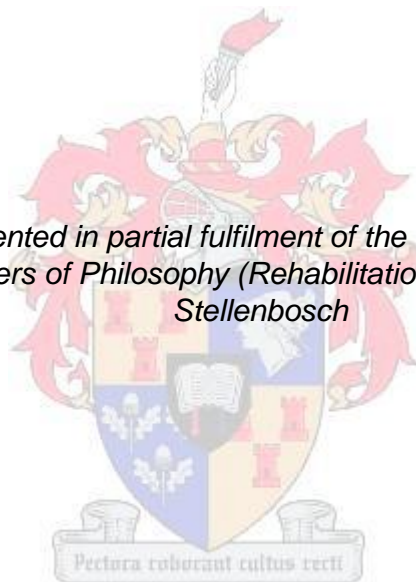


# **Rehabilitation Outcomes Of Uninsured Stroke Survivors In The Helderberg Basin**

by  
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*Thesis presented in partial fulfilment of the requirements for the  
degree Masters of Philosophy (Rehabilitation) at the University of  
Stellenbosch*



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## Abstract

**Introduction:** Rehabilitation is recognised as important in helping stroke survivors achieve their highest levels of functional independence and best quality of life. Conversely, a lack of rehabilitation services, and other environmental barriers, can prevent the attainment of optimal levels of functioning and advanced outcomes, such as community integration and employment.

**Aim of the study:** To determine if uninsured stroke survivors living in the Helderberg Basin (Western Cape) reached their optimal rehabilitation outcome levels and if not, what environmental barriers contributed to this.

**Methods:** A descriptive study was conducted. Quantitative data was obtained from 53 participants, who were selected through proportional stratified random sampling. Demographic information and the health status of participants were recorded. Other instruments utilised were the Stroke Impact Scale (SIS3), Modified Barthel Index (MBI), Loewenstein Occupational Therapy Cognitive Assessment (LOTCA), language screening test and the ICF Core Set for Stroke (Environmental Factors). Outcome levels were categorised as described by Landrum, Schmidt and McLean, 1995. Data was subjected to statistical analysis.

Qualitative data was obtained from five participants, who were chosen by means of purposive sampling. Data were analysed according to predetermined themes.

**Results:** Six (11%) participants were classified as being on rehabilitation level 1; 21 (40%) on level 2; 16 (30%) on level 3; 8 (15%) on level 4; 2 (4%) on level 5.

According to the MBI, 65% of participants required assistance with activities of daily living

LOTCA scores showed that most difficulty was experienced with tests for visuomotor organization and thinking skills. Participants experienced varying degrees of difficulty with the speech and language test. A mean score of 50.84 for questions related to feelings on the SIS3 is indicative of underlying depression.

Stroke survivors received limited physiotherapy and occupational therapy and even less speech therapy and dietary counselling. Occupational therapy had a significant impact on MBI (<0.01) and SIS3.6 (community mobility) (0.02) scores. Six (12%) reported assistance from a social worker. No psychological counselling was reported by any participant. A limited number of assistive devices, focussing mainly on mobility appliances had been issued.

Participants regarded the most significant environmental barriers as being lack of assets (89%), transportation (88%) and general social support services, systems and policies (87%). Qualitative data showed a lack of counselling, education and training by health professionals regarding primary and secondary prevention of stroke and rehabilitation.

**Conclusion:** Numerous environmental barriers impacted on the achievement of advanced rehabilitation outcomes. In addition to shortcomings in the primary and secondary prevention of stroke, many of the minimum standards for rehabilitation, as stipulated in the Western Cape *Comprehensive Service Plan for the Implementation of Healthcare 2010*, were not being met.

Recommendations include establishing a designated stroke unit at Helderberg Hospital, ensuring transport, and improving the referral system to existing rehabilitation services. Increased input from core disciplines essential to stroke rehabilitation has the potential to improve outcomes. A concerted effort by health professionals is required in terms of counselling, education and training with regards to primary and secondary prevention of stroke and rehabilitation.

**KEYWORDS:** STROKE, REHABILITATION, OUTCOMES, UNINSURED POPULATION, ENVIRONMENTAL BARRIERS.

## Opsomming

**Inleiding:** Daar word algemeen aanvaar dat rehabilitasie na 'n beroerte uiters belangrik is, want dit kan beroerte oorlewendes help om die hoogste moontlike vlak van onafhanklikheid te bereik. Daarenteen kan 'n gebrek aan rehabilitasiedienste en omgewingsstruikelblokke verhoed dat 'n oorlewende weer sy volwaardige plek in die samelewing en werksplek inneem.

**Doel van die projek:** Om vas te stel of beroerte oorlewendes, woonagtig in die Helderberg Kom (Weskaap), sonder mediese versekering, wel hulle hoogste vlak van funksionering bereik het, en indien nie, om vas te stel watter omgewingsstruikelblokke bydraende faktore was.

**Metode:** 'n Beskrywende studie is uitgevoer. Kwantitatiewe data is verkry van 53 deelnemers wat lukraak gekies is deur gestratifiseerde, ewekansige steekproefneming. Demografiese inligting en die gezondheidstatus van deelnemers is aangeteken. Ander toetse wat gebruik is, is die Stroke Impak Skaal (SIS3), Gewysigde Barthel Indeks, Loewenstein Arbeidsterapie Kognitiewe Bepaling (LOTCA), taalsiftingstoets en die ICF kern stel vir beroerte (omgewingsfaktore). Uitkomstvlakke was bepaal, soos beskryf deur Landrum, Schmidt en McClean, 1995. Die data is statisties geanaliseer.

Kwalitatiewe data was verkry van vyf deelnemers wat deur middel van doelgerigte steekproeftrekking gekies is. Tydens data analise is voorafbepaalde temas geïdentifiseer.

**Resultate:** Ses (11%) deelnemers was geklassifiseer as op rehabilitasie vlak 1; 21 (40%) op vlak 2; 16 (30%) op vlak 3; ag (15%) op vlak 4; twee (4%) op vlak 5.

Volgens die MBI het 65% van die deelnemers bystand nodig vir daaglikse aktiwiteite.

LOTCA uitslae toon dat die grootste probleme ondervind is met toetse vir visumotoriese organisasie en denkvermoëns. Deelnemers het verskillende grade van probleme ondervind met die spraak en taaltoets. 'n Gemiddelde telling van 50.84 vir vroeë met betrekking tot gevoelens in die SIS3, mag aanduidend wees van onderliggende depressie.

Beroerte oorlewendes het min fisioterapie en arbeidsterapie ontvang en nog minder spraakterapie en raad van dieetkundiges. Arbeidsterapie insette het 'n beduidende impak op MBI telling ( $<0.01$ ) en SIS3.6 (mobiliteit in die gemeenskap) (0.02) gehad. Ses (12%) het aangedui dat hulle hulp van maatskaplike werkers ontvang het. Nie een van die deelnemers het sielkundige berading ontvang nie. Beperkte hoeveelhede en tipes hulpmiddels is uitgereik, en was meesal om mobiliteit te verbeter.

Volgens deelnemers was die grootste struikelblokke 'n gebrek aan bates (89%); vervoer (88%) en algemene sosiale ondersteuningsdienste, stelsels en beleid (87%). Kwalitatiewe data het 'n gebrek aan berading, onderrig en opleiding by gesondheidswerkers in terme van primêre en sekondêre voorkoming van beroerte en rehabilitasiedienste getoon.

**Gevolgtrekking:** Verskeie omgewingsstruikelblokke het verhoed dat deelnemers gevorderde rehabilitasie uitkomst bereik het. Benewens tekortkominge in primêre en sekondêre voorkoming van beroerte, was van die minimum standaard vir rehabilitasie soos beskryf in die Wes Kaap *Omvattende Diens Plan vir die Implimentering van Gesondheidsorg, 2010*, nie nagekom nie.

Aanbevelings sluit in die oprigting van 'n beroerte eenheid by Helderberg Hospitaal, voorsiening vir vervoer en die verbetering van die verwysingsstelsel van bestaande rehabilitasie. Verhoogde insette van kern dissiplines wie se rol noodsaaklik is in beroerte rehabilitasie, is nodig. Gesondheidspersoneel moet 'n daadwerklike poging aanwend om berading, onderrig en opleiding in terme van primêre en sekondêre voorkoming van beroerte en rehabilitasiedienste te verbeter.

**SLEUTELWOORDE:** BEROERTE, REHABILITASIE, UITKOMS, MEDIESE ONVERSEKERDE POPULASIE, OMGEWINGSSTRUIKELBLOKKE

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**"BEROERTE"**

Gister kon ek nog alles doen,  
Vandag 'n gebreekte, skewe pampoen,  
Net binne 'n sekonde of twee,  
is miljoene breinselle uitgevee.  
Eers maande na die plafon gestaar  
Intussen dokters en terapeute, elkeen wil moed inpraat,  
Oefeninge en nuwe preperaas.  
Rystoel, kiere, enige apparaat.  
Nuwe plan: Kom ons gaan na die spesialis,  
Hy sal seker die antwoord wis.  
Daar gekom, en daar word getoets deur 'n  
Groot, vet, imponerende man,  
Die geofende houding van 'n belangrike meneer,  
Want kyk, hy het mos lank geleer.  
Dit praat en praat maar oplossing is daar niet,  
En as ek vra hoeveel beroertes het jy al genees,  
O Grote Gees,  
Dan skram hy weg soos 'n wille bees,  
Maar kom so oor ses maande weer,  
Dan sal ek jou beursie heel omkeer.  
Dom is ek wel, maar terug sal ek nie gaan.  
Ek leer weer soos 'n kind, loop en val,  
En twee en twee is nog vier, of is ek mal?  
Nou is daar net hoop en vertrou,  
Na die nuwe Suid Afrika.  
Het U nog 'n stukkie wonderwerk vir ons, wat pampoene is,  
oorgehou?

**Ben de Kock –Stroke Survivor (Somerset West)**

## **Definition of Key Concepts**

### **Environmental barriers**

An environmental barrier is deemed to be something that hinders the progress of the disabled person and may compound the disability. Examples include negative attitudes towards people with disabilities or the unavailability of a needed service (World Health Organization, 2001c).

### **Environmental factors**

"Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives" (World Health Organization, 2001c:161).

### **Helderberg Basin**

This describes the geographical area encompassing Somerset West, Strand, Rusthof, Lwandle, Nomzamo, Gordon's Bay, Sir Lowry's Village, Macassar, Faure and Firgrove. These communities are situated in the Western Cape Province in South Africa.

### **Rehabilitation**

"Rehabilitation is a goal orientated and time limited process, aimed at enabling an impaired person reach an optimal level of mental, physical and social functioning, thus providing the person with the tools to improve their lives. The goal of rehabilitation is to enable individuals to return home to their communities with the highest possible level of functional independence and the best quality of life, while at the same time reducing as far as possible, the burden of care on family members and significant others" (Western Cape (South Africa). Department of Health, 2007:68). Rehabilitation also encompasses the protection of human rights, equalisation of opportunities and the removal of both attitudinal and architectural barriers. Equalization of opportunities means that health and social services, transport, housing, education, employment opportunities and recreational and sports facilities must be accessible to everyone (United Nations, 2002).

### **Rehabilitation outcome levels**

Outcome levels provide a generic pathway that can be followed for all disabilities. They are guidelines to ensure a logical progression in management from the initial incident to the final outcome. Six rehabilitation outcome levels have been identified and according to these levels, guidelines are given as to where a person should be receiving rehabilitation e.g. hospital or home (Landrum, et al., 1995).

## **Stroke**

"A stroke is an illness of sudden onset, causing neurological impairment resulting from occlusion or rupture of a blood vessel that supplies a specific region of the brain" (Roos, 2010:1). "Stroke is a clinical syndrome defined by acute neurological deficit (usually focal) with a vascular basis" (Muir, 2010:14).

## **Stroke Survivor**

This refers to a person who has had a stroke. The words "stroke survivor" has been used in preference to the much used words "stroke victim." This is out of respect to the wishes of members of the Helderberg Stroke Support Group, who have indicated that they wish to be known as "survivors" or "strokies". They do not like to be seen as "victims".

## **Uninsured**

This term refers to a person who does not have medical insurance (Western Cape (South Africa). Department of Health, 2007).

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## List of Acronyms

<b>ADL</b>	Activities of Daily Living
<b>AFO</b>	Ankle-Foot Orthosis
<b>AIDS</b>	Acquired Immunodeficiency Syndrome
<b>BADISA</b>	Barmhartig, Diens, Saam
<b>BI</b>	Barthel Index
<b>BP</b>	Blood Pressure
<b>CBR</b>	Community-Based Rehabilitation
<b>CBS</b>	Community-Based Services
<b>CDF</b>	Cognitive Dysfunctioning
<b>CHC</b>	Community Health Centre
<b>CHIEF</b>	Craig Hospital Inventory of Environmental Factors
<b>CHW</b>	Community Health Worker
<b>COTNAB</b>	Chesington Occupational Therapy Neurological Assessment Battery
<b>CT</b>	Computerised Tomography
<b>DASH</b>	Dietary Approaches to Stop Hypertension
<b>DG</b>	Disability Grant
<b>DoH</b>	Department of Health
<b>FABS</b>	Facilitators and Barriers Survey
<b>FBS</b>	Facility-Based Services
<b>FICA</b>	Financial Intelligence Centre Act
<b>HIV</b>	Human Immunodeficiency Virus
<b>HSSG</b>	Helderberg Stroke Support Group
<b>ICF</b>	International Classification of Functioning, Disability and Health
<b>INDS</b>	Integrated National Disability Strategy

<b>LOTCA</b>	Loewenstein Occupational Therapy Cognitive Assessment
<b>MBI</b>	Modified Barthel Index
<b>MMSE</b>	Mini-Mental State Examination
<b>MQE</b>	Measures of the Quality of the Environment
<b>NGO</b>	Non-Governmental Organisation
<b>NHI</b>	National Health Insurance
<b>NPO</b>	Non Profit Organisation
<b>OPD</b>	Out patients Department
<b>PBO</b>	Public Benefit Organisation
<b>PGWC</b>	Provincial Government Western Cape
<b>PHC</b>	Primary Health Care
<b>PWDs</b>	People with Disabilities
<b>RHD</b>	Right Hemisphere Damage
<b>ROM</b>	Range of Movement
<b>SA</b>	South Africa
<b>SAHRC</b>	South African Human Rights Commission
<b>SANGOCO</b>	South African National Non-Governmental Organisations Coalition
<b>SASSA</b>	South African Social Security Agency
<b>SIS3</b>	Stroke Impact Scale 3
<b>SNPs</b>	Special Needs Passengers
<b>TAG</b>	Technical Assistance Guidelines
<b>TB</b>	Tuberculosis
<b>TIA</b>	Transient Ischaemic Attach
<b>TV</b>	Television
<b>UIF</b>	Unemployment Insurance Fund

<b>WAB</b>	Western Aphasia Battery
<b>WC</b>	Western Cape
<b>WCRC</b>	Western Cape Rehabilitation Centre



# Chapter 1 Introduction

## 1.1 Background Information

Worldwide, nine percent of deaths are caused by stroke (Zhang, Dewey, Cadilhac & Donnan, 2011). In Sub-Saharan Africa, stroke is considered to be the most prominent type of vascular disease (Wasserman, de Villiers & Bryer, 2009). After Human Immunodeficiency Virus (HIV) and ischaemic heart disease, stroke is considered to be the third most common cause of death in South Africa and the most common cause of death in people over 50 years of age (Bryer, Connor, Cheyip, Staub, Tipping, Duim, & Pinkney-Atkinson, 2010).

Accurate figures on the prevalence of stroke in South Africa (i.e. the number of stroke survivors at a given time), are currently unavailable. The Southern African Stroke Prevention Initiative study of 2004 gives an indication that stroke is "about half as common in rural South Africa as in typical high-income populations of the world, but twice that found elsewhere in Africa" (Bryer et al., 2010:754). These authors surmise that the prevalence of stroke in urban areas in South Africa is probably higher than rural areas due to a greater exposure to lifestyle factors which increase the risk of stroke.

At the Joint World Congress on Stroke, held in Cape Town in 2006, stroke was declared a catastrophic disease in South Africa by world experts (Herman, 2006). The International Stroke Society, Mediterranean Stroke Society and South African Stroke Foundation endorsed this declaration (Bryer et al., 2010).

The effect of a stroke is devastating not only for the survivor but also for the primary caregiver and family who are often subjected to severe stress (Hassan, Visagie & Mji, 2011b). It is well documented that rehabilitation plays a vital role in lessening the effects of impairments and activity limitations and in facilitating the return to active participation in community life and economic self-sufficiency. Young and Forster (2007) report on strong evidence linking rehabilitation with improved outcomes for stroke survivors. Treatment in a dedicated stroke unit where rehabilitation is implemented by a multidisciplinary team, results in a reduction in mortality and in improved outcomes after a stroke, (Bryer et al., 2010). Landrum et al (1995) proposed six outcome levels through which a person should progress during rehabilitation, after an incident like stroke to achieve advanced outcomes such as integration back into the community and return to work. Categorization according to these six levels forms the basis of this study.

According to the *National Rehabilitation Policy* (South Africa. Department of Health, 2000) rehabilitation in South Africa should be provided according to the social model of disability. Thus

rehabilitation should incorporate the protection of human rights and address environmental barriers that prevent inclusion. Environmental barriers and their impact on rehabilitation outcomes and function are discussed at length in the International Classification of Function, Disability and Health (ICF) document, (World Health Organisation (WHO), 2001d).

Dube (2005:4) points out that "South Africa has some of the most comprehensive legislation and policy protecting and promoting the rights of disabled people in the world" but in reality the implementation of policy and service proposals is not always realised. Although one would anticipate challenges with regard to the implementation of rehabilitation policy, it is important to identify and quantify these factors in order to develop strategies to address them.

This study is confined to the Helderberg Basin, Western Cape. The focus of the research is specifically on the rehabilitation of uninsured stroke survivors, the rehabilitation outcomes levels achieved and environmental and other factors possibly militating against access to available services and achievement of advanced outcomes.

Evaluation of the services in the Helderberg Basin does not imply criticism of those individuals involved in service provision (doctors, nurses, pharmacists, physiotherapists, occupational therapists etc.), many of whom are dedicated and committed to their work. It is appreciated by both the researcher and many of the participants in the study that poor services can be the result of lack of human resources and other environmental barriers and not necessarily the fault of a particular individual.

## **1.2 Motivation For The Study**

In her capacity as an occupational therapist, the researcher has worked for approximately 20 years with stroke survivors in the Helderberg Basin who have medical insurance or the finance to pay for private rehabilitation. Through her involvement with the Helderberg Stroke Support Group (HSSG), a local non-governmental organisation (NGO), her experience was extended to include those to whom these resources were not available. Limited therapy is available to the uninsured, but the researcher had become acutely aware of the difference in progress made, between those stroke survivors who received adequate rehabilitation and those who received minimal intervention.

The prime motivation for this study was to establish whether uninsured stroke survivors in the Helderberg Basin achieved optimal rehabilitation outcome levels and to evaluate whether or not they received the required therapy /rehabilitation and other support.

### **1.3 Study Problem**

The ICF lists multiple environmental factors which can either be a barrier or facilitator in reaching optimal rehabilitation outcome levels. For instance, lack of rehabilitation services can be seen as a barrier. Wasserman et al. (2009), comment on how in developing countries, patients with acute stroke are often discharged without an option of receiving adequate rehabilitation. Rhoda, Mpofu and de Weerd (2009) report on the lack of occupational and speech therapy services at community health centres (CHCs) in the Western Cape.

Rhoda et al. (2009), also suggest that a further barrier could be lack of transport to access rehabilitation where services are available. Transport is a major problem for people with disabilities and in particular those who are in wheelchairs. Patients should be able to make use of HEALTHNET (non-emergency transport services) when they are referred for a consultation from "one institution to another" (Western Cape (South Africa).Department of Health, 2007:169). However, the researcher was uncertain as to what extent this service was utilised.

While many barriers in the Helderberg Basin, such as the lack of support systems, inaccessible home environments and a lack of assistive devices, especially in situations of extreme poverty, were assumed by the researcher, no study had been done and no formal information existed.

Thus, the question remained whether or not uninsured stroke survivors in the Helderberg Basin reached their maximum rehabilitation outcome levels and if not what environmental barriers prevented them from achieving this?

### **1.4 Aim**

The aim of the study was to determine whether uninsured people living in the Helderberg Basin who had strokes between 01 January 2009 and 31 December 2010 had reached optimal rehabilitation outcome levels and, if not, what environmental barriers had impeded progress.

### **1.5 Objectives**

For the purpose of the study, the following objectives were identified:

#### **1.5.1 Objectives related to the participants' demographic status, health and functional abilities**

- To determine the demographic profile of the participants;
- To determine the health status of the participants;

- To determine the residual impairments, activity limitations and participation restrictions of participants;
- To determine the current rehabilitation outcome levels of participants.

#### **1.5.2 Objectives related to environmental barriers or facilitators faced by the stroke survivor**

- To determine any environmental barriers or facilitators encountered by the participants.

#### **1.5.3 Objectives related to rehabilitation**

- To determine what therapy/rehabilitation participants have received in terms of physiotherapy, speech therapy, occupational therapy and related services;
- To determine whether the extent of therapy/rehabilitation received by participants, meets the minimum requirements as stipulated by the Western Cape *Comprehensive Service Plan for the Implementation of Healthcare 2010 (Healthcare 2010)*, and
- To determine whether participants are aware of what these disciplines offer in terms of rehabilitation after a stroke.

#### **1.5.4 Objectives in terms of potential rehabilitation outcomes level**

- To analyse the information obtained through the above objectives and comment on whether or not the participants' maximum outcome level was achieved and if not, what hindered this.

#### **1.5.5 Objectives in terms of Recommendations**

- To provide feedback to the Western Cape Department of Health and the Department of Social Development and other stake holders on Rehabilitation Outcome Levels achieved by uninsured stroke survivors in the Helderberg Basin;
- To provide feedback to these organisations on environmental barriers and facilitators encountered by these participants;
- To provide feedback to these organisations on whether guidelines that are given in *Healthcare 2010* are been realised in terms of rehabilitation in the Helderberg Basin and
- To make recommendations to these organisations based on the findings of the study.

## 1.6 Significance

The *Comprehensive Service Plan for the Implementation of Healthcare 2010 (Healthcare 2010)* provides guidelines on rehabilitation services for the Western Cape. Nine minimum standards for primary health care are listed and twelve for level 1, 2 and 3 hospitals. The document states that these interventions must be delivered to ensure that people achieve the highest possible outcomes levels and those secondary complications which can result in the person needing further medical treatment do not occur, (Western Cape (South Africa). Department of Health, 2007). This study investigated whether or not these guidelines were being successfully implemented in the Helderberg Basin.

The study identifies which rehabilitation and related services are lacking and determines other environmental barriers encountered by uninsured stroke survivors. Where existing services are in place problem areas have been identified and can assist in preventing people "falling through the cracks" (e.g. if transport problems are resolved, more people might be able to access rehabilitation services that are already available in the area.)

In many respects, rehabilitation in the Helderberg Basin resembles a jigsaw puzzle with isolated pieces, scattered all over. Both the *National Rehabilitation Policy* and *Healthcare 2010* comment on the role that NGOs can play in the provision of rehabilitation services. Some of the NGOs involved in the Helderberg Basin with stroke survivors are the HSSG, Society of the Aged, Barmhartigheid, Diens Saam (BADISA), Masincedane and other organisations involved with home based caring. The researcher had contacted all these organisations for background information for the study and for assistance in obtaining names of stroke survivors in the community. Ultimately this will contribute to compiling a comprehensive picture of services available to stroke survivors in the Helderberg Basin and possibly to a better referral system between Government and NGOs.

The researcher believes that this study can form the foundation for future studies on rehabilitation and disability issues in the Helderberg basin. A number of possible studies have been identified and are mentioned in Chapter 6.

Many studies on stroke in South Africa appear to utilise measures which provide limited, impairment focussed information e.g. the Barthel Index or the Rankin Scale. Other studies focus on specific impairments or activity limitations e.g. gait or hand function. Furthermore, very little research appears to have been done on cognitive and perceptual problems in stroke survivors in South Africa. This study is possibly unique in that it provides detailed information on the impairments, activity limitations, participation restrictions and environmental factors encountered by uninsured stroke survivors once they return to their communities.

## **1.7 Study Outline**

This chapter has given an introduction to the study as well as clarifying the aim, objectives, significance and the motivation for undertaking this research. In Chapter 2, literature relevant to the study is discussed. Chapter 3 describes the methodology utilised and the results are presented in Chapter 4. These are discussed in Chapter 5 and recommendations to the relevant service providers and authorities are made in Chapter 6.

## **Chapter 2 Literature Review**

### **2.1 Introduction**

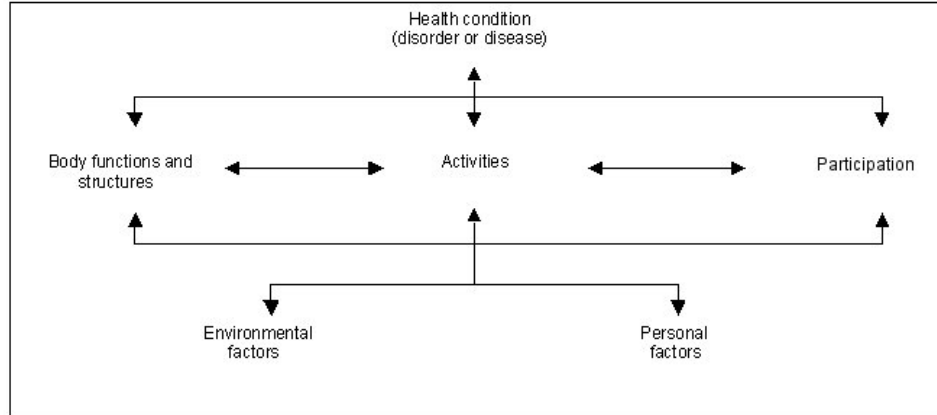
This chapter surveys literature relevant to the study. It commences with a discussion on the International Classification of Function (ICF) which provides a theoretical framework for this research project. This is followed by an investigation of stroke and stroke risk factors. The impact of stroke on function is then examined in terms of the ICF. Both general and stroke rehabilitation factors are explored, as are barriers to stroke rehabilitation in South Africa. The role of outcome levels in stroke rehabilitation is introduced. Finally social grants relevant to stroke survivors in South Africa are described.

### **2.2 International Classification of Function, Disability And Health**

The ICF provides a frame work within which disability, whether caused by stroke or some other incident, can be explored. It provides a common framework for health outcome measures. "The ICF is a classification that allows a comprehensive and detailed description of a person's experience of disability, including the environmental barriers and facilitators that have an impact on a person's functioning." (Schneidert, Hurst, Miller & Ustün, 2003:588).

The ICF has integrated the medical model of disability with the social model of disability to create a biopsychosocial approach, incorporating biological, individual and social perspectives (World Health Organisation, 2001a). The medical model views disability as a problem of the person, which occurs as a result of illness, injury or other health conditions and advocates cure through individual treatment. The social model sees disability as a problem created by society, hindering the participation of people with disabilities. The social model advocates inclusion through universal access strategies and removal of all environmental barriers (World Health Organisation, 2001a).

Figure 2.1 shows that according to the ICF a person's health, functioning and ability is determined by a complex interaction between impairment of body functions and body structures, activity limitations (inability to perform tasks) and environmental and personal factors that impact on participation (performing life roles).



**Figure 2.1 Interaction between various domains of the ICF (WHO 2001d:18).**

In this study the impairments and activity limitations that can arise from a stroke are explored. In addition, special attention is given to environmental barriers experienced by study participants. As per the World Health Organisation's classification, environmental factors are grouped in five sections. These are:

- "Products and technology
- Natural environment and human made changes to the environment
- Support and relationships
- Attitudes
- Service, system and policies" (World Health Organisation, 2001d: 173-207).

Environmental factors can either facilitate or restrict a person's performance and remove or compound their disability. A stroke survivor utilising a wheelchair may be unable to return to work because public transport is inaccessible, whereas a person with similar impairments may be able to return to work because government-subsidised transport for disabled people (e.g. Dial-a-Ride) is available. Thus the impact of the disability is lessened through an environmental facilitator.

### **2.3 Stroke – An Overview**

A stroke occurs when the blood supply to the brain is disrupted (Stroke Association, 2006b). The majority of people who have suffered a stroke in South Africa are 65 or older, with only 10 to 15% of stroke sufferers being under the age of 45 (Heart Magazine, 2007). It is estimated that in South Africa 25000 people died from stroke in 2007 and is ranked ninth in terms of major causes of disability in South Africa (Bryer et al., 2010). Many stroke survivors require extended hospitalisation, nursing home care and



rehabilitation impacting on the financial situation of individuals, their families, communities and health services. Stroke can to a large extent be prevented through the effective management of risk factors (Bryer et al., 2010).

### **2.3.1 Types of stroke**

**Ischaemic stroke (85%)** (Bryer et al., 2010).

This occurs when a blood clot blocks one of the arteries which carry blood to the brain (Stroke Association, 2006b). An ischaemic stroke can manifest in a number of ways:

- "A cerebral thrombosis occurs when a blood clot forms in an artery supplying blood to the brain and blocks the flow.
- A cerebral embolism occurs when a blood clot forms elsewhere in the body and travels to the brain, where it blocks an artery.
- Lacunar strokes occur as a result of damage to the small blood vessels deep within the brain" (Stroke Association, 2006b:5).

**Haemorrhagic stroke (15%)** (Bryer et al., 2010).

- "An intra-cerebral haemorrhage occurs when a blood vessel bursts and bleeding occurs inside the brain.
- A subarachnoid haemorrhage occurs when a blood vessel bleeds into the subarachnoid space" (Stroke Association, 2006b:5).

### **2.3.2 Risk factors for stroke**

In the South African population, hypertension is considered to be the main risk factor for stroke. The most common risk factors for stroke (Heart and Stroke Foundation of South Africa, n.d.b; South Africa. Department of Health, 2001; Bryer et al., 2010) are listed below and according to Bryer et al. (2010) an individual may present with several of these.

- High Blood Pressure. (Readings above 140/90 are considered to be high.);
- Smoking;
- Being overweight;
- High blood cholesterol;
- Physical inactivity;
- Diabetes Mellitus (diabetes);
- Excessive alcohol consumption and
- Current heart disease.

Bryer et al. (2010) also list a low intake of vegetables and fruit as a further risk factor.

New findings indicate that patent foramen ovale, aortic arch atheroma, hyper-homocysteinaemia and thrombophilia are also risk factors for stroke and can account for cryptogenic strokes or strokes caused by unknown factors (Zhang et al., 2011).

Of particular relevance to South Africa is the increased incidence of stroke caused by human immunodeficiency virus (HIV), which is mainly affecting people in younger age groups (Bryer et al., 2010). Normally, the incidence of stroke increases with age. "H.I.V infection may cause stroke through opportunistic infections, secondary to involvement of the heart by HIV, possibly by changes in coagulation factors, and through direct or indirect damage to blood vessels" (Bryer et al., 2010:755).

There is a close link between diabetes and stroke. The likelihood of diabetics having a stroke is increased three- fold in comparison to the normal population and 80% of Type 2 diabetics usually die from a heart attack or stroke (Tonkin, 2007).

Diabetes occurs because of high levels of blood glucose in the bloodstream. High blood sugar causes damage and narrowing of blood vessels (atherosclerosis) which can result in a heart attack or stroke. According to the Heart and Stroke Foundation of South Africa, the normal fasting blood glucose level should be 4-6mmol/l. High blood glucose levels occur when the body does not produce enough insulin, or when the body does not respond correctly to insulin (insulin being a hormone which is necessary for helping the body turn glucose into energy). There are two main classes of diabetes:

- Type 1: The onset of this type of diabetes usually occurs before the age of 40 years. It is caused by insufficient amounts of insulin being produced by the body, and is usually treated with insulin injections (Heart and Stroke Foundation of South Africa, n.d.a).
- Type 2: This type occurs mainly in adults and is associated with obesity. Insufficient amounts of insulin may be produced or the body may not respond to insulin. Treatment is by means of oral medication. Diet, exercise and weight loss can also play an important role in the treatment of Type 2 diabetes. In some cases, insulin injections may also be necessary.

Other types of diabetes may be caused by infections, drugs, malnutrition and genetically related syndromes. Gestational diabetes may occur during pregnancy (Heart and Stroke Foundation n.d.a).

Besides vascular damage which also results in an increase in blood pressure, further complications of diabetes can be

- Heart Attacks;

- Kidney disease (nephropathy);
- Eye damage (retinopathy). Diabetic retinopathy can lead to blindness. Diabetics are also more prone to having cataracts and glaucoma;
- Nerve damage (neuropathy);
- Foot problems. Circulation in the feet becomes poor. Diabetics are prone to ulcers and infections. Gangrene can set in (Heart and Stroke Foundation n.d.a).

As many risk factors are preventable or modifiable, management of these should be the first line of defence against stroke. A stroke can cause numerous and varied impairments which impact on performance of activities and participation in society.

### **2.3.3 Impairments, activity limitations and participation restrictions caused by stroke**

A stroke can result in one or more of the following impairments: paralysis or weakness of limbs, sensory loss, incontinence, cognitive and perceptual impairments, vision impairments, personality changes, speech and language impairments and swallowing problems (Stroke Association, 2006b; Tipping, 2008). The impairments and activity limitations caused by stroke are discussed in more detail in the following paragraphs.

#### **2.3.3.1 Paralysis or weakness of limbs**

Paralysis or weakness of the face and limbs will occur on the contra-lateral side to the brain injury. Where the cerebral motor area of the brain is affected, 65% of stroke survivors will develop spasticity (Tipping, 2008).

#### **2.3.3.2 Sensory disturbances**

The sensations of touch, pressure, temperature, pain, vibration and proprioception may be affected after a stroke. This lack of sensory feedback can have a major effect upon perceptual-motor function, resulting in disuse of affected limbs even where there has been good motor recovery, impacting negatively on activities such as walking (Pedretti, 1996).

#### **2.3.3.3 Incontinence**

Fifty to seventy percent of all stroke survivors experience some form of bladder incontinence in the first month post stroke. Less than 20% generally experience problems at six months (Tipping, 2008).

The most common difficulties experienced are urge incontinence, urgency, frequency, nocturia, difficulty with voiding, sensory loss of the bladder and the involuntary passing of urine (Stroke Association, n.d). Urge incontinence is generally managed by a bladder-re training programme which includes voiding according to a planned schedule (Tipping, 2008).

Bowel incontinence occurs in approximately a third of stroke survivors, but is generally only evident in the first few weeks post stroke (Tipping, 2008). Faecal impaction, which can be caused by immobility, a diminished intake of nutrients and fluids, depression and other factors is fairly common. This can be managed through the use of laxatives and bowel training (Tipping, 2008).

#### **2.3.3.4 Speech and language disorders**

There are 2 types of Speech and Language disorders: aphasia and dysarthria.

##### **2.3.3.4.1 Aphasia**

This occurs as a result of neurological damage. People may have difficulty with auditory and reading comprehension. Expressing themselves orally or with the written word may be problematic. Stroke survivors with aphasia may also experience difficulty with mathematical calculations. There are several different types of aphasia (Pedretti, 1996; Gillen, 2011).

- **Global aphasia:** With global aphasia, all language skills are lost. The person may be able to interpret gestures and facial expressions, which often leads people to think they understand more than they do.
- **Broca's aphasia (expressive aphasia):** In the case of Broca's aphasia, stroke survivors lose their ability to express themselves verbally, but retain auditory comprehension. They may have difficulty with reading comprehension and expressing themselves with writing.
- **Wernicke's aphasia (receptive aphasia):** With Wernicke's aphasia, auditory comprehension is impaired. Paraphasic speech occurs. Comprehension of the written word may be affected and mathematical skills may be impaired.
- **Anomic aphasia:** In this case, stroke survivors will have difficulty with word-finding.

##### **2.3.3.4.2 Dysarthria**

With dysarthria, the muscles relevant to speech production are affected. Weakness of altered sensory feedback on the movement of muscles results in the stroke survivor having difficulty articulating words. Speech may be slurred (Gillen, 2011).

It is the experience of the researcher that often family, and the stroke survivors themselves, have very little understanding of speech problems leading to severe frustration. Gillen (2011) reports on the negative impact of speech and language disorders on quality of life, often resulting in the loss of employment and causing the stroke survivor to feel isolated and depressed.

### **2.3.3.5 Perception**

Intact perception is required so that people can learn about and adapt to their constantly changing environment. It involves processing and interpretation of sensory information obtained from the environment (Pedretti, 1996). Cognitive and perception impairments may be hidden and the stroke survivor (and the family /caregiver) can be unaware of them. A stroke survivor with right hemisphere dysfunction may retain good language skills, which can mask perceptual impairments and give the impression of a high level of functioning (Pedretti, 1996).

Some of the perceptual dysfunctions which commonly affect people who have had a stroke are:

#### **2.3.3.5.1 Body scheme disorders**

This type of perceptual impairment will affect the interpretation of how the body parts fit together anatomically. Stroke survivors with this problem, often have difficulty with dressing and other self-care activities. They may experience problems with left and right orientation and in planning how to move their bodies in order to perform certain tasks (Pedretti, 1996).

#### **2.3.3.5.2 Apraxia**

This is defined as the inability to perform purposeful movements without any loss in motor power, sensation, and ability to comprehend instructions or as a result of lack of cooperation by the stroke survivor.

- **Ideomotor apraxia:** This manifests as the inability to carry out a purposeful movement on instruction. The stroke survivor may still be able to perform the task automatically.
- **Ideational apraxia:** With ideational apraxia, the person has difficulty performing routine daily tasks on command, such as brushing teeth.
- **Constructional apraxia:** This manifests in difficulty copying, drawing or in the construction of objects from designs. Stroke survivors with this impairment often have difficulty with dressing (Pedretti, 1996).

#### **2.3.3.5.3 Unilateral neglect**

This usually occurs with stroke survivors with right hemisphere lesions. The person demonstrates a lack of awareness of the affected limbs and anything that occurs in the surroundings on that particular side of the body. Stroke survivors with unilateral neglect have great difficulty performing activities of daily living such as dressing, eating. Reading, writing and arithmetic skills can also be affected (Pedretti, 1996).

#### **2.3.3.5.4 Spatial relationships**

This term refers to the ability of the person to discern the position of two or more objects in relation to each other and to themselves. Impairments in this regard are common amongst stroke survivors with right hemisphere damage. Problems will often manifest in dressing, or with transfers and ambulation where the person has to judge the distance between objects. The person will also have difficulty with copying and in constructing three dimensional designs and objects (Pedretti, 1996).

#### **2.3.3.5.5 Visual perception of vertical**

Stroke survivors with right hemisphere damage may have difficulty in visually determining what is in the horizontal or vertical position. Impairments in this regard may affect balance and walking (Pedretti, 1996).

#### **2.3.3.5.6 Figure ground perception**

This pertains to the ability to focus on selected visual stimuli whilst excluding background stimuli. Stroke survivors with this impairment, will have difficulty in selecting items on a desk or shelf, because they will not perceive the object as separate from other items (Pedretti, 1996).

#### **2.3.3.5.7 Agnosia**

This refers to the inability of the stroke survivor to recognize familiar objects by means of tactile, visual or auditory perception. With visual agnosia, the stroke survivor will have difficulty recognising familiar objects and faces, even though vision, language and other cognitive functions may be relatively unaffected (Gillen, 2011).

### **2.3.3.6 Vision-related impairments**

#### **2.3.3.6.1 Hemianopia**

This is a visual field defect that results in vision loss of the temporal half of the one eye and the nasal half of the other eye (Gillen, 2011). "Loss of the left half of the visual field accompanies left hemiplegia, and loss of right visual fields accompanies right hemiplegia" (Gillen, 2011: 403). This can cause stroke survivors to see half of a plate of food, or a page of a book placed in front of them. With walking, they can often bump into furniture or objects on the affected side.

#### **2.3.3.6.2 Visual attention**

Stroke survivors with visual attention impairments, have difficulty with visual fixation and shifting their gaze. Eye movements are slowed (Pedretti, 1996).

### **2.3.3.6.3 Age-related vision problems**

There is generally a higher incidence of stroke amongst elderly people. It is important to remember that vision problems may have been prevalent prior to a stroke and not necessarily as a result of it (Gillen, 2011). Cataract is considered to be the most common vision problem amongst the elderly. Other conditions affecting the elderly are macular degeneration, glaucoma, ptosis and diabetic retinopathy (Gillen, 2011).

### **2.3.3.7 Cognitive impairments**

After a stroke, memory, abstract thinking and reasoning may be impaired. The stroke survivor's ability to judge the consequences of their actions may be affected. People may act impulsively and lack insight into situations. They may have difficulty with problem solving and initiating tasks. Sequencing skills may be affected, resulting in difficulty in planning and organizing tasks involving more than one step (Pedretti, 1996). Cognitive impairments can impact on a stroke survivor's ability to live independently (Gillen, 2011).

It is generally recognised that intervention by rehabilitation professionals has the potential to modify many of these impairments. However, as already discussed, rehabilitation has come to mean far more than therapeutic intervention. Various factors pertaining to rehabilitation in general and in South Africa are investigated in the following section.

## **2.4 Rehabilitation**

### **2.4.1 Rehabilitation in South Africa:**

The disability movement in South Africa played an integral role in the formulation of The White Paper on an Integrated National Disability Strategy. This paper describes rehabilitation as a means "of helping people with disabilities to become fully participating members of society, with all the benefits and opportunities of that society" (South Africa. Office of the Deputy President, 1997:12).

The South African *National Rehabilitation Policy* was completed in 2000 and incorporates the principles of the social model of disability. The goal of this policy is to realise "every citizen's constitutional right to have access to health care services" (South Africa. Department of Health, 2000:2). The policy also promotes equitable and affordable health care and rehabilitation services. It further encompasses the concepts of promoting equalisation of opportunities and the protection of human rights. The importance of collaboration between the Department of Education, Health, Housing, Transport, Labour and Welfare is stressed. Community Based Rehabilitation (CBR) is also promoted. "CBR is a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of

people with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families, organizations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services" (World Health Organization, 2004b:2).

In 1994 the National Health Plan was introduced in South Africa. The main focus was to restructure the national health system according to a primary health care (PHC) approach, based on the principles of the Alma Mata Declaration of 1978. It was envisioned that community-based health care would be made available to all South Africans through the establishment of PHC centres (Padurath & English, 2011).

The four corner stone's of Primary Health Care are (Barron & Josianne, 2008):

- Promotive Services
- Preventative Services
- Curative Services
- Rehabilitation Services

Although South Africa has extremely comprehensive and advanced policies and legislation in terms of rehabilitation, services still seem to be lacking. In a study on the provision of rehabilitation services within the District Health System, Dayal (2010) concludes that the following factors have impacted negatively on the capacity to deliver rehabilitation services and on the patient's right to access rehabilitation in South Africa:

- "Bureaucratic inefficiencies
- Limited awareness of public policies
- Lack of direction to operationalise rehabilitation services within the Primary Health Care package
- Differing approaches to service delivery and lack of clarity between national, provincial and facility levels" (Dayal, 2010:26).

#### **2.4.2 Rehabilitation in the Western Cape (South Africa)**

"*Healthcare 2010* was developed to improve the quality of the healthcare service and to provide a financially sustainable health service in the Western Cape" (Western Cape (South Africa). Department of Health, 2007:1). Plans to start implementing this policy commenced in 2007 / 2008. The two main components of *Healthcare 2010* revolve around facility-based services (FBS) and community-based services (CBS) and state that rehabilitation should be available across both sectors. The Western Cape Rehabilitation Centre is currently the only high-intensity rehabilitation facility in the Western Cape (Western Cape (South Africa). Department of Health, 2007). Some low intensity rehabilitation services



are offered at level 1, 2 and 3 hospitals, sub-acute and chronic care services and other community-based rehabilitation services (Western Cape (South Africa). Department of Health, 2007).

The community-based service model is based on the PHC approach which advocates the involvement and empowerment of individual communities. *Healthcare 2010* advocates that CBS should be provided by non-profit organisations (NPOs) (Western Cape (South Africa).Department of Health, 2007).

The Helderberg Basin falls within the Cape Metropole Region of the Western Cape. *Healthcare 2010* is particularly relevant to the researcher's study as it provides guidelines on the rehabilitation services that should be available to people with disabilities in the Western Cape. These are listed below.

#### **2.4.2.1 Core packages of rehabilitation services for primary health care**

Nine points are listed in *Healthcare 2010* as "minimum rehabilitation interventions that must be delivered to ensure optimal outcomes and the prevention of secondary complications which could result in re-entry to the acute health care system:

- Follow-up of all patients discharged from hospitals
- Low-intensity rehabilitation services rendered by, at least, physiotherapists and / or occupational therapists for at least 1-2 hours per person /day but not necessarily every day
- Screening and assessment (including screening for disability grants)
- Education, training and support of the patient, family and primary care givers /home-based carers
- Establishing adequate and safe systems of nutrition, respiration, skin preservation, joint maintenance and bladder and bowel management
- Therapeutic and support groups
- Correct prescription and issue of wheelchairs, or buggies in the case of children, including correct postural seating together with the necessary pressure relief cushion(s)
- Correct prescription and supply of other required assistive devices
- Facilitating the achievement with varying degrees of assistance as required of a basic degree of functional independence in self-care, mobility, safety, communication" (Western Cape (South Africa). Department of Health, 2007:71).

#### **2.4.2.2 Core package of rehabilitation services for levels 1, 2, and 3 hospitals**

The following 12 points are listed in *Healthcare 2010* as "minimum rehabilitation interventions that must be delivered [by level 1, 2 and 3 hospitals] to ensure optimal outcomes and the prevention of secondary complications which will result in re-entry to the health care system:

- Clinical evaluation and management of all referred clients
- Alleviation of acute symptoms (curative services)
- Low-intensity rehabilitation services rendered by, at least, physiotherapists and/or occupational therapists for a minimum duration of 1-2 hours per person /day, not necessarily every day, on either an in-patient or outpatient basis
- Ensuring adequate respiration, skin preservation and joint and soft tissue maintenance
- Establishing adequate medical, nursing, bladder, and bowel management and nutritional support protocols in collaboration with other team members
- Early mobilization and initial functional re-education
- Preparation for discharge from day 1 by arranging referral to an appropriate level rehabilitation service point (high-intensity rehabilitation or low-intensity rehabilitation)
- Provision of various assistive devices to help overcome activity limitations and relieve the burden of care
- Correct prescription and issue of wheelchairs or buggies in the case of children, including correct postural seating, together with the necessary pressure relief cushion(s)
- Counselling, education, training and support of the patient, family and primary caregivers if available
- Providing information to identified consumer groups and their families e.g. for mental health consumers, traumatic brain injury, stroke
- Link clients and their families to community resources for easier management at home and promotion of community integration" (Western Cape (South Africa). Department of Health, 2007:72)

### **2.4.3 Stroke rehabilitation**

Several definitions of rehabilitation have been cited in the Key Concepts section above. In addition, the Stroke Association (2006a:5) defines rehabilitation as "the process of overcoming or learning to cope with the damage the stroke has caused, getting back to a normal life and achieving the best level of independence by: relearning skills and abilities; learning new skills; adapting to some of the limitations caused by a stroke; and finding social, emotional and practical support at home and in the community."

The *South African guideline for the management of stroke and transient ischaemic attack (2010)*, defines stroke rehabilitation as "a goal-orientated process which attempts to obtain maximum function in patients who have had strokes and who suffer from a combination of physical, cognitive and language disabilities" (Bryer et al, 2010: 775). The extensive implications of human rights in rehabilitation were discussed in section 2.4.1.

Stroke Rehabilitation can take place in different locations. The *South African National Guideline on Stroke and Transient Ischaemic Attack Management* (South Africa. Department of Health, 2001) advocates that acute management should take place at a hospital and sub-acute management should take place at specialised rehabilitation centres, secondary inpatient facilities or CHC's (Rhoda et al., 2009).

The *South African guideline for management of stroke and transient ischemic stroke 2010* (Bryer et al., 2010) advocates treatment in a dedicated stroke unit, which can be a specific ward in a hospital or section of a ward. Treatment in a dedicated stroke unit results in a reduction of mortality rates and in better rehabilitation outcomes.

Depending on their needs, the involvement of the following team members may be required in the rehabilitation of the stroke survivor: doctors, nurses, physiotherapists, occupational therapists, speech and language therapists, audiologists, psychologists, social workers, dieticians, prosthetists and orthetists (Western Cape (South Africa). Department of Health, 2007).

Generally, teamwork can take the form of a multidisciplinary, interdisciplinary or a transdisciplinary approach. The type of approach utilised will to a large extent depend on the human resources available and on the system that is the most effective or practical for a particular facility (Visagie, 2008).

- **Multidisciplinary approach**

With a multi disciplinary approach each team member will do an evaluation and set up an individual treatment programme according to these findings.

- **Interdisciplinary approach**

Assessments, planning of goals and treatment are done in conjunction with other team members. A single treatment plan is identified in consultation with the stroke survivor and all team members work according to this. The team member most suited to perform a particular treatment modality will be allocated the task.

- **Transdisciplinary approach**

Therapists may perform treatment modalities conventionally allocated to other professions. Two disciplines may work together on evaluations and treatment, often in consultation with family members (Visagie, 2008).

Bryer et al. (2010) advocate an interdisciplinary approach where team members are both knowledgeable and experienced in working with stroke survivors.

#### **2.4.4 Barriers to stroke rehabilitation**

Four studies conducted in various countries since 2000 have identified a number of regional variations in barriers to stroke recovery. In Sweden, Algurén, Lundgren-Nilsson and Sunnerhagen (2009) found geographical terrain to be a barrier. A study carried out in Korea by Han, Yajima, Lee, Meguro and Kohzuki (2005) showed services and policies to be a barrier for stroke survivors. A Canadian study by Rochette, Desrosiers and Noreau (2001) reported income security as being equally facilitating and hindering and equal opportunity and political orientation were seen to be a barrier. In the United States of America, Hollingsworth, Stark and Morgan (2008), identified assistive devices, relationships, attitudes, services and systems as facilitators.

Although specific guidelines on stroke management and rehabilitation are available in South Africa, lack of monetary and human resources means that policies or guidelines on stroke management are not always implemented (Bryer et al., 2010). Many hospitals do not regard stroke as a priority in terms of developing protocols for management (Bryer et al., 2010). Due to a shortage of beds, stroke survivors are often discharged before they are proficient in transfers and basic activities of daily living. This can result in a heavy burden upon caregivers who may also have to go out to work, resulting in the stroke survivor being neglected.

Rhoda et al. (2009) conducted a study on the rehabilitation of stroke patients at community health centres in the Cape Metropole Region of the Western Cape. The study revealed the following:

- There was a lack of therapy services to provide rehabilitation to stroke patients at the CHCs in the Cape Metropole Region of the Western Cape. Occupational and Speech Therapy services in particular were lacking
- Services that were currently available were not coordinated
- The frequency of physiotherapy, occupational therapy and speech therapy was low
- Although physiotherapy was available, the number of hours of physiotherapy received by patients was low.

#### **2.5. Rehabilitation Outcome Levels**

*Healthcare 2010* proposes an outcomes-based rehabilitation service plan addressing six clinical outcome levels. These are based on the outcome levels described by Landrum et al. (1995). The authors identified six outcome levels and according to these levels, provide guidelines on the functional outcomes the

person should achieve at each level and where appropriate rehabilitation should be conducted, for instance at a hospital or home.

This is a useful measure to guide the rehabilitation process and which all rehabilitation professionals can be trained to use, thus providing a uniform language and understanding of the person's abilities and needs, and where they are in terms of integration back into society after a stroke or relative incident. This measure has been utilised in this study.

### **Level 0: Physiological instability**

This level describes patients as they first present after the onset of an injury or illness. The patient will need to be stabilised and receive emergency medical care. A detailed medical and psychological evaluation will still need to be done and the diagnosis confirmed before the full treatment plan for the patient can be determined.

In the case of a stroke patient this would be when the person has just suffered the stroke and is still medically unstable. The *South African guideline for the management of ischaemic stroke and transient ischaemic attack 2010*, stresses the importance of an acute stroke or transient ischaemic attack (TIA) being treated as medical emergency, much as a myocardial infarction is (Bryer et al.,2010).

A neurological and general examination to determine the patient's vital sign should be done. Computerised tomography (CT) scans should be performed on all stroke patients, but in South Africa, due to financial constraints and the logistics of getting to a centre that offers this service it is not always possible. In the case of patients who could benefit from thrombolysis, a scan should be done within 30 minutes of arrival at the hospital (Bryer et al., 2010).

General treatment for ischaemic stroke "includes respiratory and cardiac care; fluid and metabolic management; blood pressure control; the prevention and treatment of conditions such as seizures, venous thrombo-embolism, dysphagia, aspiration pneumonia, other infections and pressure ulceration, and occasionally management of elevated intracranial pressure" (Bryer et al., 2010:763).

### **Level 1: Physiological stability**

This is achieved when all acute and life threatening medical and physiological problems have been attended to. Rehabilitation revolves around prevention of secondary complications, evaluations, identification of and referral to appropriate rehabilitation and planning of future care.

Family education and counselling is extremely important at this stage.

## **Level 2: Physiological maintenance**

The focus at this level will be on the maintenance of the patient's current and long-term physiological health. Functional goals revolve around bed mobility, continence and transfers. A limited degree of mobility, self-care, and communication, cognitive and behavioural outcomes is achieved.

People who have had a TIA or stroke are at risk of having further strokes. At this level, putting steps in place for long term management of blood pressure, diabetes mellitus and hyperlipidaemia is extremely important. The implementation of lifestyle changes, such as cessation of smoking, reduction in alcohol intake, weight reduction and increased physical activity is necessary. The need for antithrombotic medication (e.g. aspirin) or oral anticoagulation (e.g. warfarin) needs to be determined (Bryer et al., 2010)

## **Level 3: Residential integration**

This level considers the skills necessary for the patient to reach an acceptable level of function either at home or in a long-term residence. The patient should require minimal help with self-care activities, and with walking or propelling a wheelchair. The patient should have some ability to communicate and have basic skills in home management, and must be able to perform these tasks safely within the home or residential environment. He / she must be able to direct tasks, even if they are performed by other people.

## **Level 4: Community reintegration**

This level focuses on the client's ability to function within the community. Goals revolve around self-management, social competencies, community mobility, and complex homemaking skills, managing of finances, self directed health monitoring, recreation and involvement in other community activities.

Many stroke survivors are elderly and recreation and involvement in community activities can play an increasingly important role in their lives.

## **Level 5: Productive activity**

At this level, rehabilitation goals should be appropriate to the client's interests and stage of life and may involve vocational, avocational or educational activities. The ultimate goal of rehabilitation is for people to return to work and be able to support themselves financially.

Much has been done in South Africa in terms of policy, legislation and guidelines to facilitate the employment of people with disabilities. Toni (2011) detailed the following:

- White Paper on the Transformation of Public Service (1994). This determines the government's intention that by 2005, two percent of people working for the public service should be people with disabilities (PWD's);
- South African Qualifications Authority Act (no.58 of 1995). This is aimed at establishing a uniform set of qualifications in South Africa that will be recognised nationally and internationally.
- Skills Development Act (no.97 of 1998). This seeks to promote education and training and redress inequalities in this regard;
- Employment Equity Act (no.55 of 1998). This act promotes equal opportunities in the workplace. People applying for work or who are already employed, may not be discriminated against in terms of race, disability, gender, language or culture. The act promotes affirmative action, requiring employers to accommodate previously disadvantaged groups in the work place. (i.e. Black people, people with disabilities (PWDs) and women);
- Skills Development Levies Act (no.97 of 1999);
- The Promotion of Equality and Prevention of Unfair Discrimination Act (2000);
- The Code of Good Practice on the Employment of People with Disabilities (2002). This is a guideline for employees, employers and trade unions on the promotion of equal opportunities in the work place;
- Technical Assistance Guidelines on the Employment of people with disabilities. This is a simplified version of the Employment Equity Act and the Code of Good Practice, which is aimed at assisting both employers and employees and
- National Skills Development Strategy.

Although South Africa has advanced policies, legislation and guidelines in place in terms of employing PWDs, there are still many barriers preventing people with disabilities from gaining employment. These are:

- **Internal policies:** Maja, Mann, Sing, Steyn and Naidoo (2011) report on many employers espousing equal opportunity policies, but very few companies have internal policies regarding the recruitment and employment of PWDs;
- **Unemployment rates in South Africa:** South Africa has an extremely high rate of unemployment, making it difficult for all South African citizens to obtain gainful employment. In the last quarter of 2010, the unemployment rate was reported to be 24 % (Trading Economics, 2010);

- **Physical environment:** Inaccessible buildings, lack of parking facilities, general infrastructure, and difficulty using equipment and machinery have been found to be barriers in the employment of people with disabilities. Lack of accessible public transport is a major barrier in preventing PWDS from being employed (Maja et al., 2011).
- **Attitudes:** People without disabilities often regard people with disabilities as being inferior. Negative attitudes, and a lack of awareness and knowledge of disability can lead to discrimination and play a role in PWDS not being employed (Maja et al., 2011). Definitions of disability can also play a role in perceptions of PWDs and their abilities (Toni, 2011). Words such as "handicapped", "crippled" or "invalid" immediately give rise to a negative connotation. Many employers foster the mindset that a person with disabilities will not be able to perform a required task, that production speed will be slow and that the employee will be off work for long periods of time due to illness and the need for medical attention. There is also concern that, with current legislation, once the person is employed, it will be extremely difficult to terminate the contract if they are not able to meet the work requirements; and
- **Ignorance or apathy on the part of disabled people:** It is the researcher's experience that PWDS who do not have much education are often ignorant of their rights in terms of sick leave, return to work etc. Contracts are not necessarily drafted in the employee's home language and unless assistance is received from the employer or a social worker, great difficulty can be experienced in sorting out work-related issues.

## **2.6 Grants Which Are Relevant To Stroke Survivors in South Africa**

It is generally recognised that the largest concentration of people with disabilities come from backgrounds of extreme poverty and it has been necessary to provide for them financially through the provision of disability grants (DGs). The disability grant was not meant to be a measure for poverty relief, but with the high levels of unemployment in South Africa, disability grants are in many instances providing income for a number of people living in one home (Watermeyer, Swartz, Lorenzo, Schneider & Priestly, 2006).

### **2.6.1 Disability grant**

In determining who is eligible for a disability grant it is necessary to distinguish between people who cannot work as a result of impairments and those who cannot work as a result of unemployment. The Social Assistance Amendment Bill (B5 -2010) defines disability in terms of an applicant applying for a grant as a "moderate to severe limitation to his or her ability to (function) or perform daily life activities as a result of a physical, sensory, communication, intellectual or mental disability rendering him or her unable to:



- Obtain the means needed to enable him or her to provide for his or her own maintenance, or
- Be gainfully employed" (Pegram E, 2011:7).

### **2.6.2 Grant for older person**

This is applicable to people of 60 years or older.

### **2.6.3 Temporary disability grant**

Stroke survivors are initially issued with a disability grant for one year. This is to allow time for spontaneous recovery as well as the benefits of rehabilitation before the stroke survivor is issued with a permanent disability grant.

### **2.6.4 Grant-in-aid**

People receiving disability, older persons or war veterans' grants and who require full-time care are also eligible for a grant-in-aid.

### **2.6.5 Social relief of distress**

This grant provides temporary assistance for people in situations where they are awaiting payment for an approved grant and in situations of poverty where they cannot provide for their own or their families' most basic requirements.

All of the above mentioned grants are subject to a means test (South African Social Security Agency, 2011).

## **2.7 Summary**

This chapter has provided important background information relevant to the study. An explanation or description of various concepts and terminology utilised is given. Additional literature relevant to the findings of this study is discussed in Chapter 5.

## **Chapter 3 Study Methodology**

### **3.1 Introduction**

This chapter describes various components which pertain to the study methodology. Of relevance are the study design, quantitative and qualitative sampling procedure, instruments of measurement, the pilot study, data collection, ethical considerations and rigor.

### **3.2 Study Design**

This study is a descriptive study. It can further be classified as a mixed-method study as both quantitative and qualitative methodologies have been used in a sequential exploratory design, as described by Kroll, Neri and Muller (2005).

Joubert and Ehrlich (2007) comment on the usefulness of descriptive studies to health service planners. These studies can provide information that is helpful in developing appropriate services, allocating resources, deciding on priorities and deciding on which populations need to be targeted in terms of health care. Findings from this study signify whether or not rehabilitation in terms of *Healthcare 2010* has been successfully implemented in the Helderberg Basin, which falls within the boundaries of the Western Cape Department of Health.

Quantitative data was collected and analysed in the first phase of the study. Demographic details (e.g. age at last birthday, marital status, date of onset of stroke.) of the stroke survivor were documented. Further quantitative data was obtained through standardized tests, observation of the study participants, formal checklists, rating scales and use of questionnaires. This data indicates impairments, activity limitations, participation restrictions and rehabilitation outcome levels achieved by the study participants, as well as the environmental barriers encountered.

Qualitative methods, secondary to the quantitative data collection, were used to provide more in-depth information on the quantitative findings and environmental barriers and facilitators encountered by study participants.

### **3.3 Study Setting**

This study was conducted in the Helderberg Basin in the Western Cape, South Africa. The Helderberg Basin encompasses the following geographical areas: Somerset West, Garden Village, Helderzicht, Strand, Rusthof, Lwandle, Nomzamo, Gordon's Bay, Sir Lowry's Village, Macassar, Faure and Firgrove. The geographical boundaries of these areas were used to demarcate the setting.

In terms of healthcare, the Helderberg Basin falls within the eastern, sub-district H of the Western Cape. Two hospitals are situated in the Helderberg Basin. Vergelegen Medi-Clinic is a private hospital. Helderberg Hospital (previously known as the Hottentots Holland Hospital) falls under the jurisdiction of the Western Cape Department of Health, as do Macassar, Gustrouw and Strand CHC. Helderberg Hospital is a level 1 hospital, with ten level 2 beds available (Theron, 2011). Somerset West, Strand, Sir Lowry's Pass, Gordon's Bay and Ikwezi clinic are managed by City Health (Cape Town).

At primary level, there are some low-intensity rehabilitation services available for the uninsured in the Helderberg Basin. These are located at Helderberg Hospital, Macassar and Gustrouw CHCs. Until fairly recently there was only a physiotherapy post at Helderberg Hospital although for the last few years, an occupational therapist doing her community service year, has also been based at this institution. The employment of a full-time occupational therapist from January 2011 at Helderberg Hospital and the utilisation of the community service occupational therapist at Helderberg Hospital as well as Ikwezi, Gordon's Bay and Sir Lowry's Pass clinics can be considered positive steps. These services were established subsequent to the commencement of this study.

The occupational therapist and physiotherapist based at the CHCs, work four days per week at Macassar CHC and one day per week at Gustrouw CHC in the Strand. These therapists are treating clients with various diagnoses and are coping with an extremely demanding work load. At the commencement of the study it appeared that many people in need of rehabilitation were either not receiving it or only to a limited extent. Occupational therapy, speech therapy and psychological services in particular appeared to be lacking.

Intensive inpatient rehabilitation is provided at the WCRC which is approximately 44 kilometres from Somerset West. This service acts as a referral service for uninsured stroke survivors from the Helderberg Basin amongst other areas. However, the researcher considered that there were uninsured stroke survivors from the Helderberg Basin who should have been referred there but were not. In some cases, it appeared people had been referred but were not admitted. The researcher surmised this was related to the high patient load carried by WCRC (Hassan, 2009) and other environmental barriers, but the exact reasons were unknown.

### **3.4 Study Population**

The study population is composed of people living in the Helderberg Basin who had strokes in 2009 and 2010 and who accessed medical treatment and rehabilitation through the public health system. This particular time frame was chosen, partly as it coincided with the implementation of *Healthcare 2010* and, as such, provided useful information on the impact of that policy on current rehabilitation, health and

other services. Furthermore, the most spontaneous recovery would have taken place. According to literature, the most spontaneous recovery takes place in the first six-ten weeks after the onset of the stroke (Kwakkel, Kollen & Twisk, 2006). Green (2003) reports on the role of neuronal plasticity and that many stroke patients continue to demonstrate improvement up to six months after the incident. De Wit, Putman, Schuback, Komarek, Angst, Baert, Berman, Bogaerts, Brinkman, Connell, Dejaeger, Heys, Jenni, Kaske, Lesaffre, Leys, Lincoln, Louckx, Schupp, Smith and De Weerd (2007) state that the most functional and motor recovery occurs within the first six months post stroke. Due to the time frame of the study, one participant was evaluated five months post stroke and two of the participants were evaluated four months post stroke. All the other participants had their stroke at least six months prior to the evaluation. None of the participants were involved in active rehabilitation at the time of the assessments.

### **3.4.1 Inclusion criteria**

- Uninsured stroke survivors living in the Helderberg Basin who had strokes in 2009 or 2010.
- Uninsured stroke survivors living in the Helderberg Basin who were seen at Tygerberg Hospital, Groote Schuur Hospital, WCRC and other institutions which do not fall within the Helderberg Basin.

### **3.4.2 Exclusion criteria**

People were excluded in the following instances:

- Anyone under the age of 18 who has had a stroke;
- People who had strokes before 2009 and after 2010;
- Stroke survivors who received treatment at the Helderberg Hospital, but who resided in Grabouw or other geographical areas which do not form part of the Helderberg Basin. The researcher is not familiar with those environments or services available. Furthermore, it was decided that additional travel costs and time involved would militate against extending the geographical boundaries of the study;
- Stroke survivors who no longer lived in the Helderberg Basin;
- Stroke survivors who declined to take part in the study, or whom the researcher was not able to contact;
- Stroke survivors who received medical treatment and rehabilitation through private hospitals and private therapists;
- Stroke survivors seen at Helderberg Hospital who had limited medical insurance cover;
- Stroke survivors whose home language is not English /Afrikaans or Xhosa.

## **3.5 Sampling Procedure**

### **3.5.1 Phase 1: Quantitative sampling procedure**

The following paragraphs describe how the study population was identified and the sampling procedure utilised.

#### **3.5.1.1 Initial identification of the study population**

Permission was obtained from the Western Cape Department of Health to acquire names and contact details of uninsured people who had strokes in 2009 and 2010 from Helderberg Hospital and Macassar, Strand and Gustrouw CHCs. City Health Department (Cape Town) denied access to records at the various clinics falling under its jurisdiction. In order to ensure a list of names that was as comprehensive as possible, NGOs in the Helderberg Basin who work with stroke survivors were also contacted and asked to assist by providing names and contact details of people on their data-bases. HSSG and Masincedane Community Services assisted in this regard. A total of 326 names were obtained through all these avenues. The names of 59 stroke survivors were immediately excluded as they came from Grabouw and other locations outside the Helderberg Basin. This left the researcher with 267 names from which to sample 50. The researcher, in consultation with a statistician decided that approximately 50 participants would be used in the study. Evaluations and assessments would be detailed and time consuming and the researcher considered this to be the optimum number of participants to complete the study in the allocated time frame while ensuring a large enough sample to provide valid results.

#### **3.5.1.2 Sampling**

Proportional stratified random sampling was used. Strata were formed according to the geographical areas in which people lived. This choice of strata was used as the researcher wanted to ensure that participants from all communities in the Helderberg Basin were represented, including those areas where extreme poverty is experienced.

The following 5 strata were identified:

- A. Somerset West, Garden Village and Helderzicht
- B. Strand and Rusthof
- C. Sir Lowry's Pass Village and Gordon's Bay
- D. Lwandle, Nomzamo and Chris Nissan Park
- E. Macassar, Firgrove and Faure

The names of stroke survivors were placed alphabetically in each stratum and then numbered. Random numbers were drawn from each stratum using a computer-generated programme. This was done by a professor at the Centre for Statistical Consultation at the University of Stellenbosch. The final number of participants drawn from each stratum was proportional to the total number of names originally placed in each stratum.

Table 1 indicates the number of stroke survivors in each geographical area and the number of participants drawn per strata.

**Table 1: Sampling**

<b>Area</b>	<b>Geographical Area</b>	<b>Number of Stroke survivors in study period identified in area</b>	<b>Number of participants per stratum</b>	<b>Extra</b>
A.	Somerset West / Garden Village / Helderzicht	22	4	
B.	Strand / Rusthof	74	14	2
C.	Sir Lowry's Pass Village / Gordon's Bay	25	5	
D.	Lwandle / Nomzamo /Chris Nissan Park	41	8	
E.	Macassar / Firgrove / Faure.	105	20	
		267	51	53

Ultimately 16 participants were seen in the Strand /Rusthof area, bringing the total to 53. The extra two participants were included, as the community worker assisting the researcher had managed to locate these two stroke survivors who were next on the list and they were willing to participate. The statistician was contacted and he was of the opinion that the larger the sample, the more valid the results would be.

### **3.5.1.3 Further identification of study population**

Extra names were placed on a reserve list and numbered in order of the randomised draw. Where individuals declined to participate, failed to be contacted, were deceased or needed to be excluded in terms of the criteria for the study, the next person on the list was contacted.

Initial contact was made with those stroke survivors sampled to participate in the study in the following manner:

- Letters were sent by the researcher to the 51 participants whose names were sampled. This informed them about the study and enquired about their willingness to participate. People were asked to phone the researcher if they were willing to participate. As anticipated, not many people replied. The researcher assumed that some people don't have the finances to make telephone calls and some addresses were incomplete. Many people had died. However, as the researcher was not known to the subjects and does not work at facilities where they have been treated, a letter was provided to them with information to enable them to make an informed decision when the researcher followed up with a phone call. They thus had some knowledge of what the call or visit was about.
- Follow up was done via phone or through personal visits. Often telephone numbers which were listed did not exist. In most instances the researcher was accompanied by a community worker or person who was familiar with a particular geographical area. Sometimes the community worker went alone to the peoples' homes to establish whether or not they were willing to participate.

Due to the relatively high mortality rate (44 people had died), finding the 53 stroke survivors who ultimately participated in the study was more difficult and time consuming than originally anticipated. A total of 151 households were contacted to procure the 53 participants. Fifty people could either not be contacted as addresses and telephone numbers were incomplete or incorrect or they had to be excluded in terms of selection criteria for this study. Only four people who were eligible to take part in the study declined. This is illustrated in Table 2 below.

**Table 2: Number of households contacted to determine participants**

<b>Number of potential participants contacted who were deceased</b>	<b>Number of potential participants excluded as per selection criteria or could not be traced</b>	<b>Number who declined to take part in study</b>	<b>Final Number of participants</b>
44	50	4	53

### **3.5.2 Phase 2: Qualitative sampling procedure**

Purposive sampling was done for Phase 2 of the study. Five participants were selected whom the researcher believed could elucidate relevant information on the issues being investigated.

During Phase 1 of the study, the researcher kept a list of participants whom she considered would fulfil these criteria. One participant (who had been included in the pilot study) was selected for Phase 2, but excluded from Phase 1 as she had received a few private speech therapy sessions. As there was no speech

therapy available through the government services her employer had paid for her to have some private sessions. Her reason for consulting a private speech practitioner is pertinent to the study and as such, a decision was made to include her in Phase 2.

Two female and three male participants were selected. Ages ranged from 44 - 69 years of age. A participant from each rehabilitation outcomes level (from 1-5) was included. To cover as wide a range of experiences as possible, a heterogeneous group of participants were chosen.

