SOCIAL SUPPORT AND PARTICIPATION RESTRICTIONS IN PATIENTS LIVING WITH STROKE IN THE WESTERN CAPE, SOUTH AFRICA

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ABSTRACT

Cerebro-vascular accidents or stroke remain a leading cause of death worldwide accounting for 5.5 million deaths, leaving individuals disabled in many aspects of functioning. The International Classification of Functioning, Disability and Health (ICF) is a framework that assesses disability in relation to impairments, activity limitations, participation restrictions and environmental factors and many individuals post stroke have reported restrictions in these areas. Literature has proven that participation restrictions post stroke are very common, which means that individuals are not able to return to their normal functioning as before. Once these individuals are discharged into the community, supportive networks become an essential aspect aiding participation. There is some literature present which shows positive relations between social support and participation, however this is minimal. The aim of this study was to determine participation restrictions and social support in patients with stroke, living in the Western Cape.

To further understand the relationship between social support and participation restriction post stroke, a systematic review was conducted. The databases searched were Ebscohost full text, which included CINAHL +, Health Source: Nursing, Academic edition, Medline, Psych articles and Soc index, Science Direct, Biomed Central, Google Scholar, Cochrane Library, Pedro Central, and Wiley Online between the years 2001 - 2013. Once the methodology of the review was completed, a total of three articles were the only articles that met the study's inclusion criteria and were included in the review. These articles highlighted the importance of the quality and quantity of social support on participation. The review presented level 4 and 6 evidence, based on the hierarchical evidence model which showed a positive relationship between social support and participation. Thus, social support is found to be an important factor aiding participation.

The methodology of the survey included a target population of all individuals attending the Community Health Centres in the Southern Western and Klipfontein Mitchell's Plain Metro District Health Service who were sampled by convenience. This study was cross-sectional in design, using descriptive surveys. All individuals diagnosed with a stroke and living in the community for at least six months were included in this study. The World Health Organisation Disability Assessment Schedule 2.0. (WHODAS 2.0.) was used to determine the participation restrictions in the participants, while the Social Support Questionnaire 6

(SSQ6) was used to determine the individual's social support. Completed questionnaires were analysed using the Statistical Package for the Social Sciences (SPSS) version 23 where descriptive statistics were used to define continuous and categorical variables. The Pearsons correlation test was used to determine the association between social support and participation, with significance set at 0.05. Confidentiality was maintained throughout the study and participants were required to provide verbal and written informed consent. All questionnaires and consent forms were available in English, Afrikaans and isiXhosa to accommodate all participants. Participants were assured that their participation in the study was completely voluntary and that their agreement, refusal or withdrawal would not impact their treatment at the Community Health Centre.

A total of 106 participants met the inclusion criteria for this study and agreed to partake. An equal number of males and females participated, with a mean age of 61.5 years. The results showed that 89.9% of participants in the study were classified as having low levels of social support, with family support playing an important role in the social support of participants (P=0.000). The majority of participants (30.2%) indicated that their children, and families, were the people providing the most support to participants. Caregiver strain and burnout was highlighted as an aspect of importance. The majority of participants (51.8%) were severely affected in the domain of participation, reporting common problems joining in community activities (28.3%), emotional status (18.9%) and financial status (45.3%) which affected participation adversely. Extreme difficulty with concerns of barriers in the community (19.8%), and time spent on health condition (8.5%), with regard to participation were reported. It has been highlighted that many participants had not returned to work post stroke, a factor to consider when planning interventions in the clinical setting. When comparing the respective domains of the WHODAS 2.0., mobility, household activities and participation was discovered to be amongst the highest scoring domains. Pearsons correlation test between social support and participation produced a non-significant result (P = 0.146).

This study outlines that although an insignificant result was obtained, the participants (10.1%) who scored the highest for social support had only been moderately affected in the domain of participation. A limitation of this study include design, and it is thus recommended that additional studies be conducted in the form of controlled trials to determine the effects of social support on participation restrictions post stroke.

DECLARATION

I hereby declare that **"Social Support and Participation Restrictions in Patients Living With Stroke 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.

Toughieda Elloker

Signature…………………………........ **November, 2015**

Witness………………………........

Professor Anthea Rhoda

DEDICATION

The author would like to dedicate this thesis to her family and friends, who have played an integral part in the completion of this thesis by displaying their constant love, motivation and support.

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TABLE OF CONTENTS

LIST OF APPENDICES

LIST OF FIGURES

LIST OF TABLES

ABBREVIATIONS

ADL – Activities of daily living

CASP – Critical Appraisal Skills Programme

CHC – Community Health Centres

CVA – Cerebrovascular accident

DoH – Department of Health

ICF – International Classification of Functioning, Health and Disability

IRT – Items response theory

MDHS – Metro District Health Service

PICO – Population Intervention Comparison Outcome

PT – Physiotherapist

QoL – Quality of Life

RCT – Randomised controlled trials

SPSS – Statistical Package for the Social Sciences

SSQ – Social Support Questionnaire

SSQF – Social Support Family Score

SSQN – Social Support Number Score

SSQS – Social Support Satisfaction Score

SSQ6 – Social Support Questionnaire 6

WHO – World Health Organisation

WHODAS 2.0. – World Health Organisation Disability Assessment Schedule 2.0.

CHAPTER ONE

INTRODUCTION

1. Introduction to the chapter

This introductory chapter presents the background information about stroke, its prevalence in South Africa, as well as risk factors involved with the disease. The International Classification of Functioning, Disability and Health is discussed as a vital framework where the disability post stroke is unpacked. This is done using the respective domains within the ICF. The literature presented highlights the participation restrictions in individuals post stroke and various challenges these individuals experience when entering the community, where social support now becomes of great concern. The background information of social support is presented, and studies reporting an association between social support and functioning post stroke are assessed. The research question and specific aims and objectives are described. The definitions of frequent terms used throughout this study are explained, and an outline of the chapters to follow is provided.

1.1. Background

Cerebrovascular accidents or stroke remains a leading cause of death and disability in South Africa (Bryer et al., 2011). It is defined by the World Health Organisation (World Health Organisation, 2001), as “a condition in which there is an interruption of the blood supply to the brain, due to a blood vessel erupting or becoming blocked by a clot, causing loss of oxygen and nutrients to the brain leading to brain tissue damage”. More females are affected than males and stroke becomes more predominant with an increase in age (Conner & Bryer, 2005). More than 50% of strokes in South Africa can be attributed to hypertension, and only 38% of those diagnosed with hypertension is controlled with medication (Bertram, Katzenellenbogen, Vos, Bradshaw, & Hofman, 2013). In developed countries, 73 years is the average age at which a stroke may occur. However, in less developed countries, the mean age is younger, and reported to be between 55 to 61 years old (Rhoda, 2012; Rhoda, Mpofu, & De Weerdt, 2011). This can be attributed to differences in age structure as a result of higher mortality rates and competing causes of death (Truelsen, Begg, & Mathers, 2000). The effects of a stroke can be debilitating in many individuals. A stroke has been identified more than a decade ago as a primary cause of disability in adults (Truelsen et al., 2000).

The International Classification of Functioning, Disability and Health (ICF) was developed by the World Health Organisation (WHO)(2001) and defines disability as "a multi-dimensional concept relating to the health condition, body functions and structures, activity limitations, participation restrictions, and contextual factors which include environmental and personal factors." The ICF comprises of three health components and any injury may cause difficulty in these areas. After suffering from a stroke, the body structures and functions become impaired and because of this, the individual might experience difficulties in performing certain activities post stroke. The stroke survivor might find participating in various activities with friends or family challenging. It is important to note that the relationship between these three components are not contributory i.e. the individual might experience difficulties in one construct, but not in the other (Scott, Phillips, Johnston, Whyte, & MacLeod, 2012). Often, the main aim of an intensive rehabilitation programme post stroke is improving impairments and thereby activity limitations. However, it is proven that individuals post stroke have a tendency to direct their concentration towards achieving social integration back into the community, family and employment, as an alternative to treatment being based solely on impairment and activity (Scott et al., 2012). The above statement is strengthened by the fact that the ICF is addressing all components of disability and directing its main focus on the integration of individuals back into their social networks and community participation as this has been found to be the primary aim for successful rehabilitation (Noreau et al., 2004).

Various national and international approaches have been published with regard to the screening and treatment, focusing not only on the acute phase of disease, but on the broader context of stroke disability (Geyh et al., 2004). Beckley (2007) stated there has been a change in the focus of traditional post-discharge rehabilitation which focused mainly on activity limitations, to the more integrated ICF model which focuses on the connection between body structures and functions, activity and participation, and environmental factors. By utilising the ICF guidelines it permits for the holistic approach to improve Quality of Life (QoL). The importance of this holistic approach allows for individuals to progress through the rehabilitation programme focusing on addressing participation in daily social situations and occupations. If this remains neglected, it may impede on the individual's QoL, as community participation is an essential element thereof (Beckley, 2007).

Symptoms of a stroke, contexualised within the ICF, at the level of the impairment can include paralysis of one side of the body known as hemiplegia, loss of, or slurred speech, cognitive deficits and many more. Stroke patients living in isolation is a common finding due to difficulties with communication, physical and cognitive impairments (Chau, Thompson, Twinn, Chang, & Woo, 2009). As a result of these impairments and subsequently living in isolation, stroke survivors have explained that this has had a negative impact on their social relationships (Maleka, Stewart, & Hale, 2012). Individuals who are stroke victims frequently struggle with activities such as bathing, dressing, toileting and manipulating stairs (Geyh et al., 2004). With regard to activities of daily living (ADLs) these sufferers need assistance with meal preparation and housekeeping (Rouillard, De Weerdt, De Wit, & Jelsma, 2012) and doing the laundry (Hartman-Maeir, Soroker, Ring, Avni, & Katz, 2007).

Many studies in South Africa show participation as a restriction post stroke (Maleka et al., 2012; Rhoda, Cunningham, Azaria, & Urimubenshi, 2015; Rouillard et al., 2012). In the domain of participation restrictions, stroke survivors report spending less time on active societal pursuits with regard to leisure, such as walking long distances and gardening (O’Sullivan & Chard, 2010). The five most common participation restrictions identified are relationships, community life, driving, occupation and leisure activities (Wolf & Koster, 2013). Studies have stressed the impact of stroke on return to employment (Maleka et al., 2012; Rhoda et al., 2015), and as a result, financial problems arise. This will result in a decreased livelihood. Often, the majority of individuals post stroke wish to return to their previous work, whilst others intend to apply for a government disability grant (Maleka et al., 2012) . The factors associated with return to employment post stroke include changes in the work environment, such as being assigned to a different position due to the inability to fulfill key needs and reduced working hours owing to fatigue and weakness (Koch, Egbert, Coeling, & Ayers, 2005). Individuals who had returned to work post stroke, reported vast improvements in financial status, subjective well-being regarding work, social well-being and with life as a whole (Vestling, Tufvesson, & Iwarsson, 2003).

According to the WHO (2001), the contextual factor referred to as the environment describes the social, attitudinal and physical environment in which people reside. When assessing the social environment of individuals post stroke, it is important to consider the support structures available to them, as well as the individual’s social engagement with others. Although social engagement post stroke is often difficult, participants will require support from family and friends when entering the community. Though both these factors are important when assessing the social environment of the individual, the main focus of this research is on the aspect of social support. The attitudes of both the individual suffering from the stroke, as well as external others constitute the attitudinal environmental in which stroke survivors reside (Sumathipala, Radcliffe, Sadler, Wolfe, & McKevitt, 2011). Overprotective and negative attitudes from external others are seen as barriers towards the functioning of the individual post stroke. Similarly, individuals post stroke need to have a positive outlook toward life and living (Reid, 2004). A spacious environment can be viewed appropriate for living, and for provision of assistive devices (Reid, 2004). Furthermore, employment and financial problems, discussed above, are viewed as important contextual factors (Geyh et al., 2004).

Numerous individuals post stroke, living in under-served communities do not participate in comprehensive stroke rehabilitation programmes, which results in limited recovery and consequently contributes to long term disability. The factors associated with limiting access to rehabilitation programmes include difficulty with transport, no medical insurance and reliance on caregivers (Linder et al., 2013). Once a stroke patient is discharged from hospital, their level of recovery becomes of great concern. Once the individual returns home into their community they become dependent on others for help and support. Mudzi, Stewart, & Musenge (2013) reports that post stroke, individuals co-habiting with a caregiver or adult leads to lower levels of independent functioning with regards to ADLs, however levels of community participation is improved. This is due to the caregiver completing all the stroke individuals ADLs, hindering their independence. Participation was shown to be improved due to the caregiver's assistance in moving the stroke individual around the environment or community. Andrew, Kilkenny, Naylor, Purvis, & Cadilhac (2015) discovered that moderate to extreme impact was seen in caregivers across all domains, particularly with leisure activities and work when they cared for individuals who required assistance with their ADLs. One important factor that deemed to be closely linked to improving individuals' participation post stroke, as well as overall health and well-being, is social support (Mayo, Bronstein, Scott, Finch, & Miller, 2013; Tsouna-Hadjis, Vemmos, Zakopoulos, & Stamatelopoulos, 2000).

The term social support as defined by Sarason, Levine, Basham, & Sarason (1983) is "the existence or availability of people on whom we can rely, people who let us know that they care about, value, and love us." Furthermore, Sarason et al. (1983) states that stress can be better managed, and personal development and positive adjustments can be improved by social support. The term social networks has been described as "the structure through which perceived social support is provided" (Lin, Ensel, & Vaughn, 1981), these having a wide range of functions, in which social support is but one. The term structure in the definition above can be regarded as family, friends, spouses or significant others, as well as formal organisations which can include religious groups, social clubs as well as jobs (Mattson, 2011). According to Cohen & Syme (1985) the role of a social network is to "provide a sense of social integration, a set of stable, socially rewarded roles, as well as stability and predictability". It was discovered that the more social relations an individual has, the more that individual is integrated into their social networks (Mattson, 2011). Although the above mentioned definitions of social support and social networks are decades old, they have not changed over the years, and still remain the same, with minor variations. Dating back to the 1970s, social support and its influence has drawn the interest of health researchers, and has been found to have a profound effect on health and well-being, as well as adjustment strategies to the trauma of injury or illness (Beckley, 2006). More recently, African studies have started including social support and questioning its impact on the functioning of the stroke patient (Maleka et al., 2012; Rhoda et al., 2015). When assessing a sample of stroke participants over a twelve month period, it was discovered that 43% had challenges with social interactions (Edwards, Hahn, Baum, & Dromerick, 2006). This could adversely affect social networks. Furthermore, it is noted that social support from close personal relations, including friends and the community, provides a protective barrier against poor psycho-social outcomes, whereas too much support can lead to under-stimulation and overprotection in stroke survivors (Glass, Matchar, Belyea, & Feussner, 1993). Mayo et al. (2013) reported that factors influencing participation post stroke include social support, depression and walking capacity. Moreover, no individual with poor social support attained excellent participation although very good social support is not sufficient for excellent participation.

1.2. Problem Statement

Post stroke, participation restrictions are common (Maleka et al., 2012; Rhoda et al., 2015; Rouillard et al., 2012). This means that individuals cannot return to their normal functioning as before. This has an impact on their QoL. Barclay-Goddard, Ripat, & Mayo. (2012) stated that the main goal for rehabilitation should be improving health related quality of life. Increasing participation would positively influence the QoL of stroke individuals (Mayo et al., 2013). Research has been done to determine the effects of different aspects of recovery of motor and neurological functioning, but less on factors that influence participation. Studies have been conducted to determine the factors influencing participation restrictions post stroke (Fallahpour, Tham, Joghataei, & Jonsson, 2011; Mayo et al., 2013). The findings concluded that altered mood status, physical functioning and access to caregiving services were found to influence participation. A factor that could influence participation is social support (Mayo et al., 2013).

Some literature has been published which shows a positive relation between social support and participation (Mayo et al., 2013), however, this literature is minimal, and none present for the local setting. The available literature in this regard stems from the 1970s and are more than four decades old (Cohen & Syme, 1985; Lin et al., 1981; Sarason et al., 1983). The literature conducted more recently by Glass et al. (1993) and Beckley (2006) showed a positive relationship between social support and functional status, thereby improving participation. These results present literature from the western world and research in the non-western world is limited with regard to social support and participation (Fallahpour et al., 2011). It is noted that these studies focus mainly on social support and its effect on functional status post stroke, and how functional status then impacts on participation. According to the authors, limitations for both these studies include small sample sizes, thus the results cannot be generalised to the entire stroke population. Randomised controlled trials (RCTs) would be the most useful design to determine the effect of social support on participation restrictions post stroke, and the studies above used cohort and cross-sectional designs respectively. It is for these reasons, that this information cannot be used for the local setting. Thus, it is unclear whether or not social support would have an effect on participation. Further studies need be conducted to determine the effect of social support on participation in stroke patients (Mayo et al., 2013) . Therefore, the purpose of this study is to investigate social support and participation post stroke in order to expand the literature in this specific area. A systematic review was also included to determine the current, best evidence available on the effects of social support on participation restrictions post stroke.

1.3. Research Questions

What is the social support status of stroke patients living in the Western Cape?

What are the participation restrictions of stroke patients living in the Western Cape?

What are the effects of social support on participation restrictions in stroke patients living in the Western Cape?

1.4. Study Aim

The aim of this study is to determine social support and participation restrictions in patients with stroke living in selected areas in the Western Cape.

1.5. Study Objectives

1.5.1 To determine the socio-demographic details of the stroke patients.

1.5.2 To determine the stroke patients social support.

1.5.3 To determine the participation restrictions of the stroke patients.

1.5.4 To determine the relationship between social support and participation restrictions.

1.5.5 To determine the effect of social support on participation restrictions post stroke by conducting a systematic review.

1.6. Definition of terms

Cerebrovascular accident (CVA) or stroke - “A condition in which there is an interruption of the blood supply to the brain, due to a blood vessel erupting or becoming blocked by a clot, causing loss of oxygen and nutrients to the brain leading to brain tissue damage” (World Health Organisation, 2001).

Social support - “The existence or availability of people on whom we can rely, people who let us know that they care about, value, and love us” (Sarason et al., 1983).

The International Classification of Functioning, Disability and Health (ICF) - “A multi-dimensional concept relating to the health condition, body functions and structures, activity limitations, participation restrictions, and contextual factors which include environmental and personal factors” (World Health Organisation, 2001).

Impairment - “A problem with the body structure or function” (World Health Organisation, 2001).

Activity limitation - "A difficulty encountered by an individual in executing a task or action" (World Health Organisation, 2001).

Participation restriction - "Problems an individual may experience in involvement in life situations" (World Health Organisation, 2001).

Environmental factors – "The physical, social and attitudinal environment in which people live and conduct their lives. These are either barriers to or facilitators of the person's functioning." (World Health Organisation, 2001)

Community based participation - "The extent of participation in religious, social, recreational, vocational, political and other organisational community groups and activities" (Rintala, Hart, Priebe, & Ballinger, 1998).

1.7. Outline of chapters in the study

Chapter One presents the background of stroke in South Africa. This chapter outlines the disability following stroke within the framework of the ICF. The terms participation restrictions and social support are briefly discussed. The aims and objectives of the study are presented.

Chapter Two presents the relevant literature of stroke and the three health components, and one contextual factor of the ICF are unpacked in more detail. Literature regarding participation restrictions and social support are reported. The relationship between social support and participation is then discussed.

Chapter Three provides a brief background of social support and participation post stroke. The chapter then proceeds to describing the methodology involved in conducting a systematic review. The results of the review are presented and discussed according to common factors which emerged in the literature. A conclusion is drawn and implications for practices are emphasised.

Chapter Four provides information regarding the methodology of the survey component of the study. Information regarding the research setting, design and sample population is presented. The two research instruments are described and the procedure for data collection discussed. The process for data analysis is explained and ethical considerations mentioned.

Chapter Five presents the results of the study, using tables and figures. The results regarding participation restrictions and social support scores post stroke are revealed for this sample.

Chapter Six is a discussion of the results obtained in Chapter Five. These results are discussed with regard to clinical implications and relevant literature is presented supporting these findings.

Chapter Seven provides the summary of all chapters and draws a conclusion regarding the results from the survey and the systematic review. The clinical implications are reported and recommendations are made for the future.

CHAPTER TWO

LITERATURE REVIEW

2. Introduction

The literature review chapter presents all the relevant research available on the topic in question. It provides an overview of the background of stroke, followed by a discussion of the ICF as a framework for the study. Four domains of the ICF are presented, and literature regarding it is reported. The domains of interest are impairment, activity limitations, participation restrictions and environmental factors. Common participation restrictions post stroke are reported, and includes engaging with family and friends, restrictions in leisure activities, driving, return to work and community based participation. Factors affecting recovery are then documented. Social support is introduced, and the importance of family support is stressed. The impact of caregiver strain is then reported. A brief discussion of the effects of social support on participation is reported.

2.1. Prevalence, burden, risk factors and education of stroke

Cerebro-vascular diseases remain a prominent cause of death in South Africa (Bryer et al., 2011). Globally, it was projected that in the year 2001, 5.5 million deaths were attributed to cerebro-vascular diseases, equivalent to 9.6% of all deaths. Two-thirds of these deaths occurred in people living in developing countries, who were under the age of 70, which accounted for 40% of the subjects (Truelsen et al., 2000). Conner & Bryer (2005) reported that in South Africa in the year 2000, stroke was the fourth leading cause of death affecting more females (18 184) than males (13 930), and was responsible for 6% of all deaths. Each year, millions of individuals are forced to adjust to the limitations in ADLs, as a result of strokes, a primary cause of disability in adults. Survivors of this disease will more often rely on the assistance and support of others for survival (Connor, Thorogood, Casserly, Dobson, & Warlow, 2004). Survivors are at an increased risk of death in the first weeks after a stroke, and 20 – 50% die within the first month. This is dependent on the type and severity of the stroke, age, co-morbidities and the efficiency of managing complications. Stroke survivors may be left with mild, moderate or severe disabilities however, spontaneous recovery can occur up to six months post stroke (Truelsen et al., 2000). Furthermore, patients with a history of stroke are at a 10% risk in the first year, and a 5% risk per year thereafter of a subsequent event (Truelsen et al., 2000).

There are many risk factors for cerebro-vascular disease including age, sex, blood pressure, serum cholesterol, tobacco, alcohol consumption, diet and physical inactivity. Tobacco use and blood pressure are two of the main adaptable risk factors for the population. This is due to its high incidence, association and possibility for intervention. It has been proven that anti-hypertensive management moderates the risk of stroke by 38% (Truelsen et al., 2000). In the attempt to control the disease, factors that need to be addressed are increasing the knowledge of the public community by creating awareness of the risk factors involved. Inadequate community awareness has caused the burden of stroke to be ranked amongst the top three causes of mortality in Ghana (Donkor, Owolabi, Bampoh, Aspelund, & Gudnason, 2014). Thus, it is imperative to assess community awareness, more so in countries with high stroke mortality, as this will provide the basis for relevant health education on the subject (Donkor et al., 2014).

2.2. The International Classification of Functioning and Disability (ICF)

The ICF is directed at reflecting the dynamic collaboration between the domains of activity, participation and environmental factors, while describing participation as being influenced by them (Fallahpour et al., 2011). Therefore, for the purpose of this thesis, the domains of interest include activity limitations, participation restrictions and environmental factors. Thus, when assessing the functioning of the stroke patient, the ICF allows us to depend on a universally agreed framework and classification to define the spectrum of these problems individuals experience (Geyh et al., 2004). It is further said that the ICF has influenced the scope of outcome studies to include measures of participation that reflect the impact of disease on community integration on individuals coping with consequences of disease and injury (Hartman-Maeir et al., 2007). It is for the above mentioned reasons that this solid classification of functioning and disability will be used as a framework for the results and analysis of this study. Figure 1 below is an illustration of the ICF and unpacks disability in the domains below.

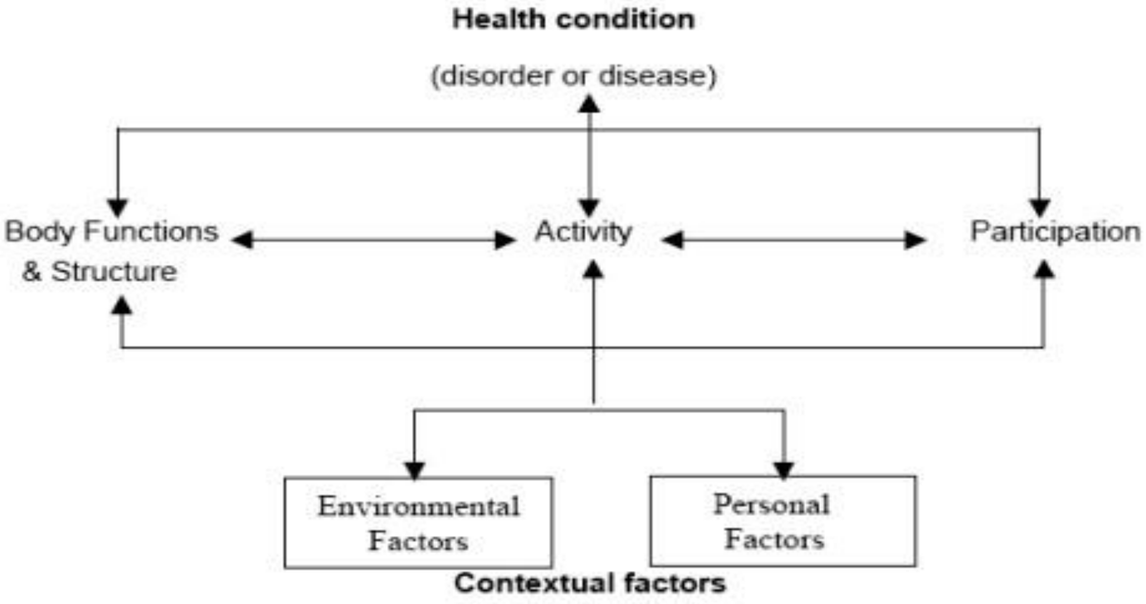


Figure 1: The International Classification of Functioning, Disability and Health

2.2.1. Impairments post stroke

The term impairment is defined as "a problem with the body structure or function" (WHO, 2001). Any part of the brain can be affected post stroke, and can therefore influence the functioning and body structures greatly. Impairment after stroke can be categorised according to either neurological or neuropsychological dysfunction. Neurological refers to the motor, sensory and visual dysfunction, whereas neuropsychological refers to the language, memory and attention deficits (Geyh et al., 2004). The literature present predominantly focuses on neurological rather than neuropsychological deficits (Ellis, Focht, & Grubaugh, 2013). Increased neurological shortfalls can lead to increased effort and dependency with ADLs which could be an explanation for the above. Common effects of a stroke include impairment to gross or fine motor movements, executive functioning, long or short term memory and speech, sight or hearing. The exact nature of the impairment is dependent on the area of the brain affected (Cookson & Casey, 2013). A study conducted by Danielsson, Willén, & Sunnerhagen (2012) showed that altered motor functioning affects walking capacity post stroke. Moreover, reduced ambulatory ability due to damage of the motor and sensory pathways have affected 65% of surviving strokes, resulting in altered motor function (Sunnerhagen, Svantesson, Lönn, Krotkiewski, & Grimby, 1999). As a result of the impairment post stroke, factors to be taken into consideration when walking include speed, terrain, and falling (Maleka et al., 2012). Altered walking capacity post stroke can influence community ambulation, which in turn can have an adverse effect on participation. Maleka et al. (2012) revealed that participants often felt embarrassed when walking within the community because of the way they walked. This was related to the impairments they experienced post stroke. Furthermore, two thirds of stroke survivors have reported impairments with regard to their vision. This has been known to have an adverse effect on social interactions, hobbies and ADLs (Jones & Shinton, 2006).

2.2.2. Activity limitations post stroke

The term activity limitation is defined as “a difficulty encountered by an individual in executing a task or action” (WHO, 2001). In a South African study conducted to determine functioning of the stroke patient six months post stroke, it was reported that bathing, dressing and stair climbing, were identified as the main activities requiring assistance (Rouillard et al., 2012). Literature further classified restrictions post stroke into four different functional areas. Fifty-three percent of participants (53%) found having an important activity to fill the day challenging. Included in this important activity were occupational, recreational and social domains. Execution of simple ADLs for survival in the community such as walking short distances, bathing and climbing stairs was challenging for 33% of participants. Fifty-one percent of the sample (51%) reported difficulties with shopping and household tasks, which included meal preparation. Lastly, half of the sample (50%) had difficulties travelling into and out of the community (Mayo, Wood-Dauphinee, Côté, Durcan, & Carlton, 2002). A study conducted by Hartman-Maier et al. (2007) found similar results when evaluating stroke survivors one year post onset in their homes. Out of the fifty-seven stroke patients included in this study, only one person returned to paid employment. These findings are similar to the findings of Mayo et al. (2002), but this study shows that these restrictions are still present a year later. This study concluded that with regard to very basic ADLs, independence was extensively achieved but support was required with more intricate ADLs.

2.2.3. Participation restrictions post stroke

The term participation restriction is defined as “problems an individual may experience in involvement in life situations” (WHO, 2001). A model of participation was established using the structural equation modeling (SEM) (Barclay-Goddard et al., 2012). The first domain in this model was achievements in relation to recreational activities, social functioning, work/activity, driving and usual activities. The second domain was restricted roles and focused on boundaries due to cognitive, emotional and physical health problems. The third domain was health efficacy in perception of recovery and health. In the attempt to analyse these variables, aspects of the individuals support structures and physical environment need to be considered. Moreover, Resnik et al. (2012) described the fundamental dimensions of participation below. The social domain was described as engaging with friends and family while work was regarded as any employment, paid or unpaid. Education included participating in learning activities while leisure is engaging in desired activities. Finally, self-care involves engaging in activities to maintain a standard of grooming and health.

2.2.3.1. Engaging with friends and family post stroke

When engaging with friends and family, a common finding reported by individuals post stroke was complications with communication and loss of speech (Lynch et al., 2008). Thirty seven percent of stroke survivors (37%) have reported difficulties with concentration and attention, and affected relationships with family and friends (Edwards et al., 2006). Prior to the stroke, individuals who enjoyed social outings now invited family and friends over to their homes, instead of meeting at a social place, to avoid having to go out as a result of their impairments (O’Sullivan & Chard, 2010). Although participants expressed the enjoyment of interaction with people, it was noted that they had to depend on friends and family members to ensure that they could participate and socialise in community activities, as their independence has been affected.

2.2.3.2. Engaging in leisure activities post stroke

Internationally, reports of improved wellbeing and health have been linked to participation in social, active and passive activities, especially in the elderly. O’Sullivan & Chard (2010) further stated that constraints regarding re-engaging in leisure activities are common post stroke. Due to the experienced complications, increases in a sedentary lifestyle have occurred. Examples of this include participants engaging in crossword puzzles, reading, watching television and staying home and having telephonic conversations with friends. Previously, participants would have preferred a more active lifestyle such as going on long walks, gardening, going to the movies and performing voluntary work. It was apparent that the activities of active leisure that was mentioned prior to the stroke were greatly enjoyed by participants (Maleka et al., 2012). Furthermore, participants viewed the inability to carry out meaningful activities as a loss in their previous life roles. Common restrictions in leisure activities as experienced by a sample of South African participants, was being able to attend church. Individuals were apprehensive about fulfilling their roles religiously and spiritually as Christians. They worried that they were unable to achieve their duties due to their inability to attend their place of worship (Rhoda et al., 2015). In a study conducted by Rochette, Desrosiers, Bravo, St-Cyr-Tribble, & Bourget (2007), all participants reported a decline in recreational activity due to either environmental constructs such as transportation or reduced mobility. The influence on their social roles and ADLs were completely affected and continued even after six months, even though participants presented with only mild impairments. Improvements usually took place within the first three months post stroke, except for the employment category which often extended beyond this timeline. A factor for consideration is that of the thirty-five participants, five of these survivors had the opportunity to go through a rehabilitation programme, while the outstanding thirty had no rehabilitation interventions after discharge. If all participants had access to rehabilitation in the study, it could have affected their mobility, and ability to participate in recreational activity positively.

2.2.3.3. Resuming driving post stroke

Many individuals are unable to resume driving due to their disability post stroke, and this has emerged as an important participation restrictor in many studies (O’Sullivan & Chard, 2010; Rhoda et al., 2015; White et al., 2012). In a study to determine restrictions in driving post stroke, it was found that seven participants did not return to driving and continued to rely on others for dependence in this regard, seven participants resumed driving within three months and lesser amounts of five and three participants resumed driving by six and twelve months respectively (White et al., 2012). Symptoms which affected the decision to return to driving included altered tone, weakness on one side of the body and problems with vision. In these participants, the inability to resume driving left them feeling less in control of decision making with regard to the activities that they could participate in (White et al., 2012). Participants felt that they had lost their independence along with their ability to drive. Even in cases where individuals were able to drive, it would only be in the vicinity where they resided and always with a passenger for fear that something would happen. As a result of this, participants were now more dependent on family and friends, or public transport for travelling.

2.2.3.4. Return to work post stroke

As most strokes occur later in life, literature regarding return to work post stroke are scarce (Vestling et al., 2003). This puts younger stroke victims at a disadvantage as these individuals' involvement in return to work are commonly affected (Treger, Shames, Giaquinto, & Ring, 2007). In a study conducted by Vestling et al. (2003), it was established that it took an average of six to twelve months for 41% of participants to return to employment post stroke. Sixty-one percent of the 41% that had returned to work reported changes such as a reduction in their working hours from full-time to part-time. A total of twenty-six participants had made a concerted effort to return to work, but had not succeeded. Those who had returned to work conveyed a significantly higher satisfaction with life as a whole, financial conditions, leisure and friends. Currently, there is minimal literature available on return to work intervention platforms for people with strokes in South Africa (Ntsiea, Van Aswegen, Lord and Olorunju, 2015). In Gauteng, South Africa, an insignificant number of facilities are equipped to screen individuals post stroke to determine their potential for return to work, where other facilities transfer these participants to specialist professionals in the field (Ntsiea, Van Aswegen, Lord, & Olorunju, 2012). Probable obstacles to returning to employment post stroke include lack of suitable transportation, architectural barriers, poor local economy and stereotypes of persons with disabilities (Treger et al., 2007).

2.2.3.5. Community-based participation

The term community-based participation refers to "the extent of participation in religious, social, recreational, vocational, political and other organisational community groups and activities" (Rintala et al., 1998). Sixty-six percent of surviving strokes who reside in the community require the support of others with at least one ADL (Connor et al., 2004). It has been reported that for stroke participants to successfully function in the community, additional support needs to be provided for those caring for individuals with stroke in the community, as the caregiving role is often very challenging (Grant, Elliott, Weaver, Bartolucci, & Giger, 2002). It is very difficult to monitor community-based participation, as the mainstream stroke literature focuses on inpatient rehabilitation and outcomes and this makes monitoring post stroke participation in the community difficult. It is thus essential to gain some insight into community participation post stroke. This will help provide an indication of the effectiveness of post stroke interventions in the community and identify areas which need community strengthening (Mudzi et al., 2013).

