A DESCRIPTIVE STUDY ON DOCTORS’ PRACTICES REGARDING DIFFERENT ASPECTS OF STROKE REHABILITATION IN PRIVATE ACUTE-CARE HOSPITALS SITUATED IN THE WESTERN CAPE METROPOLE

By

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ABSTRACT

Introduction: Stroke is a growing healthcare problem in South Africa. It contributes significantly to the burden of disease and is the largest cause of disability. Rehabilitation can significantly improve recovery and outcomes of stroke survivors particularly if implemented in the correct manner and through using certain approaches.

The aim of this study was to examine the practice of doctors with regards to stroke rehabilitation in private acute-care hospitals in the Western Cape Metropole. In particular, attention has been given to the degree to which doctors in the private health care sector shared information with first time stroke patients.

The study design was retrospective and descriptive in nature.

Data collection was primarily of a quantitative nature although some qualitative data has been collected to elaborate on quantitative findings. Two self-designed questionnaires were used to collect data. Data from doctor-participants were collected to examine the use of care protocols. Data from both groups of participants were collected to determine which practices were prefered. In particular it was sought to ascertain what team work approach was favoured by doctors. To do this the method of communication among team members was examined. It was also sought to ascertain how information regarding diagnosis, prognosis, risk factors, post–acute rehabilitation options and discharge planning was shared. In total thirty-five doctors and forty-eight patients were interviewed. Quantitative data was captured on an excel spreadsheet and analysed with the help of a STATISTICA software package. A p value of less than 0.05 was deemed statistically significant.

Results showed that none of the doctor participants had any formal rehabilitation qualification. It was found that stroke care protocols were used by 46% of doctor participants, while 89% acknowledged the advantages of a set protocol. The majority of doctors (57%) operated as part of a multidisciplinary team. Communication between team members regarding the patient's management plan was done on a very informal basis with only 11% of doctors using ward rounds and none using team meetings for this purpose. Opinions differed between the two study groups on the frequency of information sessions (p = .00039). Only six % of doctors included the patient and family in the rehabilitation team. A large discrepancy was seen when it came to opinions on sharing information regarding diagnosis, prognosis, stroke risk factors, post-acute rehabilitation and discharge planning. P values ranging from 0.00013 to 0.0041 showed that the difference between the opinions of patients and doctors on these issues was statistically significant. Opinions also differed between the two groups when the frequency of information sessions was compared (p = 0.00039). Only 28% of patient participants were included in the decision-making process regarding further post-acute rehabilitation and in most cases the final decision was made by the doctor or the medical insurance company. Qualitative data highlighted some patients' dissatisfaction regarding the post-acute rehabilitation process and indicated a problem with regard to the recognition of early stroke warning signs by general practitioners and the emergency treatment of these.

The conclusion was that there is a great need for further motivation and education of doctors with respect to advanced research projects, further specialisation as well as the implementation of important rehabilitation modalities. It is also important that the patient himself acts as a fully-fledged team member.

Recommendations were that administrators in both, the private and public health care sectors as well as non-government organisations and government welfare organisations identify the reasons for doctors' hesitation to implement existing knowledge; that they make stroke rehabilitation training available and that they ensure that doctors implement the existing and new knowledge on all aspects of acute and post-acute stroke rehabilitation i.e. use of set care protocols, team work approach and sharing information on diagnosis, prognosis, risk factors, post–acute rehabilitation options and discharge planning when managing stroke patients. It was also recommended to promote more research projects which are implemented in the private health care sector.

KEY TERMS

STROKE, REHABILITATION, ACUTE STROKE CARE, STROKE CARE PROTOCOL, PATIENT EDUCATION, PATIENT AUTONOMY, PRIVATE HEALTH CARE SECTOR.

ABSTRAK

Beroerte is reeds die grootste enkele oorsaak van gestremdheid in Suid Afrika en steeds aan die toeneem in insidensie. Navorsing het bewys dat rehabilitasie geskoei op wetenskaplik bewese metodes die uitkomste van beroerte lyers beduidend kan verbeter.

Daarom was dit die doel van die studie om vas te stel tot watter mate dokters, werksaam in die privaat sektor in die Wes Kaapse Metropool, bewese rehabilitasie metodes implimenteer tydens behandeling van akute beroerte pasiënte. Spesifieke areas waaraan aandag geskenk is, was die gebruik van beroerte protokolle, die volg van die interdissiplinêre spanwerk benadering, kommunikasie metodes tussen spanlede en die deurgee van inligting met betrekking tot die diagnose, prognose, risiko faktore, opvolg rehabilitasie en ontslag beplanning aan pasiënte na `n eerste beroerte.

Die studie was retrospektief en beskrywend van aard. Daar was primêr kwantitatiewe data ingesamel met behulp van twee self ontwerpde vraelyste. ‘n Klein hoeveelheid kwalitatiewe data is aanvullend ingesamel om kwantitatiewe bevindings toe te lig. 35 dokters en 48 pasiënte het aan die studie deelgeneem. ‘n STATISTICA sagteware pakket is gebruik vir die analise van kwalitatiewe data. ‘n P waarde van minder as 0.05 is as statisties beduidend beskou.

Nie een van die dokters wat aan die studie deelgeneem het, het nagraadse opleiding in rehabilitasie gehad nie. 46% van dokters het beroerte protokolle gebruik in hulle praktyke, terwyl 89% gevoel het dat die gebruik van protokolle voordele inhou. Waar spanwerk gebruik was (57% van dokters), is die multidissiplinêre benadering gevolg. Kommunikasie tussen spanlede het meesal op `n informele basis geskied. Geen dokter het spanvergaderings gehou nie. 11% van dokters het saalrondtes gehou waartydens met spanlede gekommunikeer is. 6% van dokters het die pasiënt en familie ingesluit in die rehabilitasie span. Volgens dokters was daar beduidend meer inligting sessies met pasiënte gehou as volgens pasiënte (p = 0.00039). Die verskil in mening tussen die twee groepe is ook waargeneem met betrekking tot die hoeveelheid inligting wat verskaf is oor diagnose, prognose, risiko faktore, post akute rehabilitasie en onslag beplanning (P waardes het gewissel van 0.00013 tot 0.0041). 25% van pasiënte het deelgeneem aan die besluitnemings proses oor opvolg rehabilitasie. Die finale besluit hieroor was in die meerderheid van gevalle deur die dokter en die mediese versekeringsskema geneem.

Dit het uit die kwalitatiewe data geblyk dat van die pasiënte ongelukkig was met die opvolg rehabilitasie wat hulle ontvang het. Voorts het pasiënte gevoel dat algemene praktisyns beter ingelig behoort te wees oor die vroeë waarskuwingstekens van beroerte sowel as die noodbehandling van die tekens.

Die navorser het tot die gevolgtrekking gekom dat dokters oortuig moet word van die belang van verdere navorsing, spesialisasie in rehabilitasie en die implementasie van bewese beroerte rehabilitasie metodes. Sy beveel aan dat administrateurs van beide die privaat en staatssektor sowel as verteenwoordigers van nie regerings organisasies betrokke raak om bogenoemde te bewerkstellig. Daar moet vasgestel word waarom dokters huiwerig is om bestaande kennis te implemteer. Beroerte rehabilitasie opleiding moet beskikbaar gestel word aan dokters en dokters moet aangemoedig word om bewese kennis soos die gebruik van protokolle, interdissiplinêre spanwerk en verskaffing van inligting oor diagnose, prognose, risiko faktore, opvolg rehabilitasie en ontslag beplanning toe te pas in die praktyk. Die doen van meer navorsing in die privaat sektor word ook aangemoedig.

SLEUTELBEGRIPPE

BEROERTE, REHABILITASIE, AKUTE BEROERTE, PROTOKOL VIR BEROERTESORG, PASIENTOPLEIDING, PASIENT OUTONOMIE, PRIVATE GESONDHEIDSORGSEKTOR.

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DECLARATION

I, Ute Leichtfuss, 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.

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Ute Leichtfuss

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LIST OF ACRONYMS

ADL	Activities of daily life
AIDS	Acquired immunodeficiency syndrome
COPM	Canadian occupational measurement scale
CT scan	Computerised axial tomography
CVA	Cerebral vascular accident
CVD	Cardio vascular disease
DVD format	Digital video disk
FIM	Functional independence measure score
HASA	Hospital Association of South Africa
HIV	Human immunodeficiency virus
ICF	International classification of functioning, disability and health
LOS	Length of stay
MGH	Massachusetts General Hospital
MRI	Magnetic resonance imaging
NGO	Non-governmental organisation
NINDS	National institute for neurological disorder and stroke
NRP	National rehabilitation policy
OT	Occupational therapist
PC	Personal computer
PM&R	Physical medicine and rehabilitation
PT	Physiotherapist
RCT	Randomised control trial
SASF	South African Stroke Foundation
SASPI	Southern African Stroke Prevention Initiative
SLT	Speech and Language Therapist
TB	Tuberculosis
TCP	Team care plan
TIA	Transient ischaemic attack
UCT	University of Cape Town
UK	United Kingdom
WCRC	Western Cape Rehabilitation Centre
WHO	World Health Organisation
WPA	The World Programme of Action

GLOSSARY OF TERMS

Acute-Care

Acute-care is a pattern of health care in which a patient is treated for a brief but severe episode of illness, for the sequel of an accident or other trauma, or during recovery from surgery. Acute-care is usually given in a hospital by specialised personnel using complex and sophisticated technical equipment and materials, and it may involve intensive or emergency care. This pattern of care is often necessary for only a short time (Mosby's Medical Dictionary 2009).

Autonomy

The principle of autonomy derives from the notion of respect for values and beliefs of others. People have the right to self-determination and the freedom to make their own choices unfettered by the intervention of others. The principle of autonomy underlies the medical doctrine of informed consent (Sliwa, McPeak, Gittler, Bodenheimer, King, Bowen and the AAP Medical Education Committee 2002).

Care Protocol

Care protocols are a methodology for the mutual decision making and organisation of care for a well-defined group of patients during a well-defined period. Defining characteristics of a care protocol includes:

An explicit statement of the goals and key elements of care based on evidence, best practice, and patient expectations;

The facilitation of the communication, coordination of roles, and sequencing the activities of the multidisciplinary care team, patients and their relatives;

The documentation, monitoring, and evaluation of variances and outcomes;

The identification of the appropriate resources.

The aim of a care pathway is to enhance the quality of care by improving patient outcomes, promoting patient safety, increasing patient satisfaction, and optimizing the use of resources (European Pathway Association 2005).

Empowerment

Empowerment, as it relates to health care, implies that patient independence is optimised by assisting patients to assert control over their lives. The goal of empowerment is to enable communities, families and individuals to conquer dependence on outside resources and services and to enhance participation and organisation that enables them to control their own destinies (Hendry 2000).

Institution Based Rehabilitation

Rehabilitation is provided during an inpatient stay in a free standing rehabilitation hospital or a rehabilitation unit of an acute or secondary care hospital. Comprehensive rehabilitation programs that encompass multiple, interactive services provided by an interdisciplinary team as well as specialised equipment are offered to the patient. A physician skilled in rehabilitation is available 24 hours a day (American Health Assistance Foundation 2006).

Interdisciplinary Team Approach

In this approach assessments and treatments are done separately, but treatment planning, goal setting and documentation are done cooperatively by all team members, usually during the patient’s case conference. The interdisciplinary model presents a viable team approach. It is reality based in delivery of health care and involves close interaction (Fletcher, Banja , Jann, Wolf 1992).

Medical Model

The medical model of disability means that organisations for people with disabilities are usually controlled by non-disabled people who provide services to people with disabilities. The medical model assumes that it is up to the individual, with the help of rehabilitation, to adapt themselves to society; to learn to fit in and to be as "normal" as possible (Office of the Deputy President 1997).

Multidisciplinary Team Approach

In this approach, professionals do parallel assessments, treatment planning and treatments. Communication mechanisms are built in to ensure feedback from team members (Fletcher 1992).

Out-Patient Rehabilitation

Outpatient rehabilitation is a service available for patients who have moderate to severe physical limitations and who can travel to receive care. It focuses on developing a patient's optimal level of function and community integration (American Health Assistance Foundation 2006).

Patient Education on Stroke

Education on stroke is paramount in the fight to prevent and treat stroke. Education must include all elements of the stroke chain of survival. It requires constant reinforcement and has potential for minimizing the stroke burden (Jauch 2009).

Private Health Sector

In South Africa the Private Health Sector provides health services to the fully paying section of the population. These include clients who pay their own bills, those with medical insurance and clients covered by Workmen’s Compensation and the Motor Vehicle Accident Fund (Department of Health 1998).

Rehabilitation

Rehabilitation includes all measures aimed at reducing the impact of disability for an individual, enabling him or her to achieve independence, social integration, a better quality of life and self-actualisation. Rehabilitation includes not only the training of disabled individuals, but also interventions in the general systems of society, adaptations in the environment (elimination of architectural and attitudinal barriers), equalisation of opportunities, adaptations of the environment and promotion and protection of human rights. Equalisation of opportunities includes access to health and social services, educational and work opportunities, the physical environment, housing, transportation, information, cultural and social life, including sport and recreational activities, to representation and full political involvement in matters of concern to them (Helander 1993).

Social Model

According to the social model there are economic and social barriers which prevent people with impairments from participating fully in society. The social model of disability shifts the focus away from the individuals’ impairment towards society's disabling environments and barriers of attitude and sees disability as a human rights issue (Disability Awareness in Action 2002).

Stroke / Cerebro vascular accident

Stroke/Cerebrovascular accident (CVA) is the sudden death of some brain cells due to lack of oxygen when the blood flow to the brain is impaired by blockage or rupture of an artery to the brain with symptoms lasting 24 hours or longer or leading to death (Webster`s New World™ Medical Dictionary 2003).

Step Down Facilities

Step down facility is inpatient care that follows or forms the latter part of an acute episode in which the patient has been investigated, diagnosed, is in a stable condition and has a treatment plan but requires ongoing inpatient nursing or rehabilitation care (Health Facility Definition, 2006).

CHAPTER 1: INTRODUCTION

1.1 Background to the Study

Stroke is the second leading cause of death worldwide, with two-thirds of strokes occurring in developing countries, such as sub-Saharan Africa (Rothwell, Coull, Giles, Howard, Silver, Bull, Gutnikow, Edwards, Mant, Sackley, Farmer, Sandercock, Dennis, Warlow, Bamford, Anslow 2004; World Health Organisation (WHO) 2004; Connor & Bryer 2006). In the United States, 794 out of every 100 000 people have had a stroke. Each year, 400 000 patients are discharged from hospitals in the United States after a stroke.

According to the South African Stroke Foundation (SAFS) (2006), stroke is the third most important cause of death in this country. The South African Medical Association (2000) predicts that the incidence of cerebro-vascular disease (CVD) in South Africa will increase even further due to an epidemiological transition from predominantly infectious diseases of developing countries to non-communicable diseases (South African Medical Association 2000; Bradshaw, Schneider, Dorrington, Bourne, Laubscher 2002; Connor & Bryer 2006).

However, the burden of stroke extends much further than just mortality, a fact which has profound social and economic implications for society. A patient's recovery after a stroke is often incomplete (Clarke, Black, Badley, Lawrence, Williams 1999; Mayo, Wood-Dauphinee, Ahmed, Gordon, Higgins, Mcewen, Salbach 1999; Mercier, Audet, Herbert, Dubois 2001; Teasell, Foley, Bhogal, Jutai, Speechley 2004) and more than half of stroke survivors are left dependent on others for their everyday functioning (Rothwell et al. 2004). Many patients who suffered a stroke are left with permanent disabilities and are unable to resume their previous lifestyle or employment. It is these factors which make the social and economic impact of stroke one of the most devastating in medicine. The SASF (2006) reports that stroke is the largest cause of disability in South Africa (Connor, Rheeder, Bryer, Meredith, Beeckes, Dubb, Fritz 2005; SASF 2006).

The effects of a stroke can vary widely, depending on its location in the brain, the severity of the attack and the general health of the person who suffered the stroke (American Health Assistance Foundation 2006). The "International Classification of Functioning, Disability and Health" (ICF), an international disease classification system developed by the WHO, classifies disability into three categories i.e. impairment, activity limitation and participation restriction. Impairment relates to the loss experienced in body function or structure, activity limitation refers to the limits imposed on a patient's ability to perform particular tasks or actions and participation restriction to the restrictions on the patient's ability to participate in day-to-day life situations (WHO 2000). There is no linear relationship between the categories; in fact one can be present without the others. In addition to the above three factors, contextual factors, i.e. - everything and everybody in the environment around the patient, - play a major role in determining his or her ultimate ability.

Impairments, activity limitations, participation restrictions and contextual factors can all be addressed by means of rehabilitation. Research projects have produced evidence showing that rehabilitation substantially improves recovery after a stroke and reduces a patient's residual disability (Teasell & Heitzner 2004).

Stroke rehabilitation is an integral part of the post-stroke recovery process (Hale & Eales 2001; Bruno 2004; Teasell et al. 2004; Teasell & Kalra 2005). Some of the factors which have a positive effect on the outcome of a stroke patient's rehabilitation include the severity of the stroke, how soon after the stroke rehabilitation commences, the manner in which rehabilitation is structured, the duration of rehabilitation as well as the availability of social support (Reddy & Reddy 1997; Rhoda 1999; Rosenberg & Popelka 2000).

Rehabilitation should not only address the patient's impairment but should also improve his or her quality of life. As much as possible, it should aim to enable the individual to live independently at home and to fully avail himself of job and recreational opportunities (Hoening, Homer, Duncan, Clippe, Hamilton 1999; Mayo et al. 2000; Ward & Madison 2000; American Heart Association 2006).

Stroke rehabilitation involves professionals from many health care disciplines such as doctors, nurses, social workers, physiotherapists, occupational therapists, speech and/or mental health professionals (Regensberg 1997). These professionals can work together with the patient and family on a multidisciplinary, interdisciplinary or transdisciplinary basis or individually (Regensberg 1997; Paolucci & Antonucci 2000; Bruno 2004; Kwakkel, Kollen, Lindeman 2004; Teasell & Kalra 2005).

The timeliness and intensity of rehabilitation interventions are important factors in maximising a patient's functional recovery (Cifu & Stewart 1999). Assessment by all members of the professional team should commence as soon as possible after a disabling stroke (South African Medical Association 2000). This will serve to determine the extent of the stroke as well as what further investigations are required and as a guideline to plan future management and determine rehabilitation potential of the patient (Bryer 2000; South African Medical Association 2000; Rhoda & Hendry 2003).

Therefore, rehabilitation should commence as soon as possible, preferably as soon as the patient is medically stable, which often means between 24 and 48 hours after the onset of the stroke (South African Medical Association 2000; Bruno 2004). It should continue until the patient has reached his or her optimal physical, sensory, intellectual, mental and/or social functional levels, thus providing patients with the tools to enhance their quality of life and achieve a higher degree of independence. Rehabilitation may include measures to provide and/or restore functions, or compensate for the loss or absence of a function or functional limitation (National Institute of Neurological Disorder and Stroke (NINDS) 2006).

An important goal of management during the acute phase is to plan for future rehabilitation and to ensure that the patient will progress to a rehabilitation setting most suitable for him or her (Jorgensen, Nakayam, Raaschou, Vive-Larsen, Stoir, Olsen 1995; Sturm, Dewey, Donnan, McDonnell, McNeil, Thrift 2002; Bruno 2004). By the time the patient can be discharged from the acute-care hospital, the rehabilitation team - and this includes the patient and family - should have gone through a decision-making process and have decided on suitable follow-up rehabilitation.

Stroke rehabilitation following discharge from the acute-care hospital can be conducted on an in-patient or out-patient basis. In-patient rehabilitation is done at free-standing rehabilitation hospitals or rehabilitation units in acute-care hospitals, or in nursing facilities. Out-patient rehabilitation can be done at the patient’s home, in a comprehensive out-patient rehabilitation facility or as out-patient rehabilation at a general hospital (Callahan 1995; Cifu & Stewart 1999; Bruno 2004; American Health Assistance Foundation 2006).

To be able to reach an optimal decision on a suitable rehabilitation setting, one needs to be adequately informed about the disease and its prognosis, as well as the different rehabilitation settings and their advantages and disadvantages (Clark & Smith 1998; American Health Assistance Foundation 2006). This information should be provided to the patient and his or her family from admission to the acute-care hospital (Jorgensen et al. 1995; Reddy & Reddy 1997; Sturm et al. 2002). From the onset of the stroke, health care professionals should encourage the patient to play an active part in all decision-making processes (Lerman, Brody, Caputo 1990; Reddy 1997; Jones 1998; Blackmer 2000). Ideally, the final decision should emerge from ongoing discussions between the patient, his or her family and the rehabilitation team (Lerman, Brody, Caputo 1990; Jennings 1993, Venesey 1995). The principles of autonomy should be adhered to at all times (Shah, Vanclay, Cooper 1989; Lerman et al. 1990; Venesey 1995; Blackmer 2000; Teasell & Kalra 2005). It is thus quite clear that as far as possible, the patient’s individuality and autonomy should always be respected.

1.2 The Motivation for and Ambit of the Study

The researcher is a practising physiotherapist who has a special interest in the treatment of stroke patients. She has gained considerable working experience as part of a multidisciplinary team, treating both in- and out-patients who suffered a stroke. As a private practitioner, she also does home visits to treat adult hemiplegia. She has worked in the public and private health care sectors both in Munich, Germany and in Cape Town, South Africa.

The researcher’s extensive working experience has shown that there are substantial differences in the benefits associated with each rehabilitation type. A stroke patient’s progress during rehabilitation depends on the provision of adequate information to the patient and the integration of both patient and family members into the entire process of the choice of rehabilitation setting.

There is a lack of co-ordination between stroke rehabilitation programmes in South Africa as well as an absence of a central health plan for the rehabilitation of stroke patients (Fritz 1995; Rhoda 1999). According to Rhoda (1999), the rehabilitation of stroke patients in the Western Cape suffers from a lack of definite structure. Clients admitted to acute-care hospitals in the public sector receive acute in-patient rehabilitation services for the duration of their hospitalisation. On discharge, they are referred to community rehabilitation services, with a small number being referred to sub-acute in-patient facilities (Rhoda 1999). On the other hand in the researcher’s experience many stroke patients, who are managed in the private health care sector in the Western Cape Metropole, are referred to specialist stroke centres. The researcher sought to ascertain the grounds on which such referrals were made. It also sought to explore what criteria were used in choosing rehabilitation settings for patients in the private sector and whether patients and their families were included in the decision-making process.

Many patients and family members agree to the choice of a rehabilitation setting simply because the doctor told them “*it is the best*” or “*this is what I would do for my mother*”. Conceivably, not all the alternative rehabilitation settings were discussed with them and the patient and his or her family did not play an active role or any role at all in the decision-making process. Such observations have led this researcher to examine the probability that some doctors from the private health care sector of the Western Cape Metropole are still working within the medical model, according to which the physician makes the decisions “in the patient’s interests” while giving little consideration to patient autonomy.

It sometimes happens that patients are discharged from the acute-care hospital on very short notice. Team members, including patient and family members, as well as other health professions, such as physiotherapists, occupational and speech and language therapists have not had enough time, to consider all the rehabilitation options. It is this researcher’s firm conviction that discharge planning is a process, which should start from the day of admission or the day thereafter and not on the final day of hospitalisation (Landrum, Schmidt, McLean 1995). This will afford patients and their family more time to consider all options and to reach a prudent decision. Through this study, the researcher also hopes to determine at what stage discharge planning is initiated and what prior action was taken to plan for discharge.

In many instances doctors form specialised stroke units are consulted and asked to assess the patient and to make a decision on whether the patient is a suitable candidate for admission to the stroke unit. Should the question not be whether the stroke unit is suitable for the patient and their family members?

The researcher has also noticed that in other instances, patients and their family were left to initiate the rehabilitation process on their own. Typically, a doctor or other professional would send a patient home with the remark “*there is nothing more we can do for you*”. In such a situation, the family would not receive any information about different rehabilitation alternatives or even about the patient’s prognosis.

Finally, the researcher has endeavoured to find out whether, in the case of a patient treated in the private health care sector, the patient and family members prefer treatment to take place within the medical model or in the social model of health care. Related questions are: how comfortable do patients and their family members feel about being included in the decision-making process; are they given adequate information about the choices available; do the patients feel free to state their own wishes or are they too traumatised by their recent impairment to do so; do they feel intimidated by health care professionals or do they feel sufficiently empowered, to express their own wishes and preferences and to contribute to the final decision?

1.3 Significance of the Study

To date, there have been several studies on the merits and demerits of various post-stroke rehabilitation settings and treatments. But this researcher has found nothing in the literature, which has tried to establish the pattern of existing referral processes or, more importantly, what criteria have informed the referral choices made by health care professionals. This study would therefore seem to be a first of its kind.

The significance of this research is thus twofold: Firstly, to make doctors and other health care professionals more aware of the merits and demerits of different types of rehabilitation settings and treatments. But secondly, and more importantly, the researcher hopes to foster awareness among doctors and other health care professionals, of the need to furnish stroke survivors and their families with adequate information about their condition and the full range of treatment choices.

The study also hopes to provide information on whether patients and their families want to be more included in the decision-making process or whether they feel overwhelmed by it.

It is hoped that the study will empower patients and their families by increasing their awareness of the right to make their own decisions on any medical procedure.

It is also hoped that this awareness will conduce to a model of stroke treatment which includes the patient and his family in the process of treatment choice and which fully respects the patient’s individuality, autonomy and dignity.

1.4 Study Process

The researcher conducted a review of the literature (chapter 2) relevant to the study’s aims and objectives. In particular, she concentrated on stroke epidemiology, including a discussion on national and international stroke incidence and prevalence as well as stroke prevention and management in general and in the private health care sector in South Africa. Concepts of autonomy and informed consent were included in the literature review as the researcher believed that these were crucial aspects underpinning this study.

The researcher then chose the study methodology (chapter 3) best suited to the study’s aims and objectives. A pilot study was conducted to ascertain the appilicability and validity of two self-designed questionnaires.

All participants in the main study were then interviewed. The results were documented (chapter 4) followed by a discussion based on the most pertinent findings (chapter 5). The study ended with a conclusion and some recommendations (chapter 6), drawn from the results.

1.5 Summary

Stroke not only has a high mortality but also leaves many survivors with residual and sometimes permament disabilities. A well-organised, well-structured rehabilitation process, which includes the timely provision of information and pre-planning of the post-acute rehabilitation setting can mitigate the effects of such disabilities and accelerate the patient’s recovery.

The researcher, a physiotherapist with experience in stroke rehabilitation both in South Africa and overseas, made a study of the rehabilitation of stroke survivors, using data collected in the private health care sector of the Western Cape Metropole. It is hoped that the findings of this study will increase the awareness of doctors, other health care professionals and patients of the benefits of a host of alternative treatment modalities and, thus make a contribution in the fight against stroke by bringing about a reduction in residual disabilities.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

The body of literature relating to stroke is vast and includes a broad range of topics such as aetiology, epidemiology, risk factors, preventative medicine, effectiveness of acute and post-acute treatment and post-stroke management. The focus of this review will however be confined to the following specific areas: the private health care sector in South Africa and in particular in the Western Cape with specific reference to stroke management in this sector, the epidemiology of stroke, including risk factors and causes of stroke, prevention of stroke, post-stroke prognostic factors, the effects of a stroke and stroke rehabilitation. Furthermore, the author will explore the concepts of autonomy and informed consent, both of which are crucial to this research.

2.2 Epidemiology of Stroke

2.2.1 Nature of stroke

Stroke is a heterogeneous condition made up of two pathological types: cerebral infarction and cerebral haemorrhage (Connor & Bryer 2006). Most strokes are cerebral infarcts (ischaemic strokes). Haemorrhagic strokes make up only between 10% and 15% of all strokes but are associated with a higher risk of fatality than cerebral infarction (Paolucci, Antonucci, Grasso, Morelli, Troisi, Coiro, Bargoni 2003; Connor & Bryer 2006; Massachusetts General Hospital (MGH) Stroke Service 2006). Computerised axial tomography (CT scan) is the most reliable and most common way of differentiating between cerebral infarct and haemorrhage (Poungvarin 1998). About one half of all patients with intra-cerebral haemorrhage die within the first month after the acute event (Paolucci et al. 2003). Despite its high mortality and morbidity rates, stroke is still the Cinderella of vascular diseases in South Africa (Connor & Bryer 2006; Steyn 2007) because it has never been independently treated as a separate health issue (Connor et al. 2005; SASF 2006).

2.2.2 Stroke mortality

In the United States more than 700 000 people suffer a stroke each year. Only two-thirds of these individuals survive (De Jong, Horn, Conroy, Nichols, Healton 2005; National

Heart Foundation 2006). In Africa, a Tanzanian study reported that age-adjusted stroke mortality rates in that country are significantly higher than in England and Wales (Walker, Rolfe, Kelly, George, James 2003; Connor & Rheeder 2005).

In South Africa, stroke accounts for between seven and ten percent of all deaths and is the fourth most common cause of death (Dewas & Patel 1997; Connor & Rheeder 2005). About 60 people die every day as a result of stroke (Steyn 2007).

Connor and Bryer (2006) state that in South Africa, more females than males die of stroke. The overall age-standardised mortality rate for stroke in South Africa is 124.9 / 100 000. Stroke is the most common cause of death in the 55 to 74 age groups and the second most common cause of death in the 35 to 54 and over 75 age group (Connor & Bryer 2006). Young adults (15 to 45 years of age) account for between 13% and 30% of the South African stroke population (Hoffmann 2000). Of those who die from stroke, 7.5 % are in the workforce (25 to 64 years of age) (Fritz 1995; South African Medical Association 2000; Connor & Bryer 2006). It is also reported that the mean age of stroke survivors (± 54 years) in African countries (Rouillard 2007, Onwuekwe, Ezeala-Adikaibe, Ohaegbulam, Chikanj, Amuta, Uloh 2008) is much lower than that in developing countries (+ 64 years) (Bonita, Mendis Truelson 2004).

The crude death rate of all cardiovascular diseases (CVD) in South Africa is 199 / 100 000, which is much lower than that in other developing and developed countries e.g. Brazil, China, India, Portugal or the USA (table 2.1). However, if one compares the crude CVD death rates in the working force in different countries, South Africa shows much higher figures than other countries (table 2.1). The economical impact on the country is a matter of considerable concern (The University of Sydney et al. 2004).

Table 2. 1: Comparison of current crude CVD mortality in 4 different countries as well as comparison of age-specific mortality in the working age population expressed as a rate per 100 000 of the population

	S.A	Brazil	India	Portugal	USA
Crude CVD death rate per 100,000	199	225	266	391	317
CVD death rate per 100,000 Age 35 – 64 (Males)	097	071	081	052	056
CVD death rate per 100,000 Age 35 – 64 (Females)	068	049	056	018	028

The burden of stroke is expected to increase in future because of the rapid rise in elderly populations in both developed and developing countries (Rothwell et al. 2004). Leeder, Raymond and Greenberg (2004) as well as other studies state that premature deaths caused by heart and blood vessel disease are expected to increase by as much 41 % between 2000 and 2030 in economically developed countries (South African Medical Association 2000; Bradshaw et al. 2002; Leeder et al. 2004; Rothwell et al. 2004; Steyn 2007). In South Africa, although not a developed country in the full sense of the word, the effect of lifestyle changes, especially in urban and peri-urban areas also cause an increase in these diseases. Work and leisure activities are becoming increasingly sedentary and fast food consumption is also on the increase (Steyn 2007). More and more people are being exposed to these lifestyle risks as a result of the rapid rate of urbanisation.

2.2.3 Stroke morbidity

The burden of stroke does not lie only in its high mortality rate. Its impact on morbidity is, if anything, even higher, as up to 50% of all stroke survivors are left chronically disabled (Agency for Health Care Policy and Research 1995). Stroke is the main cause of long-term neurological disability in adults, with more than half of all stroke survivors left dependent on others for everyday activities (Rothwell et al. 2004; Connor & Rheeder 2005). Further social and financial burden is caused by secondary complications of stroke which have been reported to occur in 48-96% of stroke survivors (Roth, Lovell, Harvey, Heinen, Semi 2001).

The age-standardised prevalence of stroke in high-income countries in a recent review of studies ranged from 461 to 733 per 100 000 (15-5) for people aged over 65 years. In Auckland, New Zealand, it is estimated that approximately 461 per 100 000 people aged over 15 years made an incomplete recovery from a previous stroke. In the United States, there are approximately 4.8 million stroke survivors, of whom 1.1 million suffer from a functional limitation of one sort or another (De Jong et al. 2005). In South Africa, the crude prevalence rate for stroke is estimated to be 300 / 100 000 (Hale & Eales 2001; SASPI Project Team 2004). Stroke prevalence is higher in females (348 / 100 000) than males (246/ 100 000). Of particular interest is the fact that South Africa’s rural stroke prevalence is about three times lower than in New Zealand, but the prevalence of people needing help with at least one daily activity due to stroke is much higher in South Africa than in New Zealand (200/100 000 compared to 173/100 000). Other studies show that 66% of South African and 60% of Tanzanian stroke survivors needed help with at least one self-care activity (Walker et al. 2003; The SASPI Project Team Stroke 2004; Connor & Rheeder 2005).

In 2005 it was estimated that the direct and indirect costs of stroke in the United States of America amounted to 56.8 billion dollars (De Jong et al. 2005). In 1991, the cost of cardiovascular disease in South Africa was approximately R5.035 billion. This did not include the costs of rehabilitation and follow-up treatment. In the year 2000 the value of cardiovascular disability payments in South Africa reached US $ 70 million (Steyn 2007).

2.3 Causes and Risk Factors of Stroke

Worldwide, studies addressing the aetiology of stroke have identified a multitude of different causes, with variations according to race, region and country. Therefore different management strategies have to be considered (Hoffmann 2000).

The clinical importance of risk factors cannot be over-emphasised, because stroke is, in many instances, a preventable disease (Bonita et al. 2004). Stroke risk factors are divided into those which are modifiable and those which are not. Modifiable risk factors include high blood pressure, smoking, alcohol and other substance abuse, obesity, diabetes, elevated blood lipid levels, atrial fibrillation, carotid artery disease and oral contraceptives. Non-modifiable risk factors include gender, age, race and family history of stroke (Fritz 2000; Hoffmann 2000; South African Medical Association 2000; Kurth, Kase, Berger, Schaeffner, Buring, Gaziano 2003; Connor & Rheeder 2005; Connor & Bryer 2006; MGH Stroke Service 2006; Steyn 2007).

In South Africa there are approximately six million people with hypertension, seven million smokers and three million people with diabetes (South African Medical Association 2000). In 2003, 62% of men and 45% of women older than fifteen years were leading a sedentary lifestyle (Steyn 2007). In the SASPI study of stroke prevalence in rural South Africa, hypertension (at 71%), was the most common risk factor, followed by current alcohol abuse at 20% (Connor & Rheeder 2005), diabetes mellitus at 12%, cigarette smoking at nine % and previous stroke or transient ischaemic attack at between two and seven % (Connor & Bryer 2006).

The highest death rates for CVD in South Africa are seen in Indian and Coloured people, while White and Black Africans have much lower CVD death rates (Steyn 2007). Although White and Black African people show similar rates for cardiovascular diseases, their patterns are quite different. White people die more often of heart attack, whereas the rate of death due to stroke is higher in Black Africans (Leeder et al. 2004; Steyn 2007).

White South Africans present more traditional risk factors, such as hypertension, hyperlipidaemia, alcohol abuse and smoking, while Black South Africans more often had an infection in the two weeks prior to the stroke (Agency for Health Care Policy and Research 1995; Connor & Bryer 2006; Steyn 2007). Fritz mentions infective causes of stroke such as TB, syphilis and HIV/AIDS (Fritz 2000). Not one study has convincingly found HIV to be an independent risk factor for stroke (Connor & Bryer 2006). However, the Durban Stroke Register found 20% of young black stroke patients to be HIV positive (Patel, Saccor, Francis, Bill, Bhigjee, Conolly 2005; Connor & Bryer 2006). Some studies have shown that people from lower socio-economic groups are at a greater risk of stroke (MGH Stroke Service 2006).

2.4 Prevention of Stroke

Over the past two decades, findings of randomised trials have shown that several interventions are effective in the primary prevention of stroke (Penn 2000; Outpatient Service Trialists 2002). If current preventative strategies are implemented, stroke incidence can be reduced by as much as 50% to 80% (Rothwell et al. 2004). Peter et al. (2004) investigated stroke incidence in Oxfordshire, UK and found a significant reduction in incidence and mortality over the past 20 years.

Prevention starts with education about stroke, its presenting symptoms and the risk factors that predispose a person to stroke. The South African Medical Association (2000) recommends that immediate priority should be given to the education of all health care workers and members of the public about stroke, especially about the risk factors, emergency and immediate urgent care, secondary prevention and rehabilitation (Hale & Eales 2001; Bhogal, Teasell, Foley, Speechley 2003; Bruno 2004). The National Rehabilitation Policy (1998) lays out strategies for preventing disabilities, including health education about preventing disability, screening programmes and the monitoring of groups at risk (Department of Health 1958). According to the policy guidelines, there should be no barriers – either financial or environmental - that hinder people in accessing preventative strategies. It is also of utmost importance that health information is presented in such a way that it catches the reader's interest and is easily understood by the lay person. Warning signs of stroke should be widely communicated to members of the public and health care professionals so that stroke patients can seek help as quickly as possible (South African Medical Association 2000; Bhogal et al. 2003).

Five major warning signs are:

- Weakness, numbness or paralysis of face or an arm or leg on one or both sides of the body;
- Sudden blurred or decreased vision in one or both eyes, sudden onset of double vision;
- Difficulty in speaking or understanding;
- Dizziness, loss of balance or any unexplained fall or unsteady gait;
- Headache, unusually severe and/or abrupt in onset or unexplained changes in the pattern of headaches (South African Medical Association 2000).

The SASF (2006), under the leadership of Professor Vivian Fritz, has promoted stroke awareness through the annual Stroke Awareness Week, using multiple media modalities, pamphlets, fun activities and various other events. Doctors, nurses and allied professionals have been educated through congresses, workshops, continuing education meetings, television programmes and printed media (Connor & Bryer 2006). This should continue on a regular base.

2.5 Effects of a Stroke

The most common impairments that occur following a stroke are loss of motor functions, sensory deficits, abnormal tone, perceptual and cognitive limitations, speech impairment, bladder control problems or incontinence, depression and/or emotional lability (Agency for Health Care Policy and Research 1995).

Activity limitations due to motor function impairment following a stroke relate mostly to difficulties in walking, standing and sitting balance. Self-care activities such as dressing and eating can become difficult due to decreased arm and hand function. Communication problems include receptive and/or expressive language deficits. (Mayo et al. 1999; WHO 2000; Mercier et al. 2001).

Participation restriction is mainly related to an inability to return to previous employment, restriction in recreational activities and restrictions on participation in social events (Clarke et al. 1999; Rhoda 1999; Mercier et al. 2001).

Many patients and therapists have rated speech and language difficulties as the most significant and frustrating impairment for a patient and one which potentially has the largest impact on the patient's sense of "well-being" (Penn 2000). Care must be taken to distinguish between cognitive deficits and difficulties in communication.

Although preventable, secondary complications like bed sores, contractures, joint and soft tissue pain, deep vein thrombosis, chest infections and depression are very common and can have a negative influence on the recovery process (Geffen 2000).

Recovery from the above-mentioned deficits is often incomplete, and residual deficits may continue to affect the functioning of the individual, contributing to limitations on activity and participation restrictions (Mercier et al. 2001). Rehabilitation is therefore essential to minimise the effects of the stroke (Farham 2004; Teasell & Kalra 2005).

2.6 Prognostic Factors

It is generally believed that haemorrhagic stroke survivors have a better neurological and functional prognosis than ischaemic stroke survivors but no clear scientific proof of this has emerged to date (Paolucci et al. 2003). Results of a case-control study showed faster functional improvement in haemorrhagic stroke patients than in non-haemorrhagic stroke survivors (Chae, Zorowitz, Johnston 1996). Many studies on the functional outcome of stroke survivors identify severity of stroke as shown on the CT scan, age and onset-admission interval as powerful prognostic factors (Rouillard 2007).

Stroke severity is considered the most powerful prognostic factor because disability is a consequence of the severity of neurological impairment (Jorgensen et al. 1995; Paolucci & Antonucci 2000; Paolucci et al. 2003). Some authors report that one can predict functional outcomes for stroke survivors by looking at indicators such as disability level on admission, incontinence, degree of motor paresis, cognitive status, recurrent stroke, sitting balance and level of perceived social support (Reddy & Reddy 1997). Dewas and Patel (1997) set up four categories, namely:

- Fully dependent and/or terminal cases;
- Patients with a low baseline level of function;
- Patients with moderate impairment, who will benefit most from ongoing rehabilitation;
- Patients with minimal disabled impairment, who will soon regain functional independence with little or no rehabilitation.

