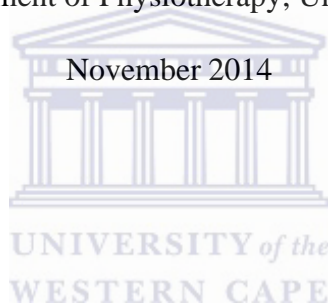


**PARTICIPATION RESTRICTIONS OF STROKE PATIENTS LIVING IN THE
COMMUNITY AT SELECTED COMMUNITY HEALTH CENTRES IN THE
METROPOLE DISTRICTS IN THE WESTERN CAPE, SOUTH AFRICA**

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3302415

A thesis submitted in partial fulfilment of the requirements for a Masters degree in
Physiotherapy in the Department of Physiotherapy, University of the Western Cape



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KEYWORDS

Stroke

Disability

International Classification of Functioning, Disability and Health

Physiotherapy

Impairment

Activity Limitation

Participation Restrictions

Community Health Centers

Metropole District

South Africa



ABSTRACT

Stroke is the second leading cause of death globally and the consequences on human and economic health are of major concern. The aim of this study was to determine and explore the participation restrictions experienced by stroke patients. The study populations were stroke patients living within the community in Western Cape, South Africa. A mixed methods approach was used to collect data in this study which consisted of two phases. For the first phase, the descriptive, observational cross sectional design was used to determine the participation restrictions of stroke patients living within the community and the factors associated with community with respect to integration. In this phase, an interviewer-administered questionnaire was used to collect data; the instrument for this study is the standard World Health Disability Assessment Schedule 2.0 (WHODAS 2.0) for disability assessment which includes the International Classification of Functioning Health and Disability (ICF) concept in disability assessment which has been tested and found to be reliable and valid, to determine various participation restrictions among stroke patients living in the society. While in the second phase of this study, two focus group discussions were conducted at the selected community health centre, these participants were conveniently selected from those who participated in the first phase of the study. This was conducted to retrieve in-depth information on difficulties encountered in participating in daily life situations. The Statistical Package for Social Sciences (SPSS) was used for descriptive and inferential statistics. Chi square and Anova t-test was used to determine the association between the demographics statistic and participation restrictions. Alpha level was set at 0.05. For qualitative findings, audiotaped interviews and note taken were transcribed and translated into English; the expressed ideas were coded and reduced into subthemes, themes and categories. Ethical clearance and permission to conduct study was sought, consents from participants were sought, clearly stating the right to participate and withdraw from the study was respected and anonymity and confidentiality has been ensured.

The result of the study showed that participants encountered difficulty with cognition, (23.3% of participants reported severe difficulty in learning a new task; 20% reported severe difficulty analyzing and finding solution to day to day activities), mobility (34% acknowledged difficulty walking a long distance like one kilometre after stroke), self-care (44% indicated difficulty staying alone for few days after stroke, while the majority, 61% complaints of difficulty with getting dressed by self), getting along with people with the majority of the difficulties (36%) are sexual activities, household activities with major complaints (46.6% and 31.4%, for severity and exemption respectively) in getting needed household work done, severe difficulty (51.7%) reported in relaxation and pleasure after stroke, 50.8% been financially restrained after stroke, 40% with difficulty in joining in the community activities, 39.2% severely affected by people perception towards them and 25.8% of the participants indicated extreme time spent on health; all difficulties investigated within the society 30 days after the incidence of stroke. However, the result of the qualitative phase reported the participation restrictions experienced by the participants. Difficulty in cognition was reported, which promotes indiscipline among family members. Limitation in activity level such as in mobility (walking for a long distance, standing from a sitting position), in self-care (washing the whole body, eating, staying alone after stroke), in getting along (maintaining friendship, sexual activities), in household activities and work activities was reported. Participants experienced difficulty in joining in community activities, emotional fluctuations, poor perception of attitudes of others after stroke, excessive use of time on health conditions, increased financial impact of health condition and burden impact on family was reported. Environmental barriers such as transportation and toilet facilities were reported. The current study findings suggest appropriate and specific programmes should be aimed at improving participation among stroke survivors in the community.

DECLARATION

I hereby declare that **“Participation Restrictions Of Stroke Patients Living In The Community At Selected Community Health Centres In The Metropole Districts In The Western Cape, South Africa”** is my own work, that it has not been submitted for any degree or examination in any other university, and that all the sources used or quoted have been indicated and acknowledged by complete references.

Arowoia, Ayorinde Ibukun

Signature.....



November, 2014

Witness.....

Professor Anthea Rhoda

DEDICATION

I dedicate this thesis to my family (dad, mom, brothers and sisters) who always believed in me, provided me with the love and constant support that was needed to complete my work. May God continue to bless you all.



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I would like to express my sincere gratitude and appreciation to the following people and institutions for their contributions:

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To all the Participants.

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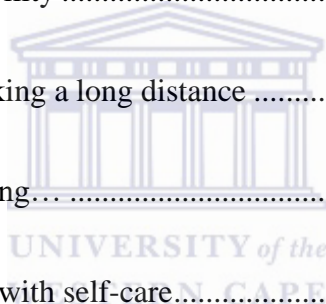


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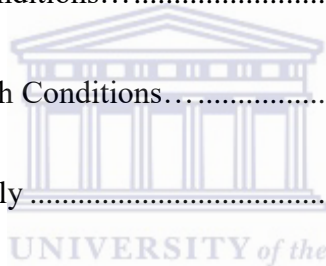
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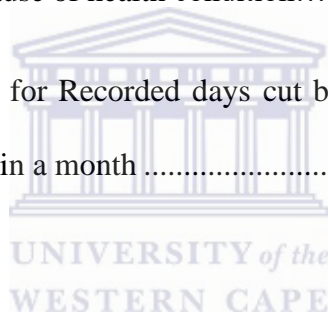
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ABBREVIATIONS

ACHPR – African Commission on Human and Peoples’ Rights

ADL – Activities of Daily Living

AHCPR – Agency for Health Care Policy and Research

DOH – Department of Health

DV- Dependent Variable

HIV – Human Immunodeficiency Virus

HRQOL –Health Related Quality of Life

ICF – International Classification of Functioning, Health and Disability

IDV- Independent Variable

IRT- Items Response Theory-based Scoring

Max - Maximum

Min- Minimum

MONICA – Monitoring of Trends and Determinants of Cardiovascular Disease

PADL – Personal Activities of Daily living

PNF –Proprioceptive Neuromuscular Facilitation

QOL – Quality of life

SASPI - Southern Africa Stroke Prevention Initiative

SD – Standard Deviation

SPSS – Statistical Package for Social Science

TIA –Transient Ischaemic Attack

UK – United Kingdom

USA – United State of America

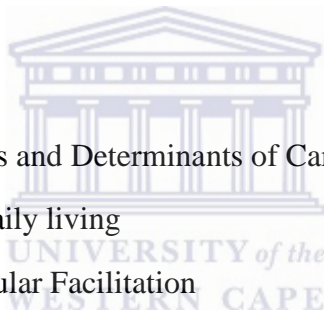
UWC – University of the Western Cape

WHOQOL – BREF- World Health Organisation Quality of Life

WHODAS 2.0 –World Health Organisation Disability Assessment Schedule 2.0

WHO – World Health Organisation

% - Percentage



CHAPTER ONE

1.1 INTRODUCTION

This chapter begins with a background to the study. It presents the history of stroke throughout the world generally, with a major focus on developing countries. The worldwide burden of stroke, participation restrictions and its impact on community in respect of integration are discussed. This chapter discusses the motivation for this research to be carried out, highlighting the problem statement, research question, aims and objectives, significance of study. The chapter ends with the definition of terms used in the course of the study, full meaning of abbreviations and the general outline of the whole study.

1.2 BACKGROUND

Worldwide, 9% of deaths are caused by stroke (Zhang, Dewey, Cadilhac & Donnan, 2011). Stroke is the second leading cause of death globally and the human and the economic consequences are profound (Chau et al., 2009). The World Health Organisation's definition of stroke is "rapidly developing clinical sign of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than of vascular origin" (World Health Organisation; Monical project investigators, 1988). A stroke is a sudden and often traumatic major life event that usually occurs with minimal warning and, for many, results in life-changing consequences with which affected people must cope (Anon, 2005). According to the Global Burden of Disease Report, stroke is the second leading cause of death for people aged 60 years or older worldwide (Lozano, Naghari & Foreman, 2012). A report from the American Heart

Association (2014) states that stroke is the third leading cause of death in women and the fourth-leading death in men (Go, Mozaffarian & Roger, 2014). Stroke was said to be the fourth-leading cause of death and serious long disability in the United States (Go, Mozaffarian & Roger, 2014). In Sub-Saharan Africa, stroke is considered to be the most prominent type of vascular disease (Wasserman, de Villiers & Bryer, 2009). After Human Immunodeficiency Virus (HIV) and ischaemic heart disease, stroke is considered to be the third most common cause of death in South Africa and the most common cause of death in people over 50 years of age (Bryer et al., 2010). Stroke is a major cause of death in South Africa (SA) and the incidence is increasing (Connor & Bryer, 2006). At the Joint World Congress on Stroke, held in Cape Town in 2006, stroke was declared a catastrophic disease in South Africa by world experts (Herman, 2006). The International Stroke Society, Mediterranean Stroke Society and South African Stroke Foundation endorsed this declaration (Bryer et al., 2010).

Presently, more than 50,000 Canadians have a stroke every year and more than 300,000 currently live with the consequences of stroke and these numbers do have an equivalent population-related proportion in other countries (Lindsay, Bayley, McDonald, Graham, Warner & Phillips, 2008). In the United State, stroke kills nearly 130,000 Americans each year – that is 1 out of every 19 deaths (Kochanek, Murphy, Minino & Kung, 2011). While in China, the prevalence of stroke ranges between 486 per 100,000-years in Northeast China and 136 per 100,000- per years in Southern China with a male to female ratio of 1.3 to 1.5 (Sousa et al., 2009). The accurate figures on the prevalence of stroke in South Africa (i.e. the number of stroke survivors at a given time), are currently unavailable. The Southern African Stroke Prevention Initiative study of 2004 gives an indication that stroke is "about half as common in rural South Africa as in typical high-income populations of the world, but twice that found elsewhere in Africa" (Bryer et al., 2010:754). These authors state that the

prevalence of stroke in urban areas in South Africa is probably higher than rural areas due to a greater exposure to lifestyle factors which increase the risk of stroke.

The effect of a stroke is devastating, not only for the survivor but also for the primary caregiver and family who are often subjected to severe stress (Hassan, Visagie & Mji, 2011). Many patients survive the initial event but are left with a disability and face the challenge of reintegrating into residential and community living (Desrosiers, Rochette, Noreau et al., 2006). The World Health Organisation (WHO) framework of Functioning, Disability and Health conceptualises disability as impairments, activity limitations and participations restrictions (World Health Organisation, 2001). Within this Framework of the WHO, the importance of people with a health condition functioning in society, this often necessitates social integration, return to work potential and work performance (World Health Organisation, 2008). Stroke is a leading cause of functional impairments, with 20% of survivors requiring institutional care after three months and 15% to 30% being permanently disabled (Lloyd-Jones et al., 2009). Stroke impacts on the patients' activities and participation in the community and may also influence their relatives' life situation (National Board of Health and Welfare 2006). Stroke decreases the survivors' performance of personal activities of daily living (P-ADL). Mayo et al (2002) found that 33% of people with stroke have some limitations in basic activities such as bathing, walking short distances and negotiating stairs six months post-stroke, compared with only 3% of the control group. According to Appelros (2006), 36% of first ever stroke survivors were dependent regarding P-ADL as measured by Barthel Index (BI) one year after suffering a stroke. The study by Paolucci et al. (2001) showed that mobility status was not stabilised at discharge and about 40% of the patients perceived some decline in mobility one year after stroke. According to Mayo et al (2002), meaningful activity is restricted for stroke patients (53%) six months post-stroke, compared to people without stroke (16%). Regarding household tasks, the ratio is

51% versus 5% and, for travel, 50% versus 8%. Lower age, male gender, higher education and fewer depressive symptoms have been found to be predictors of better P-ADL functions (Aprile et al. 2006).

The patients' goals are the recovery of the same previous roles and habits as before stroke (Bendz, 2003) and the most important aspect of recovery is the return to meaningful activities in the society which involve participation (Burton, 2000). Recovery of social activities and participation in the community is usually more essential for patients with stroke, than recovery of specific physical functions and the families' support in this recovery of social life is important (Burton 2000, Clarke & Black 2005). Stroke patients' quality of life is negatively influenced by their restrictions in pursuing leisure activities (Sveen et al. 2004) and difficulties in travelling on vacation (Robinson-Smith, Johnston & Allen, 2008). Appelros et al. (2006), showed that, one year after suffering a stroke, 59% were dependent on help in "social activities" and to a large extent, the relatives provided this help.

The measurement of participation gives a better view of information that is important in estimating recovery (Wade & Jong, 2000). Previous research has found that increased age (Hoffmann, McKenna, Cooke & Tooth, 2003), male gender, living with a partner, motor impairment (Schepers, Visser-Meily, Ketelaar & Lindeman, 2005), cognitive impairment (Pettersen, Dahl & Wyller, 2002) and limitations in personal activities (Hoffmann et al., 2003; Pettersen et al., 2002; Schepers et al., 2005) are important predictors for limitations in social activities after stroke. In addition psycho-social factors of concern in the longer term outcome of participation after stroke include depression, self-esteem, and social support, an emphasis on these as well as recovery of functional ability provides a more complete picture of the experiences of patients following stroke (World Health Organisation, 2008). Restrictions in participation could also have an effect on individual self-efficacy, while a reduction of self-efficacy after a serious health event, such as a stroke, may contribute to a

self-imposed decline in activity not accounted for by the physical impairments, such as that seen in older populations and various patient populations (Fletcher & Hirdes, 2004).

1.3. STATEMENT OF THE PROBLEM

Stroke is the leading cause of death in developed countries and recurrent stroke is a frequent and major contributor to stroke disability and death (National Institute of Neurological Disorders and Stroke, 2012; American Heart Association, 2011).

In the South African society stroke is amongst the most common chronic diseases of lifestyle as well as one of the highest causes of disability in South Africa (Puoane, Tsolekile, Sanders & Parker 2008). Although this is the case Community-based rehabilitation services in this country are poorly developed and inadequate (Rhoda & Henry, 2006; Mudzi, 2009). This was also highlighted by Wasserman et al. (2009), who commented on how in developing countries, patients with acute stroke are often discharged without an option of receiving adequate rehabilitation, which aims at facilitating re-integration and participation of individuals post stroke. Earlier studies conducted in South Africa have also highlighted that stroke patients are discharged from in-patient facilities even though community rehabilitation services have been found to be inadequate for the management of acute and sub-acute patients (Fritz, 1995; Hale & Wallner, 1996).

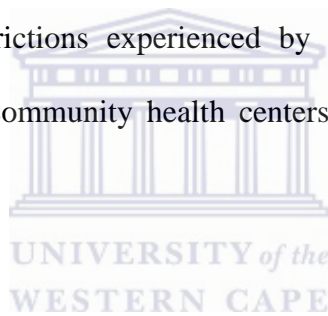
This lack of rehabilitation services affects the restoration of activities such as mobility, self-care, household responsibility, work and participation in leisure and social activities is limited or diminished, making it difficult for these patients to cope in the society.

Although, about 70% of stroke victims survived in South Africa and start to rebuild their lives (Puoane, Tsolekile, Sanders & Parker 2008), it is not clear how well these stroke patients reintegrate back into their communities and participate within the society following stroke, as

there is no follow-up on how these patients are participating in the society. This elicited the need to study the participation restrictions experienced by these stroke patient. There is also, there is dearth of information available on stroke survivor functioning in South Africa, particularly at the level of activity limitations and participation restrictions (Ustun, Chatterji, Bickenbach, Kostanjsek & Schneider, 2003). Recovery of social activities and participation in the community is usually essential for patients with stroke (Clarke & Black, 2005) which necessitates the rationale for this study.

1.4. RESEARCH QUESTION

What are the participation restrictions experienced by stroke patients living within the Community accessing selected community health centers in the metropole districts in the Western Cape, South Africa?

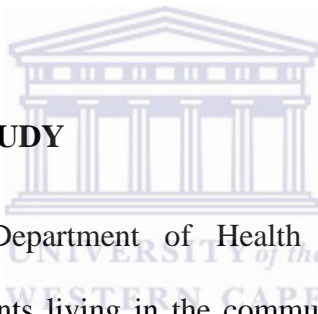


1.5. AIM

To determine and explore the participation restrictions experienced by stroke patients living in the community accessing selected community health centers in the metropole districts in the Western Cape, South Africa?

1.6. OBJECTIVES

- 1.6.1 To determine socio - demographic details of the stroke patients.
- 1.6.2 To determine and explore activity limitations and participation restrictions such as cognition, mobility, self-care, getting-along, household activities, work activities, participation in community activities, leisure activity, emotional fluctuation, time usage, environmental barrier, financial burden and family burden of stroke patients living within the community.
- 1.6.3 To determine and explore factors (age, gender, level education, marital status and employment) associated with participation restrictions of stroke patients.



1.7. SIGNIFICANCE OF STUDY

This study will inform the Department of Health (DOH), occupational therapists, physiotherapists and stroke patients living in the community of the restrictions that stroke survivors experience in participating in society, such as in cognition (in communication, understanding and remembering things), in mobility (walking a long distance, standing and staying alone), in self-care (washing their bodies, eating by self and dressing by self), in getting-along (maintaining former and new friends, sexual activities), in household activities, work, joining in the community activities, leisure activities, change in emotions, people attitude towards them because of health conditions, time usage, environmental barriers, impact/burdens on family and financial impact.

This study will inform the necessary rehabilitation bodies of areas of necessity like the environmental barriers experienced in this current study, the community barriers, like people's reactions towards stroke survivors and other mentioned limitation factors in this

study, the area of urgent attention required in promoting participation of stroke patients into the community.

This study will enlighten and remind the health practitioners especially physiotherapists in South Africa and Africa in general, their various roles in ensuring and promoting adequate participation of stroke patients in the community as a whole.

This current study will also address the paucity of literature in participation restrictions in stroke patients living in the community with regards to physiotherapy in Africa.

1.8 DEFINITION OF TERMS

Community Health Centre (CHC) – are the foundation of the national health system which is part of the coordinated district health centre which sole purpose is to provide comprehensive services including promotive, preventive, rehabilitative and curative care to the public, and management of all community health services in that district (ANC, 1994).

Participation Restriction – is defined as "problems an individual may experience in involvement in life situations" and refers to the personal and societal consequences of health conditions (World Health Organisation, 2001).

Stroke – as defined by World Health Organisation, it is a clinical syndrome characterised by rapidly developing clinical symptoms and / or signs of focal, and at times global (which applied to patients in deep coma and those with subarachnoid haemorrhage), loss of cerebral function, with symptoms lasting more than 24 hours or leading to death, with no apparent cause other than that of vascular origin (World Health Organisation, 2001).

Focus Group Discussion – These are carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment. It is

conducted with approximately seven to ten people by a skilled interviewer. The discussion is relaxed, comfortable, and often enjoyable for participants as they share their ideas and perceptions (Kaufman, 2003).

International Classification of Functions, Disability and Health (ICF) – ICF belongs to the “family” of international classifications developed by the WHO for application to various aspects of health. The WHO family of international classifications provides a framework to code a wide range of information about health (e.g. diagnosis, functioning and disability, reasons for contact with health services) and uses a standardised common language permitting communication about health and health care across the world in various disciplines and sciences (World Health Organisation, 2001).

Activities of Daily living (ADL) – This is a term used in healthcare to refer to daily self-care activities within an individual's place of residence, in outdoor environments, or both. Health professionals routinely refer to the ability or inability to perform ADLs as a measurement of the functional status of a person, particularly in regards to people with disabilities and the elderly, is usually noted with “the things we normally do...such as feeding ourselves, bathing, dressing, grooming, work, homemaking, and leisure” (Krapp, 2006).

Activity Limitation - Difficulties an individual experienced in executing activities (World Health Organisation, 2001).

Disability - An umbrella term for impairment, activity limitation and participation restriction. It denotes the complex interaction between an individual's health condition and contextual factors, which are environmental and personal factors (World Health Organisation, 2001).

Impairment: The loss and/or abnormality of mental, emotional, physiological or anatomical structure or function; this term includes all losses or abnormalities, not just those attributable to the initial patho-physiology and it also includes pain as a limiting experience (World Health Organisation, 2001).

1.9 OUTLINE OF THE CHAPTER OF THE STUDY

This thesis is organized into seven chapters.

Chapter One includes the background of study by introducing pertinent concepts that encapsulate the broad aim of the study. In addition, the statement of the problem, aims and objectives and significance of the study were included. The definition of terms and full meaning of acronyms is included in this chapter.

Chapter Two presents a review of relevant literature in order to understand the need for the study. It focuses on the different types of stroke, limitations encountered in daily life, theoretical framework for the study (International Classification of Functioning, Disability and Health) and various limitations to participation restrictions within the society.

Chapter Three presents the methodology employed to answer the study objectives. It presents the overview and rationale of the methodology used in this study. The research settings, research design, population and sampling, data collection methods, research instruments, statistical analysis, ethical consideration are described in this chapter.

Chapter Four contains the result of the statistical analysis of the quantitative data that seeks to answer the objectives of the first phase of the study.

Chapter Five discusses the result of the quantitative study and with reference to published literature, identification of possible lapses in participation restrictions of stroke patients within the community and suggested ways of promoting participation restrictions.

Chapter Six contains the result and discussion of the qualitative study data, with reference to published literature and the relevance of study to the rehabilitation bodies.

Chapter Seven summarizes the study and draws conclusions from the results. Recommendations for local and national stakeholders and for future research are made based on the study findings, as well as needs that emerged from the review of the literature. Limitations of the study are also presented.



CHAPTER TWO

LITERATURE REVIEW

2. INTRODUCTION TO CHAPTER

This chapter presents the review of the literature relevant to the study. Firstly, this chapter covers topics which range from the definition, aetiology, epidemiology, clinical features of stroke, and the prevalence/burden of stroke relevant aspect relating to stroke consequences. The second section reviewed existing literature relevant to the present study and discusses the framework of health and disability such as the International Classification of Functioning, Disability and Health (ICF) as a theoretical framework for this research project, problems encountered with participation restrictions in stroke-affected client. The third section reviewed the impact of stroke on participating in the community, the multidisciplinary management of stroke and physiotherapy rehabilitation. Finally, the barriers to stroke rehabilitation in South Africa reported in the literature were discussed.

2.1 TYPES AND CAUSES OF STROKE

The main pathological background for stroke may either be cerebral infarction (ischemic), primary intra-cerebral haemorrhagic disturbances and subarachnoid haemorrhage (Donnan, Fisher, Macleod & Davis, 2008). These classifications are based on underlying causes, which may be caused by a blocked artery (ischemic stroke), or a leaking or burst blood vessel (haemorrhagic stroke) (Brooks, 2014).

2.1.1 ISCHEMIC STROKE (CEREBRAL INFARCTION)

Ischemic stroke occurs when an artery to the brain is blocked (Emberson et al., 2014). The thrombotic cerebral infarction results from the atherosclerotic obstruction of large cervical and cerebral arteries, with ischemia in all or part of the territory of the occluded artery (Appelros, Nydevik & Viitanen, 2002). This can be due to occlusion at the site of the main atherosclerotic lesion or to embolism from this site to more distal cerebral arteries. Embolic cerebral infarction is due to embolism of a clot in the cerebral arteries coming from other parts of the arterial system, for example, from cardiac lesions, either at the site of the valves or of the heart cardiac cavities, or due to rhythm disturbances with stasis of the blood, which allows clotting within the heart as seen in atrial fibrillation (Brooks, 2014). Lacunar infarctions are small deep infarcts in the territory of small penetrating arteries, due to a local disease of these vessels, mainly related to chronic hypertension (Brooks, 2014). Several other causes of cerebral infarction exist and are of great practical importance for patient management. As they are relatively rare they can be ignored for most epidemiological purposes (Appelros, Nydevik & Viitanen, 2002).

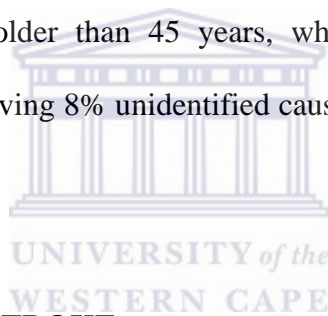
2.1.2 HAEMORRHAGIC STROKE

Spontaneous intra cerebral haemorrhages (as opposed to traumatic ones) are mainly due to arteriolar hypertensive disease, and more rarely due to coagulation disorders, vascular malformation within the brain, and diet (such as high alcohol consumption, low blood cholesterol concentration, high blood pressure) (Brooks, 2014). Cortical amyloid angiopathy (a consequence of hypertension) is a cause of cortical haemorrhages especially occurring in elderly people and it is becoming increasingly frequent as populations become older (Brooks, 2014).

2.1.3 SUBARACHNOID HAEMORRHAGE

This group of strokes is mainly due to the rupture of aneurysms at the bifurcations of large arteries at the inferior surface of the brain (Brooks, 2014). Often they do not cause direct damage to the brain and some studies of stroke have therefore excluded those (Appelros, Nydevik & Viitanen, 2002). However, patients with subarachnoid haemorrhage may develop symptoms that are in accordance with the stroke definitions and should as such be regarded as a stroke (Appelros, Nydevik & Viitanen, 2002).

Data from a hospital-based stroke register in Cape Town, of 1000 patients with first ever stroke, captured between 2000 and 2006 also revealed that ischemic infarction resulted in 81% of all stroke in patients older than 45 years, while primary cerebral hemorrhage accounted for 11% of strokes, leaving 8% unidentified causes (Bryer, Tipping, & De Villiers, 2006).



2.2 EPIDEMIOLOGY OF STROKE

The stroke is a major cause of morbidity and mortality globally and although stroke rates are declining, the number of strokes is increasing because of the growth and aging of the population (World Health Organisation, 2009). By 2005, the total number of cardiovascular disease deaths (mainly coronary heart disease and stroke) had increased globally to 17.5 million from 14.4 million in 1990. Of these, 7.6 million were attributed to coronary heart disease and 5.7 million to stroke. More than 80 percent of the deaths occurred in low and middle income countries (World Health Organisation, 2009). The World Health Organisation estimates there will be about 20 million cardiovascular deaths in 2015, accounting for 30 percent of all deaths worldwide (World Health Organisation, 2005). By 2030, researchers project that non-communicable diseases will account for more than three-quarters of deaths

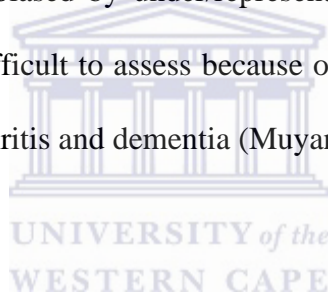
worldwide. Cardiovascular disease alone will be responsible for more deaths in low income countries than infectious diseases, maternal and perinatal conditions and nutritional disorders combined (Beaglehole & Bonita, 2008). Thus cardiovascular disease is today the largest single contributor to global mortality and will continue to dominate mortality trends in the future (World Health Organisation, 2009). The global perspective is quite different; some stated that continuing industrialisation of Asia and Africa is increasing unhealthy life-styles, which promote stroke and other cardiovascular disease (Kim & Johnston, 2011). As a result, the highest rates of stroke mortality and disability-adjusted life years lost occur in Asia, Russia, and Eastern Europe (Kim & Johnston, 2011). Stroke is increasing rapidly in Eastern Europe and Central Asia compared with Western Europe (Redon et al., 2011) and the United States (Lloyd-Jones et al., 2009). In China, rates of stroke and other cardiovascular disease are projected to increase dramatically due to combination of an aging population and the high prevalence of smoking and hypertension (Kim & Johnston, 2011). A study from Southern Africa Stroke Prevention Initiative (SASPI Project Team, 2004) showed that in a deprived rural community prevalence of stroke survivor disability was higher than expected on the basis of international studies. Between 1997 and 2004, 195 people died per day because of some form of heart and blood vessel disease (CVD) in South Africa (Bradshaw et al., 2003). In a study conducted by Norman et al. (2006) in a revised burden of disease in Cape Town Medical Research Council, it was discovered that although the white and black African people have similar rates for these diseases, their patterns differ considerably. White people mainly reflect a pattern of death caused by heart attacks, while the black African people reflect that of death caused by stroke, and diseases of the heart muscle and high blood pressure.

Another study conducted by Norman et al. (2006) showed that the highest death rates for heart and blood vessel diseases in South Africa are found in Indian people, followed by the

coloured people, while the white and black African people have the lowest rates. While premature deaths caused by heart and blood vessel diseases (CVD) in people of working age (35-64 years old) are expected to increase by 41% between 2000 and 2030. The negative economic impact of cardiovascular diseases is said to be enormous (Leeder, Raymond & Greenberg, 2004).

2.3 THE PREVALENCES/BURDEN OF STROKE

Estimating the prevalence of stroke survivors in the community is complicated by the difficulty in making a retrospective yet accurate diagnosis of stroke and stroke type months or years after the event. It is also biased by under/representation of fatal cases, and even by disabling stroke which can be difficult to assess because of overlapping disability caused by other conditions such as osteoarthritis and dementia (Muyanga, 2006).



Stroke is a major cause of death and disability worldwide (Farham, 2004). Bull (2008) found that 65% of stroke survivors were functionally independent leaving 35% being dependent on others and the community. Rehabilitation of stroke patients is long and hence expensive for both the healthcare and the stroke survivors (Bull, 2008). According to the World Health Organisation factsheet (2006), which stated that in every year, 15 million people suffer from stroke, 5 million die and 5 million are left permanently disabled worldwide, placing the burden on the family and community. The WHO factsheet further stated that stroke prevalence in white people was 500/600 per 100 000 while the prevalence of stroke in New Zealand was 793/100 000, Finland was 1030/100 000, the prevalence of France was the highest at 1445/100 000. In developing countries, the prevalence was lower than that of the developed countries. Africa, most of it being developing, has a high disease burden of

communicable diseases like Malaria, Tuberculosis, HIV/AIDS etc. and thus the burden of stroke has been neglected (Kengue, 2008). Little information about stroke is known in Africa, of which Thorogood et al., (2004) explained that this was due to the economic transition and hence the disease transitions from communicable to non-communicable diseases like cancer, cardiovascular diseases and equally stroke. Although stroke has not been studied widely in Africa, Kengue (2008) further observed that the neglected burden of stroke in Sub-Sahara Africa may interfere with economic development.

In Nigeria, a study which focused on the prevalence of an urban, mixed-income community in Lagos found the country's prevalence to be lower than that of the developed countries with more men affected than women (Mustapha, 2007). This could be the case because stroke as a non-communicable disease may appear to be insignificant due to the high burden of communicable diseases in the developing countries. Meanwhile, the African Health Monitor (2008) reports that 80% of non-communicable diseases occur in low and middle income countries where most of the population lives.

A study conducted in South Africa revealed that stroke was a significant cause of illness and disability although viewed as a chronic illness of the affluent countries and hence found the prevalence of stroke in rural South Africa to be at 300/ 100 000 (Thorogood et al, 2004).

The SASPI conducted a study in the Agincourt demographic and health surveillance site in Limpopo; and the study revealed the crude prevalence for stroke was 300/100 000 (95%, 250 to 357) (Conner, Thorogood, Casserly, Dobson & Warlow, 2004).

Labour migration was found to be an added element of complexity and stroke was found to be higher in females, 348 (276 to 436) than males (181 to 323) (Conner et al., 2004). It was discovered that this significant findings will tend to place the greatest burden on the family, community and health services (Conner et al., 2004).

In South Africa, hospital-based studies have found the following prevalence of modifiable stroke risk factors in people admitted with stroke (Hoffmann et al., 2003): hypertension in patients with cerebral infarction 32-76%, hypertension in patients with cerebral haemorrhage 76-93%, diabetes mellitus 3-10%, hyper cholesterolaemia <2-10% (although the definition used is not given in the study by Hoffmann and 10% is at least double the finding of any other study), atrial fibrillation 1-7%, cigarette smoking 15-28%, and previous stroke or transient ischaemic attack 2-7%. In the SASPI study of stroke prevalence in rural South Africans, hypertension was again the most common risk factor: hypertension 71%, diabetes mellitus 12%, cigarette smoking 9%, and current alcohol use 20% (Hoffman et al., 2003).

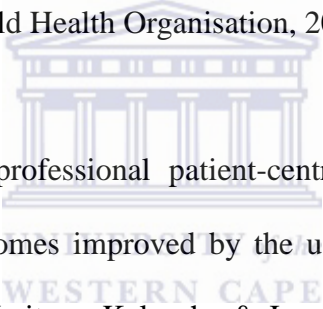
From these 'initial burden of disease estimates for South Africa, (2000), stroke was found to be the fourth most common cause of death, accounting for 6% of all deaths in 2000 (Bradshaw et al., 2003). Estimations showed more females (18 184) than males (13 930) died of stroke, and the overall age-standardised mortality rate for stroke was 124.9/100 000. Stroke is thus the most important non-communicable disease which causes death in females, compared to ischemic heart disease in males (Bradshaw et al., 2003).

2.4 INTERNATIONAL CLASSIFICATION OF FUNCTIONING, HEALTH AND DISABILITY

The ICF provides a frame work within which disability, whether caused by stroke or some other incident, can be explored; it provides a common framework for health outcome measures (WHO, 2001; Schneidert, Hurst, Miller & Ustün, 2003:588). "The ICF is a classification that allows a comprehensive and detailed description of a person's experience of disability, including the environmental barriers and facilitators that have an impact on a person's functioning." (Schneidert, Hurst, Miller & Ustün, 2003:588). The ICF has integrated the medical model of disability with the social model of disability to create a bio- psychosocial approach, incorporating biological, individual and social perspectives (World Health Organisation, 2001). The WHO, stated that the ICF conceptualises functioning from holistic and lived-experience vantage points (point of view), thereby allowing for planning interventions targeted at the whole individual or the environment. WHO hold that routine collection of functional status information across settings in the health care delivery system can facilitate more effective evaluation of outcomes, comparison of the effectiveness and cost effectiveness of treatment modalities, and prediction and management of costs.

In summary, numerous authors support the ICF framework and its utility for rendering comparable functioning information from multiple settings, across various applications, and across countries. It is also as a framework that promotes recognition of the role of environmental factors in all aspects of health and functioning (Üstün, Chatterji, Kastenjsk, Schnieder & Bickenbach, 2003). The ICF organises information in two parts, the first part deals with functioning and disability, the second part covers contextual factors such as environmental and personal factors (World Health Organisation, 2001). Components of functioning and disability are divided into body components such as body functions and

anatomical structures. A problem in body function or structure is noted as impairment, ‘activity limitation’ and ‘participation restriction’ components. Activity is defined as the execution of a task or action by an individual and participation is defined as involvement in a life situation (World Health Organisation, 2001). A difficulty at the personal level would be noted as an activity limitation, and at the societal level as a participation restriction (World Health Organisation, 2001). Component of Contextual factors is an independent and integral component of the classification and is divided into ‘environmental factors’ and ‘personal factors’. ‘Environmental factors’ have an impact on all components of functioning and disability but ‘personal factors’ are not classified in the ICF. The conceptualisation provided in the ICF makes it impossible to understand disability without consideration and description of the environmental factors (World Health Organisation, 2001).



Studies have shown that inter professional patient-centred care and rehabilitation were enhanced and rehabilitation outcomes improved by the use of setting-specific lists of ICF categories (Rentsch et al., 2003; Leitner, Kaluscha & Jacobi, 2008; Rausch, Geza & Stucki, 2008). As Uestün et al. (2004) have acknowledged, the exhaustive and comprehensive original volume of the classification poses the necessity of developing practice-friendly tools to make the classification implementable in clinical practice or research. Previous research has found that ICF could be used in assessments to describe the impact of stroke in functions, activities, participation and health (Geyh et al., 2004).

Below is Figure 2.1 which illustrates the model of ICF with the component included:

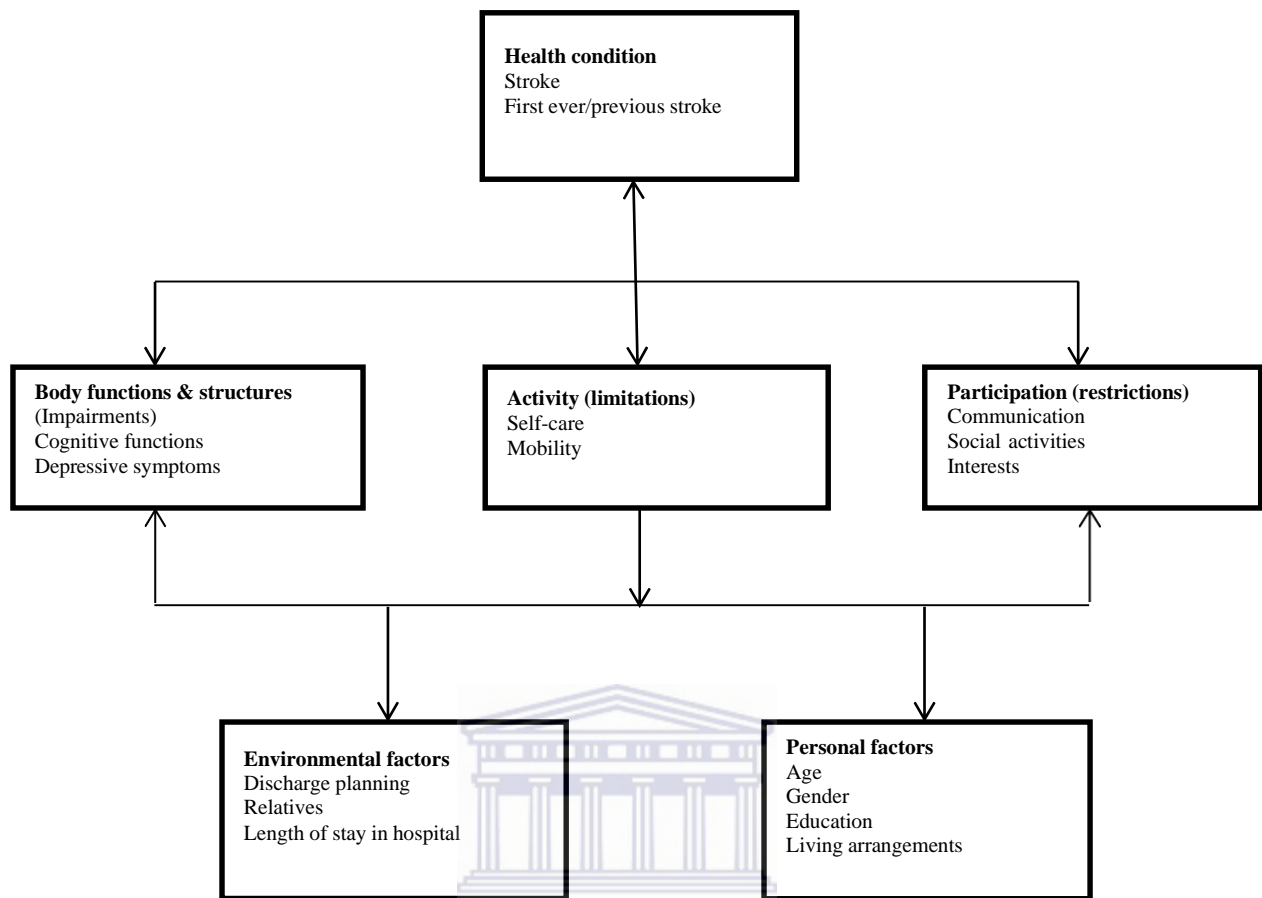
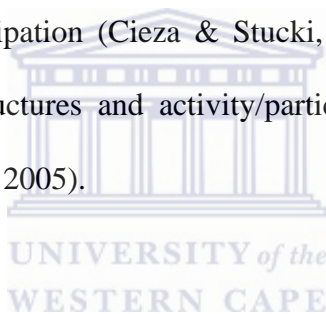


Figure 2.1 the model of ICF with the component

Personal factors are the particular background of an individual's life and living and comprise features that are not part of a health condition or health states such as gender, age, lifestyle, coping styles. The personal factors are not classified in the ICF but are included in the figure above to show their contribution, which may have an impact on the outcome of various interventions (World Health Organisation, 2001). ICF could be used as a framework in rehabilitation and improve communication between the patients and the professionals (Stucki, Ewert & Cieza, 2002). To achieve a patient-centred approach, not only external observations of the professionals but also the patients' perspective and their subjective experiences of health and quality of life need to be taken more into consideration, when using the ICF framework (Wade & Halligan, 2003).

Stroke as a component of ICF Core Sets are selections of salient ICF categories out of the whole classification, which describe the spectrum of problems in stroke patients' functioning based on the universal language of the ICF (Geyh & Szilvia, 2007). The ICF Core Sets for stroke represent the practical implementation of the classification approach in clinical practice and research. The two approaches to represent stroke related disability, the health status measurement and the classification approach, can be regarded as complementary principles. From the classification perspective, the ICF and the ICF Core Sets can serve as standards to define what to measure (Geyh & Szilvia, 2007). ICF represents two different perspectives to describe functioning and health, but earlier research showed that measurements of health-related quality of life could be described by the components of ICF especially by activity and participation (Cieza & Stucki, 2005). Therefore, in this current study, body functions, body structures and activity/participation are used to describe the impact of stroke (Cieza & Stucki, 2005).