A community-based study was conducted in Johannesburg, South Africa to determine participation at twelve months post stroke, using components of the ICF to collect data. Sixty percent of the population was cared for by relatives, while the remaining cared for by partners (Mudzi et al., 2013). All participants exhibited mild to moderate exertion with performing household tasks, which included meal preparation. The same finding was concluded by Mayo et al. (2002) when determining participation at six months post stroke. These results are suggestive that these restrictions are still persistent six months later in the community. Furthermore, having a significant activity to fill the day, performing ADLs, household chores and travelling are the most common participation restrictions affecting community dwelling stroke survivors (Barclay-Goddard et al., 2012).

2.2.4. Environmental factors affecting participation

As stated in chapter One of this thesis, the term environmental factors is described as “the physical, social and attitudinal environment in which people live and conduct their lives. These are either barriers to or facilitators of the person's functioning” (WHO, 2001). Research has concluded that a spacious house with flat terrain outside the home, no stairs or balconies and voluminous rooms inside the home, with low beds constitute an appropriate physical environment for living (Reid, 2004). Post stroke, survivors often reported making adjustments to their homes which included the installation of grab bars and railings on staircases. Bath mats and raised toilet seats were frequently used (Reid, 2004). Difficulty fulfilling social roles was often reported by participants as they socialised less with friends due to embarrassment and inability to be as active as they were prior to the stroke (Reid, 2004). Individual post stroke also experienced a restriction in the roles that they normally could perform prior to the stroke (Rhoda et al., 2015). It is in these restricted roles, that social support now becomes an important factor. In a qualitative study conducted by Reid (2004) participants reported that family and friends provided the appropriate support needed, to aid participants with functioning. Specifically, participants described how their spouses and families assisted them with activities such as house-making, and how other family members provided support with regard to caring and listening, known as emotional support. This resulted in a positive improvement in these individuals QoL. Other participants reported an absence of support from friends and families post stroke, especially when the support was required over longer periods. This led to social isolation in stroke individuals, adversely affecting their QoL (Rhoda et al., 2015).

2.3. Recovery post stroke

There are multiple factors affecting recovery post stroke. Stroke individuals who are exposed to specialist treatment such as admittance to a rehabilitation unit have been found to improve functional recovery. The exact rehabilitation techniques that worked best have not been studied (Young & Forster, 2007). Exposure to higher intensities of occupational therapy and physiotherapy had a positive effect on motor and functional recovery post stroke (Rhoda et al., 2014).

Research has shown age to be a significant predictive factor for recovery. Negative impact on function at or post discharge has been associated with an increase in age. It is difficult to determine whether age or age related co-morbidities affects function (Bagg, Pombo, & Hopman, 2002). There are reports that younger stroke survivors are able to participate in a higher number of activities prior to, and after stroke (Wolf & Koster, 2013). A study conducted by Tsouna-Hadjis et al. (2000) reported that high levels of family support affect functional status positively.

The management of the stroke patient from a rehabilitation view is relatively short in comparison to the extensive adjustments that individuals need and have to make. Therefore, when recovery persists after the completion of rehabilitation, there are explanations for it (Jones, Mandy, & Partridge, 2008). In a qualitative study, themes that emerged when assessing recovery post stroke included internal influences, such as the feeling of being in control, being optimistic and having hope about their recovery. External influences included the discharge home from hospital and therapeutic interventions from all rehabilitation staff (Jones et al., 2008). This article stressed the importance of internal feelings and thoughts to have a great impact on the recovery post stroke.

It was discovered that social support plays an important role in the recovery of a wide range of conditions (Cookson & Casey, 2013). Particularly with regard to stroke outcome, it was reported by Indredavik, Bakke, & Slordahl (1999), that the involvement of relatives in the rehabilitation process plays a vital part in improving functional outcomes. Furthermore, it was found that social integration post stroke can have a positive influence on functional status (Hershkovitz, Beloosesky, Brill, & Gottlieb, 2004). When assessing factors associated with the recovery of participation post stroke, an association with social support was revealed (Mayo et al., 2013).

2.4. Social support

2.4.1. Introduction

The term social support is a multi-faceted concept and is defined by Beckley (2006) as "the availability or provision of a relationship, information, or assistance that empowers a person to manage their day to day life effectively in the presence or absence of crisis." Social support can be categorised into four different types. Emotional support refers to caring, acceptance and listening, instrumental support entails the help of someone practically such as assisting with choirs and errands (Morelli, Lee, Arnn, & Zaki, 2015), informational support includes the provision of knowledge to help solve practical problems, companionship involves belonging and socialising, while validation refers to social comparison and feedback (Wills & Shinar, 2000). The structure and timing of support plays an equally important part and not only the types of support provided (Beckley, 2006).

Improved psychological and functional results have been strongly correlated to social support (Cookson & Casey, 2013). Earlier in the 1970s, when the concept of social support was first investigated as an aspect relating to health outcomes, Glass et al. (1993) conducted a study to determine the impact of social support on functional outcomes in first time stroke victims. High levels of social support were found to improve recovery and functional outcomes post stroke, regardless of stroke severity. Recovery progressed even after the common four to six week trend. Function was seen to decrease over time with lower levels of social support. These participants generally reached an apex after recovery in the first months, and then noticed a progressive decline in functional status. The above was noticed regardless of stroke severity. This shows that the severity of the stroke had little effect on the outcome, but the levels of social support received was deemed more significant. Furthermore, social isolation can be a factor for poor outcomes in stroke. Tsouna-Hadjis et al. (2000) found that different types of support influenced participants in different ways. Instrumental support in high measures has a positive impact on social and functional status, while large quantities of emotional support had a profound effect on patients' rehabilitation. Due to its nature as a multi-faceted concept, all social support variables should be taken into consideration to allow assured understanding on the impact of social support on health outcomes and community participation (Beckley, 2006).

2.4.2. The importance of family support

In a study conducted by Sumathipala et al. (2011), it was reported that the largest proportion of participants view social support from family and friends as a crucial facilitator of functioning. This support buffered the impact caused by disability, facilitating needs in the long term. Due to financial constraints and limitations with regard to accessing stroke-specific services, support services and rehabilitation, the burden of care often becomes the responsibility of the family members (Andrew et al., 2015). The support offered from family members was preferred over formal service provision with regard to daily activities (Sumathipala et al., 2011). In a study conducted by Tsouna-Hadjis et al. (2000), it was reported that functional, social status and depression was influenced by the amounts of family social support received. At discharge, 91% of patients returned to their homes, where a spouse, sibling or children living in the home or nearby took care of them. A further 9% were taken to a nursing home. The 9% of participants taken to a nursing home post discharge were the only participants that reported low levels of social support in the sample. This clearly shows the importance and impact of the family environment in the management of individuals with strokes.

2.4.3. Caregiver strain

It has been discovered that the majority of caregivers are often relatives of stroke survivors (Andrew et al., 2015). It is surprising to find that few studies have researched the consequences of stroke on informal caregivers and family, despite the high occurrence of stroke and the potential burden of family caregiving (Han & Haley, 1999). The typical profile for a large quantity of caregivers, are woman, usually the same age as the stroke patient, and married with a low educational level (Oliveira et al., 2013). Despite their low educational level, they were trained in caregiving skills by health professionals. For the caregivers that were married, their own families' care was neglected due to their responsibilities towards the stroke patient. Caregivers further reported problems addressing their own needs due to time limitations, withdrawals from their social life and changes in leisure activities (Oliveira et al., 2013). Financial pressure and work adjustments were reported in South African caregivers (Rouillard et al., 2012). Even in the role of the caregiver, social support becomes an important aspect. Twenty-one percent of caregivers reported that they were not receiving enough social support in their roles (Andrew et al., 2015).

2.4.4. The effect of social support on participation post stroke

In the past twenty years, the most prevalent research available with regard to social support has been of the direct effect and buffering models (Beckley 2006). The direct effect model relies on the prediction that ongoing social support resources has a positive influence on health, with or without the presence of stress, while the buffering model relies on the prediction that a recognisable form of social support has an advantageous effect in the presence of stress. The literature conducted more recently shows a positive relationship between social support and functional status (Beckley, 2006; Glass et al., 1993) with minimal literature available regarding social support and its effect on participation in the non-western worlds. A systematic review will therefore be conducted to determine the effect of social support on participation restrictions post stroke.

2.5. Summary of literature review

In this literature review, an overview of the literature relating to the burden of stroke and the outcomes with regard to functioning is presented. Participation has clearly been outlined as a restriction post stroke, particularly with return to work and community involvement. Factors affecting recovery post stroke need to be considered when assessing the functioning of the stroke patient. Research regarding social support has only recently looked at its effect regarding stroke recovery. This review thus outlines that current literature available regarding social support and participation is scarce, and that minimal research is available in South Africa about the topic. This review further highlights the need for a review pertaining to social support and its effect on participation post stroke.

CHAPTER THREE

SYSTEMATIC REVIEW

3. Introduction

This chapter presents a background of stroke in relation to social support and participation. The methods and step-by-step procedure to conducting a systematic review are reported. The results are tabulated and a flow chart developed depicting the study selection procedure. A hierarchy of evidence is presented to assess the strength of articles included. The PICO analysis and review of methodological quality are highlighted. A data extraction tool is developed to gather information from articles selected. The articles that met inclusion are discussed and characterised according to the common findings. Lastly, a conclusion is drawn from the main points highlighted in this review and implications for practice are reported.

3.1. Background relating to participation restrictions and social support

Cerebrovascular accidents can be classified as the most incapacitating chronic disease, affecting not only individuals and their families, but society as well (Mayo et al., 2002). The ICF is an appropriate tool to monitor the changes of stroke individuals functional capabilities (Joseph & Rhoda, 2013). This framework empowers medical professionals to provide care, taking into account the individuals activity limitations, participation restrictions as well as personal and environmental factors. Many studies show participation as a restriction post stroke (Barclay-Goddard et al., 2012; Chau et al., 2009; Graven, Brock, Hill, & Joubert, 2011), and this has been reported even in more mild strokes (Wolf & Koster, 2013). Two fundamental principles of participation include social and self-care aspects (Resnik et al., 2012). In a South African study conducted by Rouillard et al. (2015) it was concluded that most participants had difficulty performing activities outside their homes, which included shopping, and engaging in social activities. These participants required the assistance of others to effectively participate in activities. Participants further reported difficulties with self-care activities such as bathing and dressing. O’Sullivan & Chard (2010) concluded that constraints regarding re-engaging in leisure activities are common post stroke, and individuals reported the inability to return to their active lifestyles. As a result, a reduction in walking, gardening and participating in social outings were reported.

As stated in Chapter One of this thesis, the term social support can be defined as "the existence or availability of people on whom we can rely, people who let us know that they care about, value, and love us" (Sarason et al., 1983). Dating back to the early 1970s, social support has been found to have a profound effect on health and well-being (Tsouna-Hadjis et al., 2000), and has only recently been viewed as a significant factor to consider in relation to improvements in stroke recovery (Beckley, 2007). More than three decades ago, it was discovered that an association exists between functional recovery and social support. An increase in the levels of social support showed improvements in functional status, and acquisition in functional activities than those individuals with less social support (Glass et al., 1993). In a more recent study, social support was found to be a facilitator towards functional ability and QoL, in both mental and physical domains. Furthermore, essential ways of providing tangible support is in assisting patients post stroke with shopping, transportation, cleaning, cooking, money and childcare (Huang et al., 2010). The research available with regard to social support clearly stresses the impact on functional improvements (Beckley 2006; Glass et al., 1993). The purpose of the study conducted by Beckley (2006) was to review the influence of the buffering model of social support on functional outcomes following stroke. The findings of the study showed that with every unit increase of subjective social support, estimate of functional limitation increased by 0.003. This study did not directly assess the influence of social support on participation, but rather the impact of social support on functional status, and how functional status in turn influences participation. These results should be viewed with caution due to the small sample sizes obtained from both these studies. Due to these common gaps identified in the literature relating to social support and specifically participation, this information from the Western Worlds cannot be used. These gaps are seen in literature from the non-western countries as well (Huang et al., 2010). The evidence for social support stems from the study's conclusion that improvements in both functional limitation and community participation are dependent on social support. This means that an increase in social support, would result in improved functional status, and thereby improve community participation. However it was found that instrumental, quality and quantity of social support had no effect on functional limitation and community participation (Beckley, 2006). It is for these reasons that this review is being conducted. This review aims to systematically identify the relationship between social support and participation, in individuals living with stroke. The research question this review intends to answer is: What is the relationship between social support and participation in individuals living with stroke?

3.2. Methodology of the systematic review

3.2.1. The Search

The following databases were assessed to access articles which were published between January 2001 and December 2013 using Boolean/phrase search modes: Ebscohost full text which included CINAHL +, Health Source: Nursing, Academic edition, Medline, Psych articles and Soc index, Science Direct, Biomed Central, Google Scholar, Cochrane Library, Pedro Central and Wiley Online. The year 2001 was chosen as a starting point as it coincides with publication where the International Classification of Impairment, Disability and Handicap (ICIDH) were revised. In the ICF, the concept of participation could be seen to replace handicap, and also included the influence of contextual factors on disability. The databases were reviewed using the search terms stroke or cerebrovascular accident (CVA), social support and participation. In order to exhaust the search, a secondary search was conducted using the mesh terms. Recovery was added and all other search terms remained the same.

3.2.2. Inclusion and Exclusion Criterion

The following inclusion criteria was used: patients with a primary diagnosis of stroke, patients who were community-dwelling, studies which measured at least one domain of participation restrictions as identified by the ICF, an availability of the English full text version of the publication, and any article which outcomes measured included both participation and social support. The exclusion criteria for articles in this review included: studies measuring either social support or participation, articles where only the abstract was available with no full text version and articles conducted before the year 2001. The review included all types of study designs.

3.2.3. Assessment of Articles

Articles were screened initially by reviewing titles and abstracts. Once articles were selected following screening of titles and abstracts, the review using the PICO method was conducted.

3.2.3.1. PICO Analysis

The term PICO is described as Population, Intervention, Comparison and Outcome. The relevance of the articles during the PICO process was reviewed by two independent reviewers. Where consensus was not reached, reviewers conversed about the differences in opinions, and a unanimous decision was made. The articles that successfully underwent PICO analysis were then subject to undergo methodological quality.

3.2.3.2. Methodological Quality Assessment

The methodological quality of the articles included in this review was conducted by two independent reviewers. Both reviewers were required to score each article, using tools from the Critical Appraisal Skills Programme (CASP, 1994) and Milton Keynes Primary Trust (2002). Each tool consisted of ten to twelve questions designed to determine the studies methodological quality, two of which are screening questions that do not impact the final scoring of the article. Articles that scored between 8-10/10 were viewed to have a high score, 5-7/10 a moderate score, and 1-4/10 a poor score (Kumerenzi, Frantz, Rhoda, & Mlenzana, 2010). The articles which scored between 5 and above were included in this review.

3.2.3.3. The Data Extraction Tool

A data extraction tool was developed for the systematic review based on literature from Kumerenzi et al. (2010). The data gathered from the extraction tool included, but was not limited to: Author(s) name(s), country /geographical location, participant demographic details, study design, data collection instrument, outcomes measured, measurement tools used and the results of the study. This tool was developed to highlight important aspects of the studies included in this review.

3.3. RESULTS

A total of 22 645 articles were generated from the databases by the first hit of the key terms and the mesh terms. Out of these, 20 224 were generated by the key terms while the remaining 2 421 were generated by the mesh terms. Following an abstract and title scan of the articles, a total of thirty-three articles were identified as suitable for PICO evaluation, based on the inclusion and exclusion criteria. Of these thirty-three articles, twenty-six were selected from those that were generated by the entry of the key terms while the remaining seven were selected from the output of the mesh terms. Table 1 below highlights the output of each data base following the entry of key terms and mesh terms. It also shows the number of articles that were selected following title and abstract scan per database, while Figure 2 depicts a flow chart of the study selection. These thirty-three articles then underwent PICO analysis. Once the PICO and methodological quality of the articles were conducted, a total of three articles were included in this review. Initially, it was thought that the review would include randomised control trials (RCT) where the intervention was compared with usual care, but according to the search done by the researcher it was found that there were no intervention-based studies regarding social support and participation conducted between the years of interest. Thus, the three articles included qualitative, cross sectional and cohort studies. Table 2 represents the hierarchy of evidence, based on summaries from previous literature (Bigby, 2009; Melynyk & Fineout-Overholt, 2011; Oxford Centre for Evidence-based Medicine Levels of Evidence, 2011). Based on the evidence hierarchy below, articles identified in this review are representative of level 4 and 6 evidence.

Table 1: Database output

	KEY WORDS SEARCH		**MESH TERMS SEARCH**	
Databases	**Hits**	**Abstract scan**	**Hits**	**Abstract scan**
EBSCHOST (CINAHL +, Health Source: Nursing, Academic edition, Medline, Psych articles, Soc index)	143	10	100	0
PUBMED Central	44	2	45	1
Science Direct	1902	2	716	3
PEDRO Central	2	2	0	0
Google Scholar	18100	10	1530	3
Cochrane Library	33	0	30	0
Wiley Online	0	0	0	0
TOTALS	20224	26	2421	7

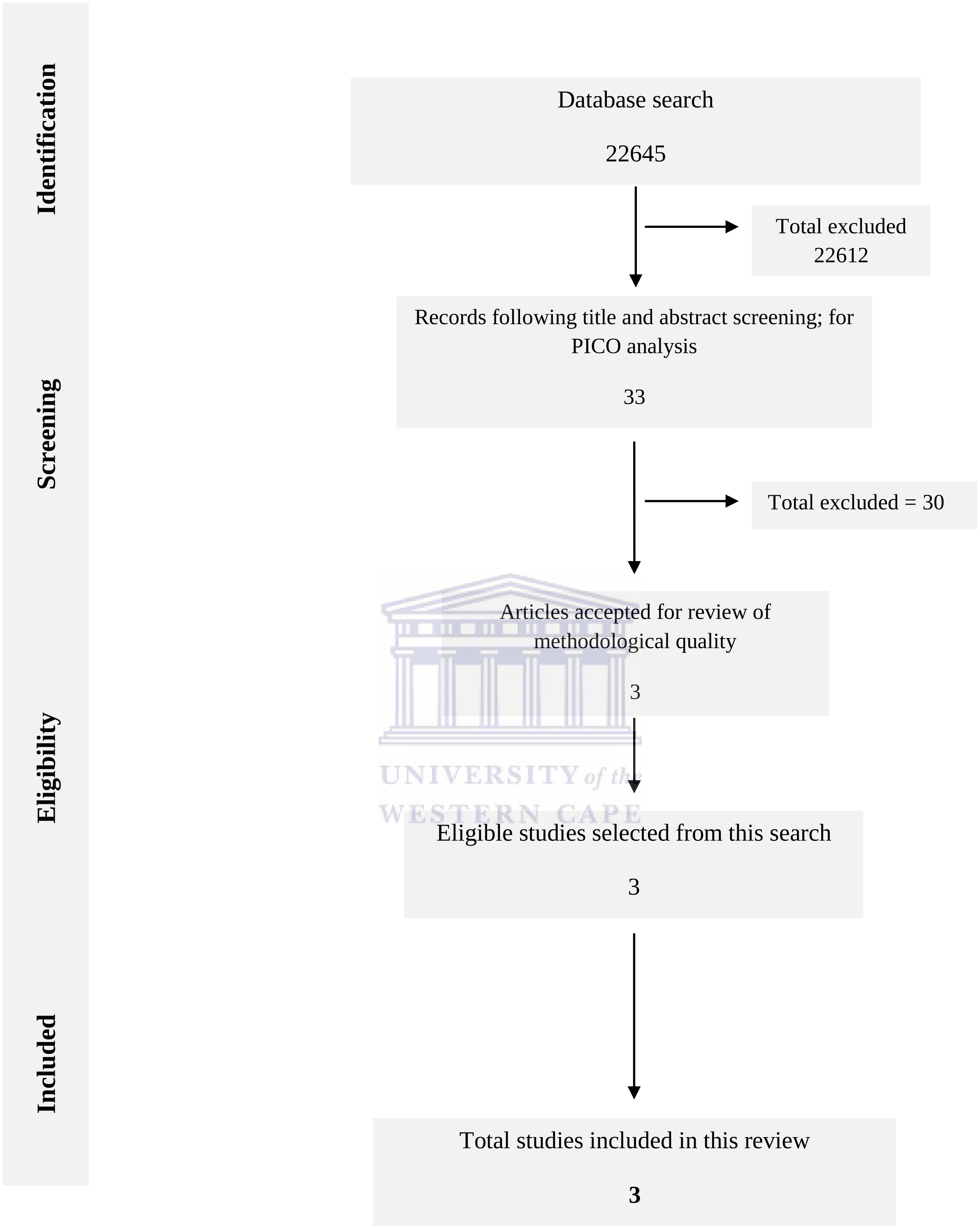


Figure 2: Flow chart depicting study selection

Table 2: Hierarchy of evidence

Evidence level	**Description**
I	Evidence obtained from a SR of all relevant RCTs.
II	Evidence obtained from at least one well designed RCT
III	Evidence obtained from well-designed controlled trials without randomization
IV	Evidence obtained from well designed cohort studies, case control studies, interrupted time series with a control group, historically controlled studies, interrupted time series without a control group or with case- series
V	Evidence obtained from SRs of descriptive and qualitative studies
VI	Evidence obtained from single descriptive and qualitative studies
VII	Expert opinion from clinicians, authorities and/or reports of expert committees or based on physiology

Key:

SR = Systematic review

RCT = Randomised controlled trials

3.3.1. PICO Analysis

A total of thirty-three articles underwent analysis using the PICO method. There were no RCTs identified, so all articles had no intervention and comparison groups. Matters discussed amongst assessors included articles which measured participation and included aspects of social support, although social support was not measured. The term social participation in relation to social support was also discussed. It was then decided that only articles measuring both social support and participation, will be included in the review. Thus, the use of an independent third party was not necessary, as the two primary assessors were able to reach consensus regarding all articles. After the two assessors conducted the PICO, a total of three articles were included to test methodological quality. The remaining twenty-nine articles were excluded as they did not measure both social support and participation. Many articles were identified as having measured either participation or social support, which is why they were excluded.

3.3.2. Review of methodological quality

The three articles which met the inclusion criteria were assessed by two reviewers to determine its methodological quality. The studies were grouped into three categories namely: cross-sectional (one article), qualitative (one article) and cohort (one article). The methodological tools identified according to the CASP appraisal tools for the cohort (Appendix S) and qualitative studies (Appendix T) were utilised to assess the methodological quality of the studies (Akobeng, 2005; Critical Appraisal Skills Programme, 1994), while the methodological tool identified by Milton Keynes Primary Trust for cross sectional studies (Appendix R) was used to determine the quality of the cross sectional study (Milton Keynes, 2002). All three articles were included in this review, as they obtained moderate - high scores for their quality appraisal. The scores below represent the unanimous scores of both reviewers (See Table 3).

Table 3: Methodological scores

Article	**Q1**	**Q2**	**Q3**	**Q4**	**Q5**	**Q6**	**Q7**	**Q8**	**Q9**	**Q10**	**Q11**	**Q12**	**%**	**MA**
Beckley (2007)	Y	Y	Y	N	Y	Y	Y	Y	Y	N			8	**Y**
Sumathipala et al (2011)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y			9	**Y**
Mayo et al (2013)	Y	Y	N	Y	N N	Y Y	n/a	n/a	Y	c/t	c/t	n/a	6	**Y**

Key:

Y = Yes

N = No

n/a = No scoring required

c/t = Cannot tell

MA = methodologically accepted

3.3.3. Data Extraction Tool

The sample size of the participants included in this study ranged from 34 – 100. The different methods used to collect data included questionnaires, as well as instruments for quantitative data. Semi-structured and in-depth interviews were utilised to gather qualitative data. The cross-sectional study reported on social support and its effect on community participation (Beckley, 2007), the qualitative study reported on how contextual factors as identified by the ICF influenced long term needs after stroke (Sumathipala et al., 2011) while the cohort study reported on walking capacity, mood and social support, to determine its influence on participation (Mayo et al., 2013). This information is provided in the table below (See Table 4).

Table 4: Data extraction tool

Authors	**Country**	**Population**	**Study design**	**Data collection instrument**	**Outcome measured**	**Measurement Tool**	**Result**
Margaret Newsham Beckley (2007)	United States of America	95 Stroke survivors discharged from a rehabilitation centre. Ages not indicated.	Cross Sectional	Interviews	Community participation Social Support Functional limitation	Reintegration to normal living (RNL). Social Support Inventory for People with Acquired Disabilities (SSIPAD) Self reported	Quality and quantity of social support played a significant role in community participation.
Sumathipala, K. et al (2011)	London	35 Stroke survivors between 1 and 11 years post stroke with ages ranging from 34 – 100 years.	Qualitative	Semi structured in depth interviews	Environmental (Physical, social and attitudinal) and personal factors	Themes classified according to International Classification of Functioning (ICF)	Participants identified a range of ICF environmental and personal factors Social support was seen as a key facilitator of functioning for participants
Mayo, N. E. et al (2013)	Canada	102 Stroke survivors with a mean age of 70	Cohort	Surveys and objective tests	Participation Mood	Stroke Impact Scale (SIS) Mental Health	The higher the proportion of people with excellent or

		years.			Social Support Walking Capacity using the Stroke Severity	Subscale (MHI) Older Americans Resources and Services system (OARS) 2 Minute Walk Test (2MWT) Canadian Neurological Scale (CNS) and Barthel Index (BI)	good social support showed excellent participation Walking capacity can be seen as a sufficient cause for participation

3.4. Discussion

This review explored the available literature relating to social support and its impact on participation in stroke survivors. The cross-sectional study was conducted by Beckley (2007) to determine the impact of the quality and the quantity of social support, and which of the two factors played a more significant role in community participation. The study concluded that both quality and quantity of support played an important role in community participation, but the quantity of social support more so. Furthermore, functional limitations appeared to be the most significant variable affecting community participation. This study utilised a cross-sectional design of participants at three to six months post stroke. Therefore, this is an inappropriate design to predict the effects of social support on community participation, as support is generally provided over long periods of time, contrary to functional status, where improvements are seen as soon as four to six weeks post stroke (Glass et al., 1993). This could have influenced the results. The qualitative study conducted by Sumathipala et al. (2011), analysed contextual factors in the framework of the ICF and described how participants are affected by long term disability. The main aspects which emerged in the theme of support and relationships was that although participants battled with multiple ADLs on a daily basis, the support provided from family and friends was seen as a facilitator towards functioning, especially in aspects of participation. A limitation to this study was the validity of the results obtained, as conducting interviews only measure one in-depth account

(Sumathipala et al., 2011). Lastly, the cohort study was conducted by Mayo et al. (2013) to determine the effects of walking capacity, mood and social support on participation. The study found a positive relationship between social support and participation. More specifically with regard to social support, participants with excellent social support initially, experienced a decrease in support as time progressed, followed by a slight increase in support after the decline. This support even later on was still ranked as very good social support. It was reported that participants who had poor social support, also displayed large restrictions in participation. According to the author (Mayo et al., 2013), a small sample size was a limitation, and results therefore cannot be generalised to the entire stroke population.

The main areas focused on in the articles included for the discussion in this review were: the quality of social support which refers to the types of support provided, the quantity of social support which refers to the amounts of people providing support and lastly, the relationship between social support and participation. These three aspects will be discussed in more detail below.

3.4.1. The Quality of Social Support

It has been reported that the quality of social support plays a role in community participation at three to six months post stroke (Beckley, 2007). The statistical significance was determined at 0.03, explaining 31% of the variance of the dependant variable. Based on the hypothesis for this study, it is clear that the author expected the quality of support to have a bigger influence on community participation than what the results show post stroke. Participants conveyed that even before the stroke, they were receiving help with ADLs from their spouse or other family members. This however was not based on need, but a reflection of the quality of support provided. This statement shows that the support was generally provided over a long term, and even prior to the disability. Post disability, participants are still receiving the same type of support, which shows that the quality of support was maintained over a long period of time. Furthermore, the ability of an individual post stroke to perform activities themselves would aid in community participation more than having people in your life that can assist you with certain activities (Beckley, 2007). A 79-year old female participant in the study conducted by Sumathipala et al. (2011), explained how the support she received from her family was not only practical, but also lessened the pressure of managing daily activities. The four people providing support to her included her daughter, son in-law and two grandsons. She stated the many ways in which they helped her with day-to-day duties such as driving her to places she needed to be at, and ensuring that her room and house was kept clean. With her children providing her with the necessary transport to engage in preferred activities, this aids participation. This is a reflection of the type of support she is receiving from her family. Even though there are only four people providing support to her, she is very pleased with the types of support provided, which is an indication of the quality of support given. She suffered a stroke eleven years ago, and is still referring to them as “gems”. This could point out that even as time progresses, the quality of social support provided by family does not change. It is conclusive that for the quality of social support to have positive outcomes on community participation post stroke, the support provided should be based on the needs of the individual and dependant on the profile of the individual.

3.4.2. The Quantity of Social Support

Beckley (2007) established a significant relationship between the quantity of social support and its effects on community participation three to six months post stroke. The P value for statistical significance was 0.004 explaining 35% of the variance of the dependant variable. It is noted that when determining the role of the quality and quantity of support on community participation, the quantity was found to have a greater impact. In this study, participants conveyed that they had always received more support from family and friends than what was needed. Having stated this, it is suspected that individuals with closer personal relationships receive more assistance than those without. Based on the reports from participants regarding the amounts of support received from others, this reiterates quantity of social support received. The stage of the disease is important when considering quantities of social support. In the acute phase of the disease individuals would require large amounts of support to cope with the burden of disability, contrary to an individual residing in the community for many months post stroke. This statement is strengthened by the finding of the study conducted by Mayo et al. (2013) which revealed that participants experienced high levels of social support initially post stroke and as time progressed, a drop in social support levels were noticed, followed by a slow increase in support. However, this was only seen in individuals who displayed large quantities of social support prior to their stroke. Even after the drop and slow increase in social support, these individuals were still classified in the group of excellent social support, obtaining scores of above 80%. This shows that although the quantities of support received were relatively inconsistent after the initial phases, due to the large amounts of support received, they were still classified as having high social support. In conclusion, for the quantity of social support to have a significant effect on participation in the community, the support needs to be established in the healthy, disease free individual, prior to the stroke. Support needs to be provided in large quantities so that even when there is a decrease in support levels, the individual would only be mildly affected.

3.4.3. The Relationship between Social Support and Participation

The three articles identified in this review each stipulate distinct relationships between social support and participation. Sumathipala et al. (2011) reported that 74% of participants found support from friends and family to be a key facilitator toward functioning which has shielded them from the impact of disability. Three individuals had moved houses to be closer to their friends and families to access the support they required to participate in activities. This clearly highlights the impact of appropriate support needed for community participation. Participants who experienced limited support from family reported difficulties with ADLs and participation. Furthermore, in the few cases (8%) where support from family members was not definite in the long run, this resulted in poor participation.

Beckley (2007) established a positive link between functional restrictions and community participation. As an individual’s independence increases, so does their community participation and the same apply for the reverse. Furthermore it was found that social support facilitates improvements in function. As subjective social support increases, the estimate of functional limitation increases by 0.003. The improvements noted in functional status post stroke, positively affects community participation. A factor significantly linked to excellent participation was safe community walking as identified by Mayo et al. (2013). The study further attempted to determine the relationship between social support and participation. In the process, participants were divided into categories based on the amounts of support they received. Participants (11.4%) scored support levels between 20 – 55 of the maximum (100) value, and were classified as having poor social support, 52.4% of the sample scored between 60 – 70 of the maximum value and were classified as having fair social support, a further 26.4% of participants scored values of 80 and classified as having very good social support and the remaining 10% scored above 80% and were classified as having excellent social support. It was confirmed that 56% of the participants in the very good social support group had excellent levels of participation, and a further 71% of the sample classified as having poor social support experienced poor participation. These results highlight the fact that adequate levels of social support are required for good community participation.

3.5. Conclusion

The three articles identified as part of this review each discuss social support and how it relates to the functioning of the stroke patient, specifically with regard to participation. The influence of the quality and quantity of social support were two of the main aspects which emerged in this discussion. There is Level 4 evidence (cohort study) which shows a positive association between social support and participation, where increased levels of social support showed increased community participation and the same can be said for the reverse. The Level 6 evidence (descriptive study) produced relates to the quantity and the quality of social support and how these factors mediate community participation. There is evidence presented which favours the quantity of social support to have a better effect on community participation. This has also been stressed in the Level 4 evidence (cohort study). The quality of social support has also been found to have a significant effect on community participation, although this was the only level of evidence presenting these findings. Furthermore, the level 6 evidence (qualitative study) re-iterates the importance of social support on community participation by explaining how participants viewed support from family and friends. It is also noted that a minor percentage of participants described over-protective approaches by friends and family as a hindrance to functional recovery. This level 6 evidence (qualitative study) was only reported from a minority of participants. Furthermore, it is evident from this systematic review that there is a lack of literature with regard to social support and participation, and no RCTs available according to the search conducted by the researcher. This can be said for the western and non-western worlds. Specifically in the non-western worlds, before conducting RCTs, there is a need for descriptive studies. This is needed to bridge the common gaps seen in the literature.

3.6. Implications for practice

Based on the findings of this review it is clear that social support is a vital factor to consider when managing the stroke patient holistically. This includes planning rehabilitation interventions for affected individuals. This information is particularly important to health professionals, especially physiotherapists and occupational therapists, working in the Community Health Centers. Rehabilitation strategies and interventions could focus on incorporating group activities. This will expose individuals to others suffering from similar difficulties as they are, and this might improve their quantities of social support. Social support interventions need to be planned by the respective professionals, as this will aid the re-integration of participants back into the community. It will also improve the stroke patients social support networks. Rehabilitation interventions should also include group sessions, with family members and care givers. Here, focus should be on assisting participants to gain independence, with the help of the families and caregivers to provide support. Furthermore, outdoor activities with family and friends should be encouraged, to aid social support and participation in the community.

3.7. Summary of systematic review

This systematic review was conducted to determine the available literature on social support and participation post stroke. Ebscohost full text which included CINAHL +, Health Source: Nursing, Academic edition, Medline, Psych articles and Soc index, Science Direct, Biomed Central, Google Scholar, Cochrane Library, Pedro Central, and Wiley Online were the databases searched for literature published between 2001 - 2013. A total of three articles were included in this review, from the 22645 identified in the first hit of the search and mesh terms. No RCTs were identified, so no intervention based studies were assessed. The studies included designs of a qualitative (one article), cohort (one article) and cross sectional (one article) natures. According to the hierarchy of evidence presented these articles provided Level 4 and 6 evidence on social support and participation post stroke. The discussion concluded that both quality and quantity proved significant in relation to participation. However the quantity ($p=0.004$) more so than the quality ($p=0.03$). The evidence also showed that social support was viewed as an essential variable when reviewing community participation post stroke. This review concluded that for social support to have an influence on participation, the support provided should be of high quantity, good quality, should be based on the needs of the individual, and lastly, it should be provided in this fashion even prior to the stroke. It is recommended that studies in future focus on conducting RCTs, and descriptive studies locally, to further understand the concepts related to an association between these two variables.

