

**Participatory Outcomes, Quality of Life and barriers faced by Stroke Survivors in the
Rural Eastern Free State**

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Declaration

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March 2017

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Abstract

Introduction: It is widely recognised that rehabilitation forms an integral part of the process to enable stroke survivors to achieve functional independence, community integration and quality of life. Environmental barriers may however negatively influence achievement of these goals.

Aim of the study: To describe functional, participation and quality of life outcomes as well as barriers experienced by stroke survivors in the catchment area of the Thebe District Hospital Complex.

Methods: A quantitative, descriptive study was conducted. Data was obtained from 38 participants who suffered a stroke and received care between 1 January 2012 and 31 December 2014 at the Thebe/Phumelela District Hospital Complex. In total 176 names were obtained from the data base. Lack of or incorrect contact details and high mortality rates left 43 participants of whom 38 consented to participate. The ICF core set for stroke was utilized to develop tools to collect data on activities, participation and environmental barriers. Quality of life was determined with the WHO QOL Bref. Descriptive analysis of data was done using an Excel spreadsheet.

Results: Functional and participatory outcomes were mostly limited to residential activities. Family relationships were good, but 66% of participants struggled to maintain intimate relationships. Community integration was limited with most participants unable to independently walk outside (55%), use public transport (55%) and drive (84%). Participation in social activities (66%), religious activities (63%), accessing services (71%), playing sport (89%), engaging in politics (66%), managing personal finances (61%), and accessing employment (74%) was difficult to impossible for many participants.

The majority (82%) of participants reported a quality of life ranging between neutral and very poor. Recurring depressive affect was found to influence 58% of participants on a regular basis. Social health had the lowest mean score (46.3) of the four quality of life domains.

The most severe environmental barriers perceived by participants included climate (82%), a lack of finances and assets (61%), mobility products (61%), as well as inability to access

public buildings (76%) and, transport- (61%), education- (79%), housing- (66%), and labour (82%) services, systems and policies.

The majority of participants (63%) received therapy for less than a month. Twenty one participants (55%) received follow up therapy at a local clinic. Few participants (11%) received vocational rehabilitation and no skills assessments, employer education or reasonable work accommodations were done.

Conclusion: Poor functional-, participatory- and quality of life outcomes were achieved by stroke survivors in the rural Eastern Free State. Environmental barriers and impairments impacted negatively on functional-, participatory-, and other outcomes of stroke survivors. Rehabilitation service provision requirements, as stipulated by the National Policy, were not met.

Recommendations: Establishing a stroke rehabilitation protocol is essential, ensuring a holistic approach by core disciplines from hospital discharge to community integration and productive activity through a model of multi sectoral collaboration. Accessibility of services to stroke survivors needs to be ensured through infrastructure development and sustainable transport solutions. Patient data systems must be optimised to allow accurate and efficient data retrieval.

KEYWORDS: STROKE, REHABILITATION, FUNCTION, PARTICIPATION, ENVIRONMENTAL BARRIERS, QUALITY OF LIFE.

Opsomming

Inleiding: Dit word algemeen aanvaar dat rehabilitasie 'n geïntegreerde deel vorm van die proses om individue wat 'n beroerte oorleef het te help om funksionele onafhanklikheid, integrasie in die gemeenskap en kwaliteit lewe te bereik. Omgewingsstruikelblokke kan moontlik 'n negatiewe impak op die verwerking van bogenoemde uitkomstê hê.

Doel van die projek: Om funksionele- en gemeenskapsintegrasie uitkomstê asook lewenskwaliteit van beroerte lyers, woonagtig in die Thebe Distriks Hospitaal Kompleks, te beskryf. Voorts is omgewingsstruikelblokke wat deur deelnemers ervaar word beskryf.

Metode: 'n Kwantitatiewe, beskrywende studie is uitgevoer. Data is verkry van 38 deelnemers wat beroertes oorleef het en gesondheidsorg ontvang het by Thebe/Phumelela Distriks Hospitaal Kompleks tussen 1 Januarie 2012 en 31 Desember 2014. 'n Totaal van 176 name is verkry vanaf die data basis. Beperkte- sowel as onakkurate kontak besonderhede asook 'n hoë vlak van mortaliteit het veroorsaak dat 43 deelnemers opgespoor kon word. Van hulle het 38 ingestem om aan die studie deel te neem. 'n Vraelys is ontwikkel gegrond op die "ICF core set for stroke", en is gebruik om data in te win rakende aktiwiteite, deelname en omgewingsstruikelblokke. Die WHO QOL Bref is gebruik om data in te win rakende kwaliteit lewe. Beskrywende analise van data is gedoen met Excel program.

Resultate: Funksionele- en deelname uitkomstê was meestal beperk to binneshuise aktiwiteite. Alhoewel familie verhoudings goed was het 66% van deelnemers probleme ervaar met intieme verhoudings. Integrasie in die gemeenskap was beperk. Deelnemers het probleme ervaar om onafhanklik buite te loop (55%), publieke vervoer te gebruik (55%) en te bestuur (84%). Deelname in sosiale aktiwiteite (66%), godsdiens aktiwiteite (63%), bereikbaarheid van dienste (71%), sport beoefening (89%), politieke aktiwiteite (66%) asook bestuur van persoonlike finansies (61%) en werk (74%) was moeilik of onmoontlik vir baie deelnemers.

Meeste deelnemers (82%) se lewenskwaliteit het gewissel van neutraal tot baie swak. Depressiewe affek het 58% van deelnemers op 'n gereelde basis geaffekteer. Sosiale gesondheid het die laagste gemiddelde waarde (64.3) van die vier areas van lewenskwaliteit getoon.

Omgewingsstruikelblokke wat die meeste probleme veroorsaak het vir deelnemers was klimaat (82%), 'n gebrek aan bates (61%) en mobiliteits produkte (61%), ontoeganklikheid van publieke geboue (76%), asook vervoer- (61%), onderwys- (79%), behuising- (66%), en arbeid (82%) dienste, sisteme en beleide.

Die meerderheid deelnemers (63%) het vir minder as n maand terapie ontvang. Een en twintig deelnemers (55%) het terapie ontvang by hul naaste kliniek. Min deelnemers (11%) het werks rehabilitasie ontvang terwyl geen deelnemers vaardigheids assesserings, werkgerers opleiding of redelike werks aanpassings ontvang het nie.

Gevolgtrekking: Swak funksionele-, deelname- en lewenskwaliteit uitkomste is bereik deur beroerte oorlewendes in die afgeleë gedeelte van die Oos Vrystaat. Omgewingsstruikelblokke sowel as fisiese beperkings het 'n negatiewe impak gehad op funksionele-, deelname-, en ander uitkomste van beroerte oorlewendes. Rehabilitasie dienste voldoen nie aan voorgestelde beleid stipulasies nie.

Aanbevelings: Dit is noodsaaklik om 'n beroerte rehabilitasie protokol te ontwikkel wat kan lei tot 'n holistiese benadering vanaf verskeie dissiplines. 'n Model van samewerking deur verskeie sektore word benodig om integrasie in die gemeenskap en produktiwiteit te verseker na ontslag vanaf die hospital. Bereikbaarheid van basiese dienste moet verseker word deur ontwikkeling van infrastruktuur asook ontwikkeling van volhoubare vervoer oplossings. Optimalisering van pasiënt data sisteme is noodsaaklik om akkurate en doeltreffende inwinning van data te verseker.

SLEUTELWOORDE: BEROERTE, REHABILITASIE, FUNKSIE, DEELNAME, OMGEWINGSSTRUIKELBLOKKE, LEWENSKWALITEIT

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Definition of terms

Activity: Activity as defined by the ICF “is the execution of a task or action by an individual” (WHO 2001: p10).

Community-based rehabilitation: “CBR is a multisectoral approach working to improve the equalization of opportunities and social inclusion of people with disabilities while combating the perpetual cycle of poverty and disability. CBR is implemented through the combined efforts of people with disabilities, their families and communities, and relevant government and non-government health, education, vocational, social and other services” (WHO 2016a).

Environmental Barrier: Environmental barriers are elements that form part of the “physical, social and attitudinal environment in which” an individual lives and functions, hindering progress and compounding disability (WHO 2001: p10).

Environmental Factors: Environmental factors are defined as the “physical, social and attitudinal environment in which” an individual lives and functions (WHO 2001: p10).

Impairment: Impairments as defined by the ICF refers to any loss of, or abnormalities in body functions or in body structure (WHO 2001).

Participation: Participation as defined by the ICF refers to an individual’s “involvement in a life situation” (WHO 2001: p10).

Quality of Life: “Quality of Life is an individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment” (WHO 1997: p1).

Rehabilitation: “Rehabilitation is a goal orientated and time limited process aimed at enabling an impaired person to reach an optimum mental, physical and social functional level, thus providing one with tools to change one’s life when and where necessary” (FSDOH 2006: p14).

Stroke: Stroke as defined by the World Health Organization (WHO) is damage to brain tissue as a result of an insufficient supply of oxygen and nutrients to a specific region of the brain, because of interruption of blood supply due to rupture or occlusion of a blood vessel (WHO 2016b).

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List of acronyms

| | |
|---------------|--|
| ADL | Activities of Daily Living |
| CBR | Community Based Rehabilitation |
| CSDPWD | Committee for Service Delivery to People with Disability |
| DOH | Department of Health |
| FSDOH | Free State Department of Health |
| FSDRSA | Framework and Strategy for Rehabilitation in South Africa |
| HRQOL | Health Related Quality of Life |
| ICF | International Classification of Functioning, Disability and Health |
| NDOH | National Department of Health |
| NGO | Non–Governmental Organisation |
| NRP | National Rehabilitation Policy |
| NSA | National Stroke Association of America |
| PHC | Primary Health Care |
| PWD | People with Disabilities |
| QOL | Quality of Life |
| WHO | World Health Organization |

Chapter 1

Introduction

1.1 Background

Stroke is one of the biggest causes of death and disability globally as well as in South Africa (Bertram, Katzenellenbogen, Vos, Bradshaw & Hofman 2013). In South Africa, it has remained one of the five highest causes of death in recent years and accounted for 5.1% of deaths in 2014. It is the 3rd highest cause of death in the Free State Province among all age and gender groups and the highest cause of death in males and females 65 and older. Diseases of the circulatory system cause the second highest number of deaths in the Thabo Mofutsanyane district where the current study was done (Stats SA 2015).

Mortality as a result of stroke is not the only burden. Healthcare and economic burdens exist due to non-fatal stroke causing long term changes in the lives of people affected (Bertram et al. 2013). Maredza, Bertram and Tollman (2015) estimated disability adjusted life years due to stroke to be 2,200 per 100,000 person years in rural South Africa. These burdens impact directly on health services as well as on the individual in terms of family and community life, financial and psychosocial factors (Connor & Bryer 2005). Non-fatal stroke often leaves a person with various impairments such as paralysis, incontinence, speech and/or language impairments, perceptual challenges and sensory disturbances of varying severity that in combination with environmental and personal factors can lead to activity limitations, participation restrictions and decreased quality of life (Teasell & Hussein 2013; Rhoda 2014).

Effective stroke rehabilitation programmes can assist a person to overcome or reduce the challenges of regaining function, participation and quality of life (Young & Forster 2007; Bryer, Connor, Haug, Cheyip, Staub, Tipping, Duim & Pinkney–Atkinson 2010). Broadly defined, the World Health Organization (WHO) and the United Nations Convention on the Rights of Persons with Disabilities (UN 2006) define rehabilitation as a process of enabling an individual in order to attain their optimal physical, sensory, psychological and social functional levels within their environments. Rehabilitation should provide people with disability, with the tools to achieve independence, self-determination and community reintegration (WHO 2010). Community integration is the ultimate outcome that rehabilitation service providers and people with disability should be working towards. This outcome is

achieved, as Sherry (2015) affirms, through intervening both in the environment and with the individual to address activity limitations and overcoming participation restrictions- this appears to be the major contribution of rehabilitation.

The Framework and Strategy for Rehabilitation in South Africa (FSDRSA) (NDOH 2013) and the National Development Plan (RSA 2013) continues to build on the platform created by the National Rehabilitation Policy (NRP) (DOH 2000). The build-up shows the South African Government's commitment to transforming the health system towards universal coverage through the primary health care (PHC) approach. These documents also recognize the importance of the rehabilitation component in bringing accessible healthcare to communities. Community level rehabilitation must assist people with disability (PWD) to have equal opportunities, through the principles of development, empowerment and social integration (DOH 2000; WHO 2010). The community based rehabilitation (CBR) approach aims at inclusion and full participation of people with disabilities in all aspects of life, and is suggested to form the basis of national rehabilitation service delivery programmes. The CBR strategy is to be supported by secondary and tertiary rehabilitation services, aligning practice guidelines with the United Nations Convention on the Rights of Persons with Disabilities (UN 2006) in bringing rehabilitation services to the community (NDOH 2013).

People with disability (PWD) should enjoy the benefits of having access and availability of all rehabilitation components in comprehensive service delivery. These components include medical-, social-, educational-, vocational-, and psychological rehabilitation and assistive devices must be available (NDOH 2013). PWD should be encouraged to participate in the management of the rehabilitation process with regard to planning and formulating policies, developing and implementation of programmes and on-going monitoring. Resources should be utilised optimally with regard to service delivery. The public sector should engage and work hand in hand with non-government organisations and the private sector to promote better service delivery. Rehabilitation programmes need to be monitored and evaluated according to norms, standards and indicators (DOH 2000; NDOH 2013).

However, providing rehabilitation and achieving community integration and participation outcomes, remains a challenge in South Africa and especially in rural communities (Wasserman, De Villiers & Bryer 2009; Bateman 2012; Ntamo, Buso & Long-Mbenza 2013; Visagie & Swartz 2016). Thus, achieving good health, quality of life, independence and economic self-sufficiency remains an up-hill battle for people living with the effects of stroke

every day. This is partly due to the impairments caused by stroke, but often hugely aided by environmental barriers.

Environmental factors can act as facilitators or barriers to function and participation. If, for example, a person has access to the necessary products such as healthy food and medication, technology such as a wheelchair, transport, and are not faced by prejudice and negative attitudes post stroke, the effects of impairments can be reduced (WHO 2001). But these, and a multitude of other environmental facilitators, are often not present; creating barriers to community integration and aggravating the experience of disability.

Accessing rehabilitation and addressing environmental barriers are directly impacted by an individual's ability to access financial resources. Numerous authors have argued the fact that poverty is both the cause and the consequence of disability (Parnes, Cameron, Christie, Cockburn, Hashemi & Yoshida 2009; Groce, Kett, Lang & Trani 2011). The relationship between poverty and disability can be described in the form of a downward spiralling circle, where poverty leads to disability which in turn leads to worse levels poverty as illustrated in Figure 1.1 (WHO 2011; Sherry 2015).



Figure 1.1: Negative cycle linking disability, poverty and vulnerability (Source: DFID, Poverty, Disability and Development 2000)

People with disability often end up living in sub-standard living conditions as a result of marginalization and poverty (WHO 2011). This might include aspects such as inadequate

housing, poor nutrition, a lack of access to clean water and sanitation as well as poor access to vital services such as healthcare and transportation. People with disability are more likely to lack education and economic opportunities, as well as be unemployed, as a direct result of social exclusion, marginalization and stigmatization; adding to the negative spiral of the poverty cycle (Trani, Bakhshi, Noor, Lopez & Mashkoor 2010; Groce et al. 2011). Further financial burdens confront families and people with disability as there are often costs involved relating to transportation, personal and medical care as well as assistive devices. These additional financial burdens increase the poverty risk of people with disability, with health expenditure often being catastrophic. Thus poverty and poor socio-economic circumstances can increase the effect of environmental barriers on activity limitations, decrease participation and negatively impact quality of life.

The FSDRSA (NDOH 2013) recognises challenges such as a lack of money, time, transport and a lack of staff and states that poor availability of rehabilitation services has led to scant rehabilitation follow up. Thebe/Phumelela District Hospital Complex consist of two district hospitals approximately 120km apart. Thebe District Hospital is the main institution in the complex with a catchment population from the communities of Harrismith, Tshiame, Warden and farming communities. Phumelela District Hospital is a small facility providing limited services according to the district hospital package, serving the catchment population of Vrede, Memel and surrounding farming communities. The secondary referral hospital for these two institutions is Mufumahadi Manapo Mopedi Hospital, 180km away from Phumelela and 60km away from Thebe respectively. The three hospitals mentioned serve a combined catchment population of 403506 over an area of 12521 km² (Stats SA 2015).

Currently at Thebe/Phumelela District Hospital Complex there is one physiotherapist and one occupational therapist. There is no permanently employed speech and language therapist or audiologist in the district. The closest medical orthotist and prosthetists is based in the town of Bethlehem. No outreach support is done to smaller hospitals by any professionals, meaning some patients will have to travel a distance of up to 300km one way in order to consult a professional. High vacancy rates and gaps in the core rehabilitation team hamper service delivery on a daily basis. With financial constraints in the Free State Department of Health, vacancy rates have gone up since the last audit in 2013 that indicated staggering vacancy rates of 30% for Occupational Therapists, 36% for Physiotherapists and 63% for Speech and Language Therapists (NDOH 2013). Currently no wheelchair repair workshops

exist in the whole of Free State. This has severe financial implications, as often wheelchairs that could have been repaired have to be replaced by a new chair. This is partly due to the fact that there are not sufficient parts available to repair chairs and skilled personnel to do so. Another challenge faced by Free State rehabilitation workers, is the inability to order from the national tender of wheelchairs. This hampers the possibility of ordering a wide range of products and parts. This heaps more pressure on long waiting lists for assistive devices, especially wheelchairs. Accessibility to rehabilitation services remains a challenge within the Free State, particularly rural areas.

1.2 Study Problem

Up to date, no evidence exists and no information could be found on the functional and participatory outcomes, quality of life and barriers faced by stroke survivors in Thebe/Phumelela District Hospital Complex in rural Eastern Free State. This lack of baseline information and evidence on the outcomes of stroke survivors and the barriers that they may face, hamper optimal rehabilitation programme development in the area. The current study evolved to gather and document some baseline information.

1.3 Research Question

What are the functional-, participatory- and quality of life outcomes as well as barriers experienced by stroke survivors in the catchment area of the Thebe District Hospital Complex?

1.4 Aim

The aim of the study was to describe functional, participatory and quality of life outcomes as well as barriers experienced by stroke survivors in the catchment area of the Thebe District Hospital Complex.

1.5 Objectives

- Determine functional outcomes of participants
- Determine participatory outcomes of participants
- Determine the quality of life of participants
- Determine environmental barriers that influence outcomes of participants

1.6 Motivation

The researcher, a service provider in the setting, desires to acquire knowledge of the impact stroke has on individuals and the daily struggles they live with. The researcher desires to be empowered by this knowledge, to be able to deliver a better and more holistic rehabilitation service to stroke survivors and people with disability in general.

1.7 Significance

The WHO Report on Disability identified a lack of reliable research and calls for research on rehabilitation and disability, as evidence based knowledge is necessary to guide policy makers in the development of appropriate programmes and assist service providers to choose suitable interventions (WHO 2011). The findings of the study should empower the management teams of Thebe District Hospital Complex and other local institutions with knowledge on outcomes of stroke survivors as well as barriers to be taken into account. This information can form a baseline to work from, to improve rehabilitation programmes in the setting, and strategies to overcome barriers, and assists with resource allocation for rehabilitation services in the study setting.

Studies on the activity and participation outcomes of stroke survivors and barriers faced by them have been identified for many South African settings (Wasserman et al. 2009; De Villiers, Badri, Ferreira & Bryer 2011; Rhoda, Mphofu & De Weerd 2011; Rhoda 2012; Rouillard, De Weerd, De Wit & Jelsma 2012; Joseph & Rhoda 2013; Mudzi, Stewart & Musenge 2013; Parekh & Rhoda 2013; Cawood, Visagie & Mji 2016). However, no such study could be identified for the Free State. This study can add to the national body of knowledge on outcomes of stroke survivors and barriers faced by them. No baseline data on quality of life, post stroke, in South Africa, could be identified. This study provides quality of life scores for participants and can thus make an important contribution in that regard.

1.8 Study framework

The International Classification of Functioning, Disability and Health (ICF) (WHO 2001) will be used as framework for the study since it allows in depth exploration of the complex interactions between health conditions, impairments, activities, participation and contextual factors. The ICF provides a framework for disability, presenting disability as a complex

interaction between health conditions, body functions and structures, activities, participation and contextual factors. The majority of data collected in the study was done with data collection tools based on the ICF. The interplay of the ICF components will be explored in Chapter two of this document.

1.9 Summary

Individuals who live in rural areas with the after effects of stroke face multiple barriers on various levels, including physical-, psychological-, emotional- and environmental barriers. The intersection of disability, poverty and rurality contribute to these multiple barriers making it extremely difficult for people with disability and their experience of disability. This may negatively impact the lives of individuals with regard to their ability to function and participate in everyday life situations. This may further lead to negative implications with regard to individuals' experience of quality of life. Comprehensive rehabilitation services within the community are required to impart positive outcomes and overcome barriers faced by people living with stroke. The rehabilitation department at Thebe/Phumelela District Hospital Complex encounters individuals with impairments caused by stroke regularly, with the vision of providing CBR and NRP guided rehabilitation. The current study evolved to determine the daily life outcomes and quality of life, as well as barriers faced by individuals with stroke. Providing this information should enable rehabilitation professionals to improve services in future and provide baseline information for monitoring and evaluation of future processes.

1.10 Study outline

Chapter one of this document provided the reader with background information regarding the study at hand. This included the aim and objectives of the study, the motivation for undertaking the study and the significance it may have in present and future. Chapter two presents a review of relevant literature, focused on stroke and the dynamic interplay that has been found between stroke and function, participation, quality of life and barriers faced. The methodology of the research is discussed in Chapter three. The results found in the study follow in Chapter four with a detailed discussion of the results thereafter in Chapter five. Conclusions and recommendations bring the document to a close in Chapter six.

Chapter 2

The literature review

2.1 Introduction

Disability as a result of stroke can lead to devastating effects in the life of an individual, which can impact on personal-, family-, social and community levels. Environmental barriers and personal factors can further aggravate the experience of disability. This review explores literature on the role of the environment and the impact of stroke on the body, activities and participation, as well as on quality of life, at the hand of the International classification of functioning, disability and health. In view of the vast body of literature on post stroke outcomes, quality of life after stroke and barriers to participation of stroke survivors, the research assignment nature of this study and the differences between high, middle and low income countries, the bulk of the literature reviewed focussed on publications from South Africa and Africa.

2.2 Stroke

Stroke is the second most common cause of mortality world-wide (Lozano, Naghavi, Foreman, Lim, Shibuya & Aboyans 2012). The global economic burden caused by stroke has been found to be significant and rising, demanding 3% of total healthcare system resources in the early 2000ths (Evers, Struijs, Ament, Van Genugten, Jager & Van den Bos 2004). According to current trends, it has been estimated that the global number of stroke survivors will rise to 70 million in 2030 (Maredza et al. 2015).

The burden of stroke is on the increase in low- and middle- income countries (Feigin, Forouzanfar, Krishnamurthi, Mensah & Connor 2014), which account for more than 80% of the global stroke burden (Johnston, Mendis & Mathers 2009; Sajjad, Chowdhury, Felix, Ikram, Mendis & Tiemeier 2013). Similarly the burden of stroke in Africa is high and growing. From 2009 to 2013 it is estimated that there has been an increase of 10.8% in stroke incidence and a 9.6% increase in stroke survivors in Africa (Adeloye 2014).

Stroke's rank as natural cause of death in South Africa varies from year to year but remained in the top five over the last six years (Stats SA 2015). Recent estimates indicate that rural South Africa has a burden of 33 500 strokes per annum for a population of some 13 million

people as found in the province of Mpumalanga (Maredza et al. 2015). In a rural South African sub-district, an estimated 842 strokes occurred over a time period of five years. A stroke incidence rate of 244 per 100,000 person-years was found with a crude mortality of 114 per 100,000 person-years (Maredza et al. 2015). The prevalence of stroke in the Eastern Free State region is unknown, however, stroke was ranked third highest as cause of natural death in the Free State in 2014 (Stats SA 2015).

Feigin et al (2014) explored stroke epidemiology through data from 58 studies done in high-income countries and 61 done in middle to low-income countries. According to them, the average age of stroke sufferers worldwide is 71 years. They found that 31% of strokes occurred in people aged younger than 64 years of whom around 80% lived in low-income and middle-income countries. In South Africa cerebrovascular diseases is the leading cause of death for people over the age of 65 and ranked tenth as cause of death for those between 44 and 64 years of age (Stats SA 2015). Maredza et al. (2015) also showed an increase in stroke incidence with age in rural South Africa. Their findings indicate a sharp increase in incidence after age 45. They found a male to female ratio of 1:1.6 (Maredza et al. 2015).

The outcome of stroke is not only seen in mortality rates; it is a debilitating condition that can have far reaching consequences on function and participation in life roles and might contribute to lifelong disability (Norrving & Kissela 2013). Before the impact of stroke on function, participation and disability is further explored these concepts are defined at the hand of the International Classification of function, disability and health (ICF) (WHO 2001), the study framework.

2.3 International Classification of Functioning, Disability and Health

Disability has been explained at the hand of various models over the years of which the medical and social models are probably the best known. The medical model presents that an individual's physical or mental limitations as a result of disease, trauma or any other health condition is the main cause of disability. According to this approach, disability is largely disconnected to contextual factors and the management of disability is aimed at cure. The medical model thus focuses on the specific individual and the impairments or limitations of the individual (Goodley 2011). On the other hand the social model views disability as a result of environmental, social and attitudinal barriers. These barriers prevent maximum societal participation of individuals with limitations, leading to discrimination. The Social Model

hence shows disability not as an attribute of an individual, rather stemming from a socio-political viewpoint, whereby society fails to adjust to meet the needs and aspirations of individuals with limitations, leading to the experience of disability. Management of disability in this context requires society at large to establish modifications in the physical and societal environment in order to facilitate full participation of people with disabilities (Goodley 2011). Standing alone both these approaches identify important issues around disability, but neither encompasses the full experience of disability which include the person, the impairment and the environment.

The International Classification of Functioning, Disability and Health (ICF) (WHO 2001) that is based on a biopsychosocial approach to disability, provides a way toward integrating the two opposing models of disability and approaching disability holistically. The ICF presents disability as the result of an individual's health condition and bodily impairments interacting with the context of the person's surroundings. It sees disability and function as part of a continuum. The ICF does not deem an individual disabled on the basis of the presence of a medical condition. Rather a detailed description of an individual's functioning in society informs the classification of disability. The ICF shows the complex relationship between health conditions, body functions and structures, activities, participation and contextual (environmental and personal) factors. In differentiating between impairments (abnormality in body function and structure) and disability (inability to perform activities and participate in life roles due to the interaction of impairments and contextual barriers) the ICF makes it clear that disability is a complex, multifaceted construct (WHO 2001).