### **3.6 Measuring Instruments**

Domholdt (2005) describes three broad categories of rehabilitation measurements which are generally used in research:

- Biophysiological measurements, obtained through the use of mechanical or electrical tools;
- Self-report measurements that require participants to give their own account of the phenomenon, for example standardised tests and interviews;
- Observational measurements. This is where the examiner will observe gait patterns or other movement strategies and may use formal checklists to organise these observations.

Observational and Self-Report measurements were used in this study and are described in more detail below.

#### **3.6.1 Phase 1**

##### **3.6.1.1 Data coding form (Appendix 1)**

A data coding form was developed by the researcher to record demographic data. This form was developed from various assessment forms that the researcher utilises in her private practice and from a survey form developed by the HSSG in 2008.

##### **3.6.1.2 Stroke Impact Scale Version 3.0 (SIS3) (Appendix 2)**

The Landon Center on Ageing at the University of Kansas Medical Center originally developed the SIS 2.0 based on feedback from stroke survivors. It measures the following aspects, which were found to be important to stroke survivors: strength, hand function, mobility, activities of daily living, emotion, memory, communication and social participation (Duncan, Bode, Lai & Perera, 2003). It was developed after intensive psychometric testing and after consultation with caregivers and stroke experts. Validity of the scale was established by comparing SIS scores to the Barthel Index, the Duke Mobility Scale, the Functional Independence Measure, Folstein Mini-Mental State Examination, NIH Stroke Scale, the Fugl Meyer and the Geriatric Depression Scale (Duncan, Wallace, Lai, Johnson, Embretson & Laster, 1999).



It was found to be valid and reliable measure and sensitive to changes in function (Duncan et al., 1999; StrokEngine Assess).

A Rasch analysis was then performed on a larger sample of individuals, which according to Duncan et al. (2003) provided further evidence of the validity of the Stroke Impact Scale. Five items were removed from the SIS 2.0 and the new version was called the SIS, version 3.0 (Duncan et al., 2003).

Prior to the commencement of this study, the researcher became aware of copy-right issues regarding the use of this measure. The developers of the SIS3 were contacted by email and the researcher was referred to the MAPI Institute in France. Special permission was obtained from this facility to have this measure translated into Afrikaans and IsiXhosa and to utilise it in the study (the researcher was required to pay for the costs of having the translations done.) The MAPI Institute requested that the translation involve both forward and backward translation from professional translators as well as clinical validation of the translation by rehabilitation professionals. Translations were done by the Language Centre at Stellenbosch University. Some modifications were made after discussion between the researcher and her two supervisors who assisted with the clinical validation. The one supervisor was fluent in Afrikaans and the other in IsiXhosa. With the necessary permission from the MAPI Institute in France to utilise this measure, the SIS3 should now be available in Afrikaans and IsiXhosa.

This measure is rated according to the stroke survivor's opinion. Scores are converted allowing for a minimal score of 0 and a maximum score of 100. Details of this conversion method are given in Appendix 2. Section 8 was particularly valuable in providing a measure indicating the current involvement of participants' in their previous life situations.

### **3.6.1.3 Barthel Activities of Daily Living Index (Appendix 3)**

The Barthel Index (BI) includes the ten most common areas included in Activity of Daily Living (ADL) Scales (i.e. personal hygiene, bathing self, feeding, toilet, stair climbing, dressing, bowel and bladder control, ambulation or wheelchair mobility and chair –bed transfers) (Wade, 1996). According to Wade (1996), the validity of the Barthel Index has been well established. Geyh, Kurt, Brockow, Cieza, Ewert, Omar and Resch, (2004b), reported that the BI was the domain-specific measurement used most often in stroke studies they researched. It should be noted that the Barthel Index was originally designed for use in Rehabilitation Centres and mobility refers to ambulation indoors (Wade1996; Shah, Vanclay and Cooper, 1989), and has been used accordingly in the current study.

Nevertheless, the researcher elected to use the MBI as, according to Shah et al. (1989) it increases the sensitivity of the score and in the researcher's opinion, made it easier to correlate findings with

rehabilitation outcome levels. Each item on the scale, as well as the whole index, is given a numerical score, with 100 being the maximum possible score. The researcher evaluated each participant according to the guidelines given by Shah et al. (1989) and the additional explanatory notes given by the Australian Government Department of Health on their website.

#### **3.6.1.4 Loewenstein Occupational Therapy Cognitive Assessment (LOTCA) (Appendix 4)**

Cognitive and perception impairments can be "hidden", with the stroke survivor and family often not being aware of them, or having no understanding of the problem. These impairments can have a devastating effect, resulting in activity limitations and participation restrictions. Where there are limited occupational therapy services, the focus of rehabilitation is often on physical problems, mobility and transfers. The researcher was of the opinion that it was extremely important that cognition and perception be evaluated in some depth in this study, as only limited occupational therapy services have been available to uninsured people in the Helderberg Basin and cognition and perception was an area that had in all likelihood been neglected.

It is the researcher's experience that many cognitive and perception tests have been criticized as not being applicable to the South African situation. However, the researcher believes the LOTCA uses material which could be understood by different ethnic groups and people with low education levels. Some tests (e.g. Chessington Occupational Therapy Neurological Assessment Battery -COTNAB) are extremely costly and time consuming to administer. Taking all these factors into account, the researcher decided that the LOTCA was the best option to use.

The LOTCA is divided into six main areas: orientation, visual perception, spatial perception, motor praxis, visuomotor organization and thinking operations. (Refer to Appendix 4 for scoring of this measure.)

The LOTCA was a useful measure to use. It was developed for use with clients with some form of brain injury and stroke is specifically mentioned in the test manual. Measures have been put in place to make it possible for stroke survivors with both expressive and receptive communication problems to participate in the test. Caregivers who accompanied aphasic participants expressed surprise at how well they performed on certain tests. Often the focus of cognitive and perceptual tests is to screen for impairments but, particularly in the case of aphasic stroke survivors, it revealed their abilities.

#### **3.6.1.5 Measurement of speech and language (Appendix 5)**

With extremely limited speech therapy available to uninsured stroke survivors in the Helderberg Basin, it was very likely that participants had received minimal help in regard to problems with reading, writing

and doing calculations. In terms of time, it was not possible to complete a full test battery such as the Western Aphasia Battery (WAB). Wade (1996) commented that the section of the Mini-Mental State Examination (MMSE) which specifically tests for language skills is considered adequate in certain situations.

Based on the researcher's experience over the past twenty years in conducting detailed evaluations on stroke survivors, she modified this section of the MMSE by adding additional material from the WAB to increase the validity of the test. The researcher is of the opinion that when one question is asked, as is the case in the MMSE, there can be a number of reasons why a participant could make an error, but if the same results are obtained with three questions, the test is more reliable. One of the objectives of the study was to obtain an indication of whether or not there are uninsured stroke survivors with speech and language difficulties, who would benefit from the intervention of a speech therapist. The researcher is of the opinion that this modified screening test combined with Section 4 of the SIS3 would provide adequate information in this regard. However, it should be noted that it was not tested for reliability and validity, and more detailed evaluations by a speech therapist, utilising a standardised test such as the WAB would increase the sensitivity of the scores. (Refer to Appendix 5 for scoring of the speech and language test utilised in this study.)

### **3.6.1.6 Measurement of environmental factors: (See Appendix 6)**

From the literature research, there are currently four measures generally used to determine environmental barriers and facilitators. The first is the Craig Hospital Inventory of Environmental Factors (CHIEF), (COMBI, 2006). Whiteneck, Gerhardt and Cusick (2004) utilised this in a study on environmental factors impacting on people with traumatic brain injury. The other three measures are the Facilitators and Barriers Survey (FABS), (Gray et al., 2008); Measures of the Quality of the Environment (MQE), (Rochette, Desrosiers & Noreau, 2001) and the International Classification of Functioning Core Set for Stroke (Geyh, Cieza, Schouten, Dickson, Frommelt, Omar, Kostanjsek, Ring and Stucki, 2004a; World Health Organisation, 2004a).

The section on environmental factors from the *Comprehensive ICF Core Set for Stroke* was used in this study. This is a list of environmental factors that are assumed to be important to most stroke survivors. It was determined by 39 experts on stroke, from 12 different countries, after a systematic review, a Delphi exercise, empirical data collection and training in ICF was completed. Thirty three categories have been included, which cover all five sections of environmental factors listed by the ICF. The experts considered this necessary as they recognised the influence these factors have in determining stroke outcomes. It "demonstrates the awareness of the important influence of patient's surroundings and life situations on their health and also on the course of rehabilitation" (Geyh et al, 2004a:139).

For scoring, responses range from:

- Barriers: mild, moderate, severe, complete, scored as minus 1 to minus 4 respectively.
- Facilitators: mild, moderate, substantial, complete, scored as 1 to 4 respectively.
- No influence on the patient's life is scored as 0.

There are two optional responses: 8 (not specified.) and 9 (not applicable.) The researcher added 10 as a further score. This was used when participants lacked knowledge of the particular environmental factor; for example where participants had no knowledge of labour or health policies and were therefore unable to comment on them or where participants had difficulty understanding the concepts of "barriers and facilitators". Appendix 6b was used to assist participants in deciding on the score they wanted.

All participants were given the same examples for each ICF code, so there was a clear understanding of what was meant or required.

### **3.6.1.7 Determining outcome levels**

In determining outcome levels, results pertaining to impairments, activity limitations and participation restrictions of participants were analysed. Contextual factors were also taken into account by analysing the data coding form which provided information on the demographic and health status of participants and rehabilitation. Results from the ICF Core Set for Stroke were also considered. Outcome levels as described by Landrum et al (1995) were utilised and participants categorised accordingly. A framework developed by Visagie (2010) giving a summary of each level described by Landrum et al. (1995) also provided a useful tool for categorizing outcome levels.

The researcher determined all outcome levels in this study herself.

### **3.6.2 Phase 2 (Interview schedule Appendix 9)**

Participants and proxy respondents were interviewed, using semi-structured interviews with open ended questions. The structure of the interviews was completed, once the quantitative data had been provisionally analysed. Questions focussed on risk factors for stroke and basic management of medical conditions which play a key role and form the foundation in determining which rehabilitation outcome level is achieved. Further questions focussed on rehabilitation, environmental barriers faced by uninsured stroke survivors and recommendations for improving services.

## **3.7 Pilot Study**

A pilot study was undertaken in January and February 2011. Five participants were selected from community groups with which the researcher is involved through the HSSG and invited to take part in the

study. The pilot study was conducted on four uninsured stroke survivors who had their stroke prior to 2009 and one who suffered a stroke in 2010. All lived in the same communities as participants who took part in the main study.

To ensure that the various measuring tools were adequately tested three participants whose right side of the body was affected and two whose left side was affected were selected. One participant had aphasia, which provided the opportunity to work with a proxy respondent and to determine the effectiveness of the language measurement (Appendix 5). One IsiXhosa speaking stroke survivor was included. This provided the opportunity to evaluate the translator's skill and provide her with guidance on what was required of her. It was also an opportunity to discuss ethics and issues of confidentiality with the translator.

Further importance of the pilot study was:

- To determine the length of time it would take to do all the evaluations and complete the questionnaires;
- To see if any questions were unclear and needed changing;
- To get feedback from participants about the length of the evaluation;
- To determine the order in which tests should be done;
- To determine if coding systems and methods of recording data were effective or if any amendments needed to be made in this regard;
- To see if data gathered would satisfy the aim and objectives of the study;
- To determine if examples given with the ICF Core Set for Stroke helped people to understand the concepts on which they needed to comment, in terms of barriers or facilitators.

On completion of the pilot study some amendments and additions were made to the demographics form. Further reading was done and discussion held with various people to overcome difficulties with scoring for the ICF Core Set for Stroke.

## **3.8 Data Collection**

### **3.8.1 Phase 1 data collection**

- On initial contact with participants, provisional consent to take part in the study was obtained. Appointments were set up with them at a venue and time convenient to them. At the first meeting, the study was explained to them and an authorised care-giver where there was any concern about the competency of the participant. (Issues related to competency are discussed further under 3.10 Ethical Considerations.) Once they had an understanding of the study and indicated their

willingness to participate, they were asked to sign a written consent form. In some cases, these forms were left with the potential participant so they could let family members who were possibly not available read through them, before signing (Appendix7).

- The researcher had envisioned conducting most of the interviews and evaluations at the home of the participants. However, when participants were given a choice, the majority of them opted to be seen at a central venue in Macassar or Somerset West. Many of the participants never leave their homes, besides going to appointments at the CHC or clinic or to collect their pension or disability grant. Apart from the importance of taking part in the research, it was also seen as an opportunity to do something different and to go on an outing. (Participation by stroke survivors in the community and society will be discussed further in the study.) Participants who wanted the evaluation conducted at their homes; were bedridden or had extreme difficulty doing transfers into a vehicle were seen in their home environment. Two respondents expressed concern about the personal safety of the researcher if she collected them from home and opted to utilise taxi services to get to the main terminal in Somerset West. The researcher paid the fare for the participants and a caregiver and collected them by car at the terminal and returned them there after the interviews and evaluation. All other participants were collected at their homes by the researcher and driven back on completion of the evaluation.
- Although the majority of the formal evaluations and interviews for the study were done at a central venue in Somerset West or Macassar, the researcher did have the opportunity to see 51 of the participants at their homes, either when making initial contact or when fetching them for the consultation. This provided valuable information on their home environment, surroundings and environmental barriers encountered. It also afforded the researcher the opportunity to observe gait, wheelchair mobility, ability to transfer in an informal manner and provided valuable insight into how stroke survivors were coping in their home environment. Conversation in the informal setting of the vehicle en route to the consultation or taking the participants home, also provided a wealth of background information. The researcher used all contact time with the participant and their families as part of the evaluation and gathering of information.
- The researcher conducted all the interviews and administered all the questionnaires and data coding forms. Although the researcher speaks a limited amount of IsiXhosa and has a reasonably good understanding of the language, a translator was used with IsiXhosa-speaking participants to ensure questions were clearly understood and that the researcher interpreted the answers correctly.
- As far as possible self-reporting by the index person (i.e. stroke survivor) was used. However, collateral information from family is extremely important and at times, it was necessary to verify information with family members. Although the researcher is experienced in working with stroke

survivors with aphasia, proxy respondents were used to assist participants with this condition. A mentally impaired stroke survivor required his sister to be the proxy respondent. Other than when a proxy respondent was required or where the competency of the stroke survivor was of concern, participants were given the choice of attending the consultation on their own, or bringing a family member with them.

- At the commencement of each session, participants were informed about what would occur and that at any time they could ask for a break, complete the session on another day or withdraw from the study if they wanted to. Interviews and evaluations were conducted in the following order: explanation and signing of Patient Information Leaflet, where this had not already been done; demographics form; SIS 3; Modified Barthel Index; LOTCA and then the Speech and Language Test. A short break (15 -30 minutes) was given after the Language Test to allow participants to use the toilet and have a cool drink. Sessions concluded with the questionnaire on Environmental Factors. This order was decided on in conjunction with participants in the pilot study. Starting with the demographics form and SIS3 afforded participants the opportunity to share information about themselves and how the stroke had affected them, and, according to pilot study participants this made them feel comfortable and at ease with the researcher, before more formal testing occurred. They found it positive to finish with the questions on environmental factors. They appreciated being afforded the opportunity to express their views on services and issues that were a barrier to them and reported that concluding sessions with questions on environmental factors left them with a positive feeling about the research and that someone was interested in their well being.
- Test results and other scores were recorded on the relevant forms and data coding sheets.
- Sessions took approximately three to three and a half hours.

### **3.8.2 Phase 2 data collection**

The five participants were contacted by telephone or visited at their homes and invited to participate. Two of the interviews were done at the participants' homes. The other three were conducted at a central venue in Somerset West and Macassar. The level 1, 2 and 3 participants had their spouses present who acted as proxy respondents. These participants were encouraged to participate in any way they could. In the case of the level 3 client who was aphasic, measures were put in place to ensure that she could let her opinion be known. (e.g. put up her hand if she did not agree with her husband). The level 4 and 5 participants were unaccompanied. Interviews were recorded with a voice recorder. Permission for this is requested on the written consent form. (Appendix 7)

## **3.9 Data Analysis**

### **3.9.1 Phase 1: Analysis of quantitative data**

All data from the demographic questionnaire, SIS3, MBI, LOTCA, Measurement of Language and Measurement of Environmental Factors forms as well as the Rehabilitation Outcomes Levels were entered on Excel spreadsheets. A statistician was consulted and statistical tools used to interpret data.

Descriptive statistics were based on the concepts of central tendency and variability. The statistical foundations of measurement theory as described by Domholdt (2005), was utilised. (i.e. frequency, distribution, mean, variance, standard deviation, normal curve, correlation coefficient, and standard error of measurement.)

### **3.9.2 Phase 2: Analysis of qualitative data**

Data was transcribed by the researcher. In order to protect the identity of the participants additional assistance was not utilised in this regard.

The researcher listened to the recordings and read through the transcribed interviews several times. Data was then coded and organized into the following predetermined themes determined from the quantitative data:

- General knowledge of risk factors for stroke;
- Knowledge and awareness of hypertension as a risk factor;
- Awareness of diabetes as a risk factor for stroke and knowledge of treatment;
- Adherence to medication;
- Knowledge and awareness of importance of lifestyle changes in primary and secondary prevention of stroke;
- Recommendations of participants and caregivers in terms of health and life style changes;
- Counselling, education and training received in terms of primary and secondary prevention of stroke;
- Referral system for rehabilitation;
- Rehabilitation received;
- Awareness of role of various rehabilitation professionals;
- Counselling, education and training received in terms of rehabilitation.

Further sub-themes were identified within these predetermined themes.



This qualitative data was then discussed in terms of its relationship to the quantitative data. Quotes from the interviews were used to illustrate and highlight the main findings of this study.

### **3.10 Ethical Considerations**

- Approval for this study was obtained from the Committee for Human Research at Stellenbosch University. (Ethics Reference Nr: N10/11/375).
- Special permission was obtained from the Western Cape Department of Health to acquire the names and contact details of people who had strokes in 2009 and 2010 from Helderberg Hospital and Macassar and Gustrouw CHC. (Reference Nr: RP 140 /2010) Guidelines given by the Department of Health were adhered to.
- The principles of the *South African Guidelines for Good Clinical Practice* (SA GCP) were applied (Moodley, 2009). The key elements are obtaining informed consent and ensuring the privacy and confidentiality of information concerning participants.
- Information about the study and consent forms were given to participants in their home language. (Appendix7.) Special consideration was given in determining the competence of the stroke survivor to make an informed decision about participation in the study. Although many stroke survivors are capable of making informed decisions, certain impairments as a result of the stroke can affect a person's ability to do this (e.g. memory problems and problems with understanding the written and spoken word.) The researcher does have experience in this regard. Through her work as an occupational therapist, she has been involved with doing medico- legal reports and evaluations to determine if someone has the ability to live independently, can manage their own affairs, drive or return to work after a stroke.
- In certain instances where the person was not able to give consent, proxy consent by an authorised caregiver was also requested (Appendix 7). Where proxy consent was given, the researcher also obtained an indication from the subject as to their willingness to participate. Many stroke survivors have communication problems, but can understand what is being said to them and can give an indication of their wishes.
- The researcher ensured that participants could not be identified in any way from research records (forms, questionnaires, tape recordings) by using a research number on forms. Data was stored in a locked filing cabinet in the researcher's office. All data stored on the researcher's computer was password-protected. The translator and community workers who accompanied the researcher had to sign a declaration stating that they would not disclose any information about the participant.

- Where the researcher concluded that a participant could benefit from further therapy, or required additional equipment, this was discussed and the necessary information and contact details were provided. Information on NGOs in the community who could give assistance was also given.
- At all times the wellbeing of the participants was taken into account and the stroke survivors and their families were treated with respect and courtesy.

## **3.11 Rigor**

### **3.11.1 Phase 1**

The validity of a research project is judged by the extent to which conclusions are believable and useful. Validity can be defined as accuracy or how close one gets to the truth. Bias can be defined as error that comes into the study via various means and can to a certain extent be controlled by the researcher (Domholdt 2005).

Besides the factors mentioned below, additional commentary on limitations to the study are given in Chapter 4 with the presentation of the results and in Chapter 6.

Selection bias can influence the validity of a study. For this reason, the researcher required the names and contact details of as many uninsured people who had strokes in 2009 and 2010 as possible. By working through hospitals, CHCs and NGOs it was presumed that most uninsured stroke survivors would be accounted for. In addition, stratified random sampling was used in the study, to ensure that a general picture of the outcome levels of uninsured stroke survivors in the Helderberg Basin was obtained. In some communities health services might have been of a higher standard and without stratified random sampling a wrong impression could be created.

It is generally accepted that the larger the sample, the greater the validity of a study. Although 53 participants may be considered a relatively small sample, the researcher is of the opinion that a reliable indication of rehabilitation outcomes of uninsured stroke survivors was obtained and that the in-depth evaluations which were conducted have provided useful information on factors which have previously been unexplored in uninsured stroke survivors in the Helderberg Basin

Information bias can occur when there is an error in collecting data or measurements are taken incorrectly. The Modified Barthel Index and LOTCA are all well known rehabilitation measurements. The LOTCA is a standardised test. Error can come in with the LOTCA and the language evaluation if clients are not seated correctly for the tests, lighting is poor and people who normally wear glasses do not use them for the tests. Of some concern in this regard was the number of participants who did not have

reading glasses and who the researcher believed required vision testing. However, items which did have to be read were given to all participants in large print.

Education of clients also needs to be taken into account. If this is not done, bias can come in. (e.g. where someone is illiterate and has never learned to read or write. The researcher may test them and document the reading problem to be an activity limitation after the stroke, which is incorrect.) It is possible that some bias may have occurred in this regard; however, the researcher is of the opinion that material used in the LOTCA and Speech and Language evaluation should have been understood by most participants.

It is also possible that an element of information bias occurred with the ICF core set for stroke, where people were questioned about the amount of assistance received from and attitudes of immediate family. In some cases, family /caregivers were present and the stroke survivor may have been reticent about giving a negative answer, for fear of reprisal.

Consistency of the rater (intra-rater) can result in bias. Items in the Modified Barthel Index cover fairly broad categories, making the likelihood of inconsistency amongst raters less than when each item being measured is more specific and detailed. With regard to rehabilitation outcomes, unresolved issues at lower levels created some difficulty in determining categories, which according to Landrum et al. (1995) should occur chronologically. Practically, it was not possible to get other therapists to take measures and compare with the researcher's results. It is possible that this resulted in some bias. These factors will be discussed in more detail in Chapter 6, under recommendations.

In selecting the correct measure to determine environmental barriers and facilitators, content validation was of concern. Content validation can be defined as "the extent to which a measure is a complete representation of the concept of interest" (Domholdt, 2005:260). Initially, the researcher considered using the short form of the CHIEF, as it is very quick and easy to administer, but was concerned that it would not give a true reflection of environmental factors in the Helderberg Basin. The comprehensive ICF Core Set for Stroke was utilised. Again, the researcher was concerned that where the ICF category titles (see Appendix 6) might be totally understood in developed countries, they might not be understood in circumstances where a person has had very little education. To counteract this, examples were given and the same examples used for all participants.

### **3.11.2 Phase 2**

Verification of qualitative data is generally done through triangulation of results, the use of multiple researchers to code data independently, member checking or to have an outside researcher audit the analysis (Joubert & Ehrlich, 2007).

In this study, verification of results from Phase 2 was done by triangulation and member checking by one of the participants. Domholdt (2005: 179) states that triangulation is conducted by "comparing multiple sources of information to determine whether they all point to similar conclusions." Findings correlate with feedback that stroke survivors and representatives from various communities have been giving to the committee of the HSSG.

## Chapter 4 Results

### 4.1 Introduction

In this chapter the study results are presented; these correlate with the objectives of the study. Section 4.2 lists results pertaining to the demographic profile of the participants and Section 4.3 their health status. Findings on impairments, activity limitations, participation restrictions and rehabilitation outcome levels are presented in section 4.4, to 4.7. Findings related to environmental factors are presented in Section 4.8 and those relevant to rehabilitation are in Section 4.9. The methods of scoring for the various measures can be found in the Appendices. It should also be noted that percentages have been rounded.

### 4.2 Demographic Profile of Participants

#### 4.2.1 Age and gender

The youngest participant was 29 years of age and the oldest was 94. The majority of the participants were over 60 years of age; the mean age was 62.56 (Figure 4.1). Twenty-nine (55%) of the participants were male and 24 (45%) were female.

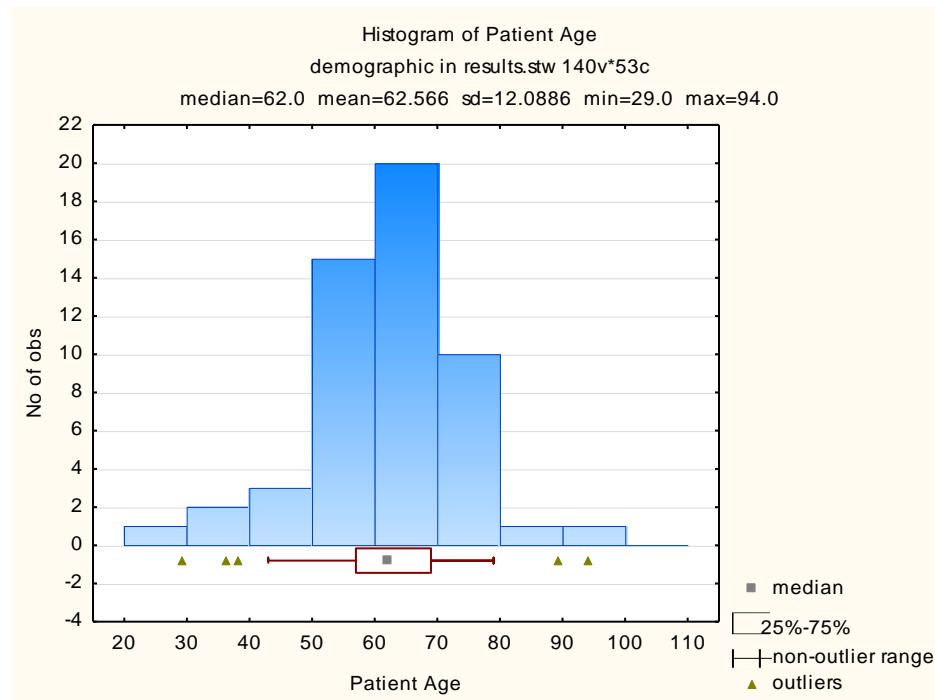


Figure 4. 1 Participant age (N =53)

### 4.2.2 Education

Eighteen (34%) participants fell into the Grades 4-7 education level, 16 (30%) into the Grade 8-11 level and six (11%) had no formal education. Four (8%) of participants had a matriculation certificate and three (6%) some form of tertiary education (Figure 4.2). Three participants with no formal education reported teaching themselves to read and write. One explained she had learned with her children: once she had helped her ten children with their primary school homework, she was able to read her bible and do simple calculations.

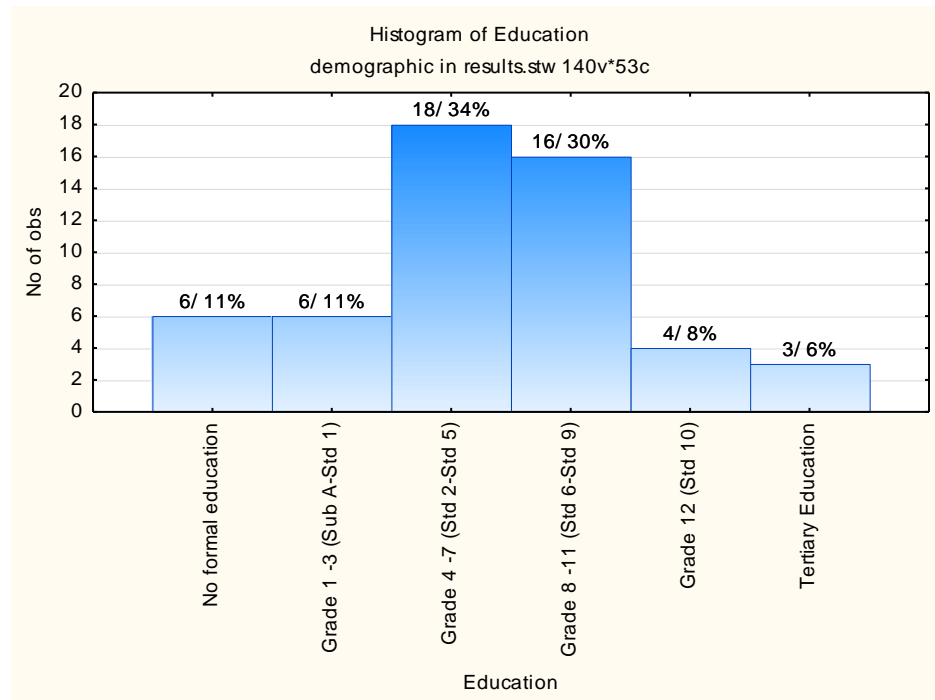


Figure 4. 2 Education level of participants (N=53)

### 4.2.3 Marital status

Twenty-seven (51%) of the participants were married. Seventeen (32%) were widows or widowers, six (11%) were single. Two (4%) were living together and one (2%) was divorced.

### 4.2.4 Minor children

Nine (17%) participants had children who were still under 18 years of age. This question was originally included to assess how many participants were still responsible for supporting children after their stroke. However, in retrospect, it would have been more to the point to determine the number of people living in one household or on one property, as it soon became apparent that the majority of participants were living

with extended family, many of whom were unemployed. In many instances, the pension or disability grant of the participant played an important role in supporting the extended family unit.

#### **4.2.5 Language and population group**

Forty- four (83%) participants were from the Coloured population group, seven (13%) were Black and two (4%) were White. Forty-four (83%) were Afrikaans speaking and seven (13%) IsiXhosa. Two (4%) of the participants' home language was English.

#### 4.2.6 Employment

Four participants were employed (Figure 4.3). A 44-year old female and a 65-year old male resumed full-time employment, performing the same job descriptions as prior to the stroke. One female participant of 43 years had temporary employment for a few hours each day. A 73-year old male who had taken on a part-time job to supplement his income, had found it necessary to further reduce his work hours after the stroke.

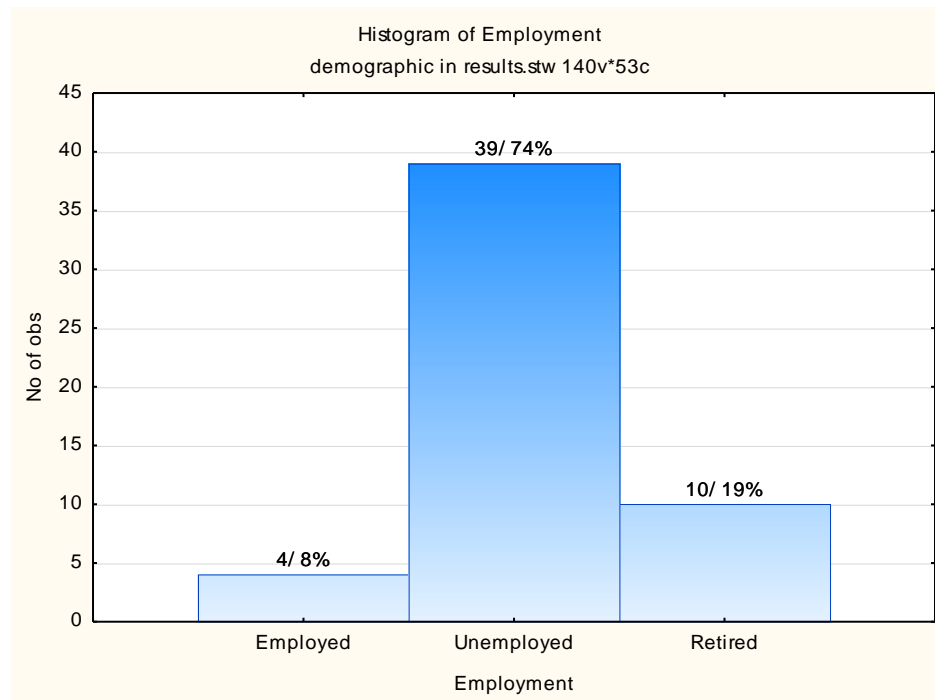
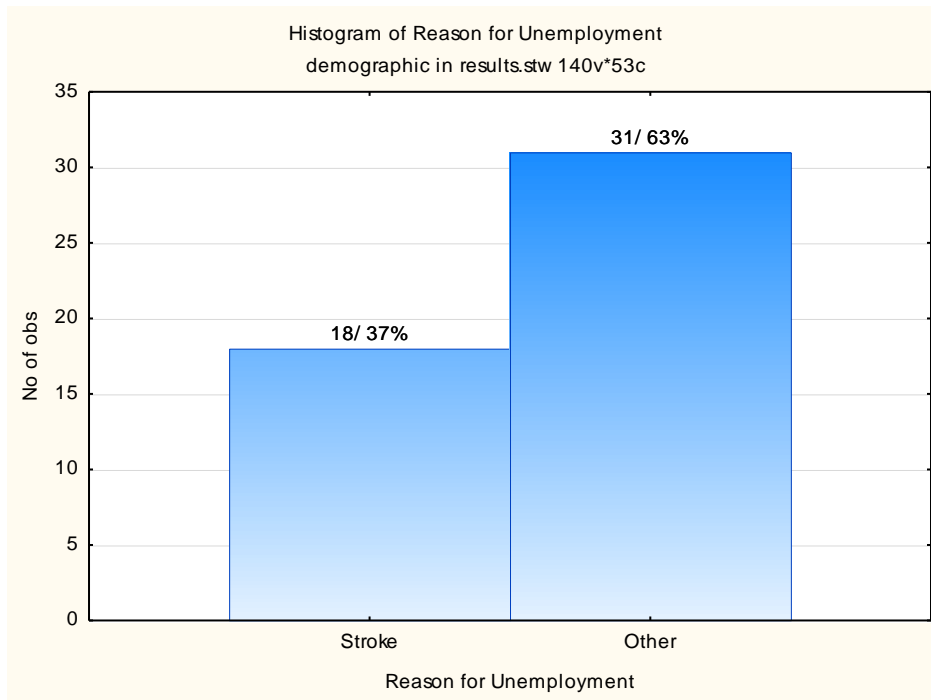


Figure 4. 3 Employment status of participants (N=53)

At the time of this survey, 39 (74%) of the participants were unemployed. Figure 4.4 shows that stroke was the cause of unemployment in 18 (37%) of these cases. Sixteen participants had been housewives prior to the stroke and although they were not receiving remuneration for their work, had been actively contributing to the wellbeing of their households. Of these, two were attempting some house hold tasks, but were requiring input from family members. A 36-year old woman who had received rehabilitation at WCRC required minimal assistance with cooking, and other domestic activities. Two participants had been boarded due to other medical conditions which occurred before the stroke, and three had been retrenched prior to the stroke. Ten (19%) had already retired at the time of the stroke.

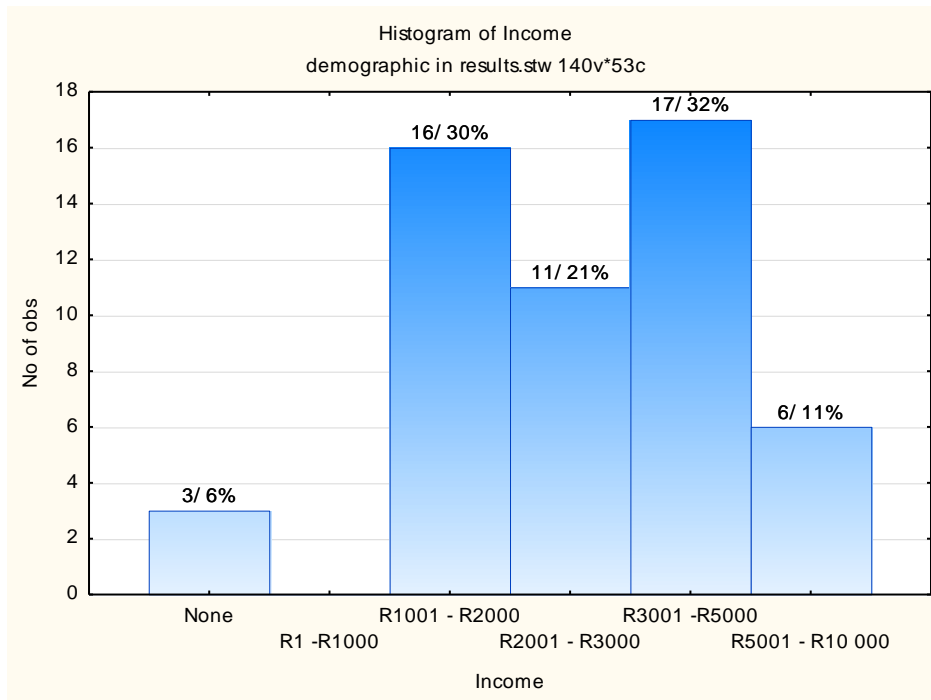




**Figure 4. 4 Stroke as cause of unemployment (N=53)**

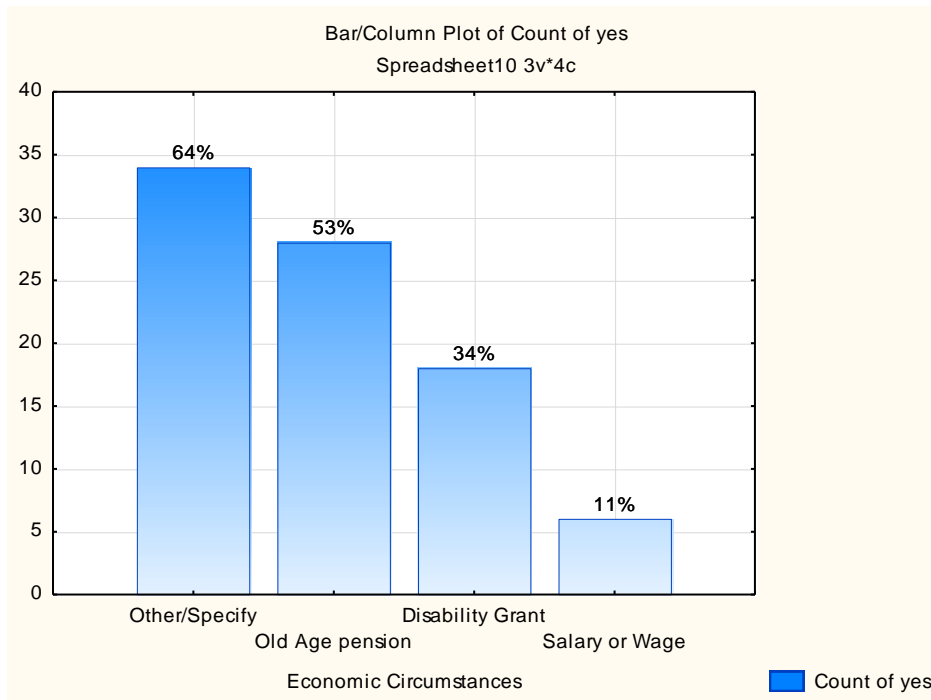
#### **4.2.7 Income**

Generally, income was pooled to support the inhabitants living on a particular plot or in a particular home. At times, there could be up to ten people residing on one plot. The majority of households (57%) were living on less than R3000 per month and of these, 16 (30%) were living on R1001 – R2000 per month. 11 (21%) were living on R2001 –R3000 per month and 3(6%) had no income at all (Figure 4.5).



**Figure 4. 5 Income of family unit (N=53)**

Income was generated through disability grants, state pensions (old age pension), income of spouses and family members living on the same property as the stroke survivor and the salaries of the four stroke survivors who were employed (Figure 4.6). In addition 64% of these family units were also supported by extended family who were not residing on the same property, received a pension from previous employment or had some form of savings.



**Figure 4. 6 Source of income**

Of the participants with no income, one was a builder and plumber prior to the stroke. Although he had recovered well physically, he had found it difficult to resume work. Testing with the LOTCA revealed cognitive and perceptual impairments which would have impacted on his work. He was being supported by his religious community. In the other two cases, a disability grant and pension payout were pending. A community feeding scheme and family members were assisting with supplying food. The one participant in particular, would have benefitted from a social relief of distress grant.

### 4.2.8 Housing

Forty five (85%) participants were living in the same home or on the same plot as other family members. Three (6%) were residing with their spouse and two (4%) with friends. Of the remaining three participants, two were residing alone and one was in a boarding care facility (Figure 4.7). The families of the participants living independently expressed their concern about their parents being alone at night.

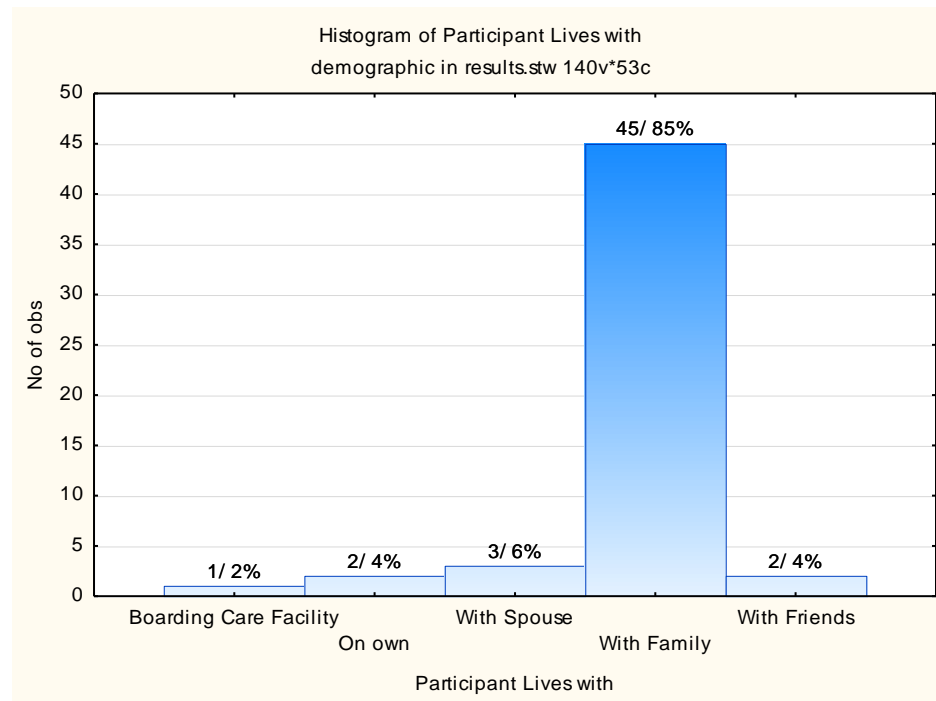
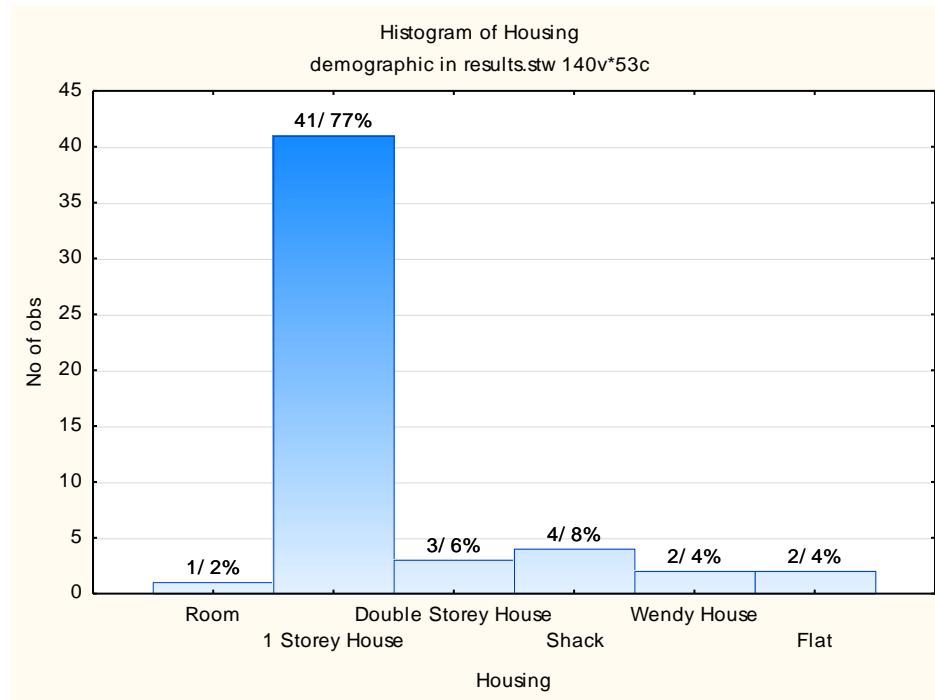


Figure 4. 7 Household information (N=53)

Figure 4.8 shows that 41 (77%) of participants were living in single storey houses. Many of these were supplied through the Reconstruction and Development Programme (RDP). Often extra rooms were added using wood and scrap material. In many cases, Wendy houses had been set up around the main housing structure, to provide extra accommodation for family members.



**Figure 4. 8 Type of housing of participants (N=53)**

Two (4%) of the participants were living in flats on the second or third storey. The only access to the flats was by using the stairs, which these stroke survivors found to be a barrier. Three people resided in double storey homes, one of whom was permanently bedridden. The family found it impossible to carry her up and down the stairs for appointments, and her bed had been moved downstairs in to the lounge, which was the main access room to the house and afforded her no privacy. For the other two, the stairs were initially a barrier, but with time they learned to manage them. The remaining six participants were living in shacks or in Wendy houses on the same property as family members or friends. One participant had been given a room in a residence for homeless people.

#### 4.2.8.1 Accessibility

Figure 4.9 shows that 74% of the homes had steps. This varied from the flights of stairs mentioned above to a step at the front or back door, which was still a barrier for participants in wheelchairs and to stroke survivors with poor walking balance. Houses were generally small and crowded and in 70% of cases, there was insufficient space to manoeuvre wheelchairs and walkers. In a number of homes (13%) the doors were not wide enough for a wheelchair. One participant was confined to her bedroom, because it was extremely difficult to get through the bedroom door with her wheelchair and she was unable to walk.

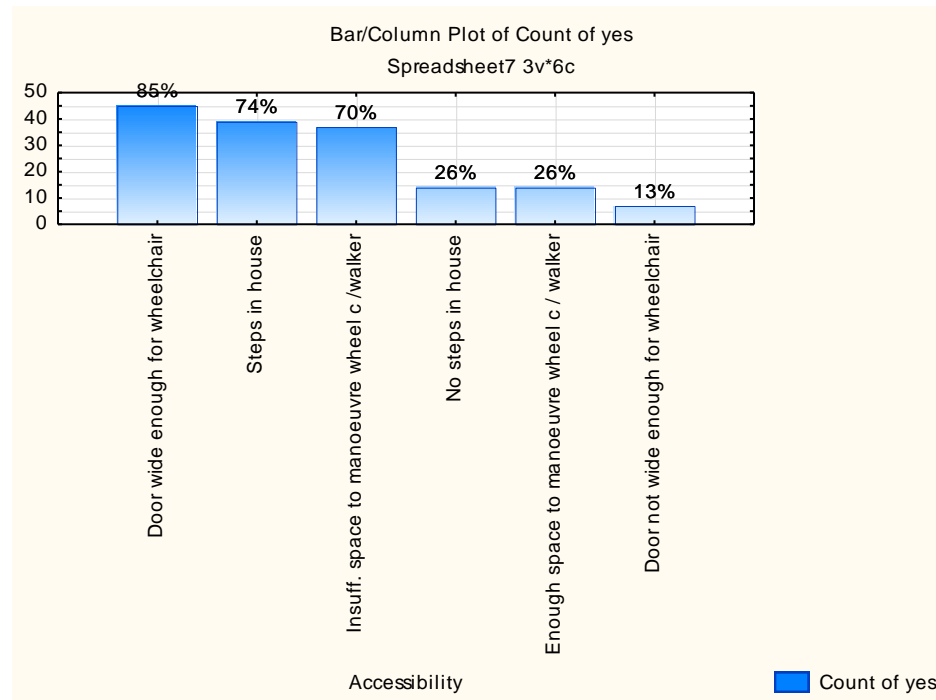


Figure 4. 9 Accessibility of housing

#### 4.2.8.2 Toilet facilities

Forty-four (83%) of the homes visited had indoor toilets (Figure 4.10). Two (4%) participants were living in Wendy houses with the toilet in the main dwelling on the property. One participant in particular would have benefitted from having a commode in the Wendy house and a ramp going into the main house to make access to the toilet easier. Seven (13%) had to make use of toilet facilities outdoors and would also have benefitted from being supplied with commodes.

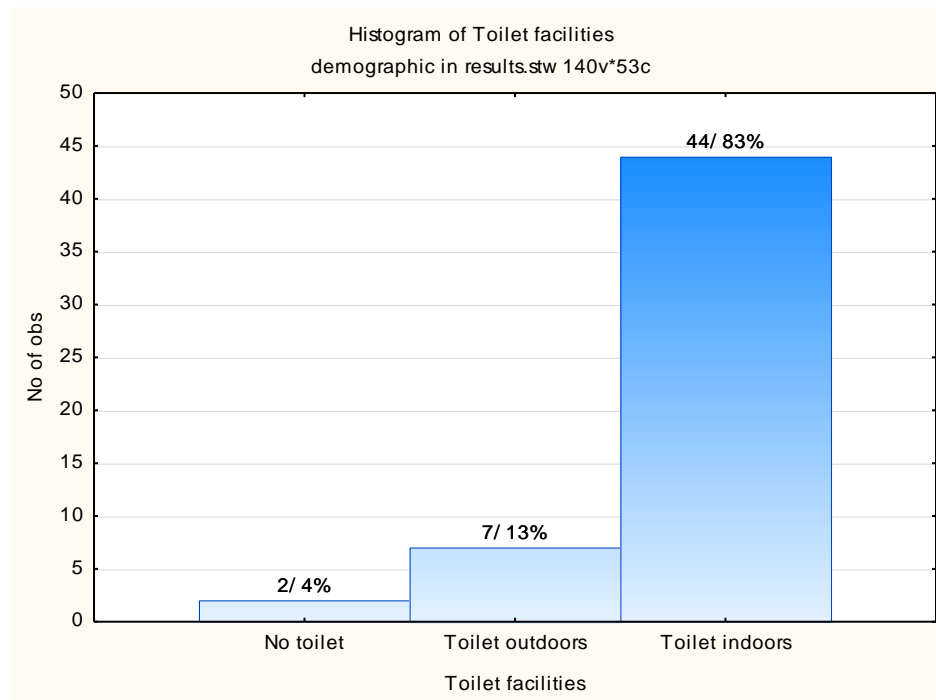


Figure 4. 10 Toilet Facilities at homes of participants (N=53)

#### 4.2.8.3 Power

All 53 participants had access to electrical power on their properties.

#### 4.2.8.4 Water

Ninety-eight percent of participants had access to running water in their homes. However, free quotas of water were used up quickly in large households. Many participants mentioned problems with insufficient water supplies and having to make arrangements with the municipality as they did not have the finances to pay for additional usage. One care giver whose husband was bedridden and incontinent reported how difficult it was to wash all his linen with the limited amount of free water available. Fifty-seven percent of the homes had a bath and 21% had a shower. However, in most cases participants used a basin, as they found it too difficult to get into a shower or bath, and also to save on water.

#### 4.2.8.5 Terrain

Figure 4.11 shows that the majority of homes were surrounded by loose sand (51%) or hard soil (38%). The ground was often uneven, making it difficult to manoeuvre wheelchairs or walk, particularly in cases where balance was poor or the stroke survivor had sensory or proprioceptive impairments. Elderly caregivers in particular found it difficult to push wheelchairs in rough terrain and through sand.

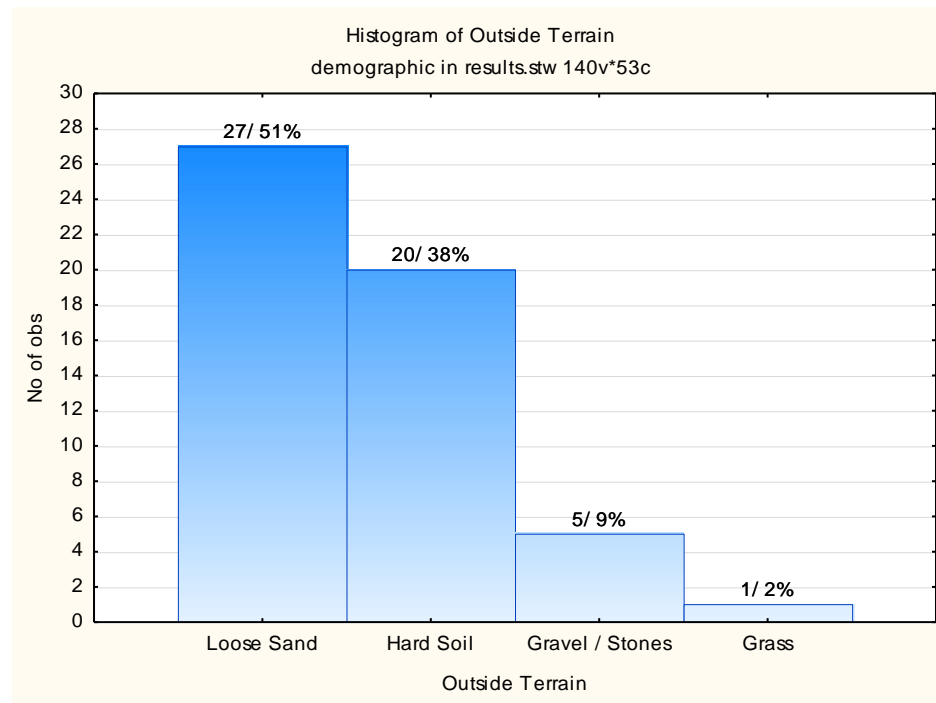


Figure 4. 11 Terrain outside participants' homes (N=53)



### 4.3 Health Status Of Participants

#### 4.3.1. Number of strokes

According to figure 4.12, thirty three (62%) of participants reported the stroke as being the first incident. For 15 (28%) it was their second stroke and five of the participants had had multiple incidents. Fifteen (28%) participants had their stroke in 2009 and 38 (72%) in 2010.

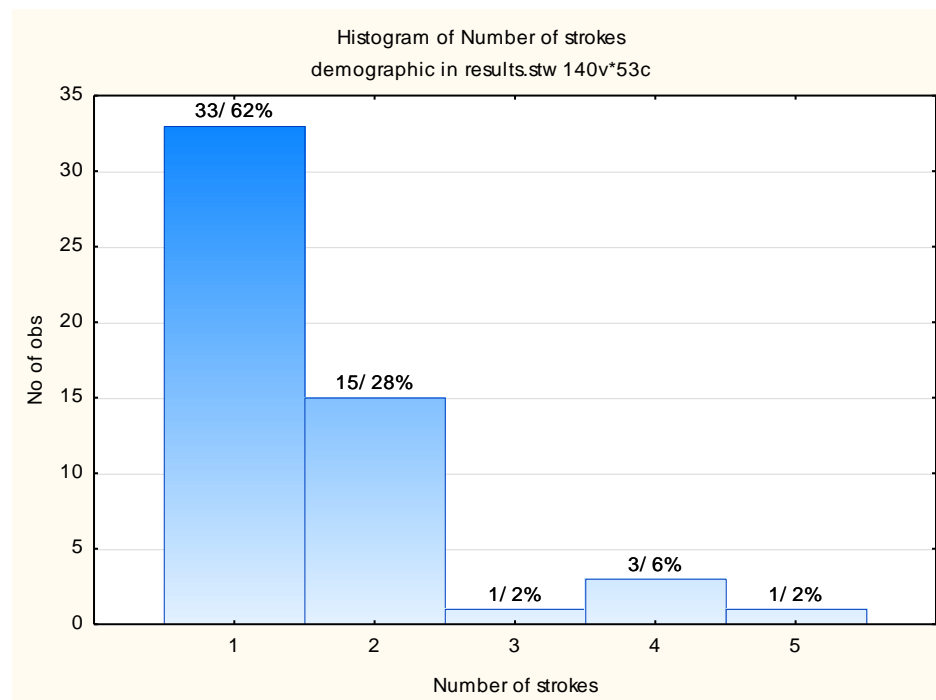


Figure 4. 12 Number of strokes suffered by each participant (N=53)

### 4.3.2 Medical conditions of participants

Figure 4.13 indicates that 85% of the participants reported they suffered from hypertension. In addition, 40% said they had high cholesterol and 38% reported a history of heart disease. Thirty-two percent of the participants were diabetic. These percentages could be higher. Many of the participants had no knowledge of cholesterol and were uncertain of their risk factors for stroke. In some cases, the researcher had to examine the medication that participants were taking, in order to determine their health status. Eleven percent of the participants reported having seizures. Amongst other conditions, eight of the participants suffered from arthritis and three participants reported having HIV and TB in addition to the stroke.

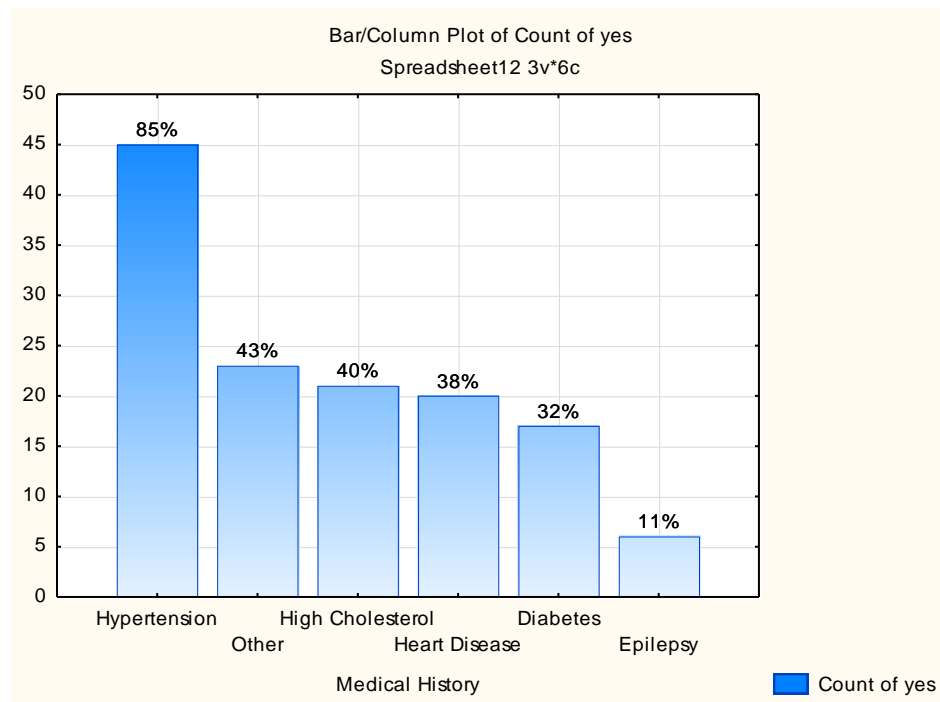


Figure 4. 13 Medical conditions pertaining to participants

### 4.3.3 Smoking

Thirty five (66%) of the participants in this study smoked cigarettes before the stroke (Figure 4.14). Fourteen (26%) of them have continued to smoke after the incident (Figure 4.15).

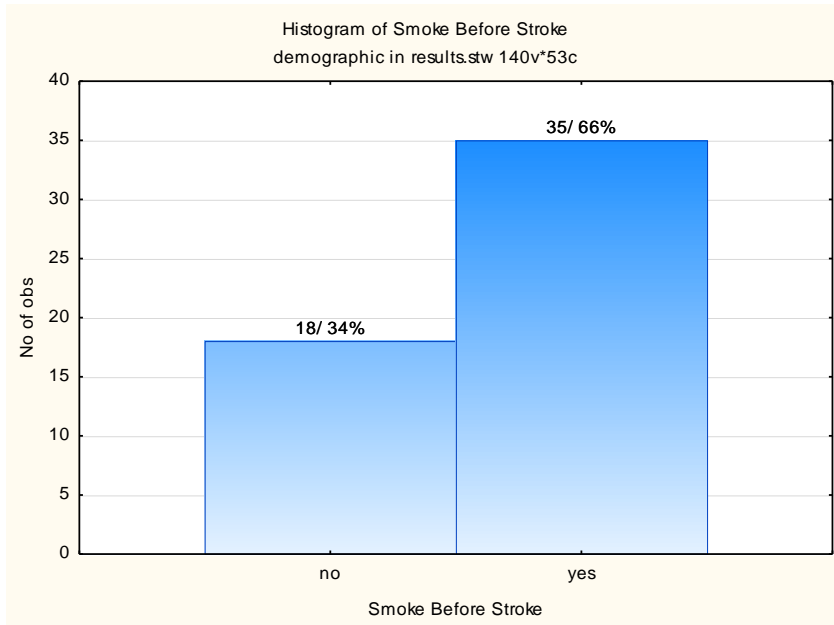


Figure 4. 14 Smoking habits prior to stroke (N=53)

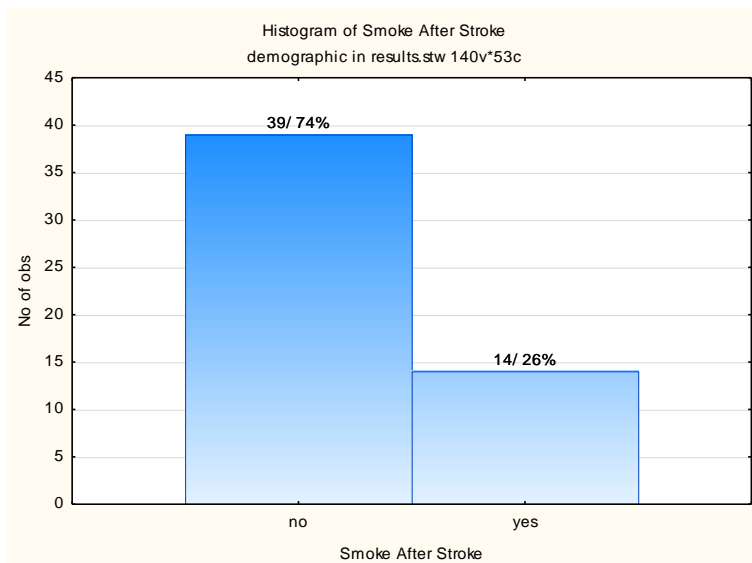


Figure 4. 15 Smoking habits after stroke (N=53)

#### 4.3.4 Participants estimates of level of recovery after stroke

In terms of participants' estimates of their level of recovery on the Stroke Impact Scale Version 3 (SIS3) the mean score was 48.30 out of a possible 100 (Figure 4.16). The left most bar indicates the number of values equal to zero.

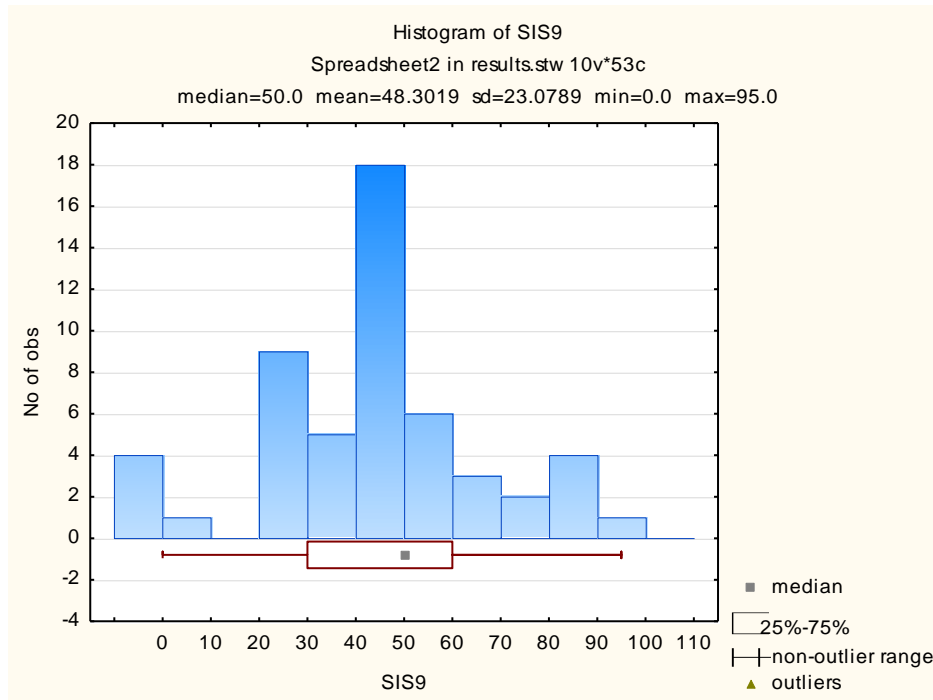


Figure 4. 16 SIS9 - Level of recovery after stroke (N=53)

The severity of the challenges faced with regard to health conditions and participants' knowledge and management of these were brought home through qualitative findings.

#### 4.3.5 Knowledge and awareness of hypertension as a risk factor

As illustrated by the following comments, it appears that participants had very little knowledge or awareness of risk factors for stroke, before the incident:

*"Before I had the stroke, we didn't know anything about high blood pressure. We only found out about this afterwards."*

*"I was not aware of high blood pressure and strokes, until I had one."*

None of the participants or caregivers knew what goals they were working towards in terms of management of hypertension. When asked what they thought their blood pressure should be, most participant and caregivers responded as these did:

*"I don't know how high it should be.... Usually they say about 150/70."*

*"I don't know how high it should be."*

*"I haven't got a clue."*

*"They told me what my blood pressure is, but they didn't tell me what it should be."*

#### **4.3.6 Management of diabetes mellitus**

This study has revealed the following problem areas in terms of the management of diabetes mellitus:

##### **4.3.6.1 Diet**

From discussions with participants in the study and their families, it appears an attempt is being made by nursing staff to give out information sheets and pamphlets on diet. However, in terms of management of diabetes, participants and caregivers expressed a tremendous amount of confusion about what they should be eating.

*"No, the first time we were basically informed that she must eat correctly. No explanation was given. I am sure doctors think that if they say someone has diabetes we know what it is all about."*

There were also complaints that they could not understand pamphlets which were distributed. Information was not always given in the person's home language and recommended food was often unaffordable. This is illustrated in the words of an Afrikaans-speaking participant:

*"Basically in English. Then one cannot always afford the food that is on the pamphlet. There must be alternatives –things that a person can afford. Things are very expensive in the shops."*

##### **4.3.6.2 Blood glucose monitoring**

According to Helderberg Hospital, diabetic patients who are on insulin are provided with glucometers. Those who are not using insulin are taught to do colour coding with accucheck active strips (Theron, 2011).

The researcher gained the impression that some participants had received glucometers and others not. As one participant said:

*"I would like to have my own machine, but they say it is very expensive."*

Some participants also expressed concern about the cost of strips:

*"We got a machine. The problem then is that the strips are very expensive".*

Other environmental barriers also impact on the effective use of glucometers as illustrated by a stroke survivor who reported that he did not have a battery for his glucometer. The battery was unavailable at any of the shops in the community and transport to the nearest large centre was costly and problematic as he was a wheelchair-user. His family did not see it as an important issue and thought that the R6.00 which the battery cost could be put to better use.

#### **4.3.6.3 Poor adherence to medication**

The following qualitative data demonstrates the lack of compliance in taking medication by some participants:

*"Quite simply, he did not take his pills and when I finally realised it, it was packets and packets of pills....."*

*"Just didn't feel like taking them."*

*"He knew it was going to cause problems, he was going to have a heart attack or have a stroke. He had to lose weight. I started work again –then he just stopped taking his pills."*

The following reasons were also given by participants for not adhering to medication:

- A 67-year old male reported getting his blood pressure medication from the CHC and putting it in the cupboard and leaving it there, as he believed God would protect him. He had a stroke six months later.
- An elderly female participant reported on how she did not like taking pills and had recently decided to stop taking all BP medication.
- A 69-year old female and 73-year old male participant described how they had stopped taking their blood pressure medication as they felt "fine" and then had a stroke several months later.
- A 69-year old participant with diabetes believed he had been bewitched after having the stroke. He had stopped taking any medication given at the clinic and rather visited a traditional healer.
- Being faced with hours in a queue can lead to non-compliance. Participants or caregivers who were employed found it particularly difficult to take off a day of work to obtain medication:

*"It is difficult to get off work. This is a huge problem".*

One participant who was a truck driver reported being aware that he had hypertension before the stroke. However, he found it impossible to take a day off work each month to get his medication as he was a key employee in the business. He was unaware of the consequences of lack of compliance in taking his medication until he had a stroke. A 43-year old male participant who had also been employed prior to the

stroke reported a similar experience. The clinic was always closed by the time he got home from work. He suffered a stroke several months after he stopped his medication.

People are individuals. As illustrated by this comment from a participant who was informed he required blood pressure medication, medical professionals need to use their skills and knowledge of clients to determine the best way to get information across to them. What might work for one patient may not work, or even be offensive to, another.

*"He said - no it is for the rest of your life. I think it is the way that he said it -I decided bugger it....."*

The same participant was of the opinion that far more emphasis should be placed on the consequences of not taking medication:

*"That shock treatment."*

They should be told:

*"That is where you are going to be. That is your future. That wheelchair is waiting for you. That potty thing is waiting for you. It depends on you. Do you want to be there –do as you please."*

#### **4.3.7 Lack of explanation and education in terms of medication**

Participants and caregivers appeared to have very little understanding of what medication was for as is illustrated by these comments from caregivers and participants:

*"About medication, I don't know much –all that I know is that pills were prescribed. Till today, I still don't know what they are for. They have to be fetched at the clinic. That is the extent of my knowledge".*

*"If I had just been more informed, then I wouldn't have been so stupid and stubborn and said -Bugger it - I'm not going to be so dependent on pills. I stopped taking the pills. I drank one or two. If he had just taken the trouble.....to explain to me, it might not have happened."*

*"They said blood pressure amongst other things. There was no explanation."*

*"No man –I got over it. I was at the hospital and then went home. I got medicine, but I was still none the wiser."*

*"Otherwise it was just pills. Off you go. I'm none the wiser."*

*"No. I haven't got a clue. Till today, I am still not sure of what they plan to do or to give me. Now they say I must come back next month and get pills."*

*"Yes –they did not tell me what else we must do. Nobody said what the pills were for. There are your pills. Move on. Nothing about this is for this and this is for this. I always like to know."*

#### **4.3.8 Lifestyle changes**

In terms of the addiction to smoking participants made the following comments:

*"At one stage we did not even have food because he carried on about that packet of cigarettes –instead of buying bread, cigarettes were bought."*

*"And small children also –like at school –they say they can smoke –just not in front of the teachers. I think it is worse than drug addiction."*

*"Difficult to stop."*

*"For me it is – probably because I am more of a compulsive smoker. It is not as if I now suddenly crave a cigarette. Second nature. You sit in the movies –doesn't worry you. You come out –first thing that you do is - where are my cigarettes? Like on the aeroplane it doesn't worry you –disembark –land. Now I want to smoke. It is a funny sickness. It is a sickness."*

*"Terrible thing. I think it is much worse than drug addicts. These days they use dangerous stuff, but smoking is a bugger."*

From discussions with participants and caregivers it appeared that while some people do manage to make lifestyle changes independently, others need significant support in this regard and were of the opinion that they were not receiving it.