CHAPTER FOUR

METHODOLOGY OF THE SURVEY

4. Introduction

This chapter presents the methodology of the survey. Information regarding the research setting, design, population and sampling are discussed. The role of the CHCs in the Western Cape is discussed briefly. The studies inclusion and exclusion criterion are stipulated. The Social Support Questionnaire 6 is described as it measures social support, while the WHODAS 2.0. is discussed as it measures participation restrictions post stroke. These two instruments and their scoring are discussed in detail. The data collection procedure and training of assistants are reported. The data analysis procedure and ethical considerations with regard to this study are noted.

4.1. Research Setting

The study was conducted at the Community Health Centers (CHCs) in the Southern Western, and Klipfontein Mitchell's Plain Metro District Health Service (MDHS) of the Western Cape. These centres are responsible for providing primary health care in the Western Cape. Primary health care is defined as essential health care, accessible to individuals in the community, at an affordable cost (World Health Organisation & UNICEF, 1978). In the community, these primary care facilities are the first line of treatment, and are mainly run by professional nurses (Mbambo, Uys, & Groenewald, 2003). The CHCs provide essential health care by the principles of promotion, prevention, cure and rehabilitation (World Health Organisation & UNICEF, 1978). The majority of the population in South Africa is attending these CHCs for medical management (Reagon, Irlam, & Levin, 2004). In the Western Cape, CHCs are primarily positioned in rural towns or large urban areas and have been found to be of the best resourced primary care systems in the country (Mash, Levitt, Steyn, Zwarenstein, & Rollnick, 2015). These services are predominantly utilised by individuals from disadvantaged communities, with low socio-economic class, poor knowledge of health and low levels of education (Mash et al., 2015). Together, there are fourteen CHCs in the Southern Western and Klipfontein Michell's Plain MDHS (Rhoda, Mpofu, & Deweerdt, 2009), and eight of these centres were used to obtain data for the current study. A pilot study was conducted at the CHCs in the Klipfontein Mitchell’s Plain MDHS. Stroke survivors requiring rehabilitation at one of the CHCs require a referral letter from a medical doctor. In exceptional cases or in patients with severe disabilities, the therapists often perform home visits. There is one physiotherapist employed at each CHC and occupational therapy (OT) services are run once a month from an OT who services all the CHCs in the surrounding areas. All rehabilitation is done one on one as group sessions in the past often failed due to poor compliance and attendance.

4.2. Research Design

This study used a quantitative approach which involves the use of effective statistics to explain the associations between variables by means of quantifying them (Hopkins, 2008). The study utilized a cross sectional design making it descriptive in nature. Cross sectional designs are used to explore the association between variables at a given point in time (Hopkins, 2008). This design is useful when attempting to describe demographics, socio – economic status and health characteristics of a population with a common condition (Kelley, Clark, Brown, & Sitzia, 2003). The data was then collected using surveys. The term survey is defined as “the selection of a relatively large amount of people from a pre-determined population, usually the population of interest and then collecting a small amount of data from this population” (Hopkins 2008). Surveys are appropriate for descriptive designs and are frequently used in literature pertaining to health and health services. The current study survey was used to gathered information on social support and participation restrictions, making it descriptive in nature (Kelley et al., 2003). This specific design was used as it provided the researcher with empirical data in large quantities, in a short amount of time at a relatively low cost (Kelley et al., 2003). Lack of detail in the data and response rates when conducting surveys telephonically or via the post are two common disadvantages of using this design (Kelley et al., 2003).

4.3. Study population

All stroke patients treated at the CHCs in the Southern Western, and Klipfontein Mitchell’s Plain MDHS who agreed to partake in the study formed the sample population. A preliminary review was conducted by the researcher between January to December 2013 at the physiotherapy departments at the CHCs of interest. An estimated 580 new patients were being treated for rehabilitation services annually, 12% of which made up the stroke population. Thus, an average of 66 new stroke patients was seen at the physiotherapy department annually, with majority being female. Approximately 200 stroke patients were selected as suitable to participate in the study. The sample size is based on a population size of 500 stroke patients treated at the centres for a six month period.

4.4. Sampling

Sampling of participants was done through convenience. Convenience sampling is where the participants included in the study are the easiest to recruit (Kelley et al., 2003). All individuals attending the CHCs at the time of data collection, diagnosed with CVA who met the inclusion criteria were invited to take part in the study. The names of suitable participants were accessed from the therapists or relevant health professionals working at the CHCs. Approximately 150 stroke patients were recruited into the study. With a population of 500 a 20% sample size is suggested (De Vos, Strydom, Fouche, & Delpoort, 2002). Thus data collection took place over a period of four weeks, from the 13th – 25th April 2015, and the 22ndJune – 03rdJuly 2015 respectively, which was determined based on the sample size needed.

4.4.1. Inclusion Criterion

All individuals diagnosed with CVA by the Medical Officer at the CHC, and living in the community for at least six months were included in this study. Individuals attending the CHC for rehabilitation who met the above criteria were also included in this study.

4.4.2. Exclusion Criterion

Stroke patients were excluded from the study if they suffered from severe cognitive deficits or speech impairments such as dysarthria, receptive or expressive aphasia.

4.5. Research instruments:

4.5.1. The Social Support Questionnaire (SSQ)

The Social Support Questionnaire (SSQ) was used to determine the level of social support in each individual (Sarason et al., 1983). This research instrument has two versions, namely the Social Support Questionnaire (SSQ), and the Social Support Questionnaire 6 (SSQ6). The SSQ comprises twenty-seven questions which consist of two parts, requiring a two part answer. Part one includes listing any person/s (up to a maximum of nine people) which the participant can depend on under any circumstances, whenever they require help and people who will care about them regardless of the circumstances. The option of selecting “no-one” was available to participants if they did not have anyone in their lives providing support with regard to the question asked. Part two requests the participant to rate their level of satisfaction of the above mentioned people. The satisfaction scale ranges from 1 - 6, where 1 indicates that participants are very dissatisfied with the support provided, and 6 indicates that the participants were very satisfied with the support provided. These values demonstrates how pleased individuals are with social support received (Sarason et al., 1983). The SSQ demonstrates exceptional reliability with ICC scores of 0.90 for the overall number score and 0.83 for the satisfaction score (Sarason et al., 1983). The values obtained for the validity of the SSQ for overall number and satisfaction scores were 0.34 and 0.57 respectively (Sarason, Sarason, Shearin, & Pierce, 1987).

The SSQ6 is a shortened version of this questionnaire and is condensed to only six of these questions, with the format remaining the same (Sarason et al., 1987). The twenty-seven questions in the SSQ were condensed to six questions in the SSQ6. The remaining twenty-one questions were condensed into the six questions available in the SSQ6. This shortened version was created by Sarason et al. (1987) for use when time administration is difficult. The test re-test method was used to determine the reliability for the SSQ6. The scores obtained for the number scores and satisfaction scores ranged from 0.90 – 0.93 (Sarason et al., 1987). The validity of the scale was determined by comparing the SSQ6 to several other measures (Klocek, Oliver, & Ross, 1997). The SSQ 6 (Appendix M) was then used for collecting data regarding social support because its reliability and validity were highly satisfactory from a psychometric point of view, and very similar to the SSQ (Sarason et al., 1987).

Three variables were taken into account to determine the scoring of the SSQ6 namely the SSQ number score (SSQN), the SSQ satisfaction score (SSQS) and the SSQ family score (SSQF). To calculate the SSQN, the total number of people for the six questions was added up to receive a maximum score of 54. This total was then divided by six to get the SSQN. Therefore, the minimum values displayed for the SSQN are 0, and the maximum value displayed is 9 (Sarason et al., 1983). Previous literature using the same tool to measure social support have classified the SSQN into two groups, namely low SSQN and high SSQN scores (Klocek et al., 1997). The same was adopted for the current study. Thus, a SSQN obtained between 0.0 – 4.0 would indicate a low score, while a SSQN obtained between 4.1 – 9.0 would indicate a high SSQN.

The SSQS was obtained by adding up the satisfaction values of the second part of the question, obtaining a maximum score of 36. This value was then divided by 6 to obtain the SSQS. The minimum values displayed for the SSQS are 0 and the maximum value displayed is 6 (Sarason et al., 1983). A similar classification of the SSQN was adopted for the SSQS. Thus a SSQS value between 0 – 3 would indicate low SSQS, while a SSQS value between 4 – 6 would indicate a high SSQS.

The SSQF was obtained by adding all people that are family members for each question. The minimum value for the SSQF is 0, while the maximum value for the SSQF is 54. The higher the scores for the SSQN, SSQS, SSQF and overall score for the SSQ, the higher the participants perceived social support. Once this questionnaire was completed and all relevant data filled in, a total score based on the calculations above was given for each participant.

4.5.2. The World Health Organisation Disability Assessment Schedule (WHODAS 2.0.)

The World Health Organisation Disability Assesment Schedule 2.0. (WHODAS 2.0.) (Appendix L) is a questionnaire used to determine the individuals functioning and participation restrictions. The initial WHODAS was published in 1988 by the WHO and has undergone immense modification in order to produce the WHODAS 2.0. In 1988, the tool was used predominantly to assess psychiatric patients and their functioning in a hospital setting. The WHODAS was then adjusted to the WHODAS 2.0. to assess disability with specific links to the ICF, and can be administered on an average time of 20 minutes (World Health Organisation, 2001). When completing this tool, the individual is required to rate the difficulty of a given task or activity on a scale from 1 (no difficulty) to 5 (extreme difficulty), where N/A (not applicable) would indicate that the participant does not participate in the activity of question. The participant is explained what the terms difficulty and health condition refers to, and then instructed to think of the past thirty days only, while answering these questions. This instrument consists of six domains namely: cognition, mobility, self-care, getting along with people, life activities and participation (Üstün, Chatterji, Kostanjsek, & Rehm, 2010). This instrument will be used to collect the data relating to participation restrictions. The test retest method was used to determine the reliability of this research instrument (Üstün et al., 2010). The WHODAS 2.0. scored ICC values of 0.69 – 0.89 for reliability with good face validity as 64% of professionals agreed that the WHODAS 2.0. content measures disability as defined by the ICF. Once the questionnaires are completed, the participants obtain a score ranging from 0 to 100, where 0 indicates no problem in the domain of question, while 100 indicates complete problems in the domain of question. There are two ways which this scoring can be conducted. Simple scoring is when the scores from each entry are added up to obtain a score, without any weighting of individual items. This method is useful when scoring by hand. Complex scoring considers numerous levels of difficulty for each entry of the WHODAS, permitting in-depth investigation by using the full information in the category response (Üstün et al., 2010). For the purpose of this study, the complex scoring method referred to as item-response-theory (IRT) based scoring was used to analyse the data and determine the distribution of the domains in the WHODAS 2.0. This process consists of three steps. The initial step requires summing up the recoded item scores within each domain, then summing each six domain scores, and finally, converting the summary score into a metric ranging from 0 – 100 (Üstün et al., 2010).To determine the total domain scoring, this metric value was broken down into categories to further classify individuals disabilities, received from the WHODAS 2.0. manual (Üstün et al., 2010). A metric ranging between 0 – 4% indicates no problem, 5 – 24% is mild problem, 25 – 49% indicates moderate problem, 50 – 95% indicates severe problem and 96 – 100% is an indication of complete problem in any given domain (Üstün et al., 2010).These classifications were used when analysing the domain specific results.

A participant demographic sheet (Appendix I) of the questionnaire was developed to determine socio-demographic and medical factors as it relates to the participant. This demographic sheet included the following information: highest qualification obtained, employment history, details relating to the stroke/s, risk factors, co-morbidities, living conditions, current status on stroke support groups and average income per month. This information was used to further understand the socio-economic status of the participants. Some of this information was questions included in the WHODAS 2.0.

4.6. Data Collection Procedure

4.6.1. Survey

Data collection commenced once permission and ethical clearance was obtained from the necessary authorities. All facility managers from the CHCs of interest were contacted telephonically asking for permission to contact the physiotherapist working at the CHC. A copy of the final proposal and the ethical approval letter were e-mailed to the facility managers after the telephonic discussion. Permission was then granted and the contact numbers of the physiotherapists obtained. The therapists were then contacted to make arrangements for data collection. Data collection took place over a period of four weeks, 13th to 25th April 2015 and 22ndJune to 03rdJuly 2015, respectively. This was decided based on the sample size needed as well as seasonal changes. These specific dates were chosen for data collection in the attempt to reduce the rate of default by participants due to seasonal changes.
The dates were given to the therapists who then contacted all stroke patients receiving rehabilitation, as well as others attending the CHC for various other reasons, explaining the study and requesting the individual to participate. In some cases, the telephone numbers of individuals were given to the researcher, who then contacted participants to recruit. Most patients were willing to assist and agreed to attend the CHC on the given date. On the day of data collection, other stroke patients collecting medication or seeing the medical doctors were invited to participate in the study. A few participants could not attend due to transport and other personal issues. These participants were then contacted after data collection at the CHC to provide a date and time which is convenient for the participant where the SSQ 6 and WHODAS 2.0 were completed at the participants' homes by the researcher.

Data collection proceeded at 09h00 or 09h30 on the given day, depending on the CHC and the participants. A group of six research assistants, and the primary researcher conducted data collection at the various CHCs. The training of the research assistants was conducted by the primary researcher. The research assistants were all undergraduate physiotherapy students, who have had previous contact with individuals post stroke. The assistants were conversant in English, Afrikaans and isiXhosa. The assistants were trained to use the WHODAS 2.0. with the help of the WHODAS 2.0. manual and the research instrument, and trained to use the SSQ6 with the assistance of the research instrument and previous literature using the tool. The clinician working at the CHC arranged for a small room or cubicle, usually at the physiotherapy department or close by, for data collection to take place. Once the researchers arrived at the placement, they would first go to the facility manager to personally introduce themselves, and then proceed to the physiotherapy department to liase with the clinician. A refreshment station was setup close by, for participants before data collection commenced. The clinician booked all participants in timeslots of forty minutes each. Some participants took longer to complete the questionnaires than others. However, most of them were completed within the forty minutes. Where cases took longer than the allocated forty minutes, the other participants were informed and were understanding about the situation. Other participants had timeslots and defaulted. On arrival at the data collection room, researchers introduced themselves to participants and the aims and objectives of the study explained. Participants were then asked what their preferred language of communication was, as questionnaires were available in English, Afrikaans and isiXhosa. Each participant had a booklet which consisted of an information sheet (Appendix C), consent form (Appendix F), demographic sheet, WHODAS 2.0. questionnaire, as well as the SSQ6 questionnaire. Participants were asked to sign the consent form and provide verbal consent before completion of the questionnaire. If participants had difficulty using their dominant hand because of the stroke, verbal consent was given to the researcher. Once consent was provided, the questionnaire was completed. Participants were first required to complete the demographic sheet, followed by the WHODAS 2.0 and then SSQ6 together with the assistance of the researcher. On completion of the booklet, participants were thanked for participating in the study and asked if they had any questions.

4.7. Data analysis

Completed data was captured and entered into the Statistical Package for the Social Sciences (SPSS) Version 23 in preparation for analysis. The demographic information from the participants was captured into the SPSS software. The SSQN, SSQS, and SSQF were manually calculated using a formula from Sarason et al. (1983) and entered into the software. The data from the WHODAS 2.0.was initially entered into Windows Excel 2010 and then recoded according to the guidelines of the IRT based scoring found in the WHODAS 2.0. user manual. Completed coded data was then transferred into the SPSS software for analysis. Frequency tables were used to describe categorical data, while means, medians and standard deviations were used to describe continuous data. This was done using descriptive statistics. The Pearsons Correlation test was used to determine statistical significance between two variables, with alpha co-efficient set at $P \leq 0.05$. Due to the nature of this study design, no confounding variables were identified affecting statistical significance.

4.8. Ethics

Permission to conduct this research was obtained from the University of the Western Cape's Faculty of Community and Health Sciences Higher Degrees Committee, The University of the Western Cape's Senate Research Committee (Appendix A) and the Department of Health of Western Cape (Appendix B), reference number 14/5/22. Participants were assured that their participation in this study is completely voluntary and that their agreement, refusal or withdrawal would not impact their treatment at the CHC. Confidentiality of participants was maintained throughout the study as the researcher and research assistants were the only persons handling the data and no names were used during the capturing and analysis of data. Written and verbal informed consent was obtained from all participants. An information sheet was issued to each participant explaining the above. Participants were made aware that there were minimal risks involved in participating in this study, and the aims, objectives, and outcomes of the study were explained. The information sheets, consent forms and questionnaires were available in English, Afrikaans and Xhosa to accommodate all participants. The questionnaires and other relevant material were translated using backward translation. Participants were referred to relevant health professionals at the CHC where necessary. The results of the study were disseminated to the relevant parties. The demographic and social support data of participants were shared with the research assistants for use in a separate undergraduate study.

4.9. Summary of the methodology

The current study was conducted at the CHCs in the Southern Western and Klipfontein Mitchell's Plain MDHS. A quantitative research approach was used, using descriptive surveys. All individuals who suffered from a stroke, living in the community and attending the CHCs of interest for at least six month were included in the study. Participants were sampled by means of convenience and were excluded if they suffered from severe cognitive deficits. The SSQ 6 was the instrument used to collect information regarding social support, while the WHODAS 2.0. was the instrument used to collect information regarding participation restrictions. Ethical approval was granted from the University of Western Cape as well as the Western Cape Department of Health, reference: 14/5/22. The data collection booklet containing the information sheet, consent form, demographic sheet, WHODAS 2.0. questionnaire, and SSQ6 questionnaire was made available for participants in English, Afrikaans and isiXhosa. Written and verbal consent was obtained from all participants prior to proceeding with data collection. Data collection took place over a period of four weeks once permission was received from the facility managers at the respective CHCs. Once the data was collected, it was entered into the SPSS version 23, in preparation for analysis.

CHAPTER FIVE

RESULTS

5. Introduction

This chapter presents the results of the current study, after analysis of the data was conducted. The demographic information of the participants is presented in the form of tables, depicting the percentages and means and standard deviations for continuous variables. The results of all six domains of the WHODAS 2.0. are presented using tables, histograms and pie charts. The domains include cognition, mobility, self-care, getting along with people, life activities and participation. A graph is depicted showing the differences in total scores between the six domains mentioned above. The data regarding social support are presented as histograms depicting the SSQN, SSQS and SSQF. Lastly, the Pearson's Correlation Test was used to determine significant relationships between variables.

5.1. Demographic Information

5.1.1. Socio-Economic Information of Participants

A total number of one hundred and six (n=106) participants were recruited to take part in this study. There were an equal number of males and females (50%), with ages ranging from 27 to 83 years with a mean of 61.49 ± 11.69 (SD). Table 5 below represents the socio-economic information of the participants.

Table 5: Socio-economic Information

Variable	*Participants (n=106)*	*Proportion (%)*
Gender		
Male	53	50.0
Age (In years)		
20 – 29	1	0.9
30 – 39	2	1.9

40 – 49	12	11.3
50 – 59	31	29.2
60 – 69	35	33.2
70 – 79	17	16.0
80 – 89	8	7.5
Marital Status		
Never married	22	20.8
Currently married	47	44.3
Separated	3	2.9
Divorced	12	11.3
Widowed	21	19.8
Co-habiting	1	0.9
Highest qualification obtained		
None	3	2.8
Primary	43	40.6
Secondary	53	50.0
Tertiary	7	6.6
Schooling (Years)		8.58 ± 3.78
Employed prior to the stroke?		
No	48	45.3
Who are you currently living with?		
Independent	5	4.7
Family	88	83.0
Friends	2	1.9
Care provider	11	10.4
Current employment status		
Paid work	1	0.9
Self employed	1	0.9
Homemaker	1	0.9
Retired	37	34.9
Unemployed (health reasons)	51	48.1
Unemployed (other reasons)	15	14.3

Income of participant (rands)		
R0 – R1000	30	28.3
R1000 – R2000	67	63.2
R2000 – R3000	3	2.8
R3000 – R4000	1	0.9
Other	5	4.8

A total of 44.3% are currently married and the remaining 55.7% have been classified as either single, widowed, divorced, or co-habiting. The participants' average schooling were 8.58 years (SD ± 3.78) with 50% having obtained a secondary qualification. Above fifty five percent (54.7%) of participants were employed prior to the stroke, and 63.2% are receiving a monthly income of between R1000 – R2000. Eighty three (83%) percent of participants are currently living with family in the community.

5.1.2. Medical History of Participants

The majority of participants' stroke occurred between 0 – 1 year ago (44.3%), and survived an average of 1.63 ± 1.12 strokes. Information regarding participants' medical history are represented in the table below.

Table 6: Medical History

Variable	*Participants (n=106)*	*Proportion (%)*
Total number of strokes		1.63 ± 1.12
How many years ago stroke occurred		
0 – 1	47	44.3
2 – 5	37	34.9
6 – 10	18	17.0
11 – 15	4	3.8
Risk factors		
None	8	7.5
HPT only	26	24.5
DM only	2	1.9

CHOL only	6	5.7
HPT, DM	29	27.4
HPT, CHOL	9	8.5
HPT, DM, CHOL	18	17.0
HPT, DM, other	3	2.8
CHOL, DM, other	2	1.9
HPT, Other	2	1.9
HPT, DM, CHOL, other	1	0.9
Tobacco use at the time of stroke	29	27.3
Alcohol use at the time of stroke	4	3.8
Tobacco, alcohol	20	18.9
Attending a stroke support group		
No	75	70.8
Yes	31	29.2

Key:

HPT = Hypertension

DM = Diabetes Mellitus

CHOL = Cholesterol

The two largest percentages noted for risk factors were for a combination of Hypertension, Diabetes Mellitus and Cholesterol (17.0%) and Hypertension (24.5%). Fifty percent (50%) of participants did not engage in smoking and/or drinking. In this study, a small percentage of participants (29.2%) were part of a weekly stroke support group.

5.2. Domain Scoring

5.2.1. Cognition

5.2.1.1.Cognition Distribution

Cognition is the first domain in the WHODAS 2.0. and participants were asked how much difficulty they may have experienced in six areas. These questions, minimum and maximum values as well as means are presented in the table below.

Table 7: Cognition values

Question	Statement	Min – Max	Mean ± SD
1	Concentrating on doing something for ten minutes?	0 – 4	1.11 ± 1.38
2	Remembering to do important things?	0 – 4	1.13 ± 1.29
3	Analysing and finding solutions to problems in day-to-day life?	0 – 4	1.47 ± 1.43
4	Learning a new task, for example, learning how to get to a new place?	0 – 4	1.48 ± 1.50
5	Generally understanding what people say?	0 – 2	0.25 ± 0.52
6	Starting and maintaining a conversation?	0 – 2	0.45 ± 0.69

The minimum and maximum values for concentrating, remembering, analysing and learning a new task are 0 – 4, while minimum and maximum values for understanding what people say and starting a conversation are 0 – 2. This was based on the IRT based scoring method. The highest mean scores are for learning a new task and analysing and finding solutions for day-to-day life, scoring 1.48 and1.47 respectively.

Figure 3 below represents the participants scoring for each of the questions above. The scoring was classified based on the IRT based scoring method (Üstün et al., 2010).

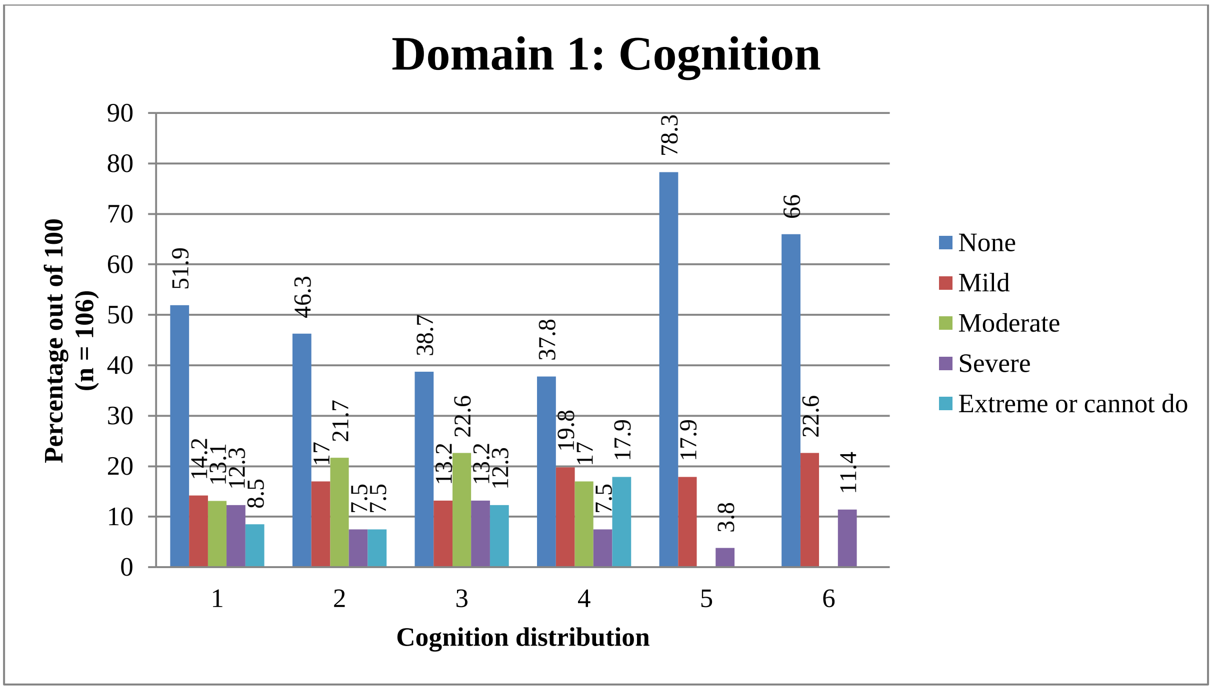


Figure 3: Cognition distribution

Key:

1 – Concentration
2 – Remembering important things
3 – Analysis
4 – Learning a new task
5 – Understanding what people say
6 – Conversation

It is evident from the information above that the majority of participants reported no difficulty with tasks associated with cognition. Over seventy-eight percent (78.3%) of participants found no difficulty with understanding what people say and 66% of participants reported no problem with starting and maintaining a conversation. Smaller percentages (17.9% and 8.5%) reported extreme difficulties with learning a new task and concentrating on something for ten minutes respectively.

5.2.1.2. Total Domain Scoring

Figure 4 below represents the distribution of the total domain scoring for cognition. The participant scores are dispersed in the figure below.

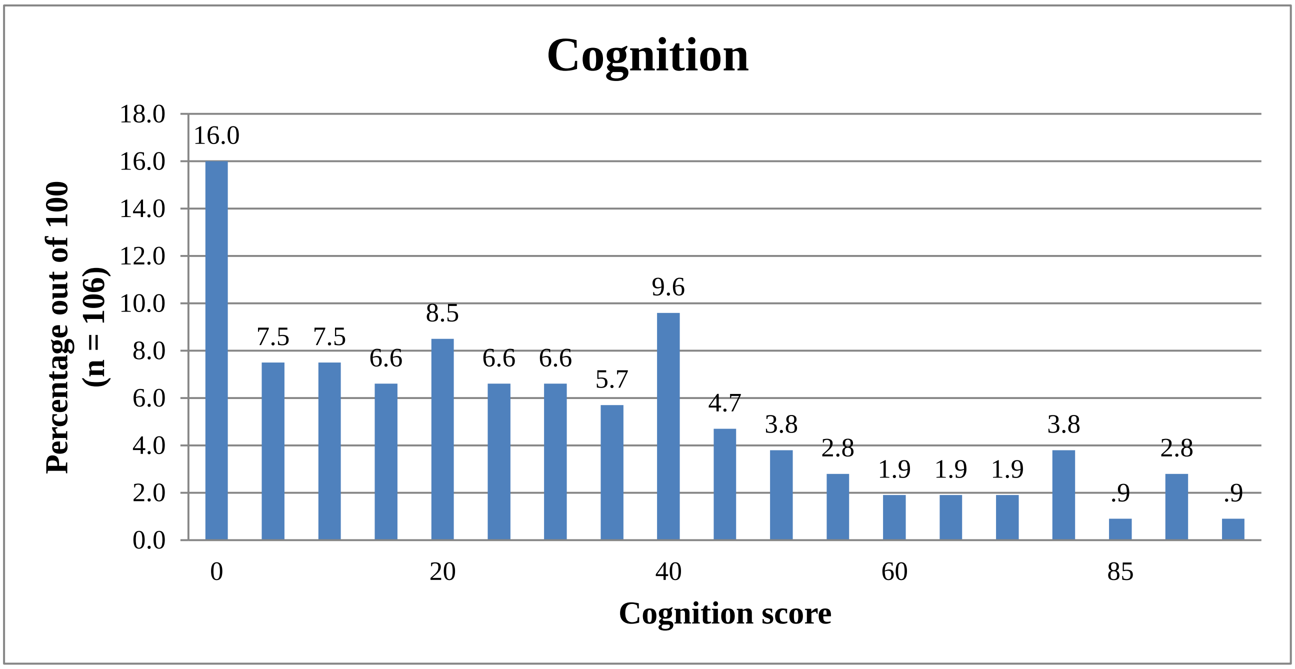


Figure 4: Total cognition scoring

The minimum and maximum values for participants in this study was 0 – 95, with a median of 25. The majority of participants (16%) scored 0 indicating that they had no problem in this domain, a further 9.6% scored 40 showing that they experienced a moderate problem, while only one participant scored the maximum value, indicating severe problems in this domain.

5.2.2. Mobility

5.2.2.1. Mobility Distribution

Mobility is the second domain in the WHODAS 2.0. and participants were asked how much difficulty they may have experienced in five areas. These questions, minimum and maximum values and means are presented in the table below.

Table 8: Mobility values

Question	Statement	Min – Max	Mean ± SD
1	Standing for long periods such as 30 minutes?	0 – 4	2.68 ± 1.50
2	Standing up from sitting down?	0 – 2	1.17 ± 0.70
3	Moving around inside your home?	0 – 2	0.81 ± 0.79
4	Getting out of your home?	0 – 4	1.48 ± 1.50
5	Walking a long distance such as a kilometer?	0 – 4	3.09 ± 1.34

The minimum values in this section are 0, with maximum values of 4 for standing, getting out of your home and walking a long distance, while maximum values for standing up and moving around inside your home was 2. This was based on the IRT based scoring method. The means displayed as obtaining the highest scores are for walking a long distance such as a kilometre followed by standing for long periods such as thirty minutes. The means are represented as 3.09 and 2.68 respectively.

Figure 5 below shows the participants scoring for each of the questions above. The scoring was classified based on the IRT based scoring method (Üstün et al., 2010).

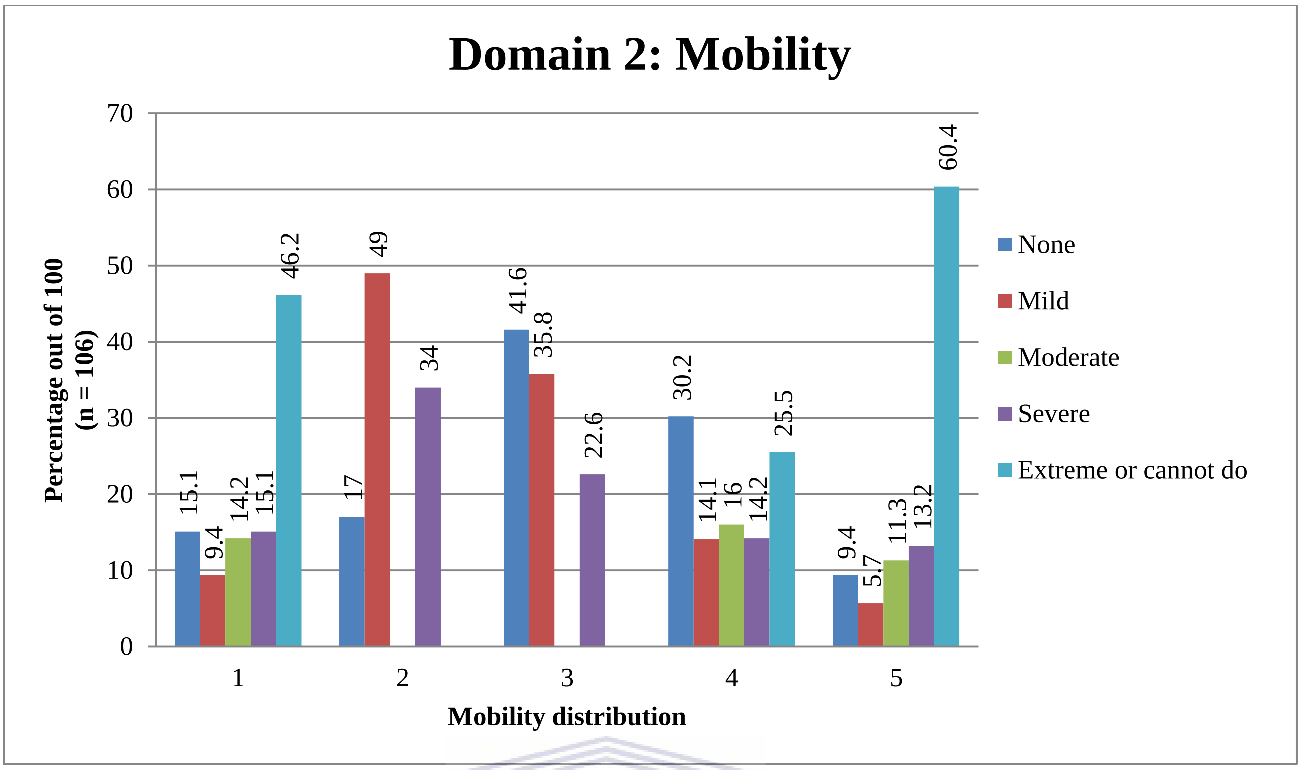


Figure 5: Mobility distribution

Key:

1 – Standing for long periods

2 – Standing up

3 – Moving around inside

4 – Getting out of your home

5 – Walking a long distance

It is evident from the information above that the largest proportion of participants experienced extreme difficulties in standing for long periods (46.2%) and walking a long distance (60.4%). Thirty-four percent of participants reported severe difficulty with standing up, while 22.6% reported severe difficulty moving around inside their homes. A further 41.6% found moving around inside their homes as not difficult, while a smaller percentage (17%) of had no difficulty in standing up from sitting.

5.2.2.2. Total Domain Scoring

Figure 6 below represents the distribution of the total domain scoring for mobility. The participant scores are dispersed in the figure below.