2.5 IMPAIREMENTS AND ACTIVITY LIMITATIONS IN STROKE

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

2.5.1 Sensory disturbances

Functionally, the problems resulting from sensory deficits and disturbances after stroke can be summarised as (1) impaired detection of sensory information, (2) disturbed performance of motor tasks that require somatosensory information, and (3) diminished rehabilitation

outcomes for the upper limb and lower limb (Hunter, 2002). Tyson et al. (2008) has found that impairment of sensation was significantly associated with mobility, independence in activities of daily living and recovery while Desrosiers et al. (2006) founded a significant association of impairment of sensation in stroke with long-term participation in the community. A study conducted by Byl, (2003) who compared different types of treatments for sensory impairment using sensory impairment outcomes with a total of 108 participants. In a cross-over trial of sensory discrimination retraining followed by fine motor retraining measured graphesthesia, kinesthesia and stereognosis but only means were presented so that effect sizes could not be calculated. The authors concluded that both groups made significant gains in sensory discrimination.

2.5.2 Paralysis or weakness of limbs

Paralysis or weakness of the face and limbs usually occur on the contra-lateral side to the brain injury. Where the cerebral motor area of the brain is affected, 65% of stroke survivors will develop spasticity (Tipping, 2008). In a study conducted by Duncan et al. (2005) on admission, 31% of stroke patients were reported to have severe motor deficits, 12% moderately severe, 21% moderate, and 36% mild motor deficit. Further, the authors concluded that, on Day one, the initial motor score accounted for only half of the variance in motor function at six months, whereas the 5-day motor and sensory scores explained 74% of the variance, and the 30-day motor score explained 86% of the variance.

2.5.3 Incontinence

Fifty to seventy percent of all stroke survivors experience some form of bladder incontinence in the first month post-stroke. Less than 20% generally experience problems at six months (Tipping, 2008). The most common difficulties experienced are urge incontinence, urgency,

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

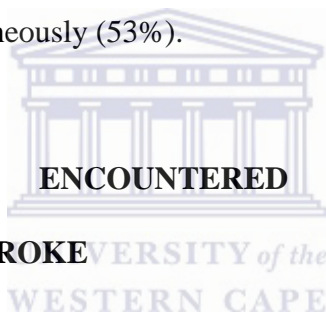
2.5.4 Perception

Intact perception is required so that people can learn about and adapt to their constantly changing environment. It involves processing and interpretation of sensory information obtained from the environment (Gillen, 2011). Cognitive and perception impairments may be hidden and the stroke survivor (and the family /caregiver) can be unaware of them. A stroke survivor with right hemisphere dysfunction may retain good language skills, which can mask perceptual impairments and give the impression of a high level of functioning (Gillen, 2011). Some of the perceptual dysfunctions which commonly affect people who have had a stroke include body scheme disorder (Gillen, 2011). Unilateral neglect usually occurs with stroke survivors with right hemisphere lesions (Gillen, 2011). The person demonstrates a lack of awareness of the affected limbs and anything that occurs in the surroundings on that particular side of the body. Stroke survivors with unilateral neglect have great difficulty performing activities of daily living such as dressing and eating. Reading, writing and arithmetic skills can also be affected (Gillen, 2011). Spatial relationships (this term refers to the ability of the person to discern the position of two or more objects in relation to each other and to themselves), visual perception of vertical, figure ground perception, agnosia (this refers to the inability of the stroke survivor to recognise familiar objects by means of tactile, visual or auditory perception) (Gillen, 2011), vision related impairments (Gillen, 2011) are also impacted.

2.5.5 Cognitive impairments

After a stroke, memory, abstract thinking and reasoning may be impaired. The stroke survivor's ability to judge the consequences of their actions may also be affected. People may act impulsively and lack insight into situations. They may have difficulty with problem solving and initiating tasks. Cognitive impairments can impact on a stroke survivor's ability to live independently (Gillen, 2011). Hospital-based studies which have applied neuropsychological testing within the first three months post-stroke report prevalence rates of cognitive impairment varying from 33% to 82% in patients with first-ever stroke (Nys et al. 2007; Hoffman, 2001). In the study of Hochstenbach et al. (2005) the most frequent cognitive complaints were forgetfulness (60%), mental slowness (56%), poor concentration (55%), and inability to do two things simultaneously (53%).

2.6 THE PROBLEMS ENCOUNTERED WITH PARTICIPATION RESTRICTIONS IN STROKE



The World Health Organisation has defined successful rehabilitation as reintegration of the individuals back into their social networks and participation in activities and the community ((Noreau et al., 2004). Participation is conceived as a dynamic complex interaction between the individual with disability, the body functions, functional status, and the contexts in which the individual lives (D'Alisa, Baudo, Mauro & Miscio, 2005; Fallahpour, Jonsson, Joghataei & Kottorp, 2011). Many persons with stroke are not able to resume the former life roles they had or engage in various activities as they did in the past, thereby restricting them from participating in society (Desrosiers et al., 2006). Empirical research has shown that participation can be markedly restricted after stroke (Desrosiers et al., 2008; Desrosiers et al., 2006; Desrosiers, Noreau, Rochette, Bravo & Boutin, 2002; Sturm et al., 2004). People who cannot return to work or re-train may face a lifetime of unemployment and dependence on the

families and state (Radford & Walker, 2008). Research that has examined the impact of having a stroke on participation, irrespective of mobility status, demonstrates that cognitive, communication and physical impairments combine with environmental challenges, frequently resulting in sudden alterations of life routines, roles and daily occupations (Clarke et al., 2002). Once living back in the community, stroke survivors have a greater need for assistance with activities of daily living (ADL) and instrumental activities of daily living (IADL) than those without stroke (Clarke et al., 2002).

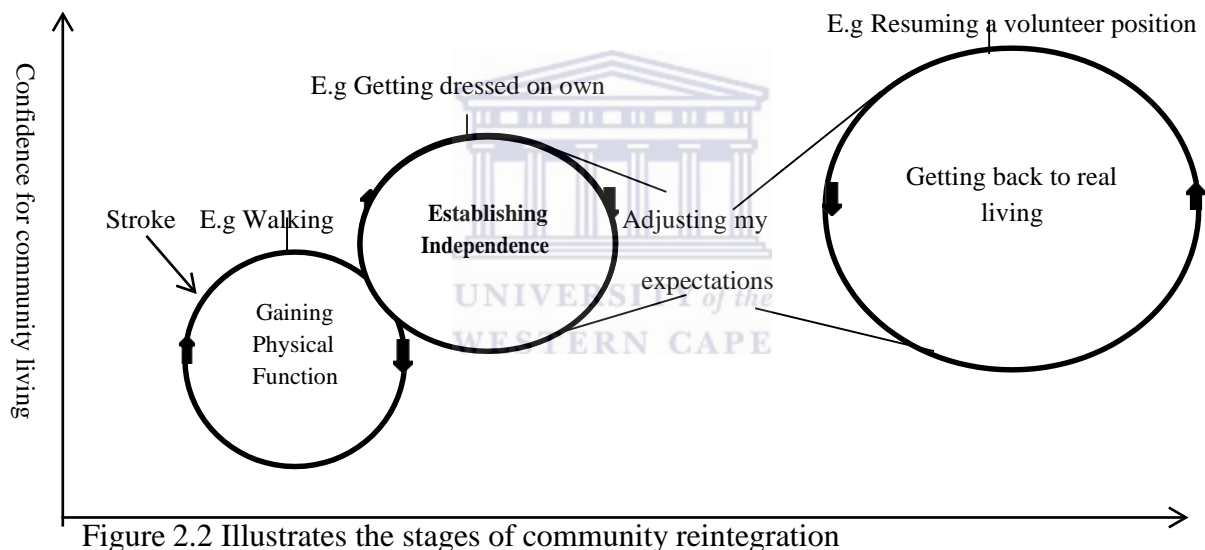
Restrictions in participation after stroke may refer to the degree to which the patient perceives that the disabilities after stroke restrict his or her ability to resume the pre-stroke roles that he/she had before the stroke (Schepers et al., 2005). The restrictions vary, but they are connected with all levels of ICF (D'Alisa, Baudo, Mauro & Miscio, 2005). Jette et al. (2003) found three distinct concepts within the concept of physical functioning which they identified as conforming to the dimensions of Activity and Participation as proposed in the ICF. These distinct, interpretable factors which together accounted for 61.1% of the variance in participation were labelled: Mobility Activities (24.4%), Daily Activities (24.3%), and Social/Participation (12.4%) (Jette, 2003). Functional disability and mood disorders may independently contribute to restricted participation of patients post-stroke (Schepers et al., 2005).

Another qualitative study using focus group discussions to explore the challenges stroke sufferers face over time during recovery revealed that great distress among the participants was associated with the loss of hobbies and activities that had previously been a source of pleasure and achievement (Ch'Ng et al., 2008).

2.6.1 THE IMPACT OF STROKE ON PARTICIPATION

While the majority of stroke survivors return to live in the community, re-integration based on the resumption of activities of daily living and the adoption of successful psychosocial roles may be an enormous challenge (Palmer & Glass, 2004). The ability to return to an acceptable lifestyle, participating in both social and domestic activities has been found to be important in patient satisfaction and in perceived quality of life post stroke (Mayo et al., 2002; Jaracz et al., 2003).

Below is Figure 2.2 which illustrates the stages of community reintegration



Community Re integration (Bandura et al., 1998)

Studies which have assessed items in terms of their importance to perceived quality of life in stroke survivors cite items such as the ability to speak, the ability to visit places outside the home, the ability to get around, the ability to do things/pursue leisure activities, independence/control in one's own life, usefulness to others, stress, sex life and not having a job as receiving high importance but low satisfaction ratings (Robinson-Smith et al., 2000). Additionally, many stroke survivors report poor social integration, loss of social contact, social isolation and loss of previous social roles (Kersten et al., 2002; Hopman & Verner,

2003). A study by Boden-Albala et al., (2005) reported that social isolation following first stroke is significantly associated with the risk for recurrent stroke or death where social isolation was defined as “knowing fewer than three people well enough to visit with in their homes”. Boden-Albala et al., (2005) suggested that social isolation may be related to poor outcome via stress, depression, poor treatment compliance and decreased participation in healthy activities. The executive summary of the ACHPR (Gresham et al., 1995) clinical guidelines for stroke rehabilitation in discussing the transition to the community noted that “return to a community residence after an acute hospitalisation for stroke, or after an in-patient rehabilitation programme, can be difficult for the stroke survivor and family alike. At this time, the person has to assume increased responsibility for independent functioning in the absence of the supportive environment of the in-patient setting, with the family or other caregivers provided needed support.

Continuity of services is important during this period, and patient and family counselling may be needed to facilitate family functioning and improved outcomes”. Physical and psychological barriers to participation that keep the individual with stroke isolated need to be addressed in order to promote personal autonomy and social re-integration (Kersten et al., 2002). Involvement of the community itself in education and rehabilitation may serve to ameliorate attitudes of fear and ignorance that negatively impact the stroke survivor’s ability to participate in paid employment or social activity (Kersten et al., 2002). According to a systematic review by McKeivitt et al. (2004) and a qualitative meta-synthesis by Salter et al. (2008) there is a sizeable body of qualitative research that seeks to document the longer term impact of stroke, highlighting the needs that should be considered when planning and delivering longer term services including rehabilitation for people with stroke. The impact of stroke on survivors has repeatedly been documented as “the loss of...” in the qualitative literature, with the significance of reduced functional ability being explained in terms of loss

of activities, abilities, personal characteristics and independence, emotional and social loss and a loss in or change in the individuals own identity (McKevitt et al., 2004). Salter et al. (2008) shared the same observation in their study (a qualitative meta-synthesis) on the experience of living with stroke. Other studies have focused on the specific problems of “loss of the ability to drive” and the problems of “returning to the work force” particularly for younger people. All these issues affect the reintegration of a person who has had a stroke (McKevitt et al., 2004). A significant correlation was also found between community reintegration and participation restriction in the study conducted by Hamzat, Olaleye and Akinwunmi, (2014) who conducted a study on “Functional Ability, Community Reintegration and Participation Restriction Among Community-Dwelling Female Stroke Survivors in Ibadan”, who suggested that the more physically able a stroke survivor is, the better her/his reintegration and participation in the community would be and this may result in better rehabilitation outcome for the stroke survivor (Hamzat, Olaleye & Akinwunmi, 2014). The following factors are documented in the literature as the most common issues that affect a person’s reintegration following a stroke.

2.6.1.1 Loss of Ability to Perform Meaningful Activities

Patients with stroke are not able to resume their previous activities (Desrosiers et al., 2006a), thus restricting their participation in daily living and social roles and limiting many aspects of their lives (Desrosiers et al., 2006a). Many people with stroke report lack or loss of meaningful activity that had an impact on their daily activities and social roles (Desrosiers et al., 2006a). Meaningful activity in this instance refers to activities that people enjoy doing at home, work or in the community. In a study by Mayo et al., (2002), 39% of patients with stroke reported a limitation in functional activities while 54% reported limitation with higher-

level functional activities of daily living such as dressing, bathing, housework and shopping and 65% reported restrictions in reintegration into community activities.

In a study by Mudzi, Stewart and Musenge, (2013) it was discovered that patients struggled with community, social and civic life activity participation in stroke. The stroke patients displayed mild to moderate and severe to complete difficulty with community life, recreation and leisure ability and political life. The patients again showed complete dependence on their caregivers, for all of them (100%) had severe to complete difficulty with the same activities when they were without assistance. This again agrees with the limited improvements that were noted in patients' functional abilities at the twelve-month follow-up.

Similar problems with socialisation were established in a previous study in the same geographical location with similar patients. Hale et al (1999) reported that post-stroke patients received very few visitors and only two could manage to visit their neighbours. Higher social participation is associated with better physical function and vitality in post-stroke patients (Jonsson et al., 2005). A study by Desrosiers et al, (2006b) has shown that patients who participate in meaningful daily activities after stroke improve in function and that the improvement in function subsequently translates to other social activities in the community.

2.6.1.2 Loss of Personal Characteristics, Role or Identity and Change in Relationship(s) as a Result of Stroke

The loss of personal characteristics referred to personality change, which is one of the most frequently voiced complaints of people after their friend or relative has had a stroke (Stone et al., 2004). The other area central to successful community reintegration of a person with stroke is the loss of their usual role within the family, community and society at large. This

role is also described as a loss of personal identity (Ellis-Hill & Horn, 2000) or change in personal characteristics (McKevitt et al., 2004). One such role change is that the person may have to depend on others for his/her basic personal and social needs; this loss of independence (Ellis-Hill & Horn, 2000), changes the position of the person within his/her family and community. Social roles can be altered when the patient can no longer work or dispense his/her responsibilities in a family and/or community. It is reported in a study by Grant, (1996) that stroke survivors recognised distinct and individual functional, cognitive and emotional changes as a result of stroke and this affected the relationship they had with their families. These changes frequently hinder performance of daily living activities and disrupt social activities they previously participated in with their family, because time is now spent assisting the survivor with his/her personal activities (Grant, 1996). Stroke survivors see this assistance as a shift in role or identity. A shift in social roles challenges relationships that are already stressed by the newly dependant status of the patient (Lynch et al., 2008). It is interesting to note that survivors often felt that their stroke placed severe pressure on family relationships, particularly when the stroke survivor had been the head of the household (brought in the majority of household income or held the most power and authority in family decision-making). In contrast, caregivers are more likely to mention ways in which the stroke strengthens the patient's relationship with significant others (i.e. spouse and children) (Lynch et al., 2008) and brings a feeling of closeness to their spouse following a stroke (McKevitt et al., 2004).

2.6.1.3 Loss of Mobility Independence and Ability to Drive

Ambulation is an important predictor of community reintegration. According to Dunsky et al., (2008), walking disabilities are considered to be the most devastating disabilities post stroke. Lord and Rochester, (2005) and Buurke et al., (2008), define community ambulation

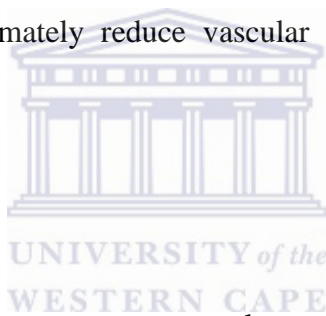
as the ability to mobilise independently outside the home, including confidently negotiating uneven terrain, shopping centres, and other public venues. Less than 50% of stroke survivors progress to independent community ambulation (Buurke et al., 2008). The loss of the ability to move around affects the independence of a person with stroke, thus leading to social isolation. Mayo et al. (2002), in a study to estimate the extent of activity and participation of individuals six months post-stroke, and their influence on health-related quality of life in Montreal, Canada, reported that almost 50% of the community-dwelling stroke population lived with the consequences of stroke such that, unless there was an able bodied caregiver at home, they needed some form of help. The loss of independence was also reported by participants in a study by Hale et al., (1999) in Soweto, South Africa although most participants were independent in ADL; they expressed concern about their perceived loss of independence. Participants in this study felt that their walking speed had been tremendously reduced, resulting in them not being able to walk fast enough to cross the road or to be in a busy place like a shopping mall or town. Hale et al. (1998) found that 55% (over the age of 50 years old) and 88% (below the age of 50 years old) of participants were able to walk without assistance. Twenty-four percent of both groups were able to walk the length of the road near their homes. The measure used to determine “handicap of gait” was the ability to catch a taxi, 46% of the older group and 69% of the younger were able to manage this activity. Ability to catch a taxi or bus in a country where most people are reliant on public transport is considered to be a measure of a person’s ability to participate in the community. In more affluent communities, driving a motor vehicle is essential to functional independence and community integration, as it enables access to work, shopping, health care and social activities (Griffen et al., 2009) and thus driving status has a considerable influence on community integration following stroke. A study by Griffen et al. (2009) showed that stroke survivors who had not resumed driving showed poorer community reintegration than did

those who had resumed driving. Even though some stroke survivors used alternative public transport, the loss of independent driving was not fully compensated. In their study, cessation of driving appeared to more adversely affect males than females (Griffen et al., 2009). Stroke may affect this skill negatively and alternate transport such as public and private transport or relying on friends and family often does not adequately meet the mobility needs of a person, especially of a person who drove before his/her stroke. Inability to drive as a work requirement affects the livelihood of a person and his family especially if the person is a breadwinner.

2.6.1.4 Social Isolation

Individuals with stroke disability often live a very isolated life thus leading to greater social isolation and withdrawal from community activities (Garbusinski et al., 2005). This social isolation is as a result of a number of factors such as loss of mobility and the lack of community based activities, for example, support groups in rural and urban areas (Boden-Albala et al., 2005). Social isolation has been defined as knowing fewer people well enough to visit them in their home or having visitors (Boden-Albala et al., 2005). This definition of social isolation/support represents the primary, informal network of relationships that incorporates family, friends or neighbours. Hence, relationships established prior to the first stroke may provide a mechanism for quicker reintroduction/reintegration into community organisations and resources. The majority of stroke survivors depend on others for their everyday activities. Therefore, social relationships are critical to survival for patients after stroke and become of critical importance to their quality of life (QoL) (Lynch et al., 2008). Socially isolated patients may be at particular risk for a poor outcome, in both function and QoL (Lynch et al., 2008). Social support may be an important prognostic factor in recovery from stroke. Lynch et al. (2008) in a study examining the impact of social

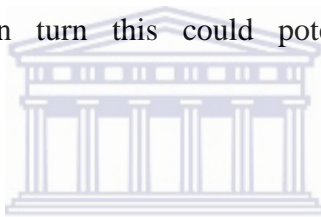
support on outcome after stroke reported that high levels of social support are associated with faster and more extensive recovery of functional status. Garbusinski et al. (2005) further endorsed the concept of social support in a prospective observational study conducted in Gambia. In this study it was reported that most participants who were socially supported by a family member in the form of a spouse, sister, or children participated in family life and resumed activities of daily living such as caring for children, attending family ceremonies, social gatherings and other community related activities sooner than those who were not supported. It has been suggested that to deal with the adverse effects of social isolation post-stroke, increased funding for community organisations to promote leisure activities and other programmes in which people get together and share common interests may be needed to promote social support and ultimately reduce vascular morbidity and mortality (Boden-Albala et al., 2005).



2.6.1.5 Loss of Hope

Feelings of despair and helplessness are commonly expressed following a stroke which hinders participation in the society (Pilkington, 1999). The concept of loss of hope can be characterised by expression of uncertain feelings of the future. The feeling of hopelessness is often due to the realisation that the newly acquired disability has to be coped with for the rest of the person's life (Pilkington, 1999) together with feelings of humiliation and loss of control (Hafsteinsdottir & Grypdonck, 1997; Western, 2007). The recovery from stroke is equally stressful, usually necessitating significant coping efforts and strategies. Difficult life events such as stroke may encourage patients to re-examine aspects of their life, and the challenges associated with stroke can promote spiritual growth and development. Hope is important to recovery as it gives individuals the motivation and strength to achieve their goals (Western, 2007). Because of the life changing experience of stroke, spiritual practices may

assist patients in finding meaning, hope and wholeness through the confidence they offer (Robinson-Smith., 2002). This notion is supported by a study by Lui and Mackenzie, (1999) on elderly Chinese patients following stroke. The researchers discovered that spirituality was important at all stages of recovery following stroke. The participants believed that religious or spiritual belief gave them a sense of psychological comfort and hope for the future. The religious/spiritual rituals that they found to be beneficial included praying, reading religious books, burning incense and going to church. Robinson-Smith (2000), in a study done in the USA, also discovered that patients who expressed moderately high personal faith in God had a higher quality of life. It is important to note this psychological coping strategy of restoring hope, because knowing from where the patients draw hope may assist in encouraging the patient during rehabilitation; in turn this could potentially assist with community reintegration.



2.6.1.6 Return to Work and School (Education in General)

Another activity that is affected by stroke or affects community reintegration is the person's ability to return to work. The inability to return to work affects the person's livelihood and existence. There are various definitions of work but the ones put forth by Vestling et al. (2003) and Malm et al. (1998) cover all aspects related to the definition of work in both formal and informal settings including schooling. Vestling et al. (2003) defined work as a "continuing occupation in the production of supplies and services for payment, meaning formal paid on a full-time or part-time-basis and Malm et al. (1998) defined work as "any employment plus homemaker, volunteer activities, or student". Returning to work for people with stroke may contribute significantly to their life satisfaction, well-being, self-worth and social identity, giving them an opportunity to maintain independence as far as physically possible with the income generated through employment (Wolfenden & Grace, 2009).

Pressures such as financial hardship may influence return to work. Return to work may be seen as an indication of the recovery of a patient with stroke. Hale et al. (1999) reported that all the participants in their Soweto-based study had financial problems. Some of the participants had been the sole sources of family income prior to the stroke and now found themselves and their families in dire straits (Hale et al., 1999). Garbusinski et al. (2005) found that less than half of the participants (n=143) in their study conducted in Gambia who were economically active before the stroke had one year later resumed a paid activity i.e. had returned to their paid jobs.

2.7 STROKE REHABILITATION

Stroke rehabilitation is an active process beginning during acute hospitalisation, progressing for those with residual impairments to a systematic programme of rehabilitation services, and continuing after the individual returns to the community (Page et al., 2002). It is an organised effort to help stroke patients maximise all opportunities for returning to an active and productive lifestyle (Page et al., 2002). Because the clinical manifestations of stroke are multifaceted and complex, stroke rehabilitation is best implemented through the coordinated efforts of a team of rehabilitation professionals (Page et al., 2002). Several definitions of rehabilitation have been cited in the Key Concepts section above. In addition, the Stroke Association (2006a:5) defines rehabilitation as “the process of overcoming or learning to cope with the damage the stroke has caused, getting back to a normal life and achieving the best level of independence by: relearning skills and abilities; learning new skills; adapting to some of the limitations caused by a stroke; and finding social, emotional and practical support at home and in the community”. In the 1960s, The World Health Organisation defined rehabilitation as the combination and coordination of medical, social, educational and vocational resources aimed at optimising a person's functional independence (WHO, 1969).

Rehabilitation methods are essentially intended to reduce a person's disabilities and prevent the onset of disabling situations in order to support an optimal quality of life (WHO, 1969). The South African guideline for the management of stroke and transient ischaemic attack (2010), defines stroke rehabilitation as "a goal-orientated process which attempts to obtain maximum function in patients who have had strokes and who suffer from a combination of physical, cognitive and language disabilities" (Bryer et al, 2010: 775). The main purpose of rehabilitation is to improve motor function and the use of the affected limb in daily life. Recovery itself can be attributed to several factors. One important aspect is to reduce spasticity, which often arises some months after a stroke in anti-gravity muscles (Bryer et al., 2010). Depending on their needs, the involvement of the following team members may be required in the rehabilitation of the stroke survivor: doctors, nurses, physiotherapists, occupational therapists, speech and language therapists, audiologists, psychologists, social workers, dieticians, prosthetists and orthetists (Western Cape, South Africa), Department of Health, 2007). The team of stroke rehabilitation specialists usually includes physiatrists, neurologists, rehabilitation nurses, physical and occupational therapists, speech and language pathologists, psychologists, social workers, recreational therapists, and case managers (National Institute of Neurological Disorders and Stroke, 2012). This team seeks to reduce disability in the following six areas: mobility (e.g., moving in bed, getting up from a chair, and sitting on a toilet), locomotion (e.g. walking or using a wheelchair, climbing stairs), self-care (e.g. brushing teeth, dressing, cooking, driving a car, etc.), communication (e.g. speech problems, difficulty remembering appropriate words, swallowing problems), cognition (e.g. mental functioning and organisation, memory problems) and control of bowel and bladder function (National Institute of Neurological Disorders and Stroke, 2012). Generally, teamwork can take the form of a multidisciplinary, interdisciplinary or a trans-disciplinary approach (Visagie, 2008). The type of approach utilised will to a large extent depend on the

human resources available and on the system that is the most effective or practical for a particular facility (Visagie, 2008).

According to a study conducted by Flansbjerg (2006) who looked at strength training after stroke, with the effects on muscle function, gait performance and perceived participation. It was concluded that the improvements in gait performance were related to improvements in perceived participation in the society.

2.7.1 PHYSIOTHERAPY ROLE IN STROKE REHABILITATION

Physiotherapy has been advocated in the management of stroke patients as an integral and important essence (AHCPR, 1995). Physiotherapy plays an important role in the process of stroke rehabilitation. As a part of the interdisciplinary team, physiotherapists work in concert with the managing doctor and other rehabilitation specialists to provide stroke patients with a comprehensive rehabilitation program (WCPT, 2010).

According to Agency of Health Care Policy and Research, Scottish Intercollegiate Guidelines Network and Royal College of Physician, management of stroke patients begins as the acute care during acute hospitalisation and continues as rehabilitative care as soon as patient's medical and neurological status has stabilised. Moreover, community reintegration of patients continues during the community care stage (AHCPR, 1995). Physiotherapy is perceived as one of the key disciplines in providing organised-stroke care (Dolmans et al., 2002).

Rehabilitation is the most universally adopted treatment strategy to improve quality of life in patients with stroke (Van Peppen et al., 2007). The main aim of organised-stroke rehabilitation is to achieve a level of functional independence that enables patients to return home and reintegrate into community life that lives up to their own expectations and desires

as much as possible in participating in the society (Van Peppen et al., 2007). The physiotherapy stroke rehabilitation programme involves a dynamic process of assessment, goal-setting, treatment and evaluation; its coverage spans from the acute stage, through their rehabilitation stage, to the community stage (Dolmans et al., 2002). The whole rehabilitation programme is predicated on two general components, the first includes preventive measures targeted at maintaining physical integrity and minimising complications that will prevent or prolong functional return (Dolmans et al., 2002). These measures should begin immediately post-stroke and continue as long as necessary. The second component is restorative treatment aimed at promoting functional recovery (Dolmans et al., 2002). This phase should begin as soon as the patient is medically and neurologically stable (Dolmans et al., 2002) and has the cognitive and physical ability to participate actively in a rehabilitation programme. Physiotherapists involved in the management of patients with stroke have to deal with establishing diagnosis of functioning, (Dolmans et al., 2002) and determine the factors for predicting functional outcome, (Van Peppen et al., 2007; Buurke, 2005; De Haart, 2005; Kitson), also starting remedial interventions to restore motor control in gait and gait-related activities and to improve upper limb activities, as well as to learn to cope with existing deficits in ADL and to enhance participation in general (De Haart, Geurts & Huidekoper, 2004; McDonnell et al., 2007), monitor patients' (progress in) functional health with help of outcome measures (Dolmans et al., 2002; Barclay-Goddard et al., 2004). Physiotherapists involved in stroke-management often apply physical exercises and assistive devices for gait (canes and walkers), besides they employ other equipment such as treadmills and electronic devices as therapeutic treatment interventions (Hammond et al., 2005). In brief, the aims of physiotherapy interventions are to promote motor recovery, optimise sensory functions, enhance functional independence, and prevent secondary complications (McDonnell et al., 2007).

2.7.2 BARRIERS TO STROKE REHABILITATION IN SOUTH AFRICA

Various barriers have been noted in enhancing full stroke rehabilitation, in a study conducted in community participation twelve months post-stroke in Johannesburg, it was discovered that the patient's ability to socialise and participate in community issues is currently poor. The identified barriers to community participation need to be addressed in order to improve patient-participation in the community post-stroke (Mudzi, Stewart & Musenge, 2013). Stroke patients experience environmental barriers which are often construed as physical, but also include prejudice, stereotypes, inflexible organisational procedures and practices, inaccessible information, buildings and transport (Swann, 2008). These environmental factors affect activities of daily living and social participation after stroke. Rather than helping, these factors can hinder the accomplishment of daily activities and social roles and hence are regarded as barriers (Vincent et al., 2007). Although there seem to be specific guidelines on stroke management and rehabilitation which are available in South Africa, lack of monetary and human resources mean that policies or guidelines on stroke management are not always implemented (Bryer et al., 2010). Many hospitals do not regard stroke as a priority in terms of developing protocols for management (Bryer et al., 2010). Due to a shortage of beds, stroke survivors are often discharged before they are proficient in transfers and basic activities of daily living. This can result in a heavy burden upon caregivers who may also have to go out to work, resulting in the stroke survivor being neglected (Bryer et al., 2010).

Rhoda et al. (2009) conducted a study on the rehabilitation of stroke patients at community health centres in the Cape Metropole region of the Western Cape. The study revealed the following: there was a lack of therapy services to provide rehabilitation to stroke patients at the CHCs in the Cape Metropole region of the Western Cape. Occupational and speech

therapy services in particular where lacking. Services that were currently available were not coordinated, the frequency of physiotherapy, occupational therapy and speech therapy was low, although physiotherapy was available, the numbers of hours of physiotherapy received by patients were low. In a study conducted by Rimmer, Wang and Smith (2008) it was noted that various personal and environmental barriers that participants with stroke report are useful in providing insight in helping individuals with stroke.

2.8 SUMMARY OF THE CHAPTER

From reviewing the literature, it is clear that stroke is a condition that is mainly caused by cerebral infarction. It affects the elderly, although it can affect people of all ages, and a clear picture is available of the extent of the condition as it affects populations globally. The main clinical features and risk factors for stroke have been well established in various studies. The review of the literature above indicates the participations restrictions encountered mostly by stroke patients are residual, cognitive impairment, activity limitations and participation restrictions following stroke. It is also apparent that social relationships are critical to survival for patients after stroke and become of critical importance to their quality of life. This literature review also shows the dearth of information about Stroke with respect to integration in South Africa and Africa as a whole. The methodology used in knowing the demographic details and determination of various restrictions in life situations of stoke is discussed in the following chapter, Chapter Three.

CHAPTER THREE

METHODOLOGY

3. INTRODUCTION TO THE CHAPTER

This chapter provides a description of the method utilised in these study. In addition, it also provides an overview and rationale for the methodology used in the first phase and second phase of the study. Research setting and design, study sample, instrument used, validity and reliability of instrument used, data collection methods, procedure and ethical considerations are aspects discussed in this chapter.



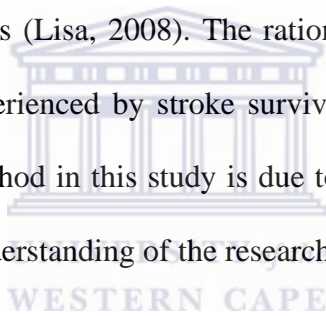
3.1 RESEARCH STUDY SETTINGS

The research study was conducted at the selected Community Health Centres in the Metropole District of the Western Cape, South Africa. Health care services in South Africa are based on a primary health care approach, which uses the district health care system as the vehicle to deliver these services. The Community Health Centre (CHC) is therefore the first point of entry into the health care system (Barron & Monticelli, 2003).

If medically stable, these patients are not referred to hospital and would be referred to tertiary institutions or a specialised rehabilitation centre if there are complications with stroke condition. Stroke patients are mainly rehabilitated at the out-patients CHCs.

3.2 RESEARCH APPROACH FOR BOTH QUANTITATIVE AND QUALITATIVE

The mixed sequential method is a type of research that involves the collection or analysis of both quantitative and qualitative data in a single study in which the data is collected concurrently or sequentially, are given a priority, and involve the integration of the data at one or more stages in the process of research” (Creswell, Plano Clark, Gutmann & Hanson, 2003). The quantitative approach was used to get the systematic empirical investigation of participation restrictions experienced by the participants via statistical technique (Lisa, 2008), while the qualitative approach was used to get the information from the participants’ personal experiences in participating in the community through asking questions and collecting verbal data directly from the participants (Lisa, 2008). The rationale was this study was examined the participation restrictions experienced by stroke survivor within the framework of ICF. The choice of using a mixed method in this study is due to the fact that, collecting different types of data allows for better understanding of the research problem (Creswell, 2003).



3.2.1 RESEARCH DESIGN

The descriptive, observational survey cross-sectional design approach was used to answer the quantitative study objectives. The descriptive study was the most appropriate for this study because they are usually the best methods for collecting information that will demonstrate relationships between variables (Schmidt & Kohlmann, 2008).

The design approach was the most suitable study design to determine the number of patients with different diagnosed health conditions such as with the case with stroke, while surveys in quantitative study were useful when wanting to collect self-reported information from participants such as the stroke victims reporting the difficulty/limitations they are

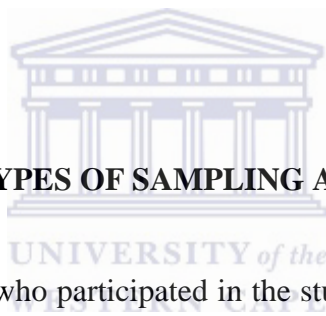
encountering such as participation restrictions within the community as a result of their health conditions. Survey was also useful for describing phenomenon and analysing relationships between variables which was utilised in this study (Domholdt, 2000). It was cross-sectional in nature because information from the participants was collected without manipulating the study environment, which was the stroke patient living within the community (Schmidt & Kohlmann, 2008).

Neuman (2000) indicated that between methods triangulation adopted in a study would make study findings more informative and comprehensive. Thus in this study, besides quantitative assessments of stroke activity limitations and participation restrictions, the participants' narratives were obtained using focus groups discussions. These assisted in investigating the in-depth difficulties encountered by stroke patients in community reintegration. A focus group is a carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment. They are useful when insights are needed into a new area of research, like barriers to reintegration post-stroke in the respondents' natural settings (Thomas, 2000). Moreover, a survey is suitable for assessing a participant's opinions, thoughts and feelings at a particular time. It is also economical and specific, with global and widespread goals (Shaughnessy, Zechmeister & Jeanne, 2011).

3.3 POPULATION AND SAMPLING FOR QUANTITATIVE

The study population was all stroke patients who had received or were receiving physiotherapy at the selected sites.

Stroke patients who were still attending or had received treatment / rehabilitation at the CHCs Metropole District in the Western Cape were the research population. Several stroke patients that attended or had being managed by CHCs Metropole District were approached to participate in this study. The quantitative research population was stroke patients living within the community, the convenient sampling method were adopted for the selection of patients, in which every consecutive participant meeting the inclusion criteria was invited to participate in the study. This sample method was used because of availability of the sample size. This non-probability sampling technique is particularly useful in cases where the whole population for the given period of time is studied and for ensuring the largest possible sample sizes, without random exclusions (Babbie, 2001).



3.3.1 STUDY SAMPLING: TYPES OF SAMPLING AND SAMPLE SIZE

The total number of participants who participated in the study was 120; this sample size was used due to availability of the stroke participants within the community and health centres. The intended recruitment was 250 participants. The convenience sampling method was used to collect the data information; this sampling method was adopted due to availability of the participants during the course of the study (Babbie, 2001). A convenient sampling is a sampling method that uses participants who are most conveniently available (Field, 2006).

3.3.2 INCLUSION CRITERIA

The inclusion criteria were all patients presenting with a stroke and who are aged 18 years old and above. Patients are members of the community living with stroke. In the case of

participants with expressive or receptive aphasia only the caregiver, relative or spouse was interviewed with the permission of both the participant and caregiver.

3.3.2 EXCLUSION CRITERIA

The exclusion criteria were patients presenting with diagnosed health conditions other than stroke, medically unstable patients, patients on nursing admission, and aphasic stroke patients with no family career or relatives.

3.4 DATA COLLECTION INSTRUMENTS

The following instruments were used to determine the activity limitations and participation restrictions of stroke patient living within the community.

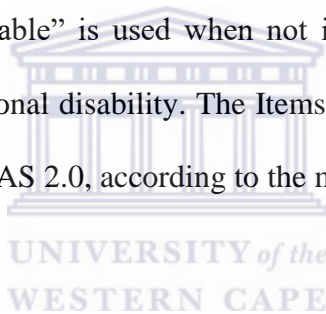


3.4.1 PART 1 -QUANTITATIVE

For Part 1 of the study sought to obtain socio-bio-demographic data of the participants and the disability assessments of the stroke patients; which were designed to evaluate the functioning of the individual with disability in six different activity domains, namely cognition, mobility, self-care, interpersonal relationship, life activities, and participation in the society., narrated in full detail how long the individual living with stroke is participating in the community. The World Health Organisation Disability Assessment Schedule (WHODAS 2.0), a generic patient-reported measure of disability was considered as a potentially appropriate routine outcome measure for multi-disciplinary community rehabilitation services (Ustun et al., 2010).

3.4.1.1 RESEARCH INSTRUMENT – THE WORLD HEALTH ORGANIZATION DISABILITY ASSESSMENT SCHEDULE 2.0

The World Health Organization's Disability Assessment Schedule 2.0, a 36-item interviewer-administered questionnaire was the tool utilised in this study to collect the data. The instrument was designed to evaluate the functioning of the individual in six activity domains: cognition, mobility, self-care, interpersonal relationship, life activities, and participation in society. This instrument consists of two sections: the first section requires demographic information (age, gender, marital status and main work status), while the second section consists of 36 items which assesses disability in daily life, scored on a 5-point Likert Scale (1–5) in the last 30 days ranging from none (1) mild (2) moderate (3) severe (4) extreme or cannot do (5), while “not applicable” is used when not involved in any of the mentioned activity, to determine their functional disability. The Items Response Theory (IRT) base was used in the scoring of the WHODAS 2.0, according to the manual (Ustun et al., 2010).



3.4.1.2 RELIABILITY AND VALIDITY OF INSTRUMENT

Reliability is defined as the extent to which an assessment tool produces the same results on repeated trials, is the consistency / stability of scores across raters (Bless & Higson-Smith, 2000), while validity is the capacity of an assessment tool to measure what it purports to measure (Silverman, 2000). The WHODAS 2.0 instruments has been tested and retested by WHO and was found to have high internal consistency (Cronbach's alpha, α 0.86), a stable factor structure; high test-retest reliability (intraclass correlation coefficient: 0.98); good concurrent validity in patient classification when compared with other recognised disability measurement instruments; conformity to Rasch scaling properties across populations, and good responsiveness (i.e. sensitivity to change) (Ardoin, Faccincani, Galati, Gavioli & Mignolli, 1991).

3.4.1.3 DATA COLLECTION PROCEDURE FOR QUANTITATIVE PART

Ethical clearance to conduct research was sought from the Senate Research Grants and Study Leave Committee at the University of the Western Cape. Also, permission was sought from the World Health Organisation to use the research instrument and permission to use WHODAS 2.0 was granted by the WHO. Permission was sought from the Department of Health in Western Cape to conduct the research accessing patients who had received treatment at the Community Health Centres and to approach the patients to be the participants, and permission was granted. The physiotherapists working at the relevant CHCs which were Macassar CHC, Strand CHC, Khayelitsha CHC, Micheal Mapongwana CHC and Nolungile CHC, were approached for the patient record books which contained names, relevant details and phone numbers of the participants. Appointments were scheduled with the patients who met the inclusion criteria, and community health workers to plan a visit. Patients were approached to make a choice of appointment that was convenient to them. The objectives and importance of study was clearly explained to participants in the language well understood by the participants. Those who were willing to participate were recruited and the freedom to withdraw, confidentiality of information and anonymity was clearly explained, after which they were asked to sign an informed and written consent form. Data was collected using the survey questionnaires; the questionnaires were in English, translated to Afrikaans and Xhosa, depending on participants' best understood language. Translated versions were obtained colleagues who had previously used it. The research assistants were trained on how to use questionnaire. Instruments were administered at the out-patient rehabilitation centres at the Community Health Centres in the Metropole District and at the patient's residence, in the Western Cape. Data was collected between May 2013 and May 2014.

