

**EXPLORING THE CHALLENGES AND EXPERIENCES OF STROKE PATIENTS
AND THEIR SPOUSES IN BLANTYRE, MALAWI.**

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Abstract

Stroke is the second leading cause of disability worldwide. Up to 60% of the survivors remain severely disabled. These people experience various challenges in such areas as self-care, mobility, accessing medical and rehabilitation services, transportation and finance. These affect them psychologically, physically and socially predisposing them to complications. Hospital based stroke records report on critical cases, which are not a true reflection of after effects of stroke in a community setting. The impact of stroke on patients and spouses cannot be underestimated considering that it is often sudden, giving no chance to patients or spouse to adjust to the predicament. The aim of this study was, therefore, to explore the challenges stroke patients and their spouses experienced during the rehabilitation process, from diagnosis through to treatment and discharge. The study was based on a qualitative approach, utilising an exploratory design. Data was collected using semi-structured in-depth interviews and focus group discussions. All interviews were tape recorded and transcribed verbatim. A thematic content analysis was used to analyse data. Ethical approval was sought from the University of the Western Cape and the College of Medicine Research Ethics Committee, University of Malawi. Permission was obtained from the General Manager of Malawi Against Physical Disabilities. The results indicates a range of challenges including dependence on spouse for basic self-care activities and activities of daily living, stress due to fear of dependence on their spouses, loss of opportunity for regular interaction with friends and family, limited facilities and accessibility to rehabilitation. Spouses are also burdened by of caregiving responsibilities. In conclusion, this study highlights that the consequences of stroke affect both patients and spouses in the areas of health, finance and social. There is need for rehabilitation professionals to give equal attention to the challenges experienced by spouses when managing stroke patients. The study

recommends that accessibility to rehabilitation should be improved by increasing patients' space at the centre, construction of more centres and expand CBR services to cover all districts in the country.



KEY WORDS

Stroke patient, Spouse of stroke patient, Coping mechanisms, Challenges, Rehabilitation, Kachere Rehabilitation Centre, Malawi



LIST OF ABBREVIATIONS

WHO World Health Organisation

MAP Malawi Against Physical Disabilities

UWC University of the Western Cape

COM College of Medicine

SACORE Southern Africa Consortium for Research Excellence

UNDP United Nations Development Program

CHAM Christian Health Association of Malawi

GDP Gross Development Product

ILO International Labour Organisation



DECLARATION

I hereby declare that “Exploring the challenges and experiences of stroke patients and their spouses in Blantyre, Malawi” is my own work, that it has not been submitted in full or part of it for any degree or examination at any university. All sources quoted there-in have been properly referenced.

Reuben Kalavina

Signature.....2013

Witness



.....
Dr Mlenzana

.....
Dr Wazakili

DEDICATION

I dedicate this work to my dear wife Charity, for her support through thick and thin, her encouragement, love and patience. My dedications also go to my beloved son Reuben junior and my lovely daughter Rachael for being my source of joy throughout my studies, I love you so much. Lastly, this work is dedicated to my beloved mother Patricia Kalavina for bringing us up single handedly, for your prayers day and night, you are a very special mother, the very best one can ever have. This is the fruit of your labour and work of your hands.



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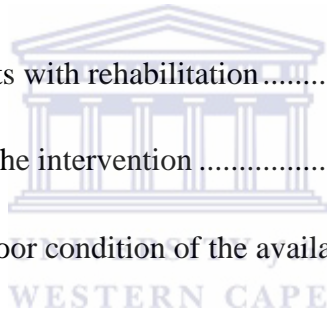
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CHAPTER ONE

1.0 Introduction

This chapter provides the background of the study. It focuses mainly on the global burden of stroke. Special attention is paid to African situation on stroke management with particular interest on Sub-Saharan African countries especially Malawi. In addition, this chapter also presents the problem statement, research question, aim and motivation. Furthermore, theoretical framework employed in the study has been described. It ends with definition of terms followed by chapter outline.

1.1 Background

Stroke is considered the second leading cause of death and disability worldwide (Donnan, McFisher, McLeod & Davis, 2008; World Health Organisation, 2006). It is estimated that 16 million people are affected by disability due to stroke while 6 million deaths are recorded annually, representing 9.9% of total deaths worldwide (World Health Organisation, 2006). According to Mackay and Mensah (2004) 60% of stroke patients die or are permanently disabled due to stroke. Hall, Levant and De Frances (2012) found that stroke is the leading cause of disability in the United States of America (USA) and it accounts for almost a million hospital admissions every year. Scarborough et al. (2009) found that 120,000 people develop stroke each year in the United Kingdom (UK).

Stroke prevalence vary from nation to nation. For example, Lee, Shafe and Cowie (2011) and Rothwell et al. (2004) reported that stroke prevalence in the UK is at the rate of 7.2 per 1000 persons of 80 years and above. In China, the average age adjusted stroke prevalence, it is rated

between 259.86 and 719 per 100,000 for all ages (Liu et al., 2007). In developing countries of Asia such as India and Thailand a prevalence of 222 and 690 per 100,000 has respectively been reported. However, more developed Asiatic countries have higher prevalence rates ranging between 4610 to 7330 (Liu et al., 2007). In Latin America, Bolivia stroke prevalence is rated between 19.3 and 48 per 1000 in people older than 60 years (Lavados et al., 2007).

Stroke incidences equally vary from place to place. Lee et al. (2011) reported that stroke incidence in UK had declined from 18.97 per 1000 in 1999 to 10.97 per 1000 in 2008. In Martinique island, in a population of mostly African origin, age adjusted incidence of stroke first ever reported at 151 per 100,000 (Lavados et al., 2007). In China, stroke incidence ranges from 115.61 to 219 per 100,000 (Liu et al., 2007). In the middle east stroke incidence range from 38.5 per 100,000 in Saudi Arabia to 123.7 per 100,000 in Qatar while in Libya stroke incidence is reported at 114.2 per 100,000 (Tran, Mirzaei, Anderson, Leeder, 2010). In Mozambique, stroke incidence is rated at 148.7 per 100,000 (Damasceno et al., 2010). There is no ideal stroke prevalence or incidence available for Sub Saharan Africa as no accurate longitudinal data has come close to the acceptable standards (Connor, Walker, Modi & Warlow, 2007). Even though stroke incidence has significantly declined in the United Kingdom, it remains a burden facing developing countries especially Sub-Saharan Africa in terms of high incidence of disability and mortality (Johnston, Mendis & Mathers, 2009).

In Africa, inadequate data, traditional beliefs, limited healthcare services, limited medical personnel, early deaths and preference for home based remedies have resulted into under reporting of stroke-related illnesses (Connor, Modi & Warlow, 2009; Walker et al., 2000). However, some studies have revealed that in Africa, stroke accounts for up to 4 % of hospital

admissions and 4.5 % of total deaths, which is equivalent to 3 million deaths every year and this is expected to rise to 5 million or more by 2020 (Connor, Walker, Modi & Warlow, 2007; Ostwald, 2006; Mackay & Mensah, 2004). Evidence has also shown that stroke in this region affects young and productive populations compared to developed countries (Matenga, Kitai and Levy, 1986).

The Sub-Saharan Africa is known for its highest burden of disease yet it has the lowest density of health care providers and institutions (Peterson, Hargis & Nebit, 2013). Agyemang et al. (2012); De-Grant Aikins (2007) and Mbewu and Mbanya (2006) found that in Ghana stroke is among the leading causes of death. It accounts for 9.1% of adult hospital admissions and 13.2% of total deaths (Attah-Adjepong 2008). In South Africa, stroke accounts for 7% of all deaths (Mbewu & Mbanya, 2006). In Tanzania, only 20-40 % of all deaths are reported in hospitals due to low hospital admissions and lack of proper death records (Kengne and Anderson, 2006; Walker et al. 2000; Quigley, Chandramohan, Setel, Binka & Rodrigues, 2000). However, stroke incidence in Tanzania are reported to be 3-6 times that of England and Wales due to, mainly, untreated hypertension and these statistics are anticipated to increase with the normal population ageing process (Kengne & Anderson, 2006; Walker et al., 2000). In Malawi, there is paucity of data on stroke. However, stroke is considered a leading cause of death and disability and HIV and uncontrolled hypertension are some of the of the major risk factors of stroke (Heikinheimo et al., 2012; Mahawishi & Heikinheimo, 2010; Kumwenda et al., 2005; Cole, et al., 2004; Mochan, Modi & Modi, 2002). Kumwenda et al. (2005) found that in Malawi stroke affected a mean age of 37.5 and 58.6 years among HIV positive and negative patients respectively. Heikinheimo et al. (2012) found a mean age of 39.8 years among young stroke patients. Hospital based stroke records tend to report critical cases which are not a true reflection of the effects of stroke on

patients in the community (Walker et al., 2000; Connor et al., 2009). The impact of stroke on patients and spouses can never be underestimated considering that it is often sudden, giving no chance to patients or spouse to adjust to the predicament (Brereton & Nolan, 2000). Stroke has negative effects on patients' personality, psychological and general wellbeing (Brereton & Nolan, 2000). Patients with stroke experience physical, psychological and social challenges which reduce their quality of life and predispose them to depression. Thompson and Ryan (2009); Ch'NG et al. (2008) and Teassell et al. (2008) reported that stroke patients are also challenged with paralysis which usually causes immobility and loss of control over personal care. In addition, stroke patients also experience visual impairments. Evidence has shown that patients with stroke sometimes develop urine and faecal incontinence which causes sleep disturbance and reduce health related quality of life (Barret, 2002). Moreover, stroke patients are also at risk of developing swallowing problems which may lead to weight loss, dehydration, malnutrition and death (Baraski, 2011; Wu, 2009). Steinhagen, Grossman, Benecke and Walter (2009) found that swallowing disorders are life threatening among stroke patients as they increase the risk of aspiration pneumonia and death.

Ch'Ng, French and Mclean (2008) stated that stroke patients experience emotional distress which manifest as anger, frustration, feelings of loss, depression and suicidal ideas which are prominent in patients who are remain in denial of their actual condition especially when full recovery is not achieved. This may worsen their condition and could explain the prevalence of mood disorders among stroke survivors.

Haley et al. (2010) and Thompson and Ryan (2009) stated that stroke patients experience social constraints which increase their risk of developing depression and further episodes of stroke.

Moreover, they undergo challenges such as loss of leisure time, reduced social participation which have detrimental effects on family life and predispose them to depression and sometimes divorce (Dayapoglu and Tan 2010; Daniel, Wolfe, Busch & Mckevitt, 2009 & Coombs, 2007). According to Martinsen, Kirkevold, Broken and Kvigne (2013) patients with stroke risk marginalisation which results in failure to fulfil various social functions within the family and at work. According to Lock, Jordan, Bryan and Maxim (2005) stroke patients are socially disconnected not just by their impairments but also because of the physical and attitudinal barriers which exist within the community. In addition, stroke patients experience financial challenges which are sometimes related to failure to return to work or previous engagements through which they earned money due to the severity of disability (Dayapoglu & Tan, 2010; Daniel et al., 2009 & Coombs, 2007).

Spouses of stroke patients are not spared from the challenges. They also experience physical challenges due to caregiving tasks. Caregiving is physically and emotionally demanding responsibility associated with reduced leisure time activities and increased levels of fatigue (Baraski, 2011; Coombs, 2007; Elavsky et al., 2005). Thompson and Ryan (2009) also found that communication and speech impairments resulted in lack of understanding between patients and spouses which reduces their sexual interest.

In addition spouses experience financial challenges which are sometimes related to failure of either the patient or themselves to return to work or previous engagements through which they earned money due to the severity of disability (Dayapoglu & Tan, 2010; Daniel et al., 2009 & Coombs, 2007). Thompson and Ryan (2009) stated that stroke patients and spouses experience social constraints which increase their risk of developing depression and stroke. Moreover, they

undergo challenges such as loss of leisure time, reduced social participation which have detrimental effects on family life and predispose them to depression and sometimes divorce (Dayapoglu and Tan 2010; Daniel, Wolfe, Busch & Mckevitt, 2009 & Coombs, 2007).

Despite the challenges faced by patients and spouses, studies done by Das et al. (2010); Lutz and Young (2010); Haley et al. (2009); McCullagh, Brigstocke, Dolnaldson and Kalra (2005) and Kalra et al. (2004) revealed a number of facilitating mechanisms which are instrumental in assisting both the patients and the spouses in dealing with the stroke related challenges. These include: social relationship and support, early identification of depression, training of spouses, education, involvement in leisure activities, religious faith, participation in special support groups, return to work, finding meaning in care of patient, positive relationship with patient, counselling and intensive rehabilitation. Das et al. (2010); Lynch et al. (2008) and Roding et al. (2003) found that social support from family, friends and community has a primary positive influence on quality of life. It has been reported that early identification of depression in patients and caregivers and early intervention has yielded significant results (Lutz & Young, 2010; Haley et al., 2009; McCullagh et al., 2005). Kalra et al. (2004) stated that training of spouses and early involvement in therapy and hands-on management of day to day care was found to be associated with lower stress and burden of care levels. According to Kalra et al. (2004) early education interventions have yielded significant results through promotion of good family function and adaptation to the condition. According to Cameron et al. (2011) and Martman-Maeir, Soroker, Ring, Avni and Katz (2007) involvement in leisure activities raises self-esteem of patients with disabilities. This improves performance in activities of daily living and promotes life satisfaction hence it reduces the risk of depression. Vijser-Meily et al. (2009) highlights that participation in active coping strategies reduces stress level and risk of depression thereby

promoting quality of life. Dayapoglu and Tan (2010); Johansson and Bernspang (2003) and Hinckley (2002) reported that return to work is one of the major predictors of good quality of life and satisfaction in younger stroke survivors.

In addition, finding meaning and positive relationship with the patient reduces depression and improves quality of life of both patients and spouses (Nilson, Axelsson, Gustafson, Lundman & Norberg, 2001; Thompson, 1991). Lutz and Young (2010); Visser-Meily (2009) and Ostwald (2008) found that stroke survivors in active rehabilitation have lower rates of depression. According to Ostwald (2008) maintenance of treatment sessions to retain already achieved function and general exercises have been found to improve function and quality of life. Counselling has been perceived by spouses and stroke patients alike as an important part of the rehabilitation process (Clark, Rubanack & Winsor, 2003). These authors further stated that counselling is more effective when combined with education. Lutz and Young (2010) and Thompson and Ryan (2009) found that counselling has significant effects in spouses and patients battling with sexual dissatisfaction during the rehabilitation process.

Stroke rehabilitation is a process that involves multi-disciplinary team members such as physiotherapist, occupational therapists, doctors and nurses (Duncan et al., 2005). The aim of rehabilitation process is to prevent the impairment from resulting into activity limitations and participation restrictions (WHO, 2001). There are three main models of delivering rehabilitation services to the people, namely institution based, outreach and CBR (Finkeflugel, 2009). However, all the models of rehabilitation service delivery are under developed in Malawi (Peterson, Hargis & Nesbit, 2013; Mulwafu, 2010). This study focused on patients that were admitted at a rehabilitation centre (institution).

1.2 Conceptual framework

The study adopted International Classification of Function, Disability and Health (ICF) framework which was developed as a revision of the International Classification of Impairment, Disability and Handicap (ICIDH) of the 1980s which focused on the consequences of a disease instead of the constituents of health (WHO, 2001; WHO, 1980). The concept was developed to provide a classification system with neutral components of health rather than consequences of disease that were often characterised with negative terminology (WHO, 2001). The ICF framework is in line with the bio-psycho-social model of disability. This model suggests that disability is not only as a consequence of a health condition or disease, but is also determined by the physical environment, availability of services in society, attitudes and legislation (Dahl, 2002). The aim of the ICF is to provide a standard language for the description of health and health related states in order to improve communication between health service providers, researchers, policy makers, people with disabilities and the public.

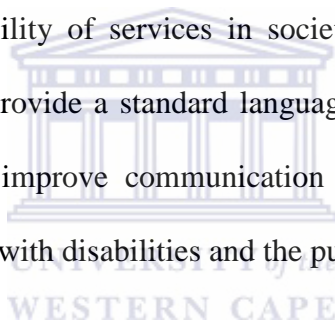
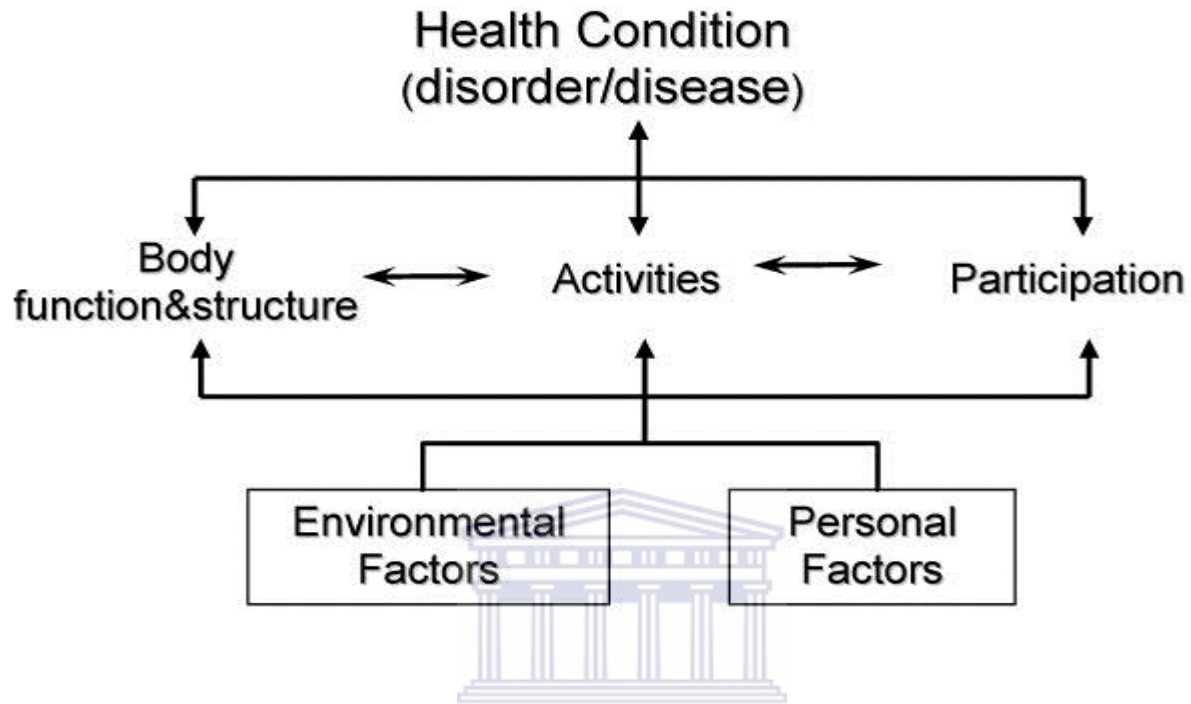


Figure: 1 ICF Framework diagram



According to ICF concept, disability is viewed in three levels of human function (WHO, 2001). The body functions and body structures level where impairment is the main cause of concern. The second level focuses on activity limitations in a person and the third level emphasises on participation restrictions to community integration which is hindered or facilitated by environmental and personal factors that are linked to the three levels (Dahl, 2002). Stroke is an injury to the brain that results in paralysis of one side of the body which is usually associated with speech and language impairment, urine and faecal incontinence, visual spatial defects and swallowing disorders among others (WHO, 2006). At this level of impairment of body structures, function rehabilitation is introduced with the aim of restoring function.

The level of activity limitation is mainly characterised by inability to perform self-care skills such as bathing, feeding, turning in bed, sitting and walking thus the aim of rehabilitation at this

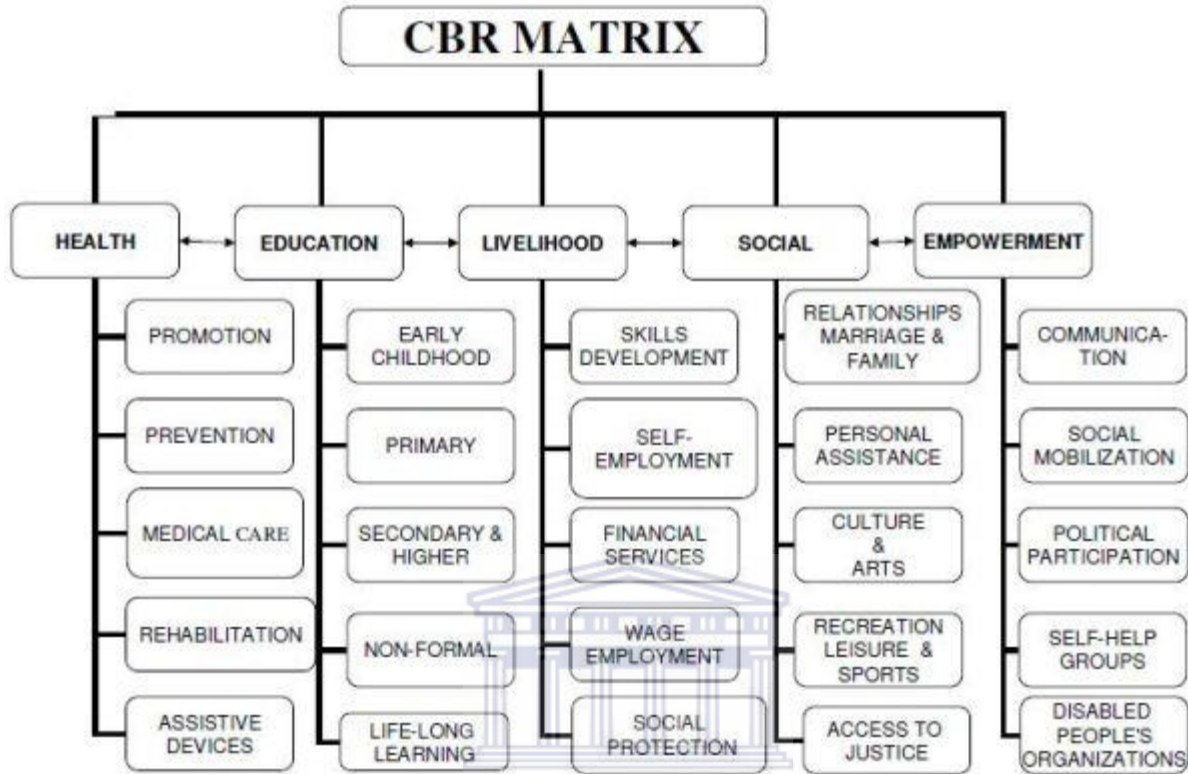
level is to gain independence in activities of daily living such as walking. Under participation restrictions, the goal of rehabilitation is to promote socialisation which usually starts within the hospital setting through group activities. However, this continues after discharge through home visits where home and environmental modifications are suggested and effected. The aim is to prepare the patients for integration back into the family, community or work. Participation level is facilitated or hindered by environmental or personal factors. The ICF concept, therefore, helps to solve the problem of stroke patients by ensuring that rehabilitation does not only focus on impairment, instead it is a continuous process that goes beyond the hospital setting to the community where patients experience a wide range of environmental and attitudinal barriers (WHO, 2001).