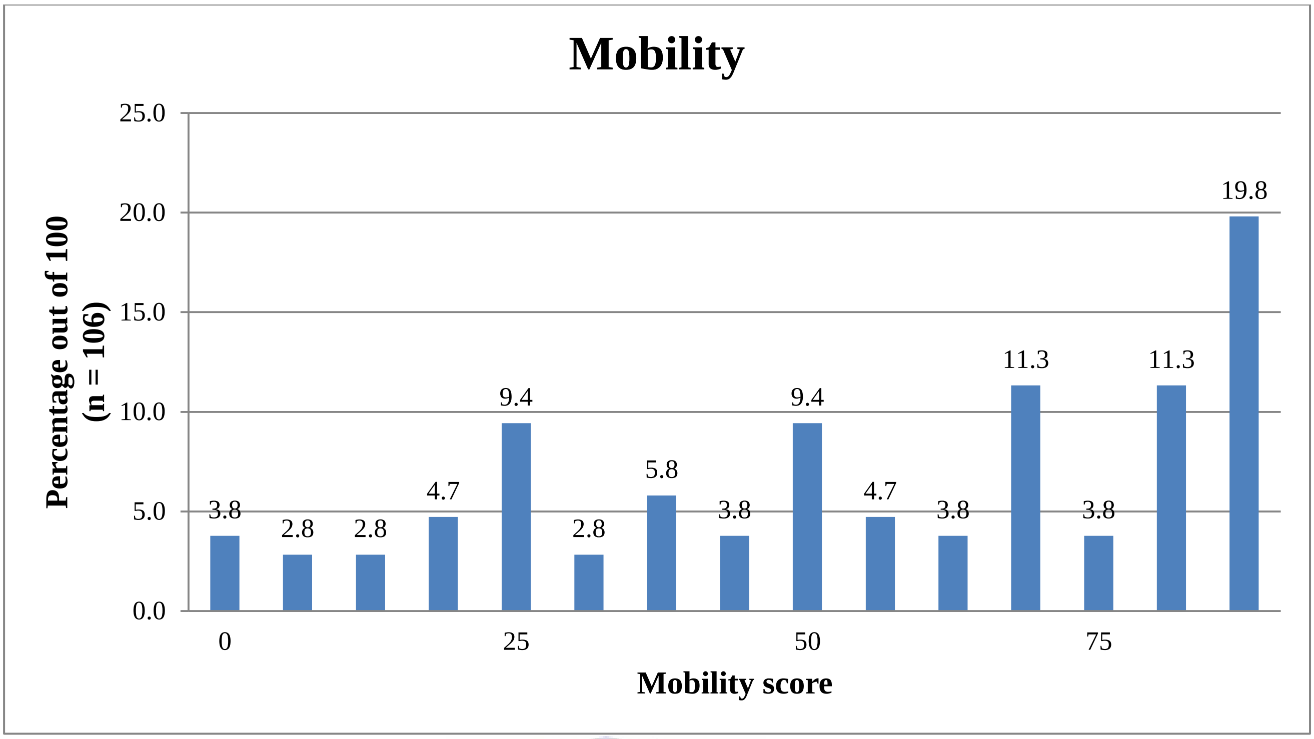


Figure 6: Total mobility scoring

The minimum and maximum values for participants in this study was 0 – 88, with a median of 59.50. The majority of participants (19.8%) scored 88 indicating severe problems in this domain, while a small percentage (3.8%) scored the minimum value indicating no problem in this domain.

5.2.3. Self-care

5.2.3.1. Self-care Distribution

Self-care is the third domain in the WHODAS 2.0. and participants were asked how much difficulty they may have experienced in four areas. These questions, minimum and maximum values and means are presented in the table below.

Table 9: Self-care values

Question	Statement	Min – Max	Mean ± SD
1	Washing your whole body?	0 – 2	1.20 ± 0.82
2	Getting dressed?	0 – 4	1.72 ± 1.63
3	Eating?	0 – 2	0.32 ± 0.59
4	Staying by yourself for a few days?	0 – 2	1.32 ± 0.87

The minimum and maximum values are presented as 0 – 2 for all questions, except getting dressed, which has a maximum of 4. This was based on the IRT based scoring method. The mean for getting dressed scored 1.72, representing the largest amount, while staying by yourself for a few days scored a mean of 1.32, representing the second highest score.

Figure 7 below shows the participants scoring for each of the questions above. The scoring was classified based on the IRT based scoring method (Üstün et al., 2010).

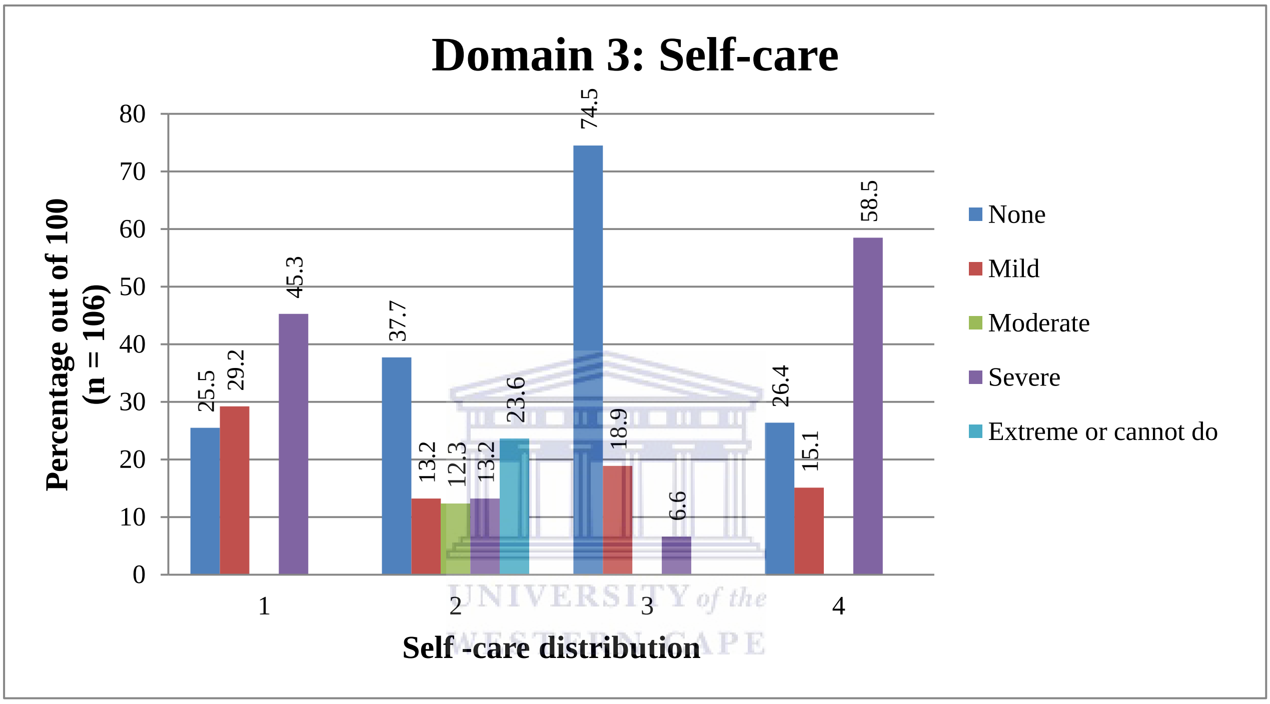


Figure 7: Self-care distribution

Key:

1 – Washing

2 – Getting dressed

3 – Eating

4 – Staying alone

It is evident from the information above that the majority of participants (45.3%) found washing and staying alone for a few days (58.5%) to be severely difficult, while 37.7% and 74.5% reported no difficulty with getting dressed and eating respectively.

5.2.3.2. Total Domain Scoring

Figure 8 below represents the distribution of the total domain scoring for mobility. The participant scores are dispersed in the figure below.

Figure 8: Total self-care scoring

The minimum and maximum values for participants in this study was 0 – 100, with a median of 50. The majority of participants (20.8%) scored 80 indicating severe problems for this section, while 16% scored the minimum value, indicating no problem in this domain. It is noted that 3.8% of participants scored the maximum value, indicating that these participants have a complete problem in this domain.

5.2.4. Getting along with people

5.2.4.1. Getting along with people Distribution

Getting along with people is the fourth domain in the WHODAS 2.0. and participants were asked how much difficulty they may have experienced in five areas. These questions, minimum and maximum values and means are presented in the table below.

Table 10: Getting along with people values

Question	Statement	Min – Max	Mean ± SD
1	Dealing with people you do not know?	0 – 2	0.48 ± 0.71
2	Maintaining a friendship?	0 – 2	0.41 ± 0.64
3	Getting along with people who are close to	0 – 2	0.19 ± 0.44

	you?		
4	Making new friends?	0 – 4	0.92 ± 1.24
5	Sexual activities?	0 – 2	1.24 ± 0.86

The minimum values for the questions displayed above are 0, with the maximum value of 2, except for the aspect of making new friends, scoring a maximum of 4. This was based on the IRT based scoring method. The activity scoring the highest average is that of sexual activities (1.24) followed by making new friends (0.92).

Figure 9 below shows the participants scoring for each of the questions above. The scoring was classified based on the IRT based scoring method (Üstün et al., 2010).

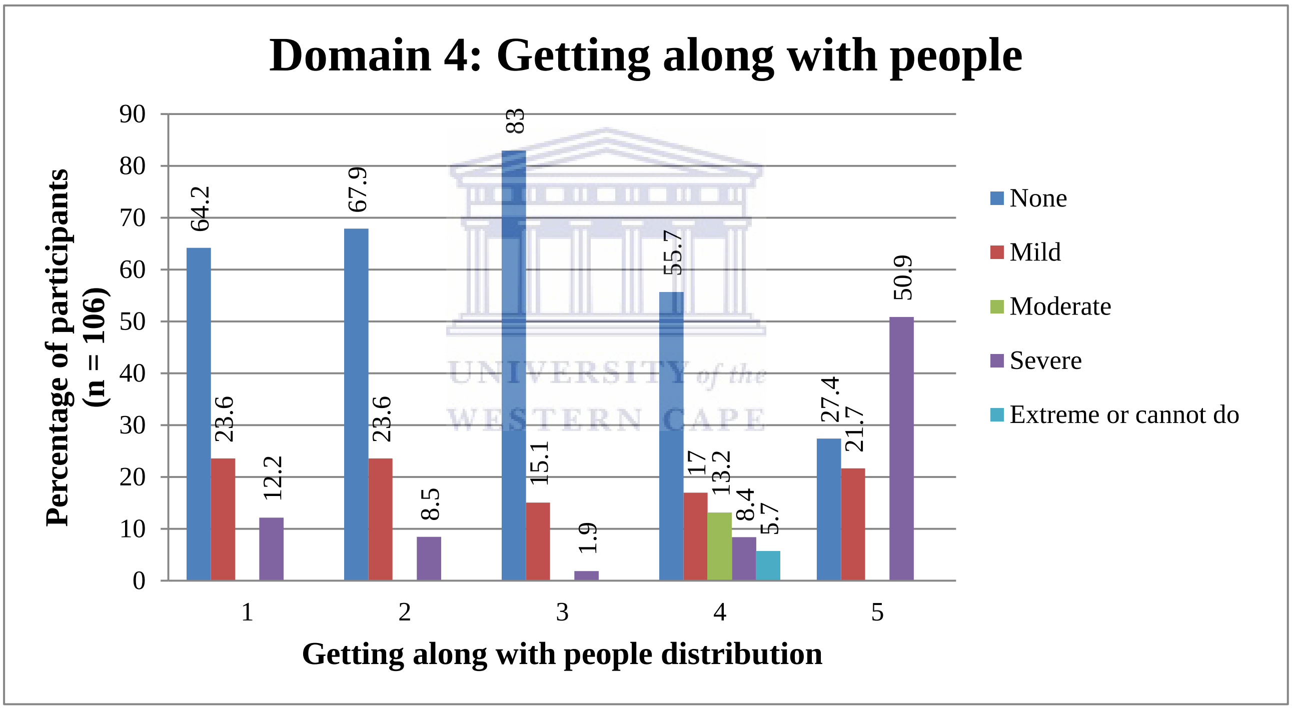


Figure 9: Getting along with people distribution

Key:

1 – Dealing with people

2 – Maintaining friendships

3 – Getting along

4 – Making friends

5 – Sexual activities

It is evident from the information above that the majority of participants (83.0%) reported no difficulty with getting along with people close to them, maintaining friendships (67.9%), dealing with people (64.2%) and making new friends (55.7%). However, the largest proportion of participants (50.9%) reported severe difficulty with sexual activities. Smaller percentages (8.5% and 12.2%) reported severe difficulty with maintaining friends and dealing with people respectively.

5.2.4.2. Total Domain Scoring

Figure 10 below represents the distribution of the total domain scoring. The participant scores are dispersed in the figure below

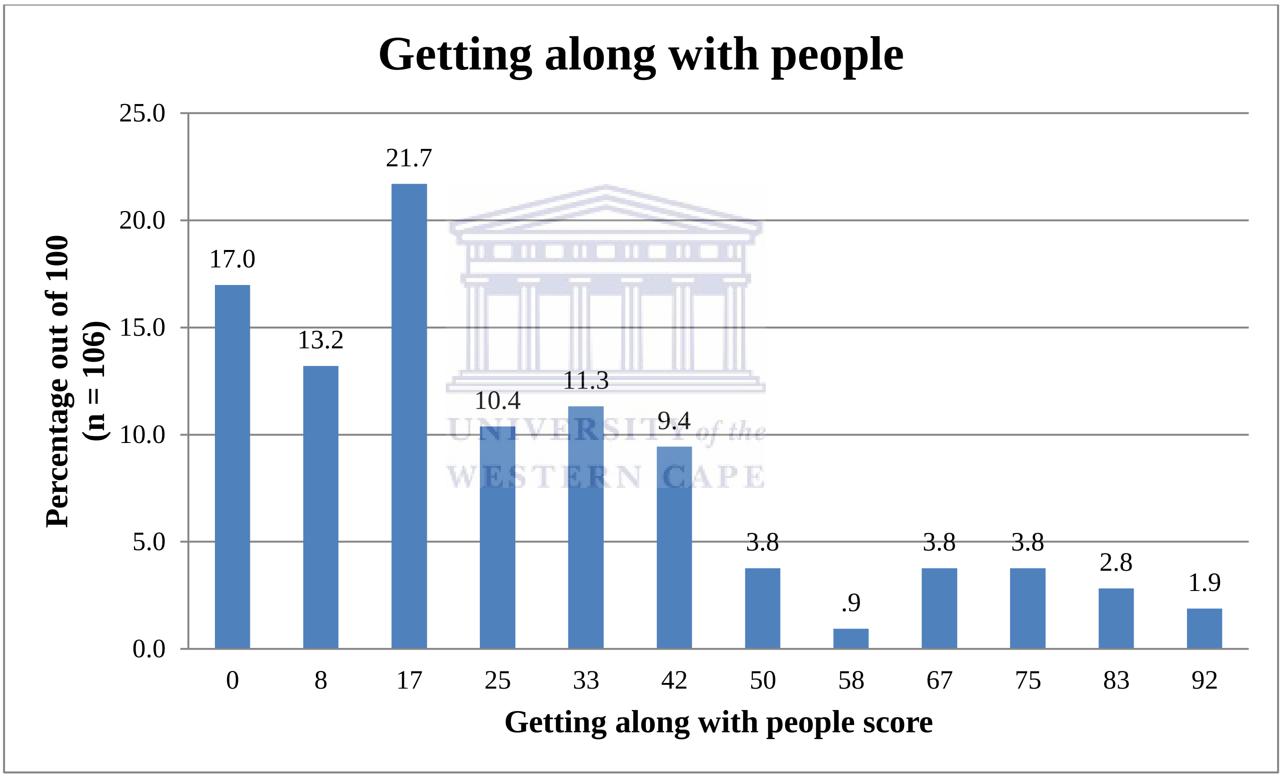


Figure 10: Total getting along with people scoring

The minimum and maximum values for participants in this study was 0 – 92, with a median of 17. The majority of participants (21.7%) scored 17, indicating mild problems in this domain, while 17% scored the minimum value, indicating no problem in this domain.

5.2.5. Life activities

5.2.5.1. Household activities Distribution

Household activities is the first section of the fifth domain in the WHODAS 2.0. and participants were asked how much difficulty they may have experienced in four areas. These questions, minimum and maximum values and means are presented in the table below.

Table 11: Household activities values

Question	Statement	Min – Max	Mean ± SD
1	Taking care of household your responsibilities?	0 – 4	1.99 ± 1.69
2	Doing your most important household tasks well?	0 – 2	1.17 ± 0.85
3	Getting all the household work done that you needed to?	0 – 2	1.18 ± 0.85
4	Getting your household work done as quickly as needed?	0 – 4	2.76 ± 1.30

The minimum and maximum values for taking care of household responsibilities and getting housework done as quickly as needed are 0 – 4, while for doing household tasks well and getting them done quickly, the minimum and maximum scores are 0 – 2. This was based on the IRT based scoring method. The highest average scores are getting work done as quickly as needed (2.76) followed by taking care of household responsibilities (1.99).

Figure 11 below shows the participants scoring for each of the questions above. The scoring was classified based on the IRT based scoring method (Üstün et al., 2010).

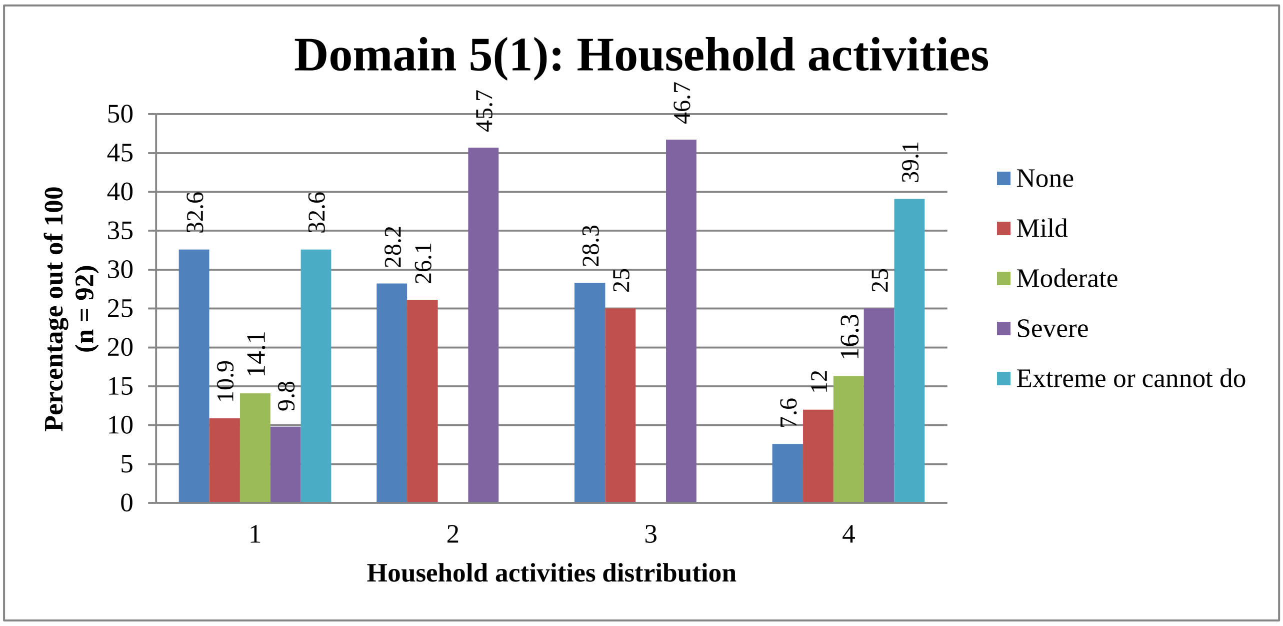


Figure 11: Household activities distribution

Key:

1 – Household responsibilities

2 – Performing household tasks well

3 – Getting all work done

4 – Getting work done quickly

It is noted that only ninety-two participants completed this section. The remaining fourteen do not take part in any household activities. It is evident from the information above that the majority of participants reported severe difficulty with performing household activities, particularly with getting all the work done that needed to be done (46.7%), and performing household tasks well (45.7%). The largest proportion of participants (39.1%) reported that they were unable to perform household duties as quickly as they needed to. A further 32.6% of participants found no difficulty with performing household tasks, and doing them well (28.2%).

5.2.5.1.1. Total Domain Scoring

Figure 12 below represents the distribution of the total domain scoring for household activities. The participant scores are dispersed in the figure below.

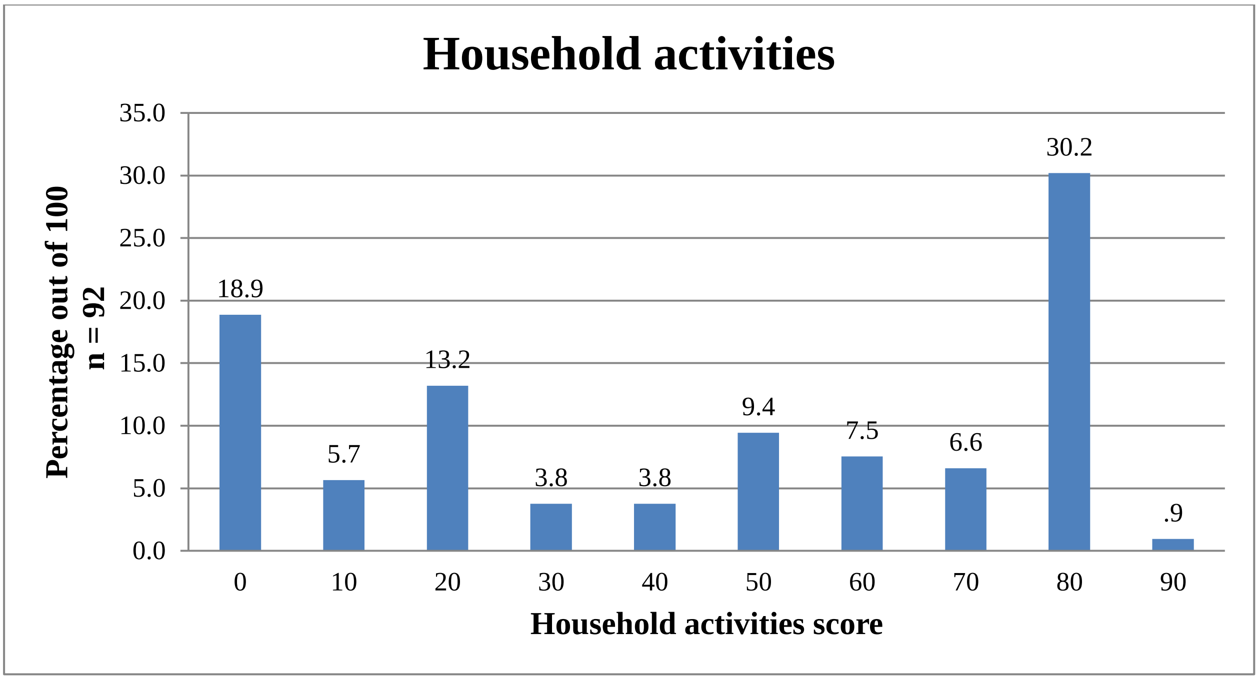


Figure 12: Total household activities scoring

The minimum and maximum values for participants in this study was 0 – 90, with a median of 50. The majority of participants (30.2%) scored 80 indicating severe problems in this domain.

5.2.5.2. Work or school activities

5.2.5.2.1. Work or school activities Distribution

Work or school activities are the second section of the fifth domain in the WHODAS 2.0. and participants were asked how much difficulty they may have experienced in six areas. These questions, minimum and maximum values and means are presented in the table below.

Table 12: Work/School activities values

Question	Statement	Min – Max	Mean ± SD
1	Your day-to-day work/school?	0 – 2	1.00 ± 1.00
2	Doing your most important work/school tasks well?	0 – 3	1.33 ± 1.53
3	Getting all the work done that you needed to?	0 – 3	1.33 ± 1.53
4	Getting your work done as quickly as needed?	0 – 4	0.67 ± 1.16

5	Have you had to work at a lower level because of your health condition?	0 – 2	0.67 ± 0.58
6	Did you earn less money as the result of a health condition?	0 – 2	0.67 ± 0.58

The minimum value represented for this domain is 0, the maximum of 2 for day-to-day school or work, working at a lower level and earning less money due to the health condition. The maximum value for doing the most important tasks well and getting all work that needs to be is 3 and 4 is the maximum value for getting work done as quickly as needed. This was based on the IRT based scoring method. The highest average is for that of doing your most important work tasks well (1.33) and getting all the work done that needs to be done (1.33).

Figure 13 below shows the participants scoring for each of the questions above. The scoring was classified based on the IRT based scoring method (Üstün et al., 2010).

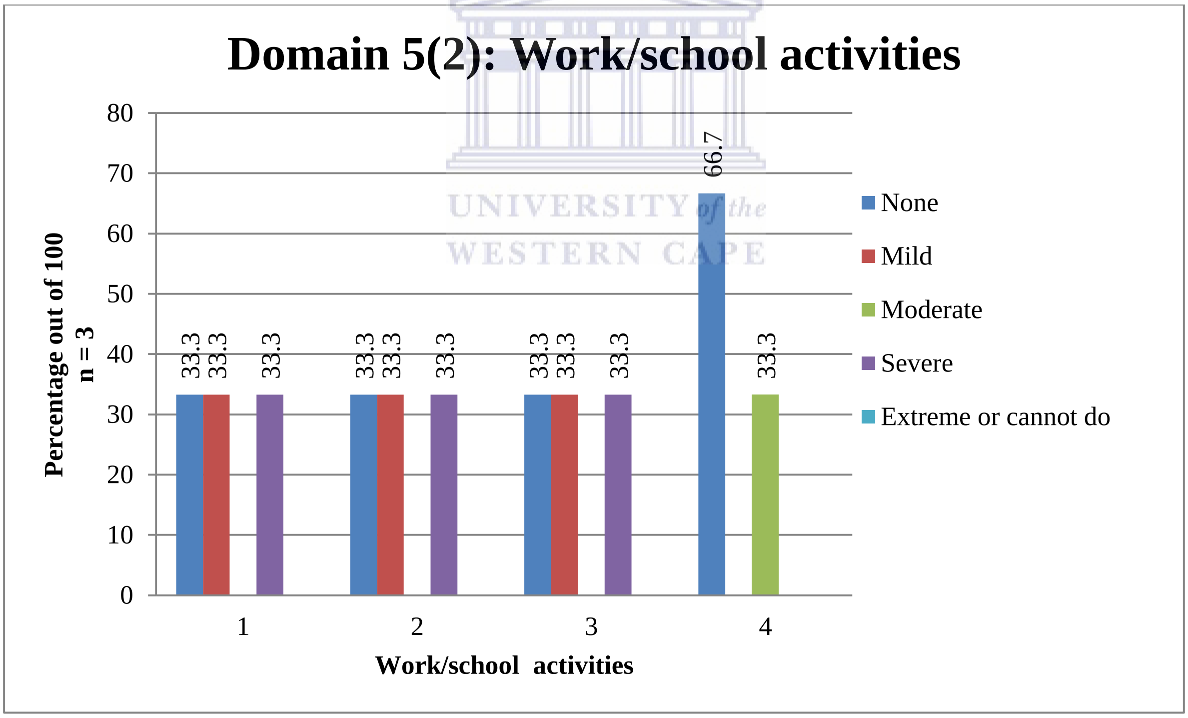


Figure 13: Work/school activities distribution

Key:

1 – Day-to-day work

2 – Doing tasks well

3 – Getting all work done

4 – Getting work done quickly

It is noted that none of the participants are of school-going age, and only three participants returned to work post-stroke. Each participant reported none, mild and severe difficulty with their day-to-day work, doing tasks well and getting all the work done that needed to be. Two participants reported no difficulty with getting work done as quickly as needed. Overall, one participant reported no difficulty in all the aspects of work, while the remaining participants reported mild to severe difficulty with getting work done and doing tasks well.

Figure 14a and 14b below are pie charts representing the remaining two questions in the domain of work/school activities. These pie charts depicts the distribution of questions 5 and 6, where participants were asked if they had to work at a lower level and earn less money because of the stroke respectively.

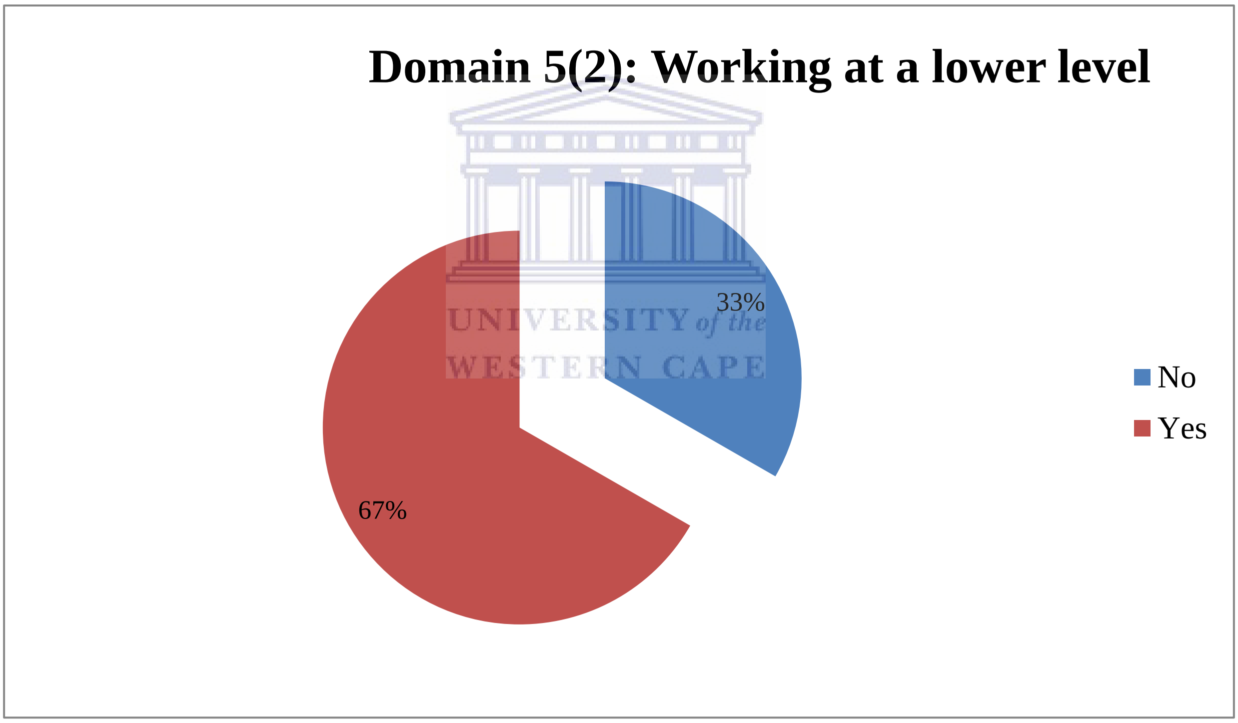


Figure 14a: Working at a lower level

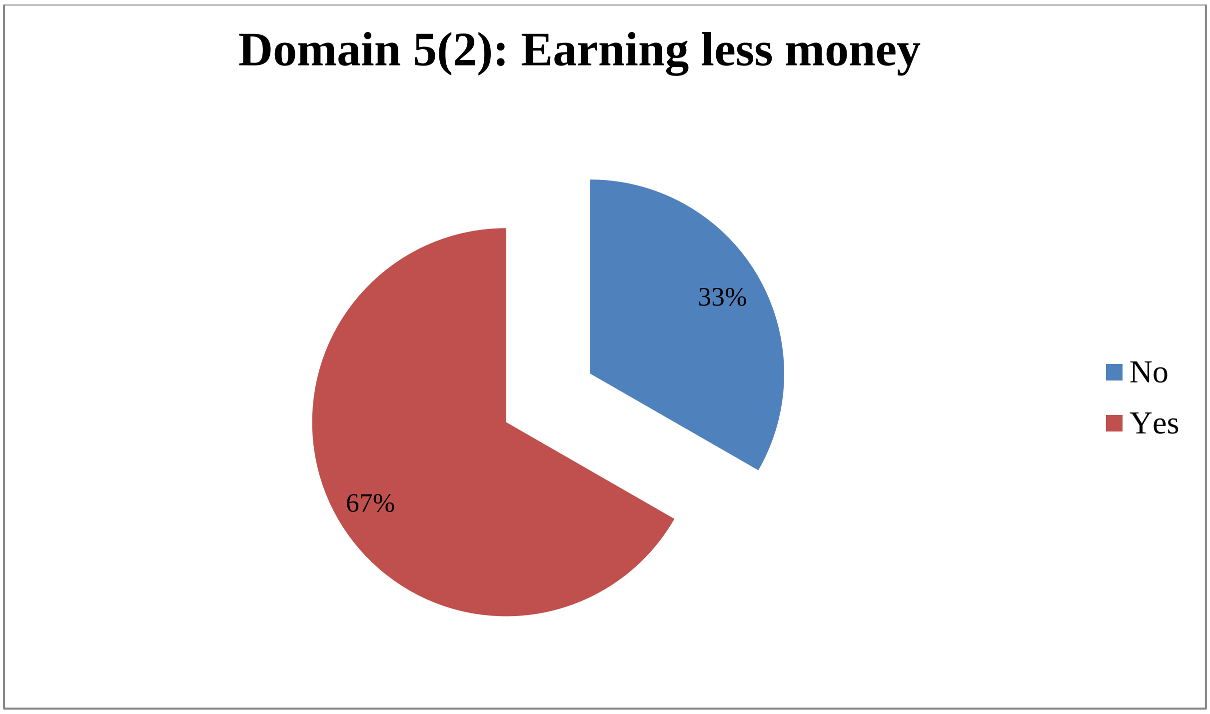


Figure 14b: Earning less money

With regard to working at a lower level and earning less money upon return to work post stroke, one participant reported that there was no drop in the level of work or salary, on return to work post-stroke, however the remaining two reported that there was a drop in the level and salary on return to work.

5.2.5.2.2. Total Domain Scoring

Figure 15 below represents the distribution of the total domain scoring for work/school activities. The participant scores are dispersed in the figure below.