3.4.1.4 DATA ANALYSIS FOR QUANTITATIVE PART

The Statistical Package for Social Sciences (SPSS) version 21 was used for descriptive and inferential statistics. The questionnaires were translated and recorded into statistical figures by strictly adhering to the rules and guidelines of the questionnaires (WHODAS 2.0 manual), in which the items rating based scoring was used (IRT). All data elements were scored and captured in Windows Excel 2010. Data was analysed using both descriptive and inferential statistics. Descriptive statistics of percentage/frequency of the socio-demographic details of the patients, descriptive statistics of mean and standard deviation of the activity domains (cognition, mobility, self-care, interpersonal relationship, life activities and participation in the society) were analysed. Frequencies of gender, marital status, educational level, main work description like paid work, self-employed, non-paid work, student, home maker/house keeper, retired, unemployed (health reason) and unemployed (other reason) was analysed. Also, factors associated with participation restrictions were analysed. Associations between demographic data such as age, gender, marital status, educational level, main work description with participations restrictions were analysed. Associations were analysed using the Chi square to investigate the relationship between different domains such as cognition, mobility, self-care, interpersonal relationship, life activities, and participation in society of stroke; and p value was reported for Pearson Chi square test. Alpha level is set at 0.05.

3.4.2 PART 2 -QUALITATIVE METHOD

3.4.2.1 SAMPLING METHOD

Purposive sampling was used to select participants for the focus group discussions. Willing participants were encouraged to give their contact numbers during the quantitative part of the study. Participants were chosen purposively, from over 10 years of stroke to one year post-stroke. Purpose sampling is a form of non-probability sampling in which decisions concerning the individuals to be included in the sample are taken by the researcher, based upon a variety of criteria which may include specialist knowledge of the research issue, or capacity and willingness to participate in the research (Oliver, 2006).

3.4.2.2 FOCUS GROUP DISCUSSIONS

Focus group discussion is a form of qualitative research whereby a group of people are asked about their perceptions, opinions or attitude of an idea, which are usually in an interactive group setting where participants are free to talk with other group members (Thomas, 2000). Focus groups were originally called “focused interviews” or “group depth interviews” (Kaufman, 2003). The technique was developed after World War II to evaluate audience response to radio programmes (Kaufman, 2003). Since then social scientists and programme evaluators have found focus groups to be useful in understanding how or why people hold certain beliefs about a topic or programme of interest (Kaufman, 2003). Focus group discussions were utilised in this study because several types of stroke patients were approached for this study under permissive and nurturing environment that encouraged different in-depth perceptions and point of views, relating to limitation encountered in their daily life situations. Focus group discussion enabled in-depth understanding, feelings and people perspective toward a particular condition; it was also used for a variety of purposes,

including needs assessment, programme refinement, issue identification, and strategic planning (Boyce & Neale, 2006).

3.4.2.3 SAMPLE SIZE

The focus group discussion consisted of total of sample size of seventeen patients, as two focus groups were conducted at two different community health centres. Discussion was continued until saturation was reached, at which point no new codes or categories emerge and when coding more transcripts would only produce repetition of themes. Participants were drawn from the initial participants that participated in Phase 1 of this study, who completed the questionnaire. The inclusion and exclusion criteria are the same as the Part 1 of the study.

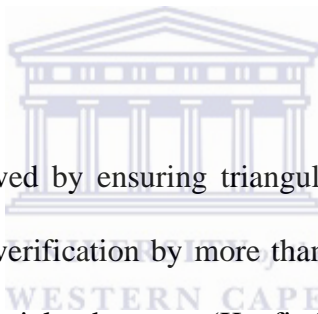
3.4.2.4 DATA COLLECTION PROCEDURE

For Part 2 of this study, focus group discussions were conducted with the willing participants at a convenient time decided upon by the participants. Permission was obtained from the Community Health Centre's administration to conduct the discussion within the Physiotherapy Department at the hospital. The venue was found to be convenient and permissive to all. Consent forms were given in advance to them to sign prior the day of the interview. The research assistants were made to understand the confidentiality of the information shared in the focus group sessions. Willing participants met at the agreed venue and were assured about the confidentiality of the information given and were informed that no names would be referred to, and no one would be identified by statements made. An interview guide was generated based on information gathered from analysis of WHODAS 2.0, and also based on literature evidence reported. Discussions were recorded through a tape recorder and field notes. The tape recorder and note-taking as tools, have been accepted as a worthy instrument to capture information in focus group discussion. The discussion

proceeded until saturation was reached (no new themes or codes emerge) (Guest & Johnson, 2006). Data was collected using a tape recorder and notes taken; a probing technique was used to clarify the participants' responses and to obtain more information (Britten, 2000). The researcher facilitated the discussion, which was interpreted by the trained research assistant, both in Afrikaans and isiXhosa. The notes were taken by the two trained research assistants in Afrikaans and isiXhosa.

3.4.2.5 TRUSTWORTHINESS

To ensure trustworthiness of the recorded data, the collected data were accessed based on the credibility, transferability, dependability and confirmability of information (Miles & Huberman, 1984).



The credibility which was achieved by ensuring triangulation of information (by ensuring validation of data through cross verification by more than two sources), peers examination, interview technique and referential adequacy (Knafi & Breitmayer, 1989), which was ensured by validation of data by supervisors and a colleague.

Transferability was achieved based on nominated sample, comparison of the sample to demographic data and dense description of information (Sandelowski, 1986).

Dependability was achieved based on triangulation of information, peers examination, dense description and dependability audit (Guba, 1981), which was ensured by triangulation of information by expert, supervisors and a colleague.

While confirmability was achieved based on confirmability audit, the triangulation of information and reflexivity of information (Aamodt, 1982), which is often obtained from coding teams, has shown high inter-rater reliability scores from coded items in the interview and thus improve reliability of findings (Miles & Huberman, 1984).

3.4.2.6 DATA ANALYSIS FOR QUALITATIVE STUDY

In exploring the activity limitations and participation restrictions of stroke patient living within the community; the data analysis identifies the meaning in the information gathered in relation to the purpose of the study (Rubin & Rubin, 2004). Data were analysed manually, which involved summarising these by words or phrases and creating a visual image of the themes that arose during the focus group discussions. The information gathered was transcribed verbatim, translated and was divided into meaningful analytic units (i.e. segmenting the data). After the interview, the fields notes were transcribed, the content of the transcribed notes were read to familiarise the researcher with the contents and to understand the data (Marshall & Rossman, 1999). This process involved identifying code for similar categories that were grouped under different pre-determined themes and the coding was moved from the descriptive to more interpretative and inferential codes (Miles & Huberman, 1994). Experts in qualitative research, which are my supervisors, were sought after in analysing the data for categories, in order to correlate the information that was identified. The independent researcher and the researcher gathered together to check the themes that were identified if similarity was noted.

3.5 ETHICAL CONSIDERATIONS

Ethical clearance was sought and granted by the Senate Research Grants and Study Leave Committee at the University of the Western Cape and from the Department of Health in the

Western Cape. Written informed consent of the participants was requested which include explicit information on the objectives and aims of the research, their right to withdraw, anonymity and confidentiality of information was explained clearly, with no obligations attached by researcher strictly keeping all information confidential and will only be made available only when necessary and to appropriate sources like supervisors and the Physiotherapy Department. Participants in focus group discussions were asked to sign a confidentiality binding form to ensure that all information shared in a focus group discussion was kept confidential and was asked to sign a form that gives permission to be audio-taped during focus group discussions. Also they were given the right to withdraw from the study any time.

3.6 DISSEMINATION OF RESULTS

Tape recordings will be kept for five years after analysis, in case the researcher wants to do further analysis to the recordings for further research. The results of this study will be made available to the Physiotherapy unit, physiotherapists and stroke patients who participated.

3.7 SUMMARY OF THE CHAPTER

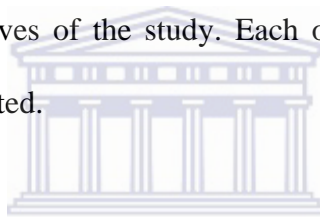
In this chapter, the methodology of the first and second phase of the study was clearly outlined. This included the population and sampling, description of the instruments used, and a brief outline of data analysis of the quantitative and qualitative analysis was provided. The results of the first phase of the study are outlined in the next chapter. The discussions of the quantitative phase were outlined in Chapter Five.

CHAPTER FOUR

QUANTITATIVE RESULTS

4. INTRODUCTION

This chapter contains the results of the quantitative study that aimed to answer the determination of socio-demographic details of the stroke patients, to determine limitations encountered by stroke patients in their daily life situations, to determine participation restrictions of stroke patients living within the community, to determine factors (age, gender, level education, marital status and employment) associated with participation restrictions and to determine the factors associated with participation. The chapter is organised such that it follows the listing of the objectives of the study. Each objective will be re-stated and the summary of the results will be stated.



The first phase of this study collected baseline data among stroke participants. The stroke participants were interviewed in order to determine the participation restrictions experienced after stroke, which followed a brief exposition on the demographic characteristics of respondents and socio-economic status. The result of the relative outcome of the problems encountered by stroke participants in the six different activity domains (cognition, mobility, self-care, getting along, life activities (household and work or school activities) and participation) and the results of factors associated with participation restrictions in stroke participants were collated.

4.1 DEMOGRAPHIC CHARACTERISTICS OF RESPONDENTS

A total of one hundred and twenty (120) were recruited to participate in the survey for a period of eight months (September 2013 – April 2014).

The majority (54.2%) of the participants were males. The ages of the participants who participated in the study ranged from 26 to 80 years old (Mean- 57.1, S.D -12.8). The date the participant had the stroke in the study ranged from the year 2001 to 2014. The majority (47.5%) of the participants were married. The demographic information of the participants are presented in Table 4:1.

4.1.1 Demographics status of the participants

Table 4.1 Gender, Age group and Marital Status (n=120)

Variable	Characteristics	Number	%
Gender	Female	55	45.8
	Male	65	54.2
Age Groups	20-29	4	3
	30-39	7	5.8
	40-49	20	16.8
	50-59	37	30.8
	60-69	29	24.2
	70-79	22	18.3
	80 ≤	1	0.8
Marital Status	Never Married	29	24.2
	Currently Married	57	47.5
	Separated	4	3.3

	Divorced	11	9.2
	Widowed	19	15.8
	Cohabiting	0	0

4.1.2 Marital status versus gender

Table 4.2 illustrates the distribution relationship between marital status and gender of the participants.

Table 4.2 Marital status versus gender (n= 120)

	Gender	Male N (%)	Female N (%)	Total N (%)	P-Value
Marital Status	Never Married	14(12.5)	15(27.3)	29(24.2)	0.000
	Currently Married	42(64.6)	15(27.3)	57(47.5)	
	Separated	0(0.0)	4(7.3)	4(3.3)	
	Divorced	5(7.7)	6(10.9)	11(9.2)	
	Widowed	4(6.2)	15(27.3)	19(15.8)	
	Cohabiting	0(0)	0(0)	0(0)	
	Total	65(100)	32(100)	120(100)	

There was a notable difference between the marital statuses of the males compared to the females. It was notable that 64.6% (42/65) of the males compared to 46.9% (15/32) of females were currently married.

At a 0.05 level of significance, the chi-square test showed that the marital status was significantly associated with gender (p= 0.000).

4.1.3 Socio-economic status

This section presents the result of the socio economic status of the participants. The majority (45.8%) of the participants' highest education is primary school. Over half of the participants (64.7%) are assisted by relatives in living within the community, which is their living situation, while 44.2% of the participants in the study were unemployed due to health reasons. This section presents educational level, living situations and main work status. (See Table 4.3).

Table 4.3: The socio economic characteristics of the participants (n = 120)

Variable	Characteristics	Number	%
Living Situation	Independent in the Community	42	35.5
	Assisted Living	77	64.7
Educational level	None	14	11.7
	Primary	55	45.8
	Secondary	51	42.5
Main work status	Paid Work	4	3.3
	Self employed	2	1.7
	Keeping home/home maker	4	3.3
	Retired	19	15.8
	Unemployed (health reasons)	53	44.2
	Unemployed (other reasons)	15	12.5

	Other	23	19.2
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4.2 PARTICIPATION RESTRICTIONS

4.2.1 DOMAIN 1 – COGNITION (UNDERSTANDING AND COMMUNICATION)

This section presents the cognition of the stroke participants, who participated in this study.

Participants were asked questions about understanding and communication. The cognitive domain determined in this study were: abilities of concentration, memory, problem solving, learning new task, general understanding, starting and maintaining conservation, all within the thirty days after stroke. The questionnaires are scored using the items rating based theory (IRT) according to WHODAS 2.0 manual for computing the data. The data relating to this domain is illustrated in table 4.4.

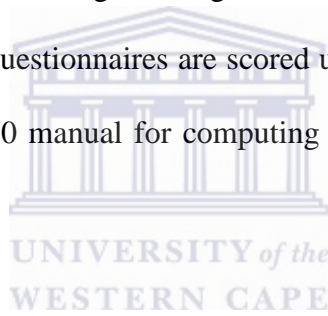


Table 4.4 Cognition Domain

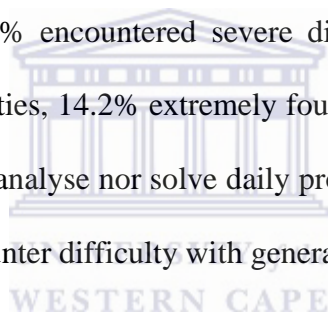
	N	Min	Max	MED	X	SD
Concentration	120	0	4	1.00	1.34	1.32
Remember important things	120	0	4	1.00	1.42	1.31
Problem solving	120	0	4	2.00	1.58	1.42
Learning new tasks	120	0	4	2.00	1.67	1.51
General understanding	120	0	2	0.00	0.59	0.72
Starting and maintaining Conservations	120	0	2	1.00	0.68	0.76

The above table reveals the minimum, maximum, median, mean and standard deviations of the participants in the study. The median was calculated due to the close range between the

mean and standard deviations. The minimum rating for the domain is 0, while the maximum rating is 4 after the Items Respond Theory (IRT) based scoring of the WHODAS 2.0 manual (Ustun et al., 2010). The highest mean score was learning new tasks with an aggregate score of 1.67, followed by analysing and solving problems of daily life situations with score of 1.58.

Cognition Distribution

The participants illustrated the level of difficulty encountered in different aspects of their ability to understand and communicate, which was shown in the figure below (Cognition Distribution). The result showed that 23.3% of the participants' experienced severe difficulty in learning new tasks, while 20% encountered severe difficulty in analysing and finding solutions in day-to-day life activities, 14.2% extremely found difficulty in learning new tasks after stroke, while 10.8% cannot analyse nor solve daily problems of life. The majority of the participants (54.2%) do not encounter difficulty with general understanding (See figure 4.1).



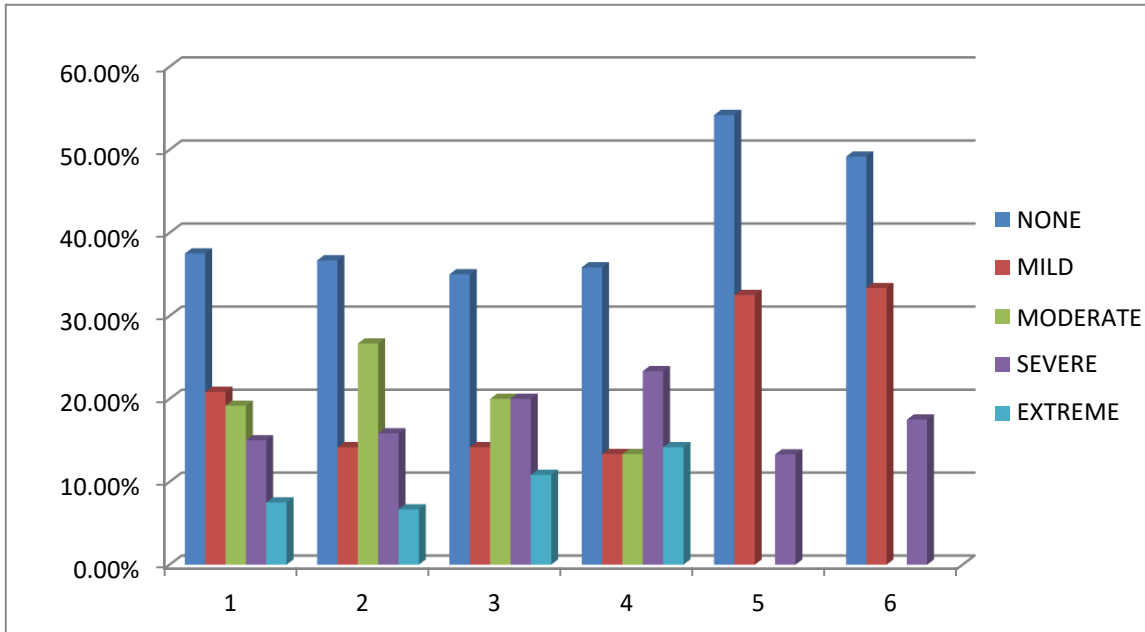


Figure 4.1 Cognition Distribution

- 1 - Concentration
- 2 - Remember important things
- 3 - Problem solving
- 4 - Learning new tasks
- 5 - General understanding
- 6 - Starting and maintaining a conversations



WHODAS IRT Based Score Distribution for Cognition

Figure 4.2 illustrates the population percentile distribution of the IRT-based score for cognition in WHODAS 2.0 -36 items. From the figure below, it was shown that an individual with 60 positive items responses (x-axis: WHODAS 2.0 IRT BASED SCORE) would correspond to the 81.7th percentile of the population that participated in the study (y-axis population percentile).

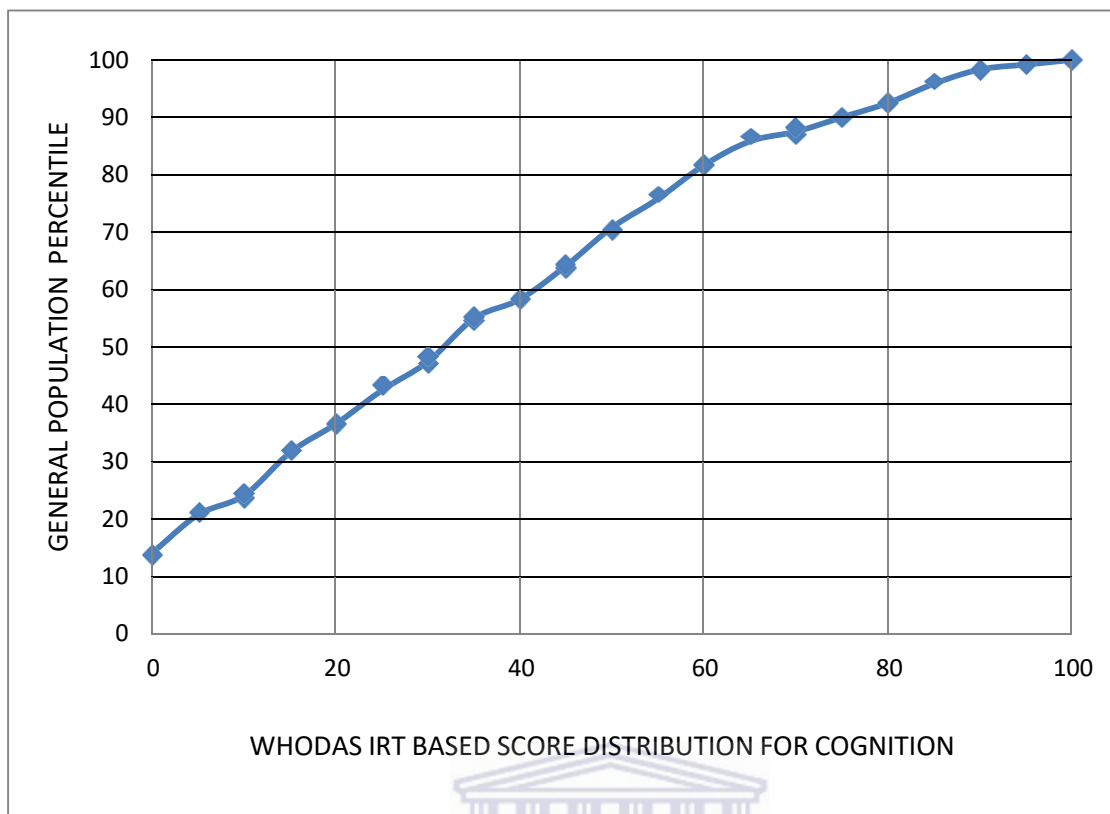
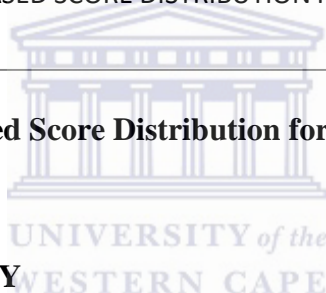


Figure 4.2: WHODAS IRT Based Score Distribution for Cognition



4.2.2 DOMAIN 2 – MOBILITY

Participants were asked about difficulties in getting around after their stroke experience. The following questions were asked: ability to stand for long period, standing up from a sitting position, moving around and inside the house, walking a long distance, all in the first thirty after stroke.

Table 4.5 illustrates the result of mobility with minimum range of 0 and maximum range of 4, with greater average noted in the walking a longer distance such as a kilometre and standing for a long period like thirty minutes with scores of 2.48 and 2.27 respectively.

Table 4.5 Mobility domain

	N	Min	Max	MED	X	SD
Standing for long period like 30mins	120	0	4	3.00	2.27	1.56
Standing up from sitting position	120	0	2	1.00	1.08	0.74
Moving around inside home	120	0	2	1.00	0.88	0.75
Getting out of the home	120	0	4	2.00	1.69	1.38
Walking a long distance such as a kilometer	120	0	4	3.00	2.48	1.47

Percentage distributions in Mobility

The figure 4.3 illustrates the distributions of the mobility post stroke; this is illustrated in the figure below. The majority of the participants (45.8%) are aware of being mildly affected by standing up from sitting position, but 34.7% acknowledge severe difficulty with walking a long distance such as a kilometre after stroke, 33.1% had extreme difficulty or cannot stand for a long period, while 31.4% experienced severe difficulty standing up from sitting position.

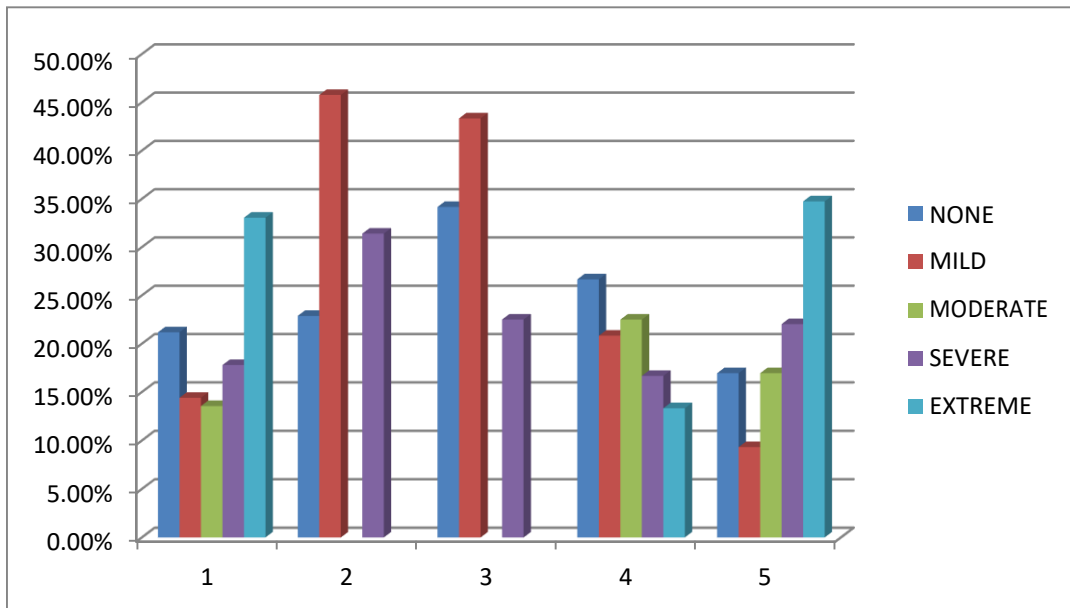


Figure 4.3 Percentage Distribution of Participant's Mobility

- 1 - Standing for long period
- 2 - Standing from sitting position
- 3 - Moving around
- 4 - Getting out of the house
- 5 - Walking a long distance



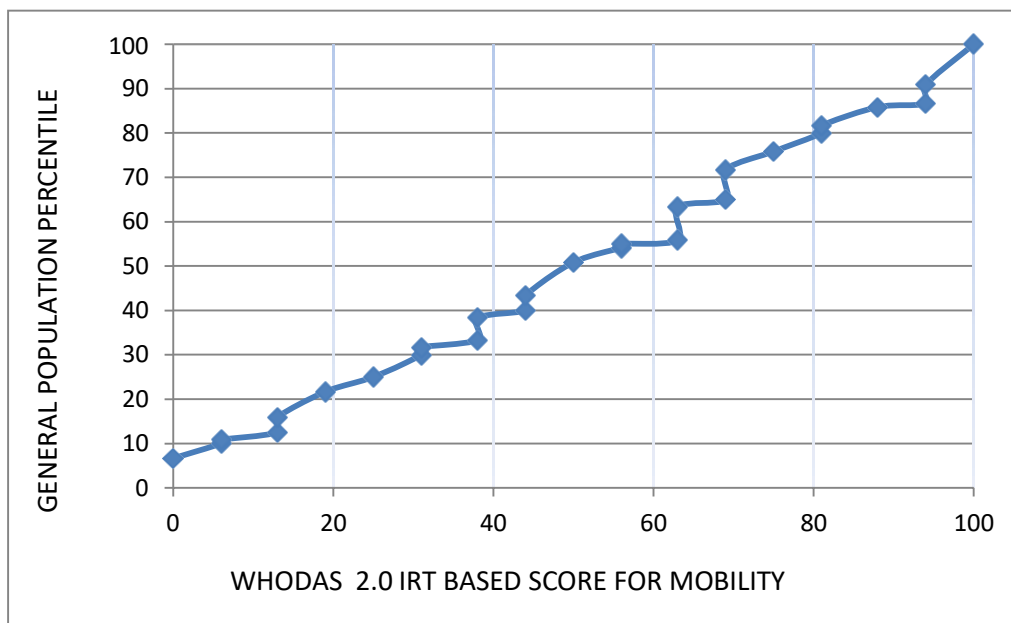
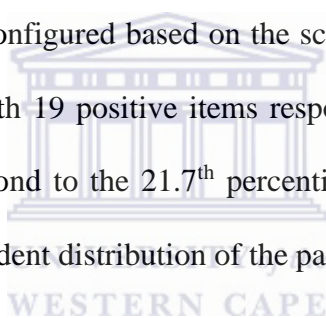


Figure 4.4 WHODAS IRT Based Score Distribution for Mobility

From the figure 4.4 which was configured based on the scored items ratings based theory, it was shown that an individual with 19 positive items responses (x-axis: WHODAS 2.0 IRT BASED SCORE) would correspond to the 21.7th percentile (y- axis population percentile). This shows the level of correspondent distribution of the participants within the community.



4.2.3 DOMAIN 3: SELF CARE

Participants were asked difficulties experienced with taking care of themselves. The following questions were asked: difficulty in washing the body, getting dressed, eating and staying by themselves alone for a few days, all in the first thirty days after stroke? Their response was shown below in table 4.6 with the minimum range of 0 and maximum range of 4, highest median of 1.50 (getting dressed), with highest mean and standard deviation of 1.64 and 1.52 respectively with difficulty experienced with getting dressed.

Table 4.6 Self-care domain

	N	Min	Max	MED	X	SD
Washing the whole body	120	0	2	1.00	1.08	0.80
Getting dressed	120	0	4	1.50	1.64	1.52
Eating	120	0	2	0.00	0.51	0.69
Staying by Yourself	120	0	2	1.00	1.10	0.89

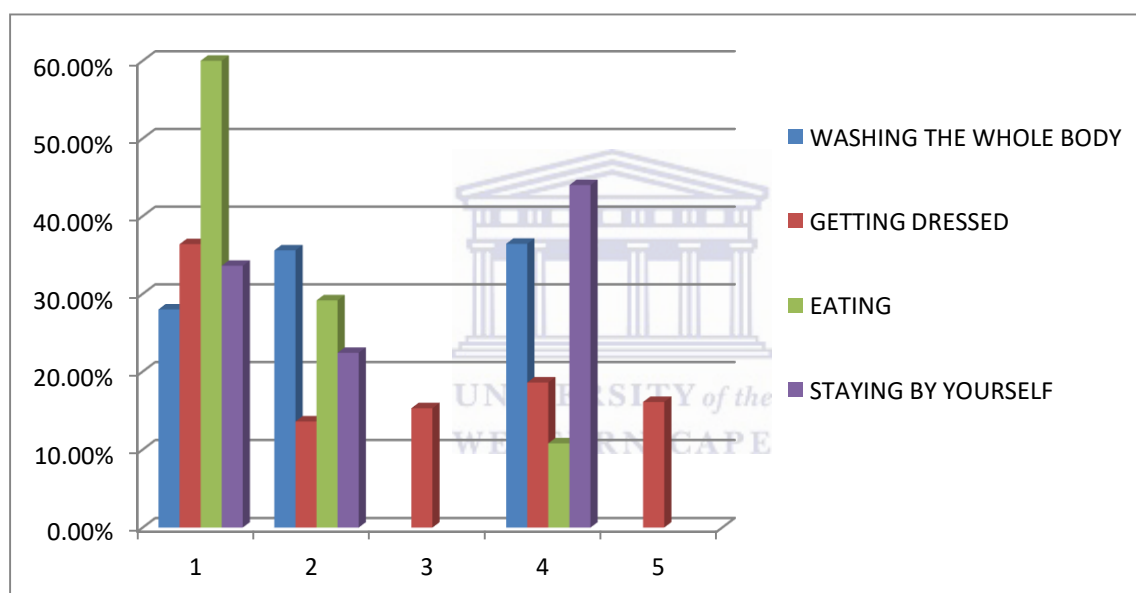


Figure 4.5 Percentage Distribution of Self Care

1 - NONE

2 - MILD

3 - MODERATE

4 - SEVERE

5 - EXTREME OR CANNOT DO

From the figure 4.5, 44% experienced severe difficulty staying alone after stroke, while 36.4% also experienced severe difficulty washing the whole body by themselves. The

majority (60%) acknowledged no difficulty with eating, while 16.1% experienced difficulty or found it extremely impossible to get dressed by self after stroke.

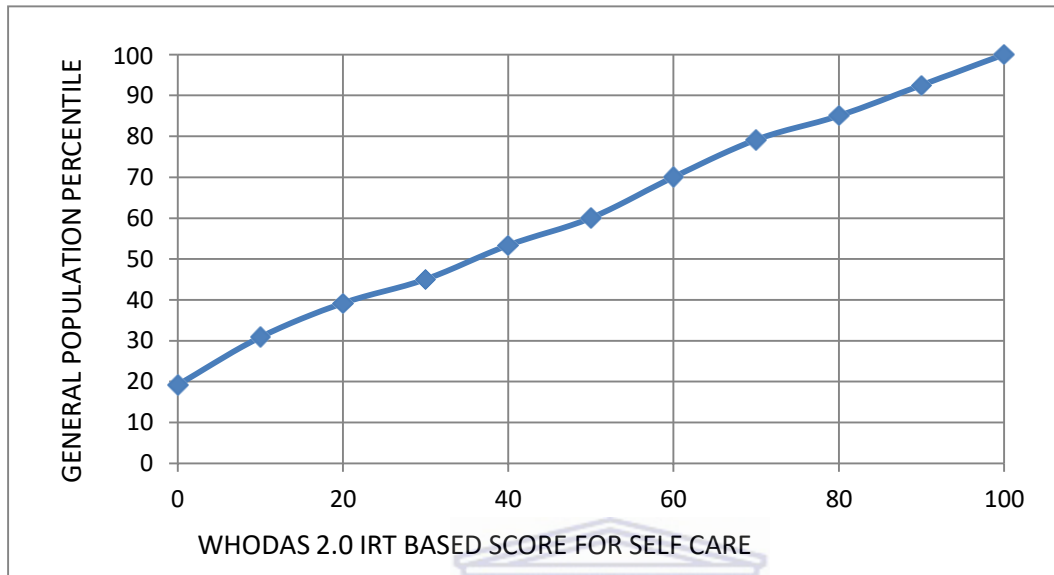


Figure 4.6 Distributions of the WHODAS 2.0 IRT Based score for self-care.

This figure shows the level of general population correspondence to world health organization based score for self-care domain, which is seen in figure 4.6; whereby 40th of the general population percentile will correspond to 20 based score of whodas 2.0.

4.2.4 DOMAIN 4: GETTING ALONG WITH PEOPLE

Participants were asked about difficulty in getting along with people, which arises as a result of their health problems, such as their mental or emotional problems, and problems with alcohol or drugs after the incidence of stroke. The participants were asked to express difficulties in dealing with people they did not know, maintaining friendship, making new friends, and with sexual activities in the first days after stroke.

Their response was shown below in Table 4.7 with a minimum range of 0 and maximum range of 4, with highest median of 1, mean of 1.01 and standard deviation of 0.85 with sexual activities in the first month after stroke.

Table 4.7 Getting Along Domain

	N	Min	Max	MED	X	SD
Dealing with people you do not know?	120	0	2	0.00	0.56	0.73
Maintaining a friendship?	120	0	2	0.00	0.56	0.78
Getting along with people who are close to you?	120	0	2	0.00	0.48	0.74
Making new friends?	120	0	4	0.00	0.88	1.22
Sexual activities?	120	0	2	1.00	1.01	0.85



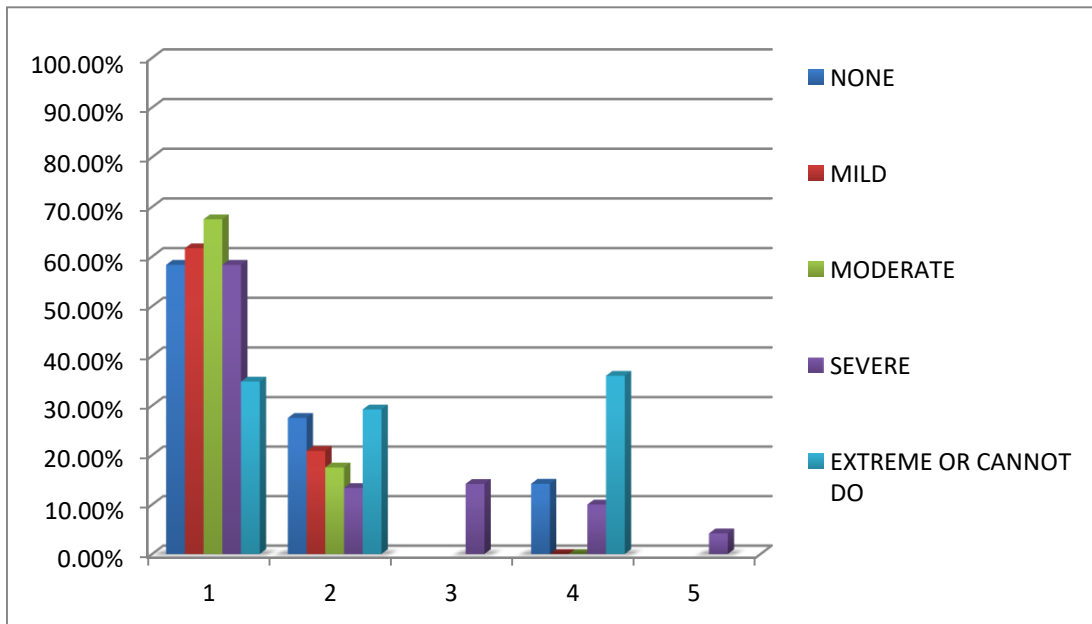


Figure 4.7 Percentage Distributions in getting along

- 1 - Dealing with people you don't know
- 2 - Maintaining a Friendship
- 3 - Getting Along with close people
- 4 - Making a new friends
- 5 - Sexual Activities



The result illustrated in figure 4.7, 14.2% had severe difficulty dealing with people they do not know after the stroke, while 10% of the participants encountered severe difficulty making a new friends, 14.2% reported moderate difficulty making a new friends while, 4.2% had extreme difficulty or cannot make any new friends a month post-stroke, while the majority, 67.5%, had no problem with getting along with close people after stroke, and 36% had severe problems with sexual activities a month after the incidence of stroke. Some participants acknowledge refraining from sex after stroke, which makes the sexual activities “not applicable” to them. The result is illustrated in the Domain 5(2) for work and school activities sections.

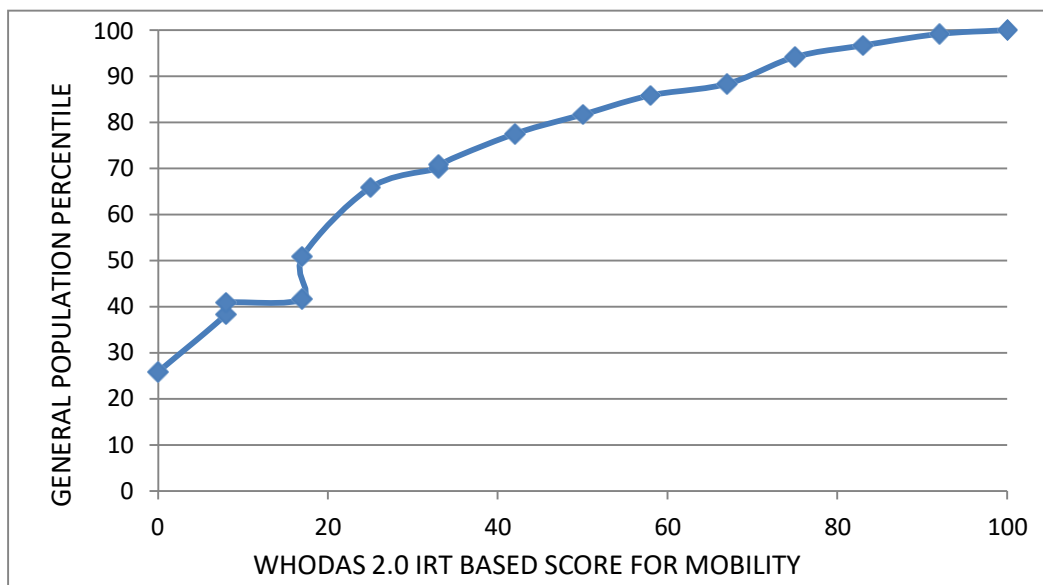
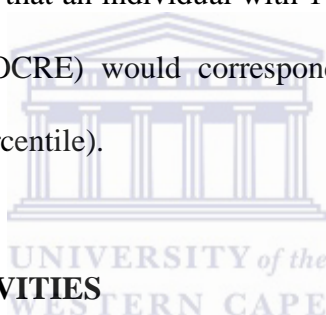


Figure 4.8 The WHODAS 2.0 IRT based score distributions for Mobility

From the figure 4.8, it was shown that an individual with 17 positive items responses (x-axis: WHODAS 2.0 IRT BASED SCORE) would correspond to the 50.8th percentile of the population (y-axis population percentile).



4.2.5 DOMAIN 5 LIFE ACTIVITIES

4.2.5(1) HOUSEHOLD ACTIVITIES

Participants were asked about activities involved in maintaining the household and in caring for people who they live with or are close to. These activities include cooking, cleaning, shopping, caring for others and caring for their belongings within thirty days after the incidence of stroke.

The result below in Table 4.8 indicated the minimum range of 0, maximum range of 4, maximum median range of 3 and minimum median range of 1; highest mean of 2.44 and standard deviation of 1.39 in getting household work done as quickly as possible in the past thirty days, also noted is median of 2, mean of 1.21, standard deviation of 1.61 in taking care of the household responsibility for the past thirty days.

