

# **THE PROFILE AND OUTCOMES OF STROKE PATIENTS DISCHARGED FROM A HOSPITAL IN THE EASTERN CAPE**

**BY**

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## ABSTRACT

Stroke is the third leading cause of death and disability worldwide. The Uitenhage Provincial Hospital admits many stroke patients. To date, no in-depth study has been conducted on stroke patients admitted to the Hospital. This study identified the profile of stroke patients admitted to the Uitenhage Provincial Hospital and explored the challenges that these patients experienced post stroke. A concurrent mixed model design was used to collect the data. Firstly retrospective data was obtained by means of a quantitative data gathering instrument designed by the researcher. The information obtained, included data relating to demographic characteristics, reported risk factors relating to stroke, stroke onset-admission interval and length of hospital stay, as well as information relating to the process of physiotherapy. Secondly quantitative prospective information was collected by means of the Barthel Index, the Modified Rankin Scale and the Facilitators And Barriers Survey. The sample for the quantitative phase was drawn from medical records of 168 stroke patients admitted to the Uitenhage Provincial Hospital from the 1 of January 2008 up to and including the 31 of December 2009. For the second prospective quantitative part of the study, participants were selected conveniently from the admitted patients. In the qualitative phase, nine participants taken of the sampled participants were selected. The Microsoft Excel 2007 Package and the SPSS 18 for social sciences were used to analyse the quantitative data. Means, standard deviations, frequencies and percentages were calculated for descriptive purposes and the Chi-square test was used to test for associations between variables. Qualitative analysis began with the transcription of voice recordings and the translation of relevant Afrikaans transcription into English. Emerging categories were identified within the pre-

determined themes. Permission and ethical clearance was obtained from the Higher Degrees Committee and the Senate Research and Grants and Study Leave Committee of the University of the Western Cape and permission to conduct this study was also obtained from the Medical Superintendent of the Uitenhage Provincial Hospital. Altogether 461 patients had been admitted with stroke during the relevant period, but only 168 could be included in the retrospective quantitative study. The mean age of the participants was 61,54 years; 59% were females and 41% males. The majority of the participants (86,9%) were admitted on the same day of stroke onset, and the mean length of hospital stay was 7,38 days. Hypertension was the most common reported risk factor, at 79%. Only 165 of the participants received physiotherapy while hospitalised, with the mean total physiotherapy sessions being 2,56 sessions. In 90% of the cases, physiotherapy sessions were discontinued due to the patient being discharged from the Hospital. The mean Barthel Index score was 81,46 and the family care domain of the Modified Rankin Scale was the most affected. Participants experienced participation restrictions and activity limitations due to stairs, gravel surfaces and kerb cuts. During the qualitative interviews participants reported activity limitations related to walking and activities of daily living. The participants also experienced participation restrictions, which included dependency on others, decreased social support and an array of emotions experienced post stroke. The current study's findings suggest that the discharge of patients from the hospital post stroke should follow a multidisciplinary approach. Rehabilitation professionals should play an active role in the discharge process in providing patient and caregiver education.

# PROFILE AND OUTCOMES OF STROKE PATIENTS DISCHARGED FROM A HOSPITAL IN THE EASTERN CAPE

NATALIE LORINDA CUNNINGHAM

## KEY WORDS

Activity limitations

Environmental Barriers

Environmental Facilitators

Impairments

Participation Restrictions

Physiotherapy

Profile

Rehabilitation

Stroke

Uitenhage Provincial Hospital



**ABBREVIATIONS**

ADLs	Activities of daily living
BI	Barthel Index
CT scan	Computerised Tomography Scan
CVA	Cerebrovascular Accident
CVD	Cerebrovascular Disease
FABS	Facilitators and Barriers Survey
FES	First Ever Stroke
HIV	Human Immunodeficiency Virus
ICF	International Classification of Functioning Disability and Health
MCA	Middle cerebral artery
MRI scan	Magnetic Resonance Imaging
MRS	Modified Rankin Scale
QOL	Quality of Life
rt-PA	Intravenous recombinant tissue plasminogen activator
SA	South Africa
SSA	Sub-Saharan Africa
TIA	Transient Ischaemic Attack
WHO	World Health Organisation

## DECLARATION

I hereby declare that “**Profile and Outcomes of Stroke Patients discharged from a Hospital in the Eastern Cape**” is my own work, that it has not been submitted for any degree or examination in any other university and that all the sources I have used or quoted have been indicated and acknowledged by means of complete references.

**Natalie Lorinda Cunningham**



Signature: ..... May 2012

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**Witness: Prof Anthea Rhoda**

Signature: ..... May 2012

## DEDICATION

I dedicate this thesis to my husband, Lucien, for his infinite love, and to our children Chloe Victoria and Matthew Paul Lingham. May this thesis serve as an encouragement when you start your own path to learning.



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## CHAPTER ONE

### INTRODUCTION

#### 1.1 INTRODUCTION

This chapter will first present with a description of stroke and its consequences. It will then consider the prevalence of stroke, both internationally and locally, in the Eastern Cape. Subsequently, the rationale and significance of the study will be explained and the research question stated.

#### 1.2 BACKGROUND



Stroke is a heterogeneous condition, consisting of different types and subtypes (Connor & Bryer, 2005). It is well documented that stroke results in high mortality and morbidity. The mortality and morbidity rates vary for different countries (Ali, Atula, Bath, Grotta, Hacke, Lynden, Marler, Sacco & Lees, 2009; Wolfe, Giroud, Kolomnsky-Rabas, Dundas, Lemelsle, Heuschman & Rudd, 2000). Stroke mortality is approximately five times higher in Eastern Europe than in Western Europe (Stegmayr, Vingrodova, Malyutina, Peltomen, Nikitin & Asplund, 2000). According to the American Heart Association (2009), stroke is the third most common cause of death in the United States of America. However, from 1995 to 2005, the stroke death rate fell 29,7%, while the actual stroke death rate declined to 13,5% (AHA, 2009). This decrease in mortality rates has been attributed to effective stroke prevention strategies and stroke care, as well as falling stroke incidence rates as confirmed in

the Oxford vascular study (Rothwell, Coull, Giles, Howard, Silver, Bill, Gutnikov, Edwards, Mant, Sackley, Farmer, Sandercock, Dennis, Warlow, Bamford & Anslow, 2004). Age-related stroke mortality in adults in Sub-Saharan Africa seems to be similar to that in higher income countries (Connor, Thorogood, Modi & Warlow, 2007b). The lack of adequate longitudinal data from various regions within Sub-Saharan Africa makes the establishment of accurate mortality data in this region a huge challenge (Connor, Thorogood, Modi & Warlow, 2007a).

In 2005 in the United States, the stroke prevalence among adults 20 years and older was 650 per 100 000 people (American Heart Association, 2009). An age standardised stroke prevalence of 100 per 100 000 people was established in France; 124 per 100 000 people in the United Kingdom; and 136 per 100 000 people in Germany (Wolf *et al.*, 2000). Each year in the United States, about 795 000 people experience a new or recurrent stroke (American Heart Association, 2009). Connor, Rheeder, Bryer, Meredith, Beukes, Dubb and Fritz (2004), established that the stroke prevalence in Limpopo, South Africa was 243 per 100 000 people in 2003 (Connor *et al.*, 2004).

Stroke patients often have predisposing modifiable risk factors. These include hypertension, diabetes mellitus, cardiac disease, hyperlipidemia, alcohol use and cigarette smoking (Gillen & Burkhardt, 2004). According to the National Guideline on Stroke and Transient Ischaemic Attack Management (2001), these risk factors also predisposes an individual to a secondary stroke. If the first stroke was from an embolus from the heart or stenosis of the carotid artery, the second stroke will in all likelihood occur within two weeks of the initial stroke. The second stroke may result



in severe disability (National Guideline on Stroke and Transient Ischaemic Attack Management, 2001).

Stroke is the leading cause of serious long term disability (American Stroke Association, 2008; Bradberry & Fagan, 2002). Disability post stroke can be conceptualised within the framework of the International Classification of Functioning, Disability and Health (ICF). The components of the ICF can be used to indicate problems with regard to disability, such as impairments, activity limitations or participation and functioning restrictions (World Health Organisation, 2001). Following a stroke, patients may experience activity limitations, which are difficulties in executing the activities of daily living (ADL) (World Health Organisation, 2001). Participation refers to the ability of people to manage the roles and responsibilities they were previously executing (World Health Organisation, 2001). Common impairments after a first-ever stroke include hemiparesis, facial weakness, dysarthria, aphasia, sensory loss, cognitive impairment and balance problems (Scottish Intercollegiate Guidelines Network, 2002). The most common activity limitations experienced by stroke survivors include difficulties with mobility, i.e. with walking or driving; and self-care limitations, such as problems with bathing, toileting, dressing and feeding (Mayo, Wood-Dauphinee, Ahmed, Gordon, Higgins & McEwen, 1999). Loss of mobility is the limitation in ADL most frequently mentioned by stroke survivors, which often requires the use of mobility devices, such as canes, walkers or wheelchairs (Mumman, 2000). The most common participation restriction experienced by stroke survivors is a change in work ability (Desrosiers, Rochette, Noreau, Bourbonnais, Bravo & Bourget, 2006; Hamel, Jones, Gossett & Morgan, 2006) as well as leisure activities and education (Desrosiers *et al.*, 2006).

In addition to activity limitations and participation restrictions, stroke patients also experience a number of barriers to participation and activity. O'Donovan, Doyle and Gallagher (2009), have established that the physical environment poses the most common barrier to participation for people with physical disabilities. Hamel *et al.* (2006) have identified that individual barriers post stroke arise from personal issues in four main areas, namely physical, social, cognitive and psychological. Physical and cognitive impairments have been frequently identified as the most important reasons for lack of participation (Hamel *et al.*, 2006). In persons with physical disabilities, mobility impairment and decreased endurance, stamina and balance have created the need for a wheelchair. The wheelchair therefore acts as a facilitator for community participation and community integration (Barker, Reid & Cott, 2006).

Environmental barriers are those that make participation in the community difficult. O'Donovan, Doyle and Gallagher (2009) found that the physical environment was the most common barrier to participation for people with a physical disability (46,6%). The identification of the barriers and facilitators post stroke is crucial if the activity levels and community re-integration of stroke patients are to be improved in future. A reduction in activity levels and participation in patients with stroke limits their re-integration into the community and they are therefore socially isolated, which often results in the patients becoming frustrated and even depressed (Dowswell, Lawler, Dowswell, Young, Forster & Hearn, 2000).

Following a stroke, proper management during the acute period will result in less disability and reduce the negative impact on the healthcare sector and society

(McNaughton, De Jong, Smout, Melvin & Brandstater, 2005). Rehabilitation is the process through which the disability experienced by stroke patients is addressed. The rehabilitation of stroke patients includes early physical, occupational and speech therapy, facilitating re-integration of patients with stroke into their communities, education of patients and their families about stroke and prevention of further complications (Wade, Smith & English, 2008). Rehabilitation can be conducted in different settings, e.g. as in-patients in hospitals, in rehabilitation units in acute care hospitals, in nursing facilities that offer structured rehabilitation programmes, in out-patient facilities, or in patients' homes (Greshan, Duncan & Stason, 2004). Kalra, Evans, Perez, Melbourn, Patel, Knapp and Donaldson (2004) and Patel, Knapp, Evans, Perez and Kalra (2004) concur that rehabilitation improves the quality of life of stroke survivors. While rehabilitation improves both the physical and the social function of patients post stroke, it has to be continued post hospital discharge in order to maintain the level of improvement that patients have reached (Aprille, Di Stasio, Romitelli, Lancellotii, Caliandro, Gilardi & Padua, 2008; Hopman & Verner, 2003).

In order to implement management interventions for patients, which includes rehabilitation, it is important to know the stroke profile in a specific region (Connor & Bryer, 2005). Factors that could be included when compiling this profile include demographic characteristics (Sturm, Donnan, Dewey, Macdonell, Gilligan & Thrift, 2004), medical characteristics (Garbusinski, Van de Sande, Bartholome, Dramaix, Gaye, Coleman, Nyan, Walker, McAdam & Walraven, 2005) and post stroke disability data (Hendricks, Van Limbeek, Geurts & Zwarts, 2002).

Although data is available on the outcomes and profile of patients with stroke in the Western Cape, South Africa (Joseph, 2011, Rhoda, Mpofu & De Weerd, 2006; Roullaird, 2006), no data is available on the Eastern Cape. It has been highlighted by Connor and Bryer (2005) that, due to socio-economic differences and past political influences, the profile of stroke could differ between the various population groups. Eastern Cape Mortality Estimates (MRC, 2000) indicated stroke as the leading cause of death in the Eastern Cape, at 6,5%. According to those statistics stroke was the leading cause of death among women and the fourth leading cause among men in the age group 45-49 years. In the age group 60 years and above, stroke was the leading cause of death in both sexes, accounting for 19% of female and 11,9% of male deaths in this age group (MRC, 2000). This confirms that stroke is a serious medical condition in this region and therefore needs to be managed properly.

### **1.3 RESEARCH PROBLEM**

From the experience of the researcher, many stroke patients are seen as in-patients by physiotherapists at the Uitenhage Provincial Hospital. Although patients are given out-patient appointments at the Uitenhage Provincial Hospital's Out-patient Physiotherapy Department or at the Community Health Centre in KwaNobuhle, not many of them honour these appointments. There is therefore a lack of follow-up management for these patients. In order to implement appropriate interventions for these patients, it is important to collect data in order to compile a profile of these patients. In addition, knowledge of the barriers to and facilitators of participation would also assist in developing appropriate rehabilitation interventions.

To date, there is no data available on the demographic and medical profiles as well as the physiotherapy given to stroke patients admitted to the Uitenhage Provincial Hospital. Therapists are also not aware of the long-term level of disability of these patients. Knowing the effect that the disability has on an individual post stroke, will help to raise an awareness and allow the rehabilitation professionals to implement more specific/task orientated programmes in their sessions in order to facilitate post stroke needs.

#### **1.4 RESEARCH QUESTION**

What is the profile and outcomes of stroke patients admitted to the Uitenhage Provincial Hospital?

#### **1.5 AIM OF STUDY**



This study aimed to determine the profile and outcomes of stroke patients admitted to the Uitenhage Provincial Hospital from 1 January 2008 to 31 December 2009.

#### **1.6 OBJECTIVES OF STUDY**

1. To determine the demographic and medical risk profile of the stroke patients at admission to hospital.
- 1.2 To determine the process of physiotherapy services.
2. To determine the outcomes of stroke patients
  - 2.1 To determine the activity limitations experienced by the patients.
  - 2.2 To determine the participation restrictions experienced by the patients.

3. To determine and explore the barriers and facilitators reported by patients with regard to activity and participation.

## 1.8 DEFINITION OF TERMS USED IN THESIS

**Activity:** the execution of a task or action by an individual (World Health Organisation, 2001).

**Activity limitations:** difficulties an individual may experience in executing activities (WHO, 2001).

**Disability:** an umbrella term for impairment, activity limitation and participation restriction (World Health Organisation, 2001). It denotes the negative aspects of interaction between an individual who has a health condition and the individual's contextual factors which are environmental and personal factors (World Health Organisation, 2001).

**Environmental barriers:** environmental barriers refer to environmental factors that impede the performance of participation in life activities (Doyle & O'Donovan, 2008).

**Environmental factors:** constituents of the person's life milieu that can influence the accomplishment of daily activities or social roles (Rochette, Desrosiers & Noreau, 2001).

**Impairment:** problem in body function or structure as a significant deviation or loss (World Health Organisation, 2001).

**Participation:** involvement in a life situation (World Health Organisation, 2001).

**Participation restrictions:** problems an individual may experience in life situations (World Health Organisation, 2001).

**Physiotherapy process :** included the participants that received physiotherapy, as well as the start, duration and frequency of the therapy.

**Stroke:** stroke, also referred to as a cerebrovascular accident “CVA”, is defined by the World Health Organisation (WHO) as fast developing signs of the focal or at times global (referring to patients in a deep coma and those with a subarachnoid haemorrhage) disturbance of cerebral function. The disturbance can last more than 24 hours or lead to death, with no apparent cause other than that of vascular origin (WHO Monica Project, 1989).

## 1.9 OUTLINES OF THE CHAPTERS

Chapter one describes the basis of the current study. This starts with a description of the background of the current study, where the burden of stroke in both developed and developing countries are highlighted. It is then followed by the research problem, research questions, aim and objectives and the significance of the study. The chapter ends with the definitions of terms used in the study.

Chapter two of the thesis presents the literature review, which includes the definition and types of stroke, as well as the epidemiology of stroke including its incidence, mortality and prevalence. It continues with the risk factors for stroke, the medical management of stroke, the clinical features of stroke, stroke disability and stroke rehabilitation. The chapter ends by looking at activity limitations, participation restrictions and environmental barriers and facilitators experienced by stroke patients.

Chapter three describes the methodology used in the current study. The research design is discussed as well as the instruments used to collect the data. The research setting, research subjects, the inclusion and exclusion criteria, sampling and the process of data analysis are discussed. The chapter ends with the ethical considerations that were adhered to throughout the study.

Chapter four presents the results of the quantitative phase of the study. Ranges, means, standard deviations, frequencies and percentages are used to present

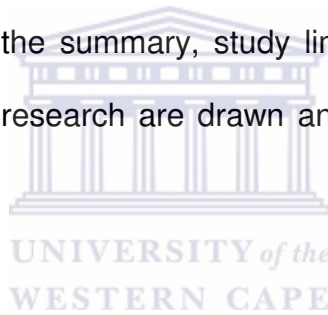


descriptive statistics while the chi-square are used to test associations between certain variables.

Chapter five discusses the quantitative results in relation to relevant and available literature, and the implications of the findings are discussed.

Chapter six presents and discusses the qualitative results. The themes that emerged are presented in this chapter. The current study findings are interpreted and compared to results or findings of similar studies or studies with related topics.

The final chapter consists of the summary, study limitations and conclusion. Here pertinent inferences from the research are drawn and recommendations are made for future research.

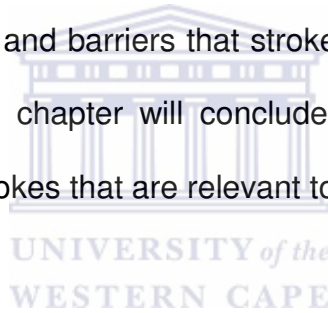


## CHAPTER TWO

### LITERATURE REVIEW

#### 2.1 INTRODUCTION

This chapter will first present a definition of strokes and describe the different types of strokes (physiology), the risk factors related to stroke, the medical management post stroke, as well as the effects of stroke. The literature review will then look at disability post stroke and the different types of rehabilitation available post stroke. Finally, the various facilitators and barriers that stroke patients could encounter post stroke will be explained. The chapter will conclude with a summary of the most important factors related to strokes that are relevant to the current study.



#### 2.2 DEFINITION AND TYPES OF STROKES

A stroke, as defined by the World Health Organisation (WHO), is a clinical syndrome. It is characterised by fast developing clinical signs of focal and at times global (applied to patients in deep coma and those with subarachnoid haemorrhage) disturbance of cerebral functioning. This disturbance can last more than 24 hours, or lead to death, with no apparent cause other than that of vascular origin (World Health Organisation, 1989). The clinical manifestations of stroke are highly variable, because of the complex anatomy of the brain and its vasculature. Therefore, the definition of a stroke is clinical, and laboratory studies, including brain imaging are used to confirm its diagnosis.

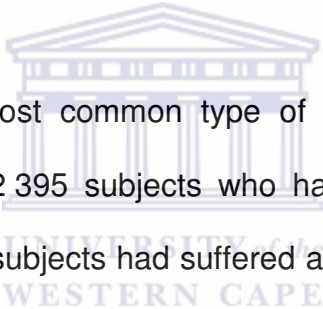
Strokes can be classified into two main types, namely ischaemic and haemorrhagic strokes (World Health Organisation, 1989). Cerebrovascular accidents can cause death and disability by ischaemia from occlusion of blood vessels (producing cerebral ischaemia and infarction) or haemorrhage, through their rupture (Allen & Lueck, 2002). Imaging studies, which include Computerised Tomography (CT) scan or Magnetic Resonance Imaging (MRI) scanning, are usually done in order to differentiate between ischaemic and haemorrhagic strokes. CT scans identify or exclude haemorrhage as the cause of a stroke and are sensitive for acute blood products. MRI scans report the extent and location of the infarction in all areas of the brain and also identify intracranial bleeding and other abnormalities. MRI scanning undertaken after the acute phase will more clearly identify the extent of tissue injury and can distinguish between new and old infarcted brain lesions (Smith, English & Johnston, 2008). In the researcher's knowledge, the Uitenhage Provincial Hospital does not have CT or MRI scanning equipment. Therefore, a stroke diagnosis is made as a clinical diagnosis.

### **2.2.1 Cerebral Ischaemia/Infarction**

“The most common cause of stroke is due to obstruction to one of the major cerebral arteries (middle, posterior & anterior, in that order) or their smaller perforating branches to deeper parts of the brain” (Downie, 1992).

Cerebral ischaemia is caused by an acute occlusion of an intracranial vessel, which results in a reduction in blood flow lasting longer than a few seconds. Neurological

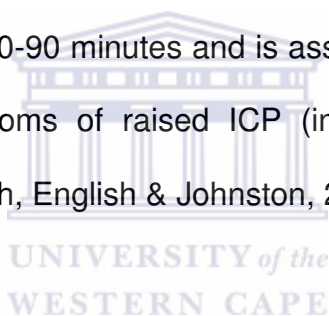
symptoms manifest within seconds; because of lack of glycogen in neurons, so energy failure is rapid (Smith, Johnston & Easton, 2005). Cerebral infarction is a process that takes some hours, even though the patient's deficit may be close to the onset of the causative vascular occlusion. After the occlusion of a cerebral artery, the reduction in perfusion pressure leads to other homeostatic changes to maintain oxygenation to the brain. The process of ischaemia starts when homeostatic mechanisms fail, which leads to infarction (Allen & Lueck, 2002). The tissue surrounding the core region of the infarction is ischaemic, but reversibly dysfunctional, and is referred to as the ischaemic penumbra (Smith, English & Johnston, 2008). This penumbra will infarct if no change in blood flow occurs.



Ischaemic strokes are the most common type of stroke. A study conducted in Perugia, which consisted of 2 395 subjects who had suffered a first-ever stroke, established that 73,4% of the subjects had suffered an ischaemic stroke (Silvestrelli, Paciaroni, Caso, Milia, Palmerini, Venti, Parnetti, 2006). An incidence study conducted in Iran, which had a subject base of 684 stroke patients, established that 81,9% of the subjects had suffered an ischaemic stroke (Azarpazhooh, Etemadi, Donnan, Mokhber, Majdi, Ghayour-Mobarhan, Ghandehary, Farzadfard, Kiani, Panadandeh. & Thrift, 2010). A prospective study in rural and urban Tanzania established that ischaemic strokes had occurred in over 80% of the populations in both settings (Walker, 2011). A hospital based study done in Cape Town, South Africa, found that out of 196 stroke patients, 37,2% had suffered an infarct (De Villiers, Baldri Ferreira & Bryer, 2011).

### **2.2.2 Intracerebral Haemorrhage**

An intracerebral haemorrhage occurs on the rupture of a blood vessel within the brain parenchyma (primary intracerebral haemorrhage). This blood entry into the parenchyma causes the immediate cessation of the function in that area, as neurons are structurally disrupted and white matter fibre tracts are split apart. Cerebral oedema forms around the resulting blood clot which, with the haematoma, acts like a mass lesion (Allen & Lueck, 2002). Haematomas usually occurs in the deeper parts of the brain and may rupture into the ventricular system (Downie, 1992). The haemorrhage usually presents as the abrupt onset of focal neurological deficit. This deficit steadily worsens over 30-90 minutes and is associated with diminishing levels of consciousness and symptoms of raised ICP (intracranial pressure), such as headaches and vomiting (Smith, English & Johnston, 2008; Downie, 1992).



### **2.2.3 Subarachnoid Haemorrhage**

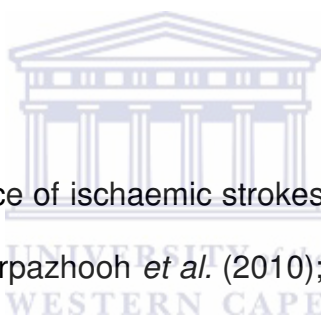
Strokes can also be caused by a subarachnoid haemorrhage. Bleeding into the subarachnoid space is usually from a berry aneurysm (Downie, 1992). A berry aneurysm is the bulging of the branches of the cerebral arteries, particularly in the region of the Circle of Willis. These develop over the patient's life from defects in the arterial wall (Allen & Lueck, 2002). Downie and Allen concur that this type of haemorrhages presents with sudden intense headache, often accompanied by neck stiffness, vomiting and loss of consciousness.