Owing to the complex nature of disability and rehabilitation, the ICF was used in collaboration with the United Nations Convention On Rights of People with Disabilities (UNCRPD). The UNCRPD was adopted in 2006 by both WHO and the American Association on Intellectual and Developmental Disability (AAIDD) as the first comprehensive human rights treaty of the 21st century based on the social-ecological model of disability (Shogren & Turnbull, 2014). It presents legally binding international treaty focussed on rights of persons with disabilities (Shogren & Turnbull, 2014). The purpose of UNCRPD is to promote, protect and ensure full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and promote respect for their inherent dignity (UN, 2006). Persons with disabilities include those who have long term physical, mental or Sensory impairments which hinder them from full and effective participation in society on an equal basis with others (UN, 2006). The UNCRPD also seek to create a new era of government accountability for policy and action that benefits people

with disabilities. In broader terms, it seeks both inclusion and anti-discrimination rights (UN, 2006).

The UNCRPD is closely linked to the Community Based Rehabilitation (CBR) guidelines contained in the CBR matrix. Nearly all domains of the CBR matrix are contained in article 3 of the UNCRPD. The CBR matrix concept was developed in 2004 with an intention of transforming CBR into a multifaceted development strategy (WHO, 2010). The matrix consists of 5 key components, which are health, education, livelihood, social, and empowerment (WHO, 2010 & WHO, 2007). The first four components focus on key development sectors indicating that CBR tackles multiple survival domains. The final component relates to the autonomy of people with disabilities, their families and communities which is fundamental to ensuring access to each development sector (Deepak, Kumar, Ortali & Pupulin, 2011 & WHO, 2010). CBR programs are not expected to implement every component or element of the matrix, instead the matrix was designed to allow programs select options which best fit in their local settings (WHO, 2010). In this study the CBR guidelines were used mainly to classify the nature of challenges that were found according to their respective domains of the matrix.

Figure 2 CBR matrix diagram



The ICF is predominantly a health phenomenon, in this study stroke patients and spouses had delayed to access to rehabilitation which resulted to avoidable disability and post stroke complications. The UNCRPD has certain articles (9, 19, 20, 25 and 26) which clearly indicate how to respond to health and rehabilitation need of persons with disabilities and access to health and rehabilitation is central to these articles. Again one of the key pillars of CBR matrix is health which is expected to be available at the grassroots level. These 3 frameworks have been used in combination in this study to describe the experiences of stroke patients and spouses at the institution and community level in relation to rights of persons with disabilities regarding health and rehabilitation.

1.3 Problem statement

It is known that the impairments caused by stroke in patients may result in loss of independence in self-care activities, transfers, standing, walking, posture and balance (Wu, 2009). In addition, economic and financial challenges also arise due to low income. Furthermore, social problems may also arise as they attempt to interact with the environment (Urimubenshi & Rhoda, 2011; Das et al., 2010). The underlying challenges that patients and their spouses face in Blantyre have neither been described nor documented. Working at the rehabilitation centre in Blantyre, dealing with patients and their spouses, I have observed that some patients and their spouses that were referred to the rehabilitation centre were sent back home without receiving assistance meant for the patients' disabilities due to lack of space. When the space is available they are called to the centre to start treatment. This process delays timely intervention resulting in deterioration of health through development of contractures and other complications such as pressure sores bowel and bladder dysfunction (Moser et al., 2006). This process worsens the patients' conditions and they become disabled even though the disability was avoidable. Consequently, some stroke survivors were not able to return to their previous occupation due to the severity of activity limitations and participation restrictions which had negative effects on their livelihood (Salter et al., 2006). This adds burden to spouse in terms of caring and finances. As such, there was need to explore the challenges and experiences of stroke patients and their spouses in Blantyre, Malawi.

1.4 Research question

What are the challenges and experiences of stroke patients and their spouses in Blantyre, Malawi?

1.5 Study aim

The broad aim of this study was to explore the challenges and experiences of stroke patients and their spouses during and after rehabilitation at the Rehabilitation centre in Blantyre, Malawi.

1.6 Specific objectives

1. To explore the experiences and perceptions of patients with stroke regarding the rehabilitation process.
2. To describe the effects of stroke on the patients and spouses.
3. To explore the experiences of spouses caring for stroke patients.
4. To explore the perceptions of spouses caring for stroke patients regarding the benefits of rehabilitation.



1.7 Definition of terms

Stroke: Rapidly developing clinical signs of focal disturbance of neurological function lasting more than 24 hours or leading to death of no other cause other than that of vascular origin (WHO, 2006).

Rehabilitation process: is also defined as a well-coordinated process of care where a multi-disciplinary team of medical professionals exist in a designated area where patients receive treatment of varying intensity according to their need (Hoenig et al., 2000).

Rehabilitation is used to refer to treatment by rehabilitation therapist in any setting and treatment at a specific time period in the recovery from an illness (Hoenig, Horner, Duncan, Clipp & Hamilton, 1999).

Stroke patient: referred to as a person that has suffered a cerebral vascular accident (Thompson & Ryan, 2009) was admitted at the centre, receiving treatment as an out-patient during the time of the study or got discharged up to 2 years before the study.

Spouse: The term was used to refer to the wife or husband of a person that has suffered a stroke (Forsberg-Warleby et al., 2004), and is providing care to the patient on a daily basis.

Challenges: referred to burdensome lived or life experiences of participants of the study (Speziale & Carpenter, 2007). In this case challenges were the patient's negative or difficult experience or consequences associated with stroke as an illness and that of caring for a stroke patient.

Impairments: are problems in body function or structure as a significant deviation or loss

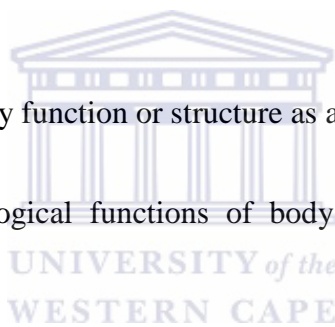
Body functions: are the physiological functions of body systems (including psychological functions).

Body structures: are anatomical parts of the body such as organs, limbs and their components.

Activity limitations: are difficulties an individual may have in executing activities.

Participation restrictions: are problems an individual may experience in involvement in life situations.

Facilitating mechanisms: Are strategies which are instrumental in assisting both the patients and the spouses in dealing with the stroke related challenges



1.8 Chapter outline

This thesis consists of five chapters. The first chapter presents the general background, problem statement, aim and rationale of the study. Chapter two presents a review of literature covering physical challenges, psychosocial challenges, coping mechanisms and rehabilitation process. Chapter three presents the methodology, including the research design, conceptual framework, research setting, population and sampling method, data collection and analysis, ethical considerations and trustworthiness of the study. Chapter four presents the results and discussion while chapter five presents study limitations, conclusion and recommendations based on the findings.



CHAPTER TWO

2.0 LITERATURE REVIEW

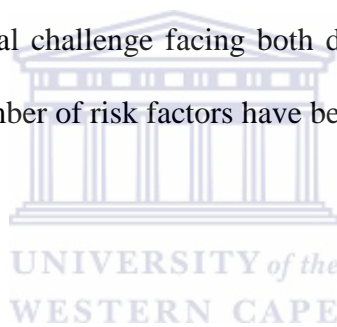
2.1 Introduction

In this section literature is reviewed under the following headings: Risk factors, physical challenges of patients, physical challenges of the spouse, psychological challenges of the patient, psychological challenges of the spouse, social economic challenges, disability models, coping mechanisms and rehabilitation process.

Stroke has become a serious global challenge facing both developed and developing countries (WHO, 2012; WHO, 2006). A number of risk factors have been identified and are presented here after.

2.2 Risk factors of stroke

According to O'Donnell et al. (2010) hypertension, diabetes, smoking, alcohol, abdominal obesity, diet, physical inactivity, apolipoproteins and psychological factors collectively are responsible to 90 % of global strokes. In developed countries, diabetes mellitus, atrial fibrillation and other cardiac diseases are among the major causes of stroke (WHO, 2005). However, tobacco use, physical inactivity, overweight, diet (low fruit and vegetable consumption), genetics (family history), serum cholesterol, fibrinogen and lack of proper medical services constitute risk factors (Truesen, Beggs & Mathers, 2006; WHO, 2006). In addition, medical conditions including previous transient ischaemic attack or stroke, ischemic heart disease, atrial fibrillation and glucose intolerance, all increase the risk of stroke (Truesen, Beggs & Mathers, 2006; WHO,



2006). In the United States of America, hypertension is the leading cause of stroke followed by diabetes and atrial fibrillation (Hall, Levant & DeFrances, 2012). However, sickle cell is ranked among the leading causes of stroke in young people especially young African Americans (Rosamond et al., 2007).

Evidence has shown that black African populations living in the United Kingdom are at higher risk of developing stroke than white populations. Khan et al. (2008) and Rosamond et al. (2007) found that blacks are nearly twice as much likely to suffer from stroke as whites due to ethnic conditions which include elevated levels of homocysteine which is a high risk factor of both ischaemic and haemorrhagic stroke. According to Rosamond et al. (2007) stroke risks rate between the ages of 45 and 84 are 6.6 per 1000 in blacks and 3.6 per 1000 in whites. Similar studies have shown that strokes are more severe in blacks than whites and that black patients survive with greater physical and functional deficits than their white counterparts (Mahawish & Heikinheino, 2010; Connor, Mondi & Warlow, 2009; Khan et al., 2008; Rosamond et al., 2007).

Ethnic differences, epidemiological transition of the population especially in Sub-Saharan Africa and untreated hypertension are among the major reasons of this discrepancy (Mahawish & Heikinheino, 2010; Connor, Mondi & Warlow, 2009; Khan et al., 2008; Rosamond et al., 2007). Markus et al. (2007) found that intracranial stenosis was common in blacks than whites presumably due to atherosclerosis, in black patients with stroke which according to their study explains why the risk of stroke in blacks was still high despite stabilisation of hypertension. Furthermore, these researchers argue that because socio-economic status and education influence accessibility to health services they should be ranked among the risk factors of high stroke prevalence in blacks.

In Africa, 90 % of haemorrhagic strokes and over 50 % of ischaemic strokes are caused by hypertension. Hypertension is the leading cause of stroke in Tanzania and Mozambique (Damasceno, 2010; Kengne, Amoah and Mbanya, 2005) while HIV and hypertension and diabetes are the leading causes of stroke in Malawi (Heikinheimo et al., 2012; Kumwenda et al., 2005). Evidence from literature indicates that limited knowledge regarding the causes of stroke has resulted in a number of misconceptions about the disease. Njoku and Aduloju (2004) highlighted that in Nigeria stroke is considered a spiritual disease requiring spiritual healing; consequently patients are withdrawn from the hospital in pursuit of traditional and spiritual remedies. Furthermore, Carroll, Hobart, Fox, Teare and Gibson (2004) indicated that knowledge about stroke is mainly obtained from friends, relatives and media rather than medical sources with only about 7.5% obtaining information from certified sources. Jones, Jenkinson, Leathley and Watkins (2010) stated that lack of knowledge among stroke survivors is worrying though there may be a number of possible reasons such as clinicians giving out inappropriate or complicated information to the public. In addition, these authors also found that older people, some minority groups and those of lower levels of education tend to have less knowledge yet stroke disproportionately affects them.

Sullivan and Waugh (2005) found that stroke patients had limited knowledge about stroke just like non-stroke survivors despite spending time in a specialist stroke treatment institutions. Damasceno et al. (2010) also found that in Mozambique stroke is attributed to a supernatural force requiring intervention by a traditional healer. In addition, Hamzat, Arulogun and Akindele (2010) highlighted that in Nigeria stroke is believed to be caused by witches, evil spirits. Furthermore, these authors state that there are beliefs about stroke being a sexually transmitted

disease and that only adults get it. Lack of knowledge affects treatment seeking habits and utilisation of health services which constitute a risk of stroke (Mbewu and Mbanya, 2006).

2.3 Impairments

Stroke patients experience physical and psychological impairments which alter or challenge their normal way of life (Baraski, 2011 & Ch`Ng et al., 2008).

2.3.1 Physical impairments experienced by patients

Stroke is an injury to the brain that results in a number of both physiological and structural impairments such as paralysis, immobility, visual defects, incontinence, swallowing (dysphagia), speech (aphasia) and loss of control over personal care (WHO, 2006). According to Baraski (2011) and Wu 2009 stroke patients faced challenges due to paralysis of one side of the body, balance, aphasia and dysarthria, bodily neglect, pain, swallowing disorders (dysphagia), bladder and bowel dysfunction. Thompson and Ryan (2009) and Ch`ng et al. (2008) found that speech impairment affects three quarters of stroke patients with conditions ranging from aphasia to dysarthria. Aphasia is a condition where the patient is not able to understand speech or written word or may understand but fails to express him or herself while dysarthria is a condition whereby a patient understands but is not able to pronounce the words clearly. (Baraski, 2011; Wu, 2009). Thompson & Ryan (2009) Ch`Ng et al. (2008) found that speech impairments interfered with expression of feelings and creates lack of understanding, tension and widens emotional distance between patient and spouse and interfere with intimate activities. According to Hilari et al. (2010) and Hilari and Byng, (2009) speech impairment increases risk of depression which negatively affected quality of life of the patients.

Neglect of one side is also common among stroke patients; neglect is a condition whereby the person is not able to pay attention to one side of the body (Baraski, 2011). Stroke patients also experience pain, numbness and strange sensations which make it hard for a patient to relax or feel comfortable (Baraski, 2011). Furthermore Baraski (2010) stated that pain in stroke patients may consequently result from muscle weakness, inflammation, poorly fitting braces, nerve damage, bed sores and immobilised joints.

Ch`Ng et al. (2008) and Teassell et al. (2008) found that stroke patients face difficulties in terms of mobility, vision, voice, speech and sexual functions. Thompson and Ryan (2009) found that stroke alters physical body image and reduces exercise tolerance due to post stroke fatigue. These authors further state that post stroke fatigue increases physical fatigability, promotes irritability and increases stress levels. Steinhagen, Grossmann, Benecke and Walter (2009); Martino et al. (2005) described swallowing disorders as a serious problem present in about 50% of acute stroke patients and further states that it increases the risk of pneumonia and death among stroke survivors. However, Steinhagen et al. (2009) argue that other factors such as insular stroke or infarction are responsible for the increased risk of pneumonia and tend to prolong the dysphagia. Stroke patients also develop bowel and bladder dysfunction. Bowel dysfunction usually manifests as constipation and involuntary bowel release, these conditions are associated with reduced fluid intake, diet, immobilisation, effects of prescribed drugs, being unaware of the need to use the toilet, weakness in the muscle that holds stool or failure to hold up until one reaches the toilet and sometimes being unable or reluctant to ask for help (Baraski, 2011; Wu, 2009).

From the literature reviewed above, it can be suggested that stroke patients' physical impairments affect patients capacity to function independently, interact with their friends, relatives and spouse and also reintegrate into their natural environment.

Urinary incontinence is another disturbing and frustrating condition affecting 40 to 60% of the victims 25 % of whom remain incontinent during discharge and 15 % is still present in long term survivors of stroke (Leary et al., 2006; Barret, 2001). Coyne et al. (2008) and Salonia et al (2004) found that incontinence is one of the factors which significantly interferes with sexual functions among stroke survivors and significantly reduces quality of life.

Sikiru, Shmaila and Yusuf (2009) found that tactile sensation is of extreme importance when it comes to sexual intercourse, arousal and orgasm, therefore, impaired tactile sensation has adverse effects on sexuality. Jung et al. (2008) and Kimura, Murata, Shimoda, and Robinson (2001) found that there is significant decline of libido, sexual satisfaction, erectile and ejaculatory properties after stroke. Bener, Al-Hamaq, Kamran and Al-Ansari (2008) in their study with a sample of 605 participants found that 43% of their participants had erectile dysfunction post stroke even though they had an active sexual life before the stroke. Jung et al. (2008) described sexual dysfunction as a serious problem which is often ignored among stroke patients. Jung et al. (2008) found that hypertension, diabetes along with other complications of stroke could together result in serious sexual dysfunction and that lack of sexual desire was the major cause for the decline of coitus. These findings were replicated by Tamam, Tamam, Akila, Yasan and Tamam (2008) and Kimura et al. (2001) which indicated that medication for hypertension, diabetes and anti-depressants do cause impotence. However, Thompson (2011)

found that psychological factors and negative attitude towards sex play a crucial role towards sexual drive than medical factors.

Jung et al. (2008) and Kim and Kim (2008) found that sexual intercourse or intimacy is an activity that is negatively affected by fear of inducing another stroke and culture especially in societies which consider sex a taboo after a stroke. Furthermore Kim and Kim (2008) found that among Korean men fear of impotence, being refused by spouse and fear of relapse were among the major causes of cessation of sexual activities. According to Keppel and Crowe (2000) stroke patients' sense of being unattractive makes them reluctant to engage in sexual or social activities with their spouses.

The literature reviewed in this section seem to suggest that sensory, cognitive and perceptual impairments interfere with their capacity to participate and live up to their marital obligations and it is made worse with speech and communication difficulties.

Pistoia, Gevoni and Boselli (2006) highlighted that sexual dysfunction was associated with geographical location of the stroke in the brain. Jung et al. (2008); using a sample of 109 participants found that patients with right cerebellum and left basal ganglia lesions were associated with erectile and ejaculation disorders. Similar findings were obtained by Sikiru, Shmaila and Yusuf (2009) using a sample size of 105 participants. Hyun, Gam, Chong, Kwon and Moon (2006) indicated that sexual disorders were associated with left basal ganglia and right cerebellum lesions respectively. However, Kimura et al. (2001) found a significant association between sexual dysfunction and left hemisphere strokes. Korpelainen et al. (1998) found that there was significant reduction of sexual function in patients with dominant hemisphere stroke than in those with non-dominant hemisphere stroke. However, Wylie and Kenny (2010);

Tamama et al. (2008); Singh et al. (2000); Berg, Palomäki, Lehtihalmes, Lönnqvist and Kaste (2003) and Korpelainen et al. (1999) found no correlation between geographical location and sexual dysfunction in stroke patients. Critical analysis of Korpelainen (1998) study reveal that it had a small sample size compared to all the other sample sizes that contradict it. There is also lack of evidence from radiological investigations to indicate whether the patients were scanned or went through Magnetic Resonance Imaging (MRI) investigation to reveal whether the subjects had multiple lesions or lesions in both hemispheres. From the literature presented above regarding geographical location it can be argued that due to conflicting findings no specific hemispheric location of the lesion is associated with depression but rather depression may result from either left or right hemisphere lesions.

2.3.2 Psychological impairments experienced by patients

The devastating consequences of stroke are not only physical, but they equally affect the psychological dimensions of the patients (Haley et al., 2010; Thompson & Ryan, 2009). Depression is a common psychological impairment affecting stroke patients which is often overlooked by medical practitioners during the rehabilitation process and consequently denying patients timely treatment interventions which would otherwise improve long term outcomes (Blonder, Langer, Pettigrew & Garity, 2007; Roding et al., 2003). Singh et al. (2000) found that depression negatively correlates with activities of daily living and functional status. Hilari et al. (2010) and Berg et al. (2005) found that a number of factors caused depression in stroke patients but stroke severity and loneliness were the major causes of depression at all times.

Bhagal, Teasell, Foley and Speechley (2004) found a significant correlation between left hemisphere stroke and depression in hospital in-patient population studies while right

hemisphere lesions appeared to contribute to depression in the community. However, it is difficult to ascertain whether it is the clinical consequences of stroke or neurophysiological changes that are responsible for depression. Kimura et al., (2001) found that sexual dysfunction was associated with both depression and left hemisphere lesions. However, Wylie and Kenny (2010) found no correlation between depression and sexuality. Singh et al. (2000) found that almost half of the right hemisphere participants of their study had developed depression compared to 17 % of the participants with left hemisphere lesion. According to Berg, Polomaki, Lehthalmes, Lonnqvist and Kaste (2003) and Kotila, Numminen Wattino and Kasle (1999) there is no association between the depression and side of hemiparesis. Keppel and Crowe (2000) indicated that being aware of one's deficits post stroke is a risk for developing depression which reduces functional abilities and independence.

Blonder et al. (2007) and Berg et al. (2005) also found that perceived lack of social support particularly from spouses was associated with depression in stroke patients. Baraski (2010) found that stroke patients experience memory loss, poor judgement or insight and emotional liability among others. Emotional liability is a condition characterised by sudden laughing and crying with no apparent reason and difficulties controlling emotional response due to cognitive impairments which in combination with memory loss and poor judgement may lead to depression. According to Daniel et al. (2009) depression negatively affects return to work in working adults which results in increased unmet financial needs and detrimental effects on family life.

Thompson and Ryan (2009) found that post stroke fatigue negatively contributes to return to work and that its mental and physical fatigability, irritability, impaired stress tolerance, sound

and light sensitivity, concentration and memory difficulties, collectively lead to depression. Blonder et al. (2007) highlighted that depression negatively correlates with sexual satisfaction. However, it is not clear whether reduced marital satisfaction causes depression or depression causes reduced marital satisfaction. Kimura et al. (2001) found that decline libido and satisfaction post stroke is associated with severe depression and severe impairment of activities of daily living (ADLs). These authors in their study found that 26% of the survivors had diminished libido while 59% of men and 44% of women were not satisfied with their sexual life and that depression combined with physical disability are the major causes of sexual dysfunction. However, Wylie and Kenny (2010) argue that there is correlation between sexual activity and depression. Furthermore, Berg et al. (2003) highlighted that even though their study was composed of mild to moderate depressed participants they did not find any association between sex, depression and rehabilitation outcomes.

According to Glader et al. (2003) severe depression is twice as common in females than males. Wylie and Kenney found no correlation between sex and depression. Thompson (2011) and Tamam et al. (2008) found that inability to discuss sexuality with one's partner was responsible for decline in coital frequency, sexual satisfaction along with unwillingness to engage in sexual intercourse. Baraski (2011) found that some patients were depressed because they were not able to drive again. The literature seems to suggest that impairment of the psychological functions which manifest as depression is a common occurrence among stroke patients regardless of gender. This condition interferes with many functional activities including spousal relationships.

Stroke patients are met with psychological barriers in the community. According to Dorza and Signori (2010) a barrier is considered as lack of a need, therefore, absence of services such as

psychotherapy, physiotherapy or speech therapy or lack of flexibility of such services constitute a barrier. According to the UNCRPD (2006) article 25, persons with disabilities have the right to enjoy the highest attainable health standards without discrimination on the basis of disability and the services should be provided if possible in the community including rural areas. In view of the literature above it can be argued that communities which lack services meant for people with disabilities are themselves a barrier to integration.