Table 4.8 Household Activities Domain

	N	Min	Max	MED	X	SD
Taking care of your household responsibilities?	120	0	4	2.00	1.71	1.61
Doing your most important household tasks well?	120	0	2	1.00	1.17	0.82
Getting all the household work done that you needed to do?	120	0	2	1.00	1.25	0.79
Getting your household work done as quickly as possible?	120	0	4	3.00	2.44	1.39



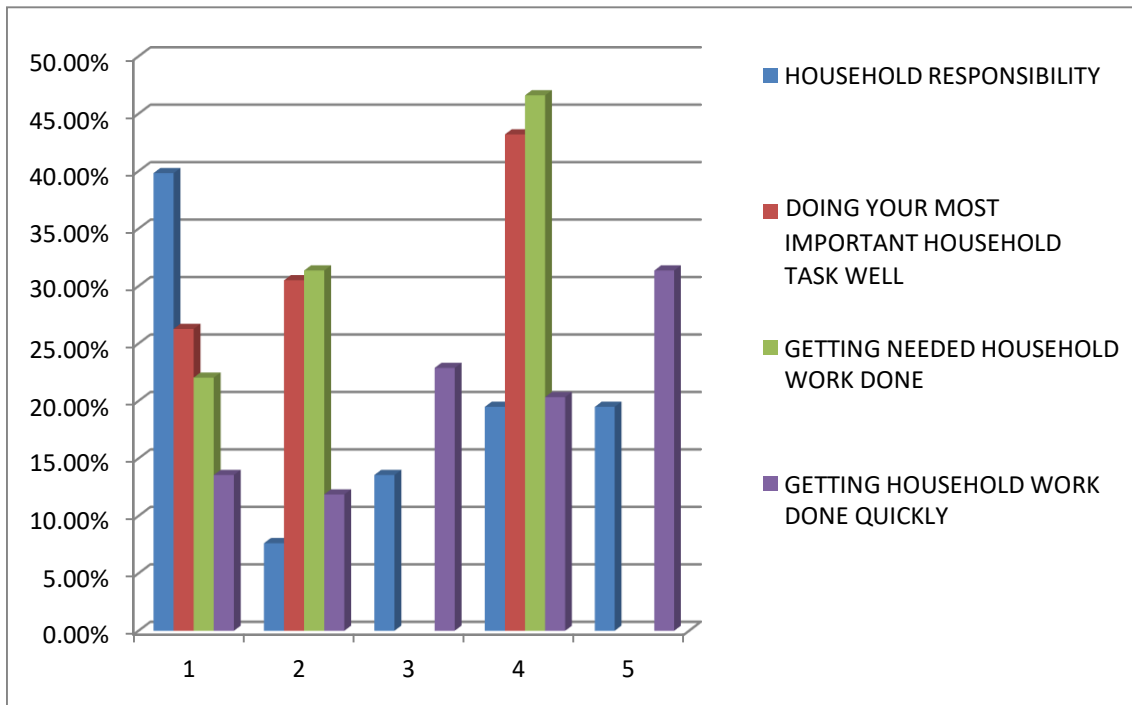


Figure 4.9 Percentage Distribution of Household Activities 30 days Post-Stroke

1 - NONE

2 - MILD

3 - MODERATE

4 - SEVERE

5 - EXTREME OR CANNOT DO



From the figure 4.9 above, it was revealed that 31.4% had extreme difficulty or cannot execute any household work needed to be done after the incidence of stroke, 19.5% experienced extreme difficulty or cannot do any household tasks. 46.6% of the participants encountered severe difficulty in getting needed household work done; 43.2% experienced severe problems in getting needed household work task well, 20.3% experienced severe difficulty with getting household work done as quickly as possible, while 19.5% had severe struggle with household responsibility. 39.8% of the participants indicated no difficulties with household responsibility after 30 days of stroke.

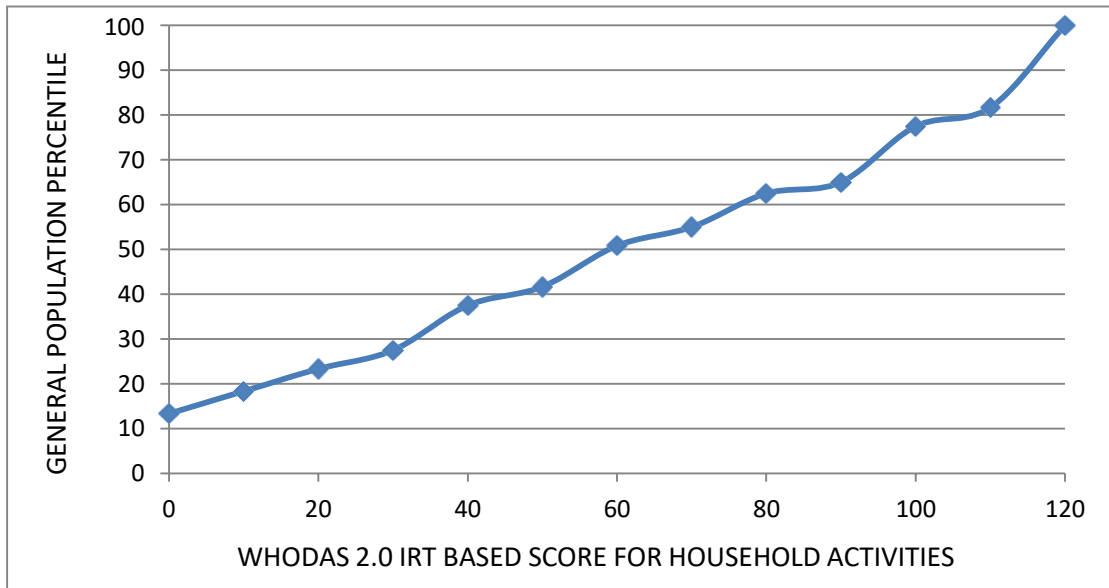


Figure 4.10 The WHODAS 2.0 IRT based score distributions for Household Activities

The figure 4.10 shows the rate at which general population percentile correspond with whodas 2.0 irt based score for household activities.



Distributions for Recorded number of days reduced or completely missed Household work for participants greater than none (recorded as “0”) because of Health condition in the past 30 days.

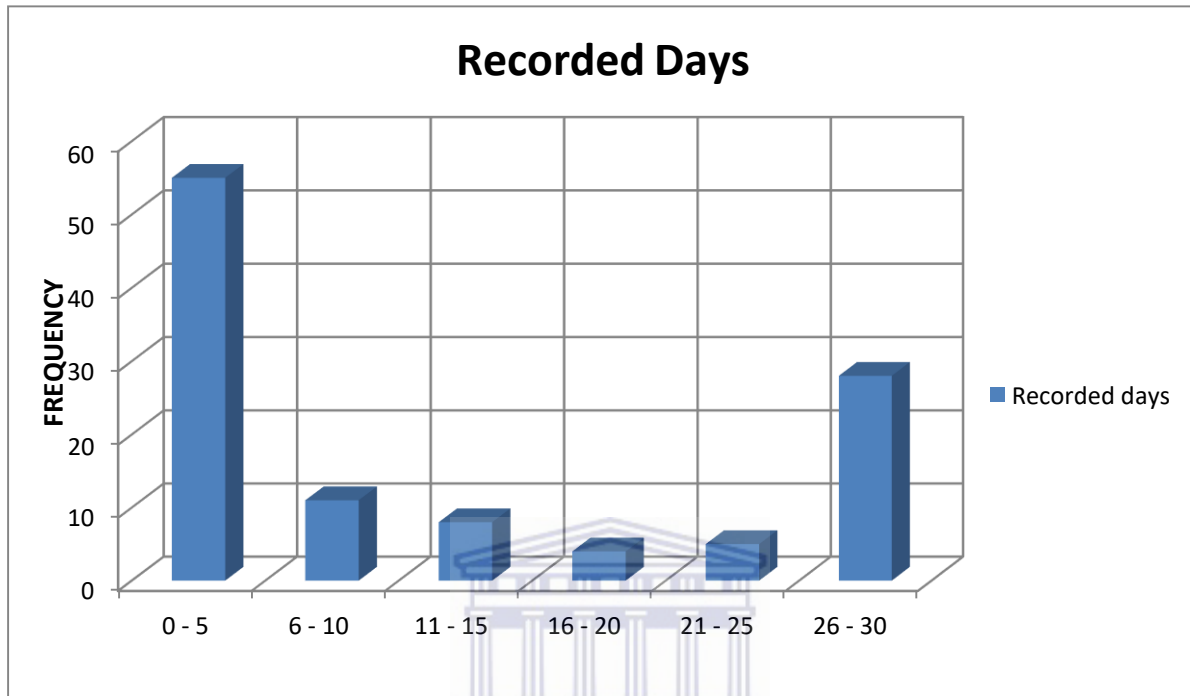
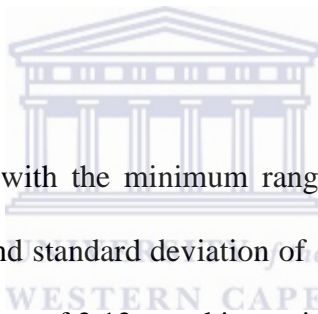


Figure 4.11 Distributions for Recorded number of days reduced or completely missed Household work for participants greater than none (recorded as “0”) because of Health condition in the past 30 days.

From figure 4.11 above, it was shown that 0 to 5 days was completely missed or reduced household work for a frequency of 55 in household work due to their health conditions, while 26 to 30 days were reduced or completely missed in household work for frequency of 28 for the past 30 days.

4.2.5(2) WORK OR SCHOOL ACTIVITIES

Participants were asked about their work or school activities. The majority indicated no involvement in work or school activities because of their health condition, which was rated as “not applicable” according to WHODAS 2.0 manual guide. However, only three participants was involved in work or school activities for those interviewed in this study. The participants were asked about: their difficulty encountered in their day-to-day work/school in the past 30 days; doing the most important work/school tasks well in the past 30 days; getting all the work done that is needed to be done in the past 30 days; getting the work done as quickly as needed in the past 30 days; whether they have to work at a lower level because of their health condition in the past 30 days; and whether they earn less money as a result of their health condition in the past 30 days?



The respond was shown below, with the minimum range of 0 and maximum range of 3, highest median of 3, mean of 2 and standard deviation of 1.73 in getting all the needed work done; and highest standard deviation of 2.12 noted in getting work done as quickly as needed. A total of 117 participants are regarded as ‘not applicable’ in this section, as participants were not involved in any work or school activities (see table 4.9).

Table 4.9 Work/study domain

	N	Min	Max	MED	X	SD
Your day-to-day work/school?	03	0	2	2.00	1.33	1.61
Doing your most important work/school tasks well?	03	0	2	1.00	1.00	1.00
Getting all the work done that you need to do?	03	0	3	3.00	2.00	1.73

Getting your work done as quickly as needed?	03	0	3	1.50	1.50	2.12
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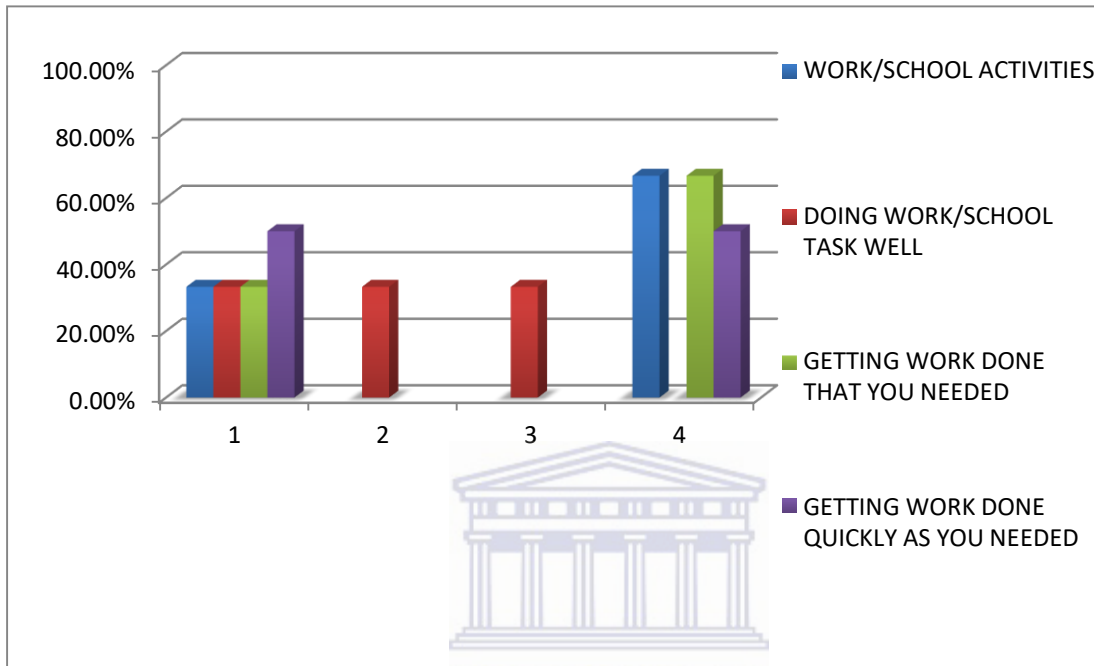


Figure 4.12 Percentage Distribution of post 30 days' Work or school Activities

1 - NONE

2 - MILD

3 - MODERATE

4 - SEVERE

From the figure 4.12 above, it was revealed that 66.7% of the 3 participants experienced severe difficulty with day-to-day work/school activities and getting work needed to be done, while 50% of the 3 participants had severe difficulty in getting work done quickly as needed. 33% of the 3 participants had moderate difficulty in doing the work/school task well as ought to be done.

Work Rank

The participants were asked to illustrate their experiences in work in a yes/no ranking depending on their level of affectation. The following questions were asked: do you have to work at a lower level due to their health condition and did you earn less money as a result of their health conditions.

The result showed a minimum range of 1 and a maximum range of 2, median of 2, mean of 1.67, and a standard deviations of 0.56 for both having to work at lower level, and earning less money, all due to health conditions. (see table 4.10).

Table 4.10 Work Rank

	N	MIN	MAX	MEDIAN	MEAN	STD
Have you had to work at a lower level because of a health condition?	03	1	2	2.00	1.67	0.56
Did you earn less money as a result of a health condition?	03	1	2	2.00	1.67	0.56

Percentage Distributions for both work at a lower level and Income earned at a lower level because of health conditions.

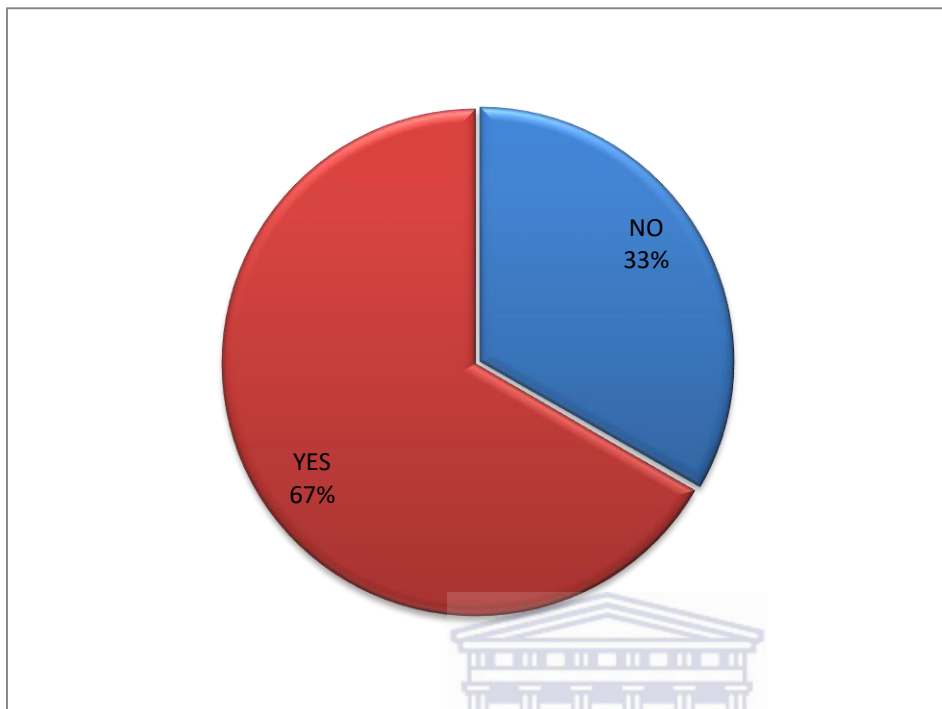


Figure 4.13: Percentage distribution for work at a lower level and income earned at work at a lower level which arises as a result of present health condition.

This figure illustrates the percentage distribution for work at a lower level and income earned at work at a lower level which arises as a result of present health condition. The majority of the participants responded that they work at a lower level as a result of their present health condition.

4.2.6 Distributions for Recorded number of days reduced or completely missed work for half a day or more because of health condition

In this section, the majority of the participants are recorded as “not applicable” as they are not involved in work or any school activities after the incidence of stroke, only one participant acknowledged missing one day of work in a month.

4.2.7 DOMAIN 6: PARTICIPATION

Participants were asked about participation within the society and the impact of their health problems on them and their families. The focus of their health problem was the physical, mental or emotional, alcohol or drug related problems.

The result in Table 4.11 showed the minimum range of 0 and maximum range of 4, highest median of 3, highest mean of 2.28 in been emotionally affected by their health problem, followed by mean of 2.03 in how much of a problem the family had because of their health condition. The highest standard deviation of 1.51 in problems encountered because of barriers or hindrances in the world around them, and standard deviation of 1.42 in problems encountered by family because of their stroke incidence.

Table 4.11 Participation Domains

	N	MIN	MAX	MED	X	STD
How much of a problem did you have joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?	120	0	2	1.00	1.10	0.83
How much of a problem did you have because of barriers or hindrances in the world around you?	120	0	4	2.00	1.85	1.51
How much of a problem did you have living with dignity because of the attitudes and actions of others?	120	0	2	1.00	0.89	0.82
How much time did you spend on	120	0	4	2.00	1.98	1.27

your health condition or its consequences?						
How much have you been emotionally affected by your health condition?	120	0	4	3.00	2.28	1.37
How much has your health been a drain on the financial resources of you or your family?	120	0	2	2.00	1.27	0.83
How much of a problem did your family have because of your health problems?	120	0	4	2.00	2.03	1.42
How much of a problem did you have in doing things by yourself for relaxation or pleasure?	120	0	2	2.00	1.24	0.86

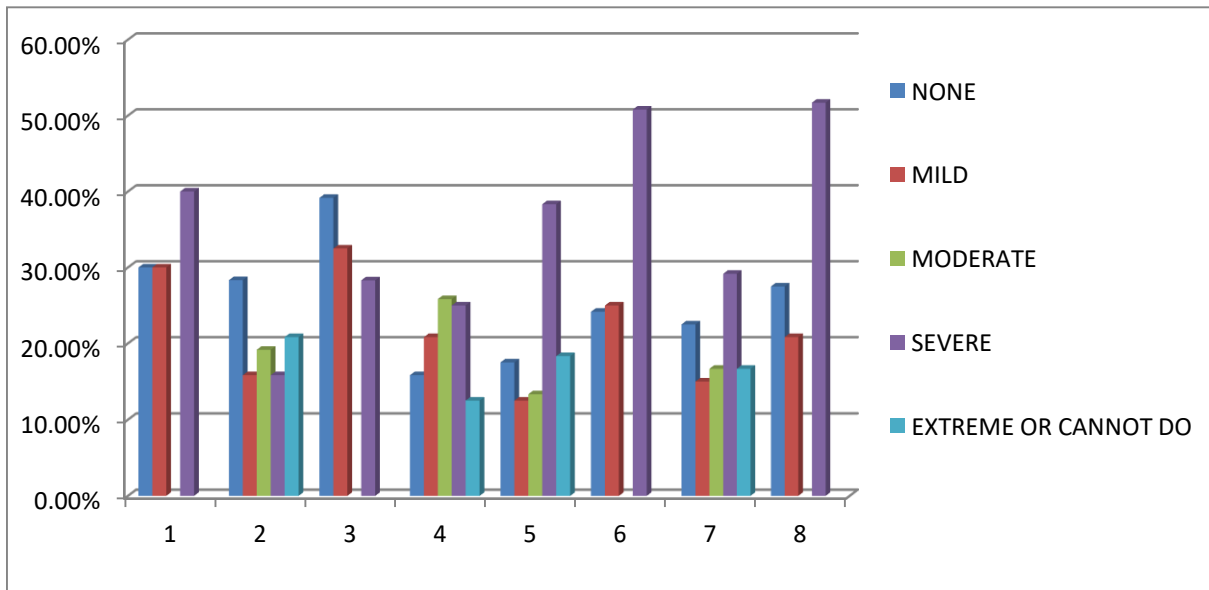


Figure 4.14 Percentage Distribution of Participant's Participation in the society

- 1 - Problem encountered in joining in community activities
- 2 - Problem had because of barriers and hindrances
- 3 - Problem had living with dignity because of attitudes and actions of others
- 4 - Times spent on health condition or its consequences
- 5 - Emotionally affected by your health?
- 6 - How much has your health been a drain on the financial resources?
- 7 - How much of a problem did your family have because of your health problem?
- 8 - How much of a problem did you have in doing things by yourself for relaxation or pleasure?

Figure 4.14 showed the distribution in percentage of stroke participants' reintegration into the society 30 days post-stroke; it was indicated that 16.7% had extreme problems within the family due to their stroke conditions, the majority (51.7%) acknowledged severe problems doing things by themselves for relaxation or pleasure after the incidence of their stroke condition, while 50.8% encountered severe financial restrained on them and on their family following their stroke problem, 40% had severe problem joining in community activities like

festivities, religious, other activities because of their health condition in the same way as anyone else can, 25.8% had extreme challenged with time spent on health condition, 39.2% had no problem living with dignity either by people action or attitude after the incidence of stroke, however 38.3% acknowledge that they have been severely affected emotionally in the past 30 days after the incidence of stroke.



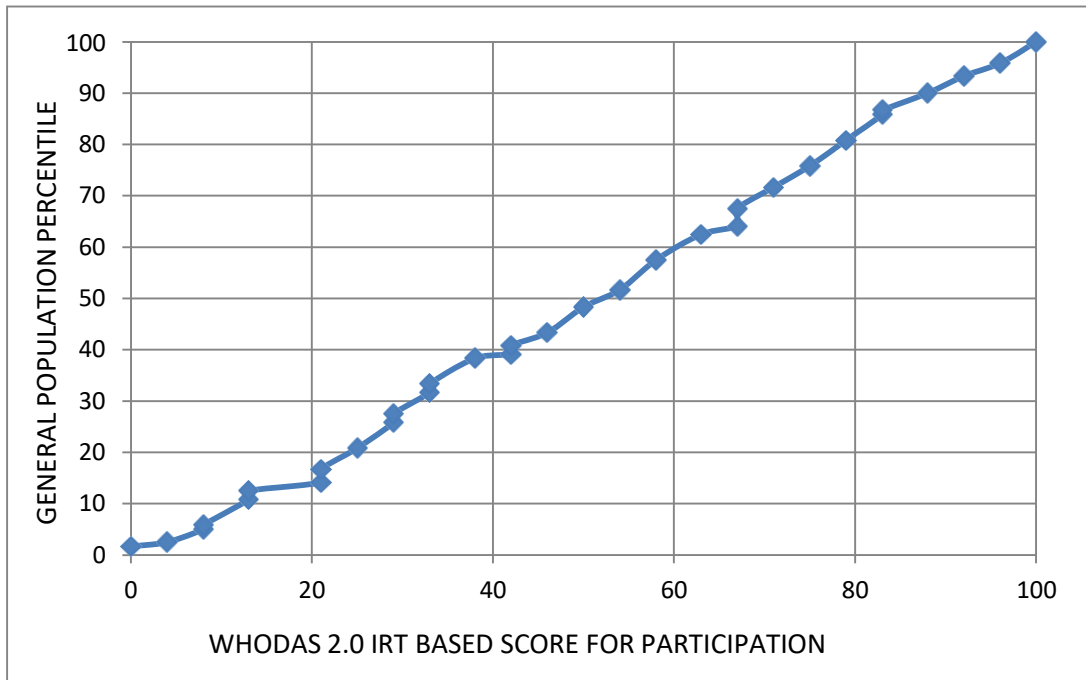
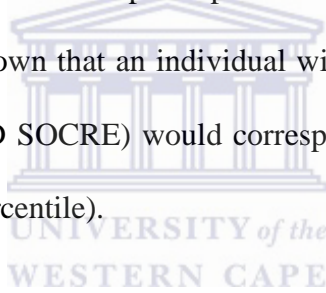


Figure 4:15 Whodas 2.0 irt based score for participation within the community

From the figure above, it was shown that an individual with 21 positive items responses (x-axis: WHODAS 2.0 IRT BASED SCORE) would correspond to the 14.2th percentile of the population (y-axis population percentile).



Overall Distribution

Figure 4.16 below showed the overall distribution in a recorded number of days in a month, the overall difficulties were encountered. The recorded days represent the number of days in a month the overall difficulty was present.

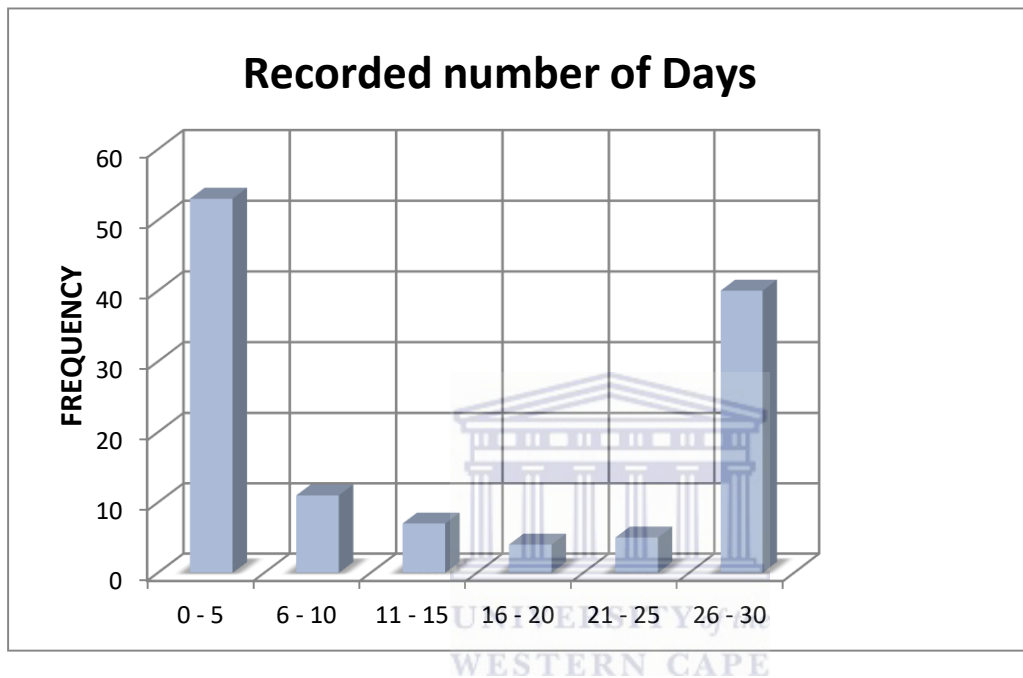


Figure 4.16 Overall distribution for recorded number of days in which the difficulties were present in a month

The figure below represent the overall distribution in recorded days that the participants were unable to carry out usual activities or work in a month because of their health problem.

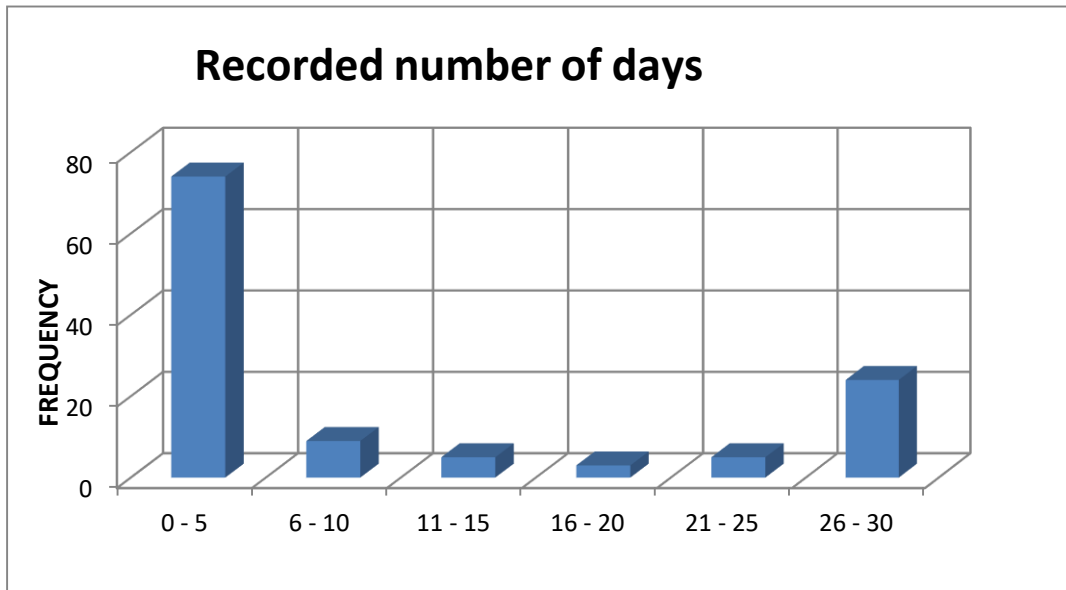


Figure 4.17 Overall distribution for recorded days totally unable to carry out usual activities or work in a month because of health condition.

The figure below represents the overall distribution in a recorded days in the past one month the participants cut back or reduced usual activities or work because of their health condition.

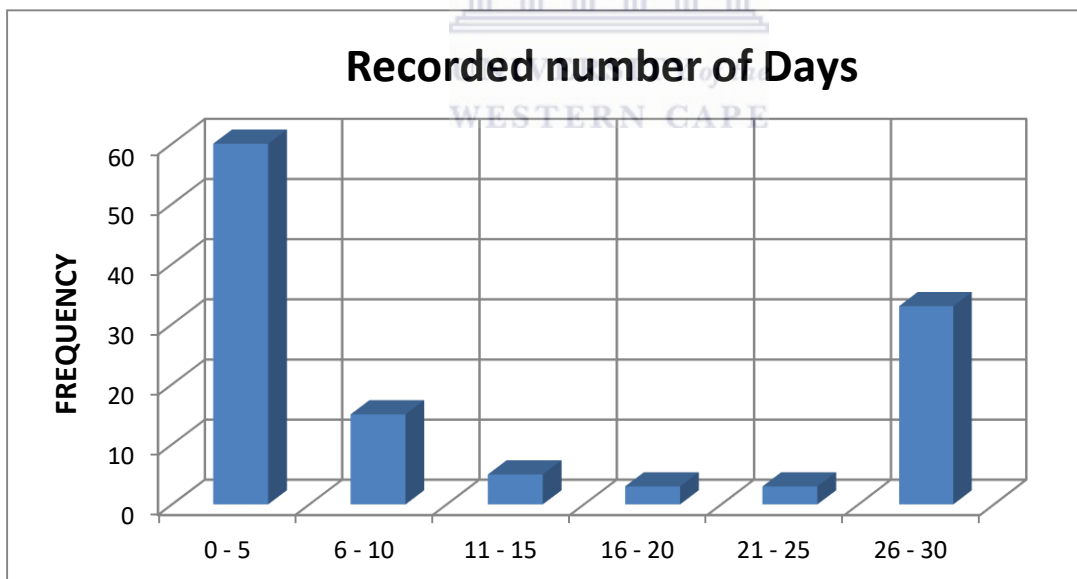


Figure 4.18 Overall Distribution for Recorded days cut back or reduced usual activities or work because of health condition in the past one month.

4.3 ASSOCIATION BETWEEN DEMOGRAPHIC FACTORS AND PARTICIPATION RESTRICTIONS

The association between the independent variables such as age, gender, educational level, marital status and main work status and the dependent variable, participants living in the community was done using the Anova one way test. Alpha level is set at 0.05. The results are summarised in Table 4.12.

Table 4.12 Association between demographics factors and Participations

	F value	P value
Age	0.91	0.608
Gender	0.98	0.513
Years of Education	0.75	0.816
Marital status	1.00	0.478
<u>Main work status</u>	<u>2.31</u>	<u>0.001*</u>

From the above table, it was shown that the association between the demographics factors and participations was significant for the main work status.

4.4 ASSOCIATION BETWEEN DEMOGRAPHIC FACTOR AND DOMAINS ASSOCIATED WITH PARTICIPATION

The association between demographic factors - age, gender, educational level, marital status and main work status was shown in the table below, and the domains associated with participation. Pearson Chi square was used to determine the association between the dependent variable and the independent variable, which shows no significance, ($p > 0.05$).

The results were outlined in Table 4.13.

Table 4.13 Association between demographic factors and participation domain

Participation		P Value
Problem encountered in joining in the community activities	Gender	0.376
	Age	0.150
	Level of Education	0.613
	Marital status	0.118
	Main work status	0.790
Problems had because of barriers and hindrances	Gender	0.594
	Age	0.426
	Level of Education	0.339
	Marital status	0.556
	Main Work status	0.942
Problems encountered living with dignity because of attitude and actions of others	Gender	0.583

	Age	0.491
	Level of Education	0.229
	Marital status	0.694
	Main Work Status	0.612
Time usage on health condition or its consequences	Gender	0.748
	Age	0.472
	Level of Education	0.131
	Marital status	0.568
	Main work status	0.237
Emotionally affected due to health condition?	Gender	0.615
	Age	0.385
	Level of Education	0.131
	Marital status	0.147
	Main work status	0.438
How much as your health been a drain on the financial resources of you or your family?	Gender	0.474
	Age	0.242
	Level of Education	0.446
	Marital status	0.246
	Main work status	0.025
How much of a problem did your family have because of your health problems?	Gender	0.058
	Age	0.941

	Level of Education	0.496
	Marital status	0.218
	Main work status	0.532
How much of a problem did you have in doing things by yourself for relaxation or pleasure?	Gender	0.236
	Age	0.011
	Level of Education	0.464
	Marital status	0.081
	Main work status	0.195

4.5 SUMMARY OF THE CHAPTER

The objective of the study is to determine participation restrictions of stroke patients living within the community and to determine factors (age, gender, level education, marital status and employment) associated with participation restrictions, in order to explore the factors responsible for the participation restrictions which is also known as the difficulty in life situations encountered on daily life basis of stroke patient living within the community.

A significant percentage of participants encountered difficulty with cognition with major difficulty in learning a new task after stroke, mobility (34% acknowledged difficulty walking a long distance like 1 kilometre after stroke), self-care (44% indicated difficulty staying alone for few days after stroke, while the majority (61%) complains of difficulty with getting dressed by self), getting along with people with major difficulty (36%) with sexual activities, household activities with major complaints (46.6% and 31.4%, for severity and exemption respectively) in getting needed household work done, work/study activities with difficulty in

day to day work activities, also in getting needed work to be done promptly and participation with severe difficulty (51.7%) in doing things themselves for relaxation and pleasure after stroke, 50.8% been financially restrained after stroke, 40% with difficulty in joining in the community activities, 39.2% with dignity affected because of people's attitudes and actions post-stroke and 25.8% of the participants indicated extreme time spent on health; all difficulties investigated within the society 30 days after the incidence of stroke, which necessitates the reason to explore why these noted difficulty have been encountered if they are adequately rehabilitated and look at the possible way of promoting participation within the society after stroke.

The next chapter outlines the discussion of the quantitative results.



CHAPTER FIVE

DISCUSSION OF QUANTITATIVE RESULTS

5. INTRODUCTION

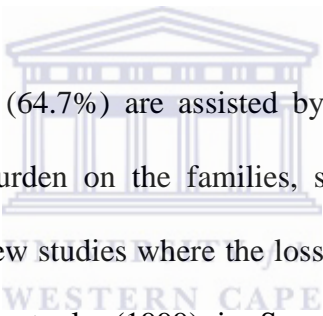
This chapter discusses the findings of the quantitative phase of the current study, with reference to other studies and relevant literature. The findings will be discussed under the following sections: demographics profile and participation (cognition, mobility, self-care, getting along, household activities, work, joining in community activities, environmental barrier, emotions, financial strain, burden on family, leisure activities).

5.1 DEMOGRAPHIC PROFILE OF THE PARTICIPANTS

The sample for the present study was heterogeneous, with a wide age range (26 – 80 years). There was no significant difference in the gender distribution and age groups of the participants, but there was significant difference of 0.000 in the age groups of the participants and marital status distribution, which shows that age groups of the participants affects their relative marital status distribution. The majorities of participants are males (64.6%) and mainly assisted by relatives living within the community.

From this current study, the age group with the highest incidence of stroke is between 50 – 59 years old; with a total percentage of 30.8%, followed by age group range of 60 – 69 years old with total percentage of 24.2%. Similarly, in a study conducted by Feigin, Lawes, Bennett & Anderson (2003) who looked at stroke epidemiology in the late 20th century and discovered that the mean age of stroke increases with age, with the mean age being > 65 years old. Although, there was significant proportion of stroke that occurred in the younger people in

this current study (40 – 59 years) with total percentage of 47.6%, which is also similar to a study conducted by Naess et al. (2004) who looked at the long-term outcome of cerebral infarction in young adults, and discovered that the majority of the participants in the current study were in the age group 45-49 years old, they will still be considered as young stroke patients who had specific needs related to the quality of life. Similarly, Busch et al., (2007) and Rothwell et al., (2004) also reported stroke incidence increases with advancing age, but a significant proportion of strokes occur in “younger” people. With rise in stroke in young adult, the quality of life could be affected, due to their challenges they experience with physical functioning, psychological and emotional functioning and fulfilling previous roles in the society.



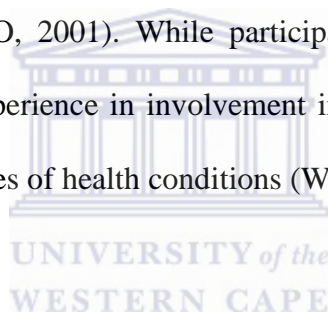
The majority of the participants (64.7%) are assisted by relatives within the community which increase the stress and burden on the families, spouse and caregiver, which was synonymous to the literature review studies where the loss of independence was reported by participants in a study by Hale et al., (1999) in Soweto, South Africa although most participants were independent in ADL; they expressed concern about their perceived loss of independence. Which was also discovered that these significant findings with loss of independence will tends to place the greatest burden on the family, community and health services (Conner, Thorogood, Casserly, Dobson & Warlow, 2004).

Most of the participants' (45.5%) highest level of education is primary school, where as 44.2% are currently unemployed due to their current health condition; which seems to impose the economic changes on the participants. Due to the chronic nature of the condition, patients become liabilities and hence are laid off from work. With the reduced activity due to the residual disability, there is reduced business activity or even loss of the business. While

Radford and Walker (2008) reported that people who had stroke and cannot return to work or re-train may face a lifetime of unemployment and dependence on families and the state. One aspect of positive community reintegration is a return to work, not only does it enhance self-esteem, return to work also assists in ensuring financial stability (Wolfenden and Grace, 2009). A return to work rehabilitation strategy needs to be developed and implemented to increase employment opportunities.

5.2 PARTICIPATION

It is a bio-psycho-social model of disability, based on an integration of the social and medical models of disability (WHO, 2001). Participation refers to engagement of a person in daily activities and social roles (WHO, 2001). While participation restriction is referred to as "problems an individual may experience in involvement in life situations" and refers to the personal and societal consequences of health conditions (WHO, 2001).



5.2.1 RECORDED PARTICIPATION RESTRICTIONS AMONG THE PARTICIPANTS

The study findings revealed the activity limitation in cognition, mobility, self-care and getting along. Restrictions in participation in household activities, work, joining in community activities, environmental barrier, people perception and actions, time consumption, emotions, financial strain, burden on family and leisure activities were reported among the participants. These findings on participation restrictions were often consistent with findings from similar studies.

It was shown in this study that participants encountered difficulty with communication and understanding, while the majority of the participants (54.2%) acknowledge no difficulty with

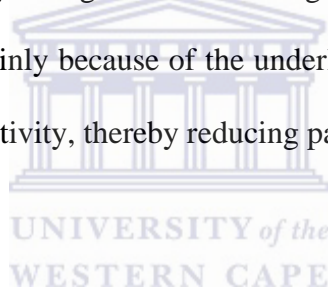
cognition, however some participant's reportedly experienced severe difficulty (23.3%) learning new tasks like learning how to go to a new place after the incidence, and (20%) finding solutions to day-to-day life activities. While difficulty with remembering things (15.8%) were also reported in some of the participants.

It was found that the cognitive impairment has a negative impact on ability to perform ADLs and social roles (Johnston, Sidney, Bernstein, & Gress, 2003). In a study conducted by Walker et al. (2004) and Walker et al. (2004) who founded that the impairment in cognition could influence basic activities of daily living (BADL) and instrumental activities of daily living (IADL) and social activities in acute as well as chronic stroke patients. The author also made mention of cognitive impairment being the major reason for dressing difficulties in stroke patients. And this could have a great impact in participating in society, as stroke patients are not able to perform activity of daily living for themselves. So, therefore, cognition impairment is said to be limiting factor in participation in society.

The participants (45.8%) reported being mildly affected standing up from sitting position, below half of the participants who participated in the study found it difficult to stand for a long period, while 22% of the participants also experienced severe difficulty walking a long distance such as kilometre, similarly in the literature review where the loss of independence was also reported in a study by Lord et al. (2008) where following stroke, the attainment of independent community ambulation was said to be a challenging rehabilitation goal, also if these patients do not have adequate ambulatory ability, this directly affects their ability to participate in the community (Taylor et al., 2006). Walking is an important human activity which enables us to be productive and participative members of a community (Ada et al.,

2009). So, difficulty in mobility of these patients will impede on their ability to participate in society in general.