### 2.3 INCIDENCE AND PREVALENCE OF STROKE

Terent, 2003, describes the incidence of a disease as the number of new cases presented over a given period. According to the American Heart Association, approximately 795 000 Americans annually experience a new or recurrent stroke. Of the aforementioned total, approximately 600 000 are first-ever stroke cases, and about 185 000 are recurrent cases (American Heart Association, 2009). The European Registers of Stroke (EROS) Investigators (2009) studied the incidence of strokes in Europe at the beginning of the 21<sup>st</sup> century. EROS established that the annual stroke incidence rates per 100 000 of the European population were 141,3 for men and 94,6 for women in all centres. The total incidence rates for men and women increased with age in all centres. A population based study conducted in Iran in the Middle East by Azarpazhooh *et al.* (2010), established that the stroke incidence rate increased significantly with each decade of life. The incidence rate was also higher among men, at 144 per 100 000 persons, than among women, at 133 per 100 000 persons. In another population based study by Vaartje *et al.* (2008), the overall incidence rate in the Netherlands was also higher among men, at 182 per 100 000 persons, than among women, at 116 per 100 000 persons.

An analysis was done of the medical records of two groups of patients admitted for stroke from January 1994 to December 1996 (Group A) and January 2003 to December 2005 (Group B) in a South Korean Emergency Medical Center. In Group A, 1 124 of 54 534 cases were confirmed with stroke, while in Group B, 1 705 of 55 381 cases. In Group A, haemorrhagic stroke incidence was highest at 67,9% compared to 32,1% of patient who had suffered an ischaemic stroke. In Group B, a

reversal in the ratio was noted, in that ischaemic stroke incidence was higher (59,6%), compared to haemorrhagic stroke incidence (40,3%) (Park, Kang & Huh, 2008). A study undertaken by Park, Kang and Huh (2008), confirm a changing trend in stroke types. A study that looked at the risk factors of first ever stroke of 2 395 subjects found that 73,4% suffered ischaemic stroke, 25,1% had intracranial haemorrhage and 1,5% were of unknown etiology (Silvestrelli *et al.*, 2006). In Cape Town, South Africa, data from a hospital stroke register, on 1 000 patients with first-ever stroke, covering the period 2006 and 2008, showed that ischaemic strokes were prevalent in 81% of stroke patients, compared to the 11% of incidence of haemorrhagic strokes, while 8% of strokes that were unknown etiology (Bryer, Tipping & De Villiers, 2006).



In various studies, the incidence of ischaemic strokes was found to be the highest of all the subtypes of stroke (Azarpazhooh *et al.* (2010); D'Alessandro, Gallo, Vitalinao, Del Col, Gorvaz, Crisofaro & Boaretto (2010); Silvestrelli *et al.* (2006). The crude annual incidence rate of ischaemic strokes in Azarpazhooh's study was 113 per 100 000 persons, compared to an incidence of 18 per 100 000 persons for intracerebral haemorrhage and an incidence of 3 per 100 000 persons for subarachnoid haemorrhage (Azarpazhooh *et al.*, 2010). Sub-Saharan Africa (SSA) lacks community based incidence stroke studies, which means that the incidence of stroke in SSA remains relatively unknown (Feigin, Lawes, Bennet & Anderson, 2003).

The American Heart Association defines prevalence as an estimate of the total number of cases of a disease existing in a population during a specified period.

Among American adults 20 years and older, the 2005 prevalence of stroke was 650 000. Of this total, about 2 60 000 occur in males and 3 90 000 in females (American Heart Association, 2009). An Italian study established the overall crude prevalence rate as 147 per 100 000 subjects aged 15 years and older, and 476 per 100 000 subjects aged 65 years and older (D'Alessandro *et al.*, 2010). In an African study, 103 cases of stroke were identified among 402 participants, which constituted a crude prevalence rate of 300 per 100 000 persons aged 15 years and older (Thorogood, Connor, Hundt & Tollman, 2007). In a systematic review of studies conducted in Sub-Saharan Africa (SSA), Connor *et al.*, found that the prevalence of stroke in SSA was less than half of that found in New Zealand. The researchers also found that that disabling stroke rate may be at least as high as the rate in New Zealand (Connor *et al.*, 2007). SSA may have a lower prevalence than New Zealand, because of a lower incidence of stroke, but a higher fatality rate because of the different methodologies that were used in the different reviews (Connor *et al.*, 2007).



## 2.4 RISK FACTORS FOR STROKE

Bradberry and Fagan (2002) classify the risk factors for stroke into non-modifiable and potentially modifiable risk factors.

### 2.4.1 Non-Modifiable Risk Factors

Age, gender, race, ethnicity and a Transient Ischaemic Attack (TIA) are regarded as non-modifiable risk factors for stroke (Barker, 2008).

Age is the most powerful predictor of stroke. A study by Hasan, Hasan and Mukhelif (2008) established an exponential increase in stroke percentage with increase of age in individuals below 80 years. This finding is in agreement with the stroke incidence and prevalence rates established in an European study, which showed that stroke incidence increased exponentially with an increase in age (Truelsen, Prechowski-Jozwiak, Bonita, Marthers, Bogousslavsky & Boysen 2006).

Several studies confirmed a higher incidence of stroke among males than among females (Hasan *et al.*, 2008; Truelsen *et al.*, 2006; Leoo, Lindgren, Petersson & Von Arbin, 2008; Ostwald, Wasserman & Davis, 2006). The American Heart Association's 2006 statistics on stroke prevalence confirmed that Black males and females were more prone to develop stroke than their White, Mexican American and Hispanic counterparts (American Heart Association, 2009).

#### 2.4.2 Modifiable Risk Factors

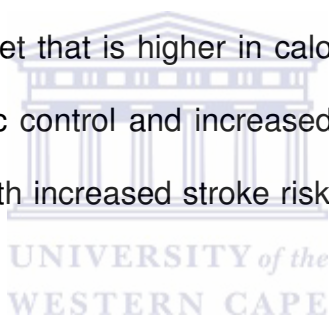
Potentially modifiable risk factors include hypertension, cardiac disease, diabetes, cigarette smoking, alcohol abuse, elevated blood lipid levels (hyperlipidemia) and physical inactivity (Barker, 2008). Of the single risk factors identified, hypertension is a major contributory factor in almost 70% of all strokes. Hypertension contributes to atherosclerosis and lipohyalinosis, associated with small vessel disease or cardiac dysfunction (Flemming & Brown, 2004). The relationship between blood pressure and risk of stroke is continuous, consistent and independent of other risk factors (Flemming & Brown, 2004). Several studies have identified hypertension as the most common modifiable risk factor for stroke (Scott, Greenfield, Bramah, Alford, Bennett, Markus & Campbell, 2010; Saxena, Ng, Yong, Fong, Gerald, 2006; D'Alessandro *et al.*, 2010). A study done in South Africa established a high prevalence of hypertension and postulated that South Africa could be facing an epidemic of vascular disease (Thorogood *et al.*, 2007). However, as stated by Thorogood *et al.* (2007), compliance with antihypertensive treatment in Africa is a major problem. Approximately 75,8% of patients with hypertension were not taking any treatment, despite the fact that treatment and drugs at South African community clinics are free. Factors associated with not taking medication ranged from difficulty with transport to the clinics and difficulty with drug supplies and problems with equipment at the local clinics (Thorogood *et al.*, 2007; Hale, Eales, Stewart & Fritz, 1999). A study by Steyn, Levitt, Patel, Fourie, Gweushe, Lombard & Everett (2008), showed that patients possessed little knowledge about their chronic condition. For instance, this study showed that 63% of patients with hypertension knew that it could cause a stroke, but that their knowledge about the consequences of untreated hypertension

was poor (Steyn *et al.*, 2008). Poor compliance with prescribed medicine could predispose stroke patients to another stroke, which could result in either more disability or death.

Diabetes has been associated with multiple lacunar infarcts. Patients with diabetes have both an increased likelihood of atherosclerosis and a higher prevalence of hypertension, hyperlipidemia and obesity (Flemming & Brown, 2004). The American Diabetes Association (ADA) recommends that all patients with diabetes and hypertension be treated with a regimen consisting of either angiotensin-converting enzyme (ACE) inhibitors or an angiotensin receptor blocker (ARB) (Ackerman, Cheng, Williamson & Gregg, 2011). A South African study that estimated the burden of disease attributable to diabetes, found that the prevalence of diabetes increased with age among both males and females (Bradshaw, Pieterse, Norman & Levitt, 2007). It also established that the Indian population had the highest prevalence rate of diabetes of all population groups and that the prevalence of diabetes was consistently higher among women in all population groups, except for the Indian group (Bradshaw *et al.*, 2007).

Diabetic patients, compared to non-diabetic patients, are at greater risk of a stroke. Poor and worsening glycemic control in diabetic patients are directly related to stroke and the risk of stroke is 150% to 400% higher among those diabetic patients (Beckman, Creager & Libby, 2002). Type 2 diabetes mellitus is associated with a cluster of lipid abnormalities, which have been associated with an increased risk of cardiovascular disease (Kengne, Anoaah & Mbanya, 2005). In diabetes there is an increased tendency toward coagulation, coupled with impaired fibrinolysis, which

favours the formation and persistence of thrombi, thus increasing the risk that diabetic patients may develop a stroke (Beckman *et al.*, 2002). Diabetes related risk factors are considered rare in Africa, but are on the rise and are regularly associated with cardiovascular risk factors. Almost 15% of patients who suffered a stroke, have diabetes (Kenge *et al.*, 2005). A 2009 review done by BeLue, Okonor, Iwelunmor, Taylor, Degboe, Agyemang & Ogebegale (2009), which consisted of scholarly papers published between 1960 and May 2009, established that there were 10,4 million people with diabetes in SSA, which is estimated will increase to 18,7 million people by 2025 (BeLue *et al.*, 2009). The rise in the increased prevalence of diabetes in Africa is partly due to the adoption of the Western lifestyle (Kenge *et al.*, 2005). The Western lifestyle includes a diet that is higher in calories and fat, but lower in fibre, leading to decreased glycemic control and increased tendency toward coagulation, which has been associated with increased stroke risk (Kenge *et al.*, 2005; Beckman *et al.*, 2002).



Cigarette smoking is a major risk factor for stroke; it may double the risk of stroke due to the stenosis that it causes on blood vessels (Barker, 2008). People who smoke, are up to three times more likely to have a stroke than those who do not (Stroke Association, 2011a). Nicotine is a vasoconstrictor and the products of tobacco combustion are absorbed into the systemic circulation (Barker, 2008). Tobacco smoke contains toxic chemicals that damage the blood vessels and lead to the narrowing of the arteries (Stroke Association, 2011a). The aforementioned damage further increases the chance of blood clot formation, which ultimately increases the risk of stroke (Stroke Association, 2011a). A follow-up study by Bak, Sindrup, Alsler, Kristensen, Christensen & Gaist (2002) on the topic of smoking

cessation after first-ever strokes established that 21,7% of the patients who were smokers on hospital admission had given up smoking within six months of their stroke. Of the patients that continued smoking, 18,2% of the moderate smokers and 21,2% of the heavy smokers had reduced their cigarette consumption by more than or equal to 50%. Kelly, Pangilinan and Rodriguez (2007) have found that the risk of cerebral infarction in those who stop smoking declines gradually over a five-year-period, and that an increased risk is no longer present in former smokers five years after quitting.

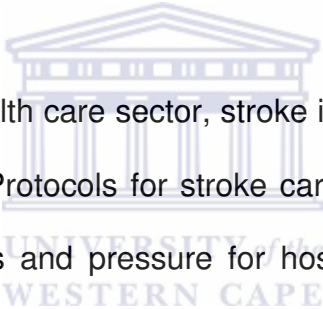
Alcohol consumption can either increase or decrease the risk of a stroke. Excessive drinking has been linked to hypertension and other conditions, in addition to atrophy of the brain over time (Barker, 2008). Light to moderate consumption ( $\leq 2$  drinks per day for men and  $\leq 1$  drink per day for women) has been associated with a reduced stroke risk. Heavier alcohol consumption ( $> 60$  ml per day) increases the risk of both ischaemic and haemorrhagic strokes (Reynolds, Lewis, Nolen, Kinney, Sathya & He, 2003). Shiton and Beevers (1989), have established that excessive alcohol consumption with cigarette smoking is a related risk factor for stroke. A study by Mostofsky, Burger, Schloug, Mukamal, Rosamund & Mittleman (2010) established that within one hour of alcohol consumption, the risk of stroke onset grew 2,3 fold higher than in periods of non-use. In the study, alcohol consumption was associated with a transient increased risk of ischaemic strokes. The researchers further found that heavy consumption may acutely lead to dehydration, which further increases the risk of ischaemic strokes (Mostofsky *et al.*, 2010).

Several authors concur that it is vitally important to address these modifiable risk factors, post stroke, in order to prevent a recurrence (Smith, English & Johnston, 2008; Gillen & Burkhardt, 2004; Allen & Lueck, 2002). BeLue *et al.* (2009), recommend that government, on both national and local levels, increase awareness of stroke risk factors. Bradshaw *et al.* (2007) state that sufficient policies for the management and prevention of diabetes and other chronic diseases have been developed at national level, but that their implementation by the provinces and local authorities remain problematic (Bradshaw *et al.*, 2007).

## 2.5 MEDICAL MANAGEMENT OF STROKE

Once the diagnosis of stroke is made an orderly process of evaluation and treatment follows. The patient's airway is checked to ensure breathing and circulation, and hypoglycaemia or hyperglycemia, if present, is treated. The first goal of treatment is to prevent or reverse brain injury. In ischaemic strokes, the aim is to increase cerebral perfusion in the surrounding ischaemic penumbra. Intravenous recombinant tissue plasminogen activator (rt-PA), given within the first three (3) hours following the onset of an ischaemic stroke improves the clinical outcome (Smith, English & Johnston, 2008; Kasner & Gorelick, 2004; Allen & Lueck, 2002). Ischaemic strokes from large vessels such as the middle cerebral arteries (MCA), the internal carotid arteries and the basilar arteries, often fail to open with intravenous rt-PA alone. The endovascular mechanical thrombectomy device has been used to restore the patency of occluded intracranial vessels within eight (8) hours of the onset of an ischaemic stroke. According to Bryer (2009), rt-PA is an accepted therapy for acute ischaemic strokes within certain time limits, but it is not yet widely available in the South African

public sector. Reasons for this include logistics, lack of scanning equipment, lack of protocols, and lack of laboratory facilities (Bryer, 2009). Ghandehari (2011) states that prehospital barriers to thrombolysis include the non-recognition of stroke symptoms and delayed hospital admission. Financial constraints, due to the high cost of rt-PA, is one of the main reasons for its low utilisation (Ghandehari, 2011). For example, thrombolysis is not available for the acute management of stroke in developing countries and there is also a lack in secondary prevention strategies due to insufficient access to pharmacological treatment and poor compliance of patients (Damasceno, Gomes, Azevedo, Camilho, Lobo, Lopes, Madebe, Pravinrai, Silva-Matos, Jalla, Stewart & Lunet, 2010).



In the South African public health care sector, stroke is usually managed as part of a generalised medical service. Protocols for stroke care have not been developed at most hospitals, and shortages and pressure for hospital beds frequently result in stroke patients being discharged too early (Bryer, Connor, Haun, Cheyip, Staub, Tipping, Duim, Pinkey-Atkinson, 2011).

## **2.6 PROGNOSIS AND MORTALITY OF STROKES**

According to Allen and Lueck (2002), 75% of patients with strokes due to cerebral infarction or primary intracerebral haemorrhage survive. Kelly (2008) found that patients with cerebral infarction had better functional abilities on admission to hospital, but that those who had haemorrhagic stroke had better long-term recovery. The mortality rate following an aneurysmal subarachnoid haemorrhage is 30%, with a recurrence rate of 50% in the first six months and 3% annually, thereafter.

According to the American Heart Association, a stroke is the third most common cause of death in the United States. In 2005, the final death rate due to strokes was 46, 6 persons per 100 000. Bryer *et al.* (2010) established in the South African National Burden of Disease study that stroke was the third leading cause of death after HIV/AIDS and Ischaemic Heart Disease in South Africa in 2010. It also stated that Black women had the highest stroke mortality rate (160 per 100 000), while mortality was lowest among White males (72 per 100 000). Deaths in the Coloured and Black population groups were double those in the White population (Bryer, Connor, Haug, Cheyip, Staub, Tipping, Duim and Pinkey-Atkinson, 2010).

## 2.7 STROKE DISABILITY



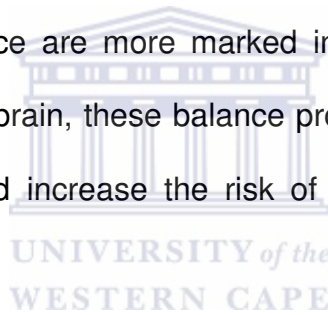
Disability post stroke can be conceptualised within the framework of the International Classification of Functioning Disability and Health (ICF) (World Health Organisation, 2001). Within the ICF disability and functioning are outcomes between health conditions and contextual factors. The bio-psychosocial model found within the ICF diversifies the view of disability. It therefore makes provision for medical, individual, social and environmental influences of functioning and disability to be explored (Kostanjsek, 2011).

Clinical features that stroke patients present with result from impairments in the body functions and structures. According to Barker-Collo and Feigin (2006) and Lawrence, Coshall, Dundas, Steward, Rudd & Howard (2001), these impairments include impaired motor function, sensory deficits, abnormal muscle tone, cognitive



limitations, emotional deficits, speech deficits, visuo-perceptual limitations, urinary incontinence and dysphagia. Post-stroke patients will therefore experience physical and/or psychological problems.

Lawrence *et al.* (2001) established in a population based study in London that motor impairments post stroke affects the upper limb more than the lower limbs. Residual motor impairments, including loss of strength and dexterity, reduced mobility, poor balance and muscle weakness are consequences of stroke that affect 50% and 70% of stroke survivors (Stewart, Cauraugh & Summers, 2006). Balance refers to the coordination and stability of the body in its surroundings (The Stroke Association, 2011b). Problems with balance are more marked in people who have suffered a stroke in the right side of the brain, these balance problems often reduce the stroke patient's confidence level and increase the risk of falls (The Stroke Association, 2011b).



Physical impairment include difficulties in walking long distances, fatigue, pain, motor impairments related to hemiparesis and respiratory problems (Hamel, 2006). Robinson, Wiles, McPherson, Hyndman & Ashburn (2009), found that fatigue was an important factor affecting participation, in that the participants in the study lacked the energy to undertake certain activities. The participants often commented that everything took longer to complete due to their stroke and that they tended to tire easily (Robinson *et al.*, 2009). Impairments in body functions have an impact on community participation. Barker *et al.* (2006), found that altered bodily functions, such as urinary incontinence, decreased endurance or stamina, and loss of function in the arm and/or leg, led to problems with mobility. Urinary problems and physical

discomfort were personal barriers that were real issues for elderly stroke survivors (Barker *et al.*, 2006).

Hemiplegia, which is paralysis (i.e. loss of voluntary movement) of an upper limb, the trunk and lower limb on one side of the body (Tortora & Grabowski, 2000), is the most common result of stroke. During ischaemic strokes the hemiplegia is initially flaccid, but gives way to the spastic type. Motor and sensory deficits and dysfunction of the cerebellum or vestibular system can produce disturbances in balance and coordination, which further impact on the mobility problems experienced as a result of the hemiplegia (Greshan *et al.*, 2004). Clients with hemiplegia have movement problems (impairments), which lead to functional limitations and disability. These movement problems manifest themselves as loss of movement in the trunk and extremities, atypical patterns of movement, compensatory strategies and involuntary nonpurposeful movement on the affected side. These impairments interfere with normal functional movement and lead to loss of independence in daily life (Daray, 2007).

Following a stroke, patients may have trouble with mental processes (cognition) (The Stroke Association, 2010). Lawrence (2001) found in a prospective study that consisted of 1 259 participants and was conducted in the United Kingdom that cognitive impairment was present in 43,9% of the participants. In a study by Saxena *et al.* (2006), stroke patients were consecutively admitted to two rehabilitation hospitals in Singapore during April 2002 and September 2002. It was found in this study that 54% of these patients suffered from cognitive impairment. Compared to the aforementioned study by Lawrence *et al.* (2001), the sample size of the study by

Saxena *et al.* (2006) was only 200; hence the higher false prevalence of cognitive impairment. The common cognitive deficit after stroke include loss or deficiency in memory, attention, learning, calculation, visual perception or executive functions, which include decision-making, problem-solving and social cognition (Gottesman & Hillis, 2010; The Stroke Association, 2010). Gottesman and Hillis (2010) found that demographic and medical factors influenced the extent to which cognitive deficits after stroke is present. They further found that older age was an important predictor of cognitive impairment and that women had higher frequencies of cognitive dysfunctions, due to the higher incidence of cardioembolic strokes in females (Gottesman & Hillis, 2010). In a study by Pirsoveanu, Zaharia, Tudorica, Mateau, Ene & Ciobanu (2008), depression was diagnosed in 49% of patients who had suffered a first-ever stroke six months following the stroke onset and in 54% of patients at 12 months. This study also established that patients with post stroke depression had more cognitive impairment (Pirsoveanu *et al.*, 2008).

Unilateral neglect is the lack of a patient's awareness of a specific part of his/her body and occurs mostly following right hemisphere strokes. The sensory stimuli in these patients are ignored or evoke a mute response (Greshan *et al.*, 2004).

Aphasia can be severe in left hemisphere lesions and there may be neglect of the contralateral side. In right hemisphere lesions, visio-spatial disturbances can occur (Downie, 1992).

Less common impairments that occur following a stroke include the following: emotional lability, anxiety, oropharyngeal dysphagia, and bladder and bowel incontinence (National Clinical Guidelines for stroke, 2004).

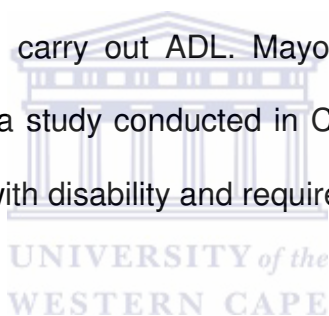
Pain, such as severe headaches, cervical or facial pain, could result from either ischaemic or haemorrhagic strokes. It could also be caused by complications post stroke, e.g. adhesive capsulitis, a rotator cuff tear in the shoulder, or sympathetic dystrophy. Neurogenic pain is a serious problem that usually starts weeks or months after stroke onset (Greshan *et al.*, 2004). Post stroke patients, therefore experience various impairments which manifests either on its own or in combination with each other.

### **2.7.1 Activity Limitations Post Stroke**



According to the World Health Organisation (2001), activity limitations are those difficulties that individuals may experience in performing the activities of daily living (ADLs). According to the ICF classification, activity is described as an individual's execution of a task, whereas participation is an individual's involvement in a life situation. Described within the ICF framework ADLs refer to mobility, self-care and domestic life. Domestic life activities include buying goods, utilising services, preparing meals and performing basic household tasks, like cleaning. Care activities include bathing, toileting, dressing, eating, drinking and looking after one's health (World Health Organisation, 2001). Mobility activities refer to lifting and carrying objects, using transportation and driving, and walking and moving around using equipment (World Health Organisation, 2001). More than 80% of patients with mild

stroke can achieve maximum improvement in ADL function within three weeks (Jorgensen, Nakayama, Raaschou, Vive-Larsen, Stoeir & Olsen, 1995). However, some stroke survivors experience limitations in physical functioning, instrumental ADL and participation (Jorgensen *et al.*, 1995). Stroke patients living with other adults demonstrate a lower degree of functioning in ADL, but better community participation, because their adult carers are able to assist them with transfers and moving from one facility to another (Schmidt, Herman, Koenig, Leuze, Monahan & Stubbers, 1986). According to Connor *et al.*, 2004, about 66% of patients post stroke who have returned to their communities need help with at least one ADL. Therefore, the stroke patients' ability to participate in community activities is compromised by their dependency on other to carry out ADL. Mayo, Wood-Dauphinee, Durcan & Carlton (2002) established in a study conducted in Canada that 50% of community dwelling stroke patients lived with disability and required help with ADL.



Many individuals who suffered a stroke are left with impairments and disabilities. No matter how intense their rehabilitation may be, some impairments will remain and may increase over time as the person's age (Rochette *et al.*, 2001). Hendricks *et al.* (2002), in a systematic review of 14 studies that investigated motor recovery after stroke, established that 20 to 25 percent of all survivors were left unable to walk without full physical assistance. In a study by Pound, Gompertz and Ebrahim (1998), it appeared from the interviews that because walking in itself is something so basic and fundamental, being able to do it satisfactorily was highly valued by stroke survivors. Difficulty in walking is a common problem in neurological diseases, such as strokes, and walking is the activity of daily living on which patients place the most value (Pearson, Busse, van Deursen & Wiles, 2004). The long-term deterioration of

walking ability in stroke patients is regarded as a major problem, as it results in a loss of ADL independency and increasing social isolation (Van de Port, Kwakkel, Van Wijk & Lindeman, 2006).