2.3.3 Activity limitations experienced by patients

Stroke patients have limitations in performing everyday activities. Nearly every impairment contributes to some degree of activity or function limitation. Ch`Ng et al. (2008) and Teassell et al. (2008) found that stroke patients experienced physical challenges in performing personal care activities such as toileting and showering which are usually emotionally upsetting and contribute to loss of dignity. Paralysis interferes with movement while balance makes sitting, standing or walking difficult even when the muscles are strong enough (Wu, 2009). Inability to walk is one of the major concern among stroke patients (Ch`Ng et al., 2008 & Teassell et al., 2008). Roos, Rudolf, Reisman (2012) highlighted that walking is a fundamental functional ability that brings satisfaction, value and is highly appreciated by stroke patients. According to Chimatiro (2012) and Baraski (2010) stroke patients face difficulties with driving due to altered body image, cognitive impairment and neglect. Driving is an essential activity which eases mobility, however, it is often compromised following stroke due to its complexity. Moreover, patients with one sided neglect are virtually missing half of their world, the person may not turn towards the weaker side or eat food or perform any activity that involves the affected half of the body (Baraski, 2011; Kats eta l., 2005).

Patients with stroke also experience difficulties relating to domestic chores such as preparing their food and sometimes feeding itself, transfers from one place to the other, bathing and toileting, dressing, grooming, turning and change of positions, taking of medication at scheduled times, proper positioning and accessibility in the home (Baraski, 2010 & Wu, 2009).

Stroke patients are hindered from moving up and down their environment by environmental barriers. Barriers are elements within the environment that obstruct or hinder successful negotiation of public facilities in the environment including accessibility of rehabilitation services by stroke patients (Swann, 2008). Physical challenges or barriers imposed by their environment include; lack of accessibility to buildings including public infrastructure due to steps, uneven terrain on roads and absence of proper transport structures (Chimatiro & Rhoda, 2013). Furthermore, these authors states that owing to travelling difficulties stroke patients were unable to access places of interest. According to UNCRPD (2006) article 9, member countries are expected to ensure that obstacles and barriers to accessibility of buildings, roads, transport, schools, medical facilities, housing and workplaces are completely eliminated so that persons with disabilities can access the physical environment on an equal basis with others. Contrary to that, Urimubeshi and Rhoda (2011) also found that in Rwanda stroke survivors and spouses are challenged by physical barriers such as in-accessible pathways due to stones, stairs and uneven terrain. Chimatiro and Rhoda (2013) indicated that inaccessible buildings and lack of mobility aids bar stroke patients from accessing places of interest due to travelling difficulties. Alguren, Lundgren-Nilsson and Sunnerhagen (2009) supported the above findings by saying that geographically hilly areas bar most stroke patients from re-integrating into their environment.

2.4 Challenges encountered by spouses

Spouses of stroke patients experience physical, psychological and social challenges during care giving process which predispose them to fatigue and depression (Wu, 2009). Below is a description of these challenges.

2.4.1 Physical challenges of the spouse

Spouses of stroke patients also experience challenges during caregiving. This is a physically and emotionally demanding responsibility associated with reduced levels of quality of life and high risk of depression (Baraski, 2011; Thompson, 2011). McPherson et al. (2011) and Coombs (2007) found that spouses are physically pressurised with care giving responsibilities which include taking of a number of responsibilities sometimes single handedly. Wu (2009) and Ch'ng et al., (2008) highlighted that spouses were challenged physically by tasks such as food preparation, transfers, dressing, grooming, pressure sore prevention, issuing of medication at scheduled times, proper positioning of patients and modification of the home environment (Wu, 2009). In addition, urine and faecal incontinence often necessitates bathing and transferring patient several times a day, an inevitable challenging task for spouses who have to enter the tub or shower rooms with patient in order to give the patient a bath several times a day, a highly strenuous activity (Haley et al., 2009; Ch'ng et al., 2008; Coombs, 2007).

Haley et al. (2009) and Wu (2009) highlighted that spouses are expected to pay undivided attention to their partners by reading every facial expression or body movement and making the right interpretation. Moreover, full time watch is usually required, which means spouses have to sacrifice their sleep when providing care during the night.

The effects of care giving tasks may physically manifest as fatigue, sleep disturbance, low energy, weight loss or gain and indigestion (Haley et al., 2009; Ch'ng et al., 2008; Coombs, 2007). Haley et al. (2010) reported that in addition to providing physically and psychologically demanding tasks and managing stressful conditions spouses are also psychologically strained by witnessing the suffering of their loved ones.

Spouses are further challenged by roles which were previously undertaken by stroke patients before the insult to the brain (McPherson et al., 2011; Backstrom, Asplund & Sundin, 2010; Lynch et al., 2008 & Coombs, 2007). Care giving strain among spouses of stroke patients has increased the risk of divorce due to failure to cope with chronic disability of their partners. (Daniel, Wolfe, Busch & Mckevitt, 2009; Ch'ng et al., 2008; Coombs, 2007). Highly strained partners have a greater chance of experiencing adverse health effects related to perceived strain of providing care which increases the risk of mortality (Perkins et al., 2013). According to Thompson (2011) Ch'ng et al. (2008) and Coombs (2007) spouses are fatigued with caregiving responsibilities thus, consider their intimate relationship with their stroke partners unrewarding. Furthermore, Thompson (2011) stated that spouses' sexual feelings are suppressed by the physically and cognitively unattractive condition of their partners resulting in loss of intimacy between couples.

The literature reviewed above seems to suggest that spousal care giving is a strenuous task that requires both physical and emotional stamina. It is associated with feelings of loss, pain, grief, anxiety and depression and it has serious consequences on marital relationship and family life.

2.4.2 Psychological challenges of spouses

Spouses of stroke patients are also psychologically challenged with the changes that occur in their lives which leads to stress and depression (Das et al. 2010). Even though in developed countries spouses of stroke survivors may manage to bridge the person power discrepancy gap by hiring a nurse or a foreign care attendant to help with care giving tasks, this has only proven to relieve the spouses of their physical burden not the psychological pressure as it does not take away the worry (Wu, 2009). Blonder et al. (2007) and Berg et al. (2005) also found that physical disability and patient dependency was a major cause of exhaustion and depression in spouses. Tooth, McKenna, Barnett, Prescott and Murphy (2005) found that poor mental capacity of patients or cognitive impairments of patients were strongly associated with the burden of care and depression among spouses. According to Das et al. (2010) lack of financial support, physical and mental stress experienced by caregivers and the influence of social relationships strongly correlated with depression. Depression and anxiety in spouses is also associated with frustration of witnessing slow improvement of their partners and dealing with the effects of dementia or depression which usually complicate stroke (Das et al., 2010). According to Haley et al. (2010) care giving strain was among the major causes of depression in spouses and that care giving spouses had elevated risk of developing a stroke. In addition, Perkins et al. (2013) highlighted that highly strained caregivers have greater chance of experiencing adverse health outcomes related to perceived strain from providing care.

According to Das et al. (2010) emotional illness is a serious problem among spouses of stroke survivors, it worsens with severity of physical and cognitive disability and may contribute to severe nervous breakdown in the spouses and consequently burdening the health and social services. However, Cameron, Cheung, Steiner, Coyte and Stewart (2011) contend that there is no

significant association between patient disability and spouse's emotional distress but caregivers are distressed by their failure to participate in valued activities, feelings of loss of control over their lives and own physical health among others. Furthermore, these authors say that spouses are challenged by emotional and behaviour consequences of the stroke other than the physical as they may be more prepared to handle physical challenges. Berg et al. (2005) found that spouses were diagnosed with depression early in acute stage even before the patients, probably because some patients had no insight of their condition in the acute stage of the illness. Spouses assume responsibility immediately after the stroke amid the uncertainty of their partner's chance of survival, which makes them anxious, confused as they experience extreme loss of leisure time, freedom and an interacting spouse (Backstrom, Kenneth, Asplund & Sundin, 2010; Coombs, 2007).

2.4.3 Social-economic challenges

International evidence suggests that ill health disproportionately affects the poor with a variety of problems such as unequal access to health care services, poor quality and unaffordable services (Badiee, 2012). In low income countries where an average household has inadequate personal as well as family income, the poor are particularly disadvantaged in using health care and experience worse health outcomes than the rich (Baidee, 2012; Raju, 2005). Stroke survivors and spouses experience a number of economic or financial difficulties which directly or indirectly affect their health; for instance, lack of food and failure to meet treatment costs (Leatherman, Christensen & Holtz, 2010; Wu 2009).

Haley et al. (2010); Das et al. (2010) and Daniel et al. (2009) described the negative socio-economic effects of stroke impairments, such as job retrenchment due to abscentism or severity

of disability, early retirement and financial difficulties which are usually compounded with limited employment opportunities in stroke survivors. Furthermore, Das et al. (2010) found that in India financial difficulties were worse among slum dwellers with little education, limited financial capacity and had no access to public financial support. Urimubeshi and Rhoda (2011) also found that in Rwanda stroke survivors and spouses from low income households, unemployed and not involved in any income generating activities experienced socio-economic barriers regarding health, rehabilitation, social participation and integration. Peterson et al. (2013); Das et al. (2010) and Brainin, Teuschl and Kalra (2007) highlighted that patients and spouses face socio-economic challenges in accessing medical and rehabilitation services which are both scarce and expensive especially in developing countries. The evidence presented above suggests that stroke patients and spouses from low income households have limitations in accessing medical and rehabilitation services which consequently affects their rehabilitation functional outcomes rendering them more dependent. Moreover, dependent patients require more support from spouse now crowned sole provider for the home.

Haley et al. (2010) and Thompson and Ryan (2009) indicated that patients with stroke and spouses are less engaged in social functions and usually socially isolated which predispose them to, anxiety, stress and depression which when unnoticed may have devastating consequences on rehabilitation outcome. Cameron et al. (2011) also found that lack of participation in leisure and esteemed activities and a sense of loss of control over life, age, gender and physical health is the major cause of depression and emotional distress in spouses. Backstrom et al. (2010) and Coombs (2007) highlighted that spouses are grieved as they have to let go a balanced and reciprocal marital relationship and take hold of a new undesirable relationship in which the partner contributes no physical or emotional support (Backstrom et al., 2010; Coombs, 2007).

Furthermore, these authors describe it as an absolute adaptation and adjustment to the reality of new life devoid of joy, excitement and fun which was once shared, even though they may live side by side with their spouses there is no deep connection between them (Backstrom et al., 2010; Coombs, 2007).

Stroke patients and spouses may experience difficulties engaging in sexual intercourse. While sexual intercourse does not solely represent and fulfil the concept of spousal relationship, it does to a greater extent play a significant role in marital satisfaction (Thompson & Ryan, 2009). In the past, stroke patients have been considered sexually inactive by medical practitioners simply because of their disability consequently, the topic of sexuality was not discussed. In addition, stroke patients and spouses suffered the changes in sexuality in silence without proper intervention despite their interest in an active sex life as they were denied the information on sex (Thompson & Ryan, 2009; Lemieux, Cohen-Schneider & Holzapfel, 2002).

Loss of marital relationship following stroke has been described by spouses as a very difficult challenge to cope with, reduced sexual and intimate contact eventually widened the sexual, social and emotional gap between patient and spouses (Thompson & Ryan, 2009). According to Backstrom and Sundan (2009) spouses grieved over their loss of marital relationship and that almost 70% of them were not satisfied with their sexual life which led to deterioration of the harmony in the relationship. Furthermore, these authors say that spouses struggle to come to terms with the loss of the person they once knew thus, they become vulnerable to emotional distress and strain. Loss of sexual intimacy deprives them of the memorable exciting moments they once shared with their partners (Backstrom et al., 2010; Wyllie & Kenney, 2010; Rees, Fowler & Maas, 2007). McLaughlin and Cregan (2005) found that disabled people have interest

in sex and calls for special skills training in the field of sexual rehabilitation for medical and rehabilitation workers who work with stroke patients and spouses to improve service delivery.

Stroke patients and spouses experience social barriers which hinder the process of re-integration as well as access to rehabilitation facilities which are essential for recovery (Scheppers et al., 2006). There are several barriers to health care accessibility described below:

Lack of rehabilitation services in some areas constitutes a barrier to rehabilitation services (Scheppers et al, 2006). Urimubenshi and Rhoda (2011) found that in Rwanda many people could not access physiotherapy because it was not available in their communities. Scheppers et al. (2006) further stated that most remote and sparsely populated regions where there are few or no health service providers the population suffer detrimentally due to lack of services. Chimatiro and Rhoda (2013); Das et al. (2010) and Scheppers et al. (2006) found that lack of financial resources due to abstract poverty can become a barrier to accessibility of rehabilitation services since economic circumstances affects one's ability to access care that is not sponsored (Chimatiro & Rhoda, 2013; Das et al., 2010; Scheppers et al., 2006). Furthermore, these authors stated that high cost of treatment acts as a barrier to access of rehabilitation. Health insurance is also one of the barriers of accessibility of health care services including rehabilitation services (McKee et al., 2013; Scheppers et al., 2006). Lack of health insurance leaves a person vulnerable when it comes to meeting treatment costs and sometimes some health insurance do not cover some services one wishes to acquire (Scheppers et al., 2006).

Employer agency factors are also considered barriers especially when sick leaves, and sick pay are not provided by the employer they hinder patient's ability to access treatment (Chimatiro & Rhoda, 2013; Lock, Jordan, Byan & Maxim, 2005). In addition, lack of family social support is a

barrier to health care access as family support is an advantage in providing emotional support to the patient (Urimubenshi and Rhoda, 2011; Das et al 2010; Chauhan, Baker, Lester, & Edwards, 2010). For many stroke survivors interventions by friends and family members is crucial in accessing appropriate care (Chauhan, Baker, Lester, & Edwards, 2010). Another social barriers is negative community attitude about stroke usually due to low education levels of community members and cultural beliefs which results in social stigmatization (Chimatiro & Rhoda, 2013; Urimubenshi & Rhoda 2011). In addition, these authors indicate that stroke patients were neglected by friends, relatives and the entire community and for working class patients it included their employers and business associates. Scheppers, Dongen, Dekker, Geertzen and Dekker (2006) stated that unreliable transport facilities and prolonged travelling time constitute a barrier to healthcare and other important social events. Other social barriers include lack of information flow to persons with stroke and their spouses which keeps them uninformed of the public and community resources available to them in a society (Dorze & Signori, 2010). Lack of awareness of the available services and lack of knowledge of the services at one's disposal constitute a social barrier (McKee et al., 2013; Jones et al., 2010). Furthermore, these authors highlighted that preference for traditional and self-remedies hinder acceptance of modern health services (Njoku & Adulaju, 2004). However, Scheppers et al. (2006) contend that there is no link between preference for traditional medicine and accessibility to modern health services.

The UNCRPD (2006) promotes access to rehabilitation and community re-integration. Member countries are, therefore, required to maximise the independence of disabled people through vocational rehabilitation and inclusion and participation of persons with disabilities in all aspects of life, particularly in health, education and social services. Member countries are also

required to ensure availability of assistive devices and technologies designed to facilitate rehabilitation of persons with disabilities.

Evidence also indicates that privacy is usually compromised during the rehabilitation process. Privacy is described as showing respect for patient's wishes, space and belonging (Barron, 1990). Deshefy-Longhi, Dixon, Olsen and Grey (2004) highlighted that privacy and confidentiality are fundamental human needs and that potential breaches of privacy and confidentiality due to carelessness are pervasive in healthcare. Moreover, overcrowding, careless display of patient information on computers and careless handling of telephone messages in health facilities are among the few violations of privacy and confidentiality noted by patients.

Barron (1990) described the inability to limit others from intruding as violation of physical privacy while the inability to control the right to determine with whom and under which circumstances to share feeling or disclose personal information is violation of psychological privacy. Burgoon (1982 as quoted by Scott et al., 2002) states that physical and psychological privacy are both classified as human needs. In addition, Burgoon (1982 as quoted by Scott et al., 2002) describes social privacy as ability to control level of social contact and information privacy as individual right to decide when and to what extent information regarding a person can be shared. Wainwright (1995) indicated that it is difficult to maintain privacy in a busy hospital environment especially in situations where patients share accommodation. However, Woogara (2005) argued that in a busy environment like a hospital it is the professional responsibility to ensure that patients' privacy is valued and that unwarranted rationalisation for why privacy is not maintained are no longer unacceptable. Furthermore, when planning patient's care their privacy and dignity should be given priority and should be seen as important as taking medication, in fact

it should become part of care. Scott et al. (2002) indicated that it is impossible to fully respect patient's autonomy without respecting their rights to participate in decision making process regarding treatment and care. Moreover, Delany (2005) describes autonomy as encompassing both rights and capabilities of a patient to make choices that meet their individual needs thus therapeutic understanding of autonomy means adopting attitudes of respect, curiosity and concern for the sake of patient's needs. In this regard, autonomy should be understood as patient's right to change bed position, sleeping space, toilet facilities, sleeping patterns, territory and space, individuality and identity of a person falling short of this is considered violation of individual control and choice (Woogara, 2005). According to UNCRPD (2006) articles 1, 3, 17 and 22 indicate that the purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Every person with disabilities has a right to respect for his or her physical and mental integrity which includes the right to privacy on an equal basis with others.

From the literature review above, it can be said that both stroke patients and spouses experience a lot of challenges which interfere with their psychological and social-economic life. However, it seems that these challenges are worse in developing countries where poverty limit strategies of intervention worsening the impact of disability. Disability has been perceived globally according to the models of intervention used. Several models have been developed through the ages which are discussed here after.

2.6 Disability models

According to the ICF disability is defined as a multi-dimensional phenomenon resulting from interaction between people and their physical and social environment (WHO, 2001). This concept indicates that it is the interaction between health characteristics and their contextual factors that produce disability. The United Nations Convention of rights of people with disabilities (UNCRPD, 2010) define disability as an evolving concept and that disability results from interaction between persons with impairments and attitudinal and environmental factors or barriers that hinder full and effective participation in a society on an equal basis with others. Several disability models have been developed, below is a description of some of the models.

2.6.1 Medical model

Also called biomedical model considers disability as a problem of individual directly caused by a disease, injury or any health related condition requiring medical treatment by professionals (WHO, 2001). This model strongly considers people disabled on the basis of not being able to function as normal people (Mitra, 2006). In this approach, rehabilitation has a role to play in bringing the people close to the norm (Mitra, 2006). This model is criticized on different grounds including viewing medical care as the main issue in disability as well as its normative strength (Mitra, 2006 & WHO, 2001).

2.6.2 Social model

This model views disability as a social construct (WHO, 2001). Disability is not the attribute of the individual but rather a complex collection of conditions created by a social environment and requiring social change (Mitra, 2006 & WHO, 2001). This model blames the society for disabling physically impaired people through isolation and exclusion of people with impairment

from active participation in society (Mitra, 2006 & WHO, 2001). Furthermore, it indicates that a collective action of the society is necessary to make environmental modifications for people with disabilities in all areas of social life (Mitra, 2006 & WHO, 2001). The social model also indicates that persons with disabilities are under privileged because of attitudinal and ideological issues making disability a human right issue (WHO, 2001).

2.6.3 Nagi model or Functional limitation paradigm

Pathology is at the centre of this model. Pathology is the disruption of normal body processes which may lead to impairment (Mitra, 2006). According to ICF, impairments are problems with body functions or structures such as significant deviation or loss of individual ability to perform tasks as required by social-cultural and physical environment (Mitra, 2006 & WHO, 2001). This model recognises impairment as the first step that leads to disability and promotes a social and realistic view.



2.6.4 The Bio-psycho social model

The Bio-psycho social model is based on the integration of both medical and social models also referred to as the ICF framework (WHO, 2001). This model attempts to achieve synthesis of both medical and social models in order to provide a coherent view of different perspectives of health from biological, individual and social perspectives (WHO, 2001). The bio-psycho-social model recognises that the genesis of disability is precipitated by health and environmental conditions that give rise to impairment and then activity limitation; both participation and restrictions within the contextual factors (Mitra, 2006).

2.7 Malawi disability policy and United Nations Convention on Rights of People with Disabilities (UNCRPD).

Disability policies are promoted by both local and international legislations. Every member country of the UN subscribes to the global regulations on disability contained in the UNCRPD. Malawi as member country now has a disability act which was legislated in 2012 (The Malawi Gazette, 2012). Contained in this act are provisions for equalisation of opportunities for persons with disabilities through the promotion and protection of their rights and public participation, prohibition of discrimination of any kind, social protection and to provide for the establishment of a disability trust. It is further stated that the state shall provide appropriate health care services to persons with disabilities, including preventive health, early identification and intervention to prevent occurrence or worsening of disability. In addition, the state shall also provide free medical rehabilitation services in public hospitals and facilitate access of such services through private hospitals should need be. Furthermore, it is stated that the state shall ensure that persons with disabilities have access to the physical environment, transport, information and communication.

2.8 Facilitators of recovery

Despite the challenges faced by patients and spouses, studies reported in literature reveal a number of coping mechanisms, which are instrumental in assisting both the patients and the spouses in dealing with the stroke related challenges. These include: social relationship and support as indicated by Adriaansen, van Leeuwen, Visser-Meily, van den Bos and Post (2011), early identification of depression (Haley et al., 2009), training and education (Kalra et al., 2004), leisure activities and religious faith and return to work among others (Martman-Maeir et al., 2007; Dayapoglu & Tan, 2010).

Social relationships and support from family, friends and community have a primary influence of quality of life and are considered to reduce stress and risk of depression, as well as burden of care (Adriaansen, 2011; Das et al., 2010; Lutz & Young, 2010; Visser-Meily et al., 2009). However, Lutz and Young (2010) and McCullagh et al. (2006) contend that social support has little effect on patients' and spouses' quality of life if not blended with counselling and physical hands on training of spouses in daily management of patients and other mechanisms. According to Das et al., (2010) and Roding et al., (2003) social support has positive effects on reduction of stress and burden of care which improves quality of life. In an Indian community where stroke patients and their spouses received support from family members and community, more than 66% indicated greater stress tolerance (Das et al., 2010). Reduced social support usually results in reactive depression (Astrom, Adolfsson & Asplundh, 1993). However, Adriaansen et al. (2011) and McCullagh et al. (2006) argued that social support has little influence on burden of care and no positive association with life satisfaction was found, highly in strained spouses. Bugge, Alexander and Hegen's (1999) arguments support the importance of social support although they contend that social support cannot bring change on family life hence suggest the need for realistic support interventions when dealing with situations that cannot change. Ch'ng et al. (2008) found that stroke survivors who participated in stroke support groups described the significant role played by stroke support groups in addition to enjoyable social gathering. They opened up to one another and understood each other's feelings in a manner family or friends could not. Social groups also provide practical tips for living with disability. In view of the literature above, it can be suggested that social support is an important facilitator of recovery from stroke and it is positive influence on acceptance of condition. However, it is effective when executed simultaneously with other facilitators.

Early identification of depression in patients and caregivers and early intervention has yielded significant results (Lutz & Young, 2010; Haley et al., 2009; McCullagh et al., 2005). It has been suggested by Moser et al. (2006) and Horner, Savanson, Bosworth and Matcher (2003) that early treatment intervention in stroke patients is advantageous. Furthermore, Horner et al. (2003) alerted us that black stroke patients who start treatment within 3 days have a 25% points advantage over their counterparts who start after 3 days.

Training of spouses and early involvement in therapy and hands-on management of day to day care was found to be associated with lower stress and burden of care levels (Kalra et al., 2004). Furthermore these authors say that training improves quality of life, reduces cost of care and promotes early independence in stroke patients.

