

**BARRIERS TO REINTEGRATION EXPERIENCED BY STROKE CLIENTS POST
DISCHARGE FROM A REHABILITATION CENTER IN MALAWI**

STUDENT:

George Lameck Chimatiro

3077278

A full thesis submitted in fulfillment of the requirements for the degree of

Master of Science (Physiotherapy) in the Department of Physiotherapy,

University of the Western Cape

September, 2012

Supervisor: Prof A Rhoda

(University of the Western Cape)

ABSTRACT

Stroke is a worldwide medical emergency, and the trend in its incidence is rising. Stroke leads to activity limitation and participation restriction among stroke clients. However rehabilitation of stroke disability has been found as lacking emphasis on reintegration issues, resulting into stroke clients facing different barriers to reintegration in the community after discharge. There is limited information about experiences of stroke clients in the communities after discharge from rehabilitation centers in Malawi. The current study was conducted to explore the barriers to reintegration experienced by the clients post discharge from a rehabilitation center in Malawi. A qualitative research was adopted to explore the perceived barriers to reintegration at Malawi Against Physical Disabilities (MAP) Kachere rehabilitation centre in Blantyre. In-depth interviews were utilized to capture data from perspectives of eight stroke clients, eight caregivers and seven service providers. The data was analyzed by means of content analysis. The findings of this study show key barriers that challenge community reintegration at two levels: individual and environmental. At individual level the barriers include impairments mainly depression and anxiety and physical weakness; and personal characteristics such as denial, gender and comorbidity. At the environmental level stroke clients experience attitudinal barriers by people in different settings of the community, poor terrain, long distance to places of interest, inaccessible structures and poverty. From the findings, therefore, stroke client experience wide range of barriers in both the activity and participation domains of community reintegration. Based on the key findings, recommendations have been made along three broad lines. To decrease barriers to reintegration, service providers could use the findings to consider equally addressing the potential negative contextual factors to reintegration when managing stroke

clients, a shift from purely medical model approach to management of stroke. To increase rehabilitation services the government of Malawi could address the problem of limited funding to rehabilitation organizations and put measures to increase number of rehabilitation personnel at community, district and national levels. Further research in the area of community reintegration and development of a model of stroke care and rehabilitation in the country has also been recommended with view to improving stroke care and enhanced community reintegration post stroke in the country.



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George Lameck Chimatiro

KEY WORDS

Stroke clients

Barriers

Reintegration

Community

Experiences

Disability

After/post discharge

Rehabilitation

Kachere rehabilitation center

Malawi



LIST OF ABBREVIATIONS

CVA	Cerebral Vascular Accident
ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairment, Disability and Handicap
MAP	Malawi against Physical Disabilities
MGDS	Malawi Growth and Development Strategy
MSDPD	Ministry of Social Development and Persons with Disabilities
SSA	Sub-Saharan Africa
UN	United Nations
UNCRPD	United Nations Convention on the Right of Persons with Disabilities
UNESCAP	United Nations Economic and Social Commission for Asia and the Pacific
WHO	World Health Organization
UWC	University of the Western Cape
COMREC	College of Medicine Research Ethics Committee
AU	Unit of Analysis
MaCoHa	Malawi Council for the Handicapped
NGO	Non-Governmental Organization

ROM Range Of Motion

MONICA **MON**itoring of trends and determinants in **CARD**iovascular disease

SOS Save Our Souls

RNLI Reintegration to Normal Living Index



DECLARATION

I hereby declare that “Barriers to reintegration experienced by stroke clients post discharge from a rehabilitation center in Malawi” is my own work, that it has not been submitted, or part of it, for any degree of examination at any other university, and that all sources I have used or quoted have been indicated and acknowledged by means of complete references.

George Lameck Chimatiro

Signature..... 2012



Witness:

.....

Professor Anthea Rhoda

DEDICATION

I dedicate this work to my wife Meria, whose unwavering support stirred me into the future even if it looked bleak at times. My dedications are also due to our two children, Waasha and Murendelhe for being the source of courage and happiness during my studies.



ACKNOWLEDGEMENTS

My gratitude cannot be fully expressed by the word of my mouth, suffice to say, I convey my heartfelt appreciations to the following:

Prof Anthea Rhoda for being an unfailing source of supported as my supervisor. Thank you for your tireless efforts to see me through in my work. There were moments I would feel overwhelmed by the amount of work, but you helped me unpack the challenge through your comments and guidance. A million thanks indeed.

Physiotherapy department staff members for the support in different forms: Prof. J Phillips, Prof. Frantz, Ms Marla Warner, Mandy, and all others. You really provided very good environment for my studies, and this research in particular. I salute you.

Dr Ina Diener for being an amazing lecturer in Movement Science and OMT that saw me to the Masters level of the program. Thanks indeed.

My fellow classmates for offering a stimulating and challenging environment: Carol Singogo, Haleluya Moshi, Paul Ndahimana, Nesto Tarimo, Piere Barayagwiza, Saimon Azaria, and Samuel Lubega. You were amazing!!

Vincent Jumbe, for being an amazing local supervisor at College of Medicine in Malawi. I salute you!

Mr S. Ndembe, the General Manager at MAP for invaluable support he has rendered towards my professional life for the past years I have worked for the organization. Thanks to you also for allowing me to carry out research at Kachere rehabilitation center.

The staff at Kachere rehabilitation center and for their availability and participation in this study, and staff at the rehabilitation Technicians School for support and peer-reviewing my transcribed data. A million thanks to you friends and colleagues.

Malawian community at the University of the Western Cape, for great interaction during the period. Sad to lose Stonard just at the end of my studies. RIP Stonard, you were a great pal.

People living with stroke and their caregivers for participating in this study.

Precious Nanlaku for being a great research assistant during data collection in Malawi. Ndathokoza ambuye!

My father, Mr. L. Chimatiro and my late mother Mary for an amazing gift of life and care from my childhood. I have no word that can describe how I feel about you. Mama I still have good memories and love for you.

My late granny, Funny Namwawa, I live to prove you right. Thanks for the trust you banked in me. I will always remember you.

My late sister Dyna Makasu Nkhoma. Painful to have lost you so early. You were my mother. A million thanks to you.

Mr FB Namwawa, for being a great uncle and guardian for a big part of my life. Thanks for everything.

My brother, Lameck and sister Dina for all the support you have rendered at different times of my life. I love you and wish you big!

And all people too many to mention here, for support rendered in different ways and forms.

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CHAPTER ONE

INTRODUCTION

1.0 Background

“More than one billion people in the world live with some form of disability, of whom, nearly 200 million experience considerable difficulties in functioning. In the years ahead, disability will be an even greater concern because its prevalence is on the rise” (WHO & World Bank 2011, pg. xi).

Stroke is one of the causes of disabilities known worldwide. It is a medical emergency that can cause permanent neurological complications and death (WHO, 2005). The Global Burden of Disease Report estimates that stroke is the third leading cause of disease burden for high-income countries, and seventh for low to middle-income countries (Lopez & Mathers, 2006). Six years ago, stroke affected an estimated number of 15 million people in the world, five million of those who survived remaining permanently disabled (WHO, 2005). The WHO has further projected that by the year 2020 stroke and coronary artery disease are going to be the leading causes of lost health life years.

Stroke has affected all parts of the world although prevalence, incidence, and mortality rates have been reported as varying not only between nations, but also between communities in a country. For example, India reports crude prevalence of stroke from several community studies as varying from 0.06 in Vellore (Southern India), to 0.15 in Kolkata (Eastern India) (Kaul, 2007).

However, as a nation, India reports 2.03 crude prevalence of stroke, which is higher than 1.85 crude prevalence reported in New Zealand but lower than South Africa's 3.0 (New Zealand ministry of Health, 2008; Das et al., 2007; Thorogood, Connor, Lowando-Hundt, Tollman, & Ngoma, 2004).

Stroke incidence has been seen to decline in affluent areas of the world (Kaul, 2007) but rising in resource-poor areas (Heeley et al, 2011). A review on incidence studies conducted in Australia and New Zealand between 1995 and 2003 reveals that the incidence of stroke ranged from 0.77 per 1000 person-years in the least deprived areas to 1.31 per 1000 person-years in the most deprived areas (Heeley et al, 2011). However in India, a community survey revealed a stroke incidence of 1.45 per 1000 person years (Das et al., 2007) which is higher than the results of the review by Heeley, et al. (2011). There is paucity of community or national surveys on incidence of stroke in South Africa and the sub-Saharan Africa (SSA) (Connor, Walker, Modi, & Warlow, 2007). However, the observation by Kaul (2007) and Heeley et al. (2011), that poorer areas experience increasing stroke incidence may be extrapolated to SSA as it is equally a severe-resource-deprived area.

Study reviews indicate that stroke mortality rate in developed countries is declining (Mirzaei, Truswell, Arnett, Page, Taylor, & Leeder, 2011; Howard, Howard, Katholi, Oli, & Huston, 2001) due to improved health care. However, though not properly documented there is strong evidence that stroke mortality rate in SSA could be higher (Walker et al., 2003; Walker et al., 2000; Rosman, 1986). Information about stroke in Malawi is generally sparse. However stroke condition has been described as a sixth cause of death and a significant cause of disability in the country (Mahawish & Heikinheimo, 2010). In addition, it is estimated that 4.18% of the total population in the country is living with a disability of some kind (Loeb & Eide, 2004).

Persons with stroke experience impairments such as unilateral or bilateral motor or sensory impairment, speech problems, visual impairment, dysphagia, bladder incontinence, spasticity, shoulder pain, falls, depression and anxiety, and cognitive impairments (Tipping 2008; WHO MONICA project; Rathore, Hinn, Cooper, Tyroler, & Rosamond, 2002). Stroke impairments may not only limit an individual's ability to perform certain activities such as Activities of Daily Living (ADLs), they may also deter the ability of the stroke client to participate in day to day life in community settings (Blonder et al., 2007; Cott, Wills & Devitt, 2007).

To address the disabilities experienced by stroke clients, rehabilitation which is based on the notion of interdisciplinary approach is employed (Duncan et al., 2005). Article 26 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) (2006: 16) defines rehabilitation as “appropriate measures including through peer support, to enable persons with disabilities to attain and maintain independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life”. In stroke rehabilitation, Langhorne and Legg, (2003) concurs with the UNCRPD views on rehabilitation by stating that stroke rehabilitation aims to reduce disability and promotes activity and participation of individuals affected by stroke. Rehabilitation can be carried out in two settings which are in-patient hospital based setting, and out-patient community based settings (Rhoda, Mpofo, & Deweerdt, 2009; Haig, 2007; Ottenbacher & Graham, 2007). The in-patient hospital based setting is often where individuals who acquire stroke are initially admitted in the acute phase. In this setting, rehabilitation draws skill from different professionals including medical doctors, nurses, Physiotherapists, occupational therapists, psychologists, and speech therapists in the spirit of interdisciplinary approach (Duncan et al., 2005; Langhorne and Legg, 2003). Findings have it that stroke clients managed in a stroke unit, in the acute stage, have better outcomes

(Stroke Unit Trialists' Collaboration, 2006). However, while this is a benefit, it may not be always possible in developing countries such as Malawi where there are limited numbers of rehabilitation service providers (Kambalmetore, 2008). The tendency of limited staff in Malawi may therefore be a barrier to positive outcomes after stroke.

In ideal situations, stroke clients are transferred from stroke units to other settings for follow up rehabilitation in sub-acute phase such as in rehabilitation centers and nursing home settings (Ottenbacher & Graham, 2007) where therapies continue. However Cott, et al. (2007) generally faults the way rehabilitation is done in the in-patient settings in that it lacks a whole person patient-centered approach with the implication that after discharge the clients experience barriers to reintegration (Pang, Eng, & Miller, 2007). Therefore the need for stroke rehabilitation interventions continues after discharge.

Out-patient community based rehabilitation settings are settings within the communities where rehabilitation interventions are offered to stroke clients after discharge (Haig, 2007), for example, at the community health centers. Although outpatient community based rehabilitation produces good results, the positive outcomes from the services by stroke clients have been reported as being constrained by limitation in facilities available and limited number of rehabilitation professionals required to provide services in Africa (Rhoda et al., 2009; Kambalmetore, 2008). However Langhorne and Pallock (2002) argue that even if the rehabilitation facilities and professionals providing services are enough and there is lack of coordination of service provision, the outcomes may still be poor. In South Africa, Rhoda et al. (2009) found that there are limited therapy services, lack of coordination of services and low frequency of physiotherapy, occupational therapy and speech therapy services to stroke clients at community health centres in the Western Cape Metropolitan region. Assistive technology is

another important aspect of rehabilitation (McCreadie & Tinker, 2005), for example, provision of orthotics and wheelchairs to enhance mobility. However rehabilitation services generally and assistive technology provision in particular is limited particularly in developing countries (WHO & World Bank, 2011). These limitations could also result in stroke clients experiencing challenge reintegrating back into their community after discharge.

Dijkers (1999) defines reintegrating into the community as reestablishing to a degree possible, previously existing roles and relationships, creating alternative ones, and assisting people in reestablishing the pre-stroke roles and relationships. To resume previous roles may be seen as being able to perform tasks and duties that one used to do before stroke such as being able to prepare meals for the family or carrying out shopping, and also being able to remain productive through participation in economic activities that helps them to sustain their role as “bread winners” (Obembe, Johnson, & Fasuy, 2002). However, following stroke, most client experiences difficulties carrying out ADLs (Blonder et al., 2002) such as failure to walk outside and difficulties performing house work and shopping (Mayo, Wood-Dauphinee, Cote, Durcam, & Carlton, 2002). A qualitative study carried out by Kochi et al., (2005) also revealed that most stroke clients experience participation restriction in life situation including inability to return to their former employment on the one hand. On the other hand, reestablishing relationships may mean linking up with people through participation in different settings which stroke client are in most cases are not able to (Blondeera et al., 2002; Mayo et al., 2002). Stroke clients therefore, with all these limitations and restrictions in the domains of reintegration to normal living, are not satisfied with their reintegration into the community after discharge (Obembe et al., 2002).

Barriers to the reintegration of stroke client in the community in this context can be seen as any element that limit the attainment of a desired task, roles, or participation in different activities

including social events and gatherings in the community (Pang et al., 2007). Based on a biopsychosocial model (Stamm & Machold, 2007), the barriers are seen at individual and environmental level.

There are several barriers at the individual and environmental levels that challenge reintegration into the community after discharge. Barriers at individual level are those barriers that are intrinsic to the individual stroke client. Firstly, stroke is a known cause of impairments (MONICA project; Mayo Clinic, 2010; Tipping, 2008; Rathore et al., 2002). These impairments challenge the ability of stroke clients to perform activities for their life and participate in life situations in the community. For example Kochi et al. (2005) found that stroke clients have problems returning to work because of fatigue, depression and cognitive problems related to thought processing. The inability to return to work or other economic activities affects stroke clients' ability to resume their roles in the family and community as their ability to generate income is affected, and socially they may not manage go out for recreation (Mayo et al., 2002).

Demographic features also determine the level of reintegration in the community. Chau, Thompson, Twinn, Chang, & Woo (2009) reports that female stroke participants have lower self-esteem than male participants and therefore less likely to take part in post stroke social and leisure activities. Presence of other conditions in a stroke client may also limit the person's ability to remain active and participative in the community (WHO 2001). Chau et al. (2009), in addition, associates old age with limited outdoor activities.

Environmental Barriers, under this, five environment barriers have been discussed. With regards to Physical/architectural barriers, people with disabilities such as stroke clients experience problems with accessibility to buildings and road/transport structures, thereby, remaining

excluded or making them dependent on others (The Dakar Framework of Action, 2000). Venter et al. (2002) highlights geographical features such as sandy roads in Maputo and steep slopes in Blantyre as limiting the mobility of persons with disabilities, including those in wheelchairs. In addition buildings with steps, inaccessible public transport, and inaccessible education and health facilities have been noted as limiting physically challenged persons' participation mostly in developing countries such as Malawi (Yeo & Moor 2003; Loeb & Eide, 2004). Furthermore, long distance to places of interest limits stroke clients' ability to travel and participate in distant settings (Mony, 2002).

Another barrier is socioeconomic, whereby studies show that poor stroke clients find it increasingly difficult to minimize the impact of impairments due to lack of resources for accessing health care and rehabilitation (May-Teerink, 1999). In addition, at household level, poverty is a likely phenomenon following stroke because of lack the ability to return to work due, in part, to impairments and that some may have lost their jobs due to stroke (Kochi, Egbert, Coeling, & Ayers, 2005).

Stroke clients also experience attitudinal barriers. Venter et al. (2002) found that the attitudes shown in the driving behaviour of drivers of public transport, as well as overcrowding in the streets constitute major barriers to the use of public transport by people with disabilities. Furthermore, in a qualitative study by Garcia, Barrette and Laroche (2000), the participating service providers perceive that some community members who come in contact with the stroke client may have attitudinal problems. This supports the observation that in many societies, attitudes held by people towards a disabled member and their families constitute barriers to participation of persons with disabilities (Yeo & Moor 2003; Lwanga-Ntala, Ndaziboneye & Nalugo 2002).

The clients also experience institutional barriers whereby the demands of work place may affect work reintegration (Kochi et al., 2009; Garcia et al., 2000); or nature of work such as that which may involve common use of electronic devices like telephone may be a challenge for stroke client with speech problems (Garcia et al., 2000).

In addition, literature shows that stroke clients' experience information-access barrier. In this regard information access among stroke clients may be limited either because the patient cannot go out to interact with others or due to impairments limiting their use of information technology (Mirza, Anandan, Madnick, & Hamme, 2006; Garcia, Barrette & Laroche, 2000). Mirza et al., (2006) therefore highlights that failure to use information technology interact with other barriers to exacerbate the clients' oppression and limit reintegration into the community.



1.1 Problem Statement

A vast amount of research on disability and stroke in particular, has been carried out in developed countries. Most African countries, including Malawi are predominantly rural (Loeb & Eide, 2004), where people are mostly small-scale farmers with conditions different from that of urbanized or industrialized countries. Therefore, most of the research findings on stroke (being carried out in developed countries) may not be extrapolated to life of a person living with stroke in Malawi, a developing country, regarding the type and magnitude of challenges they face.

Rehabilitation aims to improving individual's function, for example improving their ability to eat and drink independently; and making changes to the individual's environment like widening doors to bedrooms for a wheelchair user (WHO & World Bank, 2011). However, this researcher observed that the emphasis of rehabilitation intervention at Kachere Rehabilitation center was

mainly at impairment and activity limitation levels of the International Classification of Functioning, Disability and Health (ICF) framework. Contextual issues were not adequately being attended to. In the same line, this study also perceived that limited emphasis by service providers in addressing potential environmental barriers in the community could, in part, be due to lack of knowledge about the barriers experienced by the clients after discharge.

To the knowledge of the researcher, there is currently no information regarding the experiences of stroke clients in communities after discharge in Malawi. The current research was, therefore, conducted to answer the question “what are the perceived barriers to reintegration into the community after discharge from a rehabilitation center?” in the country.

1.2 Research Aim

To explore the perceived barriers to reintegration into the community experienced by stroke clients, after discharge from MAP Kachere rehabilitation center in Malawi.

1.2.1 Sub-Aims

- To explore the stroke clients’ perceptions, regarding experiences with their reintegration into the community after discharge.
- To explore the caregivers’ perceptions about the factors that affects their family member’s reintegration into the community after rehabilitation.
- To explore the rehabilitation personnel’ perceptions on the barriers related to reintegration faced by stroke clients after discharge.

1.3 Definition of terms in the thesis

Stroke Rapidly developing clinical signs of focal (at times global) disturbance of cerebral function, lasting more than 24 hours or leading to death with no apparent cause other than that of vascular origin (WHO, 1989). Herein used regardless of type or side affected.

Rehabilitation A goal-oriented process aimed at enabling a person with impairment to reach an optimum mental, physical and/or social functional level, thus providing him/her with the tools to improve his/her own life (Langhorne & Legg, 2003). Herein, it is used to mean stroke rehabilitation.

Stroke client In this study stroke client refers to a person affected by stroke (WHO, 1989), got admitted and treated (rehabilitated) at MAP Kachere rehabilitation center, and he/she is in the community for not more than one year after discharge.

Caregivers Used in this study to mean any person close to the stroke client and providing direct care to them on day to day basis (Teel et al 2001).

Service providers The researcher uses service providers in this study to mean anyone providing direct professional (health) service to the admitted stroke clients at MAP Kachere rehabilitation center in Malawi (Carr, 2001).

Community reintegration

Reestablishing to a degree possible the previously existing roles and relationships, creating alternative ones, and assisting people in making the

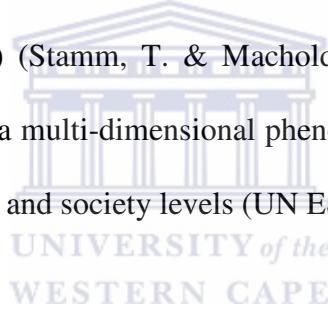
changes (Dijkers, 1999). Researcher opts to define it as getting back to normal life in the community after discharge from a rehabilitation center.

Barriers to community reintegration

A barrier can be anything that challenges attainment of a desired task or goal (Pang et al., 2007). In this study a barrier is any element that challenges the ability of the stroke client to lead a normal life in the community after discharge.

Biopsychosocial model

The basis of the International Classification of Functioning Disability and Health (ICF) (Stamm, T. & Machold, 2007) that view functioning and disability as a multi-dimensional phenomenon which is experienced at the body, person and society levels (UN ESCAP, 2010).



1.4 Chapter outline

This thesis consists of six chapters. Chapter one has provided the general background, statement of the problem, aim and sub-aims of this qualitative study. Chapter two is the synthesis of the literature covering prevalence, incidence and mortality of stroke, conceptualization of stroke disability, stroke rehabilitation, community reintegration domains, and conceptualization of barriers to reintegration experienced by stroke clients. Chapter three describes the methodology that this study used, whereas chapter four shall present the results of the study. Chapter five presents a discussion of the results and limitation of this study. Finally, chapter six shall present the summary of the study, conclusion, and the recommendations based on the results.

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This section presents the synthesis of information and research findings related to stroke and the barriers experienced by community-dwelling stroke clients. The literature review was done based on articles and studies sourced mainly from five search engines which are: CINAHL Plus, Rehabilitation and Sports Medicine, MEDLINE, MasterFILE Premier and Google. In addition the information was searched using key words of: stroke, community, reintegration, barriers.

2.1 Stroke definition and subtypes

The 1989 World Health Organization's widely used definition of stroke is a clinical syndrome which is characterised by rapidly developing clinical symptoms or signs of focal (at times global) loss of cerebral function, with symptoms lasting more than 24 hours or leading to death, with no other cause than that of vascular origin. Stroke is classed into two types which are ischemic and haemorrhagic.

Ischemic stroke is due to occlusion of cerebral blood vessel(s) resulting into deprivation of blood and nutrients to the dependent areas of the brain, leading to cerebral infarction or death of affected brain cells (Haslett, et al., 2000). Haslett, et al., (2002) says cerebral infarction process may take some hours to complete and that after the occlusion of cerebral artery the opening of anastomotic channels from other arterial territories may restore perfusion of the affected region, failure of which may lead to cerebral infarction. This may be an interesting point for

physiotherapists and clinicians assessing stroke patients, that is, duration of symptoms leading up to the focal stroke may probably inform the clinician as to whether it is ischemic (slow onset) or hemorrhagic (rapid onset).

Hemorrhagic stroke on the other hand occur due to rupture of cerebral blood vessels. The rupture leads to explosive entry of blood into the brain parenchyma. This development may cause immediate cessation of function in that particular area as neurons are disrupted in structure by the forming hematoma, and there is splitting of white matter fibre tracts (Haslett, et al., 2000).

There have been consistent findings into the incidence of ischemic and hemorrhagic strokes from both developed and developing countries as ischemic stroke occurrence in human population surpasses the incidence of hemorrhagic stroke. For example, in USA, ischemic strokes account for 80% of all stroke cases, whereas in Hong Kong Chinese only 30% of all stroke cases were hemorrhagic (Lewandowski & Barsan, 2001; Au, et al., 2000). These findings are consistent with a prospective cohort undertaken at Queen Elizabeth Central Hospital in Blantyre-Malawi where 62% of all strokes were ischemic against 21% hemorrhagic strokes (Heikinheimo-Connel, Chimbayo, Kumwenda, et al., 2009). However, though hemorrhagic stroke registers low in incidence, cerebral hemorrhage has been found to be the leading cause of fatal strokes in Sub-Saharan Africa (Walker et al., 2000).

2.2 Epidemiology of stroke

In this section, the prevalence, incidence, and mortality of stroke have been reviewed

2.2.1 Prevalence of stroke

Stroke prevalence is an estimate of how many people in the population have stroke at a given point of period in time (Roger, Go, Lloyd-Jones, et al., 2011). Prevalence of stroke is not only different between nations, but also between communities in a country. For example, India has reported crude prevalence of stroke from community surveys as varying from 0.06 in Vellore, (Southern India), 0.05 in Rohtak (Northern India), 0.14 in Shephard and cultivators in Kashmir (Northern India) and 0.15 in Kolkata (Eastern India) (Kaul, 2007).

At country level the crude prevalence reported in India, a developing country, is 2.03 (Das, et al., 2007) which is higher when compared to crude prevalence from a 2006/07 New Zealand national survey, a developed country, which reported a crude prevalence of 1.85 (New Zealand ministry of Health, 2008) but lower than crude prevalence from a community survey in South Africa which was 3.0 (Thorogood, et al., 2004). Clearly there is no consistence in the findings about the prevalence of stroke. This may be accounted for by various factors. For example, some areas within the country do naturally have a likelihood of higher incidence of stroke, “stroke belts” as defined in America (Howard, 1998) compared to others. It could also be due to methodological difference, for example, the crude prevalence from New Zealand is from a national survey whereas one from South Africa is from a community survey hence the likelihood of irregularities in findings.

2.2.2 Stroke incidence

Incidence is the number of new cases of stroke developing in a population per unit of time (Roger, et al.,2011).In India a community survey in Kolkata revealed 1.45 per 1000 person years (Das et al., 2007). This is higher than the results of the review on incidence studies carried out in Australia and New Zealand during the period 1995 to 2003.The findings of the survey revealed incidence of stroke as ranging from 0.77 per 1000 person years in the least deprived areas, to 1.31 per 1000 person-years in the most deprived areas (Heeley et al, 2011). However, it is noticeable that the Indian incidence is almost similar to 1.31 per 1000 person years in the most deprived areas if Australia and New Zealand. This is logical as stroke incidence has been seen to decline in affluent areas of the world whereas it is on the rise in poor areas (Kaul, 2007). India is one of developing countries in the world.

Community or national surveys on incidence of stroke in South Africa or sub-Saharan Africa are rare. Connor, Walker, Modi, & Warlow (2007) says the absence of incidence studies could be because of difficulties associated with performing them. Conor, et al. (2007) says even hospital-based studies that have been done in some part of SSA may not be representative due to hospital admission bias as some patients remain in homes without reporting to the hospital. However, the observation by Kaul (2007) and Heeley et al. (2011) that poor areas experience rising stroke incidence may be extrapolated to SSA as it is equally a severe-resource-deprived area.

2.2.3 Stroke mortality

Stroke mortality is number of death from stroke in a population (Roger, et al., 2011). Study reviews show that in developed countries, Europe and the US, stroke mortality rate is declining (Mirzaei, Truswell, Arnett, Page, Taylor, & Leeder, 2011; Howard, Howard, Katholi, Oli, &

Huston, 2001). The authors agree that the decline in mortality rate is due to improved health care over time.

In developing countries just like incidence and prevalence, stroke mortality has not been properly documented. This is more so in Sub Saharan Africa. However, there are strong indications that stroke mortality rate may be high. For example, in a hospital based study in Pretoria South Africa on 116 stroke clients one month mortality rate was 33.6% though follow up methods remained unclear and that there was no indication as to whether deaths outside the hospital were recorded (Rosman, 1986). Although the study by Rosman (1986) is somewhat old, similar trend in findings has been reported in newer studies elsewhere. In Tanzania, verbal autopsy data has shown that age adjusted stroke mortality rate of 15 – 64 year age group was higher when compared to age-adjusted rates for England and Wales for 1993 (Walker et al.,2000). In addition, one prospective hospital study in the Gambia, with rigorous community follow up to four years revealed that out of 106 stroke clients, by first and sixth month follow up 29 (27%) and 47 (44%) respectively had died, and only 27 (25%) survived at the final follow up and four clients were not traceable (Walker et al.,2003).

In Malawi stroke has been described as a sixth cause of death and a significant cause of disability in the country (Mahawish & Heikinheimo, 2010), however, general information about the condition in Malawi is sparse.

2.3 International Classification of Functioning, Disability and Health (ICF): Conceptualizing disability post stroke

Disability secondary to stroke can be viewed within the framework of the ICF. This ICF identifies three levels of human functioning: the body (body structure and function), the whole person (activity), and the person in relation to his/her environment (participation), with their respective opposites; impairment, activity limitation and participation restriction. The WHO (2001) further states that the patients' activity and participation are affected by contextual factors referred to as environmental (social, physical, attitudinal factors) and personal factors (age, race, background). According to the ICF, environmental and personal factors are grouped as contextual factors and can either be barriers or facilitators.

The ICF is preferable to the two prior models of the International Classification of Impairment, Disability and Handicap (ICIDH) and the 'functional limitation' or Nagi framework because, it is argued that the ICF is based on a bio-psychosocial model in contrast to biomedical model which characterizes the ICIDH and the Nagi framework (Stamm, & Machold, 2007). This view has also been projected by Hurst (2003) who on tracing the thinking about persons with disabilities before and after formulation of the ICIDH in 1980 including the ICF in its present state, discussed the major shift from medical model of disability to a holistic (bio-psychosocial) model, by including the effects of the environmental factors and all aspects of health and functioning. Hurst (2003) therefore, resolved highly about the ICF, that proper use of environmental factors as embedded in the ICF would facilitate suitable policies, systems and services for health, care and support, providing measurable indicators for health status and suitable development, and provide opportunity for recognition that disability issue is a rights issue.

The ICF has also been reported as a relevant conceptual framework in different health related fields. In nursing, Kerney and Pryor (2004) who reviewed the ICF's relevance as a conceptual framework for nursing concluded that the ICF has potential to expand the nurses' thinking and practice by increasing awareness of social, political and cultural dimension of disability. This is against the background they observed that nursing conceptualizes disability strongly from medical and individual perspective, with no regard to social aspect.

In Occupational therapy, a pilot study was carried out in America about stigma and its management where the ICF codes were used to examine the parental perception about the experiences of children with developmental coordination disorders, with valid results (Segal, Mandich, Polatjko, & Valiant-Cook, 2002).

The ICF has also been reported as potentially beneficial to physiotherapists and other health professionals in that it facilitates proper organization of clinical practice and research activities; creates an understanding between professionals; enables delivery of patient-centred, whole-person health care; and it ensures justification of intervention by a therapist (Snyder, Parsons, McLeod, Bay, Michener & Sauer, 2008).

The strength of the ICF framework on proper organization and documentation of research activities has practically been shown in Sweden where the study was carried out to identify facilitators and barrier in persons with first ever stroke discharged to their homes in the first three month. Using the ICF categories, Alguren, Lundgren-Nilsson and Sunnerhagen (2009) concluded that it was easier and possible to document facilitators and barriers in a structured way.