Impairments, as defined in the glossary of terms, refer to abnormalities in or loss of body functions or body structure. "Body functions are the physiological functions of body systems (including psychological functions). Body structures are anatomical parts of the body such as organs, limbs and their components. Impairments are problems in body function or structure such as a significant deviation or loss" (WHO 2001: p10). Stroke causes abnormalities in the structure of the brain and can impact a number of body functions such as mental, sensory, voice and speech, genitourinary and neuromuscular function. These can negatively impact the individual's ability to perform every day activities.

Activity limitations or restrictions as a result of stroke may impact an individual's ability to learn and apply knowledge, perform general tasks and demands, communicate effectively,

mobilize and take care of him/herself. The inability to perform certain activities can lead to participation restrictions (WHO 2001).

When involvement in life situations is affected, individuals experience participation restrictions. An individual who has had a stroke could experience difficulty in participation in areas such as returning to work environment, socializing with friends, participating in leisure and sport, accessing the community and services delivered like shops, the post office or bank (WHO 2001).

These three areas are further impacted by contextual factors. Contextual factors form an individual's surroundings of everyday life, consisting of environmental factors and personal factors. Environmental factors are defined as the “physical, social and attitudinal environment in which” an individual lives and functions (WHO 2001: p10). Within this environment, an individual may experience facilitators or barriers to performing activities and participation. Thus someone with a stroke might struggle to participate in employment due to environmental barriers such as negative attitudes or prejudice and physical inaccessibility amongst others (WHO 2001).

Personal factors entail particular background features of an individual that do not form part of the person's health condition. This may include gender, race, age, education, profession and behavior patterns amongst other things. A stroke survivor who did not receive formal schooling may experience difficulty in returning to the labor market due to limited formal education, which can serve as a personal barrier to participation in the workplace (WHO 2001). Doug, Fleming and Kuipers (2008) identified personal barriers that stroke survivors commonly face through qualitative, semi structured interviews with 35 participants. They found, self-awareness, drug and alcohol abuse, low motivation and initiation and behavioural problems to be most common.

The ICF shows functioning and disability as an interactive and evolving process that needs to be looked at from a multi-perspective approach. The various components interact with one another to form a complex set of relationships as visually illustrated in Figure 2.1.

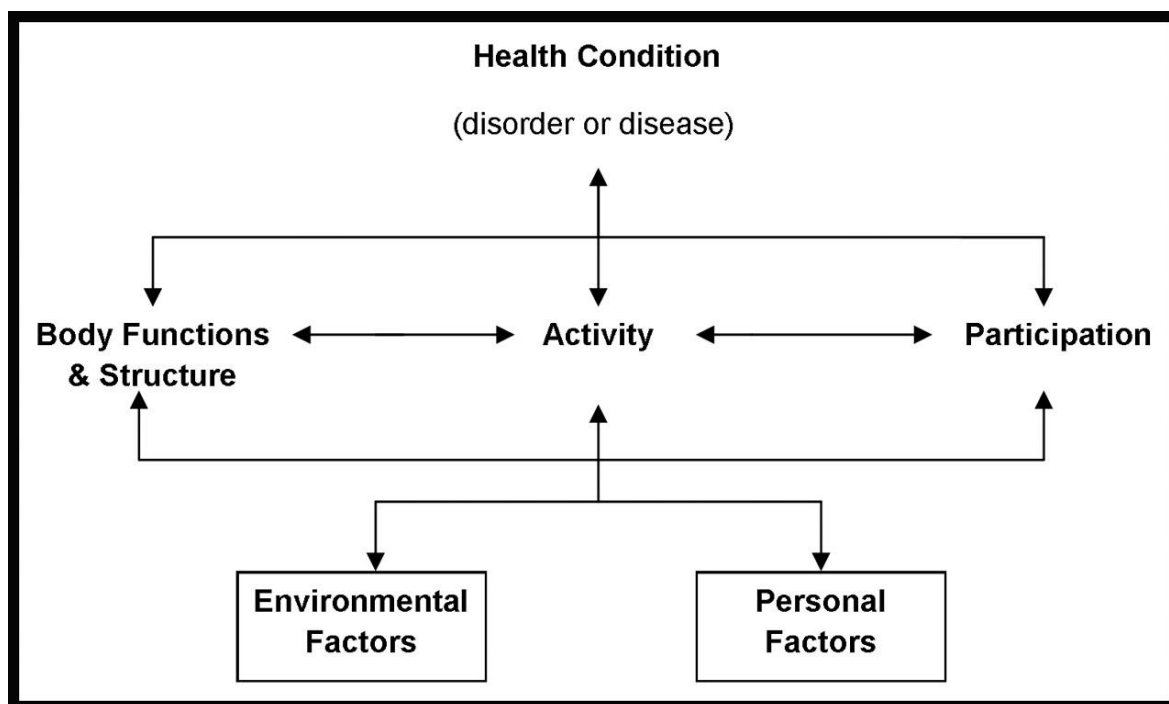


Figure 2.1: Interaction between the components of the ICF (Source: WHO 2001)

This entails that intervention in one of the domains has the probability to impact any of the other domains. For rehabilitation to be deemed successful it must address these different aspects such as impairments, activities, participation and contextual factors. It is for this reason that Sherry (2015) posits the major contribution of rehabilitation as in its approach to intervene in both environmental- and individual aspects. Therefore in this study the ICF was used as framework to assess different individuals' experiences of their daily activities, participation and environmental factors. The next section of this review of the literature takes a closer look at the impact of stroke on each of the domains and outcomes of stroke survivors in South Africa and Africa.

2.4 Impairments caused by stroke

Stroke is associated with a wide variety of symptoms. Sudden unilateral weakness of the face, arm or leg is the most common symptoms associated with stroke. The effects of stroke reach from mortality to severe impairments of different body structures and system functions (WHO 2016b). Impairments commonly associated with stroke as described by Tipping (2008), Gillen (2011), Flowers, Silver, Fang, Rochon and Martino (2013) and the National Stroke Association of America (NSA), (NSA 2016) are presented in short.

Dysphagia, aphasia and dysarthria are impairments frequently found with stroke (Flowers et al. 2013). Dysphagia as a result of stroke has an incidence of up to 50% (Tipping 2008; Flowers et al. 2013). Decreased bolus flow through the mouth and pharynx causes difficulty in swallowing. Dysphagia increases the risk of mortality as well as aspiration pneumonia in stroke survivors (Tipping 2008; NSA 2016).

Neurological damage as a result of stroke may lead to aphasia in up to 30% of acute stroke survivors (Flowers et al. 2013). Aphasia affects communication and language modalities, as an individual might be unable to comprehend or formulate these modalities. The different modalities include auditory comprehension, verbal expression, reading and writing, and functional communication (Gillen 2011). Dysarthria is a speech disorder caused by damage to the motor-speech area in the brain. Flowers et al. (2013) found that up to 42% of acute stroke survivors presented with dysarthria. Dysarthria may affect a stroke survivor by causing weakness of movement in relevant speech muscles. This leads to impaired speech production and articulation of words (Gillen 2011; Flowers et al. 2013).

Sensory disturbances occur frequently following stroke. This includes impairments of sensations such as pain, temperature, light- and deep touch as well as proprioception (Lawrence, Coshall, Dundas, Stewart, Rudd, Howard & Wolfe 2001). Rowe, Wright, Brand, Jackson, Harrison et al. (2013) found that up to 52% of stroke survivors experienced visual field loss. Hemianopia has been found to be the most common type of visual field loss, this occurs in approximately 66% of instances related to loss of visual field (Rowe et al. 2013). Hemianopia presents as loss of visual field on the same side as the hemiplegia, causing visual loss of the temporal half and nasal half of respective eyes (Gillen 2011).

Cognitive impairments can affect reason, memory, concentration, impulse control and abstract thinking. A person living with cognitive impairment after stroke may not be able to live life independently (Gillen 2011).

Hemiparesis and paralysis occurs in the body on the contra-lateral side of the injury to the brain. Muscle weakness may result in decreased mobility (Lawrence et al. 2001; Tipping 2008). Movement and coordination can be further hampered by spasticity or fluctuating muscle tone. Spasticity develops as a result of stroke to cerebral motor areas in up to 65% of stroke survivors (Tipping 2008). Increased tone in the limbs can lead to contractures if preventative practices are not followed (Tipping 2008; NSA 2016).

Incontinence has an incidence of up to 70% in people who had a stroke during the first month post stroke. This improves to 20% after 6 months (Tipping 2008). The inability to control bladder and/or bowel movements may lead to skin breakdown, social seclusion, depressive affect and increases the risk of institutionalisation of an individual (Tipping 2008; NSA 2016).

Impairments caused by stroke lead to various limitations in daily activities and participation of every-day life situations. Rehabilitation professionals have the ability to modify certain impairments in order to improve an individual's ability to participate. The environment however does play a critical part in realising participation. The following two sections will deal with participation and the environment respectively.

2.5 Impact of stroke on Activities and Participation

A number of South African studies that provided information on activities and participation post stroke could be identified. Some was cross sectional in nature and provided information for a single point in time (Rouillard et al. 2012; Mudzi et al. 2013; Cawood et al. 2016) while others were longitudinal, observational studies (Wasserman et al. 2009; De Villiers et al. 2011; Rhoda et al. 2011; Joseph & Rhoda 2013; Parekh & Rhoda 2013) that provide information at two or more points in time. Other studies such as Maleka, Stewart and Hale (2012) and Rhoda (2012) explored the participants' experiences through qualitative methods.

Two of the cross sectional studies were done in the Western Cape Province. Both assessed community dwelling stroke survivors more than 6 months post stroke, but in the case of Rouillard et al. (2012) the 46 study participants all received rehabilitation at an inpatient rehabilitation unit, while for the 53 participants in the study by Cawood et al. (2016) rehabilitation input varied from inpatient rehabilitation to none. With regard to activities Rouillard et al. (2012) found participants relatively independent with a median Barthel Index score of 90/100 (IQR 70 - 100). Cawood et al. (2016) had slightly lower Barthel Index figures with a median of 78/100 (IQR 53 – 95) and a mean of 70.5 (range 0 – 100). The studies agreed that toilet use, walking and transfers were mostly done independently and that bathing and stair climbing created most problems. Cawood et al. (2016) further found that feeding could mostly be done independently and wheelchair mobility created challenges while Rouillard et al. (2012) found that grooming caused little trouble.

Rouillard et al. (2012) assessed tasks related to participation with the Nottingham extended activities of daily living scale and found participation restrictions regarding housework (60.9%), food preparation (52.2%), shopping (80.4%), gardening (73.9%), going out socially (73.9%), use of public transport (65.2%) and driving (95.7%). 82.4% of participants indicated reduced ability or being unable to participate in leisure and social life, 58.7% of participants indicated reduced ability or being unable to participate in family responsibilities and 60.8% indicated reduced ability or being unable to participate in employment. Cawood et al. 2016 used the Stroke impact Scale to assess participation and found that participation was seriously affected by the stroke with participant's scoring and average of 31.3/100 (range 0-100). Questions on participation related to employment, social and family activities, recreation, spiritual activities and assisting others.

The third cross sectional study explored participation 12 months post stroke in a Gauteng population (n=114). Mudzi et al. 2013 used the ICF checklist as an assessment tool and found that participants were unable to carry out single and multiple tasks, lift and carry objects and walk or could do domestic activities without assistance. All had severe difficulty in basic and formal relationships and mild to moderate difficulty with participation in recreation and leisure activities.

All four longitudinal observational studies showed an improvement in activities over time. Three were also done in the Western Cape Province while the other one was done in KwaZulu-Natal. Joseph and Rhoda (2013) explored the functional status of 67 stroke survivors immediately after admission to an inpatient rehabilitation centre in the Western Cape Province and again at discharge. They found 23% functional improvement as indicated by a comparison of mean Barthel Index scores (from 58.85 to 81.59). Areas that were least affected were feeding, bathing and grooming, while stairs and mobility created the biggest challenges. De Villiers et al. (2011) studied a Western Cape population from a district hospital. They collected data on discharge and six months post discharge from 117 surviving participants. Using a different version of the Barthel Index where the maximum score is out of 20 not 100 they found an average increase of 10 from 7 to 17/20. Neither of these two studies explored participation.

Rhoda et al. 2011 studied a community base population in the Western Cape. They identified participants who received therapy at community health care centres and collected data at intake (n=100) and two (n= 88) and six months (n=76) post stroke. Barthel Index scores

showed that at 6 months follow up 17% were dependent, 22% needed moderate assistance, 41% needed minimal assistance and 20% were independent. Areas that created least functional problems included bladder and bowel function, transfers, mobility and toileting, while bathing, stairs and dressing created most challenges. Similar to Rouillard they assessed participation with the Nottingham extended activities of daily living. They found that housework (65.8%), shopping (69.7%), going out socially (69.7%), gardening (77.6%) use of public transport (67.1%) and driving (96.1%) were most affected.

Wasserman et al. (2009) studied a rural Kwa Zulu Natal cohort of 20 surviving stroke victims who were assessed at discharge and three months later. These participants received very little rehabilitation intervention, but some were visited by community-based workers trained in the management of Human Immune Virus, physiotherapists or a social worker. Participants showed functional improvement as measured by the 20 point modified Barthel Index from 5 to 14 (9). The areas that were least affected included transfers, mobility and, toileting. Participants indicated that their ability to do housework and participate in cultural and social activities was seriously affected (Wasserman et al. 2009).

Activities and participation of South African stroke survivors were also explored through qualitative research. Rhoda (2012) studied eight community dwelling stroke survivors in the Western Cape Province and Maleka et al. (2012) and colleagues explored the experiences of 32 stroke survivors in Gauteng and Limpopo. Participants in the study by Rhoda indicated that they experienced problems with walking, community mobility, self-care, grasp, accessing the community, using public transport, driving, social activities, work, shopping, keeping friendships and caring for others. They found the support of their children and therapy to be helpful. Similarly participants in the study by Maleka et al. (2012) identified loss of community mobility and social isolation as participation restrictions. In addition they identified a loss of previous roles and, loss of sustainable/productive livelihood as participation restrictions.

The situation of stroke survivors in other African countries seemed to be similar to that of those in South Africa. Rhoda, Cunningham, Azaria and Urimubenshi (2015) did a qualitative exploration of participation restrictions experienced by stroke survivors from the Eastern Cape Province of South Africa, Ruanda and Tanzania. They identified the following themes across the three countries: Social isolation, loss of friends, no participation in religious and spiritual activities, domestic activities, inability to drive, inability to work, loss of previous

roles. Urimubenshi (2015) further identified challenges with walking, self-care and domestic activities amongst the 10 Rwandan participants.

Three cross sectional studies from Africa were identified. Obemebe et al. (2013) studied 90 community dwelling stroke survivors, who had suffered a stroke more than a year before the study, in Nigeria. They measured activities with the Motor Assessment Scale and participation with the Reintegration to Normal Living Index. They found a mean Motor Assessment Scale score of 34.9/42 (sd 10.9; range: 18-42) and a Reintegration to Normal Living Index score of 57.3/100 (sd 23.5, range 39-90). Hamzat, Ekechukwu and Olaleye (2014) also measured community reintegration after stroke in Nigeria. Their population consisted of 52 stroke survivors who were assessed three months after hospital discharge with the Reintegration to Normal Living Index. They used a 4 point scale with total of 44 instead of 100. Participants had a mean score of 26/44 which convert to 59.02/100. Stroke survivors (n = 200) from Ghana experienced severe challenges in the domains of mobility (57.5%), paid or voluntary work (66%) as well as education and training (50.9%) (Amosun, Nyante & Wiredu 2013).

2.6 Environmental barriers

Persons with disabilities in developing countries face many environmental barriers in everyday life that hinder participation and life in society as a whole. Environmental factors are classified into five domains in the ICF as presented in Table 2.1.

Table 2.1: Five ICF environmental factor domains (Source: WHO, 2001)

| Domain | Environmental Factors |
|-------------------------|--|
| Domain 1: | |
| Products and technology | <ul style="list-style-type: none"> • Personal consumption i.e. Food, water and including medication • Indoor and outdoor mobility and transportation • Communication • Education • Employment • Culture, recreation and sport • Practice of religion and spirituality • Building products and technology of buildings • Land development • Assets • Design, construction and building products and technology of buildings for private use. |

| | |
|--|--|
| It is important to note that products and technology include assistive technology. For example products and technology for personal mobility include devices such as crutches and wheelchairs. | |
| Domain 2: Natural environment and human changes made to the environment | <ul style="list-style-type: none"> • Physical geography • Population • Flora and fauna • Climate • Natural events • Human-caused events • Light • Time-related changes • Sound • Vibration • Air quality |
| Domain 3: Support and relationships | <ul style="list-style-type: none"> • Immediate family • Extended family • Friends • Acquaintances, peers, colleagues, neighbours and community members • People in positions of authority • People in subordinate positions • Personal care providers and personal assistants • Strangers • Domesticated animals • Health professionals • Health-related professionals |
| Domain 4: Attitudinal environment | <ul style="list-style-type: none"> • Immediate family members • Extended family members • Friends • Acquaintances, peers colleagues, neighbours and community members • People in positions of authority • People in subordinate positions • Personal care providers and personal assistants • Strangers • Health professionals • Health-related professionals • Societal attitudes • Social norms, practices and ideologies |
| Domain 5: Services, systems and policies | <ul style="list-style-type: none"> • Production of consumer goods • Architecture and construction services, systems and policies • Open space planning services, systems and policies • Housing services, systems and policies • Utilities services, systems and policies |

- Communication services, systems and policies
- Transportation services, systems and policies
- Civil protection services, systems and policies
- Legal services, systems and policies
- Associations and organizational services, systems and policies
- Media services, systems and policies
- Economic services, systems and policies
- Social security services, systems and policies
- General social support services, systems and policies
- Health services, systems and policies
- Education and training services, systems and policies
- Labour and employment services, systems and policies
- Political services, systems and policies

A very important environmental factor are assets, defined in the ICF as “products or objects of economic exchange such as money, goods, property and other valuables that an individual owns or has right of use” (WHO 2001:181). Lives affected by poverty are one of the root causes of barriers faced by persons with disabilities. Poverty impacts all other domains as described by Cawood and Visagie (2015). Hence Duncan, Sherry, Watson and Booie (2012) conclude that many persons with disabilities in rural South Africa are subject to much environmental exclusion relative to multidimensional poverty. For instance someone who had a stroke might need to access health care for chronic medication and therapy, might need a wheelchair, might need a wheelchair accessible dwelling and community, might struggle to concentrate and thus function in a group or with noise distraction, might need assistance from social services and transport services. Each of these has economic consequences and is easier to obtain or deal with when a person has adequate assets. As a component of healthcare, rehabilitation may possibly be limited in addressing the full range of these activities; it is however a critical precondition to enable access to all other rights (Sherry 2015).

Grut, Mji, Braathen and Ingstad (2012) describe in a case study how the interaction of a number of environmental barriers leads to poor health outcomes in a rural South African setting. Qualitative in-depth interviews were done with 24 persons with disability and their families. Although all their participants did not have a stroke, the evolving picture can fit any person with an array of impairments as can be caused by stroke. Grut et al. (2012) identified social, political and cultural barriers. They further lead that, a lack of knowledge on how to acquire and sustain personal health, are major barriers in South Africa. These barriers have been formed through years of social, cultural and historical forces.

Grut et al. (2012) and Vergunst, Swartz, Mji, MacLachlan and Mannan (2015) found various environmental barriers experienced by individuals with disability in the Eastern Cape Province of South Africa. Accessibility to the nearest healthcare clinics were found to be a barrier as the distance people had to travel was very far for some. Most roads were gravel roads in a poor condition, with in some places no paths to access roads. No clean and safe drinking water was available to some neighborhoods as well as no electricity. Public transport could only be found on main roads, making it very hard to reach. This barrier to transport was found to be worsened by the cost of transport, as an extra fee has to be paid for a person travelling with a wheelchair. Attitudes also play a role with people who did not behave in a “socially acceptable” manner, and were often not allowed on the bus or taxi. An alternative to transport and a wheelchair was found in a wheelbarrow, indicating a shortage of assistive devices and assets (Grut et al. 2012; Vergunst et al. 2015). South African studies that focused on stroke survivors, specifically confirm the barriers caused by transport challenges (Maleka et al. 2012; Cawood & Visagie 2015)

Low and no family income were found to be barriers. Unemployment and poor job opportunities has led to a tendency of migrant labor, leaving less people at home to contribute to daily life. The disability grant that individuals receive was found to be the family income of some families. Some people with disability did not receive a disability grant due to the lack of resources in the area, not being issued with an identity document at birth, thus not being able to access a disability grant. Grut et al. (2012) identified the need for infrastructure development that includes roads, transport, safe drinking water, electricity and sanitation.

Urimubenshi & Rhoda (2011) researched barriers faced by stroke survivors in Rwanda. A qualitative phenomenological approach was utilized to interview 10 participants. Three major themes on the environmental barriers experienced by stroke survivors in Rwanda were identified. These were physical, attitudinal and social barriers.

Emerging sub themes under social barriers included a lack of social support and inaccessibility to rehabilitation services. Lack of support from relatives and decreasing support as time went on after stroke were reported as barriers. Accessibility to rehabilitation services was found to be a predicament. This was due to immobility, living far from health facilities and the high cost of transport. Money, as a resource, was also found to be a barrier, as little income had to cover mounting expenses (Urimubenshi & Rhoda 2011).

Negative attitudes of others towards stroke survivors created attitudinal barriers, as reported by participants. Although not frequent, negative attitudes were perceived by some participants. An example of this was that some members of the participants' community believed that stroke survivors had been punished by God (Urimubenshi & Rhoda 2011).

The sub themes relating to physical barriers were inaccessible pathways and infrastructure as well as toilets (Urimubenshi & Rhoda 2011). Inaccessible pathways included gravel roads with large stones and stairways. Walking far distances was a problem for some, as they became tired and only had a stick, creating a need for appropriate assistive devices. Toilets were found to be inaccessible to participants and coping strategies had to be made.

Cawood and Visagie (2015) utilized a mixed method descriptive study to research environmental barriers experienced by stroke survivors (n=53) in the Western Cape. The International Classification for Functioning, Disability and Health core set for stroke was utilized to collect quantitative data. A qualitative phase was used to contextualize and explore quantitative findings. Findings indicated that products and technology provided significant barriers. A very large percentage of participants (89%) experienced a lack of assets of which affordability of rent, telephone services and food was mentioned. Products and technology for daily living was found to be a barrier for 77% of participants. Transport problems created barriers to community participation for 80% of participants. Public transport problems included inaccessible infrastructure, impatient drivers that were unwilling to wait and assist, transport areas being far and inaccessible and high costs to accommodate extra space for assistive devices. Communication products provided barriers to 64% of participants, mostly due to unaffordability of phones (Cawood & Visagie 2015).

The natural environment played a significant role as 71% experienced geographical surroundings as a barrier. Uneven, rocky and sandy surfaces as well as potholes made mobility in the community difficult. The stroke survivors from Limpopo who participated in the study by Maleka et al. (2012) also described slopes and hills as barriers caused by the natural environment. Societal attitudes (53%) and community attitudes (47%) were perceived as barriers by almost half of the participants. With regard to services, systems and policies barriers were perceived with housing (70%), communication (63%), transport (88%), and social services (87%) (Cawood & Visagie 2015).

2.7 Quality of life

Overall quality of life as well as health related quality of life (HRQOL) data is limited in South Africa (Rhoda 2014). No studies that provide baseline data on quality of life (QOL) of stroke survivors in South African settings could be identified. Badaru, Ogwumike and Adeniyi (2015) found in a review of 19 articles from African countries that health related quality of life decreased significantly after stroke. The studies they reviewed reported mean health related quality of life scores after stroke that varied from around 50% to 70%. The severity of the stroke, loss of function and depression had the biggest negative impact on quality of life. Rehabilitation post stroke significantly improved health related quality of life (Badaru et al. 2015).

Rhoda (2014) performed an observational, longitudinal study and collected data from 73 stroke patients that were conveniently sampled in peri-urban areas of the Western Cape, South Africa. The EQ-5D was utilized to collect data regarding quality of life, while the Rivermead Motor Assessment Scale and the Barthel Index were used to determine functional outcomes respectively. Overall health-related quality of life was found to be decreased and significantly impacted by urinary incontinence. The study found mobility and self-care problems existed with almost 35% of participants. Every day activities were problematic to 42% of participants and almost 38% of participants presented with anxiety and depression (Rhoda 2014).

Hamzat, Al-Sadat and Jahan (2014) utilized a prospective observational study in order to determine HRQOL predictors amongst 223 stroke survivors in Nigeria. The researcher utilized the stroke impact scale 3.0, modified Rankin scale, Barthel index and Beck depression inventory scales to collect data. The study found motor impairment, disability and depression as independent predictors of HRQOL (Hamzat, Al-Sadat et al. 2014).

Overall QOL can be affected by physical, psychosocial, affective and cognitive aspects (Kranciukaite & Rastenyte 2006; Jelsma, Mkoka & Amosun 2008; Ostwald 2008; Owolabi 2011). Thus QOL needs to be measured via a multi-dimensional approach including at least the four domains i.e. of physical, psychological, social and environmental health (WHO 1995).

The social aspect focusses on family and social contact and sexual relationships.

Psychological aspects include depression and the subjective perceptions of individuals on the QOL and health they enjoy. Obembe, Boladale, Johnson, Agunbiade and Emechete (2013) researched post stroke depression under 90 stroke survivors from Nigeria with the Hamilton depression scale. The study found that 96% of participants had mild post stroke depression. In another Nigerian study, Fatoye, Mosaku, Komolafe, Eegunranti, Adebayo et al. (2009) found almost 40% of 118 participants presented with significant post stroke symptoms of depression. Predictors of depressive symptoms were cognitive deficit, paresis and low education.

The physical aspect points toward symptoms related to disease such as the severity of the stroke, mobility and self-care (Carod-Artal, Egido, González & de Seijas 2000; Jelsma et al. 2008). Abubakar and Isezuo (2012) utilized a cross-sectional and descriptive correlational design to determine HRQOL of 62 stroke survivors in Nigeria. The stroke Impact scale-16 was utilized to determine HRQOL. They found poor functional status and depression to be independent determinants of poor quality of life in the lives of stroke survivors.

Quality of life is also influenced by environmental barriers to participation. Jelsma and company explored QOL of 601 participants in Cape Town, SA through group discussions and found that individuals living in low socioeconomic communities perceived the environmental domain to affect their quality of life most severely (Jelsma et al. 2008). Other environmental factors which impact QOL post stroke includes food security, access to medical services, owning a brick home, access to water, electricity and sanitation (Jelsma et al. 2008). Personal factors also have the ability to impact on the QOL of stroke survivors.