Education of spouses and patients, according to Karla et al., (2004) and early education interventions have yielded significant results related to acceptance of condition and responsibility. Educating the patients and spouses on their condition promotes good family function, facilitates adaptation to condition, better use of social services and has a significant influence on functional and social outcomes (Clark, Rebenach & Winsor, 2003). However, Rodgers, Atkinson, Bond, Suddes, Dodson and Curles (1999) contend that although education and information improves health status, it is important to also realise that services developed by professionals do not always meet the needs of patients and spouses.

Involvement in leisure activities raises self-esteem. This improves performance and promotes life satisfaction and reduces the risk of depression (Martman-Maeir, Soroker, Ring, Avni & Katz, 2007). According to Chimatiro and Rhoda (2013) rehabilitation services should include activities that involve assessment of the environment for barriers and facilitators of leisure activities in

order to encourage active participation of survivors in leisure activities. Leisure activities cultivate enjoyment in patients, promote self-esteem and self-efficacy, and these three factors increase satisfaction (Elavsky et al., 2005).

Religious faith and positive thinking reduce the risk of depression which is among the major contributing factors to delayed recovery (Lynch et al., 2008; Giaquinto, Spiridigliozzi & Caracciolo, 2007). According to Jolley et al. (2010) beneficial effects of religion can be experienced through fellowship, formal social programmes and companionship, which reduce both physical and psychological stress. Bereavement, family problems and health problems are associated with religious affiliation. This may result in mobilisation of support from religious friends or becoming faith dependent in the coping process, both of these are significant to quality of life (Thoresen, 1999). However, Sherman et al. (2005) contend that even though religion reduces stress and other harmful effects, it has contributed to frustrations in some individuals especially cancer and HIV patients.

Participation in active coping strategies reduces stress levels and risk of depression thereby promoting quality of life (Vijser-Meily et al., 2009). Provision of post discharge therapy, organising special support groups to interact with spouses post discharge and assistance with complex disability tasks has proven to reduce stress levels in patients and spouses (Lutz & Young, 2010). Ostwald (2008) stated that participation in cognitive behaviour therapy groups has also proven successful in reducing the burden of care and improve satisfaction with of life.

Returning to work is one of the major predictors of quality and satisfaction in younger stroke survivors (Johansson & Bernspang, 2003; Hinckley, 2002). Tan (2010) found that patients who were employed or able to return to work had the highest scores of quality of life and this might

be associated with easy access to medical and other facilities, while housewives had the lowest quality of life probably due to no financial independence.

Rehabilitation services were among the active behaviour strategies that were reported as extremely helpful by stroke patients during recovery (Ch'ng et al., 2008). Physiotherapy, occupational therapy and speech therapy were described as key part of the recovery. Furthermore, Ch'ng et al. (2008) said that on top of enhancing functional abilities, therapies provide a focus and sense of working towards recovery. Lutz and Young (2010); Visser-Meily et al. (2009); Ostwald (2008) and Thomas and Lincon (2008) found that active rehabilitation plan improves function and quality of life at the same time reduces depression. However, Duncan et al. (2005) contend that rehabilitation has short term effects if it does not continue after discharge. According to Berg, Palomäki, Lehtihalmest, Lönnqvist and Kaste (2003) inactivity increases the risk of depression in stroke patients. Kalra et al. (2004) found that stroke survivors and spouses in active rehabilitation have lower rates of depression and improved quality of life. According to Ostwald (2008), maintenance treatment sessions to retain already achieved function and general exercises have been found to improve function and quality of life. However, Grevenson et al., (1991) contend that with the passing of time, stroke patients and spouses needed a more comprehensive support other than just physical rehabilitation.

Finding caregiving meaningful and positive relationship with the patient reduces depression and improves quality of life of both patients and spouses (Nilsson, Axelsson, Gustafson, Lundman & Norberg, 2001; Thompson, 1991). Spouses and patients who find meaning by focusing on the positive side of life have reduced depression, improved life satisfaction and are better adjusted in life (Nilsson et al., 2001; Thompson, 1991).

Counselling has been recommended for stroke patients, spouses and researchers as a significant part of the rehabilitation process, even in couples battling sexual dissatisfaction (Lutz & Young, 2010; Thompson & Ryan, 2009). Ch'ng et al. (2008) found that stroke patients have considered physical rehabilitation without counselling incomplete and insufficient. Psychological support has benefits such as improved mood, reduced feelings of isolation and increased ability to cope (Ch'ng et al., 2008). According to Lutz & Young, (2010); Thompson & Ryan (2009) Counselling has a positive effect on patients and spouses quality of life. Clark, Rubanack & Winsor (2003) highlighted that counselling is more effective when used in combination with education. Furthermore these authors stated that post discharge counselling of patients and spouses helps them to accept their new life situation and improves quality of life .

2.9 The rehabilitation process

Rehabilitation is defined as a process of active change by which a person with a disability attains knowledge and skills required to achieve optimal physical, psychological and social function collectively referred to as independence (Stucki, Cieza & Melvin, 2007). This process includes all measures aimed at reducing the impact of disabling conditions and promoting social integration of persons with disabilities (WHO, 1981). Rehabilitation, therefore, does not only end with training of persons with disabilities to adapt to the environment but creating a physical and socially accepting environment (WHO, 1981).

There are about 3 methods of delivering rehabilitation services and these are institutional based, outreach and CBR (Finkeflugel, 2009).

2.9.1 Institutional based model

It is the most common method of delivering rehabilitation services. It involves collocation of team members such as physiotherapists, occupation therapists, doctors, nurses who examine and treat patients or clients with different conditions (McColl., 2009). In this case, professionals deliver services in a concentrated and often specific way.

Advantages

Institution model is familiar for both medical and rehabilitation providers and it connects them exclusively within their scope of practice. It is also efficient from the professional perspective and affords the opportunity for joint appointments where several professional can work together if necessary. In addition, it has the benefit of collocation and offers possibility of developing inter-professional trust and coordination by virtue of enabled communication. This model is acknowledged for allowing patients to receive their care from various providers at a single location thus minimising costs.

Disadvantages

An institution based model is considered expensive because of the finances involved in building, maintaining and running the rehabilitation department; purchase equipment, provide meals for residents and pay staff. It is argued that less funds are required to support many people with disabilities in CBR instead. It is also criticized for failing to exploit its location in a community by extricating patients from their social context. Moreover, it is considered inefficient because patients tend to be seen, individually, leading to lengthy waiting lists and treatment delays. This

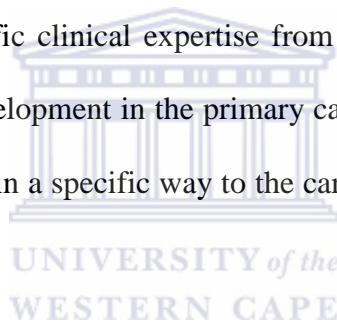
approach fails to perpetuate a multidisciplinary approach to care provision unless specific communication structures between disciplines are in place.

2.9.2 Out reach

This model is composed of service providers (professionals) who travel from an institution to the community usually a remote or resource poor location where people are not able to access specific services. Specific approaches to outreach include mobile teams and satellite units (McColl., 2009).

Advantages

This model is composed of specific clinical expertise from the tertiary care setting and offers subsequent potential for skills development in the primary care setting. The outreach therapist is seen as an expert who contributes in a specific way to the care of a particular patient or group of patients.



Disadvantages

The expertise is transient and lacks opportunity for sustained development of skills and aptitudes as the care team may be integrated in how they provide care but the team itself may not be integrated into the community. This model is expensive to operate. Furthermore, it is also dependent on the availability of tertiary care staff in the community.

2.9.3 CBR

CBR was designed to deliver rehabilitation services in developing countries where resources are inadequate and scarce (McColl et al., 2009). The role of CBR is to advocate for mobilisation of community resources in support of people with disability and disease (McColl et al., 2009). CBR

operates through non-governmental organisations and professionals who function as community development workers are considered part of the available resources within the community to assist in solving the problem (McCull., 2009).

Advantages

CBR results in broader more far reaching effects than could be achieved on one to one basis. It also results in practical skills and capacity development within the community. Moreover it raises the profile of disability issues and increases attention to the need to enhance accessibility and inclusiveness.

Disadvantages

Structural and attitudinal changes do not happen overnight, it is a process that requires commitment, time and energy over a long period of time.

Most CBR programs are donor funded as such they are not sustainable as they fade with time due to lack of government adoption into the mainstream of health.

2.9.4 Rehabilitation of stroke

A clinical hypothesis of stroke is confirmed by brain scans and imaging techniques (Scarborough, et al., 2009; Chalela et al., 2007; Fiebach et al., 2002). Rehabilitation process begins soon after diagnosis in a stroke unit within the first 24 hours and is composed of multi-disciplinary teams. The team members include physicians, physiotherapists, occupational therapists, speech and language pathologists, kinesio-therapists, psychologists, recreation therapists, nurses, patient and family members take control (Duncan et al., 2005). The aim of rehabilitation is to prevent complications, minimise impairment and disability thereby

maximising function (Knecht, Hesse & Oster, 2011; Young & Foster, 2007; Duncan et al., 2005). Inpatient rehabilitation commences soon after the patient's condition has been stabilised usually a week post onset and continues across the transition to home through visits and follow ups (Scarborough et al., 2009; Duncan et al., 2005 & Dobkin, 2005). National Stroke Association (2006) highlighted that physiatrist, neurologist, dietician, social worker, neuropsychologist, and case manager should also be added to the rehabilitation team. Furthermore, the National Stroke Association (2006) states that an excellent rehabilitation program should meet the requirements of accreditation which include offering wide range of therapies as well as having a full time physiatrist or medical doctor experienced in stroke and rehabilitation medicine. According to Scottish Intercollegiate Guidelines (2010) medical practitioners are part of the core of rehabilitation team together with, nurses, physiotherapist, occupational therapist, speech and language pathologist and social work staff. However, other disciplines also regularly involved in stroke management include clinical psychologist, dieticians and orthotics. Evidence from the literature indicated that rehabilitation therapy should be tailor made, a shift from expert based to patient based, with focus on patient's needs. Medin, Barajas and Ekberg (2006) highlighted that patients described the therapy that's not adapted to their needs as meaningless. Andreassen and Wyller (2005) also found that patients needed individual tailored information, physical training and psychological support. Visser-Meily et al. (2006) further stated that goal setting and decision making should not only focus on patient but the spouse also. The professional needs to recognise the spouse as a person with rights and aspirations and whose wellbeing is of major importance for the health of the stroke patient. The professional should realise that a spouse is a hands on expert and an equal partner in the caregiving process. Holliday, Cano, Freeman and Playford (2007) found that allowing individuals with long term neurological conditions to define and

articulate their goals results in greater perceived autonomy and greater relevance of goals. Moreover, delivering care in a manner that is meaningful to the individual is likely to contribute to long term adherence. Furthermore these authors stated that defining structures that help individuals articulate their ambitions support both the person and their family and their contribution in the rehabilitation process enable the professional to work within the individual goals (Holliday et al., 2007).

2.10 Conclusion

Several studies have revealed the challenges that stroke patients and spouses experience throughout the world. Facilitators of recovery, such as counselling, social support and intensive rehabilitation have been suggested to improve quality of life. However, most of the literature seems to originate from developed countries, where much research has been done. The circumstances surrounding resources and health policies may be different hence may not be generalised for Malawi, a resource poor nation, where this area of study remains unexplored. The next chapter presents the methodology utilised in this study.

CHAPTER THREE

3.0 METHODOLOGY

3.1 Introduction

This chapter describes the methodology used in this study. It discusses the research design, conceptual framework, research setting, study population and sampling technique, data collection procedure, method of data analysis, ethical considerations and trustworthiness of the study.

3.2 Research Paradigm and Design

This study is based on a qualitative research paradigm. A paradigm refers to beliefs, concepts or theories that govern the research community relative to the nature and conduct of research (Johnson & Onwuengbuzie, 2004). A qualitative paradigm aims to explore and describe a phenomenon in a particular context to the benefit of the participants (Zuber-Skerritt, 2001). An exploratory design was utilised in this study. A design is an outline or plan that is followed when used in conducting a study. It links up data collection and analysis processes to minimise factors that interfere with the validity of the findings thus ensuring that the complete research agenda is addressed (Bickman & Rog, 1998). An exploratory design is conducted to make preliminary investigations into relatively unknown areas of research so as to gain insight into a situation, phenomenon, community or person (Blanche & Darrheim, 2002; de Vos, Strydom, Fouche & Delpont, 2001). These studies generate an understanding of the concepts and theories held by the population under study (Bickman and Rog, 1998). Furthermore, Bickman and Rog (1998) stated that exploratory studies provided orientation and familiarization of the topic under study and

prepare the researcher for more rigorous descriptive or analytic studies. In addition, de Vos et al. (2001) indicated that exploratory studies help the researcher to develop methods which are used carefully in studies later. This design, according to Blanche and Darrheim (2002) and Straus and Corbin (1990) allow the researcher to explore people's experiences in an open, flexible, inductive and systematic manner as they look for new insights into phenomena. However, qualitative studies carry with them the element of subjectivity and biases which pose a problem with data analysis. In this study, the researcher bracketed theoretical knowledge and interests. Bracketing implies that the researcher sets aside his or her presuppositions, biases and other knowledge of the phenomenon obtained from personal or scholarly sources (Hein & Austin, 2001). This design was, therefore, considered suitable to explore the challenges and experiences of stroke patients and their spouses in Blantyre, Malawi.

3.3 Research setting

The study took place at the Rehabilitation Centre in Blantyre, Malawi. Malawi is a Sub-Saharan country bordering Tanzania, Mozambique and Zambia measuring 118,484 square kilometres (National statistics Malawi, 2010). The country has a population of about 15.2 million people (Peterson et al., 2013; National statistics Malawi, 2010). The economy is agro-based which accounts for 27% of gross domestic product (GDP) (WHO, 2012 & National statistics Malawi, 2010). Malawi is classified as a low income country ranked 165th out of 177 countries (WHO, 2012; Ministry of Health, 2007). Coupled with low GDP, it has high poverty levels such that 52% of the population lives below the poverty line which is considered less than 146.83 United States Dollars a year (Ministry of Health, 2007). Poverty is worse in the southern region and among female headed homes whose head has no formal education (WHO, 2012). Malawi's Health sector is one of the worst in the world consisting of 2 doctors and 38 nurses per 100,000

persons; communicable diseases represent the larger proportion of disease burden and non-communicable diseases are on the increase (WHO, 2012 & Ministry of Health, 2007).

Ministry of Health is the major provider of health care in Malawi. However, rehabilitation services are poorly developed with most hospitals surviving without physiotherapists (Peterson et al., 2013; Ministry of Health Malawi, 2007). Other health providers include Christian Health Association of Malawi (CHAM), Ministry of local government, private practitioners and companies and the army and police (Ministry of Health, 2007). The country has only 1 adult medical rehabilitation centre and 5 children rehabilitation centres. The adult rehabilitation centre is run by the Malawi Against Physical Disabilities which also operate the rehabilitation technicians school, it also provides outreach rehabilitation services and runs few workshops which produce locally made appliances or assistive devices in the country (Chimatiro, 2012).

The centre is strategically located next to the main referral and central hospital. The Rehabilitation Centre has a 40 bed capacity, 30 of which are non-fee-paying and 10 make up the private wing designed to generate income to support the running of the centre. The centre has 5 physiotherapists and 2 Rehabilitation technicians running the Physiotherapy section, 2 occupation therapists and 3 rehabilitation technicians running the occupational therapy section and 4 nurses running the nursing section making a total of 16 rehabilitation professionals. Patients are admitted from all over the country through regional, districts and private hospital referrals. Most of the patients admitted at the centre have neurological disorders such as spinal cord injuries, head injuries, peripheral neuropathies and stroke, which rank the highest accounting for 20 to 25 patients out of 40 on average. The centre accommodates people from all

economic backgrounds, gender, and age. The centre also provides outpatient physiotherapy services for a fee.

3.4 Study Population and Sampling

A purposive sampling method was utilised for this study. Participants are selected based on their knowledge of the phenomenon under study, thus the logic and strength of purposive sampling lies in selecting information rich cases for the interviews (Speziale & Carpenter, 2007; Brink, 2006). Purposive sampling is a practical and efficient method if used properly, and can be more effective than, random sampling (Bernald, 2002). However, Tongco (2007) indicated that when using purposive sampling the researcher should be critical especially when choosing key informants upon whom the data rests.

In this study, the population included 183 stroke patients and 183 caregiving spouses totalling 366 participants. This figure was composed of participants who were admitted at the centre during the time of the study and all patients discharged from the centre 2 years before the time of study. Eighteen participants were purposively selected and interviewed; 9 stroke patients and 9 caregiving spouses. This is in line with the recommendations by Kuzel (1992) who says 6 to 8 participants are enough for homogenous sample, and Cresswell (1998), on the other hand who recommends 5 to 25 participants. Selection was based on the researchers' judgement of characteristics that best represent the population under study. The selected sample included equal number of participants from paying and non-paying wards. Patients in the paying wards only pay for their room and meal but the treatment is offered freely to all in patients and the same therapists who treat patients from the paying wards treat patients from non-paying wards. The study also enrolled equal number of male and female patients and the spouses, sub-acute and

chronic patients, urban and rural dwellers. The study enrolled 2 patients from paying ward both male and female and their spouses, 2 from non-paying wards both male and female with their spouses, 2 urban dwellers both male and female and their spouses, 2 from rural settings both male and female and their spouses. One patient and spouse were selected from the outpatient section. Participants were selected irrespective of whether they were employed or unemployed and to ensure equal representation of gender equal numbers of male and female participants were enrolled.

3.5 Data Collection Methods

Two methods of data collection were utilised in this study namely semi-structured in-depth interviews and focus group discussions.

3.5.1 Semi-structured in-depth interviews

Semi-structured in-depth interviews are the most common qualitative method of collecting data because they are effective in exploring and identifying human experiences (Mack, Woodsong, Macqueen, Guest & Namey, 2005). An in-depth interview is a research technique in which a respondent answers the researcher's questions on one to one basis (Powell & Single, 1996). The interviews capture a respondent's subjective interpretation of a phenomenon using a loose interview guide; respondents can respond to the areas raised by the researcher much more (Powell & Single, 1996). This is a technique designed to elicit genuine views of participants relative to the topic under study during which the interviewee is considered an expert and the interviewer, a student (Mack et al., 2005 & Seaman, 1999). According to Speziale and Carpenter (2007); Mack et al. (2005) and Seaman (1999) semi-structured in-depth interviews provide opportunity for probes. Probes are neutral questions, phrases, sounds or even gestures used by

interviewers to gain depth and width of a phenomenon, and can be used to clarify information (Mack et al. 2005). In-depth interviews allow the interviewees to tell their stories as they saw it, felt it and experienced it while the researcher controlled the interview (Mack et al., 2005). According to Corbin & Morse (2003) and Fontana and Frey (1998) participants have the liberty to respond to questions at their own pace.

Advantages of In-depth

In-depth interviews gives participants opportunity to fully describe their experiences (Speziale & Carpenter, 2007). It also allows the researcher to seek clarification from respondents through probing thus obtain relevant and precise interpretation (Mack et al., 2005). Moreover, it facilitates building of rapport and trust between the interviewer and interviewee, thereby improving data quality (Speziale & Carpenter, 2007). It is a method of choice when sensitive issues are being discussed (Mack et al., 2005).

Disadvantages of in-depth interviews

In-depth interviews accumulate massive data that requires more time and experience to analyse. The interviews require high level training and skills and only small sample sizes are usually involved (10-15) due to length of interviews and associated costs.

3.5.2 Focus group discussion

The second method used in this study was a focus group discussion. A focus group discussion is a qualitative data collection method in which one or two researchers interact with a group of 4 to 12 participants that are assembled by the researcher to discuss and comment from personal experience on the topic which is the subject of research (Liamputtong & Ezzy, 2005; Mack et al.,

2005; Powell & Single, 1996). This technique employs guided interactional discussion as a means of generating rich details of complex experiences and reasoning behind an individual's actions, beliefs, perceptions and attitudes. Participants share common characteristics pertinent to the study (Powell & Single, 1996).

Focus group discussion sessions are usually audio taped or video recorded. One researcher leads the discussion by asking open ended questions while the other takes detailed notes of the discussion (Mack et al., 2005). Focus group discussions are effective in helping the researchers learn about wide range of perspectives and social norms of the community or sub groups (Speziale & Carpenter, 2007; Mack et al., 2005). A focus group discussion guide was utilised in this study to keep the researcher focused on the study topic and to probe as necessary for depth. This method also offered participants the flexibility and freedom to subscribe to their own perspective of the phenomenon instead of following a pre-arranged set of predetermined questions (Speziale & Carpenter, 2007).

Advantages of focus group discussion

Focus group discussions offer opportunity to collect diverse and spontaneous opinions about the study topic in a short time. They have the ability to enable researchers to identify full range of perspectives held by respondents. In addition, their interactive nature allows participants to clarify or expand on their earlier statements. It is easier for moderator to re-introduce the topic not adequately covered.

Disadvantages of focus group discussion

It is difficult to assemble a representative sample due to low turn up, focus groups usually generate superficial information about individuals moreover, focus group discussions may not be useful when sensitive issues are discussed.

3.6 Data collection procedure

The researcher obtained permission from the general manager of MAP and the senior physiotherapist to review patient folders to obtain demographic information. The senior physiotherapist at the centre then introduced the researcher to the patients and spouses at the centre. The researcher then contacted the participants at the centre and personally booked appointments while those discharged were contacted through the phone. The researcher was allocated a specific room within the centre where the interviews were conducted. This room was both quiet and accessible to wheel chair users thus it was convenient for the interviews. Some interviews were conducted at the participants' homes. In such cases, the interviews were conducted at a time and place convenient to the interviewees. All interviews were recorded with permission of the participants and after the interviews the researcher played back the recorded interview to verify with the participants if everything they wanted to say was indeed captured. With this approach 2 participants decided to add more information after listening to their recorded interviews. This was done to achieve member checking. A total of 18 in-depth interviews were conducted as scheduled using in-depth interview guides (see appendix J & L). The interview guides were made available in both English and vernacular (Chichewa) through backward translation. The in-depth interviews were conducted for a period of about 30 to 45 minutes. The researcher would ask a question and the participants would respond at their own

pace. Probes were utilised to seek clarity and gain depth and detail of the phenomenon during the interviews. Participants were not forced or mandated to respond to questions which they found uncomfortable to answer.