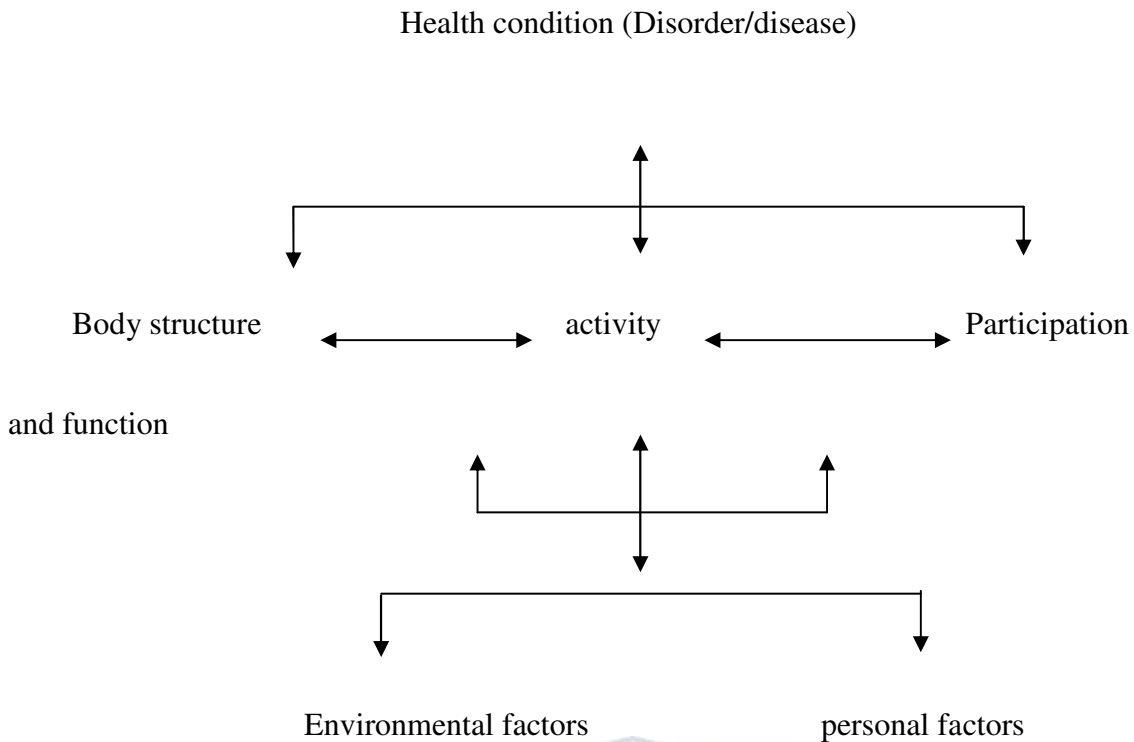


Fig 1; The ICF Model of functioning Disability and Health as adapted from World Health Organization (WHO, 2001)

Although the ICF is seen in good light, some authors have expressed some reservations on some aspects of the framework. For example Nordenfelt (2003), focusing on definition of activity and participation, concluded that the ICF framework areas rests partially on confusion between capacity for action and the actual performance of that particular action in a given setting. Hence, he notes, there is a need for revision from a conceptual perspective. Furthermore, Imrie (2004) in evaluating the theory behind the ICF argues that the ICF fails to specify in detail the content of some of its main claims about nature of impairment and disability. This, Imrie (2004) observes, may limit its educational capacity and influence. Hence, in line with Nordenfelt (2003), Imrie

(2004) is for the view that the ICF needs further conceptual clarification and development in its key areas.

In summary the ICF has been seen as a key to addressing issues about disability set on by conditions such as stroke, and managing medical conditions. The major impact of the ICF has been that it has managed to shift the focus of different medical professionals from purely medical model to holistic (bio-psychosocial) approach to treatment that is, addressing even the contextual factors. The framework has however been seen as requiring further revision and clarification in some of its key areas.

2.3.1 Post-stroke disability

Stroke presents with wide range of impairments. According to the World Health Organization **MONI**toring of trends and determinants in **CARDIO**vascular disease (WHO MONICA) project the definitive ones are unilateral or bilateral motor and/or sensory impairments, aphasia/dysphasia, hemianopia (half sided impairment of visual field), diplopia (double vision) dysphagia and perceptual deficits. The impairments as highlighted by WHO MONICA project have also been reported in some studies, with some adding spasticity, shoulder pain, incidence of falls after stroke, depression and anxiety, and cognitive impairments which affect mood and personality (Tipping, 2008; Mukherjee, Levin, & Heller, 2006; Rathore et al., 2002). Literature also says physiological changes after stroke are common and are, mostly, associated with hypertension crises such as headaches, dyspnoea and seizures (Wong & Read, 2008; Lavados, Sacks, & Prina, 2005; McGovern & Rudd, 2003).

According to the ICF (WHO 2001) the impairments may lead to activity limitation such as failure of the clients to carry out basic and instrumental Activities of Daily Living (ADLs), for

example, bathing dressing, cooking, and child care (Blonder et al. 2007). Albeit, if not managed or reversed, impairments and activity limitation may ensue difficulties with participation by stroke clients in life situations in their communities after discharge (Mayo et al., 2002). Rehabilitation is therefore necessary (Langhorne, & Legg, 2003) in addressing stroke disability.

2.3.2 Stroke rehabilitation

WHO and the World Bank (2011: 96) defines rehabilitation as “a set of measures that assists individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environment”. WHO/World Bank definition goes in the same line as what article 26 of the UN Convention on the Rights of Persons with Disabilities (2006: 16) talks about rehabilitation to mean “appropriate measures including through peer support, to enable persons with disabilities to attain and maintain independence, full physical, mental, social, and vocational ability, and full inclusion and participation in all aspects of life”. However UNCRPD definition may be perceived as giving more weight on the environmental aspect, more towards the social model approach to disability which makes sense given the treaty’s emphasis on the rights of the persons with disabilities as compared to the WHO’s which seem to attach more significance on the individual’s capacity for function first while environmental factor are not ignored.

Rehabilitation is therefore an important aspect of stroke management especially for its contribution towards ultimate functional independence and participation in real life setting, a characteristic of WHO, World Bank and UNCRPD definitions given earlier. In stroke rehabilitation, Langhorne and Legg (2003) concurs with WHO, World Bank and UNCRPD

views on rehabilitation by saying stroke rehabilitation aims to reduce disability and promotes activity and participation of individuals affected by stroke in day to day life settings.

Rehabilitation services are offered in different settings depending on the stage in the course of stroke. In this context, rehabilitation of stroke has been reviewed in two rehabilitation settings as highlighted by Rhoda, et al. (2009) and Ottenbacher & Graham (2007), that is, in-patient institutional based rehabilitation and out-patient community based rehabilitation

2.3.2.1 In-patient hospital or institutional based rehabilitation

In general stroke clients are admitted to the stroke units or wards in the acute phase (Haig, 2007). Rehabilitation at this stage is utilized to improve function through diagnosis and treatment of stroke; reducing impairments and preventing/treating complications (Stucki, Reinhardt & Grimby, 2007). At this stage also, interdisciplinary approach is advocated as stroke disability affects the whole person (Duncan et al., 2005; Langhorne and Legg, 2003). There is impeccable evidence that supports that coordinated services of physiotherapy, occupational therapy, speech therapy, nursing and medical services in stroke units, results in improved outcome after stroke (Langhorne & Pollock, 2002).

Professionals in the context of in-patient hospital based rehabilitation provide services in different ways but towards the same goal, that is, to improve the outcomes of the stroke clients related to impairments, activity limitation and participation restriction (Haig, 2007). For example, close monitoring is done by nurses and medical doctors in order to prevent medical and neurological complication, and achieving optimal outcomes (Johnsen, Husted & Thomassen, 1999). Medical doctors may also prescribe different medication such as baclofen for severe spasticity, and other pharmaceutical agents for depression and/or pain secondary to stroke, in

addition to implementing secondary prevention strategies for minimizing chances of stroke recurrence (Johnsen, et al., 1999; Tipping, 2008). Johnsen, et al. (1999) observes that secondary prevention in stroke involves detection and management of modifiable risk factors such as hypertension, smoking, diabetes mellitus, and alcohol abuse.

Physiotherapists provide education on trauma prevention and positioning as some of the important preventive measures for shoulder pain while providing other therapeutic exercises and training (Tipping, 2008; Langhammer & Stranghelle, 2000). Studies show that physiotherapy leads to fewer days of stay in the hospital, improved motor function, and improved ADLs (Langhammer & Stranghelle, 2000).

Occupational therapists work on stroke client's cognitive impairments and activities of daily living while in the hospital (Tipping, 2008). Whereas speech therapists may address language problem and dysphagia through direct interaction with patient and educating caregivers and families of persons with stroke about the conditions.

Psychologist may address problems faced by caregivers as research has shown that 55% of caregivers at six months after stroke experience emotional distress (Dennis et al., 1998). Hence, caregivers must be looked after by knowledgeable staff who understands the wider range of their needs after the onset of stroke (McGovern & Rudd, 2003).

Rehabilitation in acute and sub-acute phases of stroke have been shown to produce positive outcomes such as improved joint and limb function, pain control, wound healing, and psychosocial wellbeing (Quinn, et al., 2009). However Sabari, Meisler and Silver (2000) notes that rehabilitation fails to prepare the stroke clients for effective return to communities. This deficit is said to arise from lack of a whole person patient-centered approach when managing

stroke clients (Cott, et al., 2007). Nonetheless, policy documents on stroke rehabilitation advocate for continued rehabilitation programs at community level after discharge (The Canadian Best Recommendations for Stroke Care, 2008; South African National Rehabilitation Policy, 2000). The development of the community based rehabilitation, offered in the homes of clients or as outpatient service at community health centers within the communities as evident in the research in Cape Town Metropolitan Region (Rhoda et al., 2009) could be the result of recommendation from such policy documents.

2.3.2.2 Outpatient community based rehabilitation

Community based rehabilitation of stroke clients can be defined as care received once the stroke condition has passed the acute stage which ideally gets managed in the in-patient rehabilitation facility, and has transitioned back home within their community (Canadian Best Practice Recommendations for Stroke Care, 2008). Rehabilitation under CBR is offered either directly in the home of the clients, or services offered on outpatient basis as in community health centres which are close to the clients.

In the UK Young (1994) and Lincoln (1994) argue on what could be a better setting for stroke rehabilitation with Lincoln (1994) saying hospitals are the best setting to provide rehabilitation particularly the required therapy. This, the author notes, is because of ease with which coordination of services which is critical in interdisciplinary rehabilitation (Rhoda, et al., 2009) is afforded. Lincoln (1994) further argues that it can be practically difficult to implement coordinated services in the community setting as most often the services provided are not stroke focussed. Although this view is supported by others (Rudd, Wolfe, Tilling, & Beech, 1998;

Gladman, Whynes, & Lincoln, 1994), Young (1994) contends by saying that community care allows stroke clients to reach their full potential

“I do not believe that hospital care should be replaced by community services but that a more appropriate balance needs to be achieved; one which recognizes the limitations of hospitals and the pressing community (home) needs of stroke patients and their families”
(Young, 1994)

In this light, outpatient may be ideal as it stands midway between two extremes of opposite arguments about purely in-patient rehabilitation and typical community based, implying rehabilitation in the homes of clients.

Outpatient rehabilitation is characterised by a case coordination approach in interdisciplinary team of specialists in stroke care and rehabilitation, where services are delivered in the most suited environment based on client issues and strengths with emphasis on client and family centred practice (Canadian Best Practice Recommendations for Stroke Care, 2008). The policy document further says outpatient client's rehabilitation is also focussed on clients' re-engagement in and attainment of their desired life activities and roles and enhancing the client's quality of life through provision of intensive rehabilitation services. In this way outpatient rehabilitation contributes towards effective reintegration into the community after discharge.

In outpatient community rehabilitation, physiotherapy continues to be important in managing impairments and functional limitation amongst stroke clients. Although there is lack of coordination of services, affecting the efficacy of therapy, Rhoda et al. (2009) found that physiotherapy was the most commonly offered service in all community health centres in the Western Cape Metropolitan region, followed by occupational therapy and speech therapy.

Therapy includes training, exercises and compensational strategies, education, support and counselling, modification to the environment, as well as provision of resources and assistive technology. Therapies such as exercise have been found to contribute towards increased strength, endurance, joint flexibility, improved balance, posture, ROM, and functional mobility in diverse range of conditions including stroke (Fransen, McConnell, & Bell, 2003). These benefits are in addition to stroke clients viewing physiotherapy as beneficial; as leading to functional improvement, the exercise component keeping them active, and physiotherapists being source of information, faith and hope in the community (Pound, Burry, Gompertz, & Ebrahim, 1994).

Assistive technology is also an important aspect of long term rehabilitation which is also addressed by rehabilitation personnel in the community health centres. By definition, assistive technology is any device or piece of equipment that is used to increase, maintain or improve functional capabilities of an individual with disabilities (McCreadie, & Tinker, 2005) such as stroke. Examples of assistive technologies applicable to stroke clients include crutches, orthotics, and wheelchairs as they enhance mobility (Hunt, et al., 2004).

Although the necessity of rehabilitation in managing stroke disability is huge, evidence has emerged that not all stroke clients and people with other disabilities have access to rehabilitation services. The national studies into living conditions of people with disabilities in Malawi, Zambia, Zimbabwe, Mozambique and Namibia has shown deficits in rehabilitation service and assistive device provision (WHO & World Bank, 2011) in these developing countries.

In summary, stroke rehabilitation in the identified settings has drawn skills from different professionals including medical doctors, nurses, physiotherapists, occupational therapists, psychologists, speech therapists. However, while this is effective, it may not be always possible

in developing countries such as Malawi where there are limited numbers of health care providers. The tendency of limited staff in Malawi may therefore be a barrier to positive outcomes after stroke.

2.3.3 Community reintegration and its domains

Reintegration to normal living has been defined as reorganization of physical, psychological and social characteristics so that an individual can resume living in a well-adjusted manner after a disabling illness or trauma (Wilson, et al., 2005). In specific terms however, community reintegration is reestablishing to a degree possible previously existing roles and relationships, creating alternative ones, and assisting people in making up for the role/relationship changes (Dijkers, 1999). The definitions by Wilson, et al. (2005) and Dijkers (1999), may be seen to have been unpacked well by the Reintegration to Normal Living Index (RNLI) by Wood-Dauphinee, Opzoomer, Williams, Marchand and Spitzer (1988) which identifies eleven declarative statements that are used to determine the degree to which clients have returned to normal life (reintegrated) into the community after incapacitating condition. Using RNLI, Obembe et al. (2002) identifies ten domains of reintegration to normal living as being: in-door mobility, community mobility, distance mobility, self-care, daily activities, recreation activities, social activities, family role, personal relationships and general coping skills.

The domains of RNLI, as highlighted by Obembe et al. (2002) may therefore be regarded as the constructs of reintegration into the community, and that abilities in these areas, which are ingrained in the activity limitation and participation restriction of the ICF when highlighting disability, may indicate that stroke clients are fully reintegrated into their community after

discharge on the one hand. On the other hand dependence or lack of ability in some or all of the domains may render a failed reintegration by the client into the community.

Most studies in the area of stroke rehabilitation shows that stroke clients do not fully reintegrate into the community after discharge from rehabilitation institutions. In Nigeria, the study by Obembe, et al. (2002), the authors concluded that stroke clients are not fully reintegrated into their community for they show varying degrees of deficits across RNLI (RNLI score 100). Other studies which are mostly from developed countries also report that clients experience activity limitation and participation restriction in their communities after discharge (Kersten et al., 2002; Pound et al., 1998).

Activity limitation as embedded in the ICF relates to difficulties an individual may have in executing activities of daily living in terms of quantity or quality (WHO 2001). The ability to perform ADLs such as getting around, visit places away from home, ability to do things/pursue leisure activities, autonomy about one's own life, remaining useful to others, sex life and job have been reported by stroke clients as being necessary elements for them to be satisfied with reintegration in the community (Robinson-Smith et al., 2000; Kim et al., 1999; King, 1996). The same components are imbedded in the RNLI as seen earlier.

However, studies show that after discharge the clients face difficulties executing different activities of their life (Kersten et al., 2002; Pound et al., 1998). Blonder et al. (2007) found that stroke clients particularly women experience reduced ability to carry out IADL such as cooking and child care. In addition, Hackett et al. (2000) reports that stroke clients have problems with IADLs especially failure to walk outside. Furthermore, a Canadian survey on stroke clients revealed that 54% of the interviewed clients had marked restriction in executive functions of

house work and shopping (Mayo et al., 2002). Kochi et al. (2005) also found that stroke clients lose their ability to carry out IADLs such as driving, housekeeping and budgeting finances that lead to emotional problem due to perceived failure to carry out routine work.

Under the activity limitation domain, stroke clients also experience difficulties to engage in sexual activity with their spouses. In the evidence-based review by Salter, et al. (2008), it is clear that decline in sexual activity is very common after stroke.

Participation restriction, further, is demonstrated by stroke patient's failure to take part in vocational, recreational, and social activities such as; school, work, sport, religious activities, clubs, community gatherings or festivals, visiting friends and family members. In the Canadian survey, Mayo et al. (2002) reports that 65% of the participants had trouble participating in day to day life in the community such as social recreation, visiting family and friends.

After stroke, clients also face difficulties going back to their previous economic activity such as employment. In a qualitative study carried out by Kochi, et al. (2005) most stroke clients reported inability to return to their former employment. The study also shows that emotional problems emanating from the client's failure to perform activities leads to stroke clients avoiding challenging tasks, hence unlikely to go back to their former jobs. The findings constitute failure of stroke clients to participate in economic activity. This study is from affluent society which may be difficult to extrapolate the findings to developing countries such as Malawi where about 90% of people live in rural area and mostly engaging in heavy manual work in agriculture (National statistics office, 2008) and challenges participating in such economic activity as farming after stroke may be a commonality.

The activity limitation and participation restriction, therefore, limits the ability to reintegrate or lowers satisfaction with reintegration into the community by stroke clients, the other side of common findings that the abilities in these two ICF domains by stroke clients are important for client's satisfaction and perceived quality of life post stroke (Wood, Connelly & Maly, 2010; Mayo et al., 2002; Robinson-Smith, Johnston, & Allen, 2000; Kim et al., 1999; Clark and Smith 1999; Kim, Warren, Madill, & Hadley, 1999; King, 1996). Limitations and restrictions in activity and participation as experienced by clients in the reviewed studies therefore show that after discharge stroke clients are not satisfied with their reintegration into the communities.

2.4 Conceptualization of Barriers to Community reintegration by stroke clients

A barrier can be anything that challenges attainment of a desired task or goal (Pang et al., 2007) and so challenging the stroke clients' abilities to reintegrate and/or feel satisfied with the level of reintegration in the community. Based on ICF, a bio-psychosocial model-based framework (Stamm, & Machold, 2007), the barriers have been classed into two themes which are: barriers at individual level and barriers at the level of environment. What follows is a review of each theme.

2.4.1 Barriers at individual level

These are barriers internal to the stroke clients that affect their ability to carry out activities or participate in life situations in communities after discharge. Under this section impairments and personal factors which are age, gender and social background have been reviewed.

Impairment, by definition stroke affects brain cells following rupture or occlusion of cerebral blood vessels (Markus, 2003). The incidence of stroke leads to classical syndrome of signs and symptoms that affects (depending on the level of injury) the degree to which stroke clients can get involved in day to day life in the community after discharge. For example stroke is a known

cause of unilateral or bilateral motor and/or sensory impairment and spasticity (Tipping, 2008; WHO MONICA project; Rathore et al., 2002). These impairments affect stroke clients' ability to stand up and remain mobile in the community, or do simple tasks of their life (Obembe, et al., 2002).

Stroke also impairs speech. Speech problems among stroke clients in communities have been reported in some studies. In the USA, Rathore et al., (2002) found that 24% of participants had speech problem. Tipping (2008) equally identifies speech problems as one of the impairments stroke clients suffer. Problem with speech may therefore make it difficult to communicate needs effectively in the community thereby affecting the stroke clients' life roles including social.

Stroke causes visual problems. Hemianopia (half sided impairment of visual field) and diplopia (double vision) have been reported as being some of the focal signs of stroke by WHO MONICA project. Literature has also identified visual problems as being prevalent among stroke clients (Mayo Clinic, 2010; Tipping, 2008; Rathore et al., 2002). Visual problem may affect stroke clients' ability to move from place to place in search of leisure or work. Other impairments are dysphagia, apraxia, ataxia, and cognitive problems that includes perceptual deficit (MONICA project; Mayo Clinic, 2010; Tipping, 2008; Rathore et al., 2002).

Furthermore, there is emergence of secondary psychological impairments such as altered self-image, low self-esteem, anxiety and depression due to clients' failure to achieve the necessary equilibrium after discharge as reported by several stroke community studies (Garcia, Barrette & Laroche, 2000; Kochi et al., 2009; Chau, et al., 2009). The secondary impairment may affect the clients' ability to participate in social or leisure activities which are some of the domains within the INLI.

Equally important is that stroke impairments may lead to stroke clients' inability to go back to their productive work. In their qualitative study Garcia et al., (2000) found that service providers and persons with aphasia perceived that impairments related to fatigue and cognitive-perceptual problems associated with information processing challenge the clients' abilities to go back to work. The inability to go back to work may amount to loss of satisfaction with reintegration (Obembe et al., 2002) due to consequent loss of income that threatens the client's pre-stroke roles as "bread winners in the family, for example. Pre-stroke roles are some of the domains on the INLI (Obembe et al., 2002; Wood-Dauphinee et al., 1988) that explain whether or not stroke clients are reintegrated into the community.

The impairments also makes stroke clients become too sensitive thereby reducing their confidence and motivation for social outings (Kochi et al., 2005). The social cost of stroke impairments in this context has been confirmed in South Africa where Thomas and Greenop (2008) found that caregivers find stroke clients too sensitive and not able to adjust to new situation in the family system. This adds to the findings by Rittman et al. (2007) who says fear of falling due to weakness or incoordination, or fatigue, makes them afraid to leave the house and participate in activities in the communities.

Personal factors such gender, age, coping styles, social background, education, profession, past and current experience, overall behaviour pattern affects stroke client's ability to engage in different life situations in the community (WHO, 2005). For example, female gender in stroke has a direct effect on community reintegration especially social outings. Physical appearance such as facial asymmetry and drooling is seen to bother female stroke clients (Chau et al., 2009; Thompson & Ryan, 2009). In addition Chau et al. (2009) also report that female stroke participants have lower self-esteem than male participants and therefore less likely to take part in

post stroke social and leisure activities. Chau et al. (2009) further reports that poor functional ability in older participant hinders their ability to resume social roles in day to day lives after discharge. In addition, living in a residential care facility has been associated with significantly higher levels of participation restriction, lower self-esteem and higher levels of depressive symptoms (Chau et al., 2009). Depressive symptoms and low self-esteem due to social background of living in a residential facility may negate full reintegration into the community.

It is evident, therefore, that stroke impairments are barriers to reintegration or are a source of dissatisfaction with reintegration to normal living in the community as they challenge the client's ability to remain mobile in the community, maintain pre-stroke social and family roles, go out of the home for leisure and productive work, all of which are the domains of community reintegration. It is also evident that other personal factors such as female gender, age, and social background of living in a residential facility leads to lower levels of reintegration into the community.



2.4.2 Environmental Barriers

Environmental barriers are elements within the environment that hinders successful negotiation of public environments and rehabilitation by the stroke clients in the community (Swann, 2008). Under this theme, five subthemes have been reviewed and these are: physical/ structural/ architectural barriers, socioeconomic barriers, attitudinal barriers, institutional barriers and information-access barriers. They are discussed below.

2.4.2.1 Physical /architectural barriers

Physical environment are physical features in the stroke clients' environment in the community. The environment may enable or limit participation of disabled people generally. In the recent report the WHO/World Bank (2011) point out that accessible buildings and roads/transport is beneficial for participation in life activities such as education, health care and labor market not only to persons with disability, but also to everyone. Lack of accessibility to buildings and road/transport structures either excludes the disabled, or make them dependent on others (The Dakar Framework of Action, 2000). In a study by Venter et al. (2002) in South Africa, India, Malawi, Mozambique and Mexico to assess the access needs of persons with disabilities, many issues related to accessibility emerged. The report shows that on transport, small mini-buses in general provide better physical access (without wheelchair) than larger buses, because of small size, availability and presence at all times; sidewalks that is unpaved, poorly maintained, or crowded by vendors thereby limiting easy pedestrian mobility by the disabled. The study further says geographical features such as sandy roads in Maputo and steep slopes in Blantyre limit the mobility of people, more so with those on wheelchairs.

Indeed, buildings with steps, inaccessible public transport, and inaccessible education and health facilities have been reported as limiting disabled people's participation mostly in developing countries such as Malawi (Yeo & Moor 2003; Loeb & Eide, 2004). This general observation has also been confirmed in a study involving community dwelling stroke clients. Trigg and Wood (1999) found that some physical factors such as hilly areas pose difficulties for stroke clients to move from place to place in pursuance of leisure or other goals. Additionally, in a highly inductive study among stroke client using wheelchair by Rudman, Hebert and Red (2006), environmental or physical barriers found inside the home included stairs, narrow door, and

limited space for wheelchair use; whereas barriers outside the home were more of set up of facilities. Common in this regard were limited access to public washrooms (Rudman et al., 2006). The WHO and World Bank (2011) confirms as an example that inaccessible public toilets may limit the disabled people's ability to participate in outdoor activities.

In some situations, long distance to places of interest limits people's ability to participate access essentials of life. Mony (2002) reports that access to natural water sources can be difficult because of long distances and lack of alternative in nearby areas. In addition even if there is public transport, there is often lack of continuity in the travel chain. Travel chain refers to all elements that make up a journey from starting point to the destination including pedestrian access, vehicle and points of transfer (WHO & the World Bank, 2011) which limits clients ability to access and participate because of long destination distance.

2.4.2.2 Socioeconomic Barriers

There is now wide base of knowledge linking poverty and disability. The poverty-disability link is a global phenomenon that is observable in both the developed and the developing countries (Bonnet, 1997; UNESCAP, 1995). Poverty increases the likelihood of being disabled. Poverty has been seen to be the cause and/or effect of disability. For example, poor stroke clients who are often in developing countries such as Malawi find it increasingly difficult to minimize the impact of impairment due to lack of resources for accessing care and rehabilitation (May-Teerink, 1999).

At household level poverty is a likely phenomenon following stroke. This is so because stroke clients often lack the ability to return to work (Kochi et al., 2005). According to Kochiet al. (2005) failure to return to work is due, in part, to the fact that stroke clients have reduced energy

for work and that some have lost their jobs due to stroke. Fatigue and depression have also been common findings amongst community dwelling stroke clients (Rittman, et al., 2007; Kochi et al., 2005; Rudman, et al., 2006) affecting stroke client return to their economic activities. Furthermore Rudman, et al. (2006), found that stroke clients and their caregivers live with restrictions on occupational participation. Specifically the authors found that stroke clients tend to do what is necessary or possible, rather than what is desired, in which case, what they used to or loved to do might be energy demanding, now with stroke they are forced to take on less demanding tasks/hobbies which may be boring to them and/or of limited income-fetching.

Additionally, spouses of stroke clients are also faced by occupational restrictions by way of skepticism that arise from feeling that if they go away the stroke client can, in attempt to doing something for themselves, end up falling and injuring themselves. Therefore they end giving up even economic activities (Rudman, et al., 2006).

In some situations, economic barriers faced by that disabled generally are due to inability to access loans, land and property, leading to inability to venture into not only business but also employment as observed in Malawi (Loeb & Eide, 2004).

Thompson and Ryan (2009) observe that loss of economic activity by stroke clients and caregivers leads to perceived loss of control, loss of roles in the family and society, loss of identity and sense of self, leading into a vicious cycle of the stroke client's loss of enthusiasm in life generally and interest in any economic activity in particular.

2.4.2.3 Attitudinal Barriers

Attitude is a way of thinking, cognitive in nature, formed through interaction with the environment, and reflecting person's innermost convictions about situations good or bad, right or wrong (Mosby's Dictionary of Medicine, nursing & health professions 7th edition)

The attitudes held by people in different circles of life may limit the abilities of stroke clients or persons with disabilities generally. In the transnational study, Venter, et al. (2002) found that the attitude shown in the driving behaviour of drivers of public transport, as well as overcrowding constitute major barriers to the use of public transport by people with disabilities. Bus drivers in Blantyre-Malawi where the study also covered, for instance, do not provide sufficient time for people to board and alight in comfort and safety, and transport personnel in general are lacking in disability awareness and training in assisting people into vehicles.

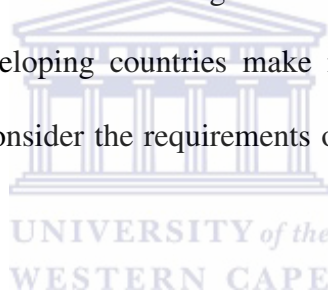
Furthermore, in a qualitative study by Garcia, Barrette and Laroche (2000), the service providers perceive that some community members who come in contact with the stroke client may have attitudinal problems. However, stroke clients in the study did not identify society members' attitudes as a barrier; therefore, the authors claim that, service providers may be using assumptions and theoretical understanding. Nonetheless, in many societies, attitudes held by people towards a disabled member and their families has been implicated as being one of the barriers to participation in life settings within the community by the members living with disabilities (Yeo & Moor, 2003; Lwanga-Ntala, Ndaziboneye, & Nalu, 2002). For example, they claim that in many parts of the world, it is common to associate disability with evil, witchcraft, and possibility of infidelity in the family of the disabled person. In some instances, family and some community members may also think that the disabled is not capable of anything. As a

result this leads to overprotection and consequent exclusion from everyday life (Yeo & Moor, 2003).

2.4.2.4 Institutional Barriers

It happens that even without the intent of the perpetrators, organizational expectations for quality and quantity when stroke has taken away some ability from an individual affects work reintegration (Garcia, et al., 2000; Kochi, et al., 2009); or nature of work naturally done by the organization where if it is more physically demanding may affect work reintegration of a stroke client; equally if the work entails use of electronic devices such as telephone may be a challenge for stroke client with speech problems (Garcia, et al., 2000).

The disabled people including stroke are also marginalized by laws, customs and/or practices. For example many NGOs in developing countries make no efforts to include persons with disabilities, or employers do not consider the requirements of disabled applicants (Yeo & Moor, 2003).



2.4.2.5 Information-access Barrier

Another form of barrier is information access barrier. This relates to inability of the person with a disability to access information due to their condition. For example, lack of brail or audio tapes for the visually impaired, and lack of sign language for the deaf (Yeo & Moor 2003). Among stroke clients, information access may be limited either because the client cannot go out to interact with others or due to impairments limiting their use of information technology (Mirza, Anandan, Madnick, & Hamme, 2006; Garcia, et al., 2000). Mirza et al. (2006) therefore, observe that failure to use information technology interact with other barriers to exacerbate their oppression.

2.4.3 Reducing Barriers to community reintegration

Even though stroke clients experience barriers, there are strategies put in place or recommended in an effort to minimize the gravity of barriers on stroke clients' reintegration to normal living after stroke. Reducing barriers to reintegration into the community entails carrying out deliberate actions (recommendations) aimed at easing the ability of stroke client to participate in life situations after discharge from a rehabilitation center or stroke unit (Cott, et al., 2007).

Initially there is a need for good preparation for stroke clients' reentry in the community. Tippings (2008) proposes that to prepare stroke clients for community and social reintegration there is a need to embrace three strategies; ongoing post-stroke family support, financial and employment assistance and also mobilization of community resources to facilitate successful return to the community. Some policy documents have also come forward with their recommendations regarding reintegration of stroke clients into the community. For example, The Canadian Best Recommendations for Stroke Care (2008) has laid down several recommendations such as: a) People with stroke living in the community should have regular and ongoing follow-up to assess recovery, prevent deterioration, maximize functional and psychosocial outcomes, and improve quality of life; b) Post-acute stroke patients should be followed up by a primary care provider to address stroke risk factors, ongoing rehabilitation needs, and to continue treatment of co morbidities and sequel of stroke. This follow-up ideally should occur at least every six months and for at least three years following stroke; c) Stroke clients and their caregivers should have their individual psychosocial and support needs reviewed on a regular basis; d) Stroke clients living in the community who have difficulty with activities of daily living should have access, as appropriate, to therapy to improve or prevent deterioration in activities of daily living; e) Stroke clients and their caregivers should be monitored and

assessed for depression; f) Any stroke client with declining physical activity, activities of daily living or mobility at six months or later after stroke should be assessed for appropriate targeted rehabilitation. Recommendations by the Canadian Best Recommendations for Stroke Care look easy to comprehend, follow, and implement. However one would think they are narrow in breadth and leaning mostly towards the biomedical model to disability by focusing mostly at the condition of stroke clients than the contextual factors such as poverty.

At individual level stroke client needs to adopt certain traits for ease of reintegration in the community, be it leisure social, or work. Patience, motivation, determination, positive attitude, and sense of humor should be developed by the clients themselves as it has been associated with effective reintegration into work place (Kochi et al., 2005; Garcia, et al., 2000).