The loss of mobility is the most frequently mentioned by stroke survivors. Often, they require the use of mobility devices, such as canes, walkers or wheelchairs (Mumman, 2000). Hammel *et al.* (2006) state that individual barriers post stroke resort under four main areas, namely physical, social, cognitive and psychological. Physical and cognitive problems are the most frequently identified and the most important reason for not participating (Hamel *et al.*, 2006). Subjects in the study undertaken by these authors frequently reported cases of distraction or inattention, which caused them to become disorientated or getting lost, which was heightened in crowded areas with high noise levels, or in places with significant multisensory stimulation (Hamel *et al.*, 2006). The highest level of disruption experienced by stroke survivors relates to accomplishment of daily tasks or social roles (Rochelte *et al.*, 2001). Activity limitations lead to dependency issues in stroke survivors. They therefore require care or services from others. Mobility impairment and decreased endurance, stamina and balance lead to the need for a wheelchair. This inability device acts as a facilitator for community participation and community integration (Barker *et al.*, 2006).

### **2.7.2 Participation Restrictions Post Stroke**

Following a stroke, the attainment of independent community ambulation is a challenging rehabilitation goal (Lord, McPhearson, McNaughton, Rochester &

Weatherall). Inadequate ambulatory ability in stroke patients directly affects their ability to participate in the community (Taylor, Stretton, Mudge & Garret, 2006). Strokes have been shown to cause social problems. Daniel, Wolfe, Busch & McKeivitt (2009) state that social problems may include social isolation, decreased community involvement, disruption of family functioning, poor motivation, dependency, and loss of control. Feelings of increasing social isolation, social withdrawal and/or altered relationships with both families and friends were confirmed to be by participants experienced in various studies in a systematic review conducted by Salter, Jutai, Teasall, Foley & Bitensky (2008). This review involved nine qualitative studies and aimed to explore the experience of living with stroke. Some of the factors that contribute towards the isolation are physical disability and incontinence. The fear of having an accident in public with reference to incontinence will result in a stroke survivor staying indoors instead of socialising with others (Salter *et al.*, 2008). The deterioration inability to engage in social activities among stroke survivors ranges from 15% to 79% (Daniel *et al.*, 2009).

A study of barriers to and supports for community living and the participation of stroke survivors, in America, established that stroke patients found it difficult to ask for help from others. When asking for help from others, many of the participants were being given responses that were either not helpful, or were dismissive or disrespectful towards them; sometimes their requests were ignored completely (Hamel *et al.*, 2006). Using public transportation is a problem among stroke patients. In a survey of transport usage by stroke patients in the community one year post stroke, 50% of participants responded that they required assistance to travel, while

52% reported that they did not go out into the community as often as they desired (Logan, Gladman & Radford, 2001).

A patient-centered study by Pound, Gompertz and Ebrahim (1998) established that inaccessible buses were a key reason why patients were not getting out of their homes. It was stated that buses did not get up close enough to the kerb to facilitate boarding. Previous frightening experiences, including falls, also served as a deterrent (Pound, 1998). In a South African based study, participants reported that they had problems accessing public transport, for example, stopping taxis (Kahonde, Mlena & Rhoda, 2010). The public transport problems experienced by the participants in this study led them to hire transport from their neighbours, which was a financial strain on them (Kahonde *et al.*, 2010).

In a study by O'Donovan *et al.* (2009), a high proportion of participants of all disability types experienced restrictions in socialising (39,9%) and leisure (31,6%). The majority of patients stated that they were bothered to some extent by the restrictions they experienced, while 68,5% stated that they had been emotionally affected by their disability.

### **2.7.3 Environmental Barriers and Facilitators**

#### **2.7.3.1 Physical Barriers**

Environmental barriers are those that make participation in the community difficult. It is important to consider barriers in the environment, as they restrict social



participation. As mentioned by Hare, Rogers, Lester, McManus and Mant (2006), the literature on the environmental barriers experienced by stroke patients is limited. A qualitative study by Rimmer, Rubin and Braddock (2002), which looked at the facilitators and barriers to participation in fitness programmes for people with disabilities, established that they perceived their natural environment as inherently inaccessible, thus hindering participation.

Traditionally, most environmental interventions focus exclusively on architectural barriers in the individual's home, but many other physical and social factors could determine how a person carries out his/her daily activities (Rochette *et al.*, 2001). The O'Donovan study established that the physical environment was the most common barrier to participation for people with physical disabilities (46,6%) (O'Donovan, Doyle & Gallagher, 2009). In a study by Rimmer, Riley, Wang, Rauworth and Jurkowski, (2004), participants stated that the lack of kerb cuts and too narrow doorways were features that made the environment inaccessible to them (Rimmer *et al.*, 2004). Barker *et al.* (2006) found that physical environmental barriers included heavy doors, narrow store aisles, crowded places, stairs, uneven sidewalks, rough ground, such as potholes and grass, inaccessible washrooms, foul weather and negative societal response. Many stroke participants could walk around with a quadropod in their homes, but needed a wheelchair for assistance in activities in the community, for fear of falls due to uneven surfaces or to cope in crowded or hurried situations (Barker *et al.*, 2006).

A study by Robinson *et al.* (2009) found that participants felt less able to control their bodies in an unfamiliar environment and sought to manage this through avoidance,

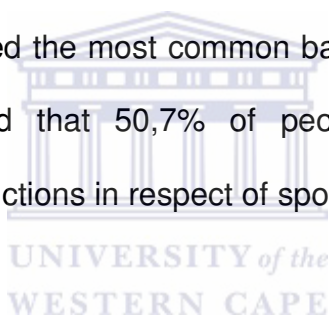
environmental change or additional support from another person. Walking outdoors was seen as an unfamiliar environment, which created a fear of falling and therefore acted as a barrier to these participants (Robinson *et al.*, 2009).

The wheelchair is seen as a facilitator for stroke survivors. However, in certain instances the environmental barriers are such that contributing to a loss of some valued activities. In retrospect, manual wheelchairs become contextual barriers due to the huge effort required for the propulsion of such chairs. This makes their users more dependent on caregivers (Barker *et al.*, 2006). Environmental facilitators mentioned by the participants were elevators, automatic door openers, parking spaces for the disabled, wheelchair accessible washrooms, ramps and the availability of caregivers for outings. Power wheelchairs were also seen as facilitators since they enabled the participants to go up slopes, something that is impossible to do with manual wheelchairs (Barker *et al.*, 2006).

Lock, Jordan, Bryan and Maxim (2005) studied barriers and facilitators regarding work after stroke. All participants in that study perceived that barriers to employment emanated mainly from within the rehabilitation system; with many stating that the negative attitudes of medical staff and other healthcare professionals had hindered their rehabilitation and well-being. Employers' negative attitude and failure to implement adaptations to the stroke survivor's work role, hours of work and adapted equipment, as well as lack of support from colleagues or managers, were also perceived as barriers by participants, who found their return to work difficult (Lock *et al.*, 2005; Alaszweski, Alaszewski, Potter Penhale, 2007). In a qualitative study by Alaszweski *et al.* (2007), participants who had had previous experience of long-term

disability had adjusted to living without the benefits of working; having a stroke created an additional barrier, which confirmed their non-working status. For some participants, the potential loss of income was an important motivator for returning to work. The perception of some participants that stress was a causative factor for stroke and that work caused stress, acted as a barrier to their returning to work. In retrospect, some of the participants treated the stress they experienced as a warning to avoid worse stress: work (Alaszweski *et al.*, 2007).

A study conducted by O'Donovan *et al.* (2009) established that in a population of 7 562 people, physical disability was the main type of disability recorded, and that the physical environment posed the most common barrier to participation for people with physical disabilities and that 50,7% of people with physical disabilities experienced participation restrictions in respect of sport or physical recreation.



### **2.7.3.2 Social environmental barriers**

Social environmental barriers include obstacles in elements such as social support from family members and the utilisation of health and social services (Vincent, Deadelin, Robichaud, Rousseau, Viscogliosi, Talbot and other members of the BRAD group, 2007).

According to Chau, Woo and Chang (2007), social support for stroke patients, whether emotional, informational, instrumental or appraisal, has a positive influence on their functional and psychosocial recovery. Poor social support is believed to be influenced by the functional and cognitive state of the individual stroke survivor

(Mackenzie & Chang, 2002). Participants in a study by Wood, Connelly and Maly (2010), felt that their independence was compromised when they required help from others, not that learning to accept help had enabled them to engage in activities and participate socially (Wood *et al.*, 2010). Participants with smaller social networks often felt like a burden to others, had low motivation and fewer opportunities to engage in meaningful activities (Wood *et al.*, 2010).

### **2.7.3.3 Attitudes of others as environmental barrier or facilitator**

Many stroke patients felt that the negative attitudes of medical staff and other health care professionals with whom they came into contact, had affected their rehabilitation and wellbeing negatively (Lock *et al.*, 2005). Participants in a study by Hamel *et al.* (2006) had experienced dismissive or distressful treatment from certain members of the community when they asked for help. Some participants stated that at times their requests had been completely ignored (Hamel *et al.*, 2006). In contrast to this, Alguren, Lundgren-Nilsson & Sunnerhagen (2009), found that the participants in their study described family members, friends and health care professionals' attitudes to them as supportive and facilitatory. In a South African-based study, the participants experienced the attitudes of service providers as respectful; communication was good and the service providers supported them emotionally (Kahonde, *et al.*, 2010).

## 2.8 STROKE REHABILITATION

### 2.8.1 Introduction

Despite optimal medical management, a large number of stroke survivors have less than full recovery (Kasner & Gorelick, 2004). An estimated one in ten patients recover almost completely from stroke. Nearly half may be left with moderate to severe impairments, which may require special care (Barker, 2008).

In this study, rehabilitation refers to the strategy used by health care professionals to address the impairments, activity limitations, participation restrictions and changes in quality of life of stroke patients (Barker, 2008). Stroke rehabilitation is undertaken by a multidisciplinary team consisting of physicians, psychiatrists, neurologists, internists, urologists, nurses, physiotherapists, occupational therapists, speech therapists, social workers and psychologists (Balabon *et al.*, 2011). Kasner and Gorelick (2004) define stroke rehabilitation as care intended to maximise recovery from strokes. It is a dynamic process, with the focus on an active programme to help patients maximise their optimal functional level as they adapt to their disabilities. According to Kwakkel, Kollen and Lindeman (2004), the goal of the rehabilitation of stroke patients is to achieve a level of functional independence that will enable them to return home and to their community life as fully as possible. Rehabilitation can be part of the management of stroke survivors either when still in hospital or on an out-patients' basis. The emotional and physical challenges that are faced by patients following a stroke are essential determinants of their successful rehabilitation after discharge from the acute setting (Aprille *et al.*, 2008; Dorsey & Vaca, 1998).

Rehabilitation should include education of patients and family members about the patients' neurological deficits and preventing post-stroke complications (Fauci, 2008).

Rehabilitation in an institutions is a time-limited process aimed at helping stroke patients reach an optimum level of functioning before discharge. It is important that a patient-centred approach is followed in rehabilitation. In a patient-centered approach, the therapists facilitate patients' problem-solving and goal achievement abilities to achieve a maximum level of functioning (Barker, 2008; Gillen & Burkhardt, 2004). In a patient-centered approach, practitioners are required to analyse patients in the contexts of their lives (Gillen & Burkhardt, 2004). Practitioners must help patients develop the skills to handle the immediate issues influencing their health, but must also teach them strategies that are linked to community resources that will promote, protect and improve their health over the long term (Gillen & Burkhardt, 2004).

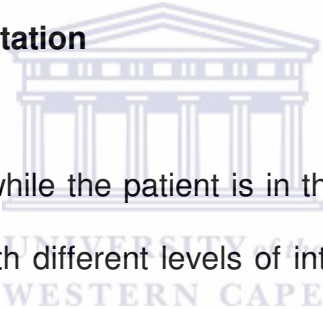
Before, during and after the implementation of a rehabilitation programme, the most important criterion is quality of life (QOL). QOL measurements are useful in identifying patients' problems, determining treatment priorities and interventions (Wennberg, 1990, as cited in Ones, Yilmaz, Cetinkaya & Calgar, 2005). This same study established that the QOL of stroke patients showed a significant higher level of disruption. This increased disruption existed in all parameters (pain, physical activity, sleep, fatigue, socialisation and emotional patterns). Therefore, the overall longterm goal of rehabilitation is to improve patients' quality of life and to help the individual reach his or her fullest physical, psychological, social, vocational and educational

potential within the limits of his or her physiological and anatomical impairment (Barker, 2008).

## **2.8.2 Rehabilitation Settings**

Rehabilitation can be conducted in different settings, including treatment as in-patients in hospitals, treatment at rehabilitation units in acute care hospitals, nursing facilities that offer structured rehabilitation programmes, out-patients' facilities, or the patient's home (Greshan, *et al.*, 2004).

### **2.8.2.1 In-hospital Rehabilitation**



Rehabilitation usually begins while the patient is in the acute care setting, usually a hospital, and may continue with different levels of intensity throughout the patient's life (Barker, 2008). McNaughton *et al.* (2005) state that proper management during the acute period following stroke, will result in less disability and a less negative impact on the healthcare sector and society. During the acute stage, rehabilitation focuses on swallowing evaluation, reducing the likelihood of aspiration pneumonia, as well as mobilising the patient out of bed and ambulation in order to prevent deconditioning. Crimmins, Levi, Gerraty, Beer & Hill (2009) state that early supported discharge services decrease in-patient length of stay, while increasing patients' level of satisfaction.

Deconditioning is the consequence of prolonged immobility and bed rest and is related to impairments from stroke. The effects of immobility include increased

resting heart rate, elevated pulse during submaximal exercise, and a reduction in cardiac size. Therefore, the best approach is to eliminate deconditioning altogether by incorporating preventative measures in the acute care stage of stroke rehabilitation (Kasner & Gorelick, 2004).

Findings from a prospective study by Hopman and Verner (2002) have revealed that inpatient rehabilitation improves the health related quality of life of stroke patients. The study further showed that in-patient gains may be followed by a significant decline after discharge. A study of determinants of length of hospital stay and institutional discharges, conducted in Singapore, established that first time stroke was a significant factor associated with prolonged hospital stay (Saxena *et al.*, 2006). This study found that the mean length of hospital stay was 34 days and the median length was 32 days varying between 3 and 136 days. Dodel, Haacke, Zamzow, Pawelzik, Spottke, Rethfeldt, Siebert, Oertel, Schoffski & Back (2004) established that the total duration of in-hospital stay, in a stroke unit in Germany, ranged from 1 to 30 days, with a median of seven days. Another study reported the hospital stay of patients with stroke to be 30 – 34 days in South Africa, Australia and Finland (Green, Valvanne, Laubser, Gordon, Paunio, Marosszeky & Richards, 2005). The sample used in this study consisted of patients with stroke who were in the sub-acute to chronic stage and the South African sample consisted of patients from private hospitals.

A retrospective study that examined the impact of a stroke unit on length of hospital stay established that the hospital stay was longer in patients who were managed in general neurological/medical wards, compared to those managed in the stroke unit



(19 versus 15 days). They further established that stroke units were associated with decreased length of stay among patients who had ischaemic strokes, compared to those who had suffered haemorrhagic strokes (Zhu, Newcommon, Cooper, Green, Seal, Klein, Weir, Coutts, Watson, Barber, Demchuk and Hill, 2009). Saxena *et al.* (2006) and Zhu *et al.* (2009) concur that age and co-morbidities are not significant associates of a prolonged hospital stay.

The majority of stroke patients in South Africa are treated in the public sector, where there is currently a shortage and, at times, absence of in-patient beds for stroke patients, especially in rural and remote areas. These shortages are the reason why stroke patients are being discharged too early from hospital (Bryer, Connor, Haug, Cheyip, Staub, Tipping, Duim & Pinkey-Atkinson, 2011).

#### **2.8.2.2 Out-patient Rehabilitation**

Out-patient rehabilitation is provided by hospitals' out-patient departments or freestanding out-patient facilities. Rehabilitation sessions may range in intensity and duration and allow patients and carers access to an interdisciplinary programme (Greshan *et al.*, 2004).

Crimmins *et al.* (2009) state that the continuation of rehabilitation is of the utmost importance and that discharge planning relies on good communication from and between the multidisciplinary team members, the patient, carers and community service providers. In a stroke prevalence study conducted in Italy, it was found that 350% of the stroke survivors were severely disabled and required assistance with

one or more of their daily activities. A large proportion of the stroke patients in that study were being looked after by their relatives (Alessandro *et.al*, 2010). Relatives therefore have to ensure that patients attend out-patient rehabilitation sessions. In South Africa, Green *et al.* (2005), found that stroke patients discharged home lived mostly with family members or friends. Return to a residence after an acute hospitalisation for stroke can be difficult for both patients and carers. The continuation of services during this period is important. Olsson and Sunnerhagen (2006) studied patients who were referred as out-patients to a university hospital's Day Rehabilitation Department, in Sweden, for the continuation of their rehabilitation programme. The patients were treated by a multidisciplinary team consisting of a physician, occupational, speech and physiotherapists, a psychologist, a welfare officer and a registered nurse. The median numbers of sessions per patient during the rehabilitation period were as follows: for physiotherapy: 12 (range 1-23); for occupational therapy: 10 (range 2-18); and for psychological therapy: 7 (range 1-12). The study also found that during six- to eight weeks' sessions of day hospital rehabilitation for patients with first ever stroke, significant improvements in physical and cognitive functioning, self-rated health and health-related quality of life were found among the patients. The study concluded that recorded improvements in stroke outcome did not occur spontaneously, but could be attributed to the rehabilitation programme. The study demonstrated that during a six- to eight weeks of day hospital rehabilitation for patients with first-ever stroke, there were statistically significant improvements in physical and cognitive functions, as well as in the patient's self-rated health and health related quality of life (Olsson & Sunnerhagen, 2006).

### 2.8.2.3 Home Rehabilitation

In studies by Dodel *et al.* (2004) and Saxena *et al.* (2006), 47,1% and 80,5% of their respective cohorts were discharged to their own homes from hospital. In a study conducted by Mayo, Wood-Dauphinee, Cote, Gayton, Carlton, Buttery & Tamblyn (2000), patients who suffered from a stroke received their rehabilitation at their homes. Various rehabilitation professionals visited the patients' homes, which led to the empowerment of the subjects and their family members (Mayo *et al.*, 2000). The study established that the home-based group recorded a 92-fold increase in physical health and superior outcomes in the independent activities of daily living. Home rehabilitation intervention appeared to promote motoric and functional gains associated with natural recovery. It also allowed for rehabilitation to be translated into a greater degree of higher level function and satisfaction with community reintegration and into a better perception of physical health (Mayo *et al.*, 2000). In a study conducted by Von Koch, Wottrich and Holmqvist (1999), clear differences in both patients' and therapists' behaviour were noted when rehabilitation sessions conducted were in patients' homes or a community setting, compared with those conducted in a hospital setting. Patients in that study were more at ease in their own environment and the therapists were more accommodating to the patients' requests. Patients who received rehabilitation at home, seemed more empowered, since they took the initiative and expressed their goals more often (Holmqvist & Van Koch, 2001).

## 2.9 STANDARDISED OUTCOME MEASURES

The outcomes experienced by stroke patients in relation to impairments, activity limitations and participation restriction can be objectively measured using standardised outcome measures, as highlighted by Salter, Jutai, Teasall, Foley and Bitensky (2005). Measuring outcomes are important as most of the stroke survivors regard ADL and participation in their home, community and environment as long-term goals of rehabilitation (Scheepers, Ketelaar, Van DePort, Visser-Meiley & Lindeman,2007). There are various outcome measures for stroke patients available. These include the Functional Independence Measure (FIM), which is used to assess the motor and cognitive functions, the Frenchay activities index, which is a measure of instrumental activities of daily living, the Modified Rankin Scale (MRS), which assess global outcomes post stroke, the Barthel Index( BI),which measure the level of independence performing functional activities, and the World Health Organisation Disability Assessment Schedule (WHODAS II), to name a few (Joseph & Rhoda,2011). The Facilitators and Barriers Survey (FABS) is used to explore barriers and facilitators in the environment (Gray, Hollingsworth, Stark & Morgan, 2008). The WHODAS II was initially the chosen instrument to address the various objectives for the study. The WHODAS measure getting around, self care, understanding, communicating, getting along with people, life activities and participation in society (WHO, 2001). Permission was granted to use and translate the WHODAS, on condition that all the parts of the instrument (and not just the one that would have been used for this study) needed to be translated. This process would have amounted to several thousands of rands, which was not an option for the researcher. Therefore in the current study, the Barthel Index (BI) was used to

determine activity limitations, the Structured interview of the Modified Rankin Scale (MRS) was used to determine participation restrictions, and the Facilitators and Barriers Survey (FABS) was used to determine the facilitators and barriers to participation. These outcome measures were superior options to the other outcome measures, as it provided the researcher with necessary tools to meet the objectives to the study.

## **2.11 SUMMARY OF THE CHAPTER**

There are different types of stroke, and from the literature reviewed, ischaemic strokes are the most prevalent type. Strokes are associated with various risk factors, which can either occur in isolation or in combination with one another. Of all the risk factors, hypertension is the most prevalently reported modifiable risk factor across the various studies. The effects of strokes are vast, ranging from physical disability, emotional problems, to social and family problems. Stroke rehabilitation has been shown across the studies to have an effect on the functional outcome of those affected. The rehabilitation can occur in different settings, either on in-hospital or on an out-patients' basis. Stroke patients experience activity and participation restrictions due to the effects of the stroke. The environment in which they live, could either act as a barrier to or a facilitator for activity or participation. Environment features such as stairs, uneven ground surfaces, potholes in the road and gravel surfaces have been cited as factors impeding or hindering participation by stroke survivors. These restrictions could be either heightened or facilitated by the social or attitudinal factors with which the patients come across within their environments.

## CHAPTER THREE

### METHODOLOGY

#### 3.1 INTRODUCTION

In this chapter, the study setting for the quantitative and qualitative phases of the study will be described. Here the researcher presents the methods that were used in the study. The study design, study population and the instrumentations used will also be described. Data collection procedures and analysis will be presented and explained. The ethical considerations pertaining to the study will be provided at the end of the chapter.



#### 3.2 RESEARCH SETTING

The study was conducted in Uitenhage, located in Nelson Mandela Bay, a metropolitan city situated in the Eastern Cape. Uitenhage has a population of 118 189. According to Census 2001, the Eastern Cape has a population of people with disabilities of 3 722 66, which constitutes 5,8% of the total population of the country. According to this same provincial statistics, the Eastern Cape has the second lowest life expectancy (60,7%) of people all the provinces in the country.

According to Statistics South Africa, the Eastern Cape has the second highest poverty levels in South Africa, combined with the highest provincial unemployment rate (55%) in the country (Statistics SA, 2005). This figure was considerably lower, at

45,3% in the Eastern Cape Provincial Statistics of 1997. The 2001 Census reveals that 23% of the Eastern Cape population aged 20 years and older had no formal school education, and 55% of those in the age group 15-64 years were unemployed. It further highlights that less than half of households (47%) lived in informal housing, and 11% and 38% respectively in informal and traditional structures.

The Uitenhage Provincial Hospital, in the Eastern Cape, was selected as the primary setting for this study. The Uitenhage Provincial Hospital is a 250-bed hospital that serves the public health sector. It is only for the past five years since 2007 that this Hospital has had full-time Physiotherapy, Occupational Therapy and Speech Therapy Departments. The Hospital offers the following services: Emergency Unit, Out-Patients', Surgical, Medical, Paediatrics, Maternity, Gynaecology, operating theatre, post trauma counselling, Anti-Retroviral Treatment (ARV), X-ray, a Laboratory, a Pharmacy, a laundry, a kitchen, an Intensive Care Unit and a Renal Unit, a Rape Crisis Centre, a social workers, speech therapist and psychologists (Eastern Cape Department Of Health). The Hospital has various sessional consultant specialists including orthopaedic surgeons, paediatricians, gynaecologists and a neurologist. Stroke patients are usually seen in the Emergency Department first. From there, they are admitted to either the male or female medical ward. The stroke patients are managed by a multidisciplinary team of professionals, ranging from the medical doctor, a neurologist (when available), nursing staff and rehabilitation professionals, which include the physiotherapist, occupational therapist and speech therapist. These rehabilitation professionals also provide out-patient sessions to those that require it. Outreach into the community and specifically to the local surrounding clinics have been started. These outreach sessions occur either

on a weekly or biweekly basis. Problems such as lack of transportation of these rehabilitation professionals hamper the availability of these services at the various clinics.

