Pattern of Recovery and Outcome after Stroke in Patients Accessing a Western Cape Rehabilitation Facility

By:
Susan Rouillard
BSc (Physiotherapy)

Supervisors:
Assoc. Prof. Jennifer Jelsma
(PhD)
University of Cape Town

Prof. Willy de Weerdt
(PhD)
Katholieke Universiteit Leuven

Janeen Hughes
BSc (Hons)
University of Cape Town

A thesis submitted in fulfilment of the requirements for the degree of Master of Science (MSc) in Physiotherapy

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
School of Health and Rehabilitation Sciences
Division of Physiotherapy

2007

University of Cape Town

The copyright of this thesis vests in the author. No quotation from it or information derived from it is to be published without full acknowledgement of the source. The thesis is to be used for private study or non-commercial research purposes only.

Published by the University of Cape Town (UCT) in terms of the non-exclusive license granted to UCT by the author.

University of Cape Town

ABSTRACT

Background: Stroke is a growing healthcare problem in South Africa, and contributes significantly to the burden of disease. Rehabilitation is thought to improve recovery and outcome, but little is known about current rehabilitation practices and outcomes in the South African setting. **Aims and Objectives:** The primary aim was to describe pattern of recovery and outcome after stroke in first ever stroke patients at a Western Cape Rehabilitation Facility. The secondary aim was to explore factors that may influence outcome after stroke. Objectives included describing characteristics of stroke patients, the rehabilitation process, and certain aspects of the environment. **Study Design:** The study was a prospective, longitudinal, descriptive study of first ever stroke patients admitted to the Western Cape Rehabilitation Centre between 22 June 2005 and 28 March 2006. **Instrumentation:** The National Institute of Health Stroke Scale (NIHSS) was used to describe severity on admission. The Barthel Index (BI) and Rivermead Motor Assessment (RMA) were used to describe functional and motor recovery respectively. The main outcome measure at six months was the Modified Rankin Scale (MRS), with secondary outcomes including the Nottingham Extended Activities of Daily Living Scale, the Caregiver Strain Index and the EQ-5D, a measure of health related quality of life. Questionnaires drawn up for use in the study collected further information on patient characteristics, residential and work status at six months, as well as environmental features. **Procedure:** Patients who met the eligibility criteria were assessed at admission, discharge and six months post stroke. **Data Analysis:** Summary statistics were used to present descriptive data. Friedmans analysis of variance and Wilcoxons matched pairs test were used to assess the significance of change across the selected measurement points. A repeated measures ANOVA was used to investigate differences in pattern of recovery between sub-groups. Bivariate analysis and logistic regression were used to analyse the influence of certain factors on MRS scores at six months. **Results:** Participants were noted to be younger (average age of 51.3 ± 14.4 SD) than those in overseas rehabilitation studies with a high proportion of haemorrhagic strokes and infective aetiologies. Participants were mostly from low income homes although the majority lived in formal housing (86.3%) with access to services. The rehabilitation process was characterised by early admission after stroke (74.5% within 30 days), and an average length of rehabilitation stay of approximately 60 days. Four participants were readmitted for further rehabilitation stays within the six month follow up period. Of the remaining patients, fewer than 10% had received any substantial rehabilitation input after discharge, although most had been seen at least once by a health professional (89.4%). The overall pattern of recovery showed change between all three time points with most change occurring between admission and discharge (median BI change of 25, $p<0.017$). However, clinically significant change (defined by >15% of total scores) was seen between discharge and six months in terms of BI scores in 55.3% and RMA Gross Sub-scale scores in 45.5% of participants. Mobility items reflected the most change with 81.8% of participants independently mobile at six months compared to 54.5% at discharge. The pattern of recovery over time did not appear to be influenced by severity of stroke ($F=2.29$, $p>0.05$) or early/ late admission to rehabilitation ($F=0.51$, $p>0.05$). Only one participant was living in an institution at six months, despite the fact that more than 20% of participants required constant care. The majority of participants (59.6%) were independent in self-care but many required assistance for extended activities of daily living such as housework, meal preparation, using public transport and shopping. Of interest were difficulties experienced with community mobility, a high prevalence of depression or anxiety (50%) as well as problems with relationships or feelings of isolation (82.6%). High levels of caregiver strain were reported in 55.8% of caregivers. Only 10% of those working prior to their stroke had returned to work at six months. Severity of stroke (NIHSS) emerged as the clearest predictor of outcome (OR 0.70, CI 0.53-0.94), but environmental factors were also seen to be significant. Income group affected outcome (adj $z=-2.08$, $p<0.05$), and the presence of at least one reported environmental barrier reduced the odds of favourable recovery according to the MRS (OR 0.18, CI 0.03-0.98). Lack of transport and financial problems were highlighted by participants as major barriers affecting participation. **Discussion and Conclusions:** Pattern of recovery followed a more or less expected course over time with greater change between admission and discharge, than between discharge and six months. The high percentage of participants improving between admission and discharge suggests appropriate selection of rehabilitation candidates and effectiveness of the rehabilitation programme. Clinically significant change occurring between discharge and six months, particularly with regard to higher mobility, implies that patients may benefit from follow up after discharge in order to optimize outcomes, especially as many participants were discharged fairly early after their strokes while recovery may still be ongoing.

In terms of outcomes, BI scores at six months were comparable to other studies, with most patients functionally independent or requiring only minimal assistance with activities of daily living (ADL). However, a higher prevalence of difficulties was seen in more complex extended ADL and at the level participation restrictions than in studies in developed countries. In particular, there were higher levels of depression, social isolation and caregiver strain, and only a small percentage of those previously working had returned to work at six months. Lack of community mobility and difficulties with transport may have contributed to restrictions in participating in activities outside of the home. These difficulties are most likely to arise after discharge from rehabilitation, as the patient tries to resume pre-stroke roles in the community. Further research is recommended to determine whether provision of follow up after discharge from rehabilitation will improve outcomes. Research is also recommended to explore how caregivers can be best supported to reduce levels of caregiver strain. Although the severity of stroke at admission was found to be the clearest predictor of outcome, the influence of adverse environmental factors on outcome was also apparent. Other characteristics of the study sample such as the young age distribution and medical profile may also have contributed to differences in recovery and outcome.

TABLE OF CONTENTS

DECLARATION

I, Susan Rouillard, hereby declare that this thesis is my own work and has not been submitted for a degree at any other university. All resources I have used or quoted are acknowledged by a complete list of references.

....

Susan F Rouillard

15 February 2007

ACKNOWLEDGEMENTS

- Associate Professor Jennifer Jelsma, Ms Janeen Hughes and Professor Willy De Weerdt for their supervision
- The Katholieke Universiteit Leuven for funding and academic support
- Dr Liesbet De Wit and Ilse Baert for their training and academic advice
- The patients at the Western Cape Rehabilitation Centre (WCRC) who participated in the study
- Management at the WCRC for permission to carry out the study:

  Ms Jenny Hendry, Deputy Director and Head of the Institution

  Ms Carin Roux, Assistant Director: Therapeutic Services
- The Therapy One and Therapy Two Teams at the WCRC, as well as the attending medical doctors
- The nursing and administration staff on Wards A, B and C, as well as Mr David Roodt in Outpatients
- The Medical Research Council of South Africa and the South African Society of Physiotherapy for funding received.
- Zolani Buhlungu for his translation services and assistance with data collection
- Nolu Ntyam for her assistance with translation of the questionnaires
- Physiotherapists and managers of the Community Health Care Centres for making space available for follow up assessments
- Greg Distiller for his assistance with the statistical analysis

Special mention of the following people for their assistance: Elsje Scheffler, Wilfred Allen, Gakeemah Inglis, Natasha Arafdien, Janine White, Hildegard Van Jaarsveldt, Jackie Goeller, Suzaan Stark, Cobie Heynes, Deona Roets, Antoinette Odendal, Doreen Samuels, Gail Stuart, Soleila Hassen, Mrs Tertia McKee, Dr Jephrey, Dr Richard Edwards, Dr Elana Van Brakel, Dr Mfeketo, Dr Danja Schulenburg, Dr Niemand, Dr Scriba, Shanaaz Abbas , Juanita Haarhoff, Nicky Cloete, David Roodt, Mavis Gidigidi, Marianne Cloete, Sr Adams, Sr Venter, Sr Arendse, Sr Steenbok, Sr Rorick, Staff Nurse Daniels, Sr Philander and Sr Burgess.

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

ADL	Activities of Daily Living
AFO	Ankle Foot Orthosis
BI	Barthel Index
CERISE Project	Collaborative Evaluation of Rehabilitation Across Europe Project
CHCC	Community Health Care Centre
CNS	Central Nervous System
CT Scan	Computed Tomographic Scan
CVA	Cerebrovascular accident
EADL	Extended Activities of Daily Living Index
EQ-5D	EQ-5D Assessment Measure for Health Related Quality of Life
HRQoL	Health Related Quality of Life
ICF	International Classification of Functioning
LL	Lower Limb
LOS	Length of stay
MRI	Magnetic Resonance Imaging
MRS	Modified Rankin Scale
OAI	Onset Admission Interval
OR	Odds ratio
PEG	Percutaneous Enterogastrostomy Tube
PTB	Pulmonary Tuberculosis
QoL	Quality of Life
RMA	Rivermead Motor Assessment
SD	Standard Deviation
TB	Tuberculosis
UL	Upper Limb
VAS	Visual Analogue Scale
WCRC	Western Cape Rehabilitation Centre

GLOSSARY OF TERMS

Activity Limitations: "Difficulty in carrying out activities where activities are defined as "the execution of a task or action by the individual" (World Health Organisation 2002). Activity limitations refer to difficulties in specific tasks, for example: dressing, toileting and driving.

Basic Activities of Daily Living: Activities essential for daily life such as washing, dressing, grooming, toileting, feeding and basic mobility.

Bobath Approach: "A problem-solving approach to the assessment and treatment of individuals with disturbances of function, movement and postural control due to a lesion of the central nervous system. It originated with the work of Berta and Karel Bobath …and has evolved with current understanding of motor control, motor learning, neural and muscle plasticity and biomechanics." (International Bobath Instructors Training Association 2007)

Caregiver Strain: The perceived burden of care in unpaid caregivers of patients.

Case Mix Indicators: Inherent characteristics of patients that may influence prognosis for recovery (for example age, gender and socio-economic status) (Segal and Whyte 1997).

CERISE Project: Multicentre stroke rehabilitation study underway in Europe: Collaborative Evaluation of Stroke Rehabilitation in Europe.

Community Health Care Centre: Local outpatient health care centres offering primary health care services, previously known as "day hospitals".

Economically Active Individuals: "Persons aged 15-65 years who are employed or unemployed." (Statistics South Africa 2005)

Education attainment:

Some Primary:	Grades 1-6 inclusive	(Previously Sub A to Std 5)
Complete Primary:	Grade 7	(Previously Std 5)
Some Secondary:	Grades 8-11 inclusive	(Previously Std 6-9)
Matriculation:	Grade 12/ matriculation	(Previously Std 10)

Higher: "Any tertiary qualification. Includes certificates and diplomas of more than six months duration and degrees. Includes a tertiary education without completion of secondary education."(Statistics South Africa 2005)

Environmental Factors: Those features of the physical, social and attitudinal environment that may influence outcome after stroke.

Extended Activities of Daily Living: Activities which are necessary for maintaining a household and for community living.

Functional Recovery: Improvement in independence in activities of daily living, or participation in pre-stroke roles not only due to neurological recovery..

Formal Housing: Permanent dwelling constructed with formal building materials usually consisting of a brick structure.

Health Related Quality of Life: Aspects of quality of life that are influenced by state of health.

Impairment: Deficit in physiological function or anatomical structure.

Incidence: "The rate of new cases of a condition that develop during a specified period of time" (Domholdt 2005).

Informal Housing: "A makeshift structure not erected according to approved architectural plans found in informal settlements and backyards." (Statistics South Africa 2005)

Interdisciplinary Rehabilitation: The rehabilitation process involves a team of diverse professionals working together closely towards common goals. Key elements include joint planning and assessment, integrated treatments and regular communication.

Monthly Household Income: "Total monthly income, before tax, of a household (where household is defined as group of persons living together, who jointly provide themselves with food and essentials, or a single person living alone.)" (Statistics South Africa 2005)

Motor Recovery: The return of movement and recovery of motor control.

Multidisciplinary Rehabilitation: The rehabilitation process involves a diverse team of rehabilitation professionals working in parallel to achieve common goals. The rehabilitation team usually includes doctors, nurses, occupational therapists, psychologist, physiotherapist, speech and language therapists and social workers.

Neurological Recovery: Improvements in neurological deficits or impairments as a result of neural repair and adaptive reorganisation of the central nervous system (CNS).

Onset Admission Interval: Number of days between stroke and admission to the WCRC.

Participation: Participation is defined as "involvement in a life situation." and refers to the ability of the individual to function in meaningful roles within in the family, community and society at large. It may refer to any pre stroke role that was important to the individual such as return to work or productive activity, return to social and leisure activities, or role in the family. Participation restrictions are described as "problems an individual may experience in involvement in life situations" (World Health Organisation 2002)

Prevalence: "Proportion of a population who exhibit a certain condition at a given point in time." (Domholdt 2005)

Quality of Life: "Refers to a person's subjective well-being and life satisfaction [including] mental and physical health, material well-being, interpersonal relationships, work and other activities in the community, personal development and fulfilment, and active recreation." (Niemi, Laaksonen, Kotila and Waltimo 1988)

Stroke: "Rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or leading to death, with no apparent cause other than vascular origin." (World Health Organisation MONICA Project 1988)

LIST OF APPENDICES

PILOT STUDY

QUESTIONNAIRES

STANDARDISED OUTCOME MEASURES

OTHER

1 INTRODUCTION

1.1 Background

Stroke is no longer perceived as a disease which affects only high income Westernised countries (Farham 2004) and the burden of this condition in developing countries continues to grow (Connor and Bryer 2006). In South Africa, stroke is the fourth main cause of death and accounted for 6% of total deaths in the year 2000 (Connor and Bryer 2006). In a rural area in South Africa the crude prevalence rate was estimated to be 300/100 000 (The SASPI Project Team 2004). Stroke is clearly a major concern in South Africa, and is set to become even more so as the country undergoes an epidemiological transition from predominantly infectious diseases of developing countries, to non-communicable diseases of the developed world (Connor and Bryer 2006). The implications of stroke extend beyond mortality rates as most patients survive the initial event, but many are left with disabilities (Connor, Rheeder, Bryer, Meredith, Beukes et al. 2005). The number of stroke survivors needing rehabilitation is expected to increase as acute stroke care improves and mortality drops.

Recovery after stroke is often incomplete and individuals experience a wide range of physical, sensory, cognitive and perceptual impairments that contribute to disability and handicap (Teasell, Foley, Bhogal, Salter, Jutai et al. 2004). The devastating effect of stroke on the individual and implications for their families are well recognized (Han and Haley 1999; Grant, Glandon, Elliot, Giger and Weaver 2004). There is also a high economic cost to society as many stroke survivors with residual disabilities will not return to work (Fritz 1995; Bresick 1997; Mayo, Wood-Dauphinee, Cote, Duncan and Carlton 2002).

The high prevalence of stroke, and associated levels of morbidity, have focused attention on how rehabilitation can influence outcome after stroke. Evidence suggests that rehabilitation does improve recovery after stroke and reduces residual disability (Dobkin 2004; Teasell, Foley et al. 2004). A large number of outcome studies have been conducted in order to predict the pattern of recovery of patients with stroke, and to determine how this process can be influenced. A number of factors that influence outcome have been identified, including individual characteristics, rehabilitation received and environmental factors (Kwakkel, Kollen and Wagenaar 1999; Evans, Harraf, Donaldson and Kalra 2002). In addition, certain sub-groups of patients with stroke have been identified as benefiting more from rehabilitation than others (Teasell 2004c). Knowledge of this nature is important, because it assists in clinical decision making and the planning of care

(Falconer, Naughton, Dunlop, Roth, Strasser et al. 1994; Hankey, Jamrozik, Broadhurst, Forbes and Anderson 2002).

In South Africa, providing effective rehabilitation within the constraints of resources has become an important issue for a health-care system that is already under pressure (Hale and Eales 2001; Bradshaw, Schneider, Dorrington, Bourne and Laubscher 2002; The SASPI Project Team 2004).

1.2 Relevance to South Africa

The body of existing knowledge on stroke outcome originates almost exclusively from studies in comparatively well resourced rehabilitation settings in developed countries. Conclusions may not be applicable in the South African context, where little information is available on outcome after stroke. In addition, there are differences in the characteristics of the stroke population of South Africa. The medical profile of patients with stroke in South Africa differs in terms of risk factors and type of stroke, and patients with stroke are generally younger than those in European and North American studies (Farham 2004; Connor and Bryer 2006). It is expected that there are differences in environmental influences (Hale, Eales and Fritz 1998), and in the rehabilitation process itself (Hale and Eales 2001). A recent study in rural South Africa shows a higher prevalence of stroke survivors with disabilities than would be expected on the basis of studies in high-income countries (The SASPI Project Team 2004). There is a need to further investigate outcome after stroke in the South African population, in order to optimize stroke care within the local setting. Little has been published regarding outcome after stroke in South Africa as a whole, and the Western Cape Region in particular, with the exception of a few hospital based studies published over a decade ago (Dewar 1990; Whitelaw, Meyer, Bawa and Jennings 1994).

1.3 Research Setting

The Western Cape Rehabilitation Centre (WCRC) is a state-funded specialised regional rehabilitation unit, situated in Mitchell's Plain in the Western Cape, which was opened in October 2004. It provides rehabilitation services to the Western Cape Region as well as the neighbouring provinces, and is considered to be a regional centre of excellence (Provincial Government of the Western Cape 2004).

The WCRC caters for a number of neurological conditions including stroke, spinal cord injury, Guillain Barre Syndrome, traumatic brain injury and amputations. It has 240 mixed rehabilitation beds and an outpatient facility. Referrals are received from primary, secondary and tertiary services, as well as self-referrals (Provincial Government of the Western Cape 2005).

The WCRC provides high intensity rehabilitation with time-limited, goal-specific admissions. Patients are selected according to their expected capacity to benefit from rehabilitation input. Severe strokes, or patients who are very drowsy, may not initially qualify for admission until such time that they are considered candidates for rehabilitation (unless family training is required or there are management issues such as pressure sores or bowel and bladder problems). The rehabilitation team comprises a full multidisciplinary complement of therapists, psychologists, social workers, nurses and doctors. Patients receive input from the different disciplines as required: most receive daily physiotherapy and occupational therapy, and speech and language therapy varies according to need. On account of high patient staff ratios, patients do not always receive one-on-one therapy from each discipline every day. Occupational therapy and physiotherapy assistants are involved in the rehabilitation programme, and patients are encouraged to participate in guided self-managed programmes of exercises. Therapists are trained in the Bobath approach; however, an eclectic approach to rehabilitation is adopted with therapists drawing from a number of different approaches including motor relearning and proprioceptive neuromuscular facilitation (PNF) techniques. There are weekly multidisciplinary team meetings, and patients are discussed at least once a fortnight or more frequently if required. Family members are involved in training and where possible also in discharge planning.

The WCRC adopts an outcome-orientated approach to rehabilitation (Personal Communication, Ms J Hendry, Deputy Director WCRC and Head of the Institution, 2004). Outcome levels are defined as groupings or categories of patient problems and conditions, which are said to represent levels of progress along a continuum in the process of rehabilitation (Landrum, Schmidt and Mclean 1995). These outcome levels are outlined in Table 1-1.

Table 1-1 Outcome Levels According to Landrum, Schmidt and Mclean (1995)

OUTCOME LEVEL	DESCRIPTION/ CHARACTERISTICS
Level 0 - Physiological instability	Usually occurring early after onset in an acute setting. Assessment, diagnosis and management of medical conditions ongoing. Includes unmanaged medical problems presenting at a later stage e.g. pressure sores/ inadequate bladder management.
Level 1 - Physiological stability	Medical problems addressed and appropriately managed. Condition is stable- no longer requires acute care setting.
Level 2 - Physiological maintenance	Management plans in place to ensure ongoing maintenance of skin integrity, nutrition, range of movement and bowel and bladder care. Basic functional goals at this stage may include bed mobility, self-care and communication.
Level 3 - Residential re-integration	Safe function at home. Includes: self-care, mobility around home, effective communication, simple housekeeping, household planning and home management.
Level 4 - Community Re-integration	Subject functions appropriately in the community. Includes: self management, self-directed care of health, ability to function socially, community mobility, recreational activities, community activities, complex home management, financial management and safety in the community.
Level 5 - Return to productive activity	Productive activities within the patient's level of ability. Includes paid work, unpaid work, volunteer work, and education/ training.

Interventions are planned to target clinical problems associated with specific outcome levels. Patients are admitted for a limited period of time and discharged when they have achieved their predicted outcome level or when it appears further improvement is unlikely. Patients who are not progressing are sometimes discharged and readmitted at a later stage if they show further potential. (Personal Communication, Ms J Hendry, Deputy Director WCRC and Head of the Institution, 2004). This practice of readmissions at intervals may be an effective way to manage limited resources but, to the knowledge of the researcher, has not been reported in literature.

It is hoped that the centre will pioneer the provision of rehabilitation services in the Western Cape and further afield, using resources in a way that is appropriate to the healthcare needs of the South African stroke population. To date, no outcomes assessment has been carried out to evaluate the effectiveness of the programme.

1.4 Aims

The primary aim of this study was to describe pattern of recovery and outcome at six months post stroke in patients with first ever stroke accessing the Western Cape Rehabilitation Centre. A secondary aim was to explore the effect of certain selected factors of interest on outcome in this patient group.

1.5 Objectives

The specific objectives of the study were as follows:

1. To describe the medical, demographic and socio-economic characteristics of patients with stroke being admitted to the WCRC.

2. To describe certain aspects of the rehabilitation process including
   - Referral patterns including onset-admission intervals
   - Average length of stay
   - Discharge planning and procedures
   - Follow up received after discharge from the WCRC

3. To describe pattern of recovery in patients with stroke at WCRC by assessment of motor recovery (Rivermead Motor Assessment) and functional recovery (Barthel Index) at admission, discharge and six months post stroke.

4. To describe outcome at six months after stroke in patients being admitted to the WCRC, and their caregivers, in terms of the following:

Main outcome: Modified Rankin Scale (mixed measure of activity and participation)

Other outcomes:
- Extended Activities of Daily Living according to the Nottingham EADL Scale
- Place of residence at six months (home or institution)

- Return to work
- Health-Related Quality of Life as measured by the EQ-5D
- Caregiver Strain as measured by the Caregiver Strain Index (CSI)

5. To describe environmental features such as
   - The physical home environment to which the patient will be returning after discharge.
   - The perception of certain environmental features as barriers/ facilitators to function as reported by participants.

6. To investigate selected factors that may influence outcome in terms of the Modified Rankin Score at six months:
   - age
   - severity of stroke
   - early or late admission for rehabilitation
   - number of inpatient rehabilitation days
   - household income
   - environmental barriers

7. To conduct a post hoc validity analysis of the instruments used in the study.

1.6 Significance of the Study

No published literature exists on the practices and outcomes of rehabilitation at the WCRC in a group of patients with stroke who may be quite different to those in studies conducted in developed countries. Patients with stroke at the WCRC constitute a selected population in that they have all met the entrance criteria of the rehabilitation unit. As such, the results cannot be extrapolated to the broader stroke population of South Africa. However, the WCRC is considered a flagship for rehabilitation. Outcomes in this group of patients are of interest, particularly as inpatient rehabilitation is costly to healthcare systems, and only a minority of patients are afforded this opportunity.

Descriptive information gathered on the characteristics of patients with stroke provides insight into the needs of patients with stroke, and case mix indicators may give some indication of prognosis for recovery. Typical severity, and the nature of impairments at admission, has implications for staffing required. Furthermore, information regarding work status prior to stroke, and socio-economic background provides insight into the needs of patients after discharge.

Physiotherapists are frequently required to make predictions regarding recovery, in order to give information to families as well as for setting patient goals and planning rehabilitation stays. Clinical decision making is influenced by expectations regarding the time course of recovery and expected outcomes. Information regarding pattern of recovery is of considerable value to clinicians.

Many patients do not necessarily receive follow up after discharge from rehabilitation, which may occur fairly early in the course of their recovery after stroke. Rehabilitation outcomes are best assessed once the patient has settled into their home environment and this information is not usually gathered routinely in clinical practice. Assessments at six months would therefore assist in evaluating outcomes of the WCRC rehabilitation programme.

No study of outcome is complete without looking at factors that may influence outcome- especially as different interactions may be at play locally compared to international studies. This information may identify patients with special needs, implicate factors that may be modifiable and assist in predictions of recovery.

This study was by necessity quite broad in its design. It aims to provide baseline information on characteristics of patients, their pattern of recovery and outcomes. Factors influencing outcome will be explored, but sample size will limit the number of analyses that can be performed without introducing spurious associations. However, it is hoped that the study may be useful in preparing the way for future research by identifying possible case mix indicators and the expected range of outcomes in this patient group.

As the incidence of stroke in South Africa rises, the provision of best possible rehabilitation within the limits of available resources will become increasingly important. Research has a role to play in gathering information regarding rehabilitation outcomes.

1.7 Links with Other Projects

This study adopts similar methodology to that being used in a large scale stroke outcome study underway in Europe, the Collaborative Evaluation of Rehabilitation in Stroke across Europe (CERISE). The CERISE study is a prospective study of pattern of recovery and outcome after stroke in four European rehabilitation centres. The aim of the study is to compare outcomes between centres and to investigate the influence of amount and content of therapy, as well as the structure and organisation of the rehabilitation centres, in order to improve stroke management and to reduce long term disability (Katholieke Universiteit Leuven 2005; Putman, De Wit, Schoonacker, Baert, Beyens et al. 2006).

A similar study is currently being carried out in the Community Health Care Centres in the Western Cape (Personal communication, Ms A Rhoda PhD Candidate, University of the Western Cape). Similarities in study designs may allow for interesting comparisons of results providing that the case mix is sufficient to allow for a valid comparison.

2 LITERATURE REVIEW

2.1 Introduction

Stroke has been defined by the World Health Organisation as: "rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or leading to death, with no apparent cause other than vascular origin." (World Health Organisation MONICA Project 1988). Stroke is a major cause of death and disability world-wide (World Health Organisation 2003). Approximately one third of stroke survivors are left with long term disability (Hankey, Jamrozik et al. 2002) which impacts profoundly on the individual, their families and the communities in which they live (Mayo, Wood-Dauphinee et al. 2002). Rehabilitation of patients with stroke is an important issue facing healthcare systems (Matchar and Rudd 2005).

In this literature review, the epidemiology of stroke in South Africa will be discussed. The International Classification of Functioning will be presented as a conceptual framework for considering stroke outcomes as well as the numerous contextual factors that may influence functioning. Characteristics of patients with stroke that may impact on outcome will be outlined. Mechanisms of recovery and typical pattern of recovery after stroke will be presented. Rehabilitation will be discussed as an intervention aimed at improving recovery and outcome after stroke. Methodological issues in stroke research will be explored including difficulties in defining and measuring outcome. Finally, results from previous outcome studies will be presented.

Articles referenced in the literature review were identified using Pubmed and African Healthline data bases, with searches for "stroke outcome", "stroke rehabilitation" and "stroke recovery". Articles were also located by hand searching the references of published articles and trawling relevant journals.

2.1.1 <u>Epidemiology of Stroke</u>

Stroke is the second most important cause of death worldwide and over two-thirds of deaths due to stroke occur in developing nations (Murray and Lopez 1997). Stroke is already known to be a major health problem in sub-Saharan Africa (Bonita and Truelson 2003) and South Africa is no exception (Fritz 1995; Farham 2004). South Africa has been said to be subject to a quadruple burden of disease with infectious diseases of poverty, injuries, the HIV/AIDS epidemic and now emerging chronic diseases contributing to morbidity and mortality (Steyn 2005). South Africa is currently undergoing an epidemiological transition from the disease profile of a developing nation, to one of the developed world. This is expected to be accompanied by an increase in the prevalence of chronic diseases of lifestyle, and an increase in the incidence of stroke (Poungvarin 1998; Fritz 2000; South African Medical Association- Neurological Association of South Africa Working Group 2000; Bradshaw, Schneider et al. 2002).

The nature of stroke within a population is said to reflect the stage that the population is at along the epidemiological transition with changes occurring in presenting risk profiles and the proportions of stroke types (Connor and Bryer 2006). Early in the transition, risk factors such as uncontrolled hypertension and infective causes of stroke are more common, while later in the transition, atherosclerosis and ischaemic heart disease may be more common due to changing lifestyles (Connor and Bryer 2006). Stroke populations of developing countries are said to reflect younger ages and a higher prevalence of haemorrhagic stroke than in high income countries (Bonita and Truelson 2003; Farham 2004). Comparisons of the epidemiology of stroke are limited by the lack of epidemiological data available for the South African population. Existing data for stroke is derived mostly from hospital based studies and only one community based prevalence study has been reported (Connor and Bryer 2006).

The effect of HIV/ AIDS on the epidemiology of stroke in South Africa is currently unknown (Connor and Bryer 2006). A co-occurrence of stroke with HIV/ AIDS has been noted in literature although the precise mechanism in the aetiology of stroke is not fully understood (Mochan, Modi and Modi 2003; Patel, Sacoor, Francis, Bill, Bhigjee et al. 2005).

2.1.2 <u>Burden of Disease</u>

The burden of disease due to stroke is reflected in part by mortality rates, which are already high in South Africa (Connor and Bryer 2006) and by decreased quality of life experienced by those large numbers of patients with stroke who survive the initial event, but are left with residual disability (World Health Organisation 2003; Connor and Bryer 2006). Stroke is the fourth main cause of death and accounted for 6% of total deaths in the year 2000 (Connor and Bryer 2006).

Prevalence rates reflect the number of stroke survivors in a population at a given time. There is little available prevalence data for South Africa and only one community based study, the Agincourt Study (The SASPI Project Team 2004), has been carried out in a rural part of South

Africa. This study is of particular interest because although a lower crude prevalence rate for stroke was reported than in high income countries, the prevalence of stroke survivors needing assistance with activities of daily living was higher than those found in previous studies (Bonita, Solomon and Broad 1997). This implies higher rates of post stroke disability than in high income countries (Bonita 1992; Farham 2004).

Stroke survivors, who are not independent in activities of daily living, require assistance with self care. In South Africa, where there is little organised social support after discharge, caregiver roles are often assumed by family members and informal carers within the community. Caregivers of patients with stroke are known to experience high levels of depression and emotional distress, and may report reduced levels of social contact, decreased life satisfaction, and deterioration in physical and psychological health (Bresick 1997; Hackett, Duncan, Anderson, Broad and Bonita 2000; Mayo, Wood-Dauphinee et al. 2002). Stroke impacts on the entire family and may disrupt functioning of the family unit (Bresick 1997).

Furthermore, stroke may have serious economic consequences as many patients with stroke do not return to work (Vestling, Tufvesson and Iwarsson 2003; Teasell, Foley et al. 2004). In a relatively young population of stroke survivors, financial implications for the family can be disastrous, particularly where other family members are forced to stop working in order to assume the role of caregiver (Whitelaw, Meyer, Bawa and Jennings 1994). In a recent profile of patients with stroke at a Community Health Care Centre in Cape Town, 50% of the stroke population were 60 years of age and younger (Rhoda and Hendry 2003), and can thus be regarded as being economically active.

The cost of stroke to the country as a whole is significant, both in terms of providing healthcare services to patients with stroke (Matchar and Rudd 2005), as well as in terms of lost productivity (Vestling, Tufvesson and Iwarsson 2003).

2.1.3 The Importance of Stroke Outcome Research

There is little published literature on pattern of recovery and outcome after stroke in South Africa, particularly with regard to residual disability and handicap (Fritz 1995; Hale and Eales 2001; The SASPI Project Team 2004). Existing stroke outcome literature originates mostly from studies conducted overseas in relatively well resourced rehabilitation settings. The rehabilitation process, as well as patient characteristics and environmental influences may differ in South Africa

(Hale, Eales and Fritz 1998; Hale and Eales 2001). Thus results from overseas studies cannot be assumed to be directly applicable to our local stroke population.

Knowledge of expected rate of recovery and prediction of outcome after stroke are important for the planning of care, providing information to stroke survivors and their families and for determining the needs of stroke survivors post rehabilitation (Jorgensen, Nakayama, Raaschou, Vive-Larsen, Stoier et al. 1995; Duncan, Jorgensen and Wade 2000; Sturm, Dewey, Donnan, Macdonell, McNeil et al. 2002; Kwakkel, Kollen and Twisk 2006) Knowledge of factors influencing recovery may assist clinical decision making in terms of the selection of patients for rehabilitation admission and the length of stay required to achieve optimal function. It may also identify groups of patients at higher risk of a poor recovery and those in need of extra intervention (Putman, De Wit et al. 2006).

In South Africa, rehabilitation within specialised stroke units is upheld as the ideal (Hale and Eales 2001), but there is little published evidence supporting the use of inpatient rehabilitation above other rehabilitation settings. Rehabilitation within a specialised setting is known to be costly, and information regarding the outcome of such intervention programmes is of interest to clinicians as well as the funders of healthcare (Fritz 1995; Hale and Eales 2001).

Where resources are limited, and placement in rehabilitation units cannot be offered to all patients, it is believed that preference should be given to those patients most likely to benefit from intervention (Hale and Eales 2001). However, little information is available on which patients with stroke benefit the most from admission to rehabilitation units, or which factors may influence outcome in the South African setting. In particular, there is little information available on how patients function after they have been discharged from hospital.

2.2 Definitions and Conceptual Frameworks

2.2.1 The International Classification of Functioning, Disability and Health (ICF)

In this document, the ICF model (Ustun, Chatterji, Bickenbach, Kostanjsek and Schneider 2003) will be used as a conceptual framework for describing outcome following stroke. The ICF replaced the previous ICIDH classification which had been criticised for using negative terminology, not recognising the role of society in creating disability, and being based in the medical model. It was accepted at the World Health Assembly in 2001, and is expected to be widely used in research and clinical practice in the future (De Kleijn-De Vrankrijker 2003; Ustun, Chatterji et al. 2003). The ICF model provides a common language, and an analytical framework for identifying where interventions can be targeted in order to improve health and functioning (Stucki, Ewert and Cieza 2002).

The ICF classification distinguishes between the domains of impairment, activity and participation. Definitions are as follows:

> Impairments refer to discrete changes in physiological function or anatomical structure. For example, in patients with stroke, impairments can refer to deficits of cognition or movement.
>
> Activity limitations are defined as "difficulties in carrying out activities where activities are defined as "the execution of a task or action by the individual". Activity limitations refer to difficulties in specific tasks, for example: dressing, toileting and driving.
>
> Participation is defined as "involvement in a life situation." and refers to the ability of the individual to function in meaningful roles within in the family, community and society at large. It may refer to any pre stroke role that was important to the individual such as return to work or productive activity, return to social and leisure activities, or role in the family. Participation restrictions are described as "problems an individual may experience in involvement in life situations"
>
> (World Health Organisation 2002)

The relationship between the domains of the ICF is not linear. For example, an individual may demonstrate favourable levels of participation in spite of considerable levels of impairment. Conversely, an individual with fairly minimal impairment may demonstrate low levels of participation. Personal and environmental factors are recognised as influencing levels of participation achieved. Personal factors may include age, personality factors and coping style. Factors relating to the physical, attitudinal and social environment are considered as either barriers or facilitators of function. In this way, the ICF combines aspects of the social and medical model of disability, and has been described as a biopsychosocial model (World Health Organisation 2002).

2.2.2 Terminology in Rehabilitation Literature

Over recent times, a number of different models have been used to explain disability. These include the medical and social models, as well as the disablement model that was originally described by Nagi and later revised (Jette 2006). Certain terminology is used commonly by these models but with differences in the meaning attached, particularly with regard to the terms of disability and handicap. Nagi used the term disability to describe "the expression of a physical or a mental limitation in a social context." (Jette 2006). The term "disability" as it was used in the ICIDH had a much narrower scope, defined as "a restriction or lack (resulting from an impairment) of ability to perform an activity". Disability usually referred to specific tasks such as toileting and did not extend to limitations of social roles, which were referred to as "handicaps". In the new ICF classification the term "handicap" has been discarded and the new terms of "activity limitation" and "participation restriction" are currently in use. The term disability has been broadened to include any impairment, activity limitation or participation restriction i.e. a limitation at the level of any domain. In this document, the ICF terminology will be adopted, except where reporting on findings from previous studies which used terminology with conflicting meanings.

2.2.3 Rehabilitation

The WHO describes rehabilitation as a process aimed at enabling the individual to achieve optimum levels of functioning (World Health Organisation- Disability and Rehabilitation Team 2006). Wade (2000) defines rehabilitation as "a reiterative, active, educational, problem solving process focused on a patient's behaviour [aiming] to maximize the functioning of the individual in his/ her social setting, minimize pain and distress, [and] to minimize distress of the family and carers". Refer to 2.4.2 for a full discussion.

2.2.4 A Rehabilitation Model of Case Mix Adjustment

Outcome after stroke is influenced by so many intrinsic and extrinsic factors, that comparison between individuals and groups can be problematic. A case mix model has been proposed as a framework in which to interpret stroke outcomes in the presence of confounding variables (Segal and Whyte 1997). Case mix indicators are inherent characteristics of stroke survivors that may be predictive of their potential for recovery and include factors such as demographics, co-morbidities, type of stroke, and factors relating to severity of stroke such as impairments and functional abilities on admission (Segal and Whyte 1997). The importance of considering case mix indicators when interpreting outcome data has been widely acknowledged (Walsh, Gompertz and Rudd 2002).

2.3 Characteristics of Patients with stroke

2.3.1 Medical Characteristics

2.3.1.1 Type of Stroke

Stroke is a heterogenous condition with considerable variation in the nature and severity of presenting deficits. Research has attempted to identify homogenous groups of patients with similar characteristics and prognostic potential for analysis in outcome studies, particularly acute stroke trials. Proposed classification systems describe stroke either according to the region of the brain affected (usually by vascular territory), or the underlying cause of the stroke (Bamford 1991; Teasell, Foley et al. 2004).

Broadly, strokes may be categorised as haemorrhage or infarction. Clinical history may be suggestive of a particular aetiology, but differentiation can only be conclusive with Computer Tomography (CT) or Magnetic Resonance Imaging (MRI) (Bamford 1991). CT's are definitive in diagnosing haemorrhages, but infarctions can only be confirmed by MRI, and some lacunar infarctions may not be visible on MRI in the first few days following the stroke (Teasell, Foley et al. 2004). In North American studies, approximately eighty percent of all strokes are ischaemic (Johnston, Connors, Wagner, Knaus, Wang et al. 2000). However, in developing countries such as South Africa there may be a higher proportion of haemorrhagic stroke (Farham 2004).

Strokes can be classified further into subtypes (Bamford 1992). Haemorrhagic strokes are commonly classified as primary intra-cerebral haemorrhage or sub-arachnoid haemorrhage. Most ischaemic stroke classifications can be considered to incorporate the following categories: atherothrombotic, cardioembolic, small vessel, unknown cause and other cause (D'Olhaberriague, Litvan, Mitsias and Mansbach 1996). It has been suggested that classifications based on clinical findings like the Bamford classification may be easier to apply in the absence of extensive investigations (Bamford 1992). However, surprisingly, aetiological classifications such as the TOAST classification [1] (Adams, Bendixen, Kappelle, Biller, Love et al. 1993; D'Olhaberriague, Litvan, Mitsias and Mansbach 1996) are no less reliable (D'Olhaberriague, Litvan, Mitsias and Mansbach 1996).

[1] Trial of Org 10172 in Acute Stroke Treatment

Prognosis for recovery is thought to differ between subtypes (Murat Sumer and Erturk 2002; de Jong, van Raak, Kessels and Lodder 2003). The proportional representation of stroke type and subtype varies between populations, and is associated with stage of health transition of the population (Connor and Bryer 2006). For this reason, when comparing stroke rehabilitation outcomes between a South African stroke population and that of a developed country, incidence of stroke type and subtype must be considered.

2.3.1.2 Risk Profile

The clinical importance of risk factor profiles cannot be overemphasised because stroke is in many instances a preventable disease (Bonita, Mendis and Truelson 2004). Recurrence of stroke is not uncommon and modifiable risk factors need to be addressed as part of rehabilitation programmes (Geffen 2000; South African Medical Association- Neurological Association of South Africa Working Group 2000; Salter, Teasell, Foley, Bhogal and Speechley 2004a). Certain risk factors are associated with less favourable outcomes and may be predictive of recurrence of stroke.

Non-modifiable risk factors include age and the male gender (South African Medical Association- Neurological Association of South Africa Working Group 2000). Other risk factors for stroke include high blood pressure, diabetes, hyperlipidaemia, carotid and vertebral artery disease, vascular conditions such as peripheral vascular disease and previous thrombosis, the use of oral contraceptives, previous Transient Ischaemic Attack (TIA), carcinoma and cardiac disease (Teasell, Foley et al. 2004; Connor, Rheeder et al. 2005; Connor and Bryer 2006). Cardiac disease includes heart failure, cardiomyopathy, atrial fibrillation, as well as valvular and ischaemic heart disease. Lifestyle factors such as smoking, substance abuse and excessive alcohol consumption have also been implicated (Fritz 2000; South African Medical Association- Neurological Association of South Africa Working Group 2000; Murat Sumer and Erturk 2002; Kurth, Kase, Berger, Schaeffner, Buring et al. 2003; Connor, Rheeder et al. 2005).

Table 2-1 Definition of Risk Factors for Stroke

RISK FACTOR	DEFINITION
High Blood Pressure	Systolic BP or ≥140mm.Hg or a diastolic of ≥90mm.Hg or a past history of hypertension (Connor, Rheeder et al. 2005)
Diabetes	Repeated fasting plasma glucose level of more than 7.8 mmol/L (World Health Organisation 1985), or a recorded history of diabetes whether treated or untreated.
Hyperlipidaemia	A high total cholesterol level of >5 mmol/l (Connor, Rheeder et al. 2005) or a recorded history of hyperlipidaemia [2]
Excessive Alcohol Intake	More than 3 units per day for men, and more than 2 units per day for women. (Hajat, Dundas, Stewart, Lawrence, Rudd et al. 2001) 1 unit is equivalent to 1 tot of spirits, 1 small glass of wine, or 300ml/ half pint of beer.

Risk profiles in developing countries are known to demonstrate a greater prevalence of uncontrolled hypertension and infective causes of ischaemia (Poungvarin 1998). Hypertension has been highlighted as a major modifiable risk factor for stroke in South Africa (Poungvarin 1998; Fritz 2000; Bogoshi, Stewart and Hale 2003). Infective causes of stroke such as TB and syphilis have also been noted (Fritz 2000; Connor, Rheeder et al. 2005). In particular, the co-occurrence of stroke in young patients with HIV/AIDS has been reported (Mochan, Modi and Modi 2003; Patel, Sacoor et al. 2005). However, it is unknown whether HIV/ AIDS is an independent risk factor for stroke and no direct causal link has been established to date (Patel, Sacoor et al. 2005; Connor and Bryer 2006). HIV/ AIDS is associated with coagulopathies and cardiomyopathy, as well as a wide range of neurological conditions such as focal and diffuse

[2] A cut off point of 5.17mmol which corresponds to 200mg/100ml is a commonly used cut off point to mark favourable cholesterol levels; however, a value of 5mmol is currently referred to in many South African documents
Connor, M, P Rheeder, A Bryer, M Meredith, M Beukes, A Dubb, V Fritz and obotSAS Foundation) (2005). "The South African Stroke Risk in General Practice Study." South African Medical Journal **95**(5): 334-339.
QUERI Stroke Executive Committee (1999). "Primary Stroke Prevention." VA Practice Matters **4**(1): 1-6,
Imperatore, G, BL Cadwell, L Geiss, JB Saadinne, DE Williams, ES Ford, TJ Thompson, KMV Narayan and EW Gregg (2004). "Thirty-year Trends in Cardiovascular Risk Factor Levels among US Adults with Diabetes." American Journal of Epidemiology **160**(6): 531-539..
QUERI Stroke Executive Committee (1999). "Primary Stroke Prevention." VA Practice Matters **4**(1): 1-6,

CNS infections, tumours, dementia, vasculitis, vasculopathy, cerebral toxoplasmosis and neuropathies (Mochan, Modi and Modi 2003). Many of the manifestations of HIV/ AIDS constitute independent risk factors for stroke, and may be the reason for the co-occurrence (Connor and Bryer 2006). Stroke-like symptoms can also result from space occupying lesions such as tumours or focal infective lesions that may present as stroke, but may not be due to a purely vascular event (Mochan, Modi and Modi 2003; Patel, Sacoor et al. 2005). In mid 2006, prevalence rates of HIV/ AIDS infection in South Africa were estimated at 11.2% (Dorrington, Johnson, Bradshaw and Daniel 2006), so the association between HIV/ AIDS and stroke is of considerable importance in the South African stroke population.

2.3.1.3 Clinical Presentation

Patients with stroke may present with impairments of motor, sensory, perceptual and cognitive function, as well as impairments of communication and swallowing (Ashburn 1997; Penn 2000; South African Medical Association- Neurological Association of South Africa Working Group 2000; Teasell and Heitzner 2004a). Recovery is often incomplete, and residual deficits may affect the functioning of the individual, contributing to activity limitations and participation restrictions (Mercier, Audet, Hebert, Rochette and Dubois 2001).

Physical impairments may include paresis (unilateral or bilateral according to the site of the lesion), hypertonia or spasticity, lack of co-ordination, balance disturbances and ataxia (Ashburn 1997; Teasell and Heitzner 2004a). Although essentially a higher function, motor planning deficits can also influence physical abilities. Secondary changes due to immobility and disuse that are not direct sequelae of stroke may become evident over time and influence physical function (Teasell and Heitzner 2004a). These include weakness and loss of range of movement.

Sensory and perceptual deficits may include altered or reduced sensation or proprioception and visual disturbances such as hemianopia (Teasell and Heitzner 2004a). Visuospatial or perceptual difficulties may occur due to disordered interpretation of incoming sensory information and include neglect, anosognosia, astereognosis, figure-ground perception deficit, and constructional apraxia (Hochstenbach and Mulder 1999; Bitensky, Teasell, Salter, Bhogal, Foley et al. 2004; Teasell and Heitzner 2004a; Teasell, Salter, Bitensky, Bhogal, Foley et al. 2004e). Cognitive impairments include deficits of memory, orientation, attention, language, praxis and executive function (Hochstenbach and Mulder 1999; Bitensky, Teasell et al. 2004). Executive function refers to goal setting abilities, problem solving, planning and execution, self-monitoring and insight (Hochstenbach and Mulder 1999). Communication impairments may include deficits of receptive and/ or expressive language (aphasia), apraxic speech disorders and dysarthria (Penn 2000; Teasell and Heitzner 2004a). Inappropriate behaviour, depression and emotional lability are sometimes observed (Hochstenbach and Mulder 1999; Teasell and Heitzner 2004a).

2.3.1.4 Co-existing Medical Conditions

Co-existing medical conditions are important in profiling patients with stroke as they may have an independent effect on function (Fultz, Ofstedal, Herzog and Wallace 2003) as well as influencing rehabilitation potential (Geffen 2000). Certain medical conditions are particularly prevalent in stroke populations due to shared risk factor profiles such as diabetes (Megherbi, Milan, Minier, Couvreur, Osseby et al. 2003) and cardiac disease (Geffen 2000; Gordon, Gulanick, Costa, Fletcher, Franklin et al. 2004). In addition, as stroke is associated with older age, many of the common diseases of ageing may co-exist in individuals with stroke such as impaired vision and hearing, arthritis and lung disease (Fultz, Ofstedal, Herzog and Wallace 2003; Megherbi, Milan et al. 2003; Gordon, Gulanick et al. 2004).

2.3.1.5 Complications of Stroke

In addition to impairments that result directly from neurological damage in the brain, there are a number of secondary complications of stroke that may affect functional outcome and rehabilitation potential. In many cases they are preventable but once manifest can result in much misery and additional medical expense. Common complications following stroke include chest infections, urinary tract infections, deep vein thrombosis, contractures, bed sores, joint and soft tissue pain, post stroke central pain, seizures, depression and falls (Black-Schaffer, Kirsteins and Harvey 1999; Geffen 2000; Roth, Lovell, Harvey, Heinemann and Semi 2001). Complications after stroke have been reported to occur in 48-96% of patients admitted to an inpatient rehabilitation facility (Roth, Lovell et al. 2001).

A higher incidence of complications has been found to be associated with severity of stroke on admission (Roth et al 2001) and the presence of indwelling urinary catheters (Geffen 2000). Overseas studies do not suggest an association of higher rates of complications in patients with longer intervals between stroke onset and admission to rehabilitation facilities (Roth, Lovell et al. 2001). However, this may not be generalizable to the South African stroke population where pressure on beds in acute medical wards may result in patients with severe strokes being discharged home very early, with little training of relatives and sometimes with urinary catheters or nasogastric feeding tubes in situ (Meiring 1990; Riley 1998). It may be some weeks or months later that these patients are admitted to rehabilitation units. Riley (1998) proposes that premature discharge of patients with stroke can result in the gains achieved in early rehabilitation being lost and the development of complications such as painful shoulder.

2.3.2 Demographic Characteristics

Demographic characteristics include age, gender and population group. These factors may influence outcome after stroke (Segal and Whyte 1997).

South Africa is a multicultural and multilingual country. The population composition of the Western Cape is 27% Black African, 54% Coloured, 1% Indian or Asian and 18 % White (Statistics South Africa 2006). South Africa has eleven official languages and the home languages most commonly spoken in the Western Cape are Afrikaans (55%), English (19%), and Xhosa (24%) (Statistics South Africa 2006). However, many South Africans are multilingual, and over one third of households use a mixture of languages at home (Pan South Africa Language Board 2000). The Western Cape has a functional literacy rate of 80% (Statistics South Africa 2006).

2.3.3 Socio-Economic Characteristics

There is a higher incidence and prevalence of stroke in lower socio-economic groups, and socio-economic factors are known to affect morbidity and mortality following stroke (Van Den Bos, Smits, Westert and Van Straten 2002; Putman, De Wit et al. 2006). Lower socio-economic status is associated with different risk profiles, increased severity of stroke and poor long term outcomes (Van Den Bos, Smits, Westert and Van Straten 2002). Socio-economic status may also influence treatment received, as well as the experience of rehabilitation (Van Den Bos, Smits, Westert and Van Straten 2002; Putman, De Wit et al. 2006). Socio-economic indicators frequently collected in health studies include educational levels, monthly household income and type of work (Van Den Bos, Smits, Westert and Van Straten 2002; Putman, De Wit et al. 2006).

Results from the 2001 Census indicate that in the City of Cape Town (Cape Metropole) region, more than half of households earn under R3200 per month (Statistics South Africa 2003). Unemployment in the area stands at 17% (Statistics South Africa 2003). In terms of education levels, of those aged 20 or above in the Western Cape region, 23% had had some primary education, 37% had had some secondary education, and 23% had completed matriculation. Only 11% had had higher education (Statistics South Africa 2006). In terms of housing, 88% of households in the Western Cape lived in formal dwellings (Statistics South Africa 2006). More than two thirds of households had access to piped water within their dwellings (Statistics South Africa 2006). Eighty-eight percent of households had access to electricity (Statistics South Africa 2006).

2.4 The Rehabilitation Process

2.4.1 Acute Stroke Care

The importance of the first few hours after stroke in defining future recovery has led to an emphasis on early stroke care. The Stroke Therapy Clinical Guidelines for South Africa (South African Medical Association- Neurological Association of South Africa Working Group 2000) recommend that stroke be treated as an emergency with assessment and treatment within six hours of onset. Treatment within a specialised acute stroke unit is recommended. Protocols for early management are said to reduce morbidity and mortality by up to 20% (South African Medical Association- Neurological Association of South Africa Working Group 2000). Rehabilitation begins in the early stages post stroke as soon as the patient is medically stable.

2.4.2 Rehabilitation

Rehabilitation is believed to reduce residual disability after stroke. It can affect outcome by reducing impairment, increasing functional independence at the level of activity, promoting participation in life situations and enhancing quality of life (Kwakkel, Kollen and Lindeman 2004). Key components of rehabilitation have been identified as goal setting and involvement of a multi-disciplinary team (Wade 2000). The multidisciplinary team usually includes doctors, nurses, physiotherapists, occupational therapists, social workers, clinical psychologists and speech and language therapists (Wade 2000). Rehabilitation interventions may be directed at the level of impairment, or function (Bode, Heinemann, Semik and Mallinson 2004). For example, individual impairments that limit the performance of a functional task may be targeted, for example, stretching a joint or muscle, improving motor control in a reaching task or strengthening. Rehabilitation may be directed at the level of activity, for example with practice of bathing and dressing tasks (Bode, Heinemann, Semik and Mallinson 2004). Participation in a particular role, such as return to work may be targeted. This may involve, for example, building of problem solving skills, community mobility, and communication skills. It may also involve liaison with employers, and adapting the work environment. In addition, rehabilitation interventions may include providing adaptive equipment or changing the environment at home to facilitate independence (Dobkin 2004). This may involve the prescription of mobility and other aids (Dobkin 2004).

A number of rehabilitation approaches have been described in literature but there is no conclusive evidence that one approach is more effective than another (Kwakkel, Kollen and Wagenaar 1999). Two common approaches to adult rehabilitation include the Bobath approach and the motor relearning approach[3]. Both approaches have developed over the years with increasing understanding of the neurophysiological processes of recovery. Historically, the Bobath technique focused on the facilitation of "normal movement patterns", with control of spasticity and abnormal movement patterns (Edwards 1996). The current Bobath concept focuses on a problem solving approach based on the principles of motor control, motor learning, plasticity and biomechanics (International Bobath Instructors Training Association 2007). The motor relearning approach emphasises aspects of active learning for motor skill acquisition, with the focus on motor control and biomechanics. Self-monitored practice is an important component of the motor relearning approach (Edwards 1996; van Vliet, Lincoln and Robinson 2001). At this stage there is little evidence to support one approach to rehabilitation as being more effective than another, other than the fact that task-orientated rehabilitation brings about the best carry-over (Cifu and Stewart 1999). There is also evidence to support the use of certain techniques or interventions such as constraint induced movement therapy and treadmill training (Dobkin 2004).

Research indicates that early intervention and greater intensity of treatment are associated with better outcomes (Cifu and Stewart 1999; Paolucci, Antonucci, Grasso, Morelli, Troisi et al. 2000; Kwakkel, Kollen and Lindeman 2004; Teasell and Kalra 2005). It has been suggested that certain sub-groups of patients with stroke benefit more from rehabilitation than others (Kwakkel, Kollen and Wagenaar 1999; Evans, Harraf, Donaldson and Kalra 2002).

Stroke rehabilitation can be delivered in a number of different settings including inpatient and outpatient facilities and by domiciliary visits in the community. Stroke unit care has been demonstrated to improve outcomes (Langhorne, Williams, Gilchrist and Howie 1993) with effects still significant five years after stroke (Indredavik, Slordahl, Bakke, Rokseth and Haheim

---

[3] Variable terminology is in use in literature: the Bobath approach is sometimes referred to as a neurodevelopmental (NDT) approach and the motor relearning programme approach has also been referred to as a movement science based approach.
van Vliet, P, N Lincoln and E Robinson (2001). "Comparison of the content of two physiotherapy approaches for stroke." Clinical Rehabilitation **15**: 398-414..

1997). Interdisciplinary care has been shown to be more effective than multi-disciplinary care (Cifu and Stewart 1999; Teasell, Foley, Bhogal, Doherty and Speechley 2004d). In general, specialist services are known to be associated with better outcomes than normal care (Kwakkel, Kollen and Lindeman 2004). There is some debate with regard to whether treatment at home or in hospital should be preferred (Cifu and Stewart 1999). Many patients will receive rehabilitation in a number of different settings during the course of their recovery.

2.4.3 Rehabilitation in South Africa, and the Western Cape

It is acknowledged that historically there has been a shortage of rehabilitation services in South Africa, including the Western Cape, largely due to lack of finances (Meyer 2004). A number of articles published in the nineties highlight these issues (Meiring 1990; Riley 1998). Short admissions to acute care hospitals after the initial event, lack of family training prior to discharge and inadequate follow up after discharge have been described (Meiring 1990; Whitelaw, Meyer, Bawa and Jennings 1994; Riley 1998). Many articles refer to the fact that rehabilitation services are often hospital based and there are few community services (Versveld 1997). Lack of transport and finances were identified as reasons for patients not accessing follow up treatment (Whitelaw, Meyer, Bawa and Jennings 1994).

Since these articles have been published there have been changes in Health Care policies in South Africa. There has been a de-centralisation of hospital services with a shift towards primary health care. In particular, there has been a greater emphasis on Community Health Care Centre services and community based rehabilitation programmes. Healthcare 2010 is the current health care plan with the aim of accessible basic healthcare for all at community level (Uys 2005). Despite these changes, many of the fore-mentioned difficulties still remain and it is recognised that rehabilitation services still do not reach many people in need (Provincial Government of the Western Cape 2004).

The Western Cape Rehabilitation Centre (WCRC) is a specialised regional rehabilitation unit that opened in October 2004. Two previous Rehabilitation Units (Conradie Hospital and Karl Bremer Centre for Care and Rehabilitation) amalgamated to form this new centre which has 240 mixed rehabilitation beds and an outpatient facility. The WCRC is expected to become a flagship for rehabilitation. (Provincial Government of the Western Cape 2005). To the knowledge of the researcher, no studies have yet been published regarding outcomes in the patients accessing the WCRC for treatment.

2.5 Recovery after Stroke

One of the major clinical issues in stroke rehabilitation is predicting expected recovery in individual patients with stroke and evaluating their rehabilitation potential. Patients and their families request this information (Jones 1998) and expectations of recovery will affect how much treatment an individual will receive in order to achieve their estimated optimal level of function. Recovery has been said to follow a non-linear, logarithmic pattern, with a levelling off of change over time (Kwakkel, Kollen and Twisk 2006). Rehabilitation is thought to modify this by influencing the processes of recovery (Kwakkel, Kollen and Lindeman 2004).

Epidemiological studies show that 60-70% of patients with stroke achieve independence in ADL, and 70-85% gain independent walking (Kwakkel, Kollen and Wagenaar 1999). Thirty to 66% of patients with stroke regain functional use of the upper limb (Kwakkel, Kollen and Wagenaar 1999). Only 5-20% demonstrate complete functional recovery of the upper limb (Kwakkel, Kollen and Wagenaar 1999). Differences in selection of patients and choice of measurement tools may explain the variability in findings between studies (Kwakkel, Kollen and Wagenaar 1999).

2.5.1 <u>Mechanisms of Recovery</u>

Recovery after stroke is thought to occur as the result of a number of processes including brain repair at tissue level, adaptive reorganisation of the central nervous system (CNS) and the establishment of compensatory strategies (Platz 2004). Different mechanisms are thought to be at work at different stages of recovery (Kwakkel, Kollen and Lindeman 2004).

The relatively rapid neurological recovery in the early stages after stroke is thought to occur due to resolution of oedema and improved perfusion of the ischaemic penumbra. The penumbra is the area around the ischemic core that may not function initially but which is not irreversibly damaged. In addition, areas remote to the infarcted area may shut down initially due to reduced input from the infarcted area, but later resume function in a process termed resolution of the diaschisis (Kwakkel, Kollen and Lindeman 2004; Page, Gater and Bach-y-Rita 2004; Rossini and Dal Forno 2004; Teasell and Bitensky 2004b).

Adaptive reorganisation refers to functional and structural reorganisation of the central nervous system that is believed to be enhanced by activity and use. Mechanisms may include dendritic branching, changes in the number of synapses and neurotransmitter production, and unmasking of alternative pathways due to disinhibition. Changes may occur in areas of motor and sensory cortical representation. In addition, here may be changes in areas of brain activation during motor tasks. These neuroplastic processes are thought to be partly activity induced. This may represent a modifiable aspect of recovery that can be influenced by rehabilitation. Adaptive reorganisation occurs over weeks and months following the stroke (Kwakkel, Kollen and Lindeman 2004; Rossini and Dal Forno 2004; Teasell and Bitensky 2004b).

Compensatory strategies occur as the individual finds alternative ways of moving or performing tasks in spite of residual deficits. These are often behavioural changes, and do not necessarily reflect change at the level of impairment. Compensation and behavioural adaptation are thought to play a larger role in the later stages of recovery (Kwakkel, Kollen and Lindeman 2004).

2.5.2 Definitions of Recovery

Some authors have distinguished between neurological or "true" recovery and functional recovery (Teasell and Bitensky 2004b). Neurological recovery is defined as improvements in neurological deficits or impairments and is considered to be the result of local processes within the central nervous system such as neural repair and adaptive reorganisation (Kwakkel, Kollen and Lindeman 2004). It is expected to occur mostly in the early stages after stroke (Teasell and Bitensky 2004b).

Functional recovery refers to improvement in abilities to perform activities of daily living, or participation in pre-stroke roles, and may occur in spite of residual deficits (Roth, Heinemann, Lovell, Harvey, McGuire et al. 1998). Functional recovery is thought to be influenced by rehabilitation, and can occur after neurological recovery is complete. Compensatory mechanisms are thought to play an important role (Kwakkel, Kollen and Lindeman 2004).

Motor recovery refers to the return of movement and recovery of motor control (Horgan and Finn 1997).

2.5.3 The Effect of Rehabilitation on Recovery

As discussed above, mechanisms of recovery are thought to include local processes of repair, adaptive reorganisation of the CNS and compensatory strategies. Evidence suggests that stimulation and training can enhance recovery, and functional MRI and animal studies have provided some insight into the processes involved (Teasell and Kalra 2005).

Randomised controlled trials in rats have shown improved recovery in groups that receive stimulation compared to controls, and have demonstrated that training and exposure to enriched environments can play a role in post-stroke cortical reorganisation (Platz 2004). In humans, functional MRI studies have identified changes in areas of brain activation that accompany neurological recovery, suggesting that alternate undamaged areas of the brain may assume a new function. The influence of stimulation and usage on structural and functional changes in brain function, suggests that rehabilitation can influence the plastic reorganisation of the CNS following stroke (Platz 2004). This is supported by evidence from clinical studies that intensive task specific training enhances recovery after stroke (Cifu and Stewart 1999). Timing of rehabilitation may also play a role. Animal studies indicate that the undamaged cortex is most responsive to rehabilitation in the early stages after stroke, and clinical studies in humans suggest that earlier admission to stroke units is associated with improved outcomes (Cifu and Stewart 1999) .

As previously discussed, compensatory strategies and behavioural adaptation are thought to be an important component of functional recovery (Kwakkel, Kollen and Lindeman 2004). This may be the reason behind a reduction in disability, in the absence of reduction in impairments, in patients undergoing rehabilitation in a previous study (Roth, Heinemann et al. 1998). The reduction in disability was attributed to learning that occurred during rehabilitation input, rather than due to natural recovery. It is interesting that this study suggested a smaller association between functional outcome and impairment than would be expected.

Motor recovery is thought to occur as a result of brain repair and reorganisation, as well as compensation. Rehabilitation techniques are thought to manipulate underlying physiological processes, in order to improve motor recovery (Dobkin 2004). Repeated training is thought to lead to activity-induced adaptive changes and functional re-organisation of the central nervous system (Platz 2004), but improvement of motor performance may also occur as a result of compensatory mechanisms and neuromuscular changes beyond the central nervous system. For example, gait velocity may improve due to strength changes in the unaffected lower limb and compensatory movement patterns of the upper limb may allow performance of a motor task in the absence of restitution of movement. In particular, gait and dexterity changes may be due to behavioural adaptation strategies to existing deficits rather than restitution of impairments (Kwakkel, Kollen and Lindeman 2004). Changes in the cardiovascular system, as well as peripheral changes in muscle function and structure may also play a role in the improved motor performance (Page, Gater and Bach-y-Rita 2004). Acquiring motor skills after stroke is considered to be a learning process and is referred to as motor relearning (Dobkin 2004).

2.5.4 Pattern of Recovery

Recovery after stroke has been said to follow a time dependent pattern, with relatively rapid change in the first few weeks. In general, the amount of recovery is highly related to initial severity and the rate of change in the early stages after stroke (Horgan and Finn 1997; Kwakkel, Kollen and Lindeman 2004). More severe strokes are thought to demonstrate a slower pattern of recovery (Duncan, Goldstein, Matchar, Divine and Feussner 1992; Jorgensen, Nakayama, Raaschou, Vive-Larsen, Stoier et al. 1995a).

In literature, there is considerable variation in reported time frames, but in general, most recovery is reported to occur in the first four to six weeks post stroke, after which improvement continues at a slower rate until a plateau is reached. Most studies suggest this occurs around three months post stroke (Jorgensen, Nakayama, Raaschou, Vive-Larsen, Stoier et al. 1995b; Horgan and Finn 1997; Teasell and Bitensky 2004b).

Horgan and Finn (1997) suggest that motor function is optimal by eight to twelve weeks post stroke. Similar time frames were reported in the Copenhagen Stroke study, where 80% of participants unable to walk at admission were reported to have reached their best walking function[4] in six weeks, and 95% in 11 weeks (Jorgensen, Nakayama, Raaschou and Olsen 1995c). Similarly, optimal upper limb function is reported to have been achieved by 12 weeks (Teasell and Bitensky 2004b). The observation that most motor recovery occurs earlier after stroke is supported by a study that reported Fugl-Meyer motor impairment scores at baseline, five days and 30 days post stroke, explained 53%, 74% and 86% of the variance at six months respectively (Duncan, Goldstein et al. 1992).

Duncan et al.(1992) report most ADL recovery in the first 30 days after stroke, with severe strokes recovering to their highest level in one to three months. In the Copenhagen study (Jorgensen, Nakayama et al. 1995a), 80% of patients with stroke had achieved their highest level

[4] Best walking function defined according to BI sub scores for the mobility item: 0- or 5- No Walking Function, 10- Walking with Assistance or 15- Walking Independently

of function in ADL within six weeks of stroke and 95% by 12.5 weeks (Jorgensen, Nakayama et al. 1995a).

Recovery beyond 12 weeks has also been reported and a number of authors point out that change can be seen up to, and beyond six months especially with regard to functional recovery which can continue after neurological recovery is complete (Horgan and Finn 1997; Dobkin 2004; Kwakkel, Kollen and Lindeman 2004; Teasell and Bitensky 2004b). Furthermore, recovery may be masked by choice of outcome measures. The Barthel Index has a low ceiling effect, and may not detect later improvements such as changes in community mobility and functional communication (Ashburn 1997). Recovery of higher physical functions and social role may occur undetected in many studies. Improvements at the level of participation have been reported up to a year after stroke (Sturm, Dewey et al. 2002) and beyond (Desrosiers, Rochette, Noreau, Bourbonnais, Bravo et al. 2006).

Kwakkel et al. (2004), suggest that after six months, 10-30% of patients will either deteriorate or show further improvement in terms of gait speed, dexterity or ADL function. However, changes after six months usually represent changes in specific functions such as mobility, incontinence and socialisation (Kwakkel, Kollen and Lindeman 2004; Teasell and Bitensky 2004b). Deterioration has been reported in long term follow ups of stroke survivors and has been attributed to the effects of aging and co-morbidities (Samuelsson, Soderfeldt and Olsson 1996; Wilkinson, Wolfe, Warburton, Rudd, Howard et al. 1997).

It has been suggested that lack of change after six months occurs due to the fact that rehabilitation usually does not continue beyond this time frame, or as a result of habituation to training programmes (Page, Gater and Bach-y-Rita 2004). Dobkin (2004) suggests that a pulse of goal-directed treatments can induce change at any time post stroke.

In summary, most neurological recovery is thought to occur in the first three months post stroke, but functional recovery can continue when neurological recovery is complete (Teasell and Bitensky 2004b). Change is most rapid in the first few weeks post stroke. After six months, changes in basic ADL and motor function are thought to be relatively small, and to occur in a minority of patients. However, resumption of pre-stroke roles and improvements in levels of participation are seen many months after stroke, as the patient settles into their home environment following discharge. Social aspects of recovery are often the most important to patients, and may be the reason why stroke survivors in a phenomenological study did not describe any end point to recovery (Burton 2000).

2.5.4.1 Current evidence: Spontaneous Recovery over Time or the Effects of Rehabilitation?

The mathematical regularity of patterns of recovery over time, has led some authors to suggest that spontaneous neurological recovery is responsible for most recovery after stroke (Kwakkel, Kollen and Twisk 2006). Kwakkel et al. (2006) suggest that the progression of time alone is responsible for 16-42% of improvements seen in the first six to ten weeks post stroke.

However, it is not possible to isolate spontaneous neurological recovery from the effects of rehabilitation. As far as this researcher is aware, no randomised controlled trial has been carried out in which a control group of patients receives no rehabilitation input after stroke. Ethical considerations would make such a study questionable in the light of existing evidence on the effects of rehabilitation (Teasell and Kalra 2005). Moreover, studies that compare the efficacy of differing rehabilitation interventions, or look at the efficacy of standard versus enhanced rehabilitation have demonstrated differences in recovery in groups of patients experiencing different interventions (Cifu and Stewart 1999). Earlier commencement of treatment as well as greater frequency of treatment results in better outcomes suggesting that rehabilitation does indeed modulate pattern of recovery. Furthermore, as presented above, there is evidence that the neurological processes of recovery themselves may be influenced by rehabilitation.

Evidence suggests that while rehabilitation plays a role in modulating recovery, initial severity of stroke is an important determinant of outcome (Duncan, Goldstein et al. 1992). In studies using multiple regression models, the effects of rehabilitation appear relatively small in comparison to the effects of spontaneous recovery, with only 10% of the variance in outcome at six months explained by rehabilitation (Duncan, Goldstein et al. 1992). In addition, there is little difference at six months implying that effects may be temporary or most marked in the first six months (Kwakkel, Kollen and Lindeman 2004). However, it seems plausible that treatment effects may be lost due to the heterogeneity of stroke and the large number of factors affecting outcome (Bode, Heinemann, Semik and Mallinson 2004).

In summary, there is evidence to suggest that rehabilitation does influence both neurological and functional recovery after stroke (Roth, Heinemann et al. 1998; Teasell and Bitensky 2004b).

Different mechanisms are expected to be involved at different times post stroke (Horgan and Finn 1997; Teasell and Kalra 2005). Mechanisms include plastic reorganisation of the CNS and the learning of compensatory strategies and behavioural adaptation. The relative contribution of rehabilitation appears small in comparison to the effects of natural recovery (Kwakkel, Kollen and Lindeman 2004).

2.6 Outcome after Stroke

2.6.1 <u>Defining Outcome after Stroke</u>

The aim of rehabilitation is for patients to become functionally independent and to return as far as possible to normal living within the community assuming their usual pre-stroke roles (Kwakkel, Kollen and Lindeman 2004). Thus in considering rehabilitation outcomes, the ICF domains of activity and participation are those of particular interest (Whiteneck 1994; Segal and Whyte 1997). One of the difficulties in measuring participation is that it is not easily observed and thus needs to be reported. Questionnaires can be biased by recall and social pressure to give the "desired" answer. In addition, limitations of cognition and language may require the use of proxies which may introduce further bias. Moreover, the domains of activity and participation are broad, and the effect of a specific intervention on outcome may be obscured by many external factors including the environment (Duncan, Jorgensen and Wade 2000). For this reason, acute stroke trials favour the use of impairment based outcome measures which are said to relate directly to the extent of the initial insult and to reflect subsequent neurological recovery (Roberts and Counsell 1998; Duncan, Jorgensen and Wade 2000). However, impairment-based measures have limitations for describing rehabilitation outcomes because stroke survivors can demonstrate participation in many of their pre-stroke roles in spite of significant levels of impairment. Important changes in function and independence can occur in the absence of change at impairment level. Conversely, restitution of impairments does not necessarily lead to meaningful functional change (Duncan, Goldstein et al. 1992; Roth, Heinemann et al. 1998). Furthermore, patients with stroke tend to focus on the social context of recovery rather than actual physical recovery and resumption of roles and quality of life are usually more important to patients than small changes in motor function (Burton 2000).

"Quality of life" is gaining increasing recognition as an important outcome concept (King 1996; Roberts and Counsell 1998). It has been defined as "satisfaction with aspects of life that are important to the individual" (King 1996). Quality of life is affected by a broad range of factors that are not necessarily related to health. For health outcomes research, measures of Health

Related Quality of Life (HRQoL) are preferred as they refer specifically to the impact of health issues on Quality of Life (Jette 1992).

Caregiver strain is another important measure of outcome. Patients with stroke are often reliant on caregiver support in order to return to community living, and the involvement of the caregiver is very important for successful rehabilitation. Caregivers report high levels of strain and depression and caregiver well-being can impact on rehabilitation outcomes (Kerr and Smith 2001; Wyller, Thommessen, Sodring, Sveen, Pettersen et al. 2003).

Previous rehabilitation outcome studies have included the following as outcomes of interest: functional independence, caregiver strain, discharge destination (i.e. home or institution), return to work, and return to social and leisure activities. Studies with a more medical focus have concentrated on outcomes of impairment after stroke, recurrence of stroke and mortality (Roberts and Counsell 1998).

2.6.2 Measuring Outcome after Stroke: Requirements of Outcome Measures

Stroke research has been criticised for a lack of outcome measures with proven validity, reliability and sensitivity (Roberts and Counsell 1998). Requirements of outcome measures are first and foremost that they measure what they are supposed to measure, that valid inferences can be made from the gathered data, and that they ask the relevant questions (validity) (Dittmar and Gresham 1997). In addition, measurements need to be repeatable regardless of the person applying the instrument, and stable measurements should be repeatable over time (reliability) (Dittmar and Gresham 1997). Instruments should be responsive enough to detect meaningful clinical change in the population of interest over the required time frame of the study (Dittmar and Gresham 1997). It is noted that many of the measurement tools commonly used in stroke outcome studies have not been thoroughly tested with regard to reliability and validity (Roberts and Counsell 1998).

The validity of a measuring tool should be established for the population in which it is being used as it may be affected by the cultural and environmental context. (D'Olhaberriague, Litvan, Mitsias and Mansbach 1996). Participation relates to social role, which may vary in different cultural settings. Furthermore, the environment in which an individual lives may dictate different requirements for a particular task. Thus where tools have been developed in Western societies, their application in international studies should be undertaken with care (Wade 1992; Ali and

Mulley 1998; Kucukdeveci, Yavuzer, Tennant, Suldur, Sonel et al. 2000). Where the translation of assessment tools is required, rigorous procedures need to be in place in order to preserve the integrity of the questionnaire. Choice of wording can have a profound impact on what a questionnaire is actually asking (Mkoka, Jelsma and Vaughan 2003; Jelsma, Mkoka, Amosun and Nieuwveldt 2004). Many of the tools used to measure participation overseas would need to be translated and validated before being used in the South African context. Jelsma, Chivaura, De Weerdt and De Cock (2000) have cautioned against attempts to translate lengthy and conceptually complicated measurement tools, as it can be challenging to establish the cross-cultural validity of even simple measures.

Communication and cognitive deficits are common in patients with stroke, and further issues of validity are introduced where patients need help with answering questions or where a proxy is required to answer on the patient's behalf (Duncan, Min Lai, Tyler, Perera, Reker et al. 2002). It has been suggested that proxies tend to report higher levels of disability and lower quality of life than stroke survivors themselves (Hackett, Duncan et al. 2000). However, it is argued that with regard to observable behaviour the effect is small and may not be clinically significant. This may be less reliable for psychological functioning and quality of life (Hackett, Duncan et al. 2000). Patients with stroke with communication or cognitive deficits are said to constitute a sub-group of their own, with specific characteristics in terms of severity and sub-type (Sneeuw, Aaronson, De Haan and Limburg 1997). Thus excluding these patients from outcome studies could potentially introduce bias and the use of proxy assessments has been justified in previous studies in spite of their limitations (Duncan, Min Lai et al. 2002).

2.6.3 Specific Outcome Measures used in Previous Studies

Decisions regarding what ought to be measured and how outcome should be defined have driven the selection of measurement tools in previous studies. No single instrument has gained universal acceptance and most outcome studies use several measuring tools. The National Institute of Health Stroke Scale (NIHSS), Modified Rankin Scale (MRS), and the Barthel Index (BI) are measures that have been widely used in the past (Roberts and Counsell 1998; Sulter, Steen and De Keyser 1999; Duncan, Jorgensen and Wade 2000; Geyh 2004) as have the two International Stroke Trial Simple Questions (McKevitt, Dundas and Wolfe 2001). Other outcome measures that appear in literature include the EQ-5D (Dorman, Waddell, Slattery, Dennis and Sandercock 1997b), the Caregiver Strain Index (Blake, Lincoln and Clarke 2003), the Fugl-Meyer (Duncan, Goldstein et al. 1992) and the FIM (Salter, Jutai and Teasell 2004b).

2.6.3.1 Measurement at the Level of Impairment

A number of stroke scales have been proposed for the measurement of mixed neurological deficits. The NIHSS has been shown to compare favourably with other stroke scales and has been recommended as the scale of choice in stroke trials (D'Olhaberriague, Litvan, Mitsias and Mansbach 1996; Muir, Weir, Murray, Povey and Lees 1996). Stroke scales provide a broad indication of neurological deficits, but other measurement tools such as the Rivermead Motor Assessment (RMA) and Mini Mental State Examination (MMSE) have been proposed to address specific areas such as motor deficit and cognitive deficit.

2.6.3.1.1 Global Measures of Neurological Impairment: the NIHSS

The NIHSS comprises 15 items that relate to motor, cognitive, communicative, visual, perceptual and sensory impairments. It does not address dysphagia, balance deficits or executive cognitive dysfunction. It has been widely used to describe the baseline characteristics of patients with stroke admitted to studies as a measure of severity of stroke and as a predictor of outcome (Adams, Davis, Leira, Chang, Bendixen et al. 1999). It has been shown to correlate with CT infarct volumes at seven to ten days post stroke as well as outcome at three months (Heinemann, Harvey, McGuire, Ingberman, Lovell et al. 1997; Adams, Davis et al. 1999). Its predictive value has been shown to compare favourably with multivariate prediction models (Muir, Weir et al. 1996). It has been used in stroke studies to adjust outcomes according to severity at baseline thus accounting for the heterogeneity of stroke (Muir, Weir et al. 1996). It has also been found to be valid for determining treatment related differences and is said to show agreement with other outcome measures (Lyden, Lu, Jackson, Marler, Kothari et al. 1999). Its reliability has been established for neurologists, non-neurologists, physicians and non-physicians (Goldstein and Samsa 1997).

Scores range from 0 to 42, with higher scores demonstrating greater levels of neurological deficit. Previous studies suggest an NIHSS score ≥ 16 is associated with death or severe disability and a score of ≤ 6 is indicative of potential for good recovery (Adams, Davis et al. 1999).

2.6.3.1.2 Measures of Motor Impairment and Motor Recovery

The Rivermead Motor Assessment (RMA) is a mixed scale of motor impairment and activity, and has been used as a measure of motor recovery in previous studies (Cole, Finch, Gowland and Mayo 1995). It consists of three sub-scales: Gross Function, Leg and Trunk, and Arm. The Gross

Function section has been validated for use as a self-standing measure, the Rivermead Mobility Index, which can be reported by the patient rather than observed (Collen, Wade, Robb and Bradshaw 1991). The Rivermead Motor Assessment has not been extensively investigated for reliability although it has been widely used in stroke outcome research (Cole, Finch, Gowland and Mayo 1995). Adequate inter-rater agreement and test-retest reliability have been reported (Lincoln and Leadbitter 1979). Construct and concurrent validity have been found to be favourable (Cole, Finch, Gowland and Mayo 1995).

2.6.3.1.3 Measures of Cognitive Impairment

Cognitive function is complex by nature, and difficult to measure. Thorough assessments of cognitive status require neuropsychological batteries that are time-consuming and expensive to apply, and require expertise. The Mini Mental State Examination (MMSE) which was designed for use in elderly demented populations, has been widely used as a screening instrument for cognitive dysfunction and has been applied in a stroke population (King 1996). However, it is biased by levels of education and may not be culturally appropriate for use in South Africa (Lenger, De Villiers and Louw 1996). In addition, the scope of the MMSE does not extend to include executive dysfunction and the instrument may not be sensitive enough to detect difficulties amongst those with mild cognitive impairments (Salter, Jutai and Teasell 2004b). The clock drawing task has sometimes been used to supplemented the MMSE (Salter, Jutai and Teasell 2004b). Even so, these assessments may not detect the aspects of cognition most relevant to patients with stroke such as complex problem solving skills and lack of insight, which often limit the potential of patients with stroke to return to independent living.

A number of assessments relate to perceptual deficits such as letter cancellation tasks and line bisection tasks (Wagenaar, van Wieringen, Netelenbos, Meijer and Kuik 1992). Tests to identify apraxia include: imitation of learned acts, use of objects, copy of designs, arrangement of blocks and assessment of dressing ability (Saeki, Ogata, Okubo, Takahashi and Hoshuyama 1995).

2.6.3.2 Measurement at the Level of Activity and Participation

2.6.3.2.1 The Barthel Index (BI)

The Barthel Index (BI), developed by Mahoney and Barthel (1965), has been recommended as the Gold Standard for measuring independence in Basic Activities of Daily Living (ADL). Basic ADL can be defined as those activities essential for daily life and include self-care activities, basic mobility and continence. The BI has been recommended as the disability measure of choice on the basis of its established reliability and validity (Wade 1992; D'Olhaberriague, Litvan, Mitsias and Mansbach 1996). It is simple to apply and has been extensively used in stroke studies (Hale, Eales and Fritz 1998; Geyh 2004). It can be applied by observation, as a measure of self-report or by proxy (Weimar, Kurth, Kraywinkel, Wagner, Busse et al. 2002; Salter, Jutai and Teasell 2004b). A limitation is that it lacks sensitivity to reflect change in high functioning patients due to a ceiling effect. (Wade 1992; D'Olhaberriague, Litvan, Mitsias and Mansbach 1996). Furthermore, it does not distinguish between gains in function as a result of motor recovery and those that result from compensation (Horgan and Finn 1997; Hale, Eales and Fritz 1998).

Validity of the BI has been well established in Western Countries and in urban settings (Ali and Mulley 1998). However, even within developed countries, there are differences between cultures that affect items such as bathing and eating utensil use. For example, people in the USA tend to use showers to wash, while in England bath tubs are more common. Similarly, use of cutlery varies between cultures. In one study, researchers concluded that the BI was not meaningful for use in rural Pakistan (Ali and Mulley 1998) due to differences in the ADL requirements of daily life and different physical requirements of many of the activities. For example, lack of furniture meant transfer to a chair was not relevant. In a study in Turkey (Kucukdeveci, Yavuzer et al. 2000), the authors concluded that the tool could be used with minor adaptations. However, it was cautioned that a score in Turkey may not have the same meaning as a score in the United Kingdom, as different levels of difficulty may result from different environmental conditions.

In South Africa, use of the Barthel Index has been reported in a geriatric residential facility to determine care requirements (Puckree, Chetty, Ramlaken, Simelane and Lin 1997). The tool was not translated and no difficulties were reported with regard to its validity (Puckree, Chetty et al. 1997). Hale, Eales and Fritz (1998) noted the limitations of the Barthel Index within the urban environment of Soweto where different environmental demands such as type of housing may influence scores. In response, they developed the Soweto Stroke Questionnaire (SSQ), consisting of an expanded BI with items describing Impairment, Quality of Life and Home Circumstances. (Hale, Eales and Fritz 1998). However, to the knowledge of this researcher, the SSQ has not been used in further published studies.

The Barthel Index was originally scored out of 20, but a more common method of scoring is out of 100 and has been adopted for use in this study. Scores on the Barthel Index range from zero (total dependency) to 100 (independence). A score of 60 has been identified as being pivotal for dependency in basic ADL (Granger, Dewis, Peters, Sherwood and Barrett 1979). Patients with a score of less than 60 require considerable assistance with activities of daily living, but the range of 60 to 85 is said to represent assisted independence with the patient being able to do some things for him or herself. Patients with a score of more than or equal to 85 are said to require minimal assistance. A score of 100 signifies independence but not necessarily normal function (Granger, Dewis et al. 1979; Sulter, Steen and De Keyser 1999).

2.6.3.2.2 The Nottingham Extended Activities of Daily Living (EADL) Index

The Nottingham Extended Activities of Daily Living Scale (EADL) is a measure of instrumental or extended activities of daily living. These are activities which are necessary for maintaining a household and for community living. It was developed by Nouri and Lincoln (1987).

The EADL Scale has sub-scales for mobility, kitchen, domestic and leisure activities. Scoring reflects what the participant has actually done, not what they may be capable of doing. The subject is asked whether in the previous few weeks they performed the activities on their own, on their own with difficulty, with help or not at all. A score of one is given for each task the patient has performed independently and a score of zero is given for tasks not performed, or performed with assistance. The maximum possible score is 22 (Wade 1992).

Validity of the EADL has been demonstrated for use in the UK (Gladman, Lincoln and Adams 1993). It has been recommended as an instrument to measure rehabilitation outcomes and progress after discharge from hospital (Lincoln and Gladman 1992). A number of studies have investigated the use of the EADL Scale in other cultural settings. One study in Taiwan supported its use with minor modifications (Hsueh, Huang, Chen, Jush and Hsieh 2000).