*"In terms of smoking, they do very little. Each time the doctor asks him –'How many cigarettes do you smoke?' They write down how many cigarettes he smokes and that is all. 'You must smoke less' –and that is all that is said."*

*"Yes, in terms of cigarettes that support is not there –Honestly. There they gave him very little support."*

*"And the fact that they put him on a diet or say that he must go on a diet, but they don't ask him to come back –let us see what your weight is....."*

*"The dietician should have made the recommendation that he came back after a month...."*

*"Couldn't they have told us to come back? You can come back after two months, or you can come back after a month. I want to see you in a month time....."*



#### **4.3.9 Recommendations of participants and caregivers in terms of health and life style changes**

The wife of a 69-year old participant was of the opinion that more needs to be done at school level to promote a healthy lifestyle.

*"In schools they must show more of those films about what smoking causes –cancer and all those things. It is education. Just like with HIV, is smoking.....it's a problem."*

*"They must do more exercise. It is just a few that play rugby and a few that do exercise. And the others don't want to –they just don't do it."*

*"They don't take part in sport –they drink –they smoke cigarettes."*

Another participant was of the opinion that more should be done in the work place in educating people on a healthy lifestyle and having regular medical examinations when you reach a certain age:

*"Look in my factory there are notices about labour laws. Maybe there should be posters –I don't know? About medical stuff –vasectomies, high blood pressure –the basic things relevant to anyone that turns 40."*

A further recommendation was that buying alcohol and cigarettes should be made increasingly difficult by making them unaffordable:

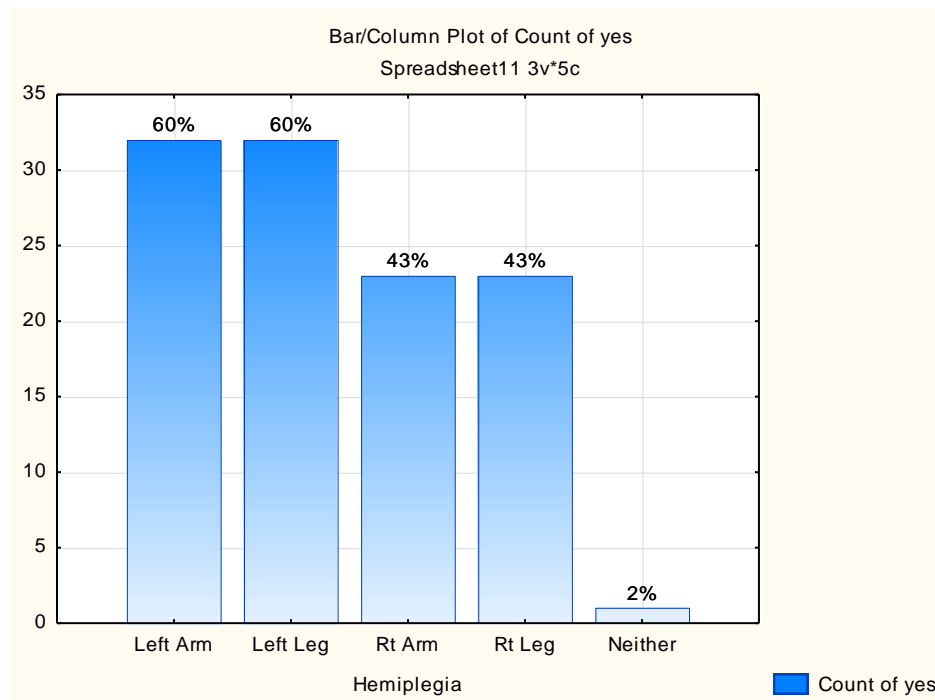
*"They must make cigarettes extremely expensive."*

## 4.4 Impairments

This section presents the results pertaining to physical, cognitive, perceptual and speech and language impairments. Results in section 4.4.7 give an indication of the emotional well being of participants.

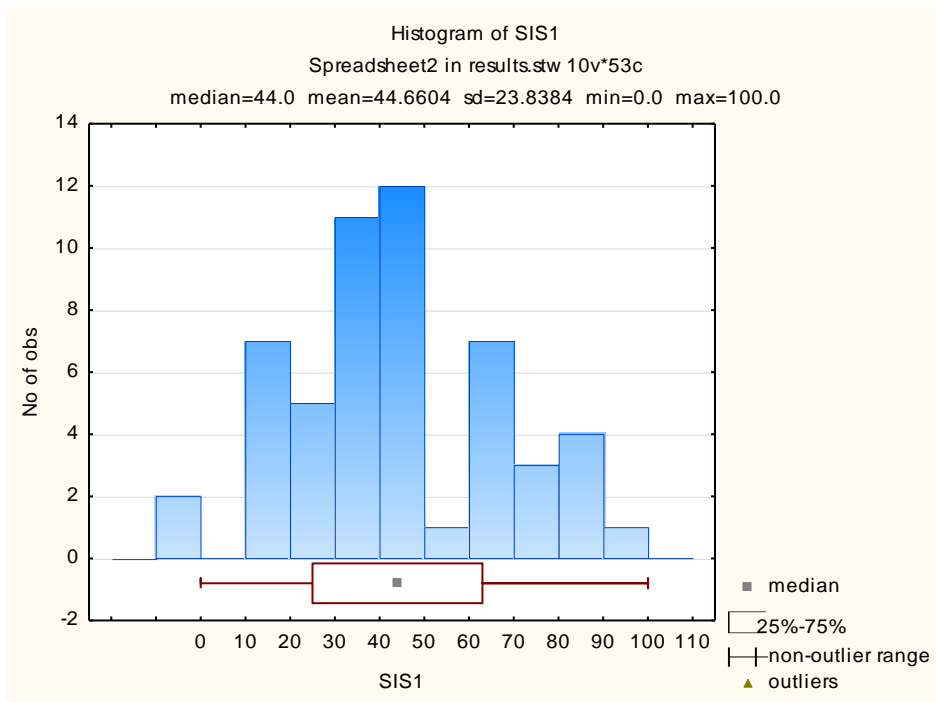
### 4.4.1 Paralysis

Figure 4.17 shows that 60% of participants suffered from paralysis or weakness on the left side of the body and 43% on the right side. As a result of multiple strokes, some participants were affected on both sides of the body. Two percent of participants reported that their limbs were unaffected.

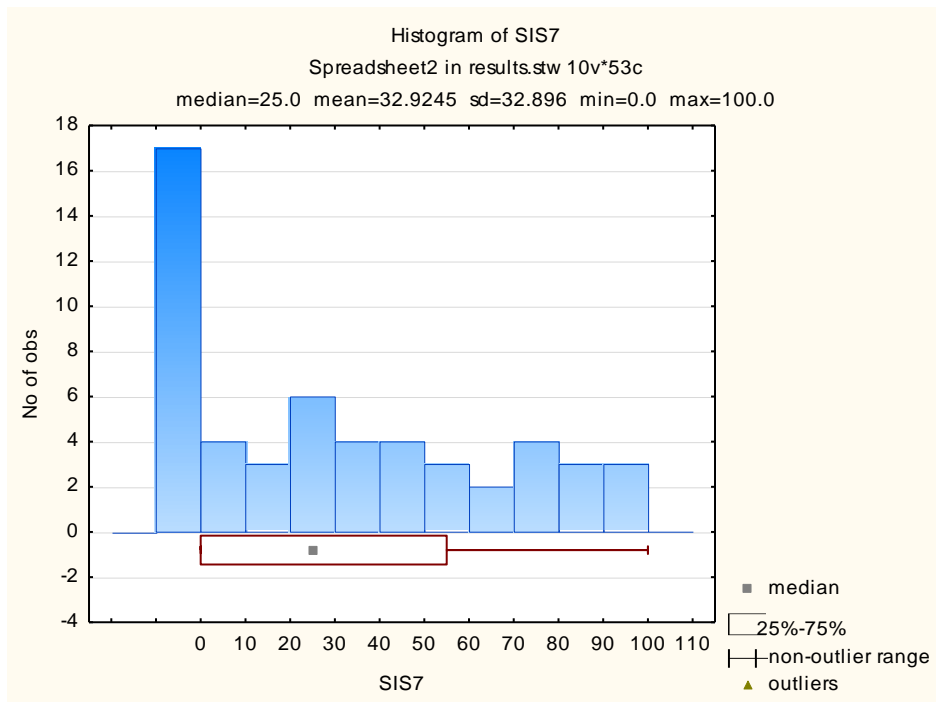


**Figure 4. 17 Limbs affected by stroke**

Utilising the SIS 3, the mean score for participants' ratings of the strength of their upper and lower limbs after the stroke is 44.66 (Figure 4.18). The mean score for the participants' ability to use the hand most affected by the stroke was 32.92; the median was 25 (Figure 4.19). Seventeen participants scored zero for hand function. On both graphs, the minimal score obtainable was zero and the maximum 100. The left most bar indicates the number of values that are equal to zero.



**Figure 4. 18 Self-reported strength of affected limbs (N=53)**



**Figure 4. 19 Functionality of hand (N=53)**

#### 4.4.2 Restriction in joint range of the upper limbs

In terms of restriction in joint range, general observations were made with active and passive movement of limbs. Differentiation between spasticity, structural limitations and soft tissue shortening were not recorded. Fifty one percent of participants had limited range of movement at the shoulder, particularly in terms of elevation and abduction; 28% complained of shoulder pain.

Twenty eight percent of participants had restricted range of movement of the fingers, 26% of the wrist and 21% of the elbow. Contractures and spasticity in the upper limb are significant barriers in regaining hand function.

#### 4.4.3 Speech and communication

Twenty seven (51%) of participants believed they had experienced some form of speech and communication difficulty post stroke. This varied from fairly mild dysarthria to more severe problems related to aphasia. In many cases there had been some spontaneous recovery. On the SIS3 the mean score for communication was 72.87 and the median 82 out of a possible score of 100 (Figure 4.20). This graph gives an indication of participants' opinions of their current communication abilities.

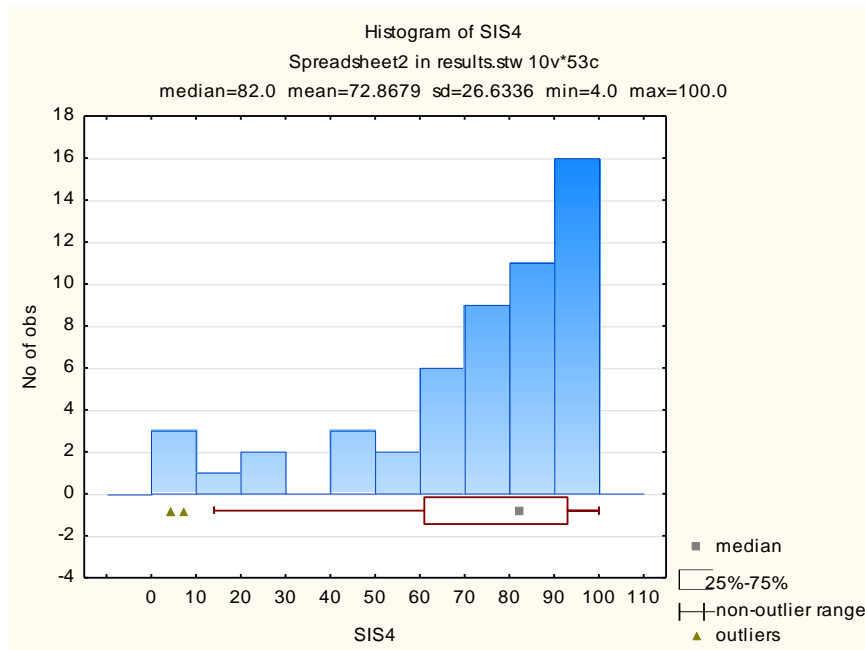


Figure 4. 20 Communication problems experienced according to SIS3 scores (N=53)

### 4.4.3.1 Speech and language test

#### 4.4.3.1.1 Naming

In this test participants were required to name objects to which the researcher pointed. Problems in this regard give an indication of expressive aphasia, anomia or dysarthria.

Twelve percent of participants had difficulty with naming, while 88% experienced no difficulty.

#### 4.4.3.1.2 Auditory Verbal

In this test, participants had to follow verbal instructions given by the researcher. Problems in this regard give an indication of the presence of receptive aphasia.

Sixty-two percent of participants were able to complete the auditory verbal section of the test, obtaining the maximum score of 19. The remainder experienced varying degrees of difficulty as indicated in figure 4.21.

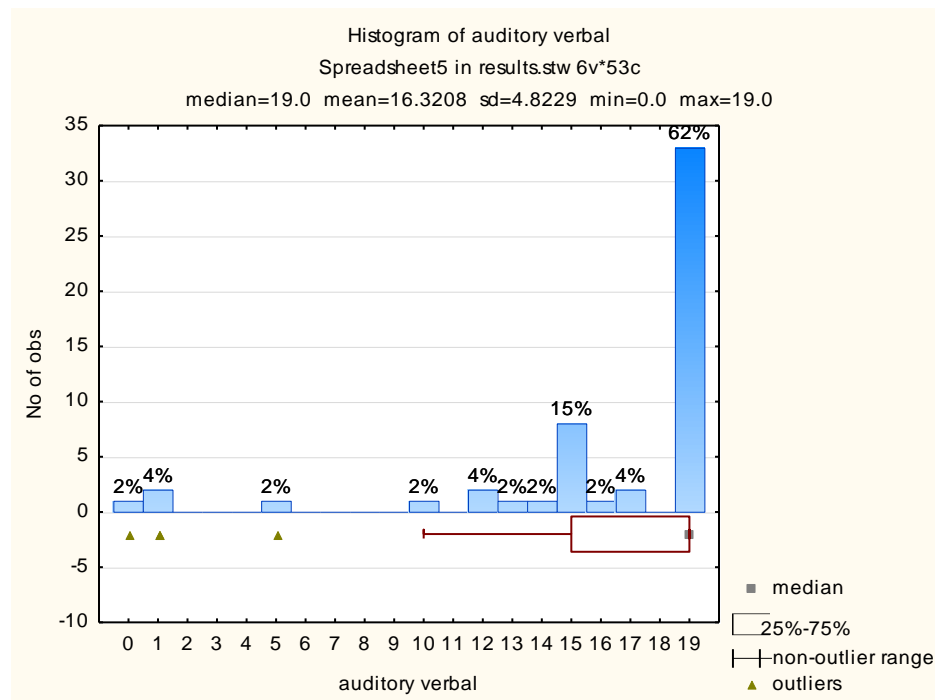


Figure 4. 21 Speech and language - Auditory Verbal Comprehension (N=53)

### 4.3.3.1.3 Repetition

Participants were required to repeat words or a short phrase. Problems in this regard give an indication of dysarthria, expressive or receptive aphasia.

The mean score was 15.52 and the median 20, out of a possible score of 20 (Figure 4.22). The minimum score was zero. (The leftmost bar indicates the number of values equal to 0).

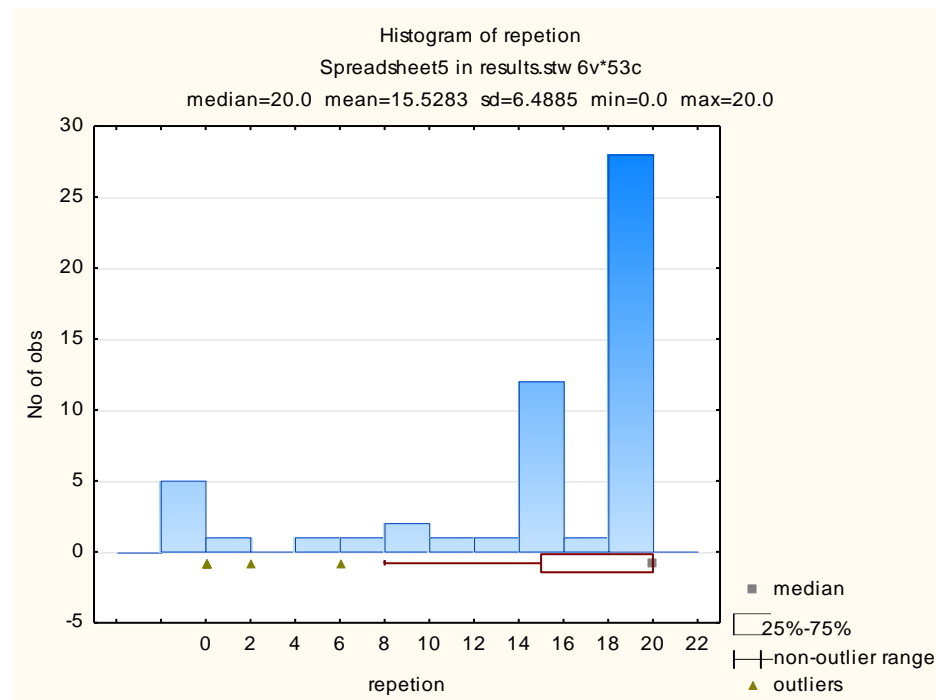


Figure 4. 22 Speech and language – Repetition (N=53)

#### 4.4.3.1.4 Reading

With this task, participants were required to read a sentence and then carry out the instruction given. Problems in this regard give an indication of difficulty with reading comprehension.

It is possible that vision impairments and lack of education impacted on results. Although many participants appeared to be in need of reading glasses or possibly had other visual problems, large print was utilised to compensate for this. The two participants who were blind from diabetic retinopathy and the one from cataracts were unable to perform the task. One participant had never learned to read.

Thirty one (58%) participants were able to complete the reading task, obtaining the maximum possible score of 12. Nine (17%) were unable to and 13 (25%) participants experienced varying degrees of difficulty. The mean score was 8.41 (Figure 4.23).

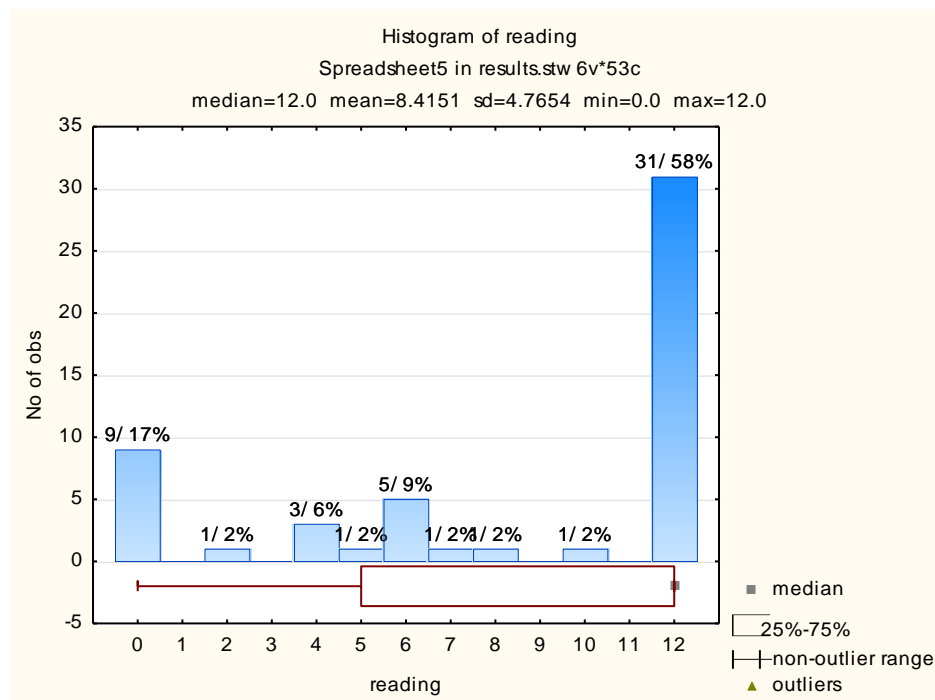


Figure 4. 23 Speech and language – Reading (N=53)

#### 4.4.3.1.5 Writing

With the writing task, participants were asked to write their name and address and the numbers from one through to 20. This test gives some indication of expressive aphasia in terms of writing and also of impairments related to number concepts.

Stroke survivors whose dominant hand was affected were asked to attempt the task using their non-dominant hand and were assured that neatness did not count. Again bias as a result of vision impairments and lack of education needs to be taken into account. Several of the participants with severe vision impairments were able to complete the task when given some guidance as to where they had to write on the paper. One participant reported that he had never learned to write and could not do the task. Forty seven percent were able to complete the task while the remainder experienced varying degrees of difficulty. The mean score was 12.71 and the median 15 out of a possible score of 16 (Figure 4.24).

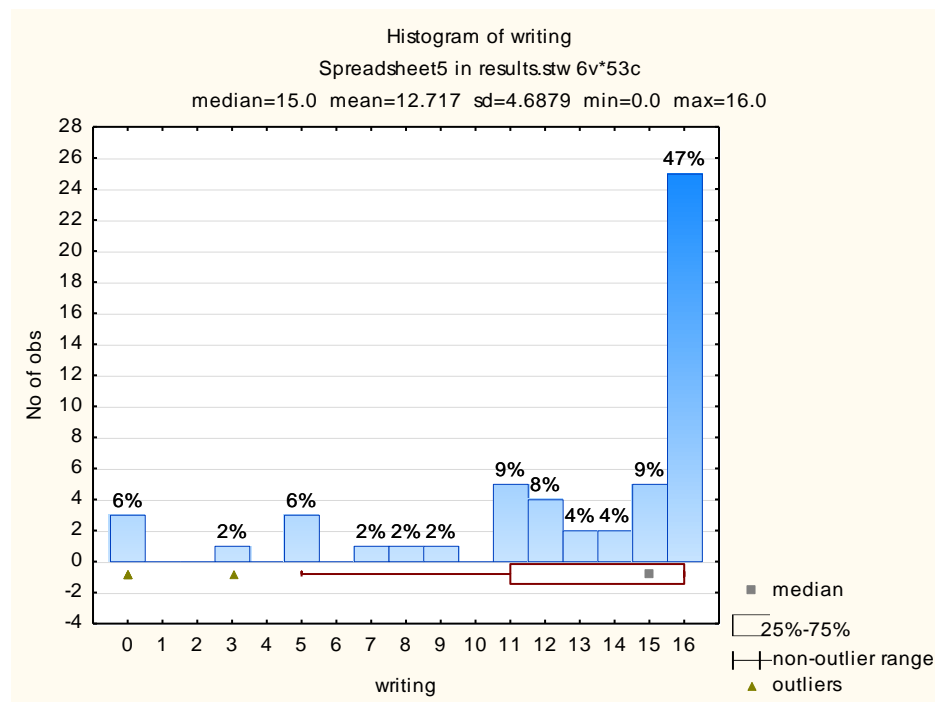


Figure 4. 24 Speech and language – Writing (N=53)

#### 4.4.4 Swallowing difficulty

Six participants reported on experiencing difficulty with swallowing.



#### 4.4.5 Vision

Sixty-six percent of participants reported increasing difficulty with their vision and reading as they aged (Figure 4.25). The researcher has recorded this as presbiopia, but this would need to be confirmed by an optometrist or ophthalmologist as it is possible that these vision impairments could be related to cataracts, diabetic retinopathy or other visual impairments. Eight percent of participants had Hemianopia and six percent complained of experiencing double vision.

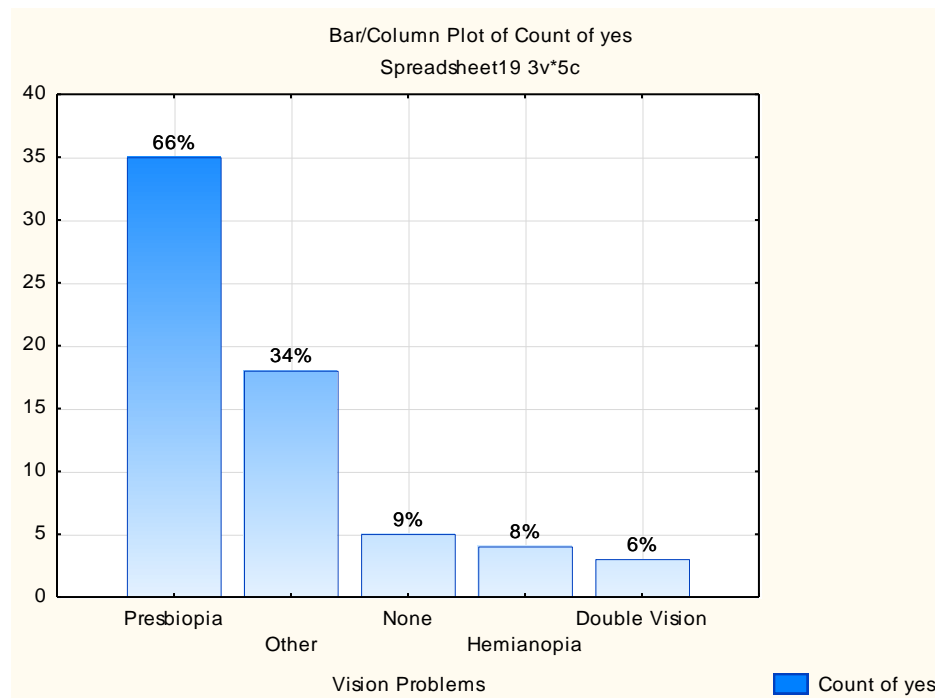


Figure 4. 25 Vision impairments experienced by participants (N=53)

Six of the participants reported diabetic retinopathy. One 57- year old was virtually blind as a result of this and consequently had to give up his job as a builder. He reported the frustration of having to go through to an institution in Cape Town for laser treatment only to find this equipment out of order and having to get another appointment, which was also cancelled. This resulted in long delays before he was treated. Another 53-year old diabetic who was also blind had to give up his employment; although he had a temporary disability grant, the family was battling financially. He was not sure of the cause of his vision problem, but it is possible it was related to diabetic retinopathy. Both participants had received limited occupational therapy and intervention from the Society of the Blind and are likely to have achieved higher outcome levels with further rehabilitation.

## 4.4.6 Cognitive and perceptual function

### 4.4.6.1 Self-reported memory and thinking skills

Figure 4.26 shows the mean score for memory and thinking skills on the SIS3 was 70.79 and the median 79 out of a possible score of 100.

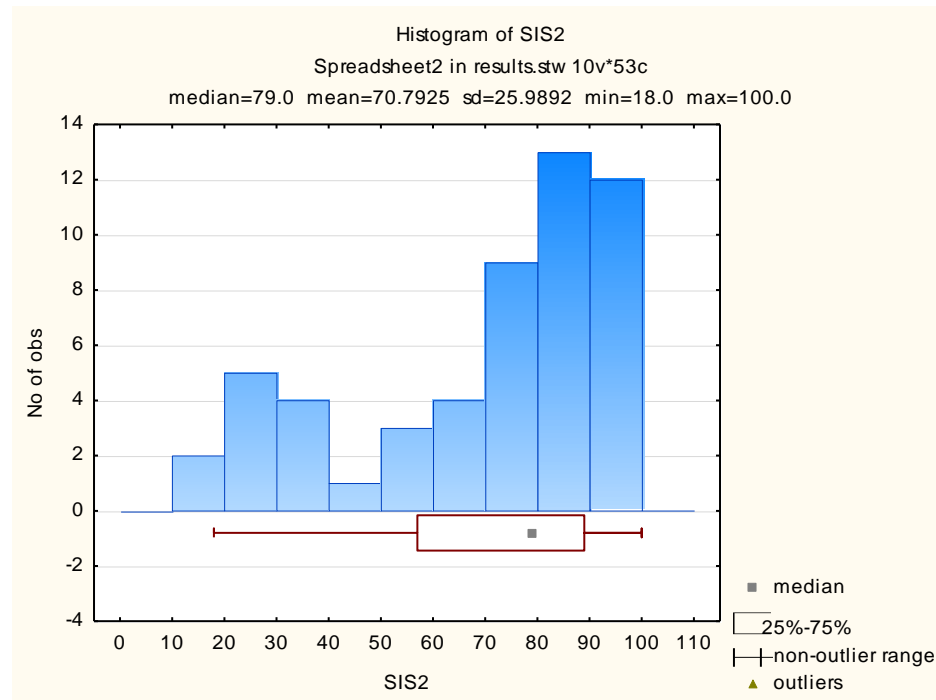


Figure 4. 26 Memory and thinking skills of participants (N=53)

### 4.4.6.2 Testing of cognition and perception with LOTCA

Severe visual impairments prevented three of the participants from completing all of the subtests of the LOTCA. It is possible that cognitive impairments related to dementia, the normal ageing process and other disorders caused some bias in the results. In the scope of this study, it was not possible to determine if any of the participants had pre-existing cognitive and perceptual impairments prior to the stroke.

#### 4.4.6.2.1 Orientation

Figure 4.27 shows that 57% of participants were orientated in terms of time and place. Others showed varying degrees of difficulty in this regard. The mean score was 13.20 out of a possible 16.

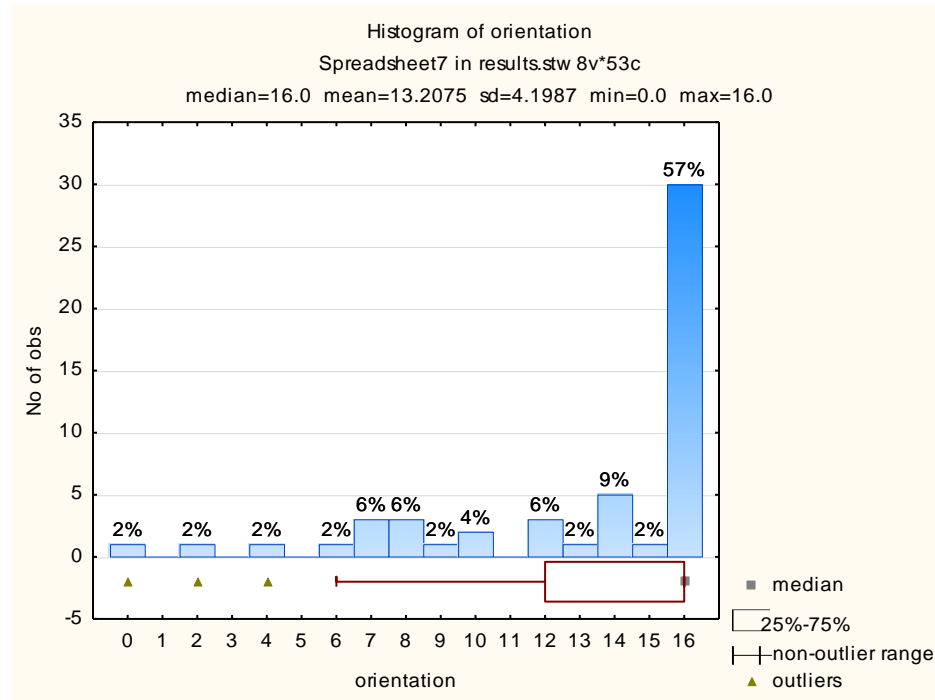


Figure 4. 27 Orientation scores according to the LOTCA (N=53)

#### 4.4.6.2.2 Visual perception

This section of the test screens for impairments related to figure ground perception and determines the stroke survivor's ability to identify shapes and objects. Fifty-three percent of participants obtained the maximum score for this test. Others showed varying degrees of impairment. The mean score was 14.09 out of a possible 16 (Figure 4.28).

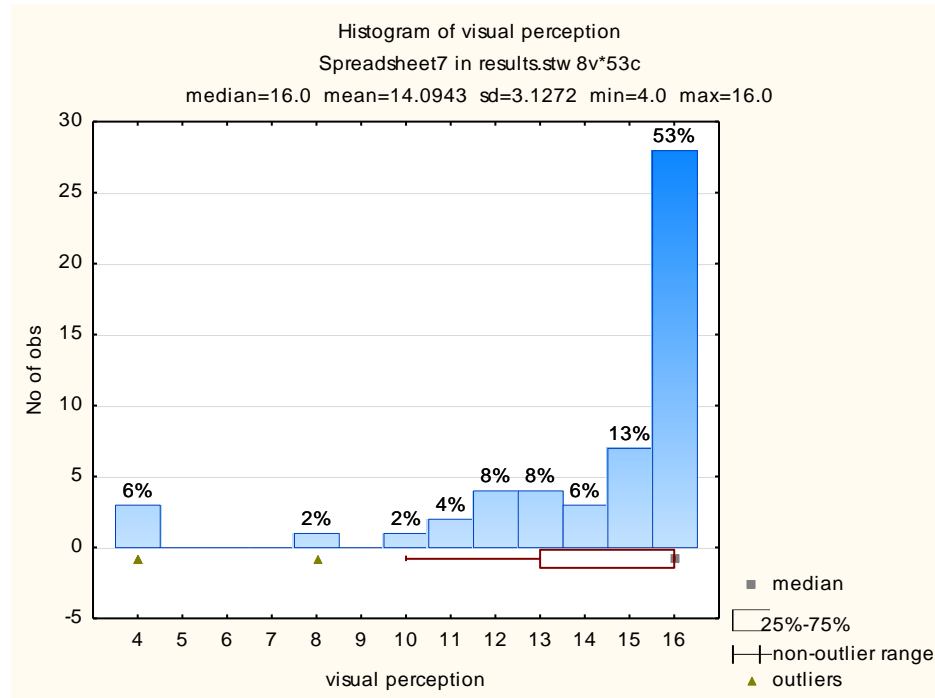


Figure 4. 28 Visual perception scores according to the LOTCA N=53

### 4.4.6.2.3 Spatial perception

This subtest identifies impairments related to body scheme disorders, unilateral neglect and perception in terms of left-right orientation and the interpretation of concepts such as behind or in front, above or below.

As indicated in figure 4.29, 49% of participants obtained the maximum score. The mean score was 9.60 out of a possible 12.

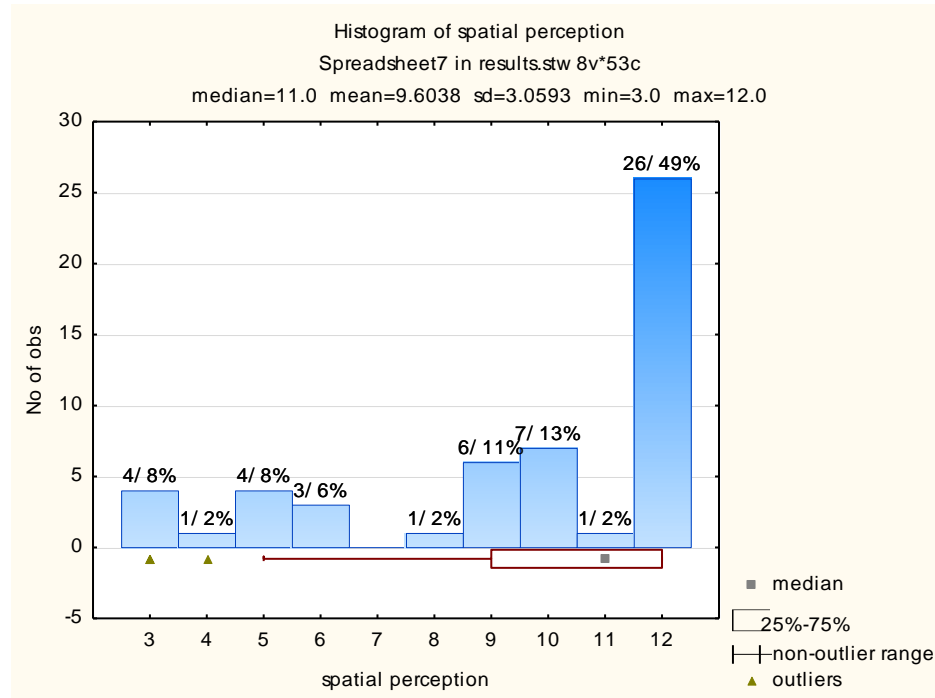


Figure 4. 29 Spatial perception scores according to the LOTCA N=53

#### 4.4.6.2.4 Motor praxis

Fifty one percent of participants obtained the maximum score for this test. The mean score was 10.18 out of a possible score of 12 (Figure 4. 30).

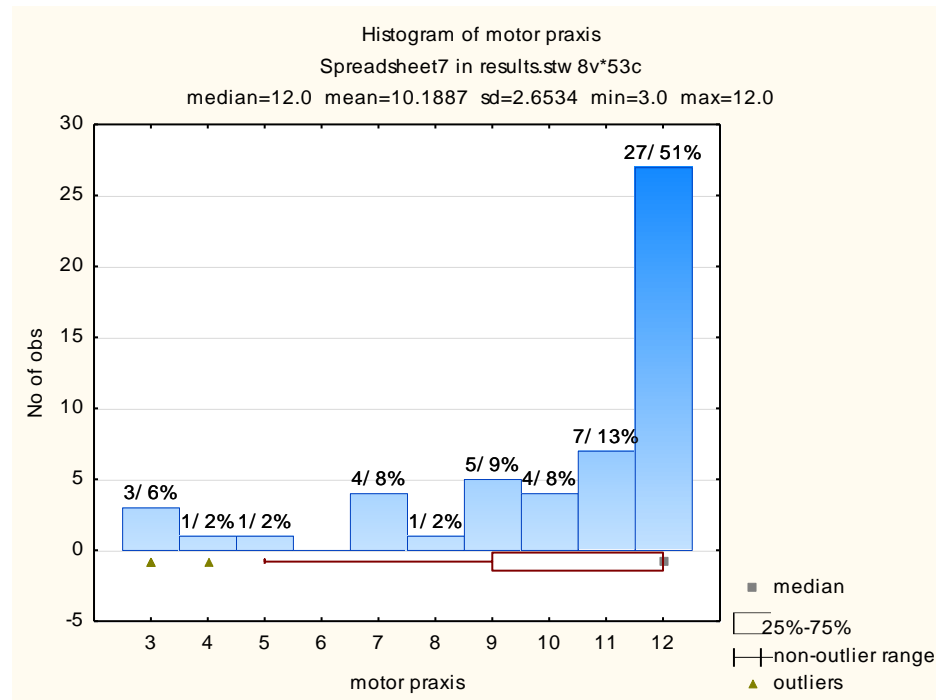


Figure 4. 30 Motor praxis scores according to the LOTCA (N=53)

#### 4.4.6.2.5 Visuomotor organisation

Impairments related to planning, organizing, apraxia, unilateral neglect, spatial relationships, visual perception of vertical and other cognitive and perceptual deficits can be identified utilising this sub-test.

One (2%) participant achieved the maximum score and two (4%) scored 27 out of a possible total of 28. The mean score was 15.66 and the median 15 (Figure 4.31).

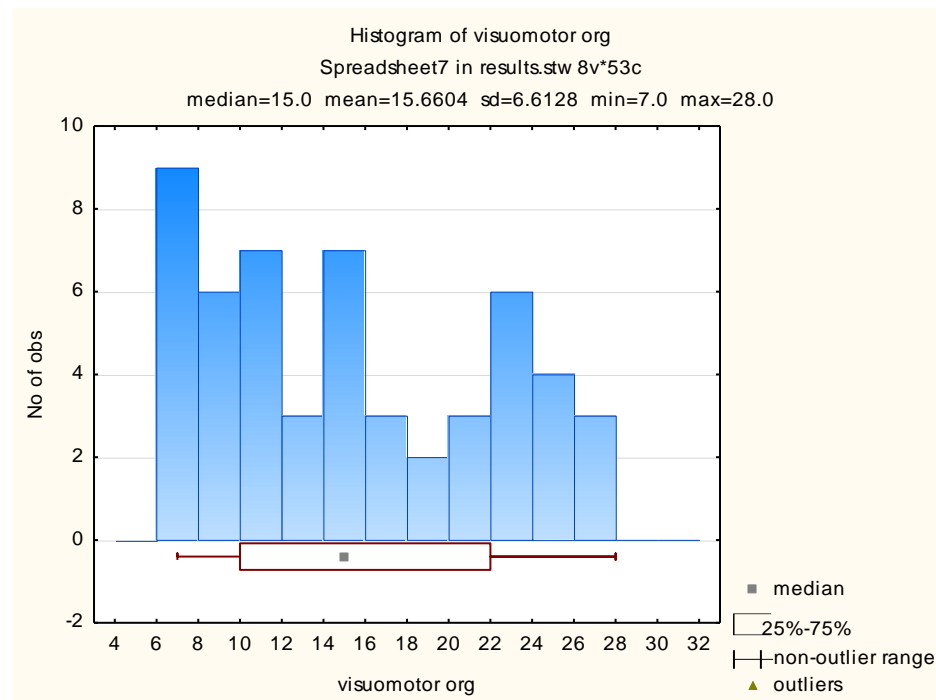


Figure 4. 31 Visuomotor organisation scores according to the LOTCA (N=53)

#### 4.4.6.2.6 Thinking skills

Various cognitive skills such as abstract thinking, short term memory, problem solving, reasoning, planning, organizing, sequencing and ability to follow instructions are tested in this section of the test. A short section incorporating simple calculations is included. Again, participants found this challenging, with one (2%) obtaining the maximum score of 31. The mean score was 16.85 and the median 15.0 (Figure 4.32).

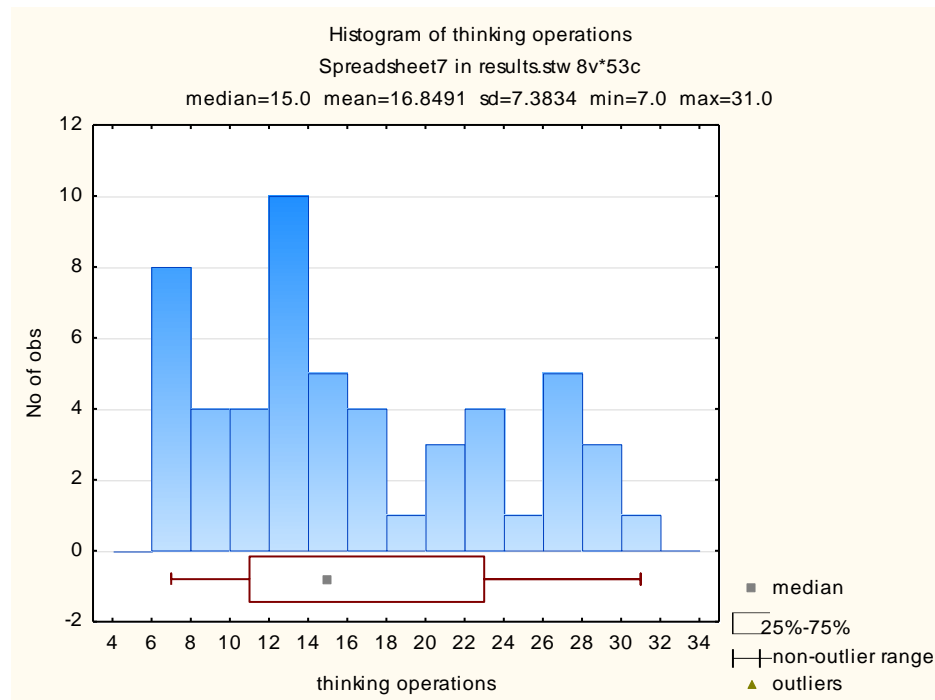


Figure 4. 32 Thinking operations scores according to the LOTCA (N=53)



#### 4.4.6.2.7 Attention and concentration

According to figure 4.33, nine percent of participants scored one and 32% scored two in this section. These scores are considered to be low. On the opposite side of the spectrum 43% of participants scored three and 15% scored four, which implies higher levels of concentration and attention.

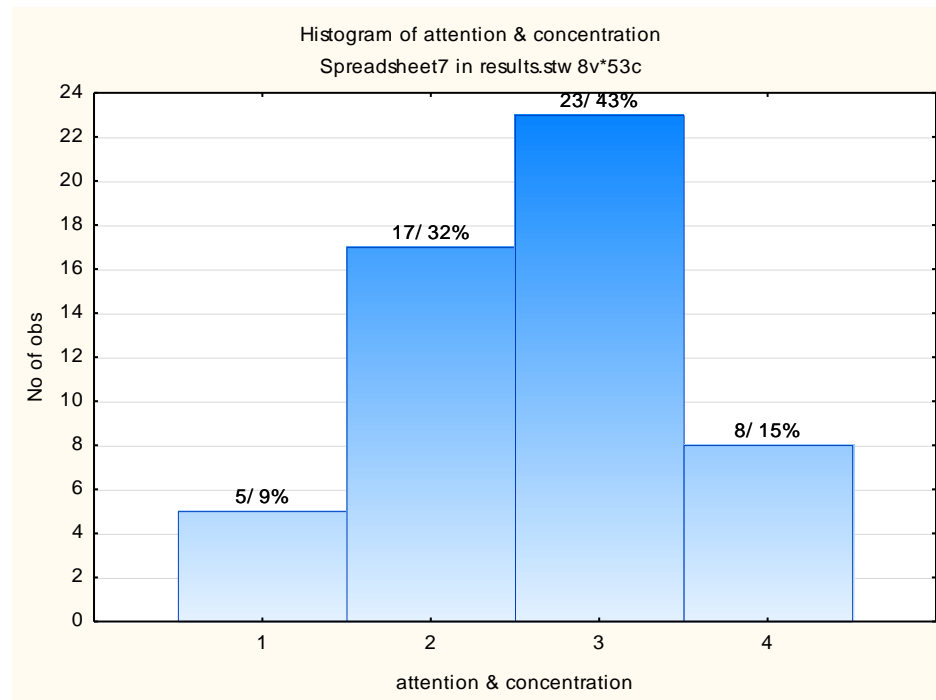


Figure 4. 33 Attention and concentration scores according to the LOTCA (N=53)

#### 4.4.7 Emotions

Questions related to feelings on the SIS3 evoked significant emotional response. Many participants cried or had tears welling in their eyes when they answered questions. The developers of the SIS3 report on this section of the questionnaire only capturing "limitations in function in the most impaired groups of patients" (Duncan et al., 2003:951). The researcher gained the impression that many participants were depressed and that this was one of the few opportunities they had had to discuss their feelings. This observation is supported by the data. The mean score was 50.84 and the median 53 out of a possible total of 100 (Figure 4. 34).

One caregiver described her husband's level of depression in the following manner:

*"Yes—even now he says that he would rather be dead. He doesn't want to get out of bed. He always used to do this every morning, but .....he is at that stage where he wants to die ...he is very depressed".*

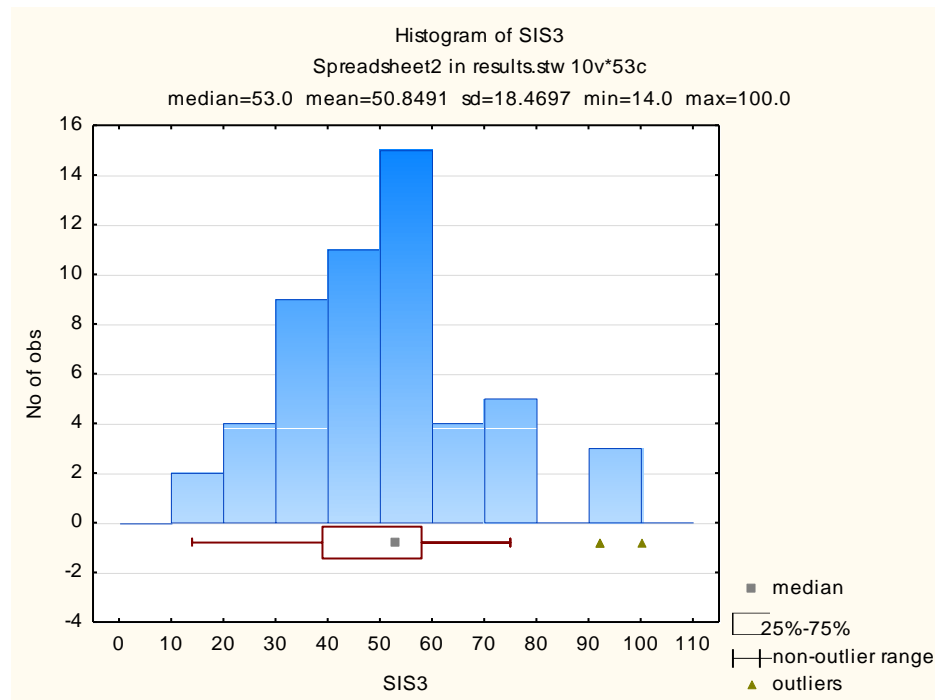


Figure 4. 34 Emotional status of participants according to the SIS3 (N=53)

## 4.5 Activity Limitations Of Participants

The MBI and the SIS3 have been used to obtain an indication of activity limitations of participants. Questions on bladder and bowel control have been included in both measures and although problems in this regard should possibly be discussed under the section on impairments, this would affect the scoring and interpretation of results. For this reason these impairments are included in section 4.5.

The MBI is scored according to the amount of assistance the stroke survivor requires in performing activities of daily living. The section on activities of daily living on the SIS3 is scored according to the participant's perception of how difficult it is to complete the activity. The minimum score for both of these tests is 0 and the maximum is 100.

### 4.5.1 Modified Barthel Index

The mean score for the Modified Barthel Index was 70.58 and the median 78 out of a possible 100. Scores of 0-24 denote total dependency, 25-49 severe dependency, 50-74 moderate levels of dependency and 75 -90 mild levels (Australian Government, Department of Health, n.d). According to Figure 4.35 21% of participants can be considered totally or severely dependant.

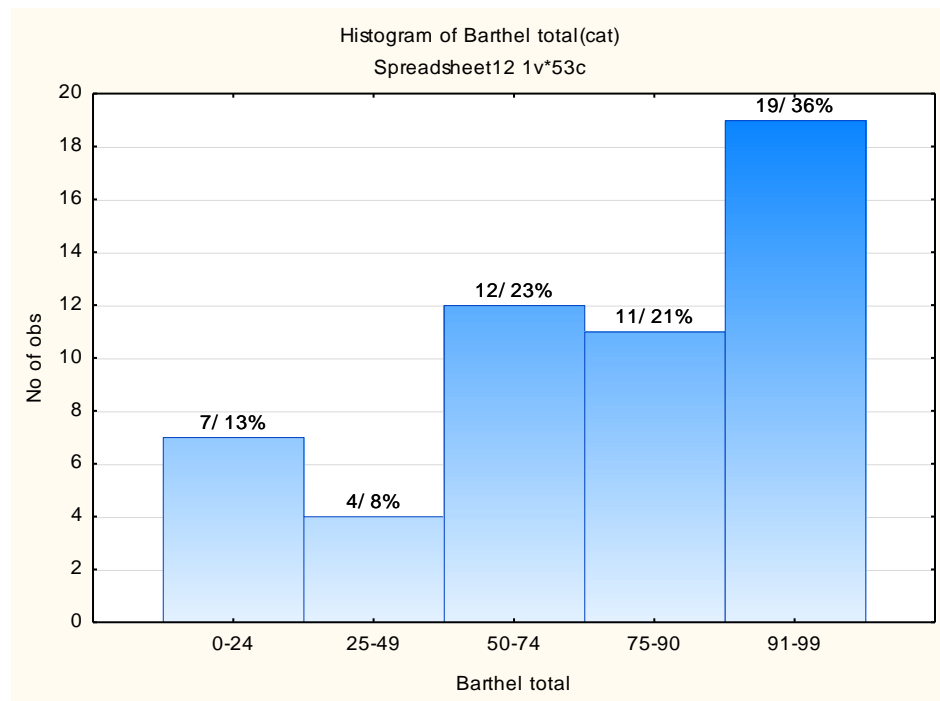


Figure 4. 35 Modified Barthel Index (MBI) scores (N=53)

**Table 3: Bartel total correlations**

merged in results.stw					
	1	2	3	4	5
	variable 1	variable 2	Spearman	Spearman p-val	# cases
1	Bartel total	SIS7	0.78	<0.01	53
2	Bartel total	SIS1	0.65	<0.01	53
3	Bartel total	Nr of hours of OT received after last stroke	-0.05	0.71	53
4	Bartel total	Nr of hours of Physio received after last strol	-0.22	0.11	53
5	Bartel total	visual perception	0.45	<0.01	53
6	Bartel total	spatial perception	0.25	0.07	53
7	Bartel total	motor praxis	0.43	<0.01	53
8	Bartel total	visuomotor org	0.48	<0.01	53
9	Bartel total	thinking operations	0.56	<0.01	53

Table 3 shows that with p values of <0.01, strength of limbs (SIS3.7), hand function (SIS3.1) and various cognitive and perceptual functions (visual perception, motor praxis, visuomotor organization and thinking operations) had a statistically significant impact on performance of activities of daily living. Trend was evident in terms of spatial perception. One would expect spatial perception to have a greater impact on activities for daily living. The difference in p value between this and the other cognitive and perceptual scores can possibly be attributed to the fact that more complex spatial perception is tested in the section for visuomotor integration of the LOTCA.

### 4.5.1.1 Personal hygiene

This refers to the stroke survivors' ability to brush teeth and hair, wash hands, face, shave and apply make-up. Eleven (21%) of participants were independent in this regard and 19 (36%) required minimal assistance (Figure 4.36).

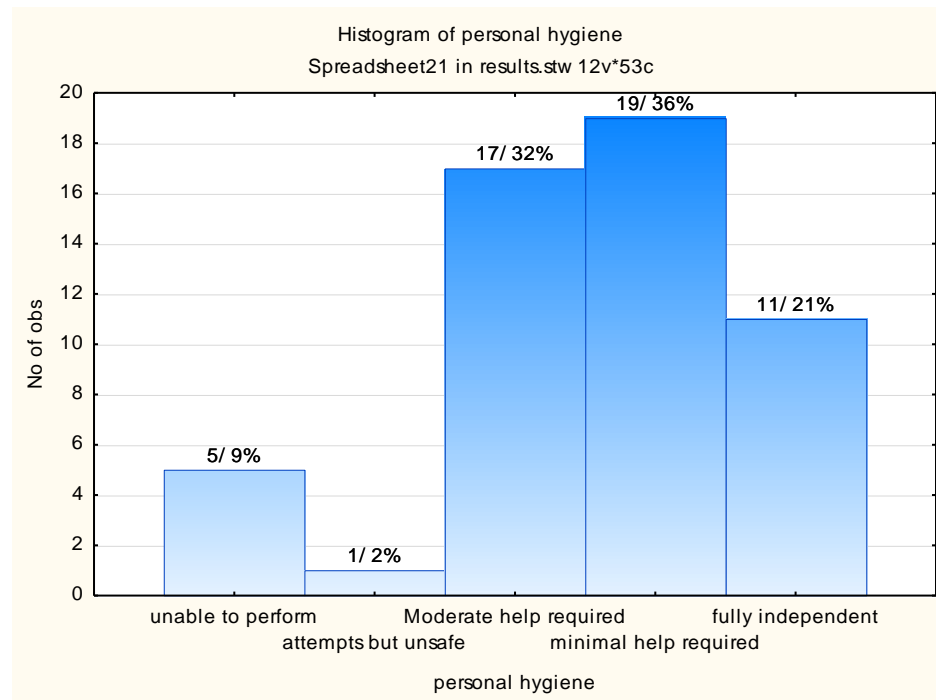


Figure 4. 36 MBI scores - Personal hygiene (N=53)

### 4.5.1.2 Bathing

According to figure 4.37, fifteen (28%) of participants were independent in performing tasks such as showering, bathing or washing their whole body (sponge bath) without assistance. Eleven (21%) required minimal assistance.

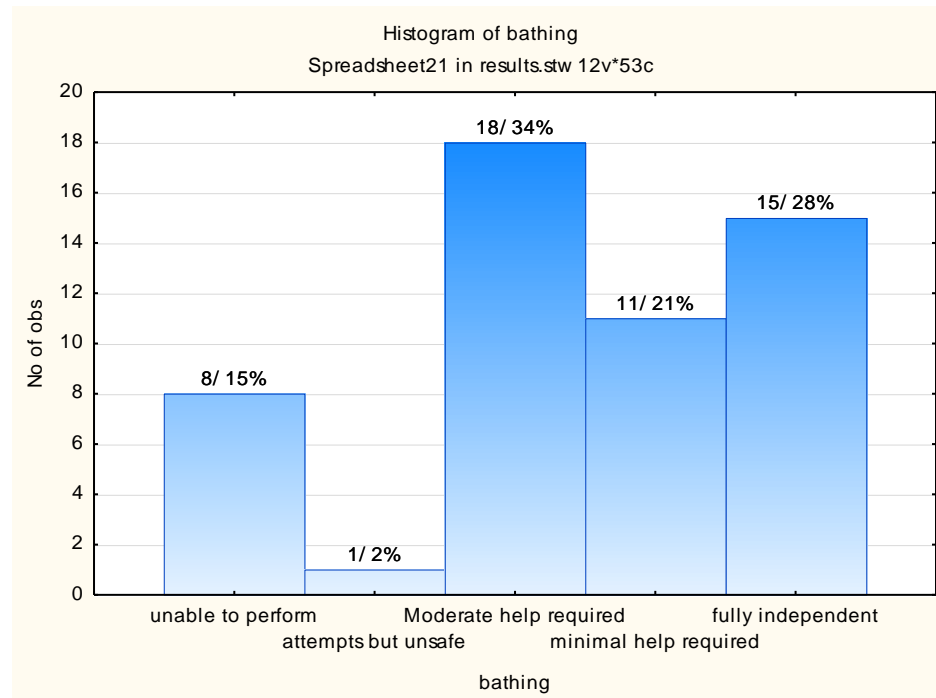


Figure 4. 37 MBI scores – Bathing (N=53)

### 4.5.1.3 Feeding

To be considered fully independent, the stroke survivor needs to be able to feed himself, cut food and spread margarine or jam on bread. Fifteen (28%) of participants were fully independent and 31(58%) required minimal help with cutting food and spreading margarine etc. (Figure 4. 38).

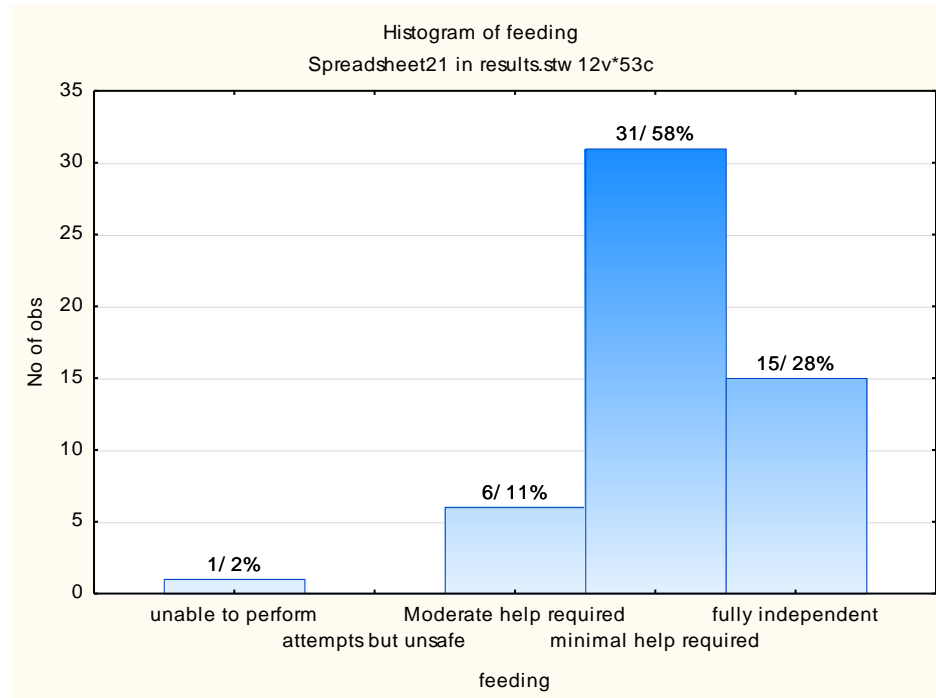


Figure 4. 38 MBI scores – Feeding (N=53)

#### 4.5.1.4 Toileting

This refers to the stroke survivors being able to handle their clothing, get on and off a toilet and clean themselves with toilet paper without any assistance. Thirty (57%) of participants were fully independent in this regard. Twenty three (43%) required some form of assistance (Figure 4.39).

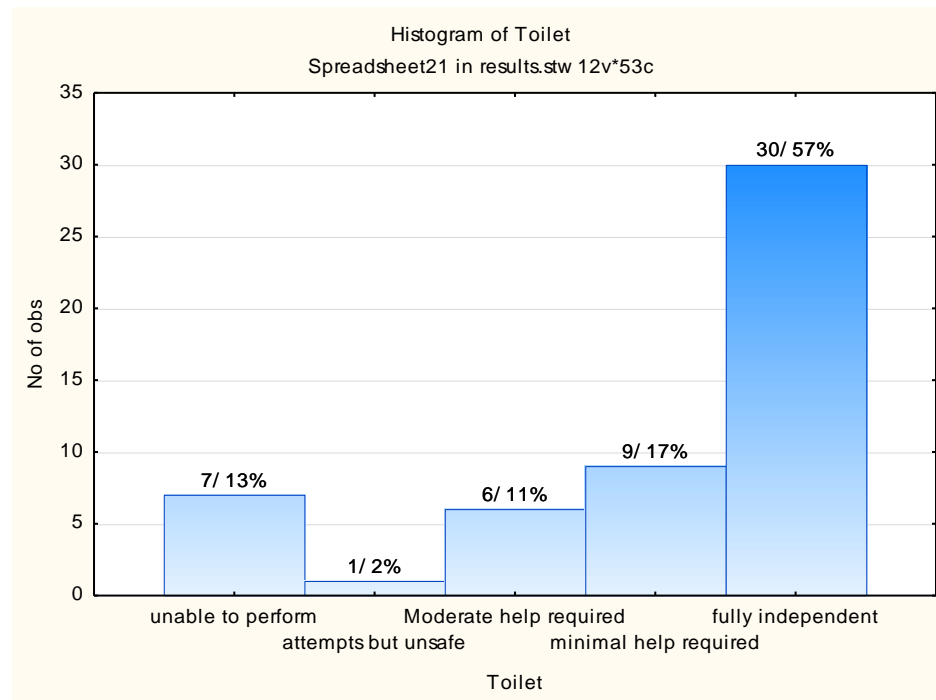


Figure 4. 39 MBI scores –Toileting (N=53)



#### 4.5.1.5 Stair climbing (i.e. a flight of stairs.)

This refers to the stroke survivors' ability to go up and down stairs safely and without any form of assistance. Fifteen (28%) participants were able to do this independently (Figure 4.40).

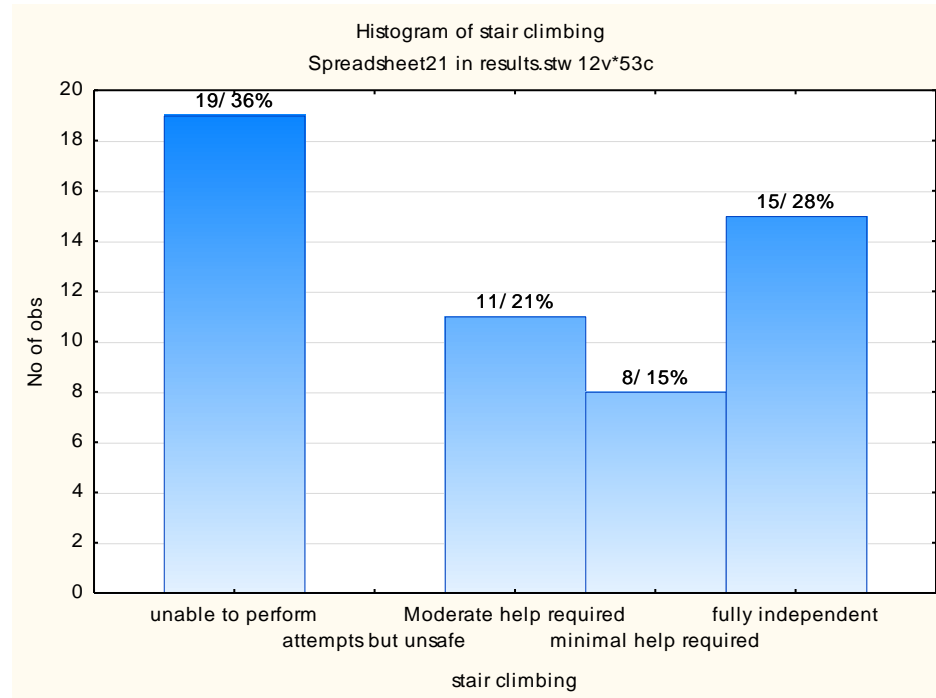


Figure 4. 40 MBI scores - Stair climbing (N=53)

#### 4.5.1.6 Dressing

Full independence in this regard, requires the stroke survivors to be able to dress /undress themselves, manage all buttons and other fastenings and tie their own shoe laces. Fifteen (8%) participants were fully independent. The others required some form of assistance (Figure 4. 41).

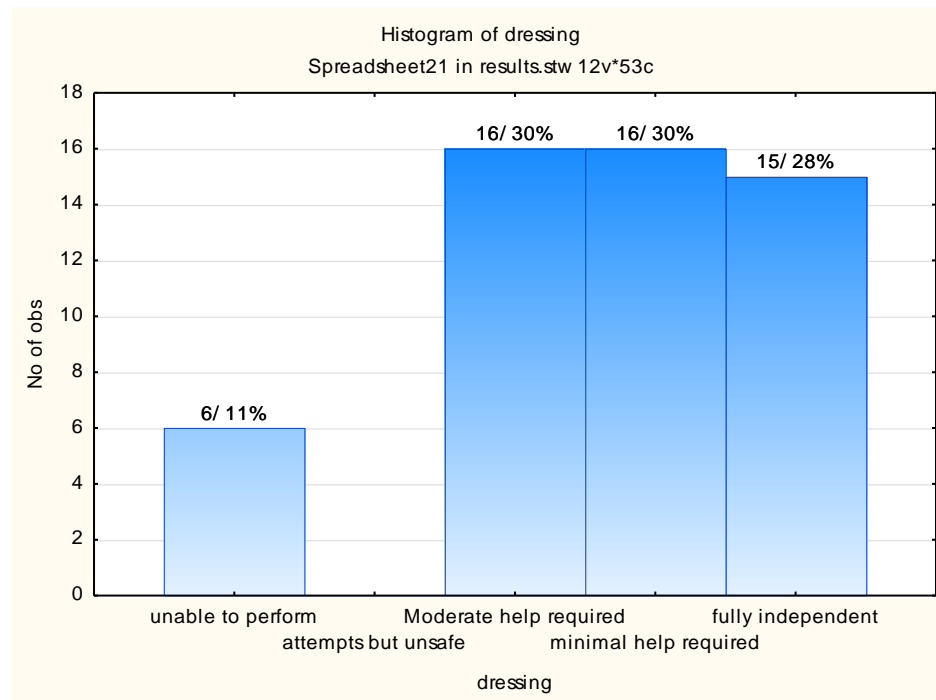


Figure 4. 41 MBI scores – Dressing (N=53)

#### 4.5.1.7 Bowel control

Thirty (57%) of participants were fully independent in this regard, which implies that they could control their bowels and intentionally have no accidents (Figure 4.42).

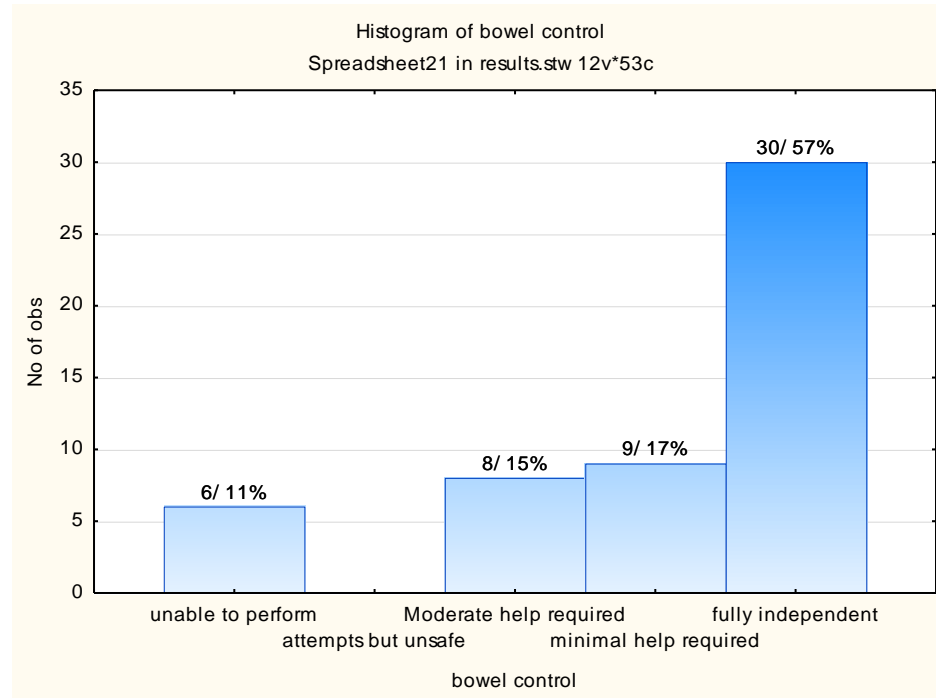


Figure 4. 42 MBI scores - Bowel control (N=53)

#### 4.5.1.8 Bladder control

Fully independent refers to the stroke survivor being continent during the day and at night. Twenty four (45%) of participants reported being fully continent (Figure 4.43).

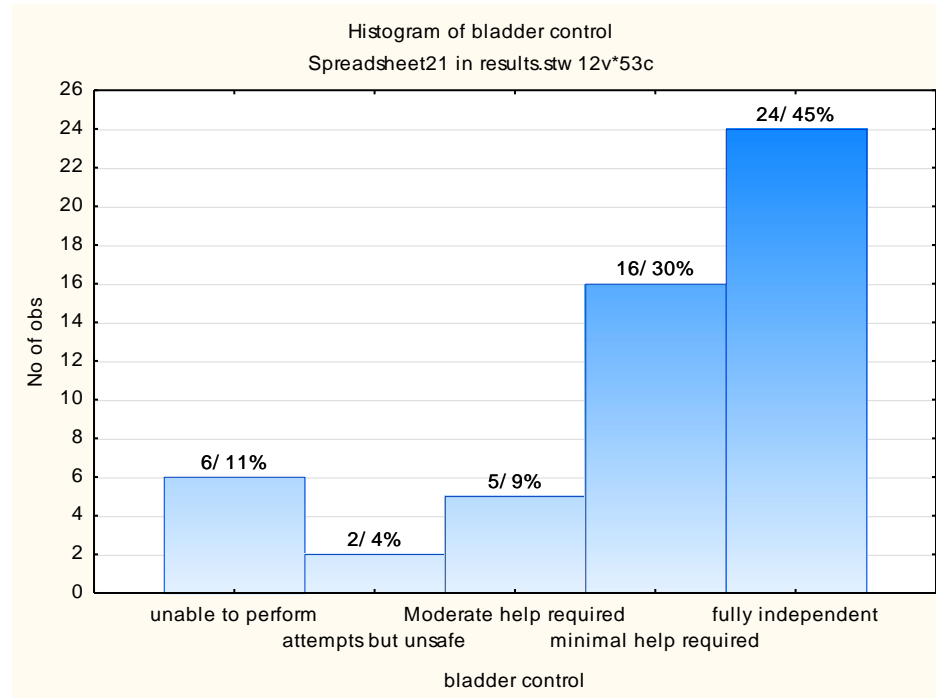


Figure 4. 43 MBI scores - Bladder control (N=53)

#### 4.5.1.9 Ambulation

In order to be classified as fully independent, the stroke survivor must be able to walk safely for a distance of 50m indoors without any form of assistance from another person. They may use some form of walking aid (e.g. crutch, walking frame). Figure 4.44 illustrates that 23 (57%) participants were able to walk independently indoors.