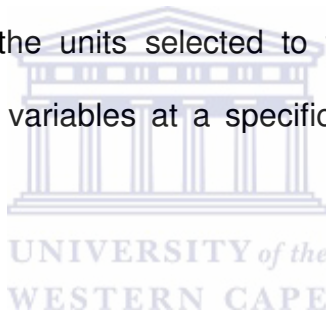




### 3.3 RESEARCH DESIGN

A concurrent mixed model design was used to collect the data. A concurrent mixed method design has two relatively independent phases; one that consists of quantitative data collection and analysis; and the other that consists of qualitative data collection and analysis (Tashakkori & Teddlie, 2003).

The quantitative part of the study included a non-experimental research design. A quantitative study describes, explains or predicts a phenomenon (Domholdt, 2000). According to Babbie & Mouton (2009), non-experimental designs are mainly used in descriptive studies in which the units selected to take part in the research are measured on all the relevant variables at a specific time. No manipulation of the variables takes place.



The quantitative study had retrospective and prospective components. The retrospective method was used to collect information from medical records of admitted stroke patients that were referred for physiotherapy while hospitalised, while the prospective method was used to collect the data relating to the outcomes of the patients post discharge.

For the qualitative part of the study semi-structured interviews were used to collect data. By conducting a qualitative research study, the researcher set out to understand how the individuals experienced the problem and to understand the problem from the respondents' own perspectives (Johnson & Christensen, 2008). Qualitative research allows the researcher to understand participants' thoughts,

feelings and viewpoints on certain issues (Struwig & Stead, 2001). This type of research can be viewed as subjective, value-laden and biased; it entails a process that evaluates multiple experiences by studying a small sample (O'Leary, 2004). Qualitative research is more grounded in a concern with people's everyday realities, following a devastating event such as a stroke (Hammell, Carpenter & Dyck, 2000).

Face-to-face semi-structured interviews were conducted. The major advantage of interviews is that it gives respondents the opportunity for personal explanations and detailed responses (Skinner, 2007). According to De Vos *et al.* (2005), the interview is the predominant mode of data collection in qualitative research. The study had retrospective and prospective components.

### **3.4 POPULATION AND SAMPLING**



#### **3.4.1 Population**

The study population consisted of 461 stroke patients admitted to the Uitenhage Provincial Hospital between 1 January 2008 and 31 December 2009, who were referred for physiotherapy while being hospitalized.

### **3.4.2 Sampling**

Non-probability, convenience sampling was used to collect quantitative data. A convenient sample is one that is readily available to the researcher (Domholdt, 2000). The retrospective data were collected from the medical records of patients admitted to the Uitenhage Provincial Hospital between 1 January 2008 and 31 December 2009. This type of sampling was also used for the follow-up prospective part of the study to determine the participants' outcomes following discharge from the Hospital. Of the 461 patients admitted during the specified timeframe, 349 folders were accessed. Of these folders 181 were excluded due to exclusion criteria, which will be discussed shortly. Therefore due to the small population size (168) the entire population was used for the retrospective part of the study. Of the 168 participants, only 24 could be reached and agreed to be interviewed. Reasons why the researcher was unable to reach participants, ranged from lack of contact numbers, incorrect contact numbers, inability to reach participants on the available contact numbers, relocation of participants and refusal to be interviewed.

#### **3.4.2.1 Inclusion Criteria for Quantitative Study**

Patients were included in the study if they:

- Were 18 years and older
- Had a definite diagnosis of stroke, as determined by a medical officer
- Had been referred for physiotherapy while hospitalised
- Had been discharged from the UPH as in-patients

### **3.4.2.2 Exclusion Criteria for Quantitative Study**

Patients were excluded from the study if they:

- Had strokes like symptoms resulting from, e.g. tumors, or other neurological conditions, such as head injuries.
- Had severe cognitive impairments as documented in the folders
- Had speech impairments as documented in the folders

### **3.4.3 Sample for Qualitative Study**

The convenience sampling method was also used to select participants for the qualitative study. Only participants who were contactable and who were willing to be interviewed, were included in the qualitative part of the study.

## **3.5 DATA COLLECTION INSTRUMENTS**

A data gathering instrument was used to collect data from the medical records. The Barthel Index, the Modified Rankin Scale and the FABS were used to collect the prospective information. The data gathering instrument, Barthel Index, Modified Rankin Scale and the FABS are discussed below:

### 3.5.1 Data Gathering Instrument for Medical Records Review (Appendix D)

The data gathering instrument was developed by the researcher based on literature (Stuifbergen, 1995; World Health Organisation, 1989). The obtained information included data such as age, gender, side of stroke, date of stroke onset, risk factors, as well as information relating to the process of physiotherapy (frequency and duration). The data gathering instrument comprised three main sections: demographic data, medical data, and rehabilitation data (in-patient and out-patient physiotherapy). The demographic data was captured as documented in the patients' folders and included age (American Heart Association, 2001); gender (American Heart Association, 2009); marital status (Nillson, Amoamsspm & Grimby, 2000); and employment status, which indicates the participation of patients prior to stroke.

The medical data included length of hospital stay, side of the body impaired, and whether a first or subsequent stroke had been suffered. The date of stroke, date of admission to hospital and date of discharge were documented as reflected in the hospital folder. This allowed calculation of the stroke onset admission intervals and the length of hospital stay. Length of hospital stay was determined by subtracting the date of discharge from the date of admission. The side of body impaired was recorded in order to determine which side was more commonly affected in the research population. Patients with left-sided hemiplegia have problems with their spatial and perceptual abilities, which may cause them to misjudge distance (leading to a fall) (National Stroke Association, 2012). Patients with right-sided hemiplegia usually develop aphasia (speech and language problems) and memory problems, which could include shortened retention spans and difficulty in learning new tasks

(National Stroke Association, 2012). The medical data also included if it was a first-ever stroke, second or more occurrence, as noted by the attending doctor taking the patient's history or as identified in the folders by the researchers. Several studies have documented a number of risk factors for stroke. The following risk factors, if documented in the patients' folders, were recorded: hypertension, diabetes, cardiac disease, smoking, alcohol abuse, and HIV (if documented as Retro positive+). It is, however, important to note that the participating patients might have other risk factors that were not recorded in their folders.

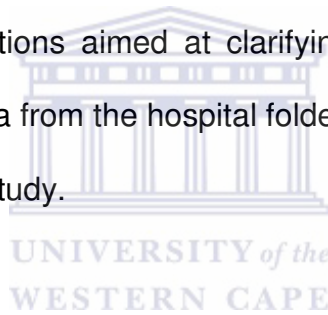
The second objective of the study was addressed by the rehabilitation section of the data gathering instrument. Here, it was documented whether the patients had received physiotherapy during their hospital stay. The process of physiotherapy, with specific reference to the start of physiotherapy since admission, was calculated by subtracting the date of start of physiotherapy from the date of admission to hospital. The frequency of the treatment, which related to the number of physiotherapy sessions received, was also recorded. The duration of physiotherapy was recorded as the difference in days from the start of physiotherapy to the end of physiotherapy received in hospital. The information relating to the main caregiver was also documented in the medical folder. If caregiver education was documented, it was captured as either "yes" (provided) or "no" (not provided).

The highest functional levels of the patients' at discharge or the last recording made by the physiotherapists, were recorded from the physiotherapists' notes obtained from the hospital folders. This was retrieved by reviewing the physiotherapists' notes. The physiotherapists usually stated what they had done or attempted to achieve with

the patient and what the patient's level of functioning was, either independently or with assistance. The functional levels included bed mobility, sitting, standing and walking.

### **3.5.1.1 Validity and Reliability of the Data Gathering Instrument**

To test content validity, the instrument was sent to two physiotherapists knowledgeable in the field of stroke rehabilitation. The experts included the study supervisor and the deputy director of the Western Cape Rehabilitation Centre, in Cape Town. The Supervisor and Deputy Director of the Western Cape Rehabilitation Centre made various suggestions aimed at clarifying certain of the items on the instrument in order to extract data from the hospital folders that was relevant to address the first two objectives of the study.



Cohen's kappa ( $k$ ) measure was then used to determine the inter-rater reliability coefficient. The inter-rater reliability coefficient was between 0,84-0,94 for the different sections of the data gathering instrument. This coefficient was good. It is generally recommended that researchers strive to achieve a minimum level of inter-rater agreement of 60% beyond chance agreement, which is a kappa value of 0,60 or greater (Worster & Haines, 2004).

### 3.5.2 Barthel Index (Appendix A)

The purpose of the Barthel Index is to assess the level of functional independence for ten activities of daily living (ADLs), primarily related to personal care and mobility (Mahoney & Barthel, 1965).

The Barthel Index (BI) tests one's ability to independently feed oneself, bathe and groom oneself, control one's bowels and bladder, use the toilet, manage transfers, and one's mobility on level surfaces and stairs. A point value is given for each section. A higher score means that the person is more independent. The 10-item BI was published in 1965 by Mahoney and Barthel to measure functional independence, specifically directed at the personal and domestic activities of daily living. It has ten questions, which address bowel and bladder management, grooming, toilet use, feeding, transfers, mobility, bathing and dressing. The values assigned to each item are based on time and extent of actual physical assistance required if a patient is unable to perform the activity (Mahoney & Barthel, 1965). The total score for the original BI was 100; the higher the score, the better the functional ability of the patient. In most studies, a score of 50 or more was used to define favourable outcome; whereas 60 was a pivotal point indicating assisted independence (Sulter, Steen & De Keyser, 1999).

Two different studies used similar scoring methods, finding that a score of 60 was the cut-off between independence and more marked dependence; while a score of 40 or below indicated severe dependence; and a score of 20 or lower reflected total



dependence (Granger, Devis, Peters, Sherwood & Barret, 1979; Finch, Brooks, Stratford and Mayo, 2002).

### **3.5.2.1 Validity and Reliability of the BI**

Data management is considered to be of high quality if the assessment tool is scientifically sound in terms of basic properties such as reliability, responsiveness and validity (Sharrack, Hughes, Soudain, Dunn, 1999). A study by Hsueh, Lin, Jeng and Hsieh (2002) established that the BI was able to meet all these requirements. Green, Forster and Young (2001) found that the measurement of basic activities of daily living and mobility post-stroke using the BI was very reliable.



### 3.5.2.1.1 Validity of the BI

The validity of the BI when used for stroke patients was shown to be high. When compared to another ADL scale, the Cronbach's alpha was 0,935 and Spearman's correlation coefficient was -0,912 (Oveisgharan, Shirani, Ghorbani, Soltanzade, Baghaci, Hosseini & Sarrafzadegan, 2006).

### 3.5.2.1.2 Reliability of the BI

In a study investigating the test-retest reliability of the BI, Green *et al.* (2001) found that the mean difference between testing was only 0,4 and that the reliability coefficient was 2,0 indicating good reliability, with little bias. Hsueh *et al.* (2002) compared the BI and the Functional Independence Measure (FIM), that the BI was in no way inferior to the motor subscale of the FIM and was in fact, establishing preferable to the FIM in measuring activities of daily living in that it took less time and was less complicated. In a study that compared the appropriateness and responsiveness of the FIM and BI in assessing patients with stroke and multiple sclerosis, the authors concurred with the previous statement (Van der Putten, Hobart, & Thompson, 1999). One of the major criticisms amongst the BI has always been that it has a "ceiling effect". However, Salter *et al.* (2005) have shown that the BI has good responsiveness, with a noteworthy ceiling effect of only 27% post discharge from rehabilitation facilities. Their study also established that the BI had excellent test- retest (regardless of the skill of the rater) and interobserver reliability, as well as excellent internal consistency (Salter *et al.*, 2005).

The BI is observer-rated generic measures (not specific to a disease/condition) of activity used in studies examining functional recovery following stroke rehabilitation. According to Hobart, Lamping, Freeman, Langdon, McLellan, Greenwood & Thompson (2001), the BI is recommended for group comparison studies and not for individual patient's decision-making (Hobart *et al.*, 2001). D'Olhaberriague, Litvan, Mitsias & Mansbach (1996) have established that the interobserver agreement of the BI is greater than that of the Rankin score and that the BI was the more reliable disability scale. The BI is very user friendly, thanks to the fact that even non-medical personnel can use it reliably (Schlote, Kruger, Topp & Wallesch, 2004). No difference in the results of the BI was found when using different methods to obtain the score (i.e. self-reporting, asking a trained nurse, and separate testing by two skilled observers) (Collin, Wade, Davies & Horne, 1988)

For this study, the BI was chosen as the instrument for collecting data on patients' functional abilities. The BI was also chosen because it is easy to apply and has been well-validated (Green *et al.*, 2001; and Collin *et al.*, 1988).

### **3.5.3 Modified Rankin Scale (MRS) (Appendix B)**

The Modified Rankin Scale (MRS) is a scale commonly used for measuring the degree of disability or dependence in the daily activities of people who had suffered strokes and it has become the most widely used clinical outcome measure for clinical stroke trials. For this study, the structured interview of the MRS was used. The purpose of choosing the structured interview, was to assign patients to MRS grades in a systematic way (Wilson, 2002).

Modified Rankin Scale Section of the Structured Interview (from Wilson, 2002):

Modified Rankin Scale	Section of Structured Interview
<b>5 Severe disability:</b> bedridden, incontinent and requiring constant nursing care and attention.	1. Constant care
<b>4 Moderately severe disability:</b> unable to walk without assistance and unable to attend to own bodily needs without assistance.	2. Assistance for bodily needs / walking
<b>3 Moderate disability:</b> requiring some help, but able to walk without assistance.	3. Assistance to look after own affairs
<b>2 Slight disability:</b> unable to carry out all previous activities but able to look after own affairs without assistance	4. Usual duties and activities
<b>1 No significant disability:</b> despite symptoms: able to carry out all usual duties and activities.	5. Symptom checklist
<b>0 No symptoms at all</b>	

A literature review conducted by Bank and Marotta (2007), established that the MRS grading could be affected by a variety of factors, including patient comorbidities and socio-economic status. They reviewed large and diverse literature that concurred that the MRS was a valid and clinically relevant instrument for assessing recovery from stroke.

Uyttenboogaart, Luijckx, Vroomen, Stewart and Keyser (2007) have established an overlap between the MRS and the Barthel Index scales. A BI of 100 (independent in all ten activities) does not imply that the patient is able to live alone. For instance, he may not be able to shop or use transportation; therefore, this patient does not have an MRS of 0. The authors in the Uyttenboogaart study then rescored the MRS after

obtaining the information from the BI, thus found the overlap (Uyttenboogaart *et al.*, 2007). A structured interview with five sections, that range from being totally dependent to having an impairment only, was developed for the MRS (Wilson *et al.*, 2005). This interview includes specific questions relating to participation in work activities, family life and leisure activities. These questions were specifically used in the present study to determine participation. The tool has been widely used in acute stroke trials (Sulter *et al.*, 1999).

### **3.5.3.1 Reliability of MRS**

Uytteboogaart *et al.* (2007), found the intra- and inter-rater reliability of the MRS to be satisfactory, while a review conducted by Quinn *et al.*, 2007, demonstrated that the overall reliability of the MRS is moderate. Inter-rater reliability with the MRS was moderate and improves with the structured interview ( $k$  0,56 versus 0,78), and strong test re-test reliability ( $k=0,81$  to 0,95) has been reported (Banks & Marotta, 2007).

### **3.5.3.2 Validity of MRS**

The MRS has demonstrated good construct and convergent validity (Banks & Marotta, 2007).

### 3.6 FACILITATORS AND BARRIERS SURVEY (FABS) (APPENDIX C)

“The facilities and Barriers Survey of environmental influences on participation among people with lower limb mobility impairments and limitations” (Gray, Hollingsworth, Stark & Morgan 2008) was used to determine the environmental barriers to and facilitators of participation experienced by the participants. The FABS includes 65 questions, 177 items and six domains that could influence participation. These domains include use of mobility assistive devices; the home environment; features of the community; ability to access destination; facilities available in the community; and community support network.

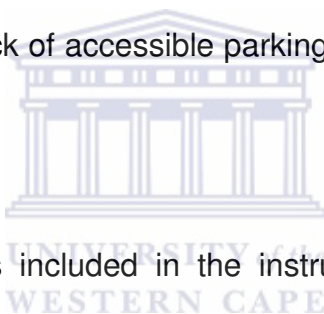
The first domain of the survey includes two questions on the primary mobility devices participants use in their community; how often they use these and the extent of the influence the devices had on participation. The second domain, home environment, includes 12 features commonly found in homes. The frequency of the encounters with a specific feature and the influence that the feature has had on participation are questioned. The third domain, community features, has four items, focusing on how much and how often a built or natural feature influences participation.

The community destination domain, which is the fourth domain, includes questions on the effect limited building access has on participation, and the extent of the limitation. Domain five consists of frequency and magnitude questions on the influence of nine services provided and the attitudes of the people providing the help. This domain also has two policy questions on the influence of standards and rules on

work and school participation. Additional questions in domain five pertain to the standards of appearance and society's definition of disability.

The sixth domain focuses on building structures access and parking at 14 community sites, restrooms in eight sites and six types of transportation. The last domain includes barriers to participation due to lack of transportation and lack of special equipment.

The items in the FABS are Likert scale items, except those in the community access and availability of resources domains, which have ordinal set of limited/not limited responses in respect of the lack of accessible parking, accessible building structures and special equipment.



The instrument specific items included in the instrument have moderate to high internal consistence (Cronbach's  $\alpha=0,35-0,94$ ) and test retest reliability (Pearson  $r=0,52-0,82$ ) (Gray,Hollingsworth, Stark & Morgan, 2008). The instrument also displays good discriminate validity (Gray *et al*, 2008). The necessary translation process will be followed to translate the (English) survey into Isixhosa and Afrikaans.

The third and fourth objectives of the study were realised through the means of interviews. A qualitative phenomological approach was used in order to obtain the viewpoints of the participants

### 3.7 TRANSLATION OF INSTRUMENTS

The BI, MRS and FABS were translated from English into both Afrikaans and isiXhosa, since English was not the majority of the participants' first language. In order to ensure that the translated documents assesses what the original English version attempted to assess, another translator translated the documents from Afrikaans and isiXhosa back into English. By so doing, accuracy was ensured.

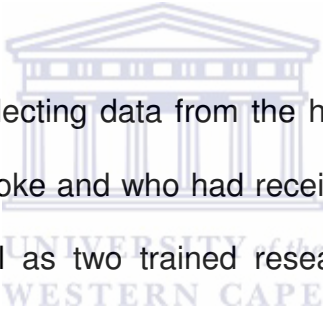
The measures of self-reporting, which included the Barthel Index and the Modified Rankin Scale, were translated from English into Afrikaans by staff at the Writing Centre at the University of the Western Cape (UWC). Translation from Afrikaans back into English were done by two Social Sciences graduates, who both had some experience of translating. Neither of the translators had prior knowledge of the tools or a background in the medical profession. A consensus meeting was then held between the researcher and the researcher involved in the WCRC study. As certain terms seemed inappropriate for the specific population, alternative words were suggested. The words suggested by the researchers were referred back to the two translators. Consensus was reached before these words were included in the questionnaire. The translation of the Barthel Index, the Modified Rankin Scale and the FABS from isiXhosa into English was handled by a lecturer in the isiXhosa Department at the UWC. The translation from Xhosa back into English was done by another lecturer in the same Department. These translators also did not have prior knowledge of the tools or a background in the medical profession. The isiXhosa-



speaking research assistants checked that the correct Xhosa terminology was used, which was tested during the pilot study.

The translation of the FABS from English into Afrikaans was done by an Afrikaans lecturer from the Nelson Mandela Metropolitan University, in Port Elizabeth. The translation back from English into Afrikaans was done by another lecturer in the same Department at the same University. Neither of the translators had prior knowledge of the tools, or had a background in the medical profession.

### **3.8 PILOT STUDY**

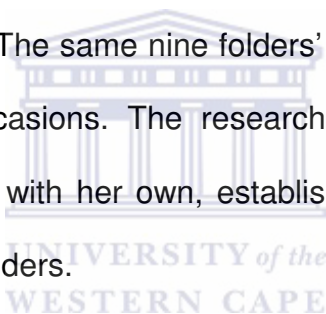


A pilot study was done by collecting data from the hospital folders of nine patients who had been admitted for stroke and who had received in-patient physiotherapy in 2007. The researcher as well as two trained research assistants used the data gathering instrument to obtain information from the hospital folders. The research assistants were a qualified physiotherapist and a university student who was studying nursing at the Nelson Mandela Metropolitan University. Each of the assistants was individually trained by the researcher to ensure the accurate collection of the data. Before the assistants began to collect data, each had to choose any two folders and undertake two practice runs. Each assistant had to do data collection from the two folders that they had obtained, and then they had to do the same with the two folders that the other assistant had obtained. The researcher then checked the information for completeness and correctness. The research assistants could then discuss any problems encountered in gathering the

information. This prior training of the research assistants ensured greater accuracy when collecting the data from the hospital folders.

### **3.8.1 Results of pilot study**

The pilot study revealed that certain abbreviations posed a problem for the university student, since her main field of study was not physiotherapy. This was remedied by writing down known abbreviations, especially related to the specific data that she was due to extract from the hospital folders. She was also invited to call the researcher immediately if problems arose or if she was not certain what the correct description or statement was. The same nine folders' data was collected by all three researchers, on separate occasions. The researcher then checked all the data obtained by all the assistants with her own, establishing that all had extracted the same data from the hospital folders.



## **3.9 PROCESS OF DATA COLLECTION**

### **3.9.1 Quantitative data collection**

The quantitative data collection process was multi-staged. First, the researcher had to obtain all the in-hospital physiotherapy statistics for the period 1 January 2008 to 31 December 2009 from the Records Department. The researcher then had to go through those statistics month by month, in order to identify the stroke patients admitted to the Hospital who had been referred for physiotherapy, since only patients that had been referred for physiotherapy while hospitalised, were included in the

study. The researcher then made up month-to-month lists for the specified time period, which included the patients' names and folder numbers. These lists were typed up and given to the research assistants, for data collection purposes. A list of the inclusion and exclusion criteria was given to each of the research assistants, in order to ensure that data would be extracted from only those folders that met the inclusion criteria.

The records had to be hand searched by both the researcher and the research assistants. The records were kept at the Central Records Department of the Hospital. The Records Department had a specific system to collect the records, which was related to the hospital folder number. It took the entire research team some time to get accustomed to the filing process, which was a time consuming and, at times, a frustrating exercise. On several occasions, each of the researchers went in with a few lists of names and folder numbers, but succeeded in locating only a few folders. On an intermittent basis, some of the clerks would go through the lists with the researcher present. They would then also only succeed in locating the folders that had already been located by the researcher herself. Some of the clerks checked the hospital computer system, which showed that while some of the patients had been readmitted, most of the folders should be in the Central Records Department. Possible reasons for the missing folders, as offered by the clerks, were that the folders had been misplaced or that patients had taken the folders home with them. That this had indeed occurred, was discovered by the researcher when conducting the prospective part of the study.

Of the 461 stroke patients admitted to the Hospital over the specified time period, only a total of 349 folders were found after numerous attempts to locate all the relevant folders. As mentioned previously, 181 of the 349 folders were excluded due to the inclusion and exclusion criteria, 112 folders were not found, despite several attempts and 168 folders were eligible for inclusion. Data was collected over the period of March 2010 to December 2010.

The information collected from the 168 folders was then captured on a Microsoft spreadsheet. All relevant demographic data and contact details were recorded and the patients were contacted by the researcher in order to set up appointments for interviews. Of the 168 patients, only 24 patients were successfully contacted and agreed to take part in the prospective study. The problems that were encountered, included: patients were not willing to be interviewed; patients were not medically fit to be interviewed; or where patients had demised or had relocated. Other logistical problems were the lack of telephone numbers on the patients' files, incorrect or disconnected telephone numbers. The researcher then arranged for an appointment at a time and place that was convenient for each participant. On the day of the interview, the researcher (student) discussed the aim of the study and obtained written informed consent from the patient. The Barthel Index, the Modified Rankin Scale and the FABS, were then completed. The majority (20) of the interviews were conducted at the patients' homes, while four were conducted at a nearby Community Health Centre. The interviews conducted at the Community Health Centre were completed in a private room. The questionnaire took approximately one hour to complete.