2.6.3.2.3 The Modified Rankin Scale (MRS)

The Modified Rankin Scale (Rankin 1957) has been used extensively as an outcome measure in acute stroke trials. It is a global outcome scale that has been criticised for mixing the domains of disability and handicap i.e. activity and participation (De Haan, Limburg, Bossuyt, van der Meulen and Aaronson 1995). However, it is said to reflect "changes in activity and lifestyle" after stroke (Wilson, Hareendran, Grant, Baird, Schulz et al. 2002).

Several different versions of the tool exist under the names of Rankin Score, Modified Rankin Score and the Oxford Handicap Scale. Earlier versions consisted of a five point rating scale, which was later adapted to form a six point scale ranging from 0- which represents no symptoms to 5 signifying severe disability. The MRS is reported to have moderate inter-rater reliability and strong test-retest reliability (Banks and Marotta 2007). A structured interview (Wilson, Hareendran et al. 2002) has been proposed to increase the reliability of the instrument. Kappa scores for inter-rater reliability improve from 0.56 to 0.78, and for test-retest reliability increase from 0.81 to 0.95 (Banks and Marotta 2007). The structured interview includes questions which address specific areas of participation such as leisure activities, family life and work activities (Wilson, Hareendran et al. 2002).

The MRS is useful in giving a broad picture of outcome and has been widely used in outcome studies and particularly in acute stroke trials (De Haan, Limburg et al. 1995; Sulter, Steen and De Keyser 1999; Wilson, Hareendran et al. 2002; Geyh 2004). It is reported to have acceptable reliability (D'Olhaberriague, Litvan, Mitsias and Mansbach 1996) and validity (De Haan, Limburg et al. 1995). Although useful in defining broad categories of outcome, as a six point scale, it lacks sensitivity, and may not be responsive to changes in the individual over time. However, it has been said to be more sensitive than the BI for assessing mild to moderate disability, as its scope extends beyond basic ADL and it does not have such a low ceiling effect (Weimar, Kurth et al. 2002). There is a lack of consensus on assigning cut off points to define good and bad outcomes. Previous studies have defined favourable outcomes as ≤1 and ≤2 (Sulter, Steen and De Keyser 1999).

2.6.3.2.4 The ICF Checklist

The ICF Checklist for Activity and Participation and the ICF Checklist for Environmental Factors are fairly recent developments which are expected to have widespread application in rehabilitation and research in the future (Stucki, Ewert and Cieza 2002; Ustun, Chatterji et al. 2003). Unabridged, the ICF Classification for Activities and Impairments consists of nine sub-scales with a total of 48 items (World Health Organisation 2002). Each item is rated separately with a performance and a capacity qualifier. Each qualifier is scored on a five point scale to express degree of difficulty or is coded as "not specified" or "not applicable". As such it is potentially lengthy to apply. Work is ongoing to develop subsets of ICF domains that are relevant to specific conditions for use in clinical practice and research. A *Brief ICF Core Set* (18 categories) has been proposed for stroke, but is presently only being recommended for validity and pilot studies (Cieza, Ewert, Berdirhan Ustun, Chatterji, Kostanjsek et al. 2004; Geyh 2004; Weigl, Cieza, Andersen, Kolleritz, Amann et al. 2004).

Although the ICF is widely acknowledged as an important conceptual framework, its reliability and validity as an outcome measure for stroke outcome studies has not yet been reported. Furthermore, although items are listed on the checklist, there is no recommended wording for questioning subjects. In a pilot study in a resource-poor HIV population in South Africa an English version of the ICF was found to be useful despite limitations (Jelsma, Brauer, Hahn, Snoek and Sykes 2006). Some of the concepts of the ICF (such as capacity and performance) proved difficult to explain and the tool was found to be lengthy to apply. A Xhosa version of the ICF checklist has been developed by Ka'Toni, Jelsma, Eide, Loeb and Maart but is not yet published (Personal Communication, J.Jelsma, PhD).

2.6.3.3 Other Measures of Activity and Participation

The two simple questions to measure recovery after stroke (McKevitt, Dundas and Wolfe 2001) have been used in a number of large scale studies such as NEMESIS (Sturm, Dewey et al. 2002): "Do you feel you have made a complete recovery from your stroke?" and "Do you need assistance with everyday activities?". Some authors have cautioned against the subjective nature of this method (Sulter, Steen and De Keyser 1999). Moreover, the interpretation of "recovery" is expected to be influenced by patients' expectations. Thus age, culture and social class may affect scoring. (Sturm, Dewey et al. 2002). Other outcome measures reported in literature include the Reintegration to Normal Living Index (Mayo, Wood-Dauphinee et al. 2002), The Craig Handicap Assessment and Reporting Technique (CHART) (Whiteneck 1994), the Functional Independence Measure (FIM) (Oczkowski and Barreca 1993) and the London Handicap Scale (Sturm, Donnan, Dewey, Macdonell, Gilligan et al. 2004). The FIM is a composite measure of disability that is widely used in the United States. Use of the FIM requires training and certification (Salter, Jutai and Teasell 2004b).

2.6.3.3.1 Health Related Quality of Life

Commonly used measures of health related quality of life for patients with stroke include the Sickness Impact Profile (Whitelaw, Meyer, Bawa and Jennings 1994; Carod-Artal, Egido, Gonzalez and de Seijas 2000; Geyh 2004), the SF-36 (Carod-Artal, Egido, Gonzalez and de

Seijas 2000; Hackett, Duncan et al. 2000) and the EQ-5D (Dorman, Slattery, Farrell, Dennis and Sandercock 1997a).

The EQ-5D has the advantage of being brief and easy to apply. It consists of only five items including mobility, self care, usual activities, pain/discomfort and anxiety/depression. Each domain is categorised according to no problems, moderate problems or extreme problems. There is also a visual analogue scale on which the subject is asked to rate his or her state of health between 0 and 100. Patients can be assigned to health states according to their responses for the five dimensions. Alternatively, the frequency of reported problems in a group of patients has also been reported by frequencies or percentages of described levels of severity. Scores cannot be aggregated as responses are ordinal and the items cannot be assumed to be of equal numerical significance (Dorman, Waddell et al. 1997b).

Concurrent and discriminant validity of the EQ-5D have been established in a population of patients with stroke (Dorman, Waddell et al. 1997b). The EQ-5D has been translated into Afrikaans and Xhosa, and its use in South Africa has been reported in literature (Jelsma and Ferguson 2004; Jelsma, MacLean and et al 2004). The Xhosa version has been favourably tested for reliability and validity (Jelsma, Amosun, Mkoka and Nieuwveld 2004).

2.6.3.3.2 The Caregiver Strain Index (CSI)

The CSI (Robinson 1983) has been used to measure the perceived burden of care giving in caregivers of patients with stroke (Wilkinson, Wolfe et al. 1997; Blake, Lincoln and Clarke 2003). It comprises 13 items which are scored 0/1. Scores range from 0 to 13, with higher scores reflecting higher levels of strain. In a previous study, caregivers who scored 7 or more on the Index were considered to be under strain (Blake, Lincoln and Clarke 2003). As far as this researcher is aware, use of the CSI in South Africa has not yet been reported in literature. However, it is currently being used in a number of studies underway in Cape Town (Lynn Kleinebst, Masters Candidate University of Stellenbosch, Personal communication).

2.6.4 Results of Previous Stroke Outcome Studies

Stroke outcome studies vary enormously in terms of how stroke outcome is measured, time frames for assessment and choice of cohort. As a result, comparison of results is problematic. Observational studies seek to describe outcome in a specific population, acute stroke trials evaluate the effects of early medical intervention and rehabilitation outcome studies evaluate the effects of aspects of the rehabilitation process (Roberts and Counsell 1998; Cifu and Stewart 1999; Hankey, Jamrozik et al. 2002). A number of studies have attempted to identify factors that influence outcomes, as well as to develop prediction models to identify likely outcomes (Kwakkel, Wagenaar, Kollen and Lankhorst 1996).

Observational stroke outcome studies mostly involve hospital or rehabilitation centre based cohorts such as the Biomed Stroke Project (Megherbi, Milan et al. 2003) and the Copenhagen Stroke Study (Jorgensen, Nakayama et al. 1995a). Other studies in the UK have been general practice based; for example, the Oxfordshire Community Stroke Project. It appears that relatively few outcome studies have been population based, such as North East Melbourne Stroke Incidence Study or NEMESIS (Sturm, Donnan et al. 2004) and the second Auckland Stroke Study (Hackett, Duncan et al. 2000). Choice of cohort may influence results; for example, hospital based studies may not include patients with milder strokes who are not admitted to hospital. Similarly, in outcome studies based in rehabilitation units, patients have already been filtered according to the admission criteria of the unit.

Different time frames for assessment further confound comparison of results between studies. Where initial assessment occurs on admission to a rehabilitation facility rather than at onset of stroke, this may lead to variation in baseline scores. In view of the rapid rate of recovery in the early stages after stroke, this can cause bias. Similarly, timing of discharge will differ between patients and is affected by many factors including policies of the rehabilitation unit (Duncan, Jorgensen and Wade 2000). The time point of six months post stroke is commonly selected as end point for assessment in rehabilitation studies, particularly as most patients are expected to have reached their highest functional potential by this stage (Duncan, Jorgensen and Wade 2000; Kwakkel, Kollen and Lindeman 2004).

Many stroke studies that compare outcome between groups of patients are not randomised and, as such, differences in the characteristics of patients can be responsible for observed differences in outcome. To compensate for this, attempts have been made to identify homogenous groups of patients with stroke in terms of type of stroke (using stroke classification systems) and by severity of stroke (using measures such as BI and NIHSS scores) (D'Olhaberriague, Litvan, Mitsias and Mansbach 1996). Case mix adjustment has been proposed as one method of dealing with differences in the characteristics of patients with stroke (Segal and Whyte 1997). It makes provision for differences in characteristics such as age, severity of stroke and socio-economic factors in the statistical analysis of results (Davenport, Dennis and Warlow 1996). However, some authors have cautioned that very large sample groups are required to allow for comparisons between groups which do not account for the effect of chance (Mant, Hicks and Fletcher 1996).

2.6.4.1 Activity: Functional Independence (ADL and EADL)

In a community based prevalence study in a rural part of South Africa (The SASPI Project Team 2004), sixty-six percent of stroke survivors needed help with at least one activity of daily living[5]. This appears higher than that reported in studies in other countries including Tanzania (60%) and New Zealand (22%) (Bonita, Solomon and Broad 1997; Walker, McLarty, Masuki, Kitange, Whiting et al. 2000). In a hospital based study at a Durban provincial hospital, Dewar (1990) reported that 63% of the patients assessed at 19 months post stroke were not fully independent in ADL. However, the selected activities of daily living included shopping, so may not be comparable with other studies of ADL which use the Barthel Index. Activities included in the assessment in the Durban study were climbing stairs, bathing, dressing, mobility on the level, toileting, getting in and out of bed, feeding and shopping. In a prospective study at a tertiary hospital in Cape Town, 71% of patients were identified as needing assistance with daily activities three to six months following discharge (Whitelaw, Meyer, Bawa and Jennings 1994). In general, levels of dependency in South African studies appear higher than those reported in stroke outcome studies overseas.

A population-based study in the United Kingdom (n=639) reported that 53% of stroke survivors were functionally independent at three months post stroke (Taub, Wolfe, Richardson and Burney 1994). Mild disability was seen in 23%, moderate disability in 15% and 9% had severe disabilities. At one year post stroke 11% of stroke survivors in this study were found to have moderate to severe disability, 23% had mild disability and 66% were functionally independent (Taub, Wolfe, Richardson and Burney 1994). In a Swedish study, at one year post stroke: 81% of patients could walk indoors, but 31% of patients could not manage stairs, or needed assistance with personal hygiene, and 60% were unable to walk out of doors (Thorngren, Westling and Norvving 1990).

In the Montreal Stroke Cohort study (Mayo, Wood-Dauphinee et al. 2002) assessments were conducted at six months post stroke. At this point: 39% of community living patients with stroke reported limitations in basic ADL and 54% reported difficulties with extended ADL. The most

[5] This was defined as needing help with washing, dressing, bathing, feeding, transfer or toileting.

important areas of difficulty were shopping (36%) and housework (48%). Other areas included travelling short distances (32%) and meal preparation (29%). One fifth of stroke survivors at six months had difficulty walking more than 50m and in stair climbing (Mayo, Wood-Dauphinee et al. 2002).

2.6.4.2 Participation/ Handicap

Handicap (participation) is not well reported in stroke outcome studies (Roberts and Counsell 1998; Sturm, Dewey et al. 2002). However, patients with stroke are known to be limited in the number and the type of activities they are able to perform (Rochette, Desrosiers and Noreau 2001). They report changes in their ability to participate in recreational activities, employment and social relationships (Samuelsson, Soderfeldt and Olsson 1996). These role limitations may be reported in patients who are completely independent in self-care (Samuelsson, Soderfeldt and Olsson 1996).

In the NEMESIS study in Australia, physical independence and occupation (including hobbies) were the domains most affected at three months and one year (Sturm, Dewey et al. 2002). Female gender, increasing age and lower economic status were associated with greater levels of handicap (Sturm, Donnan et al. 2004). In the Montreal Stroke Cohort Study (Mayo, Wood-Dauphinee et al. 2002); travel (46%), social (43%) and recreational activities (36%) and moving around the community (32%) were the areas most affected. 53% of participants felt that they lacked involvement in a meaningful activity to fill the day. Sixty-five percent of participants reported restrictions in integration in community activities (Mayo, Wood-Dauphinee et al. 2002).

There is an association between the severity of activity limitations and participation restrictions (Sturm, Dewey et al. 2002); however, many patients continue to demonstrate reduced levels of participation even after recovery of physical function (Bhogal, Teasell, Foley and Speechley 2003). Participation restrictions may be more important to patients than activity limitations (Sturm, Dewey et al. 2002), and have been closely linked with quality of life (Mayo, Wood-Dauphinee et al. 2002).

2.6.4.2.1 Return to Social or Leisure Activities

Many patients with stroke report deterioration in involvement in social and leisure activities (Belanger, Bolduc and Noel 1988; Niemi, Laaksonen, Kotila and Waltimo 1988; Bhogal, Teasell, Foley and Speechley 2003; Salter, Bhogal, Teasell, Foley and Speechley 2004), with only a small percentage of patients participating in activities outside of the home. Factors contributing to difficulties leaving the home include impairments, environmental barriers such as stairs and lack of accessible transport (Pound, Gompertz and Ebrahim 1998). In the Montreal Stroke Cohort study, at six months post stroke, 36% of participants reported difficulties with recreational pursuits, and 43% with social activities. Seventy-two percent of participants reported that they lacked meaningful activity with which to fill the day (Mayo, Wood-Dauphinee et al. 2002). This is important as loss of activity has been associated with depression (Salter, Bhogal et al. 2004).

Deterioration in social and leisure activities has been associated with the female gender, the young and those better educated (Salter, Bhogal et al. 2004). This link may be due to the importance placed on social status and body image, higher expectations and levels of pre-stroke activities (Salter, Bhogal et al. 2004).

2.6.4.2.2 Return to Work or Productive Activity

A substantial number of patients with stroke will not return to work and previous reviews have reported considerable variation in findings (9-91%) (Salter, Bhogal et al. 2004). Discrepancies have been attributed to differing study designs and variations in the definition of "return to work". Many stroke survivors who do return to work report adjustments in terms of working hours or responsibilities (Vestling, Tufvesson and Iwarsson 2003).

Factors that have been identified as influencing return to work include type of occupation and education prior to stroke; residual physical or cognitive deficits, the ability to walk; and age (Bhogal, Teasell, Foley and Speechley 2003; Vestling, Tufvesson and Iwarsson 2003; Salter, Bhogal et al. 2004). It may also be influenced by social support policies such as eligibility for sickness/ disability grants (Saeki, Ogata et al. 1995).

Return to work is an important outcome as it has been associated with increased life satisfaction (Vestling, Tufvesson and Iwarsson 2003).

2.6.4.3 Health Related Quality of Life (HRQoL)

Diminished health related quality of life has been reported in survivors of stroke. In the Montreal Stroke Cohort study, Mayo et al (2002) reported poorer HRQoL in stroke survivors at six months compared to a healthy population-based control group, matched for age and residential area. In longer term studies, differences in overall HRQoL between stroke and normal populations appear not to be as marked. In a study in the United States at one to three years post-stroke, HRQoL appeared comparable to that of a normative population (King 1996). Similarly, in the Auckland Stroke Study, HRQoL was good for most stroke survivors at six years post-stroke, in spite of ongoing physical disabilities (Hackett, Duncan et al. 2000). Timing of assessment is probably an important factor as HRQoL is influenced by how the individual is able to adapt to impairments and disabilities and this may change over time (King 1996; Dorman, Slattery et al. 1997a). Despite relatively high overall scores for HRQoL, single items may show lower levels of satisfaction. Areas of life satisfaction that have been found to be problematic in stroke survivors include dissatisfaction with sexual functioning and roles (King 1996) and not having a job (Niemi, Laaksonen, Kotila and Waltimo 1988; King 1996). The importance of individual factors is highly dependent on the value that the individual places on different aspects of their lives (King 1996), and this may contribute to variation in study results. By way of illustration, a study in an under-privileged community in an informal settlement near Cape Town found that having a brick house was rated more important to quality of life than the ability to walk (Personal communication, Siviwe Mkoka, PhD candidate University of Cape Town).

Quality of life in stroke survivors has been associated with severity of stroke (De Haan, Limburg et al. 1995), functional independence (Niemi, Laaksonen, Kotila and Waltimo 1988; Carod-Artal, Egido, Gonzalez and de Seijas 2000) and perceived social support (King 1996). Depression has been shown to be an important predictor of Health Related Quality of Life (Astrom, Apslund and Astrom 1992; King 1996), and depression has been reported in 23% (Wilkinson, Wolfe et al. 1997) to 30% (King 1996) of stroke survivors.

2.6.4.4 Caregiver Strain

Caregivers of patients with stroke are known to experience high levels of strain, and may report deterioration in their physical and mental health, reduced levels of social contact, decreased life satisfaction and an increased risk of depression (Salter, Bhogal et al. 2004).

In a study of community living patients with stroke (n=409) in the UK, 35% of caregivers were found to be under significant strain at six months (Blake, Lincoln and Clarke 2003). Similarly, a Scottish study found 37% of caregivers were under strain at six months (Bugge, Alexander and Hagen 1999). In a longer term follow up study also in the UK, 21% of caregivers interviewed had high levels of strain at 4.9 years (Wilkinson, Wolfe et al. 1997).

Factors that are known to influence caregiver strain are stroke severity, caregiver health, socio-economic status, patient behaviour and mood, amount of time required for caring and size of social network (Han and Haley 1999). Caregivers most at risk are those on a low income with little social support (Teasell, McRae and Finestone 2000). Cognitive and emotional deficits of the stroke patient appear more difficult to deal with than physical limitations (Salter, Bhogal et al. 2004). Caregiver characteristics such as negative affectivity have been shown to be associated with caregiver strain (Blake, Lincoln and Clarke 2003).

2.6.4.5 Discharge Destination

Discharge destination/ placement is considered an indicator of outcome in some stroke studies (Jorgensen, Nakayama et al. 1995a; Segal and Whyte 1997). This implies that more able patients return home because they are functioning better than patients who are admitted to institutionalised care. However, a number of other factors may impact on whether a patient is able to return home, for example the availability and involvement of family caregivers (Han and Haley 1999) and the suitability of the physical home environment.

Results from previous studies are variable. In a long term study in Perth Australia, Hankey et al (2002) reported approximately 14.2% of patients with stroke were institutionalised at 5 years post stroke. In the Copenhagen Stroke study, where the population comprised patients being admitted to an acute stroke unit, 15% of patients were discharged to institutionalised care (Jorgensen, Nakayama et al. 1995a). Institutionalisation may occur less frequently in younger patients with stroke as a Canadian study of patients aged 16 to 50 reports only 4.8% of participants required institutionalisation at three months (Teasell, McRae and Finestone 2000). The provision of carers and home help by social services in overseas settings may facilitate a number of patients with stroke living at home. In the Montreal Stroke Cohort Study, 50% of community living patients with stroke required either a full time healthy caregiver at home or additional assistance in the form of "home help" (Mayo, Wood-Dauphinee et al. 2002). Home help may include assistance with housework and shopping, and the provision of "meals-on-wheels". These services are largely unavailable in SA.

In a hospital based South African study in 1994, only two out of 59 patients were in an institution at three to six month follow up. This was in spite of 21 patients scoring 4-5 on the MRS indicating severe disability (Whitelaw, Meyer, Bawa and Jennings 1994). In South Africa, even patients with severe strokes may be discharged home due to limited beds in institutional care facilities

2.7 The Environmental Context of Functioning

Participation restrictions are said to be the result of an interaction between disability and environment. The ICF checklist refers to the physical, social and attitudinal environment of the individual and describes factors as potential facilitators or barriers to functioning (Geyh 2004). It comprises five domains, namely: Products and Technology; the Natural Environment; Social Support and Relationships; Attitudes of Individuals and Society; and Services, Systems and Policies (De Kleijn-De Vrankrijker 2003). Each domain has a number of sub-categories. Environmental factors are rated as barriers and facilitators on a scale of 0 signifying no barrier/ facilitator to 4- signifying complete barrier/ facilitator. Individual factors are not related to specific activities or areas of participation. Thus there is potential that information may be missed if the patient does not make an association between the listed factors and an activity in which he/ she is experiencing difficulty. This may introduce issues of reliability and validity. In addition, perception of barriers/ facilitators is highly subjective, and related to expectations of the individual. In spite of these limitations, the ICF Environmental Checklist has been used in a survey of isi-Xhosa speaking disabled people in South Africa, and the authors report acceptable face and construct validity (Maart et al, under review 2005).

It is expected that in a resource poor environment, environmental barriers may play an even larger role in the handicap creation process. A number of environmental features have been highlighted in South African literature. In a study of black elderly people living in Cape Town townships in 1991, aspects of housing such as overcrowding, and the lack of facilities such as electricity, indoor sanitation and water supply were linked to poor health (Barnes and Yach 1991). Access to running water and indoor toilet facilities have also been identified as influencing function in ADL in a stroke population in Soweto (Hale, Eales and Fritz 1998).

The social environment of the individual refers to attitudes of individuals and society to disability as well as social support available to the stroke survivor. It has been suggested that people with disabilities in South Africa tend to be excluded from society and socially isolated on account of negative attitudes to disability (Office of the Deputy President 1997).

The domain of Services, Systems and Policies, refers to health services and systems pertaining to disability grants and employment law. In terms of health systems, a number of shortfalls in health care provision for patients with stroke in South Africa have been highlighted in literature. In particular, heavy pressure on beds in acute medical wards which results in early discharge of patients with stroke (Meiring 1990; Riley 1998) and inadequate follow-up of discharged patients due to inadequate community based support systems have been highlighted. Problems experienced by patients in accessing follow up services due to lack of transport, financial pressures and lack of availability of an escort have been reported (Whitelaw, Meyer, Bawa and Jennings 1994).

2.8 Factors that Influence Outcome after Stroke

Knowledge of the factors affecting outcome after stroke is important for the prediction of outcome. It assists in the planning of care and the allocation of resources. Some factors that negatively influence outcome may be modifiable or identify patients that may require additional intervention or support. In addition, comparison of expected outcome with achieved outcome may give some indication of whether an intervention has been effective in influencing natural recovery. Literature proposes lists of factors that can influence outcome, individually and in combination, but the information available is contradictory. Differing methodologies are said to complicate the synthesis of results (Kwakkel, Wagenaar, Kollen and Lankhorst 1996).

Prediction models have been proposed that use multiple regression analysis, but these have been shown to be specific to individual settings (Kwakkel, Wagenaar, Kollen and Lankhorst 1996). Simple predictors such as individual features of stroke, or summed scores on stroke scales such as the NIHSS and BI have shown to have good predictive value (Kwakkel, Wagenaar, Kollen and Lankhorst 1996). The following factors are amongst those identified by Kwakkel et al (1996) as valid predictors in their review of 142 prognostic studies: age, previous stroke, urinary continence, consciousness at onset, disorientation in time and place, severity of paralysis, sitting balance, ADL score on admission and level of social support.

Including too many variables in stroke outcome studies may obscure the influence of individual factors on outcome. Too many analyses may also increase the occurrence of type 1 errors. It has been suggested that for every variable included in an analysis, there should be at least five patients for each outcome of interest (Davenport, Dennis and Warlow 1996).

2.8.1 Individual Characteristics

2.8.1.1 Type and Severity of Stroke

Severity of stroke at initial onset appears to be one of the greatest predictors of rehabilitation outcomes (Teasell 2004c). Markers associated with more severe strokes such as decreased level of consciousness, incontinence and lack of sitting balance have been shown to be associated with poor outcome (Kwakkel, Kollen and Wagenaar 1999; Hankey, Jamrozik et al. 2002).

Evidence on the influence of type of stroke is conflicting with regard to the right or left sided strokes, haemorrhagic versus ischaemic strokes, and stroke sub-type. A number of studies suggest that although haemorrhagic strokes are usually more severe (Foulkes, Wolf, Price, Mohr and Hier 1988) and have a higher mortality rate in the early stages, they demonstrate better or faster functional recovery than patients with ischaemic strokes (Adams, Bendixen et al. 1993; Chae, Zorowitz and Johnston 1996; Paolucci, Antonucci, Grasso, Bragoni, Coiro et al. 2003). However, this is not supported by systematic reviews (Kwakkel, Wagenaar, Kollen and Lankhorst 1996).

2.8.1.2 Nature of Neurological Impairments

Motor deficits, perceptual deficits and cognitive deficits have been demonstrated to affect functional independence in the listed order of importance (Mercier, Audet et al. 2001).

Certain specific motor deficits have been singled out as being predictive of outcome. These include degree of paralysis and lack of sitting balance (Kwakkel, Wagenaar, Kollen and Lankhorst 1996) . The absence of measurable grip at one month post stroke is associated with poor functional recovery of the upper limb (Kwakkel, Kollen and Lindeman 2004).

Cognitive and perceptual impairments have been found to account for some of the variance in functional recovery after stroke, and cognitive abilities at admission are predictors of functional ability at discharge (Bitensky, Teasell et al. 2004; Malouin, Belleville, Richards, Desrosiers and Doyon 2004). Patients with cognitive impairments appear less likely to be discharged home (Zinn, Dudley, Bosworth, Hoenig, Duncan et al. 2004) and demonstrate decreased instrumental ADL at six months (Fultz, Ofstedal, Herzog and Wallace 2003; Zinn, Dudley et al. 2004). Cognitive impairments may affect outcome by exerting an independent effect on functioning, or by influencing response to rehabilitation (Fultz, Ofstedal, Herzog and Wallace 2003). Specific deficits thought to affect outcome include: reduced level of consciousness at initial onset (Kwakkel, Wagenaar, Kollen and Lankhorst 1996), lack of orientation (Kwakkel, Wagenaar, Kollen and Lankhorst 1996), unilateral neglect and apraxia (Saeki, Ogata et al. 1995; Bitensky, Teasell et al. 2004).

Communication deficits and cognitive impairments are known to contribute to caregiver strain (Weimar, Kurth et al. 2002). Communication deficits in particular are have not been widely investigated probably due to methodological difficulties in measuring outcome in this sub group (King 1996).

2.8.1.3 Medical Profile

Co-existing medical conditions may have an independent effect on functioning as well as affecting the patient's ability to participate in and benefit from rehabilitation. Additive models describe conditions as exerting individual independent influences on outcome. Interactive models acknowledge that the presence of one condition may affect the outcome from another condition (Fultz, Ofstedal, Herzog and Wallace 2003). Medical conditions that commonly co-exist with stroke, and have been shown to be associated with poor outcomes include: diabetes, depression, dementia, arthritis, incontinence, injurious falls, vision problems, hearing problems, heart disease, lung disease and cancer (Desmond, Moroney, Sano and Stern 1996; Fultz, Ofstedal, Herzog and Wallace 2003). Diabetes in particular has been shown to be associated with poor outcomes of disability and handicap (Johnston, Connors et al. 2000; Megherbi, Milan et al. 2003). Previous CVA has also been associated with poor outcome (Kwakkel, Wagenaar, Kollen and Lankhorst 1996).

2.8.1.4 Demographic Factors

2.8.1.4.1 Age

While many authors report a strong association of age with functional outcome and handicap (Kwakkel, Wagenaar, Kollen and Lankhorst 1996; Sturm, Donnan et al. 2004), some argue that age-related effects account for only a small amount of variation in outcomes after adjusting for other factors (Bagg, Pombo and Hopman 2002). A ten year increase in age has been said to account for 7% less gain on ADL scores in rehabilitation outcome studies (Nakayama, Jorgensen, Raaschou and Olsen 2000). Age related differences in rehabilitation outcomes are thought to be due to a diminished ability to compensate rather than due to more severe neurological deficits or a reduced capacity for neurological recovery (Nakayama, Jorgensen, Raaschou and Olsen 2000; Wandel, Jorgensen, Nakayama, Raaschou and Olsen 2000). As such, ageing is associated with increased levels of participation restrictions more than it is with activity limitations and impairment.

Other factors may include a higher prevalence of co-morbidities (Fultz, Ofstedal, Herzog and Wallace 2003), as well as poorer social support. Age-related expectations may also play a role. For example, older individuals may elect not to resume pre-stroke roles in the anticipation of future ill health (Rochette, Desrosiers and Noreau 2001). Younger individuals may report greater deterioration in social and leisure activities, as a result of greater pre-morbid levels of activity and higher expectations (Bhogal, Teasell, Foley and Speechley 2003). Age may be a less important factor in milder strokes (Black-Schaffer and Winston 2004).

Age-related differences are also seen in risk factor profiles, and this may have implications for the type of stroke seen in different age categories. Risk factors that are more prevalent in younger patients with stroke include valvular heart disease and infective diseases such as HIV/ AIDS. In older patients, hypertension, ischaemic heart disease and peripheral vascular disease may be more evident (Connor and Bryer 2006).

2.8.1.4.2 Gender

Higher levels of disability and handicap have been reported in women compared to men (Di Carlo, Lamassa, Baldereschi, Giovanni., Basile et al. 2003; Sturm, Donnan et al. 2004).

2.8.1.4.3 Population Group

The effect of population group on outcome is thought to be complex. A number of international studies report differences in stroke incidence and mortality as well as functional outcomes in black patients with stroke (Horner, Swanson, Bosworth and Matchar 2003). This may be partly due to socio-economic factors and access to healthcare (Di Carlo, Lamassa et al. 2003; Horner, Swanson, Bosworth and Matchar 2003). In South Africa, different population groups may reflect different stages of the epidemiological transition due to the political history and socio-economic factors, and as a result, certain risk profiles and sub-types of stroke may be more prevalent in different population groups (Connor and Bryer 2006).

2.8.1.5 Socio-Economic Factors

Lower socio-economic status is associated with a poor outcome after stroke. The effect of socio-economic factors has been explained by behavioural and materialist models (Putman, De Wit et al. 2006). The former emphasises the role of education in promoting healthy behaviours and lifestyles, the latter ascribes poor health states to living conditions such as housing and work conditions. Socio-economic status may also influence access to healthcare, as well as the experience of rehabilitation (Van Den Bos, Smits, Westert and Van Straten 2002; Putman, De Wit et al. 2006).

2.8.1.6 Other Factors

Personality factors such as self-esteem, motivation and coping style may influence recovery from stroke (Dittmar and Gresham 1997; Segal and Whyte 1997; Chang and Mackenzie 1998). In addition, depression affects the individual's ability to participate in and benefit from rehabilitation input, and has been associated with poor outcomes in terms of activities and handicap (Bhogal, Teasell, Foley and Speechley 2004). Satisfaction with social support has been shown to be associated with good outcomes, in particular increased quality of life (King 1996; Kwakkel, Wagenaar, Kollen and Lankhorst 1996). Outcome after stroke is known to be better in well-functioning families and where there is emotional support (Salter, Bhogal et al. 2004)

Numerous other individual factors may influence outcome after stroke. For example, individuals who were active prior to their stroke may have better potential. Recent studies also indicate pre-morbid under-nutrition is associated with poor outcome (Davis, Wong, Schluter, Henderson, O'Sullivan et al. 2004).

2.8.2 Characteristics of the Rehabilitation Process

Greater frequency and intensity of rehabilitation have been shown to be associated with better outcomes, as has the early commencement of rehabilitation within 3-30 days post stroke (Cifu and Stewart 1999). The appropriateness of the rehabilitation setting is known to be important (Cifu and Stewart 1999). Acute stroke management within a designated Stroke Unit is associated with lesser mortality and morbidity. (Langhorne, Williams, Gilchrist and Howie 1993; Stroke Unit Trialists' Collaboration 1997). Overall, specialised care is better than generalist care, especially in more severe strokes (Evans, Harraf, Donaldson and Kalra 2002). Moderate strokes appear to benefit the most from rehabilitation. Recovery from mild strokes may be due to natural recovery but change in severe strokes appears more dependent on rehabilitation input (Teasell, Foley et al. 2004d). Management strategy may be less important in milder lacunar strokes (Evans, Harraf, Donaldson and Kalra 2002).

Interdisciplinary working and task specific training have been shown to be associated with improved outcomes (Cifu and Stewart 1999). However, research has failed to demonstrate any particular approach to rehabilitation as being more effective than another, for example in terms of the Bobath approach compared to a motor relearning approach (Cifu and Stewart 1999).

The transition from hospital to home is known to be one of the most challenging times for the stroke patient (Bhogal, Teasell, Foley and Speechley 2003). It is thought that discharge planning can play a role in smoothing the transition. Spending time at home prior to discharge has been recommended in order to identify problem areas (Bresick 1997). Training of caregivers as part of the rehabilitation programme has been associated with lower levels of strain, as well as improved quality of life and psychological outcomes in patients and caregivers alike (Teasell and Kalra 2005). Receiving therapies at home or as an outpatient after discharge from rehabilitation units has been shown to be associated with improved ADL and less chance of deterioration (Teasell and Kalra 2005).

2.8.3 Characteristics of the Environment

Despite growing recognition of the role of environment, little empirical evidence is reported in literature on the association between environment and outcome, especially with reference to stroke. However, a Canadian study has demonstrated that perceived environmental barriers explained 6.2% of the variance in handicap (participation restrictions) in a sample of 51 stroke survivors six months after discharge from hospital (Rochette, Desrosiers and Noreau 2001). Lack of resources such as assistive devices, equipment, finance and transport have been found to be instrumental in increasing handicap (Sturm, Dewey et al. 2002).

2.9 Statistical Issues in Stroke Studies

Stroke studies have been criticised for using inappropriate methods of statistical analysis particularly pertaining to the use of parametric analysis (Sulter, Steen and De Keyser 1999). Parametric assumptions require a normal distribution of data, adequate sample size to represent the population and data that is interval or ratio in nature (Sulter, Steen and De Keyser 1999). Disability scales frequently involve aggregating scores on individual items to give a summed score. This data is ordinal in nature rather than continuous (Roberts and Counsell 1998). The relative difference in ability reflected by differences in scores are not necessarily equal (Roberts and Counsell 1998). Furthermore, aggregating scores can lead to loss of detail, because the contribution of different items to the overall score may vary significantly between subjects with the same score (Feinstein, Josephy and Wells 1986). These aspects must be considered in the statistical analysis.

Acute stroke trials frequently define favourable or unfavourable outcome for statistical analysis by dichotomising scores on measures such as the BI or MRS. Considerable variation exists on the cut off points selected (Roberts and Counsell 1998). Some authors suggest that dichotomising outcomes can result in loss of detail, and shifts towards improvements being undetected (Duncan, Jorgensen and Wade 2000). Duncan et al (2000) propose that the whole range of collected data ought to be used.

2.10 Summary

Stroke is a major problem in South Africa with many stroke survivors experiencing disability. Recovery after stroke is thought to be largely due to spontaneous neurological recovery; however, rehabilitation is thought to reduce disability after stroke. Despite the extent of the problem and the financial costs associated with rehabilitation, very little is known about recovery and outcomes in South African patients with stroke, especially after discharge from hospital. Results from stroke outcome studies conducted internationally in well resourced rehabilitation settings may not be applicable in the South African context. There are known differences in the characteristics of patients with stroke, aspects of the rehabilitation process, and the environmental context of functioning.

Measurement of outcome in stroke is notoriously problematic. However, it is commonly accepted that participation and activity are the domains of interest in rehabilitation outcome studies, with most studies using a combination of outcome measurement tools. The NIHSS can be used to classify severity of stroke at the baseline assessment (Muir et al 1996) and has been shown to be predictive of outcome. The Rivermead Motor Assessment (RMA) has been used as a measure of motor recovery in previous studies. The Barthel Index (BI) has been recommended as the Gold Standard for measuring independence in Activities of Daily Living (ADL). It gives a clinically relevant picture of functional ability, but has a ceiling effect in more able subjects. (D'Olhaberriague 1996, Wade 1992). The Extended Activities of Daily Living Scale (EADL) is a more sensitive instrument focusing on instrumental activities of daily living and is particularly relevant following discharge. The Modified Rankin Scale, although a broad instrument, has been extensively used in acute stroke trials and the structured interview proposed by Wilson (2002) includes questions which address specific areas of participation in leisure activities, family life and work activities. The EQ-5D is a short measure of health related quality of life which has been validated for the South African setting. Use of the CSI in South Africa has not yet been reported in literature, however, it is currently being used in a number of studies underway in Cape Town (Lynn Kleinebst, Personal communication). Although numerous tools exist, the listed instruments have been widely used and acknowledged. Issues of validity in cross-cultural application are noted.

Stroke studies overseas have identified a large number of factors that influence stroke outcome. Many of these factors relate to the nature of stroke impairments at the time of initial onset such as drowsiness and urinary incontinence. Other factors are contextual such as satisfaction with social support and socio-economic status. Knowledge of factors influencing outcome assists clinical decision making by identifying candidates who are most likely to benefit from rehabilitation input as well as those at risk of making a poor recovery. Little published literature exists regarding these issues in a South African context.

3 METHODOLOGY

3.1 Research Design

The study was a prospective longitudinal descriptive study of patients with first ever stroke at a state funded rehabilitation facility in the Western Cape. The sample comprised patients with first ever stroke admitted to the Western Cape Rehabilitation Centre between 22 June 2005 and 28 March 2006. (The research setting is described in detail in the Introduction). Participants were assessed within the first six days of admission to the centre, within five days of discharge from the centre and again at six months (+/- five working days) after their stroke. The study followed the methodology of the CERISE project being conducted in Europe.

3.2 Participants

All patients admitted to wards A and B at the WCRC between 22 June 2005 and 28 March 2006, and Ward C between 17 August 2005 and 28 March 2006[6], with the diagnosis of first ever stroke, who met the eligibility criteria, qualified for inclusion in the sample. Stroke was defined according to the WHO definition of "rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or leading to death, with no apparent cause other than vascular origin." (WHO MONICA 1988). Diagnosis was made by the attending medical doctor at WCRC. Patients who had had neurosurgical intervention were not excluded provided they had a primary diagnosis of stroke.

Inclusion criteria

- a primary diagnosis of first ever stroke
- admission to WCRC within three months or less since onset ($\leq$90 days)
- 18-85 years of age
- patient proficient in English, Afrikaans or Xhosa
- some degree of motor impairment as defined by RMA scores: Gross Motor Function Score $\leq$11, and/ or Leg and Trunk $\leq$8, and/ or Arm Function Score$\leq$12

[6] Initially stroke patients were admitted to Wards A and B, with Ward C mainly being used for spinal patients and the occasional overflow of stroke patients. However, admission patterns changed and when Ward C started admitting stroke patients it was included in order to increase the sample size.

Exclusion criteria

- pre-stroke neurological conditions e.g. previous stroke, pre-stroke head-injury, Multiple Sclerosis, Parkinson's disease, pre-stroke epilepsy
- subdural haemorrhage
- haemorrhage due to tumour, encephalitis or trauma
- self or proxy reported pre-stroke Barthel Score of less than 50
- patient living more than 50km's away from WCRC
- major co-existing pathology that was likely to mask pattern of recovery from the stroke

Patients with an infective aetiology (such as HIV/ AIDS, TB Meningitis and neurosyphilis) were included in the study if there was no previous history of neurological deficit (clinically documented or described by the patient or a relative), and if the primary diagnosis was stroke according to the WHO definition.

3.3 Instrumentation

A short language screening test (Appendix VIII) was administered as an aid to determining capacity of the participant to give consent to participation.

The NIHSS (Appendix XV) was used as an assessment of neurological deficit on admission to the study. The Barthel Index (Appendix XVI) and the Rivermead Motor Assessment (Appendix XVII) were used to measure functional recovery and motor recovery respectively, and were applied at all three data collection points: admission, discharge and six months post stroke. Additional outcome measures were applied at six months: the Nottingham EADL Scale (Appendix XVIII), the Modified Rankin Scale (Appendix XIX), the EQ-5D (Appendix XX) and the Caregiver Strain Index (Appendix XXI).

Table 3-1 Standardised Outcome Measures Used in Study

ADMISSION	DISCHARGE	6 MONTHS
Barthel Index	Barthel Index	Barthel Index
Rivermead Motor Assessment	Rivermead Motor Assessment	Rivermead Motor Assessment
Pre stroke Barthel Index		Nottingham EADL Scale
NIHSS		Modified Rankin Score
		EQ-5D
		Caregiver Strain Index

In addition to the standardised outcome measures, questionnaires were developed in order to collect supplementary data and are outlined in the table below. The development and piloting of the questionnaires are described in Appendix VI and VII respectively.

Table 3-2 Questionnaires Developed for Use in the Study

ADMISSION	DISCHARGE	6 MONTHS
Intake Form (Appendix IX)		
Questionnaire at Admission (Appendix X) Including: - medical data - referral details - HIV/ AIDS status - demographic data	**Questionnaire at Discharge:** (Appendix XI) Including: - socio-economic data - details of the home environment pre- stroke	**Questionnaire at 6 Months** (Appendix XIII) Including: - discharge destination - mobility aids and community mobility - return to work or productive activity - use of healthcare services since discharge - changes in health since discharge - changes in discharge destination
	Rehabilitation Process Questionnaire: (Appendix XII) Including: - discharge planning and procedures - referral for follow up - cognitive and perceptual deficits	**Environmental Questionnaire:** (Appendix XIV) Including perceived environmental barriers and facilitators to function

3.4 Procedure

3.4.1 Training of Researcher

The researcher spent a week at the Katholieke Universiteit Leuven receiving training in the application of the measurement tools.

3.4.2 Permission to Conduct the Study

The Ethics Committee of the University of Cape Town approved the study (Appendix XXII) and permission to carry out the study was granted by management of the WCRC.

3.4.3 Translation of the Instruments

All self-report questionnaires were translated using a forward translation into the local languages (Afrikaans and Xhosa), followed by backward translation into English and then the drawing up of a consensus version. The translation process of BI, MRS, CSI and the EADL was led by Ms A

Rhoda, PhD Candidate, University of the Western Cape. However, the researcher had input into the development of the consensus version. See Appendix I for a full report.

3.4.4 Pilot Study

A pilot study was conducted to assess whether the standardised outcome measures were suitable for use in the study population, to pilot the questionnaires developed specifically for use in the study, and to investigate the logistics of data collection.

The standardised outcome measures, although widely used in overseas studies, had not been tested for validity and reliability in a South African setting. It was beyond the scope of this study to extensively investigate measurement properties of the instruments. However, certain aspects of validity and reliability were explored during the pilot study. Discussion with clinical experts at the WCRC and findings of the pilot study indicated that face validity of the instruments was acceptable. Certain issues that were identified are outlined in the discussion that follows. Post-hoc analysis of the correlation between scores gives some further indication of concurrent validity (See Results and Discussion).

Measures of self- or proxy report such as the BI, EADL, MRS and CSI had been translated into Afrikaans and Xhosa following a rigorous translation procedure as described above (Appendix I). These translated questionnaires were piloted in order to determine whether the integrity of the instrument had been preserved through the translation process, and to identify any problems with cross-cultural application. Wording of the questionnaires was standardised and it was expected that most variability in measurement would arise from interpretation of the questions themselves. For this reason, test-retest reliability was selected as the methodology of choice.

The NIHSS and RMA are tools that involve scoring of a performed task by an observer. Tasks are concrete and require little interpretation from the subject. Furthermore, wording of the instructions for each item is not standardized in the original instrument. For these reasons, the NIHSS and RMA were not translated. It was expected that most variability in scoring would arise from error on the part of the observer and therefore reliability of these instruments was tested using an inter-rater reliability methodology. Although the researcher conducted all assessments in the study herself, and variability between raters is not expected to be a factor within the study, inter-rater reliability is a measure of the inherent accuracy of the tool itself and also opens up the possibility of future comparisons between studies[7].

Testing of the standardised outcome measures was conducted in collaboration with Ms A Rhoda, PhD candidate at the University of the Western Cape who is currently carrying out a similar research project in the Community Health Care Centres of the Western Cape.

The objectives of the pilot study were as follows:

- To pilot the Afrikaans and Xhosa translations of the standardised outcome measures of self-report by means of a test-retest methodology (BI, EADL, MRS and CSI)[8]
- To test inter-rater reliability of the RMA and NIHSS
- To pilot the questionnaires developed for use in the study including Afrikaans and Xhosa translations
- To investigate the logistics of data collection

A full description of the pilot studies are in Appendices I - VII and the most important findings are summarised below.

3.4.4.1 Piloting of Standardised Questionnaires using a Test-Retest Format

Afrikaans and Xhosa translations of the BI, EADL, MRS, and the CSI were piloted using a test-retest methodology. A minimum of five subjects for each Afrikaans questionnaire and a smaller number for each Xhosa Questionnaire (one to five) were included in the sample. The sample size was too small to allow statistical analysis. However, based on the results minor modifications were made to the translated versions and a standardised application procedure was formulated to improve uniformity. A full report of the test-retest study can be found in Appendix II and formulated guidelines can be found in Appendix III.

[7] Although not part of this study, it is hoped that future comparisons may be made between outcomes in this sample, and outcomes in another study of first ever stroke patients in the Community Health Care Centres of the Western Cape conducted by Ms A Rhoda, PhD candidate, University of the Western Cape.
[8] Translation of the EQ-5D into Xhosa has already been reported in literature. (Jelsma 2004)

3.4.4.2 Inter-Rater Reliability Testing of the NIHSS and RMA

A full report of the inter-rater reliability study can be found in Appendix V.

In summary, two raters conducted inter-rater reliability testing for the NIHSS and RMA on 30 patients at the WCRC and Booth Memorial Hospital. Random selection was used to determine which rater gave instructions, and both raters scored the patient's performance simultaneously without collaboration.

There were 16 men and 14 women in the sample. Age ranged from 22 to 77 years with a mean age of 52.8 ± 16.0 SD. Thirteen participants were English speaking, 13 were Afrikaans speaking and four participants spoke Xhosa. Kappa scores for the RMA Sub-scales are listed in Table 3-3, and for the NIHSS in Table 3-4.

Table 3-3 Inter-Rater Scores for Sub-scales of the Rivermead Motor Assessment

RMA Sub-scale	Range of Kappa scores for Individual Items	ICC for Sub-scale Totals
Gross function Sub-scale	0.73 – 1.00	0.99
Lower Limb and Trunk Sub-scale	0.60 – 0.93	0.95
Upper Limb Sub-scale	0.41 – 1.00	0.99

Kappa reliability co-efficients are suitable for the analysis of nominal data, and account for agreement that may occur due to chance alone (Domholdt 2005). According to the criteria of Landis and Koch, Kappa scores of 0.00 to 0.20 show slight agreement, 0.21-0.40 show fair agreement, 0.41 to 0.60 show moderate agreement, 0.61 to 0.80 show substantial agreement, and 0.81 to 1.00 show almost perfect agreement (Domholdt 2005). These scores were therefore considered to reflect acceptable inter-rater reliability for individual items, even though certain items on the Upper Limb Sub-scale showed only moderate agreement. Intra-class correlation coefficients for the totals of the three sub-scales were found to be excellent.

Table 3-4 Kappa Scores for Individual Items of the NIHSS
(All z-scores significant at p<0.05 except for Item 1c where p>0.05)

Item	Agreement	Expected Agreement	Kappa	z-score
1a* Level of Consciousness	100.00	-	-	-
1b Ask Month and Age	86.67	43.56	0.76	5.06
1c* Follows commands	96.67	96.67	0.00*	0.00*
2 Best Gaze	100.00	93.56	1.00	5.48
3 Visual Field testing	93.33	58.44	0.83	4.9
4 Facial paresis	70.00	36.22	0.53	4.31
5 Motor Function Right Arm	96.67	59.00	0.92	6.95
5 Motor Function Left Arm	90.00	39.00	0.84	7.69
6 Motor Function Right Leg	93.33	58.78	0.84	6.57
6 Motor Function Left Leg	86.67	44.89	0.76	6.46
7 Limb Ataxia	73.33	47.89	0.49	4.31
8 Sensory Testing	90.00	45.22	0.82	5.82
9 Best Language	93.33	58.00	0.84	5.75
10 Dysarthria	80.00	64.00	0.44	2.48
11 Extinction/ Inattention	86.67	47.00	0.75	5.51

*** Not significant at p<0.05**

Kappa scores were calculated for 13 of the 15 NIHSS items. A kappa could not be calculated for Item (1a) on account of both raters scoring all participants zero for this item (100% agreement). Similarly, the Kappa generated for Item 2 was not significant at $p<0.05$. Individual scores for Item (2) showed little variability with agreement of 96.67%. Kappa scores for the other items ranged between 0.44 and 1.00, indicating moderate to perfect agreement. 76.9% of these items demonstrated kappas of more than 0.61 indicating substantial agreement. It is of interest that the items demonstrating the lowest kappa scores (facial paresis, limb ataxia and dysarthria) are those that have been identified as having poor reliability in other studies (Goldstein and Samsa 1997; Lyden, Lu et al. 1999).

In conclusion, both the RMA and the NIHSS demonstrated acceptable inter-rater reliability when applied in a multilingual stroke population. No major cultural or environmental problems were detected and preferred language is not expected to have influenced results.

3.4.4.3 Piloting of the Questionnaires Developed for Use in the Study

Questionnaires that were developed for use in the study were translated into Xhosa and Afrikaans and administered to patients with stroke from the WCRC. Following piloting of the questionnaires, minor changes were made to the content, format and wording of the questionnaires. It was established that assessments could be completed in a reasonable time frame so as not to be burdensome to the participants: one and a quarter hours at admission, one hour at discharge, and one and a half hours at six months. A detailed report on the piloting of the questionnaires can be found in Appendix VII.

3.4.5 Recruitment and Consent

The records of all patients admitted to the WCRC during the duration of data gathering were screened by the researcher to identify possible participants. All patients who met the eligibility criteria for the study were approached for informed consent. If the patient did not have capacity to give consent due to cognitive or receptive language problems, the next of kin was approached as proxy. Decisions regarding capacity were made in collaboration with clinical staff and with the aid of the language screening test. However, even if informed consent had been obtained from a relative, should the patient subsequently indicate they did not wish to take part in the study, this was respected. If consent could not be obtained from a family member within the five day window of assessment, the patient was excluded from the study. The consent interview was conducted in the patient's preferred language of English, Afrikaans or Xhosa, with the assistance of a translator. Informed consent was also obtained from caregivers prior to administering the Caregiver Strain Index.

3.4.6 Data Collection

Assessments were conducted in the preferred language of the participant. The researcher carried out all interviews in English and Afrikaans herself but Xhosa assessments were carried out with the assistance of a Xhosa research assistant. Two research assistants were trained in scientific method as well as in administering the questionnaires. For the RMA and NIHSS, the research assistant translated instructions as the researcher proceeded and the researcher scored. Translated measures of self-report were applied by the research assistant who had been trained in their administration. The researcher was present throughout the interview process, and where any point was unclear, scoring was discussed. On occasion, where patients were discharged unexpectedly and the research assistant was not available, Xhosa speaking nursing staff assisted with the interview process.

All assessments at admission were conducted at the WCRC within six working days of admission. The medical section of the admission questionnaire was completed by the attending doctor at WCRC. Information regarding referral details was obtained by the researcher from the medical records. Participants were asked for demographic information.

All discharge assessments were completed within five days of discharge. Participants who were discharged unexpectedly early were assessed within their own home after discharge. Assessments at six months were carried out in participants' homes, local community health care centres and at the WCRC. Participants who travelled in for assessment were paid travel costs. Family members were sometimes present for the interview. In the presence of severe cognitive or language deficits, the interviews were completed by proxy. To minimise bias the caregiver was asked to identify what the patient had actually done rather than their perception of the patient's capabilities. Proxies were not asked to complete the EQ-5D because proxy reporting has been shown to introduce bias in measures of health related quality of life (Dorman, Waddell, Slattery, Dennis and Sandercock 1997c)

All participant questionnaires were interviewer-administered to overcome problems with literacy with the exception of the CSI. The participant was asked to identify his/ her main caregiver for the purposes of completing the Caregiver Strain Index. The CSI was administered out of earshot of the patient, in order to avoid introducing bias. Caregivers who were not present for the six month assessment were initially asked to return the CSI in a stamped self-addressed envelope. However, it was found that a number of caregivers did not comply in spite of follow up phone calls, and a reminder letter. In the latter part of the study, caregivers not present at the six month assessment were interviewed telephonically wherever possible.

Professor W De Weerdt and Dr Liesbet De Wit, co-ordinators of the CERISE project in Europe, observed data collection techniques in Cape Town in October 2005 in order to ensure standardisation and allow harmonisation of results with the CERISE study.

3.5 Data Management

Data was entered into a data bank and analysed with STATISTICA 7 software package.

3.6 Data Analysis

Summary statistics were used to describe patient characteristics, the rehabilitation process, outcome at six months and environmental factors.

Pattern of recovery was described using summary statistics across the three time points of assessment (BI scores and RMA scores). Shapiro-Wilk W Tests of normality were used to confirm that most data was not normally distributed. For this reason, and on account of the ordinal nature of the Barthel Index and RMA (Sulter, Steen and De Keyser 1999), non-parametric statistical methods were utilised for analysis. Friedman's analysis of variance was used to assess differences in scores between the time points. Wilcoxons Matched Pairs Test was then conducted to assess differences between the paired time frames. Alpha was set at 0.05. Where multiple comparisons were required, a Bonferroni adjustment was carried out to compensate for multiple testing. That is the total alpha level of 0.5 was divided by the number of tests that were carried out in order to account for the increased probability of finding a significant result with repeated testing.

A repeated measures ANOVA was utilized to investigate differences in pattern of recovery in groups of participants with different levels of severity, as well as according to onset admission intervals. Repeated measures ANOVA's have been shown to be useful for non-parametric data sets provided that the residuals are normally distributed (Altman 1991). The data met these criteria.

During data exploration, bivariate analysis was conducted to investigate the association between MRS at six months and a number of selected factors. Age and severity of stroke (NIHSS) were selected on the basis of previous literature which suggests these factors explain most of the variability in rehabilitation outcomes. Onset admission intervals and number of rehabilitation days have been identified in literature as influencing factors, and it was of interest to know their influence within the chosen rehabilitation setting. The influence of socio-economic status according to income group, perceived environmental barriers and HIV/AIDS status were also of local interest. Indicators such as urinary incontinence, lack of sitting balance and disability at admission (BI) were also investigated on account of their consistent reporting in literature. The presence of a cognitive deficit was also included because clinicians felt this to be important. Spearman's rank order correlation co-efficients were calculated to investigate the relationship between MRS outcomes and continuous variables. Mann-Whitney U testing was used to explore the relationship between MRS scores and categorical variables such as household income and HIV/AIDS status.

Multivariate analysis was conducted to explore the simultaneous effects of multiple factors. Logistic regression was the chosen technique as the main outcome (MRS) is an ordinal six point scale and is therefore not suitable for analysis by linear regression. The MRS was dichotomized into scores of ≤ 2, and scores of > 2. This cut off point was chosen on the basis of previous studies. It distinguishes between patients who are independent in looking after their own affairs (considered a favourable outcome) and those requiring assistance (considered an unfavourable outcome). Independent variables were selected on the basis of the bivariate testing as well as previous literature.

3.7 Ethical Considerations

As reported above, the study was approved by the Ethics Committee of the University of Cape Town (Appendix XXII). Management of the WCRC gave permission to access suitable patients. Informed consent was obtained from participants (patients and caregivers) according to the procedures outlined above. If any clinical problems were identified at the six month assessments, patients were directed to the appropriate channels for follow up. Advice was given to participants and caregivers where appropriate. Feedback will be given to the WCRC in the form of a presentation and written report.

4 RESULTS

4.1 Participants

4.1.1 Assessment at Admission (n=51)

Fifty-nine patients met the eligibility criteria for inclusion into the study. One patient declined consent and seven patients who did not have capacity due to cognitive or language deficits were excluded from the study because their next of kin could not be reached within five working days of admission. Included within the sample were seven patients who had lacked capacity, but whose next of kin had given consent within the required time frame.

Fifty participants were assessed within five working days of admission; one participant was assessed at six working days post admission. (Consent had been obtained from the next of kin within five days of admission, however the relative asked to be present at the assessment, and this could only be arranged at six days post admission.)

4.1.2 Assessment at Discharge (n=49)

Forty-nine participants were assessed within five working days before or after discharge from the WCRC (87.8% of assessments were completed within two working days of discharge).
Where possible, assessments were conducted at the WCRC prior to discharge (n=43). However, six participants were discharged unexpectedly early. Of these participants, three were assessed at their homes and one at a community health care centre within five working days post discharge. Two participants were not available for assessment within the required time frame. One participant was out of Cape Town; the other was caring for her sick mother and did not wish to be assessed. Data for one patient was incomplete as her transport arrived early to take her to the Eastern Cape.

Table 4-1 Characteristics of Participants with Missing Data at Discharge

Sex	Age at assessment	NIHSS Total	BI-1 TOTAL	HIV/AIDS status
Female	50	14	50	Unknown
Female	38	12	65	Unknown
Female	55	12	40	Unknown

4.1.3 Assessment at Six Months (n=47)

Forty-seven patients were assessed at six months post stroke. One patient had passed away, one patient could not be contacted and one patient repeatedly did not arrive for scheduled assessments at the local community health care centre. It was decided not to see this patient in his own home due to security concerns. He was a known substance abuser, was in trouble with the law and had been aggressive to the researcher over the telephone. Characteristics of patients dropping out of the study were as follows:

Table 4-2 Characteristics of Participants with Missing Data at Six Months (n=4)

Sex	Age at assessment	NIHSS Total	BI-1 TOTAL	HIV/AIDS status
Female	46.2	3	75	Unknown
Male	20.2	9	50	Known positive
Female	53.6	10	55	Unknown
Male*	61	4	55	Unknown

***participant passed away before six month assessment**

Some descriptive data were missing at six months for one patient who passed away two days after the six month assessment. As the patient had severe receptive and expressive language deficits supplementary data needed to be obtained from the daughter as proxy. It was not possible to interview the daughter due to her bereavement and as a result some information was missing regarding socio-economic data and follow up after discharge.

Forty-three patients were assessed at six months post stroke, within five days before or after the six month time point. Late assessments were conducted on four patients for the following reasons:

- two patients did not arrive for their scheduled appointments and appointments could only be rescheduled at six days post stroke
- One assessment needed to be scheduled for seven days post stroke in order to co-ordinate availability of the patient, a Xhosa translator and a room for assessment at the local Community Health Care Centre
- One assessment was conducted nearly a month after the six month date. In this instance, the date of stroke had been incorrectly documented in the medical records on admission and perpetuated throughout the medical notes. This error was only detected when the patient was assessed for follow up at six months[9].

[9] This patient had a maximum BI score at discharge and six months. His RMA scores at discharge and six months approached the maximum possible and showed minimal change between the two time points. Literature suggests that after six months only a small percentage of patients improve or deteriorate. It appeared unlikely that this patient's scores were affected as a result of the late assessment, particularly as despite his relatively high BI and RMA scores, he did not score highly on the MRS and had not returned to work.

Figure 1 Flow Chart of Participants

n=59
59 patients met eligibility criteria

↓

- One patient declined consent
- Seven patients lacked capacity for consent and their next of kin could not be contacted within five working days of admission. As such they could not be assessed within the required time frame and they were excluded from the study

↓

n=51
51 patients were registered for the study and assessed at admission

↓

n=49
49 patients were assessed at discharge

- Two patients were contacted at home after discharge but were not available for assessment (BI scores were obtained from nursing staff for these patients. They were both followed up at six months.)
- RMA data was incomplete for one patient whose transport arrived early to take her to Eastern Cape during the assessment (data missing for the RMA Upper Limb Subscale only)

↓

n=47
47 patients were assessed at six months

- one patient had passed away
- one patient could not be contacted
- one patient declined to be assessed
- one patient repeatedly did not arrive for scheduled assessments at the day hospital and could not be seen at home due to security considerations.

(Supplementary descriptive data was missing for an aphasic patient who passed away two days after assessment, and whose daughter was therefore unavailable for interview)

4.2 Patient Characteristics

4.2.1 <u>Demographic Characteristics</u>

Composition of the sample by gender was 22 men and 29 women. Age ranged from 20.2 to 80.1 years. Mean age was 51.3 ± 14.4 SD. Approximately one third of the sample was under 45 years of age. Ten participants were 65 years or older (19.6%).

The mean age of the women (50.6 ± 13.8 SD) was found to be significantly lower than the men (52.1 ± 15.5 SD; t=-24.6, p<0.01).

Table 4-3 Frequency by Age Category (n=51)

	Count	Cumulative Count	Percent	Cumulative Percent
<45 years	17	17	33.3	33.3
45-64 years	24	41	47.1	80.4
65-74 years	8	49	15.7	96.1
75+ years	2	51	3.9	100.0
TOTAL	51	51	100	100.0

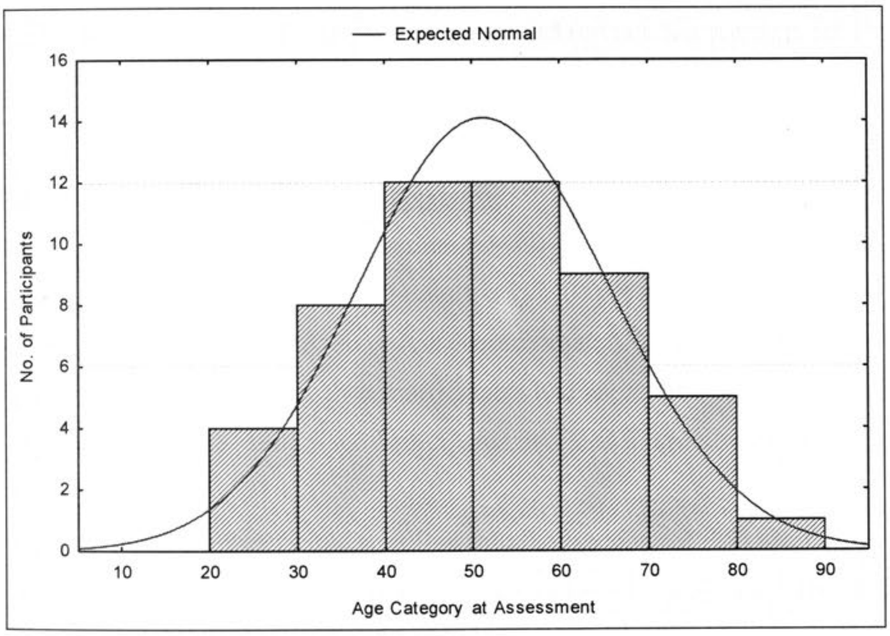


Figure 2 Histogram of Age at Assessment (n=51)

Age was normally distributed in the sample. This was confirmed by the Shapiro-Wilk W Test (W=0.98, p>0.05).

4.2.2 Population Group and Language

As population group has been identified as a differential factor in outcome, and racial classification is unfortunately still an indicator of relative life advantage in South Africa, this factor was investigated. Twenty-six participants identified themselves as coloured, 17 as black, and seven preferred not to answer this question. One participant identified herself as Muslim. No participants were categorized as white or Asian/ Indian.

Twenty-one participants identified Afrikaans as their preferred language, 16 participants preferred English, and 14 participants preferred Xhosa. However, many participants were proficient in more than one language. Eighty-two percent of participants were competent in English (n=42), 75% in Afrikaans (n=38) and 29% in Xhosa (n=15). Five participants spoke Xhosa but were unable to speak English or Afrikaans.

4.2.3 Marital Status

Twenty-six participants were married or living with a partner, eight were divorced or separated, eight were widowed, and nine had never married (n=51). Six participants lived alone before their stroke (11.8%).

4.2.4 Socio-Economic Characteristics

4.2.4.1 Monthly Household Income (n=49)

Incomes of R1000 or less (approximately US$140) per month were reported by 53.1 % of participants. Incomes of R2500 or less (approximately US$340) per month were reported by 81.6% of participants. Only three participants had an income of more than R8000 per month (approximately US$1100). Two participants declined to answer this question. (See Table 4-4)

The large number of participants falling into the category of R501 to R1000 per month may be due to 15 participants being in receipt of state grants (13 pensioners and two disability grants).

Table 4-4 Monthly Household Income (n=49)*

Category	Count	Cumulative Count	Percentage	Cumulative Percentage
No Income	1	1	2.0	2.0
R1-R200	3	4	6.1	8.2
R201-R500	5	9	10.2	18.4
R501-1000	17	26	34.7	53.1
R1001-1500	8	34	16.3	69.4
R1501-2500	6	40	12.2	81.6
R2501-4500	5	45	10.2	91.8
R4501-8000	1	46	2.0	93.9
R8001-16000	2	48	4.1	98.0
>16000	1	49	2.0	100.0
TOTAL	49	49	100.0	100.0

*** Data missing for two participants who declined to answer this question**

4.2.4.2 Employment Status Prior to Stroke (n=51)

Twenty-nine patients were working prior to stroke (56.9%), two patients were looking for work and 20 participants were not in paid employment.

Table 4-5 Employment Status Prior to Stroke (n=51)

Employment Status	No. of Participants	Percentage
Paid employment	29	56.9
Unemployed, looking for work	2	3.9
Looking after the home	5	9.8
Retired	13	25.5
Unable to work due to disability	2	3.9
TOTAL	51	100.0

Both patients who were unable to work due to disability or illness were receiving disability grants. One patient had been on a disability grant for many years due to an orthopaedic injury of her knee. The other patient had been on a disability grant for six months since acquiring Tuberculosis (TB). She also had advanced AIDS. Both patients had pre-stroke Barthel Index scores of 100.

Of the patients that had worked prior to their stroke: 21 participants worked full time, four participants worked part time and four worked irregular hours. Of the participants that worked irregular hours, two were casual workers, one was a contract worker and another had seasonal employment. Twenty-five patients were employed by others and four patients were self-employed.

4.2.4.3 Type of Work

Of the 25 participants who were employees prior to their stroke, 8% were employed as managers or professionals, 44% were in skilled or semi-skilled positions, and 48% were in unskilled positions.

Table 4-6 Frequency by Type of Work for Participants in Paid Employment (n=25)

Category	Number of participants (%)	Type of Work
Professional/ Managerial	2 (8%)	manager, nursing sister
Skilled/ Semi-skilled (includes technicians, clerical, crafts, trader, service and sales workers)	11 (44%)	welder, electrician, printing technician, audit clerk, secretarial, carpenter, chef, sales person, driver, interpreter
Unskilled	12 (48%)	labourer, cleaner, general assistant, domestic worker, paid caregiver, bakery assistant
TOTAL	25 (100%)	

Of the patients who were self-employed (n=4): one patient was a bricklayer, one patient made and sold clothes, one patient made and sold bricks and one patient sold fruit and vegetables.

4.2.4.4 Education levels (n=50)

Education levels varied from no formal education to 17 years of successful education. Mean education was 8.5 $\pm$ 3.4 years. Thirty-two percent of participants had had no formal education or primary school education only (n=16) and 54.0% of participants had had some secondary school education but had not matriculated (n=27). Only seven participants had completed matriculation or had further tertiary education (14.0%). Data was missing for one aphasic participant.

4.2.4.5 Housing and Services

Prior to their stroke, 44 participants (86.3%) lived in formal housing and seven participants (13.7%) lived in informal housing. The majority of participants (n=42) lived in self-standing or semi-detached houses. One patient lived in a ground floor flat in a block of flats, and one patient stayed in a room in a backyard. Six patients were in informal dwellings in informal settlements, and one patient lived in an informal dwelling in a backyard.

The majority of participants had access to electricity (92.0%), running water indoors (84.0%) and a telephone (86.0%). However, of the patients with telephone access, only 44.2% had a landline, 53.5% used cell phones and one patient had access to a neighbour's telephone.

Seventy percent of participants had indoor toilet facilities and 72.0% had a bathroom with a bath or shower.

Table 4-7 Percentage of Participants with Access to Services and Facilities (n=50) *

Service/ Facility	Count	Percentage
Electricity	46	92.0
Running water indoors	42	84.0
Inside toilet	35	70.0
Bathroom facilities	36	72.0
Telephone Access	43	86.0

*** Data missing for one aphasic participant**

4.2.5 Medical Characteristics

4.2.5.1 Type of Stroke

Twenty participants presented with right sided lesions (39.2%), 29 with left sided lesions (56.9%) and two had bilateral lesions (3.9%). Classification of kind of stroke was limited by the fact that a large proportion of participants (47.1%) had not been investigated with CT or MRI scans. Nine participants were classified by the admitting medical practitioner as haemorrhagic strokes (17.6%), 18 as ischaemic strokes (35.3%), and 24 strokes were classified as indeterminate cause (47.1%).

Further classification into sub-type according to the TOAST criteria was limited by lack of investigation results. Nine strokes were classified as primary intra-cerebral haemorrhages, five as small vessel infarctions, five as large vessel infarctions, and no strokes were classified as cardioembolic infarct or subarachnoid haemorrhage. The majority of strokes were classified as indeterminate or of more than one cause (62.7%).

4.2.5.2 Complications on Admission

Fourteen participants were identified as having complications on admission. There were no reported cases of urinary tract infection, chest infection, falls, depression, central post stroke pain, pulmonary embolism, lower limb thrombosis, seizures or contractures. Presenting complications included the following:

Table 4-8 Frequency of Complications on Admission (n=51)*

Condition	Frequency
Shoulder Pain	5
Other Upper Limb Pain	3
Back Pain	1
Lower Limb Pain	3
Face Pain	1
Pressure Sore	1
Severe Constipation	1
Participants with no complications	37

***Note that a participant could report more than a single complication.**

4.2.5.3 Presence of catheters/ Nasogastric Feeding Tubes (NGT's)

None of the patients admitted had nasogastric feeding tubes or PEG (percutaneous enterogastrostomy) feeding tubes. Eleven patients had urinary catheters in situ on admission.

4.2.5.4 Risk Factors

The most prevalent risk factors in the sample were high blood pressure (74.5%), diabetes mellitus (23.5%) and smoking (52.0%). Nine participants had a history of cardiac disease (17.6%) and six participants had high cholesterol (11.8%).

With regard to infective risk factors, six participants had confirmed HIV/AIDS. One participant had syphilis. Pulmonary tuberculosis (TB) was reported in five participants, four of whom had also been diagnosed with HIV/ AIDS. One participant had confirmed and one participant queried TB meningitis at the time of their stroke.

Table 4-9 Prevalence of Risk Factors (n=51)

Risk Factor	Reported Prevalence	Percentage of Sample
High Blood Pressure	38	74.5
Smoking*	26	52
Diabetes mellitus	12	23.5
HIV/ AIDS	6	11.8
Ischaemic Heart Disease	6	11.8
High Total Cholesterol	6	11.8
Pulmonary TB	5	9.8
Possible TB meningits	2	3.9
Excess Alcohol Intake	2	3.9
Other Substance Abuse	2	3.9
Oral Contraceptives	2	3.9
Previous thrombosis	2	3.9
Peripheral Vascular Disease	1	2.0
Valvular Heart Disease	1	2.0
Heart Failure	1	2.0
Cardiomyopathy	1	2.0
Previous Transient Ischaemic Attack	1	2.0
Syphilis	1	2.0
Carcinoma	0	0.0
Atrial Fibrillation	0	0.0

***n=50 for this item. Information missing for one aphasic patient**
TB=tuberculosis

4.2.5.5 Other Co-Existing Medical Conditions

In addition to the medical conditions described above, pulmonary conditions were present in ten participants, musculoskeletal conditions in five participants, and one patient was visually impaired.

Pulmonary conditions included pulmonary TB (n=5), pneumocystis carinii pneumonia (n=1), chronic obstructive airways disease (n=2) and asthma (n=2). Musculoskeletal disorders included osteoarthritis (n=2), osteoporosis (n=1), prior traumatic knee injury (n=1) and gout (n=1).

4.2.5.6 Pre Stroke Function

Forty-nine of the 51 participants had pre-stroke Barthel scores of 100. Two participants had pre-stroke scores of 90. In both cases, the participants had difficulties with continence items, but were independent in all self-care activities.

4.2.5.7 Clinical Presentation at Admission

Severity of stroke on admission is reported in Table 4-10.

Table 4-10 Severity of Stroke on Admission According to the NIHSS (n=51)

	NIHSS Score on Admission	Count	Cumulative Count	Percentage	Cumulative Percentage
Mild	≤6	10	10	19.6	19.6
Moderate	7-15	32	42	62.7	82.3
Severe	≥ 16	9	51	17.6	99.9
TOTAL		51	51	100	100

According to reporting of individual items on the NIHSS, 37.5% of patients had language deficits and 37.3% of patients presented with inattention. Swallowing problems were documented in the medical records of three patients but only one patient was on a modified diet. Seventeen patients reported incontinence of bowels and 19 patients reported incontinence of bladder according to the Barthel Index. (See Table 4-11)

Table 4-11 Characteristics of Presenting strokes on Admission (n=5 1)

	No Reported Deficit	Some Problems	Severe Problems	Total
Language Deficit	32	18 (mild to moderate)	1 (severe)	**51**
Inattention	32	13 (mild)	6 (severe)	**51**
Bowel Control	34	6 (occasional accident)	11 (incontinent)	**51**
Bladder Control	32	6 (occasional accident)	13 (incontinent)	**51**

4.3 The Rehabilitation Process

4.3.1 Referral Source

Referrals were received from the state health sector from primary (n=10, 19.6%), secondary (n=23, 45.1%) and tertiary (n=11, 21.6%) institutions. Four participants were referred from the private sector (7.8%), two participants self-referred and one patient was referred by community health workers.

4.3.2 Onset Admission Interval (OAI)

The time between stroke onset and admission to the WCRC (Onset Admission Interval) ranged from three to 82 days. The mean stroke admission interval was 24 days ± 20.5 SD. Thirty-eight participants had been admitted in the first 30 days post stroke, and 42 patients had been admitted by six weeks post stroke. Twenty-three participants were transferred to WCRC directly from hospital (82.4%) and 28 participants were admitted from their homes.

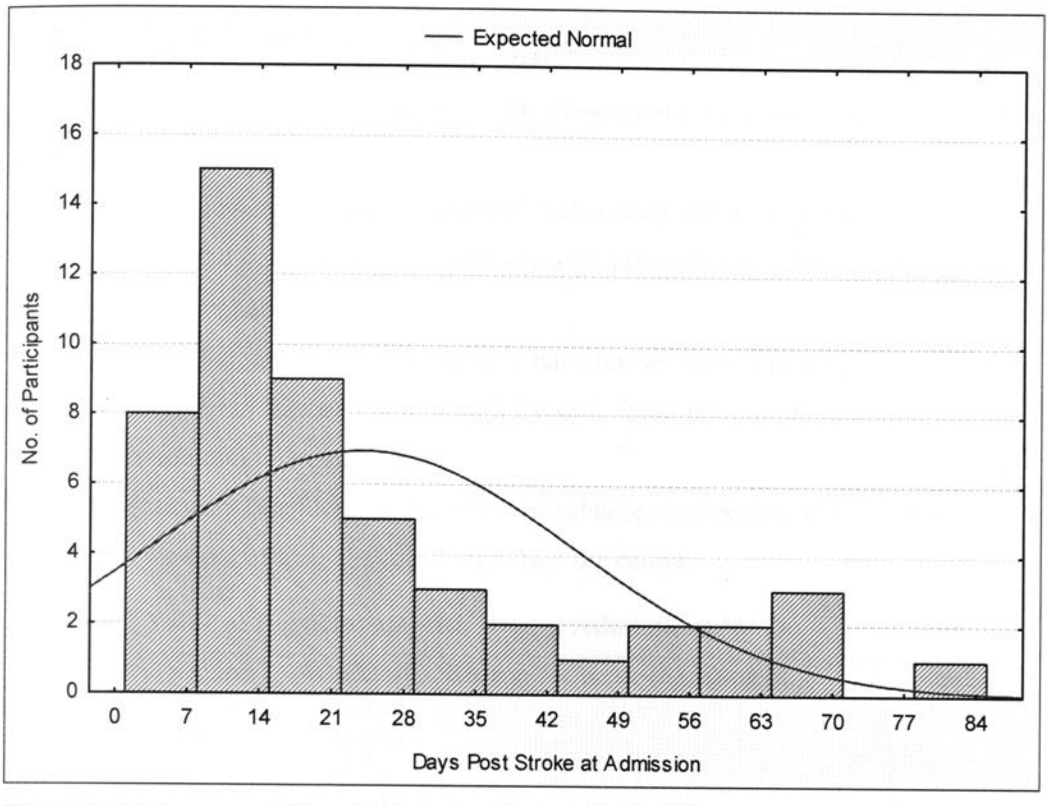


Figure 3 Histogram of Onset Admission Intervals (n=51)

4.3.3 Length of Stay

A number of participants had more than one admission to the WCRC in the six month period after their stroke, with time spent at home between admissions

Six participants had a break in treatment over the Christmas period so that they could spend time with their families. Of these, five participants returned for rehabilitation in January, and the break from treatment varied between 2.7 and 4.6 weeks. These patients were considered to have had a single admission with a break in treatment. Under normal circumstances, patients are discharged from the centre when they have achieved their predicted outcome level and are deemed no longer to require inpatient treatment. This was clearly not achieved at the time these patients went home for Christmas leave. For this reason, discharge data was obtained at the time of their discharge from rehabilitation, not at the commencement of their holiday leave. However, one participant did not return from Christmas leave in January as scheduled, and was only readmitted in March. As this patient had had a break of more than ten weeks, she was considered to have had two separate admissions. Discharge data was obtained from the time of her discharge pre- Christmas. As she had been discharged unexpectedly early in order to go on holiday, data was missing at this time point.

A number of participants were readmitted for subsequent rehabilitation stays under different circumstances:

- One participant had been discharged, but contacted the unit when she experienced unexpected recovery at home and a second admission was arranged to work further on her walking ability
- Two participants were considered to have further rehabilitation potential and were later readmitted to take part in a Bobath Course. These patients were inpatients at the time of their six month assessment.

These patients were considered to have been discharged and readmitted, and discharge data was obtained at the time of their first discharge from the centre.

Table 4-12 Table of Participants with Repeat Admissions (n=7)

First rehab period (days)	Second Rehab Period (days)	Weeks of Absence between rehab periods	Reason for break in treatment	Third rehab Period
72	52	2.9	Christmas leave	No
31	66	2.7	Christmas leave	Yes*
27	65	2.7	Christmas leave	Yes*
48	25	4.6	Christmas leave	No
48	13	10.9	Christmas leave, did not return to unit, discharged	No
57	24	11.7	Discharge	No
18	49	3.0	Christmas leave	No

***These participants were inpatients at the time of their six month assessment. Therefore length of stay was not recorded for their third admission period. However, included in the total number of rehabilitation days was the time spent in the rehabilitation unit up until their six month assessment.**

The total number of rehabilitation days was calculated by adding all days spent in rehabilitation, up until the follow up assessment at six months. Total number of rehabilitation days varied from 17 to 124, with a mean of 59.1 days ± 28.2 SD. There was a correlation between the number of rehabilitation days and severity of stroke according to the NIHSS ($r=0.39$, $p<0.05$) i.e. the greater the severity of the stroke, the greater the number of rehabilitation days.

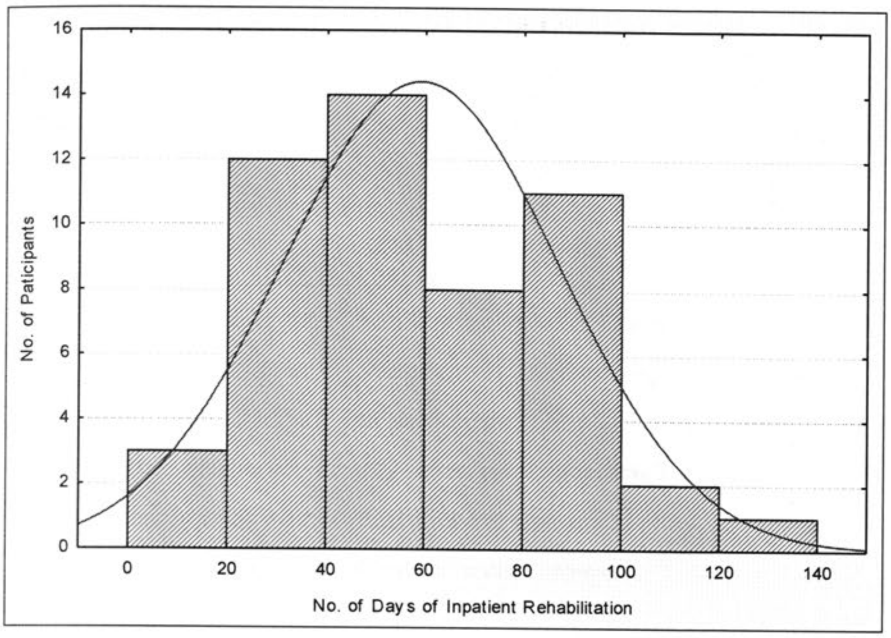


Figure 4 Total Number of Rehabilitation Days (n=51)

4.3.4 Discharge and Discharge Planning

At the point of discharge, time since stroke ranged from 26 to 160 days, with a mean of 83.3 ± 31.2 days. Two participants were discharged in the first month after their stroke, ten participants were discharged in the second month after their stroke, and 20 participants were discharged in the third month after their stroke. (See Table 4-13.)

Table 4-13 Frequency Table of Time Post Stroke at Discharge

	Count	Cumulative	Percent	Cumulative Percent
0 – 30 days	2	2	3.9	3.9
31 – 60 days	10	12	19.6	23.5
61 – 90 days	20	32	39.2	62.7
>90 days	19	51	37.3	100.0
TOTAL	51	51	100.0	100.0

Analysis of the questionnaire filled in by staff members revealed the following: Only two participants had had a home visit prior to discharge from rehabilitation; however, during the course of their rehabilitation stay, 50 participants had returned home for an overnight stay (for example over weekends). The only participant who had not had an overnight stay had had a severe stroke and never returned home, being discharged directly to an institution.

The families/ caregivers of 38 participants had received training in the form of verbal instruction or demonstration (74.5%). Four families/ caregivers had received training in the form of written instruction. The families of 12 participants had received no instruction by the time of discharge (23.5%). Most families had been involved in the planning of discharge (68.6%).

4.3.5 Follow up after Discharge

According to data from the Rehabilitation Process Questionnaire which was completed by therapy staff at the time of discharge (n=51), review appointments at WCRC had been arranged for 17 participants (33.3%). Ten participants (19.6%) had been referred on to other services for follow up after discharge. Twenty-seven participants had neither a follow up review nor had not been referred on to any other rehabilitation service (52.9%). (It must be noted that referrals for medication or medical follow up at the local community health care centre were not included in this calculation.)

In spite of the apparently few referrals, most of the 47 participants available for assessment at six months had had some contact with health services by the time of their six month assessment (n=42, 89.4%). As previously reported two participants had been admitted for a second rehabilitation stay (13 and 24 days respectively) and subsequently discharged. Two participants had recently been readmitted and were inpatients on the unit at the time. One participant had been at the WCRC for a week prior to the six month assessment; the other participant had only just been admitted and had not yet commenced his rehabilitation programme.

Participants assessed at six months who were not re-admitted for further rehabilitation (n=43) will be considered in the analysis that follows. Data was missing for one aphasic patient. Follow up received following discharge from WCRC is reported in Table 4-14 (n=42). Most commonly, follow up was received from a doctor (n=29), nurse (n=11), physiotherapist (n=14) or social worker (n=6). Most consultations took place at Community Health Care Centres (CHCC), although some participants had returned to the WCRC and other participants had been seen at home. A small number of participants had consulted private doctors or physiotherapists. Five participants had not had any contact with any medical services following their discharge (10.6%). One of these five participants had a planned readmission pending in approximately one month.

Only four participants had not received any follow up and had no appointments pending. Three of these patients complained of shoulder pain at the six month assessment and one patient enquired about receiving further rehabilitation.