The result showed that participants (44%) reported severe difficulty staying alone after stroke without the assistance of a relative, while more than half encountered absolute no problems with eating by themselves. Washing the body by themselves still seems a major challenge as participants (36.4%) found it severely challenging washing their whole body by themselves. This was supported in a study by Mayo et al., (2002), who found that 39% of patients with stroke reported a limitation in functional activities while 54% reported limitation with higher-level functional activities of daily living such as dressing and bathing. Participants found it difficult in doing basic things mainly because of the underlying impairment, which is said to have an adverse effect on daily activity, thereby reducing participation in the society.



More than half of the participants encounter no problem with getting along with relatives, close people well known to them after the stroke. In a study conducted by Palmer and Glass, (2003) which stated the importance of family systems, relatives in perspective of promotion of understanding of psychosocial outcomes in stroke, which was concluded that the role of family/relatives appears to influence stroke outcome. Although the current study stated no difficulty in getting along with relatives and close people well known to them after stroke. So, therefore, an interpersonal relationship with family members after stroke is maintained.

The study showed that 36% of the participants had severe problems with sexual activities, which was in agreement with a study conducted by Korpelainen et al. (1999) which reported

that a low quality of sexual life and a marked decline in sexuality after stroke. The problems that were identified include a decline in libido and coital frequency in both genders, a decline in vaginal lubrication and orgasmic ability in women, and poor or absent erection and ejaculation in men (Korpelainen et al., 1999). This implies that dissatisfaction and emotional decline will be reported among participants which found it difficult to resume their normal active sexual life. This could give rise to break-ups in relationships and marriages due to their inability to resume their normal sexual activities.

The study revealed that participants experienced various difficulties with household responsibilities, 31.4% of the participants cannot execute any household work needed while 19.5% cannot do any household responsibility. 46.6% of the participants had severe difficulty in doing required household work, while 43.2% also experienced severe problems in doing required household work tasks well. From a study by Martin et al. (2002), it was deduced that the extent of disabilities may vary people's ability to accomplish daily activities of living. It was shown in this current study that below an average of the participants reduced their household activities or missed household work completely for 26 to 30 days in a month, while above an average of the participants completely missed their household responsibility for 5 days in a month. This implies that participants are not able to involve in any household activities as initially done before, and could impose more stress on the family members or the need to employ a house helper which could impose more finances on the family budget.

The study revealed that more than half of the participants were not involved in any work whatsoever or study due to their health condition, while only three of the participants in this study reported that they were involved in work and had great difficulty with day-to-day work. Living with a disability has been reported to interfere with a person's ability to participate

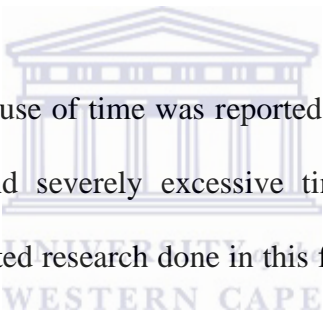
actively in economic and social life (Phillips and Noumbissi, 2004). While a major disability in stroke survivors has been reported as work inactivity, as most patients are independent in personal activities of daily living (PADL) but many do not return to work (Varona et al. 2004; Vestling et al. 2003) after stroke. Therefore, finances are not coming in as it used to before the stroke, and considering their disability status, which necessitate more finances in taking care of their health, these participants would be in financial crisis and will not have the ability to work to cater for their needs.

The result showed that joining in the community activities like festivities, religious and other activities was reported as severely difficult, as 40% of the participants decided to stay away from any community activities. It was also shown that participants intentionally avoid community activities, which according to Clark and Smith (1999), Kim et al. (1999), Mayo et al.(2002) and Jaracz et al., (2003) stated that the ability to return to an acceptable lifestyle, participating in both social and domestic activities has been found to be important in patient satisfaction and in perceived quality of life post-stroke. The participant's withdrawal from community activities could have an adverse effect on their quality of life, resulting in depression, as they will feel unhappy due to their health condition.

The results showed that 20.8% had severe problems in dealing with environmental barriers like the barriers and hindrances within the society around them. Similarly, a study conducted by Hammel, Jones, Gossett and Morgan (2006) showed that physical environment issues such as inaccessible entryways, bathroom and transportation system, with key barriers, including door thresholds and lack of handrails are barriers to community participation in survivors of stroke. This will encourage stroke patients to stay more indoors, which is not good for their

health condition, which requires they do things which make them happy always. Staying indoors could remind them more of their health condition and will encourage depression among the participants.

The result of the current study revealed that 28.3% had moderate problems living with dignity, due to people's actions and perceptions about their condition. Similarly, a study conducted by Sturm et al. (2004) showed that lower state self-esteem and a higher level of depressive symptoms have been reported among stroke survivors who lived within residential facilities. This will give rise to social isolation among the participants because of people's actions and attitudes towards them.

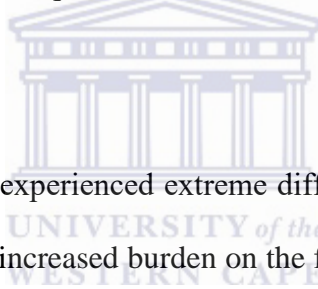


The result showed that excessive use of time was reported among the participants, as 12.5% and 25% reported extremely and severely excessive time consumption on their health condition. There seems to be limited research done in this field, as most researchers focus on length of hospital stay after stroke (Svendson, Ehlers, Anderson & Johnsen, 2009). The excessive use of time arises due to their health conditions which require medical rehabilitation and care.

The current study showed that 38% are severely emotionally affected due to health condition, which was also found in a similar study conducted by Goodman et al., (2006) who did a research on transitional life experiences of stroke victims. It was deduced that apart from spousal and network support, the emotional support given by professionals has an important role in the transitions. While lack of professional support and stigmatisation discourse on

disability in the society hinders successful transition (Meleis et al., 2000), this implies that stroke patients are not emotionally stable, due to their health condition.

The result showed that 50.8% of the participants encountered severe financial strain on them and on their family following the incidence of their health condition; this finding is consistent with the literature review by Radford and Walker, (2008) who stated that people who cannot return to work or re-train may face a lifetime of unemployment and dependence on their families and the state. This implies that stroke patients might have to depend on government grants, family or spouses as their ability to work and earn these finances is truncated, and they have various needs that would require attention.



The participants' family (16.7%) experienced extreme difficulty coping with the participants due to their health condition, and increased burden on the family was also reported especially by relatives, younger children and spouses, as also reported in a study by Lynch et al. (2008), who stated that social relationships are critical to the survival of patients after stroke and become of critical importance to their quality of life (QoL). Similarly, a study by Clarke and Black, (2005), also reported the importance of optimal social support which was said to be linked to better recovery of functional independence after stroke. This implies that stroke patients need social support, understanding of family members as difficulty in coping was reported, to encourage better recovery and participation in society.

The study revealed 51.7% reported to have severe difficulty doing things by themselves for relaxation or pleasure after the incidence of stroke, which was in line with another qualitative study using focus group discussions to explore the challenges stroke sufferers face over time

during recovery which revealed that great distress among the participants was associated with the loss of hobbies and activities that had previously been a source of pleasure and achievement (Ch'Ng et al., 2008). The difficulty in doing things by themselves for relaxation after stroke implies that the participants face great challenges with recovery and with disability after stroke, and that they forget to have time for things that brought them pleasure or relaxation.

5.3 SUMMARY OF QUANTITATIVE DISCUSSION

The study revealed the major limitations encountered in participation restriction, and reported studies conducted across developed countries which found that the incidence of stroke rises exponentially with increasing age. The participation restrictions encountered across the relevant literature review studies were found to arise in this current study.

The next chapter outlines the result of the 2nd phase of this study and the discussion - the qualitative study.

CHAPTER SIX

QUALITATIVE RESULTS AND DISCUSSION

6. INTRODUCTION

This chapter presents the result and discussion of the qualitative phase of the study, in which two focus group discussions were conducted as discussed in Chapter Three. A brief presentation of the participants' demographic information, which comprises of their gender, age bracket, education, reasons for not completing next higher education, marital status, main work status and living situation. Results of patients' experiences were presented under the main theme that emerged during the study, as direct quotations of the participant's statements are given to preserve the participant's original words that relate to specific themes. The presentation of the themes and categories were discussed with reference to relevant literature. Relevance of the study to rehabilitation bodies was emphasized.

6.1 DEMOGRAPHIC CHARACTERISTICS OF THE PARTICIPANTS

Table 6.1 below summarises the participants' demographic characteristics. This shows the gender, marital status, age-bracket, highest level of education, work status and living situations of stroke patients that participated in the current study living in the community.

Table 6.1 Participant's demographic characteristics

Participants Code*	Gender	Age Bracket	Highest level of Education	Reason for not completing next highest level of Education	Current marital status	Main work status	Living situation
P1	F	>54	Primary	Lack of instructor	Widowed	Unemployed (stroke)	Independent in community
P2	M	45-54	Primary	Lack of fees	Separated	Unemployed (stroke)	Independent in community
P3	M	>54	None	Struggle in freedom	Married	Unemployed (other reasons)	Independent in community
P4	F	>54	Primary	Lost interest	Widowed	Unemployed (stroke)	Independent in community
P5	F	>54	Primary	Nobody to assist in movement	Single	Paid work	Independent in community
P6	M	>54	None	Nobody to assist in movement	Married	Unemployed (stroke)	Independent in community
P7	F	>54	None	Nobody to assist in movement	Single	Retired	Independent in community
P8	F	>54	Primary	Struggle in freedom	Widowed	Unemployed (stroke)	Independent in community
P9	F	>54	None	Struggle in freedom	Single	Others-Grant	Independent in community
P10	F	>54	Primary	Children responsibilities	Widowed	Pensioner	Independent in community
P11	F	>54	None	Housekeeper	Married	Pensioner	Independent in community
P12	M	35-44	College	Not Available	Married	Unemployed (stroke)	Independent in community
P13	M	>54	Primary	Needed work to	Married	Unemployed (stroke)-Grant	Independent in community
P14	M	25-34	Secondary	Needed work to	Single	Unemployed (stroke)	Independent in

							community
P15	F	45-54	Primary	Lost interest	Married	Unemployed (stroke)	Independent in community
P16	F	>54	Primary	Lack of fees	Widowed	Retired	Independent in community
P17	M	45-54	Secondary	Lost interest	Married	Unemployed (stroke)	Independent in community

*Participants were given code P1 to P17 instead of their actual names to preserve anonymity,

*M = Male *F= Female, *> = Greater than, *P1 – P9 represent first group discussion, while *P10 – P17 represents second group discussion. Participants’ code will not be coded in the statement because all participants are of the same health condition (stroke).



6.2 THEMES

The themes which arose in the discussion were cognition, mobility, self-care, getting along, household activities, work activities and community reintegration.

The barriers/difficulties that were encountered in activities of daily life and in living situations of stroke patients living within the community are presented in the following themes that emerged from the data. Table 6.2 presents the themes obtained from the data.

Table 6.2 Themes, Category and Subcategory

THEME	CATEGORY	SUB- CATEGORY
1. Impairment	Cognition	<ul style="list-style-type: none"> •Participants communication •Impact of communication on family •Effect of stroke on understanding and memory
2. Life Activity	Mobility	<ul style="list-style-type: none"> •Problems with mobility •Problems with walking a long distance •Difficulty with Standing
	Self – care	<ul style="list-style-type: none"> •Difficulty with washing the whole body •Difficulty with eating •Difficulty staying along after stroke
	Getting along	<ul style="list-style-type: none"> •Effect of stroke on maintaining friendship •Effects of stoke on sexual activities
	Household Activities	<ul style="list-style-type: none"> •Effect of stroke on household responsibilities
	Work Activities	<ul style="list-style-type: none"> •Effect of stroke on work
3. Participation	Community Reintegration	<ul style="list-style-type: none"> •Joining in community activities •Barriers/hindrances in life/world around after stroke •Effect of stroke on Emotions •Perception of attitudes of others after stroke •Time spent on health conditions •Financial impact of health condition •Impact of stroke on family

6.3 PARTICIPANTS' EXPERIENCES ON COGNITION

As participants experienced similar problems and interests, it did not take a long time before they acclimatised to the discussion. They listened to each other's contributions, which often stimulated new insights and helped them to develop their ideas more clearly.

The adverse effect of stroke is well pronounced in communication (either long time communication or at the family level), in the ability to remember things and understanding ability of the participants; making it difficult for these patients to integrate into the society properly and feel different about themselves after the incidence. This was reported to have adverse effect on the family and children as well.

Participants discussed the various experiences they experienced in communication and understanding after the stroke and the adverse experiences encountered in reintegration into the society. A few of the participants had reported impairment in sight after stroke while the discussions held was centred on communication after stroke, the ability to communicate for a long period, the effect of stroke on communication, and in understanding and ability to remember things.



6.3.1 Participants' communication

The participants expressed dissatisfaction about the inability to communicate properly after stroke. They discussed the adverse effect they noticed while trying to speak with relatives. According to Loucher (2010), who quoted the importance of the close connection between communication and relationships, in that the primary aim of communication is to establish and maintain relationships. The following quotation regarding participants' experiences with difficulty in speaking are as follows:

"I can speak but sometimes I just lose my voice but I can speak."

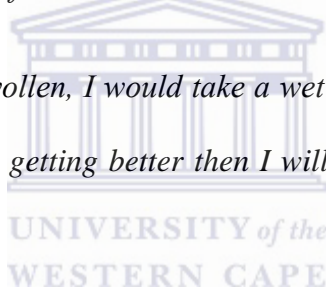
"...sometimes you would want to say something, and it won't come out from the mouth, but I'm much better now because my voice is slowly coming back."

“...stroke has taught me to not be “clever with my mouth” I have to be silent and just accept”.

Apart from the participants’ difficulties encountered during speaking, some reported stroke having an adverse effect in their tongue, making it difficult to speak. Having impaired communication ability could increase the risk of social withdrawal (Davidson, Howe, Worrall, Hickson & Togher, 2008). While the majority resolved to waiting until later in the day when the conditions seems to be better before returning to daily activities.

“My problem that I had before that I started experiencing now is with my mouth, on the side of my mouth would like it’s swollen and I would ask my children if it appears swollen and they would say no but I would still feel that it’s swollen.”

“When my mouth used to feel swollen, I would take a wet cloth and put it on my mouth and pat it and I would feel my mouth getting better then I will speak after that, when my mouth still feels swollen, I don’t speak.”



The participants resolved to waiting until they are relieved to speak, while some resolved to natural home remedies best known to them before proceeding with their activities for the day. This could promote social isolation among the participants, which was also shown in a study conducted by Murray et al. (2003) and Parr et al. (2004), who stated that communication impairment contributed to social problems for survivors, resulting in survivors being socially excluded and feelings of being isolated. In addition, due to their immobility, and sometimes inability to express oneself verbally, it was very difficult for patients to get out and establish relationships. Which meant that patients who were not being supported through their ordeal are socially isolated, an important factor that is strongly linked to recovery (Mackenzie et al., 2007). Therefore, the alteration in daily activities due to their health status is said to have a profound effect on the individual as a whole and adequate management with a scheduled

rehabilitation scheme post-stroke should be highly encouraged and holistic management by specialists and relatives is of necessity in promoting reintegration into the society.

6.3.2 Impact of communication on family

Participants were asked about how stroke had an impact on communication within the family set-up. They expressed their disgruntlement with indiscipline from their grandchildren. Participants complained of their children who see them as a ‘doll’ figure in the house, which they were greatly unhappy with. The following quotations regarding the patient experiences were as follows:

“They will play with you and make you a doll, you would want to say something and they finish your sentences by not saying what you wanted to say, so you end up keeping quiet.”

“...they listen to their mother and when I try to speak, their mother will stand up for them. So I just decided to keep quiet...”

“They will say I’m making a noise when I’m shouting at them. Naturally I speak loud and they say I’m making a noise, so I choose to keep quiet.”

The participants resolved in keeping quiet due to their present condition, which tends to promote indiscipline in their children. According to Keizer et al. (2002) stroke was said to have profound effect on family dynamics and gender roles, such as role of each member of the family. This implies that each family members have various roles to play in encouraging stroke patient participating in the society.

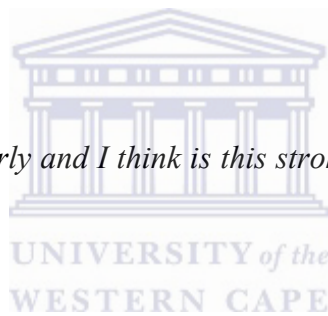
6.3.3 Effect of stroke on understanding and memory

Participants acknowledge profound impact of stroke in their ability to understand properly and on memory which was said to be enormous and disturbing. Some stated that before they had stroke, they are able to think properly, while after stroke, it is just difficult, while some try to utter the words from the mouth, but just not seems to be coming out. Aphasia simply means losing the ability to tell about 'the sense of your world' (Parr, 2001), which was experienced among the participants. The following statements relating to the participants' experienced are stated below:

"...I can't even think properly sometimes."

"....Then I will only remember the name later. But with the face I can't get to the name immediately."

"..I can't remember things properly and I think is this stroke, cause I never had this problem before".



According to a study by Visser-Keizer et al. (2002), which stated that apart from physical and cognitive impairment experienced by stroke patient, the emotional and cognitive changes following stroke included mental slowness, memory disabilities, less initiatives and hyper emotionality. Therefore, the inability to comprehend and understand is due to their present condition.

6.4 LIFE ACTIVITY

Life activities are activities engaged in during daily activities of living. Difficulty encountered in any daily activity of life are referred to as activity limitations, the life activity highlighted in this study are mobility, self-care and getting along, while the household activity and work activity are the second part of the life activity listed in this study.

6.4.1 Participants' experiences on mobility

Participants discussed their various experiences in mobility after stroke, ranging from their problems encountered in moving around, problems with walking a long distance and standing difficulty; and the relative effect it had on them and in integrating into the society in general. While some feel that the hardest challenge they face is with mobility. From the participants' experiences, it was concluded that the participants are facing great difficulty with mobility either through standing, walking a short or longer distance, which tends to increase the burden on their family, caregiver and relatives. Activity limitation in mobility, which tends to promote social isolation and reduced self-confidence, results in difficulty in participation among the participants living in the community.

6.4.1.1 Problems with mobility

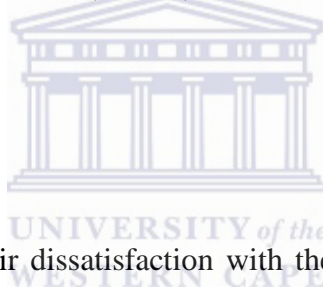
The participants complained about the difficulty they encountered on a daily basis in moving around the house; some complained of the stroke making them totally dependent on their relatives, which seems to be a burden on the family, while some complained of weakness on the affected side resulting in difficulty walking. The following statements relating to the participants' experiences were stated below:

"I have a problem with my leg, it can't walk properly and the left one shakes..."

“I can’t walk with my legs, as my right hand shakes and the left one doesn’t work”

“To be able to walk, but I’ve started walking between the poles...there has been already a lot of progress since the stroke...”

Similarly, it has been reported that the majority of community-dwelling stroke survivors live with physical deficits, including muscle weakness, poor motor control and balance instability, that significantly compromise their functional mobility and independence in performing activities of daily living, participating in the community and quality of life (Clarke et al., 2002; Flansbjer et al., 2006; Mayo et al., 2002; Patterson et al., 2007). The muscle weakness negatively affects mobility and balance, which in turn increases the risk of falling (Organised in-patient (stroke unit) care for stroke, 2002; Ramnemark, Nyberg, Borsen, Olsson & Gustafson, 1999).



Some the relatives expressed their dissatisfaction with the increased burden on the family, because of difficulty with mobility as stated below:

“So now the stroke attacked her on the left side so she can’t do anything for herself...”

“I can’t be in the toilet by myself. I must have someone there to assist me...”

“I struggle with using the toilet but have lots of people to help me”.

The impact of mobility was also experienced among the participants:

“...my left knee is weak and it just shakes, even this hand struggles as well...”

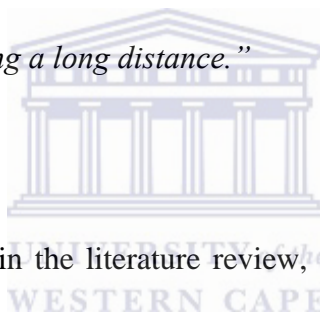
6.4.1.2 Problems with walking a long distance

Walking is one of the most important domains of the activities and participation components according to the International Classification of Functioning, Disability and Health (ICF) (International Classification of Functioning, Disability & Health, 2001), and the major aim after stroke is to improve muscle function to regain transfer and walking ability (Geyh et al., 2004). The participants expressed their difficulty with walking a long distance, while some find it difficult walking alone due to fear of falling. The quotations that expressed the participants' experience are as follows:

“...even if I'm walking I need to have a child with me who can walk with me because I cannot walk alone.”

“....What I struggle with is walking a long distance.”

“As I struggle to walk”



Similarly, Dunsky et al. (2008), in the literature review, stated that walking disabilities are considered to be the most devastating disabilities post-stroke. Community ambulation is a meaningful outcome after stroke (Lord et al., 2004). Community ambulation has been broadly defined as locomotion outdoors to encompass activities such as visits to the supermarket, shopping mall, banks, social outings, vacation and pursuit of leisure activities (Lord et al., 2004). Therefore, the inability to move around made these participants dependent on their relatives, spouse or caregiver for activity of daily living.

6.4.1.3 Difficulty with Standing

The participants expressed their experiences with standing after the incidence of stroke. The participants were aware of the imbalance in their standing after stroke, which they were fully

aware is as a result of their health condition. Their experiences were demonstrated as follows:

“...at first it was hard I could not even stand by myself, someone had to help me....”

“...ever since she was attacked by the stroke, she is like a child, and she can't get up from the bed...”

In a study conducted by Karlsson and Frykberg (2000), it was discovered that stroke patients may suffer from postural instability in all planes and frontal plane balance is said to be disproportionately affected. The standing from sitting position difficulty experienced is as result of the underlying health condition.

6.4.2 Participants' experiences with self-care

Participants discussed the various challenges they encountered in their daily life with regard to personal self-care. These were discussed in three different aspects of the challenges based on the participants experiences, which were: difficulties experienced in washing the whole body, difficulty with eating and difficulty in staying alone after the stroke incidence. All participants are stroke victims living within the communities several months after the initial attack.

From the participant's point of view, it was pinpointed that the participants struggle with personal hygiene, like washing the whole body due to paraparesis on their one limb or the other, leaving a residual disability and relatively difficult to use. It was also noted that the participants complained of incontinence, which is loss of function after the incidence of stroke, while some participants were totally dependent on relatives or a caregiver for eating and basic activities with regard to general self-care.

6.4.2.1 Difficulty with washing the whole body

The participants experienced great dissatisfaction and excessive use of time with regard to washing their whole body. The inability to wash independently, inability to use basic amenities like the toilet independently, imposed more strain on the participants and made it difficult returning to basic daily activities after the stroke. The following statement was stated regarding their experiences:

“The most difficult thing that I struggle with is to wash myself, I try with this hand but I can’t wash with the other one.”

“...in everything it’s me, with washing her it’s me, she can’t even do anything on her own.”

“And when I uhm...bath in the mornings I ask for help because I must especially for the nooks...my arm it’s a little heavy to lift. And when I’m done washing it takes about an hour...”

This affected their basic hygienic status and participants complained of losing incontinence or difficulty in using basic amenities.

“Another problem that I’m experiencing is losing continence. I would be on my way to the toilet and the urine would be coming out”

“...she can’t wash herself, we wash her, and she cannot even go to the toilet...”

According to a study by Hoffman et al. (2003) if an individual is unable to complete a self-care task due to a change in physical functioning, ADL competency is impacted. ADL competency is often the deciding measure that determines the discharge status for individuals who have experienced a stroke. Additionally, the competence of ADL time management and functioning dictates efforts spent on other occupations and can serve as an indicator of the potential of regaining independence (Hoffman et al., 2003; Hofgren et al., 2007). The ability

to wash the body is part of self-care task, and is part of everyday routine; inability to carry out this routine makes the activities of daily living impacted.

6.4.2.2 Difficulty with eating

The majority seems not to acknowledge any difficulty with eating, except few of the participants that seems totally dependent on their relative for activities of daily living. According to the International Classification of Functioning, Disability and Health (ICF), eating is classified as a component of activities and participation and is accordingly viewed as a ‘complex relationship between the individual’s health condition and environment and personal factors’ (WHO, 2001). The following statement was stated regarding the experienced encountered:

“...she can’t eat, we have to feed her.”

“...she could feed herself before, but after the stroke attack the second time, she cannot do anything for herself”.

6.4.2.3 Difficulty staying alone after stroke

While the participants tends to dependent solely on relatives or a caregiver for basic activities of daily living, the participants are either being attended to by their relative or caregiver because of their dependent status. While some felt the need of staying at home is not a problem, it is the other way round for others, because of the need of assistance anytime they are alone. The following quotation was stated regarding the participants’ experience:

“..As he decided he wants to be staying home alone”.

“...but if I have to go to the shops I will ask a neighbour or someone to look after her, then I will go by myself”.

6.4.3 Participants’ experience with getting along

Participants discuss their various problems encountered in getting along with friends and sexual activities with spouse after the incidence of stroke.

6.4.3.1 Effect of stroke on maintaining friendship

Participants expressed their dissatisfaction with maintaining friendship after stroke; while participants feel seeing a friend is more of struggle because it tends to impose financial strain on them, the quotations regarding the participant’s experience is stated below:

“I used to be a drinker and after the stroke my friends stopped coming around because I had no money”.

“Friends don’t visit me because I can’t go to them again”.

“I had lots of friends before the stroke but now they don’t have time for me anymore”.

Similarly from a study, it was deduced that disrupted embodiment and loss of self-confidence have a negative influence on gendered identity and complicate the establishment and maintenance of gendered relationships (Murray & Harrison, 2004). Participants experienced difficulties in maintaining friendships after stroke as a result of health problems and limited financial resources, which affect their ability to socially participate in the society. Social participation has been described as the performance of people in social life domains through interaction with others in the context in which they live. The presence of aphasia can

make it difficult for people to maintain friendships post-stroke (Davidson, Howe, Worrall, Hickson, & Togher, 2008b; Northcott & Hilari, 2011). Hilari and Northcott (2006) reported that 63.9% of people with aphasia had less contact with friends and 30% reported no friends 12 months post onset of aphasia. Davidson, Howe, Worrall, Hickson & Togher (2008b) found that participation in leisure and educational activities was closely tied to everyday communication with friends. The ability to communicate is core to all relationships, including friendships. The use of therapy groups is one way to address the social and emotional needs of individuals with stroke (Ferguson, 2007).

6.4.3.2 Effects of stroke on sexual activities

The uncertainty of their sexual activities after stroke seems prominent among the participants, while some avoided it completely; other disclosed difficulty in engaging in sexual activities. It caused upset in some participants, knowing the important nature of sexual activities in maintaining union with their spouse, while some seems undisturbed because of no involvement in sexual activities even before the incidence of stroke. The following statements were said regarding sexual activities:

“I still have a problem; I cannot have sexual intercourse with my wife at the moment.”

“By the time I was attacked by stroke, I was not having any sexual intercourse so it is not a problem to me.”

“It really upsets me but what can I do...”

Similarly, in study conducted by Akinpelu et al. (2013) who found that 94.8% of the stroke survivors reported dysfunction in at least one of seven sexual areas (libido, coital frequency, vaginal lubrication, erection, ejaculation, orgasm and satisfaction with sexual life). Also in a

study conducted by Thompson and Ryan (2009) who interviewed 16 stroke survivors, they found that 15 had reduced or complete lack of sexual desire post-stroke. This implies that due to their health condition, their sexual activities were affected and could have a vital implication on their marriages and relationships.

6.4.4 PARTICIPANTS' EXPERIENCES ON HOUSEHOLD ACTIVITIES

The issue of life activity involving household responsibilities and getting them done within the house were discussed, and while the majority of the participants tend to depend on people around them for carrying out basic activities of the day, some still manage to struggle and perform little activities within the house, but not done as expected. It is common that a family member, usually a spouse, is the main care provider responsible for the individual with stroke after returning home from the hospital (Hickenbottom et al., 2002; Åsberg, Johansson, Staaf, Stegmayr & Wester, 2005). The effects of stroke on household responsibility and on completing household work were the major themes which arose from the discussion.

6.4.4.1 Effect of stroke on household responsibilities

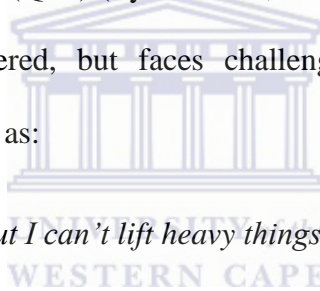
Participants expressed their dissatisfaction with cleaning the house, as they did before the stroke, while one of the participants felt the reason behind the difficulty was weakness in the left knee which shakes uncontrollably, and the hand which struggles in holding objects, while others feel they just become tired easily. The statement of the participants' experiences was quoted as follows:

“It's cleaning around the house that I can't do as I usually did before. The children clean but I feel that if I did it myself it would be done properly.”

“Sisi I can do some of the work around the house but I have a problem with things that are high as I cannot climb and reach up...”

“...For example I can’t sweep and that is something I would like to do. I want to sweep; for example the broom... I can’t explain it but you can’t hold it like you use to. I hold it wrong. I don’t know.”

The majority of the participants are totally dependent on their relatives, caregiver or spouse for household work. This was also in agreement by a study by Lynch et al. (2008), who stated that the majority of stroke survivors depend on others for their everyday activities. Therefore, social relationships are critical to survival for patients after stroke and become of critical importance to their quality of life (QoL) (Lynch et al., 2008). Some still feel a need to work despite the limitations encountered, but faces challenges, the quotation regarding the participant’s experiences is stated as:



“I can do a bit of work at home but I can’t lift heavy things.”

6.4.5 PARTICIPANTS’ EXPERIENCES OF WORK

The majority of the participants seems to be on a disability grant, but while some feel incapacitated because of the disability which arose from the stroke, participants discuss about the challenges they face during this unplanned health disaster which seems to engulfed their time in functional restoration back to normal in as a dependable state as possible. The effect of stroke on their various work activities was discussed under this theme.

Participants’ felt a disadvantage in finding work after stroke, which lead the majority in opting for a grant, while some participants felt the work they were involved with before stroke was “a no option” for them after stroke, while getting a permanent job was difficult for

some. A few participants still managed to do household tasks, but are done with difficulty and not as precisely as before.

6.4.5.1 Effect of stroke on work

While some participants stopped working due to current health problems, a participant feel the work he does is dangerous and he could not be returned to it due to its demanding nature. Others feel the grant amount they receive for disability is so small that it could not be used to open a business, but just a food, toiletries and paying children's school fees. The quotations regarding their experiences were stated below:

"I'm no longer working as the doctor booked me off I wouldn't be able to work as the job I used to do was dangerous."

"..... Since that I'm not financially stable to open a business at home because I belong in those people who get a grant, I will not be able to work again and the amount I get for the grant will not be able to satisfy my needs. The money I get is only enough for food, toiletries and the children for school...."

"I used to work for a welding company but now that I had this stroke and I can't work anymore".

A participant felt she is constantly confined to her home because of the stroke, as she used to sell second-hand clothes before the incidence, but could not go out and source them anymore. Living with a disability has been reported to interfere with a person's ability to participate actively in economic and social life (Phillips and Noubissi, 2004). Another participant felt she is slow at work due to her health condition and her services will not be required anymore:

“I used to sell second hand clothes, I used to go look for them and bring them here and sell them but now I can’t go and buy, I’m constantly stuck at home; the inability to perform this function is what is stressing me.”

“Because I believe they don’t want people who are slow like us...we are slow. For example I was a cleaner, and the bathroom was my responsibility. And we worked in the forensic section, I was a cleaner...”

According to the literature review, return to work has been said to improve stroke outcomes by contributing to life satisfaction, wellbeing, self-worth and social identity, at least partly through independence gained from income generation (Vestling, Tufvesson and Iwarsson, 2003; Medin, Barajas and Ekberg, 2006).



6.5 PARTICIPATION

“By participation, it means an individual experiences involvement in life situations” (WHO, 2001). Such life situations include festival, community activities, and religious activities and so on (WHO, 2001). The ability of a stroke survivor to reintegrate into the community properly is an aspect of great concern and the motivation behind this study, as participation is conceived as a dynamic complex interaction between an individual’s health condition, body functions, activities and external factors representing the circumstances in which the individual lives (Desrosiers et al., 2006). The major theme that arises from the discussion includes: joining in community activities like religious activities and festivals, barriers/hindrances in life after stroke, effect of stroke on emotions, living with dignity after stroke because of actions and attitudes of others, time spent on health conditions with prolonged waiting periods to be attended to by health practitioners, financial impact of health condition and impact/burden on family.

6.5.1 Joining in community activities

While a participant's relatives acknowledge avoiding church activities with the participants because of participant's temper, another participants feel there is no need to be involved in any activities whatsoever, as the people she goes to church with comes to have the service at home with her, while for some, it is about people perspective about her. The quotations regarding the participants' experiences are:

"I have not been able to go to church ever since I got the stroke, the people I go to church with come to have the service at my home, but I know that if I want to go, I will go because I will ask my son to take me..."

"I don't go to church anymore because of things people say"

According to Clark and Smith, (1999), Kim et al., (1999), Mayo et al.,(2002) and Jaracz et al., (2003), the ability to return to an acceptable lifestyle, participating in both social and domestic activities has been found to be important in patient satisfaction and in perceived quality of life post-stroke. Therefore, participants avoid community activities due to their present condition.

6.5.2 Barriers/hindrances in life/world around after stroke

In this section, participants discuss problems they experienced with barriers/hindrances in day- to-day activities within the community, a participant's relative expressed dissatisfaction with riding in a taxi to bring her mother to the clinic, due to the taxi drivers' impatience in getting the stroke patient fitted into the wheelchair. The statement relating to the participant's experience was stated as follow:

“Also another problem is that we have to hire a car to bring my mother to the clinic because she struggles, someone has to carry her and put her on the wheelchair, if we were to take the taxi and the drivers would not be patient enough to wait for her to get into the taxi...”

“..I don’t go out because there is no transport, my husband sold the car”.

A participant complained of basic amenities, due to lack of proper service in use of toileting which was in place before they experience stroke, but worse after stroke because of the challenges encountered in walking,

“I stay in the slums so there we have problem with toilets, all of them are not working and they are dirty. We use them even though they don’t work because we don’t have another option.”

“....I struggles to use the toilet”.



The participants expressed dissatisfaction with the waiting period before they are being attended to, even though they encountered difficulty standing for long.

“One of the problems we experienced as people who go to the clinic and attend the club, we get to the club and it’s already full; you will have to stand on your feet and wait for your turn even though you struggle to stand a long time because of the stroke.”

“...The real problem is where they keep our folders; for an example you would have an appointment at 11:30 or 10 o’clock and you get there as early as 6 o’clock, then they will start working and that is not a problem. When it is your turn, they just tell you to go sit in a specific place. They did not look at your card they just tell you to sit down...”

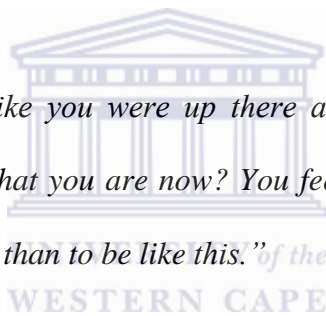
6.5.3 Effect of stroke on Emotion

The effect of stroke on emotions seems enormous, as participants seem to have lost the ability to control their emotions after stroke, while a relative of the participants highlighted the participant being short tempered after the incidence of stroke, and getting unreasonably angry over small things:

“The problem that makes me not to go anywhere with her is her temper, she is very short tempered and she gets angry over small things. Sometimes I’m just scared with how she will react with people.”

Some feel humiliated because of their health condition, and feel death is better than the health condition:

“You feel humiliated...it feels like you were up there and now you did this to yourself, everyone looked up to you but what you are now? You feel (gets emotional) you feel like it would be better if you died rather than to be like this.”



While a participant battled with incontinence, was emotionally disturbed and not generally happy with his body control:

“I feel hurt; it’s really not nice for me to see losing control like this.”

Visser (2002) also assumed that the emotional consequences of stroke are the result of a complex interaction between pre-morbid personality, damage to the brain and the emotional reaction of the patient to the consequences of stroke. Therefore, participants had emotional problems because they could not face the social stigma associated with their health condition.

6.5.4 Perception of attitudes of others after stroke

A participant feels that others do not really understand what their condition is all about, because some people's reaction could be so derogatory, but she chooses to ignore them. The statement relating to the participant's experience was:

"For me, I will speak about myself; there is a difference than when I didn't have a stroke. Now people look down on you but it's not something that I take to heart, I just ignore them because they don't know what I have."

"I feel that my friends are one-sided now, they feel shy of "me" (because I had stroke).

Some participants feel hurt being pitied by others who knew them before the stroke incidence:

"Then that hurts you because you knew how you were. Then I just say: "No it's okay. Bye, see you", because I don't like the pity and stuff, because they don't know how you feel personally."

"...It feels like everyone's on you. Their eyes are looking at how you walk. You feel like someone is staring at you."

6.5.5 Time spent on health condition

Participants admit to spending adequate time on their health, as they had to come to the clinic as early as 6am only to be kept waiting, till evening. Therefore, participants basically use the whole day waiting to be attended to at the clinic. One participant complained of staff's attitude towards their condition by prolonging their waiting period before being attended to. The statement regarding the participant's experiences were stated as:

“What I have noticed is that when you come to the club is that you wait, what stresses me is that the waiting period will raise my high blood pressure because I wake up early in the morning and come here to sit here the whole day and go home around 5pm in the evening.”

“...because I’ve been waiting here for more than 2 hours and 30 minutes in this chair”.

6.5.6 Financial impact of health condition

Participants expressed their disgruntlement with their finances, and that ever since they had a stroke, they felt the financial burden on them was increased due to their health condition. A participant felt the need to include extra burden of paying transport fare to the clinic monthly; another felt that buying second hand clothes to sell as usual before the stroke was stopped due to her health condition; while another participant who relies on a social grant, felt that the money is simply not enough. The participants’ quotations regarding their experiences are:

“...call them again to come pick me up and give him money at the end of the month.”

“I used to sell second hand clothes, I used to go and look for them and bring them here, and sell them but now I can’t go and buy due to my health condition. I’m constantly stuck at home...”

“...since am not financially stable to open a business at home because I belong in those people who get grant, I will not be able to work again and the amount I get for the grant will not be able to satisfy my needs...”

Participants identifies problems with choices of shoes after the incidence of stroke, which imposes financial stress as they struggles with finances:

“...The problem is I can't just wear any shoes, I must wear a specific shoe like Green Cross, and I don't have money to buy shoes; and you are not allowed to just wear any shoes because your heels start burning and your feet burn terribly.”

Similarly Radford and Walker, (2008) stated that people who cannot return to work or re-train may face a lifetime of unemployment and dependence on their families and the state. However, it was also discovered that the majority of the participants solely rely on social grants for survival which was reported to only cater for the food and minor needs. As expected, an independent income is more financially beneficial than relying on a social grant (De Koker, De Waal and Vorster, 2006). Therefore, the participants found it difficult returning to their work due to disability after stroke and this implies that the financial responsibility of these patients lies on their family members, spouse or government.



6.5.7 Impact of stroke on family

One participant's relative expressed their dissatisfaction that the participant's health condition is having on the younger children, as they are totally dependent on their children, to the extent of even walking. Some participants expressed dissatisfaction with being totally dependent on their family, who either gives excuse not to help, or help at their own available time.

“...I can't go anywhere alone; my child had to organise transport to bring me here and fetch me again, even if I'm walking I need to have a child with me who can walk with me...”

“It's also the dependence for me that is the hardest, that you must always ask for help with something.”

“... Scared to ask other people for help, even your own children, they don’t actually want to... sometimes it’s “no man we are going out now” or something. “No they are waiting for me; I’m going to finish now. I’m already late”It’s very hard...”

The importance of family support was reported in a study by Lynch et al. (2008), who stated that social relationships are critical to survival for patients after stroke and become of critical importance to their quality of life (QoL). This implies that the stroke survivor solely relies on the support of their family in participation in the community.

6.6 RELEVANCE OF STUDY TO REHABILITATION SERVICES

The relevance of the current study to the rehabilitation body is of immense importance in promoting and ensuring adequate rehabilitation of stroke patients into the community, according to the World Health Organisation who defined successful rehabilitation as reintegration of the individuals back into their social networks and participation in activities and the community (Noreau et al., 2004).

- The continuous holistic rehabilitation of stroke victims after acute phase is of immense importance as reintegration into society must be encouraged to ensure improved quality of life.
- Necessary support of these participants is of importance at family, society and at environmental level.
- Identifying the barriers in stroke reintegration into the society and planning of programmes to address these barriers.
- Counselling centres will be highly beneficial because of the emotional, depressive and rejuvenation of the current mindset of these participants.