Hawthorne, Herman and Murphy (2006) collected data on quality of life with the WHOQoL Bref in an Australian population based sample. They found mean quality of life scores for all four domains to be between 70 and 75. Skevington and McCrate (2012) determined baseline figures for the four domains in the United Kingdom. They included participants with different diagnoses, including a stroke group and a group who they describe as well. Their findings as presented in Table 2.2 shows similar mean scores amongst the healthy group as the Australian study. It also shows lower mean quality of life scores for those with stroke than their healthy counterparts in all four domains. The biggest difference was in physical health (16.94) and the smallest one in environmental health (6.73).

Table 2.2: Mean quality of life domain scores from international settings

| | | Mean scores | | | |
|--|-----------------------|-------------|---------------|--------|-------------|
| | | Physical | Psychological | Social | Environment |
| Australia (Hawthorne et al. 2006) | Population (n=252) | 73.5 | 70.6 | 71.5 | 75.1 |
| United Kingdom (Skevington & McCrate 2012) | Well (n=141) | 75.41 | 70.21 | 71.37 | 72.26 |
| | Stroke (n=19) | 58.47 | 51.68 | 60.39 | 65.53 |

Interest has grown in measuring stroke survivors' QOL. Information on QOL combined with information on physical impairments can be used to assess the outcomes of therapeutic and rehabilitation interventions effectiveness (Kranciukaite & RastenYTE, 2006; Mannan & Turnbull 2007).

2.8 Rehabilitation

2.8.1 Rehabilitation in South Africa

The National Rehabilitation Policy (NRP) (DOH, 2000), helped lay the foundation for rehabilitation services in South Africa by indicating the South African Government's commitment to the Primary Health Care (PHC) approach and giving recognition to the rehabilitation component of PHC in bringing accessible healthcare to communities. The NRP identified the need to strengthen and restructure rehabilitation services in order to improve accessibility of services to the community (DOH, 2000). The South African Government has since moved on to develop the Framework and strategy for disability and rehabilitation services in South Africa 2015 – 2020 (FSDRSA). Similar to the preceding NRP, the FSDRSA aims to deliver rehabilitation services to people with disability through the community based rehabilitation (CBR) approach (NDOH 2013).

CBR focusses on inclusion and equalisation of opportunities for people with disability, in all aspects of life, by approaching solutions in a co-ordinated way across multiple sectors. Various role players are seen as an essential part in realising independent functioning of people with disabilities. These include the sectors of health, education, social development, public works, transport, human settlements as well as other sectors and Non-Governmental

Organisation (NGOs). The CBR Matrix, as presented in Figure 2.2, displays the five core components that underpin the strategy. This includes health, education, livelihoods, social life and empowerment (WHO 2010).

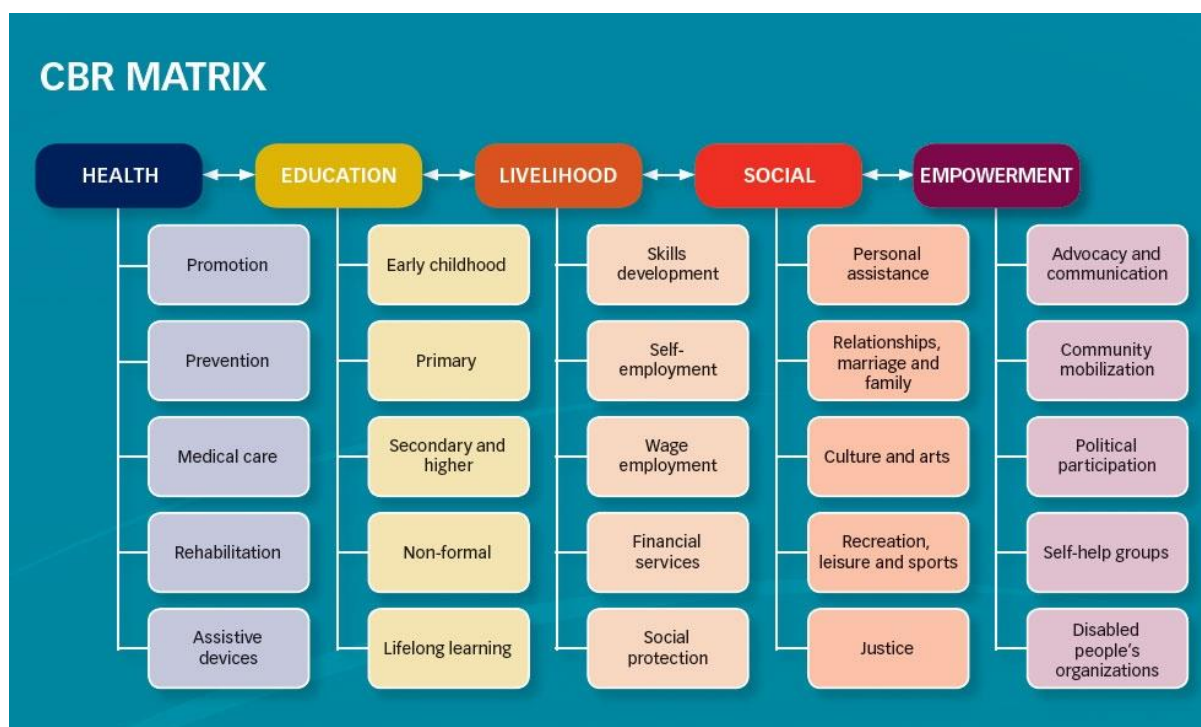


Figure 2.2: The CBR Matrix (Source: WHO 2010)

The FSDRSA established a framework for rehabilitation services to function optimally in South Africa. This includes a core professional rehabilitation service provider team that includes the following:

- Audiologist
- Medical Orthotist and Prosthetist
- Occupational therapists
- Physiotherapist
- Speech and language therapist

According to the FSDRSA services at primary level facilities should include screening, assessment and treatment of a person with various impairments, home visits, promotion and prevention activities, training of community health workers, screening and referral for vocational rehabilitation, inclusion of persons with disabilities in planning strategies, assistance to day care and other residential facilities, assessing for and issuing minor assistive devices and providing wheelchair repair services amongst other activities. The FSDRSA identified challenges in rehabilitation service delivery throughout South Africa which it aims

to rectify through the CBR approach. People living in poverty, particularly living in rural areas, face the reality of having the least access to rehabilitation services and healthcare as a whole (NDOH 2013). Further challenges included:

- The medical model approach still exists in practice, resulting in poor accessibility to services - more so in rural areas.
- Rehabilitation and disability services are delivered with minimal integration of other priority health programmes and poor intersectoral collaboration.
- Poor availability of rehabilitation services has led to scant follow up in the rehabilitation process of many people.
- Transport has been found to be inaccessible and unaffordable to people with disability.
- Inaccessible infrastructure at facilities that do provide services, remains a challenge.
- Poor availability and insufficient provision of assistive devices.
- Healthcare providers have a lack of awareness and knowledge regarding the lives of people with disabilities. Negative attitudes towards people with disability still exist.
- Poor resource allocation due to unknown effectivity of rehabilitation services across all levels of service.
- High vacancy rates and gaps in the core rehabilitation team hampers service delivery (NDOH 2013).

2.8.2 Rehabilitation in the Free State Province

Currently the Free State Rehabilitation Policy (FSDOH 2006) directs rehabilitation services in the Thebe/Phumelela District Hospital Complex. The policy is informed by the National Rehabilitation Policy (NRP) (DOH 2000). The National Rehabilitation Policy (DOH 2000), indicates that community level rehabilitation must assist people with disability to have equal opportunities, through the principles of development, empowerment and social integration as underscored by CBR principles (DOH 2000; WHO 2010).

The NRP guides rehabilitation services to be accessible, affordable and equitable. There should be a balance in service delivery between community- and institution-based rehabilitation. The two approaches complement each other and both play an important role in the rehabilitation process. People with disability (PWD) should enjoy the benefits of having access and availability of all rehabilitation components in comprehensive service delivery.

These components include medical-, social-, educational-, vocational-, and psychological rehabilitation and assistive devices must be available. PWD should be encouraged to participate in the management of the rehabilitation process with regard to planning and formulating policies, developing and implementation of programmes and on-going monitoring. Resources should be utilised optimally with regard to service delivery. The public sector should engage and work hand in hand with non-government organisations and the private sector to promote better service delivery. Rehabilitation services and resources should be provided to PWD to ensure that people work towards and achieve independence, physically, socially and economically so that social integration and participation is achieved. Rehabilitation programmes need to be monitored and evaluated according to norms, standards and indicators (FSDOH 2006).

Adding to the NRP outcomes of social integration and equalisation of opportunities, rehabilitation should assist PWD to reach a life of quality, independence, economic self-sufficiency and achieve fulfilment in reaching one's full potential. Up to date, no evidence exists and no information could be found in literature, indicating implementation of NRP guidelines as presented.

2.9 Summary

Literature has revealed that the burden of stroke in Africa as well as globally is high and on the increase, particularly in low- and middle income countries. Stroke remains one of the top causes of death and disability in South Africa and in the Free State Province. Impairments identified as commonly associated with stroke include dysphagia, aphasia, dysarthria, sensory disturbances, hemianopia, cognitive impairments, hemiparesis and incontinence. Impairments along with other factors lead to various limitations in activities and participation.

Literature indicated functional and participatory outcomes post-stroke were limited to residential activities. It seems as if stroke affected the ability to participate more than it affected performing activities. Activities such as bathing, carrying objects, stair climbing and mobility, were most affected. The aspects of participation most severely affected included community mobility, leisure activities and social life, shopping, employment and work, public transport and driving. Environmental factors possibly added to participation restrictions.

Several environmental factors seem to be a recurring theme as perceived by individuals with stroke and disability in rural areas of South Africa. Money and assets remains an extremely significant barrier to participation of people with disability. Lack of communication devices and resources seem to have posed significant challenges. A lack of basic services such as water, sanitation and electricity pose barriers to many to date. Furthermore the natural environment poses significant barriers with regard to uneven surfaces and pathways as well as poor infrastructure regarding roads. Transport seems to be one of the biggest barriers to most. Furthermore stroke survivors often experience attitudinal barriers from their respective communities and society as a whole. These barriers as well as the impairments, activity limitations and participation restrictions might impact the quality of life experienced by the stroke survivor.

No baseline data on QOL of stroke survivors in South African settings could be identified. Determinants of poor quality of life in the lives of stroke survivors included motor impairment, disability, depression, poor functional status and depression to. Determined predictors of depressive symptoms among stroke survivors were cognitive deficit, paresis and low education.

Chapter 3

Methodology

3.1 Introduction

Chapter 3 describes the various components of methodology followed by the researcher. It commences with an explanation why a quantitative descriptive design was chosen. Then the reader is introduced to the Thebe/Phumelela District Hospital Complex, in the Eastern Free State, where the study was done. The process of, and challenges with, locating study participants are described. The data collection instruments (adapted ICF core set for stroke and WHO QOL Bref) are explored, as is the processes of training the research assistant, pilot study and data analysis. Finally issues pertaining to rigor and ethical aspects are presented.

3.2 Study design

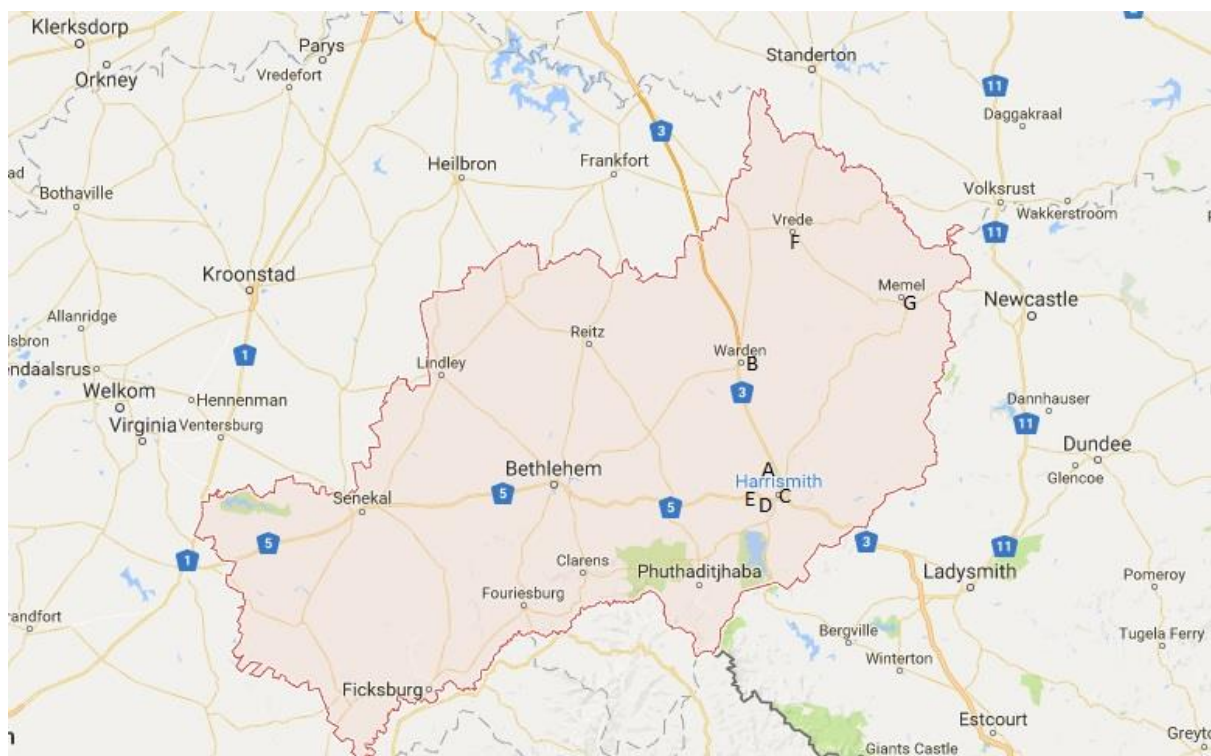
For the purpose of this study, the researcher conducted a quantitative, descriptive study. In descriptive studies participants and variables are observed and described, without any intervention. Descriptive studies can be utilized by researchers to quantify problems; in this instance it served to help quantify the extent of environmental barriers faced and the outcomes achieved by stroke survivors in the study setting. This might produce useful information that can assist with resource allocation, planning and delivering of appropriate health care and rehabilitation services to stroke survivors (Joubert & Ehrlich 2007).

3.3 Study setting

The study was conducted at Thebe/Phumelela District Hospital Complex and surrounding clinics (see Table 3.1 and Figure 3.1) serviced by the complex. This complex is located in the Eastern Free State. The complex is fed by a large catchment area. Clinics in the areas are based in very rural settings with minimal resources and poor infrastructure in terms of roads and building facilities. Thebe District Hospital, in Harrismith, is the only facility in the sub-district that has rehabilitation professionals as described in Chapter 1. The facility provides outreach rehabilitation services to the different rural communities within this vast area as indicated in Figure 3.1. Thebe District Hospital is a government funded facility of which clients are known to be of a lower socio-economic standing. Services are rendered via a Primary Healthcare approach, emphasizing community based service delivery programmes.

Table 3.1: Distance of clinics from Thebe District Hospital

| Name of Clinic | Distance from Thebe District Hospital |
|----------------------------------|---------------------------------------|
| A. Lesedi Clinic | 10 km |
| B. Thusa Bophelo Clinic | 55 km |
| C. Harrismith Town Clinic | 5 km |
| D. Tshame B Clinic | 20 km |
| E. Makgolokoeng Clinic | 20 km |
| F. Bophelong Clinic | 100 km |
| G. Memel Clinic | 150 km |

**Figure 3.1: Map of Thebe/Phumelela District Hospital Complex service delivery area**

3.4 Study population

The study population consisted of all stroke survivors that received care at Thebe District Hospital and the surrounding clinics in the time period of 1 January 2012 to 31 December 2014.

3.4.1 Inclusion criteria

People were included in the following instances:

- Patients with a confirmed diagnosis of stroke by a medical doctor. Diagnostic tests such as brain scans are not routinely done in the study setting, thus diagnosis of stroke was based on clinical assessment by doctors and not investigative testing.
- Patients 18 years and older.
- Patients able to understand and speak English, Sotho or Zulu. These are the three languages most commonly spoken in the geographical area and the research assistant's spoken languages.
- Patients who have given written consent to participate in the study.

3.4.2 Exclusion criteria

People were excluded in the following instances:

- Patients diagnosed with stroke who have any other form of physical disability i.e. amputation, spinal cord injury or traumatic brain injury. The additional impairments might impact their function, participation and barriers experienced in different ways to stroke.
- Patients diagnosed with stroke and treated at Thebe/Phumelela District Hospital Complex, who live outside of the Thebe/Phumelela District Hospital Complex catchment area.

3.5 Sampling and participants

Free State Department of Health granted the researcher permission to access names and contact details of stroke survivors that received care at Thebe/Phumelela District Hospital Complex in the time period of 1 January 2012 to 31 December 2014.

The researcher intended to utilize proportional stratified randomized sampling in order to ensure the sample is representative of the total population (Joubert & Ehrlich 2007). The researcher decided to sample approximately 50 participants after consulting a statistician. Due to the time consuming nature of the data collection process and the allocated time frame, this number was deemed enough to still provide valid results. The sample size was not calculated scientifically, and is a limitation of the study. In case the total population was found to be 50 participants or less, the entire population would be studied (Joubert & Ehrlich 2007).

The population was determined by accessing the patient database at Thebe/Phumelela District Hospital Complex. All stroke victims who received care between the time period of 1 January 2012 to December 2014, within the complex was identified. A total of 176 names were obtained, of whom six were excluded because they lived outside of the Thebe/Phumelela District Hospital Complex catchment area. The remaining 170 names were stratified according to the clinic in the specific geographic area where they lived and which they should attend as presented in Table 3.2.

Table 3.2: Identification of participants

| Area | Clinic | Geographic area | Stroke Victims identified | Could not be contacted | Diseased | Declined | Number excluded | Participated in study |
|------|----------------------|-------------------|---------------------------|------------------------|----------|----------|-----------------|-----------------------|
| A | Lesedi Clinic | Intabazwe | 57 | 16 | 19 | 2 | 1 | 12 |
| B | Thusa Bophelo Clinic | Ezenzeleni | 35 | 7 | 14 | 1 | 0 | 5 |
| C | Bophelong Clinic | Vrede | 8 | 13 | 6 | 0 | 1 | 4 |
| D | Town clinic | Harrismith | 31 | 0 | 5 | 0 | 2 | 7 |
| E | Tshiame B Clinic | Tshiame B | 31 | 12 | 9 | 1 | 0 | 7 |
| F | Makgolo koeng Clinic | Makgolo koeng | 8 | 6 | 4 | 1 | 1 | 3 |
| G | Zamani Clinic | Memel | 0 | 4 | 7 | 0 | 0 | 0 |
| H | Outside catchment | Outside catchment | 6 | - | - | - | 6 | - |
| | Total | | 176 | 58 | 64 | 5 | 11 | 38 |

Due to a high mortality rate and incomplete information from the data base, finding the stroke survivors who ultimately participated in the study was more difficult and time consuming than originally anticipated. All possible participants on the list were first contacted

telephonically. A total of 128 families were phoned as the data base did not contain phone numbers for the other 42. Out of the 128 numbers phoned, 34 participants were contacted and 37 were found to be an incorrect number. This left 79 possible participants with only addresses to follow up. The researcher contacted the Community Work Programme community health workers' coordinators in each geographic area to assist in locating participants in respective areas. Community health workers visited the respective addresses and contacted an additional 9 participants. After a comprehensive door to door search of the addresses found on the data base the following were found: A total of 64 were deceased, 58 people could not be contacted or located as addresses and telephone numbers were incomplete or incorrect and 5 had to be excluded in terms of selection criteria for this study. Ultimately 43 stroke survivors that met the inclusion criteria of the study could be located.

The 43 possible participants were provided with letters containing information about the study. This was done with the help of the community health workers. The research assistant followed up with a telephone call to discuss the contents of the letter and determine willingness to participate. This process was followed in order to facilitate well informed decisions by possible participants. Five people who were eligible to take part in the study declined participation, leaving the researcher with 38 participants who agreed to participate. Due to the fact that the population was less than 50, the entire population was used as participants.

3.6 Research assistant

The researcher identified a research assistant who was able to speak and read English, Zulu and Sotho. The research assistant was trained by the researcher to interview participants and assist with the data collection process. The assistant is a data capturer by profession, working within the primary healthcare setting. Acting as research assistant in the study provided him with valuable experience and knowledge of outreach services in the rural areas.

The assistant was trained one-to-one with regard to interviews and using the data collection tools. The training entailed explaining and understanding the data collection tools, the interview process, documenting findings and ethical aspects.

To ensure competency, the assistant practiced and was tested on how he presented the questionnaires to the researcher in a simulated situation, thus assuring correct delivery of

questions. Verbal feedback and corrections were given after conducting the practice session. Documentation was checked to ensure data sets were completed in full and any misunderstandings were clarified. The full data collection process was then conducted by the research assistant in two pilot interviews under the supervision of the researcher to provide consistency and guidance.

3.7 Data collection instruments

A demographic questionnaire (Appendix 1) was developed by the researcher to collect demographic data, medical data, and data on the rehabilitation process. Information from DiBendetto, Lewis & Conroy (1999) was used to develop the questionnaire.

An ICF based questionnaire on activities and participation (Appendix 2) was developed by the researcher, utilizing the comprehensive ICF core set for stroke (Geyh, Cieza, Schouten, Dickson, Frommelt, Omar, Kostanjsek, Ring & Stucki 2004). The language used in the original tool was adapted to the local colloquial English in order to ensure that participants understood the questions. The questionnaire was used to assess participants' activities and participation outcomes. It focused on communication and cognitive participation, mobility, self-care, domestic life, relationships, community integration and productive activity. Participants were asked to choose the option that described their ability to perform certain tasks to the best of their abilities. Options available included no difficulty, moderate difficulty, severe difficulty, not able to perform task and not applicable.

The questions on environmental barriers from the comprehensive ICF core set for stroke (Geyh et al. 2004) was adapted in the same manner. In addition information on facilitators was removed from it. The final questionnaire focused on barriers and included products and technology, natural and man-made environment, support as well as relationships, attitudes and services, systems and policies (Appendix 3). Participants were asked to choose the option that described to what extent each potential barrier impacted their ability to perform certain tasks to the best of their abilities. Options available included no barrier, moderate barrier, severe barrier and complete barrier.

The WHOQOL – BREF questionnaire (Appendix 4) was used to assess quality of life (QOL). The tool is field tested across a number of cultural contexts and has been utilized in many epidemiological studies and clinical trials (WHO 1996). The tool has 26 questions and

addresses four domains (Table 3.3) of QOL namely physical health, psychological health, social relationships and the environment from which a QOL profile can be developed. A score in each domain indicate the individual's perceived health in that domain. A higher score are indicative of better QOL than a lower one. Overall QOL and general health is assessed with two questions (WHO 1996).

Table 3.3: WHOQOL-BREF domains (Source: WHO 1996)

| Domain | Facets incorporated within domains |
|-----------------------------|--|
| Physical health | Activities of daily living Dependence on medicinal substances and medical aids Energy and fatigue Mobility Pain and discomfort Sleep and rest Work Capacity |
| Psychological health | Bodily image and appearance Negative feelings Positive feelings Self-esteem Spirituality / Religion / Personal beliefs Thinking, learning, memory and concentration |
| Social relationships | Personal relationships Social support Sexual activity |
| Environment | Financial resources Freedom, physical safety and security Health and social care: accessibility and quality Home environment Opportunities for acquiring new information and skills Participation in and opportunities for recreation / leisure activities Physical environment (pollution / noise / traffic / climate) Transport |

Tools were translated from English to Sotho and Zulu by respective language lecturers at secondary school level. Local translators able to read, write and speak Zulu and Sotho were utilized to ensure local dialects were accurately included in the tools. The translated Sotho and Zulu documents were back translated to English by two professional nurses, Sotho and Zulu being their respective first languages. This was done to ensure accuracy and to make necessary changes to documents. The researcher and research assistant spent time with the

translators to ensure tools were accurate, correct and understood. Interviews to collect data were then conducted in English, Zulu and Sotho.

3.8 Pilot study

The researcher, with the help of his assistant, conducted a pilot study before undertaking the main study. Questionnaires were piloted with three stroke patients selected from the community who did not form part of the main study. Participants were invited to partake in the study and voluntarily agreed. Pilot study participants were stroke survivors who had a stroke prior to 2012 and living in the same communities as the main study participants. This simulated similar circumstances to the main study.

The interviews were piloted with one English, one Zulu and one Sotho speaking participant. The researcher conducted the English interview. The research assistant conducted the Zulu and Sotho interviews. This provided a good opportunity to observe and evaluate the research assistant's skills in a non-simulated setting and provide corrective guidance.

The pilot study was further utilized for the following:

- To determine the duration of interviews;
- To identify areas of confusion, inconsistency and weakness in the questionnaires and data collection methods;
- To amend questionnaires if any questions were unclear and needed changing;
- To amend the coding systems and methods of recording data if deemed necessary;
- To determine whether data collected addresses the aim and objectives of the study.

Amendments to forms were made to simplify questions and make them easier for participants to understand. In the Sotho and Zulu questionnaires, academic terms were replaced by understandable and simple language throughout all questionnaires.

3.9 Data collection

Data was collected by the researcher and the trained research assistant respectively. Appointments were made with potential participants to meet them at the clinic closest to their place of living at a time convenient to them. Participants were asked if the clinic was within walking distance of their respective residences or if transport was needed. Participants that needed to hire transport were reimbursed. Immediate family or primary caregivers were

asked to be part of the research process at all times to assist in providing accurate data. A communication board was designed to assist patients with aphasia, however it was not needed.

The researcher planned to collect data from participants at central points, i.e., the clinics. The researcher did envision the possibility that, in some cases, home visits would be necessary. Most interviews however were conducted at the local clinic closest to participants' homes. A few home visits were done in order to interview participants who experienced transport difficulties. All transport fares to attend interviews were paid for by the researcher.

Self-reporting by participants was utilized as far as possible. From time to time collateral information was provided by family members and care givers to provide verification and clarity. The support and information provided by family and care givers proved to be of paramount worth.

Participants were made comfortable and offered refreshments at the start of each session. Interviews were conducted in a private, quiet room within the respective clinics. Appointments were made with participants to avoid long waiting times. Participants were informed about the content and duration of the interview. This was followed by assurance that participants would be allowed to rest or withdraw from the study at any time if they so wished. The interview process followed: Informed consent was explained to the participant and documents were signed. The demographic questionnaire was conducted with participants followed by the ICF based questionnaire on activities and participation. Participants were afforded a short break (10 – 15 minutes) before moving to the ICF based questionnaire on environmental barriers. Sessions concluded with the WHOQOL – BREF questionnaire. Answers were recorded on relevant forms and data coding sheets. The researcher went through all questionnaires to ensure data sets were complete before finishing the interview. A few times it was found that a question was missed, this was corrected immediately to ensure data sets were complete. Sessions took approximately one and a half hours including the rest period.