Table 4-14 Table of Services and Follow Up Accessed After Discharge (n=42)
(Note participants may have had follow up from more than one health professional at more than one site)

Health Professional / Service Accessed	Total No of patients having access	No of patients with contact at CHCC	No of patients with contact at WCRC	No of patients with contact at Own Home	No of patients with contact at Other Site
Doctor	29	18	5	-	10 (includes private and hospital)
Physiotherapist	14	8	5	-	1 (private)
Nurse	11	7		3	1 (hospital)
Social Worker	6	3	3	1	1 (hospital)
Occupational Therapist	3	0	3	-	-
Self Help Group	4	2	-	-	2 (includes CAFDA and a Home for the Elderly)
Community Rehabilitation Worker	3	-	-	3	-
Psychologist	2	-	-	-	2 (includes hospital and self-help group)
Speech and Language Therapist	1	-	1	-	
Other #	6				

*** Data was missing for one aphasic patient; four participants are excluded from this analysis as they had had repeat admissions to WCRC.**
 # Included herbalist, volunteer organisation, orthotist, pharmacist, medical students

Of the participants who were not readmitted for further rehabilitation at the WCRC, only four participants (9.5%) had received any substantial therapy input as defined by more than six therapy sessions since discharge from the rehabilitation centre (includes occupational therapy, physiotherapy and speech and language therapy sessions). All speech and language therapy or occupational therapy follow up after discharge took place at the WCRC. Six of the participants receiving physiotherapy had had two or fewer sessions. Only a small number of participants had had any substantial physiotherapy input by the time of the six month assessment. (See Figure 5)

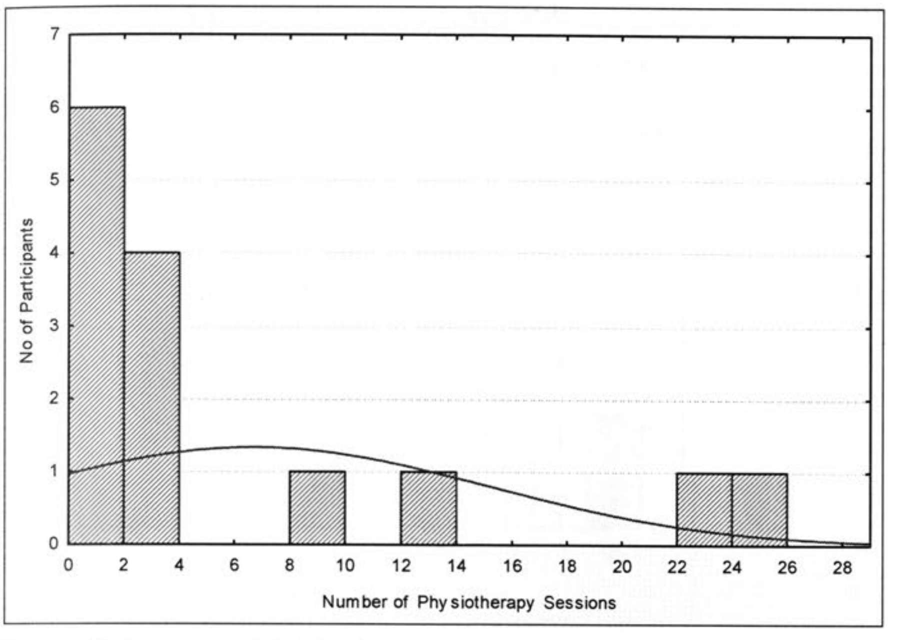


Figure 5 Contacts with Physiotherapist per Patient Receiving Follow up (n=14)

4.4 Pattern of Recovery

4.4.1 Functional Recovery

4.4.1.1 Description of Function at Each Time Point according to BI

4.4.1.1.1 BI Scores at Admission (n=51)

At admission to the unit, BI Scores ranged from 5 to 100, with a median score of 50.

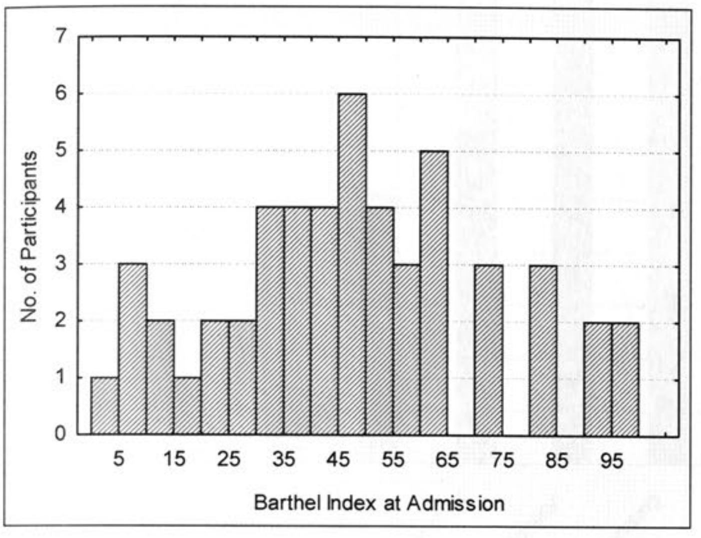


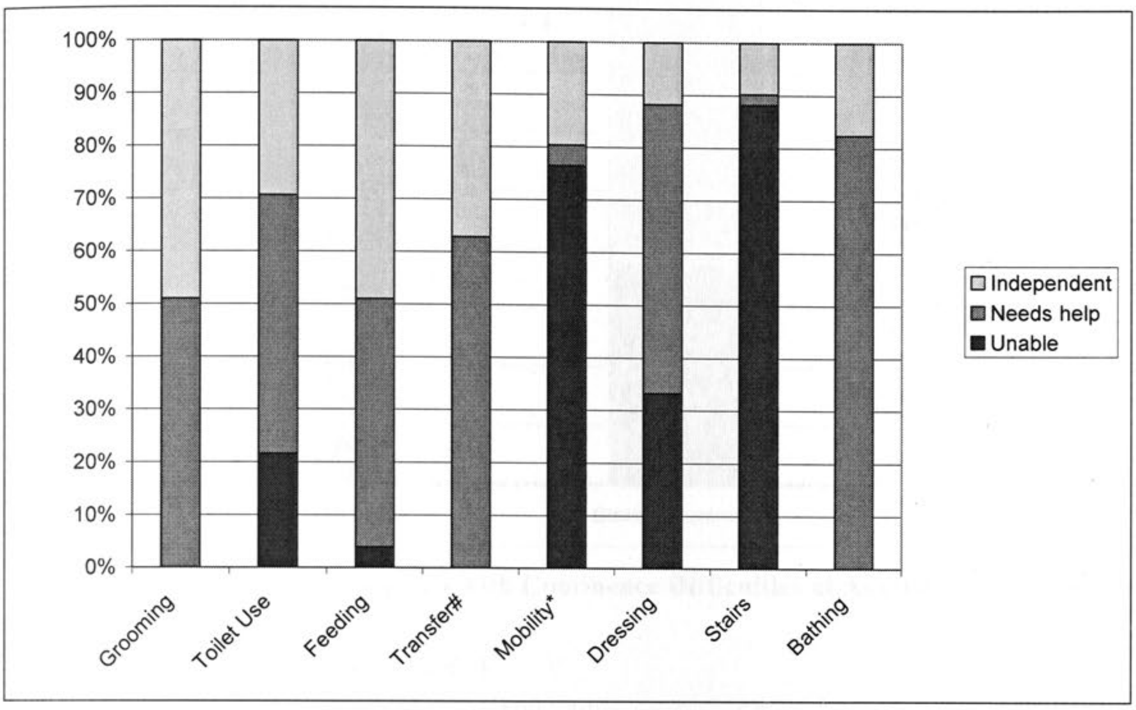
Figure 6 Barthel Index Scores at Admission (n=51)

A BI score of less than 60 implies dependency for ADL, scores of 60 to 80 indicate assistance is required for ADL, scores of 85-95 suggest only minimal assistance is required, and scores of 100 imply independence but not necessarily normal function. These categories have been selected to indicate severe disability, moderate disability, mild disability and independence respectively. Table 4-15 lists the frequency of participants in each category at admission.

Table 4-15 Frequency Table of Defined Disability Categories (BI) at Admission (n=51)

	Category	Count	Cumulative	Percent	Cumulative Percent
BI [0-55]	Dependent	33	33	64.7	**64.7**
BI [60 – 80]	Moderate assistance	11	44	21.6	**86.3**
BI [85-95]	Minimal Assistance	5	49	9.8	**96.1**
BI [100]	Independent	2	51	3.9	**100.0**
TOTAL		51	51	100.0	100.0

An analysis of individual items showed that the activities that required the most assistance at admission were stairs, dressing, bathing and mobility. (See Figure 7)



***Mobility categories of "unable" and "wheelchair independent" have been condensed into "unable"**

#Transfer categories of "major help" and "minor help" have been condensed into "needs help"

Figure 7 Percentages of Participants Needing Help with Individual Items of the Barthel Index at Admission (n=51)

The percentages of participants experiencing difficulties with continence are reflected in Figure 8.

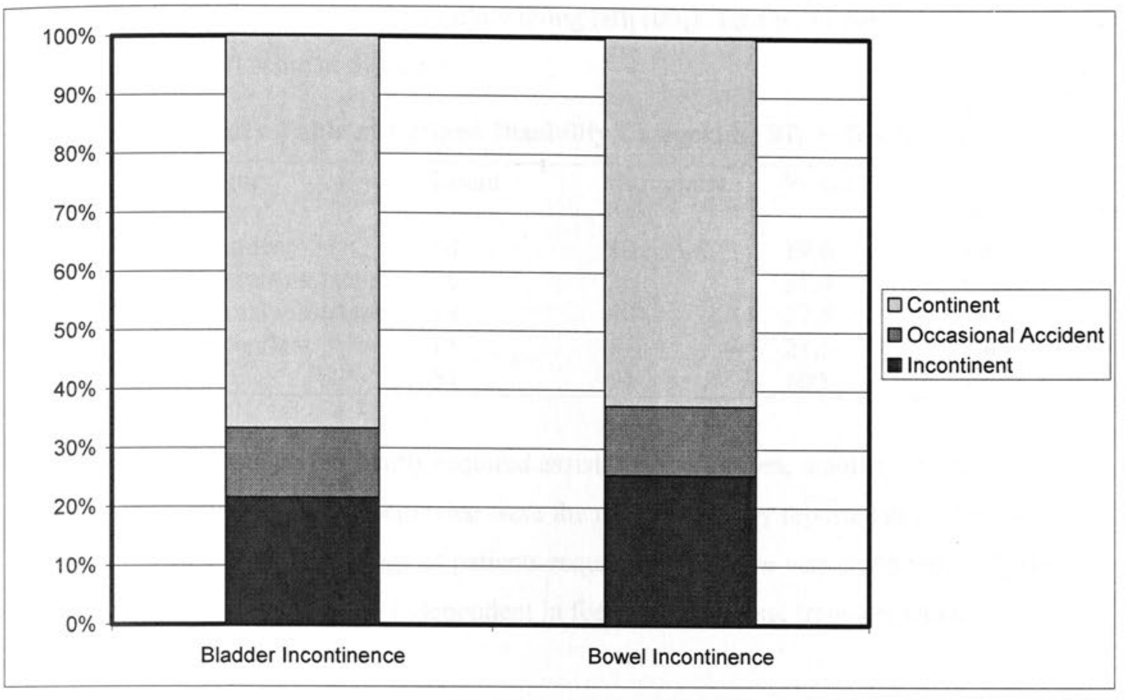


Figure 8 Percentages of Participants with Continence Difficulties at Admission (n=51)

4.4.1.1.2 BI Scores at Discharge (n=51)

At discharge, BI Scores ranged from 10 to 100 with a median of 80.

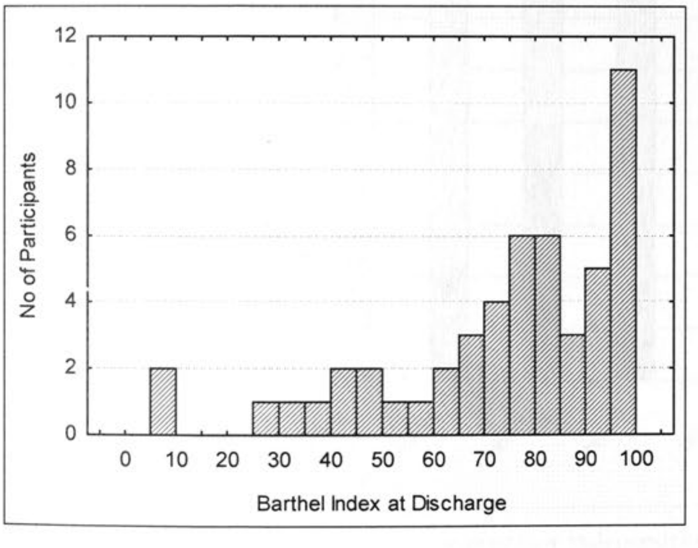


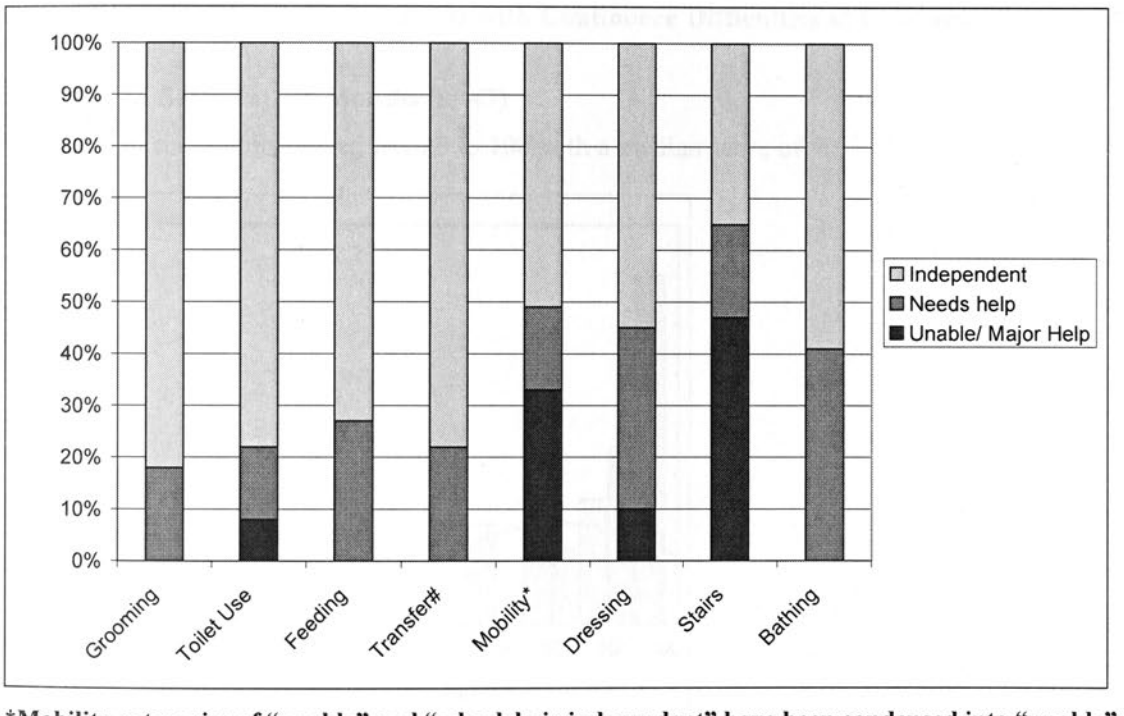
Figure 9 BI Scores at Discharge (n=51)

According to the previously described categories of disability, at the time of discharge, ten patients were dependent for basic care (BI [0-55]), 16 patients required moderate assistance (BI[60-80]), 14 patients needed only minimal assistance (BI[85-95]) and 11 patients were completely independent in activities of daily living (BI[100]). That is, 11 patients (21.6%) already had the maximum BI score at discharge.

Table 4-16 Frequency Table of Defined Disability Categories (BI) at Discharge (n=51)

	Category	Count	Cumulative	Percent	Cumulative Percent
BI [0-55]	Dependent	10	10	19.6	**19.6**
BI [60 – 80]	Moderate assistance	16	26	31.4	**51.0**
BI [85-95]	Minimal Assistance	14	40	27.5	**78.5**
BI [100]	Independent	11	51	21.6	**100.1**
TOTAL		51	51	100	100

Individual items that most frequently required assistance were stairs, mobility, bathing and dressing. These were the same items that were the most frequently reported at the time of admission, however, the percentage of patients requiring assistance was much reduced. The majority of patients (>70%) were independent in feeding, grooming, transfers and toilet use. (See Figure 10)



***Mobility categories of "unable" and "wheelchair independent" have been condensed into "unable"**

#Transfer categories of "major help" and "minor help" have been condensed into "needs help"

Figure 10 Percentages of Participants Needing Help with Individual Items of the Barthel Index at Discharge (n=51)

A number of participants had difficulties with continence and this is reflected in Figure 11

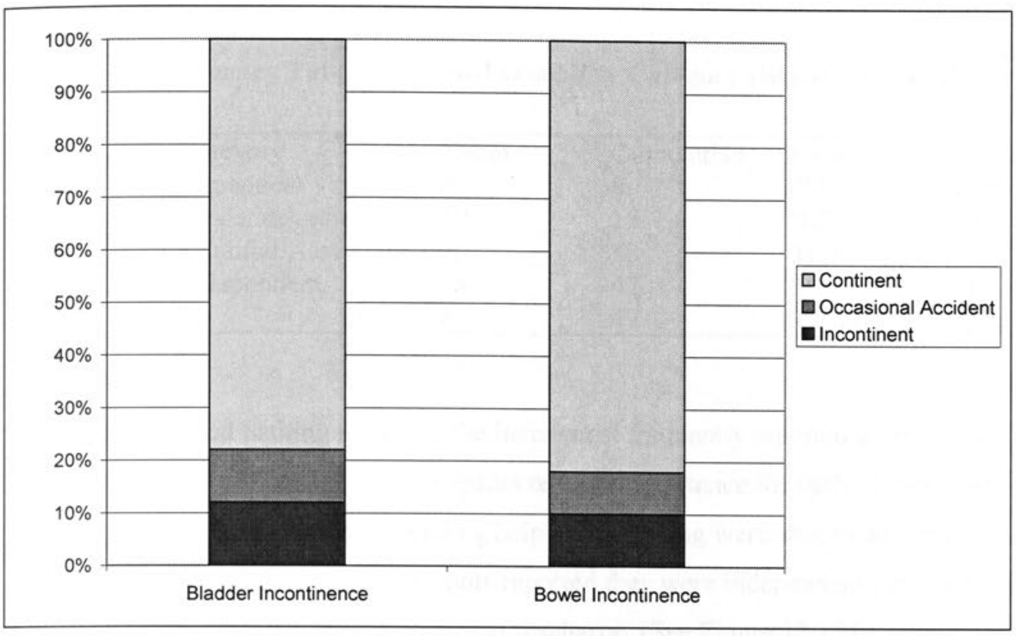


Figure 11 Percentages of Participants with Continence Difficulties at Discharge (n=51)

4.4.1.1.3 BI Scores at Six Months (n=47)

BI Scores at six months ranged from 0 to 100 with a median score of 90.

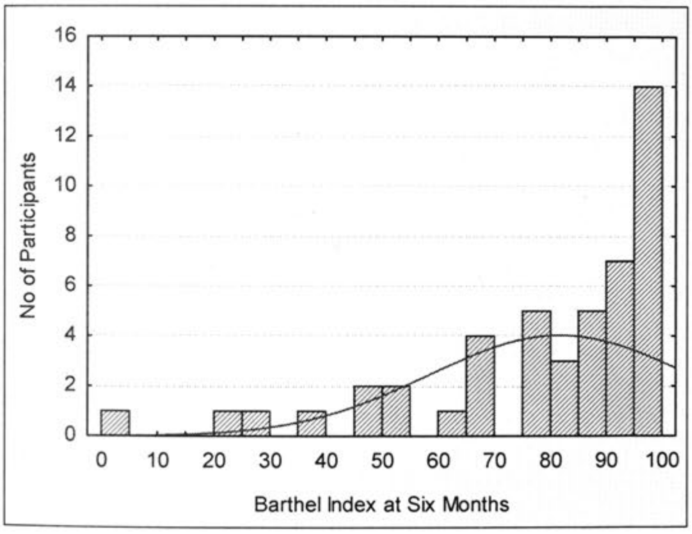


Figure 12 BI Scores at Six Months (n=47)

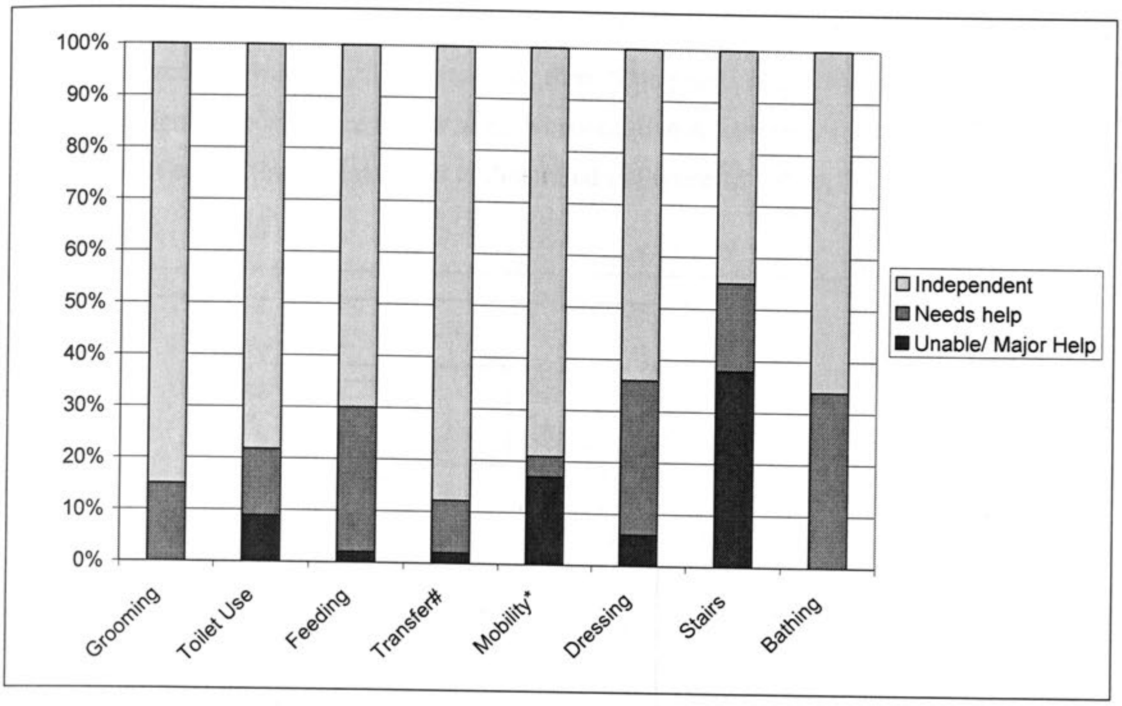
At six months after their stroke, eight patients were dependent for basic care (BI[0-55]), ten patients required moderate assistance (BI[60-80]), 15 patients needed only minimal assistance (BI[85-95]) and 14 patients were completely independent in activities of daily living (BI[100]).

That is, 14 participants (29.8%) had obtained the maximum scores of 100 by six months post stroke.

Table 4-17 Frequency Table of Defined Disability Category (BI) at Six Months (n=47)

	Category	Count	Cumulative	Percent	Cumulative
BI [0-55]	Dependent	8	8	17.0	**17.0**
BI [60 – 80]	Moderate assistance	10	18	21.3	**38.3**
BI [85-95]	Minimal Assistance	15	33	31.9	**70.2**
BI [100]	Independent	14	47	29.8	**100.0**
TOTAL		47	47	100.00	100.0

Stairs, dressing and bathing remained the items most frequently reported as problematic. However, a lower percentage of participants required assistance for each of these items. In addition, 82% of the participants needing help with dressing were able to do more than half of dressing unassisted. 78.7% of participants reported they were independently mobile indoors at six months compared to 51% of participants at discharge. (See Figure 13.) The percentages of participants experiencing ongoing difficulties with continence at six months are reflected in Figure 14.



***Mobility categories of "unable" and "wheelchair independent" have been condensed into "unable"**

#Transfer categories of "major help" and "minor help" have been condensed into "needs help"

Figure 13 Percentages of Participants Needing Help with Individual Items of the Barthel Index at Six Months (n=47)

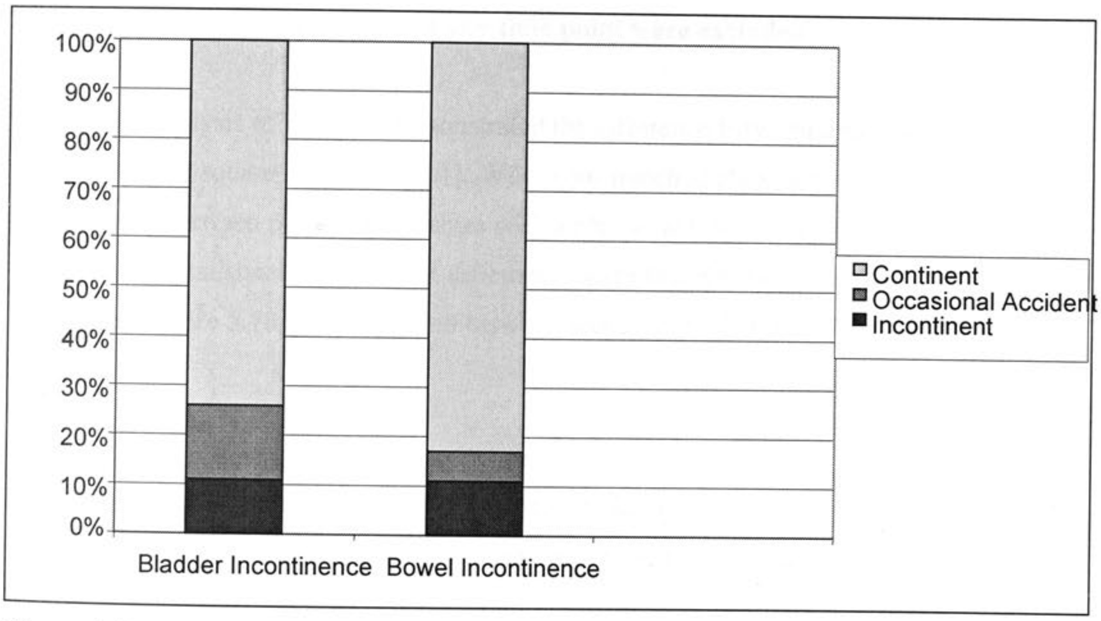


Figure 14 Percentages of Participants with Continence Difficulties at Six Months (n=47)

4.4.1.2 Change over Time

Functional recovery was described across the three time points of assessment in terms of BI scores. Median BI scores were higher at each consecutive assessment, illustrating an improvement across time points. This is illustrated in Figure 15 below.

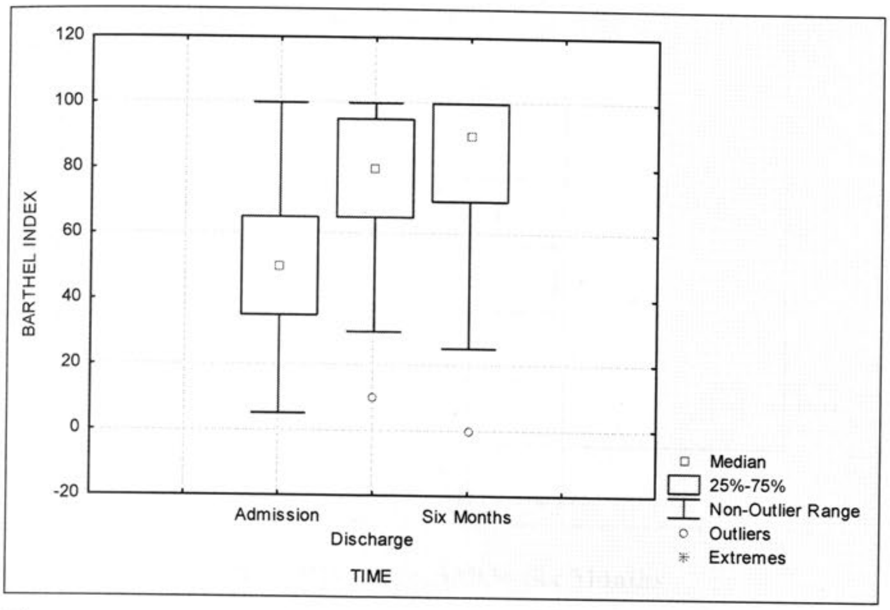
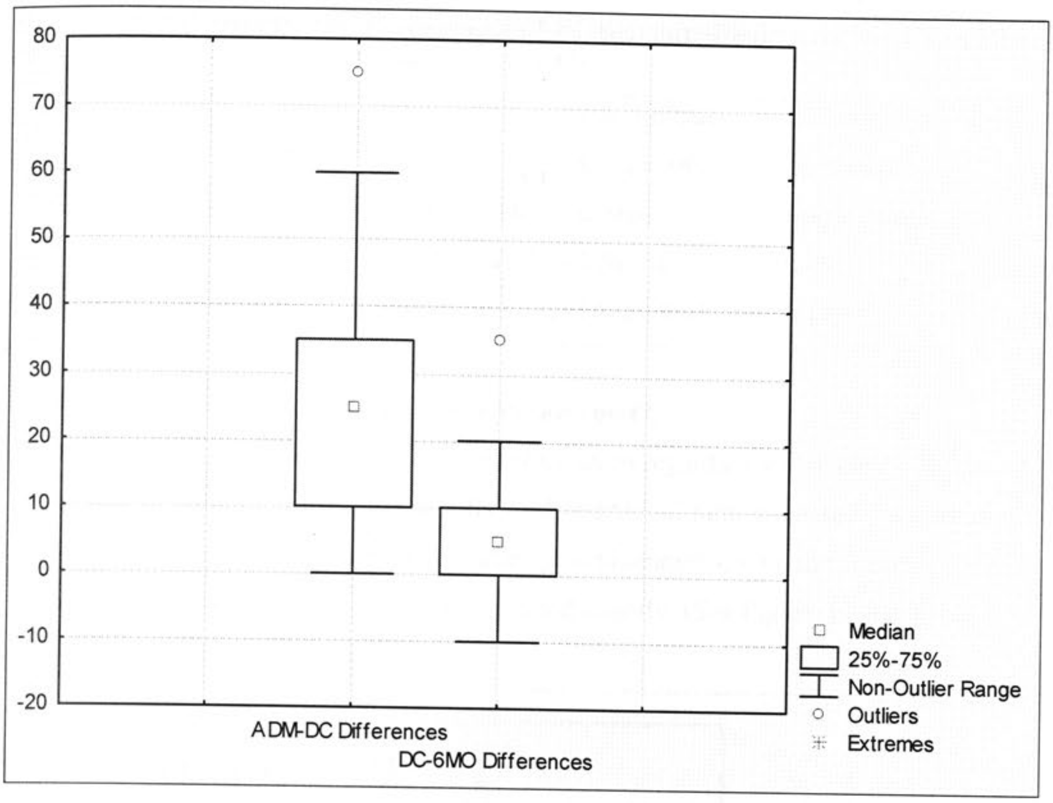


Figure 15 Box and Whisker Plot of BI Scores Across time Points (n==47*)
***Participants with data missing at any time point were excluded**

Friedman's analysis of variance demonstrated the difference between time points was statistically significant (Chi square 72.08, $p<0.01$). Wilcoxons matched pairs test was then used to conduct comparisons between paired time frames with alpha set at 0.017 to account for multiple comparisons. Statistically significant differences were found between scores at admission and discharge (z score 5.78, $p<0.017$); and between scores at discharge and six months (z score 3.61, $p<0.017$).

4.4.1.3 Differences between Time Points

The median of the differences scores (that is the differences between time points for each participant) between admission and discharge was considerably greater than that between discharge and six months. (See Figure 16)



ADM=Admission, DC= Discharge, 6MO= Six Months

Figure 16 Differences Scores across Paired Time Points of Assessment (n=47)

Between admission and discharge, the median of the differences was 25, and differences scores ranged from 0 to 75. By contrast, between discharge and six months, the median of the differences was 5, and the range was -10 to 35. (The negative difference score indicates a deterioration.)

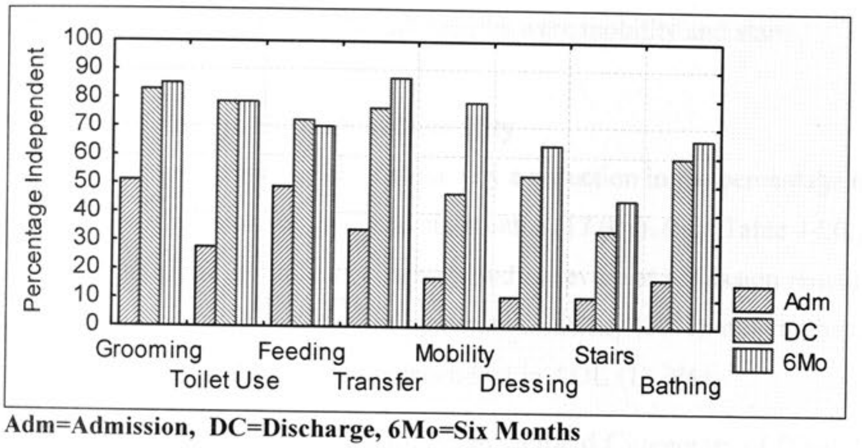
If a clinically significant change is defined as a change of more than 15% (more than 15 points on the BI score), then 93% of participants demonstrated clinically significant change between admission and discharge, and just over half of participants (55%) demonstrated clinically significant change between discharge and six months. Seven participants deteriorated (14.9%). (See Table 4-18.)

Table 4-18 Frequencies and Percentages of Participants Demonstrating Clinically Significant Change Across Time Points (n=47)

	Clinically significant improvement	No clinically significant change	Clinically significant deterioration	TOTAL
Admission - Discharge	44 (93.6%)	3 (6.4%)	0 (0%)	**47 (100%)**
Discharge - Six Months	26 (55.3%)	14 (29.8%)	7 (14.9%)	**47 (100%)**

4.4.1.4 Individual Items across Time Points (n=47)

Analysis of individual items gives further information regarding where change occurred. The percentage of participants independent for each individual item increased from admission to discharge and, to a lesser extent from discharge to six months, with the exception of toileting and feeding which remained the same or deteriorated slightly. (See Figure 17 and Table 4-19)



Adm=Admission, DC=Discharge, 6Mo=Six Months

Figure 17 Independence in Individual Items of BI Across Time (n=47)

Table 4-19 Percentages of Participants Independent in Individual Items across the Three Time Points of Assessment (n=47)

ITEM	SCORES AT TIME POINTS			DIFFERENCES BETWEEN TIME POINTS	
	Admission	**Discharge**	**6 Months**	**Differences in Percentages between Admission and Discharge**	**Difference in Percentages between Discharge and Six Months**
Grooming	51.1	83.0	85.1	31.9	2.1
Toilet Use	27.7	78.7	78.7	51.0	0
Feeding	48.9	72.3	70.2	23.4	-2.1
Transfer	34.0	76.6	87.2	42.6	10.6
Mobility	17.0	46.8	78.7	29.8	31.9
Dressing	10.6	53.2	63.8	42.6	10.6
Stairs	10.6	34.0	44.7	23.4	10.7
Bathing	17.0	59.6	66.0	42.6	6.4

The items on which the greatest change (in terms of percentage of participants independent) occurred between discharge and six months were mobility and stairs.

4.4.1.5 Change in Severity of Disability

Improvement over time is demonstrated by a reduction in the percentage of patients categorised as severe at admission (63.8%) and six months (17.0%). (See Table 4-20.) At six months post stroke, eight of the 30 patients characterised as severe at admission remained severe (26.7%), nine had moved to the category of moderate disability (30%), nine to the category of mild disability (30%), and four were independent in ADL (13.3%).

Table 4-20 Frequency of Participants in Defined Categories of Disability at Admission, Discharge and Six Months (n=47)*

Category		Admission	Discharge	Six Months
Severe	BI [0-55]	30 (63.8%)	10 (21.3%)	8 (17.0%)
Moderate	BI [60-80)	10 (21.3%)	15 (31.9%)	10 (21.3%)
Mild	BI [85-95]	5 (10.6%)	12 (25.5%)	15 (31.9%)
Independent	BI [100]	2 (4.2%)	10 (21.3%)	14 (29.8%)
TOTAL		47 (100%)	47 (100%)	47 (100%)

***Frequencies and Percentages in this table may differ slightly from those reported at individual time points of assessment, due to only patients with a full data set being included in this analysis (n=47)**

4.4.1.6 Effect of Severity on Change over Time

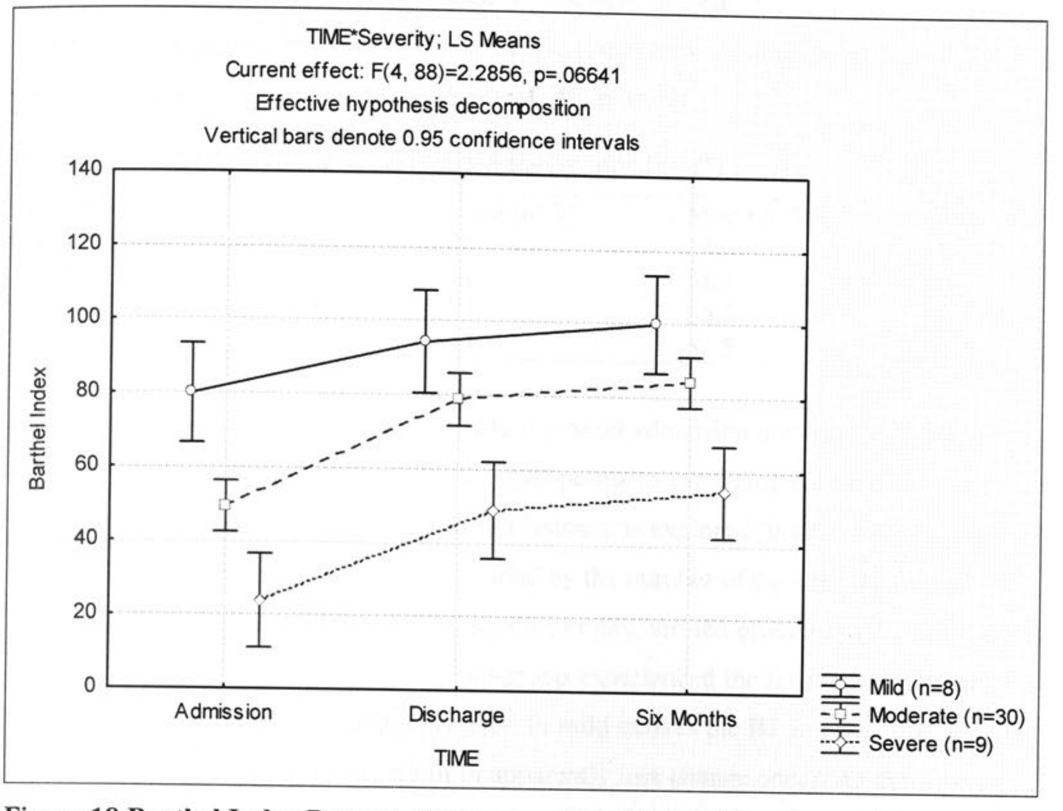


Figure 18 Barthel Index Pattern of Recovery Stratified by Severity at Admission (n=47)

Participants were stratified according to stroke severity at admission: as mild [NIHSS≤6] (n=8), moderate [NIHSS 7-15] (n=30) and severe [NIHSS ≥16] (n=9). A repeated measures ANOVA was used to test for the significance of differences between the three levels of severity over time. (See Figure 18) The BI scores were significantly different for each NIHSS Severity category ($F=18.00$, $p<0.01$), signifying a between-groups difference. BI scores were also significantly different at each time point ($F=72.44$, $p<0.01$), signifying a time effect. However the interaction between severity category and time was not significant ($F=2.29$, $p=0.066$). That is, the three BI profiles were the same across time points for the three severity groups. In other words, the rate of change and relative amount of change was equivalent in each category although the absolute scores were different.

Characteristics of each severity sub-group were explored, but none were found to be statistically significant when tested with the Kruskall-Wallis Test. (Table 4-21). The milder subgroup tended to be younger, have longer onset admission intervals and shorter lengths of stay than the moderate or severe groups. The moderate sub-group tended to have shorter onset admission intervals and shorter lengths of stay than the severe sub-group, and median age was similar. Time post stroke at discharge was similar for moderate and severe sub-groups, but considerably less for the mild sub-group. A statistically significant correlation was found between total NIHSS score (indicating severity) and length of stay (Spearmans rho=0.40, $p<0.05$).

Table 4-21 Characteristics of Severity Sub-Groups (n=47)

Median Values	Mild (n=8)	Mod (n=30)	Severe (n=9)
Onset Admission Intervals	26.5	14.5	18
Length of stay	41	58.5	64
Days post stroke at discharge	73	86.5	84
Age	47	52.5	51.5

From Table 4-21 it is clear that due to differing onset admission intervals and lengths of stay, admission and discharge did not occur at equal points in chronological time. For this reason, relative rate of change over the hospital admission was explored further. Amount of change between admission and discharge was divided by the number of days during the admission, in order to give the average increase in BI scores per day, termed efficiency (Paolucci, Antonucci et al. 2000). It appears that the moderate sub-group experienced the fastest rate of change, followed by the severe and finally the mild. However, in mild strokes the BI on admission approached the maximum BI score and this may result in apparently less change occurring across time. To adjust for this effect, the actual difference in BI scores between admission and discharge was divided by the maximum potential recovery that could be gained (100-admission BI) to provide an effectiveness score reflecting amount of change relative to potential to change (Paolucci, Antonucci et al. 2000). These scores were then divided by the number of days in the admission. The results indicate a clear trend of faster recovery rates in milder strokes. (See Table 4-22)

Table 4-22 Amount and Rate of Change in the Different Severity Sub-groups

	Amount of Change (median)	Effectiveness Score (median)	Efficiency (median)	Effectiveness/ Time (median)
	BI2-BI1	**(BI2-BI1)/ 100-BI1**	**(BI2-BI1)/LOS**	**Effectiveness/ LOS**
Mild	10	1	0.21	0.014
Moderate	30	0.63	0.44	0.0098
Severe	20	0.46	0.30	0.0042

LOS= number of rehabilitation days during admission, BI1= Barthel Index at Admission, BI2=Barthel Index at Discharge

4.4.1.7 Effect of Onset Admission Interval on Change over Time

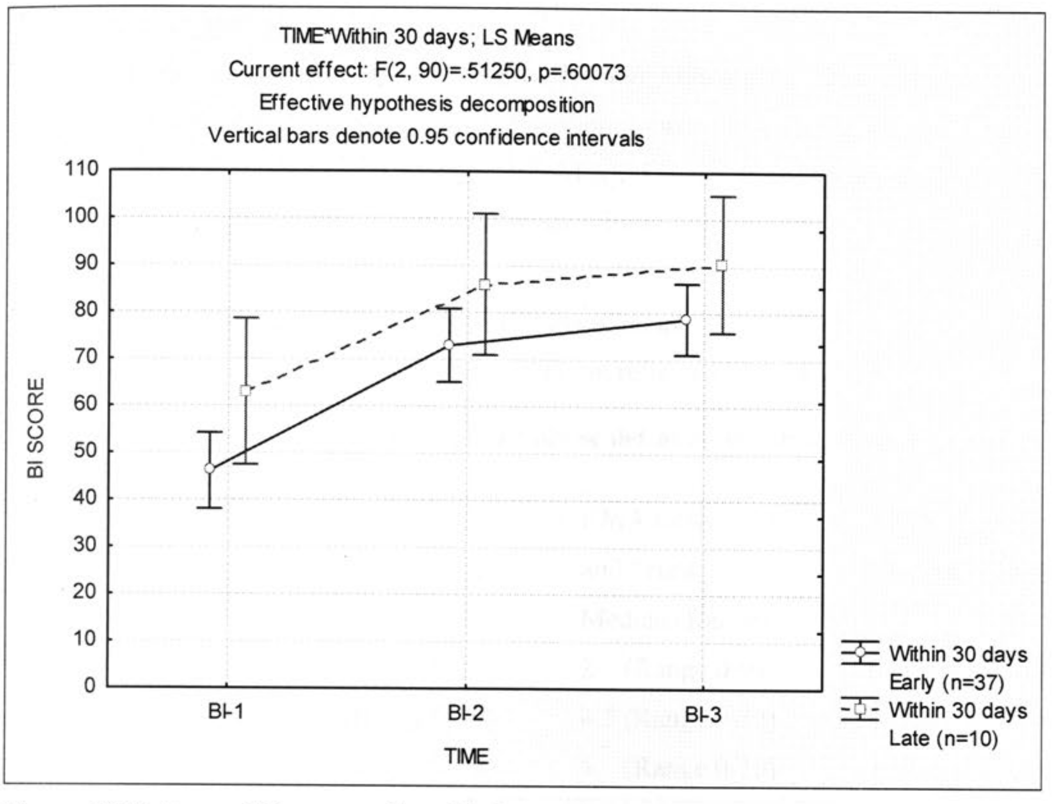


Figure 19 Pattern of Recovery Stratified according to Onset Admission Interval (n=47)

A repeated measures ANOVA was used to test the effect of early (within 30 days) or late admission (after 30 days) on change in BI scores across time. Within each group, differences across time were found to be significant ($F=72.56$, $p<0.01$). However, no significant difference ($F=3.13$, $p>0.05$) was found in BI scores between the two groups at any time point of assessment. That is, disability according to the BI was equivalent between groups. Similarly, the interaction between early/ late admission and change over time was not found to be significant ($F=0.51$, $p>0.05$). That is, the two BI profiles were the same across time points for the group admitted earlier and later after stroke. This implies that the amount of change and the rate of recovery of those who were admitted later was equivalent to that of that of the earlier admissions. (See Figure 19.)

A statistically significant correlation between total NIHSS score (indicating severity) and length of stay (Spearmans rho=0.40, $p<0.05$) has been reported above. However, no significant correlation was found between onset admission interval and length of stay, severity (NIHSS) or age.

4.4.2 Motor Recovery

Motor recovery was measured by the Rivermead Motor Assessment. There are three sub-scales which will be considered separately: Gross Function, Lower Limb and Trunk, and Upper Limb. For each sub-scale, the minimum score is zero. Maximum scores on the sub-scales are 13, 10 and 15 respectively. Higher scores indicate better performance.

4.4.2.1 RMA Scores at each time point of assessment

Median scores for each time point of assessment are reflected in Table 4-23.

Table 4-23 Median and Range Scores for Sub-Scales at Admission, Discharge and Six Months Post Stroke (n=44)

	RMA Gross Median (Range)	RMA Lower Limb and Trunk Median (Range)	RMA Upper limb Median (Range)
Admission	3 (Range 0-11)	2 (Range 0-9)	0 (Range 0-13)
Discharge	6.5 (Range 0-13)	4.5 (Range 0-10)	1 (Range 0-15)
Six Months	10 (Range 0-13)	5 (Range 0-10)	1 (Range 0-15)

A participant with a RMA Gross score of three at admission would typically be able to sit unsupported, move between lying and sitting, and stand up using his/her upper limbs to push off, but would not be able to transfer independently or walk. A patient with a RMA Lower Limb and Trunk score of two would typically be able to turn in bed, but would have poor LL control in lying and standing. In terms of upper limb function, a score of zero denotes no upper limb control, with no ability to hold and place against gravity.

At discharge, a median RMA Gross score of six would typically mean the participant would be able to transfer independently and walk short distances indoors with an assistive device. Such a patient would not be able to walk outside, climb stairs or pick objects up off the floor. The RMA LL and Trunk Sub-scale score of four would typically indicate the patient would be able to roll to either side, would have some lower limb control in lying and may be able to stand up from sitting without using upper limbs. An Upper Limb Sub-scale score of one would indicate the ability to protract the shoulder girdle with support to the upper limb, but would indicate the patient was unable to hold and place the shoulder at 90 degrees of elevation in lying.

A RMA Gross score of ten at six months would indicate in addition to the above abilities, that the patient would be able to walk short distances without an aid, climb stairs independently with a banister, pick objects up off the floor and walk outdoors for a minimum of 40m with an aid. Such a patient would typically not be able to tackle a curb without an assistive device, or a step without a hand rail. A RMA LL and Trunk score of 5 would indicate that in addition to the abilities described above, the patient would have sufficient control in the lying position to step the affected leg off the bed and return it to the starting position again.

4.4.2.2 RMA Gross Sub-scale

4.4.2.2.1 Change Across Time (n=44)

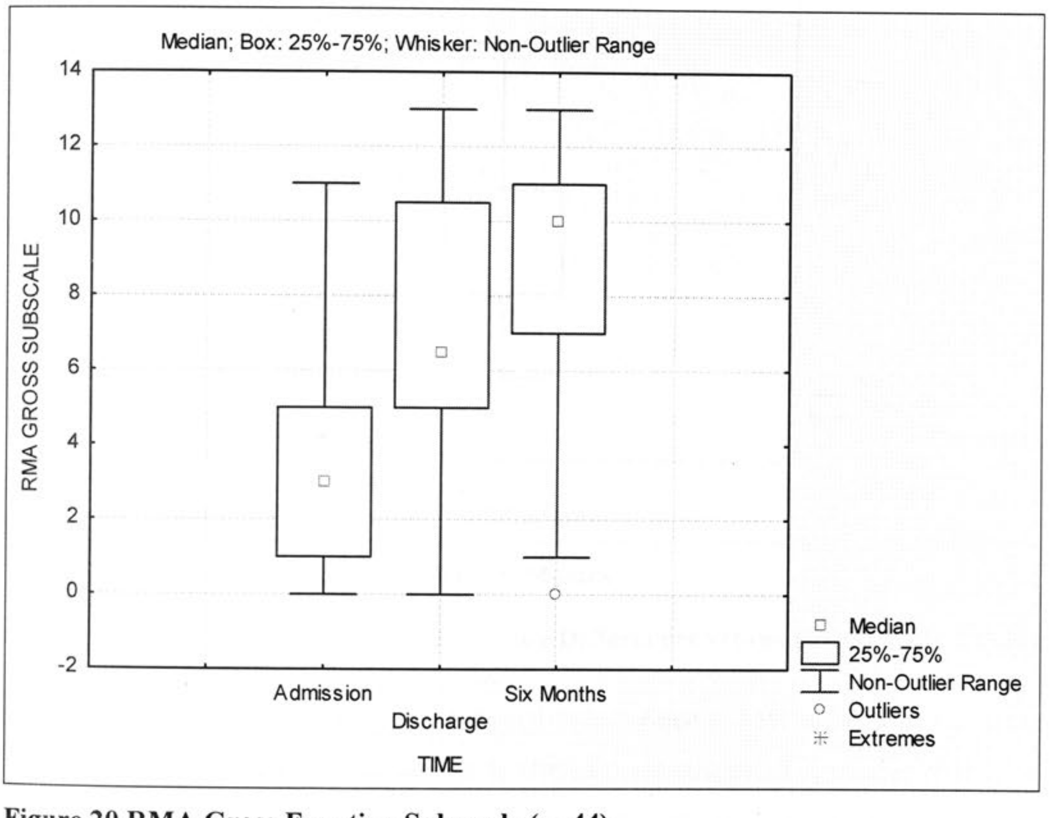
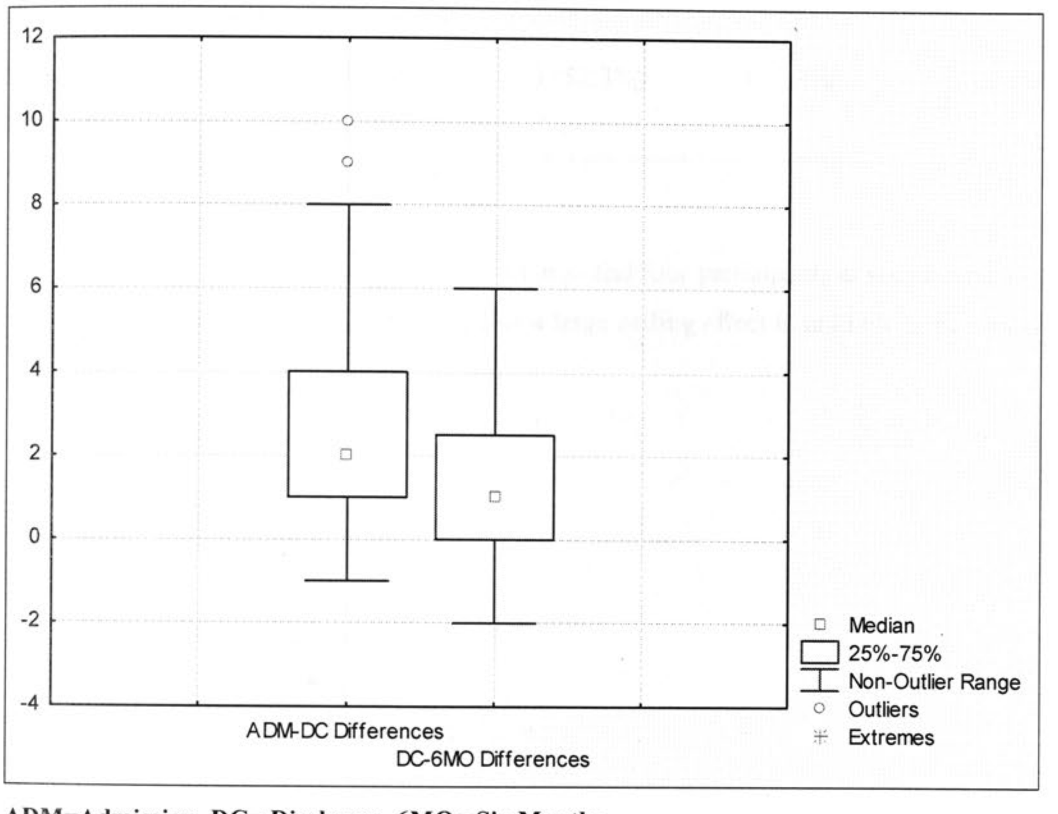


Figure 20 RMA Gross Function Sub-scale (n=44)

The Gross Sub-scale median scores were higher at each consecutive measurement point. Friedman's analysis of variance showed there were significant differences between the time points of assessment (Chi square score= 66.7, $p<0.01$). The Wilcoxon matched pairs test showed there was a statistically significant difference in RMA Gross Sub-scale scores between admission and discharge ($z=5.2$, $p<0.017$) and between discharge and six months ($z=4.5$, $p<0.017$), even when adjusting for multiple comparisons.

4.4.2.2.2 Differences between Time Points

The median of the differences between admission and discharge (i.e. the differences for participants between time points) was two, and the median of the differences between discharge and six months was one. (See Figure 21)



ADM=Admission, DC= Discharge, 6MO= Six Months

Figure 21 Box Plot of RMA Gross Sub-scale Differences Scores Between Time Points (n=44)

If clinically significant change across time points is defined as 15% of the total sub-scale score, a change of 2 or more points is deemed to be clinically meaningful. The median of the differences between admission and discharge falls within this range, but the median of the differences between discharge and six months is only one point. However, this must be interpreted in the light that there were a number of participants who deteriorated or stayed the same between discharge and six months, resulting in a lower median value. Table 4-24 reflects the frequencies of patients considered to have demonstrated clinically significant change across time points.

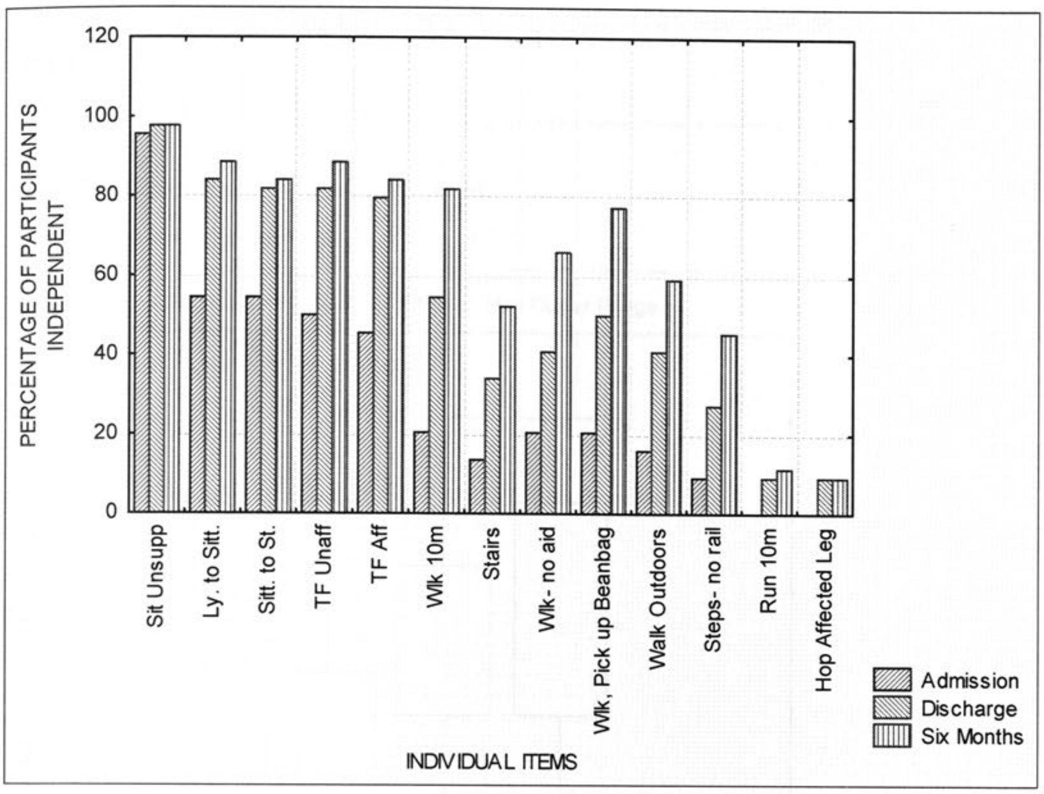
Table 4-24 Frequency and Percentages of Participants Demonstrating Clinically Significant Change*

	Clinically Significant Improvement	No clinically Significant Change	Clinically significant deterioration	TOTAL
Admission-Discharge	31 (70.5%)	13 (29.5%)	0 (0%)	44 (100%)
Discharge- Six Months	20 (45.5%)	23 (52.3%)	1 (2.3%)	44 (100%)

***Defined by change of >15% of total score**

It is noted that only three participants at discharge and four participants at six months had achieved the maximum score, indicating that a large ceiling effect is unlikely to be observed.

4.4.2.2.3 Individual Items on the RMA Gross



Sitt= sit Ly=Lie, St=stand, TF=Transfer, Unaff=unaffected, Aff=affected, Wlk=Walk,

Figure 22 Percentage of Participants Independent for each Item on Gross Sub-scale (n=44)

Most items on the RMA Gross Sub-scale showed change between admission and discharge, and between discharge and six months. Between discharge and six months, the biggest change occurred in the mobility items relating to walking (with and without an aid), stairs, steps, outdoor walking, and picking a beanbag up off the floor.

A higher proportion of participants were independent walkers (indoors, with an aid if necessary) at each time point of assessment. (See Table 4-25)

Table 4-25 Number of Independent Walkers at Each Time Point of Assessment (n=44)

	Number of Participants Able to Walk Independently (percentage)
Admission	9 (20.5%)
Discharge	24 (54.5%)
Six Months	36 (81.8%)

4.4.2.3 RMA Lower Limb and trunk

4.4.2.3.1 Change over Time

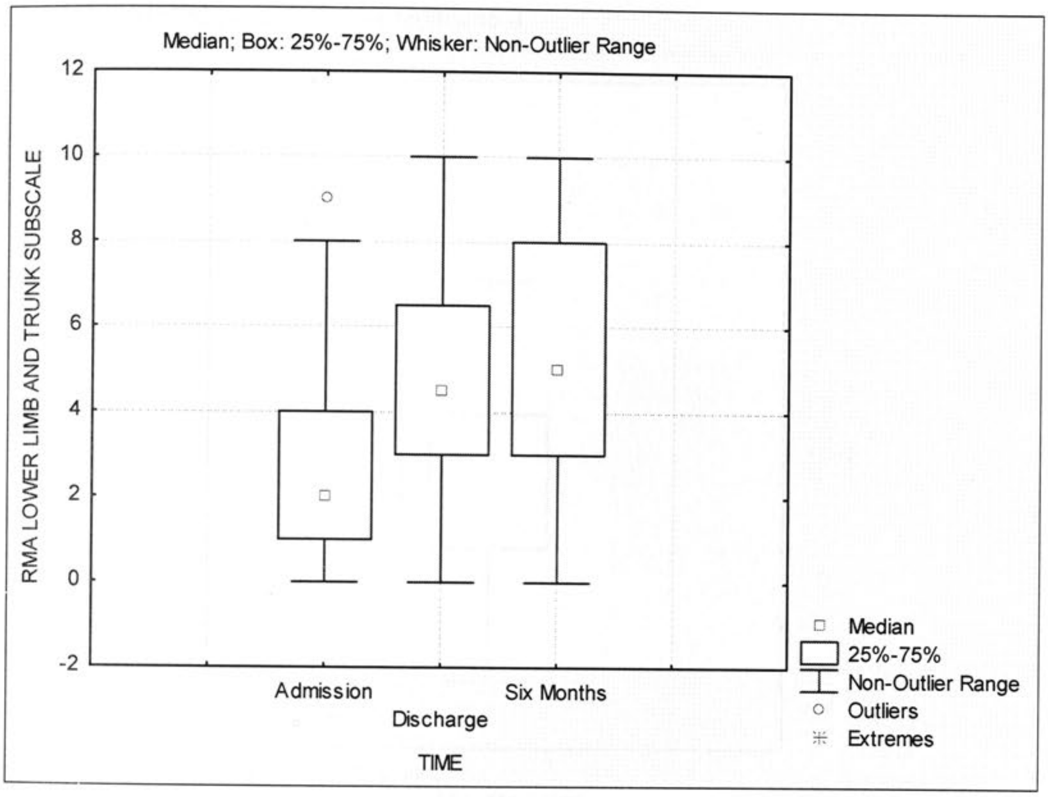
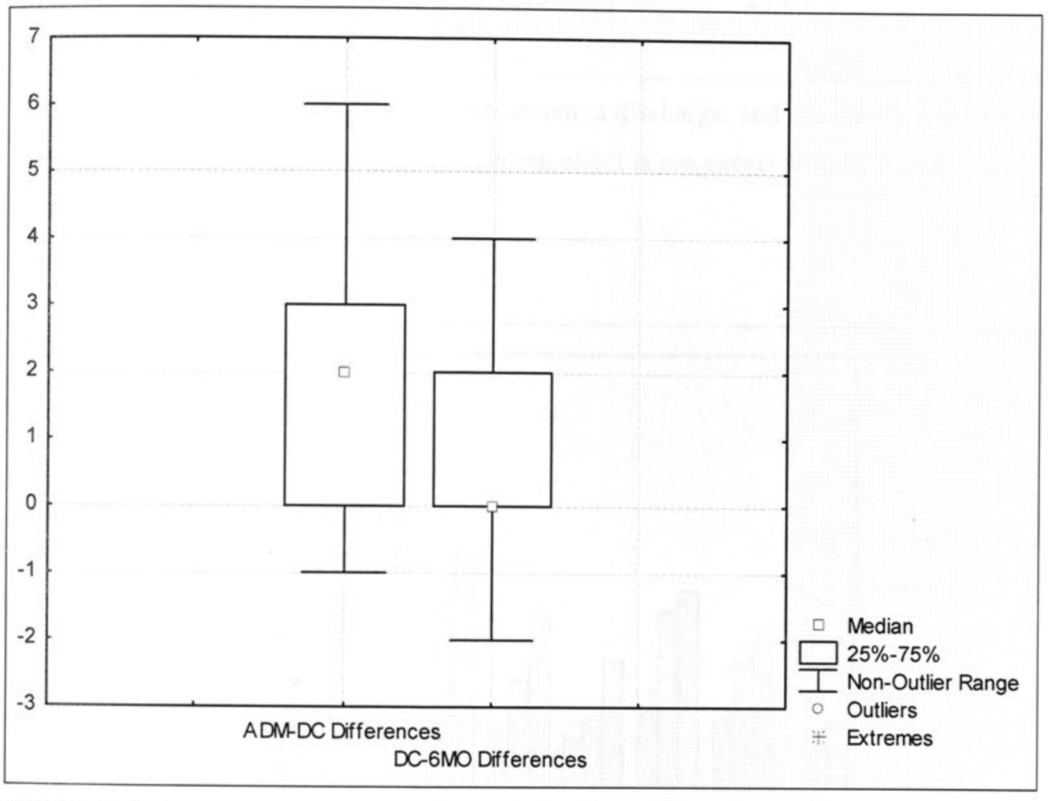


Figure 23 Rivermead Motor Assessment Leg and Trunk Sub-scale (n=44)

The RMA Lower Limb and Trunk Sub-scale demonstrated higher median scores at each consecutive time point. Friedman's ANOVA demonstrated that there were significant differences between Lower Limb and Trunk Sub-scale scores across the three points of assessment. (Chi square= 49.51, $p<0.01$). Subsequent testing of matched pairs by the Wilcoxon matched pairs test demonstrated that there were significant differences in ranks between admission and discharge ($z=4.9$, $p<0.01$) and between discharge and six months ($z=3.0$, $p<0.01$).

4.4.2.3.2 Differences across Time Points

It is noted that the median of the differences between admission and discharge was 2, with a range of -1 to six. This constitutes a 20% increase and is considered clinically significant. The median difference between discharge and six months was zero with a range of -2 to 4. Although it appears contradictory that the median score of the differences should be statistically significant, this should be understood as follows: Firstly, a large proportion of participants stayed the same between discharge and six months resulting in little variability in difference scores. Secondly, the difference across time points occurred in both directions, i.e. some participants improved and some deteriorated, so the median tended to 0.



ADM=Admission, DC= Discharge, 6MO= Six Months

Figure 24 Box Plot of Rivermead Motor Assessment Lower Limb and Trunk Differences between Time Points

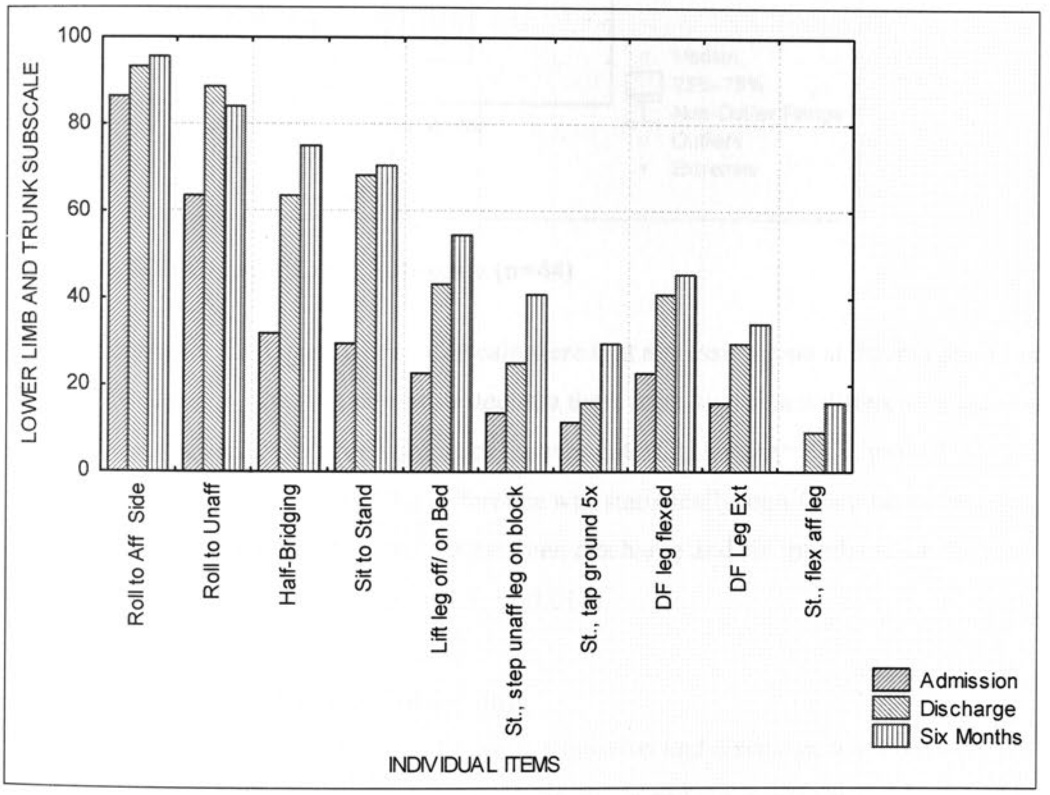
Table 4-26 reflects the frequencies of patients considered to demonstrate clinically significant change across time points where clinically significant change is defined as more than 15% of the total sub-scale score, or a change of 2 or more points.

Table 4-26 Frequencies and Percentages of Participants Demonstrating Clinically Significant Change across Time Points on the RMA Lower Limb And Trunk Sub-scale (Percentages in brackets)

	Clinically Significant Improvement	No clinically Significant Change	Clinically significant deterioration	TOTAL
Admission-Discharge	24 (54.5%)	20 (45.5%)	0 (0%)	44 (100%)
Discharge- Six Months	12 (27.3%)	30 (68.2%)	2 (4.5%)	44 (100%)

Three participants had the maximum score of ten at discharge, and five participants had the maximum score of ten at six months. A ceiling effect is not expected to be biasing results.

4.4.2.3.3 Individual Items



Aff=affected, Unaff=unaffected, St=stand, DF=dorsiflexion, Ext=extension

Figure 25 Individual Items on the RMA Lower Limb and Trunk Sub-scale (n=44)

The percentage of participants able to perform the tasks increased between admission and discharge for all items. To a lesser degree, percentages also increased between discharge and six months with the exception of the item of rolling to the unaffected side, which showed deterioration. The most change was seen on items such as half-bridging, stepping the affected leg on and off the bed in lying, and standing tasks requiring control of the affected hip and knee on weight bearing.

4.4.2.4 RMA Upper Limb (n=44)

4.4.2.4.1 Change across Time

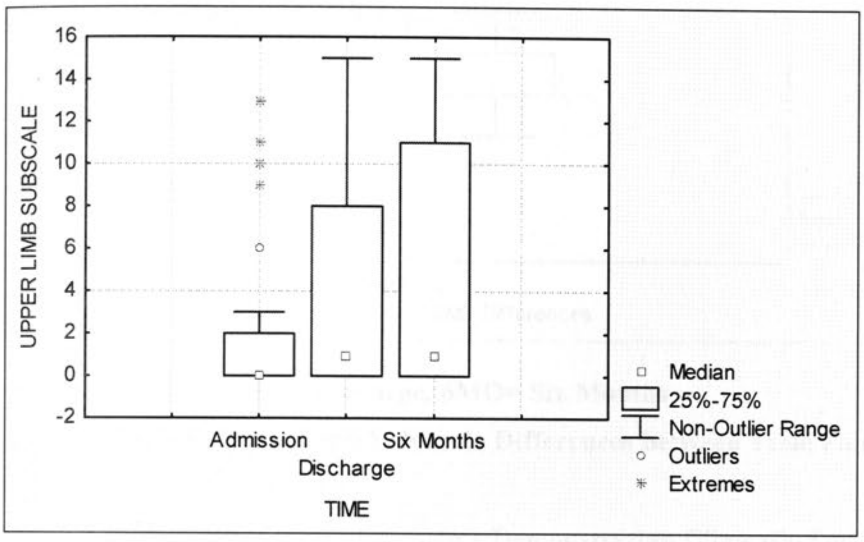
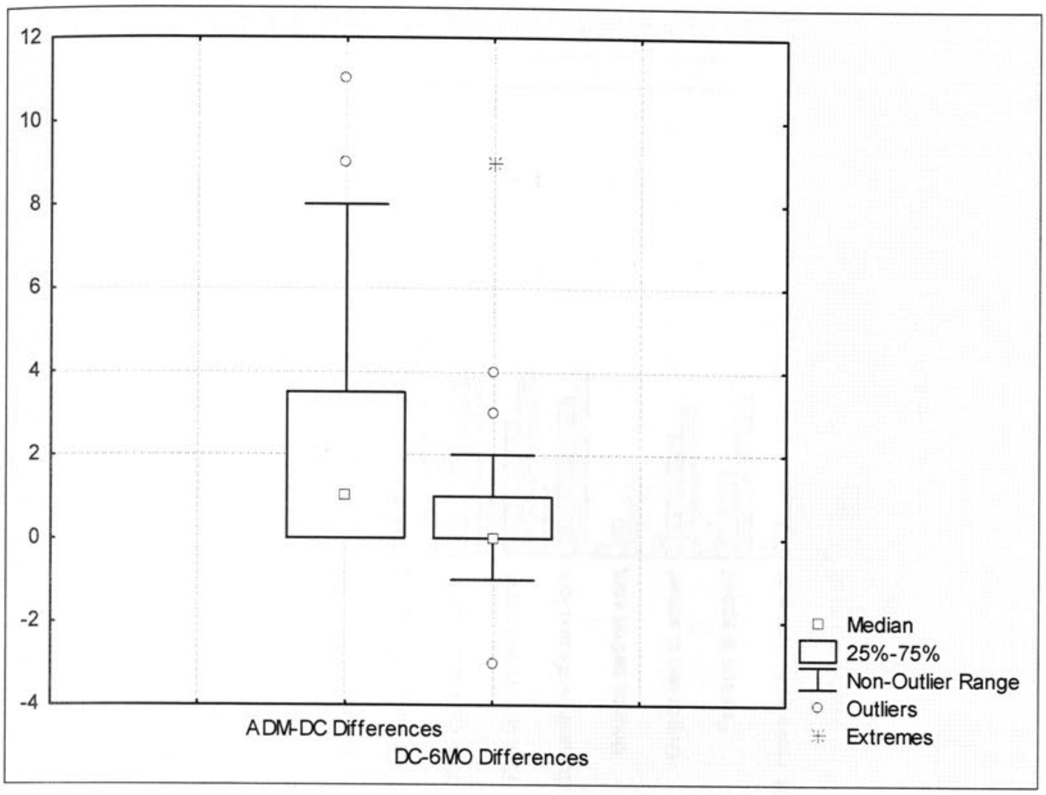


Figure 26 RMA Upper Limb Sub-scale (n=44)

Median scores for the Upper Limb sub-scale were 0 at admission, one at discharge and one at six months. Friedman's ANOVA demonstrated that there were significant differences between Upper Limb Sub-scales across the three points of assessment. (Chi square= 34.3, $p<0.01$). Wilcoxons matched pairs test demonstrated the difference was statistically significant between admission and discharge ($z=4.4$, $p<0.017$), but not between discharge and six months when the p-value was adjusted for multiple comparisons ($z=2.1$, $p>0.017$).

4.4.2.4.2 Differences between Time Points

The median of the differences scores between admission and discharge was one (range 0-11), and the median of the differences scores between discharge and six months was 0 (range -3 to 9). (See Figure 27.)



ADM=Admission, DC= Discharge, 6MO= Six Months

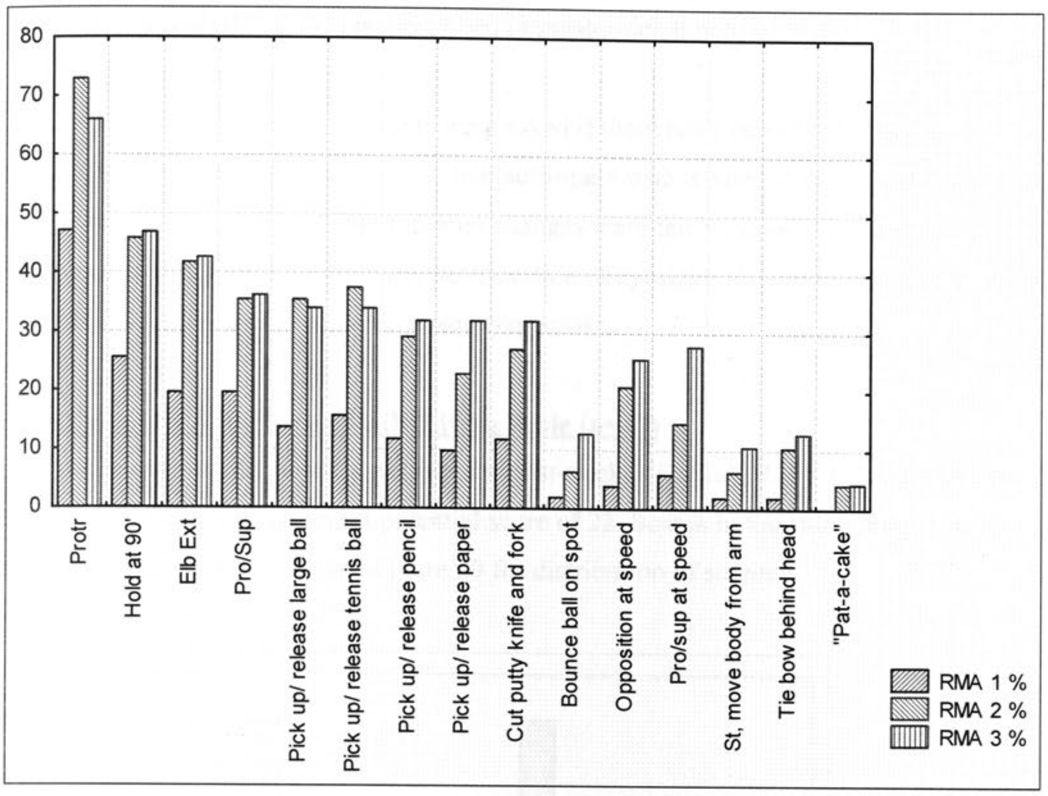
Figure 27 RMA Upper Limb Sub-scale Differences between Time Points

Table 4-27 Frequencies of Participants Demonstrating Clinically Significant Change on the Upper Limb Sub-scale

	Clinically Significant Improvement (%)	No Clinically Significant Change (%)	Clinically Significant Deterioration (%)	TOTAL
Admission-Discharge	15 (34.1%)	29 (65.9%)	0 (0%)	44 (100%)
Discharge- Six Months	8 (18.2%)	35 (79.5%)	1 (2.3%)	44 (100%)

Only one patient had achieved the maximum score for upper limb function at discharge, and one at six months, so a ceiling effect is not expected to be involved here.

4.4.2.4.3 Individual Items



Protr=protraction, Elb=elbow, Ext=extension, Pro=pronation, Sup=supination, St=stand

Figure 28 Individual Items on the Upper Limb Sub-scale (n=44)

Change was seen in terms of the percentage of patients able to perform most items between admission and discharge. A much lesser change was seen between discharge and six months. Certain items demonstrated deterioration between discharge and six months: namely, protraction with the arm at 90 degrees to body in lying, and the ability to pick up and release a large ball, and a tennis ball.

4.5 Outcome at Six Months

Of the 51 participants registered in the study, three patients dropped out of the study at six months and one participant had passed away. Of the remaining 47 participants, one participant was living in an institution, and the remaining 46 were living in the community. Nearly sixty percent (59.6%) of participants required assistance with at least one activity of daily living as defined by the criteria in the Agincourt study (The SASPI Project Team 2004) [10]. Over 80% of participants

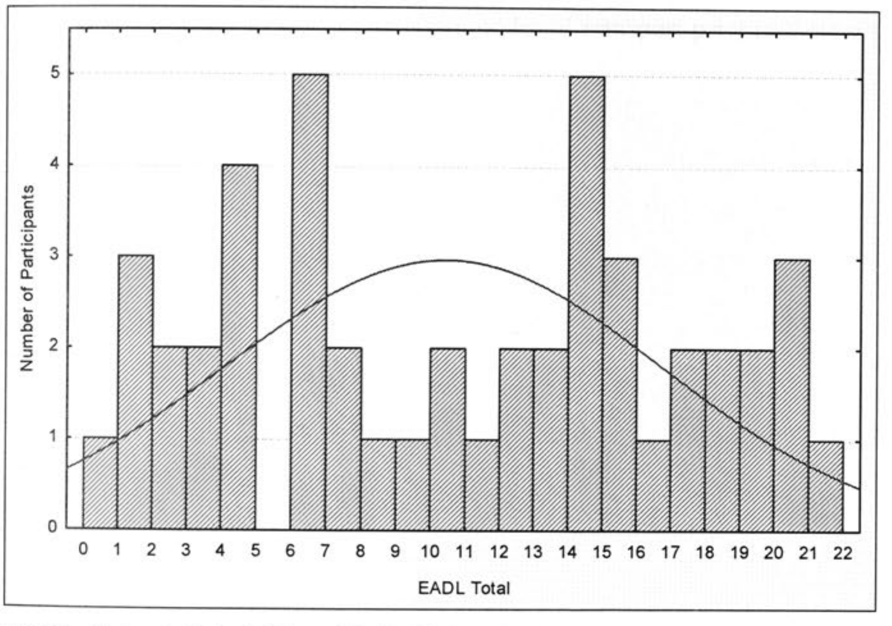
[10] Includes washing, dressing, bathing, feeding, transfer or toileting.

were able to walk short distances indoors (81.8%). Only three patients had returned to work. Specific outcomes of interest will be described in greater detail below.

At the six month assessment, participants were asked if there had been any changes in their health since they were discharged from WCRC. One participant with advanced AIDS had deteriorated markedly since her admission. Other reported changes were fairly minor: a wrist injury following a fall, progression of a knee contracture, deterioration of eyesight, shoulder pain, and amputation of the hallux. No participants reported a recurrent stroke.

4.5.1 Extended Activities of Daily Living Scale (n=47)

This scale was only administered at six months post-stroke. The EADL Scale has a minimum potential score of 0 and a maximum potential score of 22. Scores in the study ranged from 0 to 21, with a median score of 11. (See Figure 29 for distribution of scores.)



EADL= Extended Activities of Daily Living Scale

Figure 29 Extended Activities of Daily Living Scale at Six Months (n=47)

Individual items can be considered in three categories: mobility, household and leisure activities. Independence for individual items is listed in Table 4-28.

With regard to mobility: 68.1% of participants reported that they had walked outside independently, with 57.4% walking over uneven ground, 53.2% had crossed roads independently, and 38.3% reported independent stair climbing.

In the category of household activities, 38.3% of participants reported doing their own housework: 55.3% reported doing the washing up, 40.4% had washed small items of clothing and 27.7% had done a full load of washing. In terms of meal preparation, 46.8% of participants had made themselves a hot snack, 61.7% had made themselves a hot drink and 59.6% could then carry the drink through to another room. Just over a quarter of participants had been involved in managing their own garden or yard (25.5%).

Few individuals were independent in activities outside the home such as shopping (19.1%) and going out socially (25.5%). A third of participants were independent in their use of public transport, and less than 5% had driven a car since their stroke. It is noted that nine participants reported car driving as one of the main modes of transport prior to their stroke according to the Questionnaire at Six Months.

Table 4-28 Independence in Individual Items of the EADL Scale (n=47)

Item	Number of Participants Independent	Percentage of Participants Independent
Mobility		
Walk outside	32	68.1
Climb stairs	18	38.3
Get in and out of car	32	68.1
Walk over uneven ground	27	57.4
Cross roads	25	53.2
Travel on public transport	16	34.0
Household		
Feed yourself	46	97.9
Make a hot drink	29	61.7
Take hot drink from one room to another	28	59.6
Wash up	26	55.3
Make a hot snack	22	46.8
Manage own money when out	28	59.6
Wash small items of clothing	19	40.4
Do own housework	18	38.3
Own shopping	9	19.1
Wash a full load of clothes	13	27.7
Leisure		
Read newspaper/ books	33	70.2
Use telephone	37	78.7
Write letter	8	17.02
Go out socially	12	25.5
Manage own garden	12	25.5
Drive a car	2	4.3

4.5.2 Modified Rankin Score (n=47)

Using the structured interview for the Modified Rankin Scale (MRS) (Wilson, Hareendran et al. 2002), participants were categorized according to severity of disability/ handicap. Scores of zero to five indicate increasing levels of severity i.e. the higher the score, the worse the disability/ handicap. In the study sample, scores ranged from one to five with a median score of three. Frequencies in each category are reflected in the table below.

Table 4-29 Frequency Table MRS (n=47)

Score	Description	Count	Cumulative Count	Percentage
0	No symptoms at all	0	0	0
1	No significant disability	2	2	4.3
2	Slight disability	8	10	17.0
3	Moderate disability	23	33	48.9
4	Moderately severe disability	4	37	8.5
5	Severe disability	10	47	21.3
TOTAL		47	47	100

Ten participants (21.3%) had severe disability at six months implying the need for 24 hour care. Four participants (8.5%) were classified moderately severe and needed assistance with attending to bodily needs (such as toileting, hygiene and eating) or were unable to walk. Approximately half the participants were able to walk and attend to basic needs but required some assistance to look after themselves in terms of meal preparation, housework, shopping, financial management and local travel (48.9%). Eight participants (17.0%) were able to look after their own affairs, but were not able to participate in all their usual roles and activities. Less than 5% of participants were able to carry out all their usual activities. No participants had made a complete recovery in that all participants reported some residual symptoms since their stroke.

A high proportion of participants reported a change in their abilities to fulfil previous roles. See Table 4-30.

Table 4-30 Frequencies of Participants Reporting Changes in Role Since Stroke According to the MRS Structured Interview Responses (n=46)*

	Unable	Reduced Ability	No Change	Not Previous Role	TOTAL
Leisure and Social	7 (15.2%)	31 (67.4%)	7 (15.2%)	1 (2.2%)	46 (100%)
Family Life	14 (30.4%)	13 (28.3%)	6 (13.0%)	13 (28.3%)	46 (100%)
Work/ looking for work	18 (39.1%)	10 (21.7%)	2 (4.3%)	16 (34.8%)	46 (100%)

***data relating to pre stroke role was not available for one aphasic patient, therefore it was not possible to express change in role, and the patient is excluded from this analysis**

Approximately 83% of participants reported there had been a change in their ability to participate in social and leisure activities following their stroke: Approximately 15% felt completely unable and 67.4% less able. With regard to family life, approximately one third of participants felt they were completely unable to take participate (30.4%), and a similar proportion reported reduced capacity (28.3%). With regard to family and friendships: thirty-eight participants (82.6%) reported that they had experienced problems with relationships or feelings of isolation after their stroke. Of the participants reporting difficulties in this area (n=38), 37 % reported that there had been similar problems before the stroke.