### 3.9.2 Qualitative data collection

The qualitative interviews were conducted after the quantitative interviews; and these were also conducted by the main researcher (student). The aim of the interviews was to determine and explore the barriers and facilitators to participation of the participants. These interviews were, therefore, conducted a few months after the quantitative study in order to try and minimise the recollection of the questions in the questionnaires (recall bias) on the part of the participants. The participants who were part of the quantitative prospective study were contacted telephonically to ascertain their willingness to be interviewed. The qualitative interviews were conducted at times and places convenient to the participants. Many participants preferred to have the interview conducted at their homes. One patient preferred having the interview conducted telephonically. Telephonic consent was obtained to conduct the interview and to have it recorded. The qualitative interviews were recorded by means of a digital voice recorder, but where the patients did not give their consent for the recording, detailed field notes were made during and immediately after the interview. Four of the participants gave consent to be recorded, while the remaining ones refused digital recording. As previously mentioned, face-to-face interviews were used in the current study in order to obtain in-depth descriptions of and reasons for participation restrictions post stroke. According to Domholdt (2000), the value of face-to-face interviews is that they offer researchers in-depth responses, and allow them to maintain control over who actually respond and to determine the opinions of those who cannot read or write. An interview guide (Appendix E) was used to guide the interviews. The interview guide was developed, based on the literature consulted

(Wood *et al.*, 2010; Barker *et al.*, 2006; Hare *et al.*, 2006). The interviews were conducted in a language in which the participant was fluent in.

### 3.9.3 Trustworthiness of qualitative data

Tendencies from the transcribed interviews were kept as close as possible to the respondents' own mode of talking (Shepard, 1997). The participants were interviewed in a language of their choice. At no point did the researcher require the services of a translator, since the participants were comfortable to converse in either English or Afrikaans. Member checking was the form of verification used. The stories that the participants shared during the interviews, were summarised and then retold to them by the researcher to ensure that the researcher understood the information given during the interview correctly.



To enhance the credibility of the qualitative data, the themes presented were illustrated with representative quotations from the transcribed texts (Graneheim & Lundman, 2004). Peer examination was done by discussing the research process and findings with colleagues and experts at the Nelson Mandela Metropolitan University who had experience of qualitative research methods. These individuals were required to go through the field notes and transcriptions, data reduction and condensed notes, data reconstruction and thematic categories and interpretations (Lincoln & Guba, 1985) in order to ensure the confirmability of the qualitative data.

### **3.10 DATA ANALYSIS**

#### **3.10.1 Quantitative analysis**

Descriptive statistic analysis, using Microsoft Excel and SPSS 18 for Social Sciences was used to obtain the profiles of the stroke patients. Means, standard deviations, frequencies and percentages were calculated for descriptive purposes and the Chi-square test was used to test for associations between various variables. Various relationships between socio-demographic characteristics (age, gender, marital status, and employment status) were illustrated using frequency tables.

#### **3.10.2 Qualitative analysis**



Strong themes that run through data (Stuifbergen & Rogers, 1997), were identified. In this study, the analysis of the qualitative data began with the transcription of the voice recordings. The relevant Afrikaans transcriptions were translated into English. The voice recordings were compared with the field notes several times in order to verify accuracy. All the transcribed data were read through several times and the most relevant codes were identified within the pre-determined themes (as will be discussed in chapter 6), in line with the objectives of the study. The emerging categories were then identified within the pre-determined themes.

### 3.11 ETHICAL CONSIDERATIONS

Permission and ethical clearance was obtained from the Higher Degrees Committee and the Senate Research and Study Grants Committee of the University of the Western Cape (Appendix F). Permission to conduct the study was obtained from the Medical Superintendent of the Uitenhage Provincial Hospital (Appendix G & H). The aims, objectives and nature of the study were explained to all participants. Written and informed consent was obtained from all participants or their primary caregivers, upon agreement to participate in the study (Appendix I). Participation in the study was voluntary and any participant was allowed to withdraw from the study at any stage, without being penalised. The participants were ensured that confidentiality would be maintained and that the researcher would be the only person who would have access to the digital recordings and that their names would not appear in any documentation published. The researcher assured the participants that should questioning cause them any emotional distress, the participants would be referred to a counsellor at the UPH. However during the study, no participant needed the services of a councillor. Finally, the researcher assured the participants that the results of the study would be made available to all interested parties.



### 3.12 SUMMARY OF CHAPTER

In this chapter, the study setting, including the Uitenhage Provincial Hospital and the surrounding area, was described. The study consisted of various components. The quantitative retrospective approach involved reviewing the Hospital's medical records by means of a data gathering instrument, developed by the researcher. This instrument was used to obtain information on the profiles of stroke patients. The second part of the quantitative study consisted of face-to-face interviews with the stroke survivors in order to determine the activity limitations and participation restrictions and barriers and facilitators post stroke. The quantitative results were analysed using descriptive and inferential statistics.

For the qualitative part of the study, a qualitative approach was used. Face-to-face interviews were done to explore the challenges experienced by stroke patients, with specific reference to barriers and facilitators. After the qualitative data was collected, a thematic analysis was performed. Also, in this chapter, the ethical considerations pertaining to the current study were presented.

## **CHAPTER FOUR**

### **QUANTITATIVE RESULTS**

#### **SECTION A: RETROSPECTIVE STUDY**

##### **4.1 INTRODUCTION**

In this chapter, the quantitative phase of the study, which concerns the first and second objectives, as stated earlier, will be presented. The quantitative phase of the study had two components, a retrospective and a prospective component. The results of the retrospective part of the study were obtained from 168 hospital folders, as stated earlier. The retrospective part of the study will be discussed under two different sections, namely, the profiles of the stroke patients, and the physiotherapy process. The prospective part of the study will discuss the barriers and facilitators experienced by stroke patients. While conducting the study, it was noted that some information regarding the variables was missing from the folders. The data presented, is therefore the available information obtained.

##### **4.2 PARTICIPANT RECRUITMENT**

A total of 461 patients with stroke were admitted to the Uitenhage Provincial Hospital between 1 January 2008 and 31 December 2009. Of these, 181 were excluded, based on the study exclusion criteria, while 112 patient folders were missing and the

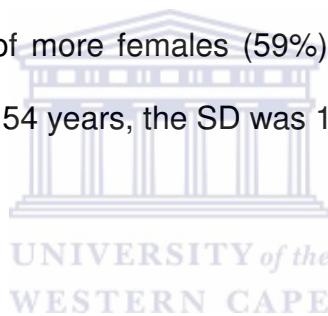
patients could therefore not be included in the study. The total population of 168 was left and all the retrospective data were obtained from these folders.

### 4.3 SOCIO DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS

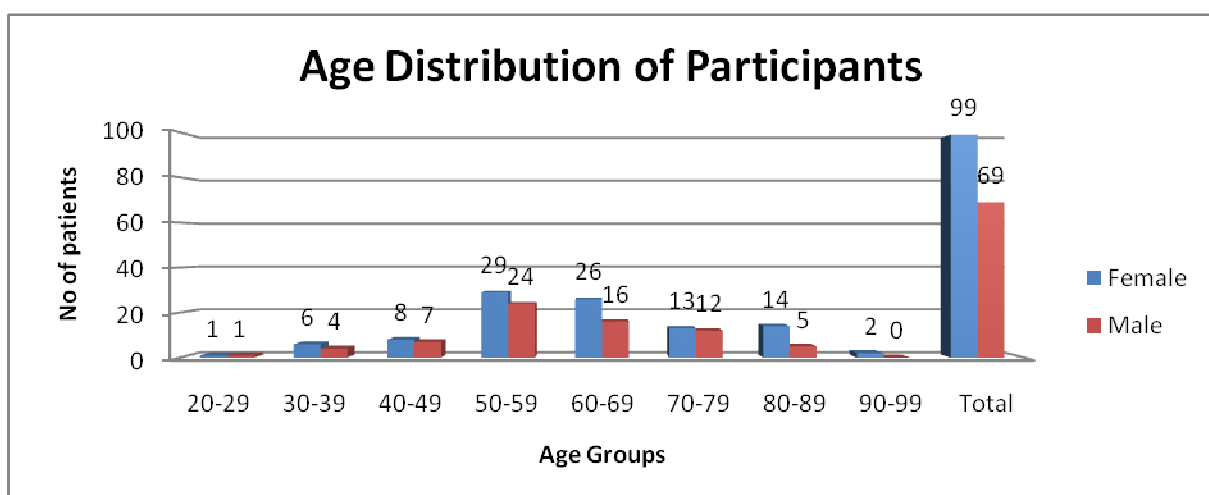
In this section the socio-demographic details of the participants will be presented, including age, gender, marital status and employment status.

#### 4.3.1 Age and Gender

The study sample consisted of more females (59%) than males (41%). The mean age of the participants was 61,54 years, the SD was 13,78, and ages ranged from 20 to 90 years.



**FIGURE 4.1: Age distribution of all participants according to gender (n=168)**

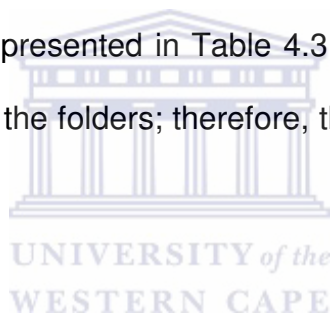


The age group 50-59 years was at 31,5% the most prevalent age group of the study population, followed by the age group 60-69 years, which comprised 25% of the population.

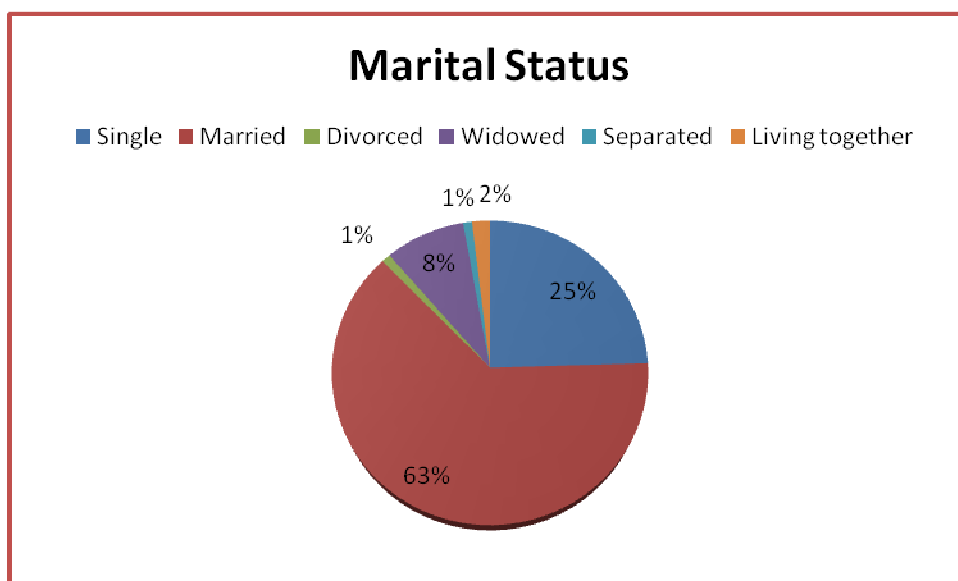
The majority of the males and females in the study fell in the age groups 50-59 years and 60-69 years.

#### 4.3.2 Marital Status

The marital status of the participants is presented in Figure 4.2, while the marital status according to gender is presented in Table 4.3. Information relating to marital status was missing from 62 of the folders; therefore, the sample for this variable was 106.



**FIGURE 4.2: Marital Status**



Of the 168 participants 67 (63%) were married, 25% were single, nine were widowed, one was divorced and two were living together with a life partner.

The relationship between gender and marital status is depicted in Table 4.1.

**TABLE 4.1: Gender and Marital Status (n=106)**

Gender	Marital Status						Total	
	Single		Married		Div./Wid./Sep.			
Female	14	27%	27	53%	10	20%	51	100%
Male	12	22%	42	76%	1	2%	55	100%
Total	26	25%	69	65%	11	10%	106	100%

Key: Div=Divorced, Wid=Widowed, Sep=Separated

More males (76%) than females (53%) in this study were found to be married. At a 0,05 level of significance, the Chi-square test showed that gender was significantly associated with marital status ( $p=0,005$ ). This meant that the male participants were more likely to be married.

#### **4.3.3 Employment status**

A total of 153/168 participants (91,2%) were not employed at the time of their stroke. Only 5,9% (10/168) of the participants had been receiving paid employment prior to

the stroke. Information relating to employment status was missing from five (2,9%) of the participants' folders.

#### 4.3.3.1 Gender vs. employment

**TABLE 4.2: Gender vs. Employment (n=168)**

<b>Gender</b>	<b>Employed Number (%)</b>	<b>Unemployed Number (5%)</b>	<b>Missing</b>	<b>Total</b>
Female	3(3%)	94(95%)	2(2%)	99
Male	7(10%)	59(86%)	3(4%)	69
<b>TOTAL</b>	<b>10(6%)</b>	<b>153(91%)</b>	<b>5(3%)</b>	<b>168</b>

Of those who were employed (10/168), the majority were males (7/168).

#### 4.4 FACTORS RELATING TO STROKE

This section will present the results relating to the stroke-onset admission interval and the length of hospital stay, as well as the chronicity of stroke and the side of impairment following the stroke.

#### 4.4.1 Stroke onset admission-interval and length of hospital stay

**TABLE 4.3: Stroke onset admission interval (n=168)**

<b>Number of days since stroke onset</b>	<b>Pts admitted to hospital</b>	<b>Percentage</b>
0	146	86,9%
1	9	5,4%
2	5	3,0%
3	3	1,8%
4	2	1,2%
5	1	0,6%
6	1	0,6%
7	1	0,6%

The participants were admitted from the same day of stroke onset to seven days after stroke onset (mean 0,32 day after stroke onset and SD=1,04). Of the total number of participants admitted to the Uitenhage Provincial Hospital, 86,9% were admitted on the day of stroke onset. Only nine patients were admitted one day following stroke onset.

**TABLE 4.4: Length of hospital stay**

<b>Days in hospital</b>	<b>Number of Participants</b>	<b>Percentage</b>
1 to 4	44	26%
5 to 9	95	57%
10 to 14	15	9%
15 to 19	8	5%
20 to 24	3	2%
25 to 29	2	1%
30 to 34	0	0%
35 to 39	0	0%
40 to 44	1	1%

The minimum amount of admitted days to hospital, were 2 and the maximum, 41 days. The mean length of stay was 7,38 days with a standard deviation (SD) of 5,10.

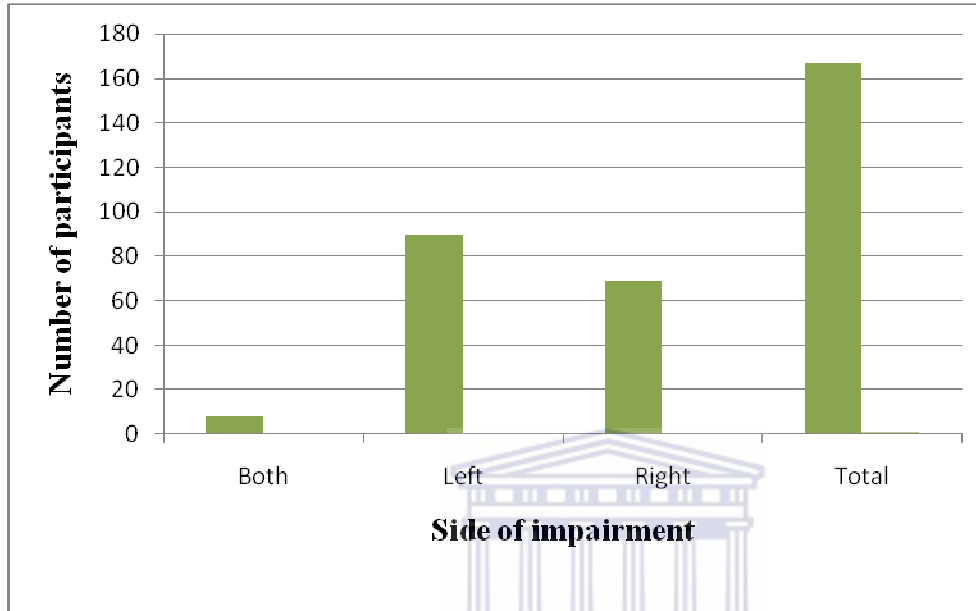
#### **4.4.2 Chronicity of stroke**

A total of 72,3% of the overall participants suffered from a first-ever stroke, followed by 22% with a second occurrence, and 4,8% with a third or more occurrence.



#### 4.4.3 Side of body impairment

**FIGURE 4.3: Side of body impairment (n=168)**



Left-sided hemiparesis was found in 54% (91) of the participants, and right-sided hemiparesis in 41% (69) of the participants. Only 5% (8) of the participants had both left and right sided symptoms, while one folder did not state which side had been affected.

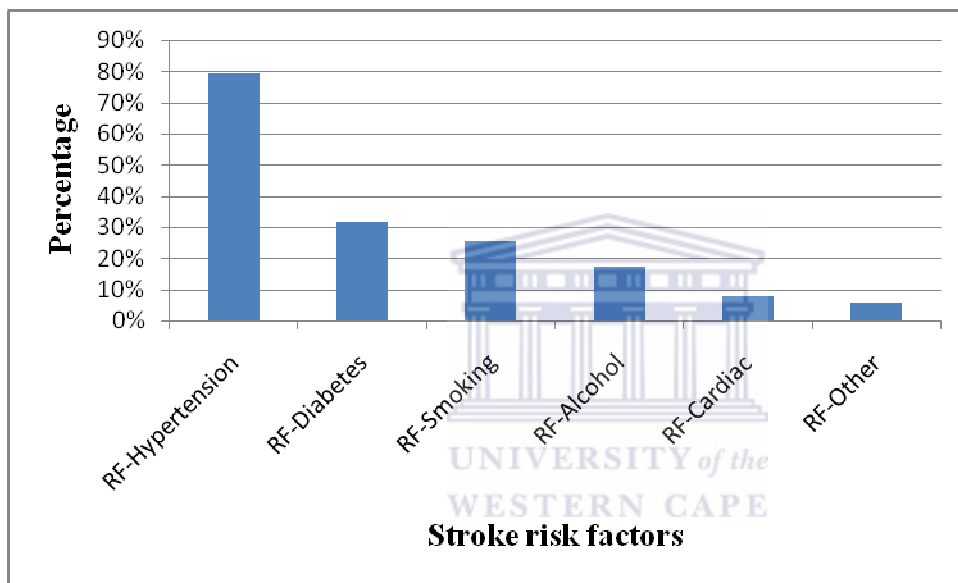
#### 4.5 RISK FACTORS RELATED TO STROKE

In this section, the risk factors relating to stroke will be presented. Specific reference will be made to the frequency distribution of the risk factors and its relationship with gender and age.

#### 4.5.1 Stroke risk factors

The frequencies and percentages of participants, with reference to the number of risk factors, are illustrated in Figure 4.4.

**FIGURE 4.4: Stroke Risk Factors (n=168)**

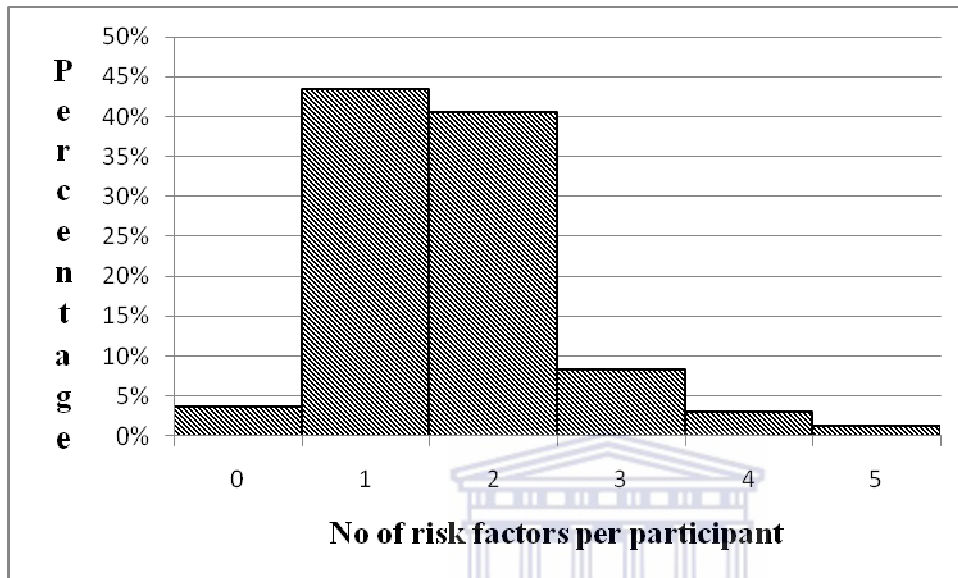


Hypertension was the most common risk factor at 79% in the study population, followed by diabetes, at 32%. The group “Other” consisted of those individuals who were HIV positive, suffered from elevated blood lipid levels, were obese and were physically inactive.

#### 4.5.2 Frequency distribution: number of risk factors

The frequency distribution with reference to the number of risk factors per participant is depicted in Figure 4.5.

**FIGURE 4.5: Frequency distribution: number of risk factors per participant (n=168)**



Most of the participants in the study had one or two risk factors present at the time of stroke onset.

#### **4.5.3 Gender and number of risk factors**

The relationship between gender and the number of risk factors is represented in Table 4.5.

**TABLE 4.5: Gender and Number of Risk Factors**

Gender	Number of risk factors per participant							
	0-1		2		3-5		Total	
Female	53	54%	39	39%	7	7%	99	100%
Male	26	38%	29	42%	14	20%	69	100%
Total	79	46%	68	41%	21	12%	170	100%

One risk factor per participant was present in 46% of the participants at the time of stroke onset, with more females (54%), having only one risk factor than males (38%). Those who had two risk factors present amounted to 70 (41%) of the total amount of the participants. More men in this study had 2 (42%) or 3-5 (20%) risk factors; therefore, altogether 62% of men with two or more risk factors were 62%, compared to 46% of women. At a 0,05 level of significance, the Chi-square test showed that gender was significantly associated with risk factors ( $p=,019$ ), which indicates that men had significantly more risk factors than women.

#### 4.5.4 Age and number of risk factors

The relationship between age at stroke and the number of risk factors is depicted in Table 4.6.

**TABLE 4.6: Age at stroke vs. no. of risk factors**

Age at stroke	Number of risk factors							
	0-1		2		3-5		Total	
20-49	15	56%	9	33%	3	11%	27	100%
50-69	37	39%	45	47%	13	14%	95	100%
70-90	27	59%	14	30%	5	11%	46	100%
Total	79	46%	70	41%	21	12%	170	100%

No significant relationship between age at stroke and the number of risk factors was found ( $p=,206$ ).



#### 4.6 CAREGIVERS POST STROKE

In this section, the relationship between the different caregivers of stroke patients will be presented.

**TABLE 4.7: Stroke Caregivers (n=165)**

Gender of patient with stroke	Spousal Caregiver		Child Caregiver		Extended Family Caregiver		Total	
	Female	24	25%	63	66%	14	15%	96
Male	39	57%	21	30%	9	13%	69	100%
Total	63	38%	84	51%	23	14%	165	100%

In this study, more males (57%) than females (25%) were being cared for by their spouses. This relationship was found to be statistically significant ( $p=,0005$ ). Therefore, the males in this study were more likely to be cared for by their spouses following a stroke.

In this study, more females (66%) than males (30%) were being cared for by their children. At a 0,05 level of significance, the Chi-square test showed that gender was significantly associated with child caregivers ( $p=0,005$ ). This implies that the females were more likely to be cared for by their children following a stroke.

A small proportion of the study population were being looked after by extended or other family members. No statistical significance was found between this relationship ( $p=,778$ ).



## **4.7 PHYSIOTHERAPY INTERVENTION**

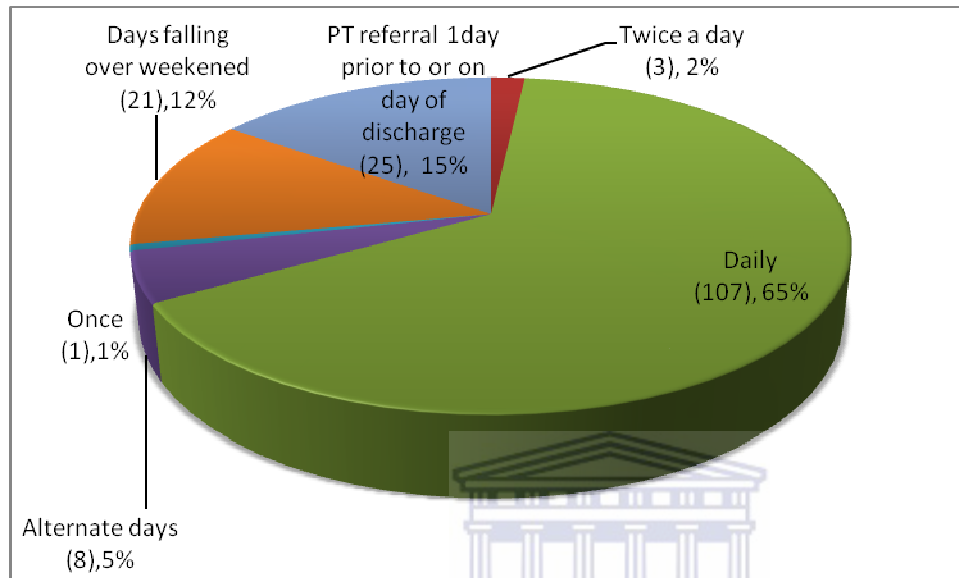
The following section will present the results relating to the process of physiotherapy, including the start of physiotherapy since admission to hospital, the frequency of the physiotherapy sessions, reasons for discharge from physiotherapy treatment, and the highest functional level at discharge. Caregiver education and referral destinations will also be presented.