Paolucci and Antonucci (2000) state that how soon after the onset rehabilitation was commenced can be seen as a relevant prognostic factor of functional outcome. He reasons that the best functional recovery occurs during the early weeks of treatment while the effectiveness of stroke rehabilitation gradually decreases after the first week of treatment. Oczkowski and Barreca (1993) found the functional independence measure score (FIM) taken on admission to be the best predictor of outcome disability. This researcher appeals to health professionals to bear in mind that a negative prognosis can demotivate and deprive a patient of hope, causing frustration and depression. Sherr Klein (2007), invoking her own experience points out how important hope is for both family and patient in the long walk of rehabilitation. She argues that reality will assert itself in due course and that a prognosis can always be changed subsequently.

Detailed knowledge of the outcome of stroke, stratified according to initial severity, impairment, age and onset of rehabilitation is indispensable to rational planning of rehabilitation and discharge placement as well as informing both patient and family about the possibility of further recovery.

2.7 Recovery after Stroke

2.7.1 Definitions of recovery

One can distinguish between neurological or “true” recovery and functional recovery. Kwakkel et al. (2004) define neurological recovery as an improvement in neurological deficits or impairments due to local processes within the central nervous system such as neural repair and adaptive reorganisation which occurs mostly in the early stages after stroke.

Functional recovery refers to improvement in abilities to perform activities of daily life, or participation in pre-stroke roles, which can occur during and also after neurological recovery. Compensatory mechanisms as well as rehabilitation lead to functional recovery (Kwakkel et al. 2004).

2.7.2 Pattern of recovery

The literature reports that the degree of recovery is related to initial severity of the stroke as well as the physical wellbeing of the patient before the stroke. Most recovery occurs in the first four to six weeks post-stroke. Improvement continues at a slower rate thereafter and might reach a plateau around three month post-stroke (Kwakkel et al. 2004).

The Copenhagen Stroke study reports that 80% of participants who were unable to walk on admission reached their best walking function after six weeks, and 95% after eleven weeks (Jorgensen et al. 1995). Optimal upper limb function seems to take longer with recovery being achieved after twelve weeks (Teasell & Bitensky 2004). Steyn (2007) reports most activity of daily life (ADL) recovery in the first thirty days post-stroke, whereas patients who had suffered a severe stroke reach a higher level of recovery after one to three months.

This researcher supports the literature which concludes that functional recovery can be seen up to and beyond six months (Kwakkel et al. 2004; Sturm et al. 2004; Desrosiers, Rochette, Noreau, Bourbonnais, Bravo, Bourget 2006). The researcher also strongly agrees with Dobkin (2004), who goes further by suggesting that if treatment is goal-directed, it can induce improvement at any time post-stroke. It is believed that the lack of improvement six month post-stroke might be due to habituation to the rehabilitation programmes or even to discontinuation of treatment at this point (Page, Gater, Bach-y-Rita 2004).

2.8 Stroke Rehabilitation

2.8.1 International and national health care policies

The World Programme of Action (WPA) concerning disabled persons highlights three areas of importance, namely the prevention of disability, rehabilitation and the equalisation of opportunities. The WHO promotes equal opportunities and the recognition of human rights for people with disabilities. It further focuses on the early identification and treatment of those with disabilities, including the provision of assistant devices (WHO 2006).

Health services in South Africa are being transformed from a primarily institution-based service to a community-based service. Government has promised that an integrated package of essential primary health care services will be available to the entire population. It will provide the solid foundations of a single, unified health system and will be the driving force in promoting equity in health care (Department of Health 2000).

The Primary Health Care Package for South Africa states that specific rehabilitative services include a basic assessment of people with disabilities followed by an appropriate treatment programme, in consultation with the disabled person and their family (Department of Health, 2006). Rehabilitation services are an integral part of the services provided at the primary level and should be effective, accessible and affordable to all disabled people in South Africa (Department of Health 1998; Department of Health 2006). In 2003, Health Minister Manto Tshabalala-Msimang announced a free health care policy at primary health care level for people with disabilities. This includes outpatient visits, admissions to hospitals as well as assistant devices such as wheelchairs. The policy was supposed to have been implemented in July 2003, but five years later, it has still not been fully implemented and assessment criteria and implementation procedures are still under investigation (Department of Health 1998).

The Department of Health speaks of the provision of rehabilitation services which are equitable, affordable and accessible to all. These services are to be provided by three main service providers: the Public Sector, Non Government Organisations (NGOs) and the Private Sector. According to the NRP, resources could be utilised much more effectively if the three providers took advantage of each other’s inherent strengths instead of providing parallel services (National Department of Health 2006).

2.8.2 Early rehabilitation during 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 2000) recommend that stroke be treated as an emergency with assessment and treatment taking place within six hours of onset. Treatment within a specialised acute stroke unit is recommended. Rehabilitation is an integral part of early stroke management and should start as soon as the patient's condition permits it. Any delay may increase mortality as well as greatly prejudice the functional outcome for the stroke survivor. (Agency for Health Care Policy and Research 1995; Bryer 2000; Paolucci et al. 2003; Hale & Eales 2001; Teasell & Kalra 2005). Several case-control studies have confirmed that early specific rehabilitation treatment enhances improvement in ADL (Cifu & Stewart 1999; Paolucci et al. 2003; Teasell & Kalra 2005). Swallowing abnormalities (dysphagia) must be recognised early on and treated appropriately by a speech therapist (South African Medical Association 2000). Nursing care, occupational- and physiotherapy are all designed to enhance the rehabilitation process. Targets need to be set, to provide access for all patients to early and efficient stroke care, especially by reducing the delays experienced by stroke patients in admission to acute in-patient and out-patient rehabilitation facilities (Paolucci et al. 1998; Rhoda 1999; South African Medical Association 2000).

2.8.3 Stroke care protocol

Evidence on both, acute and post-acute stroke rehabilitation suggests that organised care for post-stroke patients is strongly recommended in order to achieve optimal outcomes for the patient (Kwakkel et al. 2004). Therefore many health professionals suggest the use of stroke care protocols or generic treatment plans. A goal-oriented, co-ordinated approach, which incorporates optimal care principles, is required to put together the best package (Hale et al.1999; South African Medical Association 2000). Acute management plans should be used from the day of admission right through to discharge. Protocols for early management are said to reduce morbidity and mortality by up to 20% (South African Medical Association 2000).

The acute management plan should not only include guidelines on emergency assessment and treatment to improve cerebral perfusion, but also refer to the appropriate team members, team meetings, appropriate documentation, identifying of rehabilitation goals and objectives, patient and family education and counselling, risk factor modification, counselling on lifestyle changes, discharge planning and referral to post-acute rehabilitation, just to mention some of the criteria (Dewas & Patel 1997; South African Medical Association 2000). Dewas and Patel (1997) describe a team care plan (TCP) which should be developed on the post-admission ward round. This interdisciplinary document captures the results of the post-admission stroke ward round, the goals of treatment and gives a clear indication of task allocation. Using stroke care protocols will enhance the rehabilitation process with efficiency and satisfaction for both, patient and family as well as the health professionals, involved in the rehabilitation process. Patel et al. (1997) prove in a clinical trial that implementing a TCP will lead to a shorter length of stay in the acute-care hospital.

2.8.4 Length of stay in the acute-care hospital

The Department of Neurology at Orebro University Hospital in Sweden undertook a study to clarify the factors which determine the length of stay (LOS) of stroke patients in the acute-care hospital. Factors like gender, social circumstances, risk factors, dementia, stroke type, and stroke severity were registered. The items that best correlated with LOS, were paresis, unilateral neglect and level of consciousness (Appelros 2006). Results showed that independent predictors of acute LOS were stroke severity, pre-stroke dementia, and smoking as a risk factor. The mean acute LOS was twelve days (Bresick 1997). In 1998 the average length of hospitalisation following a stroke at Baragwanath Hospital, South Africa was also found to be twelve days (Hale & Eales 2001).

There is a global move towards the early discharge of stroke patients, with further follow-up and management in the community (Rhoda & Hendry 2003). Prospective payment for acute-care hospitalisation has resulted in the shifting of patient care to sub-acute-care settings and subsequent trends towards greater vertical integration of health delivery systems. Institution-based care is becoming more expensive and Medical Aids are trying to shorten LOS in both the acute and the post-acute facilities. As a result, some studies (Holmquist, Von Koch, De Pedro 2000; Larn 2001) try to find ways to shorten LOS in the acute-care hospital. Dewas and Patel (1997) prove a shorter LOS if a suitable tailored rehabilitation package is ensured for the patient, whereas Cifu and Stewart (1999) reported that the period of hospital stay was significantly shortened and the patient's functional outcome significantly improved if interdisciplinary rehabilitation services commenced within the first 72 hours after a stroke. On the other hand Strasser et al.

(2005) showed positive results of longer LOS in the acute-care hospital when patients were managed by a structured team which did efficient goal setting. Strasser, Falconer, Herrin, Bowen and Stevens (2005) speculate that there is an inverse relationship between managerial effectiveness and team cohesiveness to LOS. This, they say, is because the team succeeds in advocating longer hospitalisations despite pressure to discharge patients quickly (Strasser et al., 2005, p. 406).

2.8.5 Planning for discharge from the acute-care hospital

Discharge planning should start on the day of admission or the day thereafter and not a day or two before discharge. Discharge planning requires the close involvement of both patient and family as well as the inclusion of all the health care professionals involved (South African Medical Association 2000). Ongoing communication with the family as well as other health care professional is necessary to establish the optimal discharge placement for the patient. One needs to consider social, environmental and financial factors and preferences that will influence decisions about rehabilitation (Agency for Health Care Policy and Research 1995). Adaptive devices like wheelchairs, tripots and/or orthotic devices should not be provided immediately before discharge. The patient should have enough time to become familiar and comfortable with the use of these devices if he or she will not receive any further rehabilitation. Sometimes one has to consider whether it is better for the patient to stay for a few more days in the acute-care hospital, so that he or she can build up the capacity to cope with and benefit from an intensive rehabilitation programme, offered at specialised rehabilitation facilities. Sending the patient to a specialised rehabilitation facility too early might lead to frustration for health professionals as well as patient and family. It is also a waste of financial resources, which could be very useful at a later stage. On the other hand, one sometimes has to consider whether the patient and family are ready for discharge to the patient’s home. Once again, early discharge can lead to frustration, fear and emotional stress for patient, family and health professionals, particularly the care giver. Patient and family need to be well-informed on all rehabilitation options, including their advantages and disadvantages (SASF 2006).

2.8.6 Patient and family education

Stroke information, training and health education programmes should be available for all patients and family members (Agency for Health Care Policy and Research 1995; Hale et al. 1999; South African Medical Association 2000; Wandel, Jorgensen, Nakayama, Raaschou, Olsen 2000; Hale & Eales 2001; Milne & Pikney-Atkinson 2004). The purpose of patient education is to inform, reduce anxiety, modify the behaviour of and empower the patient to participate in high-quality stroke care programmes. This will prevent illness progression, complications, unnecessary participation restrictions and the risk of a second stroke (Hanger & Wilkinson 2001; Bhogal et al. 2003; Milne & Pikney-Atkinson 2004).

An acute stroke causes multiple stresses, making it difficult to retain and process information because of reduced concentration, anxiety, depression and/or tiredness. Single or once-off education sessions inevitably fail as learning is an evolving and incremental process for the patient. The information needs to be repeated several times and should also be presented in different ways (Hanger & Wilkinson 2001). Education should start during the acute phase, but must continue well beyond a patient's return to the community. Successful stroke education takes into consideration the fact that there should be active interaction between the patient and the information provider. The information given should be relevant and customised to the patient's specific needs (Hanger & Wilkinson 2001).

One way of providing information to the patient and family is the use of post-stroke rehabilitation fact sheets. A series of videos in DVD format is available, giving information on stroke care and rehabilitation. These information sources are published by many health organisations, for example: the National Institute of Neurological Disorders and Stroke (NINDS), USA; Information from your family doctor, USA; SASF and the American Heart Association. They are often given to the patient and/or the family members by the health care professionals. These information sources provide background information, but are generalised and do not contain information specific to a particular patient's stroke, medical condition, social circumstances and rehabilitation options within the vicinity of the patient's home and should therefore not be used in isolation (Clark *&* Smith 1998).

A systematic review of the literature showed evidence of the strong benefit of stroke education if an active educational-counselling approach is adopted (Mant, Hicks, Fletcher 1996; Rodgers, Bond, Curless 2001; Evans, Harraf, Donaldson, Kalra 2002). Bhogal et al. (2003) reports of two studies which show negative results if information packages and workbooks are used whereas information given by means of leaflets and fact sheets showed hardly any difference in outcome. Therefore information sheets should never be used in isolation. They can be used as an aid by health care professionals after several discussions with the patient and family on the relevant issues.

A study done in Soweto reported that stroke survivors showed an extreme lack of knowledge about their disease process. Of the nine patients interviewed, all knew that they had suffered a stroke, but five did not know the cause of the stroke. All nine participants suffered from hypertension and were on medication. However they did not know what the medication was for (Hale & Eales 1999). Pound, Gompertx and Ebrahim (1994) reported on a study where 28% of 219 stroke patients were dissatisfied with the amount of information they received about their prospects of recovery and the relationship between rehabilitation and recovery.

2.9 Team Work Approaches

Stroke rehabilitation is most effective if professionals from different disciplines work together as a team (South African Medical Association 2000; The University of Sydney et al. 2004). Comprehensive assessment of all aspects of the patient's illness and disability, requires close collaboration between the disciplines involved (Agency for Health Care Policy and Research 1995). All professionals participating in the stroke rehabilitation programme have a role to play in training, education and research on stroke. Ideally, the team should meet regularly to discuss the immediate and long-term management and rehabilitation of patients. The quality of team functioning can greatly influence the outcome of rehabilitation (Strasser et al. 2005).

The literature describes three different kinds of team work approaches:

- Multidisciplinary team work approach;
- Interdisciplinary team work approach;
- Transdisciplinary team work approach.

2.9.1 Multidisciplinary team work approach

In a multidisciplinary team work approach, each team member contributes his/her discipline-specific skills, resulting in a summation of individual assessments (Dewas & Patel 1997; Regensberger 1997). Each health care professional has his or her own set of documentation for each patient. This is often the start of poor communication between team members (Dewas & Patel 1997). Therapists set their own goals, seldom consulting the other health care professionals. This can lead to great frustration, not only for the other health care professionals, but also for the patient and family members. The patient and family members are informed about the rehabilitation goals and settings but are often not integrated into the planning process. Dow, Black, Bremmer and Fearn (2007) describe the multidisciplinary team work approach as one where, most often, the physician is the team leader. The disadvantage of a multidisciplinary team work approach is that often, time is lost through duplication of therapy. Patients might receive different information from the therapists and feel insecure or even confused about the rehabilitation process.

2.9.2 Interdisciplinary team work approach

An interdisciplinary team work approach is defined as one in which rehabilitation services are provided by different health care professionals, who use overlapping skills and knowledge to provide the rehabilitation process (Regensberger 1997). They set up a combined rehabilitation plan and work together towards common goals (Dewas & Patel 1997; Cifu & Stewart 1999). In most cases the TCP is kept in the nursing process file so as to be fully accessible to all team members. The TCP becomes the base of interdisciplinary communication (Dewas & Patel 1997). An interdisciplinary team meets regularly to exchange information on progress and to set new goals for the rehabilitation process (Visagie 2008). One designated team member acts as case co-ordinator and liaises primarily between the professional component of the team and the patient and family. The patient is included in planning and goal setting. By means of an interdisciplinary team work approach, delay of treatment as well as duplication of therapy in the different disciplines is avoided (Regensberger 1997; Visagie 2008).

In an interdisciplinary team work approach, patient and family are part of the team. The team leader can change during the rehabilitation process, depending on the needs of the patient (Dow et al. 2007). Strong leadership, clarity of roles and responsibilities and a willingness to devote time and effort to communication are essential (Agency for Health Care Policy and Research 1995). This approach results in an outcome which is greatly enhanced and more comprehensive than that achieved by a simple aggregation of individual efforts (Regensberger 1997). Cifu and Stewart (1999) proved that the period of hospital stay is significantly shortened and the patient’s functional outcome significantly improved if interdisciplinary rehabilitation services commenced within the first 72 hours after stroke.

2.9.3 Transdisciplinary team work approach

With the transdisciplinary team work approach**,** traditional boundaries are blurred. Assessment and treatment are often conducted by two or more health professionals at the same time, in the presence of the family. There are no formal planning sessions and documentation is often done retrospectively. The relative value of this approach has not been shown in rehabilitation settings and moreover, billing can present problems (Visagie 2008).

However, this researcher believes that team members can learn from other health professionals and integrate specific tasks into their treatment plan. They are also able to look at overlapping problems from a different perspective and tailor their treatment approach accordingly.

2.9.4 Comparison of different team work approaches

Rehabilition offered by a team of professionals following a multidisciplinary team work approach showed improved outcomes when compared to treatment given by an aggregation of health professionals. However, multidisciplinary team work appears to be less effective if there is no regular communication between team members. In an article review on eleven well-designed studies, Cifu and Stewart (1999) found that, compared to the multidisciplinary approach, the interdisciplinary team approach showed improved functional outcomes, improved quality of life, shorter length of stay and decreased costs. The Agency for Health Care Policy and Research (1995) supports the latter findings. Hale and Eales (2001) consulted South African experts in physiotherapeutic stroke rehabilitation on team work approaches and they found that most respondents (97%) voted in favour of the interdisciplinary approach (Dewas & Patel 1997; Hale & Eales 2001). Cifu and Stewart (1999) reviewed studies that compared the interdisciplinary and multidisciplinary team work approaches as a predictor of outcome following a stroke. The results showed that interdisciplinary work and task-specific training is more often associated with improved outcomes than the multidisciplinary approach. This researcher could not find any comparison between the transdisciplinary team work approach and the other two approaches in the literature. It would seem that this concept is not often used in rehabilitation facilities.

2.10 Rehabilitation Services and Settings

2.10.1 Intensity of rehabilitation services

Rehabilitation services vary in intensity from low to high. The intensity of rehabilitation services is determined by the frequency and duration of patient-therapist contacts per day. Low-intensity rehabilitation services are usually rendered by only one or two professionals for less than an hour per day and usually only once or twice a week. The patient might live at home with the family or be in a traditional nursing home, from where he is taken to a facility for treatment or, might receive treatment at home. Medium-intensity services involve more therapists and are usually provided on a daily basis for one to two hours per day. Again, these patients usually live at home or are in a traditional nursing home and are treated on an out-patient basis. High-intensity services typically involve the full complement of therapists and are provided for three or more hours on a daily basis. Patients take most often advantage of this service while admitted as in-patients to a rehabilitation unit. Ideally, the intensity of services provided to the patient should be determined by the patient's physical, mental and emotional condition, as well by the consideration of professional opinion (American Health Assistance Foundation 2006).

Unfortunately, in practice, it is often the lack of resources that determines the intensity level of rehabilitation rather than the patient's requirements and coping abilities.

2.10.2 In-patient rehabilitation units

In-patient rehabilitation units are specialist clinics, centres or hospitals, where intensive rehabilitation is offered on a daily basis by a team of health care professionals (American Health Assistance Foundation 2006).

These units are either stroke units or units which admit persons with various diagnoses for rehabilitation. A full range of rehabilitation professionals i.e. specialised nurses, physiotherapists, occupational and speech therapists, psychologists, social workers and physicians are available, often up to twenty-four hours a day. Usually an interdisciplinary team work approach is adopted and comprehensive rehabilitation programmes are provided for each patient. Team meetings are held at least weekly, to establish goals and management plans for each patient. The team assesses the patient's progress, identifies barriers or complications and constantly revises the rehabilitation plan (American Health Assistance Foundation 2006).

Rehabilitation is usually of high intensity and more comprehensive than rehabilitation in other settings and requires more physical and mental effort from the patient (Dow et al. 2007). The patient should be able to cope with at least three hours of intensive therapy from various health care professionals per day.

The advantages of a specialised rehabilitation unit are that the patient receives treatment tailored to his needs from all health care professionals, including the nursing staff. Specialised equipment can be utilised. The patient receives emotional support from fellow patients as well as the staff. Family members also have enough time to adjust to the new situation. In the researcher's experience, some patients benefit from seeing fellow patients, who are worse off than them. The fact that they can help and assist other patients also boosts their motivation and morale.

Disadvantages are that because patients are based in an institution, they often feel isolated from their family and home environment. It also involves higher health care cost. Some patients feel more depressed or demotivated when they see other patients with severe mental or physical impairments (Holmquist et al. 2000; Larn 2001; Teasell & Kalra 2005; Dow et al. 2007).

2.10.3 Out-patient rehabilitation

Out-patient rehabilitation can be provided by the out-patient departments of hospitals or out-patient facilities which might be completely independent of the hospital. They often specialise in stroke rehabilitation. These facilities offer a comprehensive programme of individual rehabilitation services. Patients attend rehabilitation daily, three times a week or once a week. These units are usually staffed by a team of health care professionals, using either a multidisciplinary or interdisciplinary team work approach. The comprehensiveness of therapy ranges from the involvement of one discipline e.g. physiotherapy, to several disciplines e.g. physiotherapy, speech- and occupational therapy (American Health Assistance Foundation 2006).

Advantages of out-patient rehabilitation facilities are: the patient can remain in his home environment, enjoying the support of his family. At the same time he benefits from the emotional support of fellow patients and staff in the out-patient facility. He can further utilise specialised equipment and rely on the skills of specialised staff. Out-patient facilities are also not as expensive as in-patient facilities (American Health Assistance

Foundation 2006). Some patients enjoy the outing, which adds a new dimension to their daily life.

The disadvantages are that the patient needs a family member to drive him to the facility which adds to the care giver's burden. In the researcher's experience, patients sometimes find the drive tiring and reach the facility with a lower capacity for rehabilitation. Sitting in a car requires balance skills - something that is often overlooked by care givers and health care professionals.

2.10.4 Nursing facilities, retirement homes

Nursing facilities are traditionally places of residential care. Their rehabilitation services can range from minimal care given by nurses without special training, to intensive and comprehensive rehabilitation programmes. Rehabilitation might be offered by the facility itself or by private therapists. Health professionals can work in a team or individually (American Health Assistance Foundation 2006).

The advantages of nursing facilities are that they are less expensive than specialised rehabilitation facilities. Nursing facilities are mostly long-term settings which provide professional support as well as support from other patients.

The disadvantages are that rehabilitation is most often given by an aggregation of health care professionals and communication among them is often poor. Most members of the nursing staff are not specialised in stroke care (American Health Assistance Foundation 2006). In the researcher's experience, some patients become very frustrated or demotivated, when they see other residents with a low mental or physical capacity.

2.10.5 Home-based rehabilitation

In home-based or domiciliary rehabilitation, patients follow individual programmes in their own home environment. They may undergo intensive therapy for several hours a week, given by one or several practitioners from different disciplines, or they may follow a less demanding programme. A number of factors may influence whether a patient is able to return home; such as the availability and involvement of family care givers and the suitability of the physical home environment (Han & Haley 1999).

Undergoing treatment at home gives patients the advantage of practising skills and developing compensatory strategies in the comfort of their own living environment.

Further advantages of home-based rehabilitation are that it is conducive to a more client-centred approach and involves lower health care costs (Holmquist et al. 2000; Larn 2001; Teasell & Kalra 2005; Dow et al. 2007). Bresick (1997) states that home visits make treatment more effective, as goal-setting becomes more family-centred and more emphasis is placed on the needs of the patient. There is also increased emotional support from family members (Cifu & Stewart 1999; Leichtfuss 2001).

The disadvantage of home-based rehabilitation programmes is that the patient often needs a care giver, which not only adds to the financial burden but can also increase emotional stress. The researcher has encountered many spouses who feel that their personal space has been invaded. Further disadvantages are the lack of specialised equipment (American Health Assistance Foundation 2006). This is not only a disadvantage for the patient but can also create occupational health and safety problems for therapists, due to low working surfaces or having to transfer patients without help (Dow et al. 2007). It also offers less professional and peer support to the patient and many studies report that it places the care giver under greater stress (Blake, Lincoln, Clarke 2003).

2.10.6 Comparison of rehabilitation settings

Kramer and colleagues (1997) undertook a study, assigning patients at random to in-patient rehabilitation units and to less intensive sub-acute nursing homes. They reported decreased mortality, improved function and better outcome in stroke patients who were admitted to in-patient rehabilitation units, compared to patients who were discharged and referred to nursing home facilities (Kramer, Steiner, Schlenker, Eilersten, Hrincevich, Tropea 1997). Cifu and Stewart (1999) examined the relationship between home therapy, out-patient therapy and therapy given in a day centre. The study revealed no differences in functional outcome but the results of the day programme therapy showed decreased incidence of mortality and less need for institutionalisation, due to the emergence of health complications. Some studies prove that ADL tasks in particular show greater improvement in the home environment (Jorgensen et al. 1995; Outpatient Service Trialists 2002; Teasell & Kalra 2005; Dow et al. 2007). This may be because, by its very nature, stroke rehabilitation in the home environment can be made more task-specific, compared to traditional motor approaches in rehabilitation facilities. Some findings show that patients in home rehabilitation have improved functional scores (Cifu & Stewart 1999; Teasell & Kalra 2005). Also, the family seems to be more at ease in the home environment and as a result, will often take more initiative and responsibility in the rehabilitation process (Dow et al. 2007; Bresick 1997). Dow et al. (2007, p. 635) state that home-based therapy "*incorporates client autonomy and a focus on enablement rather than disability*". However, in the same study, team-members from the home-based rehabilitation setting expressed concerns about occupational health and safety (Dow et al. 2007).

A study done in South Africa interviewed forty-one physiotherapists with a special interest in stroke rehabilitation. The study reported that 39% of the study sample neither agreed nor disagreed that home-based therapy was of benefit, whereas 55% agreed or even strongly agreed. One respondent stated that "*treatment in the home allows for very specific assessment and guidance of the patient in their own home environment*" (Hale & Eales 2001, p. 34).

Young and Forster (1992) compared day hospital to home physiotherapy in a randomised control trail and came to the conclusion that home physiotherapy was significantly more effective as well as more resource-efficient.

2.10.7 Rehabilitation services in the public sector in the Western Cape Metropole

Primary level rehabilitation services for stroke survivors include both facility-based as well as community-based services and are offered in a variety of formats such as step-down care, community-based care, adult day care centres and out-patient or ambulatory services offered by community health centres.

Secondary level rehabilitation services like Booth Memorial Hospital, Life Care, Maitland Cottage Home and Sarah Fox provide step-down rehabilitation for patients who are not able to participate in an intensive rehabilitation programme.

Tertiary level health care and rehabilitation services are provided at specialist hospitals, such as Groote Schuur-, Tygerberg- and the Red Cross Children's hospitals.

There is one public rehabilitation facility namely Western Cape Rehabilitation centre (WCRC) in the Western Cape Province, that provides specialised, high-intensity, outcome-orientated rehabilitation programmes on both an in- and out- patient basis.

2.10.8 Rehabiliation services in the private sector in the Western Cape Metropole

The private health care sector takes care of some seven million people, principally members of medical aid schemes (Burger 2007). At the time of this study, the researcher identified forty-eight private hospitals in the Western Cape Metropole of which fifteen provided acute stoke care. There are three private in-patient rehabilitation units, namely UCT (University of Cape Town) Private Academic Rehabilitation Centre, Intercare Sub-Acute Hospital and Panorama Rehabilitation Centre, the latter two being qualified as “step down facilities”. All three facilities offer in-patient rehabilitation to people who have suffered a stroke, spinal cord injuries, head injuries, orthopaedic problems or general weakness after major operations. Intercare Sub-acute Hospital, UCT Private Academic Rehabilitation Centre and South Peninsula House offer also out-patient rehabilitation.

The physiotherapists, speech therapists and occupational therapists, who work at these hospitals, have their own private practices as opposed to being employed by the hospital administration. UCT Private Academic Rehabilitation Centre also offers the service of a social worker. All three units employ medical practitioners. Intercare Sub-Acute Hospital has two general practitioners who consult on a daily basis and are on twenty-four hour call, while Panorama Rehabilitation Centre offers the service of one doctor who specialises in rehabilitation. UCT Private Academic Rehabilitation Centre employs two doctors who are experienced in rehabilitation.

The researcher conducted a telephonic interview with the chief physiotherapists of UCT Rehabilitation Centre and Panorama Rehabilitation Centre as well as the case manager from Intercare Hospital, to obtain admission criteria for the three rehabilitation centres. The following information was obtained:

2.10.8.1 UCT Private Academic Rehabilitation Centre

After the initial telephonic conversation with chief physiotherapist E. Du Preez (10 Nov 2008) the researcher received an email letter on the 14 October 2008, obtaining the following information:

Admission criteria for in-patients (Du Preez 2008):

- The patient must require intensive rehabilitation (Neuro / SCI / Orthopaedic);
- The patient must require intensive input from at least two to three therapists (occupational therapists (OT), physiotherapists (PT), speech and language therapist (SLT)) to benefit from a team approach. The team consists of two doctors, nursing staff, four full time and one half day PTs, three OTs , one SLT, one social worker and two part time psychologists;

- The patient must be able to actively participate in the rehabilitation process;
- The patient must have adequate funding for the required rehabilitation (i.e, if six weeks of rehabilitation is required and only funding for one week is available, then this is not fair on the patient and an alternative facility may have to be considered).

Patients with limited rehabilitation potential:

- Admission for two to three weeks maximum with the aim of arranging suitable equipment and training care givers;
- These patients must however have a placement plan for discharge before their admission to the rehabilitation centre.

2.10.8.2 Intercare Sub Acute Hospital

According to Mrs. A Wege (telephonic conversation 12 Nov 2008), employed as case manager at Intercare Rehabilitation Centre, the facility has no set criteria for admission except medical stability. Referrals come from different doctors not affiliated with the centre. Health care professionals work within a multidisciplinary team approach. Team meetings are hold once a week including all health care professionals involved. Thereafter a family meeting will be arranged, where goals and the rehabilitation plan will be established.

Patients attend treatment sessions of the necessary disciplines seven days a week, twice daily. Patients are admitted two weeks up to three months depending on their needs and funding. Wege (2008) explained that “Medical Aids often only pay for two weeks rehabilitation whereas patients with private funding can afford to stay much longer”.

2.10.8.3 Panorama Rehabilitation Centre

The researcher interviewed the chief physiotherapist (12 Nov 2008) who had worked at Panorama Rehabilitation Centre and prefers to be unnamed. She provided the following information:

Patients are referred by different doctors from different acute-care hospitals. Patients have one initial session with the OT, PT and SLT. Thereafter they are treated on a daily base by the PT for 30 - 45 minutes. Occupational therapy as well as speech therapy is offered according to necessity on a once, twice or weekly basis.

Admission criteria:

- CVA patients who are declared not fit enough to go home;
- Patients who are too difficult to be handled by the family;
- Patients who have confirmed adequate funding (Chief physiotherapist, Panorama Rehabilitation Centre 2008).

The Department of Health (1998) states that "*those who manage to access rehabilitation services in the public sector are often lost due to erratic referral systems*" (Department of Health 1998, p. 3). The researcher wants to extend this statement to the private sector. She questions how much the Department of Health had been considered when admission criteria were established. Statements like: "*Ability to pay for services should not be a prerequisite for accessing services*" (page 2) or "*Services should be accessible, affordable and acceptable to all people with disabilities*" (page 5) had not been taken into consideration. The researcher believes that admission criteria are there to facilitate the appropriate allocation of the rehabilitation services. This would lead to the maximum benefit of the patient and an optimal utilisation of the serviced offered. "*People with disabilities are individuals with particular and differing needs, beliefs and values. Rehabilitation services should therefore accommodate these and recognise the individual needs, strengths, weaknesses, abilities and opportunities*" (Department of Health 1998, p. 6).

Apart form the above rehabilitation units, there is a wide range of private practitioners from various health disciplines who provide stroke rehabilitation i.e., occupational-, physio-, speech-, social-, psychological-, musical-, acupuncture-, hydro therapy and private nursing care, just to mention some of them.

Some non-governmental organisations offer "meals on wheels". There is also a stroke club which offers mainly emotional support to patients and their carers.

In the researcher's experience, all these services are becoming increasingly expensive. More and more often patients run out of funds, as Medical Aids are not willing to pay for further important rehabilitation at either in- or out-patient facilities. Some patients consult the public sector but many are left with their impairment and activity limitation. As a result, the health care promised by all national and international policies, fails many disabled people in need, irrespective of whether it is supposed to be offered in the private or the public sector.

2.11 Selection of an Appropriate Post-acute Rehabilitation Setting

The patient’s medical stability and the nature and extent of functional limitations are the most important determinants of the need for rehabilitation and the appropriate choice of a rehabilitation programme and setting. One has to keep in mind the patient’s functional status and degree of independence prior to the stroke. Social and environmental conditions as well as community resources are crucial criteria for the choice of discharge placing (Dewas & Patel 1997; Pollack, Disler, Cameron 2002). The motivation of the patient and his family is also an important criteria when selecting the post-acute rehabilitation setting.

The Copenhagen Stroke Study reported that the discharge rates from the different settings relate closely to the initial severity of stroke. In their study, only 14% of stroke patients with initially a severe level of disability went home in comparison to 93% with mild strokes (Jorgensen et al. 1995).

Threshold criteria for admission to a comprehensive rehabilitation programme are medical stability, the ability to learn, the presence of a functional deficit and the ability to tolerate intense rehabilitation sessions (The Agency for Health Care Policy and Research 1995; Pollack et al. 2002). The patient should be able to sit unsupported for at least one hour and to participate actively in rehabilitation for at least three hours per day. Admission to an interdisciplinary programme should be limited to patients with more than one type of disability, meaning that they will benefit from the services of two or more rehabilitation disciplines. Patients with milder degrees of disability and patients, who have poor physical and mental endurance, benefit more from low-intensity programmes given in nursing facilities, at home, or in out-patient facilities. Sometimes a period of recuperation in a nursing facility or at home will facilitate initial recovery and a comprehensive rehabilitation programme can be considered at a later stage. In such a case, it would be necessary to inform the family that the patient will reap greater benefit, if a re-assessment is conducted at a later stage (Agency for Health Care Policy and Research 1995; Dewas & Patel 1997; Pollack et al. 2002).

The Agency for Health Care Policy and Research (1995) makes the following recommendations:

- Patients who are medically unstable are generally not suitable for any type of rehabilitation programme;
- Patients who are moderately stable but have complex medical problems requiring continuous monitoring, are usually better treated in in-patient rehabilitation facilities which not only have 24-hour coverage by physicians and nurses skilled in rehabilitation, but also immediately available consultation services offered by medical specialists;
- Patients who meet threshold criteria and need moderate to total assistance in mobility or performing basic activities of daily living, are candidates for an intense rehabilitation programme, provided that they are able to tolerate three or more hours of physical activity each day, or a less intense programme, if they cannot meet the above criteria;
- Patients who meet threshold criteria and require only supervision or minimal assistance in mobility or ADL, are usually candidates for home or out-patient rehabilitation, if the home environment and support are adequate, or for a nursing facility, if they are not;
- Patients who have a mild functional deficit but are able to live independently and manage both basic and more complex activities of daily living, may benefit from selected rehabilitation services, but do not require an interdisciplinary rehabilitation programme.

The literature offers several flow charts, for selecting the most appropriate rehabilitation setting after a stroke. An example is shown in figure 2.1 (Dewas & Patel 1997; Pollack et al. 2002). These guidelines should be explained to and discussed with both, the patient and family, who should then be able to make a decision on the follow-up setting.

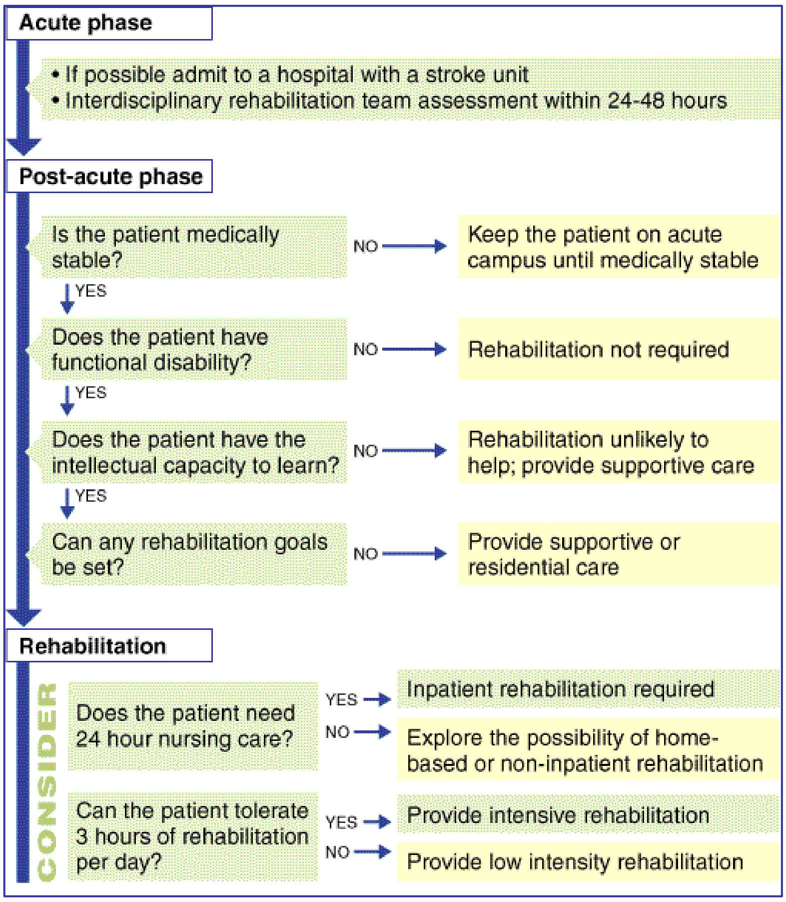


Figure 2.1: Guidelines to determine rehabilitation settings for stroke patients (Pollack et al. 2002)

2.12 Patient and Family Autonomy

It has long been recognised that the relationship between health professionals and patients has an important influence on health outcomes for the patient. Jones (1998) believes that most health decisions are made without including the family and patient in the decision-making process. Often, patients have not been involved in the choice of rehabilitation programmes and yet it is the patients themselves who have most at stake in the outcome of rehabilitation programmes (Lewinter & Mikkelson 1995). Angeleri, Angeleri and Foschi (1993) suggest that results which physiotherapists may regard as satisfactory, may not necessarily meet the satisfaction and/or expectations of stroke patients and their families.

A review of rehabilitation literature suggests that patients are not fully-fledged partners in the decision-making process (Patridge 1993). Many patients are not able to participate actively in the process as they may be too traumatised by the new impairment, may feel anxious because of pain, depression or communication problems (Haas 1993).

Sometimes it is difficult to accept the patient’s and family's choice of a rehabilitation option, particularly if it differs from the considered opinion of the health professional**.** For instance, the health care professional might believe that a particular stroke survivor will progress best in rehabilitation, if he or she is in an institution with highly sophisticated equipment (Hale & Eales 2001; Sherr Klein 2007). Yet the patient and his family might feel completely intimidated by the foreign surroundings.

On the other hand, the professional might think that the patient feels most secure and motivated in his or her own home environment (Teasell & Kalra 2005) and yet fail to realise that the patient and family feel entirely overwhelmed by having to deal with a new situation alone at home. In some circumstances, the health care professional might think it is in the patient’s best interest if they make decisions on behalf of the patient (Adams & Albers 2001). The health care professionals might reason that, with their expert knowledge of the disease and rehabilitation options, they are better suited to make these decisions.

Some authors state that factors considered important by patients are the provision of information, perceived sharing of decision-making and the feeling that their voices have been heard (Lerman et al. 1990; Jones 1998). Dow et al. (2007) did a study in which they examined the views of patients with regard to being included in the decision-making process. They had mixed findings, with some patients wishing to be included in the rehabilitation planning while others felt they had neither the knowledge nor the desire to be included.

These factors (provision of information, perceived sharing of decision-making and the feeling that their voices have been heard) possibly lead to a greater understanding by patients of their health problems and a greater sense of control over their own health (Lerman et al. 1990; Jones 1998). Some authors report that encouraging patients to take as much control as they can over their recovery from disability will lead to a more satisfactory outcome (Partridge 1993; Venesey 1995; Reddy & Reddy 1997; Clark & Smith 1998; Sherr & Klein 2007).

Callahan (1995) advocates that decisions about rehabilitation should involve a broad and ongoing dialogue with the patient and family. Professionals should have formal and informal discussion sessions with patients and their families to clarify questions, explain specific problems, gather relevant information about their circumstances and provide information on different rehabilitation options as well as the advantages and disadvantages of each rehabilitation setting (Callahan 1995; Hale & Eales 2001; Bruno 2004; Teasell & Kalra 2005).

Only a few clinicians believe that patients have the ability to understand their situation and make their own choices (Patridge 1993). The suggestion of implementing conditions conducive to patient autonomy is in contrast to many healthcare settings, where the emphasis is often on external control. This paternalistic way of thinking is based on the medical model but is increasingly being replaced by a model of patient autonomy and informed consent.