- Social isolation should be discouraged because the effect on the participants, family, caregiver and spouse are of vital importance in promoting successful rehabilitation of this participant to society, which will be important in educating necessary parties of their roles during rehabilitation.
- The provision of work will also play important role in promoting community re integration of these patients to their society.
- Identification of gaps in stroke participation within society.

6.7 SUMMARY OF QUALITATIVE RESULTS AND DICUSSION

The qualitative results revealed the participation restrictions experienced by the participants. Difficulty in understanding, communication and remembering things was reported. Limitation in activity level such as in mobility (walking for a long distance, standing from a sitting position), in self-care (washing the whole body, eating, staying alone after stroke), in getting along (maintaining friendship, sexual activities), in household activities and work activities was reported. Participants experienced difficulty in joining in community activities, emotional fluctuations, poor perception of attitude of others after stroke, excessive use of time on health condition, increased financial impact of health condition and burden impact on family was reported. Environmental barrier such as transportation, toilet facilities were also reported.

Participation, one of the main components of the International Classification of Functions, Disability and Health model is a positive descriptor of functioning and is defined as the person's involvement in a life situation (WHO, 2001). Participation is an important health related outcome as it is related to multiple factors which affect people's well-being. This factor includes gender, marital status, basic mobility, balance confidence, activity level and

various environmental facilitators and barriers (Levasseur, Desrosiers & Tribble, 2008; Keysor et al., 2010). According to the ICF, participation is stated to be estimated by the performance of an individual in his current environment (WHO, 2001). Any limitation in participation usually results in reduced quality of life of stroke participants living within society as found in referenced similar studies.



CHAPTER SEVEN

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

7. INTRODUCTION

In this final chapter, a summary of the study is provided. The limitations of the study are discussed and the most important findings of the study are highlighted in the conclusion and finally, the significance and recommendations emerging from the study are outlined.

7.1 SUMMARY OF THE STUDY

The primary purpose of this current study was to determine and explore the participation restrictions of stroke patients living in the community at selected community health centres in the Metropole districts in the Western Cape, South Africa. Using the mixed sequential method in determining and exploring the various factors associated with stroke participation, restrictions within the society, the socio-demographic statistics of stroke patients, the limitations encountered by stroke patients in their daily life situations to determine participation restrictions of stroke patients living within the community and factors (age, gender, level education, marital status and employment) associated with participation restrictions and exploring the participation restrictions encountered on daily life basis of stroke patient living within the community.

The need to conduct this study arose from the fact that there is a dearth of published information regarding the availability on stroke survivor functioning in South Africa, particularly at the level of activity limitation and participation restriction (Ustun, Chatterji, Bickenbach, Kostanjsek & Schneider, 2003). The knowledge gap regarding these limitations might be a hindrance in planning and delivering rehabilitation services that address the

persons with physical disabilities such as stroke-specific needs and preferences. Furthermore, seeking clients' perspectives on the participation in society after stroke is a useful way to inform policies directed towards disability and rehabilitation issues regarding the difficulties faced with participation in the society. The study made use of a mixed methods design which provided the advantage of combining the strengths of both the qualitative and the quantitative designs.

The quantitative results indicated the mean age of the study population was 57.1, age ranging from 26 years to 80 years old. It was found that the majority of the males (64.6%) are currently married as opposed to their female (27.3%) counterparts. The marital status was found to be significant with gender distribution. The majority of the study population (45.8%) had a primary education and 64.7% were majorly assisted within the community. The results indicated that a significant percentage of difficulty was encountered by stroke patients in participation in the society: in cognition (23.3% reported severe difficulty in learning a new task, 14.2% cannot learn a new task; 20% reported severe difficulty analysing and finding solutions to day-to-day activities, while 10.8% cannot analyse or find solutions to day-to-day activities), in mobility (31.4% reported severe difficulty in standing up from a sitting position, 45.8% were mildly affected in standing up from a sitting position; 34.7% reported severe difficulty walking a long distance like a kilometre, 33.1% cannot stand for a long period), in self-care (44% indicated difficulty staying alone for few days after stroke, while the majority, 61%, complain of difficulty with getting dressed by self), getting along with people with major difficulty (36%), with sexual activities, household activities with major complaints (46.6% and 31.4%, for severity and exemption respectively), in getting needed household work done, work/study activities with difficulty in day-to-day work activities, also in getting needed work to be done promptly and in community participation with severe

difficulty; 51.7% in doing things themselves for relaxation and pleasure after stroke, 50.8% been financially restrained after stroke, 40% with difficulty in joining in the community activities, 39.2% with dignity affected because of people's attitudes and reactions post-stroke and 25.8% of the participants indicated excessive use of time spent on health.

The qualitative result of the second phase of this current study indicated the participation restrictions experienced by the participants. Difficulty in understanding, communication and remembering things was reported. Limitation in activity level such as in mobility (walking for a long distance, standing from a sitting position), in self-care (washing the whole body, eating, staying alone after stroke), in getting along (maintaining friendship, sexual activities) were experienced, limitations in household activities and work activities were also reported. Participants expressed difficulty in joining in community activities, change in emotion, perception of poor attitude of others after stroke, excessive use of time on health condition, increased financial impact of health condition and burden impact on family was reported. Environmental barriers such as hindrances in life or the world around them after stroke was also reported. In addition, the participants in this present study reported the life hindrances comprising lack of social support, lack of transport to access the physiotherapy services, negative attitudes of others, inaccessible pathways and toilets as reported in this current study were also found in similar studies.

7.2 LIMITATIONS OF THE STUDY

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

For the quantitative phase:

- The size of the sample was small as it involved the sample of those attending physiotherapy and living within the community. As participants were mostly not available, the sample size was based on convenient sample method to recruit as many participants as possible. This method is not the best for quantitative data. The lack of randomness of this method leaves the researcher with no idea of how the results are representative of the study population and therefore limits generalisability of the results to the Cape Town Metropole Health District.
- Due to the fact that some of the participants had stroke for over 10 years ago, some could not remember some exact information. The participants might have given only what they could remember and some valuable information might have been missed.
- The missing data managed by means of a summation of the domain, if only one data was missed, but in a case of two sets of data being missed, the missing data was managed by case deletion.
- In situations whereby the participant's involved is aphasic, or he/she could not remember things, the patient's relative was interviewed, therefore some valuable information might not have been given accurately.

For the qualitative phase:

- It is important to note that although individuals who shared the experiences in question may best assess the credibility of interpretations, the researcher was unable to conduct a member check of the analysis as presented.
- The discussion was conducted in three different languages which involved translation and back translation. Despite the employment of professional translators and the back translation, there is still the risk that some of the original information tape recorded could have been missed.
- Given the fact that the interview was conducted within the physiotherapy clinic at the community health centres, the participants might have refrained from mentioning vital information due to fear of fellow participants who live within the neighborhood knowing some vital information.



7.3 CONCLUSION

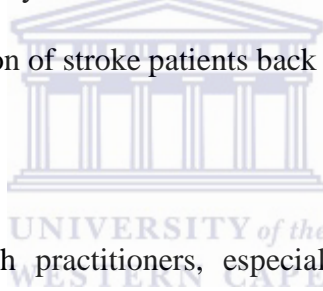
The study demonstrated that the stroke patients were not happy with the level of functional restoration, even after several months post-stroke, and this impeded heavily both on functional, environmental, societal and leisure activities. The increased burden on family, the emotional stress, the negative feeling of low self-esteem, increased depressive mood, reduced social gathering due to aphasic, loss of memory, mobility difficulty, self-care difficulty, maintaining friendship, low libido in sexual activities, reduced house hold activities and increased financial strain all had profound effect on functional restoration and in participation in the society.

7.4 SIGNIFICANCE

The findings of this study are important for health organisations, researchers, rehabilitation bodies, policy makers and physiotherapist.

This study will provide the Department of Health (DOH), physiotherapists, and stroke patients living in the community with information about participation restriction, difficulty that is usually encountered in daily life, preventing total full participation in the community and how it relate or affects their quality of life.

This study will inform the necessary rehabilitation bodies' area of necessities that is required in addition to promote participation of stroke patients back to the community.



This study will enlighten health practitioners, especially physiotherapists, occupational therapist in South Africa and Africa in general, on their various roles in ensuring adequate participation of stroke patients in the community as a whole.

This current study will also address the paucity of literature in participation restrictions in stroke patients living in the community with regard to physiotherapy in Africa.

7.5 RECOMMENDATIONS

Based on the findings of the current study, the following recommendations are made:

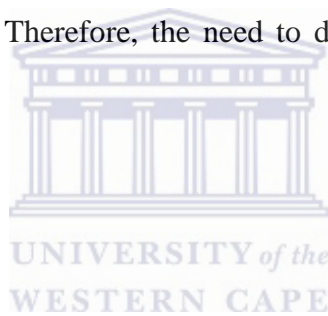
1. The need for a developmental health programme by the policy decision-makers is of necessity, as prevention is always the first cure to any disease. There is a need for the

health programme to be located in a strategic location like hospitals, market places, school, communities and busy events centres; to educate the public on preventive measures for stroke, the need for regular check-up, keeping a healthy lifestyle, both in young and older adult.

2. The need for government sectors in South Africa to introduce transport systems that are accessible, affordable and ready to accommodate people with disabilities, without which the provision of rehabilitation services and participation in society will remain ineffectual. There is also the need to educate public transport operators about disability to remove their discriminatory behaviour towards people with disabilities. It would be preferable to avail a designated transport system specifically for people with disabilities, which are accessible to them. This will improve attendance at rehabilitation services and promote a better recovery outcome.
3. The need for good toilet facilities easily accessible to the people with disability within the community will be of immense benefit.
4. Further research is still needed to be conducted in participation restriction among stroke survivors within the community in the whole of South Africa, to obtain accurate figures and strategise accurate planning development in order to bridge these gaps/lapses.
5. Various counselling centres need to be made available and accessible to these individuals, as depressive mood can easily overcome both to the stroke survivor and people attending to them.
6. An interdisciplinary approach must be emphasized and implemented by the Ministry of Health.
7. Recreational centres, especially designed for the disabled should be developed by government for people with similar conditions to be able to relax and liaise with

each other, which will help to relieve stress and promote a better rehabilitation outcome.

8. The authorities responsible for a development programme should pay special attention to the involvement of the stroke survivors in income generating activities as it is difficult for them to return to their previous manual occupations.
9. The waiting period at the clinics should be reduced to the minimum, as governments need to employ more professionals in attending to the basic needs of these individuals.
10. The need to encourage the construction of more rehabilitation centres should be encouraged by government, as the participants were said to benefit immensely from the therapy programmes. Therefore, the need to developed more centres will be of benefit.



REFERENCES

- Ada, L., Dean, CM., Lindley, R. and Lloyd G. (2009). Improving Community Ambulation After Stroke: The Ambulate Trial. *BioMed Central- Neurology series Journal* 9(8): 1-6.
- African Health Monitor, (2008). Fighting Non- Communicable Diseases: Africa's new silent killer; *World Health Organisation*, Volume 8, Brazzaville.
- Agency for Health Care Policy and Research, (1995). Better quality can cost less: the evolving role of AHCPR. Interim Report to the National Advisory Council. *Agency for Health Care Policy and Research*. Pub. No. 95-R011. Rockville.
- Akinpelu, A. O., Osose, A. A., Odole, A. C. and Odunaiya, N. A. (2013). Sexual dysfunction in Nigerian stroke survivors. *African Health Sciences*, 13 (3), 639-645. doi:10.4314/ahs.v13i3.17.
- Albrecht, GL. and Devlieger, PJ. (1999). The disability paradox: high quality of life against all odds. *Social Science and Medicine*, 48, 977-988.
- American Heart Association (2011). Medscape Medical News; Scientific sessions. Orlando, Florida.
- American Stroke Association (2012). Life after Stroke: *Post-Stroke Rehabilitation*. www.strokeassociation.org.
- African National Congress (1994): The National Health Plan. Johannesburg: ANC.
- Anon, (2005). Tackling the Global Burden of Stroke. *Lancet Neurol*; 4:689.
- Appelros, P., Nydevik, I. and Terent, A. (2006): Living setting and utilization of activity of daily living assistance one year after a stroke with special reference to gender differences. *Disability & Rehabilitation* 28, 43-49.
- Appelros, P., Nydevik, I. and Viitanen, M., (2002). Poor Outcome after First-Ever Stroke. Predictors for Death, Dependency, and Recurrent Stroke within the First Year. *Stroke*; 01.
- Aprile, I., Piazzini, DB., Bertolini, C., Caliandro, P., Pazzaglia, C., Tonali, P. and Padua, L. (2006): Predictive variables on disability and quality of life in stroke outpatients undergoing rehabilitation. *Neurological Sciences* 27, 40-46.
- Asberg, K.H., Johansson, L., Staaf, A., Stegmayr, B. and Wester, P.O. (2005). Life after stroke – a new national study, renewed follow-up of stroke; Patient shows increased dependency on the support from the next of kin, Oct 10-16;102(41):2938-41.
- Astrom, M., Asplund, K. and Astrom, T. (1992). Psychosocial Function and Life Satisfaction after Stroke. *Stroke*, 23, 527-531.
- Babbie, E. (2001). The Practice of Social Research: 9th Edition. Belmont, CA: Wadsworth Thomson.

Barclay-Goddard, R., Stevenson, T. and Poluha, (2004). Force Platform Feedback for Standing Balance Training after Stroke. *Cochrane Database Systematic Review*; (4):CD004129.

Barron, P. and Monticelli, F. (2003). Lessons Learnt in the Implementation of Primary Health Care: Experiences from Health Districts in South Africa. *Health Systems Trust*, ISBN: 1-919743-76-6. Available on the Health System Trust website [www.hst.org.za].

Beaglehole, R. and Bonita, R. (2008). Global public health: A scorecard. *Lancet*; 372(9654):1988–1996.

Bendz, M. (2003): The first year of rehabilitation after a stroke-from two perspectives. *Scandinavian Journal of Caring Sciences*, 17, 215-222.

Bhogal, S.K., Teasell, R.W., Foley, N.C. and Speechley, M.R., (2003). Community reintegration after stroke. *Topics in Stroke Rehabilitation*. 10, 107–129.

Blake, H., Lincoln, N. B. and Clarke, D. D. (2003). Caregiver Strain in Spouses of Stroke Patients. *Clinical Rehabilitation*, 17, 312-317.

Boden-Albala, B., Litwak, E., Elkind, M.S.V., Rundek, and Sacco, R. L., (2005). Social Isolation and Outcomes. *Post Stroke Neurology*, 64: 1888-1892.

Boyce, C. and Neale, P. (2006). Conducting In-depth interviews: A Guide for Designing and Conducting In-depth Interviews for Evaluation Input.

Bradshaw, D., Groenewald, P., Laubscher, R., Nannan, N., Nojilana, B. and Norman, R. (2003). Initial Burden of Disease Estimates for South Africa, 2000. *Medical Research Council Report*. Cape Town: South Africa Medical Research Council.

Brooks, M. (2014). Stroke a Race Against the Clock, Review Confirms. *Medscape Medical News*. Available at <http://www.medscape.com/viewarticle/830611>. Accessed September 2, 2014.

Bryer, A., Tipping, B., & De Villiers, L. (2006). Health in transition: Stroke Profile in a South African Urban Population. *International Journal of Stroke*, 1(1), 29.

Bryer, A., Connor, M., Haug, P., Cheyip, B., Staub, H., Tipping, B., Duim, W. and Pinkney–Atkinson, V. (2010). South African guideline for management of ischaemic stroke and transient ischaemic attack 2010: a guideline from the South African Stroke Society (SASS) and the SASS Writing Committee. *South African Medical Journal*, 100(11):747-778.

Bull, L.M. (2008). Population-based study of event-rate, incidence, case fatality, and mortality for all acute vascular events in all arterial territories: *Oxford Vascular Study*. *Lancet*; 366:1773–1783.

Burton, CR. (2000): Living with stroke: a phenomenological study. *Journal of Advanced Nursing* 32, 301-309.

Busch, M., Coshall, C., Saka, Ö. and Wolfe, CDA (2007). Socio demographic differences in return to work after stroke—a follow-up study with the South London Stroke Register. *Cerebrovascular Disease*; 23 (2): 31.

Buurke, JP., Nene, AV., Kwakkel, G., Wolter-Erren, V., IJzerman, MJ. and Hermens, HJ. (2008). Recovery of Gait after Stroke: What Changes? *Neuro rehabilitation Neural Repair* 22: 676-683.

Buurke, J.H. (2005). Walking after Stroke: Co-ordination patterns and functional recovery. Universiteit Twente.

Byl, N., Roderick, J., Mohamed, O., Hanny, M., Kotler, J. and Smith, A. (2003). Effectiveness of sensory motor rehabilitation of the upper limb following the principles of neuroplasticity: patients stable post stroke. *Neuro rehabilitation and Neural Repair*; 17(3):176–91.

Centers for Disease Control and Prevention (2007): Outpatient rehabilitation among stroke survivors-21 States and the District of Columbia, 2005. *Morbidity and Mortality Weekly Report*, 56(20):504-507.

Chau, PC., Thompson, R., Twinn, S., Chang, A. and Woo, J. (2009). Determinants of Participation restriction among community dwelling stroke survivors: A path analysis; *Biomed Central Neurology - Series Journal*.

Ch'Ng, A. M., French, D. and Mclean, N. (2008). Coping with the Challenges of Recovery from Stroke: Long Term Perspectives of Stroke Support Group Members. *Journal of Health Psychology*, 13(8), 1136-1146.

Cieza, A. and Stucki, G. (2005): Content comparison of health-related quality of life (HRQOL) instruments based on the international classification of functioning, disability and health (ICF). *Quality of Life Research* 14, 1225-1237.

Clarke, PJ., Black, SE., Badley, EM., Lawrence, JM., and Williams, JI. (1999). Handicap in stroke survivors. *Disability and Rehabilitation*, 21(3), 116-123.

Clarke, P. and Black, SE. (2005): Quality of Life Following Stroke: Negotiating Disability, Identity, and Resources. *Journal of Applied Gerontology* 24, 319-336.

Clarke, P., Marshall, V., Black, SE. and Colantonio, A. (2002). Well-being after stroke in Canadian seniors: findings from the Canadian Study of Health and Aging. *Stroke*; 33:1016-1021.

Clark, M.S, and Smith, D.S. (1999). Psychological correlates of outcome following rehabilitation from stroke. *Clinical Rehabilitation*; 13:129-140.

Cole, J.W., Pinto, A. N., Hebel, J. R., Buchholz, D. W., Earley, C. J., and Johnson, CJ et al. (2004). Acquired immunodeficiency syndrome and the risk of stroke. *Stroke*; 35:51-56.

Connor, M. & Bryer, A. (2006). Stroke in South Africa. In K. Steyn, J. Fourie & N. Temple (Eds.), *Chronic diseases of lifestyle in South Africa: 1995-2005*, pp. 195-203. Cape Town: *South African Medical Research Council*.

Connor, M.D., Thorogood, M., Casserly, B., Dobson, C., and Warlow, CP. (2004). Southern Africa Stroke Prevention Initiative (SASPI) project team: Prevalence of stroke survivors in rural South Africa: results from the Southern Africa Stroke Prevention Initiative (SASPI) Agincourt field site. *Stroke*; 35:627-632

Coyne, P. and Mares, P. (1995). *Caring for someone who has had a stroke*. London: Age concern.

Creswell, J.W. (2003). *Research design: Qualitative, quantitative, and mixed approaches*. Second edition. *London*: Sage.

Creswell, J. W., Plano Clark, V. L., Gutmann, M. L., & Hanson, W. E. (2003). Advanced mixed methods research designs. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in social and behavioral research* (pp. 209–240). Thousand Oaks, CA: Sage.

Cummins, R.A. (1999). A psychometric evaluation of the comprehensive quality of life scale– Fifth edition. In: Lim L. Y., Yuen B. & Low C. (Eds.). *Urban quality of life: Critical issues and options*. School of Building and Real Estate, National University of Singapore.

D'Alisa, S., Baudo, S., Mauro, A. and Miscio, G. (2005). How does stroke restrict participation in long-term post stroke survivors? *Acta Neurologica*; 112(3):157–162.

Damush, TM., Plue, A., Bakas, T., Schmid, A. and Williams, LS. (2007). Barriers and facilitators to exercise among stroke survivors. *Rehabilitation Nurse* 32(6): 253–62.

Darrigrand, B., Dutheil, S., Michelet, V., Rereau, S., Rousseaux, M. and Mazaux, J-M. (2011). Communication impairment and activity limitation in stroke patients with severe aphasia. *Disability and Rehabilitation*, 33(13-14), 1169-1178.

Davidson, B., Howe, T., Worrall, L., Hickson, L. and Togher, L. (2008). Social participation for older people with aphasia: the impact of communication disability on friendships. *Topics in stroke rehabilitation*, 15(4), 325-340. doi: 10.1310/tsr1504-325.

De Koker, C., De Waal, L. and Vorster, J. (2006). A profile of social security beneficiaries in South Africa: Volume 3. Data Desk, Department of Sociology and Social Anthropology: Stellenbosch University.

Desrosiers, J., Demers, L., Robichaud, L., Vincent, C., Belleville, S., and Ska, B. (2008). Short term changes in and predictors of participation of older adults after stroke following acute care or rehabilitation. *Neuro rehabilitation and Neural Repair*, 22, 288-297.

Desrosiers, J., Noreau, L., Rochette, A., Bravo, G. and Boutin, C. (2002). Predictors of handicap situations following post-stroke rehabilitation. *Disability and Rehabilitation*, 24, 774- 785.

Desrosiers, J., Noreau, L., Rochette, A., Bourbonnais, D., Bravo, D. and Bourget, A. (2006). Predictors of Long Term Participation after Stroke. *Disability and Rehabilitation* 28(4): 221-230.

Desrosiers, J., Rochette, A., Noreau, L., Bourbonnais, D., Bravo, D. and Bourget, A. (2006). Long-Term Changes in Participation after Stroke. Topic in *Stroke Rehabilitation* 13(4):86-96.

De Haart M. (2005). Recovery of Standing Balance in patients with a supratentorial stroke. Radboud Universities Nijmegen.

De Haart, M., Geurts, A.C. and Huidekoper, S.C et al. (2004). Recovery of standing balance in post-acute stroke patients: a rehabilitation cohort study. *Archives of Physical Medicine and Rehabilitation*; 85:886-895.

Dolmans, D.H., Gijsselaers, W.H. and Moust, J.H. et al, (2002). Trends in research on the tutor in problem based learning: conclusions and implications for educational practice and research. *Medical Teacher*; 24:173-180.

Dolmans, D.H., Gijsselaers, W.H. and Moust, J.H. et al. (2002). Trends in research on the tutor in problem based learning: conclusions and implications for educational practice and research. *Medical Teacher*; 24:173-180.

Domholdt, E. (2000). Physical Therapy Research: Principles and Application (2nd edition). Philadelphia: WB Saunders Publishers.

Donnan, GA., Fisher, M., Macleod, M. and Davis, SM. (2008). Stroke. *Lancet* 2; 371: 1612–23.

Duncan, PW., Goldstein, LB., Matchar, D., Divine, GW. And Feussner, J. (2005) Measurement of motor recovery after stroke. Outcome assessment and sample size requirements. *Stroke*; 23(8):1084-9.

Duncan, P.W., Samsa, G.P., Weinberger, M., Goldstein, L.B., Bonito, A., Witter, D.M., Enarson, C. and Matchar, D. (1997). Health status of individuals with mild stroke. *Stroke*; 28: 740-745.

Dunsky, A., Dickstein, R., Marcivitz, E. and Levy, S. (2008). Home-Based Motor Imagery Training for Gait Rehabilitation of People with Chronic Post stroke Hemiparesis. *Archive of Physical Medicine and Rehabilitation* 89: 1580-1588.

Edwards, D. F., Hahn, M., Baum, C. and Dromerick, A. W. (2006). The impact of mild stroke on meaningful activity and life satisfaction. *Journal of Stroke and Cerebrovascular Diseases*, 15, 151-157.

Ellis-Hill, C.S. and Horn, S. (2000). Change in Identity and Self-Concept: A New Theoretical Approach to Recovery Following a Stroke. *Clinical Rehabilitation* 14: 279-287.

Emberson, J., Lees, KR., Lyden, P., Blackwell, L., Albers, G. and Bluhmki, E. (2014). Effect of treatment delay, age and stroke severity on the effects of intravenous thrombolysis with

alteplase for acute ischaemic stroke: a meta-analysis of individual patient data from randomised trials. *Lancet*.

Ekstam, L. (2009). Changes in everyday life after stroke older individuals' and couples' daily Occupations at home during the first year after stroke. Thesis for doctoral degree (PhD), Karolinska Institutet, Stockholm.

Ekstam, L., Tham, K. and Borell, L. (2011). Couples' approaches to changes in everyday life during the first year after stroke. *Scandinavian Journal of Occupational Therapy*, 18, 49-58.

Fallahpour, M., Jonsson, H., Joghataei, MT. and Kottorp, A. (2011). Impact on participation and autonomy: Psychometric evaluation of the Persian version to use for persons with stroke. *Scandinavian Journal of Occupational Therapy*; 18(1):59–71.

Farham B. (2004). Stroke – a neglected chronic disease. *Continuing Medical Education*, 22(6):340.

Feigin, V., Lawes, C., Bennett, D. and Anderson, C. (2003). Stroke epidemiology: a review of population based studies of incidence, prevalence and case fatality in the late 20th century. *Lancet Neurology*: 2: 43-53.

Ferguson, A., (2007). Multi party interactions in aphasia. In Ball, M., & Damico, J. (1st Ed.) *Clinical Aphasiology*. New York: Psychology Press, pp. 183-193.

Ferrans, C. E. and Powers, M. J. (1985). Quality of life index: development and psychometric properties, *Advances in Nursing Science*, Vol. 8, pp. 15-24.

Field, A. (2006). *Discovering Statistics Using SPSS: Second Edition*. London. Thousand Oaks. New Delhi. Sage Publication.

Flansbjer, UB (2006). Strength training after stroke: Effects on muscle function, gait performance and perceived participation. Lunds Universitet.

Flansbjer, UB., Downham, D. and Lexell, J. (2006). Knee muscle strength, gait performance, and perceived participation after stroke. *Archives of the Physical Medicine and Rehabilitation*; 87:974-980.

Fletcher, P. and Hirdes, J. (2004). Restriction in activity associated with fear of falling among community-based seniors using home care services. *Age and Ageing*; 33:273–279. [PubMed: 15082433].

Fritz, V. (1995). Stroke, Including Rehabilitation of Chronic Diseases of Lifestyle in South Africa Medical Research Council. *Technical Report chapter X*: 161-175.

Garbusinski, J.M., Van der Sande, M.A.B., Bartholome, E.J., Dramaix, M., Gaye, A., Coleman, R., Nyan, O.A., Walker, R.W., McAdam, K.P.W.J. and Walraven, G.E. (2005). Stroke Presentation and Outcome in Developing Countries: A prospective Study in the Gambia. *Stroke* 36: 1388-1393.

Geyh, S., Cieza, A., Schouten, J., Dickson, H., Frommelt, P., Omar, Z., Kostanjsek, N., Ring, H. and Stucki, G (2004): ICF Core Sets for stroke. *Journal of Rehabilitation Medicine* 36, 135-141.

Geyh and Szilvia (2007). Connecting Perspectives on stroke disability: The measurement and the classification approach. Dissertation, Ludwig – Maximilians Universität München, Faculty of Medicine.

Gillen, G. (2011). Stroke Rehabilitation. *A Function-Based Approach*. Missouri: Mosby.

Given, Lisa M. (2008). *The Sage encyclopedia of qualitative research methods*. Los Angeles, Calif.: Sage Publications.

Goodman, J., Schlossberg, N. K., and Anderson, M. L. (2006). Counseling adults in transition: linking practice with theory. New York: *Springer Publication Co*.

Go, AS, Mozaffarian, D. and Roger, VL. (2014). Heart disease and stroke statistics—2014 update: a report from the American Heart Association. *Circulation*; 128.

Greenbaum, Thomas (2000). *Moderating Focus Groups*. Thousand Oaks, California: Sage Publications.

Greg Guest and Laura Johnson (2006). How Many Interviews Are Enough? An Experiment with Data Saturation and Variability, *Field Methods*, Vol.18, No.1, 59-82.

Griffen, J.A., Rapport, L.J., Bryer, R.C. and Scott, C.A. (2009). Driving Status and Community Integration after Stroke. *Topics in Stroke Rehabilitation* 16(3): 212-221.

Guba, E.G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. Educational Resources Information Center. Annual Review paper, 29, 75 -91.

Hale, L.A., Fritz, V. and Eales, C.J. (1999). Do Stroke Patients Realise that a Consequence of Hypertension is Stroke? *South African Medical Journal* 88(4): 451-454.

Hale, L. and Wallner, P. (1996). The Challenges of Service Provision in South Africa for Patients with Hemiplegia. *Physiotherapy*; 62 (3): 156 – 158.

Hammond, R., Lennon, S. and Walker, M.F. et al. (2005). Changing occupational therapy and physiotherapy practice through guidelines and audit in the United Kingdom. *Clinical Rehabilitation*; 19:365-371.

Hamzat, TK., Oleleye, OA. and Akinwunmi, OB. (2014). Functional Ability, Community Reintegration and Participation Restriction among Community-Dwelling Female Stroke Survivors in Ibadan. *Ethiopian Journal of Health Science*, 24(1).

Hankey, G.F., Jamrozik, K.F., Broadhurst, R.F., Forbes, S.F., Burvill, P.F., Anderson, C.F. et al. (2000) - Five-year survival after first-ever stroke and related prognostic factors in the Perth Community Stroke Study. – *Stroke*; Sep; 31(9):2080-6.2080-86.

Hagerty, M. R., Cummins, R. A., Ferriss, A. L. L.K., Michalos, A. C., Peterson, M., Sharpe, A., Sirgy, J. and Vogel, J. (2001). Quality of life indexes for national policy: A review and agenda for research. *Social Indicators Research*, Vol. 55, pp. 1-96.

Hassan, S.A.M., Visagie, S. and Mji, G. (2011b). Strain Experienced by Caregivers of Stroke Survivors in the Western Cape. *The South African Journal of Physiotherapy*. 67(2):4-8.

Herman, D. (2006). Strokes are South Africa's No 1 killer among over-50s. *Cape Argus*, 27 October.

Hickenbottom, S. L., Fendrick, A. M., Kutcher, J. S., Kabeto, M. U., Katz, S. J. and Langa, K. M. (2002). A national study of the quantity and cost of informal caregiving for the elderly with stroke. *Neurology*, 58 (12), 1754-1759.

Hochstenbach, J., Prigatano, G., Mulder, T. (2005). Patients' and relatives' reports of disturbances 9 months after stroke: subjective changes in physical functioning, cognition, emotion, and behavior. *Archives of Physical Medicine and Rehabilitation*: 1587-1593.

Hoffmann M. 2001. Higher cortical function deficits after stroke: an analysis of 1,000 patients from a dedicated cognitive stroke registry. *Neuro rehabilitation Neural Repair*15: 113-127.

Hoffman, T., McKenna, K., Cooke, D. and Tooth, L. (2003). Outcomes after stroke: Basic and instrumental activities of daily living, community integration and generic health status. *Australian Occupational Therapy Journal*, 50, 225-233.

Hofgren, C., Björkdahl, A., Esbjörnsson, E. and Stibrant-Sunnerhagen, K.(2007). Recovery after stroke: Cognition, ADL function and return to work. *Acta Neurologica Scandinavica*, 115, 73-80. doi:10.1111/j.1600-0404.2006.00768.

Hunter, SM. And Crome, P. (2002). Hand function and stroke. *Reviews in Clinical Gerontology*; 12(1):66–81.

International Classification of Functioning, Disability and Health (2001): ICF: World Health Organization.

Jaracz, K. and Kozubski, W. (2003). Quality of life of stroke patients. *Acta Neurologica Scandinavica*; 107:324-329.

Jette, AM., Haley, SM. And Kooyoomjian, JT. (2003). Are the ICF activity and participation dimensions distinct? *Journal of Rehabilitation Medicine*; 35(3):145-149.

Jette, DU., Latham, KN., Smout, JR., Gassaway, J. Salvin, DM. and Horn, DS. (2005). Physical therapy interventions for patients with Stroke Inpatient Rehabilitation Facilities. *Physical therapy*; 85: 238-248.

Jonsson, AC., Lindgren, I., Hallstrom, B., Norrving, B. and Lindgren, A. (2005). Determinants of quality of life in stroke survivors and their informal caregivers. *Stroke*; 36:803–808.

- Karlsson, A. and Frykberg, G. (2000). Correlations between force plate measures for assessment of balance. *Clinical Biomechics*; 15:365-9.
- Kaufman, M.T. (2003). "Robert K. Merton, Versatile Sociologist and Father of the Focus Group, Dies at 92". *The New York Times*.
- Kengue, S. (2008). The Neglected burden of stroke in Sub Sahara Africa, International journal of Stroke, Blackwell, London.
- Kersten, P., Low, J.T.S., Ashburn, A., George, S.L. and McLellan, D.L. (2002). The unmet needs of young people who have had a stroke: results of national UK survey. *Disability Rehabilitation*; 24:860-866.
- Keysor, JJ., Jette, AM., LaValley, MP., Lewis, CE., Torner, JC., Nevitt, MC. and Felson, DT. (2010). Community environmental factors are associated with disability in older adults with functional limitations: The MOST study. *The Journals of Gerontology series A: Biological Sciences and Medical Sciences*; 65:393–399.
- Kim, AS. and Johnston, SC (2011). Global variation in the relative burden of stroke and ischemic heart disease. *Circulation*; 124(3):314–323.
- Kitson, A., Harvey, G. and McCormack, B. (1998). Enabling the implementation of evidence based practice: a conceptual framework. *Quality Health Care*; 7:149-158.
- Kochanek, K. D. Xu, J. Q. Murphy, SL. Miniño, A. M. and Kung, H. C. (2011). Deaths: final data for 2009. *National Vital Statistics Reports*; 60(3).
- Krapp, K. (2006). "Activities of Daily Living Evaluation." *Encyclopedia of Nursing & Allied Health*. Gale Group, Inc., 2002. eNotes.com. 2006. E notes Nursing Encyclopedia. Accessed on: 11 Oct, 2007.
- Leeder, S., Raymond, S. and Greenberg, H. (2004). Race against time: The challenge of cardiovascular disease in developing economies. New York: Columbia University, 2004.
- Leitner, A., Kaluscha, R. and Jacobi E. (2008). The ICF in use: testing of a new concept in four clinics. [In German]. *Rehabilitation* ;47(4):226-35.
- Levasseur, M., Desrosiers, J. and St-Cyr Tribble, D. (2008). Do quality of life, participation and environment of older adults differ according to level of activity? *Health Quality of Life Outcomes*; 6:30.
- Lim, L. Y., Yuen, B. and Low C. (1999). Quality of life in cities – definition, approaches and research. In: Lim L. Y., Yuen B. & Low C. (Editions.). Urban quality of life: Critical issues and options. School of building and real estate, National University of Singapore.
- Lindsay, P., Bayley, M., McDonald, A., Graham, ID., Warner, G. and Phillips, S. (2008). Toward a more effective approach to stroke: Canadian Best Practice Recommendations for Stroke Care. *Canadian Medical Association Journal*; 178:1418–1425.

Lloyd-Jones, D., Adams, R.J., Brown, T.M., Carnethon, M., Dai, S., De Simone, G., Ferguson, T.B., Ford, E., Furie, K., Gillespie, C., Go, A., Greenlund, K., Haase, N., Hailpern, S., Ho, P.M., Howard, V., Kissela, B., Kittner, S., Lackland, D., Lisabeth, L., Marelli, A., McDermott, M.M., Meigs, J., Mozaffarian, D., Mussolino, M., Nichol, G., Roger, V.L., Rosamond, W., Sacco, R., Sorlie, P., Stafford, R., Thom, T., Wasserthiel-Smoller, S., Wong, N.D. and Wylie-Rosett, J. (2009). Heart disease and stroke statistics—2010 update: a report from the American Heart Association. *Circulation*. 2010; 121:e46–e215. Electronic publication December 17.

Lloyd, K. M. and Auld, C. J. (2002). The role of leisure in determining quality of life: Issues of content and measurement. *Social Indicators Research*, Vol. 57, pp. 43-71.

Locher, M.A. (2010). Relational work, politeness, and identity construction. In Matsumoto D (Ed.), American Psychological Association Handbook of interpersonal communication (pp. 111-138). Washington, DC: American Psychological Association.

Lord, SE., McPherson, K., McNaughton, H., Rochester, L. and Weatherall, M. (2004). Community Ambulation After Stroke: How Important and Obtainable Is It and What Measures Appear Predictive? *Archives of Physical Medicine Rehabilitation* 85: 234-238.

Lord, S., McPherson, KM., McNaughton, HK., Rochester, L. and Weatherall, M. (2008). How feasible is the attainment of community ambulation after stroke? A pilot randomized controlled trail to evaluate community-based physiotherapy in sub-acute stroke. *Clinical Rehabilitation* 22: 215 –225.

Lord, S. Rochester, L. (2005). Measurement of Community Ambulation after Stroke: Current Status and Future Developments. *Stroke* 36: 1457-1461.

Lozano, R. Naghavi, M. Foreman, K. (2012). Global and regional mortality from 235 causes of death for 20 age groups in 1990 and 2010: *a systematic analysis for the Global Burden of Disease Study 2010*. *Lancet*; 380:2095-128.

Lui, M.H.L. and Mackenzie, A.E. (1999). Chinese Elderly Patients' Perception of their Rehabilitation Needs Following a Stroke. *Journal of Advanced Nursing* 30(2): 391-400.

Lynch, E.B., Butt, Z., Heinemann, A., Victorson, D., Nowinski, C., Perez, L. and Cella, D. (2008). A Qualitative Study of Quality of Life after Stroke: The Importance of Social Relationships. *Journal of Rehabilitation Medicine* 40: 518-523.

MacMahon, S., Peto, R. and Cutler, J. (1990). Blood pressure, stroke, and coronary heart disease. Part 1: Prolonged differences in blood pressure: prospective observational studies corrected for the regression dilution bias. *Lancet*; 335: 765-774.

Mackenzie, A., Perry, L. and Lockhart, E. (2007). Family carers of stroke survivors: needs, knowledge, satisfaction and competence in caring, *Disability and Rehabilitation*, 29, 111-121.

Murray, J., Young, J. and Forster, A. (2003) Developing a primary care-based stroke model: the prevalence of longer-term problems experienced by patients and carers, *British Journal of General Practice*, 53, 803-807.

- Malm, J., Kristensen, B., Carlberg, B., Fagerlund, M. and Olsson, T. (1998). Cognitive Impairments in Young Adults with Infratentorial Infarcts. *Neurology* 51(2): 433-440.
- Marshall, C. and Rossman, G.B. (1999). *Designing Qualitative Research*. Third edition. London: Saga Publications.
- Martin, B.J., Yip, B., Hearty, M., Marletta, S. and Hill R. (2002). Outcome, functional recovery and unmet needs following acute stroke. Experience of patient follow up at 6 to 9 months in a newly established stroke service. *Scottish Medical Journal*, 47:136-137.
- Marmot, M.G. and Poulter, N.R. (1995). Primary Prevention of Stroke. *Lancet*, 339, 334-347. [http://dx.doi.org/10.1016/0140-6736\(92\)91659-V](http://dx.doi.org/10.1016/0140-6736(92)91659-V).
- Mayo, N.E., Wood-Dauphinee, S., Cote, R. and Durcan, L. (2002). Activity, participation and quality of life 6 months post stroke. *Archives of Physical Medicine and Rehabilitation*; 83:1035-1042.
- McDonnell, M.N., Hillier S.L., and Miles, T.S. (2007). Influence of combined afferent stimulation and task-specific training following stroke: a pilot randomized controlled trial. *Neuro rehabilitation Neural Repair*; 21:435-443.
- McKevitt, C. Redfern, J. Mold, F. and Wolfe, C. (2004). Qualitative Studies of Stroke: A Systematic Review. *Stroke* 35: 1499-1505.
- Medin, J., Barajas, J. and Ekberg, K. (2006). Stroke patients' experiences of return to work. *Disability and Rehabilitation* 28: 1051 – 1060.
- Meleis, A. I., Sawyer, L. M., Im, E., Messias, D. K. H. and Schumacher, K. (2000). Experiencing transitions: an emerging middle-range theory. *Advances in Nursing Science*, 23, 12-28.
- Mudzi, W. (2009). Impact of Caregiver Education on Stroke Survivors and their Caregiver. *Unpublished PhD Thesis*. The University of the Witwatersrand.
- Mudzi, W., Stewart, A. and Musenge, E. (2013). Community participation of patients 12 months post-stroke in Johannesburg, South Africa. *African Journal of Primary Health Care and Family Medicine*; 5 (1), Articles. 426, 9 pages. <http://dx.doi.org/10.4102/phcfm.v5i1.426>.
- Mukherjee, D. Levin, R.L. and Heller, W.(2006). The cognitive, emotional, and social sequelae of stroke: psychological and ethical concerns in post-stroke adaptation. *Top Stroke Rehabilitation*, 13(4):26-35.
- Muldoon, M.F., Barger, S.D., Flory, J.D. and Manuck, S.B. (1998). What are quality of life measurements measuring? *British Medical Journal*; 316: 542–545.
- Murray, C. D. and Harrison, B. (2004). The meaning and experience of being a stroke survivor: an interpretative phenomenological analysis. *Disability and Rehabilitation*, 26, 808-816.