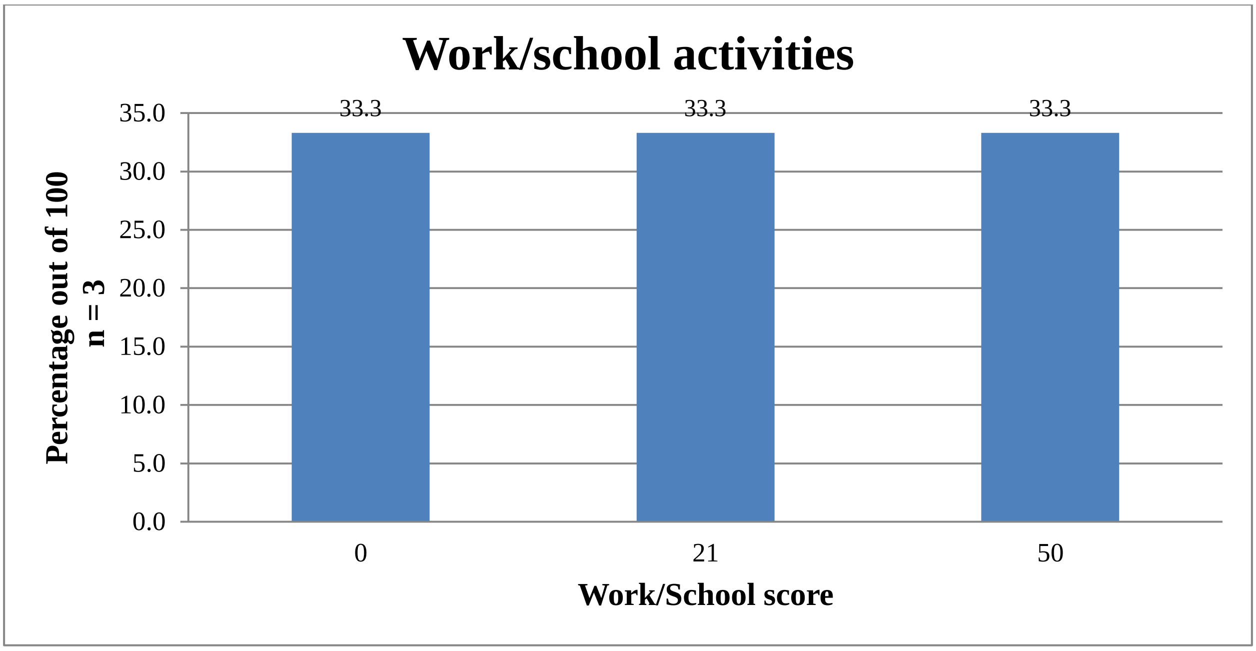


Figure 15: Total work/school activities scoring

The minimum and maximum values for participants in this study was 0 – 50, with a median of 23.67. The three participants who returned back to work post stroke scored 0, 21 and 50 indicating no problem, mild problem and severe problems respectively for this domain.

5.2.6. Participation

5.2.6.1. Participation Distribution

Participation is the sixth and final domain in the WHODAS 2.0. and participants were asked how much difficulty they may have experienced in eight areas. These questions, minimum and maximum values and means are presented in the table below.

Table 13: Participation values

Question	Statement	Min – Max	Mean ± SD
1	How much of a problem did you have joining in community activities in the same way as anyone else?	0 – 2	0.86 ± 0.83
2	How much of a problem did you have because of barriers or hindrances in the world around you?	0 – 4	2.04 ± 1.44
3	How much of a problem did you have living with dignity because of the attitudes and action of others?	0 – 2	0.63 ± 0.71

4	How much time did you spend on your health condition and its consequences?	0 – 4	1.92 ± 1.11
5	How much have you been emotionally affected by your health condition?	0 – 4	2.31 ± 1.49
6	How much has your health been a drain on the financial resources of you or your family?	0 – 2	1.21 ± 0.81
7	How much of a problem did your family have because of your health problem?	0 – 4	1.44 ± 1.37
8	How much of a problem did you have in doing things by yourself for relaxation or pleasure?	0 – 2	0.78 ± 0.83

The minimum values for the questions above are displayed as 0, while maximum values for community activities, living with dignity, financial resources and doing things for relaxation are 2, while maximum values for barriers in the community, time spent on health condition, how much have you been affected emotionally and how much of a problem did your family have was 4. This was based on the IRT based scoring method. The highest mean are for how much have you been emotionally affected (2.31) followed by barriers in the community (2.04).

Figure 16 below shows the participants scoring for each of the questions above. The scoring was classified based on the IRT based scoring method (Üstün et al., 2010).

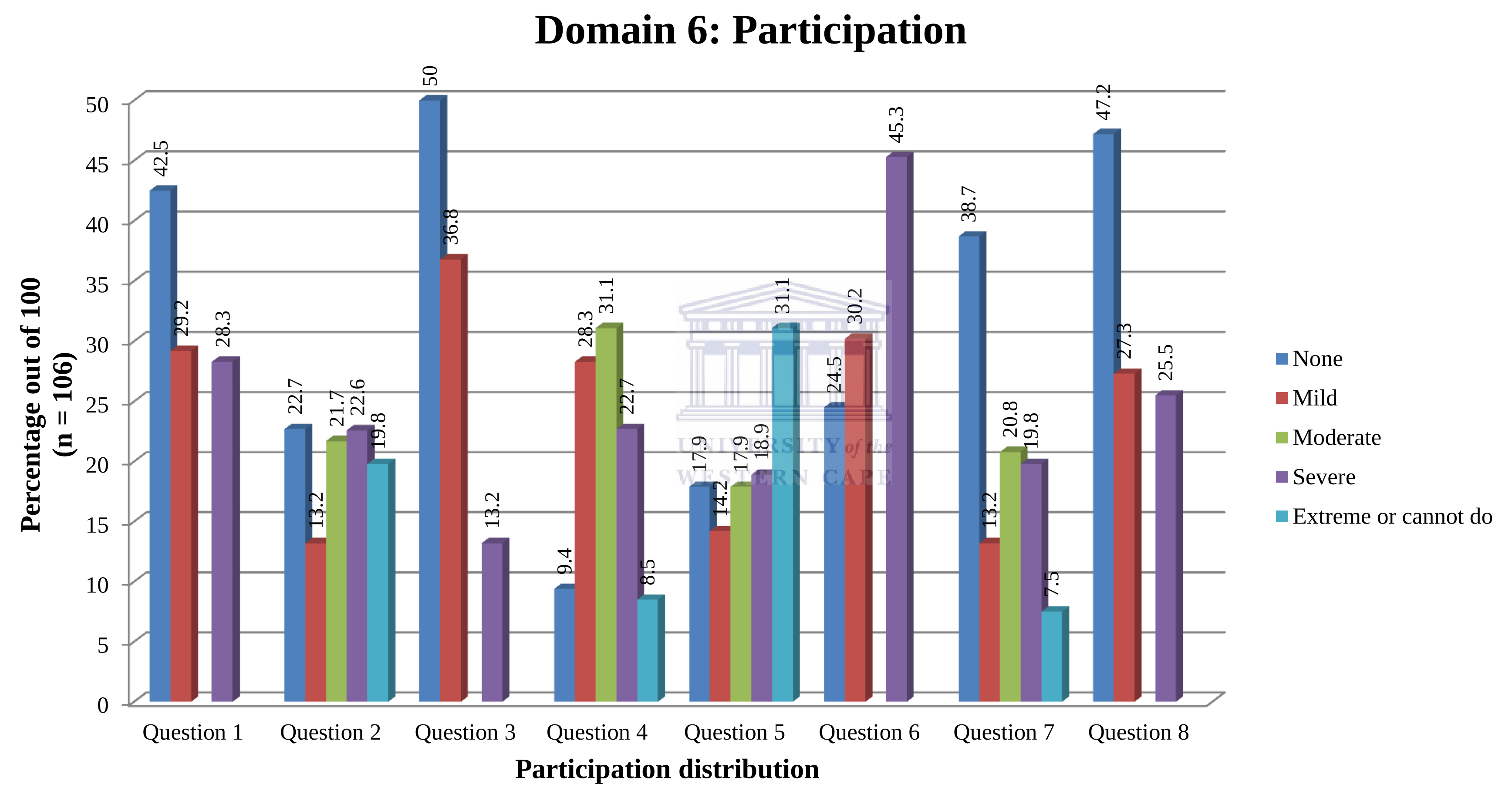


Figure 16: Participation distribution

Key:
1 – Community activities
2 – Barriers
3 – Living with dignity
4 – Time spent
5 – Emotionally affected
6 – Financial resources
7 – Family problem
8 – Doing things for relaxation

Participants (42.5%) found no problem with joining in community activities and 22.7% reported no problem with barriers in the community. However, a further 22.6% reported severe problems with barriers in the community affecting participation. The largest proportion (50%) had no problem living with dignity post stroke, and 38.7% reported that their family had no problem with their health condition. The largest percentage (31.1%) reported that they had been extremely affected emotionally and 45.3% reported that the strain on their finances had been severe. The majority (47.2%) had no problem with doing things by themselves for relaxation and a further 31.1% found that they had spent a moderate time on their health condition.

5.2.6.2. Total Domain Scoring

Figure 17 below represents the distribution of the total domain scoring. The participant scores are dispersed in the figure below.

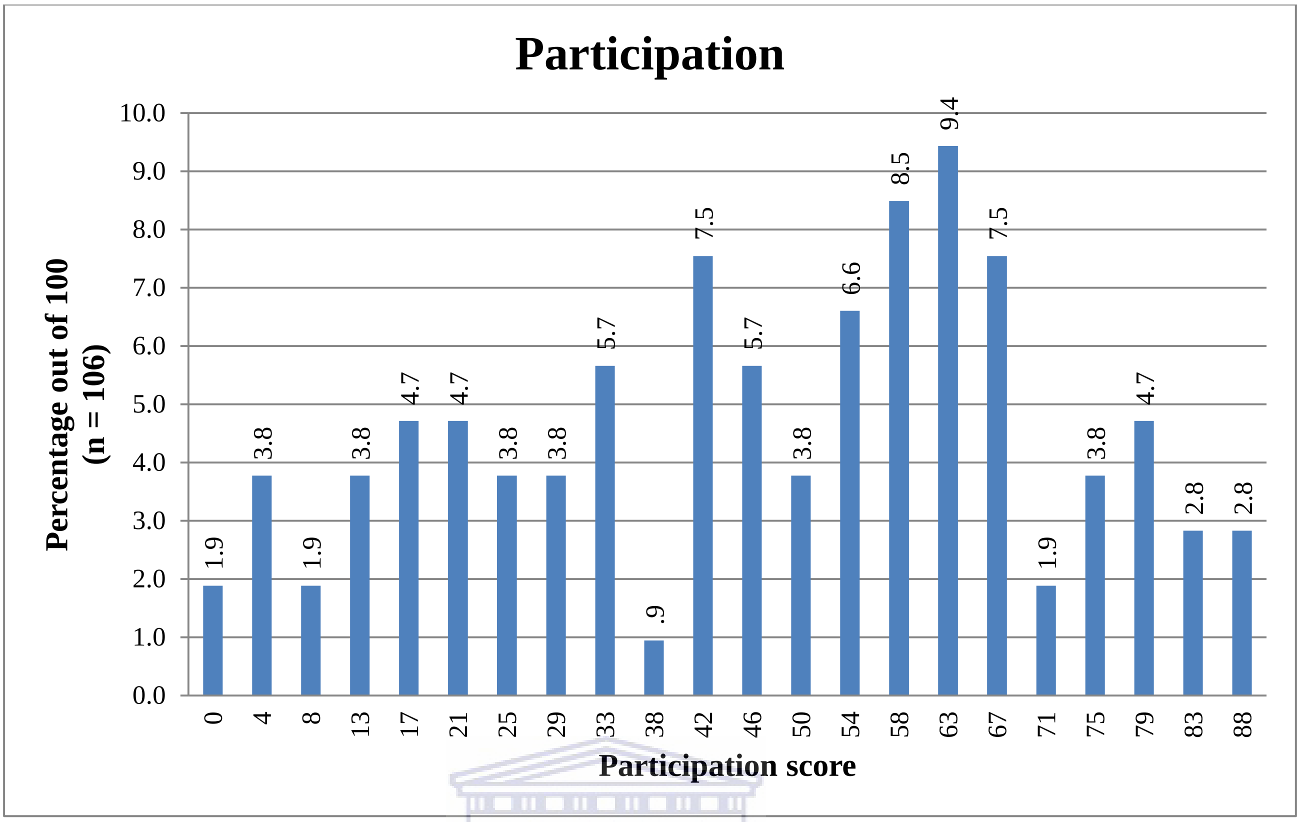


Figure 17: Total participation scoring

The minimum and maximum values for participants in this study was 0 – 88, with a median of 50. A total of 51.8% of participants had severe problems in this domain. It is noted that none of the participants indicated having a complete problem in this domain.

5.3. Comparison between domains

Figure 18 below represents the distribution of the total scoring of domains 1 – 6 for the WHODAS 2.0. The scoring was classified based on instructions from the WHODAS 2.0. user manual (Üstün et al., 2010).

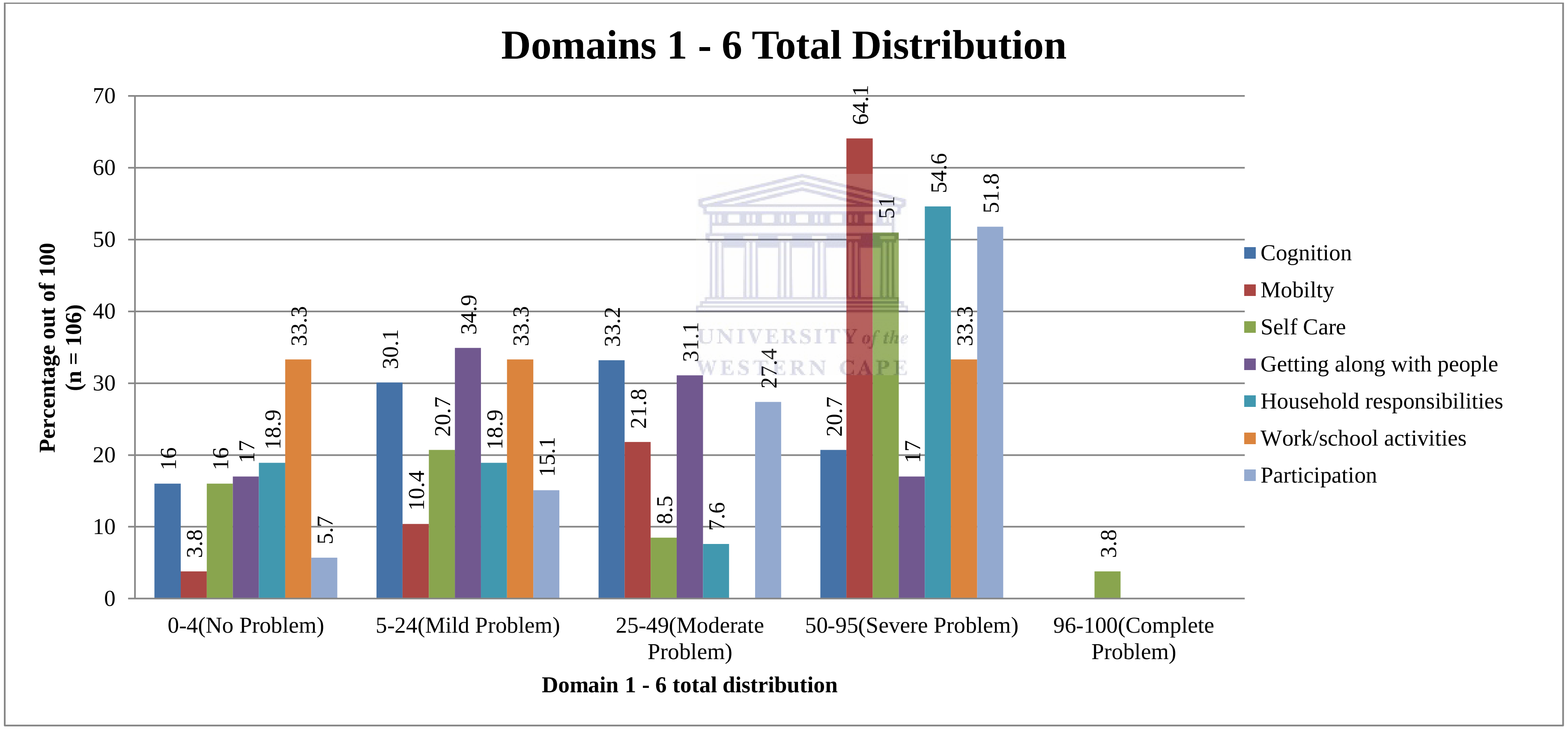


Figure 18: Domains 1 – 6 total distribution

The results of the six domains of the WHODAS 2.0. are depicted in the graph above and categorised into five different groups, ranging from 0 (no problem), to 100 (complete problem). Overall, the largest proportion of participants, indicated as 64.1%, experienced severe problems with mobility. A further 54.6% of participants reported severe problems with household activities followed by 51.8% being classified as having severe problems in the domain of participation. These three domains are thus ranked as scoring the highest overall domain scores. It is noted that the self-care domain is the only domain out of the six where participants (3.8%) scored the maximum value (100), indicating complete problems with activities in this domain. An equal number of participants (n=1), reported no problem, mild problem and severe problems in the domain of work/school activities. A similar amount of participants confirmed mild (34.9%) and moderate (31.1%) problems in the domain of getting along with people. Overall, the domains which obtained the lowest overall values with mild problems include work/school activities, getting along with people and cognition.

5.4. Social Support

5.4.1. The Social Support Number Score (SSQN)

Figure 19 below shows the total distribution of participants SSQN as calculated by Sarason et al. (1983).

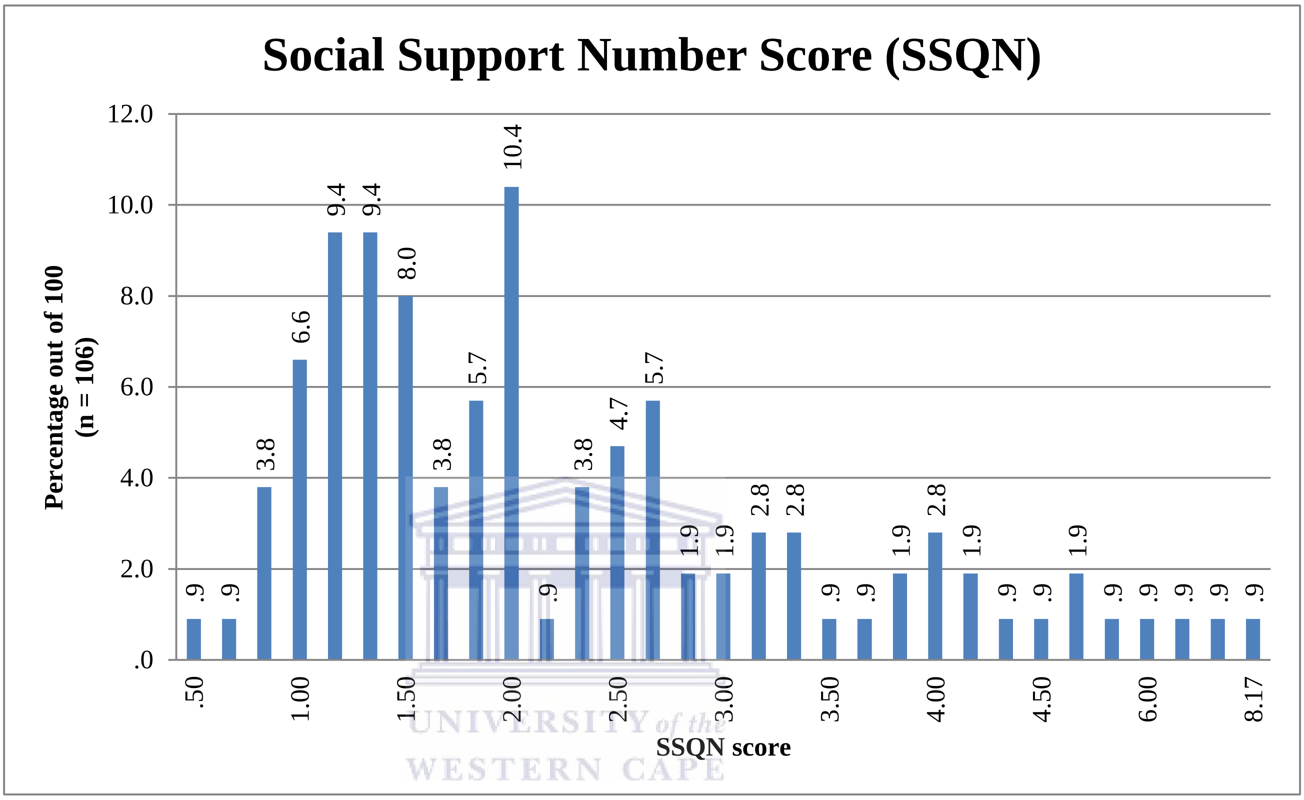


Figure 19: The Social Support Number Score

The minimum and maximum values for participants in this study were 0.50 - 8.17, with a median of 2 and interquartile range of 1.54. In this study, one participant scored the mimimum value indicating low social support. Furthermore, the majority (10.4%) of participants scored a value of 2 indicating low social support. When assessing the distribution of the SSQN, it is visible that the largest percentages scored values between 1.00 – 2.67 which is an indication of low social support. Thus, the largest proportion of participants, classified as 89.9%, has low social support scores, with the remaining 10.1% classified as having high social support.

5.4.2. The Social Support Satisfaction Score (SSQS)

Figure 20 below shows the total distribution of participants SSQS as calculated by Sarason et al. (1983).

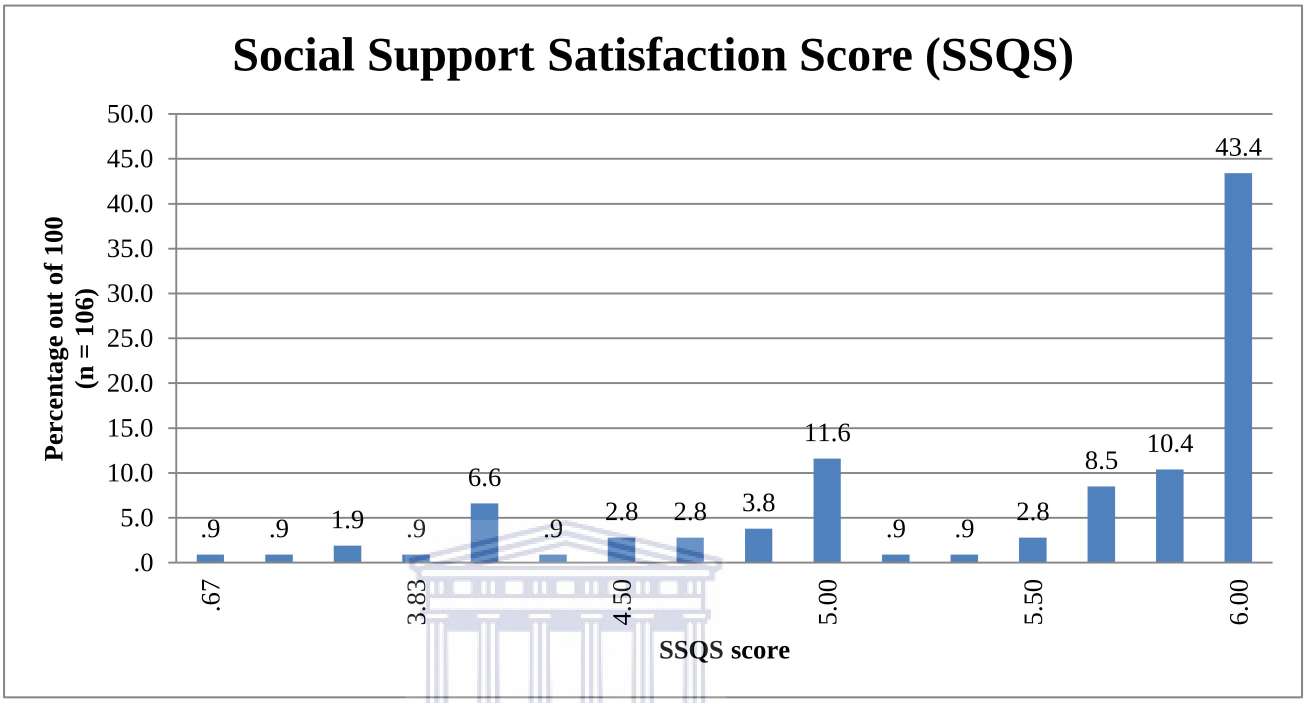


Figure 20: The Social Support Satisfaction Score

The minimum and maximum values for participants in this study were 0.67 -6.00, with a median of 5.83 and interquartile range of 1.00. In this study, the largest proportion 43.4% scored the maximum value, indicting high SSQS. When assessing the distribution of the SSQS, it is visible that the largest percentages of participants scored values between 5.00 – 6.00, which is an indication of high SSQS. Thus, the largest proportion of participants, classified as 96.3%, has high satisfaction scores, with the remaining 3.7% classified as having low satisfaction scores.

5.4.3. The Social Support Family Score (SSQF)

Figure 21 below shows the total distribution of participants SSQF as calculated by Sarason et al. (1983).

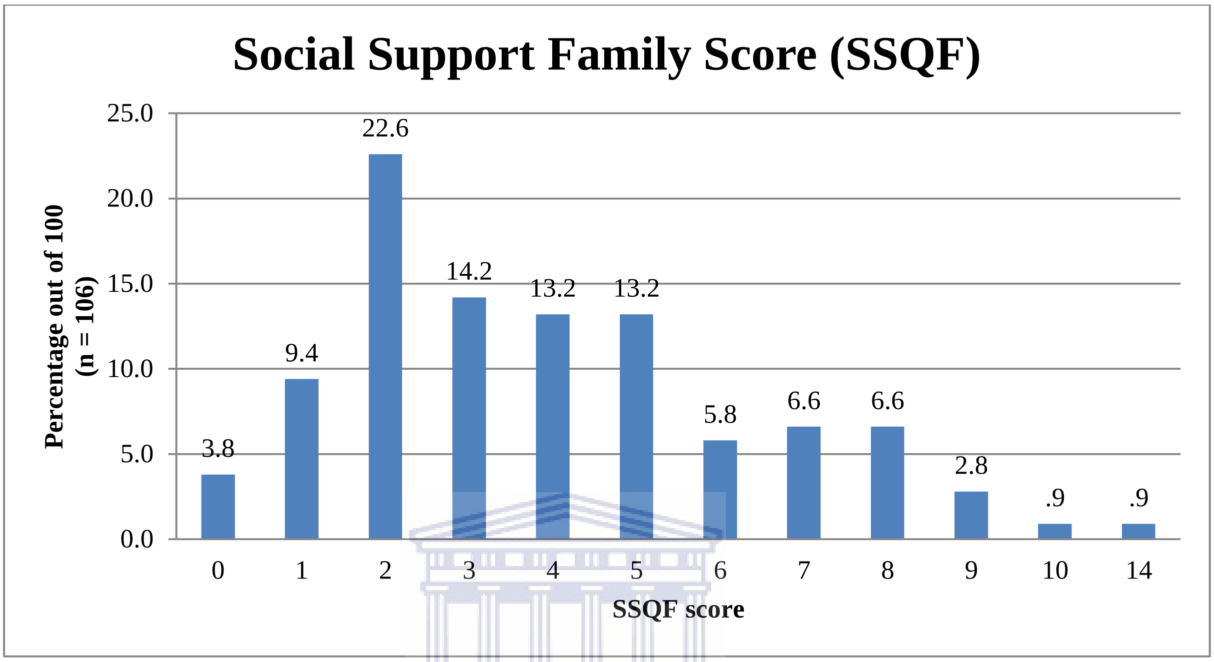


Figure 21: The Social Support Family Score

The minimum and maximum values for participants in this study were 0 -14, with a median of 5.50 and interquartile range of 3.00. In this study, the largest proportion (22.6%) had 2 family members on which to rely on for support. When assessing the distribution of the SSQF, it is visible that the largest percentages of participants, classified as 63.2% scored values between 2 – 5, an which is an indication that participants only a had few family members which to rely on for support.

5.4.3.1. Members providing support

Figure 22 below shows the total distribution of the majority of members who are providing support to participants in this study.

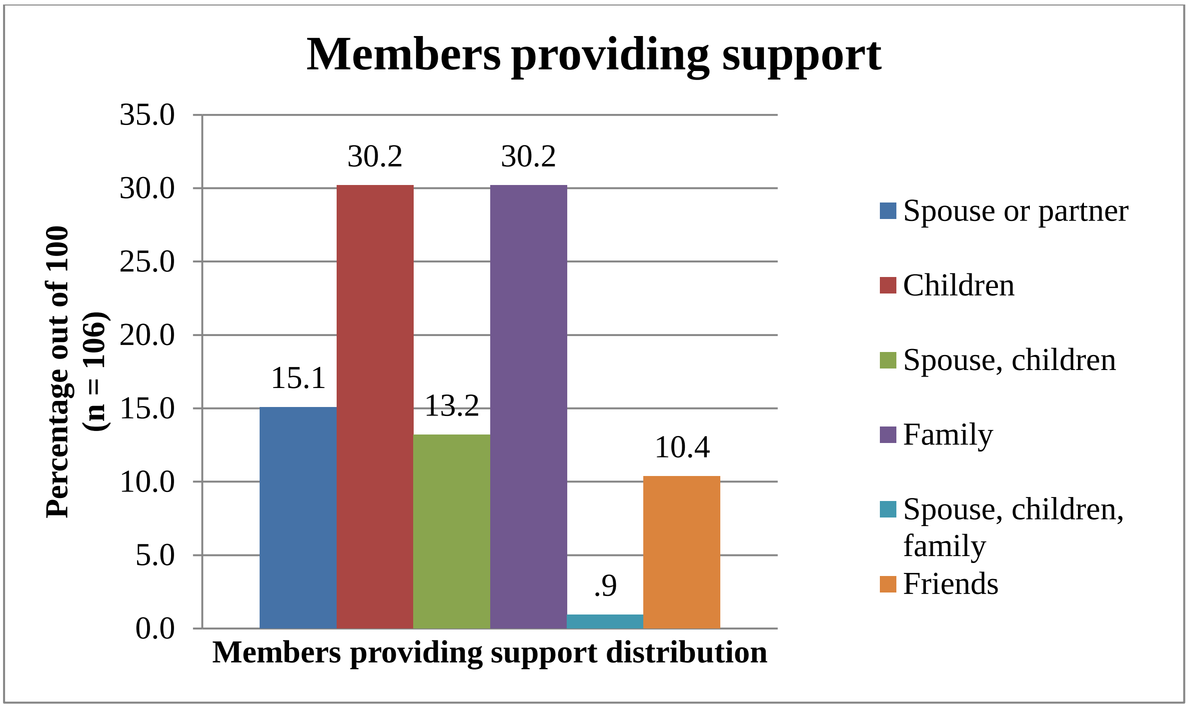


Figure 22: Members providing support

It is evident from the figure above that an equal percentage of participants (30.2%) have reported that their children and family members have been providing them with support. A further 15.1% of participants have reported that a spouse or partner is providing support, followed by friends (10.4%). One participant (0.9%) has reported that a combination of a spouse, children and family members are providing support.

5.5. Association between social support and participation

Table 14 below shows the association between variables.

Table 14: Association between variables

Variable	Variable	Participants	P value	R value
Social Support Number Score (SSQN)	Social Support Satisfaction Score (SSQS)	106	0.145	0.021
Social Support Number Score (SSQN)	Social Support Family Score (SSQF)	106	0.000	0.068
Social Support Number Score (SSQN)	Stroke support group attendance	106	0.931	0.588

Social Support Number Score (SSQN)	Cognition	106	0.161	0.137
Social Support Number Score (SSQN)	Mobility	106	0.095	- 0.163
Social Support Number Score (SSQN)	Self-Care	106	0.353	- 0.091
Social Support Number Score (SSQN)	Getting along with people	106	0.556	- 0.058
Social Support Number Score (SSQN)	Household responsibilities	92	0.383	- 0.086
Social Support Number Score (SSQN)	Work or school activities	03	0.650	- 0.522
Social Support Number Score (SSQN)	Participation	106	0.146	0.215

The table above presents the P values obtained from the Pearsons correlation test. There was no significant relationship identified between social support and participation (P = 0.146). It was found that a significant relationship exists between the SSQN and the SSQF.

5.6. Summary of results

A total number of 106 participants were included in this study containing an equal number of males and females (n=53). The majority of participants (62.2%) were aged between 50 – 69 years, with a mean age of 61.5 years, and 44% are currently married. In this study, 70.8% did not take part in a weekly stroke support group. When analysing the respective domains of the WHODAS 2.0., it was concluded that the majority of participants reported mild to moderate difficulty with cognition and getting along with people. The largest percentage of participants reported severe to complete problems with engaging in various aspects of mobility, and similar severity was reported for the self-care domain. In the domain of household activities, fourteen participants were classified as not contributing to household activities, while the majority had severe difficulty with household tasks. Post stroke, only three participants returned to employment. In the domain of participation, 51.8% reported that they had experienced severe problems in this domain. When comparing the six domains of the WHODAS 2.0., it was established that the highest scoring domains were mobility, household activities and participation. When assessing the social support status of individuals, it was revealed that the largest proportion of participants reported low social support, high satisfaction scores and low family scores. With regard to the family members providing support to participants, 30.2% of participants revealed that their children, as well as family members were the people providing support to them. When determining the association between social support and participation, an insignificant finding was concluded.

CHAPTER SIX

DISCUSSION

6. Introduction

The discussion chapter firstly presents the socio-demographic information regarding participants. Although this is not a focal point to the current study, the information reported is of importance to understand the common age groups affected, marital status and participants' current living situation, and how this relates to the findings to follow. Activity limitations and participation restrictions are outlined and the aspects which participants reported most difficulties with are described. The implications of these are then explained. Social support and the profiles of these participants are then discussed. The findings of social support and participation are combined and discussed as they relate to one another. Where appropriate, findings of the systematic review conducted as part of this thesis are also referred to. The aspects that emerged from this discussion will include participation restrictions in relation to community activities and return to work as well as role changes as a consequence to this. With regard to social support, the support status of participants in this study is emphasised, and the influence of family caregiving is stressed. Literature is presented to strengthen comments and findings of the current study. Lastly, the limitations of the current study are presented.

6.1. Socio demographic status of participants

In the current study, an equal number of males and females participated, with a mean age of 61.5 years. This result is strengthened by previous South African literature, reporting mean ages for stroke ranging between 55 to 61 years old (Rhoda, 2012; Rhoda et al., 2011). Previous research has proven that a stroke occurs more in females than in males (Conner & Bryer, 2005) but the same cannot be said for this study. However, the current study result is strengthened by a community based study conducted in a similar setting which also reared an equal number of male and female participants (Rhoda & Henry, 2003). Although not always the case, this finding implies that the breadwinner (males) and the carers (females) are equally affected. When assessing marital status in the current study sample, it was revealed that a high percentage (20.8%) of participants have never been married, which means that they would have to depend on other family members for support in the community due to the absence of a helping spouse. The majority of participants (83.0%) are currently living with family in the community which can be seen as a facilitator towards functioning and participation, especially in the early months following discharge. This statement is strengthened by a study conducted by Fallahpour et al. (2011) stating that the largest percentage (97.3%) of participants are receiving input post stroke, in the form of support from caregivers that include family, friends and neighbours. It should however be noted, that the majority of the burden of care falls upon these family members in the community (Andrew et al., 2015) and this contributes to caregiver strain.