Haas (1993) states that informed consent is based on four characteristics:

- The patient's competence to make a particular decision at a particular point in time;
- Disclosure of all relevant and necessary information in discussions with the patient;
- Adequate understanding of proposed treatment and its alternatives;
- Freedom from coercion and manipulation by others.

In practice, the final decision should result from ongoing interactions between patient, family and the rehabilitation team (Jennings 1993). Ultimately, the choice is that of the patient and his family and it is imperative that their choice be respected. Health care professionals should constantly remind themselves of the principles of autonomy. Good communication, including thorough listening, is the cornerstone of effective decision-making. Sensitivity to language problems and to cultural differences is also important (Hale & Eales 2001).

2.13 Summary

With its high worldwide prevalence, stroke remains one of the most devastating diseases afflicting modern society. South Africa expects an increase in both the incidence of stroke and mortality following cerebrovascular accident, as lifestyle risk factors increase. About 50% of all CVA patients have some residual physical or mental disability and 35% of stroke survivors are partially or completely dependent in terms of ADL.

As many risk factors are modifiable in more than half of cases, stroke can be prevented. Education programmes on the risk factors and warning signs of CVA are necessary, not only for members of the public but also for health care professionals.

Improved outcome after stroke can be facilitated through a number of different interventions such as starting the rehabilitation process early on, the implementation of stroke care plans, the integration of an appropriate team approach, comprehensive education of both patient and family, the intensity of treatment and early discharge planning.

The choice of an appropriate post-acute rehabilitation setting should evolve from ongoing discussions and information sessions between doctor, health care professionals, patient and family. Both during the acute and the post-acute rehabilitation, it is crucial to always respect the autonomy of the patient and family.

CHAPTER 3: METHODOLOGY

3.1 Introduction

The following aspects of the study are discussed in Chapter 3: aim, objectives, design, setting, population, sampling procedures, pilot study, instrumentation, data collection, data analysis, ethical considerations and study limitations.

3.2 Aim of the Study

The aim of the study was to assess doctors' practices in the private health care sector with reference to stroke care protocols and teamwork approaches. The study also aimed to evaluate information shared between doctors and first ever stroke patients with reference to aspects of acute- and post-acute stroke rehabilitation such as prognosis, severity of disability, discharge and rehabilitation options as well as post-stroke rehabilitation referral patterns in the private health care sector in the Western Cape Metropole. Further focus was placed on timing of discharge planning, reasons for choice of rehabilitation type and who was responsible for this choice.

3.3 Objectives of the Study

The objectives of the study were as follows:

- To describe the demographic profile of doctors and patients, who participated in the study;
- To determine doctors' level of the rehabilitation training
- To describe the residual effects of the stroke on patients;
- To determine doctors' beliefs on the use of stroke care protocols;
- To determine doctors' beliefs on team work approaches in acute stroke care;
- To gather data on the information that was shared with patients with regards to diagnosis, prognosis, severity of disability, discharge and rehabilitation options;
- To determine the duration of hospital stay and the patterns of discharge planning for patients;

- To describe the distribution of study participants according to hospitals;
- To determine practices, beliefs and feelings of doctors and patients on follow up rehabilitation;
- To establish patients' and their families' experiences with regard to being included or excluded in the decision making process.

3.4 Study Design

A retrospective descriptive survey was done since this design lends itself best to capture the aim and the objectives of the study. The researcher chose a retrospective study design as it is less time-consuming. However, as it relies on recall information, there is the potential for bias (Botha 2009). According to literature, one of the primary reasons for doing a descriptive survey is to gather information about the management processes of a disease in order to reveal patterns, concepts and connections that might otherwise go unnoticed (Katzenellenbogen, Joubert & Abdool Karim 1999). This is what the researcher wanted to do with regards to certain aspects of acute stroke management in the current study.

Structured interviews with closed- and open-ended questions were used since most of the information gathered was quantitative. The researcher did not want to influence participants through pre-empting any answers and therefore utilised open-ended questions. Some qualitative questions were included to enhance the quantitative findings (De Vos 1998; Katzenellenbogen, Joubert & Abdool Karim 1999).

3.5 Study Setting

The study was performed in private hospitals in the Western Cape Metropole that admit acute stroke patients. The Western Cape Metropole is subdivided into eight different health districts, namely Western, - Northern, - Eastern, - Southern, - Tygerberg, - Klipfontein, - Mitchells' Plain, - and Khayelitsha Health Districts. At the time of the study there were forty-eight private hospitals in the Western Cape Metropole. The researcher contacted all forty-eight hospitals telephonically to determine whether they admit acute stroke patients. She found that of the forty-eight hospitals, fifteen admitted acute stroke patients. These fifteen private hospitals were: Vergelegen Medi-Clinic, Constantiaberg

Medi-Clinic, Louis Leipold Medi-Clinic, Durbanville Medi-Clinic, Milnerton Medi-Clinic, Panorama Medi-Clinic, Cape Town Medi-Clinic, Gatesville Hospital, Mitchell's Plain Medical Centre, Jan S. Marais Hospital, Vincent Pallotti Hospital, Christiaan Barnard Memorial Hospital, Claremont Hospital, Kingsbury Hospital and N1 City Hospital. They formed the study setting. Table 3.1 shows into which health district each of these hospitals fall.

Table 3.1: A presentation of the hospitals that admit acute stroke patients according to health districts as well as the hospitals sampled for the initial study sample

Health districts	Hospitals	Number	Number to be sampled	Sampled hospitals
Western	CapeTown Medi-Clinic Chris Barnard Memorial Hospital Milnerton Medi-Clinic Vincent Pallotti Hospital	4	2	Cape Town Medi-Clinic Milnerton Medi-Clinic
Northern	Durbanville Medi-Clinic Panorama Medi- Clinic	2	1	Durbanville Medi-Clinic
Tygerberg	Jan S Marais Hospital Louis Leipoldt Medi-Clinic N1 City Hospital	3	2	Jan S Marais Hospital Louis Leipoldt Medi-Clinic
Klipfontein	Gatesville Hospital	1	1	Gatesville Hospital
Mitchells Plain	Mitchell's Plain Medical Centre	1	1	Mitchell's Plain Medical Centre
Khayelitsha	None	0	0	None
Eastern	Vergelegen Medi-Clinic	1	1	Vergelegen Medi-Clinic
Southern	Claremont Hospital Constantiaberg Medi- Clinic Kingsbury Hospital	3	2	Constantiaberg Medi-Clinic Kingsbury Hospital

3.6 Original Determination of Study Population and Study Sample

The researcher experienced major methodological problems. She could not determine the study population and do sampling as planned in the study protocol since permission to access hospital register books and patients' folders was refused. This necessitated changes to the methodology as well as increased bias in some instances. The researcher will explain, both the failed and applied methodology, as well as the steps taken to overcome the problem.

The fifteen private hospitals in the Western Cape Metropole, that admit patients suffering from an acute stroke, were ordered alphabetically and distributed according to the eight different health districts in the Western Cape Metropole (table 3.1) to provide eight strata. Proportional, stratified, random sampling was conducted with the assistance of an excel randomisation programme to provide the researcher with the hospital sample. The number of hospitals sampled per health district was proportional to the number of hospitals in each health district. Table 3.1 shows how stratification was done and which hospitals were sampled.

According to the initial methodology, the study population would have been drawn from the records of these hospitals. However that process failed. Below is an explanation of what happened.

The researcher mailed a letter (Appendix 1) to the managers of the ten sampled hospitals explaining the study, asking for consent to perform the study and requesting access to the hospital's admissions records as well as access to patients' folders. A consent form (Appendix 2) and a self- addressed, stamped envelope were included in the letter.

On receiving the first three letters stating that access to the register book had been denied, the researcher decided to send a letter, consent form and self-addressed, stamped envelope to the five hospitals initially eliminated by the sampling process. Unfortunately more negative responses were received. Only one hospital - Vergelegen Medi-Clinic - allowed access to the register book. However, two days later the researcher received a letter refusing any access to the register book in all Medi-Clinics.

The researcher then approached the managers of two hospitals - the Christiaan Barnard Memorial Hospital and Cape Town Medi-Clinic for assistance. They said that they are unable to help as the decision lay with the legal advisers of all Medi-Clinics.

The researcher therefore contacted the legal advisor acting for all Medi-Clinics, again explaining the nature of the study and reason for her request. The legal advisor encouraged the researcher to continue pursuing her research project, asking her to send all documents, including the following: approval for the study by the Human Research Committee of Stellenbosch University; an abstract of the research project and all letters and consent forms. This was duly done. He explained that the matter would be discussed at a committee meeting six weeks later and that the researcher should expect a call or email at that time.

When, after eight weeks, the researcher had received no response, she phoned the legal advisor, asking whether a decision had been made. He assured her that she would receive an answer in about three weeks' time. Two weeks later she was informed that she would not be allowed access to the register books of any of the hospitals.

This refusal to allow the researcher access to register books and therefore patients' names, made it impossible to identify all persons who had had a stroke in the study period and had been admitted to a private hospital for acute-care. It also made it impossible to perform random sampling and ensure a representative patient sample.

The proposed method of determining a patient population was, by using the hospital register books, to identify all persons, who suffered their first stroke between 1 January 2006 and 30 June 2006 and were admitted to one of the ten sampled hospitals in the Western Cape Metropole, for acute medical care. The researcher had further planned to randomly sample from these ten groups, ten patients from each hospital, with the assistance of an excel randomisation programme.

The researcher further proposed to select doctor participants from the patient group. It was proposed to invite all doctors who had managed and/or discharged the above-mentioned patients from the hospitals, to participate in the study. No further sampling would have been done.

3.7 Study Population and Sample of Applied Methodology

3.7.1 Doctor population

All doctors, who managed and/or discharged acute stroke patients from the fifteen hospitals in the Western Cape Metropole that admit acute stroke patients for treatment, formed the doctors' population for the study. The researcher identified these doctors through contacting the various hospitals and asking for the names of all the doctors that admit and manage acute stroke patients in the respective hospitals. The researcher identified forty-seven doctors in total.

3.7.1.1 Inclusion criteria

- Doctors who treated acute stoke patients in private hospitals in the Western Cape Metropole during the period 1 August 2007 to 31 March 2008.

3.7.1.2 Exclusion criteria

- Doctors who no longer lived or practised in the Western Cape Metropole at the time of the study;
- Doctors who had died before the time of the interview;
- Doctors who were not willing to take part in the study.

3.7.2 Determining doctor participants

All forty-seven doctors were contacted telephonically. The researcher explained the nature of the study and asked whether the doctor would be willing to participate in a fifteen minute interview. In most cases the researcher had to leave the information with the doctor's secretary. In cases where the doctor phoned back, the nature of the study was explained again and the request repeated.

In cases where the researcher did not have any reply after the first contact with the doctor's consulting rooms the researcher phoned the rooms of the doctor a second time after five days and repeated her request. Where this did not produce any response the researcher visited the rooms of the doctors and tried to get permission for an interview, convenient at time and place for both parties. In cases where no permission or response was given it was assumed that the doctor is not willing to participate in the study and the issue was not pursued any further.

In total, thirty-five doctors were willing to participate in the study.

3.7.3 Patient population

The patient population was established in the following manner:

After conducting an interview with the doctor from the doctors' study population, the doctor was asked whether he/she would be willing to provide two or three names and telephone numbers of stroke patients that he/she had treated in hospital between 1 August 2007 and 31 March 2008.

Where the doctor indicated that he/she would give names of patients but could not supply them immediately, the consulting rooms were phoned two days after the interview. Where the doctor did not have the information available, the consulting rooms were phoned a further six times in order to try and obtain the names.

Where the doctor still did not provide any names after the sixth phone call, the researcher contacted the physiotherapist working in the same hospital. The physiotherapists working at the two hospitals where no doctors were willing to be interviewed, were also contacted telephonically. The nature of the study was explained. The researcher asked the physiotherapist whether he/she would be willing to give one or two names of stroke patients they had treated in hospital between 1 August 2007 and 31 March 2008. Where the physiotherapist failed to immediately supply any names, the rooms were phoned a further six times. If the physiotherapist did not respond by the sixth call, no further calls where made.

Out of the thirty-five doctors interviewed, two were unwilling to reveal the names of any acute stroke patients for reasons of confidentiality, two doctors stated that they had not seen any acute stroke patients in the past eight months, one doctor asked the researcher to consult the physiotherapist and two doctors did not supply the researcher with any names, even after six follow up phone calls.

The researcher received fifty-eight names of patients from doctors and a further thirty-nine names from physiotherapists. Inclusion and exclusion criteria were then implemented. .

3.7.3.1 Inclusion criteria

- Patients who suffered their first ever stroke and were admitted to a private hospital in the Western Cape Metropole for acute management during the period of 1 August 2007 to 31 March 2008.

3.7.3.2 Exclusion criteria

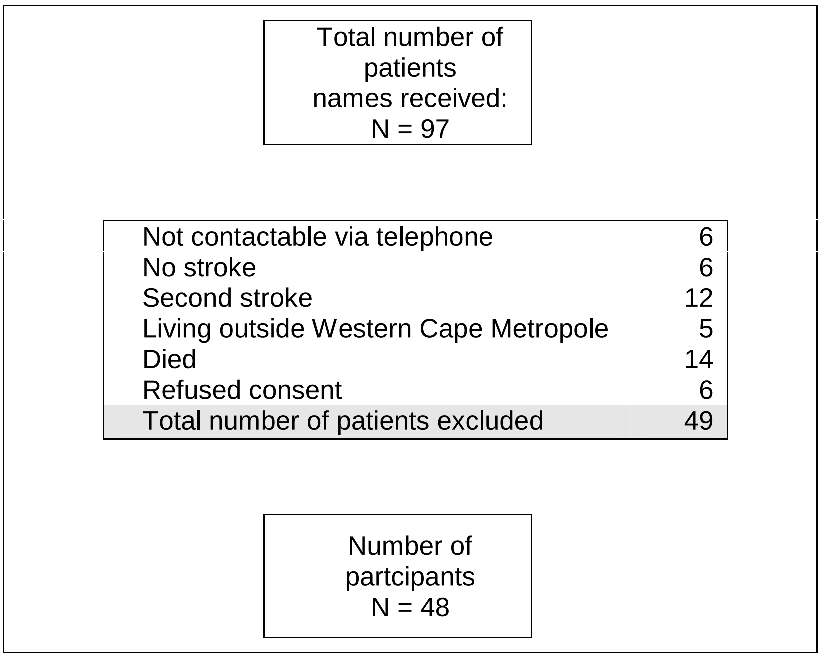
- Patients, who had suffered a previous stroke, as their knowledge of stroke and stroke care facilities might be based on the information they had previously received;
- Patients, who suffered a stroke because of major surgery or major illnesses, as this can strongly influence the choice of rehabilitation setting;
- Patients, who did not live in the Western Cape Metropole at the time of the study;

- Patients, who had died before the time of the interview;
- Patients, who were not willing to participate in the study.

3.7.4 Determining patient participants

The researcher tried to contact all ninty-seven patients and/or relatives telephonically. Where she received no reply after five attempts, she did not try to contact the patient again. Where she did make telephonic contact, the researcher explained how she had obtained their telephone numbers and the reason for the study. She then established whether the patient complied with all inclusion/exclusion criteria. If he/she did adhere to the inclusion criteria, he/she was then asked for preliminary consent.

In all, forty-nine patients were lost to the study: six were not contactable, six patients had not suffered a stroke, twelve had suffered their second stroke, five did not live in the Western Cape Metropole at the time of the study, fourteen had died and six patients refused to participate in the study. This left the researcher with forty-eight patient participants (figure 3.1). Unfortunately the researcher has no way of knowing if the size of this sample is large enough to be representative of stroke patients treated in private acute-care hospitals in the Western Cape Metropole since she has no way of identifying the entire study population.



Total number of patients names received: N = 97

Not contactable via telephone	6
No stroke	6
Second stroke	12
Living outside Western Cape Metropole	5
Died	14
Refused consent	6
Total number of patients excluded	49

Number of partcipants N = 48

Figure 3.1: Schematic description of patient population

3.8 Instrumentation

Data was collected by two self-designed questionnaires - one for doctors (Appendix 4) and one for patients (Appendices 5 & 6). These instruments were developed by the researcher and discussed with and evaluated by a variety of experienced health professionals and a statistician. Self-designed questionnaires were used, because the researcher was unable to find questionnaires that would provide the information necessary to satisfy the aims and objectives of the study, in the literature.

Both questionnaires consisted of closed and open-ended questions. In some instances open-ended questions were used to gather quantitative data e.g. stroke risk factors without providing undue guidance through predetermined response options that closed-ended questions would have done. Other open-ended questions were used to provide qualitative data on issues like feelings and satisfaction.

3.8.1 Questionnaire 1. Doctor's Questionnaire (Appendix 4)

Demographic information regarding the doctors' training and experiences in stroke management was gathered to determine if these factors influenced referral patterns or general patient management strategies. This combined with closed-ended and open-ended questions regarding stroke client management and teamwork practices formed the quantitative part of the questionnaire while questions on the doctors' beliefs and preferences on stroke rehabilitation provided qualitative information.

3.8.2 Questionnaire 2. Patient's Questionnaire (Appendix 5 & 6)

Quantitative data regarding demographic status, information on the stroke and functional status as well as information regarding stroke management and rehabilitation planning during their stay in the acute-care hospital was gathered.

Demographic data was gathered to provide a profile of participants. Data on stroke was gathered to determine if the type, severity and effects of the stroke played any role in the choice of a rehabilitation setting. To determine the client's perception of his own performance in the areas of self-care, mobility, speech, memory and leisure-activities the researcher used a performance measure scale similar to the Canadian Occupational Performance Measure (COPM) (Law, Baptiste, Carswell, McColl, Polatajko, Pollock1998).

Qualitative data was gathered on stroke management and rehabilitation planning. The patients had the opportunity to expand on their perceptions, experiences and feelings regarding the rehabilitation process during and after their stay in the acute-care hospital.

3.9 Pilot Study

The researcher had initially planned to select five patients and the doctors who managed these patients from one of the hospitals not sampled for the main study. However, as access to the hospital records was refused, the researcher decided not to do any sampling. She therefore approached five patients from her own practice (three of her own patients and two from her colleague) who had suffered a stroke three months prior to the time frame of the study, with which to pilot the patients' questionnaire. Once the researcher had interviewed all five patients and all changes had been implemented in the questionnaires, the researcher piloted the questionnaire with a further two patients. Again, the patients were sampled from her own practice.

The researcher then approached four doctors with which to pilot the doctors' questionnaire. These four doctors were a general practitioner in Sea Point, Cape Town, a physician working at Christiaan Barnard Hospital, a general practitioner who had worked at UCT Private Rehabilitation Centre and a rehabilitation specialist of the Stroke Unit at Groote Schuur Hospital.

Firstly, the researcher used the pilot study to determine whether the questionnaires were clearly understood and whether they elicited the information needed for the study's aims and objectives. It was necessary to change some wording as well as add extra questions in both questionnaires in order to enhance the clarity and contents of the questionnaires (e.g. in Question 51 of the patients' questionnaire, the patient is asked "Who explained what a stroke is?". The question was altered to read: "who from the medical team explained?". Then a further question was added: "Did you use other sources to gain information?").

Secondly, the researcher evaluated whether the sequence of the questions was correct and whether they answered the research question. Again it was necessary to change some wording, particularly in the patients' questionnaire. This was to ensure that patients realised clearly that most of the questions considered the acute-care rehabilitation management (for example, the phrase "status of self-care, mobility, mental health after the stroke" was changed to read: "status of self-care, mobility, mental health before CVA, at discharge from acute hospital and at time of interview). Sequences in the doctors' questionnaires were changed so as to ensure a natural flow of the stroke management process. Extra time frame questions were included in the area of disability and transfer time from the acute to the sub-acute hospital (e.g. in patients' questionnaire: "Did you go home first before you went to rehabilitation centre?").

Thirdly, the researcher wanted to determine whether any other information should be included in the study. Both questionnaires needed some additional demographic questions (e.g. gender in both questionnaires) as well as extra questions referring to the rehabilitation process in order to obtain all the desired information (e.g. the question: "What information did you receive on discharge?" was added to the patients' questionnaire).

Fourthly, the pilot study was used to begin identifying answer options for open-ended quantitative questions, as described in Armstrong and Grace (2000). These options were included in the questionnaire solely for the interviewer's purposes and were never disclosed to the respondent. This was done to facilitate the filling out of questionnaires and to save time during interviews. A space was left at the bottom of questions to write down options and patient's opinions that were not mentioned in the pilot study.

Finally the pilot study was used to ascertain approximately how long it would take to complete the questionnaires and whether it was necessary to give the patient a rest period. This ensured that the researcher was able to give patients and doctors accurate information about the length of the interview, when asking them to participate in the research project. Doctors particularly expressed a desire to have this certainty before agreeing to take part in the study. The doctor's questionnaire took approximately fifteen to twenty minutes to complete, while patient's questionnaires took between thirty and fifty minutes to complete.

Once all necessary changes had been made, the patient's questionnaire (Appendix 5) was translated by a professional translator into Afrikaans (Appendix 6).

The interview with the specialist of the stroke unit of Groote Schuur Hospital did not go according to plan as he refused to discuss the questionnaire. He was highly upset that the researcher was planning to do her study in the private sector, because it represented a minority group. He commented that "*nobody is interested in the private sector and thus nobody will be interested in the results of the study*". He furthermore showed strong dislike when he discovered that the researcher was not doing her studies at the university that he is affiliated to. However, he did speak at length on what should be integrated in the questionnaire if the researcher wanted to assess stroke referral patterns. Since the particular doctor is a well recognised specialist in stroke management, the researcher found his information very valuable and integrated it into the questionnaire even while she was disappointed that he would not make the effort to look at the questionnaire.

3.10 Data Collection

3.10.1 Doctors' data collection

The researcher arranged appointments with each of the thirty-five doctors at a mutually convenient time and place. Prior to conducting the interview, the researcher asked the doctor to sign a consent form.

3.10.2 Patients' data collection

All patients forming the study population were contacted telephonically and an appointment was made at a mutually convenient time and place. The patient's language preference was also determined.

On meeting the patient and/or family member, the researcher first established whether the interview would be with the patient, family member or both. Prior to the interview, the participants' written consent was also obtained.

The service of a professional translator was used for the Afrikaans interview. Even though there were eleven Afrikaans -speaking patients and one Xhosa-speaking participant, only one patient chose to have the interview conducted in Afrikaans. English was their second language and all others felt their command of the language was good enough to conduct the interview in English. This kept inter-reliability bias low.

The researcher filled out the questionnaires. Neither the patient nor the doctor saw the questionnaire at any stage during the interview. It was a pure verbal exchange of information. Therefore, participants could not determine their response through looking at the answer options on the questionnaire.

3.11 Data Analysis

A statistician was consulted to assist with the development of the questionnaires and his expertise sought throughout the pilot study, field work and analysis phase. While interviewing doctors, patients and their caregivers, the researcher recorded all information on the questionnaires.

3.11.1 Quantitative data

Quantitative data was entered into an Excel spreadsheet on the day of the interview. The statistical software package STATISTICA was used for analysing the data. A p-value of $p < 0.05$ was seen as statically significant.

Confidentiality was ensured at all times and all questionnaires and information were stored in a safe place.

The researcher analysed the patient's data from the patients' questionnaires and determined the demographic, socio-economic and medical details of patients (e.g. ratio data on age, length of hospital stay, income, nominal data on gender, ethnic groups, left/right hemiplegia, effects of the stroke, employment status, monetary source for rehabilitation, home circumstances and ordinal data on education).

The patient's data on the rehabilitation- and referral process (Appendices 5 & 6) (e.g. nominal data on receiving and understanding doctors' explanations on stroke, integration into the decision process of post rehabilitation, explanation on rehabilitation options, being followed up by doctors after discharge) was further analysed.

The researcher analysed the doctors' data, obtained from the doctors' questionnaires (Appendix 4) and determined demographic and socio-economic details from doctors (i.e. ratio data on age, number of years practising medicine, number of years being specialised, amount of time spent on giving information to patients, number of discussion sessions; nominal data on which information doctors provide to stroke patient, when and how they provide it, their knowledge and preferences on different rehabilitation options as well as team approaches). These findings were enhanced through qualitative data obtained with help of open-ended questions (see qualitative data).

3.11.2 Qualitative data

The researcher read and reread qualitative answers in order to become conversant with them.e.g. in doctor's questionnaire the advantages and disadvantages of a set protocol, advantages and disadvantages of team work approach, reasons for satisfaction/dissatisfaction of current team work approch, explanation on preferences on a specific type of post-acute rehabilitation, additional comments on the acute and post-acute rehabilitation process and in the patient's questionnaire the satisfaction of the choice of the post-acute rehabilitation setting, suggestion how the follow-up process could have been improved, The researcher looked for salient themes and recurring beliefs and patterns. Data was then organized according to emerging themes**.** The organised data was once more compared with each and every questionnaire to ensure that no data was missing. This information was then used in narrative form to highlight or explain quantitative data. The researcher took into consideration that inferences should not be drawn or casual statements made.

3.12 Ethical Considerations

- Permission to perform the study was given by the committee for Human Research at the University of Stellenbosch NR06/10/214;
- Participants (doctors, patients and family members) were informed about the aim, objectives and nature of the study (Appendix 3). They were assured that confidentiality would at all times be maintained. Written consent was obtained from all participants (Appendix 3);
- Participants were informed that they had the right to withhold or withdraw consent at any time;
- Respect for the principles of confidentiality was maintained at all times. The researcher protected the identity of all participants and at no time was the identity of any participant disclosed;
- All documents were securely stored at all times. They are kept at the researcher's office in a locked cupboard and only the researcher has access to the key.

Computer data e.g. spreadsheets are password-protected and stored on the researcher’s personal computer (PC). No other person has access to the PC;

- The researcher at all times acted professionally and showed respect, consideration and courtesy towards all participants;
- Where an interpreter was appointed to assist during an interview, the interpreter was fully trained with regards to the study as well as the ethical considerations;
- Results from this research will be published in accredited journals. Although all participation will be acknowledged in the publication, they will remain anonymous;
- Summarised reports of the outcome of the study will be made available to the managers of all study hospitals as well as to all those who participated in the study.

3.13 Limitations of the Study Methodology

- The change in methodology has the result that patients might not be representative of the wider patient group that they belong to (selection bias, hospital access bias). This is because the researcher has no way of knowing who and how many the members of the entire group are and how they differ from those who did participate. One should therefore be very careful when extrapolating these results to the same and other settings. However, with careful comparison of demographic data, extrapolation to groups with similar demographics might be possible;
- The researcher is not fluent in Afrikaans or Xhosa. Some information might be lost through second-hand information from an interpreter, even though the interpreter was thoroughly trained. Fortunately only one participant asked to have the interview conducted in Afrikaans while the only Xhosa-speaking participant felt confident with English, thus keeping interpreter bias low;
- Recall bias: Patients were asked to remember and tell the researcher what information was given to them. They might have forgotten some of it. The researcher noticed that some patients were not sure about their answer and sometimes changed the answer. This made it even more important for the researcher to do the interviews herself and to be consistent;
- Reporting bias: The participant might selectively suppress or reveal information;
- Family information bias: The family member might not be aware what information the patient had received. The interviewed family member was also not always the only person who received information from the doctor, but might have got the

information via other family members. In the process therefore, information might have been lost or the context changed;

- Recall bias: Some patients often confused the acute-care hospital experience with the post-acute hospital experience;
- Doctors might have changed their practices regarding the points under research and would now give less, more or different information;
- Positive satisfaction bias: Doctors might have wanted to please the researcher and therefore doctors did not recall their patient’s management plan as they proceeded with in their daily practice or the patient might have wanted to please the researcher and therefore did not reveal his true feelings;
- Doctors might only have given names of very mild stroke patients. It might be that doctors preferred to give the names of patients who recovered well as this would reflect positively on the doctor’s work;
- Since the questionnaires were self-developed, they were not tested for validity and reliability. Findings were validated to an extent by comparing the answers of doctors’ and patients’ answers on the same subjects e.g. on discharge planning and the sharing of information on stroke.

3.14 Summary

The aim of the study was to assess information shared on acute- and post-acute stroke rehabilitation aspects as well as post-stroke rehabilitation referral patterns by doctors in the private health care sector in the Western Cape Metropole. A retrospective descriptive survey was performed in fifteen private hospitals in the Western Cape Metropole that admit acute stroke patients. Forty-seven doctors, who managed and/or discharged acute stroke patients from the fifteen hospitals formed the doctors’ population and ninety-seven patients formed the patient population. After exclusion/ inclusion criteria had been applied thirty-five doctors and fourty-eight patient participants were left in the study.

Expert statistical advice was obtained in the development of the questionnaires, pilot study, field work and analysis phase. Quantitative data, analysed through statistical software package STATISTICA, was supported and enhanced through qualitative data. Ethical considerations were observed throughout the study through respect for the principles of confidentiality and professional behaviour. Limitation to the ambit of the study resulted from the unwillingness of several chosen hospitals to participate in the study as well as the selection of patient respondents by the doctors themselves. Further bias was introduced because some of the results were based on recall information.

CHAPTER 4: RESULTS

4.1 Introduction

In this chapter the results from doctor and patient questionnaires will be presented in an integrated fashion. This includes results on the following aspects: distribution of the study population according to the different hospitals, demographic profiles of doctors and patients, patients' socio-economic characteristics, the utilisation of stroke care protocols and team work, effects of a stroke, information relating CVA, LOS in the acute-care hospital, post-acute rehabilitation, the follow up after discharge as well as additional comments made by doctors and patients.

A total of eighty-three persons participated in the study of whom thirty-five were doctors and forty-eight patients. Of the forty-eight patient interviews, twenty-four were completed with patients, eighteen with family members and six with both, patient and family members present.

4.2 Distribution of Study Population according to Different Hospitals

Except for Milnerton Medi-Clinic, Louis Leipold Medi Clinic and N1 City Hospital, from which there were four doctors respectively most hospitals yielded three or fewer doctors as shown in figure 4.1. There were no doctor participants from Panorama Medi Clinic and Durbanville Medi Clinic.

There were nine and eight patients respectively from Vincent Pallotti Hospital and Durbanville Medi Clinic and as shown in figure 4.1, four or fewer patients from all the other hospitals. There were no patient participants from Jan S. Marais Hospital and Claremont Hospital. At Jan S. Marais Hospital both, the doctor and physiotherapist stated that they did not see any stroke survivors in the time period given by the inclusion criteria of the study. At Claremont Hospital, the doctor did not want to reveal any patients' names due to confidentiality reasons. He was also not willing to contact them himself to ask whether they would like to participate in the research project. The physiotherapist supplied names of patients but on contacting them it became clear that they had been admitted to Kingsbury Hospital.

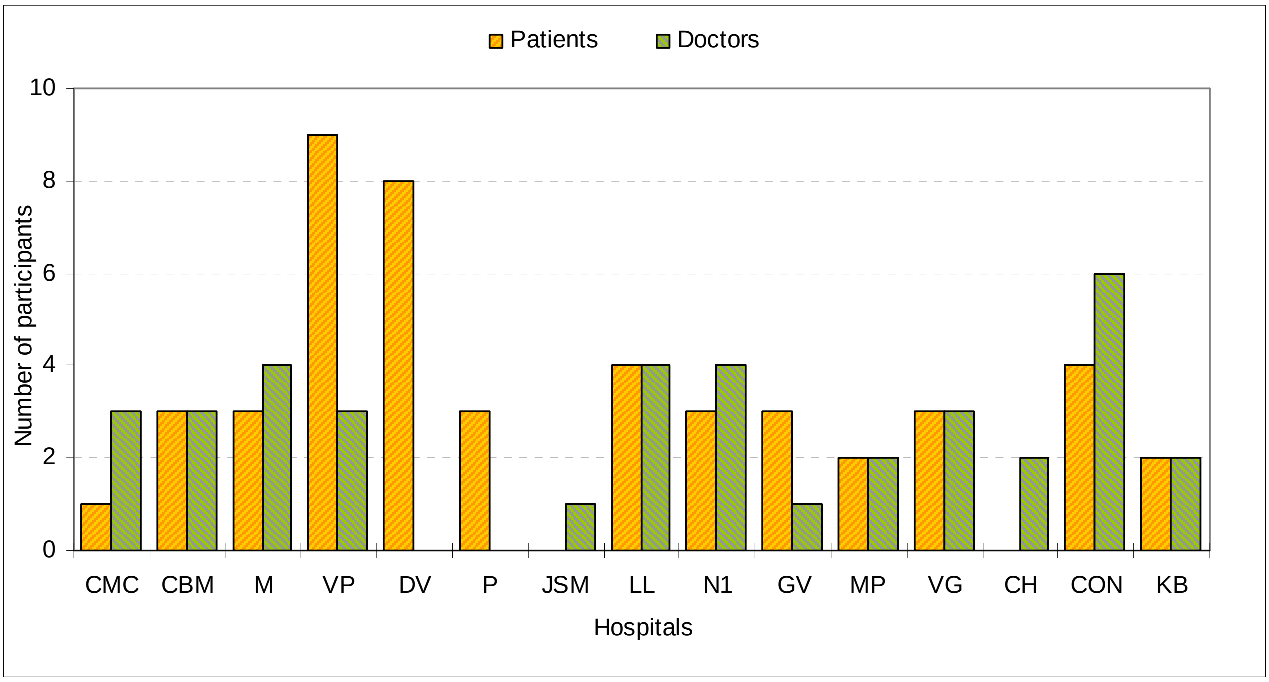


Figure 4.1: Distribution of study population according to hospitals; patients n=48, doctors n=35; CMC - Cape Town Medi-Clinic; CBM - Christiaan Barnard Memorial Hospital; M - Milnerton Medi-Clinic; VP - Vincent Pallotti Hospital; DV - Durbanville Medi-Clinic; P - Panorama Medi-Clinic; JSM - Jan S. Marais Hospital; LL - Louis Leipold Medi-Clinic; N1 - N1 City Hospital; GV - Gatesville Hospital; MP - Mitchell's Plain Medical Centre; VG - Vergelegen Medi-Clinic; CH - Claremont Hospital; CON - Constantiaberg Medi-Clinic; KB - Kingsbury Hospital

4.3 Demographic Profile of Doctors

4.3.1 Doctors' age and gender distribution

Of the thirty-five doctors who participated in the study thirty-one (88.6%) were males and four females (11.4%). The youngest doctor was a male aged thirty-five, the youngest female, being thirty-seven years old. The oldest doctor was seventy-nine.

The mean age of the doctor population was 46.9 years. As shown in figure 4.2 the majority of doctors (n=16, 45.7%) were fifty-one to sixty years old, followed by the thirty-one to forty years age group (n=12, 34.3%).

The age of doctors was compared with the following variables: the use of a set protocol, team work approach, information provided to patients and family, length and frequency of information sessions, time of discharge planning, who makes the final decision and preference of post-acute rehabilitation settings. The findings will be discussed under the relevant headings.

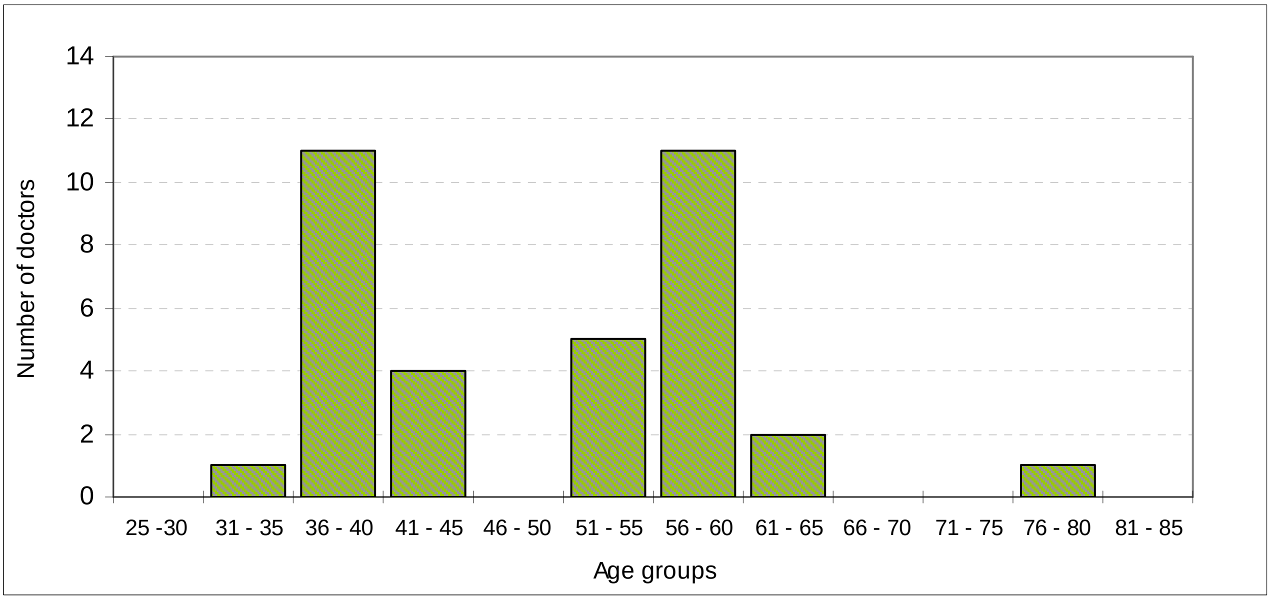


Figure 4.2: Age distribution of doctors; n=35

4.3.2 Years of qualification and specialisation

The majority of doctors (n=31; 88.5%) qualified between eleven and thirty years ago, while only one doctor qualified in the last ten years and one fifty-four years ago (figure 4.3).

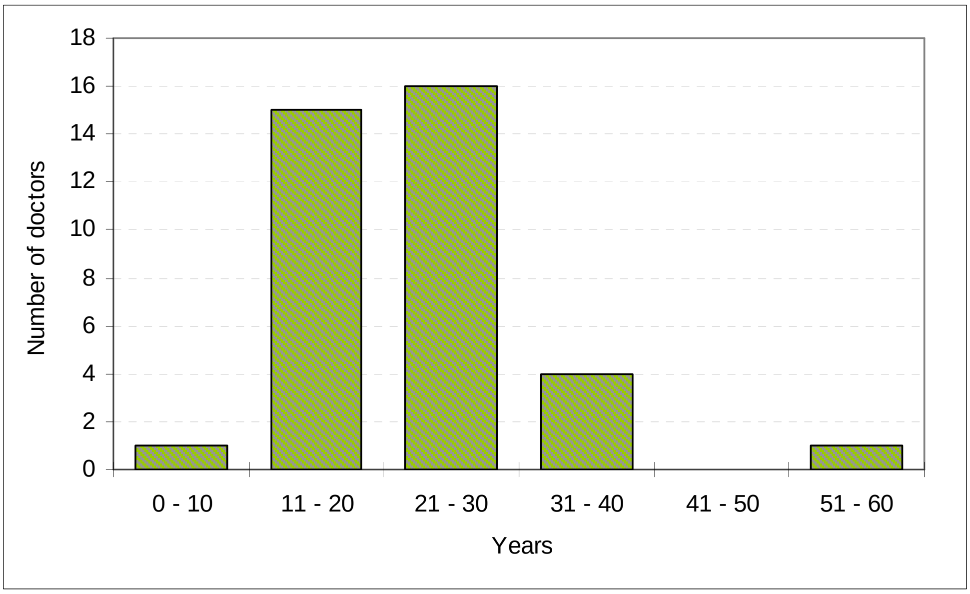


Figure 4.3: Years since qualification; n=35

4.3.3 Area of specialisation

Amongst the doctor participants there were twenty-one physicians (60.0%), twelve neurologists (34.3%) and two general practitioners (5.7%). Two doctors held qualifications for both internal medicine as well as neurology. Since they are currently practising as neurologists, they were classified accordingly. On average doctors have been qualified as specialists for twelve years.

Statistical significance in respect to the relationship between doctors' area of specialisation (neurologists or physicians) were evaluated with regards to the following aspects: the use of a set protocol; team work approach; information provided to patients and family; length and frequency of information sessions; time of discharge planning; who makes the final decision and preference on post-acute rehabilitation settings. The findings will be discussed under the relevant headings.

4.3.4 Rehabilitation training and experience

None of the doctor participants had any special training in the field of rehabiliation medicine. Only four doctors (11.4%) stated that they had specific experience in the rehabilitation field, three of them were physicians and one worked as a neurologist (holding both qualifications). All four doctors previously worked in specialised rehabilitation units where they obtained their experience. The above mentioned aspects (use of a set protocol, team approach) were also compared with the data of these four doctors but it did not show any statistical significance.

4.4 Demographic Profile of Patients

4.4.1 Age and gender distribution of patient population

There were thirty-three male- (68.8%) and fifteen female- (31.2%) patient participants. The mean age of the patient population was 64.3 years (± 13.67%SD). As shown in Figure 4.4 age was normally distributed in the sample. This was confirmed by the Shapiro-Wilk W Test (W=0.97, p>0.33).