In addition, two focus group discussions were conducted using a focus group discussion guide (see appendix N & P). The focus group discussion guides were also made available in both English and vernacular (Chichewa) through backward translation. The researcher booked the participants during the in-depth interviews and reminded them 5 days and 2 days before and on the actual day of the event by telephone. Both focus group discussions were conducted at the centre in the boardroom which was spacious, quiet and accessible by wheelchair-using participants. The two focus group discussions lasted for a period of approximately an hour and half each. Probes were also utilised during focus groups. Six participants were expected to participate in each group but less than six participated even though many participants confirmed to attend and were assured of reimbursements of transport and other related costs. The first focus group participants were exclusively stroke patients and a total of 5 participants attended the discussion: three of whom were female and 2 male. The second group composed of spouses only; a total of 4 participants availed themselves 2 being male and 2 female. The rest of the participants cancelled the appointment last minute. During both focus group discussions, it was observed that patients and spouses behaved freely and that many of them were able to discuss private issues such as sexuality more than they did during the in-depth interviews.

Both focus groups were conducted by the researcher and all deliberations were recorded. The researcher also hired a research assistant whose role was taking notes during the interviews. In the current study, in-depth interviews were utilised to explore experiences of the participants.

Focus groups were used to explore the areas that were missed during the in-depth interviews which included inquiring from the patients and spouses what would be considered the solution to their condition, to verify saturation, to ensure that the study topic was adequately covered through multiple interaction with the sample and finally as a follow up method to confirm whether data obtained during in-depth interviews were right. The information was verified through focus group discussions and playing back the interviews in the presence of the participant. Member checking was done through playing back the tapes where participants were given an opportunity to comment whether the information recorded was correct. The researcher also took the transcripts to the participants who were within reach after transcriptions to verify whether the captured information reflected what they had said.

3.7 Methods of data analysis

Data were analysed using thematic content analysis. This is a systematic process of analysing and extracting meaning from data by assigning codes, themes or patterns (Burnard, Gill, Stewart, Treasure & Chadwick, 2008; Hsieh & Shannon, 2005). It is recommended that the interviews should be transcribed verbatim (Silverman, 2000). The researcher reads the transcripts word for word over and over to familiarise himself with the content or text. Similar words, ideas, phrases are grouped together to form codes (Ely, Vinz, Downing, & Anzul, 1997). In this study, the interviews were transcribed verbatim by a private professional transcriber at the College of Medicine, University of Malawi. The researcher also consulted a private translator to translate the transcripts from Chichewa to English and a different translator to translate the English version back to Chichewa. The two Chichewa versions were compared and they contained the same information. The analysis process began with repetitive reading of transcripts and verifying the accuracy of transcripts by listening to the recordings. Then words carrying similar meaning

or concepts were highlighted with similar colours. A table was then introduced with different columns and similar coloured phrases, statements and sentences were copied and pasted in a column where crystallization and condensation of participants' literal words transformed to units of general meaning irrespective of whether they answered the research question or not. The units of general meaning were then tested against the research question to see if they were answering or illuminating the research question. At this stage, all units of general meaning which did not answer the research question were left out while all that answered the research question were re-named units of relevant meaning. The researcher then determined which units of relevant meaning naturally clustered together. The clusters of meaning were further condensed to form determining themes. Using this process the researcher arrived at codes, categories and themes. The researcher analysed the in-depth interview transcripts before conducting the focus group discussion. This approach helped the researcher to realise some information gaps which were then filled through interaction with the participants during focus group discussions. Data interpretation was based on key ideas extracted from the content which highlighted both majority and minority views in form of quotations which were interpreted in the context of the literature review.

3.8 Trustworthiness

Trustworthiness is the way of ensuring rigor in qualitative study without sacrificing the relevance of the research (Krefting, 1991; Lincon & Guba, 1985). Trustworthiness parallels validity and reliability criteria streaming from quantitative rigor (Lincon & Guba, 2000). These parallels are intended to very loosely achieve the purpose as validity in quantitative studies thus internal validity, external validity, reliability and objectivity corresponds to credibility, transferability, dependability and confirmability in qualitative studies respectively (Morrow, 2005).

Trustworthiness implies that the results of the study have scientific competence and can, therefore, be given attention (Lincon & Guba, 1985). Credibility, Transferability, Dependability and Confirmability are foundation of trustworthiness in qualitative research (Shenton, 2004 & Lincoln & Guba, 1988). Credibility is the probability that credible findings will be produced (Lincon & Guba, 1985).

Two data collection methods namely in-depth interviews and focus group discussions were utilised by which the principle of triangulation was achieved to satisfy credibility as suggested by Speziale and Carpenter (2007). The interviews were also recorded which established a much fuller data base than just taking hand written notes as indicated by Mack et al. (2005). In addition experienced transcriber and translators were hired to transcribe and translate the transcripts using backward translation to reduce biasness as recommended by Speziale and Carpenter (2007) and Tongco (2007). Moreover, all interviews were conducted in the language of the participant's choice to ensure that participants were free to give rich information without language or communication barriers as indicated by Lincon and Guba (1985). Furthermore, information was gathered until saturation was reached, this satisfied the principle of credibility as recommended by Morrow (2005), Patton (2002) and Creswell and Miller (2000).

Dependability: refers to the assurance or reliability that the study is in itself repeatable (Creswell & Miller, 2000; Lincon and Guba, 1985). In this study, dependability was achieved through dense description of data and research methods and process. In addition the research instruments have been provided in the appendix. Availability of these instruments may give potential researcher the ability to repeat the study in other settings.

The researcher engaged a private transcriber and translator to reduce biasness, this fulfilled confirmability as recommended by Shenton (2004); Creswell and Miller, (2000) and Lincoln and Guba (1985). In addition, the researcher also played back the interview before the participants to verify the information. This method plus the focus group discussions were used to fulfil member checking as suggested by Creswell and Miller (2000).

Transferability: refers to the extent at which the results can be applied in other settings (Shenton, 2004 & Lincoln & Guba, 1988). In this study, purposive sampling of participants was used to ensure that a larger population was represented in this study such that under similar circumstances and conditions the results can be applied in a different setting.

3.9 Ethical considerations

Ethical approval for the implementation of the study was obtained from the Research Grants and Study Leave Committee of the University of the Western Cape and from the College of Medicine Research Ethics Committee, University of Malawi; assent was obtained from the general manager of Malawi Against Physical Disabilities (see appendix C). Permission was obtained from the senior physiotherapist, who is also responsible for patient affairs at the Rehabilitation Centre. The participants were informed about the purpose of the study in the language they best understood and were provided with information sheets.

The researcher obtained informed consents from the participants before they took part in the interview. Participants were informed that the results of the study will only be used for research purposes and that the results would be presented to the Physiotherapy Association of Malawi and at the dissemination conference of the College of Medicine, University of Malawi. Participants were assured of their anonymity and confidentiality as names would not be used in the report and

that the information would be kept locked in a locker and computer which the researcher used to process the data will be password protected. Participants were assured of confidentiality during the in-depth interviews. They were also assured that their participation would not interfere with their current or future rehabilitation programs. Furthermore, participation was voluntary thus patients had the right to withdraw from the study anytime they wished without any consequences that would seem disadvantageous on their part.

3.10 Chapter Summary

This chapter has presented the research design and methods used to explore the challenges experienced by stroke patients and spouses in Blantyre, Malawi. Purposive sampling method was utilised. A qualitative exploratory design that employed in-depth interview and focus group discussions to gather data was utilised. Data were analysed using a thematic content analysis. All ethical requirements were observed during the research. The results and discussions are presented in the next chapter.



CHAPTER FOUR

4.0 RESULTS AND DISCUSSION

4.1 Introduction

This chapter presents the results of the study in a form of qualitative thematic content. The results describe in narrative form the lived experiences of stroke patients and spouses in Blantyre, Malawi. Data was collected from stroke patients and their spouses through 18 semi-structured interviews of which 9 patients and 9 spouses were interviewed. In addition, 2 focus group discussions were conducted at the Centre where both patients and spouses participated.

This study had no predetermined themes; all the themes have emerged from the data that was obtained through interviews. Interview guides were used to guide both in-depth and focus group discussions as provided in the appendix (L & N). The study discussion therefore, is based on the aim which explored the challenges experienced by stroke patients and their spouses during the rehabilitation process, from diagnosis through to treatment and discharge. The results demonstrate that according to ICF most of the challenges encountered were in the domain of impairment, activity limitation and participation. However facilitators in form of religious faith was identified. The results further demonstrate that according to CBR guidelines and UNCRPD challenges were encountered in the domains of health, where lack of awareness, privacy and accessibility to rehabilitation services was observed.

4.2 Social Demographic data

The study enrolled only married couples (i.e., patients and their spouses). All participants were married and living together as husband and wife before the stroke. All patients who were on salaried employment were male. Two stroke patients were serving in the civil service, (Ref/29), served as a primary school teacher while (Ref/42) combined lecturing at one of the public university and consultancy work. The third one worked in a private sector before the stroke (Ref/06). One retired clinician (Ref/04) who was previously running his private clinic was not able to go back to practice. The rest of the participants were either retired, running their small scale businesses or farming before the stroke. At the time of the study none of the participants had returned to their previous occupations. The two civil servants had retired on medical grounds due to the effects of stroke while the one in the private sector seemed unwilling to return to work but had been maintained on salary by the employer at the time of the study. The table 4.1 below presents the social demographic profile.

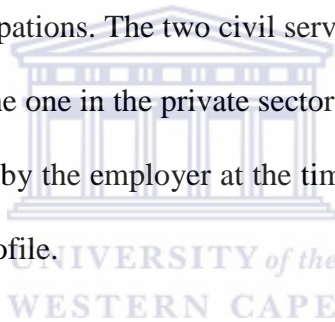


Table 4.1 Social demographic profiles of stroke patients and spouses

DEMOGRAPHIC DATA OF PATIENTS AND THEIR SPOUSES							
Patient Ref number	Gender	Age in years	Occupation	Spouse's Ref number	Gender	Age in years	Occupation
712-0004	Male	74	Retired clinician	712-0005	Female	68	House wife
712-0006	Male	55	Clerk	712-0007	Female	50	House wife
712-0020	Female	60	Housewife	712-0019	Male	65	Retired soldier
712-0024	Male	78	Retired police officer	712-23	Female	69	House wife
712-0027	Female	70	Housewife	712-0026	Male	85	Farmer
712-0029	Male	46	Retired teacher	712-0030	Female	42	House wife
712-0031	Female	77	Chief and house wife	712-0028	Male	88	Retired teacher
712-0032	Female	61	Business woman	712-0033	Male	67	Retired administrator
712-0042	Male	68	Retired lecturer	712-0041	Female	56	Secretary

Table 1 above indicates that most of the patients suffered a stroke in their middle and old age.

Similar to this finding Heikinheimo et al. (2012) found that stroke patients at Queen Elizabeth Central Hospital had a mean age of over 55years. Kumwenda et al. (2005) also found that stroke younger patients had a mean age of 58years. There was not much age difference between stroke patients and spouses in this study which could imply that spouses were themselves aged and might have had difficulties caring for stroke patients. This is similar to findings of Sit, Wong, Clinton, Li and Fong (2003) who found that most of the stroke caregivers were often elderly spouses with little education background, a condition that interfered with their accessibility of information and support.

4.3 Development of themes

The themes of the current study emerged from the data through thematic content analysis of the transcripts based on the objectives of the study. Words, statements and phrases displaying similar concepts and meaning were coded and similar codes were merged into sub themes and sub themes into themes. 4 themes emerged out of the data as narrated below:

Table 4.2 Emerging themes and sub themes

Theme 1: STROKE PATIENTS EXPERIENCE OF DISABILITY	
Sub themes	Impairment
	Activity limitation and participation
	Inability to return to work and failure to access basic necessities
	Sudden onset of stroke and feeling of being a burden
Theme 2: SPOUSES EXPERIENCE OF CARING FOR DISABILITY DUE TO STROKE	
Sub themes	Challenges of care giving
	Sexuality and companion issues
	Lack of social support from friends and relatives
Theme 3: EXPERIENCE OF PARTICIPANTS WITH REHABILITATION	
Sub themes	Positive impression of rehabilitation intervention
	Inadequate space and poor condition of the available facilities
	Lack of privacy
	Lack of awareness
	Participant's perception of staff members
Theme 4: FACILITATORS OF RECOVERY FROM STROKE	
Sub theme	The influence of faith in God, social support and Rehabilitation process

4.4 Stroke patients experience of disability

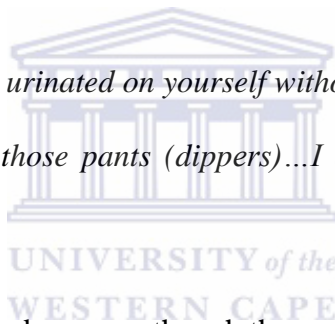
Stroke patients described their lives as characterised by impairments such as loss of mobility, generalised weakness of the body, incontinence, psychological impairments, urine and bowel

dysfunction and memory loss that resulted in state of helplessness. Stroke patients and their spouses also reported mobility challenges due to limitation of activities such as walking. The limitation of activities hindered them from returning to work or participate in different social activities.

4.4.1 Impairment

Most stroke patients and their spouses experienced challenges coping with impairments such as urine incontinence while spouses described psychological impairments such as confusion, personality changes and anger and managing cognitive changes as devastating as expressed in the quotes below.

“You sometimes find that you have urinated on yourself without control so I preferred if possible that the patients should be given those pants (dippers)...I am still using those pants.” (Male patient Ref/24).



You have combined incontinence and anger as though they mean the same

“ For me, the anger was there previously of course, he was angry a lot but now the anger is increased beyond control. Some of the maids who used to work for us have resigned and left us because of the same anger.” (FGD/2).

“It is a lot difficult to take care of a person who has suffered a stroke because stroke affects the brain so a person with stroke can say or do things that upsets the one caring for him.”

(Male spouse Ref/19).

This was confirmed by female spouse at the rehabilitation centre who said:

“The care of a person who has suffered a stroke is a little difficult, what seems difficult is that sometimes the brain does not work properly so it requires the guardian to be persevering in a lot of things.” (Female spouse Ref/05)

“ For me, the anger was there previously of course, he was angry a lot but now the anger is increased beyond control. Some of the maids who used to work for us have resigned and left us because of the same anger.” (FGD/2).

Urinary incontinence considered an involuntary leakage of urine is a strong predictor of mortality and dependence in stroke patients (Author, 2008; Abrams, 2002). The findings of this study concur with the findings of Author (2008) which indicate that post stroke urinary incontinence can occur with impaired awareness of need to micturate. Jamieson, Brady and Peacock (2010) stated that the effects of urinary tract infections on stroke patients are greater than those of other causes and that they are linked to severe disability and dependence. Leary et al. (2006) and Harari et al. (2004) highlighted that and urine incontinence may persist for a long time even though a multi-disciplinary rehabilitation intervention has shown to improve recovery.

The findings also indicates that stroke patients are aggressive towards spouses even when they are offering support to help them perform some activities. Similarly Kitzmuller (2012) found that sometimes the stroke patients’ attitude towards spouse was overshadowed by irritation and anger usually coming from their shortcomings and dependency or if the spouse comes to their aid when they did not feel the need for help. Jones and Morris (2012) found that stroke patients being cared for by their mothers expressed anger towards their parent caregivers, a very strange development considering that that the parents were offering support. However, it has been reported that feelings of shame were prominent in stroke patients, perhaps these feelings were

triggered by the fact that stroke patients were finding it hard to receive care from a parent as some stated, they were made to feel like children which induced a feeling of shame (Jones & Morris, 2012). Cognitive impairments rank among the major predictors of dependence in stroke patients (Hofgren, 2007). Evidence has shown that cognitive impairments progress slowly and may take much longer time than anticipated for recovery to occur. The findings above is an indication that spouses of stroke patients require strategies that would help them overcome the frustrations of dealing with cognitive behaviour of their partners.

4.4.2 Activity limitation and participation

Majority of patients reported facing limitations with execution of basic and instrumental activities of daily living such as walking, eating and performing domestic chores. The limitation of activities hindered their participation in different social activities such as church and religious gathering, community development functions and work. The consequences of stroke leads to a lot of changes in life as the quotations describe:

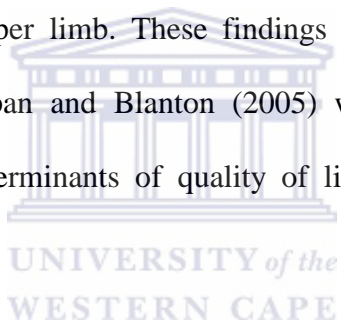
“I was in a wheelchair, it means I was stuck I could not walk...it’s not easy I could not go out to meet friends” (Male patient Ref/42).

“Even eating is hard...they have to cut for me the food. To eat myself I can’t my hands feel numb and I can’t use them.” (Female patient Ref/27)

“I am not able to participate in community development activities or attend church functions because I cannot walk though it’s a short distance to church.” (Female patient Ref/20)

The results of this study indicate that stroke patients struggle with physical activities which consequently cause limitations in performing activities of daily living such as walking. Walking

is a fundamental functional ability that brings satisfaction, value and is highly appreciated by most people (Cumming et al., 2011). The results of this study resonate with those of Several studies have (Thompson and Ryan, 2009; Ch`Ng et al., 2008; Teassell et al., 2008) that indicates that inability to walk is one of the major activity limitation facing stroke patients. In addition the findings of the current study indicate that lack of essential activities such as mobility environmental challenges interfered with other domains of life such as social interaction. Similarly Himatiro and Rhoda (2012) and Carod-Artal, Egido, Gonzalez and de Seijas (2000) highlighted that post stroke activity limitations are a major predictor of diminished social participation. The results also indicates that stroke patients have limitations performing functional activities using the upper limb. These findings support the finding of Nicholas-Larsen, Clark, Zeringue, Greenspan and Blanton (2005) which states that upper extremity function is one of the major determinants of quality of life after stroke and an underlying component of the physical domain.



The above findings reveal that patients with stroke experience activity limitation and restriction in participation domains of the ICF due impairment and other contextual factors. There is need for the rehabilitation professionals to consider environmental challenges which hinder active life styles and social integration in both patients and spouses following stroke.

4.4.3 Inability to return to work and failure to access basic necessities

The majority of the patients were unable to return to work which had serious consequences on their economic activities and consequently on their personal as well as family income, with extreme conditions experienced when a bread winner was affected. One participant of this study who was a teacher and had aphasic was told by the employer to go home and return when the

speech had improved. However, with no speech therapist in the community, it is difficult to regain the speech. Other challenges mentioned included scarcity of drugs in public hospitals, settling of medical and rehabilitation bills, and managing transport costs as quoted below:

“Since my husband suffered a stroke and could not return to work we cannot afford the same food we used to eat and at the same time we have hospital bills to take care off and sometimes we have to buy drugs from pharmacy where most of the times they are expensive.”

(Female spouse Ref/41)

“My problem is that, my business was making a lot of money on daily basis before I suffered from stroke but now I can’t. This has a bad effect on my life as I can’t afford what I want I have to depend on others for survival.”

(Male patient Ref/04)

“Drugs are not available in public hospitals around here both Thyolo district hospital and Bvumbwe Health Centre so I buy them from market vendors who are at least cheaper than buying from a pharmacy” (stroke patient Ref/29)

Most of these participants indicated that inability to return to work or resume previous activities due to stroke was the major financial set back. Patients and spouses expressed that they experience challenges obtaining basic necessities such as food in their homes due to unavailability of money as they were unable to return to work because of the stroke. It was also a challenge even to get medication to prevent further complications of stroke due to high cost of medication. The outstanding findings of the current study indicate that patients were buying medication from uncertified places and people accessed vendors due to scarcity of medication in

public hospitals and high cost of drugs in private pharmacies, consequently some couples reported selling their food to buy medicine. The results also indicate that patients and spouses especially from the rural settings complained of high transport costs that limited them to visit their relatives at the rehabilitation centre. The findings of the current study resonate with the findings of Daniel et al. (2009) which indicate that inability to return to work in working adults results in increased unmet financial needs and has detrimental effects on family life. Dayapoglu and Tan (2010) found that income positively correlated with all areas of quality of life and that those with enough income had fewer concerns and less economic burden from the disease. Hofgren, Björkdahl, Esbjörnsson and Stibrant-Sunnerhagen (2007) highlighted that return to work is an essential part of the rehabilitation outcome which is key to the treatment process. Urimubeski and Rhoda (2011) found that in Rwanda stroke survivors and spouses, that were from low income households, unemployed and not involved in any income generating activities, had difficulties finding transport to hospital and paying their hospital bills which interfered with their rehabilitation outcomes. Lock et al. (2005) found that transportation interfered with the accessibility of vital activities including work. Urimubeski and Rhoda (2011) also highlighted that in their study some patients were unable to attend therapy sessions due to transport problems. The researcher thinks that patients were at a risk of developing a recurrent stroke due to scarcity of medication. Lack of rehabilitation professionals such as speech therapist and physiotherapist in the community is a serious challenge faced by people with speech and mobility impairment. However, lack of finances could be a barrier to accessing these rare services even if they were to be stationed in the community. There is need, therefore, for a multi-disciplinary team to ensure that medication and rehabilitation services are made available to the people within the community through public health facilities at affordable rates.

4.4.4 Sudden occurrence of stroke and feelings of being a burden

Most stroke patients and spouses that participated in this study expressed shock, were not aware of their blood pressure status at the time of the study. In addition, patients and spouses also indicated that they were burdened by the illness. Patients perceived themselves as being a burden to the spouses while spouses felt burdened by the caregiving role because they did not see the immediate achievement of relief to their suffering as indicated below:

“It came unexpectedly. He was okay then his limbs just became weak, to me it was something dangerous. It was very painful.” (Female spouse Ref/30)

“I feel I am troubling this lady instead of doing her own job. I want things; she is coming this time to care for me so that something inside feels there is something wrong.” (Male patient Ref/42)

“Here at my home I do nothing (house hold chores) in my life I have lots of thoughts thinking how will I do this, how will I do that, cause I can’t walk...I was thinking that I am on the way dying.” (Ref/26).

In support of the above findings stroke has been described as a sudden onset condition that usually strikes when you least expect it (WHO, 2006). Alaszewski, Alaszewski and Potter (2006) highlighted that the lack of warning meant that stroke was experienced as a traumatic event one which undermined the confidence the patients possessed before. The results of this study concur with the findings of Lamb, Buchman, Godfrey, Harrison and Oakley (2008) which indicated that stroke experience was a sudden and an unexpected event that’s often shocking, confusing, frightening and terrifying bringing a sense of being totally disabled. Moreover, the suddenness of

the stroke created uncertainty for many stroke patients which undermined their confidence as competent adults both in the present and future endeavours (Alaszewski et al., 2006).

Evidence in the literature suggests that chronic illnesses are associated with patients' feelings of being a burden. Self-perceived burden can be defined as an empathic concern of the impact of the illness on those providing care which results in feelings of guilt, distress, responsibility and diminished sense of self-worth (Cousineau, McDowell, Hotz & Hébert, 2003).

In this study some stroke patients felt that their need to be cared for was burdening the spouse and interfering with her occupation. Oeki, Mogan and Hagino (2007) found that cancer patients in Japan perceived themselves as being a burden which affects their quality of life. Cousineau et al. (2003) further highlighted that the patients were worried of interfering with the carer's life especially of the adverse effects of strain on partner's health. McPherson et al. (2010) found that self-perceived burden is highly prevalent in stroke patients than in cancer patients.