At family level, stroke clients and their families should be supported in creating a well-functioning family. In the evidence based review about stroke reintegration into the community, Salter, Teasell, Bhogal, & Foley (2008) found that stroke clients living in communities do better with well-functioning families. According to the authors, well-functioning family is characterized by effective communication, good problem solving or adaptive coping and strong emotional interest in each other. In addition, stroke clients and their caregivers should be made aware and educated about stroke and how to manage secondary complications. There is strong evidence that skills training are associated with reduction in depression and that there is moderate evidence that basic nursing skills training improves outcomes of stroke (Salter, et al., 2008). Furthermore, to reduce the social difficulties especially at family level, Van Heugten, Visser-Meily, Post, & Lindeman, (2006) recommends that sexuality and intimacy be discussed with married couples, and changes in functioning generally and sexual functioning in particular be discussed with patients and spouses at different moments during rehabilitation, for example,

at discharge and follow up; and general information be given out to them about nature and causes of changes in stroke client. Salter, et al. (2008) agrees by reporting that there is consensus opinion that issues related to sexual activity should be discussed during rehabilitation and also addressed after transition into the community when stroke clients and their spouses are ready.

At community level, environments such as physical, social, and attitudinal may act as a barrier or facilitator to stroke clients. There is therefore a need to address the existing barriers if stroke clients have to participate and reintegrate into the community. International treaties such as the UNCRPD, article 9 talks of the need for improved access by the disabled people generally to buildings, roads, transportation, information and communication. Some authors in studies about stroke clients' reintegration speak in line with the UNCRPD. For example, while continued training at home towards stair climbing may enable stroke clients to continue visiting friends and other family friends, Rudman, et al. (2006) observes there is a need for modification of homes and public places like churches so that stroke clients can access them. The WHO and the World Bank (2011) agrees that there is a need for improved access to structures and systems. However, the authors notice that improving access alone is not enough. WHO and the World Bank (2001) argue that there is a need to overcome negative attitude by the public also, such as ignorance and prejudice surrounding disability. Education about stroke disability and raising awareness among community members is therefore also required (WHO & World Bank, 2011).

In summary it is evident that stroke clients experience various barriers in their stay in the communities. Impairments limit their ability to act and participate in the community. There are also environmental factor that limit their participation in life situations such as terrain limiting their ability to travel from place to place in the community; negative attitudes of other community members due to lack of awareness about stroke; poverty that is both cause and effect

of disability, institutional barriers caused by laws and policies for example, and other related barriers.

In an effort to ease the reintegration of stroke clients into the community, there is a need to adopt a bio-psychosocial approach to rehabilitation such as proper preparation of the clients, their families, and community to which they are going to live after discharge.

2.4.4 Facilitators to community reintegration in Malawi

Facilitators are elements that are perceived to ease the reintegration of stroke clients in the communities after discharge from a stroke unit or rehabilitation center. The elements can be deliberate efforts by the government, communities or stroke clients/persons with disabilities in attempt to enable participation in life activities. Contextually, Malawi has assented to several international treaties including the 1993 UN policy on equalization of opportunities for persons with disabilities. With the policy Malawi government has taken deliberate efforts to mainstream disability issues in all government policies, plans and program (MSDPD, 2006). However, much as the policy has created positive development regarding disability such as increased awareness about the issue in the country (MSDPD, 2006), the policy lacks force and vigor for its implementation (WHO & World Bank, 2011), and hence it has since been replaced by the 2006 UN convention on the Rights of Persons with Disabilities.

Locally, the National Policy on Equalization of Opportunities for Persons with Disabilities is also linked to some policies that address disability issues including stroke. The Malawi Growth and Development Strategy (MGDS), address development issues including training and employment of disabled people, assistance to individual persons with disabilities and the implementation of Community Based Rehabilitation programs; The National Gender Policy

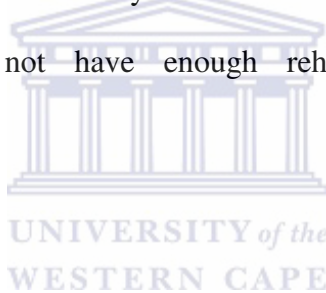
(2000) relates to disability as it promote gender mainstreaming in stakeholder organizations, that includes disability, through the gender action plan. The Tevet Policy, established by the act of parliament, the Tevet Act 1999, links very much with disability in that it specifically isolates empowerment of persons with disabilities as one of its focus areas; and the Malawi Constitution 1994, 4th Chapter of the constitution; section 20(1) prohibits any form of discrimination of persons and guarantees equal and effective protection against discrimination on any grounds including disability. These policies are targeting disability in general. However, stroke clients in the country are among the disabled hence positive impact of the policies goes a long way to addressing reintegration issues of stroke clients after discharge.

Malawi has organizations dealing with rehabilitation of persons with disability of different kinds. Malawi against Physical disabilities (MAP) is one example that has units across the four regions of the country. MAP runs both institutional based rehabilitation in Blantyre and Community Based Rehabilitation (CBR) in some districts. Such organizations minimize level of difficulties persons with disabilities such as stroke face in reintegrating into the community (MSDPD, 2006). Although this is so Malawi suffers severe shortage of rehabilitation personnel such as physiotherapist as, for example, it has been estimated that physiotherapist: patient ratio is 1: 500,000 (Kambalometore, 2008). However supportive and availability of rehabilitation and health care professional have been associated with successful reintegration, particularly employment (Garcia, et al., 2000).

Malawi is a developing country with strong traditional values. The culture of extended families may mean there are always people to morally or materially support the stroke client or a disabled member once they are back into the community. It is well known that to have nobody around or to have no close relation makes clients feel alone and isolated which constitutes a barrier to

reintegration of stroke clients in the community (Kersten et al. 2002; Pound et al., 1998). In addition people in Malawi are often members of a religious organization and mostly Christians. From Kochi et al. (2005) study on stroke clients' reintegration in America, belonging to support groups, religious organizations and informal family was associated with successful reintegration. Positive internal factors of individual stroke client also play a role in facilitating reintegration into the community. Patience, motivation, determination, positive attitude and sense of humour are associated with successful reintegration (Kochi et al., 2005; Garcia, et al., 2000).

In summary positive policies, availability of rehabilitation organizations, availability of supportive people and organizations, and some personal factors may be associated with successful reintegration into the community after discharge. However, though present the rehabilitation organizations do not have enough rehabilitation personnel to provide comprehensive services.



2.5 Chapter summary and conclusion

Stroke is a worldwide concern, causing death and disability. It results from the rupture or occlusion of cerebral blood vessels. Stroke leads to different impairments such as dysphagia, communication disorders, bladder and bowel dysfunction, spasticity, shoulder pain, depression, cognitive impairments and falls. These, as seen through the ICF framework, may lead to activity limitation and participation restriction. Rehabilitation, which tries to increase function after stroke, has been found not effective in preparing the clients for community living. This is said to be so due to lack of emphasis on reintegration issues during rehabilitation process. As a result, after discharge, stroke clients experience different barriers to reintegration which includes

barriers at individual level and barriers at the level of environment. From the literature review, therefore, stroke clients are not fully reintegrated into the community after discharge as literature has shown that there are various levels of limitations and restrictions across the domains of community reintegration. However, facilitators to reintegration in Malawi have also been reviewed and they include efforts by government to mainstream issue of disabilities in all government sectors and society.

The next chapter presents the methodology used for this study.



CHAPTER THREE

METHODOLOGY

3.0 Introduction

This chapter presents discussion about methodology and procedures used to collect data for the current study which includes: the research settings, research design, study population and sampling, data collection, procedure for data collection, data analysis and interpretation, trustworthiness of the study, and it winds up with ethical consideration issues.

3.1 Research Setting

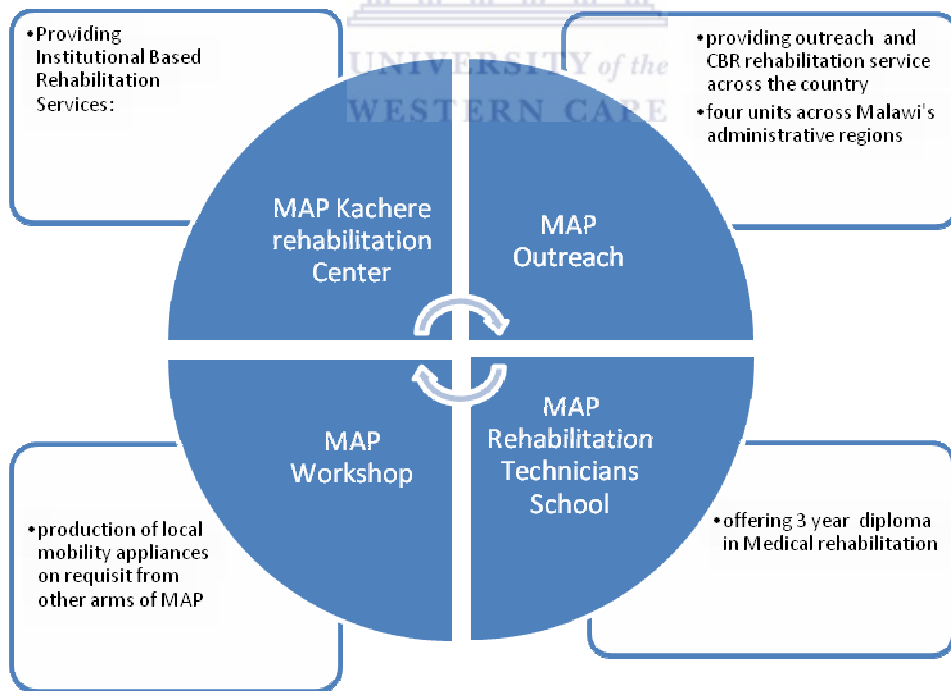
The study was conducted in Malawi at MAP Kachere Rehabilitation Center and surrounding communities. Malawi, a multiparty democracy, is populated by 13 million people (National Statistics Office of Malawi, 2008), 90% of whom live in rural areas. Being a landlocked country, Malawi is one of the least developed countries in the world. The economy is largely based on agriculture which constitutes 90% of export earnings (Malawi Growth and Development Strategy 2006 -2011).

Malawi has a low investment in health with WHO (2008) estimating per capita expenditure on health to be US\$ 20. However, the health care delivery system consists of government facilities, Christian Association of Malawi (CHAM) and private service providers (WHO, 2008). The health services complemented by traditional healers have been reported to be accessed by people with disabilities with 60% of those in need actually receiving the services (Loeb & Eide, 2004).

In addition, Malawi has had no School for training rehabilitation personnel except the rehabilitation school that trains personnel at technician level. However the school of physiotherapy has recently been instituted at College of Medicine. This therefore explains shortage of rehabilitation staff at national level (Kambalame, 2008).

Nationally, Malawi against Physical Disabilities (MAP), which is a parent organization to Kachere Rehabilitation center, could be the largest rehabilitation service provider. However there are other sister Non-Governmental Organizations (NGOs) such as Save Our Souls (SOS), Sue Ryder Foundation, and the government through Malawi Council for the Handicapped (MaCoHa) providing other rehabilitation services.

3.1.1 MAP Kachere Rehabilitation Center



Four Arms of the Malawi Against Physical Disabilities (MAP)

MAP Kachere Rehabilitation Center is the only institutionally based rehabilitation facility that provides rehabilitation services to, mostly, adult neurological patients in Malawi. Clients are referred from district and referral hospitals across the country. However, some are referred from communities by the MAP outreach team and other NGOs such as the Sue Ryder Foundation. MAP Kachere Rehabilitation Center has a bed capacity of 40, and admits between 200 to 250 patients per year, most of whom are stroke clients (personal communication, January 2010). Other conditions include peripheral neuropathy, spinal cord injury patients, and amputations. Orthopedic cases such as back pain are treated on an outpatient basis.

MAP Kachere rehabilitation center has three departments which are: physiotherapy, occupational therapy, and nursing; with their respective current rehabilitation staff numbers of seven, three and two (personal communication, January 2010). The physiotherapy section commonly known as the “Gym” by the employees at the center is the main section involved in screening of referred patients for admission; providing physiotherapy management including referral to other MAP services or sister organizations outside MAP; measuring and issuing mobility appliances; arranging home visits for clients pending discharge; conducting clinical meetings and running refresher courses for rehabilitation personnel. MAP Kachere Rehabilitation Center also offers clinical practice to students from the Rehabilitation Technicians School through placements.

Discharge plans are made during clinical meetings, communicated to the clients and their caregivers a week or two before discharge date with clients and caregivers involved in education and basic exercises to do at home as a preparation for discharge. Where the client’s home is not too far from the center, a home visit is arranged for home evaluation, and recommendations for adjustments made where necessary (Kalavina, HoD, 2010). Kalavina says limited resources affect their ability to conduct home visits for every client pending discharge. This means most

clients are discharged without thorough assessment and readjustments in their community environment.

3.1.2 Communities in Malawi

Since Malawi is mostly rural with small economy which is largely dependent on Agriculture (National Statistics Office of Malawi, 2008; Loeb & Eide, 2004), following discharge stroke clients go back to the community where they are expected to engage in farming for their living if they are not employed, and with almost no mechanization given the size of economy, an average farmer uses a hoe which needs adequate strength and balance. Furthermore, because of low investment in health by the Malawi government (WHO, 2008) the chances are that people travel long distance to the nearest clinic for the services that may not be adequate. In addition, low level of rehabilitation services at national level owing to the fact that Malawi has had no school for rehabilitation personnel means there are limited rehabilitation services to people living with residual impairment after stroke in the communities. Against this background stroke client's reintegration into the community after discharge may be a challenge.

3.2 Research Design

A qualitative research design was used to explore the lived experiences regarding barriers to reintegration of stroke clients into the community after discharge in Malawi. Miles and Huberman (1984) notes qualitative research is by large an investigative process whereby the researcher gradually makes sense out of the phenomenon by contrasting, comparing, replicating, cataloguing and classifying the objects of study. This understanding on qualitative research has been repeated by Cresswell (2003). The undertaking of qualitative research terminates into development of concepts that help us understand social phenomena in natural setting with

emphasis on experiences, meanings and views of participants (Pope & Mays, 1995), via the use of verbal data rather than scaled, calibrated measurements (Thomson, 2007).

Qualitative research paradigm is relevant in health service research. Pope & Mays (1995) observes that qualitative research not only allows health service researchers to access areas not amenable to quantitative research, but it is also a prerequisite for good quantitative research particularly in areas with very little previous investigation. Malawi is one of the countries where not much of research in rehabilitation has been conducted owing to limited number of qualified staff. In addition, qualitative research has generally been used by health service researchers in the area of stroke rehabilitation with credible results (Reed, Harrington, Dugan & Wood, 2009; Petterson & Rose-Edward, 2009; Maclean, Pound, Wolfe & Rudd, 2000).

Although qualitative research is seen in such a positive light, researcher subjectivity and biases can be a problem in the analysis of data; it can be time consuming and costly; and it may be difficult to generalize finding owing to the small size of sample and differences in setting. However to minimize researcher subjectivity during data analysis, literature search and review by the researcher was suspended for the entire period, and theoretical knowledge was bracketed (Moustakas, 1994) so that meanings of real life experiences were extracted from the data than from previous knowledge and experience. In addition, the researcher made proper arrangements well in advance so that activities related to this study were carried out according to the plan. It is not easy to extrapolate qualitative research findings when areas do not share common characteristics (Krefting, 1990); however the researcher gathered data from three different groups of participants to enhance credibility of findings and possible applicability to other areas (Altrichter, Feldman, Posch, & Somekh, 2008).

3.3 Study population and sampling

3.3.1 Study Population

The study population included all stroke clients who were discharged from MAP Kachere Rehabilitation Center, and were in the community for not more than one year after discharge, and their respective caregivers. The study also included rehabilitation service providers at Kachere who at the time of interview, have had worked at center for at least three years either as physiotherapist or occupational therapist, nurse, or a rehabilitation technician. The service provider was an individual providing therapy or care directly to the admitted stroke clients; and was willing to participate (Melton, Levine, Koocher, Rosenthal, Thompson, 1988).

3.3.2 Study Sample

Purposive sampling was used to select stroke clients (n=8) from the study population in two categories: those who were one year in the community (n=4) and those who, at the time of interview, were six months in the community after discharge (n=4). Purposive sampling is a sampling method where the researcher subjectively attempts to obtain an information-rich sample that appears to give enough knowledge of the population under study and will try to include all ranges from one extreme to another (Galloway, 1997). Black (1999) notes that purposive sampling ensures balance of group sizes when selecting multiple information rich groups, however, the method may produce unrepresentative sample due to potential subjectivity of the researcher. In this study the researcher identified not only those clients and caregivers who were information-rich, but also those who were reachable and able to articulate their experiences. According to Jacobs (n.d) representativeness of the sample is secondary to the quality of the participants' ability to provide the desired information about self and setting.

Stroke clients were identified from the center's stroke registry and also among clients who got discharged from the beginning of year 2010, could speak and lived in surrounding communities. By including two groups of participants the researcher hoped to see if there are differences in types and nature of barriers experienced by stroke clients at the two-point durations of community living as post-stroke duration has been associated with level of reintegration into the community after discharge (Obembe et al., 2002).

Caregivers of participating stroke clients (n=8) were automatically selected on selection of their relative or spouse who is affected by stroke.

Rehabilitation service providers (n=6) were conveniently selected based on their availability, from a population of service providers at Kachere rehabilitation center. The choice of six participants as service providers is in line Kuzel (1992: 41) who says "six to eight participants are enough for homogenous sample". However more participants would be added based on whether or not data saturation has been reached. In this study new data was still emerging after exhausting the initial six service providers, one more service provider was therefore conveniently selected and interviewed making service providers (n=7). Convenience sampling is a non-probability sampling technique where participants are chosen because of their ease of access and proximity to the researcher (Castillo, 2009). Convenience sampling is commonly used because it is fast, cheap, and easy to use as subjects are readily available. Castillo (2009) however, observes that the technique has been criticized for producing biased sample which often is not representative of the population. In this study, the researcher interviewed most of the service providers at the center thereby minimizing the effects of bias.

3.4 Data Collection

3.4.1 Data Collection Methods

Individualized in-depth interviews were used to collect data from stroke clients, their care givers, and the service providers in their natural settings. In-depth interviews are the most common form of qualitative data collection as it uncovers issues in much greater detail (Skinner, 2007). Denzine and Lincoln (1994) notes that dealing with one person makes it possible to discuss a phenomenon in much greater detail, while the participant does not feel neglected by the researcher. It is for this reason that in-depth interviews have also widely been used by health care researchers to understand the pressing issues related to health care delivery system (Discicco-Bloom & Crabtree, 2006).

The in-depth interviews started with one general open-ended question: to stroke clients: “this study is about life, living with stroke after discharge from the rehabilitation center. Can you tell me about your experiences for the time you have been in the community after discharge?” then probing for detail, based on what the participants’ responses are (Britten, 1995). To primary caregivers: “this study is about life, living with stroke after discharge from the rehabilitation center. Can you tell me about what you think are the experiences of the person you are caring for regarding reintegration into community after discharge from the rehabilitation center?” To service providers “this study is about life, living with stroke after discharge from the rehabilitation center. Can you tell me what you think are the barriers to reintegration into community experienced by stroke clients after discharge from this center?”

Although in-depth interview are regarded positively, limitation in their use has been reported in that there may a tendency of general lack of originality on the side of the participants related to

what they say as lacking true reflection of what they feel (Gruger & Casy, 2000). In view of this possibility the researcher took all the steps to gain the confidence of every participant before the interview. Some of the strategies were: proper articulation of research aims and objectives, assurance of confidentiality and declaration of their freedom to withdraw at any point, should they no longer want to continue.

3.4.2 Procedure for data collection

After obtaining ethical clearance from both UWC Senate Research Grant and Study Leave Committee (South Africa), College of Medicine Research Ethics Committee (Malawi), and institutional approval to carry out the research at MAP Kachere Rehabilitation Center, the researcher conveniently selected six service providers through direct communication at MAP Kachere rehabilitation center. In addition, with the help of the head of department, the researcher identified the population of stroke clients from the stroke registry, who, at the time of data collection in January 2011, were nearly one year in their community for one group, and about six months for another. Stroke clients (n=8) and their respective caregivers (n=8) were then purposively selected from the population of discharged clients (n=22) as identified by use of register and patient files. Individual calls to the identified clients and their care givers were made, where appointment for interviews were arranged. The interviews which ran from 11th to 16th January, 2011, took place at Kachere Rehabilitation Center (for service providers) where a private room was employed for the individualized interviews which lasted for about 20 minutes each. Interviews for stroke clients and their caregivers took place in their homes and lasted between 25 to 45 minutes. The date and time for interviews were agreed upon by the researcher and the research participants. Also with participants' consent, data was captured by a voice recorder and some was written down in the course of interviews. The objective of interviews was

to gain an in-depth understanding of the phenomenon in question, that is, perceived barriers to reintegration to the community after discharge.

One research assistant with the Malawi School Certificate of Education (MSCE), a form four qualification, was recruited and trained in information handling and ethical issues, preparations of environment where interviews would be conducted, field noting as a complementary to recorded interviews, and quality checking of transcribed interviews. However all interviews were conducted by the researcher. Training of the research assistant was done by the researcher.

3.5 Data Analysis and Interpretation

The field notes were read, summarized and typed up. Recorded interviews were listened to by the researcher and the research assistant to check clarity and saturation before they were sent for transcription by independent transcribers at College of Medicine. The transcribers were the college's secretaries who also had experience from transcribing most qualitative researches carried out at the college. Eight of the twenty three interviews were then sent for translation from Chichewa to English, and together, they were peer-reviewed by two independent physiotherapists working at Rehabilitation Technicians School. The peer-reviewers were conversant with both Chichewa and English languages. At the end, one interview transcript was declared null on agreement between the researcher, research assistant and peer reviewers as lacking clarity because of articulation problem of participant P/IDI/5. By faulty articulation the experience of this particular interviewee might not have been fully captured thereby affecting the representativeness of his experiences to the population (Jacobs, n.d) of stroke clients who were six months in the community after discharge. This reduced number of stroke clients who were almost 6 months in the community to (n=3) and total number of interviews to (n=22). After quality check, the data was grouped according to sub aims.

Qualitative content analysis was employed based on the framework of qualitative concepts by Graneheim and Lundman, in their 2004 review on concepts, procedures and measures to achieve trustworthiness in qualitative research. According to Weber (1990), content analysis is mostly a theory-driven process which is done by looking at documents, text, or speech to see what themes are emerging, what people talk most about, and how the themes relate to each other. Qualitative content analysis therefore leads to contextual meaning in a text through the development of emergent theme from textual data (Bryman, 2001). Roberts (1999) observes that content analysis is a reliable means of analyzing qualitative data as coding decisions are confirmed by revisiting previously coded data to check stability over time. However Burton (2000) warns against overemphasis on standardization, saying, such may lead to distraction from contextual meaning.

From the context of exploring barriers to reintegration into the community experienced by stroke clients after discharge from MAP Kachere Rehabilitation Center, the researcher had three units of analysis (UA) which are 1) exploration of stroke clients' experiences regarding reintegration into the community after discharge from Kachere rehabilitation center; 2) exploration of caregivers' perceptions about the factors that affects their family member's reintegration into the community after rehabilitation and; 3) exploration of the rehabilitation personnel's perceptions on the barriers to reintegration faced by stroke clients after discharge. Unit of Analysis (UA) is whole interview from a sample or observation protocol that is large enough to be considered a whole, or small enough to be possible to keep in mind as a context for the meaning unit (Graneheim & Lundman, 2004). Unit of analysis in this study was therefore defined by the group of participants hence three UAs.

Each unit of analysis was subdivided into meaning units, which are, a grouping together of words or statements with the same central meaning (Graneheim & Lundman, 2004;

Krippendorff, 1980). After data preparation into units of analysis and meaning units, the researcher did reduction of certain aspects of meaning units that carried a meaning, condensing them without losing the core meaning. Bunard (1991) on the one hand, observes that abstraction or aggregation of condensed meaning units involves grouping together of condensed text under higher order. On the other hand, Graneheim and Lundman (2004) claims that abstraction involves interpretation at higher logical level such as creation of codes, categories and themes on varying levels.

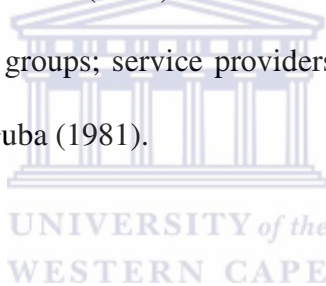
Content areas were made to facilitate coding. Content areas are parts of text that address specific topic in an interview. The researcher, then, created categories based on established codes. Themes were later created, which according to Graneheim and Lundman (2004) are threads of underlying meaning through condensed meaning units, codes, or categories at the interpretive level. Categories have been defined as a group of content that share commonality (Krippendorff, 1980) while Patton (1987) similarly observes that categories are elements of the data that are internally homogenous and externally heterogeneous. Graneheim and Lundman (2004) argue that code or category cannot fit into more than one theme. The codes, categories, and themes were then checked and confirmed by the supervisor.

3.6 Trustworthiness of the study

In early 1990s Lincoln observes that the area of qualitative research was still emerging (Lincoln, 1995) and so subject to misunderstanding by many. Nevertheless Guba (1981) produced four constructs on trustworthiness in qualitative research that has since gained acceptance by many (Shenton, 2004). Guba's (1981) constructs regarding trustworthiness in qualitative research are; credibility, dependability, confirmability and transferability.

3.6.1 Credibility

Merriame (1998) said credibility deals with “How congruent are the findings with reality?” In this study, this was achieved through proper interview techniques, and probing for further clarification making sure that clear and complete view was solicited from the participant; after transcription, the researcher checked the quality of transcription and two of the researcher’s colleagues, Physiotherapist at Rehabilitation Technicians School, peer-reviewed the transcribed data and gave their approval. Furthermore, three of the participants from each group were contacted in their homes and work places to verify that data reflects what they said fulfilling the principle of member checking by Guba (1981). In addition, the researcher also gathered and analyzed data from three different groups; service providers, clients, and caregivers, satisfying triangulation as recommended by Guba (1981).



3.6.2 Dependability:

There is tie between credibility and dependability with Lincoln and Guba arguing that “in practice, a demonstration of the former goes some distance in ensuring the latter” (Lincoln & Guba, 1985). However, dependability proper in this study has been achieved by the dense description of research methods, two independent physiotherapists peer-reviewed the data after transcription and translation, and the supervisor checked and confirmed the analysis and findings throughout the undertaking. Data was also gathered from three different groups of participants, fulfilling triangulation as recommended by Lincoln and Guba (1985) which also contributed to achieving dependability.

3.6.3 Confirmability

Polit & Beck (2006) states that confirmability demonstrates objectivity or neutrality of the data. This has been achieved through member checking of the data after transcription and triangulation (Lincoln and Guba 1985) where data was gathered from three different groups. In addition, personal biases were bracketed under the principle of epoche (Moustakes 1994). Being a physiotherapist with working experience, there could be a general tendency of underestimating some problems faced by a person seen as mildly disabled by stroke. So experiences were taken from participant's perspectives (Mays & Pope, 2000).

3.6.4 Transferability

It is not always easy to transfer qualitative research findings when areas do not share common characteristics (Krefting, 1990). Dense description of procedures and findings are used in this study, and instruments used have been included in the appendix. A complete set of data analysis documents will be available upon request. The accessibility of research instruments may give potential researchers the ability to transfer the findings of the inquiry to other areas.

3.7 Ethical Consideration

After ethical clearance was granted by the Senate, Research Grants and Study Leave Committee at UWC, and locally at College of Medicine Research Ethics Committee (COMREC) in Malawi, the researcher undertook data collection at MAP Kachere rehabilitation center and the surrounding communities.

All measures were taken to protect the feelings, rights, and privacy of the participants, and they included: clear articulation of information about the research aims, values, and risks, verbally and in form of an information sheet. In addition, each participant made an informed decision

before participating, so they all consented in writing of their involvement in this study. Furthermore, statement was given so that every participant was free to withdraw from the study at any point without any repercussion. Participants were assigned codes, for example P/IDI/1, to mean in-depth interview for patient number 1, which were used on all data forms to ensure anonymity. The participants were also informed of all data collection devices and activities before each interview took place, and referral arrangements were made in case of any emergency during the interviews. However no incident happened, in need of referral, throughout data collection. Lastly, the researcher will make available summary of the findings to the participants through MAP Kachere Rehabilitation Center.

3.8 Chapter Summary

This chapter has described the design and methods that were employed to answer the research question, that is, barriers to reintegration experienced by stroke clients after discharge from a rehabilitation center in Malawi. A Qualitative research paradigm utilizing in-depth-interviews as the data collection method was used. Qualitative content analysis with insight from a review by Graneheim and Lundman (2004) was adopted to achieve qualitative disclosure about the barriers to reintegration into the community experienced by stroke clients after discharge from the rehabilitation center. All ethical measures were considered throughout the undertaking.

Results of this study are presented in the next chapter.

CHAPTER FOUR

RESULTS

4.0 Introduction

This chapter present results of the study. It presents the socio-demographic features of the participants, domains into which the barriers are experienced, perceived barriers to reintegration from the three groups; stroke clients, care givers, and the service providers. Facilitators to community reintegration and perceived recommendations to addressing the barriers are presented last in the chapter.



4.1 Socio-Demographic Data

Almost all stroke clients were married and lived with their spouses who are equally their primary caregivers in this study. One woman is widowed and lived with her sister and she is regarded as the caregiver in this study. Four participants reported being employed at the onset of stroke but none maintained going to work by the day of interview. Participants were either retired on medical ground (P/IDI/3) or maintained without pay (P/IDI/4) or maintained with half pay (P/IDI/5) whereas one client (P/IDI/2) was a consultant so he was unable to carry on with his work due to both impairments and change in attitudes of his clientele following stroke. With regards to the Caregivers there were an equal amount of males and females with the majority being spouses and employed.

Service providers had good knowledge of stroke and its management. They were from different professional backgrounds which included physiotherapists, occupational therapist, nurse, and rehabilitation technicians with job experience ranging from three to nine years of providing direct services to the admitted stroke clients at MAP Kachere rehabilitation center.

There were altogether 23 participants in this study and all from within Blantyre district both rural and urban. Blantyre district was chosen on grounds of convenience to the researcher, as Kachere rehabilitation center is within the district. However the results are from 22 participants (one interview was declared null as explained in methodology). What follows is the presentation of findings from the three groups of participants.