Thirty of the participants interviewed had been working or looking for work before their stroke. Nearly all of these patients reported a change in their ability to work (93.3%). However, approximately a third felt they would still be able to work albeit in a reduced capacity. Only two patients felt there had been no change in their ability to work.

4.5.3 <u>Place of Residence (n=47)</u>

At six months post stroke, 39 patients (83.0%) were living in the same residence as prior to their stroke, seven were living in an alternative home (14.9%) and one patient was in an institution (2.1%). The reasons most frequently given for change in abode were that the home was not suitable, or that no carer was available at previous residence (n=6). Two participants had moved for reasons unrelated to their stroke.

Characteristics of the participants who did not return to their own home are listed in Table 4-31. Features of their previous homes that may have contributed to the home being unsuitable are also described.

Table 4-31 Characteristics of Participants Who Did Not Return to Live at Previous Home for Reasons Relating to Their Stroke (n=5)

Age	Gender	BI at Six Months	MRS at Six Months	Living alone prior to stroke	Features of Home Environment Pre-stroke
54	male	100	2	no	No electricity, running water indoors, bathroom facilities or indoor toilet
55	female	90	4	yes	No electricity, running water indoors, bathroom facilities or indoor toilet
69	female	50	5	no	No inside toilet
65	female	95	3	yes	No running water indoors, indoor toilet or bathroom facilities
51	female	25	5	no	No bathroom facilities

The patient living in an institution at the time of the six month assessment, had a BI score of 0, and an MRS of 5. She had been discharged directly into institutionalized care from the WCRC. She had advanced AIDS, but prior to her stroke she had a proxy-reported BI score of 100.

4.5.4 Return to Work or Productive Activity (n=47)

At six months post stroke, three participants had returned to work and 44 patients were not working.

Of the three participants who were working at the time of the six month assessment, two participants were domestic workers that had returned to full time employment. One participant reported she was not able to conduct all her usual duties and as a result was being paid less. The other participant was able to carry out all her previous duties. Both these patients had complained of shoulder pain that interfered with their work, but neither had had any follow up since discharge and there was no pending review at WCRC. The third participant was self-employed as a vendor of fruit and vegetables (approximately four hours per week). She continued to earn some income from this, but reported that she was unable to travel as far to sell her wares. She also assisted in a family business (unpaid). All three participants who were working at six months had MRS scores of 1 or 2, and BI scores of 100.

Forty-four participants were not working at the time of the six month assessment. Of this sub-group, one was looking for work, 28 were unable to work due to disability and 12 were retired. One participant had never worked and described herself as looking after the home. One participant had returned to work, but had subsequently been retrenched, although he reported his retrenchment was unrelated to his stroke. Another participant was about to return to work in a reduced capacity within the next week.

Table 4-32 Return to Paid Work: Comparison of Pre and Post Stroke (n=51)

	Pre Stroke (n=51)	Post Stroke (n=51)
In paid Employment	29	3
Retired	13	12
Looking after the Home	5	1
Unemployed, looking for work	2	1
Unable to work due to disability	2	28
Other	0	2
Missing/ RIP	0	4
TOTAL	51	51

Return to work outcomes are of particular interest for participants who were working prior to their stroke, and had MRS scores of 1 or 2 at six months indicating no or slight disability (n=9). At six months post stroke, only three of these nine patients were working, Of the six participants who were not working, three felt unable to work, two reported reduced capacity, and one patient felt there had been no change (according to responses in the MRS structured interview). These patients all had BI scores of 90 to 100, and four of these patients had no identified cognitive deficit. Type of work included: carpenter, printing works technician, brick maker, driver, chef and secretary.

Although a low percentage of patients were involved in paid work at six months (6.4%), a number of patients had been involved in unpaid productive activity of another kind. This data was available from an item on the Questionnaire at Six Months. Only 45.7% of participants were neither working nor participating in any productive activity.

Table 4-33 Participation in Unpaid Work or Productive Activity (n=46)*

	No of Participants	Percentage
Unpaid volunteer work	6	13.0
Unpaid work in a family business	3	6.5
Caring for others	13	28.3
Work around the home or garden	24	52.2
TOTAL	46	100

***One of the participants followed up at six months was unable to respond to the questionnaire due to severe aphasia. She passed away two days after the assessment, and due to her bereavement, her daughter was not interviewed as proxy. Data is therefore missing for this patient.**

4.5.5 Health Related Quality of Life (n=44)

In addition to the four participants for whom data is not available at six months, three participants with severe language or cognitive deficits were unable to respond to the questionnaire. Proxies were not asked to respond on their behalf in order to avoid introducing bias (Dorman, Waddell et al. 1997c).

Participants reported problems in all domains (Table 4-34), with the least problems being reported in the domain of self-care. Ability to perform usual activities was the most affected with 27% reporting severe problems in this domain.

Table 4-34 Frequency of Participants Reporting Difficulty with Individual Items on the EQ-5D (n=44)

	No problems	Some	Severe
Mobility	21 (47.7%)	21 (47.7%)	2 (4.5%)
Self-Care	31 (70.5%)	10 (22.7%)	3 (6.8%)
Usual Activities	17 (38.6%)	15 (34.1%)	12 (27.3%)
Pain/ Discomfort	18 (40.9%)	23 (52.3%)	3 (6.8%)
Anxiety/ Depression	22 (50.0%)	17 (38.6%)	5 (11.4%)

Visual analogue scores of perceived health state ranged from 30 to 100, with a mean of 71.1 ± 18.7 SD. Seven patients indicated the maximum score of 100.

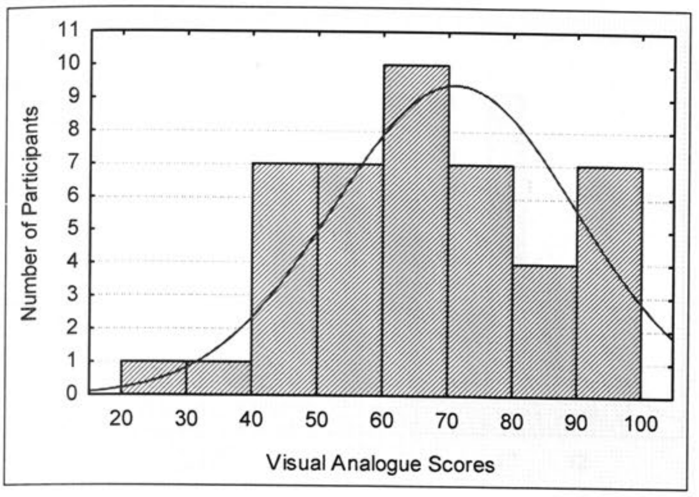


Figure 30 Histogram of EQ-5D Visual Analogue Scores (n=44)

4.5.6 Caregiver Strain Index (n=42)

In addition to the patients who had dropped out of the study and have already been described, one participant claimed not to have a caregiver, and four caregivers did not return the questionnaires despite a reminder letter. Data was available for the caregivers of 42 patients. Thirty-nine caregivers were close relatives (spouse, child, parent or sibling), two caregivers were extended relatives (nieces), and one caregiver was a friend. Approximately 90% of caregivers were women.

The Caregiver Strain Index has a minimum score of 0 and a maximum score of 13. Caregivers with a score of 7 or above are considered to experience significant strain (Blake, Lincoln and Clarke 2003) and 55.8% of respondents fell in this category. Scores in the sample ranged from 0 to 13, with a median score of seven. (See Figure 31)

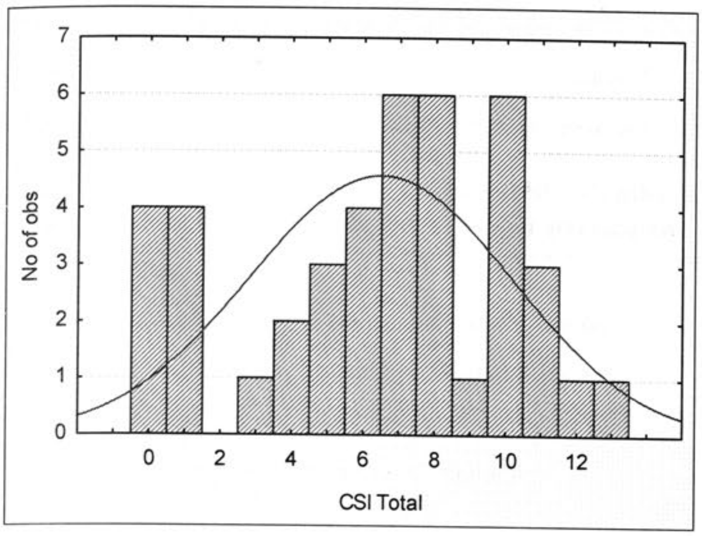


Figure 31 Distribution of CSI Scores (n=42)

Individual items are listed in Table 4-35 in order of reported frequency:

Table 4-35 Frequency of Reported Difficulties for Individual Items on the CSI (n=42)

Item	No of Participants Reporting Difficulty	Percentage
Upsetting that the patient has changed	32	76.2
Financial strain	28	66.7
Changes in Personal Plans	26	61.9
Emotional Adjustments	24	57.1
Work adjustments	23	54.8
Other demands on my time	22	52.4
It is confining	20	47.6
Family Adjustments	20	47.6
Upsetting behaviour	19	45.2
Feeling completely overwhelmed	16	39.0
It is inconvenient.	15	35.7
Physical Strain	15	35.7
Sleep is disturbed.	11	26.2

There was no statistically significant correlation of the CSI with any of the other outcome measures at six months (BI, RMA Gross, MRS, EADL or EQ-5D Visual Analogue Score). Socio-economic status in terms of education and household income were similarly found to be unrelated to CSI. There was a statistically significant but low correlation between CSI and initial stroke severity (Spearman's rho=0.32, $p<0.05$) i.e. the greater the initial severity, the more problems reported on the CSI. No relationship was observed between the presence of a cognitive deficit and reports of caregiver strain (CSI $\geq$ 7). (Pearson Chi Square=0.66, $p>0.05$).

4.5.7 Other Issues Arising at Six Months

Although not one of the initial objectives of the study, listed below are the issues that arose at the six month assessment that required the researcher to act or refer on to the appropriate channels.

Table 4-36 Frequency of Issues Arising at Six Months (n=47)
Note that more than one issue can arise per participant

Query/ problem	Frequency	Percentage
Enquiries re access to more treatment/ rehabilitation	10	21.3
Query re disability grant, housing or financial issues	7	14.9
Requires walking aid review or assessment for AFO	6	12.8
Medication enquiry or other medical enquiry	4	8.5
Shoulder pain	3	6.4
Social problems involving domestic violence	2	4.3
Sexual dysfunction	2	4.3
Requires assessment for upper limb splint	1	2.1
No queries or problems reported	17	36.2

The most common issues to arise were enquiries related to further treatment, finances or grants, as well as the review of walking aids.

4.6 The Environmental Context of Functioning

4.6.1 Living Environment at home

Characteristics of the living environment of the 46 community living participants assessed at six months are described in Table 4-37. Forty participants were in formal housing (86.9%), and six in informal housing (13.0%).

Table 4-37 Features of Housing and Access to services in Community Living Participants at Six Months (n=46)

	YES	NO
Electricity*	44 (95.7%)	2 (4.3%)
Running water indoors*	41 (81.9%)	5 (10.9%)
Bath or shower facilities*	44 (73.9%)	12 (26.1%)
Indoor toilet*	35 (76.1%)	11 (23.4%)
Steps or stairs to enter	23 (50.0%)	23 (50.0%)
Stairs indoors	2 (4.3%)	44 (95.7%)
Split level indoors (steps)	5 (10.9%)	41 (89.1%)

***Figures differ from those in Table 4-7 as community living participants may not have returned to their previous abode**

Nine participants had to walk over uneven ground or negotiate stairs in order to get to the toilet. Eight participants (17.45%) who relied on their wheelchairs to get around were unable to get to their toilet in their wheelchair due to the layout of their home.

4.6.2 Perceived Environmental Barriers/ Facilitators

Perceived environmental barriers or facilitators were reported using the Environmental Questionnaire which was developed for use in the study and is based on ICF concepts. In addition to the four participants who were not available for assessment at six months, three participants with severe cognitive or receptive language problems were excluded from this analysis (n=44). Due to the subjective nature of the questionnaire, proxies were not asked to respond on behalf of the patient, in order to prevent bias.

The most frequently reported barriers to function were finances (n=26) and transport (n=26). A relatively small number of patients reported their living environment (n=11), or the terrain outside their homes (n=15) as a barrier to function. Eight participants reported lack of equipment to be a barrier. The majority of participants indicated that their living environment at home was suitable (79.5%). It is noted that some items were reported as both barriers and facilitators; this will be explored further in the discussion.

Table 4-38 Frequency of Reported Environmental Barriers and Facilitators (n=44)*

Item	Barrier	Facilitator
Finances	26 (59.1%)	15 (34.1%)
Transport	26 (59.1%)	30 (68.2%)
Living environment at home	11 (25.0%)	35 (79.5%)
Outdoor terrain	15 (34.1%)	30 (68.2%)
Equipment	8 (18.2%)	35 (79.5%)

***Note: Some items were reported as both barriers and facilitators by the same participant**

In terms of the social and attitudinal environment, attitudes of others were reported to be a barrier to participation for 21 patients. (See Table 4-39) However, the majority of participants reported receiving support from spouse and family, friends and community. (See Table 4-40) Five participants (11.4%) reported they had not received support from any of the above.

Table 4-39 Frequency of Participants Reporting Attitudes of Others to be a Barrier to Function (n=44)

	Frequency	Percentage
Attitudes prevent leisure and social activities	8	18.2
Attitudes prevent work or studies	6	13.6
Attitudes prevent family participation	7	15.9

Table 4-40 Frequency of Participants Reporting Support from Others to be a Facilitator to Function (n=44)

	Frequency	Percentage
Support from spouse and family	37	80.4
Support from friends	36	78.3
Support from community	29	63.0
Support from colleagues/ employers	14	30.4

Only eight participants reported no barriers to function. A chi-square test of association demonstrated that there was an association between the presence of at least one reported barrier, and an unfavourable outcome on the MRS as defined by MRS≥2 (Chi-square=4.14, p=0.04). A cut off point of MRS≥2 was selected as it signifies the difference between slight and moderate disability.

Further data regarding individual reported barriers will be presented in greater detail below. Supplementary information from the Questionnaire at Six Months is included to give contextual background.

4.6.3 Finances

Finances were described by 59.1% of participants as a barrier to participation. This should be seen in the context that only three participants were in paid employment at six months, meaning that the remaining 43 participants would be reliant on grants or other sources of income. Twelve participants were retired and should be eligible for pension pay outs. However, of the 28 who were unable to work, only ten participants were in receipt of a disability grant at six months post stroke. One participant was still receiving a pay out from his work, and applications for the remaining 17 were still pending. (This data was obtained from the Questionnaire at Six Months.) Furthermore, eight participants reported cancelling or postponing medical care due to financial reasons.

4.6.4 Transport

Supplementary information collected from the Questionnaire at Six Months revealed that most participants had used a number of different means of transport prior to their stroke depending on where they were travelling. After their stroke many patients reported that they were more limited in terms of which modes of transport they were able to access. For example there was a reduction in the number of participants using buses, trains and minibus taxis. There was an increase in the number of participants travelling as passengers in a car and a number of patients were pushed in their wheelchairs to their destinations. This is reflected in Table 4-41.

Table 4-41 Frequency of Participants Accessing Modes of Transport Before and After Stroke (n=46)*

Mode of Transport	Before CVA	After CVA
Minibus Taxi	32	20
Bus	9	1
Train	10	5
Car, driver	9	1
Car, Passenger	11	31
Bicycle	1	0
Walked	26	13
Pushed in wheelchair	0	10
Other	0	0

***Participants reported up to three modes of commonly used transport**

Thirteen patients reported in the Questionnaire at Six Months that they had to cancel or postpone a medical appointment due to lack of transport.

4.6.5 Living Environment at Home

Eleven patients identified their living environment as being a barrier to function. Five of these participants were living in informal housing. A chi-square test of association demonstrated that there was a significantly higher proportion of patients living in informal housing in the group that reported living environment as a barrier, compared to the group that did not report living circumstances as a barrier (Pearsons chi-square=13.38, $p<0.05$). Repeated significance testing was not carried out on individual features of the homes where patients had reported the environment to be a barrier to function, in order to avoid finding spurious associations. Furthermore the number of participants in each category was small.

However, the following characteristics were noted in the subgroup who reported living environment as a barrier (n=11). All homes had electricity. Less than half of homes had an indoor toilet (n=5) and less than a third had running water indoors (n=3). The majority of homes (n=10) did not have bathroom facilities (no bath or shower) or facilities were inaccessible because they were upstairs. Seven participants needed to cross uneven ground or negotiate stairs to get to the toilet, and 6 participants who were wheelchair dependent were physically unable to get to their toilet with their wheelchair. (This data was obtained from the Questionnaire at Six Months).

4.6.6 Outdoor Environment

Fifteen patients (approximately one third of the sample) reported that the environment outdoors was a barrier to outdoor mobility. A chi-square test of association showed that there was a negative association between reporting of the outdoor environment as a barrier, and the frequency of participants walking independently outdoors at six months (Pearson Chi-square=5.9, $p<0.05$).

4.6.7 Equipment

Eight patients reported lack of equipment as a barrier. Four patients had started walking and felt they needed a walking aid or AFO. One patient was awaiting an orthopaedic knee splint from the orthopaedic workshop; three patients did not specify which equipment they were lacking.

4.7 Factors influencing MRS at Six Months

4.7.1 Data Exploration

The MRS at six months was selected as the dependent variable. Bivariate analysis was conducted to investigate if there was an association between MRS at six months and a number of independent variables. The MRS (0-5) was treated as an ordinal scale in order to use the full range of data. Spearman's rank order correlation co-efficient was used for continuous independent variables, and Mann-Whitney U Tests were used for categorical independent variables.

The following factors were found to have a significant association with MRS scores at six months: severity of stroke at admission (NIHSS), disability on admission (BI), monthly income, the presence of a cognitive deficit, the presence of at least one reported environmental barrier, urinary incontinence and sitting balance at admission (Table 4-42). Other factors that were tested but were found not to be significant included dysphasia, swallow and dysarthria. There was no correlation between number of rehabilitation days and MRS scores at six months.

Table 4-42 Bivariate Testing of the Influence of Selected Independent Variables on MRS Total Scores.
***Values in bold text were significant at p<0.05 (n=47)**

Variable	Nature of Variable	Where applicable: no per group	Test	Value	Significance
Age	Continuous	-	Spearmans rho	r= 0.28	p>0.05
Severity of Stroke according to NIHSS	Continuous	-	Spearmans rho	**r= 0.61**	**p<0.05***
Onset Admission Interval	Continuous	-	Spearmans rho	r=0.19	p>0.05
Number of Rehabilitation Days	Continuous	-	Spearmans rho	r=0.23	p>0.05
HIV/ AIDS status	Categorical	5 Known +ve 42 Known –ve/ unknown	Mann Whitney- U	Adj z=0.57	p>0.05
BI at Admission	Ordinal		Spearmans rho	**r=-0.73**	**p<0.05***
Housing (pre stroke)	Categorical	40 Formal 7 Informal	Mann Whitney- U	adj z= 0.13	p>0.05
Income (n=45)♦	Categorical	25<R1000/month 20≥R1000/month	Mann Whitney- U	**adj z= -2.08**	**P<0.05***
Cognitive deficit	Categorical	21 no 27 yes	Mann Whitney- U	**adj z=2.52**	**P<0.01**
Environmental barriers ∝	Categorical	yes 39 no 8	Mann Whitney- U	**adj z=2.67**	**P<0.01**
Co-morbidities#	Categorical	Yes 23 No 24	Mann Whitney- U	adj z=1.43	p>0.05
Gender	Categorical	Male 20 Female 27	Mann Whitney- U	adj z=0.47	p>0.05
Urinary continence at admission	Categorical	Continent 29 Incontinent 18	Mann Whitney-U	**adj z=-2.96**	**P<0.01**
Sitting balance at admission	Categorical	Able to sit 45 Unable to sit 2	Mann Whitney-U	**adj z=-2.90**	**P<0.05**

♦ n=45 for this item due to two participants declining to answer the question regarding income
∝ Defined as the presence of at least one reported environmental barrier

defined by presence of at least one of the following: diabetes mellitus, HIV/AIDS, IHD, pulmonary disease, musculoskeletal disease or visual impairment

A correlation analysis (Spearmans Rho) was conducted to test for correlations between continuous variables (Table 4-43). A strong negative correlation was found between number of rehabilitation days and BI and NIHSS scores at admission, respectively. That is, strokes that were more severe tended to have longer rehabilitation stays. Onset admission interval and age were not correlated with any other factor.

Table 4-43 Correlation Analysis of Relationships between Variables

	BI-1	Total No of Rehab Days	Stroke Admission Interval	NIHSS Total	Age
Barthel Index on Admission	1.00	***-0.47****	0.12	***-0.66****	-0.23
Total Number of Rehabilitation days	***-0.47****	1.00	-0.14	***0.39****	-0.13
Stroke Admission Interval	0.12	-0.14	1.00	0.13	-0.14
NIHSS Total	***-0.66****	***0.39****	0.13	1.00	-0.05
Age at assessment	-0.23	-0.13	-0.14	-0.05	1.00

*** denotes significance at p<0.05**

4.7.2 Multivariate Analysis

The MRS was selected as the dependent variable of interest. As a six point ordinal scale, it was not suitable for analysis by linear regression. For this reason, scores were dichotomised into favourable outcome MRS≤2 (n=10), and unfavourable outcome MRS>2 (n=37), and a logistic regression analysis was performed. The specified cut off point distinguishes between participants with no or mild disability, and those with moderate to severe disability.

Factors that were found to be statistically significant, or approached statistical significance (P<0.05) in the data exploration (Table 4-42 and Table 4-43) were considered for entry into the logistic regression, as well as age which is frequently reported in literature. Sitting balance was not included as only two participants were unable to sit at admission. When the factors of interest and age were entered individually into a logistic regression equation, only the NIHSS (Chi Square 10.62, p=0.011), severity of disability at admission (BI), number of rehabilitation days (Chi Square 7.71, p=0.0055) and the presence of at least one environmental barrier were seen to be significant (Chi Square 4.08, p=0.043).

Table 4-44 Table of Odds Ratios for Factors Entered Individually into the Logistic Regression Model.

***indicates significance at p<0.05**

FACTOR	ODDS RATIO	CI
NIHSS*	**0.70***	**0.53-0.94**
Age	0.98	0.94-1.04
Onset Admission Interval	0.95	0.89-1.02
Number of Rehabilitation Days*	**0.96***	**0.92-0.99**
Income Category	2.25	0.52-9.85
Housing	0.28	0.049-1.63
Cognitive deficit	3.83	0.82-18.03
Environmental barrier*	**0.18***	**0.034-0.98**
Co-morbidities#	0.63	0.15-2.72
Gender	0.68	0.16-2.88
Barthel Index on Admission*	**1.07***	**1.03-1.13**
HIV Status	1.09	0.10-11.75
Urinary Incontinence	0.13	0.01-1.21

#defined by presence of at least one of the following: diabetes mellitus, HIV/AIDS, IHD, pulmonary disease, musculoskeletal disease or visually impaired.
CI= Confidence Interval

The NIHSS odds ratio (OR) of 0.70 indicates that for every 1 unit increase in NIHSS, the odds of a favourable outcome are 0.70 times as likely as they are for someone with one point less. That is, with every other factor being identical, a one point increase in NIHSS reduces the probability of a favourable outcome by 30%. The confidence interval indicates that there is a 95% probability that the true odds ratio lies between 0.53 and 0.94.

The odds ratio for number of rehabilitation days was 0.96. This means that for every additional day spent in rehab, the odds of achieving a favourable are multiplied by 0.96 i.e. there is a reduction in the probability of a favourable outcome by 4.0%. A narrow confidence interval for the odds ratio suggests certainty about the size of the effect (0.92-0.99). However, number of rehabilitation days was also found to be significantly correlated with severity of stroke (Spearmans rho=0.39, p<0.05), with more severe strokes at onset having longer rehabilitation stays. Therefore the apparent effect of number of rehabilitation days may be due to the association with severity of stroke, rather than a true relationship, especially as literature suggests that rehabilitation improves outcomes. Fitting severity of stroke and number of rehabilitation days into the same model should adjust for these interrelationships, but this was not observed as neither factor retained its significance and the chi-square of the model increased indicating the model itself had not improved. With the small sample size and the number of potential influencing factors, it is possible there was not enough power to untangle the interrelated effects of different factors.

The odds ratio of 0.18 for environmental barriers suggests that the presence of at least one environmental barrier reduces the probability of a favourable outcome by 82%. However, closer inspection of the confidence intervals indicates that there is a 95% chance that the OR for environmental barriers falls between 0.03 and 0.98. That is there is some uncertainty about the size of the effect- it could be very small or very large. By contrast, the BI had an odds ratio of 1.07, indicating a smaller effect size, but with a narrow confidence interval there is greater certainty of the size of the effect. Better functional ability at admission (BI) was shown to be a positive predictor of outcome. For every one point increase in BI with all other variables remaining constant, the odds of achieving a favourable outcome increases by 7%. For every 5 point increase in BI the odds of a favourable recovery increase by 43%.

In summary, the clearest predictors for outcome in this sample were the presence of an environmental barrier (Chi square 7.71, $p<0.05$), NIHSS (chi square 10.62, $p<0.05$) and BI at admission (Chi square 15.92, $p<0.05$). It was not appropriate to fit NIHSS and BI Admission scores in the same model due to a strong correlation between these measures (Spearmans rho=-0.66, $p<0.05$). Similarly, total number of rehabilitation days was excluded due to the correlation with severity and its potential to confound results. Fitting combinations of independent variables into the logistic regression model did not appear to improve the model, and individual variables were insignificant when entered in combination with the NIHSS, indicating its overriding strength as a predictor. It was not possible to fit a complicated model in view of the small sample size.

4.8 Post Hoc Analysis of Validity of Outcome Measures

4.8.1 <u>Concurrent Validity</u>

Spearmans correlation co-efficients between the NIHSS and outcome measures at six months can be found in Table 4-45. It is noted that higher scores on the NIHSS, MRS and CSI reflect unfavourable outcomes while higher scores on the EADL, BI and EQ-5D reflect favourable outcomes. In this light the following observations are made:

- EQ-5D scores were not significantly correlated with any of the other outcome measures
- the CSI was weakly correlated with the NIHSS and BI-3, indicating the worse the severity on admission the higher the CSI score at six months, and the better the BI at six months, the lower the levels of caregiver strain
- A strong correlation was found between the Barthel Index at six months and all three sub-scales of the RMA (0.76-0.85)
- A strong correlation was found between the BI at six months and the MRS (-0.82) indicating the greater the independence in ADL, the lesser the disability according to the MRS
- A strong correlation was found between the EADL Scale and the BI-3 (0.86)
- Similarly a strong correlation was found between EADL scores and the MRS at six months

Table 4-45 Spearmans Correlation Matrix Between NIHSS at Admission and Outcome Measures at Six Months
Values in bold are significant at p<0.05

	NIHSS Adm	RMA3 Gross	RMA3 LL&T	RMA3 UL	BI-3	EADL Scale	MRS	EQ-5D VAS	CSI
NIHSS Adm	1.00	**-0.69**	**-0.81**	**-0.77**	**-0.75**	**-0.62**	**0.61**	-0.08	**0.33**
RMA3 Gross	**-0.69**	1.00	**0.83**	**0.72**	**0.85**	**0.86**	**-0.78**	0.04	-0.25
RMA3 LL&T	**-0.81**	**0.83**	1.00	**0.73**	**0.78**	**0.69**	**-0.69**	0.06	-0.24
RMA3 UL	**-0.77**	**0.72**	**0.73**	1.00	**0.76**	**0.66**	**-0.67**	-0.09	-0.18
BI-3	**-0.75**	**0.85**	**0.78**	**0.76**	1.00	**0.86**	**-0.82**	0.16	**-0.31**
EADL Scale	**-0.62**	**0.86**	**0.69**	**0.66**	**0.86**	1.00	**-0.85**	0.15	-0.27
MRS	**0.61**	**-0.78**	**-0.69**	**-0.67**	**-0.82**	**-0.85**	1.00	-0.27	0.28
EQ-5D VAS	-0.08	0.04	0.06	-0.09	0.16	0.15	-0.27	1.00	-0.26
CSI	**0.33**	-0.25	-0.24	-0.18	**-0.31**	-0.27	0.28	-0.26	1.00

NIHSS= National Institute of Health Stroke Scale, Adm= Admission, RMA3= Rivermead Motor Assessment at Six Months, Gross=Gross Sub-scale, LL&T=Lower Limb and Trunk Sub-scale, UL= Upper Limb Sub-scale, EADL Scale= Extended Activities of Daily living Sub-scale, MRS= Modified Rankin Scale, EQ-5D VAS= EQ-5D Visual Analogue Scale, CSI= Caregiver Strain Index

The NIHSS at admission, which is intended to describe severity of stroke, was found to be highly correlated to severity of disability on admission according to the BI and severity of motor impairment on the RMA Gross Sub-scale with $p<0.05$. See Table 4-46

Table 4-46 Correlation Matrix Between Measurement Tools at Admission to the Study (marked values indicate Spearmans rho significant at p<0.05)

	NIHSS Total	Barthel Index at Admission	RMA Gross Sub-scale at Admission
NIHSS Total	1.00	**-0.66**	**-0.66**
Barthel Index at Admission	**-0.66**	1.00	**0.89**
RMA Gross Sub-scale at Admission	**-0.66**	**0.89**	1.00

NIHSS= National Institute of Health Stroke Scale

4.8.2 Predictive Validity and Responsiveness to Change Over Time

4.8.2.1 Barthel Index

The BI scores at admission were significantly correlated with scores at discharge (Spearman r=0.78, p<0.05) and six months (Spearman r=0.81, p<0.05). The correlation between scores at discharge and six months was even higher (Spearman r=0.87, p<0.05). The BI was sufficiently responsive to reflect change between time points of assessment. However, a ceiling effect was noted as the six month assessment point approached: Eleven patients (21.5%) already had maximum scores at the time of discharge and thus the BI would not reflect any further changes.

Table 4-47 Spearmans Rank Order Correlations for BI Scores at Admission, Discharge and Six Month
Marked values indicate significance at p<0.05

	BI at Admission	BI at Discharge	BI at Six Months
BI at Admission	1.00	**0.80**	**0.81**
BI at Discharge	**0.80**	1.00	**0.87**
BI at Six Months	**0.81**	**0.87**	1.00

BI= Barthel Index

4.8.2.2 RMA

There were statistically significant, high correlations between RMA scores at admission, discharge and six months for all three sub-scales of the RMA.

Table 4-48 Spearmans Rank Order Correlations for the RMA Gross Sub-scale at Admission, Discharge and Six Months
Marked values indicate significance at p<0.05

	RMA1 Gross	RMA2 Gross	RMA3 Gross
RMA1 Gross	1.00	**0.78**	**0.82**
RMA2 Gross	**0.78**	1.00	**0.89**
RMA3 Gross	**0.82**	**0.89**	**1.00**

RMA= Rivermead Motor Assessment, RMA1= RMA at Admission, RMA2= RMA at Discharge, RMA3= RMA at Six Months, Gross= Gross Sub-scale

Table 4-49 Spearmans Rank Order Correlations for the RMA Lower Limb and Trunk Sub-scale at Admission, Discharge and Six Months
Marked values indicate significance at $p<0.05$

	RMA1 LL&T	RMA2 LL&T	RMA3 LL&T
RMA1 LL&T	1.00	**0.72**	**0.76**
RMA2 LL&T	**0.72**	1.00	**0.92**
RMA3 LL&T	**0.76**	**0.92**	1.00

RMA= Rivermead Motor Assessment, RMA1= RMA at Admission, RMA2= RMA at Discharge, RMA3= RMA at Six Months, LL&T= LL&T Sub-scale

Table 4-50 Spearmans Rank Order Correlations for the RMA Upper Limb Sub-scale at Admission, Discharge and Six Months
Marked values indicate significance at $p<0.05$

	RMA1 UL	RMA2 UL	RMA3 UL
RMA1 UL	1.00	**0.78**	**0.75**
RMA2 UL	**0.78**	1.00	**0.93**
RMA3 UL	**0.75**	**0.93**	1.00

RMA= Rivermead Motor Assessment, RMA1= RMA at Admission, RMA2= RMA at Discharge, RMA3= RMA at Six Months, UL= Upper Limb Sub-scale

4.8.2.3 The NIHSS

High correlations are found between the NIHSS at admission and most outcome measures at six months, indicating its predictive value. The correlation between the NIHSS and Caregiver Strain Index is noted to be slightly less than for other measures, indicating it accounts for only part of the variability in CSI outcomes. The NIHSS at admission was not seen to be significantly correlated with the EQ-5D at six months. (See Table 4-45)

4.8.2.4 Detailed Exploration of Concurrent validity Between the MRS, BI and EADL Scale

As reported above, Spearmans rank correlation co-efficient demonstrated high correlations between scores on the Barthel Index at six months, the EADL at six months and MRS at six months. This would be expected on account of overlapping content. When individual items were explored, slightly higher percentages of independence are found on the MRS than the EADL scale and BI respectively, for corresponding items. This is expected as the MRS addresses capacity (what would be possible for the patient) and the EADL scale addresses performance (i.e. what the participant had actually done in the few weeks preceding assessment).

Table 4-51 Percentage of Participants Independent in Individual Items of the MRS and BI at Six Months

	Percentage Independent according to MRS	Percentage Independent according to BI
Eating	97.9	70.2
Toileting	80.9	78.7
Walking	80.9	78.7

Table 4-52 Percentage of Participants Independent in Individual Items of the MRS and EADL at Six Months

	Percentage Independent according to MRS	Percentage Independent according to EADL
Meal prep	63.8	46.8
Household chores	57.4	38.3
Local travel	42.6	34
Shopping	38.3	19.1

5 DISCUSSION

5.1 Introduction

The Discussion section starts with a brief outline of the most pertinent findings. This is followed by a more detailed discussion of the demographic characteristics of the sample and an analysis of each of the objectives of the study. Finally the methodological shortcomings and limitations are presented, in order to discuss the internal and external validity of the study.

5.2 Brief Outline of Most Pertinent Findings

The sample is thought to be representative of patients with first ever stroke accessing the WCRC. It is proposed that patients with stroke at the WCRC differ from stroke populations reported in rehabilitation studies in developed countries in terms of their younger age, differing risk profiles and co-morbidities. This has implications for outcome and pattern of recovery, and findings from international studies should therefore be compared with caution.

The rehabilitation process of participants in the sample was characterised by fairly early admission after stroke (approximately 75% within 30 days of onset), and an average length of stay of approximately 60 days. This means that on discharge many participants fell within the three month window after their stroke and therefore spontaneous neurological recovery may have been ongoing at this time. As expected, the pattern of recovery demonstrated the most change between admission and discharge, but clinically important changes between discharge and six months were noted, particularly with regard to functional recovery and mobility. Surprisingly, participants who were admitted later rather than earlier after their stroke did not show any statistically significant differences in amount or pattern of recovery.

Most participants did not receive any substantial rehabilitation input after discharge and many did not receive any rehabilitation follow up or review at all. A number of issues arose at the six month assessment that required the researcher to refer participants on for further follow up. These included requests for further rehabilitation, financial or grant issues and changes in mobility that required review of mobility aids. This implies that later changes after discharge may require assessment and input, and participants may benefit from routine reviews or follow up after discharge. Literature stresses the importance of the transition from hospital to home (Burton 2000), and the need for continuity of care and ongoing support after discharge (Andersen, Eriksen, Brown, Schultz-Larsen and Forchhammer 2002). A large part of recovery after stroke is adapting to living back in the community after hospital discharge, attempting to resume previous roles, and recreating a meaningful existence in spite of residual limitations (Burton 2000). Few participants in this study received any ongoing support after discharge, and in participants discharged fairly early after their strokes this may be even more important.

Outcomes at six months demonstrate that nearly all participants were living in the community regardless of the severity of their stroke. This is despite the fact that approximately one fifth of participants required constant care and could not be left alone. They were being cared for largely by relatives who reported a high incidence of caregiver strain (58.8%). Levels of caregiver strain were higher than those reported in international studies where more severe strokes are admitted to nursing homes and support services are available in the community (Wilkinson, Wolfe et al. 1997; Bugge, Alexander and Hagen 1999; Blake, Lincoln and Clarke 2003). The lack of suitable care facilities in South Africa may also contribute to the high proportion of severe strokes living within the community.

In terms of profiling typical outcome at six months: the majority of participants were independently mobile and independent in essential self-care, but needed assistance for household activities such as meal preparation and household chores. Higher mobility tasks such as walking outdoors, stair climbing and crossing roads were problematic. A high percentage of participants reported loss of previous role including return to work, social and leisure activities and family responsibilities. This was evident in participants with mild strokes as well as severe strokes. As much as half of all participants reported depression or anxiety and more than 80% reported feelings of isolation or problems with relationships. Less than a quarter of participants were able to go out socially unassisted, and difficulty with using public transport may have contributed to isolation.

Exploration of factors affecting outcome showed that severity of stroke at admission (NIHSS) was the clearest predictor of outcome at six months. Other indicators of severity at admission that were found to be associated with outcome included disability (BI), urinary continence and sitting balance. The presence of a cognitive deficit, low monthly income, and the presence of at least one reported environmental barrier were also associated with unfavourable outcome in terms of MRS at six months. Number of rehabilitation days was found to have a statistically significant negative effect on outcome in the bivariate analysis, but was excluded from the logistic regression due to its strong correlation with severity of stroke. Contrary to the body of evidence in literature, age was not found to be a significant factor which may be due in part to the different age profile exhibited by the study sample.

Limitations of the study include the choice of assessment points at admission and discharge, which do not constitute equal points in time after stroke for all participants. In addition, three participants dropped out of the study, one passed away and data was missing for an additional three participants, resulting in a smaller group of participants for the analysis of change across time. Even so, data was missing for less than 15% of participants. The chosen outcome measures were found to be useful in the South African context and demonstrated satisfactory predictive and concurrent validity. In spite of shortcomings, the study succeeded in describing pattern and recovery and outcome after first ever stroke in patients at the WCRC. It also provided baseline information on the characteristics of patients with stroke and the rehabilitation process, within the local environmental context. Factors influencing outcome were explored but the small sample size limited the inferences that could be made.

5.3 Discussion of Specific Objectives

5.3.1 <u>Patient Characteristics</u>

5.3.1.1 Demographic Characteristics

Participants in the sample were younger than those reported in literature, with approximately 80% of participants being younger than 65, and a third of participants under 45 years of age. Surprisingly, age was normally distributed, and there was no increase in the presenting number of patients with stroke with age. There were marginally more women in the sample than men. The proportional representation of population groups in the sample was more or less as expected in terms of the typical representation in the region (Statistics South Africa 2006). Most participants were able to speak English or Afrikaans which are the languages mostly spoken by the therapy staff at the WCRC at present. Approximately 10% of participants could speak only Xhosa and this is worth noting in terms of language needs of patients. Participants were generally from low income households, but most participants lived in formal housing with access to services

The young age of participants (mean 51.3 years ± 14.5 SD) is of particular interest. It is also consistent with findings of prevalence studies that patients with stroke in developing countries have a mean age that is approximately 15 years younger than that of developed countries (Bonita, Mendis and Truelson 2004). Comparisons with mean age in overseas studies reflect this difference (Duncan, Goldstein et al. 1992; Jorgensen, Nakayama, Raaschou and Olsen 1995c;

McNaughton, De Jong, Smout, Melvin and Brandstater 2005) as does a review of 90 acute stroke studies which described a mean age range of 54-78 with a median age of 68 (Uchino, Billheimer and Cramer 2001). Admissions policies of the WCRC may also mean that younger patients are given preference for admission.

The young age of patients with stroke at the WCRC has a number of implications. Firstly, persons under 65 years of age are considered potentially economically active. In the study sample, only 10.3% of persons working prior to their stroke had returned to paid employment at six months. This suggests serious economic consequences for the families of patients with stroke as well as the economy. One third of participants were under the age of 45 years. These patients are expected to have young families with dependents. Young stroke survivors have many years of life ahead of them and rehabilitation to a fulfilling level of function and activity is extremely important. Certain special needs of young patients with stroke have been highlighted in literature including high levels of anxiety, marital stress and concerns regarding employment and child care (Teasell, McRae and Finestone 2000). Caregivers of young patients with stroke report high levels of anxiety and depression especially in the presence of lower incomes and greater disability (Teasell, McRae and Finestone 2000). Conflict in the home, particularly with spouses is frequently reported (Teasell, McRae and Finestone 2000).

In this study, age did not emerge as a determinant of functional outcome in the logistic regression analysis. This will be discussed later with reference to the multivariate analysis.

5.3.1.2 Socio-economic Characteristics

Participants in the study were mostly a low income group with more than half of participants reporting a monthly household income of less than R1000. Table 5-1 juxtaposes pre-stroke monthly household income of participants with the income of employed workers in South Africa from the Labour Force Survey 2004 (Statistics South Africa 2006). It is noted that monthly household income should be higher than individual monthly income if there is more than one earner in the home. However, the study sample also included a number of participants who were not in employment or who were receiving grants and this may result in lower reported incomes. On the whole, monthly household income of participants was consistently lower than individual incomes of earners in South Africa according to the Labour Force Survey 2004 (Statistics South Africa 2006). It is of interest that in 2006, disability grants and state pension payouts amounted to R820 per month.

Table 5-1 Comparison of Monthly Household Income in the WCRC Sample with Monthly Individual Income of the Employed in South Africa

	WCRC Sample (n=51)	Workers in South Africa*
≤R1000	51.0%	33.5%
R1001- R2500	27.5%	24.1%
R2501- R8000	11.8%	24.7%
>R8000	5.9%	8.1%
Don't Know/ Refuses	3.9%	9.6%
TOTAL	100%	100%

***From the Labour Force Survey 2004 (Statistics South Africa 2006)**

Implications of the low income are that many participants would not have resources to draw on for additional costs resulting from their stroke. For example, many participants who had previously used public transport reported they were unable to do so after their stroke and had to hire a car with a driver in order to get to destinations. For many participants, the cost involved would be prohibitive. Furthermore, many participants could not afford to employ paid caregivers in order to ease the burden on the family. Low income has been associated with poor outcomes after stroke. In the CERISE study in Europe (Putman, De Wit et al. 2006), lower income groups had a lower probability of RMA score improvements between discharge from rehabilitation and assessment at six months post stroke. That is motor recovery was worse in low income groups after discharge from hospital.

In the same study (Putman, De Wit et al. 2006), higher educational levels were associated with improved motor and functional recovery during inpatient rehabilitation. In the WCRC study, only a small percentage of the sample (14%) had completed their matriculation or had had any further training after school leaving.

Just over half the participants were in paid employment prior to the stroke, mostly in unskilled positions. Many of the unskilled positions held by participants in the study required physical labour which would have implications for return to work for those with residual physical disabilities. Furthermore, unemployment statistics from the Western Cape indicate that in the general population, unemployment is highest in those practicing unskilled occupations (Statistics South Africa 2006). Previous studies have suggested that type of work is an important factor influencing return to work (Vestling, Tufvesson and Iwarsson 2003).

Most participants lived in formal housing with access to services. However, just over 10% lived in informal dwellings and nearly a quarter of participants had an outdoor toilet or lacked bathroom facilities in their homes at six months. Features of the home environment affect the requirements for the performance of certain tasks. For example, in order to access outside toilets, participants often need to cross uneven sandy ground. Many patients who are independently mobile indoors over flat ground would need assistance with this, and it may not be possible to self-propel a wheelchair. Thus toileting becomes a potentially more difficult task. Participants without baths or showers in their homes often washed from a basin, and this has different physical requirements compared to getting in and out of a bath or managing a shower.

5.3.1.3 Medical Characteristics

The risk profile of participants indicated that high blood pressure (74.5%), diabetes (23.5%) and life style factors such as smoking (52%) were most prevalent in the sample. These risk factors are potentially modifiable, and secondary prevention should therefore be addressed as an important part of the rehabilitation programme.

A number of medical characteristics of the sample, such as a high proportion of haemorrhagic strokes relative to ischaemic strokes and the prevalence of infectious aetiologies, are typical of stroke populations in developing countries. These may signify important differences with study populations in rehabilitation studies in developed countries.

Co-existing infectious diseases such as HIV/AIDS, syphilis and TB were noted in 15% of participants. It is acknowledged that although infectious diseases such as those cited above increase the risk for strokes, neurological symptoms may also arise from space occupying infectious foci and other mechanisms which are not truly vascular events. However, six of the eight participants with infectious aetiologies had infarcts or bleeds confirmed on MRI or CT scanning. All participants had reported sudden onset of symptoms with no other apparent cause as defined by the WHO definition of stroke, and had no history of previous neurological deficit. On this basis it was decided not to exclude these patients from the study, particularly as they constitute an important sub-group.

The sub-group of participants in the sample with HIV/ AIDS was too small to permit statistical analysis, but some features of this group are worth highlighting. All six participants with HIV/

AIDS were noted to be under the age of 40, with five participants being in their twenties. All these participants had pre-morbid Barthel Scores of 100. With the exception of one patient, individuals had been relatively healthy prior to their stroke. In a population where a high percentage of patients presenting with stroke also have HIV/ AIDS, rehabilitation needs and prognosis for recovery in this sub-group merits further research.

In participants for whom imaging studies were available, ischaemic strokes occurred twice as frequently as haemorrhagic strokes (18:9). However, nearly half the sample could not be classified as a result of lack of investigations. In developed countries approximately 80% of strokes are reported to be ischaemic (Johnston, Connors et al. 2000), with a ratio of ishaemic to haemorrhagic strokes of 4:1. By contrast, the lower ratio of ischaemic to haemorrhagic in this study (2:1) can be considered to reflect the disease profile of stroke in developing countries. The impact of differences in stroke sub-types on rehabilitation outcomes is difficult to assess. Haemorrhagic strokes tend to be more severe and are associated with higher mortality rates in the early stages (Foulkes, Wolf et al. 1988); however, recovery in this group is thought to occur at a more rapid rate than in ischaemic strokes (Paolucci, Antonucci et al. 2003). Studies in developed countries describing pattern of recovery such as the Copenhagen Stroke Study (Jorgensen, Nakayama, Raaschou and Olsen 1995c) report populations with a higher proportion of ischaemic stroke (75.6%).

In summary, there are certain differences in the demographic, socio-economic and medical characteristics of patients with stroke at the WCRC compared to overseas studies, and this may contribute to differences in the course of recovery and outcome after stroke

5.3.1.4 Characteristics of Stroke Participants at Admission

Most of the participants admitted to the WCRC fell into the category of moderate severity according to the NIHSS. This is to be expected in terms of admissions policies to the unit, as literature suggests that patients with stroke categorised as moderate benefit the most from a rehabilitation unit setting (Teasell 2004c). In terms of nursing and therapy needs of patients admitted for rehabilitation, BI scores at admission revealed most participants were dependent in activities of daily living (64.7%).

Less than a third of participants admitted to the WCRC presented with complications on admission to the unit. This is lower than expected on the basis that complications have been reported to occur in 48-96% of patients in an inpatient rehabilitation facility in the United States (Roth, Lovell et al. 2001). However, comparison with other studies is limited because most studies describe reported complications during the course of a rehabilitation stay, not necessarily at the point of admission. The relatively low incidence of complications may be due to short waiting times until admission, or adequate nursing and home care. It is also possible that some complications were missed at the initial screening assessment of the patient. The most common complication was shoulder pain (9.8%) which may be of interest to acute institutions in terms of patient education for the prevention of shoulder pain. Shoulder pain is a common sequelae of stroke and is said to occur in up to 75% of patients following stroke (Geffen 2000). In the Auckland stroke study, shoulder pain was reported in 17% of participants at one week, 20% at one month and 23% at six months post stroke suggesting that the frequency of shoulder pain in this sample was less than expected (Ratnasabapathy, Broad, Baskett, Pledger, Marshall et al. 2003).

5.3.2 Rehabilitation Process

Participants were referred from all tiers of the state sector, with a smaller number being referred from the private sector (7.8%). In the light of the empowerment of patients, it was of interest that a small number of participants had self referred (n=2). Onset admission intervals (the time between stroke and admission to the rehabilitation facility) were found to be relatively short with 75% of participants admitted within the first 30 days post stroke. Participants with more severe strokes tended to be admitted earlier. This may be due to pressure from tertiary institutions to discharge patients who were occupying beds in medical wards. Patients with milder strokes tended to be discharged home and admitted to the WCRC from home at a later stage. Most participants had a rehabilitation stay of one to three months with an average rehabilitation stay of approximately two months (59.1 days ± 28.25 days). As participants were admitted for rehabilitation fairly soon after the event, many participants were not more than three months post stroke at the time of their discharge (64.71%), as such neurological recovery may still be ongoing at the time of discharge. The implications of this are that follow up within the community may be important in order to maximise recovery.

Limited comparisons can be made with length of stay in other studies as stroke services are configured differently in terms of admissions to acute and sub-acute stroke units, and the continuation of rehabilitation after inpatient rehabilitation is complete. Typical length of stay and onset admission intervals vary enormously between reported studies and stroke rehabilitation practices are extremely variable between and even within countries (Beech, Ratcliffe, Tilling and Wolfe 1996; Rudd, Irwin, Rutledge, Lowe, Wade et al. 2001).

In the UK, the National Sentinel Audit of Stroke 2001/2002 (Hoffman, Lowe, Irwin and Rudd 2002) reported a mean length of stay of 35 days, but included acute stroke units in their sample. Longer lengths of stay (49-68 days) in UK rehabilitation units have also been reported (Patel, Potter, Perez and Kalra 1998). In a comparative study of sub-acute stroke rehabilitation in New Zealand and the United States (McNaughton, De Jong et al. 2005), mean length of stay was 66 days in New Zealand and 30 days in the United States. (McNaughton, De Jong et al. 2005). In Europe, there may be longer rehabilitation stays and longer onset admission intervals than in the United States (Stuart, Ryser, Levitt, Beer, Kesselring et al. 2005). Home-based rehabilitation is offered by some stroke services in order to facilitate shorter lengths of stay in hospital (Mayo, Wood-Dauphinee, Cote, Gayton, Carlton et al. 2000).

In the WCRC study sample, participants received little rehabilitation follow up after discharge, although most had had contact with a doctor or nurse at a community health care centre. Of the participants who had had contact with rehabilitation therapists, very few had had any substantial therapy (i.e. most participants received less than six sessions of therapy). Most families were reported to have been involved in discharge planning and to have received training in the form of verbal instruction or demonstration.

It was not initially the aim of this research project to identify problems at six months, but as part of the ethical responsibilities of the researcher, any query raised or problem identified was referred on to the appropriate channel and recorded. At the six month assessment, frequently raised queries and problems included review of mobility aids or AFO, disability grant queries, problems with housing, and medical queries including questions regarding blood pressure management and medication. Several participants had ongoing problems with shoulder pain which were not currently being treated and one fifth of participants enquired about receiving further treatment or rehabilitation. Some of the queries simply required information; others required further therapy input such as the provision of walking aids or addressing shoulder pain. A number of the issues (particularly mobility aids and shoulder pain) appeared to have arisen from a change in physical status of the participants since their time of discharge. Other issues such as sexual dysfunction (n=2) are more likely to arise after the patient has returned home to live in the community. Although only two patients raised issues of sexual dysfunction this is highlighted because sexual issues were not directly addressed in any of the questionnaires. It is known that patients are hesitant to raise sexual matters so it is expected that it may have been an issue for a number of participants. Literature supports the importance of addressing sexual function in younger patients with stroke (Bhogal, Teasell, Foley and Speechley 2003).

Although patients at the WCRC are informed of the open door policy of the centre for future enquiries; it appeared that many participants had not pursued any further follow up despite having had problems. This suggests the need for routine follow up or review after discharge. A number of authors have highlighted the importance of the transition from hospital to home, and the need for ongoing support and continuity after discharge from rehabilitation (Burton 2000). It has been suggested that patients should experience an "unbroken chain of care" from the time of the initial event until they return home and reintegrate into the community (South African Medical Association- Neurological Association of South Africa Working Group 2000). For many participants in the sample, rehabilitation ended with their discharge from the WCRC.

Follow up after discharge may be useful in order to ensure the carry-over of skills into the home where the patient may be faced with very different environmental conditions compared to the rehabilitation centre. In addition, many patients move very rapidly from a highly supported rehabilitation environment at the WCRC to receiving minimal further input once at home, and this may contribute to a sense of isolation. Support given to patients and caregivers over the transition is thought to impact positively on levels of anxiety and depression as well as caregiver strain. Follow up after stroke may also play a role in supporting resumption of pre-stroke roles such as social, leisure and work activities. These are more appropriately addressed once the patient has returned home, rather than during the early stages. Furthermore, follow up may optimise changes that may occur due to later recovery, and may help prevent complications and later deterioration.

Follow up reviews at the WCRC have many advantages, as specialist rehabilitation services are offered and patients are known to the staff. However, as a regional specialist unit, the WCRC has a wide catchment area and many patients live quite far away. Logistical difficulties in attending outpatient appointments such as transport, financial costs and the availability of an escort may reduce the number of patients presenting for follow up. An alternative avenue of follow up may be CHCC's which were observed to be accessed by the majority of participants. However, not all community health care centre's have occupational therapists and speech therapists on their staff.

Many centres have physiotherapists but some are staffed by Community Service[11] therapists who may not have extensive stroke rehabilitation experience. It is suggested that the WCRC become involved in outreach programmes to facilitate appropriate follow up for their patients within the community after discharge. In addition, an interesting feature of services accessed after discharge was that a small number of participants had received quite extensive input from Community Rehabilitation Workers within their own homes. This may be another resource for follow up within the community. Further research is recommended into how patients can be best supported after discharge, in order to improve outcomes with efficient use of resources.

It was of interest that a number of participants had more than one admission for rehabilitation, not as a result of deterioration, but as a means of optimising on later recovery. Unfortunately, the sample size did not permit statistical analysis of the effect of multiple admissions on pattern of recovery. A number of participants had also had a break in treatment over the Christmas period, and the effect of this on their recovery could not be determined. However, the practice of multiple staged admissions for rehabilitation as a means of effectively managing resources may be a unique feature of the rehabilitation process at the WCRC. It has not been reported in literature and would be an interesting research topic in a longitudinal study.

5.3.3 Pattern of Recovery

Pattern of recovery in this sample was reported in terms of assessments at admission, discharge and six months. It must be noted that admission and discharge assessments did not occur at equidistant points in chronological time on account of differing onset admission intervals and lengths of stay. The fact that nearly all participants improved between admission and discharge demonstrates that patient selection for admission was appropriate, as patients admitted to the WCRC appeared to benefit from rehabilitation. This was observed regardless of early or late admission after onset and in strokes of all severity levels. Recovery during the inpatient stay is likely to be due to a combination of spontaneous neurological recovery and the effects of training and rehabilitation. Participants continued to improve after discharge on both the functional measure (BI) as well as on measures of motor recovery (RMA). However, the amount of change was much smaller, which is to be expected as rate of recovery slows and plateaus over time. A small number of participants were also seen to deteriorate after discharge, and this is also clinically important.

---

[11] It is compulsory for newly graduated physiotherapists to work for a year in a Community Service Post prior to being awarded registration as a practising physiotherapist in South Africa.

5.3.3.1 Functional Recovery over Time

5.3.3.1.1 Change across Time

Barthel Index scores showed statistically significant change across all three time points: admission, discharge and six months. The fact that clinically significant change occurred between admission and discharge in 93.6% of participants suggests that patients were appropriately selected for admission, and that the rehabilitation programme was effective. In fact, of the three participants who remained the same between admission and discharge, two participants already had the maximal score at admission, and the remaining patient was a very severe stroke for whom rehabilitation goals consisted of family training and management issues rather than functional independence. The median difference of 25 is clearly clinically significant as it indicates a 25% improvement in independence (total BI score 100). Individual items that showed the most change were toileting, transfers, dressing and bathing. These all constitute important rehabilitation goals during admissions to rehabilitation units.

Between discharge and six months a statistically significant trend was seen towards increased total BI scores. Although the changes in total BI scores were much smaller (median difference of 5), this should not be interpreted to mean that change did not occur. In fact, 55% of participants demonstrated clinically significant improvement and nearly 15% demonstrated clinically significant deterioration between discharge and six months (where clinically significant change is defined as a change of more than 15% of the total score). Both improvement and deterioration are important outcomes, and only about 30% of participants were seen to show no clinically significant change. However, a ceiling effect is expected to come into play as seven of the 14 participants reflecting no change already had a maximum BI score of 100 at discharge. Functional improvement in aspects not addressed by the BI may have occurred undetected in these patients.

5.3.3.1.2 Individual Items

Aggregation of scores on functional scales can lead to a loss of detail and can hide where change occurred. Analysis of individual items demonstrated that the greatest changes in the percentage of independent participants between discharge and six months occurred for the mobility related items of mobility. It seems that these items demonstrate change later in time, possibly as a result of being more difficult tasks, or due to the effects of practice and the familiarity of the home environment. There are some similarities with the Copenhagen stroke study , where most change between discharge and six months occurred in the items of transfer and stairs with lesser change occurring in feeding, toilet and dressing (Jorgensen, Nakayama et al. 1995a). Factors contributing to differences may include different environmental conditions after discharge, as well as differing rehabilitation practices and patient characteristics.

For all individual items, improvement was seen between discharge and six months with the exception of feeding and transfers. Environmental factors may have influenced the apparent deterioration in these abilities. More participants at six months stated they needed occasional help with cutting meat and spreading butter, than at discharge. It is expected that this does not reflect a true deterioration. The standard ward diet is a soft diet, and after returning home, participants may have experienced more variety of foodstuffs that required cutting. Another factor may be that family members may have assisted more than required, whereas in the hospital participants are expected to do as much for themselves as possible. Environmental factors may affect independence in toileting after discharge. The toilet facilities at the WCRC are especially adapted for wheelchair use, but approximately a quarter of participants had to contend with outdoor toilets after returning home, and this may have affected levels of independence.

The BI items with the lowest independence at discharge and six months included independent mobility, dressing, bathing and stairs. This is to be expected as these are more difficult items that require better motor control and cognitive function. In addition, these items are all influenced by environmental factors in the home.

It must be noted that the Barthel Index distinguishes only between the ability or lack of ability to perform tasks independently. Scores are not influenced by how the individual accomplishes the task and improve with learned compensations using the unaffected side. Tasks such as dressing, transfers and toileting may improve relatively quickly as a result of compensatory strategies, whereas walking and stairs require a definite physical improvement, and changes may be seen at a later stage in recovery.

5.3.3.1.3 The Effect of Severity and Onset Admission Intervals

Severity of stroke at initial onset is thought to influence pattern of recovery. Mild strokes are expected to improve most rapidly, moderate or moderately severe strokes are expected to demonstrate the most change, and very severe strokes are thought to demonstrate a longer and slower time course of recovery with less overall change (Duncan, Goldstein et al. 1992; Jorgensen, Nakayama et al. 1995a; Horgan and Finn 1997; Teasell 2004c). These effects were not demonstrated in the repeated ANOVA results of this study which did not identify any differences in pattern of recovery over time between subgroups of severity.

However, it is noted that admission and discharge did not occur at chronologically equal points in time, so factors such as onset admission intervals (OAI) and length of stay (LOS) may influence the BI profile of recovery. Exploration of the data suggested there were certain differences between sub-groups. Statistical significance of the trends could not be verified possibly due the small numbers in the mild and severe sub-group as well as unequal distribution between groups.

Consideration of these trends is interesting as they suggest similar patterns to those described in literature. Actual amount of change in the mild category was small between admission and discharge (median 10). However milder patients will have scores approaching the maximum of 100 at admission, and therefore have less potential to demonstrate change over time. To overcome this, an effectiveness score was calculated which expresses improvement as a proportion of potential change. This approach has been utilised in previous studies (Paolucci, Antonucci et al. 2000). As milder strokes also had shorter admissions, the effectiveness score was expressed over time, giving a value that reflects how quickly the individual reached their highest potential over time. This value effectively adjusts for the ceiling effect of the BI and differences in lengths of admissions between groups. Results suggest that patients with milder strokes reached their full potential quicker than any other group (median effectiveness/ time= 0.014) , followed by moderate (median effectiveness/ time= 0.0098) and then severe strokes (median effectiveness/ time =0.0042). The moderate sub-group showed the greatest crude change between admission and discharge as well as demonstrating the highest effectiveness score and the fastest rate of change over time (efficiency score). The severe sub-group demonstrated the slowest effectiveness/ time score. That is severe patients took the longest to achieve their maximum potential. This is in line with literature that reports a slower course of recovery in more severe strokes (Jorgensen, Nakayama et al. 1995a). In this light, it is not surprising that there was a significant correlation between severity of stroke and length of stay.

There is some debate surrounding whether patients with severe strokes benefit from admission to rehabilitation units (Gladman and Sackley 1998). However, severe strokes have been noted to have the potential to improve during rehabilitation (Jorgensen, Nakayama et al. 1995b). It is of interest that in this study, of the participants initially categorised as severely disabled (BI), only 26.7% remained severely disabled at six months, 30.0% had moved up into the categories of moderate disability, and 43.3% were either mildly disabled or functionally independent at six months. Furthermore, the analysis of pattern of recovery did not show any statistically significant difference with respect to amount of change over time in the severe sub-group. This implies that severe strokes should not be excluded from admission to the WCRC as they have been shown to benefit from rehabilitation stays.

Trends in pattern of recovery were also investigated with regard to the effect of earlier versus later admission to rehabilitation. Contrary to the beneficial effects of early commencement of rehabilitation that are reported in literature (Cifu and Stewart 1999; Paolucci, Antonucci et al. 2000; Maulden, Gassaway, Horn, Smout and De Jong 2005; McNaughton, De Jong et al. 2005), the results of the repeated measures ANOVA did not reflect any statistically significant differences between groups.

Further exploration of the data suggested that the mild sub-group had a higher median onset admission interval (26.5 days) than the other sub-groups (medians 14.5 and 18). This may be because patients with mild strokes are discharged early from acute hospitals and are usually at home at the time their referrals are received by the WCRC. By contrast, more severe strokes that are medically stable, but are hospitalised as they cannot be cared for at home, are prioritised for admission due to pressure from acute care facilities to free up the beds of medically stable patients. It is possible that severe strokes had longer onset admission intervals than moderate strokes due to having more acute medical problems and taking longer to be medically stable. However, none of these factors were found to be statistically significant on testing.

On the basis of literature, it would be expected that participants admitted sooner after their stroke would show a more rapid recovery on account of faster changes occurring in the early period after stroke (Teasell and Bitensky 2004b) as well as due to the beneficial effects of early commencement of rehabilitation. No such effects were found in this study in the repeated measures ANOVA analysis. It is possible that the findings of the study are true reflection, and early admission to rehabilitation does not influence pattern of recovery in this sample; however, the data set is not ideal for detecting differences. Assessments did not occur at equal time points post stroke and there were small numbers of participants in the severe and mild sub-groups. Furthermore, dichotomising onset admission intervals (OAI) at 30 days may lead to loss of detail. No statistically significant correlation was found between OAI's and BI scores at discharge or six months, nor was there any statistically significant relationship between OAI and severity, length of stay or age.

5.3.3.2 Motor Recovery over Time:

Statistically significant change occurred across all three time points in terms of total scores on the RMA Gross Sub-scale as well as the RMA Lower Limb and Trunk Sub-scale, but not for the Upper Limb. As expected, improvement between admission and discharge was greater than changes between discharge and six months. Greater change in the early stages is expected on the basis of other studies which suggest that motor recovery is most evident in the first 30 days and is mostly complete by 12 weeks post stroke (Duncan, Goldstein et al. 1992; Horgan and Finn 1997). In the WCRC study sample, it is noted that 25.5% of participants were not yet at 60 days post stroke at the time of their discharge, and 39.2% were 60-90 days post stroke. These participants may have been approaching a plateau of function due to the slowing down of recovery; however, they fall into the time frame that suggests further recovery may still be occurring.

5.3.3.2.1 Gross Function Sub-scale

The Gross Function score showed clearly clinically significant change between admission and discharge, with a smaller median difference between discharge and six months. Between discharge and six months, approximately half of participants did not show any clinically significant change, but 45% of participants showed clinical improvement and 2.3% clinical deterioration. The low median of the differences scores should be interpreted in this light and should not be considered evidence that there was no real change across time points for all participants. This is highlighted by the fact that there was considerable change in the percentage of individuals who were able to accomplish mobility items such as the ability to walk with and without aids, the ability to walk 40m outdoors, to negotiate stairs independently and to pick an object up off the floor. Furthermore, a statistically significant difference was found in the proportion of participants independently mobile at six months (81.8%) compared to at discharge (54.5%). It is noted that this change in ability to walk around the home could be reflected by a 1 point change in overall Gross Sub-scale scores. For this reason small changes in the Gross Function sub-scale scores should not necessarily be dismissed as clinically insignificant. Mobility at home is an important outcome for patients with stroke (Jorgensen, Nakayama, Raaschou and Olsen 1995c).

An important clinical consequence of this late change in mobility was observed in the fact that at the six month assessment, a number of participants who were not walking at discharge were noted to be walking using inappropriate walking aids, and were referred on for follow up by the researcher. It appears that participants may demonstrate clinically important changes in mobility after discharge that may lead to them requiring a review of mobility aids. These findings are unexpected in view of the Copenhagen Stroke Study (Jorgensen, Nakayama, Raaschou and Olsen 1995c) which suggests that best walking ability was reached by 80% within 6 weeks of onset, and 95% within 11 weeks. However, Jorgensen et al used categories of the mobility item of the BI in order to define best walking ability, and this constitutes a crude measure. Aspects of higher functional mobility such as walking outdoors were not considered.

5.3.3.2.2 Lower Limb and Trunk Sub-scale

The Lower Limb and Trunk Sub-scale demonstrated statistically significant change across the three time points of assessment, with a median difference of 2 between admission and discharge, and a median difference of 0 between discharge and six months. It is noted that the statistically significant median score of zero may occur due to a number of participants deteriorating as well as improving between discharge and six months, as well as the low variability in differences scores. Between discharge and six months, 68.2% did not show any clinically significant change (defined by >15% change in total scores), but 27.3% of participants demonstrated clinically significant improvement and 4.5% demonstrated clinically significant deterioration.

5.3.3.2.3 Upper Limb Sub-scale

The Upper Limb Sub-scale demonstrated the least change over time. Statistically significant changes were found between admission and discharge, but not between discharge and six months. Even during the hospital stay, the median difference was only one, which clinically does not demonstrate much functional change. Only about a third of participants showed clinically significant change (>15% total score) between admission and discharge, with 18.2% of participants demonstrating clinically significant change between discharge and six months. In a previous study, it was noted that 10% of patients with a non-functional upper limb following stroke, did not demonstrate any useful upper limb function at discharge in spite of rehabilitation (Nakayama, Jorgensen, Raaschou and Olsen 1994). Whilst upper limb rehabilitation is known to be an important aspect of therapy, it must be acknowledged that some patients will not recover upper limb function in spite of interventions.

5.3.3.2.4 Deterioration over Time

On the whole, only a small number of participants demonstrated clinically significant deterioration over time (n=1 for the Gross RMA Sub-scale, n=2 for the Lower Limb and Trunk Sub-scale and n=1 for the Upper Limb Sub-scale). This change is defined as more than a 15% decrease in total sub-scales.

However, analysis of the individual items of the sub-scales between discharge and six months, demonstrated deterioration in a number of individual sub-scale items. Some of the items on the RMA instrument constitute tasks that are often practised as part of rehabilitation programmes e.g. bridging exercises. It is expected that while undergoing daily physiotherapy in rehabilitation, there will be an effect of practice that is sometimes not maintained if the patient is relatively inactive after returning home. Deterioration on individual items of the RMA may be partly due to deconditioning due to inactivity. Certain items appeared more susceptible. In the upper limb sub-scale, some items required full extension of the elbow in order for the patient to be awarded the point. A number of patients who had been able to perform the task at discharge, were unable at six months due to flexion contractures of the elbow. Similarly, the presence of shoulder pain and loss of range was the reason for deterioration in some upper limb items. Shortening of the calf muscles and deterioration of lower limb muscle strength due to disuse may explain some of the deterioration in the Lower Limb and Trunk items.

5.3.4 Outcome at Six Months

At six months after stroke, one patient had passed away, one patient was living in an institution and the remaining 46 participants were all living in the community.

5.3.4.1 Discharge Destination/ Residential Status at Six Months

A much higher proportion of participants in this study were living in the community than reported in overseas stroke studies (98%). Only one of 47 participants assessed at six months was living in an institution (2.1%). By contrast, a comparative study of post-acute rehabilitation facilities in New Zealand and the United States reported 21.5% and 13.2% of patients were discharged to institutionalised care respectively (McNaughton, De Jong et al. 2005). In the Copenhagen study, 15% of all patients with stroke did not return to live in their own homes after rehabilitation (Jorgensen, Nakayama et al. 1995a). However, the results of the WCRC study appear to be typical of the South African context in that a study at a tertiary hospital in Cape Town reported that only two of a total of 59 participants were institutionalised at follow up (Whitelaw, Meyer, Bawa and Jennings 1994).

Discharge destination/ residential status at follow up has been used as a measure of outcome in a number of overseas studies where the ability to live at home is interpreted as a sign of favourable functional status. In the South African context it is doubtful if the same conclusions can be drawn. In the WCRC study sample, nine of the ten participants with severe disability (according to the MRS) were living in the community. By contrast, in the Copenhagen study, one third of the patients with very severe strokes were discharged into institutional care (Jorgensen, Nakayama et al. 1995a).

Options for residential care in South Africa may be limited by income and availability, and many of the state subsidised residential facilities have long waiting lists (Steckhoven 2000). Furthermore, cultural expectations may play a role in the acceptability of institutionalised care as a long term option for family members. It is noted that amongst those participants living in the community at six months, a number had not been able to return to their previous home due to the home being unsuitable or the lack of a carer. In most instances, arrangements were made for these patients to live with other family members or relatives.

The relatively younger age of stroke participants may also have influenced the high proportion of patients with stroke living in the community. In a Canadian study, 82% of young strokes under 50, were living in the community at three months (Teasell, McRae and Finestone 2000).

5.3.4.2 BI Scores and Other Classifications of Independence in ADL

At six months after stroke in the WCRC study, the median BI score was 90/ 100 with scores ranging from 0-100. This is comparable to a mean BI of 90.6/100 at six months in a Canadian study with a hospital based cohort (Mayo, Wood-Dauphinee et al. 2002), and a median of 16.8/20 (equivalent to 85/100) at one year in a population of patients with stroke in the UK who were not admitted to hospital (Lincoln, Gladman, Berman, Noad and Challen 2000).

BI scores at six months in the WCRC study, demonstrated that 17% of participants were dependent for care [BI 0-55], 21.3% required moderate assistance [BI 60-80] and nearly 60% required either minimal assistance or were independent in self-care [BI 85-100]. Other outcome studies use a variety of BI scores to define categories of disability and dependency, limiting comparisons between studies. In the WCRC study, the items most frequently reported as problematic were stairs, bathing and dressing. Most participants did not have stairs in their homes, which can be considered more a barrier to community mobility than to living at home. However, the need for assistance with bathing and dressing has implications for the amount of assistance required from caregivers.

At six months after stroke, approximately 60% of participants required assistance with at least one activity of daily living, compared to 66% of stroke survivors a prevalence study in a rural part of South Africa when using the same defining criteria (The SASPI Project Team 2004). The favourable comparison is not unexpected as patients accessing the WCRC are expected to have had considerably more rehabilitation input than stroke survivors in a deprived rural area. Clearly there are other major differences in the study populations, as community based prevalence studies do not include mild strokes who were not have required admission for rehabilitation, as well as severe strokes who may not be deemed appropriate candidates. Furthermore, prevalence studies describe all stroke survivors at a certain time regardless of time point since stroke. However, it also compares favourably with a long term follow up (median 31 months) of hospital patients at a provincial hospital in Durban which reported that 63% (Dewar 1990) of stroke survivors required assistance with at least one activity of daily living.

International studies appear to report more favourable levels of functional outcome at six months. In a Canadian study, only 39% of patients required assistance for ADL at six months post stroke (Mayo, Wood-Dauphinee et al. 2002), and a study in New Zealand reported only 22% of stroke survivors required assistance with daily living (Bonita, Solomon and Broad 1997). It is possible that environmental influences may have contributed to these differences. For example, there may be greater access to assistive devices and adaptations such as ramps and grab rails in first world countries, and this may result in less assistance being required.

In summary, comparisons with other outcome studies are complicated by different time frames, choice of cohort and outcome measures. In general, functional independence appeared better than reported in previous SA studies, but worse than that reported in studies in developed countries.

5.3.4.3 Modified Rankin Score and Extended Activities of Daily Living Scale

Scores on the MRS at six months show that 21.3% of participants required constant care, and that less than 5% of participants had no significant disability. This compares to a study at a Cape

Town tertiary hospital (Whitelaw 1994), in which 28.8% of participants had no significant disability and 27.1% required constant care on follow up. Differences are likely to be introduced by choice of cohort as the milder and more severe strokes presenting in a hospital sample are less likely to be admitted to rehabilitation units.

MRS scores at six months showed that although a high proportion of participants were able to look after their own bodily needs, many needed assistance with household activities, travel and shopping. This corresponded with findings of the EADL Scale where a minority of participants reported doing their own housework (38.3%) and meal preparation (46.8%), and only 19.1% had done their own shopping. Dependence in these activities implies participants require regular input from carers to maintain independent living in the community. It is interesting that in the Canadian study (Mayo, Wood-Dauphinee et al. 2002), the same items were reported as problematic at six months, although the percentage of patients reporting activity limitations was slightly lower for each item than those in the WCRC study. (See Table 5-2)

Table 5-2 Comparison of Percentage of Participants Reporting Difficulties with Activities in the Montreal Stroke Cohort and in the WCRC Study Population

Activity	Montreal Stroke Cohort (%)	WCRC Study sample (%)
Housework	48	62
Meal Preparation	29	53
Shopping	36	81
Local travel/ Public Transport	32	66

Different outcome measures were used to identify participants with activity limitations in the respective studies, so comparisons should be made with caution. The OARS-IADL (Older American Resources and Services- Instrumental Activities of Daily Living scale) was used in the Canadian study and in the WCRC study, percentage reporting activity limitations was defined as patients who were not independent in the corresponding item of the EADL Scale. However, it is noted that response categories of the OARS-IADL are "independent, needs assistance and cannot do" thus similar to the EADL categories of "on my own", "on my own with difficulty", "with help" and "not at all". It is also possible that environmental influences may place the WCRC study population at a relative disadvantage.

According to the MRS at six months, the vast majority of participants (95.7%) reported changes in their ability to carry out their usual duties and activities. Even participants, who were quite able in terms of BI and EADL scores, reported a change in their ability to carry out previous roles such as participation in work, social and leisure activities as well as family responsibilities. It was of interest that a number of participants reported feelings of isolation or having difficulties with relationships (82.6%) in the MRS interview, and that 50% of participants reported depression or anxiety according to the EQ-5D health related quality of life measure.

In view of the high incidence of feelings of isolation and depression, it is noteworthy that approximately one quarter of the study sample were unable to go out socially without assistance. Lack of community mobility and difficulty using public transport may have contributed to these difficulties and literature stresses the importance of addressing barriers to participation in social roles (Pound, Gompertz and Ebrahim 1998). Items on the EADL Scale indicate that only 68.1% of participants had walked outdoors, 57.4% over uneven ground, only 53.2% had crossed roads and 38.3% reported independent stair climbing. Independent functional walking in the community is an important issue for stroke survivors living at home at six months (Dobkin 2004). Only a third of participants reported independence in their use of public transport, and lack of transport was one of the most frequently reported barriers to function in the environmental questionnaire.

It is noted that many of the difficulties with EADL and resumption of pre-stroke roles would only become apparent after the patient had returned home and therefore follow up after discharge may be necessary to address these needs fully.

5.3.4.4 Health Related Quality of Life (HRQoL)

In spite of their limitations, participants in the sample reported a fairly high Health Related Quality of Life according to the EQ-5D Visual Analogue Score (mean 71 ± 18.7 SD). This is lower than that reported in large community sample living in low resource area in Cape Town (Jelsma J and Ferguson 2004), and a community sample used as a control group in a study in Khayelitsha (80.13 ± 20.4SD) (Hughes, Jelsma, MacLean, Darder and Tinise 2004; Jelsma J and Ferguson 2004). It is higher than that reported by people living with HIV before the commencement of anti-retroviral therapy (60.4 ± 22.1SD) in a sample drawn from a similar catchment area (Jelsma J, MacLean E, Hughes, Tinise X and Darder M 2004).

The percentages of participants in the study reporting problems in the domains of the EQ-5D were substantially greater than those reported in community samples (Hughes, Jelsma et al. 2004; Jelsma J and Ferguson 2004). (See Table 5-3)

Table 5-3 Comparison of Percentages of Participants Reporting Problems in the EQ-5D Domains in the WCRC Study Sample, a Resource Poor Community in Cape Town* and a Community Sample in Khayelitsha

EQ-5D Domain	WCRC Stroke Study Sample (Percentage)	Community Sample Woodstock (Percentage)	Community Sample (Khayelitsha)#
Mobility	52	21	15
Self-care	30	4	5
Usual Activities	61	13	10
Pain/ Discomfort	59	40	33
Anxiety/ Depression	50	36	24

***Refers to a study conducted by Jelsma and Ferguson (2004) in the Woodstock community in Cape Town, South Africa**
 # refers to a community sample used as a control group in a study reported by Hughes et al (2004)

In terms of potentially modifiable components of HRQoL it is noted that a high percentage of participants (59%) reported problems with pain/ discomfort and anxiety/depression (50%). Depression has been reported in 36% of stroke survivors in a long term follow up in the UK (Wilkinson, Wolfe et al. 1997) and is said to affect up to 40% of stroke survivors (Bhogal, Teasell, Foley and Speechley 2004). It impacts negatively on recovery after stroke and is known to affect levels of handicap and participation in social activities (Bhogal, Teasell, Foley and Speechley 2004; Sturm, Donnan et al. 2004). Interventions that may reduce levels of depression include after-discharge programs (Kotila, Numminen, Waltimo and Kaste 1998) and medication (Bhogal, Teasell, Foley and Speechley 2004).

The "after-discharge" programme described by Kotila (1998) included group physiotherapy, encouragement to participate in social activities of a support organisation and assistance with adapting to life after stroke. It is of interest that four participants in the WCRC sample had been involved in stroke groups or support groups after their discharge. These groups were run by volunteer organisations, or at Community Health Care Centres.

5.3.4.5 Caregiver Strain

More than half of caregivers in this study (55.8%) reported significant caregiver strain which is markedly higher than in other studies in the UK in which 21.6% to 37% of respondents reported strain (Wilkinson, Wolfe et al. 1997; Bugge, Alexander and Hagen 1999; Blake, Lincoln and Clarke 2003).

There are differences in the frequencies of individual factors identified as contributing to caregiver strain. The top five most frequently reported items in the WCRC study included two items that were prominent in other studies: namely, changes in personal plans and that it was upsetting that the patient had changed so much from their former self (Wilkinson, Wolfe et al. 1997; Blake, Lincoln and Clarke 2003). However, financial strain and work adjustments featured very highly and were reported by 66.7% and 54.8% of respondents respectively. Emotional adjustments were reported by 57.1%.

A number of factors are likely to contribute to this high incidence of caregiver strain. In the absence of support services for caregivers looking after patients with stroke at home, and considering the number of patients requiring assistance in activities of daily living, the burden of care giving falls largely on informal caregivers who are often poorly prepared for this role. In the WCRC study, patients with severe strokes requiring 24 hour care were largely living within the community (nine of the 10 patients in this category). This would place an enormous burden on caregivers who mostly did not receive any formal support services after discharge. By contrast, very severe strokes in high income countries are more likely to be discharged into institutionalised care.

Only one fifth of participants in the study were completely independent in basic ADL according to the BI, and participants who were independent with self-care may still have required assistance with tasks such as shopping, household management and cooking. In overseas studies patients unable to cook, clean and shop may receive assistance from social services, which may assist in relieving caregiver strain (Wilkinson, Wolfe et al. 1997). In the South African context there is little access to these kinds of services, and volunteer organisations only reach a small number of patients.

The role of financial concerns in caregiver strain is not surprising. Participants were largely from low income households and would have limited financial resources to employ paid caregivers, and make alternative arrangements for transport. Furthermore, only a small number of participants who were working prior to stroke had returned to work at six months (n=3) suggesting loss of income. Although disability grants had been applied for in most cases of the patient being unable to work, many participants were still waiting for this to be finalised at the time of the six month assessment (n=17). For some patients the disability grant would have constituted a drop in monthly income. (In 1996 disability grants and pensions amounted to R820 per month).

Another dimension is that family members are sometimes required to give up their work to look after the patients, for some families resulting in a double loss of income, and this is reflected by the high percentage of caregivers reporting work adjustments. In a US study 25% of caregivers under 65 years reported having had to make work adjustments in the early stages after stroke (Grant, Glandon et al. 2004). A South African study in 1994 indicated that in 17% of families of older patients with stroke someone had to give up work to look after the patient (Whitelaw, Meyer, Bawa and Jennings 1994).

The high incidence of caregiver strain at six months raises the question of what can be done to improve the situation. A number of interventions have been shown to impact positively on caregiver strain. These include information provision and opportunities for peer support. The majority of caregivers had been reported by the WCRC staff to have been involved in discharge planning and had received training either verbally, or by way of demonstration. The researcher did not verify the degree to which this training had been understood or been found to be useful to the care-givers and this is an important topic for future research. However, even if the training were adequate, there was no organised caregiver support after discharge and this may be a potential area of intervention to reduce caregiver strain.

5.3.4.6 Return to Work

Return to work or productive activity is considered to be an important rehabilitation goal, however only three participants in the study had returned to work by the time of the six month assessment (Approximately 10% of those who were working prior to their stroke). This compares to 17 - 51.4% in overseas studies of working age patients with stroke (Teasell, McRae and Finestone 2000) and 40% of breadwinners in a previous hospital based stroke study in Cape Town (Whitelaw 1994).

The low proportion of participants returning to work may be the result of a number of factors and requires further exploration, particularly as 40% of the participants who were working prior to stroke felt that they would be able to work despite some restrictions. Of particular interest are the nine participants who were working prior to their stroke and reported no or slight disability at six months. Possible factors that may influence return to work include type of work pre-stroke, the presence of a cognitive deficit and environmental factors such as support from employers and the work environment. The small size of this subgroup prohibits statistical exploration.

Another factor to consider is the influence of disability grants. Unemployment rates are high in the Western Cape particularly amongst unskilled workers. Once in place, disability grants are a reliable source of income, and in many instances support entire families. A stroke patient may be reluctant to give up a disability grant, in order to take up an insecure position in a competitive job market, in which he/she may feel at a disadvantage. In the event of job loss, the disability grant may not be reissued. It is conceivable that these factors may influence return to work in patients with stroke.

5.3.5 The Environmental Context of Recovery

Environmental factors are known to be extremely important in influencing function but they are particularly difficult to describe and measure. This research project attempted to identify participants for whom environmental factors may have influenced outcome. To some extent baseline data on income and housing can be used to identify participants who may be at risk due to unfavourable environmental circumstances. However, the subjective perception of factors as barriers or facilitators is probably a better indication of the effects of the environment on outcome.

The ICF Checklist integrates environmental barriers and facilitators into the description of disability; however, it was thought not to be a suitable tool for use in this study. Firstly it is lengthy to apply: ICF Short List of Environment comprises 32 items that can be identified as barriers or facilitators. Secondly, concepts of barriers and facilitators may not be easily understood by participants, and reporting environmental barriers and facilitators is highly dependent on the participant's insight and expectations. The Environmental Questionnaire was drawn up specifically for use in the study. It is based on the ICF checklist in that items can be linked to items on the checklist, but it constitutes only a small percentage of the many potential barriers and facilitators. Items were worded in such a way as to link environmental factors with functional activities in order to make the questions more tangible.

Unfortunately, the instrument was found to have serious limitations, not least of which was the fact that some seemingly identical factors were identified as both barrier and facilitator. Wording of the questionnaire may have inadvertently contributed but this was not detected in the pilot study. For example, transport may have been a barrier to participation in activities outside the home, but there may also have been a family member who could drive the participant to hospital appointments which could be considered a facilitator. The format of the questionnaire was such that it was possible for participants to report transport as both barrier and facilitator, resulting in ambiguity of results. It was noted that although participants appeared to have some difficulty conceptualising facilitators, reporting of barriers appeared more reliable, as the participant related the effect of a specified factor to limitations in specific activities.

However, despite the limitations of the instrument, reported barriers showed some correlation with negative outcomes, suggesting that it did provide some valid information. Lack of transport and finances were the most commonly reported environmental barriers. In particular, low income and the presence of at least on reported barrier were seen to be associated with poor outcomes at six months in terms of MRS Scores.