Mustapha, D. (2007). Prevalence of Stroke in an urban, mixed income community in Lagos, Nigeria, University of Lagos, *Neuro Epidemiology*.

Muyanga, A. (2006). A study to determine the Prevalence of Stroke patients in the Physiotherapy outpatients department at the University Teaching Hospital, 2003-2005, Lusaka, UNZA, unpublished.

Naess, H., Nyland, H., Thomassen, L., Aarseth, J. and Myhr, K. (2004). Long-term outcome of cerebral infarction in young adults. *Acta Neurologica Scandinavica*; 110: 107-112.

National Board of Health and Welfare (2006b): National Guidelines for Stroke Care 2005 National Board of Health and Welfare, Stockholm.

National Institute of Neurological Disorders and Stroke (NINDS) (2012). Post-Stroke Rehabilitation Fact Sheet. www.ninds.nih.gov/ Accessed 3/19/2012.

Neuman, W. (2000). Social Research Methods: Qualitative and Quantitative Approaches. Boston. Allyn and Bacon, a Pearson Education Company, USA.

Noreau, L., Desrosiers, J., Robichaud, L., Fougereyrollas, P., Rochette, A. and Viscogliosi, C. (2004). Measuring social participation: reliability of the life-h in older adults with disabilities. *Disability Rehabilitation* , 26(6):346-352.

Norman, R., Bradshaw, D., Schneider, M., Pieterse, D. and Groenwald, P. (2006). Revised Burden of Disease Estimates for the comparative risk factor assessment, South Africa 2000. Cape Town: Medical Research Council.

Northcott, S., and Hilari, K., (2011). Why do people lose their friends after a stroke? *International Journal of Language and Communication Disorders*, 45 (5), 524-534.

Nys, GM., van Zandvoort, MJ., de Kort, PL., Jansen, BP., de Haan, EH. and Kappelle, LJ. (2007). Cognitive disorders in acute stroke: prevalence and clinical determinants. *Cerebrovascular Disease* 23: 408-416.

Organised inpatient (stroke unit) care for stroke. Cochrane Database of Systematic Reviews. 2002(1): CD000197.

Ormel, J., Lindenberg, S., Steverink, N. and Vonkorff, M. (1997). Quality of life and social production functions: A framework for understanding health effects. *Social Science Medicine*, Vol. 45, pp. 1051-1063.

Page, SJ., Levine, P., Sisto, SQ., Bond and Johnston MV. (2002). Stroke patients' and therapists' opinions of constraint-induced movement therapy *Clinical Rehabilitation*, 16, pp. 55-60.

Palmer, S. and Glass, T.A. (2003). Family function and stroke recovery: A review. *Rehabilitation Psychology*; 48:255-265.

Paolucci, S. Grasso, MG. Antonucci, G. Bragoni, M. Troisi, E. Morelli, D. Coiro, P. De Angelis, D. and Rizzi, F. (2001): Mobility status after inpatient stroke rehabilitation: 1-Year follow-up and prognostic factors. *Archives of Physical Medicine and Rehabilitation* 82, 2-8.

Parr, S. (2001). Psychosocial aspects of aphasia: whose perspectives? *Folia Phoniatrica et Logopedica*, 53, 266-288.

Parr, S., Byng, S. and Barnes, C.(2004) Summary: Social exclusion of people with marked communication impairment following stroke, York: Joseph Rowntree Foundation.

Patterson, SL., Forrester, LW., Rodgers, MM., Ryan, AS., Ivey, FM., Sorkin, JD. and Macko, RF. (2007). Determinants of walking function after stroke: differences by deficit severity. *Archives of Physical Medicine and Rehabilitation*; 88:115-119.

Paul, Oliver (2006). Purposive Sampling; the Sage Dictionary of Social Research Methods. <http://dx.doi.org/10.4135/9780857020116>.

Pettersen, R., Dahl, T. and Wyller, TB. (2002): Prediction of long-term functional outcome after stroke rehabilitation. *Clinical Rehabilitation* 16, 149-159.

Phillips, H. and Noubissi A. (2004). Disability in South Africa. *African Population Studies* 19: 115 – 138.

Pilkington, F.B. (1999). A Qualitative Study of Life after Stroke. *Journal of Neuroscience Nursing*. December 31(6): 336-347.

Pohjasvaara, T., Vataja, R., Leppavuori, A., Kaste, M. et al., (2002). Cognitive functions and depression as predictors of poor outcome 15 months after stroke. *Cerebrovascular Diseases* 14(3-4):228-33.

Polit, D.F., Beck, C.T. and Hungler, B.P. (2001). *Essentials of Nursing research, methods, appraisal, and utilization*. Fifth edition. Philadelphia: Lippincott Publishers.

Poungvarin, N. (1998). Stroke in the developing world. *Lancet* 352(SIII), 19-22.

Puoane, T., Tsolekile, L., Sanders, D. and Parker, W. (2008). “Chronic non-communicable diseases”. *South African Health Review*.

Radford, K. A. and Walker, M. F. (2008). Impact of Stroke on Return to Work. *Brain Impairment*, 9(2), 161–169.

Ramnamark, A., Nyberg, L., Borssen, B., Olsson, T. and Gustafson, Y (1999). Fractures after stroke. *Osteoporos International*; 8(1):92-95.

Ranzijn, R. and Luszcz, M. (2000). Measurement of subjective quality of life of elders. *International journal of aging and human development*, v 50 - special issue: *Ageing and quality of life* – The continuing search for Quality of life indicators.

Rausch, A., Cieza, A. and Stucki, G. (2008). How to apply the International Classification of Functioning, Disability and Health (ICF) for rehabilitation management in clinical practice. *Europe Journal of Physical Rehabilitation Medicine*; 44:329-42.

Reding, M. J. and McDowell, F. H. (1989). 'Focused stroke rehabilitation programmes improve outcome', *Archives of Neurology*, 46, 700-701.

Redon, J., Olsen, MH., Cooper, RS., Zurriaga, O., Martinez-Beneito, MA., Laurent, S., Cifkova, R., Coca, A. and Mancina, G (2011). Stroke mortality and trends from 1990 to 2006 in 39 countries from Europe and Central Asia: implications for control of high blood pressure. *Europe Heart Journal*; 32(11):1424–1431.

Rentsch, H., Bucher, P., Nyffeler, I., Wolf, C., Hefti, H. and Fluri, E. (2003). The implementation of the 'International Classification of Functioning, Disability and Health' (ICF) in daily practice of neuro rehabilitation: an interdisciplinary project at the Kantonsspital of Lucerne, Switzerland. *Disability and Rehabilitation*; 25(8):411-21.

Rhoda, A. and Hendry, J. (2006). Rehabilitation of Stroke Patients Treated at a Community Based Rehabilitation Centre. *Journal of Community and Health Sciences*; 1(1): 4753.

Rhoda, A., Mpofu, R. and De Weerd. (2011). Activity Limitations of Patients with Stroke Attending Out-patient Facilities in the Western Cape, South Africa. *South African Journal of Physiotherapy*. 67(2):16-22.

Rimmer, J.H., Wang, E. and Smith, D. (2008). Barriers associated with exercise and community access for individuals with stroke. *Journal of Rehabilitation Research and Development*, 45(2), 315-322.

Robinson-Smith, G. (2002). Prayer after Stroke: It's Relationship to Quality of Life. *Journal of Holistic Nursing* 20: 352-366.

Robinson-Smith, G., Johnston, M.V. and Allen, J. (2008). Self-care, self-efficacy, quality of life and depression after stroke. *Archives of Physical Medicine and Rehabilitation*;81:460-464.

Rood, M. (1954). 'Neurophysiological reactions as a basis for physical therapy', *Physical Therapy review* 34, 444-449.

Rothwell, PM., Coull, AJ., Giles, MF., Howard, SC., Silver, LE., Bull, LM., Gutnikov, SA., Edwards, P., Mant, D., Sackley, CM., Farmer, A., Sandercock, PA., Dennis, MS., Warlow, CP., Bamford, JM. and Anslow, P. (2004). Change in stroke incidence, mortality, case-fatality, severity, and risk factors in Oxford shire, UK from 1981 to 2004 (Oxford Vascular Study). *Lancet*; 363: 1925–1933.

Rothman, K.J. and Greenland S. (1998). *Modern Epidemiology*. Second. Philadelphia, PA: Lippincott-Raven.

Rubin, H.J. and Rubin, I.S. (2004). *Qualitative interviewing: The art of hearing data*. Second edition. Thousand Oaks, CA: *Sage Publishers*.

SASPI Project Team (2004). Prevalence of stroke survivors in rural South Africa: results from the Southern Africa Stroke Prevention Initiative (SASPI) Agincourt field site. *Stroke*; 35: 627-632. [<http://dx.doi.org/10.1161/01.STR.0000117096.61838.C7>].

Schepers, VP., Visser-Meily, AM., Ketelaar, M. and Lindeman, E. (2005): Prediction of Social Activity 1 Year Post stroke. *Archives of Physical Medicine and Rehabilitation* 86, 1472-1476.

Schmidt, CO. and Kohlmann, T. (2008). "When to use the odds ratio or the relative risk?" *International Journal of Public Health* 53 (3): 165–167.

Schneidert, M. Hurst, R. Miller, J. Ustun, B. (2003). The role of environment in the International Classification of Functioning, Disability and Health (ICF). *Disability Rehabilitation* 25(11–12):588–595.

Shaughnessy, J., Zechmeister, E. and Jeanne, Z. (2011). Research Methods in Psychology (9th edition.). New York, New York: McGraw Hill. pp. 161–175.

Singh, R.F., Suh, I.F., Singh, V.F., Chaithiraphan, S.F., Laothavorn, P.F., and Sy, R.F., *et al.* (2000) -Hypertension and stroke in Asia: prevalence, control and strategies in developing countries for prevention. – *Journal of Human Hypertension* Oct-Nov; 14(10-11):749-63.749-63.

Silverman, D. (2000). Doing Quantitative Research: A Practical Handbook. London: Sage Publication.

Smith A. E. (2000). Quality of life: a review. Education and Ageing. *Triangle Journals*, Vol. 15, pp. 419-435.

Snoek F. J. (2000). Quality of life: A closer look at measuring patients' well-being. *Diabetes Spectrum*, Vol. 13, No. 1, p 24.

Sousa, RM., Ferri, CP. and Acosta, D. (2009). Contribution of chronic disease to disability in elderly people in countries with low and middle incomes: a 10/66 Dementia Research Group population-based survey. *Lancet* 37421821-1830.

Stone, J., Townend, E., Kwan, J., Haga, K., Dennis, MS. And Sharpe, M. (2004). Personality change after stroke: some preliminary observations Department of Clinical Neurosciences, Western General Hospital, Edinburgh EH4 2XU, UK.

Sturm, JW., Donnan, GA., Dewey, HM., Macdonnell, RA., Gilligan, AK. and Thrift, AG. (2004). Determinants of handicap after stroke: The North East Melbourne Stroke Incidence Study (NEMESIS). *Stroke*, 35(3):715-720.

Stroke Association. (2006a). *Stroke Rehabilitation* (Brochure). London.

Stroke Association. (2006). *What is stroke?* (Brochure). London.

Stroke Association. (N.d.). *Continence problems after stroke*. (Brochure). London

- Stucki, G., Ewert, T. and Cieza, A. (2002): Value and application of the International Classification of Functions, disability and health in rehabilitation medicine. *Disability & Rehabilitation* 24, 932-938.
- Sturm, J. W., Donnan, G. A., Dewey, H. M., Macdonell, R. A. L., Gilligan, A. K. and Thrift, A.G. (2004). Determinants of handicap after stroke: The North East Melbourne Stroke Incidence Study (NEMESIS). *Stroke*, 35, 715-720.
- Sveen, U., Thommessen, B., Bautz-Holter E, Wyller, TB. and Laake, K. (2004): Well-being and instrumental activities of daily living after stroke. *Clinical Rehabilitation* 18, 267-274.
- Svensden, ML., Ehlers, LH., Andersen, G. and Johnsen, SP.(2009). Quality of care and length of hospital stay among patients with stroke. *Medical Care* , 47(5):575-582.
- Swann, J. (2008). Stroke: environmental barriers. *British Journal of Healthcare Assistants*;2(11):561–564.
- Taylor, D., Stretton, CN., Mudge, S. and Garret, N. (2006). Does clinic measured gait speed differ from gait speed measured in the community in people with stroke? *Clinical Rehabilitation*, 20: 436 –444.
- Terent, A. (2003). Trends in stroke incidence and 10-year survival in Soderhamn, Sweden, 1975–2001. *Stroke*, 34(6), 1353–1358.
- Tennant, A., Geddes, JML., Fear, J. and Hillman, M. (1997). Chamberlain MA: Outcome following stroke. *Disability Rehabilitation*, 19(7):278-284.
- Tipping, B. (2008). Issues in the long-term management of stroke. *Continuing Medical Education*, 26(2), 70-72.
- Tobacco control country profiles. (2000). The American Cancer Society, Atlanta.
- Thompson, H. S. and Ryan, A. (2009). The impact of stroke consequences on spousal relationships from the perspective of the person with stroke. *Journal of Clinical Nursing*, 18(12), 1803-1811. doi: 10.1111/j.1365-2702.2008.02694.x.
- Thorogood, M. Connor, M.D., Casserly, B., Dobson, C. and Warlow, CP (2004), Prevalence of stroke in rural south Africa, The SAPSI project team, University of Warwick and University of Witwatersrand, United Nations Development Program, (2007).
- Tyson, SF., Hanley, M., Chillala, J., Selley, AB. and Tallis, RC. (2008). Sensory loss in hospital admitted people with stroke: characteristics, associated factors, and relationship with function. *Neuro rehabilitation and Neural Repair*; 22:166–72.
- Uestün, TB., Chatterji, S. and Kostanjsek, N. (2004). Comments from WHO for the Journal of Rehabilitation Medicine Special Supplement on ICF core sets. *Journal of Rehabilitation Medicine*; 44:7-8.
- United States Census Bureau. (2004). International Data Base. Retrieved May 19, 2008, from <http://www.cureresearch.com/s/stroke/stats-country.htm>.

Üstün, T., Chatterji, S., Bickenbach, J., Kostanjsek, N. and Schneider, M. (2003). The international classification of functioning, disability and health: A new tool for understanding disability and health. *Disability Rehabilitation* ; 25(11-12):565-571.

Üstün, T., Chatterji, S., Kastanjsek, N., Schnieder, M. and Bickenbach, J. (2003). WHO's ICF and functional status information in health records. *Health Care Financing Review*, 24, 77-88.

Ustun, T.B., Kostanjsek, N., Chatterji, S. and Rehm, J. (2010). Measuring health and disability. Manual for the World Health Organisation Disability Assessment Schedule WHODAS 2.0. Geneva: *World Health Organization*; 2010.

Üstün, T.B., Kostanjsek, N., Chatterji, S. and Rehm, J. (2010). World Health Organization Disability Assessment Schedule II (WHO DAS II): development, psychometric testing and applications. *Bulletin of the World Health Organization*, in press.

Van Peppen, RPS., Hendriks, HJM., Van Meeteren, NLU., Helders, PJM. and Kwakkel, G. (2007). The development of a clinical practice stroke guideline for physiotherapists in The Netherlands: A systematic review of available evidence. *Disability Rehabilitation*; 29:767-783.

Varona, J. F., et al. (2004), 'Long-term prognosis of ischemic stroke in young adults. Study of 272 cases', *Journal of Neurology*, 251 (12), 1507-14.

Vestling, M., Tufvesson, B. and Iwarsson, S. (2003). Indicators for Return to Work after Stroke and the Importance of Work for Subjective Well-being and Life Satisfaction. *Journal of Rehabilitation Medicine* 35: 127-131.

Vincent, C., Deaudelin, I., Robichaud, L., Rousseau, J., Viscogliosi, C. and Talbot L.R., et al. (2007). Rehabilitation needs for older adults with stroke living at home: perceptions of four populations. *BMC Geriatrics*; 7(20):1–17.

Visagie, S. (2008). *Outcome-Orientated Rehabilitation*. Class Notes. Tygerberg: University of Stellenbosch.

Visser-Keizer, A. C., Meyboom-de Jong, B., Deelman, B. G., Berg, I. J. and Gerritsen, M. J. (2002). Subjective Changes in Emotion, Cognition and Behavior after Stroke: Factors Affecting the Perception of Patients and Partners. *Journal of Clinical and Experimental Neuropsychology*, 24 (8), 1032-1045.

Visser-Meily, JM., Post, MW., Riphagen, II. and Lindeman E. (2004). Measures used to assess burden among caregivers of stroke patients: a review. *Clinical Rehabilitation* 18(6):601-23.

Viitanen, M., Fugl-Meyer, K.S., Bernspang, B. and Fugl-Meyer, A.R. (1988). Life satisfaction in long-term survivors after stroke. *Scandinavian Journal of Rehabilitation Medicine*; 20:17-24.

Wade ,D.T. and Halligan, P. (2003): New wine in old bottles: the World Health Organization International Classification of Functions, health and disability as an explanatory model of human behavior. *Clinical Rehabilitation* 17, 349-354.

Wade, DT. and De Jong BA (2000). Recent advances in rehabilitation. *British Medical Journal*, 320(7246):1385-1388.

Walker, C.M. Walker M.F. and Sunderland A. (2003). Dressing after a Stroke: A survey of Current Occupational Therapy Practice. *British Journal of Occupational Therapy*: 66(6) 263-268.

Walker, C.M. Walker M.F. and Sunderland A. (2004). The Impact of Cognitive Impairment on Upper Body Dressing Difficulties after Stroke: A Video Analysis of Patterns of Recovery. *Journal of Neurology Neurosurgery Psychiatry*: 75 (1), 43-48.

Warlow, C.P., Dennis, M.S. and Van Gijn, J., *et al.* (2001). Stroke: a Practical Guide to Management. 2nd edition. Oxford: *Blackwell Science*, 2001.

Wasserman, S., De Villiers, L. and Bryer, A. (2009). Community-based care of stroke patients in a rural African setting. *South African Medical Journal*, 99(8):579-583.

Western Cape (South Africa) Department of Health. (2007). Comprehensive Service Plan for the Implementation of Healthcare 2010. [Online]. Available: www.capegateway.gov.za/eng/your_gov/305. [Accessed 2010, July 13].

Western, H. (2007). Altered Living: Coping, Hope and Quality of Life after Stroke. *British Journal of Nursing* 16 (20): 1266-1270.

Wilkinson, PR., Wolfe, CD., Warburton, FB., Rudd, AG., Ross Russell, RW. and Beech, RR. (1997). A long-term follow-up of stroke patients. *Stroke*; 28: 507-512.

Wolfenden, B. and Grace, M., (2009). Returning to Work after Stroke: A Review. *International Journal of rehabilitation research* 32(2): 93-97.

Wolfe, CD. And Burney PG. (1992). Is stroke mortality on the decline in England? *American Journal of Epidemiology*; 136(5): 558-565.

World Confederation for Physical Therapy (2010). Description of Physical Therapy: what is Physical Therapy? London, UK.

World Health Organisation. (1996). WHOQOL-BREF, Introduction, administration, scoring and generic version of the assessment. Geneva: World Health Organisation.

World Health Organisation Department of Child and Adolescent Health and Development (2005). The current evidence for the burden of groups streptococcal diseases, Discussion papers on child health. Geneva: World Health Organisation.

World Health Organisation Expert Committee on Medical Rehabilitation. (1969). Second report. *World Health Organisation Technical Report Series*, 419:1-23.

World Health Organisation (2001). International Classification of Functioning, Disability and Health: Internal Classification of Functions, Disability and Health. World Health Organisation; Geneva, Switzerland.

World Health Organisation (2002). The World Health Report: Reducing risks, promoting healthy life. World Health Organisation.

World Health Organisation (2005). Surveillance of chronic disease risk factors: Country – level data and comparable estimates. *The SuRF Report 2*. Geneva: WHO.

World Health Organisation (2008): The International Classification of Functioning, Disability and Health Geneva: World Health Organisation.

World Health Organisation (2009). Geneva: World Health Organisation; 2009e.

World Health Organisation Quality of Life group (1998). Development of the World Health Organisation; WHOQOL-BREF quality of life assessment. *Psychology Medicine*; 28:551–558.

World Health Organisation Monica Project Investigators (1988). The World Health Organisation Monica Project; monitoring trends and determinants in cardiovascular disease.

World Health Organisation Monica Project Investigators (1988). The World Health Organisation Monica Project; monitoring trends and determinants in cardiovascular disease. *Journal of Clinical Epidemiology* 41; 105-114.

Wunsch, D. and Risser, R., (2002). Lebensqualität: Definitionen – Konzepte (Life quality – definition and concepts). Referat am BDP-Kongress für Verkehrspsychologie, Regensburg.

Wyller, T.B., Holmen, J., Laake, P. and Laake, K. (1998). Correlates of subjective well-being in stroke patients. *Stroke* 29: 363-367.

Young, J. and Forster, A. (2007). Review of Stroke Rehabilitation.11 *British Medical Journal*, 334:86-90.

Zhang, W., Dewey, H., Cadilhac, D. and Donnan, G. (2011). Emerging Risk Factors for Stroke. *The Journal of Clinical Medicine*. Modern Medicine, 36(2):22-26.

APPENDIX A



STRATEGY & HEALTH SUPPORT

Health.Research@westerncape.gov.za
tel: +27 21 483 6857; fax: +27 21 483 9895
5th Floor, Norton Rose House,, 8 Riebeeck Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: RP 017/2013
ENQUIRIES: Ms Charlene Roderick

University of the Western Cape
Modderdam Road
Bellville
7535

For attention: **Prof Anthea Rhoda**

Re: Development of a community-based programme to address the participation restrictions experienced by stroke patients in urban and peri-urban communities in South Africa

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.

Please contact the following people to assist you with any further enquiries in accessing the following sites:

Kleinvlei CHC	Mr Johnathan	Contact No. 021- 904 3421
Macassar CHC	Ms C Alexander	Contact No. 021-857 2330
Strand CHC	Ms L Lube	Contact No. 021-853 3380
Khayelitsha CHC	Mr M Tuta	Contact No. 021-361 4835
Michael M CHC	Ms JN Matiyela	Contact No. 021- 361 3353
Nolungile CHC	Mrs Mqikela	Contact No. 021-387 1107

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final report within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

APPENDIX B

OFFICE OF THE DEAN DEPARTMENT OF RESEARCH DEVELOPMENT

Private Bag X17, Bellville 7535, South Africa T: +27 21 959 2988/2948 . F: +27 21 959 3170 E: pjosias@uwc.ac.za
www.uwc.ac.za

13 August 2013

To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape approved the methodology and ethics of the following research project by
Ms I Arowoiya (Physiotherapy)

Research Project: Participation restriction and quality of life of stroke patients living in the community at selected community health centers in the metro pole districts, Western Cape, South Africa

Registration no: 13/6/32

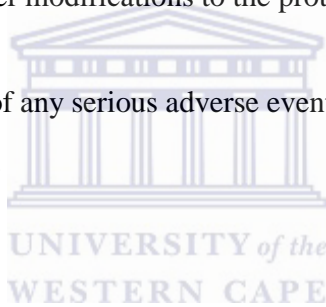
Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias

Research Ethics Committee Officer

University of the Western Cape.



APPENDIX C

WHODAS 2.0

36
Interview

World Health Organisation
Disability Assessment Schedule 2.0

This questionnaire contains the interviewer-administered 36-item version of WHODAS 2.0.

Instructions to the interviewer are written in bold and cursive – do not read this aloud.

Text for the respondent to hear is written in standard blue text.

Read this text aloud.

Section 1 Main Page

Complete items F1-F5 before the start of every interview

F1	Respondent identity number			
F2	Interviewer identity number			
F3	Assessment time score (1, 2 etc)			
F4	Interview date	_____	_____	_____
		date	month	year
F5	Living situation during time of interview (only circle one)	Independent in society	1	
		Assisted	2	
		Hospitalised	3	

Section 2 Demographic and background information

This interview is developed by the World Health Organisation (WHO) to better understand problems that people can have as a result of their health condition. The information that you provide in this interview is confidential and will only be used for research. The interview will take 15-20 minutes to complete.

For respondents from the general population (not clinical population) say:

Even if you are healthy and have no problems, it is necessary for me to ask all the questions so that the survey is complete.

I will begin with a few background questions.

A1	Document gender as observed	Female	1
		Male	2
A2	How old are you now?	_____years	
A3	How many years did you study at school, college or university?	_____years	
A4	What is your current marital status (Choose one best option)	Never married	1
		Currently married	2
		Separated	3
		Divorced	4
		Widowed	5
		Living together	6
A5	What describes your primary work status the best? (Choose one best option)	Paid work	1
		Self employed, you run your own business or farm	2
		Non-paying work, e.g. voluntary or charity	3
		Student	4
		Manage home / homemaker	5
		Retired	6
		Unemployed (health reasons)	7
		Unemployed (other reasons)	8
Other (specify) _____	9		

Section 3 Preamble

Say to the respondent:

This interview is about the problem that people have as a result of health conditions.

Hand flash card #1 to the respondent and say:

By health conditions I mean illness, or other health problems that are short or long term; injuries, mental or emotional problems and problems with alcohol or drugs.

Remember to bear in mind all your health problems as you answer the questions. When I ask you about the problem in the performance of an activity, think about....

Point to flashcard # 1 and explain that “problems with an activity” means:

- More effort
- Discomfort or pain
- Sluggish
- Change in the way you do an activity

Say to the respondent:

When you answer, I want you to think back over the past 30 days. I also want you to answer these questions while thinking about how many problems you had, on average, over the past 30 days while you are performing the activity as usual.

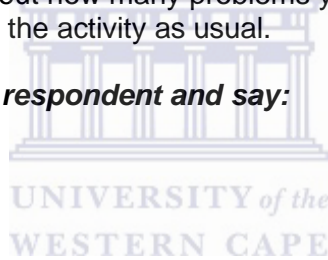
Hand over flash card # 2 to the respondent and say:

Use this scale when answering

Read the scale aloud:

None, light, moderate, serious, extreme or cannot do it.

Ensure that the respondent can easily see flash cards # 1 and #2 during the interview.



Section 4 Domain reviews

Domain 1 Cognition

I am now going to ask a few questions about understanding and communication.

Show flash cards #1 and #2 to the respondent

In the past 30 days have you experienced problems with the following:		None	Mild	Moderate	Serious	Extreme or cannot do it
D1.1	Concentration and doing something within 10 minutes?	1	2	3	4	5
D1.2	Remember to do something important?	1	2	3	4	5
D1.3	Analysis and solving of daily problems?	1	2	3	4	5
D1.4	To learn something new, e.g. to get to a new place?	1	2	3	4	5
D1.5	To generally understand what people are saying?	1	2	3	4	5
D1.6	To start a conversation and continue with it / not wander off?	1	2	3	4	5

Domain 2 Mobility

I am now going to ask about difficulty with moving around

Show flash cards #1 and #2

How much difficulty have you experienced in the last 30 days with:		None	Mild	Moderate	Serious	Extreme or cannot do it
D2.1	To stand for at least 30 minutes?	1	2	3	4	5
D2.2	To get up after sitting?	1	2	3	4	5
D2.3	To move around in the house?	1	2	3	4	5
D2.4	To leave the house?	1	2	3	4	5
D2.5	To walk for a long distance, e.g. 1 kilometre (or less than 1 kilometre)	1	2	3	4	5

Please go to the next page.....

Domain 3 Self care

I am going to ask you questions about difficulties with caring for yourself.

Show flash cards #1 and #2

In the past 30 days how much difficulty have you experienced in:		None	Mild	Moderate	Serious	Extreme or cannot do it
D3.1	Washing your body?	1	2	3	4	5
D3.2	Getting dressed?	1	2	3	4	5
D3.3	Eating?	1	2	3	4	5
D3.4	Stay by yourself for a few days?	1	2	3	4	5

Domain 4 Getting along with other people

I am now oing to ask you about difficulty with getting along with other people. Please remember that I am only asking questions in terms of health problems. By that I mean illness, injuries, mental or emotional problems, as well as problems with alcohol and drugs.

Show flash cards # 1 and #2

In the past 30 days, how much difficult have you in experienced in:		None	Mild	Moderate	Serious	Extreme or cannot do it
D4.1	Get along with strangers?	1	2	3	4	5
D4.2	Maintain a friendship	1	2	3	4	5
D4.3	Get along with people close to you?	1	2	3	4	5
D4.4	Make new friends?	1	2	3	4	5
D4.5	Sexual activity?	1	2	3	4	5

Please continue to the next page...

Domain 5 Life activities

5(1) Domestic activities

I am now going to ask you questions about activities regarding the maintenance of your household, and care of people who you live with or who are close to you. These activities include cooking, cleaning, caring for others and looking after your own interests.

Show flash cards #1 and #2

As a result of your health condition, in the past 30 days, how much difficulty have you experienced in:		None	Mild	Moderate	Serious	Extreme or cannot do it
D5.1	Taking care of your domestic responsibilities?	1	2	3	4	5
D5.2	Do you do the most important domestic chores well?	1	2	3	4	5
D5.3	Complete all the domestic chores that must be done?	1	2	3	4	5
D5.4	Complete all the domestic chores as quickly as possible?	1	2	3	4	5

In case any of D5.2 – D5.5 is rated greater than none (written as 1) ask:

D5.01	In the past 30 days, how many days have you decreased or totally left your domestic work as a result of your health condition?	Indicate how many days: —
-------	--	-------------------------------------

If the respondent works (paid, non-paying, self employed) or goes to school, complete questions D5.5 – D5.10 on the following page. Otherwise go to D6.1 on the following page.

5(2) Work or school activity

Now I am going to ask you a few questions about your work or school activities

Show flash card #1 and #2

As a result of your health condition, in the past 30 days, how much difficulty have you experienced with the following:		None	Mild	Moderate	Serious	Extreme or cannot do it
D5.5	Your day to day at work / school?	1	2	3	4	5
D5.6	To complete the most important tasks at work / school	1	2	3	4	5
D5.7	To complete the work that you have to do?	1	2	3	4	5
D5.8	To complete the work as soon as possible?	1	2	3	4	5
D5.9	Do you have to work at a lower level as a result of your health condition?				No	1
					Yes	2
D 5.10	Do you earn less money as a result of your health condition?				No	1
					Yes	2

In case any of D5.5 – D5 is rated greater than none (written as “1”), ask:

D5.02	In the past 30 days, how many days have you missed half a day, or more, as a result of your illness?	Indicate how many days —
-------	--	------------------------------------

Please go to the next page.....

Domain 6 Participation

Now I am going to ask you about your participation in society, and the impact that your health problems have had on you and your family. Some of these questions may contain problems that have lasted longer than the past 30 days, take note during answering, focus on the past 30 days. Again, be reminded to keep in mind health problems when you answer the questions: physical, mental or emotional, alcohol or drug related.

Show flash card #1 and #2

In the past 30 days:		None	Mild	Moderate	Serious	Extreme or cannot do it
D6.1	How much of a problem is it for you to participate in social activities (e.g. festivities, faith and other)	1	2	3	4	5
D6.2	How much of a problem is the obstacles in the world around you?	1	2	3	4	5
D6.3	How much of a problem is for you to feel worthy as a result of the attitude of other people?	1	2	3	4	5
D6.4	How much time have you spent on your health condition or a result thereof?	1	2	3	4	5

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D6.5	How severely were you affected emotionally as a result of your health condition?	1	2	3	4	5
D6.6	To what degree has your health condition placed financial pressure on you and your family?	1	2	3	4	5
D6.7	u gesondheidstoestand? How much of problem has your family experienced as a result of your health condition?	1	2	3	4	5
D6.8	Hoeveel van 'n probleem is dit vir u om te ontspan? How much of a problem is it for you to relax?	1	2	3	4	5

H1	In general, in the past 30 days, how many days were these difficulties present?	Indicate how many days
----	---	-------------------------------

H2	In general, to what degree has this problem affected your lifestyle?	Not at all	Reasonable	Moderate	Difficult / Serious	Very serious
H3	How many days, in the past 30 days, has this problem been present?	RECORD OF NUMBER OF DAYS ____/ ____				
H4	In the past 30 days, how many days in total was it impossible for you to do your tasks as a result of your health condition?	RECORD OF NUMBER OF DAYS ____/ ____				
H5	In the past 30 days, how many days did you have to lessen your workload as a result of your health condition?	RECORD OF NUMBER OF DAYS ____/ ____				

This concludes the interview. Thank you for your participation.

Health Conditions:

- Illness, or other health problems which are short- or long term
- Injuries
- Mental or emotional problems
- Problems with alcohol
- Problems with drugs

Problems with an activity means:

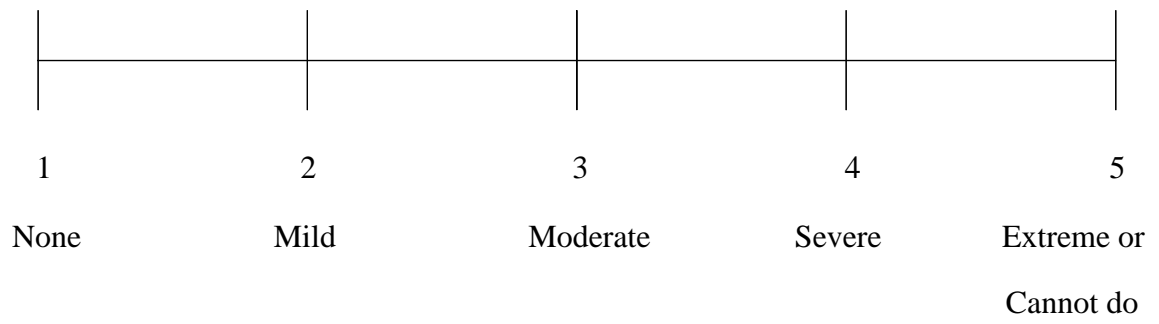
- More effort
- Discomfort or pain
- Sluggish
- Change in the way that you perform an activity

Think only of the past 30 days.



WHODAS 2.0

Flash Card 2.0



APPENDIX D

Wereld Gesondheidsgestremdeheidsasseseringskedule II

Fase 2 Veldproewe – Navorsing in Gesondheidsdienste

36-Item Selfgeadministreerde voorstelling

H1	Waar plaas u u gesondheid die afgelope 30 dae?	Baie goed	Goed	Matig	Sleg	Baie sleg
----	--	-----------	------	-------	------	-----------

Hierdie vraelys is gebaseer op die graad van u gesondheidstoestand.

Gesondheidstoestande sluit in siektes/kwale, ander lang-/korttermyn gesondheidsprobleme, beserings, geestes- en emosionele probleme en probleme met alcohol en dwelmmiddels.

Dink terug, oor die afgelope 30 dae, hoe moeilik dit vir u was om die volgende aktiwiteite te doen. Omkring slegs een antwoord.

Wat was die moeilikheidsgraad die afgelope 30 dae in:						
	<u>Verstaan en kommunikeer</u>					
D1.1	Konsentrasie en iets binne 10 minute te doen?	Glad nie	Sleg	Matig	Moeilik/erg	Baie erg/Kan nie
D1.2	Onthou om belangrike dinge te doen?	Glad nie	Sleg	Matig	Moeilik/erg	Baie erg/Kan nie
D1.3	Ontleding en oplossing van daaglikse probleme te vind?	Glad nie	Sleg	Matig	Moeilik/erg	Baie erg/Kan nie
D1.4	Om iets nuuts te leer bv. Hoe om tot by 'n nuwe plek uit te kom?	Glad nie	Sleg	Matig	Moeilik/erg	Baie erg/Kan nie
D1.5	Om oor die algemeen te verstaan wat mense se?	Glad nie	Sleg	Matig	Moeilik/erg	Baie erg/Kan nie
D1.6	Om 'n gesprek te begin en daarmee vol te hou/nie af te dwaal nie?	Glad nie	Sleg	Matig	Moeilik/erg	Baie erg/Kan nie
<u>Oor die weg te kom</u>						
D2.1	Om vir ten minste 30 minute te staan?	Glad nie	Sleg	Matig	Moeilik/erg	Baie erg/Kan nie
D2.2	Om op te staan nadat u gesit het?	Glad nie	Sleg	Matig	Moeilik/erg	Baie erg/Kan nie
D2.3	Om in die huis rond te beweeg?	Glad nie	Sleg	Matig	Moeilik/erg	Baie erg/Kan nie
D2.4	Om uit die huis te gaan?	Glad nie	Sleg	Matig	Moeilik/erg	Baie erg/Kan nie
D2.5	Om vir 'n lang afstand te loop. Bv. 1 kilometer (of min of meer 1 kilometer)	Glad nie	Sleg	Matig	Moeilik/erg	Baie erg/Kan nie

	<u>Selfsorg</u>					
D3.1	Om u liggaam te was?	Glad nie	Sleg	Matig	Moeilik/ erg	Baie erg/Kan nie
D3.2	Om u aan te trek?	Glad nie	Sleg	Matig	Moeilik/ erg	Baie erg/Kan nie
D3.3	Om te eet?	Glad nie	Sleg	Matig	Moeilik/ erg	Baie erg/Kan nie
D3.4	Om vir 'n paar dae alleen te bly?	Glad nie	Sleg	Matig	Moeilik/ erg	Baie erg/Kan nie
	<u>Om oor die weg te kom met mense</u>					
D4.1	Oor die weg kom met onbekendes?	Glad nie	Sleg	Matig	Moeilik/ erg	Baie erg/Kan nie
D4.2	'n Vriendskap in stand hou?	Glad nie	Sleg	Matig	Moeilik/ erg	Baie erg/Kan nie
D4.3	Oor die weg kom met mense na aan jou?	Glad nie	Sleg	Matig	Moeilik/ erg	Baie erg/Kan nie
D4.4	Om nuwe vriende te maak?	Glad nie	Sleg	Matig	Moeilik/ erg	Baie erg/ Kan nie
D4.5	Seksuele aktiwiteite?	Glad nie	Sleg	Matig	Moeilik/ erg	Baie erg/Kan nie
	<u>Lewensaktiwiteite</u>					
D5.1	Sien om na u huislike verantwoordelikheid?	Glad nie	Sleg	Matig	Moeilik/ erg	Baie erg/Kan nie
D5.2	Doe die belangrikste huistakies goed?	Glad nie	Sleg	Matig	Moeilik/ erg	Baie erg/Kan nie
D5.3	Voltooi alle huistakies wat gedoen moes word?	Glad nie	Sleg	Matig	Moeilik/ erg	Baie erg/Kan nie
D5.4	Voltooi alle huistakies so gou moontlik?	Glad nie	Sleg	Matig	Moeilik/ erg	Baie erg/Kan nie

VOLTOOI ASSEBLIEF DIE VRAE D5.5 – D5.8 HIERONDER AS U WERK (BETAALD, ONBETAALD, ENTREPRENEUR/IN EIE DIENS OF SKOOLGAAN), ANDERSINS SLAAN OOR NA D6.1 NET DAARNA.

	In die laaste 30 dae, hoe moeilik was:					
D5.5	U dag tot dag by die werk/skool?	Glad nie	Sleg	Matig	Moeilik /erg	Baie erg/Kan nie
D5.6	Dit om die belangrikste take by die werk/skool te doen?	Glad nie	Sleg	Matig	Moeilik /erg	Baie erg/Kan nie
D5.7	Om die werk te voltooi wat u gekry het om te doen?	Glad nie	Sleg	Matig	Moeilik /erg	Baie erg/Kan nie
D5.8	Om die werk klaar te kry so gou moontlik?	Glad nie	Sleg	Matig	Moeilik /erg	Baie erg/Kan nie



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	In die laaste 30 dae:					
	<u>Deelname in die samelewing</u>					
D6.1	Hoeveel van 'n probleem is dit vir u om deel te neem aan gemeenskapsaktiwiteite (bv. feestelikhede, geloof-en ander aktiwiteite) meer as wat dit vir ander persone is?	Glad nie	Sleg	Matig	Moeilik /erg	Baie erg/Kan nie
D6.2	Hoeveel van 'n probleem is die struikelblokke in die wereld rondom u vir u?	Glad nie	Sleg	Matig	Moeilik /erg	Baie erg/Kan nie
D6.3	Hoeveel van 'n probleem is dit vir u, as gevolg van die houding van ander mense, om waardig/deftig te wees?	Glad nie	Sleg	Matig	Moeilik /erg	Baie erg/Kan nie
D6.4	Hoeveel tyd het u op u gesondheidstoestand of die gevolge daarvan spandeer?	Glad nie	Sleg	Matig	Moeilik /erg	Baie erg/Kan nie
D6.5	In hoe 'n mate het u gesondheidstoestand finansiële druk op u en die familie geplaas?	Glad nie	Sleg	Matig	Moeilik /erg	Baie erg/Kan nie
D6.6	Hoeveel van 'n probleem het u familie gehad as gevolg van u gesondheidstoestand?	Glad nie	Sleg	Matig	Moeilik /erg	Baie erg/Kan nie
D6.7	Hoeveel van 'n probleem is dit vir u om te ontspan?	Glad nie	Sleg	Matig	Moeilik /erg	Baie erg/Kan nie

H2	In die algemeen, tot hoe 'n mate het hierdie probleem met u leefwyse ingemeng?	Glad nie	Redelik	Matig	Moeilik/erg	Baie erg
H3	Hoeveel dae, uit die afgelope 30 dae, was hierdie probleem teenwoordig?	REKORD VAN AANTAL DAE ___/___				
H4	Uit die afgelope 30 dae, hoeveel dae in totaal, was dit vir u onmoontlik om u takies as gevolg van u gesondheidstoestand te doen?	REKORD VAN AANTAL DAE ___/___				
H5	Uit die afgelope 30 dae, hoeveel dae moes u u werkslading as gevolg van u gesondheidstoestand verminder?	REKORD VAN AANTAL DAE ___/___				

APPENDIX E

IShedyuli yoVavanyo lwesi-II loKhubazeko loMbutho wezeMpilo eHlabathini

Amalinge enziwa ngaPhandle eSigaba sesi-2 – uPhando lweeNkonzo zeMpilo uHlelo lokuziPhatha lweMibandela engama-36

H1	Ingaba ungayikalisha njani <u>impilo yakho iyonke kwezi ntsuku ezingama-30 zidlulileyo?</u>	Intle kakhulu	Intle	Iphakathi	Imbi	Imbi kakhulu
----	---	---------------	-------	-----------	------	--------------

Olu ludwe lwemibuzo lukubuza malunga nobunzima obubangelwa ziimeko zempilo. Iimeko zempilo ziquka isifo okanye izigulo, naziphi na iingxaki zempilo ezinokuhlala ixesha elifutshane okanye elide, ukwenzakala, iingxaki zengqondo okanye zovakalelo, kunye neengxaki ezingotywala okanye ezingeziyobisi.