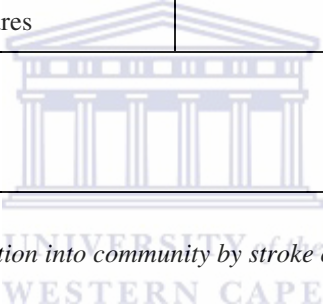


Table 4.1 Immerging themes, subthemes, categories and codes

Domains of community reintegration		
Theme 1	<i>Deficits in the domains of community reintegration of stroke clients</i>	
Sub Theme 1.1	Activity limitation	
categories	1 Loss of ADLs	2 Difficulties engaging in sex
Codes	<ul style="list-style-type: none"> • Failure to carry out basic ADLs, such as bathing • Loss of instrumental ADLs: <ul style="list-style-type: none"> - Inability to walk - Inability to carry out household chores and care for one’s family - Inability to drive as was before - Difficult managing finances/budgeting 	<ul style="list-style-type: none"> - Headache during sex associated to rise in BP. - Unbearable pain during sex by female stroke clients - Lack of strength/energy for sexual activity by male stroke clients
Sub Theme 1.2	Participation restriction	
Categories	1 Loss of participation in economic activities	2 Loss of social participation
codes	<ul style="list-style-type: none"> - inability to resume work because failure to walk - Inability to carry out high level activities proposal writing and discussing with business clientele and associates. - Fear to engage in certain businesses because of its perceived association with stroke onset. - Inability to engage in farming because of 	<ul style="list-style-type: none"> - Not able to participate in community activities because of inability “to put in what one used to before stroke” - Not able to carry out former roles and responsibilities in groups such as church - Not able to take part in community gatherings due to inability to assume certain functional postures such as sitting on the floor. - Reduced interaction skills due to tendency towards withdrawal (quietness) after stroke

	failure to walk and jump ridges			
Emerging barriers to community reintegration of stroke clients				
Theme 2	<i>Barriers at individual level</i>			
Sub Theme 2.1	Impairments			
categories	1 Depression and anxiety	2 Physical weakness	3 Physiological functional changes	6 Bladder incontinence
Codes	<ul style="list-style-type: none"> - Loss of confidence, - hopelessness, - sad-mood, - low levels of motivation, - anger-proneness, - disturbed self-image, - loss of short-term memory and - difficult with thought processing. 	<ul style="list-style-type: none"> -Loss of strength on the affected side, - loss of dexterity (grasping) of the affected hand, -inability to use the affected hand functionally, -failure of the muscle to stretch 	<ul style="list-style-type: none"> -Feeling dizzy when close to fire, - labile blood pressure, -headaches associated to rise in blood pressure 	<ul style="list-style-type: none"> -Finishes urinating before getting to the loo, -bed wetting, -not able to hold urine following the onset of stroke
Sub Theme 2.2	Personal barriers			
Categories	Lack of acceptance of the condition by clients	gender	Co morbidity	
Codes	<ul style="list-style-type: none"> - Lack of acceptance of residual impairments - Too sensitive to join others for participation in community activities. 	<ul style="list-style-type: none"> - Indoor activity limitation such as inability to carry out household chores affecting women more than men - Outdoor activities such as restriction in economic activity participation affects men more than 	<ul style="list-style-type: none"> - Most stroke clients have hypertension and after stroke it is commonly labile, presenting with headaches, seizures which affects ADLs 	

		<p>women</p> <ul style="list-style-type: none"> - Social interaction participation restriction affects stroke client regardless of gender 	<p>such as cooking and sex</p>
Theme 3	<i>Barriers at environmental environmental</i>		
Sub Theme 3.1	Environmental barriers		
categories	Attitudinal barriers	physical environment barriers	Resource limitation
Codes	<ul style="list-style-type: none"> ➤ Change in attitude by family members - Caregivers feeling sorry stroke client, - members taking advantage of the condition, - anger and disrespect towards stroke clients, - denial of situation and potential divorce of marriage by spouses of stroke clients ➤ change in attitude by friends, relatives and other community members - clients obsolete in the eyes of people - no visits by other people - clients not considered in community group activities - people consider it a burden to go around with stroke client in wheelchair - people look puzzled to see client walk, lack of awareness - labelling, witchcraft ➤ change in attitude by 	<ul style="list-style-type: none"> ➤ uneven terrain affecting mobility - hilly areas - Pothole on road surfaces. ➤ Long distance to places of interest - Difficult accessing basic services such as medical, hospitals distant. - Churches located far from clients places of residence limiting their ability to congregate. ➤ Inaccessible structures - Public and private 	<ul style="list-style-type: none"> ➤ Resource limitation at household level - General poverty - Poverty due to costs related to extra costs on transport ➤ Resource limitation at community level - Lack of mobility aids - Lack of convenient portable water points ➤ Resource limitation at organizational level - Limited number of rehabilitation staff at MAP Kachere and the country

	<p>employers and business clientele</p> <ul style="list-style-type: none"> - consumers question the ability of stroke client to deliver appropriate services after stroke - employer doubt abilities of stroke client, relieve them of their duties ➤ unhelpful attitude by public service providers and authorities - business as usual attitude by health service providers, transport operators, and community authorities when building structures 	<p>buildings with steps</p> <ul style="list-style-type: none"> - Churches not wheelchair/disability friendly 	<ul style="list-style-type: none"> - Limited training equipment at MAP Kachere - Limited financial resource at MAP for home visit and resettlement program of discharged clients.
 <p>Facilitators to community reintegration</p>			
Theme 4	<p><i>Facilitators to reintegration into community by stroke clients</i></p>		
Subtheme 4.1	<p>Supportive systems</p>		
Categories	<ul style="list-style-type: none"> - Supportive family, friends and relatives - Availability of a car in the household - Owning an income generating asset - Belief in God - Presence of health insurance in the household 		

Emerging themes of this study are presented in this section. However, before presenting the results relating to barriers experienced by stroke clients after discharge, the domains in which these barriers are experienced are presented first.

4.2 Affected Domains to community Reintegration after discharge

4.2.1 Activity limitation

Activity limitation as embedded in the ICF relates to difficulties an individual may have in executing activities in terms of quantity or quality (WHO 2001). In this section various forms of activity limitation in ADLs and difficulties with sex are presented.

4.2.1.1 Inability to carry out ADLs

In this study two forms of ADLs; instrumental ADLs and basic ADLs, have been highlighted although the limitations has mostly been seen in the area of instrumental ADLs

4.2.1.1.1 BASIC ADLS

Limitation in basic ADLs was not highly mentioned by participants. Only service providers spoke directly about loss of basic ADLs by stroke clients.

Service providers said stroke clients experience problems carrying out basic ADLs evident in what one service provider, a nurse, said that after discharge stroke clients face problems carrying out basic activities of daily living such as bathing:

“especially when her right hand is affected yes and also it is difficult for her to what to take care of herself yes, like bathing” S/IDI/4

4.2.1.1.2 INSTRUMENTAL ADLS

In this section four instrumental ADLs have been presented as being areas where stroke clients have limitation. These are: inability to walk, inability to carry out household chores, inability to drive, and difficulties managing finances.

Inability to walk

Participating stroke clients and caregivers reported problems with walking by stroke clients. Most clients related this challenge to failure to go to places outside their homes and participate in community activities as highlighted by one stroke clients:

“I cannot walk...that I cannot be going kuuuuuuutsskuu gatherings aaaaaeeeh” P/IDI/3

As confirmed by:



“Because walking I cannot walk, so to go out mh it’s not possible”. P/IDI/8

Caregivers of participating stroke clients also said the stroke client had problems with walking. Some caregivers related the inability to walk to failure of the client to participate in outdoor activities:

“... if there is any function away from here it’s difficult because of the way she has to move from here to that particular place ... she is unable to walk” G/IDI/1

Some activities such as leisure by the entire family are also affected by the failure to walk:

“The main challenge that I face I would say is at the moment is mobility because, he is not yet back on his feet actually he can’t walk properly. Socially we can’t go out to

interact, right now the only place I can go is may be to a wedding but honestly I can't go out may be to a party, leaving him here". G/IDI/2

As well as affecting productive work:

"The problem that she meet daily are walking... the work she was doing when she was ok she is not doing she has problems walking" G/IDI/3

Inability to carryout household chores

Stroke clients, caregivers and the service providers expressed that stroke clients particularly female experience difficulties carrying out household chores due to stroke impairments.

In this study, stroke clients indicated their inability to carry out particularly instrumental ADLs.

Women stroke clients were more likely to mention their failure to carry out household chores.

"... since I became sick, as I am sick I am not able to do a lot of work because I am weak. Am just staying so even if I go and wash maybe two, three clothes, but I still see that I do it with difficulty than before".P/IDI/1

Confirmed by:

"I can't cook because when am near the fire I cannot go to the kitchcen when the charcoal burner is burning Iiiii it's hot that's all I feel like fainting eeeeh".P/IDI/3

As a sequel to activity limitations the clients particularly women felt they were not able to take care of their families as they used to do:

“ ... to take care of my family I fail because I cannot cook nsima enough for the family, but only for me, I can cook a little”. P/IDI/1

That they lost their roles at household level:

“eeeh so I want I like cooking, eee so I want that my child should be eating what I cook but I can't Yees because am still a woman yea so am able to see that this worker did not do well here so I will do it myself properly so that when he sees because I don't like talking iii no but if he sees maybe he did not know how to work because he came from the village next time will do as I wanted but the fire” P/IDI/3

Caregivers for all female stroke clients said that their family member had difficulties performing house chores. The caregiver linked this inability to failure to care for their families, and they attributed this failure to physical weakness following stroke as this participant say:

“But now the problem remaining why she cannot cook mh, the left arm has a problem that he cannot cook” G/IDI/8

This is supported by:

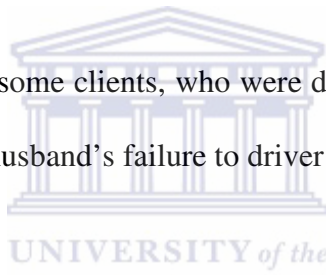
*“Uh within the home the only thing is cooking...that's it cooking is the problem .ya”
G/IDI/1*

Service providers also commented on inability to carry out instrumental activities of daily living such as cooking, attributing this to the loss of function of the arm as reported by one service provider:

“at a family level if the, if the mother or the house is affected it means that some of the works household chores they maybe not be done properly because she is not able to use his ooh sorry she is not able to use her arm or her leg as such she may not do things around maybe to cook, she is not able to cook” S/IDI/4.

Inability to drive

The results shows that after stroke some clients, who were driving prior to stroke, can no longer do so. One caregiver talked of her husband’s failure to driver following stroke:



“In terms of transport, fortunately we have a car, apart from that he can’t drive anymore, I have to drive him, take him to the hospital”. G/IDI/2.

Difficult managing finances

Lawton and Brody’s Instrumental Activities of Daily Living Scale includes ability to manage finance or budgeting as one of the instruments that people use in their day to day life in their homes and communities. After stroke, the ability to carry out such necessary instruments may be disrupted in different ways.

In this study, results show that stroke clients experience problem managing finances as observed by one stroke client that because of her failure to personally go out for groceries due to inability to go out of home, budgeting become a problem as she says in this quote:

“Since with it is yourself you could go to the market and buy as much as you can buy but now I just send a child go, with the boys who work they are a problem eeh they can come and tell you I have bought this I have bought it at such a price you just accept so maybe a day passes the money cannot suffice, it is just as if you do not know the budget and yet there is budget even if they give you 10 thousand per month you can use it for the whole month eeh but now it is not possible” P/IDI/7

Difficulties engaging in sex

Under the activity limitation, this study also presents the problems with sex life following stroke. Caregivers, spouses in particular, expressed failure of their spouses with stroke to effectively engage in sexual activity. Some of the participants (male) attributed the failure to do sex due to pain and headache their spouses experience during sex:

“Yes suppose you switch it off. Av got an excussss” (Off the recorder he said their sex life has also been affected; after sex the wife complains of headache which he attributes to high blood pressure. So much as he may need it often but he feels he has to be careful).
G/IDI/1

Whereas another participant said:

“Ah you know a wife is supposed to assist in the family yes and not only that mh ah there are certain services that a wife need to render to the husband and because of her position mh sometimes it is very difficult mh” G/IDI/8

However, a female participant attributed failure in the areas of sex to low energy levels experienced by her husband following stroke:

“Mmm, (laughs) you know as married people sometimes other marre marital issues require energy which sometimes he doesn’t have, may be because of BP sometimes you find he is not feeling well, may be sugar levels have varied extensively can’t do anything, yeah things of all sorts, we go along. Mm”.G/IDI/2



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4.2.2 Participation restriction

Participation in the community refers to the phenomenon of carrying out one’s role in a society, or getting involved in activities in a group situation (Brakel, 2010). Participation restriction on the other hand is where an individual (stroke client in this case) experiences challenge in an attempt to get involved in life situations (WHO, 2001).

In this study, participants reported participation restriction in two areas; economic and social.

4.2.2.1 Loss of participation in economic activities

In this study loss of economic activities relate to inability to carry out any productive work or any work that has economic value to an individual or their family. Stroke clients, caregivers and

service providers expressed the failure of stroke clients to engage in any activity deemed to be a source of income or food to clients and their families

Stroke clients reported their inability to return to their previous job due to the effects of stroke. Of interest was that stroke clients were able to describe the organic problems that underlie their failure to participate. For example, the clients related their failure to effectively get involved in their previous economic activity to decline in walking abilities with one client saying:

“...It has because am not able to go to work, I have to regain the ability to walk properly yaaah, ah I can't go to the garden, aah because its difficult to walk there” P/IDI/4.

However some stroke clients attribute their failure to maintain productive work to their inability to carry out executive tasks. For example one stroke client said he was no longer able to write proposals, discussing with people since the onset of stroke as he says in this quote:

“Ah well am really noticing something, because mmm, wwhat I have to do I cannot do them now (...)mmm mainly it's that. yeah. Mmh, like writing proposals, (.) mmm meetings with friends, discussing business deals, yeah”. P/IDI/2

But others said they simply cannot do their business following stroke because they associated stroke onset to the nature of their business. One woman thought stroke happened because of her being close to fire when cooking samoosa for her business:

“Before I was cooking this, samoosa, now I just stay, I just saw that may be it is the samoosa ah that started this because of cooking besides the fire, I should heal first I will be able to cook yea” P/IDI/8

The effects of failure to participate in economic activities has been unprecedented decline in income at household level where after stroke the contribution of one member in the family has been cut off due to the restrictions they experience as said by one woman stroke client:

“ummih, on money this is what we do when my husband grows tobacco I help in sawing, so I said aah I should not just be staying so I was growing groundnuts, then people coming to buy groundnuts, to buy groundnuts, and money there phwii (a lot) then am able to help myself not just staying, eeh And now even the groundnuts this year I was not able to plant, yes. it wasn't planted because I am the one who plants it” P/IDI/6

Overall, caregivers on the other hand said stroke clients had problem taking part in an economic work, formal or informal. Most attributed stroke clients' failure to work as being due to failure to walk. For example one caregiver narrated the failure of his wife to take part in farming, evident in this quote:

“She cannot work because the leg jumping the ridges it's a problem the leg cannot walk yaa around the garden but she just stays home but we do the work ourselves” G/IDI/1.

As confirmed by G/IDI/3:

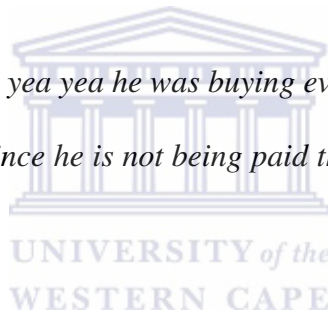
“she is no longer doing because she does not have strength to walk to work so a lot of things have stopped eee”

Caregivers linked the loss of economic activity participation to loss of role as “bread winners” in the homes especially in situations where the affected is a husband:

“It has affected us so much, so much. Financially, socially (laughs) physically it has affected us. You know men are mostly bread winners for the families. We struggle but all the same we go along”. G/IDI/2

As confirmed by G/IDI/4:

“...he was our breadwinner yea yea he was buying everything for the home we were not lacking anything, yes, but since he is not being paid things have gone, things are just in a mess yeah yeah”



However, caregiving husbands also acknowledged the impact of lost supporting roles of wives or female stroke clients evident in what one caregiver said in the following quote;

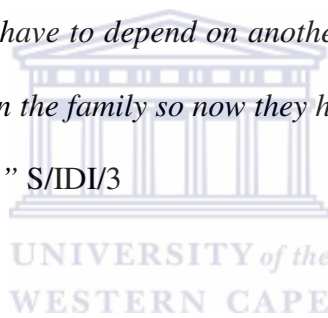
“It’s a little, now it’s little, the inflow of money has gone down, it has gone down mh because her, my strength mh combined mh maybe it was adding up to 30 power yea mh but now it is only 15” G/IDI/6

As confirmed by G/IDI/8;

“Ah my wife was born a hardworking woman aha, ah before the stroke she was able to do some business mh but immediately after she developed that stroke mh she rea... she depends entirely on me mh as a provider...”

On their part, service providers highlighted the failure of stroke client to fulfil their role as “bread winners” of the family following their inability work as stated by one service provider in the following quote:

“Because some of them they were depending on their own some of them were depending on their own and now they have to depend on another person or they were the one, they were the source of income in the family so now they have to..somebody supposed to assist them it’s a little bit difficult.” S/IDI/3



As confirmed by:

“...as the head of the family if man is affected the family do suffer a lot because financially the man is supposed to go and work and get something for the patient and maybe to pay school fees for the kids and also to buy food for the family mmmmh”
P/IDI/4

The loss of economic activity was attributed to loss of effectiveness due to weakness of extremities as one P/IDI/4 said:

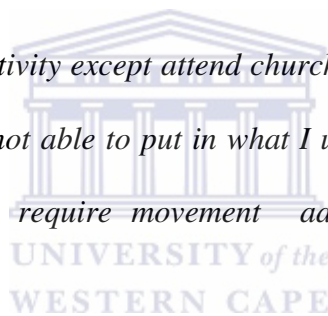
“...and they also may also lose their jobs because they may not be able to work properly since their extremities are not functioning well” S/IDI/4.

4.2.2.2 Loss of social participation

It transpired in this study that even if they want to join social grouping in church or communities stroke clients are not able to take part due to impairments.

Stroke clients said they had problems executing activities in group situations. Some felt inadequate to take part, feeling not able to do or put in what they used to as on clients states in this quote:

“Currently I, there is no activity except attend church yaah, but I don’t have any activity at the moment. I think am not able to put in what I used to... Because of my inability to move, Yaah, certain things require movement— aah, because of that am not able, yaahP/IDI/4



As supported by:

“ah my participation in the community has been affected...because even church ah I ve not been going”.P/IDI/2

In addition, another participant said she could not participate in a church choir which she was used because following stroke, her voice has been affected

“As I said that I have just come here, but at the church where I was going I was a choir member I was singing in the choir but because of stroke with the way it happened I can’t speak louder”.P/IDI/7

However, some participants may fail to participate in community gatherings due to their failure to assume certain positions such as sitting on the floor as evidenced in the following:

“...and for me to rise up from there (pointing floor), that is where there is a problem but I thank my husband very much he encourages me”.P/IDI/7

Caregivers also reported that the stroke clients may have problems interacting and participating in social groupings. They said stroke clients withdraw or remain quiet following the onset of stroke thereby affecting their ability to socially interact as evidenced in the quote by one caregiver talking about her husband:

“His relationship relationship mh for him to speak mh he doesn’t often speak mh unless somebody speaks to him mh he just stays quiet mh you have to ask him why he is just quiet mm. No he wasnt mh but now that he sick he just stays quiet yea mh ok” G/IDI/5

However, others say the stroke clients no longer take active roles and responsibilities in groups they formally belonged to. This, one caregiver said, may be frustrating to the client as they miss a lot of what they used to do:

“Normally she was an active lady at the church, she had some responsibilities but this time no just because she cannot walk normally as she used to be before, but I know she is missing certain things that she was doing before she got the stroke”. G/IDI/1

As confirmed by G/IDI/6:

“She has served in the CCAP church mh e she was a Sunday school teacher mh from there she was in Women’s Guild mh yea... when she could hear that a certain woman is sick mheeh e she would walk with her legs to visit mh. Now unexpectedly she is also sick...”

4.3 Emerging Barriers to community reintegration

The aim of this study was to explore the perceived barriers to reintegration into the community by stroke clients discharged from Kachere rehabilitation center from the perspectives of stroke clients, caregivers, and the service providers. The analysis of data terminated into two themes: Barriers individual level and environmental barriers. Under each theme there are emergent subthemes that will be described.



4.3.1 Barriers to reintegration at individual level

4.3.1.1 Impairments

Under this theme five subthemes emerged which includes depression and anxiety, physical weakness, physiological functional changes, pain, and bladder incontinence and are presented in this section.

Depression and anxiety

Stroke clients in this study indicated they psychologically experience loss of confidence, hopelessness, feeling of sadness and loss of motivation as affecting their daily lives. Lack of confidence affects their ability for interaction with others in their day to day life as stated by one client:

“Ah mainly it is because (..)erm am not confident.Yes, But (..)soon I ve come to er to realize that these things work slowly I will pick up. Yeah. The confidence that I I used to have is no longer there. But right now am picking up. Soon I will ge I will get back to life. Yes”.P/IDI/2

This, he said, has particularly affected his dealing with people as a consultant.

While confidence has been an issue, another participant said she felt so hopeless and anxious about her life with the disability from stroke, making her wonder if that’s the type of life she will live forever:

“Uhuu, this disability what the problem is, is that I would have been doing things here at home myself but now am not able to, so when am I quiet, is this how I should be living until the end of my life iieh it’s difficult” P/IDI/6

Sadness was expressed by participants who felt bad for not being able to walk outside like others do:

“I feel when I see my friends walking out there, walking around I feel pain in my heart, but I just accept that, that’s how it is so I should just accept but I feel pain in my heart”.P/IDI/1

Other stroke clients expressed lost interest in activities, do not feel motivated enough to carry them out as one female client says in this quote;

“Mmh I shouldn’t lie mh there is nothing that I do mh I just stay mh even my heart does not have any desire mh that I should do this work mh” P/IDI/8

On the other hand, caregivers especially spouses to stroke clients say that their spouse has become anger-prone since the onset of stroke. This, some caregiver said, has changed the way they relate with the spouse with stroke, that they now have to become careful not to raise the spouse’s temper as shown by a husband here;

“regularly as a normal person who has been a normal person before there is a slight change,1 the way she talks to us, the way she conducts herself just because at times she gets irritated very easily, and because of this when we notice to say, we should give her ample time of thinking and talking to us calmly ,to avoid maybe raising her temper .so were keeping her till today”. G/IDI/1

Whereas others say the tempers lead to misunderstandings as stated by one wife in this quote:

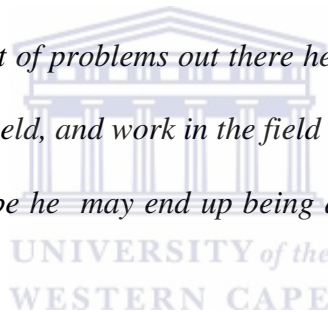
“Of course the temper was still there but, may be you know, because he is just stationed at homeeh? The could be some elements of an increased... things of that sort..., we misunderstand each other... it it becomes difficult to understand each other. Mm.” G/IDI/2.

In addition caregivers also expressed that psychologically stroke client experience altered self-image following their perceptions that people don’t want to be close to them after stroke as evidenced in the following quote:

“Ah I think sometimes he feels that he he asks me do does it mean people they think that am hopeless I can’t do anything? ... mh yea I just encourage him mh” G/IDI/4

Service providers also expressed some challenges experienced by stroke clients. They said stroke clients suffer depression and low levels of motivation after stroke. However they attributed development of depression to different challenges they face when they are back into the community such as their failure to perform their traditional roles and duties in the family as highlighted in this quote;

“Psychologically that patient is affected much he may feel that it’s better for her maybe to die because he finds a lot of problems out there he is not able to get food on his home ,he is not able to go to the field, and work in the field ,he depends on somebody, yaa. Well she maybe as a result maybe he may end up being depressed if he is depressed that is another problem” S/IDI/4



And confirmed by:

“yeah in the patient themselves somesum sometimes there is ahmahm depression, reduced motivation” S/IDI/2.

Perceptually, stroke clients experience short term memory problem after stroke. Stroke clients expressed that following stroke, they have memory problems as highlighted by one stroke client saying forgetfulness after stroke made her feel less human:

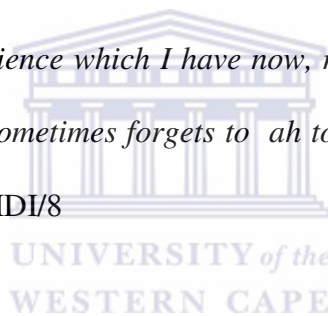
“No at first I was just like a dollemh ok mh Forgetting, am number one ok mh Better now am able to remember a little mhok ” P/IDI/8.

As confirmed by:

“Am not able to remember things It is affecting me because the way I was before I could memorize verses or something, I could remember but now I don’t know if it will ever be possible” .P/IDI/1

Caregivers also reported the tendency to forgetting that had become common in their spouses lives. This according to one guardian affects reliability about communication in the home as he says:

“Yes mh because the experience which I have now, mh, that she has that thing forgetful forgetfulness aha and she sometimes forgets to ah to tell you something which has been told by some people mh”G/IDI/8



As confirmed by”

“Where I am seeing the difference is sometimes his head seems not to be working properly mhwhen he wants to call the children, maybe another one, you so and so mh you so and so mh and the one you calling is not around, oh sorry I forgot mh eh ok” G/IDI/5

Services providers on the other hand said that following stroke, particularly in cases of severe stroke clients may be having problems with thought processing that may affect their day to day life in the community as highlighted in this quote:

“And here maybe it depends on some maybe it depend some severity of the damage some cannot do anything the cognition is affected the conception is affected in such a way that they cannot think the way they used to think so they have to depend on another person”

S/IDI/3

The service providers also said female participant particularly may suffer distorted self-image in relation to future intimate relationships particularly with their inability to carry out domestic work

“...if it’s a woman you feel like no maybe I will never marry again because no man will be happy only helping me which is very easy to do but mostly they don’t like they feel like if he is being troubled” S/IDI7



Physical weakness

After stroke, loss of strength on the affected side and loss of dexterity at the affected arm is common and remain the main element that impedes functional recovery following brain damage by the stroke (Ada, Canning, & Low, 2003). In the current study, stroke clients and service providers mentioned weakness of upper and/or lower extremities as leading to their inability to perform activities in the communities.

One stroke client, for example, said the weakness of her leg made it difficult to board a car as evidence in the following:

“No I can board but sometimes this leg appears to be weak so maybe you can board but have problems when getting off you need someone to get off” P/IDI/7

This shows that clients may have problems travelling from place to place.

Whereas weakness of upper limb was also expressed by another:

“Stroke, it is what is giving me problems yes, the problem is this arm I cannot hold anything” P/IDI/6.

However, one participant highlighted stiffness of the ankle joint and failure of the associated muscles to stretch to allow walking:

“This foot I cannot step with it, it cannot stretch, because this is the foot that bent...”
P/IDI/8

Muscle weakness and stiffness was, therefore, regarded as a source of challenge for mobility in the community.



Service providers said stroke clients have problem integrating back into the community because of residual impairments especially weakness of extremities that makes them fail to use the affected limb.

“if they don’t recover fully let’s say if it’s a stroke patient most of them they are able to walk but the hand is not functioning so some of them they are not able to use the hand, ya to do some of activities” S/IDI/3

As confirmed by S/IDI/4:

“most of the patients when they go out they do suffer a lot because they are not able to use their .. (..) their what..their Extremities Yes,yes, extremities ahaa, especially those with severe attack and these people they are not able to carry out their activities aaha,in the family as well as in the community as a whole”

Physiological functional changes

Physiological functional changes in this study relates to changes in the body that has been common and persistent in pattern, experienced by clients after stroke, and to some degree affecting the client’s ability to perform certain tasks that are perceived as triggering the onset of the symptoms.

Stroke clients, particularly female associated dizziness to going close to fire, so that the ability to cook is affected as evidenced in the quote below:

“because it is a difficult disease and fire to be near fire Eeeh! No it is difficult. it is ii the head is like it has already boiled so iiih! When you are like that you are just afraid that when am standing up ii wont I fall on the fire. Your head feels dizzy” P/IDI/7

Whereas caregivers reported constant changes in the blood pressure of their spouses who had stroke, saying raised blood pressure affects their mood, and also present with unprecedented headaches as highlighted by one caregiver:

“still there are ups and downs. she keeps quiet then later on she complains about headache. I know sorts of headache maybe the blood pressure is now high I don’t know and again because of the thinking of her friends thinking of having missed certain things

then she has got something else but the temperature has got to rise up, these is the way only think about it ya,” G/IDI/1

Whereas another caregiver associated raises in blood pressure to onset of seizures that affects the general ability to function such as the ability of the wife to drive him to the hospital:

“When he’s fallen sick of cause sometimes may be when the pressure is so high, he does things like seizures when may be people think I can’t drive somebody has got may be to drive us when am caring for him may be in the back, back sit. Mm” G/IDI/2

Pain

Stroke clients experience pain following stroke as one stroke client complained of chronic pain since the onset of stroke as she said:

“Yes, no but it is a bad disease mh, mh a lot of pain up to now nothing has changed mh yes aha” P/IDI/8

Urinary incontinence

Stroke clients experience loss of ability to control urine. For example one caregiver narrated of the development where the husband frequently lost control of his bladder, failure to control urine so that he often soaked himself before getting to the loo. The development, she said makes him feel sad

“To him the main problem mh (clears throat) like when he is standing mh and that maybe he wants to urinate and when he wants to go and help himself then before he reaches there mh then he will see that he has finished urinating mh on the way mh by the time he gets there he has finished mh also sometimes when he is asleep mh where he is sleeping and he wants to wake up mh he will see that there is already urinated there mh so he gets worried but this previously I wasn’t doing this mh but these days this is happening mm so I tell him that he shouldn’t not worryhim it’s not deliberate but because of sickness, ok, yes” G/IDI/5.

4.3.1.2 Personal barrier

In this study, personal barriers relate to factors about the stroke client that potentially limit their ability to perform or participate as well as others do. Three barriers have been highlighted and these are; lack of acceptance of the condition, gender and comorbidity.

Lack of acceptance of the condition

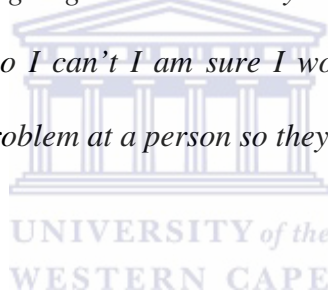
Service providers perceive that stroke clients sometimes lack acceptance of residual impairments which make them too sensitive of their condition so that their ability to associate with other community members become difficult. This is evident in the following quote:

“I cannot say because of their weaknesses maybe acceptance can we say acceptance, because some of them feel like maybe they will go home okay yah and for maybe to accept that they cannot fully use their affected side is difficult. The effect is that maybe

the community is trying to ask them about the affected side you feel like (clearing throat) they are doing something bad to you, so you are saying that both sides have to be 50-50 because if somebody maybe is affected and if you say the community is asking more questions about it and they are failing to answer they feel like the community is somehow torturing you not accepting you fully” S/IDI/1

In some situation, stroke clients are not free to meet people who used to see them when they were okay, thereby limiting their ability to participate in the community as evidenced in the quote:

“...now where I can just squeeze in the wheelchairs or some of these maybe afraid of that I used to be ok when I was going to church very well but now to go with my bend arm and with a walking stick no I can't I am sure I won't receive the reception I used to receive so its becoming a problem at a person so they decide they can't go” S/IDI/5



Gender

From the results presented already under the activity limitation domain women are more affected than men by the loss of instrumental ADLs such as inability to carry out household chores. In contrast, the study has illustrated that men are more affected than women by the activities outside the home, participation in economic activities in particular.

Hypertension: a co morbidity

From the results already presented, most stroke client are also hypertensive and both caregivers as well as stroke clients have explained how some activities such as driving, cooking, and sex can be affected by the suspected rise in blood pressure.

4.3.2 Barriers to reintegration at community level

4.3.2.1 Environmental Barriers

In the clients' communities many factors exists that are seen to affect the clients. Factors in the environment as imbedded in the ICF are those factors that are external to the patient but can directly or indirectly affect them, either positively (facilitators) or negatively (barriers) (WHO, 2001). In this section the researcher presents the environmental barriers to the stroke client's reintegration into the community, as perceived by the participants.

Three sub-themes have been arrived at as constituting environmental barriers. They includes: attitudinal change, limitation by environmental physical factors and resource limitation.

4.3.2.1.1 Attitudinal barrier

Attitudinal barriers in this study are the perceived barriers as emanating from people's deep rooted feeling towards issues of disabilities as shown through their actions, which affects stroke clients' ability to reintegrate back into their communities after discharge. Under this sub-theme attitudinal barriers will be presented in three levels a) change in attitudes by family members; b)

change in attitude by friends, relatives, and other community members; c)change in attitudes by employers/business associates/clients.

Change in attitude by family members

Changes in the attitudes by family members may be the first line of environmental barriers that stroke clients experience.

The study results shows that at family level, members including children may be taking advantage of the client's condition, not obeying orders as was the case before stroke.

Caregivers related this development of sad mood to the client as one caregiver says below:

*"... now they look at her as a fool mh e they see her as a fool because before she became sick the way we were living, all the bad things that the children are doing mh they were not doing but now they see that you think grandmother can run, ah she can't run mmh so she gets sad that mh but before you couldn't do that to me eh yes okay"*G/IDI/6

Service providers on the other hand, said after discharge some care givers feel the client is a "patient", they feel sorry for them and so develop overprotective attitude for the clients thereby not giving them a chance to participate in activities. This is evident in what one participant said:

"if they go home they don't continue because the guardians they feel sorry for the patient they feel like doing everything for the patient so they don't participate much like in decision making doing maybe ADLs". S/IDI/6

On the contrary though, some family members may change attitude towards stroke clients' failure to perform their role in the family particularly if they were breadwinners. Being angry and

disrespectful towards the client may lead to emotional problems such as depression that limit their participation in activities as one service provider says in this quote:

“...to accept that it’s not a very easy thing now they might be angry some of them they may look down upon their father that may integrate the situation of the father you know for example the patient they may face emotional problems and facing this reaction from family members is another problem” S/IDI/5

However, some service providers said there is often change in the attitude of the spouses to the stroke client who can no longer perform their roles in the family because of stroke. Three service providers said spouses end up running away from the stroke client. This is evident in the following:

“maybe if it’s a man had a wife maybe the wife would see that the man is no longer use useful is no longer getting anything for the family so maybe they run away they go for other men if it’s a woman the man feel that the woman is not doing everything for the man as you know than the man is just an a person who looks for money and the woman is cooking, washing and doing everything for the whole family so if the woman is unable to do that the man goes to look for somebody else” S/IDI/6

But other service providers said if it is not running away then it will be marked disobedience to the orders of the stroke client which end up being devastating to the client as highlighted in the quote:

“If it is a man whatever you say in the family is like the woman won’t follow much because After all when he says this himself cannot give us the practical...” S/IDI/7

Changes in attitude by friends, relatives, and other community members

Stroke clients in this study expressed their perception that people in the community are no longer the same; their attitude towards them has changed to varying extents. Most of them said they felt obsolete in the eyes of people in the community. For example, people in the community no longer maintain interest in visiting them as highlighted by one client:

“...the people are the ones am talking about that maybe when I stand outside they greet me how are you? I answer then they go on”.P/IDI/1.