Further studies for developing instruments that accurately describe environmental barriers and facilitators for use in the South African context are recommended. Qualitative studies may be more suited to exploring the effects of environmental factors than closed questionnaires.

5.3.6 Factors Influencing Outcome

The Modified Rankin Score was selected as the main outcome measure because it provided a broad view of function beyond disability by addressing participation in pre-stroke roles. The BI by contrast addresses only disability, and has a recognised ceiling effect, as seen by the fact that more than 20% of participants had already achieved the maximum score of 100 by discharge. The disadvantage of using a more comprehensive measure of outcome such as the MRS is that a wider range of factors may influence MRS scores including environment and rehabilitation process, and the effects of individual factors may be obscured. This may be one of the reasons why a number of factors were significant on bivariate testing, but did not retain their significance when entered with other variables into a logistic regression model.

However, it was not the intention of the study to draw up an equation for a prediction model, and no attempt was made to replicate existing large studies in non-selected populations by examining all possible factors that may influence outcome This would have been unrealistic in terms of the small sample size. It has been suggested that for each variable entered into a logistic regression model, there should be five participants for each outcome of interest (Davenport, Dennis and Warlow 1996). In this sample, where only 10 participants achieved a favourable outcome, only two variables are likely to be able to be fitted into the same model.

Logistic regression was used in order to explore interactions between factors of interest and outcome both individually and in combination. When examined individually, four factors emerged as significant: NIHSS at admission, BI at admission, the presence of a reported environmental barrier and number of rehabilitation days. Although at face value the odds ratio of an environmental barrier implied a large influence, the confidence interval (CI) was wide suggesting that it may or may not have had a large influence. The narrowest CI's were for number of rehabilitation days and BI on admission, but these factors appeared to have a smaller effect. The NIHSS with its substantial odds ratio and moderately broad confidence interval probably had the clearest effect on outcome. This is in line with literature which suggests that severity of stroke at admission is the most important predictor of outcome (Teasell 2004c).

The predictive value of severity of stroke on admission (NIHSS) and severity of disability on admission (BI) were entirely expected on the basis of previous literature (Kwakkel, Wagenaar, Kollen and Lankhorst 1996; Adams, Davis et al. 1999). Other widely accepted indicators of severity (urinary incontinence and sitting balance at admission) were found to be significantly associated with outcome in the bivariate analysis, but were not suitable for inclusion with the NIHSS in the logistic regression model due to their overlap as indicators of severity.

It was of considerable interest that the presence of an environmental barrier was seen to impact on the odds of a favourable outcome, although the uncertainty of the effect size is noted. Consistent with this finding, both reported environmental barriers and income were found to be statistically significant on bivariate analysis.

Unexpectedly, increased number of rehabilitation days appeared to increase the chances of an unfavourable outcome. However, the apparent relationship was interpreted to be due to the close correlation of number of rehabilitation days with severity of stroke (NIHSS). Especially as the MRS ordinal score and number of rehabilitation days were not found to be correlated in data exploration, while severity (NIHSS) and number of rehabilitation days were correlated. The interaction between severity, onset admission interval, and length of stay was examined in a logistic regression model. However, none of the factors retained significance in this model, and the Chi-square and p values indicated it was not a good fit. It was thought that the small sample size did not allow sufficient adjustment for the effects of multiple factors. More severe strokes in this study experienced longer admissions, possibly due to a longer time course of recovery and a higher incidence of complications and medical problems. This was apparent for at least two participants in the study: one had delayed discharge due to repeated bladder infections, and the other had an extended period of bed rest due to a pressure sore. In addition, it may be the intensity of therapy received that has the positive benefit rather than length of stay.

Onset admission intervals were unexpectedly found to be statistically insignificant in the multivariate analysis despite previous reporting that early commencement of rehabilitation is an important factor influencing outcome (Cifu and Stewart 1999). This emerged consistently in the results of this study. The repeated measures ANOVA showed no influence in terms of recovery over time, and there was no significant association with discrete outcome at six months in the bivariate and multivariate analyses. The relatively small number of participants experiencing a favourable recovery, and the uneven distribution of participants in the two groups may have played a role in this unexpected finding. Furthermore, dichotomising onset-admission intervals at a cut off point of 30 days may have blunted the effect on recovery and outcome. Alternatively, there may have been other more important factors masking the influence of onset admission interval.

Inherent characteristics of patients with stroke such as age and gender were not found to be statistically significant on bivariate or multivariate analysis. It was particularly surprising that age was not found to be a significant factor. A negative association between increasing age and functional outcomes is frequently reported in literature (Kwakkel, Wagenaar, Kollen and Lankhorst 1996; Sturm, Donnan et al. 2004). A sample population with a young average age would therefore be expected to demonstrate better functional recovery than an equivalent older sample (Teasell, McRae and Finestone 2000). However, the effect of age on expected outcomes and pattern of recovery is complex, and a Canadian study found that only a small amount of the variance in outcome was explained by age alone after adjusting for other factors (Bagg, Pombo and Hopman 2002). Other factors in the WCRC stroke population may have a more powerful effect. Furthermore, the stroke population at WCRC exhibits a very different age profile compared to other stroke populations overseas. Not only were mean ages in the sample lower than in overseas studies but age was seen to be normally distributed, when one would expect it to be skewed to older ages.

Only 20% of participants were aged above 65 years. It may be argued that the negative effects of age are more evident, with increasing age, as co-morbidities increase and the ability of patients to learn compensatory strategies decreases. For example, an age difference of ten years may be greater between 70 and 80, than it is between 40 and 50. A unique feature of the study population at WCRC may be that several of the younger participants were immuno-compromised (n=6) and this might have a global effect on their health. Furthermore, although younger patients demonstrate better functional recoveries in ADL, some studies have reported poorer outcomes in terms of participation in social and leisure activities and health related quality of life (Bhogal, Teasell, Foley and Speechley 2003). This is thought to be due to high expectations and previous levels of activity in younger people.

In summary, it was not possible to fit a good model of logistic regression to multiple factors. The sample size was too small to overcome interactions between factors. However, bivariate analysis and individual entering of variables in the logistic regression model gives some insight into which factors may be influencing outcome and this was ultimately the objective of the study. Indications are that the severity of stroke on admission (in terms of BI and NIHSS) is one of the most important factors influencing outcome. However, environmental factors such as income group and the presence of environmental factors may mediate this effect. No clear effect was found with regard to aspects of the rehabilitation process such as onset admission interval and length of stay. Inherent factors such as age, gender and co-morbidities were not demonstrated to influence outcome. The small sample size is expected to have limited the power of the analysis. In addition, there are limitations of the chosen method of analysis as choosing to dichotomise MRS outcomes for the multivariate analysis may have resulted in loss of detail as shifts in independence may not have been noticed.

The limitations of this study to detect the influence of factors on outcome, highlights the need for large sample sizes in stroke studies in order to compensate for the effect of multiple influencing factors on outcome.

5.4 Methodological Considerations

5.4.1 The Sample

The sample is representative of patients with first ever stroke admitted to the WCRC, but bias may have been introduced by the exclusion of participants with cognitive and speech deficits whose next of kin were uncontactable within the required time frame. These participants are likely to have had more severe strokes. This could have been avoided by extending the window period for initial assessment. However, the baseline assessments of participants would then have been biased as their rehabilitation programme would already have commenced by the time of initial assessment. Furthermore, rate of change is most rapid in patients soon after stroke and this may also have influenced findings at admission to the study.

Participants with missing data at discharge were not excluded from the study as they could still be assessed for outcome at six months. However, all participants with data missing at discharge or six months needed to be excluded from the analysis for pattern of recovery. In total, the number of participants excluded did not exceed 15%. Characteristics of participants who dropped out of the study were not discernibly different from the characteristics of the sample. However, it is unfortunate that one of the participants with HIV/ AIDS dropped out as this sub-group of particular interest was already quite small.

5.4.2 Late Assessments

Some participants at the six month assessment were assessed outside of the ten day time frame (five days before or five days after the six month time point). In most cases, the assessments were only slightly late. In one case where the assessment was one month late, it could be argued that the data should be excluded in case the patient had significantly deteriorated or improved since the six month mark. However, in this instance the patient had been very high functioning at the time of discharge and there had been little change between discharge and the six month assessment in terms of functional or motor recovery. In addition, it has been suggested that levels of activity are maintained for up to one year after stroke (Kwakkel, Kollen and Lindeman 2004). It was decided not to exclude him of these grounds. In addition, he was a case of interest because in spite of his relatively mild stroke, he had not returned to work and reported major loss of role that may have been out of proportion to his levels of impairment.

5.4.3 The Study Design

5.4.3.1 Choice of Time Frames

The initial assessment was conducted within the first few days of admission to the rehabilitation facility. Participants varied at this time in terms of the length of time that had elapsed since their stroke. As it is known that relatively rapid recovery occurs within the early stages after stroke, participants were not on an equal footing at baseline. The eligibility criteria were defined as 0-3 months post stroke. Most participants were actually admitted within the first six weeks. From the pilot study it appeared that onset-admission intervals would be longer, and one of the reasons for the wide time frame for admission was that the researcher expected to find differences with regard to outcome in participants being admitted early or late for rehabilitation. This was not the case.

Discharge was chosen as a significant time point in this study; however, again it is noted that participants were all at very different times post stroke at the time of their discharge (26 to 160 days). 51.0% of participants were discharged within the first three months after stroke, and as this is a period in which most change is expected, many participants may not yet have reached a plateau in terms of function, and might account for the improvement noted after discharge.

Six months post stroke is a commonly selected end point for stroke rehabilitation studies. Existing literature suggests that at this time, spontaneous recovery is complete and that subsequent changes are small (Teasell and Bitensky 2004b).

5.4.3.2 Choice of Outcome Measures

One of the major concerns with this study was whether the outcome measures would be appropriate for use in the local context in terms of content, as well as whether translation of the questionnaires into Afrikaans and Xhosa interfered with the integrity of the instruments. However, an extensive pilot study suggested that the reliability and face validity of the outcome measures were adequate. In addition the measures were relevant to the subjects tested and sensitive enough to detect change. Forward and backward translation procedures were employed to avoid introducing error during translation, and the piloted Xhosa and Afrikaans versions did not appear to be problematic.

Post hoc analysis showed that the NIHSS correlated highly with BI scores at admission, as well as outcome at six months thus demonstrating predictive and concurrent validity. Error may have been introduced by the language item of the NIHSS, but this constituted only a small difference in scores. In addition, the design of the tool is such that that the language item only serves to confirm the impression the tester has already formulated of the patient's language ability during the interview.

The outcome measures for recovery, the BI and the RMA were seen to be responsive enough to detect change across the three time points of study. Scores at admission, discharge and six months were highly correlated with each other, showing good predictive validity. Participants in informal housing or without access to services may have been disadvantaged in terms of BI scores due to different physical requirements of the tasks involved but no significant association was found between housing and outcome. However, the small number in this group may mean the power was insufficient to detect differences.

The MRS appeared relevant to participants, and no cultural or environmental issues arose with regard to its use. It was highly correlated with the BI and EADL at six months indicating good concurrent validity.

The EADL is perhaps the measure that can be most criticised for not being culturally appropriate. At face value, there are two possible problems with this tool. As the EADL measures actual performance rather than capacity, participants who did not need to perform certain activities received lower scores, which may not have reflected their ability. For example, patient who did not need to do housework because it was not their usual role would score the same as someone who used to do housework before their stroke but was now unable. This is not a feature unique to its South African application. A gender bias, may be introduced if male members of a household were not involved in activities such as housework or meal preparation due to gender roles. In some households, an age bias may have occurred where an elderly person was looked after by a relative, and there was no expectation for the older person to be involved in housework. There may also have been a bias in terms of socio-economic status. Driving a car was not relevant to a large number of participants who did not drive a car pre-morbidly. These potential sources of bias were noted at the time of the pilot study. The researcher considered asking participants who had not performed an item whether the reason was because they did not need to, or did not want to.

However, assessments were already quite lengthy and the researcher decided that the added increase in time was not justified. Supplementary information such as kind of transport used prior to stroke and socio-economic status were gathered in the Questionnaires at Discharge and Six Months. Furthermore, the value of this tool is in the descriptive information that it provides. No established scores denoting good recovery have been found in literature and in any case, it is probably not advisable to make comparisons of total scores between different cultural settings for an outcome measure of this nature.

The Caregiver Strain index was found to be useful for detecting caregiver strain. There was a statistically significant correlation between the CSI at six months and the NIHSS at admission, as well as BI at six months. This relationship is expected. A number of factors have been identified in literature as influencing caregiver strain so the relatively weaker correlation than those seen between other measures is expected.

The EQ-5D visual analogue score was not seen to correlate with any of the other outcome measures used in the study. This probably reflects the multi-dimensional nature of health related quality of life, and is not a concern regarding its validity. The EQ-5D has already been validated within a South African population, and shown to be useful in a number of research contexts (Jelsma J, MacLean E et al. 2004; Jelsma, Amosun, Mkoka and Nieuwveld 2004).

Although the limitations of the selected outcome measures are noted, it was decided that their use could be supported. Developing an outcome measure specifically for local use is lengthy and expensive and no existing local measure is in existence. The Soweto Stroke Questionnaire (SSQ) (Hale, Eales and Fritz 1998) would partly have fulfilled this need but to the knowledge of the researcher, published outcome studies have not reported its use beyond a report of its development and reliability and validity testing (Hale, Eales and Fritz 1998). Furthermore this study required more extensive investigation of outcomes with other tools, and then there would have been overlap and redundancy. Use of internationally recognised outcome measures allows for comparison of results between studies.

5.5 Limitations of the Study

The sample for this study was a selected group of patients with stroke and results are therefore not generalisable to the SA stroke population as a whole.

This was not an intervention study. It was beyond the scope of the project to investigate in detail the content of rehabilitation therapies at the centre. In addition, there were no means of standardising the treatment received between participants although all participants received "usual care". Furthermore, it was not possible to isolate the effect of rehabilitation from the effects of natural spontaneous recovery.

There are a large number of factors that may influence outcome, both in terms of inherent case mix indicators, as well as external factors. The sample size was relatively small. Therefore it was not possible to investigate all possible factors without increasing the risk of Type 2 errors, and finding spurious associations. It was decided to focus on a few specific factors that were thought to influence outcome based on literature, and following discussion with clinicans working in the field.

A number of inherent differences were identified in characteristics of the WCRC sample compared to those in studies in other countries. It is also noted that that social and environmental resources may influence local results and distort comparisons with studies conducted elsewhere. This needs to be considered in interpretation of results.

6 CONCLUSIONS AND RECOMMENDATIONS

Pattern of recovery and outcome after stroke in patients with first ever stroke at the WCRC were seen to be similar to those reported in other studies. Certain important differences were identified that may arise from differences in patient characteristics, aspects of the rehabilitation process and environmental factors.

Pattern of recovery showed a more or less expected course over time with more rapid change seen between admission and discharge than between discharge and six months. Gains were seen in functional independence and motor recovery, although the upper limb was less responsive to treatment than gross mobility and lower limb and trunk items. Patients showed improvement over time regardless of their categorised severity, and a proportion of severe strokes also exhibited favourable outcomes, suggesting that this group should not be denied rehabilitation access on the grounds of severity alone. The high percentage of participants showing clinically significant improvement between admission and discharge implies the rehabilitation programme was effective and patients were appropriately selected for admission.

Surprisingly, clinically significant change was also seen between discharge and six months in terms of functional recovery, as well as motor recovery, particularly for higher mobility tasks. This occurred in spite of little follow up having been received after discharge. A number of patients fell within the 90 day recovery window at the time of discharge and neurological recovery may have been ongoing at this time. As rehabilitation can enhance recovery, these improvements may reflect untapped rehabilitation potential that should be capitalised on in order to optimise rehabilitation outcomes. Only a small number of participants demonstrated clinically significant deterioration between discharge and six months.

Surprisingly pattern of recovery was not shown to follow a significantly different course in patients stratified by severity category or by early/ late admission after stroke. This apparent lack of effect may be a true reflection; however, it is expected to be due to the small sample size, uneven distribution of participants between sub-groups, or to the influence of other more powerful factors that confounded the effect on outcome.

In general, outcomes at six months post stroke appeared better than those reported in previous South African studies but less favourable than outcomes in studies in developed countries. Although the nature of the problems was similar, the extent of the problems differed. This was not seen so much at the level of activities of daily living as it was with more complex extended activities of daily living and in the area of participation restrictions. Factors such as adverse environmental conditions and lack of follow up after discharge may have contributed to less favourable outcomes in these areas.

Barthel Index scores at six months were comparable to other studies including those conducted in developed countries. At six months post stroke, most participants were either independent or required only minimal assistance with ADL. Most difficulties related to housework, meal preparation, use of public transport, going out socially and shopping. A high incidence in participation restrictions were reported in all pre-stroke roles (including social and leisure activities, work, and family responsibilities) reflecting the profound impact of stroke even in the absence of severe disability. More than half the participants reported depression or anxiety, and over 80% reported difficulties with relationships or social isolation. Furthermore, a high level of caregiver strain was observed compared to other studies. Lack of community mobility and difficulties with using public transport are likely to contribute to difficulties with activities outside of the home.

Differences in outcomes need to be considered in terms of the characteristics of the sample population as well as contextual environmental factors. Patients at the WCRC have certain unique features differentiating them from stroke populations in rehabilitation studies in developed countries. Firstly patients are considerably younger, introducing possible differences in recovery pattern and expected outcomes, and certainly influencing the needs of patients during and after their rehabilitation stay. Secondly there are major differences in medical profile: namely a greater proportion of haemorrhagic strokes as well as different risk profiles. Modifiable risk factors such as high blood pressure, diabetes and lifestyle factors were prevalent in the study sample, and should be addressed as part of the rehabilitation programme to prevent recurrence of stroke. Co-morbidities in the study reflected a high incidence of infective illnesses such as HIV/AIDS, tuberculosis and syphilis. In particular, the high proportion of young patients under 40 years of age with HIV/ AIDS is highlighted.

With regard to the rehabilitation process at WCRC the following features were noted: There was good access to rehabilitation with referrals from a wide range of sources, fairly short waiting times and relatively few complications reported on admission. Nearly all patients demonstrated clinically significant changes over their rehabilitation stay confirming the effectiveness of the programme. Lengths of stay were similar to those reported elsewhere, maybe even slightly longer than current trends in the United States, for example. However, in other countries early discharge from rehabilitation is often supported by follow up at home or in the community and this did not occur in the study sample.

The environmental context of recovery is expected to have played a major role. Participants in the study were mostly from low income homes and environmental features in a resource poor situation are expected to play an important role as barriers to functioning. Low monthly household income, an indicator of socio-economic status, was seen to be negatively associated with outcomes. The nature of informal housing and features of low cost housing such as the absence of an indoor toilet, running water and electricity is expected to have influenced functioning after stroke, although these features were present in a relatively small percentage of participants (10-25%). These factors are unknown in studies in developed countries. In particular, lack of transport and financial difficulties were identified as major barriers to function, and the presence of at least one reported barrier on the environmental questionnaire was seen to significantly reduce the likelihood of a favourable MRS outcome. It was beyond the scope of the study to explore environmental factors in any great depth.

An exploration of factors influencing outcome after stroke (defined by MRS category) revealed that the clearest determinant of outcome was the NIHSS score on admission to the WCRC reflecting severity of stroke. Other indicators of severity found to be associated with unfavourable outcomes included urinary incontinence, lack of sitting balance and disability at admission to the study. These findings suggest that in terms of the nature and severity of stroke, the study population responded similarly to those reported elsewhere. However, the influence of environment was also apparent, with the presence of at least one reported environmental barrier considerably lowering the chance of achieving a favourable outcome. In terms of rehabilitation process, contrary to expectations, onset admission interval was not demonstrated to influence outcome. Total number of rehabilitation days was found to be negatively associated with outcome, but was excluded on account of the high correlation between severity of stroke and length of stay, as this was considered to be the underlying reason for the association. No associations were found with co-morbidities, gender or age. The lack of influence of age was unexpected on the basis of previous studies but probably reflects the very different distribution of ages in the study population compared to studies elsewhere, and the markedly lower mean age. It is acknowledged that small sample size limits the potential to explore the relationship between factors and outcome, and for this reason only certain selected factors were investigated.

In terms of the internal validity of the study, the study sample was thought to represent patients with first ever stroke at the WCRC. As a selected population, results cannot be extrapolated to the wider stroke population of South Africa. However, outcomes in this patient group are of particular interest. The WCRC is considered a flag ship for pioneering best practice in rehabilitation in the South African context. Inpatient rehabilitation is known to be expensive and the opportunity is not afforded to all patients with stroke. The centre is fairly recently established and to date, no outcome studies have been published. The study was limited by the fact that it was simply an observational study. There was no comparison with a control group, and treatment at the WCRC was "usual care" rather than a standardised protocol. However, in spite of this, valuable information was obtained regarding pattern of recovery and outcome in patients with first ever stroke undergoing rehabilitation at the WCRC. Baseline information was obtained in terms of the patient characteristics, the rehabilitation process and the environmental context. Certain factors were identified as influencing outcome at six months. The limitations of the small study sample for determining the effect of influencing factors in the study, is a warning regarding the large number of participants required to reflect change in stroke outcome in the presence of many case mix factors.

On the basis of the study, the following recommendations are put forward:

In view of the prevalence of modifiable risk factors, health education is recommended both for at risk populations in the wider community, as well as for rehabilitation patients at the WCRC who are at risk of recurrent stroke. Information provision regarding secondary prevention should form part of the rehabilitation programme.

On the basis of late changes observed, follow up after discharge is recommended. A great deal is invested in inpatient rehabilitation but lack of follow up may negate some of the benefits. The significant change in mobility after discharge implies further input may be warranted, particularly as a number of participants did not have appropriate walking aids at six months. Participation restrictions may arise only once the patient attempts to return to previous activities after discharge, and the low rates of participation and resumption of pre-stroke roles may be more amenable to intervention after discharge. Furthermore, the number of issues arising at six month assessment that required referral for follow up would have largely gone unnoticed had no routine review been followed. Results from pattern of recovery suggest that not all patients undergo clinically significant change after discharge, so patients most likely to undergo improvement or deterioration after discharge should particularly be targeted for follow up.

Specific areas of outcome meriting attention include return to work, especially in this young population where financial stresses feature prominently. A number of participants indicated a reduced ability to work, but felt they would be capable of doing something. Ideally, this group should be targeted for work retraining, or assisted in finding suitable employment. However, the wider context of high levels of unemployment in the region is noted. Patients who are unable to work should be assisted where possible to receive their disability grants as early as possible in order to avoid periods without income.

Community reintegration was seen to be limited by poor community mobility and difficulties accessing public transport. As many of the higher mobility items showed improvement after discharge, and few patients were receiving rehabilitation at this time, it is reasonable to question whether aspects of higher mobility function had been adequately addressed. Crossing roads, negotiating stairs and uneven ground are an important part of community mobility and these items reflected high levels of restrictions. Difficulty using public transport suggests the need for special transport services for the disabled. The Dial-A-Ride Service is a government initiative set up for this purpose. All patients admitted to the WCRC are registered with Dial-A-Ride; however, few patients reported accessing this service. Anecdotally, the service is reported as being effective for regular transport to and from work or school, but its use for once off appointments or arrangements is reported to be problematic. Bookings need to be made far ahead of time, and the free booking telephone service may ring for up to 20 minutes before the call is answered. Although toll free from a landline, calls from cell phones are charged by the minute while waiting and costs may be prohibitive. A review of this service is called for.

High levels of isolation and depression were reported in participants and attention should be paid to how this can be reduced. Only four participants had been involved in stroke groups or support groups and this may be one way to address this problem. Caregivers in particular reported high levels of strain. Options should be investigated for reducing strain in caregivers.

A number of instruments used in the study demonstrated usefulness for use in the local population and are recommended for future research. High correlations between the MRS, EADL, BI, and RMA Gross Mobility scores suggest good concurrent validity. The NIHSS was demonstrated to have good predictive value. The RMA and BI were shown to be responsive enough to reflect change over time in the study population, and were simple to apply. However, the influence of environmental features in the home suggests that caution should still be taken in comparison of BI scores across international studies. The CSI was shown to be useful in identifying caregivers under strain, and the MRS Structured Interview for describing functional status of patients living in the community. No major cultural issues were identified during the study that invalidated their use. Some possible biases were identified with using summed scores of the EADL; however, it remains useful for describing performance on individual items. The Environmental Questionnaire designed for use in the study is not recommended for future studies on account of its limitations.

During the course of the study, several interesting topics arose for future research:

- The co-occurrence between HIV/AIDS and stroke is noted in the high incidence of young participants with HIV/ AIDS. At this stage, it is not known whether the presentation and course of recovery is any different in these patients. As the epidemic progresses, meeting the rehabilitation needs of this sub-group will become increasingly important. Unfortunately, sample size in this study prohibited statistical analysis, and this is recommended as an area of future research
- Further research is recommended to determine the benefits of follow up after discharge from rehabilitation, to identify how this could be provided in an appropriate and cost effective way and to identify whether it should be provided routinely or targeted to patients with the greatest chance of benefiting.
- Research is recommended to explore how caregivers can be best supported to reduce levels of caregiver strain
- The reasons for the low proportion of patients returning to work merit further investigation, and interventions to improve this outcome should be explored

- Further qualitative studies to explore environmental barriers and facilitators to functioning are recommended, as well as studies to develop appropriate measuring tools for use in the local setting

In summary, the study succeeded in describing pattern of recovery and outcome in patients with first ever stroke accessing the WCRC. Pattern of recovery followed a more or less expected course with certain exceptions such as late recovery of mobility items after discharge, and a lack of effect of early versus late admission for rehabilitation. Outcome at six months was similar to that reported in studies in developed countries but a higher prevalence of activity limitations and participation restrictions was noted. High levels of patient depression and isolation, as well as caregiver strain were observed. Differences between characteristics of the study population and those in high income countries were noted and the influence of environmental factors is acknowledged. Recommendations have been made for improving outcomes.

7 REFERENCES

Adams, S., A. Ashburn, et al. (1997). "The scalability of the Rivermead Motor Assessment in Acute Stroke Patients." Clinical Rehabilitation **11**(1): 42-51.

Adams, HPJ, BH Bendixen, L Kappelle, J Biller, B Love, D Gordon and E Marsh (1993). "Classification of Subtype of Acute Ischaemic Stroke. Definitions for use in a multicenter clinical trial. TOAST. Trial of Org 10172 in Acute Stroke Treatment." Stroke(24): 35-41.

Adams, HPJ, PH Davis, EC Leira, K-C Chang, BH Bendixen, WR Clarke, RF Woolsen and MD Hansen (1999). "Baseline NIH Stroke Scale score strongly predicts outcome after stroke." Neurology **53**: 126-.

Ali, SM and GP Mulley (1998). "Is the Barthel Scale Appropriate in Non-Industrialised Countries? A view of rural Pakistan." Disability and Rehabilitation. **20**(5): 195-199.

Altman, DG (1991). Practical Statistics for Medical Research. London, Chapman and Hall.

Andersen, H, K Eriksen, A Brown, K Schultz-Larsen and B Forchhammer (2002). "Follow-up services for stroke survivors after hospital discharge- a randomized control study." Clinical Rehabilitation **16**: 593-603.

Ashburn, A (1997). "Physical recovery Following Stroke." Physiotherapy **83**(9): 480-490.

Astrom, M, K Apslund and T Astrom (1992). "Psychosocial function and life satisfaction after stroke." Stroke **23**: 527-531.

Bagg, S, A Pombo and W Hopman (2002). "Effect of age on functional outcomes after stroke." Stroke **33**: 179-185.

Bamford, J (1991). "Classification and natural history of clinically identifiable subtypes of cerebral infarction." The Lancet **337**(8756): 1521(6).

Bamford, J (1992). "Clinical examination in diagnosis and subclassification of Stroke." The Lancet **339**(8790): 400(3).

Banks, J and Marotta, C. (2007). "Outcomes Validity and Reliability of the Modified Rankin Scale: Implications for Stroke Clinical Trials" Stroke. **38**: 1091.

Barnes, J and D Yach (1991). A Survey of Health Aspects of Black Elderly Living in a Settled and a Newly Developed Township in the Cape Town Metropolitan Area. MRC: Urbanisation and Helath National Programme Technical Report No. 11, March 1991.

Beech, R, M Ratcliffe, K Tilling and C Wolfe (1996). "Hospital Services for Stroke Care: A European Perspective." Stroke **27**: 1958-1964.

Belanger, L, M Bolduc and M Noel (1988). "Relative importance of after-effects, environment and socio-economic factors on the social integration of stroke victims." International Journal of Rehabilitation Research **11**(3): 251-60.

Bhogal, S, R Teasell, N Foley and M Speechley (2003). "Community Reintegration After Stroke." Topics in Stroke Rehabilitation **Summer Vol 10**(2): 107-123.

Bhogal, S, R Teasell, N Foley and M Speechley. (2004, 2/03/04). "Post Stroke Depression." Evidence-Based Review of Stroke Rehabilitation 5th Edition. Retrieved 27/05/04, from www.ebrsr.com.

Bitensky, j, R Teasell, K Salter, S Bhogal, N Foley and M Speechley. (2004). "Cognitive Disorders and Apraxia." Evidence Based review of Stroke Rehabilitation, from www.ebrsr.com.

Black-Schaffer, R and C Winston (2004). "Age and functional outcome after stroke." Top Stroke Rehabilitation **Spring 11**(2): 23-32.

Black-Schaffer, RM, AE Kirsteins and RL Harvey (1999). "Stroke Rehabilitation. 2. Co-morbidities and Complications." Arch Phys Med Rehabil **80**(May): S8-S16.

Blake, H, N Lincoln and D Clarke (2003). "Caregiver Strain in Spouses of Stroke Patients." Clinical Rehabilitation **17**: 312-317.

Bode, R, AW Heinemann, P Semik and T Mallinson (2004). "Relative Importance of Rehabilitation Therapy Characteristics on Functional Outcomes for Persons With Stroke." Stroke **35**: 2537-2542.

Bogoshi, G, A Stewart and L Hale (2003). "Knowledge of stroke risk factors amongst black diabetic, hypertensive and stroke patients." SA Journal of Physiotherapy. **59** (4): 25-30.

Bonita, R (1992). "Epidemiology of Stroke." Lancet **339**(8789): 342-4.

Bonita, R, S Mendis and T Truelson (2004). "The Global Stroke Initiative." **3**(July): 391-393.

Bonita, R, N Solomon and JB Broad (1997). " Prevalence of stroke and stroke-related disability. Estimates from the Auckland stroke studies." Stroke **28**: 1898-1902.

Bonita, R and T Truelson (2003). "Stroke in Sub-Saharan Africa: a neglected chronic disease." The Lancet Neurology **2**(October): 592.

Bradshaw, D, M Schneider, R Dorrington, D Bourne and R Laubscher (2002). "South African Cause-of-death Profile in Transition- 1996 and future trends." SA Medical Journal **92**(8): 618-623.

Bresick, G (1997). "Caring for the carer: managing the family of the stroke patient." CME **15**(3): 305-310.

Bugge, C, H Alexander and S Hagen (1999). "Stroke Patients' Informal Caregivers: Patient, Caregiver, and Service Factors That Affect Caregiver Strain." Stroke **30**(8): 1517-1523.

Burton, C (2000). "Living with stroke: a phenomenological study." Journal of Advanced Nursing. **32**(2): 301-309.

Carod-Artal, J, JA Egido, JL Gonzalez and V de Seijas (2000). "Quality of Life Among Stroke Survivors Evaluated 1 Year After Stroke: Experience of a Stroke Unit." Stroke **31**: 2995-3000.

Chae, J, R Zorowitz and M Johnston (1996). "Functional Outcome of Hemorrhagic and Nonhemorrhagic Stroke Patients After In-patietn Rehabilitation." American Journal of Physical medicine and Rehabilitation **75**: 177-182.

Chang, A and A Mackenzie (1998). "State Self-Esteem Following Stroke." Stroke **29**: 2325-2328.

Cieza, A, T Ewert, U Berdirhan Ustun, S Chatterji, N Kostanjsek and G Stucki (2004). " Development of ICF Core Sets for Patients with Chronic Conditions." J. Rehabil Med(Suppl. 44): 9-11.

Cifu, DX and DG Stewart (1999). "Factors Affecting Functional Outcome After Stroke: A Critical Review of Rehabilitation Interventions." Arch Phys Med Rehabil **80**(May): S-35-S39.

Cole, B, E Finch, C Gowland and N Mayo (1995). Physical Rehabilitation Outcome Measures. Maryland, USA., Williams and Wilkins.

Collen, FM, DT Wade, GF Robb and CM Bradshaw (1991). "The Rivermead Mobility Index: a further development of the Rivermead Motor Assessment." Int Disabil Stud. **13**(2): 50-54.

Connor, M and A Bryer (2006). Stroke in South Africa. Chronic Diseases of Lifestyle in South Africa: 1995-2005. Technical Report. K Steyn, J Fourie and N Temple. Cape Town, South Africa., South African Medical Research Council.

Connor, M, P Rheeder, A Bryer, M Meredith, M Beukes, A Dubb, V Fritz and obotSAS Foundation) (2005). "The South African Stroke Risk in General Practice Study." South African Medical Journal **95**(5): 334-339.

D'Olhaberriague, L, I Litvan, P Mitsias and HH Mansbach (1996). "A Reappraisal of Reliability and Validity Studies in Stroke." Stroke **27**: 2331-2336.

Davenport, RJ, MS Dennis and CP Warlow (1996). "Effect of correcting outcome data for case mix: an example from stroke medicine." BMJ **312**(15 June): 1503-1505.

Davis, JP, AA Wong, PJ Schluter, RD Henderson, JD O'Sullivan and SJ Read (2004). "Impact of Premorbid Undernutrition on Outcome in Stroke Patients." Stroke **35**: 1930- 1934.

De Haan, R, M Limburg, P Bossuyt, J van der Meulen and N Aaronson (1995). "The Clinical Meaning of Rankin 'Handicap' Grades after Stroke." Stroke **26**: 2027-2030.

de Jong, G, L van Raak, F Kessels and J Lodder (2003). "Stroke subtype and mortality: a follow up study in 998 patients with a first cerebral infarction." Journal of Clinical Epidemiology **56**(3): 262-268.

De Kleijn-De Vrankrijker, M (2003). "The Long Way from the International Classification of Impairments, Disabilities and Handicaps (ICIDH) to the International Classification of Functioning, Disability and Health (ICF)." Disability and Rehabilitation **25** (No 11-12): 561-564.

Desmond, DW, JT Moroney, M Sano and Y Stern (1996). "Recovery of Cognitive Function After Stroke." Stroke **27**: 1798-1803.

Desrosiers, J, A Rochette, L Noreau, D Bourbonnais, G Bravo and A Bourget (2006). "Long-term changes in participation after stroke." Topics in Stroke Rehabilitation **Fall 2006 13**(4): 86-97.

Devey, R., C. Skinner, et al. (2003). Informal Economy Employment Data in South Africa: A Critical Analysis. TIPS and DPRU FORUM 2003: The Challenge of Growth and Poverty: The South African Economy Since Democracy, Indaba Hotel, Johannesburg.

Dewar, SR (1990). "Stroke outcome in the absence of a structured rehabilitation programme." South African Medical Journal **78**: 200-202.

Di Carlo, A, M Lamassa, M Baldereschi, P Giovanni., AM Basile, CDA Wolfe, M Giroud, AG Rudd, A Ghetti and D Inzitari (2003). "Sex Differences in the Clinical Presentation, Resource Use, and 3-Month Outcome of Acute Stroke in Europe." Stroke **34**: 1114-1119.

Dittmar, SS and GE Gresham (1997). Functional Assessment and Outcome Measures for the Rehabilitation Health Professional, Aspen Publishers.

Dobkin, BH (2004). "Strategies for stroke rehabilitation." The Lancet Neurology **3**(September): 528-536.

D'Olhaberriague, L., I. Litvan, et al. (1996). "A Reappraisal of Reliability and Validity Studies in Stroke." Stroke **27**: 2331-2336.

Domholdt, E (2005). Rehabilitation Research: Principles and Applications. St Louis, Elsevier Saunders.

Dorman, P, J Slattery, B Farrell, MS Dennis and P Sandercock (1997a). "A randomised comparison of the EuroQol and Short Form-36 after stroke. United Kingdom collaborators in the International Stroke Trial." British Medical Journal **315**(7106): 461.

Dorman, P, F Waddell, J Slattery, M Dennis and P Sandercock (1997c). "Are proxy assessments of health status after stroke with the EuroQol questionnaire feasible, accurate, and unbiased?" Stroke **28**(10): 1883-7.

Dorman, PJ, F Waddell, J Slattery, M Dennis and P Sandercock (1997b). "Is the EuroQol a Valid Measure of Health-Related Quality of Life after Stroke?" Stroke **28**: 1876-1882.

Dorrington, R, L Johnson, D Bradshaw and T Daniel (2006). The Demographic Impact of HIV/AIDS in South Africa. National and Provincial Indicators for 2006. Cape Town, Centre for Actuarial Research, South African Medical Research Council and Actuarial Society of South Africa.

Duncan, P, S Min Lai, D Tyler, S Perera, D Reker and S Studenski (2002). "Evaluation of Proxy Responses to the Stroke Impact Scale." Stroke **33**: 2593-2599.

Duncan, PW, LB Goldstein, DB Matchar, GW Divine and J Feussner (1992). "Measurement of Motor Recovery After Stroke: Outcome Assessment and Sample Size Requirements." Stroke **23**: 1084-1089.

Duncan, PW, HS Jorgensen and DT Wade (2000). "Outcome Measures in Acute Stroke Trials." Stroke **31**: 1429-1438.

Edwards, S (1996). Neurological Physiotherapy: A Problem-solving Approach, pp 3-14. Singapore, Churchill Livingstone.

Evans, A, F Harraf, N Donaldson and L Kalra (2002). "Randomised Controlled Study of Stroke Unit Care verse Stroke Team Care in Different Stroke Subtypes." Stroke **33**(2): 449-455.

Falconer, JA, BJ Naughton, DD Dunlop, EJ Roth, DC Strasser and JM Sinacore (1994). "Predicting Stroke Inpatient Rehabilitation Outcome Using a Classification Tree Approach." Archives of Physical Medicine and Rehabilitation **75**(June): 619-625.

Farham, B (2004). "Stroke- a neglected chronic disease." CME **22**(6): 340.

Feinstein, A, B Josephy and C Wells (1986). "Scientific and clinical problems in indexes of functional disability." Annals of Internal Medicine **105**: 413-420.

Foulkes, M, P Wolf, T Price, J Mohr and D Hier (1988). "The Stroke Data Bank." 19: 547-554.

Fritz, V (1995). Stroke, including rehabilitation. Chronic Diseases of Lifestyle in South Africa. Review of Research and Identification of Essential HEalth Research Priorities. J Fourie and K Steyn, Medical Research Council**:** 161-175.

Fritz, VU (2000). "New initiatives to prevent and treat stroke in Southern Africa." CME **18**(1): 42-43.

Fultz, N, MB Ofstedal, AR Herzog and RB Wallace (2003). "Additive and Interactive Effects of Co-morbid Physical and Mental Conditions on Functional Health." Journal of Aging and Health **15**(August): 465-481.

Geffen, L (2000). "Surviving stroke- the GP's role in ongoing management." CME **18**(1): 31-34.

Geyh, SK, T.; Brockow, T.; Cieza, A.; Ewert, T.; Omar, Z.; Resch, K. (2004). "Identifying the Concepts Contained in Outcome Measures of Clinical Trials on Stroke Using the International Classification of Functioning, Disability and Health as a Reference." Journal of Rehabilitation Medicine **44**: 56-62.

Gladman, J and C Sackley (1998). "The scope for rehabilitation in severely disabled stroke patietns." Disability and Rehabilitation **20**(10): 391-394.

Gladman, JRF, N Lincoln and SA Adams (1993). "Use of the Extended ADL Scale with Stroke Patients." Age and Ageing **22**: 419-424.

Goldstein, LB and GP Samsa (1997). "Reliability of the National Institutes of Health Stroke Scale." Stroke **28**: 307-310.

Gordon, NF, M Gulanick, F Costa, G Fletcher, BA Franklin, EJ Roth and T Shephard (2004). "Physical Activity and Exercise Recommendations for Stroke Survivors." Circulation **109**: 2031-2041.

Granger, C, L Dewis, N Peters, C Sherwood and J Barrett (1979). "Stroke Rehabilitation: analysis of repeated Barthel Index Measures." Archives of Physical Medicine and Rehabilitation **60**: 14-17.

Grant, J, G Glandon, T Elliot, J Giger and M Weaver (2004). "Caregiving problems and feelings experienced by family caregivers of stroke survivors the first month after discharge." International Journal of Rehabilitation Research **27**(2): 105-111.

Hackett, ML, JR Duncan, CS Anderson, JB Broad and R Bonita (2000). "Health-Related Quality of Life Among Long Term Survivors of Stroke." Stroke **31**: 440-447.

Hajat, C, R Dundas, A Stewart, E Lawrence, AG Rudd, R Howard and C Wolfe (2001). "Cerebrovascular Risk factors and Stroke Subtypes." Stroke **32**: 37-42.

Hale, LA and CJ Eales (2001). "Consulting the South African Experts in Physiotherapeutic Stroke Rehabilitation." SA Journal of Physiotherapy **57**(2): 32-40.

Hale, LA, CJ Eales and VU Fritz (1998). "The Soweto Stroke Questionnaire." SA Journal of Physiotherapy **54**(4): 16-20.

Han, B and W Haley (1999). "Family Caregiving for Patients with Stroke." Stroke **30**: 1478-1485.

Hankey, GJ, K Jamrozik, RJ Broadhurst, S Forbes and CS Anderson (2002). "Long Term Disability after First Ever Stroke and Related Prognostic Factors in the Perth Community Stroke Study, 1989-1990." Stroke **33**: 1034-1040.

Heinemann, AW, RL Harvey, JR McGuire, D Ingberman, LL Lovell, P Semik and EJ Roth (1997). "Measurement Properties of the NIH Stroke Scale During Acute Rehabilitation." Stroke **28**: 1174-1180.

Hochstenbach, J and T Mulder (1999). "Neuropsychology and the relearning of motor skills following stroke." International Journal of Rehabilitation Research **22**: 11-19.

Hoffman, A, D Lowe, P Irwin and A Rudd (2002). National Sentinel Audit of Stroke 2001/ 2002, Intercollegiate Stroke Working Party.

Horgan, NF and AM Finn (1997). " Motor recovery following stroke: a basis for evaluation." Disability and Rehabilitation **19**(2): 64-70.

Horner, RD, JW Swanson, HB Bosworth and DB Matchar (2003). "Effects of Race and Poverty on the Process and Outcome of Inpatient Rehabilitation Services Among Stroke Patients." Stroke **34**: 1027-1031.

Hsueh, I-P, S-L Huang, M-H Chen, S-D Jush and C-L Hsieh (2000). "Evaluation of stroke patients with the extended activities of daily living scale in Taiwan." Disability and Rehabilitation **22**(11): 495-500.

Hughes, J, J Jelsma, E MacLean, M Darder and X Tinise (2004). "The health-related quality of life of people living with HIV/ AIDS." Disability and Rehabilitation **26**(6): 371-376.

Imperatore, G, BL Cadwell, L Geiss, JB Saadinne, DE Williams, ES Ford, TJ Thompson, KMV Narayan and EW Gregg (2004). "Thirty-year Trends in Cardiovascular Risk Factor Levels among US Adults with Diabetes." American Journal of Epidemiology **160**(6): 531-539.

Indredavik, B, SA Slordahl, F Bakke, R Rokseth and LL Haheim (1997). "Stroke Unit Treatment: Long Term Effects." Stroke **28**: 1861-1866.

International Bobath Instructors Training Association. (January 2007). "Theoretical Asssumptions and Clinical Practcie." Retrieved 13/02/07, from http://www.ibita.org/pdf/assumptions-EN.pdf.

Jelsma J, Brauer N, Hahn C, Snoek A and Sykes I (2006). "A pilot study to investigate the use of the ICF in documenting levels of function and disability in people living with HIV." South African Journal of Physiotherapy **62**(1): 7-13.

Jelsma J and G Ferguson (2004). "The determinants of health related quality of live in a diverse community in Cape Town." Bulletin of the World Health Organization **82**: 206-212.

Jelsma J, MacLean E, J Hughes, Tinise X and Darder M (2004). "An investigation into the Health Related Quality of Life of individuals living with HIV who are receiving Highly Active Anti-retroviral Therapy (HAART). AIDS Care 17:5:579-588. 2004." AIDS Care **17**(5): 579-588.

Jelsma, J, D Amosun, S Mkoka and J Nieuwveld (2004). "The reliability and validity of the Xhosa version of the EQ-5D." Disability and Rehabilitation **26**(2): 103-108.

Jelsma, J, V Chivaura, W De Weerdt and P De Cock (2000). "A bridge between cultures: a report on the process of translating the EQ-5D instrument into Shona." SA Journal of Physiotherapy **56**(4): 3-9.

Jelsma, J and G Ferguson (2004). "The determinants of health related quality of live in a diverse community in Cape Town." Bulletin of the World Health Organization **82**: 206-212.

Jelsma, J, E MacLean and et al (2004). "An investigation into the Health Related Quality of Life of individuals living with HIV who are receiving Highly Active Anti-retroviral Therapy (HAART)." AIDS Care **17**(5): 579-588.

Jelsma, J, S Mkoka, L Amosun and J Nieuwveldt (2004). "The reliability and validity of the Xhosa version of the EQ-5D." Disability and Rehabilitation **26**(2): 103-108.

Jette, A (1992). "Using Health-Related Quality of Life Measures in Physical Therapy Outcomes Research." Physical Therapy **73**(8): 528-537.

Jette, AM (2006). "Toward a Common Language for Function, Disability and Health." Physical Therapy **86**(5): 726-734.

Johnston, KC, AF Connors, DP Wagner, WA Knaus, X-Q Wang and E Clarke Haley (2000). "A Predictive Risk Model of Outcomes of Ischaemic Stroke." Stroke **31**: 448-455.

Jones, F (1998). "The accuracy of predicting functional recovery in patients following a stroke, by physiotherapists and patients." Physiotherapy Research International **3**(4): 244-256.

Jorgensen, HS, H Nakayama, HO Raaschou and TM Olsen (1995c). "Recovery of Walking Function in Stroke Patients: The Copenhagen Stroke Study." Archives of Physical Medicine and Rehabilitation **76**: 27-32.

Jorgensen, HS, H Nakayama, HO Raaschou, J Vive-Larsen, M Stoier and TM Olsen (1995b). "Outcome and time course of recovery in stroke. Part II: time course of recovery. The Copenhagen Stroke Study." Arch Phys Med Rehabil **76**(5): 406-12.

Jorgensen, HS, H Nakayama, HO Raaschou, J Vive-Larsen, M Stoier and TS Olsen (1995). "Outcome and time course of recovery in stroke. Part 1: Outcome. The Copenhagen Stroke Study." Archives of Physical Medicine and Rehabilitation **76**
(May): 399-405.

Jorgensen, HS, H Nakayama, HO Raaschou, J Vive-Larsen, M Stoier and TS Olsen (1995a). "Outcome and time course of recovery in stroke. Part 1: Outcome. The Copenhagen Stroke Study." Archives of Physical Medicine and Rehabilitation **76**(May): 399-405.

Katholieke Universiteit Leuven. "Mission Statement Cerise". (2005, 25/07/05) Retrieved 17/05/07, from
http://faber.kuleuven.be/onderzoek/dep3/neuro/cerise/mission_statement.htm

Kerr, S and L Smith (2001). "Stroke: an exploration of the experience of informal caregiving." Clinical Rehabilitation **15**: 428-436.

King, RB (1996). "Quality of Life after Stroke." Stroke **27**: 1467-1472.

Kotila, M, H Numminen, O Waltimo and M Kaste (1998). "Depression after Stroke: Results of the FINNSTROKE Study." Stroke **29**: 368-372.

Kucukdeveci, AA, G Yavuzer, A Tennant, N Suldur, B Sonel and T Arasil (2000). "Adaptation of the modified Barthel Index for use in physical medicine and rehabilitation in Turkey." Scand J Rehabil Med **32**(2): 87-92.

Kurth, T, CS Kase, K Berger, ES Schaeffner, JE Buring and M Gaziano (2003). "Smoking and the Risk of Hemorrhagic Stroke in Men." Stroke **34**: 1151-1155.

Kwakkel, G, B Kollen and E Lindeman (2004). "Understanding the Pattern of Functional Recovery after Stroke: Facts and Theories." Restorative Neurology and Neuroscience **22**: 281-299.

Kwakkel, G, BJ Kollen and J Twisk (2006). "Impact of Time on Improvement of Outcome after Stroke." Stroke **37**: 2348-2353.

Kwakkel, G, BJ Kollen and RC Wagenaar (1999). "Therapy Impact on Functional Recovery in Stroke Rehabilitation." Physiotherapy **85**(7): 377-387.

Kwakkel, G, RC Wagenaar, BJ Kollen and GJ Lankhorst (1996). "Predicting Disability in Stroke- a critical review of literature." Age and Ageing **25**(6): 479-490.

Landrum, PK, ND Schmidt and A Mclean (1995). Outcome-orientated Rehabilitation. Principles, Strategies and Tools for Effective Program Management. Maryland, USA., Aspen Publishers.

Langhorne, P, BO Williams, W Gilchrist and K Howie (1993). "Do stroke units save lives?" Lancet **342**: 395-398.

Lenger, V, L De Villiers and SJ Louw (1996). "Informant questionnaires as screening measures to detect dementia." South African Medical Journal **86**: 737-741.

Lincoln and Leadbitter (1979). "Assessment of Motor Function in Stroke Patients." Physiotherapy **65**: 48-51.

Lincoln, N and JRF Gladman (1992). "The Extended Activities of Daily Living scale: a further validation." Disability and Rehabilitation **14**(1): 41-43.

Lincoln, N, JRF Gladman, P Berman, R Noad and K Challen (2000). "Functional recovery of community stroke patients." Disability and Rehabilitaion **22**(3): 135-139.

Lyden, PD, M Lu, C Jackson, J Marler, R Kothari, TG Brott, J Zivin and NINDS rTPA Stroke Study Group (1999). "Underlying Structure of the National Institutes of Health Stroke Scale." Stroke **30**: 2347-2354.

Mahoney, FI and Barthel, DW (1965). "Functional evaluation: The Barthel Index." Maryland State Medical Journal **14**: 61-65.

Malouin, F, S Belleville, CL Richards, J Desrosiers and J Doyon (2004). "Working Memory and Mental Practice Outcomes after Stroke." Archives of Physical Medicine and Rehabilitation **85**: 177-183.

Mant, J, N Hicks and J Fletcher (1996). "Letters: Study should have had more patients or longer time scale." BMJ **313**(19 October): 1006.

Matchar, DB and AG Rudd (2005). "Health Policy and Outcomes Research 2004." Stroke **36**: 225-227.

Maulden, S, J Gassaway, S Horn, R Smout and G De Jong (2005). "Timing of initiation of rehabilitation after stroke." Archives of Physical Medicine and Rehabilitation **86**(12 Suppl 2): S34-S40.

Mayo, N, Wood-Dauphinee, R Cote, D Gayton, J Carlton, J Buttery and R Tamblyn (2000). "There's No Place Like Home: An Evaluation of Early Supported Discharge for Stroke." Stroke **31**: 1016-1023.

Mayo, NE, S Wood-Dauphinee, R Cote, L Duncan and J Carlton (2002). "Activity and Participation and Quality of Life 6 months after stroke." Archives of Physical Rehabilitation **83**: 1035-1042.

McKevitt, C, R Dundas and C Wolfe (2001). "Two Simple Questions to Assess Outcome after Stroke: A European Study." Stroke **32**: 681-686.

McNaughton, H, G De Jong, R Smout, J Melvin and M Brandstater (2005). "A comparison of stroke rehabilitation practice and outcomes between New Zealand and US Facilities." Archives of Physical Medicine and Rehabilitation **86**(12 Suppl 2): S115-20.

Megherbi, S, C Milan, D Minier, G Couvreur, G Osseby, K Tilling, A Di Carlo, D Inzitari, C Wolfe, T Moreau and M Giroud (2003). "Association between Diabetes and Stroke subtype on Survival and Functional Outcome 3 Months After Stroke." Stroke **34**: 688-694.

Meiring, PdV (1990). "The wider implications of stroke care." South African Medical Journal **78**(18 Aug): 177-178.

Mercier, L, T Audet, R Hebert, A Rochette and M-F Dubois (2001). "Impact of Motor, Cognitive, and Perceptual Disorders on Ability to Perform Activities of Daily Living after Stroke." Stroke **32**: 2602- 2608.

Meyer, P. (2004, 22/03/2004). "Opening of the World Physiotherapist Summit in Cape Town by Health Minister, Piet Meyer, 22March 2004." Retrieved 10/08/2005, from http://www.info.gov.za/speeches/2004/04032316461002.htm.

Mkoka, S, J Jelsma and J Vaughan (2003). "The pitfalls of translation." South African Medical Journal **93**
(4): 265-266.

Mochan, A, M Modi and G Modi (2003). "Stroke in Black South African HIV-Positive Patients: A Prospective Analysis." Stroke **34**(Jan): 10-15.

Muir, KW, CJ Weir, GD Murray, C Povey and KR Lees (1996). "Comparison of Neurological Scales and Scoring Systems for Acute Stroke Prognosis." Stroke **27**: 1817-1820.

Murat Sumer, M and O Erturk (2002). "Ischaemic stroke subtypes: risk factors, functional outcome and recurrence." Neurol Sci **22**: 449-454.

Murray, CJL and AD Lopez (1997). "Mortality by cause for eight regions of the world: Global Burden of Disease Study." Lancet **349**(May 3): 1269-1276.

Nakayama, H, HS Jorgensen, HO Raaschou and TM Olsen (1994). "Compensation in Recovery of Upper Extremity function after Stroke: The Copenhagen Stroke Study." Archives of Physical medicine and Rehabilitation **75**: 852-857.

Nakayama, H, HS Jorgensen, HO Raaschou and TS Olsen (2000). "The influence of age on stroke outcome. The Copenhagen Sroke Study." Stroke **81**(June): 695-699.

Niemi, M, R Laaksonen, M Kotila and O Waltimo (1988). "Quality of life 4 years after stroke." Stroke **19**: 1101-1107.

Nouri, F and Lincoln N. (1987) An extended activities of daily living scale for stroke patients. Clinical Rehabilitation **1**: 301-305

Oczkowski, WJ and S Barreca (1993). "The functional independence measure: its use to identify rehabilitation needs in stroke survivors." Arch Phys Med Rehabil **74**: 1291-1294.

Office of the Deputy President (1997). Integrated National Disability Strategy. Pretoria, Government of South Africa.

Page, S, D Gater and P Bach-y-Rita (2004). "Reconsidering the Motor Recovery Plateau in Stroke Rehabilitation." Archives of Physical Medicine and Rehabilitation **85**(August): 1377-1381.

Pan South Africa Language Board (2000). Language Use and Language Interaction in South Africa: A National Sociolinguistic Survey. Pretoria, Pan South Africa Language Board.

Paolucci, S, G Antonucci, MG Grasso, M Bragoni, P Coiro, D De Angelis, FR Fusco, D Morelli, V Venturiero, E Troisi and L Pratesi (2003). "Functional Outcome of Ischaemic and Haemorrhagic Stroke Patients After Inpatient Rehabilitation: A Matched Comparison." Stroke **34**: 2861-2865.

Paolucci, S, G Antonucci, MG Grasso, D Morelli, E Troisi, P Coiro and M Bragoni (2000). "Early Versus Delayed Stroke Rehabilitation: A Matched Comparison Conducted in Italy." Archives of Physical Medicine and Rehabilitation **81**: 695-700.

Patel, M, J Potter, I Perez and L Kalra (1998). "The process of rehabilitation and discharge planning in stroke: a controlled comparison between stroke units." Stroke **29**: 2484-2487.

Patel, VB, Z Sacoor, P Francis, PLA Bill, AI Bhigjee and C Connolly (2005). "Ischaemic stroke in young HIV-positive patients in Kwazulu-Natal, South Africa." Neurology **65**: 759-761.

Penn, C (2000). "Communication problems following stroke." CME **18**(1): 35-40.

Platz, T (2004). "Motor system recovery:Evidence from animal experiments, human functional imaging and clinical studies." Restorative Neurology and Neuroscience **22**: 137-142.

Pound, P, P Gompertz and S Ebrahim (1998). "A patient centred study of the consequences of stroke." Clinical Rehabilitation **12**: 255-264.

Poungvarin, N (1998). "Stroke in the Developing World." Lancet **352**
(suppl III): 19-22.

Provincial Government of the Western Cape. (2004, 3/12/2004). "New Rehabilitation Centre of Excellence Open on 3 December 2004." Retrieved 31/12/06, from http://capegateway.gov.za/eng/pubs/news/2004/dec/94661.

Provincial Government of the Western Cape. (2004, 8/11/2004). "Rehabilitation Services." Retrieved 10/08/2005, from http:/www.capegateway.gov.za/eng/directories/services/11516/6459.

Provincial Government of the Western Cape. (2005, 20/01/2005). "Western Cape Rehabilitation Centre." Retrieved 10/08/2005, from http://www.capegateway.gov.za/eng/directories/facilities/6442/58187 Modified 8.11.2004.

Puckree, T, TP Chetty, S Ramlaken, TVS Simelane and J Lin (1997). "An evaluatiion of the functional status of the residents of a geriatric residential facility in South Africa." Disability and Rehabilitation **19**(12): 552-555.

Putman, K, L De Wit, M Schoonacker, I Baert, H Beyens, N Brinkmann, E Dejaeger, A-M De Meyer, W De Weedt, H Feys, W Jenni, C Kaske, M Leys, N Lincoln, B Schuback, W

Schupp, B Smith and F Louckx (2006). "The effect of socioeconomic status on functional and motor recovery after stroke: a European multicentre study." Journal of Neurology, Neurosurgery and Psychiatry **Online First**(DOI 10.1136/jnnp.2006.094607).

QUERI Stroke Executive Committee (1999). "Primary Stroke Prevention." VA Practice Matters **4**(1): 1-6.

Rankin, J. (1957) Cerebral Vascular Accidents in Patients Over the Age of 60 II: Prognosis. Scottish Medical Journal **2**: 200-215.

Ratnasabapathy, Y, J Broad, J Baskett, M Pledger, J Marshall and R Bonita (2003). "Shoulder pain in people with a stroke: a population based study." Clinical Rehabilitation **17**: 304-311.

Rhoda, AJ and JA Hendry (2003). "Profile of Stroke Patients Treated at a Community-based Rehabilitation Centre in a Cape Town Health District." South African Journal of Physiotherapy **59** (4): 20-24.

Riley, MC (1998). "Stroke rehabilitation in South Africa- a physiotherapist's perspective." CME **16**(10): 965.

Roberts, L and C Counsell (1998). "Assessment of Clinical Outcomes in Acute Stroke Trials." Stroke **29**: 986-991.

Robinson, B. (1983). "Validation of a Caregiver Strain Index." Journal of Gerontology. **38** (3): 344-8.

Rochette, A, J Desrosiers and L Noreau (2001). "Association between personal and environmental factors and the occurence of handicap situations following a stroke." Disability and Rehabilitation **23**(13): 559-569.

Rossini, P and G Dal Forno (2004). "Neuronal post-stroke plasticity in the adult." Restorative Neurology and Neuroscience **22**: 193-2006.

Roth, EJ, AW Heinemann, LL Lovell, RL Harvey, JR McGuire and S Diaz (1998). "Impairment and Disability: Their Relation During Stroke Rehabilitation." Archives of Physical Medicine and Rehabilitation **79**: 329-335.

Roth, EJ, LL Lovell, RL Harvey, AW Heinemann and Semi (2001). "Incidence of and Risk Factors for Medical Complications During Stroke Rehabilitation." Stroke **32**: 523-529.

Rudd, A, P Irwin, Z Rutledge, D Lowe, D Wade and M Pearson (2001). "Regional variations in stroke care in England, Wales, and Northern Ireland: results from the National Sentinel Audit of Stroke. Royal College of Physicians Intercollegiate Stroke Working Party." Clinical Rehabilitation **15**: 562-572.

Saeki, S, H Ogata, T Okubo, K Takahashi and T Hoshuyama (1995). "Return to Work after Stroke." Stroke **26**: 399-401.

Salter, K, S Bhogal, R Teasell, N Foley and M Speechley. (2004, 5/10/2004). "Community Reintegration." Evidence Based Review of Stroke Rehabilitation 6th Edition. Retrieved 1/01/2005, from www.ebrsr.com.

Salter, K, J Jutai and R Teasell. (2004b, 15/04/2004). "Outcome Measures in Stroke Rehabilitation." Evidence-Based Review of Stroke Rehabilitation 5th Ed. Retrieved 27/05/2005, from www.ebrsr.com.

Salter, K, R Teasell, N Foley, S Bhogal and M Speechley. (2004a). "Secondary Prevention of Stroke." Evidence-Based Review of Stroke Rehabilitation 5th Ed. from www.ebsr.com.

Samuelsson, M, B Soderfeldt and G Olsson (1996). "Functional Outcomes in Patients with Lacunar Infarction." Stroke **27**: 842-846.

Segal, ME and J Whyte (1997). "Modeling Case Mix Adjustment of Stroke Rehabilitation Outcomes." Am. J. Phys. Med. Rehabil.

Shipley, K. G. and J. G. McAfee (1992). Assessment in Speech-Language Pathology: A Resource Manual. San Diego, Singular Publishing Group, Inc..

Sneeuw, K, N Aaronson, R De Haan and M Limburg (1997). "Assessing Quality of Life After Stroke, The Value and Limitations of Proxy Ratings." Stroke **28**: 1541-1549.

South African Medical Association- Neurological Association of South Africa Working Group (2000). "Stroke Therapy Clinical Guideline." South African Medical Journal **90**(3): 274-306.

Statistics South Africa (2003). Census 2001- Community Profiles (CD ROM). Pretoria, Statistics South Africa.

Statistics South Africa (2005). Stages in the life cycle of South Africans. Census 2001. P Lehohla. Pretoria, Statistics South Africa.

Statistics South Africa (2006). Provincial Profile 2004: Western Cape. Pretoria, Statistics South Africa.

Steckhoven, P (2000). "Management of Stroke Patients: A Social Work Perspective." CME **18**(1): 46-48.

Steyn, K (2005). Conceptual framework for chronic diseases of lifestyle in South Africa. Chronic Diseases of Lifestyle in South Africa: 1995-2005- MRC Technical Report, Medical Research Council: Chapter One.

Stroke Unit Trialists' Collaboration (1997). "How Do Stroke Units Improve Patient Outcomes?" Stroke **28**: 2139-2144.

Stuart, M, C Ryser, A Levitt, S Beer, J Kesselring, S Chard and M Weinrich (2005). "Stroke Rehabilitation in Switzerland versus the United States: a preliminary comparison." Neurorehabilitation and Neural Repair **Jun 19**(2): 139-47.

Stucki, G, T Ewert and A Cieza (2002). "Value and application of the ICF in rehabilitation medicine." Disability and Rehabilitation **24**(17): 932-938.

Sturm, JW, HM Dewey, GA Donnan, RAL Macdonell, JJ McNeil and AG Thrift (2002). "Handicap After Stroke: How does it relate to disability, perception of recovery and stroke subtype?" Stroke **33**: 762-768.

Sturm, JW, GA Donnan, HM Dewey, RAL Macdonell, AK Gilligan and AG Thrift (2004). "Determinants of Handicap after Stroke." Stroke **35**: 715-720.

Sulter, G, C Steen and J De Keyser (1999). "Use of the Barthel Index and Modified Rankin Scale in Acute Stroke Trials." Stroke **30**: 1538-1541.

Taub, N, C Wolfe, E Richardson and P Burney (1994). "Predicting the Disability of First-Time Stroke Sufferers at 1 year." Stroke **25**: 352-357.

Teasell, R. (2004c). "Managing the Stroke Rehabilitation Triage Process." Evidence-Based Review of Stroke Rehabilitation 5th Edition. Retrieved 24/01/05, from www.ebrsr.com.

Teasell, R and J Bitensky. (2004b). "Background Concepts in Stroke Rehabilitation." Evidence-Based Review of Stroke Rehabilitation Retrieved 24/01/2005, from www.ebrsr.com.

Teasell, R, N Foley, S Bhogal, T Doherty and M Speechley. (2004d, 9/03/04). "The Efficacy of Stroke Rehabilitaion." Evidence Based Review of Stroke Rehabilitation Retrieved 24/01/2005, from www.ebrsr.com.

Teasell, R, N Foley, S Bhogal, K Salter, J Jutai and M Speechley. (2004, 2004). "Evidence Based Review of Stroke Rehabilitation." 5th Ed., from www.ebrsr.com.

Teasell, R and J Heitzner. (2004a). "Clinical Consequences of Stroke." Evidence Based Review of Stroke Rehabilitation 5th Ed., from www.ebrsr.com.

Teasell, R, M McRae and H Finestone (2000). "Social Issues in the Rehabilitation of Younger Stroke Patients." Archives of Physical Medicine and Rehabilitation **81**: 205-9.

Teasell, R, K Salter, j Bitensky, S Bhogal, N Foley, A Menon, J Jutai and M Speechley. (2004e, Nov 12, 2004). "Perceptual Disorders." Evidence Based Review of Stroke Rehabilitation Retrieved 31/12/2004, from www.ebrsr.com.

Teasell, RW and L Kalra (2005). "Advances in Stroke 2004: What's New in Stroke Rehabilitation: Back to Basics." Stroke **36**: 215-217.

The SASPI Project Team (2004). "Prevalence of Stroke Survivors in Rural South Africa: Results from the Southern Africa Stroke Prevention Initiative (SASPI) Agincourt Field Site." Stroke **35**: 627-632.

Thorngren, M, B Westling and B Norvving (1990). "Outcome after stroke in patients discharged to independent living." Stroke **21**: 236-240.
Uchino, K, D Billheimer and S Cramer (2001). "Entry Criteria and Baseline Characteristics Predict Outcome in Acute Stroke Trials." Stroke(32): 909-916.
Ustun, T, S Chatterji, J Bickenbach, N Kostanjsek and M Schneider (2003). "The International Classification of Functioning, Disability and Health: A New Tool for Understanding Disability and Health." Disability and Rehabilitation **25**(11-12): 565-571.
Uys, P. (2005, 29/04/2005). "Western Cape Health Budget Speech 2005/2006." Retrieved 10/08/2005, from http://www.info.gov.za/speeches/2005/05050610451004.htm.
Van Den Bos, G, J Smits, G Westert and A Van Straten (2002). "Socioeconomic variations in the course of stroke: unequal health outcomes, equal care?" Journal of Epidemiological and Community Health **56**: 943-948.
van Vliet, P, N Lincoln and E Robinson (2001). "Comparison of the content of two physiotherapy approaches for stroke." Clinical Rehabilitation **15**: 398-414.
Versveld, P (1997). "Lets get walking. Mobilising resources for stroke rehabilitation: from hospital to community." CME **15**(3): 313-321.
Vestling, M, B Tufvesson and S Iwarsson (2003). "Indicators for return to work after stroke and the importance of work for subjective well-being and life satisfaction." Journal of Rehabilitation Medicine **35**: 127-131.
Wade, D (2000). "Recent Advances in Rehabilitation." BMJ **320**(7246): 1385-1388.
Wade, DT (1992). Measurement in Neurological Rehabilitation. New York, Oxford University Press.
Wagenaar, R, P van Wieringen, J Netelenbos, O Meijer and D Kuik (1992). "The transfer of scanning training effects in visual inattention after stroke: five single-case studies." Disability and Rehabilitation **14**(1): 51-60.
Walker, RW, DG McLarty, G Masuki, HM Kitange, D Whiting, AF Moshi, JG Massawe, R Amaro, A Mhina and KGMM Alberti (2000). "Age specific prevalence of impairment and disability relating to hemiplegic stroke in the Hai District of northern Tanzania." Journal of Neurology Neurosurgery and Psychiatry **68**(June): 744-749.
Walsh, K, PH Gompertz and AG Rudd (2002). "Stroke care: how do we measure quality?" Postgraduate Med J **78**: 322-326.
Wandel, A, HS Jorgensen, H Nakayama, HO Raaschou and TM Olsen (2000). "Prediction of Walking Function in Stroke Patients with Initial Lower Extremity Paralysis: The Copenhagen Stroke Study." Archives of Physical Medicine and Rehabilitation **81**: 736-738.
Weigl, M, A Cieza, C Andersen, B Kolleritz, E Amann and G Stucki (2004). "Identification of Relevent ICF Categories in Patients with Chronic Health Conditions: A Delphi Exercise." Journal of Rehabilitation Medicine
(Suppl. 44): 12-21.
Weimar, C, T Kurth, K Kraywinkel, DP Wagner, O Busse, RL Haberl and H-C Diener (2002). "Assessment of Functioning and Disability after Ischaemic Stroke." Stroke **33**: 2053-2059.
Whitelaw, DA, CJ Meyer, S Bawa and K Jennings (1994). "Post-discharge follow-up of stroke patients at Groote Schuur Hospital- a prospective study." South African Medical Journal **84**: 11-13.
Whiteneck, GG (1994). "Measuring What Matters: Key Rehabilitation Outcomes." Arch Phys Med Rehabil **75**: 1073-1076.
Wilkinson, PR, C Wolfe, FB Warburton, AG Rudd, R Howard, R Ross-Russel and RR Beech (1997). "A Long-term Follow-up of Stroke Patients." Stroke **1997**(28): 507-512.

Wilson, JTL, A Hareendran, M Grant, T Baird, UGR Schulz, KW Muir and I Bone (2002). "Improving the Assessment of Outcomes in Stroke Use of a Structured Interview to Assign Grades on the Modified Rankin Scale." Stroke **33**: 2243-2246.

World Health Organisation- Disability and Rehabilitation Team. (2006). "Medical Care and Rehabilitation." Retrieved 26 September 2006, from http://www.who.int/disabilities/care/en/.

World Health Organisation (1985). WHO Study Group on Diabetes Mellitus. Technical report Series 727. Geneva, Switzerland, World Health Organisation.

World Health Organisation (2002). Towards a common language for functioning, disability and health. Geneva, World Health Organisation.

World Health Organisation (2003). The World Health Report 2003: shaping the future. Geneva, World health Organisation.

World Health Organisation MONICA Project (1988). "The World Health Organisation MONICA Project." Journal of Clinical Epidemiology **41**: 105-114.

Wyller, T, B Thommessen, K Sodring, U Sveen, A Pettersen, E Bautz-Holter and K Laake (2003). "Emotional well-being of close relatives to stroke survivors." Clinical Rehabilitation **17**: 410-417.

Zinn, S, TK Dudley, HB Bosworth, HM Hoenig, PW Duncan and RD Horner (2004). "The Effect of Poststroke Cognitive Impairment on Rehabilitation Process and Functional Outcome." Archives of Physical Medicine and Rehabilitation **85**(July): 1084-1090.

8 APPENDICES

PILOT STUDY

APPENDIX I TRANSLATION PROCEDURES

1. Measures of Self Report

Due to errors that can arise as a result of translation of standardised measurement tools into other languages, a procedure of forward and back translation was followed, followed by development of a consensus version. The translation procedure was overseen by Ms A Rhoda, PhD Candidate at the University of the Western Cape.

1.1 Procedure for Translation of Barthel Index, Extended ADL Scale and Caregiver Strain Index into Xhosa

The tools were translated from English into Xhosa by a translator at the Writing Centre of the University of the Western Cape. The translation was carried out by a student who was a first language Xhosa speaker.

A back translation of the Xhosa versions into English, by a Xhosa speaking physiotherapist, appeared very similar to the original English instruments. However, as the physiotherapist had a good understanding of the content of the instruments, it was decided that the Xhosa version should rather be back-translated by someone who had no background knowledge of healthcare. When the same Xhosa translation was given to a Professor in the Department of African Languages at the University of the Western Cape, a number of problems with the translation were identified, particularly where the translation had been too literal.

A consensus version of the questionnaires (a more figurative version) was then produced with input from members of staff in the Department of African Languages. Some words were left in English (e.g. "enema" in the Barthel Index) as there was no Xhosa alternative. It is common practice where there is no Xhosa alternative to borrow words from other languages.

1.2. Procedure for Translation of Modified Rankin Scale (MRS) into Xhosa

The Modified Rankin Scale (MRS) was translated from English into Xhosa by a member of staff in the Department of African Languages at the University of the Western Cape. The Xhosa version produced was back translated into English by another member of staff in the Department of African languages who had not had sight of the original and had no background in healthcare. A consensus version of the questionnaire was produced.

1.3. Procedure for Translation of Barthel Index, Extended ADL Scale, MRS and CSI into Afrikaans

The tools were translated from English to Afrikaans by a graduate with a University degree and experience in translation. The Afrikaans versions were then translated back into English by a second party who had no knowledge of the original versions and no background in healthcare. Differences in the original and back-translated English versions were noted. A consensus version was produced with input from both translators and researchers.

2. Questionnaires Developed Specifically for Use in the Study

Questionnaires that were developed for use in the study were translated into Afrikaans by a university graduate with experience in translation. The questionnaires were translated into Xhosa by a first language Xhosa speaker who was a lecturer in the Department of African Languages at the University of Cape Town. With the exception of the Xhosa Environmental Questionnaire, the translated questionnaires were not back translated. In view of limited funding, the rationale was that the questions were fairly concrete in nature so error was not expected to have been introduced in the translation. Furthermore it was expected that any problem with the translation would be detected during piloting of the questionnaires. Minor adjustments in wording were made after the pilot study in consultation with the translators.

APPENDIX II TEST-RETEST RELIABILITY TESTING OF MEASURES OF SELF-REPORT

Background

The Barthel Index is used in this study as a measure of functional recovery and is applied at admission, discharge and six months post stroke. The Modified Rankin Scale (MRS) , Nottingham Extended Activities of Daily Living Scale (EADL) and the Caregiver Strain Index (CSI) are additional measures used to describe outcome at six months post stroke.

All of the above outcome measures have been widely used in stroke studies overseas; however, they have not been tested for reliability and validity in a multilingual South African stroke population. Translation of the BI, EADL, MRS and CSI into Xhosa and Afrikaans, was overseen by Ms A Rhoda, PhD candidate at UWC. The procedure involved forward translation by a first language speaker, back translation by a second party, and the establishment of a consensus version (Appendix I). Translation of outcome measures into local languages may introduce subtle changes in meaning, and cultural and environmental factors may influence their application.

It is beyond the scope of this study to investigate the validity of each of these instruments. However, before commencing the study, the researcher consulted with clinicians and experts in the field in order to discuss face validity of the instruments. In collaboration with Ms A Rhoda, PhD candidate at UWC, the translated Afrikaans versions of each instrument were piloted on a minimum of five patients each, and repeated one week later to assess test-retest reliability. Testing of the Xhosa translations were conducted on a smaller group (one to six). Post hoc validity testing for the outcome measures will be carried out as part of the main study by assessing correlation between concurrent measures.

Methodology

A sample of convenience was recruited from Community Health Care Centres (CHCC's). Informed consent was obtained for all participants. Patients with a diagnosis of stroke more than three months previously were included in the sample. Each translated questionnaire was tested on participants at the CHCC or in their own home. The interview was repeated one week later. A different group of patients was used for each tool so that if an atypical sample of patients was obtained, errors were not be perpetuated in the investigation of all the tools. Both researchers were involved in the interviewing process; however the same researcher conducted assessments at both time points on the same patients. A Xhosa speaking research assistant conducted interviews in Xhosa to test the Xhosa translations.

In addition to the instrument being tested, demographic data such as age and gender were recorded. BI scores were obtained for most patients to describe severity of stroke.

In testing of the CSI, the instrument was either interviewer-administered or self-administered according to convenience. Where possible, caregivers were interviewed out of earshot of the patient.

Results

Scores obtained on test and re-test for the respective instruments are listed in the tables below. Items on which variation arose are described.

Table I Scores on Repeated Application of the BI Afrikaans Translation (n=7)

Age	Gender	BI-1	BI-2	Variation from Item (No. of points accounted for)
62	Male	80	90	Dressing (5) and Bathing (5)
68	Male	30	30	-
48	Male	70	70	Stairs (5) and Bathing (5)
57	Male	25	25	-
63	Male	25	15	Grooming (5), Toilet (5)
56	Female	70	65	Mobility (5)
55	Female	70	70	-

Table II Scores on Repeated Application of the BI Xhosa Translation (n=6)

Age	Gender	BI-1	BI-2	Variation from Item (No. of points accounted for)
55	Female	65	45	Bowels (10), Transfers (10)
54	Male	90	90	-
54	Male	90	90	-
54	Male	95	95	-
30	Male	90	95	Bladder (5)
61	Male	60	55	Grooming (5)

Table III Scores on Repeated Application of the EADL Afrikaans Translation (n=8)

Age	Gender	BI	EADL-1	EADL-2	Variation from Item
50	Male	75	9	9	get in/ out of car, cross road, manage own money, go out socially
65	Female	55	3	1	eat, manage own money
66	Female	15	1	1	-
46	Male	95	13	14	wash up
48	Female	95	5	4	read
71	Male	25	1	1	-
68	Male	75	3	4	read
39	Female	90	15	12	uneven ground, cross road, carry drink

Table IV Scores on Repeated Application of the EADL Xhosa Translation (n=8)

Age	Gender	BI	EADL-1	EADL-2	Variation from Item
46	Male	90	18	18	-
49	Female	85	19	18	read, use telephone, write letters
42	Female	90	20	20	-
52	Female	65	3	2	write letters
51	Male	85	17	0	walk outdoors, stairs, get in/out of car, uneven ground, cross road, public transport, eat, make hot drink, carry drink, wash up, light meal, manage own money, housework, shopping, read, use telephone, go out socially
55	Male	55	5	7	cross road, manage own money
72	Male	30	1	1	-
61	Male	40	5	4	get in/out car, public transport, manage own money

Table V Scores on Repeated Application of the MRS Afrikaans Translation (n=5)

Age	Gender	BI	MRS-1	MRS-2	Variation from Item
64	Male	90	3	3	-
72	Male	95	3	3	-
42	Female	80	4	5	Do you need someone constantly with you?
53	Female	90	4	4	-
77	Female	20	5	5	-

Table VI Scores on Repeated Application of the MRS Xhosa Translation (n=5)

Age	Gender	BI	MRS-1	MRS-2	Variation from Item
65	Female	70	3	3	None
41	Male	30	5	5	None
32	Female	100	3	3	None
63	Female	55	4	4	None
Missing	Male	65	3	4	Is assistance essential for daily hygiene?

Table VII Scores on Repeated Application of the CSI Afrikaans Translation (n=7)

CSI-1	CSI-2	Variation from Item
5	4	2, 4, 6, 8, 10 It is inconvenient It is confining Changes in personal plans Emotional adjustments Upsetting the person has changed
6	7	3, 8, 10 Physical strain Emotional adjustments Upsetting the person has changed
7	9	2, 3, 4, 11 It is inconvenient Physical strain It is confining Work adjustments
1	1	-
2	1	6, 8, 10 Changes in personal plans Emotional adjustments Upsetting the person has changed
10	9	5 Family adjustments
11	13	2, 5 It is inconvenient Family adjustments

Table VIII Scores on Repeated Application of the CSI Xhosa Translation (n=1)

CSI1	CSI2	Variation from Item
11	11	1,9 Sleep is disrupted. Some behaviour is upsetting

Discussion

The first purpose of this part of the pilot study was to test that the translated questionnaires made sense and that no issues remained with regard to choice of words in the translation. The second purpose was to explore whether there were any cultural or environmental influences that would render the measurement tools inappropriate for the study population.

Test-retest methodology was selected as the parameter of choice for testing the instruments. Variability was seen to arise on a number of items. The wording of these items was examined and it was considered whether the question itself was not clear or needed further elaboration. Error arising may be due to the nature of the initial instrument itself, and does not necessarily imply that there was a problem with the translation. It is also recognised that application of any questionnaire of self-report is open to variability that might arise from the subject: Fluctuations in mood may result in patient answering questions more favourably or negatively at one assessment than another. The patient's memory may also affect accuracy of reporting and desire to give the "right" answer may influence reporting. Furthermore, levels of activity and participation may be variable over time.

Whilst small sample numbers prohibit any statistical testing of results, the test-retest format did allow exploration of the instruments.

Barthel Index

There was little variation of total BI scores for Xhosa and Afrikaans assessments. For the Afrikaans translation, there were small discrepancies only between scores and no single item was found to be consistently problematic. For the Xhosa BI, one patient demonstrated a large difference in scores, but for all other patients the discrepancies were small.

Caregiver Strain Index

Discrepancies between scores in the Afrikaans CSI were mostly small (differences of 1 or 2). Items that arose most frequently were: "there have been emotional adjustments" and "it is upsetting to find the person has changed so much from their former selves". No problems were identified with regard to wording of these items. However these items are highly subjective and variation may arise due to the nature of the questions themselves. The Xhosa CSI was only piloted on one patient, which is a limitation. For this participant, the total score was the same between assessments but there had been variation on two items.

Modified Rankin Scale

There was minimal variation in repeated scores for the MRS Afrikaans and Xhosa translations. Variation arose with only one subject regarding the question "Do you constantly need someone to be with you?" In this instance, the variation appeared to arise as the relative was anxious about leaving the patient on his own, more than an actual need for the relative to be there. According to the guidelines of the MRS Structured Interview, this patient should have been scored 4 rather than 5. This was highlighted in the guidelines drawn up for the main study.

Extended Activities of Daily Living Scale

Although variations in overall EADL scores were mostly small for both the Afrikaans and the Xhosa questionnaire, there was greater variation in reporting of individual items. This may be because the categories "not at all" and "with help" are collapsed together for scoring (scored 0), as are the categories "on my own" and "on my own with difficulty" (scored 1). In particular, the item "managed your own money while out" repeatedly gave rise to variation. One Xhosa patient had a very large difference between scores, calling into question his understanding of the questionnaire.

A number of issues arose with regard to choice of wording on the Afrikaans EADL. The wording of "on my own with difficulty" was initially translated "op my eie met moeite". The word "moeite" has a negative association of being "with trouble" or "a hassle". Some patients responded to this by saying that "it is difficult but it is no trouble". Thus it was decided that "op my eie maar dit is moeilik" conveyed the meaning most clearly. This issue had arisen during the translation process; however, the change had not been made initially as it was more grammatically correct to use the former wording. However, it was decided that it was more important to convey the true meaning of the question.

For the Afrikaans translations, a number of participants struggled with the formal wording of some of the questions. Although the formal wording was more grammatically correct, it was decided to use the more informal register in order to convey the meaning most accurately: Examples are as follows:

- Item 4: "Oor onegalige grond geloop" [walk over uneven ground] needed clarification as "oor ongelyke grond te loop."
- Item 5: "Die pad oorgesteek" [cross road] needed clarification as "die pad oorgekruis"

Variation in some items may have arisen from lack of understanding of the questions, and changes were made to elaborate.

- Item 6: Participants needed clarification that "publieke vervoer"[public transport] included "die taxi, die bus and die trein"[the taxi, bus or train]
- Item 8: "Jouself 'n warme drankie gemaak het" [Manage to make yourself a hot drink] required elaboration of "byvoorbeeld tee of koffie" [Example tea or coffee].
- Item 13: "Ligte kledingstukke gewas" [wash small items of clothing] required explanation of "byvoorbeeld klein goedjies soos sakdoeke en onderklere" [for example, small items such as handkerchiefs and underwear]
- Item 20: "Sosiaal verkeer" [go out socially]. This was often not clear to the patient. The words "byvooorbeeld vriende besoek of kerk toe gaan" [for example, to visit friends or go to church] was added and appeared to make the meaning clearer.

The EADL reports what the participant has actually done rather than what he/she is able to do. Thus certain biases may be introduced where a participant does not participate in a particular activity because it is considered culturally inappropriate. However, although it was expected that there may be a gender role bias that influenced scoring on items of the EADL relating to housework, a number of male patients reported involvement in these activities. Socio-economic biases may also be introduced as many participants were not car drivers prior to the stroke and an educational bias due to the item of writing letters. However, no major problems were detected that suggested the instruments were not suitable for the study population.

Environmental factors that may influence scoring include access to a telephone, and different environmental demands of a task such as surfaces for outdoor walking, and access to running water and electricity. While a number of participants did not have gardens, some participants related this item to work in their yard. This was allowed.

Conclusions

Sample size was too small to be able to draw statistical conclusions. Variability did arise for individual items on the outcome measures, but overall scores for all instruments were very similar between the two assessment points. No glaring cultural issues that invalidated the tools were identified. In order to reduce variability, minor changes in wording were made to address some issues that arose. Explanations were added where necessary to clarify items. Guidelines were drawn up to minimise unnecessary variation that might arise from problems in understanding of the item (Appendix III).

At face value the instruments appeared appropriate for the sample population. More detailed testing of reliability and validity is beyond the scope of this project. However, post hoc analysis of concurrent validity will be conducted at conclusion of data collection for the main study

APPENDIX III GUIDELINES FOR THE MEASURES OF SELF REPORT

These Guidelines were compiled from the published Guidelines relating to the instruments concerned, the guidelines of the CERISE study, and in response to issues arising from the pilot study.

1. Guidelines for the Use of the Barthel

Items are scored according to what the patient actually does rather than what the patient is able to do. The manner in which the patient achieves independence is not important (for example the use of aids or compensatory strategies is not relevant to scoring.)

