times a month	



4. Have you, in the past 6 months, been forced to forgo the use of health care services because of:

Financial difficulties	
Transport difficulties	
Lack of health care accessibility	
Other: Specify	

5. How have you managed, in your condition, at home?

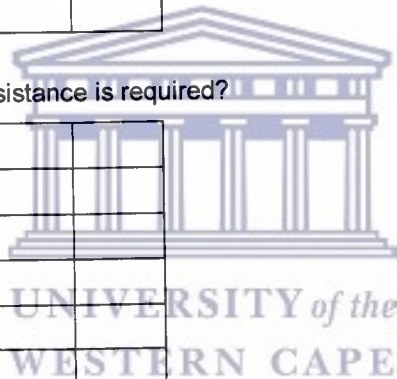
Well	
Adequately/sufficiently	
Not well	

6. How do you mostly move around inside your house?

Walk unassisted	
Walk assisted	
Wheelchair	
Unable	

7. If walking with assistance, what assistance is required?

Walking stick	
Elbow Crutches	
Axillae Crutches	
Walking frame	
Walking stick with 3 or 4 feet	
Wheelchair	
Hand-held assistance	



8. How do you mostly move around outside your house?

Walk unassisted	
Walk assisted	
Wheelchair	
Unable	

9. If walking with assistance, what assistance is required?

Walking stick	
Elbow Crutches	
Axillae Crutches	
Walking frame	
Walking stick with 3 or 4 feet	
Wheelchair	
Hand-held assistance	

10. Has your stroke affected the way in which you move around in your community or elsewhere?

Yes	
No	

11. How would you best describe the place where you are living now?

Same home as before the stroke	
Alternative home	
Institution/ nursing home/ care facility	

12. If you are not staying at your previous home, what is the main reason for this?

Not applicable	
Previous home was unsuitable	
No carer at home	
Carers unable to manage with needs	

13. Where you stay now, is there anyone to help you:

	Yes	No
During the day		
At night		