The researcher observed that many of them required some form of assistance outdoors, where greater demands were made on balance. Although not specifically tested, impairments such as loss of sensation and poor proprioception are likely to have played a role in this regard.

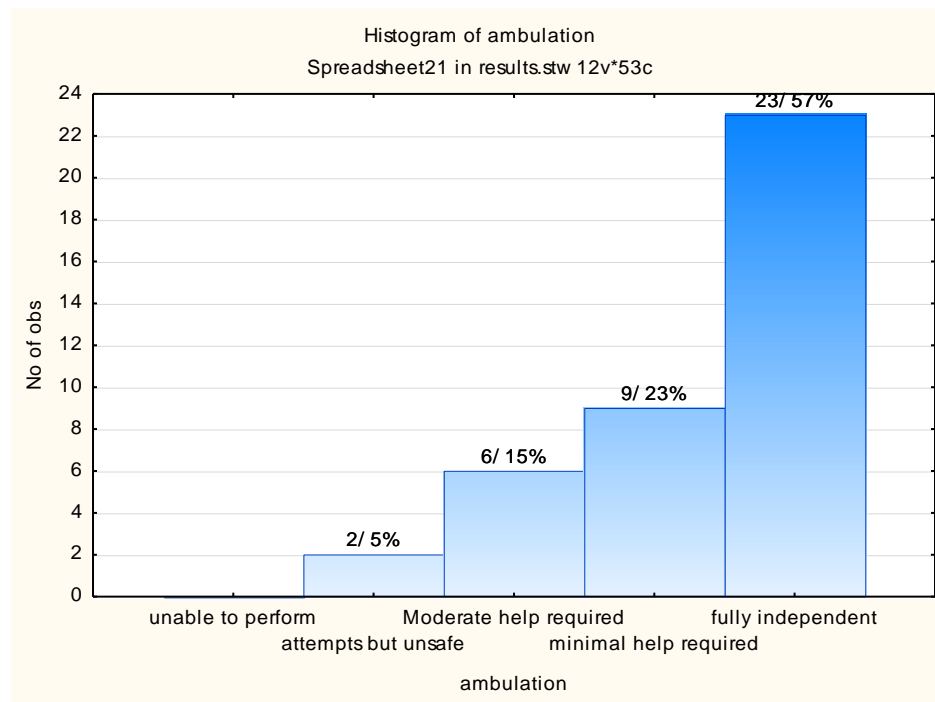


Figure 4. 44 MBI scores – Ambulation (N=40)

#### 4.5.1.10 Wheelchair mobility

Independence refers to the stroke survivor being able to propel the wheelchair independently for 50m, being able to turn corners and get to a toilet or table. As indicated in figure 4.45 the majority of wheelchair users (8: 62%) were unable to perform these activities.

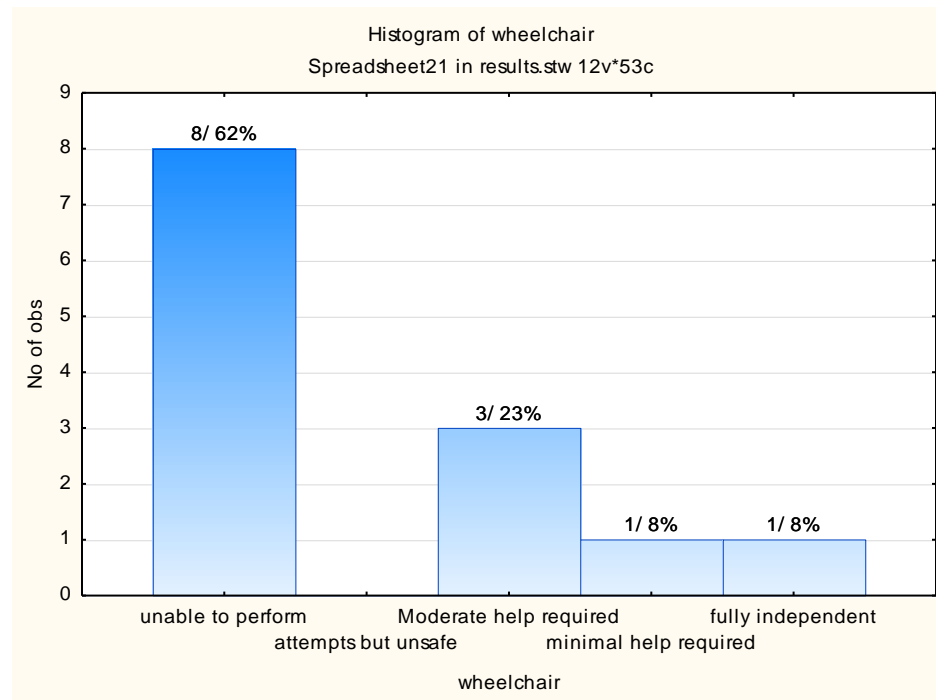


Figure 4. 45 MBI scores - Wheelchair mobility (N=13)

#### 4.5.1.11 Chair -bed transfer

The stroke survivors must be able to approach the bed in a wheelchair or from a standing position. They must be able to get onto the bed safely, lie down and return to the sitting position without any assistance.

Figure 4.46 shows that 25(47%) participants were fully independent in terms of chair –bed transfers.

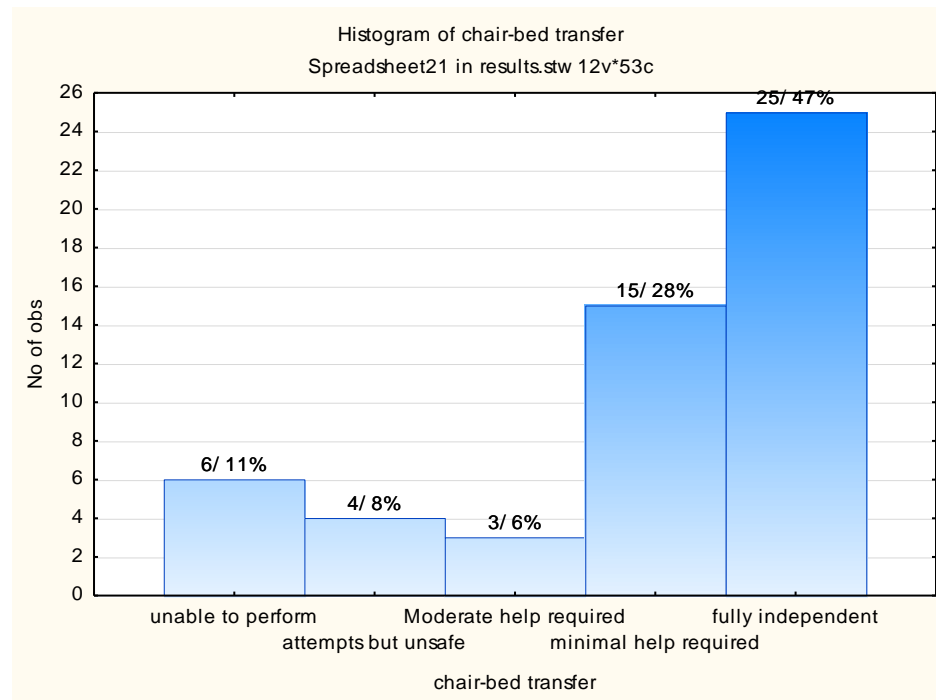


Figure 4. 46 MBI scores - Chair-bed transfer (N=53)

### 4.5.2 Activities of daily living (SIS3)

The mean score was 49.17 and Median 50.00 out of a possible score of 100 (Figure 4.47). The minimum score was zero.

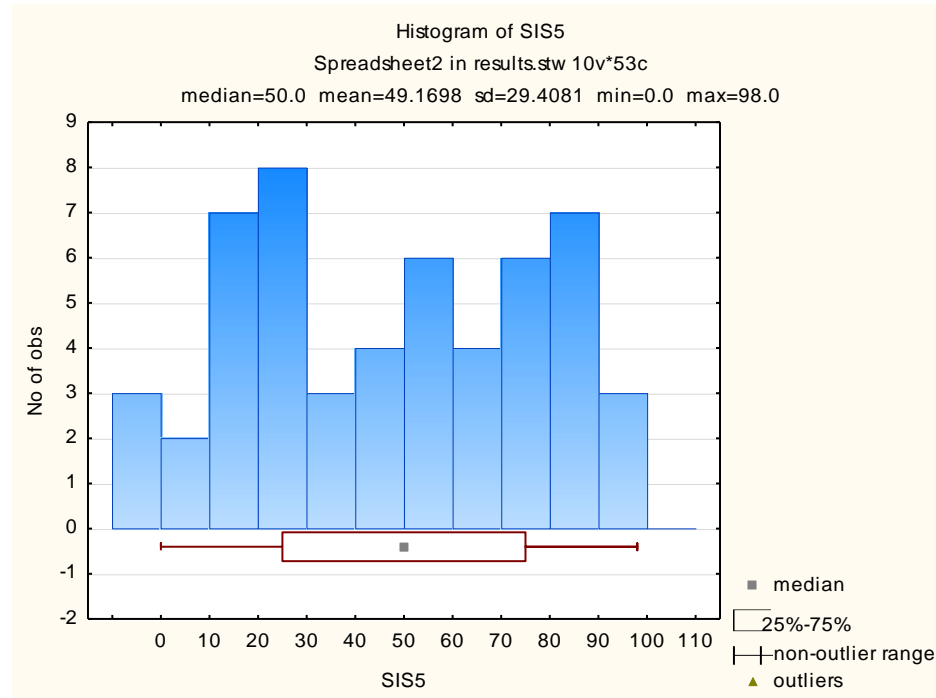


Figure 4. 47 SIS3.5 - Activities of daily living (N=53)



### 4.5.3 Mobility in the home and community (SIS3)

Mobility scores on the SIS3 varied widely, but a mean score of 51.51 and a median of 53 indicated that many participants experienced challenges in this regard.

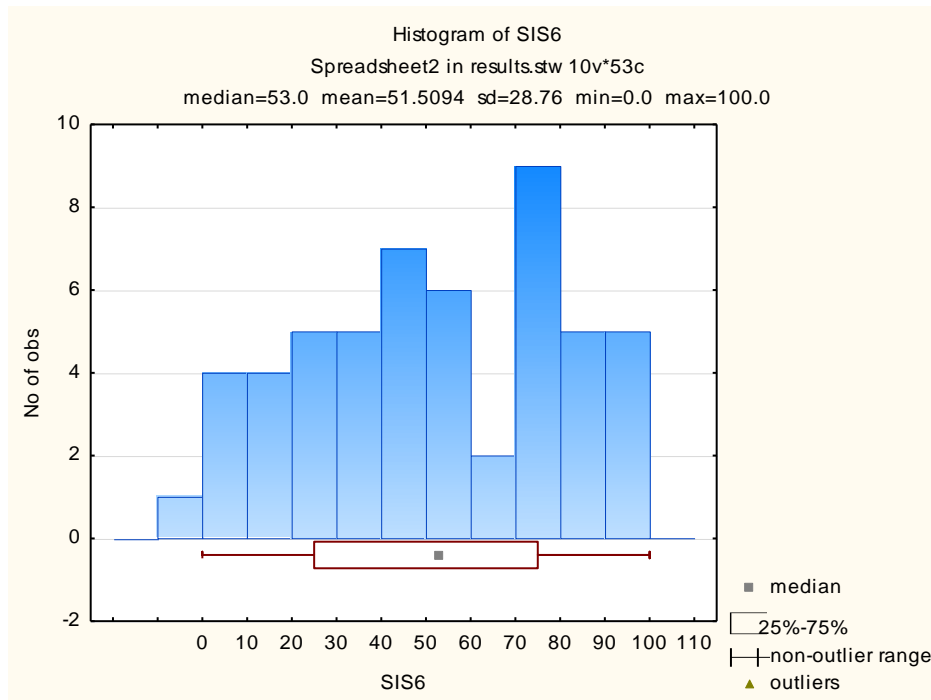
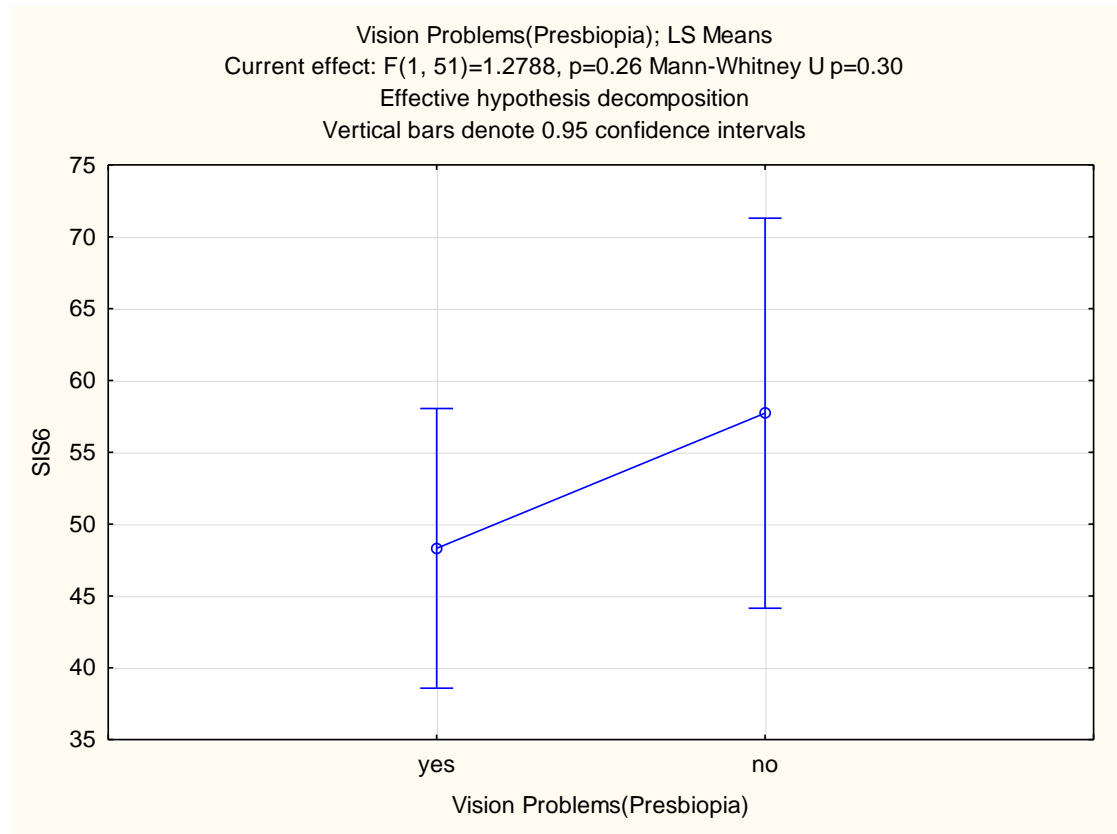
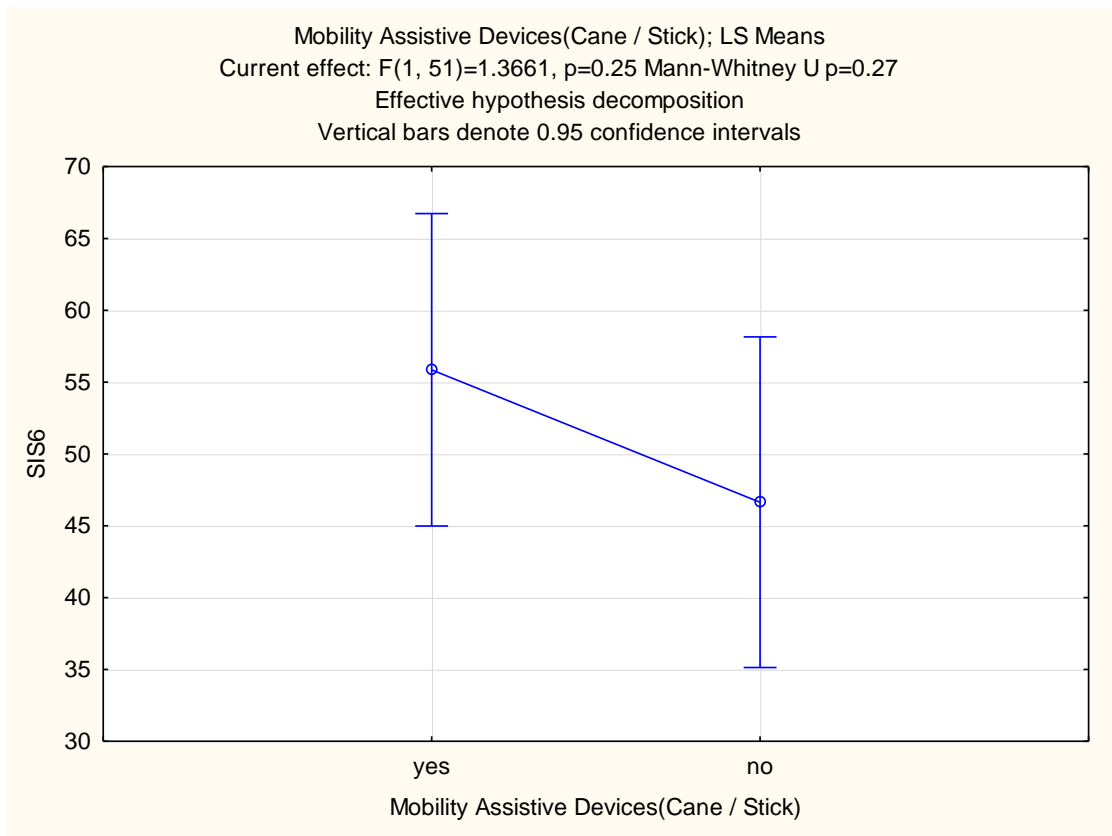


Figure 4. 48 SIS3.6 – Mobility at home and in community (N=53)



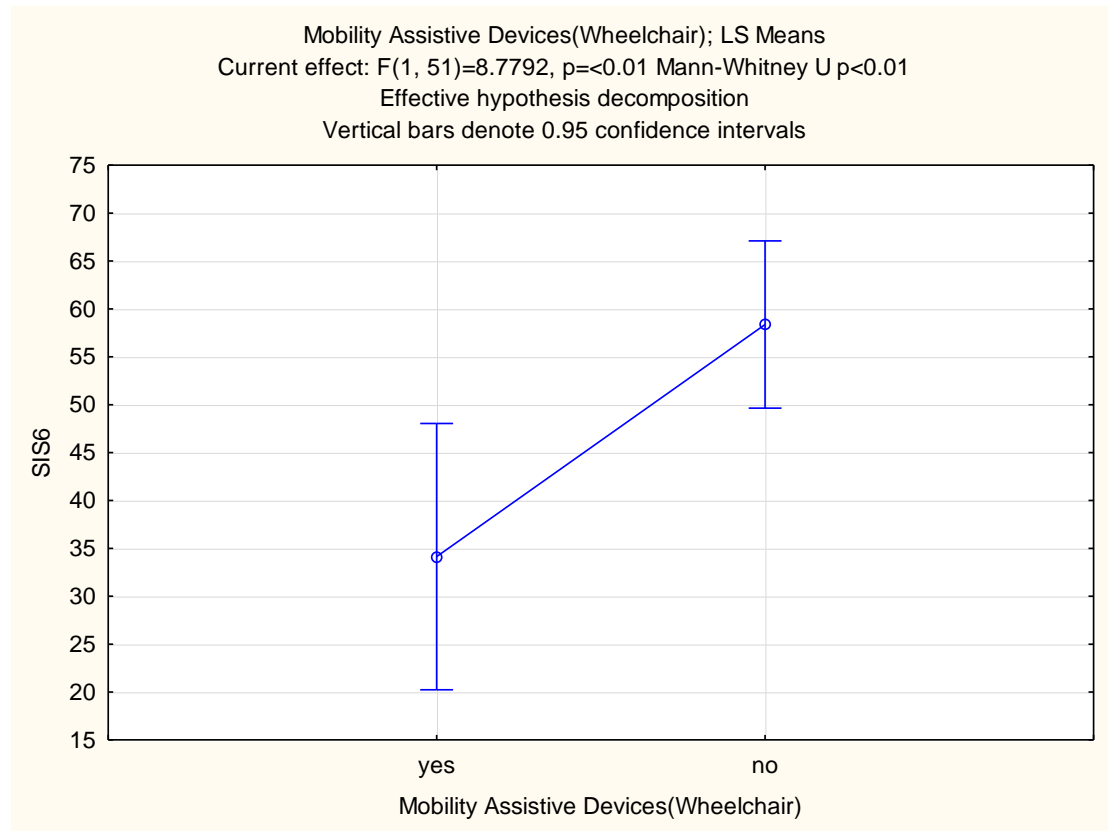
**Figure 4. 49 Statistical correlation of vision problems to SIS3.6 scores (N=53)**

Although the p value does not reveal any statistical significance, Figure 4.49 indicates that where participants had fewer visual impairments (presbiopia), scores for community mobility were higher. A similar trend was evident with other vision impairments (diabetic retinopathy and cataract).



**Figure 4. 50 Statistical correlation of mobility assistive devices (cane/ stick) to SIS3.6 scores (N=53)**

Although the p value does not reveal any statistical significance, this graph indicates that utilisation of canes /walking sticks does have a positive impact on community mobility.



**Figure 4. 51 Statistical correlation of mobility assistive devices ( wheelchairs) to SIS3.6 scores (N=53)**

This figure illustrates that issuing of wheelchairs did not improve community mobility. ( $p=0.01$ ). There was a very similar finding with custom measured wheelchairs. ( $p=0.01$ ). Issuing of walking frames did not result in improved community mobility ( $p=0.05$ ).

Patient age, visuomotor organization, physical geography, and transport all had  $p$  values of  $< 0.01$  indicating that these factors had a statistically significant impact on community mobility.

## 4.6 Participation Restrictions Of Participants

The majority of participants experienced restrictions in their ability to participate in social, religious, sport, leisure and employment activities as measured by the SIS3. This is illustrated in Figure 4.52 where the mean score was 31.34 and the median 28 out of a possible total of 100. As illustrated by the left most bar on the graph, four (8%) participants obtained a score of zero.

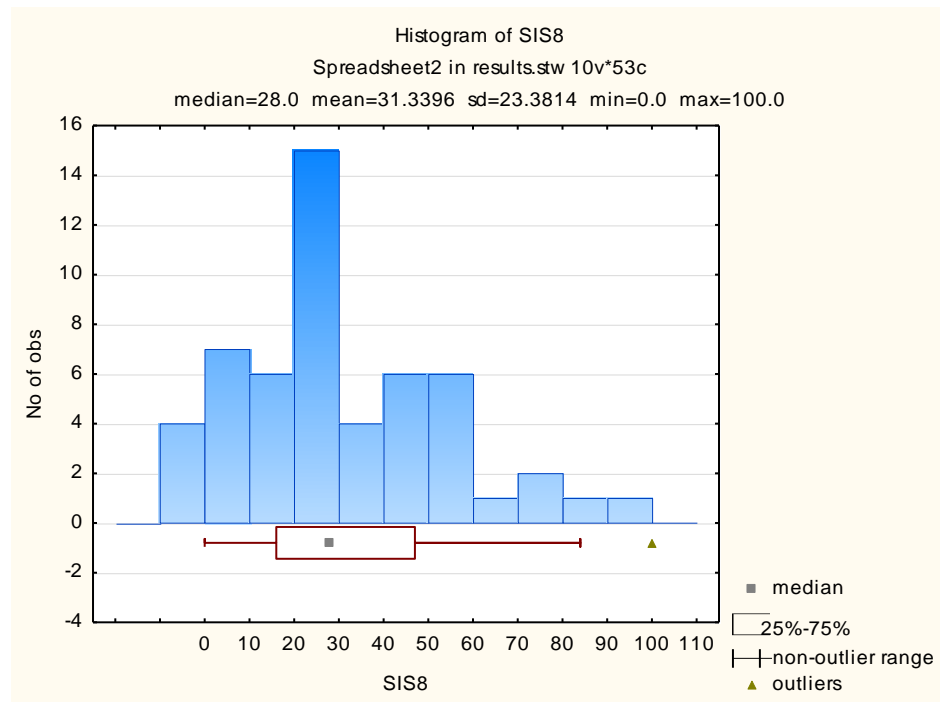


Figure 4. 52 SIS3.8 – Participation (N=53)

Table 4: SIS3.8 correlations

		merged in results.stw				
		1	2	3	4	5
		variable 1	variable 2	Spearman	Spearman p-val	# cases
1	SIS8	SIS1		0.49	<0.01	53
2	SIS8	visual perception		0.57	<0.01	53
3	SIS8	spatial perception		0.31	0.02	53
4	SIS8	motor praxis		0.58	<0.01	53
5	SIS8	visuomotor org		0.50	<0.01	53
6	SIS8	thinking operation		0.61	<0.01	53

This table shows that cognitive and perception impairments as well as physical impairments (SIS3.1) had a statistically significant impact on participation (SIS3.8)

**Table 5: SIS 3.1 and SIS3.7 scores for participants < 60**

Age	Type of Employment	SIS3.1	SIS3.7
		Score/100	Score/100
57	Builder	88	100
59	Chef	88	50
54	Welder	13	0
54	Security Guard	63	60
57	Builder / Plumber	75	65
56	Domestic Worker	63	40
58	Gardener	25	0
46	Security Guard	38	0
54	Construction Labourer	31	25

Nine participants in the economically active age group were unemployed as a result of the stroke and vision impairments. Table 5 lists the scores of these participants for the SIS3.1 where they rated the strength of their upper and lower limbs. Bilateral hand function would also have played an important role in performing work related tasks. SIS3.7 scores give an indication of their ability to use the hand most affected by the stroke.

**Table 6: LOTCA scores of participants < 60 and who were employed at the time of the stroke.**

Age	Type of Employment	Orientation Score/16	Visual Perception Score/16	Spatial Perception Score/12	Motor Perception Score/12	Visual Organiz. Score/28	Thinking Operations Score/31	Concentration Score/4
59	Chef	15	15	10	12	18	23	3
54	Welder	16	16	12	12	25	14	3
54	Sec. Guard	16	16	12	12	26	24	3
57	Builder & Plumber	16	16	12	12	23	29	4
56	Domestic Worker	14	15	12	11	12	12	3
58	Gardener	7	13	12	10	13	13	2
46	Sec. Guard	16	16	12	12	24	20	3
54	Construct Labourer	13	12	12	10	15	14	2

Table 6 lists the LOTCA scores of eight participants who fell within the economically active group and who were unemployed as a result of the stroke. The maximum possible scores are listed under each heading. The one 57-year old builder was blind as a result of diabetic retinopathy and could not return to his former employment due to his visual impairments. His scores are excluded from the table as these impairments made it difficult for him to complete all sections of the assessment.

## 4.7 Rehabilitation Outcome Levels Achieved By Participants

Analysis of all quantitative data was done to determine the rehabilitation outcome level of each participant. Six (11%) participants were classified as being on rehabilitation outcome level 1. A further 21 (40%) participants had reached rehabilitation outcome level 2 and 16 (or 30%) had reached level 3. Eight (15%) had reached level 4. Only two (4%) participants had achieved rehabilitation outcome level 5 and had returned to full-time employment (Figure 4.53).

Two participants had part-time employment. However, the researcher classified them as level 4 as they both were dealing with unresolved issues which should have been addressed earlier in rehabilitation. The one had been working part-time prior to his stroke and had to further reduce his hours after the stroke. He had received no occupational or physio therapy and was having difficulty with walking, stair climbing and bath transfers. Self-scoring on the SIS3 in terms of participation was 63.

The other participant had been given part-time employment for a few months. Scoring on the SIS3 in terms of participation was 56. She appeared to be depressed and scored 31 on the SIS3 with regard to feelings and emotions.

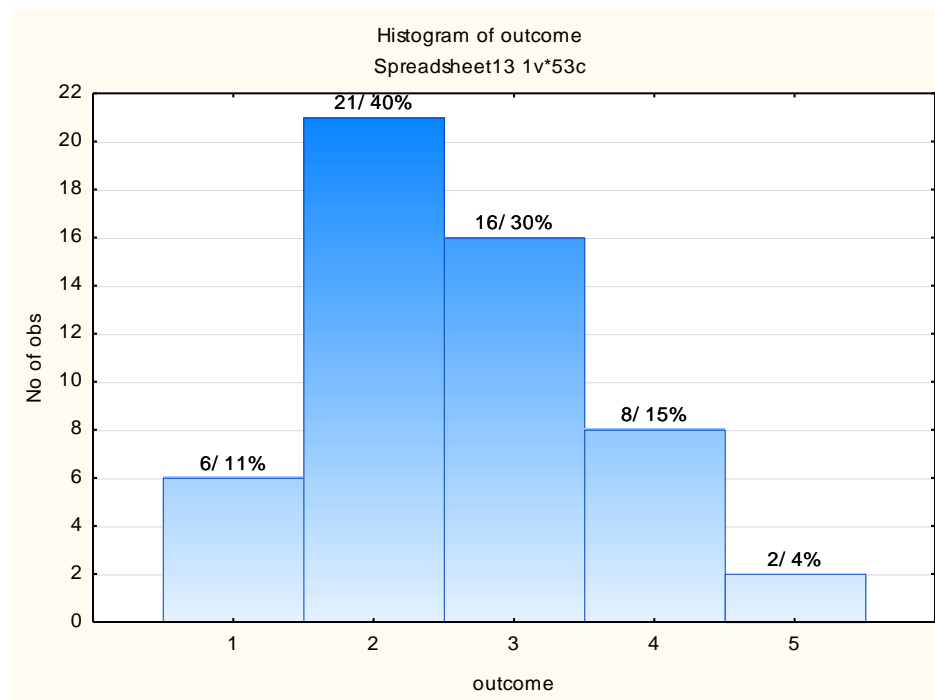


Figure 4. 53 Rehabilitation outcomes (N=53)



## **4.8 Environmental Factors**

Note that in all of the graphs in this section, negative scores indicate environmental barriers and positive scores facilitators. A score of zero indicates that the particular environmental factor had no impact on the participant.

### **4.8.1 Products and technology**

According to the ICF, this implies any "product, instrument, equipment or technology adapted or specially designed for improving the function of a disabled person" (World Health Organization, 2001d : 173).

#### 4.8.1.1 Products or substances for personal consumption

This refers to "any natural or human-made object or substance gathered, processed or manufactured for ingestion"(World Health Organization, 2001d: 173) and mainly refers to food and medication. A limitation of the study is that the researcher only recorded this in terms of food on the allocated form. Although detailed notes were kept about problems with medication, for the purpose of the study, this section on environmental factors should have been split into two categories. On the whole, participants reported being satisfied that they obtained their medication, but had problems with long queues and waiting times to receive medication. The impact of this on Rehabilitation Outcomes will be discussed further in the next chapter.

Figure 4.54 indicates that 30 (57%) participants reported a shortage of food as being a barrier, with nine (17%) indicating that this was a complete barrier. Fourteen (26%) reported food being a mild facilitator, but on the whole the researcher gained the impression that many of the study participants were battling to feed themselves and their families.

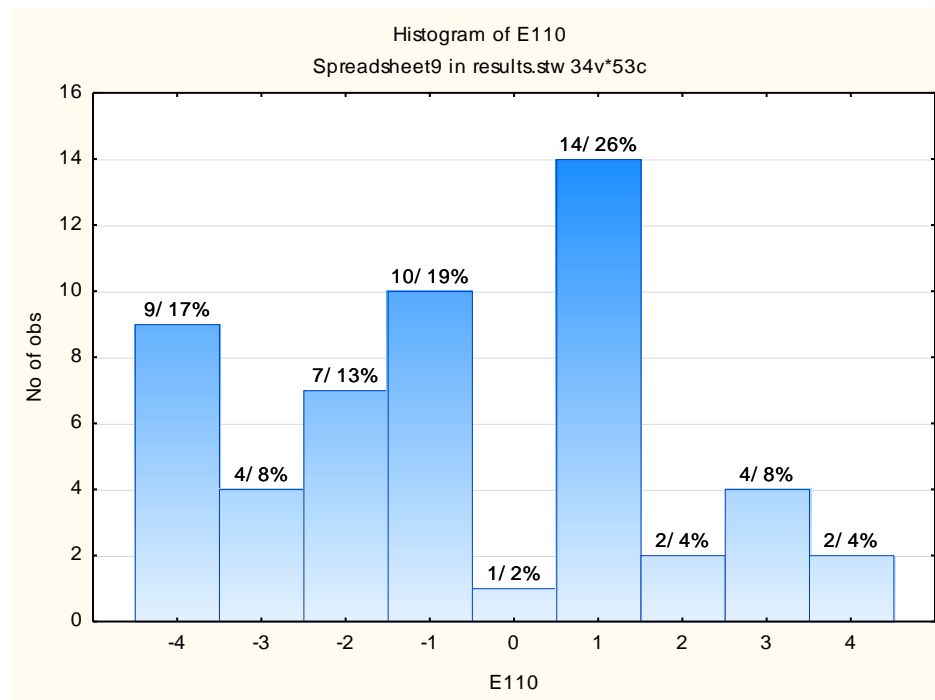


Figure 4. 54 E110 - Products or substances for personal consumption (N=53)

#### 4.8.1.2 Products and technology for personal use in daily living

This refers to the availability of such items as clothing, house-hold appliances and furniture as well as equipment which can assist people with disabilities in their daily life. Seventy-seven percent of participants perceived the shortage of these items as a barrier (Figure 4.55).

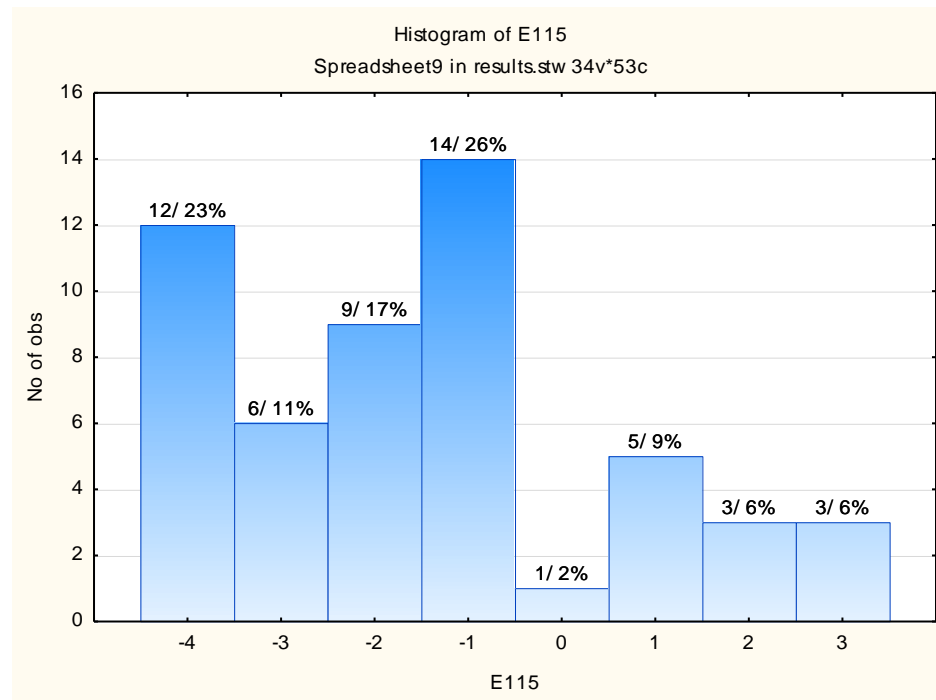


Figure 4.55 E115 - Products and technology for personal use in daily living (N=53)

### 4.8.1.3 Products and technology for personal indoor and outdoor mobility and transport

This refers not only to transport such as buses and cars, but also to wheelchairs and other specialized equipment for people with disabilities.

The lack of both public and private transport created a considerable barrier to community participation and in accessing rehabilitation and other services as the following quote from the qualitative data shows: *"Because it is so difficult to get to the hospital –I have to ask my son – often he has to put in leave at work to help."*

Eighty percent of participants reported on lack of transport as being a barrier. Of these, 45% considered transport to be a complete barrier (Figure 4.56).

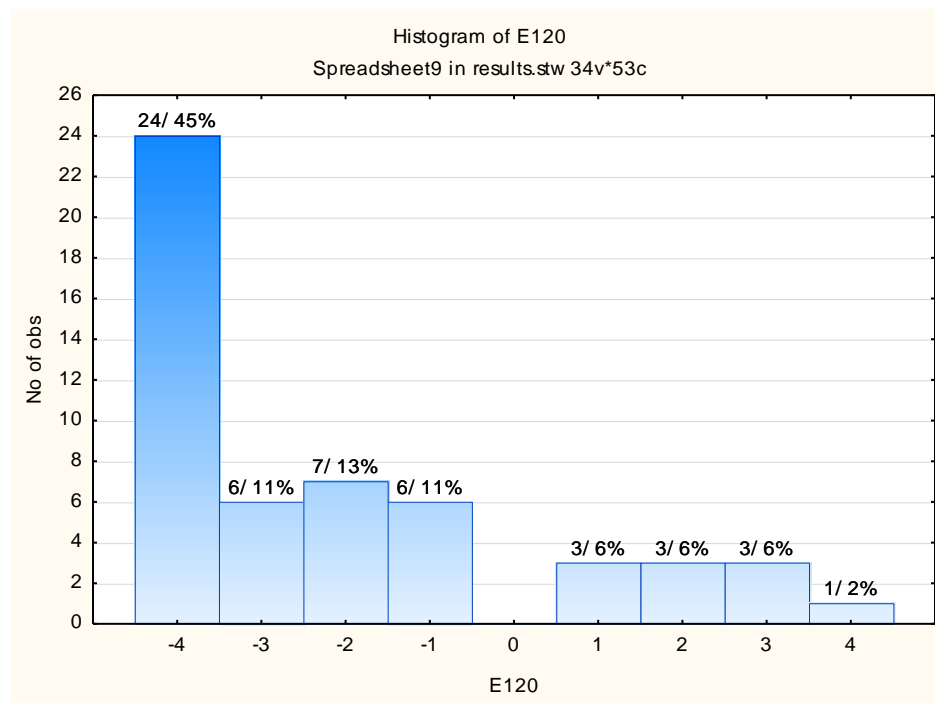
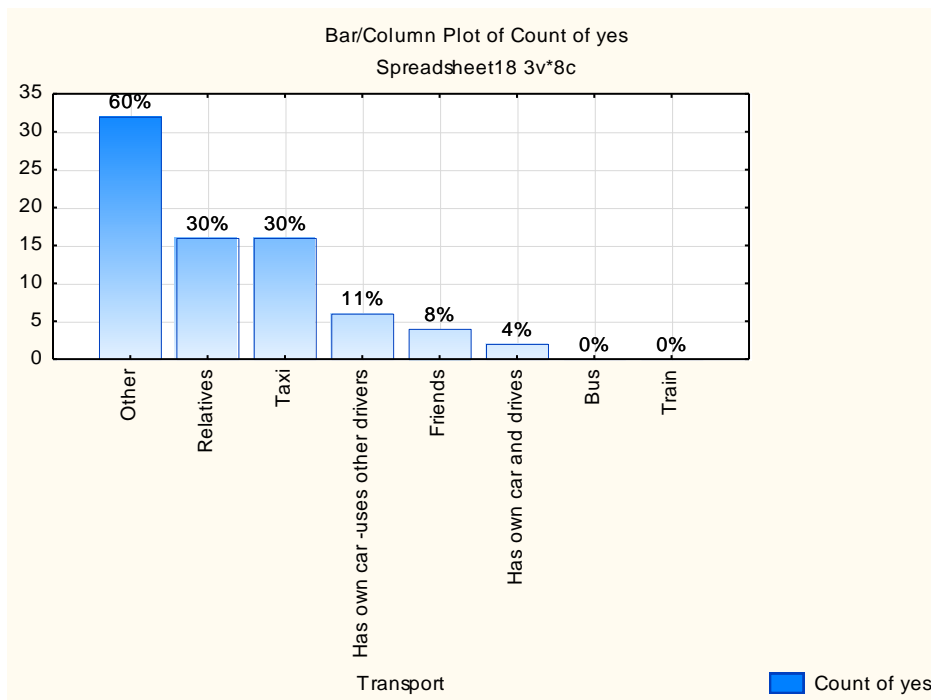


Figure 4. 56 E120 - Products and technology for personal indoor and outdoor mobility and transport (N=53)

With regard to the types of transport used, 30% of participants had sufficient mobility to access taxis. A further 30% relied on relatives for transport and 8% made use of assistance from friends. Eleven percent of participants owned vehicles but for a number of reasons could not drive after the stroke and relied on other drivers. Four percent of participants were driving their own vehicles again after the stroke (Figure 4.57).



**Figure 4. 57 Mode of transport**

Thirty-two percent of the participants reported having to pay people in the community to transport them, often at significant cost. Many were paying R250 –R300 to be transported to Tygerberg Hospital for appointments. Although HEALTHNET Services are available, participants were not aware of this service or how to access it. Others reported difficulty in getting to health facilities from where this transport departs.

Wheelchair users in particular found it difficult to access taxis which increased transport costs for them. The normal return taxi fare from Lwandle to Somerset West is R14. Wheelchair users were paying R100.00 to be transported by car. One participant who had to get from Macassar to the hospital in Somerset West on a regular basis, to have warfarin levels checked, was paying R80 for a return trip by car. The normal taxi fare is R15.

For seventeen participants wheelchairs were their only means of accessing the nearest CHC or clinic. Many of them got pushed long distances, with one participant travelling approximately 8 kms to get to the CHC and then home again. According to *Healthcare 2010*, people should not have to travel more than 3kms to access clinics (Western Cape (South Africa). Department of Health, 2007). Several participants also commented on the flight of stairs over the railway lines at the van der Stel, Somerset West and Bellville stations as being a significant barrier to them in using the train as a medium of transport.

#### 4.8.1.4 Products and technology for communication

This refers to equipment such as telephones and television, as well as communication boards, computerized software, writing devices and other specialized apparatus to assist people with communication impairments. Sixty-four percent of participants considered products and technology for communication as a barrier, mainly due to the fact that they did not have a telephone or couldn't afford the cost for this service or cellphone airtime. Twenty-one percent considered having a landline or cellular phone as a mild facilitator as they had a means of contacting acquaintances and emergency services (Figure 4.58).

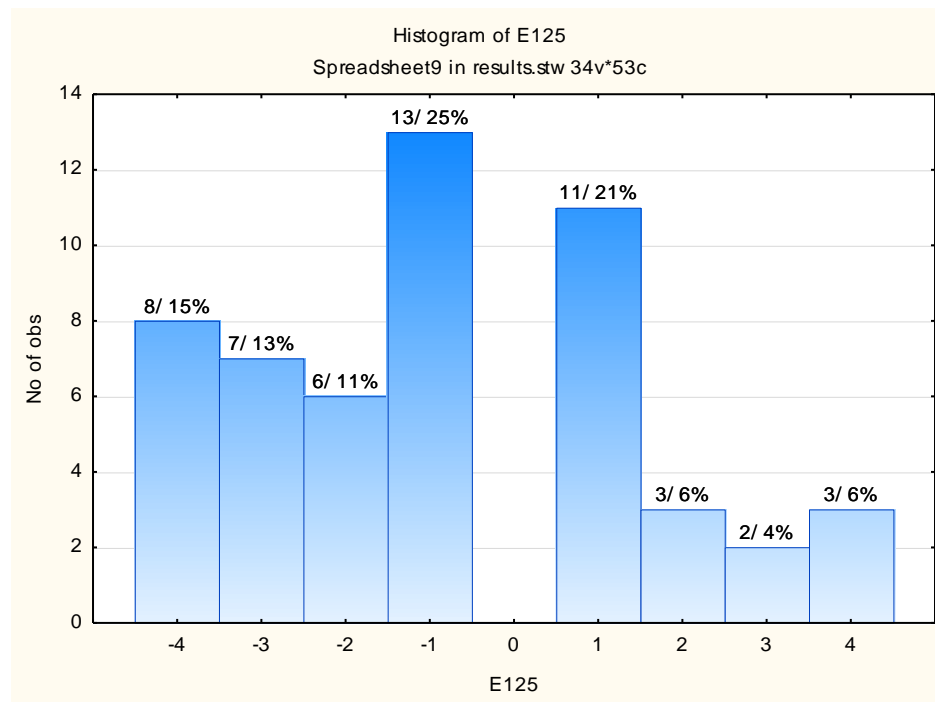


Figure 4. 58 E125 - Products and technology for communication (N=53)

The researcher noted that 50 participants had television in their homes. She found it extremely difficult to contact participants telephonically. Numbers listed were non-existent, people did not have airtime or lacked a cellphone charger. In all likelihood this makes it difficult for health services to confirm appointments and inform people of pathology results (e.g. warfarin levels.) Only two participants had access to computers, email and faxes. Obtaining pensions and disability grants, often requires detailed information from previous employers; access to email, telephones and fax machines could facilitate sorting out these issues. Participants were generally unaware of specialised products and equipment that could enhance communication for PWDs and none of them had received any assistance in this regard.

#### 4.8.1.5 Products and technology for employment

This refers to any form of equipment or technology which enhances participation in work-related activities.

Sixty percent of participants responded that products and technology related to employment were not relevant to their situation and were neither a barrier nor facilitator. This was mainly due to the fact that they were over retirement age. Thirty-seven percent considered the lack of availability of products and technology to promote participation in work-related activities to be a barrier (Figure 4.59).

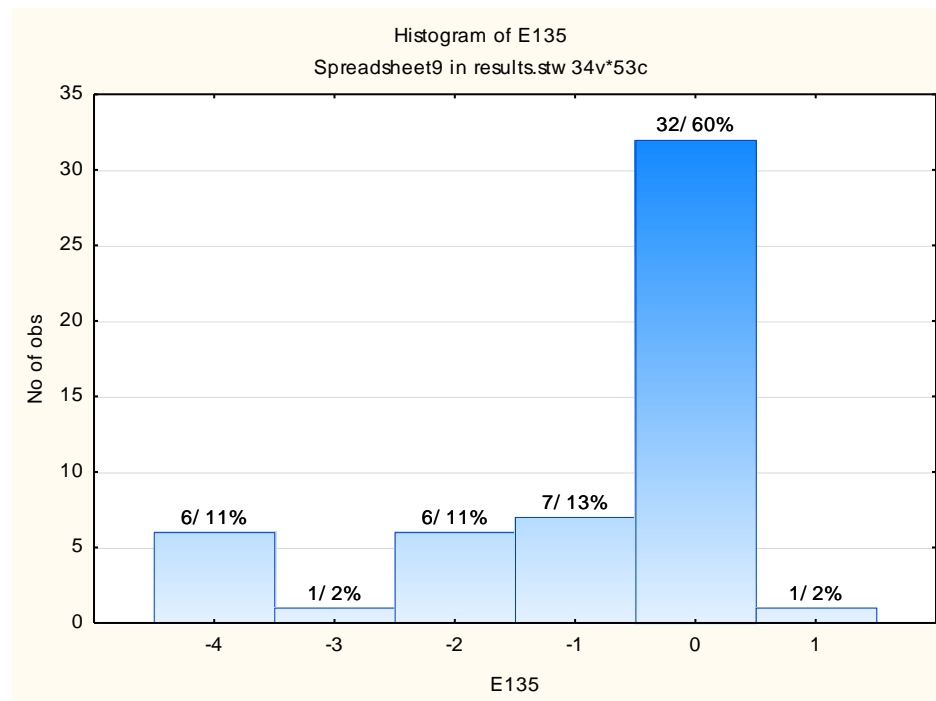


Figure 4. 59 E135 - Products and technology for employment (N=53)

#### 4.8.1.6 Design, construction and building products and technology of buildings for public use

This refers to the accessibility of entrances, exits and the facilities of public buildings. Many participants found this question difficult to answer, as the vast majority reported only leaving their homes to go to the hospital, CHC or clinic or for their pension or disability grant payment; they found all these buildings to be accessible. (The lack and cost of transport was given as the main barrier to participation.)

Many of them were also of the opinion that steps were not a problem and people always assisted if this was necessary. *"You make a plan!"*

However, 65% still rated public buildings in the Helderberg Basin as being inaccessible, mainly due to steps (Figure 4.60).

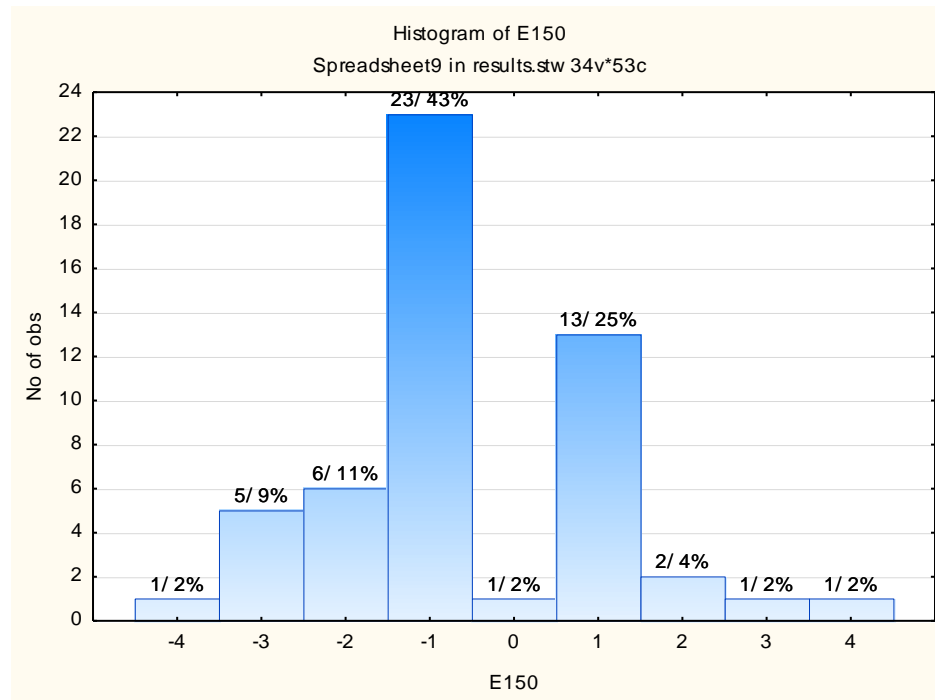


Figure 4. 60 E150 - Design, construction and building products and technology of buildings for public use (N=53)



#### 4.8.1.7 Design, construction and building products and technology of buildings for private use

This refers to the accessibility of peoples' homes and property. Fifty three percent of participants were satisfied with their accommodation and considered it to be a facilitator, but 48% found that steps/stairs, lack of facilities such as indoor toilets and the size and structure of homes were barriers (Figure 4.61).

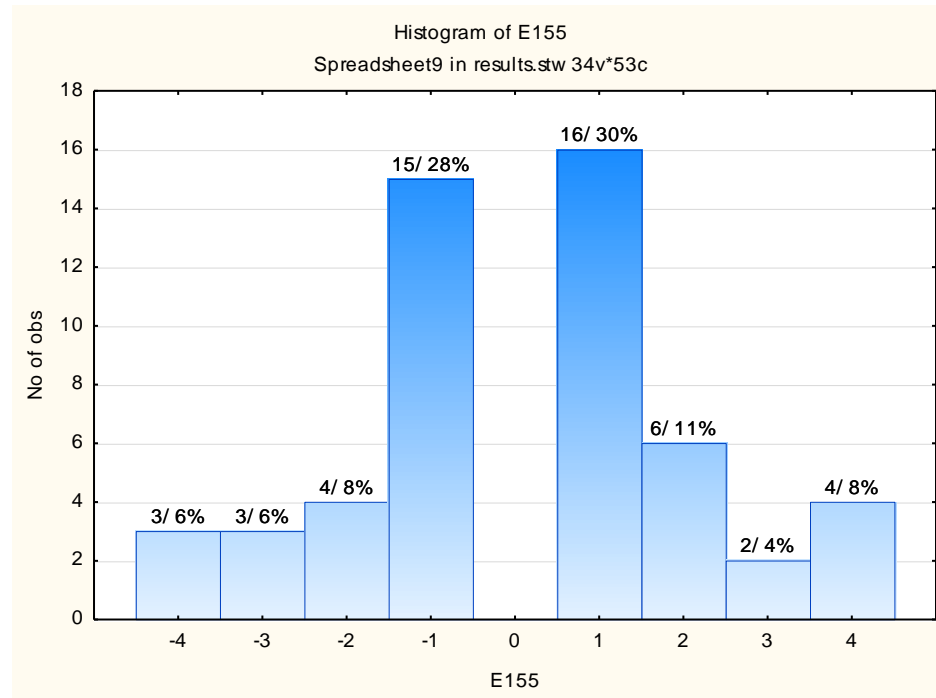


Figure 4. 61 E155 - Design, construction and building products and technology of buildings for private use (N=53)

#### 4.8.1.8 Assets

This refers to "Products or objects of economic exchange, such as money, goods, property and other valuables that an individual owns or of which he or she has rights of use" (World Health Organisation, 2001d:181).

Eighty-nine percent of participants described lack of assets as a barrier. Of these, 43% considered this to be a complete barrier (Figure 4.62).

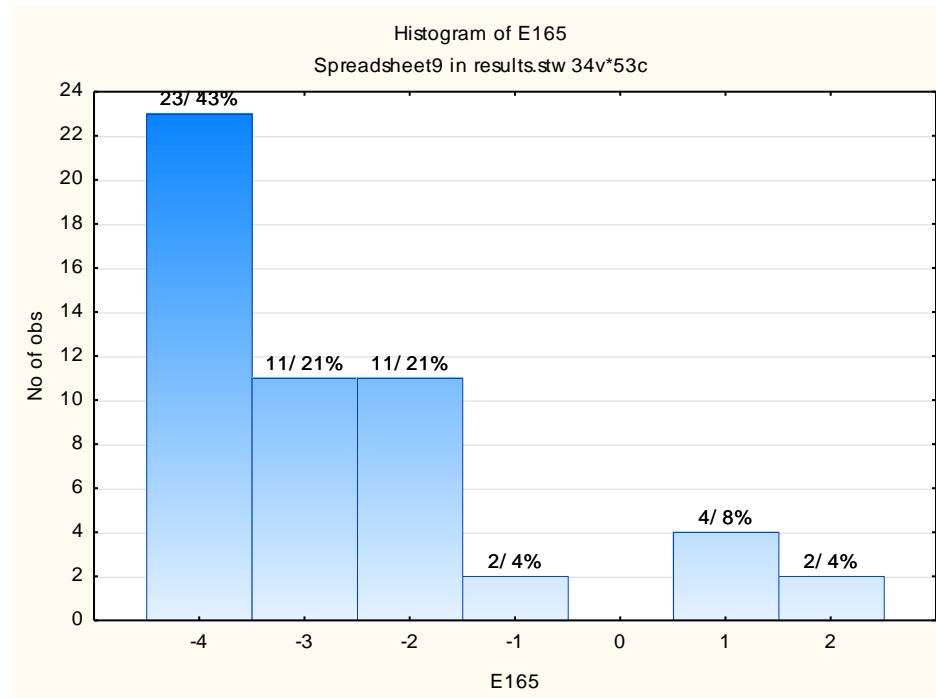


Figure 4. 62 E165 – Assets (N=53)

## 4.8.2 Natural environment and human made changes to environment

### 4.8.2.1 Physical geography

This refers to the relief and other descriptions of land masses and water.

Seventy one percent of participants reported on the physical geography of their surroundings as being a barrier. 51% reported mild barriers, 9% moderate barriers and 11% severe barriers (Figure 4.63).

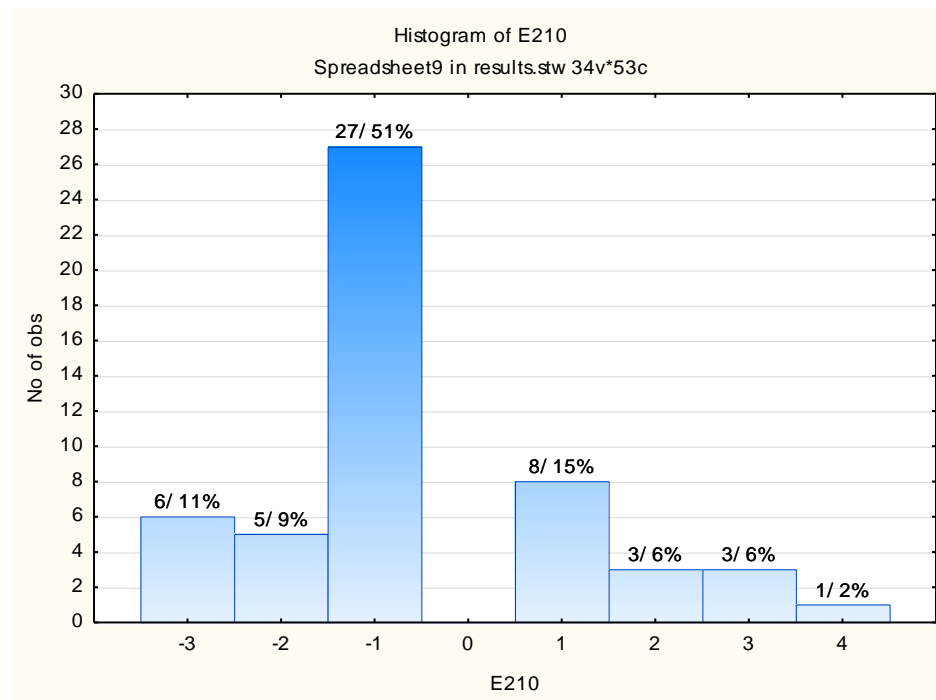


Figure 4. 63 E210 - Physical geography (N=53)

Stroke survivors and caregivers mainly commented on the difficulty of walking or pushing wheelchairs through sandy soil and over uneven terrain. Although many roads were tarred, there were potholes and often there was no pavement. Where there was a pavement, this was usually uneven and made walking and pushing wheelchairs difficult. Although in many areas the terrain was flat, some participants reported on the difficulty of having to push or walk up hills to get to the CHC or clinic.

The wife of a 54-year old participant describes the challenges encountered in the following manner: *"Because it is so difficult to get there. We have to take the wheelchair and it is difficult to get there. Once we had to go the CHC and it was also dark –we had to go in the wheelchair and that morning it was also extremely misty."*

### 4.8.3 Support and relationships and attitudes

Support and Relationships refers to the amount of "practical physical or emotional support, nurturing, protection, assistance" that is received by the person with a disability (PWD) from other people (World Health Organisation, 2001d:187).

Peoples' attitudes towards others are influenced by their "customs, practices, ideologies, values, norms, factual beliefs and religious beliefs" (World Health Organization, 2001d:190). Many people with disabilities experience the negative attitudes of people towards them as a barrier. Participants in the study also reported on people giving practical assistance but doing this reluctantly.

#### 4.8.3.1 Immediate family

Eighty-eight percent of participants found their immediate family to be helpful. Fifty-seven percent regarded their input as a significant facilitator (Figure 4.64) Seventy-two percent found attitudes of immediate family towards them as positive and helpful (Figure 4.65). However, some participants felt that family members cared for them physically, but did it reluctantly and from a sense of duty.

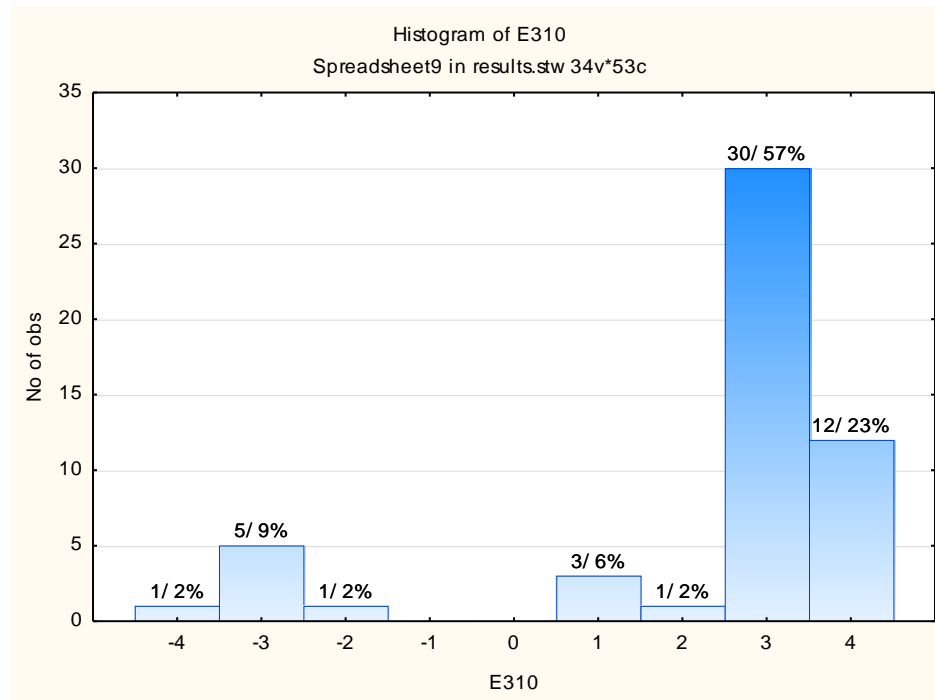


Figure 4. 64 E310 – Support and relationships - immediate family (N=53)

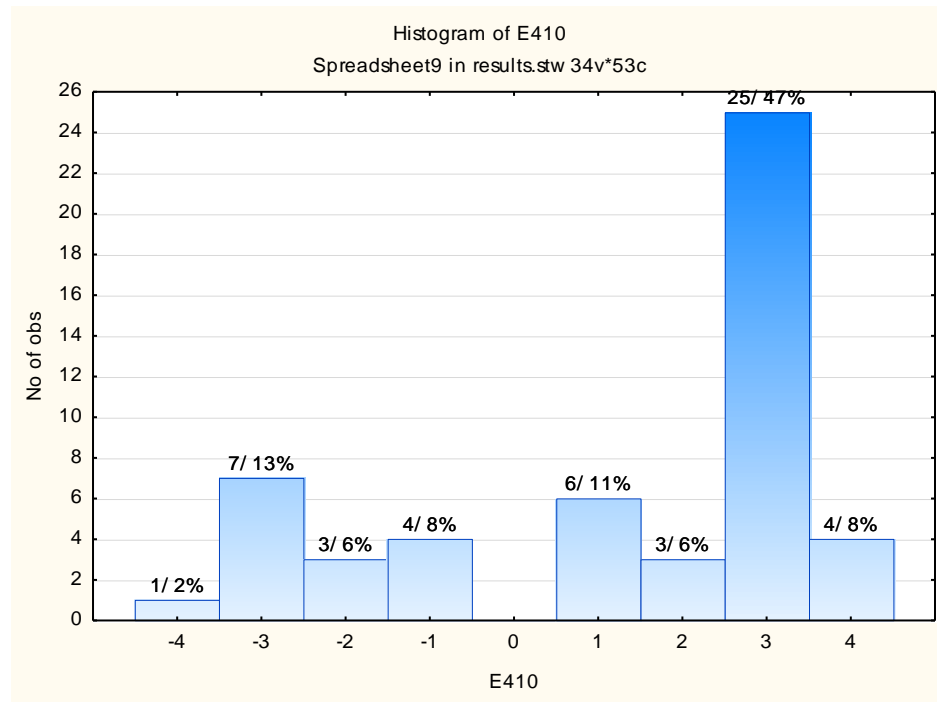


Figure 4. 65 E410 – Individual attitudes of immediate family (N=53)

### 4.8.3.2 Extended family

Less support was obtained from extended family with only 42% reporting assistance in this regard. For 23% of participants extended family lived in other provinces or towns and due to lack of transport and finances they never had contact with them and thus the extended family had no impact on their lives. Thirty-six percent saw the lack of assistance from extended family as a barrier (Figure 4.66). The impact of poverty, transport problems and attitudes is illustrated by a participant who initially stayed with family in the Strand and then moved back to her home in Macassar, approximately 16 kms away. She left her dentures in the Strand and months later she was still without them. Although she was having significant difficulty chewing and swallowing her food she reported that no one had the money for transport or the inclination to assist her by retrieving her dentures.

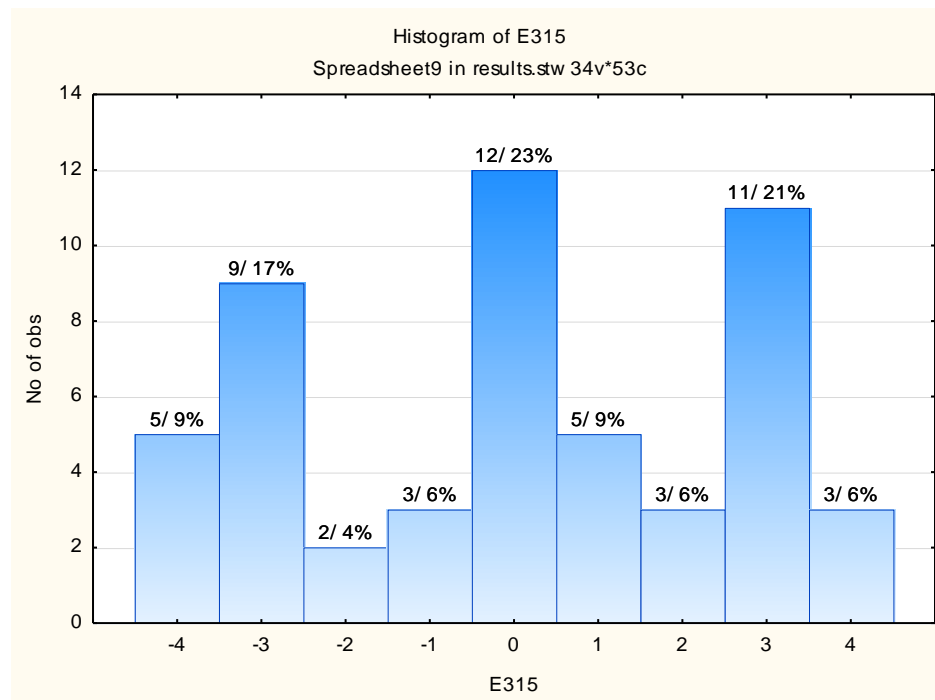


Figure 4. 66 E315 - Support and relationships - extended family (N=53)

### 4.8.3.3 Friends

Input from friends was seen as a facilitator by 51% of participants, with 28% considering this as a substantial facilitator. On the other hand, 49% felt that many friends had rejected them after the stroke and had given no form of assistance (Figure 4.67).

However, there was a clear majority consensus on the attitudes of friends as being a barrier as 54% of participants reported this. (Figure4.68). They were of the opinion that friends suddenly regarded them as being incompetent and stupid after the stroke.

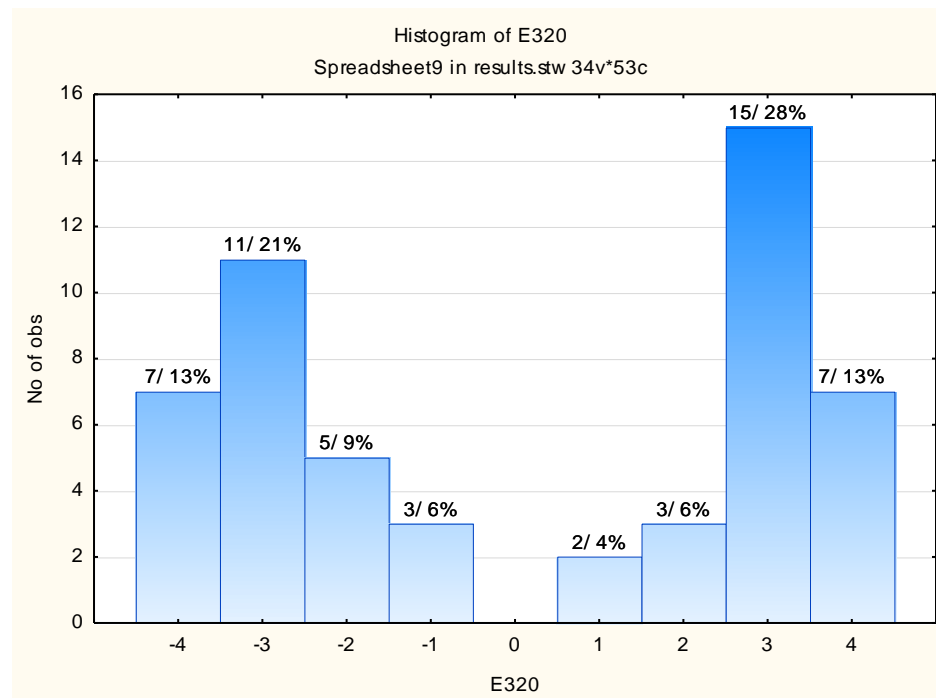


Figure 4. 67 E320 - Support and relationships – friends (N=53)

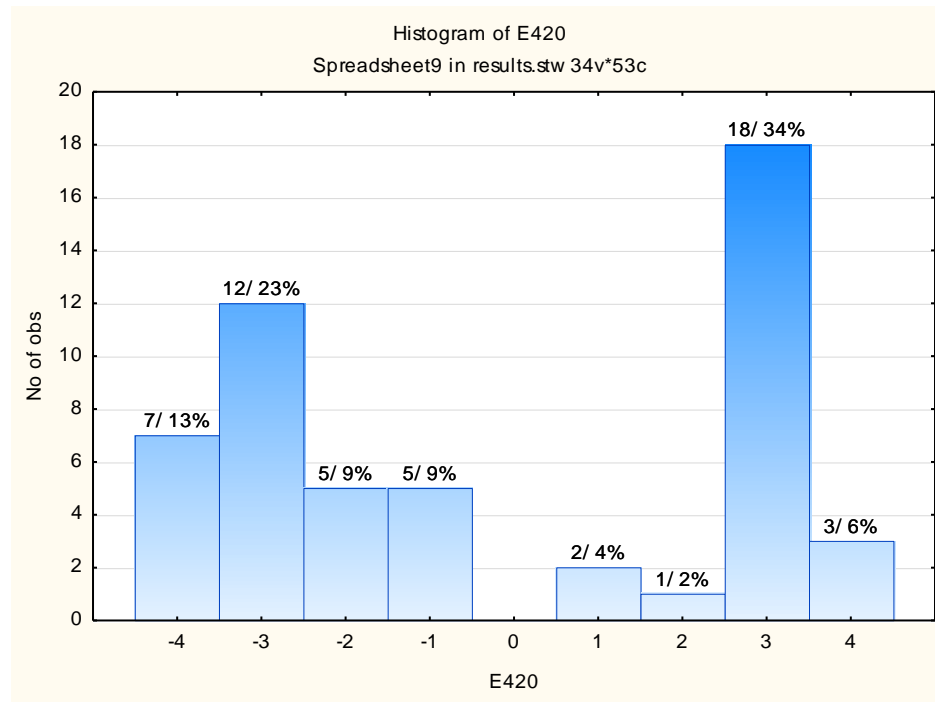


Figure 4. 68 E420 - Individual attitudes of friends (N=53)



#### 4.8.3.4 Acquaintances, peers, colleagues, neighbours and community members

Sixty percent of participants found acquaintances in the community to have been supportive (Figure 4.69). However, only 53% of them rated the attitude of acquaintances as a facilitator (Figure 4.70). Forty seven percent perceived societal attitudes as a facilitator and 53% regarded this as a barrier (Figure 4.71).

A significant barrier to participation in the community was fear of being attacked by "skollies" or "tik gangs" if stroke survivors ventured out on their own. Participants were of the opinion that they were vulnerable and likely to be harmed if they were in a wheelchair or seen to be walking with a limp or walking aid.