Item 2: Bladder

Independence with emptying of catheter bag is deemed "independent".

Item 3: Grooming

Task includes washing face, tidying hair, cleaning teeth (own teeth or dentures independently), shaving the face or tidying beard/ moustache.

Item 4: Toilet Use

Can refer to toilet or commode

Item 5: Feeding

Independence in feeding is regardless of the chosen method of feeding.

Item 7: Mobility

Refers to mobility inside the home.

Item 8: Dressing

Help required with dressing may vary with selected type of clothing. A patient who adapts what he/ she wears in order not to require help with laces, buttons, etc. is scored as independent (10). A patient who reports requiring minor help is scored 5.

Item 9: Stairs

This item refers to more than five steps. That is, it refers to a flight of stairs rather than 2-3 steps at the threshold to a house.

Item 10: Bathing

Refers to washing of the body. Does not necessarily imply use of a bath or shower. It includes a washing down of the body from a basin.

2. Guidelines for Use of the Nottingham Extended ADL Scale

All items refer to what the patient has actually done, rather than what the patient is able to do.

Item 1: Walk around outside

This refers to any walking done outside of the home regardless of the surface or distance. For example, walking out to the post box would qualify for this item.

Item 2: Climb stairs

Stairs refers to five steps or more. Two to three steps at a front door do not qualify as "stairs".

Item 5: Cross roads

Refers to any road, regardless of busyness of road or presence of traffic lights/ pedestrian crossing.

Item 6: Public Transport

Public transport includes buses, trains and taxis.

Item 7: Feed yourself

Refers to independence in eating. The manner in which the patient feeds him/ herself is not relevant. That is, if a patient is independent using their hands, or independent using a knife and fork is irrelevant. If the patient is unable to take solid food (as a result of swallowing problems or for other reasons) the patient must be completely independent in managing their own dietary intake in order to score on this item. A patient who has a PEG or NGT will be scored as "not at all" regardless of whether they would have the dexterity to feed themselves.

Item 9: Take hot drinks from one room to another

Refers to ability to take drink from one room to the other. Does not necessarily imply ability to carry the drink. That is, if a patient self propels their wheelchair to another room with the drink on a wheelchair table, this will be scored in the same way as a patient who is able to carry it through.

Item 11: Make a hot snack

It is essential that the snack involves heating. A cold snack such as a sandwich does not count.

Item 12: Manage own money while out

This refers to the patients ability to purchase items when out. It refers to the patient's ability to pay the correct amount, physically manage the exchange, and to check they have the correct change etc. This item does not refer to the patient's ability to manage others to conduct their business affairs. If the patient is housebound, but they are able to make a payment for something at their home (e.g. a purchase from a door-to-door salesperson), this is also accepted.

Item 13: Wash small items of clothing

For example: underwear, cloths and handkerchiefs. If the patient washes such items with the full load in the washing machine, the patient is considered able to perform this task.

Item 14: Do your own housework

This refers to items such as cleaning (washing floors, sweeping, dusting and vacuuming). If the patient feels they are doing all required tasks they are scored accordingly. If the patient is able to do some tasks on own, but requires help for other heavier tasks then the patient is considered to require help.

Item 15: Do your own shopping

At least one item must exchange hands. Implies ability to take purchases home after the transaction is completed.

Item 16: Do a full clothes wash

It is irrelevant whether this is in the machine or by hand.

Item 17: Read newspapers or books

If a proxy is answering on behalf of a patient and says the patient appears to read but he is unsure how much he actually reads, the patient will be scored "on my own but with difficulty."

Item 18: Use the telephone

This may apply to a cell phone, a land-line or a public telephone.

Item 20: Go out socially

Going out socially is defined as any activity outside the home involving social interaction. The primary purpose of the activity does not have to be social so long as the activity involves social interaction. As such, attendance at church can be considered a social activity. Having friends to visit does not apply as it occurs within the home.

Item 21: Manage your own garden

Implies ability to work in garden himself/ herself. If garden services are employed for the heavier tasks this is considered "with help".

3. Guidelines for the Use of the Modified Rankin Score

Guidelines for the MRS are clearly laid out by Wilson in his guidelines for the structured interview. Certain aspects are highlighted below:

- the patient is scored according to what he is able to do, rather than what he actually does. The tool relates to capacity rather than performance and focuses on change in function after stroke.

- The item regarding whether the patient requires someone to be with him/ her, refers to an actual need, rather than anxiety on the part of the caregiver about leaving the patient on their own.

4. Guidelines for the Use of the CSI

Where possible, the caregiver will be interviewed out of earshot of the patient.

The given examples are read out for each item.

The caregiver is reminded that it refers to how they are feeling at the present time, not how they were feeling soon after the stroke.

APPENDIX IV INTER-RATER RELIABILITY TESTING OF THE NIHSS AND RMA

Objective

To establish inter-rater reliability of the National Institute of Health Stroke Scale (NIHSS) and the Rivermead Motor Assessment (RMA).

Introduction

The NIHSS and RMA are measures which require an observer to score a performed task. In these instruments, variation is most likely to arise from measurement error on the part of the rater. Inter-rater reliability testing of the instruments was conducted as an indication of measurement error and reliability of the tools. Although the researcher conducted all assessments of participants at the WCRC for the main study, it is hoped that inter-rater reliability testing may allow for possible future comparisons between the study conducted by this researcher at the WCRC and the study being conducted by Ms A Rhoda in the Community Heath Care Centres of the Western Cape.

The NIHSS is a measure of overall neurological impairment consisting of 15 items which address Level of Consciousness, Eye Movement, Facial Palsy, Visual fields, Motor Impairment of Upper and Lower Limbs, Ataxia, Sensation, Language and. Neglect. Items of the NIHSS are scored on three, four or five point ordinal scales. The NIHSS has been shown to have content, concurrent criterion and predictive validity (Lyden, Lu et al. 1999). Its reliability has been established for use by neurologists and non-neurologists (Goldstein and Samsa 1997) and it is said to be one of the most reliable instruments for measurement in stroke patients (D'Olhaberriague, Litvan et al. 1996).

The Rivermead Motor Assessment is a measure of motor recovery. It is a mixed scale of impairment (arm, leg and trunk) and activity limitations (Gross Function). It consists of three sub-scales: Gross Function (13 items), Leg and Trunk (10 items), and Arm (15 items). Individual items of the RMA are scored according to a two point nominal scale: 0= unable to perform item or 1= performed item. The Gross Function and Arm sub-scales are considered to be hierarchical scales. If the subject is unable to perform three consecutive items, the remaining items are not assessed, but can be scored zero. By contrast, the Leg and Trunk Sub-scale is used as a checklist such that every item needs to be scored (Adams, Ashburn et al. 1997). The Gross Function section has been validated for use as a self-standing measure, the Rivermead Mobility Index that can be reported by the patient rather than observed (Collen, Wade et al. 1991).

The Rivermead Motor Assessment has not been extensively investigated for inter-rater reliability although it has been widely used in stroke outcome research. In one study, with seven raters there were no significant differences in scores on the Gross Function and Lower Limb and Trunk Sub-scale. However, for the upper limb scale, one rater scored significantly differently to the other six raters. Construct and content validity have been favourably reported (Cole, Finch et al. 1995).

Sampling

A sample of convenience of 30 patients who fulfilled the entrance criteria were obtained from Ward A and B at the WCRC, and the Booth Memorial Hospital. These institutions were selected because their patients are likely to have similar characteristics to those anticipated in the main study. Eligibility criteria for inclusion were a primary diagnosis of stroke, no clinically identified receptive language deficit (based on the clinical assessment of rehabilitation staff and the researchers) and informed consent.

Methodology

Informed consent was obtained from participants. Random selection was used to determine which rater gave instructions, and both raters scored the patient's performance simultaneously without collaboration. Similarly, random selection was used to determine the order in which the instruments were applied (i.e. NIHSS and RMA). Patients were asked to indicate their language of choice and the assessment was conducted in this language. For Xhosa-speaking participants, the research assistant was asked to interpret the instructions for the patient while the researchers scored the subject's performance.

Results and Discussion

There were 16 men and 14 women in the sample. Age ranged from 22 to 77 years with a mean age of 52.8 ± 16.0 SD. Thirteen participants were English speaking, 13 were Afrikaans speaking and four participants spoke Xhosa.

Kappa scores for each item were calculated as a measure of inter-rater reliability. Kappa's for the Sub-scales of the RMA are listed in Table IX, and for individual items of the NIHSS in Table X.

Table IX Inter-rater Scores for Sub-scales of the Rivermead Motor Assessment

	Range of Kappa scores for Individual Items	ICC for Sub-scale Totals
Gross Function Sub-scale	0.73 – 1	0.994
Lower Limb and Trunk Sub-scale	0.603 – 0.927	0.951
Upper Limb Sub-scale	0.41 – 1	0.987

According to the criteria of Landis and Koch, Kappa scores of 0.00 to 0.20 show slight agreement, 0.21-0.40 show fair agreement, 0.41 to 0.60 show moderate agreement, 0.61 to 0.80 show substantial agreement, and 0.81 to 1.00 show almost perfect agreement (Domholdt 2005). These scores were therefore considered to reflect acceptable inter-rater reliability for individual items. Intra-class correlation coefficients for the totals of the three sub-scales were found to be excellent.

Table X Kappa Scores for Individual Items of the NIHSS. All z-scores significant at p<0.05 except for Item 1c where p>0.05

Item	Agreement	Expected Agreement	Kappa	z-score
1a* Level of Consciousness	100.00	-	-	-
1b Ask Month and Age	86.67	43.56	0.76	5.06
1c* Follows commands	96.67	96.67	0.00*	0.00*
2 Best Gaze	100.00	93.56	1.00	5.48
3 Visual Field testing	93.33	58.44	0.83	4.9
4 Facial paresis	70.00	36.22	0.53	4.31
5 Motor Function Right Arm	96.67	59.00	0.92	6.95
5 Motor Function Left Arm	90.00	39.00	0.84	7.69
6 Motor Function Right Leg	93.33	58.78	0.84	6.57
6 Motor Function Left Leg	86.67	44.89	0.76	6.46
7 Limb Ataxia	73.33	47.89	0.49	4.31
8 Sensory Testing	90.00	45.22	0.82	5.82
9 Best Language	93.33	58.00	0.84	5.75
10 Dysarthria	80.00	64.00	0.44	2.48
11 Extinction/ Inattention	86.67	47.00	0.75	5.51

Kappa scores were calculated for 13 of the 15 NIHSS items. A kappa could not be calculated for Item (1a) on account of all participants scoring zero for this item for both raters (100% agreement). Similarly, the Kappa generated for Item 2 was not significant at p<0.05. Individual scores for Item (2) showed little variability with agreement of 96.67%. Kappa scores for the other items ranged between 0.44 and 1.00, indicating moderate to perfect agreement. 76.9% of these items demonstrated kappa's of >0.61 indicating substantial agreement.

It is of interest that the items demonstrating the lowest kappa scores (facial paresis, limb ataxia and dysarthria) are those that have been identified as having poor reliability in other studies (Goldstein and Samsa 1997; Lyden, Lu et al. 1999)

Discusssion

Demographic characteristics of the sample are thought to be similar to the study population anticipated for the main study. The small number of Xhosa speaking patients in the study is noted as a possible limitation. Overall, inter-rater reliability was found to be good for both the RMA and the NIHSS, supporting their use in the study population. No major cultural or environmental problems were detected and preferred language is not expected to have negatively influenced results. However, as two items on the NIHSS (Item 9 and 10) required assessment of language abilities, implications in a multilingual population will be considered in detail below.

Item 9.2: Identification of Pictures.

It was noted that in the absence of an apparent language deficit, a number of participants had difficulty identifying certain items: in particular:

- glove as a hand
- feather as a leaf
- Many patients knew what the cactus was without being able to give it a name (They called it "'n plant" [plant] or 'blom [flower]" or 'prickly pear". This was seen commonly in patients who in no other way demonstrated a language deficit.-
- Very few patients could identify the hammock. One participant called it a swing, several others noted it was "something that you lie on hanging between 2 trees", another called it "something for children to play with".

These responses occurred in English, Afrikaans and Xhosa participants without any bias being noted in a particular language group. In addition, similar errors are reported in overseas studies (Personal Communication, Dr L De Wit, Co-ordinator of Cerise Project).

Item 10: Dysarthria (Words and Phrases)

There was discussion about translating the words for the dysarthria task into Xhosa and Afrikaans respectively. However, it was noted that doing so may alter the properties of the tool. Literal translation of the words into Xhosa gave completely different sounds and much longer words. In addition, there is no Xhosa equivalent of "Huckleberry" or "Baseball Player". In order to preserve the validity of the tool, words would need to test the same ability to make the required sounds. For example, words such as "fifty-fifty" and "thanks" appeared to have been selected to detect dysarthria on sounds such as "f" and "th", etc. The Xhosa language has a number of very different sounds to English and Afrikaans. It was unknown which sounds should be examined to detect the presence of dysarthria. In addition, it would be difficult for the researcher who does not speak Xhosa to interpret whether a dysarthria is present, and a research assistant may not have sufficient training to make that assessment.

Guidelines for the NIHSS suggest that, in the case of illiteracy, words are read out and the patient is asked to repeat them after the examiner. It was decided that in the case of non English speakers the same approach could be adopted.

Item 9.3: Language (Reading of Sentences)

As item 9.3 specifically tests the ability to read, the issue was more complicated for this item. However, translation of the sentences could again alter the properties of the instrument. Although the sentences were translated into Afrikaans and Xhosa, it was decided to first ask the participant to try to read the sentences in English, and only if he or she was unable to, would the participant be asked to attempt the Xhosa or Afrikaans version.

In the pilot study, all participants were able to read the English words and sentences. This is not surprising considering that many participants were proficient in more than one language. In addition, formal schooling in urban South Africa until relatively recently was mostly conducted in Afrikaans and English. Thus a Xhosa patient may have been taught reading skills in English or Afrikaans, even if Xhosa is the preferred spoken language.

The recommended guidelines of the NIHSS state that the language item is to confirm the researcher's impression of the patient's language ability, to supplement what they have already observed during the assessment. The task requiring description of the picture and naming of the objects will already have provided information with regard to the participant's language ability. Thus it was decided that the error introduced by the words for the reading task is likely to be small.

Possible Cultural and Environmental Influences

Cultural and environmental influences may have had a minor effect on measurement with the RMA. For example, eating with a knife and fork may not be customary in a traditional Xhosa setting. One elderly participant remarked that he did not usually eat with a knife and fork, and this may have influenced his performance on the RMA Upper Limb Sub-scale item, as the task was unfamiliar.

Performance on the stairs item in the Gross Function Sub-scale may be influenced by environment. Many homes in South Africa do not have stairs, thus many patients would not have had the opportunity to practice stairs by the six month assessment. Even the WCRC only has a five step staircase in the gym, as it was custom built for wheelchair access. Thus this item was evaluated by assessing whether a patient could step up onto and over a wooden step consecutively four times.

Conclusions

Inter-rater reliability for the NIHSS and RMA was found to be acceptable, in spite of minor influences of language, culture and environment.

APPENDIX V ABSTRACT OF INTER-RATER RELIABILITY STUDY

The following is the abstract for a poster presented by Ms A Rhoda at the Stroke Rehabilitation Congress at the Katolieke Universiteit Leuven, Belgium, on 11 February 2006.

Interrater Reliability of the Rivermead Motor Assessment Scale in a South African Stroke Population

Authors: A. Rhoda, S. Ritchie*, J. Jelsma, R. Mpofu, and W. De Weerdt

Background: The use of standardised scales is increasingly becoming important when engaging in the rehabilitation of patients with various diagnoses. One such a scale is the Rivermead Motor Assessment Scale which was developed to assess the motor performance of people who have suffered a stroke. This scale consists of three sections, namely the gross function section which tests total body movements, the leg and trunk movements section and arm movements section. The test items are ordered hierarchically and are scored either 0 if the patient is unable to perform the activity and 1 if the patient is able to perform the activity. Specific criteria are used when assessing whether the patient is able to perform the activity. The reliability and validity of this scale has previously been determined. Results of the interrater reliability test for the subscales of the gross and leg and trunk sections indicated no significant differences on average scores for all clients across seven raters. In the same study the results for the arm section indicated a significant difference and further testing was suggested. The aim of the present study was to determine the inter-rater reliability in a multi-lingual South African population of stroke patients. The study was also done to allow for the comparison of the results of two individual studies conducted by the two raters. **Methods:** A sample of 30 patients who were receiving in-patient rehabilitation was recruited to partake in the study. Random selection was done to determine which rater gave the instructions while both raters scored the patients performance simultaneously and without collaboration.
Results: Kappa values were calculated for the individual items of the scale while the total scores for each section were calculated by means of the intra class correlation. The kappa values for the gross motor function ranged from 0.73 – 1, for the leg and trunk sections the kappa values ranged from 0.603 – 0.927 while these values for the arm section ranged from 0.41 – 1. The intra-class correlation coefficients for the total scores were .994 for the gross motor section, .951 for the leg and trunk section and .987 for the arm section. **Conclusion:** The interater reliability was found to be reliable in the present population when conducted by the two raters. Results of the studies of the two raters can therefore be compared.

*Maiden name of researcher S. Rouillard

APPENDIX VI DEVELOPMENT OF THE QUESTIONNAIRES FOR USE IN THE STUDY

A number of questionnaires were developed specifically for use in the study. Where appropriate they were modeled on the CERISE questionnaires but were adapted for the South African context. Questionnaires that were developed for use in the study were translated into Afrikaans (by a university graduate with experience in translation) and Xhosa (by a first language Xhosa speaker who was a lecturer in the Department of African languages at the University of Cape Town). With the exception of the Xhosa Environmental Questionnaire, the translated questionnaires were not back translated due to budget constraints and in view of the fairly concrete nature of the questions. However after piloting, minor adjustments were made to wording where required.

The development of the initial drafts and the rationale for their inclusion are described below. Further development of the questionnaires after piloting is described in Appendix VII.

1. Development of the Questionnaire on Admission

The questionnaire on admission was included in order to document demographic and medical characteristics of participants, as well as to collect data regarding referral patterns.

Section One: Medical Details

This was modelled on the CERISE Medical Questionnaire with the following adaptations:

- additional categories were added to risk factors on the basis of clinical expert opinion in Cape Town and literature available on the prevalence of risk factors in South Africa (Connor, Rheeder et al. 2005)
- Fewer categories were included for type of stroke as it is expected that some patients may not have had MRI's or CT scans. This was later confirmed in the pilot study. The TOAST criteria which were selected for classification of stroke in this study are described in Table XI.
- Complications on admission were added, in order to explore whether participants presenting late for rehabilitation had a higher prevalence of complications on admission. Information on the presence of nasogastric feeding tubes, PEG feeding tubes, and urinary catheters was included for the interpretation of data on complications.

- Coexisting medical conditions were included as these are expected to influence outcome after stroke
- No data was collected on medications, secondary complications of the brain and neurosurgical intervention. It was decided that this was beyond the scope of the study.

Table XI TOAST Criteria for Ischaemic Sub-Group Classification

Stroke Sub-Group	Defining Criteria
Large Vessel	- presence of an occlusion or stenosis with >50% diameter reduction found on Doppler Ultrasound or angiography - potential source of cardiogenic embolism absent
Small Vessel	- presence of one of the traditional lacunar syndromes (eg. Pure motor stroke, pure sensory stroke, sensorimotor stroke, ataxic hemiparesis, dysarthria/ clumsy hand syndrome) - infarction < 1.5.cm diameter or normal CT/ MRI - absence of acute cerebral cortical dysfunction - potential cardiac source absent - potential large artery atherosclerotic source absent (i.e. Large extra-cranial arteries should not demonstrate an occlusion of >50%)
Cardioembolic	- presence of high risk or medium risk source of cardiac embolism: (for example atrial fibrillation, recent myocardial infarction in the last six weeks, infective endocarditis, prosthetic heart valve) - potential large artery atherosclerotic source absent
Other determined Cause	- Ischaemic stroke not meeting criteria of above categories but of other determined cause - These include: spontaneous dissection, traumatic dissection, vasculitis, haematological disorders and coagulopathies. - Diagnoses of above revealed by diagnostic studies - Potential cardiac sources of embolism absent - Potential large artery atherosclerotic sources absent
Unknown or more than one cause	- no likely etiology identified despite investigations, OR - no etiology identified, but investigations incomplete, OR - more than one likely etiology eg. Potential cardioembolic source, and atherosclerosis of >50%

Section Two: Referral Details

Data from this section relates to referral patterns, onset admission intervals and source of referrals. As the WCRC was a fairly newly established centre at the commencement of data collection, and as it was formed by the amalgamation of two separate rehabilitation units in different geographical areas, it is of considerable local interest to know which patients are accessing care at this facility.

Section Three

Demographic details are included in order to characterize the stroke patients in the sample.

2. Development of the Questionnaire at Discharge

Section One: Socio-economic Information

Level of education, monthly income, type of work and details of housing were collected in order to describe the socio-economic profile of the sample. Information regarding employment status prior to stroke, and previous working hours was required for comparison at six months after stroke.

The researcher considered making a distinction between employment in the formal and informal sector, however, it was decided instead to simply ask the patient what kind of work they had been doing prior to their stroke. It is recognized that a large percentage of the work force is employed in the informal sector in South Africa, and that this may have implications for protection of rights with regard to sick pay, and support for return to work. However, definitions of labour market sectors are problematic (Devey, Skinner et al. 2003) and it is beyond the scope of the study to investigate this aspect. For the purposes of this study, it is sufficient to know whether a person who could earn a living before their stroke was able to earn a living at six months post stroke.

Questions were included regarding the number of rooms and number of residents living in the home. This question was included as it is a measure of overcrowding in homes which may reflect socio-economic status. It may also have practical implications for the patient's function, as it is more difficult to move around an overcrowded home. The number of rooms in the house was defined as: all rooms except bathrooms, garages or sheds (unless there is someone living in them).

Section Two: Details of the Home Environment

Information regarding the physical environment after discharge, is expected to be important in interpreting independence in basic and extended ADL. Access to an indoor toilet, running water indoors and electricity were included as they are expected to influence the requirements of tasks such as toileting, washing and cooking. Categories for type of housing were taken from the 2001 Census (Statistics South Africa 2005).

Section Three: Caregiver details

This section collects data concerning the patient's main caregiver for logistical reasons for follow up at six months.

3. Development of the Rehabilitation Process Questionnaire

The purpose of this questionnaire is to collect information regarding the rehabilitation process. It addresses: input the patient has received during admission, discharge planning and procedures and arrangements that are made for follow up after discharge.

In addition, the treating occupational therapist was asked to document any cognitive or perceptual deficits that had been identified during the patient's admission. It was decided to include this information as cognitive deficits are known to have a profound influence on function after discharge. Including standardized assessments of cognition in the study were considered, but it was decided that to include more detailed standardized assessments was beyond the scope of the study. Discharge was chosen as a suitable time point as not all patients are routinely screened for cognitive deficits at admission and mild cognitive and perceptual deficits are sometimes identified during the course of rehabilitation. Further questions were included to identify how the deficit was diagnosed. It is noted that the Occupational Therapists involved with this study are senior occupational therapists with a special interest and extensive experience in neurological rehabilitation. Thus their subjective clinical judgement is deemed to be sufficient for the purposes of this study in order to identify patients whose outcome may be influenced by cognitive deficits. This information may be useful in the planning of future studies.

4. Development of the Questionnaire at Six Months

The standardized outcome assessments were supplemented with the Questionnaire at Six Months in order to obtain more contextual information for considering outcome.

Section One

It was decided that discharge destination in terms of home or institution, was not sufficient detail as an outcome for a South African stroke population. The paucity of chronic care facilities in South Africa may result in patients with very severe disabilities returning to live at home. If a patient is too severely disabled to return to their normal place of residence, they are sometimes accommodated by moving to live with another family member. Thus additional information was required to interpret discharge destination.

Section Two

Although a number of the standardized outcome measures address mobility issues (BI, EADL) none of the questionnaires documented the use of mobility aids in getting around inside and outside the home. This was considered important.

In addition, further information was gathered regarding use of transport. This was included because access to transport has been identified in previous studies as a major problem of stroke patients after discharge.

Section Three

Questions were included to describe work status at six months post stroke. The Modified Rankin Scale by structured interview includes questions to identify change in the ability of the patient to work, however it does not ask if the patient is currently working. Participants who have returned to work are asked if they are doing the exactly the same job that they did prior to the stroke, a slightly different job for the same employer or a completely different job. In patients who were not working, it was also of interest to know their reason for not working, and whether they were receiving disability grants.

The researcher considered including a question regarding whether employment was sheltered, protected, or supported. However, as only a small percentage of patients were expected to work in these environments following stroke, this question was not included. (Personal communication, Ms Tertia McKee, social worker at WCRC).

As the domain of productive activity is considered to extend beyond paid work, additional questions were added regarding participation in unpaid work, in a family business, volunteer work, looking after others and work around the house.

Section Four

It is of considerable clinical importance to know whether patients being discharged from the WCRC receive any further follow up after they leave the rehabilitation centre. This section aims to determine the type and amount of healthcare they have received after discharge. Two specific questions were added pertaining to whether lack of transport or lack of finances had influenced health care services that were accessed.

Section Five

The participant is asked whether there have been any other changes to their health since their discharge from the rehabilitation Unit. This question was included to identify any new illness (since the stroke) may have influenced their functioning at this time.

Section Six

In the event that the patient was living at a different place at six months compared to the initial discharge destination, questions were repeated to find out about the physical environment in which they were living.

5. Development of the Environmental Questionnaire

The purpose of this questionnaire was to identify patients whose function at six months may have been influenced by environmental barriers and facilitators. A questionnaire of 16 items was drawn up addressing the domains of finance, transport, home environment, outdoor environment, access to equipment, attitudes and support.

The items on this questionnaire can be linked to categories in the ICF checklist for environmental barriers and facilitators on which the questionnaire was based. However, it is not a comprehensive list. The selected items are those considered by the researcher to be most relevant to the patient group, following consultation with clinicians working in rehabilitation. Each factor is expected to influence outcomes of interest in this study.

It is acknowledged that a list of this nature is limited by the researcher's perceptions of what barriers/ facilitators an individual may experience. A qualitative approach to this subject would obtain richer information. However, it is beyond the scope of the study to thoroughly investigate the influence of environment on functioning. The purpose of this instrument is simply to identify patients whose outcome may have been influenced by environmental barriers or facilitators.

There is some repetition in the questions as the statement referring to facilitators is the inverse of the statement referring to barriers. However, the alternative was to ask whether a certain environmental factor such as, for example, financial resources was a barrier, a facilitator or neither of the above. This appeared too lengthy, especially as examples would need to be given of the way in which the factor helped or hindered participation.

APPENDIX VII PILOTING OF THE QUESTIONNAIRES DEVELOPED FOR USE IN THE STUDY

Objectives

1. To investigate the logistics involved in recruitment and data collection.
2. To establish whether the assessments could be completed within a reasonable time frame
3. To pilot the questionnaires that had been developed for use in the study, particularly the Afrikaans and Xhosa translations.

Methodology

A sample of convenience was obtained from the WCRC. Informed consent was obtained for all participants. The sample included stroke patients in the rehabilitation centre for the admission and discharge questionnaires, as well as patients in the community after discharge for the questionnaires applied at six months.

Questionnaires that had been translated[1] were piloted on a minimum of five patients, including a minimum of one English, Afrikaans and Xhosa speaking patient respectively. Questionnaires that had not required translation (because they were completed by the medical doctor, therapists or the researcher) were piloted for three patients each.

[1] See Appendix I for a description of the translation procedure for questionnaires developed specifically for use in the study.

Table XII Summary of Piloted Questionnaires

Questionnaire	Completed by:	English	Afrikaans	Xhosa
Questionnaire at Admission Demographic Details:	Interviewer administered in preferred language	3	2	3
Questionnaire at Discharge:	Interviewer administered in preferred language	2	2	1
Questionnaire at Six Months:	Interviewer administered in preferred language	3	4	1
Environmental Questionnaire:	Interviewer administered in preferred language	2	4	1
Referral Details Section of the Questionnaire at Admission	Researcher from Medical Records	3	0	0
Medical Section of the Questionnaire at Admission	Medical Doctor at WCRC	3	0	0
Rehab Process Questionnaire	Physiotherapist and Occupational Therapist	3	0	0

These questionnaires can be found in Appendices VIII to XIV.

Results and Discussion

Piloting of the Questionnaires revealed that assessments on admission were completed within one and a quarter hours, assessments at discharge were completed within an hour, and assessments at six months were completed within one and a half hours. A number of minor issues arose with regard to the questionnaires and these are described below.

Questionnaire on Admission

Section One: Medical Details

The pilot study confirmed that many patients will not have had an MRI or CT scan. In addition, results from scans may not be available to the admitting doctor even if they had been carried out at the referring institution. This was also true of other investigations, for example, a patient may be referred with a diagnosis of atherosclerosis, but the extent to which the vessel is occluded may not be documented. Thus for many patients stroke subtype will be indeterminate.

Additional categories were added for complications on admission, namely Central Post Stroke Pain syndrome (referring to neuropathic pain syndromes). With regard to musculoskeletal pain, it was decided to distinguish between categories of: lower limb pain (hip, knee or ankle) and upper limb pain (shoulder) and upper limb pain (other than shoulder pain).

The definition of high blood pressure used in the CERISE study (160/95) was considered to be too high. On the advice of the medical doctor at the WCRC a definition of BP greater than 140/90 was preferred. This also corresponds to cut off points used in other South African studies to indicate high blood pressure is a risk factor for stroke.

Coexisting medical conditions that were not already included in the list of risk factors appeared to be covered by the broad categories of pulmonary disease, disorders of the musculoskeletal system and "other".

A number of patients were noted to have retroviral disease. An additional section (now section 3) was added to the admissions assessment. The researcher will record each patient as being: documented positive, documented negative or of unknown status. This information will be obtained from the medical notes

Section 2: Referral Details

"Date of Referral Received" was changed to "Date of Referral", because the date on which the referral is received is not always recorded.

The response categories for the item regarding referral source were altered. An additional response category for "Self Referral/ Referred by friend or family member" was included on the advice of the Social Worker at WCRC. The response category for Private Health Care Sector was modified to include "Private Hospital or Private Practice", as referring private practitioners may not be hospital-based.

An additional question addresses whether the patient had been admitted from home, hospital or a care facility/ institution.

Section 3: Demographic Details

Initially the patient was asked which languages they spoke and understood. However, as participants were found to be fluent in more than one language an additional question was added to ask which language they preferred the interview to be conducted in.

Patients were asked to identify which population group they described themselves as belonging to. The categories used in the 2001 census were adopted for response categories. In other studies participants have declined to answer this question, so an explanation was added describing the purpose of the question. All participants were asked at the end of the piloted questionnaires if there was any question that caused offence or that they felt should not be asked. However, in the pilot study, no complaints were raised.

After piloting, slight changes were made to the response categories for marital status in order to avoid ambiguity: "divorced" was changed to "divorced or separated" and "single" was changed to "never married".

Questionnaire on Discharge

Section 1:

Changes were made to the categories of educational attainment. Participants were asked to specify the highest standard/ grade reached at school as well as the number of years of further education subsequently obtained. This was in order to facilitate analysis according to total number of years of successful education.

Minor changes to wording were made to avoid ambiguity. "Were you in paid employment *when* you had your stroke" was changed to "Were you in paid employment *before* you had your stroke?" Participants had initially interpreted the question as whether they were actually at work at the time of onset of the stroke. Changes were made to wording in the Xhosa questionnaire for the translation of "had a stroke", which was deemed to be an inappropriate translation. The initial translation "to receive a stroke" ("Ingaba ubusebenza kumsebenzi ohlawulayo phambi kokuhlelwa kwakho isistrowukhu") had associations of a positive event, such as to receive a gift. The question was changed to "Ingaba ubusebenza kumsebenzi ohlawulayo phambi kokuhlaselwa kwakho isistrowukhu" where the wording reflects receiving something which is not favourable.

Further issues arose with regard to questions about work. Additional response categories were added for irregular working hours in order to accommodate casual, seasonal and contract work. It was decided to ask an open question with regard to type of work, and that categories will be created for analysis at the time of data capture.

A number of changes were made to the response categories for reason for not working. Patients who were unable to work who were receiving private disability payouts were included in the same response category as those receiving state disability grants. Response categories of "retired receiving state pension" and "retired receiving private pension" were collapsed into one category. This decision was made on the basis that women over 60 years of age, and men over the age of 65 qualify to receive a state pension. It is beyond the scope of this study to investigate whether those entitled to receiving a pension experience difficulties in claiming their pension.

Household income was defined according to the definition of the 2001 Census. That is, household income is the total income (before tax) of all the individuals living in a household, where household is defined a group of people living together who "jointly provide themselves with food and/ or other essentials for living, or a single person who lives alone." (Statistics South Africa 2005).

It was clear from the pilot study that there will be error involved in making this estimation. One participant said he didn't know what other members of the household were earning. A number of participants were living in homes that comprised a number of working adults who did not necessarily pool their income, but may have contributed to the household costs in some way. It is recognized that this estimation may not be accurate, but it is at least some reflection of socio-economic status. Additional categories were added for monthly household income to capture the range of incomes reported.

Section 2: Details of the Discharge Environment

Minor changes in wording were made to improve grammar and avoid ambiguity. In the question regarding telephone access, wording was changed to clarify that the response category of "telephone inside dwelling" referred specifically to a landline. "Public Telephone Nearby" was added as an additional response category.

Section 3: Caregiver Details

Some modifications were made for categories of relationship to patients: an additional category of "friend"; "Mother or father-in-law" was added to the "parent" response category, and "son or daughter-in-law" was added to response category of "child".

Questionnaire at 6 Months

Section One

Wording of the question regarding return home was changed so that the participant was asked the main reason for their failure to return to own home.

Section Two

It became clear that some patients may use more than one means of moving around. For example, a patient may walk inside, but use their wheelchair to get around outdoors. Or a patient might walk short distances inside their house with supervision, but when unassisted, would self-propel in the wheelchair. Patients were therefore asked to identify their *main* means of moving around inside the home and outside the home (i.e. Wheelchair, walking or other.). Patients were then asked to specify if they use any adaptive equipment for getting around. Elbow crutches and ankle foot orthoses were added to the original list following the pilot study. Questions regarding the amount of assistance required were excluded from the final draft as they were found to duplicate information obtained from the other measurement tools (BI and EADL).

The first draft of the questionnaire asked whether the patient was able to use the same means of transport following the stroke. In the final draft, it was decided instead to ask the patient to specify which forms of transport they are able to use after the stroke for more specific information. Participants were asked to indicate up to *three* (instead of *two*) means of transport utilized prior to the stroke, as many patients indicated they used multiple means of transport. Many participants indicated that whereas before the stroke they would use whatever means was most convenient at the time, now they were limited in their options.

Section 3

Following the pilot study, it was decided that patients who indicated they were unable to work due to illness or disability and who were not receiving a disability grant, would be asked: "Has an application for a disability grant been made?", and if they answered "yes", they would be asked: "What is the current status of your application? 1= Application still being assessed 2= Application Denied". Categories of "retired (receiving pension)" and "retired (not receiving pension)" were condensed. An additional response category, "undergoing work retraining/ vocational training" was included. "Work retraining/ vocational training" is defined as "the process of rebuilding and developing the disabled person's ability to function optimally, within the limitations imposed by his disability in a job." (Dept of National Health and Population Development.)

The question regarding participation in productive unpaid activity initially referred to participation over the previous two weeks. The reasoning had been to refer to a time interval that would be remembered by the patient. However, it was decided that this was an arbitrary cut off point and it would be better to simply specify the period since discharge from hospital.

Section 4

In specifying use of healthcare since discharge, participants in the pilot study seemed unsure of length of treatment time, which was therefore left out. Very few participants appeared to have been receiving input from health services prior to their stroke. However, it was decided to leave the question about relative frequency in place.

No changes were made to Section 5. Section 6 is only administered if the patient has moved since discharge and is simply a repeat of the Details of the Discharge Environment in the Discharge Questionnaire. As such, Section Six was adjusted according to changes in the Discharge Questionnaire.

The Environmental Questionnaire

The first draft of the questionnaire was made up of questions like: "Is lack of finance a problem that limits you participating in your usual activities since having your stroke?" Patients appeared to find this format confusing, and the interviewer found that she needed to give examples to clarify the meaning of the questions. As a result, in the second draft, each item was changed into a statement with examples and the patient was asked if the statement applied to them. Patients appeared to find this easier.

For this questionnaire a specific environmental factor was linked to a specific outcome. For example: "It is difficult to move around because I don't have access to the equipment that I need". The alternative was to pose a more general statement such as "Lack of equipment has been a barrier to me." However, it seemed that patients needed concrete examples of the effect of an environmental factor on a specific function in order to be able to answer this more easily.

It was noted in the pilot study that where one environmental factor was identified as a barrier, the same factor was not identified as a facilitator in the positive questions. This indicated consistency. With regard to attitudes affecting participation in social activities, some patients indicated that while there may have been support from friends, there had not been support from members of the community. In this way, it was clear that combining friends and community in the same category would lead to some loss of detail. However, it was decided not to make the questionnaire any longer by adding more statements

Due to the complexity of the concepts of barriers and facilitators, the research assistant was asked to back translate the Xhosa version of the final draft without having had sight of the English original. The back translation was noted to be almost identical to the original English version.

Conclusions

The pilot study showed that there were no major problems with the questionnaires developed for use in the study. Minor changes were made to improve their content. The researcher was also able to determine that assessments could be done in a reasonable time frame. Practical arrangements were made for setting up procedures for recruitment and data collection.

QUESTIONNAIRES

APPENDIX VIII LANGUAGE SCREENING TOOL

In the case of participants who lacked capacity to give consent, their next of kin was contacted as proxy. Members of the rehabilitation team were consulted and medical records were screened for any indication of a language or cognitive deficit prior to assessment. In addition to these measures, a language screening tool was applied as an adjunct to assess comprehension prior to obtaining informed consent.

The language screening test comprised a section with seven "yes/no" questions, and a section to assess the ability of the participant to follow commands. The yes/ no questions were based on the Western Aphasia Battery and the commands were taken from (Shipley and McAfee 1992).

Patient Code: ____________________ Date: ____________________

1. English

LANGUAGE TESTS: ENGLISH

Yes/ No Questions

I am going to ask you some questions. The answer should be "yes or no". Some of the questions may seem a little silly. Please try to answer them anyway.

SCORING:
1= Correct
0= Incorrect

1. Is your name Smith? ("no" should be correct)	☐
2. Is your name (real name) ?	☐
3. Do you live in (real residence)?	☐
4. Do you live in Durban? ("no" should be correct)	☐
5. Are you a man/ woman? ("yes" should be correct)	☐
6. Will paper burn in fire?	☐
7. Is a horse larger than a dog?	☐

Following Commands:

Please carry out the following commands.

SCORING:
1= Performs task correctly
0= Does not perform task correctly.

One Part Command	Touch your nose.	☐
	Raise your hand.	☐
	Look at the door.	☐
Two Part Command	Touch your head, then your mouth.	☐
	Nod your head twice, then close your eyes.	☐
Three Part Command	Look at the door, look at me, then close your eyes.	☐
	Touch your chin, then your nose, then raise your hand.	☐

2. Afrikaans

Patient Code: ____________________ Date: ____________________

LANGUAGE TESTS : AFRIKAANS

Ja/ Nee Vrae

Ek gaan u 'n paar vrae vra. Die antwoord behoort "ja" of "nee" te wees. 'n Paar van die vrae mag 'n bietjie laf voorkom. Probeer in elk geval om hulle te beantwoord. TELLING: 1= Korrek
0= Nie Korrek nie

1. Is u naam Smit? ("nee" behoort korrek te wees) ☐
2. Is u naam <u>(regte naam)</u>? ☐
3. Woon u in (regte woning)? ☐
4. Woon u in Durban? ("nee behoort korrek te wees) ☐
5. Is u 'n man / vrou? ("ja" behoort korrek te wees) ☐
6. Sal papier in vuur brand? ☐
7. Is 'n perd groter as 'n hond? ☐

Opdragte volg

Dra asseblief die volgende opdragte uit. TELLING: 1 = Verrig taak reg uit
0 = Verrig nie taak reg uit nie

<u>Een-delige Opdrag</u>

Raak u neus. ☐

Lig u hand op. ☐

Kyk na die deur. ☐

<u>Twee-delige Opdrag</u>.

Raak aan u kop, dan u mond. ☐

Knik twee keer u kop, maak dan u oë toe. ☐

<u>Drie-delige Opdrag</u>

Kyk na die deur, kyk na my, maak dan u oë toe. ☐

Raak aan u ken, dan u neus, lig dan u hand op. ☐

3. Xhosa

Patient Code: ______________________ Date: ______________________

LANGUAGE TESTS: ISIXHOSA

Imibuzo efuna u-Ewe noHayi

Ndiza kubuza imibuzo ethile. Impendulo kufuneka ibengu Ewe okanye Hayi. Eminye imibuzo iza kuvakala ifanana . Nceda yiphendule kananjalo.

Amanqaku:
Impendulu ingaba ilungile?
1=Ewe, 0=Hayi

1. Ungu (Nolitha/ Litha) igama lakho ? ☐
2. Igama lakho ngu (lokwenene)? ☐
3. Uhlala e.....(indawo yokwenene)? ☐
4. Uhlala e Thekwini? ☐
5. Uyindoda/ ungobhingqileyo? ☐
6. Iphepha liyatsha ngumlilo? ☐
7. Ihashe likhulu kunenja? ☐

Iziyaleli ezilandelayo

Nceda wenze lemiyalelo ilandelayo.

Amanqaku:
1= Ukuba ulandela kakuhle
0= Ukuba awulandeli kakuhle

Icandelo lokuqala

Bamba impumlo. ☐

Phakamisa isandla. ☐

Jonga emnyango. ☐

Icandelo lesibini

Bamba intloko, uze ubambe umlomo. ☐

Nqwala intloko kabini, uze ucimele. ☐

Icandelo lesithathu

Jonga emnyango, ndijonge/jonga kum, uze ucimele. ☐

Bamba isilevu, uze ubambe impumlo yakho, uze uphakamise isandla. ☐

APPENDIX IX INTAKE FORM

INTAKE FORM

To be filled in by researcher at admission

Patient Code:______________ Date of Admission:________________

INCLUSION CRITERIA FOR ADMISSION TO THE STUDY

Section A (To be completed for all patients admitted to Wards A&B)

Does the patient meet the following entrance criteria for admission to the study?

- First Ever Stroke ☐ 1=Yes 2=No
- Stroke not > 3 months prior (90 days) ☐ 1=Yes 2=No
  Specify date of most recent stroke:________________
- Lives not more than 50km's away from WCRC. ☐ 1=Yes 2=No
  If no, specify town/ region: ________________
- Reported pre-stroke Barthel Score $\geq$ 50 ☐ 1=Yes 2=No
- Some physical impairment following the stroke ☐ 1=Yes 2=No
- Able to speak English, Afrikaans or Xhosa ☐ 1=Yes 2=No
  If no, specify language spoken: ________________
- Can be assessed within 5 working days of admission ☐ 1=Yes 2=No
  If no, specify reason: ________________
- No history of pre-stroke neurological conditions ☐ 1=Yes 2=No
  e.g. pre-stroke head-injury, Multiple
  Sclerosis, Parkinson's disease, pre-stroke epilepsy
  If no, specify: ________________
- Primary diagnosis of stroke ☐ 1=Yes 2=No
  i.e. the following conditions are excluded: subdural haemorrhage or haemorrhage due to tumour, encephalitis or trauma.
  If no, specify: ________________
- 18 - 85 years of age ☐ 1=Yes 2=No
  If no, specify age: ________________
- Informed consent from patient or relative ☐ 1=Yes 2=No

CONFIDENTIAL PATIENT INFORMATION

Section B (To be completed for all patients who meet entrance criteria)

Title:__________First Name(s):____________________Surname:____________________

Date of Birth:____________________Age:__________Gender: ☐ Male=1, Female=2

Address:____

____ Post Code:______________

Tel (h)________________ (c) ________________ (w) ________________

If not own telephone no, please specify contact person: ________________

Please specify relation to you: ☐ Family member ☐ Friend ☐ Neighbour

☐ Other, please specify: ________________

Patient Code:_______________ Date of Admission:_________________

ADDITIONAL INFORMATION

(Includes information that researcher should be aware of during assessments.)

APPENDIX X ADMISSION QUESTIONNAIRE

ADMISSION QUESTIONNAIRE

PATIENT CODE: DATE:

PATTERN OF RECOVERY AND OUTCOME AFTER STROKE GUIDELINES FOR MEDICAL QUESTIONNAIRE AT ADMISSION

CRITERIA FOR ADMISSION TO THE STUDY

Inclusion criteria :

- a diagnosis of first ever stroke
- 3 months or less since onset
- 18 - 85 years of age
- some degree of motor impairment as defined by Rivermead Motor Assessment scores: Gross Motor Function Score $\leq$11, and/ or Leg and Trunk $\leq$8, and/ or Arm Function Score $\leq$12

Exclusion criteria:

- pre-stroke neurological conditions e.g. previous stroke, pre-stroke head-injury,Multiple Sclerosis, Parkinson's disease, pre-stroke epilepsy
- subdural haemorrhage
- haemorrhage due to tumour, encephalitis or trauma
- reported pre-stroke Barthel Score of less than 50
- patient lives more than 50km's away from WCRC
- patient unable to speak English, Afrikaans or Xhosa
- no physical impairment following their stroke
- lack of informed consent

CLASSIFICATION OF STROKE- DEFINITIONS

Haemorrhagic, Ischaemic or indeterminate

Classification of Ischaemic/ Haemorrhagic stroke is made on the basis of CT or MRI findings only. If no imaging results are available, the type of stroke is recorded as indeterminate, and no attempt is made to specify subtype.

Absence of blood on initial CT excludes primary intracerebral haemorrhage and subarachnoid haemorrhage. If imaging results are available, the stroke is further classified into sub-group in conjunction with other clinical findings and the results of investigations. See definitions below.

CLASSIFICATION OF STROKE SUBTYPE

HAEMORRHAGIC STROKE SUBTYPE

Primary Intracerebral Haemorrhage:
As identified on CT/ MRI

Subarachnoid Haemorrhage:
As identified on CT/ MRI

PATIENT CODE: DATE:

ISCHAEMIC STROKE SUBTYPE

Ischaemic: Small Vessel Disease (Includes lacunar Stroke)

- presence of one of the traditional lacunar syndromes (eg. Pure motor stroke pure sensory stroke, sensorimotor stroke, ataxic hemiparesis, dysarthria/ clumsy hand syndrome)
- infarction < 1.5.cm diameter or normal CT/ MRI
- absence of acute cerebral cortical dysfunction
- potential cardiac source absent
- potential large artery atherosclerotic source absent (i.e. Large extra-cranial arteries should not demonstrate an occlusion of >50%)

Ischaemic: Large Vessel Disease (Includes Large Artery Atherosclerosis)

- presence of an occlusion or stenosis with >50% diameter reduction found on Doppler Ultrasound or angiography
- potential source of cardiogenic embolism absent

Ischaemic: Cardioembolic

- presence of high risk or medium risk source of cardiac embolism: (for example atrial fibrillation, recent myocardial infarction in the last 6 weeks, infective endocarditis, prosthetic heart valve)
- potential large artery atherosclerotic source absent

Ischaemic: Other Determined Etiology

- Ischaemic stroke not meeting criteria of above categories but of other determined cause
- These include: spontaneous dissection, traumatic dissection, vasculitis, haematological disorders and coagulopathies.
- Diagnoses of above revealed by diagnostic studies
- Potential cardiac sources of embolism absent
- Potential large artery atherosclerotic sources absent

Ischaemic: Indeterminate or >1 cause.

- no likely etiology identified despite investigations, OR
- no etiology identified, but investigations incomplete, OR
- more than one likely etiology eg. Potential cardioembolic source, and atherosclerosis of >50%

COMPLICATIONS ON ADMISSION

- Shoulder pain and other upper limb pain are separate categories
- Central Post Stroke Pain refers to neuropathic pain occuring following stroke. It has been defined as pain occuring in the area corresponding to the CVA, where there is no other obvious cause for the pain and it is usually asssociated with sensory abnormalities.
- Contractures refers to loss of passive range of movement of a joint.

PATIENT CODE: DATE:

QUESTIONNAIRE AT ADMISSION TO THE WESTERN CAPE REHABILITATION CENTRE (WCRC)

SECTION ONE: MEDICAL DETAILS (To be filled in by doctor at WCRC. Please mark appropriate boxes.)

Characteristics of Stroke

1. Side of lesion: ☐ Right (1) ☐ Left (2) ☐ Both (3)

2. Side of impairment: ☐ Right (1) ☐ Left (2) ☐ Both (3)

3. Diagnosis based on:
   - ☐ CT (1)
   - ☐ MRI (2)
   - ☐ CT and MRI (3)
   - ☐ Clinical Assessment only (4)

   If applicable, specify: Date of CT ________________
   Date of MRI ________________

4. Type of stroke: ☐ Haemorrhagic (1) ☐ Ischaemic (2) ☐ Indeterminate (3)

   (Type of stroke is considered indeterminate unless haemorrhagic or ischaemic stroke is confirmed by CT or MRI. If no imaging results available, go to Question 6)

   If available: MRI/CT Scan Results: ____

   ____

5. If possible, specify sub type of stroke:
   - ☐ Primary intracerebral haemorrhage (1)
   - ☐ Subarachnoid Haemorrhage (2)
   - ☐ Ischaemic: Small vessel (3)
   - ☐ Ischaemic: Large vessel (4)
   - ☐ Ischaemic: Cardioembolic (5)
   - ☐ Ischaemic: Other Determined Etiology (6) Specify: ________________
   - ☐ Ischaemic: Indeterminate or >1 cause (7)

Complications on Admission

6. Were any of the following complications present on admission to the centre? 1=Yes 2=No

☐ Pneumonia/ chest infection	☐ Shoulder pain	☐ Lower limb thrombosis
☐ Urinary tract Infection	☐ Other upper limb pain	☐ Pulmonary embolism
☐ Pressure sores	☐ Back pain	☐ Seizures
☐ Depression	☐ Hip, knee or ankle pain	☐ Contractures
☐ History of fall since stroke	☐ Central Post Stroke Pain	☐ Other. Specify:

____

7. Did the patient present with any of the following on admission to the WCRC?

Nasogastric feeding tube in situ	☐YES (1)	☐NO (2)
Indwelling Urinary catheter in situ	☐YES (1)	☐NO (2)
PEG feeding tube in situ	☐YES (1)	☐NO (2)

PATIENT CODE: DATE:

8. Risk Factors Does the patient have any of the following risk factors?

Cardiomyopathy YES☐ (1) NO☐ (2)

Atrial Fibrillation YES☐ (1) NO☐ (2)

Valvular Heart Disease YES☐ (1) NO☐ (2)

Ischaemic Heart Disease YES☐ (1) NO☐ (2)

Heart Failure YES☐ (1) NO☐ (2)

High blood pressure YES☐ (1) NO☐ (2)
(DEFINED As Repeated BP ≥140/90 or history of high BP)

High total cholesterol YES☐ (1) NO☐ (2)
(DEFINED AS ≥ 5.17 mmol/L)

Oral contraceptives YES☐ (1) NO☐ (2)

Diabetes mellitus YES☐ (1) NO☐ (2)
(DEFINED AS repeated fasting plasma glucose level of more than 7 mmol/L according to the WHO diagnostic criteria, or a recorded history of diabetes whether treated or untreated)

Previous TIA YES☐ (1) NO☐(2)

Peripheral vascular disease YES☐ (1) NO☐(2)

Previous thrombosis YES☐ (1) NO☐(2)

Carcinoma YES☐ (1) NO☐(2)

Excess alcohol intake YES☐ (1) NO☐(2)
(*DEFINED AS*>3 units per day for men, and >2 units per day for women. Specify no. Of units ________ . 1 unit is equivalent to 1 tot of spirits, 1 small glass of wine, or 300ml/ half pint of beer.)

Smoking.
- Previous smoker, Quit >5 years before stroke ☐ (1)
- Previous smoker, Quit <5 years before stroke ☐ (2)
- Current smoker, <20/ day ☐ (3)
- Current smoker, >20/ day ☐ (4)
- Never Smoked ☐ (5)

Other substance abuse. YES☐ (1) NO☐ (2) Specify ____________________

Other YES☐ (1) NO☐ (2) Specify____________________

9. Co -existing Medical Conditions: Does the patient have any of the following co-existing conditions?

9.1. Pulmonary disease such as COAD, TB YES☐ (1) NO☐ (2)
Specify:____________________

9.2. Disorders of the musculoskeletal system e.g. Arthritis or gout YES☐ (1) NO☐ (2)
Specify:____________________

9.3. Other. YES☐ (1) NO☐ (2)
Specify: ____________________

PATIENT CODE: DATE:

SECTION TWO: REFERRAL DETAILS (To be filled in by researcher from medical records.)

2.1. Date of stroke: ____________________

2.2. Date of referral to WCRC: ____________________

2.3. Date of admission to WCRC: ____________________

2.4. Time Elapsed between Stroke and Admission: (days) ____________________

2.5. Time Elapsed between Referral and Admission: (days) ____________________

2.6. Referral source- Health Care Agency: ☐

1= Primary State Centre Specify: ____________________
2= Secondary State Centre Specify: ____________________
3= Tertiary State Centre Specify: ____________________
4= Private Health Care Sector: Private Hospital or Private Practice
5= Self referral/ Referred by friend or family member
6= Other. Specify ____________________

2.7. Referral source- person making referral: ☐

1= Doctor
2= Nurse
3= Physiotherapist
4= Occupational Therapist
5= Speech and Language Therapist
6= Social Worker
7= Other. Specify ____________________

2.8. Patient admitted from: ☐

1= Home
2= Hospital
3= Care Facility/ Institution
4= Other. Specify: ____________

SECTION THREE: HIV/ AIDS STATUS

(This information will be obtained from the patient's medical records at WCRC. All patients admitted to the study have given consent for the researcher to consult their medical records.)

According to the patient's medical records, which of the following is applicable? ☐

1= Documented negative HIV/ AIDS Status
2= Documented positive HIV/ AIDS Status
3= Unknown HIV/ AIDS Status (not documented in medical records)

PATIENT CODE: DATE:

SECTION FOUR: **DEMOGRAPHIC DETAILS (To be filled in by researcher: questions to be asked of the patient. Please complete appropriate section.)**

ENGLISH

3.1. What languages are you able to speak and understand? ☐
1= Afrikaans 2= English 3= Xhosa 4= English and Afrikaans
5= English and Xhosa 6= Afrikaans and Xhosa 7=Other. Specify ________________

3.2. Which language would you prefer to be interviewed in? ☐
1=Afrikaans 2= English 3= Xhosa

3.3. What population group would you describe yourself as belonging to? ☐ (This information is requested in order to assess equality of health outcomes. You do not have to answer this question.)
1= Asian or Indian 2= Black 3= Coloured 4= White 5= Other. Specify ______

3.4. Before you had your stroke, did you live alone? 1= Yes 2= No ☐
3.5. Which of the following best describes you? ☐
1= Married 2= Living with partner 3= Divorced or separated
4= Widowed 5= Never married 6= Other. Specify: ____________

AFRIKAANS:

3.1. Watter taal kan u praat en verstaan? ☐
1= Afrikaans 2= Engels 3= Xhosa 4= Engels en Afrikaans
5= Engels en Xhosa 6= Afrikaans en Xhosa 7= Ander. Noem asb. ____________

3.2. Watter taal verkies u om in ondervra te wees? ☐
1= Afrikaans 2= Engels 3= Xhosa

3.3. Aan watter bevolkingsgroep behoort u? ☐ (Hierdie informasie word slegs gevra om die mate van gesondheid na behandeling te vergelyk. U hoef dit nie te antwoord nie.)
1= Asiaties of Indiër 2= Swart 3= Kleurling 4= Wit
5= Ander. Noem asb. ________________

3.4. Het u alleen gewoon voor u beroerte aanval? 1= Ja 2= Nee ☐
3.5. Watter van die volgende is van toepassing? ☐
1= Getroud 2= Woon saam 3= Geskei of vervreemd 4= Weduwee / wewenaar
5= Nooit getroud 6= Ander. Noem asb. ____________________________

ISIXHOSA:

3.1 Zeziphi iilwimi okwaziyo ukuzithetha noziqondayo? ☐
1= IsiBhulu 2= IsiNgesi 3= IsiXhosa 4= Isingesi nesiBhulu
5= Isingesi nesiXhosa 6= IsiBhulu nesiXhosa 7= Enye. Cacisa ________________

3.2. Ukhetha ukubuzwa ngoluphi ulwimi? ☐
1= IsiBhulu/ Afrikaans 2= IsiNgesi/ English 3= IsiXhosa/ Xhosa

3.3. Ungathi ulolupho uhlanga ? (Olu lwazi lubuzelwa ukujonga iziphumo zempilo. Akunyanzelekanga ukuba uwuphendule lo mbuzo) ☐
1= Um- Eshiya/ UmNdiya (Asian/ Indian) 2= Omnyama/ Black 3= Owebala/ Coloured
4= Omhlophe/ White 5= Olunye. Cacisa ________________

3.4. Phambi kokuhlelwa sisitrowukhi, ubuhlala wedwa na? 1= Ewe 2= Hayi ☐
3.5. Kwezi zinto zilandelayo yeyiphi ekuchaza ngcono? ☐
1= Utshatile (Married) 2= Uhlala nomlingane (Living with partner)
3= Udivosile/ nahlukene (Divorced or Separated) 4= Uswelekelwe ngumyeni/ nkosikazi (Widowed)
5= Zange utshate (Never married) 6= Ezinye. Cacisa ________________

APPENDIX XI QUESTIONNAIRE AT DISCHARGE

QUESTIONNAIRE AT DISCHARGE

English Version

PATIENT CODE: **DATE:**

QUESTIONNAIRE AT DISCHARGE

The following questions are intended to provide personal information for the study. The information will be used only for the research project, and will be kept strictly confidential. If you think several answers might apply, please choose the one that best supports your view.

SECTION 1: SOCIO-ECONOMIC QUESTIONNAIRE

1. What is the highest level of schooling/ education that you have completed? ☐

1= Pre-primary/ no formal education
2= Sub A/ Grade 1
3= Sub B/ Grade 2
4= Std 1/ Grade 3
5= Std 2/ Grade 4
6= Std 3/ Grade 5
7= Std 4/ Grade 6
8= Std 5/ Grade 7
9= Std 6/ Grade 8
10= Std 7/ Grade 9
11= Std 8/ Grade 10
12= Std 9/ Grade 11
13= Std 10/ Grade 12
14= Std 8/ Grade 10 with Diploma/ Certificate - State no. of years of successful study for qualification ______
15= Std 9/ Grade 11 with Diploma/ Certificate - State no. of years of successful study for qualification ______
16= Std 10/ Grade 12 with Diploma/ Certificate - State no. of years of successful study for qualification ______
17= Std 10/ Grade 12 with Tertiary degree - State no. of years of successful study for degree ______
18= Other. Specify: ____

2. Were you in paid employment/ working before you had your stroke? ☐

1= Yes, paid employment *(Please go to question 3)*
2= No, not paid employment *(Please go to question 5)*

3. Which of the following best describes your employment status before you had your stroke? ☐

1= Employed
2= Self-employed or helping in a family business
3= Other. Specify: ______________________

4. Which of the following best describes your working hours? ☐

1= Part-time: Specify hours/ week. ________
2= Full-time: more than 20 hours a week.
3= Irregular hours: occasional work as day casual.
4= Irregular fixed term contracts. Specify typical hours/ week ________
5= Other. Specify: ______________________

5. What was the reason for your not working? ☐

1= Unemployed, looking for work
2= Unemployed, prefers not to work
3= Unable to work due to illness or disability (Receiving Disability Grant or Private Insurance Benefit)
4= Unable to work due to illness or disability (No Disability Grant)
5= Retired/ Pensioner
6= Looking after the home, no benefits (includes looking after children)
7= Scholar or student
8= Other. Specify: ____

PATIENT CODE: DATE:

6. What kind of work did you do?

Please specify: ______________________________ ☐

7. What is your monthly household income? ☐

1= R1- R200	6=	R2 501- R4 500	
2= R201- R500	7=	R4 501- R8 000	
3= R501- R1000	8=	R8 001- R16 000	
4= R1001- R1500	9=	More than R16 000	
5= R1501- R2500	10=	Prefers not to answer or does not know	

8. How many rooms in total are there in your home? ☐
(Include all rooms except bathrooms, sheds and garages unless there is someone living in them)

9. How many adults and children live in your home?

9.1. No. of Adults ☐
9.2. No of Children ☐

SECTION 2: DETAILS OF THE DISCHARGE ENVIRONMENT

1. Will you be returning to your own home? 1= Yes 2= No ☐

2. How would you best describe the place where you live? ☐

1= House
2= Block of flats
3= House/ flat/ room in back yard or on shared property
4= Townhouse, cluster, semi-detached (simplex, duplex or triplex)
5= Retirement village
6= Informal dwelling/ shack in informal settlement.
7= Informal dwelling/ shack in backyard
8= Other. Specify: __________

3. Do you need to go up steps or stairs to get into your home? 1= Yes 2= No ☐

If yes, please specify.
1= Steps. Specify approximate number: __________
2= Flights of stairs. Specify approximate number: ________
If subject answers flights of stairs, go to question 4, if not , go to question 5.

4. Is there a lift? 1= Yes 2= No ☐

5. Do you have steps, or different levels inside your home? 1= Yes 2= No ☐

6. Do you have electricity? 1= Yes 2= No ☐

7. Do you have running water inside the house? 1= Yes 2= No ☐

8. Do you have a bath or shower in your home? 1= Yes 2= No ☐

PATIENT CODE: DATE:

9. Are your toilet facilities inside or outside?
1= Inside 2= Outside ☐

10. Do you have to cross uneven ground to get to your toilet facilities? 1= Yes 2= No ☐

11. Do you have to go up stairs to get to your toilet facilities? 1= Yes 2= No ☐

12. If you use your wheelchair to get around, is it possible to get to the toilet in your wheelchair?
1= Yes 2= No 3= Not applicable ☐

13. Do you have access to a telephone? 1= Yes 2= No ☐

If yes, please specify telephone mostly used: ☐
1= Landline inside dwelling 2= Cell phone 3= Neighbour's phone
4= Public telephone nearby 5= None of the above.

SECTION 3: CONTACT DETAILS

1. Who is your main caregiver? ______________________________

2. What is their relationship to you? ☐

1= Husband/ Wife/ Partner
2= Parent / mother or father-in-law
3= Child/ son or daughter-in-law
4= Relative
5= Friend
6= Other. Please specify: ____________

3. Please give details of how they can be contacted.

Address: ______________________________

____

Telephone number: (h) (w) (c) ______________________________

4. How can I best contact you to arrange the follow up assessment at 6 months?
(Please give several alternatives.)

1.______________________________

2.______________________________

3.______________________________

4.______________________________

5.______________________________

QUESTIONNAIRE AT DISCHARGE

Afrikaans Version

VRAELYS VOOR ONTSLANING

DEEL 1: SOSIAAL-EKONOMIESE VRAELYS

Die volgende vrae verskaf u persoonlike inligting vir die studie. Hierdie informasie sal slegs vir hierdie navorsing gebruik word, en sal vertroulik gehou word. As dit vir u voel asof meer as een antwoord korrek is, kies asseblief die een wat die naaste aan die korrekte antwoord is.

1. Wat is die hoogste klas wat u geslaag het? ☐

1= Pre-primêr / geen formele opvoeding nie
2= Sub A/ Graad 1
3= Sub B/ Graad 2
4= Std 1 / Graad 3
5= Std 2 / Graad 4
6= Std 3 / Graad 5
7= Std 4 / Graad 6
8= Std 5 / Graad 7
9= Std 6 / Graad 8
10= Std 7 / Graad 9
11= Std 8 / Graad 10
12= Std 9 / Graad 11
13= Std 10 / Graad 12
14= Std 8 / Gr 10 met 'n diploma of sertifikaat. (Noem aantal jare van suksesvolle studie vir kwalifikasie)___
15= Std 9 / Gr 11 met 'n diploma of sertifikaat. (Noem aantal jare van suksesvolle studie vir kwalifikasie)___
16= Std 10/ Gr 12 met 'n diploma of sertifikaat. (Noem aantal jare van suksesvolle studie vir kwalifikasie)___
17= Std 10/ Gr 12 met 'n tersiêre graad. (Noem aantal jare van suksesvolle studie vir kwalifikasie)___
18= Ander. Noem asb. ______________________________

2. Was u in betaalde indiensneming voor u u beroerte aanval gekry het? ☐

1= Ja, betaalde indiensneming (Gaan asb. na vraag 3)
2= Nee, nie betaalde indiensneming nie (Gaan asb. na vraag 5)

3. Watter van die volgende beskryf u werksomstandighede die beste voor u beroerte aanval? ☐

1= Indiensneming
2= Eie besigheid gehad, of het gehelp in 'n familiebesigheid
3= Ander Noem asb. ______________________________

4. Watter van die volgende werksure het u gehad? ☐

1= Deeltyds. Noem asseblief hoeveel ure per week ________
2= Voltyds (Meer as 20 ure per week)
3= Ongereelde ure, werk soms as tydelike werker
4= Ongereelde kontrakte vir sekere tydperkte. Noem asseblief ongeveer hoeveel ure per week ___
5= Ander: Noem asb. ______________________________

5. Hoekom het u nie gewerk nie? ☐

1= Ek het gesoek vir werk
2= Ek het verkies om nie te werk nie
3= Ek kon nie werk nie omdat ek siek of ongeskik vir werk was (ontvang 'n Ongeskiktheidstoelae/ of private versekeringstoelae)
4= Ek kon nie werk nie omdat ek siek of ongeskik vir werk was (ontvang geen Ongeskiktheidstoelae nie)
5= Afgetree / Pensioenaris
6= Sorg vir die huishouding, geen toelae nie (dit sluit in om kinders op te pas)
7= Leerling of student
8= Ander. Noem asb.______________________________

6. **Watter soort werk het u gedoen?**

Noem asb.: ____

7. **Wat is u maandlikse huishoudsinkomste?** ☐

1= R1- R200	6= R2 501- R4 500
2= R201- R500	7= R4 501- R8 000
3= R501- R1000	8= R8 001- R16 000
4= R1001- R1500	9= Meer as R16 000
5= R1501- R2500	10= Verkies om nie te antwoord nie, of weet nie

8. **Hoeveel kamers is in u woning?** ☐
(sluit in alle kamers behalwe badkamers, hokkies en motorhuise, tensy iemand daarin woon)

9. **Hoeveel grootmense en kinders bly in u woning?**
9.1. Getal grootmense ☐
9.2. Getal kinders ☐

DEEL 2: BESONDERHEDE VAN DIE ONTSLANINGSOMGEWING

1. **Gaan u nou terug na u woning toe?** 1= Ja 2= Nee ☐

2. **Beskryf u woning.** ☐

1= Huis
2= Woonstelgebou
3= Huis / Woonstel of kamer in 'n agterplaas of erf wat gedeel word
4= Dorpshuis, meenthuis of koppelhuis
5= Aftree-oord
6= Informele woning / pondok in informele vesting
7= Informele behuising / pondok in 'n agterplaas
8= Ander. Noem asb. ____

3. **Moet u trappies klim om by u woning in te kom?** 1= Ja 2= Nee ☐

Spesifeer asseblief. ☐
1= Trappies. Omtrent hoeveel? ____________
2= 'n Trap. Omtrent hoeveel trappe? ____________

As pasiënt se antwoord trappe is, gaan na Vraag 4. So nie, gaan na 5.

4. **Is daar 'n huisbak?** 1= Ja 2= Nee ☐

5. **Het 'n trappies, of verskillende vlakke in u woning?** 1= Ja 2= Nee ☐

6. **Het u elektrisiteit in u woning?** 1= Ja 2= Nee ☐

7. **Het u lopende water in u woning?** 1= Ja 2= Nee ☐

8. **Het u 'n bad of 'n stort in u woning?** 1= Ja 2= Nee ☐

9. **Is u toilet binne of buite u woning?** 1= Binne 2= Buite ☐

10. Moet u oor ongelyke oppervlakte loop om tot by die toilet te kom? 1= Ja 2= Nee ☐

11. Moet u by trappe op loop om by die toilet te kom? 1= Ja 2= Nee ☐

12. As u gebruik maak van 'n rolstoel, is dit vir u moontlik om by die toilet te kom met u rolstoel?
1= Ja 2= Nee 3= Nie toepaslik ☐

13. Het u 'n telefoon? 1= Ja 2= Nee ☐
Noem asb.: ☐
1= Landlyn binne woning
2= Selfoon
3= Bure se telefoon
4= Publieke telefoon naby
5= Geen hierbo genoem nie

DEEL 3: KONTAK BESONDERHEDE

1. Wie is primêre versorger? ____________________

2. Wat is sy/haar verwantskap aan u?

1= Eggenoot/ eggenote / metgesel
2= Ouer / skoonma of –pa
3= Kind / skoonseun of -dogter
4= Familielid
5= Vriend
6= Ander. Noem asb. ____________________

3. Hoe kan sy / hy gekontak word?
Adres:____________________

____

Telefoonnommer: (h)__________ (w)__________ (c)__________

4. Hoe kan ek u kontak vir die volgende afspraak wat op 6 maande van vandag af sal wees? (Gee asseblief verskillende keuses)

1.____________________

2.____________________

3.____________________

4.____________________

5.____________________

QUESTIONNAIRE AT DISCHARGE

Xhosa Version

Questionnaire at Discharge

IMIBUZO YOKUKHULULWA ESIBHEDLELE

ICANDELO 1: INTLALO NOQOQOSHO

Le mibuzo ilandelayo zijongise ukunika inkcukacha zophononongo. Ulwazi luza kusetyenziselwa uphando olukhulu, kwaye olu lwazi luza kuhlala lukhuselekile.Ukuba ucinga ukunika iimpendulo eziliqela. Khetha impendulo ebhetele ukuxhasa uluvo lwakho.

1. Leliphi elona banga eliphezulu oligqibileyo? ☐

1 = Amabanga aseCreche / amabanga agekho fomali
2 = Sub A/ Greyidi 1
3 = Sub B/ Greyidi 2
4 = Ibanga lesi–1 / Greyidi 3
5 = Ibanga lesi–2 / Greyidi 4
6 = Ibanga lesi-3 / Greyidi 5
7 = Ibanga lesi–4 / Greyidi 6
8 = Ibanga lesi-5 / Greyidi 7
9 = Ibanga lesi-6 / Greyidi 8
10 = Ibanga lesi–7 / Greyidi 9
1 1= Ibanga lesi–8 / Greyidi 10
12 = Ibanga lesi-9 / Greyidi 11
13 = Ibanga 10 / Greyidi 12
14 = Ibanga lesibhozo/ Greyidi 10 nesiqinisekiso/ idiploma. Chaza inani leminyaka yokufunda kwakho: ______
15= Ibanga lethoba / Greyidi 11 nesiqinisekiso/ idiploma. Chaza inani leminyaka yokufunda kwakho: ______
16= Ibanga leshumi / Greyidi 12 nesiqinisekiso/ idiploma. Chaza inani leminyaka yokufunda kwakho: ______
17= Ibanga leshumi / Greyidi 12 nemfundo ephakamileyo. Chaza inani leminyaka yokufunda kwakho: ______
18= Enye, Cacisa ______________________________
(Chaza inani leminyaka yokufunda kwakho ungafelishi.)

2. Ingaba ubusebenza kumsebenzi ohlawulayo phambi kokuhlaselwa kwakho isitrowukhu? ☐

1= Ewe, kumsebenzi obhatalayo (nceda yiya kumbuzo 3)
2= Hayi, hayi emsebenzini obhatalayo (nceda yiya kumbuzo 5)

3. Kwezi ndlela zilandelayo, yeyiphi echaza ngcono uhlobo lomsebenzi wakho? ☐

1= Ndiqeshiwe (kuquka icandelo elifomali nelingekho fomali)
2= Uziqeshile okanye kwishishini lefemeli
3= Okanye ezinye iintlobo cacisa ______________________________

4. Kwezi ndlela zilandelayo, loluphi oluchaza ngcono iiyure ozisebenzayo? ☐

1= Ixeshana – Cacisa iiyure ngeveki ______________________________
2= Uqeshwe ngokupheleleyo (iiyure ezingaphezu kwe 20)
3= Usebenza iiyure ezingaqingqwanga ngeveki, ngamaxesha athile (uyangxungxa/ uyangxungxa)
4= Iiyure ezingenasigxina, ikhontrakhi eqingqiweyo. Cacisa iiyure ozisebenzayo. ______
5= Ezinye iinkcukacha . Cacisa______________________________

5. Ukuba awusebenzi yintoni unobangela wokungasebenzi kwakho ? ☐

1= Awusebenzi, uyakhangela
2= Awusebenzi, ukhetha ukungasebenzi
3= Awukwazi ukusebenza ngenxa yokugula nokukhubazeka (Ufumana imali yokukhubazeka/ kwi Insurance/ Inshorensi yakho/ okanye inzuzo kwi-inshorensi yabucala)
4= Awukwazi ukusebenza ngenxa yokugula nokukhubazeka (Awufumani mali yokukhubazeka)
5=Ufumana imali yomhlala phantsi kurhulumente
6= Ujonga ikhaya, akukho ncedo ulufumanayo lwemali (kuquka ukujonga abantwana)
7= Ungumfundi
8= Ezinye. Cacisa: ______________________________

6. **Wenza umsebenzi onjani ?**

Cacisa ____

7. **Uthini umvuzo wakho wenyanga ?** ☐

1=	R 100 – R 200	6=	R 2 501 – R 4 500
2=	R 201 – R 500	7=	R 4 501 – R 8 000
3=	R 501 – R 1000	8=	R 8 001 – R 16 000
4=	R 1 001 – R 1 500	9=	Ngaphezu kwe R 16 000
5=	R 1 501 – R 2 500	10=	Ndicela ukungaphenduli okanye andiyazi

8. **Mangaphi amagumbi endlu ewonke quka ngaphandle kwelokuhlambela, ishedi negarage ngaphandle kokuba kukho abantu abahlala kuzo?** ☐

9. **Bangaphi abantu abadala nabantu ekhayeni lakho?**
   9.1. Inani labantu ☐
   9.2. Inani labantwana ☐

ICANDELO 2 : INKCUKACHA ZOKUKHULULWA

1. **Uza kube ubuyela ekhayeni lakho?** 1= Ewe 2= Hayi ☐

2. **Ungayichaza njani indawo ohlala kuyo ngoku?** ☐
   1 = Yindlu
   2 = Luludwe lweflethi
   3 = Yindlu/ yiflethi/ unxusile okanye uhlala nabantu
   4 = yitown house
   5 = Kwindawo yabantu abadla umhlalaphantsi
   6 = Ematyotyombeni okanye kwindawo enamatyotyombe (informal settlement)
   7 = Ematyotyombeni/ etyotyombeni okanye ngasemva endlwini (backyard)
   8 = Enye. Cacisa: ______________________

3. **Usebenzisa izitephusi ukufikelela kwikhaya lakho?** 1= Ewe 2= Hayi ☐
   Nceda cacisa.
   1= Izitephusi. Cacisa lingakanani inani lezitephusi__________
   2= Izitephusi ezinyuka nqo. Cacisa inani______________
   (Ukuba impendulo linani lezitephusi, yiya kumbuzo 4, ukuba hayi yiya kumbuzo 5.)

4. **Kukho ilifti/ikhetshi?** 1= Ewe 2= Hayi ☐

5. **Kukho izitephusi endlwini okanye ngaphakathi endlini yakho?** 1= Ewe 2= Hayi ☐

6. **Unawo umbane?** 1= Ewe 2= Hayi ☐

7. **Unawo amanzi acocekileyo endlini?** 1= Ewe 2= Hayi ☐

8. **Unayo indawo yokuhlambela okanye ishawari ekhaya ?** 1= Ewe 2= Hayi ☐

9. **Ingaba ithoyilethi ingaphakathi okanye ngaphandle?** 1= Ngaphakathi 2= Ngaphandle ☐

10. **Kufuneka uwele ingqUzu ukuya ethoyilethi?** 1= Ewe 2= Hayi ☐

11. **Kufuneka unyuke izitephusi ukufikelela ethoyilethi?** 1= Ewe 2= Hayi ☐

12. Ukuba usebenzisa isitulo ukujikeleza ekhaya, uyakwazi ukufikelela ngesitulo sakho? ☐
1= Ewe 2= Hayi 3= Engasebenziyo

13. Unayo ifowuni? 1= Ewe 2= Hayi ☐
Nceda cacisa: ☐
1= Ifowuni endlini
2= I cell phone
3= Ifowuni yommelwane
4= Ifowuni kawonke-wonke
5= Ayikho kwezi zingasentla

ICANDELO 3: ABANTU EMAKUNXULUNYANWE NABO

1. Ngubani umnonopheli wakho? ____________________

2. Uzalana njani naye? ☐
1= ngumlingane
2= ngumzali/ ngumamazala/ ngutatazala
3= ngumntwana/ yindodakazi/ ngusibali
4= sisizalwane
5= ngumhlobo
6= Omnye. Cacisa____________________

3. Nceda nika indawo abafunyanwa kuzo.

Address ____________________

____

Ifowuni nombolo :Ekhaya____________Emsebenzini:____________Cell:____________

4. Ndinganxulumana bhetele nawe ukulandela olu phononongo emva kwenyanga ezintandathu? (Nceda ndinike bonke abantu endinokubafumana xa ndingakufumani wena)

1.____________________

2.____________________

3.____________________

4.____________________

5.____________________

APPENDIX XII REHABILITATION PROCESS QUESTIONNAIRE

REHABILITATION PROCESS QUESTIONNAIRE

PATIENT CODE:______________________________DATE:

REHABILITATION PROCESS QUESTIONNAIRE

To be filled in by member of staff.

1. Did this patient receive input from any of the following while an inpatient at WCRC?
1= Yes 2= No

1.1. Doctor ☐ 1.2. Nursing ☐ 1.3. Physiotherapist ☐

1.4. Occupational Therapist ☐ 1.5.Social Worker ☐ 1.6.Speech and Language Therapist ☐

1.7. Other ☐ Please specify____

2. Did caregivers/ family members of this patient participate in any of the following prior to discharge: 1= Yes 2= No

2.1. Training sessions involving demonstration or practice ☐

2.2. Training in the form of written information ☐

2.3. Training in the form of verbal instruction ☐

3. Did caregivers/ family members of this patient participate in planning for discharge?(includes planning of date, arrangements to make the home suitable etc.)

1= Yes 2= No ☐

4. Was a home visit carried out for this patient prior to discharge?

1= Yes 2= No. ☐

5. Did this patient have an overnight or weekend stay at home prior to discharge?

1= Yes 2= No. ☐

6. Will a follow up review at WCRC be arranged for this patient prior to discharge?

1= Yes 2= No. ☐ If yes, please specify date: ____________________

7. Has the patient been referred on to services in the local community. If yes, please specify which services:

1.____

2.____

3.____

4.____

5.____

8. Date of Discharge: ____

PATIENT CODE:______________________________ DATE:

9.1. Has the treating OT identified that the patient has any of the following cognitive deficits?

	1= YES 2= NO	If yes, 1= MILD 2= MODERATE 3= SEVERE
Memory DEFINITION: Deficit of short term or long term memory or memory retrieval.	☐	☐
Orientation DEFINITION: Deficit of awareness of time, length of time, place or person.	☐	☐
Attention DEFINITION: Deficit in the ability to sustain, shift, divide and share attention.	☐	☐
Apraxia DEFINITION: Deficit in the ability to execute willed, purposeful movement out of proportion with the degree of motor impairment.	☐	☐
Executive dysfunction DEFINITION: Executive functioning includes cognitive processes involved in goal directed and purposeful behaviour. Dysfunction includes deficits of goal setting, insight, judgement, problem solving, planning and execution, as well as impulsive/ disinhibited behaviour and lack of initiation/ lethargy.	☐	☐
Other. Specify____________________	☐	☐

9.2. Please indicate if the following were used to assess for cognitive deficits:

Clinical Assessment	YES ☐ (1)	NO ☐ (2)
Screening test.	YES ☐ (1)	NO ☐ (2) If yes, specify____________________
Cognitive assessment battery	YES ☐ (1)	NO ☐ (2) If yes, specify____________________
Other	YES ☐ (1)	NO ☐ (2) If yes, specify____________________

10.1. Has the treating OT identified that the patient has a perceptual deficit?

DEFINITION: Deficits in the ability to organise, process and interpret incoming sensory information and to react appropriately. Includes deficits of object recognition, spatial relations, figure-ground discrimination and unilateral spatial neglect.

1= YES 2= NO ☐

If yes: 1= MILD 2= MODERATE 3= SEVERE ☐

10.2. Please indicate if the following were used to assess for perceptual deficits:

Clinical Assessment	YES ☐ (1)	NO ☐ (2)
Screening test	YES ☐ (1)	NO ☐ (2)
Cognitive assessment battery	YES ☐ (1)	NO ☐ (2) Specify
Other	YES ☐ (1)	NO ☐ (2) Specify

QUESTIONNAIRE AT SIX MONTHS

English Version

PATIENT CODE: ______________________________ DATE: ______________________________

QUESTIONNAIRE AT 6 MONTHS

SECTION 1

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

1= Same home as before the stroke 2= Alternative home 3= Institution/ nursing home/ care facility

If discharged to alternative home, then complete Section 6

1.2 If you did not return to your previous home, what is the *main* reason for this? ☐

1= Not applicable
2= Previous home was unsuitable
3= No carer at home
4= Unable to manage (needs too much help)
5= Other. Specify

1.3. Where you stay now, is there anyone at home to help you:

1.3.1. During the day? 1= Yes 2=No ☐ 1.3.2. At night? 1= Yes 2=No ☐

SECTION 2

2.1. How do you mostly move around inside your house? ☐

1= Walking
2= Wheelchair
3= Unable
4= Other. Specify ______________________

2.2. Do you use any of the following to help you move around inside your house? ☐ 1=Yes 2=No

2.2.1. Ordinary walking stick ☐
2.2.2. Walking stick with 3 or 4 feet ☐
2.2.3. Elbow Crutches ☐
2.2.4. Walking frame ☐
2.2.5. Ankle splint ☐
2.2.6. Other. ☐ Please specify ______________

2.3. How do you mostly move around outside your house? ☐

1 = Walking
2 = Wheelchair
3 = Unable
4 = Other. Specify ______________________

2.4. Do you use any of the following to help you get around outside your house? 1=Yes 2=No

2.4.1. Ordinary walking stick ☐
2.4.2. Walking stick with 3 or 4 feet ☐
2.4.3. Elbow Crutches ☐
2.4.4. Walking frame ☐
2.4.5. Ankle splint ☐
2.4.6. Other. ☐ Please specify______________

2.5. Before you had your stroke, how did you mostly get to places in the community and further afield? (Allow up to three responses.) **2.5.1.** ☐ **2.5.2.** ☐ **2.5.3.** ☐

1 =Taxi
2 =Bus
3 =Train
4 = Car, driver
5 = Car, passenger
6 = Motor Bike
7 = Bicycle
8 = Walked
9 = Wheeled in wheelchair
10 =Other. Please specify ______________

2.6. Since your stroke, how do you mostly get to places in the community and further afield? (Allow up to three responses.) **2.6.1.** ☐ **2.6.2.** ☐ **2.6.3.** ☐

1 =Taxi
2 =Bus
3 =Train
4 = Car, driver
5 = Car, passenger
6 = Motor Bike
7 = Bicycle
8 = Walked
9 = Wheeled in wheelchair
10 =Other. Please specify ______________

PATIENT CODE: ______________________ DATE: ______________________

SECTION 3: RETURN TO WORK OR PRODUCTIVE ACTIVITY

3.1. Are you currently in paid employment/ working? ☐

1= Yes, paid employment (Please go to question 3.2.)
2= No, not paid employment (Please go to question 3.5)

3.2. Which of the following best describes your current employment status? ☐

1= Employed.
2= Self-employed or helping in a family business
3= Other. Specify:______________________

3.3. Which of the following best describes your working hours? ☐

1= Part-time. Specify hours/ week .________
2= Full-time (More than 20 hours a week)
3= Irregular hours, occasional work as a day casual
4= Irregular fixed term contracts. Specify typical hours/ week ________
5= Other

3.4. Is this the same job as you did before you had your stroke? ☐

1= Yes, exactly the same job
2= Same employer but different job description
3= Completely different job

If answer is (3), ask:

What kind of work do you do now? ______________________

3.5. If you are not in paid employment, what is the main reason for your not working? ☐

1= Unemployed, looking for work
2= Unemployed, prefers not to work
3= Unable to work due to illness or disability (Receiving Disability Grant or Private Insurance Benefit)
4= Unable to work due to illness or disability (No Disability Grant)
5= Retired/ Pensioner
6= Looking after the home, no benefits (includes looking after children)
7= Scholar or student
8= Undergoing work retraining/ vocational training
9= Other. Specify: ______________________

If (4), ask: Has an application for a Disability Grant been made? 1= Yes 2=No ☐

If yes, ask: What is the current status of your application? ☐

1= Application still being assessed or processed
2= Application denied

3.6. Since you were discharged home from hospital, have you participated in any of the following activities?

3.6.1.	Unpaid work as a volunteer	1= Yes 2=No	☐
3.6.2.	Unpaid work helping in family business	1= Yes 2=No	☐
3.6.3.	Looking after others, e.g. children, the elderly or the sick.	1= Yes 2=No	☐
3.6.4.	Work around the home such as cleaning, cooking, gardening, maintenance or repairs	1= Yes 2=No	☐

PATIENT CODE: ______________________ DATE: ______________________

SECTION 4: USE OF CARE

4.1. How many times have you been admitted to a hospital or nursing home since leaving the WCRC for the first time: (i.e. where you have stayed overnight)? Please give details. If reason for admission is not due to stroke, please specify reason

Name of Hospital or Nursing Home	Reason for Admission 1= Due to stroke 2= Not due to stroke. Specify.	Length of stay (No. Of nights)
1.______	☐	☐
2.______	☐	☐
3.______	☐	☐
4.______	☐	☐
5.______	☐	☐

4.2. Please give details of any input you have had from the health services since your discharge from the WCRC. Include visits to clinics, GP's, any rehab received in the community, visits from health-care workers, and appointments at hospitals.