This is so because stroke clients are no longer productive so that when those people do come to visit they don't get any economic benefit as it was before stroke. This is evident in the following:

“I think I have friends but not many. I have them but they used to come when I am okay, because even my relatives they don't show up so often..... As compared to the time I was okay, because I used to have money. They can't waste time with me (..) because if they come, what will they get (..)?”. P/IDI/2

As supported by:

“Not quite some people come but there people who no longer come to visit, yaah. Well, they feel may be there is nothing they can gain, Yaah, so they no longer come”, P/IDI/4

Caregivers also perceive that clients increasingly experience a narrowing in the base of social contacts after stroke, as friends and the community members gradually cut off their friendliness to the stroke client who is perceived as no longer reciprocating to their visits:

“only a few (people) and if she want has to meet some it means she has to go to the church otherwise there is uh absence of our friends the usual friends and because of this therefore I feel she has some feelings to say she is dead but for sure she hasn’t is dead”.

G/IDI/1

However, some of the caregivers expressed the view that people don’t come because after stroke the clients are no longer productive to give out some hand-outs such as money when those people visit. As a result only few people maintain friendship as one caregiver says:

“Yeah they do come you know but the usuals when sometimes mmost people love you when you re well and may be you can provide something to them”. G/IDI/2

As confirmed by:

*“Mh you know when people they know that you are sick aha they desert you ok because at first he was doing everything mm and he was supporting many people and he was assisting many people mh but since they heard that he had that stroke mh they just know that they think he is useless yea yea”*G/IDI/4

In addition, the caregiver say, some attitudinal change are displayed by social groups to which a stroke client belonged before stroke. This is often in form of not being considered as one who can act in a given situation as was before stroke (social exclusion). This is shown in the following quote by a caregiver:

“But where you feel people cannot even remember you mh and invite you as one of them mhthen how you can eh how can you perform while he is already sidelined like that”. G/IDI/7

On their part, the service providers expressed the same perceptions as stroke clients and caregivers saying friends and other community members gradually disappear after stroke. For example, one service provider said people don't visit the stroke clients leading to their being socially isolated:

"...they may decide to visit him for few days after discharge because now he has come from the hospital but after but after a month they disappear and they left the patient alone socially isolated people are not visiting him anymore and he cannot go out" S/IDI/5

In addition service providers said some people find it a burden to go around with a stroke client in a wheelchair so they end up isolating them:

"it's the attitude of the community mostly people say this one is disabled now he was walking fast now he is unable so carrying him on the wheelchair wherever he wants people don't like that so they end up the person not participating" S/IDI/7

On public services one participant said there is potential negative attitude by taxi operators which makes stroke clients have difficult travelling from place to place:

"else I don't know what they think they just say aah you won't fit because they say my own minibus I have to help I don't know what they fear is to touch somebody who is disabled I don't know what they fear I have seen many stroke patients failing to board minibus just because they have stroke" S/IDI/7.

Change in attitude by employers and business clientele

Change in attitude of employers and/or business clientele lead to stroke clients having problems going back to their former jobs (for those who were employed prior to stroke) or some jobs that stroke clients were engaged in for survival prior to stroke. Failure to go to their former jobs due to negative attitudes of employers or business clientele makes life in the community after stroke difficult for the clients and their families.

Stroke clients highlighted their perception that they have problems carrying out work with the former clients as they no longer trust that after stroke the clients can do a good job for their consumers. For example a client who was a consultant prior to stroke expressed that he has problem securing an order after stroke, as evidence in the quote:

“... I get paid though I mainly talking I answer their question mmhahm (..)ahm I can answer their questions but normally what happens is that the people that I I hear are not comfortable to bring their work to me because of the way they er looking at me”. P/IDI/2

Caregivers perceived that some attitudinal changes related to employment also affect stroke clients. For examples one caregiver was not satisfied why her husband’s employer cannot give a chance to work now that his condition has improved as she says:

“...those people at Poly they think he can’t do anything aha because they are not coming to see him they saw him the day he just got the stroke mh the time he was not walking, mh not talking mh so they just think he is in the same state ok they don’t know that he has improved mh...” G/IDI/4

Service providers said stroke clients suffer employer attitudinal change after stroke that often lead to clients being relieved of their duties following stroke, this, the participants said, limits chances of carrying out their intended projects and having problem in accessing day to day needs.

“consider I mean consider somebody who has had a stroke as he is no longer fit for duty so people lose their jobs simply because they had stroke if somebody was earning money that means his income is cut and if he was able to access some other issues he would not access because he has no financial muscle supporting ahm yeah”. S/IDI/2

As confirmed by:

“what I am saying is aahlets assume I want to build a house now so what I need is to come to work here and find some money of course I can do some business sometimes but if I am disabled am I going to go there? No, definitely people will now say aahMrWaekha because you were doing hands and you were using both hands to help the patients now we are relieving you of your duties now definitely of building a house I should switch off where to source the money will be a problem that is another barrier”
S/IDI/7.

Business as usual attitude by public service providers and authorities

The attitudes of some public health providers make stroke clients have problem accessing health or medical services in the community. For example, stroke clients say because organizationally there is no special arrangement for people with physical challenges such as weakness from stroke they find it difficult to compete with other able bodied people when they want to access services.

One stroke client talks:

“I at Queens it is difficult to go mh you go but you need to leave very early mh and reach there before they open mh and be on the queue mh that means you will be able to get the medication” P/IDI/8

Caregivers on the other hand highlighted that accessing public hospitals services become a challenge for stroke clients with impairment as evidenced in this quote:

“after being assisted for a certain problem possibly we go for review sometimes mh you find a big a long queue mh people standing mh of course she stopped using wheel chair but mh but we are forced because she can’t stand for a long time” G/IDI/7

In addition the caregivers perceive that the behaviour of people utilizing services such as transport makes it difficult for clients to ably utilize them. One caregiver expressed about public transport not being conducive for his wife to travel by:

“I think she is not all that ah seem to be fit for those conditions you walk into it and sometimes you are pushed that can you push that side someone wants to here, mmh so with those experiences mh I think, I think they are of ah not favourable to her mh that is what I see”. G/IDI/7

Service providers perceived that the behaviour of taxi operators make stroke clients have difficulty travelling from place to place, because they are not patient enough to accommodate a stroke clients who may be walking slowly at the time when they want to make more money out of their business.

“it’s really difficult because as you know the minibuses they are in a hurry looking for passengers so somebody hee has stroke the s pace of catching a minibus is very slow so

automatically that one is left out because of time And also if he has a wheelchair may be its not foldable they cannot accept in the minibus its difficult unless he has his or her own transport, yeah". S/IDI/6

As confirmed by:

"for him to go to the hospital it's a little bit difficult for her because as a means of transport he or she is supposed to board a minibus and for her to board it takes some time and for to other people they may think that eish that person is just wasting their time they are rushing maybe to work as a result that patient may may what he may be waiting for transport for a long time for her to get a transport it is a problem" S/IDI/4

However, some service providers said that authorities just do not consider some people with disabilities when carrying out or implementing project, as a result stroke clients have difficulties accessing the products, as one says in this quote:

"I see these people knows disability is there but still when there are implementing the churches the organizations they don't consider it to say 75% if not 80% they are not the barriers to the patient" S/IDI/5

Negative attitudes due to Lack of knowledge and awareness about stroke

The study shows there are specific negative behaviours of people due to lack of awareness about stroke and its complications. These behaviours also affect stroke clients' ability to reintegrate into the community.

Stroke clients in this study said people in the family and community do not seem to be aware about stroke condition. One client talked of how his family is not providing what he needs satisfactorily, it looked like he knew what he wanted but people around him didn't, as he say:

“ahg I can say that am getting the attention, but ah the attention am getting as compare to the time I was okay, mm (..), is abit different ... yes because the attention that I ha I get is when I am demanding something ah mmm..... but normally ahm I don't get anything more than that. (Talks to the son)”.P/IDI/2

However, some clients said people in the community did not seem to know what stroke is all about. This makes some not to appreciate the difficulties a person with stroke may be experiencing as said in the following quote:

“but it's bad to be difficult to integrate back into the community because it is you who feels something needs to be done not that that other people” P/IDI/4

Whereas, in many instances lack of awareness is shown by people's reactions when they see somebody with stroke walk:

“The people we meet in the streets stop to look at us wondering since they don't know it happened somewhere here I just came, others don't know what happened others know that am sick but they don't know what am suffering from eeh yes. Iiiii I get worried.hmmm. Eeh I really get worried” P/IDI/7

This demoralizes stroke clients leading to their opting to remain indoors and fail to participate in community activities as shown in the following”

“Mh walking is the problem mh because before I could walk up to down there mh eh so when I was walking I could see people standing along the way looking as if a beast is coming or something mh so then I could see the way they were looking at me. So I came round once this way mh then mh I stopped I did not go again ok mh” P/IDI/8

Service providers in this study talked of public awareness about stroke in the communities. The lack of awareness makes it difficult for persons with stroke to be understood and properly integrated into the community, evident in the following quote:

“there is lack of awareness I think we as a nation we have concentrated more on primary health care and issues of stroke and they are considered secondary or tertiary...this lack of awareness has contributed a lot because the people are not aware if they were they could have taken even some precautions on the issue”. S/IDI/2

As confirmed by:

“sometimes it is lack of knowledge because other people they don’t know much about their disability and the way they think is that somebody who is disabled can not participate in the society or can not do anything so lack of education could be barrier”
S/IDI/3

The lack of awareness manifests itself through different cultural beliefs that tend to be harmful to stroke clients living in the community. Service providers said people do not have the reality that stroke exists, so everybody affected by stroke is associated with witchcraft, evident in the following:

“yeah one other thing that I did not mention is stigma that’s associated with tradition it is considered sometimes in the community that somebody who had stroke is a witch, facial paralysis is misinterpreted as if you’re a witch” S/IDI/2

Service providers associated lack of awareness and labelling to stroke client’s failure to participate in economic activities due to discrimination:

“there is discrimination as it is associated with wis witchcraft so because of that they are like isolated they don’t feel to be amongst other pip, so interms of business whether development they don’t do because of that, mainly because of thatas I have said that there is that stigma of associating them with witchcraft so automatically whatever goes it itcant be as fair, yeah. They are always behind the able bodied people, yeah”. S/IDI/6

In addition, service providers said lower education level of the family may be the basis of not understanding of difficulties the person with stroke may be passing through, hence not creating a conducive environment for activity and participation

“maybe educational level of the family. If the families is well educated they easily understand the cause of the disease and how to handle somebody but if the educational level of the family is a little bit lower they may fail to understand what this is hmm and that will have negative effect to the patient” S/IDI/1

As confirmed by:

“if the family is composed of composed of learned people who understand the stroke and their effects even if they don’t understand and or but when you explain to them they get

the idea they maybe willing to ah take issues further in assisting their relatives but other families their understanding is low” S/IDI/1.

4.3.2.1.2 Limitation by physical environmental factors

Physical environmental factors that emerged as acting as barrier to reintegration are mainly those that affect the client’s ability to remain mobile especially those that limit movement outside the home environment. They are mainly three and they include uneven terrain, long distance to places of interest and inaccessible structures

Uneven terrain

Stroke clients said the nature of the road is a big concern when it comes to moving from place to place due to poor terrain as one client said in this quote:

“you can see ah the road that you have walk to come to here. That means mmm somebody like myself cannot walk properly in this road of this nature er (silences son) mmmh what can I say aah (...)”P/IDI/2

The sentiment that was also said by others:

“Where I live is not rocky am able to walk properly but here it Is rocky eeh so it makes walking difficult” P/IDI/3

*“Outside it’s not easy because of the steps, yaah and the galleries, here and there, yaah”
P/IDI/4*

Caregivers also highlighted the difficulties that stroke clients face when they have to move from one place to another because of poor terrain as reported by one caregiver below:

“He can move to the bedroom, to the toilet, outside, but not long distances may be because of the mmm I can say environment malo akewaetu (nature of this place) okuti la landscape is not really conducive, mm is not really conducive, possibly if it were somewhere in a flat place, he could participate” G/IDI/2

And confirmed by G/IDI/3:

“What hinders her is like for example over there, there is a wedding and for her to walk up on that slope to reach there she can’t with the way her leg is whereas people like us who are fine we can run up to there but she can’t walk”

Service providers also expressed that poor terrain in the home area makes it difficult for stroke client to remain mobile in the community:

“Movement yeah says from the main road to someone’s house in the village if it is mountainous, there are rocks you can hardly move with car, you cannot move with bicycle you can’t move with anything you just have to walk on foot and if you are not able to then that’s it” S/IDI/2

According to the service providers, this is especially true with rural areas where most people come from in Malawi, limiting their chances of visiting friends and relatives in other parts of the community as one participant say:

“because of the body structure functioning because sometimes you cannot achieve to the full maximum most of our patients they will need or I can say 90% of the patients we discharge them

here as you know they go hectic in the rural areas they are bumps, stones he has to think twice before he says I want to visit Mr Phiri and this is about a Km away” S/IDI/5

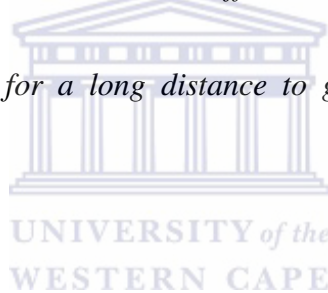
Long distance to places of interest

Sometimes because of long distance to places, stroke client may fail to access such places due to difficulties with travelling.

Some clients expressed that many places of interest, are distant from where they live:

“For me to travel on public transport to board minibus eeh when I board off the taxi there is a long distance to the center (trading center) eh it is far because now it seems am walking like this so ehh to walk it becomes difficult. Mmh”P/IDI/7

“...(places)are not flat so for a long distance to get to church, it’s what makes me fail”.P/IDI/1



Caregivers also highlighted how hard it is for stroke clients to access services such as medical because of long distance to the nearest service centre as indicated in this quote:

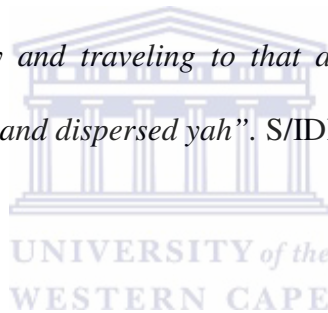
“the drugs that were prescribed to us that time we just go and buy themyaah because from here to Blantyre it needs money (for transport) and also standing in queue in order to receive drugs most cases we don’t go to Queens we stay instead we just go and buy”.G/IDI/1

This sentiment has also been said by G/IDI/3 though the main problem indicated is the long distance to go to and fro the bus stage:

“...but for her she cannot walk from here to the road to board a minibus it will not be possible transport will be required to pick her up and also when she gets off a minibus to reach the hospital another transport to pick her to the hospital that is the problem that is there” G/IDI/3:

Service providers also said that long distance to nearest health facility makes it difficult to access medical service as effective transport is not always available

“The only barrier is transport maybe because for somebody to access hospital in the rural area is 10Kms away and traveling to that area might be difficult because the hospitals are very far away and dispersed yah”. S/IDI/1



Asconfirmed by:

“I had a patient who stayed in hmmm I don’t know hmmm where is Mzimba, And that place the healthy is a stroke, several heart hypertension so he was using some of the drugs so when he went to the hospital, was very far in such way that now he is not able to access the medication because of the distance, yeah. Somost of the wards, some of the hospitals or healthy centers they are a little bit far”S/IDI/3

Inaccessible structures

Stroke clients said some buildings with steps are not accessible to somebody who has mobility problems, evidence in this quote:

“Aaah this is all its difficult when it comes to steps, that is very difficult, yaah Mmh, I really have to judge exactly how you are going to do it ,yaah”. P/IDI/4

Caregiver also expressed that stroke clients have problem accessing buildings with steps:

“Now things have stopped aha because for her move from there alone eh maybe going into the house then in the house to climb steps behind mh you have to hold her to pass mh” G/IDI/3:

Service providers, on the other hand, perceive that the inability of stroke client to travel on long distant journeys is sometimes due to the way taxis were made, not roomy for mobility aids such as wheelchairs. Evident in this quote:

“...they solely depend on wheelchairs because some of the minibuses cannot accept to carry a person on the wheelchair at the same time taking wheelchairs they are specific minibuses that can do that some they say they don't have space to put wheelchair so but that's very minimal” S/IDI/1

As confirmed by:

“Mmmm,most of them it’s a bit difficult because some of them they are using the wheelchair and as you know that our transport – the minibuses somebody in the bus…… wheelchair so it’s very very difficult/IDI/3

In addition, service providers expressed that stroke clients have difficulties accessing public institutions. They said inaccessibility to institutions makes it difficult for stroke client to utilize services from such institution, as one service provider says:

“uuhmmh I think when you discharge patients from here they really have problems in the communities the first thing is accessibility to institutions, talk of the church, talk of ah schools, also consider banking institutions which are not ah designed to suit wheelchair users or somewhere somehow people with strokes” S/IDI/2

This is confirmed by

“ok I don’t know much about the rural area but here the experience I look in Blantyre town people go to church people like going to church especially in Malawi and you know our churches in town they are really and how many churches in town are disability friendly (laughing)” S/IDI/5.

4.3.2.1.3 Resource limitation

Resource limitation in this study refers to absence of certain factors that lead to challenges on issues related to reintegration into the community by stroke client such as finance and material

resources. Resource limitation in the current study has been seen at three levels: household, community and organizational levels.

Resource limitation at household level

Limitation of financial resources due to poverty, employer policy and cost of disability related to transport has been highlighted.

Stroke clients in this study highlighted the difficulties they experience in accessing public medical services as being due to poverty and that it needs more money for transport which they often did not have as evidenced in this quote:

'Eeh, here sir it's difficult because to get to Blantyre you need to hire going and coming back you also need transport from here up to Blantyre so it becomes difficult for us, yea money Eeh money, as you can see even these children they come to me i want this, yea, iii so sir nothing to do, there are small children one does not have a mother and father, I am also a father I cry tears that aah living like this, what will i do " P/IDI/6

Whereas another said often they have no options:

"if we say no to Queens, because at Queens it's free whereas Mlambe, the hospital which is close is Mlambe but requires money so if you do not have money you cannot go... it is difficult we just try to get a minibus here to get treatment at Queens" P/IDI/1

Lack of financial resources at household level is exacerbated by some employment policies. For example, one client said he was not maintained on the payroll because stroke made him go

beyond the recommended sick leave which according to his employer is three months as shown in the following quote:

“It’s because am not been paid I think they stopped 3 months ago. Yaah, not losing work but I think they have a condition to say you cannot be sick for more than 3 months and continue being paid”. P/IDI/4

Caregivers also share the same perception about employer policy as leading to problems at home. One caregiver talked of the job experience of her husband after stroke:

“he is not going at work mh and at work they have put him on unpaid leave mh so things have really changed at home... because he has received they said because he has stayed for about more than three months aha yea ok so they stopped paying him” G/IDI/4

Service providers also expressed that at household level, poverty which is more prevalent in rural areas makes stroke clients fail to acquire nutritious food thereby worsening their condition as one service provider said:

“but poverty,I just want to say that poverty can be a barrier also yes in the sense that if you don’t have money or if you are not mmmh you can say nutritious right this can be some of the factors that can contribute to worsening the barriers because maybe if they were breadwinners and they suffer from stroke everything stops at home”. S/IDI/1

Additionally, poverty makes stroke clients have difficult living conditions thereby affecting their involvement in day to day activities in the home and communities:

“you know in Malawi most of the patients they are not from rich family I don’t know why but you see here we admit patients most rural areas where they are very poor you

discharge a patient home he has no bed the toilet is about 5 eeh not 5 but 50-60ms this patient needs to go to the toilet ok this patient needs a bed needs to transfer the bed those kind of accessibility in the daily normal life going to bed coming out of the bed eeh”

S/IDI/5

Service providers further perceive that poverty makes stroke clients even fail to access justice in times of need:

“you need money to hire a lawyer maybe or somebody of higher quality who can go and report that those people are not doing justice these people are not available because people will say aah I cannot support these people no because he is undergoing poverty”

S/IDI/5

In addition, some stroke clients said stroke clients’ poverty is exacerbated by resource intensiveness associated with the condition, especially when it comes to transport. For example, they say stroke client on wheelchair are asked to pay twice the fair because of their wheelchair as one says here:

“I have seen disabled people with stroke those who had stroke left because they are on wheelchair so most of the minibuses they buy they are not adapted for a disabled person so the wheelchair no no he is asked to cough twice where he will put the wheelchair he has to pay money” S/IDI/7

As confirmed by:

“money you have to pay for two people you can’t go by yourself two people go and come these people they are farmers they don’t sell much normally they sell to get some little money to buy food, cooking oil not to go”. S/IDI/5

Resource limitation at community level

Here lack of mobility aids, portable water and information access has been highlighted by stroke clients.

Stroke clients said public resources accessible to somebody living with stroke in the community are limited. One client particularly said there is lack of mobility aids and portable water that is accessible to a woman with stroke as she says:

“Government can do something like to us who have stroke or other people who will have stroke: like giving them things to aid them in walking like giving them the right support to help them in their life it would be better than just staying. Eeh like there are wheelchairs, sticks, another thing for example a bore hole nearby” P/IDI/1

Another participant said there are no extra services such as home visit by social workers:

“If I want to get medical attention, I have to go out. There is nobody ah from any hospital who comes here. Yes”.P/IDI/2

Another thing that is difficult to get in the community is information or news about what is happening in the community. This is so because of inability of stroke clients to go out and interact as one participant says in the following:

“No before it was ok we were visiting each other, if there is a wedding people will spread the message or funerals but these days you will just hear that there was a funeral there eh without spreading the word in the lines may be things changed ah ... but for someone to come from there to visit no, I just sleep eh nobody comes to see me ah” P/IDI/8

Resource limitation at organizational level

Under this section limitation in finances, staff, and training equipment have been highlighted as affecting the smooth running of rehabilitation services at organizational level.

Stroke clients perceived that there is shortages of staff and limitation of equipment at MAP Kachere Rehabilitation centre; and a general concern was that service are not reaching other disadvantaged people as observed by this client:

“It has just been difficult that ah there not enough workers but we people are coming from different areas like me am saying that I come from inside Blantyre and am lucky that I am near Queens hospital yet other people come from far, the time I was going there some people were coming from Lilongwe, Dedza where transport is required so it is difficult for the people who help with physiotherapy to reach those people”P/IDI/7

And also said by P/IDI/3

“but there at Kachere they are lacking some equipment eeee like for some I would go like at mphwiza in Blantyre ee it was working like this (demonstrates machine work) so they were pressing like this phaaa making sound wuwuwuwu about 3 minutes this should

be at Kachere I was going just because there is somebody to take me there but there are others who do not have anybody to take them”

Service providers said there was problem with availability of resources at the levels of organization and community.

Service providers spoke of limitation of financial resource at Malawi against Physical Disabilities (MAP) which has affected vital services such as that there is no follow up for discharge clients leading to failure to improve their living situation for increased activity and participation. This is evident in the following:

“follow-ups no, because we have transport problems and also shortage of staff like in the past we were having MAP staff going to the villages but it’s now almost a year they have stopped because of financial problems at the center. Yes, aaa”. S/IDI/4

Confirmed by:

“because of limited resources we have here you know MAP is going through financial problems so that’s the problem (no money for travel expense) we try to discuss so those which are within in our level for example let’s say we are able to advise other relatives apart from the ones we used or if it’s possible to visit the employer so that we do often I can remember that to talk to an employer for somebody to work to support” S/IDI/5

However, one participant generally said limited rehabilitation services countrywide makes stroke client not receive adequate attention that can make them remain active and participative in the community

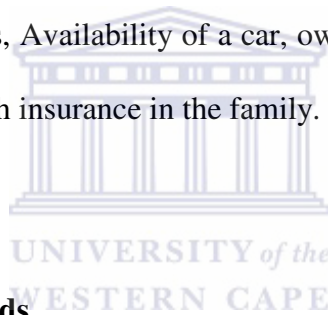
“our country Rehabilitation services are not very much developed not many Physio Departments are running this in in district hospitals as such people may not get the services there” S/IDI/2.

4.4 Facilitators

Although not part of the research, facilitators to community reintegration emerged. The factors perceived by study participants as easing life of stroke clients in the communities are presented below, from the perspectives of two groups; stroke clients and caregivers.

Good support system

Under this theme, five subthemes emerged as facilitator to reintegration by stroke clients namely Supportive family/relatives/ friends, Availability of a car, ownership of income generating asset, belief in God and Presence of health insurance in the family. They are highlighted as follows:



Supportive family/relatives/ friends

Participants in the study reported that they received financial and moral support from family members, some friends and relatives

Stroke clients had spouses who either maintained a formal employment or they had an extra hand of support from working children and/or some relatives

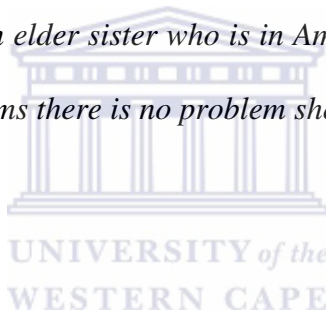
“Heee on money I was working but now I retired so there I was finding something so I have my young sister in States aaaayi so every Saturday she sends she is the last born I am the first she is the last so she sends but also my children since they are all working eeeeetu so iiiiiiiii no” P/IDI/3

As supported by

“My children love me very much, they even encourage me that I am now healed compared with how it was before because even sitting I could not ee but now am able to, ee. Friends do come here and encourage me. The relationship is still there, after time days if they think about me they come to visit. Eeh yes”P/IDI/7.

The caregivers of some stroke clients also reported availability of good support from other family members:

“She gets support because she once worked for the bank so every month she gets money they give her but she also has children who are educated and have good jobs they also held her but she also has an elder sister who is in America who sends enough support so on the part of support it seems there is no problem she gets enough support eee” G/IDI/3:



Availability of a car

Stroke clients expressed that owning a vehicle or having a readily available car for transport from the spouse's employer made travel to essential services such as hospital easier as evidenced in the following quote:

“We have a vehicle here. Mh, my wife drives to work. Ah...Basically when I want to go out I use that one. Yes”. P/IDI/2

And supported by:

“was going to the hospital mh he would ask for a car from his work place mh they would pick me up mh and drop me at the hospital mh after getting treatment they would drop me home mh then the driver would go mh” P/IDI/8

Caregivers also confirmed the role of readily available car for transport in the home as easing mobility to places as highlighted by one caregiver:

“We have the two cars, ok mh I usually use the Starlet one because that one fuel consumption is very good mh yea so that is the one which I usually use mh, the pickup is used for the boys only on Sundays” G/IDI/4

Ownership of income generating asset

Stroke clients said they having an income generating asset of some kind help a lot particularly in the event that stroke clients are no longer working. This is highlighted in the following quote:

“Aahh it’s a bit difficult but I do get some house aah rentals so that money is able to assist here and there, yaah”P/IDI/4

This was also confirmed during the interview with caregiver G/IDI/4.

Belief in God

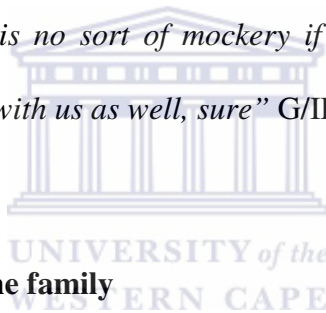
Belief in God and attendance of church services was commonly reported by participants especially stroke clients and their caregivers. Participants feel encouraged by the belief and the feeling of being close to others in a church setting.

For example one stroke client reported how she felt the Lord encouraging her, and how that makes her feel better:

“No there is a big difference ah I was doing everything myself but now it is not possible but still eeh the heart is difficult ee it took me time to accept but now the Lord is encouraging me a lot mm” P/IDI/7

This is supported by what another caregivers such as one in this quote:

“the church members in fact they are friendly to us there’s no single day when I heard to say may be laughing at her, no. everyone sympathizes with her and they give her a word of encouragement to say let what God has given receive it holy. It’s God who knows everything therefore there is no sort of mockery if they do it may be in our absence otherwise no, they feel pity with us as well, sure” G/IDI/1



Presence of health insurance in the family

Some caregivers perceived that access to medical treatment was made easy by the presence of health insurance in their family. This is evidenced in the following quote:

“Interms of hospitals, I don’t think he is suffering in any way because all along we ve been we are on MASM so we always using MASM so sometimes yeah but not much because they shortfalls for they are not to mu they are not too high. So its not a big deal in terms of accessing public public services, though mostly I still have to take him there, e, or somebody else has to, he cant go there alone” G/IDI/2

As confirmed by:

“Yea things like those, the problem is transport, mh but in terms of finances I have a MASM, mh I have a MASM card mh which is easy in terms of finances mh but the real problem is transport, ok, sure” G/IDI/8

4.5 Chapter Summary and conclusion

This chapter has presented results of the study entitled “Barriers to reintegration experienced by stroke clients post discharge from a rehabilitation center in Malawi”, including socio-demographic data of the three groups of study participants. The results have been touched across three major areas which are; affected domains to community reintegration, barriers to reintegration, and facilitators to community reintegration. The results have demonstrated that stroke clients experience activity limitations which are on loss of instrumental ADLs. The clients also experience inabilities in social and economic activity participation. In turn, several barriers emerged as causing the limitations and restrictions to community reintegration. However the barriers are cast across two themes, that is, barriers at individual level and barriers at environmental level. The chapter has also presented emerging facilitators which included presence of a car for mobility and being covered by a health insurance as easing access to medical care.

The coming chapter presents a discussion of the results outlined in this chapter.

CHAPTER FIVE

DISCUSSION

5.0 Introduction

This chapter discusses the main findings in relation to the aim and sub aims of this experiential study. The results are also discussed in relation to other studies to develop inferences. The aim of the study was to explore the barriers to reintegration experienced by stroke clients after discharge from a rehabilitation center in Malawi.

5.1 Demographic features

Almost all stroke clients who participated in this study were married and lived with their spouses except one woman who is widowed and lives with her sister. This is against what would probably be assumed that the stroke onset could have been the source of marriage breakdown. Indeed the marital status in this study is contrary to the findings from a systematic review by Daniel, Wolfe, Busch and McKeivitt (2009) whereby in identifying the social consequences of stroke, the authors found nine studies reporting marital problems after stroke, including separation or divorce. Having intact marriage and committed spouses as is the case in this study may be a facilitator to community reintegration among stroke client after discharge.

Four participants reported being employed at the onset of stroke but none maintained going to work by the day of interview. Stroke led to their being retired on medical grounds or being put on unpaid leave. This concurs with the common findings that stroke clients do not maintain employment following stroke often due to impairments (Rudman, et al., 2006; Kochi, et al., 2005). The researcher thinks retiring stroke client may be ethically wrong but profit driven

organizations where speed and accuracy are essential may have limited choices. The question could be, are the clients being treated or managed to the fullest potential of their recovery? There are generally limited rehabilitation personnel in developing countries (Rhoda, 2009; Kambalame, 2008) and rehabilitation has also been faulted in that professionals lack whole-person-centered approach in their work with individuals such as stroke clients (Sabari, et al., 2000) to the extent that the clients are not prepared for real life in communities. However, negative attitudes by employers may not be ignored.

5.2 Deficits in the domains to community reintegration

Before the barriers to reintegration are discussed, the domains in which the barriers are experienced are discussed under this theme. The domains are going to be discussed in terms of two sub themes of activity limitation and participation restriction.

5.2.1 Activity Limitation

Major discussion areas under theme 5.2.1 are inability to carry out ADLs both basic and instrumental, and difficulties engaging in sex

Inability to carry out ADLs: All the three groups of participants expressed trouble faced by stroke clients in trying to execute ADLs. The ADLs are classed into basic and instrumental, as discussed in up next sections.