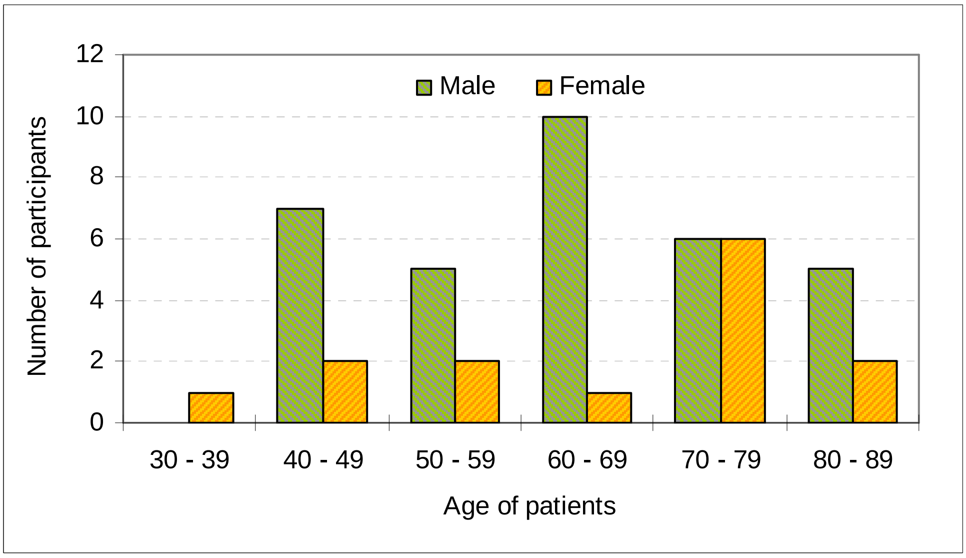


Figure 4.4: Age distribution of patient population; M: n=33, F: n=14

The youngest patient was a female aged 34, the youngest male being 40 years old. The maximum age was 87 for both female and male. The mean age of both genders was very similar (females: 65.8 and males: 63.7). However, looking at the median it is noticeable (Figure 4.4) that most of the female population was older than 70 with a median of 71 which is rather higher than the overall median (63) of the entire patient population.

4.4.2 Population group and language distribution of patients

Thirty-two of the participants (66.6%) identified themselves as White South Africans and fourteen (29.2%) as Coloured South Africans, while there was only one (2.1%) Indian and one (2.1%) Black South African in the population.

The majority of patients (n=36, 75.0%) stated that English was their first language, eleven (22.9%) were Afrikaans and one participant (2.1%) spoke Xhosa.

4.5 Patients' Socio-Economic Characteristics

4.5.1 Level of education

All patients had some formal education. The majority of participants (n=14, 29.1%) had a tertiary education, followed by those (n=12, 25%) with between eight and eleven years of schooling . One family member was not sure about the level of education attained by his mother. Thus figure 4.5 has only forty-seven participants.

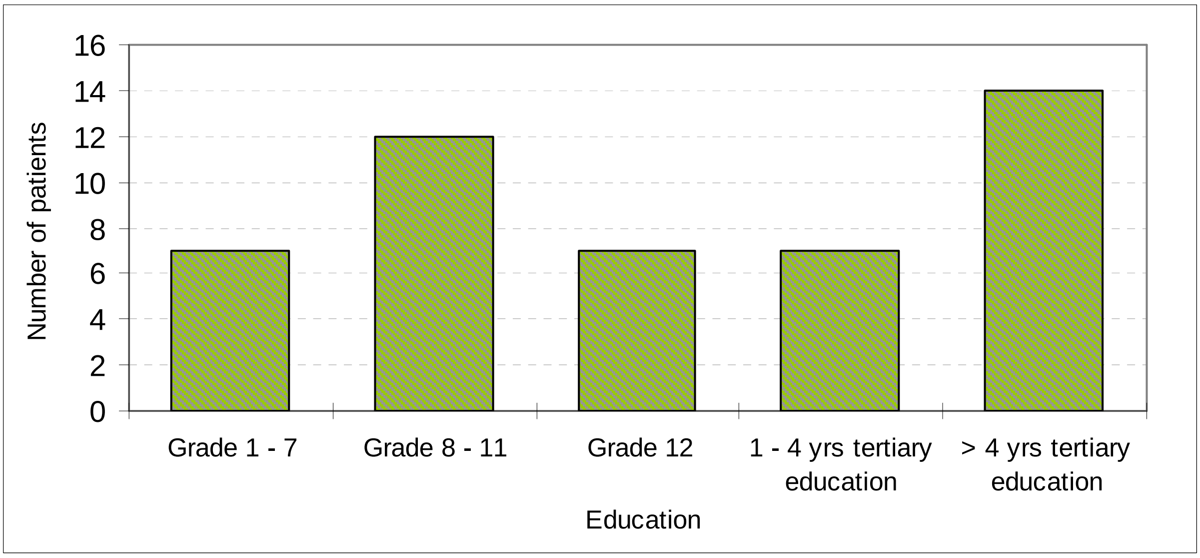


Figure 4.5: Educational status of patients; n=47

4.5.2 Employment status and change in income

According to table 4.1 the impact of the stroke influenced employment status of fourteen individuals (29.1%) of whom seven (14.6%) had to retire due to the stroke, three (6.2%) had to take on reduced workloads and four (8.3%) were not sure what the future held in terms of employment.

Table 4.1: Employment status: before and after stroke

Employment status	Prior to stroke		Change	After stroke	
	No. of participants	% of total	%	No. of participants	% of total
Self employed	6	12.5	50.0	3	6.2
Employed	18	37.5	38.9	7	14.6
Unemployed	1	2.1	0.0	1	2.1
Retired	20	41.7	135.0	27	56.4
Looking after house	3	6.2	0.0	3	6.2
Reduced work load			-	3	6.2
Not sure yet			-	4	8.3
Total	**48**	**100**		**48**	**100**

Although for fourteen participants (29.1%), their employment status changed, only five (10.4%) indicated that their income had been reduced. Of the five participants who earned less, one patient faced a 100% loss of income, one 70%, one 50% and one reported a 20% loss of income. One participant stated that he/she was receiving a greater income as a result of insurance pay-outs.

4.5.3 Housing

The majority of participants (n=45, 93.7%) had lived in a house before suffering a stroke, two patients (4.2%) lived in a flat and one patient (2.1%) in a retirement village. Only eight patients (16.7%) were forced to change their accommodation as a result of the effects of the stroke. A further nine patients (18.9%) continued to live in the same place as before, but had to engage the services of caregivers.

4.5.4 Medical insurance

Only one patient (2.1%) was not medically insured. The patient's son covered all the resultant costs.

4.6 Effects of a Stroke

The majority of patients (n=31, 64.6%) presented a right CVA while in seventeen patients (35.4%) the left side of the brain was affected.

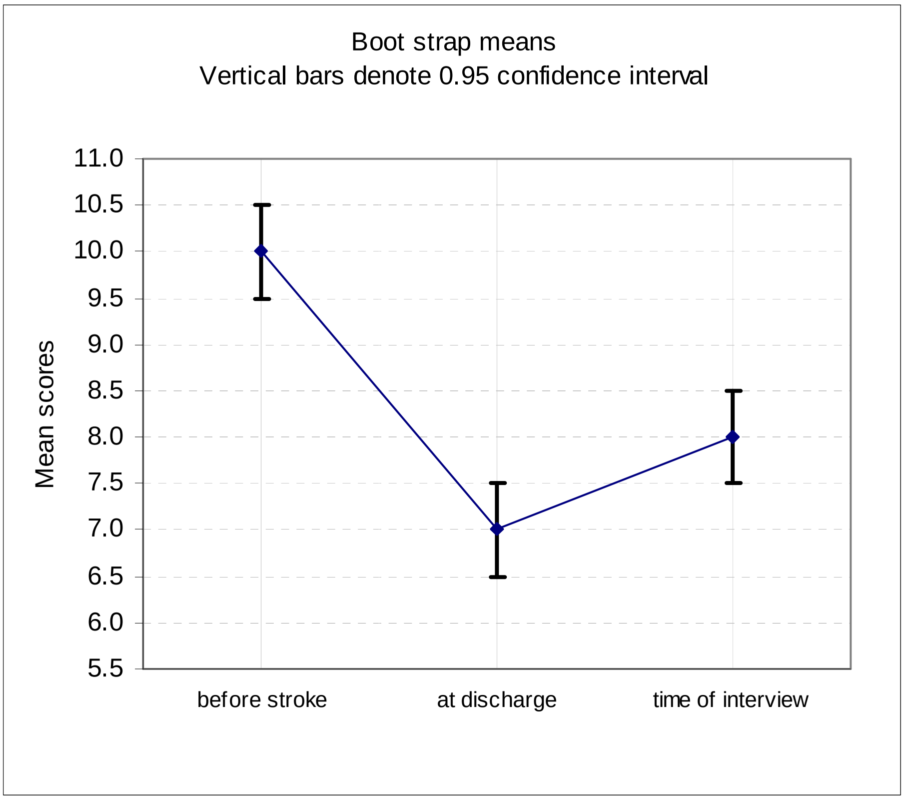


Figure 4.6: Distribution of functional limitation mean score before stroke, on discharge and at the time of the interview; n=48

Out of the forty-eight patients, seven (14.6%) indicated that they had limitations in performing some activities before suffering the stroke. Specific areas of reduced function varied widely. The function in which six patients (12.5%) experienced limitations was mobility for which one patient (2.1%) had a very low score of 2. This was followed by four patients (8.3%) who experienced short-term memory impairments. The study population showed a pre-stroke mean disability value of 9.8 when the scores for all the different functional aspects (self-care, mobility, memory and speech) were combined (figure 4.6).

As is shown in figure 4.6 the combined mean value dropped to 6.9 at the time of discharge from the acute hospital. The highest mean (8.7) was seen in the category of speech comprehension whereas the lowest mean value (5.2) and thus the most affected area was once more found in mobility.

The combined mean value of all functional limitations at time of the interview was 8.18 (figure 4.6). The lowest value (6.98) was again scored for mobility while the highest was found in long-term memory (9.23).

The mean functional scores were compared with length of stay (figure 4.21) and post-acute rehabilitation settings (figure 4.25).

4.7 Stroke Care Protocols

4.7.1 Protocols currently used by doctors

Nearly half of the doctor participants (n=16, 45.7%) stated that they worked according to a set protocol. Except for one of the above mentioned doctors all stated that this entailed direct reports and referrals to other health care professionals like nursing staff, therapists and, where necessary, other specialist doctors (n=15, 94%); it may be noticed that the researcher evaluated the percentage from the study group who utilised a protocol, n=16; 100%). The referrals typically included requests for early mobilisation, attention to swallowing problems, to mention just two. Furthermore, ten of the sixteen doctors (63%) included aspects of post-acute rehabilitation planning and -placement in their protocol. Only one doctor used a management plan which included regular meetings with other health care professionals. Another seven doctors (44% of n=16) spoke of protocols which referred to the management of medication (e.g. thrombolitics, anticoagulants) as well as

CT-scans and /or MRI. One doctor declined to reveal what his protocol entailed, due to time constraints.

Data showed no statistical significance regarding the relationship between practices of neurologists or physicians (p= 0.18141) or the age of doctors (p= 0.06) with regards to the use of a set protocol. However, it is clear from figure 4.7 that younger doctors are more in favour of using a set protocol and a p value of 0.06 is also just higher than the 0.05 which is seen as the cut-off point for a relationship to be statistically significant.

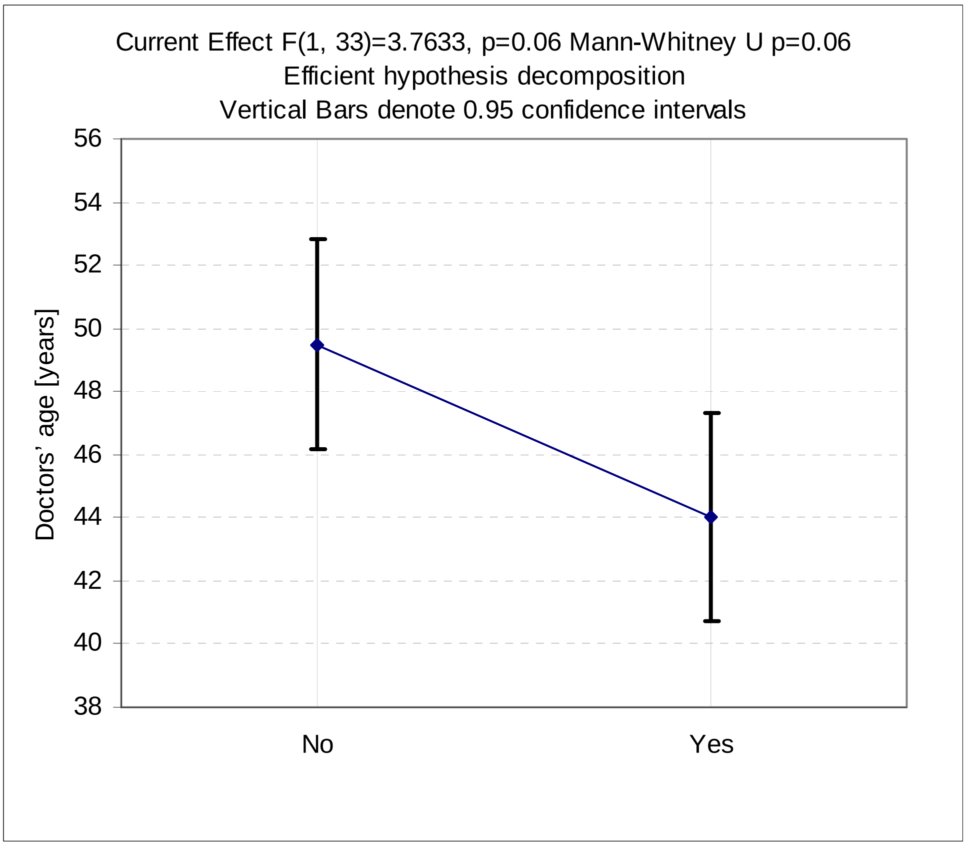


Figure 4.7: Comparison between the use of set protocol and doctors' Ages; n=35

On being asked whether they would be willing to try a set protocol in their practice if one would be supplied, thirty doctors (85.7%) responded positively whereas five doctors (14.3%) were averse to the idea.

4.7.2 Doctors' views on the advantages and disadvantages of using a protocol

The advantages of using a set protocol in acute stroke management were acknowledged by thirty-one doctors (88.6%). All of them (88.6%) stated that there was scientific proof validating the benefits of such protocols. Of these thirty-one participants twenty-two

(62.8%) were of the opinion that assessment as well as treatment was more accurate if one followed a set protocol. Furthermore ten doctors (28.6%) stated that protocols ensured that there was no delay in referral to other health professionals and that they ensured that patients were cared for in the best possible way. Only four participants (11.4%) expressed the view that a protocol ensured ongoing communication among the different health care professionals and eight doctors (22.8%) stated that the patient had a better outcome due to above mentioned advantages. One doctor (2.8%) was of the opinion that it was cost efficient to implement a protocol as this would make the rehabilitation process more organised and time-effective. The reader will notice that the accumulated number of doctors does not add up to thirty-five, as some doctors cited more than one reason for the advantages.

On the other hand, more than half of the participants (n=20, 57.1%) also saw disadvantages in the use of a set protocol. As many as 22% (n=8) believed that costs would increase if a set protocol was implemented and twelve participants (34.3%) thought that the process might be too rigid and not individualised enough. This statement was elaborated as follows: "*it will stop (us) applying our own mind*"; "*one will feel guilty if one cannot follow it due to funding problems"; "it needs to be used in a very sensitive manner*" and "*ninety-eight percent of the patients are fine but two percent will lose out*". One participant was of the opinion that "*one would be a fool to use it*". He did not given any further information on why *" one would be a fool*".

4.8 Team Work Approach

4.8.1 Current utilisation of team work approaches

The majority of doctors (n=20, 57.1%) were part of a multidisciplinary team while fifteen doctors (42.9%) stated that they were currently not working within a team. Similarly twenty-eight patients (58.3%) noticed the presence of teamwork.

There was no statistical significance (p= 0.13801) seen in the relationship between the practices of neurologists and physicians with regard to the utilisation of a team work approach (table 4.2). Data compared according to the ages of the doctors concerned also did not show any statistical significance (Mann-Whitney U test p= 0.33; Chi-square test p= 0.25937).

Table 4.2: Team work approaches being utilised compared to doctors' area of specialisation

Specialist	No team approach	Multidisciplinary approach	Total
Neurologists	5	7	12
[%]	41.7	58.3	
Physician	8	13	21
[%]	38.1	61.9	
GP	2	0	2
[%]	100.0	0.0	
Total	15	20	35

4.8.2 Suitability of current team work approach

The opinion of 48.6% (n=17) of the doctor participants was that their current approach worked well for all members, including the patient. Most of them stated that this was the only approach one could use in the private sector. This opinion was explained with comments like: "*Nobody has time for common meetings or common ward-rounds. As long as there is daily contact it will work very well for all*" and "*We work with an 'open door approach'. Health care professionals are contacted when they are needed. All aspects of rehabilitation are addressed and the patient is getting all benefits".*

However, just over half of the doctor participants (n=18, 51.4%) reported that they were currently utilising a team work approach which they believed not to be optimal. The following comments were made: "*not good for patients"; "not focused enough"; "poor communication"; "poor social dynamic" and "unavailability of staff*". All eighteen participants said they would prefer to work in a stroke centre with an interdisciplinary team work approach. Qualitative data from the doctors' questionnaires highlighted the above-mentioned findings. When doctors where asked whether they wanted to make additional comments on the rehabilitation process, four participants repeated the importance of good team work and expressed dissatisfaction with the team work approach they were currently using.

4.8.3 Optimal team work approach

Asked for their opinions on the most appropriate team work approach, thirty-two doctors (91.4%) favoured the interdisciplinary approach, leaving only three doctors (8.6%) indicating a preference of the multidisciplinary approach.

Asked "*why they believe in an interdisciplinary team work approach*", thirteen participants (37.1%) stated that assessment and treatment was better and more efficient for the patient, twelve (34.3%) commented that it was proven by evidence and eleven doctors (31.4%) believed that there would be better communication. Only one doctor (2.8%) expressed the opinion that all reasons for the current system not being suitable would be eliminated if one worked in an interdisciplinary team. More than one opinion was recorded and this explains why the figures add up to more than 100%. These findings were highlighted by qualitative data. Asked whether they wished to make additional comments on the rehabilitation process four doctors (11.4%) reinforced the need for an interdisciplinary stroke unit in the hospital in which they currently worked.

4.8.4 Team members of ideal and current team

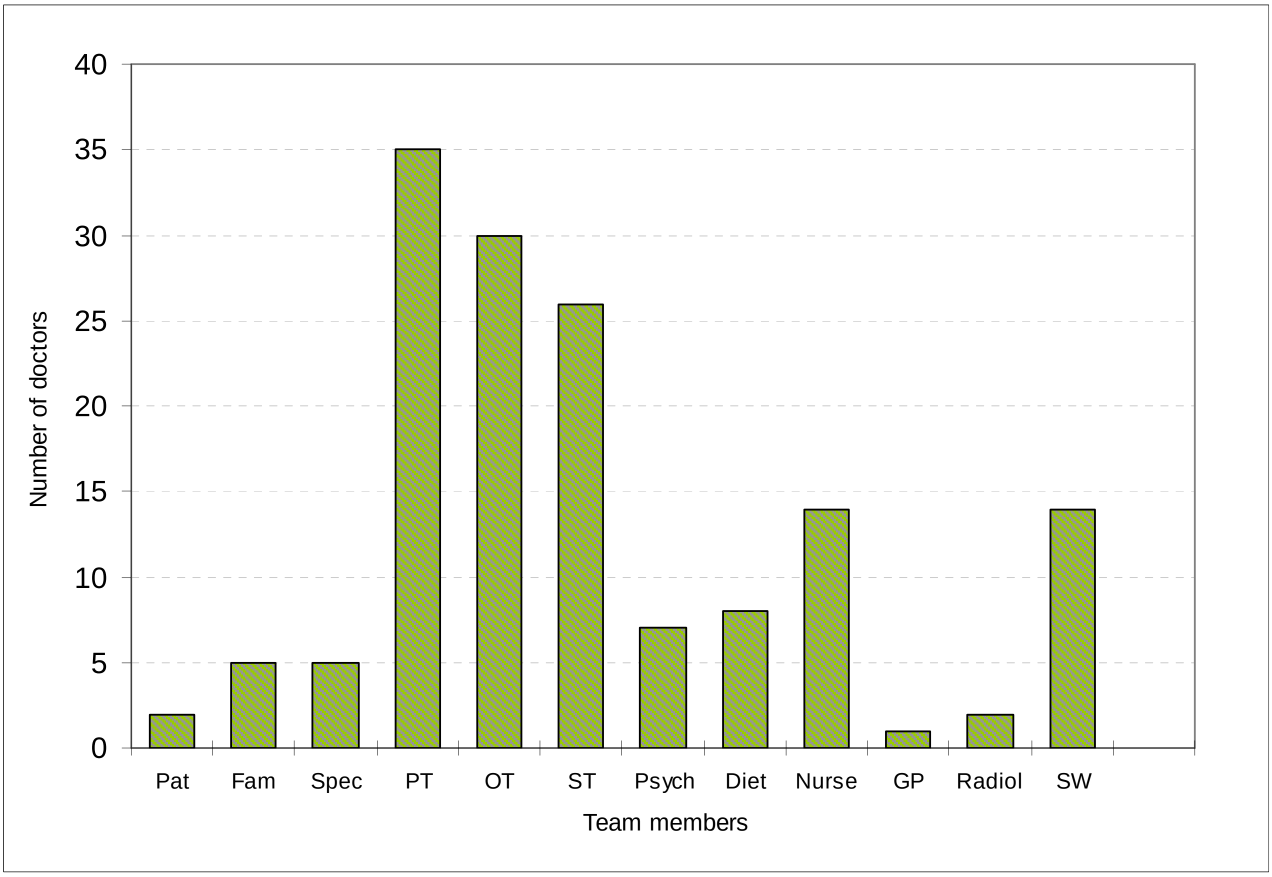


Figure 4.8: Team members who, according to doctors should be part of the ideal team; Pat - Patient; Fam - Family; Spec - Specialist; PT - Physiotherapist; OT - Occupational Therapist; ST - Speech Therapist; Psych - Psychologist; Diet .- Dietician; GP - General Practioner; Radiol - Radiologist; SW - Social Worker

Only two doctor participants (5.7%) included the patient as a team member, and five (14.3%) the family and caregivers, of the ideal team. All doctors (n=35, 100%) mentioned the physiotherapist as a team member of the ideal team. Figure 4.8 shows a detailed picture of doctors' opinions on who should be included in the ideal team.

On being asked whom they include currently in their teams, twenty-three doctors (65.7%) answered: *"All the above mentioned members will be called if they are needed"*. A further six doctors (17.1%) confirmed again that they do not work in a team but call mainly on the physiotherapist. Other health care professionals which were mentioned were the occupational therapist (n=3, 8.5%) and the speech and language therapist (n=5; 14.3%).

Regarding the question why they do not work with the ideal team as identified by them twenty-four doctors (68.6%) said that it is *"not practical"* to work within a team in the private sector; five (14.3%) reasoned it due to financial problems and six of the participants (17.1%) thought it was due to unavailability of staff.

4.8.5 Communication with team members

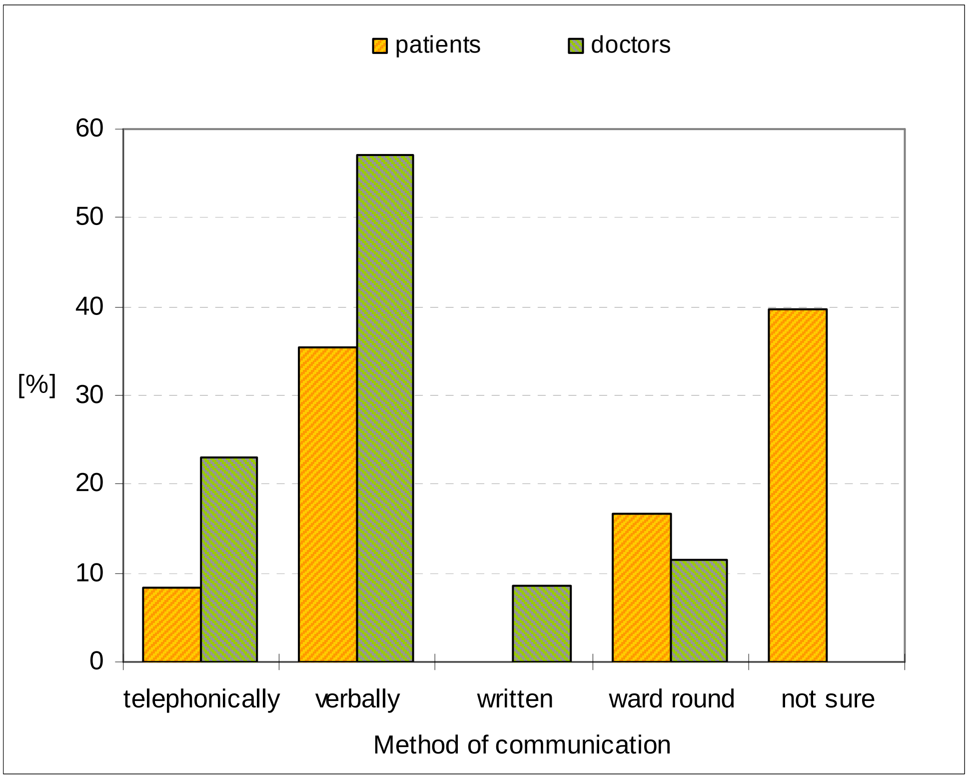


Figure 4.9: Methods of communication with team members; patients n=48, doctors n=35

As shown in figure 4.9 the two sample groups differ in their opinions on the manner of communication currently used. While 80.0% (n=28) of doctors said they communicated by means of the telephone and verbally (qualitative data highlighted that some of the verbal exchanges were very informal and related to chance encounters in the *"car park, lift or* *corridor"*), 43.7% of the patients (n=21) thought that communication was established in that fashion.

Only four doctors (11.4%) communicate through ward rounds and none with team meetings.

Unhappiness with the current way of communication was expressed by 68.6% (n=24) of the doctor sample. The percentages add to more than 100% since some participants mentioned more than one way of communicating.

4.9 Information Relating to Stroke Shared with Patients

4.9.1 Introduction

On being asked to whom doctors give information after they have done their initial assessment thirty-four participants (97.1%) mentioned the family and the patient (to be precise: two mentioned the patient, fourteen the family and eighteen both). Further persons who were mentioned were: the general practitioner (n=9), all team members (n=3), the care-giver (n=3), the nurse (n=10) and the casualty officer (n=2).

Main aspects according to doctors on which they give information to the patient and family were the following: diagnosis (n=28), prognosis (n=31), risk factors (n=22), treatment plan (n= 20), post-acute rehabilitation options (n=17), length of stay (n=8) and on the individual scan (n=6).

4.9.2 Information on diagnosis

The majority of doctors (80%) stated that they provide information on the diagnosis to the patient. However, looking at figure 4.10 only 50% (n=24) of the patients felt that the diagnosis was explained to them by the doctor. This shows a significant discrepancy with a p value of 0.00438.

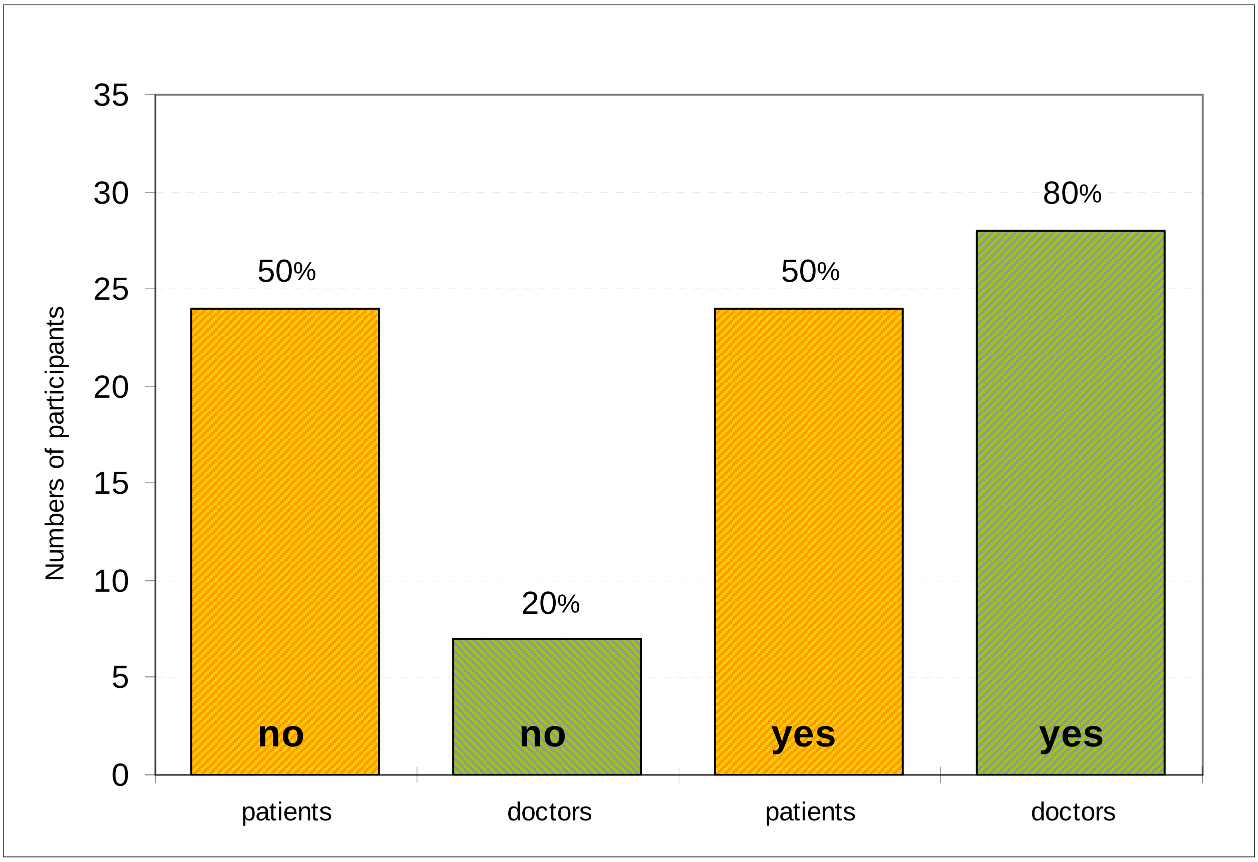


Figure 4.10: Comparison of doctors' and patients' views on whether information on diagnosis was shared with patients; patients n=48, doctors n=35

Some patients used other sources like the internet, books or family and friends to gain information on the subject. Patients did this because 8.3% (n=4) of the patients did not get any information from the medical professionals, eleven participants (22.9%) did not find the information received very clear and two (4.2%) wanted to make sure they received all possible information on CVA.

Table 4.3 provides a summary on patient information sources on diagnosis. The number of participants does not add up to forty-eight as some patients gave more than one source of information.

Table 4.3: Patients' views on who supplied information on the diagnosis

	Doctor	Nurse	GP	Therapist	Family Friends	Internet Books
Number	23	3	3	0	10	16
[%]	47.9	6.2	6.2	0	20.8	33.3

When the researcher asked the participants to explain in their own words what a stroke is thirty-six (75%) were able to give a well informed answer.

4.9.3 Information on prognosis

According to the patient participants twenty-four of them (50.0%) received information on their prognosis, however four participants (8.3%) mentioned that the information given was very vague and did not provide them with a clear picture of what to expect. Table 4.4 provides an overall view on who informed the participants about their prognosis. The number of patient participants does not add up to twenty-four as some participants named more than one source.

Table 4.4: Patients' views on who supplied information on prognosis

	Doctor	Nurse	GP	Therapist	Family Friends	Other
Number	24	1	0	0	11	5
[%]	50.0	2.1	0	0	22.9	10.4

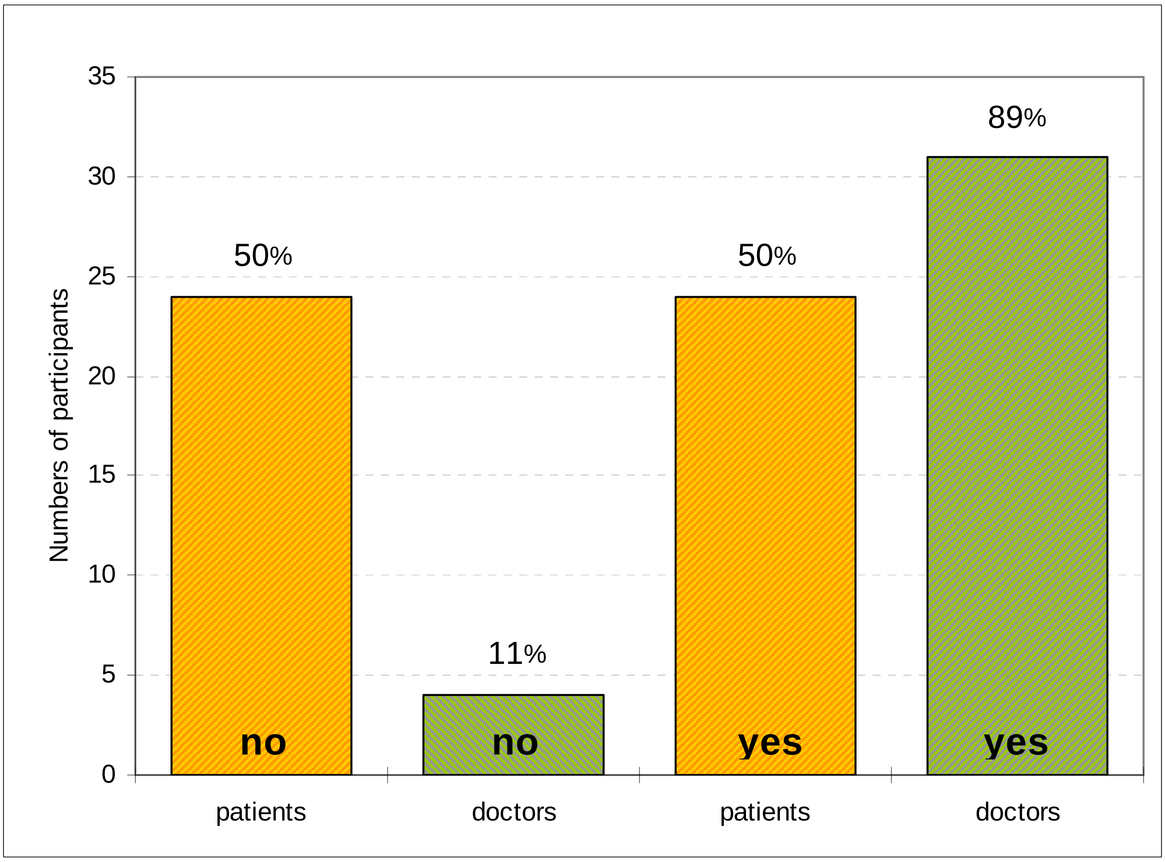


Figure 4.11: Comparison of doctors' and patients' views on whether information was shared on prognosis; patients n=48, doctors n=35

By contrast, 89% of the doctor sample stated that they discussed the prognosis with both patient and family. This discrepancy shows a statistical significance with a p value of p= 0.00013 (figure 4.11).

4.9.4 Information on risk factors

Nearly 63% of the doctors claimed that they explained the risk factors of strokes to their patients. However, only fifteen patient participants (31.2%) stated that they received this information from the doctor. The comparison is shown in figure 4.11. The difference shows again a statistical significance with a p value of p= 0.00401.

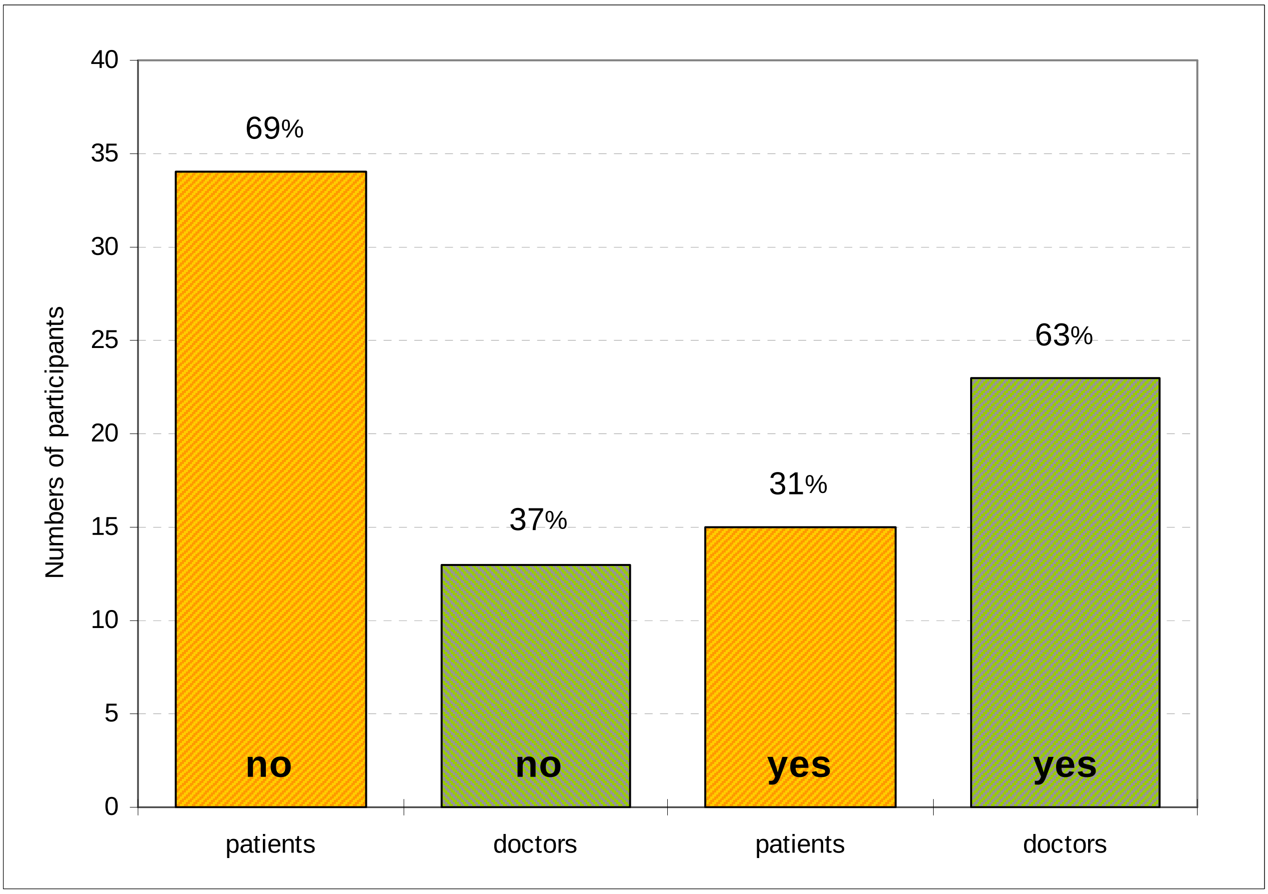


Figure 4.12: Comparison of doctors' and patients' views on whether information on risk factors was shared; patients n=48, doctors n=35

Additional information on risk factors was given to four patients (8.3%) by the therapist (two physiotherapists and two dieticians). Two patients (4.2%) received information from a family member and two patients (4.2%) confirmed the information given by means of the internet and information pamphlets.

4.9.5 Information on post-acute rehabilitation

The majority of doctors (n=23, 65.8%) supplied information on follow-up rehabilitation options. However, six doctors (17.1%) stated that it would be explained in the rehabilitation centre and a further six doctors (17.1%) explained that the therapist from the acute-care hospital supplies the follow-up information.

Most doctors explained the following aspects: the different rehabilitation options (n=14); how they can assist the patient (n=16, 45.7%); what the treatment entails (n=6, 17.1%); advantages and disadvantages of the different options (n=2, 5.7%) and the costs involved (n=6, 17.1%). In most cases this information was given (n=8, 22.8%) towards the middle of the patient's hospital stay. A further nine doctors (25.7%) stated that the time at which the information was given varied according to the patient and the circumstances.