	No of times	Relative frequency 1= more than before stroke 2= Less than before stroke 3= Equal to before stroke	Place of contact 1= own home 2= CHCC/Clinic 3= Hospital 4= WCRC
Social worker	☐	☐	☐
Physiotherapy	☐	☐	☐
Occupational Therapy	☐	☐	☐
Speech and Language Therapy	☐	☐	☐
Dietician	☐	☐	☐
Psychologist	☐	☐	☐
Nurse	☐	☐	☐
Traditional Healer	☐	☐	☐
Community Rehabilitation Worker	☐	☐	☐
Medical Doctor	☐	☐	☐
Self-help Group Eg. Stroke Support Group	☐	☐	☐
Other.	☐	☐	☐

If "Other", please specify:______________________

4.3. Have you in the past 6 months been forced to forgo or postpone the use of health care services because of lack of accessibility of transport? 1= Yes 2= No ☐

4.4. Have you in the past 6 months been forced to forgo or postpone the use of health care services because of financial reasons? 1= Yes 2= No ☐

SECTION 5: GENERAL QUESTION

5. Have there been any changes in your health since your discharge from the WCRC, that have affected what you are able to do now? 1= Yes 2= No ☐

If yes, specify:______________________

____

PATIENT CODE: ______________________ DATE: ______________________

SECTION 6: DETAILS OF THE DISCHARGE ENVIRONMENT

6.1. How would you best describe the place where you live? ☐

1= House
2= Block of flats
3= House/ flat/ room in back yard or on shared property
4= Townhouse, cluster, semi-detached (simplex, duplex or triplex)
5= Retirement village
6= Informal dwelling/ shack in informal settlement
7= Informal dwelling/ shack in backyard
8= Other. Specify: ______________

6.2. Do you need to go up steps or stairs to get into your home? 1= Yes 2= No ☐

Please specify.
1= Steps. Specify approximate number: ____________
2= Flights of stairs. Specify approximate number: ____________ ☐
If subject answers flights of stairs, go to question 4, if not go to question 5.

6.3. Is there a lift? 1= Yes 2= No ☐

6.4. Do you have steps, or different levels inside your home? 1= Yes 2= No ☐

6.5. Do you have electricity? 1= Yes 2= No ☐

6.6. Do you have running water inside the house? 1= Yes 2= No ☐

6.7. Do you have a bath or shower in your home? 1= Yes 2= No ☐

6.8. Are your toilet facilities inside or outside? 1= Inside 2= Outside ☐

6.9. Do you have to cross uneven ground to get to your toilet facilities? 1= Yes 2= No ☐

6.10. Do you have to go up stairs to get to your toilet facilities? 1= Yes 2= No ☐

6.11. If you use your wheelchair to get around, is it possible to get to the toilet in your wheelchair? 1= Yes 2= No 3= Not applicable ☐

6.12. Do you have access to a telephone? 1= Yes 2= No ☐

If yes, please specify telephone mostly used:
1= Landline inside dwelling 2= Cell phone 3= Neighbour's phone 4= Public telephone nearby
5= None of the above. ☐

QUESTIONNAIRE AT SIX MONTHS

Afrikaans Version

VRAELYS OP SES MAANDE

DEEL 1

1.1. Beskryf u huidige verblyplek ☐

1= Dieselfde woning as voor die beroerte aanval
2= 'n Ander woning
3= Inrigting / verpleeginrigting

Indien u na u ontslag in 'n ander huis bly, voltooi asseblief Deel 6.

1.2 As u nie terruggekeer het na u vorige woning nie, verskaf asseblief die hoofredes daarvoor

1= Nie toepaslik ☐
2= Vorige woning was nie geskik nie
3= Geen versorger by my woning nie
4= Nie in staat om reg te kom nie (te veel hulp nodig)
5= Ander. Noem asb.____________________

1.3. Is daar tans enigiemand wat u kan help, waar u nou bly? 1= Ja 2= Nee

1.3.1. Gedurende die dag ☐ 1.3.2. Snags ☐

DEEL 2

2.1. Hoe beweeg u gewoonlik rond in u woning? ☐

1= Loop 3= Kan nie rondbeweeg nie
2= Rolstoel 4= Ander. Noem asb. ________________

2.2. Gebruik u enige van die volgende om u te help om rond te beweeg in die huis?

1= Ja 2= Nee
2.2.1. Gewone kierie ☐
2.2.2. Kierie met 3 of 4 pote ☐
2.2.3. Elmboog krukke ☐
2.2.4. Loopraam ☐
2.2.5. Enkelsplint ☐
2.2.6. Ander ☐ Noem asb. ________________

2.3. Hoe beweeg u gewoonlik rond buite u woning? ☐

1= Loop 3= Kan nie rondbeweeg nie
2= Rolstoel 4= Ander. Noem asb. ________________

2.4. Gebruik u enige van die volgende om u te help om rond te beweeg buite die huis?

1= Ja 2= Nee
2.4.1. Gewone kierie ☐
2.4.2. Kierie met 3 of 4 pote ☐
2.4.3. Elmboog krukke ☐
2.4.4. Loopraam ☐
2.4.5. Enkelsplint ☐
2.4.6. Ander ☐ Noem asb. ________________

2.5. Voor u beroerte aanval, hoe het u rondbeweeg in u woonbuurt en ander plekke buite u woonbuurt? (Laat tot drie antwoorde toe.)

2.5.1. ☐ 2.5.2. ☐ 2.5.3. ☐

1= Mini-bus taxi 6= Motorfiets
2= Bus 7= Fiets
3= Trein 8= Geloop
4= Motor, bestuurder 9= Gestoot in rolstoel
5= Motor, passassier 10= Ander. Noem asb. ________________

2.6. Sedert u beroerte, hoe kom u meestal uit by plekke in u gemeenskap en verder? (Laat tot drie antwoorde toe.)

2.6.1. ☐ 2.6.2. ☐ 2.6.3. ☐

1= Mini-bus taxi
2= Bus
3= Trein
4= Motor, bestuurder
5= Motor, passassier
6= Motorfiets
7= Fiets
8= Geloop
9= Gestoot in rolstoel
10= Ander. Noem asb. ____________________

DEEL 3: TERRUGKEER NA WERK, OF PRODUKTIEWE AKTIWITEITE

3.1. Is u tans in betaalde indiensneming? ☐

1= Ja, betaalde indiensneming (Gaan asseblief na Vraag 3.2.)
2= Nee, nie betaalde indiensneming (Gaan asseblief na Vraag 3.5)

3.2. Watter van die volgende is toepaslik op u huidige situasie? ☐

1= Indiensneming
2= Eie besigheid, of help in 'n familiebesigheid
3= Ander. Noem asb. ____________________

3.3. Watter van die volgende werksure het u nou? ☐

1= Deeltyds. Noem asseblief hoeveel ure per week ________
2= Voltyds (Meer as 20 ure per week)
3= Ongereelde ure, werk soms as tydelike werker
4= Ongereelde kontrakte vir sekere typdperkte. Noem asseblief tipiese ure per week ________
5= Ander. Noem asseblief ____________________

3.4. Doen u nou dieselfde werk as voor u beroerte aanval? ☐

1= Ja, presies dieselfde werk
2= Dieselfde werkgewer as tevore, maar verskillende werksopdragte
3= Ander werk

Indien antwoord (3) is, vra:
Watter sort werk doen u nou? ____________________

3.5. As u tans nie werk nie, wat is die hoof rede daarvoor? ☐

1= Ek werk nie, ek soek tans werk
2= Ek verkies om nie te werk nie
3= Ek werk nie omdat ek nou siek of ongeskik vir werk is (ontvang 'n Ongeskiktheidstoelae/ of private versekeringstoelae)
4= Ek werk nie omdat ek nou siek of ongeskik vir werk is (ontvang geen Ongeskiktheidstoelae nie)
5= Afgetree / Pensioenaris
6= Sorg vir die huishouding, geen finanisiële toelae nie (dit sluit in om kinders op te pas)
7= Leerling of student
8= Ondergaan werk her-opleiding / beroepsopleiding
9= Ander. Noem asb. ____________________

Indien (4), vra: Is 'n aansoek vir 'n Ongeskikheidstoelae gemaak? 1= Ja 2=Nee ☐
Indien ja, vra: Wat is die huidige status van u aansoek? ☐

1= Aansoek word steeds geassesseer of geprosesseer
2= Aansoek geweier

3.6. Vandat u uit die hospitaal ontslaan is, het u in enige van die volgende aktiwiteite deelgeneem? 1= Ja 2= Nee

- 3.6.1. Onbetaalde werk as 'n vrywilliger ☐
- 3.6.2. Onbetaalde werk in 'n familiebesigheid ☐
- 3.6.3. Sorg vir ander, soos byvoorbeeld kinders, bejaardes of siekes. ☐
- 3.6.4. Werk in die huis, soos byvoorbeeld skoonmaak, kook, tuinmaak, instandhouding, of herstelwerk ☐

DEEL 4: GEBRUIK VAN NASORG

4.1. Hoeveel keer was u in 'n hospital of verplegingsinrigting opgeneem vandat u die Weskaapse Rehabilitasiesentrum vir die eerste keer verlaat het (waar u oornag gebly het)? Gee asseblief besonderhede. As die redes vir toelating nie as gevolg van 'n beroerte aanval was nie, gee asseblief die rede.

Naam van hospitaal of Verplegingsinrigting	Rede vir toelating 1= Beroerte aanval 2= Ander rede	Lengte van verblyf (Hoeveel nagte?)
1.____________________	☐	☐
2.____________________	☐	☐
3.____________________	☐	☐
4.____________________	☐	☐
5.____________________	☐	☐

4.2. Gee asseblief besonderhede van enige terugvoering wat u gekry het van Gesondheidsdienste sedert u ontslaning van die WCRC. Sluit asseblief in al u kliniekbesoeke, besoeke aan u mediese doktor, enige rehabilitasie wat u ontvang het in u eie gemeenskap, besoeke van gesondheidswerkers en afsprake by hospitale.

	Hoeveelheid	Ongeveerde hoeveelheid 1= Meer as voor beroerte 2= Minder as voor beroerte 3= Dieselfde as voor beroerte	Plek 1= eie woning 2= CHCC of Kliniek 3= Hospitaal 4= WCRC
Maatskaplike werker	☐	☐	☐
Fisioterapie	☐	☐	☐
Arbeidsterapie	☐	☐	☐
Spraak- en taal terapie	☐	☐	☐
Dieetkundige	☐	☐	☐
Sielkundige	☐	☐	☐
Verpleegster	☐	☐	☐
Tradisionele geneser	☐	☐	☐
Gemeenskapsrehabilitasiewerker	☐	☐	☐
Mediese doktor	☐	☐	☐
Self-help groep	☐	☐	☐
Ander.	☐	☐	☐

Noem asb. ________________________________

4.3. Was u in die afgelope 6 maande genoodsaak die gebruik van gesondheidsdienste te kanselleer of uit te stel omdat u geen toegang tot vervoer gehad het nie? 1= Ja 2= Nee ☐

4.4. Was u in die afgelope 6 maande genoodsaak om die gebruik van gesondheidsdienste te kanselleer of uit te stel om finansiële redes?

1= Ja 2= Nee ☐

DEEL 5: ALGEMENE VRAE

5. Was daar enige veranderinge in u gesondheid nadat u van die Weskaapse Rehabilitasiesentrum ontslaan is, wat dit wat u huidiglik in staat is om te doen, affekteer? ☐

1= Ja 2= Nee

DEEL 6

6.1. Beskryf u huidige woonplek ☐

1= Huis
2= Woonstel
3= Huis / Woonstel of kamer in 'n agterplaas of erf wat gedeel word
4= Dorpshuis, meenthuis of koppelhuis
5= Aftree-oord
6 = Informele woning / pondok in informele vesting
7= Informele behuising / pondok in 'n agterplaas
8= Ander. Noem asb. ____________________

6.2. Moet u trappe op klim om by u woning in te kom? 1= Ja 2= Nee ☐

Noem asseblief.

1= Trappies. Omtrent hoeveel? ____________
2= 'n Trap – omtrent hoeveel trappies op die trap? ____________
As pasiënt laasgenoemde antwoord, gaan na vraag 3. So nie, gaan na Vraag 4.

6.3. Is daar 'n huisbak? 1= Ja 2= Nee ☐

6.4. Het u trappies, of verskillende vlakke in u woning? 1= Ja 2= Nee ☐

6.5. Het u elektrisiteit? 1= Ja 2= Nee ☐

6.6. Het u lopende water in u woning? 1= Ja 2= Nee ☐

6.7. Het u 'n bad of 'n stort in u woning? 1= Ja 2= Nee ☐

6.8. Is u toilet binne of buite u woning? 1= Binne 2= Buite ☐

6.9. Moet u oor 'n ongelyke oppervlakte om tot by die toilet te kom? 1= Ja 2= Nee ☐

6.10. Moet u by trappe op loop om by die toilet te kom? 1= Ja 2= Nee ☐

6.11. As u gebruik maak van 'n rolstoel, is dit vir u moontlik om by die toilet te kom met u u rolstoel? 1= Ja 2= Nee 3= Nie toepaslik ☐

6.12. Het u 'n telefoon? 1= Ja 2= Nee ☐

Noem asb.: ☐

1= Landlyn binne woning
2= Selfoon
3= Bure se telefoon
4= Public Telephone nearby
5= Geen hierbo genoem nie

QUESTIONNAIRE AT SIX MONTHS

Xhosa Version

IMIBUZO KWINYANGA EZINTANDATHU (at six months)

ICANDELO : 1

1.1. Ungayichaza njani ngokuzeleyo indawo ohlala kuyo ngoku ? ☐

1= Njengekhaya lakho phambi kwesitrowukhi
2= Elinye ikhaya
3= Iziko labantu abakhubazekileyo /ikhaya labongikazi

Ukuba uza kukhululelwa kwelinye ikhaya , nceda uzalise le fomu ikwicandelo 6.

1.2. Ukuba awuzi kubuyela kwikhaya lakho langaphambili, yintoni isizathu esiphambili soko? ☐

1= Engasebenziyo
2= Ikhaya langaphambili aliyifanelanga imeko okuyo
3= Akukho mntu uncedayo ekhaya
4= Bendingakwazi ukuzinceda (ndifuna uncedo kakhulu)
5= Ezinye. Cacisa

1.3. Uhlala phi ngoku, ukhona umntu okuncedisayo ekhaya ?

1.3.1.	Emini	1= Ewe 2= Hayi	☐
1.3.2.	Ebusuku	1= Ewe 2= Hayi	☐

ICANDELO: 2

2.1. Usebenzisa ntoni ukujikeleza phakathi kwekhaya ? ☐

1= uyakwazi ukuzihambela 2= I-wheel chair / isitulo esihamba ngamavili 3= awukwazi 4= ezinye

2.2. Usebenzisa enye yezi zinto ukujikeleza ngaphakathi endlini?

2.2.1. Intonga eqhelekileyo	1= Ewe 2= Hayi	☐
2.2.2. Intonga yasesibhedlele enemilenze emi 3 okanye 4	1= Ewe 2= Hayi	☐
2.2.3. Elbow crutches: intonga zokuhamba eziphela ezingqinibeni	1= Ewe 2= Hayi	☐
2.2.4. Ifreyimi yokuhamba	1= Ewe 2= Hayi	☐
2.2.5. Ankle splint: into esetyenziswa ukuncedisana neqatha lakho	1= Ewe 2= Hayi	☐

2.2.6. Ezinye. Cacisa. ______________________________

2.3. Usebenzisa ntoni kakhulu ukujikeleza phandle kwekhaya? ☐

1= uyakwazi ukuzihambela 2= I-wheelchair/ isitulo esihamba ngamavili 3= awukwazi 4= ezinye

2.4. Usebenzisa enye yezi zinto ukujikeleza ngaphandle ekhayeni lakho?

2.4.1. Intonga eqhelekileyo	1= Ewe 2= Hayi	☐
2.4.2. Intonga yasesibhedlele enemilenze emi 3 okanye 4	1= Ewe 2= Hayi	☐
2.4.3. Elbow crutches: intonga zokuhamba eziphela ezingqinibeni	1= Ewe 2= Hayi	☐
2.4.4. Ifreyimi yokuhamba	1= Ewe 2= Hayi	☐
2.4.5. Ankle splint: into esetyenziswa ukuncedisana neqatha lakho	1= Ewe 2= Hayi	☐

2.4.6. Ezinye. Cacisa. ______________________________

2.5 Phambi kokuba ube nesitrowukhi, Ubufikelela njani ezindaweni kwindawo Ohlala kuyo (kwingingqi yakho) nakude? (khetha zibentathu)

2.5.1. ☐ 2.5.2. ☐ 2.5.3. ☐

1 = iteksi
2 = ibhasi
3 = itreyini/ ululiwe
4 = imoto , uqhuba
5 = imoto , ungumkhweli
6 = isithuthuthu
7 = ibhayisikile
8 = ubuhamba
9 = ubuhanjiswa ngesitulo.
10= ezinye iintlobo zokuhamba. Cacisa: ____________

2.6. Oko unesitrowukhi ufikelela njani ezindaweni ekuhlaleni nakude? (khetha zibentathu)

2.6.1. ☐ 2.6.2. ☐ 2.6.3. ☐

1 = iteksi
2 = ibhasi
3 = itreyini/ ululiwe
4 = imoto , ungumkhweli
5 = imoto , uqhuba
6 = isithuthuthu
7 = ibhayisikile
8 = ubuhamba
9 = ubuhanjiswa ngesitulo.
10 = ezinye iintlobo zokuhamba. Cacisa: ____________

ICANDELO 3: <u>Ukubuyela emsebenzini okanye indlela osebenza ngayo</u>

3.1. Ingaba usemsebenzini obhalayo /uyasebenza? Uhlobo ophangela ngalo. ☐

1 = Ewe, kumsebenzi obhatalayo (nceda yiya kumbuzo 3.2)
2 = Hayi , emsebenzini ongabhataliyo (nceda yiya kumbuzo 3.5)

3.2. Kwezi ndlela zilandelayo yeyiphi echaza ngcono uhlobo lempangelo yakho. ☐

1 = Ndiqeshiwe
2 = Uziqeshile okanye uncedisa kwishishini lefemeli
3 = Olunye uhlobo lwengqesho. Cacisa: ____________

3.3. Kwezi ndlela zilandelayo, loluphi oluchaza ngcono iiyure ozisebenzayo? ☐

1= Ixeshana – Cacisa iiyure ngeveki ____________
2= Uqeshwe ngokupheleleyo (iiyure ezingaphezu kwe 20)
3= Usebenza iiyure ezingaqingqwanga ngeveki, ngamaxesha athile (uyangxungxa/ uyangxungxa)
4= Iiyure ezingenasigxina, ikhontrakhi eqingqiweyo. Cacisa iiyure ozisebenzayo. ____________
5= Ezinye iinkcukacha . Cacisa: ____________

3.4. Ingaba lo msebenzi ukuwo, ngulo wawukuwo ngaphambi kokuqalwa sisitrowukhi? ☐

1 = Ewe, isenguwo kanye
2 = Umqeshi omnye , kodwa umsebenzi wahlukile.
3 = Ngumsebenzi owahlukileyo mpela

Ukuba ngu (3), chaza ukuba ubusenza ntoni? ____________

3.5. Ukuba awusebenzi, yintoni unobangela wokungasebenzi kwakho? ☐

1= Awusebenzi uyakhangela
2= Awusebenzi ukhetha ukungasebenzi
3= Awukwazi ukusebenza ngenxa yokugula nokukhubazeka (Ufumana imali yokukhubazeka/ kwi Insurance/ Inshorensi yakho/ okanye inzuzo kwi-inshorensi yabucala)
4= Awukwazi ukusebenza ngenxa yokugula nokukhubazeka (awufumani mali yakukhubazeka)
5= Ufumana imali yomhlala phantsi kurhulumente
6= Ujonga ikhaya , akukho ncedo ulufumanayo lwemali (kuquka ukujonga abantwana)
7= Ungumfundi
8= Uthatha uqeqesho lomsebenzi kwakhona/ uqeqesho lobuchule
9= Ezinye. Cacisa ______________________

Ukuba impendulo kumbuzo (4) inye, buza: Ingaba imali yoku? 1= Ewe 2= Hayi ☐
Khubazeka yenziwe?
1= Isicelo sisaphunyeleliswa okanye sisalungiswa ☐
2= Isicelo sikhatyiwe/ asivunywanga

3.6. Ukususela oko uphumile esibhedlele, ukhe wathatha inxaxheba kwezi zinto zilandelayo?

3.6.1.	Ukusebenza njengevolontiya ungahlawulwa	1= Ewe 2= Hayi ☐
3.6.2.	Ukuncedisa kwishishini le femeli ungahlawulwa	1= Ewe 2= Hayi ☐
3.6.3.	Ukugcina abanye umzkl: abantwana, abantu abadala okanye abagulayo.	1= Ewe 2= Hayi ☐
3.6.4.	Ukusebenza phakathi kwekhaya usenza umsebenzi ofana nokucoca, ukupheka , ukusebenza egadini, ukulungisa okanye ukuxola (repair) izinto.	1= Ewe 2= Hayi ☐

ICANDELO 4: Ukusebenzisa uncedo

4.1. Ungeniswe kangaphi esibhedlele okanye kwikhaya labongikazi oko washiya I WCRC okokuqala(ukutsho apho ukhe wandwendwela isibhedlele walaliswa)? Nceda nika isizathu sokulaliswa kwakho , ukuba ayisiso isitrowukhi, Nceda chaza isizathu.

Igama lesibhedlele Okanye Ikhaya labongikazi	isizathu sokulaliswa 1= sisitrowukhi 2= asositrowukhi	ixesha olihleliyo/ iintsuku olaliswe ngazo

1.____

2.____

3.____

4.____

5.____

4.2. Nceda nika iinkcukacha ngegalelo othe wanalo kwinkonzo zempilo kwezi nyanga zintandathu zidlulileyo, quka ukuhambela isibhedlele, I, GP's (ugqirha ozisebe nzelayo), zingaba zikhona indawo zogcina abantu ekuhlaleni, ukuhambela abongi kazi, izimiselo zexesha esibhedlele.

	Amaxesha Wonyango	Ukuya qho 1= Ngaphezu kwaphambi kwesitrowukhi 2= Ngaphantsi phambi kwesitrowukhi 3= Ngokulinganayo phambi kwesitrowukhi	Indawo yendibano 1= Ekhaya 2= CHCC okanye klinikhi 3= Esibhedlele 4= WCRC
KuNontlalontle	☐	☐	☐
Physiotherapy	☐	☐	☐
Occupational therapy	☐	☐	☐
Speech and Language Therapy	☐	☐	☐
Dietician	☐	☐	☐
Psychologist	☐	☐	☐
Umongikazi/ unesi	☐	☐	☐
Ixhwele	☐	☐	☐
Community Rehabilitation Worker (Umsebenzi wasekuhlaleni ojongene nabantu aba)	☐	☐	☐
uGqirha	☐	☐	☐
Self Help Group eg. Stroke Support Group Cacisa: ____________ (Iqumrhu/ umbutho wenkxaso wabazincedayo)	☐	☐	☐

Ukuba zikhona ezinye , cacisa ____________________

4.3. Kwezi nyanga zintandathu zidlulileyo ukhe wanyanzelwa ukuya okanye uhlehlise kusebenzisa inkonzo zempilo ngenxa yokunqaba kukufikelela kwizinto ezihambayo?

1= Ewe 2= Hayi ☐

4.4. Kwezi nyanga zintandathu ukhe wanyanzeliswa uyeke okanye unyenyise inkonzo zempilo ngenxa yengxaki yemali?

1= Ewe 2= Hayi ☐

ICANDELO 5: IMIBUZO EPHANGALELEYO

5.1. Ingaba lukhona utshintsho empilweni yakho emva kokuphuma WCRC, lo nto ichaphazele izinto obukwazi ukuzenza ngoku? 1= Ewe 2= Hayi ☐

Cacisa: ______________________________

ICANDELO 6

6.1. Ungayichaza njani indawo ohlala kuyo ngoku ? ☐

1= Yindlu
2= luludwe lwefIethi
3= Yindlu/ yiflethi/ unxusile okanye uhlala nabantu
4= Yitown house
5= Kwindawo yabantu abadla umhlalaphantsi
6= Ematyotyombeni okanye kwindawo enamatyotyombe
7= Ematyotyombeni/ etyotyombeni okanye ngasemva endlwini
8= Enye. Cacisa: ______________________________

6.2. Usebenzisa izitephusi ukufikelela kwikhaya lakho? 1= Ewe 2=Hayi ☐

Nceda cacisa .
1= Izitephusi . cacisa lingakanani inani lezitephusi ____________________ ☐
2= Izitephusi zinyuka nqo. Cacisa inani ____________________
(Ukuba impendulo linani lezitephusi yiya kumbuzo 6.3., ukuba hayi yiya kumbuzo 6.4.)

6.3. Kukho ilifti/ikhetshi? 1= Ewe 2=Hayi ☐

6.4. Kukho izitephusi endlwini okanye ngaphakathi endlwini yakho? 1= Ewe 2=Hayi ☐

6.5. Unawo umbane? 1= Ewe 2=Hayi ☐

6.6. Unawo amanzi acocekileyo endlini? 1= Ewe 2=Hayi ☐

6.7. Unayo indawo yokuhlambela okanye ishawa ekhaya? 1= Ewe 2=Hayi ☐

6.8. Ingaba ithoyilethi ingaphakathi okanye ingaphandle? 1= Ngaphakathi 2= Ngaphandle ☐

6.9 Kufuneka uwele indawo eziphakamileyo ukuya ethoyilethi? 1= Ewe 2=Hayi ☐

6.10. Kufuneka unyuke izitephusi ukufikelela ethoyilethi? 1= Ewe 2=Hayi ☐

6.11.Ukuba usebenzisa iwheel chair ukujikeleza ekhaya, uyakwazi ukufikelela nge -wheel chair ethoyilethi ? 1=Ewe 2=Hayi 3= Engasebenziyo

6.12. Unayo ifowuni? 1= Ewe 2=Hayi ☐

Nceda cacisa : ☐
1= Indlela yokuhlala ngaphakathi
2= I-cellphone
3= Ifowuni yasebumelwaneni
4= Ifowuni kawonke-wonke
5= Ayikho kwezi zingasentla

ENVIRONMENTAL QUESTIONNAIRE

English Version

PATIENT CODE: ____________________ DATE: ____________________

ENVIRONMENTAL QUESTIONNAIRE

Sometimes circumstances can affect what you are able to do after your stroke. I am going to read a list of things that some stroke patients say have made it more difficult for them to return to their usual activities. Please tell me whether any of these statements apply to you.
Please indicate: 0=No/ 1=Yes

1. Lack of finance makes it more difficult for me to participate in my usual activities since having the stroke. (For example, there are new expenses now, or I cannot afford the things that I need.)

☐

2. Lack of transport makes it more difficult for me to participate in my usual activities since having the stroke. (For example, it is too difficult now to get to the places I used to go.)

☐

3. My living environment makes it more difficult for me to move around easily within my home. (For example, because there are stairs, or there isn't enough room to move around.)

☐

4. The environment outside my home makes it more difficult to move around. (For example, because of uneven ground, sandy surfaces, lack of pavements or lack of pedestrian crossings.)

☐

5. It is difficult for me to move around because I don't have the equipment that I need. (For example wheelchair, walking stick or frame.)

☐

6. The attitudes of those around me make it more difficult for me to participate in social and leisure activities. (For example, friends or community members have not been encouraging.)

☐

7. The attitudes of those around me make it more difficult for me to participate in work or studies. (For example, my employer or colleagues have not been helpful or encouraging.)

☐

8. The attitudes of those around me make it more difficult for me to participate in family life (For example, my spouse or family members are not encouraging.)

☐

PATIENT CODE: ______________________ DATE: ______________________________

Now I am going to read a list of things that have helped some stroke patients to return to their usual activities. Please tell me whether any of these apply to you.

Please indicate: 0=No/ 1=Yes

9. There have been sufficient financial resources. (For example, I have not had to worry about money or there has been enough money for the things that I need.) ☐

10. There has been access to transport.
(For example, a relative is able to drive me or there is a bus stop or train station near my home.) ☐

11. The living environment at home is suitable.
(For example, there are no steps or there is a ramp.) ☐

12. The surroundings outside my home are easy to move around.
(For example it is tarred, there are pavements with curbs or pedestrian crossings.) ☐

13. There has been access to the equipment that I need.
(For example wheelchair, stick or walking frame.) ☐

14. There has been support from spouse or family.
(For example, they have encouraged me and helped me.) ☐

15. There has been support from friends.
(For example, they have encouraged me and helped me.) ☐

16. There has been support from community.
(For example, they have encouraged me and helped me.) ☐

17. There has been support from employers and colleagues.
(For example, my employer was understanding or there was a lot of encouragement.) ☐

ENVIRONMENTAL QUESTIONNAIRE

Afrikaans Version

PATIENT CODE: DATE:

VRAELYS OOR U OMGEWING

Soms affekteer omstandighede dit wat u moontlik vind om te doen na u beroerte aanval. Ek gaan vir u 'n lys van dinge lees wat sommige beroerte aanval pasiënte sê, wat dit moelik vir hulle gemaak het om na hulle gewone aktiwiteite terug te keer. Vertel my asseblief of enige van hierdie stellings van u tot toepassing is.

Dui asseblief aan: 0 = Nee / 1 = Ja

1. 'n Gebrek aan finansies maak dit moeiliker vir my om deel te neem aan my gewone aktiwiteite sedert die beroerte aanval. (Byvoorbeeld, daar is nou nuwe uitgawes, of ek kan nie die dinge wat ek nodig het, bekostig nie.)

1= Ja 2= Nee ☐

2. 'n Gebrek aan vervoer maak dit moeiliker vir my om deel te neem aan my gewone aktiwiteite sedert ek die beroerte aanval. (Byvoorbeeld, dit is nou te moeilik om by die plekke uit te kom waar ek eers gegaan het.)

1= Ja 2= Nee ☐

3. My lewensomgewing maak dit moeiliker vir my om gemaklik rond te beweeg in my huis. (Byvoorbeeld, omdat daar 'n trap is, of daar is nie genoeg ruimte is om rond te beweeg nie)

1= Ja 2= Nee ☐

4. Die omgewing buite my huis maak dit moeiliker om rond te beweeg. (Byvoorbeeld, omdat die grond ongelyk is, dit sanderig is, 'n gebrek aan sypaadjies of voetoorgange.)

1= Ja 2= Nee ☐

5. Dit is moeilik vir my om rond te beweeg omdat ek nie die toerusting het wat ek nodig het nie. (Byvoorbeeld 'n rolstoel, kierie of loopraam)

1= Ja 2= Nee ☐

6. Die houdings van diegene rondom my maak dit vir my moeiliker om deel te neem aan sosiale en ontspanningsaktiwiteite. (Byvoorbeeld, vriende of gemeenskapslede was nie bemoedigend nie)

1= Ja 2= Nee ☐

7. Die houdings van diegene rondom my maak dit vir my moeiliker om deel te neem aan werk of studies. (Byvoorbeeld, my werkgewer of kollegas was nie behulpsaam of bemoedigend nie)

1= Ja 2= Nee ☐

8. Die houdings van diegene rondom my maak dit moeiliker vir my om deel te neem aan familielewe. (Byvoorbeeld, my eggenoot/ eggenote of familielede is nie bemoedigend nie)

1= Ja 2= Nee ☐

PATIENT CODE: DATE:

Ek gaan nou 'n lys van dinge lees wat sommige beroerte aanval pasiënte gehelp het om terug te keer na hulle gewone aktiwiteite. Vertel my asseblief of enige van hierdie van toepassing is tot u.

Dui asseblief aan: 0 = Nee / 1 = Ja

9. Daar is genoeg finansiële hulpbronne. (Byvoorbeeld, ek hoef nie oor geld bekommerd te wees nie, of daar is genoeg geld vir die dinge wat ek nodig het.)

1= Ja 2= Nee ☐

10. Daar is toegang tot vervoer. (Byvoorbeeld, a familielid is in staat om my te ry, of daar is 'n busstop of treinstasie naby my huis.

1= Ja 2= Nee ☐

11. Die lewensomgewing by die huis is geskik. (Byvoorbeeld daar is geen trappe nie, of daar is 'n oprit)

1= Ja 2= Nee ☐

12. Die omgewing buite my huis is maklik om in rond te beweeg. (Byvoorbeeld, dit is geteer, daar is sypaadjies met rande of voetoorgange)

1= Ja 2= Nee ☐

13. Ek het toegang tot die toerusting wat ek nodig het.
(Byvoorbeeld, 'n rolstoel, kierie of loopraam)

1= Ja 2= Nee ☐

14. Ek kry ondersteuning van my eggenoot / eggenote of familie.
(Byvoorbeeld, hulle het my bemoedig en gehelp)

1= Ja 2= Nee ☐

15. Ek kry ondersteuning van my vriende.
(Byvoorbeeld, hulle het my bemoedig en gehelp)

1= Ja 2= Nee ☐

16.. Ek kry ondersteuning van my gemeenskap.
(Byvoorbeeld, hulle het my bemoedig en gehelp)

1= Ja 2= Nee ☐

17. Ek kry ondersteuning van my werkgewer en kollegas.
(Byvoorbeeld, my werkgewer is begrypend of daar was baie bemoediging)

1= Ja 2= Nee ☐

ENVIRONMENTAL QUESTIONNAIRE

Xhosa Version

ENVIRONMENTAL QUESTIONNAIRE

Ngamanye amaxesha iimeko zingachaphazela ongakwenza emva kwesitrowukhi. Ndiza kufunda uludwe lwezinto ezithi izigulane ezinesitrowukhi zenze kwanzima kakhulu kubo ukubuyela kwizinto ebebeqhele ukuzenza. Nceda undixelele ukuba enye yezi zinto iyenzeka na kuwe.

Nceda cacisa: 0= hayi / 1=Ewe

1. Ukungabinankxaso-mali kwenze kube nzima kum ukuthabatha inxaxheba kwimisebenzi ebendiqhele ukuyenza ukususela oko ndiqalwe sisitrowukhi. (Umzekelo, kukho ukongezeleleka kwinkcitho mali ngoku, okanye andikwazi kufikelela kwizinto endizidingayo.) ☐

2. Ukungabinamoto/okanye izinto zokuhamba kwenza kube nzima ngaphezulu/ngakumbi ukuthabatha inxaxheba kwimisebenzi yesiqhelo yam oko ndithe ndanesitrowukhi (umzkl,kunzima ngoku ukufikelela kwiindawo ebendiqhele ukuya kuzo). ☐

3. Indlela yokuhlala kwam yenze kwanzima ngaphezulu kum ukujikeleza ngokulula phakathi kwekhaya. (Umzkl, kuba kukho izitephusi, okanye akukho kuphangalala komhlaba kwanele ukujikeleza. ☐

4. Indlela/imeko yokuhlala yangaphandle ekhayeni lam yenza kube nzima kakhulu ukujikeleza. (Umzkl, ngenxa yeendulana, amabala esanti, ukungabinapavumente okanye ukungabinandledlana zokunqumla zeenyawo.) ☐

5. Kunzima ukujikeleza kum kuba andinazo izixhobo ezifanelekileyo endizidingayo. (Umzkl, isitulo esihamba ngamavili, intonga yokuhamba, okanye ifreyimi.) ☐

6. Ubume babantu abandingqungileyo benza kube nzima kum ukuthabatha inxaxheba kwizinto zasekuhlaleni nokuthabatha inxaxheba kwintshukumo ezonwabisayo. (Umzkl, abamelwane, abahlobo, okanye abantu basekuhlaleni abanankuthazo.) ☐

7. Ubume babantu abandingqungileyo benza kube nzima kakhulu kum ukuthabatha inxaxheba emsebenzini okanye kwizifundo.(Umzkl, umqeshi wam okanye abantu endisebenza nabo abaloncedo, okanye ifemeli yam ayikhuthazi.)

☐

8. Ubume babantu abandingqungileyo benza kube nzima kakhulu kum ukuthabatha inxaxheba kubomi befemeli yam.(umzkl, umyeni okanye amalungu efemeli abakhuthazi.)

Ngoku ndiza kufunda uludwe lwezinto ezithe zanceda abantu abanesitrowukhi ukuba babuyele kwizinto ebebeqhele ukuzenza. Nceda undixelele ukuba enye yezi zinto iyenzeka kuwe.

Nceda bonisa: 0=hayi/ 1=Ewe

9. Kukho inkxaso mali eyaneleyo .(Umzkl, andizikhathazi ngokucinga ngemali okanye kukho imali eyaneleyo yezinto endizifunayo.) ☐

10. Ndiyafikelela kwizinto ezihambayo.
(Umzkl, isizalwane siyakwazi ukundiqhuba/ukundisa okanye kukho isitophu sebhasi okanye isitishi sikaloliwe kufuphi ekhayeni lam.) ☐

11. Imeko yokuhlala ekhaya ifanelekile
(Umzkl, akukho zitephusi okanye kukho iremphu) ☐

12. Ubume baphandle ekhaya benza kube lula ukujikeleza phakathi kwekhaya. (Umzkl, kukho itha, kukho iipavumente ezinezinqandi nendledlana zokunqumla zeenyawo.) ☐

13. Ikhona indlela yokufikelela kwizixhobo endizifunayo.
(Umzkl, isitulo sokuhamba esinamavili, intonga yokuhamba okanye ifreyimi) ☐

14. Kukho inkxaso evela kumyeni okanye kwifemeli.
(Umzkl, bayandikhuthaza yaye bandincede.) ☐

15. Kukho inkxaso evela kubahlobo.
((Umzkl, bayandikhuthaza yaye bandincede.) ☐

16. Kukho inkxaso evela ekuhlaleni.
(Umzkl, bayandikhuthaza yaye bandincede.) ☐

17. Kukho inkxaso evela kubaqeshi nabantu endisebenza nabo.
(Umzkl, umqeshi wam uyayiqonda imeko yam okanye bekukho nenkuthazo eninzi) ☐

STANDARDISED OUTCOME MEASURES

APPENDIX XV NIHSS

NATIONAL INSTITUTE OF HEALTH STROKE SCALE (NIHSS)

Guidelines to use the National Institutes of Health Stroke Scale
Administer stroke scale items in the order listed. Record performance in each category after each subscale exam. Do not go back and change scores. Follow directions provided for each exam technique. Scores should reflect what a patient does, not what you think the patient can do.

You should record answers while administering the exam and work quickly. Except where indicated, the patient should not be coached. (I.e. repeated requests to patient to make a special effort).

IF ANY ITEM IS LEFT UNTESTED, A DETAILED EXPLANATION MUST BE CLEARLY WRITTEN DOWN. QUESTIONS 5, 6, 7 AND 10 HAVE ALLOWED SCORES OF 9. DO NOT ADD THE 9's INTO THE TOTAL SCORE.

2. NIHSS (National Institutes of Health Stroke Scale)

1.a. Level of consciousness

0= Alert, keenly responsive.

1= Not alert, but arousable with minimal stimulation to obey, answer or respond.

2= Not alert, requires repeated stimulation to attend, or is obtunded and requires strong or painful stimulation to make movements (not stereotyped).

3= Responds only with reflex motor or autonomic effects or totally unresponsive, flaccid, areflexic

1.b. Ask patient the month and their age

Must be exactly right

0= Answers both questions correctly.

1= Answers one question correctly.

2= Answers neither question correctly.

1.c. Ask patient to open and close eyes and then grip and release non-paretic hand

0= Performs both tasks correctly.

1= Performs one task correctly.

2= Performs neither correctly.

2. Best gaze (only horizontal eye movement)

0= Normal

1= Partial gaze palsy. This score is given when gaze is abnormal in one or both eyes, but where forced deviation or total gaze paresis are not present

2= Forced deviation, or total gaze paresis not overcome by the oculocephalic maneuver.

3. Visual field testing

0= No visual loss

1= Partial hemianopia

2= Complete hemianopia

3= Bilateral hemianopia (blind including cortical blindness)

4. Facial Paresis (Ask patient to show teeth or raise eyebrows and close eyes tightly)

0= Normal symmetrical movement

1= Minor paralysis (flattened nasolabial fold, asymmetry on smiling)

2= Partial paralysis (total or near total paralysis of lower face)

3= Complete paralysis of one or both sides (absence of facial movement in the upper and lower face)

5. Motor function - Arm (right and left)

arm right:

arm left:

0= No drift , limb hold 90 (or 45) degrees for full 10 seconds

1= Drift, limb hold 90 (or 45) degrees, but drifts down before full 10 seconds; does not hit bed or other support

2= Some effort against gravity, limb cannot get to or maintain (if cued) 90 (or 45) degrees, drifts down to bed, but has some effort against gravity

3= No effort against gravity, limb falls

4= No movement

If the score is '9', give an explanation:

9= Untestable (Joint fused or limb amputated)

6. Motor function- Leg (right and left)

leg right:

leg left:

0= No drift, leg holds 30 degrees position for full 5 seconds.

1= Drift, leg falls by the end of the 5 second period but does not hit bed.

2= Some effort against gravity; leg falls to bed by 5 seconds, but has some effort against gravity.

3= No effort against gravity, leg falls to bed immediately.

4= No movement

If the score is '9', give an explanation:

9= Untestable (Joint fused or limb amputated)

7. Limb ataxia

0= No ataxia

1= Present in one limb

2= Present in two limbs

If present, is ataxia in

right arm

1= Yes

0= No

If the score is '9', give an explanation:
9= Untestable (Joint fused or limb amputated)

left arm

1= Yes

0= No

If the score is '9', give an explanation:
9= Untestable (Joint fused or limb amputated)

right leg

1= Yes

0= No

If the score is '9', give an explanation:
9= Untestable (Joint fused or limb amputated)

left leg

1= Yes

0= No

If the score is '9', give an explanation:
9= Untestable (Joint fused or limb amputated)

8. Sensory (Use pinprick to test arms, legs , trunk and face -- compare side to side)

0= Normal, no sensory loss.

1= Mild to moderate sensory loss; patient feels pinprick is less sharp or is dull on the affected side; or there is a loss of superficial pain with pinprick but patient is aware he/she is being touched.

2= Severe to total sensory loss; patient is not aware of being touched in the face, and leg.

9. Best language (describe picture, name items, read sentences)

0= No aphasia, normal.

1= Mild to moderate aphasia; some obvious loss of of fluency or facility of comprehension, without significant limitation on ideas expressed or form of expression. Reduction of speech and/or comprehension, however, makes conversation about provided material difficult or impossible. For example in conversation about provided materials examiner can identify picture or naming card from patient's response.

2= Severe aphasia; all communication is through fragmentary expression; great need for interference, questioning, and guessing by the listener. Range of information that can be exchanged is limited; listener carries burden of communication. Examiner cannot identify materials provided from patient's response.

3= Mute, global aphasia; no usable speech or auditory comprehension.

10. Dysarthria (read several words)

0= Normal articulation

1= Mild to moderate; patient slurs at least some words and, at worst, can be understood with some difficulty.

2= Severe; patient's speech is so slurred as to be unintelligible in the absence of or out of proportion to any dysphasia, or is mute/anarthric.

If the score is '9', give an explanation:

9= Intubated or other physical barrier, explain:

11. Extinction or inattention

0= No abnormality.

1= Visual, tactile, auditory, spatial, or personal inattention or extinction to bilateral simultaneous stimulation in one of the sensory modalities.

2= Profound hemi-inattention or hemi-inattention to more than one modality. Does not recognize own hand or orients to only one side of space.

TOTAL SCORE

Additional item, not a part of the NIH Stroke Scale score.

A. Distal Motor function

0 = Normal (no flexion after 5 seconds)

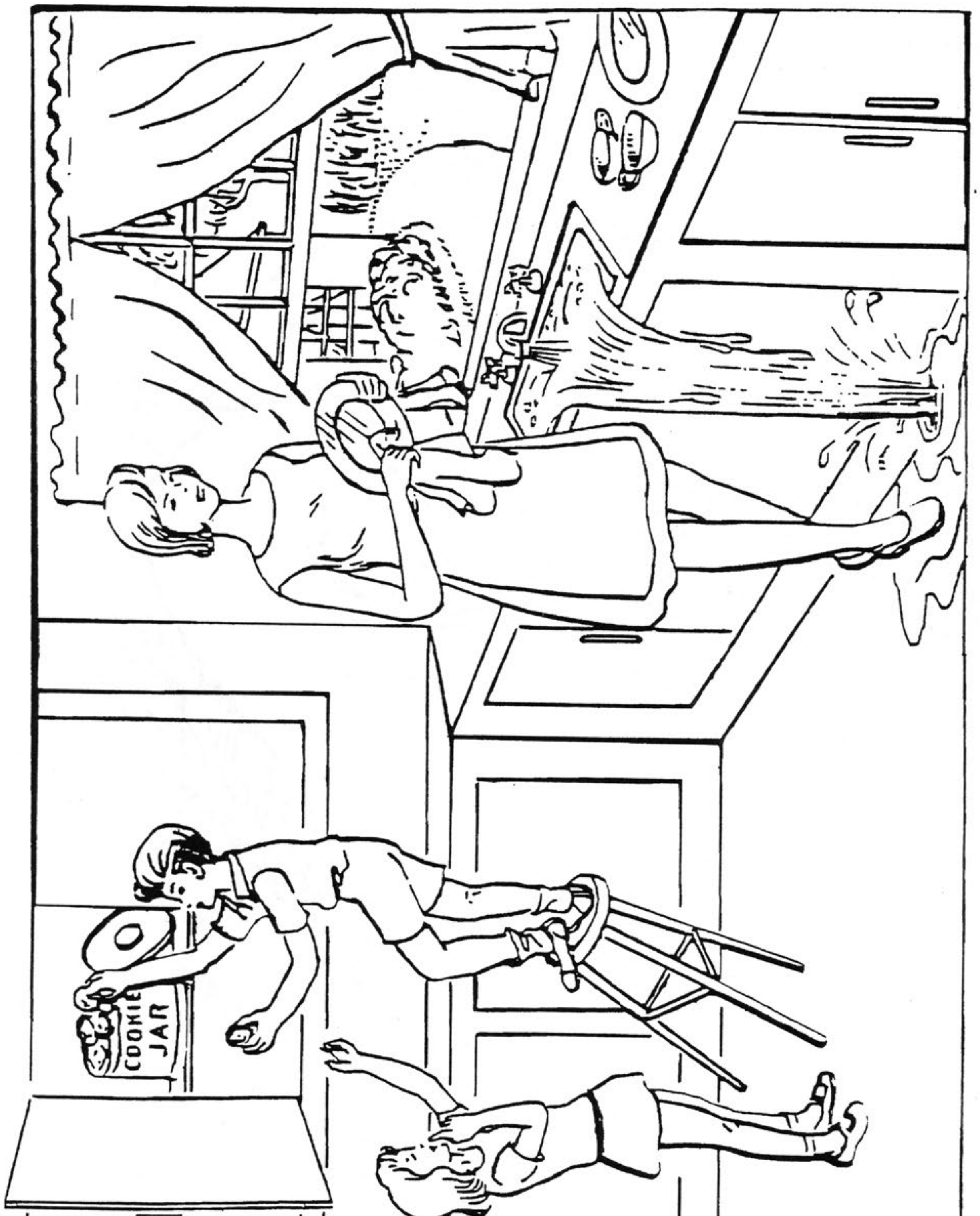
1= At least some extension after 5 seconds, but not fully extended. Any movement of the fingers which is not command is not scored.

2= No voluntary extension after 5 seconds. Movements of the fingers at another time are not scored.

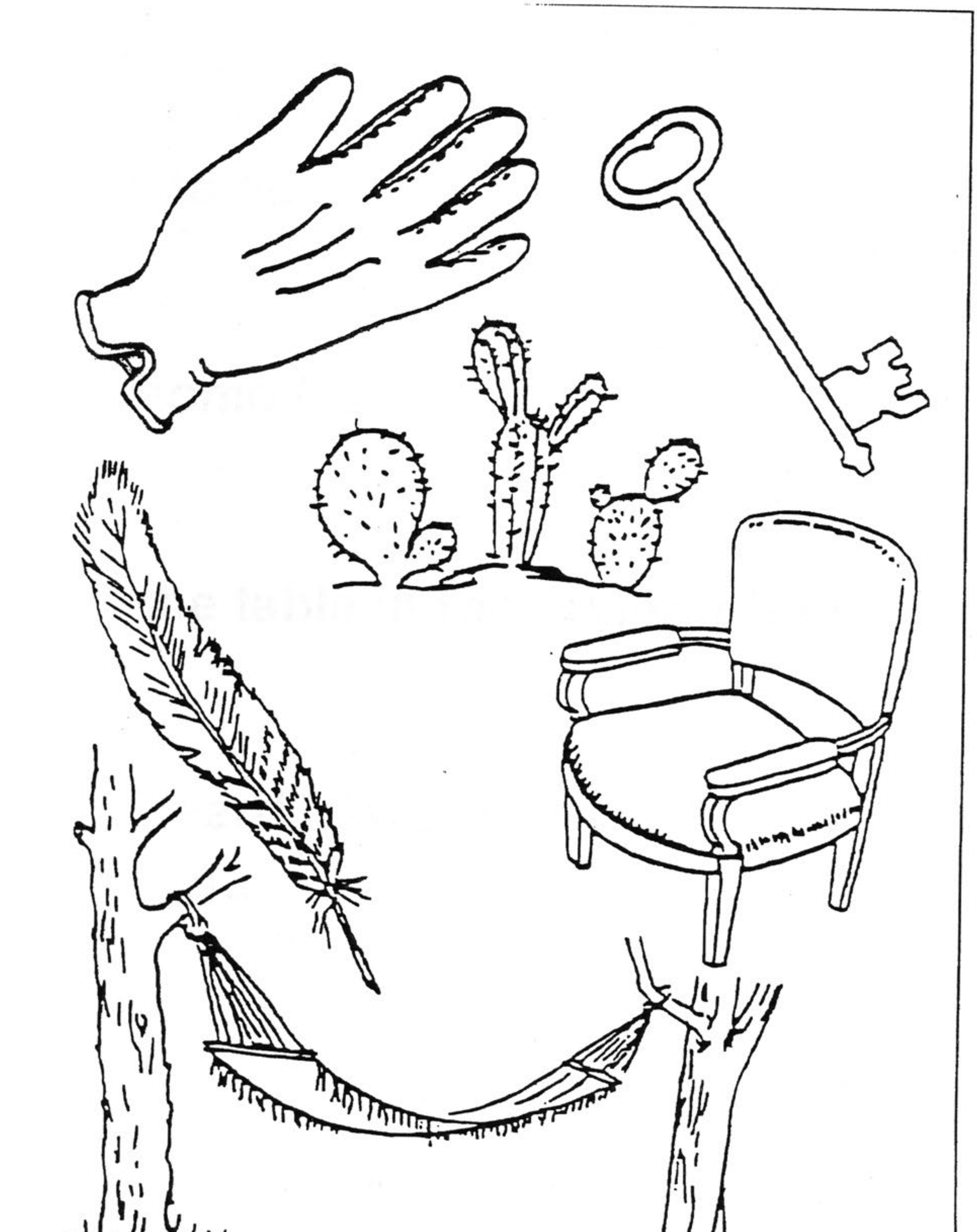
Left arm

right arm

NIHSS Item 9.1



NIHSS Item 9.2



NIHSS Item 9.3

You know how.

Down to earth.

I got home from work.

Near the table in the dining room.

They heard him speak on the radio last night.

MAMA

TIP-TOP

FIFTY-FIFTY

THANKS

HUCKLEBERRY

BASEBALL PLAYER

APPENDIX XVI THE BARTHEL ADL INDEX

The Barthel ADL Index: guidelines

1. This index should be used as a record of what a patient does, **not** as a record of what a patient could do.

2. The main aim is to establish degree of independence from any help, physical or verbal, however minor and for whatever reason.

3. The need for supervision renders a patient **not** independent.

4. A patient's performance should be established using the best available evidence. Asking the patient, friends/relatives and nurses are the usual sources, but direct observation and common sense are also important. However direct testing is not needed.

5. Usually the patient's performance over the preceding 24-48 hours in important, but occasionally longer periods will be relevant.

6. Middle categories imply that the patient supplies over 50 percent of the effort.

7. Use of aids to be independent is allowed.

(WADE, '92)

---

2. Barthel ADL Index

1. Bowels

0= incontinent (or needs to be given enema)
5= occasional accident (once a week)
10= continent

2. Bladder

0= incontinent, or catheterized and unable to manage alone
5= occasional accident (maximum once per 24 hours)
10= continent

3. Grooming

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

4. Toilet use

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

5. Feeding

0= unable
5= needs help cutting, spreading butter, etc.
10= independent

6. Transfer (bed to chair and back)

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

15= independent

7. Mobility

0= immobile

5= wheelchair independent, including corners

10= walks with help of one person (verbal or physical)

15= independent (but may use any aid; for example, stick)

8. Dressing

0= dependent

5= needs help but can do about half unaided

10= independent (including buttons, zips, laces, etc.)

9. Stairs

0= unable

5= needs help (verbal, physical, carrying aid)

10=independent

10. Bathing

0= dependent

5= independent

TOTAL SCORE

THE BARTHEL INDEX

Afrikaans Version

Riglyne vir die gebruik van die Barthel-Indeks

1. Hierdie indeks moet gebruik word as 'n rekord van wat 'n pasiënt wel gedoen het, **nie** as 'n rekord van wat 'n pasiënt sou kon doen nie.
2. Die hoofdoel is om die mate van afhanklikheid van hulp vas te stel, fisies of verbaal, hoe gering ook al en om watter rede ook al.
3. Die behoefte aan toesig laat 'n pasiënt **nie** onafhanklik nie.
4. 'n Pasiënt se vermoë moet bepaal word deur gebruik te maak van die beste beskikbare getuienis. Die pasiënt, vriende, familie en verpleegkundiges kan gewoonlik ondervra word, maar direkte waarneming en gesonde verstand is ook belangrik. Direkte toetsing is egter nie nodig nie.
5. Middelkategorieë impliseer dat die pasiënt meer as 50 persent van die poging bydra.
6. Die gebruik van hulpmiddele om onafhanklik te wees word toegelaat.

(Wade, '92)

Barthel

1. Stoelgang (maagwerk)

0 = inkontinent (of benodig 'n lawement)
5 = toevallige ongelukke (een keer per week)
10 = kontinent

2. Blaas

0 = inkontinent, of gekateriseer en kan nie alleen oor die weg kom nie
5 = toevallige ongelukke (maksimum een maal per 24 uur)
10 = kontinent

3. Selfversorging

0 = benodig hulp met persoonlike versorging
5 = onafhanklik met gesig, hare, tande, skeer (gebruiksartikels voorsien)

4. Toiletgebruik

0 = afhanklik
5 = benodig hulp, maar kan iets self doen
10 = onafhanklik (op en af, aantrek, afvee)

5. Eet

0 = kan nie
5 = benodig hulp met sny, botter smeer, ens.
10 = onafhanklik

6. Veplasing (van bed na stoel en terug)

0 = kan nie, geen balans sittend
5 = benodig baie hulp (een of twee persone, fisies), kan sit
10 = benodig min hulp (verbaal of fisies)
15 = onafhanklik

7. Beweeglikheid

0 = onbeweeglik
5 = onafhanklik met rolstoel, ook om draaie
10 = loop met hulp van een persoon (verbaal of fisies)
15 = onafhanklik (kan enige hulpmiddel gebruik, bv, kierie)

8. Aantrek

0 = afhanklik
5 = benodig hulp maar kan omtrent helfte self doen
10 = onafhanklik (insluitend knope, ritssluiters, veters)

9. Trappe klim

0 = kan nie
5 = benodig hulp (verbaal, fisies, dra van hulpmiddels)
10 = onafhanklik

10. Bad

0 = afhanklik
5 = onafhanklik

TOTAAL

THE BARTHEL INDEX

Xhosa Version

ISALATHISO
SIKA-BARTHEL

1. Amathumbu
0= Akakwazi ukuzibamba (okanye needs to be given enema)
5= uyazenzela ngamanye amaxesha (kanye ngeveki)
10= uyakwazi ukuzibamba

2. Isinyi
0= akakwazi ukuzibamba okanye ufuna uncedo ukuze akwazi ukuzilawula
5= uyaphulukwa ngamnye amaxesha (ubuninzi kanye ngeeyure ezingama-24)
10= uyakwazi ukuzibamba

3. Grooming
0= udinga uncedo ukuze akwazi ukuzicoca
5= uyakwazi ukuzihoya: ukucoca ubuso/ukukama iinwele/ukuhlamba amazinyo/ukucheba iindevu (xa ethe wanikwa izixhobo zokuzicoca ngomnye umntu)

4. Ukusebenzisa igumbi langasese
0= ufuna ukuncediswa
5= ufuna uncedo kodwa unakho ukuzenzela eyedwa
10= uyakwazi ukuzenzela engancediswanga (ukuzikhulula nokuzinxibisa, nokuzosula akugqiba ukuzinceda)

5. Ukuzityisa
0= akakwazi
5= ufuna unc
ekusikeni nasekuqabeni ibhotolo, njl njl.
10= uyakwazi ukuzenzela

6. Ukutshintsha indawo yokuhlala (ukusuka ebhedini ukuya esitulweni nokuphinda abuye)
0= akakwazi, ngenxa yokungakwazi ukuzihlalela/ ukuchopha
5= ufuna uncedo olumandla (ancediswe ngumntu omnye okanye ababini), uyakwazi ukuzihlalela
10= ufuna uncedo olungephi (ukuyalelwa ukuba enzeni okanye afunqulwe)
15= uyakwazi ukuzitshintshela ngokwakhe

7. Ukuhamba
0 = akakwazi ukuhamba
5 = akaxhomekekanga kwisitulo sokuncedisa ukuhamba esinamavili independent, including corners
10= uyahamba ngoncedo lomnye umntu (ngokuthi afunqulwe okanye ayalelwe amakakwenze)
15= uyakwazi ukuzihambela (kodwa angasebenzisa uncedo, olufana nolwentonga yokusimelela)

8. Ukunxiba
0= uxhomekeke kuncedo lomnye umntu
5= ufuna uncedo kodwa uyakwazi ukuzinxibisa ezinye izinto engancediswanga
10= akaxhomekekanga mntwini (kuquka ukukhulula nokuqhobosha amaqhosha, ukuvala nokuvula iziphu, ukuqhobosha nokukhulula imitya, njl njl.

9. Izitepsi
0 = akakwazi ukunyuka nokwehla
5 = ufuna uncedo (ngokuthi ayalelwe okanye afunqulwe)
10 =akaxhomekekanga mntwini

10. Ukuzihlamba
0= uxhomekeke komnye umntu
5= akaxhomekekanga mntwini

AMANQAKU EWONKE

APPENDIX XVII RIVERMEAD MOTOR ASSESSMENT

Rivermead Motor Assessment

General instructions: Go through the items in order of difficulty. Score '1' if patient can perform activity, ' 0' if he cannot. In the 'Gross function' and 'Arm' section you may stop that the test after 3 consecutive '0' scores. In the 'Leg and Trunk' section all actions should be tested, even if there are three consecutive '0' scores.

Give no feed-back of whether correct or incorrect, just give general encouragement. Repeat instructions and demonstrate them to the patient if necessary. All exercises to be carried out independently unless otherwise stated. All armtests refer to the affected side unless otherwise stated. 'Gross function' section can be assessed simply by asking, which makes it a rapid measure.

Section Item	Score
A. Gross function	
1. Sit unsupported *Without holding on, on edge of bed, feet unsupported.*	☐
2. Lying to sitting on side of bed *Using any method.*	☐
3. Sitting to standing *May use hands to push up. Must stand up in 15 sec and stand for 15 sec, with an aid if necessary*	☐
4. Transfer from weelchair to chair towards unaffected side *May use hands.*	☐
5. Transfer from weelchair to chair towards affected side *May use hands.*	☐
6. Walk 10 m indoors with an aid *Any walking aid. No stand-by help.*	☐
7. Climb stairs independently *Any method. May use bannister and aid--must be a full flight of stairs.*	☐
8. Walk 10 m indoors without an aid *No stand-by help. No caliper, splint or walking aid.*	☐
9. Walk 10m , pick up bean bag from floor, turn and carry back *Bend down any way, may use aid to walk if necessary. No stand-by help. May use either hand to pick up bean bag.*	☐
10. Walk outside 40 m *May use walking aid, caliper or splint. No stand-by help.*	☐

11.Walk up and down four steps

Patient may use an aid if he would normally use one, but may not hold on to rail. This is included to test ability to negotiate curb or stairs without a rail.

12. Run 10 m

Must be symmetrical.

13. Hop on affected leg five times on the spot

Must hop on ball of foot without stopping to regain balance. No help with arms.

Gross function Total

Section Item

Score

B. Leg and trunk

1. Roll to affected side

Starting position schould be lying, not crook lying.

2. Roll to unaffected side

Starting position should be lying, not crook lying.

3. Half-bridging

Starting position -- half-crook lying. Patient must put some weight through affected leg to lift hip on affected side. Therapist may position leg, but patient must maintain position even after movement is completed.

4. Sitting to standing

May not use arms-- feet must be flat on floor--must put weight through both feet.

5. Half-crook lying: lift affected leg over side of bed and return it to the same position.

Affected leg in half-crook position. Lift leg off bed on to support; for example, box, stool, floor,

so that hip is in neutral and knee at 90 degrees while resting on support. Must keep affected knee flexed throughout movement. Do not allow external rotation at hip. This tests control of hip and knee.

6. Standing, step unaffected leg on and off block

Without retraction of pelvis or hyperextension of knee. This tests knee and hip control while weight bearing through the affected leg.

7. Standing, tap ground lightly five times with unaffected foot

Without retraction of pelvis or hyperextension of knee. Weight must stay on leg. This again tests knee and hip control while weight bearing through the affected leg *but is more difficult than in 6.*

8. Lying, dorsiflex affected ankle with leg flexed
Physiotherapist may hold affected leg in position, knee at 90 degrees. Do not allow inversion. Must have half range of movement of unaffected foot.

9. Lying, dorsiflex affected ankle with leg extended
Same conditios as in 8, with leg extended. Do not allow inversion or knee flexion. Foot must reach plantigrade (90°).

10. Stand with affected hip in neutral position, flex affected knee
Therapist may not position leg. This is extremely difficult for most hemiplegic patients, but is included to assess minimal dysfunction.

Leg and trunk function total

Section Item

Score

C. Arm

1. Lying, protract schoulder girdle with arm in elevation
Arm may be supported.

2. Lying, hold extended arm in elevation (some external rotation) for at least 2 sec
Therapist should place arm in position and patient must maintain position with some external rotation. Do not allow pronation. Elbow must be held within 30 degrees of full extension.

3. Flexion and extension of elbow, with arm as in 2 above
Elbow must extend to at least 20 degrees full extension. Palm should not face out during any part of movement.

4. Sitting, elbow into side, pronation and supination
Three-quarters range is acceptable, with elbow unsupported and at right angles.

5. Reach forward, pick up large ball with both hands and place down again
Ball should be on table so far in front of patient that he has to extend arms fully to reach it. Shoulders must be protracted, elbows extended, wrist neutral or extended, and fingers extended throughout movement. Palms should be kept in contact with the ball.

6. Stretch arm forward, pick up tennis ball from table, release on affected side, return to table, then release again on table. Repeat five times
Shoulder must be protracted, elbow extended and wrist neutral or extended during each phase.

7. Same exercise as in 6 above with pencil
Patients must use thumb and fingers to grip.

8. Pick up a piece of paper from table in front and release five times
Patient must use thumb and fingers to pick up paper and not to pull it to edge of table. Arm position as in 6 above.

9. Cut putty with a knife and fork on plate with non-slip mat and put pieces into container at side of plate
Bite-size pieces.

10. Stand on spot, maintain upright position, pat large ball on floor with palm of hand for 5 continuous bounces

11. Continuous opposition of thumb and each finger more than 14 times in 10 sec
Must do movement in consistent sequence. Do not allow thumb to slide from one finger to the other.

12. Supination and pronation on to palm of unaffected hand 20 times in 10 sec
Arm must be away from body, the palm and dorsum of hand must touch palm of good hand. Each tap counts as one. This is similar to 4 above, but introduces speed.

13. Standing, with affected arm abducted to 90 degrees with palm flat against wall. Maintain arm in position. Turn body towards wall and as far as possible towards arm, i.e. rotate body beyond 90 degrees
Do not allow flexion at elbow, and wrist must be extended with palm of hand fully in contact with wall.

14. Place string around head and tie bow at back
Do not allow neck to flex. Affected hand must be used for more than just supporting string.This tests function of hand without help of sight.

15. 'Pat- a-cake' seven times in 15 sec
Mark crosses on wall at schoulder level. Clap both hands together (both hands touch crosses.) Each sentence counts as one. Give patients three tries. This is a complex pattern which involves co-ordination, speed,and memory, as well as good arm function.

Arm function total

APPENDIX XVIII EADL SCALE

Nottingham Extended Activities of Daily Living

The following questions are about everyday activities. Please answer by ticking **ONE** box for each question. Please record what you have ACTUALLY done in the last few weeks.

DID YOU..........	**Not at all**	**With help**	**On your own with difficulty**	**On your own**
1. Walk around outside?	☐	☐	☐	☐
2. Climb stairs?	☐	☐	☐	☐
3. Get in and out of a car?	☐	☐	☐	☐
4. Walk over uneven ground?	☐	☐	☐	☐
5. Cross roads?	☐	☐	☐	☐
6. Travel on public transport?	☐	☐	☐	☐
7. Manage to feed yourself?	☐	☐	☐	☐
8. Manage to make yourself a hot drink?	☐	☐	☐	☐
9. Take hot drinks from one room to another?	☐	☐	☐	☐
10. Do the washing up?	☐	☐	☐	☐
11. Make yourself a hot snack?	☐	☐	☐	☐
12. Manage your own money when you were out?	☐	☐	☐	☐

13. Wash small items of clothing?

14. Do your own housework?

15. Do your own shopping?

16. Do a full clothes wash?

17. Read newspapers or books?

18. Use the telephone?

19. Write letters?

20. Go out socially?

21. Manage your own garden?

22. Drive a car?

THE EADL SCALE

Afrikaans Version

NOTTINGHAM UITGEBREIDE DAAGLIKSE AKTIWITEITE (NOTTINGHAM EXTENDED ACTIVITIES OF DAILY LIVING)

Die volgende vrae is oor alledaagse dinge. Antwoord asseblief deur n' kruisie in een blokkie per vraag te sit. Beskryf asseblief die aktiwiteite wat jy werklik die afgelope paar weke gedoen het.

HET JY.....	Glad nie	Met hulp	Op my eie maar dit is moeilik	Op my eie
1. Buite rondgeloop?	☐	☐	☐	☐
2. Trappe geklim?	☐	☐	☐	☐
3. In en uit 'n motor geklim?	☐	☐	☐	☐
4. Oor ongelyke grond geloop?	☐	☐	☐	☐
5. Die pad oorkruis?	☐	☐	☐	☐
6. Met publieke vervoer gereis? (bv. Met taxi, bus, trein)	☐	☐	☐	☐
7. Op jou eie geëet?	☐	☐	☐	☐
8. Jouself 'n warm drankie gemaak? (bv. tee, koffie)	☐	☐	☐	☐
9. Warm drankies van een kamer na 'n ander geneem?	☐	☐	☐	☐
10. Skottelgoed gewas?	☐	☐	☐	☐
11. Jouself 'n warm ligte ete gemaak?	☐	☐	☐	☐
12. Jou eie geldsake gehanteer (terwyl jy uit was)?	☐	☐	☐	☐

13. Ligte kledingstukke gewas?	☐	☐	☐	☐
14. Jou eie huiswerk gedoen?	☐	☐	☐	☐
15. Jou eie inkopies gedoen?	☐	☐	☐	☐
16. Volle bondel wasgoed gewas?	☐	☐	☐	☐
17. Koerante of boeke gelees?	☐	☐	☐	☐
18. Die telefoon gebruik?	☐	☐	☐	☐
19. Briewe geskryf?	☐	☐	☐	☐
20. Sosiaal verkeer?	☐	☐	☐	☐
21. Tuin gemaak?	☐	☐	☐	☐
22. Motor bestuur?	☐	☐	☐	☐

THE EADL SCALE

Xhosa Version

Imisebenzi eyongezelelweyo kaNottingham yentlalo yamihla yonke

Le mibuzo ilandelayo imalunga nemisebenzi yemihla ngemihla. Nceda uphendule ngokuthi ubeke uphawu kwibhokisi ibe NYE kumbuzo ngamnye. Nceda ugcine oko uthe wakwenza kwezi veki zimbalwa ezidlulileyo.

INGABA UKHE..........	Nakanye	Bendincediswa	Bendizenzela kodwa bekunzima	Bendizenzela nje ngokwam ndingenangxaki
1. Wahamba-hamba ngaphandle?				
2. Wenyuka izitepsi?				
3. Wakhwela waphinda wehla emotweni?				
4. Wahamba kumhlaba ongalinganiyo ngokuphakama?				
5. Wawela iindlela?				
6. Wakhwela kwisithusthi sikawonkewonke?				
7. Wakwazi ukuzityisa?				
8. Wakwazi ukuzenzela isiselo esishushu?				
9. Wathatha isiselo esishushu kwelinye igumbi usisa kwelinye?				
10. Wazihlambela izitya?				

11. Wazenzela ukutyana okushushu? Umzelekelo – isonka esineqanda.				
12. Wakwazi ukuziphathela imali ngethuba ubuphumile?				
13. Wazihlambela ubumpahlana obumbalwa?				
14. Wazenzela umsebenzi wakho wasekhaya?				
15. Wazithengela izinto ozifunayo?				
16. Wazihlambela zonke iimpahla zakho?				
17. Wafunda iphepha-ndaba okanye incwadi?				
18. Wasebenzisa ifowuni?				
19. Wazibhalela iileta?				
20. Waphuma uye kuzonwabisa?				
21. Wazenzela umsebenzi wakho wasegadini?				
22. Waqhuba imoto?				

APPENDIX XIX MODIFIED RANKIN SCALE

MODIFIED RANKIN SCALE

Structured Interview for the Modified Rankin Scale

Questionnaire and Guidelines

Lindsay Wilson, University of Stirling, Stirling, FK9 4LA, UK
Asha Hareendran, Outcomes Research, Pfizer Ltd. Sandwich, CT13 9NJ, UK

May 2002

Structured Interview for the Modified Rankin Scale

Introduction

The Modified Rankin Scale (MRS) (van Swieten et al., 1988) is widely used as a functional outcome measure in stroke. The purpose of the Structured Interview is to assign patients to MRS grades in a systematic way. The interview consists of five sections corresponding to the levels of disability on the MRS (see Table).

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

General Instructions

Timing
The interview is intended for use after discharge from hospital.

Respondents
Use the best source of information available. Information can be obtained from the patient and/or a person who is familiar with the daily routine of the patient. Interview the patient and a close friend or caregiver whenever possible. If the patient lacks insight into some difficulties, or responses are inconsistent it is often helpful to interview a caregiver or relative independently.

Procedure
For sections 1, 2, 3, & 5 first ask about current activities. If there is currently no problem or limitation in a particular activity, it is not necessary to ask about status 'before stroke', but please tick the relevant boxes. If the person indicates a problem or limitation on a particular activity, then establish whether this was present before the stroke and record the response appropriately in the 'before stroke' column. (This sequence is illustrated in the diagram on the next page)

Diagram: Interview procedure for sections 1, 2, 3 & 5

Ask about current activity

→ No problem or limitation or does not need assistance → Mark 'no' in the Now column → Mark 'no' in Before Stroke column → Go on to next item

→ Problem or limitation reported or needs assistance → Mark 'yes' in the Now column → Ask whether the problem or limitation was present before the index stroke

→ Yes. If the problem/ limitation existed before stroke, mark 'yes' in the Before Stroke column: → Go to next item

→ No. If there was no limitation/problem before stroke, mark 'no' in the Before Stroke column → Go to next item

For Section 4 ask about ability to perform the activity before stroke and then ask about a change in ability after the stroke. If the person did not participate in an activity (e.g. work) before stroke then move to the next question as indicated on the questionnaire. Sometimes it can be difficult to establish whether or not someone could do an activity before stroke (particularly if the person had one or more previous strokes) - in this case use your judgement and focus on the index stroke for which the patient was enrolled in the study.

The responses to the separate sections should generally be hierarchical (for example if a person indicates that they require assistance to attend to bodily needs, then it is inconsistent if they then say that they go out alone for social and leisure activities). Thus, responses to later questions may suggest revisions to earlier responses. Check for consistency as you proceed. Ask all questions and go back to clarify, if necessary.

Notes for specific sections of the interview are given on the following pages. The document is formatted so that the notes appear opposite the interview questions when double-sided printing is used.

Sources:-

Section 2 of the interview is adapted from the Barthel Index (Collin et al. 1988), and Section 4 is adapted from the Extended Glasgow Outcome Scale (Wilson et al., 1998).

Collin, C., Wade, D. T., Davies, S., & Horne, V. (1988). The Barthel ADL Index: a reliability study. International Disability Studies, 10, 61-63.

van Swieten, J. C., Koudstaal, P. J., Visser, M. C., Schouten, H. J. A., & van Gijn, J. (1988). Interobserver agreement for the assessment of handicap in stroke patients. Stroke, 19, 604-607.

Wilson, J. T. L., Pettigrew, L. E. L., & Teasdale, G. M. (1998). Structured interviews for the Glasgow Outcome Scale and Extended Glasgow Outcome Scale: Guidelines for their use. Journal of Neurotrauma, 15, 573-585.

Notes

1. CONSTANT CARE

Patients are usually bedridden: patients may not actually remain in bed all the time, but moving them from the bed to sitting will require major assistance. Patients will also need assistance with other activities.

SECTIONS 2 AND 3: ASSISTANCE FOR ACTIVITIES OF DAILY LIVING

Assistance may be considered essential when there is the need for physical help (by another person) with an activity or there is a need for supervision, or the person needs prompting or reminding to do a task.

Mark responses based on the ability of the patient to perform the activity and not whether the patient actually performs the activity currently. Please probe using the specific questions given in the sections below. Please use your judgement to decide whether the person can actually do something before recording a response. The need for supervision for safety reasons should be due to objective danger that is posed, rather than 'just in case'. People may feel that a person who has had stroke should not be left on their own, but that does not make the person with stroke dependent. A general need for companionship, care, or protection should not be considered assistance.

2.ASSISTANCE TO ATTEND TO BODILY NEEDS/ FOR WALKING

2.1. Assistance for eating

Patient may eat a modified diet on their own. This should not be considered assistance.

2.2. Assistance for using the toilet

Using toilet without assistance include, reaching the toilet/commode; undress sufficiently; clean self; dress and leave.

2.3. Assistance for routine daily hygiene

Daily Hygiene includes just the three activities indicated (washing face, doing hair, cleaning teeth/ fitting false teeth). It does not include bathing and showering, or shaving, which are more complex activities for which the person may require assistance. The ability to bath, shower or shave is not relevant for this section.

2.4. Assistance for walking

Specific question to ask: "If absolutely necessary could you walk across the room, even if your caregiver was not present?"

3. ASSISTANCE TO LOOK AFTER OWN AFFAIRS

3.1 Preparing a simple meal. Specific questions to ask: "If the person were on their own: Would they go hungry? Might they be at risk of burning the house down if they tried to cook?"

3.2 Performing basic household chores. Specific questions to ask: "Are they *able to do* chores, if necessary, even if they do not normally do them." Men may, report that they need assistance more often than women. Please clarify by probing about the person's *ability* to perform the chores.

3.3 Looking after household expenses. Specific questions to ask: "Do you look after your own pension/income? Do you arrange to pay bills?" Look for a change from previous level of responsibility. Note: the person may be reluctant to admit a problem. The question is NOT about financial needs (e.g. assistance from benefit agencies). It refers to whether or not patients are able to take responsibility for the money that they have.

3.4 Local travel. Specific questions to ask: "If you need to get somewhere can you manage to call a taxi?" The patient should be able to at least order and take a taxi alone. This question is NOT about being able to afford a taxi, but about the tasks involved. The question refers to whether or not the patients can get around locally by themselves.

On the 'shopping' and 'local travel' questions (independence outside the home) there is quite often some restriction before stroke. Please ask about this and record the response in the 'Before Stroke' column

3.5 Local shopping. Specific Questions to ask: "If your life depended on it – could you get out and buy even single items?" "Can the person go to a local shop to buy milk or a loaf of bread?" Could also include going to the pub/bar, ordering and paying for a drink by themselves

Interview

Please mark (X) in the appropriate box. Please record responses to all questions (unless otherwise indicated in the text), including those concerning status before stroke. See guidelines on the facing page for further information.

1	**CONSTANT CARE**		
	Constant care means that someone needs to be available at all times. Care may be provided by either a trained or an untrained caregiver. The patient will usually be bedridden and may be incontinent.	**Now**	**Before stroke**
1.1	**Does the person require constant care?**	☐ Yes ☐No (5)	☐Yes ☐No

2	**ASSISTANCE TO ATTEND TO BODILY NEEDS/ FOR WALKING**		
	Assistance includes physical assistance, verbal instruction, or supervision by another person.	**Now**	**Before stroke**
2.1	**Is assistance essential for eating?** (Eating without assistance: food and implements may be provided by others).	☐ Yes ☐ No (4)	☐ Yes ☐ No
2.2	**Is assistance essential for using the toilet?** (Using toilet without assistance: reach toilet/commode; undress sufficiently; clean self; dress and leave).	☐ Yes ☐ No (4)	☐ Yes ☐ No
2.3	**Is assistance essential for routine daily hygiene?** (Routine hygiene: washing face, doing hair, cleaning teeth/fitting false teeth. Implements may be provided by others and this should not be considered assistance).	☐ Yes ☐ No (4)	☐ Yes ☐ No
2.4	**Is assistance essential for walking?** (Walking without assistance: Able to walk indoors around house or ward, may use any aid (e.g. stick/cane, walking frame/walker), however not requiring physical help or verbal instruction or supervision from another person).	☐ Yes ☐ No (4)	☐ Yes ☐ No

3	**ASSISTANCE TO LOOK AFTER OWN AFFAIRS**		
	Assistance includes physical assistance, or verbal instruction, or supervision by another person.	**Now**	**Before stroke**
3.1	**Is assistance essential for preparing a simple meal?** (For example, able to prepare breakfast or a snack)	☐ Yes ☐ No (3)	☐ Yes ☐ No
3.2	**Is assistance essential for basic household chores?** (For example, finding and putting away clothes, clearing up after a meal. Exclude chores that do not need to be done every day, such as using a vacuum cleaner.)	☐ Yes ☐ No (3)	☐ Yes ☐ No
3.3	**Is assistance essential for looking after household expenses?**	☐ Yes ☐ No (3)	☐ Yes ☐ No
3.4	**Is assistance essential for local travel?** (Patients may drive or use public transport to get around. Ability to use a taxi is sufficient, provided the person can phone for it themselves and instruct the driver.)	☐ Yes ☐ No (3)	☐ Yes ☐ No
3.5	**Is assistance essential for local shopping?** (Local shopping: at least able to buy a single item)	☐ Yes ☐ No (3)	☐ Yes ☐ No

Notes

4. USUAL DUTIES AND ACTIVITIES

The set of questions in Section 4 are about how the patient usually spends his/her day. In this section, questions concerning status before stroke are asked first, to establish which areas are relevant. If an activity is not relevant (e.g. the person was not working before stroke), then it is assumed that there is no change, and the interviewer proceeds to ask about the next area.
Concentrate on key areas relevant to the particular person. Not all will apply, but almost everyone will have some regular pre-stroke social & leisure activities.

It is change that is important. The section concerns fulfilment of major social roles, relative to the previous roles that the person had.

Change should come from impairment (not social circumstances). For example, change in financial circumstances may produce a change in social activities but this is not relevant.

Possible improvement in the future is not relevant (e.g. "I plan to go back to work next month"). The relevant time period is within the previous week or so.

4.1 Work

4.1.1 Work refers to paid employment, and does not include voluntary work (which can be included under 'social and leisure activities'). Many elderly patients will have retired and this section will not be relevant.

4.1.2 Change in ability to work or study includes loss of employment or reduction in level of responsibility; change in education, or problems with study. Special arrangements which allow someone to return to work even though they would not normally be able to work should be considered as 'reduced level of work'.

4.2 Family responsibilities

Refers to the patient's ability to look after others. Probe using specific examples such as "babysitting, looking after your partner, your parents, your grandchildren or dependent others".

4.3 Social & leisure activities

This refers to any specific free-time activities which the person did for pleasure. It is useful to first establish the person's main activities before stroke, and then ask about change in participation since the stroke. Probe with specific questions: "How did you spend your day before the stroke? How often did you get out? What activities did you do in your free time at home? Do you think your level of activity has changed?"

Interview

4. USUAL DUTIES AND ACTIVITIES. The next sets of questions are about how the patient usually spends his/her day.

4.1 Work

4.1.1	**Before stroke, was the person working or seeking work (or studying as a student)?** (If the person was not employed or seeking work before stroke, or the person was retired then indicate 'No' and go to 4.2)	☐ Yes ☐ No
4.1.2	**Since stroke has there been a change in the person's ability to work or study?** (Change in ability to work or study includes loss of employment or reduction in level of responsibility; change in education or problems with study). **If 'Yes', how restricted are they?** Reduced level of work e.g. change from full-time to part-time or change in level of responsibility. ☐(2) Currently unable to work. ☐(2)	☐ Yes ☐ No

4.2 Family responsibilities

4.2.1	**Before stroke was the person looking after family at home?** (If this was not a major role before stroke, indicate 'No' and go to 4.3)	☐ Yes ☐ No
4.2.2	**Since stroke has there been a change in their ability to look after family at home?** *If 'Yes', how restricted are they?* (a) Reduced responsibility for looking after family. ☐(2) (b) Currently unable to look after family. ☐(2)	☐ Yes ☐ No

4.3 Social & leisure activities

(Social and leisure activities include hobbies and interests. Includes activities outside the home or at home. Activities outside the home: going to the pub/bar, restaurant, club, church, cinema, visiting friends, going for walks. Activities at home: involving "active" participation including knitting, sewing, painting, games, reading books, home improvements).

4.3.1	**Before stroke did the person have regular free-time activities?** (If the person had very restricted social & leisure activities before stroke then indicate 'No' and go to 4.4).	☐ Yes ☐ No
4.3.2	**Since stroke has there been a change in their ability to participate in these activities?** *If 'Yes', how restricted are they?* (a) Participate a bit less: at least half as often as before the stroke. ☐ (b) Participate much less: less than half as often. ☐ (2) (c) Unable to participate: rarely, if ever, take part. ☐ (2)	☐ Yes ☐ No

Notes

4. <u>USUAL DUTIES AND ACTIVITIES</u>. .....Contd.
4.4 Family & friendships

It is useful to go through the problems listed, particularly change in mood. This includes the patient who has become isolated and / or withdrawn since suffering their stroke. In this case it is more relevant to consider how tolerable this for others rather than the frequency of the problem.

Patients can experience personality changes and may be more insensitive to their partners than before, and this may result in relationship problems. Patients may report that they are now more 'mellow' than before and can longer be bothered joining in conversations about trivia. This behaviour may also result in reduced social interaction and could lead to increased isolation.

It is useful to obtain the views of a caregiver on relationship problems.

5. SYMPTOMS AS A RESULT OF THE STOKE

5.1 This question is used to establish a spontaneous report of symptoms due to stroke, before going through the checklist

5.2 SYMPTOM CHECKLIST
These can be any symptoms or problems reported by the patient or found on neurological examination. It is important to exclude common problems and complaints not due to stroke.
If you are not sure that a symptom resulted from stroke indicate that it was present 'before stroke' by marking the 'yes' box in the before stroke column. The responses that are considered for scoring are those that are present now, but not present before the stroke, implying that the symptoms are due to stroke.

Assigning a grade on the Modified Rankin Scale

1. Examine the responses and discount items on which there were limitations before stroke.
2. If there is a 'yes' answer in the 'before stroke' column, indicating a problem before stroke, then discount (do not consider) that item. In section 4 if there is a 'no' answer to question 4.1.1, 4.2.1, 4.3.1 or a 'yes' answer to 4.4.2 then discount the specific subsection.
3. Rankin categories are given in brackets beside specific responses.
4. The overall rating is simply the lowest disability category indicated by the person's answers (after discounting limitations or problems before stroke). Rankin 5 is the lowest category, and Rankin 0 is the highest.