3.10 Data analysis

After interviews were done the researcher ensured that data sets were complete for each participant. Each participant was allocated a unique identification code with assessment of data after interviews were done. Data codes were utilized to identify the origin of the evidence. Raw data was captured onto an Excel spread sheet. Excel was used to present and analyze data.

Nominal and ordinal categorical data was summarized according to response frequencies. The bulk of data collected, including data from ICF based questionnaires and the WHOQOL-Bref was ordinal categorical data. This is presented in graphs. The four domain summaries of the WHOQOL-Bref provide numerical data which was summarised and is presented through descriptive statistics (means, range and standard deviation). Variation in responses was determined and displayed in showing the range of values and standard deviation from the mean. A statistician helped calculate frequencies, means, medians and distribution of the data. The clinical comparison between demographic details and quality of life scores was calculated with two by two tables.

3.11 Rigor

Bias

Selection bias: A small sample size might have contributed to selection bias as the sample might not have been a true reflection of the total population. The population of the current study might have been reduced to the point that the power of results is questioned.

Recall bias: This could have happened with retrospective data collection, as people might forget certain information from the past. In the current study recall bias could have been present where participants were asked about the rehabilitation services they received. Family members or caregivers were allowed to contribute to interviews to minimize the effect of memory loss.

Instruction bias: In order to prevent bias in the methods of interviewing participants between different data collectors, instructions were practised and tested by simulating interview scenarios and during the pilot study.

Interview bias: In order to prevent interview bias, participants were interviewed in their language of choice.

Recording bias: To assure information was recorded accurately, only the researcher and assistant conducted interviews, ensuring familiarity of the questionnaires.

Validity and reliability

The WHOQOL-BREF was tested for validity and reliability with the following conclusion:

“Analyses of internal consistency, item–total correlations, discriminant validity and construct validity through confirmatory factor analysis, indicate that the WHOQOL-BREF has good to excellent psychometric properties of reliability and performs well in preliminary tests of validity. These results indicate that overall, the WHOQOL-BREF is a sound, cross-culturally valid assessment of QOL, as reflected by its four domains: physical, psychological, social and environment.” (Skevington, Lotfy & O’Connell, 2004: 299).

Other tools were not tested for validity and reliability; this is a shortcoming of the study.

Face validity was determined by piloting questionnaires. This determined whether questionnaires yielded accurate information talking to study objectives.

3.12 Ethical Considerations

Ethical Clearance and relevant permission (SUN 2011)

The researcher registered the research proposal and applied for ethical clearance with the Health Research Ethics Committee at Stellenbosch University. Approval was obtained with reference number: S14/10/231 (Appendix 6). The researcher obtained written permission from the Free State Department of Health (Appendix 7) and Institutional heads to perform the research in Thebe/Phumelela District Hospital Complex.

Beneficence

The principle of beneficence entails that the benefits that participants will receive by participation in the study will outweigh any risks, whilst not to bring harm to participants (Joubert & Ehrlich 2007; HPCSA 2008). The possibility existed that participants might not

personally benefit from this study. Management and rehabilitation staff of institutions received much needed information and knowledge regarding realistic everyday life situations participants face as well as participatory outcomes achieved and barriers faced. This might enable staff to improve therapeutic service delivery and rehabilitation services to the disabled population and people with stroke, specifically in future.

Non-maleficence

The principle of non- maleficence points to the responsibility of the researcher not to deliberately harm participants or others in performing the research process (Carter, Lubinskey & Domholt 2011; Joubert & Ehrlich 2007; HPCSA 2008). No personal risk or harm was involved in the process of conducting this study. Participants' identity and information was protected by ensuring confidentiality at all times and ensuring security of records. None of the participants became distressed during any stage of the interview process. All participants were given information and details on how to access a clinical psychologist for counselling should they present with any form of distress or emotional trauma.

Autonomy

The principle of autonomy leads that any individual has free choice and will to participate in the research process or to decline participation. Furthermore it seeks to protect vulnerable individuals with decreased autonomy. This is done through the process of informed consent and discretion and confidentiality of information (Joubert & Ehrlich 2007; HPCSA 2008; Carter et al. 2011). South African Guidelines for Good Clinical Practice (SA GCP) principles was adhered to throughout the study (Moodley 2011). These principles include informed consent and ensuring the privacy and confidentiality concerning participants.

Confidentiality: Information was kept confidential at all times and participants' identity remained confidential during all aspects of the study. A unique code was allocated to each participant. It was used instead of the participant's name on all data collection forms and on the spreadsheet. All content of the study, including documents, remained in custody of the researcher. No information was disclosed to other people with the exception of the researcher's study supervisor and statistician for data analysis. All data was kept locked in a safe room. After publication, data will be stored in a safe, confidential place for a period of 5 years.

Results of the study will be made available to interested study participants, the Free State Department of Health and published in academic journals. At no time during dissemination will identifying information of participants be used.

Informed Consent: All participants were informed regarding purpose and the process that the research project was to follow. Written, informed consent (Appendix 5) was obtained before data collection commenced. All participants had the cognitive and physical ability to do so. This was done in the participant's home language. Opportunity was given to the participant to ask questions or raise concerns. This was immediately answered by the researcher. Where participants either verbally disagreed or showed disagreement of any sort through body language their wishes were respected and they were omitted from the study sample.

Participants were informed that participation was voluntary and that refusal of participation or withdrawal from the study would not have negative effects on future therapy or any negative consequences for them.

Justice

The principle of justice refers to equality, equity, non-discrimination and creating a balance between the beneficence the participant receives and the expectations the research burdens the participant with (Joubert & Ehrlich 2007; HPCSA 2008). Inclusion and exclusion criteria ensured equality. No participant was excluded on the basis of race, gender, socio-economic status, language spoken, cognitive status, sexual orientation or any other basis than the exclusion criteria. Participants had to meet the inclusion criteria developed by the researcher. Equality was further ensured by allowing all participants to be interviewed and give answers in their language of choice (Zulu, Sotho, and English).

Participants did not receive remuneration for participation. The researcher did reimburse transport costs of participants related to the research project. The researcher did, at no stage, seek to exploit any participant on any grounds. All participants were treated with commitment, respect and dignity regardless of the level of commitment shown by participants towards the study. Study results will be made available to all participants who would like to access the information in their language of choice.

Integrity of publication (SUN 2011)

All data, results and conclusions will be presented in an honest and accurate manner. The researcher aimed to ensure correct and accurate data for publication. The department of Biostatistics at Stellenbosch University as well as study supervisors assisted in ensuring accurate data portrayal. All forms of guidance, contributions and assistance were acknowledged by the researcher. The researcher adhered to the plagiarism declaration after reading and signing it.

3.13 Summary

The aim of this study was to describe functional, participation and quality of life outcomes as well as barriers experienced by stroke survivors in the catchment area of the Thebe District Hospital Complex. A descriptive quantitative design was used in order to achieve the aim. A total population of 176 participants were initially identified. Due to a high mortality rate and inaccurate data base information, ultimately 43 stroke survivors that met the inclusion criteria of the study could be located. Five declined participation leaving 38 participants who willingly participated. A pilot study was conducted in the same environment prior to the main study. Data collection instruments consisted of a demographic questionnaire, a questionnaire on activities and participation and a questionnaire on environmental barriers based on the comprehensive ICF core set for stroke as well as the WHOQOL – BREF questionnaire. Questionnaires were used to collect data via structured interviews. Descriptive data analysis was done with assistance of a statistician.

Chapter 4

Results

4.1 Introduction

The results of the study are presented in correlation with the objectives of the study. The main objectives of the study were to: determine functional and participatory outcomes of participants, determine perceived environmental barriers and determine the quality of life of participants. Section 4.2 presents information pertaining to the demographic profile of study participants. Section 4.3 and 4.4 presents results on medical information and rehabilitation information respectively. Findings on function and participation, perceived environmental barriers and quality of life are presented in section 4.5 to 4.7. All percentages were rounded.

4.2 Demographic details

4.2.1 Gender and age

Results showed that the ages of the 38 participants ranged between 18 and 80 years. The majority of participants were evenly spread between the ages of 41 and 70 years with nine (24%) participants in each of the three age groups. A slight decrease was seen in the age group 71 and 80 with six (16%) participants (Figure 4.1). Out of 38 participants, 16 (42%) were male and 22 (58%) female.

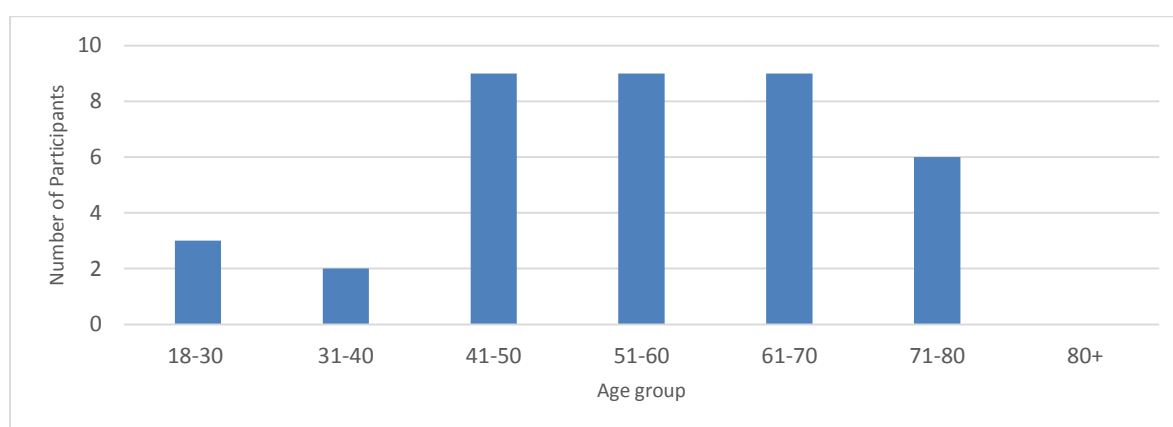


Figure 4.1: Age distribution of participants

4.2.2 Language

The majority of participants (32; 84%) were Sotho and Zulu speaking (Figure 4.2).

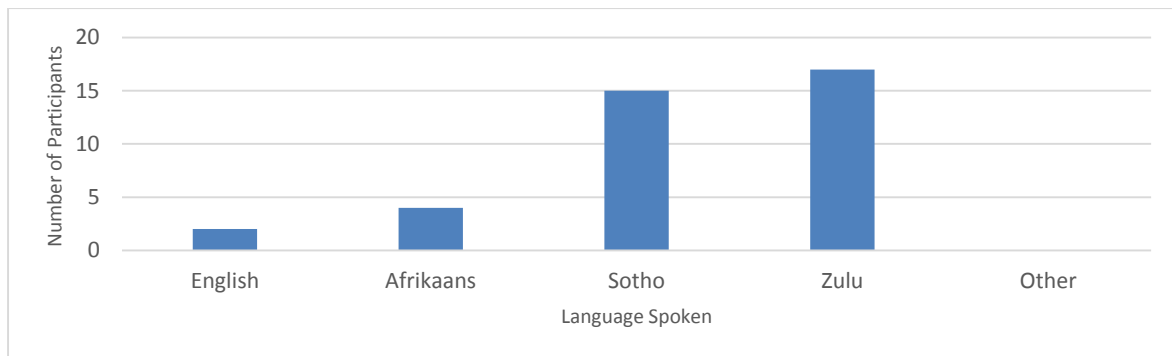


Figure 4.2: Home languages of participants

4.2.3 Education

The educational level most commonly achieved was some primary school education (13; 34%). Five (13%) participants had no formal education and four (11%) had tertiary qualifications. Ten (27%) of participants completed matric as indicated in Figure 4.3.

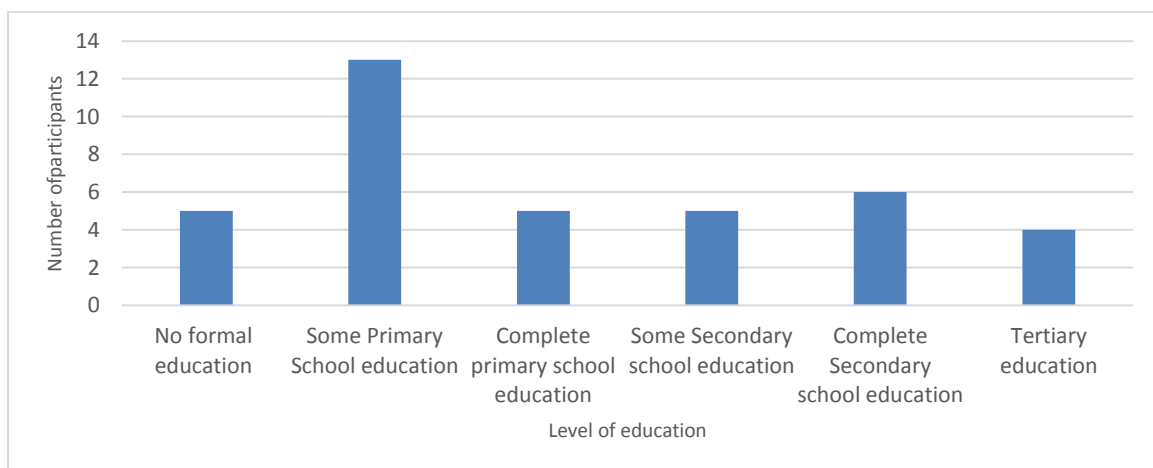


Figure 4.3: Level of education of participants

4.2.4 Employment and income

Twenty five (66%) participants held employment before the stroke. After the stroke two participants (5%) held employment (Figure 4.4).

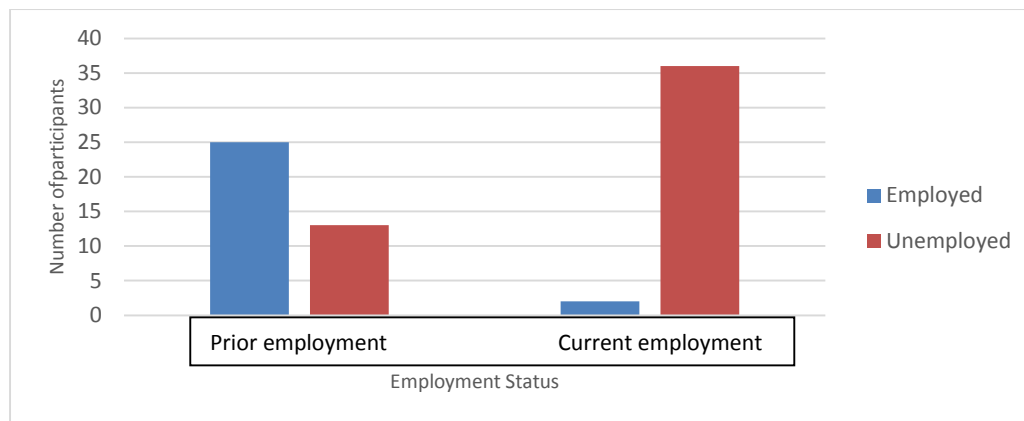


Figure 4.4: Employment status prior to and after stroke

According to figure 4.5, 84% of the 27 of participants who were primary breadwinners before the stroke remained the primary breadwinner in the family after the stroke.

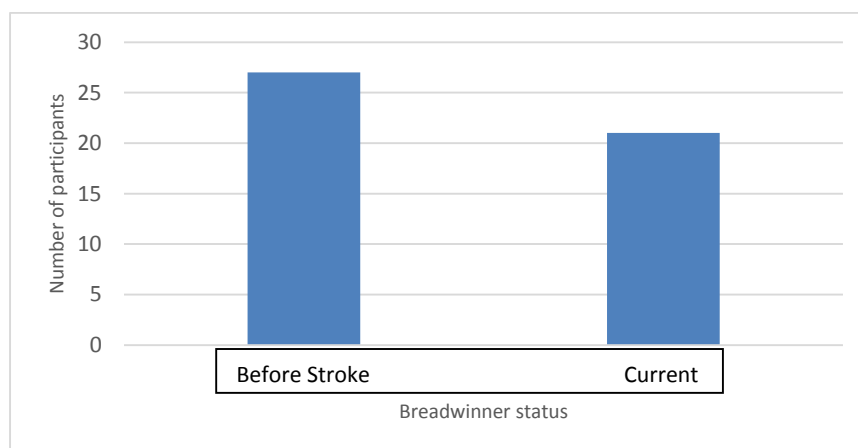


Figure 4.5: Breadwinner status prior to and after stroke

This was mainly because 23 participants (61%) received a permanent disability grant. Twenty-seven participants (71%) reported a monthly family income of less than two thousand rand of which seven (18%) reported less than one thousand rand (Figure 4.6).

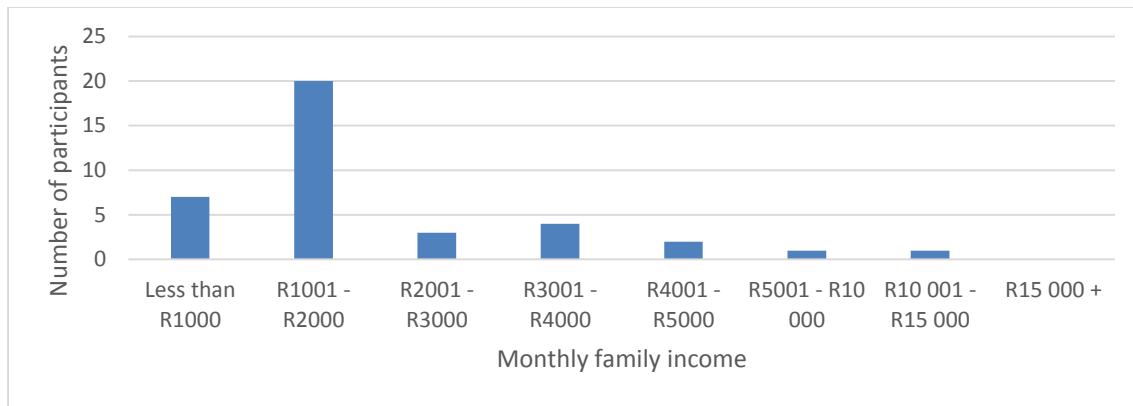


Figure 4.6: Monthly family income

4.3 Medical information

4.3.1 Previous stroke and side of stroke

Just over half of the participants (21; 55%) presented with left hemiplegia and 17 (45%) with right hemiplegia. About a third (11; 29%) of the participants reported that they have had more than one stroke.

4.4 Rehabilitation and therapy services

4.4.1 Therapy period and type

A total of 24 participants (63%) received therapy for one month or less (Figure 4.7). In most instances participants either received therapy for less than one week as in-patients at Thebe Hospital (13; 34%) or for more than four months as out patients at a local clinic or at Thebe Hospital (8; 21%).

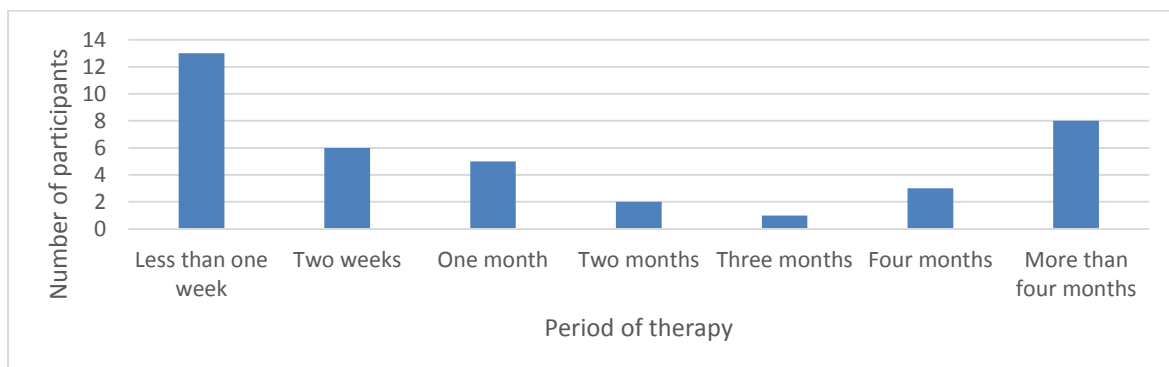


Figure 4.7: Total period of therapy

Therapy was most commonly provided through physiotherapy services (20; 25%) followed by occupational therapy (12; 32%) (Figure 4.8).

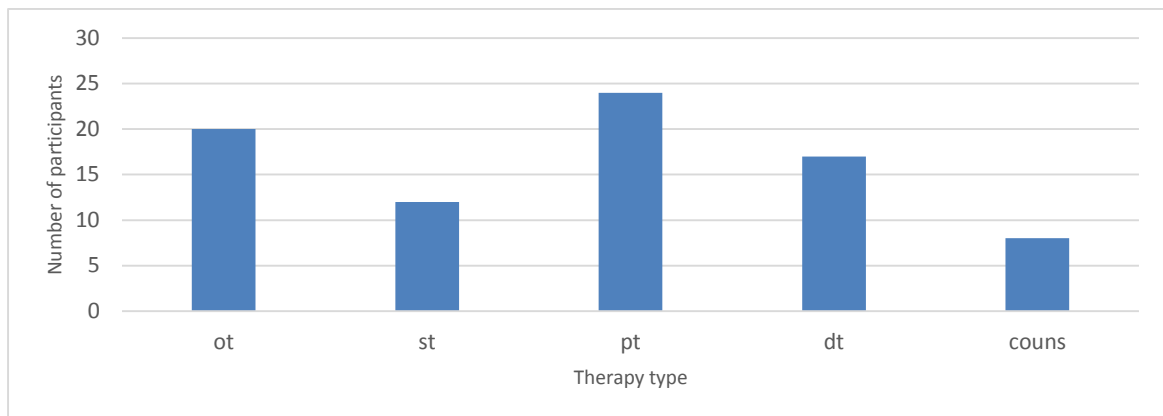


Figure 4.8: Type of therapy received

4.4.2 Follow up therapy

Some participants (15; 39%) received therapy at the hospital as an outpatient post-discharge. Twenty one participants (55%) received follow up therapy at a local clinic. Seven participants (18%) received a home visit from a healthcare worker after being discharged.

4.4.3 Training and education received

According to 14 (37%) of participants their families received education on stroke. Four participants indicated that they received some sort of vocational training. No participants received a skills assessment, employer education or reasonable work accommodations as indicated in Figure 4.9.

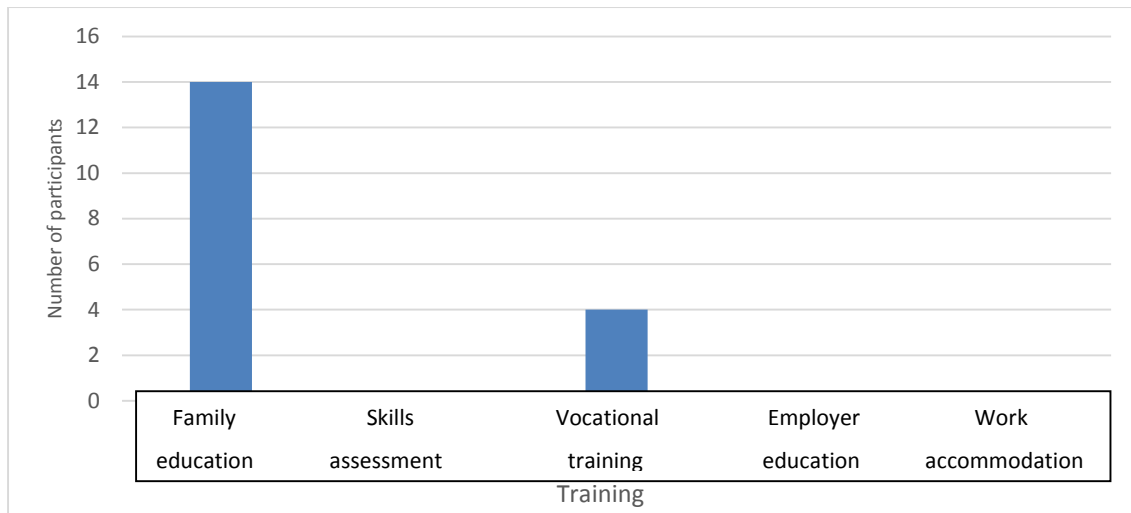


Figure 4.9: Training and education received

With regard to preventative practices participants most commonly received training to prevent contractures (11; 29%) and pressure sores (9; 24%) as shown in Figure 4.10. It should be noted that three participants (8%) received training on prevention of a painful shoulder.

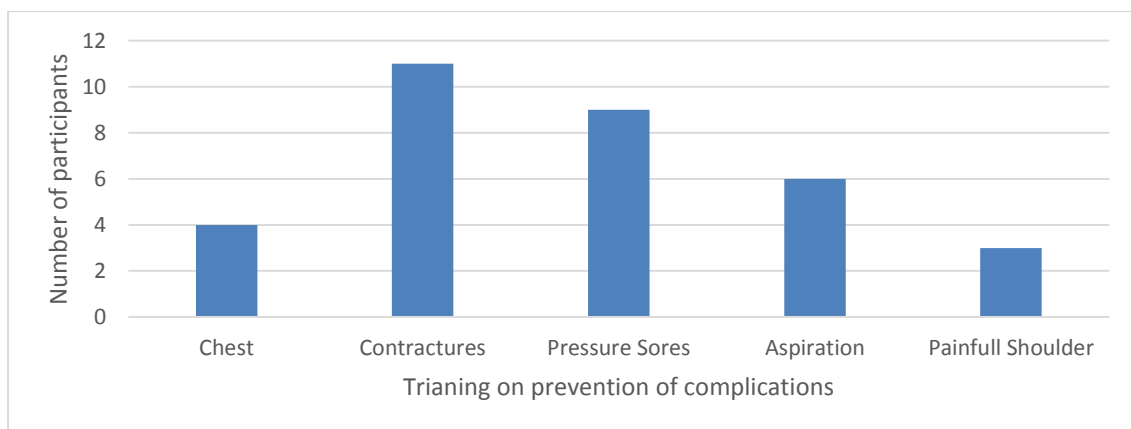


Figure 4.10: Training on the prevention of complications

4.5 Activities and participation

4.5.1 Communication and cognitive function

Figure 4.11 shows that the majority of participants did not experience problems with communication and cognition, although memory created challenges for 23 (61%) of participants. Written communication was more challenging than oral communication as 28

participants (74%) reported difficulty with writing and 25 (66%) reported difficulty in their ability to read.