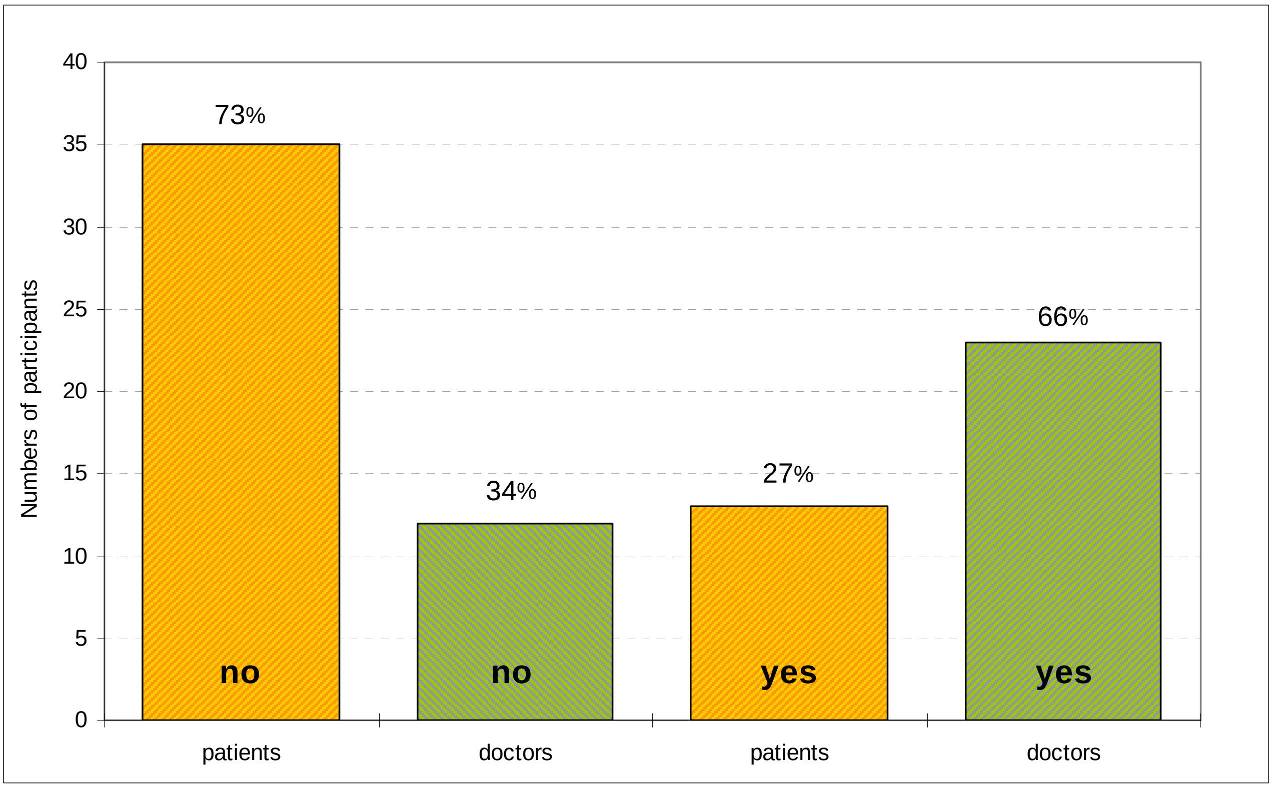


Figure 4.13: Comparison of doctors' and patients' views on whether information was shared on follow up rehabilitation options; patients n=48, doctors n=35

Only fifteen patients (31.2%) stated that they received information on all rehabilitation options, one patient (2.1%) explained that it was not necessary as he had recovered fully in the acute-care hospital. When asked to name all rehabilitation options only ten patients (20.8%) were able to list them all.

Again the discrepancy between doctors and patients perceptions (figure 4.13) on this issue is statistically significant (p=0.0004).

4.9.6 Information on discharge

According to figure 4.14 nearly half of the doctor participants (n=15, 42.8%) informed their patients at the end of their hospital stay when they would be discharged. Only 14.3% (n=5) discussed discharge planning from the beginning of the patient's hospital stay.

Similarly the majority of patients (n=16, 33.3%) reported that the discharge date was discussed the day before they left the acute-care hospital (figure 4.14). One participant told the researcher that she was not informed at all. She received a phone call that her mother had been transferred to a step down facility. There was no prior discussion or information session. The questionnaire revealed that only two patients (4.2%) took part in discharge discussions from the beginning of their hospital stay. Five patients (10.4%) no longer remembered when discharge was discussed.

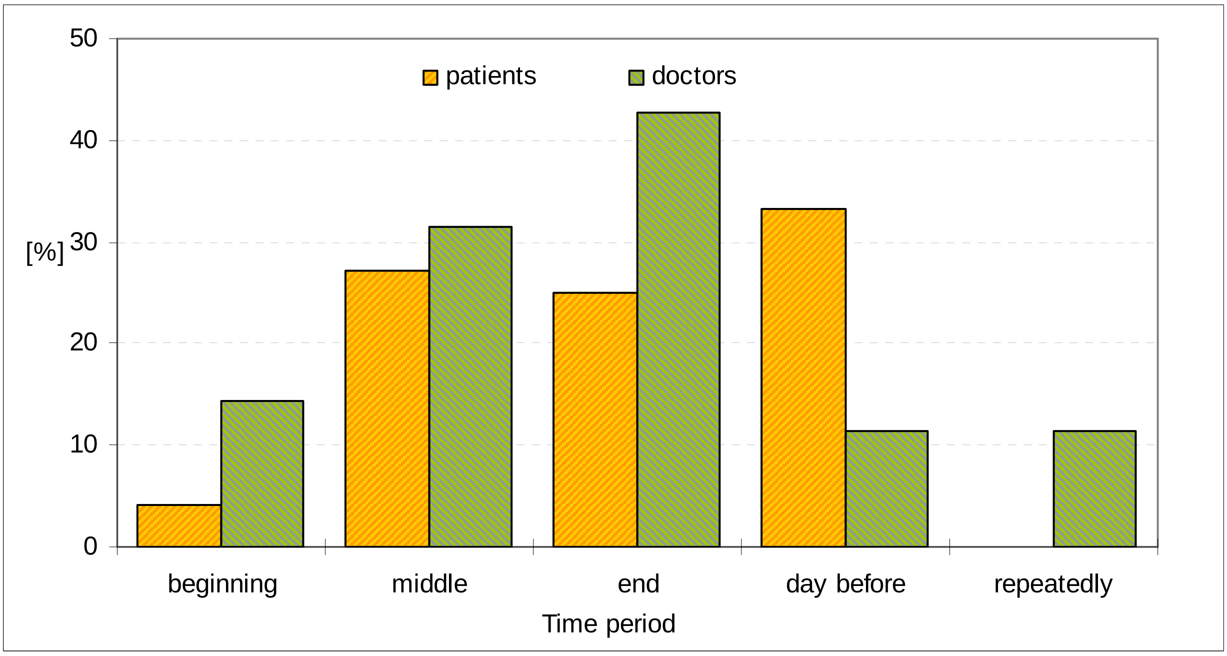


Figure 4.14: Time period in hospital stay when discharge was discussed with patient; patients n=43, doctors n=35

The data revealed no statistical significance when one compares these findings with the different areas of specialisation of the doctors (p=0.21056) (table 4.5).

Table 4.5: Time period when discharge information was discussed according to doctors' area of specialisation

Specialist	Beginning	Middle	End	Repeatedly	Total
Neurologists	2	2	7	1	12
[%]	16.7	16.7	58.3	8.3	
Physician	2	9	7	3	21
[%]	9.5	42.8	33.3	14.4	
GP	1	0	1	0	002
[%]	50.0	0.0	50.0	0.0	
Total	5	11	15	4	35

4.9.7 Information given on day of discharge

Most patient participants (n=37, 77.0%) received information about their medication on the day of discharge, eleven participants (22.9%) received more information on their prognosis and eight participants (16.7%) on risk factors as well as follow-up rehabilitation. These figures do not add up to 100% as patients mentioned more than one aspect in relation to which information was provided.

The majority of doctors (n=18, 51.4%) stated that they emphasised the information on risk factors one more time. Other aspects like follow-up rehabilitation (n=14, 40.0%), medication (n=12, 34.3%), prognosis (n=10, 28.6%) as well as complications (n=7, 20.0%) are matters commonly discussed by doctors with patients and family on the day of discharge.

The age of doctors compared with information given on discharge did not show any statistical significance (p= 0.10).

4.9.8 Methods by which information was disseminated

According to the doctors they usually provided information verbally. Similarly most of the patients (n=17, 35.4%) concurred that they had received the information verbally. Figure 4.15 compares patients' and doctors' statements on how information was shared.

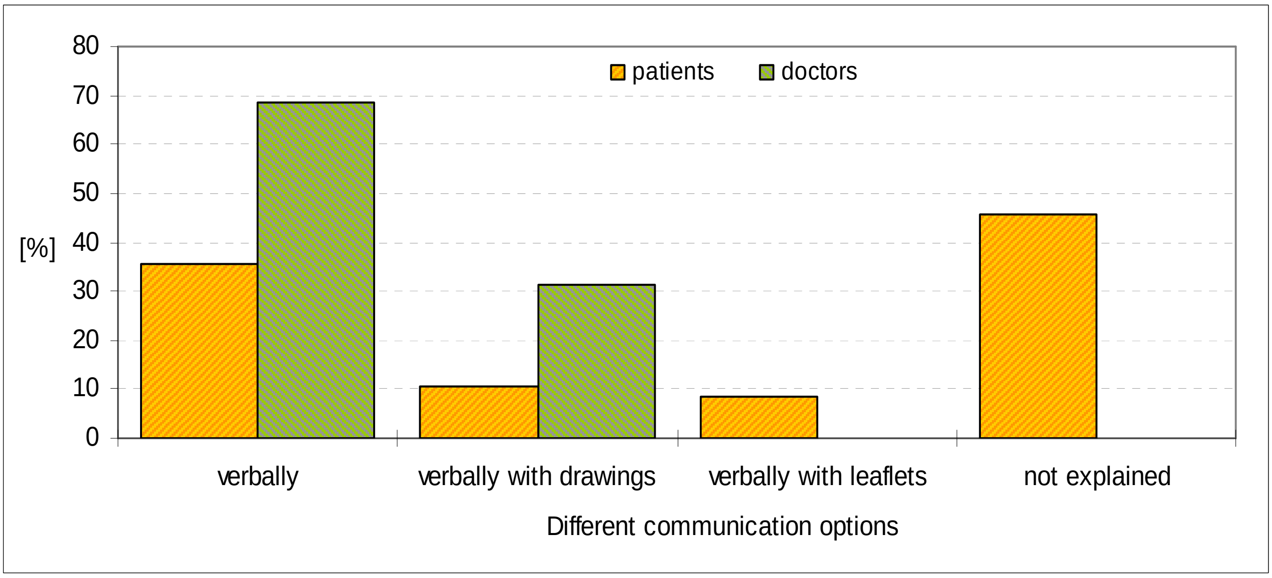


Figure 4.15: Comparison of patients' and doctors' views on the methods of sharing information; patients n=48, doctors n=35

The majority of patients (n=23, 47.9%) stated that they received information in a clear and professional manner. A further two patients (4.2%) stated that the information was adequate while five participants (10.4%) thought the information given was very vague. The expression of one participant (2.1%) was that she did not receive much sympathy and she said that she felt very depressed after every information session. Another participant (2.1%) reported that the doctor laid down the "facts" with little consideration for the emotional effects on the patient. The rest of the sample (n=16, 33.3%) stated that they did not receive any information.

4.9.9 Frequency of information sessions

Results revealed important differences between patients' and doctors' opinions on how often information on diagnoses, prognosis and risk factors was shared (figure 4.16). While most doctors (45.7%) felt that they gave information on a daily basis, most participants felt that they did not receive any information at all (43.8%). This difference was statistically significant (p= 0.00039).

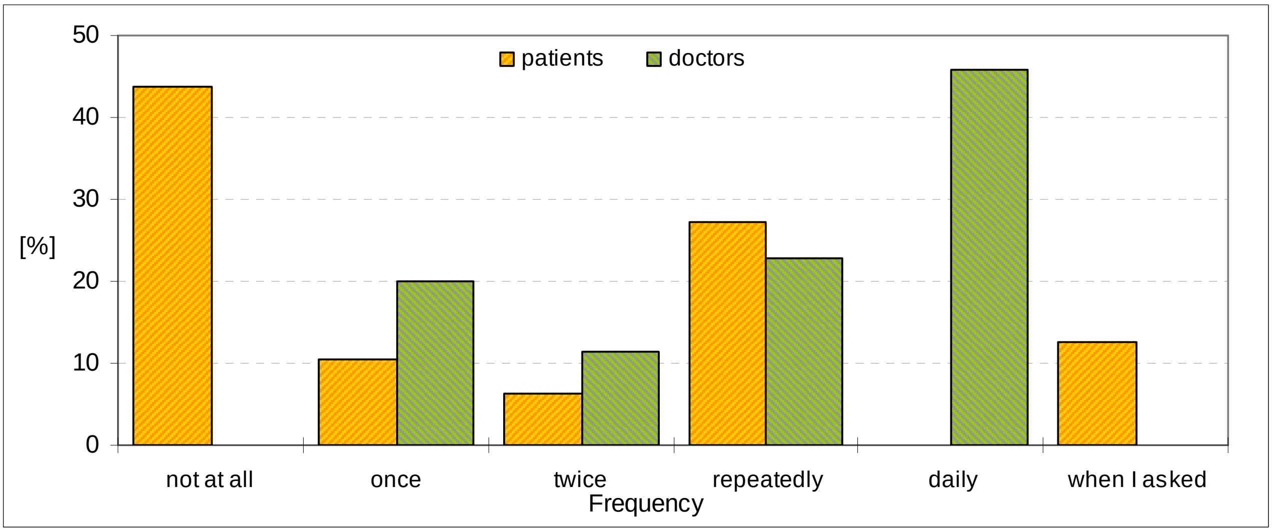


Figure 4.16: Comparison of two study groups' opinions on the frequency with which information was shared; patients n=48, doctors n=35

When frequency was compared with the different areas of specialisation of the doctors no statistical significance was found (p= 0.18722) (table 4.6).

Table 4.6: Frequency of information sharing compared to area of specialisation

Specialists	Daily	Twice	Often	Repeatedly	Total
Neurologists	6	0	4	2	12
[%]	50.0	0.00	33.3	16.7	
Physician	10	3	3	5	21
[%]	47.6	14.3	14.	23.8	
GP	0	1	0	1	2
[%]	0.0	50.0	0.0	50.0	
Total	16	4	7	8	35

However frequency with which information was shared revealed a statistically significant relationship with the age of doctors (p=0.03). Figure 4.17 shows that older doctors supplied information repeatedly, whereas younger doctors mostly gave the information only twice.

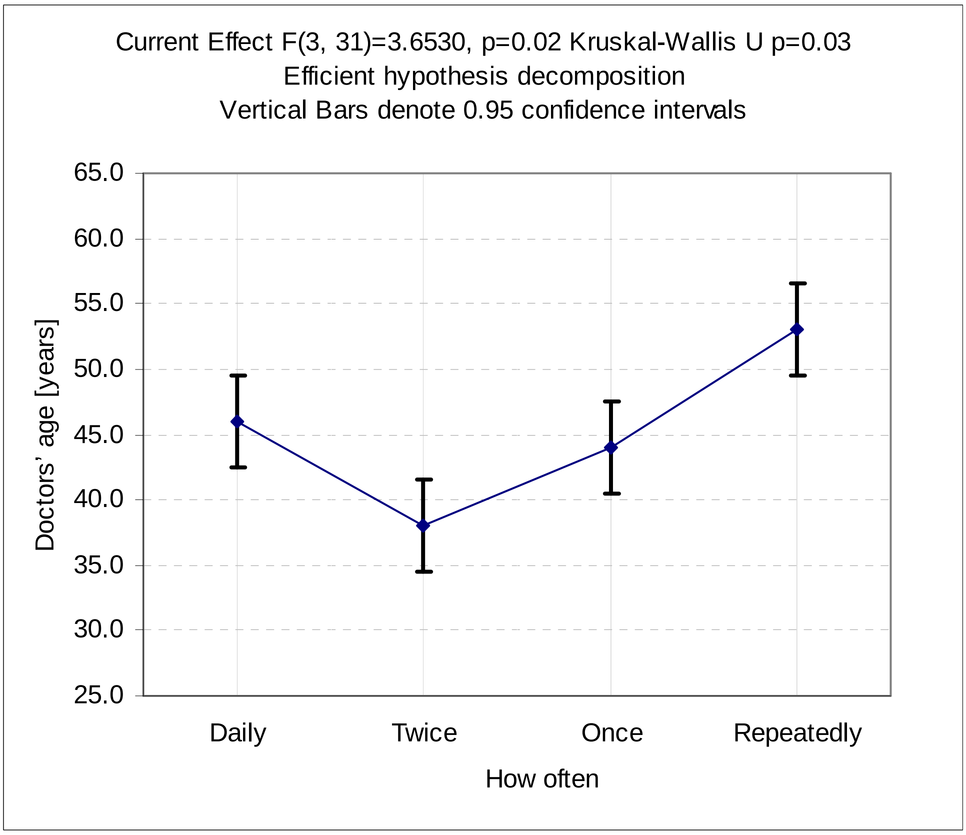


Figure 4.17: Frequency of information given compared to doctors' ages; n=35

4.9.10 Time spent per information session

The information given on "time spent per information session" differs quite drastically when one compares the mean value of the two groups of participants as is shown in figure 4.18. The results of the doctor population showed a mean of 30 minutes on "time spent per information session" while the results from the patient population revealed a mean time of only 11.3 minutes. Of note are the eighteen patients (37.5%) who said that they did not receive any information at all.

When "time spent" was compared amongst the specialists, no statistical significance (Chi square test p=0.13, Kruskal-Wallis test p=0.08) was found. However figure 4.19 shows that neurologists tend to spend more time with their patients than physicians and general practitioners. "Time spent" was also compared with the age of the different doctors. The CHi-square test showed a p value of p= 0 .7762, which confirmed no statistical significance.

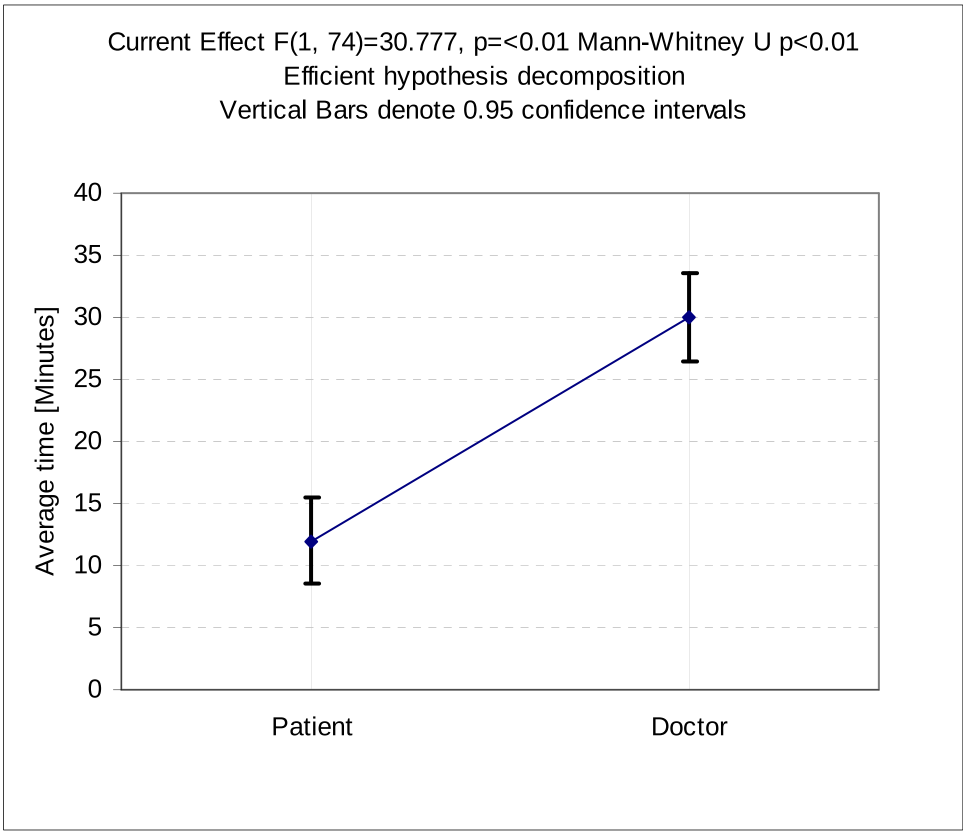


Figure 4.18: Average time (minutes) spent per information session according to patients' and doctors' opinions; patients n=48, doctors n=35

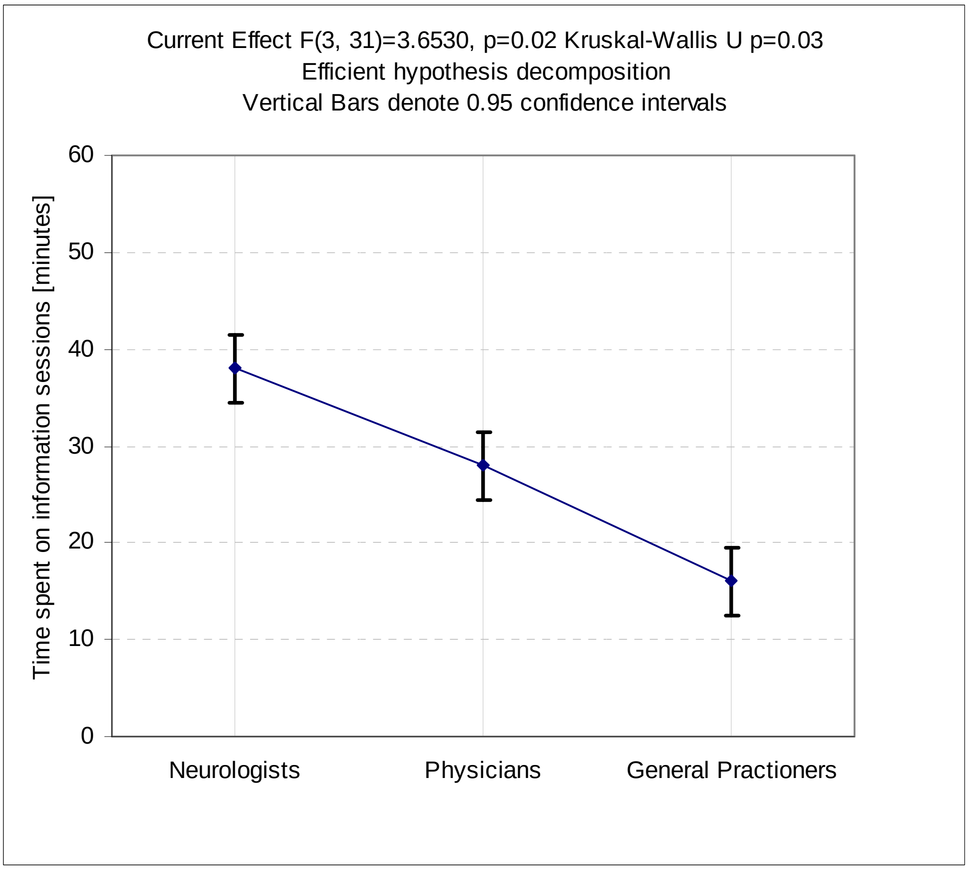


Figure 4.19: Time (minutes) spent on information sessions compared between the different areas of doctors' specialisation; n=35

4.9.11 Additional comments regarding information on stroke

Qualitative data revealed the following findings: six patient participants (12.5%) and one doctor expressed the need for an information center for stroke survivors and their family. In particular there was a need to furnish information on the necessity for treatment sessions and their length and intensity. Patients also indicated that they wanted more information on life-style and diet.

4.10 Length of Stay in the Acute-care Hospital

4.10.1 Introduction

Mean length of stay in the acute-care hospital was 12.3 days with the shortest stay being 2 days (2.1%, n=1) and the longest stay 44 days (2.1%, n=1), followed by 42 (2.1%, n=1) and 30 days (6.2 %) respectively. The majority of the patients stayed for 7 or 14 days (each 12.5%, n=6).

4.10.2 Comparison of length of stay between the different hospitals

Length of stay (LOS) was compared between the different hospitals. The findings are shown in figure 4.20. Milnerton Medi Clinic shows the shortest median LOS and Chirstiaan Barnard Memorial Hospital shows the longest median LOS. Both, the Chi-square test (p=0.46) and the Kruskal-Wallis test (p=0.28), found no statistical significance between LOS and the different hospitals.

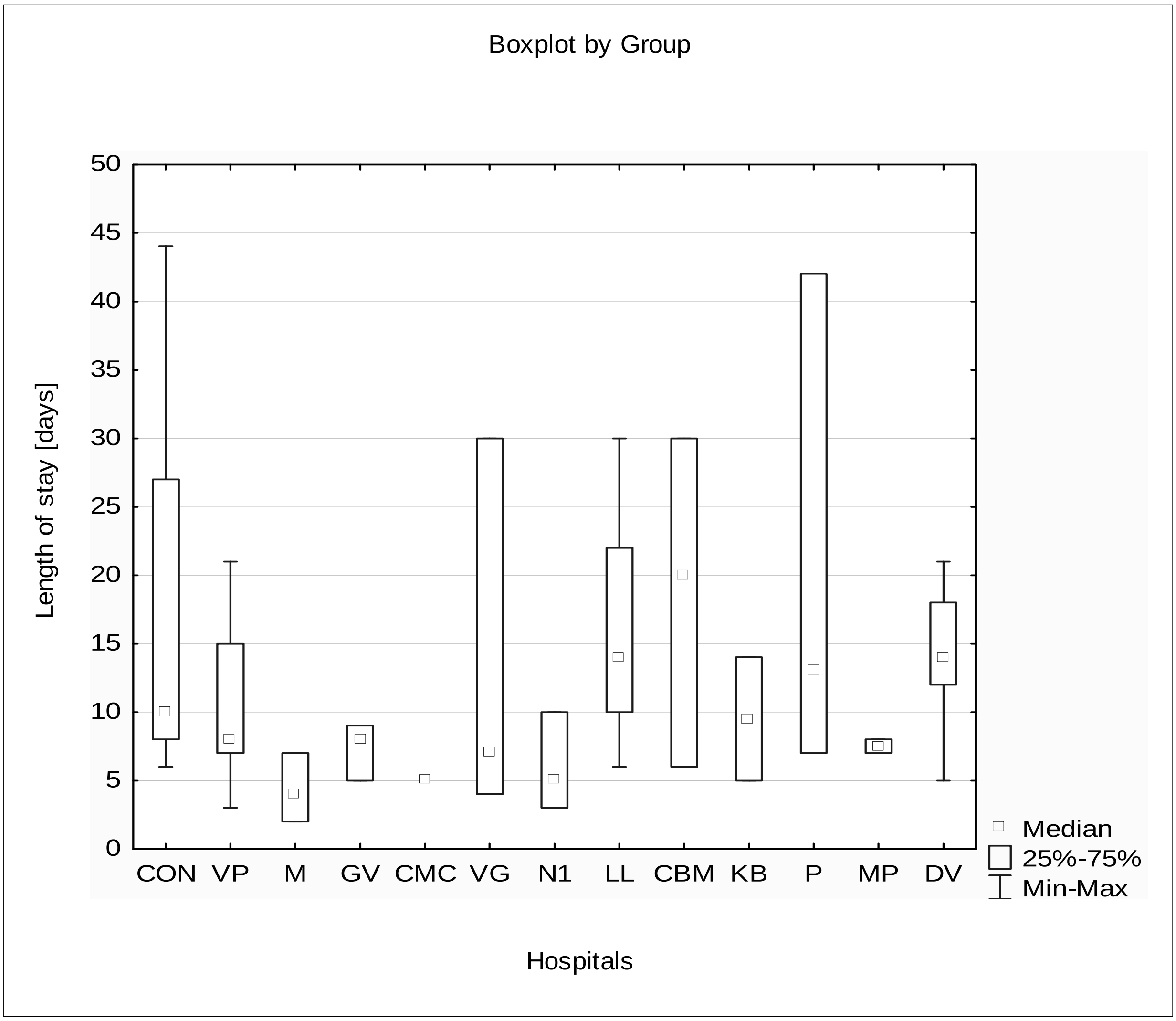


Figure 4.20: Length of stay in the different hospitals;
CON - Constantiaberg Medi-Clinic; VP - Vincent Pallotti Hospital; M- Milnerton Medi-Clinic; GV - Gatesville Hospital; CMC - Cape Town Medi-Clinic; VG - Vergelegen Medi-Clinic; N1 - N1 City Hospital; LL - Louis Leipold Medi-Clinic; CBM - Christiaan Barnard Memorial Hospital; KB - Kingsbury Hospital; P - Panorama Medi-Clinic; MP - Mitchell's Plain Medical Centre; DV - Durbanville Medi-Clinic

4.10.3 Comparison between length of stay and level of disability

The researcher compared the relationship between LOS and disability. The Spearman Correlation graph indicates that there is no correlation betweeen LOS and disability as the results showed an evenly spread picture.

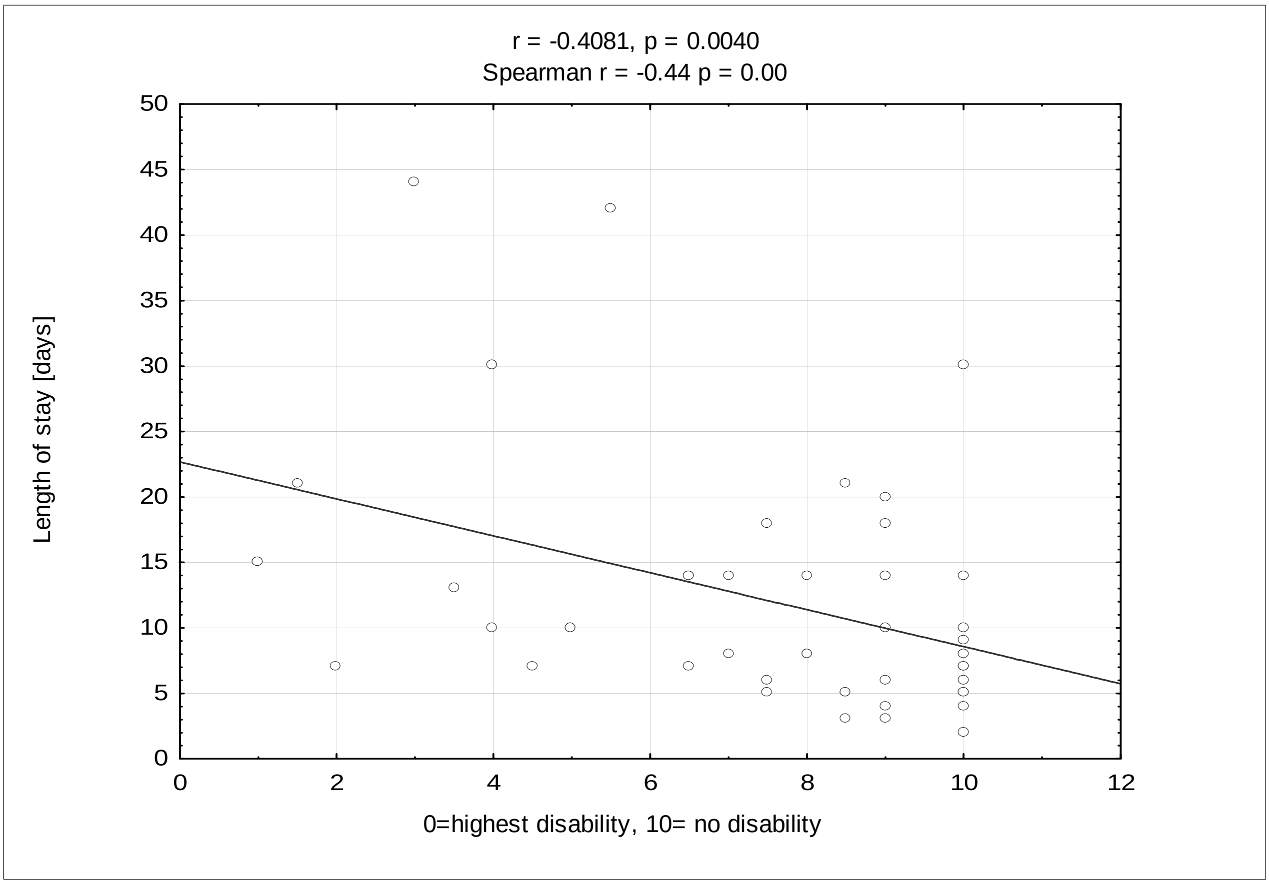


Figure 4.21: Length of stay compared with disability level; patients n=48

4.11 Deciding on Post-acute Rehabilitation

4.11.1 Patients' participation in the decision making process on the post-acute rehabilitation setting

Only thirteen patients and/or family members (27.5%) were included in the decision making process regarding post-acute rehabilitation facilities. Figure 4.22 shows patients' views on who made the decision on which post-acute rehabilitation setting they will be utilising. The number of participants in the table does not add to forty-eight as some patients stated that the decision was made by e.g. the "therapist and the doctor".

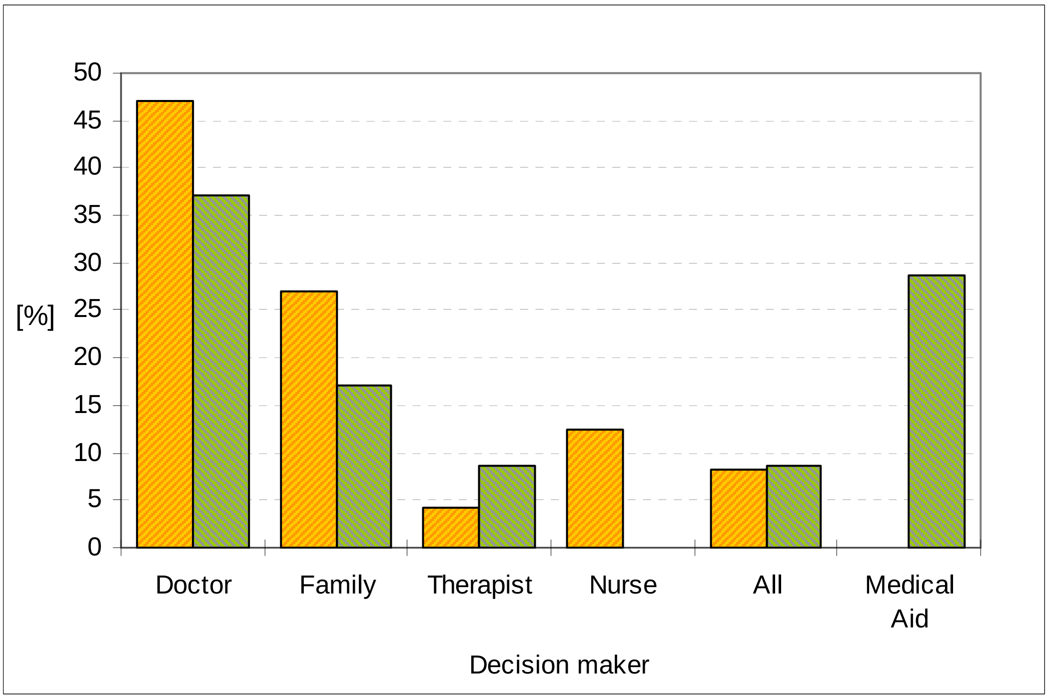


Figure 4.22: Person responsible for deciding on a post-acute rehabilitation setting

The data revealed no statistical significance (p= 0.13819) when one compares these findings with the different areas of specialisation of the doctors (table 4.7).

Results showed that younger doctors let the family and/or the Medical Aid make the decision whereas older doctors relied more on the therapists (figure 4.23). This finding was statistically significant (Kruskal-Wallis test p= 0.02).

Table 4.7: Final decision maker on post-acute rehabiliation setting according to doctors' area of specialisation

Specialists	Family	Medical aid	All	Doctor	Therapist	Total
Neurologists	2	6	2	2	0	12
[%]	16.66	50.0	16.66	16.66	0	
Physician	4	3	1	11	2	21
[%]	19.0	14.3	4.8	52.4	9.5	
GP	0	1	0	0	1	2
[%]	0.0	50.0	0.0	0.0	50.0	
Total	6	10	3	13	3	35

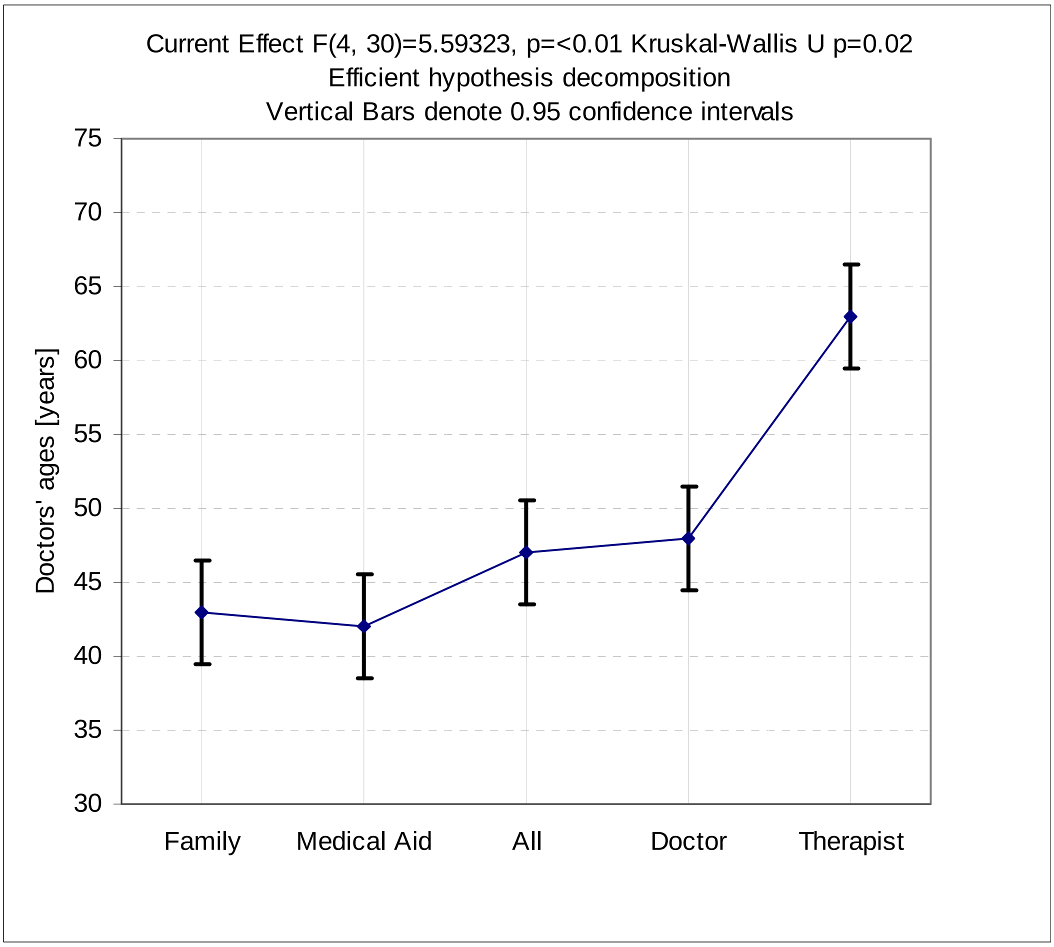


Figure 4.23: Responsibility for decision: doctors' views analysed according to age

4.11.2 Satisfaction on being included/excluded in the decision making process

Asked how they felt about being included in the decision-making process, sixteen patients (33.3%) indicated that they were satisfied, one (2.1%) participant felt ambivalent and one (2.1%) felt slightly overwhelmed.

Data from the thirty patients (62.5%) not included in the decision-making process showed the following: Four participants (8.3%) felt ambivalent, three participants (6.2%) did not want to comment; twenty-three participants (47.9%) were satisfied and fully trusted the professionals who made the decision.

Qualitative data revealed two patients (4.2%) who were upset because they had not been included in the decision making-process while in the acute-care hospital. Both of them received physiotherapy treatment without being asked whether they wanted it. Furthermore, they were not satisfied with the treatment given and had not realised that they had to pay for it additionally. A walking stick was ordered for one of the above-mentioned patients, despite the fact that he did not think that he needed it and he was most upset when he received a separate bill for it.

4.11.3 Participation of other health care professionals in the decision making process

Doctors consulted the following health care professionals regarding the decision on patients' post-acute rehabilitation: medical specialist (n=10, 28.6%), general practitioner (n=5, 14.3%), physiotherapist (n=14, 40.0%), occupational therapist (n=5, 14.3%), speech and language therapist (n=4, 11.4%), sister in charge (n=10, 28.6%). However, they stated that the final decision is made by the doctor (n=13; 37.1%) or the Medical Aid (n=10; 28.6%) (figure 4.22). The numbers do not add up to 100% as many doctors consulted more than one health care professional.

4.11.4 Doctors' opinions on the need for post-acute rehabilitation

With the exception of one doctor all other doctor participants (n=34. 97.1 %) believed that patients enjoy a better outcome if they continue with rehabilitation after discharge from the acute-care hospital. Most doctors (n=19, 54.3%) stated that there is scientific proof that patients show better function after post-acute rehabilitation. These findings were highlighted by qualitative data; eight participants (22.8%) repeated this statement on being asked for additional comments on the rehabilitation process. However, they also voiced their concern that there was not enough funding available for post-acute rehabilitation.