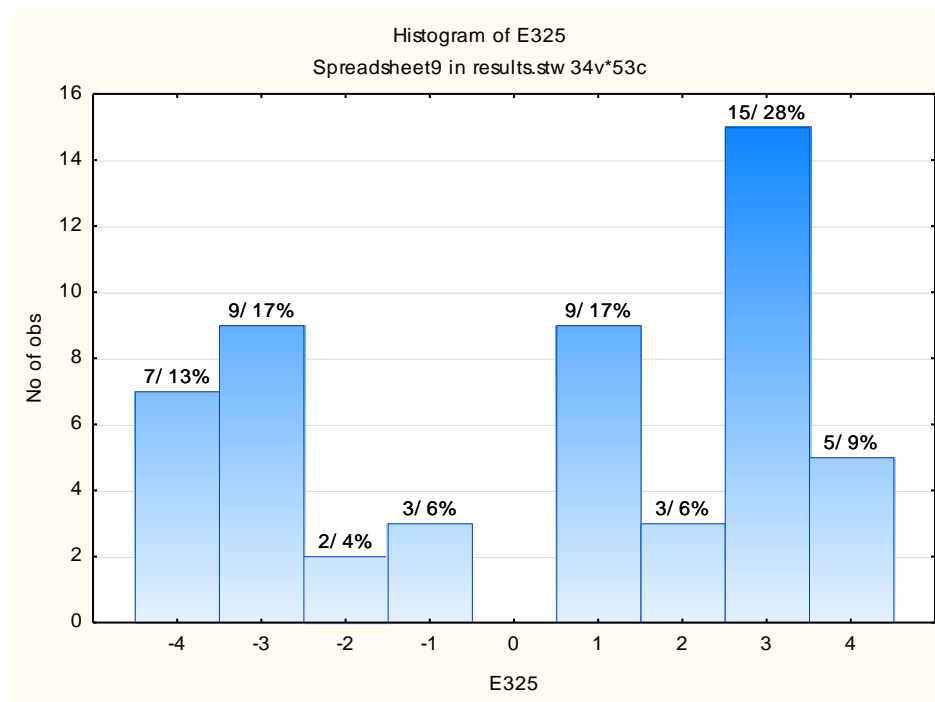


Figure 4. 69 E325 - Support and relationships - acquaintances, peers, colleagues, neighbours and community members (N=53)

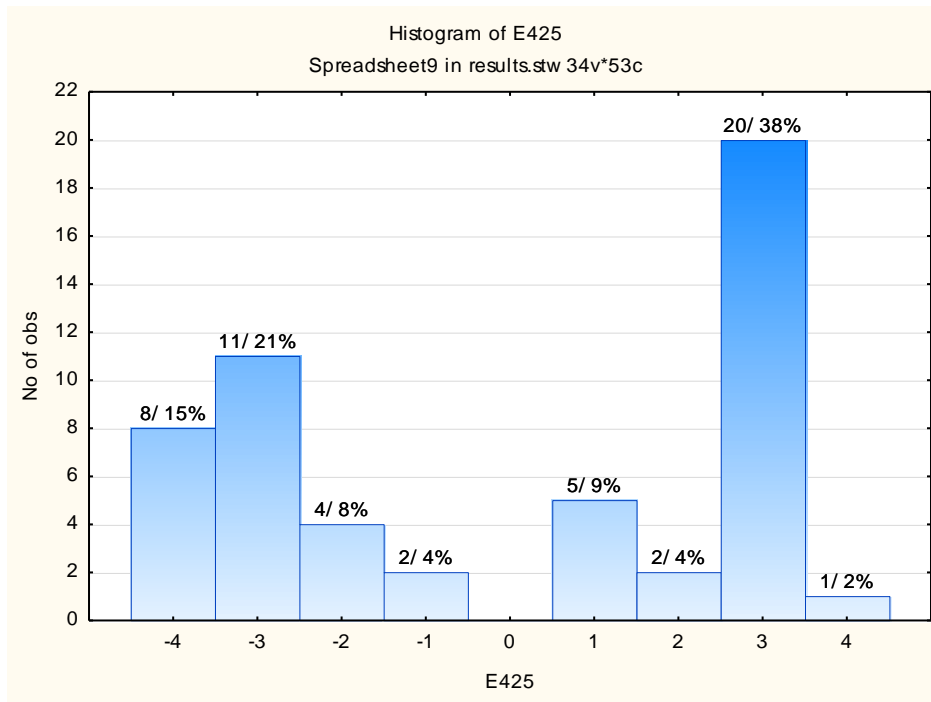


Figure 4. 70 E425 - Individual attitudes of acquaintances, peers, colleagues, neighbours and community members (N=53)

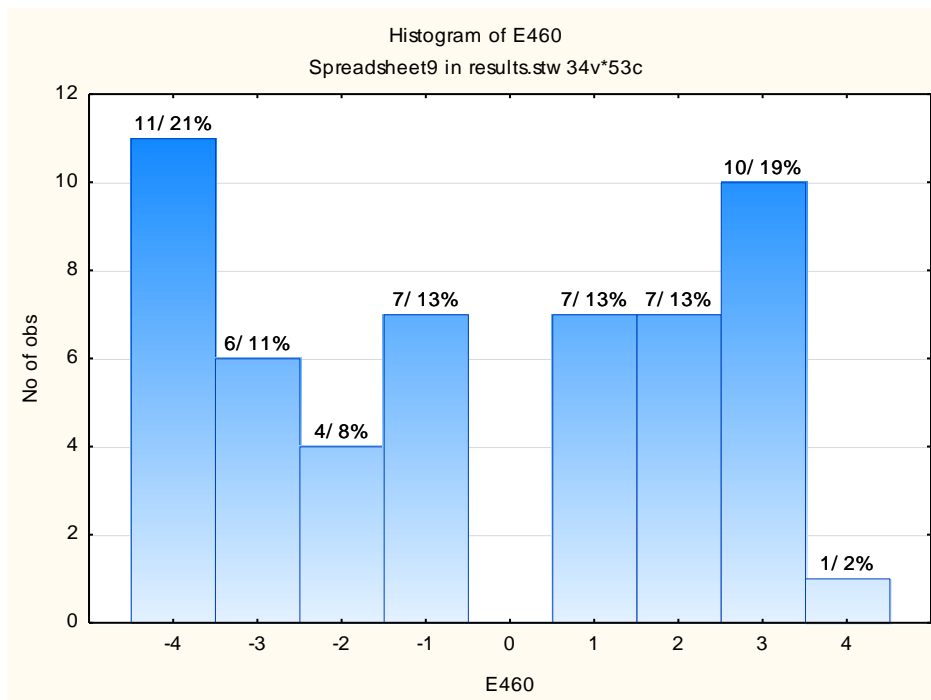


Figure 4. 71 E460 - Societal attitudes (N=53)

#### 4.8.3.5 Personal-care providers and personal assistants

For the purpose of this study, home-based carers have been regarded as personal-care providers. Home-based carers in the different communities assist with washing and dressing of stroke survivors at their homes. This service is limited and people do not necessarily receive help every day. Ultimately the burden of care rests upon family members. Thirty-two percent of participants reported receiving no assistance from home-based carers, but regarded this as neither a barrier nor a facilitator. Thirty-eight percent regarded this assistance as a facilitator. One participant chose to make use of option 9, which implies that the service was not applicable to his circumstances. (See Appendix 6. Environmental Factors form.)

The coding guidelines for the ICF state that an environmental factor can either be a barrier because of its presence or because of the lack of a service (World Health Organisation, 2001d). Twenty-nine percent of participants required assistance with washing and dressing but were not receiving this and reported this as a barrier of varied severity (Figure 4.72).

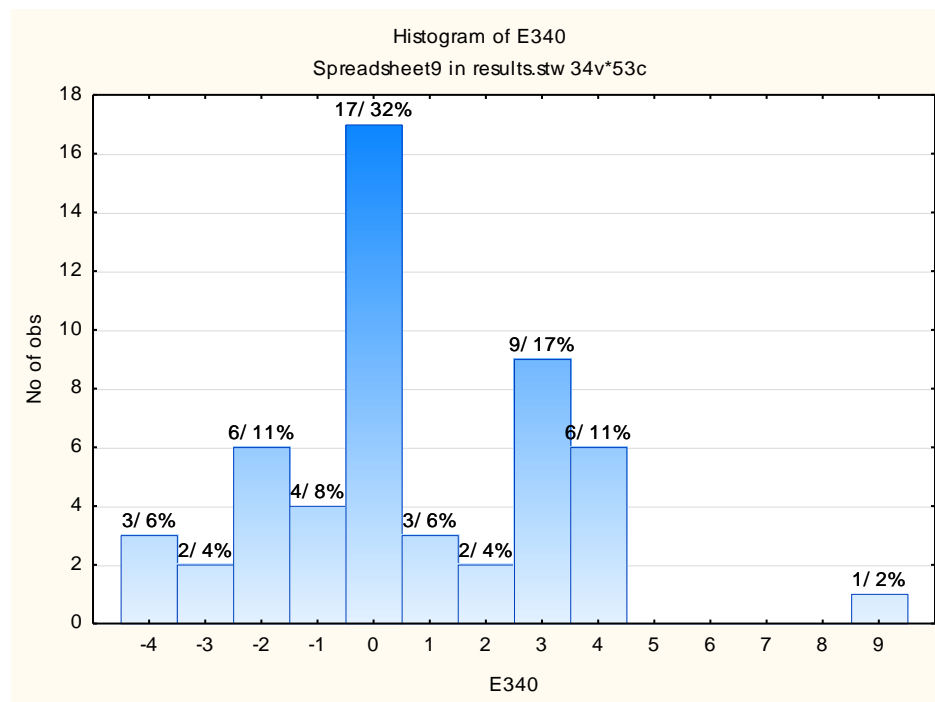
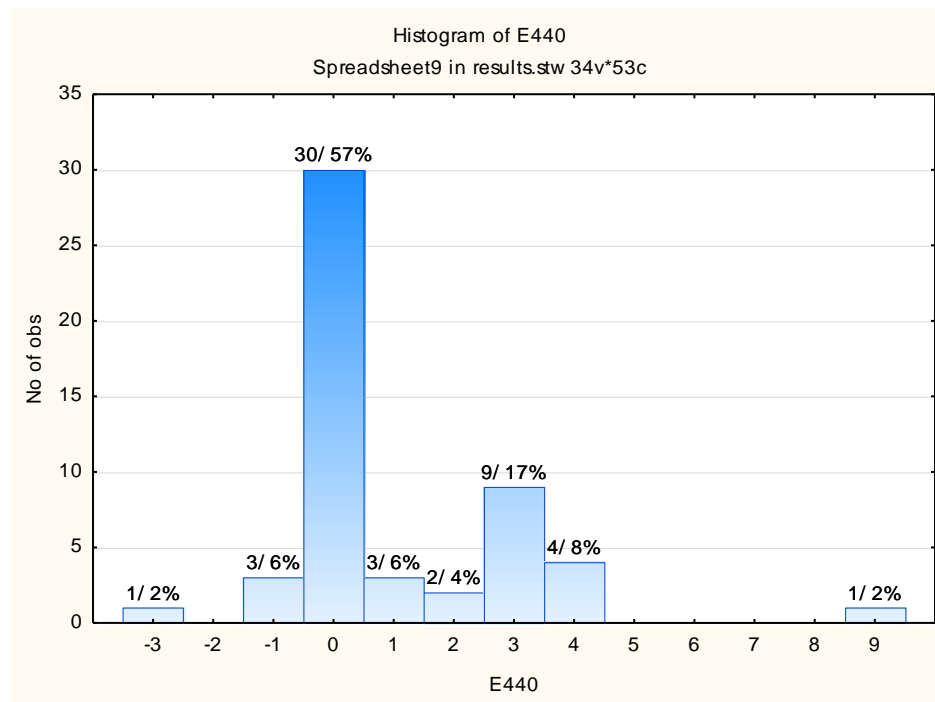


Figure 4. 72 E340 - Support and relationships - personal care providers and personal assistants (N=53)

Many participants were extremely positive about the services and attitudes of the home-based carers. Often close bonds were formed between the stroke survivor and their carer. Thirty-five percent reported on their attitudes as a facilitator. Only 8% percent regarded their attitudes in a negative light. A few participants and family members expressed concern about carers sharing confidential information about their clients with other people in the community and that this needed to be addressed. Some people also found them unreliable and reported that they did not come when they were meant to. Fifty-seven percent of participants had either not had caregivers or felt the attitudes of the caregivers did not really affect them in any way (Figure 4.73).



**Figure 4. 73 E440 - Individual attitudes of personal care providers and personal assistants (N=53)**

#### 4.8.3.6 Health professionals

The term health professionals refers to doctors, physiotherapists, speech therapists, occupational therapists, nurses, medical social workers, orthotists /prosthetists and audiologists (World Health Organisation, 2001d).

Participants and caregivers showed genuine appreciation of services rendered by health professionals in the Helderberg Basin. Ninety-seven percent of the participants reported on assistance by health professionals as a facilitator. Of these, 42% rated their input as a substantial facilitator and 23% a complete facilitator (Figure 4.74). Ninety-two percent of participants also perceived the attitudes of health professionals as a facilitator, with 43% rating their attitudes as a substantial facilitator and 11% a complete facilitator (Figure 4.75).

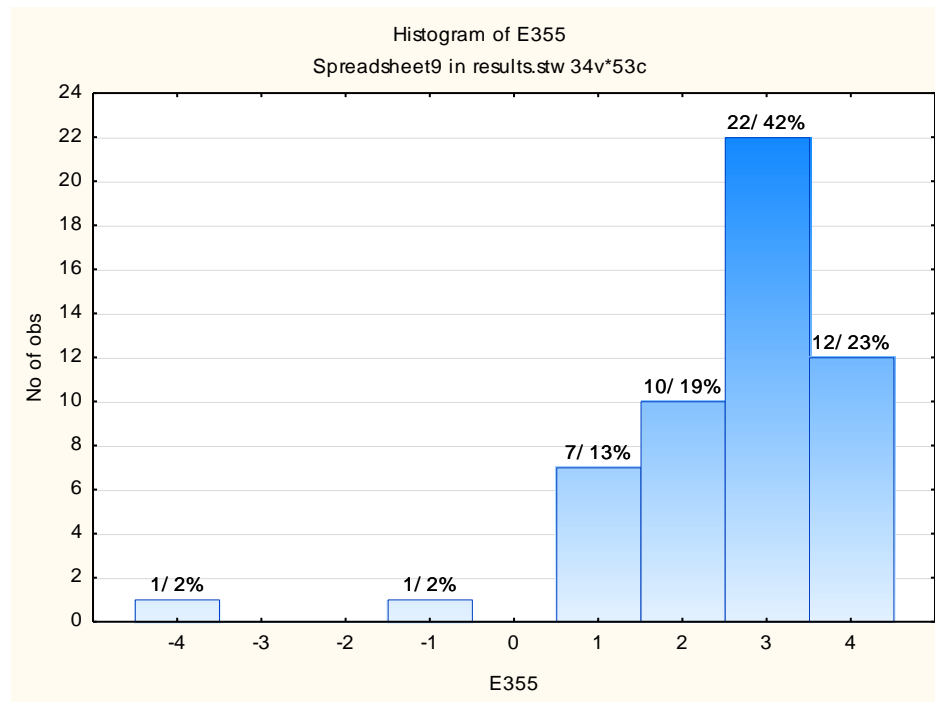
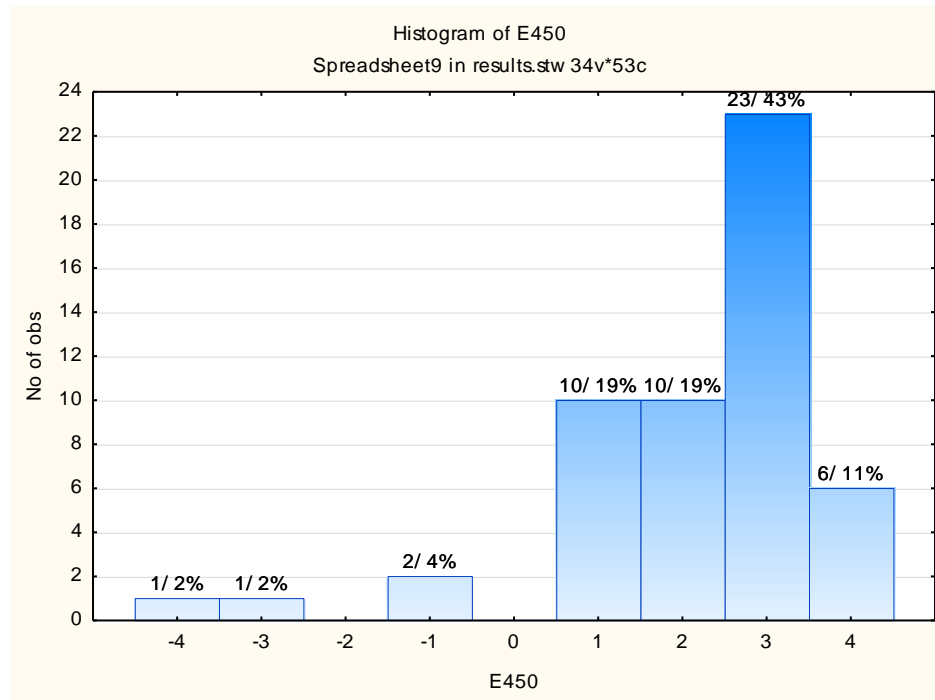


Figure 4. 74 E355 - Support and relationships - health professionals (N=53)



**Figure 4. 75 E450 - Individual attitudes of health professionals (N=53)**

#### **4.8.3.7 Health related-professionals.**

Professions such as architects, lawyers and teachers are considered to be health-related professionals (World Health Organisation 2001d).

From the perspective of participants and their families, these professions had had no impact on their lives and they were uncertain as to how they could be of assistance.

#### **4.8.4 Services, systems and policies**

Very few participants in this study, or their caregivers, had any knowledge of policies related to the administration of various services. Twelve participants were vaguely aware of efforts being made in terms of employing people with disabilities. They had become aware of this through the medium of television. Three participants had some knowledge of architectural and building regulations. One participant was aware of health policies. Some stroke survivors complained about dogs roaming the streets being a barrier to participation. With poor walking balance they felt vulnerable when dogs approached them in the street. They preferred to stay at home rather than venturing out into the neighbourhood. These participants were not aware that municipal by-laws prohibit dogs from being out on the streets unless they are on a lead.

##### **4.8.4.1 Architecture and construction services and systems**

Seventy percent of participants regarded architectural services, systems and policies as a barrier.

#### 4.8.4.2 Housing services and systems

Seventy percent of participants regarded housing as a problem (Figure 4.76). They expressed concerns about the lack of housing, RDP houses being small and of poor quality and the difficulty in getting repairs done.

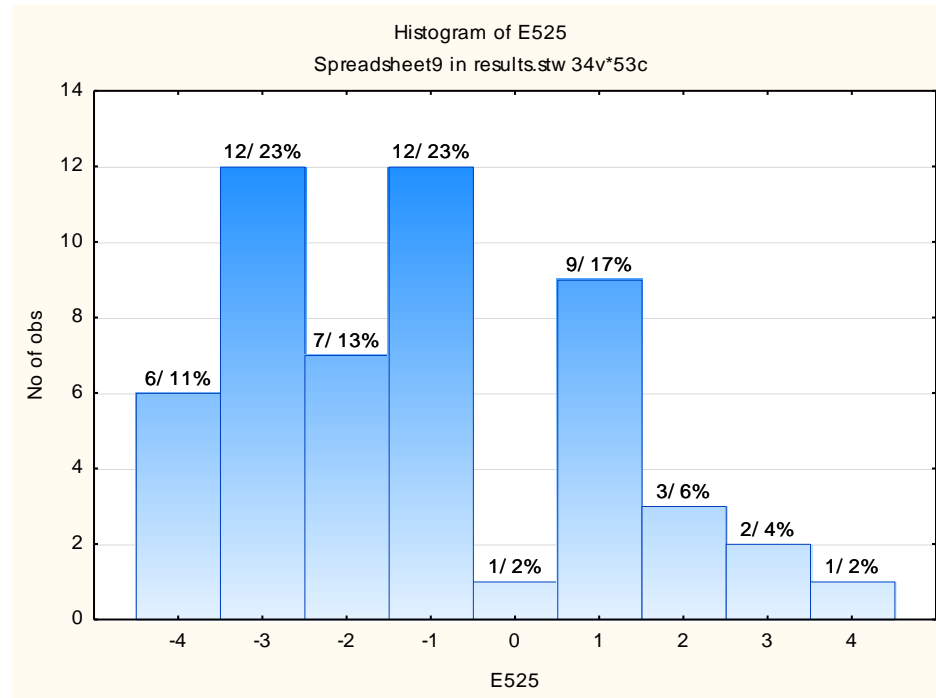


Figure 4. 76 E525 - Housing services and systems (N=53)



#### 4.8.4.3 Communication, services, and systems

Sixty-three percent regarded communication services and systems as a barrier due to the costs of airtime or having a land line, and, lack of public telephones and facilities for sending faxes and email (Figure 4.77).

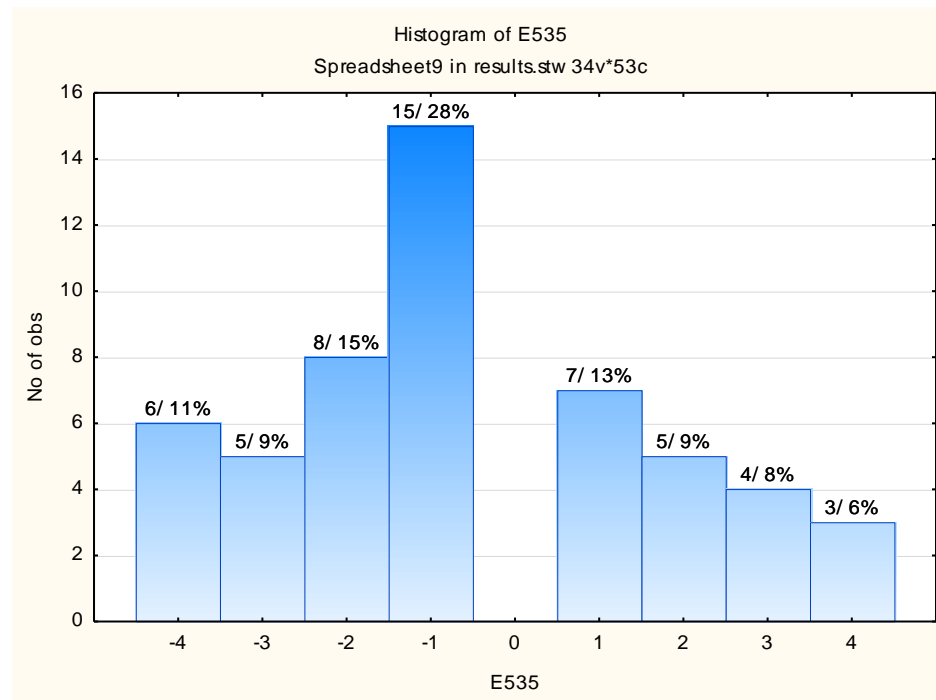


Figure 4. 77 E535 - Communication, services, and systems (N=53)

#### 4.8.4.4 Transport services and systems

Eighty-eight percent of participants regarded transport as a barrier, with 53% perceiving transport as a complete barrier (Figure 4.78).

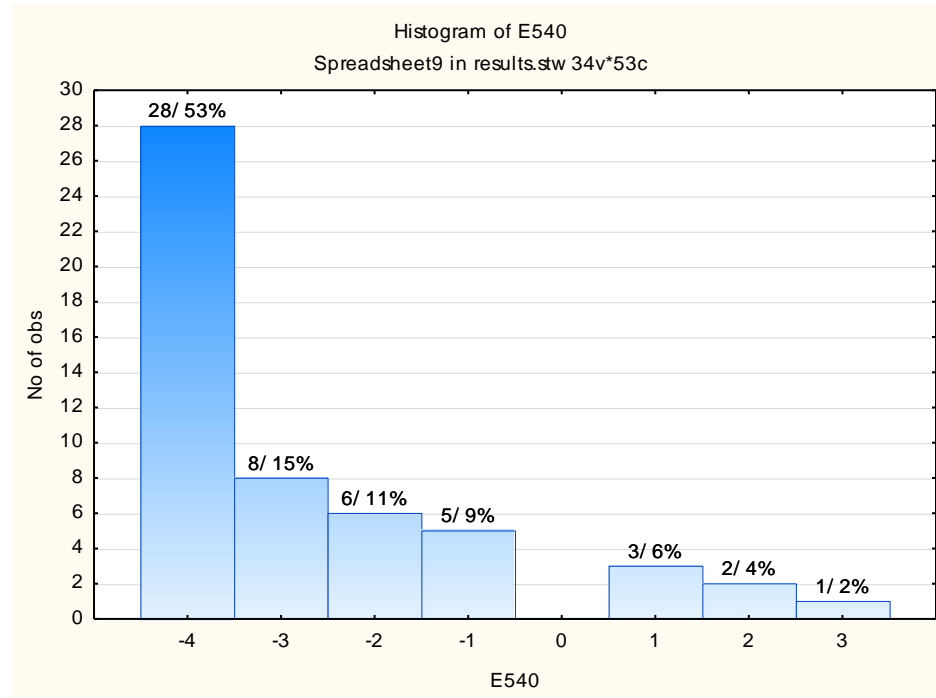


Figure 4. 78 E540 - Transport services and systems (N=53)

#### 4.8.4.5 Legal services and systems

Forty-two percent of participants reported not having much knowledge of the legal system in South Africa and found it difficult to comment on this being a barrier or facilitator. Others based their opinions on the helpfulness of the police services in their communities. Thirty-four percent saw legal services and systems as a barrier and 25% as a facilitator (Figure 4.79).

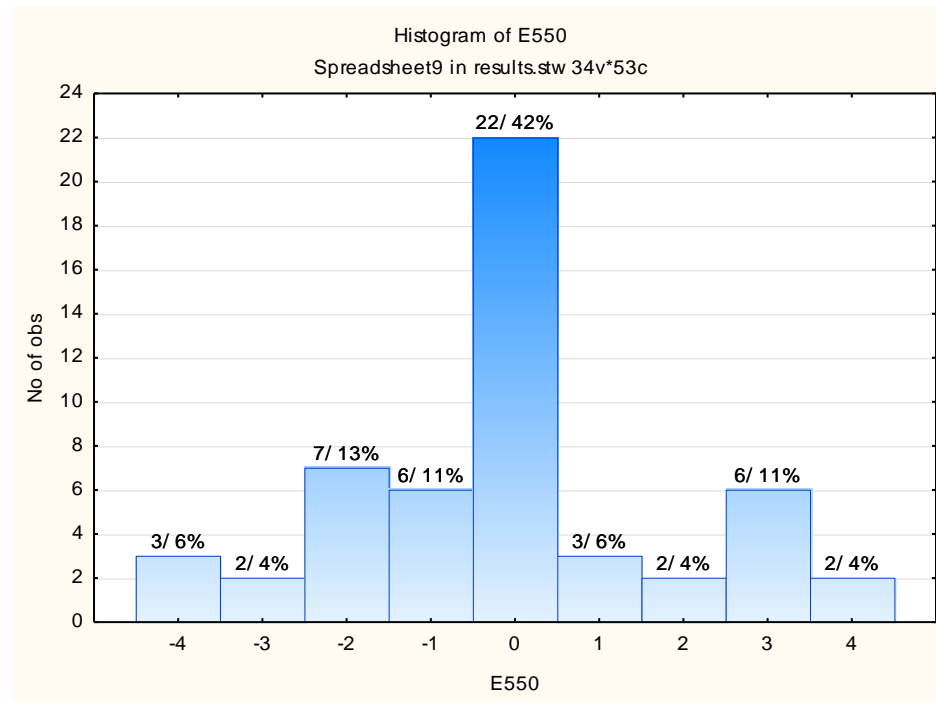


Figure 4. 79 E550 - Legal services and systems (N=53)

#### 4.8.4.6 Associations and organisational services, systems and policies

This refers to "groups of people who have joined together in the pursuit of common, non-commercial interests, often with an associated membership structure" (World Health Organization, 2001d: 198). Thirty-seven percent of participants regarded associations and organisational services as a facilitator (Figure 4.80).

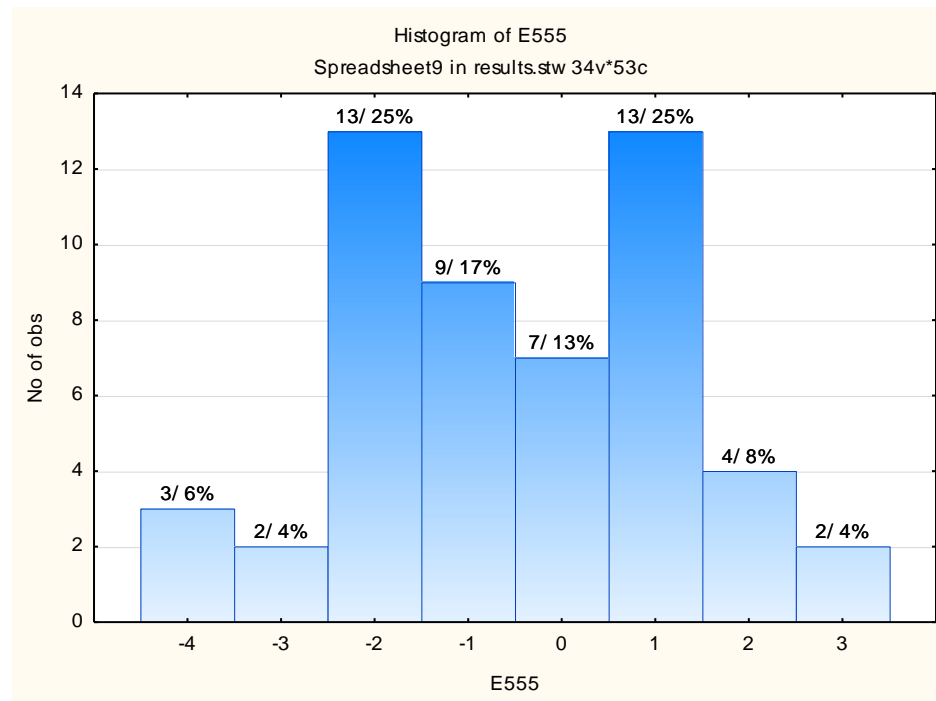
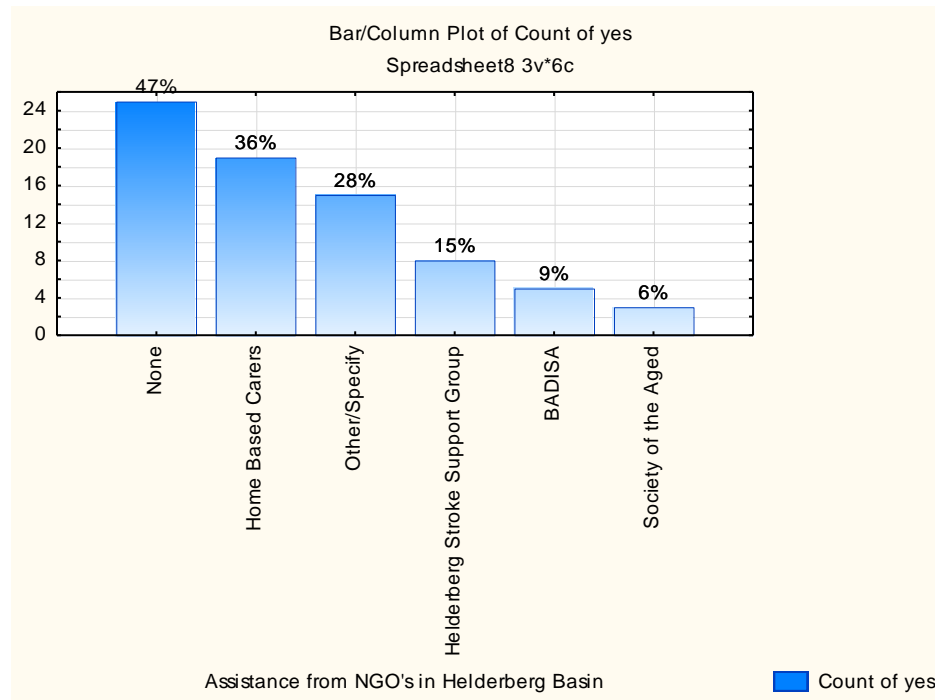


Figure 4. 80 E555 - Associations and organisational services, systems and policies (N=53)

Forty-seven percent of participants in this study reported receiving no assistance from associations (Figure 4.81).



**Figure 4. 81 Assistance from NGOs in Helderberg Basin (N=53)**

Although the HSSG gives out information at Helderberg Hospital to stroke survivors on the services they offer, and currently have nine subgroups running in the various communities of the Helderberg Basin, only 15% of participants reported attending these groups. Many of them were unaware of the existence of the organisation yet those who did attend found it a supportive and educating environment.

*"Aah! It means so much to her. Before she gets fetched on a Monday, she is so excited. She will be dressed early and be ready and waiting. Then she will tell me what happened that day."*

*"And then I read in the newspaper about the Helderberg Stroke Support Group. That is where I learned the most about stroke. Nobody else explained to me. You interact with others. This is when I really started to understand what everything was about."*

*"You speak to other people who have had the same experience or are worse off than you. I think suddenly my eyes were opened."*

*"What I benefited most from was the exercises with L and company at stroke support group".*

Thirty –six percent of participants made use of home-based carers from Masincedane. (Their role was discussed under personal-care providers.) Ten participants reported receiving some form of assistance from their churches. Two were assisted by the street people's organization in Sir Lowry's Pass Village and one participant who had no form of income received food parcels from the Muslim community. Other NGOs and service centres mentioned were Strand Care, Rotary, the Night Shelter, and the Society of the Blind, Helderberg Hospice and a private organisation where medication is collected from the local hospital and delivered to patients at their homes.

#### 4.8.4.7 Social security services

Generally participants had ambivalent feelings when discussing social security services, systems and policies. In one sense, the regular income and some form of alleviation from poverty was seen as a facilitator by 42% of participants (Figure 4.82). On the other hand, the limited payout for pensions and disability grants was considered a barrier by 47%, as was the great difficulty currently being encountered by stroke survivors in becoming registered for a disability grant. Those people who are already on the payout system reported being reasonably satisfied with services. One participant reported that collecting her pension payment at Strand Town Hall was the highlight of her month. She enjoyed the outing and it was an opportunity to socialise with her friends and acquaintances in the community. Eleven percent of participants reported on social services having no impact on their lives.

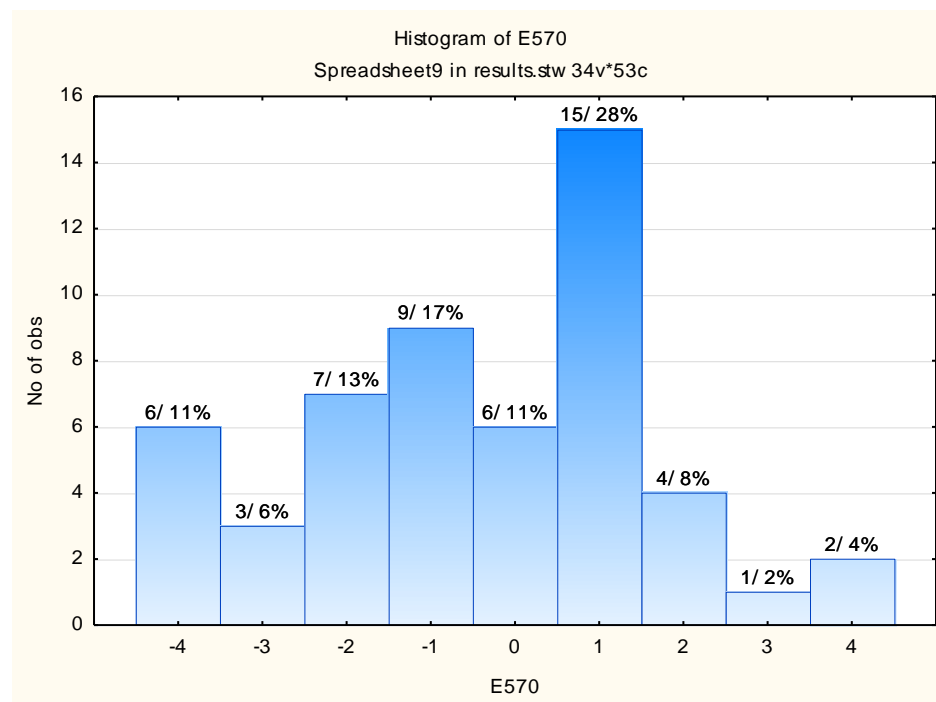


Figure 4. 82 E570 - Social security services, systems and policies (N=53)

In general, participants complained of:

- **Long queues when having to register for a pension or disability grant.** Often there were cut off points and people were told they must return the next day, as there were already too many people in the queue. Some participants regarded the queuing system as unfair and that a lot depended on who you knew, as to how soon you were assisted.

*"He knows Piet, Paul en Klaas -he knows them. Lets them through and the rest of us have to stand in the queue."*

- **Temporary disability grant.** Issuing of temporary disability grants to stroke survivors causes a lot of problems. Stroke survivors may only reapply once the final date is reached and often there is a delay of several months where they are without income while the paper work is being processed. According to the South African Social Service Agency (SASSA), people can apply for a Social Relief of Stress Grant for this period, but as participants pointed out, they have the same problems trying to process this.
- **Doctor's appointments.** At the time of this research, participants were finding it difficult to get the necessary doctor's appointment to have the medical forms filled in. Participants reported arriving at the CHC for their appointment and being told the relevant doctor was not coming that day.
- **Attitudes.** Some participants complained about the attitudes of officials from the South African Social Security Agency (SASSA). They found them unhelpful.

It was distressing to note that participants and their caregivers were afraid of lodging complaints to SASSA. There was a tremendous fear of reprisal and that they would not be assisted if they complained.



#### 4.8.4.8 General social support services and systems

This refers to services offering public assistance with activities of daily living, transport, shopping and housework to those people who due to age, disabilities and other reasons cannot manage these tasks independently. Eighty-seven percent of participants considered the lack of this form of public assistance to be a barrier while 28% considered it to be a complete barrier (Figure 4.83). The need for assistance in this regard is summed up by a participant who said the following:

*"It is like a prison sentence. I am actually a prisoner. I want to go to Checkers. Please take me quickly. Checkers is in five minutes walking distance from our house – it is a huge problem. I have to sit and plan how I can get to Checkers."*

The lack of support services is clearly illustrated in the situation where a participant's fourteen-year old son had to take off school regularly to collect her medication or get her to appointments at the clinic.

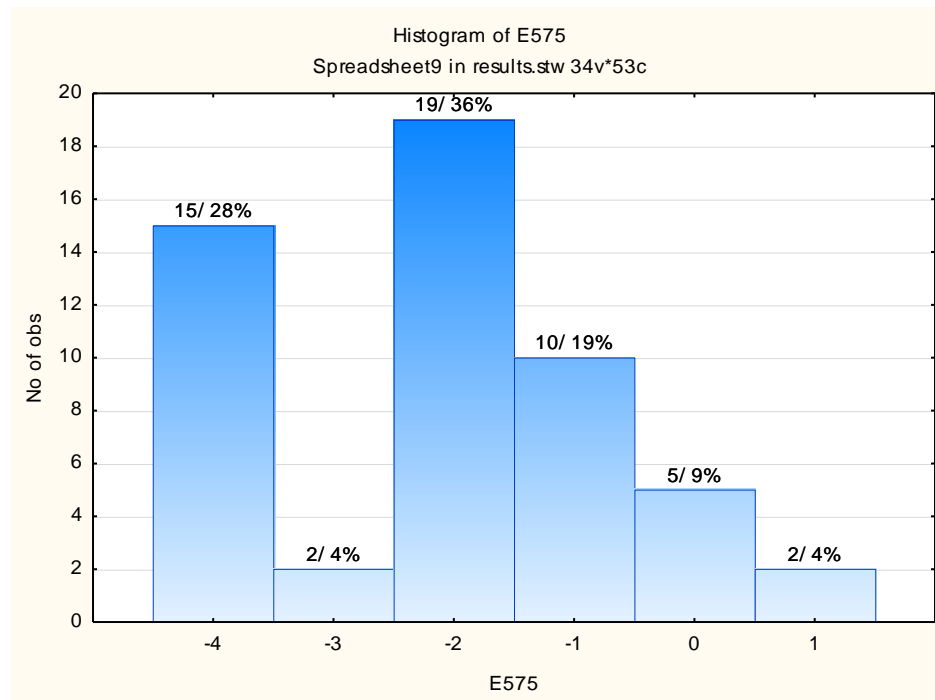


Figure 4. 83 E575 - General social support services and systems (N=53)

#### **4.8.4.9 Health services, systems and policies**

All of the participants complained about extremely long queues at hospitals, CHCs and clinics. Stroke survivors from Lwandle and those attending the Gustrouw CHC were particularly dissatisfied in this regard.

*"Long queues. It is terrible."*

*"There are just rows and rows of people that sit there."*

*"If you go to the clinic, you have to be very patient. What I can't understand is why people have to be there so early and are then only helped in the afternoon."*

*"Usually when I go – I leave the house at 6am or 6.30am. I then get back at about 4.30pm. That is how long I have to sit and wait."*

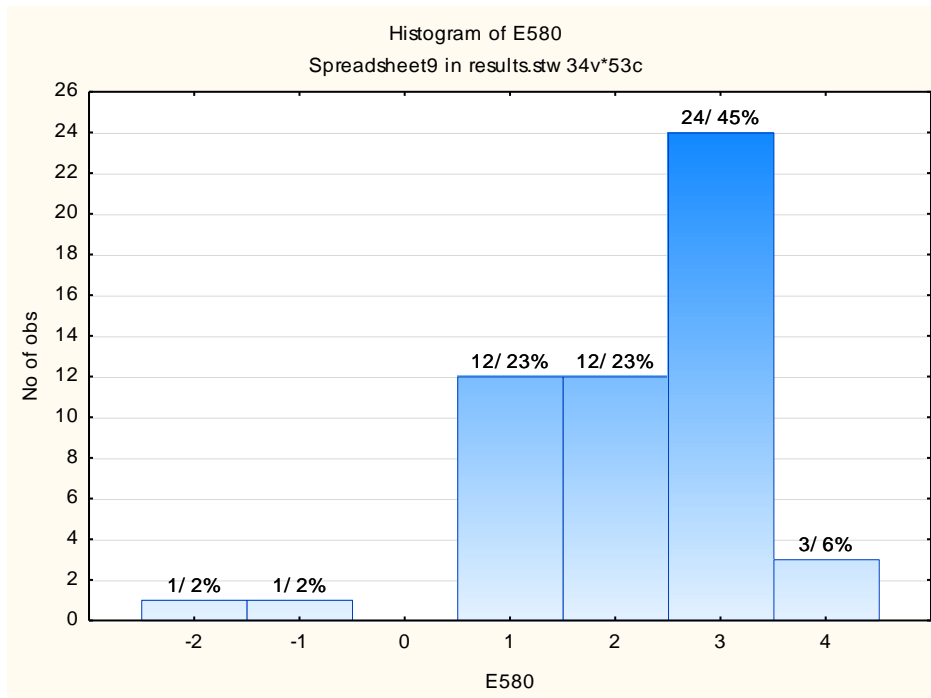
Where the caregiver or the stroke survivor was employed, long queues and the length of time it took to get their medication meant taking the day off work to be assisted.

*"Often it is difficult for me. My daughter is at home and if I am working, she collects it. When she returns to work, it is going to be extremely difficult."*

*"Difficult to get off work. It is a huge problem."*

Many participants complained about the noise level in waiting rooms and that they could not hear their numbers been called, especially if they were hard of hearing. This often meant they missed their turns.

In spite of these complaints, participants in this study were extremely positive about health services. Ninety-seven percent of participants regarded the health services as a facilitator and 45% of these rated the health services as a substantial facilitator (Figure 4.84).



**Figure 4. 84 E580 - Health services, systems and policies (N=53)**

Participants were very understanding of the shortage of human resources and the effect upon service delivery. Some participants and caregivers also gave the impression of being very passive and accepting of their circumstances.

*"One must just accept that if you go to the clinic you must take a bag of patience with you!"*

*"I am not pointing fingers at the doctors, because I think all the doctors are overworked. If you look – there are hordes of people. It is a hell of a task for them."*

*"It doesn't help to be impatient. As I said last time, you must always think about the person helping you. That person has also got things they have to do. If a patient complains and carries on, that person is not going to want to help you. That is why I am always relaxed. I keep calm, because I also consider that person. He has got lots of people he has to help and he is only one person. I am patient –I wait for my turn."*

*"You must just accept what you have got."*

Four percent of participants reported on the standard of health services as being unacceptable. One participant's son had died in casualty after a car accident and she believed the hospital had been negligent.

Another caregiver reported visiting her husband on several occasions and finding his bed and clothing soaked in urine. He was aphasic and had no bell or manner of calling for help. (Several participants reported how other patients had helped them to get to the toilet, or fed them when nursing staff were not available.)

One caregiver reported that the doctor at casualty had been drunk when his wife was admitted, but apart from this incident, was satisfied with the services received. Another stroke survivor who was also diabetic apparently sustained a leg injury while she was being moved in hospital. The injury did not heal and the leg had to be amputated. Her husband was extremely angry about this, but still reported being generally satisfied with the health services.

The husband of a 45-year old participant was particularly concerned about the lack of protocol in treating stroke patients on admission to Helderberg Hospital and was concerned that delays might have affected her outcome:

*"She knew exactly what to do, but she waited for instructions. This is something that can result in a patient's condition deteriorating ....but if the sister knows she must put up the drip and that it must be put up now..."*

A few months later, the researcher received the following SMS from the same gentleman:

*"I have not sorted the disability grant of my wife out. I have started a new job because I need to earn more. That being so, the thought that comes to mind is why is no doctor at the local hospital able to help with a stroke patient in the beginning stage as it starts to take place. Surely for the trained eye the symptoms must be known."*

#### **4.8.4.10 Labour and employment services, systems and policies**

Fifty-three percent of participants were of the opinion that because they had reached retirement age, labour-related issues did not impact on their lives. Forty-one percent considered labour and employment services and systems to be a barrier because of the unemployment rate and lack of job opportunities for their families and themselves.

## 4.9 Rehabilitation

The results in this section relate to facilities where rehabilitation was conducted, the disciplines involved and the amount of therapy received by participants. The qualitative data highlights the lack of education and counselling and other problems experienced by participants in terms of rehabilitation. (Objectives in terms of potential rehabilitation outcome levels are discussed in Chapter 5.)

### 4.9.1 Institution where participants were treated after the onset of the stroke

Figure 4.85 shows that the majority of participants (40;75%) were initially seen at Helderberg Hospital. Six (11%) were seen at the CHC and then sent home. Two participants had no immediate medical intervention. One participant was admitted to a private institution for three weeks. He was included in the study as he was transferred to a government hospital for further treatment and received all rehabilitation through the government services.

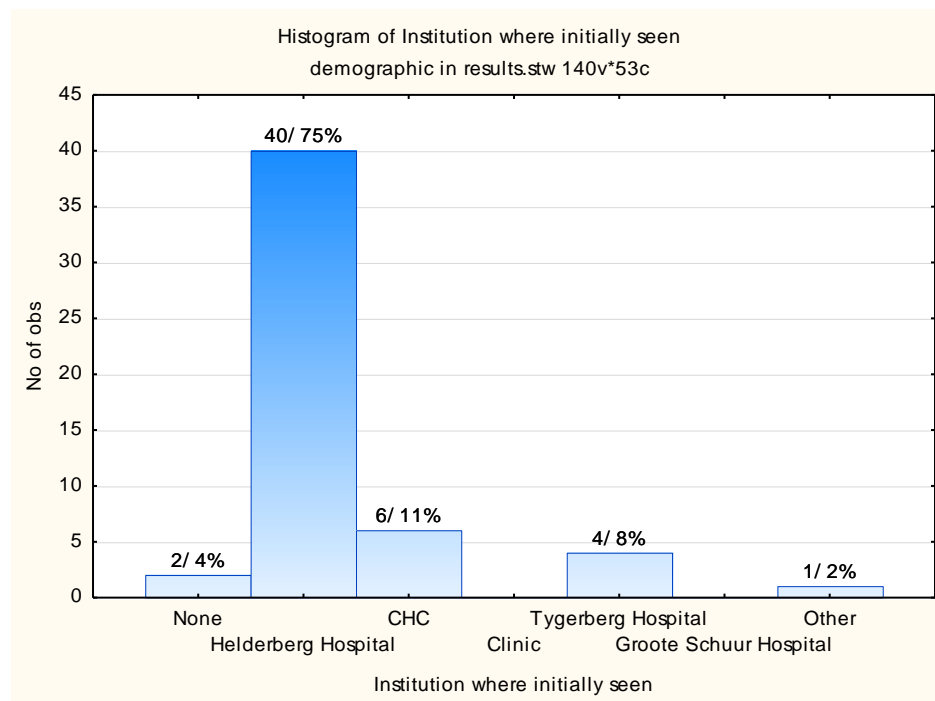


Figure 4. 85 Institution where initially treated (N=53)

#### 4.9.2 Duration of stay in hospital

Twenty-two (42%) of participants were hospitalised for more than 14 days. Conversely, 10 (19%) of the participants were not admitted to a hospital for treatment (Figure 4.86).

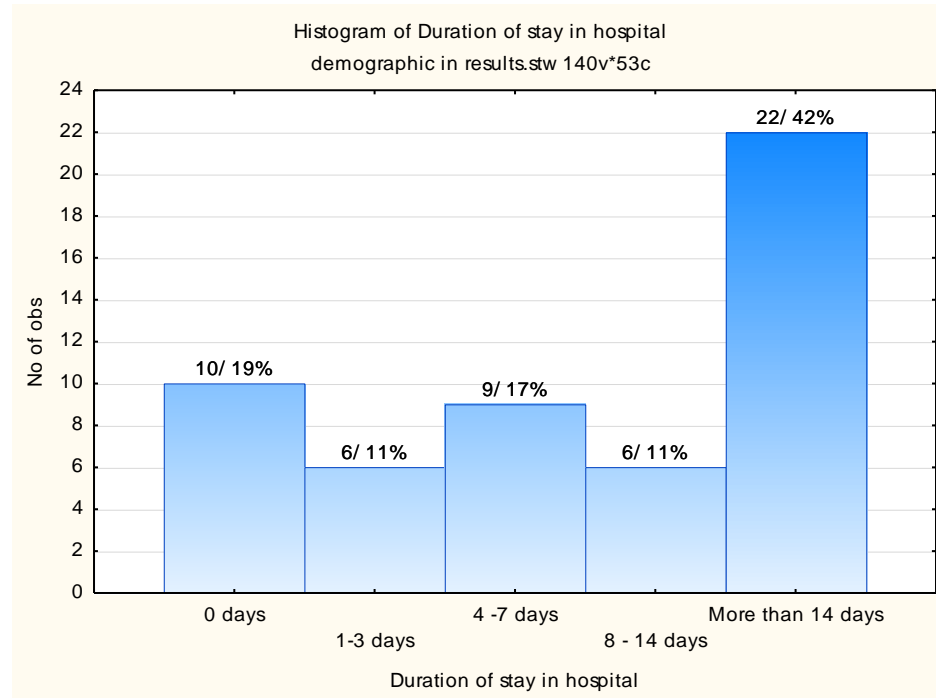


Figure 4. 86 Duration of stay in hospital (N=53)

#### 4.9.3 Specialist rehabilitation services (Western Cape Rehabilitation Centre)

Ten (19%) of the participants were apparently referred to WCRC. Of these, four were admitted. Some of the reasons that were given to participants for non-admission were:

- The wife of a 54-year old participant was told telephonically that her husband did not have "enough problems" to qualify for admission to WCRC:

*"Yes –we phoned. They told us it is only for people with more serious strokes –people that can do nothing for themselves."*

- An elderly participant was apparently told that WCRC was only admitting younger people with the potential to return to the work place.
- Other reasons given were that WCRC was at capacity and there were no beds available.

The researcher believes that other environmental factors also play a role in uninsured stroke survivors from the Helderberg Basin not being admitted to WCRC. For example a participant referred to a specialised seating clinic at WCRC was never able to attend. With his first appointment, he did not have transport. With the next appointment, he managed to organise transport but neither he nor the driver knew how to locate WCRC. The researcher also encountered cases through the HSSG where lack of communication systems (telephones, faxes, email or wrong addresses) meant that stroke survivors did not receive messages about appointments.

The positive impact of rehabilitation at WCRC is illustrated by a caregiver who worked at an old age home and whose husband was a participant in this study:

*"Where I work, there is a white man who had a stroke. This was a few months ago. Before that he could do everything for himself –everything, everything, everything and then he could do nothing for himself. And then his children –they sent him to Mitchells Plain –Rehab. Yesterday I was with him. I talked to him. Then he explained to me. He said to me "My child." He now sorts out his own room. He doesn't want you to help, to make the bed. You must do nothing for him. He does everything for himself."*

When asked if she could notice the difference after he came back from WCRC, she replied:

*"Yes. He couldn't –he walked like someone who was drunk –for a long time he could not walk. Yes, and he couldn't care for himself. When he came back from WCRC he could do everything for himself again. He did it slowly, but he could do everything for himself."*

According to Dr. Helen Sammons, WCRC has 156 beds available. Of those, approximately half are reserved for neurological cases, including stroke. Numbers vary slightly, according to the demand at a given time. WCRC takes referrals from all over the Western Cape and is often at capacity. It does have admissions guidelines; for example, preference is given to clients who have the potential to return to work. Where a client requires specialised rehabilitation or no other rehabilitation services are available, admission will be considered. The client must require input from three or more disciplines to be considered (Personal interview with researcher, 16 September 2011).



#### 4.9.4 Physiotherapy

Thirty-five (66%) participants received physiotherapy while in hospital (Figure 4.87).

It should be noted that "Not applicable" on this graph (and on those relating to received occupational therapy, speech therapy, psychological intervention and assistance from a social worker and dietician whilst hospitalised, below) refers to participants who were not admitted to hospital and does not imply that therapy was unnecessary.

Thirty (57%) received individual physiotherapy at CHC's or at Helderberg Hospital on an outpatient basis (Figure 4.88).

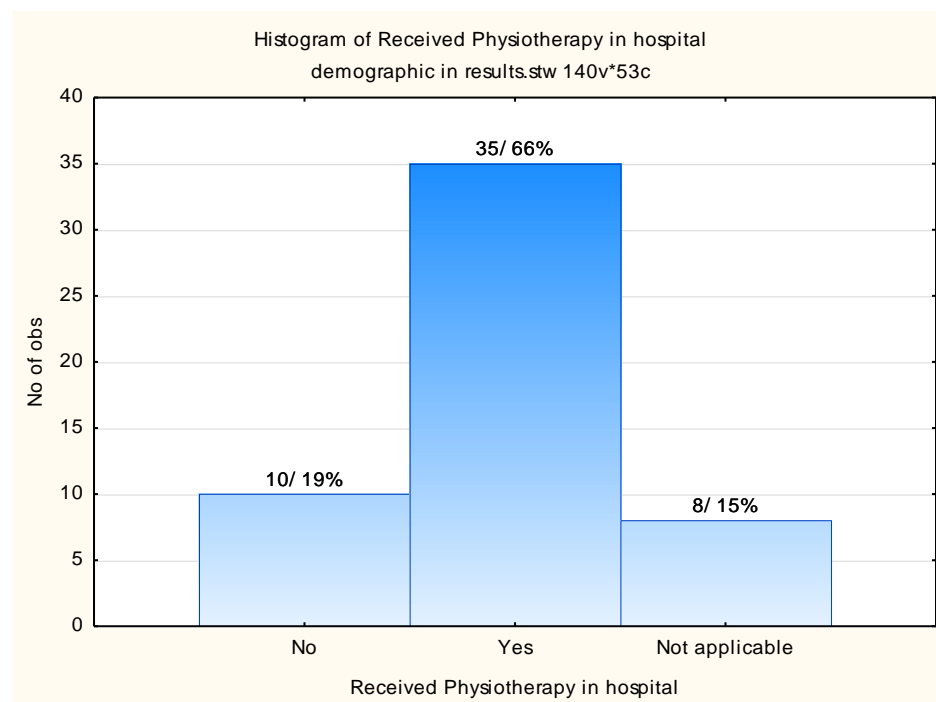
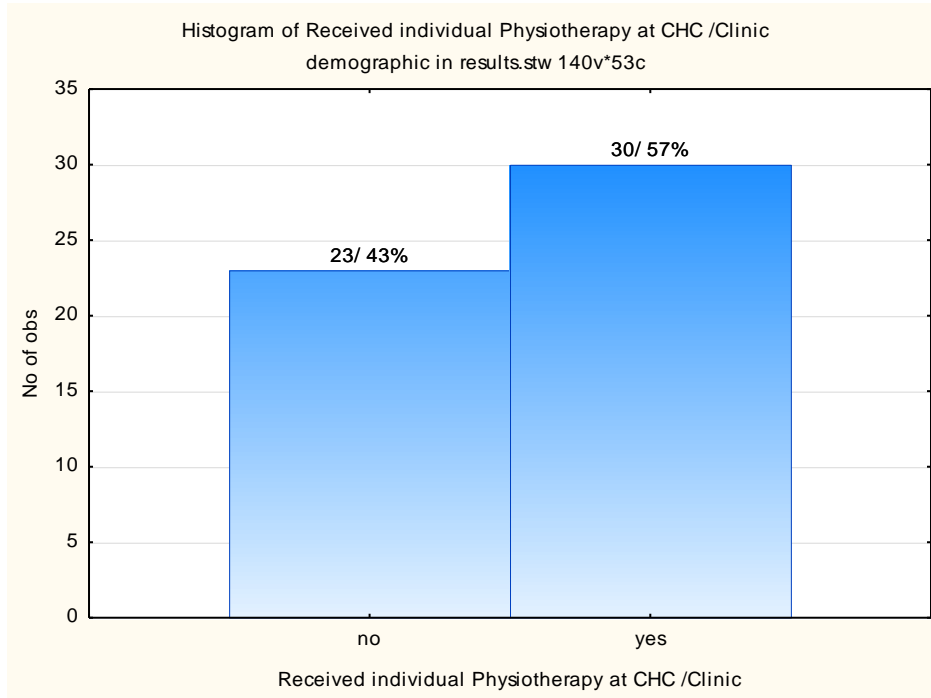
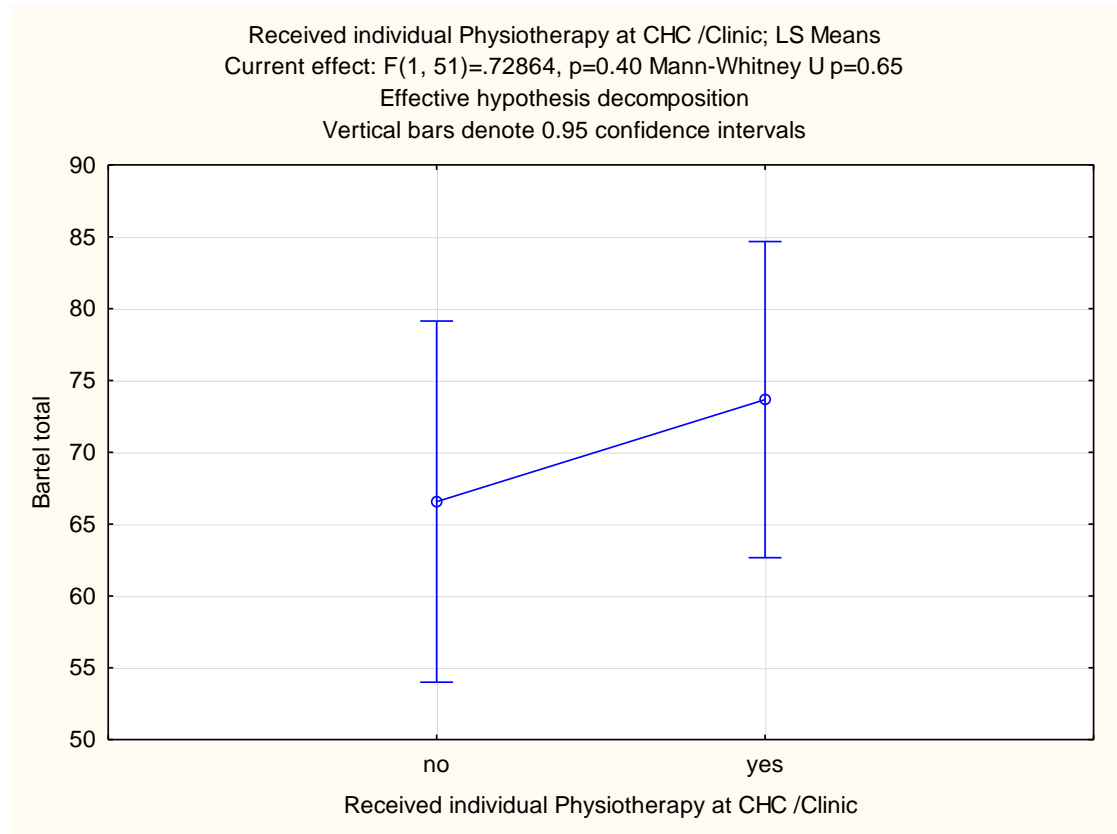


Figure 4. 87 Number of participants who received physiotherapy in hospital (N=53)



**Figure 4. 88 Number of participants who received individual physiotherapy at CHC/clinic/hospital as out-patient (N=53)**



**Figure 4. 89 Correlation of Modified Barthel Score with physiotherapy received at CHC (N=53)**

Although a p value of 0.40 reveals no significant statistical evidence, Figure 4.89 does indicate that physiotherapy received at CHCs, clinics and hospital outpatient departments had a positive influence on Barthel scores. In terms of community mobility, a similar, but slightly lesser finding is illustrated in Figure 4.90. (p=0.78)

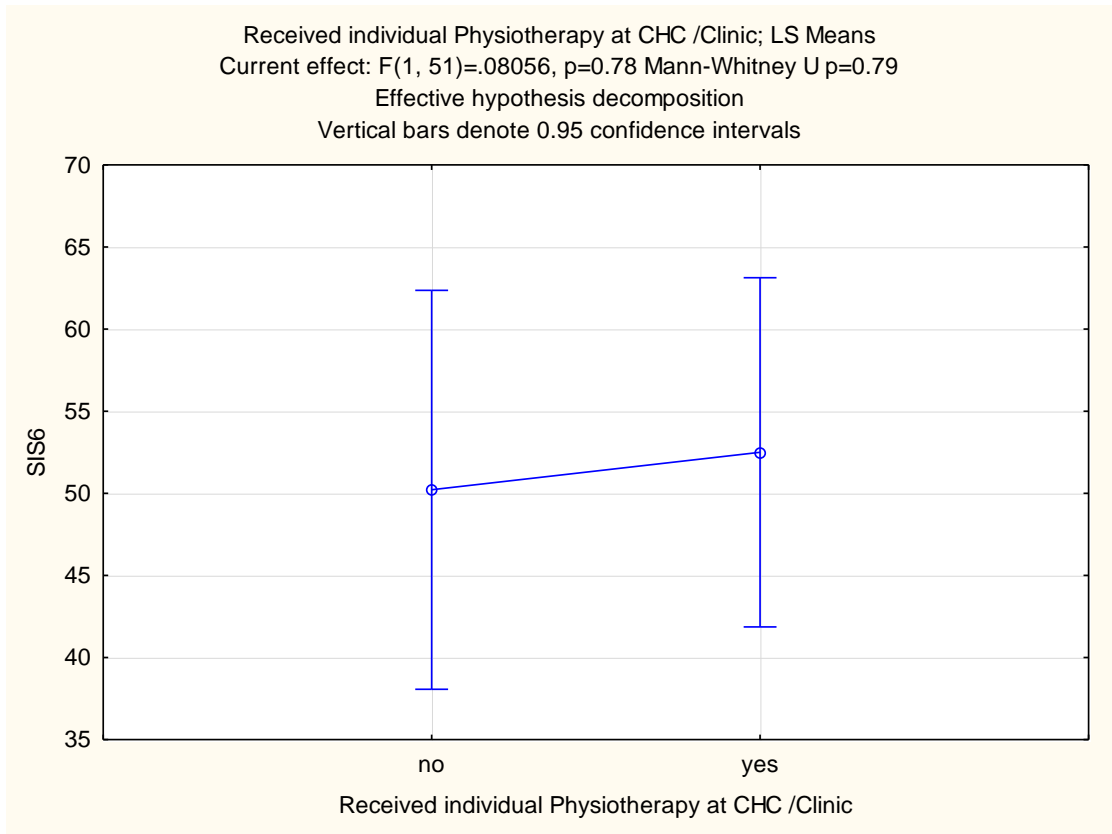
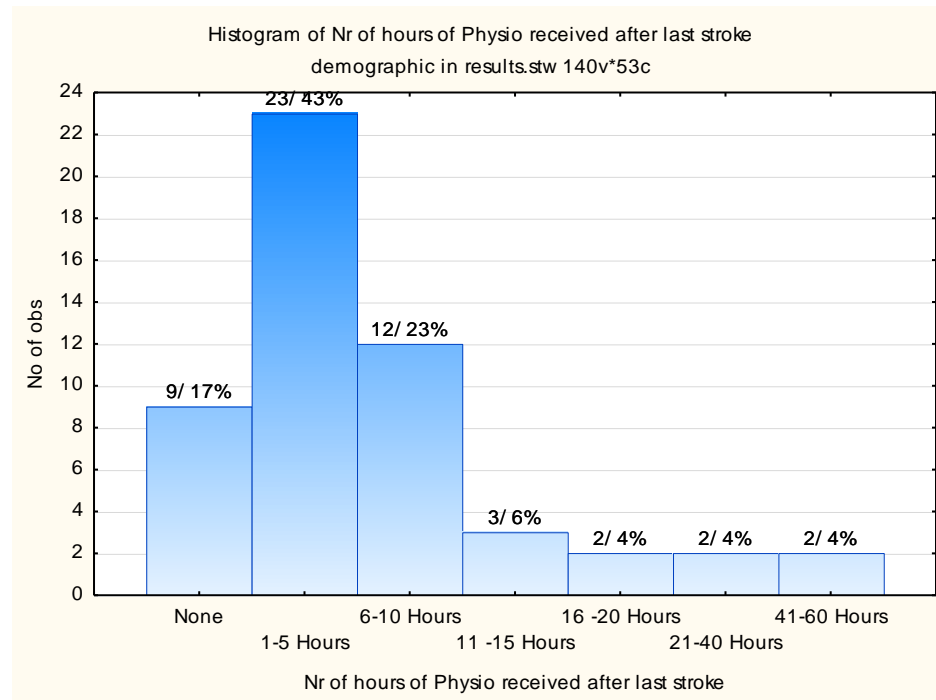


Figure 4. 90 Correlation of SIS3.6 score with physiotherapy received at CHC (N=53)

According to figure 4.91 (17%) of the stroke survivors in the study received no physiotherapy. Twenty-three (43%) reported having 1-5 hours of physiotherapy and 12 (23%) had 6-10 hours of intervention. Nine (17%) participants received more than ten hours of physiotherapy.



**Figure 4. 91 Number of hours of physiotherapy received after last stroke (N=53)**

#### **4.9.5 Occupational therapy.**

Twenty two (42%) participants reported receiving occupational therapy while hospitalised (Figure 4.92) and 21 (40%) received assistance from an occupational therapist at a CHC or as an outpatient at the hospital.

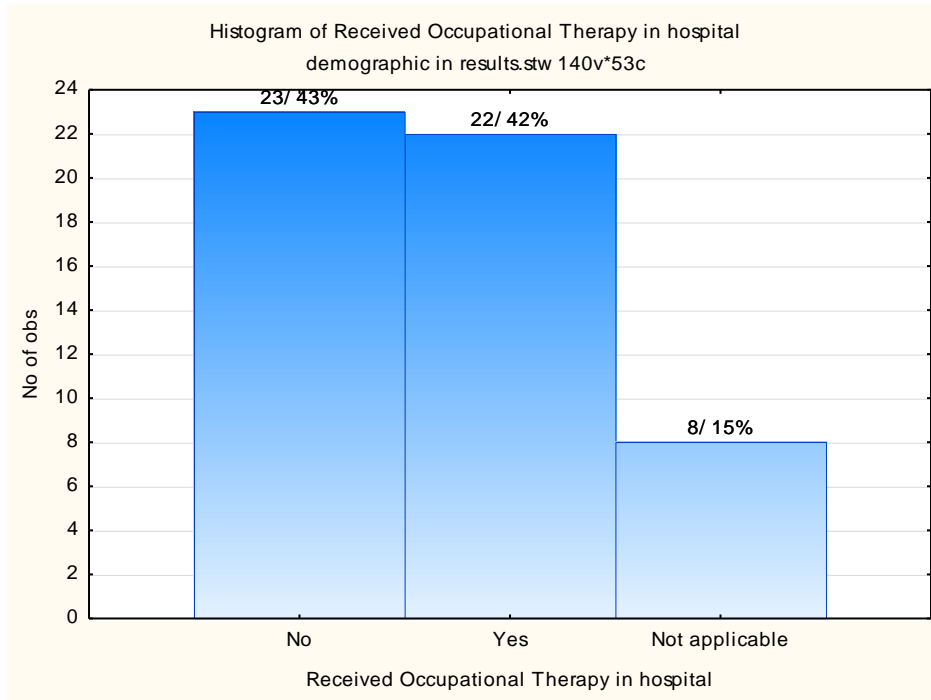
Figure 4.93 illustrates that twenty (38%) stroke survivors who took part in the study received no occupational therapy, 20 (38%) of participants received 1-5 hours, eight (15%) received 6-10 hours of therapy and only five (10%) participants received more than 10 hours.

Seven (13%) participants reported that they received a home visit from an occupational or physiotherapist.