6.2. Activity Limitations post stroke

The participants in this study found the domains of cognition and getting along with people to be the least affected post-stroke. A large proportion of participants scored low values, indicating mild to moderate disability, reporting no difficulty interacting with close friends (83%), unfamiliar people (64.2%), concentration (51.9%) and learning new tasks (37.8%). This could imply that participants would have no problem socializing and maintaining social relationships, as their ability to communicate with others has only been mildly affected. However, this is not a common result. Mudzi et al. (2013) concluded a different result, when at twelve months post stroke, all participants displayed mild to moderate and severe to complete difficulty with formal relationships and simple interpersonal interactions. The difference in result could pertain to the data collection instrument used, as well as the fact that participants were excluded from the current study if they suffered from severe cognitive defects.

The remaining three domains namely mobility, self-care and life activities were more challenging for participants. According to the findings of the current study, 64.1% found the mobility domain very difficult, and based on their final scores were classified as severely disabled. It was reported that these participants struggled with activities such as standing (15.1%), moving around (22.6%) and walking long distances (13.2%), with larger percentages of participants reporting the inability to stand for long periods (46.2%) and walk long distances (60.4%). Limitations in the ability to walk would impact on participation and community integration. Complex environmental demands such as managing uneven terrain and hilly areas often make community participation difficult (Maleka et al., 2012). As a result of altered walking ability post stroke, assistance from others is required as often as 50% of the time (Robinson, Shumway-Cook, Matsuda, & Ciol, 2011). It can therefore be said that limitations in walking may lead to increase caregiver burden, as participants are only able to be independent half of the time.

A large proportion of participants (51%) were classified as severely disabled in the self-care domain, while a further 3.8% were classified as completely disabled in this domain. It was reported that these participants struggled with washing (45.3%), getting dressed (23.6%), eating (6.6%) and staying alone for a few days (58.8%). It is noted that the self-care domain was the only domain where participants scored the maximum value (100), an indication that these participants are completely dependent on others to perform the above mentioned activities. The inability to perform certain activities could lead to role changes and depression (Dowswell et al., 2000).

These results are common and have been reported in previous literature (Hartman-Maeir et al., 2007; Mayo et al., 2002). Similarly, 33% of the participants reported challenges performing ADLs for survival such as walking short distances, stair climbing and moving around in the community (Mayo et al., 2002). Moreover, it was found that 39% of participants reported activity limitations in self-care which included dressing, bathing, feeding, grooming and a further 50% of a different sample from Hartman-Maeir et al. (2007) required support with dressing. Family, friends and caregivers would thus play an important role in the functioning of stroke survivors, as it is proven that participants are dependent in areas of self-care and mobility. Recovery following a stroke can take many months, and this can eventually lead to caregiver burnout, if there is not a sufficient amount of caregivers available to assist. Based on the findings above, it is evident that activities such as walking, stair climbing and self-care which require participants to engage physically are what individuals post stroke find challenging. This statement can further be strengthened by the fact that the majority participants in the current study (34.9%) reported mild difficulty in the getting along with people domain. However, when asked about engaging in sexual activities in the same domain, more than half of participants (50.9%) reported severe difficulty in this area. This could have an impact on the intimacy between the individual and their partner, and affect martial relationships.

In the domain of life activities, there were fourteen participants (13.2%) who do not engage in any extended activities of daily living, even though they are able to. A further 54.6% were classified as severely disabled in this domain. This means that these individuals have to rely on someone for support and assistance, as they are unable to perform these activities themselves. Already, two-thirds of a caregiver's time is consumed by household tasks (Tooth, McKenna, Barnett, Prescott, & Murphy, 2005). However, the result of the 13.2% that are able to, but chose not to engage in household activities, is an increase in dependence on caregivers and decreased ability of these individuals to do things for themselves which further increases the impact on these caregivers. Hartman-Maier et al. (2007) concluded that 70% of individuals post stroke required complete assistance with housework. Amongst the 2.7% employed participants, only one participant was classified as moderately disabled in this domain, while the remaining two were classified as having no to mild disability in this domain. With regard to employment, it appeared that participants improved slowly over time, not following the classic three-month improvement pattern that other domains displayed, which would explain why the one participant still battled with fulfilling work requirements (Rochette et al., 2007).

6.3. Participation Restrictions post stroke

According to the WHODAS 2.0. research instrument, participation restrictions include joining in community activities, time spent on health condition, emotional status, problems with family and doing things for relaxation. Return to work, and the financial consequence as a result of this is also highlighted here, and these are discussed as it relates to barriers in the community affecting participation.

When assessing the overall distribution of the final scores for participation, 51.8% of participants were classified as being severely disabled in participation post stroke. This is a common finding and in line with other South African research (Maleka et al., 2012; Rhoda et al., 2015; Rouillard et al., 2015). This is an indication that these participants will find it challenging to function in the community, in the absence of caregivers and family, and battle to fulfill roles that they did prior to the stroke. A further 27.4% of participants were moderately affected in participation post stroke, with a smaller proportion of participants (15.1%) reporting mild problems with participation. This result is strengthened by a community based study conducted by Mudzi et al. (2013), proving that participants displayed mild to moderate difficulties in community life and participation. It is possible that these participants will function effectively in the community, with minimal help from others. Lastly, the smallest percentage of participants (5.7%) reported no problems with participation, indicating that they are able to function independently, with no assistance from others, in the community. These results show that only a small proportion of participants are able to function independently, and the remaining will constantly have to rely on others for functioning in the community. This highlights the impact on caregivers.

A small percentage of participants (28.3%) reported severe difficulties with joining in community activities, with similar results found by Mudzi et al. (2013) showing that 24.6% of participants in their study had severe to complete difficulty with community life. However, the majority of participants in the current study (42.5%) had no problem with joining in community activities. A large percentage (31.1%) reported that they had spent moderate time on their health condition. This could be attributed to the fact that a large proportion of these participants are severely disabled in the self-care (51%) and mobility (64.1%) domains, and struggle with basic ADLs that need to performed daily. This would take more time to complete due to their impairments. When asked about participants’ emotional status, 31.1% explained that they have been extremely affected by their health condition. This is a common finding and in line with a study conducted by Edwards et al. (2006) which showed that a similar percentage (33%) of participants reported difficulties with emotional well-being post stroke. Furthermore, Cardol et al. (2002) concluded that emotional distress is a crucial factor impacting participation. It is clear how the inability to perform basic ADLs which was never a problem prior to the stroke can have an adverse effect on emotional status. Due to the inability to perform certain activities and fulfill roles post stroke, these duties are often taken over by family or friends. Consequently, role changes occur as these activities are now being completed by someone else (Maleka et al., 2012). This can result in altered emotional state and eventually depression (Dowswell et al., 2000).

The majority of participants (38.7%) indicated that their family had no problem with their health condition, while 7.5% of participants said that family members had extreme problems with their health condition. It is unknown how many family members this question referred to. It is possible, that the families of the 7.5% of participants are under immense pressure and caregiver burden, owing to this result. A study conducted by Mudzi et al. (2013) confirmed that activity participation was facilitated by immediate family. According to the ICF, environmental factors constitute the environment of the family. This could explain why the 42.5% of participants found no problem with joining in community activities. When participants were asked how much of a problem they had in doing things for relaxation, 47.2% had no difficulty, while 25.5% reported severe difficulty. It is possible that the 47.2% of individuals are inclined to engage in more self-contained activities such as watching television and reading, as it is reported that post stroke, social and leisure activities declined (O'Sullivan and Chard, 2010). This could explain why a large proportion of participants in this study reported no difficulty with engaging in activities for relaxation.

The inability to return to work post stroke has been found to have affected many individuals in the current study. It has been reported that environmental factors owing to participation restrictions post stroke include driving (O'Sullivan & Chard, 2010), financial costs and the use of public transport (Amarshi, Artero, & Reid, 2006). The current study discovered that 22.7% of participants experienced no barriers to participation, while a smaller percentage (19.8%) reported extreme barriers in the community affecting participation. When assessing participants' socio-economic status, it was reported that the majority of participants (54.7%) were employed at the time of the stroke and post stroke, 51% were classified as unemployed due to medical reasons with only 2.7% of participants returning to gainful employment post stroke. A study conducted by Hartman-Maeir et al. (2007)

concluded a similar finding when out of the fifty-seven participants, only one participant returned to gainful employment. Furthermore, the majority of participants (45.3%) in this sample reported that the impact on their financial resources post stroke has been severe. This could be linked to return to work post stroke. The largest percentages (63.2%) of unemployed participants are currently relying on their state pension or disability grant for financial survival. This will amount to approximately R1000 – R2000 per month, and many participants do not have the financial support of others. Based on findings from this study, and numerous others (Hartman-Maeir et al., 2007; Ntsiea et al., 2012; Vestling et al., 2003), it is clear that return to work is of major concern post stroke. What is more evident in the findings above is that the inability of participants to return to work has placed an increased financial burden on these individuals.

6.4. Social Support

The largest proportion (89.9%) of participants in this study were classified as having low social support, while the remaining 10.1% were classified as having high social support. This was based on their SSQN. A qualitative study conducted by Lynch et al. (2008) found that it was imperative to maintain social relationships post stroke. It was also discovered that numerous friends and family members were not supportive post stroke. This included abandoning individuals and ceasing communication. Another study resulted in 43% of the participants reporting difficulties with social interaction post stroke (Edwards et al., 2006). Thus, the abandonment of individuals post stroke and ceasing communication could explain why most participants in the current study were classified as having low social support. Despite this, 96.3% of participants rated their satisfactory levels as a little satisfied to very satisfied, and based on this, were classified as having high satisfaction scores, with the majority (43.4%) scoring the maximum, indicating that they were very satisfied with the support given. This indicates that despite low levels of social support, participants were still very satisfied with the few people in their lives that they could rely on. The explanation of this result is two-fold. It could explain the quality of support received from individuals, and although they do not have the support of many, they are still very satisfied which speaks to the quality of support given. However, Beckley (2007) stated that quantity and quality of social support are both vital factors aiding community participation. Secondly and more likely, is the possibility that participants were not going to express their dissatisfaction with the support they were receiving. Literature has proven that participants expressed the feeling of being a burden to others, particularly when the support extends over long periods (Rhoda et al., 2015). It is possible that participants were not pleased about the amounts of support that they were receiving, but were not willing to report it. Participants might have viewed this as being unappreciative of the support provided. The result of 70.8% of participants not attending a stroke support group could be attributed to environmental barriers as described above. This specific group is run weekly, in the Southern Western District, and participants outside of this district do not have access to transport. For some participants, the use of public transport is especially difficult, particularly if they are suffering from common impairments post stroke, making mobility difficult. It is proven from the results of the current study that there is a significant relationship between the SSQN and the SSQF (P = 0.000). This means that the more family members providing support, the higher the social support in the affected individual. Thus, higher social support number scores would indicate higher social support family scores. This result shows the importance as well as dependence on family members for support. The largest percentage (22.6%) indicated that they had only two family members which they could rely on for support, with a combined 63.2% having between 2 to 5 family members available for support. The role of primary caregivers is often taken on by family members (Andrew et al., 2015).These family members' roles are now two-fold, firstly to provide individuals with the appropriate support needed, and secondly that of caregiving. If there are minimal family members available to provide care and assistance, it is likely that the caregiver will find it challenging to provide support in both roles. Increased disability post stroke would indicate increased dependence on a caregiver. This would indicate increased time spent assisting the individual with ADLs. If this caregiver is a family member, this might result in the family member not being able to support the individual socially as required. If there are only two people available to provide caregiving, as seen in the majority of the current sample, the impact on caregivers is excessive. Literature has proven that caregivers reported a 40% decrease in their work, with 47% of carergivers reporting a decrease in their leisure activities (Andrew et al., 2015). Furthermore, when individuals' needs were not fulfilled, this resulted in greater impact on caregivers. It has been discovered, that over time, caregivers experience less informal support from people they can depend on for help and they become less satisfied with the help they receive from others (Simon, Kumar, & Kendrick, 2008). Despite the impact placed on caregivers of individuals with stroke being outlined in the literature (Andrew et al., 2015), they are still unable to effectively rely on others for support.

The highest numbers of family members were indicated by only 1.8% of participants, ranging between 10 – 14 family members available that participants could rely on for support. The researcher was unable to obtain evidence reporting how much family support is needed to reduce the impact of caregiver strain. However, when assessing the profile of this sample population, it is clear that these participants require a large amount of assistance and support, especially in domains of mobility, self-care and participation, and two family members will surely struggle to try meet the demands of the stroke patient. Thus, with the high number of family members (10 – 14) available to the 1.8% of participants on which to rely on, the burden of care is not solely placed on one person. From the results of the current study, it was revealed that 30.2% of participants received the majority of support from their children, and the same percentage of participants (30.2%) received the majority of support from their family members. These family members included siblings and close family relatives such as cousins, aunts and uncles. The finding of the current study is strengthened by a community based study which revealed that post stroke, 60% of participants were cared for by relatives (Mudzi et al., 2013), while other literature show that the majority of people providing support for patients post stroke include spouses (57%) or partners (12%) (Mackenzie et al., 2007). The possible reasons for this difference in result could be due to the fact that a high percentage of participants in the current study (20.8%) are unmarried and an even larger proportion of participants (83.0%) are residing with family in the community. It is possible that in the absence of a spouse, participants tend to rely on their family members for support whom they are living with, in the community.

6.5. Social Support and its influence on participation

Our findings suggest that social support has no statistical significant effect on participation (P = 0.146), despite other literature showing a significant effect between these two variables (Beckley, 2007; Mayo et al., 2013). In a qualitative study conducted by Amarshi et al. (2006), a strong correlation between social support was uncovered as an enabler to participation in social and leisure activities. Although a significant result was not obtained in the current study, the largest proportions of participants in this study was found to have low social support (89.9%) and has been severely affected in various aspects of participation (51.8%). Amongst the participants (10.1%) who scored the highest for social support, it is reported that their participation had only been moderately affected. In a study conducted by Mayo et al. (2013), it was reported that poor social support had an adverse effect on participation. Based on the findings from the systematic review (see Chapter Three), the aspects of quality and quantity of social support emerged as important factors when determining participation post stroke. Participants in the current study reported a high quality of support provided but a low quantity, which was seen for the majority of participants. However, both quality and quantity of support is important for community participation (Beckley, 2007). The low quantity of support provided could explain why the majority of participants had severe difficulty in the domain of participation. This study used a cross-sectional design, and an intervention based study might have concluded a different result, regarding the relationship between social support and participation. However, according to the systematic review conducted, there were no randomised controlled trials conducted on this specific topic between the years 2001 to 2013, according to the databases searched. The designs of the studies included in the review were cross-sectional, qualitative and cohort and they clearly stipulate a distinct relationship between these two variables. So, the implementation of a RCT is a good recommendation.

6.6. Study Limitations

A larger sample size could have been used for this study. Participants who resided in the Southern Western and Klipfontein Mitchells Plain MDHS were included in this study. However, participants were often not able to attend the CHC on the day of data collection due to weather, transport or cost constraints. The results of this study can be generalized to the CHCs in the Western Cape. However, this study cannot be generalised to the rural and peri – urban areas in the Western Cape as a small number of participants were used from a distinct area. The study utilised surveys, and was descriptive in nature. Intervention-based studies might have produced a different result with regard to the relationship between social support and participation.

6.7. Summary of discussion

In this study, an equal number of males and females participated, with a mean age of 61.5 years. When analysing the restrictions post stroke in the domains of the ICF, common difficulties with regard to activity limitations for this sample of participants included standing, walking, washing and getting dressed. With regard to participation restrictions, the largest proportions of participants reported difficulties in joining in community activities, emotional well-being and financial constraints. This could be due to the fact that only a small proportion (three participants) returned to paid employment post stroke. These findings above have not only been concluded in the current study, but in various other South African literature as well. Overall, participants experienced the most difficulties in the domains which required more physical activity than others. Participants reported cognition and getting along with people to be less difficult. When analysing the social support profiles of the sample, it was revealed that the largest proportion (89.9%) reported low social support. Consequently, in the domain of participation, participants (51.8%) were severely affected. A positive relationship was found between social support and family scores. This raised discussion regarding the impact on caregivers , especially in the family members of individuals with stroke. Furthermore, the majority of participants only had two to five family members on which to rely on for support. Literature highlighted the effects of stroke on the caregivers themselves. This study utilised a cross sectional design, and a different study design could have concluded a different result with regard to social support and its effect on participation. It is noted that with regard to social support, the participants in this study displayed the extreme values for the SSQN and the SSQS i.e. The majority of participants displayed very low social support, but were very satisfied with the support received. It is possible that because of the social circumstances of these participants, they are satisfied with very little.

CHAPTER SEVEN

SUMMARY, CONCLUSION AND RECOMMENDATIONS

7. Introduction

This is the final chapter and includes the summary, conclusion and recommendations. The summary component presents an overview of the entire thesis, while the conclusion draws a closing on the discussion chapter. The clinical implications of the study are identified, and recommendations are made for studies in the future.

7.1. Summary

Stroke or cerebrovascular accidents remains a primary cause of disability and death in South Africa (Bryer et al., 2011), accounting for 5.5 million deaths globally (Truelsen et al., 2000). In the year 2010, stroke was accountable for one in ten deaths worldwide, and if this tendency continues, it is suspected that stroke will be responsible for 20 million annual deaths, and a further 70 million stroke survivors worldwide by the year 2030 (Maredza, Bertram, & Tollman, 2015). Common effects of a stroke include impairment to executive functioning, fine or gross motor skills, long or short term memory and speech, sight or hearing. The nature of the impairment is dependent on the area of the brain affected (Cookson & Casey, 2013). As a result of the impairment associated with stroke, individuals are not able to return to their normal functioning as before. In community-dwelling sufferers, it was discovered that the most common limitation in participating in the community include performing ADLs, household tasks, carrying out a meaningful activity and travelling (Barclay – Goddard et al., 2012). The literature available with regard to stroke has only recently included social support as a factor to consider to enhance the outcomes associated with stroke recovery (Beckley, 2007). The literature available regarding social support and its effect on participation are minimal, and a small percentage of this is present in developing countries. Therefore, the aim of the current study was to determine social support and participation restrictions in patients suffering from a stroke, and consisted of a systematic review and a survey study.

Due to the lack of evidence in the literature, a systematic review was conducted. The databases searched were Ebscohost full text which included CINAHL +, Health Source: Nursing, Academic edition, Medline, Psych articles and Soc index, Science Direct, Biomed Central, Google Scholar, Cochrane Library, Pedro Central, and Wiley Online between the years 2001 to 2013. All articles which included a measure of both social support and at least one measure of participation as identified by the ICF were included. No RCTs were identified, so no intervention based studies were assessed. A total of three studies were included in this review which included one qualitative, one cohort and one cross-sectional study. According to the hierarchy of evidence presented these articles provided Level 4 (cohort) and 6 (descriptive and qualitative) evidence on social support and participation and shows that more research is needed in the field. The articles identified clearly outlined the importance of the quality and quantity of social support (Beckley, 2007), as well as its influence of social support on participation post stroke (Mayo et al., 2013). It was concluded that three participants in a study conducted by Sumathipala et al. (2011) reported moving away from their homes, and closer to the homes of their families and friends, as their friends and families provided support for them. A further 74% of this sample found the support of friends and family to be a fundamental part of returning to function. This review clearly highlights the factors that need to be considered regarding social support, and it shows the importance of good social support structures when trying to improve participation post stroke. The review concluded that there is Level 4 and 6 evidence which shows a positive relationship between social support and participation, with the quantity playing a bigger role in participation than the quality. However both aspects of social support have been found to have a significant role in participation restrictions post stroke.

Permission to conduct this research was obtained from the University of the Western Cape's Faculty of Community and Health Sciences Higher Degrees Committee, The Senate Research and Study Grants Committee and the Department of Health of Western Cape, reference number 14/5/22. The study was cross-sectional in nature, using two objective instruments. The sample population included all individuals who suffered a stroke, and living in the community for at least six months. These individuals were sourced from the CHCs in the Southern Western and Klipfontein Mitchell’s Plain MDHS. Convenience sampling was therefore used. The instrument used to gather information about participation restrictions was the WHODAS 2.0., and the Social Support Questionnaire 6 was the tool used to gather information about the individuals level of social support and satisfaction thereof. Prior to data collection, the participants were given an information sheet which provided information about the study, followed by a consent form. Participants were required to provide verbal and written informed consent prior to the completion of the surveys. Participants were informed that their refusal or withdrawal would not impact their treatment received at the CHC. Questionnaires were made available in English, Afrikaans and isiXhosa.

Once the data was collected, the total scores were tallied based on classifications from the WHODAS 2.0. (Üstün et al., 2010) and the SSQ 6 (Klocek et al., 1997). These total scores were entered into the SPSS version 23 for analysis. Frequency tables were used to describe categorical data, while means, medians and standard deviations used to describe continuous data. This was done using descriptive statistics. The association between social support and participation was determined using the Pearsons correlation test, with alpha co-efficient set at $P \leq 0.05$ to determine statistical significance.

A total of 106 individuals comprised the sample for this study, with an equal number (n=53) of males and females. The mean age for participants in the study was 61.5 years. The domains which scored the highest overall domain scores were mobility, household activities and participation. This means that participants found the domains requiring the most physical activity, challenging.In the domain of participation, 51.8% of participants reported severe difficulty in this domain, which included joining in community activities, doing things for relaxation as well as emotional and financial constraints. The four aspects of participation which was reported to be extremely affected by participants included emotional status (31.1%), barriers in the community (19.8%), increased time spent on their health condition (8.5%) and family problems (7.5%). A further 70.8% were not attending a weekly stroke support group. Return to work is of major concern, as proved in this study, where only three participants returned to employment post stroke, and many others (Ntsiea et al., 2014; Rochette et al., 2007).

The largest percentage (89.9%) reported having low levels of social support. Despite this, 43.4% reported that they were very satisfied with the support provided to them. This is a reflection of the quality of support given, which was further discussed in the systematic review as an important variable to improve participation. However, both quality and quantity of social support has been found to improve community participation (Beckley, 2007). The impact on caregivers was identified in this study due to the significant result obtained between the social support number scores, and social support family scores. The majority of participants reported that they had only two family members on which to rely on for support. Amongst these family members providing support, 30.2% of participants reported that the majority of family member support was provided by their children, and their family. Two family members providing support is not enough to improve social support, which explains why the majority of participants in this study were classified as having low levels of social support. Due to the disability reported by this sample, the impact on caregivers is clear. When determining the association between social support and participation, the Pearsons correlation test revealed a P value of 0.146, indicating no association between these two variables. Factors to be considered for this insignificant finding includes study design and sample size.

7.2. Conclusion

The results of the current study confirmed, according to objective tests, that no significant relationship exists between social support and participation post stroke. Contrary to the systematic review (see Chapter Three), where there was one study which produced Level 4 (cohort) evidence which clearly stipulates a positive relationship between social support and participation, i.e. increased amounts of social support results in increased levels of participation (Mayo et al., 2013). The results of the survey further revealed that the largest proportion of participants reported low social support, despite living with relatives and family. In conclusion, the survey conducted could agree that participants had low social support, with low participation. However, this relationship was not significant in any direction. Whereas the finding proven by a study included in the review conducted (see Chapter Three) would agree that the majority of participants reported high levels of social support and high levels of participation. This relationship was proved significant. The differences in the findings of the survey and the review, is the levels of social support in participants of the current study.

7.3. Clinical Implications

As a result of the participation restrictions experience by stroke survivors, social isolation is common which has been known to affect relationships (Maleka et al., 2012). Even without the effects of social isolation, literature has reported social interactions (Edwards et al., 2006) post stroke as well as the maintenance of social relationships critical (Lynch et al., 2008). At six weeks post discharge, rehabilitation services most commonly provided to stroke victims are physiotherapy (64%), occupational therapy (54%), speech therapy (20%), specialist stroke support nurse (20%) and social support from social workers (under 50%) (Simon et al., 2008). These values clearly state that social support is a factor that is often overlooked when attempting to manage stroke patients. More so, due to the minimal literature regarding the topic, many are unaware of its importance. The current study shows that 13.2% of participants do not engage in any household activities, even though they have the ability to. This increases the dependence on caregivers, which further increases the burden on them. The involvement of caregivers and family members in the rehabilitation process are encouraged by health professionals as they play a vital role in the recovery of stroke patients (Rhoda, 2012). However, the role of family members and caregivers need clarification. This can be done by the rehabilitation professionals. Rehabilitation of the stroke patient should include the family members and caregivers where family and caregivers are encouraged to play the role of a motivator, encourager of independence and participation for the stroke patient. One vital finding in this study, which needs to be stressed, is the quality and quantity of social support. Members of the family have been reported to be a key facilitator in functioning by 74% of a sample (Sumathipala et al., 2011). Support should be provided in large quantities, and be of good quality to be effective, i.e. with regard to quality, support should be given only when needed. If participants are able to perform activities on their own, independence should therefore be encouraged. Group rehabilitation sessions and support groups should be initiated. This can improve support networks in individuals and has been known to have an effect on participation (Mayo et al., 2013).

7.4. Recommendations

7.4.1. Clinical Practice

Health care professionals, especially occupational therapists, need to develop appropriate assessment tools for return to work interventions post stroke, which could improve participation and facilitate independence in the stroke survivor.

Family training should be conducted by the relevant health care professionals. This could allow family members to effectively assist individuals post stroke to gain independence and thereby improve functioning and participation.

The rehabilitation care professionals (physiotherapists and occupational therapists) at the CHCs in the Western Cape Metropole should develop a stroke support group for all stroke survivors in the community to attend, similar to the successful support group run in the Southern Western District. Support groups for stroke patients play an important role in psychological well-being and physical integration (Harrington et al., 2010), as well as QoL and reduces barriers to participation (Mayo et al., 2015). The current study did not measure the effect of attending a support group on participation and social support but a small proportion of participants (29.2%) are currently attending a weekly stroke group. Details regarding the content of the stroke group, participant attendance and how long participants have been a part of the group were not obtained. It is unknown whether the class was solely exercise-based or if social support interventions were part of the programme, and if so, how many times this intervention was used. Patient compliance is questionable due to common barriers identified in the community (Amarshi et al., 2006; O'Sullivan & Chard, 2010). Although transport to the stroke group was provided, it still constitutes public transport and constraints including physical impairment would count against individuals. These are factors which need to be taken into account when planning a support group. Lastly, clinicians should raise awareness on the importance of attending a stroke support group and should arrange for transport to aid attendance. This could improve stroke survivors' social support.

7.4.2. Policy

The South African government should make provision for people with disabilities to be provided with public transport that is easily accessible and affordable. This will allow these individuals to function in the community, thereby improving participation, and QoL.

The finances provided to people with disabilities by the state pension and government disability grant is not sufficient for people to survive. The cost of living is increasing and people with disabilities are under financial pressure. The government should assess ways of increasing the state pension and disability grants, thereby lessening the financial pressure on these individuals.

The South African government should create employment opportunities for people with disabilities as it is clear from the current study that return to work post stroke is challenging for individuals. This will assist individuals financially, and aid participation.

7.4.3. Research

The literature examined in the systematic review with regard to social support and its association with participation has mainly been conducted in the American and European countries, with minimal research present for the local setting. More so, gaps in the available literature from these countries have been presented. As social support has been known for its multi-faceted aspects, it is recommended that future research in this field utilise research instruments which measure all aspects of social support. The hierarchy of evidence indicates that there is minimal Level 1 – 3 research available regarding this topic. No RCTs were attained from the search of the systematic review, so it is suggested that future literature focus on controlled trials, to determine the effects of these two variables. Descriptive and cohort studies are recommended to provide baseline evidence in the field, while cohort studies are able to monitor the differences in support patterns over time. Lastly, it is recommended that research in developing countries focus on social support and its effects on participation.

REFERENCES

Akobeng, A. K. (2005). Understanding systematic reviews and meta-analysis. *Arch Dis Child,* 90:845 – 848.

Amarshi, F., Artero, L. and Reid, D. (2006). Exploring social and leisure participation amongst stroke survivors: Part two. *Int J Ther Rehabil,* 13(5):199-208.

Andrew, N. E., Kilkenny, M. F., Naylor, R., Purvis, T. and Cadilhac, D. A. (2015). The relationship between caregiver impacts and the unmet needs of survivors of stroke. *Patient Preference and Adherence,* 9:1065–1074.

Bagg, S., Pombo, A. P. and Hopman, W. (2002). Effect of age on functional outcomes after stroke rehabilitation. *Stroke; a Journal of Cerebral Circulation,* 33(1):179–185.

Barclay-Goddard, R., Ripat, J. and Mayo, N. E. (2012). Developing a model of participation post-stroke: a mixed-methods approach. *Quality of Life Research : An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation,* 21(3):417–26.

Beckley, M. N. (2007). The influence of the quality and quantity of social support in the promotion of community participation following stroke. *Australian Occupational Therapy Journal,* 54:215–220.

Beckley, M. N. (2006). Community participation following cerebrovascular accident: impact of the buffering model of social support. *The American Journal of Occupational Therapy: Official Publication of the American Occupational Therapy Association,* 60(2):129–35.

Bertram, M. Y., Katzenellenbogen, J., Vos, T., Bradshaw, D. and Hofman, K. J. (2013). The disability adjusted life years due to stroke in South Africa in 2008.

International Journal of Stroke : Official Journal of the International Stroke Society, 8:76–80.

Bigby, M. (2009). The Hierarchy of Evidence. *Evidence-Based Dermatology: Second Edition,* (2009),34–37.

Bryer, A., Connor, M. D., Haug, P., Cheyip, B., Staub, H., Tipping, B., Duim, W.B. and Pinkney-Atkinson, V. (2011). The South African guideline for the management of ischemic stroke and transient ischemic attack: recommendations for a resource-constrained health care setting. *International Journal of Stroke : Official Journal of the International Stroke Society,* 6(4):349–354.

Cardol, M., De Jong, B. A, Van den Bos, G. A. M., Beelem, A., De Groot, I. J. M. and De Haan, R. J. (2002). Beyond disability: perceived participation in people with a chronic disabling condition. *Clinical Rehabilitation,* 16(1):27–35.

Critical Appraisal Skills Programme. (1994). Qualitative Research Checklist, 1–7. *Critical appraisal checklist for cohort and qualitative study designs.* Retrieved from:
www.casp-uk.net/#!casp-tools-checklists/c18f8.

Chau, J. P., Thompson, D. R., Twinn, S., Chang, A. M. and Woo, J. (2009). Determinants of participation restriction among community dwelling stroke survivors: A path analysis. *BMC Neurology,* 9(1):49.

Cohen, S. and Syme, S. L. (1985). Social Support and Health. *Academic Press.*

Conner, M. and Bryer, A. (2005). Stroke in South Africa. *Chronic Diseases of Lifestyle in South Africa,* 195–203.

Connor, M. D., Thorogood, M., Casserly, B., Dobson, C. and Warlow, C. P. (2004). Prevalence of stroke survivors in rural South Africa: results from the Southern Africa Stroke Prevention Initiative (SASPI) Agincourt field site. *Stroke; a Journal of Cerebral Circulation,* 35(3):627–32.

Cookson, C. and Casey, J. (2013). Social support following stroke. *The Psychologist*, 26(8):566–569.

Danielsson, A., Willén, C. and Sunnerhagen, K. S. (2012). Physical activity, ambulation, and motor impairment late after stroke. *Stroke Research and Treatment.*

De Vos, A. S., Strydom, H., Fouche, C. B. and Delpoort, C. S. L. (2002). Research at Grassroots for the social sciences and human service professions, 2nd edition. *Pretoria: Van Schaik.*

Donkor, E. S., Owolabi, M. O., Bampoh, P., Aspelund, T. and Gudnason, V. (2014). Community awareness of stroke in Accra, Ghana. *BMC Public Health*, 14(1):196.

Dowswell, G., Lawler, J., Doswell, T., Young, J., Forster, A. and Hearn, J. (2000). Investigating recovery from stroke: a qualitative study. *Journal of Clinical Nursing*, 9:507 – 515.

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: The Official Journal of National Stroke Association*, 15(4):151–7.

Ellis, C., Focht, K. L. and Grubaugh, A. L. (2013). Perceptions of stroke recovery: An exclusion of communication and cognition. *Neurorehabilitation,* 33:233–239.

Fallahpour, M., Tham, K., Joghataei, M. and Jonsson, H. (2011). Perceived participation and autonomy: Aspects of functioning and contextual factors predicting participation after stroke. *Journal of Rehabilitation Medicine*, 43(5):388–397.

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,* 44:135 – 141.

Glass, T. A, Matchar, D. B., Belyea, M. and Feussner, J. R. (1993). Impact of social support on outcome in first stroke. *Stroke; a Journal of Cerebral Circulation,* 24(1):64–70.

Grant, J. S., Elliott, T. R., Weaver, M., Bartolucci, A. A. and Giger, J. N. (2002). Telephone intervention with family caregivers of stroke survivors after rehabilitation. *Stroke,* 33(8):2060 - 2065.

Graven, C., Brock, K., Hill, K. and Joubert, L. (2011). Are rehabilitation and/or care co-ordination interventions delivered in the community effective in reducing depression, facilitating participation and improving quality of life after stroke? *Disability and Rehabilitation,* 33:1501–1520.

Han, B. and Haley, W. E. (1999). Family Caregiving for Patients With Stroke : Review and Analysis. *Stroke*, 30(7):1478–1485.

Harrington, R., Taylor, G., Hollinghurst, S., Reed, M., Kay, H. and Wood, V. A. (2010). A community-based exercise and education scheme for stroke survivors: a randomized controlled trial and economic evaluation. *Clinical Rehabilitation,* 24(1):3–15.

Hartman-Maier, A., Soroker, N., Ring, H., Avni, N. and Katz, N. (2007). Activities, participation and satisfaction one year post stroke. *Disability and Rehabilitation,* 29(7):559 – 566.

Hershkovitz, A., Beloosesky, Y., Brill, S. and Gottlieb, D. (2004). Is a day hospital rehabilitation programme associated with reduction of handicap in stroke patients? *Clinical Rehabilitation,* 18:261 – 266.

Hopkins, W. G. (2008). Research Designs : Choosing and Fine-tuning a Design for Your Study. *Sportscience,* 12:12–21.

Huang, C. Y., Hsu, M. C., Hsu, S. P., Cheng, P. C., Lin, S. F. and Chuang, C. H. (2010). Mediating roles of social support on poststroke depression and quality of life in patients with ischemic stroke. *Journey of Clinical Nursing,* 19:2752–2762.

Indredevik, B., Bakke, F. and Slordahl, S. A. (1999). Treatment in a combined acute and rehabilitation stroke unit: Which aspects are most important? *Stroke,* 30:917 – 923.