The researcher, therefore, reasons that under the theme impairment of the brain structure and functions which also resulted in impairments of other vital functions such as speech, sensory-motor, urine and faecal among others was the main cause of limitation of functional activities such as self-care, feeding, balance and walking. Lack of these functions hindered participation in work and income generating activities resulting in low household income and high levels of poverty following stroke. The researcher also reverberate that the existence of psychological impairment such as anxiety and depression are likely to be precipitated by disability and feeling of being a burden poses a big challenge in the life of stroke patients and spouses.

This indicates the need to engage psychological interventions such as counselling among stroke patients and spouses early in the treatment process to counteract the effect of psychological impairments which interfere with long term physical and psychological outcome. However, this form of therapy is not available at Kachere nor in the community after discharge. According to article 25 and 26 of the UNCRPD (2006) patients with stroke (disabled persons) have the right to enjoy the highest attainable standards of health which refers to availability of complete and stable medical and rehabilitation services within their natural settings. Furthermore, the UNCRPD (2006) indicates that access to these facilities should be available at the earliest possible time to prevent further disabilities while the ICF proposes that these facilities should be accessible to the persons with disabilities (WHO, 2001). The UNCRPD (2006) proposes economic empowerment for stroke patients to attain a state of financial independence. Lack of accessibility to medication and rehabilitation services in the local settings as revealed in this study made patients to incur travelling cost in order to obtain medical and pharmaceutical services in distant places and sometimes from uncertified sources was a clear indication that the recommendations of the UNCRPD have not been met. Even though the ICF (WHO, 2001) promotes a friendly and accessible environment by persons with disabilities while the UNCRPD (2006) promotes availability and accessibility of quality and affordable health and rehabilitation facilities including distribution of assistive device services at the primary, secondary and tertiary levels for persons with disabilities it was observed in the current study that lack of mobility appliances was among the causes of mobility loss. The current findings reveal that the proposition of the ICF (WHO, 2001) and UNCRPD (2006) were not fully experienced by the study participants in both the institution setting and home environment. In the very same regard it can be understood that lack of health facilities and drugs in the community constitutes a barrier

to access to health services according to the IFC concept (WHO, 2001). According to the CBR guidelines (WHO, 2010) the challenges experienced described above have been classified into health, livelihood and social domains of the matrix.

4.5 Spouses experience of caring for disability due to stroke

Spouses experiences of caring for a disability due to stroke was over shadowed by challenges of care giving, sexuality and companion issues and lack of social support.

4.5.1 Challenges of care giving

In this study, the majority of spouses expressed their devastation by the demands of care giving especially those whose patients were dependent in self-care and had faecal and urine incontinence. Spouses indicated that they suffered physical and emotional demands which reduced satisfaction with life and predisposed them to depression. The special findings particular to this study indicate that caregiving task affected female spouses more than male spouses as male spouses usually had a female relation, usually a sister or daughter, helping with the tasks but most female spouses were usually left to themselves. However, both male and female spouses indicated that the illness of their partner interfered with their daily routines be it office work, business, farming, sleep and leisure time activities such as attending church and other religious activities. The failure to participate in religious programs or attend church services was mainly because they could not leave the patients unattended. Consequently, permanent change of roles was experienced as quoted:

“Like at the beginning it meant that everything had to be done for him, like feeding him whether he wants to go to the toilet, everything. Escorting him to the hospital, dressing him, everything and you realise you need a number of people to be helping you if there is a chance.”

(Female spouse Ref/41)

"Since he was urinating, and spoiling the place I had to bath him, dress him and take care of the place so that he can sleep on a good place and that people who come should not see anything filthy in the room" (Female spouse Ref/23)

"But to find a chance to leave the patient and go somewhere, it is not possible. Now I have stayed a number of weeks without going to church." (Male spouse Ref/33)

The findings of the current study resonate with those of Coombs (2007) which indicate that spouses of stroke patients faced challenges in managing patients with urine and bowel incontinence which often necessitated bathing several times a day creating inevitable situations where spouses enter bathtubs or shower rooms with patient in order to wash the patient several times a day. The results also concur with the findings of Wu (2009) who found that spouses are expected to transfer their partners from one place to the other, a task that usually involves lifting the patients, a strenuous activity especially when heavy patients are involved. Wu (2009) further highlighted that spouses face challenges with activities such as dressing and grooming, pressure sore prevention, issuing of medication at scheduled times, proper positioning of patients and modification of the home environment with regard to selection of appropriate devices for the patient. Cao et al. (2010) found that spouses change their initial role from spouse to caregiver due to additional responsibilities and duties previously carried out by the spouse.

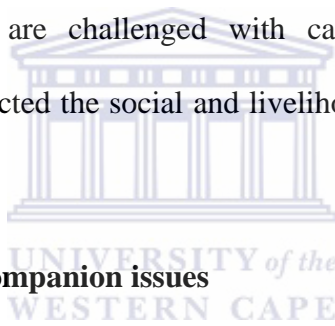
Thompson (2011) described the change of role taking place in spouse as shifting from wife to mother which eventually affects sexual function. McPherson et al. (2010) hinted that spouses and patient who experience reciprocal care have better wellbeing compared to relationships where

care flows from the direction of the spouse only. Forsberg-Wärleby, Moller and Blomstrand (2004) found that there was decline of occupation and leisure activities the first 4 months especially among spouses whose patients had physical and self-care needs. Rudman, Hebert and Denise (2006) found that occupation of both stroke survivors and carers were deeply enmeshed by the illness. Cameron et al. (2011) found that spouses experienced emotional distress due to lack of participation in valued leisure activities. Coombs (2007) highlighted that spouses lost their freedom in leisure due to care giving. Kitzmuller (2012) found that sleepless nights are a common manifestation in stroke patients which, consequently, affect spouses who are engaged in the care giving around the clock.

Based on the literature and the findings above, it is apparent that spouses agonise with caregiving responsibilities that hinder them from engaging in work, leisure activities and disturbs their sleep. Lack of leisure activities such as physical exercises may predispose the spouses to diseases of life style such as diabetes, heart diseases or stroke which may negatively affect the care giving process especially when the caregiving spouse herself becomes a patient. In this regard, the stroke patient may not only lack care but domestic duties will also be affected in the home putting children and other dependant at a disadvantage. The researcher was also considering that spouses who experience sleep disturbance may be denied rest and survive with chronic fatigue which might affect productive daily work and chores, therefore, urgent intervention to normalise patient and spouse sleeping patterns may improve productivity and quality of life.

Under the theme, spouses experience of disability due to stroke, the challenging experiences stroke patients and spouses go through have been revealed. The researcher reasons that these experiences would be worse in communities which offer no social support. Thus such

communities are barriers to reintegration as indicated in the ICF frame work (WHO, 2001). In this case, it can be understood that the caring spouse is the only facilitator of the process of rehabilitation while at the same time the patient becomes a barrier to the wife as the spouse has limitations in attending to other functions such as work due to caregiving process. Article 23 of the UNCRPD (2006) indicates that appropriate assistance shall be provided to persons with disabilities as they perform child rearing responsibilities and that support to children with disabilities should be provided to their families. However, this article is silent regarding support to adults with disabilities and their families. The researcher thinks that the UNCRPD (2006) should have advocated for social support towards people caring for adult disability including spouses of stroke patients that are challenged with caregiving process. The challenges experienced by spouses above affected the social and livelihood domains of the CBR guidelines (WHO, 2010).



4.5.2. Marital relationship and companion issues

Narrative descriptions about the impact of stroke on spousal relationship focused on loss of sexual intimacy and satisfaction, loneliness and lack of companionship. In addition, the patients experienced extended loss of relationship with relatives and friends as expressed in the quote below:

“I cannot sleep with her (have sex) now but when she came from the Rehabilitation centre that time, were able to sleep together when I noted that the sickness was becoming worse I stopped.”

(Male spouse Ref/26).

“Ah I don’t know if it is because of the drugs. Ah sexual desire disappears may be it is the drugs am taking. Yes. Sorry, it is like a stupid issue” (Male patient Ref/24)

“Ah! I want to have sex and she does not I can’t have it, meaning that it is only possible when it is her who wants me otherwise when I want ah, she says no tomorrow, yah that’s all. So what can I do?” (Male patient Ref/29)

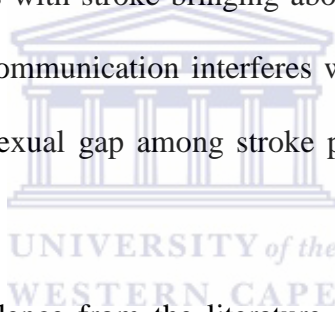
Stroke patients and spouses indicated that their relationship with their spouses was gravely affected by loss of sexual intimacy as they were no longer able to engage in sexual activities with their spouses following the stroke, thus they were deprived of joyful moments they previously shared with their spouses. Similarly Sikiru et al. (2009) found that sexual activities had reduced among couples in which a partner had suffered a stroke. Sikiru et al. (2009) and Jung et al. (2008) further hinted that severity of hemiplegia, psychological, hormonal, hypertension, diabetes and neurological factors are leading causes of declined sexual intercourse among patients and spouses. The current study also revealed limited knowledge on sexuality among stroke patients and spouses which was associated with fear of triggering another stroke. This finding concur with the finding Kim and Kim (2008) Tamam et al. (2008). The findings further support the those of Kim and Kim (2008) who indicated that patients were sexually rejected by spouse (Kim & Kim (2008). In addition, Thompson (2011) found that decline in authority of men in the family, low self-esteem and fear of being refused contributed to sexual dysfunction. The findings of this study support those of Tamam et al. (2008) which indicate that spouses of stroke patients were sexually put off by the in attractive condition of their patient partners.

Spouses also expressed concern over their loss of companionship and indicated that they were deprived of an interacting spouse. Spouses complained about the loss of companionship even if

they were living with the patients side by side. This may indicate that they experienced little or no connection between each other as quoted:

“Its like I stay alone, we used to chat before the stroke but now even though we live in the same house I feel lonely because we don’t interact anymore” (Male spouse Ref/26)

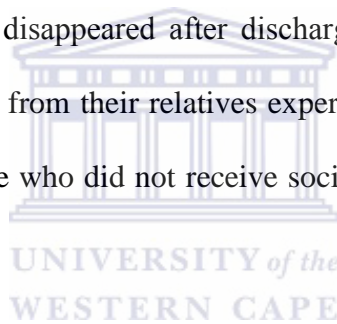
Stroke patients and spouses in this study also indicated that they felt lonely. Similarly, Hilari et al. (2010) found that loneliness is one of the important predictors of psychological distress at baseline, 3 months and 6 months and that it was more serious in people with aphasia. Thompson and Ryan (2009) found that speech and communication impairment is a major cause of misunderstanding between couples with stroke bringing about further tension between them. It was further stated that impaired communication interferes with sexual relationship in a family which further widens the psychosexual gap among stroke patients and spouses (Thompson & Ryan, 2009).



The results of this study and evidence from the literature emphasise that stroke patients and spouses experience sexual challenges related to intimacy and lack of companionship. The results further indicate that spouses may reject their patient partners due to fear of inducing another stroke as it was revealed in this study that the majority were not sure whether it was safe to remain sexually active with their spouse. The results also suggest that fatigue from both caregiving and domestic work in the home interfere with both intimate relationship and companionship as more time is spent attending to matters of the home than patient. There is need, therefore, to educate and counsel couples living with a stroke partner.

4.5.3 Lack of social support from friends and relatives

The majority of patients and spouses in this study expressed concern over their almost diminished social network. These patients reported reduced social support from family members, friends and relatives. The findings of the current study indicated that social support was notable during the acute stage while the patient was still in hospital and it declined with time. This decline in social ties between stroke patients and spouses with relatives and friends led to societal marginalisation following the stroke with aphasic patients being the most affected. However, the minority expressed that they received social support mostly from their children while others felt the support they received was short lived and inadequate as it usually coincided with patient's hospitalisation and disappeared after discharge. Couples who received material and financial and physical support from their relatives experienced good rehabilitation outcome and coped well with life than those who did not receive social support as indicated in the quote below:



“Socially the relationship is more or less like broken because I could hardly go to places we normally meet like in the clubs and so forth where people chat, share ideas and so forth. So, that life has been broken.” (Male stroke patient Ref/42)

“My friends who I was chatting with before I suffered the stroke have left me they don't come to chat with me. The ones who come to chat with me are only from church but others don't come.”
(Female patient Ref/20)

“It is hard but we should just thank God that we gave birth to children so they are our office (support) without that it was difficult. Like me, I have a number of children, they are all working and they understand each other and they do everything for us.”

(Female spouse Ref/23)

The main findings of this study indicate that stroke patients and their spouses were gradually being detached from their friends and relatives after a stroke. These findings concur with the findings of Kruithof, van Mierlo, Visser-Meily, van Heugten and Post (2013) and Aström, Asplund and Aström (1992) who state that stroke patients' social contacts gradually declined over time compared to the general population of the same age. In addition, Das et al. (2010) found that social support is a significant part of the rehabilitation process and a critical component especially in countries where stroke patients access no public support for chronic disability. Lynch et al. (2008) and Roding et al. (2003) also found that social support has positive effects on the reduction of stress and burden of care which improves quality of life among stroke patients and spouses. Visser-Meily et al. (2009) found that women were more stressed and in need of social support than men and that social support had positive outcomes on reducing stress and increasing levels of social participation. Boen, Dalgard and Bjertness (2012) found that lack of social support and physical health problems were associated with increased psychological distress while social support had a direct effect on reduction of psychological distress. Lutz and Young (2010) found that stroke patients with a strong social support system and well-functioning families that assisted with post discharge recovery needs had better recovery outcomes. In Malawi, most people live in extended families where they eat together in groups and share many other things (Vaughan, 1983). Lack of social support might also mean that such family bonds would be broken.

The evidence from the literature Kruithof et al. (2013) and Aström et al. (1992) and findings of the current study suggest that social support is an important component of the rehabilitation

process that must be incorporated to improve long term rehabilitation outcomes. The researcher also reasons that establishing stroke support groups might be an easier way to start addressing social support for both spouses and patients on a smaller scale. However, mobility problems due to lack of wheel chairs, poor roads, terrain and lack of disability friendly transport services need to be considered as they constitute an environmental barrier in Malawi. The findings also indicate that stroke patients and spouses experience attitudinal barriers in the community as friends start to side line them after the stroke. According to article 3 and 30 of the UNCRPD (2006) persons with disability shall enjoy cultural, leisure, recreation and sports activities on an equal base with others. Failure of stroke patients to socialise with friends in clubs is evident of the fact that the propositions of the UNCRPD (2006) regarding social inclusion and participation, acceptance of people with disabilities, accessibility and equality of opportunity have not been met. The challenges of experienced above are classified according to the social and livelihood domains of the CBR guidelines (matrix) (WHO, 2010).

4.7 Experience of participants with rehabilitation

Stroke patients and spouses experience indicated that they had positive impression of rehabilitation services and personnel. However they noted inadequate space, lack of privacy and awareness as hindrances to the process.

4.7.1 Positive impression of the intervention

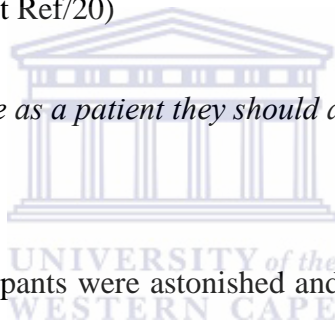
The majority of stroke patients and spouses perceived the rehabilitation intervention as very beneficial and necessary for both their recovery and survival as it improved functional independence. They considered the time they spent at home before rehabilitation as a waste of valuable time. However, the minority noted treatment approach and communication as some of

the areas which needed to improve at the centre. Patients and spouses noted that poor communication between therapists and patients interfered with treatment sessions as some health care providers were not available on time during the treatment sessions. Moreover, when a staff member was absent patients were not informed at all or were informed in time as quoted:

“... As you know, as I said already, I was on a wheelchair but I can now drive that’s the goodness of the rehabilitation.” (Male patient Ref/3)

“When I was put in sitting position I could not move but when I went to rehabilitation centre and started physiotherapy and exercises, I started rising up myself and walking slowly though I do not walk properly.” (Female patient Ref/20)

“They don’t do it properly because as a patient they should always tell me what they are doing.”
(Male patient Ref/04)



These findings indicate that participants were astonished and very impressed with rehabilitation intervention owing to the progress they achieved in terms of functional capacity and independence. The results of the current study concur with Stoller, de Bruin, Knols and Hunt (2012) and Ostwald (2008) who described rehabilitation services such as physiotherapy, occupational therapy and speech therapy as extremely helpful in enhancing functional abilities. These authors further states that these therapies provide a focus and sense of working towards recovery. Ostwald found that active rehabilitation plan improves function and quality of life at the same time reduces depression. However, Duncan et al. (2005) contend that rehabilitation has short term effects if it does not continue after discharge. Kalra et al. (2004) found that stroke patients and spouses who engaged in active rehabilitation have lower depression rates and better

quality of life. Tistad, von Koch, Sjostrand, Tham and Ytterberg (2013) highlighted that continuity of rehabilitation after stroke could be beneficial to patients and that it could bring insight of the limitations that arise post discharge. The results of the current study are in harmony with Ostwald (2008) who indicated that maintenance of treatment sessions to retain already achieved function and general exercises improve function and quality of life. In this study patients who did not keep up with treatment gradually lost the abilities and function as indicated in the quote below:

“The time at the Rehabilitation Centre my life changed...when I was coming home in the village I was really changed I was walking when I came here I don’t know what happened I just realized I couldn’t walk...but I was walking when I was coming from the Rehabilitation Centre with the walking stick” (Female patient Ref/27).

In this study some patients also complained that the therapy did not address their need. Evidence from the literature indicates that rehabilitation therapy should be tailor made, a shift from expert based to patient based with focus on patient’s needs. Medin, Barajas and Ekberg (2006) highlighted that patients described the therapy that’s not adapted to their needs as meaningless. Andreassen and Wyller (2005) also found that patients needed individual tailored information, physical training and psychological support. Visser-Meily et al. (2006) further stated that goal setting and decision making should focus on both patient and spouse. In addition Visser-Meily et al. (2006) states that rehabilitation professionals should recognise the spouse as a person with rights and aspirations and whose wellbeing is of major importance for the health of the stroke patient.

From the evidence provided above, it is apparent that rehabilitation services are beneficial to the patients and spouses in many different ways. However, the findings indicate that after undergoing rehabilitation at a rehabilitation centre (institution) patients functional abilities would deteriorate. The rehabilitation process at the centre focused mainly on patients' impairment and activity limitations which did little to prepare the patient for community reintegration as they were moving into a totally diverse setting. The absence of medical and rehabilitation facilities at the grassroots interfered with continuity of therapy the researcher, therefore, reasons that if CBR rehabilitation programmes were implemented and made available in the community they could have facilitated continuity of therapy and prevention of the complications that arise post discharge from an institution. According to article 3 of the UNCRPD (2006) persons with disabilities shall enjoy full effective participation in the society, equality of opportunity, accessibility without discrimination. Articles 25 and 26 of the same state that persons with disability have the right to access the highest attainable health and rehabilitation services within their communities. From the findings of the study, it is clear that the services were under developed hence not meeting the standards proposed by the UNCRPD (2006). The challenges experienced under this theme are classified into Health and social domains of the CBR guidelines (WHO, 2010).

4.7.2 Inadequate space and poor condition of the available facilities

When patients and spouses were requested to give their opinion of the rehabilitation centre, different views came up. They mentioned inadequate space resulting in delayed admission, poor condition of the wards and treatment rooms, inadequate toilets and bathrooms, lack of privacy as problem areas. The majority of the patients and spouses complained that it was hard to find space at the centre because the wards were usually full thus they had to wait until space was available.

In addition, they indicated that the toilets and shower room were inadequate such that they had to queue in order get into the shower every day as indicated:

“ My daughter came took us to the centre, after they examined him we were told there was no space so they could not hospitalise him but we had e to come another day. It was a Friday, they said maybe on Monday so that they should look for space.”

(Female spouse Ref/23).

“But on top of that the rooms, the treatment rooms...I think the rooms need to be improved because I think now as it is they just put boards...Even the beds if there could be beds like the ones in OPDIt’s nice.” (FGD/1)

“My stay at the rehabilitation Centre was good but the only problem was bathing, bathrooms are not enough. There was one bathroom for patients and one for the guardians so we were waiting on a queue to get into the shower. So we were waking up at 2 o’clock in the morning to be on the line so that if one gets out you should quickly get in so that was the problem, especially during cold season.” (Female patient Ref/20)

The results of the current study indicate that there was limited space to accommodate patients and facilities such as toilets, bathrooms and treatment rooms at the centre were inadequate and in poor condition. The outstanding findings of the study indicate that patients had no steady access to the centre as it was usually full to capacity as such they had to wait at home until space was available resulting in delayed intervention. In addition, the study reveal that patients were waking up at around 2 am and queued for the showers, a development they said was worse during cold season. Evidence from the literature has shown that rehabilitation can improve both

subjective and objective domains of physical function during targeted services in rehabilitation centre programs (Foley, Hillier & Bernald, 2009). However, Moser et al. (2006) found that delayed interventions directly increase morbidity and mortality in stroke patients. Farin, Follert, Gerades, Jackel and Thalus (2004) highlighted that there are high level quality rehabilitation services in Germany. Beckerman, Roelofsen, Knol and Lankhorst (2004) state that there are 26 adult rehabilitation centres against a population of 16 million people in Netherlands and that every university and general hospital offer outpatient rehabilitation services. Malawi has a population of 15.2 million with only one adult rehabilitation centre (Peterson et al., 2013, Mulwafu, 2010). The centre is challenged in developing sensitive, reliable and meaningful measures of medical rehabilitation services that meet the needs of rehabilitation personnel, consumers and promote research (Mulwafu, 2010). The centre is also facing challenges due to increased numbers of rehabilitation patients with complex conditions and less support is available in the field of disability and rehabilitation (Mulwafu, 2010). The findings above indicate that stroke patients have difficulties accessing rehabilitation services because of limited space at the centre. The researcher reasons that lack of space is likely to result in delayed intervention which may worsen disability. There is need to increase patient space and number of toilets and showers at the centre at the same time increase the number of centres offering rehabilitation services in the country. Moreover, incorporation of CBR programs to make the services available at the grass root level would lessen the current pressure facing the centre.

4.7.3 Lack of privacy

Patients and spouses indicted that the rehabilitation process denied them the privacy they needed with their spouse. They highlighted that it was not possible to discuss private matters with their patients while others were hearing them. The patients from the paying wards were also

concerned with sharing a room with another patient as they considered the room too small to accommodate 2 patients. The non-paying patients and spouses also complained of overcrowding which lead to lack of autonomy in executing some activities as quoted:

“There should be privacy. Because there is no privacy when there are two patients in one room. If there could be a single patient per room that could help, because you can’t come and ask your patient other things while someone is there. How do you ask?”

(Male spouse Ref/33).