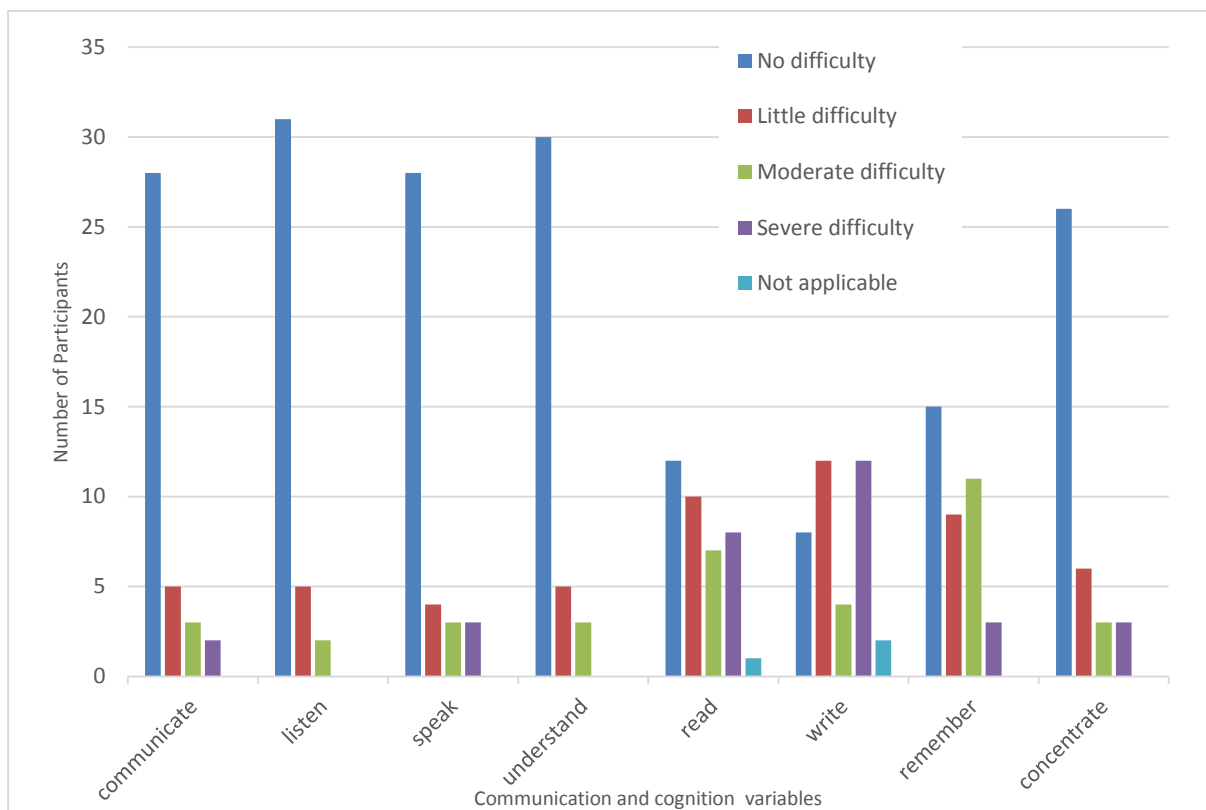


Figure 4.11: Difficulties experienced with communication and cognitive function

4.5.2 Mobility

Aspects related to indoor mobility are summarised in Figure 4.12. As shown, seven (18%) participants experienced no difficulty with regard to moving around. Walking inside, standing up and transfers created difficulties for the least number of participants. The aspect with which most participants experienced severe difficulty was getting up from the floor. Lifting and carrying objects also created challenges.

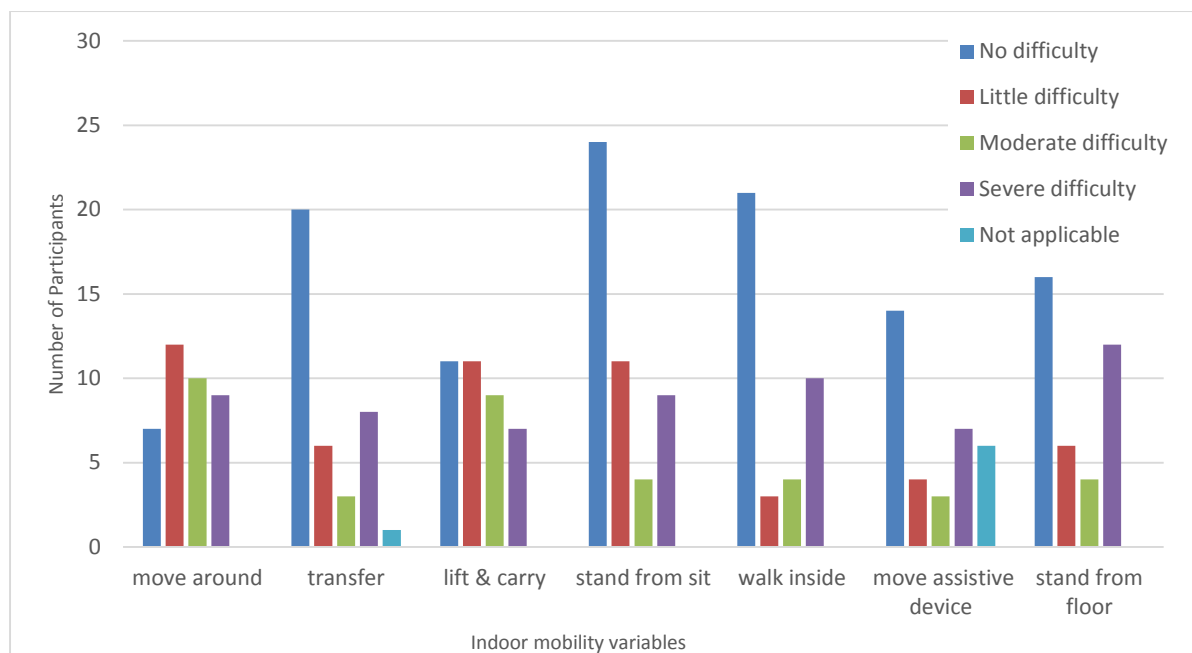


Figure 4.12: Difficulties experienced with indoor mobility

In contrast to indoor mobility, community mobility created challenges for more participants and severe difficulty was the option chosen by most participants in each of the domains tested as shown by Figure 4.13.

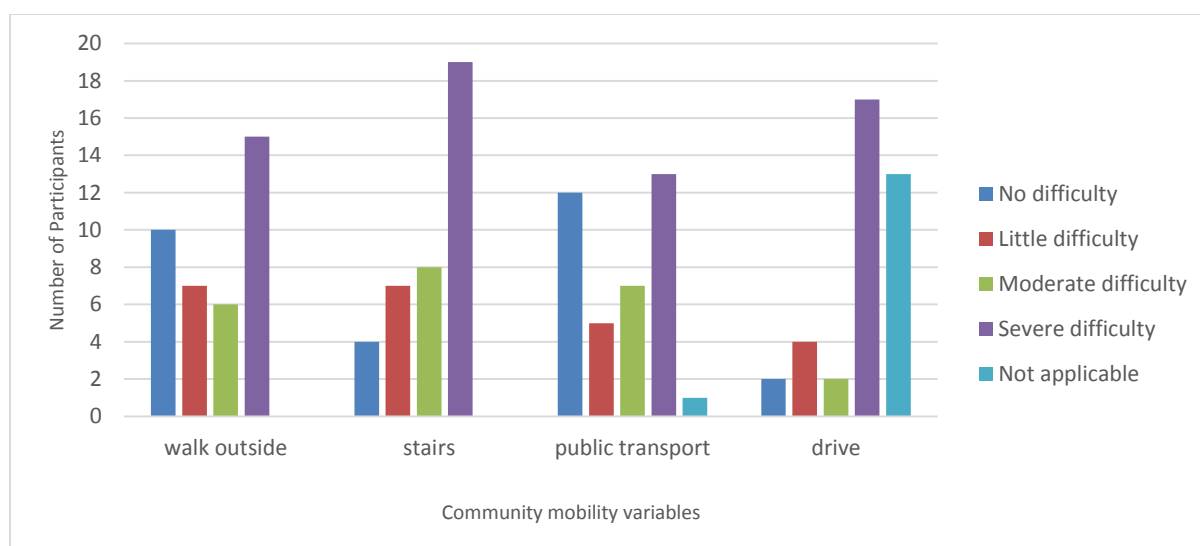


Figure 4.13: Difficulties experienced with community mobility

4.5.3 Activities of daily living

Figure 4.14 shows that most participants did not experience much difficulty with activities of daily living (ADL) and self-care activities. The activities that were the most difficult for participants included grooming, washing and dressing with which respectively (14; 37%), (12; 32%) and (11; 29%) participants had severe difficulty.

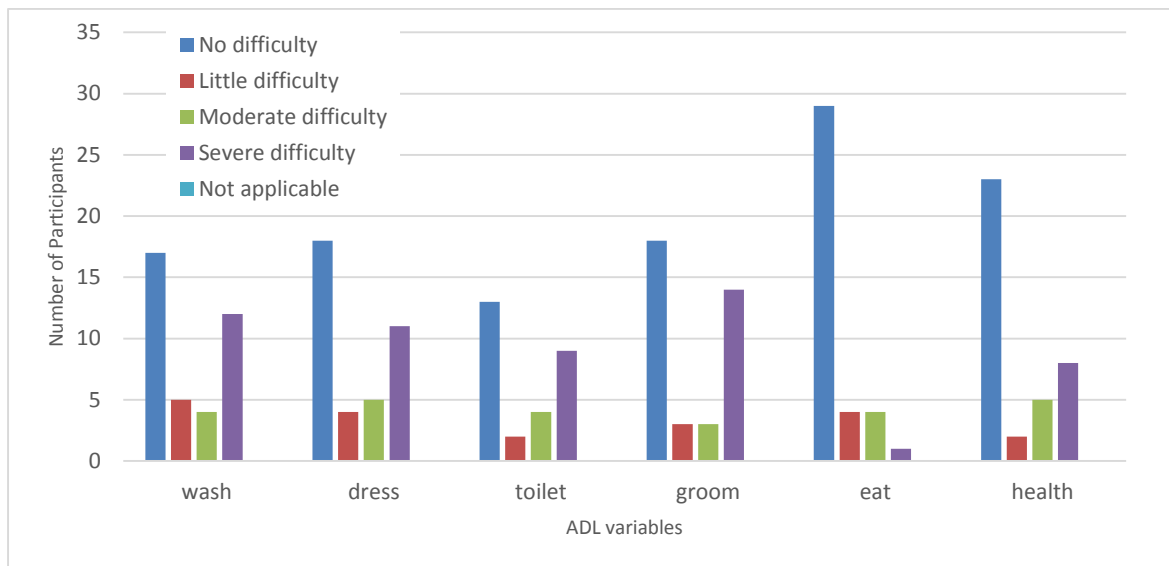


Figure 4.14: Difficulties experienced with ADL

4.5.4 Domestic life

Participants experienced more difficulty in general with domestic activities compared to self-care and ADL. Both doing chores and shopping presented severe difficulties to 17 (45%) participants, while 12 (32%) participants found cooking meals severely difficult. The majority of participants (25; 65%) felt unsafe when home alone to a certain extent (Figure 4.15).

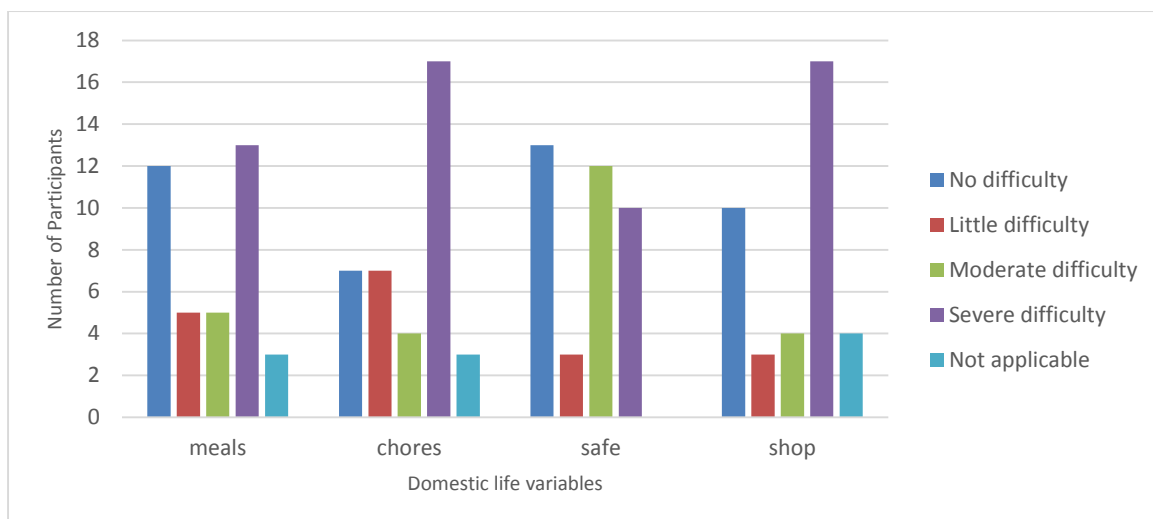


Figure 4.15: Difficulties experienced with domestic life

4.5.5 Relationships

The majority of participants (29; 76%) experienced no difficulty with relationships overall as indicated in Figure 4.16. Family relationships were found to be the strongest with 34 (89%) participants having no difficulty in this area, followed by relationships with friends and spending time in the community. The aspect that was most challenging were intimate relationships where ten (26%) participants did not experience difficulty, 12 (32%) reported some sort of difficulty and 16 (42%) felt that it was not applicable.

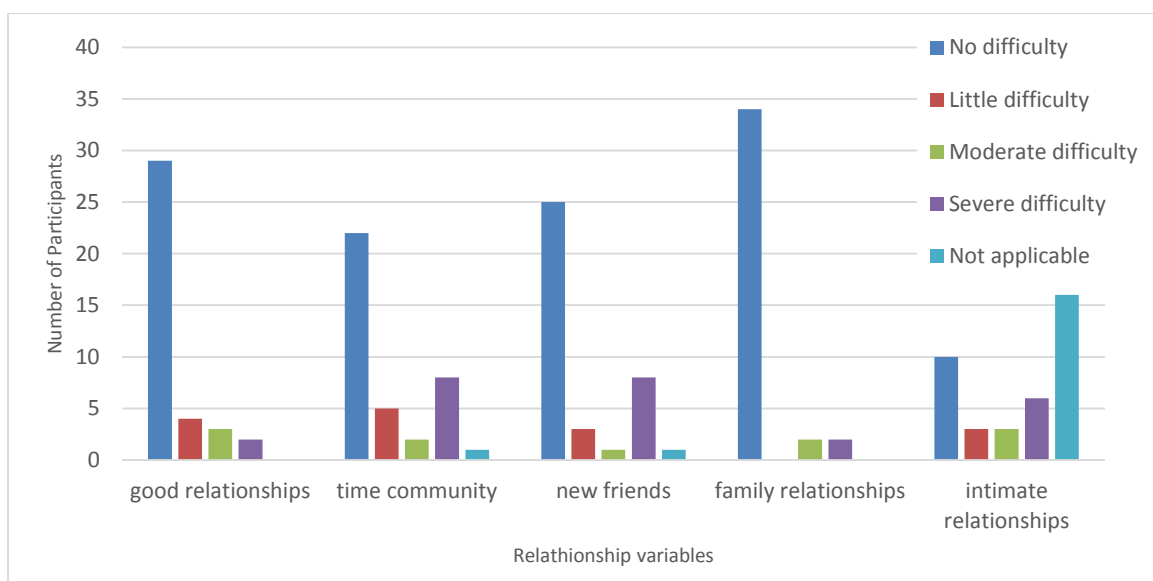


Figure 4.16: Difficulties experienced with relationships

4.5.6 Community integration

Community integration seemed to be met with much difficulty as indicated in Figure 4.17. The majority of participants found participation in different areas severely difficult, with few participants reporting no difficulty. Participating in sport, engaging in social activities, participating in politics, going to church and exercising a hobby seemed to be the most difficult areas of participation. Thirty two participants experienced some sort of difficulty in accessing services in general, while 26 participants had difficulty managing their own finances.

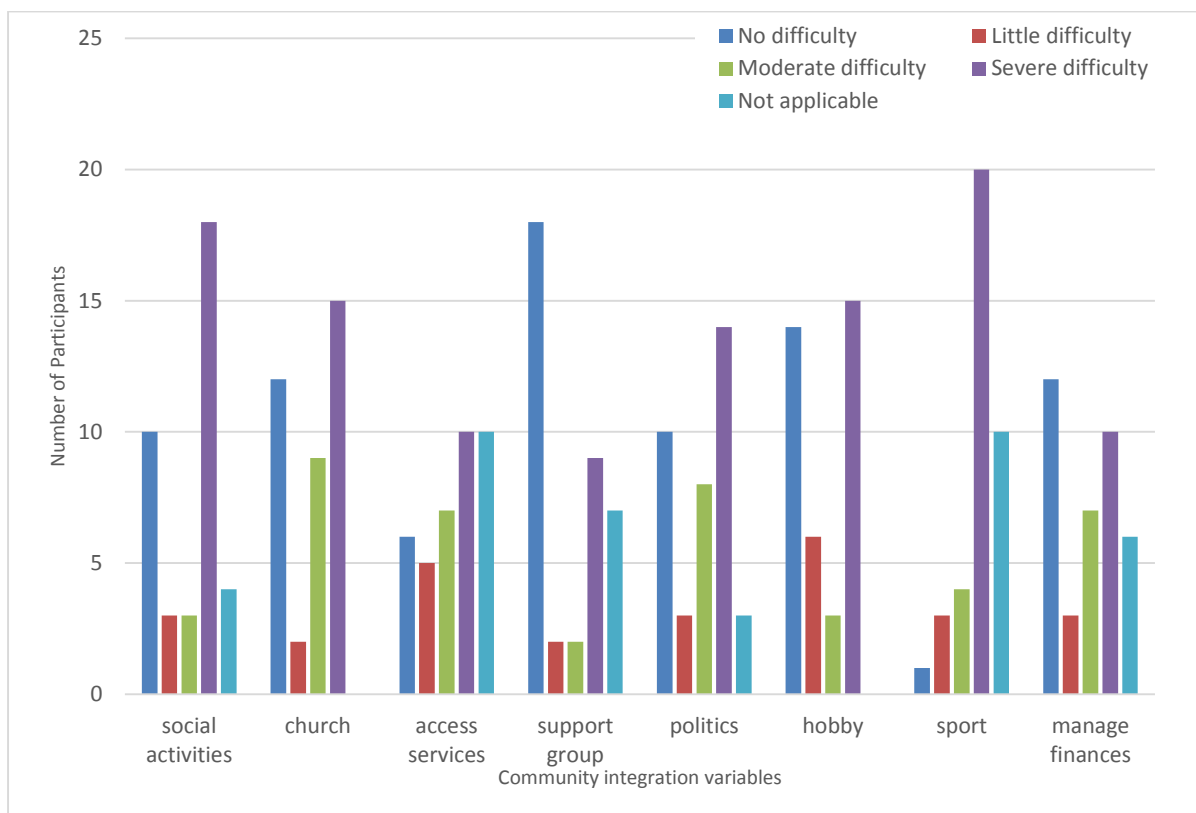


Figure 4.17: Difficulties experienced with community integration

4.5.7 Productive activity

Twenty two (58%) participants reported difficulty in looking for a job, 12 (32%) felt it was not applicable, leaving four participants (11%) who felt able to look for a job without difficulty. Similarly four participants (11%) felt they were able to generate an income, while 28 (74%) participants felt that they were unable to be economically self-sufficient without difficulty (Figure 4.18).

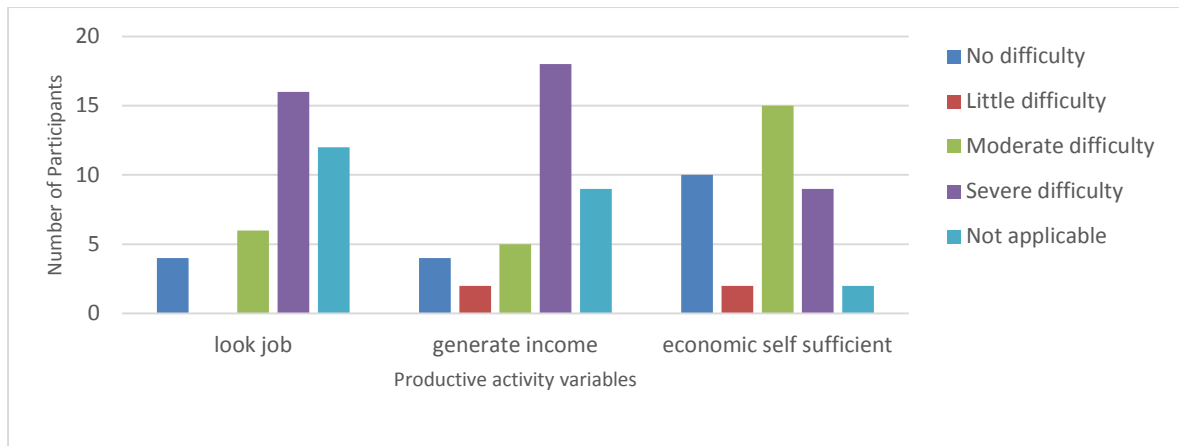


Figure 4.18: Difficulties experienced with employment and employment related factors

4.6 Environmental barriers

4.6.1 Products and technology

As shown in Figure 4.19 access to food and equipment for every-day use caused the least barriers to participants. Areas that were more challenging included access to mobility products (23; 61%), access to private buildings (28; 74%), access to public buildings (29; 76%) as well as finances and assets (23; 61%).

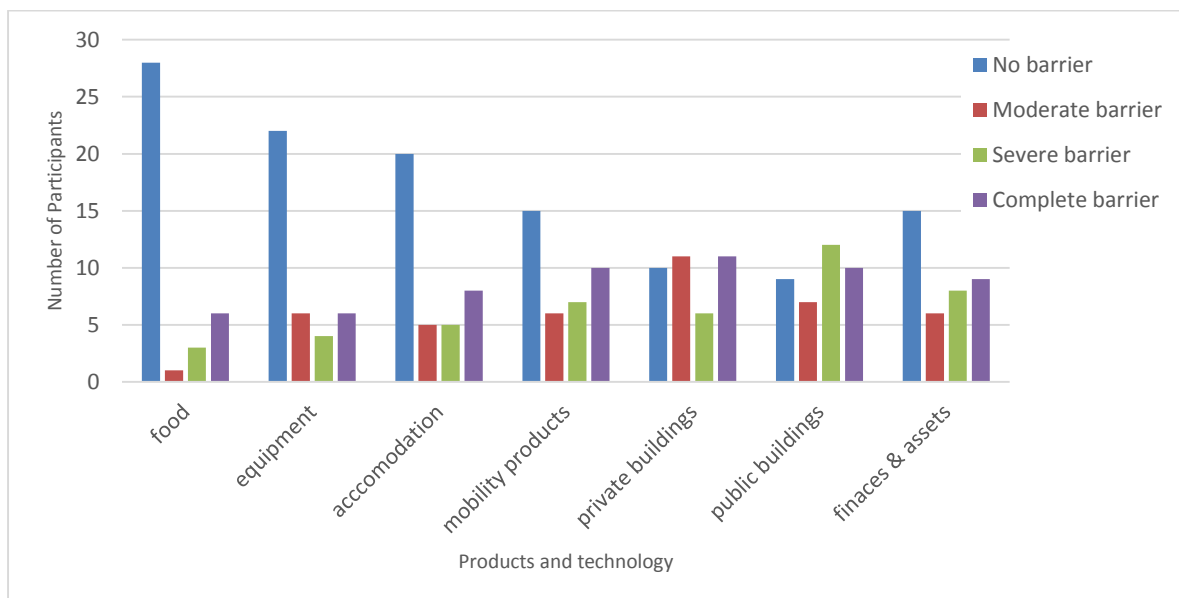


Figure 4.19: Perceived barriers to products and technology

80% of participants who received occupational therapy perceived access to mobility products as no or a little barrier, while 50% of those who did not receive occupational therapy perceived it as no or a little barrier. Similarly 67% of participants who received physiotherapy perceived access to mobility products as no or a little barrier, while 36% of those who did not receive physiotherapy perceived it as no or a little barrier.

4.6.2 Natural and man-made environment

Light and sound did not have a major impact on the majority of participants. Climate impacted on the lives of participants with 31 (82%) participants reporting barriers in this area. To a lesser extent the terrain posed barriers to 21 (55%) participants (Figure 4.20).

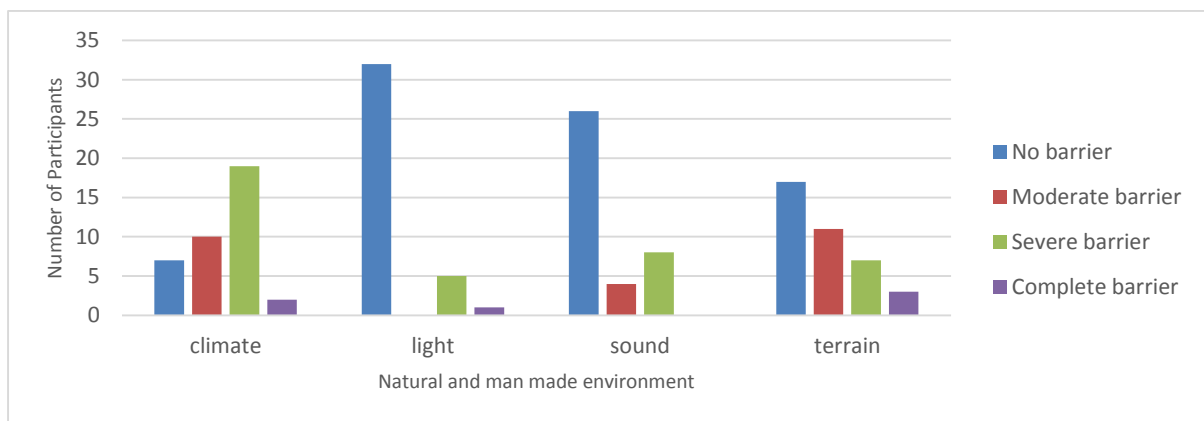


Figure 4.20: Perceived barriers due to natural and man-made environment

4.6.3 Support and relationships

Participants seemed to feel well supported in general with the majority reporting no barriers in support from family, care takers and healthcare professionals. Professionals outside of healthcare, acquaintances and friends were experienced to be less supportive and barriers were perceived to be present in these areas of engagement.