Jones, F., Mandy, A. and Partridge, C. (2008). Reasons for recovery after stroke: a perspective based on personal experience. *Disability and Rehabilitation,* 30(7):507–516.

Jones, S. A. and Shinton, R. A. (2006). Improving outcome in stroke patients with visual problems. *Age ageing,* 35(6):289 – 293.

Joseph, C. and Rhoda, A. (2013). Activity limitations and factors influencing functional outcome of patients with stroke following rehabilitation at a specialised facility in the Western Cape. *African Health Sciences,* 13(3):646–654.

Kelley, K., Clark, B., Brown, V. and Sitzia, J. (2003). Good practice in the conduct and reporting of survey research. *International Journal for Quality in Health Care,* 15(3):261–266.

Klocek, J., Oliver, J. and Ross, M. J. (1997). The role of dysfunctional attitudes, negative life events, and social support in the prediction of depressive dysphoria: a prospective longitudinal study. *Social Behavior and Personality,* 25(2):123 - 136.

Koch, L., Egbert, N., Coeling, H. and Ayers, D. (2005). Returning to work after the onset of Illness: Experiences of Right Hemisphere Stroke Survivors. *Rehabilitation Counselling Bulletin,* 48(4):209 – 218.

Kumerenzi, A., Frantz, J., Rhoda, A. and Mlenzana, N. (2010). Experiences of persons with physical disabilities regarding rehabilitation services. A systematic review. *Journal of Community and Health Sciences,* 33 – 39.

Lin, N., Ensel, W. M. and Vaughn, J. C. (1981). Social resources and strength of ties: structural factors in occupational status attainment. *Am. Sociol. Rev,* 46(4):393 – 405.

Linder, S. M., Rosenfeldt, A. B., Reiss, A., Buchanan, S., Sahu, K., Bay, C. R., Wolf, S. L. and Alberts, J. L. (2013). The home stroke rehabilitation and monitoring system trial: a randomized controlled trial. *International Journal of Stroke : Official Journal of the International Stroke Society,* 8(1):46–53.

Lynch, E. B., Butt, Z., Heinemann, A., Victorson, D., Nowinski, C. J., 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(7):518–523.

Mackenzie, A., Perry, L., Lockhart, E., Cottee, M., Cloud, G. and Mann, H. (2007). Family carers of stroke survivors: needs, knowledge, satisfaction and competence in caring. *Disability and Rehabilitation,* 29(2):111 – 121.

Maleka, M., Stewart, A. S. and Hale, L. (2012). The experience of living with stroke in low urban and rural socio-economic areas of South Africa. *South African Journal of Physiotherapy,* 68(3):25–29.

Maredza, M., Bertram, M. Y. and Tollman, S. M. (2015). Disease burden of stroke in rural South Africa: an estimate of incidence, mortality and disability adjusted life years. *BMC Neurology,* 15:54.

Mash, B., Levitt, N., Steyn, K., Zwarenstein, M. and Rollnick, S. (2015). Cost-effectiveness of a diabetes group education program delivered by health promoters with a guiding style in underserved communities in Cape Town, South Africa. *BMC Family Practice,* 13:126.

Mattson, M. (2011). Linking Health Communication with Social Support. *Health as Communication Nexus*, 6:181 – 219.

Mayo, N. E., Anderson, S., Barclay, R., Cameron, J. I., Desrosiers, J., Eng, J. J., Huijbregts, M., Kagan, A., Lyons, M. M., Moriello, C., Richards, C. L., Salbach, N. M., Scott, S. C., Teasell, R. and Bayley, M. (2015). Getting on with the rest of your life following stroke: A randomized trial of a complex intervention aimed at enhancing life participation post stroke. *Clinical Rehabilitation*, 1 - 14.

Mayo, N. E., Bronstein, D., Scott, S. C., Finch, L. E. and Miller, S. (2013). Necessary and sufficient causes of participation post-stroke: practical and philosophical perspectives. *Quality of Life Research*, 23(1):39–47.

Mayo, N. E., Wood-Dauphinee, S., Côté, R., Durcan, L. and Carlton, J. (2002). Activity, participation, and quality of life 6 months post stroke. *Archives of Physical Medicine and Rehabilitation*, 83(8):1035–1042.

Mbambo, S., Uys, L. R. and Groenewald, B. (2003). A job analysis of selected health workers in a district health system in Kwazulu-Natal. *Curationis*, 26(3):42 – 52.

Melynyk, B. and Fineout-Overholt, E. (2011). Evidence-based practice in nursing & healthcare: A guide to best practice (2nd ed), *Philadelphia: Wolters Kluwer, Lippincott Williams and Wilkins.*

Milton Keynes Primary Trust. (2002). Appraisal tool for cross-sectional study designs. Adapted from Guyatt, G. H., Sackett, D. L. and Cook, D. J. (1994, 1993). How to use and article about therapy or prevention, *JAMA.* Retrieved from: https://reache.files.wordpress.com/2010/.../cross-sectional-appraisal-tool.

Morelli, S. A., Lee, I. A., Arnn, M. E. and Zaki, J. (2015). Emotional and Instrumental Support Provision Interact to Predict Well-Being. *Emotion*, 15(4):484 – 493.

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):1–9.

Noreau, L., Desrosiers, J., Robichaud, L., Fougeyrollas, P., Rochette, A. and Viscogliosi, C. (2004). Measuring social participation: Reliability of the LIFE-H in older adults with disabilities. *Disabil Rehabil,* 26(6):346 – 352.

Ntsiea, M. V., Van Aswegen, H., Lord, S. and Olorunju S, S. (2015). The effect of a workplace intervention programme on return to work after stroke: a randomised controlled trial. *Clinical Rehabilitation,* 29(7):663–673.

Ntsiea, M. V., Van Aswegen, H., Lord, S. and Olorunju, S. (2012). Return to work services rendered for patients at stroke rehabilitation facilities in Gauteng Province, South Africa. *International Journal of Therapy & Rehabilitation,* 19(3):130–135.

Oliveira, A. R. De S., Rodrigues, R. C., De Sousa, V. E. C., Costa, A. G. De S., Lopes, M. V. De O. and De Araujo, T. L. (2013). Clinical indicators of “caregiver role strain” in caregivers of stroke patients. *Contemporary Nurse,* 44(2):215–224.

O’Sullivan, C. and Chard, G. (2010). An exploration of participation in leisure activities post stroke. *Australian Occupational Therapy Journal,* 57:159–166.

Reagon, G., Irlam, J. and Levin, J. (2004). *The National Primary Health Care Facilities Survey,* Durban, Health Systems Trust.

Reid, D. (2004). Impact on the environment on role performance in older stroke survivors living at home. *Int J Ther Rehabil,* 11(12):567 – 573.

Resnik, L., Bradford, D., Glynn, S., Jette, A., Hernandez, C. and Wills, S. (2012). Issues in defining and measuring veteran community reintegration: Proceedings of the Working Group on Community Reintegration, VA Rehabilitation Outcomes Conference, Miami, Florida. *JRRD,* 49(1):87 – 100.

Rintala, D.H., Hart, K. A., Priebe, M. M. and Ballinger, D. A. (1998). Racial and ethnic differences in community integration in a community-based sample of adults with spinal cord injury. *Top Spinal Cord Rehabilitation,* 80:1 – 7.

Rhoda, A. (2012). Limitations in activity and participation experienced by stroke patients: A qualitative inquiry. *South African Journal of Physiotherapy,* 68(3):20 – 24.

Rhoda, A., Cunningham, N., Azaria, S. and Urimubenshi, G. (2015). Provision of inpatient rehabilitation and challenges experienced with participation post discharge: quantitative and qualitative inquiry of African stroke patients. *BMC Health Services Research,* 15(1):23.

Rhoda, A. and Henry, J. (2003). Profile of stroke patients treated at a Community-Based Rehabilitation Centre in a Cape Town Health District. *South African Journal of Physiotherapy,* 59(4):20 – 24.

Rhoda, A., Mpofu, R. and Deweerdt, W. (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.

Rhoda, A., Mpofu, R. and Deweerdt, W. (2009). The rehabilitation of stroke patients at community health centres in the Western Cape. *South African Journal of Physiotherapy,* 65(3):1–6.

Rhoda, A., Smith, M., Putman, K., Mpofu, R., DeWeerdt, W. and DeWit, L. (2014). Motor and functional recovery after stroke: a comparison between rehabilitation settings in a developed versus a developing country. *BMC Health Services Research,* 14:82.

Robinson, C. A., Shumway-Cook, A., Matsuda, P. N. and Ciol, M. A. (2011). Understanding physical factors associated with participation in community ambulation following stroke. *Disability and Rehabilitation*, 33(12):1033–1042.

Rochette, A., Desrosiers, J., Bravo, G., St-Cyr-Tribble, D. and Bourget, A. (2007). Changes in participation after a mild stroke: quantitative and qualitative perspectives. *Topics in Stroke Rehabilitation*, 14(3):59–68.

Rouillard, S., De Weerdt, W., De Wit, L. and Jelsma, J. (2012). Functioning at 6 months post stroke following discharge from inpatient rehabilitation. *South African Medical Journal*, 102(6):545–548.

Sarason, I. G., Sarason, B. R., Shearin, E. N. and Pierce, G. R. (1987). A brief measure of Social Support: The Social Support Questionnaire 6 (SSQ6). *Journal of Social Support: Practical and Theoritical Implications*, 4:497–510.

Sarason, I. G., Levine, H., Basham, R. and Sarason, B. (1983). Assessing Social Support: The Social Support Questionnaire (SSQ). *Journal of Personality and Social Psychology*, 44(1):127–139.

Scott, C. L., Phillips, L. H., Johnston, M., Whyte, M. M. and MacLeod, M. J. (2012). Emotion processing and social participation following stroke: study protocol. *BMC Neurology*, 12: 56.

Simon, C., Kumar, S. and Kendrick, T. (2008). Formal support of stroke survivors and their informal carers in the community: a cohort study. *Health and Social Care in the Community*, 16(6):582–592.

Sumathipala, K., Radcliffe, E., Sadler, E., Wolfe, C. D. and McKevitt, C. (2011). Identifying the long-term needs of stroke survivors using the International Classification of Functioning, Disability and Health. *Chronic Illness*, 8(1):31–44.

Sunnerhagen, K. S., Svantesson, U., Lönn, L., Krotkiewski, M. and Grimby, G. (1999). Upper motor neuron lesions: their effect on muscle performance and appearance in stroke patients with minor motor impairment. *Archives of Physical Medicine and Rehabilitation,* 80(2):155–161.

The Oxford Levels of Evidence. (2011). Levels of Evidence Working Group Oxford*; Oxford Centre for Evidence-Based Medicine.* Retrieved from: http://www.cebm.net/index.aspx?o=1025.

Tooth, L., McKenna, K., Barnett, A., Prescott, C. and Murphy, S. (2005). Caregiver burden, time spent caring and health status in the first 12 months following stroke. *Brain Injury,* 19(12):963–74.

Treger, I., Shames, J., Giaquinto, S. and Ring, H. (2007). Return to work in stroke patients. *Disability and Rehabilitation,* 29(17):1397–1403.

Truelsen, T., Begg, S. and Mathers, C. (2000). The global burden of cerebrovascular disease. *Global Burden of Disease,* 1–67.

Tsouna-Hadjis, E., Vemmos, K. N., Zakopoulos, N. and Stamatelopoulos, S. (2000). First-stroke recovery process: The role of family social support. *Archives of Physical Medicine and Rehabilitation,* 81(7):881–887.

Üstün, T. B., Chatterji, S., Kostanjsek, N., Rehm, J. (2010). Measuring Health and Disability: *Manual for WHO Disability Assessment Schedule WHODAS 2.0.* Retrieved from: https://books.google.com/books?hl=en&lr=&id=h9fhLNiaRTgC&pgis=1

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(3):127–131.

White, J. H., Miller, B., Magin, P., Attia, J., Sturm, J. and Pollack, M. (2012). Access and participation in the community: a prospective qualitative study of driving post-stroke. *Disability and Rehabilitation,* 34(10):831–838.

Wills, T.A. and Shinar, O. (2000). Measuring perceived and received social support. *A guide for health and social sciences,* 86 – 135.

Wolf, T. and Koster, J. (2013). Perceived recovery as a predictor of physical activity participation after mild stroke. *Disability and Rehabilitation,* 35(14):1143–1148.

World Health Organisation. (2001). *Frequently asked questions.* Retrieved from:

www.who.int/classifications/icf/whodasii/en/index6.html

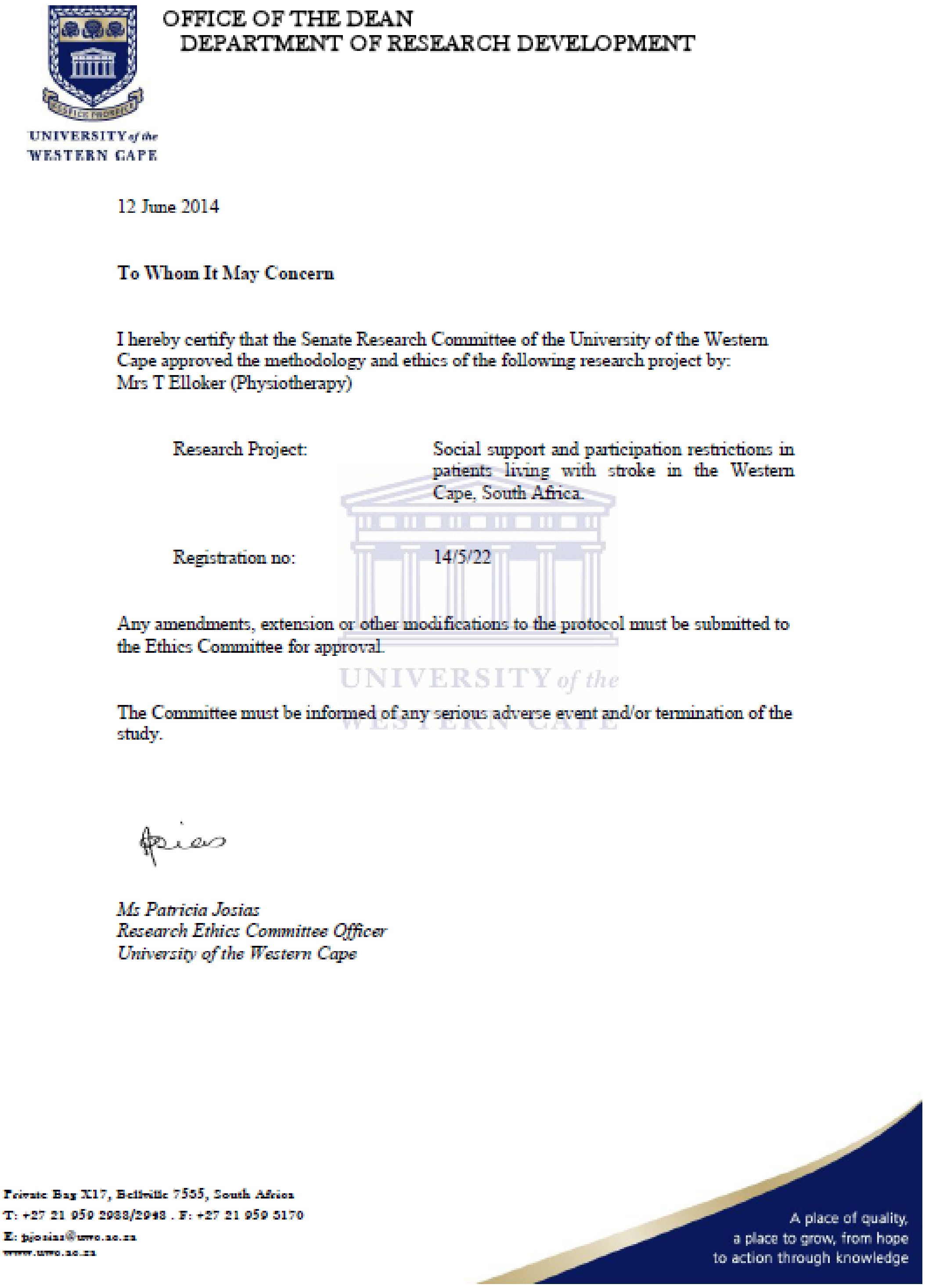
World Health Organisation. (2001). The International Classification of Functioning, Disability and Health: ICF. *Geneva: World Health Organisation.*

World Health Organization and UNICEF. (1978). Primary health care: a joint report. *International Conference on Primary Health Care, 80.* Retrieved from: http://apps.who.int/iris/bitstream/10665/39225/1/9241541288_eng.pdf?ua=1

Young, J. and Forster, A. (2007). Review of stroke rehabilitation. *BMJ (Clinical Research Ed.),* 334:86–90.

APPENDICES

APPENDIX A



UNIVERSITY of the
WESTERN CAPE

OFFICE OF THE DEAN
DEPARTMENT OF RESEARCH DEVELOPMENT

12 June 2014

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:
Mrs T Elloker (Physiotherapy)

Research Project:	Social support and participation restrictions in patients living with stroke in the Western Cape, South Africa.
Registration no:	14/5/22

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

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A place of quality,
a place to grow, from hope
to action through knowledge

APPENDIX B

Western Cape Government
Health

STRATEGY & HEALTH SUPPORT
Health.Research@westerncape.gov.za
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5th Floor, Norton Rose House,, 8 Riebeek Street, Cape Town, 8001
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REFERENCE: WC_2014RP25_284
ENQUIRIES: Ms Charlene Roderick

University of the Western Cape
Faculty of Community Health Sciences
Robert Sobukwe Road
Bellville
7535

For attention: **Prof Anther Rhoda**

Re: SOCIAL SUPPORT AND PARTICIPATION RESTRICTIONS IN PATIENTS LIVING WITH STROKE IN THE WESTERN CAPE, 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:

Dr Abdurahman CHC	**F Burger**	**Contact No. 021 638 3319**
Guguletu CHC	**L Makamba**	**Contact No. 021 637 1280**
Hanover Park CHC	**G van der Westhuizen**	**Contact No. 021 692 1240**
Heideveld CHC	**A Elsteen**	**Contact No. 021 638 3202**
Lady Michaelis	**E Weavers**	**Contact No. 021 797 8171**
Lotus River CHC	**G Jones**	**Contact No. 021 703 3131**
Retreat CHC	**H Lemmetjies**	**Contact No. 021 713 9741**
Woodstock CDC	**A Rayners**	**Contact No. 021 460 9189**

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.

APPENDIX C

UNIVERSITY OF THE WESTERN CAPE
Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2542, Fax: 27 21-9591217
Email: toughieda2003@gmail.com

INFORMATION SHEET

Project title: Social support and participation restrictions in patients living with stroke in the Western Cape, South Africa

What is this study about?

This is a research project being conducted by Toughieda Elloker pursuing a master's degree in physiotherapy at the University of Western Cape. We are inviting you to participate in this research project because of your current status following stroke. The purpose of this research project is to determine the relationship between social support and participation in stroke patients who are living in the community and attend the community health centres for on-going treatment. The information from this study will allow the researchers to gain an understanding of the participation restrictions associated with strokes based on personal experiences from the individuals. This study will create awareness of the effects of social support and participation and it will highlight the impacts of social support on the individual itself. Finally, this research can help health professionals including physiotherapists and occupational therapists develop appropriate treatment techniques to address participation restrictions after strokes.

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

You will be asked to sign a written consent if you agree to participate in this study. You will then have a one on one interview with the researcher where you be will asked to complete two (2) questionnaires. The one questionnaire will ask you about the people or family in your life and how willing they are to assist you. The other questionnaire will ask you about how difficult you find given task which you do on a daily basis. It is estimated that the questionnaire completion will take 45 minutes.

Would my participation in the study be kept confidential?

We will do our best to keep your information confidential. You are not required to write your name in the questionnaire and only your age and other personal details. We will also use codes for the questionnaire so no one will be able to know who gave this information only, the researcher. The researcher will also be the only person who will have access to the questionnaires and once data analysis is complete, the questionnaires will be destroyed. In case of publication of this journal, maximum protection will be guaranteed.

What are the risks of this research?

By participation in this research, you will not be prone to any known risk and if any do arise we will be able to refer you to relevant bodies for help.

What are the benefits of this research?

The benefit of including you in this study is to get the information about social support and participation in patients with strokes. The research is not designed to help you personally, but the results may help the researcher to learn more about social support and participation and how this influences the stroke patient. This study will expand stroke research and it will create awareness about social support and participation in South Africa. The results of this research can help health professionals develop interventions to assist stroke patients with participation restrictions which they experience.

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

Participation in this study is purely voluntary. You may choose not to engage in the study at all. Even after you have agreed to participate in the study, you may quit at your own will and at any given time and this will not impact on the treatment which you receive.

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

In case of any problem that you may encounter we will be able to send you to a doctor or a counsellor for assistance.

What if I have a question?

This research is being conducted by Toughieda Elloker, master's students in physiotherapy at the University of Western Cape. If any questions do arise about the research itself, please contact:

Mrs. Toughieda Elloker
Department of physiotherapy
University of Western Cape
Private bag X17
Bellville 7535
Cell No. 0844826162
Email. Toughieda2003@gmail.com.

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

Deputy Dean of teaching and learning: Prof A. Rhoda

arhoda@uwc.ac.za

Tel: 021 959 2542
Dean of the faculty of community and health sciences: Prof J Frantz
jfrantz@uwc.ac.za
Tel: 021 9592631
University of Western Cape,

Private bag X117

Bellville 7535

This research has been approved by the University of Western Cape senate research and study grants committee (reference number: 14/5/22).

APPENDIX D

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INFORMASIE VORM

Titel van die navorsingsprojek*: *Sosiale ondersteuning en deelname beperkings in beroerte pasiente in die Wes-Kaap, Suid-Afrika

Waaroor gaan die studie?

Die studie word gelei deur Toughieda Elloker, 'n meester's graad student in fisioterapie by die Universiteit van die Wes-Kaap. Ons nooi u om deel te neem aan die studie, want u is 'n persoon wat 'n beroerte ervaar het. Die doel van die studie is om die verhouding tussen sosiale ondersteuning en deelname beperkings in die gemeenskap, vir bereorte pasiente wat by gemeenskap gesondheids sentrums aanmeld vir behandeling, vas te stel. Die informasie wat ingesamel word sal die navorsers instaat stel om die deelname beperkings wat mense wat beroertes gehad het te verstaan vanuit die persoonlike ervaringe van die individu. Die studie sal lig werp op die effek van sosiale ondersteuning en deelname en hoe dit individue wat 'n beroerte ervaar het se lewens beinvloed. Laasstens sal die navorsing profesionele gesondheids werkers, insluitend fisio-terapete en arbeids-terapete, in staat stel om spesifieke behandelings tegnieke te ontwikkel om deelname beperkings na die aanloop van 'n beroerte aan te spreek.

Wat sal van my verwag word as ek besluit om aan die studie deel te neem?

As u besluit om deel te neem aan die studie sal u gevra word om 'n skriftelike toestemmings vorm te teken. U sal dan 'n onderhoud met die navorser voer waar u gevra gaan word om twee (2) vraelyste te voltooi. Die eerste vraelys handel oor die mense en familie in jou lewe en hulle bereidwilligheid om jou te help. Die tweede vraelys handel oor u ervaring en probleme wat u ondervind gedurende u daaglikse take. Dit sal ongeveer 45 minute neem om die vraelyste te voltooi.

Sal my deelname aan die studie vertroulik hanteer word?

Ons sal alles in ons vermoe doen om u informasie vertoulik te hou. Jy hoef nie jou naam op die vraelys te skryf nie, slegs u ouderdom en ander persoonlike informasie word benodig. Ons gebruik kodes op die vraelyste, en nie name nie, sodat slegs die navorser kan vastel wie die spoesifieke informasie veskaf het. Die navorser is die enigste person wat toegang tot die vraelyste het en sodra die data ontleding voltooi is sal die vraelyste venietig word. In die geval van publikasie van die joernaal, word maksimale vertroulikheid verseker.

Wat is die risikos van hierdie navorsing?

Ons dra geen kennis van enige risikos wat u mag ondergaan met u deelname aan die studie nie, as enige risikos te voorskyn kom sal u verwys word na ‘n geskikte professionele persoon vir verdere hulp of intervensie.

Wat is die voordele van hierdie navorsing?

Die voordeel om deel van die studie te wees is dat jy informasie kan veskaf oor sosiale onderstuening en deelname bepekings wat pasiente met beroertes ervaar. Die navorsing is nie ontwerp om u persoonlik te bevoordeel nie, maar die resultate kan die navorser in staat stel om meer te verstaan oor die sosiale ondersteuning en beperkinge wat ervaar word deur mense wat ‘n beroerte gehad het. Die studie sal beroerte navorsing aanvul en sal meer lig werp op die sosiale ondersteuning en deelname beperkinge van beroerte pasiente in suid-Afrika. Die resultate van die navorsing kan professionele gesondheids werkers help om programme te ontwikkel om mense wat ‘n beroerte gehad het, en sosiale bepekerkinge en deelname beperkings ervaar, te ondersteun.

Is dit nodig vir my om deel te wees van die studie, en kan ek my deelname staak op enige tyd?

Deelname aan die studie is heeltemal vrywillig. Jy kan kies om glad nie deel te neem aan die studie nie. As jy beluit om deel te neem in die studie, kan jy enige tyd besluit om op te hou, jy sal nie veantwoordelik gehou of negatief beinvloed word nie.

Is daar enige hulp beskikbaar as ek negatief beinvloed word deur deel te neem aan die studie?

In die geval waar u enige problem ondervind sal u verwys word na ‘n geskikte professionele persoon vir verdere hulp of intervensie.

Wat doen ek as ek enige vrae het?

Die studie word gelei deur Toughieda Elloker, ‘n meester’s graad student in fisioterapie by die Universiteit van die Wes-Kaap. As jy enige vrae oor die navorsing het kontak asseblief die volgende persoon:

Mev. Toughieda Elloker

Fisioterapie Departement

Universiteit van die Wes-Kaap

Privaatsak X17

Bellville, 7535

Selfoon No. 0844826162

E-pos. Toughieda2003@gmail.com.

Indien u enige vrae het oor die studie of jou regte as novorsingsdeelnemer, of indien u enige probleme ervaar het met betrekking tot die studie en wil dit aanmeld, kontak asseblief die volgende persoon:

Adjunkdekaan van onderring en leer: Prof A. Rhoda

arhoda@uwc.ac.za
Tel: 021 959 2542

Dekaan van die fakulteit Gemeenskap en Gesondheidswetenskappe: Prof J Frantz
jfrantz@uwc.ac.za
Tel: 021 9592631
Universiteit van die Wes-Kaap
Privaatsak X17
Bellville 7535.

Hierdie navorsing is goedgekeur deur die Universiteit van die Wes-Kaap se Senaat Navorsing Komitee (verwysingsnommer: 14/5/22).

APPENDIX E

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IPHEPHA LOLWAZI: LEZIGULANA EZINESITROWUKI

Isihloko sofundo: Uphuhliso lwenqubo yasekuhlaleni ukubonisana nabathathi nxaxheba abathe bahlaselwa sistrowuki edolophini, emaphandleni nasezilalini eMzantsi Afrika

Lungantoni olufundo?

Olufundo luququzelelwe nfundi ngumfundiToughieda Elloker kwiYunivesiti yase Ntshona Koloni. Siyakumema ukuba uthabathe inxaxheba kolufundo nanjengomnye wabantu abathe bahlaselwa sistrowuki. Injongo yesisifundo kukufumanisa ukuba abantu abanesitrowuki baphila njani ekuhlaleni. Esisifundo sizakunceda ngokufundisa sixhobise nabanye abantu ngesistrokhi eMzantsi Afrika. Sincede nengcaphephe ngokuthi zikwazi ukuncedisa ekufumaneni ezinye iindlela zoku nceda abo baphila nesistrokhi.

Yintoni elindeleke ukuba ndiyenze xa ndinokuthi ndithabathe inxaxheba?

Ulindeleke ukuba ugcwalise uphendule imibuzo eyakuthi ibuzwe kuwe. Abanye babaguli bayakucelwa ukuba bathabathe inxaxheba kwinqubo eziyakuthi zenziwe apho kwananjalo bacelwe ukuba baphendule imibuzo ekuqaleni nasekupheleni kofundo. Uzokubuzwa imibuzo apho kuzocelwa ugcwalise amaphepha amabini esisifundo. Enye yezimpepha zimalunga nokuqonda ukuba ukhona umntu okanye abantu abakuncedayo, umzekelo kusapho lwakho. Imibuzo eyakuthi ibuzwe apho imalunga nendlela owenza ngayo umsebenzi okanye indlela ongayo xa udibene nabanye abantu njengoko uthe wahlaselwa sistrowuki. Konke oku kuzothatha imizuzu engamashumi amane anesihlanu.

Ingaba ukuthatha kwam inxaxheba kolufundo luyakuba yimfihlo?

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 kuyenzaka sibhale incazelo malunga nesisifundo, siyakuzama kangangoko ukugcina iinkcukacha zakho ziyimfihlo.

Buyintoni ubungozi besisifundo?

Zingakhona iingxaki ngokuthatha inxaxheba kwesi sifundo. Konke ukunxulumana nabantu nokuthetha ngawe okanye abanye bunobungozi obuthile. Sizakuzama ngandlela zonke ukunciphisa obobungozi yaye senze ngokukhawuleza ukukunceda ukuba uva ukungakhululeki, ukuphazamiseka ngengqondo okanye phakathi ngexesha uthatha inxaxheba kwesi sifundo. Apho kufanelekileyo, uyakuthunyelwa kwingcaphephe efanelekileyo ukukunceda okanye ukwenza into.

Yintoni endiyakuyizuza malunga nesisifundo?

Ukuthabatha kwakho inxaxheba kwesisifundo kuzoba luncedo ekufumaniseni inxaso eluntwini nakunye kwabo baphila nesistrokhi. 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. Esisifundo sizakunceda ngokufundisa sixhobise nabanye abantu ngesistrokhi eMzantsi Afrika. Sincede nengcaphephe ngokuthi zikwazi ukuncedisa ekufumaneni ezinye iindlela zoku nceda abo baphila nesistrokhi.

Kunyanzelekile 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 ukungalifumani 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 mfundiToughieda Elloker kwiYunivesiti yase Ntshona Koloni Ukuba unayo imibuzo malunga nolufundo okanye uthe wadibana nengxaki malunga nolufundo, nceda udibane nomphathi nqubo wesisifundo kwezi ncukacha zilandelayo

Mrs. Toughieda Elloker

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Modderdam Road

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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.

Deputy dean of teaching and learning:

Prof A. Rhoda

University of the Western Cape

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Bellville 7535

Telephone: 021- 959 2543

Email: arhoda@uwc.a.c.za

This research has been approved by the University of the Western Cape's Senate Research Committee. (REFERENCE NUMBER: 14/2/22).

APPENDIX F

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CONSENT FORM

Title of Research Project: Social support and participation restrictions in patients living with stroke in the Western Cape, South Africa.

The study has been described to me in a 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.

This research project involves completing two (2) questionnaires with the help of the researcher. These questionnaires will be stored in a locked cabinet at the Physiotherapy department and only the researcher will have access to it. Once the data has been analysed the questionnaires will be destroyed.

___ I agree to complete two (2) questionnaires during my participation in this study.

___ I do not agree to complete two (2) questionnaires during my participation in this study.

Participant's name……………………….. Witness..

Participant's signature…………………

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: 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 G

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TOESTEMMINGS FORM

Titel van navorsingsprojek: **Sosiale ondersteuning en deelname beperkings in beroerte pasiente in die Wes-Kaap, Suid-Afrika**

Die studie is aan my verduidelik 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 teen enige tyd sonder om 'n rede te gee en dit sal my nie negetief beinvloed nie. Hierdie navorsingsprojek behels die invul van twee (2) vraelyste met die hulp van ‘n navorser. Die vraelyste sal gestoor word in 'n geslote kas by die Fisioterapie afdeling en slegs die navorser sal toegang tot dit hê. Sodra die data ontleed is sal die vraelyste vernietig word.

___ Ek stem in om die twee (2) vraelyste te voltooi tydens my deelname aan die studie.

___ Ek stem nie in om die twee (2) vraelyste te voltooi tydens my deelname aan die studie nie.

Deelnemer se naam ....

Getuie…………………………………

Deelnemer se handtekening ....

Datum ....

APPENDIX H

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IPHEPHA MVUME LOKUTHABATHA INXAXHEBA

Isihloko Sofundo: Uphuhliso lwenqubo yasekuhlaleni ukubonisana nabathathi nxaxheba abathe bahlaselwa sistrowuki apha eMzantsi Afrika, Ntshona Koloni.

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 ezimbini zoshicilelo xenikweni ndithatha inxaxheba kolufundo

___ Andikuvumeli ukushicilelwa kweempendulo zam xenikweni ndithatha inxaxheba kolufundo

Igama lomthathi nxaxheba………………………..