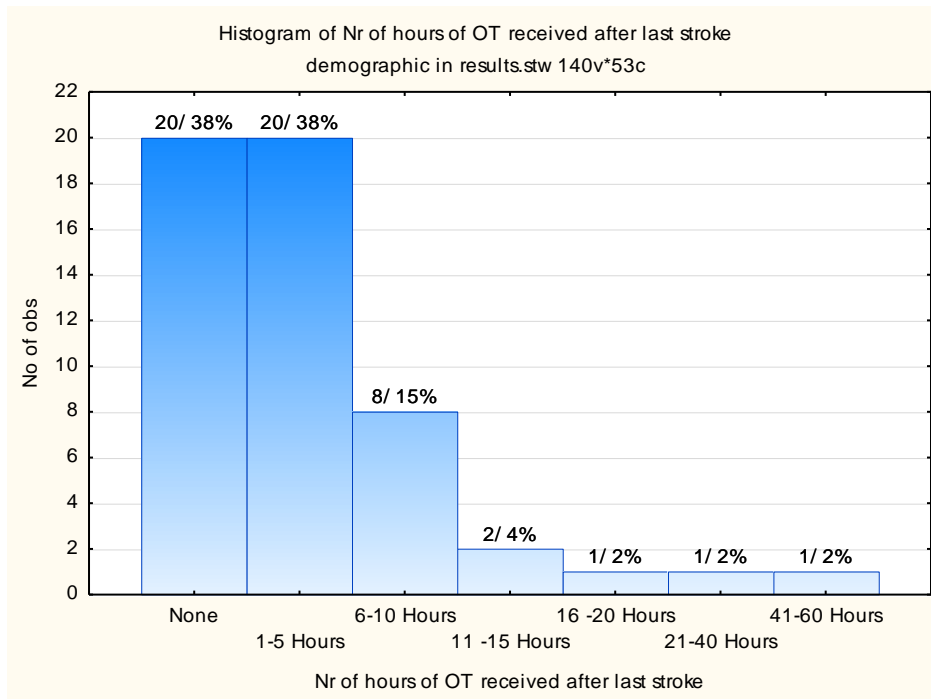
Participants were generally of the opinion that physiotherapy revolved around exercise, but could not elaborate further. However, the majority expressed uncertainty about the role of an occupational therapist, as illustrated by the following comments:

*"Physiotherapy? –That is exercises. To give exercises...I have got an idea, but occupational therapy – no."*

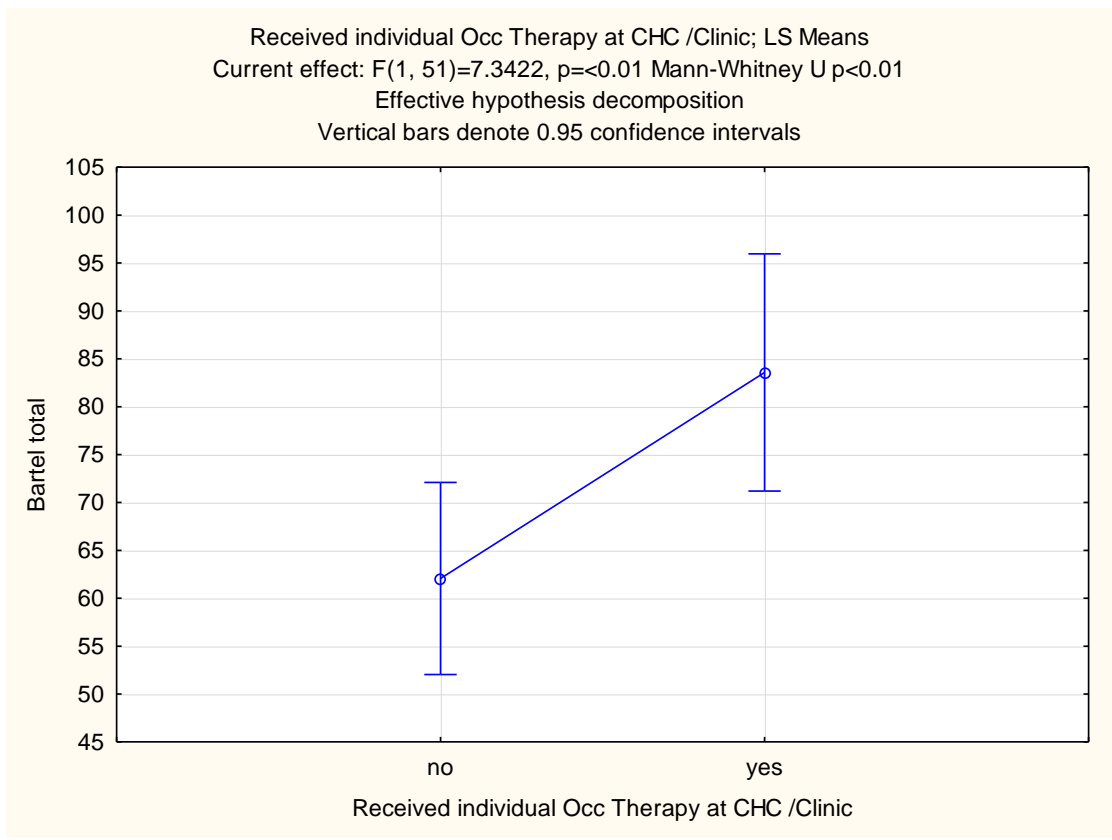
*"An occupational therapist? -No, I have got no idea."*



**Figure 4. 92** Number of participants who received occupational therapy in hospital (N=53)



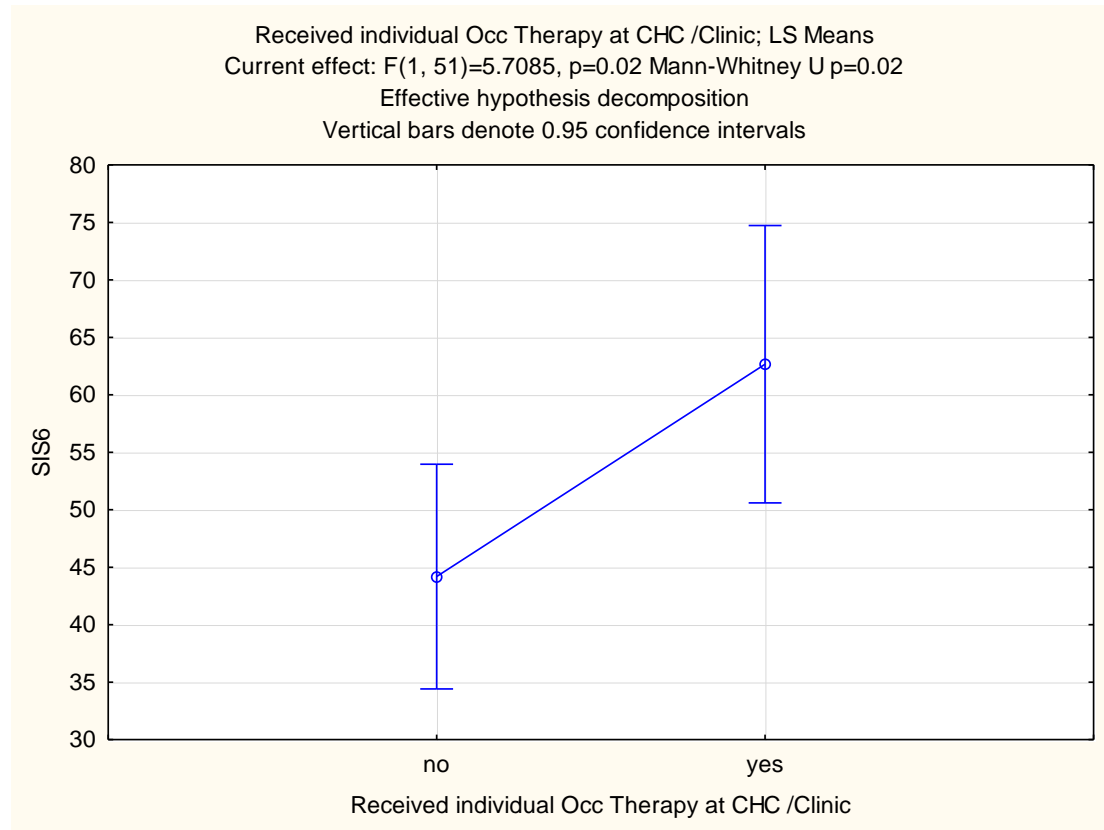
**Figure 4. 93** Number of hours of occupational therapy received after last stroke (N=53)



**Figure 4. 94 Correlation of Modified Barthel score with occupational therapy received at CHC (N=53)**

A p value of  $<0.01$  indicates that Occupational Therapy received at CHCs /Clinics or as hospital outpatients had a statistically significant impact on Barthel scores.



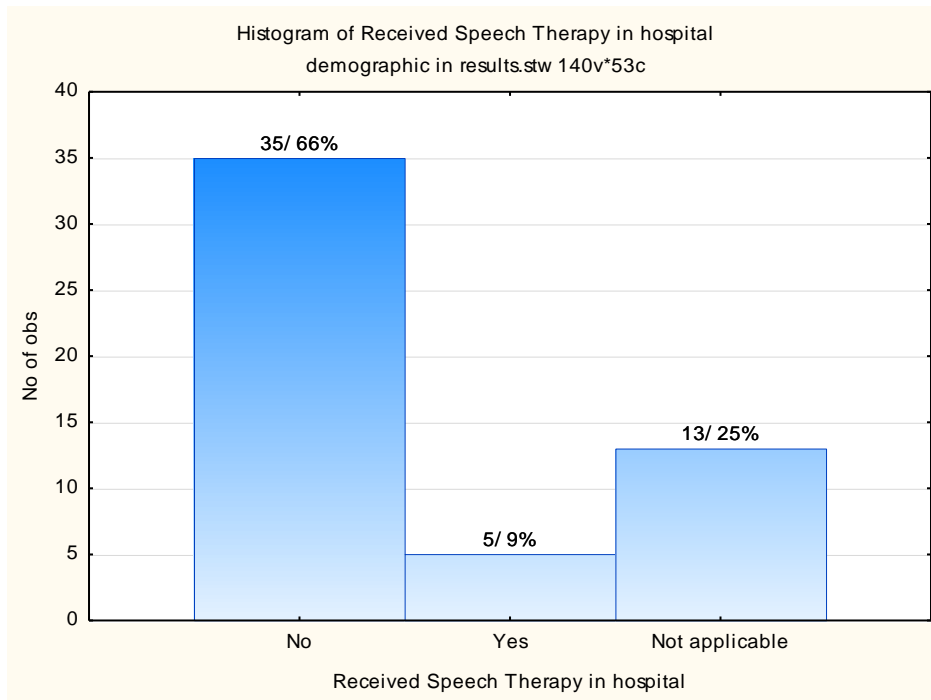


**Figure 4.95** Correlation of SIS3.6 score with occupational therapy received at CHC (N=53)

This graph show that Occupational Therapy received at CHCs, clinics and hospital outpatient departments had a statistical significant impact on community mobility. ( $p=0.02$ ).

#### 4.9.6 Speech therapy

Figure 4.96 illustrates that five (9%) participants received speech therapy. Of these, one obtained limited treatment at Helderberg Hospital. Another received speech therapy at Tygerberg Hospital and was assisted for a short period as an outpatient, but found the cost of travelling to Tygerberg a barrier to continued treatment. Two participants received speech therapy at WCRC and one at Conradie Care, a respite institution in Cape Town.



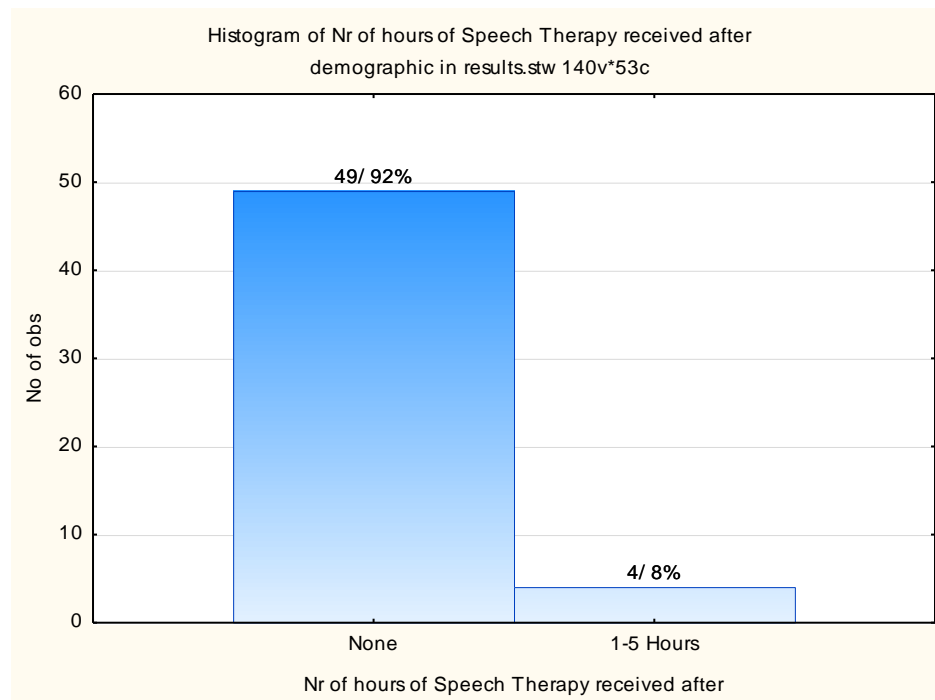
**Figure 4. 96** Number of participants who received speech therapy in hospital (N=53)

For part of 2009 and 2010 a community service speech therapist from Tygerberg Hospital came through to Helderberg Hospital once a week to see clients. This service was discontinued, apparently due to a shortage of staff.

The frustration with the lack of speech therapy services is illustrated by the husband of a 45-year old participant:

*"It is very difficult to get an appointment with the speech therapist at the hospital. One of the most difficult things at the state hospital. Perhaps you will get an appointment and that will be in about three months time. I can't see how one appointment in three months can help. What can you do in such a short time?"*

Four participants reported having 1-5 hours of speech therapy and one participant said he had a 30-minute session with the speech therapist (Figure 4.97).



**Figure 4. 97 No of hours of speech therapy received after last stroke (N=53)**

As illustrated by the following comments, participants with speech and language problems regarded speech therapy as important.

*"Speech therapy is very important. It is one of the first things that must be attended to after a stroke –so that the patient can communicate."*

*"It helped me a lot because I improved much quicker. Yes –and it is all thanks to the therapy which I got. The speech therapy."*

Some shared how embarrassing it is to be considered drunk as a result of a speech impairment. *"Man –I am not drunk –I haven't been drinking. My speech has been affected."*

#### **4.9.7 Psychological counselling**

Currently, stroke survivors and their families do not have access to psychological counselling at Helderberg Hospital, CHC's or clinics within the Helderberg Basin. This is of concern when one considers that the majority of participants scored less than 60% on the SIS3 question which deals with feelings and emotions (Figure 4.34 above).

#### **4.9.8 Assistance from a dietician**

Helderberg Hospital employs a dietician who is involved in planning hospital meals, but does not have a dietician available for counselling patients. One participant received counselling from a dietician at WCRC and one at Tygerberg Hospital.

From discussions with participants in the study and their families, it appears attempts are being made by nursing staff to give out information sheets and pamphlets on diet. However, the majority of participants and their caregivers reported being confused about what they should be eating.

#### **4.9.9 Assistance from social worker**

A full-time social worker is employed at Helderberg Hospital. Three (6%) participants and their caregivers reported receiving assistance from a social worker while the stroke survivor was hospitalised. A further three (6%) reported seeing a social worker as outpatients. One caregiver phoned for an appointment because she was desperate for help and advice on how to cope with her circumstances.

One participant particularly appreciated the assistance given by the social worker at WCRC in terms of being informed about, and applying, for her disability grant.

#### 4.9.10 Reasons for not receiving therapy

Where the relevant services do exist in the Helderberg Basin, 55% of participants reported the lack of a referral or the knowledge of the existence of the relevant service as the reason for not receiving certain forms of therapy or interventions.

The frustration of a caregiver in this regard is illustrated by the following comment:

*"Yes. Shoo! If this happens for the first time – you are in the dark. You are somewhere where you have not been before. Now what is the next step? Is there someone that can help? You hear how someone says you must go and see that person. Guidelines – not just on paper, but that are practical – if you go from A to B that person will help you and tell you what the next step is."*

Twenty-five percent of participants said they did not receive therapy or only attended a few sessions because of the cost of transport to get to the hospital or CHC; 23% said they had no transport available. Thirteen percent of participants specifically reported on the lack of transport for wheelchair users (Figure 4.98).

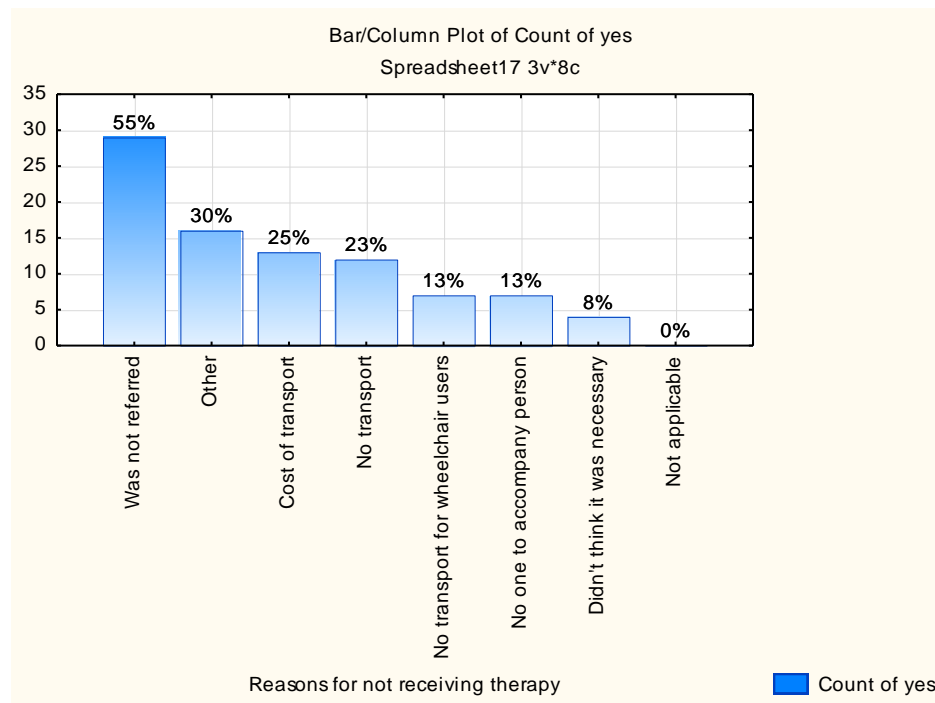


Figure 4.98 Reasons for not receiving therapy

Thirteen percent of the stroke survivors reported having no one to accompany them to therapy. Often family members work. Eight percent of the participants or their caregivers did not think therapy was necessary. Other reasons given were:

- The stroke survivor was too weak to go out or was not feeling well;
- It was too difficult to move obese stroke survivors and was easier to leave them in bed. Pushing overweight people to CHCs /clinics in a wheelchair was extremely difficult for caregivers;
- One participant reported on having to look after her grandchild and not being able to continue with any therapy, even though she would have benefitted from this. Another preferred to go to the exercise groups run by the HSSG;
- Another participant reported on therapists not keeping their commitments. There was also a complaint that the physiotherapist hurt the stroke survivor and they had declined to continue with treatment.

Another reason for people not making use of available rehabilitation services appears to be caregiver strain. This is illustrated by the following case. An elderly participant lived directly across the road from the CHC where physiotherapy and occupational therapy were available. The HSSG also organised for individual therapy for the participant with a physiotherapist experienced in stroke rehabilitation at a nearby venue. The participant did not make use of these opportunities. When her daughter was asked why this was the case, she said that she worked three days a week and spent the rest of the time caring for her mother and just did not have the energy or time to take her mother to therapy, even if it were readily available. She did not have the insight nor had she received sufficient counselling in terms of the benefits of rehabilitation. Instead, she was totally overwhelmed by her caring duties.

#### 4.9.11 Assistive devices

The Western Cape Department of Health divides assistive devices into the following categories:

- Mobility devices (e.g. wheelchairs, crutches and walking frames)
- Activities of Daily Living devices
- Communication devices (Western Cape (South Africa). Department of Health, 2007).

Fifty-one percent of participants received mobility assistive devices through the hospital where they were initially treated. Seventeen obtained them from CHCs or clinics and 34% from other sources such as NGOs, family and friends (Figure 4.99).

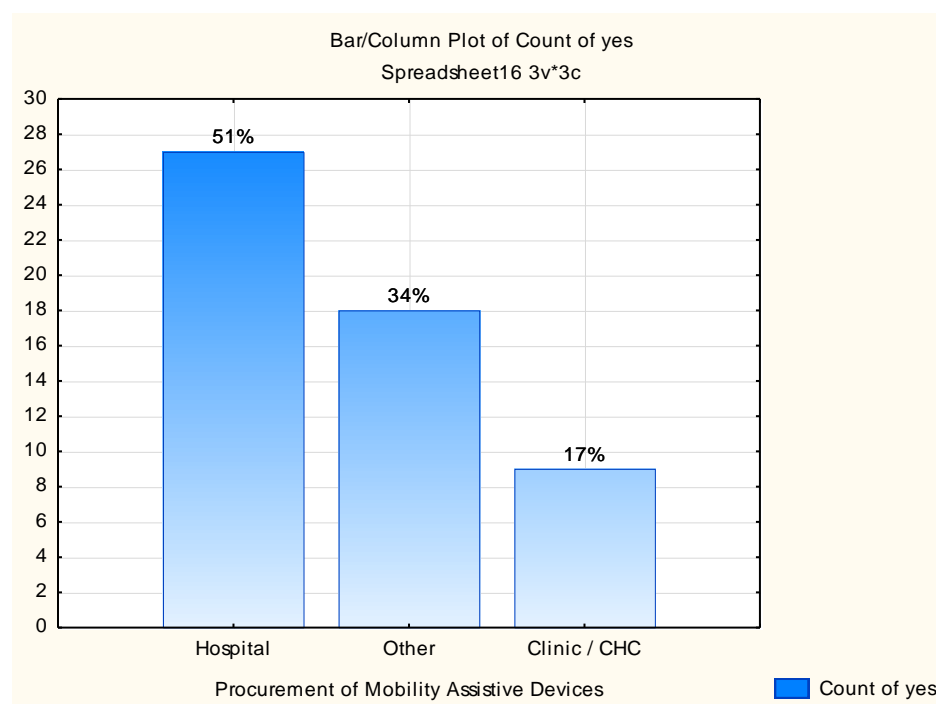
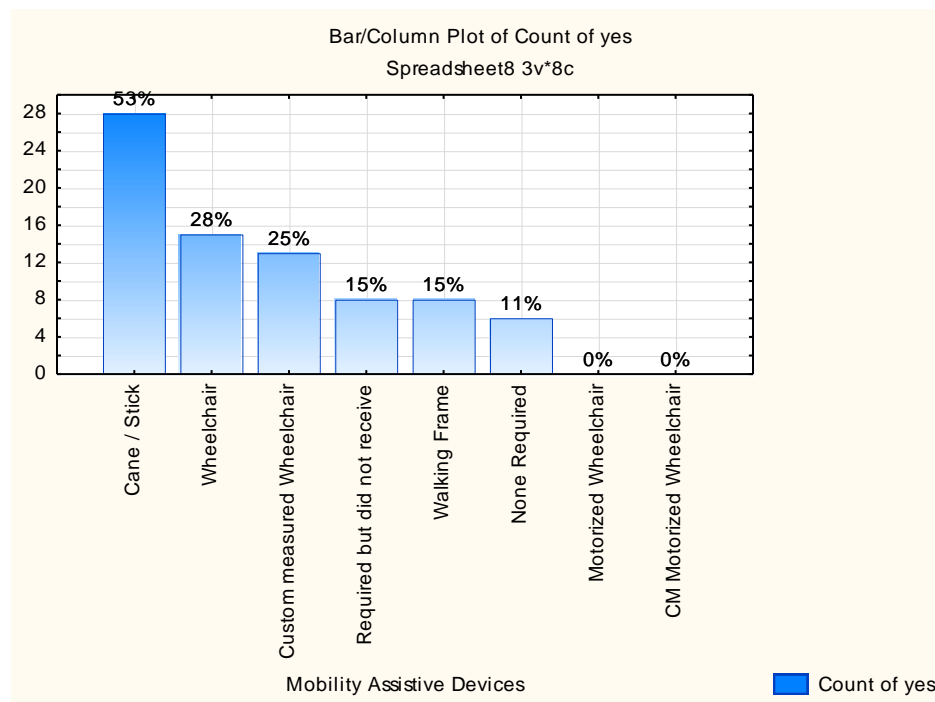


Figure 4. 99 Procurement of mobility assistive devices

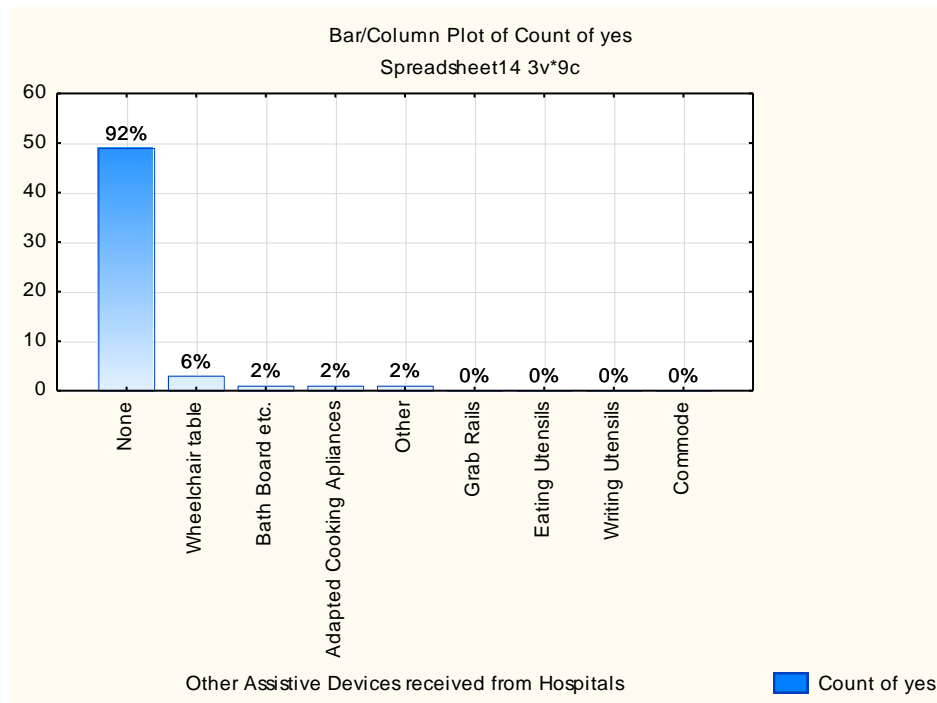


Twenty-eight percent of the participants had received some form of wheelchair. A further 25% had been issued with what the researcher has referred to as "custom measured wheelchairs". From observations, it was apparent- that some effort had been made in taking individualised measurements and ensuring that the wheelchair was the correct size for the stroke survivor and that a pressure relief cushion was issued with the wheelchair. Fifty-three percent of participants had been issued a crutch or walking stick and 15% had received walking frames. The researcher is of the opinion that 15% of the participants would have benefitted from some form of mobility assistive device, but did not receive this (Figure 4.100). Issuing of the correct mobility assistive devices enhances safety with ambulation and can help in overcoming activity limitations and promote participation in the community and society.



**Figure 4. 100 Mobility assistive devices received**

Two participants who received rehabilitation at WCRC were issued with additional devices. These were wheelchair tables, a bath board and adapted cooking utensils (Figure 4.101). It was rewarding to see how well one participant managed basic cooking skills, utilising this equipment with the training she had been given at WCRC. Considering that prior to the stroke 16 of the participants were housewives, more attention needs to be given to the issue of adapted cooking utensils.



**Figure 4. 101 Other assistive devices received from hospitals**

#### **4.9.12 Lack of education, training and support in terms of treatment of medical conditions and rehabilitation**

This study has revealed that in many areas, stroke survivors in the Helderberg Basin and family or caregivers are not receiving sufficient training and education from disciplines involved in medical treatment and rehabilitation. This is illustrated by the following comments from participants and caregivers:

*"But I believe if the doctors had educated him, told him. 'This is what you must do' at least called me in ....'This is what your husband must do.' Not just let us go –we are not clever...."*

*"Now a person just wants to know. Someone must just explain this long term situation."*

*"He probably just presumed I knew what it was about and you must not just presume that someone knows. You must make sure that he knows."*

*"There is just too little information"*

*"I don't really know what happened at the hospital -I was not there... "*

*"If you look at the numbers –he hasn't got the time to discuss therapy. It is not that he doesn't want to – there is not enough time for him to do it".*

*"Till today, I don't know what the ladies name was - very friendly. If I had only known how everything fitted together..."*

A caregiver who was asked if she received any guidance from therapists in doing transfers gave the following reply:

*"I wouldn't say they took time to explain everything. I really just watched what they were doing the one day..."*

Another caregiver who was questioned about guidance she and her husband had received from doctors and therapists turned to her husband and asked the following question:

*"When you had the stroke –I took you in the afternoon –they kept you there that night. I came home. You stayed in the hospital –you were lying in hospital. There were people who came to you –gave you therapy and spoke to you –I don't know exactly what happened. Can you remember anything?"* To this question her husband replied *"Not exactly."*

This response from a caregiver illustrates the need of follow up appointments and on-going support and training:

*"Couldn't they have told us to come back? You can come back in two months, or you can come back in a month's time. I would really have appreciated that. Then I could have gone back after a month and said this is like this and this is like this and this...They don't do that. Just like that. There are your pills. I would say they must give more attention to that. I strongly believe –if that had happened, I would have been much wiser and he wouldn't have just lain there."*

There are numerous reasons why participants /caregivers did not receive the required education and training:

- **Rapid discharge rate**

With the high demand for beds, therapists at Helderberg Hospital report that stroke survivors are often discharged before they have the opportunity to give any counselling.

- **Unavailability of family members**

Often family members are employed and do not have the time or opportunity to get to the hospital CHC.

- **Environmental Barriers**

Environmental barriers such as lack of transport and finances prevent family getting to the hospital/CHC /Clinic.

- **Lack of human resources**

Lack of human resources, where stroke survivors either receive limited therapy or services are non-existent.

- **Limited time available**

Doctors and therapists carry high case loads, limiting the time they can give to patients.

#### **4.10 Summary Of Results**

Six (11%) participants were classified as being on rehabilitation level 1. A further 21 (40%) had reached outcome level 2, 16 (30%) were on level 3 and 8 (15%) had reached level 4 (Community Integration). A total of two (4%) participants had achieved rehabilitation outcome Level 5 and had returned to full-time employment.

Utilising the MBI, 7 (13%) participants were considered totally dependent, 4 (8%) showed severe dependency levels and 12 (23%) moderate levels; 11 (21%) required minimal assistance from caregivers.

Numerous environmental barriers have impacted on the achievement of advanced rehabilitation outcomes by uninsured stroke survivors in the Helderberg Basin. In terms of the ICF Core Set for Stroke (Environmental Factors) the majority of participants considered the following factors as barriers: products or substances for personal consumption and use in daily living; products and technology for personal indoor and outdoor mobility and transportation; products and technology for communication. Further barriers were identified as design, construction and building products and technology of public buildings as well as assets, physical geography and attitudes of friends and society.

Concerning services, systems and policies the majority of participants regarded the following as barriers: architecture and construction; housing; communication; transport; associations and organisations; and general social support.

Results indicate that the following three categories were considered the most significant barriers, with 89% of participants regarding lack of assets as a barrier, 88% transportation services, systems and policies and 87% general social support services, systems and policies.

In addition to shortcomings in the primary and secondary prevention of stroke, it would appear that many of the minimum standards for rehabilitation for primary health care and level 1 and 2 hospitals, as stipulated in the *Western Cape Comprehensive Service Plan for the Implementation of Healthcare 2010*, have not been met. Physiotherapy and occupational therapy intervention was limited, with a lack of input from other rehabilitation professionals. A limited number and type of assistive devices had been issued and focussed mainly on mobility appliances.

Certain themes emerged during the quantitative research, which were explored in more detail in the qualitative phase. It was evident that in terms of primary and secondary prevention of stroke, participants lacked knowledge and awareness of hypertension and other risk factors and were not always compliant in taking medication. With regard to diabetes, there was confusion about diet and general management of the condition. Participants and caregivers in general reported on the lack of education, counselling, training and support by health professionals regarding of primary and secondary prevention of stroke and rehabilitation. .

## **Chapter 5 Discussion**

### **5.1 Introduction**

Discussion in this Chapter pertains to the results and objectives of the study. Besides covering the demographic and health status of participants and objectives related to rehabilitation, factors relating to potential rehabilitation outcome levels and the realisation of *Healthcare 2010* guidelines are considered.

### **5.2 Demographic Profile Of Participants**

As discussed in Chapter 2, the majority of people who suffer a stroke in South Africa are generally over 65 years of age (*Heart Magazine*, 2007). The median age in this study was 62 years and the mean 62.56. In other studies done in the Western Cape, Rhoda, Mpofu and De Weerd (2011) report a mean age of 61, de Villiers, Badri, Ferreira and Bryer (2011) 60 and Hassan (2009) 53 years. In the study done in northern KwaZulu-Natal, Wasserman et al (2009), report on a mean age of 68.6 years.

In the case of Hassan (2009) the discrepancy in age is possibly influenced by the selection criteria for WCRC, where preference is given to clients with the potential to return to employment (personal interview with Dr. Helen Sammons, 16 September 2011). Stroke survivors eligible for employment would most likely be under 60 years of age. At the time, male South Africans were entitled to apply for a state pension if they were 63 years of age or older and in the case of females, 60 years or older (South African Social Security Agency, 2009). From 2011, all South African citizens complying with the means test and who are 60 years of age or older are eligible for a pension (South African Social Security Agency, 2011).

With regard to gender, findings from the various studies differ. Wasserman et al. (2009) report 80% of the participants being female, whereas in the study by Hassan (2009) 42% were. The current study has a fairly similar finding to Hassan, with 45% of the participants being female. Rhoda et al. (2011) report on 50% of the participants in their study being female. In the study done in northern KwaZulu-Natal, significantly more females had strokes than in the studies done in the Western Cape.

According to the South African Census of 2001, 48.13% of the population of the City of Cape Town metropolitan municipality was Coloured, 31% black Africans, 18.75% White and 1.43% Asian (Statistics South Africa, 2001; Wikipedia, 2012). In accordance with census findings, the majority of participants in this study were Coloured, but in a higher ratio (83%). This is possibly due to the fact that most of the participants lived in Macassar, the Strand/ Rusthof area and Sir Lowry's Pass, where a predominantly Coloured, Afrikaans-speaking population resides. Lwandle /Nozamo is a smaller area comprising a mainly IsiXhosa speaking population.

Two (4%) of the participants were white. The researcher has observed that many members of the White population in the Helderberg Basin make use of private medical and rehabilitation services and this possibly accounts for the small number of participants from this ethnic group.

Although most participants lived in houses and flats (83% and 4% respectively), the needs of stroke survivors were not being met. If one considers the small size of homes, rooms that were added informally, narrow doors, stairs and steps, the many challenges faced by participants in terms of activities of daily living and mobility become more apparent.

With regard to the provision of basic amenities, it appears that some inroads are being made in the Helderberg Basin, with 83% of homes visited having indoor toilets, 98% running water and all of them access to electricity. However, it was evident that some citizens did not have the means to pay for these services. Free water quotas were used up quickly amongst large households, many of whom did not have the finances to pay for additional usage, causing considerable hardship. The study by de Villiers et al (2011) reported poorer functional outcomes amongst the 23% of stroke survivors living in shacks with no piped water.

### **5.3 Discussion Related To the Health Status of Participants**

#### **5.3.1 Risk factors**

Hypertension is considered to be the major cause of stroke, followed by smoking (Bryer et al., 2010). A similar trend is evident in this study with the majority (85%) of participants suffering from hypertension, followed by 66% who smoked prior to the stroke. In the study by Hassan (2009) 75% of participants suffered from hypertension but only 12 % smoked. In Wasserman et al., (2009) hypertension was also found to be the most prevalent risk factor.

In South Africa the prevalence of smoking is highest in the Western Cape, with 27% of women and 44% of men being smokers (Western Cape (South Africa).Department of Health, 2011). If one considers that people who smoke have double the likelihood of having an ischaemic stroke by comparison with non smokers (Bryer et al., 2010), more education needs to be done in this regard in the Helderberg Basin. Because of its addictive nature more attention needs to be given by health professionals to participants' requests for backup, encouragement and monitoring of smoking cessation.

In addition, 32% of participants had diabetes. Diabetes Mellitus is not only a risk factor for stroke but the level of management impacts heavily on the outcome levels achieved by stroke survivors. Desrosiers et al. (2006) report on the negative impact of multiple co-morbidity factors on participation by stroke survivors. With the addition of blindness, loss of a leg due to an amputation and other complications of

diabetes to the numerous impairments that can occur as a result of a stroke, the challenges in terms of rehabilitation are significantly compounded. In comparison to developed countries, mortality rates from diabetes in the Western Cape are considered high (Western Cape (South Africa). Department of Health, 2011).

The case of a stroke survivor (see page 62) not utilising his glucometer because he did not have a battery raises the questions of where state responsibility ends in terms of health care. The researcher believes that patients who have been issued with glucometers should be required to take them to all hospital and clinic appointments. A system would have to be introduced to provide strips and batteries and ensure that the recipient understands the use of the apparatus. Glucometers can play an important role in the management of diabetes but if they cannot be utilised because components are unavailable or unaffordable, issuing these devices is ineffective and a waste of financial resources.

Wasserman et al. (2009) refer to the impact that HIV is having on the prevalence of stroke in younger people. This was evident in this research: three of the younger participants reported being HIV positive.

### **5.3.2 Primary and secondary prevention of stroke**

Results from this study have made the researcher acutely aware of the importance of primary and secondary prevention of stroke, especially considering that many risk factors are modifiable (Bryer et al., 2010). Gillen (2011), reports that treating hypertension in the elderly has reduced the number of deaths in industrialized countries. It has not been in the scope of this study to determine the mortality rate, but if one considers the number of potential participants who were deceased (Table 2), it does appear to be fairly high. The researcher is also aware of a further five participants who died a few months after being interviewed for this study. Considering the number of people who had died and had multiple strokes, it is evident that more attention needs to be given to both primary and secondary prevention of stroke in the Helderberg Basin.

The *South African guideline for management of ischaemic stroke 2010* states that "Primary preventative measures reduce stroke incidence and should be universally available and actively promoted at all levels of health care in South Africa" (Bryer et al., 2010: 758). They confirm the importance of correct management in reducing the risk of survivors of a TIA or stroke having another episode. "Stroke is largely preventable by reducing vascular risk factors in the population (primary prevention), detecting and effectively managing individuals with stroke risk factors, and preventing stroke recurrence in those who have suffered a stroke through both lifestyle change and medical means (secondary prevention)" (Bryer et al., 2010:754).



The following preventative measures should be considered:

- "Blood pressure management.
- Management of diabetes mellitus
- Management of hyperlipidaemia
- Smoking cessation
- Alcohol moderation
- Weight reduction
- Physical activity
- Antithrombotic medication
- Anticoagulation
- Vascular interventions" (Bryer et al., 2010: 773-774).

Prevention of diseases and disability does form one of the corner-stones of Primary Health Care policy. This is endorsed in the Western Cape Service Plan for the implementation of *Healthcare 2010* (Western Cape (South Africa). Department of Health, 2007). The two main components of *Healthcare 2010* were facility-based services (FBS) and community-based services (CBS). The role of CBS is to make communities aware of both the burden and cause of diseases and to empower them to become involved in preventative programmes. According to both national policy and *Healthcare 2010*, CBS was to be rendered mainly by non-profit organisations and supported by facility-based services. In terms of stroke, the effectiveness of preventative programmes in the Helderberg Basin remains doubtful. Participants were generally of the opinion that there was a lot of emphasis placed on HIV /AIDS and very little on stroke. Sanders and Reynolds, (2011) report that out of approximately 65 000 community caregivers in South Africa, the majority are working for NGOs involved in HIV/Aids and TB programmes.

At the culmination of this research a draft framework for 2020 -*The future of health care in the Western Cape* was published by the Western Cape Department of Health. The main thrust of *Healthcare 2020* is to promote "wellness" (Western Cape (South Africa).Department of Health, 2011). According to this document, community health workers (CHWs) will be allocated to each household in the community. They will form a link between families and health services. Part of their role will be to promote healthy living and to ensure that people are compliant with taking medication. Hassan, Visagie and Mji (2011a) reported on participants being concerned about home-based carers sharing confidential information about their clients with other people in the community. In this study there was a similar finding. Where there is a compelling need to ensure compliance with taking medication, steps would have to be taken to guard against the abuse of human rights.

### 5.3.3 Health literacy

In this current study, participants and caregivers generally reported on the lack of counselling and education in terms of primary and secondary prevention of stroke and demonstrated limited understanding of the risk factors related to stroke. The South African *National Rehabilitation Policy* endorses the Social Model of disability and recognises the importance of people with disabilities (and their families) being involved in decision making and that they should be empowered to direct their own health management (Department of Health, 2000). Osborne (2005:3) comments on the fact that, worldwide, patients are increasingly regarded as "active consumers rather than passive recipients of treatment and care." Education and counselling plays an important role in empowering stroke survivors and their families. The researcher found that the participants and caregivers involved in this study were very passive and accepting and were not being empowered to direct their own health management and affairs, as illustrated by the comment made by this caregiver:

*"We went to see a doctor at the clinic. She made recommendations about pills. We didn't ask many questions. One just accepts that the doctor knows what she is doing."*

Where information is given to patients and caregivers it is extremely important to ensure that the relevant information has been understood. People's ability to understand and act on health information given to them depends on their health literacy (Schillinger, Grumbach and Piette (2002).

Health literacy can be defined as "The degree to which individuals have the capacity to obtain, process and understand basic health information and services to make appropriate health decisions" (National Network of Libraries of Medicine, 2011). It is important for patients to understand how to take their medication and modify their lifestyle in order to control blood pressure adequately. The management of diabetes is even more complicated. Patients are required to understand the importance of diet, giving of insulin injections and in many instances, the self monitoring of glucose levels (Williams, Baker, Parker and Nurss (1998). Schillinger et al. (2002) report that patients with poor health literacy have difficulty reading information on pill bottles, understanding what dosages are required, interpreting blood sugar levels, understanding information brochures and informed consent forms or knowing when their appointments are. They found that there was a correlation between poor health literacy, inadequate glycemic control and higher levels of retinopathy. Williams et al. (1998) found that 48% of the participants with diabetes or hypertension who took part in their study were lacking in functional health literacy and stressed the importance of educating patients with these chronic diseases in order to prevent poor outcomes in terms of health.

Various factors such as poor literacy, language, cultural barriers, advanced age, disability and emotional issues can impact negatively on people's ability to understand health information (Osborne, 2005). Schillinger, Grumbach and Piette (2002) also report on poor health literacy being evident amongst patients with minimal educational levels, the elderly, immigrants and ethnic minority groups in the United States. In a more recent study by Cavanaugh, Rothman, White and Wolff (2010: 238) they comment on the suboptimal care for diabetics, "particularly for racial and ethnic minorities, the poor and the uninsured." Many of the participants in this study were from low socio economic backgrounds, had limited education (Figure 4.2), were elderly (Figure 4.1) and uninsured and it is likely that they would experience difficulty with health literacy.

The situation in South Africa, and in the Helderberg Basin, is compounded by the number of different languages which are spoken both by stroke survivors and medical personnel and the high cost of translating information brochures into IsiXhosa. One participant described how difficult it was to communicate with the doctor at the CHC who came from elsewhere in Africa. He had no understanding of Afrikaans or IsiXhosa which were the predominate languages of the people attending the facility. Through her involvement with uninsured stroke survivors in various communities, the researcher has become acutely aware of the need for information on diet to be given in the language of the client and at a level they can understand. Culture and levels of poverty need to be taken into account and diets adapted accordingly for different communities. Often substances recommended on diet sheets are unaffordable, and, where food is in short supply, telling people not to eat the skin on chicken or to discard the fat on meat to reduce cholesterol levels does not make sense to them and is regarded as a waste. Cognitive impairments after a stroke will also impact on health literacy.

#### **5.3.4 Visual impairments**

Besides stroke, attention also needs to be focussed on strategies to prevent and reduce visual impairments. This study has left the researcher with an overwhelming sense that the evaluation and treatment of visual impairments as well as the provision of visual aids and rehabilitation is neglected amongst the uninsured population of the Helderberg Basin. According to literature, early identification and treatment of certain conditions can prevent blindness (National Eye Institute, n.d). Ten of the participants reported having cataracts and difficulty accessing treatment. In South Africa cataract is considered to be one of the leading causes of vision loss and accounts for approximately 50% of blindness (Lecuona and Cook, 2011). According to this source, the targets in terms of the number of operations required to eliminate blindness as a result of cataracts are not currently being reached. The researcher also received the impression that diabetic participants were not having their vision checked annually by an ophthalmologist, as is recommended in international guidelines. Further investigation needs to be done to determine the reason

for this, especially as early detection of diabetic retinopathy and treatment can prevent blindness (National Eye Institute, n.d). Vision problems greatly compound the difficulties faced by stroke survivors.

## **5. 4 Rehabilitation Outcome Levels Of Participants**

### **5.4.1 Level 0, 1, and 2**

Rehabilitation outcome levels should be achieved in chronological order and follow a logical progression through to higher levels (Landrum et al., 1995). Planning for the future management and care of the stroke survivor should commence at level 1 (Landrum et al., 1995). As discussed in the previous section, effective management of risk factors through medical intervention and change of lifestyle is vital for effective stroke rehabilitation. Plans for secondary prevention of stroke should be determined and implemented at this level. In a study done in rural KwaZulu–Natal, Wasserman et al. (2009) found that two thirds of stroke survivors /caregivers in their study did not receive any training on stroke management or secondary prevention before discharge from hospital.

A similar trend was evident in this study. Classification was complicated by factors which should have been attended to at lower levels and had not been adequately addressed. For example, a 44-year old participant returned to work shortly after having a stroke. However, when interviewed by the researcher, she had no idea of her risk factors and was not on any medication. When referred back to the relevant CHC by the researcher, she was found to be suffering from hypertension. She was classified as being on level 5 (Productive Activity), but should possibly have been considered as being on level 1, as not all medical issues had been addressed.

Another critical component of these lower levels is education and training. Patient and family counselling and education should take place at level 1 and 2 (Visagie, 2010; Hassan, Visagie and Mji, 2012). The *South African guideline for the management of ischaemic stroke and transient ischaemic attack 2010* also emphasises the important role of education of the stroke survivor and family/caregivers in stroke rehabilitation (Bryer et al., 2010). Hale (2001) reports on South African physiotherapists experienced in working with stroke survivors, considering education of the stroke survivor, family and caregivers, physiotherapy assistants, community rehabilitation workers and the general public as an integral part of their job description. Issues which need to be addressed by all members of the medical team are prevention of further strokes, rehabilitation interventions, the impact of stroke on the caregiver and family, sexuality, driving, taking part in leisure activities and the possibility of return to employment (Byer et al., 2010). The impact of the stroke on the financial situation of the stroke survivor also requires attention and, where necessary, information should be provided concerning the process of obtaining a disability grant. Hassan et al., (2012) stress the importance of education, setting up strategies to prevent

complications, planning of treatment and determining rehabilitation goals before commencing with hands-on therapy.

The rehabilitation guidelines in *Healthcare 2010* for levels 1, 2 and 3 hospitals states that counselling and education must be given to family or caregivers if they are available (Western Cape (South Africa). Department of Health, 2007). Guidelines for PHC states that education and training of family or a primary caregiver must be facilitated (Western Cape (South Africa). Department of Health, 2007). There is no exclusion clause regarding availability of caregivers - This possibly implies that supreme effort should be made in this regard at PHC level, where it is easier for family to attend the clinic or CHC. As illustrated by the qualitative findings of this study, participants /caregivers were clearly of the opinion that counselling, education and training was lacking.

The speech and language test revealed that 38% of participants experienced difficulty with following verbal instructions. In such cases and where stroke survivors have cognitive and perceptual impairments, it is imperative that family /caregivers are included in counselling and education.

What was evident in this study was the number of participants who had limited mobility and required assistance with self-care activities and transfers which placed them on level 2. Family and caregivers had very little idea of how to manoeuvre wheelchairs and do transfers effectively. Obese or overweight stroke survivors, who were unable to transfer independently, placed tremendous demands on caregivers. The researcher observed only one caregiver who was proficient in doing transfers. She had been trained by a therapist experienced in stroke rehabilitation who was working for HSSG. Lack of training in how to perform transfers can result in back and neck injuries to caregivers and shoulder pain to stroke survivors. This is often caused by stroke survivors being pulled by their arm when being assisted with transfers (Davies, 1985). It should be noted that 28% of participants in the current study complained of shoulder pain.

Once preventative and long term management strategies as well as education and training have been addressed, functional, cognitive and communication factors can receive attention, resulting in progression towards level 3.

#### **5.4.2 Level 3: Activities of daily living/indoor mobility and communication**

The main focus of a level 3 outcome (Home/Residential Integration) revolves around gaining a certain level of independence in terms of activities of daily living, mobility and setting up an effective communication system for stroke survivors with speech and language disorders. This is described in *Healthcare 2010* as "Facilitating the achievement with varying degrees of assistance as required of a basic

degree of functional independence in self-care, mobility, safety, communication" (Western Cape (South Africa). Department of Health, 2007). One caregiver sums up this level of independence with the following words: "*What I did notice with her is that she can dress and wash herself and do the basic things.*"

Thirty percent of study participants obtained a level 3 outcome, which meets the requirements stipulated in the guidelines for *Healthcare 2010* for rehabilitation at PHC level.

The Modified Barthel Index (MBI) and Stroke Impact Scale Version 3(SIS3) give an indication of activity limitations experienced by participants. Where the main focus of the MBI is on basic activities of daily living such as washing, dressing, eating and indoor mobility the SIS3 includes some additional questions on the ability of participants to do household chores, shopping and walking one block. According to MBI scores more than 70% of participants required some form of assistance with personal hygiene tasks, bathing, feeding and with dressing while 53% required help with transfers.

Physical impairments would largely account for this high level of dependence. Ninety-eight percent of participants experienced some form of paralysis or weakness of their limbs. Thirty-two percent of participants scored zero for hand function and the median score was 25, indicating that the majority of participants had limited upper limb function. With minimal occupational therapy intervention, this is an area of rehabilitation that the researcher considers to have been neglected. From her experience working with stroke survivors in private practice, where they would have received considerably more hours of therapeutic intervention, the researcher has noted that considerable improvement can be obtained in upper extremity function. Gillen (2011) gives guidelines on the role of the occupational therapist in retraining upper limb function and the importance of staying informed about new developments in treatment in this regard. Young and Forster (2007) report that a review of clinical trials revealed that intensive therapy is beneficial in improving upper limb function, but there is uncertainty as to which subgroup of stroke survivors would benefit the most from therapeutic intervention. More research should be done on the effectiveness of various techniques. Bilateral hand function plays an important role in tasks such as washing, drying, eating and dressing. Table 3 shows that with p values of <0.01, strength of limbs (SIS3.7) and hand function (SIS3.1) had a statistically significant impact on performance of activities of daily living.

Gillen (2011) describes the contributory role of spasticity, weakness, incorrect positioning, postural misalignment and the lack of variation in positioning of the limbs in the formation of contractures, resulting in a poor prognosis for limb function. Although there was evidence of restricted joint range among participants, the researcher observed less of the severe contractures seen amongst uninsured stroke

survivors prior to 2009, which she had noted through her involvement with the HSSG. Although limited, it is possible that physiotherapy and occupational therapy received has played a positive role in this regard.

A further factor which has contributed to poor ADL outcomes is that apart from mobility devices, 96% of participants received no other form of assistive devices. Seventy-seven percent of participants regarded products and technology for personal use in daily living as a barrier. Besides items such as clothing and furniture this category also refers to equipment which can assist people with disabilities in their daily life. As well as playing an important role in the prevention of contractures through correct positioning of affected limbs, wheelchair tables can enhance independence with eating. It should be noted that many homes did not have dining room tables. Food was often prepared on kitchen counters and people ate off their laps, which is awkward for people with affected limbs. Cutlery and other items with built up handles can also promote independence.

Although many participants washed in a basin to save water, 57% of the homes had a bath and 21% a shower. One participant had been issued with a bath board to facilitate bath transfers. It is the researcher's experience that grabs rails and a plastic chair placed in a shower for the stroke survivor to sit on can greatly enhance safety. Issuing these items or recommendations in this regard had not been made. In addition, there are numerous assistive devices available for the visually impaired which can increase independence. Assistance to visually impaired participants in terms of rehabilitation and issuing of assistive devices was seriously lacking and requires urgent attention.

In this study, the inability of many participants (43%) to use the toilet independently caused tremendous strain on caregivers and excessive use of nappies. Where other activities such as washing, dressing and feeding could be done at times that were convenient, many caregivers found it difficult to go out and leave the stroke survivors at home for fear of their falling if they attempted to go to the toilet on their own. Others found the only way they could manage was to put a nappy on the stroke survivor and leave him or her in bed when they went out. Assistance with obtaining additional nappies through health facilities was requested by the majority of caregivers. Besides affecting the quality of life of stroke survivors, Gillen (2011) reports urinary incontinence as a barrier to participation as considerable planning has to go into performing activities that were previously done spontaneously.

Considering that 83% of the homes visited had indoor toilets, far more attention needs to be given by physiotherapists and occupational therapists to independent toileting of the stroke survivor. Independent toileting would lead to cost saving for health services and clients, would reduce the burden of care on caregivers, and restore the personal dignity of stroke survivors. A 54-year old participant described how

embarrassing it was to have to use nappies and how regaining independence in toileting restored his "manhood" and dignity. Although the majority of participants had indoor toilets, there were those who would have benefitted from having a commode.

As reported by Gillen (2011), cognitive and perceptual impairments can have a negative impact on stroke survivors' ability to participate in daily activities. In the current study, statistical correlations with various impairments indicated that motor praxis, visual perception, visuomotor organization and thinking skills had a significantly negative impact on performing activities of daily living (Table 3). Poor visual perception and visuomotor organization in particular, would affect tasks such as dressing, transfers and mobility and impaired thinking skills would affect the execution of these activities.

Hassan (2009) revealed that "invisible" cognitive and perceptual impairments and personality changes caused more strain on caregivers than physical dependency. This she attributed to other family members not being aware of the impairments and therefore not offering the caregiver the necessary assistance and support. It is also the researcher's experience that stroke survivors with "hidden problems" are often perceived to be lazy and uncooperative which adds to the frustration and strain experienced by a caregiver. The researcher has observed that some understanding of these deficits can result in family and caregivers being more tolerant and understanding of the stroke survivor's difficulty with basic tasks such as dressing and transfers. Education can empower family /caregivers to give remedial assistance in this regard, which can result in higher outcomes levels being achieved.

Hassan et al (2011b) reported that 63% of participants experienced some form of speech and communication problem post-stroke, by comparison with the 51% in this study. This number was obtained by asking participants if they had experienced any speech or language difficulties post-stroke. Scores from the SIS3.4 indicate a higher percentage with 70% of participants having scores below 90 and twelve percent had scores below 30, indicating severe speech and communication impairments. The devastating effect of communication disorders on the quality of life of stroke survivors is illustrated by Gillen (2011:535). "Many stroke survivors describe issues of loneliness, social isolation, loss of independence/privacy, restricted activities, loss of work /income, and social stigmatization."

Simmons–Mackie and Kagan (2009) state that research shows that people with aphasia, who receive treatment aimed at the reduction of language impairments, make better progress than those who don't. The speech and language test revealed varying degrees of impairments related to aphasia and other language disorders. The lowest scores recorded were for the sections relevant to repetition, reading and writing. The test for repetition would have revealed impairments related to both aphasia and dysarthria.



Gillen (2011), reports on the increased burden placed on caregivers of aphasic stroke survivors. Simmons –Mackie and Kagan (2007:250) conclude that "people affected by aphasia (including caregivers) deserve intervention that promotes meaningful and positive life changes". Besides remediation, speech therapists play a vital role in educating family and caregivers how to communicate with stroke survivors and help them understand the impairments involved. It is the researcher's experience that education and counselling plays an important part in empowering aphasic stroke survivors and changing the attitudes of family and friends who often regard them as incompetent.

Physiotherapists at Helderberg Hospital have also commented on the urgent need of a speech therapist to evaluate swallowing with acute patients in order to prevent aspiration. "Failure to identify and implement appropriate measures for swallowing safety result in significant increases in morbidity and mortality" (Bryer et al., 2010:777). De Villiers et al. (2011) report on impaired swallowing on discharge from hospital as an indicator of a poor survival rate. In addition to this, these researchers report on severe disability levels and the presence of swallowing impairments at discharge, contributing to poor outcomes.

Sixty-four percent of participants considered products and technology for communication as a barrier, mainly due to the fact that they did not have access to telephonic services. None of the participants was aware of, or had been issued with, specialized communication devices. It is the researcher's experience that sophisticated computerised communication devices are not always effective with aphasic clients with cognitive impairments. Lack of education and computer literacy would have been a further barrier for effective utilisation of these devices. However, simple pictographic communication boards which can be made by speech therapists to meet each individual's needs can improve communication.

The role of depression and emotional factors also has to be taken into account. Gillen (2011) reports on the prevalence of depression, anxiety, emotional lability and aggression amongst people who have sustained a stroke and the consequent negative impact on functional outcomes. Emphasis is placed on the importance of assessing and treating these psychiatric conditions which hamper recovery. Bryer et al. (2010) also report on depression being a common occurrence after a stroke and on its association with poor rehabilitation outcomes.

As illustrated by Figure 4.34, it appears that many of the stroke survivors who took part in the study were depressed. Questions on the SIS3.4 evoked considerable emotional response and tears. Clinical psychologists are considered to be part of rehabilitation teams (Western Cape (South Africa).Department of Health 2007). They can play an important role in counselling stroke survivors and their families in adapting to the many changes and challenges they face (Bryer et al., 2010). The *South African guideline for management of ischaemic stroke* (2010) suggests that antidepressant medication and psychological

intervention should be considered with persistent depression. It appears that psychological input is a much neglected area for uninsured stroke survivors in the Helderberg Basin where the only psychological counselling that they and their families are receiving is through group sessions which are run by psychologists involved with the HSSG.

It is also the researcher's experience that a neuro-psychological evaluation done by a psychologist can provide valuable information when determining whether or not a stroke survivor can return to work.

Hassan (2009) found that 51% of participants in her study were married, which corresponds with the finding of this study. She reports on 70% of caregivers being under strain due to the amount of time required of them for care giving duties and that family had to manage mostly on their own in this regard. Caregivers perceived their duties as being "overwhelming and a great strain" (Hassan, 2009:1).

It was apparent that activity limitations experienced by participants in this study also caused considerable strain on caregivers. Possibly because women are accustomed to the nurturing role, husbands, in particular, seemed to have difficulty coping with care of the stroke survivor as well as having to earn an income. Several men reported having to take time off work several times a day in order to feed the stroke survivor and assist with transfers. Apart from two participants who were living on their own, the majority of widows or widowers were living with family. Several caregivers were of the opinion that their own health was affected by the strain of caring for the stroke survivor. One proxy respondent reported that she had considered committing suicide due to the tremendous demands of caring for her husband.

Many of the physical, cognitive and perceptual impairments manifested by participants are potentially modifiable through the intervention of rehabilitation professionals, and activity limitations can be overcome through remediation and learning of compensatory strategies. Inadequate physio- occupational and speech therapy would have contributed to the fact that 51% of participants had not achieved a level 3 outcome level. The importance of physiotherapy in regaining mobility after a stroke is generally recognized. Occupational therapists assist stroke survivors in resuming daily activities such as grooming, washing, eating, dressing and toileting. Figure 4.94 shows that occupational therapy received at CHCs, clinics and hospital outpatient departments had a statistically significant impact on MBI scores ( $p < 0.01$ ). The researcher is of the opinion that, with further occupational therapy intervention, many of the participants would have demonstrated improved hand function resulting in higher outcomes in ADL, where bilateral use of hands is often required (e.g. tying shoelaces, doing up buttons). Occupational therapists also play an important role in identifying cognitive and perceptual impairments and in remediation.

In order to relieve the burden of care on caregivers, it is vital that uninsured stroke survivors in the Helderberg Basin achieve sufficient rehabilitation and intervention to achieve outcome level 3.

#### **5.4.3 Achievement of advanced outcome levels (level 4 and 5)**

The main objective of rehabilitation is for people to resume their normal roles in their family, society and in their work environment (Bryer et al., 2010). Of concern is the limited number of participants in this study who were integrated back into the community (level 4: 15%) and employed (level 5: 4%). Scores from the SIS3.8 (Figure 4. 52) give a clear indication of the extremely limited number of participants who were able to resume their normal roles and participate in activities that were meaningful to them prior to their stroke. Wasserman et al. (2009) also report on the decreased levels of participation in social and cultural activities three months post-stroke by participants in a study in rural KwaZulu-Natal.

In the current study, statistical correlations with various impairments indicated that motor praxis, visual perception, spatial perception, visuomotor organisation and thinking skills had a significantly negative impact on the achievement of advanced outcomes (Table 4).

#### **5.4.4 Community integration (level 4)**

For stroke survivors to be considered as functioning at level 4, various goals need to be achieved. They are required to be socially competent, have community mobility and be able to function adequately in the community. They are required to manage their own personal affairs, finances, and direct their own health management. They should be able to perform complex home-management tasks and have the ability to participate in recreational activities. It should be noted that these tasks do not have to be performed independently, but need to be directed by the stroke survivor (Landrum et al., 1955).

In the current study eight participants achieved community integration. Hassan et al. (2012) reports on twenty stroke survivors who received inpatient rehabilitation at WCRC in 2006 improving by one or two outcome levels after discharge to achieve level 4, resulting in a total of 32 out of 57 participants being integrated back into the community. She proposes that this improvement could be attributed to input from caregivers rather than limited community based rehabilitation. The researcher suggests that the importance of rehabilitation in empowering stroke survivors and families to achieve advanced outcomes also needs to be explored. If one considers the limited number of participants (eight) who achieved level 4 outcomes in this study by comparison with the numbers in Hassan et al.'s study one can assume that the intensive rehabilitation and guidance received at WCRC as well as the impact of this institution's policy of empowering people with disabilities, is more effective in equipping stroke survivors (and their caregivers) to achieve advanced rehabilitation outcomes.

In many respects, it is a tragedy that not more stroke survivors from the Helderberg Basin gain admission to WCRC, especially if one considers that the facility is only 30 kilometres from Somerset West. Although WCRC has an admissions policy, with the high demand for rehabilitation at this facility the Western Cape Department of Health needs to ensure that access is equitable and that uninsured stroke survivors are not excluded due to poor referral systems and other environmental barriers.

#### **5.4.4.1 Community mobility**

The results of the SIS3.6 show that only three participants considered themselves to be completely mobile at home and in the community. In terms of community mobility, the majority of participants reported only leaving their homes to go to the hospital or CHC or to collect their pension or disability grant payment.

Being ambulant or having access to a wheelchair form key components of community mobility. It can be concluded from the results that 24 (46%) participants were mobile indoors. This figure is arrived at by combining the number of participants who could walk without assistance indoors (Figure 4.44) with the one participant who was fully independent in terms of wheelchair mobility (Figure 4.45). Insufficient data is available to comment on these participants' mobility outdoors and within their communities, but it is known that 10% scored 100 on the SIS3 for mobility at home and in the community. An additional 30% scored above 70 in this category on the SIS3. One can thus surmise that approximately 60% of participants experienced varying degrees of difficulty with community mobility.

Various factors would have contributed to these participants not achieving home and community mobility. With a mean age of 62.56 the study population can be described as elderly and pre-existing conditions such as arthritis and vision impairments could have played a contributory role. A limitation of this study is that the number of participants who were independently mobile before the stroke was not determined.

A major contributory factor would be the extent of paralysis. The mean score for participants' ratings of the strength of their upper and lower limbs after the stroke was 44.66. However, as this was not graded, further exploration of this impairment was not possible. In addition, 51% of participants had spatial perception deficits and 94% experienced problems with visual motor integration which would impact negatively on mobility, as would visual problems such as blindness, hemianopia and double vision.

Ambulation is generally one of the main goals of physiotherapy. The researcher predicates that the limited amount of physiotherapy received by study participants was insufficient to ensure safe, independent ambulation. Desrosiers et al (2006) found that participants with higher scores for motor coordination of the lower extremities showed increased levels of participation at both six months and two- four years

post stroke in comparison to those with lower scores, and stress the importance of both evaluating and treating impairments of the lower limb to promote participation.

Occupational therapy while not usually focussing directly on ambulation, does address wheelchair mobility, perception and vision impairments caused by stroke, all of which impact negatively on mobility. The number of participants who received occupational therapy is even lower, with 42% receiving intervention whilst hospitalised and 40% on discharge. This seems inadequate in the light of the various cognitive, perceptual and visual impairments as well as limited hand function of participants, all of which would have contributed to poor mobility outcomes. Of particular concern were two blind participants who had the physical ability to walk. One had received extremely limited input from a mobility instructor from the Society of the Blind. He was independently mobile in his home but not his community. The second participant had received no remediation in terms of mobility and coping with his vision loss, which is also the role of an occupational therapist, and required assistance with ambulation both at home and in the community. In both cases, no guidance had been given to family /caregivers on how to walk with a visually-challenged person.

Issuing mobility devices such as wheelchairs, walking frames and crutches is considered an integral component of rehabilitation. Fifty-three percent of participants received wheelchairs. When one considers that 53% of the participants required some form of assistance with ambulation indoors, this number seems to be appropriate. However, many more of these stroke survivors would, in all likelihood, have required a wheelchair to tackle long distances, in inclement weather conditions and in situations where terrain was uneven. As it is, 32% of participants reported that wheelchairs were their only means of accessing the nearest clinic or CHC. This study has demonstrated the importance of wheelchairs as a mode of transport for uninsured stroke survivors to access health facilities, collect pension or disability grant payments and to promote community participation. Therapists need to look further than the stroke survivor's ability to walk reasonably well indoors. Careful consideration should be given to the type of wheelchairs that are supplied for accessing the community, with due regard to rough terrain and long distances.

Of further concern is the issuing of wheelchairs that fit correctly. The researcher (who has completed a basic seating course) noted that 28% of the participants were issued with wheelchairs which had not been custom measured for the user. Sitting in an inappropriate wheelchair can result in secondary complications such as shoulder injuries and spinal deformities which in turn can impact negatively on the ability to propel a wheelchair independently. It is gratifying to see that some effort is being made in terms of the correct measurement of wheelchairs and issuing of pressure relief cushions in the Helderberg Basin but this service needs to be extended. Currently therapists at Helderberg Hospital and CHCs report a limited budget allocation for wheelchairs.

One also needs to consider the number of participants who could propel a wheelchair independently. It is not known how much of this can be contributed to the level of severity of the stroke and how much to training and the type and suitability of the wheelchair. Although perception problems can make it problematic for stroke survivors to manipulate wheelchairs, possibly more endeavour should be made in this regard. (Wheelchairs that can be propelled using one hand are available.) Greater independency in wheelchair manipulation would relieve some of the burden placed on caregivers. The researcher observed that participants who had been to WCRC for rehabilitation were more skilled in propelling wheelchairs independently than those who had not.

When considering the impact of mobility assistive devices on community mobility as illustrated in Figure 4.50 and 4.51, various factors need to be taken into account. In all likelihood, wheelchair users and those participants utilising walking frames would have had significantly more physical impairments than those utilising walking sticks or canes, which would impact on community mobility. Environmental barriers such as lack of transport for wheelchair users would also have played a role in hindering community mobility. The researcher also observed that caregivers had limited knowledge of how to manoeuvre wheelchairs over rough terrain and up and down steps. Difficulty in pushing wheelchairs outdoors possibly hindered use of these devices to access the community. However, it is apparent that one needs to correlate the community mobility of participants with similar impairments and mobility devices in order to determine their full impact on community mobility.

Figure 4.9 illustrates that the majority of participants lived in homes where there was insufficient space to manoeuvre wheelchairs. Homes were generally small and crowded. Confined space makes it difficult to store a wheelchair with a long wheelbase, such as the Worldmade3 which is designed for travelling long distances and for outdoor use. The researcher has observed that it is also cumbersome to manoeuvre indoors (e.g. at CHCs and clinics).

Another assistive device recognised as improving ambulation in stroke survivors with plantar flexion and inversion of the foot, is an ankle foot orthosis (AFO) (Gillen, 2011). One participant had received this device which can prevent stumbling over the affected foot and improve walking speed and balance. This was issued at WCRC. Considering that 98% of participants indicated that the muscles of one side of the body or both sides were affected (Figure 4.17) and 68% had been issued with walking aids such as a crutch or walking frame, one could assume that some of them would have benefitted from being issued with an AFO.

Steps at the front and back door and uneven and sandy terrain generally created a challenge for both wheelchair-bound and ambulant stroke survivors to access the nearest road. These barriers, once again,

highlights the importance of therapists obtaining detailed information on the home environment, and engaging with municipal authorities, caregivers and families with regard to the necessity of ramps, gradients, costs and the most suitable products to use (e.g. cement or wood.) In addition wheelchair users and caregivers must be trained to manoeuvre a wheelchair up and down steps, ramps and over rough and uneven terrain.

Besides the factors mentioned above, there are numerous other environmental barriers impacting on community mobility. Sixty-five percent of participants rated public buildings in the Helderberg Basin as inaccessible, mainly due to steps. However, many of them did not see it as a problem as they only went to the CHC or hospital to collect disability grants and pensions and these facilities were accessible. In one sense one cannot help admiring those participants who were of the opinion that if you had to enter a public building and there were steps you "*make a plan*" and did not regard it as a barrier. However, the South African Human Rights Commission (2002) reports on inaccessible buildings being a major factor contributing to the exclusion of people with disabilities from main stream society and denying them basic human rights such as freedom, dignity and equality. Universal access is promoted in national policy and is one of the basic principles of the social model of disability. Only three participants were aware of architectural and building regulations with regard to accessibility. In terms of empowerment, it would seem that much needs to be done in educating people with disabilities about policies and their rights.

The prevailing winds in the Helderberg Basin (South-Easter and North-Wester) and uneven terrain are a considerable barrier for wheelchair users and stroke survivors whose balance is poor. Seventy-one percent of participants reported on the physical geography of their surroundings as being a barrier. Participants and caregivers reported difficulty with pushing and propelling wheelchairs and walking through sandy soil and over uneven terrain. Therapists also need to give more attention to ambulation outdoors.

Stray dogs and the fear of being targeted by criminals present added impediments. The majority of participants based their opinion of legal services on the helpfulness of the police services in their communities. Thirty-four percent regarded legal services as a barrier and 25% as a facilitator. Lack of transport played a major role in limiting community mobility. Of significance is that 88% of participants regarded transport services and policies as a barrier and 53% perceived it as a major barrier. Fifteen percent of participants owned vehicles but only four percent were driving again after the stroke. Thirty percent made use of taxis. Others relied on family and friends or had to pay people in the community to assist them, often at significant cost.

Possibly more than the lack of transport, the cost limited community mobility. The level of poverty faced by many participants is highlighted by 89% of participants regarding assets as a barrier. Fifty seven

percent of households were living on an income of less than R3000 per month. A shortcoming of this study is that the number of people in each household, or residing on the same property, was not documented but it was evident that the disability grant or pension of stroke survivors was also supporting many unemployed family members who were in the economically-active age group. Of concern is that 57% of participants reported a shortage of food as being a barrier (Figure 4.54). If one considers the level of poverty faced by many participants and the cost of fuel and transport this would, to a large extent, explain why participants only ventured into the community for essential appointments at health facilities and to collect grant payments.

Patient age, visuomotor organization, physical geography, and transport all had p values of <0.01 in statistical correlations done between these factors and community mobility (SIS3.6).

#### **5.4.4.2 Social competency and ability to function in the community**

Besides the factors mentioned in the section above, communication impairments and attitudes of family, friends and society also impact on community integration. Simmons-Mackie and Kagan (2007) point out that as communication is a requirement for most daily activities, aphasia has a significant impact on functions of daily life and participation, resulting in social exclusion, a reduction in involvement in leisure activities and loss of gainful employment. With 51% of participants having experienced some degree of speech and communication difficulty post-stroke, the above mentioned statement once again highlights the need for speech therapy intervention to promote attainment of advanced outcomes.