On the one hand, service providers highlighted that stroke clients have difficulties with basic ADLs such as dressing and bathing. It is interesting however to note that stroke clients and caregivers did not talk of any basic ADLs as being a problem in their community life. There may be three possible explanations for this: firstly, may be they have good level of support as almost all of them remained married and lived with their spouses so they do not find it a problem

anymore; secondly, possibly because of the long duration of their stay in the community as these stroke clients had stayed in the community for minimum of about three months. They may have already established some coping mechanisms as found elsewhere by Obembe, et al. (2002); or thirdly, that some activities that are considered basic such as toileting are too private and so “it is nothing to talk about” in a public domain.

The fact that no limitation in basic ADLs were reported by stroke clients and caregivers as being problematic may be defying the findings by Israel by Hartman-Maeir et al.(2007) where one year post stroke, more than 50% of clients needed assistance with basic ADLs particularly bathing and dressing, concurring with perceptions of the service providers in the current study. The differences may also be accounted for by the fact the current study is an exploratory qualitative research where interviews used in this paradigm has been found disadvantageous as participants may lack originality on some aspects of their life that is being explored (Gruger & Casy, 2000), whereas Hartman-Maeir et al. (2007) utilized quantitative research that involved clients responding to the prepared questionnaire with predetermined domains.

On the other hand participant participants expressed deficits in instrumental ADLs. Instrumental activities of daily living are those activities that the stroke clients need to do in order to be independent in the community (Chong, 1995). This section discusses four Instrumental Activities of Daily Living (IADLs) that the clients in this study are perceived to having difficulties with, i.e. inability to walk, inability to carry out household chores, inability to drive and difficulties with budgeting.

Clients are unable to walk: although inability to walk is in most cases considered as falling under basic ADLs, in this study it is considered under Instrumental ADLs as walking is a

commonest means of being independent in the communities especially in developing areas such as Malawi where this study was conducted. Stroke clients and caregivers perceive that the clients' failure to walk is the main cause for failure to go out of the house, visit places and participate in activities at both household and community levels. Clients and caregivers related inability to walk to failure to not only go for economic activities such gardening or formal employment but also failure to take part in the community gatherings as part of socialization.

The effect of difficult walking towards community reintegration as highlighted by stroke clients and caregivers in this study is in line with quantitative research findings in Nigeria where inefficient walking was associated with lower satisfaction with community reintegration (Obembe, et al.,2002). The findings also concurs with the study done by Pound, Gompertz and Ebrahi (2011) who found that at eleven months after stroke, clients had difficulties with walking in the community; and Jorgensen et al. (1999) who found that stroke clients have compromised walking ability after the onset of stroke and that their main goal is to walk. The need to visit places out of the homes and remaining productive in the community as expressed by participants in this study, also concurs with findings from other studies (Robinson-Smith et al. 2000; Kim et al., 1999) and are part of the domains of the Reintegration to Normal Living Index.

All caregivers in this study, by talking of the failure on the part of stroke clients to walk outside the home may illustrate how the caregivers feel “trapped and tied to the home” because of inability of their partners to walk. Service providers did not talk specifically about the clients' failure to walk as a barrier to social and economic life. It could be that the service providers take the inability of the stroke client to walk as a “norm” given that they have not responded to rehabilitation by regaining walking and that other elements in the community must therefore be responsible for their failure to participate than just walking, a social model view.

Stroke clients are also unable to carry out household chores. Both stroke clients and caregivers in this study indicated that following stroke they are not able to cook, wash, mop or clean the home in which case they said they are not able to take care of their families. The results of this study agree with the qualitative study findings by Pound, et al. (2011) who found that at eleven months after onset of stroke, clients were not able to carry out household chores mainly washing, and caring for the family.

It is interesting to note that only male caregivers expressed that stroke had affected their spouses' ability to cook and care for the home. This is probably so because men in Malawi rarely get involved in cooking and other domestic duties. Domestic chores in Malawi are considered 'feminine' chores and as such are restricted to women. Therefore, failure of the clients to cook was clearly felt by the male caregivers. The female caregiver might not have noticed anything strange or difficult hence the reason she probably did not talk about it.

Outright mentioning of inability to carry out domestic work by female stroke clients may show that they are at pain for losing control of activities that are traditionally theirs. This may be a source of worry and loss of confidence and depression. Service providers (female), also expressed the inability of stroke clients especially females to cook, mop or care for the families. Household chores under activity limitation domain, therefore, have been seen to affect female stroke clients.

Inability to drive: this study shows that after stroke, some clients who were initially driving can no longer do so. This result is similar to the study findings by Heikkilä, Korpelainen, Turkka, Kallanranta, & Summala (1999), where 60% of participating stroke clients were unable to drive. Although the current study did not evaluate the cause for the failure to drive, Heikkilä, et al.

(1999) says decreased cognitive and psychomotor abilities makes stroke clients fail to drive. Inability to drive may limit autonomy of the stroke clients through failure to visit places of interest without having to rely on somebody and so their reintegration into the community is affected (Hitosugi, Takehara, Watanabe, Hayashi, & Tokudome, 2011). The researcher also reason that failure to drive by clients may put pressure on the spouse who may also have other things to sort out domestically. Additionally the pleasures of visiting places at will when caregivers are not around is not achieved and this, in turn, may create dismay in the stroke clients as well as unexpected conflict between stroke clients and caregiver.

Inability to manage finances: stroke clients talked of failure to manage finances, budgeting. This study has not found failure to manage finances as being due to impairment of cognitive status, a contrast to the findings by Koch et al. (2005) who in their study to explore the experience of right hemisphere stroke clients found that cognitive perceptual problems limited their abilities to carry out ADLs such as budgeting finances. Rather this study found that in situations of a house wife, the clients indicates, it becomes easier to manage a budget for the month if they are able to walk and buy groceries, unlike depending on children or house-servant that may, sometimes, not be honest. This also signifies a shift of role from the traditional owner to others in the home which may be a source of unhappiness to the affected person and, consequently, a source of dissatisfaction with community reintegration generally (Robinson-Smith et al., 2000). Caregivers group did not say anything on difficulties of this nature. This may be so because they probably feel they are there to do it for that client, “they must be there in times of need”, an attitude that does not consider the need for the role by the client.

Overall therefore from the perspectives of stroke clients and caregivers, this study has revealed that stroke clients have difficulties with walking, carrying out household chores, driving and

managing finances. In his review of literature to find the working definition of instrumental activities of daily living (IADL), Chong (1995) reported that the abilities relating to IADL appear to be a prerequisite for independent living in the community as (IADL) requires increased interaction with the environment. In this regard, the finding of this study shows that stroke clients in the community are not independent and hence not fully reintegrated into the community (Obembe, et al., 2002; Robinson-Smith et al., 2000; Kim et al., 1999). The current study concurs with the quantitative study by Hartman-Maeir et al. (2007) who found that the majority of the sample needed full assistance with IADL notably meal preparation (77%), housekeeping (70%) and laundry (82%) and stair walking in the community one year post stroke.

Difficulties engaging in sex: this study has also considered issues of sex under the activity limitation domain. Caregivers, both male and female in the current study expressed that it was almost impossible to have sex with their spouses who had stroke. Male participant attributed the failure of sex as being due to pain and headaches as being reported by their wives when they attempt the act, while female caregivers attributed the failure to lack of energy for sexual activity by their husbands.

Difficulty associated with sex after stroke is well known (Salter, et al., 2008; Tamama, Tamamb, Akila, Yasanc, & Tamamd, 2008). The findings from this study concur with the one carried out among 103 Turkish stroke population where problem with sex was common, and particularly so because of erection and ejaculation dysfunctions among males, lubrication and orgasm being affected in the females, and fear of recurrent stroke which was common amongst both genders (Tamama et al., 2008). Probably lack of lubrication as found in the study by Tamama et al., (2008) could be the source of painful sex among female clients in the current study. Whereas the cause for failure of engaging in sex among the male clients in this study could be more than

weakness (as reported by female caregivers) but, evidently, there is no stroke client in the current study who talked of problems with sex life.

An explanation for the failure to speak about sex could be that most people in Malawi are not open when it comes to private issues such as sex, much so with the affected population such as stroke clients. Evidence that people are not free to discuss sexual issue is the demand by one caregiver, G/IDI/1, to have the recorder switched off by the interviewer when he talked about sexual problems. In this regard, challenges on sex among married people following stroke may be a potential source of dissatisfaction among spouses of stroke clients who mostly highlighted this problem, and depression among stroke clients for the failure to engage in sex which may make them feel useless before their spouses, hence a challenge to reintegration into the community (Robinson-Smith et al., 2000).

5.2.2 Participation restriction

Discussion areas under participation restriction are failure to participate in economic activities and loss of social participation.

Failure to participate in economic activities: economic activity in this study includes any activity that the stroke clients engaged in, in order to get food and other necessities for themselves and their families prior to stroke. In Malawi such activities range from farming, hunting, business, to formal employment.

Stroke clients, caregivers and service providers in this study reported failure by stroke clients to participate in economic activities such as return to their previous employment, job or business as was the case prior to stroke. Three reasons were highlighted as being the cause for failure to

participate which are; cognitive impairments, loss of instrumental ADLs particularly walking, and fear by stroke clients through associating nature of business to the occurrence of stroke.

The current study concurs with the findings by Garcia et al. (2000) who found that stroke clients have trouble going back to their jobs after stroke. In the study, Garcia et al. (2000) found that stroke clients and the service providers agreed on fatigue and problem with thought processing at stroke clients level as being the cause of trouble with reintegration into employment, whereas only service providers thought distorted self-image and loss of confidence were the cause for failure to reintegrate into work environment. Although the current study is heterogeneous in the type of stroke clients included compared to the study by Garcia et al. (2000) who looked at stroke clients with aphasia only, problem with thought processing, distorted self-image and loss of confidence are a common finding in both studies and their effect on work reintegration may be the same.

The emphasis of failure to walk as the main barrier to going back to work in the current study shows the difference in experience of stroke clients in the two worlds; developing country (where the current study has been carried out) and the affluent society i.e. the place where Garcia, et al. (2000) conducted their study where no problem on transport as a barrier to work reintegration was highlighted.

The current study findings that no stroke client resumed their previous work, however, contradict with findings in the systematic review by Daniel et al. (2009) who found three studies saying slightly more than half of the patients had returned to paid employment at 6 to 12 months. Again here the degree of barriers to work reintegration between the two worlds, where studies were

conducted may be different. In addition, difference in severity of stroke (which is not known) between participants of the two studies could be the source of difference in study findings.

Caregivers and service providers associated failure to participate in any economic activity to the loss of role, particularly by male stroke clients who are often referred to as “bread winners of the home” by the caregivers and service providers. This is a clear shift of paradigm from loss of instrumental ADLs, especially failure to carry out household chores under the activity limitation domain, which has been perceived as afflicting mainly female stroke clients. This also reflects how Malawian society is built, and so the need to consider when rehabilitating stroke clients.

Failure to return to work may be associated with negative self-image and well-being and lack of satisfaction with life generally (Treger, Shames, Giaquinto & Ring, 2007), related to failure to maintain roles in the homes as “bread winners” for example, and feeling less useful to the community. Altered self-image and loss of satisfaction with life may spiral into emotional breakdown and failure by stroke clients to participate in life situations fully after discharge.

Loss of social participation: social participation in this study refers to engaging in common activities with other members of the community for the fulfilment that the engagement brings to participants. Examples include participating in weddings, social events, and funerals as well as spiritual gatherings.

In the current study, stroke clients and caregivers highlighted that stroke clients are unable to participate in certain group activities in the community and unable to resume their previous roles in the community groups. The groupings commonly mentioned were church congregations and choir; weddings and other community gatherings. The stroke clients attributed their failure to

participate to impairments and activity limitations such as loss of voice for singing, and inability to walk.

Another interesting reason for failure to participate is inability to assume certain positions common in societal gatherings due to failure to assume certain positions. In most community gatherings in Malawi, women sit on the floor or mat as compared to men who often sit in chairs. For example at the funeral, women sit around the coffin or dead body when men are sited outside, on chairs until the procession to the graveyard starts, which may take place several hours later. This makes it difficult for female stroke clients to attend such ceremonies.

Although some caregivers concurred with the stroke clients that they could not participate because of failure to walk, they also added that after stroke, the clients become so quiet and withdrawn, so that they do not speak to others unless spoken to. Communication which is necessary even in group setting is a two way process so when one becomes withdrawn then the whole process of interaction collapses hence participation is restricted.

Failure of stroke clients to participate in activities outside their home as seen in this research is supported by other studies (Hammel, Jones, Gossett, & Morgan, 2006; Barker et al., 2006) and the limited ability to execute ADLs may amount to less fulfilling living in the community by stroke clients (Robinson-Smith et al., 2000) which may affect them emotionally and so fail to experience satisfactory reintegration into the community after discharge.

5.3 Barriers to reintegration into community experienced by stroke clients

Two themes emerged in this study. Based on the bio-psychosocial model the two themes are barriers at individual level and barriers at the level of the environment in the community. They are discussed next.

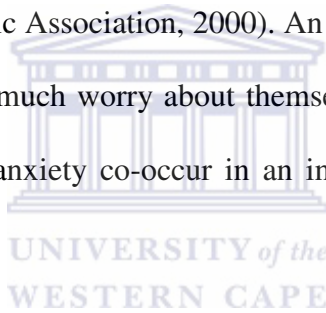
5.3.1 Barriers at individual level

Under this theme, two subthemes are discussed according to the results i.e. impairments and personal barriers.

5.3.1.1 Impairments:

The major areas of discussion under this subtheme include depression and anxiety, physical weakness, physiological functional changes, pain, and bladder incontinence.

Depression and anxiety: the Diagnostic and Statistical Manual of Mental Disorders (2000) defines depression as an emotional condition which is characterized by sad mood and a loss of pleasure from activities that were previously enjoyable, also feeling of hopelessness and worthlessness (American Psychiatric Association, 2000). An individual with anxiety on the other hand, become consumed with too much worry about themselves, their condition and the future (Watkins, 2004). Depression and anxiety co-occur in an individual at risk (Mukherjee, et al., 2006).



Participants in this study expressed disturbance in cognitive status to varying degrees among stroke clients. Stroke clients said they felt less confident than they were before stroke. Loss of confidence, they said, affected their ability to work with people necessary for their business. Stroke clients also said that they had no motivation for work while others expressed hopelessness, anxious about their future, and sadness that they were not able to do their usual tasks. Stroke clients and caregivers reported trouble with memory. They recounted that in most cases the clients were unable to remember things. Caregivers who were mostly spouses to the stroke clients said their spouse had become anger-prone whereas some caregivers and service providers perceived that the clients exposed altered self-image evident in their expressions that

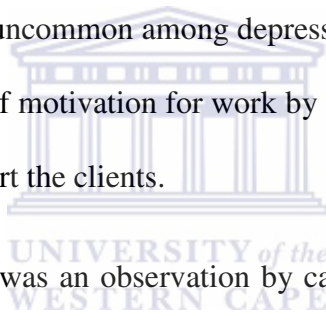
people were shunning away from them. Service providers said stroke clients suffer depression, faulty thought processing and reduced motivation for work.

The findings from the study about sad mood, hopelessness, anxiousness and loss of confidence as expressed by stroke clients are also characteristics of depression as defined by the American Psychiatric Association (2000). In addition, anger proneness and distorted self-image expressed by caregivers as characterizing their spouses' life after stroke could be a sign of underlying depression (Mukherjee, et al., 2006). Furthermore, depression and anxiety are heterogeneous constructs that have been associated with worsening the cognitive skills involving effortful processing such as memory and attention, as well as on tasks that involve initiative (Watkins, 2004; Mohanty & Heller, 2002). Therefore loss of memory as observed by stroke clients and the caregivers, loss of motivation for work observed by stroke clients and service providers and difficult thought processing mentioned by the service providers may as well be emanating from possible depression and anxiety in the participating stroke clients. The study results concurs with common findings in stroke community studies that stroke clients experience anxiety and depression (Garcia, et al., 2000; Kochi et al., 2009; Chau, et al., 2009).

Sad mood, hopelessness and loss of confidence were expressed by stroke clients, however, neither caregivers nor services providers expressed in the same line. This is understandable as they are issues of feelings than observable elements. This poses a danger in that service providers or people around may overlook them opting to work more on physical aspect of disability (Mukherjee, et al., 2006).

Loss of motivation for work mentioned by stroke client may have surface homogeny with loss of motivation as observed by service providers but maybe heterogeneous in perspective. By this,

the researcher is for the view that the clients' perspective may be purely intrinsic that they surely have no zeal for work following stroke, and no external factors are at play, whereas service providers may base their views on clients not willing to work as being due to presence of too much support from other people around them as noted by services providers that caregivers are often too willing to support the clients after discharge thereby leaving them out of all decision making about activities of the home. While the two perspectives may be true, service providers' perspective about stroke clients, may potentially lead to blaming on the client as not taking part in activities or blaming the caregivers for not giving chance to stroke client when in actual sense the loss of motivation is intrinsic to the clients. This development may lead to extra stress on stroke clients in trying to comply with "professionals" observation and advices. Overall, however, loss of motivation is not uncommon among depressed clients (Mukherjee, et al., 2006). Caregivers did not talk about loss of motivation for work by stroke clients probably because they take it their duty to work and support the clients.



Anger-proneness by stroke clients was an observation by caregivers, spouses in particular. The phenomenon as reported by caregivers in this study concurs with an exploratory study by Thomson and Ryan (2009) where spouses of stroke client said after stroke their spouses had become more intolerant, anger-prone and irritable. Caregiver most likely reported this than other group of participants because they are in close contact with the clients and that possibly they don't understand the changes that their spouse is passing through. The observation by caregivers may signal a serious gap in rehabilitation where probably family members are not prepared enough through education about stroke and its complications, and how to live well with a family member who has stroke hence the family experience "family relationship shock" after discharge.

Anger proneness may affect clients' relationship with others in the family and community hence the deficit in relationship domain of community reintegration.

Altered self-image was reported by caregivers and services providers and not the clients themselves. This is understandable as this is an element that can be observed and stroke clients are merely projectors of the phenomenon through interactions with their environment. Altered self-image may equally affect stroke clients' relationship with others, and may lead to loss of self-determination (Mukherjee, et al., 2006).

Service providers reported that stroke clients suffer depression and faulty thought processing. As seen earlier, depression affects thought processing. Service providers used the direct terms than the other groups of participants probably because of theoretical knowledge given that they are rehabilitation staff. This knowledge may be advantageous only if the service providers are able to conceptualize the feelings and different terminologies used by stroke client and their caregivers as indicators to depression. Otherwise the chance of overlooking depression from the presentation of clients is very high among service providers (Mukherjee, et al., 2006).

Physical weakness: in this study stroke clients and service providers mentioned weakness of the affected side of the body as an independent cause for failure to carry out activities such as cooking. Interestingly all participants who talked of physical weakness were female and that Weakness of the arm was commonly mentioned. This may be because of the importance associated with the arm towards the roles of the female stroke client in the family such as child caring and cooking for the family (Blonderet al., 2002). It is surprising that none of the caregivers directly mentioned physical weakness as a barrier to activity. Therefore, the researcher reasons that it could be because caregivers regard stroke clients as sick and so are not

expected to work, it is the “responsibility” of the caregiver to carry out duties on stroke client’s behalf, and so weakness does not come as a natural cause for concern to the caregivers. The possibility of this stand by the caregivers may potentially be the source of exclusion of stroke clients from carrying out certain activities that are considered satisfying by community-dwelling stroke clients in the community (Robinson-Smith et al., 2000; Kim et al., 1999; King, 1996) hence not achieving full reintegration into the community (Obembe, et al., 2002).

Weakness has also been attributed to by female caregivers as a reason for the failure of stroke clients to engage in sex by their spouses with stroke. Sex is an important aspect of life that couples and rehabilitation personnel need to discuss before and after discharge to array possibility of dissatisfaction among married people (Salter, et al., 2008), an element necessary for reintegration into the community.

Physiological functional changes: In this study stroke clients reported changes in the response of their body in different activity situations. Specifically they reported that they experience loss of breath (dyspnoea) and dizziness when they are close to fire-place which affects their ability to cook in fear of falling over the open fire. Whereas caregivers simply said that after stroke the clients experience frequent change in blood pressure which they said manifest in stroke clients complaining of headache and presenting with seizures. Headaches have also been reported by male caregivers as limiting their ability to have sex with the spouse who has stroke.

The study findings concur with literature that says physiological changes post stroke are common (Wong & Read, 2008; Lavados, Sacks, & Prina,2005; McGovern & Rudd, 2003) and according to the authors the alterations are often in blood pressure, body temperature, blood glucose, and blood oxygen saturation. The presentation of clients in this study also concurs with

the finding which characterizes a rise hypertension from the study by Zampaglione, Pascale, Marchisio, & Cavallo-Perin (1996) who found that most frequent signs for hypertensive crises were headache (10%), dyspnea (22%), faintness and psychomotor agitation (10%) and neurological deficit (21%).

Stroke clients and caregiver were able to mention negative physiological changes because of their proximity to the condition. However, service providers did not mention the physiological changes probably because of the remoteness of the situation. Another explanation could be, they probably know about the possibility of such physiological changes but they do not take it in terms of how they affect activities such as cooking, family care, and sex as experienced by the stroke clients and caregivers in the communities. In this case service providers may not provide targeted education to stroke clients and caregivers such as one that fosters compliance to medication by the clients so that effects of such physiological changes on ADLs are minimized. ADLs are important domains to community reintegration (Obembe, et al., 2002).

Pain: in this study stroke clients mentioned pain emanating from stroke. Stroke clients mentioned pain as being a continuous and disturbing phenomenon after stroke. Pain, according to their presentation, may be more than physical. It may have more of emotional element. However, physical pain after stroke is common particularly in the affected extremities. Literature estimates that almost 72% of all stroke cases experiences at least one episode of shoulder pain (Tipping, 2008). Pain is a subjective experience (Merskey, & Bogduk, 1994) that is probably the reason why only stroke clients in this study expressed pain as limiting their ability to carry out various activities. Long-term pain in stroke clients is known to interfere with physical performance (Katz Ritvo, Irvine, Jackson, & Endler, 1996), and mood changes common after stroke have also been associated with long-term pain (Craig, 1999). With the long term pain

expressed by stroke clients in this study, involvement of the client in activities of the home and community have therefore be affected.

Caregivers particularly men spoke of pain during sex experienced by their wives who had stroke as limiting their ability to engage in sex. The pain experienced could be due to lack of vaginal lubrication after stroke (Tamama et al., 2008) which may affect marital relationship after discharge (Daniel, et al., 2009).

Bladder incontinence: only the caregivers expressed challenges related inability to control bladder function when the stroke clients want to go to the toilet. The caregivers' sentiments imply that bladder incontinence leads to clients worry and possibly altered self-image because of their failure to control urine the thing which may be shameful to an adult person. Although service providers and stroke clients did not talk about bladder incontinence, studies show that there is 50 – 60% incidence of bladder incontinence that goes down to 20% by sixth month (Tipping, 2008). Here again some participants particularly stroke clients may not have talked about it probably because of bad feeling they have towards it. However, incontinence may lead to social isolation and depression among community dwelling stroke clients (Tipping, 2008; Maggi, et al., 2001) leading to their failure to participate in social roles in the community.

5.3.1.2 Personal Barriers

The areas of discussion under this sub-theme include denial, gender, and co morbidity

Denial: service providers highlighted that lack of acceptance of the condition by stroke clients leads them becoming too sensitive of their condition thereby limiting their ability to associate with others.

Although the stroke clients and caregivers in the current study did not say in the same line, the service providers' observation concurs with the findings in the study on caregivers' experiences and perceptions of stroke by Thomas and Greenop (2008). These authors found that stroke clients become too sensitive and unable to adjust to new situation even in the family. Such sensitivity may as well limit the clients' ability to engage in activities outside the home.

Gender: the study has shown that female stroke clients are affected by their failure to perform household chores such as cooking, house cleaning, and caring for the family than the male stroke clients on the one hand. On the other hand, male stroke clients are more, than the female clients, affected by their failure to engage in economic activities outside the home such as employment, paid or non-paid. This may reflect the traditional way of life typical in Malawian context where women are mostly keepers of the homes and children while men go out to work for money or go for game hunting for their family.

The findings also concurs with an explanation by Sue-Min, Duncan, Dew, & Keighley (2005), that the persistent difference between men and women in IADL post stroke may be the instrument itself, whereby many of the activities such as preparing meals, shopping for groceries, doing housework, as recognised on IADL scales have traditionally been performed by women in the home. Men's traditional role (working outside of the home) may prompt respondents not to talk much about female-linked activities when talking about restrictions faced by male stroke clients.

The implication of the differences according to gender is that rehabilitation service providers may clearly foresee the line of worry or concern by individual client hence aligning their focus to the client's areas of concern.

Co morbidity: stroke clients and caregivers in this study mentioned of hypertension and how it is presented in different ways. Hypertension has been associated with onset of seizures, headaches that have been linked to failure to carry out some instrument such as driving and sex among stroke clients and their spouses.

The symptoms of hypertension as highlighted by stroke clients and caregivers are similar to those found in the study by Zampaglione, et al. (1996) who found prevalence of seizures, headaches, dyspnoea among client with hypertension. Failure to carry out activities is one of the factors leading to dissatisfaction with reintegration into the community (Obembe, et al., 2002; Robinson-Smith et al., 2000).

5.3.2 Barriers at the level of environment in the community

These are barriers to reintegration, external to the client, that limit the clients' abilities in different life situations in the community. Under this theme, environment barriers are discussed.

5.3.2.1 Environmental barriers

Under this sub-theme the following categories will be discussed; attitudinal barriers, limitation by physical environment and resource limitation.

5.3.2.1.1 Attitudinal barriers

The study has shown that stroke clients' reintegration is affected by the changes in attitudes of people at three levels namely changes in attitudes by family members; changes in attitude by friends, relatives and other members of the community; and change in attitude by employers.

These are discussed next.

Change in attitude by family members: caregivers and service providers perceive that some family members take advantage of the stroke clients; children in particular as they do not obey orders and generally become disrespectful. In addition, service providers highlighted marital problems after stroke. They say that spouses may look down on the clients for the clients' inabilities to fulfil their traditional roles as "bread winners" when the husband is affected or inability to do household chores in situations where a wife is affected. In extreme situations, the service providers say, spouse may go for a different partner, leaving the stroke client alone.

The current study has not found similar views from stroke clients, nor has it found any marriage broken down following stroke. However, marital problems after stroke are not uncommon. In the systematic review by Daniel et al. (2009), in identifying the social consequences of stroke, the authors found nine studies reporting marital problems after stroke, including separation or divorce. In addition Teasell, McRae, & Finestone (2000) found that of the 55 patients with spouses, 8 (14.5%) had separated within 3 months of hospital discharge.

In some situations however, service providers said that after discharge some caregivers feel sorry for the client, which deny the clients chance to act or perform. There was no similar observation from stroke clients and caregivers. However, overprotection as expressed by service providers in this study as emanating from feeling sorry for the stroke clients among caregivers is not uncommon. The service providers' observation is consistent with explanations by Thompson and Sobolew-Shubin (1993) on why caregivers may be seen as overprotective thus (a) a discrepancy between patients and caregivers in judging patient functioning; (b) caregiver protective behaviours, such as restricting the patient because of fear for the patient's safety; and (c) caregivers' negative attitudes toward the patient. The negative consequence for this overprotection is that stroke clients become more depressed even when the severity of the stroke

is mild (Thompson & Sobolew-Shubin, 1993). Depression may therefore limit stroke clients' ability to go out and participate and hence a barrier to reintegration into the community.

Some negative attitudes are due to lack of awareness. Stroke clients said they suffer the effect of lack of awareness about stroke condition and its effects starting with their own families. Stroke clients perceive that family members do not know how to handle clients with impairments in meeting their needs. The clients, for example, do not seem satisfied with what they are receiving from their caregivers, yet they feel powerless to explain their needs. The reasoning could be that the caregivers are not sharing the changes and challenges that the stroke client is passing through following stroke probably because they do not know about the changes, "the silent disability that the client is suffering" and hence they do not seem interested to understand him. This development could be due to lack of education about the condition by professional to stroke clients and caregivers.

Low literacy among family members has also been perceived to have a bearing on attitude of people about stroke disability. Service providers reported that lower levels of education among family members is associated with limited understanding of general challenges experienced by stroke clients. Although, studies on literacy level among caregivers as a determinant on care giving for stroke clients are rare, the perception of the service providers in the current study may correlate with findings by Correa, Leandro-Merhi, Pagotto-Fogaca, & Marques de Oliveira (2009) who says educational level of the caregivers is a determining factor for nutritional status of the elderly in the community, meaning the higher the education of the caregivers the higher the nutritional status of the elderly. This may be so because of the higher ability to comprehend complex requirements and compliance related to nutrition by the elderly who gradually lose the ability to take care of themselves. The findings by Correa et al. (2009) are based on the

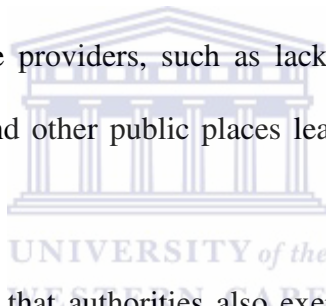
caregivers of the elderly, however the findings may be extrapolated to caregivers of stroke clients who equally provide care to dependent clients, so that the stroke clients' functional level or well-being in the community depends on the ability of caregivers to understand philosophies underpinning rehabilitation and the diverse challenges experienced by clients due to stroke condition, even after their discharge. The impact of negative attitudes by some family members' lack of awareness about stroke and lower literacy among caregivers may individually or altogether lead to limitations to activity and restrictions to participation which translate to consequent failure to fully reintegrate into the community after discharge.

Change in attitude by friends, relatives and members of the community: stroke clients, caregivers and service providers in this study highlighted that stroke clients become obsolete in the eyes of people in the community. They say people do not visit them because unlike the time before stroke, the clients are not productive now, so that when the people visit them the visitors do not get any benefit. This development, therefore, leads to reduction in contacts and interactions with other community members. In addition, caregivers and service providers perceive that stroke clients are also socially isolated by group members in the groups they formerly belonged to.

The attitudes held by people towards a disabled member and their families lead to difficulties with participation in the communities by the persons with disability generally (Yeo & Moor, 2003; Luuanga, et al., 2002). The feeling of not being thought of by others, in the current study, as was the case before stroke may be emotionally damaging and destructive to self-image. These feelings may therefore challenge full reintegration into the community by stroke clients after discharge.

Caregivers and service providers also highlighted that public transport operators do not consider problems faced by stroke clients in terms of speed, ending up being impatient with them. This affects stroke clients' abilities to travel out of their homes to visit different places. Stroke clients did not give out similar sentiments about taxi drivers. It may be because after stroke the clients have not travelled much to experience such attitudes. However, the perceptions by caregivers and service providers concurs with findings from a multinational survey that included Blantyre-Malawi by Venter et al. (2002), that bus drivers do not allow sufficient time for disabled people to board and alight in comfort and safety, and transport personnel in general are lacking in disability awareness and training in assisting people into vehicles.

Caregivers and service providers also highlighted that stroke clients suffer the effect of business as usual attitude by health service providers, such as lack of consideration for “people with physical challenges” in hospital and other public places leading to problem accessing medical services.



In addition, service providers said that authorities also exercise business as usual attitude, for example, when implementing projects they do not consider persons with mobility problems. The lack of consideration when building structures leads to stroke clients failing to access them and so they are automatically excluded in such areas as social gatherings when they are conducted in such buildings. This is in line with the findings by Rudman et al. (2006), who reported physical barriers inside the home or public building such as stairs, narrow door, and limited space for wheelchair use as leading to lack of accessibility by stroke clients. Lack of access to structures such as churches excludes stroke clients with mobility problems; hence their reintegration in the community, through failure to assemble with community groups, is affected.

Stroke clients and service providers in this study perceived that some negative attitudes or behaviours by some members of the community are due to lack of awareness about stroke. Some community members, for example, become too inquisitive when they see a stroke client walk. This makes stroke client fail to remain mobile and participate in the community activities. Lack of awareness has been seen as a major culprit that limit a better life for disabled people in the community as it reinforces negative attitude by members of the public towards disability (WHO & the World Bank, 2011).

In this study, service providers underlined that lack of awareness about stroke also strengthens traditional belief that lead to labelling stroke client as a witch. The labeling may bring a hostile environment to the stroke clients in the communities so that it is not easy for the clients to participate in community activities.