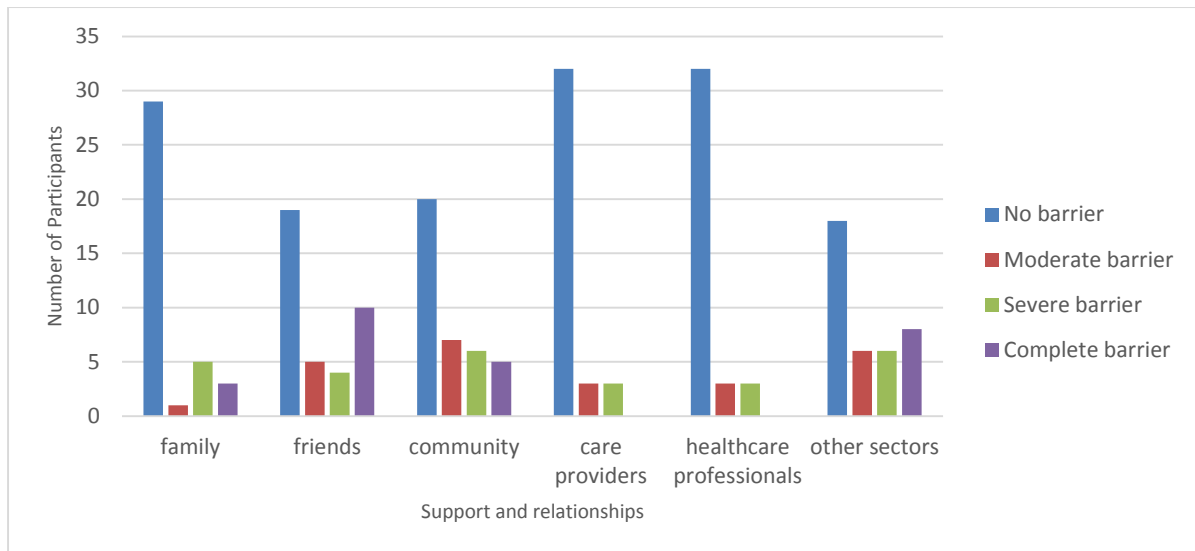


Figure 4.21: Perceived barriers to support and relationships

4.6.4 Attitudes of people

The majority of participants reported that there were no barriers in this regard with family, personal care providers, health care and other professionals. Friends' attitudes seemed to cause the biggest barriers with seven participants reporting complete barriers and 14 (37%) in total reporting some sort of barrier in this category.

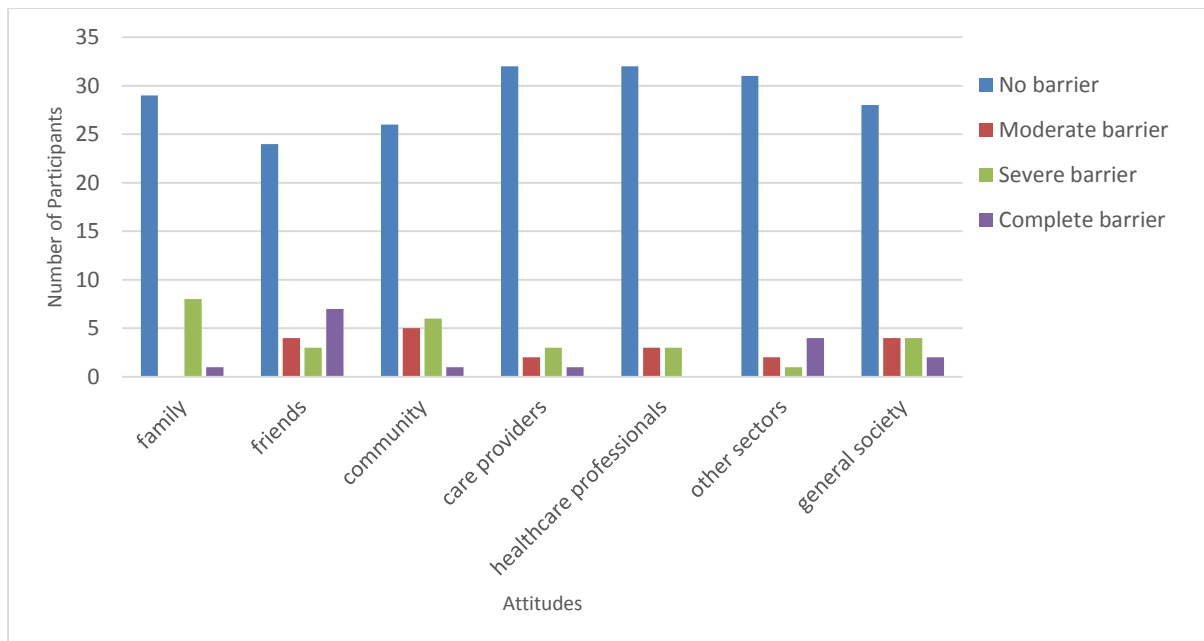


Figure 4.22: Perceived barriers due to attitudes of people

4.6.5 Services, systems and policies

Housing, education and labour services, systems and policies were found to create the most barriers. Twenty-five participants perceived barriers to housing of which fifteen complete, thirty participants to education of which nineteen complete and thirty-one to labour services of which eighteen complete. Thirty-one participants reported no barriers in healthcare and 25 reported no barriers in social services, systems and policies.

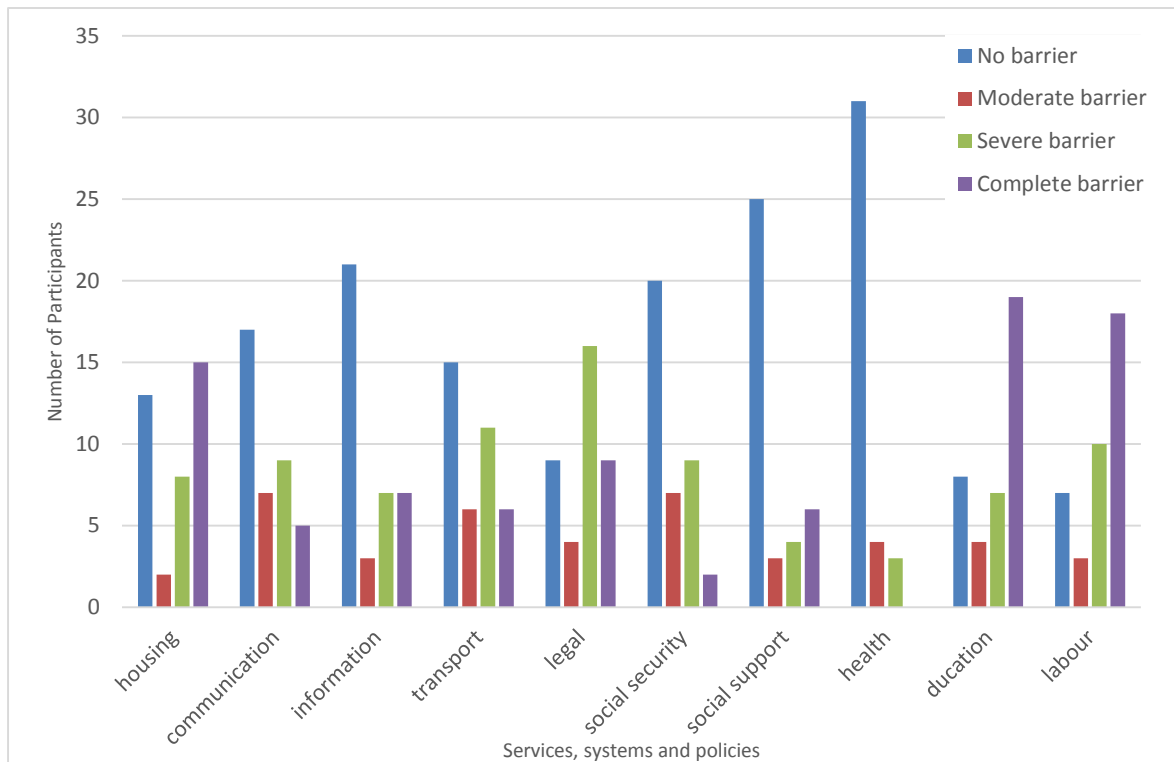


Figure 4.23: Perceived barriers to services, systems and policies

4.7 Quality of life

4.7.1 Perception of overall quality of life

Participants' general perception of their quality of life varied mostly from very poor to neither poor nor good as 31 (82%) participants reported a quality of life ranging between neutral and very poor as shown in Figure 4.24.

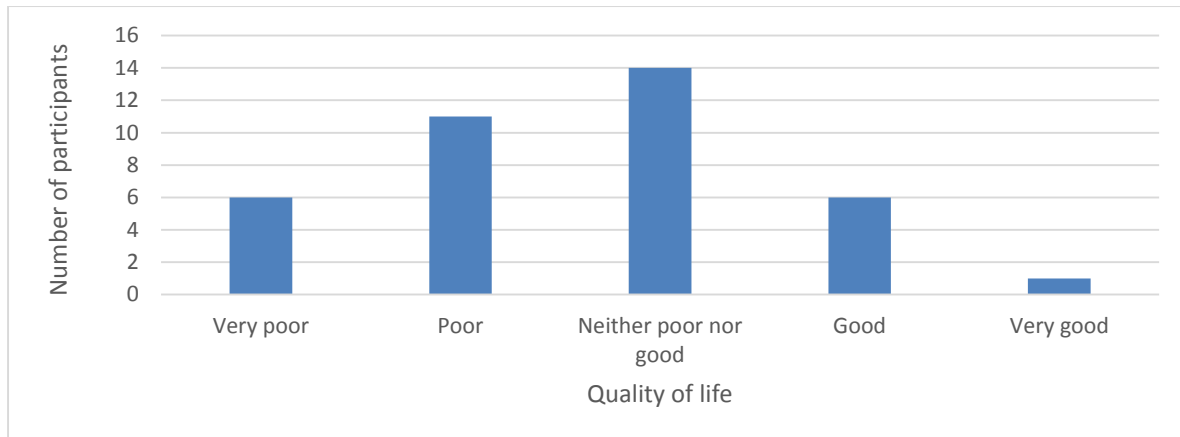


Figure 4.24: Perception of overall quality of life

4.7.2 Satisfaction with health

Participants' satisfaction with their health ranged mostly from very dissatisfied to a neutral stance with 30 (79%) participants responding between neutral and very dissatisfied (Figure 4.25).

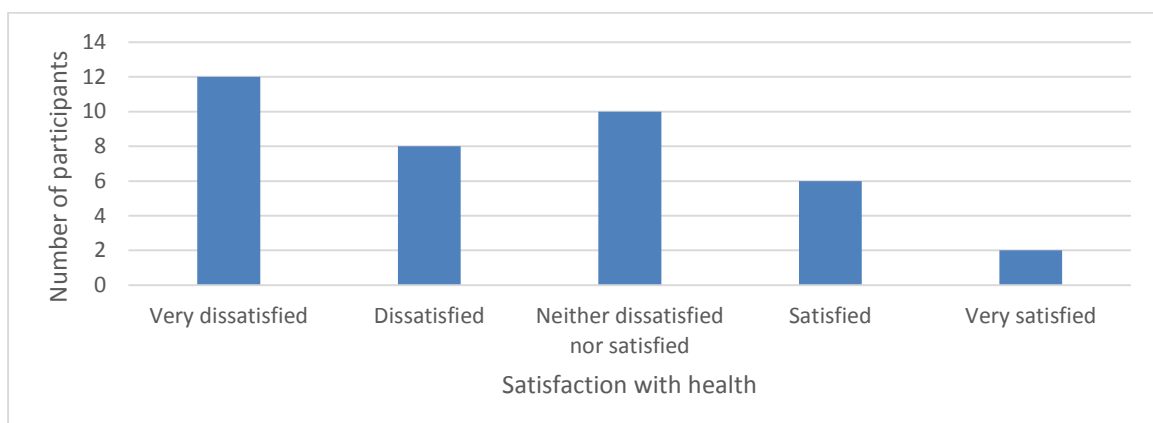


Figure 4.25: Satisfaction with health

4.7.3 Depressive affect

The occurrence of negative feelings such as blue mood, despair, anxiety and self-reported depression were common with 22 (58%) participants indicating recurring depressive affect (Figure 4.26).

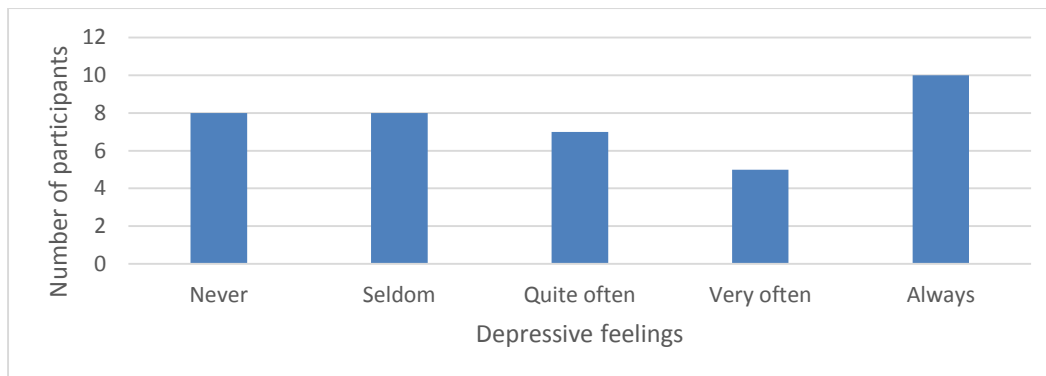


Figure 4.26: Depressive affect

4.7.4 Scores for the four quality of life domains

Table 4.1 shows that participants reported the highest mean value for psychological health (64%). Environment-, physical- and social health were found to be 52% or less.

Table 4.1: Descriptive statistics of quality of life domains

| Domain | Mean | SD | Min | Max |
|----------------------|------|------|-----|-----|
| Physical health | 50.6 | 20.5 | 6 | 88 |
| Psychological health | 64.4 | 17.5 | 31 | 100 |
| Social health | 46.3 | 23.5 | 0 | 100 |
| Environmental health | 51.8 | 21.1 | 19 | 100 |

Neither age (83% younger than 60 and 80% older than sixty scored QOL as neutral or poor), nor family income (85% with and income of less than R2000.00 and 75% with an income of more than R2000.00 scored QOL as neutral or poor) showed a clinical relationship with QOL. Similarly receiving therapy for less or more than two weeks (84% versus 79% scored QOL as neutral or poor) showed no relationship with QOL. Individual physiotherapy,

occupational therapy and counselling also made no difference to the perception of QOL. More participants who indicated access to mobility products as a severe or complete barrier scored QOL as neutral or poor than those who indicate it as no or a moderate barrier (88% versus 76%).

More than half (55%) of participants who experienced neutral to poor overall quality of life indicated severe/complete difficulties with intimate relationships or indicate that these relationships were not applicable. Similarly 58% of the participants who experienced neutral to poor health in the social domain indicated severe/complete difficulties with maintaining intimate relationships or state that intimate relationships were not applicable. In total 71% of participants indicated they were dissatisfied with their sex life in answer to this question in the WHO QOL Bref.

The severity of the impact of a lack of assets is shown in the response to the QOL Bref questions on financial resources where 80% of participants indicate that they do not have the money to meet their needs. Similar numbers of participants (42%) were satisfied and dissatisfied with access to transport according to WHO QOL Bref scores. Sixty three percent of participants were satisfied with their access to health care and 81.5% indicated that health care policies, services and systems created no barrier (Figure 4.23). On the other hand 52.6% were dissatisfied with their health (Figure 4.25) and 63% needed a lot of medical treatment to function in daily life according QOL Bref scores.

While ICF scores (Figure 4.14) show that participants could perform some ADL the QOL Bref scores show that it was still challenging and 53% of participants were dissatisfied with their ability to perform these activities. More participants who did receive occupational therapy were dissatisfied with their ability to perform ADL than participants who did not receive occupational therapy (55% versus 72%). QOL Bref scores on leisure and work activities are similar to earlier presented ICF scores (Figures 4.17 and 4.18) with 60.5% and 63% of participants dissatisfied with these two areas respectively.

4.8 Summary

Functional and participatory outcomes were limited to residential activities. Family relationships were good, but 66% of participants struggled to maintain intimate relationships. Community integration was limited with most participants unable to independently walk

outside (55%), use public transport (55%) and drive (84%). Participation in social activities (66%), religious activities (63%), accessing services (71%), playing sport (89%), engaging in politics (66%) and managing personal finances (61%), employment (74%) was difficult to impossible for many participants.

The majority (82%) of participants reported a quality of life ranging between neutral and very poor. Recurring depressive affect was found to influence 58% of participants on a regular basis. Social health was most affected of the four quality of life domains.

The most severe environmental barriers perceived by participants included climate (82%), a lack of finances and assets (61%), mobility products (61%), as well as inability to access public buildings (76%) and, transport- (61%), education- (79%), housing- (66%), and labour (82%) services, systems and policies.

The majority of participants (63%) received therapy for less than a month. Twenty one participants (55%) received follow up therapy at a local clinic. Few participants (11%) received vocational rehabilitation and no skills assessments, employer education or reasonable work accommodations were done.

Chapter 5

Discussion

5.1 Introduction

The discussion starts off with the demographic profile of participants and then proceeds to explore participatory outcomes of participants and the factors that influence these outcomes. Finally the realisation of Framework and strategy for disability and rehabilitation services in South Africa 2015 – 2020 in the study setting, is explored through the study results.

5.2 Discussion

Men represented 42% of the participants in this study. Other studies in South Africa showed different results of either more men than women or an equal distribution. According to statistics, the population of Maluti A Phofung consists out of 98.2% Black African, 1.3% White, 0.2% Coloured and 0.2% Indian / Asian people (Stats SA 2015). Similar to these findings the current study population had a majority representation of Black African people (84.2%). Interestingly the most common language spoken by participants was Zulu (44.7%) followed by Sotho (39.4%). This is different from the census findings that in the population of Maluti A Phofung the most common language spoken by far is Sotho (81.7%) followed by Zulu (10.7%) (Stats SA 2015).

According to Heart magazine the majority of strokes occurs amongst people from the age of 65 and upwards (Heart magazine 2007). However, studies in South Africa have shown mean ages ranging from 53 (Hassan, Visagie & Mji 2012) to 62 (Cawood & Visagie 2015). The majority of participants in the current study (71%) were between the ages of 40 and 70. This age range is in agreement with findings from Feigin et al. (2014) that showed stroke sufferers in low and middle income countries to be younger than the world average of 71 years.

The younger age of participants makes employment post stroke very important. Many of them are not older than 60, but rather as young as 30 and 40, thus at an age where being employed and building a career is important. Employment is the gateway to livelihood, as earning an income gives an individual the means to live an independent life. While taking cognisance of the general high unemployment figures in South Africa and the even higher unemployment figures for persons with disabilities (Schneider & Nkoli 2011), the

employment status of participants in the study is a worrisome factor, as only 5% held employment, despite the fact that 66% of participants held some form of employment prior to acquiring a stroke. This indicates a very low percentage (8%) of return to work after stroke. Duff, Ntsiea and Mudzi (2014) found that 34% of stroke survivors returned to work in a study done in Johannesburg, South Africa. Limited access to vocational rehabilitation, skills assessment, employer education and reasonable accommodations might have impacted negatively on participants' ability to return to work.

Although high unemployed figures were present, 84% of participants remained the primary bread winners of their respective families after acquiring a stroke. The reason these individuals remained the primary breadwinners might be due to a combination of the extreme poverty that these rural communities face, the high unemployment figures in the community and social security in the form of a disability grant. Very few job opportunities are available in Maluti A Phofung, with many people being jobless. The region has a 42% unemployment rate, this is exceeded by the 53% unemployment rate of youth in the region (Stats SA 2015). Of the participants' households, 61% relied on a disability grant as sole family income. However, the purpose of a disability grant is to assist one person with a disability with personal expenses. It is not sufficient to provide for the needs of a family.

Another factor that probably contributed to the low income and high unemployment is that 60% of participants achieved a level of completing primary school education or less. This figure is slightly higher than findings for the geographical area of Maluti A Phofung, which indicates that 49.9% of the population have achieved a level of completing primary school education or less. Low education levels affect an individual's ability to be employed and earn a lucrative income. This information is consistent with findings that participants perceived access to education posed significant barriers. One might also understand how 71% of participants can identify labour services, systems and policies as a barrier as low education levels can limit an individual's ability to access the labour market.

Employment might also have been negatively affected by the physical impairments (paralysis, spasticity, memory and written communication challenges), lack of community mobility and lack of access to public buildings. The physical effects of stroke make employment in jobs of a physical nature difficult if not impossible. On the other hand employment in jobs of a more sedentary nature often requires high levels of concentration, good memory, the ability to communicate in writing and formal education of grade 10 or

more. These are all aspects that some of the study participants lacked or found difficult. Economic self-sufficiency thus posed great difficulty for the majority of participants. Very few were able to generate an income or felt they would be able to look for a job without any difficulty.

Therefore it does not come as a surprise that just over 60% of participants experienced barriers to finances and assets and 80% could not finance their needs. A lack of assets impacts on all other spheres, including food security, access to services and availability of resources. This finding concurs with many other studies, indicating that a lack of finances and assets created barriers for stroke survivors in South Africa (Urimubenshi & Rhoda 2011; Grut et al. 2012; Cawood & Visagie 2015). Financial resources are considered in the domain environmental health of the QOL-Bref. The low mean score in this domain could possibly be partly attributed to a lack of assets and low household income. Other variables included in this domain, which also created barriers to participants, are transport, the natural environment, leisure and recreational activities.

Interestingly, communication was not difficult for the majority of participants as they were able to verbally communicate and listen well. This is in contrast with literature findings that indicate speech disorders in up to 47% of stroke survivors (Flowers et al. 2013). No participant needed a communication board in order to communicate. Communication enables individuals to express their needs and desires to their families and care givers. This potentially spares the frustrations associated with misunderstandings as a result of communication challenges. Communication is further, a critical part of social interaction, thus communal participation is influenced by one's ability to communicate well. Written communication however posed difficulties for the majority of participants. Participants' inability to read and write without difficulty might have been influenced by motor function and possibly vision related impairments. Educational levels, which were low for the majority of participants, however have to be taken into consideration as well, as literacy plays a prominent role in a person's ability to read and write. The inability to read and write could impact negatively on a person's ability to look for a job, rendering an individual unable to compile a resume, for instance.

More than half of the participants did experience barriers to communication services, systems and policies. This might be due to a lack of access to phones, airtime and /or computers which limits long distance communication such as emails and phone calls. Cawood and

Visagie (2015) similarly found that communication products created barriers to participants, mostly due to unaffordability of phones. Existing systems, services and policies may further act as barriers in hindering participation in the area of communication amongst others, as development of these systems might not be congruent with the community it serves. Already existing systems were not taken into consideration in development of such, rendering participants powerless within a top to bottom system (Ned & Lorenzo, 2016).

From the findings on activity limitations, functioning in a private residential setting seemed to be possible for the majority of participants. Most participants were relatively mobile inside the house with regard to transfers and walking with or without an assistive device. Most were also able to perform some self-care activities such as eating. This is similar to findings from Cawood et al. (2016), indicating that feeding could mostly be done independently while Rouillard et al. (2012) found that grooming caused little trouble. Rhoda et al. (2011) and Wasserman et al. (2009) similarly reported that areas that created least functional problems were transfers, mobility and toileting.

Living alone however would have been difficult for most participants of the current study and impossible for some. This is due to major difficulties arising with more complex activities such as standing up from the floor and lifting and carrying objects. At least 29% needed assistance with things like washing, dressing, grooming and using the toilet. Even more needed assistance with preparing meals, doing household chores and to be safe at home and over half of the participants were dissatisfied with their ability to perform ADL tasks. Poor accessibility of rehabilitation services at community level, resulting in poor continuity of care may have impacted negatively on the desired functional and participatory goals of rehabilitation. These findings are similar to findings by Rouillard et al. (2012), Mudzi et al. (2013), and Cawood et al. (2016), who agreed that toilet use, walking and transfers were mostly done independently and that bathing and stair climbing created more problems. Rouillard et al. (2012) emphasised that many participants experienced participation restrictions regarding housework and food preparation. Findings by Mudzi et al. (2013) showed that participants had difficulties with carrying out single and multiple tasks, lifting and carrying objects and doing domestic activities without assistance. Motor impairment, decreased mobility and decreased functional ability were indicated as predictors of poor QOL by other authors (Jelsma et al. 2008; Hamzat, Al-Sadat et al. 2014; Rhoda 2014). The study

findings showed challenges in these areas which might have led to the low mean score for physical health.

Since the vast majority of participants reported no difficulty in relationships with family and indicated that family support and relationships were not a barrier to participation, it seems as if the assistance they needed to function at home were available. The findings on care providers were similar, as in most instances it was family members looking after participants. Mudzi et al. (2013) showed contrasting findings that indicated that participants experienced severe difficulty in sustaining basic and formal relationships. Urimubenshi & Rhoda (2011) also indicated a lack of support from relatives and decreasing support as time went on after stroke. Rhoda et al. (2015) found similar situations emerging, indicating that participants experienced social isolation and loss of friendship. Although current study participants indicated good relationship abilities, most felt socially isolated, as the majority reported severe difficulties to engage in social activities and social health, which includes personal relationships, social support and sexual activity which had the lowest mean score of the four QOL domains. Thus it should be noted that in this specific group of participants, the problematic area might not have been found in individuals' capabilities to form and maintain relationships on a personal level, but rather accessibility to such relationships. The area of difficulty rather could be with social seclusion. This is further strengthened by the indication that participants experienced barriers to finding support and relationships (not attitudinal) from the community and friends. Grut et al. (2012) found similar results, indicating that stroke survivors experienced barriers to social and cultural participation.

It seems from the findings as if attitudes of friends and community members did not create severe barriers in most instances. Some participants however did experience some attitudinal barriers within their communities and general society as a whole. This is similar to findings by Maleka et al. (2012), indicating community- and societal attitudinal barriers. Very few experienced this closer to home from family and care providers. Grut et al. (2012) found attitudes do play a role with an example of people who did not behave in a "socially acceptable" manner, were often not allowed to use public transport. Urimubenshi & Rhoda (2011) also indicated participants experienced negative attitudes. Similar to the current study's findings, this did not happen frequently, but negative attitudes were perceived by some participants.

The majority of participants however experienced difficulties with intimate relationships, a component of social health according to the QOL-Bref. Difficulties experienced with intimate relationships and the high number of participants who indicated that intimate relationships were not applicable might point towards challenges in assuming the role of husband and wife amongst other things. Studies by Kalavina (2014) and Sikuru, Shamaila, & Yusufu (2009) similarly found that stroke patients and partners experienced loss of sexual intimacy after stroke leaving participants unable to engage in sexual activities. A lack of intimacy not only affects a person's physical needs, it implicates on an individual's emotional wellbeing and self-esteem, and could lead to a person feeling socially isolated (Kalavina 2014). Thus in addition to impacting social health negatively a lack of intimacy can also impact psychological quality of life negatively.