All twenty participants from Macassar reported being actively involved in their churches or religious communities prior to the stroke. Besides attending church services and bible study meetings, many of them had served in positions of leadership, were involved with youth work, church bazaars and other charity work. The majority of participants in other locations gave similar feedback. For most, this involvement had been curtailed post-stroke.

For many participants it was difficult to walk to church after the stroke or get there in a wheelchair. Although it was apparent that some people were visited by church elders and members at their homes, only one participant reported on someone from the church coming to fetch him, and still being included in church activities. Most participants were unconcerned about architectural barriers (e.g. steps). They reported on the lack and cost of transport and negative attitudes of people in the community as being barriers to participation in religious and church related activities.



Attitudes of family, friends, community and society will impact on participation and community integration, as it determines how much practical assistance and emotional support stroke survivors receive and to what extent they are included in social and other gatherings.

#### **5.4.4.3 Managing personal affairs**

Cognitive, perceptual, language and communication impairments as well as extremely limited therapeutic intervention by occupational and speech therapists would have affected participants' ability to conduct their own affairs, manage finances and direct their own health management. Figure 4.32 illustrates the difficulty that the majority of participants had with abstract thinking, short term memory, problem solving, reasoning, planning, following instructions and performing simple calculations. Many of these skills are vital for the management of finances and conducting of personal affairs. The ability to read and write will also impact on these tasks. Forty-two percent of participants experienced some difficulty with reading tasks on the speech and language test (Figure 4.23) and 53% with expressing themselves in writing and with number concepts (Figure 4.24). From discussion with participants and caregivers, it is apparent that none of the participants received therapeutic intervention to work on the above mentioned impairments and activity limitations.

Cognitive and perception impairments can be assessed through observation of performance of ADL, but may only be revealed with testing by a trained professional. The researcher believes it is vital for some form of cognitive and perceptual testing to be done with all stroke survivors and that they and family receive counselling and education in this regard. Although Young and Forster (2007) report on uncertainty about the effectiveness of treatment of cognitive and perceptual impairments due to the lack of research, it is the researcher's experience that remedial work and teaching of compensatory strategies can play an important role in overcoming these limitations. However, progress can be slow, and to improve outcomes considerably more hours of occupational therapy will be required than received by participants in this study.

Again, it must be remembered that to achieve level 4 stroke survivors must be able to direct these tasks, even if they cannot perform them independently. The researcher is of the opinion that here there is scope to empower stroke survivors to play a more active role in the management of their finances and affairs. Both family and the stroke survivor need to be educated in this regard. Applying principles of health literacy where information is simplified and given at a level that is understood could also play a role in more stroke survivors being able to direct their own health management.

However, where stroke survivors are unable to manage their own affairs and do not have family to help, there is a need for the state to provide assistance. The circumstance of two participants, where

competency was of concern, raises the question of adequate measures to protect stroke survivors and ensure that there is no misuse of their disability grant or pension. Here social workers can play an important role. Community health workers possibly need to be educated in this regard and procedures put in place if any form of abuse is suspected. According to South African law, a *curator bonis* should be appointed where someone is unable to manage their own affairs. Further investigation would be required to determine whether or not uninsured stroke survivors with severe cognitive impairments are being protected adequately.

Although participants were of the opinion that health-related professionals such as architects, lawyers and teachers had no impact on their lives, it is the experience of the researcher that people with disabilities do, at times, need legal assistance when policy payouts and other payments owed to them are contested. PWDs with limited finances find it extremely difficult to obtain legal assistance, due to the high cost of legal fees.

Through her involvement with members of the HSSG, the researcher has become aware of the importance, even for people with limited finances, of having a will, and particularly if they own their property. Lawyers can offer assistance in this regard. From the perspective of the researcher, the lack of legal assistance and assistance from other health-related professionals should be regarded as a barrier.

#### **5.4.4.4 Complex home-making abilities**

Complex home making abilities would revolve around planning of and ensuring the execution of tasks such as cooking, washing of clothes, cleaning the home as well as budgeting, shopping and generally caring for the needs of the family unit.

The ability to plan, organize, problem solve, follow instructions, and do basic arithmetic calculations would in many respects be a prerequisite for performing more complex home-management tasks. As discussed previously, the majority of participants obtained low scores for the section on thinking skills on the LOTCA, which gives an indication of these abilities. However, with the assistance of family and domestic worker there are those who could possibly have directed tasks.

Eighty-seven percent of participants rated social support services and systems as a barrier and indicated that they required assistance with activities of daily living, housework and with transport to access health facilities and the community. They expressed a need for transport to shops and in some cases for someone to do their shopping for them.

#### **5.4.4.5 Recreational activities**

Desrosiers et al. (2006) report on advanced age and depression impacting negatively on participation in daily tasks and social activities. Although the current study population can be considered as elderly, it appears that additional factors also hampered participation. As reported, SIS3.3 scores indicate that the majority of participants were depressed. The above-mentioned researchers stress the importance of addressing depression in stroke survivors. "The present study confirms the necessity of evaluating and treating depressive symptoms during the rehabilitation phase in order to help maintain a good level of engagement in their activities and roles. Indeed, psychological problems should be screened for and addressed as soon as possible since they can hinder the resumption of pre-stroke activities and roles" (Desrosiers et al, 2006: 227). It appears that attention to the depressed mood of participants in the current study could have improved outcomes.

The researcher has observed that with retirement, recreational activities can play an increasingly important role in people's lives. There is possibly a perception that where people have limited education, reading is not an important leisure-time activity. Although education levels of participants were generally low (Figure 4.2), many of them enjoyed reading the newspaper, magazines or their Bible but were finding this progressively difficult. As mentioned previously, several participants with limited schooling reported on teaching themselves to read. Reading can play an increasingly important role in the lives of stroke survivors who are confined to their homes.

Of concern is the number of participants who did not have reading glasses and were having difficulty obtaining them owing to cost and other environmental barriers. Vision testing and provision of glasses is not carried out at all government facilities in the Helderberg Basin and people have to travel to Cape Town for this service. The cost is R180, which includes the cost of glasses and travel expenses, but for many people living on a disability grant or pension, glasses are seen as a luxury. As one participant said, *"Either you have an appointment and you don't have the money, or you have the money and you can't get an appointment."* Although transport is organized through the CHCs, participants were of the opinion that it was not geared to wheelchair users.

An additional barrier to participation in recreational activities was the lack of additional assistive devices. This is illustrated by a 62-year old participant with a Grade 6 education, who was an avid reader. With multiple strokes he lost function in both upper limbs and was no longer able to turn the pages of books and newspapers. He expressed tremendous frustration at not being able to pursue this activity. Issuing of a relevant assistive device could possibly have enhanced his ability to continue with this pursuit.

In a more positive light, a participant, who was a wheelchair user and an avid soccer fan, described how four of his friends still came to collect him every weekend to support club matches. If they needed to get up steps in the stadium, they picked him up in his wheelchair, or got other people in the crowd to assist. This illustrates how attitudes of friends and society can facilitate participation and to a certain extent "remove" physical barriers. Universal access has come to mean far more than the removal of physical barriers. "It means the removal of cultural, physical, social and other barriers that prevent people with disabilities from entering, using or benefitting from the various systems of society that are available to other citizens" (South African Human Rights Commission, 2002:7)

The following section looks at reasons for participants in the economically active age group being unemployed.

#### **5.4.5 Level 5: Productive activity**

Various barriers preventing people with disabilities from gaining employment were discussed in the literature review. Treger, Shames, Giaquinto and Ring (2007) report on stroke survivors under the age of 65, with a high education level and having employment which does not involve heavy manual labour being more likely to return to work following stroke. These researchers also state that the more severe the stroke, the less likelihood of the person returning to gainful employment.

Hassan et al. (2012) found that only one stroke survivor who fell within the economically active group in the WCRC research project was employed after the stroke. This study reveals similar results in that a 44-year old female and a 65-year old male had returned to full-time employment after the stroke. Two participants did a few hours work each week which generated some income. One was 43 years of age and the other 73.

Although the majority of participants were over 60 years age, twenty fell within the economically active group. Besides the two mentioned above, five were house wives. Of these, two were wheelchair bound after suffering strokes and each had a leg amputated due to diabetic complications. In addition, the one was blind as a result of diabetic retinopathy. It is of concern to note how the combination of stroke-related impairments and complications as a result of diabetes impact on the lives of people still in the economically active age group.

Nine others were unemployed as a result of the stroke and vision impairments (Table 5). Two stroke survivors had been retrenched and one was unemployed prior to the stroke incident. A 38-year old participant who had worked in the sales department of a hardware store had the misfortune of the business closing shortly after his stroke occurred.

Numerous factors impede reintegration into society and performance of roles in which stroke survivors were previously involved. A study conducted by Hommel, Trabucco-Miguel, Naegele, Gonnet and Jaillard, (2009) reveals that the severity of the stroke, mood and cognitive impairments impact on social functioning and employment. Severe cognitive and perceptual impairment, in particular, can hinder employment possibilities.

According to LOTCA scores, it is apparent that many of the 53 participants overestimated their cognitive abilities in the section on memory and thinking skills of the SIS3 (Figure 4.26). The results for the section on visuomotor organization (Figure 4.31) and thinking skills (Figure 4.32) should be consulted in this regard. This observation is also supported by collateral information from caregivers. Overestimation is possibly due to fear of being labelled incompetent or through lack of insight as a result of right hemisphere damage (RHD). Cherney reports on stroke patients with RHD not being aware of the fact that they have cognitive, physical and behavioural impairments after their stroke. "Deficits that are obvious to family and caregivers are often not acknowledged by the patient or are considered to be trivial and unimportant" (Cherney, 2006: 47). It is likely that at least 60% of all participants had some form of RHD.

Stroke survivors with RHD are also more likely to present with impairments related to spatial concepts, visual perception of vertical and unilateral neglect and this possibly accounts for the generally lower scores obtained for the visuomotor organisation test.

The number of participants who obtained scores of three and four for concentration was unexpected (Figure 4.33), especially considering that the time taken to complete all the tests and questionnaires required for the research was approximately three hours. Only one participant had previously completed a standardised cognitive and perceptual evaluation. This was at Tygerberg Hospital. It is possible that participants found tests on the LOTCA Battery interesting and challenging, which enhanced concentration levels.

The possible impact of depression on test scores also needs to be considered. Jaillard et al. (2009) report on the common occurrence of depression after stroke and how this can negatively influence cognition levels. The section related to feelings on the SIS3 indicated that many participants possibly suffered from underlying depression (Figure 4.34).

Jaillard et al. (2009) discuss how subtle cognitive dysfunctioning (CDF) can be missed in the hospital situation and only become apparent when the stroke survivors return to their normal social and professional activities. They comment on the devastating effects of these impairments, especially if they are not diagnosed. This article reports on patients with high CDF ratings, but minimal neurological

impairments and how lack of identification of these deficits can hamper rehabilitation and return to employment. Gillen (2010), comments on cognitive deficits occurring in the absence of motor impairments and impacting on the stroke survivor's ability to perform tasks done prior to the incident. Both Hommel et al. (2009) and Jaillard et al. (2009), make reference to poor working memory as a "hidden" impairment impacting on rehabilitation outcomes. Hassan (2009) also expresses concern about stroke survivors who appear physically competent to return to work, but once back in employment, impairments related to cognition, perception and executive functioning may be revealed. Furthermore, they may be denied financial compensation (disability grant) to which they are entitled, because these hidden impairments were not identified. In this current study a 59- year old female, with impaired memory and thinking skills had been denied a disability grant. A 54-year old male who was experiencing difficulty with planning and slowed thought processing described how difficult it was to collate all the information required to initiate the application for a disability grant and how reluctant family were to assist as they thought he could manage it himself.

Menial labour is often the only type of work available for people with limited education and training. Consequently it is not always possible for stroke survivors with physical impairments to return to this type of employment which often requires considerable physical strength.

If one considers the job description of the nine participants mentioned in Table 5, all of them would have required physical strength and stamina. Although these scores are subjective estimates given by participants, it does give an indication that for a number of them, limited physical strength and poor hand function would have compromised their ability to perform tasks required tasks for their job description.

Although the chef and the builder /plumber had made a reasonably good physical recovery, hidden cognitive and perception problems would in all likelihood have impacted on work performance. The builder experienced difficulty with the visuomotor organization section of the LOTCA (Table 6), indicating impairments related to planning, organizing, spatial relationships, visual perception of vertical and construction apraxia. These impairments can have a disastrous effect on performance of activities related to both building and plumbing. Building plans can be followed incorrectly resulting in extra costs being incurred or building structures not been safe. It is evident that the other six participants also had cognitive and perceptual impairments that would have influenced their ability to perform required tasks. (Table 6)

It is possible that with sufficient input from physiotherapists, occupational therapists and speech therapists some of these participants may have achieved higher outcomes. However, it is apparent that there is a need for therapists and social workers to familiarise themselves with principles of reasonable accommodation and to discuss this or the possibility of alternative employment with employers where physical and other impairments render it impossible for stroke survivors to return to their former type of employment. The researcher is of the opinion that this is an area that is currently much neglected. To facilitate the return to work of stroke survivors it is essential that occupational therapists have some knowledge of policies, legislation and guidelines on the employment of people with disabilities in South Africa.

The Western Cape Department of Health recognises the role of vocational rehabilitation in achieving advanced outcomes (Western Cape (South Africa). Department of Health, 2007). In the Western Cape, the main work evaluation units are based at Groote Schuur and Tygerberg Hospital. It is the researcher's experience that lack of transport and difficulty with board and lodging are a barrier to people with disabilities from the Helderberg Basin utilising these services. The 38-year old participant, who had worked in the hardware store which closed shortly after he had his stroke, had minimal cognitive impairments and the potential to improve physically. He would in all likelihood have benefitted from further vocational rehabilitation.

Treger et al., (2009) report on a poor local economy impacting negatively on the employment of stroke survivors. The current unemployment rate in South Africa is an additional barrier to gainful employment and possibly accounts for the retrenchment of the two participants mentioned in this section and the 29-year old who was unemployed at the time of her stroke.

As reported by Hassan (2009), the researcher also found family members who had to give up work to care for stroke survivors. Of concern is the number of stroke survivors and caregivers who had operated small home industries to supplement their income and pensions prior to the stroke, but had abandoned these as the stroke survivors could no longer assist, or the caregivers were so burdened with caring tasks they could not manage additional work-loads. Prior to the stroke the one couple had created a small shop at their home where they had sold samosas and other basic commodities, but found they could not manage this after her stroke. A 65-year old participant who had done painting and "odd jobs" to supplement his pension prior to the stroke, stated how difficult it was to support his family without this extra income and how he missed been able to buy treats for his grandchildren.

Treger et al., (2007), report on architectural barriers, lack of appropriate transport and attitudes towards disabled people as additional barriers to employment. It appears that the main reasons for the extremely

limited number of participants who had achieved a level 5 outcome is that physical, cognitive, and perceptual and other impairments rendered it impossible for participants to return to work. In addition they had received extremely limited physiotherapy, occupational therapy and speech therapy which have the potential to modify these factors. No assistance was rendered by clinicians in terms of educating employers in terms of reasonable accommodation and assisting the stroke survivor to return to work. The majority of participants were over the age of 60. It is likely that the high rate of unemployment has played a role in the small number of participants being employed. If one considers that 80% of participants regarded lack of transport as a barrier, it is possible that this factor also played a contributory role.

Where stroke survivors cannot return to work as a result of impairments, they can apply for a disability grant, provided they are declared disabled in terms of the definition given in the literature review and the applicant and their spouse meet the criteria for the means test. Stroke survivors are initially issued with a temporary disability grant for one year, allowing for recovery to take place. In addition, depending on their means, citizens over the age of 60 are eligible for a state pension.

## **5.5 Grants**

Similar to the findings of Hassan (2009) this study confirms difficulties that stroke survivors experience in obtaining all the documentation required before a disability grant or pension can be processed. A caregiver reported great difficulty in processing his wife's pension as his identity document had been stolen. Lack of transport, limited finances and concern about leaving his wife on her own while he went to the Home Affairs office were impacting on obtaining her pension. Another participant had been unable to contact his previous employer as the company had relocated. He was extremely despondent as he could not process his disability grant without the necessary documentation and had no income. In the previously cited study, Hassan reports on assistance given by social workers at WCRC in completing disability grant applications prior to a patient's discharge and SASSA officials calling at the centre to process applications. This is an area where the researcher considers that stroke survivors in the Helderberg Basin require far greater assistance.

As is the case in this study, Hassan (2009) also reported on difficulties experienced by stroke survivors with temporary disability grants and the process of re-application being lengthy, resulting in a period where the stroke survivor is often without income, and causing considerable hardship to dependant families. Hassan also comments on the minimal number of care-givers who were receiving a grant-in-aid to which they are entitled. The researcher encountered a similar trend, where people were either not aware of this grant or were encountering difficulties processing it.



One caregiver was apparently told by a social worker that it was such a small amount (R250 per month); it was not worth processing all the documentation. However, in situations of poverty this extra money was valued for purchasing food and buying extra nappies for incontinent stroke survivors.

It was apparent that where people were self-employed and had no form of income protection their financial situation was seriously affected. Even if they did get a disability grant, this was often far less than they earned prior to the stroke. The researcher has noted that domestic workers and gardeners seem to be particularly hard hit. Depending on the number of hours worked, employers are required to contribute monthly payments for domestic workers and gardeners to the Unemployment Insurance Fund (UIF). Where they work for less than 24 hours per month for an employer, this is not applicable (South Africa. Department of Labour, n.d). Often domestic workers and gardeners work for a number of people in one month, reducing the number of hours per employer. UIF is then no longer compulsory, resulting in considerable hardship when illness or disability does occur.

## **5.6 Rehabilitation**

### **5.6.1 Introduction**

According to *Healthcare 2010*, level 0 and 1 outcome levels should be achieved in acute medical facilities (level 1, 2 and 3 hospitals). Level 2 rehabilitation should occur at similar facilities or at outpatient departments. Level 4 and 5 should be achieved in a community setting. The importance of referral to vocational rehabilitation units for the achievement of a level 5 outcome is also recognized (Western Cape (South Africa). Department of Health, 2007).

### **5.6.2 Discussion pertaining to rehabilitation**

The *South African guideline for management of ischaemic stroke 2010* (Bryer et al. 2010) advocates the treatment of acute stroke in a dedicated stroke unit. This document reports on improved outcomes when stroke survivors are treated by a multidisciplinary specialised team in this environment. Young and Forster (2007) discuss the increased likelihood of stroke survivors being alive and living independently at home one year after the stroke if they receive rehabilitation from a multidisciplinary team in a stroke unit. A minimal number of participants (eight percent) were admitted to WCRC where they would have received intensive rehabilitation from a specialised team as recommended in the previously cited guidelines for management of ischaemic stroke. It is possible that the eight percent admitted to Tygerberg or Groote Schuur hospitals would also have received some intensive rehabilitation.

Several South African studies report on short periods of hospitalization for stroke patients and both the difficulty of accessing rehabilitation in the community and these services being inadequately equipped to

manage acute and sub-acute stroke patients (Wasserman et al., 2009; Rhoda et al., 2009). De Villiers et al. (2011) express concern about outcomes achieved in acute stroke units being eroded as a result of the lack of rehabilitation available in the community after discharge. Rhoda et al. (2009) also suggest that if patients who have received intensive inpatient rehabilitation are not followed up on in the community, it can impact negatively on achieving advanced outcomes. The *South African Guideline for the management of ischaemic stroke 2010* recommends that rehabilitation should be continued for the duration of the first year post-stroke (Bryer et al., 2010). Follow up is important for a number of reasons. As a stroke survivor progresses, new goals can be set and additional skills developed. For example, once a stroke survivor is mobile in the home, challenges with ambulation in the community can be addressed.

Nineteen percent of participants in this study were not hospitalized. Twenty-eight percent were in hospital for a week or less. A further 11% were hospitalised for less than two weeks. This implies that 58% of participants would have been dependent on rehabilitation in the community whilst in all likelihood still in the acute or sub-acute phase. De Villiers et al. (2011) also report on the poor survival rate of patients with severe strokes who are discharged directly home.

In 2009 an occupational therapists doing her community service year was appointed at Helderberg Hospital. Until then there was only a physiotherapy post at this institution. The occupational therapist and physiotherapist based at the CHCs, work 4 days at Macassar CHC and one day per week at Gutrouw CHC. In 2009 and 2010, stroke survivors discharged to Sir Lowry's Pass, and the Lwandle /Nomzamo/ Chris Nissen Park area, would have had no access to occupational therapy in their immediate community.

The Helderberg Basin falls within the eastern sub-district of the Cape Town Metro District. In a study done by Rhoda et al. (2009), the researchers report on only 20 of the 39 CHCs in the total metropolitan region offering rehabilitation services. All CHCs provided physiotherapy, but only half provided occupational therapy. Participants received more physiotherapy than other therapeutic interventions. A similar trend was evident in this study, where 66% of participants received physiotherapy whilst hospitalised and 57% in the community. Forty two percent received occupational therapy while hospitalised and 40% in the community.

Students provided speech therapy at two CHCs in the previously cited study. The current study has identified both the lack of, and the necessity for, speech therapy services for uninsured stroke survivors in the Helderberg Basin. Currently the only speech therapy available for stroke survivors in the Helderberg Basin is through group sessions offered by the HSSG in the Strand /Rusthof community. The group is run by a speech therapist experienced in working with stroke survivors. Although this is an extremely valuable service, many stroke survivors from other communities are still excluded due to transport

problems. Due to the high demand, the group has also grown to the extent that it is not always possible to meet the individual needs of those who attend.

Rhoda et al. (2009) report on 49% of participants receiving 1-4 hours of physiotherapy at CHCs in the Cape Town Metro District and these therapy sessions generally being less than half an hour in length. Sixty percent of participants in this current study received five hours or less of physiotherapy. This figure includes physiotherapy received at inpatient facilities, possibly indicating that the availability of physiotherapy services in the Helderberg Basin is less than in other areas of the Cape Town Metro District. In contrast, De Wit et al. (2007) report on patients in four European rehabilitation centres generally receiving an hour or more of rehabilitation per day. Patients in a centre in the United Kingdom received one hour of therapy per day and in Belgium, Germany and Switzerland two hours or more per day.

The employment of a full-time occupational therapist at Helderberg Hospital from January 2011, and the utilisation of the community service occupational therapists at Helderberg Hospital as well as at Ikwezi, Gordon's Bay and Sir Lowry's Pass clinics can be considered a positive step. These services were established subsequent to the commencement of the study. The mean score for the SIS3 section on mobility at home and in the community was 51.50. Considering this and other factors discussed under the section on community mobility, it seems that there is a need for additional physiotherapy services in the Helderberg Basin, particularly in the Lwandle / Nomzamo and Sir Lowry's Pass Village communities.

However, as pointed out by Rhoda et al. (2009), providing more rehabilitation professionals does not necessarily result in patients receiving additional therapeutic intervention. In the previously cited study by De Wit et al. (2007), they found that Swiss and German patients received more rehabilitation per day than patients in the other centres. This was attributed to an efficient use of human resources and not because these centres had additional personnel. Rhoda et al. (2009) report on available services at CHCs being uncoordinated and how this can impact negatively on rehabilitation services. As mentioned in the previous chapter, 55% of participants in this current study reported the lack of a referral as the reason for not receiving particular interventions. In addition to a poor referral system, this research has revealed that the following factors play a role in stroke survivors not accessing existing rehabilitation services in the Helderberg Basin:

- Twenty-five percent of participants reported on not attending physiotherapy or occupational therapy to which they had been referred, because of lack of transport. An additional 13% specifically reported on the lack of transport for wheelchair users as a factor.

- Thirteen percent of participants reported on family members working and having no one to accompany them to therapy.
- Eight percent of participants /caregivers didn't think physiotherapy /occupational therapy was necessary. When discussing this further, it was apparent that they had been given no guidance or counselling on the benefits and availability of rehabilitation services. Many of them were confused about the identity and roles of the different professionals. The researcher is of the opinion that where therapy was considered unnecessary it was often due to ignorance of what the different disciplines could offer in terms of rehabilitation.
- Twenty-five percent of participants gave the cost of transport as a reason for not accessing existing rehabilitation services to which they had been referred.

The researcher suggests that besides ensuring an effective referral system, this last point is a factor that needs to be addressed and explored further to ensure that uninsured stroke survivors receive sufficient rehabilitation. As already mentioned, 89% of participants regarded assets as a barrier and of these, 43% regarded this as a total barrier. Lack of transport makes it difficult to access rehabilitation services that are available. Lack of financial resources compounds this. It has been the researcher's experience that where taxi transport has been paid for by the HSSG and stroke survivors collected at their homes, there is higher level of commitment to attending group therapy sessions. It appears that in situations of poverty, the cost of transport is a greater barrier than the physical difficulties of getting into a taxi, where taxi drivers and community members are often very willing to assist. The *National Rehabilitation Policy* states the following: "This policy should also serve as a vehicle to bring about equalisation of opportunities and to enhance human rights for persons with disabilities, thereby addressing issues of poverty and disparate socio-economic circumstances" (South Africa. Department of Health, 2000:2) It appears that government is failing its citizens when people cannot access existing rehabilitation services because they don't have the financial means.

Although unrelated to this study, the following anecdote illustrates the further impact that poverty can have on rehabilitation services. An uninsured paraplegic who had an appointment at the seating clinic at WCRC did not attend. When questioned by the researcher he pointed out that the people at the service organisation that he attended had all been offered a free meal at the Spur on that day and he had opted for that. This illustrates that in situations of poverty, food and other basic needs may be met before paying for transport to attend therapy. It is likely that the importance of rehabilitation is not recognised by families and finances for transport are not seen as a priority. It also highlights the need for educating patients on both the importance of rehabilitation and commitment to attending. The *National Rehabilitation Policy* states that "Users of services should also be held accountable for keeping their side of the deal, such as

keeping appointments, and the proper use and care of materials and devices entrusted to them" (Department of Health, 2000:8).

De Villiers et al. (2011) report on inferior housing (shack dwelling with no piped water) being a predictor of low functional outcomes, possibly as a result of the difficulty for these stroke survivors to access rehabilitation. This could have been as a result of the lack of services, transport, or as in this study, the lack of finances to pay for transport. These researchers suggest that priority admission to inpatient rehabilitation for stroke survivors living in these circumstances could lead to improved outcomes.

The majority of participants from this study came from poor socio-economic backgrounds and the researcher believes that, as advocated by the above mentioned researchers, there is need for these stroke survivors to receive priority admission to inpatient rehabilitation.

It would appear there is a need for careful screening of home circumstances and environmental barriers before discharging stroke survivors from poor social economic environments directly home. Besides ensuring that family are contacted and come in to the hospital or CHCs for the necessary training and education, social workers can also play an important role in determining which stroke survivors require inpatient rehabilitation or assistance with transport to access health facilities.

Rhoda et al. (2009) report on 15 social workers being employed at the 20 CHCs in the Cape Metro District. A social worker is employed at Helderberg Hospital, but not at CHCs in the Helderberg Basin. Six percent of participants received input from a social worker whilst hospitalised and a further six percent as outpatients. The researcher detected that participants with HIV were specifically contacted by a social worker and given counselling about their HIV status, whereas stroke survivors or their caregivers did not routinely receive input from a social worker. However, it must be noted that this observation requires verification.

Bryer et al.,(2010) comment on the possible impact of the fear of losing or being denied a disability grant as an explanation for some stroke survivors not completing their rehabilitation programmes. Participants were not specifically questioned on this. However, this factor should be explored further, especially as stroke survivors only receive a temporary disability grant in the first year after the stroke. None of the younger participants in the study gave this as a reason for lack of rehabilitation. Generally, participants were depressed and gave the impression that they were desperate to have their "lives" back. However, fear of not obtaining a disability grant could be a reason for participants' reluctance to attend therapy, especially if they were unemployed at the time of having the stroke.

### **5.6.2.1 Health professionals and health services**

Participants in this study were extremely positive about services rendered by health professionals in the Helderberg Basin, with 97% rating this as a facilitator and 92% perceiving the attitudes of health professionals as a facilitator. In spite of complaints about extremely long queues at all facilities, 97% participants rated health services in general as a facilitator.

These results support the findings of Kahonde, Mlenzana and Rhoda, (2010). Participants in their study, carried out at CHCs in Cape Town reported positively on both the attitudes of health professionals and the services provided at the CHCs. They recommend that future studies in this regard be done in a neutral environment where participants did not have to fear their comments being overheard by the relevant health professionals. In this study participants were seen in the privacy of consulting rooms at private health facilities and were given assurance that all information was confidential and that there would be no reprisals if they expressed dissatisfaction with services. It is possible that some participants still felt a need to be cautious about what they said.

Although the Helderberg Basin is part of the Cape Town Metropole, in many respects there is still a strong feeling of "community" amongst the residents. Places like Macassar and Sir Lowry's Pass are almost small villages in their own right. Many of the health care workers at the CHCs and clinics would probably live within these communities or, with time, get to know clients attending the facilities on a regular basis for chronic medication. The researcher gained the impression that often close bonds were formed between participants and health professionals which could play a role in generating positive attitudes about health services.

### **5.6.2.2 Additional community services**

The majority of participants were unaware of assistance offered by NGOs and NPOs. This is of some concern, if one considers the benefits reported and the many associations in the Helderberg Basin which offer assistance after a stroke, primarily Masincedane Community Services, BADISA, HSSG and the Helderberg Society for the Aged. Fifty-two percent of participants regarded associations and organizational services as a barrier. This was mainly due to their perception of the lack of community support services. Thirteen percent considered that associations and organizations had made no impact on their lives and were neither a barrier nor facilitator.

Thirty-six percent of participants had received assistance from home based carers through Masincedane Community Services. This is a higher figure than the 23% reported in the study by Hassan et al. (2011). Four percent of participants received assistance from home-based carers at two months post-stroke and one percent at six months in the study conducted by Rhoda et al. (2009). It was evident that a good

referral system had been set up in certain communities in the Helderberg Basin, but was still lacking in others. The researcher supplied a number of participants with contact details for home-based care.

The HSSG currently has nine subgroups within the various communities of the Helderberg Basin. Exercises, therapeutic games (to stimulate cognition and perception), speech therapy, psychological counselling for caregivers and stroke survivors and lectures related to stroke are offered in group settings. Rehabilitation professionals with a special interest in stroke run these groups with the assistance of volunteers. Only 15% of participants reported attending these groups (Figure 4.81). Many of them were unaware of its existence. From the comments of several participants and their caregivers, it appears that attending the various activities offered by HSSG also plays a role in elevating the mood of stroke survivors (see Pg 133). Although transport is a barrier to attendance it appears that there is a need for the organization to investigate an improved referral system to its various community groups.

Hassan et al. (2009) found in her study that on discharge, support for stroke survivors from WCRC and community services was lacking. A number of other NGOs exist in the Helderberg Basin which can be of assistance to stroke survivors (Pg 134). However it seems that these services need to be coordinated and linked to health services to form part of the "seamless network" of rehabilitation services. What is of concern is the sustainability of NGOs.

### **5.6.2.2 Sustainability of NGOs**

According to the National Health Act, health facilities have been instructed to involve communities in delivering health services. *Healthcare 2010*, states that these community-based services will be rendered mainly by non profit organisations (Western Cape (South Africa) Department of Health, 2007).

Saulse (2012), reports on many NGOs in the Western Cape having to downsize or close as a result of reduction in both international and government funding, affecting services to many marginalised communities. The Western Cape Branch of the South African National Non-Governmental Organisations Coalition (SANGOCO) has suggested that local government can play a vital role in ensuring the survival of NGOs, by providing funding, especially where they have been given a mandate to provide services by government (Saulse, 2012).

Possibly a reason why many NGOs and community-based services have difficulty in obtaining funding is due to increasing demands being placed on them to be more accountable for both finances and delivery of services. While this, in many respects, is understandable, it is the researcher's experience that NGOs are faced with increasing barriers in terms of bureaucratic demands in order to receive funding. Compliance with such issues as registration as an NPO, Public Benefit Organisation (PBO), submitting Financial

Intelligence Centre Act (FICA) documentation, obtaining audited financial statements, completing funding proposals and compiling budgets are required by all institutional donors before funding is considered. It is becoming increasingly difficult to open bank accounts. A woman actively involved in a grassroots-project, which is benefitting many impoverished and disabled people in her community, recently confided that she only has a Grade 2 education and does not have the skills to do all the administrative work required to obtain on-going funding to sustain the organisation. Considering the important role allocated to NGOs in providing health services, it is the researcher's opinion that both training and administrative support in terms of the above mentioned factors needs to be introduced by government.

Through her involvement with the HSSG, the researcher has become aware that corporates/businesses are increasingly supporting specific target groups or projects (e.g. Education / Youth Groups /HIV) and there appears to be less funding available for projects related to disability. This is a perception which would need to be verified through further investigation.

### **5.6.3 Realisation of *Healthcare 2010* guidelines**

Although it was evident that an attempt was being made to follow the guidelines on rehabilitation in the *Comprehensive Service Plan for the Implementation of Healthcare 2010*, this study reveals that many of the minimum standards for rehabilitation for Primary Health Care and level 1 and 2 hospitals as stipulated in this document, were not being met and are discussed below. (These minimum standards are listed in the Literature Review and can be found on page 17 and 18.)

#### **5.6.3.1 Core package of rehabilitation services for levels 1, 2 and 3 hospitals (Minimum Standards)**

These guidelines, do not define the exact number of hours of physiotherapy and occupational therapy that should be received. However, as discussed earlier in this chapter, quantitative data has revealed that the majority of participants received less than five hours of physiotherapy and occupational therapy. (This figure includes therapy received at CHCs or as out-patients.) Nineteen percent of participants received no physiotherapy and 43% had no occupational therapy whilst hospitalised.

The importance of referral to the appropriate facility for further rehabilitation and linking of clients to community resources is listed in *Healthcare 2010*. However, 55% of participants reported the lack of a referral or the ignorance of the existence of the relevant service as the reason for not receiving certain forms of therapy or interventions.

Figures 4.100 and 4.101 illustrate the extremely limited number and types of assistive devices issued to participants to help overcoming activity limitations and promote participation in the community and



society. In terms of the prescription and issuing of wheelchairs and pressure cushions, 25% of participants had been issued appropriate wheelchairs through government health services (Figure 4.100). However, 28% were seated in unsuitable wheelchairs, received through health facilities and other sources. It is apparent that on-going education in terms of correct seating is required and that health facilities need to budget adequately to ensure that they are able to meet the demand for supplying appropriate wheelchairs.

The support, counselling, training and educating of clients, family and caregivers is considered a vital component of rehabilitation by the Western Cape Department of Health and is listed as one of the minimal standards required. As discussed extensively in this study, this is an area that requires urgent attention. Further recommendations in this regard are made in the following chapter.

### **5.6.3.2 Core package of rehabilitation services for primary health care (Minimum Standards)**

Many of the points discussed in the previous section, are also applicable to the minimal standards of rehabilitation required at PHC level.

Forty-three percent of participants were not treated by a physiotherapist at CHCs or as hospital outpatients. Sixty percent received no occupational therapy. It is likely that this contributed to the minority (49%) of participants progressing beyond level 2 to achieve the stipulated basic level of functional independence.

Screening and assessment for disability grants is considered one of the minimal requirements for rehabilitation at PHC level. Problems in this regard have been listed in section 4.8.4.7. It appears that minimal standards are not being met in the Helderberg Basin where a participant had to return to the CHC on three separate occasions as the relevant doctor did not arrive to do the necessary evaluations

## **5.7 Potential Rehabilitation Outcome Levels**

It is apparent that numerous factors have played a role in preventing participants in this study from achieving advanced outcomes. The researcher believes that uninsured stroke survivors in the Helderberg Basin have the potential to achieve higher outcome levels. Key factors are discussed briefly in this section with further recommendations made in the following chapter.

It is generally recognised that to a large extent, outcomes are determined by the initial severity of the stroke. Medical and other goals which are not achieved at a lower level impact negatively on obtaining higher outcomes. Ensuring the effective management of risk factors for stroke through medical intervention, change of lifestyle and education of the stroke survivor and caregiver or family about these factors has the potential to form a solid base from which uninsured stroke survivors in the Helderberg Basin can progress to higher levels. Considering the vital role that diet plays, both in the management of

diabetes and other risk factors for stroke such as dyslipidaemia, the lack of assistance received by participants from dieticians is a concern. Bryer et al. (2010) also report on the role that certain diets can play in lowering blood pressure (e.g. the so-called DASH - dietary approaches to stop hypertension-diets). Input from dieticians at Helderberg Hospital, CHCs and clinics could play an important role in improving outcomes.

In order to relieve the burden of care on caregivers, it is critical that uninsured stroke survivors achieve a level 3 outcome. More intensive input in terms of physiotherapy and occupational therapy, as well as issuing the relevant assistive devices has the potential to ensure that uninsured stroke survivors achieve the level of mobility and independence described for this level and progress to level 4 and possibly 5. This study has revealed that the evaluation and treatment of cognitive, perceptual, speech and language and emotional impairments has largely been neglected. Note should be taken of the depressed mood of participants. Several articles have been cited in this study stressing the importance of diagnosing and treating depression in stroke survivors. Input from the relevant rehabilitation disciplines has the potential to improve outcomes. Guaranteeing access to these core disciplines through inpatient rehabilitation, home visits by therapists or use of HEALTHNET services to transport patients to health facilities is crucial.

The researcher believes that more participants could have achieved a level 4 outcome. Besides the need for problems related to community mobility to be addressed, stroke survivors and family need to be educated about outcome levels and encouraged to focus on progression to the next level. They should be involved with rehabilitation from the beginning and be actively involved in decision making and goal setting. Stroke survivors and their families should be educated on disability policies and their right to participate in society. Disability rights groups, NGOs and rehabilitation professionals can play an important role in educating the general public to include people with disabilities and promote participation.

In terms of productive activity, the researcher endorses the sentiment expressed by Hassan et al. (2012). It is suggested that with rendering the necessary work evaluations and educating and assisting employers to implement principles of reasonable accommodation, more stroke survivors may be able to return to work. In the following chapter, recommendations are proposed which have the potential to improve outcomes of uninsured stroke survivors in the Helderberg Basin.

## **Chapter 6 Conclusion and Recommendations**

### **6.1 Introduction**

This chapter focuses on the study objectives pertinent to recommendations. Recommendations which have the potential to improve the rehabilitation outcomes of uninsured stroke survivors in the Helderberg Basin are made. The importance of further research in certain fields is highlighted and limitations of this study are listed.

### **6.2 Conclusion**

This study indicates that uninsured stroke survivors in the Helderberg Basin who suffered a stroke in 2009 and 2010 have not achieved optimal rehabilitation outcome levels. As discussed in Chapter 5, it is apparent that many of the minimum standards for rehabilitation for Primary Healthcare and level 1 and 2 hospitals as stipulated in the *Comprehensive Service Plan for the Implementation of Healthcare 2010* (Western Cape (South Africa). Department of Health, 2007) are not being met. It appears that counselling, education, training and support by health professionals regarding primary and secondary prevention of stroke and rehabilitation were lacking.

As many of the risk factors for stroke are modifiable, far more needs to be done in terms of primary and secondary prevention of stroke. Ensuring the effective management of risk factors for stroke through medical intervention, change of lifestyle and educating the uninsured population in the Helderberg Basin about these factors could result in a reduction in the number of strokes. The important role that diet plays in the management of diabetes, hypertension, hyperlipidaemia and obesity needs to be recognised and dieticians should be available for counselling at hospitals, community health centres and clinics.

Although it is generally recognised that the severity of the initial stroke incident and extent of physical, cognitive, perceptual, communication and emotional impairments influences outcomes, numerous environmental barriers have contributed to the fact that the majority of participants in this study (51%) have not reached a level 3 outcome or progressed further to achieve advanced rehabilitation outcomes such as community integration and employment.

The impact of environmental barriers on rehabilitation outcomes is recognised by government policy: "It is also important that service providers pay particular attention to external factors such as environmental barriers and societal barriers because of the potential of such factors to limit the success of the rehabilitation processes" (South Africa. Department of Health, 2000: 1). Note should be taken of the environmental barriers encountered by uninsured stroke survivors in the Helderberg Basin.

Besides limited therapies (physio-, occupational and speech-) and lack of input from other rehabilitation professionals who play an important role in modifying impairments after a stroke, factors such as limited transport and lack of finances to pay for transport impact on the uninsured population accessing existing rehabilitation services and returning to active participation in society. Considering that occupational therapy had a significant impact on Modified Barthel Index ( $<0.01$ ) and SIS3.6 (community mobility) (0.02) scores, extension of these services should be considered.

The results indicated that negative attitudes of friends and society also impact on resumption of activities in which strokes survivors participated prior to the stroke. (A more comprehensive summary of environmental barriers is given at the end of the end of chapter 4.)

With 89% of participants regarding a lack of assets as barrier and 57% a lack of food, it would seem that far more needs to be done to ensure that applications for disability grants and pensions are processed quickly and efficiently. The need for social workers to be available at all health facilities to facilitate this process is apparent.

Due to the utilisation of different methods, direct comparisons cannot be made with studies on environmental factors in other countries which were mentioned in chapter 2. However, it is apparent that participants faced significant and extensive environmental barriers especially if correlated with barriers faced by stroke survivors in some other parts of the world. The following recommendations focus mainly on services that are lacking and are currently a barrier to rehabilitation and achieving advanced outcomes.

## **6.3 Recommendations**

This is a descriptive study. Joubert and Ehrlich (2007) report on the usefulness of this type of study to service planners in providing information that is helpful in developing appropriate services, allocating resources, deciding on priorities and which populations need to be targeted in terms of health-care. It is hoped that these recommendations will be taken into account with future planning of rehabilitation services in the Helderberg Basin and possibly other areas of the Western Cape.

### **6.3.1 Stroke prevention**

This study confirms that considerable work needs to be done among the uninsured population of the Helderberg Basin with regard to stroke prevention. It is a matter of concern to find several people in the same street of small communities, all having had strokes. Community-based workers /community-care workers and adherence-support health workers, who are adequately trained and have the necessary support of facility-based services, could play an important role in empowering communities and

individuals to take responsibility for their own health and in reducing the number of strokes in the Helderberg Basin.

#### **6.3.1.1 Community-based services**

Urgent investigation needs to be done to determine if NGOs in the Helderberg Basin have specifically been allocated the role of looking at the prevention of disease and promotion of health by the Western Department of Health and, how much emphasis is in fact placed on the prevention of stroke. NGOs and community workers providing community-based services have been allocated an extremely important role and it is essential that they are equipped to perform this task adequately. Investigation needs to be done into the effectiveness of this training in the Helderberg Basin and how much emphasis is placed on stroke prevention and lifestyle changes. Programmes that are implemented should be monitored and evaluated on an on-going basis.

- It is vital that attention be given to the concept of health literacy, not only in the training of community-based workers but also ensuring that they are equipped to extend information in a manner which is clearly understood.
- Education on stroke, risk factors and maintaining a healthy lifestyle, should be promoted at schools, especially within communities where the prevalence of stroke is high.

#### **6.3.1.2 Adherence-support community-based workers**

*Healthcare 2010* emphasises the importance of adherence to medication prescribed for treatment of TB, HIV, diabetes and hypertension in reducing morbidity and mortality, ultimately resulting in cost saving to the Department of Health. From this document it appears that specific programmes for adherence to TB and HIV medication have been formulated and it is the role of an adherence-support community-based health worker to implement this in various communities (Western Cape (South Africa). Department of Health, 2007).

- This study finds that there is an urgent need to consider programmes which will promote adherence to treatment for hypertension and diabetes.
- Effective training and utilisation of municipal ward-based PHC agents, as presented in the green paper on National Health Insurance (NHI) in South Africa (South Africa. Department of Health, 2011), have the potential to reduce the incidence of stroke. The structure and effectiveness of programmes needs to be monitored continually and evaluated to determine outcomes.

The draft framework for *"2020–The future of healthcare in the Western Cape"* refers to community health workers who will be linked to each household in a community. Their role will be to promote healthy living and to ensure that people are compliant with taking medication. In light of the fact that many of the risk factors for stroke are modifiable, it is extremely important that community health workers receive sufficient training in this regard.

It is recommended that they also do a course on ethics and confidentiality of information in their training.

### **6.3.1.3 Facility based services**

However the extremely important role that both nursing and medical staff play at CHCs, clinics and hospitals in monitoring and motivating patients to change their lifestyles and adhere to medication should not be underestimated. The researcher considers that the responsibility of disease prevention and health promotion cannot be left entirely to community workers.

A concerted effort by health professionals in terms of counselling and education of patients and caregivers in terms of primary and secondary prevention of stroke is crucial. It can be argued that with limited human resources, medical and health professionals do not have the time to do this. However, as pointed out by Osborne, it is precisely for this reason that more effort needs to be put into education and addressing health literacy issues: "In part, patients need to quickly understand health information because they have less face-to-face time with their providers, whether in outpatient settings or during hospitalization" (Osborne, 2005:3). She also suggests that "the only remaining way to manage healthcare costs is by asking people to take care of themselves (Osborne, 2005:4). This can only occur if information is given in such a way that both caregivers and patients understand it.

- If people are to be encouraged to take responsibility for their health, it is essential that information on hypertension, diabetes and other risk factors for stroke be available in their home language.
- Principles of health literacy need to be taken into account and information projected by health professionals should be given in a manner and at a level which can be understood.
- To ensure that information is clearly understood by patients, translators should be available at all hospitals, CHCs and clinics.
- The introduction of the so called "Chronic Club" in November 2010 at Ikwezi clinic has the potential to have a positive impact on stroke prevention. Patients with various chronic conditions such as hypertension and diabetes are seen on a regular basis. Blood pressure is monitored and

adherence to medication is encouraged. It appears that a motivated sister gives support and encouragement to patients in terms of lifestyle changes, such as weight reduction and giving up smoking. Patients are involved in exercises classes and receive education on their conditions through lectures and discussion with the sister. The effectiveness of this programme should be monitored and possibly introduced at other facilities.

#### **6.3.1.4 Media coverage**

- The majority of participants in this study had access to television and there is probably an overall need in South Africa to utilise this medium to educate the general population on the importance of lifestyle changes, prevention and treatment of stroke and other non-communicable diseases such as diabetes, and not focus primarily on HIV/AIDS.

### **6.3.2 Stroke management and rehabilitation**

#### **6.3.2.1 Establishing a dedicated stroke unit**

According to the *South African guideline for management of ischaemic stroke 2010*, treatment in a dedicated stroke unit by personnel with experience in stroke management is the most beneficial intervention for stroke survivors. Input from medical and nursing staff, physiotherapists, occupational therapists, speech and language therapists and social workers is required (Bryer et al., 2010).

- Results from this study show that the main entry point into the health system post-stroke is Helderberg Hospital. The feasibility of forming a stroke unit at Helderberg Hospital, which according to the literature can be a specific area in a ward where patients are cared for by professionals, experienced in stroke management should be investigated. Apart from speech therapy, psychologists and dieticians, several of the core disciplines are already in place at Helderberg Hospital.

#### **6.3.2.2 Accessing existing rehabilitation services**

In the Helderberg Basin some of the building blocks are in place for an effective rehabilitation service for uninsured stroke survivors. However many services are lacking and it appears that a poor referral system and other environmental barriers such as the lack, and cost, of transport are hindering utilisation of existing services. It is **crucial** that steps are put in place to ensure that stroke survivors can access existing rehabilitation services. The following should be considered:

- The researcher suggests that to improve outcomes, many stroke survivors need to spend longer time as inpatients at Helderberg Hospital where they can receive some intensive physiotherapy and occupational therapy before being discharged in to the community. This would provide the

opportunity for unresolved medical issues to be addressed and promote independence in terms of transfers and activities of daily living, easing the burden of care for caregivers and preventing many stroke survivors from being left in bed because family members find it difficult to move them. Improved mobility before discharge will facilitate use of taxis and transport to access community facilities.

- In particular, there appears to be a lack of inpatient rehabilitation facilities which needs to be addressed. A clear distinction should be made between these facilities and respite centres where limited rehabilitation is offered. Receiving adequate rehabilitation at an inpatient facility, prior to referral to CHCs and clinics for rehabilitation has the potential to improve outcomes and relieve caregivers of their burden. Priority admission to these facilities should be considered for impoverished stroke survivors. This study has revealed that if people cannot afford to pay for transport, they will not access existing rehabilitation services.
- Considering the close proximity of WCRC to the Helderberg Basin and the comprehensive rehabilitation offered at this facility, therapists in the Helderberg Basin need to familiarise themselves with both the criteria and the protocol involved in facilitating the admission of stroke survivors who require this level of rehabilitation. The researcher also advocates that the impact of environmental and home circumstances on the likelihood of accessing adequate medical treatment and rehabilitation should be a factor that is taken into account for admission to WCRC.
- Follow up on the status of applications and organising of transport to WCRC by the referring party is essential.
- Where inpatient facilities are at capacity, looking at admission to the stroke unit at Groote Schuur Hospital or admission to a sub-acute centre such as Booth Memorial Hospital, before patients are sent home and referred for therapy at CHCs or clinics and community- based services. However, distance and costs to get to Booth Memorial Hospital is a considerable barrier to family visiting and becoming involved in the rehabilitation process.
- Within the first three months of discharge, home visits by physiotherapists and occupational therapists based at CHCs and clinics should be considered; especially when early discharge from hospital takes place and transport to health facilities is unavailable or unaffordable. Although therapists are carrying heavy workloads, some home visits should be feasible as many stroke survivors would be living within reasonable travelling distance from where therapists are based.



Where patients are living close together, three or four home visits could be planned for the same day.

- The researcher advocates that in situations of poverty and where distances and lack of mobility impact on accessing rehabilitation, HEALTHNET services should be utilised to transport patients from their homes to rehabilitation, at least for the first three months post-stroke. Although costly, this could play a major role in improving the outcomes of uninsured stroke survivors in the Helderberg Basin.
- The suitability of these vehicles for transporting wheelchair users should be investigated and modified accordingly. Some wheelchair users in this study reported problems in this regard. However it was not in the scope of this study to explore this further.

### **6.3.2.3 Establishment of a seamless network**

*Healthcare 2010* refers to the need for a "solid base of Primary Health Care (PHC) services that is integrated with level 2 and 3 services to form a seamless service for patients" (Western Cape (South Africa) Department of Health, 2007: 1). (Bryer et al., 2010:757) maintain that "An effective stroke service requires the establishment of a seamless network consisting of acute stroke units, post-acute care and rehabilitation, as well as further care in the community". A "seamless network" needs to be put in place, ensuring that stroke survivors are referred from Helderberg Hospital to a higher level facility such as WCRC or to CHCs and clinics and then to home-based carers and relevant NGOs and other services.

- Stroke survivors should not be discharged from hospital without ensuring that they have been referred to the relevant rehabilitation services in the community. Doctors and nursing staff need to consult with physiotherapists and occupational therapists at Helderberg Hospital before discharging these patients.
- On discharge from hospital, stroke survivors and their families should be given a pamphlet or written information on how to contact rehabilitation services, home based carers and relevant NGOs in the community.
- A concerted effort should be made by both hospital staff and CHCs and clinics to link stroke survivors with home-based carers. Where this appears to be working fairly well in some areas (e.g. Macassar), reasons for this not been as effective in other areas needs to be determined.
- This research has identified a number of NGOs who can assist stroke survivors. Therapists and staff at CHCs and clinics should familiarise themselves with these and ensure that referrals are made.

#### **6.3.2.4 Protocol**

- A protocol for the treatment of stroke patients and an effective communication system between doctors, nursing staff and therapists involved with rehabilitation at Helderberg Hospital needs to be established.

#### **6.3.2.5 Occupational and physiotherapy**

- Obligatory referral of stroke patients to physiotherapy and occupational therapy services which are available at the hospital needs to be enforced.
- To ensure that "hidden problems" are not being missed even mild cases should be referred to occupational therapy for a cognitive and perceptual evaluation, even if this occurs on an outpatient basis.
- Occupational therapists working at the hospital, CHCs and clinics in the Helderberg Basin should have access to standardized cognitive and perceptual assessment tests such as the LOTCA.
- The establishment of an occupational therapy post at Helderberg Hospital from 2011 and the utilisation of a community service occupational therapist at both Helderberg Hospital and various clinics in the area, in addition to the services of an occupational therapist at Gutrouw and Macassar CHC is a positive step in improving services to uninsured stroke survivors and people with other disabilities. This study has revealed that these services probably need to be extended. Occupational Therapy had a significant impact on Modified Barthel Index (<0.01) and SIS3.6 (community mobility) (0.02) scores.
- The researcher is of the opinion that there is an urgent need for additional physiotherapy input at Ikwezi, Sir Lowry's Pass and Gordon's Bay clinic and possibly other facilities. This study revealed that participants received limited physiotherapy.
- It is apparent that, with limited therapy, very little attention is given to cognitive and perceptual impairments and addressing impairments and activity limitations related to the ability to do calculations, read and write after the stroke. Addressing these factors which can impact on self management of health, finances and personal affairs has the potential to improve outcomes.
- It is vital that physiotherapists and occupational therapists give greater attention to independent toileting. In this study, it was evident that the inability of stroke survivors to walk to the toilet or transfer independently caused considerable stress to caregivers. Therapy must also address independent stair climbing.

### **6.3.2.6 Speech therapy**

- Considering the devastating effect that aphasia and speech and language disorders have on stroke survivors and caregivers it is imperative that the necessary assistance from speech therapists should be available in the Helderberg Basin. There is an urgent need for the establishment of a government-funded speech therapy post. For this service to be effective, it possibly needs to be a shared post between City of Cape Town and the Western Cape Health Department. (Currently the clinics fall under the jurisdiction of City of Cape Town, and Helderberg Hospital and the Gutrouw and Macassar CHCs under the Western Cape Health Department.) Should this service be based only at Helderberg Hospital, many people would not be able to utilise it due to transport problems.
- There is a need for a speech therapist to be available at the hospital on certain days of the week and at CHCs and clinics on other days.
- Close networking with the HSSG which currently provides the only speech therapy service to uninsured stroke survivors would also be important.
- Further investigation needs to be done to identify other clients requiring the services of a speech therapist. The need for speech therapy has also been identified by Senecio, an NGO working with uninsured children with disabilities in the Helderberg Basin.
- It is critical that the relevant therapist should have sufficient qualifications and experience in evaluating and treating swallowing disorders. This is particularly important in the early phases to prevent complications such as aspiration and aspiration pneumonia (Gillen, 2011).

### **6.3.2.7 Psychological support services**

Both government policy and the *South African guideline for the management of ischaemic stroke 2010* recognise that psychologists and dieticians form part of the rehabilitation team (Western Cape (South Africa) Department of Health, 2007; Bryer et al., 2010). Bryer et al. comment on depression being a fairly common occurrence after a stroke and report on the negative impact on rehabilitation which ultimately leads to poor outcomes. The importance of counselling stroke survivors and caregivers on adapting to their changed circumstances and roles is generally recognized (Bryer et al., 2010).

- Findings from this study highlight the need for the availability of psychological counselling for both stroke survivors and their families.

### **6.3.2.8 Dieticians**

Dieticians can play an extremely important role in primary prevention of stroke through counselling of diabetic and obese clients on diet. Bryer et al. (2010) also comment on the importance of involving dieticians in the early management of stroke survivors in order to prevent malnutrition.

- It is apparent that there is a need for dieticians to be available at government health facilities in the Helderberg Basin. In all likelihood uninsured patients with other diagnoses besides stroke would benefit from the availability of these services.
- Taking into account the shortage of human and financial resources and the extreme difficulty experienced by stroke survivors to get to Helderberg Hospital, the feasibility of sharing posts between the City of Cape Town and Department of Health should be considered. There is a need for these services to be available at Helderberg Hospital, CHCs and clinics.
- Pamphlets and information brochures on diet need to be available in English, Afrikaans and IsiXhosa. Information should be simplified and presented at a level that is understood by target audiences.
- Training of dieticians should include information on eating habits of different cultures and the types of food eaten in situations of poverty and how to apply this when giving advice on diet for diabetes and other conditions, so that it is relevant and meaningful.

### **6.3.2.9 Social workers**

There is a need for social workers to be available not only at the hospital but also CHCs and clinics. They can play an important role in:

- Contacting family and caregivers to come in to health facilities for essential counselling, training and education by rehabilitation professionals.
- Assessing the home circumstances and financial situation of stroke survivors, to assist in determining those that need priority admission to inpatient rehabilitation facilities as they do not have assistance at home or the necessary finances to pay for transport to health facilities.
- Assisting with grant applications.

### **6.3.2.10 Education and training**

- It is essential that steps be put in place at Helderberg Hospital to ensure that both the stroke survivor and family are educated about risk factors for stroke, secondary prevention, the rehabilitation process and how to access community resources before discharge.

- A specific team member needs to be given the responsibility of contacting family members and ensuring that caregivers do come to the hospital to receive the necessary guidance and training. Traditionally this has been the role of a social worker.
- Carers need to be involved actively with rehabilitation and receive training from physiotherapists and occupational therapists to assist with mobility, transfers and activities of daily living from an early stage.
- To ensure that family members and caregivers can be contacted admission staff need to make certain that contact details are correctly recorded and, possibly, obtain details of two family members. It is appreciated that often these details are taken while dealing with emergency situations, but this study disclosed that many telephone numbers were incorrect and street numbers inaccurately recorded, making it difficult to locate stroke survivors and their families.
- In the case of a family member or caregiver not receiving education and training, this fact needs to be clearly stated on the referral form to the CHC or clinic and followed up at the next health facility.
- Stroke survivors and family members or caregivers need to be given a clear outline of the rehabilitation programme, what the different disciplines can offer and the importance of this. Through her involvement with the HSSG the researcher has observed that many families are not aware that progress can be made through rehabilitation and this could also be a reason for stroke survivors not attending therapy.
- Much needs to be done through education and awareness campaigns to empower uninsured patients to be able to demand rehabilitation services to which they are entitled. It was apparent that participants in the study were generally very passive and accepting of their situation and did not enquire about services or further assistance, unless they were directly referred. Various disciplines (e.g. physiotherapy, occupational therapy) need to do more to educate the various communities in the Helderberg Basin on rehabilitation and the role of various disciplines.

#### **6.3.2.11 Follow up appointments**

It is important to empower stroke survivors and caregivers and encourage them to take responsibility for their health. However, considering the impairments and substantial environmental barriers that uninsured stroke survivors face (e.g. lack of finances, lack of transport and lack of communication devices such as telephones, fax and email) the researcher believes that government health services do need to take more responsibility in ensuring that appointments at other facilities are kept. Therapists (and other team

members) are extremely busy and it is likely that a specific secretary is needed who can perform the following duties:

- Forward applications to WCRC and then follow up on the status of the application;
- Make appointments at other facilities;
- Book transport with HEALTHNET. (in certain cases, it may be necessary for the stroke survivor to be collected at home);
- Give the stroke survivor or family written instructions, including dates, times, where they have to access transport and whom to contact if they need to cancel or change appointment day. Educate them on the importance of keeping appointments at other facilities;
- Where private transport is utilised, ensure that the client has map and instructions how to get to facility and
- Where possible make telephonic contact with stroke survivor or caregiver the day before appointments to confirm arrangements, especially if there is a lapse of several months since the last appointment.

#### **6.3.2.12 Follow up with rehabilitation services**

- Follow up with various disciplines involved with the rehabilitation process is extremely important. The researcher recommends that in terms of occupational therapy and physiotherapy this should possibly take place at six weeks post-stroke and then again at six and twelve months, or at intervals set by therapists at discharge. This allows for further recommendations to be made according to outcomes achieved and also for any complications to be identified. Often the initial focus of rehabilitation is on basic activities of daily living and mobility. Follow up at a later stage could result in more emphasis on participation and achievement of higher outcomes which, from this research, appears to be neglected. Many participants showed potential for improving arm and hand function and it is likely that this could also be identified and receive attention with follow up.
- Should the stroke survivor miss these appointments, the reason for this should be identified. Home-based carers could be utilised in this regard.

#### **6.3.2.13 Equipment and assistive devices**

- A system needs to be set up to ensure that information can be obtained immediately regarding the allocation of equipment and assistive devices to a client by whichever government health facility is used. For example it is recommended that the issuing of glucometers be recorded on a computer system which can be accessed by all facilities (hospital, CHC or clinic). Alternatively

this information should be written on a card which the client keeps but has to take to every appointment together with the glucometers. Readings on the glucometer can provide useful information on the client's health status, the client's knowledge and ability to utilise the equipment and further training given where necessary. Issues such as the need for strips and replacing batteries can be dealt with immediately.

Apart from those who attended WCRC, participants in this study received both a limited amount and range of assistive devices.

- There is a need for basic devices such as wheelchair tables, commodes, bath boards, grab rails, and assistive devices to facilitate independence in cooking and performing household and work-related tasks.
- Issuing of more assistive devices for the visually impaired also needs to be addressed urgently.
- There appears to be a need for the development of an affordable attachment for government-tender wheelchairs, along the lines of the Freewheel Wheelchair Attachment (Freewheel), where a removable long wheelbase can be clamped to the solid footrest of a rigid-frame wheelchair for outdoor use and due to limited space in many homes, removed and folded up when not required.

*Healthcare 2010* refers to the issuing and maintenance of assistive devices forming an integral part of rehabilitation programmes (Western Cape (South Africa) Department of Health, 2007).

- Written instructions need to be given to patients and caregivers giving contact details and procedure to be followed if equipment is broken, needs replacing or is no longer required.
- Steps need to be put in place for the collection from homes of large items such as wheelchairs for repairs. Currently the logistics of trying to get a heavy item such as a motorised wheelchair returned to WCRC for repairs from a community in the Helderberg Basin are insurmountable.

#### **6.3.2.14 Long queues and waiting time at facilities**

Problems in this regard were reported at all government health facilities in the Helderberg Basin and careful consideration needs to be given to the alleviation of this difficulty.

- Recruitment of additional manpower would in all likelihood relieve the situation but, with limited finances, it is also necessary to look at innovative ways to resolve the problem. One participant commented on a cleaner at Helderberg Hospital who had been extremely helpful in sorting out the queues and directing people to where they needed to go, while at the same time performing

her cleaning function. The researcher recently noticed, at one of the Home Affairs offices, that the security guard was also extremely helpful in directing people to the right place and generally organising the queues, resulting in quicker service and less waiting time.

- Stroke survivors are given a date when they have to collect medication. The feasibility of this being pre-packed and ready for collection should be investigated.
- There is a need for procedures to be augmented enabling one person from service centres, NGOs, residences for the elderly, factories and places of employment to collect medication for their members/residents/employees and thus alleviate the number of people queuing.
- The utilisation of home based carers to deliver medication in the community should also be investigated.
- In terms of receiving medical treatment and obtaining medication, fair and equitable measures need to be developed in terms of queuing and waiting periods. From discussions with participants and caregivers it was evident that some people received quicker service because of who they were or the contacts they had at health facilities.
- It is appreciated that at some facilities wheelchair users received immediate attention but there are also many stroke survivors who are ambulant or elderly and who also require urgent assistance as they find it difficult to stand for long periods of time. It is essential that there is sufficient seating for patients at facilities.
- As many people start queuing early in the morning before facilities open there is also a need for covered seating outside the facilities.
- To ensure that they receive the necessary assistance, note should be made on the outside of folders of patients who are hard of hearing or who have visual impairments. Participants complained of the noise levels in waiting rooms and consequently failed to hear their numbers being called if they were hard of hearing.
- Several participants expressed appreciation of provision of sandwiches by service organisations and churches at some facilities, especially when they had to spend all day waiting for assistance. This community support should possibly be encouraged but with sufficient measures in place to ensure that food is hygienic and of an acceptable standard.



- In terms of primary prevention of stroke, urgent provision needs to be made for people who are employed and are on chronic medication for hypertension, diabetes and other risk factors for stroke to receive their medication quickly, efficiently and at convenient times. (This would also apply to employed clients with other diagnoses.) In the private sector, patients obtain a script from their doctor and can receive assistance from a pharmacy at their convenience including over a weekend or after hours. The researcher believes that long queues and limited hours to access facilities play a major role in compliance to taking medication. The green paper on National Health Insurance in South Africa refers to the need for the "Availability of health services at adequately convenient hours with enough professional staff to attend to their needs" (South Africa. Department of Health, 2011:28). The feasibility of booking appointments or providing limited after-hours services for people who are employed should be considered. (e.g. until 6pm or on Saturday mornings). Although additional human resources would be required, this could ultimately result in cost saving to the department of health through the prevention of stroke and other diseases and illnesses.
- Many participants and caregivers expressed the need for being given specific appointment times to see health professionals and collect medication.

### **6.3.3 Community assistance**

#### **6.3.3.1 Home-based carers**

From observations made by the researcher, it appears home based caring programmes in the Helderberg Basin are generally based on nursing principles of caring for the stroke survivor (washing and dressing etc.), rather than on rehabilitation and working towards higher outcome levels.

- Although there is a need for this type of care for bedridden and some elderly stroke survivors, consideration needs to be given to training home-based carers to think more in terms of rehabilitation and assisting people with disabilities to become more independent with transfers and basic activities of daily living.
- It is also important that they are given guidelines on when to refer their clients for further therapy or for the correct wheelchair seating.
- The most important aspects of rehabilitation should be prioritised and an effective training programme developed for home-based carers.

- Services offered by home-based carers are limited. In certain cases there is a need for longer hours of assistance during the day and at night. This would ease the burden carried by many caregivers.
- Several participants and caregivers expressed the need for assistance from home-based carers skilled in wound care, especially in the case of diabetic ulcers.

Some participants were concerned about issues of confidentiality with home-based carers and found them unreliable.

- It appears there is a need for supervisors of home-based carers to do home visits and determine that satisfactory and reliable services are being offered.

The researcher discerned that reports of unreliable services correlated to a certain extent, with complex cases, and where the stroke survivor or family were demanding or unpleasant to the home-based carer. It is possible that in cases where home-based carers have a negative experience, they tend to neglect the client. Further investigation would be required to verify this.

- It is recommended that a course on ethics, confidentiality of information and how to cope with difficult cases, should be included in the training of home and community-based workers.

### **6.3.3.2 Residence for elderly and disabled**

Some uninsured stroke survivors with limited finances and whose family are unable to care for them are accommodated at Sencit Rest Haven Old Age Home in the Strand or Zandvliet Care Facility in Macassar. Disability grants and pensions go towards covering costs for accommodation.

- This study has found that there is possibly a need for a similar type of facility in the Lwandle/Nomzamo area. It is recommended that further investigation be done in this regard and discussed with community leaders and municipal counsellors.

### **6.3.3.3 Non-governmental and non-profit organisations**

NGOs rely heavily on funding from grants and donations and, in terms of human resources, input from volunteers. This generates many challenges in terms of the sustainability of these organisations.

- Considering the important role allocated to NPOs in providing community-based services, steps need to be taken by government to ensure that reliable and consistent sources of income are available to relevant organisations and that they receive adequate information and assistance in putting together the necessary documentation required for obtaining funding.

Although several NGOs are offering assistance to stroke survivors in the Helderberg Basin, 47% of the participants in this study were unaware of these services or were not utilising them. Although the HSSG dispenses information about its services at Helderberg Hospital, only 15% of participants were aware of and were involved with the organisation (Figure 4.81).

- NGOs need to reassess how to advertise their services and network closely with health facilities in the Helderberg Basin to ensure they are regarded as part of the "seamless network" of services available to stroke survivors and receive referrals accordingly.

It is estimated that approximately 30-50 people who have had strokes are admitted to Helderberg Hospital and the private hospital in the Helderberg Basin per month. This creates huge challenges to NGOs in terms of human resources, transport and venues for various activities which are offered.

- Based on long term estimates, NGOs need to be taking steps to ensure that new stroke survivors are not excluded from benefits because groups and transport have reached capacity.
- The researcher believes that there are other support groups in the Helderberg Basin who can assist stroke survivors, or play a role in education and stroke prevention (cardiac issues, diabetes etc.) They need to be encouraged to extend their services to the less privileged communities in the area.
- There is a support group for people with visual impairments which gathers once a month in Somerset West. The researcher identified participants in other communities who would greatly benefit from this type of support but were unaware of its existence or were unable to access it due to numerous environmental barriers. This organisation should consider extending its services.
- NGOs need to be working towards extending the number of days and hours that their services are offered. This would greatly relieve the burden of care for many caregivers and be of benefit to stroke survivors.

#### **6.3.4 Visual impairments**

From this study the researcher has found that both the screening for, and treatment of, vision impairments amongst the uninsured population of the Helderberg Basin requires attention. It was evident that many participants did not ask for specific medical and rehabilitation interventions unless specifically referred.

- The uninsured population needs to be educated about vision impairments and the steps to take if they are experiencing any difficulty in this regard.

- Programmes need to be developed where routine screening for vision problems amongst the elderly and diabetics is performed. This is particularly important if one considers that early detection and treatment of certain conditions can prevent blindness.

Having to travel to Cape Town for screening and issuing of visual aids is a considerable environmental barrier to uninsured stroke survivors and probably to the elderly and other people with disabilities. The inconvenience and additional cost of having to get to the CHC or departure point for transport and travel to Cape Town are a deterrent to the utilisation of this service.

- The feasibility of offering this service at all facilities in the Helderberg Basin should be investigated.

### **6.3.5 Community access and transport**

The lack of and cost of transport, especially for wheelchair users, needs to be addressed urgently.

- A concerted effort by NGOs and people with disabilities is required to lobby for better transport services. In order to resolve the situation discussions need to be held with all relevant bodies and representatives in the Helderberg Basin, incorporating elected counsellors, community leaders, people with disabilities, NGOs, taxi consortia, bus services and the South African Rail Commuter Corporation.
- The Helderberg Basin falls under the administration of the City of Cape Town. Data secured from the 2011 census should be utilised to provide some indication of the total number of special needs passengers living in the area.
- To determine to what extent inaccessibility of public buildings is a barrier to participation, access audits should be carried out within the various communities of the Helderberg Basin.
- Cement or tarred sidewalks with kerb ramps would facilitate community mobility. A cement or brick pathway from the front door of homes and ramp with a small gradient would in most cases have improved accessibility.
- People with disabilities, families, NGOs and rehabilitation professionals should be doing far more to liaise with municipal counsellors and police services to make communities safe for disabled people to venture out of their homes without fear of being targeted by criminals.

The White Paper on National Transport Policy states that the transport needs of the disabled must be attended to and that this should be affordable (South Africa. Department of Transport, 1996). The

Provincial Government of the Western Cape also acknowledges the transport requirements of passengers with special needs "and undertakes to promote these requirements into the planning, provision and management of a public transport system in the Western Cape so the system, over time, becomes universally accessible to all its passengers" (Western Cape (South Africa).Department of Transport, 2009:5).

- Counsellors in the Helderberg Basin need to familiarise themselves with government policy related to transport for special needs passengers and ensure that there is a plan of action and time frame in place for the promotion of these services in the area.
- The City of Cape Town "Dial-a-Ride project" is aimed at providing public transport to wheelchair users. The allocation of a Dial-a-Ride vehicle specifically to the Helderberg Basin needs to be investigated.

In the Helderberg Basin the main means of transport for many commuters is by taxi. Through her work with the HSSG the researcher has noted that taxi drivers have developed a positive attitude towards stroke survivors when they become involved with transportation to various service centres.