4.11.5 Doctors' preferences in post-acute rehabilitation settings

Altogether fourteen doctors (40.0%) stated that they prefer in-patient rehabilitation units for post-acute rehabilitation. Reasons for their preference were: first (n=13, 37.1%) the intensity of therapy offered to the patient; second (n=7, 20.0%), it provided the family time in which to adapt themselves and their environment to the new situation; third (n=4, 11.4%), there was better observation for the patient and fourth (n=2, 5.7%), it was paid for by the Medical Aid (n=2, 5.7%).

There was a statistical significance (p = 0.0274) in the relationship between the practices of neurologists and physicians with regards to the preference of post-acute rehabilitation settings (table 4.8).

Table 4.8: Post-acute rehabilitation preferences according to doctors' area of specialisation

Specialists	Inpatient	Domicil	No preference	Total
Neurologists	1	3	8	12
[%]	8.3	25	66.7	
Physician	0	12	9	21
[%]	0.0	57.1	42.9	
GP	1	1	0	2
[%]	50.0	50.0	0.0	
Total	2	16	17	35

To recommend the appropriate rehabilitation option, doctors looked at different variables, which can be seen in figure 4.24. Most doctors (n=20, 57.1%) mentioned the costs involved in the follow-up rehabilitation, while the least-mentioned variable was the wishes of the patient's family.

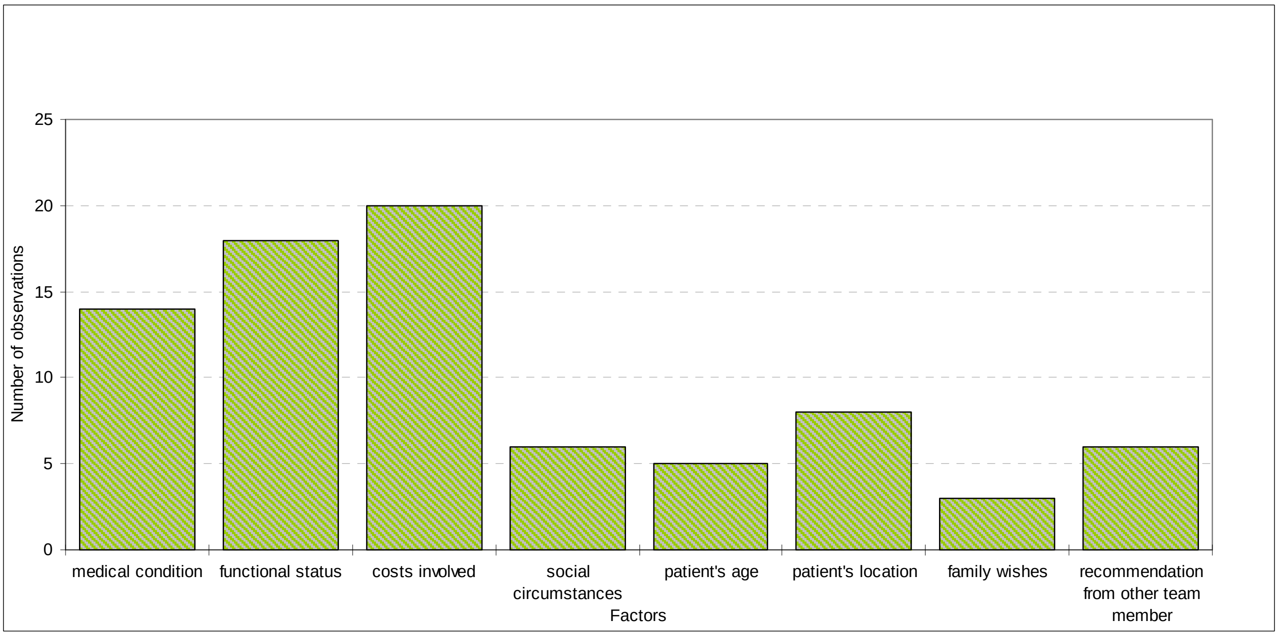


Figure 4.24: Factors impacting on selection of post-acute rehabilitation setting

The majority of doctors (n=13, 37.1%) said that they made the final decision on post-acute rehabiliation setting. This was followed by the Medical Aid who according to doctors made the descion 28.6% of the time.

4.11.6 Post-acute rehabilitation settings of patient population

The majority of patients (n=25; 52.1%) were referred to in-patient rehabilitation facilities after discharge from the acute-care hospital; eleven patients (22.9%) had no follow-up rehabilitation; six (12.5 %) attended out-patient facilities and a further six patients (12.5%) received domiciliary therapy.

4.11.7 Comparison between settings selected and functional abilities of patients

Figure 4.25 shows that patients with higher disability at time of discharge (median= 6.5) went to specialised rehabilitation centers. Patients (n=6, 10.4%) with a median disability level of 8 took advantage of services rendered at the patient's house. Patients who did not continue with any rehabilitation (n=10, 20.8%) showed a median disability value of 10 although one had a very low mean of 4 at discharge.

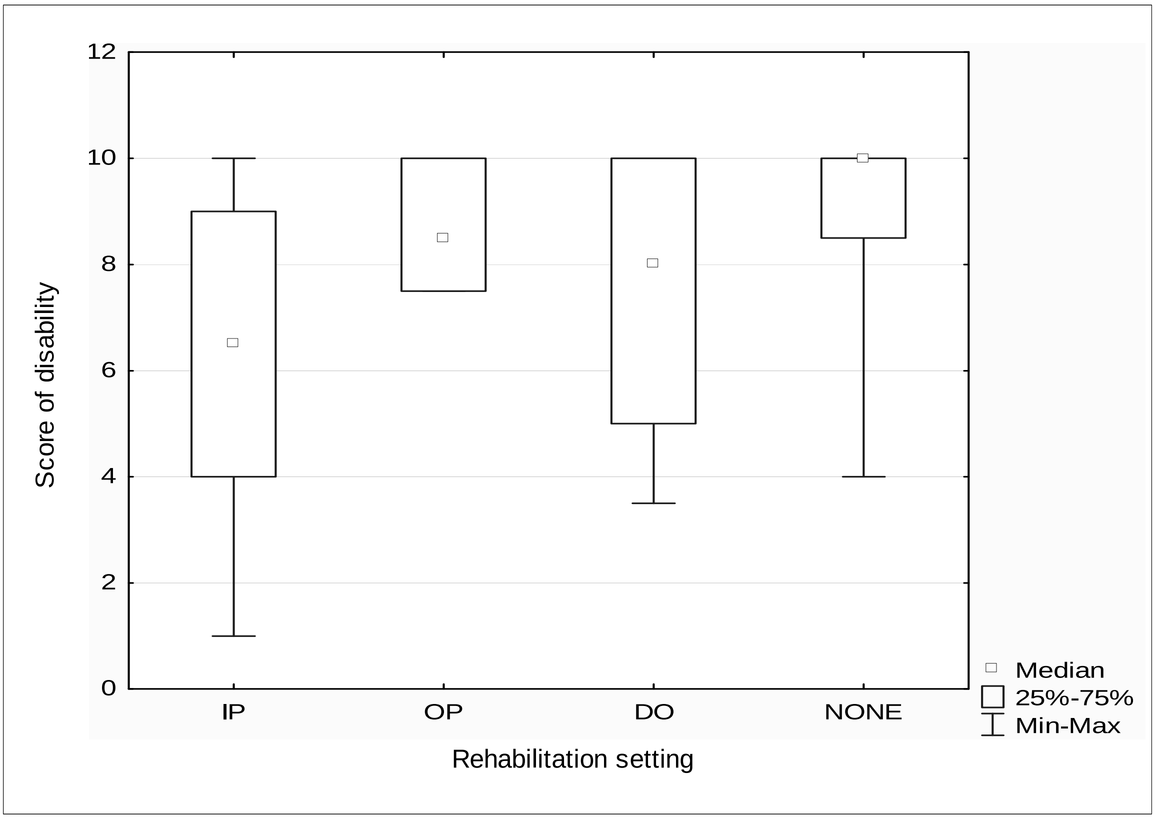


Figure 4.25: Comparison of post-acute rehabiliation setting and functional abilities of patients; IP – In-patient facility, OP – Out-patient facility, DO – Domicillary therapy

4.11.8 Choice of selected settings compared with different acute-care hospitals

Data showed no statisical signifance (p= 0.32440) when the selected settings were compared with the different hospitals.

4.11.9 Rehabilitation goals

Asked whether their goals were met during the follow-up rehabilitation process, ten patients (20.8%) answered that they did not have any goals, eleven participants (22.9%) answered "*no*", whereas more than half of the sample (n=27, 56.3%) answered "*yes*".

4.11.10 Satisfaction with choice of post-acute rehabilitation setting

The majority of the patient sample (n=40, 83.4%) was satisfied with the choice made for follow up rehabilitation at the time of discharge from the acute-care hospital. While three participants (6.2%) did not know how to answer this question, five patients (10.4%) were not satisfied. This was compared with two variables namely "follow up setting" and "different hospitals". The data was evenly spread: two patients went to a rehabilitation facility, one patient took advantage of therapy given in the home environment and two patients received no further rehabilitation. When the different hospitals were compared, the data showed no significant variation.

4.12 Follow Up after Discharge

Nearly all patients (n=35, 73.9%) were given a follow up appointment with the specialist, most of them (n=21, 43.7%) four weeks after discharge from the acute-care hospital or the rehabilitation unit.

From the twenty-five patients (52.1%) who received inpatient rehabilitation, sixteen (33.3%) were referred for further rehabilitation after discharge from the rehabilitation unit.

4.13 Additional Findings

4.13.1 Challenges in different rehabilitation areas

Qualitative data revealed certain challenges in the following areas:

Patients felt that nursing staff were not adequately trained in caring for stroke survivors; they were not efficient in their services and "*not always available when needed*". This statement was confirmed by doctors who expressed that "*there is a need for nursing staff who are well-educated in respect of stroke care*".

Patients were unhappy with the low intensity of therapy offered to them in the post-acute rehabilitation setting (this included patients who went to a post-acute rehabilitation centre and one patient who received domiciliary treatment).

Patients found that there was a lack of recreational space in the post-acute rehabilitation centres.

Two patients complained about the choice of the post-acute rehabilitation centre, since "*it was situated far away from the relatives' home whereas there was another rehabilitation centre situated much closer to home*".

The standard of post-acute rehabilitation as well as acute rehabilitation was criticised by four doctors (11.4%).

4.13.2 Accuracy of diagnosis

The researcher made one very important finding through the additional comments. Six participants (12.5%) stated that the diagnostic skills of general practitioners were lacking when it came to detecting stroke warning signs. One stated "*the general practitioner needs to improve his skills in terms of making the right diagnosis*". All six patients went to the doctor with severe headache. Two of them had additional speech problems and one showed some weakness in his right leg. Four of the patients were diagnosed with "*head flu*" and received medicine for flu. (Later one of patient was told "*that medicine for "cold" increases blood pressure*"). The fifth patient, while being away from home, was diagnosed with severe migraine. When she returned home, her husband immediately contacted their general practitioner, who confirmed the diagnosis. The following day the patient was admitted to hospital, having suffered a severe stroke. The sixth patient was diagnosed with alcohol abuse. He had not consumed any alcohol at that time, but, when questioned on assessment, his daughter said that *"her father likes his drink on Sundays"*. He was rushed to hospital three days later with an irreversible stroke.

These findings were supported through qualitative data from the doctors' questionnaires. Asked whether he wanted to add any comments on the rehabilitation process for acute stroke patients, one doctor mentioned the "*ignorance of the general practitioners*". He complained, that "*general practitioners do not refer early enough or sometimes not at all*".

The researcher heard one positive story where a patient experienced the same symptoms as mentioned above. He was rushed to hospital, diagnosed by a specialist who immediately gave him anticoagulant medication. He was one of the patient participants who suffered from no impairments or functional limitations on discharge.

4.14 Summary

The doctor population – thirty-one males and four females with a mean age of 47, consisted of twenty-one physicians, twelve neurologists and two general practitioners. None of them had any rehabilitation qualification.

Patients – thirty-three males and fifteen females with a mean age of 64 years, were mainly white, English-speaking South Africans, well-educated and retired. Nearly all of them lived in a house prior to the stroke and had medical insurance. The majority suffered a right CVA. The mean value of activity limitations at the time of the interview was eight with mobility being the most affected area.

Almost 50% of doctors used a set protocol. Almost all (86%) were willing to try a new set protocol as they saw the advantages of using such a protocol while 57% also saw disadvantages. The multidisciplinary team work approach was used by 57% of doctor participants, while 91% indicated that they would prefer to work within an interdisciplinary team. Only 6% included the patient and family as team members whereas all doctors included the physiotherapist. The most common means of communication among team members was verbal (80%).

The majority of doctors (97%) stated that they informed the patient and family members regarding the diagnosis (80%), prognosis (89%), risk factors (63%) and on the post-acute rehabilitation options (66%). This was not supported by statements given by patients (50 - 27%). Less than 50% of the participants – doctors or patients – stated that information regarding discharge timing was discussed. Doctors and patients agreed that the method by which information was disseminated was mostly verbal but disagreed with regards to the frequency and duration of information sessions.

LOS in the acute-care hospital showed a mean of 12.3 days, no statistical significance could be found in the difference between the various hospitals or the varying disability levels of different patients.

The decision on the post-acute rehabilitation facilities was mostly done by doctors or the Medical Aid but doctors consulted other health care professionals beforehand. Most of the patient participants were satisfied with both, the decision approach as well as the choice of the post-acute setting.

Additional findings, obtained from qualitative data, revealed dissatisfaction voiced by both study groups with regard to some areas such as the quality of nursing staff, the therapy given (physiotherapy, occupational therapy and/or speech and language therapy) and in particular, the diagnostic skills of doctors.

CHAPTER 5: DISCUSSION

5.1 Introduction

This chapter will discuss the most pertinent findings of this study, bearing in mind its objectives. In specific, it will focus on those areas where there are discrepancies between the results from doctors' and patients' data, such as information provided on stroke diagnosis and prognosis and aspects of stroke care. The chapter also discusses aspects of health care which, according to the literature, have important advantages, but which were underutilised by participants of this study, such as stroke care protocols, interdisciplinary teamwork approaches, the education of patients and family members on risk factors and patient autonomy. No summary follows the conclusion of Chapter 5 so as to maintain a contextual flow from the discussion to the chapter's conclusion and finally, recommendations.

5.2 Distribution of Study Population

5.2.1 Hospital sample

As mentioned in Chapter 3, (Methodology) the researcher experienced major resistance in selecting the study population. Hospital managements from all private hospitals situated in the Western Cape Metropole admitting stroke patients, refused access to the hospital register book as well as to the patient medical folders. According to Dr. Lebo Manthata, the legal advisor of one of the three biggest private hospital groups (Health System Trust 2007), namely the Medi-Clinic group, the request was denied for reasons of confidentiality and the decision based on the National Health Act of 2003 section 16 (Manthata , email 24 May 2007).

The National Health Act, 2003 (Act 16 of 2003), provides a framework for a single health system for South Africa. It highlights the rights and responsibilities of health-providers and -users and ensures broader community participation in healthcare delivery from health facilities up to national level. The Act provides for the right to emergency medical treatment, a patient's right to access to all information about his condition, the right to exercise informed consent, to participate in decisions regarding one's health, to be informed when participating in research, to confidentiality and access to health records as well as the right to complain about service, and the right of health workers to be treated with respect.

Section 16 – Access to Health Records by Health Care Provider - states as follows:
“A health care provider may examine a user’s health records for the purposes of:
a.) treatment with the authorisation of the user; and
b.) study, teaching or research with the authorisation of the user, head of the health establishment concerned and the relevant health research ethics committee.

If the study, teaching or research contemplated in subsection b) reflects or obtains no information as to the identity of the user concerned, it is not necessary to obtain the authorisations mentioned in that subsection”.

Believing that the legal adviser acting for all Medi-Clinics misinterpreted Section 16 of the National Health Act of 2003, the researcher consulted an independent lawyer, who confirmed this view. The lawyer also informed the researcher that she could obtain access to the register book only by challenging the medical legal adviser’s decision in court.

The Hospital Association of South Africa (HASA) (2005, p. 8) states that “the private health care sector is keen to partner the public sector to provide training and research to lessen the burden on the public sector”. It further reports that academic institutions should source information from providers to ensure appropriate training and research projects (HASA 2005). However, the table listing all costs spent in private hospitals in recent years such as taxes, salaries, purchases and training does not show any funds to have been spent on research projects. This as well as her own experience lead the researcher to query the credibility of HASA’s promises regarding the support of further research projects.

However, even despite these difficulties, all hospitals eligible for the study were represented in the study through doctor and/or patient participants.

5.2.2 Doctor population

Although 74% of identified doctors expressed their willingness to participate in the study, many were resistant. In her effort to engage with doctors, often the researcher got no further than the secretary’s desk. Most doctors cited time constraints and busy schedules as the reason for their unavailability. It is assumed that such resistance is against research generally and not specifically this study, since doctors declined to participate even before ascertaining what the study was about. This is regrettable since research is indispensable for the upgrading and improvement of health care.

5.2.3 Patient population

In sharp contrast to hospital administrators and doctors, only 6% of patients refused to participate in the study. It appears that the study population was a selection of middle and upper income class patients (see 5.4 Demographic profile and socio economic status of patients). Statistics South Africa 2006 reports that only 48.4% make up the middle and upper income class in South Africa (The Media Magazine 2009) and only seven million people in South Africa make use of private health care facilities (Burger 2007). It should thus be apparent that the sample group for this study is a minority group.

5.2.4 Relevance of the study

Despite these obstacles as well as the opinion of a leading stroke expert discussed under the pilot study in 3.9, the researcher continues to be confident in the relevance of this study. First, the research has been conducted in the private health care sector, where greater funds ensure the provision of a quality service. Because these patients pay for themselves (either directly or through a Medical Aid), they expect and often demand impeccable treatment. It is therefore critical to ascertain whether the private sector is able to deliver what the paying customer expects of it. Second, the private sector represents the “golden standard” which the entire South African health care system should strive to uphold (Health System Trust 2007). In 2004 the Minister of Health highlighted the fact that the private health sector has a significant role to play in the health system of South Africa (Health System Trust 2007). That is another important reason for constantly reassessing the service delivered. Third, the majority of medical practitioners (62%) and particularly specialists (75%) practising in South Africa work in the private sector (Health System Trust 2007). Since much of the study focuses on doctors’ practices and opinions regarding various aspects of stroke management, the private sector is the optimal place to perform a study of this nature. Finally, many literature reviews (Rudd & Matchar 2004; Forster, Young, Patterson, Wanklyn, Smith, Murray, Wild, Bogle, Lowson 2009) point out that there is an enormous need for further research on stroke issues. Any valid and reliable research project on stroke-related issues will contribute to the endless battle against what remains one of the leading causes of disability - both nationally and internationally.

5.3 Demographic Profile and Training of Doctors

As the majority of the doctors were male (89%) it was not feasible to statistically compare the different rehabilitation aspects according to the gender of doctors. However, the researcher did determine whether age and area of specialisation of doctors had a statistically significant influence on their practices.

With regard to rehabilitation training, the study findings revealed that four out of thirty-five doctor participants had rehabilitation experience but none had specialised rehabilitation training. Rehabilitation Medicine is a relatively new field of specialisation for doctors. To specialise in physical medicine and rehabilitation (PM&R) doctors enrol in a registrar training course lasting between three and six years. Some countries require applicants to have a previous qualification in internal medicine, orthopaedics, rheumatology or neurology. PM&R specialists offer specific interventions for patients with disabilities and work in close co-operation with the patient, family and friends as well as other health care professionals. These specialists conduct assessments of complex disabilities and include psychological and social factors and often rely on assistive technology in the management of clients. They most often play a leading role in a multi- or interdisciplinary team, with strong links to primary health care and social services (Young & Disler 2003; British Society for Rehabilitation 2008). Young and Disler (2003) list 25,404 PM&R specialists working in forty-five countries with America leading with 6 000 specialists, followed by Japan with 4 000. The distribution of PM&R specialists in African countries has been described as “very patchy” (Young & Disler 2003, p. 474). No such course is currently offered at any South African medical school.

While work experience in a rehabilitation centre is of value, it cannot be compared with a three- to six-year training course. The researcher asks why this specialty is not offered in South Africa. However, the Department of Family Medicine at Stellenbosch University has offered an optional module on rehabilitation as part of its Master’s course. In the last four years all twelve doctor participants chose to enroll for this module, thus proving the interest shown by South African doctors (Griggs H, personal assistant of Prof. Mash, Department of Family Medicine, University Stellenbosch, telephonic conversation 23 May 2009).

5.4 Demographic Profile and Socio Economic Status of Patients

The study sample reveals that more males than females suffered a stroke. On comparing these findings with the literature, the researcher found inconsistent results. Some authors report the relationship between women / men stroke survivors to be 2 : 1 (The SASPI Project Team Stroke 2004; Connor & Bryer 2006; Statistics South Africa 2006) whereas another reports 30% more males than females suffering a stroke (National Guideline on Stroke and Transient Ischaemic Attack Management 2001). The researcher therefore concludes that there is no gender pattern when it comes to stroke incidence.

The mean age of the patient population (64.3) was similar to the mean age of stroke survivors from high-income countries ($\geq$ 65). However, this study was done in a developing country where the literature reports the mean age to be fifteen years lower than those of high-income countries (Bonita et al. 2004; Rouillard 2007). Dube (2005) describes South Africa as a middle-income developing country with a small group of very wealthy people, living a lifestyle associated more with developed countries and a large group of very poor people living a lifestyle associated with developing countries. Therefore, this study's finding that South Africa has a higher mean age of stroke survivors than one would expect, can probably be attributed to the fact that the study was conducted in a high-income population group. Furthermore, the finding supports the literature which maintains that there is a connection between a privileged lifestyle and a higher mean age among stroke survivors (Dube 2005).

The racial distribution of patient participants in this study is quite skewed when compared to the racial distribution of the Western Cape Metropole. According to Cape Town Wikipedia (2008), Asian people represent 2% of the population, followed by Whites (19%), Blacks (31%) while Coloureds form the majority of the Cape Metropole's population (48%). However, the researcher believes the unrepresentative distribution of the study population is due to the fact that racial classification is an indicator of relative lifestyle advantage in South Africa.

The majority of the patient sample (75.0%) was English speaking, which is again in contrary to general Western Cape Provincial figures. According to Statistics South Africa (2006) 55% of the population from the Western Cape Metropole speak Afrikaans, 24% Xhosa and only 19% English. The Pan South African Language Board (2000) reports that many South Africans are multilingual and over one third of the population use a mixture of languages. Accordingly all patients except one from the study population felt comfortable being interviewed in English even though it was not the first language of the entire group.

Factors like the status of employment, school-education, housing as well as private health insurance can all be used as indicators of socio-economic standards of a population (Absolute Astronomy 2009). Thus a strong tendency to belong to a higher socio-economic stratum was evident in the patient sample: Only one person was unemployed, most people lived in a house and high school was the predominant educational level attained.

In keeping level of education showed a highly educated study population and figures differ hugely form the general figures on education for South Africa. According to Statistics South Africa (2006) only 23% of the South African population matriculate and only 11% hold certificates for higher education. By contrast however, among the patient population that forms the subject of this study, almost 60% have matriculated and approximately 45% have received a higher education.

Approximately 86% of the White South African population make use of private health insurance and health care while only 27% of the Black and 27% of Coloured South African population uses private health care facilities (Statistics South Africa 2006). This study shows that 97% of the study population had medical insurance - a finding which is to be expected since the study was conducted in the private health care sector.

5.5 Effects of Stroke

The mean-score (7) for functional disability on discharge was quite high, meaning that for many patient participants, the effects of the stroke were relatively minor. Most studies compare functional outcome three or six months post-stroke (Rouillard 2007) and the researcher was unable to find any literature discussing the average function of stroke survivors after discharge from the acute-care hospital. Another difficulty in comparing functional outcomes is that measuring instruments differ widely from study to study, making the comparison of results difficult. Rouillard (2007) reported on disability scores taken on admission to a post-acute rehabilitation setting. Considering that most patients in the current study were transferred directly to a post-acute rehabilitation setting, this is the closest comparative data the researcher could find. Rouillard’s study showed that 65% of the study sample depended on others for carrying out their daily activities. In the current study group, the areas most affected were mobility and self-care - both activities of daily life. Over 50% of the current patient sample scored five and/or less for self-care and almost 60% scored of five or less for functional mobility. Moreover, it is evident that almost 20% of the patients in the study sample had to employ a carer to assist them in their daily activities. The results, while slightly lower than Rouillard's findings, are close enough to point towards the same trend.

The researcher is of the opinion that the average mean score of function (6.8) at time of discharge from the acute-care hospital is relatively high. In fact four patients received emergency medical treatment while admitted to the acute-care hospital with the result that they showed hardly any residual effects on discharge. Two patients scored ten out of ten for all functional aspects while the other two scored ten and one nine for all functions. This is a credit to the acute medical management of doctors. The finding can also be interpreted to mean merely that doctors gave the names of patients who did particularly well during the acute-care phase, as discussed under study limitations in chapter 3.

Despite the high functional mean score, the study findings support the literature (Clarke et al. 1999; Rhoda 1999; Mercier et al. 2001; Farham 2004; Teasell & Kalra 2005) that many patients fail to recover fully after a stroke. Mean values from pre-stroke to discharge from the acute-care hospital dropped by three points. As expected, most patients showed improved functional scores at the time of the interview, which can be attributed to rehabilitation and/or spontaneous neurological recovery (Kwakkel et al. 2004). However, recovery was incomplete and activity limitations and participation restrictions were present, e.g. one third of the patient population experienced a change in the employment status.

This residual deficit often results in the patient needing a care-giver, who can be either a family member or an employee. Either option has a huge impact on the patient's and the family member's life. Employing a care-giver, as did nine patients in the current study, imposes an enormous cost burden. A great deal of re-organisation is also required as changes to the household routine become necessary. Most family members complained of losing their privacy and of higher food consumption. Both, employing a caregiver or relying on a family member for care can cause the patient to become aggravated or depressed and can have a similar effect on the caregiver (Blake et al. 2003).

The study also revealed how problematic it is to compare findings from research projects regarding post-stroke outcomes at a certain point of time. Many measurement scales are available (Wade 1998), in fact too many – and this makes the comparison of research results on disability levels difficult. The "International Classification of Functioning, Disability and Health" (ICF), classifies disability into three categories: impairment, activity limitation and participation restriction (WHO 2004). The ICF Core Set project is currently looking into the development of a protocol which will hopefully be used in acute-care and early post-acute rehabilitation facilities dealing with patients with neurological conditions. The ICF aims to provide a set protocol which can ultimately be used as a comprehensive multi-professional assessment and management document. This will hopefully assist not only in the patients' management but also in the communication and reporting of the functioning and health of patients suffering from neurological illnesses (Grill, Ewert, Chatterji, Kostanjsek, Stucki 2005).

5.6 Stroke Care Protocols

Almost all doctors (89%) were convinced of the advantages of using a set protocol despite the fact that less than half - (46%) used one in their practice. Most of the doctors were knowledgeable on all benefits of a set protocol as presented in the literature (Dewas & Patel 1997; Hales & Eales 1999; South African Medical Association 2000; Kwakkel et al. 2004). This confirms that awareness does not always translate into behavioural changes. This phenomenon is currently the subject of scrutiny in the field of health care and is thought to be the reason for improvement in health care remaining limited despite the advances of medical research (Neuhauser, Gary, Kreps 2008).

Although doctors felt that the protocols are too rigid, they are not and in fact the better ones are anything but rigid. The South African Medical Association (2000; p. 297) reports in their "Stroke Therapy Clinical Guidelines" that *"an algorithm should not be used as a rigid protocol but can provide guidance in the clinical decision making"*. Thomson, Lavender and Madhoek (1995) mention that one element of the use of guidelines is to describe appropriate care based on the scientific evidence and broad consensus, leaving room for justifiable variations in practice. A simple check list could help clinicians to check whether all optimal care principles have been incorporated in patients' management (Vampatella 2008).

Findings like the limited use of teamwork and team meetings as well as poor patient education on stroke, makes one question either the standard of the protocols in use or explains the limited extent to which these protocols have been utilised. As mentioned in the literature review, a management protocol should address all rehabilitation aspects including emergency assessment and treatment to improve cerebral perfusion; inclusion of appropriate team members; team meetings; appropriate documentation; identification of rehabilitation goals and objectives; patient and family education; risk factor modification; counselling on lifestyle changes; discharge planning; referral to post-acute rehabilitation. (Dewas & Patel 1997; South African Medical Association 2000). Asked what their protocol entailed, doctors mentioned hardly any of these aspects.

Furthermore, while the doctors using a protocol reported that their protocol included referral to other health care professionals, only one mentioned team meetings with other professionals. Referring to health care professionals does not imply working within a team but could simply refer to an accumulation of health care professionals whom the doctor has informed about a new patient. Indeed, it would be a sorry state of affairs if one needed a protocol to remind one to refer to other health care disciplines.

Post-acute rehabilitation planning and placement was mentioned as part of their protocol by over 60% of the doctors. This is in line with the emphasis literature places on this aspect (Hale & Eales 1999; South African Medical Association 2000). However, qualitative data revealed that some doctors referred automatically to in-patient facilities. Thus, it is uncertain whether the protocol has been correctly used and important factors like functional aspects, family preferences and funding taken into consideration. This would certainly provide proof that a protocol can be too rigid if used in the wrong manner.

There was one further finding of importance: younger doctors who had specialised for less than ten years used a set protocol more often than doctors who had specialised for an average of fourteen years. Perhaps this is because the importance and the advantages of using written guidelines are being increasingly recognised and propagated in the teaching curriculum of medical faculties.

5.7 Team Work Approach

Although almost all doctors felt that the interdisciplinary team work approach was the most suitable for stroke care, not a single doctor used it in their hospital environment. Doctors further confirmed their preference for the interdisciplinary approach by expressing their dissatisfaction with the current methods of communication (70%) among health care professionals.

Again, doctors showed superior knowledge on the subject and were well versed in the advantages and benefits of an interdisciplinary team work approach, as mentioned in the literature (Dewas & Patel 1997; Cifu & Stewart 1999; Strasser et al. 2005). However, no effort was made to apply this information in their practices. This is unfortunate as doctors – traditionally team leaders – are in a strong position to facilitate the implementation of changes like this.

The literature (The Agency for Health Care Policy and Research 1995; Cifu & Stewart 1999) reveals that interdisciplinary team work ultimately saves time and money by avoiding delayed referrals or unnecessary and overlapping treatment. Discharge time and discharge setting are also more appropriate and therefore more cost effective and beneficial to the patient and family, when an interdisciplinary team work approach is adopted (Cifu & Stewart 1999; South African Medical Association 2000; The University of Sydney et al. 2004). As already reported in the literature review, some authors proved a significantly shortened LOS and significantly improved functional outcome if interdisciplinary rehabilitation services were implemented (Cifu & Stewart 1999).

Doctors participating in this study were of the opinion that the interdisciplinary team work approach is unsuitable for the private sector due to lack of time, organisational problems, unavailability of staff and billing issues.

The researcher has however seen the successful implementation of an interdisciplinary team work approach in the South African private sector. As predicted by the literature, it required strong leadership (provided by a general practitioner, Dr Leon Geffen) and willingness on the part of all team members to devote time and effort to ongoing communication (Agency for Health Care Policy and Research 1995). The results were clear to see: an improvement in the condition of patients and greater satisfaction on the part of health care professionals as a result of consensus on goals, discharge planning and treatment approaches. The researcher also noticed that the initial team meeting had a positive long-term effect on communication among different health care professionals.

Providing strong leadership, Dr. Geffen ensures the holding of regular meetings, at which goals are established, treatment plans set and progress reports made. All health care professionals involved (e.g. physiotherapist, occupational therapist, speech and language therapist, social worker, representative of the nursing agency) as well as patient and family members are present at these meetings. As team leader, the doctor encourages other team members to co-operate and share ideas freely; he also ensures that the team adheres to treatment plans and achieves treatment goals. Should a team member be unable to attend a meeting, he or she must submit a written report on the patient's progress and this is then read to all the other team members.

The issue of billing could be addressed by using the option of complicated or intensive assessment sessions, for which health insurance companies pay.

Doctors mentioned another barrier for adopting a team work approach - the "*unavailability of staff*". If this is the case, it might be the result of an inverted relationship. If doctors do not refer to certain professions, the latter might not have sufficient work in a specific area or setting and therefore decide to practise somewhere else. If doctors do not invoke the help of occupational therapists or social workers for the acute stroke patient, these health care professionals become short of work and as a result settle in the public sector or find a different specialisation.

However, in the researcher's experience, health care workers from all the various professions are indeed available in the private acute-care sector and are willing and able to treat stroke patients. There must therefore be another reason for the failure on the part of doctors to include them as part of the team. First, some health care professions are possibly still not recognised or respected or their skills are not as well-known to doctors in this setting as they should be. Second, it is possible that some health care professionals work in competition with each other instead of promoting team work. In the researcher's experience, some general practitioners do not refer to other health care professionals because they are afraid that these other professionals might deplete the "*patients' budge*t" leaving the patient with insufficient money to pay for doctors' visits. It should not be necessary to point out that the patient's well being and recovery ought to be the main factor in deciding whether to refer to other health care professions or not. Third, there might be a link, as some doctors still work within the medical model, where the hierachy of medical care prevents the adoption of a team work approach.

When one considers the composition of the ideal team, according to doctor participants in this study, some important aspects appear. Only two doctors included the patient as a team member and only five included the family and caregivers. Department of Health (1998) strongly endorses the social model of disability, emphasising the value of full participation of the family in the patients' recovery. Patient rights and patient autonomy dictate their inclusion and the ethics of medical decision-making would require that patients be intimately involved. Jones (1998) stresses the important impact that the relationship between health care professionals and the patient and family has on the health outcomes for the patient. Human nature suggests that people perform better when they are included in decision making and are enabled to understand what is happening to them and why. Uncertainty and ignorance breed anxiety and fear, both of which are counter-productive to optimal performance. For all these reasons, the involvement of patients and their families in the rehabilitation process can be seen as axiomatic.

The exclusion of the patient and family members also highlights the fact that many doctors in the private sector still practise according to the medical model which dictates that a patient unquestioningly submit to the directions and orders of the physician. A shift from the medical to the social model is necessary if one is to respect patient's autonomy and include him and his family in decision making, thereby greatly enhancing the recovery process.

Typical of the old exclusionary model of patient treatment, some health care professionals still ask family members to leave their rooms before commencing a treatment session. If the patient and family members are to be accepted as fully fledged team members, the doctor or health care professional should first ask the patient whether he/she wants the family to stay. Not only does this respect the autonomy of the patient but it also ensures the involvement of the family member in the rehabilitation process. In the researcher's experiences, family members are often surprised to see how much the patient can do alone. This impresses on family members or friends how important it is to allow the patient to continue to engage in such activities without assistance. However, the health care professional has to be mindful of the fact that some patients struggle to concentrate on a prescribed activity in the presence of a family member or friend. In such a case, the therapist should discuss the situation with the patient and family member and reach consensus on what is in the patient's best interest.

Communication between team members highlighted another challenge. Conversations about the patients' progress in informal settings such as a car park or in the lift show the low priority currently accorded to team work and communication. This laissez faire attitude makes one wonder if and how such information is documented and if such communication still occurs where these team members do not happen to meet in the car park. Not a single doctor reported holding regular team meetings and only slightly more than 10% said that they exchanged information at ward rounds. These findings show a serious flaw in current patient management, particularly when one remembers that regular discussions on immediate and long-term management invariably improve patient outcomes (Hale & Eales 2001; Bruno 2004; Teasell & Kalra 2005).

Additionally the researcher discovered that most literature, national and international, still talks about the multi-disciplinary team work approach (Dewas & Patel 1997; South African Medical Association 2000; Department of Health 2008). Only rarely does one find articles which stress the need for interdisciplinary teams. This proves that much remains to be done to advance the implementation of the interdisciplinary team work approach both in in-patient and out-patient settings. The most important factor however is that team members become more integrated in the complete rehabilitation process including decision planning. Whatever the literature says, excluding the patient and family from decisions, and not convening meetings of the team members working on rehabilitation are the most pressing problems – the name used to describe the team approach is of secondary importance.

5.8 Information Shared with Patients on Various Stroke-related Aspects

Figure 5.1 highlights two main issues. First, the marked discrepancy between the perceptions of doctors and patients as to the degree to which doctors shared information on the various aspects of treatment and second, the low priority given to sharing information on such important aspects as risk factors for further strokes and rehabilitation options – both crucial to the health and well-being of any stroke survivor.

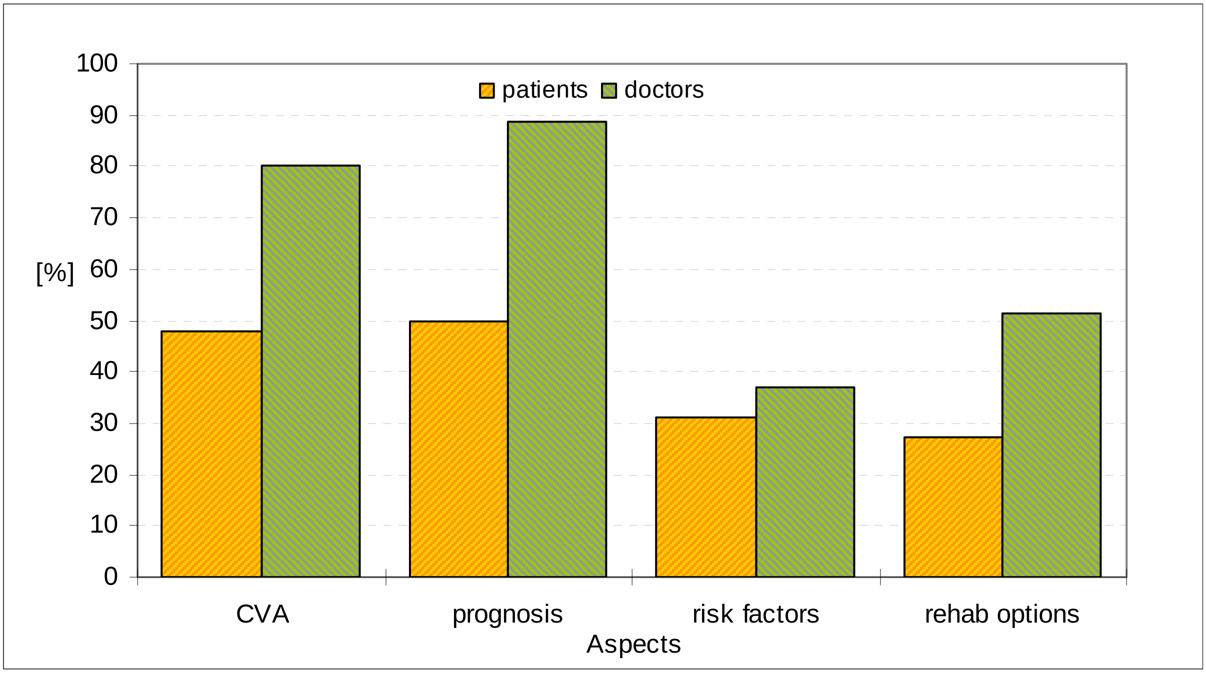


Figure 5.1: Comparison of the opinions of doctors and patients on whether information on various stroke-related issues was shared; patients n=48, doctors n=35

These findings are in contrast to the emphasis literature as well as national and international health policies place on the provision of information on the illness itself, its management and its prevention. (Agency for Health Care Policy and Research 1995; Hale, Eales, Stewart, Fritz 1999; The Department of Health 2006 for South Africa 1999; South African Medical Association 2000; Wandel et al. 2000; Hale & Eales 2001; Milne & Pikney-Atkinson 2004). The benefits of stroke education e.g. to reduce anxiety, to enhance the patient's participation in high quality rehabilitation, to prevent complications and the risk of a second stroke, to empower the patient to plan, to have goals and to make decisions about his or her own treatment, are well known and have been reported on by many authors (Hanger & Wilkinson 2001; Bhogal et al. 2003; Milne & Pikney-Atkinson 2004). This researcher supports the literature and submits that stroke information is crucial for the recovery, rehabilitation and future prospects of any stroke survivor, irrespective of whether the patient suffered from a transient ischaemic attack (TIA), mild or severe stroke.

One can also deduce from the study findings that doctors participating in the study were aware of at least some of these advantages and of the importance of sharing information, since over 80 % reported having given the information on diagnosis and prognosis to their patients. However, in both cases only 50% of patients felt that this information was shared with them. This also leads one to speculate on the effectiveness of the methods of information sharing, or even question whether some doctors actually shared the information with the patient or rather failed to do so, despite realising that they ought to.

The literature acknowledges that effective information sharing with stroke patients is problematic (Neuhause & Kreps 2008). It also identifies strategies to ensure greater effectiveness. These include: presenting the information repeatedly; tailoring information to the patient’s concentration level, cognitive capacity, level of education and cultural background; avoiding the use of jargon; combining various methods of delivery such as verbal, drawings, models, information booklets and videos; giving the patient an opportunity for questions and using questions to determine whether the patient understood the information provided (Hanger & Wilkinson 2001; Botha 2007; Neuhauser & Kreps 2008). Furthermore, communication involves not only the transfer of information from one person to another, but also ensuring that the message is understood as intended to be. It is therefore of utmost importance to provide opportunities to assess whether the patient has absorbed and understood all the given information.