This difficulty in intimate relationships could be the result of many different factors. Low self-esteem, fear of rejection and a decline in authority was found to impact negatively on men in a study performed by Thompson (2011). According to the Australian Stroke Foundation (ASF 2016) stroke may affect a person's self-esteem as well as an individual's perception of their masculine or feminine roles, thus affecting his/her sexuality (ASF 2016). Kalavina (2014) indicated that the burden of care giving and domestic work interfered with companionship and intimate relationships of stroke survivors. Tamam, Tamam, Akil, Yasan & Tamam (2008) found that stroke sufferers were sexually rejected by their partners as a result of being sexually inhibited by the unattractive condition they were in. Physical disabilities such as decreased mobility and hand function, altered sensation and pain can also affect a person's ability to perform sexual activities (ASF 2016).

On moving the focus from the home to the community the severe effects of the stroke become much more apparent. Few of the participants were able to perform activities and participate in life roles that would be required of them to integrate in their communities. The challenges start immediately on leaving the house with outdoor mobility. Walking outside, climbing stairs, driving a vehicle and using public transport created moderate or severe difficulties for the majority of participants. Doing shopping also presented moderate to severe difficulty for many participants. The overwhelming majority of participants further indicated an inability to participate in leisure activities and social life as well as the ability to participate in family responsibilities. These findings corresponded with other study findings that indicated that participants experienced restrictions in activities such as shopping (Rhoda et al.

2011; Rouillard et al. 2012), use of public transport (Rhoda et al. 2011; Rouillard et al. 2012), driving (Rhoda et al. 2011; Rouillard et al. 2012), recreation and leisure activities (Mudzi et al. 2013), going out socially (Rhoda et al. 2011; Mudzi et al. 2013), doing housework (Rhoda et al. 2011) and gardening (Rhoda et al. 2011; Rouillard et al. 2012). Gardening forms an integral part of living and independence, as vegetable gardens often form part of the food security plans of families living in impoverished communities. Wasserman et al. (2009) added an inability to participate in cultural activities.

The majority of current study participants indicated transport, services, systems and policies as a moderate to severe barrier to participation. Maleka et al. (2012), Grut et al. (2012), Vergunst et al. (2015) and Cawood and Visagie (2015) confirmed that transport caused challenges for persons with disabilities and stroke survivors. Findings indicated transport was often hard to reach, and was further challenged by high cost as big assistive devices such as wheelchairs incurred extra costs. High travel costs puts further financial pressure on individuals already experiencing extreme barriers with regards to finances. This very common problem has severe implications on the lives of stroke survivors. Community mobility is an essential component of community integration, that if impaired has far reaching consequences. Simply put if one cannot get to a place one cannot participate at the place. Thus without community mobility it is impossible for a person to participate in any community activities or to be employed outside the house. The current study findings of a lack of community mobility might severely hamper integration of persons with stroke into the community. These findings are further particularly relevant, considering that people navigate towards what is available and easily accessible (Ungar 2008). Thus, if resources that enable community participation or productivity and quality of life are not made available, quality of life is hugely influenced.

Rehabilitation programmes are not presented at a community level, and are not contextually responsive (Ungar 2008). Rehabilitation per se should be provided in a manner that enhances quality of life by being more responsive contextually. This echoes findings from around South Africa and even internationally. Access to mobility products posed barriers to the majority of participants. This further impacts individuals' ability to access transport and other services, as very often stroke survivors are dependent on a specific assistive device in order to be mobile. The study however did not specifically assess the type of assistive device needed by individuals (eg. wheelchairs) and this was a shortcoming of the study. Grut et al. (2012)

and Vergunst et al. (2015) found concurring results, indicating shortages of assistive devices and assets amongst participants.

Various community activities seemed to be met with much difficulty. The majority of participants experienced severe difficulty to participate in social, religious, sport and leisure activities. This is similar to findings from Rouillard et al. (2012), Rhoda et al. (2011) and Cawood et al. (2016). Mobility as a whole might have been the most prominent factor that influenced participation as accessing services also posted severe problems. However, impairments, personal- and environmental factors also played a role.

Difficulties with written communication and memory as experienced by around a third of participants could hamper utilising services as this often involve the completion of forms, certain leisure activities such as reading and employment in all but physical labour. Physical labour, participation in sport and more active hobbies in turn can be ruled out or markedly hampered by the physical effects of the stroke as manifested in weakness and spasticity. Assessing anatomical and physiological impairments were outside the scope of the study, so we do not know how weak the affected limbs were, but it is common to have some residual weakness of the trunk and limbs after stroke (Lawrence et al. 2001; Tipping 2008).

With regard to services, systems and policies, barriers were perceived with housing by 66% of participants. Cawood and Visagie (2015) found a similar situation with participants (70%) indicated housing barriers. Access to private and public buildings was another area that created severe or complete barriers to more than half of study participants. Grut et al. (2012) identified a serious need for infrastructure development. Urimubenshi and Rhoda (2011) similarly identified that participants perceived infrastructure to be inaccessible with a special mention of toilets. Inaccessible infrastructure can pose serious barriers to community participation.

The climate and terrain created barriers for many. The geographical area of Harrismith receives on average 529mm of rain per annum, mostly during spring and summer (SA Explorer 2014). Autumn tends to bring strong gushing winds, originating from the high Drakensberg areas and these winds are usually very cold. The region further tends to experience very cold winters, with temperatures often dropping below freezing point (SA Explorer 2014). Wet cold fronts in winter are a common occurrence. The unpredictability of the region's weather patterns has the ability to impact on the lives of stroke survivors.

Extreme cold circumstances experienced in the region often leave individuals with stiffness, pain and decreased mobility to a larger extent than the normal sunny day. This impacts negatively on people's activities and participation in everyday life situations, often as severe as not getting out of bed. Wet weather impacts severely on community mobility. Wet roads become muddy, slippery and inaccessible as poor infrastructure exists in township communities and most roads are gravel surfaced and uneven. Grut et al. (2012) indicated that gravel roads in poor conditions and often no paths to access roads served as barriers. Urimubenshi & Rhoda (2011) and Cawood and Visagie (2015) similarly found geographical surroundings caused barriers, indicating that inaccessible pathways, stairs and gravel roads with loose sand and large stones as well as potholes, caused difficulties. Findings from Maleka et al. (2012) add steep slopes and hills to the barriers caused by the natural environment.

An inability to perform life roles and environmental factors can affect quality of life in an adverse way, especially in low socio-economic circumstances (Jelsma et al. 2008). Thus with the participation restrictions and environmental barriers the current study participants experienced, it comes as no surprise that the overwhelming majority of participants (82%) perceived their general quality of life between very poor and neutral. What does seem surprising is that the domain QOL scores for these stroke participants were not dramatically lower than mean scores of stroke survivors from the United Kingdom. The mean score for psychological health was 13% higher in the current study. The mean scores for the other three domains were all lower (14% for both social and environmental health and 8% for physical health).

In the current study, recurring depressive affect was found to influence almost 60% of participants on a regular basis, for some a daily occurrence. This is within the wide range of previous figures on post stroke depression as reported in the literature review. According to findings by Abubakar and Isezuo (2012) depression is an independent determinant of poor quality of life after stroke. Thus the experience of depression amongst current participants might have negatively impacted the score of the domain psychological quality of life, which were the highest of the four domains, but still rather low at 64%, and overall quality of life.

Mannan and Turnbull (2007) suggests individual quality of life as an outcome measure of the rehabilitation process. With findings of low quality of life indications in the current study, a closer look at the rehabilitation process might bring further insight and perspective.

The package at PHC level as stipulated by the FSDRSA (NDOH 2013) requires professionals to assess and treat people with stroke at their respective local clinics. Rehabilitation teams from District Hospitals should provide services to PHC facilities within a defined health district and receive support from regional hospital specialists. Home visits are to be conducted, collaborating with Ward Based Primary Health Care Outreach Teams. Ward Based Primary Health Care Outreach Teams within Thebe/Phumelela District Hospital Complex primarily consist of PHC nurses. Current study findings indicated that only 24% of participants received a home visit from a health care worker. This was not necessarily a rehabilitation worker, rather in most instances it would have been a home based care giver. Furthermore 55% of participants indicated that they received follow up rehabilitation at their local clinic. Thus these two aspects of service delivery were lacking when compared to FSDRSA stipulations. These findings raise questions related to rehabilitation and continuity of care post institutionalisation. The aim of the rehabilitation process remains to improve the quality of life of people with disabilities, thus affirming Sherry's (2015) assertion that rehabilitation is seriously constrained, particularly in public sector and rural contexts.

The participants' activity, participation and environmental barrier scores, indicate poor outcomes and a need for intervention. Thus it is unfortunate that the majority of them (63%) received therapy for less than one month and a third received therapy for less than one week. The poor access to therapy and limited therapy received by even those who could access it probably explains why receiving therapy did not have a clinical impact on quality of life scores. The lack of therapy can probably be attributed to a number of factors. No information was gathered on whether participants did receive a follow up appointment, but did not attend or whether they did not receive an appointment. Thus not receiving an appointment might be a reason for no follow up. However, even if they did receive appointments, many barriers might have prevented attendance. Ntamo et al. (2013) showed in a study from the Eastern Cape (n=85) that 86% of participants with stroke attended physiotherapy outpatient appointments poorly. They found that a lack of money, time, transport and caregiver, as well as living in rural areas, staff attitudes and lack of staff lead to poor attendance (Ntamo et al. 2013). This tie in with service delivery challenges discussed earlier in chapter 1 within the Thebe/Phumelela District Hospital Complex.

Findings from the current study indicated that participants rarely received therapy from a multi-disciplinary team. A large number of participants did not receive Occupational Therapy

(48%), Speech Therapy (69%) and physiotherapy (37%). This concurs with existing findings that shortages of human resources for rehabilitation services are present within the public sector, especially in rural settings (Sherry 2015).

Furthermore a medical model approach still exists in practice, resulting in poor accessibility to services in rural areas (NDOH 2013). Poor collaboration between rehabilitation workers and Ward Based Primary Health Care Outreach Teams, as well as home based care givers, exist. As a result, patients who do not come to respective clinics or the hospital and are not followed up. Poor record keeping makes it extremely difficult to find individuals, with wrong phone numbers and addresses often found amongst patient data, as seen in the current study.

Transport difficulties also hamper outreach services, as often transport is not available to deliver services to rural communities. The unavailability of suitable, dedicated vehicles for rehabilitation personnel in order to reach the community with rehabilitation services remains a severe barrier. This is made worse by transport difficulties faced by people with disabilities, as transport has been found to be inaccessible and unaffordable to people with disability (NDOH 2013). Transport challenges were confirmed by the current study and previously documented by Maleka et al. (2012), Grut et al. (2012), Ntamo et al. (2013), Cawood and Visagie (2015) and Vergunst et al. (2015).

The FSDRSA indicates that rehabilitation and disability services are delivered with minimal integration of other priority health programmes and poor intersectoral collaboration (NDOH 2013). The CBR approach requires intersectoral collaboration in order to realise independent functioning of people with disabilities. These include the sectors of health, education, social development, public works, transport, human settlements as well as other sectors and NGOs. The current study population indicated barriers across the spectrum of above mentioned sectors. Most significantly education-, labour-, housing-, communication-, legal- and transport sectors provided barriers.

Just under half of the participants indicated that access to mobility products created severe to complete barriers. A wide range of assistive devices should be available for prescription at District Hospitals. Issuing of assistive devices should be done at clinics. A workshop with wheelchair repair services should be available within the community, stationed at selected clinics. Shortcomings of these much needed services within the Thebe/Phumelela District Hospital Complex were pointed out in chapter 1. Poor availability and insufficient

provisioning of assistive devices and more particularly sufficient assistive devices is acknowledged by the FSDRSA (NDOH 2013). This is further confirmed by findings, that access to mobility products posed barriers to the majority of participants in the current study, further supported by similar findings from Grut et al. (2012) and Vergunst et al. (2015).

Screening and referral for vocational rehabilitation should be provided at clinics. Vocational rehabilitation should be done at District Hospitals with referrals to specialised vocational rehabilitation centers where necessary (NDOH 2013). Vocational rehabilitation remains one of the biggest challenges in the Free State, with currently only one vocational rehabilitation centre in the province. District Hospitals remain understaffed, under-skilled and under-equipped in order to provide vocational rehabilitation services. The current study's finding that only 10% of participants under a relatively young population group received some form of vocational rehabilitation, serves as an indication of the challenges faced regarding vocational rehabilitation.

The FSDRSA further suggests healthcare providers have a lack of awareness and knowledge regarding the lives of people with disabilities and that negative attitudes towards people with disability still exist (NDOH 2013). This could be due to the educational approach towards healthcare professionals, as healthcare tuition is mostly grounded within a medical model approach. The current study however had contrasting findings, indicating that the majority of participants (84%) perceived no attitudinal barriers from healthcare workers and felt well supported by such. This is a positive indication of the direction health professionals are embarking on, with regards to rehabilitation and disability.

Inaccessible infrastructure at facilities that provide services, was found to pose accessibility challenges (NDOH 2013). Similarly, most of the current study participants perceived accessibility to private and public buildings as severe or complete barriers. Grut et al. (2012) and Urimubenshi and Rhoda (2011) confirm this and identified a serious need for infrastructure development.

Free State policy documents are outdated, with the latest available document on rehabilitation service delivery dated 2006. The Free State Rehabilitation Policy (FSDOH 2006) aims to deliver rehabilitation services that are accessible, affordable and equitable. Findings from the current study show the contrary. Rehabilitation services have been found to be inaccessible to a large extent, coming at an unaffordable cost, when the majority of participants' proportional

income is taken into account. This raises questions about the equitability of rehabilitation services in the rural areas of the Eastern Free State. Currently there is not a balance in service delivery between community- and institution-based rehabilitation as rehabilitation happens at an institutional level and follow up within the community is poor due to the various reasons discussed earlier. People with disability do not currently enjoy the benefits of having access and availability of all rehabilitation components such as social-, educational-, vocational-, and psychological rehabilitation. Shortages of appropriate assistive devices and other resources, hamper optimal service delivery. The lack of inter sectoral collaboration ensures a one dimensional approach to rehabilitation service delivery, not adhering to CBR principles. The health sector should engage and work hand in hand with other sectors, non-government organisations and the private sector ensure better accessibility to diverse services for people with disabilities.

Chapter 6

Conclusions and Recommendations

6.1 Conclusions

Transformation has been the task at hand in the Republic of South Africa since 1994, and much has been done to date. In disability and rehabilitation, the transformation process has been informed by different policies and the related changing theoretical and socio-political understandings. Most notably the Integrated National Disability Strategy (Office of the deputy president 1997) and the National Rehabilitation Policy (NRP) (DOH 2000) set the tone for rehabilitation service delivery in South Africa. Although the Free State adopted the NRP to inform service delivery, the policy seemed to be of symbolic nature only in the province. The objectives of the current study did not include evaluating rehabilitation services, but valuable information on participants' rehabilitation process was retrieved. This information shows that rehabilitation services seemed to be inaccessible, as the majority of participants received therapy for a period of less than a month. Formal vocational rehabilitation services seem to be critically insufficient and inaccessible.

The study participants from the Thebe/Phumelela District Hospital Complex achieved low functional and participatory outcomes and experience low quality of life after receiving healthcare and rehabilitation within the complex. While the causal relationship between the poor outcomes and rehabilitation service delivery or lack thereof has not been assessed, one can surmise that challenges with regard to rehabilitation service delivery did play a role, amongst other factors. These challenges were pointed out in chapter 1. Participants' informative responses regarding participatory outcomes and barriers faced as individuals and collectively, have given indications that rehabilitation services seem to be delivered in a one dimensional, medical model approach. Participants did not enjoy the benefits of having access to a comprehensive rehabilitation service which include social-, educational-, vocational-, and psychological rehabilitation that requires inter sectoral collaboration. It is clear from the findings that there is still a long way to go in the Free State towards meeting stipulations of various policies and guidelines, as this study contributes to demonstrating the failure to implement the NRP objectives.

New strategies and policies have since been established. With the National Development Plan 2030 (RSA 2013) and the Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015 – 2020 (NDOH 2013), matters regarding disability and rehabilitation services in the Free State need to be restructured and rehabilitation and other service delivery programmes need to be aligned to the stipulations of these documents.

In accordance with the ICF framework current findings showed that impairments caused by the stroke, in combination with environmental barriers, led to severe participation restrictions and disability. Participants from this Free State setting, similar to stroke survivors in other South African settings, achieved residential integration, but found participation in community activities, life roles and income generation extremely challenging and often experienced social seclusion. Intimacy was also found to be an area of significant difficulty for the majority of participants. Intimacy has not been explored in the previous South African studies on activities and participation restrictions experienced by stroke survivors.

Poor community mobility could be one of the most prominent reasons for not being able to participate in community activities. A lack of access to finances and assets remains a significant barrier to stroke survivors in rural areas, compromising the access to and participation in a number of activities. Multiple other barriers occur as a result, for instance, access to mobility products, transport and housing services.

In addition, the lack of participation and barriers might have contributed to what seems like low quality of life scores. Although the perception of an individual's quality of life remains a very personal and subjective matter, and I could find no norms for quality of life for this or similar populations to compare with, it seems as if both overall and domain quality of life scores were low.

6.2 Recommendations

The descriptive design served to help quantify the extent of environmental barriers faced and the outcomes achieved by stroke survivors in the study setting. Joubert and Ehrlich (2007) leads that studies of this nature provide useful information to service planners that can assist with prioritization, resource allocation and planning and delivering of appropriate health care and rehabilitation services. Thus the recommendations could serve to inform future planning

of rehabilitation services to Thebe/Phumelela District Hospital Complex and other rural areas in the Free State.

6.2.1 Information systems

Incomplete and inaccurate information on data base systems makes locating patients, and thus follow up, very difficult to impossible. Attention needs to be given to optimise patient data systems in order to ensure accurate and efficient patient data retrieval.

6.2.2 Resource allocation

Human resources

Without manpower it is impossible to deliver services to communities. Current vacancies of rehabilitation professionals need to be quantified and posts must be filled. Furthermore, staff establishments of health facilities need to be assessed in order to determine if there is a need to create and fund new posts for rehabilitation professionals, according to the population served and the geographical area covered. It is recommended that all district hospital based rehabilitation teams in the Free State should consist of full time employed physiotherapists, occupational therapists, speech and language therapists, social workers, psychologists and dieticians as stipulated by the FSDRSA (NDOH 2013). Audiologists and Medical Orthotist and Prosthetists should be present at all regional hospitals, supporting district facilities. Addressing the shortage of human resources, particularly community based, could contribute to the implementation of comprehensive, contextual rehabilitation services, with the ability to intervene in all areas of quality of life, including physical-, social- and psychological spheres.

Assistive devices

Assistive devices required post stroke might include mobility products, commodes and assistive devices that enable independent ADL activities such as, bathing, grooming, cooking and house work. These devices form a critical part of enablement, for an improved experience of quality of life and disability as they would enable better outcomes for functionality and participation in all aspects of life. It is recommended that managers and service providers are trained in the requirements of the South African guidelines on Assistive Device provision (DOH 2003). Knowledge of, and adherence to, the requirements of this document should enable them to secure and provide appropriate assistive devices to patients,

or if funding prevents it, to follow the correct waiting list and funding sourcing procedures. Budgets should be, in accordance to policy, allocated specifically for assistive devices and managed at facility level. Budgets can be calculated from numbers of assistive devices issued and waiting lists of previous financial years. With regard to wheelchairs it is recommended that service providers access the national wheelchair tender, instead of the current provincial one, in order to prescribe and issue specific wheelchairs, especially wheelchairs designed for rural areas.

Assistive device repair centres

It is recommended that district hospitals, which have the required space, accommodate repair workshops within their maintenance workshops. That way reparation of assistive devices could form part of the accessible services of the multi-disciplinary rehabilitation team. Facilities need to be provided with skilled technicians, or current technicians must receive further training, the necessary tools and parts.

6.2.3 Multi sectoral collaboration

Rehabilitation services should form part of a bigger team consisting of stakeholders from different government entities such as labour-, education- and social security departments in order to address environmental barriers effectively and deliver more effective services to people with stroke and other disabilities. Other role players in the community such as NGOs and community members representing disability matters should form part of the bigger team. Within this teamwork, the rehabilitation service users should be seen as playing an active role in the planning, implementing and evaluating of these rehabilitation services. This would promote a new way of looking at rehabilitation from the perspectives of persons with disabilities, bringing the notion of participation and quality of life and thus drawing indicators from communities, for rehabilitation services and resources at community level. On the other hand, rehabilitation professionals would gain a deeper understanding of the daily struggles faced by persons with disabilities/stroke at community level, which hinder community integration and what life enhancing and sustaining resources are needed to enable the negotiation and navigation of quality of life contextually.

It is recommended that an operational committee is established in each service delivery complex consisting of relevant stakeholders, including departments of rehabilitation services,

health, labour, housing, social support, social security, communication, transport, NGOs and disabled community members. The committee for service delivery to people with disability (CSDPWD) needs to function as a network, making people with disabilities and disability matters the central point of focus. This committee should further lobby for local policy development and implementation of local and national policy to benefit people with disability, arising from the needs encountered. The process of discharging a stroke patient into the community should include immediate integration into a support group, from where community integration will actively be pursued through various processes. Rehabilitation workers, as well as support groups, will act as gateways for persons with disabilities to access services in this network of service providers established by CSDPWD, and built around the interests of persons with disabilities as illustrated in Figure 6.1.

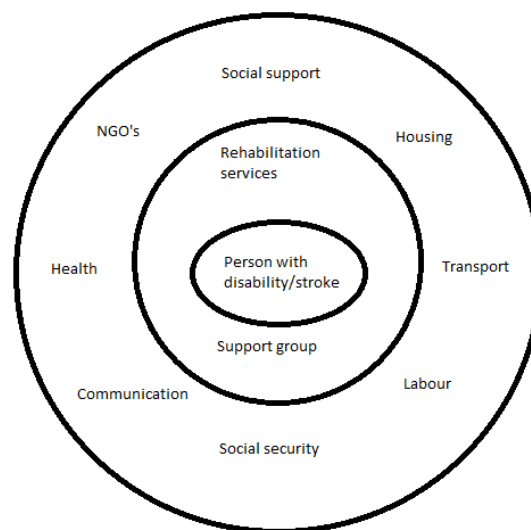


Figure 6.1: Proposed model for community based service delivery to people with disability

6.2.4 Stroke rehabilitation protocol

It is important to form a network of health professionals that engage the whole rehabilitation process of stroke survivors, facilitating independence from discharge to community integration and productive activity. It is recommended that a protocol is established, indicating rehabilitation pathways for stroke patients. This must be supported by communication and collaboration between doctors, therapists, dieticians, social workers,

psychologists, community health workers and ward based primary health care outreach teams. Included in this protocol:

- Every district hospital should have a stroke rehabilitation team consisting of one or more physiotherapist, occupational therapist, speech and language therapist, social worker, nurse, psychologist and dietician. One member of the team should act as liaison between the team and other service providers.
- All stroke patients should be referred to the rehabilitation team within 24 hours of admission.
- The attending doctor should consult the rehabilitation team before a stroke patient is discharged.
- Before discharge, stroke survivors and their families should receive family education and written information, with contact details, of different aspects of rehabilitation services. Rehabilitation professionals should inform and refer stroke survivors to access the network of services established by the CSDPWD.
- Community health workers and ward based primary health care outreach teams must be made aware of discharged stroke patients to ensure that home visits are done and patients receive healthcare. This must be done through concerted efforts by hospital and clinic staff.
- Community health workers and ward based primary health care outreach teams should work with stroke survivors to integrate them into support groups within their respective communities. To do this, training of these service providers is required. Training should be organised and done according to a structured package. Such a package is currently being developed in the rural districts of the Western Cape Province.
- Rehabilitation professionals, collaborating with community health workers and support groups, should work to integrate stroke patients into the community and access the network of services established by the CSDPWD.

6.2.5 Rehabilitation services

Specialised rehabilitation hospital

In accordance with the FSDRSA (NDOH 2013) guidelines it is recommended that the Free State Department of health facilitate the development of a specialist rehabilitation hospital.

With current district hospital bed occupancy protocols, stroke patients are discharged shortly after medical stability. This shortens the in-hospital rehabilitation period of stroke survivors. More time is needed for rehabilitation by rehabilitation service providers with specialist skills. Intensive rehabilitation should enable patients to recover many functional skills which might assist to ensure optimal functional outcomes and facilitate better residential and community integration.

Vocational rehabilitation facilities

It is recommended that district hospital rehabilitation departments are equipped to do vocational assessments and provide vocational rehabilitation services. Skills development of rehabilitation professionals and functional vocational assessment tools should be provided in order to deliver more accessible vocational services.

Development of CBR programmes

CBR programmes need to be developed to ensure inclusive communities, mainstreaming of disability and poverty reduction. Civil society and people with disabilities, with the help of NGOs and government entities, need to collaborate in order to establish a network of co-existing programmes that promote access to health, education, livelihood and social sectors for people with disabilities. People with disabilities need to be empowered and included to participate in development and decision making processes in the community.

The CSDPWD could serve as a platform to initiate CBR programmes. Challenges should be identified and answered by sustainable solutions devised by the committee. Activities such as raising awareness, building a network for service delivery, promoting inclusion by advocating for people with disability and building capacity of people with disability, play an important role to facilitate empowerment. CBR programmes should provide solutions such as rehabilitation services, environmental adaptations, assistive device provisioning, job opportunities, education and skills development, investment opportunities and more.

6.2.6 Transport and community accessibility

There is an urgent need to address transport needs for stroke survivors and people with disability, as a whole, in rural areas. This will require collaboration of government entities, NGOs, people with disabilities, taxi consortia and bus services. The CSDPWD as mentioned

earlier could be the ideal platform to lobby for better transport services, discussing viable solutions to the current challenges.

In conjunction with infrastructure developments that will enable better mobility in the community, government could look at the possibility to incentivise taxi services that accommodate PWD by changing routes and picking them up from more accessible locations in different areas of their respective communities.

A sustainable transport solution could be provided to persons with disability in different rural communities by establishing a free government transport service similar to the model of the well-known private business “Uber”. This model could be benchmarked and implemented throughout the Free State as a special project of Department of Transport and local government municipalities.

6.2.7 Infrastructure development

It is clear that there is a need for development of infrastructure in order to improve community mobility and accessibility for persons with stroke and other disabilities. Municipalities, in collaboration with department of public works, should look at improving existing infrastructure and developing new infrastructure to facilitate community mobility and accessibility. Tarred roads and paved sidewalks with low incline kerb ramps, are recommended. Municipalities and department of public works should conduct audits on accessibility of public buildings. Based on audit findings modifications should be made to meet accessibility standards. Furthermore, government entities renting private buildings in order to deliver services should stipulate and ensure minimum standards for accessibility are met before entering into rent agreements. Minimum standards for accessibility should be stipulated and enforced for all new infrastructure development projects in public spaces, including private and public sectors.