### **4.7.1 Physiotherapy since admission**

Of the 168 participants who had been referred to physiotherapy, only 165 participants received physiotherapy while admitted to hospital. The following data is therefore presented for the sample of 165 participants who received physiotherapy. Of these, 36% started treatment on the second day post hospital admission, with a mean of 2,44 days post admission and an SD of 1,63. Approximately 15% of the patients were referred for physiotherapy one day prior to their discharge, or on the day of their discharge.

#### 4.7.2 Frequency of physiotherapy sessions

**FIGURE 4.6: Frequency of physiotherapy treatments (n=165)**



Most of the participants (65%) received daily physiotherapy treatment sessions. Patients admitted over a weekend or who had to stay in hospital over a weekend or a long weekend (12% of patients) received no physiotherapy over that time period.

The total number of in-hospital physiotherapy sessions received by participants was a mean of 2,56 (SD of 2,35). The minimum number of days on which participants received physiotherapy was one day, and the maximum number of days was 22 days.



#### 4.7.3 Relationship between physiotherapy sessions and length of hospital stay

The relationship between the total number of physiotherapy sessions and the length of hospital stay is depicted in Table 8.

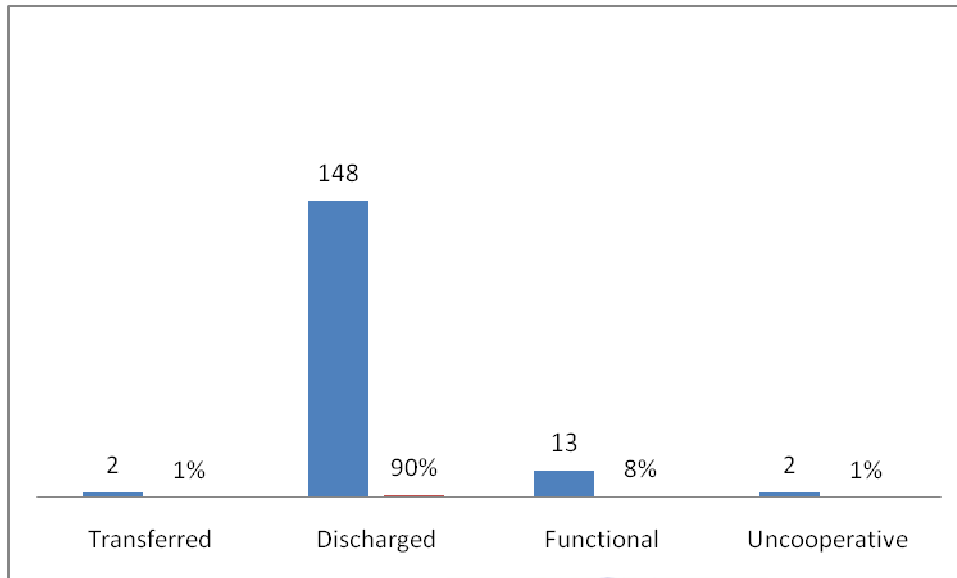
**TABLE 4.8: Physiotherapy Sessions vs. Length of hospital stay (n=165)**

TOTAL PATIENTS	Length of hospital stay						Total	
	2-3		4-7		8-41			
1	15	28%	33	61%	5	9%	54	100%
2-3	3	4%	52	63%	27	33%	82	100%
4+	0	0%	4	13%	26	87%	30	100%
Total	18	11%	89	54%	58	35%	165	100%

In the study, 63% of the participants had between two and three physiotherapy sessions, while being admitted for between four and seven days. A statistical significant relationship was found between the number of physiotherapy sessions and length of hospital stay ( $p=0005$ ).

#### 4.7.4 Discontinuation of Physiotherapy

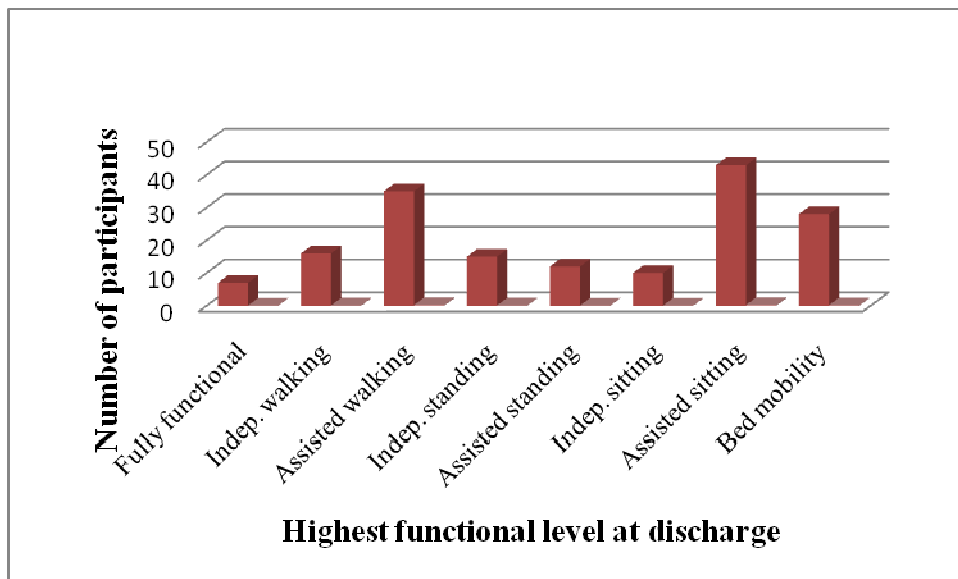
The reasons for the discontinuation of physiotherapy is presented in Figure 4.7

**FIGURE 4.7: Reasons for discontinuation of Physiotherapy**

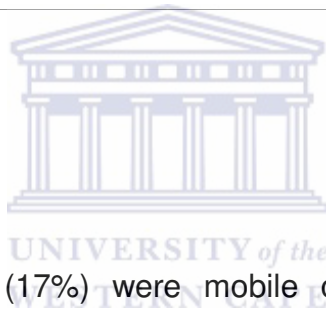
Most of the participants (90%) were discontinued from physiotherapy due to the fact that they were being discharged from hospital. Eight percent of participants were discharged from physiotherapy treatment due to their good functional level.

#### 4.7.5 Highest Functional Level of Participants on Discharge from Hospital

The information in the following section was obtained from the clinical notes that the physiotherapists had made in the hospital folders of the patients.

**FIGURE 4 8: Highest Functional Level (n=165)**

Key: Indep=Independent



Of the participants, 28/165 (17%) were mobile only in bed; 26% or 43/165 participants still needed support with sitting, and only 6% could achieve independent sitting. Twelve of the participants needed assistance to stand and 9% of or 15 participants could stand independently. Assistance during walking needed to be given to 21% (35/165) of the participants, while 10% of or 16 participants could walk independently. Only 4% of the participants were fully functional in all aspects of daily living at the time of their discharge from hospital.

#### 4.7.6 Caregiver education

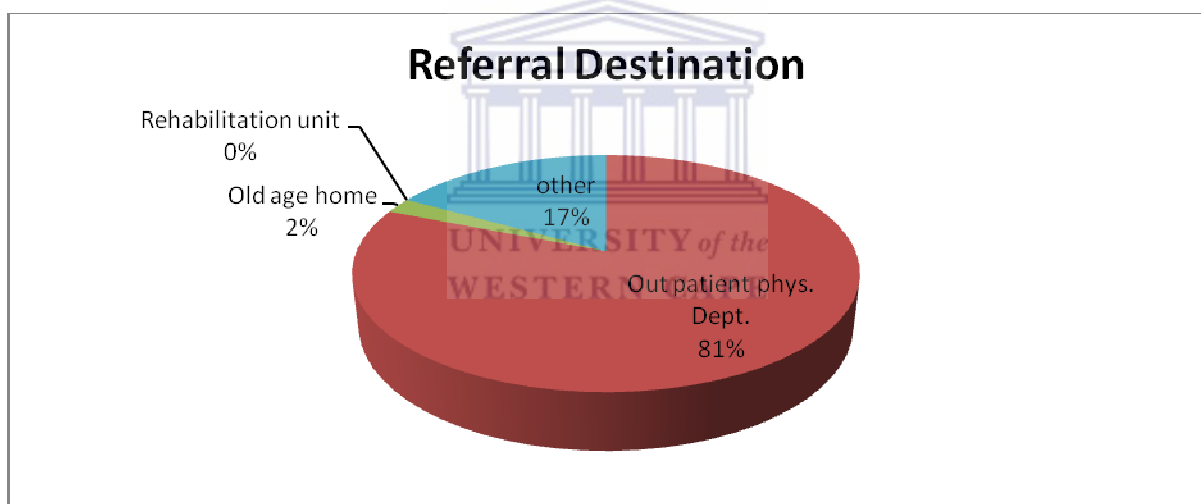
Stroke education had been given to only 60 (37%) of the families of the participants prior to discharge. Of the admitted patients, 94 had been referred for further

physiotherapy treatment. The most common referral destination was the Outpatient Physiotherapy Department at the Uitenhage Provincial Hospital.

#### 4.7.7 Referral at hospital discharge

This section will examine referral destination sites for the continuation of physiotherapy.

**FIGURE 4.9: Referral Destination**



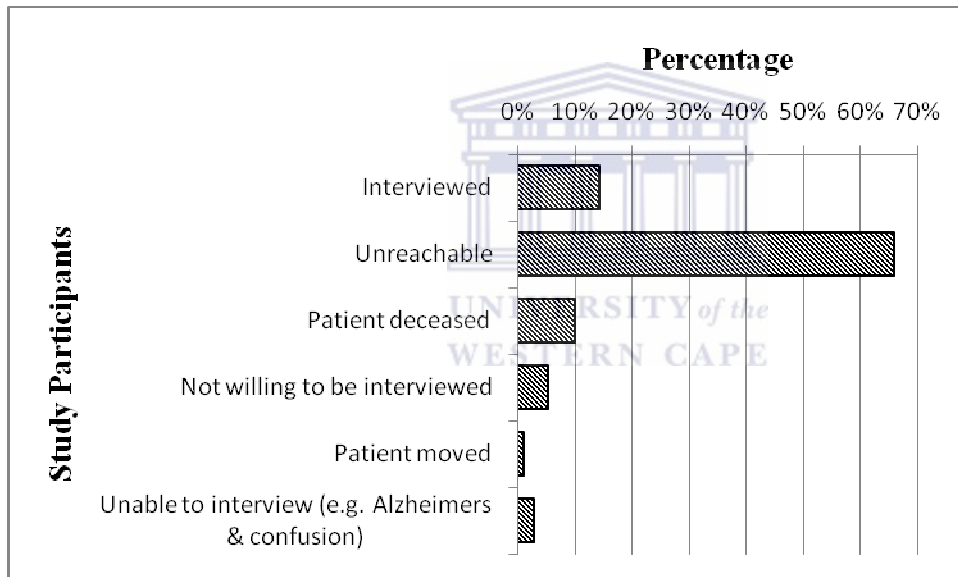
Of the admitted patients, 94 had been referred for further physiotherapy treatment. Eighty one percent of these the patients had been referred for follow-up treatment at the Out-patient Physiotherapy Department at the Uitenhage Provincial Hospital. None of this study population had been referred to a rehabilitation unit.

## SECTION B : PROSPECTIVE STUDY

A prospective follow-up study was conducted to determine the functional status of the participants post discharge from hospital.

### 4.8.1 Recruitment of Study Participants

**FIGURE 4.10: Study Participants (n=168)**



Of the 168 participant folders obtained, only 24 (14,3%) participants could be accessed and agreed to be interviewed for the purpose of this study. More than 60% of the cohort could not be reached, either due to telephone numbers being changed, incorrect telephone numbers documented in the folders, or telephone numbers that were out of service.

## 4.8.2 Ability to perform activities of daily living

### 4.8.2.1 Barthel Index Scores

The Barthel Index Scores are presented in Table 4.9.

**TABLE 4.9: Barthel Scores (n=24)**

Barthel Score	Number of Participants	Percentage
0-20	2	8%
21-40	0	0%
41-60	2	8%
61-80	5	21%
81-100	15	63%
TOTAL	24	100%

The majority of the participants scored between 61-100 on the Barthel score sheet, with a mean score of 81,46 and a standard deviation of 27,92.

### 4.8.2.2 Barthel and age

The relationship between age at time of stroke and the Barthel Index Score is presented in Table 4.10.

**TABLE 4.10: Age and Barthel Index Score**

Age at time of stroke onset	TOTAL					
	0-85		90-100		Total	
20-59	4	33%	8	67%	12	100%
60-90	6	50%	6	50%	12	100%
Total	10	42%	14	58%	24	100%

No significant statistical relationship was found between age at stroke and the higher Barthel scores ( $p=,408$ ).



#### **4.8.3 Participation restrictions of participants**

The participation restrictions experienced by the participants were measured using the Structured interview of the Modified Rankin Scale. The domains of participation that were measured included work, caring for family, and engaging in social activities.

The results in this section will represent the level of change in ability to perform certain tasks/functions post stroke.

**TABLE 4.11: Domains of Participation Restriction of Participants (n=24)**

<b>Work Ability (n = 8)</b>		
reduced level of work	4	50%
unable to work	4	50%
<b>Family Care (n = 15)</b>		
reduced responsibility looking after family	13	87%
unable to look after family	2	13%
<b>Social Activities (n = 11)</b>		
participation much less/less than half as often	6	55%
unable to participate	5	45%

Eight of the participants interviewed, stated that they had experienced a change in their ability to work post stroke. More than half of the participants interviewed, stated that they had experienced a change in their ability to look after family members at home. Less than half of the participants stated a change in free time/social activities post stroke. Five of the participants stated that they had been unable to participate in social/free time activities post stroke.

Only ten of the participants interviewed, mentioned problems with relationships with others post stroke. Half of these experienced problems on an occasional basis, which is less than weekly, while 40% experienced constant problems.



#### 4.8.4 Facilitators and Barriers

This section will present the results relating to the barriers and facilitators experienced by the participants with regard to activity participation, as measured by FABS. It will also present the activity limitations experienced by the participants, as well as the participation restrictions experienced by the participants.

##### 4.8.4.1 Mobility Devices

This section will look at the different mobility devices that participants use within their home and community settings.



**TABLE 4.12: Mobility Devices used in Home and Community**

<b>Assistive devices</b>	<b>Number of Participants</b>	<b>Percentage of Participants</b>
Canes	5	21%
Crutches	2	8%
Manual wheelchairs	4	17%
Walkers	1	4%
Other	2	8%
Do not use any device	10	42%

Over 40% of the cohort did not use any mobility devices when going out of the home or into the community. A total of 21% of the participants made use of canes/quadropods, while 17% used manual wheelchairs. Of the participants who used mobility devices, 79% stated that they always used these when they had to move about in their homes or the community, and 86% said that the devices that they used, helped them considerably to be mobile in their environment.

#### 4.8.4.2 Home and Community Environmental Barriers

The relationship between the environmental barriers (either found in the home or in the community) and the effect thereof is depicted in Table 4.13.

**TABLE 4.13: Barriers (Home/Community) and Effect of Barrier on Participation (n=24)**


Barrier	UNIVERSITY of the WESTERN CAPE		Total/Percentage
	Limits a lot	Limits some	
Stairs home	6	6	12(50%)
Gravel home	6	5	11(46%)
Outside kerb (home)	4	11	15(66%)
Community kerb	4	11	15(66%)
Gravel community	5	6	11(46%)
Summer weather	3	9	12(50%)
Rainy weather	8	10	18(75%)
Noise levels	4	5	9(37%)
Crowds	4	4	8(33%)

Stairs, kerbs and gravel surfaces were environmental features mentioned by the participants that acted as a barrier to their participation. Rainy weather had an effect on participation in 75% of the participants. Summer weather was mentioned by 50% of the participants as also having an influence on participation. Noise levels and crowds were mentioned as having an effect on participation in 37% and 33% of the participants respectively; in all cases, it limited participation of those participants.

#### 4.8.4.3 Home and Community Environmental Facilitators

The relationship between the environmental facilitator (either found in the home or in the community) and the effect thereof is depicted in Table 4.14.

**TABLE 4.14: Environmental Facilitator and Effect (n=24)**



Facilitator home and community	Effect			Total/Percentage
	Helps somewhat	Helps a lot		
Ramp home	1	1		2(1%)
Ramp community	4	2		6(25%)
Flat terrain at home	1	14		15(63%)
Flat terrain in community	1	14		15(63%)
Paved home	1	1		2(1%)
Paved community	1	9		10(42%)

Only six of the participants had come into contact with ramps in the community environment in which they lived, and all stated that those facilitated participation. Flat terrains were mentioned by 63% of the participants, and all of them stated that those facilitated participation.

#### **4.8.4.4 Community Destination Sites**

This part of the survey focused on the accessibility of various places within the community. Sites included in this survey were local grocery stores, clinic/doctor's offices, religious institutions, restaurants (fast food/dine-in), shopping malls, clothing stores, movies, libraries and sport fields.

From the results it became clear that a huge proportion of the participants did not visit the following community site destinations: grocery stores: 58%; fast food restaurants: 83%; restaurants: 79%; movies: 92%; sports fields: 88%; shopping malls: 67%; and clothing stores: 58%.

Eighteen of the 24 participants stated that their local doctor's office buildings or the local clinics were accessible. Two participants stated that access to their local clinic was limited by lack of parking and lack of transportation. Nine participants found their local church building to be accessible, while two found that it limited their participation. Of those that found that it limited participation, lack of transport and physical structure were stated as reasons.

#### 4.8.4.5 Services and attitudes

The following section will examine the frequency that the participants accessed help from certain persons within their community. It will also look at the effect of such service received on participation and the effect that the attitudes of the persons rendering the service has had on the participant or participants.

**TABLE 4.15: Frequency of use of services by participants (n=24)**

Person Rendering Service/Assistance	FREQUENCY OF SERVICE / HELP						
	MORE THAN TWO TIMES PER WEEK	ONE OR TWO TIMES PER WEEK	ONE OR TWO TIMES PER MONTH	ONE OR TWO TIMES PER YEAR	RARELY	NEVER	TOTAL
Doctor/Clinic Sister	1	2	15	3	3	0	24
Therapist	0	0	3	4	5	12	24
Paid Personal Assistant	1	0	0	0	0	23	24
Family Members	14	3	2	1	3	1	24
Friends	1	0	2	2	8	8	24
Peers	1	0	1		1	21	24
Store Clerks	0	0	2	0	1	21	24
Strangers	0	0	0	0	0	24	24

Most participants(15/24) in this study sought the services of their doctor or local clinic one to two times a month. Participants heavily relied on family members to render certain services to them.

**TABLE 4.16: Effect of Service on Participation**

Person Rendering Service/Assistance	EFFECT OF SERVICE ON PARTICIPATION					
	HAL	HS	NOEF	LS	LAT	TOTAL
Doctor/Clinic Sister	18	4		1	1	24
Therapists	8	2	1			11
Paid Personal Assistant	1	0	0	0	0	1
Family Members	21	1	0	1	0	23
Friends	7	0	0	1	0	9
Peers	2	0	0	1	0	3
Store Clerks	2	1	0	0	0	3

Key: HAL=Helps a lot, HS=Helps somewhat, NOEF=No effect, LS=Limits somewhat  
LAT=Limits a lot

Service received by the doctor and family members was seen as facilitators by most of the participants in this study. Only eleven of the participants interviewed, had continued with physiotherapy on discharge from hospital. Nine of those found physiotherapy to be a facilitator in their participation.

**TABLE 4.17: Attitude of Service Providers on Participation**

Person Rendering Service/Assistance	EFFECT OF ATTITUDE OF SERVICE PROVIDERS ON THE USE THEREOF						
	HAL	HS	NOEF	LS		LAT	TOTAL
Doctor/Clinic Sister	20	0	0	1		3	24
Therapist	9	0	1	1		0	11
Paid Personal Assistant	1	0	0	0		0	1
Family Members	22	0	0	1		0	23
Friends	8	0	0	0		1	9
Peers	2	0	0	0		1	3
Store Clerks	2	1	0	0		0	3

**Key:** HAL-Helps a lot, HS-Helps somewhat, NOEF-No effect, LS-Limit somewhat  
LAT-Limit a lot

Most of the participants in this study found that the attitudes of the different service providers had facilitated participation.

#### 4.9 SUMMARY OF QUANTITATIVE RESULTS

A total of 461 patients were admitted for stroke between 1 January 2008 and 31 December 2009. Of these, 181 were excluded because they did not meet the study criteria, and 112 of the patient folders could not be found. The total population left was 168, and all the retrospective data were obtained from these folders.

The study sample consisted of more females (59%), than males (41%). The mean age of the participants was 61,54 years, with ages ranging from 20 to 90 years. Eighty nine percent of participants were admitted on the day of stroke onset, and 72% suffered from FES. Hypertension was the most common risk factor at 79,3%, and most of the participants in the study had one or two risk factors present at the time of stroke. In this study, more males (57%) than females (25%) were being cared for by their spouses, while most females (66%), were being cared for by their children.

A total number of 165 participants had received physiotherapy while admitted to hospital. Of these, 36% started with treatment on the second day post hospital admission, with a mean of 2,44 days post admission and a standard deviation of 1,63.

Of the 168 participant folders obtained, only 24 participants could be reached and agreed to be interviewed for the purpose of the study. Eight of the participants interviewed, stated that they had experienced a change in their ability to work post stroke. Four stated that they had been unable to work since the stroke. More than



half of the participants interviewed, stated that they had experienced a change in their ability to look after the family at home.

Participants stated that stairs, kerbs and gravel surfaces were barriers to their participations, while flat terrains, ramps and paved surfaces acted as facilitators.

Participants heavily relied on family members to render certain services to them and had experienced that the services received by the doctor/nurse and family members, as well as their attitudes, had facilitated their participation in their environment.



## CHAPTER FIVE

### QUANTITATIVE DISCUSSION

#### 5.1 INTRODUCTION

This chapter will discuss the findings of the quantitative phase of the current study with reference to relevant literature. The findings will be discussed under the following main sections: demographic profiles; medical profiles; stroke onset; length of hospital stay and physiotherapy process; activity limitations; participation restrictions; and barriers and facilitators post stroke.

#### 5.2 DEMOGRAPHIC PROFILES OF PARTICIPANTS

The following items will be discussed under demographic profiles, age, gender and marital status.

The mean age of the participants in the current study was 61,54 years – younger than that in a study conducted in Germany, where the mean age was 68 years (Dodel, Haacke, Zamzow, Pawelzik, Spottke, Rethfeldt, Siebert, Oertel, Schoffski & Back, 2004). A higher mean age at stroke was also found in studies by Azarpazhoo *et al.* (2010), which recorded a mean age of 65,2 years and by Ostwald, *et al.* (2006), which recorded a mean age of 66,2 years. A South African based study by Biggs and Rhoda (2008), had a mean age of 61,4 years, which is similar to the present study.

A prevalence study in the Limpopo Province by the South African Stroke Prevention Initiative established that the highest stroke incidence was among people aged 65 years and older (SASPI, 2004). It was noted that 31,5% of the participants fell in the age group 50-59 years, while 25% fell in the age group 60-69 years. The pensionable age in South Africa is 60 years for females, and 65 years for males. A large proportion of the current study population fall within the economically active group of the country's population. An immense proportion of the study population (91%) were not employed at the time of the stroke. According to Statistics South Africa, the Eastern Cape has the second highest poverty levels in South Africa, combined with the highest provincial unemployment rate (55%) in the country (Stats SA, 2005). A study done by Loeb, Eide, Jelsma, Toni and Maart, (2008) established that in the Eastern Cape only 6% of population members of working age (15-65 years) were working. The majority of the participants in the current study were unemployed at the time of stroke. Their disability as a result of the stroke will hinder their ability to look for paid employment. The state will therefore have to provide financially, by means of a disability grant, for a group of people who should still be working to support themselves. A disability grant is an income support measure given to people who are physically or mentally disabled, unfit to work or unable to support themselves (Department of Social Development, 2012). A permanent disability grant will be given to an individual whose disability continues for more than a year (South Africa Government Services, 2012). The fact that the state has to provide for those who could have still been economically active, increases the financial impact on the state.