“The wards are difficult because people stay in tight spaces...that is what made me to see that this part is not good because we are just happy when we are outside but when we enter inside we are not happy.” (Male patient Ref/06)

“The therapists don’t do it properly because they don’t tell me what they are doing. As the problem in the wards, was that when they came back from OT (F:mm) after watching their things, when coming from there, they were making noise patient. They should always tell me what they are doing” (Male patient Ref/04)

“the problem in the wards was that when some people come from the OT (Occupational therapy room) after watching their things (Television) when coming from there during the night they were making noise and disturbing others” (Female spouse Ref/07)

The main findings of the current study indicate that there was lack of privacy at the centre. This lack of privacy was violated through overcrowding which further led to people hearing each other’s conversations. Other areas included excluding patients in planning for their treatment. Privacy is described as showing respect for patient’s wishes, space and belonging (Bargoon,

1990 as cited by Scott et al., 2003). Deshefy-Longhi, Dixon, Olsen and Grey (2004) highlighted that privacy and confidentiality are fundamental human needs and that potential breaches of privacy and confidentiality due to carelessness are pervasive in healthcare. Moreover, overcrowding is considered as violation of privacy and confidentiality. Woogara (2005) hinted that privacy includes patient's right to change bed position, sleeping space, toilet facilities, sleeping patterns, territory and space, individuality and identity of a person. Services falling short of these are a violation of individual control and choice. Scott et al. (2002) indicated that it is impossible to fully respect patient's autonomy without respecting their rights to participate in decision making process regarding treatment and care. Moreover, Delany (2005) describes autonomy as encompassing both rights and capabilities of a patient to make choices that meet their individual needs thus therapeutic understanding of autonomy means adopting attitudes of respect, curiosity and concern for the sake of patient's needs.

The information provided above indicates that congestion is a serious problem facing Kachere Rehabilitation Centre which is already contributing to violation of patient's privacy at the centre. Therefore, the centre's capacity has to increase or more such centres should get established to serve the growing demand for therapy. Furthermore, the implementation of CBR programs would reduce the demand for rehabilitation activities currently facing the centre.

4.7.4 Lack of awareness

The participants in this study indicated that they were not aware of this risk of stroke until it occurred. Moreover, after a stroke they were not aware of the services offered by the rehabilitation centre and highlighted the need for the centre to raise public awareness as indicated:

“ You must put an idea of educating the public and also educating the patients here. Some sort of health education to the patients because since I came I haven’t seen that thing happening. About the dangers of the disease.” (Male patient Ref/42)

“I didn’t know that people are admitted at the rehabilitation centre. We did not know that there are many people who are suffer stroke girls, boys, we thought it is for grown-ups and when you are out there you don’t know how much work is done here, you are doing a great job.” (FGD/2)

“Like on the radio or TV they talk about cancer but I have never heard on the radio talking about stroke. I have never heard, it is required to inform people not us patients but those who are not sick that there is this illness, it can come any time.” (FGD/1)

The majority of the patients and spouses indicated that they were not aware of the existence of the Kachere rehabilitation centre nor the services it offers even though a few admitted visiting friends and relatives before them. Some of the patients complained that there is little that the centre is doing in as far as providing awareness about stroke as an illness and rehabilitation as a treatment. Others cautioned that there was a lot of information about cancer and other conditions, readily available, on media but nothing about stroke. The outstanding finding of this study indicates that there was limited knowledge about stroke among patients and spouses even though most of them had spent some months at the centre. Similarly, Jones et al. (2010) stated that lack of knowledge among those that have already suffered a stroke is worrying though there may be a number of possible reasons such as giving out inappropriate information that is too complicated or too general to the public among others. Evidence has also shown that knowledge about stroke is mainly obtained from friends, relatives and media rather than medical sources with only about 7.5% obtaining information from certified sources. Carroll, Hobart, Fox, Teare and Gibson

(2004) and Jones et al. (2010) highlighted that improving awareness about stroke risks and signs is the key element of the United Kingdom government stroke strategy which is running several campaigns aimed at raising public awareness of stroke. Moon, Lubben, and Villa (1998) stated that awareness is crucial to utilisation of services as one can only use the services known to him. Furthermore, in their study, these authors found low levels of utilisation of community based health and social services which contributed to unmet needs even though the services they needed to meet those needs were available in their very communities suggesting that accessibility is measured in terms of awareness and utilization.

Lemogoum, Degaute and Bovet (2005) found that in Sub Saharan Africa more efforts have been channelled to the fight against Malaria, HIV AIDS and tobacco which has resulted in low awareness and underestimation of the current and future impact of non-communicable diseases. Moreover, the same efforts and partnership could help mobilise adequate financial, political and scientific support to relieve the burden of stroke. The burden of stroke in Sub Saharan Africa is preventable if more awareness and prioritisation is made towards prevention and control to avoid a full-scale epidemic. The findings above seem to suggest that increasing awareness would reduce stroke incidence and the suffering that stroke patients and spouses go through. There is need for rehabilitation workers to concentrate on public awareness campaigns to stop the stroke pandemic.

4.7.5 Patients' perception of staff members

The majority of patients and spouses indicated that they were impressed with the way the rehabilitation workers conducted their work however, they also indicated the need for a full time Medical doctors at the centre. Many patients and spouses indicated that the staff members were

committed to their work, they were recognised as hardworking people, very human and had a good sense of humour. Others mentioned that the staff members had patience because they were working with people with different range of impairments some of whom showed poor response to therapy and thus they indicated that they showed great zeal for professionalism. In the present study patients and spouses alluded that they were not happy when humour took precedence of therapy at the centre.

“the workers were good, even those working in rooms they are good people even the nurses they are all good. Those at the gym they are good especially at the gym...I should say they chose, and they do their work wholeheartedly. They don't just work to receive money but also with a heart to help there.” (Female patient Ref/20)

“I think I learnt quite a lot from these people that these people are dedicated and you are the people that really want the job. Not just for the sake of money.” (Male spouse/33)

“let me just add on the part of treatment general treatment, if there could be someone on duty to look after those who complain about simple medical conditions apart from exercises” (FGD/1)

The results of the study indicate that therapists were perceived as respectful and had good behaviour even though a minority view was that they were rude. Del Baño-Aledo, Medina-Mirapeix, Escolar-Reina, Montilla-Herrador and Collins (2013) hinted that interpersonal manners identified as showing respect, emotional support of therapist and being sensitive to changes increase patient satisfaction and quality of life. In addition, these authors say that as a way of professional development therapist should be taught to embrace respectful and supportive attitudes which are an important aspect of the rehabilitation process and service quality. Tse et al.

(2010) demonstrated that humour has non-pharmacological therapeutic effects of reducing pain and loneliness and enhancing happiness and life satisfaction. Bennett and Lengacher (2006) supported the finding but highlighted the need for further research to establish the connection.

Peris, Taylor and Shields (2012) found that patients interaction with the physiotherapists and fellow patients were the major contributing factors of positive experiences with physiotherapy rehabilitation and recovery. Moreover daily interaction with staff and other patients were considered pleasurable by the participants. Who also indicated that they found the attributes of their daily interactions with the physiotherapists more valuable than the amount and content of physiotherapy they received.

In this study, the patients also indicated that they needed a full time medical doctor to attend to medical emergencies especially at night as there was no full time clinician covering both day or night shifts. However, others preferred to be referred to be attended by their family doctor or hospital.

“Yes it is important to do so because sometimes you get sick at night and the night is long, to wait till morning then go to the hospital, that could be too late but if a doctor is around he will come to see her. She will be given treatment that she will find relief and save life at that time .”

(Female patient Ref/32)

“the drugs that I can receive should be in relation to the heart that I suffered....so I prefer to go to the hospital where I came from to be given the right drug. I look at it that way” (FGD/1)

Stroke rehabilitation is a work of a multi-disciplinary team comprising of skilled physicians, physiotherapists, occupational therapists, speech and language pathologists, kinesio therapists,

psychologists, recreation therapists, nurses, patient and family members (Duncan et al., 2005). National Stroke Association (2006) highlighted that physiatrist, neurologist, dietician, social worker, neuropsychologist, and case manager should also be added to the team. Furthermore, the National Stroke Association (2006) states that an excellent rehabilitation program should meet the requirements of accreditation which include offering wide range of therapies as well as having a full time physiatrist or medical doctor experienced in stroke and rehabilitation medicine. According to Scottish Intercollegiate Guidelines Network (2010) Medical practitioners are part of the core of rehabilitation team together with nurses, physiotherapist, occupational therapist, speech and language pathologist and social work staff. However, other disciplines are also regularly involved in stroke management such as clinical psychologist, dieticians and orthotics among others.

The findings of this study and the literature seem to suggest that interaction with patients and spouses is valuable and an essential part of therapy and that rehabilitation is a team work approach. However, the centre has by far fallen short of the required rehabilitation team. There is, therefore, need to beef up the team in order to meet the required and acceptable standards.

The findings of this study under the theme participants perceptions of the institution providing care indicates that there are inadequate adult rehabilitation facilities providing institution based rehabilitation services in the country. This institution is overcrowded and lacked privacy and most of the patients are not able to access treatment on time due to inadequate space and at the same time no rehabilitation activities exist at the grass root. According to the ICF (WHO, 2001) lack of accessible rehabilitation services constitutes a barrier to potential services which also violates article 25 and 26 of the UNCRPD (2006) which proposes that health and rehabilitation

services should be accessed in the community. Furthermore, article 22 of the UNCRPD (2006) states that persons with disabilities have the right to privacy which shall be observed regardless of place of residents or living conditions. There is also a mention of lack of awareness to the public which again violates article 8 of the same UNCRPD which emphasises on creation of public awareness on major areas including disability related matters. Stroke patients have the right to the rightful information, therefore, lack of awareness is a violation of that principle. However, the findings of this study indicate that this is still far from being a reality in Malawi. The results also indicate that the therapists treated the patients in a respectable manner which was a fulfilment of article 3 of the UNCRPD (2006). Under this theme, participants experienced the health domain of the CBR matrix (WHO, 2010) both in a positive and negative way; positively when it facilitated health and negatively when it interfered with health. Other domains that were affected are the livelihood and empowerment.

4.8 Facilitators of recovery from stroke

In this study, the majority of the patients and spouses indicated that they faced a number of challenges. However, the majority of patients and spouses also indicated that having faith in God helped them to cope with the aftermath of stroke. Other factors included social support and rehabilitation process which have already been discussed earlier in this chapter

4.8.1 The influence of faith in God, social support and rehabilitation process

The results of this study indicate that the majority of the patients and spouses believed in God and even though they were challenged with many things they believed that God was in control. This faith made them accept their condition as the will of God and most recognised their recovery as Gods intervention.

“So when we arrived we saw the greatness of God moving until he started sitting down and eventually walk, so I saw the greatness of God...he was almost finished but the power of God and the doctors that he met that is when he showed that he was feeling better.”

(Female spouse Ref/07)

“I believe God helped us because although the wife was in hospital fainting, having problems breathing, but with the faith I was having that God is there I was not having problems” (Male spouse/33)

“I do not complain much or lose heart because he did not do it deliberately, I just put everything in the hands of the Lord that the day he will want him to be okay we will help each other”

(Female spouse Ref/30)

The main finding of this study reveals that faith in God promotes acceptance of the condition by both patients and spouses and reduces the tendency of blaming the patient. The study further revealed that patients who did not attend church and religious services felt detached from society. Similar to these findings Giaquinto, Spiridigliozzi and Caracciolo (2007) indicate that prayer appears to be the common form of religious practice among individuals with persistent pain; it is a way of connecting with God to obtain strength and acquiring relief of the burden. Similarly, in this study, patients and spouses that were visited and prayed for by their friends and relatives expressed that they felt better and believed that they would be healed after they were prayed for. Jolley et al. (2010) highlighted that patients find particular comfort from religious routines of spiritual practices and carers which provide additional support in coping with the illness. The findings of this study also resonate with the findings of Sherman et al. (2005) which

highlighted that spiritual interventions include prayers, scripture reading and religious rituals and practices which aim at connecting a person to others and to God provide guidance in the search for meaning and purpose through which patients and spouses may transcend their suffering and experience of the illness. However, Sherman et al. (2005) also found that some cancer and HIV patients diverted their anger on God for not curing their illness and felt abandoned by God, thereby, turning their attention to family and friends rather than God. The study results indicate that rehabilitation requires blending of medical, social and spiritual dimensions in a multi-disciplinary team. The results also emphasise the need to break down the social and physical barriers that hinder patients' access of public facilities such as churches.

Article 9 of the UNCRPD (2006) proposes that the environment should be accessible for persons with disabilities on an equal base with others while article 25 and 26 of the same emphasises on full participation of persons with stroke (disabilities) in the community. Furthermore, article 26 indicates that persons with disability should get mobility aid to promote independence. The researcher thinks that if the recommendations of the UNCRPD (2006) were strictly followed, many people would be able to attend religious activities which have a positive influence on stroke rehabilitation. In this study, the failure of patients to attend church and religious gatherings indicate that the environment is not accessible and that mobility aids are not made available to the needy as advocated by the UNCRPD (2006). Under this theme, rehabilitation was facilitated by the social domain of the CBR guidelines (WHO, 2010).

CHAPTER FIVE

5.0 CONCLUSION

5.1 Introduction

This chapter presents the summary, significance, limitations, recommendations, and conclusion, of the study.

5.2 Summary

The challenges and experiences of stroke patients and their spouses in Blantyre, Malawi, have not been scientifically investigated and documented. The aim of the current study was, therefore, to explore such challenges and experiences so as to find ways of overcoming them in order to improve service delivery. This study was conducted at Kachere Rehabilitation Centre in Blantyre and the surrounding districts and has yielded results that will benefit the centre and the field of rehabilitation in Malawi.

The study was conducted to answer the question “What are the challenges experienced and experiences of stroke patients and spouses in Blantyre, Malawi?”

The research participants indicated the challenges they experienced regarding their illness and what they thought would be solutions to such problems. The results show similarities between the challenges that stroke patients and spouses experience in Blantyre, Malawi and other countries and that the challenges affect both the patients and spouse in numerous ways. This particular study has further shown that overcrowding conditions exist at the centre. In addition,

the findings indicate that female spouses of stroke patients are more burdened with care giving than male spouses. The results also indicate that patients and spouses could sell their food in order to buy medication due to poverty. Limited knowledge on sexuality and strained relationship which contribute to unsatisfactory sexual intimacy have been revealed in the current study as the major cause of reduced sexual intercourse post stroke. The study further found that lack of CBR rehabilitation programs at the grass root was directly linked to activity limitations and participation restrictions.

This, therefore, makes qualitative exploratory design the right method for study. The findings also prove that the ICF and UNCRPD can be used to explore experiences of stroke patients while the CBR guidelines was useful in analysing and classifying the challenges.

5.3 Significance of the study

The Rehabilitation Centre in Malawi is a home for many patients and spouses who come from distant areas to undergo rehabilitation process (Chimatiro, 2012). Throughout the years the focus has been to mobilise and improve activity levels of the patients but no attention has been on the challenges that stroke patients and spouses experience (Chimatiro, 2012). The current study revealed the challenges and experiences of stroke patients and spouses in Blantyre, Malawi. This study explored the lived experiences of both patients and spouses who are an important part of the rehabilitation process. The use of in-depth and focus group discussions made sure that both individual and group experiences or perceptions of the phenomenon were investigated.

The study has provided documentation of lived experiences (challenges) of both patients and spouses during the rehabilitation process and suggested solutions to some of the challenges. The study has highlighted necessary strategies to address the specific challenges faced by patients

with stroke and their spouses during admission, hospital stay, and after discharge. These interventions include removing environmental barriers to improving accessibility to services and facilities, extensive health and rehabilitation services which are still not available at the grass root, social support and participation in religious activities among others. The study has useful information that will also assist medical rehabilitation workers to consider social interventions as part of stroke rehabilitation. The study will also facilitate the development of stroke support groups. Through conference presentations of the findings, the study will bring insight, which policy makers can utilise to improve rehabilitation services. The study has also emphasised the need to increase facilities and incorporate full multi-disciplinary team management in stroke rehabilitation.

5.4 Limitation of the study

Many participants did not take part in the focus group discussions even though most of them had accepted to attend the focus group discussions. This was the case after they had been reminded twice before the actual date and assured of reimbursement of their transport and other associated costs. Most of the younger and middle aged patients or spouses refused to participate in the study thus most participants of the present study were older citizens. Therefore, the data collected does not reflect the experiences of younger patients and spouses.

Another limitation is that we did not investigate the perspectives of the service providers even though patients and spouses indicated that the centre needed more funding to support its operations.

The study utilised a purposive sampling method with a sample size of 18 participants. The results, therefore, cannot be generalised to reflect the experiences of all stroke patients and

spouses but can be applied to similar settings and under similar circumstances. Despite the above limitations, the current study has revealed a number of both service and structural challenges that the centre and other service providers can learn from to improve or advance quality of service provision during stroke rehabilitation process.

5.5 Recommendations

Based on the findings stated above the following recommendations are made:

5.5.1 Awareness of stroke

There is also need to create awareness on the services that are offered by the centre through the media so that many people can benefit. Furthermore, awareness needs to focus on Prevention of stroke and patient centred therapy where the patient takes part in the decision making process of their treatment. The study has shown that there is need for mass awareness on the impact of cardiovascular diseases and stroke in particular which is currently rising in the country. As indicated by the participants, most of them never considered themselves at risk thus there are many more who need to be informed so that they adopt health lifestyles that reduce the risk of stroke. Awareness is also required in the area of sexuality post stroke.

5.5.2 Reduction of overcrowding at the Centre

The current study recommends expansion of the centre to increase its capacity so that patients can access quality services. In addition the study recommends increasing number of toilets and showers and improvement of treatment rooms. The Rehabilitation Centre currently admits patients above the normal ward capacity which creates pressure on the already inadequate facilities therefore establishment of similar centres in other regions of the country would help to ease the pressure currently facing the centre.

5.5.3 Establish social support groups

The current study supports the establishment of social support in form of stroke support groups through which stroke patients and spouses can support each other. Through stroke support groups patient follow up programs and home visits which were mentioned by discharged patients can also be achieved. There are currently no home visits or follow up programs run by the centre which could have prevented deterioration of stroke patients after discharge through early intervention of post discharge syndromes.

5.5.4 Strengthening CBR program in Malawi

From the results of the study, it has been revealed that patients who undergo therapy at an institution may gain independence only to lose it when they get back home. Lack of continuity of therapy and inaccessible environment characterised by uneven terrain have been criticised for perpetuating decline in function. Therefore, strengthening a CBR programme to works concurrently with the institution would help to maintain functional abilities gained by patients at the centre and also provide services at the grass roots level.

5.5.5 Further research

The current study also recommends more research in the field of rehabilitation as very little research has been done and little is actually known and documented regarding national rehabilitation needs in Malawi. The current study explored the experience of patients and spouses on a smaller scale. However, there is need to investigate on a larger scale, using quantitative method, the extent to which the challenges are experienced and also investigate the challenges from the perspective of the service providers. Research will, therefore, provide the evidence which will aid to develop strategies of intervention as well as establish evidence based

practice rehabilitation for Malawi considering the availability, affordability, resources and services.

5.6 Conclusion

According to the findings of the study, stroke patients and spouses experienced various challenges which interfered with their physical, social, financial and health. Physical challenges hinder patients from performing basic activities of daily living such as walking, dressing and toileting while spouses' daily routines were affected by caring for their partner. Other inconveniences associated with functional limitations included failure to attend church and social events. Financial constraints negatively affect their basic household needs and accessibility to medication, which challenges the survival of the patients.

It is observable in the present study that the caregiving burden is borne more by female spouses than male spouses as male spouses are usually assisted by a female close relative. Stroke also has negative effects on patients and spouses social network as they gradually lose friends following the stroke and that rehabilitation is perceived as beneficial for recovery. Thus, patients and spouses had positive impression of the staff members. However, lack of awareness of rehabilitation services and limited space at the centre, and lack of rehabilitation services at the grass roots have interfered with accessibility of rehabilitation services.

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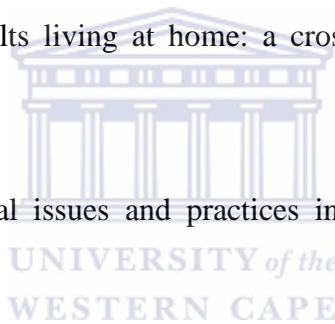
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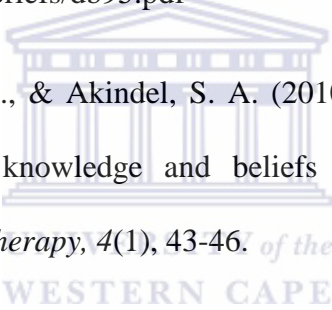
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APPENDICES

Appendix A: Ethical Approval from UWC



**OFFICE OF THE DEAN
DEPARTMENT OF RESEARCH DEVELOPMENT**

UNIVERSITY of the
WESTERN CAPE

11 March 2013

To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape has approved the methodology and ethics of the following research project by:
Mr R Kalavina (Physiotherapy)

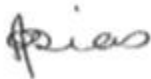
Research Project: Exploring the challenges experienced by patients with stroke and their spouses during the rehabilitation process at Kachere Rehabilitation Centre in Blantyre Malawi.

Registration no: 13/2/29

UNIVERSITY of the
WESTERN CAPE

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*

Private Bag X17, Bellville 7535, South Africa
T: +27 21 959 2988/2948 . F: +27 21 959 2170
E: pjosias@uwc.ac.za
www.uwc.ac.za

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

Appendix B: Ethical approval from COMREC



Appendix C: Approval from MAP



MAP

MALAWI AGAINST PHYSICAL DISABILITIES

To: Reuben Kalavina
MAP
P.O. Box 256
Blantyre

Dear Mr. Kalavina,

Following your request to conduct a research project entitled 'Exploring the challenges experienced by patients with stroke and their spouses during rehabilitation process at Kachere Rehabilitation Centre in Blantyre, Malawi.' As an organization we are glad to inform you that you have been accepted to conduct the stated medical research at our centre.

Any other information do not hesitate to contact the undersigned.

Yours sincerely,

S. A. Ndembe DBS (MW) DMA (UK) DMRS (Zw) MBA
GENERAL MANAGER.

SAN/lcn

IN WAGING WAR ON DISABILITIES IN MALAWI,
WE NEED YOUR SUPPORT

P.O. Box 256, Blantyre, MALAWI - Phone 01 877 951, 874 634, 0888 895 993, 0999 560 376 Fax 01 874 604
Email: headoffice@mapmw.org

All communications to the General Manager

Appendix D: Consent form



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

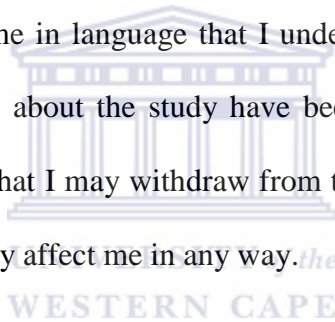
Tel: +27 21-959, Fax: 27 21-959

E-mail: kalavinar@yahoo.com

CONSENT FORM

Title of Research Project:

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



Participant's name.....

Participant's signature.....

Witness.....

Date.....