- The feasibility of Government providing incentives and financial assistance to taxi drivers who wish to convert their vehicles to accommodate wheelchair users should be investigated.
- There is also the need for the development of a training programme or provision of information on transferring people with disabilities into a taxi.
- Currently, taxi services from the various communities in the Helderberg Basin take commuters to a central point in Somerset West, which leaves a 2 kilometre walk to Helderberg Hospital. The possibility of extending taxi routes to ensure that people from various communities can get directly to Helderberg Hospital should be discussed with local taxi consortia.

### **6.3.6 Social services**

From this study it appears a number of issues relating to social services need to be addressed. Participants were generally happy with services once pensions and grants had been processed. However, participants/caregivers were extremely fearful of reprisal should they complain about services.

- It is strongly recommended that applicants for grants should be given an information sheet in their home language assuring them of their rights and indicating the procedure to follow should they have complaints or queries.

As in the case of healthcare facilities long queues are problematic and this needs to be addressed.

- Fair and equitable systems need to be set in place to ensure that favouritism does not occur in terms of queuing.
- When applicants have been given a doctor's appointment for evaluation for a disability grant, health services need to ensure that a doctor is available to perform this service.
- Where stroke survivors are initially issued with a temporary disability grant (for one year), social services and health services need to ensure that the person is given a doctor's appointment to re-evaluate the application immediately the year lapses. This appointment should be made when they are issued with the temporary grant, or the stroke survivor or caregiver should be instructed to contact the relevant authorities at least three months before the temporary grant expires in order to make the necessary appointment. If stroke survivors who may be eligible for a permanent disability grant are only able to book an appointment once a year has elapsed, it appears that there can be a delay of up to a few months before payment is resumed. Such cases must be streamlined to avoid unnecessary delay and considerable financial hardship to the applicant.
- It is essential that retrospective pay is given where time lapses do occur.
- Telephonic devices should be provided for SASSA officials at all processing points in the communities. Some participants complained of their cell phones being utilised when officials had to phone head office or anywhere else, with queries relevant to their applications.

As was evident in this study, some stroke survivors who have made a good physical recovery can have hidden cognitive and perceptual impairments which can have a devastating effect on their ability to perform in the work place.

- To ensure that deserving cases receive compensation to which they are entitled the researcher recommends that some form of cognitive and perceptual testing be done with all stroke survivors applying for a disability grant.

- Participants seen at WCRC expressed appreciation of assistance they received from the social worker in obtaining information and processing applications for disability grants. It is apparent that there is a need for this type of assistance at health facilities in the Helderberg Basin, especially where the stroke survivor has cognitive and perceptual impairments or where family cannot take off work or are not available to assist the stroke survivor in this regard.
- Very few caregivers in this study were aware of the social-relief-of distress grant or the possibility of receiving a grant-in-aid and should be made aware of this.
- The researcher has noted that with the move towards adopting the social model of disability in South Africa many people with disabilities are resistant to having social workers intervene in their circumstances. However, the researcher considers that the state does have an obligation to protect stroke survivors and other people with disabilities who cannot manage their own affairs and to ensure that their pension or disability grant is being used in their best interest and that they are adequately cared for.

#### **6.4 Recommendations For Further Research**

- It is recommended that more detailed quantitative research be done with regard to the extent and effectiveness of the management of hypertension, diabetes and other risk factors for stroke amongst the uninsured population in the Helderberg Basin.
- The reasons for the high prevalence of stroke in certain communities in the Helderberg Basin should also be identified.
- Further research is required to determine the mortality rate and causes of death of uninsured stroke patients in the Helderberg Basin.
- To determine the extent of vision impairments amongst the uninsured population in the Helderberg Basin, further quantitative research is recommended.
- Utilising the Rehabilitation Outcomes model incorporating the six clinical outcomes levels (Landrum et al.,1995) is a valuable tool in determining at what stage a stroke survivor is on the continuum of care and in planning future goals for rehabilitation. However, for research purposes it is recommended that further work be done on this model to introduce a scoring system to assist in determining which level a client has achieved. This is particularly relevant to level 4 (community integration) where numerous factors have to be taken into account in determining whether or not the client has reached this outcome level – (e.g. are they able to manage their own

personal affairs? Do they have community mobility? Are they able to direct their own health management?). A client may have achieved some of these goals, but not all of them. Problem areas may still exist at level 1 and 2, making it difficult to determine where the client should be placed. In terms of research, bias could occur. It is possible that two researchers could place the same participant on different levels, depending on their interpretation of findings. The development of a scoring system would increase the likelihood of consistency amongst raters.

- There is also a need for further research to determine the most effective types of treatment for cognitive and perceptual impairments resulting from stroke and in the retraining of upper limb function.
- A useful study in terms of investigating the validity of the LOTCA as a cognitive and perceptual measure in the South African context would be to assess a control group with similar demographic characteristics to the study participants but who had not had a stroke with this measure, and then to compare the results with the LOTCA results from this study.
- Further research needs to be done on the correlation between stroke and HIV and the specific impairments, activity limitations and participation restrictions of these stroke survivors. As many of these stroke survivors will in all likelihood be from a younger population group, the impact on the possibility of return to work in this particular group also needs to be investigated.
- The suitability of HEALTHNET transport for wheelchair users also needs to be investigated.

## **6.5 Specific Requests From Participants And Caregivers**

- The researcher was overwhelmed with requests from caregivers for a greater allocation of nappies to be supplied by health services for incontinent stroke survivors. It appears a limited amount of nappies can be obtained through health facilities but many caregivers found this to be insufficient. Although the researcher advocates that more should be done to ensure independent toileting of stroke survivors, which also restores their dignity, there are cases where issuing additional incontinence products are required.
- Considering the extensive barriers faced by participants in terms of transport, measures should be put in place, where this need can be evaluated and attended to at all health facilities: Helderberg Hospital, CHCs and clinics.
- Caregivers looking after participants with HIV requested assistance from health facilities in supplying gloves that they could use when attending to the personal needs of these stroke survivors. This request should be considered.



## **6.6 Limitations Of The Study**

Throughout the study, various references have been made to limitations of the study. Additional factors are mentioned below.

- In terms of the diagnosis of stroke, the researcher had to rely on information provided by health facilities and other sources. As CT scans are not available at Helderberg Hospital, it has not been possible to verify that in all cases the relevant brain insult was caused entirely as a result of a vascular event, which pertains to stroke.
- Medical history of participants was obtained through interviews with the stroke survivors/ caregivers and where uncertainty existed, looking at medication that they were taking. A limitation of the study is that the researcher did not have access to all medical folders of participants.
- The amount and type of therapy or intervention received (physiotherapy, occupational therapy and speech therapy) and assistance from psychologists, dieticians and social workers was mostly obtained from information provided by participants and caregivers. Where uncertainty or discrepancies were apparent the researcher did verify information with the relevant facility or therapist with the permission of the participant.
- Note was made of how many participants received various rehabilitation interventions (physiotherapy, occupational therapy etc.), but no differentiation was made as to whether that service was required or not.
- Besides a trial in the pilot study, no testing of the reliability and verification of the speech and language test has been conducted.

## **6.7 Dissemination Of Results**

To ensure that the above mentioned recommendations are considered, the researcher envisages the following:

- Sending a summary of these conclusions and recommendations to the Western Cape Department of Health and City Health Department (Cape Town), with a request that the information be forwarded to the relevant health facilities.

- Setting up meetings with the relevant authorities from these two departments which are specifically responsible for the Eastern Sub District within which the Helderberg Basin falls and with the Department of Social Development.
- The researcher will deliver a presentation of the study at the Western Cape Neuro Rehabilitation Physiotherapy Interest Group on the 11 September 2012. The relevant physiotherapists and occupational therapist from the Helderberg Basin will be notified.
- Delivering a presentation of the findings to municipal councillors in the Helderberg Basin, to be followed by discussion on the problems of transport for people with disabilities.
- Arranging a meeting with the relevant authorities and NGOs involved with home based caring, to discuss the recommendations.
- Contacting SASSA officials in the Helderberg Basin to discuss problem areas and recommendations.
- Arranging a presentation on the study for relevant NGOs and other stake holders in the Helderberg Basin.
- Contacting the dietetic departments at various universities in the Western Cape and discussing the importance of considering the last two recommendations listed under 6.3.2.8 in the training of students.

## **6.8 Closure**

Many changes have taken place in South Africa since 1994. Major restructuring has occurred within the health system. Some of the key policy documents introduced by the new South African government have been the White Paper on the Transformation of the Health System in South Africa of 1997, followed by the National Health Act of 2004 which advocated a Primary Health Care approach (Padurath, and English, 2011). The 1995 Health Plan *and Comprehensive Service Plan for Healthcare 2010* have formed the foundation for planning of health services in the Western Cape (Western Cape (South Africa). Department of Health, 2011). Of particular relevance to rehabilitation have been the Integrated National Disability Strategy and the National Rehabilitation Policy of 2000. This study has given an indication that in terms of rehabilitation of uninsured stroke survivors in the Helderberg Basin many factors still need to be addressed to meet the stipulations of various policies and guidelines. With the publication of the Green Paper on National Health Insurance and *2020 - The Future of health care in the Western Cape*, towards the end of 2011, it is likely that further restructuring will take place in the health system.

The researcher concludes this study with the sentiment expressed in the poem, written by a stroke survivor from the Helderberg Basin. "In the new South Africa may there still be a miracle that will

transform the lives of stroke survivors". Effective implementation of South African rehabilitation policies and guidelines has the potential to be this "miracle".

## 7. References

- Algurén, B., Lundgren–Nilsson, A.S.A. and Sunnerhagen, K.S. (2009). Facilitators and barriers of stroke survivors in the early post-stroke phase. *Disability and Rehabilitation*, 31(19):1584-1591.
- Australian Government Department of Health. (2006). The claim and advance Payment Cycle – Information for the Transition Care Program 2006, Modified Barthel Index. [Online]. Available: [www.health.gov.au/internet/main/publishing.nsf](http://www.health.gov.au/internet/main/publishing.nsf). [Accessed 2011, July 24].
- Barron, P. and Josianne, R. (2008). *South African Health Review*. [Online]. Available: [www.hst.org.za/publications/south-african-health-review-2008](http://www.hst.org.za/publications/south-african-health-review-2008). [Accessed 2012, March 12].
- Bryer, A., Connor, M., Haug, P., Cheyip, B., Staub, H., Tipping, B., Duim, W. and Pinkney–Atkinson, V. (2010). South African guideline for management of ischaemic stroke and transient ischaemic attack 2010: a guideline from the South African Stroke Society (SASS) and the SASS Writing Committee. *South African Medical Journal*, 100(11):747-778.
- Cavanaugh, K., Rothman, R., White, R. and Wolff, K. (2010). Addressing health literacy and numeracy to improve diabetes education and care. *Diabetes Spectrum*, 23(4):238.
- Center for Outcome Measurement in Brain Injury (COMBI). (2001). Introduction to the Craig Hospital Inventory of Environmental Factors. [Online]. Available: <http://www.tbims.org/combi/chief>. [Accessed 2010, November 7].
- Cherney, L. (2006). Ethical Issues involving the right hemisphere stroke patient: To treat or not to treat? *Topics in Stroke Rehabilitation*, 13(4):47-53.
- Davies, P. (1985). *Steps to follow. A Guide to the Treatment of Adult Hemiplegia*. Berlin Heidelberg: Springer-Verlag.
- Dayal, H. (2010). Provision of rehabilitation services within the District Health System – the experience of Rehabilitation Managers in facilitating this right for People with Disabilities. *South African Journal of Occupational Therapy*. 40(1):22-26.
- Desrosiers, J., Noreau, L., Rochette, A., Bourbonnais, D., Bravo, G. and Bourget, A. (2006). Predictors of long-term participation after stroke. *Disability and Rehabilitation*. 28(4):221-230.
- De Villiers, L., Badri, M., Ferreira, M. and Bryer, A. (2011). Stroke Outcomes in a socio-economically disadvantaged urban community. *South African Medical Journal*, 101(5):345-348.

- De Wit, L., Putman, K., Schuback, P., Komarek, A., Angst, F., Baert, I., Berman, P., Bogaerts, K., Brinkmann, N., Connell, L., Dejaeger, E., Heys, F., Jenni, W., Kaske, C., Lesaffre, E., Leys, M., Lincoln, N., Louckx, F., Schupp, W., Smith, B., and De Weerd, W. (2007). Motor and Functional Recovery after stroke. A Comparison of 4 European Rehabilitation Centers. *Stroke*, 38:2101-2107.
- Domholdt, E. (2005). *Rehabilitation Research. Principles and Applications*. Missouri: Elsevier Saunders.
- Dube, A.K. (2005). The role and effectiveness of disability legislation in South Africa. East London: Samaita Consultancy and Programme Design.
- Duncan, P.W., Wallace, D., Min Lai, S., Johnson, D., Embretson, S., and Laster, L. (1999). The Stroke Impact Scale Version 2.0: Evaluation of Reliability, Validity and Sensitivity to Change. *Stroke*, 30(10):2131-2140.
- Duncan, P.W., Bode, R.K., Min Lai, S., Perera, S., Glycine Antagonist in Neuroprotection Americans Investigators. (2003). Rasch analysis of a new stroke-specific outcome scale: the Stroke Impact Scale. *Archives of Physical Medicine and Rehabilitation*, 84(7):950-963.
- FreeWheel. *FreeWheel Wheelchair Mobility*. [Online]. Available: [www.gofreewheel.com](http://www.gofreewheel.com). [Accessed 2012, May 14].
- Geyh, S., Cieza, A., Schouten, J., Dickson, H., Frommelt, P., Omar, Z., Kostanjsek, N., Ring, H., and Stucki, G. (2004a). ICF Core Sets for Stroke. *Journal of Rehabilitation Medicine Supplement*, 44:135-141.
- Geyh, S., Kurt, T., Brockow, T., Cieza, A., Ewert, T., Omar, Z. and Resch, K. (2004b). Identifying the concepts contained in outcome measures of clinical trials on stroke using the international classification of functioning, disability and health as a reference. *Journal of Rehabilitation Medicine, Supplement*. 44: 56-62.
- Gillen, G. (2011). *Stroke Rehabilitation. A Function-Based Approach*. Missouri: Mosby.
- Gray, D.B., Hollingsworth, H.H., Stark, S. and Morgan, K.A. (2008). A subjective measure of environmental facilitators and barriers to participation for people with mobility limitations. *Disability and Rehabilitation*, 30:434-457.
- Green, J.B. (2003). Brain reorganization after stroke. *Stroke Rehabilitation*, 10(3):1-20.

- Hale, L.A. (2001). Consulting the South African Experts in Physiotherapeutic Stroke Rehabilitation. *South African Journal of Physiotherapy*, 57(2):32-39.
- Han, C., Yajima, Y., Lee, E., Nakajima, K., Meguro, M. and Kohzuki, M. (2005). Validity and utility of the Craig Hospital inventory of environmental factors for Korean community-dwelling elderly with or without stroke. *Tohoku J. Exp. Med.*, 206:41-49.
- Hassan, S.A.M. (2009). The impact of stroke on the primary caregiver. Unpublished Master's Thesis MPhil (Rehabilitation). Stellenbosch: Stellenbosch University, Centre for Rehabilitation Studies.
- Hassan, S.A.M., Visagie, S. and Mji, G. (2011a). Community Support Services after Stroke. *The Social Work Practitioner-Researcher*, 23(2):1-14.
- Hassan, S.A.M., Visagie, S. and Mji, G. (2011b). Strain Experienced by Caregivers of Stroke Survivors in the Western Cape. *The South African Journal of Physiotherapy*. 67(2):4-8.
- Hassan, S.A.M., Visagie, S. and Mji, G. (2012). The achievement of community integration and productive activity outcomes by CVA survivors in the Western Cape Metro Health District. *South African Journal of Occupational Therapy*, 42(1):11-15.
- Heart and Stroke Foundation of South Africa (n.d.a). *Diabetes* (Brochure). Cape Town.
- Heart and Stroke Foundation of South Africa. (n.d.b). *Stroke...the brain attack* (Brochure).Cape Town.
- Heart Magazine*. (2007). Stroke Statistics in South Africa. Autumn:21.
- Herman, D. (2006). Strokes are SA's No 1 killer among over-50s. *CapeArgus*, 27 October 2006
- Hommel, M., Trabucco-Miguel, S., Naegele, B., Gonnet, N. and Jaillard, A. (2009). Cognitive determinants of social functioning after a first-ever mild to moderate stroke at vocational age. *Journal of Neurology, Neurosurgery and Psychiatry*, 80(8):876.
- Jaillard, A., Naegele, B., Trabucco-Miguel, S., LeBas, J. F., and Hommel, M. (2009). Hidden Dysfunctioning in Sub-acute Stroke. *Stroke*, 2009(40):2473-2479.
- Joubert, G. and Ehrlich, R. (2007). *Epidemiology. A Research Manual for South Africa*. Cape Town: Oxford University Press.
- Kahonde, C., Mlenzana, N. and Rhoda, A. (2010). Persons with physical disabilities' experiences of rehabilitation services at Community Health Centres in Cape Town. *South African Journal of*

*Physiotherapy*, 66 (3).

Kroll, T., Neri, M.T. and Miller, K. (2005). Using Mixed Methods in Rehabilitation Research. *Rehabilitation Nursing*, 30(3):106-112.

Kwakkel, G., Kollen, B. and Twisk, J. (2006). Impact of Time on improvement of Outcome after Stroke. *Stroke*, 2006, 37(9):2348-2353.

Landrum, P.K., Schmidt, N.D. and McLean, A. (1995). *Outcome–Orientated Rehabilitation. Principles, Strategies and Tools for Effective Program Management*. Maryland: Aspen Publishers.

Lecuona, K. and Cook, C. (2011). South Africa's cataract surgery rates – why are we not meeting our targets? *South African Medical Journal*, 101(8):510-512.

Maja, P., Mann, W., Sing, D., Steyn, A. and Naidoo, P. (2011). Employing people with disabilities in South Africa. *South African Journal of Occupational Therapy*, 41(1):24-32.

Medlineplus. [Online]. Available: <http://www.nlm.nih.gov/medlineplus/stroke.html>. Accessed 2010, August 19].

Moodley, K. (2009). Module 1: Introduction to good clinical practice in research. Class Notes. Tygerberg: University of Stellenbosch.

Muir, K. (2010). Stroke. Update. *The Journal of Continuing Education for General Practitioners*, XXX11(9):14.

National Eye Institute. *Facts about Diabetic Retinopathy*. [Online]. Available: [www.nei.nih.gov/health/diabetic/retinopathy.asp#2a](http://www.nei.nih.gov/health/diabetic/retinopathy.asp#2a). [Accessed 2011, September 12].

National Network of Libraries of Medicine. *Health Literacy*. [Online]. Available: <http://www.nlm.gov/outreach/consumer/hlthlit.html>. [Accessed 2011, September 5].

Osborne, H. (2005). *Health Literacy from A to Z. Practical Ways to Communicate Your Health Message*. New York: Jones and Bartlett Publishers.

Padurath, A. and English, R. *South African Health Review*. (2011). [Online]. Available: [www.hst.org.za/publications/south-african-health-review-2011](http://www.hst.org.za/publications/south-african-health-review-2011). [Accessed 2012, March 12].

Pedretti, W.L. (1996). *Occupational Therapy Practice Skills for Physical Dysfunction*. St Louis: Mosby.

- Pegram, E. (2011). Lecture on Portfolio Committee on Social Development/Social Assistance Amendment Bill, B5-2010. Class notes. Tygerberg: University of Stellenbosch.
- Rhoda, A., Mpofu, R. and De Weerd. (2011). Activity Limitations of Patients with Stroke Attending Out-patient Facilities in the Western Cape, South Africa. *South African Journal of Physiotherapy*, 67(2):16-22.
- Rochette, A., Desrosiers, J. and Noreau, L. (2001). Association between personal and environmental factors and the occurrence of handicap situations following a stroke. *Disability and Rehabilitation*, 23:559-569.
- Roos, J. (2010). Notes from lecture to Helderberg Stroke Support Group. Somerset West.
- Sammons, H. (2010). Interview with the researcher on 6 September, 2010. Cape Town
- Sanders, D. and Reynolds, L. (2011). Community care givers hold the key. *Cape Times*, 20 September, 2011.
- Saulse, K. (2012). Funding dries up for NGOs as EU's hard times hit home. *The Big Issue*, 191(16):4.
- Schillinger, D., Grumbach, K. and Piette, J. (2002). Association of Health Literacy with Diabetes Outcomes. *The Journal of the American Medical Association*, 288(4):475-482.
- Schneidert, M., Hurst, R., Miller, J. and Ustün, B. (2003). The role of the Environment in the International Classification of Functioning, Disability and Health (ICF). *Disability and Rehabilitation*, 25(11):588-595.
- Shah, S., Vanclay, F., and Cooper, B. (1989). Improving the Sensitivity of the Barthel Index for Stroke Rehabilitation. *Journal of Clinical Epidemiology*, 42(8):703-709.
- Simmons-Mackie, N., and Kagan, A. (2007). Application of the ICF in Aphasia. *Seminars in Speech and Language*, 28(4):244-252.
- South Africa. Department of Health. (2000). *National Rehabilitation Policy. Rehabilitation for all*. Pretoria: Government Printer.
- South Africa. Department of Health. (2001). *The South African National Guideline on Stroke and Transient Ischaemic Attack Management*. [Online]. Available: [http://www.capegateway.gov.za/Text/2003/stroke\\_transient\\_ischaemic\\_attack\\_management.pdf](http://www.capegateway.gov.za/Text/2003/stroke_transient_ischaemic_attack_management.pdf). [Accessed



2010, August].

South Africa. Department of Health. (2011). *National Health Insurance in South Africa*. Green Policy. Pretoria: Government Printer.

South Africa. Department of Labour. (N.d.) *Know your UIF rights and obligations*. Pretoria: Department of Labour.

South Africa. Department of Transport. (1996). *White Paper on National Transport Policy*. [Online]. Available: [www.info.gov.za/whitepapers/1996/transportpolicy.htm](http://www.info.gov.za/whitepapers/1996/transportpolicy.htm). [Accessed 2012, February 20].

South Africa. Office of the Deputy President. (1997). *White Paper on an Integrated National Disability Strategy*. Pretoria: Rustica Press.

South African Human Rights Commission. (2002). *SAHRC Report. Towards a barrier-free society: a report on accessibility and built environments*.

South African Social Security Agency. (2009). *You and Your Grants2009/10*. [Online]. Available: [www.sassa.gov.za](http://www.sassa.gov.za). [Accessed 2009].

South African Social Security Agency. (2011). *You and Your Grants2011/12* [Online]. Available: [www.sassa.gov.za](http://www.sassa.gov.za). [Accessed 2011].

Statistics South Africa. *Census 2001*. [Online]. Available: [www.statssa.gov.za/census01](http://www.statssa.gov.za/census01). [Accessed 2012, August].

Stroke Association (N.d.) *Continenence problems after stroke*. (Brochure). London.

Stroke Association. (2002). *After your stroke: a first guide* (Brochure). Burningham, S.: Author.

Stroke Association. (2006a). *Stroke Rehabilitation* (Brochure). London.

Stroke Association. (2006b). *What is stroke?* (Brochure). London.

StrokEngine Assess. *In Depth Review of SIS*. [Online]. Available: [www.medicine.mcgill.ca/strokengine./module-sis-indepth-en.html](http://www.medicine.mcgill.ca/strokengine./module-sis-indepth-en.html). [Accessed 2010, November].

Theron, A. (2011). Email to J. Cawood re: Research Project, 6 Sept. 2011.

Tipping, B. (2008). Issues in the long-term management of stroke. *Continuing Medical Education*, 26(2), 70-72.

Toni, M. (2011). Lecture on Disability and Employment Equity. Class Notes. Tygerberg: University of Stellenbosch.

Tonkin, R. (2007). Making the link between diabetes and stroke. *Stroke News*, Spring, 26-27.

Trading Economics. (2010). *South African Unemployment Rate*. [Online]. Available [www.tradingeconomics.com/south-africa/unemployment-rate](http://www.tradingeconomics.com/south-africa/unemployment-rate). [Accessed 2011, May 13].

Treger, I., Shames, J., Giaquinto, S. and Ring, H. (2007). Return to work in stroke patients. *Disability and Rehabilitation*, 29(17):1397-1403.

United Nations. (2002). *World Programme of action concerning disabled persons*. Division for social policy and development. New York: United Nations.

Visagie, S. (2008). *Outcome-Orientated Rehabilitation*. Class Notes. Tygerberg: University of Stellenbosch.

Visagie, S. (2010). *Outcome Levels*. Class Notes. Tygerberg: University of Stellenbosch.

Wade, D. (1996). *Measurement in Neurological Rehabilitation*. Oxford: Oxford University Press.

Wasserman, S., de Villiers, L. and Bryer, A. (2009). Community-based care of stroke patients in a rural African setting. *South African Medical Journal*, 99(8):579-583.

Watermeyer, B., Swartz, L., Lorenzo T., Schneider, M., and Priestly, M. (2006). *Disability and Social Change*. Cape Town: HSRC Press.

Western Cape (South Africa). Department of Health. (2006). *Rehabilitation Services*. [Online]. Available: <http://capegateway.gov.za/eng/directories/services/11516/6459>. [Accessed 2010, July 13].

Western Cape (South Africa). Department of Health. (2007). *Comprehensive Service Plan for the Implementation of Healthcare 2010*. [Online]. Available: [www.capegateway.gov.za/eng/your\\_gov/305](http://www.capegateway.gov.za/eng/your_gov/305). [Accessed 2010, July 13].

Western Cape (South Africa). Department of Health. (2011). *2020: The Future of Health Care in the Western Cape. A draft framework for dialogue*. [Online]. Available: [www.westerncape.gov.za/eng/your\\_gov/305](http://www.westerncape.gov.za/eng/your_gov/305). [Accessed 2012, June 6].

Western Cape (South Africa). Department of Transport. (2009). *Public Transport Policy Statement for Special Needs Passengers in the Western Cape*. [Online]. Available:

[www.westerncape.gov.za/other/2009/5/final\\_snp\\_policy.pdf](http://www.westerncape.gov.za/other/2009/5/final_snp_policy.pdf). [Accessed 2012, February 20].

Whiteneck, G., Gerhart, K., and Cusick, C. (2004). Identifying environmental factors that influence the outcomes of people with traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 19(3):19-204.

WHO *see* World Health Organization.

Wikipedia. *Cape Town*. [Online]. Available: [en.Wikipedia.org/wiki/Cape Town](http://en.Wikipedia.org/wiki/Cape_Town). [Accessed 2012, April 3].

Williams, M., Baker, D., Parker, R., and Nurss, J. (1998). Relationship of Functional Health Literacy to Patients' Knowledge of their Chronic Disease. *Archives of Internal Medicine*, 158(2):166-172.

World Health Organization. (2001a). *International Classification of Functioning, Disability and Health. ICF Introduction*. Geneva: World Health Organization.

World Health Organization. (2001b). *ICF Checklist Version 2.1a, Clinical form for international classification of functioning, disability and health*. Geneva: World Health Organization.

World Health Organization. (2001c). *International Classification of Functioning, Disability and Health (Short Version)*. Geneva: World Health Organization.

World Health Organization. (2001d). *International Classification of Functioning, Disability and Health*. Geneva: World Health Organization.

World Health Organization. (2004a). *Comprehensive ICF Core Set for Stroke*. [Online]. Available: [www.icf-research-branch.org](http://www.icf-research-branch.org) [Accessed 2010, September 17].

World Health Organization. (2004b). *Community Based Rehabilitation: A strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities. Joint Position Paper: ILO, UNESCO, WHO*. Geneva: World Health Organization.

Young, J. and Forster, A. (2007). Review of Stroke Rehabilitation. *British Medical Journal*, 2007, 334:86-90.

Zhang, W., Dewey, H., Cadilhac, D., and Donnan, G. (2011). Emerging Risk Factors for Stroke. *The Journal of Clinical Medicine. Modern Medicine*, 36(2):22-26.

## Appendix 1: Data Set Specification For Uninsured Stroke Survivors Helderberg Basin 2009-2010

Variable Code	Variable Name	Variable Values
Reference	Reference Number	01-50
GA	Geographical Area	1 = Somerset West\Garden V\Helderzicht
		2= Strand \ Rusthof
		3 = Sir Lowry's P Village\ Gordon's Bay
		4 = Lwandle \ Nomzamo\Chris Nissen Park
		5 = Macassar \ Firgrove \ Faure
Sex	Patient Sex	0 = Male
		1 = Female
Age	Patient Age	In years at last birthday
MS	Marital Status	0 = Never Married
		1 = Widow/Widower
		2 = Married
		3 = Living together
		4 = Divorced
Dep	Minor or dependant children /Number	0 = None
		1 = Yes
Lang	Home Language	1 = Afrikaans
		2 = Xhosa
		3 = English
		4 = Other-Specify
Edu	Education	0 = No formal education
		1 = Grade 1 -3 (Sub A-Std 1)
		2 = Grade 4 -7 (Std 2-Std 5)
		3 = Grade 8 -11 (Std 6-Std 9)
		4 = Grade 12 (Std 10)
		5 = Tertiary Education
EC	Economic Circumstances (Family Unit)	1 = Disability Grant
		2 = Old Age pension
		3 = Salary or Wage
		4 = Other/Specify
Emp	Employment	1 = Employed
		2 = Unemployed
		3 = Retired
RU	Reason for Unemployment	1 = Stroke
		2 = Other/Specify
Inc	Income	0 = None
		1 = R1 -R1000
		2 = R1001 - R2000
		3 = R2001 - R3000
		4 = R3001 -R5000
		5 =R5001 - R10 000
		6 = R10 001 -R15 000
		7 = R15 000 +
H	Housing	1 = Room
		2 = 1 Storey House
		3 = Double Storey House
		4 = Shack
		5 = Wendy House
		6 = Flat
PLW	Participant Lives with	1 = Boarding Care Facility
		2 = On own
		3 = With Spouse
		4 = With Family
		5 = With Friends
Ter	Outside Terrain	1 = Loose Sand
		2 = Hard Soil
		3 = Gravel / Stones
		4 = Grass
		5 = Cement / Paving / Tar

T	Toilet facilities	0 = No toilet 1 = Toilet outdoors 2 = Toilet indoors
W	Washing facilities	1 = Running water 2 = Basin 3 = Shower 4 = Bath
P	Power	1 = Paraffin 2 = Gas 3 = Electricity
Acc	Accessibility	0 = No steps in house 1 = Steps in house 2 = Door not wide enough for wheelchair 3 = Door wide enough for wheelchair 4 = Insuff. space to manoeuvre wheel c / walker 5 = Enough space to manoeuvre wheel c / walker
Tr	Transport	1 = Has own car and drives 2 = Has own car -uses other drivers 3 = Relatives 4 = Friends 5 = Taxi 6 = Bus 7 = Train 8 = Other/Specify
Yr	Year in which stroke occurred	1 = 2009 2 = 2010
NS	Number of strokes	1 = 1st 2 = 2nd 3 = Multiple
Med H	Medical History	1 = Hypertension 2 = Diabetes 3 = Epilepsy 4 = High Cholesterol 5 = Heart Disease 6 = Other/Specify
SMB	Smoke Before Stroke	0 = No 1 = Yes
SMA	Smoke After Stroke	0 = No 1 = Yes
HEMI	Right or Left Hemiplegia	0 = Neither 1 = Rt Arm 2 = Rt Leg 3 = Left Arm 4 = Left Leg
HC	Hip Contractures	0 = No 1 = Yes
KC	Knee Contractures	0 = No 1 = Yes
AC	Ankle Contractures	0 = No 1 = Yes
TC	Toe Contractures	0 = No 1 = Yes
SC	Shoulder Contractures	0 = No 1 = Yes
EC	Elbow Contractures	0 = No 1 = Yes
WC	Wrist Contractures	0 = No 1 = Yes
FC	Finger Contractures	0 = No 1 = Yes

VP	Vision Problems	0 = None
		1 = Hemianopia
		2 = Double Vision
		3 = Presbiopia
		4 = Other/Specify
COMS	Communication Problems	0 = None
		1 = Yes
Ins	Institution where initially seen	0 = None
		1 = Helderberg Hospital
		2 = CHC
		3 = Clinic
		4 = Tygerberg Hospital
		5 = Groote Schuur Hospital
		6 = Other/Specify
DS	Duration of stay in hospital	0 = 0 days
		1 = 1-3 days
		2 = 4 - 7 days
		3 = 8 - 14 days
		4 = More than 14 days
WCRC	Referred to WCRC	0 = No
		1 = Yes
	Admitted to WCRC	0 = No
		1 = Yes
PT1	Received Physiotherapy in hospital	0 = Not applicable
		1 = No
		2 = Yes
OT1	Received Occupational Therapy in hospital	0 = Not applicable
		1 = No
		2 = Yes
ST1	Received Speech Therapy in hospital	0 = Not applicable
		1 = No
		2 = Yes
Psy1	Received assistance form Psychologist while in hospital	0 = Not applicable
		1 = No
		2 = Yes
SW1	Received assistance from Social Worker while in hospital	0 = Not applicable
		1 = No
		2 = Yes
D1	Received assistance from Dietician while in hospital	0 = Not applicable
		1 = No
		2 = Yes
PT2	Received individual Physiotherapy at CHC /Clinic or Helderberg Hospital as Outpatient	1 = Yes
		2 = No
OT2	Received individual Occ Therapy at CHC /Clinic or Helderberg Hospital as Outpatient	1 = Yes
		2 = No
ST2	Received individual Speech therapy at CHC /Clinic or Helderberg Hospital as Outpatient	1 = Yes
		2 = No
Psy2	Received counselling from Psychologist at CHC Clinic or Helderberg Hospital as Outpatient	1 = Yes
		2 = No
SW2	Received assistance from Social Worker at CHC Clinic or Helderberg Hospital as Outpatient	1 = Yes
		2 = No
D2	Received assistance from Dietician at CHC Clinic or Helderberg Hospital as Outpatient	1 = Yes
		2 = No
PTS	Nr of hours of Physio received after last stroke	0 = None
		1 = 1-5 Hours
		2 = 6-10 Hours
		3 = 11 -15 Hours
		4 = 16 -20 Hours
		5 = 21-40 Hours
		6 = 41-60 Hours
		7 = More than 60 Hours

OTS	Nr of hours of OT received after last stroke	0 = None
		1 = 1-5 Hours
		2 = 6 -10 Hours
		3 = 11 -15 Hours
		4 = 16 - 20 Hours
		5 = 21-40 Hours
		6 = 41-60 Hours
		7 = More than 60 Hours
STS	Nr of hours of Speech Therapy received after last stroke	0 = None
		1 = 1-5 Hours
		2 = 6 -10 Hours
		3 = 11 -15 Hours
		4 = 16 - 20 Hours
		5 = 21-40 Hours
		6 = 41-60 Hours
		7 = More than 60 hours
PsyS	Nr of hours of Psychological Counselling received after last stroke	0 = None
		1 = 1-5 Hours
		2 = 6 -10 Hours
		3 = 11 -15 Hours
		4 = 16 - 20 Hours
		5 = More than 20 Hours
HV	Did you receive a home visit from a Physiotherapist or an Occupational Therapist	1 = Yes
		2 = No
P	Reasons for not receiving therapy	0 = Not applicable
		1 = No transport
		2 = Cost of transport
		3 = No transport for wheelchair users
		4 = No one to accompany person
		5 = Didn't think it was necessary
		6 = Was not referred
		7 = Other
MAD	Mobility Assistive Devices	0 = None Required
		1 = Required but did not receive
		2 = Wheelchair
		3 = Custom measured Wheelchair
		4 = Motorized Wheelchair
		5 = CM Motorized Wheelchair
		6 = Cane / Stick
		7 = Walking Frame
PMAD	Procurement of Mobility Assistive Devices	1 = Hospital
		2 = Clinic / CHC
		3 = Other/Specify
AssD	Other Assistive Devices received from Hospitals WCRC / CHC's / Clinics	0 = None
		1 = Wheelchair table
		2 = Bath Board etc.
		3 = Grab Rails
		4 = Eating Utensils
		5 = Writing Utensils
		6 = Commode
		7 = Adapted Cooking Appliances
		8 = Other/Specify
NGO	Assistance from NGO's in Helderberg Basin	0 = None
		1 = Helderberg Stroke Support Group
		2 = BADISA
		3 = Home Based Carers
		4 = Society of the Aged
		5 = Other/Specify
Have you benefitted from any other source not mentioned?		
Please specify:		
Anything else that would have been of assistance to you after your stroke?		

## Appendix 2: Stroke Impact Scale VERSION 3.0

### Scoring:

The SIS uses the algorithm of the SF-36 (Stuart AL, Ware JE: Measuring functioning and well-being: the Medical Outcomes Study approach. Durham, North Carolina. Duke University Press, 1992: 375-376). The SIS is scored in the following way, for each domain:

$$\text{Transformed Scale} = \left[ \frac{(\text{Actual raw score} - \text{lowest possible raw score})}{\text{Possible raw score range}} \right] \times 100$$

There are 3 items that change polarity in the emotion domain, 3f, 3h and 3i. If scoring manually, the scores must be reversed –i.e. 1 becomes 5, 2 becomes 4, 3 remains the same, 4 becomes 2 and 5 becomes 1, prior to manual calculation. For these items, use the following equation to compute the individual's score:

$$6 - \text{individual's rating} = \text{item score}$$



# Stroke Impact Scale

## VERSION 3.0

The purpose of this questionnaire is to evaluate how stroke has impacted your health and life. We want to know from YOUR POINT OF VIEW how stroke has affected you. We will ask you questions about impairments and disabilities caused by your stroke, as well as how stroke has affected your quality of life. Finally, we will ask you to rate how much you think you have recovered from your stroke.

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# Stroke Impact Scale

These questions are about the physical problems which may have occurred as a result of your stroke.

1. In the past week, how would you rate the strength of your....	A lot of strength	Quite a bit of strength	Some strength	A little strength	No strength at all
a. Arm that was <u>most affected</u> by your stroke?	5	4	3	2	1
b. Grip of your hand that was <u>most affected</u> by your stroke?	5	4	3	2	1
c. Leg that was <u>most affected</u> by your stroke?	5	4	3	2	1
d. Foot/ankle that was <u>most affected</u> by your stroke?	5	4	3	2	1

**These questions are about your memory and thinking.**

<b>2. In the past week, how difficult was it for you to...</b>	<b>Not difficult at all</b>	<b>A little difficult</b>	<b>Some-what difficult</b>	<b>Very difficult</b>	<b>Extremely difficult</b>
a. Remember things that people just told you?	5	4	3	2	1
b. Remember things that happened the day before?	5	4	3	2	1
c. Remember to do things (e.g. keep scheduled appointments or take medication)?	5	4	3	2	1
d. Remember the day of the week?	5	4	3	2	1
e. Concentrate?	5	4	3	2	1
f. Think quickly?	5	4	3	2	1
g. Solve everyday problems?	5	4	3	2	1

**These questions are about how you feel, about changes in your mood and about your ability to control your emotions since your stroke.**

<b>3. In the past week, how often did you...</b>	<b>None of the time</b>	<b>A little of the time</b>	<b>Some of the time</b>	<b>Most of the time</b>	<b>All of the time</b>
a. Feel sad?	5	4	3	2	1
b. Feel that there is nobody you are close to?	5	4	3	2	1
c. Feel that you are a burden to others?	5	4	3	2	1
d. Feel that you have nothing to look forward to?	5	4	3	2	1
e. Blame yourself for mistakes that you made?	5	4	3	2	1
f. Enjoy things as much as ever?	5	4	3	2	1
g. Feel quite nervous?	5	4	3	2	1
h. Feel that life is worth living?	5	4	3	2	1
i. Smile and laugh at least once a day?	5	4	3	2	1

**The following questions are about your ability to communicate with other people, as well as your ability to understand what you read and what you hear in a conversation.**

<b>4. In the past week, how difficult was it to...</b>	<b>Not difficult at all</b>	<b>A little difficult</b>	<b>Some-what difficult</b>	<b>Very difficult</b>	<b>Extremely difficult</b>
a. Say the name of someone who was in front of you?	5	4	3	2	1
b. Understand what was being said to you in a conversation?	5	4	3	2	1
c. Reply to questions?	5	4	3	2	1
d. Correctly name objects?	5	4	3	2	1
e. Participate in a conversation with a group of people?	5	4	3	2	1
f. Have a conversation on the telephone?	5	4	3	2	1
g. Call another person on the telephone, including selecting the correct phone number and dialing?	5	4	3	2	1

**The following questions ask about activities you might do during a typical day.**

<b>5. In the past 2 weeks, how difficult was it to...</b>	<b>Not difficult at all</b>	<b>A little difficult</b>	<b>Some-what difficult</b>	<b>Very difficult</b>	<b>Could not do at all</b>
a. Cut your food with a knife and fork?	5	4	3	2	1
b. Dress the top part of your body?	5	4	3	2	1
c. Bathe yourself?	5	4	3	2	1
d. Clip your toenails?	5	4	3	2	1
e. Get to the toilet on time?	5	4	3	2	1
f. Control your bladder (not have an accident)?	5	4	3	2	1
g. Control your bowels (not have an accident)?	5	4	3	2	1
h. Do light household tasks/chores (e.g. dust, make a bed, take out garbage, do the dishes)?	5	4	3	2	1
i. Go shopping?	5	4	3	2	1
j. Do heavy household chores (e.g. vacuum, laundry or yard work)?	5	4	3	2	1

**The following questions are about your ability to be mobile, at home and in the community.**

<b>6. In the past 2 weeks, how difficult was it to...</b>	<b>Not difficult at all</b>	<b>A little difficult</b>	<b>Some-what difficult</b>	<b>Very difficult</b>	<b>Could not do at all</b>
a. Stay sitting without losing your balance?	5	4	3	2	1
b. Stay standing without losing your balance?	5	4	3	2	1
c. Walk without losing your balance?	5	4	3	2	1
d. Move from a bed to a chair?	5	4	3	2	1
e. Walk one block?	5	4	3	2	1
f. Walk fast?	5	4	3	2	1
g. Climb one flight of stairs?	5	4	3	2	1
h. Climb several flights of stairs?	5	4	3	2	1
i. Get in and out of a car?	5	4	3	2	1

**The following questions are about your ability to use your hand that was MOST AFFECTED by your stroke.**

<b>7. In the past 2 weeks, how difficult was it to use your hand that was most affected by your stroke to...</b>	<b>Not difficult at all</b>	<b>A little difficult</b>	<b>Somewhat difficult</b>	<b>Very difficult</b>	<b>Could not do at all</b>
a. Carry heavy objects (e.g. bag of groceries)?	5	4	3	2	1
b. Turn a doorknob?	5	4	3	2	1
c. Open a can or jar?	5	4	3	2	1
d. Tie a shoe lace?	5	4	3	2	1
e. Pick up a dime?	5	4	3	2	1



**The following questions are about how stroke has affected your ability to participate in the activities that you usually do, things that are meaningful to you and help you to find purpose in life.**

<b>8. During the past 4 weeks, how much of the time have you been limited in...</b>	<b>None of the time</b>	<b>A little of the time</b>	<b>Some of the time</b>	<b>Most of the time</b>	<b>All of the time</b>
a. Your work (paid, voluntary or other)	5	4	3	2	1
b. Your social activities?	5	4	3	2	1
c. Quiet recreation (crafts, reading)?	5	4	3	2	1
d. Active recreation (sports, outings, travel)?	5	4	3	2	1
e. Your role as a family member and/or friend?	5	4	3	2	1
f. Your participation in spiritual or religious activities?	5	4	3	2	1
g. Your ability to control your life as you wish?	5	4	3	2	1
h. Your ability to help others?	5	4	3	2	1

## 9. Stroke Recovery

**On a scale of 0 to 100, with 100 representing full recovery and 0 representing no recovery, how much have you recovered from your stroke?**

\_\_\_\_\_ 100 Full Recovery

—

\_\_\_\_\_ 90

—

\_\_\_\_\_ 80

—

\_\_\_\_\_ 70

—

\_\_\_\_\_ 60

—

\_\_\_\_\_ 50

—

\_\_\_\_\_ 40

—

\_\_\_\_\_ 30

—

\_\_\_\_\_ 20

—

\_\_\_\_\_ 10

\_\_\_\_\_ 0 No Recovery

**Appendix 3a: Modified Barthel Score****Modified Barthel Score**      Reference No:

Items	Unable to perform task	Attempts task but unsafe	Moderate help required	Minimal help required	Fully independent
Personal Hygiene	0	1	3	4	5
Bathing Self	0	1	3	4	5
Feeding	0	2	5	8	10
Toilet	0	2	5	8	10
Stair Climbing	0	2	5	8	10
Dressing	0	2	5	8	10
Bowel Control	0	2	5	8	10
Bladder Control	0	2	5	8	10
Ambulation (wheelchair)	0	3	8	12	15
	0	1	3	4	5
Chair -Bed Transfers	0	3	8	12	15

## **Appendix 3b: Guidelines for Modified Barthel Index Functions**

(Notes in parenthesis are to facilitate application)

### **Personal Hygiene**

**1. The patient is unable to attend to personal hygiene and is dependent in all aspects.**

[Patient is totally dependent on assistance to brush teeth /dentures, comb hair, wash hands, wash face, shave and /or apply make-up.]

**2. Assistance is required in all steps of personal hygiene.**

[Patient may complete one or two of the above activities. Generally requires assistant to provide more effort than self for each of the activities, loosen dentures, shave etc.]

**3. Some assistance is required in one or more steps of personal hygiene.**

[Assistance is required in applying make-up, help to wash one hand, help to apply pressure to brush teeth, shave under chin, comb back of hair, help to dry one hand. Needs constant cueing or coaxing to complete tasks.]

**4. Patient is able to conduct his /her own personal hygiene but requires minimal assistance before and /or after the operation.**

[There may be concerns about safety such as plugging in plug, fixing a razor blade, hot water or some assistance may be required with set up and /or tidy up or smoothing smudged make-up.]

**5. The patient can wash his/her hands and face, comb hair, clean teeth and shave. A male patient may use any kind of razor but must insert the blade, or plug in the razor without help, as well as retrieve it from the drawer or cabinet. A female patient must apply own make-up, if used, but need not braid or style her hair.**

[Patient can perform all personal hygiene tasks independently and safely.]

### **Bathing Self**

**1. Total dependence in bathing self.**

[Patient is totally dependent in bathing self, or bathing is not performed or drying all parts of the body is not performed.]

**2. Assistance is required in all aspects of bathing.**

[Patient requires assistance and direction in all aspects of bathing. May be able to wash chest and both arms.]

**3. Assistance is required with either transfer to shower/bath or with washing and drying; including inability to complete a task because of condition or disease, etc.**

[Assistance is required with either transfer to shower /bath or washing/drying. Help with bathmat, soap, towel, wash cloth, upper and /or lower limbs may be required. Patient may need cueing, coaxing and supervision.]

**4. Supervision is required for safety in adjusting the water temperature, or in the transfer.**

[Bathing may take more than three times the normal time. Assistance may be required to set up bathing equipment, the water, washing material, etc. Some prompting or supervision with transfers may be required.]

**5. The patient may use a bath tub, shower, or take a complete sponge bath. The patient must be able to do all the steps of whichever method is employed without another person being present.**

[Patient may use specialised equipment, long-handled sponge to wash legs and feet. Patient is able to complete all steps independently, and may take up to twice the normal time to complete the tasks.]

## **Feeding**

**1. Dependent in all aspects and needs to feed.**[Patient only chews and swallows food while an assistant scoops and brings it to mouth. Maximum help with tube feeding such as pouring, connecting, purging, regulating the rate is required.]

**2. Can manipulate an eating device, usually a spoon, but someone must provide active assistance during the meal.**

[Patient can bring food to mouth but an assistant scoops all food onto the utensil].

**3. Able to feed self with supervision. Assistance is required with associated tasks such as putting milk and sugar into tea, adding salt and pepper, spreading butter, turning a plate or other "set up activities."**

[Patient scoops food, brings it to mouth, and eats. May need assistance with pouring, drinking, opening containers and /or cutting meat, with application of cuffs, orthosis, prosthesis. Assistance with set up is required. Standing by cueing, coaxing and supervision throughout meal may be required for possible choking and eating in a hurry.]

**4. Independence in feeding with prepared tray except assistance may be required to cut meat, open milk carton, jar, lid etc. Presence of another person is not required.**

[Longer than usual time is taken to eat. There may be some concern for safety due to quality of swallowing or may require modified food for consistency, but no further help from assistant is required.]

**5. The patient can feed self from tray or table when someone puts the food within reach. The client must put on an assistive device if needed, cut the food, and if desired, use salt and pepper, spread butter etc.**

[The patient is able to use spoon, fork, cup, glass, long straw, adapted devices, cuff, opens containers, pours liquid, and cuts meat with no risk. No help required.]

## **Toilet**

**1. Fully dependent in toileting.**

[Patient is dependent in all aspects of toileting.]

**2. Assistance required in all aspects of toileting.**

[Patient requires maximal assistance with transfers, clothing adjustment , use of toilet paper and perineal hygiene.]

**3. Assistance may be required with management of clothing, transferring, or washing hands.**

[Supervision and assistance with transfer /balance while washing hands, adjusting clothing, with zipping/unzipping fly/skirt, may be required.]

**4. Supervision may be required for safety with normal toilet. A commode may be used at night but assistance is required for emptying and cleaning.**

[Supervision for safety, initial preparation such as handing the patient the toilet tissue may be required. May use commode at night. Prompting and cueing to locate toilet may be required.]

**5. The patient is able to get on and off the toilet, fasten and unfasten clothes, prevent soiling of clothes and use of toilet paper without help. If necessary, the client may use a bedpan or commode, or urinal at night, but must be able to empty it and clean it.**

[Patient adjusts clothing prior to using the toilet, wipes front or back, approaches, gets on and off the toilet, adjusts clothing after using the toilet, and fastens clothing. Can use required equipment such as tongs, dressing stick, zipper –pull, or grab bars. Maintains balance and is safe.]

## **Stair Climbing**

**1. The patient is unable to climb stairs.**

[The stairs imply a flight of stairs.]

**2. Assistance is required in all aspects of stair climbing, including assistance with walking aids.**

**3. The patient is able to ascend /descend but is unable to carry walking aids, and needs supervision and assistance.**

**4. Generally no assistance is required. At times, supervision is required for safety due to morning stiffness, shortness of breath, etc.**

**5. The patient is able to go up and down a flight of stairs safely without help or supervision. The patient is able to use hand rails, cane or crutches when needed and is able to carry these devices as he/she ascends or descends.**

## **Dressing**

**1. The patient is dependent in all aspects of dressing and is unable to participate in the activity.**

[Patient may lean forwards, backwards, may be able to use bed side rails, may thread a sleeve or bring a garment together, but the assistant dresses client totally. If patient wears a gown, the score is 0.]

**2. The patient is able to participate to some degree, but is dependent in all aspects of dressing.**

[Patient requires maximal assistance in set up of dressing. Patient may wear a sweat shirt on his upper body and thread the sleeves, but assistance, brings it over the head. Patient can thread bra straps but the assistant fits and fastens the bra hook. Patient may assist pulling the pant legs but the assistant completes the lower limb dressing.]

**3. Assistance is needed in putting on and /removing any clothing.**

[Assistance is needed in obtaining clothing, applying devices, and initiating and completing upper and lower extremity dressing and undressing.]

**4. Only minimal assistance is required with fastening clothing, such as buttons, zips, bra, shoes etc.**

[Patient may require start up assistance but patient dresses and undresses. Assistant may obtain clothing from closet, may assist in application of orthosis or prosthesis, and may assist with fastening clothing, buttons, zips, bra etc. Coaxing, prompting and /or cueing on sequencing may be required and dressing may take up to three times the normal time.]

**5. The patient is able to put on, remove and fasten clothing, tie shoe laces, or put on, fasten and remove corset or brace as prescribed.**

[Patient is able to obtain clothes, put on, remove and fasten clothing and shoe laces, or put on, fasten and remove corset, brace or prosthesis as prescribed. Patient manages underpants, slacks, skirt, belt, stockings and shoe laces. Patient manages bra, turtle necks, zippers, buttons and snaps and can use special adaptive closure such as Velcro and zipper pull, and dressing stick, reacher, sock aid, and complete task in reasonable time.]

## **Bowel Control**

**1. The patient is bowel incontinent.**

[The patient needs to wear diapers, or absorbent pads.]

**2. The patient needs help to assume appropriate position, and with bowel movement facilitatory techniques.**

[Despite assistance, patient may be soiled frequently and necessitates wearing absorbent pads.]

**3. The patient can assume appropriate position, but cannot use facilitatory techniques, or clean self without assistance, and has frequent accidents. Assistance is required with incontinence aids, such as pads etc.**

[Patient can assume position, but has occasional accidents, needs assistance to clean self /and or to apply incontinence aids.]

**4. The patient may require supervision with the use of suppository or enema, and has occasional accidents.**

[Patient requires supervision with the use of suppository, enema, or an external device. Bowel accidents are rare, and prompting, cueing and adherence to the routine to maintain continence may be required.]

**5. The patient can control bowels completely and has no accidents. Can use suppository, or take an enema when necessary.**

[Patient can control bowels completely and intentionally and has no accidents, can use digital stimulation or stool softeners, suppositories, laxative use, or enemas on a regular basis. If patient has colostomy he /she maintains it.]

## **Bladder control**

### **1. The patient is dependent in bladder management, is incontinent, or has indwelling catheter.**

[Patient may be catheterised, is incontinent of urine day and night, wet on daily basis. External catheter, drainage bag, night bag, all require to be cared for by assistant.]

### **2. The patient is incontinent but is able to assist with the application of an internal or external device.**

[Patient requires to be positioned but can hold bedpan or urinal in place. External urinary drainage devices, tubing drainage bag, all require to be cared for. Patient is incontinent but able to assist with application of devices.]

### **3. The patient is generally dry by day, but not at night, and needs assistance with devices.**

[Patient voids but needs help in positioning self, equipment, pads and other devices. Can place penis in the urinal, hold legs apart, insert catheter, and is occasional incontinent. Coaxing, cueing and supervision may be required.]

### **4. The patient is generally dry by day and night but have an occasional accident, or need minimal assistance with internal or external devices.**

[If unable to find toilet or if not quick enough, patient may have accident. May require minimal assistance with set-up and/or devices, may need medication to maintain voiding pattern. Prompting, cueing and adherence to the routine to maintain continence may be required.]

### **5. The patient is able to control bladder day and night and / or is independent with internal or external devices.**

[Patient is independent, is continent and independent in the use of equipment required and use of medication. Is able to change pads, diapers before soiling.]

## **Ambulation**

### **1. Dependent in ambulation.**

[Patient does not ambulate. To attempt to ambulate requires two assistants.]

### **2. Constant presence of one or more assistants is required during ambulation.**

[Patient requires maximal assistance to ambulate.]

### **3. Assistance is required with reaching aids and /or their manipulation. One person is required to offer assistance.**

[Patient requires assistant to reach for walking aids and to provide a steadying effect around corners, over thresholds, and over rougher terrains, but is able to ambulate.]

### **4. The patient is independent in ambulation but unable to walk 50m without help, or supervision is needed for confidence or safety in hazardous situations.**

[Patient may require cueing and prompting, and more than reasonable time to complete distances.]

### **5. The patient must be able to wear braces if required, lock and unlock these braces, assume standing position, sit down and place the necessary aids in position for use. The patient must be able to use crutches, canes or walkerette and walk 50m /yds without help or supervision.**



[Patient walks length of corridor back and forth. There is no concern for safety, falling or wandering. Patient is independent with walker, cane, prosthesis, orthosis, special shoe etc.] Do not score ambulation if patient is unable to ambulate and is trained in wheelchair management.

#### **Or Wheelchair**

**1. Dependent in wheelchair ambulation.**

**2. The patient can propel short distances on flat surface but assistance is required for all other steps of wheelchair management.**

[Assistant needs to push wheelchair for the majority of the time, is especially required to apply brakes, adjust armrests, cushion, manoeuvre around furniture, over ledges, loose rugs, and rougher terrains.]

**3. Presence of one person is necessary and constant assistance is required to manipulate chair to table, bed etc.**

[Patient can propel wheelchair, but needs assistance with manoeuvring in and around furniture and in limited spaces.]

**4. The patient can propel self for a reasonable duration over regularly encountered terrain. Minimal assistance may be required in tight corners.**

[Occasional verbal prompting and assistance with manoeuvring in limited spaces may be required.]

**5. To propel wheelchair independently the patient must be able to go around corners, turn around, manoeuvre the chair to a table, bed, toilet, etc. The patient must be able to push the chair at least 50m /yds. Not applicable if patient is ambulate.**

#### **Chair/bed transfers**

**1. Unable to participate in transfer. Two attendants are required to transfer the patient with or without a mechanical device.**

**2. Able to participate, but maximum assistance of one other person is required in all aspects of the transfer.**

**3. The transfer requires assistance of one other person. Assistance may be required in any aspect of the transfer.**

**4. The presence of another person is required, either as a confidence measure, or to provide supervision for safety.**

[Can position sliding board or move footrest or set-up, position chair, and lock brakes. Minimal help is required.]

**5. The patient can safely approach the bed in a wheelchair, lock the brakes, lift the footrests, move safely to bed, lie down, come to a sitting position on the side of the bed, change the position of the wheelchair, transfer back into it safely. The patient must be independent in all phases of the activity.**

[Patient can come to a standing position if walking is the mode of locomotion. If walking, client approaches sits down, and gets to a standing position from a regular chair, transfers from bed to chair, performs tasks safely. Can approach, enter, and leave a tub or shower stall. Patient may use a sliding

board, a lift, grab bars, or special seat. Patient may take more time than usual time, but less than three times the usual time to perform tasks.]

(Australian Government Department of Health, 2006; Shah et al. 1989)

### **Appendix 3c: Modified Barthel Index (Dependency Needs)**

Categories	MBI Total Scores	Dependency Level	Hours of Help Required per Week (maximum)
1	0-24	Total	27
2	25-49	Severe	23.5
3	50-74	Moderate	20
4	75-90	Mild	13
5	91-99	Minimal	<10

(Australian Government Department Health, 2006).

## Appendix 4: LOTCA

Reference No: _____		Date: _____							
<b>LOTCA Battery: Scoring Sheet</b>									
(circle the appropriate number)									
<b>SUB-TESTS</b>		<b>SCORE</b>						<b>COMMENTS</b>	
		low			high				
<b>ORIENTATION</b>									
1. Orientation for Place	(OP)	1	2	3	4	5	6	7	8
2. Orientation for Time	(OT)	1	2	3	4	5	6	7	8
<b>VISUAL PERCEPTION</b>									
3. Object Identification	(OI)	1	2	3	4				
4. Shape Identification	(SI)	1	2	3	4				
5. Overlapping Figures	(OF)	1	2	3	4				
6. Object Consistency	(OC)	1	2	3	4				
<b>SPACIAL PERCEPTION</b>									
		1							
7. Direction on Cs' Body	(SP1)	1	2	3	4				
8. Spatial Relations	(SP2)	1	2	3	4				
9. Spatial Relations on Picture	(SP3)	1	2	3	4				
<b>MOTOR PRAXIS</b>									
		1							
10. Motor Limitation	(P1)	1	2	3	4				
11. Utilization of Objects	(P2)	1	2	3	4				
12. Symbolic Actions	(P3)	1	2	3	4				
<b>VISUOMOTOR ORGAIZATION</b>									
		1							
13. Copying Geometric Forms	(GF)	1	2	3	4				
14. Two-Dimensional Model	(TM)	1	2	3	4				
15. Pegboard Construction	(PC)	1	2	3	4				
16. Coloured Block-Design	(CB)	1	2	3	4				
17. Plain Block-Design	(PB)	1	2	3	4				
18. Reproduction of a Puzzle	(RP)	1	2	3	4				
19. Drawing a Clock	(DC)	1	2	3	4				
<b>THINKING OPERATIONS</b>									
20. Categorization	(CA)	1	2	3	4	5			
21. ROC Unstructured	(RU)	1	2	3	4	5			
22. ROC Structured	(RS)	1	2	3	4	5			
23. Pictorial Sequence A	(PS1)	1	2	3	4				
24. Pictorial Sequence B	(PS2)	1	2	3	4				
25. Geometric Sequence	(GS)	1	2	3	4				
26. Logic Questions	(LQ)	1	2	3	4				
<b>ATTENTION AND CONCENTRATION</b>									
Indicate Length of Time:									
Assessment was Performed in: _____ one sessi _____ two sessions or more									

## Appendix 5: Speech And Language Test

### Reference No:

#### 1. Naming:

Point to a pencil, key and fork. Have the participant name them as you point.

Wys na die potlood, sleutel en vurk.

Ndibonise ipesile, isitshixo, ifoloko.

3

#### 2. Auditory Verbal Comprehension

The participant must follow these commands:

- Raise your hand. Lig jou hand. Phakamisa isandla.

1

- Point to the pen and the book. Wys na die pen en die boek. Ndibonise ibolipeni ne ncwadi.

4

- Put the pen on top of the book and then give it to me. Sit die pen bo op die boek en gee vir my. Beka ipeni phezulwencwadi undinike yona.

14

#### 3. Repetition:

The participant must repeat the following words:

- Banana. Piesang. Ighanana

2

- The telephone is ringing. Die wit telefoon lui. Ifouwni imhlophe I yakhala.

8

- No ifs, ands or buts. Nog vis, nog vlees, nog voël. Ukuba, Kunye, Kod

10

#### 4. Reading:

The participant must read the following aloud and then do what it says:

(Half the marks are for reading correctly and half for following the instruction.)

- Close your eyes. Maak jou oe toe. Vala amehlo 2
- Point to the chair and then to the door. Wys na die stoel en daarna die duur.  
Ndibonise isitulo nomnyango. 4

Pick up the pencil, knock three times and put it back. Tel op die potlood, klop drie keer daarmee en sit dit terug. Phakamisa ipensili, ubethe kathathu uphinde uyibeke.

6

#### 5. Writing:

- Have the participant write his or her name and address 6

(Score 1 point for each recognizable word or number. Deduct half a point for each spelling mistake.)

- Ask the participant to write the numbers from 1 through to 20

10

(Score half a point for each number, even if out of order.)

**Total:**



**Appendix 6b: Table To Assist Participants With Scoring Environmental Factors**

<b>Environmental factors</b>		<b>Score</b>
<b>Very Helpful</b>		<b>4</b>
<b>Helpful</b>		<b>3</b>
<b>Moderately Helpful</b>		<b>2</b>
<b>Slightly Helpful</b>		<b>1</b>
<b>No Impact</b>		<b>0</b>
<b>Slightly Unhelpful</b>		<b>-1</b>
<b>Moderately Unhelpful</b>		<b>-2</b>
<b>Unhelpful</b>		<b>-3</b>
<b>Very unhelpful</b>		<b>-4</b>

## Appendix 7: Patient Information Leaflet

**TITLE OF THE RESEARCH PROJECT:** Rehabilitation Outcomes of uninsured stroke survivors in the Helderberg Basin.

**REFERENCE NUMBER:** N10/11/375

**PRINCIPAL INVESTIGATOR:** Judy Cawood  
Occupational Therapist

**ADDRESS:** 22 Helderzicht Rd  
Somerset West  
7130

**CONTACT NUMBER:** Tel: 072 0246463

You are being invited to take part in a research project. Please read the information below carefully and ask me if there is anything you do not understand. Please be aware that you do not have to take part in this study. It is entirely voluntary and if you say no, it will not affect you negatively in any way. You may also withdraw from the study at any point if you do decide to take part in it. The study has been approved by the **Committee for Human Research at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the International Declaration of Helsinki, South African guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research. (Ethical guidelines are rules which are there to protect people who are taking part in a research project and to make sure that the person who is doing the research does everything correctly.)

### **What is this research study all about?**

This study is being done on people who had strokes in 2009 and 2010 in the Helderberg Basin and who are not covered by medical aid. Fifty people have been selected to take part in the study.

The extent or level to which you have made progress after your stroke is known as **Rehabilitation Outcome Levels**. The researcher will want to know the following kind of information: Can you walk after your stroke? Do you have problems with speech? Can you dress and feed yourself? Can you do the things you used to do like going shopping, going to church or playing sport? Have you been able to go back to work?

There might also be other difficulties that you face: You might not be able to use public transport because they don't take wheelchairs. You might not be able to get to the doctor, or you might not have had sufficient therapy (physiotherapy, occupational therapy etc.) There may be other services that are lacking or things that



cause a problem for you. It might be difficult to go out or get into your house, because of steps or doors which might be too narrow for wheelchairs. People's attitudes or how they treat you might have changed since you had the stroke. These types of problems are known as **Environmental Barriers**. The researcher will want to know what environmental barriers you face. The word **uninsured** refers to people who do not have medical aid and who have to make use of the government services for medical treatment.

The Western Cape Department of Health has specific guidelines on rehabilitation that people should receive after an incident like a stroke. This study will help determine if stroke survivors in the Helderberg Basin are getting the help they should be getting and identify their needs in terms of healthcare, rehabilitation and other services.

### **Why have you been invited to join in?**

To get an indication of the rehabilitation outcome levels achieved and problems that people face, the names of people from different communities in the Helderberg Basin who had strokes in 2009 and 2010 and who do not have medical aid, have been obtained through various health services and other organizations. Fifty people have been selected to take part in the study and your name was one of the names drawn.

### **What will my responsibilities be?**

The study has 2 parts. You will be involved in Part 1.

Six people will be invited to be in Part 2 of the study. You may be one of these people.

You will need to be available for an evaluation by the researcher that will take approximately 3-4 hours. The length of time will depend on your needs and how quickly the tests and questionnaires can be completed. (After a stroke some people have difficulty with concentration and it might take you longer to do tasks than before the stroke.) The researcher will discuss with you, whether everything will be completed in one session or whether it may be necessary to do it in 2 sessions.

Some of the time will be taken up with an interview and answering questions. Part of this may be recorded. The researcher might want to see how you walk or if you can do things like move from your wheelchair. Certain tests will be done to determine if you have any difficulty with speech, reading, arithmetic or have cognitive and perception problems after the stroke.

The evaluation will be done either at your home or at a central venue in Somerset West. The researcher will discuss which will be the best option with you.

### **Part 2.**

This will take place at a later stage. Should you be asked to participate in this part of the study, it will involve an interview of approximately an hour. You will be asked to tell "your story" about having a stroke and what

has helped and what have been obstacles or difficulties for you. This interview will be recorded with a tape recorder.

**Will you benefit from taking part in the research?**

You may not benefit directly from the study, but it is hoped that information gained from this study will be used to improve services for stroke survivors in the Helderberg Community. The information that you provide could play an important role in this. A study like this can provide information that is helpful to Provincial Health Services in developing appropriate services, allocating finances, deciding on priorities and deciding on which populations need to be targeted in terms of health care.

**Are there any risks involved in your taking part in the study?**

This is a low risk study. The researcher is experienced in moving and working with people who have had strokes and it is unlikely that you would fall or hurt yourself in any way.

**If you do not agree to take part, what alternatives do you have?**

Not applicable to the study.

**Who will have access to your medical records?** At no time will your name be used in the study. Evaluation forms and questionnaires will only have a number on them. Only the researcher will know what your number is. This is to ensure that no one else will know what your problems are or what you said. Should an interpreter be used, they will also not be allowed to reveal any of your information.

**What will happen in the unlikely event of some form of injury occurring as a direct result of your taking part in this research?** It is unlikely that you would sustain any injuries during the evaluation, by taking part in interviews or by completing questionnaires.

**Will you be paid to take part in this study and are there any costs involved?**

You will not get paid to take part in the study. There will be no costs involved for you. Should you need to come in to Somerset West for an evaluation, the researcher will cover the taxi or travel costs for you and 1 caregiver.

**Additional information.**

If you have any further queries, please contact the researcher at Tel: 072 0246463.

You can also contact the Committee for Human Research at 021 -938 9207 if you have any concerns or complaints that are not adequately addressed by the researcher.

If you are happy to participate in this study, please read and sign the attached consent form. You will receive a copy of this form for your own records.

## Declaration by participant

### Part 1

I, ....., voluntarily consent to participate in this research study as described above. I have had a chance to ask questions of the researcher and have had my questions answered to my satisfaction.

I also give permission for the interviews to be tape recorded and for the researcher to access any information from my medical records.

I would like a summary of the research results and recommendations. Yes / No.

### Part 2 (To be completed by authorized caregiver.)

I confirm that the above document has been fully explained to both my .....(insert wife, husband, father, mother or whoever), and that we fully understand and accept the conditions of the above document.

Signed at (*place*).....on (*date*).....

.....  
**Name of participant**

.....  
**Signature of participant**

.....  
**Name of authorised caregiver**

.....  
**Signature**

.....  
**Name of witness**

.....  
**Signature of witness**

## Declaration by investigator

I .....declare that  
the information in this document was explained to.....



## Appendix 8: Letter Of Permission



Departement van Gesondheid  
Department of Health  
iSebe lezeMpilo

Verwysing  
Reference  
Isalathiso

Navrae  
Enquiries  
Imbuzo E ERASMUS

Telefoon  
Telephone 021 850 4704  
Ifowusi

Datum  
Date 2010-10-18  
Umhla

---

Ms J Cawood  
Somerset West

Dear Ms Cawood

### **MASTERS DEGREE RESEARCH**

Your research for a masters degree in Rehabilitation and Disability Studies through the University of Stellenbosch with the preliminary title: "Rehabilitation outcome levels achieved and environmental barriers encountered by uninsured stroke survivors in the Helderberg Basin" has reference.

Subject to approval by the Western Cape Department of Health and Ethics Committee for Human Research at Stellenbosch University, Helderberg Hospital will gladly be of assistance in providing information of people who have had strokes in 2009 and 2010 that you can follow up in the community. You may also obtain names and contact details through the Physiotherapy Department at Helderberg Hospital.

Regards

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Senior Medical Superintendent

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## Appendix 9: Qualitative Questionnaire

**Progress made after a stroke will depend on a number of factors:**

- **What area of the brain was affected and how severe the stroke was.**
- **Medical condition and management of these problems. (Blood Pressure /Diabetes etc.)**
- **Rehabilitation (Physio /Occupational Therapy etc.) How much was received.**
- **Other factors.**

### **A. Medical Factors:**

1. Before you had the stroke, did you know that you had any risk factors for stroke? (E.g. High Blood Pressure). What do you think your Blood Pressure should be? What has your doctor told you in this regard? How often did you have your Blood Pressure checked? Have you taken your medication regularly? Do you know what your different pills are for? Do you have any problems in getting your medication? How do long queues at Hospitals /CHC/Clinics impact on this?
2. What do you think stops people from taking medication?
3. If you have diabetes, what did the doctor and other medical personnel tell you to do to manage it? Is any of this difficult for you to carry out?
4. Did you smoke before the stroke? Do you smoke now? What can be done to encourage people to stop smoking?

### **B. Rehabilitation:**

1. Which therapists did you see? (Physio /OT/Speech?)
2. Who referred you to therapy, or how did you end up seeing a therapist?
2. What do you think the role of each one is?
3. In terms of basic needs when discharged from hospital, did anyone show you /your husband /wife how to do transfers from bed into wheelchair or onto toilet etc? How to get up and down steps in wheelchair /put footplates on and off wheelchair? How to dress yourself? Get in and out of bath /shower?

4. Some therapy is available. Transport is a big problem for people. Sometimes only limited therapy can be given because therapists carry a big patient load. What is the main reason why you did not get more therapy? Who terminated therapy?