The present study consisted of more females (59%) than males (41%). These results are consistent with the results (54% females and 46% males) found in studies done by Rhoda and Hendry (2002) and in Biggs and Rhoda (2008) (59,2% females and 40,8% males) in South Africa. Different results were however, found in international studies. In a study by Ostwald *et al.* (2006), the study population consisted of 76,3% males. Four other studies found an increase occurrence in males compared to females. These studies were Saxena *et al.* (2006) (54%); Van der Port *et al.* (2006), (59%); Bonaiuti, Sioli, Fumangalli, Beghi, Agostoni (2011) (60%); and Balabon, Tok, Yavuz, Yasor & Alaca (2011), in which 62,5% were recorded.

It has been shown that women generally take care of the domestic duties at home (Henderson, 1998). More females experienced stroke in the current study, implying that there would have been an immediate effect on the internal household structure. Others within the household would have had to take on the responsibilities of domestic duties, that the female stroke patient had been fulfilling.

There is a notable significant association between gender and marital status in relation to those who have been widowed. More females (88,9%) than males (11,1%) were widowed at the time of stroke. This could be linked to the results indicating that the females in the study were generally older than the males. According to Beales (2000), this is to be expected, since females are known to live longer than males. Worell (2001) states that women are much more likely to become widowed than men, since they have a longer life expectancy and also tend to marry older men. Also, following a divorce or the death of a partner, women are unlikely to remarry (Worell, 2001). This explains the fact that in this study, more males (76%)

were married than females (53%). In the current study, 57% of the males were being cared for by their spouses, while 66% of the females were being cared for by their children. The occurrence of the child caregiver could be linked to the fact that 47% of the females in the study were not married, widowed, divorced or separated. A study conducted by Cho, Suh, Kim, Hong & Kim (2000) established that spouses could be a source of practical help and emotional support. It has been shown that women are generally the main informal caregivers and when women do care giving duties, it is considered an extension of their domestic responsibilities (Henderson, 1998). Wasserman, De Villiers and Bryer (2009), found in their South African based study that 90% of primary caregivers of stroke survivors were female.

### **5.3 MEDICAL PROFILE OF PARTICIPANTS**



This section will discuss the findings around the clinical features and risk factors for stroke among the participants. Data on clinical features and risk factors for stroke were collected to determine a medical profile of the participants.

#### **5.3.1 Recorded stroke clinical features among participants**

A total of 72,3% of the overall participants suffered from a first-ever stroke, followed by 22% who had suffered a second and 4,8% who had suffered a third or more occurrence. According to the American Heart Association, about 795 000 Americans annually experience a new or recurrent stroke. Of the aforementioned total, approximately 600 000 first-ever stroke (FES), and about 185 000 a recurrent stroke (American Heart Association, 2009). In a study conducted in Iran, a first-ever stroke

was recorded in 91,2% of the participants (Azarpazhooh *et al.*, 2010). The same study found the crude annual incidence of first-ever stroke to be 139 per 100 000; 144 per 100 000 men and 133 per 100 000 for women. In a South African-based study, 77% of the cohort had suffered a first-ever stroke, followed by 10% who had suffered a second occurrence and 13% who had had more than two episodes of stroke (Rhoda & Hendry, 2003). Since most of the participants suffered a FES, education regarding occurrence and recurrence is of the utmost importance. Health professionals should educate stroke survivors, as well as their caregivers, on stroke prevention.

It was noted in this study that hemiplegia post stroke was mostly prevalent on the left side of the participants (at 54%), while right-sided hemiparesis was recorded in 41% of the participants, while 5% of the participants had been affected in both sides. This result is similar to a study by Ones *et al.* (2005), in which 60,2% left-sided hemiparesis was recorded among the participants, and 39,72% right-sided hemiparesis. In a study by Balabon *et al.* (2011), 52,5% of the participants had left-sided hemiparesis, while 47,5% had right-sided hemiparesis. The difference in the results of the two studies mentioned may be explained by the different methodologies used in the studies. The study by Balabon *et al.* (2011), was conducted in a rehabilitation setting and had a small sample size (n=80). The study conducted by Jette *et al.* (2005) was also conducted at a rehabilitation setting, but used a bigger sample size of 972 participants. The study by Ones *et al.* (2005) had a sample size of 88 participants. Right-sided hemiplegia is associated with speech problems (Barker-Collo & Feigin,2006).

### 5.3.2 Risk Factors among Participants

The study found that hypertension (79%) was the most prevalent risk factor in the study population. This was followed by diabetes (32%), smoking (26%), alcohol abuse (17%), cardiac disease (8%) and other risk factors (6%).

This result is similar to the results of various studies, which established that hypertension was the most prevalent risk factor among stroke survivors. Leoo *et al.* (2008), found in a study of 889 patients who had suffered recurrent strokes, that hypertension was the most frequently observed risk factor, at 75%. Scott *et al.* (2010), found that 75% of the cohort had hypertension, as did Hasen, Hasan & Mukhelif (2010). Thorogood *et al.* (2007) and Connor, Modi and Warlow (2006), found in their two South African based studies that hypertension was the most common risk factor in stroke at 42% and 69% respectively. Similar results to that found in this study were recorded in the study by Rhoda and Hendry (2003), in which 73% of the population had hypertension, followed by smoking (29%) and diabetes (27%). Hypertension has been found across literature to be the most prevalent risk factor related to stroke. It is therefore disturbing to note that hypertension still remains the most prevalent risk factor documented in this current study. This raises the question whether interventions with regard to modification and management of risk factors are reflective.

Modifiable risk factors such as hypertension, diabetes, cardiac disease and smoking, were documented, either alone or in a combination with one another in the current study and in previous studies (Scott *et al.*, 2010; Leoo, *et al.* (2008); Rhoda &

Hendry (2003); Radanovic (2000)). A total of 68 (40%) participants had only one risk factor present. Those that had two risk factors present, amounted to 67 (40%) of the total number of the participants. Three risk factors were present in 20(12%) of the participants, while four risk factors were present in 3% of the participants. A study done by Ostwald, *et al.* (2006), established that stroke survivors experience an average 2,38 stroke related comorbidities.

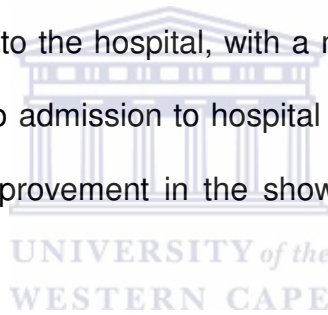
Other common risk factors found in the current study were diabetes (32%) and smoking (26%). These results are lower than those found in studies by Saxena *et al.* (2006) and Hasan *et al.* (2008), in which the occurrence of diabetes was 47% and 52% respectively, and smoking 45% and 61,5% respectively. It is estimated that about six million people in South Africa are hypertensive, with seven million smokers and three to four million diabetics who are all at risk of having a stroke (Department of Health, 2000). The improved management of the risk factors could be key to reducing the stroke mortality figures in South Africa and the number of individuals living with disabilities as a result of strokes. The management and the control of modifiable risk factors are of extreme importance. A huge percentage of the population suffers from hypertension, either as a sole risk factor or in combination with other risk factors. The proper use of medication could play a significant role in the management of the chronic condition. Important components of successful adult learning include interaction between the learners (stroke patients and caregivers) and teachers (health professionals) (Hanger & Wilkinson, 2001). Physiotherapists are in a good position to offer health education regarding stroke prevention and recurrence. Physiotherapists surveyed in a study by Schmid, Butterbaugh, Egolf, Richards, Williams (2008) used verbal instructions and printed literature to teach



their stroke patients about stroke risk factors. As with learning many new skills in life, repetition is the key. Therefore, health professions should reiterate the importance of stroke risk factor management on every available contact with their stroke patients and caregivers, to prevent or reduce the recurrence of another stroke.

#### **5.4 STROKE LENGTH OF HOSPITAL STAY**

The majority of the participants (86,9%) were admitted to hospital on the same day of the stroke onset. Findings by Hong, Kang, Koo, Yu, Han, Cho, Park, Bae & Lee (2008) were that 30,3% of patients were admitted to hospital between 6-24 hours following stroke onset. In a South African-based study, the authors found that most of the patients presented late to the hospital, with a mean delay of almost two days from the onset of symptoms to admission to hospital (Wasserman *et al.*, 2009). The current study recorded an improvement in the shown delay of hospital admission following a stroke.



On average patients, in the current study stayed in hospital for between five and nine days, while in the Wasserman study, the average length of hospital stay was six days (Wasserman *et al.*, 2009). In a retrospective study by Bonaiuti *et al.* (2011), the average length of hospital stay for men was 9,7 days and for women 10,8 days. The average length of stay of stroke patients managed in the medical wards in Calgary was 19 days (Zhu *et al.*, 2009) and the average length of stay in high-income countries such as the Netherlands and United Kingdom were around 28-34 days (Green *et al.*, 2005). Therefore, the average length of stay of this study is similar to the Wasserman study which was also conducted in South Africa.

Jette, Latham, Smout, Gassaway, Slavin & Hoorn (2005), found that patients that were discharged earlier from acute treatment hospitals were discharged to rehabilitation facilities or long-term care facilities. This, however, is unfortunately not the case at the Uitenhage Provincial Hospital. In South Africa, stroke is usually managed as part of a generalised medical service. Protocols for stroke care have not been developed at most hospitals and human resources and funding shortages and pressure for hospital beds frequently result in stroke patients being discharged too early (Bryer *et al.*, 2011).

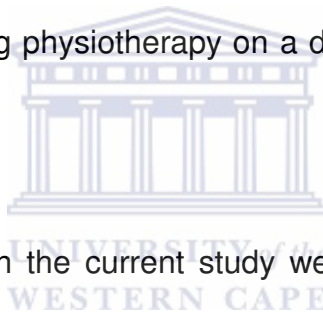
Green *et al.* (2005) found that patients with stroke in South Africa were discharged with a lower functional status than Finnish and Australian patients. Inadequate rehabilitation and poor functional status at discharge result in patients going home to unprepared caregivers, with the potential of placing an enormous burden on them (Khondowe, Rhoda & Mpofo, 2007). Patients' functional status is one of the determinants of quality of life in patients with stroke and their caregivers (Jonsson, Lindgren, Hallstrom, Norrving & Lindgren 2005). It is thus of concern that studies in South Africa found that there is insufficient focus on early intervention and the early rehabilitation of patients with stroke and that rehabilitation sometimes occurs quite a long time after the initial acute episode (Green *et al.*, 2005).

#### **5.4.1 Physiotherapy Process**

The physiotherapy intervention that was investigated in this study, included participants that had received physiotherapy during their hospital stay. The

commencement of the physiotherapy since admission, its frequency and the duration of the physiotherapy before discharge will be discussed below.

The study revealed that a total number of 165 (98%) of the participants who were referred for physiotherapy received physiotherapy during their hospital stay. In developed countries like Belgium and Switzerland, physiotherapy comprises an important and relatively large component of the rehabilitation of stroke patients (Jette *et al.*, 2005). Physiotherapy in the current study started one day following admission to hospital in 24% of the participants, with 65% of the participants received daily physiotherapy sessions. In a study by Galvin, Cusack and Stokes (2009), 63% of the respondents reported receiving physiotherapy on a daily basis. This result is similar to the current study finding.



The physiotherapy sessions in the current study were discontinued in 90% of the cases due to the patients being discharged from hospital. Only 4% of the participants in this study were discharged from physiotherapy sessions as they reached the appropriate level of function. The increase in the financial constraints on the healthcare system (Anderson *et al.*, 1992) and, in addition to that, the pressure for beds (Bryer *et al.*, 2011) have prompted a shift from institutional care to community care. The study found that the average length of hospital stay was between 5 to 9 days, compared to high income countries, where patients were admitted to hospital between 28-34 days. Also, as mentioned previously, a small amount of participants were discharged from physiotherapy due to good functional ability. Therefore, more often than not, stroke patients are sent home prematurely, as was the case in this study, to families that have to cope with changed individuals without prior training on

how to manage them and with little or no supported care (Hankey, 2004; Hale, 2002) as previously mentioned in the literature.

Stroke education in this study had been given to only 60 (37%) of the families of the participants prior to discharge. In another South African-based study, all patients were discharged into family care, as there was no stroke rehabilitation facility, while two-thirds of the families in that study had not received any stroke education on or before discharge (Wasserman *et al.*, 2009). These results are similar to findings by Galvin *et al.* (2009), with 79% of the respondents in their study reporting that their family members had not been invited to attend any of their physiotherapy sessions, since they commenced physiotherapy post stroke onset. Despite the fact that patients are discharged early from hospital, probably still needing some interventions to improve their level of functioning, only a small percentage of caregivers are provided with education upon or prior to hospital discharge. In the study of Khondowe *et al.* (2007), the caregivers of stroke survivors expressed the need to gain information about stroke as well as training in caring for the patient at home.

## **5.5 ACTIVITY LIMITATIONS AND PARTICIPATION RESTRICTIONS**

### **5.5.1 Activity Limitations**

Of the 168 participant folders obtained, only 24 participants could be reached and agreed to be interviewed for the purpose of the study. Most of the participants interviewed, had a Barthel score of between 61-100, with a mean score of 81,46. These results imply that the majority of the participants were able to perform

functional activities. However, a Barthel Index score of 100 does not mean that a patient is independent or able to live alone and would for example, be able to shop or use transportation (Uyttenboogaart, *et al.*, 2007).

### 5.5.2 Participation Restrictions

Eight of the participants interviewed mentioned that they had experienced a change in their ability to work post stroke. Of these, 50% mentioned that they had been unable to work since the stroke. The majority of the interviewed participants mentioned a change in their ability to care for their family post stroke. In a qualitative study by Wood *et al.* (2010), an inability to fulfil previous roles had led to dissatisfaction in participants. Participants were upset to see others assume the roles and responsibilities that they could no longer perform. This major change in ability and roles had resulted in a sense of rolelessness, which could result in participants becoming depressed (Dowswell *et al.*, 2000).

Six of the participants mentioned a decreased ability to participate in social activities post stroke, compared to before stroke onset. Only five participants stated that they had been unable to participate in social activities since the stroke. Stroke patients' self assessment scores in a multi-centre longitudinal cohort study in KwaZulu-Natal, South Africa reflected a reduction in participation in activities after stroke in the categories of work, social, housework/family care, community and sporting activities (Wasserman *et al.*, 2009), which is a similar finding to that of the current study. Social isolation can lead to a myriad of feelings consisting of being a burden, helpless, frustrated, depressed, sad and angry (Dowswell *et al.*, 2000).

Various studies have looked at functional outcomes and patients' ability to participate in their community post stroke (O'Donovan *et al.*, 2009; Barker *et al.*, 2006; Hamel *et al.*, 2006;). O'Donovan *et al.* (2009) established that a high proportion of participants experienced restrictions to employment, socialising and leisure. In the same study, about 41% of the participants stated that the difficulties that they experienced, had interfered with their life. In a study by Barker *et al.* (2006), the participants also mentioned that they experienced difficulties in participating in social activities. These participants mentioned that the impairments that they experienced as a consequence of the stroke had resulted in their decreased engagement in social activities. Problems relating to mobility impairment were stated as reasons for the decreased participation (Barker *et al.*, 2006).

In this study, the activity limitations and participation restrictions were therefore further explored, using qualitative interviews (to be discussed in more detail in Chapter Six).

## **5.6 FACILITATORS AND BARRIERS EXPERIENCED BY PARTICIPANTS**

Most of the participants in the current study had been making use of some sort of mobility device post stroke. Over 86% of these mentioned that the mobility device that they used served as a facilitator. Similar results were found in a study by Alguren, Lundgren-Nilsson and Sunnerhagen (2009), in which participants perceived walking devices, wheelchairs or other assistive devices as facilitators. Participants in a study by Hamel *et al.* (2006) discussed barriers to participation when using mobility

devices. They highlighted the fact that certain environments did not consistently support access with a particular device, thereby rendering the specific device in that situation a barrier instead of a facilitator (Hamel *et al.*, 2006).

The home and community barriers that were frequently reported by the study participants were stairs, kerbs and gravel surfaces. These home and community physical environmental features have been mentioned by participants as having an effect on their participation. All of the participants in this study stated that these features limited their participation within their home and community. The physical environment was found in some studies to be the most common barrier to participation (O'Donovan *et al.*, 2009; Levasseur, Desrosiers & Tribble, 2008). In a study that focused on the experience of stroke survivors, similar barriers to those in the current study were mentioned, which included heavy doors, stairs, uneven sidewalks and rough terrain (Barker, Reid & Cott, 2006). Reid (2004) found that the outside of their homes (uneven ground and stairs) acted as a barrier to participation for many individuals who had suffered a stroke. The barriers mentioned by the participants result in reduced activity levels and participation. This reduction in activity levels and participation could, conversely, result in the participant becoming increasingly isolated socially (Dowswell *et al.*, 2000).

Ramps, flat terrain and paved surfaces were mentioned by the participants in the current study as facilitators within their home and community environments. Facilitators in the environment mentioned in a study by Barker *et al.* (2006) were similar to those mentioned in the current study. Although the ramp was mentioned as a facilitator, only a small portion of the study participants had access to ramps.

Comparing the facilitators and the barriers, participants more frequently came into contact with home and environmental barriers. This can then be linked to a reduction in participation in those environments.

The majority of the study participants experienced no problems when visiting their local clinic or doctors' offices. None of the participants experienced problems with the physical structure of these buildings. Two participants mentioned that they struggled with access to these sites due to lack of parking and lack of transportation. Inaccessible physical environments have been reported in the literature to hinder access to certain services (Rimmer, Rubin & Braddock, 2000). However in the present study, physical access was reported as generally good by the participants, which will then lead to an increase in community participation.

Most participants in this study sought the services of their doctor or local clinic one to two times a month. Participants relied heavily on family members to render certain services to them. The study participants reported that the services that they received, were good and that the attitudes of the service providers acted as facilitators to them. The study findings are similar to results found in studies by Alguren *et al.* (2009) and Gray *et al.* (2008), in which participants found family, friends and colleagues to be facilitators and described family and health professionals' attitudes to be supportive. Receiving service of good quality and pleasant attitudes will definitely be considered as an indicator of continued participation in the varied instances.



## 5.7 SUMMARY OF CHAPTER

The retrospective study discussed the profile of the relevant group of stroke patients that had been admitted to the Uitenhage Provincial Hospital. In this part of the study, the profile of this specific group of participants was discussed. The predominant risk factors and clinical features of stroke are well established. The prospective part of the study further examine the various changes that these participants had experienced as a result of a stroke, such as activity and participation restrictions. Home and community barriers and facilitators were explored, as well as the services received by the participants. The results indicate that many participants still experienced continued challenges post stroke.



## CHAPTER SIX

### QUALITATIVE RESULTS AND DISCUSSION

#### 6.1 INTRODUCTION

The qualitative phase of the study explored the barriers and facilitators experienced by stroke survivors with regard to activity and participation. Due to the fact that this part of the study took place a few months after the initial interviews, certain logistic problems crept in again. Telephone numbers of the participants changed or were disconnected, some of the participants had relocated, others fell ill and were unable to be interviewed and some of the participants we could not get hold of. This chapter will first present a description of the nine participants that were contacted and agreed to be interviewed. The pre-determined themes fit into the ICF framework of activity limitations, participation restrictions and environmental barriers (World Health Organisation, 2001).

Verbatim quotations of data from the interviews will be used in this chapter. For the intent of anonymity and confidentiality, these transcribed interviews will be cited in cryptogram P1 to P9. The emerging themes and their subcategories will be discussed with reference to relevant literature.

## 6.2 DESCRIPTION OF PARTICIPANTS

Semi-structured interviews were conducted with nine participants. Six of the nine were female, and three were male. The age of the participants ranged from 39 to 73 years; the youngest being a female and the eldest a male. Six of the participants were married, one was single and one was widowed.

**TABLE 6.1: Demographic data of participants**

<b>PARTICIPANT NUMBER</b>	<b>GENDER</b>	<b>CHRONICITY OF STROKE</b>	<b>MARITAL STATUS</b>	<b>AGE</b>	<b>CAREGIVER</b>	<b>EMPLOYMENT STATUS</b>
1	FEMALE	FIRST-EVER	WIDOWED	65	CHILDREN	PENSIONER
2	FEMALE	FIRST-EVER	MARRIED	53	HUSBAND/CHILD	UNEMPLOYED
3	MALE	FIRST-EVER	MARRIED	66	WIFE	PENSIONER
4	FEMALE	FIRST-EVER	SINGLE	39	NIECE	UNEMPLOYED
5	MALE	FIRST-EVER	MARRIED	73	WIFE	PENSIONER
6	MALE	FIRST-EVER	MARRIED	70	WIFE	PENSIONER
7	FEMALE	SECOND	MARRIED	62	HUSBAND/CHILD	UNEMPLOYED
8	FEMALE	THIRD/MORE	LIVING TOGETHER	48	LIFE PARTNER	UNEMPLOYED
9	FEMALE	SECOND	MARRIED	49	HUSBAND/CHILD	UNEMPLOYED

Support structures of these participants consisted mostly of family support, either from the spouse or the children.

### 6.3 PRE-DETERMINED THEMES AND SUBCATEGORIES

The results of the study were analysed within the pre-determined themes of activity limitations and participation restrictions, as conceptualised within the ICF. The categories that emerged within the pre-determined themes relating to the barriers and facilitators are presented in the table below.

**TABLE 6.2: Pre-determined Themes and Emerging Sub-themes and categories**

<b><u>PRE-DETERMINED THEME</u></b>	<b><u>EMERGING SUB-THEME</u></b>	<b><u>EMERGING CATEGORIES</u></b>
Activity limitation	Walking ADL	Fear of falling Fatigue Impairments Environmental barriers Limitations in self care
Participation restrictions	Dependency Social support Emotions Environmental barriers Environmental facilitators Participation facilitators	Inability to drive Decreased support Decreased social interaction Sadness Loss of independence Stairs and uneven surfaces Railings Physiotherapy

### 6.3.1 Activity Limitations

#### 6.3.1.1 Walking

The most common activity limitations mentioned by participants were walking and ADL.

##### 6.3.1.1.1 Fear of falling

The most common reason for activity limitations stemmed from the fear of falling among stroke participants. Fear of falling was mentioned by the majority of the participants interviewed. Most of these participants mentioned decreased confidence, reduced balance and unsteadiness as reasons for developing a fear of falling. This is illustrated in the quotations below:

**P2** *“I have to walk on a level surface. If it is not level, then I need to have someone to hold me. I have a terrible fear of falling, even of the wind that is blowing against me when I stand outside.”*

**P6** *“My balance is at this moment my biggest problem, it makes me scared of falling, and I have little self confidence after the stroke.”*

A similar finding was reported in a study by Dowswell *et al.* (2000), where the results indicated that the fear of falling had reduced the possibility of the relevant stroke patients going out, thus resulting in social isolation (linking in with the theme of

participation restrictions). People who experience falls, take a long time to regain their confidence. Fear of falling while out of the house could lead to isolation (Pound *et al.*, 1998).

Participants in this study mentioned that they could move comfortably within the home environment and that their fear of falling was increased when attempting to walk alone outside the house. The participants therefore stated that they would only venture outside with the aid of someone.

The abovementioned will now be presented in the form of direct quotations from the participants:

**P2** *“My husband usually helps me to walk outside. If he is not here, I stay indoors. I will rather wait for him.”*

Some of the female participants stated that they would only go outside if their respective male helpers were there. One lady mentioned that her daughter had tried to help her to visit her neighbour across the road, commenting:

**P2** *“My daughter does not hold me as tight as my husband. I do not feel as secure with her as I do with him.”*

From this it is clear that this person lacked trust and confidence in both her and her daughter’s ability to help her when walking over uneven surfaces, up steps or over kerb cuts.

**P2** *“She will not be able to catch me if I fall and then I will get hurt.”*

The participant was clearly scared of falling and of the consequences of potential injuries.

In a study by Boyd and Stevens (2009), the majority of the participants who reported fear of falling consisted of women. This result is similar to the current study finding, in that more women mentioned that they were afraid of falling, thus limiting their activity levels in certain situations, as mentioned previously.

Most of the participants mentioned that their fear of falling was heightened when they came into contact with environmental features such as steps (without railings), uneven ground surfaces and kerb cuts in the road (this is linked to the sub-theme of environmental barriers). Most of the participants also stated that they would be able to walk in those situations with the help of another person.