Cinga emva kwiintsuku ezingama-30 ezidlulileyo uze uphendule le mibuzo ucinga malunga nokuba ingaba bungakanani na ubunzima obe unabo ekwenzeni le misetyenzana ilandelayo. Ngombuzo ngamnye, nceda wenze isangqa kwimpendulo enye kuphela.

Kwiintsuku ezingama-30 ezidlulileyo, bungakanani ubunzima obe unabo:						
	<u>Ekuqondeni nasekuqhagamshelaneni</u>					
D1.1	Ukuzikisa ingqondo ekwenzeni into kangangemizuzu elishumi?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/ Abenzeki
D1.2	Ukukhumbula ukwenza izinto ezibalulekileyo?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/ Abenzeki
D1.3	Ukuhlalutya nokufumana izisombululo kwiingxaki zobomi bemihla ngemihla?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/ Abenzeki
D1.4	Ukufunda umsebenzi omtsha, umzekelo, ukufunda ukufumana indawo entsha?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/ Abenzeki
D1.5	Ukuqonda into abayitsho ngokuthe gabalala abanye abantu?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/ Abenzeki
D1.6	Ukuqalisa nokulondoloza incoko?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/ Abenzeki
	<u>Ukuhamba-hamba</u>					
D2.1	Ukuma amaxesha amade njengemizuzu engama-30?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/ Abenzeki
D2.2	Ukuma ngeenyawo ungahlali phantsi?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/ Abenzeki

D2.3	Ukuhamba-hamba ngaphakathi ekhayeni lakho?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/Abenzeki
D2.4	Ukuphumela ngaphandle ekhayeni lakho?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/Abenzeki
D2.5	Ukuhamba umgama omde njengekhilomitha (okanye elingana nayo)?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/Abenzeki
Kwiintsuku ezingama-30 ezidlulileyo, bungakanani ubunzima obe unabo:						
<u>Ekuzikhathaleleni</u>						
D3.1	Ukuhlamba umzimba wakho wonke?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/Abenzeki
D3.2	Ukuzinxibisa?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/Abenzeki
D3.3	Ukutya?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/Abenzeki
D3.4	Ukuzihlalela uwedwa kangangeentsuku ezimbalwa?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/Abenzeki
<u>Ekuvaneni nabanye abantu</u>						
D4.1	Ukwabelana nabantu ongabaziyo?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/Abenzeki
D4.2	Ukulondoloza ubuhlobo?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/Abenzeki
D4.3	Ukuvana nabantu abakufuphi kuwe?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/Abenzeki
D4.4	Ukwenza abahlobo abatsha?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/Abenzeki
D4.5	Ukwenza isondo?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/Abenzeki

	<u>Imisetyenzana yoBomi</u>					
D5.1	Ukukhathalela uxanduva lwendlu yakho?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/ Abenzeki
D5.2	Ukuyenza kakuhle eyona misebenzi ibalulekileyo yasendlwini?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/ Abenzeki
D5.3	Ukwenza wenziwe wonke umsebenzi wendlu ekudingeka wenziwe?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/ Abenzeki
D5.4	Ukwenza wenziwe wonke umsebenzi wendlu ngokukhawuleza njengoko kudingeka njalo?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/ Abenzeki

UKUBA UYASEBENZA (UYAHLAWULWA, AWUHLAWULWA, UZIQESHE NGOKWAKHO) OKANYE UHAMBA ISIKOLO, GQIBEZELA IMIBUZO ENGAPHANTSI KU-D5.5-D5.8. KUNGENJALO, TSIBA UYE KU-D6.1 NGAPHANTSI.

	Kwiintsuku ezingama-30 ezidlulileyo, bungakanani ubunzima obe unabo:					
D5.5	Kumsebenzi/kwisikolo sakho semihla ngemihla?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/ Abenzeki
D5.6	Ukuyenza kakuhle eyona misebenzi ibalulekileyo yasemsebenzini/esikolweni?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/ Abenzeki
D5.7	Ukuwenza wenziwe wonke umsebenzi ekudingeka wenziwe?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/ Abenzeki
D5.8	Ukwenza wenziwe umsebenzi wakho ngokukhawuleza njengoko kudingeka njalo?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/ Abenzeki

	Kwiintsuku ezingama-30 ezidlulileyo:					
	<u>Ukuthatha inxaxheba ekuhlaleni</u>					
D6.1	Ube nengxaki engakanani ukujoyina kwimisetyenzana yasekuhlaleni (umzekelo, kwimibhiyozo, kwimicimbi yezenkolo okanye eminye) ngendlela efanayo njengoko nomnye umntu enako ukwenza?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/ Abenzeki
D6.2	Ube nengxaki engakanani ngenxa yemiqobo okanye izithintelo ezikwihlabathi elikungqongileyo?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/ Abenzeki
D6.3	Ube nengxaki engakanani ukuphila ngondiliseko ngenxa yezimvo nezenzo zabanye abantu?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/ Abenzeki
D6.4	Lingakanani ixesha olichithe kwimeko yakho yezempilo,	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/ Abenzeki

	okanye iziphumo zayo?					
D6.5	Ingaba impilo yakho ibe yephelelisa amandla njani kwizibonelelo zezemali zakho okanye zosapho lwakho?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/Abenzeki
D6.6	Ingaba usapho lwakho lube nengxaki engakanani ngenxa yeengxaki zempilo yakho?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/Abenzeki
D6.7	Ube nengxaki engakanani ekuzenzeleni izinto zokuzonwabisa okanye zokuphola ngokwakho?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/Abenzeki

H2	Ngokukonke, ingaba ezi nzima ziphazamisene njani nobomi bakho?	Nakanye	Ngokuncinci	Ngokuphakathi	Ngokukhulu	Ngokugaba deleyo
H3	Ngokukonke, kwiintsuku ezingama-30 ezidlulileyo, ingaba ezi nzima bezikho iintsuku ezingaphi?	REKHODA INANI LEENTSUKU ____/____				
H4	Kwiintsuku ezingama-30 ezidlulileyo, zingaphi iintsuku apho ubungenako ngokupheleleyo ukwenza imisetyenzana okanye umsebenzi wakho wesiqhelo ngenxa yayo nayiphi na imeko yempilo?	REKHODA INANI LEENTSUKU ____/____				
H5	Kwiintsuku ezingama-30 ezidlulileyo, ungazibali iintsuku apho ubungenako ngokupheleleyo, zingaphi iintsuku apho ubuyekisa okanye ubunciphisa imisetyenzana okanye umsebenzi wakho wesiqhelo ngenxa yayo nayiphi na imeko yempilo?	REKHODA INANI LEENTSUKU ____/____				

Oku kukuphela koludwe lwemibuzo. Enkosi.

APPENDIX F

<i>Please fill and hand in this form. Do not indicate your name.</i>								
S/No.	PART A: Demographic and Background information							
1.	Gender	Male	1.		Female			2.
2.	Which is your age bracket	15-24 years	25-34 years	35-44 years	45-54 years	Over 54 years		
3.	Highest level of formal education	None						
		Primary						
		Secondary						
		Vocational Training						
		College						
		University						
4.	Reason for not completing next higher level of education.	a) Lost interest b) Nobody to assist in movement c) Lack of instructor d) Lack of fees Others specify						
5.	What is your current marital status?	Single			1.			
		Married			2.			
		Separated			3.			
		Divorced			4.			
		Windowed			5.			
		Cohabiting			6.			
		Other			7.			
6.	What describes your current work status best?	Paid work			1.			
		Self-employed, such as own your business or farming			2.			
		Non-paid work, e.g. volunteer/ charity			3.			
		Student			4.			
		Housekeeping /house maker			5.			
		Retired			6.			
		Unemployed (health reasons)			7.			
		Unemployed (other reasons)			8.			
		Other specify.....			9.			
7.	Living situation	Independent in community			1.			

			Assisted living	2.
			Hospitalized	3.

Part B: Questions for Focus group discussion

Cognition

1. As an individual, what can you say concerning your understanding under 10mins?
 - a. Please elaborate on this point?
 - b. Communication within 10mins?
 - c. Please clarify?
2. As a member of this group, how easy can you communicate well with an individual?
 - a. What else?

Mobility

3. As a member of this group, what can you say concerning
 - a. Moving around? Please clarify?
 - b. Standing for long period? Please clarify?
 - c. Walking for a long distance? Please clarify?
4. As an individual, what can you say concerning your getting out of your home?
 - a. Please elaborate?

Self – care

5. As a member of this group, have you encountered limitation with
 - a. Getting dressed?
 - b. Staying by yourself?
 - c. Washing the whole body?
 - d. Eating?

Getting Along

6. As an individual, how easy do you find making new friends?
 - a. Please elaborate?
7. As a member of this group, what can you say concerning your sexual activities /life?
 - a. Please elaborate?
8. As an individual, what can you say concerning maintaining a friendship?
 - a. Please, clarify?
9. As a member of this group, how easy do you find dealing with people you don't know?
 - a. Please, clarify?

Life Activities (Household Activities)

10. As a member of this group, what can you say concerning performing
 - a. Household responsibilities?
 - b. Getting household work done quickly?
 - c. Doing your most important household?

- d. Getting household work done?

Life Activities (Study/Work Activity)

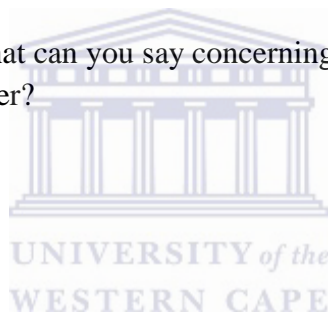
- 11. As a member of this particular group, what can you say concerning your work?
 - a. Please clarify?

Participation

- 12. As an individual with similar challenges, what can you say concerning
 - a. Emotional impact of health condition? What else?
 - b. Impact on family? Elaborate?
 - c. Barriers or hindrances in the environment? Like?
 - d. Time spent on health condition? Please clarify?
 - e. Financial impact of Health condition? Why?
 - f. Relaxation & Pleasure? Please, clarify?
 - g. Joining in community activities? What else?
 - h. Living with dignity cause of health condition? Please clarify?

Overall

- 13. In your day to day life, what can you say concerning your health overall?
 - a. Please, elaborate further?



APPENDIX G

<i>Vul vorm uit en handig in. moet nie jou naam aan dui nie</i>						
S/No	Afdeeling A: demografiese en agtergrond inligting					
8.	Geslag	Manlik	3.			
		Vroulik	4.			
9.	Wat is u ouderdomsgroep ?	15-24 jare	25-34 jare	35-44 jare	45-54 jare	Over 54 jare
10.	Hoogste vlak van formele opleiding	Geen				
		Primere				
		Sekondere				
		Beroeps opleiding				
		Kollege				
		Universiteit				
11.	Rede dat u nie die volgende vlak van opleiding voltooi het nie	e) Belangstelling verloor f) Niemand om te help nie g) Gebrek aan instrukteur h) Gebrek aan fooie Ander spesifiseer				
12.	Wat is jou huidige huwelikstatus ?	Single	8.			
		Getroud	9.			
		Vervreemed	10.			
		Geskei	11.			
		Weduwee	12.			
		Samewoning	13.			
		Ander	14.			
13.	Wat is u huidige werks status?	Betaalde werk	10.			
		Eie onderneming	11.			
		Onbetaalde werk bv. Liefdadigheids werk	12.			
		Student	13.			
		Huis bewarder	14.			
		Afgetree	15.			
		Werkloos (gesonheids redes)	16.			
		Werloos (ander redes)	17.			
		Ander spesifiseer.....	18.			

14.		Lewende situasie	Onafhandlik in die gemeenskap	4.
			Bygestaande lewe	5.
			Hospitaliliseer	6.

Afdeling B: Vrae vir fokusgroep bespreking

Kognisie

14. As n individu, wat kan u se oor jou verstand onder 10 minute
- Kan u aseblief uitbrei
 - Kommunikasie in 10 minute?
 - Verduidelik aseblief
15. As n lid van hierdie groep, hoe maklik kan u goed kommunikeer met n individu?
- Wat nog

Mobiliteit

16. As n lid van hierdie groep wat kan u se oor:
- Rondom beweeg? Verduidelik aseblief ?
 - Vir n lank tyd staan? Verduidelik aseblief ?
17. Vir n lang afstand loop? Verduidelik aseblief ?
18. As n individu, wat kan u se oor uit jou huis kom?
- Kan u aseblief uitbrei?

Self sorg

19. As n lid van hierdie groep het u beperkings gekry met die volgende:
- Antrek?
 - Allen bly?
 - Jou hele ligaam was?
 - Eating?

Vreedsaam

20. As n individu, hoe maklik is dit vir jou om vriende te maak?
- Kan u aseblief uitbrei?
21. As n lid van hierdie groep, wat kan u se oor jou seksiuele aktiwiteite/lewe?
- Kan u aseblief uitbrei?
22. As n individu, wat kan u se oor vriednskappe haanhaaf?
- Verduidelik aseblief
23. As an lid van hierdie groep, hoe maklik is dit vir jou om met mense wat jy nie ken nie te assosieer?
- Verduidelik aseblief

Lewens aktiwiteite (Huis Houding Aktiwiteite)

24. As an lid van hierdie groep wat kan u se oor die volgende uit te voor:
- Huis houdilike verantwoordlihedede?
 - Gou met jou huishoudilike werk klaar te kom?

- g. Jou belangrikste huishoudlike werk doen?
- h. Huishoudlike werk klaar te kom?

Lewens aktiwiteite (Studie/Werk Aktiwiteite)

25. As an lid van hierdie groep, wat kan u se oor jou werk
- b. Verduidelik aseblief

Deelname

26. As n individu met soosgelyke uitdagings wat kan u se oor die volgende:
- i. Emosionele impak op jou gesondheids toestand? Wat nog?
 - j. Impak op familie? Kan u aseblief uitbrei
 - k. Hindernisse in die omgewing? soos?
 - l. Tyd gespandeer op gesondheids toestande? Kan u aseblief verduidelik?
 - m. Finansiële impak van gesondheids toestand? hoekom?
 - n. Ontspanning & Plesier? Kan u aseblief verduidelik?
 - o. In gemeenskap aktiwiteite aansluit? Wat nog?
 - p. Met waardigheid oor gesondheids toestand? Kan u aseblief verduidelik?

Algehele

27. In jou lewe dag tot dag wat kan u se oor jou algehele gesondheid
- b. Kan u aseblief meer uitbrei



APPENDIX H

Sicela ugcwalise ufake le form. Uze ungalibhali igama lakho kuleform.

iS/N o.	ICANDELO A: Iincukhacha ngobuni bakho kunye nemvelaphi yakho					
15.	Sithini isini sakho?	Indoda		5.		
		Ibhinqa		6.		
16.	Khetha uba ungena kweyiphi iminyaka kule ibandakanyiweyo	Una 15-24	Una 25-34	Una 35-44	Una 45-54	Ungaph ezulu kwe 54
17.	Uye kangakanani esikolweni?	Andiyanga				
		Ndiphele ePrimary				
		Ndiphele eSecondary				
		Ndifunde emsebenzini				
		Ndiphelele eCollege				
		Ndiphelele eUniversity				
18.	Isizathu sokungasigqibi isikolo okanye ukungayi kwinqanaba eliphezulu sithini?	i) Ndaaphelelwa ngumdlala j) Kwakungekho mntu wokundincedisa ekuqhubekeni nesikolo k) Kwakungekho mntu wokundinika iingcebiso noluleko l) Kwakungekho mali yokufunda(iifiz) Chaza ezinye uba zikhona.....				
19.	Sithini isimo sakho somtshato?	Anditshatanga				15.
		Nditshatile				16.
		Sohlukene				17.
		Sawuqhawula umtshato				18.
		Ndingumhlolo okanye umhlokokazi				19.
		Ndiyahlalisana				20.
		Ezinye				21.
20.	Ungayichaza njani imo yokuphangela kwakho?	Ndinomsebenzi obhatalayo				19.
		Ndiziqashile, umzekelo ndineshishini lam				20.
		Andibhatalwa, umzekelo ndilivolontiya kumbutho okhathalela abantu abadinga uncedo okanye abahluphekileyo				21.
		Ndingumfundi				22.

			Ndineejobhu zokuklina izindlu (iithsa)	23.
			Ndidla umhlalaphantsi	24.
			Andiphangeli (ngenxa yempilo yam)	25.
			Andiphangeli (ngenxa yezinye izizathu)	26.
			Zichaze ezinye izizathu.....	27.
21.		Ungayichaza njani indawo ohlala kuyo?	Uhlala wedwa	7.
			Uhlala nomntu okanye abantu abakuncedisayo	8.
			Uhlala kwisibhedlela okanyekw iziko lempilo	9.

ICANDELO B: Imibuzo yeqela lentlanganiso yophando (IFocus group discussion)

Ukuqonda

1. Ungathetha uthini ngokuqonda kwakho izinto kangagemizuzu elishumi nangaphantsi?
 - a. Kha ucacise ngalento uyitsho ngasentla?
 - b. Uqhakamshelana nabanye abantu kangagemizuzu eyi-10 kunjani?
 - c. Kha ucacise?
2. Njenglungu lalentlanganiso okanye lweliqela, kulula kangakanani ukuqhakamshelana nabanye abantu?
 - a. Ikhona enye into ofuna uyitsho ukongeza kule ingentla?

Ukuhamba-hamba

3. Njenglungu leliqela ungathini ngezizinto zilandelayo:
 - a. Ukuhamba-hamba? Cacisa?
 - b. Ukuma ixesha elide? Cacisa?
 - c. Ukuhamba imigama emide? Cacisa?
4. Ungathi ukuphuma ekhayeni lakho kunjani kuwe?
 - a. Cacisa?

Ukukhathalela uxanduva lomzimba wakho

5. Njenglungu leliqela, ikhona imida oyifumanayo xa:
 - a. Unxiba?
 - b. Uzihlalela wedwa?

- c. Uhlamba umzimba wakho wonke?
- d. Usitya?

Ukuvana nabanye abantu

- 6. Kulula kangakanani ukwenza izihlobo ezitsha kuwe?
 - a. Cacisa?
- 7. Njengalungu leliqela okanye lentlanganiso, ungathetha uthini malungana nokwabelana ngesondo?
 - a. Cacisa?
- 8. Ungathini wena malungana nokugcina nokulondoloza ubuhlobo nezihlobo zakho?
 - a. Sicela usicacisele?
- 9. Njengalungu leliqela okanye lentlanganiso, kulula kangakanani ukusebenzisana nabantu ongabaziyo?
 - a. Sicela ucacise?

Imisebenzi yobom (Imisebenzi yasekhaya)

- 10. Njengalungu leliqela okanye lentlanganiso, ungathini malungana nokwenza lemisebenzi:
 - a. Uxanduva lwendlu?
 - b. Ukuwenza umsebenzi wasendlini ngokukhawuleza?
 - c. Ukuyenza eyona misebenzi yasendlini ibalulekileyo?
 - d. Ukuyenza uyiqqibe imisebenzi yasendlini?

Imisebenzi yobom (Isikolo/Umsebenzi)

- 11. Njengalungu leliqela okanye lentlanganiso, ungathetha uthini malungana nomsebenzi wakho?
 - a. Sicela ucacise?

Uthatho nxaxheba ezintweni

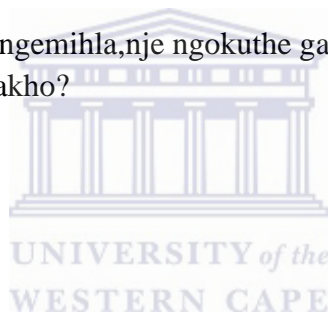
- 12. Ungathini malungana nezi zinto zilandelayo, njengamntu onemicela mngeni okanye iichallenges ezibufana :
 - a. Igalelo lwemo yokungaphili emphefumleni linjani? Ikhona enye into ofuna ukuyongeza?

- b. Igalelo lwemo yongaphili kusapho lunjani? Cacisa?
- c. Ungathini ngemida ekwindawo eyonqga umntu ongaphilanga ? Umzekelo?
- d. Igalelo lwemo yongaphili kwixesha alichitha kwimo yempilo yakhe lunjani? Cacisa?
- e. Igalelo lwemo yongaphili kwezezimali lunjani? Ngoba?
- f. Igalelo lwemo yongaphili ekwenzeni izinto zokuzipholisa nokuzonwabisa lunjani? Sicela ucacise?
- g. Igalelo lwemo yongaphili ekuzibandakanyeni kwizinto ezenzeka ekuhlaleni lunjani? Uyafuna ukongeza?
- h. Igalelo lwemo yongaphili ekuphileni impilo yakho ngondiliseko okanye ngesidima lunjani? Sicela ucacise?

Ngokuthegabala

13. Kwimpilo yakho yemihla ngemihla,nje ngokuthe gabalala, ingaba ikhona into ongayitsho malungana nempilo yakho?

- a. Sicela ucacise?



APPENDIX I
INFORMATION SHEET

Project Title: Participation Restriction of stroke patient living in the Community at selected Community Health Centres in the Metropole Districts; Western Cape, South Africa

What is this study about?

This is a research project being conducted by AROWOIYA AYORINDE IBUKUN at the University of the Western Cape. We are inviting you to participate in this research project because you are a person who have experienced stroke. The purpose of this research project is inform necessary re-integration of patients with stroke into the communities

What will I be asked to do if I agree to participate?

You will be asked to complete a questionnaire. In addition to completing the questionnaire you could also be asked to participate in a group discussion where your experiences with re-integration will be discussed. Certain stroke patients would be asked to take part in the programme that will be developed and they will be asked to complete questionnaires at the start and end of the programme. The questions that will be asked will mainly involve your ability to perform certain activities such as return to work or going out socially now that you have had a stroke.

Would my participation in this study be kept confidential?

We will do our best to keep your personal information confidential. To help protect your confidentiality, (1) your name will not be included on the survey and other collected data; (2) a code will be placed on the survey and other collected data; (3) through the use of an identification key, the researcher will be able to link your survey to your identity; and (4) only the researcher will have access to the identification key. If we write a report or article about this research project, your identity will be protected to the maximum extent possible.

What are the risks of this research?

There are no known risks associated with participating in this research project.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about the participation restrictions experienced by patients with stroke. We hope that, in the future, other people might benefit from this study through improved understanding participation restrictions experienced by stroke patients and implement programmes that could address this restrictions.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

Is any assistance available if I am negatively affected by participating in this study?

If you negatively affected by the research you will be referred to an appropriate health professional at the Community Health Center in your area.

What if I have questions?

This research is being conducted by AROWOIYA AYORINDE IBUKUN at the University of the Western Cape. If you have any questions about the research study itself, please contact: Arowoia Ayorinde Ibukun at:

Physiotherapy Department,
University of the Western Cape
Modderdam Road
Bellville, 7535
0795419918,
Arowoia.ibukunoluwa@gmail.com

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Head of Department: Professor Anthea Rhoda
Department of Physiotherapy
And
Dean of Faculty of Community and Health Sciences: Prof J. Frantz
jfrantz@uwc.ac.za
University of the Western Cape
Private Bag X17
Bellville 7535
Telephone: 959 2631

This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.

APPENDIX J
CONSENT FORM

Title of Research Project: Participation Restriction of stroke patient living in the Community at selected Community Health centers in the metropole districts; Western Cape, South Africa

The study has been described to me in language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

Participant's name.....

Participant's signature.....

Witness.....

Date.....



Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

Study Coordinator's Name: Mrs Nondwe Mlezana

University of the Western Cape

Private Bag X17, Bellville 7535

Telephone: (021)959-2542

Cell: 0795419918

Fax: (021)959-1217

Email: 3302415@myuwc.ac.za

APPENDIX K

INFORMASIE BLAD VIR: Patients met beroerte

Titel van navorsing projek: Deelnemange Beperking van pastiente met beroerte in die Gemeenskap by gekiesde gemeenskap gesondheid sentrums in die metropool distrikte, Wes Kaap Sud –Afrika.

Waaroor gaan die studie?

Dit is 'n navorsingsprojek onder leiding van Prof Anthea Rhoda by die Universiteit van die Wes-Kaap. Ons nooi u om deel te neem in hierdie navorsingsprojek, want jy is 'n persoon wat 'n beroerte ervaar het. Die doel van hierdie navorsingsprojek is om die re-integrasie van pasiënte met 'n beroerte te verbeter in hul gemeenskappe.

Wat sal van my verwag word om te doen as ek instem om deel te wees ?

Jy sal gevra word om 'n vraelys te voltooi. In bykomend tot die voltooiing van die vraelys kan jy ook gevra word om deel te neem in 'n groep bespreking waar jou ervarings met re-integrasie sal bespreek word. Sekere beroerte pasiënte sal ook gevra word om deel te neem in die program wat ontwikkel sal word en hulle sal gevra word om vraelyste te voltooi aan die begin en einde van die program. Die vrae wat gevra sal word, sal hoofsaaklik betrek jou vermoë om sekere aktiwiteite soos terugkeer na werk of sosiaal te vekeer, nou dat jy 'n beroerte gehad.

Sal my deelname aan hierdie studie vertroulik hanteer word?

Ons sal ons bes doen om te verseker dat jou persoonlike inligting vertroulik hanteer word. Om te help beskerm jou vertroulikheid, (1) jou naam sal nie ingesluit word op die opnames en ander data wat ingesamel is, (2) 'n kode sal geplaas word op die opname en ander data wat ingesamel is; (3) deur die gebruik van 'n identifikasie kode, sal die navorser in staat wees om jou informasie van die opname ann jou te koppel en (4) Slegs die navorser sal toegang het tot die identifikasie kode. As ons 'n verslag of artikel oor hierdie projek skryf, sal jou identiteit beskerm word tot die maksimum mate moontlik.

Wat is die risiko's van hierdie navorsing?

Daar is geen bekende risiko's wat verband hou met deelname aan hierdie navorsingsprojek.

Wat is die voordele van hierdie navorsing?

Hierdie navorsing is nie ontwerp om jou persoonlik te help nie, maar die resultate kan die navorser help om meer te leer oor die beperkinge ervaar deur pasiënte met beroertes . Ons hoop dat in die toekoms , ander mense kan voordeel trek uit hierdie studie deur middel van verbeterde begrip van beperkinge ervaar deur 'n beroerte pasiënte en programme te implementeer wat hierdie beperkings kan adresseer.

Moet ek in hierdie navorsing, en kan ek ophou deelneem op enige tyd ?

U deelname aan hierdie navorsing is heeltemal vrywillig . Jy kan kies om glad nie deel te neem nie. As jy besluit om deel te neem in die navorsing , kan jy ophou om deel te neem op enige tyd. As jy besluit om nie deel te neem aan hierdie studie nie of as jy ophou om deel te neem, jy sal nie gestraf word of enige voordele waarop u andersins kwalifiseer verloor nie.

Is enige bystand beskikbaar as ek negatief geraak word deur deel te neem aan hierdie studie?

As jy negatief geraak word deur die navorsing sal jy verwys word na 'n toepaslike gesondheidswerker by die Gemeenskap Gesondheids Sentrum in jou area.

Wat as ek vrae het ?

Hierdie navorsing word gedoen deur Prof Rhoda by die Universiteit van die Wes-Kaapland. As jy enige vrae oor die navorsing self , kontak :

Anthea Rhoda

Fisioterapie Departement ,
Universiteit van die Wes-Kaap

Modderdamweg

Bellville, 7535

Telefoon: 021 9592542

E-pos: arhoda@uwc.ac.za



Indien u enige vrae oor hierdie studie en jou regte as 'n navorsings- deelnemer , of indien u enige probleme ervaar het met betrekking tot die studie aan te meld , kontak Dekaan van die Fakulteit Gemeenskap en Gesondheidswetenskappe : Prof J. Frantz
jfrantz@uwc.ac.za

Universiteit van die Wes-Kaap

Privaatsak X17

Bellville 7535

Telefoon: 021 959 2631

Hierdie navorsing is goedgekeur deur die Universiteit van die Wes-Kaap se Senaat Navorsing Komitee en Etiekkomitee .

APPENDIX L
CONSENT FORM

Titel van navorsing projek: Deelnemange Beperking van pastiente met beroerte in die Gemeenskap by gekiesde gemeenskap gesondheid sentrums in die metropool distrikte, Wes Kaap Sud –Afrika.

Die studie is aan my beskryf in 'n taal wat ek verstaan en ek stem vrylik en vrywillig in om deel te neem . My vrae oor die studie is beantwoord . Ek verstaan dat my identiteit nie bekend gemaak sal word nie en dat ek uit die studie kan ontrek sonder om 'n rede te gee eniger tyd en dit sal my nie negatief beïnvloed nie.

Deelnemer se naam

Deelnemer se handtekening

Datum



Indien u enige vrae oor hierdie studie of wil enige probleme wat jy ervaar het met betrekking tot die studie aan te meld , kontak die studie koördineerder :

Studie -koördineerder se Naam: Prof A. Rhoda

Telefoon: (021) 959-2543

Cell : 0827757748

Faks: (021) 959-1217

E-pos: arhoda@uwc.ac.za

Universiteit van die Wes-Kaap

Privaatsak X17 , Bellville 7535

APPENDIX M

INFORMATION SHEET : For non- stroke

Isihloko Sophando Lwaleprojekthi: Ubundzima obufunyaniswa ngabantu abanestrokhu ekuhlaleni. Lwenziwa kuMaziko Empilo okanye iiCommunity Health Centers ezikwii distrikthi needolophu zase Ntshona Koloni, eMzantsi Africa.

Lungantoni olufundo?

Olufundo luququzelelwe nguProfesa Anthea Rhoda kwiYunivesiti yase Ntshona Koloni. Siyakumema ukuba uthabathe inxaxheba kolufundo nanjengomnye wabantu abathe bahlaselwa sistrowuki. Injongo yesisifundo kukufumanisa ukuba abantu abanesitrowuki baphila njani ekuhlaleni.

Yintoni elindeleke ukuba ndiyenze xa ndinokuthi ndithabathe inxaxheba?

Ulindeleke ukuba ugcwalise uphendule imibuzo eyakuthi ibuzwe kuwe, kwananjalo usenokucelwa ukuba uthabathe inxaxheba kwakunye neqela labanye abantu kwigumbi elinye apho kuyokuthi ubunzima okanye uncedo enithe nalufumana ngexesha niphila ne strowuki kuxoxwe ngazo. Abanye babaguli bayakucelwa ukuba bathabathe inxaxheba kwinqubo eziyakuthi zenziwe apho kwananjalo bacelwe ukuba baphendule imibuzo ekuqaleni nasekupheleni kofundo. Imibuzo eyakuthi ibuzwe apho imalunga nendlela owenza ngayo umsebenzi okanye indlela ongayo xa udibene nabanye abantu njengoko uthabathe wahlaselwa sistrowuki.

Ingaba ukuthatha kwam inxaxheba kolufundo luyakuba yimfihlo?

Iinkcukacha zakho zizogcinwa ziyimfihlo. Siyokwenza kangangoko ukugcina iinkcukacha zakho ziyimfihlo. (1) Igama. Ifani okanye amanani esazisi sakho asisayikuzibhala phantsi kumaphepha lawo sobe siwasebenzisa; (2) sizakupha inani okanye ikhowudi leyo siyakuthi siyibhale phantsi endaweni yegama lakho (3) inani okanye ikhowudi leyo yiyo esiyakuyisebenzisa xa sifuna uphinda sibuyele kuwe (4) Ndim kuphela oyokwazi ngelonani okanye ikhowudi. Ukuba kuyenza sibhale incazelo malunga nesisifundo, siyakuzama kangangoko ukugcina iinkcukacha zakho ziyimfihlo.

Buyintoni ubungozi besisifundo?

kukho ubungozana malunga nesisifundo.

Yintoni endiyakuyizuza malunga nesisifundo?

Ungangafumani uncedo wena kodwa omnye umntu olandelayo angancedakala ngolwazi esiyakuthi siluqokelele apha, kwaye siyathemba kananjalo abantu bayakuncedakala kwixa eliziya ngexa yokuqonda ubunzima obukhoyo ngenxa yesisifundo.

Kunyazelekile ukuba ndithabathe inxaxheba kwesisifundo/ ndingakwazi ukuyeka uthabatha inxaxheba ukuba andifuni nokuba kunini?

Ukuthabatha inxaxheba kwesisifundo kungothanda kwakho akunyanzelekanga. Ungakhetha ukungathabathi nxaxheba konke- konke. Ukuba ukhethe ukuthabatha inxaxheba kwesisifundo unako ukuyeka nanini na. ukuba ufuna ukuyeka kwaye akukho ncedo ongazi ukulifumana ngenxa yoko.

Ingaba lukhona uncedo endiyakulifumana ukuba kuyenzeka ndingancedakali sesisifundo?

Ewe, ukuba awuncedakalanga sesisifundo uyakuthunyelwa kwiziko labantu abaqeqeshelwe ukusebenza ngabantu abanestrowuki kwindawo ohlala kuyo.

Ukuba ndinemibuzo ndingenza njani?

Olufundo luququzelelwe nguProfesa Anthea Rhoda kwiYunivesiti yase Ntshona Koloni Ukuba unayo imibuzo malunga nolufundo okanye uthe wadibana nengxaki malunga nolufundo, nceda udibane nomphathi nqubo wesisifundo kwezi ncukacha zilandelayo

Anthea Rhoda
Physiotherapy Department,
University of the Western Cape
Modderdam Road
Bellville, 7535
Telephone: 021 9592543
Email: arhoda@uwc.ac.za



Ukuba unayo imibuzo malunga nolufundo okanye uthe wadibana nengxaki malunga nolufundo, nceda udibane nomphathi nqubo wesisifundo kwezi ncukacha zilandelayo

Nceda ukhumbule ukuba udibana nomphathi sifundo xa uthe wadibana nengxaki malunga nesisifundo kuphela.

Dean of the Faculty of Community and Health Sciences: Prof J. Frantz
jfrantz@uwc.ac.za
University of the Western Cape
Private Bag X17
Bellville 7535

Telephone: 959 2631

APPENDIX N

IPHEPHA MVUME LOKUTHABATHA INXAXHEBA

Isihloko Sophando Lwaleprojekthi: Ubundzima obufunyaniswa ngabantu abanestrokhu ekuhlaleni. Lwenziwa kuMaziko Empilo okanye iiCommunity Health Centers ezikwii distrikthi needolophu zase Ntshona Koloni, eMzantsi Africa.

Olufundo lucacisiwe kum ngolwimi endiliqondayo kwaye ndizonyule ngokuthanda khona ukuze ndithathe inxaxheba. Imibuzo yam ebendinayo ngolufundo iphendulekile. Ndiyayiqonda into yokuba inkcukaca zam azisayi kuvezwa nokuba kubani, umzekelo, amagama wam kwakunye nenombholo yesazisi. Ndiyayiqonda into yokuba ndingayeka ukuthatha inxaxheba nangowuphi na umzuzu ngaphandle kokunika isizathu kwaye lonto ayiyi kuphazamisana nonyango lwam.

Kolufundo kuyakubakho ixesha lokuba kushicilelwe amacwecwe empendulo endiyakuthi ndiziphendule, kwaye loo macwecwe ayakugcinwa kwindawo ekhuselekileyo etixiweyo apho iyakuba ngulowo ebendibuza imibuzo onelungelo lokuvula apho.

___ Ndiyakuvumela ukushicilelwa kweempendulo zam xenikweni ndithatha inxaxheba kolufundo

___ Andikuvumeli ukushicilelwa kweempendulo zam xenikweni ndithatha inxaxheba kolufundo

___ Ndiyakunika imvume yokuhlola amaphepha wam asesibhedlele.

___ Andikuniki imvume yokuhlola amaphepha wam asesibhedlele.

Igama lomthathi nxaxheba..... Inggina

Umsayino womthathi nxaxheba.....

Usuku.....Inyanga.....Unyaka.....

Ukuba unayo imibuzo malunga nolufundo okanye uthe wadibana nengxaki malunga nolufundo, nceda udibane nomphathi nqubo wesisifundo kwezi ncukacha zilandelayo.

Nceda ukhumbule ukuba udibana nomphathi sifundo xa uthe wadibana nengxaki malunga nesisifundo kuphela.

Study Coordinator's Name: Prof. A. Rhoda

University of the Western Cape

Private Bag X17, Belville 7535

Telephone: (021)959-2543

Cell: 0827757748

Fax: (021)959-1217

Email: arhoda@uwc.ac.za

APPENDIX O
FOCUS GROUP CONFIDENTIALITY BINDING FORM

Title of Research Project: Participation Restriction of stroke patient living in the Community at selected Community Health centers in the metropole districts; Western Cape, South Africa

The study has been described to me in language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way. I agree to be audi-taped during my participation in the study. I also agree not to disclose any information that was discussed during the group discussion.

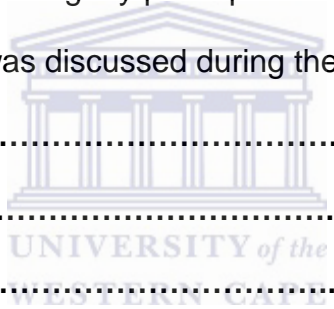
Participant's name.....

Participant's signature.....

Witness's name.....

Witness's signature.....

Date.....



APPENDIX P

FOKUSGROEP VERTROUOLIKHEID VERBINDEND VORM

Titel van navorsing projek: Deelnemange Beperking van pastiente met beroerte in die Gemeenskap by gekiesde gemeenskap gesondheid sentrums in die metropool distrikte, Wes Kaap Sud –Afrika.

Die studie is aan my verduidelik in n taal wat ek verstaan , en my deelname in die studie is vrylik en vrywillig , my vrae oor die studie is beantwoord. Ek verstaan dat my identiteit nie bekend gemaak sal word nie. Ek verstaan dat ek teen enige tyd van die studie kan ontrek sonder om n rede te gee en dat dit nie vir my in enige manier negatief sal afekteer nie. Ek stem saam dat ek op band geneem kan word tydens my deelname in die studie. Ek stem ook saam dat ek geen inligting wat in die groep bespreking sal openbaar nie.



Deelnemer naam.....

Deelnemer handtekening.....

Getuie.....

Getuie handtekening.....

Datum.....

APPENDIX Q

IFOCUS GROUP CONFIDENTIALITY BINDING FORM

(Ifom yokuqinisekisa ukuba iincukacha zengxoxo yeqela zihlala ziyimfihlo)

Isihloko Sophando Lwaleprojekthi: Ubundzima obufunyaniswa ngabantu abanestrokhu ekuhlaleni. Lwenziwa kuMaziko Empilo okanye iiCommunity Health Centers ezikwii distrikthi needolophu zase Ntshona Koloni, eMzantsi Africa.

Oluphando lucaciswe kum ngendlela endiyivayo nendiyiqondayo futhi ndiyavuma ngokukhululekileyo ukuthatha inxaxheba kulo. Imibuzo endinayo ngoluphando iphenduliwe. Ndiyayiqonda into yokuba iincukacha ngam azizukvezwa koluphando futhi ndingayeka nanini na xa ndifuna ngaphandle kokunika isizathu. Ukuyeka kwam akuzukundichaphazela kakubi nangeyiphi na indlela. Ndiyavuma ukurekhodwa xa ndithetha koluphando. Ndiyavuma nokuba yonke into ethethiweyo kule ntlanganiso yoluphando andizukuyithetha kwenye indawo.

Igama lomntu othatha inxaxheba.....

Isignitsha yomntu othatha inxaxheba(Tyikitya)

Igama lenqgina.....

Isignitsha yenqgina(Tyikitya)

Umhla.....