The researcher was surprised to find that younger doctors provided fewer information sessions than their older counterparts. Since this aspect of stroke management currently receives so much attention, the researcher had presumed that younger doctors would have been more sensitised to this during their training. Possibly older doctors have come to realise through experience that patients and family members need repeated sessions to absorb the information given.

Furthermore, there was considerable variation between the opinions of doctors and patients with regard to the length of information sessions. The researcher however believes that this data was heavily influenced by the fact that patients who received no information were included and a time period of “zero minutes” recorded next to their name. If one discards the eighteen patients who received no information, the mean of the time period given per information session comes to almost twenty minutes. The researcher is of the opinion that this should be sufficient time for explanations provided that the information is explained repeatedly or even daily; is tailored to the patients’ cognitive capacity and assessments conducted to ascertain whether the information was absorbed. This would be more compatible with the thirty-minute time stated by doctors.

An interesting finding is that neurologists spend more time on explanation with their patients than physicians. This leads the researcher to ask the following question: does the specialisation curriculum for neurologists place more emphasis on the importance of the amount of time devoted to information sessions or is it merely because neurologists are more cognisant of the patient's mental capacity and capacity for concentration?

The second main issue highlighted by figure 5.1 is the low priority which was given to sharing information on risk factors for further strokes. When one bears in mind that one third of all stroke patients suffer further strokes (American Heart Association 2006) one would assume that risk factors of stroke and prevention of further strokes are always explained and discussed at great length. Health education plays a major role in the rehabilitation process as well as in preventative medicine.

Many health care foundations, national and international policies and health care practitioners emphasise the importance of ongoing education regarding stroke risk factors (Hale & Eales 2001; Bhogal et al. 2003; Bruno 2004; South African Stroke Foundation 2006). The researcher agrees with this literature and is of the opinion that risk factors cannot be explained often enough. Furthermore, she believes that the hospital is not only the most important but also most effective environment in which to provide stroke education to the patient and family members. Empathy and other emotions that are evoked in this atmosphere are well known as powerful mediating factors, when one wants to create awareness or change of behaviour patterns (Neuhauser & Kreps 2008).

Risk factors should be discussed with patients and family members on a continuous basis to highlight their importance. The purpose of patient and family education is to inform as well as modify behaviour patterns and to empower the patient, family member and friends to participate in interactive health care programmes. This will decrease the risk of a second stroke and keep stroke incidence low (Hanger & Wilkinson 2001; Bhogal et al. 2003; Milne & Pikney-Atkinson 2004). As previously mentioned, the health care professional should approach the discussion sessions as part of an interactive communication process and should allow time for reflection and questions as well as to assess whether the information has been understood.

Finally, only about 30% of each group of participants reported that information on the different rehabilitation options was shared. Providing information on post-acute rehabilitation settings is of utmost importance. First, it emphasises the importance of post-acute rehabilitation, which can lead to a better functional outcome for the patient and a therefore smaller emotional and financial burden. Second, information on post-acute rehabilitation is part of secondary prevention and third, it allows the patient and family to familiarise themselves with the different options and is conducive to an optimal decision being taken. Too little or no information can lead to disappointment, dissatisfaction and frustration in the post-acute rehabilitation process (Smith, Forster, House, Knapp, Wright, Young 2008). The effects of choosing an inappropriate post-acute setting will be discussed at length under 5.12 (Post acute settings).

Given the results regarding shared information, it is not surprising that some patients expressed the need for an information centre. Often patients want confirmation of the correctness of their treatment, type and/or amount of therapy or they simply want more information on new means of treatment. The researcher strongly believes that a stroke centre could provide this kind of support for many stroke survivors and their family members. Since recovery is an ongoing process, such information and any other information about modifying therapy is useful at any stage of the patient's path to recovery. While this type of centre would be beneficial to all stroke sufferers, it is important to stress that it will still not absolve the doctor from his/her responsibility to provide information to patients. The problems and impairments of stroke survivors are never the same and only the treating team members can provide information which take into account the subtle differences between one patient and another.

At the time of discharge, information on medication was provided by almost all doctor participants, while only a few doctors again discussed prognosis (23%) and risk factors (18%) with patients. This final contact session should be used to ask questions to again ensure that patient and family have understood the different aspects relating to CVA. The need for information on risk factors cannot be over-emphasised and repeating its importance can only enhance the knowledge of the patient and family member. Doctors might believe that time constraints prevent them from doing this. However, if the information is furnished beforehand it should not require much more time to verify this. The researcher therefore once again emphasises that ensuring that the patient has and understands such vital information is invaluable.

5.9 Discharge Planning

The literature stresses the fact that discharge planning should start at the beginning of the rehabilitation process i.e. just after admission and as soon as the patient is medically stabile (South African Medical Association 2000). However, only 15% of doctor participants in the current study practised early discharge planning. Discharge planning entails much more than just the setting of a date for discharge. Future care, management and rehabilitation plans as well as adaptations to home and community environments and the training and education of patients, family and caregivers are all incorporated under discharge planning. Thus, if the process does not commence early enough, family members will not have time to arrange the necessities for the new situation e.g. physical modifications to the home or finding a suitable caretaker.

Families will need to assess step-down facilities and nursing homes thoroughly before a patient is discharged and transferred to one of these, so as to avoid disappointment and dissatisfaction. This will be discussed in length in 5.11 (Post-acute rehabilitation). Scenarios in which family members are given no information on discharge – as happened to one patient who participated in the study - should not happen at all.

5.10 Length of Stay in the Acute-care Hospital

Data on length of stay in the acute-care hospital parallels findings from the literature review (Bresick 1997). There was found to be no relationship between LOS and level of disability. The data was evenly spread, particularly if one discards the two out-liers which proved that there was no dependency on LOS in the acute-care hospital and the disability level of the patients. The researcher interprets this finding to mean that patients with a higher range of disability are most often transferred to step-down facilities for follow up rehabilitation and therefore spend the same time in the acute-care hospital as patients suffering from a lesser degree of disability.

5.11 Post-acute Rehabilitation

5.11.1 Inclusion/exclusion in the decision-making process on post-acute rehabilitation setting

Almost half of the patient sample reported that doctors made the final decision on the post-acute rehabilitation setting. This finding is verified by the data of doctors, which state that in 37% of cases, they made the final decision; over 80% of the doctor sample did not include the patient and family in the decision-making process at all. However, almost all patient participants had no objection to exclusion from the decision-making process, as they fully trusted the knowledge and integrity of the doctor. This sentiment is understandable since, as is seen in shared information, patients were so uninformed about their condition and aspects related to it that they could not be expected to take control of their own health and rehabilitation process.

Furthermore, the researcher believes that if different options are not explained to a patient, there is simply no decision to be made. Looking at “information shared”, one third of the doctor sample did not even reveal the different rehabilitation options to the patient and only 6% of the doctor sample explained the advantages and disadvantages of the different rehabilitation options. This information is crucial if one is to make an appropriate decision and the lack of information must lead to an automatic exclusion from the decision-making process.

Second, the provision of information on the illness itself, its management and its prevention and therefore a perception by the patient that he has a role in the decision-making process, will lead to the patient having a greater understanding of his health problems and their implications. It will give the patient and family a greater sense of control over their own health and will allow them to arrive at an informed decision, based on ongoing discussion with the entire team (Lerman et al. 1990; Venesey 1995; Reddy & Reddy 1997; Clark & Smith 1998; Jones 1998; Sherr Klein 2007).

Third, the researcher interprets the above findings as confirmation that many people still think according to the medical model. Patients are not fully integrated in the decision-making process. Doctors often think that because they are most knowledgeable, it is in the patient’s best interest for them to decide on the rehabilitation setting. They might even believe that the patient is too traumatised and overwhelmed by the new situation (American Academy of Family Physicians 2001) and therefore incapable of making any decision. However, national and international health policies stress the importance of respecting the patient’s autonomy as fully-fledged partners in the decision-making processes (Agency for Health Care Policy and Research 1995; Hale et al. 1999; South African Medical Association 2000, Department of Health 2006).

The opinion that many doctors and patients still think according to the old patriarchal medical model which dictates that the doctor makes all the decisions, was confirmed by asking two related questions: 1: “Were you included in the decision-making process?” and 2: “Who made the final decision?”. The results showed that while seven participants stated that they were included in the decision-making process, in all seven instances, the final decision was still made by the doctor. By taking the decision alone, the doctor is ignoring the patient’s autonomy. Haas (1993) states that disclosure of all relevant and necessary information in discussions with the patient is most important if one wishes to adhere to the principles of informed consent. These principles also require that the patient and family be free from coercion and manipulation. Of course the patient’s competence to make a particular decision has to be taken into consideration (Haas 1993). This highlights the importance fully informing the family member who is to be responsible for the patient’s future planning when the patient himself is incapable of deciding. Taking factors of informed consent into careful consideration does not only respect the patients’ autonomy but also absolves the doctor of any potential legal responsibility for what may turn out to be an incorrect decision.

Some patients voiced unhappiness about not having been included in decisions on other rehabilitation aspects such as receiving therapy or the ordering of assistive devices. These findings highlighted the importance of the inclusion process as well as informed consent on all rehabilitation aspects. The study revealed that the autonomy of some patients was completely undermined. Once again, an ongoing process of information sharing, discussion as well as sensitivity to patient’s preferences and wishes and allowing the patient to make the final decision and accepting that decision, is necessary to uphold patient autonomy (Dewas & Patel 1997; Pollack et al. 2002). It is unacceptable to simply order equipment without consulting the patient or family beforehand. It is also most important to first introduce the means and methods of certain therapies before implementation. For example, even though the health care professional believes that it is in the patient’s best interest to have physiotherapy or speech and language therapy, he or she can never be absolutely certain that one is correct. It is often very difficult for health care professionals to accept or interpret patient’s wishes. It is often not clear whether the patient’s demotivation is an effect of the stroke, or whether the patient is confused or overwhelmed as a result of a traumatising new situation. It is therefore a very fine line that the health care professional has to walk on. Always, the patient’s autonomy and individual preferences have to be taken into careful consideration.

Furthermore, not even 10% of doctors or patients were of the opinion that the decision evolved from ongoing discussions by the entire team. According to the literature, decisions should emerge from ongoing discussions with all team members including the family and patient (Jennings 1993; Dewas & Patel 1997; Cifu & Stewart 1999). These results are to be expected since it has already been established that teamwork is a very low priority.

Another finding was that the group having the second biggest input regarding the decision on post-acute rehabilitation settings, were the medical insurance companies. It is not in the patient's best interest when medical insurance companies state what they are willing to pay. While the concept of making provision for one's medical expenses is a good one, the entire process is now beyond the control of the consumer. Medical insurance companies no longer fulfil the role of a service provider, but rather a dictator for whom expenses determine the choice of treatment, with little or no consideration for the needs and wishes of the patient. This is another factor making it impossible for patients and families to take control of a situation which is so critical to the outcome of the patient's recovery process.

An interesting finding also emerged when the age of doctor participants was compared with the different members who made the decision on post-acute rehabilitation settings. Younger doctors seemed more inclined to leave the decision to the patient, family and the medical insurance company while older doctors more often consulted therapists. The importance to acknowledging patient autonomy is a relatively new concept which might explain why older doctors still work within the medical model.

5.11.2 Doctors' beliefs and preferences on post-acute rehabilitation

The researcher found that all doctors, but one, believed in the value of follow-up rehabilitation. These findings were also confirmed by most patients who received follow-up therapy once discharged from the acute and post-acute hospitals. It also shows a link to the literature which concludes that functional recovery can be seen up to and beyond six months. (Kwakkel et al. 2004; Sturm et al. 2004; Desrosiers et al. 2006). Many doctors had a preference on the post-acute rehabilitation setting, which is to be expected. However, one has to be extremely careful not to allow one's preference to influence one's objectivity when introducing and recommending different options to patients and family members. As seen in selection criteria for the rehabilitation setting, it is again noticeable that only 3% of the doctor sample mentioned the family wishes as part of the selection criteria. As previously stated, one must not only be open to preferences and cultural differences of the patient (Hale & Eales 2001) but one also has to continuously remind oneself of the principle of patient autonomy (Haas 1993).

5.11.3 Selecting the post-acute rehabilitation setting

As discussed in 5.11.1 (Inclusion/exclusion on decision on post-acute rehabilitation settings) coming to a correct decision on the post-acute rehabilitation options is extremely important since it plays a crucial role in the patient's ultimate outcome and also has financial implications. Post-acute rehabilitation should be an individualised process for every person and therefore, patient, family and the rehabilitation team must carefully assess and weigh up the different options and even the different options within a certain category e.g. differences in rehabilitation units and what they offer before, reaching a decision. Choosing an inappropriate post-acute rehabilitation setting can lead to under-stimulation for patients and therefore hamper the recovery progress; choosing a rehabilitation setting which offers a programme that the patient cannot follow because he does not yet have sufficient ability to concentrate or sufficient endurance, will cause frustration for patient, family and staff alike. Sometimes, this results in wasting valuable funding, which could be positively used at a later stage or for a different approach. Qualitative data from this study confirmed these statements.

In the current study, patients who were admitted to in-patient rehabilitation units reported feeling under-stimulated, bored and depressed when confronted with fellow patients who were severely impaired. These findings are well reported in the literature (Holmquist et al. 2000; Larn 2001; Teasell & Kalra 2005; Dow et al. 2007). Expanding on this, one patient explained that not only did he not get enough stimulation at the rehabilitation centre but that there was also no recreational area where he could spend time before or after therapy sessions. As a result he spent much of his time in bed waiting for the time to pass.

The researcher would like to use this opportunity to question the intensity of therapy offered at some rehabilitation centres in the Western Cape Metropole. As reported in the literature review, one particular rehabilitation centre offered physiotherapy sessions of thirty to forty-five minutes as well as occupational and/or speech and language therapy on a once, twice a week or weekly basis (Chief physiotherapist, Panorama Rehabilitation Centre 2008). This is certainly not compatible with the standard of rehabilitation centres reported in the literature review, which should deliver high intensity therapy programmes where patients participate for at least three to four one-hour therapy sessions a day (American Health Assistance Foundation 2006; Dow et al. 2007). Furthermore, if one looks at the high costs of admission as an in-patient to such a centre, this type of low-intensity treatment is not justifiable. The researcher attributes the above scenario to doctors’ remarks on the poor rehabilitation standard in this country. She proposes that rehabilitation programmes offered by private rehabilitation units in the Western Cape Metropole be submitted to external auditing and that performance measurement become an integral part of such programmes.

Another point is the importance of assessing the time when the patient will be admitted to the centre. The study reported the case of one patient who was admitted to a local rehabilitation centre just before the Christmas holidays. He experienced hardly any therapy for the first two weeks as most staff members were on year end holiday. This is a rare case but one which nevertheless should be taken into consideration.

5.11.4 Post-acute rehabilitation settings utilised by patient population

While the distribution of the selected settings for post-acute rehabilitation in the patient population did not show any statistical significance, the reader might notice the uneven spread. The majority of the patient sample (52%) went to in-patient facilities. While patients who went to in-patient rehabilitation facilities, did show lower functional mean scores, on closer assessment, they were not particularly low. Patients also mentioned that they did not receive enough stimulation in the centre. This might be because their functional status was already so good that they were eager to participate in their social roles. In general, most patients (85%) were satisfied with the choice of the post-acute rehabilitation setting. Thus, not withstanding criticism of the selection process followed, it would seem that in the end, settings were well chosen.

5.11.5 Goal setting

As much as 21% of the patient sample did not have a goal during their rehabilitation process and 23% reported that their goal was not met. These findings might be a result of poor team work or also a lack of information and communication with the patient and with other health care professionals. As reported in the literature review, ongoing communication on the rehabilitation plan and on goal setting should be given during the acute and post-acute rehabilitation process (Hale & Eales 1999; South African Medical Association 2000). Protocols or simple treatment plans should include goal setting, which is an important factor for the motivation of the patient (Dewas & Patel 1997; South African Medical Association 2000). It is however important that the team or therapist sets realistic goals, which can be achieved in a short period of time (Diabetiker Ratgeber 2008). Failing the goal can be devastating and frustrating for the patient and family and often leads to demotivation in the subsequent rehabilitation process (Diabetiker Ratgeber 2008) whereas meeting a goal can accelerate subsequent progress.

5.12 Misdiagnosing Stroke Warning Signs

It still happens that patients are misdiagnosed even though they are showing strong warning signals of a stroke. As many as 12% of the study sample might have walked away with no permanent disability if immediate action had been taken by general practitioners. This supports the literature that stroke incidence could be drastically reduced (Rothwell et al. 2004) if treated in the right manner. This suggestion is also supported by the case of the patient who received excellent professional service from the ambulance staff and doctor and walked out of the hospital with no further signs or symptoms of a stroke. He did also state that he was lucky because he now is well-informed on all risk factors and will adjust his lifestyle in future accordingly.

CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS

6.1 Introduction

In chapter 6 conclusions and recommendations are drawn from the main arguments made in the discussion (chapter 5). This includes the resistance towards the research project, the poor rehabilitation specialisation in this country, the underutilisation of set protocols and the interdisciplinary team work approach by doctors, the poor quality of sharing information on stroke, importance of goal setting and of patients' autonomy. It is followed by a summary on the recommendations and also by a summary of further research options. Chapter 6 ends with an overall summary of the study.

6.2 Study Population

The participants of this study were a selected group of doctors and stroke patients from the private health care sector of the Western Cape Metropole. One must however be wary of using these results as a basis for generalising and should bear in mind that the results must to some extent have been influenced by the researcher's being denied access to the register books of hospitals. In particular, it could be argued that findings of this research project might be artificially favourable because of the possibility that doctors chose to reveal the names of those patients who did particularly well in the recovery process. It could therefore be assumed that the results of this study reflect a picture which is far better than would have been the case had the study been based on the general stroke population of the Western Cape Metropole.

6.3 Resistance to the Research Project

Resistance to the research project came from three areas: Private hospitals, many doctors from the private sector and a leading stroke expert from the public sector. This reflects poorly, considering that there is still such a desperate need for stroke-related research, particularly on acute and post-acute stroke rehabilitation. The National Department of Health (2006) states that health resources could be utilised much more effectively if the three health providers i.e. the Public Sector, Non Government

Organisations (NGOs) and the Private Sector, took advantage of each other's inherent strengths instead of providing parallel services. This statement can be taken one step further by pointing out the importance of the co-operation of all three sectors in further research projects. The researcher is of the opinion that all stake-holders from the private health care sector need to change their attitudes to research studies. Research projects must not only be paid lip service to but must be applied and mission statements implemented.

The researcher recommends that government organisations like the Health Professional Council of South Africa (HPCSA) and the Medical Research Council support research in private health care by monitoring the number of research projects being run in the different private hospitals. This could even result in it becoming compulsory for every private hospital to facilitate a minimum number of research projects over a stipulated period. Government organisations like the Medical Research Council and National Department of Health should offer incentives (e.g. bursaries, financial support, study leave) for research programmes both in the public and private health care sector. The researcher also believes that NGOs like the Stroke and/or Heart Foundation should be encouraged to appeal for more research affiliated to both sectors. It goes without saying that the private sector itself (HASA, private hospitals and health professionals working in the private sector) must take responsibility for supporting and particularly implementing sound research projects, particularly as the private sector is regarded as the leading health care example of the South African Health System (Health System Trust 2007). This would enhance the educational approach by means of which the habitual behaviour of health care professionals has changed through learning from experience (Grol 1997).

6.4 Rehabilitation Training of Doctors

South Africa's private health care sector needs improved specialisation by doctors in the field of rehabilitation. According to the study findings, the way in which doctors addressed important aspects of stroke care indicates a lack of special rehabilitation skills. The lack of well-presented rehabilitation services was seen not only in the results of the patients' and doctors' questionnaires but was also voiced by doctors themselves in the qualitative data. The researcher believes that a lack of specialisation in the field of rehabilitation is one of the reasons for the unsatisfactory findings in most aspects of stroke management addressed in this study.

It is therefore necessary first, to convert the awareness and interest that doctors have shown, into participation in specialisation courses which need to be offered in South Africa; second, to create and motivate ongoing professional health care education which refreshes as well as stimulates the utilisation of the existing knowledge of stroke-related issues like stroke warning signs, stroke risk factors, immediate treatment procedures, the merits and demerits of important rehabilitation aspects as well as the advantages and disadvantages of the different types of rehabilitation settings.

To stimulate the interest of doctors and encourage them to participate in these courses, certain aspects have to be taken into consideration. First, the courses must be well promoted and clearly advertised, second, these courses need to be tailored to different levels of knowledge and specialisation. e.g. not only for the already specialised doctors like neurologists and physicians but also and in particular for general practitioners and third, the courses must be affordable and offered at a convenient time and venue. It might be valuable to conduct research into doctors' interests as well as the reasons for posssible hesitation to participate in ongoing courses related to stroke and rehabilitation aspects.

Many stakeholders like the medical schools, the Health Professional Council of South Africa, Private Practitioners Association as well as the management of private and public hospitals should be made responsible for motivating and facilitating existing and new specialisation training courses in rehabilitation.

6.5 Stroke Care Protocols

It is time that doctors begin to apply their knowledge on the use of protocols and start using them. It is therefore necessary to address the obstacles which prevent doctors from doing so. The credibility of the protocols as well as that of the organisations developing and offering these protocols has to be sound and valid and they need to be scientifically proven (Grol1997). It is thus important that the protocols in use are implemented in the right manner; that they include all the important aspects of rehabilitation and that the protocol is used as a synthesis of consensus guideline and not merely as a rigid protocol. Many stakeholders e.g. NGOs like the Stroke Foundation could become active and introduce well-tested and scientifically proven stroke management plans. It is also advisable that the stakeholders initially do regular check ups on the “true” usage of the protocol. These strategies could be implemented by hospital management or other stakeholders e.g. medical insurance companies.

As almost all doctors (86%) were willing to test a new protocol, this presents a perfect opportunity for research projects. A protocol can be developed, implemented and evaluated through interaction with the doctors who will be the ultimate user of the protocol. Research has revealed that people are more open to learning or changing behavioural patterns if they are taught by means of an interactive approach. Some authors report that “self-efficacy” and “perceptions of control” are the strongest mediators for changing habits and behaviour (Bull, Holt, Kreuter, Clark, Scharff 2001; Institute of Medicine 2001). Doctors would learn from their own experiences and would then have a sense of “owning” the achieved changes (Grol 1997). This “educational approach” would be one strategy of changing habitual behaviour.

6.6 Team Work Approach

Stakeholders have to approach the ideology of team work. It needs to be found out why doctors are reluctant to work in interdisciplinary teams despite acknowledging their advantages. Acknowledgement of all other health care professionals, improved communication among all health care professionals and integration of the patient and family member into the team are the cornerstones of successful rehabilitation. All three aspects are often achieved through team meetings. Traditionally these meetings are facilitated by the doctors. However this study has revealed that doctors find this impractical.

One way of changing the habit might be for these team meetings to be organised by the case manager, who works for the hospital. Therefore, hospital management could initiate these meetings. Further, therapists who work with the patient on a daily basis could be approached to become the team leader. This often gives a person a sense of achievement and importance, which could be seen as an incentive for making the effort to organise and co-ordinate the meeting. Doctors would then experience the effects of team meetings and be motivated to work within a team. Medical Aids could become more active and promote or even require team meetings and the presentation of joint team planning. Medical Aids could provide incentives by paying members at higher rates if assessments and goal setting are done by using an interdisciplinary team work approach (or making smaller payments if they are done individually).

Credibility as well as persuasiveness based on sound and valid evidence are necessary to prove to all stakeholders (e.g. Medical Aids, Hospital management, doctors) the advantages of implementing the interdisciplinary team work approach especially in terms of reducing the time and cost. This could lead to more research projects, which, as previously stated, would be an example of how an educational approach can be used to achieve changes (Grol 1997). Another strategy for effecting change in the habitual practice of professionals is the “social interaction approach” in terms of which leading and highly- recognised specialists are motivated to utilise protocols and interdisciplinary team work and then report on their experiences. They can be seen as role models who “*spread the message in the network*” (Grol 1997; p 419). This approach needs to be looked at by NGOs who can identify the “leading specialists” and facilitate professional meetings with and lectures by them.

Needless to say both aspects – usage of a set protocol and an interdisciplinary team work approach should be well addressed in rehabilitation courses as well as in courses on stroke management.

6.7 Information Sharing with Patient and Family on Various Stroke-related Issues

Another important finding of the study was the poor dissemination of successful, quality stroke-related education by doctors to their patients. Once again, particular attention must be given to the dissemination of information on stroke risk factors. It is timely that the importance and particularly the long-term effects of stroke education are not only acknowledged but implemented by all health care professionals. Reinforcement of the correct manner and frequency of the supplied information must be taken seriously. The study showed that doctors still do not give enough attention to the following aspects: repeated information sessions, enough time spend on each information session, utilisation of additional information sources like pamphlets, videos or internet information as well as assessing whether information given was comprehended. Health care professionals should make a concerted effort to tailor the information to the different cultural, intellectual and personal needs of patients. One has to continually ascertain whether the patient has absorbed the information. A stroke rehabilitation protocol or a simple tick off list can help the practitioner so as to ensure that all information is provided, absorbed and understood by the patient and family member.

Much effort, time and financial resources are spent on promoting stroke awareness and yet it seems that a very powerful environment is not considered as the feeding ground for information. The researcher believes that not only is the hospital environment the most important but this is also a very effective time at which to promote stroke education to patients, family members, friends and even persons who happen to be visiting patients sharing a hospital ward with a stroke survivor. Humans are more open to information when they can see or relate it to direct examples (Grol 1997). The fact that the family member or a friend is suffering from a stroke will result in the visitor being more amenable to risk factor education and various aspects of the rehabilitation process. Many visitors are anxious, curious, nervous or even bored when visiting the patient. Such information brochures and pamphlets can help to distract, entertain and at the same time educate such a person. Therefore information leaflets or fliers with stroke information (in particular on risk factors) could be distributed or displayed in the patient's hospital ward so as to support the verbal means of information. The researcher suggests that NGOs like the Stroke or Heart Foundation become actively involved and develop pamphlets and/or supply them to the hospitals. It is also important that it is monitored and encouraged that these pamphlets are given to the patients or better still, that they are presented at a point where many patients and visitors can obtain useful contact details if they require further information. At the same time hospital management can be made responsible to supply or distribute the information leaflets.

Serious measures need to be taken to improve the standard of supplied information on all post-acute stroke rehabilitation settings. Patients from this study group received far too little information on all the advantages and disadvantages of the different options available to them. This highlights how important it is that:

- Doctors have a comprehensive knowledge of the advantages and disadvantages of all post- acute rehabilitation options;

- Doctors are sufficiently knowledgeable to inform the patient and family members in such a manner that the latter understand such information thoroughly;
- (Most importantly), doctors know and apply the rules of informed consent and autonomy. This embraces the notion that, despite his or her personal preferences, the doctor remains objective and takes cognisance of the patient's personal and cultural biases, when advising both patient and family on the different options available.

Furthermore the researcher believes that doctors from the private health care sector have to recognise that the day of discharge presents the perfect opportunity to:

- explain once more the risk of getting a second stroke and to ensure that the patient and family member are aware of all stroke risk factors;
- confirm, that all information (e.g. follow-up rehabilitation, medication) was given and that it is understood and has been absorbed by the patient and family member.

The above points will be taught and practised in depth if one participates in any rehabilitation specialisation course. If doctors already have such knowledge, they need to be reminded and encouraged to use and apply it. Both, the teaching and the reinforcement of rehabilitation knowledge can be encouraged by means of ongoing education. One possibility is to offer rehabilitation courses in conjunction with Continuing Professional Development (CPD). The act of CPD - Health Professional's Act No 56 of 1974 - has been implemented by the Health Professional Council South Africa (HPCSA) to stimulate new and updated knowledge, skills and ethical attitudes of the health care professional. This will ultimately lead to improved measurable benefits to the professional practice of medicine and health care. It also aims to promote professional integrity, which will ultimately benefit the patient. Every practising health care professional needs to be registered with the HPCSA and has to accumulate thirty Continuing Education Units (CEU) within a year, which can be obtained through participation in accredited CPD activities (PPB News 2008; Steele 2009). The researcher suggest that NGOs as well as the private sector motivate and support HPCSA to offer ongoing education regarding general rehabilitation aspects and specialised stroke rehabilitation.

6.8 Post-acute Rehabilitation

6.8.1 Exclusion of patients in the decision-making process on post-acute rehabilitation

Fortunately the importance of patient autonomy and empowerment is being increasingly recognised, which will hopefully result in changes to the behaviour and practice of the health carer. One example is given by the HPCSA, which sees human rights and ethics as a compulsory element in the CPD initiative for all health care practitioners. All health care practitioners have to accumulate at least five CEUs, earned through participation in lectures and related activities on human rights and ethics (PPB News 2008). Nevertheless, this study has shown that 47% of doctors admitted that they made the final decision on post-acute rehabilitation settings. This leads one to ask to what extent they acknowledge the patient’s autonomy.

The researcher stresses the need to change society’s habitual use of a medical system, for both doctors and patients, which allows paternalistic practices to flourish. If one wants the patient to take care of his/her own recovery process, one has to treat the patient as a fully-fledged member of the team. This requires one to acknowledge the necessity of informing the patient and family member on all aspects of the disease and rehabilitation, without exception. It also requires that the information be supplied in the right manner, for the right amount of time, as often as necessary, in an appropriate language and that all information sources (pamphlets, videos, internet) are utilised.

The researcher believes that not only health care professionals but the patient population as well need to change their habitual behaviour if one wants to convert from the medical model to the social approach to rehabilitation. The study revealed that most patients were quite satisfied not being included in the decision-making process. It is time that patients realise that they are responsible for their own recovery process, that this lies to some extent in their own hands and that their attitudes can determine how much they are able to recover and how they will progress with further rehabilitation. An interactive relationship between the health care professional and the patient will enhance the recovery process. Patients and family members should take advantage of all services and sources of help, which support stroke rehabilitation. Patients and family members should demand information and need to complain if they feel that they have not received all important or necessary information.

These demands on both the patient and the health care professionals are important factors if one wants to create an interactive approach among health care professionals and the patient. These are stated to be enforceable human rights both in the Bill of Rights as well as in the Health Act (2003). As discussed previously, the mass media can play an important role in spreading this knowledge. The hospital is the perfect environment to distribute information material. Magazines, available in different health shops, need to repeatedly report on these issues. The public and therefore the patient too need to be educated not only on their rights of autonomy but particularly on the benefits and results of implementation of the latter. NGOs can become active and create awareness by using mass media like magazines or even talk shows on the radio or television.

6.8.2 Inclusion of team members in the decision-making process on post-acute rehabilitation

The importance of inclusion/exclusion of other team-members in the decision-making process on rehabilitation aspects has been discussed in 6.5 (Team work approach) and the recommendations for working as a team have been laid out at length. The final decision on rehabilitation aspects should always evolve from the entire team. These issues must be stressed through ongoing professional education.

6.8.3 Selection of settings for post-acute rehabilitation

The selection for the post-acute rehabilitation should be an individualised process for every patient. First, it is important that the family and patient are well informed on all the advantages and disadvantages of the different types of rehabilitation settings. Second, the health care professional has to know the cultural and individual preferences of the patient and family. With this knowledge, patient, family and the rehabilitation team must carefully assess and weigh up the different options before coming to a conclusion. All health care professionals have to remain objective when advising the patient on the different settings.

It is unfortunate that financial issues often impinge on the optimal final decision but this highlights how important it is to find the optimal setting at the right point of time. This will not only help the patient to optimise the financial means but also prove to the health care funder, the benefit of well chosen rehabilitation. It might be of value to conduct a research tool which assists with the decision-making process on the post-rehabilitation options. Further research is needed on the benefits and disadvantages of the different rehabilitation settings to convince medical health funders on the benefits of well-organised and well-placed rehabilitation.

The researcher suggests in particular that health care funders abandon their passive role and become more active in motivating the suggested research. Health funders like Medical Aid associations could provide their own case manager who assesses the situation, liaises with the entire team and then comes to a consensus decision on the best post-acute rehabilitation setting for the patient. This process could also be facilitated and motivated through other stakeholders like NGOs.

6.8.4 Goal setting

Health care professionals still need to be reminded of the fact that correct goal setting plays an important role in the success of acute and post-acute rehabilitation. This should be underlined in rehabilitation specialisation courses as well as in ongoing professional education lectures and courses. “Goal setting” should also be included in treatment protocols. The researcher suggests that Medical Aid funders could ask for ongoing progress reports including those on goal setting and goal achievement. One example is given by the Compensation For Occupational Injuries And Disease Act, 1993 (Act No 130 0f 1993, p 17-18) which demands in the rehabilitation report a statement on the “*overall goal of treatment*”.

6.9 Creating Awareness of Risk Factors and Warning Signs of Stroke

This study has shown the results of both well and badly managed emergency treatment for stroke victims. Stroke victims who receive immediate emergency treatment, have a chance of leaving the hospital with hardly any adverse effects due to the stroke. On the other hand, misdiagnosis of or ignoring of initial signs and symptoms can lead to delayed treatment and more severe lasting effects. There is thus a need for a well-educated population from the lay person, who might be experiencing warning signs and symptoms, through general practitioners and ambulance and emergency staff through to specialised doctors. Therefore, ongoing education on early stroke warning signs as well as the appropriate emergency treatment for a patient presenting with these warning signs is necessary. This would support literature reports stating that stroke incidence can be reduced by as much as 50 to 80% (Rothwell et al. 2004). It could further diminish the high figure (50%) of stroke survivors who are left chronically disabled (Agency for Health Care Policy and Research 1995; World Health Organisation 2003). Even though South Africa proudly hosted the International Stroke Conference in October 2006 and one can find the "Stroke Awareness Week" in September 2009 (Health System Trust 2009) on the Health Calendar, the researcher believes that not enough is done with regard to primary prevention. She believes that primary prevention needs to be addressed by all three health care sectors and that careful planning as well as the use of a combination of different interventions is necessary for a successful implementation (Grol 1997).

Currently the private sector is contributing very little to the achievement of the primary prevention of diseases. As a matter of fact, primary prevention is not even contained in the current Prescribed Minimum Benefits (PMB) (Health System Trust 2007).

The time has come for private health insurance organisations to take on a more active role and thereby contribute to the prevention of strokes among other diseases. Regular check ups for cholesterol levels and/or blood pressure should be made compulsory as this can be a step towards early prevention of stroke. As many as 3.3 million South Africans suffer from high blood pressure and are therefore prone to becoming stroke victims (Stroke Awareness Week 2009). Many developed countries (e.g. Germany & Sweden) implemented compulsory check ups in different medical areas. If the member suffers from a disease or illness and fails to prove that he adhered to the compulsory check up related to the disease, the medical insurance will not pay for any costs incurred as a result of the disease. The researcher recommends that both the private and the public health care sector of South Africa should assess this type of intervention and preferably adopt it as part of the health care system.

Another successful approach of spreading knowledge is utilising the mass media (Grol 1997). This approach is well-known in South Africa in the context of awareness campaigns for diseases like HIV/AIDS and Heart disease. Information posters and placards can be seen in many places –on high buildings, in public places like train or bus stations, waiting rooms, hallways, lifts and corridors of public and private hospitals – only to mention a few. Furthermore, reference to these diseases is frequently made on national television, radio and in newspapers. However, very rarely does one find posters advertising information on stroke-related aspects e.g. risk factors and warning signs. The waiting rooms of doctors in particular should display information posters.

Further sources of mass media are pharmaceutical magazines which report on important and common health issues. They are or should be available free of charge in pharmacies, private as well as public hospitals, health shops, health spas, hydras and holistic healing centres. However, not only can one rarely read articles on stroke awareness in such magazines but they are also very seldom presented to the public. The researcher searched in ten different pharmacies but could not find any display of health magazines. She did find two magazines in health shops, one called *"Health Encounters*" and one "*Absolute Health*". In Germany, these magazines e.g. "*Apotheken Umschau*", "*Diabetiker Ratgeber*" or "*ORTHO press*" are not only available free of charge in all different stores but are automatically added to goods purchased in pharmaceutical stores as well as in many other health shops. These magazines repeatedly report on the most common and potent health issues, thereby creating public awareness and knowledge. This source of the media is extremely powerful and the researcher highly recommends that all stakeholders involved with disability and stroke-related issues (NGO's like the Stroke Foundation; private and public medical insurance organisations, disability welfare organisations, Medical Research Council) should take the initiative and facilitate the use of similar instruments of the media to promote stroke awareness. The researcher also recommends that stakeholders involved in stroke-related issues should approach the Pharmaceutical Society of South Africa for support in this matter.

Further, popular magazines (e.g. Fair Lady, You Magazine) could be approached and asked to use their editorial content to focus more on stroke victims, their experiences and what can be done to prevent a stroke.

The study revealed that it is not only important to educate the public but also the health care practitioner about the warning signs and risk factors of stroke. The fact that 50% of strokes are preventable, is a sign of the lack of knowledge and action. The researcher appeals to all stakeholders to facilitate and promote ongoing professional education regarding all stroke issues, particular warning signs and risk factors. Stakeholders like the Stroke Foundation, Private Health Practitioner Association and/or Pharmaceutical Society, to mention only a few, could motivate the HPCSA to offer ongoing education regarding important aspects of stroke to the different health care professionals. This will refresh existing knowledge as well as update practitioners on the newest findings, techniques and medication options. As mentioned above, it is important that the courses offered are tailored to the existing knowledge of the practitioner. This remains an important factor as it is necessary to keep the practitioner stimulated, interested and not under-minded.

6.10 Summary of Recommendations

The Public Sector, Non Government Organisations (NGOs) and the Private Sector must take advantage of each other's inherent strengths and encourage, facilitate and support the following:

- Research projects regarding any health issues, no matter whether it is done in the private or public health care sector;
- Availability and attendance of short- and long-term courses as well as full specialisation in the field of rehabilitation;
- The role of the private sector in contributing to the achievement of primary care and prevention of diseases;
- A more active role by the private health insurance organisations, including the implementation of regular or even compulsory check ups on certain health issues;
- Ongoing education for the public regarding early stroke risk factors, warning signs of a stroke as well as stroke rehabilitation. This must be provided on a regular basis and can be achieved through:
  - Mass media (e.g. Pharmaceutical Society of South Africa, television and radio-broadcasting),
  - Stroke information pamphlets distributed in the hospital as well as other public places;
- Ongoing education for health care professionals regarding stroke risk factors, warning signs and rehabilitation issues. This should be provided on a regular basis and can be achieved through:
  - Health Professional Council South Africa (HPCSA) by offering specialised courses in conjunction with CPD;
- Ongoing education of the public on their rights and responsibilities in their own health management;
- The implementation by doctors of a rehabilitation management which is best for their patients.

6.11 Summary of Further Research Options

During the course of the study, the researcher discovered several interesting areas for future research projects namely:

- To research doctors’ interests as well as the reasons for their hesitation to participate in the existing specialisation courses;
- To examine or develop disability scores which will be used at discharge from the acute-care hospital and to explore and link the post-acute rehabilitation management process;
- To explore the effectiveness and implementation of new and existing generic treatment protocols;
- To implement and assess the usefulness of interdisciplinary team work approach in acute stroke management in the private and public health care sectors in South Africa;
- Studies on the effectiveness of post-acute stroke rehabilitation as offered by the various role players in private health care in South Africa.

6.12 Overall Summary of the Study

In summary, the study succeeded in describing pattern of doctors’ practises regarding certain rehabilitation aspects implemented in the acute-care rehabilitation process of stroke survivors. The findings confirm the researcher’s supposition that there is a lack of shared information regarding acute and post-acute stroke rehabilitation aspects for first ever stroke patients’ who were admitted to private hospitals situated in the Western Cape Metropole. It provides evidence that there is a great need for further motivation and education for doctors from the private health care sector regarding the implementation of important rehabilitation aspect e.g. team work approach, utilisation of treatment protocols and sharing information on stroke related issues with their patients. The onus is therefore on administrators from the private and public health care sector as well as NGOs and Government Welfare Organisations to identify the reasons for the hesitation of implementing existing knowledge, to make stroke rehabilitation training available and to ensure the implementation of the gained and refreshed knowledge regarding acute and post-acute stroke rehabilitation aspects.

The researcher wants to end this paper with the message to all involved with disability, stroke and rehabilitation: Let us all make a combined effort to “turn every stroke into a TIA or every major stroke into a minor stroke” (Fritz 2000).