6.3 Recommendations for further research

- Studies to determine quality of life norms in various South African communities are recommended.
- Studies that provide baseline information on environmental barriers experienced by communities and prioritise addressing of barriers are recommended.

- Research is required to determine the accuracy and efficiency of current patient data collection systems in the rural areas and upgrade these where needed in order to better monitor and evaluate patient information.
- Further research on the mortality rate and causes of death of stroke patients in rural areas is needed.
- Studies on the needs, provision, services and use of assistive devices throughout South Africa is recommended.
- Research to determine norms for rehabilitation professionals needed proportional to population groups served in different service delivery areas, is recommended. The same needs to be done for vocational rehabilitation centres as well as dedicated rehabilitation facilities.
- Research needs to be done to determine skills levels of stroke survivors and PWD, as well as needs for skills development and employability.
- Further research on source of income of stroke survivors and the sufficiency of disability grants is recommended.

6.4 Limitations of the study

All participants were diagnosed with stroke by a medical doctor. Due to the unavailability of brain scans diagnosis of stroke was based on clinical assessment by doctors and not investigative testing. Due to inaccurate data base information not all possible participants could be identified and traced. Thus the findings might not be a true reflection of the entire stroke population of the geographic area. Rehabilitation process information was acquired through interviews with participants. The researcher did not use medical files for verification of information provided by participants and did not collect data from service providers and managers. Participants indicated therapy received from different rehabilitation professionals. The information provided did however not cover whether there was a need for the various mentioned rehabilitation services. The researcher did not evaluate the need and availability of specific assistive devices, especially wheelchairs. ICF based questionnaires on activities and participation as well as environmental barriers were not tested for reliability and validity in rural South African settings. A mixed method design, with a qualitative component, would have provided a deeper understanding of the findings. However, the requirements of a research assignment (being a small contained study) and the time frame precluded that.

6.5 Dissemination of Results

Conclusions and recommendations of the study will be summarised and made available to health facilities involved in the study. A meeting will be arranged where the contents will be discussed with different stake holders. This will include the manager of Thebe Hospital, clinic managers, district managers, clinical teams and rehabilitation staff. A summary of conclusions and recommendations of the study will be presented and discussed with all rehabilitation managers in the district at the district rehabilitation meeting. The researcher will submit an abstract to Free State Department of Health, in order to present feedback and results at the 2017 annual provincial research day. Meetings will be set up with different government entities, municipal councillors, NGOs and people with disability in the region to present and discuss results of the study. The aim is to initiate the process of mobilisation towards establishing the CSDPWD.

Findings will also be published in an accredited, peer reviewed journal.

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Appendix 1: Questionnaire on demographics and rehabilitation process

Patient reference number

Questions will be directed to participants by the researcher in a structured interview.

Kindly answer all questions to the best of your ability.

Demographic Data:

1. Gender

| | | | |
|------|---|--------|---|
| Male | 1 | Female | 0 |
|------|---|--------|---|

2. Age group

| | | | | | | | | | | | | | |
|-------|---|-------|---|-------|---|-------|---|-------|---|-------|---|-----|---|
| 18-30 | 1 | 31-40 | 2 | 41-50 | 3 | 51-60 | 4 | 61-70 | 5 | 71-80 | 6 | 80+ | 7 |
|-------|---|-------|---|-------|---|-------|---|-------|---|-------|---|-----|---|

3. Home language

| | | | | | | | | | |
|---------|---|-----------|---|-------|---|------|---|-------|---|
| English | 1 | Afrikaans | 2 | Sotho | 3 | Zulu | 4 | Other | 5 |
|---------|---|-----------|---|-------|---|------|---|-------|---|

4. Marital status

| | | | | | | | |
|--------|---|---------|---|----------|---|----------|---|
| Single | 1 | Married | 2 | Divorced | 3 | Widow/er | 4 |
|--------|---|---------|---|----------|---|----------|---|

5. Educational status

| | |
|-------------------------------------|---|
| No formal education | 1 |
| Some Primary School education | 2 |
| Complete primary school education | 3 |
| Some Secondary school education | 4 |
| Complete Secondary school education | 5 |
| Tertiary education | 6 |

6. Employment prior to stroke

| | |
|----------------------|---|
| Self employed | 1 |
| Permanently employed | 2 |
| Temporary employed | 3 |
| Unemployed | 4 |

7. Employment status currently

| | |
|----------------------------------|---|
| Employed | 1 |
| Unemployed, looking for work | 2 |
| Unemployed, not looking for work | 3 |
| Student/Scholar | 4 |

8. Do you receive a disability grant?

| | | | |
|-----|---|----|---|
| Yes | 1 | No | 2 |
|-----|---|----|---|

9. Were you the primary breadwinner in your family before the stroke?

| | | | |
|-----|---|----|---|
| Yes | 1 | No | 2 |
|-----|---|----|---|

10. Are you the primary breadwinner in your family currently?

| | | | |
|-----|---|----|---|
| Yes | 1 | No | 2 |
|-----|---|----|---|

11. Family income per month

| | |
|-------------------|---|
| Less than R1000 | 1 |
| R1001 - R2000 | 2 |
| R2001 - R3000 | 3 |
| R3001 - R4000 | 4 |
| R4001 - R5000 | 5 |
| R5001 - R10 000 | 6 |
| R10 001 - R15 000 | 7 |
| R15 000 + | 8 |

12. What type of dwelling is your home environment?

| | |
|-------------------------|---|
| Brick house | 1 |
| Flat/Apartment | 2 |
| Traditional dwelling | 3 |
| Informal dwelling/Shack | 4 |
| Institution | 5 |
| Other | 6 |

13. Do you have the following resources INSIDE your house?

| Resource | Yes | No |
|-----------------|-----|----|
| Electricity | 1 | 2 |
| Flushing toilet | 1 | 2 |
| Running water | 1 | 2 |

Medical Data:

14. What side is your hemiplegia?

| | | | |
|------|---|-------|---|
| Left | 1 | Right | 2 |
|------|---|-------|---|

15. Have you had a previous stroke?

| | | | |
|-----|---|----|---|
| Yes | 1 | No | 2 |
|-----|---|----|---|

Rehabilitation Data:

16. Did you receive rehabilitation after you had a stroke?

| | | | |
|-----|---|----|---|
| Yes | 1 | No | 2 |
|-----|---|----|---|

17. Did you receive rehabilitation at any of the following places?

| Place of rehabilitation | Yes | No |
|----------------------------------|-----|----|
| Thebe Hospital as an In-patient | 1 | 2 |
| Thebe Hospital as an Out-patient | 1 | 2 |
| At your local clinic | 1 | 2 |
| At your house | 1 | 2 |

18. What type of rehabilitation did you receive?

| Type of rehabilitation | Yes | No |
|------------------------|-----|----|
| Occupational therapy | 1 | 2 |
| Speech therapy | 1 | 2 |
| Physiotherapy | 1 | 2 |
| Dietetics | 1 | 2 |
| Counselling | 1 | 2 |

19. How often did you receive rehabilitation at Thebe Hospital as an IN-PATIENT?

| | |
|---------------------------|---|
| Once a day, every day | 1 |
| Twice a day, every day | 2 |
| Two to three times a week | 3 |
| Once a week | 4 |
| Not once | 5 |

20. How often did you receive rehabilitation at Thebe Hospital or your local clinic as an OUT-PATIENT?

| | |
|---------------------------|---|
| Once a day, every day | 1 |
| Two to three times a week | 2 |
| Once a week | 3 |
| Once a month | 4 |
| Less than once a month | 5 |
| Not once | 6 |

21. How long was your total period of rehabilitation?

| | |
|-----------------------|---|
| Less than one week | 1 |
| Two weeks | 2 |
| One month | 3 |
| Two months | 4 |
| Three months | 5 |
| Four months | 6 |
| More than four months | 7 |

22. Did you and your family receive training and education on stroke?

| | | | |
|-----|---|----|---|
| Yes | 1 | No | 2 |
|-----|---|----|---|

23. Did you receive information on avoiding the following secondary complications:

| Complication: | Yes | No |
|-------------------------------|-----|----|
| Preventing chest infections | 1 | 2 |
| Preventing contractures | 1 | 2 |
| Preventing pressure sores | 1 | 2 |
| Preventing aspiration | 1 | 2 |
| Preventing a painful shoulder | 1 | 2 |

24. Did you receive a home visit from a healthcare worker?

| | | | |
|-----|---|----|---|
| Yes | 1 | No | 2 |
|-----|---|----|---|

25. Did you receive a work and skills assessment?

| | | | | | |
|-----|---|----|---|----------------|---|
| Yes | 1 | No | 2 | Not applicable | 3 |
|-----|---|----|---|----------------|---|

26. Did you receive vocational training?

| | | | | | |
|-----|---|----|---|----------------|---|
| Yes | 1 | No | 2 | Not applicable | 3 |
|-----|---|----|---|----------------|---|

27. Did you and your employer receive education on your disability?

| | | | | | |
|-----|---|----|---|----------------|---|
| Yes | 1 | No | 2 | Not applicable | 3 |
|-----|---|----|---|----------------|---|

28. Was reasonable accommodations made in your working environment?

| | | | | | |
|-----|---|----|---|----------------|---|
| Yes | 1 | No | 2 | Not applicable | 3 |
|-----|---|----|---|----------------|---|

Appendix 2: Questionnaire on activities and participation

Patient reference number

Questions will be directed to participants by the researcher in a structured interview.

The following questions deal with your ability to perform certain tasks and participate in activities that you might find important.

Kindly choose the option that describes your ability to perform certain tasks to the best of your ability.

Communication and cognitive participation

1. Overall, how do you feel you communicate with others?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

2. Are you able to listen to others when they speak to you?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

3. Are you able to speak and express yourself with words?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

4. Are you able to understand others when they speak to you?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

5. Are you able to communicate with a communication board?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

6. Are you able to read?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

7. Are you able to write?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

8. Are you able to remember things well?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

9. Are you able to concentrate for long periods of time?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

Mobility

10. How do you feel you are able to move around overall?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

11. Are you able to do transfers? (Move from bed to chair, chair to toilet etc...)

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

12. Are you able to lift and carry objects?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

13. Are you able to stand up from sitting?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

14. Are you able to walk around INSIDE the house?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

15. Are you able to walk/move around INSIDE the house using an assistive device or walking aid?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

16. Are you able to walk/move around far distances outside of the house?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

17. Are you able to stand up from sitting on the floor?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

18. Are you able to climb stairs?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

19. Are you able to use public transport?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

20. Are you able to drive?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

Self-Care

21. Are you able to wash yourself?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

22. Are you able to dress yourself?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

23. Are you able to use the toilet by yourself?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

24. Are you able to groom yourself?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

25. Are you able to eat by yourself?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

26. Are you able to look after your own health? (Take medication, prevent complications etc.)

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

Domestic Life

27. Are you able to prepare meals for yourself?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

28. Are you able to do shopping and buy necessary things for home?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

29. Are you able to access and make use of services? Bank, post office etc.

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

30. Are you able to do chores and housework? (Washing dishes, ironing etc.)

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

31. Do you feel safe at home alone?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

Relationships

32. Overall do you feel you have good relationships with different people?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

33. Do you spend time with people within your community? (Neighbours etc.)

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

34. Are you able to make new friends within your community?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

35. Do you feel you have good relationships with family members?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

36. Are you able to have an intimate relationship with your life partner? (Sexual relations)

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

Community integration

37. Do you participate in social activities?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

38. Do you go to church/ religious events and activities?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

39. Do you spend time with a support group?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

40. Do you participate in politics by voting or attending meetings?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

41. Do you exercise a hobby?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

42. Do you participate in sport activities?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

43. Do you manage and control your own finances? (Collect own grant, spend money)

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

Productive activity

44. Are you able to look for a job? (Apply for job, have a CV)

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

45. Are you able to work to generate an income?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

46. Are you able to be economically self-sufficient?

| | | | | | | | | | |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|
| No difficulty | 1 | Moderate difficulty | 2 | Severe difficulty | 3 | Not able to do task | 4 | Not applicable | 5 |
|---------------|---|---------------------|---|-------------------|---|---------------------|---|----------------|---|

Appendix 3: Questionnaire on environmental barriers.

Patient reference number

Questions will be directed to participants by the researcher in a structured interview.

The following questions deal with certain things in your environment that could hinder you to perform tasks and participate in activities that you might find important.

Kindly choose the option that describes to what extent each of these things impact your ability to perform certain tasks to the best of your ability.

Please indicate whether you experience any barriers in the following areas:

Products and technology

1. Do you access food, water and medication to use as necessary?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

2. Do you access equipment to perform your everyday tasks?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

3. Do you access items used for communication. (Cell phone, computer etc.)

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

4. Products used for mobility and transport

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

5. Are you able to access private buildings? (Homes, private businesses etc.)

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

6. Are you able to access public buildings? (Post office, library, banks etc.)

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

7. Do you have finances and other assets you are able to use? (Money, property etc.)

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

Natural and man-made environment

8. Does the climate in your everyday environment impact your life?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

9. Is it light enough to see well in your everyday environment?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

10. Does sound/noise in your everyday environment impact your life?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

11. Does the terrain in your everyday environment impact your life? (Uneven, loose ground, stairs etc.)

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

Support and relationships

12. Do you feel supported by relationships with your family?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

13. Do you feel supported by relationships with your friends?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

14. Do you feel supported by relationships with acquaintances, community members etc.

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

15. Do you feel supported by relationships with personal care providers?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

16. Do you feel supported by relationships with your professional healthcare providers?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

17. Do you feel supported by relationships with professionals in other sectors than health?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

Attitudes of different people towards you

18. Do you experience bad attitudes from family members?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

19. Do you experience bad attitudes from friends?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

20. Do you experience bad attitudes from acquaintances, community members etc.

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

21. Do you experience bad attitudes from personal care providers?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

22. Do you experience bad attitudes from professional healthcare providers?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

23. Do you experience bad attitudes from professionals in other sectors than health?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

24. Do you generally experience bad attitudes from society?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

Services, systems and policies

25. Do you access/benefit from housing services, systems and policies?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

26. Do you access/benefit from communication services, systems and policies?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

27. Do you access/benefit from information services, systems and policies?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

28. Do you access/benefit from transport services, systems and policies?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

29. Do you access/benefit from legal services, systems and policies?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

30. Do you access/benefit from social security services, systems and policies?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

31. Do you access/benefit from general social support services, systems and policies?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

32. Do you access/benefit from healthcare services, systems and policies?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

33. Do you access/benefit from education services, systems and policies?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

34. Do you access/benefit from labour and employment services, systems and policies?

| | | | | | | | |
|------------|---|------------------|---|----------------|---|------------------|---|
| No barrier | 1 | Moderate barrier | 2 | Severe Barrier | 3 | Complete barrier | 4 |
|------------|---|------------------|---|----------------|---|------------------|---|

Appendix 4: WHOQOL-BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. Please choose the answer that appears most appropriate. If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last four weeks.

| | | Very poor | Poor | Neither poor nor good | Good | Very good |
|----|--|-----------|------|--------------------------|------|-----------|
| 1. | How would you rate your quality of life? | 1 | 2 | 3 | 4 | 5 |

| | | Very dissatisfied | Dissatisfied | Neither satisfied nor dissatisfied | Satisfied | Very satisfied |
|----|---|-------------------|--------------|---------------------------------------|-----------|----------------|
| 2. | How satisfied are you with your health? | 1 | 2 | 3 | 4 | 5 |

The following questions ask about how much you have experienced certain things in the last four weeks.

| | | Not at all | A little | A moderate amount | Very much | An extreme amount |
|----|--|------------|----------|-------------------|-----------|-------------------|
| 3. | To what extent do you feel that physical pain prevents you from doing what you need to do? | 5 | 4 | 3 | 2 | 1 |
| 4. | How much do you need any medical treatment to function in your daily life? | 5 | 4 | 3 | 2 | 1 |
| 5. | How much do you enjoy life? | 1 | 2 | 3 | 4 | 5 |
| 6. | To what extent do you feel your life to be meaningful? | 1 | 2 | 3 | 4 | 5 |
| | | | | | | |

| | | Not at all | A little | A moderate amount | Very much | Extremely |
|----|---|------------|----------|-------------------|-----------|-----------|
| 7. | How well are you able to concentrate? | 1 | 2 | 3 | 4 | 5 |
| 8. | How safe do you feel in your daily life? | 1 | 2 | 3 | 4 | 5 |
| 9. | How healthy is your physical environment? | 1 | 2 | 3 | 4 | 5 |

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

| | | Not at all | A little | Moderately | Mostly | Completely |
|-----|--|------------|----------|------------|--------|------------|
| 10. | Do you have enough energy for everyday life? | 1 | 2 | 3 | 4 | 5 |
| 11. | Are you able to accept your bodily appearance? | 1 | 2 | 3 | 4 | 5 |
| 12. | Have you enough money to meet your needs? | 1 | 2 | 3 | 4 | 5 |
| 13. | How available to you is the information that you need in your day-to-day life? | 1 | 2 | 3 | 4 | 5 |
| 14. | To what extent do you have the opportunity for leisure activities? | 1 | 2 | 3 | 4 | 5 |

| | | Very poor | Poor | Neither poor nor good | Good | Very good |
|-----|--------------------------------------|-----------|------|-----------------------|------|-----------|
| 15. | How well are you able to get around? | 1 | 2 | 3 | 4 | 5 |

| | | Very dissatisfied | Dissatisfied | Neither satisfied nor dissatisfied | Satisfied | Very satisfied |
|-----|--|-------------------|--------------|------------------------------------|-----------|----------------|
| 16. | How satisfied are you with your sleep? | 1 | 2 | 3 | 4 | 5 |
| 17. | How satisfied are you with your ability to perform your daily living activities? | 1 | 2 | 3 | 4 | 5 |
| 18. | How satisfied are you with your capacity for work? | 1 | 2 | 3 | 4 | 5 |

| | | | | | | |
|-----|---|---|---|---|---|---|
| 19. | How satisfied are you with yourself? | 1 | 2 | 3 | 4 | 5 |
| 20. | How satisfied are you with your personal relationships? | 1 | 2 | 3 | 4 | 5 |
| 21. | How satisfied are you with your sex life? | 1 | 2 | 3 | 4 | 5 |
| 22. | How satisfied are you with the support you get from your friends? | 1 | 2 | 3 | 4 | 5 |
| 23. | How satisfied are you with the conditions of your living place? | 1 | 2 | 3 | 4 | 5 |
| 24. | How satisfied are you with your access to health services? | 1 | 2 | 3 | 4 | 5 |
| 25. | How satisfied are you with your transport? | 1 | 2 | 3 | 4 | 5 |

The following question refers to how often you have felt or experienced certain things in the last four weeks.

| | | Never | Seldom | Quite often | Very often | Always |
|-----|--|-------|--------|-------------|------------|--------|
| 26. | How often do you have negative feelings such as blue mood, despair, anxiety, depression? | 5 | 4 | 3 | 2 | 1 |

Do you have any comments about the assessment?

Appendix 5: Participant information leaflet and informed consent form

Functional and Participatory Outcomes and quality of life of Stroke Survivors in the Rural Eastern Free State

Project number:

Principal investigator: Petri Cook

Address: Thebe District Hospital

End of Mauritz Street

Harrismith

9880

Contact number: 058 6241840(W) / 0764855158(C)

You are hereby invited to partake in a research project for Stroke survivors. Participation in this project will be voluntary and will be kept confidential. You have the right to decline participation, which will not affect you negatively in any way. You are free to withdraw from the study at any time, even if you first agreed, without any consequences or negative effect on future rehabilitative treatments. Carefully read the information provided which explain the details of the research project. Please do not hesitate to ask any questions regarding the study you do not understand. It is important that you understand what the research project entails and what your role will be in the project.

This study has been approved by the Health Research Ethics Committee (HREC) 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. (Ref nr S14/10/231)

What is this research study all about?

The aim of this research study is to evaluate the outcomes of participation and quality of life that stroke survivors achieve after rehabilitation and what stands in the way of achieving it.

Who will be involved in this study?

All willing persons above the age of 18, who have survived stroke and received care at Thebe District Hospital between the time frame of 1 January 2012 and 31 December 2015. It is estimated that more or less fifty (50) participants will partake in this study.

Why have you been invited to participate?

You have been invited because you have survived a stroke and received care in Thebe District Hospital. Your inputs will be very valuable to the study and will help us to improve services.

What will your responsibilities be?

You will have to give feedback on questions asked about what you are able to do, how you feel about certain things and life in general. This will be done at your nearest local clinic. This will take approximately one hour of your time.

Will you benefit from taking part in this research?

You will have the opportunity to give feedback and give your views on matters. Your feedback will help therapists to improve therapeutic service delivery and rehabilitation services to the disabled population and people with stroke specifically.

Are there risks involved in your taking part in this research?

There will be no personal risks involved by taking part in this study. Should the process cause any form of distress, counselling will be provided by a clinical psychologist.

Will other people have access to this information?

All information will be protected and regarded as confidential. Your identity will remain anonymous at all times.

Will you have access to information/answers?

Information regarding the study outcomes only will be made available to you and other study participants upon request.

Will you be paid to take part in this study and are there any costs involved?

There will be no remuneration and your participation in this study is voluntary. Travel costs for the purpose of this study will be reimbursed.

Do you require any other information, clarity or have any questions?

Please do not hesitate to contact the researcher, Petri Cook, at Thebe District Hospital, Harrismith if you have any questions or concerns. You can contact him telephonically at 0764855158 or 0586241840. You can visit him at your local clinic or at Thebe District Hospital. The Committee for Human Research can be contacted at 021-938 9207 if you have any complaints or concerns. A copy of this information will be given to you for record purposes.

Declaration by investigator

I (full name) _____ declare that:

The information in this document was explained clearly to the participant. He/she was encouraged to ask questions. All questions were answered to the participant's satisfaction. I am satisfied that he/she understands all aspects of the research study, as discussed above.

Signed at (place) _____ on (date) _____ 2015.

Participant Signature

Witness Signature

Declaration by translator

I (full name) _____ declare that:

I assisted the researcher to explain the information in this document to the participant in his/her language of choice which is _____. The participant was encouraged to ask questions. All questions were answered to the participant's satisfaction. Information was translated and conveyed factually and correctly. I am satisfied that he/she understands all aspects of the research study, as discussed above.

Signed at (place) _____ on (date) _____ 2015.

Participant Signature

Witness Signature

Declaration by participant

I (full name) _____ agree to take part in a research study entitled

I declare that:


- I have read or had read to me this information and consent form and that it is written in a language with which I understand and am comfortable with.
- I have had a chance to ask questions and all my questions have been answered to my satisfaction.
- I understand that taking part in this study is my own choice and I have not been pressurised to take part.
- I may choose to withdraw from the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished if the researcher feels it is in my own best interests, or if I do not follow the study plan as agreed to.

Signed at (place) _____ on (date) _____ 2015.

Participant Signature

Witness Signature

Appendix 6: Ethical approval letter

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| <div style="text-align: center;"> UNIVERSITEIT • STELLENBOSCH • UNIVERSITY jou kennisvenoot • your knowledge partner</div> <div style="text-align: center;">Approved with Stipulations New Application</div> <p>01-Dec-2014 Cook, Petri PJ</p> <p>Ethics Reference #: S14/10/231</p> <p>Title: Participatory outcomes, quality of life and barriers faced by stroke survivors in the rural Eastern Free State.</p> <p>Dear Mr Petri Cook,</p> <p>The New Application received on 30-Oct-2014, was reviewed by members of Health Research Ethics Committee 2 via Expedited review procedures on 19-Nov-2014.</p> <p>Please note the following information about your approved research protocol:</p> <p>Protocol Approval Period: 27-Nov-2014 -27-Nov-2015</p> <p>The Stipulations of your ethics approval are as follows:</p> <ol style="list-style-type: none">1. All instruments as attached require instructions to users.2. Qualitative data analysis - it is advised to use a standardised process of data analysis - a number of such frameworks are available.3. You will need to compile 3 different informed consent forms (ICF's) i.e.<ol style="list-style-type: none">3.1 Phase 1 of study for participants: This is the ICF that you currently have. However, you need to include in this ICF the length of time it will take the participants to complete the 4 questionnaires; also under the section of payment, you need to include that they will be reimbursed for travel expenses.3.2 Phase 2 of study for participants: You need to compile a separate ICF for the interviews that will be conducted.3.3 Interviews with health professionals: You need to compile a separate ICF for the interviews that will be conducted <p>Please remember to use your <u>protocol number</u> (S14/10/231) on any documents or correspondence with the HREC concerning your research protocol.</p> <p>Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.</p> <p><u>After Ethical Review:</u></p> <p>Please note a template of the progress report is obtainable on www.sun.ac.za/rds and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.</p> <p>Translation of the consent document to the language applicable to the study participants should be submitted.</p> <p>Federal Wide Assurance Number: 00001372 Institutional Review Board (IRB) Number: IRB0005239</p> <p>The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).</p> |
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Appendix 7: Permission letter



health

Department of
Health
FREE STATE PROVINCE

16 February 2015

Mr PJ Cook
University of Stellenbosch
Faculty of Health Science

Dear Mr PJ Cook

Subject: Participatory outcomes, quality of life and barriers faced by stroke survivors in the Rural Free State

The above mentioned correspondence bears reference.

- Permission is hereby granted for the above – mentioned research on the following conditions:
- Participation in the study must be voluntary.
- A written consent by each participant must be obtained.
- Ascertain that your data collection exercise neither interferes with the day to day running of the health facilities nor the performance of duties by the respondents.
- Serious Adverse events to be reported to the Free State department of health and/ or termination of the study.
- Confidentiality of information will be ensured and no names will be used.
- Research results and a complete report should be made available to the Free State Department of Health on completion of the study (a hard copy plus a soft copy).
- Progress report must be presented not later than one year after approval of the project to the Ethics Committee of the University of the University Stellenbosch and to Free State Department of Health.
- Any amendments, extension or other modifications to the protocol or investigators must be submitted to the Ethics Committee of the University Stellenbosch and to Free State Department of Health.
- Conditions stated in your Ethical Approval letter should be adhered to and a final copy of the Ethics Approval should be submitted to khusemj@fshealth.gov.za or sebeelats@fshealth.gov.za before you commence with the study
- No financial liability will be placed on the Free State Department of Health
- Please discuss your study with the institution manager on commencement for logistical arrangements
- Department of Health to be fully indemnified from any harm that participants and staff experiences in the study
- Researchers will be required to enter in to a formal agreement with the Free State department of health regulating and formalizing the research relationship (document will follow)
- You are encouraged to present your study findings/results at the Free State Provincial health research day
- Future research will only be granted permission if correct procedures are followed see <http://nhrd.hst.org.za>

Trust you find the above in order.

Kind Regards

Dr D Motau
HEAD: HEALTH

Date: 28/02/2015

Head : Health
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