Ingqina……………………………………

Umsayino womthathi nxaxheba…………………

Usuku……Inyanga……Unyaka……………

Ukuba unayo imibuzo malunga nolufundo okanye uthe wadibana nengxaki malunga nolufundo, nceda udibane nomphathi nqubo wesisifundo kwezi nkcukacha 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 I

Participant demographic sheet (Please circle appropriate answer)

Participant ID number	
Highest qualification obtained	Primary
	Secondary
	Tertiary
Were you employed at the time of the stroke? If yes, please state occupation	Yes (Occupation):
	No
How many strokes have you had?	1
	2
	3
	4
	5
When did you have your stroke?	_____________ (MM/YYYY)
Do you suffer from any co-morbidities?	None
	Hypertension
	Diabetes
	Cholesterol
	Other (Specify):
Risk factors?	Tobacco
	Alcohol
	Other (Specify):
Who are you living within the community?	Family (Including spouse)
	Friends
	Care Provider
	Other (Specify):

Which area are you living?	Retreat
	Lotus River
	Plumstead
	Hanover Park
	Gugulethu
	Woodstock
	Other (Specify):
Are you currently part of a stroke support group?	Yes
	No
Average income per month	R0 – R1000
	R0 – R2000
	R0 – R3000
	R0 – R4000
	Other (Specify):

APPENDIX J

Deelnemer demografiese informasie (Sirkel die gepaste antwoord)

Deelnemer ID nommer	
Hoogste kwalifikasie verwerf	Primêre
	Sekondêre
	Tersiêre
Was u in diens (werkend) tydens u beroerte? As ja, wat is u beroep?	Ja (Beroep):
	Nee
Hoeveel beroetes het u al gehad?	1
	2
	3
	4
	5
Hoe lank gelede het u die laaste beroerte gehad?	_____________ Maande/Jare
Het u enige van die volgende mediese kondisies?	Geen
	Hipertensie
	Diabetes
	Cholesterol
	Ander (Spesifiseer):
Risiko Faktore?	Tabak
	Alkohol
	Ander (Spesifiseer):
Saam met wie woon u in die gemeenskap?	Familie (Insluitend lewens maat)
	Vriende
	Sorg Verskaffer (Versorger)
	Ander (Spesifiseer):

In watter area woon u?	Retreat
	Lotus Rivier
	Plumstead
	Hanover Park
	Gugulethu
	Woodstock
	Ander (Spesifiseer):
Is u deel van ‘n enige beroerte bystands groepe?	Ja
	Nee
Gemiddelde inkomste per maand.	R0 – R1000
	R0 – R2000
	R0 – R3000
	R0 – R4000
	Ander (Spesifiseer):

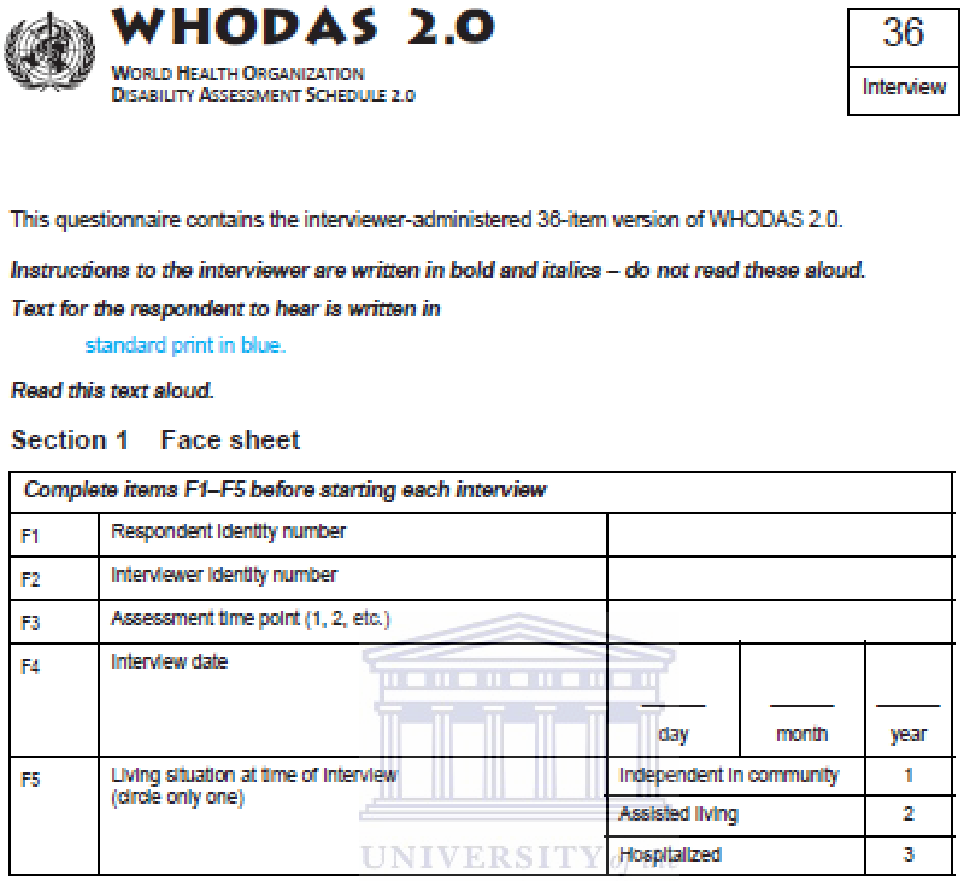
APPENDIX K

Iphepha lomthathi nxaxheba (Khetha impendulo ekulungeneyo)

Inombolo yesazisi	
Izifundo ephezulu onayo	Kumabanga aphantsi
	Kumabanga aphakathi
	Kumabanga aphazulu
	Ayikho
Ubuphangela ngexesha uhlaselwa sistroki? Ukuba ewe, ubuphangela phi	Ewe (Lomsebenzi):
	Hayi
Zingaphi izitroki ezikhe zakuhlasela?	Inye
	Zimbini
	Zintathu
	Zine
	Zintlanu
Ugqibele nini ukufunyanwa a sistroki?	________________ Iinyanga/Iminyaka
Unazo ezinye izigulo onazo ngaphandle kwesitrowuki?	Hayi
	Uxinizelelo
	Tswekile
	Izifo zemithambo yegazi
	Ezinye (cacisa):
Uyatshaya?	Ewe / Hayi
Uyasela?	Ewe / Hayi
Uhlala nabani?	Usapho (no mlinganiwakha)
	Abahlobo
	Umongikazi
	Ezinye (cacisa):

Uhlala phi?	Retreat
	Lotus River
	Plumstead
	Hanover Park
	Gugulethu
	Woodstock
	Ezinye (cacisa):
Ukwiqela lenxaso yabantu abaphila nesitroki ekuhlaleni?	Ewe
	Hayi
Umrholo wakho wenyanga	R0 – R1000
	R0 – R2000
	R0 – R3000
	R0 – R4000
	Ezinye (cacisa):

APPENDIX L



WHODAS 2.0

WORLD HEALTH ORGANIZATION
DISABILITY ASSESSMENT SCHEDULE 2.0

36
Interview

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

Instructions to the interviewer are written in bold and italics – do not read these aloud.

Text for the respondent to hear is written in

standard print in blue.

Read this text aloud.

Section 1 Face sheet

Complete items F1–F5 before starting each interview				
F1	Respondent identity number			
F2	Interviewer identity number			
F3	Assessment time point (1, 2, etc.)			
F4	Interview date	____ day	____ month	____ year
F5	Living situation at time of interview (circle only one)	Independent in community		1
		Assisted living		2
		Hospitalized		3

Section 2 Demographic and background information

This interview has been developed by the World Health Organization (WHO) to better understand the difficulties people may have due to their health conditions. The information that you provide in this interview is confidential and will be used only for research. The interview will take 15–20 minutes to complete.

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

Even if you are healthy and have no difficulties, I need to ask all of the questions so that the survey is complete.

I will start with some background questions.

A1	***Record sex as observed***	Female	1
		Male	2
A2	How old are you now?	______ years	
A3	How many years in all did you spend studying in school, college or university?	______ years	
A4	What is your current marital status? ***(Select the single best option)***	Never married	1
		Currently married	2
		Separated	3
		Divorced	4
		Widowed	5
		Cohabiting	6
A5	Which describes your main work status best? ***(Select the single best option)***	Paid work	1
		Self employed, such as own your business or farming	2
		Non-paid work, such as volunteer or charity	3
		Student	4
		Keeping house/ homemaker	5
		Retired	6
		Unemployed (health reasons)	7
		Unemployed (other reasons)	8
		Other (specify)____________ __________________	9

Section 3 Preamble

Say to respondent:

The interview is about difficulties people have because of health conditions.

Hand flashcard #1 to respondent and say:

By health condition I mean diseases or illnesses, or other health problems that may be short or long lasting; injuries; mental or emotional problems; and problems with alcohol or drugs.

Remember to keep all of your health problems in mind as you answer the questions. When I ask you about difficulties in doing an activity think about …

Point to flashcard #1 and explain that "difficulty with an activity" means:

- Increased effort
- Discomfort or pain
- Slowness
- Changes in the way you do the activity.

Say to respondent:

When answering, I'd like you to think back over the past 30 days. I would also like you to answer these questions thinking about how much difficulty you have had, on average, over the past 30 days, while doing the activity as you usually do it.

Hand flashcard #2 to respondent and say:

Use this scale when responding.

Read the scale aloud:

None, mild, moderate, severe, extreme or cannot do.

Ensure that the respondent can easily see flashcards #1 and #2 throughout the interview

Section 4 Domain reviews

Domain 1 Cognition

I am now going to ask some questions about understanding and communicating.

Show flashcards #1 and #2 to respondent

In the past 30 days, how much difficulty did you have in:		None	Mild	Moderate	Severe	Extreme or cannot do
D1.1	Concentrating on doing something for ten minutes?	1	2	3	4	5
D1.2	Remembering to do important things?	1	2	3	4	5
D1.3	Analysing and finding solutions to problems in day-to-day life?	1	2	3	4	5
D1.4	Learning a new task, for example, learning how to get to a new place?	1	2	3	4	5
D1.5	Generally understanding what people say?	1	2	3	4	5
D1.6	Starting and maintaining a conversation?	1	2	3	4	5

Domain 2 Mobility

I am now going to ask you about difficulties in getting around.

Show flashcards #1 and #2

In the past 30 days, how much difficulty did you have in:		None	Mild	Moderate	Severe	Extreme or cannot do
D2.1	Standing for long periods such as 30 minutes?	1	2	3	4	5
D2.2	Standing up from sitting down?	1	2	3	4	5
D2.3	Moving around inside your home?	1	2	3	4	5
D2.4	Getting out of your home?	1	2	3	4	5
D2.5	Walking a long distance such as a kilometre [or equivalent]?	1	2	3	4	5

Please continue to next page...

Domain 3 Self-care

I am now going to ask you about difficulties in taking care of yourself.

Show flashcards #1 and #2

In the past 30 days, how much difficulty did you have in:		None	Mild	Moderate	Severe	Extreme or cannot do
D3.1	Washing your whole 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	Staying by yourself for a few days?	1	2	3	4	5

Domain 4 Getting along with people

I am now going to ask you about difficulties in getting along with people. Please remember that I am asking only about difficulties that are due to health problems. By this I mean diseases or illnesses, injuries, mental or emotional problems and problems with alcohol or drugs.

Show flashcards #1 and #2

In the past 30 days, how much difficulty did you have in:		None	Mild	Moderate	Severe	Extreme or cannot do
D4.1	Dealing with people you do not know?	1	2	3	4	5
D4.2	Maintaining a friendship?	1	2	3	4	5
D4.3	Getting along with people who are close to you?	1	2	3	4	5
D4.4	Making new friends?	1	2	3	4	5
D4.5	Sexual activities?	1	2	3	4	5

Please continue to next page...

Domain 5 Life activities

5(1) Household activities

I am now going to ask you about activities involved in maintaining your household, and in caring for the people who you live with or are close to. These activities include cooking, cleaning, shopping, caring for others and caring for your belongings.

Show flashcards #1 and #2

Because of your health condition, in the past 30 days, how much difficulty did you have in:		**None**	**Mild**	**Moderate**	**Severe**	**Extreme or cannot do**
D5.1	Taking care of your household responsibilities?	1	2	3	4	5
D5.2	Doing your most important household tasks well?	1	2	3	4	5
D5.3	Getting all the household work done that you needed to do?	1	2	3	4	5
D5.4	Getting your household work done as quickly as needed?	1	2	3	4	5

If any of the responses to D5.2–D5.5 are rated greater than none (coded as "1"), ask:

D5.01	In the past 30 days, on how many days did you reduce or completely miss household work because of your health condition?	*Record number of days ____*

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

5(2) **Work or school activities**

Now I will ask some questions about your work or school activities.

Show flashcards #1 and #2

Because of your health condition, in the past 30 days how much difficulty did you have in:		**None**	**Mild**	**Moderate**	**Severe**	**Extreme or cannot do**
D5.5	Your day-to-day work/school?	1	2	3	4	5
D5.6	Doing your most important work/school tasks well?	1	2	3	4	5
D5.7	Getting all the work done that you need to do?	1	2	3	4	5
D5.8	Getting your work done as quickly as needed?	1	2	3	4	5
D5.9	Have you had to work at a lower level because of a health condition?				No	1
					Yes	2
D5.10	Did you earn less money as the result of a health condition?				No	1
					Yes	2

If any of D5.5–D5.8 are rated greater than none (coded as "1"), ask:

D5.02	In the past 30 days, on how many days did you miss work for half a day or more because of your health condition?	*Record number of days* ___

Please continue to next page...

Domain 6 Participation

Now, I am going to ask you about your participation in society and the impact of your health problems on you and your family. Some of these questions may involve problems that go beyond the past 30 days, however in answering, please focus on the past 30 days. Again, I remind you to answer these questions while thinking about health problems: physical, mental or emotional, alcohol or drug related.

Show flashcards #1 and #2

In the past 30 days:		None	Mild	Moderate	Severe	Extreme or cannot do
D6.1	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?	1	2	3	4	5
D6.2	How much of a problem did you have because of barriers or hindrances in the world around you?	1	2	3	4	5
D6.3	How much of a problem did you have living with dignity because of the attitudes and actions of others?	1	2	3	4	5
D6.4	How much time did you spend on your health condition or its consequences?	1	2	3	4	5
D6.5	How much have you been emotionally affected by your health condition?	1	2	3	4	5
D6.6	How much has your health been a drain on the financial resources of you or your family?	1	2	3	4	5
D6.7	How much of a problem did your family have because of your health problems?	1	2	3	4	5
D6.8	How much of a problem did you have in doing things by yourself for relaxation or pleasure?	1	2	3	4	5

H1	Overall, in the past 30 days, how many days were these difficulties present?	*Record number of days ____*
H2	In the past 30 days, for how many days were you totally unable to carry out your usual activities or work because of any health condition?	*Record number of days ____*
H3	In the past 30 days, not counting the days that you were totally unable, for how many days did you cut back or reduce your usual activities or work because of any health condition?	*Record number of days ____*

This concludes the interview. Thank you for participating.

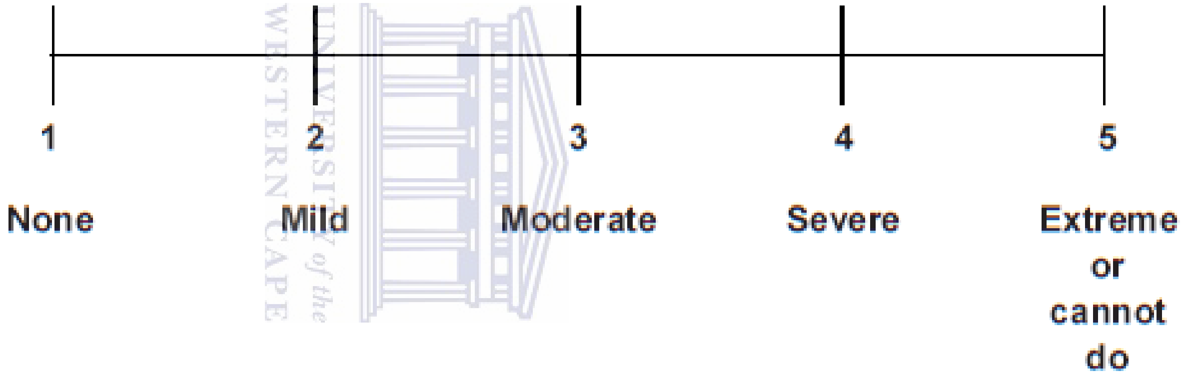
Health conditions:

- Diseases, illnesses or other health problems
- Injuries
- Mental or emotional problems
- Problems with alcohol
- Problems with drugs

Having difficulty with an activity means:

- Increased effort
- Discomfort or pain
- Slowness
- Changes in the way you do the activity

Think about the past 30 days only.


1
None
2
Mild
3
Moderate
4
Severe
5
Extreme or cannot do

APPENDIX M

THE SSQ6 QUESTIONNAIRE

1. Whom can you really count on to be dependable when you need help?

No one	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

How Satisfied?

6 – very satisfied	5 – fairly satisfied	4 – a little satisfied	3 – a little dissatisfied	2 – fairly dissatisfied	1 – very dissatisfied

2. Whom can you really count on to help you feel more relaxed when you are under pressure or tense?

No one	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

How Satisfied?

6 – very satisfied	5 – fairly satisfied	4 – a little satisfied	3 – a little dissatisfied	2 – fairly dissatisfied	1 – very dissatisfied

3. Who accepts you totally, including both your worst and your best points?

No one	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

How Satisfied?

6 – very satisfied	5 – fairly satisfied	4 – a little satisfied	3 – a little dissatisfied	2 – fairly dissatisfied	1 – very dissatisfied

4. Whom can you really count on to care about you, regardless of what is happening to you?

No one	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

How Satisfied?

6 – very satisfied	5 – fairly satisfied	4 – a little satisfied	3 – a little dissatisfied	2 – fairly dissatisfied	1 – very dissatisfied

5. Whom can you really count on to help you feel better when you are feeling generally down-in-the-dumps?

No one	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

How Satisfied?

6 – very satisfied	5 – fairly satisfied	4 – a little satisfied	3 – a little dissatisfied	2 – fairly dissatisfied	1 – very dissatisfied

6. Whom can you count on to console you when you are very upset?

No one	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

How Satisfied?

6 – very satisfied	5 – fairly satisfied	4 – a little satisfied	3 – a little dissatisfied	2 – fairly dissatisfied	1 – very dissatisfied

TO SCORE SSQ6:

1. Add total number of people for all 27 items. (Max. is 243).

Divide by 27 for per item score. This gives you SSQ Number Score, or SSQN. 2. Total satisfaction scores for all 27 items. (Max is 162).
Divide by 27 for per item score. This gives you SSQ Satisfaction score or SSQS

3. You can also add up total number of people that are family members and that can give the SSQ family score.

APPENDIX N

WereldGesondheidsgestremdheidsasseseringskedule II
Fase 2 Veldproewe – Navorsing in Gesondheidsdienste
36-Item Selfgeadministreerdevoorstelling

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:						
	Verstaan en kommunikeer					
D1.1	Konsentrasie en iets binne 10minute 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	Bie 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
	Oor die weg te kom					

D2.1	Om vir ten minste 30minute 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
	Selfsorg					
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	Biaie erg/Kan nie
	Om oor die weg te kom met mense					
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
	Lewensaktiwiteite					
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 he tom 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

	In die laaste 30 dae:					
	Deelname in die samelewing					

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 finansiele 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 gevolge 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 O

SSQ: Vraelys

1. Op wie kan u regtig staat maak indien u hulp makeer?

Niemand	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

Tevredenheid

6– Baie tevrede	5– Redelik tevrede	4 – Minder tevrede
3– Bietjie ontevrede	2– Redelik ontevrede	1 – Baie ontevrede

2.Op wie kan u regtig staat maak om u te help ontspan indien u onder druk is of dalk gespanne voel?

Niemand	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

Tevredenheid

6– Baie tevrede	5– Redelik tevrede	4 – Minder tevrede
3– Bietjie ontevrede	2– Redelik ontevrede	1 – Baie ontevrede

3. Wie aanvaar u heeltemal/ onvoorwaardelik, insluitend u goeie sowel as u slegte punte?

Niemand	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

Tevredenheid

6– Baie tevrede	5– Redelik tevrede	4 – Minder tevrede
3– Bietjie ontevrede	2– Redelik ontevrede	1 – Baie ontevrede

4. Op wie kan u regtig staat maak om vir u om te gee ongeag wat met u gebeur?

Niemand	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

Tevredenheid

6– Baie tevrede	5– Redelik tevrede	4 – Minder tevrede
3– Bietjie ontevrede	2– Redelik ontevrede	1 – Baie ontevrede

5. Op wie kan u regtig staat maak om u op te beur indien u teneergedruk voel?

Niemand 1) 4) 7)
2) 5) 8)
3) 6) 9)

Tevredenheid
6 – Baie tevrede 5– Redelik tevrede 4 – Minder tevrede
3 – Bietjie ontevrede 2– Redelik ontevrede 1 – Baie ontevrede

6. Op wie kan u regtig staat maak om u te bemoedig indien u ontsteld is.

Niemand 1) 4) 7)
2) 5) 8)
3) 6) 9)

Tevredenheid
6 – Baie tevrede 5– Redelik tevrede 4 – Minder tevrede
3 – Bietjie ontevrede 2– Redelik ontevrede 1 – Baie ontevrede

APPENDIX P

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 impilo yakho iyonke kwezi ntsuku ezingama-30 zidlulileyo?	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:						
	Ekuqondeni nasekuqhagamshelaneni					
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
	Ukuhamba-hamba					
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:						
	Ekuzikhathaleleni					
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
	Ekuvaneni nabanye abantu					
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

	Imisetyenzana yoBomi					
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:					
	Ukuthatha inxaxheba ekuhlaleni					
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, okanye iziphumo zayo?	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/ Abenzeki
D6.5	Ingaba impilo yakho ibe yephelelisa amandla njani kwizibonelelo zezemali zakho okanye zosapho	Abukho	Buncinci	Buphakathi	Bukhulu	Bugabadele/ Abenzeki

	lwakho?					
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	Ngokugabadeleyo
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 Q

Social Support Questionnaire 6 (SSQ6) (Xhosa)

Imigaqo:

Le mibuzo ilandela ibuza ngabantu abasebomini bakho abakuncedayo kwaye baphinde bakuxhase ngezinto ezenzeka ebomini bakho. Umbuzo ngamnye unezigaba ezimbini. Kwisigaba sokuqala, dwelisa bonke abantu obaziyo, ngaphandle kwakho, onokwazi ukuthembela kubo ngoncedo nangenxaso ngendlela ekuzochazwa ngayo apha.Bhala isiqali gama salomntu ufuna ukumbhala kunye nobudlelwane bakhe kuwe(bona umzekelo). Ubhala umntu omnye ngakwinani lombuzo ezantsi kombuzo.

Kwisigaba sesibini, yenza isangqa ngendlela owaneliseka ngayo ngenxaso onayo ebomini bakho.

Ukuba awunanxaso yalo mbuzo, jonga la magama athi ”akukho mntu”, kodwa chaza indlela owaneliseka ngayo. Ungabhali abantu abangaphezu kwesithoba kumbuzo ngamnye.

Sicela uphendule imibuzo ngeyona ndlela inyanisekileyo kangangoko. Zonke impendulo zakho zizakuba yimfihlelo akho mntu uzozazi.

Umzekelo:

Ngubani oyena mntu unokumthemba ngolwazi olunokuthi lukufake engxakini xa lunokuvela?

Akukho mntu	1) T.N. (umnakwethu)	4) T.N (utata)	7)
	2) L.M (isihlobo)	5) L.M (umqashi)	8)
	3) R.S (isihlobo)	6)	9)

Uneliseke kangakanani?

6-waneliseke kakhulu 5-waneliseke nje 4-woneliseke kancinci

3-andonelisekanga nje kancinci 2-andonelisekange nje 1- andonelisekanga kakhulu

1. Ngubani umntu onokuthembela kuye xa usengxakini udinga uncedo?

Akukho mntu	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

Woneliseke kangakanani?

6-waneliseke kakhulu 5-waneliseke nje 4-woneliseke kancinci

3-andonelisekanga nje kancinci 2-andonelisekange nje1- andonelisekanga kakhulu

2. Ngubani oyena mntu ongathembela kuyo ukuba athobe umoya wakho ukhululeke xa kukho into ekuxhalabisileyo or uxakekile?

Akukho mntu	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

Woneliseke kangakanani?

6-waneliseke kakhulu 5-waneliseke nje 4-woneliseke kancinci

3-andonelisekanga nje kancinci 2-andonelisekange nje1- andonelisekanga kakhulu

3. Ngubani umntu okwamkela ngokupheleleyo, kubandakanya izinto zakho ezilungileyo ezintle kunye neziphoso zakho nezinto zakho ezimbi?

Akukho mntu	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

Woneliseke kangakanani?

6-waneliseke kakhulu 5-waneliseke nje 4-woneliseke kancinci

3-andonelisekanga nje kancinci 2-andonelisekange nje1- andonelisekanga kakhulu

4. Ngubani umntu onokuthi uyakhathala ngawe, nokuba kuqhubeka ntoni empilweni yakho?

Akukho mntu	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

Woneliseke kangakanani?

6-waneliseke kakhulu 5-waneliseke nje 4-woneliseke kancinci

3-andonelisekanga nje kancinci 2-andonelisekange nje1- andonelisekanga kakhulu

5. Ngubani umntu ocinga ungathembela kuye ukuba akuvise kamnandi xa uziva ukuba ukhathazekile kwaye umoya wakho uphantsi kakhulu?

Akukho mntu 1) 4) 7)
2) 5) 8)
3) 6) 9)

Woneliseke kangakanani?

6-waneliseke kakhulu 5-waneliseke nje 4-woneliseke kancinci

3-andonelisekanga nje kancinci 2-andonelisekange nje1- andonelisekanga kakhulu

6. Ngubani umntu onokuthembela kuye ukuba akuthuthuzele xa ukhathazekile?

Akukho mntu 1) 4) 7)
2) 5) 8)
3) 6) 9)

Woneliseke kangakanani?

6-waneliseke kakhulu 5-waneliseke nje 4-woneliseke kancinci

3-andonelisekanga nje kancinci 2-andonelisekange nje1- andonelisekanga kakhulu

Ukufumana amanqaku kwi SSQ6

1. Dibanisa amanqaku abantu kuzo zonke ezizinto zingamashumi amabini anesixhenxe (27) (Ayidluli ku amakhulu amabini anamashumi amane anesithathu (243)
   Yahlula phakathi ngamashumi amabini anesixhenxe (27) kwinto nganye.
   Lonto ke izokunika inqaku lakho le SSQN.

2. Amanqaku okoneliseka wona kwezizinto zingamashumi amabini anesixhenxe (27)
   (Ayidluli kwikhulu elinamashumi amathandathu anesibini).
   Yahlula phakathi ngamashumi amabini anesixhenxe (27) kwinto nganye.
   Lonto ke izokunika inqaku lakho le SSQS.

3. Ungadibanisa wonke umntu okusapho lwakho oye wamsebenzisa kulemibuzo, lonto ke iyokuthi ikunike amanqaku akho e SSQ yosapho

APPENDIX R

11 questions to help you make sense of descriptive/cross-sectional studies

How to use this appraisal tool

Three broad issues need to be considered when appraising the report of a descriptive/ cross-sectional study (e.g., a study that collects data on individuals at one time point using a survey or review of medical charts):

Are the results of the study valid?
What are the results?
Will the results help locally?

The 11 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions. You are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicized prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided. These questions are adapted from Guyatt GH, Sackett DL, and Cook DJ, Users’ guides to the medical literature. II. How to use an article about therapy or prevention. *JAMA* 1993; 270 (21): 2598-2601 and *JAMA* 1994; 271(1): 59-63 © Milton Keynes Primary Care Trust 2002. All rights reserved.

Screening Questions

1. Did the study address a clearly focused issue? Yes Can’t tell No

HINT: A question can be focused in terms of:
– the population(s) studied
– the health measure(s) studied (e.g., risk factor, preventive behavior, outcome)

2. Did the authors use an appropriate method to answer their question? Yes Can’t tell No

HINT: Consider
Is a descriptive/cross-sectional study an appropriate way of answering the question?
Did it address the study question?

Detailed Questions

3. Were the subjects recruited in an acceptable way? Yes Can't tell No

HINT: We are looking for selection bias which might compromise the generalizability of the findings:
- *Was the sample representative of a defined population?*
- *Was everybody included who should have been included?*

4. Were the measures accurately measured to reduce bias? Yes Can't tell No

HINT: We are looking for measurement or classification bias:
- *Did they use subjective or objective measurements?*
- *Do the measures truly reflect what you want them to (have they been validated)?*

5. Were the data collected in a way that addressed the research issue? Yes Can't tell No

Consider:
- *if the setting for data collection was justified*
- *if it is clear how data were collected (e.g., interview, questionnaire, chart review)*
- *if the researcher has justified the methods chosen*
- *if the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted?)*

6. Did the study have enough participants to minimize the play of chance? Yes Can't tell No

Consider:
- *if the result is precise enough to make a decision*
- *if there is a power calculation. This will estimate how many subjects are needed to produce a reliable estimate of the measure(s) of interest.*

7. How are the results presented and what is the main result? Yes Can’t tell No

Consider:
- *if, for example, the results are presented as a proportion of people experiencing an outcome, such as risks, or as a measurement, such as mean or median differences, or as survival curves and hazards*
- *how large this size of result is and how meaningful it is*
- *how you would sum up the bottom-line result of the trial in one sentence*

8. Was the data analysis sufficiently rigorous? Yes Can’t tell No

Consider:
- *if there is an in-depth description of the analysis process*
- *if sufficient data are presented to support the findings*

9. Is there a clear statement of findings? Yes Can’t tell No

Consider:
- *if the findings are explicit*
- *if there is adequate discussion of the evidence both for and against the researchers’ arguments*
- *if the researcher have discussed the credibility of their findings*
- *if the findings are discussed in relation to the original research questions*

10. Can the results be applied to the local population? Yes Can’t tell No

HINT: Consider whether
- *The subjects covered in the study could be sufficiently different from your population to cause concern.*
- *Your local setting is likely to differ much from that of the study*

11. How valuable is the research?

Consider:
- *if the researcher discusses the contribution the study makes to existing knowledge (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?)*
- *if the researchers have discussed whether or how the findings can be transferred to other populations*

APPENDIX S

Critical
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12 questions to help you make sense of cohort study

How to use this appraisal tool

Three broad issues need to be considered when appraising a cohort study:

- ☐ **Are the results of the study valid?** **(Section A)**
- ☐ **What are the results?** **(Section B)**
- ☐ **Will the results help locally?** **(Section C)**

The 12 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions.

There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

These checklists were designed to be used as educational tools as part of a workshop setting

There will not be time in the small groups to answer them all in detail!

(A) Are the results of the study valid?

Screening Questions

1. Did the study address a clearly focused issue? **Yes☐ Can’t tell ☐ ☐No**

HINT: A question can be ‘focused’ In terms of

The population studied
The risk factors studied
The outcomes considered
Is it clear whether the study tried to detect a beneficial or harmful effect?

2. Was the cohort recruited in an acceptable way? **☐Yes ☐Can’t tell ☐No**

HINT: Look for selection bias which might compromise the generalisibility of the findings:

- ☐ Was the cohort representative of a defined population?
- ☐ Was there something special about the cohort?
- ☐ Was everybody included who should have been included?

Is it worth continuing?

Detailed questions

3. Was the exposure accurately measured to minimise bias? ☐**Yes** ☐**Can’t tell** **No**

HINT: Look for measurement or classification bias:

- Did they use subjective or objective measurements?
- Do the measurements truly reflect what you want them to (have they been validated)?
- Were all the subjects classified into exposure groups using the same procedure

4. Was the outcome accurately measured to minimise bias? ☐**Yes** ☐**Can’t tell** ☐**No**

HINT:

Look for measurement or classification bias:

Did they use subjective or objective measurements?

Do the measures truly reflect what you want them to (have they been validated)?

Has a reliable system been established for detecting all the cases (for measuring disease occurrence)?

Were the measurement methodssimilar in the different groups?

Were the subjects and/or the outcome assessor blinded to exposure (does this matter)?

5. (a) Have the authors identified all important confounding factors? ☐**Yes** ☐**Can't tell** ☐**No**

List the ones you think might be important, that the author missed.

(b) Have they taken account of the confounding factors in the design and/or analysis? ☐**Yes** ☐**Can't tell** ☐**No**

List:

HINT: Look for restriction in design, and techniques e.g. modelling, stratified-, regression-, or sensitivity analysis to correct, control or adjust for confounding factors

6. (a) Was the follow up of subjects complete enough? ☐**Yes** ☐**Can't tell** ☐**No**

(b) Was the follow up of subjects long enough? ☐**Yes** ☐**Can't tell** ☐**No**

HINT: Consider

- ☐ The good or bad effects should have had long enough to reveal themselves
- ☐ The persons that are lost to follow-up may have different outcomes than those available for assessment
- ☐ In an open or dynamic cohort, was there anything special about the outcome of the people leaving, or the exposure of the people entering the cohort?

(B) What are the results?

7. What are the results of this study?

HINT: Consider

- ☐ What are the bottom line results?
- ☐ Have they reported the rate or the proportion between the exposed/unexposed, the ratio/the rate difference?
- ☐ How strong is the association between exposure and outcome (RR,)?
- ☐ What is the absolute risk reduction (ARR)?

8. How precise are the results?

HINT: Look for the range of the confidence intervals, if given.

9. Do you believe the results? ☐**Yes** ☐**Can't tell** ☐**No**

HINT: Consider

Big effect is hard to ignore!

Can it be due to bias, chance or confounding?

Are the design and methods of this study sufficiently flawed to make the results unreliable?

Bradford Hills criteria (e.g. time sequence, dose-response gradient, biological plausibility, consistency)

(C) Will the results help locally?

10. Can the results be applied to the local population? ☐**Yes** ☐**Can't tell** ☐**No**
HINT: Consider whether

- ☐ A cohort study was the appropriate method to answer this question
- ☐ The subjects covered in this study could be sufficiently different from your population to cause concern
- ☐ Your local setting is likely to differ much from that of the study
- ☐ You can quantify the local benefits and harms

11.**Do the results of this study fit with other available eveidence?** ☐**Yes** ☐**Can't tell** ☐**No**

12. What are the implications of this study for practice?

HINT: Consider

- ☐ One observational study rarely provides sufficiently robust evidence to recommend changes to clinical practice or within health policy decision making
- ☐ For certain questions observational studies provide the only evidence
- ☐ Recommendations from observational studies are always stronger when supported by other evidence

Critical
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APPENDIX T

10 questions to help you make sense of qualitative research

How to use this appraisal tool

Three broad issues need to be considered when appraising the report of a qualitative research:

2. **Are the results of the review valid?**
3. **What are the results?**
4. **Will the results help locally?**

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is
"yes", it is worth proceeding with the remaining questions.

There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

These checklists were designed to be used as educational tools as part of a workshop setting
There will not be time in the small groups to answer them all in detail!

Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist 31.05.13 ©

Screening Questions

1. Was there a clear statement of the aims of the research? ☐ **Yes** ☐ **Can't tell** ☐ **No**

HINT: Consider

What was the goal of the research?
Why it was thought important?
Its relevance

2. Is a qualitative methodology appropriate? ☐ **Yes** ☐ **Can't tell** ☐ **No**

HINT: Consider

If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants

Is qualitative research the right methodology for addressing the research goal?

Is it worth continuing?

Detailed questions

3. Was the research design appropriate to address the aims of the research? **☐Yes☐☐☐☐☐Can't tell☐☐☐No**

HINT: Consider

- If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?

4. Was the recruitment strategy appropriate to the aims of the research? **☐Yes ☐Can't tell☐☐☐No**

HINT:Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

5. Was the data collected in a way that addressed the research issue? **☐Yes ☐Can't tell ☐No**

HINT: Consider

- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
- If methods were modified during the study. If so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recordings, video material, notes etc)
- If the researcher has discussed saturation of data

6. Has the relationship between researcher and participants been adequately considered? ☐ **Yes** ☐ **Can't tell** ☐ **No**

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during
  - (a) Formulation of the research questions
  - (b) Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

7. Have ethical issues been taken into consideration? ☐ **Yes** ☐ **Can't tell** ☐ **No**

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

8. Was the data analysis sufficiently rigorous? ☐ **Yes** ☐ **Can't tell** ☐ **No**

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

9. Is there a clear statement of findings? ☐**Yes**☐☐☐☐**Can't tell**☐☐☐**No**

HINT: Consider

☐ If the findings are explicit

☐ If there is adequate discussion of the evidence both for and against the researchers arguments

☐ If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)

☐ If the findings are discussed in relation to the original research question

10. How valuable is the research?

HINT: Consider

☐ If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature?

☐ If they identify new areas where research is necessary

☐ If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used