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

Study Coordinator's Name: MR R. KALAVINA

University of the Western Cape

Private Bag X17, Belville 7535

Telephone: (021)959-

Cell: 0787246770 Fax: (021)959- Email: nmlenzana@uwc.ac.za



Appendix E: Chikalata cha chilolezo



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959, Fax: 27 21-959

E-mail: kalavinar@yahoo.com

FOLOMU YA CHILOLEZO

MUTU WA KAFUKUFUKU:

Ndondomeko ya kafukufuku ndauzidwa mchilankhulo chomveka bwino ndipo ndamvetsa, mwakufuna kwanga ndavomera kuchita nawo. Mafunso anga onse pa nkhani imeneyi ayankhidwa. Ndikudziwanso kuti nkhani ya zokhudza ine zidasungidwa mwa chinsinsi ndipo nditha kusankha kusiya kuchita nawo kafukufuku ameneyu popanda kupereka chifukwa chilichonse komanso ndikatelo sindilandila mkwiyo uliwonse.

Dzina la ochitidwa kafukufuku.....

Chidindo cha wochitidwa kafukufuku.....

Tsiku.....

Ngati muli ndi mafunso pa nkhani ya kafukufuku ameneyu kapena mufuna kunena za mavuto omwe mwakumana nawo pa kafukufuku ameneyu (musachedwe) lankhulani ndi woyendetsa kafukufukuyu:

Dzina la woyendetsa kafukufuku: MR R. KALAVINA

University of the Western Cape

Private Bag X17, Belville 7535, Telephone: (021)959 Cell: +265888148477/ 0787246770



Appendix F: Information sheet for stroke patients



UNIVERSITY OF THE WESTERN CAPE

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Tel: +27 21-959, Fax: 27 21-95

E-mail: kalavinar@yahoo.com

INFORMATION SHEET

For stroke patients

Project Title: Exploring the challenges experienced by patients with stroke and their spouses during the rehabilitation process at Kachere Rehabilitation Centre in Blantyre Malawi.

What is this study about?

This is a research project being conducted by REUBEN KALAVINA at the University of the Western Cape. We are inviting you to participate in this research project because you suffered from stroke and you possess lived experiences of stroke which are relevant in this study. The purpose of this research project is to explore the challenges experienced by stroke patients and their spouses during the rehabilitation process, from diagnosis through to treatment and discharge. There is a need to investigate how stroke affects patients and their spouses' quality of life at Kachere Rehabilitation Centre in Blantyre, Malawi in order to improve service delivery.

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

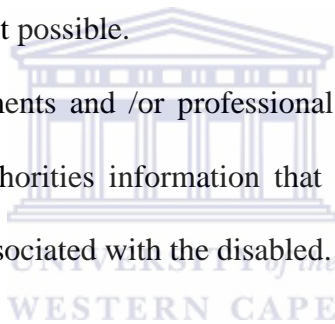
You will be asked to tell your own story regarding challenges and experience in the way you see it, feel it and know it. This study will be conducted at Kachere Rehabilitation and Training

Centre in Blantyre or at a patient and client`s private home. The project information will be obtained through interviews which will take about one hour and will be tape recorded

Would my participation in this study be kept confidential?

We will do our best to keep your personal information confidential. To help protect your confidentiality names will not be used in this project hence numbers will be used instead to conceal your identity. The information will further be kept in a lockable cupboard of which only the researcher can access while the laptop will have a password that is only known by the researcher and should we write a report or article about this research project, your identity will be protected to the maximum extent possible.

In accordance with legal requirements and /or professional standards, we will disclose to the appropriate individuals and/or authorities information that comes to our attention concerning abuse, neglect or potential harm associated with the disabled.



What are the risks of this research?

There are no risks of participating in this study however an emotional reaction due to memories of difficult times and experiences might be expected and the researcher will refer such for appropriate management.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about the experiences of stroke patients and spouses relative to rehabilitation process

at Kachere Rehabilitation Centre. We hope that, in the future, other people might benefit from this study through improved understanding of the management of patients and spouses.

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

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

What if I have questions?

This research is being conducted by REUBEN KALAVINA at the University of the Western Cape. If you have any questions about the research study itself, please contact REUBEN KALAVINA at: 0888143477 or 0787246770 or kalavinar@yahoo.com

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

Head of Department: Professor A. Rhoda email arhoda@uwc.ac.za

Dean of the Faculty of Community and Health Sciences: Professor Franz

University of the Western Cape

Private Bag X17

Bellville 7535

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

Appendix G: Ndongomeko ya kafukufuku kwa odwala matenda opha ziwalo mbali imodzi.



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Tel: +27 21-959, Fax: 27 21-959

E-mail: kalavinar@yahoo.com

NDONDOMEKO YA KAFUKUFUKU

Kwa odwala matenda owumutsa ziwalo mbali imodzi (sitiloko)

Mutu wa Kafukufuku: Kufufuza zobetchera zomwe odwala ,matenda owumutsa chiwalo mbali imodzi a sitiroko, ndi amuna (akazi)awo amakumana nazo pamene akulandira chithandizo pa chipatala cha Kachere Rehabilitation Centre ku Blantyre dziko la Malawi.

Kodi kafukufukuyu ndi wokhudza chani?

Kafukufukuyu akupangidwa ndi REUBEN KALAVINA wa kusukulu ya ukachenjede ya Western Cape. Inu mukufunsidwa kupanga nawo kafukufukuyu chifukwa munadwalapo sitiroko ndipo munakumana ndi zambiri zimene zikukhuze kwambiri kafukufukuyu. Cholinga cha kafukufukuyu ndi kufufuza zobetchera zomwe odwala sitiroko ndi amuna (akazi) awo amakumana nazo kuyambira pomwe apezaka ndi matendawa kufikira pamene akulandira thandizo mpaka kutulutsidwa muchipatala. Pakufunika kuyang'ana mmene amakhudzidwira odwala sitiroko komanso amuna (akazi) awo mmoyo wawo wa tsiku ndi tsiku pa Kachere

Rehabilitation Centre ku Blantyre mudziko la Malawi ndi cholinga chopititsa patsigolo kagwiridwe kantchito pachipatalachi.

Zimene nditafunsidwe kuchita ndi chani ngati ndivomera kuchita nawo?

Mufunsidwa kunena zobetchera zimene munakumana nazo munjira yomwe inu mukuonera, kumvera komanso kudziwira. Kafukufukuyu achitikira pa Kachere Rehabilitation and Training Centre ku Blantyre kapena kunyumba kwa odwala. Zokhuza kafukufukuyu zipezeka pomafunsa mafunso omwe adzitenga ola limodzi ndipo adzijambulidwa pa kaseti.

Kodi ndikatenga mbali mukafukufukuyu zidzakhala zachinsinsi?

Tichita zotheka kuti tisunge mbiri yanu mwachinsinsi. Pofuna kuthandiza kuti zikhale za chinsinsi mayina sagwiritsidwa ntchito mukafukufukuyu koma tidzigwiritsa ntchito ma nambala ndi cholinga chobisa inuyo. Zonse zimene tipeze zidzasungidwa mmoyikira motseka ndi makiyi amene yekhaya opangitsa kafukufukuyu adzidzakhala nawo ndipo laputopu (laptop) ikhala ndi chinsinsi chomwe chidzidziwika ndi opangitsa kafukufuku yenkha ndipo ngati tidzalemba nkhani yokhudza kafukufukuyu, mbiri yanu idzatetezedwa kotheratu.

Kodi pali zoopysa zANJI pa kafukufukuyu?

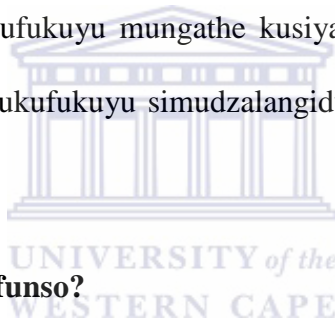
Palibe zoopysa zilizonse koma kungoti odwala amatha kukhuzidwa pokumbukira nthawi yovuta ndi zomwe anakumana nazo ndipo opangitsa kafufukuyu adzachita dongosolo loyang'anira za zimenezi.

Nanga phindu la kafukufukuyu ndi chiyani?

Kafukufukuyu siwokuthandizani inu panokha koma zotsatira zake zingathe kuthandiza opangitsa kafukufukuyu kuphunzira zambiri pa zimene odwala sitiroko ndi amuna (akazi) amakumana nazo malingana ndi chithandizo cha pa Kachere Rehabilitation Centre. Tili ndi chiyembekezo kuti mutsogolomu anthu ena adzapindula chifukwa cha kafukufukuyu kupyolera mukumvetsetsa kwambiri pa momwe angamachitire ndi odwala komanso amuna (akazi) awo

Kodi ndikuyeneraka kukhali ndikuchita kafukufukuyu kapena ndingathe kusiya nthawi iliyonse?

Kutenga mbali kwanu mukafukufukuyu sikokakamizidwa. Mungathe kusankha osatengapo mbali. Mukasankha kuchita kafukufukuyu mungathe kusiya nthawi ina iliyonse. Mukasankha kusachita nawo kapena kusiya kafukufukuyu simudzalangidwa kapena kutaya mwayi uliwonse omwe inu mumakhala nawo.



Nanga ngati ndingakhale ndi mafunso?

Kafukufukuyu akupangidwa ndi REUBEN KALAVINA pa sukulu ya ukachenjede ya Western Cape. Ngati muli ndi funso lililonse lokhudzana ndi kafukufukuyu chonde funsani REUBEN KALAVINA pa nambala izi: 0888143477 kapena 0787246770 kapena kalavinar@yahoo.com.

Koma ngati mutakhala ndi mafunso okhudzana ndi kafukufukuyu ndi ufulu wa munthu otenga nawo mbali pakafukufukuyu kapena ngati mukufuna kunena mavuto amene mwakumana nawo okhudza kafukufukuyu chonde adziwitseni otsatirawa:

Head of Department: Professor A. Rhoda email arhoda@uwc.ac.za

Dean of the Faculty of Community and Health Sciences: Professor Franz

University of the Western Cape

Private Bag X17, Bellville 7535

Kafukufukuyu wavomelezedwa ndi uphungu wa University of the Western Cape Senate

Research Committee and Ethics Committee.



Appendix H: Information sheet for spouses of stroke patients



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959, Fax: 27 21-959

E-mail: kalavinar@yahoo.com

INFORMATION SHEET

For spouses of stroke patients

Project Title: Exploring the challenges experienced by patients with stroke and their spouses during the rehabilitation process at Kachere Rehabilitation Centre in Blantyre Malawi.

What is this study about?

This is a research project being conducted by REUBEN KALAVINA at the University of the Western Cape. We are inviting you to participate in this research project because your spouse suffered from stroke and you possess lived experiences of stroke which are relevant in this study.

The purpose of this research project is to explore the challenges experienced by stroke patients and their spouses during the rehabilitation process, from diagnosis through to treatment and discharge. There is a need to investigate the effects of stroke on patients and their spouses' quality of life at Kachere Rehabilitation Centre in Blantyre Malawi in order to improve service delivery.

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

You will be asked to tell your own story regarding challenges and experience in the way you see it, feel it and know it. This study will be conducted at Kachere Rehabilitation and Training Centre in Blantyre or at a patient and client's private home. The project information will be obtained through interviews which will take about one hour and will be tape recorded

Would my participation in this study be kept confidential?

We will do our best to keep your personal information confidential. To help protect your confidentiality names will not be used in this project hence numbers will be used instead to conceal your identity. The information will further be kept in a lockable cupboard of which only the researcher can access while the laptop will have a password that is only known by the researcher and should we write a report or article about this research project, your identity will be protected to the maximum extent possible.

What are the risks of this research?

There are no risks of participating in this study however an emotional reaction due to memories of difficult times and experiences might be expected and the researcher will refer such for appropriate management.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about the experiences of stroke patients and spouses relative to rehabilitation process at Kachere Rehabilitation Centre. We hope that, in the future, other people might benefit from this study through improved understanding of the management of patients and spouses.

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

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you

decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

This research is being conducted by REUBEN KALAVINA at the University of the Western Cape. If you have any questions about the research study itself, please contact REUBEN KALAVINA at: 0888143477 or 0787246770 or kalavinar@yahoo.com.

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

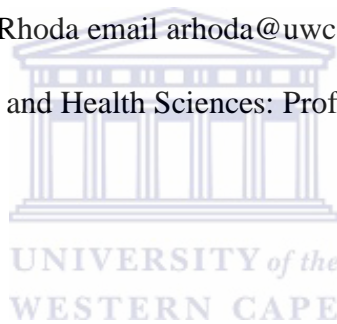
Head of Department: Professor A. Rhoda email arhoda@uwc.ac.za

Dean of the Faculty of Community and Health Sciences: Professor Franz

University of the Western Cape

Private Bag X17

Bellville 7535



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

Appendix I: Ndongomeko ya kafukufuku kwa osamalira odwala



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959, Fax: 27 21-959

E-mail: kalavinar@yahoo.com

NDONDOMEKO YA KAFUKUFUKU

Kwa mkazi kapena mamuna yemwe wokonedwa kapena wa banja wake wagwidwa ndi matenda owumitsa ziwalo (sitiloko)

Mutu wa Kafukufuku: Kufufuza zobetchera zomwe odwala ,matenda owumitsa chiwalo mbali imodzi a sitiroko, ndi amuna (akazi)awo amakumana nazo pamene akulandira chithandizo pa chipatala cha Kachere Rehabilitation Centre ku Blantyre dziko la Malawi.

Kodi kafukufukuyu ndi wokhudza chani?

Kafukufukuyu akupangidwa ndi REUBEN KALAVINA wa kusukulu ya ukachenjede ya Western Cape. Inu mukufunsidwa kupanga nawo kafukufukuyu chifukwa mwakhala mukusamala kapena kuyang`anila abanja anu pamene anadwala matenda asitiroko ndipo mwakumana kapena munakumana ndi zambiri zimene zikukhuze kwambiri kafukufukuyu. Cholinga cha kafukufukuyu ndi kufufuza zobetchera zomwe odwala sitiroko ndi amuna (akazi) awo amakumana nazo kuyambira pomwe apezaka ndi matendawa kufikira pamene akulandira

thandizo mpaka kutulutsidwa muchipatala. Pakufunika kuyang'ana mmene amakhudzidwira odwala sitiroko komanso amuna (akazi) awo mmoyo wawo wa tsiku ndi tsiku pa Kachere Rehabilitation Centre ku Blantyre mudziko la Malawi ndi cholinga chopititsa patsigolo kagwiridwe kantchito pachipatalachi.

Zimene nditafunsidwe kuchita ndi chani ngati ndivomera kuchita nawo?

Mufunsidwa kunena zobetchera zimene munakumana nazo munjira yomwe inu mukuonera, kumvera komanso kudziwira. Kafukufukuyu achitikira pa Kachere Rehabilitation and Training Centre ku Blantyre kapena kunyumba kwa odwala. Zokhuza kafukufukuyu zipezeka pomafunsa mafunso omwe adzitenga ola limodzi ndipo adzijambulidwa pa kaseti.

Kodi ndikatenga mbali mukafukufukuyu zidzakhala zachinsinsi?

Tichita zotheke kuti tisunge mbiri yanu mwachinsinsi. Pofuna kuthandiza kuti zikhale za chinsinsi mayina sagwiritsidwa ntchito mukafukufukuyu koma tidzigwiritsa nthito ma nambala ndi cholinga chobisa inuyo. Zonse zimene tipeze zidzasungidwa mmoyikira motseka ndi makiyi amene yekhayo opangatsa kafukufukuyu adzidzakhala nawo ndipo laputopu (laptop) ikhala ndi chinsinsi chomwe chidzidziwika ndi opangitsa kafukufuku yenkha ndipo ngati tidzalemba nkhani yokhudza kafukufukuyu, mbiri yanu idzatetezedwa kotheratu.

Kodi pali zoopysa zANJI pa kafukufukuyu?

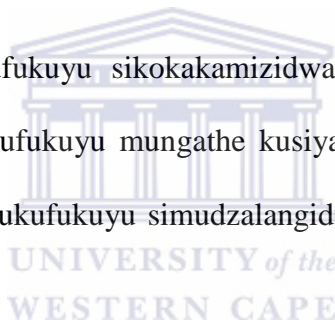
Palibe zoopysa zilizonse koma kungoti odwala amatha kukhuzidwa pokumbukira nthawi yovuta ndi zomwe anakumana nazo ndipo opangitsa kafufukuyu adzachita dongosolo loyang'anira za zimenezi.

Nanga phindu la kafukufukuyu ndi chiyani?

Kafukufukuyu siwokuthandizani inu panokha koma zotsatira zake zingathe kuthandiza opangitsa kafukufukuyu kuphunzira zambiri pa zimene odwala sitiroko ndi amuna (akazi) amakumana nazo malingana ndi chithandizo cha pa Kachere Rehabilitation Centre. Tili ndi chiyembekezo kuti mutsogolomu anthu ena adzapindula chifukwa cha kafukufukuyu kupyolera mukumvetsetsa kwambiri pa momwe angamachitire ndi odwala komanso amuna (akazi) awo

Kodi ndikuyeneraka kukhali ndikuchita kafukufukuyu kapena ndingathe kusiya nthawi iliyonse?

Kutenga mbali kwanu mukafukufukuyu sikokakamizidwa. Mungathe kusankha osatengapo mbali. Mukasankha kuchita kafukufukuyu mungathe kusiya nthawi ina iliyonse. Mukasankha kusachita nawo kapena kusiya kafukufukuyu simudzalangidwa kapena kutaya mwayi uliwonse omwe inu mumakhala nawo.



Nanga ngati ndingakhale ndi mafunso?

Kafukufukuyu akupangidwa ndi REUBEN KALAVINA pa sukulu ya ukachenjede ya Western Cape. Ngati muli ndi funso lililonse lokhudzana ndi kafukufukuyu chonde funsani REUBEN KALAVINA pa nambala izi: 0888143477 kapena 0787246770 kapena kalavinar@yahoo.com.

Koma ngati mutakhala ndi mafunso okhudzana ndi kafukufukuyu ndi ufulu wa munthu otenga nawo mbali pakafukufukuyu kapena ngati mukufuna kunena mavuto amene mwakumana nawo okhudza kafukufukuyu chonde adziwitseni otsatirawa:

Head of Department: Professor A. Rhoda email arhoda@uwc.ac.za

Dean of the Faculty of Community and Health Sciences: Professor Franz

University of the Western Cape

Private Bag X17, Bellville 7535

Kafukufukuyu wavomelezedwa ndi uphungu wa University of the Western Cape Senate
Research Committee and Ethics Committee.



Appendix J: In-depth interview guide for patients

1. What are the challenges you have experienced regarding rehabilitation process and social life from the onset of your illness?
2. Tell me of the experiences of your illness
3. Tell me the experiences of your stay at Kachere Rehabilitation Centre
4. What are your perceptions regarding the rehabilitation process?
5. Tell me how stroke has affected your quality of life



Appendix K: Mafunso kwa odwala

1. Kodi ndi zobetchera zANJI zomwe mwakumana nazo panthawi yomwe mumalandira chithandizo komanso mmoyo wanu wa tsiku ndi tsiku kuyambira pamene munayamba kudwala?
2. Tandiuzani zomwe munakumana nazo chifukwa cha matendawa?
3. Tandiuzani zomwe munakumana nazo mmene munali pa Kachere Rehabilitation Centre?
4. Kodi muli ndi chinthunzithunzi chotani cha chithandizo chomwe chimaperekedwa?
5. Tandiuzani mmene matenda a sitiroko akhudzira moyo wanu ?



Appendix L: In-depth interview guide for spouses

1. What are the challenges that you have experienced regarding rehabilitation process and social life from the onset of your partner`s illness?
2. What does it mean to care for a spouse who has had a stroke?
3. Tell me your perception of the rehabilitation process
4. What is your experience of caring for a stroke patient?
5. How has your partner`s illness (stroke) affected your quality of life?



Appendix M: Mafunso kwa osamala odwala

1. Kodi ndi zobetchera zanzi munakumana nazo panthawi yomwe chithandizo chimaperekedwa nanga moyo wanu wa tsiku ndi tsiku unakhudzidwa bwanji chifukwa cha matenda a amuna anu (akazi anu)
2. Kodi zimatanthawuuza chiyani kusamalira mwamuna (mkazi) wa munthu amene anadwalapo sitiroko
3. Tandiuzani ndi chithunzithunzi chotani chomwe muli nacho pachithandizo choperekedwa pamatendawa?
4. Kodi mwakumana ndi zotani posamalira wodala sitiroko?
5. Kodi kudwala kwa amuna (akazi) anu sitiroko kwakhudza bwanji moyo wanu?



Appendix N: Focus group discussion guide for patients

1. What are the challenges you have experienced regarding rehabilitation process and social life from the onset of your illness
2. Tell me of the experiences of your illness
3. Tell me the experiences of your stay at Kachere Rehabilitation Centre
4. What are your perceptions regarding the rehabilitation process?
5. Tell me how stroke has affected your quality of life
6. How can this situation be remedied?



Appendix O: Mafunso kwa gulu la odwala

1. Kodi ndi zobetchera zANJI zomwe mwakumana nazo panthawi yomwe mumalandira chithandizo komanso mmoyo wanu wa tsiku ndi tsiku kuyambira pamene munayamba kudwala?
2. Tandiuzani zomwe munakumana nazo chifukwa cha matendawa?
3. Tandiuzani zomwe munakumana nazo mmene munali pa Kachere Rehabilitation Centre?
4. Kodi muli ndi chinthunzithunzi chotani cha chithandizo chomwe chimaperekedwa?
5. Tandiuzani mmene matenda a sitiroko akhudzira moyo wanu ?
6. Nanga ndi zinthu ziti zomwe zingathandize kuti moyo ukhale wabwino nthawi imeneyi



Appendix P: Focus group discussion guide for spouses

1. What are the challenges that you have experienced regarding rehabilitation process and social life from the onset of your partner`s illness?
2. What does it mean to care for a spouse who has had a stroke?
3. Tell me your perception of the rehabilitation process
4. What is your experience of caring for a stroke patient?
5. How has your partner`s illness (stroke) affected your quality of life?
6. How can this situation be remedied?



Appendix Q: Mafunso kwa gulu losamala odwala

1. Kodi ndi zobetchera zANJI munakumana nazo panthawi yomwe chithandizo chimaperekedwa nanga moyo wanu wa tsiku ndi tsiku unakhudzidwa bwanji chifukwa cha matenda a amuna anu (akazi anu)
2. Kodi zimatanthawuuzza chiyani kusamalira mwamuna (mkazi) wa munthu amene anadwalapo sitiroko
3. Tanduzani ndi chithunzithunzi chotani chomwe muli nacho pachithandizo choperekedwa pamatendawa?
4. Kodi mwakumana ndi zotani posamalira wodala sitiroko?
5. Kodi kudwala kwa amuna (akazi) anu sitiroko kwakhudza bwanji moyo wanu
6. Nanga ndi zinthu ziti zomwe zingathandize kuti moyo ukhale wabwino nthawi imeneyi?