If the person has no limitations or symptoms then the Rankin grade is 0.

Interview

4. USUAL DUTIES AND ACTIVITIES. .....Contd.

4.4 Family & Friendships

(Problems with relationships include difficulties in relationships with people at home, loss of friendships or increase in isolation. Changes in the person may include: communication problems, quick temper, irritability, anxiety, insensitivity to others, mood swings, depression, and unreasonable behaviour).

4.4.1	**Since the stroke has the person had problems with relationships or become isolated?** *If 'Yes', what is the extent of disruption/strain?*	☐ Yes	☐ No
	Occasional- less than weekly	☐	
	Frequent- once a week or more, but tolerable	☐ (2)	
	Constant- daily & intolerable	☐ (2)	
4.4.2	**Before stroke were any similar problems present?**	☐ Yes	☐ No

5. SYMPTOMS AS A RESULT OF THE STOKE

(Can be any symptoms or problems reported by the patient or found on neurological examination).

5.1	**"Does the patient have any symptoms resulting from stroke?"** (Record spontaneous answer to the question from respondent)	☐ Yes (1)	☐ No		
5.2.	**SYMPTOM CHECKLIST**	**Now**		**Before stroke**	
5.2.1	**Does the person have difficulty reading or writing?**	☐ Yes (1)	☐ No	☐ Yes	☐ No
5.2.2	**Does the person have difficulty speaking or finding the right word?**	☐ Yes (1)	☐ No	☐ Yes	☐ No
5.2.3	**Does the person have problems with balance or co-ordination?**	☐ Yes (1)	☐ No	☐ Yes	☐ No
5.2.4	**Does the person have visual problems?**	☐ Yes (1)	☐ No	☐ Yes	☐ No
5.2.5	**Does the person have numbness (face, arms, legs, hands, feet)?**	☐ Yes (1)	☐ No	☐ Yes	☐ No
5.2.6	**Has the person experienced loss of movement (face, arms, legs, hands, feet)?**	☐ Yes (1)	☐ No	☐ Yes	☐ No
5.2.7	**Does the person have difficulty with swallowing?**	☐ Yes (1)	☐ No	☐ Yes	☐ No
5.2.8	**Any other symptoms?** (Please record: ....)	☐ Yes (1)	☐ No	☐ Yes	☐ No

Rankin Grade = ☐

© 2002 Lindsay Wilson, University of Stirling, Stirling, FK9 4LA, UK and Asha Hareendran, Outcomes Research, Pfizer Ltd. Sandwich, CT13 9NJ, UK

MODIFIED RANKIN SCALE

Afrikaans Version

Onderhoud

Plaas asseblief 'n kruisie in die korrekte blokkie. Skryf die antwoorde van al die vrae (tensy andersins aangedui word in die teks), insluitende die wat betrekking het tot die toestand voor die beroerte aanval. Raadpleeg die aangehegte riglyne vir aanvullende inligting.

1	VOLTYDSE VERSORGING		
	Voltydse versorging beteken dat iemand ten alle tye beskikbaar moet wees. Versorging mag deur 'n opgeleide of 'n onopgeleide versorger verskaf word. Die pasiënt is dan gewoonlik bedleënd en het geen beheer oor sy of haar blaas nie.	**Nou**	**Voor beroerte**
1.1	**Benodig die persoon voltydse versorging?**	□ Ja □ Nee (5)	□ Ja □ Nee

2	HULP MET LIGAAMLIKE BEHOEFTES / MET LOOP		
	Hulp sluit fisiese hulp, mondelinge opdragte, of toesig van 'n ander persoon, in.	**Nou**	**Voor Beroerte**
2.1	**Word hulp benodig om te eet?** (Eet sonder hulp: kan self eet maar voedsel en messegoed mag deur iemand anders aangegee word).	□ Ja □ Nee (4)	□ Ja □ Nee
2.2	**Word hulp benodig om die toilet te gebruik?** (Gebruik die toilet sonder hulp; kan self die toilet bereik, ontklee; reining en self weer aantrek en toilet verlaat).	□ Ja □ Nee (4)	□ Ja □ Nee
2.3	**Word hulp benodig vir daaglikse reinigingsroetine?** (Reinigingsroetine: was van gesig, borsel van hare, borsel van tande / insit van vals tande. Benodighede vir reiniging mag deur iemand anders aangegee word maar word nie as hulp beskou nie).	□ Ja □ Nee (4)	□ Ja □ Nee
2.4	**Word hulp benodig vir loop?** (Loop sonder hulp: kan binne die huis of saal rondloop, mag van 'n hulpmiddel gebruik maak (bv. stok of kierie, loopraam), maar het nie fisiese hulp of mondelinge opdragte of toesig van 'n ander persoon nodig nie).	□ Ja □ Nee (4)	□ Ja □ Nee

3	HULP OM NA EIE SAKE OM TE SIEN		
	Hulp sluit fisiese hulp in, mondelinge opdragte, of toesig van 'n ander persoon, in.	**Nou**	**Voor Beroerte**
3.1	**Word hulp noodsaaklik benodig om 'n eenvoudige maaltyd voor te berei?** (Byvoorbeeld: kan ontbyt of 'n peuselhappie voorberei)	□ Ja □ Nee (3)	□ Ja □ Nee
3.2	**Word hulp noodsaaklik benodig vir ligte huiswerk?** (Byvoorbeeld: die vind en wegpak van klere, skoonmaak na die maak en eet van 'n maaltyd. Uitsluitende take wat nie elke dag gedoen hoef te word nie, soos stofsuig.)	□ Ja □ Nee (3)	□ Ja □ Nee
3.3	**Word hulp noodsaaklik benodig om na die huishoudlike uitgawes om te sien?**	□ Ja □ Nee (3)	□ Ja □ Nee
3.4	**Word hulp noodsaaklik benodig om plaaslik te reis?** (Pasiënte mag bestuur of van openbare vervoer gebruik maak. Die vermoë om 'n taxi te gebruik is voldoende, op voorwaarde dat die persoon self die taxi kan ontbied en self die taxibestuurder opdragte kan gee.)	□ Ja □ Nee (3)	□ Ja □ Nee
3.5	**Word hulp noodsaaklik benodig om plaaslike inkopies te doen?** (Daaglikse inkopies: koop ten minste 'n enkele item)	□ Ja □ Nee (3)	□ Ja □ Nee

Onderhoud

4. GEWONE TAKE EN AKTIWITEITE

Die volgende vrae het betrekking tot hoe die pasiënt gewoonlik sy/haar dag spandeer.

4.1 Werk

4.1.1	**Voor die beroerte, het die persoon gewerk, of het die persoon werk gesoek (of studeer)?** □ Ja □ Nee (In die geval dat die persoon nie gewerk het nie, of nie werk gesoek het nie, of afgetree was voor die beroerte aanval, antwoord asseblief "Nee" en gaan na vraag 4.2)
4.1.2	**Na die beroerte aanval, was daar 'n verandering in die persoon se vermoë om te werk of studeer?** □ Ja □ Nee ('n Verandering in die vermoë om te werk of te studeer sluit in die verlies van werk of 'n vermindering in verantwoordelikhede by die werk; verandering in leervermoë of onvermoë om te studeer.) **As die antwoord "Ja" is, in hoe 'n mate is die persoon beperk?** Verandering in tydsduur van werk, bv. van voltydse werk na deeltydse, of 'n verlaging van die vlak van verantwoordelikhede □ (2) Kan tans nie werk nie. □ (2)

4.2 Verantwoordelikheid vir die Familie

4.2.1	**Het die persoon voor die beroerte na sy/haar familie by die huis omgesien?** □ Ja □ Nee (As dit nie 'n belangrike rol was nie, merk "Nee" en gaan na 4.3)
4.2.2	**Sedert die beroerte, is daar 'n verandering in die persoon se vermoe om na die familie by die huis om te sien?** □ Ja □ Nee Indien "Ja", in hoe 'n mate is die persoon beperk? (a) Verminderde verantwoordlikheid van versorging van familie. □ (2) (b) Nie meer in staat om familie te versorg nie. □ (2)

4.3 Sosiale & Ontspanningsaktiwiteite

Sosiale en ontspanningsaktiwiteite sluit stokperdjies en ander belangstellings in. Dit sluit aktiwiteite by die huis en weg van die huis in. Aktiwiteite weg van die huis: uitgaan na 'n kroeg, restaurant, klub, kerk, bioskoop, vriende besoek of vir 'n wandeling gaan. Aktiwiteite by die huis (Aktiwiteite behels aktiewe deelneming): Aktiwiteite sluit in brei, stik, verf, speletjies speel, lees van boeke en verbeterings aanbring aan die woonhuis.

4.3.1	**Het die persoon voor die beroerte gereeld aan vrye tyd aktiwiteite deelgeneem?** (As die persoon min of geen sosiale- en ontspanningsaktiwiteite voor die beroerte gehad het nie, merk "Nee" en gaan na 4.4.)	□ Ja □ Nee
4.3.2	**Sedert die beroerte, is daar 'n verandering in die vermoë van die persoon om deel te neem aan hierdie aktiwteite?** Indien "Ja" in hoe 'n mate is hy / sy beperk? (a) Neem minder deel: ten minste helfte soveel as voor die beroerte. (b) Neem baie minder deel: minder as die helfte soveel. (c) Kan nie meer deelneem nie: weining, of glad nie.	□ Ja □ Nee □ □ (2) □ (2)

Onderhoud

4. <u>GEWONE PLIGTE EN AKTIWITEITE</u> .... Voorstetting.

4.4 Famille en Vriende

Probleme met verhoudings sluit probleme in verhoudings met persone tuis, verlies van vriendskappe of 'n toename in isolasie in. Veranderinge in die persoon kan die volende insluit: Kommunikasie probleme, 'n vinnige humeur, irritasie, angstigheid, onsensitiwiteit teenoor ander, buierigheid, depressie, en onredelike gedrag.

4.4.1 Sedert die beroerte aanval, het die persoon probleme met verhoudings met ander ondervind, of begin geisoleerd te raak?	□ Ja	□ Nee
Indien "Ja", wat is die omvang van die ontwrigting / spanning?		
Soms – minder as weekliks	□	
Dikwels – een keer per week of meer, maar draaglik	□ (2)	
Aanhoudend – daagliks and ondraaglik	□ (2)	
4.4.2 Was daar soortgelyke probleme voor die beroerte	□ Ja	□ Nee

5. <u>SIMPTOME AS GEVOLG VAN DIE BEROERTE</u>

Dit kan simptome of probleme wees wat deur die pasiënt gerapporteer is, of wat ontdek is tydens 'n neurologiese ondersoek.

5.1	**Het die pasiënt enige simptome wat die gevolg is van die beroerte?** (Skryf spontane antwoord op die vraag deur die respondent neer).	□ Ja (1)	□ Nee		
5.2	SIMTOME OORSIGLYS	**Nou**		**Voor Beroerte**	
5.2.1	**Vind die persoon dit moelik om te lees en skryf?**	□ Ja (1)	□ Nee	□ Ja	□ Nee

5.2.2	**Vind die persoon dit moeilik om te praat of die regte word te**	□ Ja □ Nee (1)	□ Ja □ Nee
5.2.3	**Ondervind die persoon probleme met balans of koördinasie?**	□ Ja □ Nee (1)	□ Ja □ Nee
5.2.4	**Het die persoon visuele probleme?**	□ Ja □ Nee (1)	□ Ja □ Nee
5.2.5	**Het die persoon 'n dooie gevoel (gesig, arms, bene, hande, voete)?**	□ Ja □ Nee (1)	□ Ja □ Nee
5.2.6	**Het die persoon die gebruik van beweging verloor (gesig, arms, bene, hande, voete)?**	□ Ja □ Nee (1)	□ Ja □ Nee
5.2.7	**Vind die persoon dit moeilik om te sluk?**	□ Ja □ Nee (1)	□ Ja □ Nee
5.2.8	**Enige ander simptome?** (Teken aan asb. ....)	□ Ja □ Nee (1)	□ Ja □ Nee

Klasifiseeringsgraad = ☐

MODIFIED RANKIN SCALE

Xhosa Version

Udliwano-ndlebe

Nceda ufake olu phawu (X) kwibhokisi efanelekileyo. Uyacelwa ukuba ubhale iimpendulo zayo yonke imibuzo (ngaphandle kokuba uyalelwe ukuba ungakwenzi oko), kuquka nezo zimalunga nesimo somguli phambi kokuba ahlaselwe si-stroke. Jonga izikhokhelo kwiphepha elingaphambili ukufumana ulwazi oluthe vetshe.

1	**UNCEDO LWAMAXESHA ONKE**		
	Uncedo lwamihla yonke luthetha ukuba ubani kufuneka abekho ngamaxesha onke. Uncedo lunganikezelwa ngumntu oqeqeshiweyo okanye ongaqeqeshwanga ojangana nomguli. Umguli uya kusoloko elele ebhedini, aze akholise ukuba ngumntu ongakwaziyo ukuzibamba okanye ukuzilawula.	**Ngoku**	**Phambi kokuba abe ne-stroke**
1.1	**Ingaba lo mntu ufuna uncedo lwamihla yonke?**	□Ewe □Hayi (5)	□ Ewe □ Hayi

2	**UNCEDO LOKUJONGANA NEEMFUNO ZOMZIMBA/UKUHAMBA**		
	Uncedo luquka uncedo ngokwasemzimbeni, imiyalelo ngokomlomo okanye ukujongwa ngomnye umntu.	**Ngoku**	**Phambi kokuba abe ne-stroke**
2.1	**Ingaba uyalufuna uncedo ukuze atye?** (Utya ngaphandle kokuncediswa: ukutya nezixhobo zokutya angaziphathelwa ngabanye abantu).	□ Ewe □Hayi (4)	□ Ewe □ Hayi
2.2	**Ingaba ufuna ukuncediswa ukusebenzisa igumbi langasese?** (Usebenzisa igumbi langasese ngaphandle kokuncediswa: uyafikelela kwindawo yokuchopha; uyakwazi ukuzikhulula ngokupheleleyo; uyakwazi ukuzosula; uyazinxibisa aphume esakugqiba).	□ Ewe □Hayi (4)	□ Ewe □ Hayi
2.3	**Ingaba ufuna uncedo kwimisebenzi yamihla yonke yokujongana nococeko lwakhe?** (Ucoceko lwamihla yonke: ukuhlamba ubuso, ukukama iinwele, ukucoca amazinyo okanye ukufaka amazinyo emboleko. Angazinikwa izinto zokusebenza ngabanye abantu, yaye oko makungathatyathwa njengoncedo.)	□ Ewe □Hayi (4)	□ Ewe □ Hayi
2.4	**Ingaba ufuna uncedo ukuze ahambe?** (Uhamba ngaphandle koncedo: Uyakwazi ukuhamba-hamba ngaphakathi endlwini, ajikeleze indlu okanye ahambe apha kwigumbi lakhe lasesibhedlele, angasebenzisa nayiphi na into yokumncedisa (umzekelo. intonga/umsimelelo, intsimbi yokuncedisa ukuhamba), nangona kunjalo akafuni luncedo okanye ukuyalelwa, okanye ukunyamekelwa ngomnye umntu.)	□ Ewe □Hayi (4)	□ Ewe □ Hayi

3	**UNCEDO LOKUZIJONGELA IMICIMBI YAKHE NGOKWAKHE**		
	Uncedo luquka ukuncediswa ngokwasemzimbeni, okanye ukuyalelwa ngomlomo, okanye ukunyamekelwa ngomnye umntu.	**Ngoku**	**Phambi kwestroke**
3.1	**Ingaba ufuna ukuncediswa ukwenza isidlwana nje esiqhelekileyo?** (Umzekelo, ukukwazi ukuzenzela isidlo sakusasa okanye isidlwana esikhawulezileyo)	□ Ewe □ Hayi (3)	□ Ewe □ Hayi

3.2	**Ingaba ufuna uncedo ekwenzeni imisetyenzana yasekhaya?** (Umzekelo, ukukhangela iimpahla nokuzibuyisela endaweni yazo, ukuqoqosha emva kwesidlo. Ungabandakanyi imisebenzi engafuni kwenziwa yonke imihla, efana nokusebenzisa umatshini wokufunxa inkunkuma.)	□ Ewe □ Hayi (3)	□ Ewe □ Hayi
3.3	**Ingaba ufuna uncedo lokujongana nokusetyenziswa kwemali ekhaya?**	□ Ewe □ Hayi (3)	□ Ewe □ Hayi
3.4.	**Ingaba ufuna uncedo xa ethabatha uhambo olufutshane?** (Izigulane zingaqhuba okanye zisebenzise izithuthi zikawonke-wonke ukuya kwindawo nje ekufutshane. Ukukwazi ukusebenzisa nje iteksi kwanele, kuphela ukuba umntu angakwazi ukuyifowunela ngokwakhe aze akwazi nokunika umqhubi wayo imiyalelo.)	□ Ewe □ Hayi (3)	□ Ewe □ Hayi
3.5.	**Ingaba ufuna ukuncediswa ukuthenga kwiivenkile ezikwalapha ekuhlaleni?** (Ukuthenga kwiivenkile ezikwalapha ekuhlaleni: ubuncinane akwazi ukuthenga into ibe nye.)	□ Ewe □ Hayi (3)	□ Ewe □ Hayi

Udliwano-ndlebe

4. IMISEBENZI EQHELEKILEYO. Olu ludwe lwemibuzo lulandelayo lumalunga nendlela isigulane esichitha ngayo usuku lwaso.

4.1. Umsebenzi

4.1.1	**Phambi kokuba abe ne-stroke, ingaba lo mntu ebesebenza okanye ebesafuna umsebenzi (okanye efunda)?** □ Ewe □ Hayi Ukuba lo mntu ebengasebenzi okanye ebesafuna umsebenzi phambi kokuba abe ne-stroke, okanye ebesele ethathe umhlala-phantsi, bonisa ngo –'hayi', wandule ukuya ku-4.2)
4.1.2	**Ukuhlaselwa kwakhe si-stroke, ingaba kwabakho utshintsho ekukwazini kwakhe ukusebenza okanye ukufunda?** □ Ewe □Hayi (utshintsho ekukwazini ukusebenza okanye ukufunda kuquka ukulahlekelwa ngumsebenzi okanye ukuthotywa kwezinga lomsebenzi ebekade ewenza; utshintsho emfundweni okanye iingxaki malunga nokufunda). **Ukuba impendulo ngu-'ewe', ingaba oku kumbophelele kangakanani?** Kuthotywe umgangatho womsebenzi umz. Ususwe ekubeni ngumsebenzi osisigxina wenziwa umsebenzi wethutyana/ongxungxileyo, okanye utshintsho kumgangatho wesikhundla ebesibambile. □ (2) Akakwazi ukusebenza kungokunje □ (2)

4.2. Imisebenzi yakhe elusatsheni lwakhe

4.2.1	**Phambi kwe-stroke, ingaba lo mntu ebelujongile kusini na usapho lwakhe ekhaya?** □ Ewe □ Hayi (Ukuba oku yayingenguwona msebenzi wakhe ekhaya phambi kokuba abe ne-stroke, bonisa ngo-'hayi' wandule ukuya ku-4.3)
4.2.2	**Emva kokuhlaselwa kwakhe si-stroke, ingaba lube kho utshintsho kwindlela athe walukhathalela ngayo usapho lwakhe?** □ Ewe □ Hayi Ukuba impendulo ngu-'ewe', ingaba ubambeke njani ukuba angakwazi? (a) Kuthotywe izinga lomsebenzi wokujongana nosapho. □ (2) (b) Kungokunje akakwazi ukujongana nosapho. □ (2)

4.3. Ezentlalo nolonwabo

Ezentlalo nezolonwabo ziquka izinto umntu aziqhelisa ukuzonwabisa ngazo, kwanezo zinomtsalane kuye. Ziquka imisebenzi ngaphandle okanye ngaphakathi ekhayeni lakhe. Imisebenzi yangaphandle kwekhaya: ukuya kwindawo yentselo/ebharini, erestyu, embuthweni, ecaweni, kwimiboniso bhanya-bhanya, ukundwendwela abahlobo, nokuthabatha uhambo lokolula nje imilenze. Imisebenzi yasekhaya: iquka ukuzibandakanya ngqo, okufana nokunitha, ukuthunga, ukwenza imizobo, imidlalo, ukufunda iincwadi, nokuphucula ikhaya).

4.3.1	**Phambi kokuba afunyanwe si-stroke, ingaba lo mntu ebekholisa ukuyenza imisetyenzana ayenza ngexesha lokuzipholela?** □ Ewe □ Hayi (Ukuba lo mntu ebenemisebenzi embalwa yokuzonwabisa phambi kokuba ahlaselwe si-stroke, bonisa ngo- 'hayi', wandule ukuya ku-4.4
4.3.2	**Emva kokuba efunyenwe si-stroke, ingaba kubekho utshintsho ekubeni akwazi ukuthabatha inxaxheba kule misebenzi** □ Ewe □ Hayi Ukuba impendulo ngu-'ewe', uye wathinteleka njani? (a) Uthabatha inxaxheba ngaphantsi kunesiqhelo: ubuncinane kangangesiqingatha kunokuba ebeqhele ukwenza phambi kokuba ahlaselwe si-stroke. □ (2) (b) Uthabatha inxaxheba kancinane kakhulu: ngaphantsi kunesiqingatha kunesiqhelo. □ (2) (c) Akakwazi ukuthabatha inxaxheba: ukwenza manqapha-nqapha oko, ukuba uthe wakwenza. □ (2)

Udliwano-ndlebe

<u>**4. IMISEBENZI YESIQHELO.**</u> ....isaqhuba.

4.4 Usapho nobuhlobo
(Iingxaki malunga nobuhlobo ziquka iingxaki kunxulumano nabanye abantu apha ekhaya, ukulahlekelwa ngabahlobo okanye ukwanda kobulolo (ukuba likheswa okanye ube wedwa). Iinguqu emntwini zingabandakanya: iingxaki zonxibelelwano, ukukhawulezelwa ngumsindo, ukucaphukisa, inkxalabo ukungabacingeli abanye, ukuhlala engatyhilekanga, ukudakumba, kwanendlela engamkelekanga yokuziphatha).

4.4.1 Emva kokuba ethe wahlaselwa si-stroke ingaba lo mntu ukhe waneengxaki zonxulumano nabanye abantu, okanye wazibona eyedwa? □ Ewe □ Hayi Ukuba impendulo ngu-'ewe', oku kumonakalise okanye kumphazamise kangakanani? Ngamathuba athile – ngaphantsi kweveki nganye □ (2) Amathuba amaninzi – kanye ngeveki okanye nangaphezulu, kodwa enyamezeleka □ (2) Ngalo lonke ixesha – yonke imihla yaye akanyamezeleki □ (2)
4.4.2 Phambi kokuba ahlaselwe si-stroke, zazikho iingxaki ezifana nezi? □ Ewe □ Hayi

5. **IIMPAWU EZISISIPHUMO SE-STROKE**
(Isenokuba zizo naziphi iimpawu okanye iingxaki ezichazwe ngumguli okanye ezifunyenwe kuvavanyo lwengqondo).

5.1	**"Ingaba umguli unazo iimpawu ze-stroke?** □ Ewe □ Hayi (Bhala phantsi zonke iimpendulo ezingacingisiswanga/ezizenzekelayo kulo mbuzo ezivela kulowo uphendulayo. (1)		
5.2	**ULUDWE LOKUJONGA IIMPAWU**	**Ngoku**	**Phambi kwe-stroke**
5.2.1	**Ingaba lo mntu unengxaki yokufunda okanye ukubhala?**	□ Ewe □ Hayi (1)	□ Ewe □ Hayi
5.2.2	**Ingaba lo mntu unengxaki yokuthetha okanye ukufumana igama elililo?**	□ Ewe □ Hayi (1)	□ Ewe □ Hayi
5.2.3	**Ingaba lo mntu unengxaki yokuzimela okanye ukuxhathisa?**	□ Ewe □ Hayi (1)	□ Ewe □ Hayi
5.2.4	**Ingaba lo mntu unengxaki yokubona?**	□ Ewe □ Hayi (1)	□ Ewe □ Hayi
5.2.5	**Ingaba lo mntu ukhathazwa bubundindisholo (bobuso, beengalo, bemilenze, bezandla, beenyawo)?**	□ Ewe □ Hayi (1)	□ Ewe □ Hayi
5.2.6	**Ingaba lomntu ukhe akakwazi ukushukumisa (ubuso, iingalo, imilenze, iinyawo)?**	□ Ewe □ Hayi (1)	□ Ewe □ Hayi
5.2.7	**Ingaba lomntu unengxaki yokuginya?**	□ Ewe □ Hayi (1)	□ Ewe □ Hayi
5.2.8	**Ingaba zikho ezinye iimpawu?** (Nceda uzibhale : ....)	□ Ewe □ Hayi (1)	□ Ewe □ Hayi

Uhlelo ngokodidi =

APPENDIX XX EQ-5D

EQ - 5D

Health Questionnaire

South African English version

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

Mobility

I have no problems in walking about	❑
I have some problems in walking about	❑
I am confined to bed	❑

Self-Care

I have no problems with self-care	❑
I have some problems washing or dressing myself	❑
I am unable to wash or dress myself	❑

Usual Activities *(e.g. work, study, housework, family or leisure activities)*

I have no problems with performing my usual activities	❑
I have some problems with performing my usual activities	❑
I am unable to perform my usual activities	❑

Pain/Discomfort

I have no pain or discomfort	❑
I have moderate pain or discomfort	❑
I have extreme pain or discomfort	❑

Anxiety/Depression

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

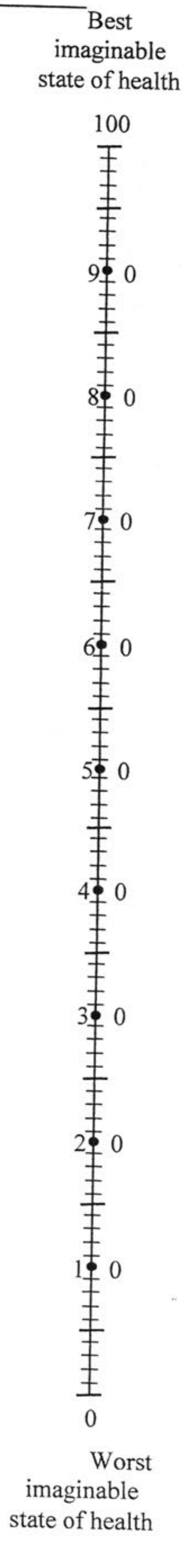
Compared with my general
level of health over the past 12 months,
my state of health today is:

Better	❑	PLEASE TICK
Much the same	❑	ONE
Worse	❑	BOX

To help people say how good or bad their state of health is, we have drawn a scale on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale, in your opinion, how good or bad your own health is today. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your state of health is today.

Your own state of health today



EQ - 5D

Gesondheidsvraelys

Afrikaanse veergawe
(Afrikaans version)

Dui asseblief aan watter stellings u eie gesondheidstoestand vandag die beste beskryf deur 'n regmerkie in een blokkie by elkeen van die onderstaande groepe te maak.

Beweeglikheid

Ek het geen probleme om rond te loop nie ☐

Ek het sommige probleme om rond te loop ☐

Ek is beperk tot die bed ☐

Selfversorging

Ek het geen probleme om myself te versorg nie ☐

Ek het sommige probleme om myself te was of aan te trek ☐

Ek is nie in staat om myself te was of aan te trek nie ☐

Gewone Aktiwiteite (*bv. werk, studeer, huiswerk, familie- of ontspanningsaktiwiteite*)

Ek het geen probleme om my gewone aktiwiteite uit te voer nie ☐

Ek het sommige probleme om my gewone aktiwiteite uit te voer ☐

Ek is nie in staat om my gewone aktiwiteite uit te voer nie ☐

Pyn/ Ongemak

Ek het geen pyn of ongemak nie ☐

Ek het matige pyn of ongemak ☐

Ek het uiterste pyn of ongemak ☐

Angstigheid/ Neerslagtigheid

Ek is nie angstig of neerslagtig nie ☐

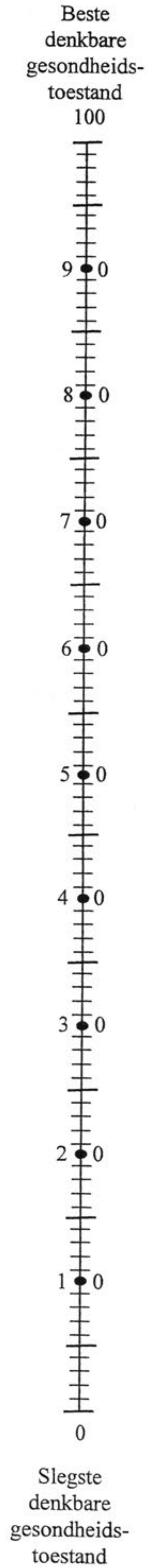
Ek is matig angstig of neerslagtig ☐

Ek is uiters angstig of neerslagtig ☐

Om mense te help om te sê hoe goed of sleg hul gesondheidstoestand is, het ons 'n skaal (baie soos 'n termometer) geteken waarop die beste gesondheidstoestand wat u u kan verbeel, gemerk is met 100 en die slegste gesondheidstoestand wat u u kan verbeel, gemerk is met 0.

Ons wil graag hê dat u op hierdie skaal aandui hoe goed of sleg u eie gesondheid vandag na u mening is. Doen dit asseblief deur 'n streep te trek vanaf die blokkie hieronder (waar dit sê: "u eie gesondheidstoestand vandag") tot by enige punt op die skaal wat aandui hoe goed of sleg u gesondheidstoestand vandag is.

U eie gesondheidstoestand vandag



EQ - 5D

Iphepha lemibuzo ngezempilo

(Inguqulelo yesiXhosa saseMzantsi Afrika)

Beka uphawu kwibhokisi ibenye kwiqela ngalinye echaza imeko yempilo yakho namhlanje, kwezi bhokisi zilandelayo.

Musa ukuphawula ngaphezulu kwebhokisi enye kwiqela ngalinye.

Ukuhamba

Andinangxaki zokuhamba ❑

Ndinazo ingxakana zokuhamba ❑

Ndingumlwelwe obopheleleke ebhedini ❑

Ukuzinonophela isiqu

Andinangxaki zokuzinonophela ❑

Ndinazo ingxakana zokuhlamba okanye ukuzinxibisa ❑

Andikwazi ukuzihlamba okanye ukuzinxibisa ❑

Izinto zesiqhelo (Umsebenzi, Ukufunda izifundo Umsebenzi wasekhaya, Usapho, Ezolonwabo)

Andinangxaki nokuzenzela izinto zesiqhelo ❑

Ndinazo iingxakana zokuzenzela izinto zesiqhelo ❑

Andikwazi kuzenzela izinto zesiqhelo ❑

Iintlungu / Ukungaziva kakuhle

Andinazintlungu okanye ukungaziva kakuhle ❑

Ndinentlungwana okanye ukungaziva kakuhle okungephi ❑

Ndinentlungu ezigqithileyo okanye ukungaziva kakuhle okugqithileyo ❑

Ukuxhalaba / Ukudakumba

Andinaxhala okanye andidakumbanga ❑

Ndibuxhalaba okanye ndibudakumba ❑

Ndixhalabe gqitha okanye ndidakumbe gqitha ❑

Xa ndithelekisa umgangatho wobunjani bempilo yam jikelele kwezi nyanga zili-12 zidlulileyo imeko yempilo yam namhlanje:

Ingcono ❑

Ibufana ❑

Imandundu ❑

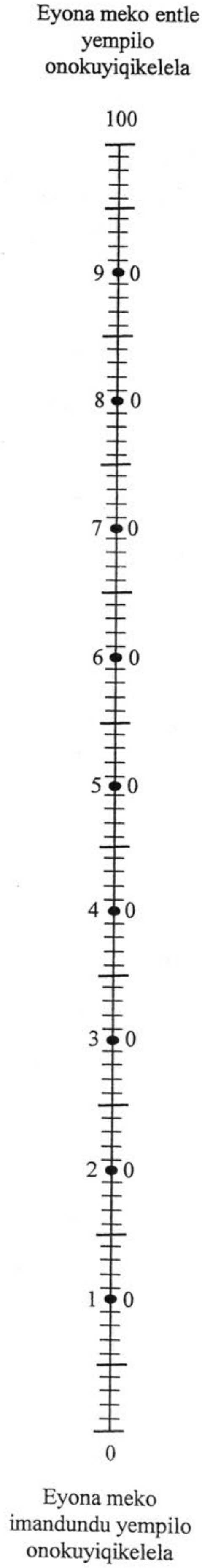
Phawula ibhokisana efanelekileyo

Ukunceda abantu ukuze baxele okokuba imeko yabo yempilo intle okanye imandundu na sizobe isikali (esifana nethemometha). Eyona meko entle yempilo iphawulwe ngo-100, eyona meko imandundu iphawulwe ngo-0.

Singathanda ubonise kwesi sikali ngokoluvo lwakho ukuba impilo yakho intle okanye imandundu kangakanani namhlanje.

Nceda wenze oku ngokuzoba umgca osuka ebhokisini engezantsi ukuya kulo ndawo esikalini ibonisa ukuba imeko yempilo yakho intle okanye imbi kangakanani namhlanje.

Imeko yempilo yakho namhlanje



APPENDIX XXI CAREGIVER STRAIN INDEX

A Caregiver Strain Index

I am going to read a list of things which other people have found to be difficult in helping with. Would you please tell me whether any of these apply to you?

Score: 0= No/ 1= Yes

	Score
1. Sleep is disturbed (e.g. because person X is in and out bed or wanders around at night).	
2. It is inconvenient (e.g. because helping takes so much time or it's a long drive over to help).	
3. It is a physical strain (e.g. because of lifting in and out of a chair; effort or concentration is required).	
4. It is confining (e.g. helping restricts free time, or cannot go visiting).	
5. There have been family adjustments (e.g. because helping has disrupted routine; there has been no privacy)	
6. There have been changes in personal plans (e.g. had to turn down a job; could not go on vacation).	
7. There have been other demands on my time (e.g. from other family members).	
8. There have been emotional adjustment (e.g. because of severe argument).	
9. Some behavior is upsetting (e.g. because of incontinence; person X has trouble remembering things;or person X accuses people of taking things).	
10. It is upsetting to find person X has changed so much from his/ her former self (e.g. he/she is a different person than he/she used to be).	
11. There have been work adjustments (e.g. because of having to take time off).	

12. It is a financial strain.

13. Feeling completely overwhelmed
(e.g. because of worry about person X; concerns about how you will manage).

Relation to the patient:
1 partner
2 relative
3 close friend
4 neighbour
5 other
If the answer is '5', please specify.

TOTAL

CAREGIVER STRAIN INDEX

Afrikaans Version

(A Caregiver Strain Index)

A. VERSORGER SPANNINGSINDEKS

Ek gaan 'n lys voorlees van dinge waarmee ander mense dit moeilik gevind het om iemand te help wat uit die hospital ontslaan is. Dui asseblief aan of dit van toepassing is op jou

Punte: 0 = Nee / 1= Ja

1. **Slaap word versteur.** (bv. omdat persoon X rusteloos is en in die nag rondwandel.) ☐
2. **Dit is ongerieflik.** (bv. om te help neem baie van my tyd of dit is ver om te gaan om hulp te verleen.) ☐
3. **Dit is fisies inspannend.** (bv. omdat die persoon in en uit 'n stoel opgelig moet word, inspanning of konsentrasie word vereis.) ☐
4. **Ek voel beperk.** (bv. daar is 'n tekort aan vrye tyd, of kan nie gaan kuier nie.) ☐
5. **Die familie moes aanpassings maak.** (bv. omdat die gewone roetine versteur is; daar is geen privaatheid nie) ☐
6. **Ek moes my persoonlike planne verander.** (bv. moes 'n werksaanbod weier; kon nie met vakansie gaan nie.) ☐
7. **Daar is ander eise op my tyd.** (bv. van ander familielede.) ☐
8. **Emosionele aanpassings is gemaak.** (bv. as gevolg van ernstige argumente.) ☐
9. **Sekere gedrag is ontstellend.** (bv. as gevolg van inkontinensie; persoon X ly aan geheueverlies; of persoon X beweer dat ander mense van hom/haar steel.) ☐
10. **Dit is ontstellend dat persoon X so baie verander het.** (bv. hy/sy is 'n verskillende persoon as wat hy/sy eers was.) ☐
11. **Werkaanpassings is gemaak.** (bv. Ek moes tyd by die werk afneem.) ☐
12. **Dit plaas my onder finansiële druk.** ☐
13. **Ek voel heeltemal oorweldig.** (bv. bekommernis oor persoon X; besorgdheid oor hoe ek gaan byhou met alles ☐

Verwantskap aan die pasiënt:

1 eggenoot/eggenote
2 familielid
3 goeie vriend/vriendin
4 buurman of –vrou
5 ander

As u antwoord 5 is, gee asseblief besonderhede:

CAREGIVER STRAIN INDEX

Xhosa Version

ISalathiso sokubulaleka kwabo bagcina bekwajongene nabaguli

Ndiza kufunda uludwe lwezinto abantu abafumanise kunzima ukunika ngazo uncedo.
Ndicela undixelele ukuba zikhona na ezikuchaphazelayo wena.

Amanqaku: 0= Hayi / 1= Ewe

1. Ubuthongo buyaphazamiseka
(umz. kuba lo mntu ungena ephuma ebhedini okanye uhla esenyuka ebusuku.)

2. Kuyaxakekisa
(umz. kuba ukunceda kuthabatha ixesha elide okanye mde umgama owuhambayo ngemoto ukuya kunika uncedo).

3. Kuyawuduba umzimba
(umz. Ngenxa yokumfunqula, umphakamisa uphinde umbeke esitulweni; yimigudu efuna inyameko.

4. Kuyabophelela
(umz. umntu onika uncedo akabinalo ixesha lokuziphumza, okanye akanalo ithuba lokutyelela abanye abantu).

5. Kubekho iinguqu elusatsheni
(umz. kuba uncedo luphazamise indlela izinto ebeziqhele ukwenzeka ngayo; akusekho mfihlelo)

6. Kube kho utshintsho kwizicwangciso
(umz. kuye kwafuneka ukuba ale umsebenzi; akakwazanga ukuthabatha ikhefu emsebenzini).

7. Kube kho ezinye izinto ekuye kwafuneka ndizenze ngexesha elilelam
(umz. ndisenzela amanye amalungu osapho).

8. Kube kho utshintsho kuvakalelo
(umz. ngenxa yeengxoxo ezinzulu).

9. Ezinye iindlela zokuziphatha ziyakhubekisa
(umz. ngenxa yokuzenzela okanye ashiywe ngumchamo; umntu lowo unengxaki yokungazikhumbuli izinto; okanye utyhola abanye abantu ngokuba bathatha izinto zakhe).

10. Kuyakhubekisa ukufumanisa ukuba lo mntu utshintshe mpela kunomntu ebekade enguye).
(umz. ungomnye umntu kunalo ebekade enguye).

11. Kube kho utshintsho emsebenzini
(umz. ngenxa yokuba kufuneke athabathe ixesha angayi emsebenzini).

12. Bubunzima ngokwasezimalini.

13. Uziva woyisakele ngokupheleleyo
(umz. ngenxa yokuzikhathaza ngalo mntu; ukucinga ngendlela oza kumelana ngayo nale meko).

Ukuzalana/unxulumano nomguli:
1 iqabane
2 isizalwane
3 umhlobo osenyongweni
4 ummelwane
5 omnye umntu nje
Ukuba impendulo ngu-'5', nceda ucacise.

Amanqaku ewonke

OTHER

APPENDIX XXII ETHICS PERMISSION

ETHICS PERMISSION

UNIVERSITY OF CAPE TOWN

Research Ethics Committee
E53 Room 44.1, Old Main Building
Groote Schuur Hospital, Observatory,
7925
Queries : Xolile Fula
Tel : (021) 406-6492 Fax: 406-6411
E-mail : Xfula@curie.uct.ac.za

26 January 2005

REC REF: 405/2004

Ms SF Ritchie
P O Box 578
Milnerton
7435

Dear Ms Ritchie

PATTERN OF RECOVERY AND OUTCOME AFTER STROKE IN PATIENTS ACCESSING A WESTERN CAPE REHABILITATION CENTRE

Thank you for submitting your study to the Research Ethics Committee for review.

It is a pleasure to inform you that the Ethics Committee has formally approved the above-mentioned study on the 24 January 2005.

Thank you for your letter of response to the issues raised by the Committee.

I would like to comment that the responses were presented in a difficult manner to clarify the issues and made evaluation of the study approval difficult due to complexity of presentation to the questions raised.

Please quote the REC. REF in all your correspondence

Yours sincerely

PROF T. ZABOW
CHAIRPERSON

APPENDIX XXIII CONSENT FORMS

ENGLISH CONSENT FORMS

PATTERN OF RECOVERY AND OUTCOME AFTER STROKE IN PATIENTS ACCESSING A WESTERN CAPE REHABILITATION CENTRE

INFORMATION SHEET FOR PATIENTS PARTICIPATING IN THE STUDY

My name is Susan Rouillard. I am a physiotherapist and am completing a masters degree at the University of Cape Town. I am in the process of carrying out a study into the pattern of recovery and outcome after stroke in patients admitted to the Western Cape Rehabilitation Centre. The purpose of the study is to identify characteristics of stroke patients and factors that might influence how well they recover after their stroke. It is hoped that this information will assist in identifying the needs of stroke patients whilst they are undergoing rehabilitation and after they have been discharged in order to improve patient care.

If you agree to take part in this study, you would be assessed by a researcher on three occasions.

1. In the first few days after your admission at the Rehabilitation Centre. This assessment would take approximately one and a quarter hours of your time.

2. A few days before you are discharged at the Rehabilitation Centre. This assessment would take approximately one and a half hours of your time.

3. Six months after your stroke you would be assessed at the Western Cape Rehabilitation Centre, a local Community Health Care Centre or equivalent, or at your home. (If travel were required, your transport would be paid by the research project.) This assessment would take approximately two hours of your time.

Assessments will involve some simple physical tests to evaluate how the stroke has affected you. You will also be asked questions about your health and abilities prior to your stroke, and your ability to function and participate in activities since having your stroke. You will be asked about the place where you live, your daily activities and factors that may make it easier or more difficult to manage. You will also be asked about income, education and work. Nursing staff and medical staff may be asked for additional information. If you are unable to answer all the questions due to your stroke, family members or relatives may be asked to help. Your main caregiver would also be asked questions about how they manage in looking after you.

You would be free to withdraw from the study at any stage without giving a reason, and without your medical care being affected as a result. You would be free to choose not to answer any of the questions or perform any of the tests should you wish not to do so. All information would be used only for the purposes of the research and will not be disclosed to anybody beyond the study. You will be given a code number, and all collected information will be stored under a code, rather than your name. All information will be anonymous and you will not be personally identified in any publication containing the results of this study. The coded information may be made available to a stroke study that is underway in Belgium so that differences in stroke outcome in South Africa and Europe can be compared.

If you require any further information about the study or if you experience any problems as a result of the study, please contact me on (Tel.) 552 7731 or (c) 0721 263 867.

PATTERN OF RECOVERY AND OUTCOME AFTER STROKE IN PATIENTS ACCESSING A WESTERN CAPE REHABILITATION CENTRE

CONSENT FORM FOR PATIENTS PARTICIPATING IN THE STUDY

Please mark the correct response.

1. Have you read the information sheet or had its contents explained to you?	YES	NO
2. Have you had an opportunity to ask questions about the study and have all your questions been answered to your satisfaction?	YES	NO
3. Do you understand the reason for the study?	YES	NO
4. Do you understand that you are free to withdraw from the study at any point and without giving a reason?	YES	NO
5. Do you agree to the researcher having access to your medical records and obtaining information from medical staff?	YES	NO
6. Do you agree to the researcher approaching family members or caregivers for information?	YES	NO
7. Do you agree to take part in the study?	YES	NO

NAME OF PATIENT: ______________________________

SIGNED: ______________________ DATE: ______________________

NAME OF RESEARCHER: ______________________________

SIGNED: ______________________ DATE: ______________________

IN THE EVENT OF THE PATIENT BEING UNABLE TO GIVE INFORMED CONSENT DUE TO DIFFICULTIES WITH UNDERSTANDING, PLEASE INDICATE DETAILS OF FAMILY MEMBER GIVING CONSENT BELOW.

NAME: ______________________________

SIGNED: ______________________ DATE: ______________________

RELATIONSHIP TO PATIENT: ______________________________

PATTERN OF RECOVERY AND OUTCOME AFTER STROKE IN PATIENTS ACCESSING A WESTERN CAPE REHABILITATION CENTRE

INFORMATION SHEET FOR CAREGIVERS PARTICIPATING IN THE STUDY

My name is Susan Rouillard. I am a physiotherapist and am completing a masters degree at the University of Cape Town. I am in the process of carrying out a study into the pattern of recovery and outcome after stroke in patients admitted to the Western Cape Rehabilitation Centre. The purpose of the study is to identify characteristics of stroke patients and factors that might influence how well they recover after their stroke. It is hoped that this information will assist in identifying the needs of stroke patients whilst they are undergoing rehabilitation and after they have been discharged in order to improve patient care. One of the aspects that is being investigated is the strain experienced by people who care for stroke survivors.

_________________________ has agreed to take part in the study and will be assessed by researchers soon after admission to the Rehabilitation Centre, before discharge from the Rehabilitation Centre and again at 6 months after their stroke. This final assessment will be performed at the participant's home, a local Community Health Care Centre or at the Western Cape Rehabilitation Centre, if he/she is willing to travel. (Travel costs will be paid.)

_________________________ has indicated that you are his/her main carer. If you agree to take part in the study, you would be asked to answer questions about the impact that caring for him/ her is having on your life. This is a short questionnaire that would only take about 10 to 15 minutes. The questions could be answered by filling in a paper questionnaire, verbally over the telephone, or face to face in an interview. The interview would be held at the participant's home, a local Community Health Care Centre or equivalent, or at the Western Cape Rehabilitation Centre. Travel costs incurred to attend the interview will be paid.

Every effort will be made to ensure you are not interviewed in the presence of _________________.
You would be free to withdraw from the study at any stage without giving a reason, and without the medical care of him/ her or your standing as caregiver being affected as a result. You would be free to choose not to answer any of the questions should you wish not to do so. All information would only be for the purposes of the research and will not be disclosed to anybody beyond the study. All information will be anonymous and you will not be personally identified in any publication containing the results of this study. The coded information may be made available to a stroke study that is underway in Belgium so that differences in stroke outcome in South Africa and Europe can be compared.

If you require any further information about the study or if you experience any problems as a result of the study, please contact me on (Tel.) 552 7731 or (c) 0721 263 867.

PATTERN OF RECOVERY AND OUTCOME AFTER STROKE IN PATIENTS ACCESSING A WESTERN CAPE REHABILITATION CENTRE

CONSENT FORM FOR CAREGIVERS PARTICIPATING IN THE STUDY

Please mark the correct response.

1. Have you read the information sheet or had its contents explained to you?	YES	NO
2. Have you had an opportunity to ask questions about the study and have all your questions been answered to your satisfaction?	YES	NO
3. Do you understand the reason for the study?	YES	NO
4. Do you understand that you are free to withdraw from the study at any point and without giving a reason?	YES	NO
5. Do you agree to take part in the study?	YES	NO

NAME OF CAREGIVER: ______________________________

SIGNED: ______________________ DATE: ______________________

NAME OF PATIENT FOR WHOM HE/ SHE IS THE CAREGIVER: ______________________

RELATIONSHIP TO PATIENT: ______________________________

NAME OF RESEARCHER: ______________________________

SIGNED: ______________________ DATE: ______________________

AFRIKAANS CONSENT FORMS

PATRONE VAN HERSTELLING EN NAGEVOLGE IN BEROERTE PASIËNTE WAT TOEGANG HET TOT 'N WESKAAPSE REHABILITASIESENTRUM

INFORMASIEBLAD VIR PASIËNTE WAT IN DIE STUDIE DEELNEEM

My naam is Susan Rouillard. Ek is 'n fisioterapeet en voltooi tans 'n Meestersgraad te Universiteit van Kaapstad. Ek bestudeer tans die patrone van herstelling en nagevolge van 'n beroerte in pasiente opgeneem in die Weskaapse Rehabilitasie Sentrum. Die doeleindes van die studie is om die karaktertrekke van beroerte pasiënte te identifiseer en die faktore wat die herstelling van pasiënte beïnvloed. Die verwagting is dat hierdie informasie sal bydra tot die identifiseering van die behoeftes van beroerte pasiënte terwyl hulle rehabilitasie ondergaan and nadat hulle ontslaan word, met die doel om pasiëntesorg te verbeter.

As u saamstem om in die studie deel te neem, sal u op drie geleenthede deur die navorser ondersoek word.

1. Binne die eerste paar dae na u toelating by die Rehabilitasiesentrum. Die ondersoek sal omtrent een en 'n kwart ure van u tyd neem.

2. 'n Paar dae voordat u ontslaan word van die Rehabilitasiesentrum. Die ondersoek sal omtrent een en 'n half ure van u tyd neem.

3. Ses maande na u beroerte sal u by die Weskaapse Rehabilitasiesentrum, 'n Gemeenskapsgesondheidssentrum, of gelyke, ondersoek word, of by u woning. (As vervoer nodig is, sal dit deur die navorsingsprojek betaal word.) Die ondersoek sal omtrent twee ure van u tyd neem.

'n Ondersoek behels eenvoudige fisiese toetse wat evalueer hoe die beroerte u affekteer het. U sal ook vrae beantwoord oor u gesondheid en u geskiktheid voor u beroerte, en u vermoë om te funksioneer en aan aktiwiteite deel te neem na u beroerte. U sal gevra word oor u blyplek, u daaglikse aktiwiteite en faktore wat dit makliker of moeiliker maak om oor die weg te kom. U sal ook gevra word oor u inkomste, opvoeding en werk. Verpleegpersoneel en mediese personeel mag gevra word vir aanvullende informasie. As u nie in staat is om al die vrae te beantwoord nie as gevolg van u beroerte, mag familielede gevra word om te help. U primêre versorger sal ook vrae gevra word oor hoe hulle u versorg.

U sal vry wees om op enige stadium van die studie te onttrek sonder om 'n rede te verskaf, en sonder dat u mediese sorg as a gevolg daarvan geaffekteer sal word. U sal vry wees om te kies om enige van die vrae nie te antwoord nie, of enige van die toetse nie deur te gaan as u nie wil nie. Alle informasie sal net vir die doeleindes van hierdie studie gebruik word, en sal nie aan enigeen buite hierdie studie onthul word nie. 'n Kode sal aan u gegee word, en alle informasie sal onder 'n kode, nie u naam, gestoor word. Alle informasie is anoniem and u sal nie persoonlik geidentifiseer word in enige publikasie waarin die resultate gepubliseer word nie. Die gekodeerde informasie mag wel met 'n beroerte studie in Belgieë meegedeel word so dat die verskille in beroerte nagevolge in Suid Afrika en Europa vergelyk kan word.

As u enige addisionele inligting oor die studie nodig kry, of as u enige probleme teekom as gevolg van die studie, skakel my asseblief telefonies by 021 5527731 of 072 1263 867.

PATRONE VAN HERSTELLING EN NAGEVOLGE IN BEROERTE PASIËNTE WAT TOEGANG HET TOT 'N WESKAAPSE REHABILITASIESENTRUM

TOESTEMMINGSVORM VIR PASIËNTE WAT IN DIE STUDIE DEELNEEM

Merk asseblief die korrekte respons:

1. Het u die informasieblad gelees, of is die inhoud daarvan aan u verduidelik?	JA	NEE
2. Was u die geleentheid gebied om vrae te vra oor die studie, en was al u vrae bevredigend beantwoord?	JA	NEE
3. Verstaan u die redes vir die studie?	JA	NEE
4. Verstaan u dat u vry is om op enige stadium van die studie te onttrek?	JA	NEE
5. Gee u toestemming dat die navorser toegang het tot u mediese afskrifte en mag informasie van die mediese personeel verkry word?	JA	NEE
6. Gee u toestemming dat die navorser in verbinding tree met familie-lede of versorgers vir informasie?	JA	NEE
7. Stem u saam om deel te neem in die studie?	JA	NEE

Naam van Pasient: ______________________________

Handtekening: ____________________ Datum: ____________________

Naam van Navorser: ______________________________

Handtekening: ____________________ Datum: ____________________

IN DIE GEVAL DAT DIE PASIËNT NIE IN SKIK IS OM DIE NODIGE TOESTEMMING TE KAN GEE NIE OMDAT SY/HY DIT MOEILIK VIND OM DIT TE VERSTAAN, GEE ASSEBLIEF BESONDERHEDE VAN 'n FAMILIELID WAT TOESTEMMING GEE.

Naam: ______________________________

Handtekening: ____________________ Datum: ____________________

Verwantskap met pasiënt: ______________________________

PATRONE VAN HERSTELLING EN NAGEVOLGE IN BEROERTE PASIËNTE WAT TOEGANG HET TOT 'N WESKAAPSE REHABILITASIESENTRUM

INFORMASIEBLAD VIR VERSORGERS WAT IN DIE STUDIE DEELNEEM

My naam is Susan Rouillard. Ek is 'n fisioterapeet en voltooi tans 'n Meestersgraad te Universiteit van Kaapstad. Ek bestudeer tans die patrone van herstelling en nagevolge van 'n beroerte in pasiënte opgeneem in die Weskaapse Rehabilitasiesentrum. Die doeleindes van die studie is om die karaktertrekke van beroerte pasiënte te identifiseer en die faktore wat die herstelling van pasiënte beïnvloed. Die verwagting is dat hierdie informasie sal bydra tot die identifiseering van die behoeftes van beroerte pasiënte terwyl hulle rehabilitasie ondergaan and nadat hulle ontslaan word, met die doel om pasiëntesorg te verbeter. Een van die aspekte wat ondersoek word is die spanning ondervind deur mense wat beroerte pasiënte versorg.

______________________________ het saamgestem om deel te neem in die studie en sal deur navorsers ondersoek word pas na toelating tot die Rehabilitasiesentrum, net voor ontslaning van die Rehabilitasiesentrum en weer ses maande na die beroerte. Die finale assesseering sal in by die woning van die deelnemer plaasvind, 'n plaaslike Gemeenskapsgesondheidssentrum of by die Weskaapse Rehabilitasiesentrum, as hy/sy gewillig is om te reis. (Vervoeronkostes sal betaal word.)

______________________________ het aangedui dat u haar/sy primêre versorger is. As u saamstem om aan die studie deel te neem, sal u gevra word oor die uitwerking wat die versorging van hom/ haar op u lewe het. Dit is 'n kort vraelys wat slegs omtrent 10 tot 15 minute sal neem om te beantwoord. Die vrae kan beantwoord word deur 'n geskrewe vraelys in te vul, mondelings per telefoon, of persoonlik in 'n onderhoud. Die onderhoud sal by die deelnemer se huis, 'n plaaslike Gemeenskapsgesondheids Sentrum, of by die Weskaapse Rehabilitasie Sentrum. Vervoeronkostes om die onderhoud by te woon, sal betaal word.

Na die beste van ons vermoë sal ons seker maak dat u nie in die teenwoordigheid van hom/ haar ondervra word nie.

U sal vry wees om op enige stadium van die studie te onttrek sonder om 'n rede te verskaf, en sonder dat hy/sy mediese sorg of u reputasie as versorger as a gevolg daarvan sal geaffekteer word. U sal vry wees om te kies om enige van die vrae nie te antwoord nie, of enige van die toetse deur te gaan, as u nie wil nie. Alle informasie sal net vir die doeleindes van hierdie studie gebruik word, en sal nie aan enigeen buite hierdie studie onthul word nie. 'n Kode sal aan u gegee word, en alle informasie sal onder 'n kode, nie u naam, gestoor word. Alle informasie is anoniem and u sal nie persoonlik geidentifiseer word in enige publikasie waarin die resultate gepubliseer word nie. Die gekodeerde informasie mag wel met 'n beroerte studie in Belgieë meegedeel word so dat die verskille in beroerte nagevolge in Suid Afrika en Europa vergelyk kan word.

As u enige addisionele inligting oor die studie nodig kry, of as u enige probleme teekom as gevolg van die studie, skakel my asseblief telefonies by 021 5527731 of 072 1263 867.

PATRONE VAN HERSTELLING EN NAGEVOLGE IN BEROERTE PASIËNTE WAT TOEGANG HET TOT 'N WESKAAPSE REHABILITASIESENTRUM

TOESTEMMINGSFORM VIR VERSORGERS WAT IN DIE STUDIE DEELNEEM

Merk asseblief die korrekte respons:

1. Het u die informasieblad gelees, of is die inhoud daarvan aan u verduidelik?	JA	NEE
2. Was u die geleentheid gebied om vrae te vra oor die studie, en was al u vrae bevredigend beantwoord?	JA	NEE
3. Verstaan u die redes vir die studie?	JA	NEE
4. Verstaan u dat u vry is om op enige stadium van die studie te onttrek?	JA	NEE
5. Stem u saam om deel te neem in die studie?	JA	NEE

Naam van versorger: ______________________________

Handtekening: ____________________ Datum: ____________________

Naam van pasiënt wat u versorg: ______________________________

Verwantskap met pasiënt: ______________________________

Naam van navorser: ______________________________

Handtekening: ____________________ Datum: ____________________

XHOSA CONSENT FORMS

IPHEPHA LOLWAZI LEZIGULANA EZITHATH'INXAXHEBA KOLU PHANDO: INDLELA YOKUFUMANA KWAKHONA EBEKULAHLEKILE KUNYE NESIPHUMO KWIZIGULANA EZINESITROWUKHU EZIZAMA UKUFIKELELA KUMZI WOKUBUYISELA ABANTU KWIMEKO YESIQHELO ENTSHONA KOLONI.

Igama lam nguSusan Ritchie. Ndiyiphysiotherapist yaye ndigqibezela izifundo zam zeemasters kwiYunivesiti yaseKapa. Ndikwindlela ebhekisa ekwenzeni ufundo ngomzekelo wokufumana kwakhona ebekulahlekile kunye nesiphumo emva kwesitrowukhu kwizigulana ezamkelwe kuMzi Wokubuyisela aBantu kwiMeko yesiQhelo.eNtshona Koloni. Injongo yoPhando kukuchonga iimpawu zezigulana ezinesitrowukhu kunye neemeko ezinokuphembelela indlela abanokuphinda ngayo babe bhetele emva kokufumana isitrowukhu. Kuyathenjwa ukuba olu lwazi luyakunceda ekwalatheni izidingo zezigulana ezinesitrowukhu ngexesha bephantsi kokubuyiselwa kwimeko yesiqhelo nasemva kokuba bekhululiwe ukwenzela ukuphucula unyamekelo zigulana.

Ukuba uyavuma ukuthath'inxaxheba kolu phando, uyakuphicothwa nguMphandi kwizihlandlo ezintathu.

1. Kwiintsuku ezimbalwa zokuqala emva kokwamkelwa kuMzi Wokubuyisela aBantu kwiMeko yesiQhelo. Olu phicotho luyakuthatha iyure enesiqingatha yexesha lakho.
2. Phambi kweentsuku ezimbalwa zokukhululwa kwakho kuMzi Wokubuyisela aBantu kwiMeko yesiQhelo. Olu phicotho luyakuthatha iyure enesiqingatha yexesha lakho.
3. Emva kweenyanga ezintandathu zokuba nesitrowukhu uyakuphicothwa kuMzi Wokubuyisela aBantu kwiMeko yesiQhelo, kuMzi wezeMpilo noNyamekelo loLuntu okanye kwindawo enjengaleyo, okanye ekhayeni lakho. (ukuba ukukhwela into ehambayo bekufuneka, inqwelo yakho ibiyakuhlawulwa yiprojekhi yophando). Olu phicotho luyakuthatha iiyure ezimbini zexesha lakho.

Uphicotho luyakuhlanganisa iimvavanyo nje ezincinane ukulinganisa ukuba isitrowukhu sikufumene kangakanani. Uyakubuzwa imibuzo ngempilo yakho kunye nezinto obukwazi ukuzenza ngaphambi kokuhlaselwa sisitrowukhu, kunye nokukwazi kwakho ukusebenza nokuthath'inxaxheba kwimisebenzi ethile okokoko ubuthe wanesitrowukhu. Uyakubuzwa ngendawo ohlala kuyo, imisebenzi yakho yemihla ngemihla kunye neemeko ezenza kube lula okanye kube nzima ukusebenza. Uyakubuzwa kwakhona nangomvuzo, imfundo kunye nomsebenzi. Abongikazi kunye noogqirha banokubuzwa ngolwazi olongezelelweyo. Ukuba akukwazi ukuphendula yonke imibuzo ngenxa yesitrowukhu sakho, amalungu osapho okanye izizalwana zinokucelwa ukuba zincede. Oyena mntu ukunyamekelayo naye uyakubuzwa imibuzo ngendlela abakwazi ngayo ukukujonga.

Uyakukhululwa ukuba ubuye umva kolu phando nangaliphi na ixesha ngaphandle kokunika isizathu, nangaphandle kokuchatshazelwa kogonyo lwakho njengesiphumo. Uyakuvunyelwa ukuba ukhethe ukungaphenduli nayiphi na imibuzo okanye ukwenza naluphi na uvavanyo xa unganqweneli kwenza njalo. Lonke ulwazi luyakusetyenziselwa kuphela iinjongo zophando yaye alusayi kuxelelwa nabani na ongaphandle kophando. Uyakunikwa inombolo yekhowudi, yaye lonke ulwazi oluqokelelweyo luyakugcinwa ngaphantsi kwekhowudi, endaweni yegama lakho. Lonke ulwazi luyakuba yimfihlo yaye akusayi kwalathwa nakulo naluphi na ushicelelo oluqulathe iziphumo zolu phando. Ulwazi olukwikhowudi lunganikezelwa kuphando olumayela nesitrowukhu olunyenyezeya lusuka eBelgium ukuze umahluko ophakathi kweziphumo zesitrowukhu eMzantsi Afrika naseYurophu uthelekiswe.

Ukuba ufuna ulwazi olongeziweyo ngophando okanye ukuba uncengxaki ngenxa yophando, nceda unxulumane nam kwezinombolo (tel) 021 5527731 (c) 072 1263 867.

IFOMU YESIVUMELWANO SABAGULI ABATHABATHA INXAXHEBA

SIVAVANYA I-WESTERN CAPE REHABILITATION CENTRE

Makisha impendulo ezifanelekileyo

1. Ukhe wayifunda ifomu equlathe ulwazi okanye okuqulathwe yiyo Ukucaciselwe ? Ewe Hayi

2. Ukhe walifumana ithuba lokubuza imibuzo ngophononongo kwaye Yonke imibuzo yakho iphendulwe ngokwanelisayo ? Ewe Hayi

3. Uyasiqonda isizathu solu phononongo ? Ewe Hayi

4. Uyaqonda ukuba unelungelo lokurhoxa kolu phononongo Nagaliphi ixesha ngaphandle kokunika isizathu? Ewe Hayi

5. Uyavuma umphandi afumane imvume yokujonga iziphumo Zokugula kwakho Ewe Hayi

6. Uyavuma ukuba umphandi athethe nefemeli okanye umnonopheli Ukufumana ulwazi? Ewe Hayi

7. Uyavuma ukuthabatha inxaxheba kuphononongo ? Ewe Hayi

IGAMA LOMGULI : ____________________

ISAYINWE: ____________________ UMHLA: ____________________

IGAMA LOMPHANDI: ____________________

ISAYINWE: ____________________ UMHLA: ____________________

KWIMEKO APHO UMGULI ANGAKWAZIYO UKUNIKA IMVUME YOKUNGAQONDI, NCEDA THATHA INKCUKACHA ZELUNGU LE FEMELI ELINIKA IMVUME NGEZANTSI.

IGAMA: ____________________

ISAYINWE: ____________________ UMHLA : ____________________

UBUZALWANE KUMGULI: ____________________

IPHEPHA LOLWAZI LWABATHATH'INXAXHEBA EKUNYAMEKELENI IZIGULANA KOLU PHANDO

INDLELA YOKUFUMANA KWAKHONA EBEKULAHLEKILE KUNYE NESIPHUMO KWIZIGULANA EMVA KOKUFUMANA ISITROWUKHU EZIZAMA UKUFIKELELA KUMZI WOKUBUYISELA ABANTU KWIMEKO YESIQHELO ENTSHONA KOLONI.

Igama lam nguSusan Ritchie. Ndiyiphysiotherapist yaye ndigqibezela izifundo zam zeemasters kwiYunivesiti yaseKapa. Ndikwindlela ebhekisa ekwenzeni ufundo ngomzekelo wokufumana kwakhona ebekulahlekile kunye nesiphumo emva kwesitrowukhu kwizigulana ezamkelwe kuMzi Wokubuyisela aBantu kwiMeko yesiQhelo.eNtshona Koloni. Injongo yoPhando kukuchonga iimpawu zezigulana ezinesitrowukhu kunye neemeko ezinokuphembelela indlela abanokuphinda ngayo babe bhetele emva kokufumana isitrowukhu. Kuyathenjwa ukuba olu lwazi luyakunceda ekwalatheni izidingo zezigulana ezinesitrowukhu ngexesha bephantsi kokubuyiselwa kwimeko yesiqhelo nasemva kokuba bekhululiwe ukwenzela ukuphucula unyamekelo zigulana. Omnye wemiba ezanywa ukuphandwa luxinzelelo olufunyanwa ngabantu abanonophela abo basinde kwisitrowukhu.

....uvumile ukuthatha inxaxheba kolu phando yaye uyakuvavanywa ngabaphandi kamsinyane emva kokwamkelwa kuMzi Wokubuyiselwa kwaBantu kwiMeko yesiQhelo, phambi kokukhululwa ukuba awushiye lo Mzi Wokubuyiselwa kwaBantu kwiMeko yesiQhelo yaye kwakhona kwiinyanga ezintandathu emva kokufunyanwa sisitrowukhu. Olu phicotho lokugqibela liyakwenziwa ekhayeni lomthathi-nxaxheba, uMzi woGonyo noNyamekelo-Mpilo yaBantu okanye kuMzi Wokubuyisela aBantu kwiMeko yesiQhelo eNtshona Koloni, ukuba uyavuma ukuhambela khona. {Iintlawulo zokuhambela ziyakukhutshwa}.

...................................utshilo ukuba ungoyena Mnonopheli wakhe. Ukuba uyavuma ukuthath'inxaxheba kolu fundo, uyakubuzwa imibuzo ngempembelelo oyifumanayo nokunonophela u...................................Le yincwadana emfutshane yemibuzo eyakuthatha imizuzu engange-10 ukuya kwi-11. Imibuzo ingaphendulwa ngokugcwalisa iphepha lemibuzo, ngomlomo efowunini, okanye ubuso ngobuso kwimbuzwano. Imbuzwano ingabanjwa ekhayeni lomthath'inxaxheba, okanye kuMzi woGonyo noNyamekelo – Mpilo yaBantu okanye kwindawo efana naleyo, okanye kuMzi Wokubuyiselwa kwaBantu kwiMeko yesiQhelo. Ixabiso lemali oyidliweyo yokuhambela imbuzwano iyakuhlawulwa.

Yonke imigudu iyakuthatyathwa eyokuqinisekisa ukuba akubuzwa mibuzo phambi kuka.....................

Uyakuvunyelwa ukuba ukhululeke kuphando nangasiphi na isigaba ngaphandle kokunika isizathu, nangaphandle kogonyo lwamayeza luka ....okanye indawo ome kuyo njengomnonopheli oye wachaphazeleka ngenxa yoko. Uyakukhululeka ukuba ukhethe ukungaphenduli nayiphi na imibuzo xa unganqwenela ukungenzi njalo. Lonke ulwazi luya kuba lelenjongo zophando kuphela yaye lingasayi kuchazelwa nabani na ongaphandle kophando. Lonke ulwazi luyakuba yimfihlo yaye akusayi kwalathwa mntu nakoluphi na ushicelelo oluyakuqulatha iziphumo zolu phando. Ulwazi olufakwe ikhowudi lunganikezelwa kufundo ngesitrowukhu olunyenyezayo eBelgium ukuze umahluko ophakathi kweziphumo zesitrowukhu eMzantsi Afrika uthelekiswe nowaseYurophu.

Consent form for caregivers

ISIVUMELWANO SABANONOPHELI ABATHABATHA INXAXHEBA KUPHONONONGO.

INDLELA YENKQUBO YOKUCHACHA NEZIPHUMO KUBAGULI SIVAVANYA I-WESTERN CAPE REHABILITATION CENTRE

Nceda makisha impendulo efanelekileyo

1. Ukhe wayifunda ifomu equlathe ulwazi okanye okuqulathwe yiyo Ukucaciselwe ? Ewe Hayi

2. Ukhe walifumana ithuba lokubuza imibuzo ngophononongo kwaye Yonke imibuzo yakho iphendulwe ngokwanelisayo ? Ewe Hayi

3. Uyasiqonda isizathu solu phononongo ? Ewe Hayi

4. Uyaqonda ukuba unelungelo lokurhoxa kolu phononongo Nagaliphi ixesha ngaphandle kokunika isizathu? Ewe Hayi

5. Uyavuma ukuthabatha inxaxheba kolu phando ? Ewe Hayi

IGAMA LOMNONOPHELI: ______________________________

ISAYINWE : ____________________ UMHLA ______________________

IGAMA LOMGULI ANGUMNONOPHELI WAKHE : ______________________

UBUZALWANE KUMGULI: ______________________________

IGAMA LOMPHONONONGI ______________________________

ISAYINWE : ____________________ UMHLA: ______________________

APPENDIX XXIV STATISTICAL ANALYSES: MULTIVARIATE ANALYSIS

Logistic Regression Models for Single Factors

Highlighted factors are statistically significant.

1. NIHSS

Model: Logistic regression (logit) N of 0's: 37 1's: 10
Dep. var: MRS
Loss: Max likelihood (MS-err. scaled to 1)
Final loss: 19.019552615 Chi^2(1)=10.615 p=.00112

	Const.B0	NIHSS Total
Estimate	1.934	**-0.351**
Standard Error	1.234	**0.144**
t(45)	1.568	**-2.438**
p-level	0.124	**0.019**
-95%CL	-0.551	**-0.640**
+95%CL	4.419	**-0.061**
Wald's Chi-square	2.458	**5.946**
p-level	0.117	**0.015**
Odds ratio (unit ch)	6.918	**0.704**
-95%CL	0.577	**0.527**
+95%CL	82.982	**0.941**
Odds ratio (range)		**0.000**
-95%CL		**0.000**
+95%CL		**0.193**

2. TOTAL NO. REHAB DAYS

Model: Logistic regression (logit) N of 0's: 37 1's: 10
Dep. var: MRS Categ 4 Nov
Loss: Max likelihood (MS-err. scaled to 1)
Final loss: 20.469731113 Chi^2(1)=7.7148 p=.00548

	Const.B0	Total No of Rehabilitation days
Estimate	1.035192	-0.04398526
Standard Error	0.9468246	0.01853804
t(45)	1.09333	-2.372703
p-level	0.2800673	0.02199217
-95%CL	-0.8718109	-0.08132277
+95%CL	2.942194	-0.006647738
Wald's Chi-square	1.195371	5.629721
p-level	0.2742572	0.01766431
Odds ratio (unit ch)	2.815646	0.9569681
-95%CL	0.4181936	0.9218961
+95%CL	18.9574	0.9933743
Odds ratio (range)		0.00903705
-95%CL		0.00016633
+95%CL		0.4910016

2. URINARY INCONTINENCE

Model: Logistic regression (logit) N of 0's: 37 1's: 10
Dep. var: MRS
Loss: Max likelihood (MS-err. scaled to 1)
Final loss: 21.823977196 Chi²(1)=5.0063 p=.02526

	Const.B0	**Urinary incontinence**
Estimate	-0.7985077	-2.034706
Standard Error	0.40139	1.104564
t(45)	-1.989357	-1.842089
p-level	0.05276087	0.07205752
-95%CL	-1.606948	-4.259412
+95%CL	0.009933171	0.1900007
Wald's Chi-square	3.957539	3.393293
p-level	0.04667037	0.06547134
Odds ratio (unit ch)	0.45	0.1307189
-95%CL	0.2004985	0.01413061
+95%CL	1.009983	1.20925
Odds ratio (range)		0.1307189
-95%CL		0.01413061
+95%CL		1.20925

4. SITTING BALANCE

Model: Logistic regression (logit) N of 0's: 37 1's: 10
Dep. var: MRS Categ 4 Nov
Loss: Max likelihood (MS-err. scaled to 1)
Final loss: 23.836778958 Chi²(1)=.98069 p=.32204

	Const.B0	**Sitting Balance**
Estimate	-1.25276	-26.4996
Odds ratio (unit ch)	0.28571	0.0000
Odds ratio (range)		0.0000

5. ENVIRONMENTAL BARRIER

Model: Logistic regression (logit) N of 0's: 37 1's: 10
Dep. var: MRS
Loss: Max likelihood (MS-err. scaled to 1)
Final loss: 22.288775300 Chi²(1)=4.0767 p=.04349

	Const.B0	**Env Barrier yes1 no0**
Estimate	0.000	**-1.705**
Standard Error	0.707	**0.835**
t(45)	0.000	**-2.042**
p-level	1.000	**0.047**
-95%CL	-1.424	**-3.387**
+95%CL	1.424	**-0.023**
Wald's Chi-square	0.000	**4.168**
p-level	1.000	**0.041**
Odds ratio (unit ch)	1.000	**0.182**
-95%CL	0.241	**0.034**
+95%CL	4.154	**0.977**
Odds ratio (range)		**0.182**
-95%CL		**0.034**
+95%CL		**0.977**

6. COGNITION

Model: Logistic regression (logit) N of 0's: 37 1's: 10
Dep. var: MRS
Loss: Max likelihood (MS-err. scaled to 1)
Final loss: 22.665103690 Chi²(1)=3.3240 p=.06828

	Const.B0	**Cog deficit present**
Estimate	**-2.037**	1.344
Standard Error	**0.614**	0.769
t(45)	**-3.318**	1.748
p-level	**0.002**	0.087
-95%CL	**-3.273**	-0.205
+95%CL	**-0.800**	2.892
Wald's Chi-square	**11.009**	3.055
p-level	**0.001**	0.081
Odds ratio (unit ch)	**0.130**	3.833
-95%CL	**0.038**	0.815
+95%CL	**0.449**	18.034
Odds ratio (range)		3.833
-95%CL		0.815
+95%CL		18.034

7. BI AT ADMISSION

Model: Logistic regression (logit) N of 0's: 37 1's: 10
Dep. var: MRS
Loss: Max likelihood (MS-err. scaled to 1)
Final loss: 16.362262008 Chi²(1)=15.930 p=.00007

	Const.B0	BI-1
Estimate	-5.574332	0.07180682
Standard Error	1.565176	0.02300801
t(45)	-3.561473	3.120949
p-level	0.0008852204	0.003144977
-95%CL	-8.726759	0.02546631
+95%CL	-2.421906	0.1181473
Wald's Chi-square	12.68409	9.74032
p-level	0.000369315	0.001804298
Odds ratio (unit ch)	0.003794008	1.074448
-95%CL	0.0001621873	1.025793
+95%CL	0.0887523	1.12541
Odds ratio (range)		917.4957
-95%CL		11.23798
+95%CL		74906.55

8. INCOME BY CATEGORY

Model: Logistic regression (logit) N of 0's: 35 1's: 10
Dep. var: MRS
Loss: Max likelihood (MS-err. scaled to 1)
Final loss: 23.209033026 Chi²(1)=1.2555 p=.26251

	Const.B0	Income by category
Estimate	-1.658228	0.8109302
Standard Error	0.5455635	0.7319248
t(43)	-3.039478	1.107942
p-level	0.004022957	0.2740459
-95%CL	-2.758462	-0.6651368
+95%CL	-0.5579944	2.286997
Wald's Chi-square	9.238425	1.227535
p-level	0.0023718	0.2678952
Odds ratio (unit ch)	0.1904762	2.25
-95%CL	0.0633892	0.5142031
+95%CL	0.5723558	9.84533
Odds ratio (range)		2.25
-95%CL		0.5142031
+95%CL		9.84533

8. AGE AT ASSESSMENT

Model: Logistic regression (logit) N of 0's: 37 1's: 10
Dep. var: MRS
Loss: Max likelihood (MS-err. scaled to 1)
Final loss: 24.138183254 $Chi^2(1)$=.37788 p=.53874

	Const.B0	Age at assessment
Estimate	-0.511	-0.016
Standard Error	1.332	0.026
t(45)	-0.383	-0.611
p-level	0.703	0.544
-95%CL	-3.194	-0.067
+95%CL	2.172	0.036
Wald's Chi-square	0.147	0.373
p-level	0.701	0.541
Odds ratio (unit ch)	0.600	0.984
-95%CL	0.041	0.935
+95%CL	8.780	1.037
Odds ratio (range)		0.398
-95%CL		0.019
+95%CL		8.304

9. STROKE ADMISSION INTERVAL

Model: Logistic regression (logit) N of 0's: 37 1's: 10
Dep. var: MRS
Loss: Max likelihood (MS-err. scaled to 1)
Final loss: 22.533117573 $Chi^2(1)$=3.5880 p=.05821

	Const.B0	Stroke Admission Interval
Estimate	-0.433	-0.048
Standard Error	0.602	0.033
t(45)	-0.720	-1.482
p-level	0.475	0.145
-95%CL	-1.645	-0.114
+95%CL	0.778	0.017
Wald's Chi-square	0.518	2.196
p-level	0.472	0.138
Odds ratio (unit ch)	0.649	0.953
-95%CL	0.193	0.892
+95%CL	2.178	1.018
Odds ratio (range)		0.022
-95%CL		0.000
+95%CL		3.938

Logistic Regression Models for Combinations of Factors

Model: Logistic regression (logit) N of 0's: 35 1's: 10

Dep. var: MRS Categ 4 Nov Loss: Max likelihood (MS-err. scaled to 1)

Final loss: 15.145398733 Chi²(5)=17.383 p=.00383

	Const.B0	Stroke Admission Interval	NIHSS Total	Income by category	Cog deficit present	Env Barrier yes1 no0
Estimate	2.843	-0.050	-0.300	0.286	1.072	-1.455
Standard Error	1.970	0.035	0.167	0.953	0.984	1.192
t(39)	1.444	-1.405	-1.796	0.300	1.089	-1.220
p-level	0.157	0.168	0.080	0.766	0.283	0.230
-95%CL	-1.141	-0.121	-0.638	-1.643	-0.919	-3.865
+95%CL	6.827	0.022	0.038	2.214	3.063	0.956
Wald's Chi-square	2.084	1.974	3.227	0.090	1.185	1.490
p-level	0.149	0.160	0.072	0.764	0.276	0.222
Odds ratio (unit ch)	17.174	0.952	0.741	1.331	2.921	0.234
-95%CL	0.320	0.886	0.528	0.193	0.399	0.021
+95%CL	922.779	1.022	1.039	9.153	21.388	2.601
Odds ratio (range)		0.020	0.000	1.331	2.921	0.234
-95%CL		0.000	0.000	0.193	0.399	0.021
+95%CL		5.616	2.776	9.153	21.388	2.601

Model: Logistic regression (logit) N of 0's: 35 1's: 10
Dep. var: MRS Loss: Max likelihood (MS-err. scaled to 1)
Final loss: 16.665999019 Chi²(4)=14.342 p=.00629

	Const.B0	**NIHSS Total**	Income by category	Cog deficit present	Env Barrier yes1 no0
Estimate	1.782	**-0.306**	0.196	1.229	-1.310
Standard Error	1.692	**0.145**	0.888	0.937	1.025
t(40)	1.053	**-2.106**	0.221	1.312	-1.278
p-level	0.298	**0.041**	0.827	0.197	0.209
-95%CL	-1.637	**-0.599**	-1.599	-0.664	-3.380
+95%CL	5.201	**-0.012**	1.991	3.122	0.761
Wald's Chi-square	1.110	**4.437**	0.049	1.721	1.633
p-level	0.292	**0.035**	0.825	0.190	0.201
Odds ratio (unit ch)	5.942	**0.737**	1.216	3.417	0.270
-95%CL	0.195	**0.550**	0.202	0.515	0.034
+95%CL	181.428	**0.988**	7.324	22.689	2.141
Odds ratio (range)		**0.000**	1.216	3.417	0.270
-95%CL		**0.000**	0.202	0.515	0.034
+95%CL		**0.716**	7.324	22.689	2.141

Model: Logistic regression (logit) N of 0's: 37 1's: 10
Dep. var: MRS
Loss: Max likelihood (MS-err. scaled to 1)
Final loss: 18.287237288 Chi²(2)=12.080 p=.00238

	Const.B0	**NIHSS Total**	**Env Barrier yes1 no0**
Estimate	2.525065	**-0.3151469**	-1.163583
Standard Error	1.362043	**0.1425546**	0.9544879
t(44)	1.85388	**-2.210711**	-1.219065
p-level	0.07046761	**0.03230041**	0.2293149
-95%CL	-0.2199528	**-0.6024467**	-3.087226
+95%CL	5.270082	**-0.02784704**	0.7600613
Wald's Chi-square	3.436872	**4.887241**	1.486119
p-level	0.06376549	**0.02706293**	0.2228286
Odds ratio (unit ch)	12.4917	**0.7296817**	0.3123651
-95%CL	0.8025567	**0.5474705**	0.04562833
+95%CL	194.432	**0.9725371**	2.138407
Odds ratio (range)		**0.0002016522**	0.3123651
-95%CL		**0.00000008624598**	0.04562833
+95%CL		**0.4714841**	2.138407

Model: Logistic regression (logit) N of 0's: 37 1's: 10
Dep. var: MRS
Loss: Max likelihood (MS-err. scaled to 1)
Final loss: 18.077800582 Chi²(2)=12.499 p=.00193

	NIHSS Total	Cog deficit present
Estimate	-0.3568057	1.164815
Standard Error	0.1493505	0.8833688
t(44)	-2.38905	1.318605
p-level	0.02124538	0.1941237
-95%CL	-0.6578017	-0.6154983
+95%CL	-0.05580961	2.945128
Wald's Chi-square	5.707559	1.738719
p-level	0.01689777	0.1873106
Odds ratio (unit ch)	0.6999085	3.205329
-95%CL	0.5179887	0.5403716
+95%CL	0.9457192	19.01309
Odds ratio (range)	0.0000654808	3.205329
-95%CL	0.00000001934856	0.5403716
+95%CL	0.2216048	19.01309

Model: Logistic regression (logit) N of 0's: 37 1's: 10
Dep. var: MRS Loss: Max likelihood (MS-err. scaled to 1)
Final loss: 16.945023530 Chi²(2)=14.764 p=.00062

	Const.B0	Stroke Admission Interval	NIHSS Total
Estimate	3.285	-0.052	-0.398
Standard Error	1.627	0.031	0.173
t(44)	2.019	-1.686	-2.303
p-level	0.050	0.099	0.026
-95%CL	0.006	-0.113	-0.747
+95%CL	6.565	0.010	-0.050
Wald's Chi-square	4.076	2.844	5.303
p-level	0.043	0.092	0.021
Odds ratio (unit ch)	26.719	0.950	0.671
-95%CL	1.006	0.893	0.474
+95%CL	709.712	1.010	0.951
Odds ratio (range)		0.017	0.000
-95%CL		0.000	0.000
+95%CL		2.214	0.261

Model: Logistic regression (logit) N of 0's: 37 1's: 10 Dep. var: MRS Loss: Max likelihood (MS-err. scaled to 1) Final loss: 14.818783390 $Chi^2(3)=19.017$ p=.00027				
	Const.B0	Total No of Rehabilitation days	Stroke Admission Interval	NIHSS Total
Estimate	**4.451**	-0.048	-0.059	-0.210
Standard Error	**1.721**	0.026	0.029	0.142
t(43)	**2.587**	-1.861	-2.008	-1.484
p-level	**0.013**	0.070	0.051	0.145
-95%CL	**0.981**	-0.099	-0.118	-0.497
+95%CL	**7.921**	0.004	0.000	0.076
Wald's Chi-square	**6.692**	3.464	4.031	2.201
p-level	**0.010**	0.063	0.045	0.138
Odds ratio (unit ch)	**85.731**	0.954	0.943	0.810
-95%CL	**2.667**	0.906	0.889	0.609
+95%CL	**2755.692**	1.004	1.000	1.079
Odds ratio (range)		0.006	0.009	0.003
-95%CL		0.000	0.000	0.000
+95%CL		1.530	1.021	7.700

Model: Logistic regression (logit) N of 0's: 37 1's: 10 Dep. var: MRS Loss: Max likelihood (MS-err. scaled to 1) Final loss: 18.287237288 $Chi^2(2)=12.080$ p=.00238			
	Const.B0	**NIHSS Total**	**Env Barrier yes1 no0**
Estimate	2.525	**-0.315**	-1.164
Standard Error	1.362	**0.143**	0.954
t(44)	1.854	**-2.211**	-1.219
p-level	0.070	**0.032**	0.229
-95%CL	-0.220	**-0.602**	-3.087
+95%CL	5.270	**-0.028**	0.760
Wald's Chi-square	3.437	**4.887**	1.486
p-level	0.064	**0.027**	0.223
Odds ratio (unit ch)	12.492	**0.730**	0.312
-95%CL	0.803	**0.547**	0.046
+95%CL	194.432	**0.973**	2.138
Odds ratio (range)		**0.000**	0.312
-95%CL		**0.000**	0.046
+95%CL		**0.471**	2.138