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APPENDICES

Appendix 1	Request for permission to access hospital records
Appendix 2	Consent form to access hospital records
Appendix 3	Participant information and consent form
Appendix 4	Questionnaire for doctors
Appendix 5	Questionnaire for patients
Appendix 6	Pasient vraelys

APPENDIX 1

REQUEST FOR PERMISSION TO ACCESS HOSPITAL RECORDS

5 Moray Place
Oranjezicht
8001

5 March 2007

Dear Sir/Madam

REQUEST FOR PERMISSION TO ACCESS
ADMISSION RECORDS AND PATIENT'S FOLDERS

I am presently conducting a research project as partial fulfilment of the degree MPhil in Rehabilitation at Stellenbosch University. The aim of the study is to assess post-stroke rehabilitation referral patterns in the private health sector in the Western Cape Metropole. Specific focus will be placed on information that was shared with patient and family, timing of discharge planning, reasons for choice of rehabilitation type and the person responsible for this choice.

To conduct this study I require information on stroke survivors who have been admitted to your hospital during the period 1 January 2006 to 30 June 2006. I am therefore requesting permission to access admission records as well as records of patients who suffered a stroke in the above mentioned period.

The proposal of the study has been approved by the Committee of Human Research (US) (Nr: N06/10/214). All information obtained will be kept strictly confidential. No files will be removed from the premises. Results will be made available to patients, doctors and the study hospitals. Results will also be published in relevant scientific publications and presented to peers.

Should you approve of this request, will you kindly sign the letter of consent and post it in the stamped, self-addressed envelope, which I will include for your convenience? Your approval of this request and support for this study will be highly appreciated.

Yours Faithfully

Ute Leichtfuss

Student number: 13500767

Supervisor: Ms G. Mji

APPENDIX 2

CONSENT FORM TO ACCESS HOSPITAL RECORDS

Ute Leichtfuss
5 Moray Place
Oranjezicht 8001

PERMISSION TO ACCESS HOSPITAL RECORDS

I, ……………………. hereby give permission to Ms U. Leichtfuss to access our admission records as well as patients folders. She is allowed to obtain the necessary information required for her research study in partial fulfilment of the degree MPhil (Rehabilitation) at Stellenbosch University.

Yours Faithfully

Date

APPENDIX 3

PARTICIPANT INFORMATION AND CONSENT FORM

TITLE OF RESEARCH: A DESCRIPTIVE STUDY TO DETERMINE STROKE REHABILITATION REFERRAL PATTERNS IN THE PRIVATE HEALTH SECTOR IN THE WESTERN CAPE METROPOLE

PROJECT NUMBER:	N06/10/214
PRINCIPLE INVESTIGATOR:	UTE LEICHTFUSS
ADDRESS:	5 MORAY PLACE, ORANJEZICHT 8001

STATEMENT BY PARTICIPANT

I, the undersigned, …………………………………….(participant), confirm that:

1. I have been invited to participate in the above mentioned research project initiated through the University of Stellenbosch.
2. It had been explained to me that the aim of the study is to assess post stroke rehabilitation referral patterns in the private health sector in the Western Cape Metropole. Specific focus will be placed on information that was shared with patient and family, timing of discharge planning, reasons for choice of rehabilitation type and the person responsible for this choice.
3. It was explained to me that an interview will be conducted with me.
4. It was explained to me that all information will be dealt with confidentiality. The information may be used for thesis, publications in scientific journals, and/or professional presentations. The researcher will protect the identification of participants at all times.
5. I was informed that I may refuse to participate in this project and that I may withdraw from the project any time should I wish to.
6. I participate as a volunteer in this project.
7. Participation in this project will not lead to any costs to myself and I am aware that I will not benefit from it financially.

I DECLARE THAT I AM WILLING TO PARTICIPATE IN ABOVEMENTIONED RESEARCH PROJECT.

Signed at………………………………………on……………………………..2006

.... (Participant)

.... (Witness)

STATEMENT BY RESEARCHER:

I, U. LEICHTFUSS STATE THAT:

1. I have explained the information in this document to……………………
2. I have invited him/her to ask me questions in case of uncertainty.
3. The conversation was held in English/Afrikaans/Xhosa.

Signed at………………………………………on……………………………..2006

.... Researcher (U.Leichtfuss)

.... (Witness)

IMPORTANT NOTICE

Dear Participant, Thank you for agreeing to participate in this research project. Your willingness is much appreciated. Should you have any further questions about the research project please do not hesitate to contact me at the following numbers:

1. 021 461 4406
2. 082 774 1616

Thank you,
(MISS) UTE LEICHTFUSS

APPENDIX 4

QUESTIONNAIRE FOR DOCTORS

1.	Doctors research number:	☐☐
2.	Consulting room’s phone number:	☐☐☐☐☐☐☐☐☐☐
3.	Name of acute hospital	☐☐
4.	Age:	☐☐
5.	Gender:	☐ Female ☐ Male
6.	Number of years post MBCHB degree:	☐☐
7.	Speciality of doctor:	☐ General Practitioner ☐ Family Physician ☐ Physician ☐ Neurologist ☐ Neurosurgeon ☐ Other *(Specify)*……………………………
8.	If you are a specialist, how many years have you been qualified?	☐☐
9.	Do you have any specific rehabilitation training or experience?	☐ Yes ☐ No
10.	If yes, specify: ………………………………………………………………………………………………… ………………………………………………………………………………………………… ………………………………………………………………………………………………… …………………………………………………………………………………………………	
11.	Do you follow a set protocol or pathway of care with regard to discharge management & rehabilitation referral of the acute stroke patient?	☐ Yes ☐ No
12.	If yes specify, what that entails. ………………………………………………………………………………………………… ………………………………………………………………………………………………… ………………………………………………………………………………………………… …………………………………………………………………………………………………	

13.	Do you see any advantages in such a protocol/pathway?	☐ Yes ☐ No
14.	If yes, what do you think the advantages of such a protocol/pathway could be? ………………………………………………………………………………………………… ………………………………………………………………………………………………… ………………………………………………………………………………………………… …………………………………………………………………………………………………	
15.	Do you see any disadvantages in such a protocol/pathway?	☐ Yes ☐ No
16.	If yes, please name them. ………………………………………………………………………………………………… ………………………………………………………………………………………………… ………………………………………………………………………………………………… …………………………………………………………………………………………………	
17.	Would you be willing to try a proposed pathway in your practice?	☐ Yes ☐ No
18.	While managing the acute stroke patient, to whom do you provide information on aspects regarding the CVA?	*(Tick all relevant options)* ☐ Patient ☐ Family ☐ Both ☐ None ☐ Other
19.	On which aspects regarding a CVA do you provide information to the patient and family after you have performed your initial assessment?	*(Tick all relevant options)* ☐ Diagnosis ☐ Prognosis ☐ Risk factors ☐ Expected length stay in acute hospital ☐ Rehabilitation options ☐ Other *(Specify)*……………………………
20.	How much time do you spend on average on this explanation?	☐☐ *(In minutes)*

21.	How do you provide this information and explanation to the patient and family?	*(choose one)* ☐ Verbally ☐ Verbally with drawings, pictures, models ☐ Information leaflets ☐ Both verbally and information leaflets ☐ Other *(Specify)*……………………………
22.	Do you complete your explanation in one session?	☐ Yes ☐ No
23.	If no, how often do you give this information?	*(choose one)* ☐ Once ☐ Twice ☐ Often/repeatedly ☐ Daily ☐ When requested
24.	Do you have a team approach in your acute stroke management?	☐ Yes ☐ No
25.	If yes, which teamwork approach do you currently use?	*(choose one)* ☐ Multidisciplinary ☐ Transdisciplinary ☐ Interdisciplinary
26.	Do you think it is optimal for your circumstances?	☐ Yes ☐ No
27.	Please explain why. …………………………………………………………………………………………… …………………………………………………………………………………………… …………………………………………………………………………………………… ……………………………………………………………………………………………	
28.	What team work approach is, in your opinion, most suitable for stroke rehabilitation?	*(choose one)* ☐ Multidisciplinary ☐ Transdisciplinary ☐ Interdisciplinary ☐ None
29.	Please explain why you think so. …………………………………………………………………………………………… …………………………………………………………………………………………… …………………………………………………………………………………………… ……………………………………………………………………………………………	

30.	Who do you think **should be** included in a patient management team?	*(Tick all relevant options)* ☐ Patient ☐ Family ☐ Carer ☐ Medical specialists ☐ Physiotherapist ☐ Occupational therapist ☐ Speech therapist ☐ Social worker ☐ Psychologist/psychiatrist ☐ Dietician ☐ Nursing staff ☐ Other *(Specify)*……………………………
31.	Which of the above mentioned members **are** included in your stroke management team?*)*	*(Tick all relevant options)* ☐ All members above ☐ Patient ☐ Family ☐ Carer ☐ Medical specialists ☐ Physiotherapist ☐ Occupational therapist ☐ Speech therapist ☐ Social worker ☐ Psychologist/psychiatrist ☐ Dietician ☐ Nursing staff ☐ Other *(Specify)*……………………………
32.	If the members mentioned in 30 differ from those in 31 can you explain why? …………………………………………………………………………………………… …………………………………………………………………………………………… …………………………………………………………………………………………… ……………………………………………………………………………………………	

33.	In what way do you involve these professionals?	*(Tick all relevant options)* ☐ Verbal referral ☐ Written referral ☐ Telephonic conversation ☐ Ward round ☐ Team discussion ☐ Other *(Specify)*……………………………
34.	Are you satisfied with this approach?	☐ Yes ☐ No
35.	Please explain, why you are satisfied/not satisfied? ……………………………………………………………………………………………… ……………………………………………………………………………………………… ……………………………………………………………………………………………… ………………………………………………………………………………………………	
36.	Do you provide information on follow up rehabilitation to patient and family members?	☐ Yes ☐ No
37.	If yes, what information do you provide to the patient and family about follow up rehabilitation?	*(Tick all relevant options)* ☐ How it can assist them ☐ List different options only ☐ Explain different options with all advantages and disadvantages ☐ Discuss costs involved ☐ Explain one option only ☐ Treatment in follow up setting ☐ Other *(Specify)*……………………………
38.	When do you give these explanations to patient and family?	*(choose one)* ☐ Beginning of hospital stay ☐ Middle of hospital stay ☐ End of hospital stay ☐ Day before or on discharge ☐ Repeatedly ☐ Other *(Specify)*……………………………

39.	List all the different types of rehabilitation options which you discuss with the patient?	*(choose one)* ☐ Inpatient rehabilitation ☐ Outpatient rehabilitation ☐ Nursing home ☐ Domiciliary rehabilitation ☐ Other *(Specify)*……………………………
40.	How do you decide which rehabilitation option to recommend to the patient?	*(Tick all relevant options)* ☐ Medical condition ☐ Functional status ☐ Financial circumstances ☐ Social circumstances ☐ Age of patient ☐ Your own preference of rehabilitation type ☐ Patient and family's choice of rehabilitation type ☐ Recommendations of rehabilitation team ☐ Other *(Specify)*……………………………
41.	Who makes the final decision on the type of follow up rehabilitation?	*(Tick all relevant options)* ☐ Doctor ☐ Nurse ☐ Therapist ☐ Patient/Family member ☐ All of the above ☐ Other *(Specify)*……………………………
42.	When do you inform the patient and family of a discharge date?	*(choose one)* ☐ Beginning of hospital stay ☐ Middle of hospital stay ☐ End of hospital stay ☐ Day before or on discharge ☐ Repeatedly ☐ Other *(Specify)*……………………………

43.	With which other medical professionals do you discuss the discharge date?	*(Tick all relevant options)* ☐ Medical specialists ☐ Physiotherapist ☐ Occupational therapist ☐ Speech therapist ☐ Social worker ☐ Nursing staff ☐ Team ☐ Other *(Specify)*……………………………
44.	What information do you provide to the family and patient on discharge?	*(Tick all relevant options)* ☐ Medication ☐ Prognosis ☐ Risk factors for a further stroke ☐ How to access follow up rehabilitation ☐ Date of follow up appointment ☐ Other *(Specify)*……………………………
45.	What type of follow up do you provide to your CVA patients following discharge from the acute hospital?	☐☐ weeks ☐☐ weeks after discharge from rehab facility
46.	Do you believe that a CVA patient has a better outcome if s/he receives follow up rehabilitation after discharge from the acute hospital?	☐ Yes ☐ No
47.	Explain why …………………………………………………………………………………………… …………………………………………………………………………………………… …………………………………………………………………………………………… …………………………………………………………………………………………… ……………………………………………………………………………………………	
48.	Do you prefer any specific type of post acute rehabilitation?	☐ Yes ☐ No

49.	If yes, which one?	*(choose one)* ☐ Inpatient rehabilitation ☐ Outpatient rehabilitation ☐ Nursing home ☐ Domiciliary rehabilitation ☐ Other *(Specify)*……………………………
50.	Why do you prefer this type of rehabilitation? …………………………………………………………………………………………… …………………………………………………………………………………………… …………………………………………………………………………………………… …………………………………………………………………………………………… ……………………………………………………………………………………………	
51.	Would you like to add any other comments on the subject of post acute rehabilitation process? …………………………………………………………………………………………… …………………………………………………………………………………………… …………………………………………………………………………………………… ……………………………………………………………………………………………	

APPENDIX 5

QUESTIONNAIRE FOR PATIENTS

1.	PATIENT NUMBER:	☐☐☐
2.	Name of acute hospital:	☐☐
3.	Interviewed:	☐ Patient ☐ Family member ☐ Both
4.	Patient’s age:	☐☐
5.	Patient’s Gender:	☐ Female ☐ Male
6.	Ethnic Group:	☐ African ☐ Coloured ☐ Indian ☐ White ☐ Other *(Specify)*……………………………
7.	Date of Stroke:	⌊ ⌋⌊ ⌋⌊ ⌋⌊ ⌋⌊ ⌋⌊ ⌋⌊ ⌋⌊ ⌋
8.	Was it the first stroke?	☐ Yes ☐ No
9.	Length of stay in acute hospital:	☐☐ Days
10.	Affected side?	☐ Left ☐ Right
11.	Language:	*(choose one)* ☐ English ☐ Afrikaans ☐ Xhosa ☐ Other *(Specify)*……………………………

12.	Has your employment status changed following the CVA?	☐ Yes ☐ No
13.	**Before CVA** Employment status:	*(choose one)* ☐ Employed ☐ Unemployed ☐ Self employed ☐ Retired ☐ Other *(Specify)*……………………………
14.	**Current** Employment status:	*(choose one)* ☐ Employed ☐ Unemployed ☐ Self employed ☐ Retired ☐ Other *(Specify)*……………………………
15.	Educational Level:	*(choose one)* ☐ No formal education ☐ Grade 1-7 ☐ Grade 8-11 ☐ Grade 12 ☐ 1- 4 Tertiary Education ☐ > 4 Tertiary Education
16.	Does your current income differ from your income prior to the stroke?	☐ Less than before ☐ More than before ☐ No change
17.	If changed, estimated %	☐☐ %
18.	Monetary source for rehabilitation	*(choose one)* ☐ Private self ☐ Private relative/friend ☐ Medical Insurance ☐ WCA ☐ Other *(Specify)*……………………………

19.	Have your home circumstances changed following the stroke?	☐ Yes ☐ No ☐ As before but with carers
20.	**Before CVA** Housing:	*(choose one)* ☐ Flat ☐ House ☐ Retirement village ☐ Nursing home ☐ Informal settlement ☐ Other *(Specify)*……………………………
21.	**Current** Housing:	*(choose one)* ☐ Flat ☐ House ☐ Retirement village ☐ Nursing home ☐ Informal settlement ☐ Other *(Specify)*……………………………
22.	Have your living circumstances changed following the stroke?	☐ Yes ☐ No
23.	**Before CVA** living with	*(choose one)* ☐ No one (alone) ☐ Spouse/ life companion ☐ Other family /friends ☐ Nursing care ☐ Other *(Specify)*……………………………
24.	**Currently** living with	*(choose one)* ☐ No one (alone) ☐ Spouse/ life companion ☐ Other family /friends ☐ Nursing care ☐ Other *(Specify)*……………………………

25.	**Before CVA**	*(1= poor, 10 = very good)* *(choose one)*
26.	Self care:	1 2 3 4 5 6 7 8 9 10
27.	Mobility:	1 2 3 4 5 6 7 8 9 10
28.	Mentally: Short term memory	1 2 3 4 5 6 7 8 9 10
29.	Mentally: Long term memory	1 2 3 4 5 6 7 8 9 10
30.	Speech Expression	1 2 3 4 5 6 7 8 9 10
31.	Speech Comprehension:	1 2 3 4 5 6 7 8 9 10
32.	Transport own car:	☐ Independent ☐ Passenger ☐ No
33.	Transport public:	☐ Independent ☐ Assisted ☐ No
34.	**At time of discharge from acute hospital**	*(1= poor, 10 = very good)* *(choose one)*
35.	Self care:	1 2 3 4 5 6 7 8 9 10
36.	Mobility:	1 2 3 4 5 6 7 8 9 10
37.	Mentally: Short term memory	1 2 3 4 5 6 7 8 9 10
38.	Mentally: Long term memory	1 2 3 4 5 6 7 8 9 10
39.	Speech Expression	1 2 3 4 5 6 7 8 9 10
40.	Speech Comprehension:	1 2 3 4 5 6 7 8 9 10
41.	Transport own car:	☐ Independent ☐ Passenger ☐ No
42.	Transport public:	☐ Independent ☐ Assisted ☐ No

43.	**Currently**	*(1= poor, 10 = very good)* *(choose one))*
44.	Self care:	1 2 3 4 5 6 7 8 9 10
45.	Mobility:	1 2 3 4 5 6 7 8 9 10
46.	Mentally: Short term memory	1 2 3 4 5 6 7 8 9 10
47.	Mentally: Long term memory	1 2 3 4 5 6 7 8 9 10
48.	Speech Expression	1 2 3 4 5 6 7 8 9 10
49.	Speech Comprehension:	1 2 3 4 5 6 7 8 9 10
50.	Transport own car:	☐ Independent ☐ Passenger ☐ No
51.	Transport public:	☐ Independent ☐ Assisted ☐ No
52.	When you were admitted to the acute hospital following your stroke, did anybody from the medical team explain to you what a stroke is?	☐ Yes ☐ No
53.	Did you understand the explanation?	☐ Yes ☐ No
54.	Who from the medical team explained it to you?	*(Tick all the relevant options)* ☐ Doctor ☐ Nurse ☐ Therapist ☐ All of the above ☐ Other *(Specify)*……………………………
55.	Did you use other sources such as the internet/ medical books to gain information on a stroke?	☐ Yes ☐ No

56.	What did you use?	*(Tick all the relevant options)* ☐ Books ☐ Magazine articles ☐ Friends/relatives ☐ Internet ☐ Other *(Specify)……………………………*
57.	Why did you consult these sources?	*(choose one)* ☐ To ensure you had all possible information on the subject ☐ Because the explanation given was unclear or incomplete ☐ Because the medical team did not provide any Explanations ☐ Other *(Specify)……………………………*
58.	If you received any explanation from the medical team, do you remember how it was explained to you?	*(choose one)* ☐ Verbally ☐ Verbally with drawings, pictures, models ☐ Information leaflets ☐ Both verbally and information leaflets ☐ Other *(Specify)…………………………….*
59.	Can you tell me in your own words what a stroke is? …………………………………………………………………………………… …………………………………………………………………………………… …………………………………………………………………………………… …………………………………………………………………………………	
60.	Did anybody tell you your prognosis / what to expect / whether you will recover?	☐ Yes ☐ No ☐ Vague explanation

61.	What did they say was your prognosis?	
62.	Who explained your prognosis to you?	*(Tick all the relevant options)* ☐ Doctor ☐ Nurse ☐ Therapist ☐ All of the above ☐ Other *(Specify)*……………………………
63.	How do you feel it was explained to you?	*(choose one)* ☐ Well explained ☐ Misleading ☐ Vague ☐ Other *(Specify)*……………………………
64.	Did anybody explain to you the risk factors for having a second stroke?	☐ Yes ☐ No
65.	What are the risk factors for a stroke?	
66.	Who explained this to you, or how did you gain this information?	*(Tick all the relevant options)* ☐ Doctor ☐ Nurse ☐ Therapist ☐ All of the above ☐ Internet ☐ Other *(Specify)*……………………………

67.	How often were all those factors (diagnosis, prognosis, implications, risk factors) explained to you while you were in the acute hospital?	*(choose one)* ☐ Not at all ☐ Once ☐ Twice ☐ Often/repeatedly ☐ Daily ☐ When requested
68.	How much time on average was spent on these explanations?	☐☐ *(In minutes)*
69.	Did you receive any kind of therapy/rehabilitation in the acute hospital?	☐ Yes ☐ No
70.	Were you aware of any teamwork/ongoing communication amongst the different professionals, such as doctors, physiotherapists, speech therapist, nursing staff?	☐ Yes ☐ No ☐ Do not know
71.	If yes, how do you think they communicated amongst each other?	*(choose one)* ☐ Verbally ☐ Written ☐ Telephonically ☐ Ward round ☐ Discussion sessions ☐ Other *(Specify)*……………………………
72.	When was your discharge date first discussed with you?	*(choose one)* ☐ Beginning of hospital stay ☐ Middle of hospital stay ☐ End of hospital stay ☐ Day before or on discharge ☐ Repeatedly ☐ Other *(Specify)*……………………………
73.	Who discussed it with you	*(choose one)* ☐ Doctor ☐ Nurse ☐ Therapist ☐ All of the above ☐ Nobody ☐ Other *(Specify)*……………………………

74.	Did anybody explain the different rehabilitation options to you while you were in the acute hospital?	☐ Yes ☐ No
75.	When during your stay at the acute hospital was it discussed with you?	*(choose one)* ☐ Beginning of hospital stay ☐ Middle of hospital stay ☐ End of hospital stay ☐ Day before or on discharge ☐ Repeatedly ☐ Other *(Specify)*……………………………
76.	Can you remember what they were and tell me about them? ……………………………………………………………………………… ……………………………………………………………………………… ……………………………………………………………………………… ………………………………………………………………………………	
77.	Who explained this to you?	*((Tick all the relevant option)* ☐ Doctor ☐ Nurse ☐ Therapist ☐ All of the above ☐ Internet ☐ Other *(Specify)*……………………………
78.	Which type of follow up rehabilitation was chosen?	*(choose one)* ☐ Inpatient rehabilitation ☐ Out patient rehabilitation ☐ Nursing home ☐ Home base rehabilitation ☐ None
79.	Who chose it?	*(Tick all the relevant options)* ☐ Doctor ☐ Nurse ☐ Therapist ☐ Yourself/Family member ☐ All of the above ☐ Other *(Specify)*……………………………

80.	Were you included in the decision making process of the follow up rehabilitation?	☐ Yes ☐ No
81.	How did you feel about being included in the decision making process?	*(choose one)* ☐ Satisfied, Good ☐ Ambivalent ☐ Scared, Overwhelmed
82.	How did you feel about not being included in the decision making process?	*(choose one)* ☐ Satisfied, Good ☐ Ambivalent ☐ Scared, Overwhelmed
83.	**At time of discharge**: Were you satisfied with the choice?	☐ Yes ☐ No ☐ Do not know
84.	Explain why? …………………………………………………………………………………………………… …………………………………………………………………………………………………… …………………………………………………………………………………………………… …	
85.	**In retrospect**: Were you satisfied with the choice?	☐ Yes ☐ No
86.	Explain why? …………………………………………………………………………………………………… …………………………………………………………………………………………………… ……………………………………………………………………………………………………..	
87.	Do you think you could have achieved the same outcome with a different rehabilitation set up?	☐ Yes ☐ No ☐ Do not know
88.	What information did you receive on discharge?	(*Tick all relevant options)* ☐ Medication ☐ Prognosis ☐ Risk factors for 2nd stroke ☐ How to access follow up rehabilitation ☐ Follow up appointment ☐ Other *(Specify)*……………………………

89.	Did anybody from the acute hospital follow up on your progress once you were discharged from the acute hospital?	☐ Yes ☐ No
90.	If yes, who followed up your progress?	*(Tick all the relevant options)* ☐ Doctor ☐ Nurse ☐ Therapist ☐ All of the above ☐ Other *(Specify)*……………………………
91.	If yes, how long after discharge was the follow up appointment?	☐☐ weeks ☐☐ weeks after discharge from rehab facility
92.	Have you got any suggestion as to how your follow up rehabilitation process could have been improved? …………………………………………………………………………… …………………………………………………………………………… …………………………………………………………………………… ……………………………………………………………………………	
93.	Did you go home initially?	☐ Yes ☐ No
94.	What were the reasons that you went home initially?	*(Tick all relevant options)* ☐ Waiting for a place in the rehabilitation centre ☐ Waiting for medical aid clearance ☐ The decision to go to the rehabilitation centre was only made once you were home ☐ Other *(Specify)*……………………………
95.	Were your goals met during follow up rehabilitation?	☐ Yes ☐ No

96.	Explain in which way they were/were not met: …………………………………………………………………………… …………………………………………………………………………… …………………………………………………………………………… ……………………………………………………………………………	
97.	Were you referred to anybody for follow up on discharge from the rehabilitation setting?	☐ Yes ☐ No
98.	If yes, to whom were you referred?	(*Tick all relevant options)* ☐ Doctor ☐ Nurse ☐ Therapist ☐ All of the above ☐ Other *(Specify)……………………………*
99.	Do you have any other comments about your rehabilitation process that you want to share with me? (Five minutes time limit): …………………………………………………………………………… …………………………………………………………………………… …………………………………………………………………………… ……………………………………………………………………………	

APPENDIX 6

PASIENT VRAELYS

1.	Pasient Nommer:	☐☐☐
2.	Naam van akute hospitaal:	☐☐
3.	Onderhoud gevoer met	☐ Pasient ☐ Familielid ☐ Beide
4.	Pasient se ouderdom:	☐☐
5.	Pasient: se geslag	☐ Vroulik ☐ Manlik
6.	Etniese groep:	☐ Etniese Afrikaan ☐ Kleurling ☐ Indier ☐ Blank ☐ Ander *(Spesifiseer)*……………………………
7.	Datum van beroerte:	☐☐☐☐☐☐☐☐
8.	Was dit die eerste beroerte?	☐ Ja ☐ Nee
9.	Lengte van verblyf in akute hospital:	☐☐ Dae
10.	Aangetaste kant?	☐ Links ☐ Regs
11.	Moedertaal:	*(Kies een)* ☐ Engels ☐ Afrikaans ☐ Xhosa ☐ Ander *(Spesifiseer)*……………………

12.	Het jou werkstatus verander na die SVO?	☐ Ja ☐ Nee
13.	**Voor SVO:** Werkstatus:	*(Kies een)* ☐ Het gewerk ☐ Werkloos ☐ Het gewerk ☐ Afgetree ☐ Ander *(Spesifiseer)……………………………*
14.	**Tans:** Werkstatus	*(Kies een)* ☐ Het gewerk ☐ Werkloos ☐ Het gewerk ☐ Afgetree ☐ Ander *(Spesifiseer)……………………………*
15.	Geleerdheid:	*(Kies een)* ☐ Nee formele skool opleiding ☐ Graad 1-7 ☐ Graad 8-11 ☐ Graad 12 ☐ 1- 4 jaar tertiere opleiding ☐ > 4 jaar tertiere opleiding
16.	Verskil jou inkomste nou van die bedrag wat jy verdien het voor jy die beroerte gehad het?	☐ Minder as voorheen ☐ Meer as voorheen ☐ Geen verandering
17.	Indien ja, geskatte %	☐☐ %
18.	Bron van fondse vir die rehabiliatsie	*(Kies een)* ☐ Privaat / self ☐ Privaat familielid / vriend ☐ Mediese fonds ☐ Ongevalle kommisaris ☐ Ander *(Spesifiseer)……………………………*

19.	Het jou huislike omstandighede verander na die beroerte?	☐ Ja ☐ Nee ☐ Soos tevore maar met versorgers
20.	**Voor SVO:** Behuising:	*(Kies een)* ☐ Woonstel ☐ Huis ☐ Aftreeoord ☐ Versorgingsoord ☐ Informele nedersetting ☐ Ander *(Spesifiseer)*……………………………
21.	**Tans:** Behuising: :	*(Kies een)* ☐ Woonstel ☐ Huis ☐ Aftreeoord ☐ Versorgingsoord ☐ Informele nedersetting ☐ Ander *(Spesifiseer)*……………………………
22.	Het jou lewensomstandighede verander na die beroerte?	☐ Ja ☐ Nee
23.	Voor SVO woon saam met	*(Kies een)* ☐ Niemand (alleen) ☐ Eggenoot / Lewensmaat ☐ Ander familie / vriende ☐ Vepleegsorg ☐ Ander *(Spesifiseer)*……………………………
24.	Woon tans saam met	*(Kies een)* ☐ Niemand (alleen) ☐ Eggenoot / Lewensmaat ☐ Ander familie / vriende ☐ Vepleegsorg ☐ Ander *(Spesifiseer)*……………………………

25.	**Voor SVO**	***(1 = swak, 10 = baie goed)*** *(Kies een)*
26.	Selfsorg:	1 2 3 4 5 6 7 8 9 10
27.	Mobiliteit:	1 2 3 4 5 6 7 8 9 10
28.	Verstandelik: Korttermyn geheue	1 2 3 4 5 6 7 8 9 10
29.	Verstandelik: Langtermyn geheue	1 2 3 4 5 6 7 8 9 10
30.	Spraak: Uitdrukking	1 2 3 4 5 6 7 8 9 10
31.	Spraak: Begrip	1 2 3 4 5 6 7 8 9 10
32.	Vervoer eie motor:	☐ Onafhanklik ☐ Passasier ☐ Nee
33.	Publieke vervoer:	☐ Onafhanklik ☐ Met hulp ☐ Nee
34.	**Ten tye van ontslag uit die akute hospitaal**	***(1 = swak, 10 = baie goed)*** *(Kies een)*
35.	Selfsorg:	1 2 3 4 5 6 7 8 9 10
36.	Mobiliteit:	1 2 3 4 5 6 7 8 9 10
37.	Verstandelik: Korttermyn geheue	1 2 3 4 5 6 7 8 9 10
38.	Verstandelik: Langtermyn geheue	1 2 3 4 5 6 7 8 9 10
39.	Spraak: Uitdrukking	1 2 3 4 5 6 7 8 9 10
40.	Spraak: Begrip	1 2 3 4 5 6 7 8 9 10
41.	Vervoer eie motor:	☐ Onafhanklik ☐ Passasier ☐ Nee
42.	Publieke vervoer:	☐ Onafhanklik ☐ Met hulp ☐ Nee

43.	**Tans:**	***(1 = swak, 10 = baie goed)*** *(Kies een)*
44.	Selfsorg:	1 2 3 4 5 6 7 8 9 10
45.	Mobiliteit:	1 2 3 4 5 6 7 8 9 10
46.	Verstandelik: Korttermyn geheue	1 2 3 4 5 6 7 8 9 10
47.	Verstandelik: Langtermyn geheue	1 2 3 4 5 6 7 8 9 10
48.	Spraak: Uitdrukking	1 2 3 4 5 6 7 8 9 10
49.	Spraak: Begrip	1 2 3 4 5 6 7 8 9 10
50.	Vervoer eie motor:	☐ Onafhanklik ☐ Passasier ☐ Nee
51.	Publieke vervoer:	☐ Onafhanklik ☐ Met hulp ☐ Nee
52.	Het enige lid van die mediese span vir jou verduidelik wat `n beroerte is toe jy in die akute hospital toegelaat is nadat jy jou beroerte gehad het?	☐ Ja ☐ Nee
53.	Het jy die verduideliking verstaan?	☐ Ja ☐ Nee
54.	Wie van die mediese span het dit aan jou verduidelik (Merk al die relevante opsies?	*(Merk al die relevante opsies)* ☐ Dokter ☐ Verpleegster/suster ☐ Terapeut ☐ All die genoemdes ☐ Ander *(Spesifiseer)*……………………………
55.	Het jy ander bronne soos die internet/mediese boeke gebruik om inligting oor beroerte te bekom?	☐ Ja ☐ Nee

56.	Wat het jy gebruik?	*(Merk al die relevante opsies)* ☐ Boeke ☐ Tydskrif artikels ☐ Vriende / familie ☐ Internet ☐ Ander *(Spesifiseer)*……………………………
57.	Hoekom het jy die bronne raad gepleeg?	*(Kies een)* ☐ Om te verseker dat jy alle moontlike inligting oor die onderwerp het ☐ Omdat die verduideliking wat gegee was onduidelik of onvoldoende was ☐ Omdat die mediese span geen verduidelikings gegee het nie ☐ Ander *(Spesifiseer)*……………………………
58.	Indien jy `n verduideliking van die mediese span ontvang het kan jy onthou hoe dit aan jou verduidelik was?	*(Kies een)* ☐ Mondelings ☐ Mondelings met sketse, prente, modelle ☐ Inligtings pamflette ☐ Beide mondlings en met inligtings pamflette ☐ Ander *(Spesifiseer)*……………………………
59.	Kan jy vir my in jou eie woorde vertel wat `n beroerte is? …………………………………………………………………………………… …………………………………………………………………………………… …………………………………………………………………………………… ………………………………………………………………………	
60.	Het enige iemand vir jou vertel wat jou prognose is / wat jy kan verwag / of jy sal beter raak?	☐ Ja ☐ Nee ☐ Vae verduideliking

61.	Wat het hulle gese is jou prognose? …………………………………………………………………………………… …………………………………………………………………………………… …………………………………………………………………………………… ……………………………………………………………………………	
62.	Wie het jou prognose aan jou verduidelik?	*(Merk al die relevante opsies)* ☐ Dokter ☐ Verpleegster/suster ☐ Terapeut ☐ All die genoemdes ☐ Ander *(Spesifiseer)*……………………………
63.	Hoe voel jy was dit aan jou verduidelik?	*(Kies een)* ☐ Goed verduidelik ☐ Misleidend ☐ Vaag ☐ Ander *(Spesifiseer)*……………………………
64.	Het enige iemand aan jou verduidlik wat die risiko faktore vir `n tweede beroerte is?	☐ Ja ☐ Nee
65.	Wat is die risiko faktore vir `n beroerte? …………………………………………………………………………………… …………………………………………………………………………………… …………………………………………………………………………………… ………………………………………………………………………………	
66.	Wie het dit aan jou verduidelik?	*(Merk al die relevante opsies)* ☐ Dokter ☐ Verpleegster/suster ☐ Terapeut ☐ All die genoemdes ☐ Internet ☐ Ander *(Spesifiseer)*……………………………

67.	Hoeveel maal is al die faktore (diagnose, prognose, implikasie, risiko faktore) aan jou verduidelik terwyl jy in die akute hospital was?	*(Kies een)* ☐ Glad nie ☐ 1 maal ☐ 2 maal ☐ Baie kere / herhaaldelik ☐ Daagliks ☐ Wanneer jy daaroor gevra het
68.	Ongeveer hoeveel tyd is aan die verduidelikings spandeer?	☐☐ *(Minutes)*
69.	Het jy enige vorm van terapie/rehabilitasie in die akute hospital ontvang?	☐ Ja ☐ Nee
70.	Het jy die gevoel gekry dat daar tekens van spanwerk / volgehoue kommunikasie tussen die verskillende professionele persone soos dokters, fisioterapeute, spraakterapeute, verpleegpersoneel ens was?	☐ Ja ☐ Nee ☐ Weet nie
71.	Indien ja, hoe dink jy het hulle met mekaar gekommunikeer?	*(Kies een)* ☐ Mondelings ☐ Geskrewe ☐ Telefonies ☐ Saal rondte ☐ Besprekingssessies ☐ Ander *(Spesifiseer)*……………………………
72.	Wanneer is die ontslag datum vir die eerste maal met jou bespreek?	*(Kies een)* ☐ Begin van die hospital verblyf ☐ Middel van die hospital verblyf ☐ Einde van die hospital verblyf ☐ Dag voor ontslag ☐ Herhaaldelik ☐ Ander *(Spesifiseer)*……………………………

73.	Wie het dit met jou bespreek?	*(Kies een)* ☐ Dokter ☐ Verpleegster/suster ☐ Terapeut ☐ All die genoemdes ☐ Niemand ☐ Ander *(Spesifiseer)*……………………………
74.	Het enige iemand die verskillende rehabilitasie opsies met jou bespreek terwyl jy in die akute hospitaal was?	☐ Ja ☐ Nee
75.	Wanneer tydens jou verblyf is dit met jou bespreek?	*((Kies een)* ☐ Begin van die hospital verblyf ☐ Middel van die hospital verblyf ☐ Einde van die hospital verblyf ☐ Dag voor ontslag ☐ Herhaaldelik ☐ Ander *(Spesifiseer)*……………………………
76.	Kan jy onthou wat hulle was en vir my daarvan vertel? …………………………………………………………………………… …………………………………………………………………………… …………………………………………………………………………	
77.	Wie het dit aan jou verduidelik?	*(Merk al die relevante opsies)* ☐ Dokter ☐ Verpleegster/suster ☐ Terapeut ☐ All die genoemdes ☐ Internet ☐ Ander *(Spesifiseer)*……………………………
78.	Op watter tipe opvolg rehabilitasie is?	*(Kies een)* ☐ Binne pasient rehabilitasie ☐ Buite pasient rehabilitasie ☐ Verpleeginrigting ☐ Tuis rehabilitasie ☐ Geen

79.	Wie het dit gekies?	*(Merk al die relevante opsies)* ☐ Dokter ☐ Verpleegster/suster ☐ Terapeut ☐ Jyself / familielid ☐ All die genoemdes ☐ Ander *(Spesifiseer)……………………………*
80.	Is jy ingesluit tydens die besluitnemingsproses oor opvolg rehabilitasie?	☐ Ja ☐ Nee
81.	Hoe het jy gevoel daaromtrent dat jy ingesluit was in die besluitnemingsproses?	*(Kies een)* ☐ Tevrede/Goed ☐ Onseker ☐ Bang/oorweldig
82.	Hoe het jy gevoel daaromtrent dat jy nie ingesluit was in die besluitnemingsproses nie?	*(Kies een)* ☐ Tevrede/Goed ☐ Onseker ☐ Kwaad / teleurgesteld
83.	**Ten tyde van ontslag**: Was jy tevrede met die keuse?	☐ Ja ☐ Nee ☐ Weet nie
84.	Verduidelik hoekom? …………………………………………………………………………………………………… …………………………………………………………………………………………………… …………………………………………………………………………………………………	
85.	**In retrospek**: Was jy tevrede met die keuse?	☐ Ja ☐ Nee
86.	Verduidelik hoekom? …………………………………………………………………………………………………… …………………………………………………………………………………………………… ………………………………………………………………………………………………….	
87.	Dink jy dat jy dieselfde uitkoms sou bereik het met `n ander tipe rehabilitasie?	☐ Ja ☐ Nee ☐ Weet nie

88.	Watter inligting het jy met ontslag ontvang?	*(Merk al die relevant opsies)* ☐ Medikasie ☐ Prognose ☐ Risiko faktore vir `n tweede beroerte ☐ Hoe om toegang tot opvolg rehabilitasie te verkry ☐ Opvolg afspraak ☐ Ander *(Spesifiseer)*……………………………
89.	Het enige iemand van die akute hospitaal jou vordering gemonitor nadat jy ontslaan is uit die akute hospital?	☐ Ja ☐ Nee
90.	Indien ja, wie het jou vordering gemonitor?	*(Merk al die relevante opsies)* ☐ Dokter ☐ Verpleegster/suster ☐ Terapeut ☐ All die genoemdes ☐ Ander *(Spesifiseer)*……………………………
91.	Indien ja, hoe lank na ontslag was jou opvolg afspraak?	☐☐ Weke ☐☐ Weke na ontslag van die rehabilitasie fasiliteit
92.	Het jy enige voorstel wat jou rehabilitasie proses kon verbeter het tydens opvolg rehabilitasie? …………………………………………………………………………………… …………………………………………………………………………………… …………………………………………………………………………………… ……………………………………………………………………………………	
93.	Het jy eers huis toe gegaan?	☐ Ja ☐ Nee

94.	Hoekom het jy eers huis toe gegaan?	(*Merk al die relevante opsies)* ☐ Gewag vir `n plek by die rehabilitasie sentrum ☐ Gewag vir mediese fonds goedkeuring ☐ Die besluit om na die rehabilitasie sentrum te gaan is eers geneem nadat jy reeds tuis was ☐ Ander *(Spesifiseer)……………………………*
95.	Is jou doelstellings bereik tydens opvolg rehabilitasie?	☐ Ja ☐ Nee
96.	Verduidelik op watter manier hulle bereik /nie bereik is nie: …………………………………………………………………………………… …………………………………………………………………………………… …………………………………………………………………………………… ……………………………………………………………………………………	
97.	Is jy na enige iemand verwys vir opvolg na ontslag uit rehabilitasie?	☐ Ja ☐ Nee
98.	Indien ja, na wie is jy verwys?	(*Merk al die relevante opsies)* ☐ Dokter ☐ Verpleegster/suster ☐ Terapeut ☐ Al die Genoemdes ☐ Ander *(Spesifeer)……………………………*
99.	Het jy enige ander opmerkings oor die rehabilitasie proses wat jy met my wil deel? (5 minute tyd beperking): …………………………………………………………………………………… …………………………………………………………………………………… …………………………………………………………………………………… ……………………………………………………………………………………	