The findings on allegations about witchcraft in this study concurs with Yeo and Moor (2003) who in their report said in many parts of the world, it is common to associate disability with evil, witchcraft. As a result this leads consequent exclusion from everyday life (Yeo & Moor, 2003). However, stroke clients and caregivers in this study did not talk about the witchcraft allegations by the members of the community. It may be that those who allege do not come in the open so that the clients and their families are not aware of, or that it is just mere speculation and theory by the service providers because the issues of witchcraft may not be as rife in the communities as they ordinarily think. Nevertheless, such labeling may lead to exclusion of stroke clients and hence their failure to reintegrate into the community after discharge.

Change in attitude by employers: Employer in this study embraces both formal (if client was employed before) and informal which include business clientele or consumers of the services offered by the stroke client prior to stroke

In the current study, all the three groups of participant said there is often a change in the attitude of employers and business associates/clients towards people with stroke. For example, stroke clients said they are no longer approached for contracts or deals by the members of the public (business associates/clients), perceiving that the clientele has grown to question the abilities of the person after stroke. This affects mostly those clients who were consultants before stroke.

In addition, this study also shows that employers may stereotype stroke clients so that they do not consider that stroke client can recover and come back to their work. They, therefore, end up relieving them of their duties.

On the one hand, studies on attitudes of employers towards stroke client produce mixed outcomes. However those clients who find that work colleagues or managers are not supportive and do not recognize and support them, find returning to work difficult (Alaszewski, Alaszewski, Potter, & Penhale, 2007).

On the other hand, perceived negative stances by employers could be emanating from underlying organizational policies (Yeo & Moor 2003). This study shows that some stroke clients are not maintained on pay role after a certain period of sick leave as a policy of the organization. Stroke clients and caregivers said that such policies are not supportive to the employee who suffers stroke as it affects them economically. This finding is in line with the observation that the disabled people are marginalized by laws, policies, customs and/or practices, for example, some employers do not consider the requirements of disabled employee (Yeo & Moor 2003). Loss of

employment and financial support may be the source for emotional breakdown and depression associated with loss of roles as bread winners of the family. Pre-stroke roles are some of the domains of community reintegration, therefore, lack of ability in this domain due to loss of income following loss of productive work or employment means stroke clients may not be fully reintegrated into the community (Obembe, et al., 2002).

5.3.2.2 Limitation by physical environment

In the current study three forms of barriers immersed under this subtheme. They are uneven terrain, long distance to places of interest, and inaccessible structures.

Uneven terrain: stroke clients, caregiver, and service providers perceived that stroke clients face difficulties moving from place to place in the communities because of land form, which is either steep or full of potholes. The areas where the study was carried out, it is observable that the land is generally not flat, road to the locations are not tarred, and some places are full of sand which may be difficult to walk or propel wheelchair on.

Mobility in the community enables clients to access community destinations to pursue daily activities. However, the negative effect of poor terrain on mobility is well known (Barker et al., 2006; Trigg & Wood, 1999). The finding in the current study concurs with results of the qualitative study by Barker et al., (2006), where “uneven sidewalks, rough ground such as potholes and grass”, were perceived as limiting the mobility of stroke clients in wheelchair to different areas for participation. Furthermore, pedestrian stroke clients are also limited. In their study Trigg and Wood (1999), found that some physical factors such as hilly areas pose difficulties for stroke clients to move from place to place in pursuance of leisure or other goals. Because of the failure to remain mobile in the communities due to uneven terrain stroke clients

may fail to participate in outdoor activities or not able to return to work after stroke, or being unable to return to pre-stroke leisure activities hence unable to be fully reintegrated into the community.

Distance to places of interest: In this study, participants from the three groups produced similar observation that clients fail to access some places and services such as taxi stage and public hospitals because they are too far from where they are living. Therefore, it becomes difficult to access basic services such as medical.

The results of the current study concurs with findings from a study in New Guinea by Shaw (2004) where the author reported that rehabilitation and medical services are often located at places far from where persons with disabilities live. The distance, therefore, makes it difficult for the persons with disabilities to access the services. In Malawi, poor network of health services has also been reported particularly in rural areas where because of distance people face difficulties accessing services including medical (Hofman, Dzimadzi, Lungu, Ratsma, & Hussein, 2008). The findings in this study also concurs with the results of research by Mony (2002) who reported that access to water sources in communities can be difficult because of long distances and lack of alternative in nearby areas among the disabled people. Although Mony (2002) study is not specific to stroke clients, the report on distance to source of water may highly be applicable to mostly female stroke clients in Malawian communities which affect their role of caring for their family.

Inability to access place and services outside the stroke clients' homes may lead to the clients feeling cut from the outside world and less important to it and also likely to experience poor health due to lack of timely access to health service for example (Shaw, 2004). They may not

therefore feel fully reintegrated into the community after discharge as the domains to community reintegration such as ability to travel long distance, family roles through provision of basics such as water, and recreation and social activities are compromised because of long distance to places.

Inaccessible structures: again the three groups in this study had similar observations that some stroke clients are not able to access buildings that have steps. Disability issues in Malawi are a relatively new area of interest by policy makers, therefore public structures and buildings are mostly not disability-friendly (MSDPD Malawi, 2006). This may validate the perceptions by research participants in the current study about inaccessibility to structures.

The findings in this study also concurs with results of a qualitative study by barker et al. (2006), who reported that stroke client experience difficulties related to “heavy doors, narrow store aisles, stairs,...inaccessible washrooms, difficulties getting the wheelchair into the car”. In addition the findings are in line with Rudman, et al. (2006), who also reported physical barriers found inside the home included stairs, narrow door, and limited space for wheelchair use; whereas, the authors say, barriers outside the home were more of set up of facilities.

Service providers further said that most min-buses on the roads of Malawi are not wheelchairs friendly. This limits the ability of stroke client who are wheelchair bound to travel on distant journeys. Stroke clients and caregivers did not give views similar to an extension by service providers on min-buses, probably because none of the stroke clients owned a wheelchair by the day of interview so they had no experience to that effect. However, service providers' perceptions concurs with results from a multinational study about access issues by persons with disability where Venter et al. (2002) found that it is not always deliberate that operators of buses

leave out persons travelling on wheelchair, but many min-buses just did not have room for mobility aids such as wheelchair.

5.3.2.3 Resource limitation

The barriers under this subtheme are seen under three levels namely resource limitation at household level, resource limitation at community level, and resource limitation at organizational level. They are discussed below.

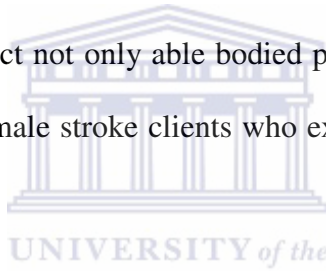
Resource limitation at household level: In the current study, stroke clients and service providers perceived that stroke clients experience poverty at household level. Stroke clients said lack of financial resource makes it difficult to travel by taxi from place to place, in pursuit of accessing services such as medical. Service providers also said that poverty which is more prevalent in rural areas makes stroke clients fail to acquire nutritious food thereby worsening their condition.

It is interesting to note that caregivers did not directly mention limitation of resources in their homes as affecting their stay in the community after discharge. However, according to the Integrated Household Survey 2004/05, 52.4 % of the population in Malawi lives below the poverty line, with the poorest people in the Southern Region (where this study took place) and rural areas being poorer than urban areas where poverty rates are at 25% (Malawi Growth and Development Strategy 2006 – 2011). In addition, there is a growing base of knowledge linking poverty and disability and that the phenomenon is observable in both the developed as well as the developing countries (Bonnet, 1997; UNESCAP, 1995).

Poverty at household level therefore leads to difficulty accessing services, care and rehabilitation they need (May-Teerink, 1999) and failure to participate in community activities.

Resource limitation at community level: in this study, only stroke clients talked about limitation of resources at community level. The clients said there is limitation in the provision of public resources in the community such as mobility aids and portable water accessible by people with mobility problems such as stroke clients as and they said so as a plea to the government. In addition the stroke clients also said there is lack of home based care service after discharge.

Caregivers and service providers did not say anything related to limitation in provision of public resources as affecting stroke clients, and to the knowledge of the researcher studies about community resources accessible to stroke clients in developing countries are rare. However, problem with access to portable water concurs with report by Gutierrez (2007) who says due to lack of access roads, poorer areas with less infrastructure in Malawi tend to get less water points. Sparse water points, therefore, affect not only able bodied people, but more so it affects people with mobility problems such as female stroke clients who expressed this problem in the current study.



Lack of mobility aids may limit stroke clients' abilities to go out and participate in outdoor activities in the community, and long distance to water points may affect the role of mainly female stroke clients who traditionally are expected to fetch water for their family. Loss of role in this instance may lead to altered self-image by the clients who may feel useless by not fulfilling their roles which are a domain in community reintegration (Obembe, et al., 2002).

Resource limitation at organizational level: in this study, stroke clients and service providers said there are limited resources for rehabilitation of people with stroke. Specifically stroke clients said that there is shortage of rehabilitation staff and limited equipment at Kachere rehabilitation centre. This they said affects the quality and quantity of rehabilitation services to those who need

it. Though not supported by the caregivers in this study, the observation by the stroke clients may be valid as there are two physiotherapists, one occupational therapist, and seven rehabilitation technicians against the bed capacity of 40 (personal communication, January 2010). In addition, limited number of staff at Kachere may reflect the deficit of rehabilitation personnel at national level as observed by the Physiotherapy Association of Malawi (Kambalame, 2008). Lack of sufficient staff may limit the level of function attainable after stroke and probably lead to limited attention to reintegration issues after discharge, thereby making clients meet avoidable barriers to reintegration in the community.

Service providers on the other hand said there is limited financial support for Malawi Against Physical Disabilities, (parent organization to Kachere rehabilitation centre) in addition to countrywide shortage of rehabilitation services which they said also affect rehabilitation service delivery at community level. The service providers said the financial problems limits external trips for resettling stroke clients and increasing awareness about stroke in the communities. The limitation in funding rehabilitation services as perceived by service providers is in accord with report by WHO and the World Bank (2011) that many countries, especially low-middle-income countries struggle to finance rehabilitation, in spite of the positive role rehabilitation play in building human capital.

The limitation in financial resources as mentioned by service providers may indeed affect resettlement and awareness trips by the organization. For example, during data collection the researcher observed that the outreach team of the organization was grounded for months without conducting outreach clinics due to financial problems rocking the organization. In addition, the observation by stroke client about limitation of staff at the centre may be a reflection of this

financial situation although national wide shortage of rehabilitation personnel may be another explanation.

Limitation in raising awareness may reinforce negative attitudes by people in the community (WHO & World Bank, 2011) such as labelling stroke clients as ‘witches’ and excluding them. The failure to conduct home visits also may limit elimination of avoidable physical barriers to mobility in the home, steps to the house for example, thereby impeding stroke clients’ successful reintegration into the community.

5.4 Facilitators

Under the emerging theme of facilitators, the following are discussed; supportive family friends and relatives, availability of a car, ownership of income generating asset, belief in God, and presence of health insurance cover in the family.

It is worth noting that the facilitators are mostly from the perspectives of stroke clients and caregivers. This is logical as they are the ones who are in close proximity with stroke phenomenon as compared the service providers.

Supportive family, friends and relatives: stroke client and caregivers said the clients often receive financial and moral support from some family members, friends and relatives in the community.

Availability of others, receiving support from others and interaction with others in the community at large, are reported to be some of the elements that constitutes to the feeling of connectedness in the community by stroke clients which is necessary for reintegration into the community (Rittman, et al., 2007). However, the study also shows absence of other elements that are necessary for complete connectedness among the clients which in line with Rittman et al.

(2007) comprise of ability to contribute, where in this study participants feel stroke clients lose friends because they are no longer able to give them something; and ability to engage in intimate relationship, whereas this study there is conscious awareness that stroke clients and their spouse miss an element in intimate relationship, sex.

Though not enough but receiving support and presence of other friends and relatives has been a supportive element in as far as leaving in the community after stroke in this study is concerned.

Ownership of supportive resources: stroke clients and caregivers said having access to a car in their household made mobility to places of interest easier. This means accessing public services such as hospitals become easier to them and that in absence of cognitive and psychological impairments stroke clients can still take part in activities away from home. However, Malawi being a developing country with bigger population living below the poverty line (Malawi Growth and Development Strategy 2006 – 2011) it is unlikely that many households own a car.

Stroke clients and caregivers also indicated that owning an income generating asset ensures a continuous flow of income even if they are not able to go back to work after stroke. In this study, almost all participant did not go back to their economic activities; formal or informal employment, by the day of interview. Hence, having an income generating asset may be a relief towards the day to day running of their life in the community.

Belief in God: stroke clients and caregivers in this study continuously talked of the involvement of the clients in church affairs and how stroke clients find relief in suffering from stroke impairments and accepting their condition as one of God's manifestations in their life.

The role of spirituality and attending spiritual gathering in people with different medical conditions is well known (Koeniget al., 1997; Strawbridge, Cohen, Shema, & Kaplan, 1997). For

example, in both studies, the authors hypothesize that religious commitment may improve stress control by offering better coping mechanisms, richer social support, and the strength of personal values and worldview. Spirituality among stroke clients may therefore be a good capital for stroke clients' ease of reintegration into the community after discharge.

Presence of health insurance cover in the family: some caregivers associated the presence of health insurance to some stroke clients and their family to the ease of access of medical services.

The benefit of health insurance after stroke is enormous. The study conducted in China to determine effects of stroke at household level at three months post stroke, Heeley et al. (2009) found that overall, 3384 (71%) patients had experienced catastrophic out-of-pocket expenditure, and that workers without health insurance were 7 times more likely to experience catastrophic payments than workers with insurance. The authors further found that health insurance also protected against catastrophic payments in patients who were either retired or not working. The findings in China therefore concurs with the current study's results that medical insurances eases stroke clients access to medical services in Malawi. However, not all stroke clients in this study are covered by any health insurance company, and also it is most unlikely that people in rural areas of the country (except probably those who have sons and daughters working in the city and on medical scheme) are on any medical scheme. Hence, access to health for such people may remain a challenge after stroke.

5.5 Chapter summary and conclusion

The current study aimed at exploring the barriers to reintegration experienced by stroke clients post discharge from a rehabilitation center in Malawi, from the perspectives of stroke clients, caregivers and service providers. This chapter first discussed the domains in which barriers to

reintegration are experienced before discussing on emerging barriers to community reintegration. Facilitators to community reintegration were also discussed.

The domains that have been discussed as clients having difficulties in are activity limitation which included loss of abilities for ADLs and difficulties with sex; and participation restriction which included failure to participate in economic activities, and social participation. Two themes on barriers have been discussed, that is, barriers at individual level which included impairments and personal barriers that included lack of acceptance of the condition by stroke clients, gender, and co morbidity; and barriers at the level of environment which included environmental barriers such as attitudinal barriers, physical environmental barriers, and resource limitation.

The discussion, then, centered on the perceived facilitators that included positive support from family, friends and relatives; ownership of supportive resources, membership with healthcare insurance, and spirituality.

This study has not found any differences in the types and level of barriers experienced by stroke clients related to the differences in the period of stay in the communities after discharge.

5.6 Study limitations

Without the intent of the researcher some of the interviews were carried out in the presence of the third party, such as presence of caregiver when the interview was with stroke client, and the other way round in some situations. However, the influence of this on the result could be minimal if at all there is any, as the researcher took measures that made sure the other party does not interfere with the interview process such as not helping the respondent answer the questions through verbal or cue guidance.

The study summary, conclusion and recommendations have been presented in the next chapter.

CHAPTER SIX

SUMMARY, CONCLUSION, RELEVANCE OF THE STUDY, AND RECOMMENDATIONS

6.0 Introduction

This chapter summarises the study, and highlights the major findings and conclusions that emanated from the study. The relevance of the study and recommendations are also made based on the results.

6.1 Summary and Conclusion of the study

As there has been no scientific finding about the experiences of stroke clients in their communities after discharge from a rehabilitation center in Malawi, the current study aimed to explore the barriers to reintegration experienced by stroke clients post discharge in the country. The study which was conducted at Kachere Rehabilitation Center, and surrounding communities in Blantyre-Malawi has yielded interesting results in three categories namely, affected domain to community reintegration, barriers to community reintegration, and facilitators to community reintegration.

According to the findings, barriers to community reintegration are experienced in two domains of: activity limitation and participation restriction. The current study has also displayed the barriers to reintegration across two themes i.e. barriers at individual level and barriers at the level of environment in the community

It is evident that stroke clients in the current study experience limitations and restrictions in the activity and participation domains of community reintegration. In particular, stroke clients are not able to carry out different ADLs such as domestic chores and mobility in the community. Stroke clients are, in addition, not able to participate in different life situations including failure to engage in economic activities that negatively affect their roles in families and communities at large. Based on this background, one would think stroke clients may not be satisfied with their reintegration into the community after discharge.

The barriers experienced by stroke clients in the communities are wide ranging. At individual level impairments such as depression and anxiety, physical weakness, physiological functional changes, pain and bladder incontinence; and personal characteristic such as lack of acceptance of the condition by stroke clients, gender, and co-morbidity limits the clients' active involvement in various domains of community reintegration. In addition, several environmental barriers also emerged. They include attitudinal barriers, where clients experience overprotection on the part of family members, lack of respect for client, labelling stroke clients 'as witches' by community members, and social isolation by community groups. Stroke clients also experience physical environmental barriers such as poor terrain, long distance to places of interest, and inaccessible structures. In addition, this study shows that the client's reintegration is also affected by resource limitation due to poverty at household and community levels, lack of sufficient public resources in the community, lack of funding for rehabilitation programs and limited number of rehabilitation personnel at organization and national levels resulting into failure to facilitate reintegration through different programs on accessibility and awareness.

Amidst these barriers however, stroke client's living in the community is eased or facilitated by some factors. This research further demonstrated that financial and moral support from

significant others, ownership of supportive resources, belief in God, and the presence health insurance in the household as having a positive impact in the life of stroke clients and their families in the communities after discharge.

There is no difference in the barriers perceived by stroke clients who have been about six months in the community as compared to those who, on the day of interview, were about one year post discharge in the community.

The ICF made it easy to systematically present the findings of this study. It has also made it clear that barriers to reintegration emanates from both an individual as well as the environment.

6.2 Relevance of the study to physiotherapists and other service providers

Institutions such as Kachere Rehabilitation Center, providing in-patient rehabilitation services, focus their attention on impairment and activity limitation levels when treating clients (Sabari, Meisler, & Silver, 2000). Little attention is given to participation level in the community thereby not addressing the potential challenges that the clients experience after discharge (Cott et al., 2007). The current study has unearthed grass root information related to barriers experienced by stroke clients at different levels after discharge in Malawi.

The strength of the current study has been that it has sourced perceptions from three relevant groups of participants; stroke client, caregivers and service providers and the difference in perceptions related to barriers within, and between groups making it particularly rich as it informs the lived experiences of stroke clients against what might be perceived by other quarters including service providers.

The study has revealed perceptions of the stroke clients through various descriptions such as loss of confidence, hopelessness, and sad mood that point to possibilities of depression among the

clients. These are elements not easily noticeable by service providers (Mukherjee, Levin, & Heller, 2006) in the course of their duties. This finding could alert the service providers of possibility of depression in individuals at risk and therefore, manage it as early as possible.

The current study could also raise awareness among service providers against some traditional thinking in rehabilitation on issues related to community reintegration. For example, the service providers' common perceptions such as allegations of witchcraft as thwarting stroke clients' reintegration revealed in this study, may not be as strong a challenge in the community as compared to misunderstandings that ensue in families that clearly comes out in this study from perspectives of caregivers and supported by other studies (Thomson & Ryan 2009) probably due to lack of knowledge or awareness about stroke and how to live with the clients by family members.

The study also has brought to the light common issues from across the three groups of participants such as attitudinal barriers. Such common issues could underline the need for redress by stakeholders in rehabilitation. For example, attitudinal problems have been seen in this study as emanating from lack of awareness about stroke by the public. Lack of awareness as a source of attitudinal barriers has been backed by the WHO and the World Bank (2011) in which case the role of advocacy may be imperative in raising awareness about stroke disability among members of the public. Service providers may use this finding to localise the focus of their service delivery.

The study also reveals the deficits in the public services at community level which are that there are no public health services such as home visit program that would benefit stroke clients with residual impairments; transport service that is not disability friendly; and community structures

that are not accessible by stroke clients. In this light the service providers could use this finding as evidence towards the areas of focus in their role of advocacy.

In addition, the study has also brought to the light the main cause for challenge in the rehabilitation service delivery at organization level, which is lack of funding to the rehabilitation organization seen in this study as impacting negatively on reintegration issues. The WHO and the World Bank (2011) also highlights problems faced by rehabilitation organizations due to lack of funding particularly in developing countries. This revelation could also give a pathway for service providers' roles of advocacy to policy makers in different levels of the society and government.

Although there are all these barriers, this study shows, rehabilitation is highly appreciated by the stroke clients and caregivers as an approach that takes away part of their suffering, though it came out also that the consumers of the service acknowledge the small scale the service is being offered in the country, and that most people, particularly, in the rural areas do not access the service. These findings could be used by the government through the Ministry of Health in planning for expansion of service provision in the country.

The findings in this study therefore add to the body of knowledge among service providers with potential to modifying the foci of management of stroke clients against the traditional ways of how rehabilitation is carried out in the country as per the observation of the researcher and other study findings (Cott, et al., 2007; Pang, et al., 2007).

6.3 Recommendations

6.3.1 Holistic management of stroke in Malawi

The study has shown that barriers to reintegration of stroke clients into the community are both at personal and environmental levels. The researcher, therefore, suggests that service providers could equally consider addressing contextual or environmental challenges experienced by stroke clients, a bio-psychosocial approach to rehabilitation. The service providers could adopt the use of the ICF in assessment and management of stroke clients as a way of implementing the whole-person-patient-centred approach.

As this study has revealed misunderstandings in the family system after discharge, caregivers and stroke clients could be involved in decision-making at an earliest possible time in the process of rehabilitation: share goals, education about stroke and its effects to the client and family members and counselling them as part of addressing possibility of depression and anxiety that also immersed in the current study.

Sexual matters that have been shown to be difficult in this study need not be overlooked. The researcher suggests that issues related to sexual life be discussed at every stage of rehabilitation including after discharge as recommended by Salter, et al. (2008) and other policy documents (Canadian Best Practice Recommendations for Stroke Care, 2008).

6.3.2 Step up measures to boost rehabilitation services at community, district and national levels in Malawi

In as far as the outcomes of this study are concerned; there is limited rehabilitation service delivery due to small number of rehabilitation personnel in the country, and lack of funding to rehabilitation organizations such as Malawi against Physical Disabilities. Based on these findings, the government of Malawi could consider increasing the funding to rehabilitation organizations in order to boost rehabilitation services against the trend revealed in this study. In addition, the government of Malawi could consider increasing the numbers of rehabilitation training institutions and that the existing schools may need to also consider increasing their intake as the demand for the rehabilitation services is enormous.

6.3.3 Research and developing a model of stroke care and rehabilitation in Malawi

Being the first of its kind in Malawi and the region, this research opens wider chances for further research. As this research looked at all the domains of the ICF, it is possible that it lacked detail, although the barriers displayed in this study are undisputable as they came first to the minds of the participants showing their significance, studies dealing with individual domains are encouraged.

The researcher also recommends that a model of stroke care and rehabilitation, which currently Malawi does not have, be developed after thorough research and consultations so that the model is consistent with local conditions. This would ensure uniform approach to management of stroke clients and consequently minimize the barriers associated with reintegration into the community by stroke clients in the country.

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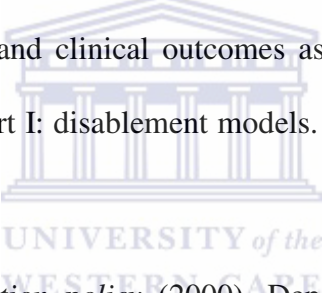
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APPENDICES

Appendix A: Ethical clearance form UWC

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

Private Bag X17, Bellville 7535
South Africa
Telegraph: UNIBELL
Telephone: +27 21 959-2948/2949
Fax: +27 21 959-3170
Website: www.uwc.ac.za

27 October 2010

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 the ethics of the following research project by:
Mr. G Chimatiro (Physiotherapy)

Research Project: Barriers to reintegration experienced by stroke clients post discharge from a rehabilitation centre in Malawi

Registration no: 10/9/24


Peter Syster
Manager, Research Development Office
University of the Western Cape



**UNIVERSITY of the
WESTERN CAPE**

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

AppendixB: Application for approval to conduct research at MAP



UNIVERSITY of the
WESTERN CAPE

Private Bag X17, Bellville 7535, South Africa
Tel.: +27 (0) 21 959 2542/3647.
Fax: +27 (0) 959 1217
Email: jphillips@uwc.ac.za
Website: www.uwc.ac.za

DEPARTMENT OF PHYSIOTHERAPY

University of Malawi - College of Medicine Research & Ethics Committee
Private Bag 360
Chichiri
Blantyre 3,
Malawi

Dear Sir/Madam

Application for Permission to Conduct Research at Kachere Rehabilitation Center

I am George Chimatiro, an employee at Kachere Rehabilitation Center who is currently studying as MSc Physiotherapy at the University of the Western Cape in South Africa. As part of my masters, I am carrying out a research project entitled 'Barriers to reintegration experienced by stroke clients post discharge from a rehabilitation center in Malawi'.

The aim of the research is to explore the perceived barriers to reintegration into the community experienced by stroke clients, after discharge from Kachere rehabilitation center. To achieve this aim, six rehabilitation personnel at Kachere, eight discharged Stroke clients living in the community, and eight care givers of participating stroke clients will be interviewed. The data collection is expected to be carried out within the months of December and January 2010/11.

Application to the institution has been made and permission granted. I therefore request your permission to conduct the study at the mentioned institution.

Hoping my request will be considered favourably.

Yours Sincerely, —


George Chimatiro

Research student

Dr A Rhoda

Supervisor


.....
Signature of Research Student


.....
Signature of Supervisor

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

AppendixC: MAP approval to conduct research



MAP

MALAWI AGAINST PHYSICAL DISABILITIES

Ref. No. G/1

28th October, 2010

Dear Mr Chimatiro

Thank you for your email. As an organization we have accepted you to conduct a 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/

AppendixD: Checklist for proposal submission to COMREC Malawi

UNIVERSITY OF MALAWI - COLLEGE OF MEDICINE RESEARCH and ETHICS COMMITTEE CHECKLIST TO ACCOMPANY RESEARCH PROPOSALS SUBMITTED TO THE COMMITTEE

TITLE OF PROPOSAL:

Barriers to reintegration experienced by stroke clients post discharge from a rehabilitation center in Malawi

Name of Principal Investigator: George Lameck Chimatiro

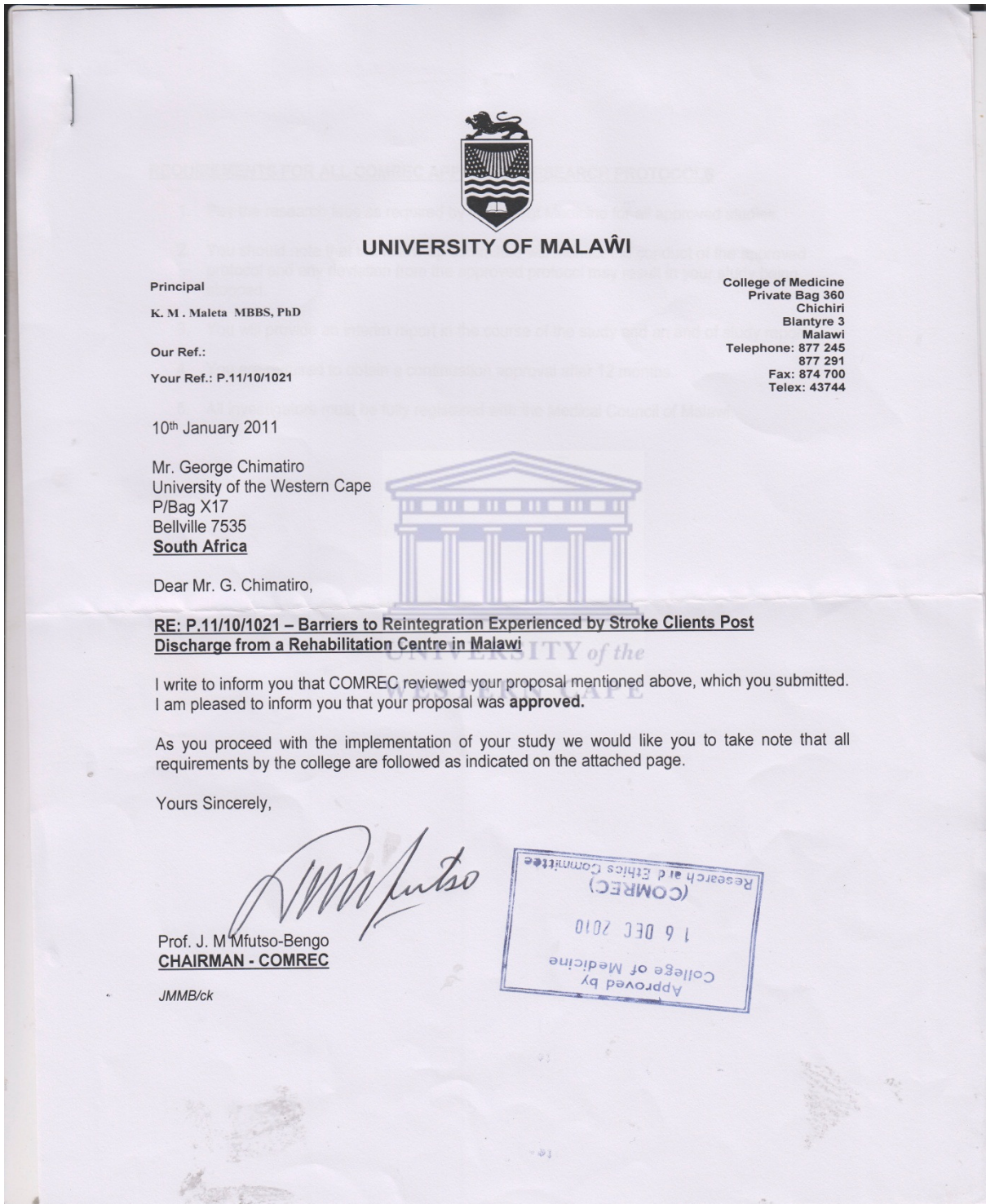
Name of Sponsor and amount of sponsorship: Self, 132660.00Mk 10% COMREC inclusive

The following are included in or with this proposal:

(tick boxes)

- 1. Covering letter of introduction from Investigator
- 2. Letter of support from Head of Department(s) in which work will be done
 - (a) Principal Department hosting the research
 - (b) Each other Dept. in which any work will be done
- 3. A copy of registration from Medical Council of Malawi for Principal Investigator and other investigators which are involved in clinical research
- 4. Submit an **electronic copy** and **4 hard copies** of the proposal and attached documents (which should include:
 - Title
 - Investigators
 - Brief CV of each investigator, Institution involved, Executive Summary
 - Background/Introduction
 - Rational/J justification
 - Objectives of the study
 - Methods
 - type of study - place of study
 - study population
 - study period
 - sample size
 - data collection *[NB: include data proformas]*
 - data management/analysis
 - Presentation of results
 - Dissemination of results
 - Ethical considerations
 - *NB: include consent forms in both English & Chichewa*
 - Possible constraints
 - Requirements
 - Training provided for
 - Budget and Justification of budget
 - References
 - Material transfer agreement forms/documents
 - Indemnity cover
 - If any item is not ticked, explain why this is not included with the submission.

Signed:  Name: George Lameck Chimatiro Date: 27th October, 2010



Appendix F: Consent for research participants



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

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

E-mail:

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.....

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: students name

University of the Western Cape

Private Bag X17, Belville 7535

Telephone: +27219592542

Cell: +27732006834

Fax: +27219591217

Email: 3077278@uwc.ac.za

Appendix G: Consent form – Chichewa



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

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

E-mail:

FOLOMU YA CHILOLEDZO

MUTU WA KAFUKUFUKU

Ndondomeko ya kafukufukuyu ndauzidwa mchiyankhulo chomveka ndipo ndamvetsa, mwakufuna kwanga ndavomela kuchita nawo. Mafunso anga onse pa nkhani imeneyi ayankhidwa. Ndikuziwanso kuti nkhani zokhuza ine zidasungidwa mwachinsisi, ndipo kuti nditha kusiya kuchita nawo kafukufuku ameneyu popanda kupeleka chifukwa chilichonse. Komanso ndikatelo sindilandila mkwiyo uliwonse.