The aforementioned will now be illustrated by the following direct quotations from participants:

**P2** *“Since the stroke, climbing stairs is difficult: I need to have someone to help me up the stairs. If there is no-one at home, then I do not go up the stairs.”*

**P1** *“I can walk outside, but the gravel scares me; I walked one day and my foot slipped over the gravel – I landed on my bum. “*

Related findings were reported by Dowswell *et al.* (2000), who found that physical obstacles and fear of falling decreased activity levels, which then further resulted in participation restrictions due to decreased social interaction. The participants in this study who had a fear of falling demonstrated increased activity restrictions due to the need for support, which then further resulted in participation restrictions due to social isolation. A similar finding was reported by Yang and Sandford (2012), confirming that dependence in getting in and out of the house and going up and down stairs was related with less frequent community participation.

#### 6.3.1.1.2 Fatigue

Fatigue was also highlighted by the participants as a factor that impacted on their walking ability, as illustrated in the quotations below:

**P2** *“I cannot walk far, because I get very tired.”*

**P7** *“Since the stroke, I do not go out much, because I cannot walk too far; I get tired easy.”*

Participants in a study by O’Sullivan and Chard (2010), stated fatigue as a reason for their inability to re-engage in active activities post stroke. Fatigue is closely linked to physical functioning, which is established to have a negative influence on the quality of life of the person post stroke (Ness, Waje-Anderson, Thomassen, Nyland & Myhr 2006). Similarly, fatigue in the current study, negatively affected the participants due



to their inability to walk long distances. The participants mentioned that they grew tired; therefore, they preferred to rather stay at home and avoided any specific activity.

Post-stroke fatigue kept stroke survivors from being actively involved with family and friends on a social basis (Flinn & Stube, 2009). In a study by Ones *et al.* (2005), the quality of life of participants post stroke had a significant level of disruption with regard to physical activity, fatigue, socialisation and emotional reactions. The findings of the aforementioned study are similar to that of the current study's findings. The participants in the current study opted to rather stay indoors or only walk shorter distances, thus affecting their interaction with their family and community. Participants in a study by Flinn and Stube (2009), mentioned that physical activity in the form of walking was helpful in coping with fatigue, while our study participants rather stopped walking due to the fact that they felt fatigued.

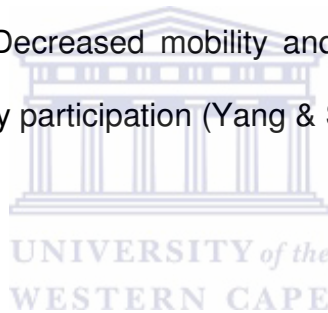
#### **6.3.1.1.3 Impairments**

Poor balance, decreased arm or leg functioning and weakness of the legs were of the impairments mentioned by participants that limited or hindered their ability to perform certain activities. These are highlighted in the following quotations by two of the participants:

**P8** *"I cannot climb stairs on my own, not with my poor balance and weak leg. At times, this leg drags the entire day."*

**P6** *“I cannot do household tasks any more; I do not have the balance to stand on my own and work.”*

In a study focusing on reintegration into the community after stroke, participants stated that, initially, post stroke, poor balance and weakness had limited their ability to perform task such as self care and walking (Wood, Connelly & Maly, 2010). In an explorative study into participation in leisure activities post stroke, participants voiced impairments such as poor mobility or loss of hand or arm function as reasons for their inability to re-engage in active activities (O’Sullivan & Chard, 2010). The participants in the current study mentioned similar experiences as those recorded in the aforementioned studies. Decreased mobility and balance have been found to increase difficulty in community participation (Yang & Sanford, 2012).



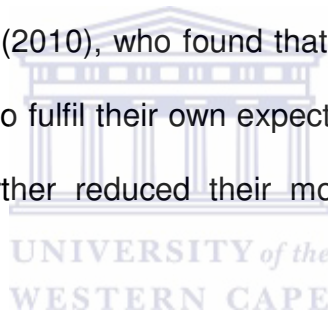
### **6.3.1.2 ADL**

#### **6.3.1.2.1 Limitations in self care**

The participants highlighted that they were limited in conducting activities of daily living. A lack of or inability to groom themselves limited their social activity. A female participant made specific mention of her appearance and her lack of ability to undertake her own hair care, as illustrated in the quotation below:

**P2** *“My appearance keeps me away from many things. My hair is not nice/right and I cannot see to it myself. Some people speak out of turn and leave comments about my hair or appearance. I therefore would rather stay at home.”*

The aforementioned was highlighted in a study by Robinson *et al.* (2009), which established that an indirect effect of physical disability was related to the inability of stroke patients to present themselves as attractively they would have liked. The aforementioned participant made specific reference to the fact that her inability to self groom was limiting her participation in certain social activities. Similar findings were reported by Wood *et al.* (2010), who found that participants limited their social activities due to their inability to fulfil their own expectations in self care. Participants became frustrated, which further reduced their motivation to participate socially (Wood *et al.*, 2010).



### **6.3.2 Participation Restrictions**

Participation refers to the ability of the person to manage the role that they were previously fulfilling (World Health Organisation, 2001). The barriers to participation restrictions experienced by the participants were dependency on others, social support, and emotions.

### 6.3.2.1 Dependency

#### 6.3.2.1.1 Inability to drive

Many of the participants mentioned that they possessed their own vehicle, but that they needed a friend or a family member to take them on certain errands, making them dependent upon that individual, as illustrated in the following quotations:

**P4** *“I have my own car, but my husband is not driving. We have to phone someone from KwaNobuhle to come and get us, if not possible, then we phone a cab. We plan our things according to his availability. Its difficult with the cab – they don’t wait for u.”*

**P5** *“I have my own car, but cannot drive myself. We have a driver that takes us up and about, but he does not drive for us alone. We therefore have to contact him in advance and arrange with him to take us somewhere on a specific day. If he is not available when we need to go, we have to wait till he can take us.”*

Both of these participants voiced the limitation to adhere to the availability of another’s schedule in order to perform a certain activity. This fact was also highlighted in a study by O’Sullivan and Chard (2010), that explored participation in leisure activities post stroke. The availability of others and the need to adhere to other people’s timetables were mentioned by many of the participants in that study. Their sudden dependency after stroke was discussed by the participants, touching

on the need for the involvement of family, friends or services to ensure their participation in leisure activities (O'Sullivan & Chard, 2010). Dependency after stroke therefore increases the effort required to participate in the community (Yang & Sanford, 2012), resulting in a deterioration in stroke sufferers' social lives (Dowswell *et al.*, 2000).

### 6.3.2.2 Social Support

#### 6.3.2.2.1 Decreased social interaction and family support

Two of the participants mentioned that they had received absolutely no support from their extended family members and that it was only their life partner and wife (respectively) that cared for them. This had affected social interaction. The aforementioned is illustrated in the quotations below:

**P3** *"Family and friends do not come and visit me any more. I was last out of this house two years ago .... I only sit at home .... I go nowhere. It makes me sad and depressed."*

The first participant mentioned, was totally wheelchair dependent and required constant care and assistance.

**P8** *"People/family does not want to help us by driving us around. I do not have good support from my family. When they see it's me calling, they don't answer the phone."*

The second participant was a little more independent, but because of balance problems, needed to have someone close by for assistance.

Social support in the form of social relationships is of paramount importance if one is to survive the long-term effects of a stroke (Lynch, Butt, Heinemann, Victorson, Nowinski, Perez & Cella, 2008). Poor social support has also been linked to poor quality of life post stroke (Mackenzie & Chang, 2002). This is believed to be influenced by the functional and cognitive state (Mackenzie & Chang, 2002); therefore, the burden of stroke highlights the need for greater social support (Huang, Hsu, Hsu, Cheng, Lin, & Chaung, 2010). Increased social support is directly linked to increased quality of life (Huang, *et al* 2010). In both these instances, the level of disability of the participants had been increased and the social support had decreased, which would inevitably lower their quality of life.

### **6.3.2.3 Emotions**

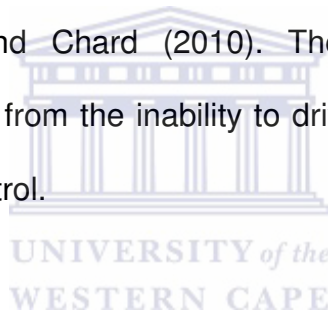
#### **6.3.2.3.1 Feelings experienced post stroke**

Some of the participants in the study mentioned feeling sad, depressed, frustrated and useless due to their inability to perform certain tasks post stroke and also due to the lack of social interaction, as explained above.

One participant expressed his frustration at his inability to drive his own motor vehicle:

**P6** *"I have my own car, for 30 years I drove. Now, I can't. It is difficult to sit in the passenger seat – it's frustrating!"*

The inability to return to driving could affect the participant through the development of feelings of frustration, as this constituted a loss of independence, as was also noted in a study by Robinson *et al.* (2009). This loss of independence impacted on the activities in which the respondents could engage (Robinson *et al.*, 2009). Re-engaging in driving was associated with being independent and having control over being able to go out and participate in other leisure activities, such as socialising, as highlighted by O'Sullivan and Chard (2010). The above quoted participant's frustration therefore stemmed from the inability to drive post stroke, which means a loss of independence and control.



Depression and cognitive changes are the most common reasons why people decrease physical activity and limit participation (community reintegration, social participation and community engagement) after stroke (Schmid *et al.*, 2008). Some of the study participants made specific reference to feeling sad, depressed and useless post stroke, as highlighted by the following quotations:

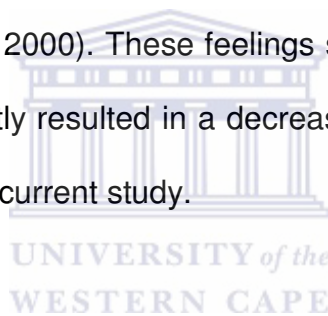
**P5** *"Since the stroke I got worse, I feel useless, I cannot do anything for myself, I cry constantly."*

**P7** *"Since the stroke I feel sad, lonely, frustrated and depressed."*

The participant who mentioned experiencing feelings of depression and uselessness rather opted to avoid being around able-bodied people to prevent the feelings which he experienced, thus leading to further social isolation, as illustrated by the following quotation:

**P6** *“I feel useless, like a handicapped person, especially when I am around normal people; that makes me depressed – rather stay away”.*

Stroke survivors mentioned a plenitude of feelings post stroke, which ranged from feeling angry, ashamed, frustrated, helpless, useless, sad, depressed and burdensome (Dowswell *et al.*, 2000). These feelings stemmed from role changes as a result of stroke and frequently resulted in a decrease in social participation, which is similar to the findings of the current study.



#### **6.3.2.4 Environmental Barriers**

These are features within the home and community that have a limiting effect on participation (Gray *et al.*, 2008).

##### **6.3.2.4.1 Steps/Stairs and Uneven Surfaces**

Most of the participants interviewed, mentioned common environmental barriers that they encountered within the community. Of these, steps – especially those without railings – were mentioned as a barrier to participation in the environment. Other common community features mentioned, were uneven surfaces and the presence of



kerb cuts, which was seen as a step and therefore a barrier to participation, as illustrated in the following quotation:

**P4** *“I cannot climb steps alone without rails; I must get someone to help me up those steps”.*

A commonly mentioned occurrence was the participants' ability to manipulate these features only with the help of another person (as previously mentioned under the section on fear of falling). They mentioned their physical as well as psychological inability to interact with these environmental features independently, as illustrated by the following quotation:

**P6** *“I can climb the steps, but I need to have someone behind me; I am scared to climb the steps by myself; I am scared that I will get hurt”.*

Similar findings were reported by studies internationally and in other African countries, which established that features of land forms, such as hills, were common barriers for more than half of the study population (Alguren *et al.*, 2009; Yang & Sanford, 2012). Negotiating stairs and narrow doorways have also been identified as major barriers to role performance for stroke survivors (Reid, 2004a). For many individuals, the outside of the home poses barriers, with key issues including uneven ground, poor lighting, and stair access (Reid, 2004b). Therefore, environmental features, such as steps and kebs, are significantly correlated to dependence, leading to decreased activity (Yang & Sanford, 2012).

### 6.3.2.5 Participation and Environmental Facilitators

These are features that aid the participation of the stroke survivors with their environment. A number of factors were identified that facilitated participation of patients in the study. These included physiotherapy and features in the physical environment.

#### 6.3.2.5.1 Physiotherapy as a participation facilitator

Many participants commonly stated that physiotherapy post stroke had helped them with balance retraining and to walk again, as illustrated by the following:

**P4** *“The physiotherapist taught me to walk again using a stick and also with dressing and undressing.”*

**P9** *“The therapy helped me to walk, I can go to church again, now that I can walk alone”.*

A study by Olsson and Sunnerhagen (2006) supported the aforementioned statement, in that participants in that study recorded improvements post stroke as a result of the rehabilitation that they had received. The participants in the current study mentioned that physiotherapy had helped to make them more functionally active within their home and community environment, similar to the findings in studies by Dowswell, Dowswell, Lawler, Green and Young (2002) and Robinson *et al.* (2009)

### 6.3.2.5.2 Railings as an environmental facilitator

Community features such as railings at stairs were described by participants as aiding their engagement in their environment, as expressed by the following quotations:

**P2** *“Railings at some places give support, it takes away my fear a bit and it gives me more confidence.”*

**P6** *“I can only go into shops in town that have railings by the stairs, those I can climb, the others that don't have, I will rather sit in the car.”*

Facilitators such as ramps, paved surfaces, escalators and automatic doors and facilitators for individuals with mobility problems were identified in a study by Gray *et al.* (2008). An environment that facilitates the ability of a stroke patient to actively move around is conducive to the overall independence of the person (Gray *et al.*, 2008).

## 6.4 SUMMARY OF QUALITATIVE RESULTS AND DISCUSSION

From the emerging themes, it became clear that the participants in the current study had experience various barriers to their activity and participation post stroke. In many cases, most of these barriers did not occur individually, but rather as a combination of factors. Although the participants were mildly affected according to the BI, they

were still experiencing activity limitations, specifically related to walking outdoors, heightened by the fear of falling; impairments post stroke; fatigue; and environmental barriers. Environmental barriers affecting activity and participation levels have been linked by both the quantitative and qualitative results of this study, which highlighted the integral effect of these barriers on the participants.

The qualitative results with regard to participation are linked to the quantitative findings regarding role changes, stemming from the change in ability related to work and family life post stroke, which then resulted in decreased social interaction.



## CHAPTER SEVEN

### SUMMARY, SIGNIFICANCE OF STUDY, LIMITATIONS OF STUDY, CONCLUSION AND RECOMMENDATIONS

#### 7.1 INTRODUCTION

In the final chapter, a summary of the study will be provided. The various limitations of the study will be discussed. The most important findings of the study will be emphasised in the conclusion. The chapter ends by making recommendations with regard to the study findings.

#### 7.2 SUMMARY OF STUDY



The aim of the current study was to identify the profile of stroke patients admitted to the Uitenhage Provincial Hospital from January 2008 up to and including December 2009. The study identified the challenges experienced by stroke patients with regard to activity limitations and participation restrictions. The study further determined the environmental barriers and facilitators that had an effect on participation.

A retrospective quantitative method was employed by means of the data gathering instrument, in order to obtain the profile of stroke patients' from the patient hospital folders. The profile included the demographic and medical characteristics, stroke onset admission intervals and length of hospital stay, as well as the physiotherapy interventions which the patients in the study received.

A prospective quantitative method was used to collect the data relating to the outcomes of the patients post discharge. This was done by using standardised outcome measures, which consisted of the BI, MRS and the FABS.

The qualitative part of the study used a qualitative approach by means of semi-structured interviews in an attempt to understand how the individuals experienced the problem and to understand the problem from the persons' own perspective.

The quantitative results indicate that the mean age of the participants was 61,54 years, which is younger than international studies, but similar to a local study. The results show that more females (59%) participated in the study and that more males (76%) were married than females. The study found hypertension to be the most prevalent risk factor among stroke survivors, which is in line with current literature.

The majority of the study participants were admitted to hospital on the same day of stroke onset. This finding is in contrast to local and international findings, which show a delay in admission to hospital following a stroke.

The mean length of stay was 7,38 days, which is too short for both acute care and rehabilitation. Physiotherapy intervention started within two days in 60% of the participants.

The BI score of between 61-100 implied that the participants were not faced with a lot of activity limitations. These were however further explored qualitatively.

Participation restrictions included dependency, decreased social interaction and support, as well as an array of feelings experienced post stroke, which limited participation and environmental barriers. The MRS revealed that some of the participants experienced an altered ability to work post stroke as well as a change in the ability to care for the family at home.

The results indicate that the home and community environmental features such as stairs, gravel and kerbs are barriers to participation. Environmental features that consist of flat terrain, ramps and paving acted as facilitators within the environment.

The qualitative part of the study further explored the barriers to participation. It found that activity limitation was exacerbated by a reduction in walking ability and ADL. The study found that the limitations on walking were further heightened by the fear of falling, fatigue and impairments. Another study finding was that participation restrictions stemmed from the stroke survivors' dependency on others, decreased social support, and an array of emotions stemming from the loss of dependence, resulting in sadness, frustration and helplessness.

The environmental barriers identified in the qualitative study related to features such as stairs and uneven surfaces. This was related to the quantitative finding that stairs, gravel surfaces and kerb cuts acted as barriers to participation. This finding further highlights the significance of environmental barriers in the lives of stroke patients.

The study also identified facilitators in the physical environment in both the quantitative and qualitative components of the study. These facilitators were ramps,

flat terrains and railings (at stairs). The qualitative aspect of the study found that physiotherapy services enhanced the participants' participation post stroke.

### 7.3 SIGNIFICANCE OF STUDY

The findings of the study will add to the limited knowledge relating to stroke patients' outcomes in South Africa. The study identified some of the facilitators and the barriers experienced by stroke survivors.

The study attempted to identify the profile of stroke patients, with specific reference to the risk factors relating to strokes. Rural and Sub-Saharan Africa are at early stages of economic and health transition, and there is currently very little published information on the prevalence of risk factors in the population (Thorogood, Connor, Tollman, Hundt, Fowkes & Marsh, 2007). By identifying the factors relating to stroke, such as risk factors, interventions should be put in place in order to educate stroke survivors and their families, with specific regard to stroke prevention. The activity limitations and the participation restrictions identified, need to be used as a basis to improve the available rehabilitation care offered to stroke survivors. A common finding of the study was that the fear of falling, heightened by the presence of environmental features/barriers, for example, stairs, hindered participation. Due to the commonality of the finding, more specific and task orientated rehabilitation should be done addressing this issue. Not only will it strive to increase the patient's ability, but it could also have an effect on their participation within their community. This in turn, if improved, can have an effect on the psychological well being of the stroke survivor and it could lead to a reduction in the caregiver burden.



## **7.4 LIMITATIONS OF STUDY**

This section highlights the various limitations of the quantitative and qualitative phases of the study.

### **7.4.1 Quantitative Phase**

- Many of the folders could not be found, reducing the size of the study population.
- Data were obtained from a records review, and much of the data were missing.
- The lack of information noted regarding date of follow-up limited the ability to determine the chronicity of stroke.
- Only data pertaining to physiotherapy services were included in the retrospective part of the study, therefore the full extent of the rehabilitation services that are available at the Uitenhage Provincial Hospital and the other rehabilitation services which the participants may have received have not explored.

### **7.3.1 Qualitative Phase**

- Interviews were conducted face to face or telephonically. Telephonic interviews took away the ability of the researcher to see the participants' facial expressions and behaviour in response to the questions being asked.

- Qualitative research is an interpretive process and representation is an individualised process.

#### **7.4 CONCLUSION**

The aim of the study, namely to identify the profile and activity and participation restrictions of patients admitted to the Uitenhage Provincial Hospital, was successfully achieved. It is encouraging to know that the majority of patients who suffered from a stroke, presented immediately to the Hospital for management. Despite this fact, the length of stay of stroke patients is too short in comparison to first World countries. The time that these patients are admitted for is in no way adequate to provide both acute care and rehabilitation of a condition with such a vast array of post occurrence impairments. The study findings demonstrate that stroke-related activity limitations, participation restrictions and environmental barriers, hinder the functional and social activities among the stroke survivors.

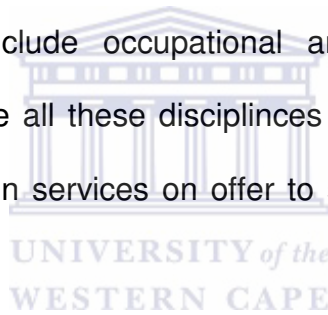
#### **7.5 RECOMMENDATIONS**

From the study findings and conclusion, it is therefore recommended that the Uitenhage Provincial Hospital relook their discharge protocol. Discharge of patients post stroke should not be only be based on their medical stability. The rehabilitation professionals should play an active role in the discharge process. Medical officers should be advised to consult with the rehabilitation professionals on the functional level of stroke patients prior to discharge. The

implementation of this recommendation could result in greater adaptation of the stroke survivor and their caregiver to this multifactorial medical condition.

The study findings also recommend that the Uitenhage Provincial Hospital relook their record keeping. Records are legal documents, and many of the folders were misplaced during the data collection period. The Uitenhage Provincial Hospital should update its record filing system to enhance record keeping and to assist future research.

A major limitation of the study was that only data from physiotherapy services were obtained. Other rehabilitation services available at the Uitenhage Provincial Hospital, include occupational and speech therapy. Future research should include all these disciplines in order to get a more holistic view of the rehabilitation services on offer to stroke patients admitted to the hospital.



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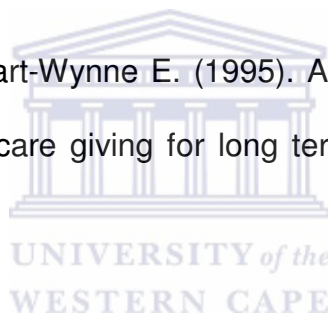
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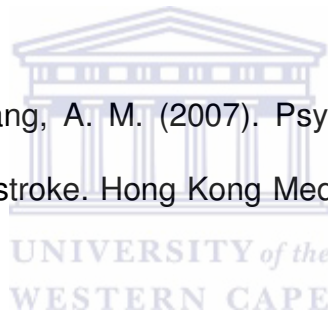
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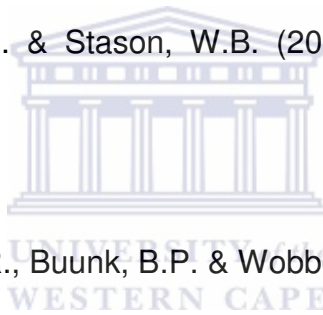
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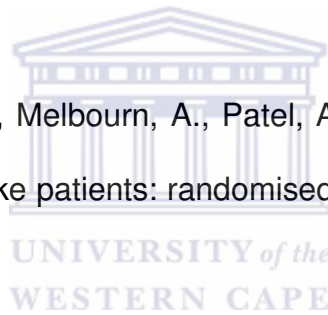
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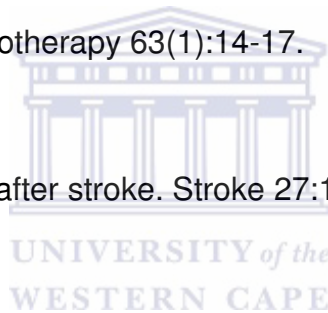
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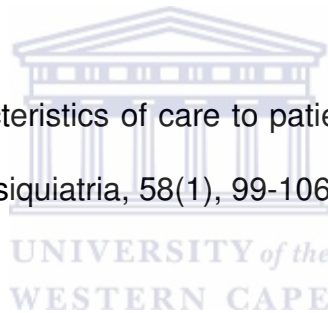
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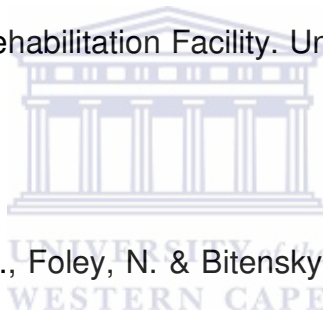
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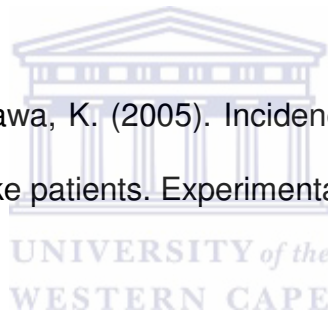
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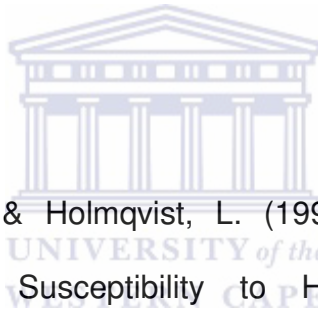
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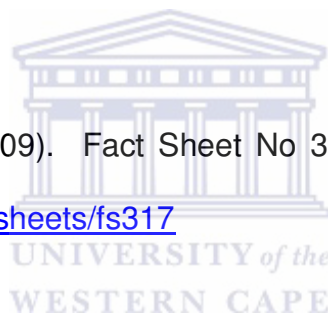
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