Dzina la ochitanawo kafukufuku:.....

Chidindo chaochitanawo kafukufuku:.....

Tsiku:.....

Ngati muli ndi mafunso pa nkhani ya kafukufuku ameneyu, kapena mukufuna kunena za mavuto omwe mwakumananawo pa kafukufuku ameneyu (musachedwe) yankhulani ndi woyendesa kafukufukuyu:

Dzina la woyendesa kafukufuku: George Chimatiro

University of the Western Cape

Private Bag X17, Belville 7535

Telephone: +27219592542

Cell: +27732006834

Fax: +27219591217

Email: 3077278@uwc.ac.za

Appendix H:Information sheet for stroke clients



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

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

E-mail:

INFORMATION SHEET

Stroke client

Project Title:

Barriers to reintegration experienced by stroke clients post discharge from a rehabilitation center in Malawi



What is this study about?

This is a research project being conducted by George Chimatiro, Masters student at the University of the Western Cape. We are inviting you to participate in this research project because you underwent rehabilitation following stroke and that you are back into community. The purpose of this research project is to explore the perceived barriers to reintegration into the community experienced by stroke clients after discharge from Kachere rehabilitation center.

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

After signing the consent form you will be asked to spare time to meet those carrying out research at a place and time of your convenience. At the meeting you be asked to fill a form that seeks your socio-demographic information such as age, sex, marital status, time since onset of

stroke, side of body affected, and time since discharge from a rehabilitation center. A general question will be put forward by the researcher, related to life of your member in the community after discharge from a rehabilitation center, which you will be answering according to your experience. The researcher and/or research assistant will be available and ready to answer your questions should you have some, in a meeting that may last about 30 minutes.

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, we will not ask for or write your name on all papers related to this research. Instead identification codes using numbers will be used on data forms to ensure anonymity, and the researcher will personally collect all data collection forms and will ensure their storage in a locked and secure place. When we will finally write a report about this study your identity will remain protected and not displayed at any point.

What are the risks of this research?

There are no known risks associated with participating in this research project. However if you experience any problem in the course of the study such as mental or physical trauma, we will make sure you are referred to appropriate services such as counselling.

What are the benefits of this research?

This research may not be personally helpful to you, but the results may help the investigator learn more about the experiences of people living with stroke in their communities. We hope that, in the future, other people might benefit from this study through improved understanding by people generally and rehabilitation personnel in particular. This is hoped to improve service delivery for people affected by stroke.

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 George Chimatiro, Masters student under physiotherapy department of University of the Western Cape. If you have any questions about the research study itself, please contact George Chimatiro at: University of the Western Cape, physiotherapy department on telephone number: +27219592542, or mobile number: +27732006834, or email: 3077278@uwc.ac.za

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:

Dean of the Faculty of Community and Health Sciences:

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: Information sheets to stroke clients: Chichewa



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

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

E-mail:

Ndondomeko ya kafukufuku

Kwa anthu odwala matenda opuwalitsa ziwalo (stroke).

Mutu wa kafukufuku

Zolephelesa kubweleranso ku moyo wathanzi wakale pakati pa anthu odwala matenda opuwalitsa ziwalo (stroke) pamene atulusidwa ndikubwelela kwawo pakutha polandila chithandizo cholimbikitsa ziwalo mdziko la Malawi.

Kodi kafufukuyu ndiokhuza chiani?

Akuchita kafufukuyu ndi a George Chimatiro, omwe akuchita ma phunziro a pamwamba (Masters Degree) ku South Africa pa sukulu ya ukachenjede ya University of the Western Cape. Mukupemphedwa kuchita nawo kafukufuku ameneyu chifukwa munalandirapo chithadizo cholimbikitsa ziwalo ku Kachere Rehabilitation Center pamene munadwala matenda opuwalitsa ziwalo, sopano muli kunyumba. Cholinga cha kafufukuyu ndikudziwa zinthu zomwe anthu odwala matenda opuwalitsa ziwalo amakomana nawo, zomlepheletsa kukhala mmoyo wa tsiku ndi tsiku monga momwe ankakhallira asanadwale matendawa.

Kodi ndidzafunsidwa chiani ngati ndidzafune kuchita nao?

Mukabvomera ndi kusaina mapepala osonyedza kuti mwavomela, ochita kafufukuyu azakumana nanu pa malo ndi nthawi yomwe inu mungagwirizane nayo. Panthawiyo muzapemphedwa kuti mulembe kapena kunena zinthu zina zokhuza inu monga; zaka zanu zakubadwa, kaya ndiinu amayi kapena abambo, wokwatiwa/wokwatila, nthawi yomwe munadwala matenda opuwalitsa ziwalo, komanso mbali ya thupi lanu yomwe inakhuzidwa

ndimatendawa, ndi nthawi yomwe mwakhala kunyumba mutatulutsidwa ku Kachere. Kenaka mudzafunsidwa funso lomwe mudziyankhe malangana ndi zinthu zomwe mwakumana nazo monga mmozi wa anthu okhala mmuzi. Ochita kafukufukuyu adzakhala okonzeka kuyankha mafunso aliwonse omwe mongakhale nawo okhuza kafukufuku ameneyu. Kukumanaku kudzatenga mphindi zosaposela makumi atatu.

Koma chinsisi pa kuchita nawo kafukufuku ameneyu chizasungidwa?

Tidzayesesa kwambiri kusunga chinsisi chanu. Mwachitsanzo simudzafunsidwa kupereka kapena kulemba dzina lanu pa mapepala okhuza kafukufukuyu. Mmalo mwake nambala yoimila dzina lanu (code) idzagwilisidwa ntchito, ndipo wochita kafukufukuyu adzaonesetsa kuti mapepala onse agwiritsidwa ntchito popeza zofunikira za kafukufuku ameneyu atenga ndipo asungidwa pa malo obisika. Pakutha pa kafuku ameneyu dzina kapena chilichonse chokhuzana ndinu sichizaonetsedwa kwa aliyense kapena paliponse.

ndizoopsa ziti zomwe ndingakumane nazo pa kafukufuku ameneyu?

Palibe zoopsa zilizonse zomwe mungakumane nazo. Koma ngati mutapeza mavuto aliwonse mkati mwa kafukufuku ameneyu kaya mthupi kapena mmaganizo mwanu, tidzakhala okonzeka kukutumizani ku malo komwe mungalandire chithandizo choyenelera.

Pali phindu lanji pa kafukufuku ameneyu?

Mwina kafukufuku ameneyu sangakhale wothandiza chilichonse kwa inu monga munthu, koma zotsatila zake zingazathandize wochita kafukufuku ameneyu kudziwa bwino zovuta zomwe odwala matenda opuwalitsa ziwalo amakomana nazo pa moyo wao wa tsiku ndi tsiku kunyumba. Tili ndi chikulupiliro kuti mtsogolo muno anthu ena osiyanasiyana adzapindula kuzela mu nzelu zatsopano zimene zidzapezeke chifukwa cha kafukufuku ameneyu, komanso ma dotolo ogwira ntchito ya zolimbisa ziwalo adzapindulanso. Pakutelo odwala matenda opuwalitsa ziwalo azathandizidwa bwino komanso mokwanila.

Kodi nkofunika kupanganaye kafukufukufukuyu? Nanga ndili mkati mochita naye kafukufukuyu ndingathe kusiya kapena kuchoka nthawi iliyonse?

Kafukufuku ameneyu mutha kuchita nawo mwakufuna kwanu. Muthanso kukana. Ngati musankha kuchita nawo mudziwe kuti muthanso kuchoka nthawi iliyonse ngati mwafuna kutelo. Ngati simukufuna kuchita nawo, kapena mwaganiza zosiya kutenga nawo mbali pa kafukufuku ameneyu, simudzalandila chilango kapena mkwiyo uliwonse kuchokera kwa omwe akuchititsa kufukufukuyu.

Kodi nanga ntakhala ndi mafunso?

Akuchita kafukufukuyu ndi a George Chimatiro, omwe akuchita ma phunziro a pamwamba (Masters Degree) ku South Africa pa sukulu ya ukachenjede ya University of the Western Cape, ku departimenti yophunzitsa anthu oyang'anila anthu odwala matenda opuwalitsa ziwalo. Ngati muli ndi mafunso okhuza kafukufukuyu (musachedwe), lankhulani ndi a George Chimatiro, University of the Western Cape, Physiotherapy department. Telefoni: 0027219592542/0027732006834. Kapena tumizani kalata pa: 3077278@uwc.ac.za

Mukakhala ndimafunso okhudzana ndi kafukufukuyu komanso ufulu wanu ngati mmozi mwa ochita nawo kafukufuku ameneyu, kapena mukufuna kunena za mavuto aliwonse amene mwakumana nawo pankhani imeneyi (musazengereze) tumizani nkhwana zanu kwa:

**Head of Department,
Dean of the faculty of community and health sciences
University of the Western Cape,
Private Bag X17,
Bellville 7535,
Republic of South Africa.**

Kafukufukuyu walolezedwa ndi Senate Research Committee and Ethics Committee ya University of the Western Cape.

Appendix J: Information sheet to caregivers



UNIVERSITY OF THE WESTERN CAPE
Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959, Fax: 27 21-959
E-mail:

INFORMATION SHEET

Caregivers

Project Title:

Barriers to reintegration experienced by stroke clients post discharge from a rehabilitation center in Malawi



What is this study about?

This is a research project being conducted by George Chimatiro, Masters student at the University of the Western Cape. We are inviting you to participate in this research project because the person you are caring for underwent rehabilitation following stroke and that he/she is back into community. The purpose of this research project is to explore the perceived barriers to reintegration into the community experienced by stroke clients after discharge from Kachere rehabilitation center.

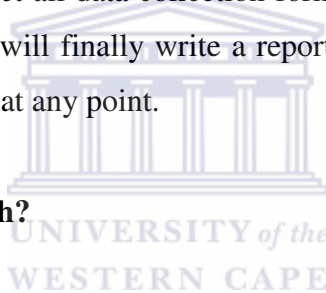
What will I be asked to do if I agree to participate?

After signing the consent form you will be asked to spare time to meet those carrying out research at a place and time of your convenience. At the meeting you be asked to fill a form that seeks your socio-demographic information such as age, sex, relation to the stroke client. A general question will be put forward by the researcher, related to life of your member in the community after discharge from a rehabilitation center, which you will be answering according to your experience. The researcher and/or research assistant will be available and ready to answer your questions should you have some, in a meeting that may last about 30 minutes.

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, we will not ask for or write your name on all papers related to this research. Instead identification codes using numbers will be used on data forms to ensure anonymity, and the researcher will personally collect all data collection forms and will ensure their storage in a locked and secure place. When we will finally write a report about this study your identity will remain protected and not displayed at any point.

What are the risks of this research?



There are no known risks associated with participating in this research project. However if you experience any problem in the course of the study such as mental or physical trauma, we will make sure you are referred to appropriate services such as counselling.

What are the benefits of this research?

This research may not be personally helpful to you or your member, but the results may help the investigator learn more about the experiences of people living with stroke in their communities. We hope that, in the future, other people might benefit from this study through improved understanding by people generally and rehabilitation personnel in particular. This is hoped to improve service delivery for people affected by stroke.

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 George Chimatiro, Masters student under physiotherapy department of University of the Western Cape. If you have any questions about the research study itself, please contact George Chimatiro at: University of the Western Cape, physiotherapy department on telephone number: +27219592542, or mobile number: +27732006834, or email: 3077278@uwc.ac.za

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:

Dean of the Faculty of Community and Health Sciences:

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 K: Information sheet to caregivers: Chichewa



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

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

E-mail:

Ndondomeko ya kafukufuku

Kwa omwe akusamalila munthu wodwala matenda opuwalitsa ziwalo (stroke).

Mutu wa kafukufuku

Zolephelesa kubweleranso ku moyo wathanzi wakale pakati pa anthu odwala matenda opuwalisa ziwalo (stroke) pamene atulusidwa ndikubwelela kwawo pakutha polandila chithandizo cholimbikitsa ziwalo mdziko la Malawi.

Kodi kafufukuyu ndiokhuza chiani?

Akuchita kafukufukuyu ndi a George Chimatiro, omwe akuchita ma phunziro a pamwamba (Masters Degree) ku South Africa pa sukulu ya ukachenjeda ya University of the Western Cape. Mukupemphedwa kuchita nawo kafukufuku ameneyu chifukwa ndinu mbale kapena munthu amene akusamalira ndikupeleka chithandizo kwa munthu yemwe analandirapo chithadizo cholimbikitsa ziwalo ku Kachere Rehabilitation Center pamene anadwala matenda opuwalitsa ziwalo, sopano ali kunyumba. Cholinga cha kafukufukuyu ndikudziwa zinthu zomwe anthu odwala matenda opuwalisa ziwalo amakomana nawo, zomlepheletsa kukhala mmoyo wa tsiku ndi tsiku monga momwe ankakhalira asanadwale matendawa.

Kodi ndidzafunsidwa chiani ngati ndidzafune kuchita nao?

Mukabvomera ndi kusaina mapepala osonyedza kuti mwavomela, ochita kafukufukuyu azakumana nanu pa malo ndi nthawi yomwe inu mungagwirizane nayo. Panthawiyi muzapemphedwa kuti mulembe kapena kunena zinthu zina zokhuza inu monga; zaka zanu zakubadwa, kaya ndiinu amayi kapena abambo, wokwatiwa/wokwatila, komanso ubale wanu ndi

wodwala matenda opuwalitsa ziwalo. Kenaka mudzafunsidwa funso lomwe mudzayankhe malangana ndi zinthu zomwe mukuona wodwalayo akukumana nazo monga mmozi wa anthu okhala mmuzi. Ochita kafukufukuyu adzakhala okonzeka kuyankha mafunso aliwonse omwe mongakhale nawo okhuza kafukufuku ameneyu. Kukumanaku kudzatenga mphindi zosaposela makumi atatu.

Koma chinsisi pa kuchita nawo kafukufuku ameneyu chizasungidwa?

Tidzayesesa kwambiri kusunga chinsisi chanu. Mwachitsanzo simudzafunsidwa kupereka kapena kulemba dzina lanu pa mapepala okhuza kafukufukuyu. Mmalu mwake nambala yoimila dzina lanu (code) idzagwilisidwa ntchito, ndipo wochita kafukufukuyu adzaonesetsa kuti mapepala onse agwiritsidwa ntchito popeza zofunikira za kafukufuku ameneyu atenga ndipo asungidwa pa malo obisika. Pakutha pa kafukufuku ameneyu dzina kapena chilichonse chokhuzana ndinu sichizaonetsedwa kwa aliyense kapena paliponse.

ndizoopsa ziti zomwe ndingakumane nazo pa kafukufuku ameneyu?

Palibe zoopsa zilizonse zomwe mungakumane nazo. Koma ngati mutapeza mavuto aliwonse mkati mwa kafukufuku ameneyu kaya mthupi kapena mmaganizo mwanu, tidzakhala okonzeka kukutumizani ku malo komwe mungalandire chithandizo choyenelera.

Pali phindu lanji pa kafukufuku ameneyu?

Mwina kafukufuku ameneyu sangakhale wothandiza chilichonse kwa inu monga munthu, koma zotsatila zake zingazathandize wochita kafukufuku ameneyu kudziwa bwino zovuta zomwe odwala matenda opuwalitsa ziwalo amakomana nazo pa moyo wao wa tsiku ndi tsiku kunyumba. Tili ndi chikulupiliro kuti mtsogolo muno anthu ena osiyanasiyana adzapindula kuzela mu nzelu zatsopano zimene zidzapezeke chifukwa cha kafukufuku ameneyu, komanso ma dotolo ogwira ntchito ya zolimbisa ziwalo adzapindulanso. Pakutelo odwala matenda opuwalitsa ziwalo azathandizidwa bwino komanso mokwanila.

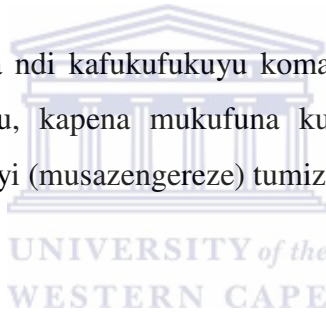
Kodi nkofunika kupanganaye kafukufukufukuyu? Nanga ndili mkati mochita naye kafukufukuyu ndingathe kusiya kapena kuchoka nthawi iliyonse?

Kafukufuku ameneyu mutha kuchita nawo mwakufuna kwanu. Muthanso kukana. Ngati musankha kuchita nawo mudziwe kuti muthanso kuchoka nthawi iliyonse ngati mwafuna kutelo. Ngati simukufuna kuchita nawo, kapena mwaganiza zosiya kutenga nawo mbali pa kafukufuku ameneyu, simudzalandila chilango kapena mkwiyo uliwonse kuchokera kwa omwe akuchititsa kufukufukuyu.

Kodi nanga ntakhala ndi mafunso?

Akuchita kafukufukuyu ndi a George Chimatiro, omwe akuchita ma phunziro a pamwamba (Masters Degree) ku South Africa pa sukulu ya ukachenjede ya University of the Western Cape, ku departimenti yophunzitsa anthu oyang'anila anthu odwala matenda opuwalitsa ziwalo. Ngati muli ndi mafunso okhuza kafukufukuyu (musachedwe), lankhulani ndi a George Chimatiro, University of the Western Cape, Physiotherapy department. Telefoni: 0027219592542/0027732006834. Kapena tumizani kalata pa: 3077278@uwc.ac.za

Mukakhala ndimafunso okhudzana ndi kafukufukuyu komanso ufulu wanu ngati mmozi mwa ochita nawo kafukufuku ameneyu, kapena mukufuna kunena za mavuto aliwonse amene mwakumana nawo pankhani imeneyi (musazengereze) tumizani nkhwana zanu kwa:



**Head of Department,
Dean of the faculty of community and health sciences
University of the Western Cape,
Private Bag X17,
Bellville 7535,
Republic of South Africa.**

Kafukufukuyu walolezedwa ndi Senate Research Committee and Ethics Committee ya University of the Western Cape.

Appendix L: Information sheet to service providers



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

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

E-mail:

INFORMATION SHEET

Service providers

Project Title:

Barriers to reintegration experienced by stroke clients post discharge from a rehabilitation center in Malawi

What is this study about?

This is a research project being conducted by George Chimatiro, Masters Student at the University of the Western Cape. We are inviting you to participate in this research project because you provide rehabilitation services to stroke clients and that after therapy you discharge them back to their community. The purpose of this research project is to explore the perceived barriers to reintegration into the community experienced by stroke clients after discharge from Kachere rehabilitation center.

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

After signing the consent form you will be asked to spare time to meet those carrying out research at a place and time of your convenience. At the meeting you will be asked to fill a form that seeks your socio-demographic information such as age, sex, work experience. A general

question will be put forward by the researcher, related to life of stroke clients in the community after discharge from Kachere rehabilitation center, which you will be answering according to your knowledge and experience with patients. The researcher and/or research assistant will be available and ready to answer your questions should you have some, in a meeting that may last about 30 minutes.

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, we will not ask for or write your name on all papers related to this research. Instead identification codes using numbers will be used on data forms to ensure anonymity, and the researcher will personally collect all data collection forms and will ensure their storage in a locked and secure place. When we will finally write a report about this study your identity will remain protected and not displayed at any point.

What are the risks of this research?

There are no known risks associated with participating in this research project. However if you experience any problem in the course of the study such as mental or physical trauma, we will make sure you are referred to appropriate services such as counselling.

What are the benefits of this research?

This research may not be personally helpful to you but the results may help the investigator learn more about the experiences of people living with stroke in their communities. We hope that, in the future, other people might benefit from this study through improved understanding by people generally and rehabilitation personnel in particular. This is hoped to improve service delivery for people affected by stroke.

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 George Chimatiro, Masters Student under physiotherapy department of University of the Western Cape. If you have any questions about the research study itself, please contact George Chimatiro at: University of the Western Cape, physiotherapy department on telephone number: +27219592542, or mobile number: +27732006834, or email: 3077278@uwc.ac.za

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:

Dean of the Faculty of Community and Health Sciences:

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 M: Interview Guide to Stroke Clients

INTERVIEW GUIDE

To Stroke Clients

“This study is about life, living with stroke after discharge from the rehabilitation center. Can you tell me about your own experiences for the time you have been in the community after discharge?”

Probes:

- Tell me of your life in the community currently as compared to before the stroke.
- How is your relationship with the immediate family after discharge compared to before the condition?
- How has the condition affected your role as a father/mother?
- Tell me of your current role status as community member, meaning your participation in community activities and occasions.
- How do you meet your financial needs after discharge?
- Tell me your experiences about access to public services such as hospital, transport, justice.
- Any last word?

Appendix N: Interview guide to stroke clients: Chichewa

MLODZO WAKAFUKUFUKU

Kwa odwala matenda opuwalitsa dziwalo

“kafukufukuyu diokhuza moyo wa tsiku ndi tsiku kunyumba pamene mwatulutsidwa kuchokela ku chipatala cholimbikitsa ziwalo. Ndiuzeni zinthu zimene mwakumana nazo kuyambira pomwe munatulutsidwa ku chipatala”

- Ndiuzeni za moyo wanu wa tsiku ndi tsiku kudela komwe mumakhala, panopo pofanizila ndi kale musanadwale.
- Ubale wanu ndi anthu a m’banja lanu ndiotani panopo pofanizila ndi kale musanadwale?
- Kodi chilema chomwe mulinacho pano chikukukhuzani bwanji pa udindo wanu ngati abambo kapena amayi?
- Ndiuzeni za udindo wanu ngati mmodzi mwa anthu amdela lomwu mumakhala. Pazintchito zosiyanasiyana mmuziTell me of your current role status as community member, meaning your participation in community activities and occasions.
- Kodi mmapeza bwanji chithandizo choyendetsela moyo wanu wa tsiku ndi tsiku, monga ndalama?
- Tandiuzeni za moyo wanu kumbali ya chithandizo cha boma, monga chipatala, maulendo (transport) kapena chiweluzo/chilungamo.
- Pali mau alionse omwe mukufuna kuonjedzela?

Appendix O: Interview guide to caregivers

INTERVIEW GUIDE

To Caregivers

“This study is about life, living with stroke after discharge from the rehabilitation center. Can you tell me about what you think are the experiences of the person you are caring for regarding reintegration into community after discharge from the rehabilitation center?”

Probes:

- Tell me about life of the person you are caring for in the community currently as compared to before the stroke.
- How is his/her relationship with the immediate family after discharge compared to before the condition?
- Tell me about his/her current role status as community member, meaning his/her participation in community activities and occasions.
- How does he/she meet financial needs after stroke?
- Tell me about his/her experience related to access to public services such as hospital, transport, justice
- Any last word?

Appendix P: Interview guide to caregivers: Chichewa

MLODZO WAKAFUKUFUKU

Kwa othandiza anthu amene adwala matenda opuwalitsa dziwalo

“kafukufukuyu diokhuza moyo wa tsiku ndi tsiku kunyumba pamene mwatulutsidwa kuchokela ku chipatala cholimbikitsa ziwalo. Ndiuzeni zinthu zimene anthu omwe mukuwasamalira atadwala matenda opuwalitsa ziwalo akukumana nazo kuyambira pomwe anatulutsidwa ku chipatala”

- Ndiuzeni za moyo wawo wa tsiku ndi tsiku kudela komwe mumakhala, panopo pofanizila ndi kale asanadwale.
- Ubale wawo ndi anthu a m’banja lawo ndiotani panopo pofanizila ndi kale asanadwale?
- Kodi chilema chomwe alinacho pano chikuwakhuzwa bwanji pa udindo wawo ngati abambo kapena amayi?
- Ndiuzeni za udindo wawo ngati mmodzi mwa anthu amdela lomwu mumakhala. Pazintchito zosiyanasiyana mmuzi.
- Kodi amapeza bwanji chithandizo choyendetsela moyo wawo wa tsiku ndi tsiku, monga ndalama?
- Tandiuzeni zomwe amakumananadzo kumbali ya chithandizo cha boma, monga chipatala, maulendo (transport) kapena chiweluzo/chilungamo.
- Pali mau alionse omwe mukufuna kuonjedzela?

Appendix Q: Interview Guide to Service Providers

INTERVIEW GUIDE

To Service Providers

“This study is about life, living with stroke after discharge from the rehabilitation center. Can you tell me what you think are the barriers to reintegration into community experienced by stroke clients after discharge from this center?”

Probes

- Tell me about the rehabilitation at your center particularly for stroke clients
- Tell me about challenges that the clients meet in their communities after discharge.
- Any last word?



Appendix R: Transcript, stroke client

Project Title:

Barriers to reintegration experienced by stroke clients post discharge from a rehabilitation center in Malawi.

Event ID	P/IDI
Principal Investigator	PI/IDI
Participant code	P/IDI/3
Transcriber (Initials)	RL
Quality checker (Initial)	CP, RK
Translator (initials)	RL
Quality checker (Initials)	PC

KEY

P = Stroke Client

IDI = In-depth Interview

PI = Principle Investigator

(.) = Short pause

(...) = Long pause

Setting the scene.

P1 is a widow living in a big house, wide area in the fence though the landscape is uneven. P3 walked with a crutch to the toilet. She was at the time of interview in company of her young sister who periodically act as her guardian. The interview lasted for 25minutes. P3 struggled to produce clear words at times because of her slurred speech. She said she is financially stable as she is supported by her pension and support from her children who are working now. The interview P3 said she has problem with walking because of what she said is a landscape problem.

This makes her fail to participate in day to day life activities such as joining her friends out and cooking.

Transcription/Translation

PI/IDI: Yes mum am here eeh as I said we are doing a research that I talked about on the phone yea so the research we are doing is a research that is trying to find out aah the daily life of people who have come from who have been discharged from Kachere Rehabilitation Centre so can you tell me you as a patient who suffered stroke your experiences that ah are reducing the chances of you living a normal daily life without problems.

P/IDI/3: Iiiii it's a lot eeh but (..)hmm walking is a very big job walking to get there to get there is a problem uhmm so at least am walking with the help of people at Kachere but ii walking is making daily life very difficult eehh

PI/IDI: So you are saying you have problems with walking uuh is it because you are weak or the area you are living in is hard to walk?

P/IDI/3: Hmm all that is possible because like where I live is not rocky am able to walk properly but here it is rocky eeh so it makes walking difficult

PI/IDI: Okay, no fine

P/IDI/3: Eehh yes

PI/IDI: So if you compare your life now and the life before stroke, what is the difference?

P/IDI/3: Iiiii there is a lot of differences because I was farming I was able to do anything that a woman could do but not I just stay because now I can't cook because when am near the fire I cannot go to the kitchen when the charcoal burner is burning

PI/IDI: Why ?

P/IDI/3: Iiiii its hot that's all I feel like fainting eeeh if it were that there is no fainting aaaa I would have been telling that young one that she should be cooking nsima while am putting in flour, I would also have been cooking with one arm but *ndimachita befu kwambiri eee*

PI/IDI: fine ee can you tell me now that you are home how is your relationship with your family compared with before stroke?

P/IDI/3: Aaaa but no I cannot say there is any difference but sometimes you find that they are laughing at the kitchen while am here alone but I cannot go there because of the fire, yea

PI/IDI: Hmmm

Appendix S: Transcript, caregiver

Research Title

Barriers to reintegration experienced by stroke clients post discharge from a rehabilitation center in Malawi.

Event ID	G/IDI
Principal Investigator	PI/IDI
Participant code	G/IDI/6
Transcriber (Initials)	JMM
Quality checker (Initial)	CP, RK
Translator (initials)	RL
Quality checker (Initials)	PC

KEY

G = Guardian

IDI = In-depth Interview

PI = Principle Investigator

(..) = Short pause

(...) = Long pause

Setting the scene

The 19 minute interview took place in Lirangwe, rural side of Blantyre. He is articulate and audible. There were background noise of birds chickens and passing vehicle. G/IDI/6 said because of stroke the wife can no longer work in a kitchen, in the garden or go to the church. He thinks she worries too much now. Therefore the home is both socially and financially affected as she cant go to work or visit relatives and friends.

Transcription

PI/IDI: Aa this research we are doing is concerning the daily life at home ah the patient, the wife that was discharged and now she is in the community from the rehabilitation centre of Kachere Kachere Rehabilitation center, ah tell me what are her experiences ah after discharge from hospital, and now that she is home, what problems does she meet?

G/IDI/6: Eh the problems that this woman meets, what she meets is she fails to do what she wants or work as she used to do before she met this problem therefore she is always sad because of that. Even me as guardian I accept that it is true. So the main problem that is there is that in her life she wonders that I was not like this but now I am like this no fine nothing I can do. Yea!

PI/IDI: How does it affect her?

G/IDI/6: This affects her mainly when there is poverty because the work that she was doing is now on me so to her she feels sorry that she is troubling me because this work is not supposed to be done by him but today he is doing it because of how I am. So I encourage her that no, don't be sad because you did not want to be like that no. yea, yea

PI/IDI: Ah tell me clearly ah now as she is, with the work she was doing before, what is the difference?

G/IDI/6: As she is now she is working as before? Aha today we can say the life she has these days, it is the life that she is sad because she met the disability yea but there is not any other disease that she has. This is the only disease. Before she became sick, she was someone who was found on her programme everytime which she was making herself, I will do this I will do this ehe yea.

PI/IDI: What is making her fail to do that?

G/IDI/6: E what is making her fail to do her desire like oh in the morning I will do this, it is because, one she cannot stand up on her own to do what she wants!

PI/IDI: Why?

G/IDI/6: Because she does not have enough strenght to walk because of the leg which has stroke but also for the hand to lift something, no she is using one hand which is alive. Yea!

PI/IDI: Okay. Which jobs have been affected by this problem?

G/IDI/6: One I can say that on the work she was doing for this family, she was going to draw water, today that is not possible, she was going to the garden to find relish, today she cant do that. Now to sweep the house no, ok let's go to the kitchen no, she cannot go. She just receives

Appendix T: Transcript, service provider

Project Title:

Barriers to reintegration experienced by stroke clients post discharge from a rehabilitation center in Malawi.

Event ID	S/IDI
Principal Investigator	PI/IDI
Participant code	S/IDI/2
Transcriber (Initials)	CK
Quality checker (Initial)	CP, RK
Translator (initials)	
Quality checker (Initials)	

KEY

S = Service Provider

IDI = In-depth Interview

PI = Principle Investigator

(.) = Short pause

(...) = Long pause

Setting the scene

The 27 minute interview took place at Kachere rehabilitation center in a cubicle within the gymnasium. S/IDI/2 is the head of department. The interview went well, there was background noise from the far end of the gym by other therapists. It was lunch hour. The main barrier to reintegration according to him are lack of knowledge about stroke to communities leading to attitude change of people towards the client. And also inaccessibility to many places of interest.

Transcription

PI/IDI: What do you feel are the barriers to community reintegration of these stroke patients when you discharge them from here?

S/IDI/2: uuh mmh I think when you discharge patients from here they really have problems in the communities the first thing is accessibility to institutions, talk of the church, talk of ah schools, ahm talk of the organizations like Farmers associations, ahm and I mean Hospitals sometimes the roads infrastructure to the village sometimes it is very poor that the stroke patient may not able to practice even how to walk and in some other roads the wheelchair my not even be useful again on institutions we can also consider banking institutions which are not ah designed to suit wheelchair users or somewhere somehow people with strokes ah maybe there may be no hand rails and things like that and the second thing would be that lets talk of ah employers some people consider I mean consider somebody who has had a stroke as he is no longer fit for duty so people lose their jobs simply because they had stroke if somebody was earning money that means his income is cut and if he was able to access some other issues he would not access because he has no financial muscle supporting ahm yeah.

PI/IDI: so you have talked on accessibility basically ofcourse you have included some answers within what you have said but what would you basically say is the main cause for failure to access these services or institutions that you have mentioned.

S/IDI/2: yeah one other thing that I did not mention is stigma thats associated with tradition it is considered sometimes in the community that somebody who had stroke is a witch, facial paralysis is misinterpreted as if you're a witch I mean to co to mean that somebody is a witch and he fell off from a plane at night so somewhere somehow when people go back to the community they are isolated ah their friends will run away from them because they are stigmatized they are labeled to be associated with witchcraft in one way or the other ahm and the other thing is the community is not away of the ah conditions they have no basic understanding on whatsoever ahm